Good care
Enacting a complex ideal in long-term psychiatry

Jeannette Pols

GOOD CARE
ENACTING A COMPLEX IDEAL IN LONG-TERM PSYCHIATRY

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1 Introduction

This book is about good care and about improving care. I think it is safe to say that everybody wants care to be *good*. However, there is no agreement what this 'good' should look like. In care-practice, policy and the health sciences there are different, sometimes conflicting ways of conceptualising good care. There is, for instance, the idea that care is good when it is just, effective, or ethically legitimated. There is the idea that care will be good when it is managed well and does not put unnecessary strains on public money. Or care can be judged to be good when it is aimed towards patient emancipation or the participation of patients in society, or when it is tailored towards the needs and demands of its 'users'. And sometimes some combination of these goods is asked for in order to be able to call care good.

So there are different ideas about what makes care good, and these are hard to compare and weigh, because they are so different. However, they all influence care-practice, even if we do not know how and if they may be combined. This is also true for the care reported on in this book: long-term mental health care. In this book I study how notions of good care are part of or interfere with present day practices of long-term mental health care in the Netherlands. I do this by analysing how participants, specifically psychiatric nurses and patients, try to shape good care in their daily activities. The first aim of this book is thus to *articulate* different forms of good care that exist in long-term mental health care, by giving words to what happens in a variety of practices. What are the ideals that circulate there and in what kind of practices are they embedded?

The second aim of this book is to reflect upon the question *how to deal* with this diversity in forms of good care. When the question 'what is good?' has so many different answers, how might these differences be dealt with? Can the articulations of different ideals of good care help to point out 'good' or 'better' ways of improving care?

1.1 Ethnography in long-term mental health care

To tackle these questions I draw upon ethnographic fieldwork (observations and interviews) in daily practices of long-term mental health care. In this fieldwork I studied different ways of shaping good care in two sites. First, at five wards in three residential homes for the elderly, where elderly patients from the long-stay wards had moved to, and second, in the long-stay wards of two Dutch psychiatric hospitals where younger patients live. Much improving of care was going on in both places. The residential homes wanted to provide a community based care service for the elderly as an alternative for the (stigmatising and expensive) long-stay wards of the psychiatric hospitals. Professionals from mental health care and care for the elderly came to work together to shape a new form of care in this new setting. But however clear the idea may have sounded when policy makers designed it, working together turned out to be difficult when the actual move had taken place. Good care meant something different to psychiatric nurses and geriatric assistants, while there were considerable differences among psychiatric nurses as well.

In the psychiatric hospitals, psychiatric nurses and other professionals were actively developing new forms of rehabilitation. They adapted existing forms of rehabilitation to make them fit for patients who were unable to leave the long-stay ward so as to live outside the hospital. The new forms of rehabilitation were developed in different ways, although in both hospitals the aim was to emancipate patients and involve them in decisions about their situation.

1.2 Positioning the book

The chapters of this book are written as journal articles. This is the reason why this introduction is brief; there are five introductions to come that cover specific research questions and methods. What I will do here is position my research, in order to help the reader understand its history and some of its theoretical backgrounds.

This research started with a study in residential homes for the elderly.[1] I was doing fieldwork there and I was looking for ways to frame the analysis. The central question our research team was trying to answer was if the residential homes were indeed a good alternative for the long-stay wards in the psychiatric hospital. And there it was: a *good* alternative. What could this 'good' be? One way of addressing this problem might have been to first

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[1] The original report is: Pols, A.J., M.F.I.A. Depla, J. de Lange, (1998) Gewoon oud en chronisch. Mogelijkheden en beperkingen in de zorg voor ouderen met een psychiatrische achtergrond in het verzorgingshuis. Utrecht: Trimbos-instituut. Trimbosreeks 98-2. The ministry of Public Health (VWS) and the participating residential homes funded this study. This study was part of a more extensive study into the residential homes as a new caring facility for people who had grown old in the psychiatric hospitals. See also: Depla, M., Pols, J. Smits, C., De Graaf, R., Heeren, T. Integrating Mental Health Care into Residential Homes for the elderly: An analysis of six Dutch programs for older people with severe and persistent mental illness. Journal of the American Geriatric Association. 51,1275-9.

define what we, as researchers, thought was good care in the residential home. This would allow us to find out whether or not the practices investigated lived up to the standards we had formulated. This possibility did not appeal to us. It would not do justice to the innovative nature of this practice. It would imply a critical judging of my informants from a safe position outside of the practice where they struggled to accomplish good care.

An alternative approach was to look *inside* these practices to find out how the professionals themselves framed 'good care'. Thus it became clear that the different participants answered the very question of how good care should be defined, differently. Some psychiatric nurses stressed that it was crucial that the psychiatric problems of the residents were dealt with in a professional way, whereas the residents should be free to live their daily lives in the way they wanted. Most geriatric assistants thought the residential home should be a safe haven for a pleasant old age. They aimed for a friendly atmosphere, service and personal care. Then there were also psychiatric nurses who stressed the emancipatory side of the move to the residential home. Instead of being stigmatised as psychiatric patients, the elderly could now live just like other people of their age, and take advantage of community facilities. Good care, they said, should support the residents to – finally – become full citizens after having lived in a psychiatric hospital for most of their lives.

So whose type of good does one choose as a standard by which to judge the success of the residential homes? Or should they be added up? Interestingly, however, trying to combine the various forms of good care proved to be difficult. They did not fit. Not surprisingly then, the different ways of framing and doing good care appeared to be a source of conflict and misunderstanding between professionals in practice. Professionals often did not understand why their colleagues would work in a certain way, because the different definitions of good care were implicit. This could lead to rather polarised situations in which the respective aims for making care good were not recognised.

Our research team concluded that our analysis would be of more help to the participants and others planning new wards in residential homes if it would not *judge* the professionals, but make the frictions between them understandable. By giving words to the different ways in which various professionals were trying to shape good care, all these efforts could be acknowledged. The possibility of a discussion about which forms of good care might actually be best for whom could be opened up. Future projects could learn from such an analysis, too, since it might help them to anticipate some of the problems to come. Thus, the first outline for an ‘ethnography of good care’ was created. When diverging ideals about and ways of shaping good care could be made visible to the participants, this would enable them to understand each other’s positions and negotiate about what to do.

Although the style of analysis was not critical, neither was it the opposite that is, merely applauding what participants did. We articulated the ideals and good intentions of the participants by showing how they were practiced. Whether an inspiring ideal actually makes good *practice* is an open question. As anyone knows, best intentions are no guarantee for success. And indeed, in tracing ideals in practice we hit upon ambivalences in the way they worked out, and upon sometimes unforeseen and undesirable effects. This again helped to open up the various ideas about good care for reflection and discussion.

When we started our second project, the research in the psychiatric hospitals, there appeared to be not too little text, but too much.[2] This time the question the research team tried to answer was what rehabilitation might mean for patients who are not able to live outside the hospital. Many ideals were put forward under the heading ‘rehabilitation’. These ideals shared the aim of empowering patients and of helping them to integrate in the community. However, how these ideals should actually be practiced, particularly in the context of the psychiatric hospital was unclear. An ethnographic study was started to articulate actually practised ways of ‘doing’ rehabilitation ideals. In the study it became clear that the more or less shared vocabulary of rehabilitation hid different ways of practicing it. There were different ways of empowering patients and of thinking about – and working on – their participation in the community. Articulating these different ways to ‘do rehabilitation’ made explicit that there were actually different ideals and rehabilitation philosophies at stake, and allowed for a discussion on which form of rehabilitation would be best for whom.

With these two studies the first contours of an ethnography of good care were drawn. But intriguing questions remained. In both the residential home and the psychiatric hospitals an important element of the notions of good care is the strengthening of the position of patients. How exactly is this ‘done’, though, and what does it mean that it is done in different ways? Can a comparison of different ways of improving the position of patients help to understand this aim better? And what about the diversity in styles or genres

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[2] The original report is: Pols, J. Depla, M. Michon, H. Kroon, H. (2001) Rehabilitatie als praktijk. Een etnografisch onderzoek in twee psychiatrische ziekenhuizen. Utrecht, Trimbos-instituut. The Dutch Federation of Mental Health (NFGV) and GGz Noord-Holland Noord funded this study.

of improving care (juridical, ethical, evidence based medicine)? How do these different forms of good care relate and influence care-practice?

Funding from the Incentive Programme Ethics and Political Issues, which is supported by the Netherlands Organisation for Scientific Research (NWO), made it possible to systematically engage with these questions. As the Programme aims to stimulate research that combines empirical studies with ethical reflection, it formed an excellent space for theoretically developing the ethnography of good care. In the present study, then, I mobilise the ethnographic material of both the residential homes and the psychiatric hospitals in order to articulate different versions of 'good care' and to reflect upon the possibilities for improving care that take this diversity seriously.

Modes of good care

Two theoretical backgrounds and inspirations will become apparent in this book. The first is Actor Network Theory (ANT). With ANT I share the interest in questions how to think about what is 'true' and what is 'real'. The second inspiration is the work of Boltanski and Thévenot. With them I share the interest in the question of how we might think about what is 'good', specifically when this 'good' concerns day-to-day activities. Scholars of ANT scholars such as Bruno Latour, Michel Callon, John Law and Annemarie Mol (to name a few), study reality as it is formed within 'material semiotic networks'. In a material semiotic network, 'entities take their form and acquire their attributes as a result of their relations to other entities' (Law 1999, p. 3).[3] Important to my study is the notion that elements are not something solid in and of themselves. They come into being in connection to one another. Neither human nor non-human elements are privileged in the analysis, because they are both seen as actors that hold the networks together.[4] This explains a partiality to ethnographic methods; these methods allow one to go and see people and objects 'in action', as *enacting* different realities. [5]

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[3] Law, J. (1999). After ANT: complexity, naming and topology. In: Law, J., Hassard J. (eds). Actor Network Theory and After. Oxford: Blackwell Publishers.

[4] Pickering, A. (ed.) (1992) Science as Practice and Culture. Chicago & London: University of Chicago Press. Law, J. (1997) Traduction/ trahison: notes on ANT. Published by the Department of Sociology, Lancaster University at: http://lancaster.ac.uk/sociology/stslaw2.html.

[5] I draw upon studies in ANT using the notion of 'enactment'. See Mol, A. (1998) Missing Links, Making Links. The Performance of some Atheroscleroses, in: Berg, M. and Mol, A. (eds) Differences in Medicine: Unraveling Practices, Techniques and Bodies. Durham, London: Duke University Press, 144-65. Mol, A. (2002) The body multiple. An ontology of medical practice. Durham: Duke University Press. In earlier studies the metaphor of 'production' is used. See Latour, B. (1987) The Pasteurization of French Society. Cambridge MA: MIT Press. Latour, B.

The concept of the material semiotic network points to an inspiration by the work of Michel Foucault. Foucault used the term 'discourse' to describe grand shifts in material semiotic orderings pertinent to Western societies over the centuries. In the 19th century, 'madness' became 'illness', and a discourse of (ab) normality came to order our buildings, bodies, organisations, activities and talk, in- as well as outside the clinic.[6] Like many others, I use the notion of discourse on a rather smaller scale. John Law called such small-scale discourses 'modes of ordering', and this term perfectly fits my purpose of analysing everyday care-practices.[7] However, within ANT much work has been done to study the ways in which truth and reality are enacted. In the present study I want to slightly shift the focus to learn more about how *goodness* is enacted. To this end I changed 'modes of ordering' into 'modes of doing good'.

To think about these modes of doing good I could learn from Boltanski and Thévenot.[8] Boltanski and Thévenot framed a theoretical vocabulary that allows one to study how ordinary people justify their actions. They discerned different 'repertoires of justification'. People draw upon these repertoires in varied ways, using different types of justification in the same situation. But each repertoire, in and of itself, is internally consistent and has its own hierarchy of values and its own conception of the world. According to Boltanski and Thévenot there are six repertoires of justification. There are, for instance, justifications related to the realm of industry (where *efficiency* is the central value), the market (where wealth is strived after and *scarcity* is the central term), the home (where *closeness* is important) or fame (where *honour* and *reputation* are valued).

I do not copy the repertoires that Boltanski and Thévenot described so extensively, but I use their work as an inspiration to study goodness as part of specific orderings. These orderings I trace within the practices I study: long term mental health care. What relations are there between ways of acting, objects used and ways of knowing situations? When did the participants, patients or professionals, actually think of the situations I

(1987) Science in Action: How to Follow Scientists and Engineers through Society. Cambridge, MA: Harvard University Press.

[6] Foucault, M. (1975). The Birth of the Clinic: an Archaeology of Medical Perception. New York: Vintage Books.

[7] Law, J. (1994) Organising Modernity. Oxford: Blackwell Publishers.

[8] Boltanski L, Thévenot L., De la justifications. Les économies de la grandeur. Editions Gallimard, 1991. Their work was introduced to the Dutch speaking public by the writers collective 'Lieve de Recht & co' (1992) Camembert, rechtvaardigen en geweldloze liefde. Het politiek-economisch-sociologisch-antropologisch raster van Luc Boltanski en Laurent Thévenot. (Camembert, justification and love without violence. The political-economical-sociological-anthropological grid of Luc Boltanski and Laurent Thévenot.) Krisis. (47) 1992, 12, 5-22.

observed as 'good care' or not, and for what reasons?[9] What elements make out this 'good'?

Empirical ethics

With these backgrounds, tools and insights I develop a specific style of empirical ethics. To practice this style of empirical ethics is to ask ethical questions, such as the question 'what is good care?' *somewhere*, inside the practices of long-term mental health care. The aim is to articulate how ideals of good care are enacted in day-to-day caring situations, by analysing the relations between activities, events, routines, things and talk about practice. I reflect upon the question what this implies for the daily life and work of patients and professionals as well as for the desirability of the ideals or ways of practicing them to improve care.

1.3 The chapters

After this introduction, in the second chapter I discuss ways of framing good care in *ethics*. The chapter is positioned in the current debate about the relation between empirical research and ethics. It explains the methods I engage with and the theoretical questions I learned to ask during this study. Meanwhile, it traces some characteristics of the ideal of individualisation in the practice of long-term mental health care. The questions explored are: what should be the relation between the researcher or ethicist *studying* good care and the professionals and patients *practising* it? Who has the final word? And in what way can the paradoxical term 'empirical ethics' reconcile the quest for 'what is true' with the quest for 'what is good'?

The third chapter deals with forms of goodness such as they are framed in *political theory* and shows their interferences with daily professional practice. I study the framing of 'citizenship' in practices that may seem far away from politics: practices of washing patients. In different practices 'good washing' is understood and lived in different ways. I will argue that these differences relate to specific notions of citizenship that are embedded in the practices of washing presented. This analysis leads to a

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[9] See for inspiring examples of drawing patients into ANT: Moser, I.B. (2003) Road traffic accidents: the ordering of subjects, bodies and disability. PhD thesis, University of Oslo. Hendriks, R. (1998) Egg timers, human values and the care of autistic youths. Science, Technology & human values, vol 23, no 4, 399-424.Winance, M. (2001) Thèse et Prothèse. Le Processus d'Habilitation comme Fabrication de la Personne. L'Association française contre les Myopathies Face au Handicap. Ph.D. dissertation Department of Socio-Economie de l'Innovation, ENSMP, CSI.

reflection which type of citizenship best serves the aim of integrating people with chronic mental illness in the community. Are there good or better ways of framing citizenship with regard to this aim? And what kind of an activity is 'washing' that makes it central as well as peripheral to notions of citizenship?

The fourth chapter is about juridical framings of good care and their interferences with different professional notions and practices of good care. In the two psychiatric hospitals I studied caregivers related very differently to the so-called 'patient-laws'. In one hospital professionals enthusiastically supported the law and its ideals, whereas in the other hospital professionals actively resisted both the law and the ideals embedded in it, and instead put forward alternative ideals. However, in the practice where caregivers were enthusiastic about the law, many 'translations' of the intentions of the law were made by which the ideals behind the law were changed. In the practice of the rebellious caregivers the law's intentions were not changed, but the law had little influence on care-practice. The analysis raises the question whether it is actually possible to improve care by legal means. Might regulation ever work out as intended?

The fifth chapter is about different styles of making sure professional forms of good care are actually practised. In this chapter *accounting* as a way of legitimating care (either by showing that only *effective* care is put into practice or by showing that *proper principles* are being respected) is compared with other forms of ensuring that care is good. Accounting is a popular good, not only for the government, so it turns out, but also for professionals. How do professionals account for their practices? And how does accounting relate to the aim of making care good? In this chapter, the case of washing patients is used, again, this time to study accounting-in-action.

The sixth chapter is about the hermeneutic (and also political) good of listening to the perspectives of different stakeholders or interest groups in care. Attending to the patient perspective is a way of learning *from* patients instead of *about* them. But what does it mean to ask for a 'patient perspective'? In my studies I kept wrestling with the concept, as it seemed that in order to have a perspective, one should make transparent verbal representations of ones' situation. However, a lot of patients in my studies do not speak, or not in a transparent way. How to learn from these patients as subjects in research? To explore this question I analyse what it actually means to tell a story *somewhere*, and how this is part of doing something *in* the world rather than making representations *of* the world. What, for instance, did 'interviewing patients' do with them? And can people, alternatively, be observed as ‘enacting’ their subjectivity, and what kind of subjectivity are we talking about then?

In the concluding chapter I return to the question of what these studies teach us about the activity of improving care amidst a diversity of ideals and ways of improving. How can we understand the more prominent ways of improving care and why do these often lead to unintended consequences? Is it possible to avoid these problems and think about alternative ways for improving care? This finally leads to the question how the present study in its turn might be implicated in the improvement of care.

2 Which empirical research, whose ethics? Articulating ideals in long-term mental health care

> I ask Lisa, a psychiatric nurse, if she notices any differences between before and after rehabilitation was introduced on the long-stay ward. She says she does. She says care used to be oriented towards managing the patients as a group. 'Now an individualised approach is central. Much more attention is given to the patients' self-organisation and their own responsibility.'

This fieldnote shows one of the most influential ideals in long-term mental health care these days: the ideal of individualised care. Individualising care is regarded as a way of improving care and contrasts with older forms of care that did not help patients to develop and be cared for according to their own preferences and possibilities. In this chapter I will study the ideal of individualisation in order to demonstrate a specific form of doing empirical ethics: a theoretically informed ethnography of good care.[10] What charachterises this style of empirical ethics?

First, the object of research is 'good care'. However, what consitutes *good* care is not defined beforehand, but is studied in an ethnographic way. The charachteristics of good care are explored by observing how nurses and patients in their daily life and work try to shape good care. I analysed everyday care situations and discussed these with the participants. How can actual care practices be perceived of as *good* practices, or as attempts to practice good care? And what ideals of good care are thus at stake?

Thus, analysing the nature of good care is done in a specific way. Instead of attending to 'culture' or 'talk about' good care, I specifically attend to *practices* of good care. Good care is analysed as it is shaped in daily activities, events and routines. Together, people and artefacts are observed as *doing* different forms of good care. This is called the 'performance' or 'enactment' of ideals (Mol 1998; 2002).[11] I will study the ideal of individualisation as it is enacted in daily care practice, rather than as an abstract ideal that influences practicgere.

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[10] Creswell describes ethnography as: 'a description and interpretation of a culture or social group or system. Ethnography involves prolonged observation of the group, typically through participant observation, in which the researcher is immersed in the day-to-day lives of the people or through one-on-one interviews with members of the group.' (Creswell 1998).

[11] Mol uses the term 'praxiography' for the type of ethnography that specifically attends to practices. However, the use of this term does not bring out the other charachteristics of the form of empirical ethics I am concerned with here. So for lack of a good alternative I stick to the term 'ethnography'.

A result of such an analysis is that forms of good care are made explicit. Thus, ideals that are taken for granted can become topics for discussion, for instance by analysing what type of practices come into being by enacting specific ideals. I question whether a certain ideal is dominant, are there other ideals that are pushed away? And is this what we actually want? This is an important characteristic of this style of doing empirical ethics: it *articulates* ideals and their related practices that were tacit, taken for granted, pushed away or 'forgotten'.[12] In this process, words are given to implicit ways of framing good care. As I will show later, the ideal that runs the risk of being pushed away by the dominant ideal of individualisation is the ideal of patient sociability.

By articulating ideals that are embedded in care-practices, this style of empirical ethics aims not merely to *describe* practice, but neither does it aim to *judge* it. The aim is to interfere in the practices studied by opening up implicit notions of good care for (self) reflection. Thus this style of empirical ethics does not restrict itself to describing what others think is good, but neither does it impose its own norms in the form of judgements.[13] Instead, it *questions* norms and ideals by articulating and unravelling 'goods' hidden in activities and routines. Such an analysis provides participants with new ways to look at their practice.

In order to present this style of empirical ethics I will not 'talk about' it, but demonstrate it by analysing the enactments of the ideal of individualisation.[14] How is individualisation enacted and which ideals are marginalised in the process? The fieldwork for this study was done in four long-stay wards in two psychiatric hospitals, and five residential homes for the elderly that started housing patients who left the long-stay ward.[15] Individualisation of care is often presented as the guiding ideal in inspiring reforms. In the psychiatric hospital, individualisation inspired the development of a method of caring called rehabilitation. Rehabilitation in itself was not new, but it was for the patients who did not make it out of the

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[12] The term 'articulation' is borrowed from Donna Haraway (1991). Haraway's term articulation means that every empirical study is an articulation of a certain, situated way of knowing. Articulations are partial, as they join some things together and not others. Thus she attempts to make stories heard that are pushed away by dominant discourses.

[13] Hans Harbers (in press) uses the term re-scription, as an alternative to pre-scription and de-scription. Re-scribing the world is an activity that interferes with the world rather than represents or judges it.

[14] This is consistent with the point of departure that studying phenomena 'in action' leads to different stories than 'talk about' them. The idea that concepts get their meaning by the way they are used is developed by Wittgenstein (1953). Explicitly involving materiality and practice shows the influence of Foucault (1971) on this style of doing empirical ethics.

[15] See Pols, Depla & De Lange 1998; Pols, Depla, Michon & Kroon 2001 for the original reports. In the psychiatric hospitals 40 days of participant observation took place, 19 members of staff were interviewed and 8 patients. In the residential homes, 60 days of participant observation took place, 14 residents and 39 members of staff were interviewed.

hospital. The psychiatric nurses were actively adapting forms of rehabilitation in order to individualise care for the patients who had nowhere else to live but the long-stay ward.

The psychiatric nurses in the residential homes tried to combine psychiatric care with care for the elderly to enable residents to live in the more community-based setting of the residential home rather than on the long-stay ward of the psychiatric hospitals where they came from. Individualisation of care is thought of as one of the benefits of this new care setting. I will discuss more backgrounds of this ideal in section 5, but I will start with developing the concept of enactment. What does it mean to study enactments and how can the ideal of individualisation be seen as enacted in daily care?

2.1 Enactments of individualisation

I will outline two ways in which individualisation is enacted. In the first way of 'doing individualisation', the nurses help patients to develop their individual skills. In the second, the nurses create space for individual preferences.[16]

For the first way to individualise care, the nurses formulate the aim to make individual patients more independent from their caregivers. In order to become more independent, the nurses help patients to develop their individual skills. The idea behind the individual skills training is that people lose skills in the hospital environment, because they never have to practice them. Everything is taken care of. Thus, they became passive and numb, hospitalised, and this process should be reversed.

> *Psychiatric nurse*: An extreme example is from another ward where I worked, also with long-term mentally ill elderly persons. For years and years sugar and milk was mixed with the coffee in the coffeepot by the nurses, and then served. And we said at a certain moment: 'We want these people to do this themselves again, and how can they learn this'. We put the coffeepot and the empty cups on the table: nothing happened. Nobody moved a finger, because it was always done for them. And, well, eventually they would pour the coffee, but the relations between sugar, milk and coffee appeared to be far from clear. They would put in the milk, and when they wanted to pour the coffee, they saw that the cup was already full. [laughs]

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[16] There are other forms of individualisation, for example in discourses about patients as consumers, juridical regulations in care and medical discourse. I choose the two ways of enacting individualisation in this chapter because they can be clearly observed in daily care, and serve the purpose of this chapter to clarify how this style of empirical ethics works.

By letting people practice these little routines themselves, the idea is that they will learn these skills again and keep them intact. Eventually, this may lead to patients becoming independent from their caregivers, even allowing them to move out of the hospital. But even if moving is not an option, practising individual skills makes the patients as independent as possible. Being able to do things for yourself allows a person to organise the day according to individual preferences. The nurses only take over tasks people are not able to do, but leave as much activity as possible to the patients.

Part of the attractiveness of individual skills training for the nurses is that psychiatric symptoms in itself are not seen as disruptive for individual skills. Rehabilitation by training individual skills allows for individual progress, even when 'cure' is not an option. To do so, the nurses divide the work with the doctors and psychiatrists. The nurses help the patients to develop their skills, while they assist the psychiatrist at other times to look after symptoms and medication.

So ideals are enacted in seemingly trivial routines such as making coffee. But there is another way of enacting individualisation. Instead of 'becoming skilled', in this second way of enacting individualisation more importance is attached to being enabled to live according to *individual preferences*. A way to give space to individual preferences is, for instance, to flexibly organise breakfast, so that whoever wants to can sleep in. On one of the hospital wards this lead to the abolishment of breakfast altogether, because all patients sleep in. Sleeping rooms are now kept open during daytime, enabling individual patients to use them as private rooms. The sleeping rooms are turned into the domains of the individuals who live there, instead of being places to sleep for temporary inhabitants.

> *Psychiatric nurse*: Take Harold. He also has the right to withdraw to his room. But he smokes like a chimney, so we were worried he would set the sheets on fire. How to solve this problem? He now has loads of little boxes around, filled with sand so he can put out his ciggies. And we bought a fireproof bedspread, so he can lie on the bed and smoke without setting it alight. His door has to be locked in the night [because he wanders], but you try to make it as pleasant as possible for him. A nice little nightlight, because he likes the light on, but the big white light is too bright. He is extremely fond of classical music, so he has loads of CD's and a player. We put pictures from his family album on the wall. We try to offer people a home, as far as possible.

The nurses try to find out what a person's interests and hobbies are and look for clues via family members if patients cannot put things forward themselves. Especially for the patients who do not speak, this can be a quest for the nurses with trying things out and by learning about somebody's hobbies in the past from family members.

Psychiatric symptoms are not seen as affecting the possibility of having individual preferences. Again, a vocabulary for rehabilitation and nursing is developed that does not depart from symptoms, but from positive possibilities. It allows the nurses to give 'good care', even though this type of caring does not lead to cure.

These two short outlines show a sensitivity to everyday activities, such as ways of organising coffee, the decoration, lay-out and use of private rooms, and the material objects that are used to bring about good care.[17] These practical matters can be connected to activities of the nurses, and to their stories about what they are doing. By relating these elements, nurses and patients can be seen to 'enact', or as trying to enact good care in their daily activities.

But something else is enacted too. With the help of these practical arrangements, specific forms of subjectivity for the patients are enacted. For the skills training, it is important that patients are active and *do* things to become independent, or as independent as possible. Whether they *want* to learn skills is of less relevance. Deciding what one wants comes *after* the skills training. When individual preferences are at stake, however, deciding or wishing comes first. It is deemed important for the patients to decide things for themselves, or recognise themselves in objects and arrangements around them. It is not important to be active, as with the training of skills, but to find one's individuality reflected in the ways one's life is organised.

Thus, the nurses and patients enact two types of subject positions, one in which 'independence' is a central concern and another in which 'identity' is a key word. The role of the nurses differs likewise. Instead of assisting the doctors with 'treating patients', the nurses become trainers of skilled individuals, or rather facilitators of individuals living their personally preferred lives.

Thus, by analysing 'doing' and practical matters, this analysis of individualisation as it is enacted can make visible that an ideal may inspire different practices. For both practices of individualisation, the overall ideal is said to be the same. The ways in which individualisation is enacted, however, are different. Attending to activities and practicalities makes it

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[17] This shows a theoretical inspiration from Actor Network Studies of science, technology and societies (Latour 1987; Law 1994). Examples are the research of the ethical workings of technical artefacts in medicine, such as respiratory devices for people with asthma (Willems 2001) egg-timers for autistic youths (Hendriks 1998), protocols for general practices (Berg 1997), or the technicalities involved in producing (dis) ability (Winance 2001, 2002; Moser 2000). 'Things' or 'non-humans', are not seen as passive entities that are put to use by people, but as devices that actively structure care, as 'actors' or 'actants'.

possible to articulate different forms of 'tacit ethics' that travel by the same name, and the different ways of enacting patients as subjects in good care.

2.2 Conflicting ideals and embedded theories

This ethnographic analysis of good care articulates how ideals are embedded in different sets of practical activities, and what kinds of subject positions are enacted with it. It shows that one ideal may inspire different practices, or ways of enacting this ideal. But these matters become even more urgent when an ideal encounters other ideals that are in conflict with it. How can such a conflict be analysed? Again, the ideal of individualisation is the example. This ideal helps to bring about improvements in care, but also runs into conflict with other ideals, or even marginalises these. In this case, the conflicting and marginalised ideal turns out to be the ideal of sociability among patients.

> *Geriatric assistant*: Yes, taking care of people was always the first thing here, with a lot of attention for the residents. To play on the needs they have. It wasn't a therapeutic happening here, really. That is still a strong motivation in this team [of geriatric assistants]: life has to be enjoyable [gezellig][18]. There should be nice things to do with the residents. Not forgetting their freedom, of course. But you look at what people want. And what is always a success, are the afternoons with a video, or to get everyone together for a drink. Every day there is a round for a drink, but sometimes it is extra special. With a bite to eat, and then 'all together'. And then people really start telling stories. Yes, this 'being together', this feeling, that has always been most appealing.

Specifically in care for the elderly, the so-called 'group care' (groepsopvang) was thought to bring pleasure as well as a healing and safe environment for people suffering from dementia or other psychiatric problems. The geriatric assistants still put forward this ideal on positive patient sociability. However, the psychiatric nurses who are new professionals in the residential

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[18] The Dutch term 'gezellig' is a characteristic word and is hard to translate. It denotes an easy and relaxed way of being together with others. In a master-class with the linguist Anna Wierzbicka, she and the students set themselves the task of defining 'gezellig here!' by using 'primitives', which Wierzbicka claims are 61 basic semantic concepts that can be found in all languages, and can define any other term. The result for defining 'gezellig here!' was: Everyone can think like this: I am here now with some other people/ these people are all doing some things at the same time/ because they want to feel something good/ They don't want anyone here to feel something bad/ they all feel something good/ I want to be here with these people NRC, 20-9-2003, p. 35.

homes argue for individualisation and contest the ideal of patient sociability as unprofessional and 'group oriented'.[19] Individualisation and patient sociability seem to be in conflict with one another. But in what ways exactly? To answer this question I will look again at the enactments of individualisation described earlier and show how such a conflict can be analysed.

Take the skills training, for example. That the training of individual skills leads to conflicts with notions of sociability can be demonstrated by the practice of 'learning to make coffee'. In the residential home everybody has their own coffeemaker in their private apartments. The idea is that if everybody learns to make coffee, nobody is dependent on staff to get it.

> Elsa [geriatric assistant] talks about the little refrigerators the residents have in their apartment: nobody uses them! That's a mere electricity bill, she complains. She says the same counts for the individual coffeemakers. Nobody uses them, the residents come out to the common room for coffee. But Jolene [psychiatric nurse] is hopeful: when new people arrive [who are not hospitalised] this will work out better, and people can make coffee when they feel like it.

Being able to make coffee in your own apartment allows for individualisation of coffee-routines. Making coffee is thus seen as an individual skill that is needed to organise one's life in ways one prefers. Not using this skill is perceived as an effect of hospitalisation and a lack of ability to use individual opportunities.

However, on another residential home ward residents do make coffee. They do not do this in their private apartments, but in the common room.

> Kim has put the cups on the table, together with the milk and the sugar. She has also made the coffee. She has a strange way of moving, she swings dangerously from side to side, and does not seem to be very stable on her feet. Just putting the milk on the table seems to be a major effort. But she manages, even tough it takes her about half an hour to organise the morning coffee.

On this ward, Kim often organises the morning coffee. Other residents alternate in preparing the afternoon tea and coffee. Making coffee here is not seen as an individual skill to be practised, but as a means to bring about the social event of 'having coffee together'. People, who like making coffee over other little domestic duties, take up the work. Ironically, this rather instrumental approach to making coffee seems to encourage practising coffee-making skills better for the persons concerned than the individualised coffee making of the ward mentioned before.

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[19] The opposition of group and individual is also made in the literature. See Atkinson 1998.

When making coffee is approached as an individual skill and activity, the individual and the social can be in conflict. Individual activities are valued as meaningful, whereas social activities are perceived as marking an established routine and lack of individual abilities, and therefore: choice. The problem to be solved was defined as 'depending on staff', but the value of social events was not even considered: 'old routines, this will change when new patients arrive'. That having coffee together might be an activity residents actually *enjoy*, is made invisible by a perspective on individual skills; following preferences comes after the training of skills, otherwise there can be no choice.

There is another way that skills' training is in tension with patient sociability. When individual skills are stressed, *everybody* has to practice them. For each patient, the highest possible level of independence and activity is aimed for. Because individual activity is important, 'helping each other' can be valued negatively.

> *Meeting to inform residents about changes in care on the ward.*
> The co-ordinator talks about sharing responsibilities for the domestic work. Mrs Crow is asked to stop setting the tables for the meals, as she always does. Mrs Crow does not understand this: shouldn't the tables be set? And wasn't that what she was doing? The co-ordinator explains that others may want to do this as well, and that this would be good for them, if only to get some exercise for the hands. Mrs Crow looks puzzled. Mr Blanche interferes. He says people can do sports if they want to exercise. He points to the two oldest women on the ward, Mrs Blackburn who is 102 years old, and her 97-year-old neighbour. "Look at these old ladies," he says, "Should they do the work?" "Oh, yes, I put the dirty linen in the vacuum cleaner everyday!" Mrs Blackburn comments cheerfully. The co-ordinator says that it can be nice to have responsibilities and that nobody is asked to do things they cannot do. Mr Blanche does not agree: 'Isn't this an economic thing, that we have to work because the house cuts down on staff?' The co-ordinator cannot deny that staff is going to be reduced, and he says that everything can be brought back to money, but that he prefers to see this as the sharing of responsibilities together.

Neither Mrs Crow nor Mr Blanche connects 'setting the table' with individual skills or responsibility. They rather see links between 'work' and setting tables. Laying the table is a necessity, and has to be done before one is able to have a meal. Who does it is of minor importance, as long as the person volunteers and is not 'too old to work'. For developing individual skills, however, it does indeed matter who is active, because everybody should be trained to keep fit, to become active and independent. It is a difference in ideals and pragmatics between patients and staff.

Individualising care by developing individual skills is in tension with more instrumental visions and social values the patients hold dear.

In this analysis, seemingly prosaic activities such as making coffee or doing domestic work are described. What makes these activities of ethical interest, is that the ways of practising these daily routines, the ideals that inspire them and the subjects enacted, are in conflict. In the situation described, the patients put forward alternative, competing forms of subjectivity. Instead of enacting themselves as skilled individuals, they put forward social and pragmatic forms of subjectivity. These alternative forms of subjectivity point to different ideals of good care, such as taking care of older persons by doing work for them, or helping others. These ideals are hard to interpret for nurses who practice individual skills training. The different practices incorporate different 'practised philosophies' or 'embedded theories' of what is a good life and what is good care. Articulating these brings these tensions to the fore.

In this analysis, the patients can be seen as incorporating ideals of good care in their activities. The patients here do not have an ethical mission as being 'responsive receivers of good care', as Joan Tronto positions the patient, or as patients suffering from severe mental problems who can nevertheless become skilled individuals, as the nurses position them. Instead, the activities of the patients put forward substantial ideals of what is good care. They do not always proclaim these ideals verbally, as could be seen on the ward where the residents did not use their individual coffeemakers, but went out to have coffee together. Nevertheless, these patients can be seen as enacting ideals and theories of good care.

