Narelle Warren and Courtney Addison

Abstract

The curative imaginary is a powerful driver of hope and investment in medicine, often displacing attention and resources given to other illness-related fields of practice. Whereas cure implies an end to the sick role and the possibility of an absolute state of health, in practice those fields that are touted as having high curative potential grapple with the ongoing nature and incompleteness of post-cure care. By capturing the public imagination and channelling research and funding in particular directions, the motif of cure risks drawing resources away from other, less seductive forms of treatment, and towards the technological at the expense of the social. Drawing on our research into precision medicine and deep brain stimulation, we track how cure operates as a concept in these fields, and compare this to how medical practitioners actually care for patients. We argue that a critical engagement with post-cure possibilities offers an opportunity to challenge and rethink what constitutes good medical care, as well as the social, political, and economic underpinnings of medical innovation.

Keywords

cure, care, precision medicine, neurodegeneration, potentiality

Introduction

The idea of medical cures for serious diseases is more frequently invoked in rhetoric than delivered in practice. 'Cure' is an organising motif in biomedicine, generating interest, support,

and investment in medical research. It brings with it the potential to alleviate or remove suffering, both in the present and extending into the future, and to extend the possibility of a well-lived life. Since the mid-1980s, 1 for example, the field of gene therapy sought to locate a cure for genetic diseases. Early proponents argued that gene therapy was uniquely positioned to cure disease at the level of DNA. This 'promise' drove cycles of intense investment – and subsequent disappointments – from the first clinical trial of a gene therapy technology, which was used to successfully treat two children with genetic conditions, in 1990 (Addison 2017). This Position Piece advocates for a post-cure analysis of biomedical technologies. In so doing, we call for an anthropology that not only looks at what happens to a person's life after they receive a cure (as Heinemann 2016 evocatively demonstrates in the case of organ transplant), but which extends our - as publics, anthropologists, and scholars, and as potential future recipients of such technologies – gaze beyond cure. By 'beyond cure', we do not advocate for a dismissal of cure; rather, we argue for a more nuanced consideration of its value (personal, social, and economic) to individuals and communities than is currently found in most discussions. In so doing, we highlight the ongoing need to recognise the value of informal care - that is, the intersubjective and relational activities that develop between people who are invested in the process of living with illness, as well as those practical actions that one person undertakes on behalf of or for another (see Warren and Sakellariou 2020).

Over the past four decades and in response to rapid technological developments in the treatment of illness and disease, cure has become an imaginary that directs resources in particular ways (i.e., towards medical/pharmaceutical research and, thus, the creation of new markets, as detailed by DelVecchio Good [2001] in her work on the medical imaginary and the biotechnical embrace), but which do not necessarily benefit patients and their close others. Philosopher of science Jacob Stegenga (2018) contends that biomedicine has in fact achieved very few cures. Yet, the mythology of the curative power of biomedicine persists, and, as Scheufele et al. (2017) showed in a recent survey of US attitudes towards gene editing, publics express high levels of confidence in the notion of biomedical cure (Petersen 2015).

In this Position Piece, we question what would happen if publics, broadly conceived, shifted resources and attention away from an almost exclusive focus on cure to a more inclusive approach that also considers care. We argue that medicine's overemphasis on cure jeopardises other forms of care, while undermining other perspectives on health and medicine – including

Although gene therapy technologies have been reported as being in development since the early 1970s, we refer to this date, sourced from the US National Institutes of Health online exhibit entitled 'Human Genetics and Medical Research: A revolution in progress' (n.d.), as this is when tissue culture trials commenced. This exhibit can be accessed at: https://history.nih.gov/exhibits/genetics/sect4.htm.

those of anthropologists. To show this, we trace how cure operates across two medical fields; first examining how ideas of cure manifest in medical discourse and then comparing these to the care that patients actually receive.² The first field we examine is precision medicine, which we treat here as the field of medical research and practice concerned with developing molecular-scale diagnostics and therapeutics. The second is the highly aspirational field of neurodegenerative cure, which is based in ongoing and unresolved controversies about the origins of dementias including Alzheimer's disease, Parkinson's disease, and motor neuron disease (Lansbury and Lashuel 2006; Obeso et al. 2010; Turner et al. 2013; Morris, Clark, and Vissel 2014).

