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# Reflections on the use of patient records: Privacy, ethics, and reparations in the history of psychiatry

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## Abstract

One of the most common questions we get asked as historians of psychiatry is “do you have access to patient records?” Why are people so fascinated with the psychiatric patient record? Do people assume they are or should be available? Does access to the patient record actually tell us anything new about the history of psychiatry? And if we did have them, what can, or should we do with them? In the push to both decolonize and personalize the history of psychiatry, as well as make some kind of account or reparation for past mistakes, how can we proceed in an ethical manner that respects the privacy of people in the past who never imagined their intensely personal psychiatric encounter as subject for future historians? In this paper, we want to think through some of the issues that we deal with as white historians of psychiatry especially at the intersection of privacy, ethics, and racism. We present our thoughts as a conversation, structured around questions we have posed for ourselves, and building on discussions we have had together over the past few years. We hope that they act as a catalyst for further discussion in the field.

## KEYWORDS

ethics, patient records, privacy, psychiatry, racism

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## Q: What can patient records bring to the history of psychiatry?

Jonathan

Patient records *can be* revealing. They can lead the researcher beyond diagnosis and demographics into specifics about patient experience, of their treatment, of their symptoms not to mention their world and lives beyond the fact of being patients. While we can not presume people in psychiatric institutions were in fact ill, especially if their commitment was involuntary, in a great many cases their behavior was judged anomalous in some way, by somebody. This offers inferences about hegemonic ideas of normality. Psychiatric institutions are agents of social control, but asserting that tells you little by itself. Patient records can sometimes tell more, revealing the operations of psychiatric power in a more granular way than records produced further from the bedside. But that hope requires us to ask, how should we read the patient records, once we have them?

I opened a conference paper many years ago by asking the question: What if we routinely started our histories of psychiatry with discussions of Frantz Fanon, instead of the usual ritual gestures to Michel Foucault?<sup>1</sup> Most overtly, I meant to draw attention to the history of race and racism in psychiatry, at that time a badly neglected topic (New work in this vein includes, Doyle, 2016; Gambino, 2010; Gonaver, 2018; Matthew, 2008; Mendes, 2015; Raz, 2013; Segrest, 2014, 2020; Smith, 2021; Summers, 2019). But I was also wondering what different questions Fanon might lead us to even in situations where race did not seem paramount. Fanon's critiques of both colonial psychiatry and colonialism were derived from an eclectic clinical vision. He developed critiques of the operations of psychiatric power with a deep belief in its therapeutics, not just its use for social control.<sup>2</sup> He did so in part by frequently asking what clinical judgments might look like to patients who did not share the cultural and medical assumptions of their clinician.<sup>3</sup> He was searching out the patient's voice in psychiatry long before it occurred to historians to do so.

As for Foucault, the brief invocations of his work that often populate our introductory chapters, whether as endorsements or dismissals, often lack deep engagement with his work; he is both over-cited and underread. One merit of his work is showing the complexity of power—how it dwells in naming, how it is distributed broadly even though unevenly, how it is multidirectional. Patient records can often yield these complexities in ways that government and administrative records cannot.

Education and Indigenous Studies scholar Eve Tuck has cautioned against damage-centered research, which risks representing historically oppressed communities as *only* harmed and depleted (Tuck, 2009). Tuck's critique is complex and nuanced, but in partial exposition: she argues that prioritizing damage is based on mistaken assumptions of what drives political change, risks obscuring the long-term and ongoing contexts of colonization and racism which cause the damage, and could cause damage itself. These risks are multiple and layered when researching psychiatric patients in contexts of racism and colonialism. Tuck proposes a focus on desire, understood as a complex constellation of motivations and even accrued wisdom, as an alternative that captures more complexity. Patient records can be used both ways. They can and have been read to document damage. Used with Tuck's cautions in mind, they can also open paths to seeing the patients with more completeness and complexity than other sources might.

Looking at patient records, though, is invariably and inevitably an invasion of privacy. Whether they were produced in oppressive and punitive institutions, or in more supportive contexts, neither the clinicians nor the patients expected a nosy historian to be reading the files. The patients did not give consent, informed or otherwise. Add to this the intensely private nature of mental health and illness. You don't have to be a macho gangster like Tony Soprano to want to keep a voluntary psychotherapy private. Most patient records that historians access are from the even more fraught contexts of hospitals, asylums, or prisons, and are created when the patients, possibly in the worst and most vulnerable and private part of their lives, often have not even given consent to be there or be treated, much less have the experience rendered for posterity.