2.3 Subjects as results

Analysing good care as conflicting embedded theories has implications for the analysis of who or what the 'ethical subject' is. Who can be the 'ethical subject' in practical situations?[20] To demonstrate this, I will use an example from the practice of giving space to individual preferences, where it is in conflict with notions of patient sociability. The example here is the puzzling wish of patients to not leave the hospital when chances are provided to move to a better situation.

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[20] Note the difference between the 'ethical subject', who is a person that is ascribed responsibility for what is good, and the actor, which is active in producing a form of good care. The ethical subject is not necessarily active, and the actor can also be non-human, such as the coffee makers. One can be an ethical subject without being an actor and vice versa.

> *Interviewer*: And the patients, did they want to move from the psychiatric hospital to the residential home?
> *Psychiatric nurse*: No, they didn't. A survey was done to ask them, and none of them wanted to go. No, really, one wanted to go, because this village has a Hema [popular discount warehouse]. But the people who did the survey were against the move. And now nobody wants to go back.

The nurses were happy they could suggest the move to a residential home. The residential homes provide private apartments in a non-stigmatising living environment, service for the elderly, and are located nearer to the community, family and friends. The patients, however, did not applaud this improvement beforehand. They made it clear they did not want to move. This is nothing typical for the patients discussed in the interview. During the years of research in psychiatric hospitals and residential homes, I have heard many patients expressing their attachment to even the most worn out buildings on partly abandoned hospital terrains. One 60 year old patient who *did* make the move from the hospital to a modern building on the other side of the street, positioned his chair in front of the window, so he could sit and stare at the old hospital building where he had spent his days since his 18th birthday.

The refusal of patients to move and their attachment to the hospital has baffled well-meaning reformers in mental health care, and is not always taken seriously. The patients seem to refuse an obvious improvement of their situation. Their reluctance to move is, again, interpreted as a sign of hospitalisation, a lack of idea, or fears for what opportunities await them elsewhere. Hospitalisation here is not so much the effect of *not being able* or missing the skills to act differently, but of not making an individual decision to act differently. Staying in the hospital is not seen as the consequence of individual choice and is not different from the old situation of the hospital. After their move they will see this, and be happy they have left the hospital.

With an analysis of practices in which notions of good care are embedded, it can, however, be articulated how the patients *value* the hospital environment, or are attached to their routines or to one another. The patients can be seen to organise their routines together and stick to them. If patients would leave the hospital individually, they would probably lose more contacts than they would ever be able to re-establish. Thus, the patients can be seen as putting forward an ideal of sociability in their activities. In this explanation, the refusal to move can be interpreted in a way that takes the patients seriously and does not describe them as 'irrational' or as unable to make decisions that are in their best interest. The explanation of hospitalisation runs the risk of dismissing social preferences too quickly, because social values are not considered and 'explained away' as unfree, because they are not individual, and are not choices because they are not different compared to what people are used to.[21]

In these examples, the shaping of the ethical subject, or person pursuing what is good, differs according to the situation one observes. To be a subject who decides for him or herself in his or her best interest, proposes a different form of subjectivity from the one in which social interests are valued. In this analysis of good care, the characteristics of the ethical subject are not defined beforehand, but are analysed as the *outcome* of ways in which ideals are put into practice. It is not questioned that people pursue what is good in their practices, but rather, the specific forms this goodness takes. Hence the characteristics the ethical subject has are analysed as the result of these practices rather than preceding them. In this way, this form of empirical ethics does not put forward a substantial (e.g. Kantian) ethical theory that grounds ethics in human faculties such as Reason or on principles such as Justice or Autonomy. Rather, it analyses what an ethical subject is as the result of the different ways of ethically framing situations in practice.[22] In our example, enhancing autonomy appears not to work as such when people do not perceive themselves as autonomous individuals. Ironically, this contradicts the aim to which individualisation was put forward in the first place: to make the patients heard and emancipate them. The different forms of subjectivity and their related embedded theories of good care are analysed as effects rather than intentions, thus allowing for a critical appreciation of the desirability of these effects.

2.4 History of ideals: connecting heterogeneous elements

So far, I have shown that this way of analysing good care looks for relations between ideals, activities, practical events and things. Different ideals are enacted in different repertoires of activities, incorporating different embedded theories of good care. Who or what the ethical subject is, is analysed as the outcome of these specific practices and embedded theories, rather than preceding them, and the same person may take different subject-positions in different situations.

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[21] This is not to say that the patients are always right, or this interpretation is the 'correct' one. But at least it can make the participants aware of different motivations and problems, and look for ways to deal with them.

[22] See Moser (2000) and Winance (2001; 2002) for ways in which the physically disabled subject is created as able or disabled in interactions with people and objects, and by discourses on care and disability. For a reflexive turn towards 'practising bioethics', see Gallagher et. al 1998,

Now I want to turn to the question what makes care 'good care' for the persons practising it. What is this good and what is it made of? Why do participants think one form of good care is better than another? Again I take the ideals of individualisation and patient sociability as examples. I will look more closely at the historical and practical context in which individualisation became popular. To what problem is individualisation supposed to be the solution? What was changed and what remained the same? The analysis serves to draw out that what is thought of as 'good' does not only relate to ethical questions, but also to historical developments, ways in which hospitals are built and ways in which the problems of patients are defined.

Counterposition of individualisation

The nurses in my study articulated a clear counter-position of individualisation: the 'hospital regime' or 'group regime'.[23] In the images of the old hospital regimes invoked in the interviews, patients lived under strict and general rules that organised the day for them. The institution dictated at what time everybody should get out of bed, when breakfast ended and therapies started. Time schedules were fixed and were to be followed by all patients. Showering, for instance, was in groups on fixed days and was supervised by the nurses. [24] In this horrific institution there was no privacy. Sleeping rooms were shared and closed to the patients during the day.

Individualisation of care was a solution to what came to be called the 'regime of the group', but with the regime, patient sociability also came under attack. The hospital itself became suspicious; nobody had chosen to live there, nobody chose the persons they were forced to live with, or the amount of persons to live with.

> I have been a psychiatric nurse for fifteen years now. And in the early days you were not exactly a dictator, cruising the ward saying: you should do this or that', but the approach was much more directive and it was more common to take measures [use coercion, most often seclusion]. However I have worked on a ward where everybody had to be up at eight and you took care to make sure that this happened. And you weren't a good nurse if you could not do that. Now, though, you would, maybe not at eight in the morning, but you would discuss it

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[23] There are other counter positions that inspired reforms in long term mental health care, such as the therapies by 'token economy', but the hospital regime is specifically linked with pleas for individualisation.

[24] Cécile aan de Stegge studies the history of psychiatric nursing in the Netherlands in the last century, and describes how the showering could be a real division of labour, where a different nurse took care of one part of the showering process (washing, drying, dressing) for all patients, one after the other. (ad Stegge, forthcoming)

> with individual patients. "What do you want to do with your day? You do not want to get up at eight, but you do want to be at vocational therapy at nine. It is impossible to do both. How can we solve this, do you have a suggestion how you can get yourself out of bed? Or do you want to go to therapy later?" In this way things are discussed, whereas the standard used to be: therapy starts at nine, so we make sure everyone is there.

Instead of subordinating the individual to the institution, caregivers now help the patients to develop their individually preferred routines. Working from this individual approach, patients are stimulated to find a better place to live, outside the hospital, outside of large groups. However, if institutional care is the only alternative, care can be organised in ways that leave the patients as much individual space as possible.

So the nurses present individualisation as the answer to a grim situation in urgent need of an alternative. 'Everything has to change', were the revolutionary terms used. Psychiatric nurses were supposed to 'turn 180 degrees' in order to change 'thinking for the patients' into 'thinking with each individual patient'. But with this image of the group regime, the other patients are perceived as irrelevant to or hindering the individual. This is an unintended consequence of the ideal of individualisation. How could this link be made?

A first explanation for the way this counter-position leads to the negative value of patient sociability can be found in the image of the group regime. Instead of the group regime being a way of thinking about social relations between patients, in the way the nurses describe it, it appears to be a way of *not* thinking about the social. How patients should relate to large quantities of other patients was not relevant for the regimes, but merely provoked questions for the nurses of how to maintain order. The group regime served the purpose of smooth hospital organisation, reducing relations between patients to the orderly co-existence of 'inmates'. Their being together on the ward was not considered to be in any way beneficial or of therapeutic value, or even pleasurable, but was a practical way of organising medical treatment. Both in the hospital regime and in notions of individualisation, the value of patient sociability is discredited. Historically speaking, this negative evaluation of patient sociability stems from a situation where sociability was not valued in the first place.

Supporting positions for individualisation

The counter-position of the group-regime pointed out the forced living together of patients as the main problem. On the other hand, thinking in terms of individuals appears to be not so new. The nurses and doctors were already used to thinking about individual cases, in terms of patients with individual diagnoses and treatment. This form of individualisation came, historically speaking, before the skills and preferences and was directed towards 'cure' (see Boschma 2003).[25] Hence, the treatment in hospitals came into being. Nursing care and medical reasoning share the common value of improvement of individual patients. The aim of dismissing patients from the hospital is shared in both rationalities, either in the form of functioning better by developing individual competence or wishes, or by the treatment of symptoms. So if individualisation was presented as a revolutionary turn against hospital regimes, it is certainly not a revolution from medical, and thus, individualised ways of thinking and acting.

From this analysis, it can be seen that with the framing of a counter-position, a specific solution is favoured over another. At the same time, there were elements established in practice that supported some ways of thinking (here: in terms of individuals and individual progress) over others. So instead of the change from forced sociability to individualisation, the analysis shows this process can be better be understood as an elaboration and strengthening of notions of individuality that were already there. The 'revolution' (almost) did away with ideals of patient sociability in psychiatric nursing, but the history shows continuity concerning assumed revolutionary notions of individualisation. And while neither way of reasoning incorporates positive ideals of patient sociability, when they are combined, patient sociability becomes hard to imagine at all.

What I want to draw out with these examples is that what good care is, is not only connected to questions or principles that we can intuitively label as *ethical*. The framing of the hospital regime links the way hospitals are built and organised (good at one time, bad in later times), routines of the nurses and perceptions of 'what is the matter'. The 'diagnosis' of the old situation provides important clues for framing the right 'treatment'.

On the other hand, the underlying rationality for organising hospital care on large wards, a medical rationality, was (and is) not perceived as problematic.[26] That this medical rationality incorporates notions of individuality provides fertile grounds for the new ideals in care. However, individual treatment is not perceived as an *ethical* notion, but as a way of framing good psychiatric knowledge and treatment. 'Knowing patients' in a

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[25] Before these reforms in the 1920's patients were not primarily perceived as (mentally) ill, but as mad, but most of all *poor* people. Their housing was paid for by the ministry supporting the poor, not by the ministry of health care. See: De Goei 2001.

[26] Same as in the case study, rehabilitation is often perceived as a *complement* to treatment, not as an alternative to it. See for instance Anthony et. al 1990. Recently, this separation is problematised and the active client movement in mental health care questions 'treatment' itself. A vocabulary of 'recovery' is being developed, and redefinitions of mental illness are combined with goals of participation in the community (see Deegan 1993, and in the Netherlands: Boevink et. al 2002).

medical way, however, brings with it specific forms of 'good treatment', i.e. improving individuals and repairing functioning. This connects perfectly well with the new solutions in nursing care. So the practically interpreted and historically evolved definitions of 'good care', can be seen to link specific ways of 'knowing' the object of care, and acting accordingly. This ethnographic analysis of good care articulates the relations between facts, values, routines, activities and buildings. How good care is defined cannot be separated from practical matters or ways of defining what the problem is. Rather, their interrelations show that different repertoires of doing good are also different repertoires of knowing psychiatry, and of building and arranging hospitals.[27] Good care is made by connecting heterogeneous elements and should be studied accordingly. Articulating how the ideal of patient sociability in the historical and conceptual development of ideals of individualisation is almost accidentally marginalised, opens up possibilities for a rehabilitation of this ideal.

2.5 Co-existence of conflicting ideals

This empirical ethical analysis studies what is 'good care' as the complex relations of diverse and heterogeneous elements. Because of their interdependencies, revolutionary turns in care are not taken at their advocates' word, but can be seen to incorporate change as well as continuity. These (dis) continuities may or may not be transparent to the participants. But how can ideals in care be in conflict, and still be practised together? Discerning different repertoires or embedded theories of good care does not mean that nurses and others always consistently act according to *one* of these repertoires. There are overlaps and shared values, as with the medical and other individualisation repertoires. It is also possible to change repertoires from the inside. This happened for instance when the geriatric assistants incorporated skills training in their care practice for the reason that 'this makes the patients feel better' (instead of doing this to improve individual functioning).[28] The ideal of patient sociability has a hard time here, but it can still be traced. So if an ideal is still there, how can it be practised next to caring repertoires that seem to be in conflict with them? Let's look again at the ideal of patient sociability. In some places notions of patient sociability are valued, and even psychiatric nurses perceive a lack of

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[27] Networks of heterogeneous elements are also studied in Actor Network Theory, to study how *knowledge* is produced in scientific practices. Recently, this ethnographic type of analysis is used to study how normativity is embedded in care-practices. See for instance Harbers et. al 2002.

opportunities for positive interactions as a problem. A first example is a ward where the meals were delivered on individual trays. The trays were put on the tables where everyone gathered to eat. Sure, you can choose what to eat and you can start with the dessert; have the soup as a main dish and skip the potatoes altogether. But these individual variations were consumed in silence. The team reorganised the meal by serving it in dishes.

> We have an eating-project here. People do not get individual meals on trays put in front of their noses, but have to dish up the food, because the meal is served in dishes for each table. What you see happen then, is that contacts between the residents develop, also in between meals. Because, simply put, you have to pass a person a dish, or ask for the salt. And they clear up the table together. And you can see that, apart from the meals, they get along more with each other. The thing is: now people notice each other, and become interested in their environment. They suddenly see that their neighbour wears a nice dress, and they *never* noticed that before, let alone that they would say something about it. But it happens here.

The new material infrastructure allowed for interactions that cheered up the meal. This enabled a more meaningful way of 'having a meal together' and influenced social contacts on the ward. In this scenario, the others are not only thought of as restrictive to the individual, but can become of value too.

Another example is a ward where the residents did the housekeeping together. To organise domestic work, the nurses made a schedule, so everybody could read who is on for what task. Is this an example of new institutional regimes and restriction of individual freedom? At a closer look it was not. All kinds of individual variations could be spotted. One man chose to organise all his duties one after the other for two weeks and after that he had a week and a weekend 'off'. Three women did specific tasks they appreciated; one made the coffee, the other made the table and the third cleared away the dishes from the dishwasher. Others traded their jobs amongst each other for cigarettes or money.

And there are more variations. One woman was very active when she was not scheduled and did more domestic work than anybody else did. But she only did this spontaneously. When she was put on the list, she refused to work. It also happened that the residents decided together who was to be set free from the work. One lady was, under protest of the nursing-team, excepted from domestic work by the others, because she was in a wheelchair and was 'to be pitied'. Even if the nurses put her on the list, the others took over the work. The lady in question was quite happy to be dismissed and the nurses gave up pushing. Sometimes the group-decision was less favourable

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[28] This example is analysed in detail in Pols 2000.

to an individual resident. Mrs Jones indicated that the work was too much for her, but the other residents did not take her seriously. They thought Mrs Jones was lazy and put her to work.

So rather than being a form of general ward rule in disguise, the domestic work list allows for individual variations, and creates a complex social dynamics. Nobody wants to do the work for the others, so everybody sees to it that nobody escapes his or her turn. Passivity in waiting for meals is swapped for meaningful –though not always friendly- interaction. The conflicting ideals seem to be reconciled. Or are they?

> *Psychiatric nurse*: It [the group regime] is hard to influence. But the other side is that you notice that the dynamics of the group is what keeps it together. Then you can think: I want to go around that for the sake of the individual, but this stirs up so much in the group that I should maybe leave it alone. And that is what I notice more and more: this group has such a positive influence; I can still be surprised how people are able to arrange things together. They can really fight, swear at each other, but after ten minutes they can arrange things together again 'Ok, fight's over, we have to go on.' That is really amazing. And then I think: I shouldn't interfere with this. This is really valuable.

This nurses' positive labelling of living in groups is still contrasted with 'the sake of the individual'. But it is there and the nurse accepts it as a 'different, alternative good', even though this will not mean she gives up on her own ideals of individualising care by developing individual skills or by creating space for individual preferences. So this analysis shows that care is made up of different, sometimes conflicting embedded repertoires and ideals of good care. 'Revolutions' do not seem to make ideals disappear, but insert new (or re-insert not so new) ideals in practice. These ideals are interpreted in relation to embedded theories of good care that already exist in practice. The older ideals do not – or not completely- disappear, but can still be put into practice, even if they do not 'match'.

In this case, the residents educated the nurse. They found a way of living together that allowed for conflicts and co-operation. Rather than being a sad and passive hospitalised group, they could deal with each other very well. Part of the reason why they could is that they have lived together for a long time. They have learned how to develop a supporting sociability, and this may be a good thing. The loneliness and depressions of people living among others in care institutes are well documented. The problem of the group-regimes and hospitalisation practices could be that it is hard to live among others with whom one shares nothing but their mere presence.

Thus a diverse array of co-existing ethics *in* practice can be articulated.[29] How ideals of 'good care' take shape within daily practice can be explored, with nurses and patients as *practising ethicists*, people who orient their practice to and incorporate different notions of doing good in their activities. These notions of doing good are formed, as I argued before, by connecting heterogeneous elements, such as knowing what is the matter, organising daily practice and objects that are used. Therefore, empirical research and ethics go together in this ethnography of good care. Ethics, morality and ideals do not (only) come 'from the outside', but are abundant *inside* everyday care-practice, in activities, objects and concepts that intend to bring about 'good care'. The researcher can articulate this by relating even small routines in care to (tacit or explicit) notions of good care, and ideals can be made explicit by analysing successful as well as more troublesome situations. The relations between ways of solving problems can be developed into embedded theories of good care, linking implicit and explicit concepts and values to things and routines. Articulating these forms of everyday morality, questions their self-evidence.

2.6 Conclusions: interventions

To what kind of contributions might this style of doing empirical ethics lead? What kind of ethical interventions can it make? In opposition to a position where empirical research and ethics are kept separate and the ethicist adds the ethical reflection to the empirical study, this ethnography of good care creates a different relation to 'the field'. Instead of judging care-practices, by classifying acts as good or bad, or providing guidelines and rules practice should adhere to, ethics and morality that are enacted in daily care-practice, implicit or explicit, are articulated. Thus, not only the 'big' ethical issues, such as euthanasia, involuntary treatment or Ulyssess contracts can be reflected upon, but also day-to-day dilemma's can be articulated as effects of specific ways of framing good care.

I see the *articulation* of these different and complex ways in which good care gets its shape as the first intervention of this style of doing empirical ethics. Articulating different practices of good care makes it

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[29] Much has been written about the different ways that conflicting realities can exist together. See Mol (2002) for an analysis of ways in which different realities of 'atheroscleroses' are co-ordinated in hospital care. Boltanski & Thévenot (1991), asked 'ordinary people' how they justify their actions, and related the type of justifications to different 'worlds' (mondes). Their work is a good example of how different 'logics' can co-exist and be used together in everyday language. See also: Law 1994 for a description of embedded theories as 'modes of ordering' and Pols 2003 for examples of their interference in mental health care.

possible to reflect upon their differences. To realise that there is not just one form of good care but that there are different, conflicting forms that each have good and bad effects by enacting different kinds of subjects and embedded theories, invites participants to critical (self-) reflection.

But there is another intervention. This is an intervention that takes the form of a *proposal*. Showing the alternative workings of the ideal of patient sociability next to its marginalisation by ideals of individualisation is also a suggestion for the *rehabilitation* of this ideal. This ethical intervention does not take the form of prescription or rule formulated by the ethicist who is outside of practice ('You must attend to patient sociability'). It is a suggestion by demonstration of possibilities of this ideal. Participants in the field may be moved or seduced to work with its' positive potentials, and become cautious considering the workings and the blind spots of individualisation ideals.

In this way the ethnographer of good care does not merely describe how others do good, but neither does s/he 'know best' and present external guidelines for practice, other than insisting on stimulating reflexivity in practice.[30] This may be seen as a loss. But what is won is that this style of empirical ethics speaks to professionals and patients as striving for the good in their practice. What these goods are may be contested, but they are there and they are taken seriously.

Finally, I think this type of empirical ethics also speaks to ethics as an academic discipline. It points to the workings of ideals, not only to their theoretical characteristics. By studying ideals of good care ethnographically, it can be articulated what types of psychiatric practices and ethical subjects they bring into being. These effects are hard to predict by theorising, as they are the result of the interaction and connections of ideals, specific types of knowledge, routines, problems to be solved, characteristics of and positions taken by participants. The effects of ideals can only be learned by studying these interactions in practice.

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[30] Practically, this self-reflexivity can be organised on different levels. It is possible to organise team-meetings, meetings between different professions, patients and family-memebers, over different organisations and so on. In the Netherlands, meetings are organised to involve professionals and patients in a 'Socratic Dialogue', to discuss ethical problems they encounter and analyse them in terms of values that are at stake. See for instance Delnoij & Van Dalen, 2003.

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3 Washing the citizen: washing, cleanliness and citizenship in mental health care

Abstract

Common ideals that inspire improvements in mental health care are participation in the community and citizenship for patients. But what is meant by citizenship? Here an analysis is made of washing practices in psychiatric nursing in long-term mental health institutions. Four repertoires of washing are described, each oriented towards a specific notion of citizenship. In the first repertoire, washing is part of individual privacy; the patient is performed as an individual whose authenticity should be respected in order to equip him or her for participation in the community. In the second repertoire, washing is a basic skill; the patient must learn to take care of her body in order to become an independent citizen. In the third repertoire washing is a precondition to citizenship; patients are to be helped to develop their potentials so that they can find their way in the community. In the fourth repertoire, washing is one opportunity among others to develop social relations; the extent and quality of these relations define a citizen. This analysis opens up not the question *if*, but *which type* of citizenship should be promoted.

3.1 Introduction

Since the 1960s, the ideals that have inspired mental health care practices have centered on notions of citizenship. According to these ideals, people with chronic mental disorders should be guaranteed the same rights and opportunities as other citizens. Patients have been moved out of psychiatric hospitals to enable them to participate in the community. Rehabilitation programs have been developed to support people with chronic psychiatric illnesses, to strengthen their autonomy, to find them places to live in the community, and to find jobs for them outside of the 'total institution' (WHO 1996; Anthony, Cohen and Farkas 1982, 1990; Watts and Bennett 1983). The question this article raises is who this citizen is. What kind of citizenship is aimed at for mental health care patients? I will analyze this question by studying the practice of washing in psychiatric nursing.

3.2 Washing and citizenship?

At first glance, ideals of citizenship appear unrelated to mundane activities like washing. The change from ideals of cleanliness to those of citizenship can be seen in the short history of psychiatric nursing in the Netherlands. Cleanliness and washing patients was part of good psychiatric nursing around the turn of the 20th century. Mentally ill persons were hospitalized, provided with therapies, and, just like real patients, put to bed to get well. In those days, psychiatry tried to establish itself as a legitimate branch of medicine, signified by clean hospital wards and proper hygiene (Boschma 1997).

This is the type of hospital psychiatry that became the target of criticisms and reforms in the last years of the sixties. With the arrival of the new ideals - first, the humanizing of hospital care, and later, the struggle for community care and citizenship, washing and cleanliness became old-fashioned themes in psychiatric nursing (Dankers and Van der Linden 1996; Tonkens 1999). Even more, attention to washing and cleanliness became symbols for the wrong type of psychiatric nursing, aimed at cure for patients rather than support for citizens.

But can washing and cleanliness so easily be separated from citizenship? Classic texts in cultural anthropology and sociology have drawn attention to how washing practices are embedded in culturally specific forms of social order. Mary Douglas (1966) describes ‘rituals of cleaning’ as ways of positively shaping societies and presenting personalities. Dirt is the metaphorical ‘matter out of place’ that does not fit into the categories people use to think about their society.[31] [32]For Western societies, Norbert Elias (1976) argues that in modern times people have become increasingly reserved in matters regarding bodies, their excretions, display, and relation to other bodies. The changed interdependencies of Western people, he argues, have resulted in modern practices of etiquette, including privatization of bodily matters like washing. Alongside the civilized public interactions, these private interactions have brought into being a new private space.[33]

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[31] Some authors using Mary Douglas’ work have described people with schizophrenia as always escaping categories of modern societies, as ‘liminal persona’, neither inside or outside the social order, but always in transition (see Barrett 2000). This is not the standpoint taken here, as positions are more complex and depend on how the ‘social order’ is conceived.

[32] See for inspiring examples a special issue of Social Studies of Science and Medicine (1985) Devisch, Thompson and Constantinides.

[33] Elias’ main examples are formed by detailed analyses of changing etiquettes concerning table manners and the use of cutlery, relieving oneself, blowing one’s nose, bedroom manners, fighting and relations between the sexes. Washing is discussed in the last footnote of the first book, where the example is used to summarize his theory of civilization. Washing oneself has

Thus, even though Western washing is an activity that takes place behind closed doors, it is also an articulation of a specific social order. Furthermore, at least theoretically, it has connections with notions of citizenship, or ways of being in a social order. In Elias' work these connections between private and public persons are made rather direct; his analysis connects household relations directly to changes on the level of nation-states.[34] In political theory citizenship is conceptualized as the relations between citizens and the state. The emergence of the market complicates this idea. The market is either seen as a new form of public sphere and a way of organizing citizens (Nauta 1992), or as a private sphere where individuals should be free to act without the interference of the state.[35] Globalization and plurality further complicate neat distinctions between public and private spheres (Van Gunsteren 1992).

In this article I will sketch the 'theories' of citizenship as they find expression in daily practice in mental health care institutions in the Netherlands, without defining beforehand what a citizen is. One thing is clear, though: citizenship is connected to participation in the community. What form this participation takes, as well as which community is deemed relevant, varies with the different care practices. Accordingly, distinctions between public and private, and what place the public or private spheres occupy are sought *within* these practices, and not in philosophy books or policy documents. This might result in some surprising new conceptions of citizenship, in which washing has a specific, more or less valued place. What are these washing practices, who does the washing, and who are these citizens?

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not always been an individual need but started as 'Fremdzwänge', force by important others (like children who wash because their educators tell them to), gradually evolving to the unquestioned 'Selbstzwänge' or internalized conditioning to wash we know nowadays. There is no rational or hygienic reason to do so. On the contrary, people in the Middle Ages were afraid of epidemics that were thought to spread from 'poisoned water'. Changing washing habits coincides with changed relations in the public sphere. Vigarello (1988) wrote a fascinating French history specifically on bathing, and links this history to changing concepts of the body. He makes it clear that washing with water in order to clean the body only became common practice as late as the 19th century. 'Wiping', the use of powder, and later 'changing linen' served the purpose of maintaining cleanliness.

[34] De Swaan (1988) describes the connection of private households to public sewage works in modern society as the 'immediate connection between the private citizen and the collectivity.' (1988:139-40).For an interesting analysis of the bathroom as a 'public private affair' see: Gastelaars 1994.

[35] Most positions will be somewhere between these two extremes: especially in the latter it is often added that there is a kind of 'citizen-ethics' to which participants in the market will adhere (for De Toqueville this ethics was to be found in religion, and in a secular world this civil ethics poses a problem to liberal notions of citizenship). See for instance: Van Gunsteren 1991.

3.3 Background and methods

I studied nursing care and washing practices in the long-stay wards of two Dutch psychiatric hospitals and in five Dutch residential homes that provide housing for elderly chronic psychiatric patients. In both the psychiatric hospitals and the residential homes, I observed how psychiatric nurses perform 'good care' (Pols, Depla and De Lange 1998; Pols et al. 2001).[36] In the psychiatric hospitals, my aim was to describe the general ideals of rehabilitation by observing psychiatric nurses at work. How do ideals of rehabilitation gain substance when living outside the hospital is not an option?[37] In the residential homes, the concept of 'rehabilitation' was not used, though comparable ideals of developing citizenship and community participation were worked with (Chiu, Jastrubetskaya and Williams 1999). Elderly patients did move from the hospital to residential homes that are meant to be more 'community based', less stigmatizing, better equipped for physical disabilities and closer to family and other relations.[38]

My analysis of citizenship was inspired by the work of Boltanski and Thévenot, who asked 'ordinary people' how they justify their actions (Boltanski and Thévenot 1991). Instead of justifications, however, I studied performances (Mol 1998) by observing actions of the psychiatric nurses and discussing these with them later. This made it possible to reflect on routines and sensitivities in care that were taken for granted by the nurses, but were nevertheless oriented towards different conceptions of citizenship. I will describe four repertoires of washing in psychiatric nursing, each containing a different ideal of citizenship. A repertoire brings together specific actions, ideals and knowledge, forming 'modes of ordering' (Law 1994). A seemingly neutral activity like washing gets its specific meaning, value, and form of practice through its relation to an ideal of citizenship. The object of the washing, the place of mental disorders and the specific problems encountered differ for each repertoire.

The four repertoires of washing that I separate out for analysis are not restricted to one institution, ward, nurse or nursing team. Although some of the repertoires are dominant in one setting and absent in another, switches between repertoires can and are made with more or less difficulty. Some of the repertoires, however, conflict so much with one another that

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[36] In the psychiatric hospitals participant-observation took place over a period of 40 days. 19 caregivers and 8 clients were interviewed. In the residential homes 60 days of participant-observation took place, divided over five wards and two observation periods. 39 caregivers were interviewed, as well as 14 residents.

[37] In each hospital 2 open long-stay wards were studied.

[38] Five wards were studied in three residential homes. In two other homes psychiatric nurses, geriatric assistants and residents were interviewed. Residents were older than 65.

switches cannot be made and differences become a matter of explicit debate in practice. Spelling out repertoires, then, structures the messier complexities of daily life by articulating the -often inexplicit- patterns of values, knowledge and actions.[39]

3.4 First repertoire: washing is part of individual privacy

In the first repertoire, psychiatric nurses treat washing as part of individual privacy. Individual private space is not light-heartedly to be interfered with without the consent of the patient.[40] How and how often washing occurs is left up to the patients. Nurses can, however, try to make use of the patients' preferences to facilitate washing. They can try to *seduce* patients to wash and make washing easier and more pleasant. To this end, they can try to arrange objects in a way that would gain a response. Does the patient prefer a washcloth or a sponge? A nice perfumed shower gel or good old plain soap?

> *Psychiatric nurse:* Care used to be a group event, you went to the shower as a group, so to speak. In a huge institution such as this hospital, everything is centrally arranged. There's always the same food, always the same jam and cheese. And everybody has the same soap and shampoo. Then we said: Give us the money, we'll arrange it for ourselves. And then the clients realized: We can decide for ourselves what we want to put on our bread and what shower gel we like. And they learned to deal with a budget. If you buy ham or expensive shower gel, you can't buy something else. So they became aware of how to deal with money. And they really liked it!

Apart from citizenship, other gains associated with following personal preferences are mentioned in the quote: tempted by good food and bathing preferences, the patients learn to deal with money and budgets, which enables and secures the possibility of pursuing their personal tastes. Knowing how to organize and deal with your personal preferences and interests is an important ability for the private individual in matters of washing and elsewhere.

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[39] The list of washing repertoires is not complete: one repertoire of washing was identified that is not explicitly related to notions of citizenship, and it is therefore not discussed. It will be briefly touched upon along with the third repertoire, where washing is seen as a precondition to citizenship.

[40] The term 'patient' is contested by client movements in mental health care, where the term 'client' is preferred and deemed more respectful. I use the term as I see it fit to the context I want to discuss.

Preferences and tastes are individual matters, but they can also reflect more general norms. The individual is a bearer of these norms, and the biography of a person's norms and habits is used to guide personal care. The question is: How did a patient perform washing in the past?

> *Discussion in the team of geriatric assistants*
> *Diana*: Yes, Mr. Siegel. He's unmanageable. Washing and dressing is such a fight, it's really terrible.
> *Leader of Team*: Hmm. Are others having problems with Mr. Siegel?
> *Hazel*: I don't have any problems with Mr. Siegel. I go to him in the morning, I give him clean underpants and I wash him. No problem. I just wash him.
> D: But what about this unruly behavior!
> H: I have no trouble with him. I give him a down-below[41], and he has a sense of humor too, this grumpy old man. I really like him.
> LoT: I don't think Mr. Siegel needs a down-below every day. He's not used to it. He`s a person who went to the public bath once a week. He always did that. You shouldn't get into a fight with him. There`s no need for him to get upset about washing. If he refuses, just let him be.

By relating to a patient's history of washing, the activity can be tailored to what he or she is used to and prefers. People who washed once a week are not pressed to take a shower every day, but are encouraged to stick to their habits. Individually preferred objects and arrangements are important for nurses looking for clues to influence washing.

Preferably, there is a private individual space where patients can go about their washing alone. This is uncommon in psychiatric hospitals, however, where sanitary places are shared by patients living on the same corridor. The layout of hospitals and the lack of private spaces are thus the object of ongoing criticism. But even when there are no private spaces, nurses try to privatize washing as much as possible. The first step is to abolish the routine of the twice-a-week showering days. Although some of the patients stick to the old routines, others happily use their new freedom to reduce the number of showers they take. The nurses are cautious about interfering in matters of personal hygiene. They hold themselves back and give patients space to privatize washing rituals that other people so self-evidently perform alone.

> The citizen defined by this washing repertoire is an individual who differs from other citizens, because each citizen has different tastes, interests and norms.

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[41] This is a translation of an untranslatable Dutch term that would literally read 'to give a person an under-wash'. For the translation I used a term more common in the United Kingdom. Thanks to Vicky Singleton for suggesting it to me.

> Individual preferences are (historically) contingent desires and habits. They are trivial most of the time: it is not a matter of debate whether a person prefers pinewood scented shower gel or jasmine shampoo. But based on the more trivial fancy for jasmine soap are more troublesome wishes, such as wanting to die, or refusing a treatment the doctor thinks is necessary. In all instances, though, the notion of individual freedom, and the ability to pursue one's desires and self-defined interests, goes along with respecting privacy. Not being able to live out even trivial preferences would in this practice be an unacceptable and unnecessary restriction of individual freedom.

> *Psychologist:* You can ask yourself: why didn't we do this before? It's so obvious. You deal with people, they may be a little bit ill, but they`re people with tastes and desires. However ill you are, you can still appreciate the difference between, say, nuts and potato chips. There are always differences in taste. Everyone can understand that.

Permitting self-governance and allowing differences in norms and preferences implies a relative tolerance for dirt. The possible advantages of 'being clean' if the person does not automatically take care of it, compete with the strong value of individual freedom. In some cases this can lead to persons and environments that look very dirty to visitors from the tidier outside world.

> Monday morning, two cleaners are busy mopping up a huge pile of cigarette butts with a large rag. Burn marks are on every object that is capable of sustaining them. The common rooms are empty, except for ashes, cigarette butts, and coffee stains. The psychiatrist explains: 'We are looking for a balance between clients' norms and pollution. We do not want a sterile and clean ward like elsewhere in the building.'

The line the nurses draw between 'dirty' and 'too dirty' is guided by the preferences inferred from the practice of the patients living on the ward. Where individual privacy is an important value, dirt is much more acceptable than elsewhere. Dirt cannot be dealt with by professional authority, but needs consensus between nurse and client. Sometimes this leads to situations where all participants agree that dirt has become too dirty, and that something has to be done about it.