Cure in these contexts is a dual process of problem identification and solution: diagnosis (problem identification) occurs through treatment (solution) (Warren and Manderson 2015). While these medical fields differ in many respects, taken together they represent the dominant medical discourse that has occupied biomedical and popular imaginaries in recent decades, and illustrate how the figure of cure holds its shape across contexts and time. Examining these two domains, we argue that cure operates as an ideal, unmoored from the specifics of place, time, and body – and, in consequence, is general and generalisable. That is, cure is not only an outcome of treatment for particular illness conditions (for example, the goal of cancer treatment is five year survival, which represents a 'cure' [NIH National Cancer Institute 2018]), but has also become an overarching aim of technological developments in biomedicine (for example, as evident in the call for a 'cure for cancer').3 Yet, it is the specifics of people's experiences that make spaces for care essential: even in the journey towards successful treatment or cure, ill people require care – from healthcare providers, from formal services, and from informal caregivers. Presenting interview and observational data from patients, we demonstrate that the claims about technological outcomes - cures - made on behalf of experimental medicine contradict clinical realities; this can be seen, for example, in claims that the bionic eye (visual prosthesis) will restore sufficient clarity of vision to distinguish facial features, whereas current prostheses only offer a highly pixelated greyscale differentiation of light (see figure 4 in Maghami et al. 2014). Finally, we consider how the biomedical ideology

- We frame 'cure' in the singular to foreground that our interest is in the idea or motif of cure (e.g., the cure for cancer), and to distinguish this from more diverse individual cures (e.g., targeted cancer therapies, such as trastuzumab for HER2 receptor positive breast and stomach cancers [Nahta, Hung and Esteva 2004]).
- The call for 'a' cure for cancer is significant, as it obscures the multiplicity of conditions that are often collapsed into the singular term 'cancer'.

of cure has real implications for patients and those who love and support them, devaluing their experiences and side-lining the importance of care in biomedical encounters.

* * *

Medicine is organised in response to bodily events or states of being that are seen to be in need of correction – the pathological. Georges Canguilhem ([1943] 2012) saw the aim of medicine as returning patients to the state of health that preceded their sickness;⁴ he highlights the irony of this project, which, if successful, negates its own necessity and thus resembles a long exercise in obsolescence. Building on these observations, Matthew Wolf-Meyer (2014, 145) argues that this project 'is thwarted by the inability to return individuals to their actual prior state, instead only approximating the patient's prepathological condition'. In practice, medicine cannot effect a return to past health or a restitution of the body; it moves only forward, in time and matter. As Lenore Manderson (2011) demonstrates, the idea of a return to the previously well body does not account for the perpetual contingency of health, nor the many aspects of illness that exceed biology (e.g., its impacts on identity, relationships, orientation towards the future, etc.). The notion of cure is laden with assumptions about the temporality of sickness and integrity of the body that reinforce precisely these often unachievable ideas of return and restitution, bodily wholeness, and the potential for absolute health (cf. Manderson 2011).

Hitched to biomedical disease models and market dynamics, the idea of cure crowds out other possibilities of care – even when the cure itself does not exist (Chaufan et al. 2012). The 'triumph of cure over care' (ibid., 792) is revealed in the material value assigned to the labour of caregiving as compared to that of medicine. In 2017, the mean wage of 'care workers and home carers' in the UK was £13,948, and that of 'senior care workers' was £17,394; 'medical professionals', by comparison, enjoyed a mean annual wage of £71,203, and 'biological scientists and biochemists' earned an average of £38,647 (ONS 2017).

Bharat Venkat's (2016) history of tuberculosis (TB) treatment offers another example of cure overwhelming care. His Madras study demonstrating the efficacy of combined antibiotics for TB became the grounds for arguing that, if properly administered, antibiotics eliminated the need for admission to a sanatorium or hospital, which had previously been considered essential to managing the disease. Subsequent evidence showed that women who received their

4 Similarly, Talcott Parsons (1951) provides a sociological analysis of the return to health in his seminal work *The Sick Role*.

antibiotics at home relapsed more frequently than men or women in sanatoria – a finding that suggests a cure is only as good as its context.

Recent work from science and technology studies (STS) with people living with hepatitis C has again showed this privileging of cure over care by public health bodies (including governments) and health providers (Madden et al. 2018). For people who have lived with hepatitis C, the relationship between cure and care is nuanced: while participants in Madden's study valued successful treatment (i.e., cure), they prioritised other (non-cure-related) outcomes, including wellness, social relationships, preserving their sense of identity, and feeling capable of managing their future health. Here, a focus on cure that excludes the social dimensions of illness – elements that comprise care – misses key aspects of individuals' illness experiences and potentially undermines the curative project.

As these examples show, medical cure, despite appearances, may not be a panacea. Cure, like biomedicine more broadly, is deeply normative: it implicitly positions medicine as the only acceptable form of resolving sickness. Once available, cures direct patients down specific avenues of action and resolution, and make these morally imperative. As Wolf-Meyer (2014) suggests, cure refigures relationships between individuals, treatments, and their condition, and by extension, between patients, the market, and the healthcare profession. The patient/consumer is obliged to find and embrace (re)solutions to their pathology, and the existence of a cure (however impermanent or incomplete) hitches the pathology to market medicine. Furthermore, the *absence* of cure generates its own normative force, driving potential future imaginaries and reframing biomedical priorities, as in precision medicine.

