

# Carer narratives of fatigue and endurance in Japan and England

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**Abstract** Caring for an elderly person often requires constant attention, physically challenging tasks, and emotional strain, all of which accumulate over periods and manifest as fatigue. Despite the prevalence of descriptions of fatigue in carer narratives, and the massive clinical literature on ‘carer burden’ and ‘exhaustion’, the significance of fatigue as a component of care rather than a mere by-product has not been fully explored. Drawing on Levinas’ phenomenological theory of fatigue I argue that experiences of fatigue shape carer subjectivities as both vulnerable and enduring, qualities that are essential for inaugurating new ways of being towards and taking ethical responsibility for the cared-for. At the same time, fatigue can become tragic if not supported by social and cultural narratives that recognize it and give it value.

**Keywords** Aged care · Fatigue · Endurance · Japan · England

## Introduction

Unlike other intersubjective states like empathy (Zahavi and RoCHAT 2015), caring tends to be described as an active process of ‘experimenting’ (Mattingly 2014), ‘tinkering’ (Mol et al. 2010) and ‘doing good’ (Kleinman 2014). This active orientation stems in part from a dynamic understanding of subjectivity as always partial, in a process of ‘assembling itself into a response to life’ (Parish 2008, p. 8), or ‘a force for making worlds’ (Blackman et al. 2008, p. 16). When listening to carers of elderly family members talk about their feelings and experiences, however, I was struck not only by their descriptions of active forms of subjectivity and care,

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but also by the profound fatigue and weariness that shadowed every move. It was as if there could be no care without collapsing into fatigue, and no fatigue without the repeated effort and endurance of care.

The aim of this paper is to examine the phenomenon of fatigue within carer narratives in order to move beyond the limited conception of it as mere corporeal exhaustion, and instead to engage with fatigue as a key aspect of carers' desire for ethical subjectivity. As phenomenologists Emmanuel Levinas, Hannah Arendt, and others observed, subjectivity is fundamentally relational, arising out of the act of facing the Other, and therefore ethical. Furthermore, these ethical relationships are not considered fixed along a priori laws of moral justice, nor are they completely determined by socio-historical circumstances, but are, as anthropologist Jarrett Zigon (2007, p. 138) argues, 'situationally sensitive'; they take place within a 'range of possible responses' or forms of responsibility for the Other, which exceed moral norms and conventions and constitute moments of 'moral breakdown' (Zigon 2007, pp. 138–139). Narratives of fatigue articulate these moments of moral breakdown, where ethical choices animate subjectivity.

In addition, I argue that individual narratives, often fragmented, poetic, and lacking a coherent meta-narrative themselves, contend with cultural narratives, logics and ideologies. Where personal meaning diverges from or exceeds the overarching narrative context, fatigue leads to exhaustion and moral tragedy. Where it seeks to expand the bounds of that overarching narrative through the imaginative work of constructing counter-worlds, the ethical demand of care is intensified, and fatigue endured. These two scenarios are by no means mutually exclusive, as I hope to show through the narratives later on.

Rather than turning to the clinical literature that tends to pathologize carer fatigue, I adopt a narrative phenomenological approach (Mattingly 2010, 2014), which considers the process of making experience meaningful through stories that exceed tidy cultural categories, and reveal an ongoing negotiation of possible selves, of remaking the world, and of forging a life lived otherwise (Han 2012; Parish 2008; Sakellariou 2015; Stevenson 2014). This approach is similar to that taken up by philosophers of the ethics of care (Kittay 1999; Noddings 2003; Tronto 1993), in that it views subjectivity as fundamentally intersubjective and grounded in embodied moral practices and relations to the Other (cared-for). Anthropological interest in the lived experience of care of older people has similarly drawn on theories of narrative, ethics and embodiment (Brijnath 2014; Buch 2015; Cohen 1998; Grøn 2016; Hromadžić 2015; Lamb 2000) in ways that foreground the transformative becoming of subjectivity, the ways that it is continually made and undone like Penelope at her loom (Briggs 2014). As John Borneman (1997) argued, such a perspective moves the focus of theories of subjectivity away from Foucauldian formulations of 'power/knowledge and technologies of the self' and towards a picture of the 'fragility, variability and riskiness of the human project as it unfolds' (p. 582). This is certainly not to say that power relations and normalizing practices are incidental to carer narratives; as Clara Han (2012) notes, care "takes shape and is experienced through concrete relations inextricably woven into unequal social arrangements" (2012, p. 5). These arrangements can also tell us something about narratives of fatigue and endurance.



