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The Politics of Care: Dementia and Accounting versus Caring for Mortification

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A patient who refuses food is encouraged, but not forced to eat, even if the refusal might lead to a further deterioration in the patient's condition. This nursing home is reluctant to administer artificial nutrition. [The administration of] artificial nutrition is considered in cases of a disorder from which recovery is possible, but when it is given, it is given for a previously agreed period of time. If recovery does not ensue and the condition does not improve sufficiently for the resident to remain alive without artificial nutrition, this is accepted as a sign of approaching death.¹ [From a directive at Nursing Home Blauwbörgje in Gronigen, the Netherlands.]

In 1997 in the Netherlands, only 13 percent of the nursing homes had established directives relating to (some) medical decisions surrounding the final stages in the life of demented patients. Most of these directives concern the administration of tube feeding, and this reveals the existence of problems surrounding food in the final stage of Alzheimer's disease.² Eating is one of the skills that is affected by dementia. In the course of their disease, demented people encounter increasing difficulties with eating. In the final stage of their lives, this often results in a continuous refusal of food, which presents physicians, nurses, and relatives with the difficult decision whether, and when, to proceed to tube feeding.

In the Dutch public debate on the refusal of food by demented patients, this phenomenon is called *versterving*, which I here translate as "mortification."³ In modern nursing homes, mortification is a quite common way that people with Alzheimer's disease die. In the public debates on mortification, two vocabularies are used alternately to account for it. From a medical point of view, mortification is described as a "disappearing need for food," the "final stage of dementia," a "natural process."⁴ In these contexts, mortification here seems to be a matter of the body. From an ethical perspective, however, mortification is directly related to the question of whether a patient who is refusing food is still competent—a matter of the mind. In this context, food refusal, just like the refusal of other medical treatments, is considered to be an act of will, a more or less conscious choice. Some of the more intermediate positions in the debate try to take both body and mind into account, but do so by switching between the two discourses, not by integrating them. Although the parties in the debate may not be convinced that there is a dichotomy between mind and body, such a dichotomy is still reflected in the vocabularies they use to account for mortification. However, when

observing the daily practices of care in a nursing home and listening to nurses' descriptions of it, neither of the two vocabularies in the discourse seem to apply. In practice, neither the mind-body dichotomy nor the competence-incompetence distinction holds.

When one is *caring* for a patient, however, neither the attribution to body or mind, nor the arbitrary distinction between competence and incompetence, is used. Nurses consider the refusal of food neither as merely the lack of a physical need, nor as a purely conscious action. In the practice of care, mortification seems more like an event, a mixture of action and behavior taking place within a network of other (human and nonhuman) "actors."⁵ This may have some consequences for the notion of rational autonomy (which is considered to be the foundation of informed consent). Could we instead speak of *relational autonomy*—based on, and dependent on, social and material relations? In a case of food refusal, nurses do not assess whether a patient is still competent enough to want anything. To face a patient's food refusal, nurses check and use their entire arsenal of food, other objects, and their social skills to discover whether the patient needs anything. Good care practice might thus consist of an ongoing fine-tuning of human and nonhuman "actors" to the changing needs of the patient who refuses food, while simultaneously unraveling what her or his needs are.

ACCOUNTING FOR MORTIFICATION

Nursing Home Accused of Attempted Murder

AMSTERDAM—Relatives of a 62-year-old man accuses the staff of psychogeriatric Nursing Home Blauwbörgje . . . in Groningen of attempted murder and reported this to the police. The wife and daughter of the patient believe that the nursing home deliberately allowed him to dehydrate, to cause him a mild death.⁶

In summer 1997, the Dutch media had a field day with the theme of mortification. A Mrs. Mulder accused Nursing Home Blauwbörgje in Groningen of attempted murder. Her ex-husband, 62 years old and demented, lived in the nursing home and gradually stopped eating and drinking. His physician and her colleagues decided, considering the circumstances and according to the directives of the nursing home, to accept this as a sign of approaching death. However, when Mrs. Mulder returned from a short holiday and discovered what had happened, she had Mr. Mulder transferred to a hospital where he was tube fed. Some newspapers reported on his first day at his home again, where he was welcomed by his ex-wife and their daughter with a meal of spinach and mashed potatoes and a dessert of custard.

