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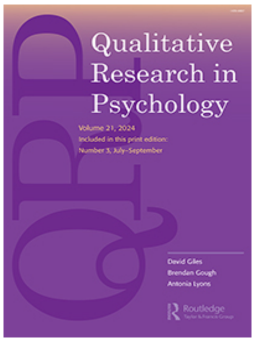

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Failing ethnographies as post-qualitative possibilities: reflections from critical posthumanities and critical disability studies

Bojana Daw Srdanovic[a,b], Nikita Hayden[c,d], Dan Goodley[c,d], Rebecca Lawthom[c,d], and Katherine Runswick-Cole[c,d]

[a]University of Plymouth, Peninsula Medical School, Plymouth, UK; [b]Cornwall Partnership NHS Foundation Trust, Cornwall Intellectual Disability Equitable Research (CIDER), Truro, UK; [c]University of Sheffield, iHuman, Sheffield, UK; [d]University of Sheffield, School of Education, Sheffield, UK

ABSTRACT

Recent moves from qualitative to post-qualitative inquiry can be traced back to various developments and methodological quandaries. Posthuman philosophy and methodology is one origin story of the move to post-qualitative inquiry. This broad approach contests the humanist impulse at the heart of qualitative inquiry and demands imaginative forms of post-qualitative inquiry, theory and research that engage with the more-than-human realities and nuances of everyday life. What might it mean to hold post-qualitative sympathies and tackle a foundational methodology of qualitative inquiry (ethnography) from a quintessentially posthuman position (disability)? With reference to an ongoing ESRC funded project – *Humanising Healthcare* – we provide two writings about the possibilities and challenges of failing ethnography. Through reference to critical posthumanities and critical disability studies theory, we attend to broken, patchwork, kintsugi and crip ethnographies that, we argue, allow us to sit in the liminal space between qualitative/post-qualitative research and human/posthuman theory.

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Introduction

What might it mean to hold post-qualitative sympathies while tackling a foundational methodology of qualitative inquiry (ethnography) from a quintessentially posthuman position (disability)? In seeking to address this question we do so from a specific time and place. Our place is a research project: an Economic and Social Research Council (ESRC)[1] funded project entitled *Humanising Healthcare*. Our time is in the early stages of empirical work and ethnographic research. As we write this we are yet to enter the field.

CONTACT Bojana Daw Srdanovic bojana.dawsrdanovic@plymouth.ac.uk University of Plymouth, Peninsula Medical School, Plymouth, UK

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[1] The Economic and Social Research Council is the largest UK funder of social, economic, human, and behavioural research.

The *Humanising Healthcare* project explores what compassionate, caring, enabling and responsive healthcare looks like for people with learning disabilities.[2] This research is important given the numerous high profile cases of people with learning disabilities experiencing severe neglect and abuse in both social care and healthcare settings.[3] We will be conducting ethnographic field work in a neurology service and an intellectual disability service in the UK. Along with ethnographic observations, we will draw on creative methods and conduct narrative interviews with 12 people with learning disabilities and up to 48 people who are close to them and implicated in their social networks, including family members, carers, and clinicians. The work is being co-produced with researchers with learning disabilities, who are skilled and experienced researchers and self-advocates. Our work together has and will involve: designing the study and methods, gaining funding, producing resources and outputs, theorising humanising healthcare, and analysing the data.

We continue to struggle with various organisational procedures. While our research has been approved by the Health Research Authority (the national body through which all research based in the UK's National Health Service should be processed and assessed) we are now caught up in a bureaucratic complex. We are liaising with our clinical research partners and our NHS site teams in order to work through our research proposal to eventually trigger, we hope, ethical access to people with learning disabilities that access two services: a neurology service based in South Wales and a Learning Disability service based in the South West of England. This is a frustrating and productive experience, generating discussions with the team which are critical, personal, political, relational and professional about the very idea, promise and possibility of ethnography. This paper is a piece of frozen text: a snapshot of a given time and place when we considered the possibilities and challenges of ethnography. But this paper is also more than this. Alongside grappling with the ethical, pragmatic and gatekeeping challenges of our empirical work we are also caught up in an intellectual space of reflection, deliberation and uncertainty. We think it is worthwhile reminding readers that scholarly work can at times emerge *in spite* of the bureaucratic demands of project management.

The *Humanising Healthcare* project and the writing for this paper emanates from a particular intellectual space: **critical disability studies**. This

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[2] The term learning disabilities is the one used in Britain with other labels adopted in different nations ranging from 'development disabilities', 'intellectual disabilities' and 'cognitive impairments'.

[3] For example, during the earliest stages of the COVID-19 pandemic, people with learning disabilities admitted to UK hospitals received 'do not resuscitate' orders without their informed consent. This meant that hospitals and clinicians were, as a policy, barring patients with learning disabilities from receiving emergency treatment if they went into cardiac arrest or stopped breathing. No other groups in society received this dehumanising (lack of) treatment during the pandemic so explicitly. The following care homes have been involved in scandals involving the neglect and physical abuse of people with learning disabilities: Winterbourne View, Whorlton Hall, Mendip House, Slade House and Yew Trees Hospital. These scandals are not isolated incidents, but are indicative of sustained structural discrimination and dehumanisation of people with learning disabilities.

interdisciplinary community of researchers, theorists, activists and artists takes disability as its driving subject of inquiry (Goodley et al. 2021). Disability is *the* phenomenon through which we read the world around us. All of the authors of this paper have a very personal and therefore political engagement with disability. This includes identifying with disability, familial experiences of disability, and many years of being with disabled people in relations of friendship, care, advocacy and research. It is important to acknowledge that disability is not simply a curious object of inquiry for us (although we do find disability to be a very curious thing). We align with critical disability studies because disability is important to us. In many cases disability is defining. And disability is always challenging. So we share an interest in putting disability front and centre; to rethink not only our politics but also the kind of research and scholarship that we want to enact. We also acknowledge that where there is disability then there will also be exclusion, marginalisation and oppression. For example, disablism refers to those times when disabled people are excluded from mainstream society (Thomas 2007). In contrast, ableism refers to wider processes (often associated with other ideologies such as white-privilege, patriarchy, heteronormativity and middle-class entitlement) that value some kinds of solitary, self-sufficient human beings while devaluing others (Nario-Redmond 2019; Wolbring 2008, 2012). Armed with this knowledge as critical disability scholars we are always open to transformative intellectual spaces that might treat disability with care, consideration and recognition; that might in some small way contest the processes of ableism and disablism. One of these spaces is **critical posthumanities**. Posthuman public intellectuals like Braidotti (2019, 2020) have, in many ways, mainstreamed critical posthumanities into research and scholarship across the social sciences and humanities. It has been argued that disability is the quintessential posthuman condition precisely because disabled people have always led entangled lives with other humans, non-human animals, technologies and environments (Goodley, Lawthom, and Runswick-Cole 2014). Take for example the following figure relating to non/human connections in the disability community:

