The different faces of autonomy. A study on patient autonomy in ethical theory and hospital practice

Schermer, M.H.N.

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CHAPTER 9

Who cares for Mrs. Dekker’s autonomy?

9.1 The case of Mrs. Dekker

Mrs. Dekker is a 76-year-old widow. She used to own a pub and has worked hard all her life. She always got on well with her regular customers, but if someone made trouble, she had no difficulties in kicking him out. The customers sometimes said, “Watch it Mary, the customer is king!” upon which she would answer, “You are forgetting that I am the empress!” Mrs. Dekker has one daughter with whom she has a good relationship. She lives in a home for the elderly that she finds very pleasant. Due to kidney failure, she has been dependent on haemodialysis for over a year.

Mrs. Dekker was admitted to the hospital for an elective replacement of her knee prosthesis. The operation went well, but afterward she had a heart attack. Then, while recovering from that, she fell out of bed and broke her leg. She was operated on again and due to angina pectoris and congestive heart failure, she was transferred to the cardiac control unit for a few days. After her situation had stabilised, she was transferred to internal medicine because that department could better manage the dialysis and the treatment for her heart failure than the surgical department. When I first met her, she had been in the hospital for exactly ten weeks and there was still no prospect of her being discharged.

Over the next six or seven weeks, Mrs. Dekker’s condition remained more or less the same. She went through two episodes of cystitis and one episode of gastroenteritis and she developed a small bedsore on her heel. She suffered from obstipation that caused her a lot of trouble and pain. Despite the total bed rest she had to maintain, her leg fracture did not heal properly. After a few weeks, the orthopaedic surgeon decided she could start mobilising and she received physiotherapy, starting to sit up in bed and on the edge of the bed, but the dizziness this caused made her frightened and there was little progress. She went for dialysis three times a week, but apart from that she stayed alone in her room. Her daughter visited her daily, her son-in-law also came regularly, and sometimes an acquaintance from the home paid a visit, with greetings and good wishes from the other residents.

Mrs. Dekker often made the impression of being rather depressed by the long hospital stay and lack of progress. She sometimes told the nurses that she did not want to go on like this, and that she would rather die, but there were also periods during which she felt better and was a little more cheerful.

During her stay, the relationship between Mrs. Dekker and the attending nurses became more and more problematic. Mrs. Dekker was rather critical, complained a lot and, according to the nurses, demanded a lot of attention.

\[1\] This is the Dutch expression for ‘the customer is always right’.
in a very negative way. She frequently refused to take her medication, stating that she had trouble swallowing all these pills (she had to take twelve each day), or that she did not need them any more, or that she just would not take them. The nurses found it difficult to understand this, mainly because they found her behaviour very ambivalent in regard to the reasons she gave for not taking her pills. A nurse who frequently attended her, told me that “she often complains that she cannot swallow her pills and she retches in your presence. But if she has not noticed you are there, she just swallows them.” Another nurse said, “She is very unclear as to what she wants because she is so unpredictable and inconsistent. Sometimes she refuses medication, but a few moments later she takes it anyway. It is often unclear why she doesn’t want something.” Both nurses stated that they would find it easier if Mrs. Dekker would be more distinct and more consistent. They believed she really did understand what the medication was for, since they had both explained it to her more than once. By that time, however, they were no longer trying to persuade her to take the medication and considered that it was her responsibility to take it or not, though one nurse remarked that “if you take your medicines the one time and then don’t take them another time, you lose the effect of taking them; it would be better if she made a clear choice, and then, if she decided she didn’t want them, they should not be offered to her any more.”

The attending physician, Dr. Kramer, knew that Mrs. Dekker sometimes refused her medication. Though this was generally dealt with by the nurses, he occasionally discussed the taking of the medication with Mrs. Dekker herself. On one of the daily rounds, for instance, when Mrs. Dekker told him that she did not want any medication anymore, Dr. Kramer said he wanted to negotiate with her about what pills to take but he insisted that some of the pills were really important. When I asked him about it, Dr. Kramer told me that he believed Mrs. Dekker refused the medication because she could not stand having to lie in bed all that time and also because she had lost hope. Besides, she also had trouble swallowing. He believed he was justified in putting some pressure on her to take the pills because her depressed mood seemed to influence her decision, but he also stated that if she really did not want to take the medication, it was her own responsibility and she should not be forced to take it.

Mrs. Dekker herself found Dr. Kramer’s remark about negotiating the medication absurd. “I say: I won’t take them. And then he says, ‘then we will negotiate it’ Really, you don’t say that to a patient!” I asked her what the physician should have said, in her opinion, and she answered, “He should say, ‘You either take them, or you don’t take them. That’s your business.’ And then I will do what I want to do... And then I will take them.”

Apart from the taking or not taking of medication, there were other problems that made the relationship between Mrs. Dekker and the nurses difficult. The nurses became irritated by the way in which Mrs. Dekker always complained, by the frequency with which she rang for the bedpan without ever producing anything, and her often unfriendly attitude towards them. At a certain point, one nurse even said he did not want to attend to her any more.

At the same time, Mrs. Dekker appeared to be becoming more and more
Who cares for Mrs. Dekker's autonomy?

