

CONTEXT MATTERS:
UTILISING VIZENOR'S THEORY OF NATIVE SURVIVANCE TO
EXPLAIN EXPERIENCES OF GENETIC DIFFERENCE IN ENGLAND
AND WALES

NAOMI MARSHALL¹

This article explores the appropriateness of utilising Vizenor's writings on 'survance' outside of Native American contexts. I ask whether survance is a fitting analytic tool for understanding the actions and perspectives of my participants who live with an unpredictable genetic condition. While residents of England and Wales – both my own participants and those involved in other ethnographic projects – may utilise irony and creativity to resist both misrepresentation and stigma, I contend that the use of survance as a critical term must be qualified and translated. In this article, I consider differences between the context in which Vizenor writes and the experiences of my own participants. Namely, I attend to the contrast wherein Native Americans have been understood as 'the celebrated survivor[s] of cultural genocide' (Vizenor 2008), while my participants are at times discouraged from reproducing people like themselves because of their genetic difference. The purpose of this consideration is threefold. First, I wish to find new ways of analysing the creativity of my participants. Does survance help elucidate the agency and wisdom of my participants with NFI in the United Kingdom? Second, I intend to add to Vizenor's discourse. What might survance look like in a biosocial community as opposed to a cultural group? Can we understand 'survance' as an expression of 'biopower'? How do we fully divorce survance from survival in contexts of reproductive surveillance? Thirdly, and ultimately, the purpose of this article is to consider, more broadly, the role and flexibility of theory in anthropology.

Keywords: neurofibromatosis, survance, biopolitics, ethnography, positionality

¹ Institute of Social and Cultural Anthropology, University of Oxford.

Introduction

This paper considers whether Vizenor's writings on survivance can be applied out of their original context. Can ideas which were developed in and for Native American cases be faithfully and effectively utilised in the academic analysis of non-Native subjects? To fully answer this question requires a comprehensive exploration of the role and flexibility of theory in the social sciences. I cannot offer a resolution on this matter in one article. I do, however, hope to provide reflections on the translation of theory as a part of a discipline which has often grappled with the viability and value of the translation of cultures. Should I, as a sociocultural anthropologist, make use of Vizenor's conceptual work in my analysis of the experiences of my participants in England and Wales? Would such usage be ethical? Would it be productive? These are my central questions for this investigation. In the first half of this article, I consider how survivance relates to my participants' experiences of biomedical uncertainty and genetic stigma. I scope various ways in which my participants' lives and philosophies might be characterised as survivance. Then, in the second half of the paper, I begin questioning whether – in future outputs – I *should* utilise survivance as an analytic tool. I consider why a blunt co-option of Vizenor's analytic might be problematic, and offer exposition on crucial contextual differences, both present and historic, between my participants' and Vizenor's subjects. This paper's conclusion centres on questioning the adaptability and applicability of regionally specific anthropological theorisation more broadly. But before I begin this investigation, I first wish to offer some background on Vizenor's concept of survivance. After all, as this paper intends to demonstrate, context matters.

Vizenor's 'survivance' is difficult to define in a succinct manner. Vizenor asserts that 'theories of survivance' are 'imprecise by definition' (2008: 1). However, for the purpose of clarity in this article, I will work with the following definition. At its core, Vizenor's survivance refers to the active ways in which Indigenous peoples inherit the past, and by doing so nullify lazy and inaccurate characterisation of such peoples as mere victims. Lockard summarises survivance as 'the arch-opponent of victimization' (2008: 210). That being said, Lockard also uses the following quote from Sonya Atalay to emphasise that survivance does not downplay the seriousness of attacks made on Indigenous ways of life: 'the concept of survivance is not about avoiding or minimizing the horrors and tragedy of colonization. It includes agency and Native presence but does not refuse stories of struggle' (2008: 209). Vizenor claims 'survivance' is not a 'theory' (2008: 11), but an action. He writes, it is 'the action, condition, quality, and sentiments of the verb survive, 'to remain alive or in existence,' to outlive, persevered with a suffix of survivancy' (2008: 19). King, Gubele, and Anderson summarise the term survivance as Vizenor's 'vision of Indigenous nations'. They continue, 'survivance is survival and resistance together: surviving the documented, centuries-long genocide of American Indian peoples and resisting still the narratives and policies that seek to marginalize and – yes, still now – assimilate indigenous peoples.' (King, Gubele, Anderson 2015: 7)

