

Pre-conference Nurses' Course



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Patients' experience of hepatitis C: implications for a new treatment era

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A new hepatitis C treatment era

- Direct acting antivirals – effective, tolerable, shorter & simpler regimes
 - Not currently available to all
- Implications for treatment prioritisation
 - Treat now or defer?
- Implications for service delivery
 - Does treatment simplicity threaten the CNS role?
- What insight can the patients' experience of hepatitis C provide?



The research

The Hepatitis C Treatment Journey (2012-2016)

AIM: To assess HCV support needs: patient/provider & system perspectives

Sites: 2 London hospitals, 1 drug treatment service

Data collection:

- 1-5 interviews with 28 people with HCV. From referral up to a year after tx
- Interviews with 8 stakeholders & 10 providers
- 3 focus groups exploring issue of delayed diagnosis (n=16)
- 5 focus groups/workshops targeted at resource production (n= 17)
- 100 hours of clinic observations

NIHR funded.

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Treatment prioritisation

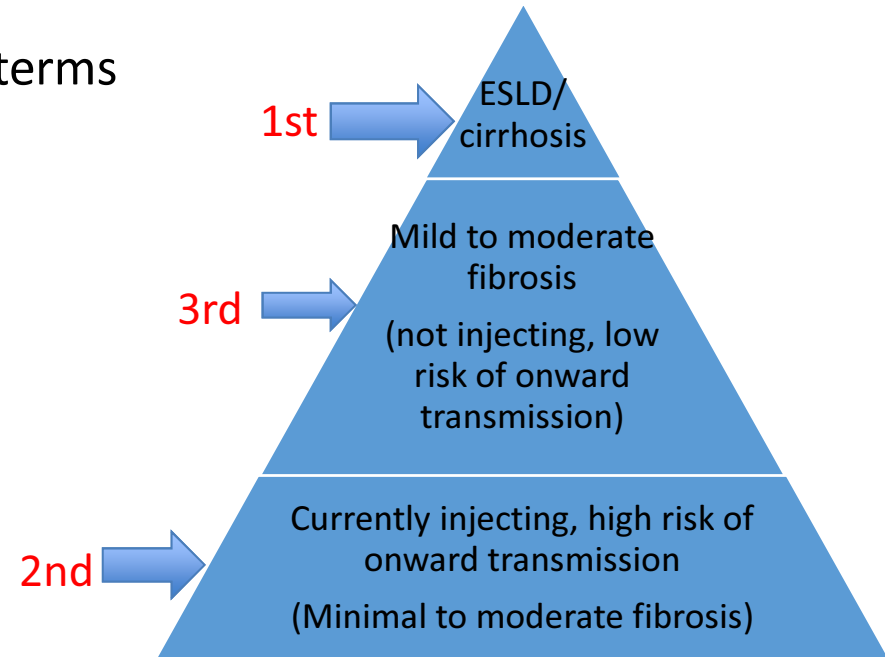
- Increasingly framed in population health terms

The challenge for health systems will be whether they can orientate health services to offer therapy to individuals with both advanced fibrosis and PWID in the context of the current high drug prices [1].

- Who is omitted & how is this justified?
 - Questioning SVR 'benefit' for moderate disease

Do high percentages of sustained response translate into long term clinical benefit?" [2]

More realistic expectations may lead to patients making more conservative treatment choices if the benefits on offer are accepted to be modest" [3]



1. Doyle et al., 2015, *International Journal of Drug Policy* 2. Koretz et al. 2015, *BMJ*. 3. Innes et al. (2014). *Gut*.

What constitutes treatment ‘benefit’?

