Stigma and power in health care for people affected by blood-borne viruses: normative expectations and buried processes

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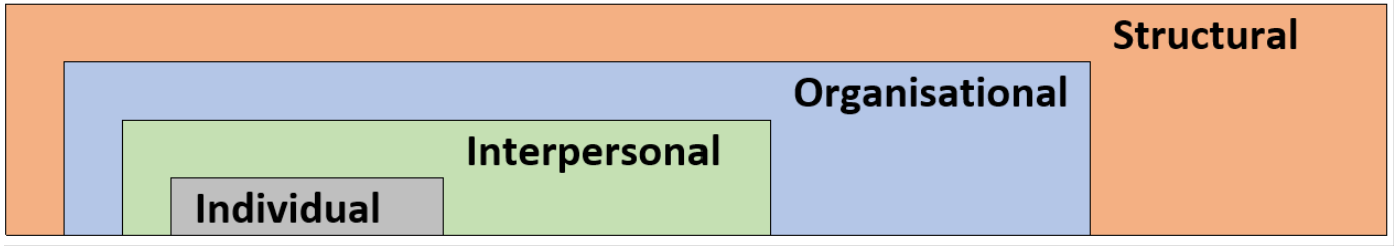
Background



- Stigma - social process of exclusion of a person or groups of people who are perceived to have characteristics or identities that are viewed negatively by the broader social group (1).
- Multiple levels of stigma
- Less focus on structural stigma - a problem 'hidden in plain sight' (2) – Macro turn (3):
- Structural stigma - how stigma may manifest within socio-cultural norms and discourse, and institutional policies, which act to restrict the rights and opportunities or result in negative consequences for stigmatised people (4, 5).

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Method

- Interviews with 24 key informants in BBV/STI
- Key stakeholders – knowledge/expertise on stigma in health care, experience in designing and implementing programs to address stigma

- Stigma power:
  - Societal norms + “hidden, misrecognised processes serve the interests of stigmatisers and are part of a social system that gets them what they want” (1)
- Stigma craft:
  - “the mechanisms through which stigma is produced, and the processes through which it becomes attached to bodies (and places), by whom, and for whose gain” (2)

1. Link, B., & Phelan, J. (2014). Stigma power. *Social Science and Medicine*, *103*, 24-32.
2. Tyler, I. (2023). Stigma: The Machinery of Inequality. Bloomsbury Publishing.

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Results

- Societal norms and structural stigma: “different world views” (Participant 22)
- Norm of “healthy regulated body”
- Contrasted with societal beliefs about BBV/STIs that are “tainted with moralism” (participant 21)
  - It comes down to basically a judgmentalised set of behaviours. That society somewhere on the line in its wisdom have decided that there are bad behaviours, and therefore [people who] engage in those behaviours are bad, and therefore not worthy in the same way. (Participant 12)

Results

- Societal norms rooted in the design, operation, delivery, and evaluation of health services
  - the health bureaucrat, or the policy writer, or the person that's writing the legislation or designing the clinical service. They come from a very moralistic perspective (Participant 21).
- Health services built on assumptions that do not match and work to keep out the people supposed to be assisted
- Extra work to access care for people who deviate from normative assumptions
  - “chisel away to find the door into a system” (Participant 2)

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Results

- Societal norms as stigma governance in hidden, taken for granted processes in health care: “hidden within the system, within the language” (Participant 23)

    - we are providing care for you, but somewhat reluctantly. Relationships and hidden assumptions that are in those environments which are about power and control, and who has influence is a is a really key issue … they’re influential in policy decisions and hidden biases and assumptions and judgmental attitudes that are seen in the division … and the allocation of resources (Participant 12)

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Results

- Clinic signs reveal taken for granted assumptions of legitimacy
  - One sign - “talk to us about HIV treatments. Come and talk to us about hep C treatment”
  - Another sign – a list of medications, all noted as medications for opioid dependence, that were not prescribed by the service.

  - [I]t's messaging to people about what's acceptable and what's not acceptable with regards to what drugs are acceptable and what treatments are acceptable and what aren’t. … What the rules, policies, and procedures do is affirm the norms. They say that those norms are okay. Those structures, those rules, policies and procedures give the permission, … for the stigma and discrimination, because it's also how they are interpreted. So, it's just at a systems level, it's affirming what they're doing, which is stigmatizing and discriminating (Participant 9).

