

# Concepts and Issues in Healthcare Ethics



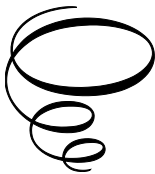
# Concepts and Issues in Healthcare Ethics:

*The ABC of Ethical Care*

By

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*In memory of Theo de Boer (1932-2021), teacher and friend*



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## PREFACE

This book is about theory, primarily philosophical theory, and practice, especially healthcare practice. Theory and practice belong together in several ways. Firstly, philosophical theory can elucidate complex issues in healthcare practice and place them in a new light. Secondly, philosophical concepts can be better comprehended by applying them to practice and examining their relevance for day-to-day life. Thirdly and fundamentally, theory and practice are intrinsically related, as theory develops not in the mind of the philosopher but in the practice of people who experience challenges and together find ways to deal with them, and practice can be understood and improved by theories which express what is important in life and motivate participants to jointly reflect and act.

The theories presented in this book are multiple, coming from phenomenology, hermeneutics and care ethics, to mention the most important philosophical approaches. However, they show family resemblances, being attentive to practical issues and contextual and relational aspects of meaning-making. The cases in this book are based on conversations with participants in healthcare practice, both caregivers and carereceivers. They are situated in different settings: hospital care, general practice care, mental health care, elderly care, disability care, home care. These settings entail diverse kinds of care, but also have similarities, in that participants in the care process have to find joint ways of dealing with vulnerability. Moreover, they are not isolated from each other, as care-receivers come to each setting with previous expectations and keep connected after leaving, and caregivers work together across settings and disciplines.

The examination of theoretical concepts and their application to healthcare practice are motivated by previous work with many colleagues, mentioned as sources. The articles and chapters have not been reproduced but rather used as inspiration. The sources also refer to relevant books and articles of the philosophers who are presented. Given the aim to provide insight into theoretical approaches in an accessible way, focusing on practical relevance, quotations and page references have been omitted. This should not be regarded as a lack of recognition of the solid and detailed philosophical work behind the theories, but as an attempt to introduce the style of thinking

and to clarify core notions which pervade the philosophical approach as a whole.

This book is not structured as an overview of philosophical theories, building upon or criticizing one another. Rather, it takes its departure from ethical concepts and issues as they are encountered in healthcare practice. These are presented alphabetically, implying that there is no logical principle behind the various topics addressed. The essays can be read in any order, inviting the readers to examine an issue which is most relevant to them at a specific point in time, for instance because it presents itself prominently in care practice or is puzzling and deserves to be further scrutinized.

During the research and writing of this book I enjoyed the help of many people. I thank Emma Mulder, Patricia Brinckman and Manal Bouazza for their practical support. I am grateful to the patients, relatives and professionals who participated in Moral Case Deliberation Meetings and joined in individual and group conversations in the context of empirical ethics projects, and were willing to share their experiences and creative perspectives on the ethical issues involved, thus providing material for the cases and input for the theoretical reflections. Colleagues who supported the development of ideas include Yolande Voskes, Suzanne Metselaar, Natalie Evans, Jenny Slatman, Tineke Abma, Bert Molewijk, Ron Berghmans, Annemie Halsema, Margreet Stolper, Josine Widdershoven, Gerben Meynen, Henriëtte van der Horst, Hanneke Hulst, Martijn Huisman, Raymond Ostelo, Michiel Korthals, Joan Tronto, Rosamond Rhodes, Mike Parker, Noam Zohar and Rouven Porz. Many thanks to all. A great debt of thanks to Tony Hope and Ineke Widdershoven.

# AUTONOMY

Autonomy is an important value in society. People should be able to lead their own life and make their own decisions about what is important for them. Autonomy is an alternative to paternalism, which in healthcare was dominant for a long time. The current emphasis on autonomy also raises questions. What to do if persons in need of care make decisions which limit their options for leading a good life? Do such decisions really contribute to their autonomy?

