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Project Title:

Understanding how the experience of living with Hepatitis C impacts on accessing hepatitis C treatment for people who are clients of a rural opiate treatment unit.

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Abbreviations

D&A – Drug and Alcohol

GP - General Practitioner (doctor)

HCV – Hepatitis C Virus

IVDUs - Intravenous drug users.

IPA – Interpretative Phenomenological Analysis

OST – Opiate Substitution Treatment

OTU – Opiate Treatment Unit

TTM- TransTheoretical Model

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Abstract

Background: Of the 21,000 people who live with chronic HCV infection in Australia and also receive Opiate Substitution Treatment (OST), only 5% have actually commenced hepatitis C treatment ⁽¹⁾. This compelling statistic highlights the need to find ways to engage OST clients into HCV treatments and prevent a strain on the health care budget in the future. This study aims to understand how the experience of living with hepatitis C impacts on accessing HCV treatment for people who are clients of a rural opiate treatment unit.

Methods: Drawing from a phenomenological approach, information was gathered through five, face to face, semi structured interviews of clients attending the rural opiate treatment unit. Interpretative Phenomenology analysis was used to provide three super ordinate themes to explain why people do not seek treatment.

Results: The three super ordinate themes identified were; Worry, shame and embarrassment, Feeling Supported or unsupported and Identity change. Participants expressed negative feelings about being HCV positive and over time for some, led to a movement towards contemplating treatment. At times this seemed more like a see-sawing effect towards or away from treatment depending on their level of worry, shame or embarrassment, if they were being supported and what information they were receiving at the time. When changes occurred within their identity, the path to the new self was realised and behaviour change followed. The Trans Theoretical Model (TTM)⁽²⁾ was used to highlight where people fit on the continuum of change which showed the move towards or away from treatment.

Conclusions: Participants were at various points along their hepatitis C journey, depending on how much change had occurred within their identity. These findings reflect how people encounter various amounts of shame, stigma and discrimination from the community and health care setting and how that directly impacts on how they access care. It showed that the effects of a hepatitis C diagnosis spans across the person's life. All participants except one explained the lived experience of having hepatitis C in this rural area as a negative one.

Implications for Practice: Recommendations to increase education and support for General Practitioners (GPs) and health care workers in this rural area to reduce stigma and discrimination surrounding a HCV diagnosis and increase access to care. To build stronger networks with Allied health and the OTU in an attempt to deal with the social aspects and needs of the clients in view to readying them for treatment.

Key phrases; hepatitis c, opiate treatment unit, rural, hepatitis C treatment.

Executive Summary

Implications: The study results provide insight into how people with hepatitis C are currently experiencing care in this local area health service. While people experience worry, shame and embarrassment around their diagnosis, it is vital that health workers are aware of their interactions with this client group and help provide quality nonjudgmental care.

Recommendations: Increase in Health worker education by providing regular in services from the hepatitis C nurse and gastroenterologist to all health workers on the local campus. This will provide a greater understanding of hepatitis C; its transmission, natural history and treatment available and also address discrimination and stigma surrounding this diagnosis. With this information health care workers will be able to provide opportunistic interventions such as testing, counselling and basic treatment information, as well as offering timely referrals to the liver clinic.

Priority areas would be emergency department and pathology, but all wards of the hospital and community health areas would benefit from education. A follow up quiz post in service could evaluate the learning that took place and show if the frequency of in services needs to be increased or decreased.

Increase in GP education by providing yearly updates / dinner meetings to increase awareness around hepatitis C and its treatments. This would help improve GPs preparing clients for treatment and offering chronic care plans to help start addressing the complex needs of this group

Network with Medicare Local, Hepatitis NSW and ASHM to assist with GP education and utilize the hepatitis nurse and gastroenterologist for case presentations from the current liver clinic.

A post meeting evaluation form could be utilized to address if learning needs were met and if any further information was sought or if frequency of the meetings were needed at the GPs request.

Improve OTU and Hepatitis C Clinic collaboration by providing intermittent in services to the OTU workers by the hepatitis nurse to improve knowledge around hepatitis C, effects of diagnosis, treatment and its side effects. Discuss whether this could be seen as part of their role during case management to introduce discussions around hepatitis. Continue to offer opportunistic testing and early referral to the liver clinic.

This collaboration will help address the needs of the clients, expedite referral pathways and take a more holistic approach towards the clients care. Since high prevalence rates are reported in the OTU, greater engagement with the clients may increase rates of treatment within this group.



Context: statistics show that there is a high proportion of clients in OST who have hepatitis C, although less than 5% are being treated for hepatitis C⁽¹⁾. Current treatments have a cure rate of between 50-80%⁽³⁾ and recent economic studies⁽⁴⁾ into the cost of liver disease show the advantages of treating hepatitis C before it becomes a chronic, end stage disease. This study tells of three reasons why people have not sought treatment, and can help raise awareness around how we can change practices to effectively engage this group.

Approach: This qualitative study drew from an Interpretative Phenomenology Analysis perspective (IPA). This strives to understand the nature of human beings and the meanings they impart upon the world by examining language in its cultural context, the way language is given meaning and interpreted⁽⁵⁾. Data was collected using semi structured interviews with five clients from the rural OTU. Three super ordinate themes were found to explain why people did not seek treatment for hepatitis C in this rural area.

Findings: This report shows that being hepatitis C positive is a lifelong experience, having an effect on relationships, family and being treated differently in the community and in the healthcare setting. It pervades their everyday life. Participants reported being worried about side effects but also about what might happen if they do not have treatment, continuing that see-sawing effect between action and inaction. Participants have given an insiders view of what it is like to have hepatitis C and the three themes found here show things such as worry, shame and embarrassment, support and identity change all impact on their experience of having hepatitis C and may determine if they move towards treatment or not. These experiences may not be unique to rural OST clients therefore being aware of the huge impact a HCV diagnosis has on peoples lives and even years later will give a greater awareness of this client group across all areas.

These results are significant as it shows how a HCV diagnosis changes their lives, their relationships and ultimately their health outcomes. As health care providers, contributing in a positive way can make significant changes to how people are currently experiencing health care in this rural area, knowing that every interaction affects their access to health care.

Introduction:

It is estimated that there are 150 million chronic cases of hepatitis C worldwide, and more than 350 000 people die from hepatitis C related liver diseases each year⁽⁶⁾. In Australia 270 000 people are infected with the hepatitis C virus (HCV), with 10 000 new cases occurring every year⁽³⁾.