Two answers are often given to the problem of privacy. One favors the practical step of de-identifying the record, so readers of our work can't know who, specifically, we are writing about. One can even sometimes take steps to blind oneself to the specific subject of the record. These steps, in my opinion, are better than nothing,

though historian Julie Parle has argued cogently for an opposing view. Parle argues that de-identifying mental patient records represents a further stripping of the patients' identity and humanity that began with their confinement in an asylum (Parle, 2007). The second answer is, do issues of privacy matter if the patient is dead, especially long dead? (Lawrence, 2016) This thought salves the conscience somewhat. Questions remain, though: would you want a historian looking at your health records? If not, how long would you want them embargoed, if you had a choice in the matter? How would you feel if you had no choice in the matter?

All research with marginalized or persecuted people and groups, who usually do not have the ability to create accounts of their lives in conditions of their own choosing, runs some of the same risk of intrusiveness. A concern for privacy arises in part because psychiatric patients almost inevitably face some degree of stigma—but then, so do all marginalized or persecuted groups.<sup>4</sup> Whether psychiatric patients require any special treatment from historians is a question we will bracket. We are historians of psychiatry, though, so we raise the issues of ethics and privacy with reference to what we do. And psychiatric history, particularly if it is about patients, is a form of human subjects research. All human subjects research requires a calculus of the benefits of the knowledge produced and the possible harms.

*Kylie*

I am very much torn on this question of the quest for and use of patient records especially when it intersects with concerns about stigma. Jonathan has written elsewhere and eloquently about our responsibilities of historians of psychiatry, which I think we both feel keenly as we are not inherently anti-psychiatry (Sadowsky, 2016, 2020). I am personally an advocate of more and better access to mental health service provision, but I am concerned that it be access that is liberatory and justice oriented. I would like there to be less stigma and more openness about the experience and prevalence of mental illness, and that does come from my own personal "skin in the game" as much as it does from my historical work which does focus largely on the damage done by racial segregation which has led to increased stigma and lack of services for Black communities. But part of my hesitance about patient records relates to the issues Jonathan raises when he brings Fanon into the equation. Of course, using Foucault gives us tools for a critique of the patient record as technology of surveillance, the medical gaze at its most acute. As Jonathan discusses later in this article, the veracity of those records is something that should give us pause. But if we engage Fanon, then something else happens. In his own psychiatric writing and use of patient case notes, he is explicit about the sociogenic origins of the so-called pathologies of the colonized, of the Black person in a white world (Fanon, 1952, 1994, 2020). He subverts his own psychiatric practice to use the patient record as a record of colonialism, as a record of epistemic violence (Spivak, 1998). This is not necessarily to say that the patient record is worthless, but it is to call into question the nature of the story we think it tells, and to proceed accordingly. That is, it is not necessarily a *prima facie* clinical encounter being documented, but a kind of shorthand for much bigger social and political forces.

There are also issues that arise simply in the act of looking for patient records. When it came to accessing psychiatric hospital records in the United States South, where I am working, there was an added layer of defensiveness and silence wrought by years of public exposure and fear of litigation. As Kacie Butcher has described, this protectiveness on the part of state archives or the institutions they represent is designed not as they would argue to protect family or patient privacy, but to protect themselves. In doing so, they cause untold harm to the people who now find they cannot even access their own family history (Butcher, 2022). But historians also run the risk of contributing to this defensiveness and restriction.<sup>5</sup> When I started the research for my current project, my enquiries of southern archives were met with suggestions about the need for lawyers and complicated applications to state archivists for access.<sup>6</sup> These requests were not for access to patient records, I was specifically looking for administrative correspondence or files, official policy or procedure documents, or correspondence from family or community. Yet repeatedly, I would request a box that was listed in the finding aid only to have it subsequently removed entirely from my table because there were some patient names in the box. In the case of Georgia, this happened twice in the space of two years before I was finally allowed to even request access to the boxes from the state university system Board of Trustees. It took 9 months for that request to be granted, and then

more time while the boxes were redacted, and they didn't contain actual patient files only letters from family. Every time I have been back to that archive, more and more boxes are restricted, because my enquiries raised awareness of what was in the boxes, and now they have become even harder to find. I decided to stop asking, not simply because it's frustrating but because of the harm I might be doing to families looking for records.<sup>7</sup>

