Competing goods and fallacies of care: Moral deliberations at the end of life in the nursing home

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A B S T R A C T

While care is often either implicitly or explicitly conceived in terms of "doing good," the morality of care is more complex than this association would suggest. Nursing home care, in particular, is both characterized by institutional demands for regulation and standardization, and the subjective practices of care workers. These can represent different notions of good care. Based on ethnographic fieldwork among people with dementia, family members and professional caregivers in nursing homes in the Netherlands, I present a case of a resident's sudden death, which revealed a fallacy of care. A fallacy of care refers to an uncritical approach to the "good" in care that overlooks its potentially harmful outcomes. I show that recognizing such fallacies is not only a matter of recognizing the "bad" that may result from "good" care, but of the friction between multiple "goods." In this case, protocols and care practices advocate different notions of the good that coexist, compete, and exclude one another, producing moral distress and forming hierarchical, if contested relations.

Introduction

A nursing home resident, Mr. Bergman, was found dead in the bathroom.[1] It was December 14, and the two caregivers who found him lying on the floor first placed a pillow under his head. Then, contemplating that this was not enough, they moved him from the bathroom and placed him in his bed. In doing so, they acted against the nursing home protocol, which prescribes that, in cases of a suspected "unnatural" death, moving the body of the deceased may only happen with explicit approval of the geriatrician. Whether or not to move Mr. Bergman, and thus whether or not to follow protocol, was a moral consideration in which several values were at stake. The caregivers' response of moving his body, on the one hand, was framed as an act of care, motivated by concerns with human dignity. The protocol, on the other, contained a notion of good conduct that was related to standardized professionalism and accountability. These different "goods" in care (Mol, 2008, Buch 2015), in this case represented by the caregivers' practices and the stipulations in the protocol, were placed in opposition rather than working in complementary ways. Clearly, acting upon one "good," in this situation, precluded the other.

In this article, I discuss Mr. Bergman's case, to demonstrate how pursuing a particular "good" may have harmful outcomes, which I refer to as a fallacy of care (Leibing, 2018; Leibing, 2019). This fallacy emerges from the complexity of a care setting where multiple "goods"

coexist, compete, and exclude one another. I address how well-meant practices can have adverse consequences in light of competing goods. Pursuing a particular "good" can, of course, fail, but I am interested here in practices where doing so stands in tension with other (fallacious) "goods." Hence, fallacies of care are not only a matter of recognizing the "bad" that may result from "good" care, but of the friction between "good" and "good," whereby both are valued from different positionings.

These moral deliberations took shape within the context of nursing home care at the end of life. I conducted 18 months of ethnographic fieldwork in nursing homes in the Netherlands with people with dementia, their family members, and professional caregivers. In the Netherlands, as in many Western contexts, elderly care, and particularly dementia care, is infused with notions of human dignity and personhood. Due to the degenerative character of dementia, dignity and personhood are often considered to be at stake (Kaufman, 2006; Leibing, 2006). Care comes to be directed towards the protection and maintenance of dignity and personhood. Emphasis is placed on person-centered care, and care workers are expected to know the residents in small-scale living arrangements of six residents per unit. At the end of life, the care provided resonates, to a large extent, with palliative care principles (e.g. Sampson, 2010; Van der Steen et al., 2013). Care practices are then oriented towards providing comfort, and the maintenance of dignity is based in the imperative to relieve suffering. A slow

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process of decline implies that, in most cases, the death of a resident is more or less expected. A sudden, unexpected death, such as Mr. Bergman's, is experienced as out of the ordinary, which produces, as I will show, particular concerns and frictions in how to secure dignity and triggers particular institutional demands.

The nursing home is a context that is characterized both by institutional demands for regulation and standardization and by the intersubjective practices of care for elderly people. Long-term care, in other words, is embedded in bureaucracies as well as everyday activities. Ideally, these forms (care protocols and care practices) align well or work in complementary ways. As such, care protocols, including nursing home policies and tools, can offer support to care staff in their everyday practices (Lemos Dekker, Gysels, & van der Steen, 2018). By offering concrete actions, they can provide a sense of control over complex care situations. Further, protocols work to standardize processes within the nursing home, which are often large organizations with high staff turnover and many residents (in Mr. Bergman's nursing home, the psychogeriatric ward alone consisted of about 85 residents). Through standardization, the nursing home policies seek to guarantee certain standards of care throughout the organization.