## Case: Back home?

*Anna is 56 years old. She has a mild intellectual disability and has lived for 20 years with other people with an intellectual disability in a house in a village. Because the house needed to be renovated, she moved to a house in a neighbouring village a year ago. She has been told by her former personal caregiver, Betty, that she can return to her home after the renovation.*

*Anna is doing well in her new living environment. She participates in social life and regularly drinks coffee with Clarence, her new boyfriend who lives in an opposite house. She is loved because she helps everyone. Anna's brother Martin and her sister Daisy do not want her to return, because she had little to do in her old environment and saw few other people. Carla, her current personal caregiver, also thinks it would be better if Anna stays where she lives now.*

*Anna regularly asks Carla, "When will my house be ready?" Carla responds by saying that Anna is doing well and that everyone likes her in her new environment. Although Anna agrees that it is nice to live in her current house, she does not change her mind. She says: "I know, but I want to go back to my former house because that was promised."*

*Carla has a meeting with Betty. She says: "It would be better for Anna to stay but I think we should not decide for her." Betty is not satisfied with this conclusion and proposes that she will talk to Anna.*

*The next day, Betty visits Anna and says that it is not a good idea for Anna to return to her old house. Anna says: "But you promised that I would return after the renovation." Betty answers that the promise was a mistake. Anna replies: "Okay, everyone can make a mistake."*

### **Paternalism and respect for autonomy**

Care professionals are trained to help others to maintain their lives and foster their health. They pay attention to what people need and take responsibility for organizing care. Given that care professionals want to help, they may have the idea that they know what is best for the other and may want to guide them like a parent guides a child. This is called paternalism, after the Latin word *pater*, which means father. In the case above we see that both Carla as professional caregiver and Martin and Daisy as family think they know what is best for Anna, which is to stay in the house she currently lives in. They are against the idea that she goes back to her old house, where she had limited options for leading a meaningful life.

Not long ago, paternalism was a normal attitude of caregivers. Care-receivers were regarded as ignorant about their own situation, and in need of guidance. The idea was that in case of a choice regarding care or treatment, the professional caregiver knew the right solution. Often, the care-receiver would not be informed about the options but just be told what was going to be done. In care for a person like Anna, professionals would not even discuss a possible return to her old house and simply ignore or overrule any suggestion in this direction on her part. Nowadays, paternalism is no longer the standard attitude. Tom Beauchamp and James Childress present respect for autonomy as a core principle in healthcare ethics. This implies that care-receivers should be enabled to make their own informed decisions. Although Carla thinks it is best for Anna to remain living in the new house, she does not want to decide for Anna. She wants to respect her autonomy and allow her to make her own decision about where to live. Thus, Carla focuses on explaining the advantages of her current house to Anna and hopes this will make her decide to stay where she is now.

The notion of autonomy implied in Carla's approach entails that people are allowed to make wrong decisions if they know the consequences. Anna should be free to go back to her old house, as long as she knows that this will diminish her options for leading a social life. If this is what Anna wants, it should be accepted. Yet, Carla, like Martin and Daisy, is not happy with Anna's wish, as returning to her old house diminishes the opportunities for

leading a meaningful life. Are there other views on autonomy, which might provide different ways of dealing with the situation?

### **Self-determination and self-development**

When autonomy is conceptualized in terms of making one's own decisions, the focus is on self-determination. Autonomy as self-determination implies that people should be free to make their own choices. According to Isaiah Berlin, this implies a negative concept of freedom: persons are free if they are not influenced by others. Berlin distinguishes this from positive freedom: persons are free if they are able to lead a meaningful life. The latter notion of freedom refers to self-development. The central question is not whether people can choose without interference from others but whether the choices they make contribute to living a meaningful life.

From the perspective of self-determination, Anna has little say in decisions about care. When her house is renovated, others decide where she will live in the meantime. In her new house, she accepts what is expected from her, joining in social activities. She only expresses a clear choice regarding the return to her former house. If one focuses on autonomy as self-determination, Anna's wish to move back to her old house should be acknowledged and prioritized over other considerations.

From the perspective of self-development, Anna's autonomy is enlarged in her new environment. She has more options to join in meaningful activities and is appreciated for helping others. She enjoys drinking coffee with Clarence. If she returns to her old house, the possibilities for leading a meaningful life will be reduced. For the sake of autonomy as self-development, it will be better if she stays where she lives now, even if this would be against her wish to go back to her old house. In trying to convince Anna that in her current environment she is doing well and is liked by everyone, Carla refers to autonomy as self-development.

### **Reflective autonomy**

Autonomy as self-development implies a distinction between what a person incidentally wants and what that person actually values. The difference between incidental wishes and wishes that express more fundamental values can be further explained in terms of the distinction between first-order and second-order preferences, introduced by Gerald Dworkin. A first-order preference refers to something which a person merely wants, a second-order

preference refers to what a person, after reflection, values in life. Take the example of smoking. A person might want to take a cigarette. However, the same person might want to stop smoking, considering that it is detrimental to health. The wish to light a cigarette is a first-order preference; the wish to stop smoking, if well-considered, is a second-order preference. Suppose someone you know has decided to stop smoking and asks you for a cigarette. In that situation, respect for the person's autonomy would not imply giving the cigarette but refusing it, as the decision to stop smoking expresses what that person, after reflection, values in life.

