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Experiences of diagnosis, care and treatment among Aboriginal people living with hepatitis C

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

Loren Brener, Hannah Wilson, Clair Jackson, Priscilla Johnson, Veronica Saunders and Carla Treloar.

Introduction

- Aboriginal Australians are disproportionately affected by HCV
- In 2008, it was estimated that the Aboriginal and Torres Strait Islander population (3% of Australia's population) represented around 8.3% of the total living with chronic HCV
- Over representation of Indigenous persons among high risk groups such as people who inject drugs and people in custodial settings.

Introduction

- Few studies have focused specifically on Aboriginal people living with HCV.
- How the HCV diagnosis is delivered may be critical in determining on-going engagement with HCV care.
- Particularly relevant for HCV which is highly stigmatised (injecting drug use)
- Barrier to health care access, treatment uptake and retention.
    - Stigma
    - Feelings of shame
    - Mistrust towards mainstream services
    - Fear of being ‘outed’ at Aboriginal service

Introduction

- There are a range of barriers to HCV care and treatment which often begin with poor experiences at diagnosis.
- Having a negative experience at diagnosis and being provided little information, has been found to deter people from seeking medical care

Research aims

- This study aimed to:
  - describe patterns of HCV care and treatment, and the experiences of living with a stigmatised illness among Aboriginal people who have HCV.
  - establish implications of delivering diagnosis in a culturally sensitive manner on experiences of living with HCV and on engagement with health care and treatment for HCV.

Research protocol

- A specialised team - Aboriginal Mentor and Aboriginal Liaison Officer
- Recruitment postcards–designed with culturally appropriate designs, without referring specifically to HCV - distributed at a range of NSW health service
- Post card had free call numbers. Participants contacted the Aboriginal Liaison Officer to receive further information about the study.
- Eligibility - identify as Aboriginal or Torres Strait Islander, 18+years, live in NSW, currently be living with HCV, undertaking treatment or cleared HCV.

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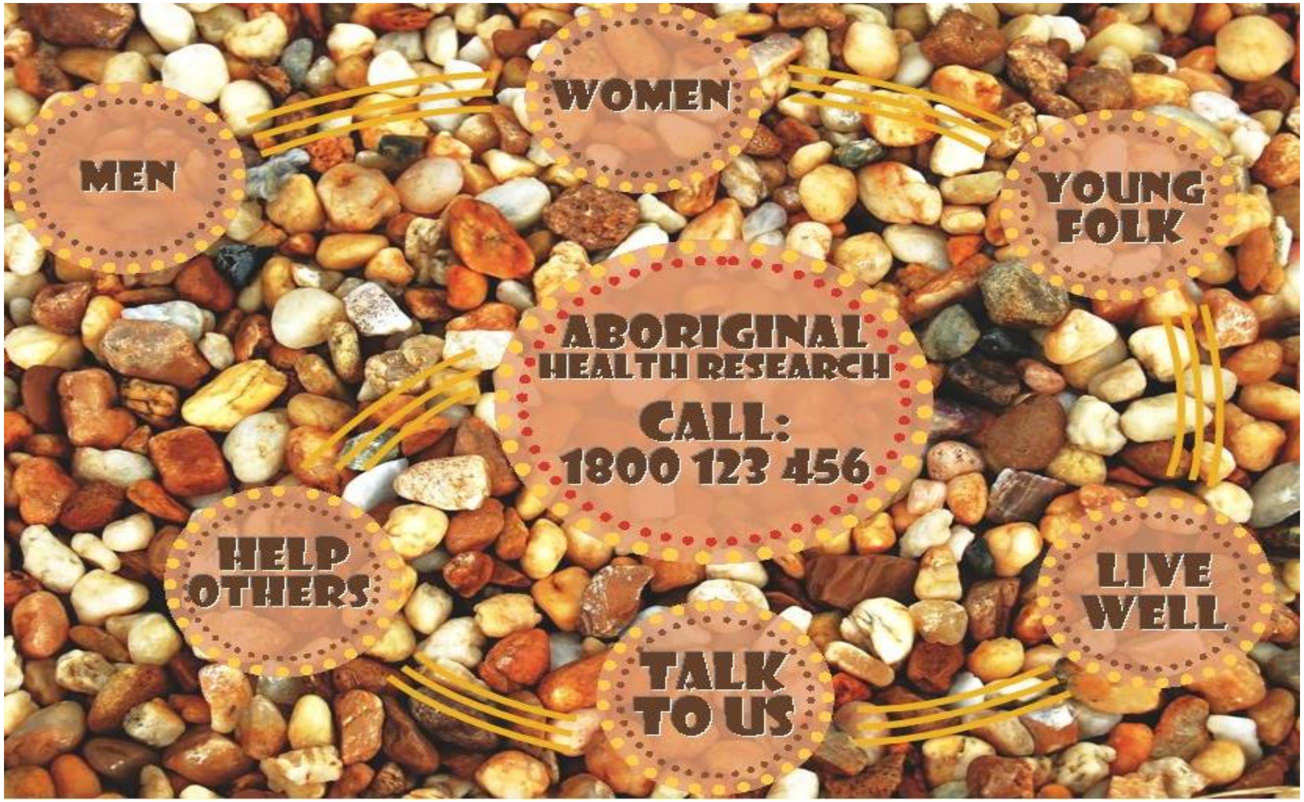

