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Medical records and stigma production: Insights from a national research project to reduce stigma in healthcare

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<u>Key informants and health workers' understandings and perceptions of stigma and stigma reduction</u>

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A ‘universal’ approach to stigma reduction

Stage: Key informants and health workers’ understandings and perceptions of stigma and stigma reduction

- In-depth qualitative interviews with 30 clinical (15) and non-clinical health professionals (15)

Approach stigma as a problem is best reformed through ‘universal’ measures applied across all populations and healthcare settings:

1. Feasibility and acceptability of the terminology universal precautions in context of stigma;
2. Understandings of the impact of stigma within healthcare settings;
3. Priority areas for, and opportunities to, embed stigma interventions.

Background: Stigma in healthcare

- Encounters with stigma in healthcare settings are well-documented as are the profound negative consequences of stigma on health and social outcomes.
- Sociologist Erving Goffman defined stigma as ‘an attribute that is deeply discrediting’, as ‘any socially devalued characteristic or attribute serving to reduce an individual from a whole and usual person to a tainted, discounted one’. (1963: p. 3, 13)
- Shift towards understanding stigma not simply as an individual problem produced by negative attitudes and belief systems, but as a structural concern; embedded in and reproduced by institutional policies, frameworks, laws and regulations.

The accumulated activities of organizations and systems that deliberately or inadvertently create and maintain social inequalities (Knaak et al., 2020, p. 2).

- Emergent theme: The constitutive role of medical records in the production of stigma.

Electronic health management systems

- Healthcare systems are complex and constantly evolving.
- Medical institutions increasingly reliant on electronic health management systems, reconfiguring ways that complex institutions 'encompass multiple specialities, infrastructures, workflow and expertise with busy, resource-constrained organisations' (Gardner, 2022, p. 755) operate.
- They are a repository of sensitive and personal patient data, including retrospective, concurrent, and prospective information with the primary purpose of ensuring patient care and safety in the care continuum. (Barmecha and Last, 2023)
- Medical records have been the subject of sociological inquiry, examining them as technologies that govern bodies and the body politic (Foucault, 1963; Berg and Bowker, 1997); however can be overlooked because they are so commonplace. (Isah and Byström, 2020)

Stigma and medical records

- Stigma can be certainly transferred in the notes, it's the way that people write their notes and [...] because our big communication system is within the notes and we read someone else's notes and [...] if that person is a senior person and they're very smart, we go, 'Oh, that's very good. That's the way that we'll frame the way that we talk about things'. (John, clinical)
- You'd see those notes and you'd just be like 'I can't look at this person in another way now because I've been told that they're like this', and it takes away from the fact that people can change and people can evolve. (Kemi, clinical)
- The language they write in the notes, that they are 'a diabetic', they are 'a HIV patient', I guess, rather than they are 'a person with HIV' [...] Because, at an unconscious level, it seems to seep into peoples' brains, and then right after that, 'He's obese, but then diabetes, and he doesn't exercise', you know? You think about half the things behind these things, the stories. Why don't they exercise? Because basically they've had bilateral knee replacements and basically they're scared to go outside. (Alistair, clinical)

Relevance and medical records

- A lot of [consumers] say that with certain specialists, they say they don't want to disclose their HIV status and it's not relevant. So, we just don't disclose. (Tun, clinical)

- [My client] would really love it if it [his HIV medical records] could be sort of compartmentalised, so they could get what's relevant, and then he could sort of traverse through that health system with a minimum number of people knowing that he's HIV positive, and he's actually seen by the Director of the [infectious diseases] department, one of the very senior doctors, who looks after his HIV, and he's very, very happy with that person, feels very supported, listened to. I think from what he describes, that person really understands patient-centred care and has relatively quite a lot of power in the hospital system and the medical […] circles, but isn't really able to affect change either. (Sonny, non-clinical)

Alerts, flags and medical records

- Flags if someone's BMI is over a certain number, which that number is actually not that high. But it comes up like an alert like with an exclamation mark, and in red and all this sort of thing and you drop it down and it then has, you know, recommended weight and all this sort of thing […] It's encouraging anyone that doesn't have the training to interpret that sort of data to perhaps bring it up with someone when that's not what they are there for. (Anne-Marie, non-clinical)

- So, it'll be highlighted, 'HIV positive' or, you know, 'hep C positive, active infection', And so the residents [doctors in training] don't really […] pick them because they know that there's a risk of infection and there's an inherent stigma […] Then you automatically assume they're going to be aggressive or they're going to be dysregulated. So, there's already a preconceived sort of cognitive bias thing […] So, we don't want to take that patient. [The view is:] 'I could just see, like, a tummy ache or abdominal pain, which is easier'. (Ravi, clinical)

Summary

- Stigma re/production is a process that inheres in structures and institutional practices that can be difficult to identify, articulate, and therefore reform.
- Medical record production may benefit from critical reflection, evaluation, and oversight, especially with a view to considering whether the way information is gathered and recorded has stigmatising affordances.
- The affordances of any technology and its role in addressing stigma are not an innate design quality, but can be fragile, reliant on a network of practices for them to emerge.

- Add one thing about UP?