Precision medicine: Promise and peril

With its rhetoric of cure and the widespread support this has generated, precision medicine is an archetype of promissory biosciences. Encompassing gene and cell therapies plus increasingly fine-resolution diagnostics, precision medicine has gained backing around the world. The USA launched a Precision Medicine Initiative in 2015, while the UK recently routinised the use of genetic testing for cancer patients. In 2018, Australia committed to investing A\$500 million in genomics research, following the launch of a report on the national prospects of precision medicine.⁵

A useful overview of these national precision and personalised medicine projects can be found in an Australian Council of Learned Academies report by Robert Williamson et al. (2018).

These initiatives reinforce claims about the imminent breakthroughs that precision medicine will realise. Social scientists argue that such 'promissory' rhetoric typifies the biosciences, and genomics specifically. Cure discourse is fundamentally performative, realising its own claims about the value of specific medical pursuits through strategic 'hype' (Petersen and Krisjansen 2015). The dominant motif of cure is reproduced through a 'genetic knowledge economy', new modes of interaction and new markets which draw upon genetic knowledge (as can be seen in the marketisation of genetic information and knowledge via companies such as 23andme). Steve Sturdy (2017) argues that this has the effect of rendering the public benefit of genomic medicine inseparable from the commercial forces that underlie it. Developments in precision medicine thus produce expectations about the possibilities of cure – each new development is lauded as transforming the practice of medicine – and simultaneously redefine how health and illness are conceptualised (Petersen 2006).

This rhetoric's efficacy hinges on the status of cure as potential rather than actual. Karen-Sue Taussig, Klauss Hoeyer, and Stefen Helmreich (2013, S4) write that in biomedicine, potentiality is articulated 'as a hopeful idiom through which to imagine the benefits of new medical interventions'. As the *potential* end point of medical research, cure transcends the imperfections and compromises of actual medicine, and is imagined to exist in an ideal state of total efficacy (cf. Stegenga 2018). This capacity to inspire hope is what lends cure its power, as realised in clinical trials enrolment, investment, research activity, and the machinations of medical research more widely. Cure may thus be the most powerful fiction of promissory discourse – an abstract idea presented to patients, investors, and medical practitioners as if it were a material actuality that could be realised if enough resources were available, rather than as a potential outcome which could only be accessed if future technoscientific developments occurred (Stegenga 2018). Indeed, central to biomedical potentiality is the possibility that the sought-after outcome may never exist (Tausig, Hoeyer, and Helmreich 2013); it is a collective faith (or, as Stegenga 2018 argues, misplaced confidence) in the odds presented by biomedical imaginaries that perpetuates the myth of cure.

In practice, cure operates differently in different contexts. A productive fiction at the level of medical fields, the notion of cure is often actively evaded in clinical settings. In interviews, medical practitioners employ language that captures more precisely measurable improvements in patients' health and demonstrable research successes rather than relying on an idiom of 'cure'.

Insights from interviews with Alex,⁶ a primary school-aged boy, illustrate this point. In the months prior to our interview, Alex received a form of genetic medicine to treat a rare and life-threatening immunological condition that meant he lived without a functioning immune system. The treatment improved Alex's health and wellbeing on several counts: his skin was less prone to rashes and he had fewer bloody noses. These apparently minor outcomes indexed more significant improvements in his immune function and platelet counts. In real-life terms, they made for a much-improved childhood, which Alex embraced by participating eagerly in school and social life. What had previously been a debilitating and life-shortening disease was now, by his doctor's interpretation, a 'very mild' variant of that original condition.

The changes Alex experienced transformed his life expectancy and wellbeing to a degree that would have been unthinkable prior to the advent of genetic medicine. However, cure implies an end to the 'sick role', such that the cured patient resumes their pre-sickness state of health (Parsons 1951). Alex will continue to participate in the monitoring and treatment regimes of the medical world. His experience complicates the notion of cure in another way: because he was born with this condition, there is no prior state of health for Alex to return to. The implicit division between well and ill becomes impossible to entertain.

In one respect, Alex is a beneficiary of cure rhetoric. One could argue that the hype cycles that shadowed early genetic medicine supported research in this area, and then, after the field crashed at the turn of the millennium, only the best researchers and projects persisted. Alex's treatment is an outcome of these processes. Yet the concept of cure seems meaningless, if not obfuscating, in relation to his own health changes – indeed, his medical team tend not to talk about cures at all, pointing instead to more modest and measurable outcomes such as neutrophil levels and clinical symptoms (e.g., nose bleeds). Cure (as motif) works very differently in patients' lives and in actual medical practice on the one hand, and at the level of public discourse and the bioeconomy on the other.

