AHA CONSENSUS-BASED NURSING GUIDELINES FOR THE CARE OF PATIENTS with Hepatitis B, Hepatitis C, Advanced Liver Disease and Hepatocellular Carcinoma

AUSTRALIAN VERSION – SEPTEMBER 2012

Endorsed by:
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<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AASLD</td>
<td>American Association for the Study of Liver Diseases</td>
</tr>
<tr>
<td>AFP</td>
<td>Alpha-fetoprotein</td>
</tr>
<tr>
<td>AHA</td>
<td>Australasian Hepatology Association</td>
</tr>
<tr>
<td>ANF</td>
<td>Australian Nursing Federation</td>
</tr>
<tr>
<td>ANMC</td>
<td>Australian Nursing and Midwifery Council</td>
</tr>
<tr>
<td>Anti-HBe</td>
<td>Hepatitis B E antibody</td>
</tr>
<tr>
<td>Anti-HBs</td>
<td>Hepatitis B surface antibody</td>
</tr>
<tr>
<td>APASL</td>
<td>Asian Pacific Association for the Study of the Liver</td>
</tr>
<tr>
<td>BCLC</td>
<td>Barcelona Clinic Liver Cancer</td>
</tr>
<tr>
<td>BMI</td>
<td>Body mass index</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and linguistically diverse</td>
</tr>
<tr>
<td>cccDNA</td>
<td>Covalently closed circular deoxyribonucleic acid</td>
</tr>
<tr>
<td>CHB</td>
<td>Chronic hepatitis B</td>
</tr>
<tr>
<td>CT</td>
<td>Computer assisted tomography</td>
</tr>
<tr>
<td>EASL</td>
<td>European Association for the Study of the Liver</td>
</tr>
<tr>
<td>ECOG</td>
<td>Eastern Cooperative Oncology Group</td>
</tr>
<tr>
<td>GESA</td>
<td>Gastroenterology Society of Australia</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HBeAg</td>
<td>Hepatitis B E antigen</td>
</tr>
<tr>
<td>HBIG</td>
<td>Hepatitis B immunoglobulin</td>
</tr>
<tr>
<td>HBsAg</td>
<td>Hepatitis B surface antigen</td>
</tr>
<tr>
<td>HBV</td>
<td>Hepatitis B virus</td>
</tr>
<tr>
<td>HCC</td>
<td>Hepatocellular carcinoma</td>
</tr>
<tr>
<td>HCV</td>
<td>Hepatitis C virus</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>MDT</td>
<td>Multidisciplinary team</td>
</tr>
<tr>
<td>MELD</td>
<td>Model for End-stage Liver Disease</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
</tr>
<tr>
<td>NAFLD</td>
<td>Non-alcoholic fatty liver disease</td>
</tr>
<tr>
<td>NASH</td>
<td>Non-alcoholic steatohepatitis</td>
</tr>
<tr>
<td>PegIFN</td>
<td>Pegylated interferon</td>
</tr>
<tr>
<td>RBV</td>
<td>Ribavirin</td>
</tr>
<tr>
<td>SBP</td>
<td>Spontaneous bacterial peritonitis</td>
</tr>
<tr>
<td>SVR</td>
<td>Sustained virological response</td>
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ACKNOWLEDGEMENTS

The Australasian Hepatology Association (AHA) gratefully acknowledges the commitment and support of individuals who contributed to the development of the AHA Consensus-based Nursing Guidelines, including the AHA Board and the AHA Membership, the AHA Members involved in the Expert Writing Groups and those involved in the Expert Review Panel.

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<table>
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<table>
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<tbody>
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</tbody>
</table>

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<table>
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<tbody>
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*Note: The information provided is for illustrative purposes and may not reflect the complete list of all experts involved.*
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#### Care of Patients with Hepatitis C

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INTRODUCTION

The Australasian Hepatology Association (AHA) is a membership-based organisation representing and supporting nurses and allied health professionals caring for people with, or affected by, liver disease. The AHA was formed in 2002 and incorporated in 2004.

The AHA aims to:

- Build expertise, knowledge and quality practice in the field of hepatology.
- Contribute to policy and planning in order to advocate for improvement of care and treatment for people with, or affected by, liver disease.
- Promote and gain recognition for the specialist skills and knowledge that nurses and allied health professionals bring to this specific area of practice.

The AHA defines a Hepatology Nurse as:

- A registered nurse who applies advanced knowledge and skills in the testing, management and treatment of liver diseases to optimise the health and wellbeing of people with, or affected by, liver disease across the continuum of care.1

In 2006, the AHA commissioned the development of competency standards to document the fundamental principles of hepatology nursing practice and provide guidance for advanced nursing practice.2 The AHA Competency Standards for the Hepatology Nurse were published in 2008. In 2010, the AHA embarked on the development of consensus-based nursing guidelines for hepatology nursing care in Australia, in response to member requests to define the Hepatology Nurse’s scope of practice and the desire to operationalise the AHA Competency Standards for the Hepatology Nurse. These AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B, Hepatitis C, Advanced Liver Disease and Hepatocellular Carcinoma (AHA Consensus-based Nursing Guidelines) capture the essence of hepatology nursing care in Australia.

THE IMPORTANCE OF CONSENSUS-BASED NURSING GUIDELINES

The clinical evidence guiding hepatology nursing practice is focused on the medical model of healthcare delivery, fundamental to the practice of Western medicine. Although hepatology nursing care is aligned to evidence-based medical practice, it is important to acknowledge that many elements of the delivery of hepatology nursing care are not captured by the existing evidence base. There is limited research investigating the role of nurses in delivering care for patients with hepatitis B, hepatitis C, advanced liver disease and hepatocellular carcinoma (HCC). However, Hepatology Nurses are recognised as fundamental to the delivery of healthcare for people with liver disease.3,4 Therefore, in the context of limited hepatology nursing evidence, guidelines based on a consensus of experts are regarded as an appropriate and suitable substitute.5,6,7

Across many fields of medicine and nursing, consensus-based methods are increasingly being used to capture expert opinion and form therapeutic and management guidelines.8 The methodology involved in developing consensus-based guidelines provides an opportunity for the subjective judgements and opinions of experts to be collated, organised and documented.9 The characteristics of those involved in reaching a consensus are integral to the validity of the consensus reached. A large, heterogeneous group of experts with credibility in their specialty area is ideal, producing a more robust result.10 Involving health professionals in the process of developing consensus guidelines that will impact on their practice may encourage a sense of ownership and result in a greater commitment to incorporating the guidelines into their clinical care.11 However, it is acknowledged that consensus-based guidelines do not replace evidence-based practice and should only be employed in the absence of relevant and rigorous evidence.12,13
The AHA Consensus-based Nursing Guidelines are intended to complement the existing medical evidence, and support Hepatology Nurses to achieve best practice through embedding the provision of nursing care in an evidence-based framework, while reflecting those aspects of healthcare that are considered ‘clinical common sense’. In addition, the AHA Consensus-based Nursing Guidelines contribute to validating the concept that hepatology nursing care encompasses more than clinical skills, knowledge and activities; it also incorporates fundamental nursing values, principles and conduct.

A review of the evidence indicates that nurses are able to effectively incorporate clinical guidelines into their practice, resulting in optimal patient outcomes. In practice, nurses refer to practice guidelines as an important source of information and knowledge, which they employ to legitimise their decision-making and mediate their communication with medical colleagues. Reference to guidelines allows nurses to validate their autonomy and clinical decision-making. As such, the availability of guidelines is vital.

While the Hepatology Nurse’s role in caring for patients with hepatitis C is highly valued, as well as recognised as crucial to the clinical management of hepatitis C, the nurse’s role in caring for patients with hepatitis B, advanced liver disease and HCC is continuing to evolve. The AHA Consensus-based Nursing Guidelines assist in establishing a benchmark for nursing practice in the field of hepatology and will assist to define the role of Hepatology Nurses in caring for patients with hepatitis B, advanced liver disease and HCC. Importantly, the lack of evidence to support the practice of Hepatology Nurses highlights the urgent need for research to ensure optimal patient care, appropriate resourcing and workforce development.

DEVELOPMENT OF THE AHA CONSENSUS-BASED NURSING GUIDELINES

Development of the AHA Consensus-based Nursing Guidelines began in November 2010. An extensive literature review was conducted by the project consultants using keywords (hepatitis B, hepatitis C, advanced liver disease, HCC/liver cancer; nursing care, nursing practice, hepatology nursing care, nursing scope of practice; practice guidelines, clinical guidelines, consensus guidelines) and the following databases: CINAHL, Medline, PubMed, Cochrane, the Johanna Briggs Institute and Google Scholar. Limited relevant literature was identified.

As a result of the limited published research investigating hepatology nursing practice, a further literature review was performed using the previously identified databases and the keywords: consensus, consensus methods, Delphi technique.

Methodology

The AHA Consensus-based Nursing Guidelines were developed using the Delphi technique, which focuses on establishing a reliable consensus of opinion among a group of experts where accurate information or evidence does not exist. The Delphi technique has been widely used in the fields of business, education and healthcare research generally and nursing research in particular.

The Delphi technique brings together a panel of experts to reflect and comment on outcome measures (for example, consensus guidelines) through a structured process of consultation rounds. Consultation rounds are continued until consensus is reached. Initial rounds focus on gathering all relevant qualitative information, which is then collated and presented back to the experts for interpretation and confirmation of the content. This process is repeated in a structured way with the information gathered through each round of consultation, informing the refinement of the next iteration of the document.

Table 1.1 details the six rounds of consultation conducted during the development and validation of the AHA Consensus-based Nursing Guidelines.
Table 1.1: Overview of the six consultation rounds, including participants, methodology and outcomes achieved during the development and validation of the AHA Consensus-based Nursing Guidelines.

<table>
<thead>
<tr>
<th>Consultation round</th>
<th>Timeline</th>
<th>Participants</th>
<th>Aim of the consultation</th>
<th>Method</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Round 1</td>
<td>May 2011</td>
<td>Members of the AHA who attended the AHA Summit (n=120, comprises approximately 85% of the total membership).</td>
<td>To develop the content of the AHA Consensus-based Nursing Guidelines.</td>
<td>Face-to-face, small group discussions. Participants rotated between three facilitated workshops of 30 minutes duration. Each small group (n=6-8) discussed, debated and documented the Hepatology Nurse's role and responsibilities in caring for patients with hepatitis B, hepatitis C, advanced liver disease or HCC.</td>
<td>Collation and documentation of a comprehensive overview of the Hepatology Nurse's role in caring for patients with hepatitis B, hepatitis C, advanced liver disease and HCC.</td>
</tr>
<tr>
<td>Round 2</td>
<td>October 2011</td>
<td>The AHA Membership (n=140).</td>
<td>To ensure the content of the draft AHA Consensus-based Nursing Guidelines represented the role of the Hepatology Nurse caring for patients with hepatitis B, hepatitis C, advanced liver disease and HCC.</td>
<td>Consultations via e-mail. The four draft documents outlining the Hepatology Nurse's role and responsibilities were circulated to AHA Members for further consideration and feedback.</td>
<td>Additional information was collected and included to represent the role of the Hepatology Nurse in caring for patients with hepatitis B, hepatitis C, advanced liver disease and HCC.</td>
</tr>
<tr>
<td>Round 3a</td>
<td>November 2011</td>
<td>Four Expert Writing Groups (EWGs) (n=21) were convened by the AHA Board.</td>
<td>To discuss the content of the documents after two rounds of consultation.</td>
<td>Face-to-face meetings.</td>
<td>The content of the documents were expanded further to create an aspirational perspective of the role of the Hepatology Nurse in the respective clinical areas. Pivotal literature and feedback was incorporated after discussion and agreement.</td>
</tr>
<tr>
<td>Round 3b</td>
<td>December 2011</td>
<td>EWG Members.</td>
<td>To seek consensus on the content, breadth and scope of the AHA Consensus-based Nursing Guidelines.</td>
<td>Consultations via e-mail.</td>
<td>Further feedback about the role of the Hepatology Nurse was provided and incorporated to inform the next round of consultation.</td>
</tr>
<tr>
<td>Consultation round</td>
<td>Timeline</td>
<td>Participants</td>
<td>Aim of the consultation</td>
<td>Method</td>
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</tr>
<tr>
<td>Round 4</td>
<td>April 2012</td>
<td>Expert Review Panel</td>
<td>To measure consensus amongst a panel of experts on the scope, accuracy and appropriateness of the AHA Consensus-based Nursing Guidelines.</td>
<td>Self-administered questionnaire to measure the level of consensus (refer to Appendix 1).</td>
<td>The panel of experts provided positive feedback on the development, purpose and content of the four documents. In particular, revisions were made to the content of Domain 4 and reference to recommended literature was also included.</td>
</tr>
<tr>
<td>Round 5</td>
<td>June 2012</td>
<td>Members of the AHA who attended the AHA Summit (n=140, comprises approximately 80% of the total membership).</td>
<td>To measure consensus amongst the AHA Membership and explore how the AHA Consensus-based Nursing Guidelines would be implemented and applied in practice.</td>
<td>Face-to-face small group discussions; participants self-selected the document they preferred to provide feedback on and were allocated into small groups, facilitated by an EWG Member, to discuss the content and as a group complete a modified version of the questionnaire used in consultation rounds 4 and 6.</td>
<td>The AHA Members enthusiastically embraced the AHA Consensus-based Nursing Guidelines and reached consensus that the content represented their scope of practice. Feedback indicated the documents would be used to guide clinical practice, identify professional development needs and lobby internally and externally for additional resources to expand the Hepatology Nurse’s role.</td>
</tr>
<tr>
<td>Round 6</td>
<td>July 2012</td>
<td>EWG Members.</td>
<td>To conduct the final round of consultation for the development of the AHA Consensus-based Nursing Guidelines and confirm the clarity, scope and content of the documents.</td>
<td>Self-administered questionnaire to measure the level of consensus (refer to Appendix 1).</td>
<td>Final confirmation of the content of the AHA Consensus-based Nursing Guidelines.</td>
</tr>
</tbody>
</table>
Participants
Three groups of experts were consulted to reach a consensus on the role and responsibilities of Hepatology Nurses caring for patients with hepatitis B, hepatitis C, advanced liver disease and HCC, including:

1. AHA Members – National consultation with the AHA Membership included approximately 120 to 140 Hepatology Nurses who care for patients with, or affected, by liver disease in a variety of settings and services.

2. Expert Writing Groups – Experts from the AHA Membership were selected by the AHA Board to form Expert Writing Groups (EWGs). Each EWG comprised four to six members. Experts were selected because they each had extensive knowledge and experience in caring for patients with hepatitis B, hepatitis C, advanced liver disease or HCC. The Board reached consensus on the identity of the experts through a series of anonymous votes.

3. Expert Review Panel – An Expert Review Panel (n=16) was convened and included a nursing academic, hepatology clinicians (medical and nursing), an expert in nursing policy development, and viral hepatitis consumer representatives.

Measuring consensus
The questionnaire (refer to Appendix 1) circulated to the Expert Review Panel and EWG Members in consultation rounds 4 and 6, and used in round 5 with the AHA Members, was based on the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument. The language used in the questionnaire was modified to correspond to the four consensus-based nursing guideline documents. Consensus was measured using a five point Likert scale (1-2 disagree, 3 neutral, 4-5 agree) with consensus agreement set at a mean of four. The questionnaire explored the acceptability of the guidelines’ scope and purpose, rigour of development (these questions were excluded in the questionnaire used in round 5 because participants did not review the section relevant to these questions), clarity and presentation of each domain and the corresponding consensus guidelines, and the overall assessment and use of the guidelines. Space for free-text comments was also available. If consensus was not reached (median score of less than two), the EWGs reviewed and discussed the consensus guideline and revised the text to achieve consensus.

The purpose of measuring consensus was to validate the AHA Consensus-based Nursing Guidelines with the AHA Membership, EWGs and the Expert Review Panel and to review the:

• Purpose and scope of the AHA Consensus-based Nursing Guidelines to ensure the relevant aspects of nursing care were addressed.

• Process used to develop the AHA Consensus-based Nursing Guidelines, in the absence of evidence.

• Consistency of the AHA Consensus-based Nursing Guidelines with current clinical practice and available medical, nursing and scientific evidence.

• Clarity and presentation of each domain and the corresponding consensus guidelines.

• The potential implementation of the AHA Consensus-based Nursing Guidelines by the AHA Membership and the wider sector.

Results
Based on the criteria that four or above denoted consensus agreement, a mean score of greater than 67 represented consensus in rounds 4 and 6, and a mean of greater than 51 represented consensus in round 5. The total score for round 4 and 6 was 84. A modified version of the questionnaire was used in consultation round 5, which excluded questions about the introduction because the AHA Membership did not review this section of the document, resulting in a total score for round 5 of 64. Therefore, consensus was achieved in rounds 4, 5 and 6. Table 1.2 details the mean score from the Expert Review Panel, the AHA Membership and the EWGs.
Table 1.2: Mean results of the consultation rounds involving the Expert Review Panel, the AHA Membership and the Expert Writing Groups (EWGs) measured by the questionnaire.

<table>
<thead>
<tr>
<th>AHA Consensus-based Nursing Guideline</th>
<th>Consultation round 4: Expert Review Panel</th>
<th>Consultation round 5: AHA Membership*</th>
<th>Consultation round 6: EWGs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care of Patients with Hepatitis B</td>
<td>77.7 out of 84 (n=4)</td>
<td>62.6 out of 64 (n=16)</td>
<td>77.6 out of 84 (n=5)</td>
</tr>
<tr>
<td>Care of Patients with Hepatitis C</td>
<td>78 out of 84 (n=3)</td>
<td>63.3 out of 64 (n=24)</td>
<td>82.3 out of 84 (n=6)</td>
</tr>
<tr>
<td>Care of Patients with Advanced Liver Disease</td>
<td>78 out of 84 (n=4)</td>
<td>61.8 out of 64 (n=22)</td>
<td>81.6 out of 84 (n=3)</td>
</tr>
<tr>
<td>Care of Patients with Hepatocellular Carcinoma</td>
<td>76.3 out of 84 (n=4)</td>
<td>63.3 out of 64 (n=24)</td>
<td>81.6 out of 84 (n=3)</td>
</tr>
</tbody>
</table>

* Consultation round 5 did not include assessment of the document's introduction, therefore questions regarding the rigour of development were not included in the questionnaire.

Results from consultation rounds 4, 5 and 6 were incorporated into the documents and were reviewed by the AHA Board, before being launched at the Australasian Viral Hepatitis Conference in September 2012.

**OVERVIEW OF THE AHA CONSENSUS-BASED NURSING GUIDELINES**

The AHA Consensus-based Nursing Guidelines are intended to be used in conjunction with the AHA Competency Standards for the Hepatology Nurse. To strengthen the relationship between the documents, the five domain headings from the AHA Competency Standards for the Hepatology Nurse frame the structure of the AHA Consensus-based Nursing Guidelines. The domain headings include:

- Domain 1: Provision and management of nursing care for people with, or affected by, liver disease.
- Domain 2: Interdisciplinary coordination and care.
- Domain 3: Non-discriminatory practice.
- Domain 4: Professional self-care and development.
- Domain 5: Clinical and community leadership.

In addition, each consensus guideline has been linked to a corresponding competency standard in the affiliated domain of the AHA Competency Standards for the Hepatology Nurse. Aligning the AHA Consensus-based Nursing Guidelines with the AHA Competency Standards reflects the holistic approach adopted by Hepatology Nurses caring for patients with liver disease. In some settings, nurses will be caring for patients with many different aetiologies of liver disease, whereas in other settings, nurses may specialise in the care of patients with one aetiology or virus. It is important that all Hepatology Nurses, regardless of their clinical setting or specialty, are aware of the management of hepatitis B, hepatitis C, advanced liver disease and HCC to ensure a holistic approach and continuity of care throughout the spectrum of liver disease. As such, the documents are designed to be considered concurrently.