depressed and apathetic. At weekly staff meetings, Mrs. Dekker was discussed extensively. Most of the nurses could understand that it was a difficult situation for Mrs. Dekker, especially because in the past she had always been an active and independent woman, but they resented the negative way in which she asked for attention and found it difficult that she would not talk to them about what was really troubling her. The nurses suggested to consult with the psychologist, and Dr. Kramer agreed to this. He thought the psychologist might be able to help Mrs. Dekker with her feelings "that the walls were closing in on her". After some objections, Mrs. Dekker (who did not see the necessity of consulting a psychologist and who maintained that she was fine) agreed to give it a try. The psychologist came to talk to her about once a week and he advised the nurses not to try to have 'deep talks' with her any more but just to accept that she might be thinking and brooding a lot but would never say so. In order to distract Mrs. Dekker a bit and bring her into contact with some of the other patients, she was moved first into a two-person room and later to a four-person ward. Although Mrs. Dekker at first objected to being moved (and once moved, maintained that it did not matter to her where she lay), she seemed less moody and, according to the nurses, became somewhat easier to handle and more friendly. Sometimes, one of the nurses would take Mrs. Dekker to the recreation ward or have coffee with her, and the tensions seemed to lessen a bit. Later, however, after having been in the hospital for eighteen weeks and still not showing much progress, Mrs. Dekker started to become more depressed again. She was gloomy and silent. She often cried, frequently refused medication, ate and drank less, and made an apathetic, desperate impression. Her temperature rose once again, the dialysis became rather difficult, and it also became clear that the leg fracture would not heal and that she would remain bedridden. One day, she refused to go to dialysis. Nevertheless, after a talk with her daughter, she went. The psychiatrist who was consulted found her competent. A few days later, she refused dialysis again. This time, she had an in-depth talk with her nephrologist who decided to respect her wishes. This decision was also discussed with Mrs. Dekker's family who were not really surprised and, though grieving, approved of the decision. Dialysis was stopped and only palliative treatment was given. Mrs. Dekker died four days later after having spent almost twenty-two weeks in the hospital.

9.2 Autonomy: a right, a condition, an ideal

The case of Mrs. Dekker can be interpreted and analysed in several ways (Schermer 1997). One can focus on her treatment refusals: first, her occasional refusals of medication, and later her refusal to continue the dialysis. By means of those refusals, one could say that she exercised her right to self-determination. Mrs. Dekker did not let others decide for her but did what she wanted to do. She made her own choices, decided about her own life, and ultimately about her own death. Mrs. Dekker was an autonomous woman. From this point of view, the central issues in the case concern the right to self-determination, the provision of information, the process of
decision-making, the quality of Mrs. Dekker’s refusals, her capacities for reasoning and deliberating, and so on.

Mrs. Dekker’s treatment refusals can also be interpreted in a different way, however. Her ambivalent refusals of medication did not constitute an isolated factor. Instead, they fit into a pattern of “difficult” and demanding behaviour. According to many of the nurses, her refusal of medication was a cry for attention, as were her frequent rings for the bedpan, her grumbling and her critical attitude. Most of the staff agreed that it was very hard for Mrs. Dekker to handle and accept her situation. The social worker who knew Mrs. Dekker rather well from previous admissions once remarked, “I believe it [her troublesome behaviour, MS] is mostly frustration - not being able to determine the course of events. She did that all her life, so naturally she has difficulty with it now.” She interpreted Mrs. Dekker’s behaviour as an expression of discontent with her situation of dependence - a reaction that was in line with her character. At the same time, Mrs. Dekker was also brooding about her illness and her perspectives for the future. She hoped she could return home but doubted more and more that this would be feasible. She frequently expressed a desire to die. According to one of the nurses, however, during the first months of her admission, this desire had been very ambivalent and not clear and unequivocal, a fact that made it difficult to “do something with it”\(^2\). The ambivalence of Mrs. Dekker’s wishes makes one wonder how authentic they were. Were they expressions of her real self? And what is her real self in this situation of uncertainty and doubt?

This second interpretation does not focus on autonomy as the right to self-determination but on autonomy as a descriptive feature of persons: as the actual condition of authentic self-governance. In this second approach, the main question is whether Mrs. Dekker was still capable of giving meaning and direction to her life now that she was being confronted with existential questions that upset her own self-image and that made it difficult for her to do the things she valued. How did she deal with her situation; how did she cope with her illness and her dependence?

The actual condition of autonomy - of self-governance - is associated with concepts such as self-selection, self-creation, self-identity, integrity and independence (Feinberg 1986). The primary focus of the theoretical work on this subject, however, has been directed toward the notion of authenticity. The various ‘authenticity models’ of autonomy discussed in Chapter 2 all focus on the question of what it means for a person’s values, goals and preferences to be genuinely her own. Although these models (generated by authors such as Dworkin, Frankfurt and Christman) have had a certain amount of influence on healthcare ethics, the emphasis has been on autonomy as the right to self-determination, interpreted primarily as a right to non-interference.

\(^2\) This nurse sounded a bit annoyed when he told me that “she often says she wants to die, or that she has a written request for euthanasia [in Dutch: euthanasieverklaring] but if you try to respond to that in a serious way, she doesn’t really want to do anything about it. If you ask her whether she wants to die, then, it turns out that she doesn’t really want that after all.”
Lately, however, a more positive account of individual autonomy has been introduced into medical ethics by authors from a very different background: that of the ethic of care. These authors have not directed their attention to the right to self-determination and non-interference (though most of them do acknowledge the importance of this right), but instead have focused on the condition and ideal of autonomy (cf. Hill 1987).

The next section introduces the ethic of care and its view on autonomy. Section 4 discusses the implications of this view in regard to the concept of respect for autonomy and argues that from this point of view, respect for autonomy implies positive support in the development of autonomy and the promotion of respect and self-respect. Next, I examine how this view can be applied to hospital practice and how assistance in the development of autonomy can take shape. Section 6 poses some critical questions and discusses some problems with the care perspective on autonomy. I then examine the limits of positive support in the development of autonomy and discuss the tension between a procedural conception of autonomy and a more substantial conception.