Following the notion of reflective autonomy, it is important to investigate the status of Anna's wish to return to her old house. Is this something she incidentally wants, or is it what she truly values? In stimulating Anna to consider the positive consequences of her new house, Carla aims to foster reflection. Anna agrees that the activities in her current house are valuable. Yet, she emphasizes that returning to her old house refers to a value that is dear to her: promises should be kept. Thus, a reflective approach results in two conflicting values. One of these is experiential, expressing what is important for Anna in daily life. The other is intellectual, referring to what Anna considers as being treated in a right way by caregivers. Looking at Anna's insistence on the latter, it seems that that value is more important to her. Stimulating further reflection will probably not result in a change of mind.

### **Actual autonomy**

Self-development does not necessarily require reflection. George Agich argues that values are developed in daily practice, in which a person actually expresses what is important in life. From this perspective, values are enacted in meaningful patterns of behaviour and practical habits. Being attentive to what matters for a person in daily life and fostering the development of meaningful patterns of action is more important than stimulating critical thinking. Take again the example of smoking. In order to assist a person in stopping, it may not be sufficient to refer to previous reflections about the risk of smoking. Rather, it might be useful to help them to avoid tempting situations and to support alternative behaviour, so that the wish to smoke gradually disappears and they actually get used to a life without smoking.

When applying the notion of actual autonomy to the case above, we can see that Anna has developed a meaningful way of life in her current environment, including helping others and visiting Clarence. Compared to the values which are concretely enacted in her current life, her wish to return

to her former house is abstract. Organizing a move to her former house would mean disrupting Anna's current meaningful habits. The hesitations of Martin, Daisy and Carla can be regarded as expressions of their concerns for Anna's autonomy in the sense of being practically able to live a meaningful life. Following this approach to autonomy, providing arguments to convince Anna that it is better to stay will not really help. Good care implies preventing Anna to move back to her old house and supporting her in continuing practical self-development in her current environment.

### **Relational autonomy**

A third approach to autonomy as self-development focusses on the role of others in developing a meaningful life. Without the attention and assistance of other people, it is difficult, if not impossible, to maintain life and give meaning to it. Autonomy as self-development is not in contradiction with involvement of others but presupposes their concern and support. According to Catriona Mackenzie, this implies a relational view of autonomy. A person does not develop in a vacuum but requires others to flourish. Applying this to the example of stopping smoking, support of others is important. They can stimulate one's decision to stop or remind one of it. By refraining from smoking themselves, they may provide a context in which not smoking is a normal thing to do. They can show solidarity, give assistance during the process and be there when it is difficult to continue.

In the case above, the move to the new house fosters Anna's relational autonomy. By participating in social life and regularly drinking coffee with Clarence, she expresses that relationships are important for who she is and can become. The conviction of Martin, Daisy and Carla that it is best if she stays where she is are in line with a relational concept of autonomy. From the perspective of relational autonomy, it is important not to immediately accept Anna's wish to return to her old house but to establish a relationship of mutual trust and cooperation. Carla, in emphasizing the advantages of staying in the new house, seems to express mistrust in Anna's judgment and her insistence on keeping promises. Betty's approach is different, as she acknowledges that promises are important. She does not imply that Anna's views are wrong but that her own promise was not wise. Rather than ignoring the value that Anna attaches to keeping promises, she creates a basis for mutual understanding and collaboration. Anna's response confirms that promises may be shortsighted and, in that case, need to be revised. The conversation between Betty and Anna thus results in a joint commitment to continue living and fostering development in Anna's current environment.

## Conclusion

Autonomy is a crucial concept in care, since it is important to allow people who receive care to lead their own life based on their own values, which express what is dear to them. However, autonomy can have different meanings. Above, four concepts of autonomy were distinguished. Next to autonomy as self-determination, three approaches of autonomy as self-development were discussed. These four concepts of autonomy have their own merits. Depending on the situation, one of them may be more relevant for the provision of care than another. Sometimes, giving information and allowing people to make their own choice is adequate. In other circumstances, it may be good that the caregiver questions the wishes of the care-receiver by fostering reflection on core values, supporting the development of meaningful patterns of action, or involving relevant others in the process of finding out what matters in life. Ethical care requires awareness of a variety of ways to do justice to autonomy and applying the approach which fits to the situation.

