

## ‘It Rips you to Bits!’: Woundedness and Compassion in Carers’ Narratives

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### Vulnerability and Becoming

‘HIS BODY IS ...’ the nurse paused for a moment, searching for the word. Her face lit up again when she remembered: ‘*It is one open wound.*’

These are words that no parent wants to hear, and in the daze of the late-night bedside, the well-meaning explanation left me stunned. Beside me, my eight-year-old son was shivering violently under four thin cotton blankets in different pastel shades of hospital blue and green. His skin was blistery red, raw, and inflamed. He could not help himself from scratching at it violently despite my warnings about how dangerous it was. We had been given a bed in a private room because of the risk of infection. This was not what we had planned for our Christmas holiday. For the nurse, wounds were knowable conditions, more or less the same between patients, that could be effectively resolved. Her role, and the confidence in her skills needed to embody that role, rested on this biomedical narrative, which she likely believed I held as well (hence her cheerful satisfaction when she could articulate her assessment). Yet for me and my son, woundedness was also a space of uncertainty, an uncharted territory where alternative narratives of suffering and care could emerge.

On one particularly difficult night, when he was exhausted from vomiting his foul-tasting antibiotics, I put my hands on his shaking arm. He had been upbeat and positive for most of the day, even trying to comfort me at times, but I could see now how scared he was. Tears poured out.

‘What do you think would make you feel better?’ I asked.

‘If *you* had to do all this too.’

‘That would help? But they only give you medicine and things like that if you are hurt or if you’ve got some “mysterious illness” like you do ...’

‘So? Couldn’t you do *something*? Like if you just *cut* yourself or something?’

And I admit that, in the moment, I wondered if that would work. It seemed a poetic, if not violent solution to our problem – a dangerous compassion indeed. We talked for a while about how we might enact our bloody plan, and eventually he started calming down and drifted off into sleep.

As his carer,<sup>1</sup> and one who places our attachment, intimacy, and love for each other above all other commitments, I did my best to understand his wounds and to be present to his pain. I became vulnerable to his vulnerability (Nortvedt 2003), not in such a way that paralysed me, but that allowed me to listen and engage with other possible narratives. Being vulnerable does not aim at a diagnostic calculus, but rather heightens the 'imperative to hope in the face of fear' (Mattingly 2014: 4), to experiment with storytelling, even in ways that threatened to disturb or erase boundaries between woundedness and well-being, where a cut could comfort. Perhaps putting my own bodily integrity at risk was the corporeal metaphor (Kirmayer 1992) of vulnerability the situation called for. To my son, this image was more tangible than the distant clinical narratives of blood results and alien medical terminology. For me, it provided a visceral image of the anxiety, guilt, and fear I felt, and transformed it into a means of care. Our mutual vulnerability generated a collaborative story that opened wounds and possibilities for interrelating and becoming, rather than a singular story that would close the case or stop the flow.

In this chapter, I want to follow this observation to ask what forms of becoming are afforded through narratives of care and vulnerability. Furthermore, how might these narratives, emerging from untidy affective and aesthetic empathetic engagements with vulnerable others, reveal ways to escape and critique dominant discursive practices of care? In exploring these questions, I will look at carer narratives drawn from ethnographic interviews I conducted with adult children caring for older parents in Japan and England. While the circumstances of these interviewees in many ways differed from my own experience described in this opening vignette, they also contain resonances that can guide us towards developing broader theoretical tools for understanding vulnerability and care across cultures.

In particular, I want to take a closer look at how vulnerability, which makes it possible to care and be cared for, might also form the basis of a shared lifeworld of compassion. Compassion, as I use it here, is not reducible to a singular emotion, event, or narrative, but rather, emerges as an assemblage of both receptive engagement with the other's suffering (com-passion as 'feeling-with' the other) and the responsive disposition to care (Bein 2013; Porter 2006; Schulz *et al.* 2007; Spikins 2015). Compassion contains and exceeds the fixed positions of carer and cared-for, emptying out these categories as it recalibrates the situation at hand. Being present

<sup>1</sup> I use the term 'carer' here in a similar way to Noddings' (2003) use of 'one-caring' to refer to anyone who cares for another in the role of 'cared-for'. These are constructed categories and therefore do not reflect the complicated shifts that take place in real encounters. However, carer is also a narrative identity that individuals take on and embody through social practices. In this chapter, unless otherwise specified, this refers to an unpaid family caregiver.

to my son's sickness, his pain and restlessness, rattled my emotions, but it also made me more compassionate: sensitive, responsive, and committed to his care. This responsiveness is revealed in the ways our stories became entangled in spaces of mutual becoming, where things were left unsaid, inaccessible, opaque, unfinished. Thus, the connection between vulnerability and compassion is not given, but is composed through narrative experimentation.

