

Enacting Appreciations: Beyond the Patient Perspective

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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.”

KEY WORDS: ethnography; health research; language; patient perspective; performativity; representation.

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

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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 and 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 and Strauss, 1988) or as illness careers (Gerhardt, 1986; Robinson, 1986) through which the patient moves.³ 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 and 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 and Dodier, 2002) and how the study of practices affects theorizing about disease and illness (Mol, 2002).

³I 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.

Finally, the patient perspective is attended to not as a story about illness, but as comments on “disease-practices.”⁴ Patients’ narratives of their 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; McGlynn, 1997). 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 these subjects 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 and Ridley, 1983; Waisman and Rowland, 1989). The literature also warned me about the problems met with in getting the perspective of the elderly (Willits and Crider, 1988; Clark and Bowling, 1989, 1990).⁵ 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 and 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.

⁴These 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 and Lock, 1993; Mattingly, 1994; Csordas, 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.

⁵Willits and Crider (1988) note that elderly persons often talk about problems in terms of physical problems. Clark and 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; Kleijnen 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).

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.⁶

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.

⁶Chatterji (1998) notes this same problem in the under-representation of experiences of patients suffering from dementia in sociological literature, by its focus on illness *narratives*.

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 situation of the interview has specific characteristics and demands; these were made apparent when the patients "breached" them.⁷

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

⁷Instead 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*?"

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.”

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.⁸ 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.⁹ 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

⁸The 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.

⁹Examples are: "I open the meeting" which actually opens the meeting, or to say "I do" to perform "getting married." See Austin 1962.

interactions and establish social relations. Talking in this sense is not *about* the world, but is performative in *making* the world.

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, and 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.

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.¹⁰ 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 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.¹¹ 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. Patricia¹² 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

¹⁰With 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.

¹¹The 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.

¹²Personal and surnames are used for different residents on this ward by nurses as well as patients, even though all residents are older than 65.

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.¹³ 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 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:¹⁴

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

¹³I 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.

¹⁴The optimism that a mere closing down of hospitals would "cure" all patients has, however, proved to be premature (see Shephard and Phil, 1995).

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 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.¹⁵ They take a position towards the suggestion of the nurse to individualise breakfast. Not

¹⁵Meals 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 and Snaith, 1980.

by *discussing* it in words, but by *acting* against it. They enact appreciations as a group, and the nurses give in.¹⁶

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.

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 and Law, 2003, 1998; Winance, 2001; Law and 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 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

¹⁶Note 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.

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 intertwining 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.¹⁷

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”

¹⁷Note 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.

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.¹⁸

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 [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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¹⁸For a thorough reflection on a symmetry relating to autistic children see Hendriks, 1998.

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