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# BODY

Healthcare involves care for the body. Often, the body is seen as an object of care, which has to be repaired if it does not function well. Yet, our body is first and foremost the vehicle of interaction with the world. We inhabit the world by being in contact with the things around us, touching them and making use of them to orient ourselves and organize our lives. When this process of interaction breaks down, care is needed. This may entail repair of bodily functions, but it also and more importantly means restoration of the interaction with the world. What does care as restoration of the interaction between body and world imply?

## Case: The broken leg

*Bob is 10 years old. He is healthy and active. He likes going to school and playing football. He has a sister, Julie, who is 8 years old. His parents, Christine and Benjamin, combine work with looking after the children, taking them to school and to sports.*

*During breaks at school, Bob plays football with his friends. After school, he attends the football training. He especially likes keeping the ball high.*

*One day Bob falls at the school playground. He screams and is in severe pain. He cannot move his right leg. Benjamin, who works nearby, is called by the teacher and comes to see what is wrong. Together they wait for the ambulance to take Bob to the hospital, where Christine joins them. After a scan, Bob is diagnosed with a broken leg. The leg is put in plaster. Meanwhile, Giulia, Christine's sister, picks Julie up from school and looks after her.*

*Bob, Benjamin and Christine come home in the evening. Bob is in pain and in shock. Benjamin lays him down on the couch, where he will sleep, because he cannot go up the stairs to his bedroom. Giulia makes dinner for the family and brings Julie to bed.*

*The next days, Bob remains confused. His leg hurts, and he can hardly move. He has no appetite and sleeps much of the day on the*

*couch. Benjamin, Christine and Giulia take turns watching over him. The formerly smooth living arrangements of the family are disturbed.*

*After two weeks of staying at home, Bob is doing better. He is accustomed to the plaster and no longer experiences it as annoying. He visits the hospital for a check of his leg. The physician is positive and expects that the leg will heal well. Bob gets crutches and a wheelchair, so that he can learn to move around without straining his leg.*

*Three days later, Giulia comes by to stay with Bob for the day. She is surprised to see him in a positive mood. He shows her that he can move around swiftly with his crutches. He is also able to use the wheelchair by himself. When Julie comes home, they have tea. Bob quickly rolls the wheelchair to the table, making a pirouette. Bob challenges Julie to use his crutches, and they all laugh when she is unable to manage them well.*

*The next week, Bob goes back to school, being driven by Christine in their car. In school, Bob uses his wheelchair to go to the classroom. His friends are glad that he is back and help him to enter and exit the building.*

*After six weeks, the plaster is removed at the hospital. The physician says that the leg is fine, and that Bob can play football again with his team. At first, Bob is still concerned about his leg while playing. After a few trainings, he moves around as before.*

### **The body as object and the body as subject**

In healthcare, the body is often regarded as part of the objective world. This view of the body focuses on physiological responses to causal factors, for instance, the sensation of pain when one burns a finger. The physiological response may be healthy, when pain results in withdrawing the finger from a hot pan and avoiding further damage. Yet, the response may also interfere with normal functioning. The pain may remain after the finger has been withdrawn, and the finger may swell which limits its functioning. In that case, a painkiller and an ointment may be needed to reduce the pain and repair the damage to the skin.

However, the body is not just a part of the objective world. Through our body we experience the world and give meaning to it. According to Maurice

Merleau-Ponty, the body is a subject, involved in embodied engagement with the world. When touching a pan, the finger does not come into contact with the pan in an incidental way. The movement of the hand is part of handling the pan in a meaningful way, for example to prepare a meal. Even when touching a pan seems to be merely accidental, for instance when a child touches a pan on the fire and burns its hand, meaning-making is involved. The child is attracted by the pan and wants to hold it because it is shining or because the child has seen a parent handling a pan before.

Merleau-Ponty characterizes the relationship between body and world as dialogical. The body responds to the world, like a partner in a dialogue answers the question of the other. The response is not caused by the question but motivated by it. In order to explain what motivation entails, Merleau-Ponty gives the example of making a trip. The trip can be motivated by referring to the sights one intends to see. That does not mean that the sights are the cause of the trip but that they provide a reason to make the trip. Referring to the sights is more than giving an intellectual explanation; the sights attract one to make the trip and make one look forward to the future experience. Likewise, a bodily response to a phenomenon is not caused by the phenomenon but motivated, in the sense that the phenomenon provides a reason for the response. It does not causally determine the response but motivates it and gets meaning through the response.

