Researching delusions:

A search for epistemic justice
An interview with Hamilton Kennedy

Hamilton Kennedy interviewed by David Denborough

Hamilton Kennedy is a researcher, animal lover and ex-patient of psychiatry. They are completing their PhD at La Trobe University. Their PhD explores the concept of delusion and the truth contained with these beliefs. Hamilton completed the Master of Narrative Therapy and Community Work at The University of Melbourne in 2019. Hamilton.kennedy@latrobe.edu.au

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Abstract

In 2024, this journal published a paper by Hamilton Kennedy highlighting the dismissive responses often experienced by people who hold beliefs that have been labelled as delusional. Hamilton argued that this dismissal constitutes a form of epistemic injustice. We received a number of responses to this article, and decided to interview the author about the wider research project they are engaged in. Hamilton has developed innovative qualitative research methods to explore the history and meanings of beliefs that have been labelled as "delusions", and to collaborate with research participants in non-pathologising ways. In this interview with David Denborough, Hamilton reflects on some of the practical and ethical considerations involved in conducting research with people whose beliefs have been labelled delusional. They set out how their approach differs from much research in psychiatric contexts, favouring a stance of solidarity, care and reciprocal trust.

Key words: qualitative research; epistemology; delusion; paranoia; schizophrenia; hallucination; narrative practice

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Author pronouns: Hamilton Kennedy, they/them; David Denborough, all pronouns welcome

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DD: I'm so pleased to have the chance to talk with you about your research with people who have been labelled as "delusional" in relation to their beliefs. Prior to conducting this research, you were working as a peer mental health worker. As an ex-patient of psychiatry, you've written influentially about how as a practitioner, you have brought together intentional peer support work and narrative therapy (Kennedy, 2019). Now you are researching beliefs labelled as delusional. Before I ask you more about this qualitative research, can you say a little about this movement between peer mental health worker–narrative practitioner and researcher?

Hamilton: My connection to delusion and mental health is not just academic. Many people I love and have loved experience or have experienced mental illness. It has also been asserted that I fit within this category! As a result, I have found little meaningful distinction in my practice between the compassion and care in professional relationships from that within personal relationships (Kennedy, 2019). In the past, when working within a psychiatric unit, I have unexpectedly encountered someone who was personally known to me. And in my friendship networks I sometimes cross paths with people who I first met when they were an in-patient and I was their peer worker. These sorts of experiences mean that distinctions between myself, those I know and others labelled by psychiatry feel genuinely semantic. Who is a patient admitted to the psychiatric hospital but a friend I haven't met yet? In both my practice and my research, I have attempted to resist drawing arbitrary distinctions between myself, those labelled mentally ill whom I know personally, and those I know professionally.

During 2023 and 2024, as part of my PhD research, I conducted a series of interviews aimed at understanding and documenting the experiences of individuals labelled as "delusional". This involved multiple conversations with people over several months in an attempt to explore the histories and origins of the experience that was labelled "delusional". Some participants were a similar in age to me and/or lived in the same area; some participants shared the same diagnosis as me; many shared what they considered to be traumatic experiences with psychiatry. I, too, have had such traumatic experiences. Participants had all had life-changing experiences which would be considered mental illnesses. I have also. There was a discordance between their own beliefs or experiences and the perceptions of others. I have also had this experience. There was also a similarity, at times, between our political or ideological perspectives outside of our perspectives about mental health.

DD: Your ethical approach to this research reminds me of the kind of solidarity that narrative therapist Michael White considered in the relationship between therapist and person consulting them:

> I am thinking of a solidarity that is constructed by therapists who refuse to draw a sharp distinction between their lives and the lives of others, who refuse to marginalize those persons who seek help, by therapists who are constantly confronting the fact that if faced with the circumstances such that provide the context of troubles of others, they just might not be doing nearly as well themselves. (1993, p. 132)

Hamilton: Yes, this concept of solidarity has been considerably influential in my approach. I need to think through how to create research relationships that do not marginalise but instead bring together the participant and myself to research the phenomenon of delusions.