### Wounded Narratives

Following Ochs and Capps (1996), I contend that self (the unfolding of subjective experience into awareness of being-in-the-world) and the world (as constituted through our involvement with immanent reality) is mediated by narratives, or 'embodiments of one or more points of view, rather than objective, omniscient accounts' (Ochs and Capps 1996:21).<sup>2</sup> Selves, worlds, and narratives are intertwined and indeterminate, as new possible pasts and futures afforded by memory and imagination offer new points of reflection on the present (Mattingly and Lawlor 2001; Parish 2008). Narratives are given meaning, power, and moral force as they are performed and communicated as 'stories' (Frank 1995; 2015; Kleinman 2007; McAdams 2005; Mattingly 2010; 2014). Storytelling is a process of mobilising narratives to adapt experience to a multi-storied cultural world, selecting certain tropes, figures, or styles and closing out others, changing or maintaining stories over time.

Stories need both tellers and listeners, but stories of woundedness and care also need a space between that allows the roles to shift and exchange, for the listener to tell the other's story as their own, and the teller to listen to their own story reshaped by the other (Ochs and Capps 1996: 21–23). I couldn't take on my son's wounds, but together, we could be more present to each other by composing our own story of woundedness and care, where words were blunt and broken tools, but where a touch, a tone of voice, a gently sustained look, could bring new worlds into being. Thus, the story imagined together with my son emerged as a dialogue (Frank 2015) that called into question the story of care as an asymmetrical relationship between an invulnerable carer and a vulnerable cared-for, and foregrounded our mutual struggle with broken narratives.

When narratives are disrupted by events that challenge the ways one has come to dwell in the world with others, as is so often the case for carers, stories and the moral sense of things they provide can become broken, fragmented, or incoherent. As others have argued, however, broken stories of wounded worlds reveal the vulnerability of the body, of relationships, and of narratives themselves, in ways that can generate openings for radical reconfigurations of the self (Becker 1997; Frank 1995; Hydén and Brockmeier 2008; Kirmayer 1992; Kleinman 2007; Mattingly

<sup>2</sup> Thus, when the self or others are taken up as objects of reflection they are constituted in the world.

and Lawlor 2001; 2008; Parish 2008). It is through this storytelling process that vulnerable subjects become compassionate carers. Carers' stories are constantly in a process of revision since what it means to care depends as much on the lived experience of responding to the cared-for as it does on scripted cultural roles and narrative conventions. The vulnerability, or mutual affection in care, renders stories about its moral value ambiguous. Most of the carers that I spoke with struggled with doubts about whether or not their experiences mattered: if they were doing the right thing, for example, by saving a family member from the indignity of receiving care from a 'stranger' (i.e. a professional carer), or if they were putting the life of their family member in danger by taking on more than they could handle without expert training. The days were unpredictable and exhausting; embodied narrative fragments (e.g. feelings of vigilance, fatigue, grief, tenderness) did not seem to compose a coherent and compelling story. Over time, experiences accumulated and reshaped these fragments into stories with a different feel, as carers found ways their experiences resonated with others or with broader cultural stories (e.g. family traditions, religious worldview, etc.); but as long as the care continued (and sometimes long after the death of the cared-for), this process of becoming continued.

If conventional ethnographies describe what 'is' (i.e. durable structures and systems), engaging compassion and woundedness requires an ethnography of 'becoming', described by Biehl and Locke (2017: 10) as 'a style of noticing, thinking, and writing through which to capture the intricate relations, movements, and dynamics of power and flight that make up social worlds'. The uncertainties and exposures of vulnerable subjectivity interrupt the life narratives of carers, producing new possible lines of flight and imagination,<sup>3</sup> while at the same time, calling our attention to the ethical and political terrains from which the excess of carers' compassionate becomings leak and transgress normative boundaries. Becoming a carer to my son in the hospital meant not only taking on a particular relationship to the institutional spaces, practices, and systems of surveillance and confinements, but also finding myself excluded from the fixed set of roles of patient and healthcare provider. Where we waited or were treated, the kinds of questions or complaints that we could voice, the pace of the day (both the restless waiting during testing and tightly structured chemically dictated schedule of treatment), were overt ways in which care was scripted through regimes of spatially and temporally entrenched knowledge/power acting directly on the body. Within such a milieu, I became *excessive*, as was my care. Even the narrow bench in the hospital room where I slept made me feel that there was no place for me. Carers of elderly parents felt similar constraints, struggling to find a balance between adherence to expectations of doctors or social welfare services and their own feel for the needs of the person they cared for. A common complaint was that they don't feel 'recognised' for their

<sup>3</sup> 'Lines of flight' is a phrase used extensively in the work of philosophers Gilles Deleuze and Felix Guattari in relation to the politics of becoming. Ingold (2011: 102–104) and Biehl and Locke (2017: 7–12) discuss at length the relevance of this concept for anthropology.

care. As this story of care becomes ordinary, as we accept that care does not come without a certain cost to one's agency, we risk reproducing other social inequalities embedded within care and marginalising other responses to suffering that may be more situated, intimate, and vulnerable (Berlant 2004; Gunaratnam 2008; Han 2018; Mol 2008).

