The Hopeless Hopeful Time of Caring

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In these two chapters we are asked to consider: How does the enacting of care, as a response to the wounding, injury, sickness and fragility of others, generate new forms of vulnerability? Why and how does care fall short, even in environments where there is an expectation that one receives the attention needed to enable care to be provisioned and performed? While there has been considerable scholarship of late focused on what states and conditions of vulnerability do to ourselves and others, these chapters direct us towards what the experience of vulnerability might require of others, when the capacity to care, whether human or institutional, is expected but not provided, or is stretched to its limit. This situation is described through accounts of health-care and the ensuing anticipations and failings of people, systems and infrastructure. Asking how we care, and how we might keep caring while existing in states and systems of exhaustion, sparks a conversation about responses to the experience and witnessing of vulnerability where ethics is framed as an obligation to ‘do something’, even when that doing something might involve more of the same: maintenance, waiting, inaction as a form of activity, or where caring for others might in fact lead to “bad feeling, moments of silence and brittleness” (Muñoz 2009: 14).

The vulnerability of responses to the exposure and wounding of others is articulated through reference to two distinct institutionalised caring systems: The National Health Service in the UK, and the Senior Citizen’s Grant in Northern Uganda. While seemingly different in their disciplinary approach, the two chapters each engage with the paradox of provision: what is needed in order to sustain a life, if even just to provide a little bit more time. The suffusion of violence and ethics permeates the nature and practice of caring, evoking Adriana Cavarero’s (2009) description of vulnerability as involving “two poles of the essential alternative... wounding and caring” (Ibid.: 20). Cavarero suggests that the ambivalence within the condition of vulnerability resides in how the “singular body is irremediably open to both responses” (Ibid.). In Lisa Baraitser and William Brook’s chapter, we see how practitioners working within the NHS are faced with limitations to care provision due to time, funding, and resources; in Lotte Meinert’s chapter, individuals receiving cash are expected to distribute these funds in order to receive care from family members. Even within care it seems there nestles a wound that never quite closes.

For Baraitser and Brook, care is positioned as a challenge to linear, chronological notions of time. Contrary to time being an ever-decreasing resource, where the success of treating illness can depend on detecting and diagnosing ailments often ahead of time, care can, both literally and metaphorically, buy a person time. In this way, care may be a race against time, but it is also simultaneously “a practice that produces time in conditions that are otherwise felt to be stuck and unable to change.” This raises a question as to who has access to this production of time, and in which environments and bodies might such time become a replenishing rather than depleting resource? José Esteban Muñoz (2009) alerts us to the ways in which time discriminates, constricts and normalises, through presenting queerness as occupying its own time and belonging, one that
steps out of “straight time’s” conforming linearity (25). Straight time is “laden with temporal obstacles and challenges that ensure a certain kind of queer failure as axiomatic for the queer subject and collectivity” (173). If certain subjects cannot sustain lives within particular forms of time, and in considering waiting as a method of both losing but also gaining time, it might be useful to ask, as Tavia Nyong’o does, “what’s queer about waiting?” (Nyong’o 2010: 82). Nyong’o reminds us of the temporal positions occupied by certain subjects who are more likely to have to wait: for freedoms, healthcare, acceptance, resources, an apology, and where “the relation of the queer subject to waiting cannot cleanly be divided between refusal and acquiescence” (Ibid.). I am interested in Nyong’o’s understanding of the degree of willingness to wait as occupying a liminal space where time as a property of the self is discharged from the body both willingly and unwillingly in ways that exceed a simple binary explanation of either consenting to the timetable of another, or rebellion. If waiting as a form of queerness is closely connected to anticipation (Ibid.: 83) but also resignation, with continual oscillations between the two leading to the ensuing emotions of hope and frustration, when do we give up on time? When do we decide that we are out of time, or something (or someone) has had too much of our time? If to be patient is to accept or tolerate delays and problems, without becoming annoyed or anxious, then what is the state of mind, or physical experience of delays placed upon particular bodies that are anxious and frustrated? It feels as if at times we exist more readily in this state – what does it mean to be patient with agency? What is waiting when it is tinged with hope and anger?

