Role of AOD Workers in Facilitating Access to Hepatitis C Care

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Overview

• Hepatitis C Awareness Project- HAP
• Consultations
  o Surveys
  o Interviews
• Recommendations
Hepatitis C Awareness Project - HAP

Raise awareness and understanding of hepatitis C:

- Testing
- Diagnosis
- Liver health and monitoring
- Treatment

HAP Consultations

Surveys

Feb and March 2016

Total = 35

Multiple choice, one page self-administered surveys

Completed in NSW, ACT, WA and QLD
Survey Results Summary

Q 1. “Do you have hepatitis C”?
Total = 25 (10 surveys didn’t include this question)
“Yes” = 22
“No” = 2
“Don’t know’ = 1

Q 2. “What motivated you to get tested”?
Total = 35
Total responses = 42
“Worried about health or feeling sick” = 14
“A health care worker suggested I get tested” = 11
“Shared needles or have needle stick injury” = 9

Survey Results Summary

Q 3: “Do you get regular Hep C check-ups”?
Total = 35
“Yes” = 20
“No” = 14
“Don’t Know” = 1

Q 4: “What motivated you to get follow up tests to monitor your liver health”?
Total = 35 (no response by some and multiple responses by others)
“A health care worker suggested I get follow up tests” = 15
“I was worried about my health or was feeling sick” = 11
“Other reasons” = 6
“Family or friend said I should” = 3
Survey Results Summary

Question 5: “Are you currently on treatment or thinking about Hep C treatment”?
Total = 35
“On treatment” = 2
“Thinking about treatment” = 19
“Not thinking about treatment” = 14

Question 6: “Were there any barrier or difficulties to getting tested, getting follow-up test or getting treatment”?
Total = 34 (no response by some and multiple responses by others)
“Other reason” = 10 “treatment regime too hard until new DAA’s” “transport” and “side effects”.
“Blood tests are difficult for me” = 7
“Don’t feel sick” = 6
“Staff at clinic not friendly” = 3
“Hospital or clinic too far away” “Wasn’t a priority for me” “Waiting time too long” and “Health care worker didn’t mention the need for further tests” = 2 each

Survey Results Summary

Question 7: “What are your main sources of information about Hep C testing, monitoring and treatment”?
Total = 58 (multiple answers provided)

“Health care workers” = 20
“Peers” = 9
“Pamphlets and magazines” = 8
“The internet” = 7
Survey Results Summary

Question 8: “If there was just ONE reason why you would start Hep C treatment, what would it be”?

Health
“To avoid damage”
“Getting older and concerned about increasing health impacts”
“I’d like to feel better”
“If sick or getting sicker”
“Prevent long term complication, cancer, transplant, disability, death”
“To be 100% healthy, have my life back, not be held back by my past”

Family
“To save my life and be there for my 3 children”
“To get healthy for my kids”
“To live long enough to see my son live a full life himself”
“For living longer and happier for my family”

Survey Results Summary

Question 9: “Any further comments? or Suggestions on help to improve access to information, support, health services”? 
More services
More Dr’s talking to patients
Discrimination laws don’t extend to us drug users so don’t trust treatment outlets
Stop discrimination
GP’s need more training
A more understanding treatment of users instead of being looked at as criminals
More advertising and promotion of available or soon to be available treatments
Put brochures in more places
More places to get free fits to minimise the use of using dirties or used fits
Get the doctors to stop being Smarty *#*#* and not be so *#*#*#*
Interviews

Nov and Dec 2015
Total = 77
Face to face interviews taking approx. 15 to 20 minutes
Conducted in ACT, WA, QLD
$10 payment for interviews

Interview Results Summary

Knowledge of Hep C tests
The majority of participants had been tested for Hep C
Very few knew what type of test – whether antibody or PCR
Interviews included prompts - antibody or PCR tests
Around half said yes
Very few could provide explanation

Motivators for testing
A family member or friend had urged them to be tested
and/or
For the sake of family “Want to be around to see kids grow up.”

Money
Interview Results Summary

**Barriers to testing and treatment**
- Poor experiences with health care professionals
- Difficulty with blood test
- Hep C not a priority

**Making testing easier to access**
Many of the people interviewed in the ACT commented that they would do more to follow up on their Hep C “if it was made quick and easy like today”

**Format of Hep C resources**
- Approx 50-50 split
- On the internet – Not just the internet
- Hard copy resources in reception areas -read while waiting for appointments

Where do you get your Hep C information?
- Drug user organisation most common response
- From the service where the interviews were being conducted
- Peer services/NSP
- DUO magazines and brochures
- Informal chats with staff at AOD (NSP and OST) services including DUO, and
- Formal peer education sessions rated as extremely useful and informative
- Peers

- Very few from their GP
- Did not understand or did not retain the information
- Didn’t trust the information
- Felt GP didn’t have very good knowledge of Hep C
- GP seemed disinterested
- Contradicted their current knowledge of Hep C
Strategies to challenge stigma and discrimination and reduce barriers

- Being polite, non patronising and non judgemental
- Having a balance between professional and personal beliefs
- Being respectful of people regardless of their choices
- Language
- Appearances
- Building relationships
- Creating a PWID friendly environment
- Building capacity for self-management and self-care
- Compassion – understanding the pain needs of PWID

Strategies to challenge stigma and discrimination and reduce barriers

- Confidentiality and privacy – as individual worker and organisational policies that protect confidentiality and privacy
- Speaking out
- Policy development which is consistent with human rights principles
- Revision of standard forms and questionnaires
- Providing outlets for feedback
- Supporting PWID to make complaints
- Eliminating punitive approaches – most relevant for OTS services
- Ongoing training and education
HAP Consultation Recommendations

- Information = increased level of engagement and empowerment
- Proactive with Hep C information
- Providing written, take home information
- Testing with knowledge and informed consent
- Providing test results in a supportive, non-judgmental manner

HAP Consultation Recommendations

- Acknowledge place of family and/or peers
- Consider options around offering incentives
- Easier access
- Building relationships
HAP Consultation Recommendations

• Blood test easier
• Taking extra blood
• Allowing people to take their own blood
• Engaging with DUO
• Peer support workers

Ways Forward

Include Hep C as part of core business

Ensure that all PWID have access to information that can empower them to make their own informed decisions about their health

Building relationships with consumers, developing trust, respect and understanding

Ensure ease of access to new Hep C treatment

Partnership building

Continued support for prevention initiatives
Thanks

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