The idea that there are patient records just waiting to be "discovered" is I think one of the great misconceptions in the history of psychiatry scholarship. Some people have written entire books based on the chance discovery of files in a cupboard somewhere, or have written about particular institutions because the records exist (Foote, 2018).<sup>8</sup> But it is the case that the official state archives that I have looked at in the Deep South—Alabama, Mississippi, Georgia—do not and probably never have had, patient records stored in their official repositories. In this sense, the lack of records tells us something about both psychiatric and archival power as a tool of white supremacy. I have plenty of anecdotal evidence here: visiting journalists finding records strewn across the floor like so much trash in the haste of deinstitutionalization; records shredded by head office in the wake of the Health Insurance Portability and Accountability ACT (HIPAA) that was intended to increase patient privacy; records removed into deep storage where uncatalogued boxes are protected by a security guard. These silences and absences are heightened for the Black patient, for whom individual case files were barely created in the first place.<sup>9</sup> All of this means that I am attempting to write a book about the Black patients experience of psychiatric institutions in the United States south when the Black voice is systemically and routinely excluded. I have had to learn to read between the lines, and to look for agency and resistance wherever I can, and to center those stories. And I am trying to do so in a way that does not exploit the spectacle for my own person gain (Hartman, 1997).

Yet as an academic the personal gain is inevitable and substantial. We write books because it's part of our job. It's how we get tenure. Sometimes it's how we make money, or also, rarely, fame. Those are not my motivations. Accountability and reparations are my goal. Yet I do earn royalties, and I did get tenure. And I have achieved those things because of the stories I have told about other peoples' suffering. I have tried to mitigate some of this potential harm and exploitation by finding funding and a publishing model that will allow me to publish my book entirely free and online (see <http://jimcrowintheasylum.com>). But this does not solve all my problems. Because of the structure, power, and silences of the archives, and because of the lack of patient records, my history is still largely a top-down one. This is the perceived lure of patient records, this idea that they allow us to personalize and humanize people who have been forgotten and sometimes, deliberately disappeared. As Jonathan sets out later in this article, the social history movement in the history of medicine argued that patient records could help to shift the perspective from that of the institution or the clinic or the psychiatrist to that of the person most affected. We are told this is why we should value them, why we should use them when we find them. But do they, really? And is that good enough reason to use them?

Having "good intentions" doesn't automatically mean that we can or should use records that were initially created within the confines of a private clinical encounter. While HIPAA was intended to legally protect patient privacy it doesn't necessarily help historians deal with the complicated ethical quandaries posed by the redacted or otherwise patient record that sometimes falls into our lap. As an example, I have been conducting research into a court case here in Georgia from the late 1970s about the rights of institutionalized children. As part of my research, I have been granted access to the full court case records here in Georgia, and one day, as I was making my way through the 11 boxes of testimony, I found an unsealed envelope addressed to the judge overseeing the case. Inside were 100 patient records, delivered as evidence about the types of children being admitted. They were not always full records, but they all contained a cover "admission details" sheet that was redacted but had the child's age and race, and usually the "route" of admission, and the initial diagnostic detail given by the relevant code from the DSM in use at the time (DSM-II). Sometimes the record would contain many pages of extra information including a full social and family history that painted story after story of trauma, abuse, neglect, and racism. And most tragically, the records showed serious and systemic racial biases, with a statistical analysis revealing that Black children were more likely to be diagnosed with "aggressive" behavioral disorders.

