

Beyond Bodily Integrity: the bioethics of the disordered body

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My focus on vulnerability and bioethics – which acknowledges but goes beyond mainstream feminist ethics – will take a phenomenological perspective that understands the self as having no meaning or existence beyond its embodiment. As such we are always open, and therefore vulnerable, to the constant changes of embodied experience. The transformations in embodiment are both necessary for development and continuous over the life course, but it is only when something breaks the cycle of normative development that the intimation of vulnerability and disorder arise. Corporeal disorder operates in a highly individual and differentiated way as it manifests, for example, in the experience of disability, pain, ageing and dying. These are not exceptional moments of vulnerability in a life otherwise secure and predictable, but they do clearly set out the limits of the western imaginary, and more particularly of modern western biomedicine and conventional healthcare. In offering a critique of the positivist enterprise of biomedicine, I want to suggest a different understanding of the embodiment that has radical implications for bioethics.

In going beyond the notion of bodily integrity to focus instead on vulnerability, I want to suggest from the start that there is nothing intrinsically negative about the state on being vulnerable. I explicitly reject the notion that the vulnerability and integrity of the self are binary opposites and question whether vulnerability must always signal some breakdown in integrity and must follow after it. That latter approach would surely presuppose that there is something unharmed, some integrity (Latin *integer*: unharmed) that could be wounded or harmed, but such a notion is by no means self-evident. Levinas, for example, takes a very different view and attempts to position vulnerability as the mobilising feature of an ethics that precedes and thus constitutes the ontological moment. As he works through it in *Otherwise than Being*,¹ it is my pre-ontological vulnerability – induced by the naked claim of the other – that is the provocation of ethical subjectivity. My own approach takes an initially phenomenological perspective that follows on from the work of Merleau-Ponty before briefly addressing some feminist accounts of vulnerability and finally turning

¹ Levinas, Emmanuel *Otherwise than Being, or, Beyond Essence*, trans. Alphonso Lingis. Pittsburg, PA: Duquesne University Press.

to a more radical postmodernist approach. For Merleau-Ponty, the self is conceived as having no meaning or existence beyond its embodiment and as such is always open, and therefore vulnerable, to the constant changes of embodied experience; while for later theorisations such contingency is rejected and vulnerability is no less than the very possibility of becoming an embodied self at all. Indeed, I take it as axiomatic – though in preferring to focus on the implications, I am not fully arguing for it here – that vulnerability is an inherent and irreducible aspect of the human condition.

What, then, is that is meant by vulnerability? Given that the phenomenological approach posits that body and mind are inseparable. I will dispense with any purely abstract argument and insist on the material register of human corporeality where the transformations in bodily form are both necessary for development – from a new-born infant to an adult – and enduring over the life course. Such transformations are not considered vulnerabilities as such precisely because it is taken for granted that it is only when something breaks the cycle of *normative* development that the full intimation of vulnerability and disorder arise. Two aspects of vulnerability are in play here: first a grounded and very material sense of indeed being open to contingent harm; and second an existential mode which speaks to a profound counter to any sense of a stable, fully-integrated and invulnerable self that endures over time. Despite the continued privileging of mind in western discourse, our embodied selfhood is a matter of complex interweaving. Whenever the body is at risk, it is the integrity of the self that is threatened. In short corporeal and ontological disorder are inseparable. And if we understand embodiment as a highly dynamic modality, none of us can finally escape the realisation that the invulnerable self is an illusion.

It should be stressed, nonetheless, that bodily disorder operates in a highly individual and differentiated way as it arises, for example, in the experience of disability, ill-health, pain, and dying, with the everyday transformations of ageing serving as a less dramatic scenario for similar considerations. My invocation of those areas is not because they are singular moments of vulnerability in a life otherwise secure, predictable, and controlled but because they so clearly set out the limits and shortcomings of the western imaginary, and more particularly of modern western biomedicine and conventional healthcare. In offering a critique of the positivist enterprise of biomedicine in particular, I want to suggest that a different understanding of the embodiment has implications not only for the operative models of many substantive areas of health care, but for the arena of bioethics. It is salutary to recall that bioethics has been a relatively recent addition to the philosophical canon, tainted perhaps by its too close association with the messy materiality of living bodies and not easily lending itself to the imposition of abstract principles. It is more suited to the practicalities of applied morality where a utilitarian calculus can guide and judge bioscientific behaviour while appearing to take specific circumstances into account. And yet, bioethics is too often out of touch, disembodied, and still clinging the sense of the subject as an autonomous self detached from a more or less unruly body.² The emergence of phenomenology as an alternative perspective on embodiment is hardly new, and yet it is still a somewhat niche concern within bioethics, while challenges emanating from a postmodernist – let alone a posthumanist – approach are strikingly rare. And though I strongly favour the latter post-conventionalities, the trajectory in this paper is limited to a questioning of what the privileged terms of biomedical discourse imply.

² See Shildrick, Margrit (2005) 'Beyond the Body of Bioethics' in M. Shildrick and R. Mykietiuk (eds) *Ethics of the Body*. Cambridge, MA: MIT Press. for a fuller analysis of the shortcomings of bioethics.

If we take pain, ageing, and death – and all are heavily medicalised – as overt instances of vulnerability, the remarkable thing is that despite their ubiquity as life experiences, relatively little bioethical attention has been paid to the materiality of those conditions. In effect, any real sense of embodiment tends to be left out. With few exceptions, we will all age, and experience pain, and all of us will die, as an intrinsic part of the life course, and yet those experiences are threaded through with forms of silencing, not simply in the realm of biomedicine – which is strongly oriented to threats that are temporary and manageable – but as a kind of disavowal that operates widely in everyday life. There are of course several specific discourses that deal with such experiences. Feminist academics of the 2nd wave have increasingly addressed the issue of aging and the disabilities that may accompany it;³ while life-writing, which often focuses on the disorders of embodiment, has become a prominent literary form.⁴ Too often, the narrative themes of loss and precarity hold sway, resulting in either grief and anger, or transcendent tales of vulnerability survived. Either approach is problematic, but perhaps partially escape the more general context in which whenever those experiences *are* spoken, it is as an external description, rather than as the phenomenological experience.

Until recently, the notion of human vulnerability has played very little part in the standard parameters of philosophy, except indirectly in the context of death and suffering. Yet even death which has been a significant focus of classical philosophy, and a necessary topic in bioethics insofar as it relates to the relative value of life or invites interventional procedures, has been largely dematerialised or hidden away. Even though it is a modality that encompasses us all, event of dying clearly evokes a disturbance to epistemological and ontological certainty that constrains discussion. As something that is finally unpredictable, and irreversibly transformative of the embodied subject, it remains a disruptive point of ambiguity and disorder that grounds both anxiety and denial. Equally pain is at the centre of much biomedical research and clinical practice, but it remains poorly understood even in those limited contexts,⁵ largely unspoken as such in the wider medical encounter, and mostly absent from philosophical discourse. The main issue appears to be to establish protocols for the management of pain as though bioethics were no more a strategy of effective control, rather than the pursuit of flourishing in a fleshy encounter.