Bodily meaning-making can be regarded as a hermeneutic experience of interpreting the world. According to Hans-Georg Gadamer, hermeneutic interpretation has the character of play. Like a play, interpretation has no underlying cause and no external goal, it is a process of being immersed in meaning-making. In line with Merleau-Ponty, Gadamer emphasizes that meaning-making is neither a causally determined nor an intellectual activity. In explaining the notion of hermeneutic experience, Gadamer refers to the movement of a child bouncing a ball. The bouncing ball invites the child to continue and as such motivates the play. There is an interaction between player and play in which neither of the two causes the other. Although play is not causally determined, it is not random. A play is serious and involves rules. These rules do not produce the play but come about during the play. The play gets a structure through the repetition of the movements. Bouncing the ball creates its own regularity, with variations which are meaningful without being predictable.

In the case above, the views of the body as object and the body as subject are both relevant. In the description of Bob's life, the focus is on the meaningful relationship between body and world. Bob is active and likes

sports. His devotion to football is an example of the dialogical relationship between body and world. The ball is attractive and motivates the play during the school breaks and at the training. During the play, Bob's response to the ball gives force to the ball's motivation. Keeping the ball high is a serious activity which creates a meaningful pattern. When Bob falls at the school's playground, the meaningful relationship with the world breaks down. His leg is no longer part of embodied interaction with the world, as he cannot move it anymore. In the hospital, the leg is treated as an object. The physician observes that it is broken and needs to be repaired. The leg is put in plaster and is literally objectified. The goal of the intervention is to restore bodily meaning-making and enabling Bob to play football again after treatment. The approach of the body as object is an *intermezzo* in the process of bodily engagement with the world.

### **Living with a disability**

According to Merleau-Ponty, the relevance of the body as subject and the embodied interaction with the world become apparent when the process of meaning-making breaks down and the normal way of responding to phenomena in the world comes to a standstill. Take the example of losing a tooth. Whereas the tooth used to be part of the structure of the body and its presence was not noticed during the process of eating, it becomes apparent that something is wrong when the tooth is lost. The loss of the tooth is not just an intellectual conclusion but primarily a bodily experience. The place where the tooth used to be is constantly palpated by the tongue, in an attempt to make sense of the tooth's disappearance. After a while, the cavity becomes integrated in the body scheme, and the absence of the tooth is no longer noticed.

The experience of missing a tooth is a small illustration of what it means to have a disability. In case of an acquired disability, for example the loss of eyesight, the way of meaning-making which previously was taken for granted is painfully disrupted. Whereas the use of the eyes in the interaction with the world before passed largely unnoticed, the absence of the ability to visually orient oneself in the world makes the eyes the centre of attention. Again, this not only implies intellectual deliberation but also and foremost a bodily experience of not being able to see and having to rely on hearing and touching. When the disability is present from birth, there will not be an experience of loss. Yet, also then, the person will have to learn to live with the disability and find a sense of direction by using the other senses and will constantly be aware of being different from other people.

From the perspective of the body as subject, living with a disability involves developing a new way of embodied meaning-making. This can be supported by the use of tools. According to Merleau-Ponty, such tools are an extension of the body. Merleau-Ponty gives the example of a blind person using a cane. The cane serves as an extension of the body, touching the ground and showing the blind person where to go. It does not provide information about the environment which has to be intellectually analysed, but it enables the blind man to immediately make sense of the world. Merleau-Ponty emphasizes that learning to use a tool such as a cane involves a process of habituation. The body becomes accustomed to the tool and the tool becomes part of the body. Because the tool is integrated into the body, it is not a limitation of one's access to the world but the means of communicating with the world.

In the case above, the relevance of the body as subject in living with a disability is visible. Although Bob's disability is temporary, and in that sense not as severe as a permanent handicap, he has to learn to orient himself in the world in a new way. This is a difficult challenge for him. He cannot walk as he used to do and has to learn to move around differently. The plaster, which at first is annoying, gradually becomes a normal part of his body scheme. He learns to handle tools to find his way around. He develops a habitual way of using his crutches and his wheelchair and is evidently more agile in this than Julie. The case also shows that treating a person with a broken leg requires more than putting on plaster. The provision of tools to enable meaningful interaction with the world is equally, if not more relevant as it enables Bob to find his way around at home, go to school and thus continue his life.