There is an important story to tell here, and a necessary one, because it shows the way that Black children in particular have always been classified as “just bad kids” rather than having their complex history and social circumstances taken into account (Muhammad, 2019; Suddler, 2019). In these files, I have the evidence to interrupt many existing narratives about both mental health practices, psychiatric history, and the criminal justice system, and yet I hesitate. I hesitate out of respect for privacy. Even though the files are mostly redacted, this court case is recent history. Some of the children whose records I have in front of me, if they survived, are now adults about my own age. Do I have the right to repeat their stories without their knowledge? I have consulted numerous lawyers, including General Counsel and the Institutional Review Board of my university. I have even spoken to one of the original lawyers who argued the case at the Supreme Court of the United States. Everyone agrees I have the *legal right* to use and publish from the files. Yet I hesitate. I think of the traumatic lives and explosive revelations that the files contain, and how my telling those stories would be a remaking of that trauma, a repeat of the violence and the spectacle, recasting people as victims. There are complicated dynamics to consider here. If I am driven by a desire to write “reparatory history” which seeks to document the evils that have been, and that continue to be done, how do I balance this with the desire not to reframe entire communities as sites of deprivation? (Hall, 2018; Scott, 2017, 2018) Documenting oppression, as Eve Tuck has shown, also runs the risk of casting the oppressed as eternally victimized and broken, and in the case of mental health this is problematic as we see continuing disparities and stereotypes play out in current diagnostic and treatment approaches (Hansen et al., 2019). The goal is to make psychiatry antiracist, not to scare people away from seeking help if they need it.

But my ethical hand-wringing however needs to be more than performative. If I am also going to be true to my goal of writing reparatory history than I need to find a way to tell these stories. But I need to do it in a way that doesn't center myself or give only my version of their stories. I am currently talking to the original lawyers who brought the case to explore the possibility of finding some of the children (now adults) in the class action and have them tell their own stories on film. I would flesh out the background history, but the stories of the children themselves, and their lives after their hospitalization, remain theirs to tell. This means letting go of significant control. It means I have to be willing to accept whatever narrative emerges. Maybe it will be the case that people needed to be hospitalized, maybe they didn't feel exploited or abused, maybe they got help and flourished (of course I hope that is the case). But also, maybe they won't want to talk to me at all. Maybe they'd just rather move on and forget it ever happened. Maybe there will be no stories to tell.

But if there are, I also need to be willing to let go of some traditional academic outcomes. Of course, now that I have tenure there is little career risk to me in pursuing a documentary film rather than a traditional monograph. But this actually raises important questions about the way that academic expectations—the need for some great discovery, uncovering something original or horrific—is linked to the academic promotion system. Aside from its own internal ethical problems, that is a system that in fact rewards the exploitation of marginalized people for academic gain. We see this particularly clearly in the health sciences or global health work, but it's less clear in historical work, and historians are far less likely to admit this about their own projects. The push for public humanities is helping us to think through some of these positionality and ethical questions, but will it be enough? Erika Dyck's work in Canada has revealed the complicated dynamics of this kind of work and demonstrates what the academic must be prepared to let go of to bring truly community facing work to fruition (Dyck, 2021). This way of working makes me think that reparatory history might one day be possible if we can pay attention to the needs of the communities we write about, rather than our own disciplinary norms.

*Jonathan*

How we determine the needs of communities, or even what constitutes a community, are essential questions raised by Kylie's last point, and they are not always easily answered. Some historians, for example, have written as though psychiatric patients themselves constitute a group, which may be true in some senses, but runs the risk of eliding huge differences among them—some are voluntary and some are not, some received beneficial treatments, and some got more discipline and punishment, some self-identified as mentally ill and some rejected that label, some have seen themselves as survivors of illness and others as survivors of treatment, and so on. One thing does

unite almost all, though, from those incarcerated in the most horrific institutions to those grateful for helpful therapeutics in voluntary office practice—none of them expected us, historians, to be nosing around in their stories.

For this reason, my own barriers to using patient records are as due to internal queasiness as they are to missing documentation or lack of institutional access. I ask increasingly ask myself, do I really need to see this?

But like Kylie, I retain hopes for a reparatory history of psychiatry, and believe that it requires reckoning with patients' representations of their experiences. I've turned to published memoir literature. Memoirs are easily obtained, and the authors have already relinquished their privacy. Their use carries risks of its own, particularly the risk of missing the silences. People who can get books published have several advantages—they were well enough to write, and they had the material and cultural capital to pitch a book to an editor. And, while some of the published memoirs can be bleak, or at best ambivalent, one does wonder if publishers are more interested in redemptive stories of therapeutic success.