This paper comes from a larger project looking at compassion in Japan (Kansai area) and England (South Midlands area). In both sites, I conducted open-ended interviews with current or recently bereaved carers (Japan  $n = 22$ , England  $n = 13$ ). I also sat in on both formal and informal carer peer support groups, volunteered at adult day service centres (respite care), and participated in community activities for the elderly, from which I learned a tremendous amount about the ways care was managed and understood. Fatigue/exhaustion and endurance/perseverance were among the strongest emergent themes across both samples of carers. Here I will discuss some of these findings as they relate to cultural narratives of personhood, relationality, and care, while situating these cases within broader philosophical and ethnographic discussions.

### **Becoming the other's feeling**

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. When I'd wake up I would see how she is doing, and when the helper came, the helper would take care of her for a little while and I would get a little time to do something for myself. In the evening a nurse would come and ask 'is she ok going to the toilet?' 'She doesn't have a temperature?' 'Shall I take her blood pressure?' and once a week, on Sunday, my older brother would come over for three hours. I'd go to this gyoza restaurant that I love, and eat, then have cup of coffee and go back home and switch places with my brother. That Sunday, once a week, that rest was so important. And then once again when Monday began, it would be the same thing all over again... (Kiyomi, age 44).

Kiyomi was not the only carer who experienced the sleepless sleep, the days and weeks spent watching, feeling, listening for signs of pain, loneliness, confusion (never for laughter or song or a smile), wondering how long this would go on, and then shaking off the thought. The reality was hardly comforting: it would go on until her mother died. And so Kiyomi's story, as with many other unpaid carers, became one of enduring the fatigue of caring.

Her fatigue would make the weight of her care almost too much, the calls of her mother unbearable, and she could only wait for that weekly respite to make her escape. In her narrative, Kiyomi describes how the constant attention, monotony and uncertainty of care were relieved only when another carer would take her place. This time to herself allowed her to rest from the demanding work of both managing her own feelings as well as taking on the feelings of her mother. After some difficulty trying to articulate this, she explained:



When my mother is 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 'If I do this or that now, it might be a little painful for her' and do on. So, for myself, me, Kiyomi-chan—it is about more than what I want. Well, I can't become my mother, but I try to become her.

Japanese carers often spoke of 'becoming the other person's feelings' or 'becoming the other person's body'. These expressions echo popular beliefs in the care of divine beings, such as Bodhisattvas, who relieve suffering through corporeal exchange (*migawari*) (Fujiwara 2012). Kiyomi expresses her striving towards this ideal by cultivating an embodied sense of attention and responsive empathy (*omoiyari*) with her mother, 'as a witness to the other's sufferings' (Frank 1997, p. 179). Kiyomi explained, "If you're caring every day, that's how your body becomes. You become super sensitive". As a result, she continued, "I was burned out (*moetsukita*), in a daze (*hōshin jōtai*), all my power, my energy was being spent on taking care of this person". The ways Kiyomi had come to respond to and join the world as a self, had to be re-envisioned and re-narrated as something more sensitive, more exposed, a being enduring fatigue. However, this subjectivity was being narrated within a context of other cultural narratives where radical intersubjectivity was symbolically articulated and valued.

By looking closely at narratives like Kiyomi's, that link fatigue, endurance and subjectivity, we see how a reductive model of fatigue understood as an epiphenomenon of 'carer burden', or a weakness of the carer's coping or 'resilience', overlooks the ways it figures into experiences of vulnerability and intersubjectivity in care. If care can be considered fundamental to human survival and foundational to subjectivity (and I believe it is), then why not fatigue as well? Here I want to consider fatigue in the carers' cycle of effort (enduring through fatigue), exhaustion (the recoil into fatigue after an effort), and recovery (what Levinas (1978) calls a 'stirring' to action from fatigue), as modes of being that shape the way care is embodied and enacted rather than by-products that exist outside of or in contrast to the event of care.

