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Never Stand Still Arts & Social Sciences Centre for Social Research in Health

Assessing the knowledge, care and treatment of Aboriginal people living with hepatitis C in New South Wales: Information, stigma and resilience

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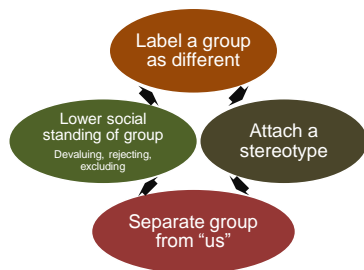
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Stigma

- Increases burden of illness/health condition
- Cause of health inequality
- Individual notions – beliefs and attitudes – obscures power and control
- Needs to be considered as a process of social power

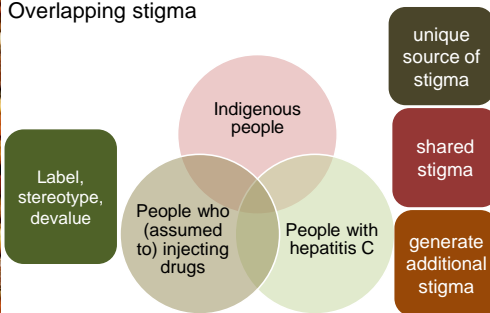
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Stigma processes



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Overlapping stigma



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This research

Question

- How HCV stigma differs by identity
- Understand how people live with HCV perceive and manage stigma
- Contribute to efforts to address stigma

Methods

- Interviews with 39 people completing surveys
- 15 women, 23 men, 1 transgender
- 11 had had HCV treatment, 1 just about to start

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Stigma central to experience of HCV

- Disclosure decisions
- Similar to research in other settings/populations

I was shattered, I felt dirty ... I still to this day haven't really, I haven't told any of my family, haven't told anyone you know ... I have just kept it to myself. (#24, 44, female, currently on treatment)


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Stigma central to experience of HCV

I used to have my own cupboard at my mother's house. She didn't talk about it but she always made sure she gave me the same coffee mug and stuff like that (Laughs uncomfortably). (#15, late 40s, female, completed treatment)

You are viewed like a grot, you know, like everyone thinks you're grotty, that's why I don't like telling anyone and that, you know, because then they get like the wrong idea, you know, like you said, the blood to blood contact but most people don't know that ... they keep their distance and that and that makes you real ashamed, you know? ... Well, I feel sort of ashamed about it but that's because of that stigma and that, that people put with it and that. Sort of, you don't wanna tell no one. Yeah. (#20, early 20s, male, not on treatment)


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Resistance to stigma

just don't have any stigma involved, um don't shame anyone for having an illness ... Not to be ashamed of it and don't ever let anyone make you feel worthless for having an illness. ... treat it with as much seriousness as you possibly can but don't let anyone ever shame or make you feel ashamed of having Hep C. (#37, 33, female, not on treatment)

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Overlapping stigma

- Racism entangled health workers' expectations

I think I would have to say that um, the automatic racist attitude that you know you'll come up against, you know, like, I expect you to have these things, you are black. Very negative things. (#14, late 50s, female, not on treatment)


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Overlapping stigma

The doctor came in while I was sitting there and was talking about treatments, that he couldn't give me that treatment because I am hep C you know, in front of them ... I have lost my family members ... [my family] looked at me like I don't mean anything to them. They walked straight out and they never came back. I feel isolated from them, like ... and it made me think suicidal thoughts because (very emotional, talking and crying) I have got no and I just feel like it was a life sentence, that, for me. ... I don't talk to no one about it. ... There are doctors and nurses at the clinic but I don't trust them after what that doctor done. ... It's probably because they were black and they were family, that's what he probably thought. But any other time he would have like shut everyone out. (#31, 33, male, not on treatment)

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Overlapping stigma

- Stigma and colonisation

It's just that when you find out you have got it they treat you like some type of leper. So you have got to always hide it, so if you go to the doctors and you get anything that says hep C on it, I always hide that and make sure it's in a safe part of me drawer, so anything to do with my hep C is in that safe. And just it's a shame, it brings shame on my family you know. Well that's what it feels like anyway. ... I just feel embarrassed and that I shouldn't have this, you know this disease wouldn't be here if these arseholes didn't invade our land in the first place. (#18, mid 30s, male, not on treatment)

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Stigma within ACCHS

- Only one comment

You know I watched this lady come in last week and I could tell that she was a drug user through experience, life experience and I could see, they were treating her really, really bad, like on to a point where it was like discrimination, you know what I mean – not that they were saying anything, but you know this is happening and what I find, what I think is a shame that the old people that are connected to the AMS have still got some of these mentalities like we don't want to help those people ... (#39, 30s, male, completed treatment)

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Discussion

Seen before

New finding

Additional layers

- Separated via cutlery
- (perceived) poorer treatment in health care
- Perceive themselves as "grot"
- Reveal shame

- Combination of stigmas
- Aboriginal people "expected" to have "disease of dirty and downtrodden"

- shame – even more complex
- within ACCHS?
- Note: others in this sample chose to attend ACCHS for hep C care