- Conflation of clinical and overall patient benefit

*“Since most people infected with HCV never develop symptoms and will die from other causes, exposing them to the harms of treatment **with no possible benefit** might outweigh the benefits for the minority who develop end stage liver disease” [1]*

- Two assumptions: HCV asymptomatic, ESLD a primary patient concern

*“The **main concern of patients** with chronic hepatitis C infection is developing end stage liver disease.” [2]*

- Undone by study findings – treatment urgency irrespective of disease stage
*I’d get rid of it straightaway ... I’d seen what it said about the side-effects and I thought, I don’t care ... I just said, **get me on it. Now!** (Ryan)*

1. Koretz et al. (2015) *BMJ*. 2. Innes et al. (2014). *Gut*.



The patients' experience

- Profound impact of stigma: contagion fears → social isolation
- Treatment as enabling social reconnection

I have a son from my country ... I want to go back for my son ... without the hepatitis ... Because she [mother] tell me "oh no, you don't see your son, because it's infection". (Ivor)

I found out I got hep C ... right, that's it, me life's over, that means women are gone ... I'm scared of giving it to them ... It was the biggest [treatment incentive] for me. Definitely, quite far and away the biggest one. (Ryan)

I knew what would happen when I told [my wife] ... "we all sit at this side of the table and you can sit on the settee over there. Don't play with the kids too rough". "Don't cuddle up at night ... I'm not touching you." (Garry)

I went to the dentist, you fill in a form, and I put hep C. And she said we can't take you back on the books. And I went why? And she said it's the illness ... You feel a bit shit, you feel about that small. (Andy)



Asymptomatic? The white noise

- Debilitating impact of hepatitis C symptoms for many – often unrecognised

“The natural history of HCV infection is to remain largely asymptomatic” [1]

I find it annoying ... people don't actually realise how much it really does affect you. The most thing is no energy and no will to do anything, just not the gumption to get up and go ... it knocks it out of you. (Harry)

I always talk about it as the white noise, it's in the background so long you don't realise it's there and it's only when somebody switches it off that you suddenly realise what silence is and it's the same with this. We see that all the time regardless of what type of treatment they've had. Patients come back saying “I didn't realise I could feel this well”. (Hepatologist)



Moving on: a break from the past

- Hepatitis C as a symbolic link to drug use & associated stigma
- For some, treatment is a final or a first step, in moving on

*People fear illness ... [with cancer] you wouldn't be isolated would you? You'd just be an unlucky cancer victim. This way **you've brought it on yourself through sex and drugs.** (Bella)*

*You can be 110% sure that I will carry on with the treatment because I want rid of this affliction ... I thought **new treatment, new start.** (Liam)*

*If I can get rid of the hep C then **I know I'm on the way back** I know I can come off the methadone and all that, it's just this. (Declan)*



Benefits of an SVR: only clinical?

My mood is different, my thinking is different ... I feel like a different person, I feel like the person I used to be some years ago ... I was overwhelmed with the symptoms but not recognising them and putting them down to different things.
(Moir)

None of this would have happened if I hadn't done the treatment, I wouldn't have got fixed, I wouldn't have sorted me drinking out and I wouldn't have had any future. So the treatment has been massive, it's made a big difference.
(Ryan)

I didn't realise how ill I was. It [HCV] affected my brain, it affected my sex drive, it affected all parts of my body ... it's all gradually reappearing ... it's like being born again ... it's funny how you get used to something and don't realise.
(Connor)



The role of the CNS

“HCV care has traditionally been the provenance for specialists and tertiary care given the complexity of care ... Task-shifting to primary care or other healthcare workers accompanied by appropriate workforce training and development will be critical” [1]

*Once treatments get easier ... they’re going to say “well why do we justify a team of nurses when treatment is so much easier and, you know, do you need to be so specialist? Can’t they just be seen in clinics?” And so **I think that we may eventually end up having to justify what we’re doing.** (London CNS 1)*

*Do I think that things will change, what CNS wise? **Oh you won’t need us we’ll need to find new jobs** ... I don’t think you’ll lose us completely but I think we will be halved at the very least ... why would you need six nurses when you’re giving drugs that are one tablet once a day for 12 weeks with no side-effects, you’ll probably do bloods once, **why do you need so many CNSs?** (London CNS 2)*

1. Doyle et al., 2015, *International Journal of Drug Policy*



The patients' experience

- Supporting through difficulty & isolation

*I saw [nurse] and I'm just really glad to be with her. Unbelievable. She is, I'm so lucky ... **she honestly gives you a backbone** ... she tells it how it is and she's behind you all the way, if she can do anything for you she will, **she keeps you good I think, for me, she's very good.** (Bella)*

*He's brilliant because **he talks to me as well**, you know "**How you feeling mentally, emotionally?** How are you coping? You know if it's too much you know, let me know, like if it's moving too fast". Yeah, he's really good (Abel)*

*She'll always come up to me and say something like "Oh I meant to tell you this", or whatever, she'll send me, I usually, I'll get an email "I forgot to tell you" or something, **she does stay in contact quite a lot she's become like my grandma to me**, something like that. (Harry)*

*When I came in here it cheered me up ... In a way **I used to look forward to the day with catching a bus and meeting someone else.** (Bobby)*



More than just a nurse ...

