Prevention and treatment of hepatitis C virus infection among people from CALD backgrounds who inject drugs

Professor Lisa Maher
National Centre in HIV Epidemiology and Clinical Research
Culture, risk and hepatitis C

Background

- Prospective observational study in 3 sites in NSW, 1999-2002
- High rates of incident HCV infection (44/100 PYO) in South Western Sydney (Maher et al. 2006; 2007)
- CALD PWID a priority group in Hepatitis C Strategy but limited research involving CALD background PWID
- Lack of research exploring ethnic and cultural differences in vulnerability to HCV
HCV infection and CALD PWID

Background

- 215 HCV Ab negative PWID in SW Sydney
- 204 NIDUs (aged below 30 years or injecting for ≤6 years at baseline) identified
- Followed up and re-interviewed and tested at 3-6 monthly intervals, 80% retention
- Mean age 21.8 years, 37% female
- 41% CALDB, 30% language other than English at home
- HCV incidence = 45.8/100 PYO
HCV infection and CALD PWID

Background

- **Independent predictors HCV infection in NIDU**
  - Duration of injecting < 1 year (IRR=3.10; 95%CI 1.47-6.54)
  - IV cocaine use (IRR=2.37; 95%CI 1.26-4.44)
  - Female gender (IRR=2.0; 95%CI 1.16-3.45)
  - Culturally & linguistically diverse background (CALDB) (IRR=2.03; 95%CI 1.06-3.89)
HCV infection and CALD PWID

Background

- High HCV incidence in recent initiates (injecting < 1 year) in almost all subgroups (age, gender, recruitment strategy, frequency of injection and injection risk behaviours) but not Anglo-Australians
  - Anglo Australian (30 per 100 py; IRR 1.29)
  - CALDB (142 per 100 py; IRR 2.43)

Important distinctions between Anglo-Australian and CALDB NIDUs

- Strong associations between sharing syringes (AOR 2.24), other injecting equipment (AOR 2.60) and backloading (AOR 3.16) observed in CALDB but not in Anglo-Australian initiates
HCV infection and CALD PWID

Background

- Still the only data on HCV incidence in CALD PWID
- Extremely high rates of incident HCV infection in CALDB NIDUs associated with injecting risk behaviours
- CALDB NIDUs vulnerable but hard-to-reach subgroup with short interval to seroconversion
- Culturally appropriate prevention efforts designed to increase awareness, as well as access to sterile injecting equipment
Culture, risk and HCV

Data sources

• Ethnographic and qualitative research exploring cultural beliefs and behavioural practices of Indo-Chinese PWID and influences on risk and health-seeking behaviour

• Draws on work of 4 former PhD students: Adrian Dunlop, Hien Ho, Peter Higgs and Heidi Coupland
Culture, risk and HCV

Four main cultural characteristics influence vulnerability to BBVs:

- Trust and obligation
- Stoicism
- “Face”
- Beliefs in fate
Culture, risk and HCV
Trust and obligation

- SE Asian cultures traditionally characterised by strong sense of obligation to family and community
- In particular, ethnic Vietnamese PWID, especially those estranged from their families, extend these obligations to fictive kin, treating each other as “brothers” and “sisters”

*Because the majority of Vietnamese people here have no family, the majority have no brothers and sisters here, so we love each other a lot. We see each other like family.*
• Expectations of mutual trust between those in close relationships (fictive kinship, friendship and sexual partnerships) may encourage unsafe injecting

• Within such relationships, syringe sharing may be perceived not as risky, but as a way of communicating other meanings such as trust and reciprocity

_**I went to rubbish bins to find needles. There’s still blood in it. Better use needles from your friends. It makes you less worried. Using needles from nowhere make you feel more scary.**_
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Stoicism

- Need and desire to maintain self-control an important trait in many SE Asian cultures
- Rooted in Buddhist and Confucian philosophies where suffering, including pain & illness, viewed as part of life
- Seeking medical help for physical pain or preventive care may be delayed or considered inappropriate

My wife used to hit me – “Get up and go doctor”, she said, “You’ll get worse”, you know? But my wife, she’s Australia, they are different. When they got sick, they go straight to doctor. Me, I just wait. You know I always wait, you know, until it go serious. But my wife and children, Western people, they always go to doctor even for small sickness, cold and that they go to doctor straight away, and they complain. I am different, I don’t go.
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“Face”

- Many Indo-Chinese PWID seek to hide their drug use because they fear that they will lose “face”
- Collectivist cultural orientation means individual behaviour also reflects on family and community groups
- Fear of losing “face” frequently reported as a barrier to accessing sterile injecting equipment

*Our Vietnamese people here are different you know. Foreigners they do whatever and don’t care while Vietnamese when they do something, they’re afraid this and that. Friends and relatives will rumour if you do something, you will lose face.*
Many Asian cultures attribute undesirable events to fate.