Vizenor intended for his work to be utilised broadly in Indigenous-American studies but came to write about survivance from a more specific regional focus. An esteemed professor of American and Literature studies, Gerald Robert Vizenor is an Anishinaabe scholar and

enrolled member of the Minnesota Chippewa Tribe. He first discusses ‘survivance’ in his 1993 book, *The ruins of representation*, but his interest in a better analytic vocabulary for Native experiences can be traced back to his time as a graduate student (Vizenor 2008: 1-19). Against advice from his master’s supervisor, Vizenor chose to conduct archival work on *The Progress*, a historic newspaper with which Vizenor had a personal connection. First published in 1886 on the White Earth Reservation, *The Progress* was an English language newspaper which reported political issues of relevance to those who lived on the reservation (Vizenor 1965). One of the editors of the paper was one of Vizenor’s ancestors. This editor opposed the federal allotment of reservation land and utilised mockery and political commentary in *The Progress* to express his discontent (Vizenor 2008: 10-11). One can understand Vizenor’s development of the term ‘survivance’ as a means to describe the actions of people, such as this editor, who creatively refused to abide by the logic of settler colonialism.

Vizenor’s writings on ‘survivance’ have been seminal. To give but one example of the flexibility and advantage of survivance as an analytic tool, consider Henry’s (2021) work among Indigenous gangs in Manitoba and Saskatchewan. Whereas a settler imaginary has ‘pathologized understandings of Indigenous lifeworlds, especially within street spaces’ (Henry 2021), survivance offers an alternative understanding. By framing street activity as survivance, Henry argues that his participants should be respected as providers for their families, rather than misjudged as delinquents. Moreover, Henry locates these young men among other Indigenous peoples who ‘have found and continue to find innovative ways to survive, resist, and resurge themselves within settler spaces.’ Survivance evidently has important analytic potential, even beyond Vizenor’s Anishinaabe regional focus. But how might survivance work outside of Native American contexts altogether? What is its potential for other discourse?

NFI and survivance

I was introduced to Vizenor’s writings on survivance by a colleague, Wesam Hassan. During the past few years, Hassan and I have discussed the palpable ‘uncertainty’ present in the everyday lives of our participants, a comparison we invite despite evident contrasts between our field sites. Hassan’s work explores attitudes towards – and experiences of – games of chance in Istanbul. In my work, I focus on people’s experiences of an uncertain genetic condition in England and Wales. From the outset, I could see that survivance was relevant to my research. The people I work with are – much like people in the context of Vizenor’s writings – too often eschewed as tragic victims rather than perceived as powerful agents. Yet unlike the people for whom Vizenor writes, who live in the continuing spectre of cultural genocide, my participants persist against genetic stigmatisation.

My participants have, or have an immediate relative with, neurofibromatosis type 1 (NFI). Although the cause of this genetic condition is limited to a change in one gene, neurofibromatosis manifests as a ‘multi-system disorder’ (Ratner and Miller 2015). Symptoms of NFI include, but are not limited to, progressive disfigurement and disability from benign tumour growth throughout the nervous system, skin pigmentation abnormalities, congenital cognitive differences, bone deformities, and rarer complications – such as NFI-associated

cancers (Carrieri, Farrimond, Kelly and Turnpenny 2016). As well as being highly varied in presentation, NFI symptoms are also highly unpredictable. Symptoms can appear, or worsen, without warning at any point in the affected person's life (Ratner and Miller 2015; Carrieri, Farrimond, Kelly and Turnpenny 2016). As one of my participants reflected, people with NFI live with 'certain uncertainties'. That is, whilst there is a long list of NFI symptoms which certainly *might* happen, there is always uncertainty over when or whether they *will* happen. The idiosyncrasy and unpredictability of each NFI case means patients cannot know when they are fully symptomatic according to Konrad's 'post-diagnosis, pre-symptomatic' categorisations (Konrad 2005: 14). Instead, people with NFI have a liminal diagnosis which troubles how they define themselves and the extent of their illness. In summation, my participants live with a potentially serious genetic condition.

From the summer of 2020 to the spring of 2022, I conducted ethnographic fieldwork with a London-based NFI charity. This organisation, which I will call Neurofibromatosis Communal (NFC), works to serve the interests of people with nerve tumour causing conditions such as NFI and NF2-related schwannomatosis. During this fieldwork period, I spent considerable time observing this biosocial² group's successful enactment of biopower. That is, I attended to how my participants acquired specialised medical knowledge to better navigate the nationalised health service in the United Kingdom, and to receive appropriate support from their employers and the government. Accordingly, while people with NFI are geographically isolated from each other, my participants still enjoyed a certain degree of imagined community with other people with NFI in the UK. NFC certainly helps foster this community.