## Fatigue as undoing the body-in-action

In much of the psychological literature, 'carer burden' and 'compassion fatigue' are measured and gauged with diagnostics, as if pathological conditions of individuals who must be controlled and rehabilitated (Day and Anderson 2011; Zarit et al. 1980). By contrast, those who do respond to fatigue with resilience are credited with having successfully undertaken a project of meaning-making, or of embodying the ideological values of their culture, be it filial piety, debt repayment, charity, or perseverance. An approach based on a phenomenology of fatigue, I suggest, might allow us to hear another story in these narratives based on vulnerability and susceptibility rather than intentionality, resilience, and the 'body-in-action' (Harrison 2008), and that appears unfinished because it is in suspense, open to both quiet accompaniment (Ross 2009), and also to the voices of 'devils'. In this



story, it is not the body-in-action, but the body undone by the encounter with the face of the Other that reveals the source of care.

I am interested in how ‘broken’ or ‘disrupted’ narratives (Becker 1997; Kirmayer 2000) describe the coming-to-be of carer subjectivities as ‘wounded storytellers’ (Frank 1997). Here is where something like the common experience of carer fatigue can emerge from the narrative as a critical object of analysis. We might ask then, how does fatigue break down narratives or become enfolded within them? Does carer fatigue enrich the empathic engagement with the cared-for or amplify their alterity?

In pursuing these questions in the context of eldercare, I enlist the help of Emmanuel Levinas, who, particularly in his early work *Existence and Existents* (1978[1947]), grasped the lightness yet heaviness of Being, the former lifting us up into a transcendent view, the latter dragging us down into the embodied self. Fatigue, as Levinas argues, cannot be separated from effort, the two composing the phenomenology of labour. In a passage that struck me as strongly indicative of the kind of carer narratives of fatigue and endurance I was hearing, Levinas likens fatigue to

a hand little by little letting slip what it is trying to hold on to, letting go even while it tightens its grip. Fatigue is not just the cause of this letting go, it is the slackening itself. It is so inasmuch as it does not occur simply in a hand that is letting slip the weight it finds tiring to lift, but in one that is holding on to what it is letting slip, even when it has let it drop but remains taut with the effort (1978 [1947]).

It seems to me that Levinas, whose work on embodiment and the ethics of alterity has been recently gathering more attention in anthropology (e.g., Benson 2008; Rapport 2015), would have a lot to say about the care of older people, a care which often depends on the carer’s ability to be vulnerable, exposed and open to the cared-for. For Levinas, who began work on *Existence and Existents* as a French prisoner of war, the displacement and devastation of the Second World War formed a backdrop for a project of recovering the possibility of relationally and the responsibility for the Other as an ontological foundation for ethical life (Topolski 2014). This is a philosophy of fatigue and recovery, exhaustion and endurance, modes of being that I immediately found resonant with the narratives of family carers that have become the focus of my own research. Perhaps this sort of hopeful interference (not intervention) can break up some of the entrenched parameters of research on care for older people, helping us to think about fatigue not as moral failing, nor a hurdle by which we can judge the earnestness of the carer, but as a moment of vulnerability with social and political consequences (Butler 2004; Danely 2016; Harrison 2008).

‘Fatigue’ writes Levinas, ‘presents itself first as a stiffening, a numbness a way of curling up into oneself’ (1978[1947]), and in that ‘curling up into oneself’, there is a sense of endurance and survival, of protectiveness when the world has fallen to pieces:

“To suspend”, to escape, from this corybantic necessity, to take refuge in oneself so as to withdraw from being, to, like Penelope, have a night to oneself



to undo the work looked after and supervised during the day” (Levinas 1978[1947], pp. 65–66 quoted in Harrison 2008, p. 435).

Reading and re-reading this passage, I can’t help but be reminded of Kiyomi’s three-hours to herself, alone in the gyoza restaurant, no longer having to be trapped in the face-to-face care of her mother. Fatigue is not a wholesale denial of responsibility, nor is it merely a way to “escape from intolerable social circumstances” (Kirmayer 1994, p. 100), but rather an embodied subjectivity of enduring that prefigures responsiveness. Like Penelope waiting for Odysseus to return, fatigue can be heroic in its commitment to a larger narrative.

In the following sections, I will examine narratives collected in Japan and England with particular attention to their phenomenological dimensions and cultural and political contexts.

