Suffering, Agency, and the Value of Early and Late Life

2019-06-27 11:59:28

By

‘Do no harm’ is the first principle in both research ethics and bioethics, conveying an inherent ambiguity in the biomedical imperative to create healthier and longer human lives. As such, both medical intervention and research have always straddled the delicate border between care and violence, exposing how doing good can be easily transformed into or confused with doing harm. This border between care and violence appears even more delicate for people made vulnerable to harm by their proximity to the margins – the beginnings or end-stages – of life. So, how do people who care for people living at the margins experience the tension between care and violence?

To answer this question, in this essay we explore the moral perils of professionals who care for premature infants hovering between life and death, and people with dementia in the last stages of their disease. In both cases, these people are totally dependent on professional care to stay in life, and professionals are totally dependent on interpreting the situation of their charges as premature infants and people with late-stage dementia cannot verbalize their situation. Bringing together ethnographies from a Neonatal Intensive Care Unit (NICU) and a dementia nursing home located in Copenhagen, Denmark, we demonstrate that boundaries between caring and violence are porous. Further, the ways these boundaries are experienced by each group of professionals reveals the different role that notions of suffering play in care practices across the lifespan. In particular, care for suffering not only prompts negotiations of a life worth living, but also of a death worth dying.

Anthropologists Lisa Stevenson (2014) and Miriam Ticktin (2011) have made seminal contributions to what has been termed ‘the darker side of care’ (Ortner 2016; Martin et al. 2015). Writing about the imbrication of violence and care, Stevenson argues that “[s]hifting our understanding of care away from its frequent associations with either good intentions, positive outcomes, or sentimental responses to suffering allows us to nuance the discourse on care so that both the ambivalence of our desires and the messiness of our attempts to care can come into view” (Stevenson 2014:3). Drawing on Stevenson, we take as our analytical focal point the suffering produced by efforts to care for people at the fringe of life; efforts that are indeed associated with ambivalent experiences among those who provide the care. Following Ticktin we ask "how the suffering body comes to be known as such: what does it look like, to whom, and why?" (Ticktin 2011:15). Considering Ticktin's figure of the suffering body as a political device that creates the conditions for care, we trace the agentive role of claims to suffering in decisions about life and death and life-prolonging care practices for infants and people with late-stage dementia.

The NICU

In the most specialized pediatric/neonatal intensive care unit (NICU) in Denmark, advanced medical expertise and technology keep alive infants hovering between life and death. Laura, the second author, encountered Alina during ethnographic fieldwork in this NICU in 2014.[1] Born on time, nobody suspected anything was wrong with Alina's health until she showed signs of developmental delays, four months after birth. By the age of 18 months, she had been admitted to the NICU due to what was believed to be a respiratory tract infection, and put on a mechanical ventilator. Then followed a long diagnostic process and almost three months in the NICU, during which time Alina gradually lost her ability to sit, talk, eat, and breathe on her own. Two months into her admission, the doctors diagnosed Alina with a rare disease, understood to be both incurable and lethal, that was causing her brain, muscles, and spine to deteriorate.

Throughout Alina's time in the NICU, Laura often heard the staff mention how caring and active the infant's parents were, exemplified by the mother's success in feeding Alina to make her grow bigger, against all odds. Indeed, for the NICU staff, Alina's story came to constitute a space for ethical self-reflection (Mattingly 2012:5). For example, Nurse Sarah came to question the ethics of continued care while attending Alina's bedside for several weeks in a row:

> "To justify dragging very sick children through suffering, you need to know that they will eventually have a good life…With Alina we knew for sure that death was the only possible outcome because no cure or treatment exist. Standing there beside her week after week, as we did, watching her getting weaker and worse every day and still having to keep her alive by respirator …we felt it was unethical. With Alina we had a suffering child, she was scared, she was sad, and you could read that in her eyes."