Historically, fate provided a special form of rationalisation which helped to protect people from being overwhelmed by adversity.

Beliefs in fate also influenced by strong beliefs in karma which are deeply rooted in Buddhist teachings.

*I thought OK, let it go, whatever can come can come. If it’s my fate to get sickness, I will get it anyway.*

*Sometimes I think it’s fate, it’s determined by God. At that time I thought, “Let it go, I don’t give a fuck about life”. What will come will come because if my fate is getting it [HIV], I will get it.*
Pluralist approach to managing health problems

- Western biomedical approaches
- Traditional/cultural approaches (folk remedies)
Indo-Chinese PWID embraced pluralistic approaches to prevention, diagnosis and treatment, relying on co-existing layers of medical beliefs and utilising both traditional and Western beliefs, practices and technologies.

Traditional beliefs and practices also provided Indo-Chinese PWID with a way of articulating and asserting their ethnicity.

Acknowledgement of traditional belief systems and approaches and potential to complement biomedical approaches pre-requisite to engaging and responding to their needs.
Culture, risk and HCV

Self-managed care

**Strong preference for self, rather than provider-managed, health care:**

- Family/cultural networks
- Herbal preparations
- Coin rubbing, cupping, moxibustion
- Stoicism and “suffering”
- Self medication: OTC medications, “leftover” antibiotics
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Barriers to accessing health services

- Fear of “losing face”
- Concerns about confidentiality
- Culturally shaped expectations of Rx encounters
- Concerns regarding Western approaches to diagnosis and history-taking
- Long waiting times
- Financial barriers
- Language barriers

I shared needle but haven’t got an opportunity to go for test ... I don’t have money so I am afraid it costs money. I didn’t know if I have to pay or not so I didn’t go.
Limited awareness

Among those aware of Rx:

- Most were unclear about potential outcomes
- Not sure what was involved
- Concerned about side effects

Even lower awareness of HBV and HIV Rx
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Attitudes to drug Rx

- Preference for detoxification or short-term treatment/low doses vs maintenance treatment
- Reluctance to view addiction as a chronic, relapsing condition (Dunlop 2005)
- Counselling approaches not recognised as having much therapeutic value
- Reluctance to discuss family problems openly/express negative feelings
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Attitudes to OST

While integrating/co-locating HCV Rx and OST preferred model of service delivery, many Indo-Chinese PWID preferred to avoid long term OST:

Biomedical model of addiction/dependence not acceptable – preference for short-term treatment on low doses

Family pressure to quit “totally”

OST stigmatised as synonymous with dependence and weakness

OST viewed as a model for Anglos
Understanding and engaging with cultural beliefs and values first step in attempting to reduce risk behaviour and increase health service utilisation

Rather than seeking to ‘correct’ beliefs and challenge underlying EMs, HCWs should promote pluralist approaches that recognise both the strengths and limitations of specific approaches to particular applications – e.g. working with clients to identify appropriate and inappropriate examples of self-managed care
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Conclusions

- Although traditional health beliefs and practices have obvious benefits in terms of health promotion (e.g. encouraging people to live moderately), provide little guidance for the management and treatment of complex conditions like hepatitis C or B.

- HPs need to be aware of and acknowledge the existence of these beliefs and practices and their relationships to clients’ EMs in order to negotiate uptake and adherence to biomedical Rx where indicated.
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Conclusions

Cultural factors such as trust and obligation, beliefs in fate, and the role of families in health-related decision-making need to be considered.

Stigma and discrimination major barriers to this group accessing mainstream services.

Outreach programs provide an important point of first contact.