> Nurse Jan says, grinning maliciously: 'You sure missed out!' Lowie [a client who lives outside the hospital and is taken care of by the nurses of the ward] had a haircut and a shave. The barber refused to do it. 'The barber does everything for money, but for this he couldn't be bribed', says Jan. He gestures to indicate that

> Lowie had an inch-thick crust on his head. Under the crust was eczema, and in between were lice. Very many lice. 'The GP has seen a lot, but even he was impressed.' Jan says. Lowie is under the shower, soaking, to make up for a year of not washing his hair.

This extreme example is typical for a practice where individual privacy is highly valued: the citizen should be left in peace unless he or she volunteers for a bath. There is a consensus between patient and caregiver and the patient stopped by with his itching head to see if something could be done about it. Most people's limits will be reached much earlier, but from the perspective of individual privacy this is not a problematic situation.

Respecting individual privacy means allowing patients to be dirty if that is their choice or way of being. It's Mary Douglas upside down: instead of cleanliness and cleaning being the way of creatively crafting order and personality, dirt becomes an expression of an authentic self. Dirt becomes a matter '*in* place', an acceptable individual wish.

> *Psychiatric nurse*: People can be who they are on this ward, with all their handicaps, with all their odd behaviors. That`s our vision of rehabilitation. In principle, people are allowed to behave madly, as long as you can handle it on the ward. People are allowed to stay in bed for a day because they experience strange things. They are not obliged to get up and go to therapy. Let the people just be people to start with. They have so little left to themselves.

The tolerance for individual cleaning practices, with dirt being a private matter, includes admission of incurable anxieties and psychotic fears into this private sphere of preferences.[42] As one of my more eloquent patient-informants told me, patients, including himself, are anxious about showering and undressing.

> I ask Gilbert if he has an idea why nobody likes to take a shower on this ward. He answers me solemnly: 'Washing changes your body. Your skin and your pores. You have to undress, and that is unpleasant. These are fears. For myself, I do not undress when I go to sleep. Well, I take off my jersey, but not the rest. And I take a shower once a week, which is more than enough. You get a wash, change clothes, that's enough.'

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[42] Poor grooming and neglect of personal hygiene are listed as (negative) symptoms of schizophrenia in DSM-IV. Although 'positive symptoms' (delusions, hallucinations) have gained more attention, in schizophrenia of the 'Residual Type', that would concern the patient group I followed, the negative symptoms are more in the foreground. With the call for citizenship, the attention of rehabilitation has shifted away from pathology. For a classic critique of rehabilitation as regards this issue, see: Estroff 1995.

One lady was afraid her hair would fall out and her skin would come off if she took a shower. Another person associated the showers with torture-chambers, so he wisely avoided them. The nurses accept this and consider these arguments legitimate. They do not try to change the authentic self by training, learning, therapy or interactions with the outside world, *unless* the individual makes this decision herself. Personal development is a private matter as well, as are incurable psychiatric symptoms that become part of the person's characteristic habits and particularities, like being dirty.

The nurses experience problems respecting privacy when consensus between nurse and patient is absent. They do not refrain from interfering, but when they do so it is not to change the authentic self, but to put limits to conflicting forms of authenticity.

Nurse William says he could not stand the way Bill looked any longer, all dirty and with scabs on his face [he has a skin-problem]. They had tried 'personal responsibility' and gentle insistence, even a prohibition to enter the common room in this dirty state, long enough, with no result. William ordered Bill out of bed, dragged him under the shower and scrubbed off all the scabs. 'Harder!' Bill had called. He was in the shower for almost two hours. William put clean sheets on the bed and discovered about thirty empty cartons of apple juice behind it. Now Bill is in the common room, his head as red as a fire engine. Martha says there is ointment for it.

Because non-interference is valued and interference is suspect, when patients like Bill do not wash themselves, it is rarely clear when the point to do something about it is reached. In the example cited a negotiation takes place about individual privacy: Bill can continue his behavior, but he is not allowed to disturb others by entering the common room. This allows Bill to be free and maintains the nurses' non-interference in Bill's privacy. Thus, individual privacy seriously restricts the possibilities for professional assertiveness in matters of washing.

When nurses do interfere without the invitation of clients, they sometimes justify this in terms of the intolerance of others. Other persons limit self-expression. Just as the individual is a private person, other people are equally private individuals with different, sometimes competing, interests and norms. By invoking (negative) rights (the right not to be disturbed unless harm is done to others), nurses also legitimate their interference in legal terms.

> *Psychiatric nurse*: Well, you know, you are allowed to do that according to the law. We use the following phrase very often and very creatively: to cause inconvenience to patients, roommates, or others. Then we get someone by the short hairs and see that it gets done. We have a few of those here. Gerald, for instance. Yeah, he looks nice enough from the outside, but when you bathe him you see that the front is yellow and the back is brown. And a change of clothes is badly needed.

Framed in this way, the relation of the individual to others (patients, nurses, family) is oppositional. Other persons restrict the liberty of the person living out his or her authenticity. It is hard to think of being clean as of value to a person who does not automatically do it or explicitly ask for help. At the same time, relations with others are not seen as of value to the individual.[43] The nurses construct relations between individuals in terms of conflicting interests.

A private wash for the authentic individual: the private citizen

Just what does this practice of washing tell about citizenship? In order to become a citizen in this care practice, an individual private sphere is needed. In this individual private sphere the ‘atoms’ of public life can be developed: the authentic individuals. Authenticity in the individual private sphere can be lived without others interfering in it. The authentic individual has a specific form of autonomy, which is related to self-governance and freedom. The individual private sphere is needed to enable individuals to participate in a community of citizens that take care of their own interests and defend their authentic ways of being. Individual qualities and preferences need to be developed by the individual to be equipped for participation in a community where other individuals are equally autonomous, pursue their own goals, take care of themselves, and express their preferred way of living. Everyone has a right to be a private individual, but specific competences are also necessary. Authenticity for these patients needs to be developed by providing material conditions and individual responsibilities. In this way, the patient is paradoxically regarded as already being a citizen, and as becoming a citizen.

From this it appears that the mind of a person is more private and individual than the body. The citizen is free to think and decide whatever he

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[43] Most of the time the other patients on the ward are perceived as the ones hindered by foul smells or scruffy individuals. This is also a strong way to phrase the resistance against group ward life. Behind this resistance lies the idea that people should be able to choose with whom they want to live (see for instance: Atkinson (1998)). But apart from the patients, nurses and family members are also seen as individuals with specific norms that they bring into the situation.

or she wants, either publicly or in an individual private space. But the body presents a more ambiguous part of the private sphere. On the one hand the body is private, because people have the freedom to express their authenticity by making what use of it they like.[44] But care practices clearly show there is a limit beyond which nurses will interfere. At that point, the body is drawn into a social sphere of individuals with competing interests, or of caregivers with nagging feelings that something is wrong. Being dirty as a way of authentically living your body results in dirty bodies becoming a matter of public scrutiny. The hospital then becomes a social or public place, though not completely: the nurses' interference, however justified it may seem in a specific instance, is still seen as a transgression of the private boundary protecting individual freedom.

Thus, respecting privacy of individuals as a way of preparing for citizenship makes it very difficult for caregivers to interfere when patients pollute for whatever reason. Psychiatric nurses have to contain the feeling that 'this goes too far' or equally unspecific legal rationalizations of hindrance. This inarticulate urge to interfere has to somehow overrule the larger principles of personal freedom and responsibility. (Not) washing brings a tension to the fore between what can be seen as private individual attributes that are of no interest to others (like color of skin or hair), and individual interests that affect (or harm) others.

3.5 Second repertoire: washing is a basic skill

In the second repertoire washing is performed as a basic skill. As such, washing is not left to personal preferences. Washing skills are general skills, which should be learned or trained. Nurses often make an analogy with muscles and brain cells. You have to exercise them, or they will shrink and deteriorate: 'use it or lose it'.[45] Armed with these athletic metaphors for bodily functioning, nurses do not take washing tasks from the hands of the patients. The trick is, as much as possible, to induce patients to perform the acts for themselves. This can help in *relearning* a skill one has lost, for instance because of hospitalization. A patient who never had to wash herself may not be able to do it anymore. Doing it yourself also serves the purpose of *keeping the skills intact*, trained and fit.

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[44] More generally accepted ways of manipulating bodies are the piercing of ears, wearing of extensive tattoos, or even changing of sex.

[45] This is also the reason for playing 'memory games' with elderly people: to keep the cognitive functions trained.

> Nurse Rose has helped Mrs. Brisbane out of bed, out of her nightgown, into the wheelchair, and has wheeled her to the bathroom. Rose turns on the taps, puts a washcloth in front of Mrs. Brisbane and says: 'Put your hand on it. Okay, now wet it. Now go ahead and wash your face.' 'No' says Mrs. Brisbane. ' Come on, it's nice if you can do that for yourself!' Rose says. 'No' says Mrs. Brisbane. But she starts washing her face anyway. And I see she is perfectly able to do it. 'Your ears too!' Rose calls from the other room, where she is making the bed. 'Yes' says Mrs. Brisbane, but I can see that she isn`t doing it. Rose returns to the bathroom. 'Now the upper part of your body, with soap. Put some soap on the cloth, okay now.' Mrs. Brisbane fiddles with the soap and with an efficient movement Rose puts soap on the cloth. Mrs. Brisbane starts washing her chest while Rose gives directions. 'Your armpits too!' Mrs. Brisbane washes her armpits. 'And under your breasts!' Mrs. Brisbane obediently lifts the left breast and washes the skin underneath. 'Very good', Rose says, 'Now the other breast. Otherwise you'll get a rash, you have it a little bit already'. Rose helps her. Now Mrs. Brisbane is finished and she puts the washcloth in front of her. Rose rinses the cloth and says: 'Put your hand in again. Just to rinse off the soap. You're doing great!' And the ritual repeats itself.

Although it is doubtful that Mrs. Brisbane will ever wash herself without assistance, the acts she does engage in herself serve the purpose of keeping her fit and keeping some of her basic motor skills intact. The nurses and geriatric assistants explained that this way of washing a person is much more demanding than just taking over. And the result is often less satisfying to them in terms of cleanliness. Caregiver and patient perform the act together. The nurse gives verbal cues, and acts as a 'prosthesis' by performing the parts the patient cannot do so as to enable what she can do. Where learning and maintenance of skills is the goal, 'functional diagnosis' becomes important in psychiatric nursing: what can a person do, what can't she do, what can he learn? Assessment and planning are tools in nursing care with a basic skills perspective. Care-plans become necessary props, and a smooth exchange of information in the nursing team is organized. All members of the nursing team should know what a patient can and cannot do, where assistance is needed, and what goal the training aims for. Every nurse should approach the person in the same way, especially because the training is not always without a struggle, as I will show below.

The goals of the training are written up in care-plans, and the nurses write reports on the progress made and trouble encountered. The training of skills implies improvement; evaluations can and should be made. Not surprisingly, this brings in an element of optimism in care for severely disabled persons, because a new form of progress is defined: not the removal of symptoms, but the development of skills. The body is active in its striving for independence.

This type of care is associated with rehabilitation. It is assumed that the individual would like to be independent in order to be able to live in the community. Washing oneself contributes to this ideal of living with as little dependence on professionals as possible: if you learn to do for yourself what you can, you will be less dependent on supporting professionals. On the other hand, the image of physical fitness and learning makes basic skills fit in as well with medical formulations of treatment. Training skills can be seen as a therapeutic goal that, once reached, implies a return to a normal, civil life.

Positing washing oneself as a basic therapeutic aim and as a source of freedom gives the nurses the authority to force individuals to do it. This authority is not perceived as problematic, because it is implicit that the person also *wants* to be independent: either you *have* the skills and you would want to use them, or you do not have the skills and you would be happy to learn them. Passivity is to be avoided from the point of view of basic skills training, because it would cause skills to deteriorate.

But why are washing skills regarded as *basic* skills? This is because, excepting serious physical handicaps, washing is a skill that everybody has and that must be practiced before any other activity is attempted or skill is learned. Having a diagnosis of, say, schizophrenia does not damage washing skills (although it might be thought of as damaging motivation to use them, see below). This disconnection of physical skills from mental illness provides an opening for turning the patient into an active and autonomous citizen. Because the skill is basic, everybody *should* wash him- or herself. On this basis, other skills and activities can be built.

> *Geriatric assistant*: I have the feeling that they, well [searches for the right word] they felt more *grandeur*. They decide for themselves when they will wash. For some of them the whole morning ritual changed. First they went to breakfast in their dressing gown, and afterwards they went to their rooms to have a shower. Instead of: seven-thirty, call everybody and wash immediately. Some people got a much larger territory; they became interested in different things. They began to get involved in setting the table.

Regarding washing as a basic skill is closely linked to theories of hospitalization. Taking activities and responsibilities out of people's hands will make them passive and will cause skills to disappear. It is also related to the idea that hospitalized and socially excluded people should learn skills in order to get around in the community. Making telephone calls, budgeting, and filling out forms all are important skills for the citizen-to-be. But washing is the most *basic* skill; it comes before filling out forms. It is lowest in the pyramid of self-management and is practiced also in care where training is not otherwise important. As the geriatric assistant says, changing caregiver routines also changed client routines. Clients' new assertiveness in other areas supports the idea of washing as a basic skill, from which other activities can be developed.

So, from a professional point of view, it becomes imperative to practice or learn skills. This can lead to disputes with patients who resist doing the washing themselves.

> *Geriatric nurse*: Most of the residents are psychiatric. This requires a specific approach. You see, Mrs. Albert, she can help herself. She can wash herself, she can walk. However, she will *never* say that she can. 'I can't do anything', is what she keeps saying. And if you give in to this, you take away all her independence. It's a fight, over and over again, every morning, to get her to do it herself. Just to dress herself and walk over to the living room. So, despite the fact that you don`t have to do much work with this woman in the way of actually helping her, she's got a morning's work cut out for you, supervising her.

The geriatric nurse argues with Mrs. Alberts so that she will not lose her washing and dressing skills. Although Mrs. Alberts denies being able to do it herself, her statement is not credited, because the nurse sees no physical handicaps. Mrs. Alberts' objections are seen as a consequence of her psychiatric problem, not as a 'real' (physical) impairment. Psychiatric disorder is not seen as a valid reason to leave responsibility for one's personal care to others. This frames the person with mental illness as irrational and unpredictable, or even as sabotaging or manipulating care.

> Sandra [geriatric assistant] tells me that she deputized on the other ward with less severely disturbed clients. She thinks it's a world of difference. 'You could think: this is the psychiatric ward, so you have to work harder, now and again. But that`s not the point. Of course the people here are physically in need of more care, but that isn't the point either. The work gets hard when someone doesn't *co-operate*. When you say: "Put your hand through this sleeve," and she doesn't do it. Take Mrs. Best. She´s a small person, but she doesn't co-operate at all. So sometimes you help her with a good wash-up, get her dressed, and you say: "Come on, I'll walk you to the living room". And she refuses, she says: "I can't walk." So then I think: "Okay, I'll let her be alone in her room for a minute, I'll come get her later." And when you come back, she´s shit her pants. She does that, I told you before. So then you have to put her under the shower again.

Seeing the refusal to practice basic skills as sabotage is a consequence of the specific way in which skills and learning define a person's autonomy and normality in this care practice. Autonomy is found in activities that enable decisions or freedom afterwards. To be a citizen is to act independently. To refuse to do so is not a serious position in a basic skill repertoire. Mrs. Best is treating her body not as a citizen-to-be, but as a disturbed person.

A skilled wash for the independent body: the independent citizen

Where washing is a basic skill, washing is an explicit competence to be learned by the aspiring citizen, who must be independent to live among other independent citizens. Autonomy is characteristic of this citizen, but before freedom and choosing comes 'doing'. Being autonomous is doing things oneself as much as possible. If you can do that, you can organize your life as you like. Skilled bodies provide the conditions for free choices.

Washing is not optional: everybody has to do it. Bodily activity is of importance to a skilled person striving for independence. It is assumed that the patient wants to become an independent citizen. Citizenship involves freedom of mind, but not of bodily actions, because freedom of mind is obtained through specifically trained body skills. The independent person can function in the community by being self-supportive. Professionals, like psychiatric nurses, provide temporary support; by successful training, they have to make themselves superfluous. In this way, they try to equip the citizen-to-be with the necessary competences. Nurses do not define themselves as part of a public sphere, but as providers of 'therapies' (training programs) that enable patients to become competent to leave the hospital and go back to the community 'out there'.

'Psychiatric disability' does not disrupt the skill itself. Psychiatric problems might damage co-operation with goals that nobody in their right mind would question. People with a mental illness are able to wash and they should be pushed to do so, just like everybody else. Being dirty is not an option. It is the reluctance to wash that has to be overcome. Objecting to a basic skill scenario would be an objection to citizenship and a choice for patienthood. This leaves patients not many possibilities to propose alternative ways of becoming a citizen. Their psychiatric disabilities are not the object of care, yet they are still treated, like patients, in order to become skilled citizens.

3.6 Third repertoire: washing is a precondition

This repertoire of washing is complicated, because it is not about washing. However, even though it is ‘not about washing’, it establishes certain conditions for washing. In this repertoire, washing and getting dressed are preconditions for doing things in life that really matter. One simply needs to be washed and dressed to be able to go to work, get around in the community, use services, get an education, or re-establish one’s contacts with family. These are goals for professional nurses: to help a person develop the project of his or her life.[46] Much in line with the historical change mentioned in the introduction, washing is not seen as a part of professional nursing aimed at developing citizenship.

In a life project, being clean and well dressed is not considered an important thing in itself but is taken for granted. It would be best if the person took care of these matters herself, just like everybody else. If problems arise and a person cannot do this, help can be arranged, for instance by hiring professionals specialized in washing people. It is seen as a practical problem that needs a pragmatic solution. If a person looks a bit different, this is not of great importance when measured against the challenges that await him or her in the real world. But offensive smells or dirt are of no help, either. It is not questioned whether or not washing should be done, but rather who should take care of it.

In this way, the performance of washing is more a matter of organization than of specific techniques. Hiring the residential homes’ geriatric assistants is a way of doing this. In the psychiatric hospitals, there are mixed teams of geriatric assistants and psychiatric nurses in wards for the elderly. However, there were no washing professionals on the wards with younger persons in the psychiatric hospitals I studied. The psychiatric nurses had to assist if necessary.

The care where washing is a precondition aims at citizenship by ‘self-actualization’; psychiatric nurses help the patient to develop and sort out their priorities and help them to develop the project of their lives. This is resonant with humanistic psychology.[47] Self-actualization is a specific form of rehabilitation in psychiatric nursing. The focus is on personal growth, not on symptoms or pathology. Patients can discuss pathology with the

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[46] Thanks to John Law who suggested the metaphor of ‘project development’ to me.

[47] For instance, Carl Rogers (1969) discusses how to help people ‘to become a person’. Abraham Maslow’s ‘pyramid of needs’ assigns bodily needs to the base of the pyramid, and the more spiritual matters of self-actualization to its top. Indeed, Maslow’s term ‘peak-experience’, an experience that transforms a person’s understanding of self and world, reflects the pyramidal order of a life project.

psychiatrist if they specifically want to put it on the agenda. Development of a life project, however, is the main task of the nurses, a way to turn patients into clients and citizens.

> *Psychiatric nurse*, team leader: You know, they de-patientize if you see what I mean. Specific disorders or deviations exist, but you don't have to act on them. You just have to take care that nobody is bothered by it, especially not the person suffering from it, that he can get along with it in a pleasant way. And if you are coaching people and want to get to know them, patient records are not the first things you need.

For the self-actualizing citizen it is important to explore individual goals and projects for the future, one that holds the promise of the fulfillment of personal potential and leads to a development of a respectable place in the community. People pursuing their personal goals and strengths are of benefit to society as a whole. Skills can also be trained but in quite a different way than as a basic skill. While it is obligatory to practice basic skills, there is no need to have specific skills for self-actualization. The skills to be developed have to be meaningful to a person's life project.

> *Psychiatric nurse*, team leader: Well, yes, we do try to let people keep their independence as much as possible. And that is something different than wanting people to function as independently as possible. In that case you will teach people to do tricks. Everybody does the dishes; everybody cleans his own room, and so on. While here, we look at the person and ask: 'Is it meaningful to them, does the person benefit from it, can the person handle it, and do things get messed up if he doesn't do it.' It has to be an improvement for someone's life.

Autonomy in care for self-actualization is a matter of developing and choosing rather than doing things oneself (basic skills) or being free to decide on one's individual private life (privacy). What skills should be learned is left to the discretion of the individual. The nurses do not push the individual to learn or practice specific skills, as would be done in a basic skill care practice. And they do not leave it to individuals to privately decide on their goals, but actively engage in helping them articulate these decisions, and assist them in realizing their individual projects.

Clients, however, are not often explicit about what they perceive as meaningful to their life project. After years of hospitalization they have learned to keep their dreams and stories to themselves, and lost track of options existing outside the hospital. Deciphering hints and looking for clues are part of a nurse's job, in order to support individuals in discovering what they value, and to help them to develop their lives.

However, when geratric assistants are hired to support patients with washing, 'precondition' and the 'real thing' turn out to be very different.

> *Psychiatric nurse* [in residential home]: We do deputize for the geriatric nurses on other wards, out of office hours. One day a person was on the point of dying. And those girls [geriatric assistants] ran around, they were extremely busy. So there was no time to pay attention to the dying person. And they talked about it, about dying alone: 'Oh yes, this happens now and again'. You see? I think it's so terrible! I talked about it with my colleague, Nettie, about how this could be possible. A person on the point of death will not get dirty and get bedsores, that care he will get. They'll wash him and turn him in bed a few times all right. But with us, we would sit at the bedside and the person will get dirty and get bedsores, but we`re there [laughs], we`re with him! On the other ward they will wash you and turn you in bed, no problem, but beyond that you can fend for yourself. It's very strange. I could never work like that! Never.

This quote points out how care for the body is thought of as a precondition or even as irrelevant to care for the mind. This splitting of mind and body is mirrored in the division of labor among professionals. The patient has a body and a mind, and specific professionals take care of the one or the other.

Yet the psychiatric nurses are critical of the routinized and authoritative way that geriatric assistants wash their clients.[48] Here, precondition and life projects become connected more substantially: care for preconditions cannot take just any form. Notwithstanding the division of labor, routinized and systematic washing appears to contradict ideals of self-development and setting priorities. Routinized washing might be appropriate in dealing with patients suffering from dementia and incontinence, but it is unacceptable for psychiatric nurses who are trying to encourage their patients to develop their own potentials. At this point, a solution can be that professionals concerned with self-actualization take up the washing and dressing themselves. This way, they adapt the washing to their own practice and values of good care: washing has to become part of a life project.

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[48] Washing as an activity that is routinely done is yet another repertoire of washing. Values of hygiene, predictability, discipline and control form part of this practice. This practice is, however, not one of psychiatric nursing, nor is its content aimed toward citizenship, although patients are confronted with it in the residential homes. I have described this practice elsewhere (forthcoming).

When this occurs, psychiatric nurses try to stimulate the development of a life project by making patients choose and consider even little things that are important to them. It seems inconsistent to help patients go to the local community center, but not to give them the opportunity to choose their own clothing and decide on their own shower time. It can also be the case that a patient has specific reasons to refrain from washing. This includes washing and dressing in the person's project; hence these activities regain importance.

If washing is put back on the agenda of the psychiatric nurses, however, self-actualization seems to end and transform itself into something else. For nurses for whom washing is a precondition, the goals associated with washing and getting dressed are typically not seen as very challenging. They remain in a way 'precondition matters' that should come before the development of citizenship.

> *Psychiatric nurse*: I applied for this project [a psychiatric ward in a residential home] with the idea that we would coach people to live independently in the residential home, away from this ward. Or even outside the residential home! That was my main motivation to come here. For those people who would keep on living here, I thought of them as a bonus. But in fact, they make up the majority. And it takes a lot of time to help them with washing and dressing. So I am not sure yet if I will continue working here or if I will move on to another project.

The coaching this nurse had hoped to engage upon sets goals related to community life: living on one's own, choosing a place to live, and talking about what is needed for domestic life. It is not about things as mundane as washing.

A preconditional wash for life project developers: the self-actualizing citizen

The citizen for whom washing is a precondition is one who engages in community life by developing his or her personal potentials. By developing their strong points, they can become participants, for instance by getting a job, by traveling or by establishing contacts. Nurses help patients realize they can have goals, help them decide which ones to pursue, and help them to reach these goals and become a citizen.

Again, autonomy is important for the would-be citizen. In this repertoire it is related to choosing which potentials (however buried or flattened by hospitalization) to develop. Developing strong points, abilities, and possibilities helps a person find a satisfactory way into the community. Psychiatric nurses take an active approach in care, but because of their mission (developing the life project of the client), they do not have the authority to decide which goals are worthy of pursuit. These are, after all, personal matters.

The agenda of the psychiatric nurses, however, makes care for washing less attractive to them than the more publicly appealing goals that relate to community life. Taking washing tasks upon themselves means that ideals of self-actualization are brought back inside the house from outside, or brought from the top of the pyramid of needs to its base. This does not seem to work easily: a qualitative difference between precondition (including washing and medication) and self-actualization persists. People having trouble with washing do not seem to be people who are on the verge of participating in society. Dealing with washing seems to imply a step back from helping clients to become citizens, to seeing clients as patients again. They remain in the hospital or in the residential home, and do not develop towards community life. Apparently, washing is a precondition after all.

3.7 Fourth repertoire: washing is a relational activity

In this repertoire of washing *relations* are purposefully developed as the goal of care.[49] Establishing a relation between caregiver and patients is a central aim, and also a means to other ends: without good relations, everything stops. Because the relation, and not a specific (form of) activity is central, washing becomes an activity like any other. Neither is it a basic skill, nor are there 'higher ends' for which washing can be a precondition. There are different aims or activities, and washing is one of them. This also implies that it is not of primary interest that the patient performs the washing herself, whether or not she is capable of doing so.

> *Psychiatric nurse*: For most people living here, it is important to build up their independence and self-management, starting with the ADL [Activities of Daily Life: washing and getting dressed]. But OK, we help Mrs. Smith. This is a choice we`ve made. We help her with ADL because physically she is in bad shape. She has a heart and lung condition, and she gets oxygen on a regular basis. So you can say: 'You have to do it yourself', but then she's laid up for the rest of the day. She`d sit in her room, staring at the television. She was simply too exhausted to do anything else. And look at her now: she's hardly in her room, and she has lots of contacts.

At first Mrs. Smith found it strange to be assisted with washing, because she was still able to do it by herself. But here washing is not a basic skill; neither is it a private activity to be done alone. Although it could be seen as a precondition, it isn't, because Mrs. Smith has the choice to wash herself or to have more contacts, and the nurses help her with washing without questioning if this should be their task or not. There is no hierarchy between activities. The person who does the washing can change: it can be the caregiver or the patient, whichever is more convenient, pleasant, or effective. You-must-do-it-yourself is not as important as you-may-do-it-yourself. Assisting a person with washing can be a way of doing things together; it can also be that washing a person serves the purpose of pleasure.

The image of the patient/ citizen is not so much an image of an individual; rather, it is about 'living together' with others. The proposed self is a social self: to exist, it must relate to others. Relations make the citizen more or less integrated. The nurses help to develop the patients' social network as a way of becoming part of a community, which is not 'out there', but 'right here'. Family, friends, even 'arranged friendships' with volunteers, community centers and so on are thought of as more important for citizenship than trying to improve or change patients by therapy programs directly acting on the individual level (skills training, making decisions for yourself). Nurses help their clients to establish stable relations with their family members.

However, the nurse herself is an important member of the network; she forms a first link to citizenship or a life in the community. More than trying to change their clients, nurses live with them. Being there for birthday parties and other festivities is part of their job, just as assistance with washing can be.

What kind of relations make a citizen, then? Negotiations are very important in this form of care. There are no fixed positions, with one person imposing norms on another. Rather, there is give and take, which is influenced by moods and changes over time. There is no clear strategy that always works in dealing with other people.

> *Psychiatric nurse*: I think these things aren't plannable. On one day you can say: 'Hey, Ben, come on, time for your shower!' And I think 'That's nice, I can talk to him in an informal way.' Another day I think: 'Ben, today I am not going to ask.' There is no standard that is always successful. Some other time I would probably say: 'Ben, you can do it on your own.' Or he would say: 'I don't want to.' I think it is very hard to lay down rules about how to do these things.

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[49] Of course the other repertoires of washing are also about organizing relations, but this is not the goal of the care practice.

The shifting positions make it hard to prescribe general rules for behavior. The relationship must accommodate different moods and uncertainties. A nurse should be flexible and able to adapt to new situations. The best bet for some stability is to establish a relation with the patient; after that, she has to react when the time is right. Any techniques are allowed, as long as coercion is not used. Violence is not a part of relations between citizens. No professional authority could replace negotiations; neither does the patient dictate what has to be done. The result of the flexibility can be that some patients are a little dirtier than they would have been if they were routinely washed. It can also mean that stubbornly refusing patients become far dirtier than the nurses would like.

> *Psychiatric nurse*: Mr. Jones has lived here for four years without taking a shower.
> *Interviewer*: Really? And he doesn't smell?
> PN: Of course he smells. But there is a difference; some people don't attract dirt, so to speak. Take Jensen: if he can, he`ll escape the shower as well, but he doesn't look dirty. But people like Ger and Frank: put them under the shower, and after half an hour you would like to advise them to go wash themselves. They seem to attract dirt, and their shirts hanging out of their trousers doesn`t look so smart. Others dress so nicely that they camouflage whatever you would find if you looked or smelled underneath. But with Mr. Jones it took four years. Booming psychosis. They took him once to put him under the shower and he really thought: I am going to the gas chambers. I will never forget that, it was so intense, the way he screamed. Dear God, that was a heart-rending cry. Then you wonder: Should you do that? In the crisis ward they would have picked up a person much earlier. But that`s not our way. We try to negotiate, be flexible, and talk. That has its limits, of course. But I always think it`s fascinating: these people are really ill, really disturbed. But you can establish some form of relation; you can communicate in certain ways. You can understand them and you will always discover that there is some place from which to work. But you have to be patient, put in a lot of effort, and be happy with very small changes.

Relational care also means that patients can refuse to wash at a given moment. However, because establishing and keeping relations is the objective, the nurse is much more assertive than could be the case when washing is seen as a private activity. She is not stopped by her own scruples, but by the resistance of a patient, or by the impossibility of establishing a relationship by means of which she can reassure a patient that showers are not gas-chambers.[50] Her input in the relation is legitimate: opinions can be

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[50] Thanks to Wubbien Wesselink who pointed out a similar case from her own practice, where a long-established relation made it possible to convince a patient that her fears of showering were imaginary. The patient believed this because she trusted her and took her shower without problems.

given, suggestions can be made. The caregiver just has to be clever enough to get things her way, or know the patient well enough to see what she will respond to. The same conditions obviously apply for the patient, who does not have the final word either. The essential thing is to be sensitive to the contingencies and particularities brought by every new day.

Citizenship seems to begin with personal relations. Ideally, there is give-and-take between citizens and, consequently, between nurses and patients. Each brings with them their specific differences, personalities and changing moods. To establish relations, these differences are appreciated and acted upon. A co-ordinated, unified team approach, which is favored in practices that emphasize development of basic skills, would be bad nursing here. And washing, just like any other activity, can help to establish the relation.

> *Psychiatric nurse*: I like to do it [washing and dressing of clients] with people. It`s a much more relaxed way of making contact; you have a very clear goal. And the rest just comes with it. It's a simple way of communicating, very informal. Because, see, if you talk to someone, you don't have the same conversation the next day. After a while, you get to *know* Jeannie, if you see what I mean. With dominoes, too, you`ve played that game for days on end. These people are not really able to make contact or keep themselves occupied. [...] So when you come in one day, and you`re not all that motivated, or there`s not much to discuss with a certain patient, you still have this caring for washing and dressing. And while you do that, it`s possible for something to happen that deepens communication or that enables you to do something extra for the person.

As this nurse shows, communication is not always easiest by 'talking'. On the contrary, he perceives verbal communication as often difficult. Washing creates an alternative situation for communication. There is a clear task at hand and 'the rest comes with it'. The situation is not determined by conversation alone.

The idea of citizenship advanced here does not bring with it many prescriptions. There is no pre-set hierarchy of worthy or less worthy goals: goals are subject to change, and they should function to support relations with others. With the re-valuation of washing, other types of 'non-heroic' communication are also valued more.

> *Psychiatric nurse*: You should simply see that you work with people-- that's what it's all about. It's a terribly stupid profession, being a nurse. What matters is that you can empathize with other people. To learn that, you go to school for four years, see what I mean? I don't want to downplay the profession, but I do want to put it into perspective. Because it`s about investing in people, and

> getting something back. And it doesn't matter if this is about washing, dealing with voices [hallucinations] or moving to another place. If you can work it out together, you can really do a lot. Then you can cheer up the craziest nutcase.

This informant questions the professionalism of relational care. Elements of friendship enter the relation from the active attitude adopted by the caregiver, who makes comments and gives unsolicited advice out of a sense of commitment or concern. But there are also elements of professionalism: the professional relation guarantees the continuity in 'cheering up nutcases'; talking about psychiatric problems is a part of the job, and this, just like assisting a person with washing, can be more difficult to do for a friend or neighbor or in some intimate relations, for instance, between parent and adult child (see also: Borgesius 1988)[51].

A relational wash for getting along together: the relational citizen

When washing is a relational activity, to be a citizen is to be connected to other people. It is not of central importance to be autonomous; instead, the citizen has to establish and maintain relations with other people. Friendships and personal relations are ways into the community. Living in an institution does not automatically imply a marginal position. There is no pre-set spatial division between what is inside or outside the community. A lack of good relations would marginalize an individual, so this is where the psychiatric nurses begin their work. They start by making the caring relation more personal and more balanced. The nurse becomes part of the social network.

There is no autonomous self to be defined as apart from others; the self is variable and inconsistent. This is true for nurses as well as for patients. Flexibility and improvisation become important qualities for citizens. They can be active, but they have moods, styles and inconsistencies that must be taken into account. Washing, as well as other matters, are framed from this perspective. There is no hierarchy of activities, nor is preference given to matters of bodies or minds. These will have to be dealt with on a day-to-day basis.

Establishing living together in a convenient way as the goal of this care practice means downplaying professional claims of psychiatric nursing. Caring is unpredictable; it is not easy to prescribe 'methods' or rules of how to act. Caregiver and patient will have to work it out together. Instead of a

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[51] Borgesius and De Lange studied psychiatric nursing and point out that one of their main professional qualities is that they are 'experts in acting normally with special people'. See also Borgesius, De Lange and Meurs 1988. The nurses and patients find ways to establish new norms together.

clearly outlined *citizen*, this practice of washing presents us with a way of *negotiating* or *practicing* citizenship.

3.8 Discussion: civilizing the wash

The establishment of ideals of citizenship in psychiatric nursing aims to achieve the (re-) integration of persons with mental disorders into community life. Patienthood should be traded for, or at least complemented with, citizenship. As a result of this paradigm shift in mental health care, washing was rendered tacit, as it ceased to be part of 'good mental health care'. Although tacit, it never stopped being a part of daily care. Practices of washing and promoting citizenship merged in complex ways, resulting in the different repertoires of washing.