For Sarah, the pain and anxiety she saw in Alina's eyes were partly caused by medical intervention: keeping Alina alive also prolonged the infant's suffering. In this way, attending to Alina transgressed moral standards of what Sarah and her colleagues considered good care. Thus, as professionals caring for a person at the margins of life, they experienced their work as highly ambivalent and messy (Stevenson 2014).

Three months into Alina's hospitalization, the doctors recommended withdrawing life-sustaining treatment. Her parents disagreed with this drastic recommendation. The doctors argued that Alina was suffering unnecessarily without any future prospects of an autonomous life. She would—for the few months or years she might survive—be totally dependent on the help of a respirator to breathe, a probe to eat, and dialysis to clean her blood. Yet, Alina's parents insisted on trying out an experimental vitamin treatment.

In Denmark, according to law, it is the medical doctor's final decision to end life-prolonging treatment (Danish Health Authority 2012). However, doctors are obliged to try to have the parents agree with their decision. Therefore, during the weeks following the doctor's recommendation, several dialogues about Alina's condition and situation took place between parents and staff. The head of the clinic, Dr. Hans, took over the case and correspondence from the doctors who had been responsible for treatment up until this point. Dr. Hans tried to convince Alina's parents that she was in great pain and was not getting any better, doing his utmost to communicate what in his view would be the best act of care for Alina: to let her die. Still, disagreement prevailed.

One day, Dr. Hans made a radical move, asking Alina's father: "When you meet Alina in the next life, what would you tell her if she asked why you kept her alive [in this condition]?" In response, Alina's parents agreed to an increase in pain relief medication, but they remained reluctant to end medical treatment. By invoking Alina's afterlife, Dr. Hans reinforced the fact that her death was inevitable and enacted Alina as an active agent and participant in treatment, who would embrace the decision of welcoming death as the only morally acceptable solution. However, Alina's parents continued to demand active treatment. Finally (and reluctantly), Dr. Hans raised the issue of lack of parental care, in order to end what he and his colleagues believed was severe suffering. In an interview with Dr. Hans, he shared his doubts about the way he communicated this move to Alina's parents: "I chose to categorize the situation as neglect of the child's best interest. Maybe my move was wrong, but I felt it was my only way out, and that the parents' wishes were unethical from the child's point of view." To the parents he said: "To question your ability to protect Alina's best interest would be against all our departmental policies and ideals of parental collaboration, […], but we feel obliged to [do so]." Thus, he redefined the parents' active engagement in caring for Alina’s life as neglect or a violation of the child’s best interest.

Following this dispute, the parents agreed to stop treatment, and the next day Alina was detached from all mechanical life support. She exhaled her final breath shortly after. After a few days, the parents expressed relief, gratitude and pain regarding the loss of their daughter. Thinking with Stevenson, we might conclude that the unceasing effort to keep someone alive—as expressed by Nurse Sarah and made explicit here by Dr. Hans—can “effectively be decoupled from care” (Stevenson 2014:177). Stevenson develops this argument in dialogue with Nancy Scheper-Hughes’ argument that for mothers living in Brazilian favelas, allowing certain babies to die was actually a form of care (Scheper-Hughes 1993). In Dr. Hans’ struggle to convince Alina’s parents to let go of their daughter, he attempted to decouple the act of prolonging life from care. Thus, for Dr. Hans, Alina created a space for understanding care as the opposite of prolonging life. This case suggests that in connection to premature life, death comes to operate as a form of care; death becomes a broker in the tension between care and violence.

The nursing home

How then is life guarded at the other end of the life span, when people with late-stage dementia come to lose the capacities normally associated with personhood, such as autonomy, consciousness, agency and language? In the field of dementia, questions and dilemmas regarding the balance between care and violence, and life and death, are not negotiated or mediated through advanced medical technology, as is the case in the NICU, but rather through everyday, low-tech care practices and the basics of food and drink.

