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# Under the watchful eye of 'a benevolent dictator'

## General practitioner and patient experiences of hepatitis C treatment initiation and shared-care in general practice

### Background

Innovative models of hepatitis C treatment delivery are needed to increase treatment uptake.

### Method

A qualitative evaluation of the Australasian Society for HIV Medicine's Initiation of Hepatitis C Treatment in General Practice Pilot was conducted between November 2010 and June 2012. Structured interview schedules collected data on the treatment experiences of seven general practitioners (GPs) and eight of their patients.

### Results

GPs were satisfied with the process of initiating hepatitis C treatment. They were generally positive about the support they had experienced under shared-care arrangements with tertiary clinics and they saw few barriers to initiating treatment. Similarly, patients appreciated the continuity of care that this treatment model affords, the convenience of accessing treatment from their GP and being treated by a GP they trusted.

### Conclusion

The initiation of hepatitis C treatment through general practice is a viable model that could increase the number of people accessing hepatitis C treatment.

### Keywords

communicable/infectious diseases; hepatitis C; qualitative research; delivery of health care

Australia has up to 10 000 new hepatitis C infection notifications each year and an ageing population of affected people.<sup>1</sup> There is an increasing need for treatment to avoid the social and economic burdens associated with advanced liver disease.<sup>2</sup> Currently, the uptake of treatment in Australia is low, especially among people who inject drugs: only 2% of an estimated 217 000 people living with chronic infection are treated each year.<sup>3</sup> Over the past decade innovative models of hepatitis C treatment delivery have been trialled in opiate-substitution treatment settings,<sup>4</sup> general practice,<sup>5</sup> community health clinics<sup>6,7</sup> and via nurse-led outreach.<sup>8</sup> The aim of diversifying models of treatment delivery is to increase treatment awareness, accessibility and uptake among affected populations.<sup>9</sup>

In an effort to expand the reach of hepatitis C treatment, the Australasian Society for HIV Medicine (ASHM) developed a pilot project of hepatitis C treatment initiation in general practice. The initiation pilot limited recruitment to patients with genotypes 2 or 3 because the duration of treatment is a relatively short 24 weeks and around 80% of patients with genotypes 2 and 3 can expect a sustained virological response (SVR).<sup>10</sup> On the other hand, treatment for genotypes 1, 4, 5 and 6 is for 48 weeks; the SVR rates are significantly lower, at around 50%, and adverse events are more likely to occur because of the extended time patients spend in treatment.

By the time the pilot concluded in June 2012, 38 people with hepatitis C had been treated by eleven initiation prescribers from metropolitan and regional general practices throughout New South Wales. The initiation pilot connected

general practitioners (GPs) with specialist physicians and shared-care teams of allied health professionals who treat hepatitis C patients in authorised tertiary liver clinics. Training of GPs during the pilot included a 2-day workshop with leading specialist physicians, presentations from positive-speakers and information modules. An evaluation of the pilot project explored GPs' and patients' experiences of treatment initiation in general practice. This article reports on findings from the evaluation regarding the criteria for and barriers to becoming an initiation prescriber, and the dynamics of shared-care.

### Method

In 2009, the Highly Specialised Drugs Program gave approval for a 3-year pilot project for accredited community-based medical practitioners to initiate s100 antiviral therapy for chronic hepatitis C. ASHM developed and implemented a treatment initiation training program for GPs, and a qualitative evaluation of the ASHM initiation pilot was concomitantly conducted by the National Centre in HIV Social Research between September 2010 and November 2011. Two brief, structured interview schedules, each comprising nine open-ended questions, were used to explore seven GPs' and eight patients' experiences of the ASHM Initiation of Hepatitis C Treatment in General Practice Pilot. Telephone interviews with GPs and patients averaged 15–20 minutes each.

### Participants: general practitioners and patients

Seven of a total of 11 GPs who participated in the initiation pilot were interviewed for this evaluation. All were long-term opioid-substitution treatment (OST) prescribers, and one GP was also a HIV-treatment prescriber. Four out of the seven GPs worked in community-based practices

with high hepatitis C case loads. The GPs' clinical roles included general health care, hepatitis C-specific health care, and initiation of hepatitis C treatment. These roles were in addition to the GPs' involvement in OST. No specialist physicians were interviewed for this evaluation.

In addition, eight male hepatitis C patients with genotypes 2 or 3 volunteered to participate in the pilot. These men were recruited because they were patients of the GPs involved in the pilot and were interviewed 4–12 weeks after treatment initiation. The men were aged 38–53 years, four were unemployed and four worked, and all were either currently receiving OST or had received treatment in the past. This paper presents a descriptive content analysis of interview data collected during the initiation pilot.<sup>11</sup> This analytical approach highlighted the issues most often raised by participants during interviews.

## Results

### 1. General practitioners in the initiation pilot project

#### a. Becoming an initiation prescriber

Participants identified several key criteria for becoming an initiation prescriber. First, it was believed necessary to have a good, trusting relationship with a specialist physician. Second, it is desirable to have previous experience of working in a shared-care environment. Finally, it is important to have prior experience of caring for people with hepatitis C.