DD: There is a broader context that is relevant here in that there is a pretty terrible history in relation to research in psychiatric contexts, including psychosurgery experiments and sleep experiments, and this wider history would surely influence the participants' reticence to be involved in any research project. I am really interested in the ways you went about negotiating what you call a “reciprocal trust”. Can you say more about this – in particular in the initial stages?

Hamilton: Given that the people I was hoping to involve in this research had all been told that they were delusional by psychiatrists and the mental health system, many were explicitly fearful of mental health services. My role as a researcher initially placed me within the realms of understandable suspicion and I was prepared for this. Participants posed numerous questions to establish whether I was a credible and safe person to speak with. This often took the form of direct and specific questioning during initial phone conversations. For example, they inquired about my academic background, the nature of my research, my intentions and my affiliations. These inquiries were crucial for them to feel assured of my authenticity and trustworthiness. This self-initiated vetting and research process was an essential step for participants to feel secure in sharing their personal experiences.

DD: I love this – that the first part of this research project actually involved participants researching you!

Hamilton: Yes, I could read some transcript about this to paint you the picture … Bill wanted to know what professional background I would be bringing to the research.

> Bill: Are you a psychiatrist?
>
> Hamilton: No.
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> Bill: Are you a psychologist?
>
> Hamilton: Uh, no.
>
> Bill: Thank Christ, because if you were, I don’t know if I’d be talking to you.

This conversation was instructive as it highlighted the importance of transparency with participants in relation to my identity. Subsequently, during future phone conversations, I adopted a more thoughtful approach in response, like in this transcript:

> Michael: What is your professional background?
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> Hamilton: Well, I did study social work and have worked in mental health services but always found myself questioning how they operate.
>
> Michael: Good, me too. I don’t like how they treat people.

DD: Didn’t some participants also go so far as to research your supervisor?

Hamilton: Participants conducted due diligence by researching my previous publications, inquiring about my contributions to journals like *International Journal of Narrative Therapy and Community Work* as well as mental health journals. Somehow, one participant discovered my past work with a government health service, which did not reflect well upon me. Others followed and viewed my Twitter feed and asked me questions. And yes, it wasn’t just myself under scrutiny, but humorously, my primary supervisor. Two participants researched his background and noted his prominence in Australian mental health discourse. They wanted to know: What is his role? Is he good for you to work with? One even commented, “I don’t know if I can trust him”. The normative credibility of both my supervisor and the university my PhD is associated with sometimes contributed to undermining my credibility with participants.

DD: Can you say more about why you refer to this as negotiating a “reciprocal trust”?

Hamilton: I was prepared for my role as a researcher initially placing me within the realms of suspicion, but I wasn’t aware that participants might feel I would not trust them. Participants’ comments like “Trust of the patient is so important because you're questioning the patient, but at the same time, you need to trust the patient" reminded me that people diagnosed as "delusional" have been treated with great cynicism.

DD: In order to create this reciprocal trust, they had to believe that you would believe them. It also seems to be that the stance you took as researcher was crucial, and this included you openly sharing your own sadness about what some of the participants had experienced. I found some of the stories from your research very moving. For instance, the story of Janelle, a Christian woman in her 30s who is married with children, who was initially diagnosed with depression with psychotic features, and later with schizophrenia, in the context of her belief that she was dead. She was living a relatively normal life with this belief until the psychiatric system forcibly intervened, and she described this intervention as worse than the initial belief itself. In your conversations you traced the history of this belief, which was linked to the deaths of her two children, including one in utero, and you also explored in skilful ways – by asking epistemological questions in relation to how she had "come to know" – how her understandings were shaped from within her Christian worldview. She spoke movingly about the concept of the "afterlife" and how her religious community "didn't have that barrier of death as permanent." I found the story in itself moving, and also a little devastating when contrasting the care you took in understanding her experiences compared to the brutality and what you call the "epistemic injustice" of the psychiatric system (Kennedy, 2024). Within your research interviews, you spoke quite often about your own sadness when you heard stories of suffering. Can you say something about that?

Hamilton: Yes, I took a particular stance in this research which involved explicitly caring about the marginalisations and harms that the people I was talking to had experienced. Whilst the experience of delusion itself does not necessarily lead to misery, it's quite common. The incredible sadness and fear and isolation that people who are labelled as delusional have experienced is the reason I am doing this research. When I first met with people, I wanted to make a big deal of how much I was thankful for them talking with me and how much I cared about it.

