

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

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

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"Aboriginal Australian" is respectfully used to refer to Aboriginal and Torres Strait Islander people.



Background

- Few studies focused specifically on Aboriginal Australians living with HCV
- How HCV diagnosis is delivered may be critical for on-going engagement with health care.
- Especially given stigma associated with HCV

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Study aim

- To describe patterns of HCV care and treatment for Aboriginal people who have HCV.
- To assesses the impact of being informed of the HCV diagnosis in a culturally sensitive manner on engagement with health care and treatment.

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Methods: Sample

Recruitment postcards

- Culturally appropriate, no mention of HCV
- Widely distributed
- Free call number

Participant criteria:

- Identify as Aboriginal or Torres Strait Islander
- Over 18 years,
- Live in NSW
- Currently living with HCV, undertaking treatment or cleared the virus naturally or through treatment.

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Methods

- Ethics approval from AHMRC, UNSW Australia and various LHDs
- Aboriginal liaison officer assessed eligibility
- Survey over phone at convenient time
- Indicated interest in participating in follow-up interview
- Either Aboriginal or non-Aboriginal interviewer
- Confidential
- 30-40 min to complete

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Survey

Demographics

Experiences around testing and diagnosis

- When diagnosed, why tested, pre/post test counselling
- Satisfied that they were informed of diagnosis in a culturally appropriate way

Experiences of HCV treatment and care

- given information on HCV, main place attended for HCV and general health care, recent testing, referral to specialist, HCV treatment uptake, treatment intentions, satisfied with care

7

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Survey

HCV knowledge and lifestyle changes

- 16 knowledge items (natural history, transmission, testing, treatment)
- lifestyle changes since HCV diagnosis- (changed diet, reduced alcohol, increased exercise, more regular HCV check-ups, reduced illicit drug use, accessed information about HCV)

Stigma measures

- 9 items perceived stigma around HCV
- 9 items stigma related to HCV disclosure
- 12 item Group-Based Medical Mistrust Scale (eg "I feel that Aboriginal people are not treated the same as people of other groups by doctors and healthcare workers")
- 8 item Perceived HCV-related discrimination and exclusion in the healthcare sector ("they are careful no to touch me")

8

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Demographics – 203 participants

	n (%)
Gender	
Male	117 (57.6)
Female	84 (41.4)
Transgender	1 (0.5)
Cultural identity	
Aboriginal	195 (96.1)
Torres strait islander	0 (0.0)
Both Aboriginal and Torres Strait Islander	7 (3.4)
Age [M (SD)]	38.1 (9.6)
Education	
≤ Year 10	176 (86.6)
>Year 10	26 (12.7)
Employment	
Full/ part time	18 (8.8)
Centrelink/ government financial assistance	179 (88.2)
Other	6 (3.0)
Ever been in Prison	163 (80.3)

9

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Experiences around testing and diagnosis

	n (%)
Time since diagnosis [M (SD)]	9.8 (8.2)
1 year	38 (18.7)
2-4 years	33 (16.3)
5-10 years	48 (23.6)
10 years or more	82 (40.4)
Reasons for being tested for HCV	
A doctor or other health care worker suggested it	36 (17.7)
I asked for a test	82 (30.5)
Part of a routine screening (e.g. antenatal screening, entering the judicial system)	86 (42.4)
I learnt about the importance of having a hepatitis C test through a recent community awareness campaign (e.g. poster, radio advertisement, workshop, stall at a community event)	3 (1.5)
Other	16 (7.9)
Offered counselling	
Pre-test	60 (30.0)
Post-test	66 (32.5)
Satisfied that diagnosis was informed in a culturally sensitive/appropriate way	
Very dissatisfied	19 (9.4)
Dissatisfied	37 (18.2)
Neither satisfied or dissatisfied	37 (18.2)
Satisfied	88 (41.9)
Very satisfied	23 (11.3)

10

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Information on HCV (1 in 10 no info at all)

	n (%)
Ever given information about*	
Safer injecting practices	139 (68.5)
A healthy lifestyle (e.g. diet and exercise)	133 (65.5)
Treatments that are available for hepatitis C	129 (63.5)
Cutting down alcohol	125 (61.6)
How to access treatment for hepatitis C	109 (53.7)
Possible side effects of treatment for hepatitis C	105 (51.7)
A referral to a healthcare worker (e.g. Aboriginal health worker/counsellor/ liver nurse/ social worker/ Drug & Alcohol worker/ nurse)	63 (31.0)
Hepatitis community services (e.g. Hepatitis NSW, hepatitis C telephone counselling line)	56 (27.6)
Complementary/ alternative therapies including bush medicine and side effects of such therapies	20 (9.9)
No information	25 (12.3)

11

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Treatment uptake and intentions

	n (%)
Ever received a referral to a specialist about treatment for hepatitis C	84 (41.4)
Ever gone to see a specialist about hepatitis C (n=84)	46 (54.8)
Currently on hepatitis C treatment	6 (3.0)
Ever been on treatment (n=196)	28 (14.3)
Plan to go on treatment in the future (n=134)	
Within the next two years	99 (73.9)
Not for at least another two years	35 (26.1)