### **Disability care**

From a phenomenological point of view, the body can adapt to a disability by developing a new way of meaning-making and integrating tools to enable interaction with the world. This has consequences for disability care. From the perspective of the body as subject, the goal of care is not to compensate for a loss of function but to support the person with a disability in developing ways to deal with the limitations. Whereas a view of care as compensation makes the person with a disability dependent, the view of care as support focuses on helping the person to find a new way of making sense of the world. Blind persons are not supported by continuously taking them by the hand but by enabling them to learn how to handle a cane.

Although disability care should avoid making the person with a disability dependent, this does not mean that the goal of care is independency. Human life implies being related to others and being part of a network of interdependencies. In disability care, professional caregivers often see their work as fostering self-reliance of the care-receiver. Care for people with a spinal cord injury, for instance, tends to focus on fostering their ability to do household activities, so that they can remain living in their own home. Yet, the training in household work can be tiring, so that the person has no energy left to meet with friends or relatives. Although fostering living in one's own home can be regarded as an important goal of care, this should not imply focusing on the ability to be self-sufficient at the expense of having social contacts. The suggestion that a person with a disability should be able to function without any assistance overlooks the relational character of human existence. Rather, care should enable persons with a disability to deal with limitations in a relational context.

In the case above, the relational context of dealing with a disability is clearly visible. Although it is important that Bob learns to move in the house by himself and to go to school, this requires a social network. Giulia assists in the household and prepares meals. Christine takes Bob to school in the car. His classmates help him to access the school building. The organization of these extra activities puts strain on the people involved in the network. Care for Bob requires a context of solidarity and joint commitment.

## **Conclusion**

In healthcare, the body is often regarded as an object which needs to be repaired. However, the goal of repairing the body as object is to restore meaningful interaction with the world. This requires a focus on the body as subject and on fostering new ways of meaning-making, both during and after interventions aimed at repair. Dealing with a disability involves developing new ways of communicating with the world, learning to handle tools and integrating them in the body scheme. Disability care aims to support this process, while paying attention to the relational context of living with a disability.

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# CARE

Care is a central activity in human life. We care for the world in which we live, both our material environment and the people around us. Care also has a normative orientation, it implies that people should have attention and concern for what needs to be done, do it as well as possible and check the outcome. An important area of care is healthcare. What does good care mean in this context? How can care be improved?

## Case: The hairbrush

*Christine, age 82, has dementia. She lives in a nursing home since a year, as her husband Ben is no longer able to care for her at home. Although, according to the policy of the nursing home, pets are not welcome, as an exception she was allowed to bring her pet Guin, a guinea pig. Recently, Guin died, and Christine is often sad.*

*Christine sits in the common living room and suddenly starts crying. Several residents, who sit close to her, show concern but refrain from action. Mary, a resident who knows her well, comes to Christine and asks whether she wants a cup of tea. When Christine accepts, Mary brings the tea and sits down next to her. While drinking her tea, Christine relaxes.*

*After ten minutes, Christine starts crying again. She refuses Mary's offer to bring her another cup of tea. Michael, a professional caregiver, comes to Christine and takes her to a separate room next to the living room to prevent further disturbance of the other residents. She calms down and asks him to get her hairbrush from her room so that she can tidy herself up.*

*When Michael returns with the hairbrush, Christine becomes furious and says: "This is not the right one!" Michael, in turn, becomes frustrated and answers: "I found this brush in your room, and I am not going to get another one; this will have to do." He leaves Christine with the hairbrush and goes back to the living room. Mary has heard what happened and comes to Christine. She asks: "What*



*is wrong with the hairbrush?" In tears Christine explains it is the brush she used for combing Guin; she never uses it on herself.*

*After hearing about the incident from Mary, Ben asks to see Doreen, the manager, to make a complaint. Doreen receives him and explains that she does not understand the complaint, since she has read in Christine's personal file that she became angry when Michael brought her the hairbrush on her request. After Ben has clarified that it was the wrong brush, Doreen says she is sorry to hear that. She also says that she will request Michael to make apologies to Christine.*