Carers of older adults are similarly embedded within institutional structures and cultural norms that often fail to attend to the ambiguities and excesses of woundedness and care. At the same time, as Judith Butler (2016: 25) has pointed out, it is precisely through this ambiguity that 'receptivity and responsiveness become the basis for mobilising vulnerability' towards contesting horizons of the possible. I present these cases as things in the becoming, unfinished stories that best illustrate what Berlant (2004:9) calls the 'aesthetics of compassion – the cultivation of the senses toward a more nuanced and capacious engagement with scenes of human activity', as well as the ethical 'struggles for a good life' (Mattingly 2014) in the face of suffering.

What kinds of narratives open up ways of being-with someone who is suffering, and how much do these narratives vary depending on the kinds of cultural stories available (see Scully, this volume)? This question guided my research in England and Japan with adult children caring for elderly parents.<sup>4</sup> Most of these carers had witnessed scenes of suffering more dramatic than I saw in the few days I spent in the hospital with my son. A few Japanese carers spent weeks and even months virtually taking up residence at the hospital while their mother or father recovered.<sup>5</sup> Even at home, carers sometimes slept with the person they cared for, or on the floor or sofa next to them, to make it easier to respond to night-time wakings. But, similar to my experience, dramatic crisis situations were relatively rare; carers also had moments of gracious tenderness, fatigue, boredom, and confrontation that unsettled them slowly (Danely 2017). Each day involved trying to find a rhythm, adjusting to disruptions, being attentive to fluctuations of mood, to appetite, and energy. Maintaining and enduring this process of attentive coordination of bodies and feelings at the edges of life led carers to reflect on the fundamental meaning of their relationships, their responsibility, and the human condition more generally in profound ways. Bringing this observation out of its specific context and into a form that tells us something about the broader moral or political significance of carer narratives requires a fuller picture of what it means to be persons, faced with each other's wounded imperfections, called to respond to this mutual regard with care.

<sup>4</sup> This was part of a larger project that aimed to examine the ways family members (including spouses, children, spouses of children, and grandchildren), whose responsibilities and roles are more ambiguous than those of professional care workers, ascribe meaning to care through practices and reflections on self-transformation. Here 'elderly' is used to describe those over 65 (the age at which pensions and long-term insurance become available in Japan). This research was funded by the Japan Society for the Promotion of Science (PE13251) and the John Templeton Foundation Enhancing Life Project.

<sup>5</sup> Japanese hospitals expect family members to wash the patient's laundry, bring in familiar items from home, and feed the patient if necessary.

The narratives of 'wounded storytellers' (Frank 1995) trace the vulnerable spaces between persons, the lasting ways we belong to each other in grief, love, shame, or compassion. Just as we articulate these stories, the stories articulate us. The articulations or enjoinings of persons through care and mutuality create 'hinged subjects' (Guenther 2013). Importantly, this intersubjective hinging is embodied and intercorporeal (Csordas 2008). Like Levinas' image of a 'slap in the face',<sup>6</sup> joining with others brings us back to our 'senses' and to our vulnerable bodies 'from head to foot, to the marrow of our bones'<sup>7</sup> ([1972]1987: 104), leaving us speechless. This space of attentive presence to one's own embodied vulnerability through the encounter with the other was a persistent feature of the lives of carers I spent time with, and it helped me better appreciate Arthur Frank's (1995: 2) observation that the same stories that attempt to make the wounded body familiar again paradoxically make it alien and 'strange', mixing realism and fantasy. For Frank (2015: 88), meaningful stories often begin where narratives become strange.

Strange stories of compassion accentuate wounds rather than cover them up. They trace along the edges of feelings like a finger running across the smooth ripple of a scar. They can soothe and cause a shudder at the same time. This sensual, aesthetic response, and the ethical responsibility it produces for those who share in these vulnerable spaces, distinguishes narratives of compassion from care. Care can be dispassionate, performed at a distance, and with its primary aims directed towards the annihilation of vulnerability. Compassion demands we become more than who we were, that we imagine other possible selves, that we open up our wounded subjectivities, attuning ourselves to strange narratives of a shared life-world (Jackson 2002; Parish 2008; 2014).

In the sections that follow, I focus on two cases of adult child carers of older parents, briefly situating their narratives within the broader context of care services in Japan and the UK respectively.<sup>8</sup> I am less concerned with determining the 'actual events' of care than the ways 'strange' narratives and imagination fill in the fissures between the world and the carers' knowing of it. By interjecting some poetics

<sup>6</sup> 'La vulnérabilité ... est l'aptitude – que tout être dans sa "fierté naturelle" aurait honte d'avouer – à "être battu", à "recevoir des gifles"' (Levinas [1972]1987: 104).

<sup>7</sup> 'Le Moi, de pied en cap, jusqu'à la moelle des os, est vulnérabilité' (Levinas [1972]1987: 104).

