Introduction

This report features testimony from liver nurses from across England regarding their experiences of caring for hepatitis C patients. The report particularly focuses on the effects, both on patients and the nurses themselves, of NHS England’s current approach to delivering new direct acting antiviral (DAA) treatments, which is to limit access to these treatments to just 10,011 people in 2016/17 (rising to 12,500 in 2017/18).

The nurses’ testimony came in response to a survey conducted by The Hepatitis C Trust, which was sent to members of the British Association for the Study of the Liver (BASL) Nurse Forum, along with liver nurses on The Hepatitis C Trust and HCV Action mailing lists, in December 2016.

The Nurses’ Perspectives report is a companion piece to The Hepatitis C Trust’s Patient Perspectives report and backs up many of its findings. In particular, the nurses’ responses echo those of the patients we interviewed in relation to the distress, uncertainty and frustration being caused by the current restriction on access to treatments for hepatitis C.

The report emphasises the negative impact the cap is having on the nurse-patient relationship, with the vast majority of nurses who responded to the survey reporting having been unable to give patients a clear idea of when they would receive treatment, leading to anger, distrust and even disengagement from care. Given the importance of mutual trust and good faith between nurses and patients, this is extremely concerning.

The responses gathered in this report highlight the stress nurses feel as a result of the treatment cap. Nurses enter the profession due to a desire to help people and many feel that the cap prevents them from offering patients the care they need. The effect on nurses’ morale is considerable, with many feeling undermined by their involvement in having to deny care to those who need it.

It is clear from the nurses’ testimony in this report that the rationing of treatment for hepatitis C is harmful to both patients and nurses. Delivering new hepatitis C treatments in the same manner as other NICE-approved therapies (i.e. without restrictions on access) would not only help to restore the morale of nurses dealing with hepatitis C, but would ensure we are able to make real progress towards achieving the UK’s international commitment to eliminate hepatitis C as a major public health concern by 2030.

Background

Hepatitis C is a blood-borne virus that can cause fatal liver damage and cancer if left untreated. Around 160,000 people are chronically affected with hepatitis C in England.

In 2015, NHS England took the unprecedented step of placing a cap on the number of patients able to access treatment, specifying a limit of 10,011 treatment initiations for 2016/17. Together with local ‘run rates’ for treatment that determine the number of people able to be treated in areas across England, this approach denies people with hepatitis C their right to NICE-approved treatments as enshrined in the NHS constitution, and limits the potential that exists to eliminate hepatitis C as a serious public health concern.

Hepatitis C care is coordinated by 22 Operational Delivery Network (ODNs) across the country. ODNs are the structures through which hepatitis C treatment in England is being delivered. They involve regional centres which manage treatment decisions and prescribing, and which have a dispersed treatment model, or ‘hub and spoke’ model, which NHS England says aims to support partnership working and access for local patients. ODNs are responsible for meeting the run rates in their area by treating no less than 90% and no more than 100% of their run rate, with a failure to comply resulting in substantial financial penalty for that NHS trust.
A particularly concerning effect of the treatment cap is the damage that is being done to the nurse-patient relationship. Nurses who responded to the survey highlighted the range of ways their relationship with patients has been harmed.

Many spoke of patients losing trust in healthcare professionals after being informed that they would have to wait for treatment. This was a source of real distress to nurses, compounded by the fact that they had to inform patients of decisions which they themselves had no say in. One nurse said they felt ‘frustrated’ that patients had lost trust in them despite decisions about access to treatment being “beyond our control”. The loss of trust has knock-on effects, with one responder to the survey noting that setbacks in trust can make it extremely difficult to rebuild relationships in order to properly support and monitor patients.

One respondent said that informing patients that they must wait for treatment “damages our relationship and makes it about money and not care”. Others said that they want to advocate for patients “but end up being the one that has to let them down again”, and that “it is somewhat depressing to always be the bringer of bad news”. The emotional toll of having to inform patients that they are not going to be receiving treatment is considerable. Nurses felt that they were “left to deal with the fallout. It is heart-breaking as you see the penny drop and they begin to realise they are being told ‘no’. Then, as a nurse you are left holding all that distress.”

“Managing patient expectations can be hard enough, but to have navigated a system and then to have the rug pulled out from under your feet at the last minute makes it particularly difficult.”

Nurses were particularly unhappy about having to inform patients of delays in scheduled treatment timeframes, saying that it made them feel “unprofessional”, with one saying it gave patients the impression “that I don’t know what I am doing”. Again, nurses felt frustrated that they had to pass on decisions that they were not responsible for, with one telling us: “It is infuriating when the patient has been motivated, plans have been made, and due to bureaucracy, not capacity, you have to let a patient down.”

Respondents also noted the inefficiency of the processes for getting access to treatment for patients. For example, one nurse expressed frustration at the delays caused by the requirement for another Operational Delivery Network (ODN) to sign off on more expensive treatments, known as ‘second line sign-off’. At the time of the survey, the nurse knew of 20 patients awaiting second line sign-off, with some decisions still pending after eight months. Other nurses felt that time they should be using to care for patients was being taken up with unnecessary bureaucracy, with one saying “Because we are only allowed to treat low numbers we spend more time assessing people to go on a waiting list.”