### Carer narratives in Japan

A large table, just big enough to fit twelve chairs around it, filled the small storefront shop that sold care supplies in a residential neighbourhood of Kyoto. Surrounded by aprons, cleaning supplies, and packages of adult diapers, ten women, mostly in their eighties, gathered for their monthly lunch together. ‘The Cherry Blossom group’, as they now call themselves, began when a friend of the shop owner began to have symptoms of dementia, but in a year’s time, it had evolved into an informal support network for women caring for older family members. As the women ate, gossiped and joked, they also exchanged practical information and updates on the health of the person they cared for as well as their own health. While most family carers in Japan are in their fifties and sixties, long lives and the increase in spousal care are quickly raising the age. The youngest at this meeting was 74, and the oldest, 90. These lunches gave them two short hours to recover from their fatigue before returning to care.

“No fatigue (*tsukare*) compares to care fatigue”, the woman next to me explained as we passed small dishes of supermarket sushi around the table, “It is deep, and there is no hope that things will get better”.

The loudest of the group, a 90 year old woman caring for a husband with dementia, spoke up from the end of the table: “You can’t really understand what it means to be a carer unless you have really experienced this [kind of fatigue]. With children at least you can look at them and think that they’ll eventually grow up and learn to take care of themselves, but with old people is just gets worse”.

“The end of the day was the hardest”, another woman began, as the others nodded and voiced their agreement. At 74, she was the youngest of the group, caring for her 96 year old mother-in-law. “When everyone is asleep”, she continued, “I could just feel things getting really dark. Sometimes I would sit down at the kitchen table and just cry”.

The Japanese terms for ‘fatigue’ used by these women most often were ‘*tsukare*’, a general term for weariness felt after some labour, or ‘*shindoi*’, a local (Kansai) colloquial adjectival expression used to express both tiredness usually resulting from hardship. *Tsukare* appears frequently in the polite expression “*O-tsukare-*



*sama*”, which might be translated as something like “good work”. To say someone is “fatigued” is therefore a way of acknowledging the effort spent on some task, and performs a collective closure to that task. To bear one’s fatigue stoically is considered a mark of virtuous discipline, and while it may be seen as a symptom of other harmful conditions, it is not pathological in itself. That said, “carer fatigue” (*kaigo tsukare*) is frequently cited as the underlying cause in cases of both carer homicide as well as suicide. “Shindoi”, also connotes the fatigue of withstanding a demanding (mentally or physically) situation, but rather than the positive valence of “o-tsukare-sama”, it usually signals a more emotionally painful response to fatigue. Both terms stand in contrast to ethnopsychiatric categories for fatigue, such as the French *fatigué* or Latin American *triste*, described by Gaines (1992), both of which are considered valid conditions for psychiatric treatment.

The association of ‘tsukare’ with the care of the elderly, more so than with child care, indicates a different configuration of fatigue, endurance and affective labour. Carers know that the condition of the cared-for, no matter how hard they work, will eventually worsen. Although Japan relies on this unpaid labour to care for its ageing population, direct carer support consists only of locally organized salons like the Cherry Blossom group, and a few groups organized by non-profit charities like the Alzheimer’s Association. There are no direct cash allowances or carer support NGOs like Carers UK, nor is there an equivalent to the British Care Act (2014), which recognizes and protects the rights of carers and the responsibilities of employers and local councils to look after their needs. Carers come to occupy life on the political periphery, where Elizabeth Povinelli (2011) observed excess, exhaustion/fatigue and endurance become entwined in late liberal capitalism. Like other marginal groups, the women of the Cherry Blossom group daily faced what Povinelli calls “modes of exhaustion and endurance that are ordinary, chronic, and cruddy rather than catastrophic, crisis-laden, and sublime” (2011, p. 132). They are dealing with ‘excess’ older people that ought not to be acknowledged in the (post)welfare society, doing exhausting work that goes unrecognized and uncompensated. The Cherry Blossom group might appear to be merely a gossip circle, but taken in this broader context, it had a vital function as not only an escape from fatigue, but an effort to collectively narrate their subjectivity, coming together like soldiers in the trenches, to expose their wounds without shame and to feel relief from the isolation of care.

Carer narratives of fatigue in Japan also resembled other work narratives in the rundown of the day’s tasks. At first I thought of this as merely a way to answer my interview questions, but I found that it was also a form of narrative used between carers as well. For example, the excerpt below was recorded as one man who cares for his mother was speaking to another carer in a support meeting:

If I can put her to bed on the early side, it is about 10 pm. Then she’ll wake up around 11 pm and I’ll put her back to bed. Then usually the next time she wakes is 1 am or 2 am. Then she wakes up at 4 am. Sometimes she wakes me up seven times in one night. Tell you the truth, last night I only slept about three hours. In a couple of months we’ll start being allowed to let her stay



overnight at a short-stay for two nights, but if she stays for three nights, she's like "Where am I?" and it's really bad.