This introduction, which outlines the background, methodology and guiding principles, is shared between the four consensus-based nursing guideline documents. Each document has a unique background section that provides an overview of the current evidence supporting the delivery of care for the specific patient group. However, the consensus guideline titles vary between the documents and are presented in Table 1.3.
Table 1.3: Consensus guidelines according to the domain heading for the AHA Consensus-based Nursing Guidelines

<table>
<thead>
<tr>
<th>Domain 1: Provision and management of nursing care for people with, or affected by, liver disease</th>
<th>Domain 2: Interdisciplinary coordination and care</th>
</tr>
</thead>
<tbody>
<tr>
<td>AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B</td>
<td>AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis C</td>
</tr>
<tr>
<td>1.1: Optimise testing for people at risk of hepatitis B</td>
<td>1.1: Optimise testing for people at risk of hepatitis C</td>
</tr>
<tr>
<td>1.2: Undertake a comprehensive nursing assessment of the patient with chronic hepatitis B</td>
<td>1.2: Undertake a comprehensive nursing assessment of the patient with chronic hepatitis C</td>
</tr>
<tr>
<td>1.3: Conduct a nursing assessment to identify clinical symptoms and signs of advanced liver disease</td>
<td>1.3: Conduct a nursing assessment to identify clinical symptoms and signs of advanced liver disease</td>
</tr>
<tr>
<td>1.4: Assess the patient's level of knowledge about hepatitis B and provide relevant education</td>
<td>1.4: Assess the patient's level of knowledge about hepatitis C and provide relevant education</td>
</tr>
<tr>
<td>1.5: Optimize the patient's health and wellbeing</td>
<td>1.5: Optimize the patient's health and wellbeing</td>
</tr>
<tr>
<td>1.6: Advocate and support the patient with chronic hepatitis B who is considering treatment</td>
<td>1.6: Advocate and support the patient with chronic hepatitis C who is considering treatment</td>
</tr>
<tr>
<td>1.7: Provide ongoing monitoring-related nursing care for the patient with chronic hepatitis B</td>
<td>1.7: Provide ongoing monitoring-related nursing care for the patient with chronic hepatitis C</td>
</tr>
<tr>
<td>1.8: Provide nursing management for the patient with chronic hepatitis B</td>
<td>1.8: Provide nursing management for the patient with chronic hepatitis C</td>
</tr>
<tr>
<td>1.9: Provide hepatitis B treatment-related nursing care for the patient with chronic hepatitis B</td>
<td>1.9: Provide hepatitis C treatment-related nursing care for the patient with chronic hepatitis C</td>
</tr>
<tr>
<td>1.10: Discuss the importance of hepatocellular carcinoma surveillance for the patient with chronic hepatitis B</td>
<td>1.10: Discuss the importance of hepatocellular carcinoma surveillance for the patient with chronic hepatitis C</td>
</tr>
</tbody>
</table>

| 1.1: Perform a nursing assessment to identify clinical symptoms and signs of advanced liver disease | 1.1: Perform a nursing assessment to identify clinical symptoms and signs of advanced liver disease |
| 1.2: Conduct a comprehensive nursing assessment of the patient with advanced liver disease | 1.2: Conduct a comprehensive nursing assessment of the patient with advanced liver disease |
| 1.3: Assess the patient's level of knowledge about advanced liver disease and provide relevant education | 1.3: Assess the patient's level of knowledge about advanced liver disease and provide relevant education |
| 1.4: Provide education and support for the patient's significant other(s)/caregiver(s) | 1.4: Provide education and support for the patient's significant other(s)/caregiver(s) |
| 1.5: Advocate and support the patient with advanced liver disease to be actively involved in their treatment and management plan | 1.5: Advocate and support the patient with advanced liver disease to be actively involved in their treatment and management plan |
| 1.6: Optimize the patient's health and wellbeing | 1.6: Optimize the patient's health and wellbeing |
| 1.7: Perform a pre-treatment nursing assessment | 1.7: Perform a pre-treatment nursing assessment |
| 1.8: Provide patient education at the commencement of hepatitis C treatment | 1.8: Provide patient education at the commencement of hepatitis C treatment |
| 1.9: Provide hepatitis C treatment-related nursing care | 1.9: Provide hepatitis C treatment-related nursing care |
| 1.10: Discuss the importance of hepatocellular carcinoma surveillance for the patient with advanced liver disease | 1.10: Discuss the importance of hepatocellular carcinoma surveillance for the patient with advanced liver disease |

| 1.1: Support the patient to participate in hepatocellular carcinoma surveillance | 1.1: Support the patient to participate in hepatocellular carcinoma surveillance |
| 1.2: Support the patient to participate in targeted surveillance if there is an abnormal lesion or suspicion of a hepatocellular carcinoma | 1.2: Support the patient to participate in targeted surveillance if there is an abnormal lesion or suspicion of a hepatocellular carcinoma |
| 1.3: Conduct a comprehensive nursing assessment of the patient with hepatocellular carcinoma | 1.3: Conduct a comprehensive nursing assessment of the patient with hepatocellular carcinoma |
| 1.4: Assess the patient's level of knowledge about hepatocellular carcinoma and provide relevant education | 1.4: Assess the patient's level of knowledge about hepatocellular carcinoma and provide relevant education |
| 1.5: Advocate and support the patient with hepatocellular carcinoma to be actively involved in their treatment and management plan | 1.5: Advocate and support the patient with hepatocellular carcinoma to be actively involved in their treatment and management plan |
| 1.6: Optimize the patient's health and wellbeing | 1.6: Optimize the patient's health and wellbeing |
| 1.7: Perform a pre-treatment nursing assessment | 1.7: Perform a pre-treatment nursing assessment |
| 1.8: Provide patient education at the commencement of hepatitis C treatment | 1.8: Provide patient education at the commencement of hepatitis C treatment |
| 1.9: Provide hepatitis C treatment-related nursing care | 1.9: Provide hepatitis C treatment-related nursing care |
| 1.10: Discuss the importance of hepatocellular carcinoma surveillance for the patient with hepatocellular carcinoma | 1.10: Discuss the importance of hepatocellular carcinoma surveillance for the patient with hepatocellular carcinoma |

2.1: Discuss the roles of each member of the interdisciplinary team in relation to the implementation of the patient's management plan
2.2: Recognise and enhance the existing therapeutic relationship with the general practitioner and/or referring practitioner
2.3: Liaise with general practitioners and/or referring practitioners about patient referral and management
2.4: Facilitate patient referral to members of the interdisciplinary team and community allied health services
2.5: Liaise with, and support, health professionals working with patients with chronic hepatitis B who have additional needs
2.6: Liaise with, and support, health professionals working with patients with chronic hepatitis C who have additional needs
2.7: Discuss the roles of each member of the interdisciplinary team in relation to the implementation of the patient's management plan
2.8: Recognise and enhance the existing therapeutic relationship with the general practitioner and/or referring practitioner
2.9: Liaise with general practitioners and/or referring practitioners about patient referral and management
2.10: Facilitate patient referral to members of the interdisciplinary team and community allied health services
2.11: Discuss the roles of each member of the interdisciplinary team in relation to the implementation of the patient's management plan
2.12: Facilitate the care coordination for the patient with advanced liver disease
2.13: Recognise and enhance the existing therapeutic relationship with the general practitioner and/or referring practitioner
2.14: Facilitate patient referral to members of the interdisciplinary team and community allied health services
2.15: Discuss the roles of each member of the multidisciplinary team (MDT) in relation to the implementation of the patient's management plan
2.16: Coordinate the care for the patient with hepatocellular carcinoma
2.17: Recognise and enhance the existing therapeutic relationship with the general practitioner and/or referring practitioner
2.18: Facilitate patient referral to members of the multidisciplinary team and community allied health services
### Domain 3: Non-discriminatory practice

<table>
<thead>
<tr>
<th>AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B</th>
<th>AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis C</th>
<th>AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease</th>
<th>AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.2: Facilitate appropriate disclosure by patients with chronic hepatitis B</td>
<td>3.2: Facilitate appropriate disclosure by patients with hepatitis C</td>
<td>3.2: Facilitate appropriate disclosure for patients with advanced liver disease</td>
<td>3.2: Facilitate appropriate disclosure for patients with hepatocellular carcinoma</td>
</tr>
<tr>
<td>3.3: Discourage discriminatory behaviour against patients with chronic hepatitis B</td>
<td>3.3: Discourage discriminatory behaviour against patients with hepatitis C</td>
<td>3.3: Discourage discriminatory behaviour against patients with advanced liver disease</td>
<td>3.3: Discourage discriminatory behaviour against patients with hepatocellular carcinoma</td>
</tr>
<tr>
<td>3.4: Provide culturally appropriate nursing care for patients with chronic hepatitis B</td>
<td>3.4: Provide culturally appropriate nursing care for patients with hepatitis C</td>
<td>3.4: Provide culturally appropriate nursing care for patients with advanced liver disease</td>
<td>3.4: Provide culturally appropriate nursing care for patients with hepatocellular carcinoma</td>
</tr>
</tbody>
</table>

### Domain 4: Professional self-care and development

| 4.1: Identify and define the hepatology nursing scope of practice |
| 4.2: Actively participate in reflective practice |
| 4.3: Actively engage in continuing professional development |
| 4.4: Actively engage in professional self-care |

### Domain 5: Clinical and community leadership

| 5.1: Actively promote the Hepatology Nurse’s role in the delivery of care for patients with chronic hepatitis B |
| 5.2: Mentor nurses to be involved in caring for patients with chronic hepatitis B |
| 5.3: Provide ongoing education, support and leadership for health professionals involved in caring for people with, or at risk of, hepatitis B |
| 5.4: Provide education to raise the community’s awareness of hepatitis B |
| 5.1: Actively promote the Hepatology Nurse’s role in the delivery of care for patients with hepatitis C |
| 5.2: Mentor nurses to be involved in caring for patients with hepatitis C |
| 5.3: Provide ongoing education, support and leadership for health professionals involved in caring for people with, or at risk of, hepatitis C |
| 5.4: Provide education to raise the community’s awareness of hepatitis C |
| 5.1: Actively promote the Hepatology Nurse’s role in the delivery of care for patients with advanced liver disease |
| 5.2: Mentor nurses to be involved in caring for patients with advanced liver disease |
| 5.3: Provide ongoing education, support and leadership for health professionals involved in caring for people with, or at risk of, advanced liver disease |
| 5.4: Provide education to raise the community’s awareness of hepatitis C |
| 5.1: Actively promote the Hepatology Nurse’s role in the delivery of care for patients with hepatocellular carcinoma |
| 5.2: Mentor nurses to be involved in caring for patients with hepatocellular carcinoma |
| 5.3: Provide ongoing education, support and leadership for health professionals involved in caring for people with, or at risk of, hepatocellular carcinoma |
| 5.4: Provide education to raise the community’s awareness of hepatitis C |
GUIDING PRINCIPLES OF THE AHA CONSENSUS-BASED NURSING GUIDELINES

The Code of Professional Conduct for Nurses in Australia\textsuperscript{26} highlights the importance of nurses practising in a way that upholds and strengthens the community’s trust in the nursing profession. To achieve this in the hepatology context, there are a number of principles underpinning the interpretation of the AHA Consensus-based Nursing Guidelines including:

- patient-centred care
- non-discriminatory practice
- culturally competent nursing care
- working within own scope of practice
- collaboration and partnerships.

Patient-centred care

Patient-centred care involves health professionals responding respectfully to every patient within their care, treating them as an individual, rather than as an illness or condition requiring management.\textsuperscript{27} Facilitating this approach, the dimensions of patient-centred care include respect, physical comfort, emotional support, communication, information, continuity, transition, care coordination, access to care and involvement of family, significant others and carers.\textsuperscript{28} Patient-centred care is a fundamental nursing concept, in which all nursing practice is grounded. The principle is acknowledged in the codes, guidelines, decision-making frameworks and competency standards that guide nursing care.\textsuperscript{29}

Nurses endorse the delivery of healthcare through a holistic, patient-centred approach. As a patient advocate, the nurse acts to develop a therapeutic relationship with the patient and actively involve them in their care, respecting their values, beliefs and concerns. The stigma associated with aspects of liver disease, for example hepatitis C,\textsuperscript{30} requires nurses working in the field of hepatology to uphold and respect this principle of nursing practice.\textsuperscript{31} Fostering an environment that promotes and respects the patient’s right to make informed decisions is recognised as a fundamental nursing role.\textsuperscript{32,33}

It is also important to acknowledge that there are potential emotional, psychological and physical challenges associated with engaging with patients, and nurses should be mindful of the consequences of prioritising patient care over self-care. Self-care has been demonstrated to effectively equip nurses to continue to engage emphatically and therapeutically with patients.\textsuperscript{34,35}

Non-discriminatory practice

The Code of Ethics for Nurses in Australia\textsuperscript{36} and the Code of Professional Conduct for Nurses in Australia\textsuperscript{37} outline the framework for accountable, responsible and reflective nursing practice and represent the overarching code of ethical standards that the nursing profession subscribes to, both nationally and internationally. The AHA Competency Standards for the Hepatology Nurse\textsuperscript{38} emphasise the hepatology nursing profession’s commitment to non-discriminatory practice, including respecting the beliefs, values, practices and dignity of patients receiving treatment and care.

Adhering to the principles of privacy and confidentiality are essential standards of nursing care. Nurses treat all those in their care with compassion, dignity, sensitivity and humanity and provide equal care to all.\textsuperscript{39,40} Particularly relevant to the hepatology context is the belief that people with blood-borne viruses (BBVs), such as hepatitis B and C, are entitled to the same care and access to health services as any other individual.\textsuperscript{41} Valuing the diversity of patients is important and the nurse has a role in ensuring that individuals are not denied the right to healthcare, based on their health condition, religion, age, disability, economic or political status, appearance, language or culture.\textsuperscript{42,43,44}
Culturally competent nursing care

Pivotal to the patient’s understanding of health and access to, and engagement with, health services is the influence of culture. Culture encompasses an individual’s beliefs, values, behaviours and upbringing.\textsuperscript{45} The patient’s culture is not the only variable impacting on their health; the culture of those caring for the patient, the service in which care is delivered and the broader culture of the health system also impacts on the patient’s health.

Culturally competent care involves a set of congruent behaviours, values, attitudes and policies held collectively by a service or group of professionals that effectively and appropriately facilitates the provision of cross-cultural care.\textsuperscript{46} Culturally competent care also involves the organisational factors, systems and processes in which Hepatology Nurses practise.\textsuperscript{47} Ensuring that individuals, the health service and the associated model of healthcare delivery are sensitive to the beliefs, values and practices of all patients is vital.

To deliver culturally competent nursing care, nurses must be aware of their own cultural values, beliefs and practices and reflect on how these could impact on interactions with patients. Through reflection and recognition of one’s own culture, nurses develop an awareness, sensitivity and respect for different cultural constructs, which are integral to culturally competent nursing care.\textsuperscript{48} This promotes the understanding that there is a complex interaction between the patient’s culture and the nurse’s own culture, as well as the culture of the nursing profession, and the institutional and organisational contexts in which nurses practise. Communication is also a product of our culture. Recognising the impact of both the nurse’s and the patient’s culture on health beliefs, negotiation and communication is integral to the provision of patient-centred care.

Working within own scope of practice

Nurses in Australia must practice in accordance with standards established through legislation, common law and the relevant professional standards and frameworks (refer to Diagram 1.1). Underpinning the principles of hepatology nursing practice, is the acknowledgement that Hepatology Nurses need to have an understanding of their individual scope of practice.\textsuperscript{49} Consideration of own scope of practice is integral to the interpretation and implementation of the AHA Consensus-based Nursing Guidelines. An individual Hepatology Nurse’s scope of practice refers to the activities which that nurse is educated and authorised to perform.\textsuperscript{50} In reality, the actual scope of an individual nurse’s practice is influenced by the context in which they work, the patient’s health needs, the level of competence, education and qualifications of the individual nurse and the service provider’s policies.\textsuperscript{51} The International Council of Nursing suggests that the scope of nursing practice is not limited to specific tasks, functions or responsibilities but includes direct care giving and evaluation of its impact, advocating for patients and for health.\textsuperscript{52} Therefore, in defining the scope of practice, individual nurses need to consider all of the activities they achieve in the course of their employment; while the hepatology nursing specialty must acknowledge the variation in the role of Hepatology Nurses between clinical or workplace environments.

Hepatology nursing is constantly evolving in response to the needs of people with, or affected by, liver disease, advances in nursing and medical knowledge, healthcare system reform and the subsequent delivery of nursing care. Hepatology Nurses and the specialty have a responsibility to continually incorporate new knowledge and skills into clinical practice, and to maintain the competencies that are specific to hepatology nursing for the benefit of people living with, or affected by, liver disease. As the hepatology nursing role evolves, the nurse’s scope of practice must be dynamic and flexible to respond appropriately to the changing environment.

Decisions about both the individual’s and the specialty’s scope of practice can be guided by the use of decision-making tools. The Australian Nursing and Midwifery Council (ANMC) National Decision-Making Framework\textsuperscript{53} supports and encourages nurses to expand their scope of practice by incorporating new developments into their practice in a planned and structured manner.
Collaboration and partnerships

The AHA Consensus-based Nursing Guidelines have a strong emphasis on the collaborative nature of nursing practice. This is guided by the AHA Competency Standards for the Hepatology Nurse,\(^5^4\) which acknowledges the importance of the nurse’s role within the interdisciplinary team,\(^A\) and reflects the collaboration and interaction with other health professionals in providing holistic care to patients with, or affected by, liver disease. In the field of hepatology, the nurse may be the primary contact for the patient throughout their interaction with the health system, providing continuity of care and acting as an advocate for the patient when needed. Both nationally and internationally, the fundamental principles of nursing practice also widely acknowledge the role of the patient, their significant other(s) and carer(s) in decisions about care, recognising the capacity for those accessing healthcare to be informed and have an active role in their healthcare.\(^5^5,5^6\)

Guidelines developed in other areas of health have encouraged improvements in the collaboration and communication between health professionals.\(^5^7\) Effective communication between health professionals themselves and between health professionals and patients is necessary to establish and sustain collaborative relationships. Nurses need to employ a variety of communication methods to facilitate nursing care across the many specialities involved in hepatology, always ensuring respect for the privacy of patients and colleagues and the appropriate documentation of nursing practice.\(^5^8,5^9\)

HOW TO USE THE AHA CONSENSUS-BASED NURSING GUIDELINES

The AHA Consensus-based Nursing Guidelines have been designed to guide the development of practice-related tools such as nursing care plans. At a local level, the AHA Consensus-based Nursing Guidelines could be used to inform the development of policies and procedures for individual clinics/services. From a broader perspective, the documents could also be used to inform the development of educational activities and guide Hepatology Nurses to identify their professional development needs. Colleagues working in other clinical settings, and outside the clinical arena, may find the Guidelines useful in clarifying and understanding the role of Hepatology Nurses in caring for patients with, or affected by, liver disease.

Hepatology Nurses, like the broader nursing profession, must practise in accordance with the legislation, common law and the relevant professional standards and frameworks. Broadly, the AHA Consensus-based Nursing Guidelines are one of the documents that form a framework for guiding professionally accountable hepatology nursing practice. Diagram 1.1 illustrates the relationships between each of the relevant documents and where the AHA Consensus-based Nursing Guidelines are positioned in this framework.

Although the AHA Consensus-based Nursing Guidelines are designed to guide individual nursing practice, it is important to consider the context of the organisation in which the individual works. The literature acknowledges that although nursing practice is the responsibility of the individual nurse, the organisation also has responsibilities, which cannot be disregarded when developing principles for nursing care. The culture of the organisation in which the nurse works must be open to changes in clinical practice, to foster an environment in which nurses feel empowered to instigate changes to reflect the evolution of evidence-based care, or where evidence is lacking, the evolution of thinking documented in consensus-based guidelines.

The settings in which nurses care for patients with hepatitis B, hepatitis C, advanced liver disease and HCC are diverse, and it is unrealistic to summarise the expected responsibilities of the nurse in each of these settings. Therefore, nurses must consider the AHA Consensus-based Nursing Guidelines from the perspective of their own setting and organisational culture.

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\(^A\) Refer to Definitions relevant to the AHA Consensus-based Nursing Guidelines (page 21) for discussion on the terminology used in this document to describe the team approaches to patient care.
Diagram 1.1: The relationship between international and national policies, clinical practice guidelines and nursing codes of conduct and their impact on hepatology nursing practice.

Scope of Practice

Professional Practice Framework

- Code of Professional Conduct for Nurses in Australia
- Code of Ethics for Nurses in Australia
- ANF Competency Standards for the Advanced Registered Nurse
- AHA Competency Standards for the Hepatology Nurse
- National Competency Standards for the Registered Nurse
- A Nurse’s Guide to Professional Boundaries
- National and International Guidelines for Hepatitis B, Hepatitis C, Advanced Liver Disease or Hepatocellular Carcinoma

State Strategies, Action Plans and Implementation Plans

State, Territory and Local Health Districts/Network Policy Directives and Guidelines

National Strategies (Hepatitis B, Hepatitis C)
National Testing Policies (Hepatitis B, Hepatitis C)

Individual clinic policies and protocols

Defining the Hepatology Nurse’s role
Nursing care plans

Nursing care of people with, or affected by, hepatitis B, hepatitis C, advanced liver disease or hepatocellular carcinoma
TARGET AUDIENCE FOR THE AHA CONSENSUS-BASED NURSING GUIDELINES

The AHA Consensus-based Nursing Guidelines are designed for nurses caring for patients with hepatitis B and associated liver disease, hepatitis C and associated liver disease, advanced liver disease of varying aetiology, and HCC and associated liver disease. This includes, but is not limited to, nurses who identify as working in the field of hepatology and those caring for people with, or affected by, liver disease within a range of health settings such as:

- tertiary hospitals including gastroenterology/hepatology, infectious diseases, liver transplant, oncology and medical imaging departments
- community health services
- general practice/primary care settings
- alcohol and other drugs services
- sexual health clinics
- mental health services
- Aboriginal and Torres Strait Islander health services
- multicultural health services
- refugee health services
- immunology and haemophilia services
- antenatal services
- rural and remote services
- custodial settings.

The AHA Consensus-based Nursing Guidelines may also be a useful resource for nurses working in other related specialties, other areas of nursing practice and settings that are yet to be identified, national nursing and midwifery organisations, allied health professionals, government and non-government organisations, hepatitis organisations, educational institutions and affiliated peer organisations.

REVIEW OF THE AHA CONSENSUS-BASED NURSING GUIDELINES

The AHA Board intends to review the AHA Consensus-based Nursing Guidelines biennially, at a minimum, in order to incorporate the emergence of evidence, clinical developments and to reflect the evolution of hepatology nursing practice. The procedure used to update the guidelines will depend on the resources available at the time.

DEFINITIONS RELEVANT TO THE AHA CONSENSUS-BASED NURSING GUIDELINES

*Multidisciplinary team vs interdisciplinary team*

There is a trend in the literature to replace the traditional terminology of *multidisciplinary team* (MDT) with *interdisciplinary team*.

The *multidisciplinary team* (MDT) is defined as a collaboration of individuals from differing disciplines assessing the patient, often through separate consultations, from the perspective of their own discipline and experience. Often the MDT will meet as a group, without the patient, to discuss each team member’s assessment and recommended management and treatment.\(^{75}\)
The interdisciplinary team incorporates different disciplines into a single assessment of, and consultation with, the patient. This approach is more holistic than traditional MDT arrangements as the patient is involved in discussions and decisions regarding their condition, care, management and treatment. Interdisciplinary teams allow team members to question each discipline’s approach and explore alternative approaches as a group.