Most of the confusion in the newspapers was caused by the notion of mortification itself: is "to mortify" a transitive verb (something done to the patient by the physician) or is it an intransitive or a reflexive verb: something the patient does (to himself)? The articles that use the first sense are mostly written by journalists. They describe mortification as an active intervention: the physician decides and "commits" mortification. Others (especially physicians) soon tried to straighten out this dreadful vision of mortification-as-policy. According to these writers, to mortify is not to kill, but to die. In this medical discourse, people try to account for mortification by explaining its physical causes. They consider it to be part of dementia: the need for food and drink disappears as the illness progresses.⁷ Whereas these physicians emphasize the sick body and the natural course of the disease, ethicists stress the mind and appeal to moral principles. In their contributions to the newspapers, ethicists define mortification as the refusal of food by patients. It is viewed as an act of will that is, or should be, respected by physicians.

The overall picture in the media is thus that, according to the representatives of the *medical discourse*, ceasing to eat is a matter of the body: the final stage of dementia, a natural process, the disappearing need for food. But physicians also show that an interpretation is involved. There is a process of attribution in cases when food is refused. In the first instance, one looks for temporary, physical causes that may underlie the eating behavior. The refusal of food is ascribed to the body. Only "when that refusal is not incidental and

there is no clear and treatable cause to be found . . . the behavior of the patient can support the decision to not proceed to tube-feeding." Thus, food refusal is a matter of the body, in the absence of any proof to the contrary.

The mind is central to the *ethical discourse*: mortification is the refusal of food and drink. Food refusal, just like the refusal of other treatments, is an act of will, a conscious choice. Ethical problems begin when patients are incompetent; when patients can no longer be held responsible for their decisions. However, even then the starting point for ethicists is that refusers "sometimes have lucid moments" during which they can explain the reason for their refusal.

What is important, within the framework of this article, is that two dichotomies are implicitly being referred to in accounting for mortification. The first is the *mind-body* distinction. Within the medical discourse, physicians adhere as long as possible to a physical cause of mortification, whereas ethicists attribute food refusal, as long as possible, to a mental cause.⁸ Behind this relatively obvious observation lays the assumption of another distinction: the *competence-incompetence* dichotomy. This distinction concerns the decision-making ability of patients, usually with respect to medical treatment. Besides medical professional norms, medical action is also guided by norms derived from patients' rights: patients' wishes and preferences, and informed consent. There can be no medical treatment without patients' permission.⁹ This also holds for demented patients in nursing homes, even after enforced admission.¹⁰ If one takes into consideration that the administration of tube feedings is a medical act, together with the informed-consent requirement, this means that there are three different decision situations regarding the treatment of mortification: (1) the patient is competent to decide, (2) there is doubt as to the patient's competence, (3) the patient is incompetent to decide.

Both dichotomies together form the heart of the account of mortification. When the refusal of food is an act of will (the patient is competent and there is no physical cause), it is a choice that should be respected. Patients are autonomous subjects who bear full responsibility for their actions. However, when mortification might not be an act of will (there might be a physical cause), matters become more complicated. Perhaps then it should be treated by administering food artificially. As long as patients are considered competent, there's nothing wrong. The usual biomedical ethics approach is followed, which starts from the premise of a rational actor, from autonomy and self-determination, from informed consent. When patients refuse treatment, it should be respected; if they agree to treatment, they will be treated. Patients' informed consent is used as a means by which patients themselves are made responsible.

However, as soon as it is no longer obvious whether a patient really is competent, people become uncertain. Boudewijn Chabot, a psychiatrist, states: "When an old, sick cat withdraws into a corner and doesn't touch her food, we accept that she 'wants' to die. When a demented person does the same, we get confused."¹¹ The participants in public or professional practices of accounting nevertheless want a clear, individual allocation of responsibilities. Hence the persistent efforts to attribute mortification to body or mind and to explain food refusal from an emphasis on body or mind. For as soon as—and as long as—an answer is found to the question, "What is going on?" the medical action and the allocation of responsibility that go with it are clear, too. As Jessica Mesman notes, "when facts are not settled yet . . . and we look at how facts are made, it appears that the moral choice is made simultaneously. Prescriptive ethics separates the questions 'What is the case?' 'How do we act?' but they are in fact answered in one and the same process."¹² I would add that, in this process, the question, "Who is responsible?" is answered as well.