If as many commentators note, biomedicine can often be characterised by its committed defences against uncertainty, and by the practice of warding off and denying

³ Mackenzie, Catriona, Wendy Rogers and Susan Dodds (eds) (2013) *Vulnerability: New Essays in Ethics and Feminist Philosophy*. Oxford University Press. Sandberg, Linn (2013) 'Affirmative Old Age – The Ageing Body and Feminist Theories on Difference.' *International Journal of Ageing and Later Life* 8.1: 11-40. Finlay, Jessica (2021) 'Intimately Old: From an Embodied to Emplaced Feminist Approach to Aging', *Hypatia* 36(1), 80-100.

⁴ Couser, Thomas (2016) 'Body Language: Illness, Disability, and Life Writing', *Life Writing* 13:1, 3-10, doi: 10.1080/14484528.2016.1132376 Adams Rachel (2017) 'Disability Life Writing and the Problem of Dependency in The Autobiography of Gaby Brimmer', *Journal of Medical Humanities* 38(1):39-50.

⁵ See Raffaelli and Arnaudo who write: 'despite the scientific knowledge already available on the pathologic mechanisms underlying this condition and the socioeconomic burden of chronic pain, pain does not gain the attention it deserves.' Raffaelli William and Arnaudo Elisa (2017) 'Pain as a disease: an overview', *J. Pain Research* 10: 2003-2008, p.2007. A recent editorial in Nature reiterates the point: 'Approaches that fail to prioritize the many complex drivers of chronic pain and even deny its existence are causing unnecessary suffering for millions.' Nature Editorial (2023) 'Treat pain as a priority, not an afterthought', *Nature* 615: 765.

death even to the point of disembodiment those it seeks to aid,⁶ then it becomes clearer why a condition like pain - that we would expect to be central to the endeavour - is so marginalised, even covered over within the positivist and objectifying ideals of medical enterprise. Corporeal unpredictability or fluidity in any form is a disconcerting problem to a discourse that has worked traditionally through classification, normalisation and regulation. In particular, chronic pain contests the imposition of definitive strategies by frustrating the legitimating search for localization and causal connections. But even beyond the rationalism of the clinic, pain struggles to find adequate expression. Like the experience of ageing and disability, it is both a matter of exterior public display, and an interior transformation of the embodied subject that remains largely unacknowledged. And perhaps ageing has been most silenced of all, in western culture at least. Elders are both deprived of a voice and scarcely spoken of except as somewhat burdensome others. Their experience is so effectively privatised, considered so peripheral to socio-cultural normativities, that the ordinary effects of ageing can come as a surprise, the changes about which our mothers neglected to speak.

What sets pain, ageing, death and the like apart is that each challenges the normative imaginary of the embodied self as properly self-determining, constant and well integrated. Given the vastly differential experiences of embodiment, we should acknowledge the impossibility of that ideal state, and yet we continue to hold onto the model of always being in control of both mind and body. As Rosemarie Garland-Thomson, puts it in relation to disability: 'One of our most tenacious cultural fantasies is a belief in bodily stability, more particularly the belief that bodily transformation is predictable and tractable. Our cultural story of proper human development dares not admit to ... vagaries, variations and vulnerabilities.'⁷ What is at stake is the postEnlightenment fantasy that drives the cultural imaginary of the invulnerable self, an image that biomedicine has taken as its own ideal. The problem is that the more potential human vulnerabilities are made manifest, the more they are projected onto the bodies of others, and those others held apart. The point is not simply that we habitually refuse to acknowledge the distress of others, but that it *cannot be seen* without risk because it threatens the stability of the normative self-image. The western modernist tradition dictates that bodies are at our disposal, subject to our will, whole and integrated, and not liable to cast doubt on our ontological security, even though few people really live the Cartesian mind/body split, if only because most of us are obsessed with our corporeality and never quite certain of it. What matters is the tension between the aspiration to normative standards of self-management and the actual struggle (and failure) to maintain that control. Aside from the biomedical interventions that respond to evident crises in personal health, our society's preoccupation with keep-fit regimes, dieting, cosmetic surgeries, wearable digital monitors and more, speaks to a constant need to discipline the body in order to circumvent its own inherent instability and lack of order.

The problem is that as we become disabled, experience ill-health or simply age, the body increasingly falls short of self-determination and becomes visibly more limited in its capacities. Alongside the negative perception of any inability to participate fully in the

⁶ Brown, Nik and Andrew Webster (2004) *New Medical Technologies and Society: Reordering Life*. Cambridge: Polity Press. Shildrick, Margrit (2005) 'Beyond the Body of Bioethics' in M. Shildrick and R. Mykitiuk (eds) *Ethics of the Body*. Cambridge, MA: MIT Press. Bishop, Jeffrey (2011) *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying*. Notre Dame, IN: University of Notre Dame Press.

⁷ Garland-Thomson, Rosemarie (2007) 'Shape Structures Story: Fresh and Feisty Stories about Disability', *Narrative* 15, 1: 113-123, p.114.

capitalist labour market, the representation of the physical and cognitive changes of old age as unquestionably a decline can only be understood within the normative standards of specific socio-cultural contexts. This seems particularly unthinking in the case of the *ageing* that will affect the majority of us. Long before literal death, older people commonly experience social death, a culturally mediated shrinking of horizons that is both material and metaphorical.⁸ On a phenomenological level, the external context in which a self takes shape and is continually transformed becomes increasingly limited so that older people – in the global North at least⁹ – are devalued, not fully seen, and yet simultaneously made subject to increased surveillance over, and management of, their putative vulnerabilities. Either way, ageing bodies must not be allowed to disorder the familiar norms of sociality. Certainly, changes both in health care and social policy could alleviate some of the distress borne by older people, but my argument is that that process of othering – properly called in this case gerontophobia, which the *Oxford Companion to Medicine* defines as ‘a morbid dislike of old people or a dread of growing old’ – is entrenched as much at a psychic, as material, level. The underlying issue is our refusal to accept the innate instability of the body and the embodied self regardless of its material condition. It is not that bodies *in extremis* are the problem, but that all bodies are inherently precarious and vulnerable. At best the body is in a state of provisional stability and equilibrium that can never fully escape the imminence of breakdown. In other words, the ambiguity of ageing is no more than the ambiguity that informs all bodies. It is the unspoken meaning of ageing – the intimation of instability and uncertainty – not the condition itself that is unacceptable and must be disavowed.

