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Changes in attitudes, knowledge and everyday life throughout direct-acting antiviral treatment for hepatitis C: a longitudinal qualitative study

Stelliana Goutzamanis, Dr Peter Higgs, Dr Joseph Doyle,
Prof Margaret Hellard

Acknowledging people who inject drugs, people with a lived experience of hepatitis C and in particular the generous and insightful research participants of this study

Disclosures

- Nothing to declare

About me and transparency

- Biomedical background…not social science
- Began working with people who inject drugs in 2016
  - ‘The learner’ position and participants are ‘the expert’
- Belief that DAA treatment is beneficial to the individual and population and that treatment should me made readily accessible and available to all worldwide

(Berger 2016)

Botany assignment (Eucalyptus pauciflora)

Population-level impact of direct acting antivirals (DAA)

Cost effective	↓ Prevalence	↓ Liver disease	↓ Hep C deaths

(Scott et al 2016; Sievert et al 2014; Martin et al 2013; Van Santen et al 2016)

Personal impact of direct acting antivirals (DAA)?

AIMS:

1) Understand the DAA treatment experience among people who inject drugs
2) Understand and the meaning of treatment in people's lives and networks

Methods- study design

Recruitment (N=20)

Treatment and Prevention Study
n=10
12 weeks of treatment

Community health clinics
n=10
8 or 12 weeks of treatment

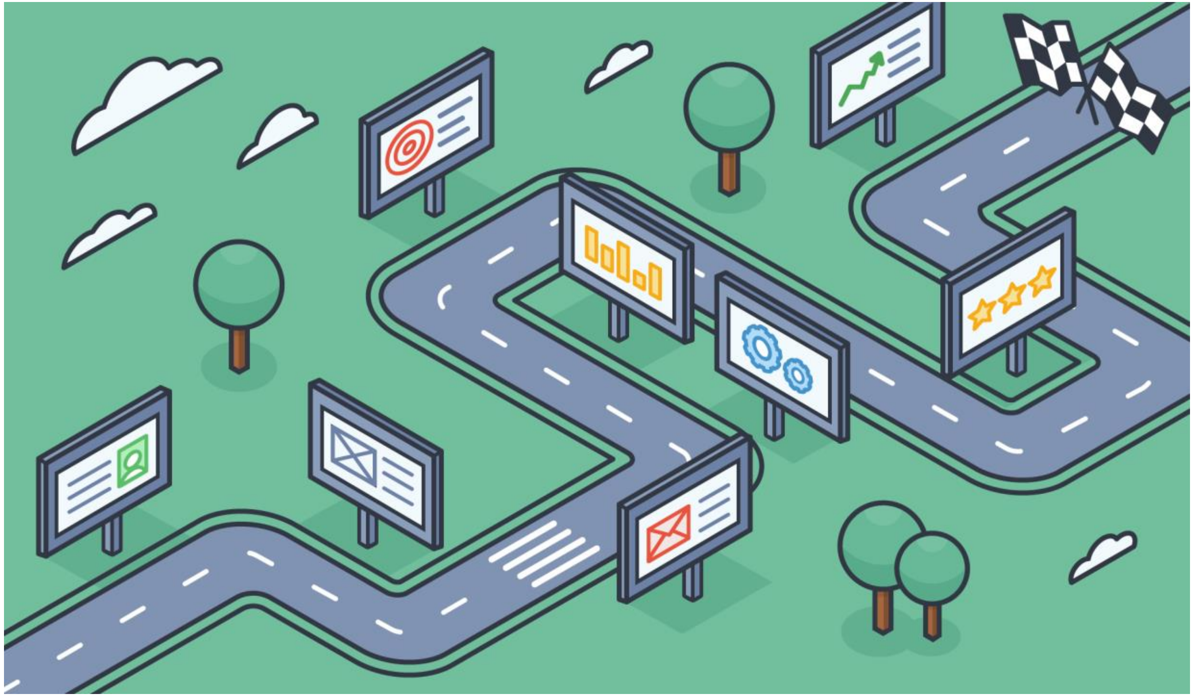
Data collection

In-depth interviews
Treatment knowledge, perceptions, attitudes, experiences, overall wellbeing

Field notes, reflexivity journal

Why longitudinal qualitative?

“longitudinal data offers a movie rather than a snapshot”



(*Berthound 2000*)

Methods- analysis

Thematic analysis

Data familiarisation
Transcribe verbatim, read, re-read

Initial coding
Inductive & deductive

Searching for themes

Reviewing themes

Defining and naming themes
Independent theme checking

Produce report

(Braun & Clarke, 2006)

Trajectory analysis

Time sequential matrices
Participant level then cohort level

16 questions for analysis
"What remains constant or consistent through time?"
"Which changes interrelate through time"

(Grossoehme & Lipstein, 2016)