However, between the lines of the newspaper articles, one can also read a few other statements—statements that do not fit into the dichotomy of body versus mind. Eating is not just a bodily need; it also has important *social* dimensions. Mrs. Mulder had welcomed her ex-husband home with a meal of spinach, mashed potatoes, and custard. And she visited him twice a day to feed him; out of love and out of a sense of duty. Stopping eating can have social causes too. Thus, Mrs. Mulder wondered whether her ex-husband was homesick. Maybe he had refused food to protest her going on a holiday? These divergent positions are amplified by a few intermediate positions. For instance, one nursing home physician writes that mortification is not about "refusal," but about "not liking" anything to eat, and a colleague describes food refusal as a "decision of the body."¹³

The (rare) occurrence of these divergent and intermediate statements, mostly made by people working in nursing homes, might point to the fact that *accounting* for mortification by using vocabularies that refer exclusively to either body or mind is not in accordance with *caring* for mortification, with experiences from actual caring practice in nursing homes. To see whether this assumption is correct, let's take a look inside a nursing home.¹⁴

MR. VAN DER VELDE

I remember Mr. Van der Velde fell ill quite suddenly. And um. . . . Yes, now I remember: he had pneumonia, and then, presumably because of his fever and a lack of oxygen, his heart started to fail . . . and was not able to pump round all the blood any more and then one gets fluid behind the lungs. That played a part too, that was treated. . . . But actually it all went so fast. We talked it over with his family, that we had the impression that he . . . was not strong enough to make it. And then the very next day he was no longer communicative. However, for a description of when he actually started to refuse drinking . . . I would really need the file. That's what is important to you, of course.

This nursing home physician was right: I was doing ethnographical research on the role of food and drink in nursing homes.¹⁵ The nursing home in question (the same one that was accused by Mrs. Mulder) specializes in psychogeriatric care: caring for, nursing, and treating aged people who suffer from dementia. Alzheimer's disease is the most frequently encountered form of dementia. It begins with loss of memory, but ultimately skills like speaking, dressing, and moving also gradually start to deteriorate. This nursing home provides care that aims at retarding the decline and preserving the skills people still have. Some of the symptoms may be treated, but this is a fatal disease with no prospect of recovery.

The brochure that this particular nursing home hands to its new residents and their relatives assures them that euthanasia (*ending* a life at the request of a patient) is not performed, nor will lives be ended without a request. The nursing home does, however, pursue a careful policy in regarding medical action that *prolongs* life. The booklet explains that there comes a moment when medical acts aimed at improving health become pointless. Then the omission or suspension of those acts is required. The physician will discuss this with the relatives, after which medical care will concentrate on relieving pain.¹⁶

So what about Mr. Van der Velde? I met Mr. Van der Velde when I spent two days on one of the wards in the nursing home. He was one of the 15 residents on this ward. The first thing I noticed was that the nurses give him his coffee in a plastic cup, instead of giving him a coffee cup. And he wears a plastic bib. Every now and then he takes a sip of his coffee. But then he stares straight ahead, his head inclined. Some coffee drips from the corner of his mouth. He does not swallow. Julie, the nurse responsible for life in the living room, sits down next to him and helps him drink. After each sip she reminds him that he should swallow. And when he still does not swallow, she rubs one finger under his chin. In this way, he finally finishes the whole cup.

A few weeks later, when I came back to the nursing home to do some interviews, Mr. Van der Velde had died. When I asked his physician what had happened, he recalled all the medical details of his illness, but wondered when Mr. Van der Velde started refusing drinks. "Yes, he did that way before. . . . Sorry, I don't really remember. A lot of people have the flu, so we concentrate on treating the diseases that prevail at the moment. And then one loses sight of daily matters like this. That's what the nurses know better than us." So I decided to ask Julie, his nurse. Here is the story of Mr. Van der Velde, reconstructed with Julie's help.

For Mr. Van der Velde, drinking is connected to *knowledge*. He takes a sip of his coffee, but doesn't know what to do next. According to his psychologist, part of it is breakdown in the "neurological program" that controls swallowing. "Plus disorders of comprehension. No longer knows what to do with what's in his mouth. He'll look at a cup of tea in utter amazement without recognizing it. As a cup of tea that one can drink. It's almost Roald Dahl-ish." But the psychologist doesn't consider this stage to be food refusal yet. For now, it's just ". . . not knowing what to do with food."