It might be expected that the conventional characterisation of overt vulnerability as a quality of the other would elicit a sense of moral responsibility and invoke care, as for example in the normative philosopher Robert Goodin’s claim¹⁰ that the degree of our obligation to offer aid is proportionate to the level of dependent vulnerability suffered by the other. In reality, the opposite is often the case. As with people with disabilities, women who are pregnant, infants, and children, it is well-established that those who are elderly experience higher levels of physical and mental violence than the interpersonal norm. In short, the disembodied ethics of the modernist convention fails to account for the depth of ontological anxiety that may motivate such violence. The non-normative body, the body that cannot be classed as ‘clean and proper’ and may present as especially vulnerable, is not just disavowed but abject. Above all, there is no sense in conventional discourse that there might be a mutual ethical encounter. Rather than Goodin’s ideal moral actor taking responsibility for an other, could we at very least rethink the encounter with the other’s vulnerability as an openness that renders the self vulnerable? The task then would be to take the risk of working through the incommensurable layers of power and emotion that mediate the relational economy.

⁸ Brannelly Tula (2011) ‘Sustaining citizenship: People with dementia and the phenomenon of social death’, *Nursing Ethics*; 18 (5): 662-671. Králová, Jana (2015) ‘What is social death?’ *Contemporary Social Science* 10 (3): 235-248.

⁹ The popular view that elders have a much more positive status in traditional societies than in the global North is undercut by the encroachment of westernised ideals throughout the world. See: North, Michael and Fiske, Susan (2015) ‘Modern Attitudes Toward Older Adults in the Aging World: A Cross-Cultural Meta-Analysis’, *Psychological bulletin* 141. 5: 993-1021. Nonetheless, concepts such as autonomy and consent in health care can show significant differences in meaning.

¹⁰ Goodin, Robert E. (1998) ‘Vulnerabilities and Responsibilities: An Ethical Defence of the Welfare State’ in Gillian Brock (ed.) *Necessary Goods*. Lanham: Rowman and Littlefield.

A further complexity is that older people inevitably internalise the same cultural norms that mobilise the experience of alienation to the extent that many may refuse to acknowledge their own corporeal transformations. The autobiographies of Simone de Beauvoir in which she confronts both death and ageing are a good illustration. In the account¹¹ of her mother's terminal illness with an aggressive cancer, the older woman's fear of dying is eased only insofar as Françoise, the mother - with the collusion of Simone, her sister, and the attending physician - tacitly refuses to accept that death is imminent. To the end Françoise clings to some semblance of control, even as her body dis-integrates. In the later books,¹² Beauvoir often seems repelled by her own ageing process, experiencing a protective sense of self-distancing. As she puts it: 'Old age is something beyond my life, outside it - something of which I cannot have any full inward experience.'¹³ But if one strategy of attempting to maintain self-determination is to deny the materiality of ageing and death, then we might notice that the alternative of acceptance - which may include opting for physician-assisted suicide - perhaps represents only another form of control, a conscious act of self-will that would cover over the embodied anxiety of approaching death.

The bioethical import of such struggles is not that of resolving the tension between the control of denial and the control of acceptance, but that the ambiguity and uncertainty of embodiment should be so threatening to human selfhood, at least in the sphere of western influence. Insofar as death has meaning both as a materiality and in the cultural imaginary, the impulse of all those involved is to intervene to settle on one or another path, not so much for the sake of the one who is dying as for the need to exercise control over unruly elements. Amongst terminal patients - and dying *is* usually institutionalised - the 'good' ones are those who are docile and manageable, who have suspended their own anxieties and ceded agency and control to their familial or professional carers. It is an aspect of what Heidegger calls a tranquilisation about death.¹⁴ As with the lay public, the medical profession itself seems singularly unwilling to openly admit to uncertainty.¹⁵ The urge to impose order and rationality in the face of disorder, and to give hope where none is justified, finds expression in biomedical procedures that may postpone the moment of dying, but fails to attend to the on-going changes to the being-in-the-world of the patient.

The apparent binary choice between the two extremes of high-tech intervention to preserve life at all costs, and the shutting down of care attendant on the decision of clinical futility, have much in common: both are about the desire to impose rational control. Neither is necessarily bioethically wrong in any particular case; rather, the imperative to do something - to exercise a determining agency - may calm lay and professional anxieties alike, but at the cost of disregarding other less reductionist alternatives. In the case of Françoise, it could be argued that her daughters' implicit agreement to endorse her denial is morally permissible. In the context of our society's shared investments in disavowing anxiety it could scarcely be wholly altruistic, but that is very different from the distanced

¹¹ Beauvoir, Simone de (1965) *A Very Easy Death*. New York: Pantheon Books.

¹² Beauvoir, Simone de (1968) *Force of Circumstance*. Harmondsworth: Penguin. Beauvoir, Simone de (1972) *Old Age*. London: Andre Deutsch and Weidenfeld and Nicholson.

¹³ Beauvoir, Simone de (1972) *Old Age*, p.291. London: Andre Deutsch and Weidenfeld and Nicholson.

¹⁴ Heidegger, Martin (1962) *Being and Time*, trans. J. Macquarrie and E. Robinson. London: SCM Press.

¹⁵ Schneiderman, Lawrence and Nancy Jecker (2011) *Wrong medicine: doctors, patients, and futile treatment*. Baltimore Johns Hopkins University Press. Gawande, Atul (2014) *Being Mortal: Medicine and What Matters in the End*. New York: Metropolitan Books.

control of the clinicians who authorise a supposedly life-saving operation, even though knowing that its effects will be temporary at best. Beauvoir worries about agreeing to participate in the highly deceptive scenario, but finally compromises in order to satisfy the bodily needs and desires of her dying and vulnerable mother. As such, there is a case to be made that hers is an ethics of relationship which does not simply fall back on abstract principles in order to enact the good. Healthcare professionals, in contrast, are traditionally trained to defy that emotive, affective relation, and find instead a trajectory through the messiness of life and death without becoming personally unsettled. In the convention, the biomedical encounter is a relation in which the one acts, within their own moral framework and professional protocols, on the vulnerable other. The material and psychological status of the professional's embodiment is considered irrelevant. In effect, the rigid hierarchical structure, faith in technology, and emotional detachment of modern western medicine, combine with an understanding of death as adversarial¹⁶ to mobilise procedures that are broadly unreceptive to human needs and desires. I do not mean that conventional approaches are always ethically inadequate, but that often they fail to respond to the embodied specificity of a given situation.