But not only washing is rendered tacit. The different ideals of citizenship are also not discussed. Analyzing citizenship through washing practices poses questions about what norms, (bodily) conditions, competences, and barriers there are to being or becoming a citizen. By making the different forms of citizenship explicit, it is possible to turn to the question, to which political strategies do we want to subscribe? Why choose one concept of citizenship over another, for whom, and at what cost?[52]

Washing the citizen

Certain remarkable characteristics of the differing notions of citizenship can be made explicit by looking at the four washing repertoires described. It is striking that the first three notions of citizenship, but not the fourth, share as characteristics that they structure social relations by developing different forms of *autonomy* for the patient. To become an autonomous citizen is to cultivate individual interests (private citizen), to become independent (independent citizen), or to develop one's potentials (self-actualizing citizen). Community life consists of autonomous individuals living among other autonomous individuals, and the services and goods they use. These individuals can be more or less in competition with one another, yet they are the atoms of social life. The 'bourgeois', with specific interests,

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[52] Of course it would not be fair to analyze citizenship on the basis of washing practices only, because some care practices that aim at citizenship for patients do not claim to solve washing problems. Some notions of citizenship seem to be tacitly displaced when they became attached to washing. But despite these reservations, specific points about citizenship can be made.

competences and projects is promoted rather than the ‘citoyen’, who has responsibilities for the common good (Nauta 1992).[53]

But relating citizenship to autonomy leads to certain problems with regard to the political goal of community participation of these patients. A first problem is that it is unclear how the autonomous individuals can relate to one another, apart from not hindering each other. The private citizen has to be protected from others; the independent citizen has to take care of his or her own affairs regardless of what others do. It is subtler with the self-actualizing citizens, because they may develop relations as part of their life project and the preconditional nature assigned to washing signifies an awareness of the importance of dealing with others. Yet in all three cases the first thing to be strengthened and developed is individuality and specific individual competences, in order to become sociable later. ‘Participation in the community’ seems to imply the addition of new individuals who are taught how to behave, leaving the community ‘out there’ to function as before. The care practices directed at autonomous citizenship seem to promote conditions and competences for the individual to survive outside the hospital or residential home. The new citizens do not make connections or argue for changes that make it easier for them to be accommodated in the community, but instead have to adapt themselves to its conditions.

A second problem with the concepts of autonomous citizenship is that the hospital or the residential home does not seem to be the place to practice citizenship in relation to other citizens. There are not many ‘real’ citizens around (with the exception of the residential homes, where ‘normal elderly’ live and relatives live close by). The patients are ambiguously seen as citizens or citizens-to-be (they are being taught to be citizens). Individual competences are to be learned in hospitals or residential homes, by those ‘excluded’, and are to be practiced ‘out there’, in order to be ‘included’ in the community. Autonomous citizenship locates psychiatric services outside of the community.[54]

In this spatial division between being inside or outside the community, with psychiatric services being outside, the nurses take a

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[53] The exemplary public sphere here is the (labor) market (and not, for instance, the polis where citizen gather to argue for the common good). The new citizens are to become part of the social sphere of selling and buying goods. The citizens are concerned foremost with acquiring individual competences and finally, personal happiness and access to services and goods. What makes this *political* is that both market and political sphere organize relations between citizens in specific ways (Nauta, 1992). Furthermore, the presupposition of the market, in its most optimistic, liberal form, is that if everybody strives for his personal welfare, the common good is pursued at the same time (see Smith 1994).

[54] But once ‘released’, this still seems to leave some people ‘outside’ the community, even if not separated by hospital walls. They wander the streets, but they are not ‘integrated’ or ‘participating’.

remarkable position regarding their own autonomous citizenship. It seems that they are there to promote citizenship of their patients, without acting as autonomous citizens themselves. Instead of arguing for their own interest or taking care of themselves, they are professionals helping others to become citizens. By doing so, they bracket their own citizenship to support patients (which is not part of the definition of citizenship but is part of their professionalism).[55] Their citizenship, like that of the patients, seems to start outside the hospital doors.

A third problem is that the three notions of autonomous citizenship try to create citizens who are *equal* to other citizens in their rights, obligations and competences. If someone deviates in an unconventional way, for instance by not washing, this is hard to deal with in terms of autonomous citizenship. As became clear in the analysis, the perception of washing as a private activity, a basic skill or a precondition runs into problems when patients pollute, do not want to wash themselves or experience trouble with washing. The notions of autonomous citizenship make these problems hard to deal with for the nurses. Washing ceases to be a private matter, the wish to be independent is challenged, or washing becomes a central issue rather than a precondition.

For that matter, psychiatric disorders are also marginal to the notions of autonomous citizenship.[56] Psychiatric handicaps can organize or categorize *patients* as a group. To the autonomous citizen these handicaps are private particularities, leave skills and independence untouched or are irrelevant to self-actualization. They are not relevant to the definition of autonomous citizenship, which is about the equalities (and normalities) of citizens rather than their differences. With the entrance of the citizen, the patient seems to disappear. Troubles for patients are privatized or delegated to other professionals in the precondition repertoire. In the repertoire where washing is a basic skill it is even more complicated: although psychiatric symptoms are not seen as disruptive for the skills themselves, the development of skills is approached in a therapeutic way.

So using autonomy as a concept to define citizenship leads to certain problems in thinking about participation in the community for these patients. Community life demands changes for ‘newcomers’, but does not support them by adapting its standards; spatial divisions between private and public locate professionals, patients and mental health care

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[55] An exception could be when nursing is seen as a form of self-actualization by helping others.

[56] Similar precautions as with citizenship should be made here: dealing with psychiatric disorders is only analyzed in relation to washing practices, leaving out other practices that revolve around medication and dealing with symptoms.

conceptually outside the public sphere; and differences between citizens are hard to reflect upon or to deal with because autonomous citizenship stresses equality with other citizens, and this defines differences –however unsuccesfully- as private or irrelevant.

Are these problems inescapable? The notion of relational citizenship seems to avoid them. Relational citizenship is developed by building constructive and helpful relations with others through negotiation or mutual accommodation. It implies a form of sociability in which the citizens acknowledge their dependence on others. In this way, it is not only the *patients* who have to be or to become a citizen, but the nurses as well. By being part of the network of their patients, they enact the citizenship they proclaim. Both nurses and patients shape citizenship through their relations, notwithstanding differences such as professionalism, patienthood or hospitalization.

The concept of relational citizenship does not imply equality or the exclusion of deviance. Psychiatric problems are as susceptible to negotiation and accommodation as are problems associated with washing, or questions about applying for a place in the community center. Multiplying differences implodes ‘equality’. Not only can preferences differ from person to person; they can also differ in the same person from day to day. Divisions do not run between the mad and the sane, the private and the public, the patient and the citizen, the autonomous and the dependent, the clean and the dirty, but between *situations* with specific characteristics. Spatial metaphors of private and public spheres do not hold for relational citizens. Relational citizens move through *time* in differing and changing connections from one place to another, in and out of the hospital and even to the bathroom. In doing so the citizens establish new norms together. ‘Normality’ in relations between citizens does not refer to norms that are given (such as autonomy), but have to be performed, refreshed and re-established in each situation (see Winance 2001, 2002).[57] In the interaction not only the patients change in order to become citizens, the ‘other’ citizens take their part in defining new norms as well. Everyone is responsible for civil relations, it is not just a matter of acquiring the same competences and skills. One can react to strange behavior in an even stranger way, or try to accommodate it and thus ‘make it normal’. In order to welcome newcomers on the labor market one can try to train them to become ‘normal employees’, or competitive demands of the working situation can be adapted. The notion of relational citizenship implies opportunities for two-sided political action and critical

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[57] Winance eloquently argues that differences and equalities are constantly made in interactions and are not linked to ‘stigmata’ or essential differences residing in the (body of a) person.

reflection on what is the common good, approaching the ideal of the 'citoyen' who has responsibility for others.[58]

The concepts of autonomous citizenship inferred from washing practices bring out tensions to which the notion of relational citizenship provides solutions. Practicing relational citizenship allows for relations and situations that enable different groups to participate on mutually acceptable terms. Yet the relational notions of care and citizenship have a hard time surviving the actual focus on professionalisation and planning in Dutch psychiatric nursing. Patient autonomy is the key-word nowadays, notwithstanding its specific limitations for conceptualising community participation for marginal groups.

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[58] One can argue that the concept of relational citizenship also links citizenship to 'the good life' or 'being human'. The intimate connection between citizenship and the good life goes back to the Greek conceptions of the citizen that Foucault describes. According to Foucault, in the polis the (male) citizen defines himself by an'ethics of life', in which governing and being governed both demand controlling one`s desires. In this way the self becomes sovereign, wise and virtuous and is able to rationally govern the self as well as well as others (Foucaul 1985, 1986). Thanks to Baukje Prins who pointed this out to me. Cecile aan de Stegge (personal comunication) further illustrated the link between washing and 'being human' when she met up with a patient of whom she is a volunteer-friend (maatje). One day she found him, dirty, with a three-week beard and shabby clothing. She went shopping with him for new clothes and to the hairdresser for a shave. Once shaven her friend said with surprise, looking in the mirror: 'A human is hiding in me.' Reports from former victims of war camps also stress that being hungry was far easier to bear than not being able to wash (Withuis 1990). Washing, being human, and being a citizen can indeed be closely related.

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4 Enforcing patient rights or improving care? The interference of two modes of doing good in mental health care[59]

Abstract

New state laws are intended to bring about formal changes. These juridical activities inevitably interfere with the content of care of substantially changing health care practice. The case is argued by means of an analysis of ethnographic material gathered in the long-stay wards of two psychiatric hospitals in the Netherlands.The question raised by the ethnography is which ‘mode of doing good’, juridical or caring, is relevant to daily practice. A ‘mode ofdoing good’ is defined as a pattern of ideals, procedures, routines and knowledge that is oriented towards a specific form of ‘goodcare’. The interference of these different modes of doing good explains the impact of recent juridical changes in Dutch mental health care. The potential tensions between juridical and caring traditions are accommodated in different ways. Either juridical and caring modes resonate and gradually merge into new patternsof day-to-day practice, or there is dissonance and they remain oppositional. Rather than securing patient rights, juridical measures change daily life and work on the wards in far more complex ways.

4.1 Improving mental health care

Juridical regulation of care is generally understood as the *formal*, procedural structuring of the relation between professional caregivers and patients. Patient rights are enforced, but the *content* of care is not changed. How to treat a patient remains the expertise of the medical profession. Juridical measures only formalise the conditions under which patients can, or have to,accept the treatment the doctor proposes. In this paper I will argue that the implementation of laws *substantially* changes care practice. This is because laws bring with them a specific knowledge about the nature and behaviour of people, as well as ways to relate to them. A specific rule brings forth an understanding of the practice it regulates, of its desired state, and of ways to get there.

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[59] Pols, J. Enforcing patient rights or improving care? The interference of two modes of doing good in mental health care, *Sociology of Health & Illness*, vol 25, no 3, 2003, p 320-347.

To show this, the paper presents a theoretical analysis by way of empirical material, gathered by studying nursing care as it is practised in two long-stay wards in two psychiatric hospitals in the Netherlands. In both hospitals,so-called 'patient laws' were being implemented. The improvement of care was sought by implementing 'rehabilitation' programmes. To analyse these changes, I will read juridical measures as a specific 'mode' of ordering the world, that is, a specific pattern of ideals, practices and knowledge. The term'mode of ordering' (Law 1994) can also be seen as a variant of 'paradigm' (Kuhn 1970) or 'discourse' (Foucault 1971).[60] The term refers to a pattern of practices and ways of talking about practices. Objects, activities and words get their meaning and value in relation to one another. What is true, just, valuable, rational or relevant in one mode of ordering is not necessarily valued in the same way in another.

Care is a different mode of ordering the world, in which different actions form a pattern with other actions, values and knowledge. To stress their normativity, I will read both juridical and caring modes as modes of 'doing good' (Boltanksi and Thévenot 1991). In both modes the aim is to change the situation of the psychiatric patient for the better, either by enforcing lawsabout patients or by improving care. To acknowledge these different aims for doing 'good', the good of patient laws and the good of caring will be treated symmetrically. The analysis thus does not privilege the one over the other beforehand, even if the juridical mode has the force of law. Rather, the analysis will make clear that 'obeying the rules' is not as straightforward as it may seem. Postponing judgement helps one to understand how the implementation of rules works in the specific context of a psychiatric hospital.

The differences between caring and juridical modes become apparent when the juridical and the caring mode 'meet'. In this encounter, not only the content of care changes, but the content of the legal measures as well.To describe the way law and care mutually change each other's workings I will use the term 'interference'. This term is drawn from the encounter of waves (light or sound) that diffract in different patterns (see Haraway 1996, Law and Mol 2001). Instead of a situation where one of the 'original' patterns imposes itself on the other, new, original patterns emerge. Both juridical and caring modes change in the encounter because the elements that form them are integral. If one element changes, the others will change too.

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[60] The terms share their links between knowledge, ideals and practice. Earlier ways of thinking about meaning as coming into being in the relation between terms can be dated back to Wittgenstein (1953). The 'language game' poses its own rules that set the boundaries for speakers to act, as in a game with specific rules. For my use of the term 'mode of ordering' it is important to include practice and materiality, more in line with Foucaults' work and Actor Network Theory (Law 1999).

Juridical and caring modes of ordering have to accommodate one another. When they do not, they clash and this creates serious tensions in daily life and work on the wards.

Interferences between caring and juridical modes differ from place to place. The analysis explores how different kinds of interference are possible. In the first hospital presented in this study, hospital Z, juridical and caring modes resonate with one another. The similarities are stressed and that allows them to merge into a new pattern. In the second, hospital H, dissonance between juridical and caring modes dominates. Here, juridical and caring modes are framed and lived so differently that most of the time they are incompatible. The outcome of an attempt to improve care by juridical means thus appears to be dependent on the different local ways of enacting both caring and juridical modes.

Before developing the analysis, I will introduce the juridical procedures which aimed to improve the position of patients in psychiatric hospitals in the Netherlands. Subsequently I will sketch the developments which aimed to improve mental health care, called rehabilitation, and introduce the background of the empirical study. Both the juridical and the caring modes will be elaborated upon in the analysis on their interference in the respective hospitals. In conclusion, the nature of these interferences will be discussed, as well as the consequences for living and giving daily care.

Patient laws

The most important Dutch laws that aim to enforce patient rights are the WGBO (Wet Geneeskundige Behandelings Overeenkomst/Law on Medical Treatment Contract) and the reformedBOPZ (Bijzondere Opneming in Psychiatrische Ziekenhuizen/Psychiatric Hospitals Compulsory Admissions Act)[61]. These laws must guarantee the influence of patients on their treatment by informed consent and regulate cases in which consent can not be given. In the Netherlands, contrary to most other countries (with the exception of Austria and Canada), involuntary admission to a psychiatric hospital ispossible without compulsory treatment. Compulsory treatment is only allowed in extreme cases of 'serious danger' to self or others.

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[61] In the BOPZ, the criteria for involuntary admission to a hospital were recently sharpened: 'for someone's own good' is changed to 'danger to self, others or public safety for persons or goods' that has to be made plausible before involuntary admission in a psychiatric hospital is possible. Once admitted, even stricter criteria apply for treating a person against his or her will: the treatment should be necessary to avert 'serious danger' as a consequence of mental illness. Recently, the Dutch parliament decided that 'serious' is to be removed from the second criterion, so it is expected that this will become the new law. For a critical discussion about the importance of this criterion, see Van de Klippe 1997.

The Dutch patient advocate (patiëntenvertrouwenspersoon) is the most directly accessible juridical help for hospital clients (Besluit patiëntenvertrouwenspersoon) under the Psychiatric Hospitals Compulsory Admissions Act (BOPZ Stb. 1993: 565). Contrary to other countries (again with the exception of Austria and Canada), the task of the Dutch patient advocate is of a strictly juridical nature. The Ministry of Health, Welfare and Sport states that the task of the patient advocate is 'to inform the patient about his rights and support him to get these rights exercised. The patient advocate supports exclusively the rights of the patient' (Ministerie van VWS/Trimbos-instituut 2000: 5). An information leaflet states:

> [The patient advocate] represents the interests of the patient, as the patient sees them. The demands of a patient are decisive on whether the patient advocate should act, when s/he should stop and how much weight is attached to these actions. [. . .] The patient advocate [. . .] takes everycomplaint seriously, even if the doctor links the complaint to the disorderof the patient (Stichting Patiëntenvertrouwenspersoon Geestelijke Gezondheidszorg 1996: 6).

Patient advocates are obliged to move regularly to other hospitals, to avoid becoming too comfortable with the routines of a specific hospital. A situation of opposition between caregivers and patients is thus inscribed in law and procedures aim rationally to settle disputes. The Psychiatric (Compulsory Admissions) Act stipulates that a psychiatric disorder is a precondition for overruling the will of the patient, but never a sufficient reason to do so. The patient is seen as autonomous, and autonomy can only be overruled to avoid (the consequences of) certain acts that are considered to be dangerous to self or others as a consequence of a psychiatric disorder.[62] Thus, the law enforces the autonomy of the patient in disputes with their caregivers, and specifically demarcates situations in which this autonomy can be overruled.

'Rehabilitation' and the background to the study

Reforms in mental health care in western countries to improve the welfare of patients are referred to as rehabilitation (WHO 1996, Anthony, Cohen and Farkas 1982, 1990, Watts and Bennett 1983, Shepherd 1995). Rehabilitation aims at emancipation, empowerment and citizenship for

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[62] Another situation in which autonomy is not the most important criterion is described in the WGBO, when a person lacks the competence to judge his or her situation with regard to the proposed treatment. A person's competence isdefined as the 'ability to reasonably assess his interests with regard to the proposed treatment'.

patients with chronic psychiatric handicaps.[63] Patients are addressed as clients as a way of acknowledging their identity as a citizen.[64] The most significant change is probably the closing down of psychiatric hospitals to provide 'care in the community'. In the Netherlands, de-institutionalisation has gradually evolved since the 1980s (Ministerie van Welzijn, Volksgezondheid en Cultuur 1984) yet the Dutch institutionalisation rate remains the highest in comparison to other western countries (Ten Have et al. 1998).[65]

The psychiatric hospitals in this study pioneer in the application of rehabilitation goals to long-stay care. Although these patients are not able to live in the community, their emancipation is taken seriously. To clarify how the general concepts of rehabilitation are performed in hospital practice, an empirical field study was set up to observe nurses 'doing' rehabilitation (Pols et al. 2001, Mol 1998, Silverman 1998). Participant observation took place in two hospitals (hospital Z and hospital H), for a period of 40 days in total. Observations were registered in detailed fieldnotes. Additionally, semi-structured interviews were held with 19 caregivers and eight clients. The caregivers were selected according to their involvement in developing rehabilitation in the hospitals, and included leaders of the nursing team, team-members and other caregivers connected with the wards studied. Interviewed clients represent the minority of clients who were able and willing to talk about their situation and experiences with rehabilitation. I will quote from the fieldnotes and interviews in this paper.

The wards in the different hospitals were selected because patient groups and aims of care (rehabilitation for long-term hospitalised, severely mentally ill clients) were comparable.[66] The wards housed 16 clients (hospital Z) and 20 clients (hospital H), aged between 40 and 64. Both wards offered 24 hour care.

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[63] The term 'handicap' is also a sign of renewed citizenship and saving the diseased subject: the World Health Organisation (1980) distinguished impairments (psychiatric disorders, symptoms), from disabilities (problems in daily functioning),and handicaps, the latter being the social problems the subject encounters.

[64] The term 'patient' is used in the juridical documents, but is contested by client movements in mental health care, where the term 'client' is deemed more respectful. Because I question the identities used in care as well as in juridical texts, I use the term differently, according to the context I want to discuss. When the context is not decisive I follow the term preferred by the (representatives of the) people I am writing about, i.e. 'client'.

[65] In 1995 Ten Have et al. (1998) counted 21,440 patients in psychiatric hospitals in the Netherlands.

[66] Hospital Z houses about 130 clients in long-term care, of whom 78 live on the hospital wards. Hospital H houses 111 clients in long term care, of whom 58 live on the hospital wards. The clients in Z had lived in the hospital for a longer period (average of 21.3 years), while in H this period was shorter (average of 10.2 years), but admissions to the hospital were more frequent. Additional quantitative research, however, points at more severe psychotic symptoms for clients in Z (see also Pols et al. 2001).

Surprisingly, the results of the study show that rehabilitation practices differ markedly between the two hospitals. In hospital Z, individualisation is the central theme. Rehabilitation forms a specific domain in care. Caregivers try to develop independent functioning of their clients and build a personal rehabilitation plan, stating the goals formulated by the clients and ways to reach them. In hospital H the focus of rehabilitation is the development andmaintenance of the social networkof the client, as a way of becoming integrated in the community. The caregivers try to establish a personal and balanced relationship with their clients. This 'rehabilitational relationship' extends itself to every aspect of care (Pols et al. 2001).This paper presents the analysis of the interference of the caring and juridical 'modes of doing good' in Z and H. The result is not a representative picture of life and care on the wards, but is a condensation of (mostly troubled) situations, in which juridical practice interferes with care practice.The first part of the analysis serves to unfold how juridical measures and care resonate (hospital Z). In the second part of the analysis, dissonance willbe discussed (hospital H).

4.2 Hospital Z: resonances and transformations

Modification

To demonstrate the substantial changes brought about by juridical interventions in care practice, I will analyse an ordinary situation in the long-stay ward in hospital Z. Contrary to the formal distance the law assigns to the patient advocate, in hospital Z this advocate's work can be seen as taking over tasks that were formerly assigned to the caregivers. The patient advocate is involved in the daily routine of nursing care, and this changes his work considerably.

> Sitting on the ward, I hear a terrible screaming. It's Eugenia quarrelling with Claude, two clients of the ward.[67] I had noticed Eugenia's gloomy mood this morning, as I saw her walking around in her dressing gown, grumbling. But now she attacks Claude in full force. 'Do you want tothreaten me! Do you dare to threaten me!' Eugenia screams. Her face is all purple and her eyes bulge out of their sockets. Because of her short height and corpulence, she looks like an outrageous, scary, firespitting dwarf. Claude is aphasic and cannot speak, but does not want to give in either, so he 'intonates' some angry phrases back to Eugenia. Sophie, the nurse,comes out of the office and sends them both to their rooms. Eugenia refuses. She sits down on a couch and starts to roll a cigarette.

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[67] Names used in fieldnotes and interview fragments are fictitious.

> Sophie goesaway to get two male nurses from the neighbouring ward. They look friendly enough, but they are really tall. They ask Eugenia to come with them. 'I'm not coming!' Eugenia shouts while continuously rolling her fag. The nurses try to take her handbag. Then they take an arm each and escort Eugenia to her room. 'Let go of me! Don't touch me!' Eugenia screams, but she walks along to her room, frees herself and runs ahead of the nurses and bangs her door shut. The now sad-looking giants go back to the office. Claude comes out of his room, gesturing, apparently pleading his case; Sophie sends him out of the door 'Just go outside to cool off!' I hear screams from Eugenia's room. I sit with the other inhabitants and try to think of a proper response to the situation. The others sit in front of the TV and tensely try to act as if nothing is wrong. Only Jack sneaks a glance at the nurses now and then.Sophie briskly says something about laying the table and having lunch.Then Eugenia rushes out of her room, dressed this time, screaming:'I will make a complaint! I will make a formal complaint and get all of you!' She points to the giant nurses in the office 'What is your name! I will charge you all!' The giants tell Eugenia their names. 'I want my money!' she screams now, 'I'm going to a hotel!' A few moments later we see her run past with her money in her hands. Jack inquires anxiously: 'Has she stolen your money?' Violet, another nurse, says, 'No, she didn't. Don't you worry about that'. Eugenia returns and screams in front of the office. She wants to call her lawyer, to make a complaint. Violet goes to the office to help her call her lawyer.

The nursing staff talk about Eugenia as a typical example of a person suffering from borderline personality disorder. The nurses explain that people suffering from this disorder quarrel and seek to destroy their relationships. They are prone to blackmailing, acting manipulatively and offend those they can. They are also experts in what the nurses call 'splitting', setting people up against each other. This behaviour poses extreme difficulties on wards,where it can effectively break up a nursing team. In this case, the quarrel is handled via Eugenia's lawyer, who is reached by the nurse, Violet. Violet takes this stoically. This is part of the nurses' policy towards Eugenia. The nurses use the mediation of the patient advocate or the lawyer in care for patients like Eugenia. It allows the nurses some distance from the situation, and at the same time gives Eugenia the possibility to fight them. Care is transformed by redistributing tasks between nurses and juridical consultants.

> *Team-co-ordinator*: Rule number one: Never get into a fight with them [patients with borderline personality disorder].They will always try to do that. Rule number two:See to it that they quarrel elsewhere, not on the ward, not with you. Then you are rid of it.
> *Interviewer*: Is this how you see the patient advocate?

> *Co-ordinator*: Sure as anything. [laughs] He [the advocate] knowsher for what she is, of course. That's his job. So I keep saying: 'go to the patient advocate'. You should stay out of the battle with them.

In these examples the role of the patient advocate has very little to do with juridical mediation. It is an example of fitting the demands of the law to the local ideas and practices of good care. 'Quarrelling' in this case is not regarded as a (juridical) dispute over a problem that has to be brought to a final decision. It is seen as a pathological habit of some patients that has to be channelled in a clever way. This entails a transformation of the juridical role of the patient advocate; the patient advocate obtains knowledge on psychiatry:

> *Team co-ordinator*: Most patient advocates I dealt with, are really well informed, they know the clients really do need their pills. And they will, eventually, help you to convince people that they need their medication. Explain that it is useful to them. But it is a fact that clients can refuse to take their pills. If they do so, we can not force them to take them.

The formal mission of the patient advocate is to support a patient refusing to take medication. In this case, he is 'well informed' that clients 'need their medication'. Instead of siding with the patient against the caregivers, the juridical consultant takes the perspective of the nurses into account. Advocacy is changed. The patient advocate collaborates with the nurses as well as opposing them occasionally. The nursing team sends quarrelling clients to the patient advocate. These examples show that the influence of juridical measures is substantial; both juridical and nursing practices are modified.

Ideation

While the patient advocate learns about pathology, the nurses in Z take interest in the juridical idea of advocating. The juridical relation between patient and advocate is adopted as the *ideal caring relationship*. The nurses in Z try to be 'advocates' of their clients and help them to become autonomous persons. This means that patients should be encouraged to set their own goals and receive support to leave the hospital and live as independently as possible. This is a way of 'doing' rehabilitation in Z. Budgeting, identifyingpriorities and handling responsibility are part of what nurses in Z try to teach their clients. The rehabilitation nurses sometimes call themselves'advocate nurses' (belangenbehartigers), because their task is to support the goals of the client as the client perceives them.

The nurses contrast this form of caring with *paternalistic care*, in which the nurses are the experts and define what is in the best interest of the patient. The nurses explain that this is a reaction to a situation where patients were subjected to the routines of hospital organisation, regardless of their own interests and desires. Rehabilitation is seen as the solution to this repression, where clients are encouraged to speak and act for themselves.This is a tough job, as most clients do not necessarily welcome changes demanding their participation and self-care. Becoming an autonomous person and developing your own goals is hard work which clients sometimes resist.

The normativity of rehabilitation in hospital Z resonates with juridical normativity, which protects and supports patients as autonomous persons who are able and willing to decide on their own goals. The good caregiver relation mirrors the role of the patient advocate in that it acts upon goals stated by the client. Yet it is also transformed in an important way. While the *patient* in rehabilitation mirrors the patient inscribed in the law, the *caregiver* does not. The caregiver practising rehabilitation in Z does not 'treat' patients. Advocate nurses try to act on the interests the patient formulates,like the juridical consultants and patient advocates. Instead of adopting the position of the *doctor*, they adopt characteristics of the *lawyer*.

In this way, juridical normativity is not used formally to regulate certain practices, but is translated into an *ideal* for how to relate to patients. When care is defined like this, theoretically speaking, juridical interference would be superfluous, because the possible trespasser is eliminated from the scene.Caring is modelled to the juridical mode of relating to the patient and the nurses think this is the way to improve care and stay out of trouble with juridical consultants.

Division and protocolisation

The resonances of juridical discourse and care in hospital Z are paramount. The patient advocate learns from the nurses and changes in care practice are modelled on the good inherent in juridical relations. Rehabilitation provides examples of a care practice where patient autonomy is acknowledged. Nurses help patients to work towards independent living outside the hospital, and help them to learn the necessary skills to do so, or arrange the necessary aids. They help them represent themselves in conflicts by calling in patient advocates or other juridical consultants. Even in the case of quarrelling patients, their autonomy is not made a problem, because everything is done in openness, with their consent, and according to their treatment-plan.

This type of care (rehabilitation), crafted along the lines of a more or less clear image of patient autonomy, inevitably creates situations on the long-stay ward in which autonomy is not an issue or is problematic.[68] This is the realm the nurses identify as 'necessary care' or 'care as usual', care that cannot be described in terms of rehabilitation-ideals. It is about care where supporting autonomy cannot be the priority. For example in care where the caregiver supports a group of patients living together (serving meals, house cleaning, solving problems between clients), or where caregivers correct or 'take care' of clients (force them to wash, or do things for them). The nurses perceive this type of caring as less heroic than rehabilitation. It is formed by the things that have to be done, like the cleaning of rooms and the day-to-day organisation of ward-life.

Because the nurses define 'care as usual' negatively (care that is not rehabilitation), it is not strictly described, with the exception of 'compulsory care', a realm of care that is regulated by the law (BOPZ). The intervention of the 'giant' nurses is an example of this. The form coercion takes in mentalhealth care is specific to the country where it is used. In the Netherlands, compulsory care in psychiatric hospitals is mainly 'seclusion' (Langelaan 2001), not 'compulsory treatment' or the tying up of patients, as would be the option in other countries.[69] So apart from rehabilitation, there are two other realms of care in hospital Z: compulsory care and care as usual. The relation between compulsory care and care as usual is, however, sometimes fuzzy.

> *Rehabilitation coach*: I support nurses to switch roles, from 'necessitynurse' to 'advocate nurse' and back. When all is well, you are 'advocate nurse' (belangenbehartiger). At other times you should take the role of the 'necessity nurse' (verpleegkundige); when the client is getting worse, there is a threat of relapse, then you have to take over again. And this is the most difficult for the nurses: the switching between roles. This is especially so in closed wards. We try to teach the nurses to be 'advocate nurses', so that you act upon the interests the clients formulate. But in the closed wards, there are lots of people with juridical measures, lots of drug-problems.These clients receive punishment as well, housearrest for instance. So there is a tension between advocacy and, well, I sometimes just call it 'being a policeman', a person who punishes. Nurses find this extremely difficult. And we thought of solutions, for instance: two nurses.
> *Interviewer*: One is the strict one, the other the nice one.
> *Coach*: Something like that, these roles. Sometimes it works, sometimes it doesn't.

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[68] See Moser 2000 for a critical appreciation of 'normalisation' as a way of producing and reproducing deficiency.

[69] In Great Britain, the use of forced medication is the form compulsory care takes. In Denmark, the practice of seclusion is considered very cruel: here coercion mainly consists of tying up patients, but patients are never left alone when this is done (see Langelaan 2001).

In this interview with the rehabilitation coach, there is a gradual difference between 'taking over again', 'giving penalties' and 'carrying out house arrest'.Being a little strict is not that difficult for the nurses. The nurses in hospital Z handle situations pragmatically and put some pressure on clients, with a good sense of humour where possible. They put someone under the shower or clean up the mess themselves. It is when the autonomy of patients is explicitly and forcefully overruled that the formal paperwork comes in. The restriction of freedom in compulsory care is legally formalised and ordered by protocols.

> Evelyn, a nurse, explains the forms to me that they light-heartedly name 'M&M's [short for Means and Measures]. It is a standard form which the nurses have to fill out in case of isolating a client: isolation (in one's own room) or seclusion (in a specific seclusion room); with consent and according to treatment-plan; without consent and according to treatment-plan; without consent and without treatment-plan. This last situation needs the consent of a doctor who is asked for an emergency consultation immediately. Each of the different forms of seclusion is better controlled, more centrally in the organisation. A form has to be filled out at all times.[70]

Obligatory or not, in hospital Z the careful use of protocols is seen as 'goodcare' in this type of situation. The act itself, the actual restriction of freedom, is seen as a sad, yet unavoidable, side effect of working with the specific patients on the long-stay ward. Patients generally view seclusion negatively (see for instance Mann, Wise and Shay 1993, Norris and Kennedy 1992), and often experience seclusion as a punishment rather than as a therapeutic intervention (Nijman et al. 2001).

When seclusion is part of the treatment-plan, however, some routine can be established (see also Lendemeijer 1998). For instance Bram, a patient who wanders at night and wakes up the whole ward is regularly and routinely secluded when this happens, as is stated in his treatment-plan. Although, formally, the treatment-plan has to be agreed upon and signed by the patient, Bram, who is chronically psychotic, refused to be informed about his rights and put his X on the unread document.

At other times, specifically in acute cases when clients strongly resist the nurses, the nurses experience it as much more unpleasant. They feel that the use of coercion should be regulated properly to avoid abuses of power and to guide their actions on this slippery terrain in care. Some of the nurses are very keen on living up to the demands of this type of good care and doing things the right way. They do not practise the laws and protocols

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[70] The rules surrounding the Means and Measures are legally enforced by the BOPZ.

prescriptively, but in spirit. This projection of the ‘spirit of the law’ to other situations shows the extensive resonance of juridical and caring normativity in hospital Z.

> Evelyn tells me the team of nurses debated the question of Mr Vanderbilt. When he was throwing crockery or had started to offend the other clients, the nurses would put him in the corridor, with his wheelchair on the brake. He could not move himself and would ‘cool down’ a little. Some nurses interpreted this as a kind of measure to bring about a form of seclusion, without the consent of Mr Vanderbilt. They were worried that a form was never filled out to report this. And should they do this or not, since the measure implicated coercion and not consent. The discussion was never resolved: some nurses did fill out a form, others did not.

The filling out of forms is designed for surveillance of the nurses, but also functions as a way of delegating responsibility for unpleasant measures in care. Juridical legitimations and prescriptions make the use of coercion acceptable and ‘de-moralise’ it, by making it a question of formal, agreed-upon procedures. Seclusion according to treatment-plan is not a situation for continuously renewed moral contemplation for individual professionals. The use of coercion is, literally, rationalised. Juridical formalisation does not stimulate the search for alternative solutions.

Clash

So far, the caring mode in hospital Z, although not identical, is nevertheless resonant with the juridical mode. Conflicts between patients and caregivers are handled in accordance with patient laws, or rules are projected on to situations which are not governed by the law. Although ‘juridical’ and ‘nursing’ tasks sometimes appear in unforeseen forms, these seem to be in harmony, or in the form of manageable problems, with care and juridical consultation in hospital Z. Transformations and adaptations are mutual.

When the autonomy of the patient is *problematic* and caregivers act against it (compulsory care) rules and protocols are brought in. The nurses adhere to these rules and feel supported by the moral guidance that the law guarantees. There is no opposition between patient and caregivers that could not reasonably have been prevented. In rehabilitation, the opposition of caregivers and patients is unnecessary. Here caregivers, as advocates, act in the interest of the patient as the patient formulates it. In compulsory care the opposition formally dissolves by carefully regulating the actions of the nurses who are guided by the law that is likewise designed to protect the rights of patients. Necessary care, or care as usual, remains a grey zone in between.