<sup>8</sup> I conducted interviews with approximately 25 current or recently bereaved carers in Japan and 12 in England. These cases were not chosen as 'representative' in any statistically meaningful way (either of my sample or of any broader population, e.g. national, ethnic, class, gender, etc.). However, neither of the two cases I chose would be considered extreme or unusual either. They are 'typical' amongst the carers I spoke with in each location. While I strive to stay close to the specific cases, I also draw on my broader experience with other carers as well. My choice of a female carer in Japan and a male carer in England should not be taken as a reflection of an attempt to represent those cultures as either feminine or masculine or to exclude other gender orientations in this research. Feminist scholarship has powerfully articulated the ways women's labour is disproportionately exploited for care, amounting to a form of coercion. Such analyses are able to challenge embedded structures of inequality. However, I am also concerned that such an approach alone risks overlooking the complexity of individual experience and identity within and across gendered categories. I have therefore chosen not to refer to gendered aspects of these cases in detail for this chapter.

into the politics of care, I aim to show how narratives of woundedness resist fixed positions by imagining possibilities and perspectives between and among – new forms of dwelling life (Harrison 2007; Jackson 2002; Porter 2006) that can maintain compassion in the face of suffering. I show how narratives in both locations contrast with those of social care policies that locate vulnerability in the individual care recipient rather than in the unfinished intersubjective space of compassion. However, each case also reveals the importance of other cultural stories in shaping the embodied aesthetic experience of care and its integration with identity.

### Story-Site I: Japan

Japan implemented its current universal mandatory Long Term Care Insurance (LTCI) system in 2001, and while this has led to a proliferation of private care service providers, the system still depends heavily on family carers to cover much of the day-to-day care of frail, disabled, and cognitively impaired older adults (Ochiai 2009). With more than 295,000 older people on waiting lists for residential care homes,<sup>9</sup> and a severe national shortfall of qualified care staff, preference for services is given to insured older people who do not reside with family members. According to the 2016 Ministry of Health, Labour, and Welfare census, family members, usually a spouse or adult children, are considered the primary carer for more than 70 per cent of older adults who qualify for care services, and in 85 per cent of these cases, the older person lives together with the carer (Ministry of Health, Labour, and Welfare 2017).

Discourses of Japan's elderly care crisis have found a visceral metaphor in the epidemic of *kaigo tsukare* (literally 'eldercare fatigue'), often cited in extreme cases of carers killing the cared-for (sometimes in 'suicide-homicides'<sup>10</sup>) circulated widely in the media (The Mainichi Newspapers 2016). Japan's homicide rate is one of the lowest in the world,<sup>11</sup> yet it is estimated that one in every ten homicides is linked to *kaigo tsukare*, or about one new case every two weeks (Shimada 2016).

<sup>9</sup> This number peaked in 2014 at 523,584 applicants on waiting lists. The following year, the Ministry of Health, Labour, and Welfare's revised LTCI guidelines increased the level of care needs for eligibility considerably, resulting in a drop of more than a third. Since then, the number on the waiting lists has decreased despite the increase in older people needing care. However, the reason for this decline is not because of the increased number of facilities and beds, but mainly because of the increased difficulty in qualifying. Applicants can wait a year or longer, in which time the condition of the older person can decline considerably. All of this is part of a directed effort to shift care from institutions to the community, in what is called the Community-based Integrated Care System. The most recent revision of LTCI (2017) places an even stronger emphasis on 'maintaining independence' of older people.

<sup>10</sup> The Japanese term for 'suicide murders' is *muri shinjū*, or an 'impossible suicide'. In other words, where both parties cannot commit suicide simultaneously, one partner aids the other first, then follows with their own suicide.

<sup>11</sup> Data from the 2016 UN Office of Drugs and Crime puts Japan's homicide rate per 100,000 at 0.3. In comparison, the rate for England and Wales was 1.2. See <https://dataunodc.un.org/crime/intentional-homicide-victims>.

Sensational as these events are, the stories, for the most part, involve very ordinary people in ordinary situations. When I asked groups of carers if the thought had ever crossed their minds, almost everyone said yes. 'We all have those thoughts!' said a man in one of the groups. 'Anyone who has been a carer thinks, "Maybe it would be better if [the cared-for] were dead" or "we could die together" – you think it!' No one in the group recoiled or showed discomfort, but instead they leaned forward, nodding in agreement. This was obviously a compelling 'strange' story, where reality and fantasy, affect and discourse precipitated moral reflection. Rather than condemning those who killed, the carers instead 'felt sorry' for them, pitying them in the sense that they too could see themselves in the same position. I was struck by the way violence, in this context, could be reconceived as care, a 'better' solution to suffering where the carer could offer a compassionate death together.

As I spent more time with Japanese carers, observing care interactions in their homes as well as listening to their reflections in interviews, I began to see *kaigo tsukare* as an embodied expression of vulnerability that opened up possibilities for compassion and intercorporeal hinging (Danelly 2017). In this sense, both narratives of care and of violence expressed intimate bodily intersubjectivity, suffering, and moral ambiguity. Yet for most carers, these narratives did not lead to actual violence, but were mediated by other cultural stories, including reflections on their own life histories.