As an alternative approach, a recognition of the phenomenological significance of the interdependency of living in a world of others more readily lends itself to a corporeal ethics that might acknowledge the insecurities and vulnerabilities on all sides of an encounter. While no patient should be compelled to partake of a different relationship - and some might prefer the convention of 'doctor knows best' - that does not diminish the ethical necessity of exploring other ways of openly negotiating the biomedical encounter to respond more productively to the overt and hidden needs and desires at stake. The difficulty for bioethics is that the change to a radically less objectifying approach demands a reconsideration of the conventional Western intellectual tradition and its investments in ontological and epistemological certainties. In relation to death, there is already a substantial body of literature on the significance of self-determination around contentious issues like euthanasia, compliance or non-compliance with living wills, or on the ethics of organ and tissue transplantation, but little of it shows any awareness of the mutually constitutive relation between patients and practitioners. In recent years, feminist bioethicists have led the way in rethinking the biomedical encounter in general,¹⁷ they too remain largely silent with regard to the materiality of dying.¹⁸

Let us consider now a specific area that encompasses the vulnerability of both aging and impending death. The incidence of dementia in older age groups - and it is by no means a purely western concern - grows year on year and constitutes an area of unresolved ethical concern, even though that may be rarely spoken of as such. Despite its ubiquity, the mental and physical state of dementia carries - in many societies but not all - a postulation of pathology, reflecting an assumption in the global North that alterations in the embodied self signify a loss of value. The experience of dementia is seen to exemplify precisely the breakdown of integrity that vulnerability implies. Dementia care seems either

¹⁶ Pascalev, Assya (2018) 'Is death the enemy? The normative power of metaphor in bioethics' in *Ethics of emerging biotechnologies: From educating the young to engineering posthumans*, 87-106. Trivent Publishing.

¹⁷ O'Neill, Onora (2002) *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press.
Prainsack, Barbara (2018). 'The "We" in the "Me": Solidarity and Health Care in the Era of Personalized Medicine', *Science, Technology, & Human Values* 43. 1: 21-44.

¹⁸ The leading journal of feminist bioethics (IJFAB) exemplifies the omission. Despite publishing 6-8 articles twice a year, over the last 10 years, just three dealt directly with death or dying.

directed towards preserving some form of autonomy - or at least self-direction - or to an infantilisation that scarcely acknowledges agency at all. In the face of cognitive decline and an increasing inability to negotiate the functions of everyday living that eventually ends in death, sensitive care focuses on strategies of eliciting a recognisable interaction that intimates continuing sociality. Nonetheless, dementia *is* taken to herald a collapse in communicative competence that finally puts the subjectivity of the one affected beyond recall.

In research for my recent book, *Visceral Protheses*,¹⁹ I have looked at the care for those living with dementia in residential homes through the specific locus of new robotic technologies that are claimed to emulate some dimensions of human affective relations. These come in many forms, but my interest is in what are called empathy robots that are designed to engage in a life-like way with the users. Many are designed with a humanoid face, but I am more interested in the zoomorphic forms that resemble small animals such as cats, dogs and baby seals.²⁰ The usual aim of such biotechnological interventions is to offer people with dementia ways of prolonging the expression of their previous sense of self. Regardless of the evident breakdown of the usual markers of autonomy and rationality - and remembering of course that dementia is always socio-culturally inflected²¹ - western-based interventions occur within a socio-cultural imaginary saturated with notions of the singular self. What should interest us as philosophers and bioethicists is not primarily the empirical mechanics of providing alternative forms of care, but the extent to which the ideal integrity of the self is thrown into question.

There is of course nothing exceptional about the use of technological enhancements in the pursuit of flourishing life, and the normative life course necessarily co-evolves with multiple prosthetic practices. Nonetheless, in the case of empathy robots, the dominant focus on preserving selfhood and having a positive impact on sustaining sociability has generated a plethora of moral concern.²² Sceptics offer a very limited discussion of robot care in terms of the putative ethical dangers of replacing human with mechanized or digital support, raising fears that it undermines the value of in-person human to human interaction and neglects the real needs of those with dementia. In contrast, a recent paper by Karen Lancaster²³ offers a robust defence of both the practical and emotional caring aspects of so-called carebots. While many agree that robots can potentially offer invaluable physical care, Lancaster argues that their simulation of emotional care is sufficient to satisfy user needs. As she puts it: 'What is of paramount importance is the patient's feeling that someone or something cares for them - and when a carebot can... simulate emotional care, there will be no good reason to prefer "the human

¹⁹ Shildrick, Margrit (2022) *Visceral Protheses: Somatechnics and Posthuman Embodiment*. London: Bloomsbury.

²⁰ See Shildrick, Margrit (2023) 'Robotic Technologies, Touch and Posthuman Embodiment in Queer Dementia Care', *Senses and Society* 18. 2: 126-138. <https://doi.org/10.1080/17458927.2023.2179239>

²¹ In many non-western societies, dementia is typically seen as a normal and acceptable part of ageing. See: Tanaka, Shogo (2015) 'Reconsidering the Self in Japanese Culture from an Embodied Perspective', *Civilizations* 20. 3: 35-39

²² Sharkey, Amanda and Noel Sharkey (2012) 'Granny and the robots: ethical issues in robot care for the elderly', *Ethics and Information Technology* 14 (1): 27-40. Ienca, Marcello, Jotterand, Fabrice, Vică, Constantin et al. (2016) 'Social and Assistive Robotics in Dementia Care: Ethical Recommendations for Research and Practice', *International J of Social Robotics* 8, 565-573. Sparrow, Robert (2016) 'Robots in aged care: a dystopian future?' *AI & Society* 31: 445-454.

²³ Lancaster, Karen (2019) 'The robotic touch: Why there is no good reason to prefer human nurses to carebots', *Philosophy in the Contemporary World* 25 (2): 88-109.

touch” to “the robotic touch.”²⁴ For Lancaster the actual absence of emotions within a robot is irrelevant, particularly as human nurses may well ‘fake’ emotional care and compassion, without their patients feeling uncared for. Within a normative framework, some ethicists may want to consider whether such deception – robotic or human – is ever morally permissible, but there is general agreement that even those who understand that a care robot is non-living can be touched by its emotionally evocative behaviours.²⁵

For the most part, however, robots are carefully positioned as pragmatic technologies intended to augment, not supersede, the *interhuman* aspects of the caring situation.²⁶ Whether explicit or not, the underlying anxiety concerns the supposed affront to autonomous agency, even though the injunction to respect the dignity and intrinsic value of every human being whatever their physical or cognitive status,²⁷ is widely overridden in end-of-life scenarios. In any case, such sentiments are grounded in a highly exclusionary liberal humanist conception of what constitutes worthwhile life. Any critique of the notions of rights, dignity, and interests as referencing a deeply normative standard of human being has little traction in the practicalities of dementia care where vulnerability is taken for granted and dependency is both denied and inevitable. With this in mind, consider the much-researched benefits of PARO – a widely used empathy robot that resembles a baby seal. Predictably, what most research studies stress is not the affective interaction between human and non-human, but the extent to which users demonstrate greater social engagement – whether physical, verbal or visual – with other human beings in care settings. Despite plentiful evidence that users experience increased calm and comfort in their interactions with PARO, a user focus on the human-robot interaction may be seen as an unwanted substitution for human-*human* relations in that it lacks any symmetry.²⁸

My argument is that we should ~~we~~ look beyond the entrenched humanist principles that focus on the ethics and practicalities of asymmetrical power, user vulnerability, and the artificiality – and implicitly the in-humanity – of robot touch. Why should such interactions be symmetrical? In any lifespan, especially for people with moderate or advanced dementia, few relationships are truly symmetrical. And with a shift of perception to thinking the encounter in terms of mutuality that particular ethical problem disappears. Typically, however, little value is given to human-machine sensory interactions even as they expand the limits of normative human behaviour. In any case, relations between human carers and those they assist are often fraught, with *human* tactile proximity perceived by disabled elders as painful, uncontrollable and unwanted. Yet, as multiple studies have demonstrated, opponents of the digitalisation of dementia care continue to privilege human to human interaction above any evidence of the efficacy of robot mediations, including zoomorphic ones. With regard to bioethics, we need to rethink

²⁴ Lancaster, Karen (2019) ‘The robotic touch: Why there is no good reason to prefer human nurses to carebots’, *Philosophy in the Contemporary World* 25 (2): 88-109, p.103.