Sun Vale nursing home is a leading institution within the Danish dementia care field. At the time of first author Iben’s fieldwork, 7 residents with very advanced dementia lived in a specialized unit at Sun Vale, where they received around-the-clock care. These residents could no longer speak or move, and were confined to bed or a wheelchair all day long. Thus, these residents were in a comparable condition to Alina: totally dependent on their caregivers to survive. However, unlike the doctors in the NICU, nursing home caregivers have no legal authority to make medical decisions, meaning that the everyday care context for people with dementia is not a space for end-of-life decisions (Danish Health Authority 2014). Rather, caregivers are obliged to ensure that residents receive sufficient amounts of food and drink, take their medication, and stay well-groomed and safe in the nursing home. The focus of caregivers thus turns towards perseverance, as “the value of life becomes the ground from which all efforts and arguments about caring stem” (Stevenson

2014:7-8). Yet the residents in the specialized unit were not able to chew or swallow properly, meaning that the preparation of food and feeding required meticulous care. As most of the residents were unable to manage lumpy food and liquids, caregivers blended meals into a smooth puree and mixed cranberry juice with thickening powder that turned the liquid into jelly. This enabled caregivers to spoon-feed the residents with fluid and minimized the risk of residents choking on the food. To help the residents swallow, caregivers provided jaw massage during meals, sharing their experiences with each other when they discovered new ways of providing food and drinks successfully.

The experimentation, adjustments, and refinements of feeding techniques appeared to prolong lives remarkably in the unit, as half of the residents had lived there much longer than imagined possible by staff (some residents more than four years). Yet due to the profound physical and mental impairment of the residents in the specialized unit, it took them a long time to eat enough food to stay nourished. To counter this problem, the daily leader of the unit asked the kitchen to develop smaller but more energy-dense portions and foods. At the same time, caregivers expressed that when caring for the frailest residents, they doubted the very practice of feeding altogether, as they were uncertain of whether having food was at all in compliance with the assumed wishes of the residents. Said differently, caregivers suspected that the residents' reluctance to eat was not only a cause of impairment; rather it should be interpreted as a conscious or autonomous will to die. In the caregivers' experience, then, keeping patients alive through care work of feeding could sometimes be understood as violence.

This fine-grained balance between care and violence was particularly evident in the care for Ellen, a very frail female resident.[2] The daily leader of the unit expressed the balance this way: "I found it difficult to know for how long I should keep trying to facilitate Ellen's desire to eat food. She got it down the wrong way almost all the time, and she needed to cough it up, yet it still lay down there rattling in the throat. (…) When residents have difficulty in coughing up food, I come to question whether I'm doing the right thing by offering yet another spoonful." Other staff also found it hard to balance caring enough and caring too much for residents during meals, so the caregivers approached the head manager for a solution. Together they settled on a 20-minutes meal agreement, meaning that after 20 minutes of helping residents eat, caregivers should stop with clear conscience. Such a rule constitutes what Charles Taylor (1994) has termed "bureaucratic ways of proceeding" that according to Stevenson "lift the burden of decision or responsibility from us;" and are "designed to mitigate the failure of the state or its agents and to ensure prompt and professional action" (Stevenson 2014:79). Yet despite the moral compass of rules and professionalism, peril prevailed. As another caregiver expressed: “In a situation like [Ellen’s], I think it’s a huge ethical dilemma as my professional standards are confronted with the ethical issues. [Ellen] didn’t find meaning in continuing (…) Had I been another person with another kind of authority or placed higher up the hierarchy, I would presumably have said: ‘Let’s stop now’.”

Like the doctors and nurses in the NICU who felt convinced that Alina would prefer to die, Ellen’s caregivers believed that she would choose death over life could she express herself and act autonomously. Relatives of these frail residents echoed the experiences of caregivers, wishing that their compromised loved-ones would die and have peace. Yet in the field of dementia care, a different kind of entitlement was operating than in the NICU, as caregivers, care leaders and relatives of people with dementia all seemed to agree that independent of the amount and extent of suffering, human beings are not allowed to die from hunger or thirst. Despite the wish of everyone involved to avoid extending the lives of residents like Ellen, there was no way to ethically end life. For professionals caring for people with late stage dementia, this desire to ensure the morally right death was indeed what prolonged life and suffering for the residents. When professionals were unsure whether feeding was in compliance with residents’ wishes, there was no authority which could help them and as a result, caregivers at Sun Vale experienced confusion between care and violation.