Recently the economic impact of hepatitis C in Australia has been studied and shows that for every one dollar spent on treating hepatitis C another four dollars more were spent to combat the consequences of a failure to prevent, treat and cure it⁽⁴⁾. The number of advanced liver disease cases is expected to double over the next 20 years unless hepatitis C treatment uptake is increased⁽³⁾.

Current hepatitis C treatments have a cure rate of between 50 and 80%, therefore increasing the number of people receiving early treatment will markedly reduce the burden of liver disease on the health care system⁽³⁾.

Over 46,000 people currently receive Opiate Substitution Treatment (OST) Australia-wide and it is estimated that of these, 21,000 live with chronic HCV infection, yet less than 5% have commenced treatment⁽¹⁾. This compelling evidence shows the need to find ways to engage OST clients into HCV treatments and prevent an increased burden on the health care budget in the future.

In 2011 a new hepatitis service known as the Liver Clinic, commenced in the Western NSW LHD. This service is located in the Specialist Clinic at a Base Hospital and has had a slow uptake of treatment to date of OST clients.

The aim of this study is to understand the experience of living with hepatitis C in a rural area and its effects on accessing treatment. This information will be used to guide recommendations in providing more appropriate service provision for these clients.

Literature search

Using the Clinical Information Access Portal, databases were searched for articles with key terms relating to hepatitis C, methadone clients and experiences of living with hepatitis C. This yielded over 50 articles worldwide. Peer reviewed journal articles were then restricted to the year 2000 onwards and were further limited to Australian and New Zealand articles to gain a local picture of hepatitis C. Grey literature was reviewed such as health policies, economic reports and poster presentations to add to the diversity of information.

Literature review

As the imperative to treat HCV is being recognised, the literature and study of HCV and intravenous drug users (IVDU) has expanded rapidly over the last decade. Previous research has been conducted related to; prevalence amongst the IVDU community, trialling integration of services to drug and



alcohol centres, predictors of deferral after clinical assessments, and knowledge and interest in treatments ^(1, 7-11), unfortunately the rural community has been under represented in these studies, with the vast majority of studies focussing on metropolitan areas. This review shows that there is an obvious gap in research pertaining to the experience of hepatitis C in rural areas in Australia.

Significant changes in the treatment of HCV over the years have led to the identification of varying reasons for not seeking treatment. Due to the low efficacy of past treatment and high rates of side effects it has taken some time to change people's perceived knowledge of hepatitis C treatment ⁽³⁾.

The literature recognises a wide variety of topics related to hepatitis C and reasons for not having treatment; this review will focus on three major themes which emerge repeatedly throughout the literature.

Opiate treatment clients and hepatitis C treatment

Various studies have been undertaken to establish OST clients knowledge and attitudes towards HCV treatment ^(8, 10-12). High prevalence rates are often reported in OST, up to 75% of people having HCV ⁽⁸⁾, although many are not suitable for treatment with contraindications in 56% of the clients. These namely being severe psychiatric illness, medical illness, heavy alcohol use and psychosocial instability ⁽⁶⁾. This leaves a small number of clients potentially being referred for treatment. This data exemplifies how complex this client group is and that a number of factors need to be taken into consideration prior to commencing treatment for hepatitis C, not just liver disease severity but psychosocial issues.

Due to the restrictions of the Pharmaceutical S100 criteria, many OST clients have not been suitable for treatment as discussed above, leaving many clients on the repetitive cycle of monitoring and no treatment. This leads to people making multiple attempts at seeking access to treatment but being denied for the above reasons ⁽¹¹⁾. Participants who were referred for treatment but declined cited reasons such as; being worried about adverse side effects, not feeling sick enough, having other health priorities and not wanting to undergo a liver biopsy. Almost all participants gave more than one reason for declining treatment ⁽¹¹⁾, indicating that the relationship between suitability for treatment and client enthusiasm for treatment is a complex one.

Commonly OST clients cite a lack of physical symptoms of liver disease and a perception that hepatitis C was controlled or not serious, as to deferring treatment ⁽¹³⁾. There is also a lack of consistency in the monitoring of HCV and clients knew very little about interpreting their results. It is often felt that they could not differentiate the symptoms of hepatitis C from their drug and alcohol related behaviours complicating matters further ⁽¹³⁾. Level of risks associated with liver failure and liver cancer were generally overestimated by the participants ⁽¹³⁾. Consideration of treatment in a number of scenarios was high, yet relatively few IVDUs in Australia have received treatment as earlier stated with only 5% of people receiving Opiate substitution also having HCV treatment ⁽¹⁾. Other than clinical issues, personal barriers and organisational



structures also impinge on the OST client's decision making process to seek treatment.

Personal barriers are recognised in playing a role in deferring treatment, where family responsibilities, unstable housing, co morbidities and perceptions of unsatisfactory level of treatment efficacy are listed as issues⁽¹³⁾. Concerns around confidentiality have been named as organisational barriers with the OTU setting along with; lack of discussion about HCV treatment, or what was perceived as a normal activity for OST workers⁽¹⁰⁾. Treloar et al⁽¹³⁾ showed that drug and alcohol (D&A) workers felt some obligation or “duty of care” to discuss hepatitis C, but some felt it was a “non-core business” for the OST workers. This also existed for the clients who were interested versus indifference to HCV treatment⁽¹³⁾. This illustrates that there is not a universal answer to increasing uptake of treatment with OST clients but a myriad of ways that may potentially affect how people go about seeking care.

Impact of HCV on quality of life

Literature describing the psychological and social impacts of HCV, agree that hepatitis C has a pervasive impact on people's quality of life with a universal experience of fear and anxiety about stigma and discrimination^(14, 15). Data suggests that symptoms and psychological consequences such as fatigue, nausea and vomiting, headaches and short term memory loss are commonly reported, which at times disrupts their normal routine in life⁽¹²⁾. Stigma, disclosure and concerns about transmission have also been reported to highlight that the wider populations' perception of hepatitis C has a large impact on peoples' lives⁽¹²⁾. At times there is an overwhelming burden for people also trying to protect others from accidentally being infected by them, leading to the need to disclose to protect others⁽¹²⁾.

A 2008 study⁽⁷⁾ showed that family support led to a favourable impact on health related quality of life scores, and although this study compares D+A and HCV Clients, both groups fall below the Australian norm⁽⁷⁾.

