Chapter 8

Citizenship and autonomy in Acquired Brain Injury

‘I’m getting tired from the battle between the things they want and believe and I want and believe’

(quote of a patient, participating in the study as described in this chapter)

Karen Schipper
Guy A.M. Widdershoven
Tineke A. Abma.

Abstract

In ethical theory, different concepts of autonomy can be distinguished. In this article we explore how these concepts of autonomy are combined in theory in the citizenship paradigm, and how this turns out in the practice of care for people with Acquired Brain Injury (ABI). The stories of a professional caregiver and a client with ABI show that the combination of various concepts of autonomy in practice leads to tensions between caregivers and clients. These dynamics are discussed from a care ethics perspective, stressing the importance of relationships and interdependence, as well as paying attention to various, sometimes conflicting, perspectives in a deliberative dialogue.
Introduction

Autonomy is a key principle in nursing ethics. It is associated with freedom of choice and the right to make one’s own decisions. This means that people should be free to decide for themselves, without judgments from others on the quality of the choice.\(^1\) Care ethics have proposed another conceptualization of autonomy, focusing on self-development instead of self-determination. From a care ethical perspective autonomy is not just making decisions, but also finding a way to live in line with one’s values and identity.\(^1\) Moreover, care ethics argues that autonomy is relational, assuming that all people are vulnerable at some time in their lives and therefore interdependent.\(^2\) In this vision people need each other to determine the values that matter in their lives and to be protected from impulses and decisions which are not in line with their identity.\(^3\) In theory, approaches to autonomy are often presented as conceptually different and as if they are conflicting and mutually exclusive.\(^2,3\) Yet, it is also argued that they can be combined in practice, giving priority to the one over the other depending on the situation.\(^1\) The question remains whether and how such theoretical suggestions actually work in practice. In practice nurses and clients also rely on notions of autonomy, albeit not formally defined. How varying and sometimes conflicting notions of autonomy are handled in daily practice remains largely unknown. In this article we explore how this works out and to what sort of tensions this may lead.

We do so by exploring the meaning of autonomy in a case in the context of care for people with Acquired Brain Injury (ABI). Since people with ABI experience serious disabilities, ranging from cognitive impairments to physical limitations, this case example may throw a new light on existing approaches to autonomy. ABI is damage to the brain that is acquired after birth and can result from traumatic brain injury, such as a car crash and non-traumatic brain injury caused by, for example, a brain tumour. The injury can lead to mild or more severe symptoms. These include cognitive deficits like memory problems, but also motor deficits such as paralysis and communication problems. Clients may also develop problems in social interactions, as their understanding of situations and reflexivity become poor, and they can become self centred. Most clients report extreme tiredness. Personality changes or neuropsychiatric symptoms can occur. Even a mild injury sometimes
results in serious disabilities that interfere with a person’s daily functioning for the rest of his or her life.\(^{(4)}\)

In the Netherlands, people with ABI used to live in institutions for intellectually disabled people, mental hospitals or residential homes for older people. As professionals increasingly stressed the particular needs of people with ABI, new specialized residential homes have been developed. Yet, the nurses and other healthcare professionals working within these institutions tend to rely on existing paradigms developed for persons with a mental disability, like person-centred care\(^{(5)}\) and the idea of citizenship.\(^{(6)}\) Especially, the so-called citizenship paradigm has gained popularity in the Netherlands. This paradigm considers people with an intellectual disability as fellow-citizens with the same rights as anyone else.\(^{(6,7)}\) They should be enabled to live in society, to make their own choices and to have control over their lives.\(^{(7)}\) In order to make choices and participate within society, clients require support.\(^{(6)}\) The client, considered as a citizen in his own right, determines by whom, where and how this support is given.\(^{(7)}\)