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Results

- Disrupting stigma power in health systems
- Taken for granted processes are “normal” and align with social values – so not noticed as exclusionary and require disruption to bring to light, re-shape and maintain change in face of status quo/inertia

- Training – limited effect
  - So much of this is you’re trying to fix issues in isolation of broader social change, and it's very difficult to do (Participant 24)

- Complaints mechanisms and centring people with lived/living experience

Results

- Aus quality standards: complaints should inform improvements, BUT
- ineffective and harmful, onus on individuals already “unwell”, “exhausting” process, likely seen as “troublemaker” in service they rely on (Participant 23).
- “squeaky wheel” - cannot return to service, fear repercussions (Participant 19).
- dismissed with impunity using stereotype: “that’s just one person, and they were disaffected, probably drug seeking” (Participant 17)
- “protective mechanisms [within health systems] to stop [stigma] becoming visible” (Participant 1)
  - obfuscation within clinical jargon or organisational processes
  - “political” need for “health efficiencies”, focus on metrics (eg waiting times) - perceived “qualitative” issues of stigma erased by other agendas of governance (Participant 17).

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Results

- Centring people with lived/living experience in service delivery, program oversight roles
  - addressing “relationships and hidden assumptions about power and control” (Participant 12)

- Not straightforward or unproblematic: little power, governance upholds hierarchical structures, more legitimacy, credibility, and validity to workers other than peer workers.
  - Stereotypes disempower, reinforce differences and distance, draw on moralism/disgust re BBVs
  - where a peer challenges the norm it becomes a tension point … that credibility gap gets triggered where people think “well, that of course, you would think that, because you're a gay man who has gay sex, or you are an injecting drug user. Of course, you would think that” … this is kind of automatic side-lining of the views which gets back to that starting point about “do you think that drug use is OK? Do you think and feel OK about sex work? You feel absolutely neutral about gay men and the sex that they have?” (Participant 12)

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Results

- Governance roles: meaningful engagement with people with lived/living experience?
- Hidden processes that could work to maintain normative power relations
  - “We are one community voice … and then there's like five clinicians”, Participant 18
  - Difficult and stigmatising administrative processes
  - Not supported to effectively engage in governance systems for services that they have been systematically excluded from as consumers.

- How much training and professional coaching do [consumer representatives] get in the art of advocacy and in the art of policy making? And how well do they know the health systems at a broader sense? And can we better equip them with those skills? (Participant 12)

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Results

- Outside of the BBV sector - little opportunity or appetite for people affected by BBV to have peer roles in governance processes of mainstream health systems.
- Excluded from a voice in services that affect them by recruitment processes that avoid or block participation.

- Invitation sent by mistake:
  - I took the opportunity to go “this is so exciting. No one's ever come to us to look for somebody living with BBVs or a member of the drug using community to be part of this. How do we do it?” And they said, “Sorry wrong person” and shut down the conversation. (Participant 5)

Discussion

- Structural stigma – macro gaze
  - see past the clinical interaction, stigma between service user and provider
- Reciprocal and mutually productive relationships between societal beliefs and health systems
  - Produce health systems, infrastructure, practices, and attitudes
- Stigma power is sustained by societal norms
  - Challenges to the natural order dismissed using stereotypes of illegitimacy
  - Long process of struggle, multiple modes of action to disrupt status quo power relations
- Why do health care services continue to perpetuate stigma, when this is clearly inconsistent with imperatives to promote health and quality health care?
  - And how do we disrupt these power relations?

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Conclusion

- Quality standards – equity and access
  - Accreditation and funding – vital strategic lever
- Unlike other factors of stigma
- Have to be aware of porous boundary between health system and societal norms
- Norms feed “taken for granted” ways of doing things, fed by moral judgements (disgust)
  - Not visible without critical analysis and lived/living expertise

- Complaints – hostile and harmful
  - New collectives to take on the challenge of stigma
  - Community-controlled complaints mechanisms – individual support/redress and info collated in advocacy for structural reform

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Tackling Stigma

Overcoming Stigma as a Barrier to Healthcare - Nov 2024, UNSW Sydney

A new conference focused on stigma research & interventions

Where: UNSW Sydney campus
When: 21-22 November 2024