With the above importance of family noted, further investigation into the experience of hepatitis C treatment and how it impacted on the patient's relationships has been undertaken⁽¹⁵⁾. Results showed that support from partners was evidenced by listening, comforting and encouraging while on treatment, and also adapting the home, shortening work hours and trying to keep daily life as normal as possible. There was an obvious increased burden on the partner when the family member underwent hepatitis C treatment⁽¹⁵⁾.

Psychological implications, disclosing and the medical encounter

Hepatitis C is an illness that attracts a large amount of stigma and discrimination because of its association with injecting drug use, which is also perceived as deviant and immoral⁽¹⁶⁾. Research suggests that health care workers may have a major impact on receipt of care and may act as an impediment to disclosure, testing, and treatment^(16, 17).

Initial diagnosis, follow up care and attempts at seeking treatment from health care professionals can be an arduous process. Harris⁽¹⁷⁾ highlights the



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“*narratives of unconcern*”^{(17)(pp1028)} which sheds some light onto how people make sense of their HCV diagnosis. This social study highlighted two main pathways after diagnosis. Clients who were diagnosed with HCV either became distressed, ceased IVDU and took on a healthy lifestyle or conversely clients who were positive and thought it was “no big deal” continued IVDU, thought it was acute and would disappear. Harris⁽¹⁷⁾ also identified that there was little knowledge about HCV in the 1980-90s which may have validated the GPs lack of concern for hepatitis C positive people⁽¹⁵⁾.

With negative reports of peoples’ experiences at diagnosis, it is interesting to note that pre and post-test counselling for hepatitis C did not become a mandatory task until 2005. The National Hepatitis Testing Policy⁽¹⁸⁾ dictates that pre and post-test counselling form an integral part of hepatitis C testing, which aims to minimise the personal impact of diagnosis, to change health-related behaviour and to reduce anxiety of the person being tested⁽¹⁹⁾.

Regardless of the guidelines, there is little evidence to suggest recent improvements in quality of care especially during diagnosis and follow up care for clients with HCV.

A minority of infected Australians have participated in antiviral treatment for their HCV, thus the majority of those infected with HCV are managing their health care needs in a non-specialist setting⁽²⁰⁾. Treatment uptake in GP surgeries is a new initiative to try to address the burden of liver disease with a push to enrol GP S100 prescribers to initiate or co-manage HCV clients. The difficulty of this process is highlighted by Tremper⁽²¹⁾ who investigated enablers and barriers to getting GPs to become hepatitis C prescribers which identified more support from specialists, difficulty with sharing information in a timely, secure manner, minimal incentives provided to GPs for extra provision of services to name a few⁽²¹⁾.

Harris⁽²²⁾ highlights that the biomedical model is flawed and believes the social context of the person must be addressed to improve the care given to HCV clients⁽²²⁾. Some models of care such as Enhancing Treatment of Hepatitis C in Opiate Substitution settings (ETHOS)⁽¹²⁾ provide innovative ways to incorporate HCV treatment in Opiate treatment units, but still raise concerns from some clients about confidentiality between the two linked services and how this could affect the treatment received in the other⁽¹²⁾.

The literature reflects the complex issues relating to Hepatitis C and how they may impact of people’s choices to have HCV treatment; however the rural community is under represented in these studies.

Method

Study aims: This study aims to understand how the experience of living with hepatitis C impacts on accessing hepatitis C treatment for people who are clients of a rural opiate treatment unit.

Study design: This qualitative study drew from an Interpretive Phenomenology Analysis (IPA) perspective. This strives to understand the nature of human beings and the meanings they impart upon the world by examining language in its cultural context, the way language is given meaning



and interpreted ⁽⁵⁾. IPA uses an idiographic focus offering a personally unique perspective of the phenomenon of interest ⁽⁵⁾.

Participants and setting: The participants were purposefully sampled from the OTU in a rural area. The unit has high rates of HCV people, which would be able to give information rich accounts of being hepatitis C to answer the study aims.

The inclusion criteria was

- Self-reported hepatitis C antibody positive people
- Attendance at a rural opiate treatment unit
- 18yrs or over
- Male or female
- People who have not had previous treatment for hepatitis C

The exclusion criteria for the study will be:

- People who have difficulty with speaking or understanding English
- People highly dependent on medical care.

Data collection: Opiate treatment workers agreed to participate in the recruitment phase of the study. There were a potential of 100 clients that are case managed on a three monthly basis that they could access for the study. Nineteen people were invited to participate in the study and recruitment extended over a 12 month period. A total of five interviews took place. Patient information sheets were distributed to the interested clients at their case meetings. Following this the interested participants were referred to the researcher who organised a convenient time for the interview to take place. Informed consent was obtained. All interviews were attended at the specialist clinics at the local hospital, by the researcher with the participant only. No repeat interviews were attended.

The researcher has been working in this field for three years in the current position as a hepatitis C nurse, and previously six years' experience through the Justice Health system. The researcher is a treatment nurse whose role has a goal to increasing treatment rates. The motivation for the study is to help health workers understand the issues experienced by opiate treatment clients that influence their decision to commence treatment for hepatitis C.

Data was collected from face to face, semi structured interviews that were digitally recorded and transcribed verbatim by the researcher. Semi structured interviews were chosen to provide some structure to the interview while still allowing for the participant to give as much detail about a topic ⁽⁵⁾. An interview guide was used. Interview questions were not piloted due to difficulty accessing the client group on more than one occasion, but were shown to the experienced research supervisor for comment. Participants were given a health related token gift bag to the value of \$35, to thank them for their participation in the study. (refer to appendix for contents) Field notes were also made during and after the interview to help give a detailed understanding and richness to the information ⁽²³⁾.

Data was de-identified during the transcribing phase to maintain confidentiality and pseudonyms have been used. Transcriptions were checked against the digital recordings for accuracy by the researcher. The duration of the interviews varied from eight to 20 minutes.

After each interview was completed, participants questions were answered regarding hepatitis C treatment and other health concerns. Plans for follow up occurred with all five participants as a result of participation in the research.

Table 1: **Demographics features of setting and participants**

Rural population	35 000
OST clients	100
Clients approached	19
Participants	5
Age Range	32-50yrs
Male	4
Female	1
Length of Infection	6-20yrs

Data analysis: analysis occurred using IPA as described by Smith, Flowers and Larkin ⁽⁵⁾ “with a focus on personal meaning and sense-making in a particular context for people who share a particular experience” ⁽⁵⁾ (pp45). The analysis aimed to remain as close to the interpretation of the reading in the passage as possible. The following steps were used to maintain an IPA focus: Immersing oneself in the data, initial noting, developing emergent themes, searching for connections across themes, leading to themes being contextualized into super ordinate themes and developing a detailed analytic interpretation of the text ⁽⁵⁾ .