²⁵ Calo C.J., N. Hunt-Bull, L. Lewis et al. (2011) ‘Ethical Implications of using the Paro Robot’, AAAI Workshop WS-2011-2012: 20–24.

²⁶ Khaksar, Seyed Mohammad Sadegh, Rajiv Khosla, Mei Tai Chu et al. (2016). “Service Innovation Using Social Robot to Reduce Social Vulnerability among Older People in Residential Care Facilities.” *Technological Forecasting & Social Change* 113: 438–453.

²⁷ Barcaro, Rosangela, Martina Mazzoleni and Paolo Virgili (2018) “Ethics of Care and Robot Caregivers.” *Prolegomena* 17 (1): 71–80.

²⁸ Turkle, Sherry (2011) ‘Authenticity in the age of digital companions’ in M. Anderson & Susan Leigh Anderson (eds) *Machine Ethics*. New York: Cambridge University Press.

what new forms of non-conventional and potentially non-organic connections might entail and ask which encounters best promote comfort for people with dementia.

Leaving aside the often brute reality of death and dying, what does the phenomenological account of embodiment faced with its own vulnerability have to offer? I am not implying that we are all ready to go beyond the modernist ideals that privilege integrity, but it seems to me that phenomenology offers better resources to deal with some very common but deeply disordering encounters with vulnerability, such as living with cancer. The feminist writer Audre Lorde's *Cancer Journals*²⁹ offers a powerful illustration of what those experiences intend.³⁰ Lorde is never dismissive of the fear and often hopelessness that she and others with cancer feel, but she sees survival in terms of the subject's capacity to make meaning out of the experience. After her mastectomy operation, Lorde is swiftly faced with the normalising forces of society - that seek to obscure bodily differences, and particularly those that signal vulnerability - by the expectation that she will wear a breast prosthesis, not least because as one of her consultants tells her, her evident breastlessness is bad for the morale of others who attend the same clinic. In response, Lorde declares that she is more interested in maintaining her own control over what she calls 'the new me'. Like Simone de Beauvoir's mother, Lorde's desire for self-control is scarcely surprising - it is the ideal of both postEnlightenment culture in general, and a specific aim of early *Women's Liberation*, where women explicitly sought to escape the gendered attribution of vulnerability, seeking instead to exercise autonomy, particularly in relation to biomedical care. But where Francoise desperately tried to deny that her embodied self had changed, Audre is determined to celebrate her new self, or as she puts it, to 'live myriad selves'. Her very personal account moves instinctively towards the theorisation of embodiment as insecure, fragmented, and - despite the desire for control - ultimately ungraspable.

In the model most associated with Merleau-Ponty,³¹ phenomenology positions embodiment as a concept in which both mental and physical components are always intimately intertwined as the structure of all lived experience. I live not *in* or *through* my body as though the 'I' were somehow already existent: I *am* my body such that all experiences of and changes to my corporeal interface with the world of others establish and continually re-establish my shifting sense of self. For most of the time, while my body is operative within the normative parameters of biological function, social interaction, affective experience and so on, my acquired habitus is so familiar that I have no ongoing awareness of my corporeality as such. In mainstream phenomenological theory at least, the body in good health is not a conscious presence for me, but simply the unremarkable ground of my well Being. It is the body that is forgotten. But we need to be cautious here; as Iris Marion Young pointed out,³² the propensity to eliminate conscious thought of one's own corporeality may be less apparent in women - and indeed other subjugated groups - for whom body awareness is a matter of paying attention to specific vulnerabilities. Even besides such pressures, it is clear that the supposedly healthy body itself is subjected to

²⁹ Lorde, Audre (1985) *The Cancer Journals*. London: Sheba Feminist Publishers.

³⁰ I have deliberately chosen examples from 2nd wave feminist scholarship (work by Beauvoir followed by Lorde, Brison and Sedgwick) to demonstrate that issues of vulnerability have always had the potential to disrupt feminist thought long before the turn to a fully embodied bioethics or to new materialism.

³¹ Merleau-Ponty, Maurice (1962) *The Phenomenology of Perception*. London: Routledge and Kegan Paul.

³² Young, Iris Marion (1990) *Throwing Like a Girl and Other Essays in Feminist Social Theory*. Bloomington: Indiana University Press.

ongoing conscious oversight to avoid slippage beyond the norms. That everyday performative awareness may be substantially different from the awareness that imposes itself when the body shows signs of putatively 'biological' breakdown in terms of illness, ageing and so on, but we cannot claim that the embodied self is invulnerable or ever in a state of static integration. The usual phenomenological understanding is that the body that fails to operate as expected demands attention by opening up a dissonance between self and body. It becomes an unwelcome presence that makes us aware of our limitations and vulnerabilities. Arthur Kleinman provides the classic phenomenological account: 'The fidelity of our bodies is so basic that we never think of it...illness is a betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost.'³³ In effect, the previously taken-for-granted integration of embodiment is challenged by a scenario in which the security and stability of the self appears threatened by the otherness of bodily affects. Body and mind appear antagonistic.

Now, if body and mind *are* irreducibly intertwined as phenomenology insists, then the restoration of well Being – call it good health, though it is as much ontological as empirical – cannot finally rest on strategies that privilege the one over the other, but only on re-incorporation. Nonetheless, the goal of modern healthcare is more likely to attempt to once more cover over the uncertainty of the body, by restoring self-control *over* corporeality, and by renewing the illusion of invulnerability. And even when – as Kleinman asserts it must – biomedicine assists in the bioethical task of re-embodiment, that too is misdirected if the ultimate goal is to discount the body once again by restoring normative forgetfulness. If, as I've suggested the body is already inconstant in the normal course of events, and not simply at exceptional moments, then disorder is a dimension of embodiment that is not susceptible to remedial practices. At most, certain specific procedures may restore ordinary disorder, but embodiment as such can never be made invulnerable. In the face of illness, disability, pain or simply ageing, the body can be experienced as estranged, and yet so overwhelmingly present that it threatens to fragment the self.³⁴ One self-protective response to that condition of vulnerability is to imagine the abstract self as a would-be controlling agent in opposition to the materiality of the body that resists control. For the sake of maintaining the supposed integrity of selfhood, we make an object of the body that demands attention. That reiteration of the modernist mind-body split appears to be a strange way of dealing with the dis-ease of an ontological vulnerability and can ground only a bioethics that stresses abstract principles such as autonomy detached from their material operation³⁵. What does seem clear is that however much we might wish to transcend the body, our being in the world *is* always embodied, and therefore intrinsically vulnerable and uncertain.

