Improving the Processes of Care

Exploring the need for hepatology nurses and allied health professionals in Victorian liver clinics

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Abstract

Objective: To examine the need for hepatology nurses and allied health professionals in Victorian liver clinics to meet the increasing demand from people seeking treatment for hepatitis C infection.

Design: We reviewed the literature, analysed data from nine Victorian liver clinics, and conducted a qualitative rapid assessment with key stakeholders including hepatology nurses.

Participants: Fourteen key stakeholders including clinicians and directors of liver clinics were invited to take part in interviews; two declined to participate. All ten members of the Victorian Hepatology Nurses Group were invited to participate in a focus group discussion, and six attended.

Results: Participants reported that hepatology nurses played a critical role in improving treatment uptake and compliance, in particular, in educating, counselling and managing treatment for people with hepatitis C infection. Psychiatric and social work staff assisted patients to overcome side effects associated with treatment. Interpreters increased access for those from culturally and linguistically diverse communities.

Conclusions: Hepatology nurses and allied health professionals are central to enhancing treatment outcomes for people who are infected with hepatitis C. Further research is necessary to estimate the number of nurses and allied health professionals required to meet the current and future needs of people receiving treatment for hepatitis C infection.

What is known about the topic? Hepatitis C virus (HCV) causes a significant public health burden on the community, and the demand for treatment will increase. Effective delivery of treatment is complicated by serious side effects and resultant difficulties for patients in complying with treatment.

What does this paper add? Hepatology nurses were found to be central in enhancing patients’ understanding and management of their treatment, and thus contributing to better outcomes. Psychiatric support assisted patients to overcome psychological side effects associated with treatment. Social work staff and interpreters were integral in addressing the non-medical needs of patients. Funding of services is ad hoc, with reliance on clinical trial funding.

What are the implications? Growing demand for HCV treatment will require a secure source of ongoing funding for clinics, including hepatology nurses and other allied health and support staff. Further research is needed to identify the optimal mix of health professionals.

Hepatitis C Virus (HCV) is a prevalent flavivirus responsible for the vast majority of cases of viral hepatitis and can lead to chronic hepatitis, with an estimated 75% of affected individuals becoming chronic carriers. Twenty-five per cent of chronic carriers are at risk of developing liver cirrhosis within 20 years, and a quarter of those with cirrhosis will develop primary liver cancer within a further 5 to 10 years. The burden of HCV is difficult to estimate because the condition is chronic and largely asymptomatic until cirrhosis and end stage complications develop. Modelling suggests that around 210,000 Australians are currently living with HCV with about 16,000 new
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infections each year. The number of people infected with HCV is expected to continue to increase, with an estimated 321,000 to 836,000 Australians predicted to be living with HCV by 2020. Based on these figures, it is anticipated that there will be a threefold increase in the number of people living with HCV-related cirrhosis and in the number of HCV-related deaths by the year 2020.

An estimated 80% of infections in Australia are acquired through injecting drug use. People who inject drugs are often marginalised and reportedly experience difficulties in accessing mainstream health and social services. There is evidence to suggest that individuals accessing HCV treatment have been dissatisfied with their care, reporting communication difficulties, feelings of abandonment or being misled and feeling stigmatised by their physician.

Pegylated interferon injection self-administered once a week in combination with oral ribavirin twice daily is an improvement in therapy which was listed on the Pharmaceutical Benefits Scheme (PBS) in November 2003. Sustained viral and histological responses to therapy translate into long-term remissions with potential reversal of fibrosis and a reduction in the incidence of liver cancer. However, the current treatment has serious side effects including fatigue, influenza-like symptoms, myalgia, nausea and/or vomiting, weight loss, reversible hair loss, injecting site irritation, insomnia, bone marrow suppression, and major depression including suicide attempts. Not all patients complete their course of treatment, and in 2003 only 1500–2000 of the 30,000 individuals eligible for government-funded treatment accessed it through the PBS. Nevertheless, the advances in treatment and the anticipated increase in demand will pose numerous challenges for tertiary public hospitals where the majority of liver clinics are situated.