However, protocols can also fail to address the complexity of a situation in practice. In simplifying the messiness of everyday life in the nursing home, protocols and guidelines encompass many dangers involving inappropriate use and inadequate education. Unsuitable care management on the basis of tools that proclaim to improve care, for example, has been criticized extensively (Kontos, Miller, & Mitchell, 2009; Neuberger, Guthrie, Aaronovitch, et al., 2013). A heavy reliance on protocols detaches care from its concrete practices and "threatens to take the heart out of care" (Mol, Moser, & Pols, 2010, 7). Although I agree with these critiques, my point here is not to write against the use of protocols in general. Protocols are not all-determining, and, in Haeusermann's (2018, 917) words, "it is impossible to create too neat a division between the personal and social (good) on the one hand, and bureaucracy and industry (evil) on the other hand." Care workers do also work around such regulations through selective and contextual rule-breaking, for example when they experience regulations as working against the best interests of residents and what they considered good, personalized care (Kontos, Miller, Mitchell, & Cott, 2010). In such cases, rule-breaking may contribute to quality care. Furthermore, rule-breaking can illustrate how care workers engage with the tensions that can emerge between protocols and practices in the everyday. By elaborating on the case of Mr. Bergman, I underline how the moralities embedded in care protocols and care practices become expressed and relate to each other. As I demonstrate, they might clash and form hierarchical, if contested relations.

The morality of care

Care is often either implicitly or explicitly conceived in terms of "doing good." However, various authors have, in the last decade, demonstrated that the morality of care is more complex than its association with "doing good" would suggest. In her research on the treatment of, and life with, diabetes in the Netherlands, Annemarie Mol (2008) has shown that the morality of care is complex and fragile. Contrasting what she terms the "logic of care" with the "logic of choice," she argues that good care is not a matter of offering patients the possibility to make individual choices. Rather, it involves negotiated and collaborative attunement to their lives and bodies. What is "good," is not fixed and cannot be assessed in general terms, but is embedded in the negotiated context of care practices and their underlying values. Building further on this, Mol, Moser, and Pols (2010, 13) also point to the moral ambivalence of care practices, writing that "good and bad may be intertwined; good intentions may have bad effects; if one looks hard enough any particular 'good' practice may hold something 'bad' inside it (and vice versa)." This ambivalence, Mol (2010) adds, not only emerges from possible intertwinements of "good" and "bad," but also from the friction

between various, plural "goods." Thus, care practices do not appeal to a single, overarching "good," but consist of attuning to a fluctuating morality comprising multiple, and sometimes competing "goods."

This is not to make an uncritical assumption that care is always based on good intentions. Lisa Stevenson (2014), in her work on Canadian policies addressing tuberculosis and suicide epidemics among Inuit, has already decoupled care and good intentions. Care, she shows, can take bureaucratic and biopolitical forms, where it is concerned not with individuals but populations—keeping them alive for the sake of statistics, rather than addressing their needs or taking into consideration what kind of life they live. In a similar line, Ticktin (2011) pays attention to the exclusionary mechanisms of what she calls "regimes of care." She describes a context of immigration in France, wherein exceptions are created for those undocumented migrants who have life-threatening illnesses. While this is based on "a moral imperative to relieve suffering" (2011, 3) and framed in terms of apolitical, humanitarian care, she argues it also keeps otherwise exclusionary politics in place. Both Ticktin and Stevenson highlight the political character of care; beyond unintended outcomes, it may structurally produce harm. The moral project of care thus involves the possibility of its own failure (Seaman, Robbins, & Buch, 2019).

The fallacy I describe here, however, is not simply a question of failure. Rather, I discuss a case where competing goods produce a fallacy of care: an instance where the assumption of good intentions behind care practices and protocols does not resonate well with their combined outcomes. Such a fallacy can be experienced as a failure; when an attempt to care is made that does not succeed, the deliberation of how to act may be experienced as choosing between different forms of wrongdoing. These different notions of the good, as advocated by different actors in nursing home care structures, are always embedded in power relations. In what follows, I elaborate on such an instance of competing goods. While care workers experienced their response as humane care and as the right thing to do, it foreclosed following protocol, which entailed a conception of doing good through a notion of accountability. After elaborating on these two perspectives, I highlight the distress and reflections that emerged from this moral deliberation.

A humane response

"Have you heard about Mr. Bergman?" Andrea, the team coordinator, asked as I entered the ward, on the morning of December 14th. I shook my head. "Well, he died a couple of minutes ago," she said hastily. "The care workers have found him in the bathroom." Together we walked to the unit where the two care workers, Laura and Sonja, were helping one of the other residents getting out of bed. I waited for them at the kitchen table. Once they were ready, they joined me for a cup of coffee and started telling me about what had happened a few moments earlier. Both were visibly affected. Several times, they repeated the sequence of events, as if to make sense of it for themselves, each time adding small details.