In this light, consider how ontological and material vulnerability come together in multiple instances of individual and institutional violence that not only threatens the body,

³³ Kleinman, Arthur (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*, p.45. New York: Basic Books.

³⁴ Jean-Luc Nancy's account of his failing heart and subsequent organ transplantation in *L'Intrus* speaks precisely to this scenario. Nancy, Jean-Luc (2002) *L'Intrus*, trans. Susan Hanson. East Lansing: Michigan State University Press.

³⁵ Most scholars promoting a relational ethics do not fully reject the notion of autonomy but argue that the principle should be reconceptualised as non-individualist and reflective of values such as justice and social solidarity. Gómez-Virseda, C., de Maeseneer, Y. & Gastmans, C. (2019) 'Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature' *BMC Med Ethics* 20, 76. My own approach gives no place to autonomy and turns to distributed agency instead.

but disorders the embodied self. In this time of nationalist wars, racism, misogyny, heterosexism and more, assaults on corporeality have far-reaching consequences evidenced, for example, in the public acceptance of the reality of post-traumatic stress disorder. It is not my claim that all those who experience substantive vulnerability situate its effects within a wider understanding of the irreducibility of the body-mind union, but that it is always at work. In many personal narratives the horror of the material situation may overwhelm further philosophical analysis, but I turn here to the highly self-aware account of the aftermath of a violent, life-threatening, rape, experienced by the philosopher Susan J. Brison. Brison characterises herself as someone whose self-image had previously been highly abstract, yet whose response to the violation of her body is phenomenologically complex. She writes:

My body was now perceived as an enemy...a site of increased vulnerability. But rejecting the body and returning to the life of the mind was not an option, since body and mind had become nearly indistinguishable. My mental state ... felt physiological, like lead in my veins, whereas my physical state ... was the incarnation of a cognitive and emotional paralysis resulting from shattered assumptions about my safety in the world.³⁶

Brison refers to trauma as 'the undoing of the self' which compels her to accept that the fragility and vulnerability of the embodied self is a permanent condition of being, and that she should not attempt to regain her former self by further objectifying her body. Instead, she must heal the dissonance of mind and body and remake her self by building on the embodied connections of living-in-the-world-with-others, rather than chasing after an illusory state of transcendence. Certainly, reaching for some form of corporeal detachment may bring some temporary relief to the dis-integrated body, but as a more permanent strategy for living in the world it is limited and invites the very discordance that underpins ontological anxiety. Despite its significance, however, does the phenomenological model itself, which Brison adopts, imply too great a possibility of an integrated bodyliness?

A rather different way of understanding embodiment that acknowledges the impossibility of it ever settling in a predictable form, is offered by a more explicitly postmodernist approach that moves from a deconstruction of a fixed notion of embodiment to the Deleuzian notion of assemblage. The literary scholar and queer theorist, Eve Kosofsky Sedgwick had already written extensively about AIDS and death, before her own unexpected encounter with breast cancer. Whilst acknowledging the experience of diagnosis and treatment as 'draining and scary', Sedgwick also characterises it as 'an adventure in applied deconstruction'. Rather than accepting the relative calm of determinate prognosis, she sets out to trace out the imbrication of her now 'turbulent' material embodiment with her theoretical resources. As she puts it:

The phenomenology of life-threatening illness; the performativity of a life threatened, relatively early on, by illness; the recent crystallisation of a politics explicitly oriented around grave illness: exploring these connections *has...*to mean hurling my energies outward to inhabit the very furthest of the loose ends where representation, identity, gender, sexuality, and the body can't be made to line up neatly together.³⁷

³⁶ Brison, Susan J. (1997) 'Outliving Oneself: Trauma, Memory and Personal Identity' in Diana Tietjens Meyers (ed.) *Feminists Rethink the Self*, p.13. Boulder, CO: Westview Press.

³⁷ Brison, Susan J. (1997) 'Outliving Oneself: Trauma, Memory and Personal Identity' in Diana Tietjens Meyers (ed.) *Feminists Rethink the Self*, p.13. Boulder, CO: Westview Press.

Unlike Brison and earlier Lorde who speak of remaking themselves, Sedgwick's experience of overt vulnerability and the threat of death leads her to an *embrace* of dislocation as an intrinsic dimension of human embodiment, which marks every aspect of living-in-the-world. Her reflections illustrate is that while body and self are surely indivisible, that does not imply any stable conjunction of the multiple elements that constitute lived experience. Things fall apart in ways that resist her conscious agency. As Sedgwick understands it, her ongoing survival is not ensured by the attempt to reintegrate an illusory wholeness, but by an appreciation that her *self-disorder* has been there from the start and could not be otherwise.³⁸

All such reflections are deeply discomfoting not only for the operation of biomedicine, where the fundamental drive is to eliminate uncertainty, but also for the socio-cultural context in which our values, expectations and bioethics are constructed. Disability, illness, ageing and dying are all about indeterminate transformations in which dis-integration is more or less inevitable, and the desire to enforce some degree of order, to reintegrate the embodied self, is bound to end in failure. I have long favoured a (bio)ethics of uncertainty and believe that Derrida's meditations on death in works such as *Adieu to Emmanuel Levinas*³⁹ are full of insights that do much to enrich our understanding of the consequences of the undecidability that marks both the sick and healthy body. What Derrida always makes clear is that predetermined ethical principles will not suffice, and that following a clear and easy path finally evades ethical responsibility. That is not to say, however, that principles play no part but that they must be recognised as less than adequate to a fully evolved ethical relation where ambiguity and uncertainty are inevitable. Where Derrida focuses on responsibility toward the other, feminist theory in particular has long promoted an ethics of relationality which better opens up the bidirectionality of the encounter and makes clear the commonalities of vulnerable embodiment without sacrificing the specificity of this or that condition or form of distress. Clearly an empathetic reaching out to, and reception of otherness is vital to such an ethics, but more important is the acknowledgment of internal anxieties about our own fragility and vulnerability that so often compel us to silence and disavowal, or to an attempt to impose order on distress. And whatever the claim to corporeal separation, there is finally no division between the embodied self and other but only an effective and affective relationality that is as much internal as external.