While there is some regularity to the run-down, one also senses the potential for both spontaneity and crisis. Some nights were good, others were bad, but there was no telling what it would be. The short stay would offer temporary relief, but then things would return to how they were. Care work, then, resembles other precarious work in late liberal economies, requiring flexibility and hypervigilance.

Unlike the Cherry Blossom women, most of whom were housewives or held only part-time work, care is increasingly removing men from regular employment as well. One man, who quit his job ahead of retirement age to help his wife take care of her mother described the simultaneous fatigue and hyper-vigilance of caring: "I can't really get much sleep at night" he complained, "I can't ever relax (*ki ga sumanai*). You wonder how long this will go on". Hyper-vigilance and anxiety about an uncertain future maintain fatigue by denying rest or sleep. Carers persist in this state in part because of a model of moral selfhood based on empathic relations with others, as in the case of Kiyomi in the introductory vignette. However, the lack of social support for carers exploits this subjectivity and reproduces embodied modes of social inequality. With little support, family carers strive to endure in the safety of a routine, knowing all the while that, as one carer put it, 'things go on, but only in one direction'.

### **Carer narratives in the England**

England has approximately 40% of the population of Japan (55 million in England, 127 million in Japan), 18% of whom are aged 65 or over (compared to 27% in Japan). While I only interviewed carers in England, some descriptions of national policies are useful to situate the narratives.

As mentioned above, compared to Japan, the UK system for supporting unpaid carers is much more extensive, offering direct carer allowances, one-off small grants, support for taking holidays either alone or with the cared-for, and services for supporting carer well-being beyond the standard respite care services. While full-day care in one's home is impossible to receive using the standard Long-Term Care Insurance (LTCI) in Japan, many carers in the UK are able to use this service frequently, allowing them to work or take longer respite time away from care responsibilities. Many of these benefits vary across different County Councils, just as they vary between municipalities and wards in Japan.

As with Japan, many carers do not have a clear understanding of the care system and put the information together bit by bit as needed, sometimes leading to delays, bureaucratic miscommunications, appeals to insurance companies and providers and so on. It was clear that for most people, accessing services and benefits was a major preoccupation and rarely enjoyable.

I met Paul, a single (divorced) man in his late sixties, when he responded to a recruitment letter from his local County Council. Paul was one of hundreds flagged as "vulnerable" according to their responses to six items on a lengthy online self-assessment survey. Vulnerability criteria included items that dealt with isolation,





aggressive behaviours of the cared-for and lack of hobbies or similar leisure activities.

Paul began caring for his 94 year old father after his father had collapsed in his home and had to be hospitalized. While he was in the hospital, his father, who had been living alone, was diagnosed with dementia. No longer able to live on his own, Paul, who was recently retired, decided that given the high costs of care homes, he would try to look after him, despite having no experience as a carer. However, as the days and months wore on, Paul's father's symptoms began to get much worse, often resulting in sudden confusion and violent outbursts. Exhausted by the daily struggle to care for his father, and concerned with the safety of keeping him at home, Paul tried to move him into care facility, only to be turned away when his father became belligerent with the care staff.

When we met, Paul was only able to get a few hours of sleep each night, and seemed nervous, speaking as if out of breath. He told me that the hardest part was not knowing what was going to come next, when the next outburst was going to come. Sometimes this would be in the middle of an apparently lucid conversation. He described a typical interaction between the two of them like this:

He'd be talking away quite normally... and he'll say, "Is he here?" "What?" "Is he here?" "Who?" [in a low, 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.

The way Paul would go back and forth, voicing his father's sudden and dramatic changes of tone, like someone channelling an angry spirit, lent the narrative a bizarre, uncanny tone. The first indication of the slide into confusion was spoken normally, an innocent question, but one coming from a place outside the 'normal' conversation. Paul tried to understand, but couldn't follow, and his father interpreted this as a threat, suddenly speaking in a different, gruff, booming voice. For Paul, this was the change that 'rips you to bits', as if ripping apart the script, the narrative, the body itself—leaving nothing to hang on to.