Initial transcripts were coded by hand by the author and an experienced research supervisor and themes emerged from these codes. Regular discussions with a supervisor occurred to describe and clarify emerging themes.

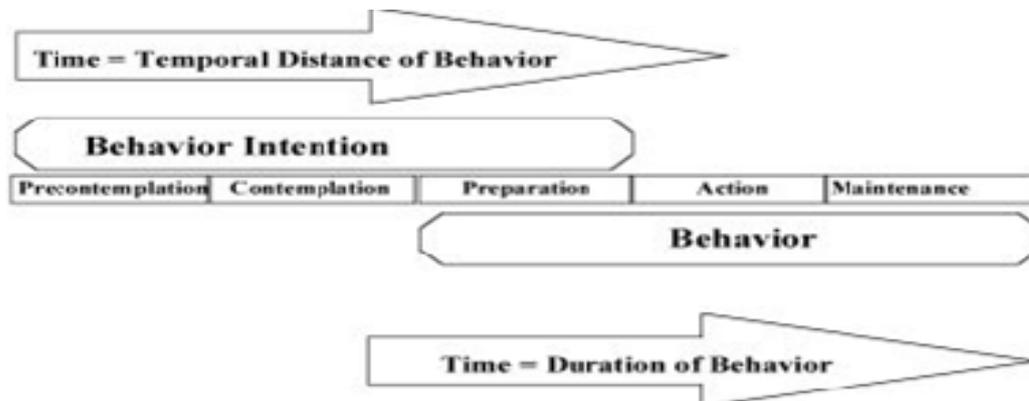
Results: Super-ordinate themes identified from the transcripts:

- **Worry, shame and embarrassment:** concerns that keep people fixed in pre contemplation and contemplation phases of change.
- **Feeling supported or unsupported:** leads to contemplation or preparation and action phase of change depending on the type of support.
- **Identity change** – the move towards preparation and action phases of change

The TTM of change ⁽²⁾ describes a process of behavior change that is often used in drug treatment settings. It is a model that focuses on the decision making of the individual. Therefore it has been applied to these participants to

show their thought processes about hepatitis C treatment and if they have had some behavior change since their diagnosis.

Figure 1. The Temporal Dimension as the Basis for the Stages of Change



Cancer Prevention Research Centre 2013 [06/08/2013]. Available from:
<http://www.uri.edu/research/cprc/TTM/detailedoverview.htm>.

Overall view of where participants fit on the TTM stages of change:

Nick and Keith sat in the pre contemplation phase which describes no intention to take action in the foreseeable future. A lack of information about the consequences of their behavior may keep people in this stage ⁽²⁾. Nick and Keith both admit they do not know much about hepatitis C and avoid reading, talking or even thinking about the effect of hepatitis C on their lives. This creates a dilemma for the clinician attempting to reach clients who are not ready to engage in these activities.

Ricky fits between pre contemplation and contemplation stage of change when there is an intention to change. Ricky shows that he is aware of the advantages of changing behavior by going on a “hardcore health kick” but he is also very aware of the disadvantages, that treatment may have a negative effect on his mental health.

Karen falls between contemplation and preparation stage of change, where people intend to take action in the immediate future (next few months) Karen has sought a plan of action to see the specialist about treatment and is working on a self-change approach, changing her identity from being a drug user to a grandmother.

Neville also fell into the preparation phase when interviewed, showing he has made multiple attempts at seeking treatment with his GP, changing his



lifestyle behaviors to prevent worsening liver damage and looking forward to treatment in the near future.

Worry

This theme describes how worry is a constant in the participants' lives not only at the beginning of their diagnosis but over the span of their lives with the disease and continuing to treatment. This endless worry can have a long term effect on coping, resilience and self-worth for the participant and their families (24, 25).

One participant reported being worried about just getting the initial diagnosis.

"They were doing tests through the methadone clinic and they just happened to say one day you know we'll put you forward for blood tests and I said that would be great, umm I was worried about my hepatitis C status".

Ricky

Although Ricky says he was worried about his status he had avoided getting tested himself from fear of finding out for certain that he was HCV positive and admits he probably wouldn't have been tested if it was not offered opportunistically by the OTU staff.

Sometimes effects of a diagnosis of hepatitis C extends to other family members, Keith explains that his dad was worried about possible transmission within the family home.

"Dad was worried about it, a few years ago like he um wouldn't drink out of bottles that I had, and that, but I told him he couldn't get it that way, but he was worried. " Keith.

Family dynamics may be affected when faced with a disease that is perceived to be easily transmitted, but in reality is limited to blood to blood contact only. Lack of information for the family members can create a sense of isolation for the person with the virus, and perpetuate myths around actual transmission. These common myths are a bound in the general population.

Mostly participants were worried at some time during the hepatitis C journey but Nick gave the opposed view by saying he was not too worried at all and it didn't really affect him.

"It doesn't really bother me, I don't think about it because I don't have any symptoms." Nick

While Nick remains asymptomatic he believes that he is fit and well and does not require any further intervention.



Karen has found it extremely difficult to disclose her hepatitis status to her own family because of worry about their possible reaction.

“well I actually told my eldest daughter just in the last two weeks that I was coming to see a doctor and that I might have to start treatment...and she was like ‘oh my god...oh my god...why?’ and I said it was my liver...and she was really shocked I suppose, but I still couldn’t bring myself to tell her because they don’t...well I think they don’t know...I had the perfect opportunity and still didn’t tell her.”

Karen is hesitant to articulate exactly how she feels and cannot imagine how her children would cope with her hepatitis C diagnosis, knowing that she may have to disclose her past IVDU. This worry and fear prevents her from opening up to her children about her health, evidenced by how ‘shocked’ her daughter was on hearing that she may be sick, showing they do not share this sort of information. According to the TTM Karen is heading into the preparation phase of change by making doctors’ appointments and addressing her treatment plans.

Other peoples stories weigh heavily on the participants and information from others who have had treatment is often the only source of information they have access to or remember. Nick is happy to avoid feeling worse on treatment, especially while he feels unaffected by symptoms and decides not to seek out any further information. Keith continues this line of thinking with;

“Well I’ve just found out about the Interferon, and I’m a bit umm...worried about the side effects...they can make you feel sick, put weight on...” Keith.