Even if that bias exists, though, memoirs can yield important critiques of psychiatric practice. Many memoirists of electroconvulsive therapy complain of permanent, severe, long-term memory loss. According to much clinical science, that adverse effect should be rare—but it is close to universal in the memoirs. ECT's most enthusiastic proponents often complain that unhappy patients have louder public voices than the many who feel helped, but complaints about severe and permanent memory loss are present in the majority of patient memoirs by people who say they valued the treatment and would recommend it to others—by far.<sup>10</sup> The patient's voice here doesn't prove the clinical science wrong, but it raises serious questions about what the science is missing. Put another way, clinical science has silences of its own, and patient writing can help fill them.

**Q: Can writing about past suffering, trauma, and abuse be done in an ethically sensitive way?**

*Kylie*

I am very conscious of the way so much of my work focuses on how Black people in Southern psychiatric hospitals were so often the “victims” of severe abuse. I am wary of exploiting and replicating the pain and trauma of people who have suffered at the hands of psychiatry in the past. But it is true that people have suffered. In January of 2021, after a long summer of racial reckoning, the American Psychiatric Association published an apology for its role in “the support of racism in psychiatry” (<https://www.psychiatry.org/newsroom/news-releases/apa-apologizes-for-its-support-of-racism-in-psychiatry>). This vague statement gave no real specifics about what this “support” looked like, nor did it really account for what I would call the internal racism of psychiatric thought and practice itself. I try to use my work as a direct attempt to document the ways that American psychiatry has not just supported racism but is in fact directly implicated in the creation of the ideologies and practices which create and reinforce false ideas about racial difference. My overt aim is to hold psychiatry to account, and to consider the possibilities for a reparatory history of psychiatry. But I am frequently bound by the limits and power relations of the official archives, and by my own hesitancy about how to use what I find. As Michel-Rolph Trouillot and Achille Mbembe have eloquently argued, the silences and power of the “official” archive are painfully obvious at the intersection with race (Mbembe, 2002; Trouillot, 1995).

There are two ways I am trying to counter this problem. Using Trouillot, Mbembe, and Stoler among others, I am thinking about ways to write about the silences themselves, to articulate them and highlight them, and make them clear where they exist. This is uncomfortable territory for historians I think because we are not supposed to be writing fiction, right? We don't make things up, we report on the “evidence.” But absence of evidence should not be taken as evidence of absence, as we know. It is possible for me to write about those silences to show what should be there, and to make suppositions about why it is not. In this way, I aim to reveal the way that power works to eliminate the Black story from the “official” archive. And in this instance of psychiatry, that absence speaks to the dehumanization and invisibility of the Black patient—they are treated by the archive in the same way they were treated in the asylum. I have also been very active in looking for signs of resistance and activism—the whole second half of my current book is focused on that, using sources from the Black press and civil rights leaders. And finally, there are choices we can make about publication options. For this book, I have pursued funding to allow for the public open access version of the text that will be available free and online.<sup>11</sup> Digital publication also allows for

added resources, including video, photo and audio, and also for the publication of full open-source data sets. All of my research materials will eventually become a publicly accessible collection in my university library. This approach is only possible because of my immense privilege to be working somewhere so well-resourced, so it falls on institutions to own this aspect of their own existence, and do more to make the work we do meaningful to the people that the entire academic system benefits from. When it comes to reparations, maybe this is one way the American Psychiatric Association, which has now closed its archives to the general public, could also be more accountable.

*Jonathan*

We do need to hold psychiatry accountable for its role in oppressive structures and practices. But I also worry about a one-sidedness in the historiography. Many histories of psychiatry document only abuse, coercion, and clinical limitations. Many show the contingency or political valence of diagnostic categories without according any of them any clinical value. We have an ethical obligation to show therapeutic success when appropriate.<sup>12</sup> Contexts like the ones Kylie is studying now may have little success to show, and I don't think she should root around for some in search of a spurious "balance." But people do benefit from psychiatric care, and we know this from copious patient testimony. With specific relation to race, whether in segregated America or colonial Africa, absence of care, neglect, was as big a problem as social control and invasive treatment, and this can only be true if there is value to be had from psychiatric care.