Another nurse said the extra work involved in adhering to the treatment cap is “a logistical nightmare”, believing that it would be far more efficient to treat patients immediately upon, or as soon as possible after, referral. The treatment cap is also, according to respondents, having a significant effect on nurses’ ability to plan ahead, with regular changes by NHS England making it difficult to manage workloads. These bureaucratic inefficiencies in the system further strain the relationship between nurses and patients.

The treatment cap and the subsequent change in the nurse-patient relationship is having a significant impact on nurses’ morale. Nurses expressed anger, frustration and even guilt, describing the situation as “stressful”, “upsetting” and “demoralising”. Many felt that their role was being undermined, with one nurse saying they felt like “an unappreciated cog in the wheel of a machine, purely in place to deliver the message no-one else wants to deliver”. Others said they had “no control” and felt “like the middle man delivering the bad news”, “like I am giving sub-standard care” and “like a manager, not a carer”.

“Second line sign-off is a way of stopping treatment. It does not benefit patients, it is causing them harm. It only protects NHS England’s finances.”

“Managing patient expectations can be hard enough, but to have navigated a system and then to have the rug pulled out from under your feet at the last minute makes it particularly difficult.”

“Even if a patient knows it is not your choice and outside of your power, it has a knock-on effect on their confidence in you and being able to trust what you say.”

“Sometimes I can feel anxious if the patient is upset or angry. I also feel empathy for the patient, and am frustrated that I know there is an effective treatment that is not being made available.”
Effect on patients

Nurses are keenly aware of the effect the treatment cap is having on patients, with nurses reporting widespread resentment and disappointment among those denied access to treatment.

It is clear from the responses received that nurses are concerned about their patients’ mental health, as well as the physical risks of delaying treatment. Respondents reported that being unable to access treatment “reinforced low self-esteem” among patients, leaving them feeling “very upset” and “in limbo”.

As well as encountering angry and frustrated patients, however, many nurses had met patients who felt so undervalued and demoralised that they accepted having to wait for treatment without complaint. We were told that “most patients are very accepting, as it is a population who are made to feel worthless by society”, with patients feeling

“People just feel defeated by the rules and the fact that they have no right to appeal or question decision makers as to how they can justify denial of treatment.”

so ‘tired, depressed and stigmatised’ that they are resigned to being treated unfairly. One nurse felt that the other issues in many hepatitis C patients’ lives made the decision to ration treatment possible, saying: “If it was cancer, there would be outrage if effective treatment was available but people were told they would have to wait for the cancer to progress before they could access it because too many people had had treatment in that month”.

“Patients are angry and frustrated that such a good treatment is available but that they have to have more fibrosis or cirrhosis to qualify immediately.”

The nurses who responded to our survey were clear about the perverse effects of the treatment cap, and the impact on patients as a result. By prioritising access to treatment for those with the most severe damage to the liver, patients are being forced to wait for their physical condition to worsen before they are able to receive the new drugs.

“I am fearful that we are encouraging the spread and potential increase of the virus, despite talks that we should be aiming to eradicate it completely. It is totally hypocritical.”

Many had encountered seriously ill patients who were not receiving care, with one nurse aware of patients not receiving treatment despite being on a waiting list for a liver transplant or having liver failure or cirrhosis. Another spoke of a patient that had died of hepatitis C-related liver cancer while still waiting to receive treatment.

A number of nurses said that the cap on the new treatments was leading to patients disengaging with care after being informed that they would have to wait for treatment. One nurse said that she believed some people with hepatitis C knew they were infected with the virus but chose not to engage with healthcare services because they heard they would not be able to access treatment – which increases the risk of spreading infection.

“Some patients tell me they won’t bother coming back.”

It is clear from the responses to the survey that nurses are extremely concerned about the effects the treatment cap is having on patients – not only in terms of their physical condition, but also in relation to the significant mental strain of continuing to live with the disease while awaiting treatment.

Conclusion

It is evident from the testimony in this report that the restriction on access to treatment for hepatitis C is eroding patients’ trust in nurses and putting the nurse-patient relationship under pressure.

Respondents to the survey felt that bureaucracy was preventing them from providing adequate care and had changed their role from ‘carer’ to ‘manager’. The result of these changes is falling morale among nurses, with many feeling that they are left to deal with the consequences of decisions taken by others.

Nurses are also witnessing the widespread distress among patients who are being forced to wait for treatment. Their experiences with angry and demoralised patients support the findings of The Hepatitis C Trust’s Patient Perspectives report and further highlight the harmful effects of the treatment cap.

Overturning the treatment cap would benefit both patients and nurses. It is also imperative in order for the UK to meet its international commitment to eliminate hepatitis C as a major public health threat by 2030. Nurses were sceptical about the prospect of the UK achieving this commitment while the cap is in place, with one saying that “we are not likely to get rid of hepatitis C within the next 10 years at the rate we are going”. This, along with the harmful effects of the cap outlined in this report, emphasises the urgency of increasing access to treatment for hepatitis C patients.