



Beyond disease: Responding to accounts of 'addiction'-related stigma and discrimination

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Introduction

- Definitions of addiction have never been more hotly contested.
- The brain disease model has been embraced by some researchers and clinicians convinced that it will both explain addiction and destigmatise it.
- Nora Volkow (Director of NIDA):

“If we embrace the concept of addiction as a chronic disease where drugs have disrupted the most fundamental circuits that enable us to do something that we take for granted—make a decision and follow it through—we will be able to decrease the stigma, not just in the lay public, but in the health care system, among providers and insurers.”



- Conviction that disease labels destigmatise addiction also evident among many critics of neuroscience.
- The idea that labelling something a disease will alleviate stigma is questionable.
- In this presentation I take up the issue of stigma as it plays out in relation to addiction, raising questions about claims made about the progress associated with disease models.



Literature

- Research that takes in issues of stigma in relation to drug use can be seen in terms of two main forms:
 - highly specific studies of stigma in particular settings such as hospitals, workplaces etc, and on how individuals cope with stigma, as well as meta-analyses of these bodies of work.
 - broader research projects on life with drug use that incorporate operations of related phenomena such as power, marginalisation and inequality in the lives of consumers.
- This presentation relates to both these forms of research. It seeks to understand stigma experiences within broader social and political forces by attending to very specific, targeted data on these experiences.



Approach

Goffman, *Stigma* (1973 [1963])

- According to Irving Goffman, stigma exists where a personal attribute is viewed negatively in society, and where the affected individual is marked by that attribute in such a way that she or he is aware of the potential or actual negative judgements of others.
- As Goffman puts it (1973 [1963]: 15):

“By definition, of course, we believe the person with a stigma is not quite human. ..We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences such as social class.”



- Goffman focuses on how individuals cope with stigma, saying much less about stigma as a social and political phenomenon.
- But some of Goffman’s observations point to a broader political way of understanding stigma processes:
 - “the perceived undesirability of a particular personal property...has a history of its own, a history that is regularly changed by purposeful social action.” (1973 [1963]: 164-5)
- Presumably the case too for addiction, and at present it seems labelling addiction a disease is considered an important way to change stigma. But addiction stigma remains a primary experience for our very diverse participants.



Results

- Participant accounts emphasise many, varied manifestations of prejudice and negative judgements.
- As has research on experiences of stigma among people with hepatitis C, our participants identified the health system as a key site for stigma and discrimination, but other settings such as the workplace, the family and the criminal justice system were also discussed.



Workplace

- “I don’t think people judge based on performance [...] If they think you’re [a drug] user, then [...] the judgment is made that you are not employable.”
Jenna (F, 31, studying, cannabis)

Healthcare system

- “I was unconscious and I came to in the hospital [...] I became conscious but I couldn’t move a muscle [...] I could feel pain but I couldn’t move, and I could hear what the doctors and the paramedics were saying about me [which was] just really derogatory, you know: ‘Stupid fucking junkie, [we] get them all the time’. It upsets me even thinking about it [crying]. They were being very, very rough with my body. There was no care.”
Zadie (F, 33, works in the health sector, heroin)



Policing and criminal justice system

- “As soon as the police see [...track marks], just, they know and they do treat you different. They treat you with such little respect. I’ve had them drag me into an alley before and fully strip search me in an alley, just because they thought I had drugs on me, they thought I was dealing and I had nothing on me. And anyone could’ve walked down that alley. And just little things like that, and your lack of dignity really. They really do take away [that] from you.”

Peter (M, 41, unemployed, heroin)



The media

- “[...According to the media] everyone falls into this category [of being addicted] They’re the junkie, you know, they’re the useless person on the street, they’re the bottom feeders, you know [...] It’s not questioned in the mainstream media and that’s the unfortunate thing [...that there is] that level of stigma.”

Harry (M, 52, works in the Arts, heroin)

Family and friends

- “The relatives didn’t want their kids associating with me any more – my cousins – even though I didn’t encourage them to take drugs or anything of the kind. Yeah, that hurt a bit [...] It had a big impact. [...] They don’t trust me. And they think that a user is a junkie, a stereotypical junkie that’ll steal from anybody.”

Nick (M, 50, not working due to illness, heroin)



Resisting stigma

- Some say they talk about drug use or addiction openly in an effort to challenge stereotypes.
- Some criticise the very idea of addiction or dependence, saying that it implies illness and suffering.
- Instead they describe their regular consumption as an important part of, rather than a threat to, their lives.
- Some argue that it's the stigma itself that causes harm by turning drug use into a source of shame and a sense of failure and illegitimacy.



Conclusions

- The implications of addiction-related stigma and discrimination are far reaching.
- Reluctance to disclose and seek support can follow, as can social isolation and the magnification of distress.
- Treating addiction as a sickness of the brain characterised by a “diseased” “free will” (Volkow, 2015) said to be destigmatising, but doesn’t seem to be working.
- Having a “diseased free will” automatically renders one marginal in liberal societies that venerate freedom and agency.



Conclusions

- Importantly, the neuroscientific approach isn't the only one to claim that diseaseing addiction will reduce stigma.
- Need to look carefully at all disease models and their claims, comparing them with the experiences of affected people.
- Need to recognise that diseases attract stigma – but different kinds of stigma from those that accompany judgments of criminality or evil.
- Need to think up new ways of thinking addiction beyond disease.

Thank you



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Advisory panel



- Ms Nicky Bath, Formerly of NSW Users and AIDS Association (NUAA)
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- Ms Anna Keato, Victorian Department of Health and Human Services
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INTERVIEW PARTICIPANTS

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