9.3 Autonomy as seen in the ethic of care

The ethic of care can be briefly described as a perspective on morality that centres on notions such as care, responsibility, interdependence, vulnerability and relationality. As Little (1998) states in an illuminating article, it is not so much a theory as a stance from which to engage in theory; it is a specific orientation towards moral life. A moral orientation can be defined in terms of its emphases of concern and discernment, its habits and proclivities of interpretation and its selectivity of skills. How one looks at a situation, the things one notices as morally important, the aspects one emphasises or minimises, the terms in which one chooses to describe a situation or define a moral problem, or the way in which one argues about them - all of these are determined by one's orientation. The care orientation, is often presented in contrast with the more traditional liberal orientation of moral philosophy (somewhat confusingly termed the 'justice' orientation) in which there is an emphasis on rights and duties, on contractual relationships between 'moral strangers', and on abstraction and universality. The care perspective focuses more on responsibilities, on connectedness and interdependence, on concrete situations and on differences. As Little explains, this difference in perspective does not necessarily mean that there is also a difference or even a conflict between the propositions accepted by either of the two perspectives. The propositions that the two perspectives are committed to can be compatible, but this does not mean that the difference between the perspectives is 'merely' one of emphasis. As Little demonstrates, "emphasis matters" (1998, p. 197).

Though the ethic of care is still mainly a perspective and has not, or not yet, yielded one or more full-fledged moral theories, some initial steps towards theory development have been taken. The concept of autonomy is one of the subjects that have been criticised by various care ethicists. Their critique has primarily been directed against autonomy understood as an
ideal of independence and self-sufficiency, as was discussed in Chapter 2. Some care ethicists, such as Keller, Verkerk and Manschot, have also started to develop alternative conceptions of autonomy. Though I am aware that the care view on autonomy does not exist, what I will be doing here is singling out one care-inspired concept of autonomy and referring to it as ‘the care view on autonomy’. Moreover, my primary concern here is with this specific interpretation of the concept of autonomy and not with the care ethic itself. Although its view on autonomy cannot, of course, be completely detached from the care perspective as such, my focus will be on the former. Even so, I am aware that this approach may at some points fail to do full justice to the care perspective.

The ethic of care finds some of its inspiration in feminist theory where the concept of autonomy has also been a subject of discussion and criticism. Feminists have criticised the image of the autonomous man as a completely autarkic, atomistic, ‘disembedded and disembodied’ individual as being both unrealistic and undesirable. They have also questioned the possibility of authenticity vis-à-vis gender-specific socialisation [Meyers 1987, Keller 1997]. Starting from the idea that in order to be self-governing one must be able to act in accordance with self-chosen rules and to reflect critically on one’s own values and one’s own identity, Meyers has developed the concept of autonomy competency [Meyers 1987, 1992]. Autonomy competency is the “repertory of coordinated skills, including introspective skills, communicative skills, reasoning skills, imaginative skills, and volitional skills” necessary to perform such critical reflection. By exercising these skills people “come to grasp who they are, what matters to them, how they want to develop or change, and how they can best give expression to their integral desires, beliefs, affections, values and the like” [1992, p. 126]. These skills make self-definition, self-direction and self-discovery possible; they enable one to develop one’s own identity and integrity. The procedure in which these skills are used, and through which one can make values and choices ‘one’s own’, is that of responsibility reasoning. This entails that one should ask oneself whether one can take responsibility for a particular choice or action while retaining one’s self-respect and integrity. Put more concretely, “one asks what choices are compatible with or reinforce desirable aspects of one’s personal identity. Questions like: ‘What would it be like to have done that?’ and ‘Could I bear to be the sort of person who can do that?’ are foremost” [Meyers 1987, p. 151]. In this view, the autonomous or authentic self is the “evolving collocation of traits that emerges when someone exercises autonomy competency” [Meyers 1992, p. 126]. Although at times the care view appears to see autonomy or authenticity as a condition that can be attained, at other times, it sees it more as a continuous process of self-

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3 It is interesting to note the similarities between this view and that expressed by Gerald Dworkin in his later work, who describes autonomy as “a second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes, and so forth and the capacity to accept or attempt to change these” and who states that: “by exercising such capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are” (1988, p. 20).
development guided by an ideal of authenticity. This later interpretation fits in with the developmental view on autonomy presented by Agich [see Chapter 2].

Care ethicist Keller (1997) has used Meyers' view of autonomy as a starting point for developing the idea of 'autonomy in relation'. According to Keller, Meyers shows that autonomy need not be understood as opposed to relationality, connectedness or embeddedness. Instead, autonomy is made possible by our social relationships: first because the values, commitments and beliefs with which one comes to identify oneself are learned through interaction with others, and second because the skills that make up autonomy competency are learned from others and are best developed and exercised within the context of supportive intimate relationships. Moreover, autonomy does not exclude the possibility that an autonomous person is relationship-oriented in the sense of attaching much value to making and maintaining connections with others. Finally, as Verkerk has noted, the relationships we have with others make up an important part of our self-conception [Verkerk 1999]. Since autonomy competency can best be exercised and developed in interaction and dialogue with others, Keller understands autonomy as an intersubjective activity (Keller 1997). The importance of close relationships for the exercise of autonomy skills and the development of an autonomous self is also discussed by Manschot who refers to ancient Greek practices of care for oneself and the crucial role of friendship therein (Manschot 1992, 1994).

Briefly, the care view understands autonomy as both a condition and an ideal for personal development. It is something one can be to a greater or lesser degree and something one can and should strive to enhance and develop. This development can be seen as directed towards an end-state, but I believe it is better understood (as it is in the developmental view on autonomy) as a process of self-adjustment and self-change through the exercise of autonomy skills, resulting in temporary conditions of authenticity. Much attention is devoted to the competency or skills necessary to achieve or enhance autonomy, to the active nature of exercising these skills, and to conditions (most importantly: relationships with others) that facilitate or hinder the development of an autonomous self.

9.4 Respect for autonomy as an ideal of authenticity

If autonomy is understood to be a character ideal - a condition that is never fully attained but can be seen as a developmental process and which requires continuous work on and care for one's 'self' - then what does it mean to respect autonomy?