In this context of this disturbance we might also ask - what’s queer about care? Through the work of scholars such as Muñoz (2009) we can see how the very act of caring might be framed as queer, where queerness is understood as “collectivity” that is “primarily about futurity and hope” (Ibid.: 11). We might see echoes of this form of care in the story of Nakong provided by Meinhardt, where as a grandmother in her 60s, cash transfers became a means of altering a collective future consisting of not only her own but that of her family, “making her life and relations ‘just a bit better’. ” Nakong’s understanding of herself also appears to be based on her temporal and kin relationships to others: being a grandmother is marker of time, and of the quality of that time. Muñoz’s queerness is one steeped in vulnerability, care and belonging, with the time of queerness presenting an “ecstatic and horizontal temporality” providing a “path and a movement to a greater openness in the world” (25). Judith Butler (2018) describes this notion of ecstasy in the work of Muñoz as that “which is precisely a form of standing outside oneself that is also standing with another” (13). These queer lifeworlds that refuse to accept straight time and hold onto the possibility of utopian potential suggest they are built upon foundations of caring - always and by necessity a collective response, and therefore based on relations of dependency (Butler 2016) that are future focused. To care for someone right now is an attempt, however hopeful and futile, to make the future, even if that means just the coming moments or minutes, a little more bearable, “just a bit better.” We can think of how relations of care have always been queered, from those who care for strangers or treat friends as intimates as family members in need of care, to the refusal and rejection of caring for those we know and are supposed to love, precisely because of having that familial knowledge. We can know too much to be able to care. Queering care enables us to view it also as a collective, willful response, where refusal is not a withdrawal but instead might invoke a shift to care of the self, or a means by which to acknowledge different bodily capacities and traumas, where caring for individual and collective others can become harmful to the self over time.
Baraitser and Brook and Meinert task their inquiries with the difficulties of understanding the role of care in communities where there is not enough care to go around without its exhaustion. Caring often involves forms of confronting this exhaustion: in demanding care, resources, attention, and refusals to accept the (un)evenness of its distribution. A theme that transpires across both chapters is the ways in which care-work produces its own vulnerabilities and wears down those who do or may wish to care. What emerges are the costs of caring: what caring takes from a person, in the ongoing obligations to sustain another life, and the ways in which individuals and communities can be depleted by the provision of care. The vulnerabilities that materialise from caring, from the very act of attempting to respond to the precarity and needs of another, are both personal and institutional. In these narratives we also see the depletion of infrastructures resulting from how institutions respond and fail in their responsibilities to the vulnerability of others within their care, and the decisions that determine the cost and value of care. When structures designed to prevent human forms of precarity are themselves made vulnerable the mobility and circulation of vulnerability between individuals and institutions is exposed. The withdrawal of resources and funding make systems unable to function, increasing the precarity of those who need to access such services. Vulnerability becomes a barrier to institutional support, rather than its catalyst. The interplay of movement between institutions and individuals seeking stability and reassurance that consistency and equity of access may provide is disrupted, a rupturing of a relation of dependency that can cause new forms of trauma.

Lauren Berlant (in Evans 2018) suggests that the structure of vulnerability isn’t always felt as vulnerability. Instead it can be felt “as desperation, numbness, realism, misery, mania, rage at others, radical confidence loss, or exhaustion and depletion.” Differentiating structural vulnerability, as well the institutional bodies and actions that enable and create such vulnerability, from the “piercing social atmospheres it generates” can lead to different kinds of conversations about how people live with these particular conditions, experiences and emotions, and how these may differ among individuals and communities (Ibid.). This in turn can help inform discussions about the notion of crisis, and the responses to those who live within such times. In considering as Baraitser and Brook do new forms of vulnerability that emerge from slow forms of care within a health system that is wearing down and wearing out, and the specificities of who is enduring the crisis and how they might do so, Berlant (2011) reminds that “People born into unwelcoming worlds and unreliable environments have a different response to the new precarities than do people who presumed they would be protected” (Ibid. 20). We can return again to Muñoz (2009) and how the experience and responses of those living within straight time might also relate to their expectations of being in a world that needs to be reconfigured in order to live (Berlant 2011: 20). If the NHS is in a “permanent crisis” then how does this feel to those held within these temporalities in requiring forms of care? Berlant puts forward a notion of crisis as “not exceptional to history or consciousness but a process embedded in the ordinary that unfolds in stories about navigating what’s overwhelming” (Ibid.: 10). We can see the potential to be overwhelmed in care, or by the need to care, or for there to be a breakdown of care, as Yasmin Gunaratnam explains, especially in intercultural contexts where experiential as well as “cultural, gendered and generational differences” between those being cared for and carers expose new vulnerabilities (2011: 110). These vulnerabilities include the ways in which certain bodies are prevented from receiving the care that’s needed, when “pain and suffering can become obscured by the attention that is given to what they are rather than also to who and how they are” (original italics; Ibid.: 113).
In her chapter, Meinert develops a conception of vulnerability and its relation to human security after following elderly members of the Ik community in Northern Uganda who receive cash transfers from the state as a means of providing both financial and familial security. For Meinert, vulnerability is a means by which we understand our relational existence through our interdependence with others. This reliance upon family and others interwoven through a relationship of dependency with local and national government is addressed through examining what happens when this familial connection is both altered and defined by money. Waiting plays a role, with family members in Meinhart’s two narratives waiting for the day each month that cash is distributed. What also emerges in these stories infused with the complications of care, is what is expected of those who require it. In order to receive health-care something is offered in exchange – in this case a distribution of resources that may lead to care, but also may produce new forms of vulnerability if that care is not provided.