Interdisciplinary teams facilitate greater collaboration between health professionals and disciplines and theoretically deliver optimal patient outcomes. The evolution in terminology also reflects changes in health professional collaborations, where from earlier in their career health professionals are participating in interprofessional education and learning, which involves different professions training alongside each other. Interprofessional education and learning encourages interprofessional practice.

The trend towards interprofessional-based activity is driven by the increasing health workforce shortages and resulting healthcare reform that requires health professionals to work more effectively in teams, maximising the roles and scope of each professional group. It is anticipated that the shift towards interprofessional activity will encourage health professionals to collaborate across disciplines and traditional hierarchies and/or boundaries, to manage complex clinical situations in a safe, efficient, effective, informed and systematic way.

In line with the literature, throughout the AHA Consensus-based Nursing Guidelines, the collaboration of health professionals caring for patients with, or affected by, hepatitis B, hepatitis C, advanced liver disease or HCC is referred to as an interdisciplinary team. Where specific reference is given to the team of doctors, nurses and allied health professionals caring for patients with HCC, the team is referred to as a multidisciplinary team (MDT), consistent with the current terminology used in clinical practice.

Patient vs person

The AHA Consensus-based Nursing Guidelines use the term patient to refer to an individual who is in the process of seeking, or is receiving, healthcare. This is distinct to the use of the word person to describe an individual who has not yet sought healthcare.

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AHA CONSENSUS-BASED NURSING GUIDELINES FOR THE CARE OF PATIENTS WITH HEPATITIS B

EPIDEMIOLOGY OF HEPATITIS B

Despite the existence of a safe and effective vaccine, hepatitis B continues to have a profound impact on global health. It is estimated that between 350 and 400 million people have chronic hepatitis B (CHB), resulting in over 1,000,000 deaths every year.1 The World Health Organization estimates that hepatitis B is the tenth leading cause of death worldwide,2 accounting for 60% to 80% of the world’s liver cancer diagnoses.3 Approximately 75% of people with CHB live in Asia and the Western Pacific.4

In Australia, there are an estimated 170,000 people living with CHB.5 Over 80% of people with CHB in Australia acquired hepatitis B at birth or in early childhood, as they were born in high prevalence countries.6 This reflects the pattern of immigration to Australia from countries with high hepatitis B prevalence.7 There are an estimated 2,600 acute hepatitis B infections in Australia annually;8 however the majority of these are undiagnosed and unreported.9

HEPATITIS B TRANSMISSION

Hepatitis B virus is present in blood, saliva, semen and vaginal fluids and is transmitted when virus from these body fluids enters the bloodstream of a susceptible individual, either through mucous membranes or a break in the skin.10 Worldwide, the most common mode of hepatitis B transmission occurs from mother to infant, during, at, or soon after delivery.11,12 In Australia, administration of vaccination and hepatitis B immunoglobulin (HBIG) is recommended for all infants born to a hepatitis B surface antigen (HBsAg) positive mother. Timely administration of the first dose of vaccine and HBIG to the infant will reduce the risk of hepatitis B transmission by approximately 90%.13 Access to infant vaccination and HBIG is often limited in developing countries, which significantly increases the risk of vertical transmission of hepatitis B.

In developed countries, such as Australia, transmission from hepatitis B E antigen (HBeAg) positive women, or those who have high hepatitis B viral load, can still occur despite administration of HBIG and vaccine, with rates of between 7%14 to 28%.15,16 Interventions, such as use of anti-viral therapy during the third trimester of pregnancy, have been shown to reduce the risk of transmission.17,18 Infants born to a HBsAg positive mother should be tested for HBsAg and hepatitis B surface antibodies (Anti-HBs), three to 12 months after the final dose of hepatitis B vaccine.19

In Australia, other common routes of hepatitis B transmission include sexual exposure, reusing injecting or tattooing equipment and possibly household contact through sharing equipment such as razors and toothbrushes.20 Breaches of infection control in the healthcare setting during exposure to infectious blood and body fluids can result in transmission of hepatitis B. Vaccination is an important infection control strategy for the prevention of hepatitis B. All healthcare workers should be vaccinated and be aware of their post-vaccination immunity status.21

DISEASE COURSE OF CHRONIC HEPATITIS B

Chronic hepatitis B is defined as the detection of HBsAg for greater than six months.22 There is a clear relationship between age of infection and clearance of hepatitis B infection. Between 90% and 95% of infants exposed to the hepatitis B virus will develop CHB, however only 30% of children aged five years or older will develop CHB.23 Infection as an adult is most often cleared by the immune system; five percent of adults will develop CHB, whereas the majority (95%) clear the infection.24 Adults who have a suppressed immune system, such as people with human immunodeficiency virus (HIV) or people on dialysis, have a higher risk of progressing to CHB if they are infected with the virus.
The natural history of CHB is complex and highly variable. The disease course is defined by four distinct phases (refer to Diagram 2.1): immune tolerance, immune clearance, immune control and immune escape. Transition through these phases is dependent on a complex interaction between the individual’s immune system, viral and environmental factors and the age at infection. Of significance is the loss of HBeAg and development of hepatitis B E antibodies (anti-HBe) which indicates the transition from immune clearance to immune control. Therefore, it can be assumed that people in the immune tolerance and immune clearance phases are HBeAg positive, whereas people in the immune control and immune escape phases are HBeAg negative. In some circumstances, patients can progress directly from the immune clearance to the immune escape phase.

Diagram 2.1: The natural history of chronic hepatitis B.

Chronic hepatitis B causes inflammation of the liver that can lead to advanced liver disease and significant scarring of the liver tissue, known as cirrhosis. Between 15% and 40% of people with CHB will develop serious sequelae such as cirrhosis, liver failure and/or hepatocellular carcinoma (HCC) in their lifetime. Chronic hepatitis B is a significant cause of HCC. The hepatitis B virus is potentially carcinogenic as it integrates into the patient’s DNA. Therefore, there is a significant risk of developing HCC without hepatitis B-related liver disease or cirrhosis, which emphasises the importance of formal HCC surveillance programs for people with CHB. In patients with cirrhosis, the five year cumulative risk of developing HCC is between 10% and 17%. There is increasing evidence that treating CHB can prevent liver cancer.

For further information detailing the complications of CHB, including advanced liver disease and HCC, refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease and the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma.

GUIDELINES FOR THE MANAGEMENT OF HEPATITIS B VIRUS INFECTION

In Australia, the clinical management of hepatitis B is guided by both Australian and international clinical practice guidelines. The American Association for the Study of Liver Diseases (AASLD) and the European Association for the Study of the Liver (EASL) represent the pivotal international guidelines. Locally, the Gastroenterological Society of Australia (GESA) guidelines support clinicians caring for patients with CHB in Australia and New Zealand. In addition, the first
National Hepatitis B Testing Policy has been developed to guide clinicians involved in testing for and diagnosing hepatitis B.37

Each of these clinical practice guidelines are medical documents. They have not been designed to guide nursing practice. However, without an understanding of the medical evidence, Hepatology Nurses will be unable to meet the following competency standards identified in the AHA Competency Standards for the Hepatology Nurse:

• 1.1 Provides comprehensive, evidence-based nursing care for people with or affected by liver disease.
• 1.2 Provides specialised information and education from a nursing perspective.
• 1.4 Provides evidence-based nursing care.
• 2.3 Participates in and contributes to interdisciplinary clinical decision-making.
• 3.2 Advocates for and promotes the rights of people with or affected by liver disease.
• 5.2 Provides expert advice and guidance to the multidisciplinary team and external agencies on the care of people with or affected by liver disease.38

The evidence presented in the medical guidelines is embedded in the AHA Consensus-based Nursing Guidelines and creates the benchmark for best practice.

**TREATMENT OF CHRONIC HEPATITIS B**

The aim of treating CHB is to limit replication of the hepatitis B virus and suppress the amount of hepatitis B virus circulating in the blood, therefore reducing the risk of disease progression and limiting the development of cirrhosis, end-stage liver disease, HCC and death.39 Of the 170,000 Australians living with CHB, less than three percent are estimated to be receiving anti-viral therapy.40 Although it is projected that five times the number of patients currently receiving treatment could benefit.41,42

There are significant barriers to patients with CHB accessing specialist clinical services, including lack of patient awareness about the significance of CHB and availability of anti-viral therapy as well as the need for lifelong disease monitoring.43 Inaccurate information is often reinforced by health professionals and can result in inadequate referral of patients with CHB.44

Treatment for CHB involves administration of either a nucleoside/nucleotide analogue (oral tablet taken daily) or pegylated interferon (PegIFN) delivered by subcutaneous injection. Although nucleoside/nucleotide analogues are well tolerated, the course of treatment is often long-term (can be many years). Pegylated interferon can have significant side effects; however, it is administered for a defined period of time (48 weeks).45 Cure of hepatitis B is rarely achieved because the virus integrates into the individual’s DNA and creates covalently closed circular DNA (cccDNA) molecules within the liver cells which act as a replication template for new viruses. Therefore, patients are encouraged to consider treatment of CHB in terms of control of liver disease progression, rather than cure. Although loss of HBsAg and seroconversion of HBsAg to anti-HBs is the ultimate goal of therapy (referred to as a cure), it is uncommon, with less than five percent of patients receiving nucleoside/nucleotide analogue therapy achieving a cure and only three to eight percent of patients achieving a cure after a course of PegIFN therapy. More common is the seroconversion of HBeAg to anti-HBe positive, which can coincide with reduced viral replication and improved liver health.46

Treatment of CHB is generally considered during the immune clearance or immune escape phases, when there is active viral replication and the immune system is stimulated.47 The decision to treat is based on a number of clinical factors, as well as the patient’s choice. As therapy may be life-long, it is important that the patient has a good understanding of treatment and is involved in the decision-making process.
PREVENTION OF HEPATITIS B INFECTION

Hepatitis B infection can be effectively prevented through the administration of the hepatitis B vaccine. Adult immunisation occurs over six months with the administration of three injections. Susceptible individuals and members of priority populations should be targeted for vaccination. Simultaneously education about preventing the transmission of hepatitis B for people at risk is encouraged.

HEPATITIS B POLICY IN AUSTRALIA

The First National Hepatitis B Strategy 2010-2013 identifies the priority populations as:
- people from culturally and linguistically diverse (CALD) backgrounds
- Aboriginal and Torres Strait Islander people
- children born to mothers with CHB
- children with CHB
- unvaccinated adults at high risk, such as men who have sex with men and people who inject drugs.

Given the growing burden of disease related to CHB, and the need to improve monitoring and treatment uptake by people with CHB, the Strategy highlights the importance of trialling innovative models of care to improve access to clinical services. Therefore, Hepatology Nurses have an important role in developing and managing innovative services that improve access to hepatitis B care and support.

DEFINING THE NURSE’S ROLE IN CARING FOR PATIENTS WITH CHRONIC HEPATITIS B

The Hepatology Nurse’s role in caring for patients with hepatitis B is emerging as a distinct speciality in hepatology nursing, and is supported by the First National Hepatitis B Strategy 2010-2013. Chronic hepatitis B requires lifelong clinical management; therefore, patients will need to regularly engage with the healthcare system. Hepatology Nurses have a critical role in caring for patients with CHB, as they support the patient during the implementation of the management plan, including both monitoring with and without treatment. Hepatology Nurses also play an important role in advocating and negotiating on behalf of patients with CHB, to improve access to care and meet their health needs across a range of healthcare settings. Engaging and supporting General Practitioners (GPs) in the management of CHB is emerging as another important role for Hepatology Nurses.

Nurses are ideally positioned to refer HBsAg positive children of their adult patients to a paediatric service with expertise in viral hepatitis. Research indicates that such referrals are rarely occurring, despite the potential risk of liver disease in children with CHB.

There is greater cultural diversity in communities affected by CHB in Australia, when compared to communities affected by other conditions such as hepatitis C and HIV. The settings in which nurses care for patients with CHB also reflect the affected community’s diversity and include general practice, tertiary hospitals, refugee health, community-based services, antenatal services, Aboriginal and Torres Strait Islander health services and custodial settings.

Hepatology Nurses need to support the prevention of hepatitis B infection. As the majority of patients with CHB in Australia contract hepatitis B through vertical transmission in countries with high prevalence, the Hepatology Nurse has an important role in educating and supporting family members/close contacts of patients with CHB to be tested and vaccinated, if susceptible. In addition, the Hepatology Nurse has a role in promoting vaccination for people at risk, including people who inject drugs and men who have sex with men.

The Guiding Principles of the AHA Consensus-based Nursing Guidelines, described in the Introduction (page 17), underpin the five domains and respective consensus guidelines outlined in this document.
DOMAIN 1: PROVISION AND MANAGEMENT OF NURSING CARE FOR PATIENTS WITH, OR AT RISK OF, HEPATITIS B

Domain 1 of the AHA Competency Standards for the Hepatology Nurse incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to provide comprehensive, evidence-based and culturally appropriate care and education for people with, or at risk of, hepatitis B. Each consensus guideline addresses one or more of the competency standards from Domain 1; details are presented after each guideline.

Consensus guideline 1.1: Optimise testing for people at risk of hepatitis B

- Identify people at risk of hepatitis B infection by conducting a thorough blood borne virus (BBV) risk assessment.
- Refer to the National Hepatitis B Testing Policy for an overview of the procedure for gaining informed consent and conveying a test result.
  - Where possible and relevant, ensure an accredited interpreter is present (either face-to-face or on the telephone) during the process of obtaining informed consent for testing and during the delivery of the negative or positive test results.
- Outline the process of compulsory notification of hepatitis B diagnosis to the local State/Territory health department.
- Provide relevant and appropriate health promotion messages and education to people with, or at risk of, hepatitis B infection, for example, information about safe sex practices, the possible risk associated with household contact and, if needed, use of harm reduction practices during injecting drug use.
- Recommend (if appropriate) the testing and vaccination of close contacts of individuals diagnosed with hepatitis B; provide information about the testing process and vaccination, providing or referring to supportive educational resources.
- Ensure appropriate referral for the patient and their significant other(s), including partner and children, parents, and siblings, to the interdisciplinary team according to their needs and/or requests.

Consensus guideline 1.1 addresses competency standards 1, 2 and 4.

Consensus guideline 1.2: Conduct a comprehensive nursing assessment of the patient with chronic hepatitis B

The nursing assessment of the patient with CHB is based on Gordon’s Functional Health Patterns. The purpose of performing the nursing assessment is to inform the development of the nursing management plan.

Health Perception-Health Management Pattern:

- Document the patient’s hepatitis B history and assess:
  - risk factors for infection (including ethnicity), duration of infection and date of diagnosis
  - hepatitis B symptomology
  - viral characteristics (for example, HBeAg status and viral load; co-infection with hepatitis Delta
  - impact of CHB on the patient’s life (health, social, sexual, work, economic and self-esteem)
  - treatment history.
- Explore the patient’s cultural understanding and meaning of having CHB.
- Explore and document the patient’s drug and alcohol history including use of illicit drugs, alcohol and tobacco.
• Explore the patient’s medical history including other co-morbid illnesses.

• Assess the patient’s family medical history:
  – Including, but not limited to, viral hepatitis, liver disease and/or HCC; endocrine disorders, autoimmune diseases, mental health, renal disease and cardiac conditions.
  – Provide information about contact tracing, if necessary.59

• Assess the need for vaccination according to the current edition of the Australian Immunisation Handbook.60
  – Discuss hepatitis B vaccination for close contacts.

• Discuss the patient’s current medication use including prescription, over the counter and complementary and alternative medicines.

• Document allergies.

Nutritional-Metabolic Pattern, Elimination Pattern and Activity-Exercise Pattern:
• Perform a physical assessment of the patient, including:
  – Monitor vital signs.
  – Nutritional and metabolism assessment including calculation of the patient’s body mass index (BMI), waist to hip ratio and dietary intake.
  – Assess the patient’s activity and exercise routine.
  – Consider autoimmune diseases, cardiac, liver, dermatological, endocrine, oral, ophthalmology, renal issues or other significant co-morbidities.

Cognitive-Perceptual Pattern and Coping-Stress Tolerance Pattern:
• Explore and document the patient’s psychosocial history, including:
  – mental health history
  – coping and stress patterns
  – pain management
  – social support including housing, financial, employment and social activities
  – any legal issues.

Role-Relationship Pattern:
• Explore the roles and relationships of the patient’s significant other(s)/carer(s).

Sexuality-Reproductive Pattern:
• Discuss the patient’s sexual and reproductive health and contraception choices.

• Discuss the potential risk of hepatitis B transmission to unvaccinated sexual contacts and appropriate preventative strategies.

• If relevant, provide information about maternal and infant care in the setting of hepatitis B including the need for regular monitoring during pregnancy, and the option of anti-viral treatment to reduce the risk of vertical transmission.

Sleep-Rest Pattern:
• Discuss the patient’s sleep and rest patterns, including:
  – sleep, rest and relaxation practices
  – dysfunctional sleep patterns.

Value-Belief Pattern:
• Explore the cultural considerations relevant to the patient, acknowledging the social, economic, political and language barriers that affect the healthcare experiences of minority communities.61

Consensus guideline 1.2 addresses competency standards 1 and 4.
Consensus guideline 1.3: Conduct a nursing assessment to identify clinical symptoms and signs of advanced liver disease

- Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease:
  - Consensus guideline 1.1: Perform a nursing assessment to identify clinical symptoms and signs of advanced liver disease.

Consensus guideline 1.3 addresses competency standard 1 and 4.

Consensus guideline 1.4: Assess the patient’s level of knowledge about hepatitis B and provide relevant education

- Assess the patient’s level of hepatitis B knowledge and health literacy, and the cultural meaning of having CHB, and provide relevant education on:
  - hepatitis B transmission
  - hepatitis B natural history and disease progression:
    - potential for hepatitis B reactivation if the patient is immune suppressed
  - factors influencing disease progression
  - health promotion and health maintenance advice
  - harm reduction
  - disclosure and privacy issues
  - hepatitis B discrimination
  - treatment options.

- Discuss the patient’s investigative and diagnostic results and:
  - Educate the patient, with the hope of empowering them, and where appropriate, their significant other(s), to develop a better understanding of their investigative and diagnostic results.
  - Interpret the patient’s pathology results with regard to the disease phase of the natural history.
  - Discuss relevant monitoring and management algorithms consistent with institutional policies and procedures, and best practice.\textsuperscript{62,63,64}
  - Discuss the importance of life-long monitoring for symptoms of advanced liver disease and HCC surveillance.

- Educate and empower mothers with CHB, and their partners, to vaccinate their infant(s):\textsuperscript{65}
  - Discuss the risk of hepatitis B vertical transmission and provide supportive educational resources for the mother and her partner.

Consensus guideline 1.4 addresses competency standards 2 and 4.

Consensus guideline 1.5: Optimise the patient’s health and wellbeing

- Provide culturally appropriate education and support to encourage the patient’s adherence to their management plan including the importance of:
  - attending appointments
  - monitoring and surveillance needs
  - importance of having a regular GP.

- Discuss strategies to prevent liver disease progression.

- Provide culturally appropriate education about lifestyle choices including dietary considerations, alcohol intake and exercise.

- Document the patient’s use of complementary and alternative medicines.
• Discuss current and future management strategies of the patient’s condition depending on their disease severity:
  – Identify and advocate for the patient’s preferred health and management choices.

  Consensus guideline 1.5 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.6: Advocate and support the patient with chronic hepatitis B to be actively involved in their treatment and management plan

• Assist the patient and their significant other(s) to negotiate the healthcare system:
  – Negotiate access to timely referrals and interventions in accordance with the patient’s management plan.

• Work in collaboration with the patient to develop a management plan which includes goal setting around healthy behaviours by incorporating motivational interviewing techniques.66

• Establish the patient’s awareness of, and access to, pathology, medical imaging, alternative medical services (if the patient moves) and costs associated with accessing healthcare.

• Advocate for the patient in the interdisciplinary team.

  Consensus guideline 1.6 addresses competency standards 1 and 3.

Consensus guideline 1.7: Provide ongoing monitoring-related nursing care for the patient with chronic hepatitis B

• Discuss the importance of life-long monitoring with patients with CHB:
  – Explain to the patient the rationale supporting regular hepatitis B monitoring for patients in the immune tolerant and immune control phases, specifically reinforcing the details regarding the natural history of CHB and the potential to progress through the phases of the disease.
    ~ Reinforce the misleading nature of the term “healthy carrier of hepatitis B”.67

  – Confirm the patient’s awareness of possible reactivation of hepatitis B in the setting of immune suppression.

• Explore the patient’s understanding of CHB monitoring and their likely adherence to the monitoring plan.
  – Assess the patient’s adherence to the monitoring plan and respond as required.

• Explore options to encourage and support adherence to ongoing monitoring including HCC surveillance:
  – Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma:
    ~ Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.

• Discuss alternative models of monitoring care including GP and/or nurse-led models, if available.

  Consensus guideline 1.7 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.8: Provide nursing management for the patient with chronic hepatitis B who is considering treatment

• Discuss CHB treatment options to enable the patient to make an informed choice:
  – Discuss the reason for treating CHB.
  – Provide information about current and future treatment options for CHB.
  – Discuss the use of liver biopsy and non-invasive interventions to assess liver damage.
- Discuss the potential impact of hepatitis B treatment on the patient’s life.
- Discuss the management plan if the patient chooses not to commence treatment.
- Provide relevant resources.