The escape from disease labels and the lived experience of sickness that cure implies is misleading. Cure itself does not remove an individual from ecologies of biomedicine. In fact, it creates new modes of engagement by shifting former patients' relationships to risk and susceptibility. Alex no longer 'has' (that is, lives under the diagnosis of [Martin 2007]) his previous, life-threatening immunological condition. Nonetheless, that legacy is documented in

6 'Alex' is a pseudonym, as are all patient names provided in this piece. Because Alex's disease is extremely rare and risks de-identifying him, I (Addison) cannot reveal the specific disease nor his site of treatment. I met Alex at a European hospital in 2015, during six months of fieldwork that formed part of my doctoral research.

his medical records and never disappears from his biography, creating a 'risk profile' and necessitating further care (albeit different to his initial care). Comparing the complicated reality of Alex's care to the rhetoric of precision medicine suggests that, rather than remove this illness from his future, his cure instead re-inscribes his illness as 'risk' and gives rise to new engagements with biomedicine. In discourse, precision medicine straddles a blurry zone between what is actually possible and what remains only potential, allowing the notion of cure to generate resources and activity that then feed into the more precise and modest goals of actual patients' actual care.

Neuroscientific potentialities of cure

Seductive futures, such as those offered by precision medicine, can also be found in the neurosciences, where they inform the development of neurological interventions and technologies. These 'neuro-curative imaginaries' capitalise on neuroscientific and biomedical understandings of disease causation to generate new spaces where ideas of cure can be examined, promoted, or challenged (cf. Rhodes et al. 2019). Ultimately, these neuro-curative imaginaries act to displace care by a focus on cure in scientific and public discourse (discussed further below). Our own work (Gardner et al. 2019) analysing amateur YouTube videos of deep brain stimulation (DBS) for Parkinson's disease (PD) exemplified this: patients filmed their symptoms disappearing as their devices were turned on, underscoring the technology's curative potential. At the same time, the social context was removed: few other people were featured in the videos and material environments were often obscured. Here, the image of cure papered over the social compromises and reciprocities involved in Parkinson's care (Gardner et al. 2019; Warren and Sakellariou 2020).

Neuro-curative imaginaries are most visible in the allocation of funding around neurodegenerative disease. In such contexts, cure stands in contrast to the 'living with' chronicity that characterises other long-term conditions (Manderson and Smith-Morris 2010). Since 2014, in Australia, 'The Big Freeze' fundraising and awareness-raising campaign for research on motor neuron disease (MND, also termed amyotrophic lateral sclerosis [ALS]) have been phenomenally successful, generating over A\$22 million in 2017/2018. Of this, just A\$1.25 million (or around 5 percent) was directed at care initiatives, with the remainder funding curative research.⁷ The aetiology of MND is unclear in the vast majority of cases (Mehta et al. 2018), and development of a cure is not possible without understanding causation (Collins-Praino and Katharesan 2017). The distribution of funding to curative pursuits

illustrates the powerful promissory rhetoric of techno-solutionism (Gardner and Warren 2019). This rhetoric contains a sense of futurity, which imagines, via the deployment of novel technologies, a transformed self and body free of the challenges of illness. Potentiality (Taussig, Hoeyer, and Helmreich 2013) is evident here in both future orientation and transformative potential. The concept of cure is productive in the context of neurodegenerative conditions precisely because of existing limits of medical treatment and management (Warren and Manderson 2015), as we consider in the example of DBS below.

Parkinson's disease and DBS

PD is an idiopathic neurodegenerative condition commonly associated with tremor and rigidity (for an overview, see Warren and Manderson 2015). While some people have significant degeneration over a relatively short period, others experience a prolonged disease course. As the condition progresses, it becomes increasingly hard for people living under a diagnosis of PD – whether as the person so diagnosed or as caregiver – to manage; dopamine-replacement (or agonist) medications may steadily reduce in effectiveness (Olanow, Obeso, and Stocchi 2006). Some patients who experience reduced efficacy of standard medications may seek, or be offered, treatment with DBS. While DBS was originally offered to people some years into their lives with PD, it is increasingly offered to people early in their illness course (Hacker et al. 2018). A relatively new, high-cost, high-efficacy therapy, DBS involves the implantation of fine wires deep into the basal ganglia region of the brain, where they deliver constant electrical stimulation through a cardiac pacemaker-like device (Gardner and Warren 2019; Okun 2014). While the wires remain inserted on a permanent basis, patients can turn the device on and off, and neurosurgeons can adjust stimulation levels.

The promotion of DBS as a 'cure' for PD illustrates how transformative potential is attributed to novel technologies. For the YouTube video makers described above (Gardner et al. 2019), DBS brings forth the promise of a changed body and thus a reduced need for informal and formal care, greater autonomy, and a restitution of sorts, where PD is paused so long as the device is on. However, DBS, as a technological cure for PD, raises deeper questions about the socioeconomic realities of illness and healthcare, particularly around questions of equity and access.