### **Care as a central human activity**

According to Martin Heidegger, care is fundamental to our existence and characteristic of how we relate to the world around us. Human existence is not primarily thinking but being engaged with the world. It implies being concerned about something. Care involves both intention and action. Heidegger mentions some examples: producing something, attending to and looking after something, and making use of something. Care can also include social activities, such as interrogating or discussing. In such activities, there is always something at stake. This can be seen in the case above. Both Mary and Michael show concern about Christine. They try to calm her down by making tea or fetching her hairbrush. When Christine becomes furious about the brush, Michael points out that he did find it in her room. This is not merely a statement of fact; for him, his role as professional is at stake. The discussion between Ben and Doreen also shows concern on both sides. Ben is critical about the quality of care provided to Christine, because Michael did not understand her needs. Doreen shows concern for the organization of care, as she refers to the personal file and the professional responsibility of Michael to make apologies.

The central role of care in human life is highlighted by proponents of care ethics. They emphasize that human beings are immersed in a shared world, and that moral insights are contextual and open for improvement through interaction with others, with whom they share relationships of care. Berenice Fisher and Joan Tronto define care broadly as "a species activity that includes everything we do to maintain, contain, and repair our world so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment, all of which we seek to interweave in a complex, life-sustaining web." Compared to the conceptualization of care developed by Heidegger, care ethicists focus explicitly on the relational

nature of care. Care aims at maintaining a shared world. Mary not merely brings tea, she sits next to Christine, expressing that they both live in the nursing home and belong there. By bringing Christine to a separate room, Michael takes into account the needs of other residents in the living room. When complaining, Ben is first of all interested in the well-being of Christine, but his concerns can also be relevant for other residents. In saying that she is sorry and arranging Michael to make apologies, Doreen shows consideration for repair of relationships in the nursing home.

### **Care as process**

Care is not just showing concern; it should also result in meeting the needs for which care is required. If needs are not met, care is not realized, and further action is necessary, based on an investigation of what went wrong. This implies that care is a process, consisting of identification of needs, taking action, evaluating the results and reiterating the identification of needs if the results are not satisfactory.

Tronto identifies four phases in the process of care, which are intertwined, and each require specific ethical qualities. The first phase is caring about. In this phase, someone notices a caring need. This requires the ethical quality of attentiveness. The second phase is caring for. Someone arranges that the caring need is met. This implies responsibility as an ethical quality. Taking responsibility is not the same as actually providing care, which is the third phase, that of caregiving. The ethical quality here is competence. The fourth phase is care-receiving. When care has been provided, it should be observed whether the care needs have actually been met; this requires the ethical quality of responsiveness to the reaction of the care receiver.

The four phases of care can be recognized in the case above. Mary cares about the crying of Christine, takes responsibility and provides care by getting tea; this at first is successful but later turns out to provide only temporary relief, as Christine again starts crying. Michael is attentive to this, takes responsibility, and provides care by taking Christine to a separate room and fetching the hairbrush. However, he lacks competence and is unable to find the right brush. This results in a negative response from Christine. Instead of being responsive and investigating what is wrong, Michael ends the care process. Mary does inquire about Christine's negative response and finds out what the problem is. She takes responsibility by informing Ben, who makes a complaint. Doreen at first lacks attentiveness, as she does not see what caring need is involved, but after listening to Ben takes responsibility for repair by requesting Michael to make apologies.

## **Care as relational practice**

The four phases distinguished above show that care is relational. Care entails interaction between caregiver and care-receiver. This implies that care is not a unidirectional activity of the caregiver. The reaction of the care-receiver contributes to the process of care. Taking responsibility and providing care are relevant, but accepting care is equally important. If the care-receiver refuses care, the process does not come to an end, and it needs to be continued. In the process of care the care-receiver and the caregiver are both vulnerable. The care-receiver has needs which require care; the caregiver may lack the capability to adequately meet the needs of the care-receiver. In the case above, Christine is vulnerable and needs consolation. Michael is also vulnerable, which is visible in his frustration when he is not successful in calming her down. Instead of making explicit his vulnerability by asking Christine why she refuses the care provided, he leaves her with the brush and walks away, ending the care process. This shows that care requires recognition of vulnerability of all people involved. The relational character of care implies that human beings are dependent on each other because they are fragile. Some may be more fragile at certain moments, for instance when they are old and ill, like Christine, but also those who are less fragile and are in a position to take care of others, like Michael, are vulnerable. Michael's vulnerability not only comes to the fore in the lack of success of his care for Christine but is also apparent in Ben's complaint. A complaint makes a care-provider vulnerable to corrective action. In the case above, Doreen asks Michael to make his apologies, which includes expressing one's vulnerability by admitting the mistake.