Fear and having limited knowledge allows Keith to continue avoiding the issue, he goes on to explain what he had heard on the grapevine about treatment, alluding to a deeper reason to not having treatment.

“They couldn’t sleep; it made them irritable, um sometimes like their hanging out...and I’ve been through that for twenty years and I don’t want to be...like I’m a sook when it comes to hanging out and feeling sick”

Keith’s long drug history reminds him of how he does not want to feel anymore. “Hanging out” is like a flashback to his drug days and somewhere he does not want to revisit. Describing himself as a “sook” refers to a childlike state where he does not have the skills to deal with it as an adult. Keith states he has been diagnosed for at least 14 years and yet he “only just found out about Interferon” highlighting that he has not had access to or sought any information over the years. After a moment Keith then says

“...and if I don’t do it, I suppose I’ll be sicker.”



He is weighing up the pros and cons about treatment, worried about his health but still stuck see-sawing between the two. Keith's explanation about the side effects is also shared by Karen.

"I'm still very scared about treatment options, like very worried and scarred about what I've got to go through." Karen.

This may also be another time when feeling bad, and suffering from symptoms would remind of her of her old self, like Keith's previous explanation of "hanging out".

Shame and embarrassment

The following passages demonstrates the pervasive feeling of shame and embarrassment that participants feel when discussing being hepatitis C.

- With past behaviors

Neville explains

"I feel disgusted in myself for even doing...like doing the things I was doing to put myself at risk, to catch it, umm too late now you know, but yeah I'm really upset with myself, disgusted." Neville.

Even though Neville does not say how he caught it there, he just stumbles over the ambiguous territory of the things he was doing, unable to say the words out loud. He is clearly embarrassed to admit to it now, and since time has passed, many years, he is quite ashamed of his past even now. This is mirrored by Karen's experience,

"I feel terrible that, that I got, more than likely got it from sharing needles, I feel terrible to have to admit to that." Karen.

Karen reflects on her past identity and is ashamed of her drug taking history, knowing that it is extremely stigmatized in the community as deviant behavior. The repetition of 'terrible' highlights her anxiety, and using 'admit' shows how hard it is for her to own up to doing something wrong in the eyes of the community and to herself.

- In relationships and the future

Karen goes on to explain about disclosure within her family ...

"they don't know I was using drugs, it's never been openly discussed, and I still didn't tell her when I had the perfect opportunity...I shut it off and went onto something else, like I mean I don't know if embarrassed is the right word or ashamed...I don't know." Karen



Family dynamics can be complicated, without the added pressure of a well-kept secret like ‘mum uses drugs’ It is understandable why Karen has not shared this information as she fears that the sheer magnitude of the information could cause unrest within the family unit, a place where she is trying to find her new identity as a grandmother rather than her old self.

Disclosing within a new relationship adversely affects Ricky, and prefers to avoid having a relationship than dealing with the sensitive issues his diagnosis adds to a relationship. He explains how it affects him;

“Very poorly, I sort of don’t go after relationships now, I worry about trying to tell them that I am hepatitis positive and you know it means having to have protected sex for the rest of our lives, it’s a lot to handle, so I tend to withdraw rather than put it out there.” Ricky.

He does not want to put unnecessary stress on the relationship so makes the decision for everyone that he will not have a relationship. “Rest of our lives” indicates a long term relationship and maybe consciously this is something he would like. He makes the judgment that maybe no one could or should have to “handle it”, maybe to avoid disclosing and preventing being rejected. Although men who have sex with men are at a higher risk of contracting hepatitis C through sexual intercourse, it would still be a risk that could be managed and it feels like Ricky is worried about both disclosure and having to have safe sex for the rest of his life. This is really limiting his opportunities to engage in a meaningful relationship in his future. These are complex issues compounding a sensitive subject. Karen gets around this issue by not disclosing.

“The last relationship I was in with a man, he knew nothing about my past and definitely didn’t know I had hepatitis C...and I would have been too embarrassed or ashamed...whatever the word is to tell him.” Karen.

Karen repeats the use of embarrassed and ashamed as she struggles to explain exactly how she feels. Karen has serious concerns trusting people with her personal information, either in a sexual relationship or within her own family unit and also reports she has never disclosed within the workplace for fear of discrimination. She is quite guarded about who she tells her information to.

Conversely Neville has also disclosed to his boss in the past and felt quite supported by them saying

“And there are a lot of people out there that are tolerant.”

➤ Shame and health services

When people try to access the local health services, they report being met by prejudice and discrimination. The participants carry the shame of being



hepatitis C all the time. When health care professionals maintain an environment where this is acceptable, it exemplifies why this client group is reluctant to seek medical care.

“believe it or not the hospital staff treat me different, it’s like I’ve got leprosy, mainly the nurses, you hear them chattering and chattering “you know he’s got track marks on his arm” you know stuff like that...I just thought regardless what you have, a hospital is for all kinds of people, all sorts, you’re supposed to be treated like equals.” Neville.

“Um quite often when I’m in casualty here, I quite often wander um yeah, I don’t know whether it’s the hep C status, or drug, um methadone patients stigma or what, yes, it’s definitely present...just by being treated completely different, you are treated like a ‘junkie’ that can’t be trusted with a needle anywhere near them, and you know they are really off putting. I’ve had that many people walk out of this hospital because of the treatment purely because they’ve gone in there with you know, infected arms from shooting up and that, and the way they’ve been treated is just disgusting, absolutely disgusting.” Rick;

“I had a really bad experience once when I went to the eye doctor, and he was o.k., put on a pair of gloves and then when he read my file, he realized I was hep c and um oh he looked at me like I was a piece of dirt and he put double gloves on and it made me feel really bad, and I ended up walking out without having the eye test done.” Karen

Karen would rather forgo having treatment then having to put up with being treated poorly. This continued discrimination led to her feeling hyper sensitive to how people treated her when she talks about going for a blood test;

“I don’t know if it’s just me or when I go to have blood tests, you know I say I have hep C, like they just look at, not all of them, but some of them, and I’ve noticed here in pathology at the hospital, like there’s a couple of ladies that look at you like your just dirt...and they don’t talk to you they just (shrugs) and they were talking to you o.k. until they looked at your file, but I don’t know it’s it’s just me being paranoid or not but they seem to...” Karen.