Despite a well-funded universal healthcare system, Parkinson's treatments are not available equally to all patients in Australia. Indeed, patterns in treatment provision – particularly for DBS – reveal the social fault lines (Heckert 2018; Hammad Mrig, this issue) of neurodegeneration. While DBS is routinely offered as a cost-effective, long-term solution that responds to both disease progression and reducing effectiveness of medication, it is only realistically available to those who have private health insurance and funds to cover the

significant out-of-pocket costs (A\$10,000-\$25,000+). For most people with PD, this is out of reach, especially on top of other PD management costs (e.g., medication, specialist appointments, and adjunct therapies). In this way, cure brings structural inequalities to bear – it is not accessible to all. This raises a fundamental question for health economics and healthcare policy: how many resources should be allocated to finding 'new' cures while existing cures remain out of reach for the majority of the population? Such questions of equity present challenges to how states provide care: here, unlike in the interpersonal care defined earlier, discussions of care (as an obligation of a state towards its citizens) are inseparable from considerations of cure and access to cure.

The economic unevenness of DBS access echoes broader social trends in Parkinson's treatment and advocacy, thus informing agenda setting around the disease. In Narelle Warren's ethnographic research with Australians living with PD and their caregivers (see Warren and Ayton 2018; Warren and Sakellariou 2020), wealthier people (that is, self-funded retirees) participated more in Parkinson's-related activities and organisations – for example, taking up roles on boards of management and planning local fundraising activities - than those who relied on state-based welfare (e.g., old age or disability pensions). Accordingly, their personal priorities informed the strategic directions of key support organisations. This was further complicated by a shifting funding context, including government funding, which encouraged NGOs' greater engagement with biomedicine. Influential for Warren's ethnographic research was how global neurodegeneration fundraising events dramatically shifted what research was supported and by whom: at the start of her project, in 2011, relevant NGOs repeatedly reiterated their commitment to the provision of support and care to those living with PD. However, following the widespread success of the 2014 Ice Bucket Challenge for MND in raising significant monies to 'search for cure', with amounts raised matched by the Federal Government, the NGOs not only altered their fundraising strategy but, importantly, shifted their focus to almost exclusively supporting research concerned with cure.

While such a shift ostensibly benefits everyone with PD, poorer people in her study felt silenced in representations of PD and in advocacy efforts. They were also less likely to have access to programmes for ongoing support or more effective treatments, compounding social isolation and worsening health status (Manderson and Warren 2016): for these participants, DBS offered much, but its promises were impossible to attain. Those who cannot afford 'curative' technologies thus face a new moral dilemma, introduced and subsequently reinforced by the cure motif. There is a moral imperative to want a cure if it is available, or if it might become so; yet cure is not accessible for poorer patients. A post-cure analytic – which encourages an interrogation of, rather than broad acceptance of, curative technologies – is thus required to understand what the cure motif does.

Post-cure engagements do more than highlight social fault lines. Our analysis of amateur YouTube videos of DBS (Gardner et al. 2019) reveals the socialities – positioning of the self and others within social environments – of PD. An exclusive focus on cure not only strips out others or environments (as described above), but also transforms personhood. YouTube video-makers focused on functional outcomes, largely motor function: their bodies were the material through which cure was effective, but the sense of who they were as people was (for the most part) absent. Yet, in Warren's interviews, concerns about personhood played a central role in the considerations of cure they reported. Participants described their need to weigh the potential outcomes of DBS against the social, emotional, and economic costs of the treatment. Pam, for example, explained that she felt the 'trade-offs' of DBS were too costly, and so the therapy was not appealing:

I'm not keen on it... I belong to [a] group and every one of those women has had the operation, except for me, and from what I have observed, every one of them, the reasons why they had the operation was great. I mean, not great, but was understandable. But every single one of them has had to have a trade-off... [those] trade-offs have been worse than the original symptoms in my way of thinking. Like, for instance, Sharon, her main love besides her family was dancing and reading, and she had the deep brain stimulation and her trade-off was that she um, could no longer dance and she could no longer read... For me, not being able to dance, or... to read... would be [unacceptable].

Pam's discussion of the transformation of personhood following DBS highlighted the tension between cure and care. She believed the psychosocial changes of the treatment raised far more concerns than the motor symptoms of the disease ever did. On the one hand, she emphasized the limits of techno-solutionism: 'every single one of them has had to have a trade-off'. Simultaneously, she acknowledged the attractiveness of cure (i.e., where she stated 'the reasons why they had the operation was great').

Pam's quote demonstrated the differential impacts of DBS. For example, Sharon's tremor resolved after the DBS surgery and thus she had a good outcome in this aspect; however, losing her ability to dance and read represents a poor outcome. This highlights how some potentialities of technology are realised, while others are undermined. Pam understood this in terms of 'trade-offs'.