The law does create clashes on other occasions. As a consequence of the division of the advocacy position of the nurses in rehabilitation from the caring position in necessary care and the protocolised situations of compulsory care, this clash takes the shape of caregivers being opposed to *themselves*, not to their clients:

> *Nurse*: Now there is one person refusing his meds [medication]. And he should not refuse his meds. But OK, he goes to the patient advocate, so all is fine. We talk and try to come to asolution. The patient advocate is on the side of the patient and represents his interest.
> *Interviewer*: And the patient advocate talks to the advocate nurse about this?
> *Nurse*: Yes. And with the doctor, who prescribes medication.
> *Interviewer*: So the advocate nurse does not really represent the client's interests here.
> *Nurse*: Well, not in the way when someone needs pills but refuses to take them. Then there's a conflict and the advocate nurse does not represent the interest of the client. Taking pills is not in the interest of the client at that moment. The advocate nurse will try to talk to the patient: 'You don'twant to take your pills, but why is this the case? Is it the side effects that are bothering you?' In this way you try to find out why he doesn't want his pills at that moment. And the nurse can go to the psychiatrist and say: 'this is the reason he does not want his pills, do you see an alternative, is it really necessary that he takes these pills'. So the nurse is anadvocate nurse, but not in the way that she says: 'Okay, no pills', because we know the ultimate result, that things will turn out wrong. Medication is just an example, by the way, food and drink is another, or persons with health problems like diabetes who do not want to be injected. If someone really refuses, this is really against his interest. You can feel powerless as a nurse; it can be a really horrible feeling. You cannot square it with your conscience. But that is where it ends, finito! At a certain point the only thing left is waiting.You are only allowed to interfere when there is serious danger.[71]

At first glance, it seems the client is in conflict with his own interests. Asthe nurse explains, the patient is not really aware of the consequences when he states that it is his right not to take medication. On closer inspection, however, it is not the client experiencing problems. The client in the example refuses his medication, and sits back to look at the circus that starts when he does so. It is the nurse who is trying to defend other interests of the client. Even if she knows one interest of a patient/client, she finds out that there is another, conflicting interest. In juridical terms, this is not a problem, because the (most recently) phrased interest is juridically valid (at

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[71] This 'danger-criterion' is much debated, because it is thought that, specifically for the persons wandering the streets, care is brought in far to late. Opponents feel that 'respect for autonomy' gets in the way of caring relationships in the community and argue for 'bemoeizorg' (meddling care). This discussion was started by Henselmans 1993.

least, if the personis not declared 'incompetent'). In terms of necessary care or advocacy nursing, however, this multiplication of interests is problematic. The nurse knows the consequence for this person when he stops taking pills. But this cannot be framed as the interest of the patient in the juridical sense.

The nurse who wants to act in the interest of the patient by supporting and improving his autonomy, in the spirit of the law, is put in opposition to herself. In this circumstance, to be a patient without suffering is not the patient's interest, but the nurse's. The advocate nurse and the necessity nurse here come face to face with each other. Although, predictably, the client will suffer in the end, it is the nurse who has the moral problem now.

> Evelyn and Elise [nurses] come into the office and say that Eugenia has charged them through the Board of Complaints [a formal institution, independent of the hospital organisation, handling complaints made by clients]. Elise tells me that Eugenia had accused her of pinching her, resulting in a bruise. Eugenia 'lost her case' by saying that the spots were on the left arm, while Elise had stood on the other side. So she couldn't have pinched Eugenia. The board had asked Eugenia if it was possible that she had got the bruises any other way? Eugenia had admitted that this was possible [. . .].
>
> A few days later, Elise is still very sad. She says she feels very alone in this case. She does not feel supported by her boss. She complains that on the ward everybody knows what Eugenia is like, but the Board did not know that. What could they do if all patients were like Eugenia? Stop working?[. . .]
>
> A few days later Evelyn and Amanda tell me that Elise has called in sick. It is because of a combination of circumstances and the following critical incident: Eugenia is talking to a visitor, Bernard, from the adjacent ward. As usual they talk abusively of the nurses. They see Eliseand Amanda sweeping the floor and they both comment that this job is very well suited for them. Because nurses are so stupid that they cannot complete their education. As a matter of fact, they say, all nurses are whores. 'They should really do better to work in a brothel', Bernard says maliciously and Eugenia agrees. 'They fuck everybody'. This goes on and on. Until they say that, of course they know that Vanderbilt, a patient who lived on Eugenia's ward, didn't die of natural causes. They know who is behind this.
>
> At this point Elise intervenes. She talks to Bernard, how are his kids, and does he know that visiting hours are over. And Bernard leaves the ward. Eugenia says to Amanda that she knows who killed Vanderbilt, 'she did!' and she points to Elise. Amanda gets very mad and says that she has had enough of false accusations and that she will make a complaint against Eugenia if that is what she wants. Eugenia's reaction is the big smile of the person who has got what she wanted. Amanda tells me thatshe feels she has lost this discussion. Elise is

> Eugenia's second 'victim'. Amanda wonders when the team will acknowledge that they cannot handle Eugenia.

Though in hospital Z the nurses tried to live in harmony with the juridical mode of strengthening the position of clients, Elise is 'caught' in the end.She does not feel she has the powerful position assigned to her by the law. She cannot 'treat' her borderline clients. Caring for them becomes instead 'staying out of conflict' with them. But some patient's capacity for conflict, now aided with juridical means, clashes with this form of caring. Neither the advocate nurse nor the necessity nurse provides a repertoire to act here. Eugenia cannot be supported to work on her own goals, nor be cared for. Compulsory care is not an option either. Apart from the absence of a situation that legitimates the use of coercion, it is not a situation where coercion would provide a solution. Juridical measures work as intended (following up a complaint against caregivers), but can also work in situations that are not intended (it is a fake complaint).

4.3 Resonance in hospital Z

Above I have illustrated how juridical measures interfered with the development of care and rehabilitation in substantial ways. They were transforming and being transformed to fit in with daily care. I described the resonating interferences in terms of modification, division, ideation and protocolisation. Care is thus divided into different realms that define different ways of relating to clients. In the sphere of rehabilitation, the nurses adapt the relation of lawyer and client as an ideal one for the (advocate) nurse and client. The autonomy of the client is supported and encouraged as a way of obtaining a good life. A 'side effect' of preserving this sphere of 'goodness in care' and keeping it pure is that one has to accept situations where these conditions are not met. In such situations, patient autonomy is not central, or is gradually overruled. This is the realm of 'necessary care' or 'care as usual'. At times necessary care results in the use of compulsory care. As indicated, compulsory care, although in conflict with patient autonomy, is rendered acceptable by carefully protocolising it. An effect of this is that the use of coercion is not problematised but is embedded in care. Lastly, I have shown how resonant interference can also lead to a clash when 'difficult clients' become unattractive to care for, or when nurses become the victims of the juridical situation and find no way to relate to the good of the law. The analysis shows that patient laws bring about substantial changes in the caring mode. In the process, the juridical mode changes as well, and the results are different from the ones expected by lawyers. A new pattern is formed in daily care practice.

4.4 Hospital H: dissonance and polarisation

Juridical influences look quite different when traced in care-practices where the juridical mode of problem solving *does not* resonate with the local mode of practising care. This is the case in the long-stay ward in hospital H, as I illustrate below.

Oppositional psychologies

In hospital H the patient laws and good care are miles apart. This has to do with the specific practice in which the patient laws interfere in hospital H, but also with the normativity and psychology inherent in the laws.

> The first reference to patient laws I see is a proposition on a flip-chart in a room where caregivers frequently meet. It reads something like: 'Formal means of participation and other juridical possibilities for patients can be a serious obstacle to their rehabilitation'. I have an idea who might be the author of this 'politically incorrect' phrase: the social worker, a pioneer in rehabilitation in H. So I ask him about it. William confesses that he wrote this, and explains it has to do with the former patient advocate they had.He thinks this person acted very destructively. He focused on rules and laws, and set about breaking routines that had existed for years and which had proved their value. William tells about patients who had found the right level of medication. The reduction of medication was often tried, but relapse always followed. The patient advocate asked patients if 'they knew that they could refuse their meds?' Which they did, with predictable consequences. 'Or there was the case of the patient who went, day in, dayout, for years, to vocational therapy. The patient advocate said he did not have to go. And, according to William, the patient ended up 'rotting in his bed on the ward'. He says that a patient advocate is bad when he is preoccupied only with rules and regulation. 'This can kill people!' was his angry comment.

Contrary to hospital Z, and more in accordance with the legal prescriptions, the patient advocate does not participate in care for a client. In contrast, he is directly opposed to care practices in hospital H. In H caregivers see the formalisation of the relation between client and caregiver as a direct threat to that relationship. They see this relation as their most important tool in crafting care, which in H is equal to rehabilitation. Caregivers try to establish a balanced and personal relationship with their clients to be able to communicate with them. They become part of their social network to help them establish stable contacts with others. Patients are seen as essentially dependent for their survival on relations with other persons. In extreme cases the only relationship they have is with their personal caregiver.

> The social worker is very keen on this; he does not think you can train these people to function independently. 'There is too much emphasis on skills', he tells me, 'In hospital H you emphasise relations, you use your relationship to make clients do things. If you have a good relationship with a person, you can use it to let them do things you want them to do.You give patients attention, food and coffee. This makes them dependent on you. And you use this to make your demands. Like Albert. He takes a shower because you tell him to. Otherwise he would simply never do it. Instead of training you have to work on peoples' motivation. It's not that people are *unable* to wash or clean up. They just don't do it, or do not want to do it. They are not motivated. You can motivate them through your relationship [. . .] You see that we are very tolerant on the ward.Not many demands, a tolerance for mad behaviour and dirt. But we negotiate. We manage things, we give and take. We even manoeuvre and keep knocking on doors. This is how the game has to be played'.

In the long-stay ward of hospital H it is obvious that clients do not like to take showers or take care of themselves or their living environment.Where the common rooms on the ward in Z looked orderly and homely, in H they look particularly unattractive. Clients give all kinds of reasons for their reluctance to wash, mainly of a scared, psychotic type (fear that skin will come off, vulnerability of a naked body, fear of getting too cold or not being able to get away quickly). Caregivers do not see this as a lack of ability. Surely clients know how to use the shower. Instead, they take the 'psychotic arguments' seriously as a motivation for not wanting to take a shower. Caregivers feel that the problem with juridical discourse, as well as with the discourse on skills training, is that it does not take into account the *irrationality* of us humans. People do not act because it is good for them, or in their best, if not their own, interest. People do things either because they feel like it or because someone who is important to them asks them to.

So here, the juridical mode presents itself in a more oppositional way. In the juridical mode individual interests are stable and explicit and disputes can be brought to a close by deciding who was right by an agreed-upon procedure. Juridical psychology seems to be incompatible with the psychology used in hospital H. A client – and the same is true for caregivers – is not seen as an individual with singular transparent interests who can settle disputes with good arguments. Rather, a person is seen as having changing fancies as well as better or worse strategies for survival. This person can be influenced, seduced or tricked into changing behaviour by using the capricious, non-rational power any relationship inevitably brings with it. This makes a relationship unpredictable and unstable. The participants have to fight for it every day. Psychopathology may change or complicate the relation, but this does not disqualify the clients as speakers.[72] Unconventionaland incurable behaviour is accepted.

Oppositional forms of relating to other people

Divisions between rehabilitation and other types of care, as in hospital Z, are not made in hospital H. There are no separate spheres for rational deliberation and rehabilitation, for care as usual, and for compulsory care. Inhospital H's vision, the ideals embodied in the laws cannot exist in real life. The implementation of the law in the form of the formalistic patient advocate means a downright clash between two modes of understanding people, dealing with relations and solving problems.

> *Social worker*: You cannot formulate rules for how to get along with persons. Nurses ask me this sometimes: 'What should I do when this or thathappens ...' But I just cannot tell. I refuse to tell! There are many factors in a situation. What you can get, I do not get from Axel. What I am able to manage today with Jane, I may not be able to tomorrow. Did you work 10 days in a row? Which is what happens with the nurses sometimes because the ward is understaffed. Or are you starting afresh and happy to see the lot again? What mood is he in? There are no rules! There is no law.Or it must be this one: people have to keep thinking. If you make rules, you kill their reflexivity. We grew up with these people. We have known them this long. You learn that sometimes you have to do something so things do not get out of hand. This is very difficult to explain, and very dependent on the person. You cannot even put trust in your brains either, for a large part is your intuition.

This can be read as a somewhat Machiavellian view on relations, where fortune and contingencies are important factors, and nobody can be sure of a stable and solid position.[73] There is always an interaction between various

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[72] Note that this view criticises the possibility of 'Kommunikatives Handeln' as Habermas formulates it. In Habermasian public debate, mad people are not allowed to participate. The citizens should have finished their psychotherapies first, because mad people supposedly do not aim for consensus (Verständigung) but for effect (Erfolg). In hospital H this would leave the public arena without participants (see Habermas 1985: 445).

[73] For this reading of Machiavelli I refer to the interpretation given by Pitkin 1984. In her analysis of Machiavelli's political as well as literary work, Pitkin beautifully shows how republican man is struggling for autonomy and manhood, yet is constantly threatened in obtaining it by feminine unpredictability and fortune. The Macchiavellian prince can never be sure of his position; the wheel of fortune that went up will eventually come down. Autonomy, as a gendered concept is related to manliness in complex, highly ambivalent ways. The paranoid atmosphere in Machiavelli's works nicely sets the stage for describing psychologyin the long stay ward.

influences and disturbances, the hope for small success and the possibility of times when nothing will work out. Then you have to wait for better times to come. A specific form of autonomy forms part of this relation too: each person in the caring relation tries to get things his or her way. But in the end things can only be done in relation with other people. Without the help of others, you die. This is the reason why the central goal of rehabilitation in hospital H is to help clients to develop their social network. The caring mode in H frames relations very differently from juridical relations with their transparent and fixed forms of negotiation.

Oppositional forms of goodness in care

So far it seems to be psychology, not morality, that is defining the caring mode in hospital H. Yet, it is important to see that in the caring relation between patient and caregiver, all kinds of manoeuvring and negotiation are acceptable, but *coercion* is not part of the repertoire. On this ward, no Means and Measures can be taken. Also, there is no seclusion-room on the ward.

> *Nurse*: A few months ago I had to go to Mr Finsen [a client who, unlike most others, lives outside the hospital, but is taken care of by nurses of the ward]. I had to give him his shot [depot medication, injected in the buttock] and he suffered from diarrhoea. So this didn't look too good. So I said, 'Mister Finsen, this is the last time that you let your trousers down for me this way, with all this shit ...' Because I really think this is too crude. I said to him, 'You take a bath *now*, I see to it that you get clothing which you can wear while I wash yours ...' Well, I stood on my head and I talked myself blue in the face, with three colleagues. But he left. He left! 'I will not take a bath, blah blah blah,' and I said 'You can't stay here like this, your trousers are dirty. You sit on thechairs, it's impossible. You want to help with the cooking, it's not hygienic. We offer you a bath ...' He didn't step in the bath, he left. So then you say, 'What do we do next?' Wait and see if he comes again on Thursday. He came on Thursday. But if you are pushing him *again*, the next step will be that he does not open the door if William comes for him, that he stays at home. We know this. So maybe this will take some more years, before he accepts the need for a shower.

Caregivers see the use of coercion as inevitably damaging the caring relationship. It puts caregivers in a position of physical power, and this will harm, if not destroy, the possibility of good rapport later. The vulnerable bond between patient and caregiver can be broken beyond repair. When a psychotic or manic state gets out of hand, the patient will recover on the (closed) crisis-ward, not on their own ward. By this rejection of coercion, as in the example with Mr Finsen, the outcome can be that clients get away with 'unconventional behaviour'. When the matter is pushed to its limits, dirt is more acceptable than a forced bath.This morality, that excludes coercion, does allow for different kinds of manoeuvring. That is to say: all means to motivate a person to do something,or influence him or her, are allowed.

> Harry, a nurse, comes in and Charlie asks him for his pocket money. With Charlie, the deal is that he cleans up his room first, before he gets his money. He leaves to clean up, and later we inspect the result. I think it's rather tidy. Harry says his standards are already blurred. Well, maybe it isn't that clean, but the bed looks somewhat made. 'Well?' asks Charlie.'B minus,' says Harry. And Charlie gets his money. I ask Harry about this later, because it looks like a strategy that conflicts with their plea for negotiations with clients. 'Yes, some traditional methods are used on the ward; I don't even think that they are allowed, formally. You cannot withhold money or food from a person if he does not clean himself. It's always a bit of give and take. It means some day-to-day victories. But on the other hand, it is done with Charlie, but we do not expect Charlie to learn from it. It's a survival-strategy. But I would really like it if Charlie would say: 'I won't take this, you can't do this, I'll go to the patient advocate'. That would be really good for Charlie'.

In this example, the nurse points to the difference between the psychology of the law and H's irrationalist psychology; if the rationality of the law worked, this would give caregivers ways and means to negotiate with Charlie about cleanliness. They would be happy to do so; it would make negotiations with Charlie a lot easier. But it does not work that way with Charlie, the nurse says, because he does not stand up for himself. The way to the patient advocate would mean that negotiations are opened. The law helps patients who possess a minimal repertoire of juridical reasoning to talk about their interests. Because Charlie is outside the grasp of argument, this makes it more difficult to influence him. You cannot simply exchange arguments with him to decide what is best. The way of negotiating with him depends on a different form of rationality. This includes forms of manoeuvring that are not within the reach of legal protection, because Charlie does not think like that. Physical coercion is banned, but subtler forms of restraint are thought of as inevitable.

Goodness in the juridical mode, by ending disputes in a formal way by deciding who is right, is opposed to the goodness lived in the caring mode in hospital H, where caregivers try to keep negotiating, even if a logical structure is absent. According to the caregivers, this would give more space for the patients. And by doing so, they try to exclude coercion, which is acceptable in specific circumstances in the juridical mode (as was shown in hospital Z).

Oppositions between clients and caregivers

> Nurse Harriet tells me John [client] wanted to make a formal complaint against her, because she had spoken with John's financial consultant about his abuse of alcohol. John thought that this was intruding on his privacy.Harriet pushed him to make an official complaint, so that they could settle this dispute, if John wants to play it this way. But he backed off and didn't go through with it.

This fragment shows the difficulty in the position of both caregiver and client regarding the juridical way of solving conflicts. You have to play the juridical game if you want to solve problems in this way. By pushing John to do so, Harriet points out to him that this is a risky change of discourse for John. Making a formal complaint shifts the repertoire from irrationalist negotiations to the formal mode of juridical negotiations. Words are weighed for transparency, not for hidden meanings or mistakes. The implicationis that clients who make the move, should be able to handle the terms in which disputes are juridically settled. Does John really know the rules this game is played by?

Apart from putting them in a difficult position, such situations are also tricky because clients put their relationship with their caregiver at risk. The give and take, and the mutual influencing, is exchanged for the formal, overtly oppositional position inherent in a conflict with juridical means. The teaming up of the client with the patient advocate is seen as corrupting the caring relation by disturbing the power-balance between caregiver and client. This takes away the means the caregiver has to avoid the use of coercion: the personal relationship with his or her client. In this perspective, the conflict with juridical means is disadvantageous for both client and caregiver.

So in hospital H, juridical and caring modes are oppositional in the extreme. Whereas in hospital Z co-operation between caregivers and advocate is possible, in H the caring and juridical modes are incompatible. Aligning with one mode means a statement against the other. The patient is torn between camps: going to the patient advocate implies immediate juridical action, but would disturb the equilibrium of autonomy and dependency with their caregivers. Indeed, the patients who can deal with this have to be very sure of their case.

Oppositions between clients: unresolved tragedies

In hospital H there are oppositions between patients and caregivers, but caregivers try not to bring them to a head. Positions are constantly shifting, and all means are allowed to influence others, except physical force. In this way, a form of equality or symmetry is maintained; that is, a chance for both partners in the interaction to get things their way. This also means a situation on the wards that some people describe as 'anarchistic'. The sad effect of the 'formalistic patient advocate' who tries to solve conflicts in a juridical way is that this does disturb relationships between clients and their caregivers, but it does not protect them from violence on the ward:

> The psychiatrist is very upset. For a few months there has been a new patient advocate in hospital H. She came to see him and told him that patients on the long-stay wards do not come to her to make formal complaints. But during her visits to the different wards she heard that a lot of them felt unsafe on the wards, because of sexual violations, the smoking of soft drugs, small thefts and begging.

By disconnecting the juridical mode from the local mode of caring, juridification works against some patients. In the case of the first patient advocate, if clients do not make formal complaints, the patient advocate does not help them. There is no 'spirit of the law', an orientation towards the aims of the law that can be translated to other situations. The main result is the polarisation of positions. A resonance and distribution of tasks in care, as in Z, is not obtained. The new patient advocate, however, takes it as her task to see to the rights and wellbeing of the patients in a more broadminded way. This second patient advocate talks about matters in a way that is immediately and urgently recognisable to the caregivers. She shows that not only caregivers are involved with the clients, but other clients and visitors as well. Caregivers may be very tolerant; the premise that a good life is to be free of coercion and violence also stands in other relationships:

> Today's disaster is that Janice went to the doorkeeper of the hospital to complain that Charlie sexually abuses her. The doorkeeper told nurse Letty and Letty is close to tears that Janice went to the doorkeeper and not to the nurses of the ward. Janice had said to her, 'It's no use talking to the nurses. You never help me. And I can't help myself'. The nurses knew this problem existed. Charlie is not allowed to go into the corridor where Janice lives. But Charlie does not understand the problem at all. He asked if it is possible for him to call Janice from the hall, if the corridor is forbidden territory. Janice does not refuse him to his face. Nurse Jan is very angry and says he is going to talk to Charlie. Nobody is convinced this will help. Letty wonders if there is medication to reduce sexual appetite. She says this is rape and maybe they should go to the police. But Janice is angry today and says nothing on the following day. The patient advocate is not an option, because no complaints from patient against patient are handled. The social worker comes in and suggests that he will speak to Charlie, together with the psychiatrist. And he wants to help Janice to be more

> assertive. To go to the nurses if Charlie bothers her, lock her door and keep Charlie out of her room. Everybody is very upset and they feel helpless that there is no solution to protect Janice.

In spite of hospital H's commitment not to use coercion, violence enters the ward through relations other than that of patient and caregiver. The focus on caregiver-patient relationship does not take the situation on the wards into account where people live together. The clients, however, have made no moral commitments about the non-use of violence. Some clients do use their power over others. Inter-patient relations form a blind spot for the caregivers *and* for the formal patient advocate who is focused on caregiver-patient conflicts only.[74]

4.5 Dissonance in hospital H

Contrary to hospital Z, caring and juridical modes in hospital H are incompatible.The interference is one of dissonance. No resonance can be established, because psychology, relations and values differ too much in each mode, and no translations are made. The juridical way of supporting patients is beyond the reach of many of them. This is because of polarised positions that are too demanding for many of the patients or would seriously damage their relation with the caregivers on whom they are dependent, and who aremore flexible in dealing with conflicts or differences of opinion. Dissonance and polarisation prove to be fruitless for the juridical mode to bring about patient emancipation. Only when patients have nothing to lose will they seek juridical assistance. A lot of day-to-day problems, where a more flexible patient advocate could probably help, remain unsolved. The hostility between patient advocate and caregivers certainly does not help to improve ward-life in H.

4.6 Conclusion: Substantial interferences

In this paper I have analysed the implementation of laws in psychiatric hospitals as the interference of two modes of doing good. Where juridical changes intend to bring about formal changes, I have argued that they

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[74] In comparable practices cases like this are handled in the form of a complaint against caregivers for not intervening. In this case this is not an option because the victim does not go

interfere with the content of care. Laws are not filling a moral void in practice, but interfere with caring modes. Both juridical and caring modes bring forth their own values, knowledge and procedures. When these modes interfere, an accommodation of juridical and caring modes will have to take place, to gradually form new patterns. To regulate only specific actions, and not others, is problematic precisely because of the relations between actions. Doing one thing one way has implications for doing other things. The success of the forming of new patterns is dependent on the possibility of mutual translation or 'interessement', to make different ideals and ideas 'fit' (see: Callon and Law 1982, Callon 1985, Latour 1987, Law 1987).[75] Yet the ways of interference differ. There can be resonance and dissonance, and within these there are clashes.

When the interference takes the form of resonance, the intended juridical goodness also changes. Hospital Z employed a patient advocate who learned about nursing care and took part in day-to-day life on the ward. This meant a change from the ideas inscribed in the law of rigorously taking the patient's side. More dramatic were the changes I described as ideation and division. Juridical division is to be read as a division-in-two: 'compulsory care' versus'care for autonomous persons'. Seen from the care practices in hospital Z, the division turns out to be a division-in-three; apart from compulsory care and care for autonomy (rehabilitation), there is a grey, not well-defined zone called 'necessary care' or 'care as usual'. This leaves a no-mans-land in care that is not about promoting autonomy or its opposite (as in: 'urging someoneto take a shower' or 'taking care of the group'). Modelling care practice and caregivers' identity on the juridical mode leaves 'blanks'; when taken asa substantial philosophy of caring, it is an incomplete philosophy.

How the juridical mode changes can also be seen by looking at the 'exemplary situation', the empirical situation the patient laws implicitly try to regulate (Nauta 1986).[76] The exemplary situation is treatment by a doctor.

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to the patient advocate and the nurses will not go because relations between nursing staff and patient advocate are so bad.

[75] The term 'interessement' is from Latour (1987), Callon (1982, 1985) and Law (1987). As an alternative Latour also uses the term 'translation', but the term 'interessement' is more specific in describing the process of mutual changes that mirrors a resonating interference.

[76] See for the term 'exemplary situation' Nauta 1986. It is a reconstruction of themspecific empirical situation to which a seemingly abstract definition or philosophy refers. The exemplary situation of patient laws is a doctor making an intervention in case of a disease at a discrete moment in time. The intervention has statistically known probable outcomes of which the patient can and should be informed. In the long-stay ward, there are not many doctors; nurses are much more prominent. Only a small part of their job is to 'treat' patients. Most of the time nursing is about getting through the day, deciding what to do and how clean a patient should be. There is also a difference in time-scale: where the doctor sees patients for a short time, the

In hospital Z, however, *treatment* is part of the grey zone in care. Informed consent and signed treatment-plans should legally precede treatment. But everyday medication and changes in medication are hardly discussed on the long-stay ward in Z. The caregivers decide on this. The influence clients have over their treatment is limited to reading their treatment-plan or 'refusing medication', both of which they rarely do.

So there is division, but what is divided and how the division works out differs. Legally-intended changes, such as informed consent on medication, are not made, whereas unintended changes in the caring relation, such as nurses becoming an 'advocate nurse', emerge instead. The interference has resulted in a new pattern, not anticipated by either designers of laws or caregivers promoting emancipation.

Interference resulting in resonance thus brings about changes in life and work on the wards that are neither 'just' care or 'just' juridical. Neither standpoint is privileged. Resonance blurs boundaries. This poses a problem for care as usual, when local practice does not provide routines or answers to fill in this unmarked part of care in an acceptable way. And this leads to clashes. Crucial variables change places and value, as in the case where a false complaint was taken seriously in a juridical procedure. Nurses trying to do things the right way face the impossibility of living up to juridically-defined goodness when they are unable to find ways to relate to the painful and 'unjustified' insults of patients. Resonance thus involves paradoxes for the nurses who want to do the right thing for their patients, but are punished by exactly the same mode they are trying to adopt to do things right. Anotherway of phrasing this is to say that the caring mode in hospital Z must become stronger in matters of 'care as usual', or indeed create some opposition, to enable the nurses to do good, even if it leads to problems with the juridical mode. This might also be helpful in the situation where the law works as intended, but where all is not well. This was the case with the protocolisation of some forms of coercion. By its very protocolisation, coercion is also firmly embedded in care. It is accepted that it has to be part of care practice andthe law confirms that it is. It is not a topic of reflection for the nurses and this can be a disadvantage for patients who are routinely secluded. An alternative caring morality, as opposed to juridical morality, could help to improve dealing with these situations.

Interference resulting in dissonance leads to a very different practice, as I have illustrated in the case of hospital H. The new pattern is one of polarisation and hostility, featuring repetitive clashes. No fruitful

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nurse spends her days with them. Nauta further develops the concept of the exemplary situation by analysing different notions of citizenship (Nauta 1992).

translations are made, no merging of values and knowledge takes place. Where caregivers try to keep negotiating with clients, the patient advocate wants to end disputes in formal ways. Where caregivers strive to abolish coercion, the law seems to bring it back to the ward. Where caregivers think relations make the person, the autonomous individual is the unit of analysis of the law. Where caregivers argue that patients can have different and shifting worldviews, the law accepts only one, or would ultimately decide on the right one.

Caring and juridical ways of ordering the world are very different, in hospital H more than in hospital Z, and the form of interference in H polarises positions even more. As the example of the second patient advocate in H shows, this dissonant interference could have been more harmonious, notwithstanding the substantial differences. The second patient advocate is able to translate her worries to those of the caregivers. The first did not attempt such a translation, and this makes the threshold to consult with him too high for many patients and makes the dialogue with caregivers impossible. Hereby, the patient advocate misses the opportunity to help most patients to improve their situation. Going to the patient advocate would imply the risk of damaging the relation with their caregivers, with whom they have to live on a day-to-day basis. Real problems where the patient advocate could have been of help, such as the sexual violations between patients, are unaddressed.

The dissonant interference also shows that the juridical mode *needs*, if not merging, at least the *co-operation* of the caring mode. Indeed, caregivers and patients in the situation of the long-stay ward are hard to separate completely. As the situation in Z shows, caregivers are needed to help patients call their lawyer or the patient advocate, and also help sustain patients, enabling them to fight their caregivers by juridical means. Otherwise, the juridical mode remains out of reach for these patients.

So the transformation of care practice by juridical means is indeed complex, often leads to unexpected interferences and is never without clashes. The nature of the interference is contingent on the specific, local enactment of the juridical mode, as much as on the specific enactment of the local mode of caring.[77] The paradoxes are abundant. Problems arise when and where the juridical and the caring modes merge too much, but equally so when the opposition between the two becomes too polarised. The

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[77] There are more differences within the caring mode than those described here (see Pols, Depla and De Lange 1998, Pols 2000). The interference with these different genres of good care with the juridical mode are still open for exploration.

paradox for the nurse is to obey the laws, without losing their caring morality – indeed, amission that needs further analysis and reflection.

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5 Accounting and washing: good care in long-term psychiatry[78]

Abstract

This article analyses how the recent call for 'accounting' in health care interferes with daily care-practice and raises the question of how accounting practices relate to the aim of 'making care good'. The most influential ways of accounting in the Netherlands are framed in terms of Evidence Based Medicine and ethics (procedures and laws), and suggest particular activities to professionals in order to legitimise their activities. The analysis of an ordinary action in long-term mental health care, i.e. washing patients, shows that there are different styles of accounting and that ways of accounting do not merely evaluate and legitimise care, but also structure notions of what good care is. A specific style of accounting enforces certain values, but does not tell about the tragic or unexpected effects that come with it, nor does it provide a repertoire to deal with these. Thus, care-practices incorporating specific styles of accounting remain dependent on forms of care that are not accountable or ask for new forms of reflexivity.

Keywords
Accounting, justification, good care, ethnography, evidence based medicine, ethics, long-term mental health care.

There are strong advocates as well as severe opponents of accounting in health care. On the advocacy side, for instance Evidence Based Medicine promises transparency, evidence and equal access to good care (Sackett et al. 1991; Sackett et al. 1996), resulting in the best care for patients at the lowest possible cost. Ethicists and lawyers develop rules and protocols, and treatment contracts are implemented to protect patients from unacceptable, unnecessary or unasked for interventions in their lives and bodies, and secure their autonomy.[79] The opponents, on the other hand, analyse accounting as oppressive bureaucratic systems that corrupt good care by bringing external elements such as 'costs' into the clinic. In doing so, values such as altruism and love (Robins 2001) and good professional rationality are threatened (Kirschner & Lachicotte 2001; Bourgeault ea. 2001 Hopper 2001).

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[79] Good examples in the Dutch context are the implementation of the law on medical treatment contract (WGBO) and the sharpening of laws of involuntary admission to psychiatric hospitals.

Yet other authors, working in an STS tradition, approach the matter in a different way. Instead of advocating or condemning accounting practices, they study accounting systems as they function in practice (Berg 1997; Timmermans, Bowker & Star 1998). These authors stress that systems and standards do indeed change health care practice, but that the effects differ greatly, as they are negotiated and changed by stakeholders. How protocols work out is hard to predict, and the effects are to be studied empirically and locally before their acceptability can be discussed (Mol & Berg 1998). Starting from this empirical scepticism, in this paper I will study what accounting means in long-term mental health care practice in the Netherlands. How do nurses and other caregivers deal with demands for accountability in care-practice? How does this relate to the aim of making daily care 'good'?

5.1 The case of washing

To study 'accounting in practice' I will analyse an ordinary activity in long term mental health care: 'washing patients'. The analysis is based on ethnographic research in four long-stay wards in two psychiatric hospitals and five residential homes for the elderly that house patients who grew old in psychiatric hospitals. In both settings, *improving* care is an important concern. Alternatives for lifelong hospitalisation are sought by implementing (preferably evidence based)[80] rehabilitation programs and by approaching patients in ways that support their autonomy and their re-integration in the community.

'Washing' in both settings is the topic of considerable debate. Different professionals argue about how the washing is to be done, to what end and how this should be accounted for. In the residential homes, psychiatric nurses formerly working in psychiatric hospitals, confront new colleagues, professionals in elderly care, who are mainly geriatric assistants. Debates on washing and accounting are on the surface in this new 'community based' care setting. In the psychiatric hospitals discussions emerge in the process of changing from 'institutional care' to the 'rehabilitation' of the patients. The question here involves what rehabilitation means in specific situations and which ways of washing would support it best.

Troubling these discussions is the reluctance of some patients in this study to wash. Explanations differ and the reluctance alters between

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[80] See for instance: Torrey et al. 2001

attribution to (negative) symptoms of schizophrenia, physical disabilities, and hospitalisation or to the wish to 'fight nurses'. Although in all practices nurses will finally wash reluctant patients, when and how this should be done well is a controversial matter. I will present four different ways of 'good washing' and bring out their controversies in order to analyse how accounting works in daily practice.

5.2 Tacit accounting

This first practice of washing does have an elaborate notion of 'good washing', but accounting for this is not part of the practice. Let me first explain what 'good washing' is here.

> 'Good morning!' Julia, the geriatric assistant says as we enter the room. When there is some movement in the bed she pulls back the blankets. Julia asks Mrs Norris to lie on her back as she wheels in a washbasin. Julia takes off the incontinence pads. She takes a facecloth, puts soap on it and washes Mrs Norris' legs and genitals. She drenches a fresh facecloth and rinses off the soap. Then she dries the body with a soft towel. She covers Mrs Norris with the sheet and goes to look for clothing. She also brings a bottle of perfume. 'Her favourite!' she says to me with a wink. She brings new pads and underpants made of some elastic, net-like structure to keep the pads in place. She turns Mrs Norris to lie her on her side to wash the underside of the legs humming a cheerful tune. 'Good', says Julia. 'She prefers lying on her side, she has a nasty bedsore on the heel of her foot.' she explains to me. She puts cream on the buttocks. On the wardrobe is a list with which ointment has to go where on Mrs Norris's body. The new incontinence pads are put on and the foot is bandaged. Then sock one, and sock two, slipper one and slipper two Julia counts. 'One, two, three', Mrs Norris says sleepily. Then the nurse helps Mrs Norris to put her trousers on. 'No, not two legs in one trouser-leg!' Julia says. 'Two legs in one leg', Mrs Norris says. 'Good', says Julia, and the lower half of the body is ready.

The morning rituals of Mrs Norris present a way of washing patients that has its basis in care for the elderly in residential homes. Here, cleanliness and washing patients is an uncontested, routinised, even exemplary form of good care. Caregivers, mainly geriatric assistants, perform the washing. A lot of machinery is present to facilitate the washing of patients. The residential homes sport seats in the showers, tools to lift people out of bed and into the bath and transportable washbasins. Face clothes and towels are delivered in huge quantities. Wheelchairs are everywhere to wheel the person to the shower or the bath on the corridor. Incontinence material is supplied in many forms, shapes and brands.

Cleanliness is institutionally enforced by the routinised nature of cleaning. The work is organised in 'rounds' (see also De Lange 1990) to guarantee the routine of cleaning. The first round is to wake everybody, the second to wash and dress everybody, after which breakfast follows and so on. Washing has its institutionally enforced space and returns every day, which makes it ordered and predictable. This routine is important, because it is unacceptable that patients are left lying in bed, and, possibly, in dirt. The geriatric assistants are the authorities on cleanliness and make sure that everybody gets a regular wash, even people who object. To 'stay dirty' is not an option; to let patients wander around the ward dirty is thought of as very bad care, because dirt would signify that a patient could not take care of him or herself but is not assisted. It would be a form of professional failure and neglect if that would happen.