12

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Reasons for no treatment

Reasons against treatment* (n=168)	n (%)
Worried about side effects	52 (31.0)
Currently injecting drugs	31 (18.5)
Other health problems	26 (15.5)
Fear of being stigmatised/ judged about hepatitis C	25 (14.9)
Lack of support from health professionals	22 (13.1)
Lack of knowledge that treatment was available	22 (13.1)
Lack of information about HCV	21 (12.5)
Fear of disclosing my hepatitis C status to others	19 (11.3)
Lack of support from family and friends	17 (10.1)
Waiting list too long	16 (9.5)
Drinking alcohol too heavily	10 (6.0)
Too far or too difficult to travel to treatment	8 (4.8)
Fear of job loss	4 (2.4)
Other	85 (50.6)

13

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Knowledge

Overall knowledge good, mean score 11.41 out of 16 (SD = 2.53).

Nearly all participants knew that using new needles/syringes and other equipment reduces the risk of being infected (n=191, 94.1%).

Majority aware that alcohol increases a person's risk of complications (n=184, 90.6%).

But participants were less knowledgeable about what the different tests for HCV meant (e.g. a positive hepatitis C PCR test means you are infected with hepatitis C, n=84, 41.4%) and that treatment can cure HCV (n=140, 69.0%).

14

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Lifestyle changes

Majority reported making positive lifestyle changes since diagnosis

Less than 10% made no changes (n=16, 7.6%)

Average three positive lifestyle changes.

Biggest change reduction in alcohol - two thirds (n=134, 66%)

Half had changed their diet (n=106, 52%)

Half increased their level of exercise (108, 53%)

Half reduced or stopped their illicit drug use (101, 50%).

46% (n=94) accessed information about HCV

36% (n=73) had more regular check ups

15

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Stigma and Discrimination

Overall participants felt that they would experience discrimination as a result of being HCV positive

Mean score for the perceived HCV discrimination was 3.1 (SD=0.9, range 1-5).

Mean score for HCV disclosure 3.3 (SD=0.9, range 1-5).

Participants also reported experiences of stigma and discrimination related to their Aboriginality.

Mean score on the modified Group-Based Medical Mistrust Scale was 3.2 (SD=0.8, range 1-5).

But not much reported HCV discrimination/exclusion in the healthcare sector (mean = 0.5, SD = 0.7, range 0-4).

16

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The importance of how the diagnosis is delivered

Correlation analysis revealed that satisfaction with the cultural appropriateness of the diagnosis was associated with

- being offered both pre and post-test counselling
- satisfaction with HCV care,
- decreased feelings of HCV-related stigma,
- lower scores on the medical mistrust scale
- less perceived stigma associated with disclosure
- HCV treatment intentions (amongst the group who report that they intend to go into treatment)

17

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Qualitative data

They just gave me information to go off and read it myself. ... So no one actually talked, all they gave me was a kit to take home with me. ... well, I haven't really read it, no. I get more from you know, sitting down and speaking to someone, verbally and stuff like that. Yeah and you know I have got issues with my eyesight and whatever so. ... Yeah, so people, they need to take that into account as well ... a hep C nurse and the hep C nurse may need to explain stuff to him orally. And there are people with literacy problems. ... like just giving that information to me as a lay person and sending me to read it doesn't versus someone who knows it and works in it and knows the effect that it has on the body and the liver. (#7, mid 40s, male, not on treatment)

No, they just give me like a pamphlet kind of. ... they just told me I had it and that, basically told me to go. (#21, mid 20s, male, not on treatment)

I was a bit shocked you know 'cos they didn't give me a, "hey are you feeling alright," just "oh you've got hep C, here's your result, see you later", more or less, you know? (#22, late 30s, male, not on treatment)

18

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Discussion CSRH

- Pre/post-test counselling does not occur often enough – one third of participants offered pre/post-test counselling
- Counselling at HCV testing should be standard and offered to everyone - ideal time to give information.
- On-going care, difficult to achieve, attrition from specialist referral to uptake
- Strategies to promote uptake of specialist referrals may increase the numbers into HCV treatment


19



Discussion CSRH

- Substantial number report making healthy lifestyle changes following HCV diagnosis.
- Health-related changes NB in managing long term consequences of chronic liver disease
- Many Aboriginal people living with HCV may not want HCV treatment
- Changing their health behaviours may lead to better health and slow disease progression


20



Discussion CSRH

- Over half of participants felt that they had received their HCV diagnosis in a culturally appropriate way
- Experiences at diagnosis very NB - this is when person learns they have HCV
- The way the diagnosis is provided may determine whether people continue to engage in health care
- As noted, culturally appropriate diagnosis experiences associated with perceived less HCV specific and general health care discrimination and with greater satisfaction with HCV care


21



Discussion CSRH

- Those who feel more satisfied with the cultural appropriateness of their diagnosis more likely to take up HCV treatment in the next 2 years.
- Findings confirm previous research emphasizing the importance of the diagnosis
- Data suggests that the cultural appropriateness of the diagnosis is important in establishing patterns of better engagement with HCV care and treatment
- May play a significant role in positive health outcomes for Aboriginal people living with HCV.

22



Acknowledgements CSRH

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23



Follow-up interviews...

24