Agency and authority at the scene of care

As exemplified by our two cases, the value of agency and autonomous personhood in early life and late life is sometimes unmade and other times confirmed, as NICU and nursing home staff care for people at the margins of life. In the NICU, Alina, the infant suffering without any prospect of long-term relief is entitled to die, whereas in the nursing home, the suffering person with late-stage dementia is entitled *not* to die of hunger or thirst. The enactment of these different entitlements is very closely linked to the care context and the authority of care providers. The suffering infant body rendered through medical facts and technologies and the medical doctors’ authority to deem “unnecessary” and inhumane the suffering of severely compromised infants opens up a space for decision-making and for discontinuing life. In contrast, no such exceptional suffering exits in the everyday nursing home care, prompting no morally mandated response. Instead, the plight of nursing home caregivers to continuously nourish people with advanced dementia prolongs life and suffering in ways that confuse the sense of doing good with doing harm.

In both sites, caretakers of precarious lives are challenged in their perceptions of what constitutes humane care. In early life, doctors’ care for the infants who are suffering without future prospect enables them to end lives. In late life, no authority is in place to judge the state of suffering in people with late-stage dementia as being either acceptable or futile; rather the avoidance of a certain form of death prolongs violence in life. Normally, the infant/child is considered sacred and a symbol of vitality and the future (death in children is considered unnatural); that is, a life worthy of guarding, whereas the person with very advanced dementia in institutional care has reached the 'last station' and is considered ready to die (death is considered natural) (Svendsen et al. 2018). Yet, infants and toddlers with their uncertain futures and the entitlement not to suffer in vain may be let go, whereas the people with late-stage dementia are kept in life. How can that be? Thinking with Ticktin (2011), we suggest that the prematurely born infants come to inhabit the exception in the social construction of suffering bodies, whereas people with dementia constitute the rule. However, while Ticktin identifies a politics of care that allows certain bodies to be identified as morally legitimate and thus worthy of being saved much like the most fragile residents in Sun Vale, in the NICU, our conclusion is opposite in sign. Here necropolitics—defined by Achille Mbembe as the power and the capacity to dictate who may live and who must die (Mbembe 2003)—is operationalized by claims to care and protection. Our comparisons between the NICU and nursing home produce not only vivid images of what Ticktin identifies as ways in which care and compassion can push bodies in need of care into life, but also how care and compassion can push them out of life.

From what perspective is an act considered caring or violent? How to respond when well-intentioned care constitutes the violating act? As mentioned in the introduction, bioethics searches for guidelines describing morally correct ways of responding to dilemmas of violation. Our ethnography, however, demonstrates that care and violence co-exist and that the boundaries between them are porous, fluid, and shifting in and of themselves. Moreover, what counts as legitimate responses to suffering depends on caregivers' agency and authority. Paradoxically, maybe, the NICU—aiming at facilitating good beginnings of life—becomes the site in which ambivalent experiences of care as violence facilitate a space for including death in life.

Decades of anthropological scholarship has investigated the inequalities related to differentiated care. The present study widens this horizon. Not only are the processes that exclude humans from life and society important to investigate. Equally worthy of anthropological attention are the processes that exclude humans from death.

Notes

[1] Alina's trajectory (including quotes from health professionals) has been described and analyzed elsewhere, see Navne and Svendsen 2018.

[2] Ellen’s case (including quotes from caregivers) has also been described and analyzed elsewhere; see Gjødsbøl, Koch and Svendsen 2017.

Works Cited

Gjødsbøl, I., Koch, L., and Svendsen, M.N. (2017) Resisting Decay: On Disposal, Valuation, and Care in a Dementia Nursing Home in Denmark. *Social Science & Medicine* 184:116-123.

