

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

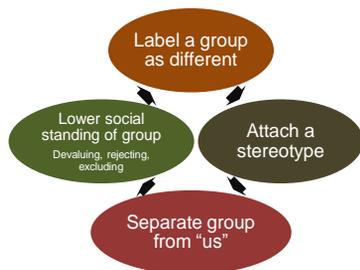
Assessing the knowledge, care and treatment of Aboriginal people living with hepatitis C in New South Wales: Information, stigma and resilience

Carla Treloar, Clair Jackson, Jamee Newland, Rebecca Gray, Hannah Wilson, Veronica Saunders, Priscilla Johnson, Loren Brenner

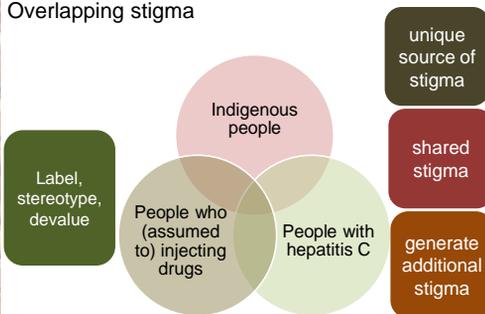
Stigma

- 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

Stigma processes



Overlapping stigma



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

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)

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)

7

UNSW

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)

8

UNSW

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)

9

UNSW

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)

10

UNSW

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)

11

UNSW

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)

12

UNSW

## 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

13

## 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

14

## Acknowledgements

Aboriginal people who trusted us

Many agencies who assisted

Advisory committee

Research assistance

NSW Health support for project

CSRH supported by grant from Aus Gov Dept Health

15

## CSRH website

[csrh.arts.unsw.edu.au/research/populations/indigenous-aboriginalians](http://csrh.arts.unsw.edu.au/research/populations/indigenous-aboriginalians)

Full report

Report to community

Other research with Indigenous people

c.treloar@unsw.edu.au

@carlatreloar

16

## Journey to HCV treatment

Of the respondents who had ever received a referral to a specialist about HCV treatment, 52% 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)

17

## 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)

18