Around 7:30 a.m. they heard a strange noise coming from the bathroom. "It was not quite snoring, but also not gurgling," Laura said. They rushed towards it, and found Mr. Bergman lying on the floor, who at that moment clenched his fist as his final movement. Mr. Bergman used to fall or purposefully drop himself to the floor occasionally, Laura explained, and so she had not realized immediately that he was dead. Sonja responded that she did know straightaway. Upon realizing that Mr. Bergman had died, Sonja and Laura took a pillow and placed it under his head "because he lay there on the cold floor." Then they used the mobile hoist that stood in the bathroom to lift Mr. Bergman and place him on his bed. Sonja noted that she found this very difficult. "Maybe it's because I am religious and believe in demons," she said, "but when I heard him making that sound I got very scared. I thought they were coming for us all. So I did not want to touch his body. I only helped to steer the hoist." She took a deep breath, and said, "we handled the situation from what we thought was the right thing to do at the

moment. We acted with our human consciousness. We could not leave him on that cold floor."

Sonja and Laura framed their response to the situation as a "humane response." The practice of first resting his head on a pillow and then placing Mr. Bergman in his bed, was infused with a notion of human dignity. Human dignity, Wilkinson and Kleinman (2016, 161) attest, is dependent on care in the sense that, through care, recognition and value are affirmed. As Kleinman (2009, 293) has noted, caregiving "is a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human." Similarly, Mattingly (2014, 91) has stated that being cared for is central to having a moral standing. This relation between care practices and the maintenance of human dignity does not end when the person dies, as Mr. Bergman's case shows. To the contrary, aftercare and death rituals are of great importance to provide the deceased with a dignified end of life (Howarth, 2007; Robben, 2004). Such forms of care can give shape to the end of life and have an impact on the extent to which a death can be framed as "good" or "bad." In my research, care workers attached great importance to the end of life. "You only get one chance to do it right," they often said, emphasizing that the care they provided in anticipation of, or in response to a resident's death was of great value as "the last thing you can do for someone." In many cases, care workers had cared for residents for several years and felt strongly about providing good care at the end of life. As mentioned above, most deaths in the nursing home were preceded by a gradual decline and more or less expected. The case of Mr. Bergman is exceptional in that his death was sudden. Hence, the possibility of a "good" (dignified) end was significantly premised on the care provided while—and after—he died. To care for Mr. Bergman after he had fallen and died meant attuning to their perception of his needs as a human being.

Care has been conceptualized as the opposite of neglect or disregard (Biehl, 2015; Buch, 2018; Mol, 2008), and contains an imperative to act upon perceived suffering (Mattingly, 2014; Tronto, 1993; Wilkinson & Kleinman, 2016). For Sonja and Laura, leaving Mr. Bergman on the floor—a cold, bathroom floor—would have been precisely this, a form of neglect. This moral imperative to act was also embedded in their professional role within the nursing home. As care workers, they felt responsible for the care Mr. Bergman received. Moving Mr. Bergman from the bathroom to his bed, Sonja and Laura did what they considered the right thing to do, whereby values of human dignity substantiated these practices as "good care." The care workers' response, however, contrasted sharply with the practices prescribed in the nursing home post-mortem protocol and the demands of the geriatrician.

The protocol

Carol, the geriatrician, was very angry when she arrived at the unit, and shouted: "Don't you know the protocol? You should not have moved him!" It was unclear if Mr. Bergman had died due to his fall, or had fallen because he was dying. The mobile hoist in the bathroom had been misplaced and should have been stored in the corridor instead. There was also a laundry cart, and with Mr. Bergman's walker, the bathroom had been cramped. This might have caused Mr. Bergman to fall. When Sonja and Laura found him, he had one leg stretched out over the foot of the hoist. If Mr. Bergman had indeed tripped because of the hoist, his death would be considered unnatural. The protocol Carol referred to, distinguishes between "expected" and "unexpected" deaths and gives specific instructions for cases where a death is considered or suspected to be "unnatural." The document was established by the nursing home to direct the actions taken after a resident had died. It sets general directives on which parties (including care workers, physicians, the coroner, and family) are responsible for aftercare, death rituals, and transport of the body. In the case of an "unnatural" death, the protocol stipulates that "moving and caring for the body may only take place after explicit permission by the geriatrician." The geriatrician, in turn, can only give this permission after an external coroner has been called

in to determine the cause of death.