Consensus guideline 1.8 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.9: Provide hepatitis B treatment-related nursing care for the patient with chronic hepatitis B

- Ensure the patient understands the treatment regimen:
  - Provide an overview, and management of, possible treatment-related side effects.
  - Discuss the importance of medication adherence and consequences of non-adherence.
- Discuss the importance of treatment-related monitoring:
  - Explain the rationale supporting regular monitoring during hepatitis B treatment specifically the potential to detect drug resistance and/or viral flares.
  - Explore options to encourage and support adherence to regular monitoring during long-term treatment.
  - Assess the patient’s adherence to the treatment-related monitoring plan on a regular basis and respond as required.

Consensus guideline 1.9 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.10: Discuss the importance of hepatocellular carcinoma surveillance for the patient with chronic hepatitis B

- Explain to the patient the rationale supporting HCC surveillance for patients with CHB.
- Refer to AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma:
  - Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.

Consensus guideline 1.10 addresses competency standards 1, 2, 3 and 4.

DOMAIN 2: INTERDISCIPLINARY COORDINATION AND CARE FOR PATIENTS WITH HEPATITIS B

Domain 2 of the AHA Competency Standards for the Hepatology Nurse incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to facilitate, coordinate and evaluate interdisciplinary care for people with, or at risk of, hepatitis B as they seek to achieve optimal health outcomes. Each consensus guideline addresses one or more of the competency standards from Domain 2; details are presented after each guideline.

Consensus guideline 2.1: Discuss the roles of each member of the interdisciplinary team in relation to the implementation of the patient’s management plan

- Explain the role of each member of the interdisciplinary team in terms of the professional responsibilities and areas of expertise.
- Provide the patient with the contact details for the most relevant members of the interdisciplinary team.
- Outline the communication pathways between members of the interdisciplinary team.

Consensus guideline 2.1 addresses competency standard 2.
Consensus guideline 2.2: Recognise and enhance the existing therapeutic relationship with the general practitioner and/or referring practitioner

- Establish a communication pathway with the patient's GP/referring practitioner.
- With the patient's consent, communicate with the GP/referring practitioner regarding the details of the patient's health and disease status, and their treatment and management plan.
- In collaboration with the medical specialist and GP/referring practitioner, coordinate and manage the patient's ongoing care including:
  - hepatitis B monitoring plan
  - advanced liver disease monitoring plan
  - hepatocellular carcinoma surveillance plan
  - treatment-related monitoring requirements
  - emotional and social support.
- Communicate with the GP/referring practitioner about the patient's progress during the implementation of the patient's management and treatment plan including:
  - Adherence to the hepatitis B monitoring plan.
  - Anti-viral treatment plan including details about the:
    - prescribed anti-viral medication and potential side effects
    - required monitoring tests
    - frequency of monitoring tests
    - parameters for contacting the specialist service if concerned about the patient's health.
  - Advanced liver disease management plan:
    - Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease.
      > Consensus guideline 1.7: Provide ongoing monitoring and assessment-related nursing care for the patient with advanced liver disease.
  - Hepatocellular carcinoma surveillance plan:
    - Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma:
      > Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.

Consensus guideline 2.2 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 2.3: Liaise with general practitioners and/or referring practitioners about patient referral and management

- Educate GPs/referring practitioners to identify patients at risk of hepatitis B and diagnose patients with CHB and appropriately refer them for specialist care:
  - Encourage GPs to test and vaccinate the patient's close contacts for hepatitis B, if appropriate.
- Consider reviewing the clinical information included in the patient's referral letter prior to the patient's appointment and coordinate the collection of additional clinical information either from the patient or their GP/referring practitioner.
- Inform and discuss the option of participating in hepatitis B shared care programs with GPs/referring practitioners and assess their willingness to participate.
- Educate GPs/referring practitioners about the role of the hepatology nurse in caring for patients with CHB.

Consensus guideline 2.3 addresses competency standards 1 and 2.
Consensus guideline 2.4: Facilitate patient referral to members of the interdisciplinary team and community allied health services

- Refer patients with CHB to allied health support services in the hospital and the community, as required, including:
  - alcohol and other drug services
  - community health nursing
  - dentists
  - dietitians
  - medical specialists
  - multicultural workers for social and cultural support
  - psychologists
  - psychiatrists
  - palliative care
  - physiotherapists
  - podiatrists
  - settlement workers for patients with a refugee background
  - sexual health services
  - social workers
  - other health services, as required.

Consensus guideline 2.4 addresses competency standards 1 and 2.

Consensus guideline 2.5: Liaise with, and support, health professionals working with patients with chronic hepatitis B who have additional needs

- Liaise with health professionals who care for patients with CHB who have additional needs, including pregnant women, patients co-infected with hepatitis C and/or hepatitis Delta and/or HIV, paediatric patients, patients with renal disease and/or prisoners with CHB about:
  - appropriate referral to the specialist clinic
  - management and treatment options
  - developing shared care protocols.

- Encourage and participate in interdisciplinary communication including case management services.

Consensus guideline 2.5 addresses competency standards 1, 2 and 4.

DOMAIN 3: NON-DISCRIMINATORY PRACTICE

Domain 3 of the AHA Competency Standards for the Hepatology Nurse incorporates two competency standards and related performance criteria that reflect the non-discriminatory practice of Hepatology Nurses, and their respect for the choices of people with, or at risk of, hepatitis B with regard to alcohol and drug use, sexual orientation, religious and cultural beliefs, social circumstances and physical and mental health. Each consensus guideline addresses one or more of the competency standards from Domain 3; details are presented after each guideline.

Consensus guideline 3.1: Promote confidentiality for patients with chronic hepatitis B

- Discuss the patient’s right to confidentiality of their personal information in the healthcare setting.
  - Seek to understand the meaning of confidentiality from the patient’s perspective.

- Understand and adhere to relevant medico-legal obligations including documentation.

Consensus guideline 3.1 addresses competency standards 1 and 2.
Consensus guideline 3.2: Facilitate appropriate disclosure by patients with chronic hepatitis B

- Facilitate appropriate disclosure by advising the patient that they should consider disclosing their hepatitis B status in the following circumstances:
  - Blood, blood products and organ donation; life and health insurance; military services; healthcare workers performing exposure prone procedures. \(^7\)
- Advise the patient regarding when they are not required to disclose their hepatitis B status.
- Refer the patient to their local State/Territory Hepatitis Organisation for further information about appropriate disclosure of hepatitis B status.

Consensus guideline 3.2 addresses competency standards 1 and 2.

Consensus guideline 3.3: Discourage discriminatory behaviour against patients with chronic hepatitis B

- Respectfully challenge discriminatory attitudes towards patients with CHB.
- Educate and support health professionals to provide non-discriminatory care for patients with CHB.
- Enable the patient to be aware of their diagnosis and make informed choices about disclosure.
- Provide support, information and appropriate referrals to complaints services for patients who have experienced discrimination.
- Advocate for the patient's equity of access to treatment and management regardless of the aetiology of their disease and lifestyle choices.

Consensus guideline 3.3 addresses competency standards 1 and 2.

Consensus guideline 3.4: Provide culturally appropriate nursing care for patients with chronic hepatitis B

- Be aware of the various health belief models and cultural differences and their impact on the patient's health behaviour.
- Develop an awareness of own cultural beliefs and attitudes and consider how these affect the delivery of nursing care.
- Advocate for the delivery of culturally appropriate and sensitive healthcare. \(^7\)
- Seek support from specialist services in the delivery of culturally appropriate nursing care, for example, multicultural services, Aboriginal and Torres Strait Islander services and/or drug and alcohol services.

Consensus guideline 3.4 addresses competency standards 1 and 2.

DOMAIN 4: PROFESSIONAL SELF-CARE AND DEVELOPMENT

Domain 4 of the AHA Competency Standards for the Hepatology Nurse \(^7\) incorporates five competency standards and related performance criteria that reflect the Hepatology Nurse’s ability to adapt to the changing clinical environment through involvement in professional development activities and reflective practice. Each consensus guideline addresses one or more of the competency standards from Domain 4; details are presented after each guideline.
Consensus guideline 4.1: Identify and define the hepatology nursing scope of practice

• To assist Hepatology Nurses to identify their individual scope of practice and the scope of practice of the speciality, the following questions are presented for consideration:
  – What is the profile of the patients with, or affected by, liver disease that the Hepatology Nurse cares for and what could the Hepatology Nurse be doing to improve the health outcomes for these patients?
  – What education and professional development activities has the Hepatology Nurse completed?
  – What is the previous experience of the Hepatology Nurse?
  – What additional education does the Hepatology Nurse need to provide the required standard of nursing care to patients with, or affected by, liver disease?
  – Is the scope of practice used by nurses in other settings?
  – What is the nurse’s legal position? For example, do Australian and/or State/Territory Government legislation and regulations permit nurses to deliver the care being considered as part of the Hepatology Nurse’s scope of practice?
  – Are there policies and procedures in place to support the Hepatology Nurse providing this care?
  – How will competency assessment take place given the Hepatology Nurse’s current scope of practice and if the Hepatology Nurse is expanding their scope of practice?

The scope of hepatology nursing practice is an important consideration when interpreting the AHA Consensus-based Nursing Guidelines. It is important to highlight that the AHA, as the professional organisation representing Hepatology Nurses in Australia, has a responsibility to its members to assist in identifying the speciality’s scope of practice and to provide a forum for individuals to consider what constitutes their scope of practice.

Consensus guideline 4.1 addresses competency standards 2, 3, 4 and 5.

Consensus guideline 4.2: Actively participate in reflective practice

• Reflective practice is an important skill that Hepatology Nurses may choose to develop to identify their scope of practice and to continuously learn and evolve as a result of their professional practice.

• In addition to formal teaching and learning, reflective practice encourages individuals to participate in life-long learning from their own professional experiences.

• In order to inform future iterations of the AHA Competency Standards and the AHA Consensus-based Nursing Guidelines, Hepatology Nurses may consider using reflective practice to assist in their professional evolution, and that of the speciality.

Consensus guideline 4.2 addresses competency standards 1, 2 and 3.

Consensus guideline 4.3: Actively engage in continuing professional development

• The Nursing and Midwifery Board of Australia’s National Registration Standards stipulate that continuing professional development is a requirement of nursing registration.

• Identify and participate in professional development activities that maintain one’s own advanced level of knowledge and skills with regard to caring for patients with liver disease.

• Participate in life-long learning to ensure ongoing development of the individual and the hepatology nursing speciality.

Consensus guideline 4.3 addresses competency standard 1.
Consensus guideline 4.4: Actively engage in professional self-care

• Actively maintain one’s own physical, mental and spiritual health by seeking support, as required.

• Accept the responsibility for self-care by acknowledging one’s own physical, mental and spiritual strengths and limitations, and recognise one’s intrinsic worth.

• Foster qualities that encourage beneficial practices and relationships with colleagues.78

Consensus guideline 4.4 addresses competency standard 3.

DOMAIN 5: CLINICAL AND COMMUNITY LEADERSHIP

Domain 5 of the AHA Competency Standards for the Hepatology Nurse79 incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to provide clinical leadership and expertise in the nursing profession with regard to liver health and disease, and community leadership through advocacy and policy development. Each consensus guideline addresses one or more of the competency standards from Domain 5; details are presented after each guideline.

Consensus guideline 5.1: Actively promote the Hepatology Nurse’s role in the delivery of care for patients with chronic hepatitis B

• Actively promote the Hepatology Nurse as an expert resource in hepatitis B for health professionals as well as the community, education, government and non-government sectors.

• Maintain and foster relationships with key stakeholders in clinical and non-clinical organisations and promote the Hepatology Nurse’s role in the management of patients with CHB.

• Disseminate the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B to clinical and non-clinical colleagues.
  – Advocate for their use as evidence to support the Hepatology Nurse’s role in caring for patients with hepatitis B.

• Initiate and/or contribute to the research activities that strengthen the evidence-base of the Hepatology Nurse’s role in caring for patients with hepatitis B.

• Act as a change agent to influence local and national policy to ensure the needs of hepatitis B priority populations are addressed.

Consensus guideline 5.1 addresses competency standards 1 and 4.

Consensus guideline 5.2: Mentor nurses to be involved in caring for patients with chronic hepatitis B

• Mentor and support nurses with an interest in caring for patients with CHB to build their confidence and competence in CHB care and management.

• Support nurses new to the field of hepatology nursing to interpret and implement the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B.

• Provide expert education and support to Hepatology Nurses interested in caring for patients with CHB.

Consensus guideline 5.2 addresses competency standard 3.
Consensus guideline 5.3: Provide ongoing education, support and leadership for health professionals involved in caring for people with, or at risk of, hepatitis B

• Seek opportunities to contribute to, participate in and/or lead hepatitis B education forums.
• Actively engage in own professional development activities to ensure knowledge currency.
• Provide expert information regarding the meaning of test results, the natural history of hepatitis B, treatment options and appropriate referral to members of the interdisciplinary team caring for patients with, or at risk of, hepatitis B.
• Provide education and support for health professionals involved in caring for people with, or at risk of, hepatitis B including, but not limited to, medical practitioners, primary healthcare workers, drug and alcohol workers, workers in the custodial setting, registered and enrolled nurses, midwives, multicultural health workers, community-based organisations, allied health professionals and health assistant workers.

Consensus guideline 5.3 addresses competency standard 2.

Consensus guideline 5.4: Provide education to raise the community’s awareness of hepatitis B

• Seek opportunities to work collaboratively with hepatitis organisations and other community-based organisations to raise awareness of hepatitis B in the local community.
• Provide education for local community groups to raise awareness of hepatitis B and local clinical and community services.

Consensus guideline 5.4 addresses competency standard 2.

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HEPATITIS C TRANSMISSION

Hepatitis C is a blood-borne virus (BBV), which means it is primarily spread through blood-to-blood contact. In Australia, hepatitis C is most commonly spread through unsafe injecting drug use, which accounts for approximately 90% of all new infections and 83% of prevalent infections. Five percent of prevalent infections occurred through contaminated blood or blood products transfusions prior to 1990, and the remaining 12% of people with hepatitis C were infected in other ways, including:

- unsterile tattooing or body piercing procedures
- unsterile medical procedures or vaccinations (particularly in countries with high hepatitis C prevalence)
- occupational exposure, primarily needlestick injuries
- other forms of blood-to-blood contact including mother-to-child transmission and sexual contact.

Between four and six percent of mothers who are hepatitis C virus positive will transmit hepatitis C to their infants perinatally, with conservative estimates indicating this will result in an average of 125-250 new paediatric cases of hepatitis C each year in Australia. The majority of children who develop chronic hepatitis C remain undiagnosed. Mothers with hepatitis C should be educated and supported to have their children tested and if they test positive, children should be referred to a Paediatric Gastroenterology or Infectious Diseases Unit for management and treatment.

Recent evidence has emerged that the risk of sexual transmission of hepatitis C is increased between men who have sex with men who are human immunodeficiency virus (HIV) positive but do not inject drugs. Blood-to-blood contact through high risk sexual behaviour is the presumed risk factor.

DISEASE COURSE OF HEPATITIS C

Chronic hepatitis C causes inflammation of the liver, which can lead to advanced liver disease and significant scarring of the liver tissue, known as cirrhosis. Disease progression is accelerated by other factors such as older age at infection (older than 40 years), male gender, co-infection with HIV or hepatitis B, alcohol consumption and obesity. Research has shown that approximately 25% of people with hepatitis C will clear the virus within two to six months of infection; this group will be hepatitis C antibody positive but they do not have the hepatitis C virus in their blood.
therefore, they cannot transmit the virus to others. The remaining 75% of people infected with hepatitis C who do not clear the virus will develop chronic infection and are at risk of developing cirrhosis of the liver.

After an average of 15 years, between 40% and 60% of people with chronic hepatitis C will experience symptoms of, and develop, some liver damage. After 20 years, between five and 10% with hepatitis C-related liver damage will develop cirrhosis. Between two and five percent of these people will experience liver failure or develop a form of liver cancer known as hepatocellular carcinoma (HCC).13

GUIDELINES FOR THE MANAGEMENT OF HEPATITIS C VIRUS INFECTION

In Australia, the clinical management of hepatitis C is guided by international clinical practice guidelines generated by the American Association for the Study of Liver Diseases (AASLD)14,15 and the European Association for the Study of the Liver (EASL).16 In Australia, the National Hepatitis C Testing Policy has been developed to guide clinicians involved in testing and diagnosing hepatitis C.17 Each of these clinical practice guidelines are medical documents. They have not been designed to guide nursing practice. However, without an understanding of the medical evidence, Hepatology Nurses will be unable to meet the following competency standards identified in the AHA Competency Standards for the Hepatology Nurse:

• 1.1 Provides comprehensive, evidence-based nursing care for people with or affected by liver disease.
• 1.2 Provides specialised information and education from a nursing perspective.
• 1.4 Provides evidence-based nursing care.
• 2.3 Participates in and contributes to interdisciplinary clinical decision-making.
• 3.2 Advocates for and promotes the rights of people with or affected by liver disease.
• 5.2 Provides expert advice and guidance to the multidisciplinary team and external agencies on the care of people with or affected by liver disease.18

The evidence presented in the medical guidelines is embedded in the AHA Consensus-based Nursing Guidelines and creates the benchmark for best practice.

TREATMENT OF HEPATITIS C

Treatment of hepatitis C is currently undergoing a rapid evolution. Standard of care treatment in Australia remains the combination of PegIFN and RBV. However, direct acting anti-viral therapy administered in combination with PegIFN and RBV are resulting in a higher response rate and the possibility of a shorter duration of treatment. The primary goal of hepatitis C treatment is to achieve a sustained virological response (SVR) or cure, defined as undetectable hepatitis C virus in the blood 24 weeks after ceasing treatment.19,20 Achieving an SVR is associated with reduced morbidity and mortality and the potential resolution of liver disease in patients without cirrhosis.21,22 Successful treatment for people with cirrhosis can be associated with reversal of liver damage, however, patients may remain at risk of developing complications related to cirrhosis, such as HCC.23

SOCIAL IMPACT OF LIVING WITH HEPATITIS C

People with hepatitis C often report experiencing stigma and discrimination in relation to their hepatitis C status and/or their mode of infection, specifically injecting drug use.24 Almost one in five people with hepatitis C in New South Wales reported that their hepatitis C negatively impacted them at their place of work, and one in four reported it had affected their personal relationships.25
Healthcare-related stigma and discrimination encompasses a variety of actions including inappropriate comments, unnecessary infection control procedures, breaches of confidentiality and refusal to provide healthcare. Stigma and discrimination towards people with hepatitis C can create barriers to accessing healthcare, social isolation and poor self-image and confidence.

HEPATITIS C POLICY IN AUSTRALIA

The Third National Hepatitis C Strategy 2010-2013 identifies the following groups as priority populations:

- people with hepatitis C
- people who inject drugs
- people in custodial settings
- people from culturally and linguistically diverse (CALD) communities
- people with hepatitis C and co-morbidities.

Hepatitis C is clinically managed in a range of settings in Australia, including tertiary hospital clinics, general practice, opiate substitution treatment services, community health services, outreach clinics in regional Australia and custodial settings. The Strategy highlights the need to increase the number of patients being treated for hepatitis C, in order to reduce the long-term morbidity and mortality associated with the infection and associated liver disease. To address this, access to hepatitis C management and treatment services needs to be expanded beyond the traditional tertiary-based models of care.

DEFINING THE NURSE’S ROLE IN CARING FOR PATIENTS WITH HEPATITIS C

The Hepatology Nurse’s role in caring for patients with hepatitis C varies according to geographic locations, including State and Territory jurisdictions, metropolitan and regional/rural environments, and the model of health service delivery. Therefore, Hepatology Nurses are encouraged to consider their scope of practice while interpreting the AHA Consensus-based Nursing Guidelines.

Hepatology Nurses caring for patients with hepatitis C challenge the traditional structures and practices of the nursing profession because of the breadth of their work and diversity of the occupational settings in which they work to meet the patient demand. Hepatology Nurses have an important role in advocating and negotiating on behalf of patients with hepatitis C to improve access to care and meet their health needs across a range of healthcare settings. It has been demonstrated that Hepatology Nurses play an integral role in providing patient-centred education, support and care for patients with hepatitis C from a diverse range of socioeconomic backgrounds.

The administration, education and management of patients with hepatitis C on anti-viral treatment is a significant component of the Hepatology Nurses’ current role and an area of professional expertise. Hepatology Nurses have been identified as being central to enhancing patients’ understanding and management of their hepatitis C treatment. In addition, Hepatology Nurses have the ability to enhance treatment adherence and treatment response rates through the development and implementation of individualised therapeutic education and nursing plans for patients with hepatitis C.

The Guiding Principles of the AHA Consensus-based Nursing Guidelines, described in the Introduction (page 17), underpin the five domains and respective consensus guidelines outlined in this document.
DOMAIN 1: PROVISION AND MANAGEMENT OF NURSING CARE FOR PATIENTS WITH, OR AT RISK OF, HEPATITIS C

Domain 1 of the AHA Competency Standards for the Hepatology Nurse incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to provide comprehensive, evidence-based and culturally appropriate care and education for patients with, or at risk of, hepatitis C. Each consensus guideline addresses one or more of the competency standards from Domain 1; details are presented after each guideline.

Consensus guideline 1.1: Optimise testing for people at risk of hepatitis C

- Identify people at risk of hepatitis C infection by conducting a thorough BBV risk assessment:
  - Offer or refer for hepatitis C testing for people at risk and/or people who ask to be tested according to the National Hepatitis C Testing Policy.
  - Refer to the National Hepatitis C Testing Policy for an overview of the procedure for gaining informed consent and conveying a test result.
  - Where possible and relevant, ensure an accredited interpreter is present (either face-to-face or on the telephone) during the process of obtaining informed consent for testing and during the delivery of the negative or positive test results.
- Provide relevant and appropriate health promotion messages and education to people with, or at risk of, hepatitis C infection, for example, use of harm reduction practices during injecting drug use and blood awareness.
- Ensure appropriate referral for the patient and their significant other(s) to members of the interdisciplinary team according to their needs and/or requests.