The citizenship paradigm entails various notions of autonomy. It shows both aspects of self-determination (making own choices) and self-development (participation in society, supported by others). How the citizenship paradigm and its implicit notions of autonomy are actually enacted in the care for people with ABI is the central question of this article. Its purpose is to throw a new light on the various approaches to autonomy. We do so by following an empirical ethical approach. We start off with the story of Ann (pseudonym), a social worker who works for clients with ABI. Ann’s story will be completed with the experiences of Sue (pseudonym) who has ABI and lives in a residential home. Both their stories show what issues arise when working according to the principles of the citizenship paradigm. The stories of Ann and Sue can teach us something about the tensions involved in combining autonomy as self-determination and autonomy as self-development, and about the conflicting perspectives between professionals and clients involved.\(^{(8)}\) We will start with a theoretical analysis of the notions of autonomy in the citizenship paradigm, followed by a description of the research project. Then we will present the stories of Sue and Ann and our analysis of the stories. The article ends with a discussion and suggestions for practice.
In ethical theories of autonomy, two strands can be distinguished. On the one hand, autonomy is associated with control or decision making by the individual without influence or interference from others.\(^1\) According to this view, autonomy implies self-determination and independence:\(^9\) ‘A behaviour is considered to be autonomous if the person acts according to own preferences, interests, and/or abilities and acts independently, free from undue external influence or interference.’\(^{10}\) Autonomy as self-determination can be characterized as negative freedom: the person is free from external interference.\(^{11}\) The opposite, autonomy as positive freedom, means being free to achieve a certain goal.\(^{11}\) This implies having the capacity to direct one’s life according to personal convictions and goals, responding to external circumstances.\(^1\) An aspect of this approach to autonomy is moral self-development or self-realization: ‘Autonomy requires that individuals critically assess their own values and preferences; determine whether they are desirable; affirm, upon reflection, these values as ones that should justify their actions; and then be free to initiate action to realize values.’\(^9\) This requires interaction with others, who can stimulate reflection and foster self-development.\(^{1,3}\) Autonomy as self-determination has become an important value in the care for persons with a disability. This is an improvement compared to the period in which protection and dependency were dominant values. These values led to paternalism and a belittling attitude of professionals towards disabled people.\(^{12}\) Partly in reaction to this situation, the citizenship paradigm was developed. The citizenship paradigm embraces autonomy as self-determination. According to the citizenship paradigm, all people have the right to make their own decisions based on their subjective values. This includes freedom of choice and action regarding personal matters.\(^{13}\) Yet, the citizenship paradigm also entails aspects of autonomy as self-development. It stresses that people should learn to live a meaningful life, and get support in this process from other people. As such the paradigm acknowledges the vulnerability and interdependence as is stressed by care ethicists, while it also envisions the client as citizen who is equal and should be treated equal. Thus, the paradigm actually combines aspects of negative and positive freedom, as well as it combines equality with vulnerability.

One might argue that this combination is desirable, because it may give people with intellectual disabilities and professionals working with them the opportunity
to focus on those elements of autonomy which are most relevant to the situation at hand. Sometimes freedom of choice without interference could be the guiding principle; while, at other moments, the focus could be on developing capacities and jointly finding ways to deal with one’s vulnerability and dependency. Ideally, the citizenship paradigm leaves room for a variety of approaches and for situational adaptation. Yet, the question arises whether and how this balance is actually realized in practice. Are people with ABI and professionals who support them able to find the best approach in a given situation and work together in developing full citizenship?