These kinds of interactions creates some confusion for her, is she paranoid or over sensitive towards people, or are they really treating her differently, making her second guess herself. She uses the repetition of “I don’t know” and shrugs as if she does not know what she can do, a sense of having no control over it. Previous research has shown that the impact of perceived discrimination is a serious impediment to testing, treatment and disclosure and acts as a significant barrier to accessing HCV information and support⁽²⁴⁾.

Keith discusses monitoring with his GP, which includes pathology collection.



“He would have over the years (discussed it) but because they find it hard to get blood out of me, I try not to go there.”

Past IVDU's often have problems accessing their veins for pathology collections, but it also may be an easy fall back excuse to avoid monitoring. He knows people will not question this, and therefore continues to avoid the issue of monitoring or treatment. There may be some level of shame around having to show his scarred veins or explain to a phlebotomist why he does not have any veins to access. Ricky also cites this as a barrier to treatment as he has trouble getting access for pathology as well.

Feeling Supported or Unsupported

This theme shows there is a link between getting the right information at the right time to allow people to move towards treatment. If that does not happen, people are likely to stay in the pre contemplation stage about treatment. Support and information at the time of diagnosis is considered best practice, clearly stated by pre and post test counseling guidelines ⁽¹⁶⁾ and with the advent of newer treatments becoming available, keeping up to date with treatment information is vital for OTU staff and GPs to be able to pass on the correct information.

Participants described support in various forms such as; from family members, from the local methadone clinic, peers and GPs. When seeking information about hepatitis C they tended to utilize the methadone clinic nurses and resources or their GP, all participants said they did not use the internet to seek information, mostly due to not owning a computer or having internet access. One participant said they were still learning how to use their phone let alone the internet.

Karen's initial diagnosis was given over the phone, with very little support but since she has formed a good relationship with the OTU nurses, she has sought help from them, she says;

“Oh a lot more than I have anywhere else, yeah a lot of pamphlets, talking and that to the ladies down there (at the methadone clinic).” Karen.

Her supported environment and case management through the clinic shows that community services can have a strong impact on information sharing and managing the patient in a holistic way.

Conversely Ricky was diagnosed through the methadone clinic and found that he was given little information or support;

“Mainly that it does massive amounts of damage to my liver, which apparently was in bad shape before I got the hep C...yeah so other than that, they didn't really talk about it.” Ricky.



The limited information given at diagnosis, reflects the over estimation of potential for damage. Even though Ricky feels hepatitis C is causing “massive” amounts of damage, it still did not lead him to seek further information or treatment at that stage. He has had only two further tests done. His possible lack of connection with his case manager at the OTU, and the fact he was still in the pre-contemplation stage of change may have some effect on his willingness to seek information.

Reports from a gaol diagnosis varied,

“I just got the results and that was it.” Nick.

While Neville’s diagnosis in gaol, led to support from peers and limited support from the nurses.

“One of the nurses that was at the gaol, called me up and told me about it...that it was causing my indigestion and that’s as far as it went, Umm anything else I found out about it, I found out through some of the inmates that were there, and obviously educated about it, and yeah that helped me a bit.”

With high rates of hepatitis C reported in gaol ⁽²⁶⁾ it is possible that other inmates may have had a good understanding of hepatitis C, and shows the value in peer support in these environments.

Family support was found to be important to Neville, but there was some ambiguity around what that support was.

“They do know I’m positive but the good thing with my parents, they tend to support me, rather than put me down, so they don’t bring it up much, but for instance, now that I’ve started doing something about it (getting treatment), they’re really happy about it.”

Neville is motivated to change and feels good that he is making his family proud. “Don’t bring it up much” shows that the family do not discuss the matter and whether that makes him feel supported or if it is just a way of avoiding talking about it, he seems happy with that. When discussing if Nick’s family treat him any differently he answers

“No not really...I don’t really talk about it that much.” Nick.

Avoidance of discussing hepatitis is often common amongst this group.

Although Neville has been receiving information and ongoing care from his GP, he does feel that his treatment journey was not helped in any way.

“Like after 5 years or something I said, you know, “am I eligible to go onto treatment?” And I really didn’t get a reply, it was like, “your readings



aren't that high or that low, their pretty good", so it never went any further than that, so every time I asked it was the same reply". Neville.

This shows that Neville was committed to seeking treatment over a long period of time, but kept encountering a lack of support from his GP. The criteria to gain access to treatment were much stricter in previous years, but even a referral to a specialist for review was not offered.

"I knew that it couldn't last too long, well the proofs in the pudding, I've got cirrhosis you know, and if my doctor did something when I asked, I probably wouldn't have cirrhosis, and I'm sort of peeved about it." Neville.

Neville feels that the doctor also should have played an active role in helping him get some treatment. This sense of betrayal, regret and frustration is amplified by "the proofs in the pudding, I've got cirrhosis". Neville has moved from the preparation phase and trying to get into the action phase of change even though he has met with resistance along the way.

The following experience relates to trust in the GP and being guided by their expertise.

"the biggest reason I haven't been put forward to do it is because of my depression...the doctor always tells me that I would not be able to handle the depression...yep they were quite adamant that someone like me who already suffers depression, there's absolutely no way that you would handle being brought down that far." Ricky

Previous criteria for treatment has been quite strict with level of fibrosis and previous mental health co morbidity, therefore it is understandable that these reasons were given.

Identity change

This theme highlights how some participants realized that there needs to be a complete identity change from the person they were as a drug user to a new self before they could start making changes in their behavior and health status.

The importance of social acceptance can be seen in Karen's transcripts and also the lifestyle amongst this group. Karen alludes to the ability to disclose to her friends within her circle. She can be assured that there will be no judgment there, allowing her to be herself.

"Well back then, I was just chasing the monkey, I was just going around in circles chasing the drugs..yep" Karen.

This lack of direction and control over her life shows how she sees her old self.



“it was...it was like if you didn’t have hepatitis, it was sort of like “oh you sort of hadn’t been around too long, sort of stupid now, but that’s what it was like.” Karen.

Karen can identify now that her old self thought differently to how she thinks about it now, even embarrassed by that way of thinking now.

When asked about who she does disclose to she says..

“Friends, I’ve sort of ...people I know who have been in that circle anyway, and my best friend, she’s straight, like no drugs, she never judges me” Karen.