My methodology consisted of a mixture of semi-structured online interviews and in-person participant observation. Although upwards of 56 participants took part in my research, I would characterise my project as focusing on the lives and philosophies of seven key participants, all of whom I came to know well over several regular meetings. One of these key participants – William – is of particular relevance to this investigation into the applicability of survivance out of its original context. While I hypothesise that all my participants enact survivance to a certain extent, William's wit, direct manner of speaking, and loud and proud demeanour make him an obvious case study for this article. By introducing William's experiences and outlook, my intent is twofold. First, I wish to treat this as a heuristic exercise to help me better unpack the nuances of my participants' actions and experiences. Secondly, and of foremost relevance to this paper's focus, my aim is to consider how Vizenor's conceptualisation of survivance might be applied out of context.

²As a point of interest, Paul Rabinow referenced neurofibromatosis groups when he first theorised 'biosociality'. He wrote, 'There already are, for example, neurofibromatosis groups whose members meet to share their experiences, lobby for their disease, educate their children, redo their home environment and so on. That is what I mean by biosociality ... Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and "understand" their fate.' (Rabinow 1996: 102)

William's practice of survivance

William is a retired nurse in his seventies living in Bristol. His politics, language, and energy seem more in line with a young student than with what some might expect from an upper-middle-class, southern English man raised in the 1950s. Passionate about transgender rights, young adult literature, and the right-to-die movement, William is kind, foul-mouthed, and – as I increasingly appreciated over the course of my research – exceptionally wise. William's diagnosis of NFI seems the least interesting facet about him, although it is perhaps the first thing you will notice upon meeting him. William has numerous benign neurofibroma tumours on his face and neck. He is more than aware of stolen glances from strangers. He is far fonder of outright questions posed by young children who are open and – in his opinion – innocent in their curiosity about his visible difference. 'Why do you have bumpy skin?' and 'what do your lumps feel like?' are inquisitions frequently fielded by William. In one of our earlier meetings, he joked to me, 'how do you explain clinical genetics to a four-year-old?' It struck me that William was, in fact, more than adept at explaining his neurofibromatosis to children and adults alike. 'I was born different', he explains to young children. To slightly older children, he might describe genetics by referencing eye colour: 'we all have recipes that make us, *us*. Your recipe gives you green eyes, and my recipe gives me these spots on my skin. That's why you can't catch my lumps, they're unique to me.' One could attribute William's communication skills to his decades as a paediatric nurse on neurology ward. A substantial portion of his job was explaining complex conditions to scared parents and too-often-belittled children. However, my inference is that it is not simply his career which enabled such clear explanations about his NFI. William's introspection, candour, and humour are all his own.

William is different to many of my other participants in the degree to which he is willing to openly analyse, and at times criticise, NFC – the NFI charity with whom I worked. William has quite the reputation for writing passionate letters to NFC. He dislikes how the charity champions the voices of parents of patients; he feels this comes at the expense of offering space for people with NFI to speak about and for themselves. Furthermore, he takes particular issue with the portrayal of people with NFI as objects of pity. He explained to me that he understands why NFC paints people with NFI this way in their social media posts. These depictions evidently increase fundraising revenue. After all, he speculates, what better way to motivate generosity than by playing up the sad struggle of a sweet young child with NFI complications? The problem is, in William's mind, that this implicitly paints all people with NFI as pitiable. According to William, such a picture is not only inaccurate but also unhelpful.

William attests that people with NFI should not be portrayed as, or made to feel, 'invalid' – a phrase he has deliberately reappropriated from the outdated term 'invalid'. William argues that 'the problem' is with society, not with people with NFI. He elaborates that his experiences of exclusion should not be attributed to *his* difference, but *society's* inability to accommodate such differences. Similarly, when I asked William if he identified as 'disabled', he explained that he does not, because it is society which has 'not-abled' him to participate. Consider the following writing excerpt by William, which he sent to me after one of our calls to synthesise much of what we had covered in the interview:

NFI is not something I 'have', it is part of who I am. It's not all of who I am, but it's an intrinsic part of me and I would not be the 'me' that I am without the NFI. How can I then deny it and wish it away? It is not me that creates a problem. It's a culture that looks at me and finds something lacking or something unacceptable. A culture that imposes on me the perception that I would be a better, more whole person if NFI was not part of my make up. A culture that tells me I can never be good enough.

William's challenging of the victim slot, and the articulation that he is not being accepted on his own terms, has evident relevance to Vizenor's writings. The 'difference' of Vizenor's subjects can be located in their indigeneity, while William's difference is in his genome, yet both insist their 'differences' are relative to imposed ethnocentric norms and biases. William is not responding to a 'settler mindset', but he is nevertheless resisting the norms of British culture – where some claim eugenics still has a function in modern discourse (Rose 2001: 3). Although people may posit that negative eugenics no longer exists legally in Euro-America, one cannot deny societal preferences wherein some people are encouraged to reproduce over others (Lewis 2019: 5).