Results- Participant summary

54 interviews
20 participants

7 field-sites

14 male

20 - 54 yrs old

18 unemployed

14 born in Australia

19 injected in past month

11 no-mild fibrosis

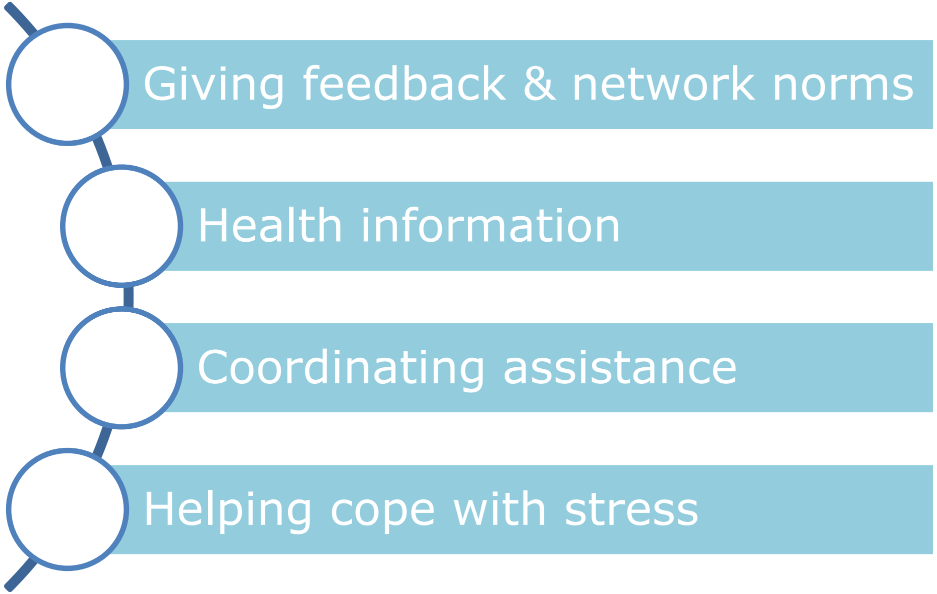
Results- Themes

- Attitudes to DAA treatment
- Treatment expectations
- Attitudes towards reinfection
- Physical impact of hep C and DAAs
- Emotional impact of hep C and DAAs
- Stigma and discrimination
- **Peer distribution of knowledge**

Field site 1

Social support, social networks, and health

- Peer network is a “safe base”, communication within network is social support → improves health engagement through:



Giving feedback & network norms

Health information

Coordinating assistance

Helping cope with stress

(Goldsmith & Albrecht)

Peer distribution of knowledge

Pre treatment

During treatment

Post treatment

Sources of information

Doing it together

Treatment anecdotes

Becoming a treatment advocate

Field site 5

Peers as a trusted source of information

“**Off the street**, from peers and other people who have gone through treatment. **That’s all I’ve listened to**, I haven’t listened to anyone else. **I don’t believe the doctors**, the doctors; all they want is to give you another prescription so they can get money, pretty much. I reckon it’s better to hear back from the horse’s mouth rather than someone who is just promoting it and they don’t care what they give you and they don’t care how much they give you.” -Hans

“I go to **my doctors**’ or just off **the internet or other services**. Bits and pieces from everywhere. I think it’s just the whole community in Melbourne, everyone learnt off a doctor or something like this and **Chinese rumours just got better and better and better**.” -Finn

DAA treatment anecdotes

"Yeah, the main thing for me was side effects and stuff. Because I had my mate with interferon I thought; 'fuck this is going to do something crazy', and **none of them said that they got any symptoms or like anything, so I just thought 'oh mate, I want to do this'.** From seeing [my friend] doing interferon like losing hair and like looking like he was gonna die, and these blokes just looked like normal like you know?" -Simon

"My dad's been on it and he finished and I've already seen him and **he was fine so I figure I'm going be fine**." -Kiran

Field site 5

Doing it together

Just **so you can feed off each other’s information**. Like if he’s not going through the same side effects as you can find out if it’s wrong, like if something is adverse, you know? Like you never know, you could have an adverse allergic reaction to anything. So **it’s always good to have someone doing the exact same thing as you**, to mirror your own experience, make sure you are going through the same, similar steps and it’s not working differently for you or the other person.” –Hans

“Yeah, um yeah. For example me and my brother do it together so **if I forget about it that day he’ll remember and vice versa and yeah it’s good like that.** Same with my girlfriend, she helps me out a lot with it, so it’s good.” -Alex

Becoming a “treatment advocate”

“**I’ve asked questions because I’ve been interested in whether it works or not**…I said; ‘how was the treatment?’, ‘how did you feel?’, ‘did you get rid of it?’ ‘Do you still feel tired like you used to?’, and yeah ‘any side effects?’ and that” –Zara, interview one

Oh yeah, **I tell them the same thing; ‘it’s good, you’ll have more energy**, you know what I mean, in your daily life’ …I’d go; ‘see the doctor and ask the doctor if they have that hep C treatment and get referred to the hep C specialist and then you’ll do the test and then he’ll see where you’re at and then he’ll write you out a script.’ –Zara, interview three

Becoming a “treatment advocate”

“I’ve said; ‘all it really is is a tablet now’. It’s not like where it was in the past where you had to go get injections you know what I mean? **It’s just a tablet, it’s no more different to you taking a benzo tablet.** That’s all it is, you know what I mean? It will be over with in a couple of months.” -Rohan

“I would let them know what I thought, my intel, my thoughts on if it was worth it or if it was just a waste of fucking time, I’d let them know; **‘mate you should give it a go, yeah?’”** -Mai

Conclusion and implications

- First qualitative study to follow participants throughout DAA treatment
- Importance of peers in shaping treatment perceptions and engagement
- Highlights what messaging resonates with individuals and their peers
- People who inject drugs living with hep C are playing an important role in elimination efforts

Field site 1

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Thank you

Stelliana Goutzamanis

stelliana.goutzamanis@burnet.edu.au

Field site 1

Field site 5