4 As discussed in Chapter 2, Feinberg, Dworkin, Christman and many others have noted that autonomy is not incompatible with social influences, relationships and the like. Nor does a procedural view on autonomy (as promoted by these authors and Meyers alike) rule out certain values or value systems (such as a strong orientation toward relationships) as non-autonomous. However, keeping in minds Little's characterisation of the care orientation, the difference is in the emphasis, concern and elaboration this relational side of autonomy receives.
CHAPTER 9

Supporting the exercise of autonomy skills

First of all, respect for autonomy can be seen as respect for the capacities it requires: the capacities for critical reflection such as introspective skills, communicative skills, reasoning skills, imaginative skills, and volitional skills (i.e. the skills that make up Meyers’ autonomy-competency). Respect can be interpreted as non-interference with the exercise of these skills. It can be argued that by respecting a person’s free and informed choices, the exercise of her autonomy skills is respected and protected from interference by others (den Hartogh 1997). The care view, however, interprets respect more positively; as maintaining, supporting, and enhancing these skills. Since people are understood as connected and interdependent, the skills necessary for autonomy are not seen as things people simply possess to a certain degree but as things that are learned and developed through interaction with others - and that can also be thwarted or undermined by others. This means that our responsibility for others, especially for others with whom we have a relationship, does not stop at non-interference with the exercise of their skills but also requires active support in developing and using them. The concept of relational autonomy implies a responsibility to protect and enhance others’ autonomy skills.

Apart from maintaining and enhancing autonomy skills, respect for autonomy can also imply helping people with the process of critical self-reflection and with the process of developing an integrated, authentic self with more or less consistent and coherent values and goals. In fact, the idea of relational autonomy implies that dialogue and interaction with others are essential to these processes. According to Verkerk, the enhancement of autonomy is one of the goals of care: “Care should always be related to enhancing the capacity of people to define who they are, to understand themselves and to direct their lives. [...] care should facilitate autonomy” (1999, p. 367).

Respect and self-respect

An interesting observation is that self-trust and self-respect are preconditions for the exercise and development of autonomy skills (Govier 1993, Verkerk 1998). Self-respect is conceptually linked to autonomy since the procedure of responsibility reasoning implies that in order to be autonomous one must be able to answer the question of whether one’s preferences or actions are compatible with one’s self-image and self-respect. Moreover, autonomy is also empirically linked to self-respect and self-trust: if one does not trust one’s own judgement and capacities, or does not value and respect one’s own goals and commitments, one cannot develop one’s autonomy. At the same time, self-respect and self-trust can be enhanced by the very exercise of autonomy skills (cf. Christman 1988). Thus, as Keller rightly remarks,

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5 Note that this does not exclusively mean non-interference, but also asks for some positive action such as providing information. The intention of the doctrine of informed consent is to facilitate and promote autonomous decision-making by patients and not just to refrain from interfering with patients’ choices.
autonomy and self-respect are mutually reinforcing. It can even be argued that autonomy and self-respect largely coincide. Self-respect is expressed by acting in an autonomous way, i.e. acting according to one's own values and goals instead of someone else's, or acting in a way that preserves one's integrity. Having self-respect also means that one values oneself and attributes oneself a certain status: the status of a person who can determine for himself what is worthwhile and what is not, who can set out and follow his own course in life, who can make his own decisions, and who is, in short, autonomous.

It can be argued that part of what it means to respect autonomy is to grant people this status and to treat them in a way that shows respect for them as human beings with the right to self-determination and self-government and the capacities to exercise them. The importance of such respect can be illustrated by the case of Mrs. Post, a 76-year-old woman who was admitted for an ERCP procedure. She complained to me that "they" (the doctors and nurses) told her hardly anything. "If you want to know anything about what's going on, you have to ask them about it yourself" she said. "They actually do explain it to you when you ask them about it, but they are all so busy, so you often simply don't have the nerve to ask." She paused briefly and continued, "I do understand they're busy, and they can't help that, but still, you are a human being, aren't you, and not some object. Because when you're in the hospital, you just lie there, and you just have to wait and see what happens. Nobody tells you anything, but you should be allowed to have a say in things, shouldn't you? You are expected to just let it all happen, but you're not a child anymore, now, are you?"

Although the ERCP was performed with Mrs. Post's consent, she literally felt treated like a child and as if she had no right to or was incapable of having a say in things that directly concerned her body and her life. She even expressed the feeling of being treated as if she were not a human being at all but a mere object: a thing, without feelings or thoughts of her own.

Authors like Feinberg, Christman and Berlin also mention the feelings of belittlement and insult that a lack of respect from others can cause. As mentioned in Chapter 2, Christman has even suggested that the right to autonomy should include a right not to be treated as if one did not have any (capacities for) autonomy. I agree with him on this point, and I also believe that respect for autonomy requires a certain attitude towards people by which we grant them a certain status and recognise them as persons with their own capacities who can and do lead their own lives in their own way. Because self-respect and self-trust are influenced by others - they can be either enhanced or threatened by the actions and attitudes others take towards us - Verkerk has argued that respect for autonomy requires the creation and maintenance of surroundings in which patients can feel respected and trusted and of relationships that foster rather than thwart the self-

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6 An ERCP is an Endoscopic Retrograde Cholangio Pancreaticography, a procedure by which a tube is inserted through the oesophagus and stomach into the small intestine to the mouth of the bile and pancreatic ducts. This procedure serves to diagnose and remove gallstones.
respect and self-esteem of patients (Verkerk 1998). Here, a respectful attitude and a respectful treatment are not understood primarily as expressions of respect for autonomy, but rather as 'instruments' for enhancing or supporting self-respect and, as a consequence, autonomy as well. Nevertheless, the close connection between autonomy, respect and self-respect makes it impossible to clearly separate the mere expression of respect for autonomy from the promotion of self-respect and autonomy.

Ultimately, exactly what kind of relationships and interactions really do foster or enhance self-respect is an empirical matter, but from a theoretical perspective, various claims can be made in regard to the respect one shows others by means of certain behaviours or interactions, and about the effects this may have on that person’s self-respect. From the care perspective, it is often argued that examining a patient's motives, trying to elucidate her goals and values, discussing her choices, or helping a patient in other ways to develop her autonomy are all signs of sincere interest, concern and respect. One can also argue, however, that too much questioning and discussing can become meddlesome, paternalising or disrespectful and actually undermine the patient's self-trust and self-respect. It is therefore important to note that non-interference with patients' choices can also enhance self-respect and self-esteem. Simply accepting a patient's decisions without questioning or discussion can be a way of showing respect for and trust in the patient's capacities to live her own life in her own way (cf. the citation of VanDeVeer in Section 8.4). Being respected in this way and being allowed to follow her own course without being asked too many questions can add to a patient’s self-respect.