Meanwhile, the nurses do everything they can to get Mr. Van der Velde to drink enough liquid. From the beginning until the very end they take *care* of his food and drink. "One tries one's utmost to get him to drink and to eat."

They soon find out that it is not a problem of taste preference. And in the meantime, the physician has had a look at Mr. Van der Velde's throat. Nothing to be seen. Could it be the liquid consistency of the food then? They try to give him thickened tea, coffee, and yogurt, which is sometimes easier to swallow. But that isn't the solution, either. Rubbing under his chin works for a while, but in the long run, Mr. Van der Velde becomes fed up (!) with it. He won't let them help him any more, and gets angry when they try anyway. Then he falls ill and becomes bedridden. The nurses go to his room dozens of times to bring him drinks. Julie says: "Even if it's just a couple of sips a day, one does try."

But Mr. Van der Velde makes it very clear that none of that's for him. Sometimes he does it verbally: "Get lost!" or "Piss off!" But usually the *communication* on (not) eating is nonverbal. He knocks the cup out of their hands. Pushes the spoon or the plate aside. Often, he communicates *by means of* food.¹⁷ Sometimes he splutters out his drink. Or even spits it in their face. He tightens his lips; one arm stretched to ward them off, the other hand in front of his mouth. He even manages to show via his eating behavior that he prefers some people to others: he doesn't respond well to the people he doesn't like. With others, like Julie, he colluded with their actions: "Sometimes I said something to him in French, like 'Bon appetit,' and then he smiled again."

Then, when Mr. Van der Velde fell ill and became bedridden, they ran out of alternatives to make him eat or drink. Before this, he sometimes would unexpectedly drink a whole cup of Nutridrink (a special nutritious drink for sick people); but that no longer happens. He gets pneumonia and liquid collects behind his lungs. During all this, Julie becomes increasingly convinced that Mr. Van der Velde really does not want any more. Not just because of what he shouts in his anger; she also observes it in his behavior: "Whatever we did, he really wouldn't swallow." Well, what else could they do? Eating or not eating is a matter of *autonomy*, something one has to respect. At those moments it is repugnant to Julie: ". . . to force someone, to make someone drink by coercion. If he really does not *want* to, who am I to . . . hold his nose and shove that cup into his mouth? I just can't."

What matters to the physician is Mr. Van der Velde's physical condition. The psychologist is not sure whether this eating behavior can be classified as food refusal. Losing the skill of swallowing is probably a neurological disorder. But when the elderly man starts closing his mouth and no longer even takes a sip, matters become clearer: "Then it seems more like a refusal." And in the end, Julie knows for sure that Mr. Van der Velde ". . . just doesn't *want* any more."

But what is it that Mr. Van der Velde doesn't seem to want any more? Although part of it might be due to his slowly disappearing appetite, according to Julie it is not just food he refuses. She sheds some light on another possible dimension of his refusal: when demented people become bedridden in the final stage of their illness, and especially if they develop an additional disease, they usually start declining food, and they make themselves clear, either verbally or nonverbally. Julie had witnessed this process very often. However, she thinks Mr. Van der Velde's behavior is ". . . very extreme: being so aggressive that he knocks the drinks out of your hands or even hits you. Then I think: there's so much anger in there, such a conscious . . . not wanting. Because he just doesn't want this situation." Thus Mr. Van der Velde starts to offer resistance: to the care he is being offered in the form of food and to everything that goes with it. To the whole situation. By his resistance to food he resists the whole *network* that goes with it: care, communication, location, sociality, company. He no longer wants to be part of it. As he once said when Julie brings him a drink: "Leave me alone. Can't you just let me die?"

CARING FOR MORTIFICATION

Joan C. Tronto writes, "On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web."¹⁸ Public debates offer us words and dichotomies to account for mortification. But they do not describe what happens in daily care. Attributing Mr. Van der Velde's food

refusal either to body or mind would violate the story Julie told us. And assessing Mr. Van der Velde as competent or incompetent would be to miss the point. For in daily care the point is not how to *account* for food refusal, but how to face it. How to *practice* good care?