For Paul, being ripped to bits led to continual, inescapable feelings of doubt and inadequacy that kept him up at all hours of the night, and his sleeping pattern became erratic. "I'd just go and sit on a chair in the living room with a sleeping bag and hope that I'd wake up if he moved" he explained, a little embarrassed.

Even when he did manage to get to sleep at night, he would often be awoken in the middle of the night to his father's cries, finding his father tearing off bandages that had become soaked from a broken colostomy bag. Paul would clean the mess and replace the bandages, all the while listening to his father's confused abuse. Although I had not asked Paul about fatigue directly, it didn't take long for his narrative to make its way there:

There are periods I'd go twenty-four 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!" [gently] "C'mon you need to go back down" [gruff] "LEAVE



ME ALONE! LEAVE ME ALONE!”– This would be at 4 o’clock in the morning!

‘Brokenness’ was not just part of the content of Paul’s narrative, but characterized the disruptive, polyvocal flow of the narrative itself. It was not the face, or even the body of his father that ripped him to bits, but his disjointed self as expressed in his swings of verbal tone. Responding to this broken narrative from a place of vulnerability meant that Paul too would become broken in a way, unable to follow a clear path to a resolution. Trying to assert his will was met with forceful resistance, leaving Paul bewildered.

Paul’s case is illustrative of other English carer narratives in the sense that he struggled to find ways to uphold the barrier of personhood between himself and his father only to find that in his fatigue, these barriers were being broken down. His efforts to right his father’s confused behaviours, and to continue to act as if he and his father were separate and autonomous individuals (as represented by their different voices in the narrative) heightened Paul’s anxiety and fatigue. Whereas Japanese carers understood fatigue, and embodied sensitivity as a sign of an emerging intimacy and vulnerability that enabled care, English carers like Paul often lacked a similar narrative.

### **Tragic fatigue: seductive exhaustion**

Thus far, I have been interested in characterizing fatigue, in all its wounded vulnerability as an orientation towards subjectivity, the body, and the cared-for, that, consistent with Levinasian ethics, opens one up to alterity and ethical responsibility for the Other. Fatigue is both ‘recoil’ from the effort of care and the place of exhaustion from which new efforts must arise, and new possible selves can form in consciousness. I relate these efforts towards Being to what Povinelli (2011) calls “quasi-events” that permeate the embodied experience of marginalization in late liberalism. The excerpts from carers’ narratives reveal both the numbing monotony of care tasks and the hypersensitivity and rawness of emotions. Fatigue is like drifting into a sleep from which one is easily startled and brought back, however broken, into the world.

I want to be clear, however, that I do not mean to romanticize fatigue as somehow a moral virtue in its own right. The challenge for any ethics based on fatigue is not to defend its role in empathic mutuality, but to contend with the dangers of ethically problematic thoughts and feelings, especially in cases of over-exhaustion and isolation where corporeal vulnerability to pain and suffering begins to entertain desperate solutions.

Here again we need to be cautious about the relationship between fatigue and violence, and not overly polarize carers into categories of resilient/good and exhausted/abusive. Carers who I have seen give the most tender and patient attention to the one they cared for are the same ones who have thought about ‘mercy killing’. Or they have considered suicide, only stopping short because they couldn’t bear to leave the cared-for behind. They still feel the tug of attachment and love, even if they find corporeal being unbearable and “desire to belong differently to the



world” (Stevenson 2014, p. 173), to story the self into a world that makes sense to the exhausted body.

Even after Paul had finally found a place for his father in a care home specializing in dementia, much of the daily worry remained. In the care home, his father’s dementia had progressed, and although there were fewer aggressive outbursts, there were also no longer any times when he would recognize the man who came to visit him as his son. He no longer said ‘I love you’.

When I suggested that Paul might take his father back at some point, he looked downcast and shook his head, saying,

I don’t know - I don’t know - you run out of knowing where to, where it should go, apart from doling out suicide pills. Because again people I talk to, you might not have heard it but I’ve heard it, and you say if it was a dog - you know, it’s a wicked thing to say, but it’s true - or it’s a difficult thing to say or to admit that you’ve thought that, but it’s true.

In fact, Paul was far from being the only carer who admitted having thoughts about killing himself or the person being cared for. The first time I cautiously mentioned care murders at a men’s carer meeting in Japan, I was surprised when the man sitting across from me identified, saying, “We’ve all had those kind of thoughts. Anyone who has cared full time has thought about that if it is someone you really care about”. There were nods around the table from the other men. “I can really understand [the care murders], that feeling. I think we all do”, said another man at the table, “So they make a big deal of it in the news, but I think the real issue is that we’re all feeling like that. The important thing is keeping control over those feelings. Not getting too tired”.