Outside of the use of physical infrastructure, when, in the context of the Ik community, the nearest hospital is 50km away, responsibility for care becomes folded into the bonds and tensions of community and kin. Transactional forms of care, where people are paid to be responsible, whether as employees or family members, opens up vulnerabilities within those relational dynamics. What if we do not wish to or cannot care, or care enough? While Meinert resists assigning blame for Locham’s death, and perhaps this hesitation is in recognition of the complications of the care transaction – the actions of relatives are left vulnerable to judgements and blame. Here I consider an assumption of ethics attached to the notion of care that we might need to attend to: that we would care for others, if we could. Meinert puts forward that “The ways in which we respond to others’ vulnerabilities rely on our ability to imagine what it is like to be in another person’s situation, and thus on moral, social and political imaginations of care.” Is there a danger to relying on our imagination rather than an uncomfortable acknowledgement that we cannot possibly understand the pain of another in order to act in any way that would ever be sufficient? This may be one point upon which the difficulties of conceptualising and enacting care pivot: Is our propensity to care based on imagining the needs or suffering of others, or, as Sara Ahmed suggests, that an ethics of response instead could involve its own form of vulnerability, in “being open to being affected by that which one cannot know or feel” (2014: 30). In Gunaratnam’s (2011) research on older people, ethnicity and palliative care, she puts forward that this openness might help in the resisting of finding answers or assigning blame when care inevitably falls short. These insufficiencies might shape and give texture to care, where “the responsibility for the inadequacy of an appropriate response is recognized and held rather than being outsourced to the role of cultural difference” (Ibid.: 114). Similarly, the vignettes by Brook that generously and gently let us in to the affective tensions of general practice caring suggest, in the story of J, the inability to understand what another’s life may be like, and the continued attempts to deliver care. Brook in a sense cannot imagine the life of J, for in his imagination, it is “a life that would defeat me after 3 days.”

Familial relations can at times be imagined and figured as being founded on forms of knowledge, that we will care for, and care more for, those we know. But we know equally that familial relationships can be the most harmful, that we are more likely to be wounded by those we know (and love) than strangers. When money enters the equation, or in fact structures a relation into an equation, it complicates the vulnerabilities implicit in forms of intimacy. Refusal to care takes on
different meanings when involving those who we can name, and know something of, where we might well know the implications of our deciding to withhold care. The relationship care has to knowledge, imagination and resources might mean the response is always fraught, always lacking. What these two chapters enable us to see are the inequalities and insecurities of care provision—that we can’t always care in ways we’d like to, that at times we have to refuse to do so, and the difficulties in assigning responsibility when forms of care, or our understandings of care as responsibility, fail. These failures weigh heavily on bodies within this relation, both those that respond and those that might be waiting (and hoping) to receive. And yet we appear to want to remain within a hopeless hopeful time (Muñoz 2009), where people mean to care but either cannot or fail in its delivery, and where we don’t always mean it when we say “I’d like to see you again.” It is equally within this conflicted time that caring continues to hold onto its promise that it will be possible, that something can be done, if not now, then in the future, “letting us imagine...an escape from this world that is an insistence on another time and place that is simultaneously not yet there but able to be glimpsed in our horizon” (Ibid.: 183).

References