



YEARS OF IMPACT

**We're
just getting
started.**

Who defines good care? Comparing clinicians' and parents' perspectives on the management of perinatal hepatitis C using care ethics

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The Kirby Institute at UNSW Sydney is located on the Traditional Lands of the Bidjigal peoples.

We acknowledge the Traditional Owners of Country throughout Australia, and First Nations people's continuing connection to culture, land, sea, waters, and community.

We pay our respects to Elders, both past and present.

Acknowledgements and Affiliations



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School of Medicine and Psychology
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Background

- Globally and in Australia, women with substance use challenges are less likely than men to initiate HCV treatment, especially if they are of childbearing age (15-44 years) or have a recent pregnancy (1,2).
- Evidence for the safety and efficacy of the use of DAAs in pregnancy is increasing (3).
- Concurrently, support for removing restrictions to prescribing HCV treatment in pregnancy is growing (4,5).

Background

- However, the possibility of treatment alone is not enough to ensure uptake/initiation.
- Previously, women with HCV have reported negative experiences of perinatal care in Australia (6,7).
- **AIM:** We sought to understand and compare people with recent pregnancy and clinicians' experiences of receiving and delivering HCV-related care.

Methods

- Between September 2024 and May 2025 we conducted semi-structured interviews with two groups.

People with lived experience (Parents)	Clinicians
Recruited through flyers	Invited by email
Experience of injection drug use and HCV care	Purposively selected for relevant HCV, drug use and pregnancy expertise
Given birth since 2016 and/or planning pregnancy in the next two years	
≥18 years	
Proficiency in English	
Willing to have the interview audio-recorded	
Provided informed consent	

Methods

- Analysis was informed by narrative analysis methods (8,9).
 - This involves putting transcripts into chronological order and organising them into coherent narratives with defined beginning, middle, and end points.
- Interpretation of the data was informed by an ethics of care lens.

Ethics of care

- Within this theory, Joan Tronto defines “good” care as a practice that involves (10):
 - **Attentiveness** – recognising the needs of those around us
 - **Responsibility** – a willingness to respond and take care of need
 - **Competent** – providing the best quality of care possible
 - **Responsiveness** – consideration of the care-receivers position in the way one delivers care
- Importantly, the judgement of whether care can be classified as good can only come from the person receiving care.

Results

- 30 clinicians were interviewed.
- The median number of years in practise was 25 years (range:10-44).

Clinicians' Specialties	n
Nurse (including nurse practitioners and clinical nurse specialists)	6
Addiction medicine specialist	5
Obstetrician/maternal-fetal medicine specialist	4
Paediatricians/neonatologist	4
Infectious disease specialist	3
General Practitioner	3
Gastroenterologist/hepatologist	2
Midwife	2
Geneticist	1

- 19 parents were interviewed.
- The median age was 41.5 years (range: 31-59).

Parents' Medical History	n
HCV history	
Ever had HCV	14
Never had HCV	5
Currently have HCV	3
Detectable HCV RNA during pregnancy	5
Obstetric history	
1 birth since 2016	15
Currently pregnant	2
2 births since 2016	1
Planning to become pregnant in the next 2 years	1

Clinicians' experiences and definitions of care

- Clinicians' accounts tended to focus on the processes related to performing antenatal HCV testing and referrals (**responsibility and competence**).
- Their evaluations of what was good about HCV care seemed to align with quality control measures like adherence to procedures, timing of testing, referral uptake.

I think our uptake is extremely high..we would do hepatitis C antibodies as the initial screening test and then progress to RNA testing for people who have positive antibodies..because of the involvement of this senior ID specialist [with an interest in pregnancy], those referrals and pathways are seamless and the care is quite smooth. So, I think this is an area that, at our hospital at least, we do quite well.