First of all, care takes a lot of *persistence*. Julie explains: "One tries to the utmost and to the very end to get that man to drink and to eat." This does not mean that they will force Mr. Van der Velde to drink, but that they continue offering drinks, even after the decision has been made not to proceed to tube feeding. "Abstaining [from administering food artificially] does not mean that we ask the physician whether we have to stop giving food and drink. You don't even talk about that. You just carry on offering them." She repeats over and over: ". . . you just keep on trying."

When caring for a demented person who stops eating or drinking, to keep on trying has yet another sense. It consists of *experimenting* by trial and error: Is it the liquid consistency of the drinks? Is it a matter of taste? Is there a problem with Mr. Van der Velde's throat? Does rubbing his chin work? To which nurse does he respond best? Does it help to say, "Bon appetit"? All possible remedies are tried; "the entire arsenal" is checked and used. Mr. Van der Velde's reactions are observed and his daily care is adjusted accordingly.¹⁹ When a patient can no longer verbally communicate what he wants or doesn't want, good care consists in continuous, creative, and rich experimentation.

The experiments are not about the two options of "forcing" versus "leaving be": not about either administering artificial food as the remedy to a presumed physical cause without considering the possibility of an act of will, or the unquestioned translation of the patient's behavior into wishes, accepting food refusal as a death wish, with no further enquiry. Both options would amount to neglect. No, experimenting in care means *adding*: adding a thickening powder to Mr. Van der Velde's coffee to make it easier to swallow, adding sugar or milk to change its taste, adding a physician to see whether there is a problem with his throat, adding words to encourage and remind him to swallow, adding a finger under his chin to help him swallow, adding Julie rather than another nurse. . . . The list of possibly helpful human and nonhuman "actors" is virtually endless.²⁰

Yet all these human and nonhuman actors do not make Mr. Van der Velde a helpless person, a medicalized object, or a subject with no autonomy: this would imply an individualistic conception of autonomy as being rational, free and independent. What matters in daily care is not rational autonomy (the ideal of rational choice theory), but "relational autonomy," that is based on and dependent on social and material relations.²¹ Human beings are social beings: agents are socially embedded and their identities and capacities, like autonomy, are constituted in interactions with other agents. Moreover, agents are not only embedded socially, but also materially, in interactions with nonhuman actors.²² This becomes especially clear in the context of care practices. Mr. Van der Velde's story illustrates that his autonomy is produced and sustained by experimentation, adding other human and nonhuman actors: nurses, bibs, words, plastic cups, physicians, thickening powder, fingers, tastes. . . . Together they create the conditions for *prolonging his autonomy*.

Besides producing and prolonging autonomy by adding possibly helpful actors, experimentation has another advantage: it *avoids both under- and overinterpretation*. It does not immediately reduce action to behavior (by looking for physical causes only), nor does it interpret any behavior instantly as action (by paying attention only to mental causes). Experimentation helps to *suspend a definite attribution* of mortification to either body or mind. Or, in other words, good care neither objectifies nor subjectifies—it humanizes.

This is why in daily care drawing a distinction between competent and incompetent is not even needed: as long as there is no doubt as to the ability of Mr. Van der Velde to reason, or at least to express a preference or choice, for the nurses there is no motive to consider the possibility of incompetence.²³ And when Mr. Van der Velde's cognitive and communicative skills start to decrease, a definite attribution of action-behavior to only mental or only physical causes is postponed. Even in the end, when Julie is sure that Mr. Van der Velde "just doesn't want any more," she continues to offer him drinks and keeps on trying. She does not diagnose Mr. Van der Velde as either competent or incompetent, once and for all; she doesn't reduce him to either a

subject or an object, but up to the very end continues to experiment and add to prolong his relational autonomy—his *humanity*.²⁴

RELATIONAL AUTONOMY

Over the last few decades there has been a development toward more patient autonomy in healthcare. Dutch law no longer allows any justification for coercive treatment: the right to self-determination overrules considerations of protecting a patient's well-being. The principle of autonomy has replaced the principle of beneficence.²⁵ Competence is seen as the main precondition for making an autonomous choice. Two other preconditions are listed in the doctrine of informed consent: did the patient receive enough information, and did he or she really grasp this; is the patient not being forced to make a choice that is actually not the patient's. Informed consent is considered to be *the* means to achieve and respect autonomy.²⁶ Autonomy refers here especially to self-determination, patients' right to decide whether or not they agree to a treatment. Thus, competence and participation in decision making are central to mainstream biomedical ethics.