Taken from Goodley (forthcoming) Figure 9.1: Human and non-human connections: Thinking with disability

Assistance animals, assistive technology, assisted living, prosthetic limbs and devices, the independent living movement, personal assistants, support workers, voice-recognition software, braille, augmentative communication, group advocacy, alliance of ecopolitics and disability politics, biodegradable straws and face-masks, respiratory technologies, guide dogs, online communities, email distribution lists, online seminars and symposia, wheelchair users, eye-movement technology, assisted horse-riding, blind football, wheelchair tennis, hearing aids, wearable tech, distributed models of mental capacity, sex robots, Alexa, Siri, mobility chair, driverless cars ...

Posthuman and disability studies correspond in some generative, considered and thoughtful ways (Blume, Galis, and Pineda 2014; Feely 2016; Goodley, Lawthom, and Runswick-Cole 2014; Murray 2017a, 2017b; Reeve

2012; Romanska 2024; Taylor 2011, 2017). Theorists have been keen to emphasise disabled people's interdependencies with technology; the blurring of bodies with other human bodies and significant non-human others; disability's propensity to create complex forms of interconnection, assemblages and networks and the idealisation of the disabled person as already cyborg. Moreover, embedded in this work is an appeal to responsive research methods that attend to the posthuman condition, one of which we might define as post-qualitative. In *Writing postqualitative Inquiry* St Pierre (2018, 603) advises to 'break the habit of rushing to *preexisting* research methodologies and, instead, to follow the provocations that come from everywhere in the inquiry that is living and writing'. In this paper we sit with the provocation of failed ethnographies.

As researchers on the *Humanising Healthcare* project, we find ourselves in a tricky relationship with the posthuman. When some of us struggled to come out of the pandemic – with numerous people still very much living with the precarity of a world that still feels like being in the midst of a global pandemic – then the posthuman has never felt so unequal. The transmission of COVID-19 across space and time was a very dangerous posthuman event. The intermingling of non-human relationships and the turn to the promissory hopes of science – eventually realised through vaccination and healthcare treatment – illuminated the porous borders between nation states, between humans and animals, between the hardware of medicine and the wetware of bodies. The pandemic was a monstrous realisation of the contemporary posthuman condition. While we might all be posthuman this does not mean that we are equally so. The pandemic revealed to us, yet again, '"We" Are In *This* Together, But We Are Not One and the Same' (Braidotti 2020).

As signalled above, people with learning disabilities (as an example of just one group of human beings) were devastated by the pandemic. As reported in Goodley (2023), UK data suggests that before the pandemic, people with learning disabilities and/or autism were dying 20–30 years earlier than their non-disabled peers and twice as likely to die from an avoidable death. In the midst of the pandemic, this group of disabled people were up to six times more likely to die from the virus than the rest of the UK population. Our project sits with this legacy – its very meaning – and its implications for our research and scholarship. We find ourselves committed to the humanities of people with learning disabilities and feel deeply humanist in our convictions, our ambitions and our affiliations (see Goodley 2023). Our project team feels so angered by the dehumanisation of people with learning disabilities that this seeps into our theory and our empirical research. This paper explores the tensions of being qualitative and post-qualitative – of being humane and posthumane – to explore how our human and posthuman affiliations impinge on the doing of our research. The paper addresses the challenges that disability creates for research methodologies and our epistemological and ontological assumptions. We want to think again of both the human and the posthuman as we engage in a research project that is always in the shadow of the pandemic.

Through reference to critical posthumanities, critical disability studies and post/qualitative literature, this paper works with the tensions of ethnographies that fail to meet normative standards of successful qualitative research. We attend to the ideas of broken, patchwork, kintsugi and crip ethnographies to sit in the liminal space between qualitative/post-qualitative research and human/posthuman theory. While much of the writing in this paper is definitely (and perhaps defiantly) qualitative, failings inherent within the qualitative methodology of ethnography open up some very post-qualitative considerations. We adopt a necessarily fragmented approach to writing. What follows are two readings written by Nikita and Bojana that open up a post-qualitative space to revisit the offerings of disability. We are reminded of Ruby Goodley's (2023) assertion that ethnography – anthropology's perhaps greatest methodological gift to research – is always failing, especially when engaging with the disruptive qualities of disability. Perhaps, ethnography and disability are already post-qualitative and posthuman in their constitution and their application, but this does not deny more human and humane considerations.

Writing 1: Broken, Patchwork and Kintsugi Ethnographies by Nikita Hayden

When I first started this job role I was told by several people that the *Humanising Healthcare* project would not involve a 'proper' ethnography. 'Pure' or 'traditional' ethnographies are not only long-term (Roberts 2005), but they are also immersive, and involve the researcher embedding themselves in the field. It is true that it will not be possible to conduct a fully immersive and holistic ethnography on the *Humanising Healthcare* project. Even those patients[4] who use the outpatient service most intensively spend little more than a couple of hours a month at the neurology service. I struggle however, perhaps somewhat egotistically, with the implication that we are somehow about to embark on something lesser, something illegitimate. It struck me as an odd concern, given that there are serious pragmatic and ethical reasons for not embedding ourselves in the field. It is unethical to over-research a population which has been made vulnerable and is over-monitored. It is unethical to bunker down in a hospital department, forcing yourself into clinical appointments with people who have not agreed to the research. It would be unethical to take excessive time and resources from the NHS at a time when it is already struggling. I do not believe it would be possible or

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[4] I do not use the terms 'clients' or 'service users' to describe patients in an effort to avoid the capitalistic implications that see patients as customers. Free, universal, high-quality healthcare is a human right, and not a consumer choice.

desirable to complete a more embedded or in-depth ethnography for the *Humanising Healthcare* project. Must we therefore resign ourselves to doing junk ethnography? I have used the writing that follows to explore concepts of patchwork, brokenness, and anti-hero ethnographies. I revisit the question about how these non-traditional ways of drawing on ethnographic methods can help us to value and legitimise studies that draw on ethnographic methods, rather than merely understanding these types of studies as subordinate to traditional ethnographies. I will also consider what these approaches may mean for the *Humanising Healthcare* project, specifically.