Consensus guideline 1.1 addresses competency standards 1, 2 and 4.

Consensus guideline 1.2: Conduct a comprehensive nursing assessment of the patient with hepatitis C

The nursing assessment of the patient with hepatitis C is based on Gordon’s Functional Health Patterns. The purpose of performing the nursing assessment is to inform the development of the nursing management plan.

Health Perception-Health Management Pattern:

- Document the patient’s hepatitis C history and assess:
  - risk factors, duration of infection and diagnosis
  - hepatitis C symptoms and signs
  - viral characteristics and disease progression through review and interpretation of laboratory and imaging tests
  - impact of hepatitis C on the patient’s life (health, social, sexual, work, economic and self-esteem)
  - extrahepatic manifestations
  - treatment history.
- Discuss the patient’s medical history.
- Assess the need for vaccination according to the current edition of the Australian Immunisation Handbook.
- Assess family medical history as it relates to the patient’s current health.

Please note that the nursing assessment presented in this document is only one of many nursing assessment tools available. Hepatology Nurses are encouraged to consider which assessment tool best suits their clinical practice.
Including, but not limited to, hepatitis C, liver disease and/or HCC; endocrine disorders, autoimmune diseases, mental health and cardiac conditions. Provide information about contact tracing, if necessary.44

- Assess the patient’s current medication use including prescription, non-prescription, illicit and complementary and alternative medicines (including vitamins).

- Explore and document the patient’s drug and alcohol history including overuse of prescription and non-prescription medications, use of illicit drugs, alcohol and tobacco.

- Document allergies.

Nutritional-Metabolic Pattern, Elimination Pattern and Activity-Exercise Pattern:

- Perform a physical assessment of the patient, including:
  - Monitor vital signs.
  - Nutritional and metabolism assessment including calculation of the patient’s body mass index (BMI), waist to hip ratio and dietary intake.
  - Assess the patient’s activity and exercise routine.
  - Consider autoimmune diseases, cardiac, chronic liver disease, dermatological, endocrine, oral, ophthalmology, renal issues or other significant co-morbidities.

Cognitive-Perceptual Pattern and Coping-Stress Tolerance Pattern:

- Explore and document the patient’s psychosocial history, including:
  - mental health history
  - coping and stress patterns
  - pain management
  - social support including housing, financial, employment, transport requirements and social activities
  - any legal issues.

Role-Relationship Pattern:

- Explore the roles and relationships of the patient’s significant other(s)/carer(s).

Sexuality-Reproductive Pattern:

- Discuss the patient’s sexual and reproductive health and contraception choices.

Sleep-Rest Pattern:

- Discuss the patient’s sleep and rest patterns, including:
  - sleep, rest and relaxation practices
  - dysfunctional sleep patterns.

Value-Belief Pattern:

- Explore the cultural considerations relevant to the patient, acknowledging the social, economic, political and language barriers that affect the healthcare experiences of minority communities.45

Consensus guideline 1.2 addresses competency standards 1 and 4.

Consensus guideline 1.3: Conduct a nursing assessment to identify clinical symptoms and signs of advanced liver disease

- Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease:
  - Consensus guideline 1.1: Perform a nursing assessment to identify clinical symptoms and signs of advanced liver disease.

Consensus guideline 1.3 addresses competency standards 1 and 4.
Consensus guideline 1.4: Assess the patient’s level of knowledge about hepatitis C and provide relevant education

- Assess the patient’s level of hepatitis C knowledge and health literacy, and provide relevant education on:
  - hepatitis C transmission and household prevention
  - hepatitis C natural history and disease progression
  - factors influencing disease progression
  - health promotion and health maintenance
  - harm reduction
  - disclosure and privacy issues
  - discrimination
  - treatment options; current and future
  - discuss relevant diagnostic, monitoring and surveillance testing.

Consensus guideline 1.4 addresses competency standards 2 and 4.

Consensus guideline 1.5: Optimise the patient’s health and wellbeing

- Provide health promotion messages and education, for example safe injecting practices and blood awareness.
- Provide education about lifestyle choices, for example, dietary considerations and exercise.
- Provide education for strategies to manage mental health issues, for example, stress and anger management.
- Promote and refer the patient to local services that enable and support lifestyle changes.
- Discuss the use of complementary and alternative medicines.
- Discuss current and future management strategies of the patient’s condition depending on their disease severity:
  - Identify and advocate for the patient’s preferred health and management choices.

Consensus guideline 1.5 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.6: Advocate and support the patient with hepatitis C to be actively involved in their treatment and management plan

- Assist the patient and their significant other(s) to negotiate the healthcare system.
  - Negotiate access to timely referrals and interventions in accordance with the patient’s management plan.
- Work in collaboration with the patient to develop a management plan which includes goal setting around healthy behaviours by incorporating motivational interviewing techniques.46
- Establish the patient’s awareness of, and access to, pathology, medical imaging, alternative medical services (if the patient moves) and costs associated with accessing healthcare.
- Advocate for the patient in the interdisciplinary team.

Consensus guideline 1.6 addresses competency standards 1 and 3.

Consensus guideline 1.7: Perform a pre-treatment nursing assessment

- Assess the patient’s social support network and discuss possible sources of support during treatment.
- Assess the patient’s psychological support needs during treatment:
  - Refer to allied health and/or mental health, if required.
  - Refer the patient to a hepatitis C support group, if appropriate and available.
• Provide relevant patient education during the pre-treatment phase including:
  – Information about the treatment process, including possible outcomes (availability of clinical trials, projected response rates, the potential for treatment failure, response guided therapy and treatment stopping rules).47,48,49
  – Overview of possible side effects of treatment and possible duration of treatment-related side effects:
    ~ Educate and support the patient and their partner(s) to use two forms of contraception and avoid pregnancy while on treatment and for six months after treatment completion.
  – Interpretation of pathology results whilst on treatment.
  – Recommendations about side effect management.
  – Importance of adherence and consequences of non-adherence to the treatment.
  – Models of care including option for shared care with a General Practitioner (GP) or referring practitioner.
  – Provide information about, and referral to, community support services such as national, State and Territory hepatitis organisations.
• Establish effective communication pathways with the patient’s GP and relevant members of the interdisciplinary team.
• Manage or refer the patient for HCC surveillance if advanced liver disease is present:
  – Liaise with the relevant members of the interdisciplinary team responsible for managing HCC surveillance.
  – Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma:
    ~ Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.
    ~ Consensus guideline 1.7 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.8: Provide patient education at the commencement of hepatitis C treatment
• Provide relevant patient education at the commencement of hepatitis C treatment:
  – Discuss the patient’s responsibilities to themselves and the healthcare team whilst on treatment and after the completion of treatment:
    ~ Provide information about available support services: emergency telephone numbers (mental health, accident and emergency, drug and alcohol), Hepatology Nurse contact details and other out-of-hours support services.
• Provide instructions about the storage and self-administration of the medication:
  – Assess the patient’s understanding of medication administration.
  – Discuss the importance of adherence to the medication.
• Provide information on potential SVR rates, the potential for treatment failure, response guided therapy and treatment stopping rules.
• Discuss common treatment-related side effects and recommendations about side effect management.
• Discuss monitoring requirements whilst on treatment.
• Confirm appointment schedule.
• Establish the patient’s awareness of pathology services and hospital pharmacy service.
• Discuss aspects of disclosure specifically relating to treatment.
  ~ Consensus guideline 1.8 addresses competency standards 1, 2, 3 and 4.
Consensus guideline 1.9: Provide hepatitis C treatment-related nursing care

- Discuss the patient’s progress on treatment, including:
  - Meaning of pathology results.
  - The patient’s understanding of medication administration.
  - Medication adherence.
  - Identify, assess and manage treatment side effects.
  - Discussion of preventative strategies for avoiding and/or minimising side effects.
  - Assessment and discussion of dose reduction with the specialist and the patient.
  - Assessment and encouragement of adherence to effective contraception methods during treatment and for six months post-treatment.

- Continue to monitor and assess the patient’s psychological support needs:
  - Refer to allied health and/or mental health support, as appropriate.
  - Refer to a hepatitis C support group, as appropriate and available.

- Monitor and assess the patient’s alcohol and drug use (abstinence and misuse) during treatment.

- Continue to provide health maintenance advice.

- Facilitate communication with members of the interdisciplinary team.

- Manage or refer the patient for HCC surveillance if advanced liver disease is present:
  - Liaise with the relevant members of the interdisciplinary team responsible for managing HCC surveillance.
  - Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma:
    - Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.

Consensus guideline 1.9 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.10: Provide hepatitis C-related nursing care after the patient has completed treatment

- Identify, assess and manage any ongoing treatment-related side effects including:
  - Preventative strategies for avoiding and/or minimising side effects.

- Provide support and ongoing education regarding the patient’s treatment response:
  - The meaning attached to achieving an SVR for the individual.
  - Discuss future treatment options in relation to treatment failure including relapse, partial response or non-response.

- Provide ongoing education and support about future and long-term options for:
  - health maintenance
  - harm reduction
  - prevention of hepatitis C transmission.

- Provide referrals as appropriate:
  - Support services including the local hepatitis organisation, alcohol and other drug service, counselling services, multicultural health services and Aboriginal and Torres Strait Islander health services.

- Develop a nursing management plan in consultation with the patient, the patient’s significant other(s) and the interdisciplinary team.

- Discharge from specialist care to the primary care provider/referring practitioner, if appropriate.

Consensus guideline 1.10 addresses competency standards 1, 2, 3 and 4.
Consensus guideline 1.11: Discuss the importance of hepatocellular carcinoma surveillance for the patient with hepatitis C

- Explain the rationale for HCC surveillance to the patient.
- Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma:
  - Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.

Consensus guideline 1.11 addresses competency standards 1, 2, 3 and 4.

DOMAIN 2: INTERDISCIPLINARY COORDINATION AND CARE FOR PATIENTS WITH HEPATITIS C

Domain 2 of the AHA Competency Standards for the Hepatology Nurse incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to facilitate, coordinate and evaluate interdisciplinary care for patients with hepatitis C as they seek to achieve optimal health outcomes. Each consensus guideline addresses one or more of the competency standards from Domain 2; details are presented after each guideline.

Consensus guideline 2.1: Discuss the roles of each member of the interdisciplinary team in relation to the implementation of the patient's management plan

- Explain the role of each member of the interdisciplinary team in terms of the professional responsibilities and areas of expertise.
- Provide the patient with the contact details for the most relevant members of the interdisciplinary team.
- Outline the communication pathways between members of the interdisciplinary team.

Consensus guideline 2.1 addresses competency standard 2.

Consensus guideline 2.2: Recognise and enhance the existing therapeutic relationship with the general practitioner and/or referring practitioner

- Establish a communication pathway with the patient’s GP/referring practitioner.
- Communicate with the GP/referring practitioner regarding the details of the patient’s health and disease status, their treatment and management plan and monitoring required according to treatment outcome.
- In collaboration with the GP/referring practitioner, coordinate and manage the patient’s ongoing care including:
  - hepatitis C monitoring plan
  - hepatocellular carcinoma surveillance plan
  - treatment-related monitoring requirements.
- Communicate with the GP/referring practitioner about the patient’s progress during the implementation of the patient’s management and treatment plan including:
  - Anti-viral treatment plan including details about the:
    - prescribed anti-viral medication and potential side effects
    - required monitoring tests
    - frequency of monitoring tests
    - parameters for contacting the specialist service if concerned about the patient’s health.
- Advanced liver disease management plan:
  - Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease.
    > Consensus guideline 1.7: Provide ongoing monitoring and assessment-related nursing care for the patient with advanced liver disease.

- Hepatocellular carcinoma surveillance plan:
  - Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma.
    > Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.

Consensus guideline 2.2 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 2.3: Liaise with general practitioners and/or referring practitioners about patient referral and management

- Educate and support GPs/referring practitioners to identify patients at risk, as well as diagnose patients with hepatitis C and appropriately refer them for specialist care.
- Consider reviewing the clinical information included in the patient’s referral letter prior to the patient’s appointment and coordinate the collection of additional clinical information either from the patient or the GP/referring practitioner.
- Inform and discuss the option of participating in hepatitis C shared care programs with the GPs/referring practitioners and assess their willingness to participate.
- Educate the GPs/referring practitioners about the role of the Hepatology Nurse in caring for patients with hepatitis C.

Consensus guideline 2.3 addresses competency standards 1 and 2.

Consensus guideline 2.4: Facilitate patient referral to members of the interdisciplinary team and community allied health services

- Refer patients with hepatitis C to allied health support services in the hospital and the community, as required, including:
  - alcohol and other drug services
  - community health nursing
  - dentists
  - dietitians
  - medical specialists
  - multicultural workers for social and cultural support
  - psychologists
  - psychiatrists
  - palliative care
  - physiotherapists
  - podiatrists
  - settlement workers for patients with a refugee background
  - sexual health services
  - social workers
  - other health services, as required.

Consensus guideline 2.4 addresses competency standards 1 and 2.
Consensus guideline 2.5: Liaise with, and support, health professionals working with patients with hepatitis C who have additional needs

- Liaise with health professionals who care for patients with hepatitis C who have additional needs, for example, pregnant women, patients co-infected with hepatitis B and/or HIV, pediatrics patients, patients with drug and alcohol using history, patients with mental health issues and/or prisoners with hepatitis C about:
  - appropriate referral to the specialist clinic
  - management and treatment options
  - developing shared care protocols.

- Encourage and participate in interprofessional communication, including case management services.

Consensus guideline 2.5 addresses competency standards 1, 2 and 4.

DOMAIN 3: NON-DISCRIMINATORY PRACTICE

Domain 3 of the AHA Competency Standards for the Hepatology Nurse incorporates two competency standards and related performance criteria that reflect the non-discriminatory practice of Hepatology Nurses, and their respect for the choices of people with hepatitis C, with regard to alcohol and drug use, sexual orientation, religious and cultural beliefs, social circumstances and physical and mental health. Each consensus guideline addresses one or more of the competency standards from Domain 3; details are presented after each guideline.

Consensus guideline 3.1: Promote confidentiality for patients with hepatitis C

- Discuss the patient’s right to confidentiality of their personal information in the healthcare setting.
  - Seek to understand the meaning of confidentiality from the patient’s perspective.
- Understand and adhere to relevant medico-legal obligations including documentation.

Consensus guideline 3.1 addresses competency standards 1 and 2.

Consensus guideline 3.2: Facilitate appropriate disclosure by patients with hepatitis C

- Facilitate appropriate disclosure by advising the patient that they are legally required to disclose their hepatitis C status in the following circumstances:
  - Providing blood, blood products and organ donation; applying for life and health insurance; applying for military services; receiving care from healthcare workers performing exposure prone procedures.
- Advise the patient regarding when they are not required to disclose their hepatitis C status.
- Refer the patient to their local State/Territory Hepatitis Organisation for further information about appropriate disclosure of hepatitis C status.

Consensus guideline 3.2 addresses competency standards 1 and 2.
Consensus guideline 3.3: Discourage discriminatory behaviour against patients with hepatitis C

- Respectfully challenge discriminatory attitudes towards patients with hepatitis C.
- Educate and support health professionals to provide non-discriminatory care for patients with hepatitis C.
- Enable the patient to be aware of their diagnosis and make informed choices about disclosure.
- Provide support, information and appropriate referrals to complaints services for patients who have experienced discrimination.
- Advocate for the patient’s equity of access to treatment and management regardless of the aetiology of their disease and lifestyle choices.

Consensus guideline 3.3 addresses competency standards 1 and 2.

Consensus guideline 3.4: Provide culturally appropriate nursing care for patients with hepatitis C

- Be aware of the various health belief models and cultural differences, and their impact on the patient’s health behaviour.
- Develop an awareness of own cultural beliefs and attitudes and consider how these affect the delivery of nursing care.
- Advocate for the delivery of culturally appropriate and sensitive healthcare.
- Seek support from specialist services in the delivery of culturally appropriate nursing care, for example, multicultural services, Aboriginal and Torres Strait Islander services and/or drug and alcohol services.

Consensus guideline 3.4 addresses competency standards 1 and 2.

DOMAIN 4: PROFESSIONAL SELF-CARE AND DEVELOPMENT

Domain 4 of the AHA Competency Standards for the Hepatology Nurse incorporates five competency standards and related performance criteria that reflect the Hepatology Nurse’s ability to adapt to the changing clinical environment through involvement in professional development activities and reflective practice. Each consensus guideline addresses one or more of the competency standards from Domain 4; details are presented after each guideline.

Consensus guideline 4.1: Identify and define the hepatology nursing scope of practice

- To assist Hepatology Nurses to identify their individual scope of practice and the scope of practice of the speciality, the following questions are presented for consideration:
  - What is the profile of the patients with, or affected by, liver disease that the Hepatology Nurse cares for and what could the Hepatology Nurse be doing to improve the health outcomes for these patients?
  - What education and professional development activities has the Hepatology Nurse completed?
  - What is the previous experience of the Hepatology Nurse?
  - What additional education does the Hepatology Nurse need to provide the required standard of nursing care to patients with, or affected by, liver disease?
  - Is the scope of practice used by nurses in other settings?
What is the nurse’s legal position? For example, do Australian and/or State/Territory Government legislation and regulations permit nurses to deliver the care being considered as part of the Hepatology Nurse’s scope of practice?

Are there policies and procedures in place to support the Hepatology Nurse providing this care?

How will competency assessment take place given the Hepatology Nurse’s current scope of practice and if the Hepatology Nurse is expanding their scope of practice? 56

The scope of hepatology nursing practice is an important consideration when interpreting the AHA Consensus-based Nursing Guidelines. It is important to highlight that the AHA, as the professional organisation representing Hepatology Nurses in Australia, has a responsibility to its members to assist in identifying the speciality’s scope of practice and to provide a forum for individuals to consider what constitutes their scope of practice.57

Consensus guideline 4.1 addresses competency standards 2, 3, 4 and 5.

Consensus guideline 4.2: Actively participate in reflective practice

- Reflective practice is an important skill that Hepatology Nurses may choose to develop to identify their scope of practice and to continuously learn and evolve as a result of their professional practice.58
- In addition to formal teaching and learning, reflective practice encourages individuals to participate in life-long learning from their own professional experiences.
- In order to inform future iterations of the AHA Competency Standards and the AHA Consensus-based Nursing Guidelines, Hepatology Nurses may consider using reflective practice to assist in their professional evolution, and that of the speciality.

Consensus guideline 4.2 addresses competency standards 1, 2 and 3.

Consensus guideline 4.3: Actively engage in continuing professional development

- The Nursing and Midwifery Board of Australia’s National Registration Standards stipulate that continuing professional development is a requirement of nursing registration.59
- Identify and participate in professional development activities that maintain one’s own advanced level of knowledge and skills with regard to caring for patients with, or affected by, liver disease.
- Participate in life-long learning to ensure ongoing development of the individual and the hepatology nursing speciality.

Consensus guideline 4.3 addresses competency standard 1.

Consensus guideline 4.4: Actively engage in professional self-care

- Actively maintain one’s own physical, mental and spiritual health by seeking support, as required.
- Accept the responsibility for self-care by acknowledging one’s own physical, mental and spiritual strengths and limitations, and recognise one’s intrinsic worth.
- Foster qualities that encourage beneficial practices and relationships with colleagues.60

Consensus guideline 4.4 addresses competency standard 3.
DOMAIN 5: CLINICAL AND COMMUNITY LEADERSHIP

Domain 5 of the AHA Competency Standards for the Hepatology Nurse incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to provide clinical leadership and expertise in the nursing profession with regard to liver health and disease, and community leadership through advocacy and policy development. Each consensus guideline addresses one or more of the competency standards from Domain 5; details are presented after each guideline.

Consensus guideline 5.1: Actively promote the Hepatology Nurse’s role in the delivery of care for patients with hepatitis C

- Actively promote the Hepatology Nurse as an expert resource in hepatitis C for health professionals as well as the community, education, government and non-government sectors.
- Maintain and foster relationships with key stakeholders in clinical and non-clinical organisations and promote the Hepatology Nurse’s role in the management of patients with hepatitis C.
- Disseminate the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis C to clinical and non-clinical colleagues
  - Advocate for their use as evidence to support the Hepatology Nurse’s role in caring for patients with hepatitis C.
- Initiate and/or contribute to the research activities that strengthen the evidence-base of the Hepatology Nurse’s role in caring for patients with hepatitis C.
- Act as a change agent to influence local and national policy to ensure the needs of hepatitis C priority populations are addressed.

Consensus guideline 5.1 addresses competency standards 1 and 4.

Consensus guideline 5.2: Mentor nurses to be involved in caring for patients with hepatitis C

- Mentor and support nurses with an interest in caring for patients with hepatitis C to build their confidence and competence in hepatitis C care and management.
- Support nurses new to the field of hepatology nursing to interpret and implement the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis C.
- Provide expert education and support to Hepatology Nurses interested in caring for patients with hepatitis C.

Consensus guideline 5.2 addresses competency standard 3.

Consensus guideline 5.3: Provide ongoing education, support and leadership for health professionals involved in caring for people with, or at risk of, hepatitis C

- Seek opportunities to contribute to, participate in and/or lead hepatitis C education forums.
- Actively engage in own professional development activities to ensure knowledge currency.
- Provide expert information regarding the meaning of test results, the natural history of hepatitis C, treatment options and appropriate referral to members of the interdisciplinary team.
- Provide education and support for health professionals involved in caring for people with, or at risk of, hepatitis C including, but not limited to, medical practitioners, primary healthcare workers, drug and alcohol workers, workers in the custodial setting, registered and enrolled nurses, midwives, multicultural health workers, community-based organisations, allied health professionals and health assistant workers.