This classical style of ethics takes the wishes of patients literally. Wishes are interpreted as acts of will that should be respected without further questioning. However, in daily care, especially as applied to people with Alzheimer's disease, the limitations of this approach are revealed: immediately interpreting food refusal as an act of will and respecting this without taking pains to nurture the resident would be gross neglect. On the other hand, dismissing food refusal as mere behavior based on incompetence, and administering tube feeding without any responsiveness to what the resident may try to communicate, would also be neglect. How can one deal with the principle of autonomy without risking either kind of neglect?

During the brief visit to the nursing home described above, I defined autonomy as based on and dependent on social and material relations. Using this relational conception of autonomy allows one to avoid the shortcomings of the received views that were mentioned above. Theorizing relational autonomy on the basis of ethnographies of daily care for demented people does not focus on competence and decision-making moments. The nurses do not definitely assess whether a resident is still competent enough to *wish* anything; until the very end they add all kinds of human and nonhuman actors to check by trial and error whether patients *need* anything. In this way they prolong residents' relational autonomy—not a given asset, but a continuous achievement.

This observation is in line with an approach of ethics called an *ethics of care*.²⁷ This growing body of theory shifts attention from wishes to needs, and from decision-making moments to the context and content of nonlinear, collective caregiving and care-receiving processes. Reflecting on psychiatry, the care ethicist Marian Verkerk pleads for the introduction of "compassionate interference" as a form of good psychiatric care, because it may help to overcome the dichotomy between coercion and autonomy.²⁸ It prevents situations in which only two strategies remain: leaving patients as they are or using coercion. Likewise, the care given to Mr. Van der Velde was to avoid the two extremes of forcing versus leaving be; objectification versus subjectification; too much versus too little care.

This compassionate interference seems to me a good way to face food refusal, and the people who are trying to account for mortification might learn something from the people who are caring for it. This does not mean that they should never conceptually distinguish between body and mind, or competence and incompetence. But, within daily care itself, and within an alternative kind of accounting that better allies with providing care, it is more helpful to realize that attributions to body or mind are never finite, and that autonomy is not given *a priori*, but is a continuous accomplishment. So I would enter a plea that moral discussion concerning mortification should no longer confine itself to autonomous decision making, to develop a more relational account of autonomy, and to open its mind—and heart—to an ethics of care. My objective in this article is to support care ethics, as well as to add some nonhuman actors to it. I hope this compassionate interference of mine will be fruitful, not only for an ethics of care, but also for the daily care of people with Alzheimer's disease.