In Japan, incidents of carers killing family members or of murder-suicides churn in the public imagination as their heart-wrenching gruesome details appear in newspapers and television programmes. An NHK documentary that aired 1 July 2016 called “‘I have killed a family member’—Care murder: Confessions of those involved” reported that since 2010, there have been at least 138 care homicides in Japan (homicides committed by the carer). A further survey indicated that at least one in four carers have thought about harming either themselves or the cared-for (NHK 2016).

The perpetrators interviewed for the documentary hardly looked like killers at all. Most were older people themselves, dressed conservatively, and speaking politely. But the ‘confessions’ are strikingly familiar. One woman described how she counted up to 15 as she held a pillow over her husband’s face to smother him. “I reached the absolute bottom. The person caring gets so exhausted that their head can’t work right...Then a devil (akuma) would come. ‘It’s the only way, it’s the only way, it’s the only way [it would say]”.

I was struck by the similarity between this woman’s story and that of a woman I met, whose voice, near the end of our talk began trembling, as tears welled up and fell down her cheeks:

When my heart would become a devil, I really, it was really like, ‘if only she would die’, I would think horrible things like that. How could I have thought



such a horrible thing? I would wonder afterwards. But it was like at that point, I was backed into a corner, you know, I thought about just setting the house on fire and burning it all down. We would die together. I had times when I thought like that. And so now I really understand how a person feels when they say they wanted to die together [with their care recipient].

If fatigue is the thing that endures after the ‘end of the world’ (Levinas 1978[1947]), without intention or meaning but rendering the body vulnerable, it is no assurance that devils will stay put. The devils of these Japanese narratives bear in common the temptation of a solution to fatigue, a promise that even death would grant escape and resolution to the broken narrative.

### **Recovery: enduring fatigue**

Carers like Paul longed for just an occasional day, or even a few hours free from the weight and weariness of care. This was true not only for carers of persons living with dementia, but even for those who could still communicate with the cared-for. The weight of care had to do not only with physical tasks, but the uncertainty of the overall narrative. Even if one gave excellent care, the result would be decline and death. One carer put it this way:

It’s the feeling that there is no end in sight. That you’re just ploughing on through this fog of tasks that, giving you no sense of—‘hope’ is the wrong word... it’s just being totally immersed and having no space...”

Enduring through care meant giving up the idea of progress towards an ultimate goal, but somehow holding onto a kind of hope. Perhaps this is why this carer stopped short, breaking the flow of her own narrative thread, before she gave up on the idea of hope. In making this split-second decision, she became more resolute that enduring itself was a hopeful process, even if it gave ‘no space’ to fall back into fatigue, but drove one on and on and on.

The temporality of caring seems to swing carers back, forth and around until they have lost orientation, wanting desperately to collapse and let the world stop spinning. Care seems to go on and on in monotonous repetition, while at the same time it is suspended in the instant, the engrossment or immersion in the world of the vulnerable person being cared-for. It appears endless, yet it could very well end at any time.

Persevering is one way to get through this, and both English and Japanese carers spoke of the importance of “getting on with it” or “doing what has to be done” without debate or reflection. One Japanese carer traced this attitude back to feudal Japan, when loyalty to one’s lord meant having to persevere in whatever station one was born to. “I have the same blood running in my veins” he added, patting his forearms. Perseverance in care can leave little room for others, let alone oneself, but fills the space with little events, little stories, of care.

Paul seemed done with perseverance. He was exhausted. He wanted to escape his responsibility, to avoid the accumulation fatigue: “And then it all piles back, I can’t describe it any other way, the tsunami effect—it sounds rather dramatic but



everything just piles up and piles up”. Paul is self-conscious of his own “dramatic” delivery here, but I found his poetic metaphor of piling up and piling up of fatigue like a great wave appropriately sublime. The force and scope of a tsunami pushes the edges of the imaginable, and like care, from the perspective of the person in its shadow, there seems to be no end in sight. For carers who pull back from the tragic, who imagine an alternative, a way of being otherwise, the ethical demand returns intensified.