Stigma associated with injecting may affect not only the individual but also the status of the family.
Culture, risk and HCV
Conclusions

- Remove institutional barriers to services such as long waiting times and long waiting lists
- Provide services in a way that is sensitive to perceived stigma and discrimination and with regard to confidentiality
- Integrate BBV prevention and treatment programs with other programs such as employment and housing programs in order to reduce structural and environmental vulnerability
Risk, Resilience and Redemption

Heidi Coupland, PhD 2009

- Identify explanatory models of Indo-Chinese PWID in relation to HCV prevention and management
- Explore the influence of these models on HCV-related risk and health-seeking behaviour
- Document barriers to HCV treatment uptake experienced by this group
- Inform the development of culturally-appropriate public health strategies and services
Methods

Ethnography
Fieldwork
In-depth interviews
(n=72)

Bi about HCV treatment
In-depth interviews
(n=23)
Methods

- Trial of BI about HCV treatment (n=23)
  - Baseline interview and BI
  - Follow-up at 3 and 6 months

- Brief intervention: approx. 15 minutes
  - HCV treatment duration and outcomes
  - Eligibility of PWID following removal of liver biopsy
  - Facilitated referral to tertiary liver clinic
Methods

Eligibility criteria:

- Aged 16 years and over
- Cambodian, Lao or Vietnamese cultural background
- Injected drugs in last six months

Interviews conducted in English
Aged 17-50 yrs (most 21-35 yrs); 81 % male
Cambodian (19%)/ Lao (24%)/ Viet (57%)
86% born outside Aust, 80% arriving <12 yrs
74% language other than English at home
90% unemployed;
77% <10 years education
Heroin main drug injected
Mean age first injection: 19 years
33% in OST
61% self-report HCV Ab+
Decision-making about HCV treatment

- HCV a chronic “disease” that can be managed but not cured; inevitable degeneration and premature death

- “Good health” (from participants’ perspective) could get rid of HCV, particularly in “early” stages

- Most had heard of treatment but unsure or did not believe it could “get rid of” HCV permanently

- Limited awareness of what treatment involved (medication and duration) or how to access it

- Need to “quit” first
Decision-making about treatment

- **Strong desire to “get rid of” HCV:**
  - Stigma: corporeal marker of injection drug use, contagion
  - Incapacity, ability to support extended family
  - A barrier to social acceptability/ opportunity for marriage and children
  - Seeking redemption

- Prefer to wait till after cessation of injecting
  - Cleansing body
  - Risk of reinfection/inevitable

- Very reluctant to disclose HCV to partners, friends and family
### Summary of Outcomes (n=23)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>Made appointment</td>
<td>6 (26%)</td>
</tr>
<tr>
<td>Arrived at clinic for appointment</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Completed nurse assessment</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Seen by specialist</td>
<td>0</td>
</tr>
<tr>
<td>Missed appointment</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Unable to make appointment first attempt</td>
<td>4 (17%)</td>
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Hepatitis C treatment

Seeking treatment potentially highly significant for some Indo-Chinese PWID

Some highly motivated to seek treatment, particularly as part of broader process of making life changes and moving away from injecting drug use

Some had heard about severe side effects and were very concerned about how drug use would exacerbate side effects
Hepatitis C treatment

- Limited engagement (or none) with liver clinic staff regarding their drug use or reality of their personal circumstances (access to support/accommodation)

- Concerns about side effects of medication, interactions with other illicit and licit drugs (including methadone and buprenorphine)

- Heightened concerns about their capacity to complete treatment, predict their personal circumstances 12 months in advance
Hepatitis C treatment

- Strategies for managing drug-related issues focused on detoxification and cessation rather than drug treatment during HCV treatment

- But preference to avoid OST and prophylactic use of anti-depressants during treatment among many Indo-Chinese PWID

- Concerns about HCV treatment raised with others outside liver clinic (researcher, case manager)
Conclusions

- GPs identified as a common first point of contact with health system and for HCV screening

- GP not identified as “drug services” - more discrete, in local areas, minimal waiting times, choice of CALD background providers

- Indo-Chinese PWID expressed strong preference to see a GP who was not part of their cultural community - confidentiality concerns

- However few GPs “know about drugs” or HCV and some not aware HCV treatment exists

- Building GPs’ capacity to become more involved in HCV prevention and treatment, particularly GPs from CALD backgrounds
Conclusions

- Developing peer and outreach approaches to assist in:
  - Mobilising PWID regarding harm reduction
  - Building trust
  - Providing information about HCV treatment
  - Acting as a conduit/bridge to the health system
Conclusions

- Important to address cultural diversity in Australia’s policy response to HCV epidemic among PWID

- Culturally-competent responses to HCV prevention and treatment among PWID needs to focus on:
  - Developing integrated health service systems, to establish pathways into HCV testing and treatment from community settings, to reach Indo-Chinese PWID
  - Providing culturally-appropriate forms of support-address mistrust, respond to stigma

- Cultural competence won’t have an impact if the service is not being accessed!
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