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NOTES

1. From the directives of Nursing Home Blauwbörgje in Groningen, the Netherlands.
2. Alzheimer's disease is the most frequently occurring form of dementia. Both terms are often used to refer to the same disease, and so do I in this text.
3. In the English medical vocabulary, the word "starvation" is used. However, I prefer to translate *versterving* more literally, in order to retain some of the Roman Catholic connotations of mortification: abstaining from food and drink—earthly pleasures—to be able to better attend to spiritual matters.
4. These quotations are from articles in Dutch newspapers: "Verpleeghuis ontkent bewust uitdrogen van Alzheimerpatiënt," *De Volkskrant*, 25 July 1997; "Kwaliteit leven moet zwaarder wegen dan durer," *De Volkskrant*, 7 August 1997; "U gaat moeder toch niet uitdrogen?" *Trouw*, 27 September 1997; "Rusdie en 't Blauwbörgje," *Het Parool*, 14 August 1997, and a magazine: "Versterven in Nederland," *De Groene Amsterdammer*, 20 August 1997.
5. On the notion of "event" as a mixture of action and behavior, of making happen and letting happen in a socio-material network, see E. Gomart and A. Hennion, "A Sociology of Attachment: Music Amateurs, Drug Users," in *Actor Network Theory and After*, ed. J. Law and J. Hassard (Oxford, U.K.: Blackwell, 1999): 221-47. This is also where philosophy of action comes in. See for example J. Raz, "When We Are Ourselves: The Active and the Passive," in *Engaging Reason: On the Theory of Value and Action* (Oxford, U.K.: Oxford University Press, 2000): 5-22. For a good overview, see A.L. Mele, ed., *The Philosophy of Action* (Oxford, U.K.: Oxford University Press, 1997).
6. "Verpleeghuis beschuldigd van uitdroging," *De Volkskrant*, 24 July 1997.
7. They do not specify whether this need is physical or psychological, but by linking it to "illness" and "natural course," the need appears to be of a more bodily kind.
8. This reflects the guidelines of the Dutch Board on Decision-Making with Dementia Patients, which say that one should not conclude too quickly that a dementia patient is no longer competent and would no longer have the capability to practice the right to self-determination and—hence—would be incompetent. "Everyone is considered competent until the contrary has been proved." Commissie Besluitvorming bij Demeterende Patiënten (Board on Decision-Making with Dementia Patients), *Medische zorg met beleid; Handreiking voor de besluitvorming over verpleeghuisgeneeskundig handelen bij demeterende patiënten* (Utrecht, the Netherlands: Nederlandse Vereniging van Verpleeghuisartsen, 1997), 15.
9. There are some exceptions to this rule, for example, in case of emergency, but mortification is not considered to be a case of this kind. Further, several varieties of autonomous consent can be distinguished, and surrogate decision making is a way—although not an unproblematic one—to reach decisions for incompetent patients. See T. Beauchamp and J. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York: Oxford University Press, 2001).
10. D.P. Engberts, "De dienstbaarheid van het recht: Het juridische kader van complexe behandelbeslissingen" (The servitude of justice: The legal framework of complex treatment decisions), in *Medisch-ethische casuïstiek; Complexe behandelbeslissingen aan het einde van het leven*, ed. H.M. Dupuis (Leiden, the Netherlands: Boerhave Commissie voor Postacademisch Onderwijs in de Geneeskunde, 1997).

11. Boudewijn Chabot, quoted by Patrick Arink, "Veel discussie over versterving," (Much discussion of mortification), *Tijdschrift voor Verpleegkundigen* no. 15/16 (1997): 448.

12. J. Mesman, "Dwingende feiten en hun verborgen moraal: Over doen en laten in de neonatologiepraktijk" (Compelling facts and their hidden moral: On what is done and left undone in neonatal practice), *Kennis & Methode, Tijdschrift voor empirische filosofie* 20, no. 4 (1996): 393.

13. "U gaat moeder toch niet uitdrogen?" *Trouw*, 27 September 1997; "Rusdie en 't Blauwbörgje," *Het Parool*, 14 August 1997.

14. There are two ways to show the complexities and subtleties of concepts and dichotomies. One is analytical philosophy, the other is *empirical philosophy*, an approach that uses empirical description to generate and/or answer philosophical questions. In this article I choose the latter mode for two reasons: (1) it better suits the attentiveness of care ethics to particulars and context; (2) in attempting to overcome dichotomies—beyond refining them—the complexities of practice often turn out to be rich resources. For arguments on using ethnography in a moral study of mortification, see H. Harbers, A. Mol, and A. Stollmeyer, "Food Matters: Arguments for an Ethnography of Daily Care," in *Sociality/Materiality: The Status of the Object in Social Science*, ed. D. Pels, K. Hetherington, and F. Vandenberghe, in a special issue of *Theory, Culture & Society* 19, no. 5/6 (2002): 207-26. For the broader argument that ethnography can be a valuable approach to studying moral problems in healthcare, see B. Hoffmaster, "Can Ethnography Save the Life of Medical Ethics?" *Social Sciences of Medicine* 35, no. 12 (1992): 1421-31.

15. At the time (1998) I was a graduate student in philosophy, supervised by Hans Harbers and Annemarie Mol. I used the ethnographical field work for my master's thesis. For the publication that followed the thesis, see: A. Stollmeyer, "Voedsel in het verpleeghuis: lichaam, geest of meer?" (Food in the nursing home: body, mind or more?), in *De bindkracht der dingen* (The cohesive power of things), ed. H. Harbers and S. Koenis, in a special issue of *Kennis & Methode: Tijdschrift voor empirische filosofie* 23, no. 1 (1999): 102-28.