'[Y]ou know, if [a] GP who's never seen a hep C patient before can start doing this stuff, I think you're gonna get some curry floating around. You're gonna get wrong doses. You're gonna get patients, you know, sick with neutropenias.' (GP 4)

Participants stated that a GP needs to have a reasonable case load of hepatitis C patients for the initiation training to be effectively applied. Two participants estimated that to become an initiation prescriber, a GP should care for a minimum of 5 patients all the way through treatment and have a minimum ongoing hepatitis C case load of 10 patients per year. Participants warned against underestimating the challenges of initiating and managing the regimen.

'... I remember having some sort of scary

moments along the way ... I'd only caution most people to bear in mind that when they do carry the can that they might find that they'd want to have a little more experience behind them than they think.' (GP 1)

A majority of participants reported high levels of satisfaction with the initiation training and saw no major barriers to applying the knowledge they had acquired. However, some had experienced a delay of several months between receiving the training and initiating treatment for their first patient. Similarly, the length of time some patients take to decide to have treatment, and then prepare for treatment, could delay applying the knowledge gained during the training.

'The main barrier is getting patients treatment-ready, which takes a long time. It takes years, on the whole, for people to get around to getting treatment. So the time lags here are enormous.' (GP 3)

Initiating hepatitis C treatments in a community-based practice requires access to adequate levels of psychosocial support for managing depression, anger and other psychiatric impacts of treatment among patients. Poor access to psychosocial support was reportedly a potential barrier to GP initiation of treatment.

'[I]t's quite hard sometimes to, to engage enough support. And that's why there's a focus in the course on using peer support organisations and counselling services, and so on.' (GP 6)

#### b. Shared-care: the pros and cons

The most satisfying aspects of shared-care, according to GPs who participated in this pilot, were: (i) the opportunity to network with health professionals who specialise in hepatitis C treatment; (ii) being mentored and supported by a specialist physician; and (iii) being part of a scientific milieu connected to clinical trials where innovation shaped clinical practice.

'Well the thing that works best is the ... access to information so that means that I'm able to give up-to-date information about hepatitis C treatment and outcomes ... cause it's a changing field ... so I can tell people ... "We can treat you. I can tell you what your outcome is likely to be" ... ' (GP 3)

'[H]aving a benevolent dictator at the top of the tree there, the collaborating specialist

available, is useful.' (GP 4)

However, developing a network of allied health professionals for shared-care was described as difficult and time-consuming. Similarly, there was a lack of stability in some shared-care arrangements because of ongoing changes to staffing at local hospitals; this had undermined the effectiveness of at least one team during the pilot.

'So we had a great ... dietician also and a social worker but ... those services have been taken off us. We had a full-time nurse, now we're down to a part-time nurse ... So just constant changes is what's incredibly frustrating for us at the moment ... they've not been able to offer [our nurse] a full-time job so ... she's moved on ... it just does interfere [with shared-care].' (GP 2)

### 2. Patients in the initiation pilot

The eight patients whose treatment was initiated by their GP and who participated in the evaluation of the pilot had experienced symptoms from hepatitis C infection that had reduced their quality of life. The appeal of GP-initiated treatment for these patients centred on the benefits of continuity of care, where hepatitis C treatment was seen as an extension of health services already being provided by their GP. Other factors that attracted participants to GP-initiated treatment included a familiarity with practice staff, avoidance of stigma and discrimination, which participants perceived as more likely in tertiary health care settings, ready access to emotional support, and high levels of trust in their GPs.

'Well I think the reason I took it up was ... purely because my GP sort of assured me that, "If anything goes wrong, we're there for you all the time." So ... I felt more comfortable.' (Patient 7)

'I think the GP is probably gonna understand your problems and stuff a lot, a lot more than some stranger in a hospital.' (Patient 8)

The regulations surrounding the dispensing of hepatitis C treatment medications via the community pharmacy led to access difficulty for some participants who were required to travel long distances to reach major hospitals to fill their prescriptions. Despite this minor

difficulty, GP-initiated treatment afforded greater convenience for participants as GPs were able to coordinate the ongoing testing and monitoring that is required during treatment. Participants valued the convenience, safety and personal care provided by their GPs and practice nurses.

'... [My GP] has people to do the blood tests. You get to see your GP once a week also ... and ... the nurse, they explain [the results] to you. They ask you how you're feeling. They make you feel a lot more comfortable. And, since you've known them for a while, you do feel comfortable.' (Patient 6)

All participants reported that the offer of treatment through their GP had been the primary motivating factor in deciding to commence treatment.

## Discussion

All GPs who participated in the ASHM Initiation of Hepatitis C Treatment in General Practice Pilot reported a high level of satisfaction with the training they had received during the trial. The training for the pilot gave GPs the expertise and confidence to initiate hepatitis C treatments for patients with genotypes 2 and 3. Similarly, patient-participants in this pilot reported high levels of satisfaction regarding their experience of GP treatment initiation.