The current treatment with pegylated interferon and ribavirin is expected to remain the cornerstone of therapy for several years to come. There is anecdotal evidence to suggest that a number of hepatology nurse positions are funded by clinical trials to provide care for patients participating in research. Once the trials are completed it is unclear how the positions could be maintained to provide ongoing care and support for continuing and new patients.

The literature documents the positive impact of nursing care on patient compliance and improvement in quality of life during interferon and ribavirin treatment. Effective management of individuals undergoing treatment for HCV requires a partnership approach based on open communication, trust, shared decision making and information exchange.

In their role as patient advocates, hepatology nurses have the ability to enhance treatment compliance. This involves treating the patient as a whole person, with many potential interacting issues rather than a person with one disease, and requires a non-judgmental and respectful attitude towards patients’ needs, treatment preferences and lifestyle. The provision of information on the full range of non-medical approaches to managing HCV infection fosters a supportive treatment environment by addressing the personal, lifestyle, occupational and social needs of individuals.

The purpose of this study was to explore the role of hepatology nurses and allied health professionals in meeting the current and future needs of HCV patients for care, and to identify the current levels of demand for HCV treatment in both rural and metropolitan areas.

Participants and methods
A qualitative rapid assessment was undertaken with key informants in the hepatitis C sector and with hepatology nurses. Interviews were conducted at the informants’ workplaces in late 2003 and early 2004 by JPE and MK with assistance from a colleague. JPE subsequently shared the findings of the interviews with nurses participating in the focus group discussions, and incorporated their feedback in the emerging research.

We invited 14 key informants to take part in the interviews, including clinicians and directors of Victorian liver clinics, Victoria’s Viral Hepatitis Educator and representatives from the Hepatitis C...
Council of Victoria. All ten members of the Victorian Hepatology Nurses Group were approached to provide a written response to a questionnaire and attend the focus group. JPE and MK, with the assistance of a colleague, recruited participants by letter or email followed up by a telephone call. Sampling was purposive as participants were identified because they had the required expertise and experience. A semi-structured interview schedule was developed to guide the interviews and was sent to the informants before their interviews. The interview schedule was flexible enough to allow both respondent and interviewer to pursue other relevant leads and avenues of discussion. Interviews were recorded onto audiotapes and transcribed. Question areas included in the schedule were the demographic characteristics of patients accessing liver clinics, the estimated level of unmet demand and waiting times for accessing the clinics, the number and role of hepatology nurses and other health professionals employed in the clinics, current sources of funding, and options for meeting the expected increase in demand for services in both rural and metropolitan areas.

A separate schedule was developed for the nurses’ focus group discussion, focused specifically on the nurses’ roles and responsibilities, and the key issues facing health professionals employed in liver clinics. We invited the nurses to respond individually and collectively to the schedule before the focus group discussion. The focus group discussion was also taped and transcribed.

JPE transcribed and analysed the audiotapes using content analysis with a thematic approach. Data were de-identified and presented in an aggregate form. A draft report was sent to all participants to ensure that their comments were not misrepresented or taken out of context, with a 14-day response period. The views of nurses and the key informants (doctors, a health educator and representatives of non-government organisations) were compared, to identify patterns of convergence and to ensure a more reflexive analysis (taking into account possible personal and professional biases).

Data on patient numbers and treatment episodes from nine clinics across Victoria (six metropolitan and three regional) were also collected and collated.

Results

Of the fourteen participants invited to take part in the interviews, twelve accepted and two did not respond despite repeated attempts to contact them. Ten interviews were conducted face-to-face. Two participants were unable to be interviewed and provided responses to the question areas by mail. Six out of ten nurses completed the written questionnaire and six nurses from metropolitan clinics attended the focus group discussion. Some nurses provided written responses and also participated in the focus group discussion.

The need for and role of hepatology nurses in HCV treatment

All clinicians stressed the central role of hepatology nurses in enhancing patient outcomes. One reported, “The role of the hepatology nurse in a liver clinic setting is absolutely essential. I think liver clinics sink or swim on their ability to provide decent nursing care.” The clinicians referred to hepatology nurses as “a physician extender” and stated, “They are critical because of the issues around adherence to the medications”. The support that nurses provided for patients on therapy and its effect on compliance and quality of life during interferon and ribavirin treatment was found to be central in enhancing patient outcomes, “If you don’t give them good nurse education with these drugs, then the drugs don’t work”.