**Method**

The case study presented was part of a larger project, aimed at the development of an integrative treatment programme for professionals working for clients with ABI. In 2009, we held interviews and focus groups with clients, their family and professionals. We used a conversational interview style, which is appropriate for assembling personal stories. The conversations started with an open question and were further guided by the issues that came up in the dialogue. If the respondents did not address certain issues, we introduced them, based upon a topic list of relevant issues. The interviews were sometimes confronting for the respondents and evoked emotions. By telling their story the respondents were able to give meaning to their lives, selves and identity. Some conversations, like the interviews with Sue, took several sessions, because they were too rich and enervating to finish them in one session. All participants were happy and relieved to tell their story, and to listen to those of others (patients as well as professionals). It gave them a voice and a sense of control. Sue became more aware of her situation, her feelings and values and hence more aware of the possibilities to influence her life. The interviews were empowering for Sue; by talking about her life and her interactions with others and the way she reacts, Sue discovered how her responses evoked and how she could respond and react in an alternative manner to gain more influence. It also helped her and the other clients to hear the stories of the professionals. Sue used to experience the professionals as invulnerable and strong, and by hearing their doubts, she saw the other, vulnerable side of professionals which helped her to understand their points of view and reactions. It made the working relationship more equal. This process of relational
empowerment also occurred among the professionals who began to realize that both professionals and clients are vulnerable and powerful.\(^{(17)}\) The focus groups were organized in order to validate and deepen the information from the interviews and in order to create mutual understanding between clients and professionals. In the focus groups, participants became aware of their mutual uncertainty and vulnerability; this strengthened them to explain their feelings and thoughts and listen to those of others.

All interviews were audio-recorded, transcribed, analysed and discussed in project-team meetings. In the analysis we focused on the particularities of each story, but also paid attention to recurring themes.\(^{(18)}\) This holistic content analysis\(^{(19)}\) aimed to identify recurring themes in a story and their interrelatedness. Next, the recurring themes were related to relevant issues in the literature. We deliberately searched for theoretical notions literature relevant to the themes in the empirical data and compared our findings with theoretical concepts in order to deepen our understanding of the practice under consideration. To check the validity of the interpretations of the interviews, the interviewee received a short summary of the interview and our analysis of the transcript (member check).\(^{(20)}\) Participants were asked to carefully read the analysis, whether or not they recognized it, and to give their comments on it. By doing this we checked our interpretations. When clients were not able to read, we conducted the member check in a face-to-face encounter. For some professionals, including Ann, reading the story was confronting, but they all agreed with the analysis and agreed with the publication of the results in order to improve the practice of care for people with ABI.

The study presented here is a single case study.\(^{(8)}\) The aim was to unravel the unique characteristics of the case and to do this from the perspectives of the participants. We selected the stories of Ann and Sue, because they provide us with a useful learning experience; their stories are full of tensions around the notions of autonomy. Our choice for these stories and our interpretation of them is motivated by the analysis we made of all our material, both the interviews and the focus groups. The stories of Ann and Sue are not the most representative ones, but rather the stories with the largest learning potential.\(^{(21)}\) It is therefore not possible to generalize the findings to a larger population, but, through a thick description of
meaning and context, to provide readers with a vicarious experience, so that they are able to translate the findings from the studied context to their own context.\(^{(18)}\)

**Case study: wrestling with the citizenship paradigm**

The citizenship paradigm was fully embraced in the organization in which the research was done. This organization is specialized in care for people with intellectual disabilities and ABI. The paradigm was implemented in 2006 in a new residential home for clients with ABI. Both Ann, the professional, and Sue, the client, were engaged in this implementation process from the very first start. The implementation process was complicated by financial reductions in Dutch healthcare which resulted in less staff members doing the same work\(^{(22)}\) and other organizational constraints.

**Ann’s story**

Ann is a middle aged social worker who has a lot of experience with clients with an intellectual disability and ABI. She is familiar with the citizenship paradigm and tells us how this paradigm was implemented within the home for persons with ABI in which Ann works together with other social workers and nurses:

‘At first we started, following the citizenship paradigm, with a vision that emphasized enhancing control among clients and the aspect of stimulating the independence of clients as much as possible. We focused on the questions of the clients: the clients asked a question and we supported him or her with this question. We tried to foster the possibilities of our clients and to respect their choices. We didn’t intervene with their choice. Clients indeed told us they wanted to make their own choices. They didn’t want us to interfere. But there was no limit to this; we tolerated everything. Clients became victims of the room we gave them.’