Vizenor's writing on survivance calls attention to the past, present, and – perhaps most pressingly – the future. This analytic focus also resonates with William's experience. Consider the following dialogue from William in our second meeting, wherein he recounts his difficult relationship with his mother. In his reflection, he discusses not only his challenging childhood but also the stolen future – insofar as he was encouraged not to have children lest they be like himself:

I was the messenger of bad news to my mum, [because once I was diagnosed with NFI, she and my older sister were also diagnosed with NFI.] I wasn't and never could be good enough [for her] because I have this condition. My mother would have wished [I did not have NFI], which is understandable, and even more understandable, I think, in the context of the 1950s – how disability and things like that, things like having conditions like NFI, was seen then. I think the way she viewed me has to be viewed within the context of societal attitudes of the time. Nevertheless, it still affected me profoundly.

The other phrase I come up with is this: I think I was 'damaged goods' [to my mum]. I was damaged goods in her mind because she herself was damaged goods [because she also had NFI]. I think if she could have put me in a parcel, sent me back to [the] Amazon [warehouse], and ask to be replaced with a better child [she would]! I laugh but it's something that's stuck with me. [There was] something in her attitude. I can understand her feelings, but I find it difficult to reconcile her actions, her repeatedly telling me throughout my childhood and adolescence that 'you must never have children'. Because I internalised that...

I think the internalisation comes from an actual belief that, 'she's right, that I must never have children.' It wasn't until I was an adult that I questioned [the idea that I should not have children], but by that point it was already internalised. Like I said, I could rationalise my way out of it, but there was still that inner feeling somewhere. Mum said, 'if I had known I had NF, I would have never had

children myself', which is tantamount to saying, 'you shouldn't exist'. I felt there was a lack of acceptance of me as I was.

William is arguably here still trapped in a situation of survival rather than *survivance*. He faces not only a complex chronic medical condition, but also the need to justify his existence and the existence of future of people like himself. By contrast, Vizenor defines *survivance* as the projection of Native culture into an unknown yet promising future. Kroeber summarises *survivance's* relationship with temporality as follows: *survivance* concerns not only 'recalling a cherished past but also carrying the promise of a vital future (necessarily still unimagined and surprising)' (2008: 30-31). My participant William does not exemplify Vizenor's writing here. However, by attending to *why* William is unable to exemplify this facet of *survivance*, I am able to unpack the nuances of William's marginalisation – including his denied reproductive future – better than other theorisations I had previously considered in my analysis.

Previously in my work, I have drawn on Goffman's (1963) theory of stigma. Joan Ablon, an anthropologist who worked with North Americans with NFI in the 1990s, also used this to account for the exclusions and obstacles faced by her participants. Goffman writes:

Society establishes the means of categorizing persons and [the complementing set] of attributes felt to be ordinary and natural for members of each of these categories... While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others... and of a less desirable kind – in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted and discounted one. Such an attribute is stigma, especially when its discrediting effect is very extensive: sometimes it is also called a failing, a shortcoming, a handicap. (Goffman 1963: 2-3 quoted in Ablon 2012: 674).

Goffman's theorisation has good descriptive value insofar as he accounted for – decades before our current discourse on intersectionality and allyship – the mechanisms of exclusion and inclusion. However, his writings do not centre on creative resistance to stigma. What is more, he does not discuss very much how stigma might vary in different cultural contexts.

Ablon (1999) says her intended audience consists of psychologists and other clinical professionals – who exist within a specific biomedical understanding of the world – rather than anthropologists. Contrasting Goffman and Ablon's use of stigma with Vizenor's *survivance*, and we can see that the latter gives a more precise explanation of William's exclusion. In a natalist society structured around ideas of the nuclear family, being discouraged from reproducing people like yourself is a critical judgement. Whereas Vizenor's ideal for *survivance* involves imagining a future where marginalised people 'stop defining, and even celebrating, themselves as survivors' (Kroeber 2008: 30), William is as of yet unable to escape this self-perception as someone whose likeness should not survive into the future via descendants. Vizenor's work on *survivance* thus adds nuance to William's experiences of stigma by identifying William as a *survivor* of prejudice not yet able to fully embody *survivance* because of continued, oftentimes internalised eugenic logic.