> *Geriatric assistant*: A person who can take care of him or herself having a wash and getting dressed, you give them a good cleaning under the shower once a week. For a check-up, for hygienic reasons. And in doing so my opinion is: I want to wash them from head to toe, even if this person could do it herself. Of course, you let them assist, but I want to inspect the skin. To verify that nothing is wrong. Because otherwise, if something is wrong, nobody sees it. That is our [the geriatric assistants] responsibility. Because very often people do not tell things. They are ashamed, they are in doubt and when you take care of them, you are confronted with the problems.

The preservation of the body and prevention of physical pain is part of the expertise of the geriatric assistants. They take care of a person, and when something is wrong, they report it to the doctor. The doctor is in charge of possible treatment.

Prevention, hygiene, service and control are important values in this type of caring.[81] But pivotal to all this cleaning is that a persons' dignity depends on a clean and well-kept appearance. This is directly related to a person's place in the social order of the hospital or the residential home and it's visitors. To be dirty would be to lose dignity in the eyes of the community one lives in. Mental disturbances or 'irrationality' are less central to the person and are often not recognised as such by the geriatric assistants who have no training in psychiatry. They constantly correct skirts creeping up, messed up collars, and spots on dresses. 'Auditorial dirt' such

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[81] In the history of the Dutch residential homes these homes started out as a service for the rich elderly and gradually changed in to the form of nursing home, where disabled elderly are looked after. Since the residential home is financed according to the AWBZ (General Law for special costs considering illness) a medical 'indication' is necessary for admission in a residential home. See: Bijsterveld 1996.

as swearing and cursing and sexual misbehaviour is seen as very offensive and threatening to this social order. Other forms of deviant behaviour are often perceived as ‘typical characteristics’ that are easy to accept. To quietly hallucinate in a corner is seen as less disruptive than not being clean. The geriatric assistants relate symptoms that would be signs of psychiatric disorder elsewhere to individual characteristics and particularities.
This non-verbal style of nursing does not ask for a justifying analysis or verbal account. There is no time for talking, discussing ways of approach in the nursing team or building extensive care-plans. This would distract from doing the ‘real work’.

> *Interviewer*: Do you have something like care-plans?
> *Head of geriatric assistant team*: No, no. We have care-plans in the computer, of all the people, how they are ADL [washing and dressing] and mentally, and so on. But they are not used. It’s in the planning, but not yet started.
> *Interviewer*: Would you think it is useful to work with care-plans?
> *Head*: No, no. You know, these days, so many things are done, quality improvements, care-plans, and.... And then I think: ‘Just go to work and help these people and...’ It is all so much paperwork, you see. So many meetings, and talking... If a new assistant comes to work on my ward, I just say: ‘This person has so and so, and that person this and that, and you have to help this way.’ And you do not say: ‘Well, why don’t you read the dossier, see what the care-plan is.' There is simply no time. So I think: there is a lot of time involved, but if you can actually do something with it...

Care-plans are part of a practice of accounting that is self-evident to psychiatric nurses, but are not seen as improving this type of caring because it is exactly the routinised nature of practice that would make it *good* practice. Nobody is neglected. No trouble can arise from disease spreading from overlooked filth. If everybody does her work, care will be good. Washing and cleaning function as goods in themselves, the clean and orderly ward signifies that everything is well looked after. This can be ‘inspected’, for instance by the head-nurse, but it makes washing an act that is not regularly verbally justified. There is not much ‘text’ to this type of care. This is explicitly contrasted with the ‘talking’ that other professionals, such as the psychiatric nurses do.

> *Geriatric assistant*: And then, to sit with people [patients], to talk to them, *I* would feel very miserable. I couldn’t do that, when so much work has to be done and I would sit and talk to people while others work their fingers to the bone

‘Sitting’ and ‘talking’ are not good because they are opposed to ‘work’. The work that turns care into good care in this logic is not verbal. If you would sit and talk to patients, you would not be behaving like a good colleague because you would let them do the work. And to be a good colleague is important to make care function in a routine way. Indeed, *not* working would need a justification. As long as the work is done this is in itself the justification of this practice.

> *Psychiatric nurse*: I had to deputise one day [on the other wards where geriatric assistants work], but I thought is was terrible. The day before we were discussing Jake Elster, with the doctor. And then you talk about questions: ‘Does he need more medication, or doesn’t he.’ So for a nurse these are very interesting matters. And the other day I had to deputise and it was a Saturday or a Sunday. And all clients were out of their beds at nine. And after nine o’clock we had to clean the night tables. And I could not detect a spec of dirt on them! I could have cried. I thought: ‘How can I explain to these people that I do not want to do that.’ But this was *so*... they were *so*... they would not understand if I told them I do not want to do it. That was how I felt it.
> *Interviewer*: So you didn’t tell them. [No] You washed the night tables.
> *Nurse*: I washed the night tables. Isn’t that terrible? I think it’s really bad. I didn’t see the point.

This informant could cry about routines he thinks are pointless. Crying is the option, because words to argue against established routines and for values he finds so self-evident are lacking. The non-verbal nature of the practice and the negative value attached to ‘talking’ make it hard to ‘argue’. Arguments can be given in interviews, but are not part of the daily practice in which the work simply has to be done. Accounting is not part of this practice of good washing. Or to put it differently: to be accountable to outsiders is signified by clean wards and clean patients; by doing, not by explaining.

This practice where accounting is not part of everyday care, points out that accounting can indeed be seen as a practice on this level. Accounting is declined, because it takes time, props and words and this time is supposedly better spent on actually washing patients. The geriatric assistants do not *explain* or *justify* why washing has to be routinely done in order to make it good care, but the result can be inspected. When pressed in interviews, the geriatric assistants account for their care in terms of ‘hygiene’. The importance of hygiene can be traced back to its historical origins (Boschma 1997), but as a repertoire of accounting it has become tacit. Indeed, this practice does not seem to fit with recent calls for accounting. No scientist has considered a design to prove effectiveness of routine washing, nor are there ethicists who argue for treatment contracts in this case. Quite the contrary: when routine washing ever reaches the public debate, it is to argue for more rigorous washing routines.[82]

Criticism of Routinised Washing

It is this way of 'routinised washing' that has gained severe of criticism from the new colleagues, the psychiatric nurses. The criticism does not only concern the way of washing, but also the way of (not) accounting for the practice of routinised washing.

> Project leader, psychologist: This is a form of cultural difference [between mental health care and care for the elderly]. In mental health care people are used to call one another to account for something, to discuss one another's behaviour, or attitude, to make agreements. While in the residential home, there is a team on each ward, but there is no such thing as structural team-meetings or discussions of progress. You know how busy they are in the residential home and to put four people together... just one has to be ill and there is no team-meeting. And this is *unthinkable* in mental health care. There is *always* a team meeting. So these are essential cultural differences.

To just go ahead and do things is incomprehensible to methodical nurses. It is incompatible with their norms of professional nursing and this is referred to as 'cultural difference', signifying differences that are hard to argue because they are firmly embedded in a 'strange' and tacit worldview of related and indisputable values. Because these values are hardly articulate, the practice of routine washing is hard to defend, and also hard to change, as there is no space (or time) for reflexivity.

5.3 Effectivity

The practice of 'effective washing' can illustrate the different approach to good washing as washing that can and should be accounted for. The main argument against routinised washing is that *hospitalisation* of patients is a consequence of taking over tasks that patients are able to perform themselves. They become passive, helpless and depressed. They are made

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[82] See for instance: NRC Handelsblad, a Dutch newspaper, 4 April 2002. In Denmark it has been recently debated whether it should be legally allowed to use coercion (fixation) to force elderly people who resist hygienic routines to be washed. See for this debate for instance the Danish newspaper Information, February 26, p8. Thanks to Estrid Sörensen and Brit Ross-Winthereik who pointed this out to me and translated part of the debate for me.

dependent on caregivers, and lose the skills to wash and take care of themselves. This is not the way professional nurses should work. Washing should be taken care of in a way that leads to results. Washing skills should be trained or re-learned.

> A fragment of Mrs Townsends' morning ritual:
> 'Okay now, first give your face a wash', Jolene [psychiatric nurse] says. 'Like this?' Mrs Townsend asks when she puts her hand in the face cloth. 'Yeah, like that. Now wet it. Open the tap. That is the cold tap, see. Do you want hot or cold water?' 'Hot water' says Mrs Townsend. Jolene helps mixing hot and cold. 'This is better. Now start with your face. 'Mrs Townsend rubs her face and her neck. 'Now get the soap off. Just rinse the cloth.' says Jolene. 'What should I do?' Jolene repeats. Mrs Townsend wipes the soap off.
> Jolene: 'Right, now just dry your face. Now wash your arms, and your armpits. Can you do that?' [Mrs Townsend points to her armpits] 'Yes, that's your armpits. Put some soap on the face cloth.' She then asks: 'Shall I wash your back?' 'Yes please, ah, that is nice.' Mrs Townsend closes her eyes and enjoys the washing as well as the drying of her back.

The nurse tries to make Mrs Townsend perform the washing act for herself, forming 'prosthesis' for the bits she cannot do. She gives verbal cues to trigger Mrs Townsends' remaining washing skills. Nurse and patient perform the washing together. It is pivotal that the patient is active; the nurse cannot simply take over. The idea is that Mrs Townsend has to practice her skills or she will lose them. Even if the expansion of skills is not possible, it is important to train whatever skills are left, to keep them fit and to take care they do not deteriorate. Psychiatric symptoms are not seen as disruptive to bodily skills. To hallucinate or be depressed does not affect the *skill* to wash oneself, although it might affect motivation to practice them.

> *Interviewer*: Do you actually notice patients progressing?
> *Psychiatric nurse*: Yes, Mrs Vanderveen for instance, she has clearly improved since she came here. She walks again, every now and then she goes to bed by herself. She even cracks a joke at times. And also with personal hygiene. On the outset we took care of her completely and now she does the upper part of her body herself very often.

Instead of the more physical work of washing a patient, with the professional good of the maintenance of skills 'talking' becomes an important act in nursing, as is functional diagnosis: what can a person do, what can't she do, what can he learn? Assisting and planning are essential. The skills approach can be seen as a professional and methodical way of organising washing. It can (and should) be applied to all patients who do not suffer from physical disabilities.

The methodical approach to washing explains the need for the organisation of nursing care and the materials needed. Care-plans become important and a smooth exchange of information in the nursing team. Every nurse is supposed to be informed of what a patient can and cannot do, where assistance is needed and what goal the training aims for. Every nurse should approach the person in the same way. Apart from the standard items (diagnosis, medication) care plans describe the training and are evaluated at regular intervals. The training of skills implies improvement; evaluations can and should be made. The nurses write reports on the progress made, troubles encountered, etcetera.

So *accounting* takes the form of justifying care in terms of effects. Care-plans and team-meetings are necessary to account for the training between colleagues and for inspections from outside. Procedures are transparent and methodical. Because the training has to lead to results for individual patients, the ways of accounting these nurses use are oriented towards is the epidemiological rationality of clinical trials. The training should be well documented and should be evaluated to see whether there is any progress towards independence, or if the patient can handle more complex tasks. What can be argued by measuring effects is that the professional method of training 'works'. As such it can ultimately be compared with alternative methods that pretend to bring about patient independence and are more or less successful. In this way, nursing care can be based on knowledge of what works or does not work.

This practice of washing-and-accounting shows that accounting is not only functional on a formal level of gathering knowledge and legitimating care-practice to outsiders. Nor is the washing training a form of implemented therapy that has been proven effective. To be accountable on the level of daily practice here it is *intertwined* with the logic of clinical trials and interferes with notions of what good care *is*. Daily practice is organised in ways that produce effective care. 'Accounting' is not merely a way of legitimising care, but also structures care on a practical level.

Criticism of Effectivity

So the practice of skills training is transparent and accountable. Yet geriatric assistants criticise the effective washing practice because they feel that nurses are too strict on the patients, notwithstanding the fact that they are living in a residential home or hospital, signifying their inability to act for themselves. Effective washers push them do this anyway.

> *Geriatric assistant*: Some things are really obligatory, a certain structure. And not: 'you don't feel like it today, ok, so don't go today.' No: 'you *must* go.' That was really hard to swallow for a lot of people [geriatric assistants].

This informant would rather take over washing than force people to do it for themselves. The effective washers partly acknowledge this criticism. [83] They do experience problems with patients resisting to be trained to wash. If the struggle cannot be brought to the desired conclusion (of patients washing themselves), the nurses sometimes slip out of their professional mode and merely (or routinely) wash the patients. That patients should be clean is not debated.

> *Geriatric nurse* [moved from psychiatric hospital to residential home]: It's a fight, over and over again, every morning, to get her to do it herself. That she dresses and walks over to the living room. [...] And it is difficult, because if you 'give in' you set back the training for a month. You should be persistent, consequent, constantly. And that usually works. But yes, sometimes you have a day that you cannot take that much and then you just quickly take over and wash the person. But in this case it is wise to just mention it: 'Today I will help you a little, but tomorrow that's over.' Indeed, there are patients who find it very comfortable if you just do it. Because they cannot do it. So the fight remains.

In line with the criticism from the geriatric assistants, but with a very different solution to the problem, other nurses question the goal of physical independence. These nurses propose a different goal instead: to respect the right of patients to privacy and to decide on their own treatment. Professional training, these colleagues argue, does not respect individual differences and self-governance of patients. They compare it to the approach of the geriatric assistants, who routinely apply 'a good wash' to patients. Washing patients or forcing them to learn washing skills both provoke hospitalisation, because it is still the caregiver who decides. Instead of routinely demanding patients to do things or force them to train skills, what these nurses argue is that it is important to leave it to the patient to decide. Instead of guarding patients, the nurses should facilitate that patients make their own decisions.

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[83] A comparable complaint is heard from doctors troubled by translating results from clinical trials to individual patients. The patients in the trial are often selected for having a singular diagnosis, while 'real patients' often suffer from complicating other diseases that interact with the treatment prescribed. (see for instance Rothwell 1991). Likewise, the tension between patient autonomy and evidence based medicine is a matter of debate (see for instance: Chervenak & McCullough 1995).

5.4 Autonomy and privacy

The objections to effective washing made by the nurses mentioned above is part of a practice of washing-and-accounting where *applying principles* is an important way to make care good and accounting for it. What does this mean for 'good washing'? To encourage patients to make their own decisions, these nurses try to *individualise* washing. They do this by relating to the washing norms of elderly patients (a shower once a week, the wash basin for the other days), or by helping them to find out what washing attributes patients prefer. Instead of the institutionally provided soaps and shampoos, the nurses go shopping with the patients to buy showering attributes the patient likes.

The patient is perceived as an individual with personal preferences and norms. Yet these preferences and norms are not often transparent, but have to be developed because patients have got used to the institutional provisions and are unfamiliar with going to town to buy things for themselves. They do not know how to choose, because there used to be no alternatives. Another way to develop their individuality is guaranteeing patients' privacy and responsibility. Preferably they should be enabled to go for their shower alone. The surveillance of the nurses should be done away with.

> *Rehabilitation coach*: We discussed this in the team. 'Yes, we are always there to see that he takes his shower. But do we *have* to be there? If he has got his towels and his things, he can manage without us.' And thus people [nurses] began to think about it.

To wash privately is a topic of concern and asks for creativity in the psychiatric hospitals, where sanitary facilities are shared by patients in the same corridor. In the residential homes every person has his or her own bathroom, in the hospitals privacy and individuality is created by abolishing general shower-routines, surveillance by the nurses and by bringing in personal objects.

To encourage patients to decide over their own life, the preferred mode of nursing is to work from a consensus between nurse and patient. Patients are not forced to accept things. This is also apparent in the way these nurses use care-plans that differ from that of the effective washers. Instead of goals decided by the nurses, the plans should list the goals formulated by the *patients*. Apart from the standard items the plans contain information on the history of the patient, hobbies, preferences, contacts and so on.[84]

The accent on consensus can also mean that patients can refuse a wash. When patients refuse a wash, the reason for this is not always clear. But for nurses who take patient autonomy seriously, what is a good reason not to wash can be stretched to hospitalisation or delusions.

> *Psychiatric nurse*: These patients are here for a long time, and you might say they are much hospitalised. They loose their sense of dignity. And I think they don't really care what they look like; they just sit around in the hospital. That is what you hear some of them say: 'What do we have except for our coffee and cigarettes? Why would I take care of myself? I am locked up in a madhouse.' And with some people it has to do with their disorder. Like Mrs Andersen, she says: 'I have to be dirty or terrible things will happen to me. If I take a shower and wash, my skin will fall off.' That's very extreme; some people have bizarre notions of their bodies. And her hair is not supposed to be washed either, it has to be just fatty, otherwise she thinks it will all fall out.

Indeed there are some good reasons given for not wanting to wash. But even if the nurses would think the reasons are bad, they feel they have to respect the principle of patient autonomy. Washing or not washing is a personal matter, to be decided upon by the patient. Caregivers postpone interference to respect individual privacy as long as possible.

'Good care' here is to respect and sustain the individual in the choices he or she makes. It is about *principles*. Washing is good and legitimate if it is done with a person's consent and as individualised as possible. Caregivers should not interfere light-heartedly in a person's private space. They can try to seduce patients to wash by using objects and routines the individual prefers. Or they can respect their way of being 'not so clean' as a way of authentically living their bodies and expressing their individuality. How one chooses to wash is a matter of (historically contingent) preferences, norms, interests or even psychiatric disorder.

So again, *accounting* is an important part of this practice, but in a different way than when it concerned the effectiveness of skills training. To account for or to justify this practice would be to spell out the *ethical* standards of the practice, to point out that principles are applied in a consistent way. Where washing has to be effective, caregivers orient their practice to quantities of progress, which is already more verbal than the tacit accounting of the geriatric assistants. But the form of accounting in this

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[84] These can also be present in the care-plans of the effective washers, but would not be relevant for effective washing, whereas they are relevant in ethical washing.

practice is even more articulate. The 'ethics' of care is reasoned about with the use of principles that should guide and justify psychiatric nursing.

That the principle of choice is patient autonomy and privacy fits with recent legislation and values proposed in policy documents.[85] In daily practice, however, the *procedural* ways of accounting, by treatment contracts for example, are not used for 'good washing'. Instead, the principle of patient autonomy is taken out of its procedural context and is projected on other situations in daily care. Again, the type of accounting interferes substantially with what good care is.

Criticism of Autonomy and Privacy

This practice of applying the principles of autonomy and privacy to account for good care also has its limits. Geriatric assistants would label this practice as neglect because the nurses do not take disabilities, and therefore, the limits to autonomy into account.

> *Geriatric assistant*: Personally, I think that the hominess is very nice for most of the residents. And I see this as the big difference, at least, from what I hear from the nurses that came from the psychiatric hospital. This is typical for geriatric assistants, we just do it all, and we make it nice and cosy. And the psychiatric nurses are different. Colleagues who have been there say: 'Jeez, if you saw those rooms, they [the psychiatric nurses] don't do a single bit about them.' They think that the residents should take care of that themselves. But these people are here because they are unable to do certain things. So we arrange a lot.

The effective washers also question the professionality of neglecting patients: they do not consider that patients can be dirty. And these problems are also encountered within this practice. This happens when the principles and local ethics clash with situations that were not foreseen when patient autonomy was proclaimed. Such a situation occurs when the nurses feel a patient has become too dirty, but cannot be persuaded to wash or be washed. No consensus can be obtained. At this time the nurses will wash a patient, but there are no words to account for this transgression of the principles of patient autonomy and privacy. This 'subversive washing' remains unaccounted for, even if the nurses feel it is 'good'.

> Nurse William says he could not stand it any longer the way Bill looked, all dirty and with the scabs on his face [he has a skin-problem]. They had tried it long enough, with 'own responsibility' and with gentle insistence. Even with a

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[85] See for the substantial interference of legal procedures and daily care: Pols 2003.

> prohibition to enter the common room in this dirty state. To no avail. William commanded Bill out of bed, dragged him under the shower and scrubbed off all the scabs. 'Harder!' Bill had called. He has been in the shower for almost two hours.

Washing without consent is hard to think of as good if it has to be accounted for in terms of privacy and autonomy. The caregiver takes a passive attitude and waits until she really feels that a limit is reached. Sometimes this feeling is discussed in terms of the 'hindrance of others'. A bad smelling patient would disturb other patients living on the ward. However, in most cases the unease can be brought back to the nurse herself. The other patients do not complain, but the nurse feels that this time 'dirty' has become 'too dirty'. She then grabs the face cloth and gives the patient a wash. To do so can indeed be seen as a form of good care, as the example shows, however hard to justify in terms of patient autonomy or authenticity, or indeed in any terms at all. The origin of the urge to wash a dirty patient is not known because it is not verbalised and cannot be accounted for in terms of patient autonomy. In ethical washing dirt can be accounted for better than a forced wash.

5.5 Criticism of accountable washing: contextual accounts

Yet other nurses criticise both effective and principled washing-and-accounting practices. What both practices seem to overlook, it is argued, is the complexity of everyday care-practice, of 'getting through the day' with 'difficult' patients. With all their accounting, these practices cannot deal with patients who experience little or no progress or are exceptions to rules and good principles. In order to make care-practice 'good practice', these nurses argue that the practice has to come first, not the secondary aim of accountability.

Washing is then not an activity that needs a clear method of approach, nor do principles or rules surround it. In this style of washing it is one of the elements of the 'daily muddle' of things that have to be done. It is looked upon as something that has to be negotiated in relations between nurse and patient. There is no hierarchy in the kind of activities to undertake. It is not even imperative that the person should wash him or herself: the caregiver, patient or both can do the washing, whatever is most convenient. The nurse can give opinions or negotiate with a patient if she feels the patient needs a wash. The washing can be adapted by looking for a convenient time, by doing it together with the nurse, or by exploring preferred washing habits.

Actions such as washing thus are thought of as dependent on different contingencies such as moods, events that took place and they change over time.

> *Psychiatric nurse*: I think these things are un-plannable. On one day you can say: 'Hey, Ben, let's go for your shower!' And then I think 'That is nice, I can talk to him in an informal way.' And the other day I think: 'Ben, today I am not going to ask you this.' There is no standard that is always successful. Some other time I would probably say: 'Ben, you can do it on your own.' Or he says: 'I don't do it.' I think it is very hard to lay down rules how to do these things.

A person is not necessarily seen as autonomous or even coherent, but changes over time and according to different relations and events. Nurses have to time their interventions to the right moment if they want the patient to do something (and the same is true for the patient wanting something from the nurse). In order to get through the day in an acceptable, or preferably, convenient way, they try to establish and maintain good relations with their patients. There is continuous negotiating and give and take.

> *Psychiatric nurse*: O, I know that every once in a while Frank [patient] puts his head under the shower and then it's done. But I don't think you should be too rigid in these things. I try to get him in the bath once a week, I fill the tub and then I know he has soaked at least once a week. And you have to accept that, you see? You shouldn't want it all. You should be a bit flexible, if you notice that he is doing well and his mood is good, then you shouldn't insist and say: 'Take your shower now!' You have to give and take a bit with your relation, the trust you've built. Without being walked all over, of course. But you should show them the other side. And in this way you can do a lot with these people. Because you are not rigid, but show them the middle of the road, or the other side.

The flexibility in relating to patients and the process of contextual washing can also lead to patients remaining dirty, either because they strictly refuse to wash or a relation with them can not (yet) be established to persuade them otherwise. There is no clear directive how a good relation is to be established. Some people get along better than others and differences in personal style are used rather than standardised. To establish a form of balanced relation, continuity is provided and the nurses take an emphatic attitude. But there is no 'endpoint' to which the relation should lead. It would be hard to establish the effect of contextual washing or of 'getting through the day'. Nor does 'getting through the day' imply a set of principles or rules that have to be respected at all times. There is one minimal principle: coercion is to be avoided, as this would affect the building of a balanced relation between nurse and patient. In order for care to be good here, it would have to adapt to the circumstances, and juggle with different ways of entrance. There is no general 'method of approach'.

Criticism for Contextual Washing

The everyday contingencies and flexibility makes *accounting* difficult in this style of washing. This is the main criticism that comes from accountable practice. As a patient you can just hope for a caregiver you can relate to. There is no protection offered by rules or methods from the much-feared abuse of power or 'bad treatment' for which accounting procedures were designed in the first place. It is not easy to account for a 'good relationship' and the specificity that goes with that.

This is indeed worrying the caregivers a little. The solution they propose is to be open to visitors from the outside world.

> *Psychiatric nurse*: Yes, you want to be dynamic about things, in the process of caring, for your own development as well. We discuss things in our team. But best is when new workers come in, with a critical perception, without the burden of the traditions that have established themselves. And they ask you things, so that you start thinking again: "Why am I doing things like this, why do I talk like this?' You really need a fresh vision.

The way of accounting this nurse suggests is as flexible and contextual as the care it has to fit in with. But what form of accounting is being suggested here? The nurse is not proposing to give a justifying analysis or explanation of practice to outsiders. Nor does she point to good results. The nurse here suggests a different type of accounting, a kind of reflexivity that does not justify practice with reference to pre-defined standards, such as effective treatment or respect for principles. This form of reflexivity needs 'fresh visions' that are 'not burdened by traditions'. Instead of justifying that what they did was good, it opens up the possibility for others to say that a specific act in care 'was not so good after all' and 'wouldn't it be better to try it another way' in a comparable situation. Accounting her is oriented towards improvement rather than justification. It does not deny the need for routines, but tries to avoid automatisms by creating moments for reflection.

Because there are no standards or goals compared to which this style of washing can be measured or weighed, washing would be good practice if it were done with taking into account the specificities of persons and situations. One could imagine nurses travelling around to visit other practices, or the writing of case stories to be exchanged with colleagues. This could lead to inspiring stories and the exchange of ideas and fresh perspectives. However, because the practice is flexible and fluid, contextual and connected with specific, changing individuals, it is hard to justify in a general way, and so is hard to defend or transport to other situations.

Conclusions: Accounting in Daily Practice

What is asked from health care professionals when they are asked to be accountable? It seems that, both from the point of view of Evidence Based Medicine and health care legislation, caregivers must show that they have implemented therapies that have been proven effective, or procedures that protect patient autonomy. In this way care-practice can *legitimate* itself by showing effective therapies are used and procedures are attended to. Care is justified by showing specific, pre-defined standards were met.

However, the analyses of the practice of washing show that accounting is entangled more substantially with defining and practising good care. Effective washing, for instance, is not a practice in which an evidence-based treatment is implemented. Instead, the practice of washing is structured in a way that would make it possible to measure effects. Rather than positioning themselves as caregivers who administer some kind of effective therapy, the caregivers can be seen as taking the position of *researchers* preparing practice for a clinical trial. Other nurses translate the principle of patient autonomy from formal procedures such as treatment contracts, to other situations in care. Rather than behaving like professionals using guidelines, they can be seen to be actively practising ethicists who reflect on ethical principles and put them to use.

Notwithstanding these substantial changes however, in both practices the style of accounting as a practice of legitimisation can be recognised. These nurses explain that their practice is good because specific standards are applied. However, the activity of legitimising enforces certain predefined goals, but does not tell about their actual workings. It does not 'make care good'. This became clear because both care-practices incorporate tragic situations, unexpected exceptions and manoeuvring with methods and principles. Methods working towards effectivity run into problems when patients refuse their washing training. When this happens, the nurses apply a routine washing because they do not accept that patients can walk around in a dirty state. Principles of autonomy run into problems with washing unconsenting polluting patients. The nurses do think it is good to wash these patients, but they cannot account for this in terms of autonomy and privacy. These forms of washing take the shape of wordless, 'subversive' (because unaccounted for) improvisation.

The activity of legitimising makes it difficult to discuss tragedy or unforeseen limits, or find repertoires to deal with them. When one legitimises ones work, one addresses successes rather than blanks or exceptions. This implies that, in order to provide 'good care', practices using a legitimising style of accounting are dependent on types of caring that ask for other forms of reflexivity or indeed are hard to account for at all. There are times when routinised washing or some flexibility with principles is inevitable because methods or principles do not provide an answer to a specific situation or a dirty patient. There are always patients who do not progress, or who do not fit in with the principle of the autonomous self, when this would imply neglect. In order to function well, legitimised care needs other forms of caring.

Contextual Reflexivity as a Practice

If it is impossible for care-practices that incorporate legitimising styles of accounting to function without forms of caring that cannot be legitimated, it suggests that there is something to gain by giving these forms of care some reflexive back up. This would be hard for the routine practices, but contextual care has a space for reflexivity that can be developed. To establish practices of contextual reflexivity and open them up for 'fresh visions' is a way a nurse suggested to think of such an aim. How can this be done?

In order to create space for contextual reflexivity, what is needed is to think of a solid link between ways of 'knowing', reflecting on what is good, and practising both, while taking difficult situations into account. It would have to acknowledge that a certain amount of routine is necessary to practice care, without making these routines inflexible or turning them into single inflexible standards, however implicit or explicit.

Contextual reflexivity would need 'involved descriptions'[86] that articulate 'goodness' in care practice without defining what is 'good' or 'knowing' its object beforehand. Its analysis of 'good care' holds back on judgements; instead it tries to show what facts and values circulate in care-practice and what type of practice this brings about.[87] It does not ask: *is* a certain therapy (method, value, artefact) *effective*? But rather: *what effects* does it bring about? This enables analyses that make care-practice understandable without erasing troublesome situations. The good as well as the more doubtful situations can be analysed as a consequence of specific patterns of traditions, values, knowledge and routines used. Routines can

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[86] 'Involved' here is opposed to 'neutral', but does not mean 'subjective'. Dona Haraway would talk here about 'situatedness' in her attack on realist epistemology (Haraway 1991). Harbers, Mol & Stollmeyer (2002) use the term 'involved description' and argue for an ethical position. Here I explicitly add the link to an epistemological position.

[87] Boltanski & Thévenot set the inspiring example by classifying ways 'ordinary people' (not in care situations) use to justify their actions into five different repertoires or worlds ('mondes'). They do not criticise legitimations, but study their use.

momentarily become ‘unroutinised’, by reflecting on their values and effects. Instead of legtitimations, this could lead to improvements in care.

Contextual reflexivity can be practised on different levels, by nursing teams, between different professions, in an organisation, between two organisations, by an ‘involved ethnographer’ and so on. It provides a form of knowledge that does not ‘discipline’ participants in the field, nor loses sight of moral sensitivities considering specific situations or persons. Instead of imposing predefined standards of knowing, the participants follow professionals and patients in their (accounts of) daily life and work and seek to spell out what concepts and values can describe its internal logic and what this logic enables or restrains.

Studying values and other types of practical orderings avoids the light-hearted ‘taking of sides’ by specific parties in the field (for instance ‘the patients’ or ‘the professionals’).[88] But showing different practices of ‘good care’ and tacit knowledges, also challenges these same practices. To realise that there is not one form of good care, but that there are different conflicting ones that each have good and bad effects, invites critical self-reflection. Instead of the suspicion built in in accounting procedures ‘from the outside’, involved descriptions are made from the analytical position that caregivers aim to ‘give good care’ and ‘know’ what they are doing, however much one might disagree with the specific aims or effects.

This is a way of putting contextual reflexivity into practice by telling stories to involve(d) insiders as well as involving outsiders. Both outsiders and insiders are challenged to think for themselves; to become involved. Practice is not ‘justified’ as good, but is opened up to show tragic situations as well as best practices. Wins and losses can be compared and weighed; different ways of thinking can be mobilised to imagine alternatives. This might be an interesting way to help professionals striving for something as complex as good care’.

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[88] For a thorough analysis of the politics of orderings as opposed to the politics of conflicts between groups, see Mol & Mesman 1996.

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6 Enacting appreciations: beyond the patient perspective

Abstract

The ‘patient perspective’ serves as an analytical tool to present patients as knowing subjects in research, rather than as objects known by medicine. This paper analyses problems encountered with the concept of the patient perspective as applied to long-term mental health care. One problem is that ‘having a perspective’ requires a perception of oneself as an individual and the ability to represent one’s individual situation in language; this excludes from research patients who do not express themselves verbally. Another problem is that the idea of ‘talk’ as a representation of the world ignores the fact that talk is also performative in the world: it requires, at least, the ability to deal with an interview situation. To think up alternative ways of including patients as subjects in research, I develop an approach that takes this performativity as a starting point. Analysing practical situations and activities, I argue that patients enact appreciations, making known what they like or dislike by verbal or non-verbal means in a given material environment, in situations that are co-produced by others. Thus, subjectivity is linked to situations and interactions, rather than just to individual characteristics; to ‘patient positions’, rather than ‘patient perspectives’.

6.1 Introduction

Nowadays researchers are asked to attend to the ‘patient perspective’, or at least to appoint a representative of this perspective to the research committee. This is a reaction to earlier studies, in which patients were represented by diagnostic labels or outcome variables; that is, they were included only by representations which were not ‘their own’. Patients did not appear in research texts as subjects-who-know, but rather as objects-that-are-known by medicine. Pressing researchers to attend to the patient perspective is a way of addressing these shortcomings, and of making the patients heard.

One reason for attending to the patient perspective is to improve patients’ faithfulness to therapies and instructions from their doctors (Helman 1978; Blumhagen 1980). When doctors know how patients interpret what is wrong with them and what remedies they deem appropriate, doctors are better equipped to influence patients to a course of action that is medically sound.

In later studies in medical sociology and medical anthropology, the patient perspective became a valuable object of study in its own right, and a way to improve the work of doctors by 'complementing' biomedical knowledge. For instance, experiences of illness, suffering and dying (Kleinman 1988) were studied and interpreted in various ways: as biographical disruptions (Bury 1982; 1991 S. J. Williams 2000), or as turning points in the lives of people who fall ill. What patients relate can be analysed as expressions of (lay) systems of belief or explanatory models (Kleinman 1980; Reynolds & Schwartz 1993; Cohen et al 1994) or as narratives of experience (Mattingly 1994; G.H. Williams 1984; 2000; Bury 2001). These studies put forward ways of thinking and telling that had been impossible in medical ways of framing patients. Other scholars describe illness experience in time: as trajectories (Corbin & Strauss 1988) or as illness careers (Gerhardt 1986; Robinson 1986) through which the patient moves.[89] In all of these studies, the patient perspective is seen as a separate alternative to biomedical knowledge, which often is tacitly assumed to be, at least potentially, a coherent unity of medical knowledge and practice. Patients tell stories about *illness,* whereas the doctors are dealing with knowledge of *disease* (Eisenberg 1977; Hunt et al. 1989; Fulford 1998). The division of labour, with medical sociologists and medical anthropologists on the one hand, and biomedical researchers on the other, made it possible to attend to patients as subjects in research.

In another way of addressing the patient perspective, relations between illness and disease are questioned. Biomedicine is not regarded as a coherent body of knowledge, but as multiple, sometimes contradictory realities (see Mol & Berg 1998). Prior et al. (2000) describe how patients 'bricolage accounts' rather than 'have beliefs'. They try to manage their different social and medical worlds by collecting stories from different (medical) practices (Charmaz 2000). Thus, patients' experiences are not separated from biomedical knowledge, but are seen as being influenced by heterogeneous 'disease-practices'. Challenging new questions are how patients respond to this multiplicity (Barbot & Dodier 2002) and how the study of practices affects theorizing about disease and illness (Mol 2002).

Finally, the patient perspective is attended to not as a story about illness, but as comments on 'disease-practices'.[90] Patients' narratives of their

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[89] I cannot hope to be complete here, as the literature is vast. A good historical overview in lines of thought or 'theoretical paradigms' on chronic illness research (grounded theory and symbolic interactionism; ethnomethodology and phenomenology; and historical biographical constructionism) is provided by Gerhardt 1986; 1990, and more recently: Bury (2001).