Patchwork ethnographies

Patchwork ethnographies draw on ethnographic methods in ways that can be seen as falling short of 'traditional' ethnographies. Traditionally, ethnographers have set out to 'study' minoritised people in their 'environments' using a mixture of observation and interview methods (Mead 1928). Patchwork ethnographies are sensitive to the criticisms of ethnographies (e.g., roots in colonialism and ableism, racialized and gendered hierarchies) and seek to centre researchers' own needs (Günel, Varma, and Watanabe 2020). As Günel, Varma, and Watanabe (2020: 2) write:

> Even prior to the arrival of the COVID-19 pandemic, 'traditional' anthropological fieldwork was in trouble. For some time now, ethnographers have been questioning fieldwork truisms: separations between 'field' and 'home', the gendered (masculineist) assumptions of the always available and up-for-anything fieldworker, and anthropology's proclivities toward suffering subjects (Anjaria and Anjaria 2020; Robbins 2013) [...] Family obligations, precarity, other hidden, stigmatized, or unspoken factors—and now Covid-19—have made long-term, in-person fieldwork difficult, if not impossible, for many scholars.

According to Günel, Varma, and Watanabe (2020), separations between the 'field' and 'home' are so often gendered – the ability to be available and away from home at all times and to be hyper-flexible is masculinist. Long-term field work, however, is difficult, with Günel, Varma, and Watanabe (2020) highlighting that family and care responsibilities, precarious work or home situations, and the researchers' own physical and mental health support needs are all barriers to conducting the type of fieldwork that 'traditional' ethnographies demand. The neoliberal focus in academia on productivity is ableist in its orientation, and this is an area in which patchwork approaches seek to disrupt.

There is a sense that there already exists an arsenal of ethnographic tools that have been applied flexibly to fields in response to the needs of a setting or particular participants, particularly outside of anthropology. We can see how these approaches have been employed when designing the *Humanising Healthcare* project, for example. What distinguishes patchwork ethnographies, is that these more flexible and open approaches are not just about responding to the demands of the project or the needs of participants (which are common adaptations made in health ethnographies), but are about also incorporating and addressing, perhaps even centering, the researchers' needs. These adaptations can include online methods, multi-site fieldwork, conducting insider research or auto-ethnographies, 'short-term field visits, using fragmentary yet rigorous data, and other innovations that resist [. . .] fixity, holism, and certainty [. . .] ' (Günel, Varma, and Watanabe 2020, 3) of traditional ethnographies.

A key question for us arises from these adaptations: how do we ensure that patchwork ethnographies are not lesser, or seen as lesser, than 'traditional' ethnographies? How do we avoid patchwork approaches being seen as some sort of pragmatic fumbling for something meaningful, or, at the very least, something publishable? For Günel, Varma, and Watanabe (2020), it is about working with, rather than against, these 'gaps, constraints, partial knowledge, and diverse commitments that characterise all knowledge production' (Günel, Varma, and Watanabe 2020, 4). We need to look for what new opportunities emerge, and what we get to let go of, when we adopt patchwork approaches. For example, traditional ethnographies are inextricably intertwined with the colonial project and othering. Patchwork ethnographies provide a space to move away from these legacies and seek to disrupt hierarchies and injustices.

Traditional hierarchies have privileged and centred a very specific type of researcher (often coded as white, non-disabled, male, and without dependants) who has been able to embed themselves in the field, uninterrupted, for months or even years at a time. I find it rather peculiar that anthropology seems to have privileged the perspectives of researchers who are somehow so unconnected from their own culture and community, with no one that they depend on and who depends on them, that they can run off to do fieldwork for months and years. It seems odd to me that this type of researcher becomes the objective authority on culture, on connection, and on community, when one must question to what extent these individuals themselves really value and understand community. I am not sure that I am particularly interested in the views of an ethnographer on a particular community or culture who are not themselves connected and embedded with a community of their own.

Continuing to centre the work of these somehow socially 'unencumbered' researchers, comes at a great expense in terms of who we exclude from conducting ethnographic-type research, or whose work we minimise and see as lesser, and I say this as a relatively socially 'unencumbered' researcher myself. The work that patchwork ethnographies bring into the fore are the dependent, the dependable, the connected, and the embedded researchers. I want to hear from people and be connected with people who are a part of this world – not someone who sits on the edges and observes. I want to caveat this perhaps rather harsh argument with a dose of reality: the socially 'unencumbered', rolling-stone-type ethnographer probably does not, and has never, existed. Conducting intensive fieldwork involves great personal and familial sacrifice. Ethnographers have perhaps not been open enough about these sacrifices, particularly about how their fieldwork has harmed or demanded free labour from others in their own social networks (particularly the under-acknowledged 'free' labour of women). Nonetheless, patchwork approaches highlight that some ethnographers are unable or unwilling to make these sacrifices, and it is their stories and their insights that are being lost in this privileging of traditional ethnographies. The question then becomes, how do we show commitment to the field and build meaningful relationships without embedding ourselves in the field as a traditional ethnographer would? It seems evident to me that those researchers who are so connected to their own communities that conducting traditional ethnographies would be near impossible, are perhaps best equipped to build and maintain meaningful connections with the field under reduced conditions.