16. "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." World Health Organization definition, <http://www.who.int/cancer/palliative/definition/>.

17. In families where one of the children has bulimia nervosa (an eating disorder), many conflicts arise from this kind of caring food. Bulimia may be seen as resistance to this care in the form of food: it is "the passive rebellion of a person who cannot rebel more directly against overprotective, intrusive parents, in a family where eating has special significance." R. Schwartz, M.J. Barrett, and G. Sabe, "Family Therapy for Bulimia," in *Handbook of Psychotherapy for Anorexia and Bulimia*, ed. D.M. Garner and P.E. Garfinkel (New York: Guilford Press, 1985), 280.

18. J. Tronto, *Moral Boundaries; A Political Argument for an Ethic of Care* (New York/London: Routledge, 1993): 103.

19. "The Board on Decision-Making with Dementia Patients is of the opinion that a refusal of a dementia patient, even though this only takes the form of physical defense or resistance, should weigh heavily at all times." Commissie Besluitvorming bij Dementerende Patiënten, *Medische zorg met beleid*, see note 8 above, p. 16.

20. Seducing a patient into eating by offering chocolate is another example; for the argument that with different modes of care come different modes of dying—and of living—see Harbers, Mol, and Stollmeyer, "Food Matters: Arguments for an Ethnography of Daily Care," in note 14 above.

21. Even for healthy people, the model of rational autonomy may not be the most appropriate. For feminist critiques of the classical, individualistic notion of autonomy within moral and political philosophy and for the development of the notion of relational autonomy, see C. Mackenzie and N. Stoljar, ed., *Relational Autonomy; Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford, U.K.: Oxford University Press, 2000). See also B. Barnes, *Understanding Agency: Social Theory and Responsible Action* (London: Sage, 2002) for the argument that it is the inherent sociability of human beings that calls for

another conception of agency: "social," "collective," and "responsible" agency are the notions the author uses. However, in my use of the notion of relational autonomy, I move beyond the humanist conception of interactions of both feminist philosophy and Barnes (above), by including also interactions with nonhuman actors.

22. The symmetrical study of the human and nonhuman actors in science, technology, and medicine is what distinguishes the Actor Network Theory, a relatively recent approach within science and technology studies that blurs the distinctions between the social and the natural, between humans and things. See for example B. Latour, *We Have Never Been Modern* (Cambridge, Mass.: Harvard University Press, 1993); Law and Hassard, *Actor Network Theory and After*; see note 5 above; M. Berg and A. Mol, ed., *Differences in Medicine: Unraveling Practices, Techniques and Bodies* (Durham, N.C.: Duke University Press, 1998).

23. See note 8 above for the moral counterpart to this empirical observation.

24. I do not refer to a humanism that supposes an autonomous subject: like "autonomy," "humanity" is not given *a priori*, but something that is given shape differently in different socio-material practices. Some of the questions I would like to tackle in the near future are about what "humanity," "human" dignity, and (relational) "autonomy" are. Or, more precisely, about how they are *done*: whether and how they are constructed, promoted, sustained, and prolonged—or shortened—in different caring practices.

25. M. Verkerk, "A Care Perspective on Coercion and Autonomy," *Bioethics* 13, no. 3/4 (1999): 358-68. Pellegrino and Thomasma argue for the restoration of beneficence as the fundamental principle of medical ethics in E.D. Pellegrino and D.C. Thomasma, *For the Patient's Good: The Restoration of Beneficence in Health Care* (New York: Oxford University Press, 1988).

26. M. Schermer, *The Different Faces of Autonomy: A Study on Patient Autonomy in Ethical Theory and Hospital Practice* (University of Amsterdam, PhD thesis, 2001).

27. Two classics on care ethics are N. Noddings, *Caring: A Feminine Approach to Ethics & Moral Education* (Berkeley, Calif.: University of California Press, 1984), and S. Ruddick, *Maternal Thinking: Towards a Politics of Peace* (London: Women's Press, 1989). For more recent elaborations of an ethics of care, see, for example, Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care*, in note 18 above, and S. Sevenhuijsen, *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics* (London: Routledge, 1998).

28. Verkerk, "A Care Perspective on Coercion and Autonomy," see note 25 above.