Consensus guideline 5.3 addresses competency standard 2.
Consensus guideline 5.4: Provide education to raise the community’s awareness of hepatitis C

- Seek opportunities to work collaboratively with hepatitis organisations and other community-based organisations to raise awareness of hepatitis C in the local community.
- Provide education for local community groups to raise awareness of hepatitis C and local clinical and community services.

Consensus guideline 5.4 addresses competency standard 2.

References
4 Ibid.
5 Ibid.
7 Ibid.
10 Hepatitis C Testing Policy Expert Reference Committee, a joint working party of the Blood Borne Virus and STI Subcommittee (BBVSS) and the Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections (MACB8VS), op. cit.
16 European Association for the Study of the Liver, op. cit.
17 Hepatitis C Testing Policy Expert Reference Committee, a joint working party of the Blood Borne Virus and STI Subcommittee (BBVSS) and the Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections (MACB8VS), op. cit.
19 European Association for the Study of the Liver, op. cit.
20 Ghany, et al., 2011, op. cit.
23 European Association for the Study of the Liver, op. cit.
26 Antidiscrimination Board of New South Wales, op. cit.
28 Ibid.
30 Ibid.
34 Larrey, et al., op. cit.
36 Larrey, et al., op. cit.
38 Australasian Hepatology Association, op. cit.
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52 Ibid.
53 Antidiscrimination Board of New South Wales, op. cit.
55 Australasian Hepatology Association, op. cit.
61 Australasian Hepatology Association, op. cit.
AHA CONSENSUS-BASED NURSING GUIDELINES FOR THE CARE OF PATIENTS WITH ADVANCED LIVER DISEASE

Advanced liver disease describes the stage of liver damage involving the progression from bridging fibrosis to cirrhosis. Cirrhosis refers to the end-stage of fibrosis. In the context of this document, the phrase advanced liver disease is used to describe the spectrum of disease from bridging fibrosis to cirrhosis. Where the information refers specifically to cirrhosis, this will be identified.

PATHOPHYSIOLOGY OF ADVANCED LIVER DISEASE

The pathophysiology of advanced liver disease involves scarring of the liver tissue through repeated hepatocyte injury and regeneration, resulting in the development of fibrous tissue and nodules. The development of significant fibrous tissue, known as cirrhosis, may alter the blood flow in the liver, which can lead to the development of portal hypertension and associated complications including cognitive impairment (hepatic encephalopathy), ascites (accumulation of fluid in the abdomen), oesophageal varices (dilated veins) and renal impairment. Cirrhosis may also result in altered synthetic function specifically low albumin and prolonged clotting. Cirrhosis is a significant risk factor for the development of hepatocellular carcinoma (HCC).

Patients with compensated cirrhosis may live for many years without significant complications of their liver disease, or they may progress to decompensated cirrhosis, defined as the first onset of one of the associated complications previously listed. Decompensated liver disease occurs because the scarred liver is no longer able to function adequately.

AETIOLOGY OF ADVANCED LIVER DISEASE

Defining the aetiology of advanced liver disease is important, as is investigating the severity and assessing for complications. In the context of hepatitis C, the risk of progression to advanced liver disease is highly variable and dependent on the presence of co-infection with human immunodeficiency virus (HIV) or hepatitis B, alcohol intake, extent of fibrosis, age and gender. However, the lifetime risk of developing advanced liver disease as a result of chronic hepatitis B (CHB) is between 20% and 30%.

In addition to viral hepatitis, advanced liver disease may be caused by excessive alcohol intake, non-alcoholic fatty liver disease (NAFLD), which may progress to non-alcoholic steatohepatitis (NASH), or metabolic, genetic, autoimmune or idiopathic factors. Regardless of the cause, the progression of advanced liver disease is similar.

MANAGEMENT OF ADVANCED LIVER DISEASE

Advanced liver disease can be diagnosed using a liver biopsy; a Metavir score of F3 to F4 indicates advanced liver disease. Abdominal ultrasound is also used as a diagnostic tool for cirrhosis as it demonstrates altered texture, irregular liver contour and other signs of portal hypertension. More recently, non-invasive assessment of liver stiffness is also being used to diagnose advanced liver disease. In addition to the histological diagnosis of cirrhosis, altered synthetic function is an indicator of advanced liver disease.

The physical signs of advanced liver disease are quite distinct and include palmar erythema, spider naevi, jaundice, gynaecomastia, ascites, splenomegaly, oedema and the presence of a hepatic flap if the patient is encephalopathic. The presence of ascites and splenomegaly are indicative of portal hypertension and suggest that the patient may also have oesophageal varices.
Management of advanced liver disease involves treating the underlying cause, for example, supporting the patient to reduce their alcohol consumption or treating viral hepatitis.\textsuperscript{16} However, in the short term, managing the immediate complications of decompensated advanced liver disease, such as oedema, ascites, oesophageal varices, variceal bleeding and/or hepatic encephalopathy, may be the priority.\textsuperscript{17} Following this, it is important that the patient has ongoing care to allow for early identification of severe complications of cirrhosis, and that a treatment/management plan is developed and adhered to.\textsuperscript{18} Bone disease and malnutrition should also be regularly assessed and managed.\textsuperscript{19}

People with advanced liver disease are at greater risk of developing HCC and should undergo regular surveillance for HCC.\textsuperscript{20} Ideally, patients with cirrhosis and HCC should be considered for a liver transplant; however this is often unachievable because the patient has been diagnosed late in the HCC disease process and does not fit the criteria for a transplant. The Hepatology Nurse has an important role in supporting patients with advanced liver disease at risk of HCC to adhere to HCC surveillance strategies.

**GUIDELINES FOR THE MANAGEMENT OF ADVANCED LIVER DISEASE**

In Australia, the clinical management of the underlying causes of advanced liver disease including hepatitis B, hepatitis C, NAFLD, alcoholic liver disease, Wilson’s Disease, autoimmune hepatitis and primary biliary cirrhosis are guided by the international literature, specifically clinical practice guidelines produced by the American Association for the Study of Liver Diseases (AASLD)\textsuperscript{21-28} and the European Association for the Study of the Liver (EASL).\textsuperscript{29-32} Management guidelines for the complications of advanced liver disease including ascites,\textsuperscript{33,34} variceal haemorrhage\textsuperscript{35} and portal hypertension\textsuperscript{36} are also available. Australian guidelines have been developed to support clinicians caring for patients with CHB,\textsuperscript{37} fatty liver disease\textsuperscript{38} and haemochromatosis.\textsuperscript{39}

Each of these clinical practice guidelines are medical documents. They have not been designed to guide nursing practice. However, without an understanding of the medical evidence, Hepatology Nurses will be unable to meet the following competency standards identified in the AHA Competency Standards for the Hepatology Nurse:

- **1.1** Provides comprehensive, evidence-based nursing care for people with or affected by liver disease.
- **1.2** Provides specialised information and education from a nursing perspective.
- **1.4** Provides evidence-based nursing care.
- **2.3** Participates in and contributes to interdisciplinary clinical decision-making.
- **3.2** Advocates for and promotes the rights of people with or affected by liver disease.
- **5.2** Provides expert advice and guidance to the multidisciplinary team and external agencies on the care of people with or affected by liver disease.\textsuperscript{40}

The evidence presented in the medical guidelines is embedded in the AHA Consensus-based Nursing Guidelines and creates the benchmark for best practice.

**DEFINING THE NURSE’S ROLE IN CARING FOR PATIENTS WITH ADVANCED LIVER DISEASE**

The role of the Hepatology Nurse in providing care for patients with advanced liver disease is not well defined. Currently, the care of patients with advanced liver disease is the responsibility of many disciplines, primarily medical. However, care of patients with advanced liver disease could, and has been, successfully coordinated by specialist nurses. The introduction of a Hepatology Nurse to coordinate and support primary prevention (baseline endoscopy, symptoms of portal pressure and surveillance regime) and secondary prevention (endoscopy surveillance, medication...
This document has been developed for two audiences. Firstly, to assist Hepatology Nurses caring for patients with viral hepatitis and other causes of advanced liver disease to understand and prioritise their role in the management of advanced liver disease. Secondly, for Hepatology Nurses who wish to develop their expertise in managing patients with advanced liver disease regardless of the aetiology – the specialist Advanced Liver Disease Nurse.

The first iteration of this document is deliberately instructional and educational and reflects the fledgling context of the specialist nursing role in advanced liver disease. The aim of the document is to assist in the development of the hepatology nursing workforce’s capacity in Australia to provide nursing care for patients with advanced liver disease.

The Guiding Principles of the AHA Consensus-based Nursing Guidelines, described in the Introduction (page 17), underpin the five domains and respective consensus guidelines outlined in this document.

**DOMAIN 1: PROVISION AND MANAGEMENT OF NURSING CARE FOR PATIENTS WITH, OR AT RISK OF, ADVANCED LIVER DISEASE**

Domain 1 of the AHA Competency Standards for the Hepatology Nurse incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to provide comprehensive, evidence-based and culturally appropriate care and education for patients with, or at risk of, advanced liver disease. Each consensus guideline addresses one or more of the competency standards from Domain 1; details are presented after each guideline.

**Consensus guideline 1.1: Perform a nursing assessment to identify clinical symptoms and signs of advanced liver disease**

- Identify which patients with chronic liver disease are at risk of developing advanced liver disease specifically:
  - People with chronic hepatitis including, but not limited to, the following aetiologies:
    - alcoholic
    - autoimmune
    - biliary
    - diabetes
    - non-alcoholic fatty liver disease
    - viral hepatitis.
  - Patients with a previous hospital admission for liver-related problems.

- Assess for the symptoms and signs of advanced liver disease in the patient:
  - Stigmata of advanced liver disease can include:
    - abdominal distension (ascites)
    - asterixis (hepatic flap)
    - bruising
    - clubbing
    - cognitive impairment (encephalopathy)
    - gynaecomastia
    - jaundice
    - muscle wasting and signs of malnutrition
    - palmar erythema
    - peripheral oedema
~ pruritus
~ thrombocytopenia
~ spider naevi.

* Assess for signs of altered synthetic function in the patient:
  - Persistently raised, or a history of raised, liver enzymes.
  - Deranged synthetic liver function:
    ~ hypoalbuminaemia (low serum albumin)
    ~ coagulopathy (extended prothrombin time)
    ~ hyperbilirubinaemia (high bilirubin).

* Review medical imaging results of the patient in consultation with the treating physician, including:
  - Abdominal ultrasound, computer assisted tomography (CT), magnetic resonance imaging (MRI) for the following characteristics:
    ~ liver size
    ~ irregular liver surface
    ~ heterogenous echogenicity
    ~ focal lesions
    ~ portal hypertension including:
      > splenomegaly
      > varices
      > ascites.

* Interpret the patient’s stage of liver fibrosis in consultation with the treating physician, according to the results of the following assessment tools:
  - liver biopsy
  - transient elastography
  - serum fibrosis markers.

Consensus guideline 1.1 addresses competency standards 1 and 4.

**Consensus guideline 1.2: Conduct a comprehensive nursing assessment of the patient with advanced liver disease**

The nursing assessment of the patient with advanced liver disease is based on Gordon’s Functional Health Patterns.43,C The nursing assessment of a patient with advanced liver disease is an ongoing process that aims to inform the development of the nursing management plan.

Health Perception-Health Management Pattern:

* Document the patient’s health history and assess:
  - Risk factors for underlying liver disease.
  - Context leading to the diagnosis:
    ~ Explore the patient’s understanding of their liver disease.
  - Liver disease symptomatology including extrahepatic manifestations.
  - Liver disease progression.
  - Impact of liver disease on the patient’s life (health, social, sexual, work, economic and self-esteem).

C Please note that the nursing assessment presented in this document is only one of many nursing assessment tools available. Hepatology Nurses are encouraged to consider which assessment tool best suits their clinical practice.
- Assess for previous and/or current complications of advanced liver disease:
  - ascites and/or oedema
  - gastrointestinal bleeding
  - hepatic encephalopathy
  - malnutrition
  - spontaneous bacterial peritonitis (SBP)
  - vitamin D deficiency and bone loss.
- If appropriate, document the patient's viral hepatitis treatment history.
- History of autoimmune diseases, body mass index (BMI), cardiac, liver, dermatological, diabetes, endocrine, oral, ophthalmology and/or renal issues or other significant co-morbidities.
- Explore and document the patient's drug and alcohol history, including use of illicit drugs, alcohol and tobacco.
- Assess the need for vaccination according to the current edition of the Australian Immunisation Handbook.
- Assess the patient's family medical history as it relates to the patient's current health:
  - including, but not limited to, HCC, hepatitis B and C and/or any form of liver disease; endocrine disorders including diabetes, obesity, autoimmune diseases, mental health and cardiac conditions
  - Assess the need for contact tracing, if relevant.
- Assess the patient's current medication use including prescription, non-prescription, illicit and complementary and alternative medicines (including vitamins):
  - Discuss which medications should not be used in the context of advanced liver disease.
  - Discuss the impact of analgesics on the body in the context of advanced liver disease.
- Explore and document the patient's drug and alcohol history including overuse of prescription and non-prescription medications, use of illicit drugs, alcohol and tobacco.
- Document allergies.

Nutritional-Metabolic Pattern, Elimination Pattern and Activity-Exercise Pattern:
- Perform a physical assessment:
  - Monitor vital signs.
  - Nutritional and metabolism assessment including calculation of the patient’s BMI and waist to hip ratio.
    - Assess the patient’s eating patterns including intake of salt (preferably low intake), protein (preferably high intake), and fruits and vegetables.
    - Assess adherence to dietary restrictions, such as a diabetic diet, low salt diet and/or high protein diet, if appropriate.
    - Assess for signs of muscle wasting in the upper body.
  - Assess the patient’s activity and exercise routine.
  - Consider autoimmune diseases, cardiac, chronic liver disease, dermatological, endocrine, oral, ophthalmology, renal issues or other significant co-morbidities.

Cognitive-Perceptual Pattern and Coping-Stress Tolerance Pattern:
- Explore and document the patient’s psychosocial history, including:
  - mental health history
  - coping and stress patterns
  - pain management
  - social support including housing, transport, financial, employment and social activities
  - any legal issues.
Role-Relationship Pattern:
• Explore the roles and relationships of the patient’s significant other(s)/carer(s).

Sexuality-Reproductive Pattern:
• Discuss the patient’s sexual and reproductive health and contraception choices.

Sleep-Rest Pattern:
• Discuss the patient’s sleep and rest patterns, including:
  – sleep, rest and relaxation practices
  – dysfunctional sleep patterns.

Value-Belief Pattern:
• Explore the cultural considerations relevant to the patient, acknowledging the social, economic, political and language barriers that affect the healthcare experiences of minority communities.46

Consensus guideline 1.2 addresses competency standards 1 and 4.

Consensus guideline 1.3: Assess the patient’s level of knowledge about advanced liver disease and provide relevant education
• Assess the patient’s level of knowledge about advanced liver disease as well as its complications and provide relevant education on:
  – Natural history of advanced liver disease and cirrhosis.
  – Symptoms and signs of worsening liver disease, including discussion about:
    ~ Factors influencing disease progression.
    ~ Severity of their disease measured by the Child-Pugh Turcott score and Model for End-stage Liver Disease (MELD) score.
    ~ Management plan in event of symptoms developing.
  – Behavioural changes including reduction or elimination of alcohol and other drug use, including tobacco.
  – Nutritional status and possible dietary changes, where required.
  – Interpretation of the blood test and medical imaging results.
  – Recommended vaccinations.47
  – Treatment and management of advanced liver disease.
  – Liver transplantation in the setting of advanced liver disease.
  – Support services in the hospital system and the community that will assist the patient to manage advanced liver disease.
  – Provision of appropriate patient resources including contact details of relevant support organisations, such as the local hepatitis organisation.

Consensus guideline 1.3 addresses competency standards 2 and 4.

Consensus guideline 1.4: Provide education and support for the patient’s significant other(s)/carer(s)
• Provide education and support for the patient’s significant other(s)/carer(s) about the following issues:
  – Symptoms and signs of hepatic encephalopathy.
  – Symptoms and signs of oesophageal variceal bleeding.
  – Symptoms and signs of fluid overload.
  – Dietary requirements including low salt, high protein and high energy diet.
  – When and how to seek medical and nursing assistance.
  – Importance of adhering to the treatment and management plan.
• Provide encouragement and resources for supporting the patient’s abstinence from alcohol, if appropriate.

• Inform significant other(s)/carer(s) about community resources and refer to a social worker for assistance (if available) for:
  – General Practitioner (GP) involvement in developing a chronic disease management plan.
  – Centrelink pensions and support.
  – Local government community-based care.
  – Travel assistance.
  ~ Patient and significant others to be educated about driving restrictions if encephalopathic.

• Educate the patient about the roles of the interdisciplinary team members.

  Consensus guideline 1.4 addresses competency standards 2 and 4.

Consensus guideline 1.5: Advocate and support the patient with advanced liver disease to be actively involved in their treatment and management plan

• Assist the patient and their significant other(s)/carer(s) to negotiate the health care system.
  – Negotiate access to timely referrals and interventions in accordance with the patient’s management plan.

• Work in collaboration with the patient to develop a management plan which includes goal setting around healthy behaviours by incorporating motivational interviewing techniques.48

• Support the patient during the treatment journey.
  – Respect and support the patient’s treatment and management choices and their right to change their choice at any time.49

• Support the patient and their significant other(s)/carer(s) through the referral and work up for liver transplantation, if appropriate.

• Support the patient to develop an end-of-life care plan, if appropriate.
  – Refer the patient to a social worker for assistance with accessing financial support and entitlements including superannuation, insurance and income protection insurance.

• Advocate for the patient in the interdisciplinary team.

  Consensus guideline 1.5 addresses competency standard 1 and 3.

Consensus guideline 1.6: Optimise the patient’s health and wellbeing

• Encourage and support the patient to adhere to their management plan including the importance of:
  – Attending outpatient appointments.
  – Monitoring, screening and surveillance needs.
  – Over the counter and prescription medication use and avoidance.
  – Importance of having a regular GP.
  – Appropriate balance between exercise and rest.

• Discuss strategies to prevent liver decompensation including:
  – Avoiding alcohol; refer for drug and alcohol counselling as required.
  – Discussion of the importance of appropriate dietary management for example:
    ~ low salt, high protein, high energy diet
    ~ malnutrition indicators
    ~ small frequent meals during the day
    ~ high protein bedtime snacks
    ~ dietary supplements.
• Discuss the use of complementary and alternative medicines.

• Discuss current and future management of the patient’s condition depending on their disease severity:
  – Identify, and advocate for, the patient’s preferred health and management choices.

  Consensus guideline 1.6 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.7: Provide ongoing monitoring and assessment-related nursing care for the patient with advanced liver disease

• Discuss the importance of life-long monitoring of advanced liver disease:
  – Encourage and support adherence to ongoing monitoring including screening and surveillance activities and outpatient appointments at the specialist clinic.
  – Establish the patient’s awareness of, and access to, pathology, medical imaging, alternative medical services (if the patient moves) and costs associated with accessing healthcare.
  – Monitor liver disease severity using Child-Pugh Turcott and MELD score.

• Coordinate and monitor current, and potential, complications of advanced liver disease including:
  – Variceal bleeding:
    ~ Encourage attendance at endoscopy appointments.
    ~ Monitor and encourage adherence to medication for prophylaxis:
      > Observe for adverse effects of prophylaxis.
  – Malnutrition and weight loss:
    ~ Monitor dietary intake and frequency of intake.
    ~ Reinforce the importance of appropriate dietary intake on liver health.
    ~ Monitor adherence to special dietary requirements including low salt, high protein and/or high energy diet.
  – Weight gain, development of oedema and ascites:
    ~ Encourage patient self-management of daily weight.
    ~ Encourage and support diuretic and electrolyte monitoring.
    ~ Support adherence to a low salt diet.
    ~ Encourage adherence with prophylactic antibiotics for SBP, if appropriate.
  – Vitamin D deficiency and bone loss:
    ~ Monitor vitamin D levels regularly, including after the commencement of supplements.
  – Cognitive impairment (encephalopathy):
    ~ Investigate possible causes of cognitive impairment.
    ~ Observe for behavioural or personality changes.
    ~ Monitor sleep disturbance.
    ~ Encourage and support the patient’s significant other(s)/carer(s) to stop the patient from driving a motor vehicle.
    ~ Educate the patient and their significant other(s)/carer(s) about informed consent and decision-making.
    ~ Support the patient and their significant other(s)/carer(s) to titrate Lactulose dose to effect and avoid over diarrhoea:
      > Monitor bowel actions.
  – Assist the patient to adhere to the variceal surveillance and/or monitoring plan:
    ~ Monitor adherence to the surveillance and/or management plan.
– Oral health:
  ~ Encourage attendance to dentist appointments.

• Management of general symptoms of advanced liver disease including nausea, pruritus, muscle cramping and pain.

• If appropriate, refer the patient for management and/or treatment of hepatitis B and/or hepatitis C.

• Coordinate support (telephone and/or face-to-face) for the patient to monitor for the symptoms of decompensation.

• Support the patient through the referral and work up for liver transplantation, if appropriate.

• Develop a database that includes a patient recall system to manage monitoring and surveillance requirements.

• For patients with end-stage liver disease who are not eligible for transplantation, consider:
  – palliative care referral
  – advance directives (legal documents that document decisions about end-of-life care ahead of time)
  – community supports.

• Coordinate or refer the patient with advanced liver disease for HCC surveillance:
  – Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma:
    ~ Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.