As Kylie suggests, we need to be attentive to our own motivations. At a small interdisciplinary meeting of scholars studying schizophrenia some years ago, an anthropologist reminded us that people with schizophrenia have done more for us than we can ever do for them.<sup>13</sup> We can acknowledge the gains we get from our work, and still maintain hopefully that it has value for others. While the quest for patient records has become a bit of a fetish in the field, the original motivation for it—the attempt to unearth the patient's perspective—remains commanding (Vaughan, 1983).<sup>14</sup> Our era of biomedical psychiatry, which itself effaces patient subjectivity, heightens the urgency still more. As I put it many years ago, in biologically reductionist psychiatry, what the patient has—their diagnosis—is more important than what they say.<sup>15</sup> Many historians of psychiatry have shown that diagnostic labels can be reductive, stigmatizing, and politically invidious. Showing this can be a helpful way of reflecting on the dangers and limits of current diagnostic practices, and in patient records we may see signs of patient resistance to the labels. We also must simultaneously remember, though, that many psychiatric patients have valued diagnoses as, for example, a validation of the realness of their illness experience (see Callard, 2014; Moran, 2022, Murray, 2020).

All historical sources are imperfect. Patient records are written mostly by clinicians, and can require vigorous reading against the grain. The patient's voice can come through in remarkable ways, though. Only a little critical sophistication uncovers the protest registered by Ida Bauer, Freud's "Dora," even though his *Fragment of an Analysis of a Case of Hysteria* contains only the sparsest of verbatim quotes from her.

When I began work on my latest book, *The Empire of Depression*, I did not want any reader with clinical depression to conclude that all psychiatry had to offer was social control, toxic treatments, biomedical reductionism, and arbitrary labels. The last thing a person in severe depression needs is confirmation that there is no hope. The field of the history of psychiatry has tended sometimes to equate critical thinking with relentless negativity. Patients who feel they have been helped by treatment should have a voice in our historiography. Ambivalence is a dominant theme in patient accounts of electroconvulsive therapy, the majority of which combine grateful meditation on relief from terrible symptoms of illness with mourning of lost memories and other cognitive losses. A damage-centered historiography cannot encompass this combination, and cannot serve the patients, or the history, with justice.

**Q: Does our positionality—our own personal identity—matter when it comes to writing the history of psychiatry?**

*Kylie*

My positionality within my own project gives me frequent pause, and I am tentative and cautious about my approach and the claims I make because of it. I am a white woman working in the US South where the issues of racial disparities in mental health stare me in the face daily. My whiteness does not give me any authority to tell the



history I am trying to tell, but it does in fact give me the responsibility. White supremacy, and the damage it has wrought, is a white person's problem to fix. I am overtly not "objective" in this process, I am driven by a particular call to social justice because I don't see a clear rupture between the past and the present. So my positionality is also driven by my politics, which probably makes me guilty of all sorts of terrible presentism and putting theoretical carts before the horse. Partly this is because so much of what I'm coming across in the archives is actually damage-centered, but also because I believe that historians can and should be agents of reparation.

In his "Preface: A Reparatory History of the Present" David Scott writes "In the face of the dead ends of racial justice that define our present, it is reparatory history that ought to command our attention."<sup>16</sup> By reparatory history, Scott is referring to the type of history that "is concerned with those historical evils and injustices that remain unrepaired in the present, whose wrongs continue to disfigure generations of human lives" and that seeks to "reconstruct these evil and unjust pasts in ways that potentially enable us to rethink the moral responsibility that the present owes in respect of them."<sup>17</sup> Scott is largely referring to the "big evils" here of slavery and the Holocaust, but in my work I want to suggest that psychiatry is not simply an artifact of the racism that fueled slavery, but rather an active and foundational technology of the continuation of the racism that enabled and sustained slavery in the first place.

I do think though that there is something to be learnt from Jonathan's approach which isn't so much about balance or "both-siderism" but is about nuance, about being able to hold both the oppressive evils and the therapeutic promise of psychiatry together at the same time. This is one justification I think for mining patient records when we find them, to try and get some sense of what was actually done to and for people, and trying to evaluate whether it was therapeutic or abusive.