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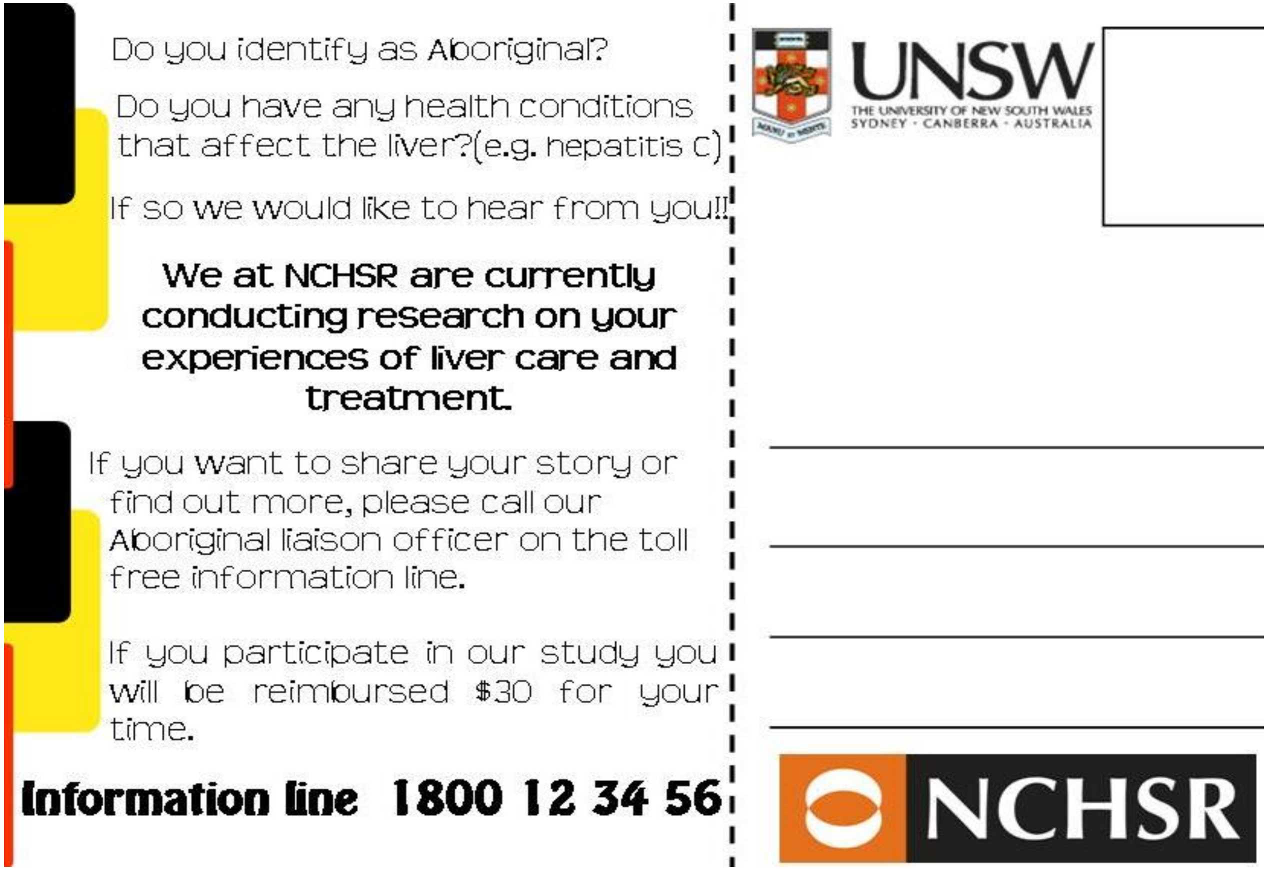

Do you identify as Aboriginal?

Do you have any health conditions that affect the liver?(e.g. hepatitis c)

If so we would like to hear from you!!

We at NCHSR are currently conducting research on your experiences of liver care and treatment.

If you want to share your story or find out more, please call our Aboriginal liaison officer on the toll free information line.

If you participate in our study you will be reimbursed $30 for your time.

Information line 1800 12 34 56

Data collection

- Called the free call number and spoke with the ALO
- survey confidential and option of Aboriginal or non-Aboriginal researcher.
- Over phone or face to face at some sites.
- Participants were reimbursed $30.
- Ethics approval - Aboriginal Health and Medical Research Council, The University of New South Wales and relevant health service authorities.