9.5 Care-for-autonomy in hospital practice

Within the context of health care, special attention should be devoted to the effect of illness and disease on autonomy. It has often been argued that illness diminishes autonomy because it can disturb a patient's rational thinking capacities and because it causes a psychological regression to a more infantile state in which patients primarily desire attention and care and no longer want to decide for themselves (Ingelfinger 1980).

The care viewpoint points to yet another way in which illness and disease can affect autonomy. Illness can disrupt one's self-image and necessitate renewed reflection on one's goals, values and self-identity. The direct confrontation with the fragility of existence and with vulnerability, mortality

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7 In the case of Mrs. Verwoerd (mentioned briefly in Chapter 8), the physician rather forcefully tried to convince her to stay in the hospital. At one time, he bluntly said that he believed her decision to go home to be stupid although he immediately added that he would respect it if she stuck to it. At the time, I wondered whether he was not putting too much pressure on Mrs. Verwoerd (I could imagine her feeling rather intimidated by his remark), but when I later asked Mrs. Verwoerd about it she told me she appreciated the clear and direct way in which her physician stated his point of view. It made her feel taken seriously and respected as a partner in the dialogue.
Who cares for Mrs. Dekker’s autonomy?

and dependence can trigger self-reflection and thus stimulate the development of autonomy. Illness can also make one reflect on ideas and values one has always accepted without questioning. From this point of view, illness can be seen as a task or even as a positive challenge to autonomy. An example of the latter view is presented by Manschot (1992, 1994), who has developed a specific concept of autonomy that revolves around the individual’s attitude towards (and her way of coping with) fragility and finiteness. Existential autonomy, as this can be called, is seen as the ongoing process of giving meaning to one’s finiteness, integrating one’s vulnerability into one’s self-image and shaping one’s own life in a way that takes the limitations of human existence into account. The core notion of such existential autonomy is independence vis-à-vis the fragility of human existence. As Manschot explains, people who are ill, disabled or otherwise dependent on care can actually be more autonomous than others since they have been more emphatically confronted with the vulnerability of existence (Manschot 1994). I believe this represents a rather idealistic and romantic view of illness and disease. Though illness can sometimes constitute a learning experience that will lead to inner growth, this is certainly not the case for everybody.

A less idealised view on the relationship between illness and autonomy is one that understands autonomy in terms of dealing with the experience of illness and the consequences of disease. This view is represented by Thomasma (1995), who understands autonomy primarily as the continuous and lifelong struggle of individuals to develop and structure their values and to develop their personal identity and integrity. Respect for autonomy, according to Thomasma, means entering the individual’s life as an aid to the process of developing and structuring her values. In the case of illness this respect for autonomy requires that one should provide in a healing relationship the necessary conditions for individuals to develop their own reintegrating techniques, and thus help them to restore or maintain their identity. A similar view is expressed by Donchin who believes that health care providers should “actively support the patients’ struggles to integrate their illness experiences into their distinctive identities in a way that nurtures their autonomy competencies, their capacities for innovation, development, and change” (Donchin 1995, p. 53).

In everyday hospital practice, the kind of support required by the care view on autonomy (and which I would like to term ‘care-for-autonomy’), can easily be accommodated within the goals and methods that have been adopted by such disciplines as social work, medical psychology, pastoral care and nursing. A social worker I interviewed told me that one of her tasks was to help patients and their families or friends answer questions such as “What does that disease do to you, how can you give it a place in your life, and how can you handle it. If you have only a short period left to live, how are you going to give shape to that piece of life.... And how to... well... place it, in practical as well as emotional terms? [...] How do you handle yourself and that illness.” She usually asked these questions in a series of conversations with her clients. She tried to find out, together with the patient, how he or she usually coped with things, or what their stance in life was. “I
always try to find out: how do you usually deal with difficult situations, how do you do that, what is your way of doing that and, well, to find out how you can use that way now, to activate that, someone's usual coping skills, to deal with this situation as well." Sometimes, she also confronted patients with their own inconsistencies or ambiguities in order to help them reflect on how they wanted to handle their situation.

According to one of the nurses, a good way to help patients sort out things and to support them in coping with the unsettling experience of illness and hospital admission was to simply listen to a patient's story, both her life history and the history of her illness. "Just by telling it ... the telling is the therapy. The therapy is the help you offer by letting people tell their story. And in doing that, they themselves put things into perspective and find out a bit more about what it is they really want and what they don't want, and you can give that back to them [...]. It is a way of giving it [their experiences, MS] a place in their life story."

These activities can be interpreted as supporting the patient's autonomy and autonomy skills in a way that is in line with the care perspective. They illustrate how dialogue, attention and involvement can be important ' tools' and how relationships need to be understood in more than just contractual terms in order to do justice to their role in supporting autonomy.

Further research into the preconditions, possibilities and moral problems related to this kind of care-for-autonomy needs to be performed and could start by examining the practices in which this kind of care is already being given, such as those of social work or medical psychology.

In addition to looking at the possibilities of professional help, the care perspective would also emphasise the importance of the support from family or friends or others with whom the patient has a close relationship. One of the nurses attending Mrs. Dekker remarked that she would like to speak to Mrs. Dekker's daughter to see what she thought about the situation. The nurse had not found the time and opportunity to do so at that time (and did not speak to her at a later time either, as far as I know), but she believed this would be a good thing to do. Perhaps professionals should stimulate and facilitate discussions amongst family and friends about a patient's way of dealing with her illness and about the meaning and direction of her life. Perhaps the professional's focus should not be on the patient alone but on the whole 'system' (as the social worker called it) that includes the patient and her significant others. Such attention for both the patient and the relationships she is in would be in line with a care perspective, even though it might easily be considered too meddlesome from a more liberal perspective.