Although patchwork ethnographies are in no way a new methodology (Cardoza et al. 2021), it is no accident that the global pandemic provided the opportunity for more explicit thinking and writing about patchwork ethnographies. The early stages of the pandemic meant that many ethnographers were having to face being unable to complete fieldwork or being unable to travel or start fieldwork. The pandemic has not only been (and continues to be) a mass disabling event, but barriers related to researchers' own disabilities (defined broadly) and caring responsibilities were magnified. There also seems to have been a shift, with researchers craving a better work-life balance, and there being more conversations in the workplace about support needs. Patchwork approaches emphasise that these are all legitimate reasons to adapt projects. For example, the pandemic has legitimised online methods to data collection and network building, and Cardoza et al. (2021) posit that a researcher's disability, care responsibilities, or precariousness should also be legitimate reasons for employing online methods.

The metaphor of a patchwork quilt is particularly useful for thinking about collaborative ethnographies. Patchwork ethnographies appear antithetical to the concept of an ethnographic 'hero': a hyper-individualised and fictionalised (often male) figure who succeeds in mastering the field due to their own hard work, ingenuity, and grit alone. Patchwork projects have traditionally been collaborative women's work, with women working together with kin to produce patchwork quilts. For example, we can understand this writing task as an attempt at patchwork writing: we each are producing our patchwork square(s) of writing, and only once we have each done this, can we bring it together, and consider whether and how these writings could be brought in conversation with one another. Patchwork writing would therefore call us to avoid finishing off the seam edges too neatly so that we are better able to accept the help and the input of other people in our research and our writing. Patchwork ethnography therefore requires honesty from us to make 'the seams visible' (Cardoza et al. 2021) – to show our work and to reveal our process. As Yates-Doerr emphasises, 'having our ideas corrected or adjusted – another way of saying learning from others – is so much easier if you are not aspiring to be a hero' (Yates-Doerr 2020, 241). For Alava, patchwork writing requires openness about ourselves and our 'families, failures and fatigues' (Alava and Robertson 2022, 104). This openness creates new ways of conducting ethnographies and theorising (Cardoza et al. 2021).

Patchwork is about taking items that are no longer useful to us that we are perhaps sentimental about – perhaps an out-grown and threadbare dress that your child once loved – and turning it into something useful again. Applied to ethnographies, patchwork approaches give researchers permission to take the most valuable aspects of ethnography, whilst discarding aspects that are not useful or workable in their context. In relation to the *Humanising Healthcare* project, a key question for us will be about how best to draw on the expertise of the researchers on the project team who have learning disabilities themselves, using ethnographic tools such as narrative interviewing, observation, and self-reflexivity. Patchwork ethnographies allow us to let go of and avoid reproducing 'hierarchies of knowledge and value based on extraction' (Cardoza et al. 2021: np) that can be the premise of more traditional approaches to ethnographies. Cardoza et al.(2021) suggested that offering co-authorship to co-researchers would be an important aspect of disrupting these hierarchies.

At this stage, the *Humanising Healthcare* project is not a patchwork ethnography, because the reasons why the ethnographic approach is not 'traditional' is in response to the needs of the field and our future participants rather than the needs of the researcher. It is not possible to do a traditional ethnography in a field where even the patients who use the service most intensively, spend no more than a couple of hours a month at the healthcare service, and where the only space we will have access to without restriction will be the clinic waiting room and the hospital canteen. I am, however, a disabled researcher myself and I am also aware that Bojana is a parent, so I expect a patchwork approach to this ethnography will be relevant at some point over the course of the project. I also believe that the practical outcomes and lessons to learn from conducting a non-traditional ethnography overlap with whether or not the reason for those adaptations are related to the needs of the field, the participants, or the researchers. Therefore we can learn from patchwork ethnographies about how to draw on 'impure' ethnographic methods to best serve our field, our participants, and ourselves. Looking after our own interests makes a lot of sense to the disability field. Given that we care and value disabled people and carers, it makes sense to extend that care to ourselves. The value of this care cannot be underestimated, given that the *Humanising Healthcare* project will hopefully be for us just one project in a career full of work that supports disabled people and contributes to the disability field. To burn oneself out on a single project would not serve the population or the field of study that we seek to help on the *Humanising Healthcare* project.

The importance of these conversations about patchwork ethnographies is that there is an understanding that these approaches to ethnographies are not lesser than traditional anthropological ethnographies. Instead, it is about how these tools can be refined, almost, to suit our needs – and for us to see these adaptations as not limitations, but as appropriate and valid ways of working, with their own strengths. Patchwork ethnographies have great potential in making a fortune out of necessity in adapting the best parts of ethnographic approaches to suit different researchers, participants, settings, and circumstances, whilst letting go of some of the most problematic and inauthentic aspects of traditional ethnographic approaches.

Anti-heroism and broken ethnographies

A part of ethnographies that patchwork approaches attempt to move past, is the individualistic approach to anthropological ethnographies that are not always realistic, nor desirable. Contreras (2019) writes about how ethnographers often position themselves as the authoritative and calm 'heroes' of their narratives. Although Contreras (2019) acknowledges that more recent ethnographers have written more vulnerably about the setbacks and difficulties that they faced during their field work, these ethnographers ultimately overcome these setbacks. This sort of narrative, produces a more complex, modern day 'hero', where a conflicted, and fallible human succeeds against great adversity to complete their ethnography. In sum, it produces an even more satisfying hero story, or as Contreras puts it, they 'emerge' as 'heroes in the truer and non-pejorative sense of the term' (Contreras 2019, 164). These ethnographers might be seen as the 'deserving' heroes. The stories that never get told, according to Contreras (2019), are the broken ethnographies, the ethnographies that never get off the ground, or that fall apart due to setback after setback. Yates-Doerr (2020) also discusses the concept of ethnographic heroes, the:

> [. . .] long celebrated 'lone fieldworker' — presumably male, presumably *unencumbered by kinship* — who would venture into the unknown to return with captivating stories, that is, *stories that capture* (Yates-Doerr 2020, 234). (emphasis my own)

Circumstances related to precarity, inflexible academic structures, parenting, and care work, meant that Yates-Doerr (2020) had to cut her fieldwork short, and in facing an incomplete and 'failing' ethnography, adopted an anti-hero care approach. Anti-hero care refers to an ethnographic approach that decentres the individual, lone ethnographer, mastering the field, and instead privileges connection, dependency, and the honest acknowledgement of fallibility and the limited ways we have of knowing the field. Importantly, Yates-Doerr

(2020) sees this as a strength, and not as a limitation, of her work. In this way, Yates-Doerr is resisting a hierarchical view of ethnographies that inevitably privileges ‘pure’ and ‘traditional’ ethnographies, instead allowing ‘different goods to coexist – one good need not be triumphant over another’ (2020, 235).