Such a protocol can offer guidance and support to care workers in situations that are emotionally and morally complex. Through standardization it aims to bring clarity as to what actions must be taken and prescribes moral standpoints (Timmermans & Epstein, 2010, 71). Implicit are particular notions of doing "good" that are linked to transparency, accountability and good care. It enables understanding what happened to learn from mistakes and preventing future incidents, which can be understood as a way of caring for residents. It further involves an assumption that if the protocol is followed, caregivers will have acted correctly. Finding what happened can serve to establish who (if anyone) is responsible for a certain incident. In this way, it could serve to protect the institution and its employees legally (Rodriquez, 2014). Not following the protocol, however, could have consequences for the nursing home in terms of accountability. "This can cause great trouble for the home," Carol spoke sternly at Laura and Sonja. "We may have to involve the police because it may be an unnatural death." Offering an alternative perspective, Sonja noted that Mr. Bergman always stretched out his leg when he dropped himself to the ground, in other words opening up the possibility that he might not have tripped over the hoist. Later on, Carol told me that she and a colleague examined Mr. Bergman and consulted the external coroner. Since Mr. Bergman did not have any bruises or injuries, they concluded that he most likely died of "natural" causes and not due to falling.

Working with protocols can offer a sense of professionalism (Bludau, 2014), and not following protocol can also be framed as being unprofessional. Carol questioned Sonja and Laura's professionalism when she confronted them for not having followed protocol. "And then to be scolded like that. Because that's what it felt like," said Laura, "as if we were treated like little children." The way Carol had approached the care workers, "pointing her finger at us," had been stressful and painful—even more so, as they had meant well in caring for Mr. Bergman. "We did not act with bad intentions, but precisely from a humane point of view," they repeated. The "good" envisioned in the protocol, in prescribing how to handle a situation such as Mr. Bergman's, had seemed immoral to the care workers at that moment. A hierarchy between these competing goods became visible as the care workers were scolded for having responded "inappropriately."

Care and moral distress

If the protocol and the care workers' response presented two competing goods, the nursing home context further complicated this. After the confrontation with the geriatrician, both Sonja and Laura initially returned to their work in the unit. "What can you do? One lady had wet herself and was cold. I just had to continue with the residents." Laura said. Sonja nodded: "I also continued, but between the work it all started to dawn on me, everything that happened." Despite their concern for Mr. Bergman, care for the eleven other residents in the unit needed to be provided as everyday life continued. Sonja reflected that they needed the bathroom to wash the other residents, and that some residents tried to enter the bathroom themselves. Leaving Mr. Bergman there would have caused practical inconveniences and conflicted with the care needs of others. The "good" in care for the other residents complicated this balancing act, even as it provided a practical argument to justify why the care workers had moved Mr. Bergman.

Having to continue their work with other residents in the unit also meant that there was little room for their own frustration and emotions. I asked if there was someone in the organization they could turn to at moments like these, but Laura told me there was not. "It wouldn't be much use to have someone available to talk to next week. It's good to have this conversation now, so we can let it all out and get going again." Sonja agreed: "It's a relief to be able to sit here now and talk it through." She continued telling that the noise Mr. Bergman made was very similar to the noise her father made when he passed away. Even though, as Laura said, "it has been over ten years now," this brought up emotions

that went beyond the events of this morning. They told me they had witnessed many deaths as care workers, but also that "no single death is the same. Even if you do this work for years, it will always be difficult." Care workers in my research were concerned with timing palliative care, observing and responding to pain signals, communication with family, and experiencing the loss of a resident. Particularly difficult in this case were the way Mr. Bergman had died and the circumstances in which it happened. "The difference is that most residents are in bed when they die," said Sonja. Mr. Bergman had lived in the nursing home for four years, and both care workers knew him well. They related how he had still been able to read when he first moved to the nursing home, and how they had seen his condition deteriorate. Several times, he had indicated that he was tired of living. "I think it may be a kind of relief for him," said Laura. "It may be a good death, but the way he died was hard." Having to continue their work in the ward, and the emotional impact of the event, show the messiness in which moral deliberations can take place and in which competing "goods" may have to be apprehended and acted upon.

The impact of this moment can be seen as a form of moral distress: the "experience of knowing the right thing to do while being in a situation in which it is nearly impossible to do it" (Jameton 1984 in Bender et al., 2019, 1). From one perspective, the right thing to do would have been to leave Mr. Bergman where they had found him, which was reprehensible in a situation where they considered his dignity to be at stake. From another perspective, the right thing to do was to lift Mr. Bergman to his bed, which was unacceptable given the nursing home's concerns with accountability. As a result, having to engage with competing goods can be experienced as choosing the lesser of two evils. Doing good becomes nearly impossible as acting upon one "good" inherently evokes the undesirable flipside of the other.