Giving all control to clients without any interference with the content of the choices led to a situation in which professionals lost any say in the caring process while they noticed risks and clients not getting the care they needed. This situation was the beginning of a change in attitude among the nurses and social workers and their way of working. Ann states that they started to determine more, to set limits:
‘We felt helpless. We saw clients making, in our eyes, foolish choices. We felt responsible for them and we were worried and started to control more and more in order to feel better, to avoid risks and because we doubted if clients were capable to be responsible for their choices.’

To handle the situation better and regain control, the staff decided to make arrangements with the clients in order to provide structure and to have something to rely on in their interaction with the clients. Ann says:

‘We implemented the daily work dossier, since people with ABI need structure, intelligibility and an overview. But this tool has become our thing instead of a guide for clients. It is right that clients need a certain structure and intelligibility, but it ended up in an overshooting structure and a strict time-schedule. For clients it is, for example, not important whether you arrive at 7.00 a.m or 7.20 a.m. They care more about communication!’

Also, the staff started to focus more on autonomy in terms of self-care: having to do the things you can do, on your own without any help. Ann explains how this was initially conceptualized as a way to enhance the responsibility among clients, and how it, unintended, changed into a sort of principle:

‘We meant with this, that clients have to make their own decisions and have to take the responsibility for their behaviour and choices. But it has, maybe because of our feelings of powerlessness, changed into something we didn’t want. It became a principle: you have to do everything you can by yourself, without help from us.’

The idea that clients should be self-sufficient created new tensions and challenges, which Ann describes as follows:

‘We had struggles in the morning, since we thought that clients should come out of their beds and follow the pre-scheduled day activities, activities that they sometimes even don’t like. But day activities are part
of the deal, so they have to go to work, just like everybody else. Our clients should, however, have a reason to leave their beds without pushing them. Together we have to find a balance and together we have to set and move limits, but how?’

Ann’s story illuminates the trouble professionals encountered when implementing the citizenship paradigm. Each time the paradigm was adjusted without knowing the consequences, each time new challenges occurred. First, control was handed over to the clients, then control was regained emphasizing that clients should adapt to the structure and be self-sufficient. Let us now have a look how this struggle, to find the right approach to people with ABI, was experienced by the clients themselves.

**Sue’s story**

Sue (born in 1962) was 40 years old, living together with her husband and daughter (2 years), when she was diagnosed with a brain tumour. An operation was necessary to save her life. This was not without risks. The doctors told her that she would not be the same after the operation. Due to the operation, a few months after the diagnosis, she obtained severe ABI. Directly after the operation, Sue was not able to walk, talk, smile or eat and she had problems with her sight. About 7 years later, at the time of the interview, she still needs a wheelchair. Her face is paralysed so she is not able to express her emotions and it is difficult to understand what she says. Besides these problems she has cognitive impairments and is not able to read or write. She has problems with her memory and concentration and feels terribly tired. She does not have the energy to do the things she really wants to do.

Sue’s husband asked for a divorce during her rehabilitation period at a rehabilitation centre. At first, this felt like a rejection, but later Sue realized that it was a good decision, since their relationship had not been good before she got the tumour. In the beginning her little daughter did not want to see Sue, which hurt her tremendously. Nowadays their relationship is good - although, because of her restrictions, Sue is not able to take care of her daughter. She has lived in a specialized habitat for people with ABI since 2006. Before she moved in, she stayed for about half a year in a rehabilitation centre where she learned daily skills. An
important aim of the rehabilitation is to regain one’s autonomy. The goal is to become independent again, as much as possible, without needing help from others. Sue didn’t like the strong focus on learning skills. Performing activities on her own is not that important for her. After the rehabilitation, Sue moved to a home for older people, where she lived for about three years. In 2006, four years after the operation, she moved to her current apartment.

Because of her brain injury and tiredness, Sue has to find a balance between not doing anything and doing too much. She has to adapt constantly, depending on her level of energy at that moment. Her energy level changes from day to day. One day she is able to do (small) things, the other day she is not. This leads to misunderstandings, and sometimes people think that she tries to mislead them. Sue tells us they say things to her like:

‘You are lazy; I am not going to help you. I know you are able to do that, yesterday you did it, so you have to do it again today.’