In describing their ‘broken’ ethnography, Contreras (2019) describes how he himself were broken in the process, describing anguish, uncertainty, suffering, and accepting appearing weak in that ‘revealing oneself as a “vulnerable observer” as a feeling human being – risks losing readers, even if it clarifies the research process and analysis’ (Contreras 2019, 162). Contreras (2019) describes how, as a researcher, he was broken by the process of conducting a seemingly impossible ethnographic project, but what about the researchers who were already ‘broken’ to begin with? What about disabled or other minoritised researchers who have already been burnt out by the academy? How do they interact with the field? What about the researchers who are unable to, as Contreras puts it, pull ‘themselves up by the bootstraps’ (2019, 171)?

Like Yates-Doerr, who sees benefits rather than mere limitations in her anti-hero care approach to ethnographic fieldwork, Contreras (2019) begins to allude to benefits (i.e., clarity, transparency) in his work related to being vulnerable, open, and human. Ethnographic research appears to me to be about human connection, and so how can it be possible to do this without revealing our own humanity and fallibility? Attempting to conduct fieldwork as a lone hero without showing our humanity and vulnerability is ultimately hierarchical, and, given the dark histories of ethnographic methods, all modern ethnographers should seek to extinguish hierarchies in their fields. Writing traditional hero narratives risks writing inauthentically and without self-awareness at best, and downright dishonestly at worst.

The stakes for all these issues seem heightened on the *Humanising Healthcare* project. We are asking what it means to be human, how people with learning disabilities have been included or excluded by this concept, and seeking to understand what humanising healthcare does and could look like for people with learning disabilities. With this exploration of patchwork and anti-hero ethnographies, we ought to also consider what it means to be human[e] researchers, and with that, how we are challenging, or are embedded within, the hierarchical nature of the systems that we are a part of (e.g., the academy, co-production work), and the field we are entering (i.e., healthcare settings, the NHS). It feels impossible to enter the field without becoming, in some way, part of the medical and healthcare institution that continues to exert control over, and at times real harm on, people with learning disabilities. We are seeking to build meaningful connections with those we are researching and to work with researchers who have learning disabilities, but we cannot do this without acknowledging the power imbalances inherent in our interactions and work with people with learning disabilities. Bojana and I are not at the top of these hierarchies within our fields of study, of course. The heads of service are positioned as both participants and gatekeepers in the fields we seek to study, along with being colleagues and collaborators on this project. Furthermore, Bojana is directly line-managed by the head of the service and consultant psychiatrist where she will conduct her ethnography, and the consultant neurologist where I will conduct my ethnography is the sister-in-law of my line manager, and the sister of my head of department. The potential power imbalance between researcher and participant, or a person with learning disabilities and a person without learning disabilities, is just one aspect of the hierarchies that could potentially exert power and influence on this project.

A way of moving past these hero stories (or his-stories), according to Yates-Doerr is to do away with the individualism of these stories and tell Herstories:

> Herstorying, to make this an active verb, is a mode of caring for the stories we tell. It does not tell final-word narratives but narratives that make openings for new kinds of stories to tell. (Yates-Doerr 2020, 240)

In this way, herstorying does not seek or accept mastery of the field. A criticism made of anthropology by Yates-Doerr (2020) is that it embraces holism, and that an anti-hero care approach does not seek to master the field in such a totalising way. The anti-hero care approach is more open than this. I expect that most researchers accept that it is not possible to fully know any phenomena, particularly social phenomena. Nonetheless, measures of validity and reliability, remnants of positivistic thinking applied to qualitative research, are regularly applied to qualitative projects. I see this most commonly when researchers seek to reach data saturation. Data saturation thinly veils a desire for mastery and holism. Therefore, I think these criticisms about holism and field mastery are still relevant.

Applying the issues with holism to our question about how we can ensure that patchwork ethnographies or anti-hero ethnographies are not seen as lesser than traditional ethnographies, I think we need to apply some epistemological sense to this anthropological holism. Mastery of the field feels antithetical to qualitative research, both from a social justice perspective (we should want to challenge the hierarchies between researcher and researched), but also that none of us (I hope!) actually believe that we can know our field fully and completely – therefore, mastery may be another part of traditional ethnographies that patchwork approaches allow us to let go of. In doing so, we accept and adopt a more sophisticated way of knowing, which supports a way of approaching the field and our connections with more honesty, openness, and humility, allowing us to more fully respect and accept the expertise of those we are studying. After all, doesn't claiming mastery of a field take something away from genuine members of that field? If we fully accept –

not just theoretically – but empirically, that no ethnography is complete, then perhaps ethnographers can move past the shame and sense of failure that these ethnographers felt when they were unable to complete their ethnography in the ways that they had originally intended. All ethnographies are incomplete, it is simply a point of degree.

Kintsugi ethnographies

This concept of patchwork ethnographies led me to think about what other metaphors may help us to think about 'broken' ethnographies, such as mosaic or kintsugi (Japanese art of repairing broken pottery) ethnographies. The metaphor of mosaics has already been used to write about the combining of quantitative and qualitative data in ethnographic research (Hayre and Blackman 2021), and in early years research to combine multiple methods – including participatory, visual, and creative methods – to be inclusive of younger children (Clark and Moss 2001; Kingdon 2019). An ethnographic mosaic is used to describe a variety of methods drawn upon to study social and cultural phenomena (Hayre and Blackman 2021). For Hayre and Blackman, 'the ethnographic mosaic critiques the reductionism and dehumanisation of the clinical gaze' (Hayre and Blackman 2021, 3261) and seeks to centre patients'/participants' experiences and agency. By not privileging one type of knowledge production, the knowledge authority remains the patients (or group of study), rather than the ethnographer's data and stories.