This reference to “going around in circles” shows that although the above mentioned circle is comforting and accepting in some way, it can also lead to an endless lack of control or direction over her life when seeking drugs were the only priority at the time. These vulnerable periods of time also led to a decrease in monitoring her liver as her lifestyle didn’t allow her to prioritize her health at the time. Even though her best friend is not a user or part of her “drug circle” she knows that the trusting relationship will support her. A commonality within the group if everyone was positive also makes it easier to fit in. It is interesting to see that her choice of best friend now is someone “straight” another move away from her old self and previous lifestyle. Karen reflects on her past life as she has ceased IVU now and is working towards creating a new identity as a grandmother. Treating hepatitis C could be a part of the picture that needs completing before she can shed that old life completely.

Neville explains how he has moved away from his previous drug taking lifestyle by focusing on working towards treatment and creating a new identity.

“I’ve wanted to do this for a long time, I’m sick of doing nothing about it. I knew my liver would be getting bad, mm, I haven’t been like using drugs and I stopped drinking. It wasn’t like I was being an idiot, so yeah I just avoided doing stuff that could affect me and hopefully it would keep it at bay.” Neville.

Neville feels that he has managed his liver disease to the best of his ability and recognizes that he had to stop using drugs and alcohol to improve his chances of liver health. As time passes, Neville has set new goals to concentrate on, lifestyle changes are happening and he identifies as an uncle and a grandfather, giving him an important role to play in the family which has now become his main focus.

Four participants acknowledged in some way that as time was passing, their hepatitis C was affecting them in some way or another. During monitoring phases two participants explain that initial tests results that were good led them to believe hepatitis C was controlled, and if blood tests were bad, they were then motivated towards healthy lifestyle changes.



“yeah like close to normal, the doctor said that it didn’t seem to much to be worried about, I was living better and that, I just assumed...I felt all right, just assumed it had gone.” Karen

“ umm...and it came back really really bad um then I started taking better care of myself and really went on a hard core health and wellbeing sort of thing and managed to get it back up to healthy, so yeah it’s around the healthy mark now.” Ricky

Ricky uses strong language to emphasize how much things were affecting him such as “really really” and “hard core”. It shows he was making a huge effort to correct his health.

As time progressed turning points occurred for the participants. Karen identified her age and the fact that she was a grandmother now. Karen’s identity has transformed from a drug user in the circle to a grandmother and someone searching for the person she used to be before the drugs.

“When my grandchild was born, I thought well, he can’t have a grandmother that’s on drugs!...hmm. Umm I suppose just my age, I’m not getting any younger and I just want to be well, like I’m a grandmother now and you know I just want to be...the person I was.”

Karen’s shame at being an IVDU is something she wants to prevent the next generation knowing about. The span of her drug use has reached across her life, her children’s lives and now their children’s lives, and she feels this is the time to end the “old self”.

Neville echoes the importance of family, a huge motivator for him to create a new self.

“I’m excited about going through the treatment because I know it can help and if I do the right things, it can help me...and I mean I’ve got grandkids now...I’ve got nephews and I’ve got a lot to live for, and if I can get another ten years out of my life I will take it.”

Neville identifies that he needs to do the right things as opposed to what he was doing in the past, showing he has transformed from the drug user he was to his new self, mindful of his health. Neville moves into the action phase of the TMM.

Keith’s lack of knowledge about the long term effects of hepatitis C keeps him locked in the pre contemplation stage. It makes it easy for him to avoid thinking about doing anything now. He hints that it may affect him in the future, a far off time that he does not grasp now.



“I suppose it’s gonna affect me when I get older, my life might be shorter, but health wise, like I get psoriasis pretty bad, I don’t know whether that adds to it or what really, I don’t know much about hep C to be honest.”

Although Keith goes on to say;

“well I think my livers getting umm.. I had a few drinks over Christmas and I had a lump here (points to his liver) and it’s still there a little bit, I think my liver must be...I am gonna do this thing, I just have to be in the right frame of mind to do it, like I’m coming off the bup...”

He reflects on how he felt at Christmas, usually a carefree time and became quite worried about his liver. Trailing off and not finishing sentences shows he is in deep thought about what he is saying but unable to find the right words to explain, also avoiding saying the words and not admitting it to himself how bad things really may be. He identifies that his head has to be in the right space to contemplate treatment but rushes on to make an excuse to why he has not started yet, having other priorities like his withdrawal off buprenorphine. He is telling us he only can do one thing at a time, when the time is right. Clearing hepatitis C and being off buprenorphine may also be a sign of closing that chapter in his life, which he may be tentative about as he remains in the pre contemplation phase. Keith is struggling with the transition as he continues occasional IV and alcohol use, so not letting go of the old self, but still torn between the decision to move toward treatment as symptoms become worse.

Discussion: the participants in this study expressed negative feelings about being HCV positive and over time for some, led to a movement towards contemplating treatment. At times this seemed more like a see-sawing effect towards and away from treatment depending on how they felt, how they were treated, what was happening in their lives and what information they may have been receiving at the time. When changes occurred within their identity, the path to the new self was realized and behavior change then followed. Two participants seemed rooted in the pre-contemplation phase probably due to lack of information and education around long term effects of hepatitis C, personal motivation and lack of support. These participants did not engage with the interview fully, they do not engage with seeking information and prefer not to talk or think about it.

Karen and Neville are two examples of contemplation moving into the action phase of change, while the others remain in the pre contemplation stage.

This study shows that a significant personal identity change can lead toward treatment of HCV. Worry, shame and embarrassment may be demotivating factors that lead them to remain untreated. The participants have shown it can be difficult getting useful and timely information from health services at diagnosis, during management of symptoms and seeking treatment. The reported experience of engaging with local health services have been



described as being treated in a way that brings them shame. Previous research by Doab⁽¹¹⁾ recognizes that GPs are generally the first person they access for information, monitoring and discussions about treatment, supporting the results found in this study where clients have identified GPs and the OTU as places they predominately seek information and services from. It should also be noted that none of the participants used the internet to access information about HCV and its treatments, therefore being mindful how we do disseminate information to this client group.

Treloar's study⁽²⁵⁾ found that OST clients had a greater willingness to undertake hepatitis C treatment than those not on OST. This can be linked with the TMM that people accessing OST are engaging in a conscious act of change, by changing drug behavior. This may lead to a natural progression to want to clear HCV, leaving both the drug history and HCV in the past. Two out of the five participants in this study showed a willingness to seek treatment as they had changed their identity and behaviors, compared with those who still engaged in drug behaviors and thought HCV was doing them no harm. Harris⁽¹⁷⁾ supports this by reporting that the majority of participants who described hepatitis C diagnosis as "no big deal" reported regular injecting at the time of diagnosis, and nearly half of her participants described hepatitis C diagnosis as of little concern, giving some strength to Nick's experience.