Based on the interviews and feedback from the questionnaires, the responsibilities of the nurses could be divided broadly into the categories of education and support, management of treatment and research. As one clinician put it:

Their primary function is one of education, because someone’s got to teach them how to actually give themselves the drug (pegylated interferon), spend half an hour to an hour
Talking to them about potential side effects of this difficult treatment and the more time you spend advising people and encouraging people the better off you are.

The hepatology nurses interviewed felt that the development of effective relationships with the patients was also a vital part of their work. Nurses discussed their role in “starting [an] ongoing relationship with the patient during their care”. They were also reported to be the first point of call for patients seeking advice or assistance with their treatment. One clinician said, “People taking the particular treatments need someone who they can contact fairly quickly and easily and feel comfortable with, which isn’t always the case with the doctors prescribing the treatments”.

Nurses felt they were in a position to identify with this role more than clinicians due to the competing demands on doctors. “Nurses are trusted and are approachable. Patients identify really quickly with the nurses”. One nurse highlighted the situation that arose in the absence of an ongoing relationship: “Patients don’t have ownership, not just [for] their treatment but their care and management — those that don’t turn up — they haven’t made that connection”.

From the nurses’ questionnaires, the effective management of the treatment of patients included “assessing suitability to commence treatment”, and “follow-up and monitoring”. Several nurses felt that the “provision of an on-call service for advice and psychological support for clients while having treatment” was necessary. Their role was described as acting as a continual “liaison with the treating doctor on dose reductions to ensure client safety [and] with various allied health professionals including pharmacy, pathology and outpatients to ensure optimal service and outcomes for clients on treatment”. Nurses’ participation in research was seen as essential to “liaise with drug companies and complete required documentation” and “assist with documentation for Therapeutic Goods Administration and ethics [committees]”.

Clinicians emphasised the cost-effective nature of the work of hepatology nurses, with one stating, “This is the best way to spend the dollar, because this really gets patients treated properly.” The nurses surveyed felt that their work merits consideration as a nursing specialty. From the nurses questionnaire it was evident there was concern about the lack of recognition, with one nurse stating it was “… imperative for nurses … to be officially recognised to perform the functions they are already doing”. They believed this area of nursing parallels that of other specialties such as diabetes educators: “Diabetes educators are allied health — ideally hepatology nurses would be there”.

Roles of other health professionals in providing care and support for those with HCV

During the course of treatment, patients can develop psychological and physical side effects that can be debilitating. It was reported that the current treatment with pegylated interferon and ribavirin has been associated with the development of depression and anxiety among some patients. One clinician stated, “Depression is an important factor in getting patients to the end of treatment … if you can manage depression, you’re more likely to get a person all the way through to the end of successful treatment”.

Five liver clinics reported that they provided psychiatric support on an ad-hoc basis for those experiencing acute psychiatric episodes. However, dedicated psychiatrists were not available for each service. It was reported that several clinics provided privatised psychiatric services to patients as a means of bypassing waiting lists. In all, interviews revealed that three clinics had access to the services of social workers. One clinic reported that psychiatric services were not provided to patients, and this was significantly affecting treatment outcomes for those patients with pre-existing psychiatric comorbidity. “One of the biggest problems we have is lack of psychiatric assistance … a lot of these patients have pre-existing psychiatric comorbidity and the treatment induces a lot of it so we’ve had patients who’ve become manic on therapy”.
**Funding arrangements**

Key stakeholders shared the concern that securing funding was an ongoing challenge for hepatology clinics across Victoria. Funding sources for clinics varied according to their mode of operation. Outpatient services in the larger tertiary (Group A) public hospitals in Victoria are currently funded through the Victorian Ambulatory Classification and Funding System (VACS). At the time of the study, the majority of the large metropolitan clinics were also reliant on clinical trial funding to employ nurses and their support staff. However, this source of funding was unpredictable. One clinician stated, “Every unit around Melbourne . . . right now is using their own resources . . . and looking after standard patient care”.

Several clinicians reflected on the reasons why the provision of services for the care and support for HCV was limited. One clinician said, “They’re a marginalised group that don’t have a lot of political clout” and another commented, “The problem is that hep C patients have no lobby group . . . here we have a curable virus that we can often do things about and prevent people from getting long-term problems and I think their background shouldn’t be part of the story, they just don’t have the voice”.