Although mosaic approaches have been used to describe multi-method and mixed method research approaches, I am more interested in drawing on the metaphors of mosaic and kintsugi to think about brokenness in research. Kintsugi is a Japanese art form that refers to repairing broken ceramics using lacquer and gold or silver, allowing the fractures and fault lines of the repaired object to be accentuated and illuminated. Philosophically, kintsugi considers breakages to be part of the story of an object, rather than something to hide or disguise (Buetow and Wallis 2019) and the beauty of the object is seen in its imperfection (Keulemans 2016). Kintsugi is about accepting change and embracing imperfections, rather than discarding objects or things that did not turn out the way that one had hoped or expected. It is about offering care to objects (Keulemans 2016). Kintsugi is not about returning an object to its former state, but instead creating 'something stronger, more beautiful . . . more valued and appreciated' (Buetow and Wallis 2019, 392). Applying this idea to ethnographies, rather than concealing fractures, or throwing out an ethnography that did not go to plan, we would instead sit with these issues, embrace and emphasise these fractures, and we would be more honest and open about our processes. An underlying principle related to kintsugi is wabi-sabi: the appreciation of asymmetry, incompleteness, imperfection, irregularity, and impermanence (Buetow and Wallis 2019). The concept of wabi-sabi then, may be a useful way of thinking about how we value humans with all their imperfections and how we think about disability. This metaphor of kintsugi and its underlying philosophies can help us to think about all that we can learn and appreciate from 'broken ethnographies'. In this way, broken or unfinished ethnographies should not be relegated to fieldnotes, but should be written up and published.

The concept of brokenness feels particularly relevant for the *Humanising Healthcare* project. We are working with broken methods and methodological approaches, we are working within broken systems (NHS, the Academy), and we are working through, what feels like right now, broken ethical and administrative procedures. We could also apply the term 'broken' – not unproblematically – to people. The people we are studying have learning disabilities, and I myself am a disabled researcher (a term I still use with trepidation for fear of taking up space as someone with a 'hidden' disability). Intellectually, I understand neurodivergence to be a natural feature of human variation that is othered and problematised because society has been built for allistics. I also probably agree with Thomas Stephen Szasz, that feeling anxious or depressed is perhaps the only 'sane' response to an 'insane' world. Yet, I cannot help feeling a bit broken and ashamed that, for example, I was unable to get this piece of writing over to my colleagues by our agreed deadline.

This concept of wabi-sabi would help us to embrace and appreciate an NHS that is crumbling and yet still does amazing work every day. It would help us accept that these laborious administrative and ethical barriers are protecting the NHS's valuable and limited resources. Most importantly, it would challenge the views of many: that neurodivergent people and people with learning disabilities do not need 'fixing' or discarding. The *Humanising Healthcare* project is not going to fix the NHS, and it is not going to stop all the dehumanising experiences that people with learning disabilities have gone through and continue to go through. The practice of Kintsugi feels like a valuable metaphor for what we are trying to do here though, because it focuses on how we might be able to take these broken pieces and experiences, and hold them together to create something meaningful and tangible, using something precious, which in this case would be the stories of people with learning disabilities.

Writing 2: towards crip ethnography by Bojana Daw Srdanovic

First thinking steps

In our email thread, Katherine Runswick-Cole (an academic working on our project) asked 'how we can think through ethnography in the context of the project where disabled people are driving the research'. This has been very much on my mind as I was reading about ethnography. I read as an invitation Katherine's question:

'we need a crip ethnography?'

Writing strategy

I embark on thinking in response to this invitation. In doing so I focus on appreciating the complexity of both the ethnographic method and the field. I realise that, at this moment, both method and field are unknown forms, the contours of which I explore through reading, past experience, imagination and yes, assumption. This method is imperfect and yet, at this moment, all I have at my disposal. I remember bricolage and how it 'exists out of respect for the complexity of the lived world' (Kincheloe et al. 2018, 244). I think of the researcher/bricoleur who 'views research methods actively rather than passively' and 'construct[s] [. . .] research methods from the tools at hand rather than passively receiving the "correct", universally applicable methodologies' (Kincheloe et al. 2018: 244.).

I decide that it is ok to not know. The image of the quilt stays with me, and I realise that I am now at the tacking stage, sewing temporary stitches, firm enough to keep parts in place (for now), loose enough to be easily undone. That metaphor is limited, however, as it presupposes a knowledge of what form the finished garment will take. I therefore think of the early stages of creating a performance, when you try on for size some movement, perhaps some text. When you check how it fits and flows with your imagination. You note it down in the knowledge that you may not use it in that form – or at all. You trust the process as you try to find content for a yet unknown form. As a result, my writing is loose, explorative, inviting correction and change. In keeping it such, I also seek to foreground (for reasons that will soon become apparent) the researcher as the not-(yet?)-knower. That is scary: it pushes against the desire to be perceived as knowing, as *competent*.

Cripping ethnography

> As a consequence of the tools and technologies of qualitative research being of limited use, either to the researchers who brought them or to co-authors described by Atkinson and Walmsley (1999) as the 'ultimate other,' the people who meet through the research performance of the Article 19 project had no option but to enter a transformative third space as equally dis/abled. (Milner and Frawley 2019, 393)

Not so long ago, it would have been ok to say that the limitations described by Milner and Frawley (2019) arise not methodologically from the limitations of tools and technologies, but 'naturally' from the person with learning disabilities. Today, we may, in line with the social model, recognise as environmental such methodological issues – the ruptures, failures and impossibilities of 'squeezing' the person with learning disabilities into a research environment that was never designed for, let alone by them. We may, however, also recognise the productive potential of such ruptures, failures and impossibilities. In this designation, the rupture is not a void, but a crucible of possibility. Positioning success as a measure of conformity to the dominant culture, queer and crip theorists have long analysed failure's disruptive, resistant and creative potential, with McRuer (2018, 5) suggesting, after Halberstam, that crip spaces (the spaces of bodies broadly regarded as failed/failing) are spaces where 'alternatives to capitalism [. . .] already exist and are presently under construction'.

Down the rabbit hole...could this be productive?