Notions of personhood, and its transformation in response to neurodegeneration, provide at least a partial explanation of why cure is so compelling: the association between physical neural structures, mental concepts of mind, and social concepts of personhood are all troubled following a diagnosis of neurodegenerative disease. Dominant understandings conflate these

different elements, making them seem inextricable. As Nina Strohminger and Shaun Nichols (2015) demonstrate, cognitive impairment is commonly associated with a lost or changed identity. For people living with neurodegenerative conditions, and their close others, curative technologies seem to offer a way to reclaim the lost self, or the self in process of becoming lost.

Conclusions

Cure is central to social imaginaries of sickness, dominating discourse and research agendas. We have argued that prioritising cure over care can misdirect our expectations of science, medicine, and doctors. This dynamic has implications for patients and their families, whose hopes may be pinned on vanishingly small statistical odds, and whose preferences and voices are devalued or subsumed by curative hype (Stegenga 2018).

Further, as we have demonstrated in this Position Piece, the idea of cure influences not only individual patients but also the economic dynamics of experimental medical science. In the latter domain, to focus on cure to the exclusion of other concerns is to commit a form of structural violence, as only people with sufficient social, political, or economic resources will be able to realise the promises associated with cure. In this way, cure is an ideology that shifts resources unequally amongst those living with illness (Stegenga 2018). It sets all sights on an outcome that is unlikely to be achieved, an impossible possibility, and where it is realisable, will not be realised by all without significant commitment by the state.

In this Position Piece, we initiate a post-cure analysis of biomedical technologies: cure has implications that extend beyond the illness and, sometimes, beyond the person. These must be interrogated. As we have demonstrated, cure shifts temporalities of life and of illness, prompts new engagements with risk, generates new socialities and materialities, reveals questions of equity and access, and transforms personhood. For those who live under a diagnosis that offers no hope of restitution, curative technologies are not the only source of hope, although cures are often positioned as the only way for patients to conceive a potential future or a future with potential. Life with illness, regardless of prognosis, has meaning beyond engagement with technology. A post-care analytic illuminates the complexity of life under diagnosis, and recognises the role of care – within and between individuals – in constructing lives worth living.

Acknowledgements

The authors wish to thank Professor Lenore Manderson, Professor Klaus Hoeyer, Assistant Professor Martha Lincoln, and Dr. John Gardner for their comments on early versions of this

manuscript. Dr. Amanda Pavey's insights on the Big Freeze initiative allowed us to track down useful contextual information. This Position Piece originated as discussant comments from a panel on 'Post-Cure Care: Discoveries at the Edge of Biomedicine' organised by Ellen Rubinstein and Emily Hammad Mrig.

About the authors

Narelle Warren is a medical anthropologist and senior lecturer in anthropology and sociology at Monash University. Her research focuses on the lived experiences of ageing and neurological disabilities in Australia and Malaysia, particularly focusing on Parkinson's disease, stroke, and dementia. In addition, she undertakes interdisciplinary research on innovative disability technologies.

Courtney Addison is an anthropologist of science and medicine and lecturer in the Centre for Science in Society at Victoria University of Wellington. Her research explores the place of genetics in medical and environmental contexts, and for human and non-human actors. She is also interested in the ethical dimensions of experimental science, and the social and cultural dimensions of ethical life.

References

- Addison, Courtney. 2017. 'Spliced: Boundary-Work and the Establishment of Human Gene Therapy'. *BioSocieties* 12 (2): 257–281. https://doi.org/10.1057/biosoc.2016.9.
- Canguilhem, Georges. [1943] 2012. Writings on Medicine. New York: Fordham University Press. Chaufan, Claudia, Brooke Hollister, Jennifer Nazareno, and Patrick Fox. 2012. 'Medical Ideology as a Double-Edged Sword: The Politics of Cure and Care in the Making of Alzheimer's Disease'. Social Science & Medicine 74 (5): 788–795. https://doi.org/10.1016/j.socscimed.2011.10.033.
- Collins-Praino, Lyndsey, and Viythia Katharesan. 2017. 'What We Know, Don't Know and Suspect about What Causes Motor Neuron Disease'. *The Conversation*, 20 June. https://theconversation.com/what-we-know-dont-know-and-suspect-about-what-causes-motor-neuron-disease-79409.
- DelVecchio Good, Mary-Jo. 2001. 'The Biotechnical Embrace'. *Culture, Medicine & Psychiatry* 25 (4): 395–410. https://doi.org/10.1023/A:1013097002487.
- Gardner, John, and Narelle Warren. 2019. 'Learning from Deep Brain Stimulation: The Fallacy of Techno-Solutionism and the Need for "Regimes of Care". *Medicine, Health Care & Philosophy* 22: 363–374. https://doi.org/10.1007/s11019-018-9858-6.
- Gardner, John, Narelle Warren, Courtney Addison, and Gabby Samuel. 2019. 'Persuasive Bodies: Testimonies of Deep Brain Stimulation and Parkinson's on YouTube'.