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Discussion

Strategies to avoid stigma

- Some pockets of resistance
- Limiting disclosure
 - Stigma power
 - Internalised pervasive cultural and social messages re HCV and Aboriginal people
- Responses to HCV stigma has to address social position of Aboriginal people

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Acknowledgements

Aboriginal people who trusted us

Many agencies who assisted

Advisory committee

Research assistance

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CSRH website

csrh.arts.unsw.edu.au/research/populations/indigenous-aboriginalians

Full report

Report to community

Other research with Indigenous people

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Journey to HCV treatment

Of the respondents who had ever received a referral to a specialist about HCV treatment, 53% had gone to see a specialist

Of the respondents who had not completed treatment, 56% said they intended to have treatment over the next 2 years

Of the total sample, 34 participants were either currently on HCV treatment or had previously been on HCV treatment

These results are similar to those found in other studies

For some participants, having HCV treatment was important so that they could be healthy to look after their family

"I have had this disease for about over 20 years now. My liver function is up and down sometimes it's good and sometimes it's bad and I just don't want to die young you know. I am only 42 years old and I don't want to die at 50 or something you know... Can I get a family now and I just don't want to die and leave them in the lurch you know... I just want to get rid of this disease that I have got because it is hanging over my head." (male, 42, completed HCV treatment)

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HCV diagnosis and perceived stigma

Participants spoke about the impact of diagnosis on their feelings. For some people, diagnosis was given with little other information. "I was a bit depressed at the beginning, not knowing the full extent of it. I didn't have all the information available to me, I didn't deal with it really good." (female, late 30s, not on HCV treatment)

55% agreed or strongly agreed

"I feel shame because of my HCV"

66% agreed or strongly agreed

"I AM VERY CAREFUL WHO I TELL THAT I HAVE HCV"

59% agreed or strongly agreed

"Most people believe I am dirty because I have HCV"

63% agreed or strongly agreed

"Some people act as though it's my fault that I have HCV"

64% agreed or strongly agreed

"I WORRY THAT PEOPLE MAY JUDGE ME WHEN THEY LEARN THAT I HAVE HCV"

Participants spoke about the impact of stigma on their lives

"I was shattered, I felt dirty... I still to this day haven't really... I haven't told any of my family, haven't told anyone you know... I have just kept it myself." (female, 44, currently on HCV treatment)

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HCV knowledge

Overall HCV knowledge was good, however there were some gaps.

Statement	Percentage of respondents who correctly answered
There is treatment for HCV (94%)	94%
There is a treatment which can cure HCV (89%)	89%
It is possible to get HCV from mosquito bites (87%)	87%
Using clean or being clean increases your risk of contracting from HCV (87%)	87%
Alcohol increases a person's risk of complications from HCV (81%)	81%
HCV does not always cause symptoms (55%)	55%
You cannot get HCV from kissing (49%)	49%
HCV can be passed on by sharing an insulin drip of infected blood (49%)	49%
People can get infected with HCV from tattoo and piercings (45%)	45%

Participants spoke about not knowing very much about hepatitis C before their diagnosis.

"I haven't seen anything or come across anyone that has been informed. In the whole 48 years of my life, nobody has come out and told anything. I thought that when I was in jail, as this is how we're kept, I thought that the top down that got when I was a kid that would have stopped me from getting anything. And it doesn't and I know that now." (male, 46, currently on HCV treatment)

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Culturally appropriate diagnosis

53% of the sample were either satisfied or very satisfied that their HCV diagnosis was given in a culturally sensitive and appropriate way.

Satisfaction with culturally appropriate diagnosis was associated with:

- Higher rates of pre and post test counseling
- Greater satisfaction with HCV care
- Decreased feelings of HCV related stigma
- Decreased feelings of racially based stigma and discrimination in health care
- Less perceived stigma associated with disclosure of HCV status
- Greater intention to have HCV treatment in the future

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Resilience

Resilience is a measure of how people feel they are coping with the hard times in life. Understanding resilience is important to understand living with HCV.

73% of people reported they **found it easier to bounce back after illness or hardships** as a result of disclosure to their partner.

72% of people reported they **think of myself as a stronger person** as a result of disclosure to their partner.

"But don't have any regrets involved, one don't blame anyone for having an illness. Not to be ashamed of it and don't even let anyone make you feel worthless for having an illness... need it with as much information as you possibly can but don't let anyone ever blame or make you feel ashamed of having the C." (female, 32, not on HCV treatment)

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Lifestyle changes

Since being diagnosed with HCV...

- 52% reported changing their diet
- 36% reported having more regular HCV check ups
- 66% reported reducing or cutting out alcohol
- 50% reported reducing or stopping illicit drug use
- 46% reported accessing information about HCV and HCV treatment
- 55% reported increasing their level of exercise

Most participants made some changes to their lifestyle to promote liver health, especially cutting down on alcohol.

"I always went on the fact that as long as I look after my liver I will be alright, so that was when I went off alcohol as anything to make sure my liver was strong... I sort of took the treatment on myself. I always had healthy vegetables, had a fairly good diet but yeah, I don't know I just sort of opened my eyes a little bit more, like I'm not ashamed." (female, 45, completed HCV treatment)

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