Yet, not everyone's failure is read in the same way. What about body/minds whose 'failure' is taken as a given? In order to illustrate this point, it is useful to briefly look at failure as a trope of postmodern performance. In that designation, it takes a lot of skill both to perform and to 'correctly' receive the pauses, the awkward uncertainties, the failures that theatre usually disavows. Here, the *successful* failing performance interrogates the mechanisms of representation, it speaks to and of the limitations of theatre. As Bailes (2011: 12) suggests, failure in this designation appears as 'a resistant and potentially radical strategy'. However, this effect changes when the performing body is one of 'naturalised' failure.

Owing to its genealogy, its rootedness in alternative theatre (Kershaw 1992, 138), much theatre produced with and by people with learning disabilities, deploys post-dramatic tropes. Yet, the readings of such performances as radical and skilfully disruptive often fail (Hargrave 2015). For illustration's sake, let's take the post-dramatic trope of a performer appearing as 'themselves' without straightforwardly assuming a discernible character. When used by performers with learning disabilities this blurring of acting and being *may* be read as a strategy for the interrogation of the representational frame. It may, however, also be read as 'authenticity'. While authenticity is a hallmark of excellence when achieved by an actor who is recognised as a professional, authenticity performed by an actor with learning disabilities, and on the edge between being and acting, may be read as evidencing a lack of 'agency, intentionality, or craft' (Reason 2019: 171). After all, the actor is 'just being themselves'.

There is a parallel here to researchers with learning disabilities. Sometimes (and tellingly) referred to as 'experts-by-experience' such researchers may be perceived as not being 'proper' when, in fact, it might be the audience who is failing to properly read their performance. What may be in one discipline a radical interrogation of research 'tools and technologies', may in another be regarded as the centering of a person who, yes, has something to contribute to the performance (experience, presence, legitimacy . . . funding?), but not to its broader framework. There is, however, an interesting tension here: when I talked with actors with learning disabilities, I didn't get the impression that they wanted to post-dramatically interrogate the representational frame. Instead, they wanted to be recognised as 'proper' actors. What's more, they were grounding their claims to such recognition not in authenticity, but in their skills. Due to pervasive marginalisation in mainstream theatre education, many of these actors acquired their skills in alternative spaces such as theatre companies that work with people with learning disabilities. Noting that the companies' attitudes towards care and mutuality create scope for a sense of belonging across dis/ability, I thought that those spaces were in many ways the locations where 'alternatives to capitalism [. . .] already exist and are presently under construction' (McRuer 2018, 5).

Back to cripping ethnography

If Crip foregrounds as a productive force the failure to conform to compulsory able-bodiedness, then the question for me is how we, individually and as a collective, interrogate conformity to hegemonic narratives of success. I don't want to suggest that academia is a monolith, but broadly speaking the academic environment is an ableist one: it at once valorises ability and disables its members, even as it appears to be celebrating diversity and difference. Take, for example, the recent manifesto of patchwork ethnography where Günel and colleagues note that '[f]amily obligations, precarity, other hidden, stigmatized, or unspoken factors – and now the pandemic – have made long-term, in-person fieldwork difficult, if not impossible, for many scholars' (Günel, Varma, and Watanabe 2020, 2). In other words, the requirements of the academy render researchers unable to conduct their work – they disable them. As Nikita's above discussion of Contreras (2019) illustrates, the new age ethnographer-heroes' attributes not only respond to an institution's need for heroes, but also resonate with the desire to fashion oneself in the best possible light at a time when we are learning to be more comfortable with our vulnerabilities. But what changes if the vulnerabilities are such that they don't fit into the template of the hero? When they are sources of shame, rather than pride? How does the research environment change when we cannot conceal our shameful vulnerabilities? How might it be altered if we decided that we don't wish to conceal them?

A dis/ability research culture

On the face of it, research co-produced between researchers with learning disabilities and non-learning-disabled academics is a meeting of two groups with contrasting public perceptions. We know that incompetence is one of the stereotypes projected onto disability (Nario-Redmond 2019), and my above journey into the rabbit hole of performance illustrates how difficult it can be for people constructed as incompetent to be read as, in fact, performing competently. There is perhaps no need to rehash that. But how about academic researchers? As an early career researcher, I fear being 'found out' as incompetent; the persistent imposter syndrome that plagues not only me but many of my colleagues (Breeze 2018) is surely an echo of this impossible pressure. Longing to become accepted as an academic, I (often successfully, always shamefully) conceal my incompetencies. The co-produced research space highlights such practices of concealment as socially harmful. As my colleagues with learning disabilities openly and publicly ask questions that I myself had, I realise that my silence is complicit in perpetuating stereotypes, that I am part of a system that produces that silence.

Thinking of co-production as not only the meeting of individuals, but a meeting of two cultures with distinct 'institutions, manners, customs, family memories' (Williams 1958, 248), I think about disability culture and ways in which it can be cultivated in the research space. Petra Kuppers, a performance scholar, community artist and disabled activist, writes:

> I do not think that disability culture is something that comes 'naturally' to people identified or identifying as disabled. And I do not think that disability culture is closed to non-disabled allies, or allies who do not wish to identify as either disabled or not. To me, disability culture is not a thing, but a process. (Kuppers 2011, 4)

Kuppers (2011, 4) describes disability cultural spaces as ones where 'a whole slew of rules' is suspended in an effort to 'undo the histories of exclusions that many of its members have experienced when they have heard or felt "you shouldn't be like this"'. This process is creative and requires labour, but it also 'needs an ongoing flow of contact, touch, questioning and affirmation, a flow of love' (Kuppers 2011, 4). If the co-production research space allows this then it can be, like Kuppers' dance studio, a 'laboratory of disability culture' (Kuppers 2011, 2). If, as Brewer (2000, 59) suggests, ethnographers bring to the 'field' not just themselves but their culture, then the allied academic researcher might bring to the 'field' the perspectives, values and customs of disability culture. What slew of rules would then be suspended, what vulnerabilities revealed? Most importantly for me as I try to imagine the 'field' – how might that culture come to bear on the encounter between the researcher, patient and medical professional?