- Social
 Science
 & Medicine
 222:
 44–51.

 https://doi.org/10.1016/j.socscimed.2018.12.036.
- Hacker, Mallory L., Mahlon Delong, Maxim Turchan, Lauren E. Heusinkveld, Jill L. Ostrem, Anna L. Molinari, Amanda D. Currie, et al. 2018. 'Effects of Deep Brain Stimulation on Rest Tremor Progression in Early Stage Parkinson's Disease'. *Neurology* 91 (5): e463–e471. https://doi.org/10.1212/WNL.000000000005903.
- Heckert, Carina. 2018. Fault Lines of Care: Gender, HIV and Global Health in Bolivia. New Brunswick: Rutgers University Press.
- Heinemann, Laura L. 2016. Transplanting Care: Shifting Commitments in Health and Care in the United States. New Brunswick: Rutgers University Press.
- Lansbury, Peter T., and Hilal A. Lashuel. 2006. 'A Century-old Debate on Protein Aggregation and Neurodegeneration Enters the Clinic'. *Nature* 443: 774–779. https://doi.org/10.1038/nature05290.
- Madden, Annie, Max Hopwood, Joanne Neale, and Carla Treloar. 2018. 'Beyond Cure: Patient Reported Outcomes of Hepatitis C Treatment among People who Inject Drugs in Australia'. *Harm Reduction Journal* 15: 42. https://dx.doi.org/10.1186%2Fs12954-018-0248-4.
- Maghami Mohammad Hossein, Amir Masoud Sodagar, Alireza Lashay, Hamid Riazi-Esfahani, and Mohammad Riazi-Esfahani. 2014. 'Visual Prostheses: The Enabling Technology to Give Sight to the Blind'. *Journal of Ophthalmic & Vision Research* 9 (4): 494–505. https://dx.doi.org/10.4103%2F2008-322X.150830.
- Manderson, Lenore. 2011. Surface Tensions: Surgery, Bodily Boundaries and the Social Self. Walnut Creek: Left Coast Press.
- Manderson, Lenore, and Carolyn Smith-Morris. 2010. 'Introduction: Chronicity and the Experience of Illness'. In *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*, edited by Lenore Manderson and Carolyn Smith-Morris, 1–20. New Brunswick: Rutgers University Press.
- Manderson, Lenore, and Narelle Warren. 2016. "Just One Thing After Another": Recursive Cascades and Chronic Conditions'. *Medical Anthropology Quarterly* 30 (4): 479–497. https://doi.org/10.1111/maq.12277.
- Martin, Emily. 2007. Bipolar Expeditions: Mania and Depression in American Culture. Princeton: Princeton University Press.
- Mehta, Paul, Wendy Kaye, Jaime Raymond, Ruoming Wu, Theodore Larson, Reshma Punjani, Daniel Heller, et al. 2018. 'Prevalence of Amyotrophic Lateral Sclerosis United States, 2014'. *MMWR Morbidity Mortality Weekly* Report 67 (7): 216–218. https://doi.org/10.15585/mmwr.mm6707a3.
- Morris, Gary P., Ian A. Clark, and Bryce Vissel. 2014. 'Inconsistencies and Controversies Surrounding the Amyloid Hypothesis of Alzheimer's Disease'. *Acta Neuropathologica Communications* 2: 135. https://doi.org/10.1186/s40478-014-0135-5.