Within feminist theory, the work of Judith Butler,⁴⁰ and my own⁴¹ has gone further in widely addressed the issue of how vulnerability could form the grounds for thinking ethical relationality in a way that goes beyond the more usual acceptance of a distinct self and other. The argument in summary is that we are always already not just interconnected, but inextricably dependent on others by virtue of our shared corporeal vulnerability. Butler in particular has linked this vulnerability to the wider notion of precarity which opens up the problematic to social and political concerns, and their associated ethics. The turn to vulnerability and precarity moves away from the humanist ethics of how we might care

³⁸ Again, Nancy comes to mind when he comes to the realisation that '(t)he intrus is none other than me, my self.' Nancy, Jean-Luc (2002) *L'Intrus*, trans. Susan Hanson, p.13. East Lansing: Michigan State University Press.

³⁹ Levinas, Emmanuel (1999) *Otherwise than Being, or, Beyond Essence*, trans. Alphonso Lingis. Pittsburg, PA: Duquesne University Press.

⁴⁰ Butler, Judith (2006) *Precarious Life: The Power of Mourning and Violence*. London: Verso.

⁴¹ Shildrick, Margrit (2005) 'Beyond the Body of Bioethics' in M. Shildrick and R. Mykitiuk (eds) *Ethics of the Body*. Cambridge, MA: MIT Press. Shildrick, Margrit (2022) *Visceral Prostheses: Somatechnics and Posthuman Embodiment*. London: Bloomsbury.

for suffering others, and instead exposes the fundamental interdependencies and entanglements of living in the world with others. In that sense, the disembodied and abstract principles that have dominated western ethics segue into a highly material bioethics. As Butler puts it: 'we cannot understand bodily vulnerability outside of this conception of its constitutive relations to other humans, living processes, and inorganic conditions and vehicles for living,'⁴² The ethical debt is mutual and unavoidable, and allows us, then, to think beyond *human* vulnerability alone. If we think ethical responsibility through our interconnectedness and relationality, then it operates not just with human beings but should extend to our relations with animals and environmental others. This of course is precisely what has long been suggested by Deleuze's notion of assemblage.

In the Deleuzian canon, what is called the *body-without-organs* – that is a disorganised and uncertain body – is a dynamic assemblage that emerges at the cross-over point of multiple relations, variously human, animal and inorganic. This approach moves away from both the humanist and phenomenological aspects of embodiment, which presuppose a series of singular embodied subjects, and expands onto the shifting materiality of the relations between bodies and their environments. For Deleuze, to be a subject at all is merely a provisional state that is always in a process of unravelling,⁴³ which can surely be read as a form of vulnerability. Each one of us is enmeshed in a fluctuating series of assemblages that constitute life itself. The webs of interconnections are multiple and fluid, encompassing both organic and inorganic elements. There is no necessary structure to the assemblage; rather it is no more than an impermanent constellation of contingent relations that over time coalesce, evolve and transform, before equally unpredictably disassembling. The subject itself does not entirely disappear but it is no longer privileged in its putative agential singularity. But it is not only ontology that must be rethought, but the very process of ethical engagement. In evoking multiple heterogeneous orders, Deleuzian philosophy directs attention to the effects and ethics of mutual interactions, not to identifying individual moral agents who might respond to the perceived vulnerability of others. In terms of the bodily conditions of dis-order that I have focused on, what that implies is that the push for relational *autonomy* – much endorsed by reformist bioethicists – is misdirected. And although we should welcome any turn towards a recognition that ethical responsibility is multiple, it shows little awareness of the inadequacy of existing principles. We need to reconfigure relational economies as transitory, complex, decentred and multifaceted.

The Deleuzian approach makes no claim to provide final answers, and there is no suggestion that it exempts everyday ethics from the task of adequately protecting the interests of all equally. The unpredictability of what shape a fully interrelational ethics might take, can - and must - operate alongside a clear recognition of what constitutes the unethical at the present time. The bioethical question of how to respond to the encounter with those whose vulnerability has become overt, nevertheless, cannot be detached from the interlinked and mutual exposure and opportunity that marks the vulnerability of all living beings. Beyond the limits of material relief, the task is to remain open to the varying needs and desires of inconsistent embodiment, and to engage in making and remaking

⁴² Butler, Judith (2014) 'Bodily Vulnerability, Coalitions, and Street Politics', *Critical Studies*, 37: 99–119, p.103

⁴³ Deleuze, Gilles and Guattari Felix (1984) *Anti-Oedipus*, trans. Robert Hurley. Minneapolis: Minnesota University Press. Deleuze, Gilles and Guattari Felix (1987) *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi. Minneapolis: Minnesota University Press.

connections, not as settled vectors of communication, but as dynamic and fluid networks. It is not that we have arrived at an impasse, but that our responses must subject the limits of current principles and protocols to a thoroughgoing critique. The remit is to open up present structures to continual re-evaluation and renewal. In declining to settle on immediate answers, and with assemblage thinking in mind, we can encompass both vulnerability and strength, and offer the hope, and risk, of thinking differently. Finally, let us think vulnerability, not as an exposure to risk but as the threshold to an imaginary of irreducible interconnections – more properly entanglements – in which self and other (whether human, animal or inorganic) are mutually constitutive and provisional entities. without independent agency. For all of us, it signals that resistance to the comforting lure of stable certitude is a move towards a necessary recognition of vulnerability and ambiguity as the very condition of life.

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Bibliography

- Adams Rachel (2017) 'Disability Life Writing and the Problem of Dependency in The Autobiography of Gaby Brimmer', *Journal of Medical Humanities* 38(1):39-50.
- Barcaro, Rosangela, Martina Mazzoleni and Paolo Virgili (2018) "Ethics of Care and Robot Caregivers." *Prolegomena* 17 (1): 71-80.
- Beauvoir, Simone de (1965) *A Very Easy Death*. New York: Pantheon Books.
- (1968) *Force of Circumstance*. Harmondsworth: Penguin.
- (1972) *Old Age*. London: Andre Deutsch and Weidenfeld and Nicholson.
- Bishop, Jeffrey (2011) *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying*. Notre Dame, IN: University of Notre Dame Press.
- Brannelly Tula (2011) 'Sustaining citizenship: People with dementia and the phenomenon of social death', *Nursing Ethics*.;18 (5): 662-671.
- Brisson, Susan J. (1997) 'Outliving Oneself: Trauma, Memory and Personal Identity' in Diana Tietjens Meyers (ed.) *Feminists Rethink the Self*. Boulder, CO: Westview Press.
- Brown, Nik and Andrew Webster (2004) *New Medical Technologies and Society: Reordering Life*. Cambridge: Polity Press.
- Butler, Judith (2006) *Precarious Life: The Power of Mourning and Violence*. London: Verso.
- (2014) 'Bodily Vulnerability, Coalitions, and Street Politics', *Critical Studies*, 37: 99-119.
- Calo C.J., N. Hunt-Bull, L. Lewis *et al.* (2011) 'Ethical Implications of using the Paro Robot', *AAAI Workshop WS-2011-2012*: 20-24.
- Couser, Thomas (2016) 'Body Language: Illness, Disability, and Life Writing', *Life Writing* 13:1, 3-10, doi: 10.1080/14484528.2016.1132376
- Deleuze, Gilles and Guattari Felix (1984) *Anti-Oedipus*, trans. Robert Hurley. Minneapolis: Minnesota University Press.
- (1987) *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi. Minneapolis: Minnesota University Press.