– Clinician 23, obstetrician

Parents' experiences and definitions of care

- Most parents' had negative experiences during perinatal care.
- Commonly, their experiences were marked by their knowledge and expertise not being believed. Participants did not seem to feel that their self determined needs were **attended** or **responded** to.

So, every time I've been pregnant, I would tell them I've got antibodies. And every single time I've had any contact with the hospital, nurses, etc, they would always come running in and go, "Oh, we've got some news! We've got some news! You've got hep." And I go, "No, I've told you: I've got antibodies." But they would always act like they had to deliver this news..And it was really frustrating 'cause I would know I don't have fresh hep because I hadn't injected. – Parent 3

Parents' experiences and definitions of care

- Many parents' experienced stigma at every phase of their pregnancy.

I felt really stigmatised getting ultrasounds; especially, when my baby moved and changed position, and they couldn't get a good reading, and she started questioning me about drug use, even though I wasn't using drugs at the time..They were just being rude, just saying—this is at 20 weeks—saying, “[it's] not too late to terminate.”
– Parent 14

I gave birth at [Hospital] and I actually wanted to complain..There were a couple of instances where they wouldn't even bring my food into my room because my room had signs on it saying that there needs to be infection control..they never let me know that it [my lunch] was there. I felt very uncomfortable and I felt like I was being judged. – Parent 4

Parents' experiences and definitions of care

- When parents did recount positive experiences, they often emphasised how clinicians were **attentive** to their relational needs as well as their pregnancy and other clinical needs. For example, by clinicians being nonjudgmental and advocating for them during interactions with other social and legal services (e.g., child protection).

The midwife told me not to worry about things, and with the hep C stuff, she was like, “You’re alright. It happens sometimes.” I didn’t feel one bit of shame from her..She just made it [the birth] such a beautiful experience..she made me feel like she didn’t care that I had hep C..They need more midwives like her. – Parent 4

Experiences and definitions of care

- Many clinicians were aware that outcomes for women with HCV in pregnancy would be improved by practice that more strongly emphasised relational aspects of care.

I think like we've definitely come a long way in terms of how we manage conditions like hep C but this mum [with HCV in pregnancy] had a really bad time in hospital..just a lot of stigma and discrimination..in my work with mums who use drugs, so much of the work has just been like, "You are doing your best. You really love your baby. Like you can use drugs and be a good mum." – Clinician 22, nurse

Experiences and definitions of care

- At the same time, clinicians felt that their ability to provide more ideal care was constrained by the systems they work—that health systems do not necessarily prioritise being caring (at least from an ethics of care perspective).
- For example, Antenatal HCV care seems to fall outside of any particular specialty’s “core business”.
- The result of which is fractured care.

I think what's tricky is that services will have done a lot of the work to gain a good rapport and a relationship with individual people, and then have to transfer them to us or vice versa. And that work has to be done again. It may or may not always be successful again—I think there is some sort of risk in that separation [of services].
– Clinician 19, addiction medicine specialist

Discussion

- Our results indicate that parents with substance use challenges receive suboptimal perinatal care, especially in hospital settings, even in the DAA era.
- Parents' relationships and interactions with clinicians have a significant influence on the quality of their experiences.
- The clinicians we interviewed hold both pragmatic and relational understandings of what good care entails.
- The systems they work in seemed to make it difficult to implement care in ways that are more aligned with an ethics of care approach (i.e., with attentiveness, responsibility, competence, responsiveness).

Discussion

- Our findings align with prior research evaluating parents with substance use challenges experiences of engaging with health services during pregnancy (7,11). Including with research conducted 20 years ago (6).
- Despite great progress towards HCV elimination, parents with substance use challenges experience intense stigma, discrimination, and disempowerment in antenatal settings.
- Implementing HCV treatment in pregnancy will not only require updates to guidelines, but continued efforts to eliminate stigma towards parents with substance use challenges in clinical settings.
- Using ethics of care could help us envision models of care that better meet parents' needs, enhancing their access to HCV related care.

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