[90] These types of studies are often done in health care policy research, but in medical sociology and medical anthropology this combination of the patient perspective in relation to treatment is also made, see for instance Pinder 1992; Lindenbaum & Lock 1993; Mattingly 1994; Csordas

personal situations and illnesses are not sought, and neither are the ways in which their lives are shaped by the medical practices they engage in. Instead, patients' evaluations of medical practices, the information they receive about treatment, the possibility of negotiating with their caregivers and their satisfaction with the results of treatment are studied (see for instance Campbell et. al; 2000; McGlynn1997). Thus, patients are not seen as adding to or being shaped by medical knowledge and practice, but as critically and expertly judging a diverse array of medical practices.

Questions can be raised in all these diverse theoretical positions, however: What are the specificities and assumptions of asking for the patient perspective? What does asking for the patient perspective imply? What kind of subjects are patients supposed to be? And how do thessubjects relate to the world?

In this article I report on my search for the patient perspective in a study of long-term mental health care in the Netherlands, and on the problems I encountered in this search. For some years I studied daily care on the long-stay wards of psychiatric hospitals and in residential homes where some of the elderly patients moved. From the start I realised that hearing the patients' perspective, which I understood as representations of their experience and their situation, might be difficult. Especially on the long-stay wards where people live who 'didn't make it' outside of the hospitals and stayed behind when the 'more successful' patients left to more community -based facilities (Corrigan et al. 1996; Brandon & Ridley 1983; Waisman & Rowland 1989). The literature also warned me about the problems met with in getting the perspective of the elderly (Willits & Crider 1988; Clark & Bowling 1989; 1990).[91] Armed with these precautions, I started out by doing participant observation (Keith, 1986) so people could get used to me and I could have a chance to hear their stories (Booth & Booth 1994). During my quest, however, I learned that even the concept of the patient perspective was problematic. If I was to consider the patients in my study as subjects, I had to look for different concepts.

1994. In these texts the influence of biomedicine on the lived experience and accounts of the body are studied. In health studies, however, the patient perspective is conceptualised as a more or less autonomous perspective on biomedical practices.

[91] Willits & Crider note that elderly persons often talk about problems in terms of physical problems. Clark & Bowling found that elderly persons are less good judges of their own situation than younger persons, because they tend to accept the situation or are afraid of criticism. Dutch authors stress the post-war situation that taught the elderly of today 'not to complain, but to bear' (Pouels et.al 1994; Kleijen et.al 1989) or compare the interpretive styles used by the elderly with those of 'group-oriented cultures', where the social group in which one lives is more important than individual development (Kleijnen 1989).

6.2 Language and normality: patients who do not speak

A major problem I encountered in my search for the patient perspective was that a lot of the patients in my research do not speak, or do not speak in ways that are understandable to me. Some people have speaking disorders such as aphasia, or cognitive problems that make it difficult to communicate in coherent sentences. Others are unable or unwilling to communicate in words for reasons that did not become apparent.

> I talk to Jane [a patient] in the common room. As usual, her speech sounds incoherent, but I notice that her brother pops up in the conversation a few times. It is also clear to me that she is angry or upset. When a nurse passes, Jane gestures and intonates some angry comments. The nurse seems to have done something wrong, though precisely what is lost on me. Jane gets more excited; at a given moment I hear her say: 'I will not be interrogated'. Oops. Gerry, another patient, asks me something, but I can't seem to understand the question. Yet another woman asks in an irritated way if Jane wants to 'translate'. Jane says that Gerry asked me if I can cook. I answer that I can cook and I ask her 'Why do you want to know?' Gerry doesn't answer my question; she is absorbed in looking for something in her handbag.

This frustrating situation is not uncommon; it illustrates some of the problems in talking to patients who speak little or not at all. My understanding of these patients improved as I got to know them better, thanks to their patience in allowing me to understand them. Yet these situations were a first lesson in what it implies to look for the patient perspective. To have a perspective, one needs *language*. To have a perspective means to formulate an individual vision, opinion or narrative about the world that represents your experiences. Consequently, if you cannot speak or fill out questionnaires, you cannot produce a perspective. Thus, if a patient is not able to produce words, he or she is excluded from inquiries into the patient perspective. Silent patients cannot be represented as subjects in research. In this sense, the patient perspective is a normalising concept. To study perspectives assumes that it is normal to be able to talk about and reflect on a specific situation, and formulate opinions about it. Kelly (quoted in Bury 2001:273) suggests that 'patient talk' is 'an attempt to normalise oneself in the face of serious and threatening symptoms, not simply a commentary upon it.' In this sense, silent patients can be seen, consciously or not, as failing to perform this normalisation in relation to the researcher. Asking for a perspective thus creates a difference between those with a perspective and those without one. It fails to represent silent patients. And that was precisely what I had hoped to avoid.[92]

6.3 The interview as a situation

The problem of finding the patient perspective turned out to be even more complex when I did find patients who were willing to sit down and talk to me. In two residential homes I was able to do interviews only, as the budget didn't stretch to do observations. So, apart from staff, I interviewed patients who were carefully selected by the nurses. This resulted in a strange group of interviews. I could hardly use these interviews to quote the patients' perspectives on living in a residential home, or on the care they received, because these topics were scarcely mentioned in the transcripts. For some time I tormented myself with questions trying to find an explanation for this. Did I fail as an interviewer? Did the patients fail as respondents? Both answers seemed unsatisfying.

I kept returning to the interviews to discover that they do contain messages. The clearest one is the unease of my respondents with the interview situation. Some clearly feared the one-to-one situation, and started the interview by asking if they would have to move again or by making a specific request not to tell anybody what was said in the interview. Others used the interviews to talk uninterruptedly about their psychiatric history; some were glad of the company but disliked the tape-recorder; some spoke five lines in half an hour; still others tried to flee the interview situation after about 15 minutes. One man tried to make a deal with me: I would put his shirts in the closet, and then he would answer one of my questions. But it soon became clear that he did not plan to keep his end of the bargain.

What this exercise taught me, finally, was that neither the respondents, nor the interviewer, but the *technique of interviewing* failed to produce a 'perspective'. I was asking my respondents to participate in a situation they experienced as unpleasant. It appeared dangerous to them to have an opinion, or to talk in the rather formal one-to-one interview situation. For some informants, the interview situation was threatening; alternatively, it made them talk about things they thought would be appropriate, such as their psychiatric history (see also: Mishler 1984). The

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[92] Chatterji notes this same problem in the under-representation of experiences of patients suffering from dementia in sociological literature, by its focus on illness narratives.

situation of the interview has specific characteristics and demands; these were made apparent when the patients 'breached' them.[93]

6.4 Talking as an act

Interpreting the interview as a situation provided me with clues for understanding these strange interviews. The merits of such an analysis became clearer when I combined interviews with observations. In the following interview, the informant allowed me to take notes, but not to use a tape recorder.

> I speak with Mrs Johansen. She complains about the terrible life she leads in a bitter and cynical tone. 'It's just like a kindergarten. You have to make postcards! It's devastating. I can't get used to this place. I'm scared to go out on the street. I always sit by myself, the other people here mean nothing to me.' She would prefer to do things for herself, and to live on her own again, '... but then, you have been out of society for so long already...' She tells me her partner left her when she was admitted to a psychiatric ward for the first time. Now she lives in a residential home, but she thinks it's too far from the city. She can take a bus every now and then, but 'Ouch!' and she waves her hand dismissively. 'And the food is really disgusting.' She goes on to say that she hates the medication and wants to stop taking it. She dislikes her room, things don't work as they should, it is terrible, and she doesn't feel at home. She points to a closet and says: 'Look, even this little closet doesn't work. And isn't it just ugly!' She says she just sits and waits for the meals to come. Nothing is right, she would rather be dead. Her leg hurts and the medication is killing her. She says she ran out of tears, because she has wept so much.

This story Mrs Johansen tells about her life paints a very black picture. But I also felt that Mrs Johansen took the opportunity of the interview to specifically stress all the bad things in her life. Couldn't there be some spots of light? Was she in a particularly gloomy mood when I interviewed her? During the fieldwork, Mrs Johansen didn't appear to me to be as dissatisfied and unhappy as she described herself in the interview. She was fairly sociable, participated in all kinds of activities, and had a friend on the ward, Mrs Petersen. She went out now and then, more than a lot of the others on this and comparable wards. How does this match up with the ink-black story she told in the interview? I later discovered that Mrs Johansen and Mrs Petersen had a 'swearing practice'.

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[93] Instead of Riessman's (1990) questioning strategic reasons for patients 'telling stories in this way', I had to ask: 'Why couldn't a story be told here?

> Mrs Johansen enters and takes her seat at the table. She sits with her back to Mrs. Petersen and me. She grumbles 'It's a shitty, rotten rubbish-heap here. A nauseating pigsty,' and she continues in the same vein. The women now swear together – the activities are boring, the same people always have to do the dishes. In a feeble attempt to turn complaints into action, I suggest that they could discuss this with the lady organising the activities. But it soon becomes clear that the interest of the women lies exactly in swearing together. 'It's not her fault', Mrs Petersen says dismissively, and they rant on about the house and how it is run. I cautiously slip away.

It turned out that together with a companion in misfortune, Mrs Johansen had 'swearing-matches'. It was advisable for the delicate-minded to go for a walk when this happened, as the cursing and swearing was very harsh. But the swearing-match didn't last long. After it was done, both women proceeded to the order of the day. It appeared they had a limited practice of abuse. Some of the nurses were accomplices in this swearing practice.

> I ask the nurse about the swearing of the two women. He says: Yes, it is a sort of game they play together. Well, if they leave it at that, it's fine with me. If it goes too far, I sound the alarm: 'Hey girls, back to ordinary life!' And that works fine. We discussed this some time ago, and they don't want the atmosphere to be just gloomy and grouchy either. But they do have to get rid of their negative feelings. And I think this is a better way than acting it out; that's also possible. Mrs Johansen now, she has to let off some steam somehow, and this way she gets something too. If you talk with her, she's really nice. There's nothing wrong with her, she's alert, and she makes good suggestions. And so if you can arrange that between yourselves, I think it's fine. Don't you think so?

The 'talk' in the situation of Mrs. Johansen and Mrs. Petersen can be seen as producing a vision of the world, a representation of their experience. But this is not its only function, and maybe not its most important one. Talking can be seen as a specific, situated act that does not produce straightforward correspondences to the world. The swearing is something these ladies do at certain times, and not at others. It is not meant primarily to 'tell something about the world' or the situation, but rather is part of Mrs Johansen's and Mrs Petersen's way of organising their lives. They need the swearing matches, or they like them. They do not intend to take action to change things for the better. The nurses are also aware of the temporary and activity-like nature of the swearing. They help the women set time limits to the swearing matches, and encourage them to practice 'talking' in other ways, too.

This is not to say that Mrs Johansen was not 'telling the truth' in the interview, but that the act of ventilating opinions or telling stories does not imply a direct correspondence with daily life.[94] It is not *the individual perspective* of Mrs Johansen or Mrs Petersen – the nice things are left out, and the intention is not to represent, but to practice 'eloquent' swearing. The talking appears to have a definite function: rather than representing reality, it organises practice. Talking is *performative* here, but not in the sense of Austin's 'performative speech acts'; a term that refers to a limited set of propositions where what is being said also brings about what is being said.[95] In my example, this would mean that the world is made bad and beyond saving simply by saying that it is. Mrs Johansen does not position herself 'morally' or culturally (Williams 2000; Skultans 2000) by the content of what is being said. 'Talking' is performative in other ways, too. The swearing is woven in as one activity among others, and it helps to organise the events of the day. It may even be useful, as it clears the rest of the day from unhappiness.

One can think of other situations where talking is a specific act in which representing the world is subordinate to the talking itself. A good example are chats about the weather that are not meant to accurately describe meteorological phenomena, but are ways of being social with a neighbour. I learned that 'weather talk' is an important repertoire of talking in the context of a nursing home for elderly suffering from dementia. In the nursing home, a lot of residents had problems addressing one another or understanding what was being said. Yet the social convention of neighbour-talk about the weather was one they all understood. This enabled them to have conversations even with people suffering from aphasia who did not use words in a conventional way. The intonation was right for a chat about the weather, so the urgency to produce the right content was less. The transcript of such a conversation does not make sense at all, but in the specific situation the conversation can be smooth, pleasant and clear to everyone present (Pols 1992). There are many more examples. Talking without giving others a chance to interrupt can also be a way to avoid questions. Formalised greeting rituals are polite exchanges rather than swapping of information. Written-out interviews can hide the emotional story that is 'told' non-verbally (Lillrank 2002). These acts of talking do not primarily aim to signify a certain content, but to organise interactions and establish social relations. Talking in this sense is not *about* the world, but is performative in *making* the world.

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[94] The observation that narratives do not provide 'authentic' and corresponding accounts of experience leads Bury (2001) to the suggestion to speak about narratives as 'factions', neither fact nor fiction.

[95] Examples are: 'I open the meeting' which actually opens the meeting, or to say 'I do' to perform 'getting married'. See Austin 1962.

6.5 Situations, acts and the patient perspective

Interpreting an interview as a way of creating a situation with specific demands, and studying talking as an act, is a way of 'foregrounding practicalities' (Mol 2002) – of analysing practical matters, activities and situations. Such an analysis shows the limitations of studying perspectives. Firstly, the patient perspective is not something that is 'already there' in the mind of the patient, to be put into words vis-à-vis a passively recording researcher. Instead, the patient perspective (or any other perspective) can be seen as being produced in a practical situation marked by specific possibilities and constraints. Thus, the *situation* tells those participating what is expected, and what is the expected way to deal with its demands. The subject who is asked to produce a perspective in an interview needs to be a more or less fluent user of language, and needs specific individual and cognitive competences. He or she needs to produce individual opinions and narratives to have a perspective of her own, and needs some courage, education or power to be able to produce it. Many patients do not meet these requirements.

Secondly, analysing talk as an act of representation ignores the various *performative aspects* of talking that link the talking to a specific situation. What a person 'does' by uttering certain words (and not others) in this particular situation cannot be made visible with the concept of the patient perspective. Strategic answering (Riessman 1990) or unease with the interview cannot be taken into account. The 'act of representation' is separated from the situation in which the representation is produced. It provides a story *about* the world, but does not account for what that story does *in* the world.

As a consequence of these specific limitations, non-speaking or scared patients cannot participate in research. Their perspective does not exist. Without language and cognitive abilities, there appears to be no perspective – and thus no subject.

However, these theoretical and practical problems do not seem to hinder nurses and other carers for silent patients very much. They attend to what silent patients like or dislike every day. They seem to know what individuals prefer, and if they don't, they try to find out by trial and error, or by investigating what someone liked in the past (Harbers, Mol & Stollmeyer 2002). How do they do this? I think they do it exactly by constantly attending to practical matters, activities and situations. They attend to performativity even when there is no language. Rather than thinking of performativity as an obstacle to getting to know what the silent patients like, they take it as the starting point for finding this out.

Could researchers also come to do this? I think we could indeed, if we analyse appreciations as being *enacted* instead of as being opinions given or narratives told. In their actions, people 'demonstrate' what they like or dislike. Thus, it is possible to represent silent patients in research as subjects who enact certain appreciations. This does, however, have implications for thinking about the subject of these appreciations. Instead of the subject being an active, autonomous and authentic individual with a perspective on the world, the subject becomes a *co-production*, a result of interactions with others and a material world. I will now explore the implications and possibilities of such an approach.

6.6 Enacting appreciations as co-productions: from perspectives to positions

How can the analysis of enacted appreciations and the subject as being co-produced help to represent silent patients as subjects without relying too much on talk? Here is an example of a patient who does not speak:

> I sit with the nurses to drink coffee, chat and smoke. Nelis [patient] was sitting at the same table, but when he sees that we are not disappearing quickly, he moves off to another table. Vincent [patient] joins us. Nurse Gijs talks about the plans that were made to discuss the death of Mr Vanderbilt with the other patients. He says it's a good initiative, but a bit late. Mr Vanderbilt died two weeks ago. The leader of the nursing team, Jan, drops by with papers for a meeting this afternoon. He greets everyone present and shoves the papers towards Vincent. 'Here', Jan says to Vincent 'You can start preparing for the meeting.' Vincent is obviously not going to attend the meeting, but he studies the papers nevertheless. 'Yes', says Evelyn [psychiatric nurse], 'Vince helped Jeannette yesterday with her reports as well.' The conversation goes on and Vincent participates, without words, but with the right gestures for a member of a meeting, nodding agreement and occasionally gesturing a 'remark' or 'discussion'.

Vincent does not speak, but he acts as if he does. He practices 'being in a meeting' and performs this rather well, using gestures instead of speech. Yet this situation might also provoke criticism: Are not the nurses talking 'over his head' instead of talking to him? It turns out that this is a way in which the nurses are able to communicate with Vincent, because most of the time there is a problem with addressing him directly. I found this out for myself as well.

Just before lunch Vincent comes out of his room. By the look of him he is in good spirits. He smiles his rare beautiful ugly smile and waves at me 'Yoo-hoo!' 'Revolutionary!' I think: Would it be possible to make contact with Vincent now that he is used to me hanging around the ward? I never had the chance to speak to him before. I walk to the table where Vincent is sitting, and sit down opposite him. Wrong! Poor Vincent immediately clams up, turns his head down and stares at the noses of his shoes until some time after I move away.

This 'clamming up' turned out to be a pattern. Vincent does not speak when addressed too directly. The nurses confirmed that he gets confused and upset when asked to make a choice or to formulate an opinion. Yet he does have a communication practice. Although he does not speak, he is one of the more sociable persons on this long-stay ward, in his own way. He is not sociable because he speaks, but because he is present and participates in ways that are available to him.

This situation does not tell what Vincent's *perspective* is and it seems impossible to get it due to a lack of words. What the situation does show, however, is what Vincent appreciates and how he can participate. The nurses, albeit tacitly, know this, and know how to live with Vincent. In other words: Vincent shows what he appreciates and what he dislikes or cannot handle. Vincent enacts certain propositions, such as: 'Don't speak to me directly' and 'I like to join in with the coffee'. In a practical situation, people *do* certain appreciations. [96] Nurses and others who try to find out what the enacted appreciations are can observe this. Thus, they help to produce a situation in which Vincent can enact these appreciations: it is a co-production.

In the co-production of the situation, Vincent is both enacting himself and is enacted by the nurses as a subject. Thus, Vincent is not objectified as being determined by a medical condition, however ill he may be. But neither is the subject characterised by an isolated autonomous position and a free will. The appreciations are neither the consequence of Vincent's activities alone, nor of the activities of the nurses; they result from the activities of both. In this co-production, Vincent could be enacted as a sociable person, notwithstanding the unconventional nature of this

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[96] With the notion of 'enacting appreciations' I develop a concept that is introduced by Annemarie Mol in her suggestion to think of ways of not separating 'judging' and 'being', a liberal will versus a biologically determined body, but to locate the merging of the two in the body, recognising that bodies 'appreciate' certain situations (Mol 2002). Knowing and judging, being and wanting go together in the concept of enacting appreciations. This relates to Csordas' (1994) attempt to study the body as subjectivity or 'being in the world' rather than as representation.

sociability. Yet this subject is a result of *interactions* rather than authenticity. It is neither completely determined, nor completely free.

In these practical situations, the way the space is structured also influences how and if appreciations can be enacted. The disabling or enabling role of the material environment is stressed over and over in disability-studies.[97] Take the following example:

> Morning coffee is a sociable business on this ward in the residential home and, indeed, there is a lot of talking going on. Mrs. Fransen tells Mr. Gregson the score of yesterday's soccer game: '2-0 for the Netherlands!' It appears that Mrs Fransen's favourite team can remain in the premier league. Patricia[98] says to me that it is a beautiful day to go for a walk, but that, alas, there is bingo this afternoon, so the walk is off. Other people are looking forward to the bingo. Mrs Winter has to see the doctor, so she'll miss the event. 'Do you know where the word 'bingo' comes from?' Mr Gregson asks nurse Jack. 'Because here they say 'kienen' and that is maybe an old-fashioned word.' Jack says: 'That's a good one, we'll look it up.' "Kienen' is an old-fashioned word', says Mrs. Fransen. Jane is looking for an ashtray; Mrs Jones hands one over to her.
> Dora does not join in the conversation. She sits just around the corner, knitting with admirable speed. She has her cup of coffee there. From where I sit I can see that she is listening to the conversation and occasionally smiles at what is being said, never stopping with her knitting. When coffee time is over she collects the coffee cups and washes them.[99] She then returns to her spot and continues her knitting.

Dora joins in the morning coffee in her own way. Unlike Vincent, she does not take part in the conversation, but remains on the side. Dora is a woman of few words. She could, however, skip the coffee altogether and withdraw to her room. She does not do that, though. Instead, she creates a situation with which she feels comfortable. Again, this cannot be said to be Dora's perspective, as she does not tell us how she sees it. From her 'practicing morning coffee', her appreciations can be observed. Her being sociable is in

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[97] The idea that the environment is the cause of disability, and not a physical or mental handicap, was the motor of criticism on medicalisation (Illich 1975 a, b; Castel et. al 1979), hospitalisation (Goffman 1961), and for anti-psychiatry (Laing 1985), and it is developed in disability studies (Shakespeare 1998; Oliver 1990). This social criticism argues against a position where the individual is responsible for getting cured or for restoring functioning. Instead, the environment has to accommodate or 'enable' the person. No stairs would mean: no disability for a person in a wheelchair. In its most radical form, the existence of stairs is an expression of a social unwillingness to change the situation. Society disables patients. Discriminatory laws and policies have to change to enable persons. For an overview, see Winance 2001.

[98] Personal and surnames are used for different residents on this ward by nurses as well as patients, even though all residents are older than 65.

[99] I know that this is a spontaneous act, because Dora simply does not do domestic work when somebody tells her to do it. When not pushed, Dora does a lot of domestic work.

this case enabled by the presence of the wall, her knitting work and the washing of the cups. It is a co-production of a material environment which allows Dora to enact her appreciations; this situation is also co-produced by supporting nurses and other patients.

The opposition that is overcome here is that of a disabling material environment versus an individual who is free to act in the way he or she wants. The co-production of Dora as a subject takes place within certain material conditions. If the set-up of the room had been different, Dora may not have participated at all. The material environment plays an important part in interactions, enabling or restraining the enactment of appreciations. The subject, when conceptualised as a co-production, is the result of the interaction of the various participants in a material setting. Dora as a subject is neither determined by her environment, nor independent from it. The individual and the environment are weighted differently in different situations.

The interdependence of the material environment and the subject allows for an analysis of subjectivity *between* situations. Take the following discussion about the importance of the organisation of space for the hospital as a living environment:[100]

> Tom, a nurse, is telling me about the history of this psychiatric hospital. He's not completely convinced that the latest developments in care are actually for the good. He says 'protection' and 'feeling at home' seemed to have been swapped for 'individual skills' and 'autonomy'. He shows me a picture of a ward taken in the late sixties. It is a black and white snapshot of a spacious room divided by cane screens and plants. It has a high ceiling, and cane tables and chairs. It gives me the impression of a grand café, with the sun coming in through the large windows. 'You see', Tom says, 'at that time you had all kinds of corners, where you could sit by yourself, and withdraw a bit and where you could feel safe. Of course, in those days the groups were too large, but people used the quiet corners to sit by themselves or in small groups.' Tom explains that this withdrawal can be connected to 'negative symptoms' of schizophrenia and the quiet some people need when their heads are so busy with all the voices they hear. He finds the modern building where we are now less 'homey' and the smaller groups in rooms without places to 'hide' much more demanding; people withdraw instead to their own rooms, leaving the common room empty.

A corner to sit quietly without having to be completely on your own is not only appreciated by Tom. I could also observe this appreciation in the patients. Dora's ward has several places for sitting quietly, and these are

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[100] The optimism that a mere closing down of hospitals would 'cure' all patients has, however, proved to be premature (see Shephard & Phil 1995).

often occupied. The fact that the modern living rooms (small, no corners) on Tom's ward are empty most of the day strengthens his suggestion.

In this analysis, subjectivity of patients is not only regarded from *within* a certain situation, but also by *comparing* different situations. The patients' in Tom's ward may not realise or put forward that the common room could be made more attractive to them. Yet this may be inferred from the observation of another ward, and may thus be taken as a lesson to improve the situation for the patients in Tom's ward. Appreciations are not simply there: they are structured by material possibilities that allow for certain appreciations and not others, and these can be compared with other situations. The situation can be seen to structure certain subject *positions*. Subjectivity, then, is related to situations, rather than to individuals
This conception of subject positions also makes it possible for subject positions to be shared. Thus far I have discussed individuals enacting their appreciations (Vincent not appreciating to be addressed directly); in a situation co-produced with the nurses (Vincent having coffee with the nurses); in a material environment (Dora behind the wall, different structures of living rooms). Appreciations can also be enacted by a group, as in the following example::

> When I came in at 7.30, I expected to be the first person awake on the ward. But no, most people are already up, dressed and ready for breakfast. I learn that people here rise early and go to bed early. A nurse explains to me later that they tried to individualise breakfast. Nurse: You know, there are people who want to sleep in. So I proposed once: 'Why don't we make a breakfast-buffet on the weekends, so that everybody can come in when they want and we'll set the breakfast on one table, or we'll make up one table. But no, they didn't want to do that. Everybody is there at eight o'clock, every day, even on the weekends. They put 'the group' first. And the group should have breakfast at eight. As long as everybody goes along with that, it will stay that way.

The patients do not verbally justify their attachment to the breakfast routine. 'I'm not lazy', is all one patient says when I ask around. People simply stick to these routines and take them for granted. One strong character seems to be influential in maintaining the breakfast order; the others go along. The nurses explain this as a remnant of old hospital routines and power structures. The other side of it is, however, that the patients can be seen to *appreciate* having meals together.[101] They take a position towards the suggestion of the nurse to individualise breakfast. Not

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[101] Meals in institutes are usually important rituals for residents, as they break up the time and bring some structure to a possibly unstructured day. See Davies & Snaith 1980.

by *discussing* it in words, but by *acting* against it. They enact appreciations as a group, and the nurses give in.[102]

In this example, the patients enact an appreciation together. This allows for the production of a 'collective', of shared forms of subjectivity. In this case, the subject is a 'we' that enacts appreciations, thus creating a specific subject position. Subject positions can be taken by more than one person; they are not individual, but frame possibilities for others. In this case the appreciated position is a social one, but the patients could also have opted for the shared appreciation of the individualised subject position suggested by the nurse. What the subject is, is connected to interactions in specific situations. It is about positions one is able or willing to take, rather than about individual characteristics or authentic experiences.

6.7 Conclusion and discussion

The concept of the patient perspective is problematic, because analysing perspectives ignores the performativity of talk and excludes the possibility of representing silent patients as subjects in research. Alternatively, observing practices in daily life does not produce a patient perspective, but 'situations' with specific characteristics in which people are allowed to enact or restrained from enacting appreciations. Studying practice and ways of enacting appreciations can show how patients live their specific and diverse daily lives with the people and objects around them. In these local co-productions, the appreciations of patients become understandable not primarily by talking, but by describing practices. Studying practice is not demanding, nor does it normalise the people studied: everyone has a practice, even though not everyone can make verbal representations of it. Studying what patients do can make visible what they appreciate and what they would rather avoid. Patient's daily lives are overflowing with practicalities, but these have been taken up for theoretical and empirical analysis only recently (Moser & Law 2003, 1998; Winance 2001; Law & Moser 1999; Hendriks 1998). Observing the enacted appreciations of silent patients generates ideas for dealing with different appreciations, and for thinking about different ways of bringing them about, that is, co-producing them.

The concept of co-production stresses that the act of appreciation takes place in a specific situation in which a person, however quietly, enacts

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[102] Note that even when patients seem to appreciate certain situations this does not necessarily invalidate the nurses' idea that this is a consequence of hospitalisation. A 'true' explanation cannot be given.

an appreciation vis-à-vis certain constraints and possibilities. Patients are not isolated from their situation as individuals. Instead, patients enacting appreciations are part of a material and social situation in which their appreciations are located and by which these are co-produced. There are quiet corners or not, understanding nurses or not, or others with whom one can enact appreciations. Environment (the hospital set-up, professional staff, other patients) and individual characteristics (disease or impairment of functioning, the wish to do something) come together in the appreciation a patient enacts in the co-production of everyday life and care.

Stressing the act of co-production does not describe a patient as determined by disease or a disabling environment. But neither does it leave much room for thinking about patients as authentic, free individuals who are disconnected from everything and everyone around them. The subjects enacting appreciations do not exist apart from their material environment and the interactions within that environment, even if they are not completely determined by them. Being a patient (or, for that matter, being a professional) can hardly be called an identity, as one is a patient at certain times and in certain situations and not in others. When ways of being a patient (or a subject) are seen as different possible co-productions, it is more correct to speak about practices in which patient or subject *positions* (rather than perspectives) are created. In care practice, but also by research methods, in research texts or texts from the patient movement, patients are positioned and position themselves in certain ways. These positions enable certain appreciations, and make others invisible. They are not restricted to a certain individual, but include some and exclude others. This can be made visible by attending to different appreciations enacted, but also by comparing different patient positions.

Studying how appreciations are enacted as co-productions that create different patient positions does not lead to different perspectives on one and the same world. Instead, different worlds of co-producing patient lives are opened up for study. There are multiple, temporary coherences of being a patient, linking individuals with other patients, professionals and material situations. Thus one can shift from being a patient being urged to take anti-psychotic medication in a meeting with the doctor, a patient who is asked for his or her perspective in an interview, or a patient who joins others in a meeting of the patient representatives of the hospital. Together, these different co-productions can be studied as a temporary 'patchwork' of positions and negotiations, or they can be studied in comparison to other 'patchworks'. The questions to ask are then : How do patient positions change over time? How are these changes negotiated? And what are the main differences in patient positions between one material and social set-up and another?

However, to get to know the different patient positions, it is necessary to study the patients' part in the production of these positions, as patients are both active and passive in the creation of these positions. As mentioned before, to master the skills for observing appreciations, much can be learned from professionals and others caring for silent patients. Nurses and other carers are not only co-producers; they can also be informants on learning about appreciations. In the co-production of daily patient reality, professionals play an important part, and even more so when care is provided in homes or hospitals for patients who are dependent on this care in their daily lives. Patients are not put in opposition to professionals or 'biomedicine', but their lives are co-produced in heterogeneous ways. Illness- and disease-practices are intermingled.

Still, this analysis of the intertwinement of patients' and professionals' lives has some potential problems. In this paper I mainly used examples of 'helpful nurses' to show how one can see silent patients as subjects enacting appreciations. But does not the researcher studying enacted appreciations run the risk of colluding with the observations of the nurses? There are situations in which a conflict is clear, and in which nurses do not take the appreciations of patients into account or overrule them. Here, the 'third position' of the researcher is of importance. The observer is involved in daily practice and interacts with patients and professionals alike, and may thus discern different patterns of activities. It is possible to describe conflicts between appreciations of nurses and patients.

> Mrs Johnson makes a sandwich for her neighbour at the table, Mrs Nelson. A geriatric assistant walks past and says: 'No, Mrs Johnson, Mrs Nelson can do that by herself!' Mrs Johnson looks hurt, shrugs and puts down the knife and pushes the plate to Mrs Nelson.

In this example, Mrs Johnson enacts an appreciation for helping her neighbour, but is overruled by the geriatric assistant who finds 'self-management' more important. Mrs Johnsons' appreciation is overruled, but it is clearly visible to the observer. The situation can be analysed as a clash of different appreciations of the situation. Of course, the overruling of patients can be so profound that there is little room for actually enacting different appreciations. But the absence of any kind of resistance or attempts to act differently should make the researcher suspicious. The researcher can look for the spaces where caregiver influence is less, and the situation can be analysed as singularly enforcing one patient position (e.g. self-management) to the exclusion of other positions (e.g. helping others). Comparisons with other care-practices are also fruitful for pointing out different possible positions, as was shown by comparing the wards with and without quiet corners.[103]

But there is a second problem to consider. Describing appreciations of silent patients does not dissolve the asymmetry between researcher and patients. After all, it is the researcher who writes the articles or tells the stories. Even though he or she makes explicit that the descriptions do not 'give voice' to the silent patients, but give a third position-account, in the end there is no 'true story' or final interpretation of how to deal with the observed appreciations. Notwithstanding the use of active and imaginative involvement, a sensitivity for practicalities of daily life and careful checking of observations, it is clear that there is no way of assessing 'what the patient really wants'.

Framing this problem in terms of asymmetry, however, seems to imply that there are positions that escape the pitfalls of asymmetry. The 'patient-perspective' seems to promise a representation of the patient, as if 'they' are directly speaking to 'us'. However, as I mentioned before, any representation or framing of a position includes some, and excludes others. There is always an asymmetry between the one framing patient positions (the researcher) and the ones taking patient positions, even if the researcher takes a patient position herself. Apart from the impossibility of symmetry, the fiction of representing the patient in a supposedly authentic account, presents difficulties; one has to show oneself to be a member of this supposed collective subjectivity, or one runs the risk of being accused of not taking the patients seriously.

In this paper, however, I moved from a problem of representation to a problem of interaction. Instead of supposing I can speak on behalf of patients by truthfully representing their perspective, I am looking for ways to interact with these patients, both in real life and as a researcher writing about them. In any interaction, one is by definition negotiating differences and ways to relate to asymmetries, even if there are no obvious power-balances at stake. So instead of hiding an asymmetry that is always there, I suggest opening up possibilities for exploring and discussing ways of dealing with it. And indeed, only by trying to learn about the appreciations of the silent patients, can these appreciations be taken into account at all.[104]
A move that might follow is to study appreciation practices, co-productions and positions taken by storytellers. What does it mean to tell a story? What can be told? How is it told? Where? Winklers' and Daniels' [in Csordas

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[103] Note that there can also be situations in which patients are oppressive or violent. Being a patient does not necessarily imply that the patient position is the 'good' position.

[104] For a thorough reflection on a symmetry relating to autistic children see Hendriks 1998.

(1994)] articles on rape and torture, and the client movement in mental health care as it struggles to reformulate what it means to live with a psychiatric disorder (Deegan 1993; Boevink et. al 2002) show how unspeakable events can eventually be described in terms that can be understood by others and are acceptable to the speaker. To talk about these matters is an *act*, and a different act in different situations. This work makes the reader acutely aware of the politics and practicalities involved in 'storytelling'. Development of the analysis that foreground practicalities and activities may lead to accounts of patient storytelling in which the politics of speaking can be articulated and challenged.

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7 Conclusions: enacting improvement

In this book many forms of good care and ways of improving care were articulated on the basis of observations of everyday caring activities and routines, and discussions about these with participants. Good care was analysed as something *enacted* or 'done' in daily practice. It became clear that each mode of good care relates heterogeneous elements together. What good care *is*, be it in a juridical (ethical, professional...) sense, takes the shape of an ordering of material and immaterial elements. These modes of good care relate techniques and methods, buildings and directions for organisation, presuppositions about what 'is', ideals and considerations of how it should be, and practical ways to bring that about. Each mode of good care frames a world in which certain activities can be thought of as 'good' in specific situations.

In the first chapters of this book I claimed that articulating these forms of good care does not simply 'reproduce' or describe them. This study in empirical ethics has normative dimensions, although this normativity is not formulated in traditional ethical styles of judging or legitimating. Articulating ideals, I claimed, is also a way of questioning or promoting these ideals, by explicating their effects, possibilities and limitations. In doing so, this book interferes with attempts of improving care. In this last chapter, by way of conclusion, I will draw out what follows from the analyses in this book as regards the aim of 'improving care'. How is improvement done? And might it be possible to improve improving? I will talk about these questions, first by discussing why improvements tend to have other effects than intended, and second, by reflecting upon alternative strategies for improving care that this study suggests.