- Derrida, Jacques (1999) *Adieu. To Emmanuel Levinas*, trans. Pascale-Anne Brault and Michael Naas. Stanford, CA: Stanford University Press.
- Fineman, Martha (2008) 'The vulnerable subject: Anchoring equality in the human condition', *Yale Journal of Law and Feminism*, 20. 1: 1-23.
- Finlay, Jessica (2021) 'Intimately Old: From an Embodied to Emplaced Feminist Approach to Aging', *Hypatia* 36(1), 80-100.
- Garland-Thomson, Rosemarie (2007) 'Shape Structures Story: Fresh and Feisty Stories about Disability', *Narrative* 15, 1: 113-123.
- Gawande, Atul (2014) *Being Mortal: Medicine and What Matters in the End*. New York: Metropolitan Books.
- Gómez-Vírveda, C., de Maeseneer, Y. & Gastmans, C. (2019) 'Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature' *BMC Med Ethics* 20, 76.
- Goodin, Robert E. (1998) 'Vulnerabilities and Responsibilities: An Ethical Defence of the Welfare State' in Gillian Brock (ed.) *Necessary Goods*. Lanham: Rowman and Littlefield.
- Heidegger, Martin (1962) *Being and Time*, trans. J. Macquarrie and E. Robinson. London: SCM Press.
- Ienca, Marcello, Jotterand, Fabrice, Vică, Constantin *et al.* (2016) 'Social and Assistive Robotics in Dementia Care: Ethical Recommendations for Research and Practice', *International J of Social Robotics* 8, 565-573.
- Khaksar, Seyed Mohammad Sadegh, Rajiv Khosla, Mei Tai Chu *et al.* (2016). "Service Innovation Using Social Robot to Reduce Social Vulnerability among Older People in Residential Care Facilities." *Technological Forecasting & Social Change* 113: 438-453.
- Kleinman, Arthur (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*. New York: Basic Books.
- Králová, Jana (2015) 'What is social death?' *Contemporary Social Science* 10 (3): 235-248.
- Lancaster, Karen (2019) 'The robotic touch: Why there is no good reason to prefer human nurses to carebots', *Philosophy in the Contemporary World* 25 (2): 88-109.
- Levinas, Emmanuel *Otherwise than Being, or, Beyond Essence*, trans. Alphonso Lingis. Pittsburg, PA: Duquesne University Press.
- Lorde, Audre (1985) *The Cancer Journals*. London: Sheba Feminist Publishers.
- Mackenzie, Catriona, Wendy Rogers and Susan Dodds (eds) (2013) *Vulnerability: New Essays in Ethics and Feminist Philosophy*. Oxford University Press.
- Merleau-Ponty, Maurice (1962) *The Phenomenology of Perception*. London: Routledge and Kegan Paul.
- Nancy, Jean-Luc (2002) *L'Intrus*, trans. Susan Hanson. East Lansing: Michigan State University Press.
- Nature Editorial (2023) 'Treat pain as a priority, not an afterthought', *Nature* 615: 765.
- North, Michael and Fiske, Susan (2015) 'Modern Attitudes Toward Older Adults in the Aging World: A Cross-Cultural Meta-Analysis', *Psychological bulletin* 141. 5: 993-1021.
- O'Neill, Onora (2002) *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press.

- Pascalev, Assya (2018) 'Is death the enemy? The normative power of metaphor in bioethics' in *Ethics of emerging biotechnologies: From educating the young to engineering posthumans*, 87-106. Trivent Publishing.
- Prainsack, Barbara (2018). 'The "We" in the "Me": Solidarity and Health Care in the Era of Personalized Medicine', *Science, Technology, & Human Values* 43. 1: 21-44.
- Raffaelli William and Arnaudo Elisa (2017) 'Pain as a disease: an overview', *J. Pain Research* 10: 2003-2008.
- Ricoeur, Paul (2007) 'Autonomy and vulnerability' in *Reflections on the Just*, ed. P. Ricoeur, trans. D. Pellauer, Chicago: University of Chicago Press.
- Rogers, Wendy, Catriona Mackenzie and Susan Dodds (2012) 'Why Bioethics Needs a Concept of Vulnerability', *International Journal of Feminist Approaches to Bioethics* 2.5: 11 – 38.
- Sandberg, Linn (2013) 'Affirmative Old Age – The Ageing Body and Feminist Theories on Difference.' *International Journal of Ageing and Later Life* 8.1: 11-40.
- Schneiderman, Lawrence and Nancy Jecker (2011) *Wrong medicine: doctors, patients, and futile treatment*. Baltimore Johns Hopkins University Press.
- Sedgwick, Eve Kosofsky (1994) *Tendencies*. London: Routledge.
- Sharkey, Amanda and Noel Sharkey (2012) 'Granny and the robots: ethical issues in robot care for the elderly', *Ethics and Information Technology* 14 (1): 27-40.
- Shildrick, Margrit (2005) 'Beyond the Body of Bioethics' in M. Shildrick and R. Mykitiuk (eds) *Ethics of the Body*. Cambridge, MA: MIT Press.
- (2022) *Visceral Prostheses: Somatechnics and Posthuman Embodiment*. London: Bloomsbury.
- (2023) 'Robotic Technologies, Touch and Posthuman Embodiment in Queer Dementia Care', *Senses and Society* 18. 2: 126-138. <https://doi.org/10.1080/17458927.2023.2179239>
- Sparrow, Robert (2016) 'Robots in aged care: a dystopian future?' *AI & Society* 31: 445-454.
- Tan Kiak Min, Mark (2017) 'Beyond a Western bioethics in Asia and its implication on autonomy', *New Bioethics* 23. 2:154-64.
- Tanaka, Shogo (2015) 'Reconsidering the Self in Japanese Culture from an Embodied Perspective', *Civilizations* 20. 3: 35-39
- Turner, Bryan S. (2006), *Vulnerability and Human Rights*. University Park: Pennsylvania State University Press.
- Turkle, Sherry (2011) 'Authenticity in the age of digital companions' in M. Anderson & Susan Leigh Anderson (eds) *Machine Ethics*. New York: Cambridge University Press.
- Young, Iris Marion (1990) *Throwing Like a Girl and Other Essays in Feminist Social Theory*. Bloomington: Indiana University Press.