Some carers used cultural narratives of body to make claims not only about themselves, but about 'Japanese people' as a whole. 'For Japanese people, it's here,' one carer told me, softly slapping the naked skin of his arm like a phlebotomist preparing a vein. 'We take care of our family – the same blood,' he continued. 'That's why we don't like to rely on social care. We don't understand why we're supposed to help care for strangers.' Another carer simply said that he cared for his mother because they were two parts of the 'same life', just like a body that might have strong parts and weaker parts. For these carers, the story of a shared body or life made care meaningful and endurable, even as it also expressed vulnerability.

One carer in her 40s, who I call Tomomi, described this space of endurance in a narrative characterised by various forms of bodily, communicative, and affective disruption to the everyday rhythms of life. She told me,

I couldn't sleep. my mother was next to me and I would always be hearing her [saying] 'Ooo! Ooo!' and it really felt just like I was hearing the devil's voice. It was excruciating. I would say 'what's wrong mum?' but all she'd do was moan. And when she couldn't eat food, [I'd say] 'What's wrong?' and all I could do was just rest my hand on her body, or hold her hand. I'd be like, 'What should I do for her?' But it was like that every day, when I was caring. It felt like I wasn't sleeping even when I was sleeping.

These disruptions produced a kind of hypervigilance and exhaustion that she endured by putting the self aside and imagining a kind of intercorporeal shared life with her mother. She continued:

When my mother was in pain – well there are times when I can't tell if she is in pain, but I always imagine that she was – I would think things, like, like, 'If I do this or that now, it might be a little painful for her' and so on – So, for myself, me – it is about more than what *I* want ... Well, I can't become my mother, but *I try to become her*.

When describing this feeling her way towards her mother, Tomomi's words seem to stumble on themselves as they are voiced (indicated in the passage by dashes and commas); the thoughts are more broken and stuttered than usual. Her narrative described both her mother's woundedness and her own, not only as mutually constituted, but also as responsive and intensely emotional. Because her mother could no longer speak, each interaction Tomomi had with her mother called on her to use her senses to question and imagine her mother's sensations, feelings, and pain. Tomomi learned to attune herself to her mother's feelings and reshape her own actions, speech, and even feelings in response:

Tomomi: I had to always try my best to keep my voice low and calm and use the same voice over and over again.

Danely: And your feelings –

Tomomi: None! You have to get rid of your own feelings. You can't do it if you have feelings for yourself. I wondered if I would be able to have my own feelings again. But then she would call me and I would change, just like that. I would say, okay, here I go!

When she began spending more time living with her mother, the fatigue of caring in this way started to make her more isolated and irritable.

I was so tired sometimes and I would think, how long can this go on? I would have thoughts like that. I would start to get hurt by things she said that were spiteful. She would always be saying things and it was hard not to take it personally.

In the final months, however, she missed hearing any words. Tomomi became completely engrossed in the care, sharing in its pleasures and pains with her mother, while at the same time coming up with new bodily metaphors for their shared life and her responsibility.

It's much more complex than I had imagined it would be at the start. I would feel really sad seeing her change like that ... I thought, how can I accept this? I would just think, 'she's ill'. So that's how I would endure. She's ill and I'm healthy. I'm healthy. I have this really amazing thing. So, if the person who's healthy perseveres for the sake of the other person, that's all you can do. So if I try my best, the story will turn out for the best ... really getting to know her feelings made me happy.

When Tomomi referred to her mother as ill and herself as healthy, it was as if they were still part of the same body, and the attentiveness and care was a way of compensating for the decline of part of that body. Even after her mother died, she told me that she continued to feel the urge to offer care to others who needed it, as if to continue that process of responsive becoming, of being open to the other.

Stories of carers like Tomomi don't fit well with either the image of the capable and dutiful daughter, on the one hand, or that of the overburdened and burnt-out carer, on the other (Yamamoto-Mitani and Wallhagen 2002). What is clear is that the experience of care changed her narrative identity, her sensitivity and attentiveness to others, and the future possible selves she could imagine. After her mother died, she reflected on this change, saying,

The important lesson is that I learned how to face others. Everything was always about mother, you know? I was only focused on mother. [When she died] I thought, how should I live from now on? ... I think I've become much stronger now. I can understand other people's feelings.