All metropolitan clinics reported they were well staffed with respect to clinicians. This is an inconsistent finding given that five of six metropolitan clinics reported funding shortages. Clinicians were candid when asked about the number of clinicians servicing the clinics: “There’s a lot more doctors . . . in this clinic, it’s very well staffed as far as doctors are concerned”.

**Persons seeking treatment for HCV**

Data from clinics indicated that all metropolitan clinics provided treatment for individuals from culturally and linguistically diverse communities, with two clinics reporting 50% of clients from backgrounds where English was not the first language spoken.

Three clinics reported an upward trend in the number of patients seen, while the remainder recorded stable demand. Nurses and clinicians consistently commented on the increasing demand for services. One clinician lamented, “There is no doubt that we have not seen the majority of people we should see” and another stated, “With the registration of pegylated interferon . . . the demands are now increasing because of new drugs and better drugs, more importantly, better drugs — and so how do you cover that?”

Clinicians also noted the demands were affecting doctors and nurses differently. One said, “There’s demand as far as doctor demands are concerned, there’s demands as far as patient waiting times and then there’s demand for our nursing time, and if we have one weak point, one problem, it’s the nursing time.”

This was echoed by the nurses in their responses to the questionnaire, “[There is] insufficient time made available for patient interviews, assessment and counselling re liver disease, treatment options, treatment management”. Another nurse commented on the effect of these demands, stating there was “burn out for existing staff, lack of appropriate training for nursing staff to fulfil roles left vacant [and] many nurses work in excess of hours paid for”.

Waiting times for clinics varied from 2 weeks to 6 months, with the average waiting time about 10 weeks across all clinics. Clinicians reported that individuals from culturally and linguistically diverse communities experienced the longest waiting time due to limited access to interpreter services. “The most difficult ones for us are the ones who don’t speak English — the worst waiting time is the liver clinic in the hospital where they don’t have interpreters”. The shortest waiting times were for those patients prepared to see clinicians in their private practices, where waiting times were short or non-existent.

**Improving access for those from rural and regional areas**

Clinicians agreed that the number of health professionals currently providing hepatitis care and treatment in regional and rural Victoria was insufficient. Various models of operation to provide services to these areas were explored. One clinician suggested the employment of “up to three or four hepatology
nurses who are based at a teaching hospital and then do a session of outer suburbia and country during the week” stating that “It would be wrong to put the nurses [in rural areas] or make the nurses part time. They’re better off being full time and travel[ling]”. Another proposed a regionally based service where nurses would operate in a shared care model: “It might be a regional nurse and . . . interested doctors who will then liaise with that regional nurse”. Several clinicians supported the establishment of regional centres with local expertise to address issues of access for those living in rural areas, emphasising there was a need to “establish a community-based specialist clinic in those areas and have those people locally trained”. 

A number of clinicians proposed establishing alternative models of practice, such as enhancing the role of the hepatology nurse to take a lead in therapy, as part of an overall strategy to cope with demand. “We have to develop some innovative model. I’m thinking using nurse practitioners in a different style clinic — the head of the unit will be a doctor and you will have three nurse practitioners”. Nurses felt they had the “skills to manage most of their [patients’] care. Obviously [with] doctors in the background making sure everything is OK with no problems and giving you authority . . .” and discussed the possibility of working autonomously in the first line of treatment, for example patient triage, providing testing and counselling before connecting patients with clinicians for the prescription of treatment.

Several clinicians also flagged the issue of stigma in rural and regional areas. One stated, “The other issue in rural regions . . . often people are not very comfortable that their confidentiality may be maintained in their local health services and stigma associated with hep C is still so big in those communities”.

**Discussion**

Study participants emphasised the critical role of nurses in enhancing patient compliance with therapy and agreed that this was a cost-effective means of preventing cirrhosis and liver failure associated with chronic HCV infection. However, study findings suggested that support service arrangements for patients on HCV treatment were often limited and administered in an ad-hoc manner. A systematic approach for the referral of patients to psychiatric and social support services, and effective coordination of these care processes would be likely to enhance treatment compliance and subsequently improve the long-term health outcomes for patients. The anticipated increase in demand for treatment and support services necessitates an examination of the current disciplinary mix within liver clinics in order to identify the deficiencies and inform future action.