*Jonathan*

I faced some similar issues as a white man writing about Nigeria. I also wanted to explore historical oppression, and colonialism is of course one of the greatest of historical injustices. While writing the book that resulted, I grew increasingly mindful of the limits of my grasp, and this partly explains why I turned to look at my own society for my second project. I do not argue that people can only study their own communities. Much excellent work in all the humanities and social sciences has been produced by outsiders. The effort does, as Kylie says, exact responsibilities. Turning my attention to the United States did not eliminate those responsibilities, or resolve as many contradictions, as it might seem. To study electroconvulsive therapy in America also required me to try to grasp the subjectivity of people from vastly different backgrounds from my own.

Our own psychiatric history is another part of our positionality. Many people upon hearing about my work have made audacious assumptions about my connection, or lack of connection, to the material. Some have assumed that I am an outsider, in the sense of never having been a psychiatric patient myself. Others have assumed the opposite, that my interest in the subject must be based in personal experience. Neither of these has any basis, as an assumption.

*Kylie*

I tend not to talk about my positionality in this way very much, because I am more conscious of my racial and social standing in relation to my current project, but it's interesting that you raise it because in the back of my mind always is the memory of where I have come from, and the life I lived before I came to the United States. I am always torn about how much to tell people, how to protect my own privacy for example, given my immigration status. And I am not going to do some major reveal here, but there are personal reasons why I'm interested in the history of psychiatry and when I feel it's needed I will disclose some of that to the people I'm working with, usually if I'm taking an oral history. I think that's important for me, to try and remove any barriers of class or race or prestige, to let people know that I'm not there to make a spectacle of them but because I understand a little of what they've been through. Historians don't usually write about or admit this aspect of their own identity in relation to their projects.<sup>18</sup> I am often asked why I am interested in this topic, and I hesitate to answer for the same reasons Moran sets out in her insightful *Perspective* article how much is it safe to reveal, how much do people really want to know?<sup>19</sup> At the same time, there is no obligation for historians to be from the "population" they seek to understand, otherwise we

would not have any medievalists at least! So calls for that kind of positionality quickly become ludicrous. But what disability studies has given us, in the call for “nothing about us without us” is the need for partnership and collaboration as much as possible, and the commitment not to make spectacles out of people's past suffering (Charlton, 2000). To be tender, careful, and empathetic, that's the very least we owe.

*Kylie and Jonathan*

Can a conclusion be drawn from these ruminations? What, for example, might we advise a PhD student embarking on a project in this area? Our central message is that we need to avoid the temptation to treat the records as a big scoop or pay dirt (pick your metaphor). Instead, we need to ask ourselves, what are we trying to add to historical knowledge that cannot be obtained in any other way? And how important is that gain? Some might decide yes and some no—it could depend on the quality of the records, or what gaps in the historical knowledge are being filled, for example. We are not suggesting a formula or set of rules, but urging that the questions always be thought out. We should not treat it as self-evident that the records have great historical utility, and that finding them automatically justifies their use. We do not argue that the benefits of using patient records always outweigh the harms, or vice-versa. What we do argue is that the question must always be asked, and the answers are rarely obvious.

## DATA AVAILABILITY STATEMENT

No data were created for this article.