I realise that as I think about this, the as of yet ambiguous forms of both method and field are constant stumbling stones. I worry about how open medics will be to my observing presence, and struggle to rid myself of the idea that I need to 'uncover' some hidden truth. I am not sure why the idea of uncovering a truth has negative connotations, even in the context of a project that, concerned with finding good practice, is not hostile to the medical profession. Perhaps an antagonism between medics and me is simply something I assume, a form of disciplinary habit?

Paranoia and the (futile) attempt to discover the hidden

As a sociologist who worked closely with neuroscientists in the field of medical humanities, Des Fitzgerald (2017) favours interviews over participant observation. He highlights that interview data should not be seen as 'supplementary to ethnographic entanglement' but rather as 'worth gathering in its own right' (Fitzgerald 2017, 24). I find it interesting that he views interviews as an 'important part of the commitment' to 'nonparanoid talking, thinking and working *with* other agencies' (Fitzgerald 2017, 24). Here, the 'interviewer [is] a much more compelling figure of nonparanoid engagement than the participant observer' (Fitzgerald 2017, 24), precisely because the interview sets the stage for 'accept[ing] the gift of that "which insists on being looked *at* rather than what we must train ourselves to see *through*"' (Best and Marcus 2009, 9, emphasis in original, as quoted in Fitzgerald 2017, 24). Transposed onto my imagination of the medical appointment, the idea of 'things insisting to be looked at' moves me to reflect on the limits of observation. I am reminded that I will be conducting an ethnography in the highly bound and curated space of a hospital. I will be coming and going, staying for short, perhaps irregular, periods of time. I am reminded that medical appointments are performances in so many ways: the performance of a society's duty to care for its 'sick', a performance of care … perhaps a performance for the researcher. Bound by all these limitations the medical appointment as an object of ethnographic observation might be productively regarded as a theatrical gift, a unique offering that, being at once curated and co-created, provides an imagination and experience (however brief) of a better world.

Discussion and conclusions

We asked at the start of this paper what it might mean to hold a post-qualitative sympathy while tackling a foundational methodology of qualitative inquiry (ethnography) from a quintessentially posthuman position (disability). Our analysis has sought to respond to St Pierre's (2018, 603) words of advice 'to break the habit of rushing to preexisting research methodologies and, instead, to follow the provocations that come from everywhere in the inquiry that is living and writing'. The *Humanising Healthcare* research team has found itself caught up in a complex: on one hand there is something deeply comforting in recognising the ways in which failed ethnography aligns well with the post-qualitative posthumanist literature (which values fragmentation, movement, connection and uncertainty). On the other hand, we are troubled by a humanist imperative that is often tied to qualitative research: to truly capture the perspectives of people with learning disabilities, to rehumanise their stories and healthcare experiences. We find connection with Adams and Weinstein (2020, 235), who assert that they are '*in but not of* the posthuman turn' (our italics). While we are drawn to the generative possibilities of post-qualitative work that seeks to deconstruct the impossibilities of the humanist mode of research engagement (an impossibility that becomes a reality each day that our ethnography fails) we are also reminded of our commitment to people with learning disabilities whose humanities continue to be ignored and denied on a daily basis in a political, cultural and social context that still frames them in less than humanist-human ways. There is still much work to do before we throw the humanist ethnographic baby out of the post-qualitative bathwater.

Perhaps one of greatest offerings of the post-qualitative space is the opportunity it gives us to review our research and scholarship not in binary terms of completion or failure but in terms of responsiveness, openness and potential to capture the state of becoming in research and scholarship. As St Pierre (2018) notes, theory often comes too late to research and study. Engaging from the outset with critical posthuman and disability studies theories – alongside post/qualitative literature – equips us, as a research team, to sit with the possibilities and opportunities offered by what we have proudly claimed as failed ethnography. Perhaps, above all else, we are left with a writing project where:

> Deconstruction happens. The text undoes itself. The movement of writing takes over, and the writer, the person (neither noun works in post qualitative inquiry) loses control and finds herself barely able to keep up in the thinking-writing as words appear on the computer screen she could not have thought without writing. (St Pierre 2018, 605)

Following Adam, Gold, and Tsui (2024, 9), we might read our failed ethnographies as entanglement-framed critical ethnographies that usher 'working with the disembodied, the distributed, and the extended bodymind'. The work of Adam and colleagues resonates with critical posthuman disability studies literature that has attended to disability's distributed, extended, interdependent and distributed qualities (Blume, Galis, and Pineda 2014; Feely 2016; Goodley, Lawthom, and Runswick-Cole 2014; Murray 2017a, 2017b; Reeve 2012; Romanska 2024; Taylor 2011, 2017). It is precisely in the broken, patchwork, kintsugi and crip ethnographies that we might find an affirmative liminal space between qualitative/post-qualitative research and human/post-human theory. And it is in these failed ethnographies where we might find humanising entanglements of healthcare that are fundamentally posthuman by design but seek to affirm the humanities of people with learning disabilities. Too often people so-labelled are cast off, dismissed and excluded on the basis of their failed humanities. We wonder if failing ethnographies offer more progressive readings of these humanities; where we sit with and ponder our own failings in research and life itself.

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Notes on contributors

Bojana Daw Srdanovic is a researcher on the Humanising Healthcare project at the University of Plymouth. With a background in theatre, her research interests coalesce around learning disability, care and co-production.

Nikita Hayden is a researcher on the Humanising Healthcare project at the University of Sheffield. She is a researcher in the field of disability and family studies.

Dan Goodley is co-director of iHuman and Professor of Disability Studies. Recent work includes Disability and other human questions (Emerald, 2020).

Rebecca Lawthom is a Professor of Community Psychology and Head of the School of Education. She has researched extensively in the fields of critical disability studies using values and principles of community psychology.

Katherine Runswick-Cole is Professor of Education in the School of Education at the University of Sheffield, UK. She has published extensively in the field of critical disability studies working with people with learning disabilities and their family carers in co-production.

ORCID

Bojana Daw Srdanovic http://orcid.org/0009-0003-3911-0186
Nikita Hayden http://orcid.org/0000-0003-1104-3885
Dan Goodley http://orcid.org/0000-0002-0660-5671
Rebecca Lawthom http://orcid.org/0000-0003-2625-3463
Katherine Runswick-Cole http://orcid.org/0000-0001-9658-9718

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