Clinical trial funding for the employment of hepatology nurses and support staff in the larger metropolitan hospitals represented an unpredictable source of funds, recurrent only if the trials continued. Clinicians speculated that clinical trial funds might be reduced or discontinued as the current treatment with pegylated interferon and ribavirin would continue to be the cornerstone of therapy for several years.10 The absence of nursing and social support for those who are seeking or who are on treatment may have a negative impact on the number of people commencing and adhering to treatment. The establishment of consistent recurrent funding for liver clinics would be a requisite for the provision of optimal treatment support and care and would assist in meeting the anticipated increase in demand for treatment.

Current demand for HCV treatment had resulted in an average waiting time of about 10
weeks across all clinics. Participants in the study explored possibilities for coping with demand growth, including increasing the existing number of public outpatient clinics, increasing private hepatology clinics, implementing a nurse practitioner model and expanding shared care arrangements, and regional centres to provide services for patients living in rural areas.

There is a growing number of general nursing staff caring for people with HCV, yet in Victoria there is no provision for specific training and ongoing funding for hepatology nurses to ensure this practice area continues. Wide variation in position classifications and the diversity within the position descriptions of study participants reflected the ad hoc nature of their training and employment. Further research is required to inform the current understanding of funding and workforce needs with respect to hepatology nurses. Further, comparative patient outcome studies to determine the relative efficiency of clinical structures and the role of hepatology nurses in enhancing patient outcomes would be valuable to identify the most cost-effective models of operation.

Data from the interviews indicated that waiting times for clinics varied widely depending on the level of support required by the patient and their ability to access the private system. For example, clinicians noted that patients who required interpreter services in public outpatient clinics experienced unacceptably long waiting times. At the time of the study, private clinics did not provide interpreter services and this compounded the access issue for this group. Any shift towards private hepatology clinics could potentially disadvantage these populations as treatment at these clinics includes a possible copayment and an absence of interpreters. The provision of adequate interpreter services in both public and private settings would increase access and reduce waiting times for this already marginalised group.

A uniform standard of record keeping across clinic databases is essential for quantifying individual patient nursing care and treatment support requirements as well as documenting provision of services across Victoria. Data collected must be administratively appropriate, as well as complete and clinically meaningful, with both patient level and episode level data collected in order to ascertain the number of patients accessing clinics, the proportion initiating treatment and the occasions of care per patient.

**Limitations**

The purposeful sampling of study participants may have biased the study results. Those who refused or could not participate may have had differing views. The researchers and interviewers represented the Department of Human Services in Victoria, which is a potential source of funding for clinics, and this could have influenced participants’ responses. As this was a rapid assessment to inform future studies, we did not interview liver clinic patients, so this study lacks the perspective of health care consumers.

**Conclusion**

HCV infection is a significant public health burden with a considerable estimated cost to the health system due to the long-term sequelae of the disease if it is left untreated. The advent of an improvement in therapy coupled with its availability through the Pharmaceutical Benefits Scheme means the number of people seeking treatment for HCV is likely to increase significantly.

This study found that hepatology nurses and allied health professionals played a central role in the care of those seeking treatment and support for HCV. Hepatology nurses enhanced patient outcomes and were identified as a cost-effective means of meeting the anticipated demand for HCV treatment. Support staff such as psychologists and social workers complemented the clinicians and nurses by providing ongoing assessment and support during the treatment cycle and beyond. In addition, interpreters provided language support and assisted with cultural issues for patients from culturally and linguistically diverse backgrounds. Securing ongoing funding for hepatology nurses, psychiatric servi-
ices and support staff would improve patient compliance and, consequently, health outcomes.

Identifying the appropriate mix of models to respond to the anticipated increase in demand and ensure equitable access to HCV treatment is a task that merits further consideration. Research is also necessary to quantify individual patient nursing care and treatment support requirements and to estimate the number of nurses and allied health professionals required to meet current and future demands for HCV treatment services.

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Competing interests
The authors declare that they have no competing interests.

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