Sue tells us that she has noticed changes in the home she lives in. Sue moved in three years ago when the home had just opened:

‘Staff members were more easy-going in the beginning and they gave us more freedom. We were allowed to do more and to decide more, in comparison with the current situation. They also helped us more when we asked for help. But suddenly, they started to determine things for me: staff members told me when I was allowed to call for help and when I was not. The daily work file was introduced; it is a dossier with all the arrangements between clients and staff. It is a nice idea in itself, since you know what will happen at different moments during the day. But sometimes the arrangements are handled too strictly. Sometimes you do not want things to happen exactly as they were planned.’

Sue also experiences the staff members as more patronizing:

‘They think that they know what is good for me and sometimes they belittle me. I have to do the things by myself, since, theoretically, I am
able to do so. They put themselves above me but I don’t like that. I want to discuss things. Now they act as if they know everything better! They say ‘we are not going to do that, you are able to do that by yourself’. You have to do everything by yourself, if you’re able to do so, but for me doing things by myself it not that important. I want to make my own choices, and they should help me with making choices and to accomplish these.’

Sue is highly dependent on others given her physical limitations. She is well aware that her choices can be different from those of the staff. Sue reasons that she knows who she is better than anyone else knows her, so she wants to make her own decisions. Professionals stress the value of self-care; that this will help Sue to keep up her skills. So they push her to do whatever she can. For Sue, however, it is more important to have a phone call with a friend; these personal contacts and intimate social relations add to her well-being and quality of life:

‘I want to make my own decisions and stay in control as much as possible. For me it is not that important to wash my own clothes, or always to put my teabag into my mug. For me it is much more important to have a phone call with a friend. I value my friendships highly, and the loyalty of my friends. I am not able to do everything, and I want to choose for myself what is most valuable to me at a particular moment.’

When Sue asks a staff member to put her laundry into the washing machine since she is tired and has to go to physiotherapy later, she tends to get a response like the following: ‘No, you can do that by yourself.’

If Sue then proposes to do her laundry tomorrow, they might say: ‘No that is not possible. Wednesday is your washing day. That’s the agreement, so you have to do it today.’

Sue continues:

‘I was really surprised a few weeks ago when I asked one of the staff members to wash my dishes. Without discussion and commentary she did
it for me. She only said: ‘if it is too much for you to do it right now, I will do it for you’. It should be like that all the times. I really don’t misuse them!’

Given the critical reactions she normally gets, it is difficult for Sue to ask for help, to be responsive to help and to accept that she is dependent. When at last she calls the staff, they often say: ‘Why are you calling me? You can do that by yourself ’ or they say: ‘It is not that important, this question can wait.’

Sue says that she understands they are busy:

‘I know my questions are not always that important in the eyes of other people, but for me they are important at that moment so it makes me feel frustrated and angry; and since I have communication problems I cannot express these emotions in a good manner which makes it all even more difficult.’

Sue’s story shows that the implementation of the citizenship model, while initially creating room for more autonomy, later hampers her being in control of her life. This is not the result of the paradigm in itself, but this is caused by the way staff members interpret and implement the paradigm.

Analysis

The stories of Sue and Ann show that it is not easy to work within the citizenship paradigm when trying to support clients with ABI. The narratives show a development, in which the emphasis is first on the control of the client. Later, professionals take more control since they have problems with the way the freedom of clients works out in practice. Initially Sue has room to make choices, and Ann follows her directions. This seems the logical application of the citizenship paradigm, since it emphasizes the client’s choices. Sue is glad with this policy, but Ann and the other professionals are less so. They doubt whether this is actually the best support. Clients are in charge, but they make choices which in the end are not optimal for their development and integration. They tend to become dependent on the professionals, instead of being able to take care of themselves. In response to
this the professionals change their policy and stop responding immediately to every wish uttered by the clients. They no longer automatically follow clients’ goals, but emphasize that clients should do things themselves and stick to arrangements. While clients were in control at first, now the professionals take over. This seems not in accordance with the citizenship paradigm, but it can be regarded as part of it, since it follows the idea that clients should be supported in making choices in line with their capacities and enabling further development and integration. Clients’ wishes are not immediately obeyed, but challenged in order to develop better choices and foster self-development. Yet, while ideally, according to the citizenship model, clients should be supported in making their own autonomous choices, in practice, the support resulted in control of the professional over the client. The professionals started to determine the lives of clients.