Consensus guideline 1.7 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.8: Provide nursing support for the patient during hospital admissions

• Support the patient during their hospitalisation.
• Provide information about community and/or outpatient management, if appropriate.
• Assess the patient’s medication management and ensure it matches their current medication plan.
• Ensure the patient’s surveillance plan is current and organise monitoring appointments, as required.
• Coordinate communication between the members of the interdisciplinary team.
• Advocate for the patient’s involvement in decision-making.
• Facilitate the referral pathways for medical and nursing staff on the ward to the community.

Consensus guideline 1.8 addresses competency standards 1, 3 and 4.

Consensus guideline 1.9: Discuss the importance of hepatocellular carcinoma surveillance for the patient with advanced liver disease

• Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma:
  ~ Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.

Consensus guideline 1.9 addresses competency standard 1, 2, 3 and 4.
DOMAIN 2: INTERDISCIPLINARY COORDINATION AND CARE FOR PATIENTS WITH ADVANCED LIVER DISEASE

Domain 2 of the AHA Competency Standards for the Hepatology Nurse incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to facilitate, coordinate and evaluate interdisciplinary care for patients with, or at risk of, advanced liver disease as they seek to achieve optimal health outcomes. Each consensus guideline addresses one or more of the competency standards from Domain 2; details are presented after each guideline.

Consensus guideline 2.1: Discuss the roles of each member of the interdisciplinary team in relation to the implementation of the patient’s management plan

• Explain the role of each member of the interdisciplinary team in terms of their professional responsibilities and areas of expertise.
• Provide the patient and their significant other(s)/carer(s) with the contact details for the most relevant members of the interdisciplinary team.
• Outline the communication pathways between members of the interdisciplinary team.

Consensus guideline 2.1 addresses competency standard 2.

Consensus guideline 2.2: Facilitate the care coordination for the patient with advanced liver disease

• Establish communication pathways between the medical specialist, junior medical staff, gastroenterology and hepatology registrars and the Hepatology Nurse.
• Coordinate and manage the patient’s treatment and management plan as developed by the interdisciplinary team.
• Establish communication pathways between the gastroenterology/hepatology unit and:
  – the liver transplant unit
  – allied health professionals
  – GP/referring practitioner
  – drug and alcohol services
  – hepatology nursing colleagues.
• Coordinate the patient’s referrals and appointments in consultation with the patient and their specific requirements (including late appointments for people who live in rural areas).
• Monitor the patient’s symptoms and communicate findings to the interdisciplinary team.
• Enlist the support of a community case manager, if required and available.

Consensus guideline 2.2 addresses competency standards 1, 2 and 3.

Consensus guideline 2.3: Recognise and enhance the existing therapeutic relationship with the general practitioner and/or referring practitioner

• Establish a communication pathway with the patient’s GP/referring practitioner regarding the patient’s health and disease status and their adherence to the advanced liver disease treatment and management plan.
• Educate and support the GP/referring practitioner in the early identification of patients with, or at risk of, advanced liver disease.
• Educate and support the GP/referring practitioner to understand the patient’s ongoing care including:
  – screening and surveillance plan
  – monitoring
  – treatment-related side effects.

• Communicate with the GP/referring practitioner about the patient’s progress during the implementation of the patient’s management and treatment plan including:
  – Anti-viral treatment plan, if relevant:
    ~ Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B:
      > Consensus guideline 1.8: Provide nursing management for the patient with chronic hepatitis B who is considering treatment.
      > Consensus guideline 1.9: Provide hepatitis B treatment-related nursing care for the patient with chronic hepatitis B.
    ~ Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis C:
      > Consensus guideline 1.7: Perform a pre-treatment nursing assessment.
      > Consensus guideline 1.8: Provide patient education at the commencement of hepatitis C treatment.
      > Consensus guideline 1.9: Provide hepatitis C treatment-related nursing care.
      > Consensus guideline 1.10: Provide hepatitis C-related nursing care after the patient has completed treatment.
  – HCC surveillance plan:
    ~ Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma:
      > Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance.

  Consensus guideline 2.3 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 2.4: Facilitate patient referral to members of the interdisciplinary team and community allied health services

• Refer patients with advanced liver disease to allied health support services in the hospital and the community, as required, including:
  – alcohol and other drug services
  – community health nursing
  – dentists
  – dietitians
  – medical specialists
  – multicultural workers for social and cultural support
  – psychologists
  – psychiatrists
  – palliative care
  – physiotherapists
  – podiatrists
  – settlement workers for patients with a refugee background
  – sexual health services
  – social workers
  – other health services, as required.

  Consensus guideline 2.4 addresses competency standards 1 and 2.
DOMAIN 3: NON-DISCRIMINATORY PRACTICE

Domain 3 of the AHA Competency Standards for the Hepatology Nurse\(^2\) incorporates two competency standards and related performance criteria that reflect the non-discriminatory practice of Hepatology Nurses, and their respect for the choices of people with, or at risk of, advanced liver disease, with regard to alcohol and drug use, sexual orientation, religious and cultural beliefs, social circumstances and physical and mental health. Each consensus guideline addresses one or more of the competency standards from Domain 3; details are presented after each guideline.

Consensus guideline 3.1: Promote confidentiality for patients with advanced liver disease

- Discuss the patient’s right to confidentiality of their personal information in the healthcare setting.
  - Seek to understand the meaning of confidentiality from the patient’s perspective.
- Understand and adhere to relevant medico-legal obligations including documentation.

Consensus guideline 3.1 addresses competency standards 1 and 2.

Consensus guideline 3.2: Facilitate appropriate disclosure for patients with advanced liver disease

- Empower and support the patient to decide to whom, and at what time, they disclose their advanced liver disease diagnosis.
- Consider advising the patient regarding when they are not required to disclose their diagnosis.
- For patients with hepatitis B and/or hepatitis C, refer to the:
  - AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B:
    ~ Consensus guideline 3.2: Facilitate appropriate disclosure by patients with chronic hepatitis B.
  - AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis C:
    ~ Consensus guideline 3.2: Facilitate appropriate disclosure by patients with hepatitis C.

Consensus guideline 3.2 addresses competency standards 1 and 2.

Consensus guideline 3.3: Discourage discriminatory behaviour against patients with advanced liver disease

- Respectfully challenge discriminatory attitudes towards patients with advanced liver disease.
- Educate and support health professionals to provide non-discriminatory care for patients with advanced liver disease.
- Enable the patient to be aware of their diagnosis and make informed choices about disclosure.
- Provide support, information and appropriate referrals to complaints services for patients who have experienced discrimination.
- Advocate for the patient’s equity of access to treatment and management regardless of the aetiology of their disease and lifestyle choices.

Consensus guideline 3.3 addresses competency standards 1 and 2.

Consensus guideline 3.4: Provide culturally appropriate nursing care for patients with advanced liver disease

- Be aware of the various health belief models and cultural differences and their impact on the patient’s health behaviour.
• Develop an awareness of own cultural beliefs and attitudes and consider how these affect the delivery of nursing care.

• Advocate for the delivery of culturally appropriate and sensitive healthcare.

• Seek support from specialist services in the delivery of culturally appropriate nursing care, for example, multicultural services, Aboriginal and Torres Strait Islander services and/or drug and alcohol services.

Consensus guideline 3.4 addresses competency standards 1 and 2.

DOMAIN 4: PROFESSIONAL SELF-CARE AND DEVELOPMENT

Domain 4 of the AHA Competency Standards for the Hepatology Nurse incorporates five competency standards and related performance criteria that reflect the Hepatology Nurse’s ability to adapt to the changing clinical environment through involvement in professional development activities and reflective practice. Each consensus guideline addresses one or more of the competency standards from Domain 4; details are presented after each guideline.

Consensus guideline 4.1: Identify and define the hepatology nursing scope of practice

• To assist Hepatology Nurses to identify their individual scope of practice and the scope of practice of the speciality, the following questions are presented for consideration:
  – What is the profile of the patients with, or affected by, liver disease that the Hepatology Nurse cares for and what could the Hepatology Nurse be doing to improve the health outcomes for these patients?
  – What education and professional development activities has the Hepatology Nurse completed?
  – What is the previous experience of the Hepatology Nurse?
  – What additional education does the Hepatology Nurse need to provide the required standard of nursing care to patients with, or affected by, liver disease?
  – Is the scope of practice used by nurses in other settings?
  – What is the nurse’s legal position? For example, do Australian and/or State/Territory Government legislation and regulations permit nurses to deliver the care being considered as part of the Hepatology Nurse’s scope of practice?
  – Are there policies and procedures in place to support the Hepatology Nurse providing this care?
  – How will competency assessment take place given the Hepatology Nurse’s current scope of practice and if the Hepatology Nurse is expanding their scope of practice?

The scope of hepatology nursing practice is an important consideration when interpreting the AHA Consensus-based Nursing Guidelines. It is important to highlight that the AHA, as the professional organisation representing Hepatology Nurses in Australia, has a responsibility to its members to assist in identifying the speciality’s scope of practice and to provide a forum for individuals to consider what constitutes their scope of practice.

Consensus guideline 4.1 addresses competency standards 2, 3, 4 and 5.

Consensus guideline 4.2: Actively participate in reflective practice

• Reflective practice is an important skill that Hepatology Nurses may choose to develop to identify their scope of practice and to continuously learn and evolve as a result of their professional practice.

• In addition to formal teaching and learning, reflective practice encourages individuals to participate in life-long learning from their own professional experiences.
• In order to inform future iterations of the AHA Competency Standards and the AHA Consensus-based Nursing Guidelines, Hepatology Nurses may consider using reflective practice to assist in their professional evolution and that of the speciality.

Consensus guideline 4.2 addresses competency standards 1, 2 and 3.

**Consensus guideline 4.3: Actively engage in continuing professional development**

• The Nursing and Midwifery Board of Australia’s National Registration Standards stipulate that continuing professional development is a requirement of nursing registration.\(^{58}\)

• Identify and participate in professional development activities that maintain one’s own advanced level of knowledge and skills with regard to caring for patients with liver disease.

• Participate in life-long learning to ensure ongoing development of the individual and the hepatology nursing speciality.

Consensus guideline 4.3 addresses competency standard 1.

**Consensus guideline 4.4: Actively engage in professional self-care**

• Actively maintain one’s own physical, mental and spiritual health by seeking support, as required.

• Accept the responsibility for self-care by acknowledging one’s own physical, mental and spiritual strengths and limitations, and recognise one’s intrinsic worth.

• Foster qualities that encourage beneficial practices and relationships with colleagues.\(^{59}\)

Consensus guideline 4.4 addresses competency standard 3.

**DOMAIN 5: CLINICAL AND COMMUNITY LEADERSHIP**

Domain 5 of the AHA Competency Standards for the Hepatology Nurse\(^ {60}\) incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to provide clinical leadership and expertise in the nursing profession with regard to liver health and disease, and community leadership through advocacy and policy development. Each consensus guideline addresses one or more of the competency standards from Domain 5; details are presented after each guideline.

**Consensus guideline 5.1: Actively promote the Hepatology Nurse’s role in the delivery of care for patients with advanced liver disease**

• Actively promote the Hepatology Nurse as an expert resource in liver health and disease for health professionals as well as the community, education, government and non-government sectors.

• Maintain and foster relationships with key stakeholders in clinical and non-clinical organisations and promote the Hepatology Nurse’s role in the management of patients with advanced liver disease.

• Disseminate the AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease to clinical and non-clinical colleagues.
  – Advocate for their use as evidence to support the Hepatology Nurse’s role in caring for patients with advanced liver disease.

• Initiate and/or contribute to research activities that strengthen the evidence-base of the Hepatology Nurse’s role in caring for patients with advanced liver disease.

• Act as a change agent to influence local and national policy to ensure the needs of people with advanced liver disease are addressed.

Consensus guideline 5.1 addresses competency standards 1 and 4.
Consensus guideline 5.2: Mentor nurses to be involved in caring for patients with advanced liver disease

- Mentor and support nurses with an interest in caring for patients with advanced liver disease to build their confidence and competence in advanced liver disease care and management.
- Support nurses new to the field of hepatology nursing to interpret and implement the AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease.
- Provide expert education and support to Hepatology Nurses interested in caring for patients with advanced liver disease.

Consensus guideline 5.2 addresses competency standard 3.

Consensus guideline 5.3: Provide ongoing education, support and leadership for health professionals involved in caring for people with, or at risk of, advanced liver disease

- Seek opportunities to contribute to, participate in and/or lead advanced liver disease education forums.
- Actively engage in own professional development activities to ensure knowledge currency.
- Provide expert information regarding the meaning of test results, the natural history of advanced liver disease, treatment options and appropriate referral to members of the interdisciplinary team.
- Provide education and support for health professionals involved in caring for people with, or at risk of, advanced liver disease including, but not limited to, medical practitioners, primary healthcare workers, drug and alcohol workers, workers in the custodial setting, registered and enrolled nurses, midwives, multicultural health workers, community-based organisations, allied health professionals and health assistant workers.

Consensus guideline 5.3 addresses competency standard 2.

References

3 Sargent, op. cit.
4 Pavendranathan, Strasser, op. cit.
6 Pavendranathan, Strasser, op. cit.
8 Pavendranathan, Strasser, op. cit.
11 Sargent, op. cit.
12 Pavendranathan, Strasser, op. cit.
15 Pavendranathan, Strasser, op. cit.
16 Ibid.
17 Ibid.
18 Ibid.


50 Garcia-Tsao, et al., op. cit.

51 Australasian Hepatology Association, op. cit.

52 Ibid.


54 Australasian Hepatology Association, op. cit.


60 Australasian Hepatology Association, op. cit.
AHA CONSENSUS-BASED NURSING GUIDELINES FOR THE CARE OF PATIENTS WITH HEPATOCELLULAR CARCINOMA

EPIDEMIOLOGY OF HEPATOCELLULAR CARCINOMA

Hepatocellular carcinoma (HCC) is a primary cancer of the liver and one of the most common types of cancer worldwide.1 Globally, it is the fifth most common cancer and the third most common cause of cancer-related death.2 Over 80% of HCC worldwide is attributable to the combined effects of chronic hepatitis B (CHB) and hepatitis C; between two and eight percent of people with CHB or hepatitis C-related cirrhosis develop HCC every year.3 Hepatocellular carcinoma can also develop in people with minimal liver inflammation and/or fibrosis, primarily in the setting of CHB, because the hepatitis B virus is itself carcinogenic.4 In Australia, the incidence of HCC has been increasing over the last 20 years.5

Hepatocellular carcinoma is frequently detected late, when the patient has advanced stage HCC. Prognosis is uniformly poor in the advanced stage. However, early detection of HCC improves the patient's outcomes and prognosis.6

HEPATOCELLULAR CARCINOMA SURVEILLANCE

Hepatocellular carcinoma is often asymptomatic which can lead to late diagnosis. Therefore, repeated application of screening tests, known as surveillance, is recommended.7 The aim of surveillance is early detection of HCC when intervention (such as surgical resection or liver transplant) may result in cure.8 It is recommended that HCC surveillance is performed in the high-risk groups as outlined in Table 5.1.

Table 5.1: Recommended priority populations for hepatocellular carcinoma surveillance.

<table>
<thead>
<tr>
<th>Population</th>
</tr>
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<tbody>
<tr>
<td>Asian-born males with chronic hepatitis B (CHB) over the age of 40 years</td>
</tr>
<tr>
<td>Asian-born females with CHB over the age of 50 years</td>
</tr>
<tr>
<td>African-born people with CHB over the age of 20 years</td>
</tr>
<tr>
<td>People with CHB and hepatitis C-related cirrhosis (irrespective of age)</td>
</tr>
<tr>
<td>People with cirrhosis of any cause</td>
</tr>
<tr>
<td>People with a family history of HCC</td>
</tr>
<tr>
<td>People with alcohol-related cirrhosis</td>
</tr>
<tr>
<td>People with haemochromatosis-related cirrhosis</td>
</tr>
<tr>
<td>People with non-alcoholic steatohepatitis (NASH)-related cirrhosis</td>
</tr>
</tbody>
</table>

A single randomised controlled trial compared the survival of patients who underwent HCC surveillance to those who did not undergo HCC surveillance. The trial found that a surveillance strategy including the combination of serum alpha-fetoprotein (AFP) and liver ultrasound improved survival.11 These results informed the development of the current international practice guidelines for the management of HCC.12 The optimal surveillance interval is debated. However, six monthly surveillance intervals are recommended because it considers the estimated doubling time for a small HCC.13
MANAGEMENT OF HEPATOCELLULAR CARCINOMA

The prognosis of HCC is generally related to tumour stage at the point of diagnosis. Tumour stage characterises tumour-related factors (including size, number and tumour spread) and host factors (including liver function, physical status and cancer-related symptoms). Worldwide, the most commonly used staging system is the Barcelona Clinic Liver Cancer (BCLC) classification. The BCLC staging classification comprises four stages (A, B, C and D) and links the stage of the disease to a specific treatment strategy.

Therapeutic options for early stage disease (BCLC early stage A) include surgical resection, liver transplantation or percutaneous ablation. Patients with stage B or C disease may receive palliative treatments or new chemotherapy agents in the setting of clinical trials. People with end-stage disease (stage D) receive symptomatic treatment.

Symptom management is a vital component of HCC care throughout the disease process, to preserve the health, wellbeing and quality of life for people with HCC. Pain, fatigue, anorexia, ascites and jaundice, secondary to biliary obstruction, are common symptoms resulting from HCC and/or HCC treatment modalities.

GUIDELINES FOR THE MANAGEMENT OF HEPATOCELLULAR CARCINOMA

In Australia, the surveillance, diagnosis, staging and treatment strategies of HCC are guided by the international literature, specifically clinical practice guidelines produced by the American Association for the Study of Liver Diseases (AASLD), Asian and Pacific Association for the Study of Liver Disease (APASL) and the European Association for the Study of the Liver (EASL).

Each of these clinical practice guidelines are medical documents. They have not been designed to guide nursing practice. However, without an understanding of the medical evidence, Hepatology Nurses will be unable to meet the following competency standards identified in the AHA Competency Standards for the Hepatology Nurse:

• 1.1 Provides comprehensive, evidence-based nursing care for people with or affected by liver disease.
• 1.2 Provides specialised information and education from a nursing perspective.
• 1.4 Provides evidence-based nursing care.
• 2.3 Participates in and contributes to interdisciplinary clinical decision-making.
• 3.2 Advocates for and promotes the rights of people with or affected by liver disease.
• 5.2 Provides expert advice and guidance to the multidisciplinary team and external agencies on the care of people with or affected by liver disease.

The evidence presented in the medical guidelines is embedded in the AHA Consensus-based Nursing Guidelines and creates the benchmark for best practice.

DEFINING THE NURSE’S ROLE IN CARING FOR PATIENTS WITH HEPATOCELLULAR CARCINOMA

This document has been developed for two audiences. Firstly, to assist Hepatology Nurses caring for patients with viral hepatitis and other causes of liver disease to understand and prioritise their role in HCC surveillance, management and care. Secondly, for Hepatology Nurses who wish to
develop their expertise in managing patients with HCC, and develop the specialist hepatoma nursing role. Hepatoma nursing is an emerging speciality that draws on the evidence-base of hepatology, oncology and palliative care.

There are several points at which nurses become involved in the care of patients with HCC. Hepatocellular carcinoma surveillance may be initiated and supported by Hepatology Nurses caring for patients with viral hepatitis and other forms of liver disease. Once the diagnosis of HCC is either suspected or confirmed, the Hepatology Nurse, or where available the specialist Hepatoma Nurse, may become involved in the patient’s care.

The management of HCC is a unique speciality because it involves input from many health professionals. Patients with HCC are most commonly managed in the tertiary health system by a multidisciplinary team (MDT). The MDT usually comprises health professionals from different disciplines, including hepatologists, surgeons, liver transplant teams, oncologists, palliative care teams, interventional radiologists and to some extent radiation oncologists, and allied health professionals including social workers. The Hepatoma Nurse is the primary care coordinator for the patient and is a critical member of the MDT. The Hepatoma Nurse’s role involves coordinating all aspects of the patient’s care and management to ensure continuity of care as the patient moves through the health system. Membership of the MDT will vary between clinical settings, and nurses must be aware of the resources and personnel available to support their patients.

Throughout the disease process, the Hepatoma Nurse advocates for the patient and provides education and support to facilitate the patient’s decision-making about their treatment and management options. Aggressive symptom management is often necessary, and the Hepatoma Nurse has a significant role in coordinating the management of the patient’s symptoms. The nursing role is guided by the evidence-based recommendations for clinical management, and involves actively engaging the patient in the decision-making process about their management and care. Nurses are in the ideal position to provide education and counselling about symptoms and potential options for symptomatic management for patients with HCC. Importantly, the Hepatoma Nurse can advocate for the patient by liaising with the MDT about the patient’s symptoms and facilitating referrals to support services and allied health professionals, as required.

As the incidence of HCC increases in Australia, the demand for specialist nursing care will also intensify. The Hepatoma Nurse is an expert resource for nursing colleagues and other health professionals, through the provision of education and support. Nurses have a responsibility to provide colleagues, including medical professionals, with education and support to assist with identifying patients at risk of developing HCC and to enhance patient care.

The first iteration of this document is deliberately instructional as well as educational and reflects the fledgling context of the specialist nursing role in the delivery of HCC care and coordination. The aim of the document is to assist in the development of the hepatology nursing workforce’s capacity in Australia to provide nursing care for patients with HCC.

The Guiding Principles of the AHA Consensus-based Nursing Guidelines described in the Introduction (page 17), underpin the five domains and respective consensus guidelines outlined in this document.