Endurance does not stop the world from happening to the self, but it does bear the hope that time does pass, and perhaps can “heal all wounds”. For others, this process of living with fatigue and paying attention to its voice required a scaling back of expectations. Russell was in his late seventies and suffering minor arthritis when I spoke to him about caring for his mother. For him, ageing and pain made it easier to pay attention to his fatigue and tend to it right away:

There are times, if I’m tired I get very irritable. My whole life I’ve been like that, if I get tired I get irritable. I get tired quicker nowadays, but some time back I learnt from myself to understand my body better. I can go out in the garden on a day like today, I can do that job and that job and that job, it’ll all need doing, but there’s no way I’ll get them all done today because I know that when my body says you’ve done enough for today you need to stop now.

Others endured by placing their experience within a larger framework, whether religious, or, like Cathy, a more humanist and ecological worldview:

Jason: you said when you’re in the midst of it you don’t have the time to – “to get frustrated, just getting on with it”.

Cathy: Surviving, yeah. So when you, when I see about these people who are coming out of Syria I think to myself well at least I’ve got a warm bed at night. And when it was all happening I thought you can always see somebody who - in the winter, people who sleep on the streets, at least I have a warm bed at night. Even though you hit the bed exhausted. And I listen to music too, usually in the night when I first go to bed, [she describes the program she enjoys] That’s something that - I’ve never thought about it before - that’s something else that was missing. I didn’t have the time to sit and listen to music, and music is very important to me. So when I just sit - actually, I’m not just sitting, I’m listening to sounds, so if it’s the sea, if it’s the trees, if it’s wildlife... yeah. That’s what I do - it’s a sort of escapism I guess. No it isn’t really is it - it’s reality, because it’s there as well.

Cathy intuitively felt a soulful connection to the ‘reality’ of time listening to the world, letting both the unrelenting duties of care and its fatigue slip away. However, unlike the escapism of the tragic ending described earlier, Cathy and Russell approach these moments of disengagement from care tasks, moments of fatigue and recovery, that reframe the sensing body, its rhythm, and ultimately, ethical subjectivity. Would this transformation have happened without fatigue?



## To accompany the ‘devil’

Taking on the responsibility of care means taking on the risk of accompanying the cared-for in their wounded world and creating a space of vulnerability, susceptibility and sensitivity. Vulnerable carers’ experience of fatigue can contribute to isolation, depression, and even tragedy, but I argue that fatigue is not in itself the ‘devil’ that must be exorcized through rituals of resilience and meaning-making. Rather, fatigue should be considered as a component of care, a brokenness that allows for a reorganization of carer subjectivity and deserves recognition and space. This reorganization is revealed in narratives, which afford the opportunity to construct images, metaphors, and small dramas in ways that open possibilities for becoming through and for the Other.

Perhaps the most obvious example of the ways ‘broken’ narratives of fatigue console the wounded carer is in sharing these narratives with other carers. Indeed most of the carers who spoke to me for this research were motivated not by the hope for better social policies but by the desire to have their stories reach and help other carers—people ‘like them’.

When carers speak to each other, they share their narratives of fatigue, insomnia, frustration and despair, as ways of being-in-common, as witnesses to the same suffering, as those who endure. Even when these narratives are not voiced, carers recognize that fatigue forms an affective baseline of experience, and this makes them more comfortable speaking without reservation. “When I talk to someone who isn’t a carer”, one woman told me, “It’s like, if I talk about something good that happened, like [mother] ate all her food, they think that everything is alright and I’m doing just fine, which isn’t the case! But if I go around talking about things that are hard, it just sounds like complaining, and people don’t want to listen to that. When I talk to a carer, it’s different because we all know that it is hard”.

Narratives reveal the ways bodies and selves are culturally elaborated, and I have sought to show how cross-cultural comparison can illustrate this notion while at the same time paying attention to the ways cultural similarities can play out differently due to historical and institutional structures. In general terms, Japan lags behind the UK in terms of institutional support for carers, while Japanese cultural values of empathic attention, interdependence, and family connections through suffering and care are not as strongly developed in the UK. Yet in both countries, the experience of fatigue and endurance bears close resemblance. I have drawn on the phenomenology of Levinas to help me make sense of these fundamental resonances, but as the work of Povinelli, Butler and others suggests, fatigue, vulnerability and endurance must also be situated within the political and social worlds that they emerge within. These approaches lift the personal narratives and transient quasi-events out of their limited context, at the same time allowing the narratives to bring flesh and blood to language.

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