The new policy of the professionals focuses on independence and self-care. Clients should develop the capacity to take care of themselves and organize their lives, so that they are no longer dependent on professional support. Sue’s story illuminates that this definition of autonomy in terms of self-sufficiency is one sided. It emphasizes daily household activities and training of skills, but does not take into consideration embodied and relational aspects of self-development. While having to take care of herself, Sue become so tired that she has no time left for contacting friends. The fatigue isolates her from friends and family, and makes her feel lonely. Sue expresses her wishes to have social contacts and maintain friendships, but finds no hearing for this among her caregivers. Sue is forced to carry out personal daily activities without being able to realize other values in her life. Carrying out activities on an ‘obligatory’ basis leads to a loss of energy and this hinders Sue to realize the values that are important to her and that add to her well-being. Her identity, relationships and value commitments come under pressure, because the staff one-sidedly promotes the value of self-sufficiency and does not enter into a conversation about the diverging perspectives on what is good care in this situation.

The new policy also leads to an emphasis on strict arrangements. The work dossier is introduced as a means to structure life for the clients and to make them more responsible. Initially the focus was on the rights of clients; they should be in control. The professionals had little rights and were not allowed to set any limits.
By introducing the dossier, the duties of clients are emphasized. This is in line with the citizenship model that promotes equality among citizens; everyone should be treated equally and have the same rights. Yet, with the rights, also duties get introduced in the healthcare practice for ABI clients. It is expected of the client that he or she will carry out these duties after they have been negotiated and regulated in the dossier. The dossier thus acts as a sort of formal contract between the professional and client. This leads to formalization and bureaucratization, and leaves little room for adapting the work to the situation at hand and the (changing) needs of clients. Instead of enabling clients to gain more control over their life, the dossier becomes a straightjacket in which they feel trapped. This is clearly expressed by Sue, and recognized by Ann. It leads to tensions between clients and professionals which are not discussed openly and therefore remain unresolved.

This development has emotional aspects as well. At first Sue is confident, and glad that Ann and other professionals respond to her needs. Sue feels personally recognized and acknowledged. Then the professionals become uneasy with the situation, and doubt whether they should always be so cooperative. They also doubt whether the clients make the right decisions. They become more demanding, and expect that clients keep to the arrangements and the schedule as preset in the work dossier. As a consequence of this, Sue becomes doubtful about the right way to express her wishes. Sue feels she lacks the support she needs but does not know how to ask for it in a proper way. Especially since the professionals do not seem to trust her and accuse her of being lazy and manipulative. This evokes strong emotions in Sue as her moral behaviour and identity are put into question. Ann also shows uneasiness about the new regime. Both parties, clients and professionals, lack motivation for working along the new lines. Change is needed, to regain trust and mutual commitment.