I heard about participants being admitted to hospital, relapsing or being placed on long-term involuntary treatment orders, which amount to monthly forced injections. These stories brought me enormous sadness and I was open with participants about this. I would take an explicit position towards the harm and suffering participants had experienced, either inherently from the experience of the unusual belief or due to responses to them from others, including mental health systems. I was not neutral in relation to their suffering. I took a stance to name that some of what they have endured was unconscionable, whether this occurred in their personal lives or within the psychiatric system which was intended to help. Saying so allowed for people to share honestly because they felt that I care, and I do.

The stories of suffering shared with me still impact me today, especially when considering they are a fraction of the hardship endured by these people. Not only had these people experienced such incredible sadness and fear but they'd often not had the opportunity to talk to people about their experiences. Many people said that they didn't share their experience with others for fear of being sectioned [involuntarily detained in psychiatric units] or having to go back into hospital. Suffering with friends and family is one thing, but suffering alone breaks my heart.

DD: It's a multi-layered suffering, isn't it? They may be quite tormented by some of these unusual beliefs, and this may also affect their relationships, but then to be treated with disrespect or coercion from psychiatric systems, and then to have nowhere to speak or try to make sense of their experiences—this leads to a further suffering. Can you say something about how you understand this as forms of epistemic injustice (Kennedy, 2024) and how your research is therefore a search for justice?

Hamilton: Within psychiatry, thoughts are labelled as delusional when sincere beliefs and expressions are deemed to be a combination of bizarre, fixed, irrational, resistant to counter-argument, and most notably, false. People's experience of these unusual thoughts can be jarring, confusing and extremely upsetting, but when individuals' sincere stories of suffering or excitement are labelled as delusional, it typically renders their belief false and not worthy of further inquiry. This I consider a form of injustice, despite its ostensibly benevolent intentions. I've found the concept of epistemic injustice helpful to understand this.

According to Fricker (2007), epistemic injustice consists of two forms: "testimonial injustice", where someone is discredited or not believed, and "hermeneutical injustice", where a person is unable to express or make sense of their experience due to a lack of support or shared perspective.

Labelling someone as delusional is a form of "testimonial injustice" as it creates an identity marker that leads them to be disbelieved on account of that label. It is not just a belief that comes to be labelled delusional but the person themselves. Earlier you mentioned Janelle. For Janelle, her belief "I am dead" was identified as delusional, and this also rendered Janelle herself as delusional. As a result, neither Janelle's belief nor Janelle as a person were seen as warranting substantive engagement. The delusional label meant that she was ignored by those around her and was unable to discuss the matters that were most significant to her. Janelle considered her belief that she had died to be related to significant loss in her life, which would suggest a need for compassionate inquiry, but once defined as delusional no such compassion was forthcoming.

This relates to the second concept Fricker (2007) offers – "hermeneutical injustice" – which refers to individuals lacking the support or opportunity to understand or express their own experiences. This form of injustice is also regularly experienced by people with unusual beliefs and those labelled as delusional.

Epistemic justice involves recognising individuals as knowers, ensuring they are heard fairly, and supporting them in making sense of their experiences. My research seeks to provide an opportunity and an environment for people to discuss and attempt to understand their own beliefs. Of the participants in my research, few, if any, had previously experienced this.

DD: Am I right that this is linked to the field of Mad Studies?

Hamilton: Yes, the field of Mad Studies is about seeing people who have mental illness or who have been considered mad as having knowledge to contribute about that experience. In my qualitative research, informed by Mad Studies and narrative therapy, I explore what knowledge those who have been labelled as delusional have to contribute in relation to the most unusual of beliefs.

DD: There were numerous research enquiries you used for this, including what's known as externalising conversations in narrative practice, so that participants could come up with their own namings of their experience. You'd ask questions such as "If it's not delusion, then what do you call it?" or "Do you have a name for this?" You didn't use any illness or psychiatric language unless endorsed by the participant. And as I mentioned earlier in relation to Janelle, you would explore the histories and wider contexts for how these beliefs had come to be believed. I think you understand these as pathways towards epistemic justice. But I want to ask you about your "co-investigations" – how you and your participants collaboratively researched these unusual beliefs. This seems particularly consonant with Mad Studies.