In seeking to examine the difficulties faced by my own participants, I have drawn on the conceptual work of philosophers, sociologists, and anthropologists specialising in geographic regions other than my own. In addition to Goffman's writings on stigma which he developed in the United States, I have drawn on comparisons with Melanesian cultures, South American literature on genetic identity, and theorisation based on fieldwork in Senegal. Can I not simply add survivance into the mix? This analytic has evident benefits. Why then do I feel unease? Why does it feel wrong to compare the ingenuity of Native American populations to the experiences of my largely white, middle-class, British participants. Should I ask permission from Vizenor? Surely utilising theory in novel contexts is the *modus operandi* of anthropology?

The significance of contextual differences

There are obvious differences between my participants' experiences and the historical context for which Vizenor developed the analytic tool of survivance. The purpose of this next section is to further define these differences and consider their significance, with the eventual aim of evaluating the appropriateness of utilising survivance outside of Native American contexts. I hold that it is important to appreciate not only the historic annihilation of Indigenous peoples and their ways of life, but also the history of anthropology's treatment of such peoples. Vizenor is writing against what has been called 'salvage ethnography'. In 19th and 20th century anthropological practice, academics of Amerindian studies sought to study Indigenous peoples to preserve cultures which they believed were becoming less authentic and thus erased (Arnedo-Gómez 2023). In salvage ethnography, contemporary people were reductively understood as curious relics of the past, a supposedly more pure and more authentic version of human existence.

Vizenor can be understood to be directly countering this anthropological practice by discussing the famous experiences of Ishi as 'a native of survivance' rather than just the 'celebrated survivor of cultural genocide' (Vizenor 2008: 4-5, 8). Vizenor's use of the word 'celebrated' is of interest to me, along with what motivated the practice of salvage ethnography in the first place. Whilst histories show us that Native American peoples and cultures are certainly not always celebrated, salvage ethnography speaks to a more recent – and perhaps equally problematic desire – to encourage the continuation of Native Americans 'as they were'. In contrast, my participants are not always encouraged to reproduce people like themselves. Put another way, my participants are oftentimes not perceived to be objects worthy of preservation. They exist against a preference for 'people like them' to *not* survive into the future.

I hold that there are two important reasons for this diverging treatment. The first is that my participants and Vizenor's face differing forms of discrimination. Whereas the basis of discrimination towards people with NFI is their supposedly abnormal genome, Native American peoples have faced and continue to face discrimination based on their 'indigeneity' vis-à-vis racist hierarchies. Whilst both 'genetic health' and 'race' are sociobiological constructs – constructs which have historically been weaponised to reinforce the legitimacy of the other – they are not equivalent. Indigeneity has been understood as a form of radical alterity,

whereas genetic difference – or ‘disease’ – is conceived of as a risk which is inherent in every population (Rabinow 1996; Rose 2007). Moreover, Indigenous identity pertains not simply to ethnogenetic identity,³ but also to culture and history, among other facets. The second reason for the differing conceptual treatment for my participants and those of Vizenor’s concerns their respective relationships to the state. Indigenous peoples existed before and apart from nation states of the Americas. In contrast, patient advocacy groups in the United Kingdom often work in tandem with the government. Consider that the term ‘native’ can be an appropriate descriptor of both my participants and Vizenor’s, but that the meaning of this term differs radically in each context. Biosocial communities can be understood as being *native* to the neoliberal state because they are formed within it. Moreover, groups such as NFC are made necessary by the complex bureaucracy of nationalised healthcare systems. In contrast, Indigenous peoples were originally *external* to the modern states, or else forcibly incorporated into them.

These differences – in how people relate to the state, as well as in the faulted logics which underpin discrimination – not only explain differing reproductive surveillance – as already mentioned – they also call for specialised theoretical approaches. While biopolitical frameworks of analysis have called attention to the impactful enactment of biopower by people such as William, such Foucauldian frameworks would be insufficient in Indigenous contexts. To understand Indigenous experiences, it is necessary to attend to the systemic violence and structural inequality they face. As such, a political economy approach appears more apt. Although it is tempting to see survivance as a bridge between discourses in biopolitics and political economy, to do so in the abstract would be clumsy. My recommendation for theoretical progress on the matter is to call for greater contextual precision. If we want to reconcile the diverging models of biopolitics and political economy – which holds the potential for substantial theoretical innovation – then what is necessary is a specific ethnographic comparison. What is needed is a comparative project between a biosocial ‘Western’ self-help group and a Native American self-help group dealing with trauma, or with another medicalised issue brought about by their history of colonial oppression. Within such a project, it would be necessary to reconfigure Native American experience from only ‘indigenous’ to also ‘biosocial’. Only then would it be possible to compare these otherwise disparate cases. For the purposes of this investigation – into the use of survivance out of context – I cannot claim that survivance is an example of biopower. The contexts in which these theoretical tools were developed are simply too dissimilar. This leaves me to consider whether I can still claim, conversely, that my participants are practising survivance, albeit in their own context. This brings me on to further points of divergence.