Tomomi's intense intersubjective hinging with her mother led at first to a sense of becoming unhinged or set adrift after her death. But from this break in the narrative, Tomomi was able to tell a new story about her own vulnerability and the possibilities it opened up to a story of growing stronger and more compassionate towards others. This story maps readily on to Japanese narratives of interdependent personhood. The same kind of movement from individuated being to a vulnerable and compassionate *being-with* was at the heart of Japanese phenomenologist Watsuji Tetsuro's ([1937]1996)<sup>12</sup> notion of the person. Watsuji is known for his interpretation of the word *ningen* (typically glossed as 'human'), which is composed of two joined ideographic characters, the first meaning 'person' and the second meaning 'space-between'. In other words, in Japanese society, 'humanity' is not found in exemplary individuals with the will to rise above the crowd, but in the cultivation of the spaces between worlds, articulated beings, hinged subjectivities.<sup>13</sup>

Contemporary philosopher Washida Kiyokazu (2015: 115), writing specifically on contemporary issues of ageing and social care, thinks Watsuji's interrelatedness further, arguing that it is our human condition of vulnerability that joins us:

In the background, there is an *I (watashi)* who is still deeply hurt by the breakdowns and wounds from the slightest mockery or betrayal. There is an I who has been tossed around by misunderstandings and entanglements with other people. There is an I who keeps holding onto the restless question, is it really better to be here? It even becomes unclear what I hoped for in the first place. Our shared life is a matter of 'vulnerable' subjects (*moroi shutai*), those uncertain about themselves mutually intertwined, supporting each other.

For Washida, the separation of the life course into categories of more and less vulnerable persons produces violent exclusions that prevent the emergence of shared

<sup>12</sup> Like his European counterpart, Heidegger, some of Watsuji's work was used in the early twentieth century to support ideologies of cultural nationalism. I take these claims seriously and introduce him primarily as a phenomenologist whose work formed the basis of that of later scholars such as Washida.

<sup>13</sup> This is not to claim that there is anything inherently Japanese about the interdependent self (see Rosenberger 1994). Rather, self may appear more individual or interdependent based on historical and social context (D'Andrade 2008). Nevertheless, cultural narratives may place more or less value on particular orientations and, thus, affect the relative distribution of an orientation over time.

life. What I find most interesting in Washida's notion of vulnerable subjectivity is the way it opens us up to considering new ways a person becomes situated in a world rather than merely oppressed by it, how they can be with others in a shared space of fragile compassion.

Although both she and her mother were vulnerable in the sense of being open to and responsive to each other, Tomomi's care and her sense of herself as a carer meant constantly attending to the space-between, where fluctuating conditions of pain and comfort or illness and health were enhanced and endured. For Tomomi and many other Japanese carers I spoke with, men and women alike, this space of fragile compassion manifested as an intercorporeal feeling for bodies and their sensations. While the thoughts and feelings that pass through the carer's mind are often troubled by doubt and uncertainty, 'tossed around by misunderstandings and entanglements', this engagement with the body of the cared-for seemed to ground the narrative in an aesthetics of relatedness. When I began speaking with carers in England, however, I found a very different narrative about bodily vulnerability in care.

### Story-Site II: England

When I first met Paul,<sup>14</sup> he was in his late 50s, and had just taken early retirement when he found himself suddenly assuming responsibility for his father's care. Paul and his father had not had a close relationship when Paul was growing up, and had practically lost touch with each other for years. Anthropologist Daniel Miller's (2017) ethnographic account of people approaching the end of life in an English village shows that Paul's situation could hardly be seen as exceptional. Miller observes that English restrictive norms around entering a person's home extend to all but very close kin, contributing to widespread loneliness among less mobile older adults even when they have many friends and family living in the local vicinity (Miller 2017: 127–129). When Paul's father's health declined, Paul relied on a few village contacts to look in on his father from time to time as a favour. But after a time, even this trailed off, as people didn't like to be so 'nosy'. Then, one day, Paul received a call from the hospital asking him if he was the next-of-kin. His father had been discovered alone in his house, foaming at the mouth and bleeding from self-inflicted stab wounds. When he was brought to the hospital, he attacked nurses and had to be restrained.

Paul's father did appear to recover (although in a very confused state) after a few days, but the hospital staff concluded that he could no longer live independently, and since Paul was the only one of his three adult children who had some space at his house and money to provide for his father, he decided he would try to

<sup>14</sup> Pseudonym.

make it work. It wasn't long after that, however, that things started going sideways. Paul explained:

It just started to go wrong within a week or so. He'd be getting up at 3 o'clock in the morning, ... you know, you sort of think okay I've got him settled ... and there was another problem with the fact that I'd got a double hernia at the time, and he couldn't – I had to sort of lift him into bed and move him and this sort of thing and it was ... um ... and social services at that time were brilliant and saying 'you know you shouldn't be doing this,' and I said, 'Well what else? Do I send him back to bloody, back to the hospital?' And no care home was interested in taking him because of his violence, plus also when he was lucid, 'I'm not paying money to go in a bloomin' care home', and this kind of thing.

I listened to Paul, as he breathlessly recounted those harrowing first weeks of becoming a carer. His mind seemed to be racing as sentences were aborted and then recomposed mid-way, jumping between voices, then trailing off again, uncertain.

I didn't tell Paul that he was sent an invitation to participate in the study because he was identified as one of the most 'vulnerable' carers in the county, that is, according to the self-report survey of carers conducted by the county council. This survey had four questions used to identify what they considered to be 'vulnerable carers', and Paul ticked the boxes:

Q1: Which of the following statements best describes how you spend your time?