Hamilton: The research design was initially intended to centre around conducting interviews and allowing participants time between sessions to reflect on experiences, write some reflections, and if possible, research the background and histories of their beliefs. This approach aimed to supplement interview findings with participants' independent reflections and investigations, acknowledging that interviews alone might not fully capture the depth of their experiences.

However, I did not anticipate the enormity of opportunities that would emerge beyond the information collected through interviews. Participants wanted to share more, and I was open to receiving it. It was perhaps naïve to assume that people hadn't already spent significant amounts of time reflecting on or researching their own beliefs.

Participants shared with me hundreds of thousands of words of reflections, letters, timelines, medical records, countless media articles, photographs they had taken and comics they had created. They were not interested in being merely research participants but were keen to participate as co-researchers and co-authors, in spirit and in name, in potential upcoming publications. Recognising the limitations of my own capacity to uncover the histories of these beliefs, I relied on participants not only to share information but to act as investigators themselves. The process being conducted over several months, coupled with providing reimbursement for their time spent investigating, facilitated participants' sincere engagement and contributions.

This level of involvement transformed the research process. Participants' extensive contributions enriched the study with a depth and breadth of data that far exceeded initial expectations.

DD: I really appreciate these flourishing co-investigations as forms of epistemic justice! And how in your research you did find that people's unusual beliefs were connected in some way to true and meaningful events in their lives. Having talked earlier about the sadness that accompanied some of this research, I realise that there was a lot more than sadness …

Hamilton: Oh yes. The relationships with participants were consistently meaningful and often enjoyable. When I learnt of small victories such as a reduction of medication, a lessening of fear about alleged persecutors, or stories about their family and loved ones, it brought real joy, especially as this can be hard to find in their lives. And participants would ask about my mental health with care and thoughtfulness. They enquired about my personal life, and I enquired about theirs. I offered and at times did help in small ways in their personal lives. Significantly, with many of the participants our relationships continue in meaningful ways. I took care to write into the initial ethics application of the project that this might be the case, and it is proving to be so. These may continue as relationships of mutual solidarity, care, compassion, friendship and co-authorship on various future publications.

DD: These solidarity relations, friendship relations, will they also be relevant in your future practice? I'm really interested in how practice informs research that then informs practice again. Can you say something about that?

Hamilton: Oh yes. In a future work practice environment, if I am meeting with others who have unusual beliefs, I will now have people whom I might be able to consult, to draw upon their know-how and experience, to bounce ideas off.

When I think about my next steps, I want to acknowledge that I have substantially more privilege than many people who are most impacted by madness. In almost every possible realm, I have significantly more privilege based on where I was born, and the colour of my skin, and my class background, and even things like what medication I was put on when I was first admitted to hospital. If any of these things had been different, then the outcomes in my life could have been starkly worse. It is tremendously unfair the degree to which there are highly inequitable outcomes in relation to mental illness.

This means it's a sort of privilege for me to be in a position to be able to try to make an impact on other people's lives. And to be joined with some of the participants from this research, who have far less privilege, to then be able to assist others, well that is one of my hopes for the future.

DD: Finally, I really like how you draw on Howard Zinn's notion of a counterforce. Can you say something about that?

Hamilton: To conclude his influential book *A People's History of the United States*, Howard Zinn (2010, p. 593) stated that his book is "a biased account, one that leans in a certain direction. I am not troubled by that … we need some counterforce". The history of mainstream research on delusion leans in a certain direction, in which the researcher claims to be ambivalent, apolitical or amoral towards the experience and history of these beliefs and their impact, and in which the researcher is detached from the participants. My research is different in that it is biased towards understanding the experience of people's unusual beliefs, the histories of these beliefs, cares deeply about the effects of these, and values the participants as connected to (not different from) the researcher. In this way, I hope it acts as a "counterforce" and offers new perspectives.

DD: Thanks, Hamilton. It's certainly offered me new perspectives, and I find it really moving, thoughtful and invigorating research. Please pass on my respect to all the participants. I'll be interested in their thoughts on this interview if they read it.

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