In the end, clients and professionals no longer communicate to reach mutual understanding. They lack the flexibility which is needed to adjust to circumstances, and to search for solutions that work for both parties. The emphasis on self-care and rights and duties has resulted in a lack of attention for interpersonal relations of engagement. They have ended up in a struggle over tasks and accuse each other of being distrustful. There is no room for engagement, care, vulnerability, dependency and connection, values emphasized by care.
These aspects of care are important for both Sue and Ann. Ann clearly feels uneasy about the caring relationship with Sue; intuitively she feels this is not good care. Given her disabilities, Sue can only realize her autonomy with the help of others. Only if others take over activities, such as cleaning up the dishes, Sue will be able to do what she values in life. This can be seen as a limitation of autonomy in terms of independence and self-care (negative freedom), but for Sue practical assistance and support is essential in order to live a valuable life. The support of others can be seen as stimulating her autonomy in terms of moral self-development or self-realization (positive freedom). This indicates that stimulating autonomy can go together with dependency. The acknowledgement of vulnerability and dependency creates possibilities for the development of autonomy in terms of self-development. The recognition of the dependency of clients, allows professionals to take over daily activities, which provides the basis for self-direction as well as self-development. By admitting some dependency of clients and by taking over some activities, real autonomy can be improved. (10)

After some time, staff members begin to realize more and more that the legalistic attitude and the focus on self-sufficiency and control is not the right way to foster the autonomy of clients with ABI. As Ann says: ‘together we have to find the balance and together we have to set and move limits, but how?’ From a care ethics perspective, this relational question offers a starting point for finding a way out of the impasse. It opens the way for partnerships and for a joint search for what good care means in this particular situation. Only in this relational context, self-determination and self-development can grow without undermining professional responsibility as well as support.

**Discussion and conclusion**

The citizenship paradigm was partly developed as a critique to the traditional caring relationship of protection, dependency and paternalism which forced the client into a docile role. (12) The citizenship paradigm stresses autonomy in terms of rights and duties and self-determination. By doing this, it overlaps with the more traditional concept of autonomy in terms of negative freedom. Yet, the citizenship paradigm stresses that people should learn to live a meaningful life, and get support in this process. (13) The paradigm thus combines the more traditional
concept of autonomy in terms of self-determination (negative freedom) with the concept of living a meaningful life with the support of others (positive freedom). It legitimizes professionals to assist clients in the most optimal way. In theory the paradigm stimulates professionals to support clients to live their own life without losing the professional responsibility to care for others. Yet from our case study we can learn that it is not easy to work with the assumptions of the citizenship paradigm in practice with persons with ABI. It is hard to find a balance between self-determination (negative freedom) on the one hand and self-development with support (positive freedom) on the other hand. Sue and Ann’s stories show us the tensions involved in this. In their stories, both concepts of autonomy can be recognized. Sue sees autonomy in terms of making one’s own choices without interference of others (negative freedom). She clearly values autonomy as self-determination. Yet, she also stresses that she needs support to be able to build up a meaningful life, and have contact with others. Her need for support and her wish to lead a meaningful life fit well with the concept of self-development. Ann describes that she and her colleagues are willing to respect clients’ wishes (negative freedom). This matches the concept of autonomy as self-determination. Yet, the professionals also feel uneasy with simply obeying clients’ choices; they think clients can make wrong choices, not leading to a better life. Their concerns about clients’ self-determination (negative freedom) are coloured by a concept of autonomy as self-development (positive freedom).

Given that both parties show consideration about negative as well as positive freedom, one would expect that there is a basis for agreement and joint work. Yet, in practice, this turns out to be difficult since their views of a meaningful life differ. Both Sue and Ann’s stories show that the clients are confronted with a one-sided view of a meaningful life: being independent and taking care of oneself. Other values hardly find a hearing and acknowledgement. The focus is on autonomy as being independent. Sue asks for recognition of other, relational, aspects of autonomy: being able to have contact with her family and friends. She also wants recognition for being vulnerable, and not always being able to perform as agreed. She needs support in daily activities, to have enough energy left for interacting with important others. Apart from challenging the value of independence and self-care, Sue is also critical about the dossier system and its logic of rights and obligations. It has created a situation where professionals are not open to
situational needs and do not provide adequate support. The formalistic discourse that comes with the citizenship model somehow prohibits a genuine and ongoing dialogue between client and professional. Care is treated like a stable product that can be planned in advance and measured. In reality chronic care is unstable as needs vary and change over time.