Danish Health Authority. (2012). Guideline concerning refusal of life-extending treatment including resuscitation attempts, and ceasing of treatment. Number 33, 11/04/2012. https://www.retsinformation.dk/Forms/R0710.aspx?id=141135 [Accessed 05.02.19].

Danish Health Authority. (2014). Guideline concerning refusal of life-extending treatment including resuscitation attempts, and ceasing of treatment, outside hospitals. Number 9025, 17/01/2014. https://www.retsinformation.dk/forms/R0710.aspx?id=161404 [Accessed 05.02.19].

Martin, A., Myers, N. and Viseu, A. (2015). The Politics of Care in Technoscience. *Social Studies of Science* 45(5):625-641.

Mattingly, C. (2012). Moral Selves and Moral Scenes: Narrative Experiments in Everyday Life. *Ethnos* 78(3):301–327.

Mbembe, A. (2003). Necropolitics. *Public Culture* 15(1):11-40.

Navne, L., and Svendsen, M.N. (2018) Staff Experiences of Navigating Decisions in Neonatology in Denmark. Medical Anthropology 37(3):253-266.

Ortner, S.B. (2016). Dark Anthropology and Its Others: Theory Since the Eighties. *HAU: Journal of Ethnographic Theory* 6(1):47-73.

Scheper-Hughes, N. (1993). *Death Without Weeping: The Violence of Everyday Life in Brazil*. Berkeley, Los Angeles, London: University of California Press.

Stevenson, L. (2014). *Life Beside Itself: Imagining Care in the Canadian Arctic*. Oakland: University of California Press.

Svendsen, M.N. Navne, L.E., Gjødsbøl, I.M., Dam, M.S. A Life Worth Living: Temporality, Care, and Personhood in the Danish Welfare State.

American Ethnologist, 45(1): 20–33.

Taylor, C. (1994). Philosophical Reflections on Caring Practices. In: *The Crises of Care: Affirming and Restoring Caring Practices in the Helping Professions*. S.S. Phillips and P.E. Benner, eds. Pp. 174-187. Washington DC: Georgetown University Press.

Ticktin, M. (2011). *Casualities of Care: Immigration and the Politics of Humanitarianism in France*. Berkeley and Los Angeles: University of California Press.

Iben Mundbjerg Gjødsbøl, *PhD, is assistant professor in the Center for Medical Science and Technology Studies, Department of Public Health, University of Copenhagen. Her research explores how medical technologies and clinical practices shape understandings and experiences of health and illness. The present article is based on her PhD research that was part of the research project "A Life Worth Living" led by Professor Mette Nordahl Svendsen at University of Copenhagen.*

Laura Emdal Navne, *PhD, is a researcher at The Danish Center for Social Science Research (VIVE) and a post.doc. in the Center for Medical Science and Technology Studies, Department of Public Health, University of Copenhagen. She has specialized in the social and cultural implications of reproductive and genetic technologies. The research presented in this article originates from her PhD work that was part of the research project "A Life Worth Living" led by Professor Mette Nordahl Svendsen at University of Copenhagen.*

Mette Nordahl Svendsen *is Professor of Medical Anthropology in the Centre for Medical Science and Technology Studies, Department of Public Health, University of Copenhagen. Her research concerns the ethical and existential dimensions of medical science and technology. The present article is based on her research project "A Life Worth Living" (2013-2019) funded by the Danish Research Councils (Sapere Aude grant 12–133657).*

AMA citation
. Suffering, Agency, and the Value of Early and Late Life. *Somatosphere*. . Available at: . Accessed July 16, 2019.

APA citation
. (). *Suffering, Agency, and the Value of Early and Late Life*. Retrieved July 16, 2019, from Somatosphere Web site:

Chicago citation
. . Suffering, Agency, and the Value of Early and Late Life. Somatosphere. (accessed July 16, 2019).

Harvard citation

, *Suffering, Agency, and the Value of Early and Late Life*, Somatosphere. Retrieved July 16, 2019, from <>

MLA citation

. "Suffering, Agency, and the Value of Early and Late Life." . Somatosphere. Accessed 16 Jul. 2019.<>