Measures

- *Experiences around testing and diagnosis (including how they were informed of their diagnosis – culturally appropriate)*
- *Experiences of HCV treatment and care*
- *HCV knowledge (16 items)*
- *Lifestyle changes as a result of HCV diagnosis (6 behavioural changes)*
- *Stigma Measures (HCV and racial stigma)*
- *Demographics*

Results

- 203 participants
- 58% (n=117) were male , 41% (n=85) were female, one transgender.
- Majority identified as Aboriginal (n=195, 96%), 7 identified as Aboriginal and Torres Strait Islander.
- Mean age was 28 years (SD=9.6).
- **80% (n=163) of the sample had ever been in prison.**

Table 1: Experiences around testing and diagnosis

	n (%)
Time since diagnosis [M (SD)]	
1 year	38 (19)
2-4 years	33 (16)
5-10 years	48 (24)
10 years or more	82 (40)
Reasons for being tested for HCV	
A doctor or other health care worker suggested it	36 (18)
I asked for a test	62 (31)
Part of a routine screening (e.g. antenatal screening, entering the judicial system)	86 (24)
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 (2)
Other	16 (8)
Offered counselling	
Pre-test	60 (30)
Post-test	66 (33)
Satisfied that diagnosis was informed in a culturally sensitive/appropriate way	
Very dissatisfied	19 (9)
Dissatisfied	37 (18)
Neither satisfied or dissatisfied	37 (18)
Satisfied	85 (42)
Very satisfied	23 (11)

Table 2: Experiences around HCV treatment and care

	n (%)
Ever given information about	
Safer injecting practices	139 (69)
A healthy lifestyle (e.g. diet and exercise)	133 (66)
Treatments that are available for hepatitis C	129 (64)
Cutting down alcohol	125 (62)
How to access treatment for hepatitis C	109 (54)
Possible side effects of treatment for hepatitis C	105 (52)
A referral to a healthcare worker (e.g. Aboriginal health worker/counsellor/ liver nurse/ social worker/ Drug & Alcohol worker/ nurse)	63 (31)
Hepatitis community services (e.g. Hepatitis NSW, hepatitis C telephone counselling line)	56 (28)
Complementary/ alternative therapies including bush medicine and side effects of such therapies	20 (10)
No information	25 (12)
Ever received a referral to a specialist about treatment for hepatitis C	84 (41)
Ever gone to see a specialist about hepatitis C *(n=84)*	46 (55)
Currently on hepatitis C treatment	6 (3)
Ever been on treatment *(n=196)*	28 (14)
Plan to go on treatment in the future *(n=134)*	
Within the next two years	99 (74)
Not for at least another two years	35 (26)

Results

- HCV knowledge was good, mean score of 11.4 out of a 16 (SD = 2.5).
- Majority reported making positive lifestyle changes since diagnosis, less than 10% stating that they had made no changes.
- On average 3 positive lifestyle changes. The biggest reported lifestyle change was a reduction in alcohol consumption (n=134, 66%).
- 52% had changed their diet, 53% increased their level of exercise and 50% reduced /stopped their illicit drug use.
- 46% reported accessing information about HCV and just over a third had more regular check-ups.

Results

- Participants perceived experiencing discrimination as a result of being HCV positive or disclosing their HCV status (mean score HCV discrimination scale 3.1 SD=0.9, range 1-5 and for the HCV disclosure scale it was 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 of 3.2, SD=0.8, range 1-5).

- Finally, participants did not perceive much HCV-related discrimination and exclusion in the healthcare sector (mean = 0.5, SD = 0.7, range 0-4).

Results

- A key focus - how the diagnosis was delivered to Aboriginal people living with HCV and whether this was done in a culturally appropriate way.

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

  - being offered both pre-test 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 of HCV status
  - Increased HCV treatment intentions

Conclusions

- Research contributes to the small literature focussing specifically on Aboriginal Australians living with HCV.

- Nearly all participants reported positive lifestyle changes and 34 participants reported either currently or ever been on treatment.

- participants were mostly satisfied with their HCV care, but did note stigma and discrimination related to both their HCV status and Aboriginality.

- Receiving a culturally appropriate HCV diagnosis was found to have positive implications on both experiences of living with HCV (e.g. decreased feelings of HCV-related stigma) and engagement with HCV care (e.g. greater intend to go into treatment).

Conclusions

- Despite perceiving that they would experience stigma in relation to having HCV, participants did not perceive much HCV-related discrimination and exclusion in the healthcare sector.

- This is encouraging and different from research finding stigma and discrimination around HCV to be most prevalent amongst health workers.

- But participants did report group based medical mistrust and they may perceive any health related stigma or discrimination to be aimed at their Aboriginality rather than to their HCV.

Conclusions

- A substantial number of participants report making healthy lifestyle changes following HCV diagnosis (not an indication of actual lifestyle change though)
- These health-related changes are important in managing the long term consequences of living with a chronic liver disease
- Finding is encouraging as many Aboriginal people living with HCV may not wish to or may not be ready to engage with HCV treatment
- Changing health behaviours to better manage HCV likely to slow the progression of the disease

Conclusions

- Delivering an HCV diagnosis in a culturally sensitive way shows cultural competence and respect

- Very NB in paving the way for positive health care experiences for Aboriginal people

- These findings confirm the importance of providing a HCV diagnosis in a culturally appropriate way for Aboriginal people.

    - Leads to greater engagement with HCV care and treatment
    - plays a role in ensuring positive health outcomes for Aboriginal people living with HCV.

Acknowledgements

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- Thanks to all the participants who gave of their time to participate in this research.