7.1 Unintended effects of improving

Throughout this book there were many examples of how improving care turned out differently than expected. Each chapter showed some surprising, unexpected, sometimes troublesome, and often unintended effects of attempts to improve care and of ideals shaping this improvement. Even with the best intentions and the broadest consensus over goals and values that are formulated as explicitly as a law text, improvements turned out to work differently. How, after this study, might we understand this?

A first thing that became clear is that practicing care does not happen in a moral vacuum. Care-practices are full of diverse forms of knowledge and ideals oriented towards *good* care. This diversity makes care-practices complex, as there can be different forms of good care within a single site. Different professionals may enact different forms of good care, or a single professional may engage with different forms of good care in different situations. Professionals are not passively waiting for improvement by laws, ethical rules, procedures or results of clinical trials, but they have their own morality and know-how.

It adds to the complexity that there is not one logic of improving, even though health care policy and professional organisations suggest as much. Take for instance the way that ethical-juridical styles of improving are related to the professional style of improving proposed by evidence-based medicine. Laws and evidence-based medicine might each order different parts of care-practice: the way in which to decide about treatment (through patient autonomy) and the content of the treatment (evidence-based therapies) respectively. But the analyses presented here show that both styles of improving put forward their own theory about the good life, as well as their own notions of what the facts are. They are different modes of good care. Ethics incorporate an empirical world, whereas empirical knowledge incorporates a form of ethics.

Sometimes, there are frictions between these different modes of good care. In the example of the laws and evidence-based medicine, the world of patient autonomy and the world of effective care clash when a patient refuses a treatment that the doctor judges to be effective in his or her situation. Or they clash because a patient wants a treatment the doctor thinks is ineffective, or when an activity in care is not a discrete event in time about which the patient can be informed and make a decision. Professionals do not only face diversity, but contradictory demands as well.

And there are more styles of improving, so one may seriously wonder how professionals manage to avoid chaos at all. Juridical measures, evidence-based medicine, quality guidelines, reforms to turn healthcare into a market, re-organisations, cost-reductions, all these ways of improving reach practice as different modes of good care. How these different modes of good care are put to practice is hard to predict, because this depends on local specificities.

So when an attempt is made to improve care, there is no encounter between good rules and a wrong or void practice. Instead, a new mode of good care has to be inserted into the morality and know-how that already exists in practice. Thus, different modes of good care *interfere*. This interference may be a hostile one: one mode of good care is rejected in favour of another. It may be a partial one: the improvement reaches certain parts of practice and not others. Tensions between different modes of good care are not necessarily resolved or made explicit; they may as well lead to a tacit co-existence and occasional fights over practical matters. But most characteristically, the analyses showed that interference leads to *translations*. Ideals and intentions are changed to make them 'fit' with existing ideals, routines and situations in a specific practice.

Sometimes translations result in the opposite effect of what was intended. This was the case when the regulation of coercion in the psychiatric hospital lead to a bureaucratisation of coercion rather than to its moralisation. Coercion came to require the administrative routine of reporting the incident, rather than being lived as a situation in need of moral consideration. The aim was to add morality to practice, but the effect was that morality was taken away from the nurses while it was being delegated to the law.

The interference of different modes of good care leads to new practices. These new 'improved' practices are the result of the mutual translations of the interfering modes of good care. The translations are mutual because both the existing modes of good care and the mode of good care added to improve practice are changed. Only when professionals explicitly oppose two modes of good care, they remain 'pure'. But, as became clear with the juridical and caring modes that remained oppositional, the price of purity is a lack of influence. Even laws that are designed to *control* caregivers need the co-operation of these same caregivers in order to have any effect at all.

Finally, improvements turn out differently than expected because general theories of good care do not take the specificities of local care-practices into account. Professionals and patients may act differently than expected, and will have to translate rules and prescriptions to make them 'fit' with their own practice, morality and know-how. Thus, they will make their own interpretations of suggestions for improvement, and translate these to make them fit into the specific context in which they work. How they manage to do this is an open question. That they will do this is inevitable and is a professional virtue rather than a vice.

7.2 Different ways of improving

The analyses presented in this book provide an understanding of the complexity of 'designing' improvements and make them work as intended. But it is not my sad conclusion that we might better give up on improving all together. For by unravelling and articulating the knowledge and morality inside care-practices, self-reflection *within* these practices can be mobilised to bring about improvement. Rather than trying to regulate care-practices by trying to subject them to rules, the analyses in this book suggest that improving care will be more successful when morality and know-how from within is attended to more seriously.

7.3 Articulating the workings of ideals

A first way to help care-practices improve from within that is demonstrated in this book is the analysis of the workings of specific ideals and the articulation of their effects and limitations. The analyses of the ideal of patient autonomy form good examples of this. The ideal of patient autonomy is probably the most influential ideal in (mental) health care these last decades. It never fails to surprise me that a situation in which peoples' inter-dependency is so apparent as the situation of sick people needing professional help are so heavily cast in notions of independence and autonomy. This is especially strange because the other central ideal in long-term mental health care in western countries is the participation in society, as an alternative to hospitalisation. Being disabled, chronically ill or in need of professional care, it is argued, is no reason for being excluded from rights, citizenship and community participation.

However, when autonomy is the model for citizenship, and citizenship is the model for participation, the burden of integration is singularly assigned to the aspiring citizens. The other citizens can continue to do what they always did. It is hard to think of solidarity, a common good, or helping others in terms of autonomy. The notion of autonomy does not help to reflect on ways people can relate to each other in constructive ways. The autonomous individuals only connect when they get in each other's way. They are not allowed to hinder each other, but there is no vocabulary to articulate what constructive relations between autonomous individuals could look like. The autonomy of one person rather figures as a potential threat to the autonomy of the other.

There turned out to be another problem with the ideal of autonomy: it makes it difficult to take the differences between people into account. Irrationality, deviance, speechlessness, psychiatric problems or unclean and smelly appearances are hard to grasp in terms of autonomy. The only conceivable way to deal with them is 'letting them be'. They are private matters, not relevant for defining autonomy. In some cases it may be possible to be seen as a psychiatric patient at one time, while being thought of as a competent and autonomous citizen at other times. But when psychoses do not lift, autonomy becomes a problematic concept. 'Madness' and autonomy turn out to be mutually exclusive terms.

So the critical appreciation of the ideal of patient autonomy is an example of the first way in which this study may be mobilised in improving care. It articulates the problematic effects and limitations of certain ideals. These analyses can be the input for discussions within practices. What is it we want to achieve? And which ideals, concepts and vocabularies might help or hinder achieving it?

7.4 Articulating alternatives

The second way in which this study suggests to help improve care is by articulating ideals that are marginal, but turn out to be very interesting nevertheless. These ideals can be helpful because they are embedded in new vocabularies to think about situations in care, thus articulating problems and solutions in a different way. The most important alternative ideal this study brought to the fore is the ideal of sociability, linked up with the notion of humans as relational beings. It appeared as a promising alternative to the ideal of patient autonomy, and provided solutions in situations where practising autonomy was problematic.

When people are thought of as relational beings, inter-dependency becomes the key-characteristic of 'being human'. Who we are is the always temporary and changing result of our interactions with the world. This relational view changes the way in which differences and relations between people are conceptualised. The individual is not a stable entity, but is seen as changing over time and over different situations. One can, for instance be positioned as a psychiatric patient, a health care consumer or an elderly person in different situations. Differences are then a characteristic of interactions within social and material situations. Norms are negotiated and practised within situations, and do not exist as standards outside of them. All partners in the interaction face the task of negotiating these norms.

There is another interesting consequence of perceiving humans as relational beings. Interactions, individuals and relations are seen as changing over *time*, and so is care. Instead of care being understood as ordered by a logical coherence, care is considered as a process that shifts over time. In this view there is not one situation in which a decision has to be made about how to organise activities in care, but there is a chain of situations in time, in which to negotiate new problems and challenges again and again. There is not one approach that is supposed to work in all situations, but there are different possibilities that can be explored when dealing with specific situations. Care is about creativity, improvisation or 'tinkering' rather than 'applying methods' or 'following rules'. What the problem is may shift over time and is dependent on all kinds of contingencies. The 'good professional' here takes evolving situations into account and changes his or her strategies accordingly. And the same obviously counts for the patient.

Thus, the notion of relationality in care-practices incorporates a specific understanding of care-practice and a specific way of conceptualising good care and improvement. Good care cannot be established at one point in time, once and for all. Practices are never perfect, but are under constant construction. And the patients, likewise, are never 'finished', but have to live with ups and downs. Changing situations, different patients and unexpected problems in care over time need flexibility and an ongoing development and adjustment of notions of good care. The open-endedness of processes of caring in time asks for repeated reflections on routines to see if they still fit with the needs and worries of the day. Improvements in care thus cannot be seen as a singular implementation of some form of good care, with a clear endpoint. There is no point in time when all knowledge is gathered and all values are stable. Morality and know-how have to be *maintained* as the caring process changes over time.

So this is an example of the second way to help improve care-practices. By articulating ideals and know-how that may be marginalised by popular ideals or ways of improving, interesting suggestions for framing good care can be made available. Again, this can be the input for discussions with participants in care-practices and others concerned.

7.5 Dealing with diversity

And this brings me to the last way in which the analyses in this book suggest to improve care-practices: by extending and supporting the practices of self-reflexivity within care-practices. Improvements, I argued, may turn out better when the diversity of morality and know-how within practice is more seriously attended to. The reason for this is not only that this diversity actually *exists*, but also that there are forms of good care in practice that merit support on their own terms. When care-practices change by negotiating and making translations, this should be the starting-point for innovations. Furthermore, it became clear that morality and know-how are best safeguarded when the professionals, patients and others involved guard it themselves. As with the example of coercion, when caregivers feel the need to reduce coercion themselves, this is a better guarantee for the actual reduction of coercion than regulating it by an external rule, even if this rule is followed.

So how can self-reflexivity be supported? Next to the substantial way of supporting self-reflexivity by articulating ideals, the practical organisation of self-reflexivity can also be strengthened by setting up meetings for reflection with participants in care. In these meetings situations and events as well as ideals embedded in them can be analysed and discussed. This can take the form of a reflection on problematic situations. It is for instance possible to discuss every case in which coercion is used. Was it right to use coercion in this specific case? And how might the future use of coercion be improved? But it is also possible to discuss supposedly 'good', or ordinary situations, or ongoing attempts at improvement. The aim is not to look for legitimations or rules, but to think of ways to improve care by learning from problems and successes. These meetings can form a space for negotiating changes and translations and for analysing their effects.

The 'self' in self-reflexive can be different persons: different professionals from the same organisation, the same professionals from different organisations, patients, family-members, cleaners and others involved. It can also involve 'external improvers' who may explain their ideas for improvement and help the process of translation of these improvements to the specific context. Outsiders' visions, unburdened by local traditions and routines can thus be mobilised for improving care. In this way diversity is used as a resource rather than being thought of as problematic.

Rather than this being an eclectic use of different modes of good care, I would suggest this is a mode of good care and improving in itself, incorporating its own rationality. Instead of aiming for logical coherence by enforcing fixed standards, this mode of good care incorporates a fluid ordering, linking relationality and temporality, and the linking of concrete events with different rationalities of improving. 'Good professionals' in this sense are not only experts in translating different modes of good care to specific situations and vice versa. Their professionality is to use this contextual mode of reasoning about dissimilar situations in time. They may have to adjust procedures for a particular function, listen to worried patients and try out different strategies if a specific one fails, and they weigh the contingencies in a situation. When good care is a never-ending task of maintaining know how and morality, so should be its practice of improving.

Nederlandse samenvatting

Goede zorg. Een complex ideaal in de praktijk van de langdurende psychiatrie.

Er zijn veel idealen van goede zorg. Zorg wordt bijvoorbeeld goed genoemd als die effectief is, rechtvaardig, of ethisch gelegitimeerd. Andere keren is heet zorg goed als ze efficiënt gemanaged is, spaarzaam met publiek geld omgaat of gericht is op de emancipatie van patiënten. Er is dus een veelheid aan manieren in omloop om vorm aan goede zorg te geven, en dat is niet anders in het veld waar deze studie over gaat: de langdurende psychiatrische zorg voor oudere (65+) en jongere volwassen (65-). De praktijken van zorg voor oudere en jongere volwassenen hebben elk hun eigen tradities en organisaties, waarin goeddeels verschillende maar deels ook overlappende idealen van goede zorg figureren. In deze empirisch ethische studie worden die idealen samen geanalyseerd.

Voor het empirische deel van de studie werd gebruik gemaakt van participerende observatie en semi-gestructureerde interviews. Ik heb situaties, gebeurtenissen, routines en activiteiten geobserveerd en die met de participanten (hulpverleners, vooral psychiatrisch verpleegkundigen, en cliënten) in interviews besproken. In welk opzicht is in hun ogen de dagelijkse zorg *goede zorg* en in welk opzicht niet? Welke idealen proberen ze gestalte te geven?

De mensen die aan dit onderzoek hebben deelgenomen is dus niet naar hun mening gevraagd, maar zij zijn geobserveerd terwijl zij (een of andere variant van) ‘goede zorg’ *doen* – zij het als hulpverlener, zij het als cliënt. Dat wil ook zeggen dat de idealen in de zorg die hier in hun complexiteit ontrafeld worden, zijn onderzocht zoals ze *worden gedaan* in het dagelijks leven en werken op de afdelingen waar ik rond mocht kijken. Ik heb het niet over idealen aan de horizon, maar over idealen-in-actie.

Maar die idealen-in-actie hier ter sprake brengen, ze *articuleren*, behelst niet zomaar een weergave van de praktijk. Het voegt iets toe aan die praktijk. Laten zien dat er in de praktijk verschillende idealen naast elkaar bestaan die met verschillende handelwijzen vervlochten zijn, is een manier om deze idealen op een nieuwe manier te bekijken en ze ter discussie te stellen. Zijn er misschien ook idealen bij die al te veel aandacht krijgen (zoals het bevorderen van autonomie voor patiënten, wellicht) terwijl andere idealen (zoals dat van de sociabiliteit tussen mensen) ten onrechte in de verdrukking raken?

Een eerste doel van dit onderzoek is daarmee om de verschillende vormen van goede zorg die in dagelijkse praktijken van de chronische psychiatrie gestalte krijgen, te articuleren. Een tweede doel is om inzicht te verwerven in de vraag hoe met deze verschillende manieren van goede zorg om te gaan. Kunnen articulaties van verschillende idealen van goede zorg helpen om goede manieren te vinden om zorg te verbeteren? De twee vragen die in dit onderzoek voorop staan, zijn dan ook:

- Welke vormen van *goede zorg* worden er gepraktiseerd in de langdurige geestelijke gezondheidszorg voor oudere en jongere volwassenen?
- Hoe kan, gegeven de diversiteit aan idealen, de zorg verbeterd worden?

Het veldwerk voor dit onderzoek vond allereerst plaats op vijf afdelingen in drie verzorgingshuizen waar ouderen wonen die zonder dit alternatief op de langverblijfafdelingen van het psychiatrisch ziekenhuis zouden zijn aangewezen. Vervolgens zijn vier afdelingen voor langverblijf in het psychiatrisch ziekenhuis onderzocht. Wat goede zorg is, is op deze plekken een belangrijk punt van onderhandeling en ontwerp.

In de verzorgingshuizen werken professionals uit de geestelijke gezondheidszorg en de ouderenzorg samen. Het idee is dat het wonen in een verzorgingshuis het voor de ouderen mogelijk maakt om te zowel te integreren in de samenleving als om de zorg te krijgen die ze nodig hebben. Daarbij zijn de verzorgingshuizen een goedkoper alternatief voor de ziekenhuisafdelingen. Op de werkvloer blijken echter grote verschillen te bestaan tussen de manier waarop verpleegkundigen denken dat goede zorg vorm moet krijgen en de manier waarop verzorgenden goede zorg nastreven. Bovendien zijn er ook grote verschillen in opvattingen over goede zorg *tussen* psychiatrisch verpleegkundigen onderling. Deze verschillen liggen soms aan de oppervlakte, vaker zijn ze impliciet en onduidelijk.

In de psychiatrische ziekenhuizen zijn verpleegkundigen op verschillende manieren bezig om rehabilitatie te ontwikkelen voor cliënten die het niet redden om te integreren in de samenleving. Ze zoeken naar manieren om de zorg bij deze cliënten te laten aansluiten, en hen zoveel mogelijk invloed te geven op de manier waarop zij op de afdeling wonen.

Veldonderzoek (participerende observatie en interviews) vond plaats op iedere afdeling over een periode van een maand. In de verzorgingshuizen vond daarnaast nog een tweede, kortere observatieronde plaats na een half jaar. In een tweetal extra verzorgingshuizen werden om financiële redenen alleen interviews gehouden. In de psychiatrische ziekenhuizen werden vele informele gesprekken gevoerd, en werden 19 professionals geïnterviewd die betrokken waren bij de ontwikkeling van rehabilitatie. Daarnaast werden 8 cliënten geïnterviewd. In de verzorgingshuizen werden 14 bewoners geïnterviewd en 39 professionals. De interviews zijn opgenomen op cassette en uitgetypt.

De hoofdstukken die volgen op het introducerende hoofdstuk van dit boek zijn geschreven in de vorm van artikelen voor internationale tijdschriften. Voor dit boek zijn daaraan een inleiding, conclusies en deze samenvatting toegevoegd.

Het tweede hoofdstuk heet vrij vertaald: 'Welk empirisch onderzoek, wiens ethiek? Het articuleren van idealen in de langdurende geestelijke gezondheidszorg'. In dit hoofdstuk demonstreer ik de stijl van empirische ethiek die in dit boek bedreven wordt: de etnografie van goede zorg. Dit doe ik aan de hand van een casus. De casus is het invloedrijke ideaal van individualisering in de zorg. Ik onderzoek hoe verpleegkundigen en cliënten individualisering *doen* in hun dagelijks werk en leven. Door idealen te articuleren en zo beschikbaar te maken voor reflectie, wil deze vorm van empirische ethiek niet descriptief blijven, maar ze wil ook niet prescriptief worden. Ik beperk me dus niet tot het beschrijven van wat anderen vinden dat goede zorg is, maar presenteer evenmin eigen normen in de vorm van oordelen over de beschreven praktijken. Idealen articuleren vormt een derde genre. Het reikt de participanten nieuwe manieren aan om na te denken over de zorgpraktijken waarin ze betrokken zijn.

De casus 'het ideaal van individualisering' illustreert dit. Die casus laat zien dat, hoewel in discussies over goede zorg individualisering steeds gepresenteerd wordt als was het één ideaal, er in de praktijk tenminste twee manieren bestaan waarop individualisering vorm krijgt. De eerste manier is om individuele vaardigheden van cliënten te trainen. De tweede manier is om ruimte te maken voor individuele voorkeuren. Deze manieren van 'individualisering doen' verbinden heel verschillende praktijken en idealen van individualisering: actief zijn en onafhankelijk worden aan de ene kant, en zelf kiezen en de eigen identiteit in de omgeving en de organisatie van het leven kunnen terugvinden aan de andere kant.

Deze verschillen komen naar voren door alledaagse gebeurtenissen als koffiedrinken en eten te observeren, evenals de objecten waarmee individualisering gestalte krijgt, zoals koffiezetapparaten en andere attributen om kamers in te richten. Zo wordt zichtbaar hoe verpleegkundigen en cliënten verschillende varianten van individualisering *doen*. Maar naast een ideaal van individualisering wordt er nog iets anders 'gedaan': de participanten geven de subjectiviteit van zowel cliënten als professionals op verschillende manieren vorm. In deze empirisch ethische analyse gaan subject posities dan ook niet vooraf aan zorgpraktijken, maar worden ze gepresenteerd als het *resultaat* van zorgpraktijken.

Bovendien blijken idealen van individualisering niet de enige idealen die in de praktijk worden nagestreefd. Er bestaat ook zoiets als het ideaal van sociabiliteit tussen cliënten. Dit botst herhaaldelijk op het individualiseringsideaal. Dat blijkt bijvoorbeeld in situaties waarin (met name cliënten) in hun handelen de waarde van sociabiliteit uitdragen. Daar wordt duidelijk dat het ene ideaal het andere haast onzichtbaar kan maken. Maar het dominante ideaal van individualisering heeft de idealen van sociabiliteit tussen cliënten onderling niet helemaal verdrongen. Want, hoewel marginaal, bestaan die idealen nog steeds, als alternatieve vormen van goede zorg.

Het derde hoofdstuk, getiteld ‘De burger wassen. Wassen, netheid en burgerschap’, gaat over idealen van burgerschap zoals die zijn ingebed in een praktijk die ver van burgerschap af lijkt te staan: het wassen van cliënten. Het bevorderen van burgerschap is er in deze context op gericht dat cliënten van de psychiatrie integreren in de samenleving. Veel cliënten hebben echter problemen met douchen en schoon zijn. Dat brengt met zich mee dat er fricties ontstaan tussen de verschillende vormen van burgerschap die de verpleegkundigen willen bevorderen.

Verpleegkundigen gaan op diverse manieren met wasproblemen om: door de privacy van cliënten zoveel mogelijk te respecteren; door hen vaardigheden aan te leren om zichzelf (zoveel mogelijk) te kunnen wassen; door het wassen te zien als een voorwaarde voor belangrijke kwesties in het leven; of door het wassen vorm te geven binnen de relatie cliënt-verpleegkundige. Elk van deze vier benaderingen van wassen draagt een ideaal van burgerschap in zich. Wanneer wassen privé is, is de burger een autonoom individu dat zijn of haar authentieke voorkeuren najaagt. Wanneer wassen een vaardigheid is, is de burger autonoom en onafhankelijk. Wanneer wassen een voorwaarde is voor werkelijk belangrijke zaken, is de burger er vooral op uit om zichzelf te ontplooien en op die manier deel uit te maken van de samenleving. Wanneer wassen vorm krijgt in de relatie, is ook de burger relationeel: door relaties met anderen kan de cliënt integreren in de samenleving.

Wat één ideaal leek, burgerschap, bestaat in de praktijk dus in heel verschillende vormen. Het is de vraag welke vorm van burgerschap cliënten het beste helpt met hun integratie in de samenleving. Van deze vier idealen van burgerschap lijken de eerste drie het meest op elkaar. Ze hebben gemeen dat ze (elk een eigen vorm van) autonomie centraal stellen. Dat brengt een aantal problemen met zich mee. Ten eerste is het altijd de cliënt die de normen, waarden en competenties die nodig zijn om te kunnen participeren moet leren. Andere burgers zijn immers ook autonoom, en hoeven zich niet aan te passen om de integratie van cliënten van de psychiatrie mogelijk te maken. Van hen is dus geen hulp te verwachten. Ook verpleegkundigen praktiseren geen burgerschap, maar bevinden zich als professional in het psychiatrisch ziekenhuis of het verzorgingshuis buiten de samenleving. De cliënten moeten daarom uit het ziekenhuis of verzorgingshuis om in de maatschappij te komen, waardoor ze binnen deze voorzieningen geen burgers zijn maar mensen die het nog moeten worden. Verder zijn de idealen van autonoom burgerschap gebaseerd op gelijkheid tussen mensen, niet op verschillen. Het denken over psychiatrische problemen past daar niet in. Psychiatrische problemen zijn als privé-zaken niet van belang voor autonoom burgerschap, of ze bedreigen autonomie. En op deze manier levert ook het wassen steeds problemen op.

De relationele opvatting van burgerschap kent deze problemen niet. Het idee dat mensen burger worden in relatie tot andere burgers, legt de verantwoordelijkheid voor integratie in de interactie en niet alleen bij de cliënt. Ook kwesties van (ab)normaliteit worden deel van interacties. In hun interacties onderhandelen betrokkenen over wat zij acceptabel vinden en wat niet. Daarmee is ook gekte niet alleen iets van een persoon maar iets dat in onderlinge betrekkingen bestaan krijgt. De verpleegkundigen zijn in deze visie ook burgers, en oefenen hun burgerschap uit door relaties aan te gaan met cliënten. Als relationele activiteit is wassen niet meer of minder belangrijk dan andere activiteiten. Al met al biedt relationeel burgerschap dan ook betere mogelijkheden voor de integratie van cliënten dan het streven naar een bestaan als autonome burger.

Het vierde hoofdstuk, met de titel ‘Patiëntenrechten handhaven of zorg verbeteren?’ gaat over de interferenties tussen juridische pogingen om de zorg te verbeteren en bestaande zorgpraktijken. Voor dit hoofdstuk is alleen de situatie in de twee psychiatrische ziekenhuizen geanalyseerd. In het eerste ziekenhuis staan hulpverleners en cliënten positief ten opzichte van de wettelijke regels. De idealen die zijn ingebed in de wet worden onderschreven in de dagelijkse zorgprakijk. In het tweede ziekenhuis daarentegen bestaat er een vijandige relatie tussen hulpverleners en vertegenwoordigers van de wet. Hulpverleners verzetten zich tegen de idealen die de wet probeert te realiseren en stellen daar andere idealen tegenover.

Is het nou zo dat men in het eerste ziekenhuis de wet goed naleeft en in het tweede ziekenhuis niet? Bij nadere beschouwing is het antwoord op deze vraag nog niet zo eenvoudig. In het eerste ziekenhuis, waar de idealen van de wet niet zo ver af staan van professionele idealen van goede zorg, blijken de meeste 'vertalingen' gemaakt te worden. De oorspronkelijke missie van de wet vermengt zich met de doelen van goede zorg die de verpleegkundigen formuleren. De zorg en de wet gaan op elkaar lijken, maar daardoor vinden er juist de meeste veranderingen plaats in vergelijking tot de intentie van de wet.

Soms leiden die vermengingen tot het tegenovergestelde van wat er beoogd werd. Zo is de bedoeling van de wet om dwang te verminderen door handelingen als het separeren van cliënten strikt te reguleren. In de praktijk kan dat er toe leiden dat verpleegkundigen het separeren van cliënten gaan zien als een administratieve routine, in plaats van een situatie waarin ze morele overwegingen moeten maken. Op die manier voegt de wet geen moraliteit aan de praktijk toe, maar haalt die juist weg.

In het ziekenhuis waar hulpverleners en vertegenwoordigers van de wet tegenstrijdige idealen bepleiten blijven zowel de hulpverleners als de juridische medewerkers trouw aan hun eigen missie. De goede zorg van de hulpverleners en die van de wet blijven daardoor 'puur', maar tegelijkertijd blijven ze ook zover uit elkaar liggen dat de wet geen effectieve invloed kan hebben op de situatie van de cliënten op de langverblijfafdeling.

Zo beschouwd kan de wet alleen invloed kan hebben als ze wordt aangepast aan en ingepast in de specifieke praktijk waarin ze gehandhaafd moet worden, terwijl de wet haar originele betekenis slechts behoudt als ze ineffectief blijft. Dit betekent dat het verbeteren van zorgpraktijken door die juridisch te reguleren een hachelijke zaak is. Ofwel de wet 'werkt', maar doet dat op onverwachte en onbedoelde manieren. Ofwel de wet houdt haar oorspronkelijke betekenis, maar kan de praktijk niet beïnvloeden. In geen van beide gevallen is het resultaat het beoogde.

Het vijfde hoofdstuk, getiteld 'Wassen en verantwoorden. Over goede zorg in de chronische psychiatrie' gaat over manieren om de zorg te *verantwoorden*. Verantwoorden is een 'goed' van deze tijd waar van overheidszijde sterk op wordt aangedrongen. Maar wat betekent dat eigenlijk, zorg verantwoorden? In dit hoofdstuk laat ik zien hoe een activiteit in de zorg, wederom het wassen van cliënten, in de praktijk verantwoord wordt. Er komen vier stijlen van verantwoorden naar voren.

De eerste stijl van verantwoorden is eigenlijk geen verantwoorden. Vergaderingen, cijfers, papieren en discussies worden resoluut afgewezen, omdat die tijd onttrekken aan het eigenlijke zorgen. Dit 'eigenlijke zorgen' gebeurt weliswaar vanuit bepaalde idealen, maar die worden bij voorkeur niet verwoord maar in praktijk gebracht.

De tweede stijl van verantwoorden oriënteert zich op de logica van de 'clinical trial'. De betrokkenen vinden dat over de zorg inderdaad verantwoording moet worden afgelegd, en wel in termen van effectiviteit. Zorg is goed als die effectief is. Zorg voor het wassen krijgt de vorm van een training die cliënten moet leren zich zelfstandig te wassen. Er dienen regelmatig evaluaties plaats te vinden om de effectiviteit van de training te kunnen volgen. Ook moet de training overdraagbaar zijn aan collega's, zodat iedereen de cliënt op dezelfde, methodische manier benadert.

De derde stijl van verantwoorden doet een beroep op ethische principes. Zorg is goed als de juiste principes zijn toegepast. In verband met wassen zijn dat principes als die van het respecteren van de autonomie en de privacy van de cliënt. Deze principes leren in eerste instantie dat wassen een zaak van het individu zelf is. Iemand helpen met wassen is eventueel wel te verantwoorden, als er dan maar wel consensus over bereikt is met de cliënt.

Een vierde stijl van verantwoorden is contextueel. Of wassen in deze of gene context goed is, wordt hier afhankelijk gemaakt van de mate waarin allerlei variabelen op elkaar zijn afgestemd. De relatie tussen verpleegkundige en cliënt, hun beider humeur, recente of komende gebeurtenissen, enzovoorts. Omdat routines de context soms dreigen te stollen, kan een 'frisse blik van buiten' helpen om de vraag of de onderlinge afstemming eigenlijk niet beter zou kunnen, van tijd tot tijd weer eens aan de orde te stellen.

Het blijkt dat van de verschillende manieren van verantwoorden alleen de tweede en de derde stijl als 'rechtvaardigen' te kenschetsen zijn. Dat brengt echter niet met zich mee dat waar effectiviteit als ideaal geldt, alleen gewassen wordt op een manier die gebleken effectief is. Veeleer wordt de zorg er zo georganiseerd dat het mogelijk zou zijn om de mate van effectiviteit ervan eventueel vast te stellen. In plaats van zichzelf als toepassers van effectieve therapieën te positioneren, gaan de verpleegkundigen op de stoel zitten van onderzoekers die een praktijk onderzoekbaar maken. En iets vergelijkbaars geldt voor de stijl van verantwoorden die zich beroept op ethische principes. In plaats van formele procedures toe te passen die autonomie van cliënten garanderen, nemen de verpleegkundigen de positie van de ethicus op zich die principes niet toepast, maar nadenkt over de legitimiteit van handelingen in de zorg.

Maar deze pogingen om de zorg rechtvaardigbaar te maken, maker haar nog niet *goed*. Beide stijlen van verantwoorden komen in de problemen wanneer er zich onverwachte situaties voordoen. Het ideaal van 'effectief wassen' heeft geen antwoord op het probleem van cliënten die effectieve zorg weigeren. Het wassen volgens de principes van autonomie en privacy bereikt een grens als cliënten vervuilen en niet instemmen met de hulp van de verpleegkundige. In de praktijk blijken de verpleegkundigen dan wel in te grijpen, maar ze kunnen dat niet verantwoorden in termen van autonomie. Contextueel verantwoorden biedt, zo betoog ik in dit hoofdstuk, dan ook betere aanknopingspunten om de zorg te verbeteren.

Het zesde hoofdstuk, 'Voorkeuren doen. Voorbij het patiëntenperspectief', gaat over het concept 'patiëntenperspectief'. Dit concept beleefde haar gloriedagen toen het werd gebruikt om patiënten zichtbaar te maken als mogelijk subject in onderzoek. Dit concept is echter problematisch als patiënten niet spreken of niet op een begrijpelijke manier, en geen verbale representaties maken van hun visie op de wereld. Het produceren van een perspectief veronderstelt praktische manieren van subject zijn die een beroep doen op taal en cognitieve competenties. Een tweede probleem van het concept patiëntenperspectief is dat het ons ertoe brengt verhalen op te vatten als representaties, terwijl de context van het vertellen van die verhalen buiten beeld verdwijnt. Wat 'iets vertellen' *doet*, welke performatieve werking het heeft, wordt niet geanalyseerd.

Om die problemen op te lossen ontwerp ik in dit hoofdstuk een alternatief dat de 'stille patiënten' wel als subject in onderzoek ten tonele voert door performativiteit als uitgangspunt te nemen. Daarbij laat ik mij inspireren door de manieren waarop verzorgers schijnen te weten wat de stille patiënten op prijs stellen en wat niet. Stille patiënten kunnen worden geobserveerd als subjecten die verschillende voorkeuren *doen*. Daarbij is de sociale en materiële omgeving co-productief. Het subject dat zo verschijnt is een interactief subject. Patiënt zijn (subject zijn, professional zijn) is in deze benadering geen onvervreemdbare identiteit maar een positie die iemand tijdelijk inneemt in een sociale en materiële omgeving. Ook de problemen van zo'n analyse worden besproken, zoals het gevaar om met de observaties van de professionals mee te gaan, en het gevaar van de geïmpliceerde asymmetrie tussen onderzoeker en geobserveerd subject. In plaats van omwille van deze problemen de mogelijkheid om stille patiënten als subject in onderzoek te laten zien helemaal op te geven, pleit ik ervoor te zoeken naar passende manieren om met deze problemen om te gaan.

In de conclusie, getiteld 'verbetering doen', stel ik de vraag wat de analyses ons leren over de vraag hoe zorg te verbeteren en de vraag of deze studie zelf ook zou kunnen bijdragen aan het verbeteren van zorg. Duidelijk is geworden waarom het verbeteren van zorg vaak anders uitpakt dan verwacht. Dit is omdat praktijken verschillende vormen van kennis en moraal over goed zorgen bevatten. Verbeteringen komen dus niet in een vacuüm terecht, maar temidden van een diversiteit aan vormen van goede zorg die in praktijken al bestaan. Hierdoor moeten verbeteringen ‘vertaald’ worden om een werkbare interferentie met bestaande vormen van goede zorg te bereiken. Tel daarbij op dat ook de manieren van verbeteren zelf divers zijn: er is niet één stijl van verbeteren waaraan de praktijk onderworpen wordt, maar er zijn er meer. Dan lijkt het eerder verbazingwekkend dat pogingen tot verbetering ooit *wel* het beoogde effect hebben.

Deze studie laat echter een andere stijl van verbeteren zien, die probeert beter aan te sluiten bij de kennis en moraal die bestaan in de praktijk. Door die kennis en moraal van binnenuit te articuleren, wordt wat het goede is niet aan de praktijk opgelegd, maar wordt de reflexiviteit van praktijken over wat goed is gevoed. Bijvoorbeeld door de werking van idealen te articuleren en te ontrafelen. Zo is bijvoorbeeld zichtbaar geworden dat het uiterst populaire ideaal van autonomie voor patiënten tot verschillende problemen leidt. Maar ook het articuleren van en nadenken over idealen van goede zorg die de moeite waard zijn maar uit het zicht dreigen te verdwijnen past binnen deze stijl van zorg verbeteren. Een voorbeeld hiervan is het ideaal van sociabiliteit en de bijbehorende notie van mensen als relationele wezens. Het articuleren van noties van goede zorg die in praktijken gedaan worden leidt tot voorstellen om die praktijken opnieuw te bekijken.

Zo maakt de relationele visie op mensen het zorgen zichtbaar als een proces in de tijd dat nooit af is en bestaat uit het steeds opnieuw afstemmen en ‘vertalen’ van nieuwe variabelen in en naar concrete situaties. En hierbij past de laatste, praktische manier van zorg verbeteren die uit dit onderzoek naar voren komt: het uitbreiden van praktijken van zelfreflectie door professionals, cliënten en andere betrokkenen in de zorg. In bijeenkomsten van verschillende samenstelling kunnen de deelnemers over hun zorgpraktijken nadenken en suggesties voor verbetering bespreken. Op die manier kunnen ze kennis en moraal onderhouden en opfrissen, en elkaar helpen die te vertalen naar concrete situaties. Als ‘goed zorgen’ alsmaar door gaat, kunnen verbeterpraktijken maar beter proberen daar bij aan te sluiten.