The relational character of care is not only visible in the interaction between individual caregivers and care-receivers but also in the involvement of other people in the process of care. This is expressed in the definition of Fischer and Tronto, quoted above, which specifies that care implies the weaving of a complex, life-sustaining web. In care, people are interdependent and alternate in giving and receiving care, not just bilaterally but in larger social networks. In order to address the relevance of the wider network of care and the importance of a fair distribution of caring within that context, Tronto adds a fifth phase, caring with, which requires specific ethical qualities, such as trust, respect and solidarity. Central to this phase is securing that caring needs and the way in which they are met are consistent with democratic commitments to justice, equality and freedom for all. The fifth phase of care is relevant for the case above which involves several people contributing to the process of care. With this phase in mind, several questions can be raised. Does Michael have enough time to provide care to the residents in the living

room or is the number of residents too large for him to devote attention to them all? Is Mary's concern for Christine and her support adequately appreciated as a contribution to care in the nursing home? Do relatives, like Ben, have a role in the care process, for instance by joining meals, and do they have a voice in the organization of care? What is the position of the management in organizing care? Does Doreen respect and support Michael when requesting him to make apologies to Christine, instead of doing this together with him? The fifth phase goes beyond the specific care situation. It not only regards the relationships in the nursing home but also the position of nursing home care in a wider societal and political context. Does nursing home care entail adequate arrangements for participation of residents and relatives? Is the social position and payment of professionals in the nursing home sector right?

### **Power and participation**

Care is often identified with being kind and loving. Yet, relationships of care involve issues of power. In the case above, Michael decides to take Christine to a separate room, and Doreen requests Michael to make apologies. Both actions imply a relationship of power. Care ethics emphasizes the role of power relations and underlines that those who are most vulnerable are often less privileged and have less power. In a nursing home, residents have little influence on the organization of care. They are dependent on professional caregivers who decide their daily routines. Often, these routines are shaped in the interest of professional caregivers rather than in those of residents. Activities which structure daily life, such as getting up in the morning, washing, dressing, having meals and going to bed in the evening are adapted to the shifts of professionals. Not only is the time schedule of care activities dependent on professional interests but also the content is defined by professionals. Food options are determined by logistic imperatives. Sometimes, residents may choose between several alternatives but in such cases the choice in general is made one or more days before, with the consequence that the resident might not remember what was chosen when the meal is served.

How can nursing-home care be better aligned with the needs of the people involved, both caregivers and care-receivers? A way to improve the process of care and the division of caring responsibilities is to include all people who are involved in a dialogue about good care. What are the experiences of professional caregivers, care-receivers and family members concerning the process of care? Are their needs met? Are caring responsibilities justly

allocated in the healthcare organization? This dialogue can foster trust and solidarity in the institution. It can serve as a vehicle for a democratic process of assigning responsibilities. A dialogue on good care should give voice to all people concerned. This implies reducing power differences and listening to those who have less power. It requires that care-receivers are allowed to express their views and caregivers are willing to take these seriously. This may lead to interactive improvement of care arrangements, fostering interdependent practices of responsibility.

How can a dialogue about care be organized in the nursing home in the case above? The incident with the brush might serve as a starting point for a wider conversation about the needs of those involved in the process of care. Doreen could organize a meeting with residents and family members about the organization of care in the living room. What to do when one of the residents needs extra attention, for instance because of being emotional, like Christine? Should the professional caregiver call a colleague to take over care of the group? Can other residents or family members who are present contribute to the continuation of the activities in the living room, for instance by serving coffee or assisting in the distribution of the meals? This may lead to a further reflection on the participation of residents and family in the organization of care in the institution. Next, the conclusions of the meeting with residents and family members might be discussed in a meeting with professional caregivers. Do they recognize the experiences of residents and family members? How do they envisage the implementation of the suggestions which have been made? Finally, a joint meeting with residents, family members and professionals might be organized to make plans for future action, including ways to evaluate the results, ensuring active participation of all groups involved.

## **Conclusion**

Care as a central human activity is a process with various overlapping phases. Next to being attentive, taking responsibility, being competent in providing care and being responsive to the reaction of the care-receiver, it entails being aware of interdependency and fostering participation in assigning care responsibilities and solidarity between all who are involved. Improving care practice requires dialogue, giving voice to those who have less power. This may contribute to the further development of democratic care practices and organisations.

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