- Nahta, Rita, Mien-Chie Hung, and Francisco J. Esteva. 2004. 'The HER-2-Targeting Antibodies Trastuzumab and Pertuzumab Synergistically Inhibit the Survival of Breast Cancer Cells'. *Cancer Research* 64 (7): 2343–2346. https://doi.org/10.1158/0008-5472.can-03-3856.
- NIH National Cancer Institute. 2018. *Understanding Cancer Prognosis*. https://www.cancer.gov/about-cancer/diagnosis-staging/prognosis.
- Obeso, Jose A., Maria C. Rodriguez-Oroz, Christopher G. Goetz, Concepcion Marin, Jeffrey H. Kordower, Manuel Rodriguez, Etienne C. Hirsch, Matthew Farrer, Anthony H. V. Schapira, and Glenda Halliday. 2010. 'Missing Pieces in the Parkinson's Disease Puzzle'. *Nature Medicine* 16 (6): 653–661. https://doi.org/10.1038/nm.2165.
- Okun, Michael S. 2014. 'Deep-Brain Stimulation Entering the Era of Human Neural-Network Modulation'. *New England Journal of Medicine* 371 (15): 1369–1373. https://doi.org/10.1056/NEJMp1408779.
- Olanow, C. Warren, Jose A. Obeso, and Fabrizio Stocchi. 2006. 'Continuous Dopamine-Receptor Treatment of Parkinson's Disease: Scientific Rationale and Clinical Implications'. *The Lancet Neurology* 5 (8): 677–687. https://doi.org/10.1016/S1474-4422(06)70521-X.
- ONS (Office for National Statistics). 2017. Occupation Annual Survey of Hours and Earnings (ASHE) Provisional. Data set and guide to results. https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/earningsand-workinghours/datasets/occupation4digitsoc2010ashetable14.
- Parsons, Talcott. 1951. The Social System. London: Routledge
- Petersen, Alan. 2006. 'The Genetic Conception of Health: Is it as Radical as Claimed?'. *Health* 10 (4): 481–500. https://doi.org/10.1177%2F1363459306067315.
- Petersen, Alan. 2015. *Hope in Health: The Socio-Politics of Optimism*. London: Palgrave MacMillan. Petersen, Alan, and Ivan Krisjansen. 2015. 'Assembling "The Bioeconomy": Exploiting the Power of the Promissory Life Sciences'. *Journal of Sociology* 51 (1): 28–46. https://doi.org/10.1177%2F1440783314562314.
- Rhodes, Tim, Siri Egede, Pippa Grenfell, Sara Paparini, and Cameron Duff. 2019. 'The Social Life of HIV Care: Making of "Care Beyond the Virus". *BioSocieties* 14: 321–344. https://doi.org/10.1057/s41292-018-0129-9.
- Scheufele, Dietram A., Michael A. Xenos, Emily L. Howell, Kathleen M. Rose, Dominique Brossard, and Bruce W. Hardy. 2017. 'US Attitudes on Human Genome Editing'. *Science* 357 (6351): 553–554. https://doi.org/10.1126/science.aan3708.
- Stegenga, Jacob. 2018. Medical Nihilism. Oxford: Oxford University Press.
- Strohminger, Nina, and Shaun Nichols. 2015. 'Neurodegeneration and Identity'. *Psychological Science* 26 (9): 1469–1479. https://doi.org/10.1177%2F0956797615592381.

Sturdy, Steve. 2017. 'Personalised Medicine and the Economy of Biotechnological Promise'.

The New Bioethics 23 (1): 30–37.
https://dx.doi.org/10.1080%2F20502877.2017.1314892.

- Taussig, Karen-Sue, Klaus Hoeyer, and Stefan Helmreich. 2013. 'The Anthropology of Potentiality in Biomedicine'. *Current Anthropology* 54 (S7): S3–S14. https://doi.org/10.1086/671401.
- Turner, Martin R., Orla Hardiman, Michael Benatar, Benjamin R. Brooks, Adriano Chio, Mamede de Carvalho, Paul G. Ince, et al. 2013. 'Controversies and Priorities in Amyotrophic Lateral Sclerosis'. *The Lancet Neurology* 12 (3): 310–322. https://doi.org/10.1016/S1474-4422(13)70036-X.
- Venkat, Bharat Jayram. 2016. 'Cures'. *Public Culture* 28 (3 [80]): 475–497. https://doi.org/10.1215/08992363-3511502.
- Warren, Narelle, and Darshini Ayton. 2018. '(Re)negotiating Normal Every Day: Phenomenological Uncertainty in Parkinson's Disease'. In *Disability, Normalcy, and the Everyday*, edited by Gareth M. Thomas and Dikaios Sakellariou, 142–157. London: Routledge.
- Warren, Narelle, and Lenore Manderson. 2015. 'Credibility and the Inexplicable: Parkinson's Disease and Assumed Diagnosis in Contemporary Australia'. In *Diagnostic Controversy: Cultural Perspectives on Competing Knowledge in Healthcare*, edited by Carolyn Smith-Morris, 127–146. New York: Routledge.
- Warren, Narelle, and Dikaios Sakellariou. 2020. 'Neurodegeneration and the Intersubjectivities of Care'. *Medical Anthropology* 39 (1): 1–15. https://doi.org/10.1080/01459740.2019.1570189.
- Williamson, Robert, Warwick Anderson, Stephen Duckett, Ian Frazer, Carrie Hillyard, Emma Kowal, John Mattick, et al. 2018. *The Future of Precision Medicine in Australia*. Melbourne: Australian Council of Learned Academies. https://acola.org/hs2-precision-medicine-australia/.
- Wolf-Meyer, Matthew. 2014. 'Therapy, Remedy, Cure: Disorder and the Spatiotemporality of Medicine and Everyday Life'. *Medical Anthropology* 33 (2): 144–159. https://doi.org/10.1080/01459740.2013.792812.