Another incongruence between Vizenor’s context and my own ethnographic fieldwork concerns the nature of the object which is surviving. Joe Lockard writes, ‘The concept of survivance – survival through resistance – entails defining what it is that has been survived’ (2008: 209). Whereas survivance has been defined as the perpetuation of ‘native consciousness’ (Lockard 2008: 209), my participants identify themselves with others based on

³Gibbon, Santos, and Sans’ (2011) publication, *Racial identities, genetic ancestry, and health in South America*, includes various nuanced discussions of situations where Native American identity is associated with specific genetic markers.

their shared genetic condition. This distinction begs the question - does survivance concern the continuation of a people or a culture?⁴ Is it even helpful to make this separation in the context of Native American studies? An important clarification I should make regarding my own context is that my participants do not have a unique 'culture' unto themselves. Whilst there are certainly cultures formed around disabilities – see for instance Deaf communities (Sayers and Moore 2013) – my participants were geographically separated and of vastly different backgrounds. I thus find myself confused as to what survivance might look like in a community united around a genetic – not cultural – identity.

When I spoke to William about my interest in writing this article, he pointed out that the word 'inheritance' means something quite distinctive to him. For William, when he hears the word 'inheritance', he thinks about how he has inherited his NFI gene from his mother, and how he was denied the possibility of passing-on his heritable condition. Can a genetic variation on the NFI gene be 'actively inherited' in the same way a cultural symbol can?⁵ Even if I could construct a convincing argument on the matter, the inheritance of genetic material and genetic difference was certainly not what Vizenor was discussing in his writings on survivance. Vizenor's survivance can be understood as the active process whereby Indigenous peoples pass on 'symbols, ideas, identities, and cultural forms from one generation to another' (Henry 2021). While my participants can be seen as passing on values and identities as well as genetic difference to their offspring, these facets are not 'native' in the same way. To unpack the consequences of the distinction between Indigenous and non-indigenous symbols, and to begin my weighing of the benefits and drawbacks of using survivance out of context, I return to my participant William.

William has a great sense of humour. One need only look to the joke he made in the earlier excerpt – that is, saying that his mother would wish to 'return' him in an Amazon box – to appreciate William's dark humour. William is moreover quite the expert at mocking certain tropes. He once quipped to me that 'you don't have to climb Mount Everest to be a good person with NFI', to poke fun at the sponsored hikes on the NFC website. However, despite these creative inversions, one must appreciate that William's actions and worldview is European. Consider the following observations made by King, Gubele, and Anderson:

In terms of indigenous rhetorics, survivance can mean many things. It can refer to the survival and perpetuation of indigenous communities' own rhetorical practices, it can refer to indigenous individuals' and communities' use of Euro-American rhetorical practices... It is the recognition of how, when, and why indigenous peoples communicate, persuade, and make knowledge both historical and now. Teaching survivance is therefore an act of recognition: acknowledging the ongoing presences and work of indigenous peoples, particularly the way indigenous communities negotiate language and rhetoric. [In order to even begin appreciating] indigenous rhetorics and what can be learned

⁴ Or should 'survivance' be understood as a reference to something more abstract? It is interesting to note that the term 'survivance' originated in French legal theory in the 18th century and was later utilised by Derrida to discuss how goods can be created with the express intent of outliving their creator (Henry 2021).

⁵ I hold that it is dangerous to compound culture and genetics – although one could posit that reproductive partners are chosen on a social basis, and as such people's genetic makeup is a sociocultural product.

from them, students must understand American Indian rhetorical practices as survivance. (King, Gubele, Anderson 2015: 7-8)

William does not and cannot use 'rhetorical turns [to] reorient the framework' from Euro-American to Indigenous perspectives (King, Gubele, Anderson 2015: 7-8). Neither he nor I have sufficient knowledge of such practices to do so. Whilst William uses his humour to satirise norms which condemn him as – in his words – 'damaged goods', this humour is not a part of an Indigenous resistance. As such, although survivance has helped me better understand William's situation, I would be wary of utilising 'survivance' as an easy description of his actions without extensive qualification and contextualisation.

In review, survivance can help unpack why my participants' experiences of stigma are so devastating. By attending to Vizenor's writings, I have come to better recognise the fact that my participants are still fighting for the right for people 'like themselves' to exist in the world. Moreover, by applying survivance out of context, I have called attention to the specifics of what is actively inherited in practices of survivance. This invites further discussion about what exactly constitutes cultural, as opposed to genetic, inheritance. However, despite these two productive advances, I conclude that survivance is not an easy concept to use out of context. Survivance is specific to the skills, expertise, and creativity of people who persist against unique hardships where they are simultaneously romanticised and erased. To conclude this article, I wish to make some wider reflections on the translation of theory in anthropology, before considering how we might borrow from ideas of survivance without bluntly appropriating the term.

