

# Decisions about hepatitis C treatment and resilience during treatment

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## 2 studies

### Survey of people living with hepatitis C

- NSPs, Methadone Clinics, Methadone dosing pharmacies
- HCCNSW Mail out
- Haemophilia Foundation Mail out (to each state)

### Qualitative study of hepatitis C treatment experience

- Max Hopwood
- 20 people on treatment, 6 health care workers
- Sydney based

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# Survey

## Treatment decisions about hepatitis C



# Demographics, total=98

Gender	n	%
Male	86	87.8
Female	12	12.2

Age	
Mean	49.0 years
Minimum	20 years
Maximum	89 years

# Genotype

Genotype	n	%
Genotype 1	31	31.6
Genotype 2	6	6.1
Genotype 3	13	13.3
Don't know	42	42.9
No answer	6	6.1
Total	98	100.0

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# Previous and current treatment

	n	%
Currently on treatment	3	3.1
Previously been on treatment	57	58.2
No treatment	38	38.7
Total	98	100

## Last on hepatitis C treatment

	n	%
Less than 6 months ago	1	1.8
6 – 12 months ago	5	8.8
More than 12 months ago	15	26.3
More than 4 years ago	13	22.8
More than 6 years ago	20	35.1
No answer	3	5.3
Total	57	100

# Completed hepatitis C treatment?

	n	%
Yes	44	77.2
Yes, with reduced dose	1	1.8
No, stopped before the end	9	15.8
No answer	3	5.3
Total	57	100

# Successful hepatitis C treatment?

	n	%
Yes, successful	26	45.6
No, unsuccessful	28	49.1
No answer	3	5.3
Total	57	100

# Treatment intentions

	n	%
Yes in next 12 mths	3	7.9
Yes in next 1-2 yrs	2	5.3
Yes in next 2-5 yrs	4	10.5
Yes but not for at least 5 years	5	13.2
No never	14	36.8
No answer	10	26.3
Total	38	100.0

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On waiting list	4	10.5
Told to treat	18	47.4
Told not eligible	11	28.9

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# Reason not eligible for treatment

	n	%
Liver too damaged	2	18.2
Not enough liver damage	3	27.3
LFT normal	1	9.1
Other	3	27.3
No answer	2	18.2
Total	11	100

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# Last see GP for hepatitis C

	n	%
Last 6 months	6	15.8
6 - 12 months ago	4	10.5
More than 1 year ago	13	34.2
Never	14	36.8
Missing	1	2.6
Total	38	100

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Last 6 months	6	15.8
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# Impact of hepatitis C

<b>My HCV has a greater impact on my day to day life than my bleeding disorder</b>	<b>n</b>	<b>%</b>
Agree	15	40.5
Neither agree or disagree	8	21.6
Disagree	14	37.8
Total	37	100

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# Survey Summary

- 57 had treatment (+ 3 current treatment)
  - 44 completed with no reductions (77%)
  - 26 successful (46%)
- 38 no treatment
  - 9 intend to treat in next 5 years (24%)
  - 14 do not intend to have treatment (37%)
- 11 told ineligible
  - Not enough and too much liver damage
- HCV vs bleeding disorder – equal impacts

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# Interview study

Resilience and coping during interferon-based treatment for hepatitis C infection

# Background

- Growing interest in factors which contribute to the development of adaptive outcomes
- Resilience is a class of phenomena characterised by good outcomes in spite of serious threats to adaptation or development
- Resilience is not a personality trait

# Background

Resilience is fostered by:

- connections to competent and caring adults in the family and in the community
- use of community resources
- cognitive and self-regulation skills
- self-confidence
- maintaining good relationships

## Method

- Purposive sampling frame (n=26)
- n=20 people currently in HCV treatment or completed treatment within previous 6 months
- Participants treated with interferon + ribavirin
- n=6 clinic staff (i.e. CNCs & social worker)

# Sample

n=20 people treated for HCV

- Age: 35 to 73 years, mean=49 years
- 7 women & 13 men
- Most diagnosed with HCV since 1995
- 7 IDU acquired infections
- 5 medically acquired infections
- Remainder reported multiple risks or did not disclose

## Resilience and coping

Yeah, I just think that [hepatitis C treatment] is a reality that you have to deal with. That's learned only through having been through heroin addiction and stuff like that ... and even my friends would say that to me, before I started treatment "You'll breeze through it! You've been through heroin addiction; it'll be a walk in the park" ... And in a way I kind of agree ... I do feel sorry for people who've never experienced ... that level of discomfort in their lives. Yes, it would be tough for them but I've kind of been through it before ... just the rough knocks during my life too ... because I've been through withdrawals and all of that, so of course I could handle, you know, itchy skin or that physical side of things ... because heroin addiction ... and actually getting off methadone was worse.

■ **Kate, 38**

## Resilience and coping

... [H]aving lived with chronic pain for the whole of my adult life basically, I already had coping mechanisms to handle those things ... I'm used to just not being able to get out of bed for two or three days in a row. That happens occasionally; I just live with it ... [I] may be in a better position than some other people to cope with the [hepatitis C] treatment because I'm used to being in a debilitated state ...that's not a good thing, but it's a fact. I guess the coping mechanisms were always there, from over a long period of time.

**Gerry, 48**

## Resilience and coping

I don't sort of wear [hemophilia] like a badge. I generally have a hemorrhage once a week but I have intravenous injections. I self-treat and have done since I was about ten. I just self-manage, self-regulate it. I think, with haemophilia too, you tend to be a bit onwards and upwards in your approach to things. It's like okay, right, you started day one with haemophilia and it throws a whole lot of challenges and you sort of deal with those however you wish.

**Sean, 35**

## Resilience and coping

So I've coped [with depression] without any antidepressants. So I just keep to myself. You know, I get very irritated and very short with people and I've got no time talking crap ... So I just keep to myself. I'm like a hermit at the moment, to keep ... safe, you know. So that I don't hurt anybody and I don't hurt myself. And I don't have a problem with that because as a child being sexually abused, I put myself in an isolated world anyway to protect myself ... So I don't have a problem isolating myself and that's how I cope with the hep C [treatment] ... I realize it's not what happens in life, it's how you deal with it; you have to deal with it the best way you can. And isolating myself works ... maybe the sexual abuse as a child was a lesson to be able to cope with this now.

Marsden, 50

## Resilience and coping

I went to Narcotics Anonymous for about five, six years, pretty religiously ... and they gave me lots of great tools ... I think I've adopted a lot of the principles that are suggested and I try to keep them as part of my life.

**Gavin, 48**

## Resilience and coping

... [S]ome [clients] are more resilient because they say “I've been through everything in life” or “Life's thrown everything at me. Well, I'll be fine”. But some are really resilient like that. And I suppose they tend to draw on services a lot more to help them through ...

**Claire, CNC**

# Conclusion

- Promoting resilience may improve the treatment experience
- Close attention to resilience theory and the application of an integrated framework
- Focus on strength-based assessment

## Final comments

- Some room to promote HCV treatment among people with bleeding disorders
  - ? Advice re treatment eligibility
- Room for additional strategies to support those choosing treatment
  - Strengths-based assessments
- Survey – NSW Health, collaborators
- NCHSR – grant from Aus Govt Dept Health & Ageing
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