Participants explained that they were worried about various aspects of hepatitis C from the initial diagnosis, treatment and its potential side effects, disclosing to others and in most cases worry had continued over the span of the illness, apart from Nick. This coupled with stigma and discrimination can only exemplify how difficult it is for people to move forward to the intention of change and transform themselves. Previous studies^(15, 26) support this insight into the enormous impact that hepatitis C has on quality of life both physical and psychological that should not be underestimated. Issues such as disclosing, encountering stigma, relating to others, dealing with health professionals, feeling isolated and managing ill health, have all been previously found and are also supported by these results.

One participant felt strongly about the potential negative effects of treatment on his current mental health which has been shown previously as a source of concern for patients as an increased risk of a depressive episode under interferon treatment was a major barrier to treatment⁽⁹⁾. The advent of the hepatitis nurse, who case manages the clients on treatment, offering referrals to D+A or mental health services, may help to decrease this particular barrier.

This study identified disturbing findings from three participants describing their experience of discrimination from the local health service. Being treated like a "junkie", like "dirt" and as if they had "leprosy" were all direct quotes from the participants. This study demonstrates the vast amount of stigma attached to a diagnosis of hepatitis C that lasts a life time for the participant. The mistreatment by health professionals only perpetuates this stigma, and prevents people from accessing treatment services that they require. These



findings are supported by an Australian survey of women and men ^(18, 28) reporting that 48% of women and 40% of men surveyed with hepatitis C, believed that they received less than favorable treatment from health workers than people without hepatitis C, showing this is not just a rural or local issue with discrimination and stigma, but a widespread issue. Recently an Australian report was produced documenting that many of the experiences of discrimination towards people with HCV go unreported, but some examples of discrimination in the health care settings can be breach of confidentiality, unwillingness to provide appropriate care and limited knowledge among health care workers about HCV leading to poor quality care ⁽²⁹⁾.

This report shows supported environments and relationships help people to feel positive about their HCV status and motivate them towards treatment. When people don't think about it, talk about it or read about it, they stay stuck in limbo and continue to not work towards change.

Strengths: The use of phenomenology to investigate this phenomena and the purposeful selection of participants to gain an insider's view of being hepatitis C positive adds rigor to the research. The interviews were audiotaped and transcribed verbatim providing at least verbal accuracy. These findings may contribute to current knowledge as well as improve clinical practice to reduce stigma and discrimination with in this rural health service. The results may be generalized to the wider OTU clients, as they are not necessarily specific rural qualities that the participants speak of, but of an overarching feeling of shame and discrimination that would be felt in any area.

Limitations: Time constraints affected how many interviews were possible and difficulty engaging this client group was also an issue, although 3-6 participants can be ideal in an IPA study ⁽²¹⁾. In addition the interviews were brief. The majority of interviews were with men, in line with statistics that say more men than women have hepatitis C, ⁽²⁰⁾ but also does not represent a homogenous sample of the opiate treatment unit

Conclusion: This report shows that being hepatitis C positive is a lifelong experience, having an effect on relationships, family and being treated differently in the community and in the healthcare setting. It pervades their everyday life. It was found that there was an overall lack of general knowledge about hepatitis C and its long term effects or even treatment options. Participants reported being worried about side effects but also about what might happen if they do not have treatment, continuing that see-sawing effect between action and inaction.

Participants have given an insiders view of what it is like to have hepatitis C and the three themes found here show things such as worry, shame and embarrassment, support and transforming the 'self' all impact on their experience of having hepatitis C and may determine if they move towards treatment or not. These experiences may not be unique to rural OST clients therefore being aware of the huge impact a HCV diagnosis has on peoples

lives and even years later will give a greater awareness of this client group across all areas.

These results are significant as it shows how a HCV diagnosis changes their lives, their relationships and ultimately their health outcomes. As health care providers, contributing in a positive way, can make significant changes to how people are currently experiencing health care in this rural area, knowing that every interaction affects their access to health care.

Recommendations: from this research the following recommendations are made.

Increase in Health worker education by providing regular in services from the hepatitis C nurse and gastroenterologist to all health workers on the local campus. This will provide a greater understanding of hepatitis C; its transmission, natural history and treatment available and also addressing discrimination and stigma surrounding this diagnosis. With this information health care workers will be able to provide opportunistic interventions such as testing, counseling and basic treatment information, as well as offering timely referrals to the liver clinic.

Priority areas would be Emergency department and Pathology, but all wards of the hospital and community health areas would benefit from education. A follow up quiz post in service could evaluate the learning that took place and show if the frequency of in services needs to be increased or decreased.

Increase in GP education by providing yearly updates / dinner party meetings to increase awareness around hepatitis C and its treatments.

Network with Medicare Local, Hepatitis NSW and ASHM to assist with GP education and utilize the hepatitis nurse and gastroenterologist for case presentations from the current liver clinic.

Further education would include improvement around pre and post test counseling skills. Knowing the GP is the first person clients will access for assessment and diagnosis makes it paramount that these initial consults are done well. Actively involving GPs in preparing clients for treatment and offering chronic care plans to help start addressing the complex needs of this group.

A post meeting evaluation form could be utilized to address if learning needs were met and if any further information was sought or if frequency of the meetings were needed at the GPs request.

Improve OTU and Hepatitis C clinic collaboration by providing intermittent in services to the OTU workers by the hepatitis nurse to improve knowledge around hepatitis C, effects of diagnosis, treatment and its side effects. Discuss whether this could be seen as part of their role during case



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management to introduce discussions around hepatitis. Continue to offer opportunistic testing and early referral to the liver clinic.

This collaboration will help address the needs of the clients, expedite referral pathways and take a more holistic approach towards their care. Since high prevalence rates are reported in the OTU, greater engagement with the clients may increase rates of treatment within this group.

Unintended outcomes from research: All participants (5) had fibroscans (staging of liver disease) and pathology collection with explanations of results. Two participants have sought treatment and one has commenced treatment since the research. One partner of a participant has commenced treatment.



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Appendix 1

Token Gift Bag Contents: health related

Relaxation or Yoga CD	\$5
Coffee Bags	\$5
Herbal Teabags	\$3
Harris Farm Market Voucher	\$20
Up and Go Drinks (protein Supplements)	.60c

Dental Hygiene products Donated from Bathurst Base Hospital Dental Clinic

Approximate value of each gift bag \$35

Pamphlets about Hepatitis C treatment, lifestyle education, and available support was included.