Conclusions

'[Anthropological] ideas are as useful in making sense of an Amazon warehouse as in an Amazon jungle'. – Gillian Tett, 2021

'Is there not a danger in assuming simply from introspection that very different people to ourselves will act as we would? Economists realizing the danger have turned to psychologists, but psychologists study motivation in general, outside any real context of situation. However useful this might be, it never comes near to the necessity of explaining the behaviour of the very different specific people who inhabit the world in specific situations and who are the product of specific histories. That can only be got from the kind of information that ethnography provides.' – Bloch 2017: 41

These two quotes illustrate a tension in anthropologists' opinions on the purpose and function of the discipline. Whereas Tett argues – in a book aimed at a general audience rather than at the academy – that anthropological ideas are useful in all contexts, Bloch asserts that it is context which makes ethnography valuable. Careful readers might note that Tett is discussing ideas whereas Bloch is discussing ethnographic practice. However, I maintain that it is impossible to disentwine theory from practice (Ingold 2014). I thus find myself aligning with Graeber and Abu-Lughod, who respectively caution that 'we tend to write as if theory is

concocted in a kind of autonomous bubble' (Graeber 2014: 84), when in fact theory develops both from ethnographic specificity and our own positionality as authors (Abu-Lughod 2006: 155). Given this entanglement between context and ideas, the obvious implication is appreciating that anthropological theorisation can never be fully divorced from the context in which it was developed. So, instead of asking if anthropologists can ever use theory out of context, perhaps a better question is *how* to better acknowledge the inevitable effects our personal-cum-professional contexts have on our understandings of our participants.

Here, I find Abu-Lughod's (2006) paper 'against culture' of great help. Her general argument is that anthropologists' interest in 'culture' is itself problematic as it promotes the very difference it purports to translate:

I will argue that "culture" operates in anthropological discourse to enforce separations that inevitably carry a sense of hierarchy. Therefore, anthropologists should now pursue, without exaggerated hopes for the power of their texts to change the world, a variety of strategies for writing against culture. For those interested in textual strategies, I explore the advantages of what I call "ethnographies of the particular" ... In telling stories about particular individuals in time and place, [by] focusing closely on particular individuals and their changing relationships, one would necessarily subvert the most problematic connotations of culture: homogeneity, coherence, and timelessness. (Abu-Lughod 2006: 153; 162)

The utility of Abu-Lughod's argument to this conclusion is two-fold. First it challenges me to admit the limits of my investigation in the first place. Abu-Lughod, along with an earlier feminist anthropologist Henrietta Moore, cautions against hiding behind ethnocentrism. My acknowledgement of my positionality, as a non-Native anthropologist writing in a British context, is not the same as rectifying power imbalances in the discipline. Some might argue that British sociocultural anthropologists inevitably use Euro-American ideas to understand Native American discourse – why is it therefore inappropriate to use Native American ideas to understand my participants in the United Kingdom? In avoiding using theories such as *survivance* out of context, do we not run the risk of 'ghettoizing' Indigenous thought, much as feminist anthropologists were ghettoised into women's studies (Moore 1988: 5)? Are we thus guilty of perpetuating Euro-American perspectives as the epistemological default? After all, my very assertion that we should not appropriate *survivance* out of context evidences a biased assumption that the 'we' I am addressing is not Native. The second utility of Abu-Lughod's work for my analysis – a practical utility, which avoids a digressive poetics of *Writing culture* (Clifford and Marcus 1986) – concerns language.

Abu-Lughod questions why anthropologists are so interested in using and borrowing anthropological terminology to increase their supposed authority (2006: 159). She begs the question of why we do not, in our analysis, use words and phrases more familiar to our participants. If William had never hitherto heard of 'survivance', why should I impose this idea upon him? I here wish to confess to my own short-sightedness in inserting language where it is not welcome. Consider the following exchange I had with one of my participants:

Marshall: Do you think it is hard for people to foster a sense of community given the fact NFI is such a variable condition?

NFC Employee: I don't know what 'NF community' is. I'm not really sure what that is. I think, from a medical point of view, there's a bunch of doctors and nurses who have been in the field quite a long time, and I suppose that's a medical community in that we all share and use the same skills and knowledge, we all share the aim of wanting to help patients. Does that extend to patients? I don't know. There are so many patients with NF1. With NF2, it's slightly different because there's a smaller patient group, but again, my [NF2] patients wouldn't think of themselves as a community.