*X Finished Boceprovir 7 weeks ago. Still feels weak... He has an Xbox mag which he keeps flicking through, he asks the nurse to read one of the names of a new game to him, then pulls out an envelope – asks her what it means. **She reads the letter and explains that it is about National Insurance.** She is incredibly patient, going over implications of the letter and assuaging his fears re payments etc. When we later talk she says **he is dyslexic and brings all his official letters for her to read.** (field notes)*

***We write housing letters, we write solicitors letters,** yeah, many a time I've had solicitors email me and can I have that, you know, housing, DLA but you just do, the key workers as well, they'll phone you and say, do you mind and I say, no, and it's easier for us to do it, we see them on treatment. (London CNS 3)*

*I feel like we should be providing an holistic service and that is as far as I'm concerned, if **I have to fill in someone's benefit application then that's what it is,** you know, I'll do that. (London CNS 4)*



Unanticipated treatment benefits

- Role of the therapeutic encounter?

I don't think I'll be going back to injecting drugs...The treatment's really handy in the sense that I'm going to jeopardise so much if I use.. It's much easier to just abstain from [injecting]. (Sam)

He's become so much more positive, he really feels like he's achieving something because he's on treatment, he's cut down on his alcohol. He's not using, he's was using a lot of cocaine at the weekends, he's not doing any of that, his blood's really improved, he feels really good about himself, he's mind's really clear. He just feels brilliant. And we're talking about exactly that, as to whether it is the fact that he's getting a lot of [support] you really do end up building a very close rapport with patients more so probably the patients who've a history of using drugs, because they might have some self-esteem [issues]. sometimes I phone patients between appointments to see how they are and they're like really kind of, like oh I can't believe you're phoning me ... generally speaking we seem to have found that it does have a very positive impact on people moving forward with their lives. (London CNS 1)



Implications for the DAA era?

- Simplified regimes impact on patient benefit?

I always used to say we, we eliminate the virus but we also cure the patients, which are two different thing and the new treatments will carry on eliminating the virus but may not cure the patient, and I think we have to, we have to looking into how we replace that role, and that is going to be difficult. (London Hepatologist 1)

It is a therapist, you get a free therapist for an hour a week, it's great. I think there are all sorts of complex issues, it's certainly as we go forward, it will not be as simple as just handing out the pills, there's more to this, you know, human beings are not simple machines that you slot pills in and they get better or they behave by an algorithm. (London Hepatologist 2)



Learning from the patient experience

- Hepatitis C stigma profound
 - Contagion fears & drug use associations → social isolation
 - For MSM hepatitis C often experienced as more stigmatising than HIV
- Symptoms (fatigue, nausea, 'brain fog') not validated
 - self doubt / social isolation
- Treatment rationales have a strong social dimension
 - Enabling social reconnection, a break from the past
- Experience of the therapeutic encounter
 - As an antidote to isolation
- Unanticipated treatment benefits
 - Due to combination of treatment difficulty & nurse care?



Summary & questions for discussion

- The hepatitis C experience can exacerbate social isolation
 - Feeling unwell, diminished capacity to work, stigma, strain on intimate relationships & self-worth
- The experienced benefits of an SVR are more than clinical
 - Enabling social reconnection, a break from drug using past, enhancing self-worth
 - Requires acknowledgement in treatment prioritisation debates
 - For some, treatment feels urgent, despite availability of DAAs (treat with ifn?)
- Simplified drug regimes – impact on ‘cure’?
 - Can we see eradicating HCV and ‘curing the patient’ as distinct?
 - How can the benefits of the therapeutic relationship be maintained in DAA era?
 - What applicability do these findings have for co-infected patients?



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