### 9.6 Some problems with the care perspective on autonomy

In the case of Mrs. Dekker, some of the staff interpreted her behaviour as a cry for attention and a sign that she found it difficult to cope with her illness and to handle her situation of dependence and vulnerability. If they were right and Mrs. Dekker was indeed struggling with her illness, with the dim perspectives for her future and with her situation of dependence and vulnerability, this means that she was struggling with some existential
questions that directly concerned her self-definition, her self-image and her values and goals in life and thus directly affected her autonomy. From the care perspective, it can therefore be argued that Mrs. Dekker should have received more support in coping with her situation. Her capacities for critical self-reflection, introspection, communication and the like should have been supported or enhanced by the staff involved in the case, and she should have received more help in the process of reflection on her goals, values and the direction of her life in the light of her disabilities. The consultation of the psychologist may be seen as a step in this direction, but it was rather late in coming.

However, the case of Mrs. Dekker poses some problems in regard to the care view. While the nurses made some attempts to talk with Mrs. Dekker about her situation and her behaviour, she did not want to talk to them, and she was not very open or friendly to the psychologist either. When I asked her whether he was of any help to her, she scorned: "That guy? No. He only talks funny". Mrs. Dekker did not seem to be the kind of person who liked to talk to others about her inner self; she was the kind of person who wanted to deal with her own problems herself and who wanted to be independent and do things on her own. In short, Mrs. Dekker did not fit neatly into the care model of autonomy and therefore raises some interesting questions for the care view on autonomy.

How far should promotion of authenticity go?

First of all, Mrs. Dekker's remarks about the psychologist and her general refusal to have 'deep talks' point out that the ideal of developing an autonomous self through critical self-reflection, self-assessment or care-for-the-self is a rather intellectual, psychological ideal. It is asking a lot of people, and not everybody is able or willing to muster the necessary introspection, self-reflection and the like. Moreover, not everybody may consider this to be equally important. Though I believe this ideal has a strong basis in Western culture, one can wonder whether it should be promoted within the context of health care. Is the promotion of patient autonomy in this way really a task that needs to be provided by health care? It can be argued that it is one of the goals and tasks of mental health care, and some authors have argued that it should be a goal for health care in general (Pellegrino & Thomasma 1988, Cassell 1977).

I am of the opinion that the enhancement and promotion of autonomy in the sense discussed previously is not among the primary tasks or goals of somatic care and certainly not in the case of acute hospital care. Where hospital care is concerned, I believe that only when illness or disease causes a serious disruption of a patient's self and necessitates a re-thinking and re-evaluation of her values and goals does it become the task of health care to provide active support. In such cases, the disruption of the self can be seen as one of the negative consequences of disease. It follows, thus, that physicians, nurses and other health care providers should be alert to existential crises and disruptions of a patient's self-image and self-identity - and perhaps they should be more alert to these than they generally are now. Professional support (varying from paying more attention to these matters
in daily interactions to more systematic and therapeutic approaches) should be offered in such cases. This might require more time and personnel, or a shift in priorities and status in favour of this kind of care.

Support of a patient's autonomy can be a goal in itself but it can also be understood as a means to promote autonomous decision-making. When a patient's pattern of values is shifting and changing due to the existential crisis that illness can be, it can be very difficult for a patient to make authentic choices, or even to make choices at all, as is illustrated by the ambivalent attitude displayed by Mrs. Dekker. Though most of the staff appeared to be rather willing to respect her wishes (as the right to self-determination requires), they also seemed to expect that these wishes should be clear and unambiguous. In this respect, their attitude is in line with an assumption that is implicit in many writings on informed consent and shared decision-making: that patients make choices based on their values, while being in possession of a reasonably stable and organised set of values. The care view on autonomy points out the dynamic character of values and goals, especially during existential crises (see also Chapter 7).

This means that a patient may sometimes need support in finding out what she really wants, or what her own well-being consists of, before she can make any meaningful choices about her treatment. In such cases (when a person's values, goals and identity are upset or shifting), non-interference with a patient's choices may not be enough to respect that patient's autonomy. Active support, helping the patient to sort out her values and wishes might be what is necessary. The social worker also described this kind of support as an aspect of her work: "What I'm trying to do is to see, together with people and by questioning them ... how can you collect your thoughts, how can you sort out what it is you really want. [...] Well, that can be a very difficult process. After all, how do you find out? Because sometimes you just don't know anymore." Without such support, a patient may not even be able to make any choice at all and may too easily leave important choices to physicians or blindly follow their advice. This does not mean that patients' choices only deserve to be respected if they are the product of critical reflection by an autonomous self, as seems to be Beauchamp and Childress's interpretation of theories that understand autonomy in terms of self-reflection and authenticity (Beauchamp & Childress 1994, pp. 121-123.) Unless the confusion in a patient's values is so great as to lead to incompetence, his expressed consents and refusals should be respected. Neither does it mean that patients should never be allowed to leave a decision up to their doctor. What it does mean, however, is that effort should be made to support patients in determining their own route through illness, therapy and hospital admission. According to the model of collaborative decision-making developed in Chapter 6, a physician should be informed about the wishes, values and goals of her patient in order to be able to give individual-centred advice. It can now be added that physicians should also be more alert to situations in which illness and admission have disrupted

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8 Actually, this is one of the requirements for competence as discussed by Buchanan and Brock 1990.
the patient’s identity and values to such an extent that some help in sorting out her wishes and priorities (e.g. by a social worker or psychologist) would be welcomed. The relevance and consequences of the care view on autonomy will most probably be different for various care situations, such as nursing homes care, care for the mentally disabled, care for the chronically ill or mental health care. The possibilities and problems related to this view should be researched and assessed for each of these specific situations separately.