A1: I don't do anything I value or enjoy with my time.

Q2: Which of the following statements best describes how much control you have over your life?

A2: I have no control over my daily life

Q3: Thinking about your personal safety, which of the statements best describes your present situation?

A3: I am extremely worried about my personal safety.

Q4: Thinking about how much time you have to look after yourself – in terms of getting enough sleep and eating well – which statement best describes your present situation?

A4: I am worried that I am not getting enough sleep or eating well.

The clerk at the council who generated the list was a former biology researcher who was very good with numbers but who told me she was less comfortable with the kinds of subjective questions that I was interested in. She explained the calculations and made sure that I kept notes. Satisfied that I understood the system, she added, 'Actually, I don't think carers are "vulnerable". I think it is better to think of them as "at risk" or something. But they're not vulnerable.'

Vulnerability, for her and other English care staff I spoke with, held negative connotations of an internal weakness of character, that we might contrast with cultural narratives of the proper moral posture of a dispassionate 'stiff upper lip'. 'At risk', on the other hand, placed the focus of danger outside the person, in the

conditions surrounding them. Both vulnerability and risk signalled a possible need for further support, yet for the clerk I spoke with, risk management made more sense than trying to change someone's character. The items of the questionnaire appear consistent with her view on risk. The subject they interrogate is not the 'vulnerable subject' Washida writes about, but a subject whose care takes them away from the self-sustaining practices of eating, sleeping, enjoying hobbies, securing personal safety, and practising self-determination. Risk management for carers like Paul, who provided around-the-clock care for a person with erratic and sometimes violent behaviour, meant relieving him from responsibility rather than accompanying him through it.

Like Tomomi's early narrative style, Paul's narrative was often broken and unresolved. He tended to turn this brokenness into a kind of performance, with Paul voicing his father and his sudden swings of mood rather than integrating it with his own voice:

And then he'd be talking away quite normally ... and he'll say, 'Is he here?' 'what?' 'is he here?' 'who?' [in a gruff, mean voice] 'I'm not bloody telling you!' [bewildered] 'what?' [gruff] 'PISS OFF!' ... And all that kind of behaviour *it just rips you to bits*.

This sudden unpredictable confusion was not only upsetting for Paul, but it 'ripped [him] to bits'. Paul's father did try to stab him on a few occasions, even though Paul did his best to hide the knives and anything sharp. More often Paul was less afraid for himself than he was afraid that his father would get hurt. He would be awoken early in the morning, for example, to find his father crawling up the stairs or cutting off his bandages, which had become soaked from a broken colostomy bag.

There were periods I'd go 24 hours with no sleep, he'd be up and then down ... I'd hear something in the night and he'd be trying to get up the stairs. 'C'mon you need to go down' [gruff voice] 'I'm not fucking going anywhere!' 'C'mon you need to go back down' [moaning loudly] 'LEAVE ME ALONE! LEAVE ME ALONE!' this would be at 4 o'clock in the morning.

The cruel voice of his father still ringing in his ears, Paul tried to maintain control and separation from his father. He did not touch him, nor was his touch welcomed the way Tomomi described her own experience of care. At this point, Paul's story began to roll on ahead of him, picking up speed. I hardly asked any questions and the interview continued for more than two hours.

Frank (1995) might call Paul's narrative a 'chaos story', or those stories told 'on the edges of a wound' and in 'the silences that speech cannot penetrate or illuminate' (1995: 101). This sort of narrative is difficult to sit with, but it is not uncommon among people caring for family living with dementia (Frank's (1995) main example of a chaos narrative was drawn from a woman caring for a mother living with Alzheimer's disease). But Paul's story did not end here. The vulnerability revealed in the chaotic narrative sometimes took other, 'strange' bodily metaphors in ways that took Paul by surprise. He noticed how those raw wounds of fatigue and frustration, of being ripped to bits and reassembled, had changed his

sensitivity, not only to his father, but even to strangers. He found himself in tears, in one instance, after listening to a news story about a rescued elephant on the radio. Caring had made him more emotionally close to the surface, more compassionate, and while he was learning to grieve for his father, he was also becoming more politically aware, always sending me links to articles on social care cuts and videos on dementia care. It seemed important to him that what he was going through was part of a larger story that put others 'at risk' as well.

Paul's frustrations with England's social care bureaucracy were shared by other carers. Unlike Japan, the UK passed major legislation not only acknowledging the value of unwaged carers, but also stating that carers were entitled to the same rights as those they cared for in terms of support for physical and psychological problems (the 2014 Care Act). While the Care Act is still very new, it has already had major effects on employee care leave benefits and stabilised the work of carer support organisations that provide information and support groups.