I should note that William is also quick to rectify my linguistic slips. He has corrected me on several occasions. An instance which always comes to my mind is when I mistakenly said 'passed away': William had already specified he prefers the more direct term, 'died' – a preference which I should expect and respect from someone so passionate about euthanasia advocacy and candid conversations about death. I find this realisation – on the dangers of inserting language, Native or otherwise – helps offer a resolution to my dilemma. I can utilise Vizenor's survivance to unpack facets of my participants' experience, but ultimately, I should use language specific to my participants' context to account for their experiences. To put Abu-Lughod's recommendation to the test, I wish to close my investigation by examining an ethnographic book which I believe well-balances idiosyncratic terminology with general anthropological interest and out-of-context language.

Calkins (2016) does not mention either Vizenor or survivance. However, I have found her writing both relevant and exceptional in its ability to attend to the contextually specific whilst still referencing broader theorisation. One of Calkins' analytic tools is uncertainty. She writes that there is uncertainty in all action because outcomes are always unknown – but that uncertainty is not a *uniform* property of all action since it is perceived and experienced differently depending on context (Calkins 2016: 2). Calkins conducted fieldwork among rural families in Sudan. In this context, 'uncertainty is processed and managed in a situation of scarcity' (2016: 6). Calkins is quite clear that she is not attempting to represent all the lives and social forms in the geographic area she studied. She states that she is instead looking at a universal dimension of human experience by focusing on the small and specific (2016: 7), thus exemplifying Abu-Lughod's recommendations on the utility of ethnographies of the specific. Calkins – in my opinion – is brilliant precisely because she is aware of when she is talking about the specific and when she is talking about abstract or universal phenomena. Calkins writes that her discussions of survival and uncertainty do not concern war, as was the focus of her colleagues who attended to resisting Muslim Arab identities, but instead centres on 'the daily struggle of getting by when little is at hand to actually make a living and receive one's bread.'

Part of Calkins' successful precision can, I believe, be attributed to her qualification of analytic terms. She talks of 'subtypes of uncertainty' (Calkins 2016: 5) and brackets and differentiates 'based upon the degree of reflexivity with which the knowledge in the situation itself is questioned' (Calkins 2016: 7). Reflexivity, in her writing, refers to critical probing about premises and grounds of interpretations and actions (Calkins 2016: 3). To give another example of her qualifying analytic terms, one needs only look to a moving comparison wherein

she highlights that, 'We can hardly claim that the uncertainties experienced daily by [my participant] Rashaida in north-eastern Sudan are the same uncertainties that people experience elsewhere when engaging in highly risky activities, for instance, at the London Stock Exchange.' (Calkins 2016: 12) Her participants must 'secure their survival', and that makes all the difference.

My participants are in a markedly different situation to Calkins'. One of my key participants, Sharon, notes that a significant struggle for her is resisting overindulging in food. And yet, I find Calkins' writing on reflexivity of great relevance. Just as survivance helps me articulate to the nativist components of William's experience, Calkins' writing on reflexivity in the face of uncertainty may in turn help me attend to my participants' existential reflections. So, again, while Calkins' work is relevant to my own, just as Vizenor's writing are, and while I can and should acknowledge their impact on my theorisation, I should endeavour to let my participants speak for themselves by ultimately relying on language specific to them. 'Conceptual tools' – as termed by Calkins – are important, even necessary. But they are not a replacement for a full account our of participants' experiences and philosophies in their own words.

I wish to close with a final quote by William. While I do not put stock in the Sapir-Whorf hypothesis per se, I find I concur with William's sentiment – and perhaps I have more work to do vis-à-vis disagreeing with my participants' analysis. In my very first meeting with William, he cautioned:

Words are loaded. I don't know if you know that saying, 'language does not just describe reality, language also creates the reality it describes'. Language creates the reality that it describes. Yeh? And it does. Look at the word 'terrorist' for instance. Who gets called a terrorist and who doesn't? And yet they might have done identical things. Words are loaded. And I think, particularly, you know, when it comes to things that make us different from each other, they make you see things through a particular lens. So, calling something a 'disease' or a 'condition' or a 'problem' – particularly if you call it a problem – who is it a problem for? Is the problem for you or is it a problem for me?

William is careful with his language, and I owe it to him to be precise with my own. After all, Vizenor's purpose in writing about survivance was to write against lazy and inaccurate caricatures of Native Americans. If there is any universal, it should be that there is no room for the laziness of shorthand, approximations, or placeholders. All participants deserve their own language.

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