The aspects missed by Sue in the approach of the professionals fit in with care ethics. Ethics of care stresses mutual engagement, vulnerability and dependency.\(^{(25)}\) Care ethics is critical of rules and protocols, which make the relationship between client and professional into a contract with specific rights and duties.\(^{(25)}\) Care should focus on responsibility for oneself and each other in a process of dealing with vulnerability and dependency.\(^{(24)}\) Care ethics is critical of overvaluing independence and having control over one’s life as many of us are not able to live up to that norm. Think of people with dementia and intellectually disabled persons. Autonomy as self-determination is in that sense not inclusive. It denies those people who are not capable to make decisions or to express their moral principles, and overvalues the rational and cognitive basis of autonomy.

Care ethics can also be relevant in that it stresses the need to take into account various perspectives and expectations. The stories of Sue and Ann show that expectations between clients and professionals can and do conflict. This creates tensions in the caring relationship.\(^{(26)}\) These tensions can only be resolved if they are acknowledged and explored. The participants should be aware of differences in expectations and be prepared to negotiate. Not just once to make appointments which are then formalized, but participants should be willing to enter an ongoing dialogue about good care.\(^{(27)}\) The differences that have to be negotiated are not merely differences in view; they entail normative expectations about oneself and the other.\(^{(28)}\) In their interactions people develop shared understandings over what they expect of themselves and others, and vice versa. When (re)defining responsibilities people (re)define themselves, their roles and their relationships. This requires narrative, dialogical and relational work. The specific interpretation of the question ‘who is responsible to whom and for what?’, is context-bound, and depends on the particular circumstances and the people involved in the situation. From a care ethics perspective, a good client-professional relationship requires a process of negotiation and shared understanding about mutual normative
expectations and responsibilities. Mismatches between these expectations lead, like our stories showed, to misunderstandings or conflicts. If caregivers listen to the narratives of identity of clients and engage in a deliberative dialogue about their values they will be better able to attune care to the needs of clients\(^{(26, 29)}\) and respect their autonomy, not just by immediately answering the clients’ wishes, nor by promoting specific values in life, such as self-care, but by developing a joint view on what is important in life at a certain moment in time. Such partnership may empower both professional and client and support clients in realizing a good life.

**Acknowledgments**

We want to acknowledge the willingness of Sue and Ann for telling their story and for their permission to use their stories. We also want to thank those who participated in this study, among them clients, staff and direction of the organization in which the research was done. We also want to thank the other members of the research team and the board of management and direction for funding this project.
References

15. Larson CL. Re-presenting the subject: problems in personal narrative inquiry. 
17. Van der Plaat M. Locating the Feminist Scholar: Relational Empowerment and Social 
   Activism. Qual Health Res. 9; 773-785.
18. Abma TA. Struggling with the Fragility of Life A Relational-Narrative Approach to Ethics 
19. Lieblich A, Tuval-Mashiach R, Zilber T. Narrative Research: Reading, Analysis, and 
20. Meadows LM, Morse JM. Constructing Evidence Within The Qualitative Project. In: 
   Morse JM, Swanson JM, Kuzel AJ (Eds.) The Nature of Qualitative Evidence. 
22. Abma TA, Schipper K. ZZP in de zorg: hoe goede intenties verzanden in 
23. Tronto J. Moral boundaries. A political argument for an ethic of care. New York: 
24. Sevenhuijsen S. Citizenship And The Ethics Of Care Feminist Considerations on 
25. Verkerk M. ’Zorgethiek: naar een geografie van verantwoordelijkheid’ in: Manschot 
   H, van Dartel H (Eds). In gesprek over goede zorg. Overlegmethoden voor ethiek in 
   relationships. Psychology Research and Behavior Management 2009; 2: 39-45
   Responsive evaluation and moral deliberation, Health Care Anal 2009, 17(3): 217- 
   235.
29. Abma TA, Oeseburg B, Widdershoven GAM, Goldsteen M, Verkerk MA. Two Women 
   with Multiple Sclerosis and Their Caregivers: conflicting normative expectations. 