**Procedural autonomy and substantial values**

The second question raised by the case of Mrs. Dekker stems from the observation that independence and self-sufficiency were important values for her, as well as for many other elderly patients. However, along with autarchy and individuality these are exactly the values that proponents of the care view find objectionable as being reflections of a liberal view on autonomy. As long as autonomy is understood in procedural terms, as it is in Meyers’ model, there is no reason why an autonomous person could not value independence and self-sufficiency and try to live her life according to them. Just as an autonomous person can be relationship-oriented (Keller 1997), she can be individualistic, and just as she can value interdependence, she can place little value on it. Obviously, in individual cases, the degree to which such ideals are autonomous can be questioned; maybe the emphasis on independence and self-sufficiency in Western culture makes it difficult for people to see the value of connectedness, dependence and the like. Nevertheless, a procedural view on autonomy does not rule out any specific substantial view of the ‘good life’. In addition to a procedural view on autonomy, however, the care perspective also tends to associate itself with a specific view of the good life⁹, a view in which relationships, connectedness, vulnerability and interdependence are seen as important and valuable aspects of human existence.

This tension (present within the care view itself) between a procedural view of autonomy and a substantial view of the good life raises the question of how such a substantial view can be promoted while at the same time respecting individual autonomy. Is there any room for the promotion of such a substantial view within individual contacts between patients and health care professionals? One of the goals of liberal health care ethics has been to ban substantial views of the good life to the private domain and to protect patient autonomy by minimising the influence of the physician’s values on the patient’s decisions. This goal has been criticised, and various other approaches have been proposed in which there is room for the discussion of substantial views of the good life and individual well-being between the patient and the caregiver (Emanuel & Emanuel 1992). I believe that since the hospital patient is often in a vulnerable and dependent position because of the inequalities in knowledge, status and power between her and profes-

⁹ It is frequently remarked by care ethicists that the primary question of the care ethic is not “what ought I to do?” but “how ought I to live?”. 
sional caregivers (especially physicians), the liberal caution is justified. In the hospital setting, discussion of such views is only indicated, as I have argued previously, in cases in which the patient’s value pattern and self-identity are seriously disrupted or shifting due to the experience of illness. In such cases, care-for-autonomy can imply that a caregiver should offer the patient new values, show her possible alternative ways to understand and appreciate her situation or propose alternative views of the good life. As Donchin (1995) argues, a person’s autonomy is proportional to the diversity of perspectives available for assessing his or her values and principles. Discussing such alternative values and perspectives should not be done with the intention of convincing or persuading the patient of one specific view but with the intention of helping her to find out what fits her own experiences and previous or present values and views.

The conflict between authenticity and sovereignty

A final question prompted by the case of Mrs. Dekker is whether the enhancement of autonomy can be more important than respect for the right to self-determination. If Mrs. Dekker refuses to have deep talks, if she turns her head and waves the psychologist away, should he insist on speaking with her or should he accept her refusal? Can one imagine any situation in which it would be right to try to enhance a patient’s autonomy against her wishes? This conflict can be understood as the classic conflict of paternalism, except that in this case the patient’s well-being is defined in terms of autonomy understood as an ideal of authenticity. From the care perspective, respect for a person’s autonomy can sometimes require interference with a patient’s choices. As Verkerk puts it, “In developing a more relational model of autonomy, interventions in care can be shown to be in the interest of patients, that is, they can be seen as interventions for attaining autonomy, instead of threatening autonomy” (1999, p. 363). This suggests that in the case of Mrs. Dekker, it might have been right to try to get her to accept help in dealing with her situation, in redefining her values and goals in life and in developing or adjusting her self-identity. It might have been a form of ‘compassionate interference’ (Henselmans 1993, Verkerk 1999) to pressure her into talking about her feelings and into sharing her existential worries in order to improve her autonomy. From the point of view of mainstream health care ethics, such compassionate interference may be (but need not necessarily be) seen as undue pressure that violates Mrs. Dekker’s

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10 Cf. Benn’s argument that autonomy is an ideal only available to a plural tradition (Benn 1976).

11 This makes the complexity of the relationship between autonomy and well-being or beneficence even more clear than it has been until now. While autonomy as a right can conflict with well-being, autonomy as a condition can be understood as an aspect of well-being. As mentioned in Chapter 7, autonomy is an item on the list of things that promote individual well-being. Moreover, in a subjectivist theory of well-being like the one developed in Chapter 7, autonomy is also constitutive of well-being, since well-being, by definition, depends on the critically reflected values, goals and self-identity of a person.
Who cares for Mrs. Dekker’s autonomy?

right to self-determination. This judgement would depend on the way in which one went about the attempt to get Mrs. Dekker to accept some assistance. According to the theory of informed consent, there would be nothing against trying to convince or perhaps even persuade her; the only limitation would be manipulation or coercion. However, one of the problems of the informed consent theory is that it leaves room for doubt as to how forceful one may be in trying to convince a patient (What means are justified? When does persuasion become coercion?) or how long one may go on trying.

From the perspective of mainstream health care ethics and its theory of informed consent, many kinds of interventions aimed at getting a patient like Mrs. Dekker to accept some support in order to maintain or restore her autonomy would thus be allowed. So, even though the point of the care view is not merely that such attempts should be allowed but that they are part of the responsibilities and tasks of health care providers, the theory of informed consent and the care view are not necessarily incompatible at this point. If attempts to convince or persuade a patient fail, however, a choice must be made between accepting the patient’s refusal or coercing her. Though the care view does not approve of coercion [Verkerk explicitly remarks that more attention should be paid to the prevention of coercion], it is not clear beforehand whether from this perspective coercion can ever be justified with an appeal to the ideal of autonomy. This is a very relevant question in such fields as psychiatry where the forced use of anti-psychotic or anti-depressive drugs will undoubtedly enhance and improve many patients’ autonomy skills. As discussed before, the generally accepted view in health care ethics is that coercion is only acceptable if the forced treatment will prevent serious harm and the patient is judged to be incompetent. Judgements about such cases are thus made largely dependent on criteria in regard to competence, as well as to several questions concerning the seriousness of the expected harm. Why would the disturbance of a person’s autonomy or autonomy skills be harmful? How great could this harm be? Can a certain therapy restore autonomy to such a degree that the benefits outweigh the harm of the coercion itself? Unfortunately, I cannot explore all these questions here, but I believe that one important difference between the care perspective and a more liberal view that is relevant at this point lies in the appreciation of sovereignty. The case of Mrs. Dekker makes it clear that people can value making their own decisions even if these decisions are not reasonable, well-considered or based on their authentic values. Mrs. Dekker rejected her physician’s suggestion to negotiate about