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## ENDNOTES

- <sup>1</sup> The paper was for a conference on race and medicine organized by Keith Wailoo in 2001; the paper was later published as Jonathan Sadowsky, “The Reality of Mental Illness and the Social World: Lessons from Colonial Psychiatry,” *Harvard Review of Psychiatry*, 11, 4 (July 2003) with the question about Fanon and Foucault omitted.
- <sup>2</sup> Fanon was an eclectic clinician, an avid user of somatic treatments as well as psychoanalytic theory and technique. Many readers of his work might be surprised to know that he used Insulin Coma Therapy and Electroconvulsive Therapy liberally, for example. See Frantz Fanon, *The Psychiatric Writings from Alienation and Freedom*, Jean Khalfa and Robert J. C. Young, eds., Steven Corcoran, trans., London: Bloomsbury Academic, 2019.
- <sup>3</sup> For example, looking at the unwillingness of Algerians to confess to crimes, some French psychiatrists concluded a primitive inability to take responsibility was at work, whereas Fanon pointed out that confession is a ritual of re-inclusion into a social contact, and refusal to do it was more likely a refusal of a particular social arrangement—colonialism—that Algerians rejected the legitimacy of; Fanon, *The Psychiatric Writings from Alienation and Freedom*, 28–31.
- <sup>4</sup> As I suggest below. I think it is misleading to automatically regard all psychiatric patients as persecuted—though it is more likely valid to say that they are all at least to some extent stigmatized.
- <sup>5</sup> Susan Lawrence has documented some of these issues in her book (see Lawrence, 2016). Lawrence's argument is that historians need to push back against defensive and protective archives.
- <sup>6</sup> This new project is called *Jim Crow in the Asylum: Psychiatry and Civil Rights in the American South* and is under contract with UNC Press, due for publication in 2024.
- <sup>7</sup> There are two Facebook sites dedicated to the “memories” or “friends” of Central State Hospital in Georgia, and people are constantly posting requests for help trying to find family records and getting nowhere. I stopped answering those too.
- <sup>8</sup> Two examples at least are Gonaver, Wendy. *The peculiar institution and the making of Modern psychiatry, 1840–1880*. UNC Press Books, 2019 and Foote, Susan Bartlett. *The Crusade for Forgotten Souls: Reforming Minnesota's Mental Institutions, 1946–1954*. U of Minnesota Press, 2018. Martin Summer's commented on the completeness of the archive that made his work on St. Elizabeths Hospital possible, and in her recent book, Elodie Edwards-Grossi explains that she wrote about the states she did because those records were plentiful and available. See Summers, *Madness in the City of Magnificent Intentions: A History of Race and Mental Illness in the Nation's Capital*; Elodie Edwards-Grossi, *Mad With*

Freedom: The Political Economy of Blackness, Insanity, and Civil Rights in the U.S. South, 1840–1940. (New Orleans: Louisiana State University Press, 2022).

- <sup>9</sup> Mab Segrest has some evidence of the scarcity and superficiality of records related to Black patients in her work but the files she used have now been removed from the state archives entirely. See for example, Segrest, “Exalted on the Ward”; Segrest, *Administrations of Lunacy: Racism and the Haunting of American Psychiatry at the Milledgeville Asylum*.
- <sup>10</sup> Examples are numerous, but see for example, Carrie Fisher, *Shockaholic* (New York: Simon and Schuster, 2011).
- <sup>11</sup> Jim Crow in the Asylum will be published both in print and online using the Manifold Scholar Digital Publishing Platform, with subvention support from the Mellon Foundation through Emory’s Digital Publishing in the Humanities grant.
- <sup>12</sup> I argue these points at length in “Before and After Prozac: Psychiatry as Medicine and the Historiography of Depression,” *Culture, Medicine, and Psychiatry* 45 (June 2021) 479–502.
- <sup>13</sup> The meeting resulted in the volume *Schizophrenia, Culture, and Subjectivity: The Edge of Experience*, Robert Barrett and Janis Jenkins, eds. (Cambridge: Cambridge University Press, 2003).
- <sup>14</sup> Roy Porter helped to set the agenda in the mid-1980s. See Porter (1985). Megan Vaughan pioneered the historical study of colonial psychiatric institutions around the same time, and also posed the challenge of capturing the patient’s voice. “Idioms of Madness: Zomba Lunatic Asylum, Nyasaland, in the Colonial Period.” *Journal of Southern African Studies* 9, 2 (1983): 218–238 and *Curing Their Ills: Colonial Power and African Illness*. Stanford: Stanford University, 1991, ch. 5. Porter thought that the value of capturing the patient’s voice would lie in its challenge to biomedical authority. I worry that this starting point reproduces the damage-centered framework Tuck warns against.
- <sup>15</sup> Imperial Bedlam, p 50.
- <sup>16</sup> Scott “Preface: A Reparatory History of the Present.”
- <sup>17</sup> Scott. Px See also Scott, “Preface: Evil Beyond Repair”; Hall, “Doing Reparatory History: Bringing ‘race’ and Slavery Home.”
- <sup>18</sup> It is interesting to see this start to shift with new pieces by Rachel Moran and also recently by Ariel Lambe: Ariel Mae Lambe, “Seeing Madness in the Archives,” *American Historical Review* 127, no. 3 (September 2022): 1381–1391.
- <sup>19</sup> Rachel Louise Moran, “Spitting on My Sources.”

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