Throughout my time following English carers, it seemed like I was always tripping over policies, documents, petitions, paperwork, on my way to find 'the care'. Gradually, however, I came to see this as part of carers' stories. For English carers, it was as though care management was a task that required more skill and sensitivity (and therefore more 'care') than what they considered more menial 'body' work. For example, Catherine explained:

I'm the one who would kind of gather information and make the phone-calls [like], when can I upgrade her attendance allowance to the higher level, what kind of thing should I watch out for in the form when I upgrade to the higher level and then trot around and get the signatures and you know – it's that kind of managing the bureaucracy of a sophisticated social welfare providing government that kind of was my remit as a carer, rather than the kind of physical here's your breakfast here's your medication I'm going to help you change your clothes now. I didn't really do that.

Catherine was not one of the 'vulnerable' carers identified in the council survey, and in many respects, her narrative reflects cultural stories about state bureaucracy around physical care common among other English carers, yet rarely mentioned in Japan.

Yet despite this strong moral narrative of managerial care among English carers like Catherine, Paul's story also contained meaningful moments of vulnerability and compassion. He described how his father would surprise him, for example, with incredibly tender words. Paul struggled to find a way to reconcile the disparate parts of his dad: the person he saw before him and the person he thought he knew before care. The moments of spontaneous connection helped him to re-narrate the past in ways that allowed him to see his father as a person he could care about and care for. As they went through some of his father's old belongings, for example, his father began to tell stories of his past that Paul had thought he would never hear. Paul told me,

He would say things like, 'I really love you [Paul]. I really love you.' Y'know, Jesus Christ! He never said stuff like that to me before. And I'm sure that was a result of his

‘illness’ if you want to call it, but you counter that with the kinds of abuse, and (sigh) the sleepless nights, and ... I still have trouble sleeping. I couldn’t sleep last night. Things hang on in your mind more.

Paul’s heart and his narrative were ‘ripped to bits’ and his piecing them back together created something fragile and incomplete. Paul’s story was not always clearly ordered in terms of a clear sequence of past, present, and future. Yet this unfinished becoming was also yielding to new ways of thinking and feeling, even if he struggled to endure.

In some ways, however, I found reasons to be optimistic about Paul and his father. For all the chaos, Paul accepted his decision to take responsibility for the care of his father, and this inscribed a new kind of space-between to reconfigure their relationship. While far from an ideal bond, Paul did put himself in a position that his brothers avoided; he was able to respond to his father’s pain with his own untidy compassion. The aesthetic sensibility was different from the close intercorporeal attunement in Tomomi’s case, however, in that the tempest of pain and love struggled to find a broader cultural narrative to map on to.

### Closing/Opening Wounds

In *The Vulnerable Observer*, anthropologist Ruth Behar reflected, ‘as a mode of knowing that depends on the particular relationship formed by a particular set of people in a particular time and place, anthropology has always been vexed about the question of vulnerability’ (Behar 1997: 5). The vulnerability Behar refers to is not only the exposure of the ethnographer as part of the story, nor the vulnerability of participants whose experiences of suffering or precarity anthropologists bear witness to. The ‘question of vulnerability’ is also the question of *becoming*, where a new mode of relationality emerges shimmering between two subjects (as Cahill so beautifully puts it in this volume). In these spaces of becoming, brokenness is reconfigured in the storytelling as vulnerable subjects reflect on their embodied response to a mutually constituted wounded world.

In each of the cases I have explored here, narratives and selves were broken and reassembled, wounded, dependent, and loved. Despite very different contexts and cultures, carers of older family members appeared to develop wounded narratives for reorganising the self in the process of taking responsibility for and responding to the demands of care. These narrative subjectivities, to the extent that they are bound up with a kind of unmaking of persons, contain potential for remaking interdependent shared life across communities. However, this potential is also contingent on the political, cultural, and social capacities and constraints of particular sites and situations. In Japan, where selves and bodies, particularly among kin, were experienced as coextensive, carers often strived to endure a process of becoming-with the cared-for, imagining their way into the other in ways that involved intercorporeal engagement. Tomomi did not take her responsibility

lightly, but she did choose it in a context where embodying interdependence was a culturally valued response to the other's suffering. This was less so in England, where carers like Paul often struggled to reconcile their ideals of bodily and volitional autonomy and their vulnerability in care. Paul's narrative voiced this dramatic tension, keeping the cared-for at a distance by voicing them as if in a one-person radio play. At times, Paul too would adopt a cultural role as a care manager, but emotional sensitivity and sleepless nights would drain the meaning from that narrative, and he would be thrown again into doubt, seeking to make sense of his fragile compassion.

The personal narratives of 'wounded storytellers' reveal the spaces-between that 'hinge' carers and those they care for and the ways certain regimes of knowledge, like medical or social diagnostic third-person categories, can unhinge subjects from each other (Mattingly 2014). By bringing my focus back to the vulnerability, becoming, and the uncertainty that underlies the possibility of compassion, I suggest that carers' narratives locate ways to resist local political foreclosures about who is deserving of care or who bears its responsibility. Vulnerable subjectivities initiate new reflections on one's place in the world, but they also pose questions to society about the value it places on the care of the old, ill, and disabled. Perhaps a politics of shared life begins with the wound and our response to it, our choice to incorporate it into our narrative or to look away.

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