12 More attention to prevention does not subtract from the necessity of rules or guidelines for cases of conflict. I believe the right to self-determination remains indispensable as a final constraint on the good intentions of caregivers (Schermer 2000). Though the care view focuses on many subjects that remain underexposed in an ethic of rights and duties, it does not provide the necessary safeguards in cases of conflict or abuse of power. Attitudes of attentiveness and responsiveness (Tronto 1993) may be appealed to, but they cannot be enforced in the same way a right to self-determination can. This is one reason to believe that the care view and a rights-based view should be seen as complementary.
taking the medication because she simply wanted to decide for herself. She did not want anyone to discuss her values with her or to help her find out what would be best for her. She just wanted to make some decisions by herself. Perhaps this wish for sovereignty is even stronger in situations in which people have already lost a great deal of control over their own lives (cf. Collopy, Boyle & Jennings 1991, see also Chapter 10). Mrs. Dekker's resistance and non-compliance may have been the only way in which she felt she could retain some self-determination and control and the only way in which she could still keep her own life in her own hands. Though sovereignty may not be equally important to everybody or equally important in every situation, it is a very fundamental value that is protected by the right to self-determination. The care perspective tends to undervalue or even disregard this sovereignty aspect of autonomy.

9.7 Summary and conclusions

The term 'autonomy' can be used to refer to a psychological condition: a condition which is never fully attained but functions to a large degree as an ideal or as something to try to live up to. Recently, such a view on autonomy has been brought forward by proponents of an ethic of care. The ideal of autonomy is interpreted here mainly in terms of self-governance in accordance with authentic values and goals. This can be reached by introspection and critical self-reflection and by examining how different actions, values and goals are appropriate to one's self-image, one's self-identity and one's integrity. It is argued that autonomy is something we can only develop and attain through interaction with others who can help us develop and exercise the necessary skills and show us worthwhile values and goals. These relationships with others can also foster and enhance the self-trust and the self-respect that are both part of our autonomous selves and necessary conditions for further development.

Illness and disease can disrupt a patient's autonomy and necessitate her renewed reflection on values and goals. Restoring, maintaining and perhaps even enhancing autonomy in such situations of existential crisis is an active process that can and should be supported by health care professionals, and that involves coping with the consequences of disease and with questions about values, goals and meaning. I have argued that although care-for-autonomy is not one of the primary goals of somatic hospital care,

13 The care perspective, however, does offer some starting points for appreciating the value of sovereignty. Making one's own choices, even if they are non-authentic, stupid or harmful can be conducive to self-respect and self-esteem and can thus indirectly enhance autonomy skills. Moreover, the possibility to learn from one's foolish or mistaken decisions also offers an opportunity to improve the exercising of autonomy skills such as self-reflection, introspection, self-understanding and the like. Just as we cannot do without others to develop and enhance our autonomy, we cannot do without practice, without learning from our mistakes and without the self-respect that comes from doing or choosing at least some things by ourselves.
Who cares for Mrs. Dekker's autonomy?

it does deserve more attention and should be offered to patients if necessary, either because the disruption of the patient's self-image and self-identity causes suffering or because it hinders the patient's decision-making. This kind of care is not the kind of care that physicians are best suited to provide, but they should be alert to these kinds of problems. Disciplines such as social work, medical psychology or pastoral care would be the obvious caregivers here.

One problem associated with the care view is that although autonomy is defined in procedural terms, it is simultaneously associated with a substantial view of the good life in which connectedness and interdependence are central. Different views on the good life can sometimes be discussed with a patient, or brought to her attention, but because of the differences in power between the patient and the caregiver, this should be done with great caution.

Finally, I examined the tension between autonomy as a right to self-determination and autonomy as an ideal of authenticity, and concluded that such an ideal should not be imposed or forced on patients. The care view tends to do so, probably because it undervalues sovereignty.

9.8 Preview

In this chapter, I have explored what patient autonomy can mean in a hospital setting, apart from making decisions or giving consent. This question was prompted by the observation that many patients are not very eager to be involved in medical decision-making. While the care view on autonomy inspired me to redirect my attention from decision-making to concepts such as self-development, self-reflection, self-adjustment, and self-respect, my empirical observations shifted my focus from medical decisions to the smaller and apparently less significant decisions concerning everyday life.

As mentioned in the initial analysis of my empirical material in Chapter 5, I noticed that having some control over their own situation and their daily life in the hospital was important to many patients. Since autonomy, globally understood as the right to make one's own decisions and the capacity to do so, need not be exclusively associated with determining the course of one's life over longer periods of time but can also be interpreted as having control over the day-to-day affairs of daily life, this appeared to be an aspect of autonomy relevant to hospital practice. The next chapter will therefore address the issue of control.

More or less opposed to control is trust. During the analysis of the empirical material, it struck me that patients frequently justified or explained their lack of involvement in medical decision-making with an appeal to their confidence and trust in their physician(s). Trust thus seems to diminish patient participation, control and autonomy. The issue of trust has not received much attention or elaboration in medical ethics. In as far as it is discussed at all, it is treated with a certain ambiguity. On the one hand, trust is considered to be an important aspect of the physician-patient relationship, while on the other hand the docile, trusting patient is seen as being little autonomous. Therefore, in the next chapter, the issue of trust will be discussed next to that of control.