This emotional charge was invoked again during a meeting organized one month after Mr. Bergman's death. This follow-up conversation, the team coordinator Andrea tried to make clear at the beginning of the meeting, was "not meant to point fingers at anyone, but to see what happened and what we might learn from it." She asked Sonja if she remembered what happened the morning Mr. Bergman died, to which Sonja replied: "I am never going to forget that, nor the date of December 14." Sonja retold the story of what had happened that morning. Again, she emphasized the horrific sounds and the anguish she had felt. Both she and Laura had been troubled by what happened and, on top of that, were concerned with having done wrong in not following protocol. She continued telling that "rationally" she knew they should have left Mr. Bergman in place, but that at that moment, "the rationality was gone." Instead, she claimed to have responded "emotionally, he was lying on the floor, and that was inhumane." Throughout the conversation, the care workers framed their response as emotional, contrasting this with the rationality ascribed to the protocol and the knowledge of how to act or, in this case, how not to have acted.

Explaining their response in terms of emotions on one hand substantiated it: emotions form a legitimate and sincere basis from which to act (Lutz, 1998, 11). Pointing to their experience of being overpowered by emotions could justify why they had not acted according to protocol. On the other hand, framing their response as emotional, as opposed to rational, also devalued it: acting emotionally can evoke a sense of unreliability and be seen as a sign of weakness (Lutz, 1998, 64–5). Emphasizing the emotional means that the resulting outcome could be ascribed to the weakness of the individual care workers, rather than fostering acknowledgement for the different perspectives of what would be a good response in that particular situation. In this way, a moral deliberation of different "goods," each with detrimental outcomes, was reduced to a hierarchical dichotomy between emotion and rationality, and a fallacy projected upon the conduct of individuals.

Wrapping up the conversation, three concluding points were made: first, the hoist and laundry basket should not be stored in the bathroom, to prevent such incidents; second, the body of the deceased should not be moved without permission; and third, the geriatrician should communicate in a more gentle way, "even when she is right," in a moment that is already stressful for care workers who have just been confronted with someone's sudden death. While these conclusions were discussed in terms of how to act in such a challenging case in the future, they effectively repeated what had been written in the protocol. "I will think more rationally next time," said Sonja. The hierarchy between "goods" that had temporarily been disrupted by the care workers' response, was reinstated.

Conclusion

In this article I have illustrated the potentially harmful frictions that can emerge from conflicting interpretations of good care in a nursing home setting in the Netherlands. To understand how fallacies of care can emerge from competing goods, it is important to acknowledge that nursing home care encompasses both regulation and the experience and reflections of care workers (Kontos et al., 2010, 126). Both the protocol and care workers' views are infused with good intentions as well as practical considerations. Valued notions of accountability, dignity, responsibility, and indeed care fuse and mingle in everyday practices but, as Mr. Bergman's case demonstrates, may also unexpectedly clash. For the care workers, I have shown, moving Mr. Bergman's body was an act of care, with a concern for dignity and opposite from neglect. The conflicting regulations in the end-of-life protocol prescribe a standardization of care. In doing so, it can choreograph how care workers act in the messy reality of a resident's death. As long as practices and protocol align, these practices tend to be accepted as the right thing to do. When protocols and practices conflict, however, the very question of what is "good" becomes unsettled.

The care workers' acts and the protocol's regulations, I have shown, formed competing goods. What was framed as doing good in one view was incommensurable with the assessment of the good in the other. Based on different sets of values, versions of the good were not understandable in each other's terms. Either way, the care workers would have done "wrong": the situation produced moral distress, evoking feelings of anger, insecurity, and fear among the people involved. Competing goods may be experienced as having to choose the lesser of two evils. While neither protocols nor practices are inherently good or bad (Kontos et al., 2010; Timmermans & Epstein, 2010), the social organization of care reveals how the different goods it encompasses are organized and arranged hierarchically, if contested at times. Furthermore, these competing goods become entangled in the complexity of everyday life in the nursing home, where residents are in need of care and care workers had to continue their work.

To conclude, the fallacy that good intentions (under the rubric of care) will lead to good outcomes is not simply a matter of failing to do good within a certain logic. Instead, such fallacy can better be understood in terms of the different values and positions that care actors, including care workers, institutions, and policies, take on. This could open up the conversation, both in care studies and in practice, as to the intentions and logics behind protocols and practices. This is not to underline when and how protocols fail, care workers fail, or care, generally, fails, but to acknowledge the moral deliberation that substantiates such "failure."

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