### Becoming an initiation prescriber: criteria and barriers

As has been noted in previous research,<sup>12</sup> to meet the criteria for initiation prescribing, GPs need a sufficient hepatitis C case load to enable the knowledge and skills obtained during the training to be applied in a timely manner. While most GPs in the pilot project prescribed opioid-substitution treatments, worked in high case load practices and had expertise in providing psychosocial support for their patients, some had reported substantial time lags between their training and initiating their first patient, or they had few patients under their care who required treatment at the time of the pilot. Time delays and small case loads can potentially reduce GPs' expertise and confidence in applying the training. Strategies such as evening seminars, workshops and other opportunities for professional development can be implemented

to keep prescribers up to date. Another approach to keeping updated, and which was suggested by several GPs, is uploading the content of the training modules to the internet. It is likely, however, that many GPs who are interested in becoming hepatitis C treatment initiation prescribers will have sufficient case loads to sustain their skills.

### The dynamics of shared-care

Currently, there is little evidence-based support in the literature for shared-care.<sup>13</sup> Building stable and productive shared-care teams can be difficult and expensive because it involves complex, cross-system coordination of health care resources and staffing. Nonetheless some research has found that shared-care has contributed significantly to improving hepatitis C treatment adherence,<sup>14</sup> including among people with psychiatric and substance use disorders.<sup>15</sup> Shared-care has also been described as an important asset for treating patients in regional areas<sup>16</sup> and other community settings.<sup>17</sup> Generally, GPs viewed shared-care in the pilot project as an opportunity to develop professional relationships with specialists and allied health professionals. In some instances during the pilot, suitable professional networks for shared-care were pre-existing; however, it often requires considerable time and effort to constitute shared-care teams.

It is likely that for GP-initiated hepatitis C treatment to work, GPs need to establish a strong relationship with a specialist, built on mutual respect and trust, or they risk being marginalised within shared-care arrangements. Conversely, the tertiary treatment centres have to embrace shared-care for treatment initiation in general practice to work. Notwithstanding these dynamics, the coordination of procedures, such as testing, and the communication of test results, which were integral to the success of shared-care, had generally worked well throughout the pilot.

### Patient perspective

Most patient-participants in the pilot contrasted the relatively intimate model of GP-initiated treatment with their experience of large, impersonal hospital-based services. Patient-participants conceptualised GP-initiated treatment as a personable, safe, convenient

and logical extension of their health service needs: many patient-participants had known their GPs for years, sometimes since childhood. They trusted their GP and they also had a good rapport with the general practice staff, including receptionists and practice nurses. GP participants knew their patients' medical history and their drug use history, and participants felt no pressure to explain themselves or their past behaviour. The GPs were often managing participants' OST, so having them also manage hepatitis C treatment was viewed as a natural continuation of this care – a one-stop-shop approach.<sup>18,19</sup> The patient-participants liked their GPs doing all the blood testing, because it was more convenient than attending a large hospital where people are more likely to be shunted between departments, and where they risk encountering hostile attitudes from unfamiliar hospital staff. Community-based practices are often closer to home than tertiary clinics, there is usually a wide choice of appointment times available, and it is possible to book appointments at short notice. Patient-participants wanted the opportunity to have hepatitis C treatment in a safe and familiar environment, which was convenient and well supported.

It should come as no surprise that people with a history of injecting drug use are enticed by the prospect of GP-initiated hepatitis C treatment. This model of treatment delivery circumvents a need to regularly attend large health care facilities, where stigmatisation of, and discrimination against, people with hepatitis C remains a considerable concern.<sup>20</sup>

This article draws upon data from a qualitative evaluation of the ASHM's Initiation of Hepatitis C Treatment in General Practice Pilot. Although the sample of GPs in this pilot was small, it comprised seven of the total of 11 GPs in NSW who participated in the pilot, which is approximately 64% of participating GPs. As patient-participants were interviewed before treatment concluded, no data on SVR rates were collected, so it was not possible to compare SVRs for GP-initiated treatment with SVRs from clinical trials or tertiary liver clinics. Finally, this evaluation did not include interviews with specialist physicians, so their views on all aspects of the pilot remain unknown. Future evaluations should record the experiences of

specialist physicians.

## Implications for general practice

- Hepatitis C treatment delivery through general practice can significantly increase the number of sites throughout Australia where people will be able to access hepatitis C treatment.
- GP-initiated treatment under a shared-care model encouraged hepatitis C patients to have treatment.
- The evidence presented in this article supports the initiation of hepatitis C treatment by GPs within a program of shared-care.
- Hepatitis C treatment initiation can enhance GPs' clinical skills, increase the breadth of GPs' professional networks and facilitate an ongoing therapeutic relationship between GPs and patients with hepatitis C, many of whom fear stigmatisation from health care services.

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