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\[D\] In HCC care, the collaboration of health professionals working together to care for the patient is widely referred to as the multidisciplinary team (MDT). See section on Definitions relevant to the AHA Consensus-based Nursing Guidelines (page 21) for clarification of the terminology used in this document.
DOMAIN 1: PROVISION AND MANAGEMENT OF NURSING CARE FOR PATIENTS WITH, OR AT RISK OF, HEPATOCELLULAR CARCINOMA

Domain 1 of the AHA Competency Standards for the Hepatology Nurse incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to provide comprehensive, evidence-based and culturally appropriate care and education for people with, or at risk of, HCC. Each consensus guideline addresses one or more of the competency standards from Domain 1; details are presented after each guideline.

Consensus guideline 1.1: Support the patient to participate in hepatocellular carcinoma surveillance

- Identify which patients with liver disease are at risk of developing HCC (refer to Table 5.1).
- Build rapport with the patient from the beginning of the surveillance intervention.
- Provide education and resources for the patient about the importance and utility of HCC surveillance, including potential risks and the benefits of early detection.
- Provide education for the patient about the treatment and management options for HCC if a tumour is detected during surveillance.
- Assess and develop a management plan that enables the patient to participate in HCC surveillance.
- Develop and implement a patient recall system to support the patient to participate in regular HCC surveillance.

Consensus guideline 1.1 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.2: Support the patient to participate in targeted surveillance if there is an abnormal lesion or suspicion of a hepatocellular carcinoma

- If indicated, HCC surveillance involving a shorter follow-up interval (every 3-4 months) may be recommended in particular circumstances. Further monitoring and support the patient’s adherence to the targeted HCC surveillance plan.
- Provide education to the patient about the importance and utility of targeted HCC surveillance and the consequences of non-adherence to the surveillance plan.
- Provide education to the patient about the benefits of early HCC detection as well as subsequent treatment and management options.

Consensus guideline 1.2 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.3: Conduct a comprehensive nursing assessment of the patient with hepatocellular carcinoma

The nursing assessment of the patient with HCC is based on Gordon’s Functional Health Patterns. The purpose of performing the nursing assessment is to inform the development of the nursing management plan.

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E Targeted HCC surveillance involves the application of additional and more frequent screening tests if there is a suspicion of an abnormal lesion.

F Please note that the nursing assessment presented in this document is only one of many nursing assessment tools available. Hepatology Nurses are encouraged to consider which assessment tool best suits their clinical practice.
Health Perception-Health Management Pattern:

- Document the patient’s health history and assess:
  - Risk factors for underlying liver disease, including:
    - Consumption of alcohol
    - Autoimmune
    - Biliary
    - Diabetes
    - Non-alcoholic fatty liver disease
    - Viral hepatitis.
  - Context leading to the diagnosis:
    - Explore the patient’s understanding of their HCC diagnosis.
  - Assess the BCLC staging\(^\text{32}\) and review the planned treatment course for the patient.
  - Liver disease symptomology.
  - Liver disease progression.
  - Impact of liver disease on the patient’s life (health, social, sexual, work, economic and self-esteem).
  - Extrahepatic manifestations.
  - Viral hepatitis treatment history, if appropriate.
  - Autoimmune diseases, cardiac, chronic liver disease, dermatological, endocrine, oral, ophthalmology and/or renal issues or other significant co-morbidities.
  - The patient’s drug and alcohol history, including use of illicit drugs, alcohol and tobacco.

- Assess the need for vaccination according to the current edition of the Australian Immunisation Handbook.\(^\text{33}\)

- Assess the patient’s family medical history as it relates to the patient’s current health:
  - Including, but not limited to, HCC, hepatitis B and C and/or any form of liver disease; endocrine disorders, autoimmune diseases, mental health and cardiac conditions.
  - Assess the need for contact tracing of underlying medical condition such as viral hepatitis, if relevant.\(^\text{34}\)

- Assess the patient’s current medication use including prescription, non-prescription, illicit and complementary and alternative medicines (including vitamins).

- Explore and document the patient’s drug and alcohol history including overuse of prescription and non-prescription medications, use of illicit drugs, alcohol and tobacco.

- Document allergies.

Nutritional-Metabolic Pattern, Elimination Pattern and Activity-Exercise Pattern:

- Perform a physical assessment of the patient, including:
  - Monitor vital signs.
  - Nutritional and metabolism assessment including calculation of the patient’s body mass index (BMI) and waist to hip ratio.
  - Assess the patient’s activity and exercise routine.
  - Initiate the patient’s Eastern Cooperative Oncology Group (ECOG) Performance Status Assessment.\(^\text{35}\)
    - Consider autoimmune diseases, cardiac, liver, dermatological, endocrine, oral, ophthalmology, renal issues or other significant co-morbidities.

Cognitive-Perceptual Pattern and Coping-Stress Tolerance Pattern:

- Explore and document the patient’s psychosocial history, including:
  - Mental health history
– coping and stress patterns
– pain management
– social support including housing, financial, employment and social activities
– any legal issues.

Role-Relationship Pattern:
• Explore the roles and relationships of the patient’s significant other(s)/carer(s).

Sexuality-Reproductive Pattern:
• Discuss the patient’s sexual and reproductive health and contraception choices.

Sleep-Rest Pattern:
• Discuss the patient’s sleep and rest patterns, including:
  – sleep, rest and relaxation practices
  – dysfunctional sleep patterns.

Value-Belief Pattern:
• Explore the cultural considerations relevant to the patient, acknowledging the social, economic, political and language barriers that affect the healthcare experiences of minority communities.\(^{36}\)

Consensus guideline 1.3 addresses competency standards 1 and 4.

**Consensus guideline 1.4: Assess the patient’s level of knowledge about hepatocellular carcinoma and provide relevant education**

• Assess the patient’s level of knowledge about HCC and its management, and provide relevant education on:
  – stages of HCC progression
  – signs of HCC progression
  – when and how to seek medical and nursing assistance
  – purpose and importance of adhering to the HCC treatment and management plan.

• Provide the patient with education about possible diagnostic and assessment interventions including:
  – Risks, benefits and what to expect from the diagnostic and assessment interventions.
  – Interpretation of investigations and results.
  – Intervention side effects.

• Educate the patient about the role of their General Practitioner (GP) with regard to HCC management.

• Educate the patient about the roles of the MDT members.

• Educate the patient about the roles of the allied health support services in the hospital and the community including:
  – members of the palliative care team
  – social workers
  – dietitians
  – psychologists
  – Respecting Patient Choices program.\(^{37}\)

Consensus guideline 1.4 addresses competency standards 2 and 4.
Consensus guideline 1.5: Provide education and support for the patient’s significant other(s)/carer(s)

- Inform significant other(s)/carer(s) about community resources, including referral to a social worker (if available) for:
  - Centrelink pensions and support
  - Local government community-based care
  - Travel assistance
    ~ Patient and significant other(s)/carer(s) to be educated about driving restrictions if encephalopathic.
  - The roles of the MDT members.

- If the patient has HCC and advanced liver disease, refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease:
  - Consensus guideline 1.4: Provide education and support for the patient’s significant other(s)/carer(s).

Consensus guideline 1.5 addresses competency standards 2 and 4.

Consensus guideline 1.6: Advocate and support the patient with hepatocellular carcinoma to be actively involved in their treatment and management plan

- Provide the patient with education about being actively involved in their HCC management:
  - Support the patient with their healthcare-related decision-making processes.
  - Encourage and support the patient to actively participate in their health management, as they feel comfortable.
  - Support the patient to consider lifestyle and behavioural changes including reduction or elimination of alcohol and other drug use, including tobacco.
    ~ Refer to appropriate support resources, as required.
  - Support the patient to evaluate their nutritional status and implement dietary changes, as required.

- Provide care coordination to assist the patient and their significant other(s)/carer(s) to negotiate the healthcare system.
  - Negotiate access to timely referrals and interventions in accordance with the patient’s management plan.

- Work in collaboration with the patient to develop a management plan which includes goal setting around healthy behaviours by incorporating motivational interviewing techniques.38

- Establish the patient’s awareness of, and access to, pathology, medical imaging, alternative medical services (if the patient moves) and costs associated with accessing healthcare.

- Support the patient during the treatment journey.
  - Respect and support the patient’s HCC treatment and management choices and their right to change their choice at any time.39

- Support the patient to develop an end-of-life care plan.
  - Assist the patient with accessing financial support and entitlements, including superannuation, insurance and income protection insurance.

- Advocate for the patient in the MDT.

Consensus guideline 1.6 addresses competency standards 1 and 3.
Consensus guideline 1.7: Provide nursing management for the patient with hepatocellular carcinoma who is considering treatment

- Provide care coordination for the patient by liaising between the patient and members of the MDT.
- Explore the patient’s understanding of the HCC treatment options and possible outcomes, and provide additional information as required about:
  - HCC treatment options and related side effects.
  - Nursing recommendations about side effect management.
- Explain the importance of adhering to the treatment regime.
- Discuss the benefits for the patient and significant other(s)/carer(s) of seeking palliative care services.
- Identify and ensure appropriate referral to relevant allied health services.
- Provide relevant patient resources to support the patient in their decision-making about HCC treatment choices.

Consensus guideline 1.7 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 1.8: Provide nursing care for the patient with hepatocellular carcinoma during treatment

- Consult with the patient about their information and support needs during treatment.
- Implement and facilitate care coordination depending on the treatment modality identified in the management plan, including:
  - surgery resection
  - loco-regional interventional treatment
  - liver transplant
  - pharmaceutical treatment including clinical trials
  - palliative care.

Consensus guideline 1.8 addresses competency standards 1, 2 and 4.

DOMAIN 2: INTERDISCIPLINARY COORDINATION AND CARE FOR PATIENTS WITH HEPATOCELLULAR CARCINOMA

Domain 2 of the AHA Competency Standards for the Hepatology Nurse incorporates four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to coordinate, facilitate and evaluate interdisciplinary care for patients with, or at risk of, HCC as they seek to achieve optimal health outcomes. Each consensus guideline addresses one or more of the competency standards from Domain 2; details are presented after each guideline.

Consensus guideline 2.1: Discuss the roles of each member of the multidisciplinary team (MDT) in relation to the implementation of the patient's management plan

- Explain the role of each member of the MDT in terms of the professional responsibilities and areas of expertise.

G Consistent with the AHA Competency Standards for the Hepatology Nurse and the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B, Hepatitis C and Advanced Liver Disease, the use of the word interdisciplinary will be used in the domain heading, although the content of the guidelines refers to the multidisciplinary team to reflect the terminology used in HCC care. See section on Definitions relevant to the AHA Consensus-based Nursing Guidelines (page 21) for clarification of the terminology used in this document.
• Provide the patient and their significant other(s)/carer(s) with the contact details for the most relevant members of the MDT.

• Outline the communication pathways between members of the MDT.

  Consensus guideline 2.1 addresses competency standard 2.

**Consensus guideline 2.2: Coordinate the care for the patient with hepatocellular carcinoma**

• Establish communication pathways between the medical specialists, radiology specialists, allied health professionals and the Hepatology Nurse.

• Confirm communication pathways between all the members of the MDT.

• Develop clinical partnerships with members of the MDT to support patient care.

• Coordinate and manage the patient’s treatment and management plan as developed by the MDT.

• Coordinate the patient’s referrals and appointments in consultation with the patient and the MDT.

• Ensure all necessary investigations have been performed and the results are available, as required.

• Coordinate the follow-up care for the patient with members of the MDT.

  Consensus guideline 2.2 addresses competency standards 1, 2, 3 and 4.

**Consensus guideline 2.3: Recognise and enhance the existing therapeutic relationship with the general practitioner and/or referring practitioner**

• Establish a communication pathway with the patient’s GP/referring practitioner.

• Liaise with the patient’s GP/referring practitioner about the HCC surveillance plan and the enhanced HCC surveillance plan, as required.

• Communicate with the patient’s GP/referring practitioner regarding the patient’s health and disease status and their treatment and management plan.

• In collaboration with the GP/referring practitioner, manage the patient’s ongoing care including:
  – treatment-related side effects
  – access to community-based services, including dietetics, podiatry and psychology
  – access to community-based palliative care.

• Communicate with the GP/referring practitioner about the patient’s progress during the implementation of the patient’s management and treatment plan, including:
  – Anti-viral treatment plan, if relevant:

  ~ Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B:

  > Consensus guideline 1.8: Provide nursing management for the patient with chronic hepatitis B who is considering treatment.

  > Consensus guideline 1.9: Provide hepatitis B treatment-related nursing care for the patient with chronic hepatitis B.

  ~ Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis C:

  > Consensus guideline 1.7: Perform a pre-treatment nursing assessment.

  > Consensus guideline 1.8: Patient education at the commencement of hepatitis C treatment.

  > Consensus guideline 1.9: Provide hepatitis C treatment-related nursing care.

  > Consensus guideline 1.10: Provide hepatitis C-related nursing care after the patient has completed treatment.
Advanced liver disease management plan:

Refer to the AHA Consensus-based Nursing Guidelines for the Care of Patients with Advanced Liver Disease:

- Consensus guideline 1.1: Perform a nursing assessment to identify clinical symptoms and signs of advanced liver disease.
- Consensus guideline 1.7: Provide ongoing monitoring and assessment-related nursing care for the patient with advanced liver disease.

Consensus guideline 2.3 addresses competency standards 1, 2, 3 and 4.

Consensus guideline 2.4: Facilitate patient referral to members of the multidisciplinary team and community allied health services

- Coordinate the referral of the patient with HCC to allied health support services in the hospital and the community as required, including:
  - alcohol and other drug services
  - community health nursing
  - dentists
  - dietitians
  - medical specialists
  - multicultural workers for social and cultural support
  - psychologists
  - psychiatrists
  - palliative care
  - physiotherapists
  - podiatrists
  - settlement workers for patients with a refugee background
  - sexual health services
  - social workers
  - other health services, as required.

Consensus guideline 2.4 addresses competency standards 1 and 2.

DOMAIN 3: NON-DISCRIMINATORY PRACTICE

Domain 3 of the AHA Competency Standards for the Hepatology Nurse comprises of two competency standards and related performance criteria that reflect the non-discriminatory practice of Hepatology Nurses, and their respect for the choices of people with, or at risk of, HCC, with regard to alcohol and drug use, sexual orientation, religious and cultural beliefs, social circumstances and physical and mental health. Each consensus guideline addresses one or more of the competency standards from Domain 3; details are presented after each guideline.

Consensus guideline 3.1: Promote confidentiality for patients with hepatocellular carcinoma

- Discuss the patient’s right to confidentiality of their personal information in the healthcare setting.
  - Seek to understand the meaning of confidentiality from the patient’s perspective.
- Understand and adhere to relevant medico-legal obligations including documentation.

Consensus guideline 3.1 addresses competency standards 1 and 2.
Consensus guideline 3.2: Facilitate appropriate disclosure for patients with hepatocellular carcinoma

• Empower and support the patient to decide to whom, and at what time, they disclose their HCC diagnosis.
• Consider advising the patient regarding when they are not required to disclose their HCC diagnosis.
• For patients with hepatitis B and/or hepatitis C, refer to the:
  ~ AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B:
  ~ Consensus guideline 3.2: Facilitate appropriate disclosure for patients with chronic hepatitis B.
  ~ AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis C:
  ~ Consensus guideline 3.2: Facilitate appropriate disclosure for patients with hepatitis C.

Consensus guideline 3.2 addresses competency standards 1 and 2.

Consensus guideline 3.3: Discourage discriminatory behaviour against patients with hepatocellular carcinoma

• Respectfully challenge discriminatory attitudes towards patients with HCC.
• Educate and support health professionals to provide non-discriminatory care for patients with HCC.
• Enable the patient to be aware of their diagnosis and make informed choices about disclosure.
• Provide support, information and appropriate referrals to complaints services for patients who have experienced discrimination.
• Advocate for the patient’s equity of access to treatment and management regardless of the aetiology of their HCC and lifestyle choices.

Consensus guideline 3.3 addresses competency standards 1 and 2.

Consensus guideline 3.4: Provide culturally appropriate nursing care for patients with hepatocellular carcinoma

• Be aware of the various health belief models and cultural differences and their impact on the patient’s health behaviour.
• Develop an awareness of own cultural beliefs and attitudes and consider how these affect the delivery of nursing care.
• Advocate for the delivery of culturally appropriate and sensitive healthcare.
• Seek support from specialist services in the delivery of culturally appropriate nursing care, for example, multicultural services, Aboriginal and Torres Strait Islander services and/or drug and alcohol services.
• Assist patients with HCC to navigate the healthcare system, acknowledging that some patients with HCC may encounter additional barriers in understanding their HCC diagnosis and management because:
  ~ They experience significant isolation as a result of low English language proficiency.
  ~ They have low health literacy.
  ~ They come from a low socioeconomic background.
  ~ Their culture may influence the role of their family in the care of the patient with HCC, for example, significant other(s)/carer(s) not wanting the patient to be informed of their HCC diagnosis.

Consensus guideline 3.4 addresses competency standards 1 and 2.
DOMAIN 4: PROFESSIONAL SELF-CARE AND DEVELOPMENT

Domain 4 of the AHA Competency Standards for the Hepatology Nurse incorporates five competency standards and related performance criteria that reflect the Hepatology Nurse’s ability to adapt to the changing clinical environment through involvement in professional development activities and reflective practice. Each consensus guideline addresses one or more of the competency standards from Domain 4; details are presented after each guideline.

Consensus guideline 4.1: Identify and define the hepatology nursing scope of practice

To assist Hepatology Nurses to identify their individual scope of practice and the scope of practice of the speciality, the following questions are presented for consideration:

- What is the profile of the patients with, or affected by, liver disease that the Hepatology Nurse cares for and what could the Hepatology Nurse be doing to improve the health outcomes for these patients?
- What education and professional development activities has the Hepatology Nurse completed?
- What is the previous experience of the Hepatology Nurse?
- What additional education does the Hepatology Nurse need to provide the required standard of nursing care to patients with, or affected by, liver disease?
- Is the scope of practice used by nurses in other settings?
- What is the nurse’s legal position? For example, do Australian and/or State/Territory Government legislation and regulations permit nurses to deliver the care being considered as part of the Hepatology Nurse’s scope of practice?
- Are there policies and procedures in place to support the Hepatology Nurse providing this care?
- How will competency assessment take place given the Hepatology Nurse’s current scope of practice and if the Hepatology Nurse is expanding their scope of practice?

The scope of hepatology nursing practice is an important consideration when interpreting the AHA Consensus-based Nursing Guidelines. It is important to highlight that the AHA, as the professional organisation representing Hepatology Nurses in Australia, has a responsibility to its members to assist in identifying the speciality’s scope of practice and to provide a forum for individuals to consider what constitutes their scope of practice.

Consensus guideline 4.1 addresses competency standards 2, 3, 4 and 5.

Consensus guideline 4.2: Actively participate in reflective practice

Reflective practice is an important skill that Hepatology Nurses may choose to develop to identify their scope of practice and to continuously learn and evolve as a result of their professional practice.

In addition to formal teaching and learning, reflective practice encourages individuals to participate in life-long learning from their own professional experiences.

In order to inform future iterations of the AHA Competency Standards and the AHA Consensus-based Nursing Guidelines, Hepatology Nurses may consider using reflective practice to assist in their professional evolution and that of the speciality.

Consensus guideline 4.2 addresses competency standards 1, 2 and 3.
Consensus guideline 4.3: Actively engage in continuing professional development

- The Nursing and Midwifery Board of Australia’s National Registration Standards stipulate that continuing professional development is a requirement of nursing registration.47
- Identify and participate in professional development activities that maintain one’s own advanced level of knowledge and skills with regard to caring for patients with liver disease.
- Participate in lifelong learning to ensure ongoing development of the individual and the hepatology nursing specialty.

Consensus guideline 4.3 addresses competency standard 1.

Consensus guideline 4.4: Actively engage in professional self-care

- Actively maintain one’s own physical, mental and spiritual health by seeking support, as required.
- Accept the responsibility for self-care by acknowledging one’s own physical, mental and spiritual strengths and limitations, and recognise one’s intrinsic worth.
- Foster qualities that encourage beneficial practices and relationships with colleagues.48

Consensus guideline 4.4 addresses competency standard 3.

DOMAIN 5: CLINICAL AND COMMUNITY LEADERSHIP

Domain 5 of the AHA Competency Standards for the Hepatology Nurse49 comprises of four competency standards and related performance criteria that reflect the ability of the Hepatology Nurse to provide clinical leadership and expertise in the nursing profession with regard to liver health and disease, and community leadership through advocacy and policy development. Each consensus guideline addresses one or more of the competency standards from Domain 5; details are presented after each guideline.

Consensus guideline 5.1: Actively promote the Hepatology Nurse’s role in the delivery of care for patients with hepatocellular carcinoma

- Actively promote the Hepatology Nurse as an expert resource in liver health and disease for health professionals as well as the community, education, government and non-government sectors.
- Maintain and foster relationships with key stakeholders in clinical and non-clinical organisations and promote the Hepatology Nurse’s role in the management of patients with HCC.
- Disseminate the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma to clinical and non-clinical colleagues.
  - Advocate for their use as evidence to support the Hepatology Nurse’s role in caring for patients with HCC.
- Initiate and/or contribute to the research activities that strengthen the evidence-base of the Hepatology Nurse’s role in caring for patients with HCC.
- Act as a change agent to influence local and national policy to ensure the needs of people with HCC are addressed.

Consensus guideline 5.1 addresses competency standards 1 and 4.
Consensus guideline 5.2: Mentor nurses to be involved in caring for patients with hepatocellular carcinoma

- Mentor and support nurses with an interest in caring for patients with HCC to build their confidence and competence in HCC care and management.
- Support nurses new to the field of hepatology nursing to interpret and implement the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatocellular Carcinoma.
- Provide expert education and support to Hepatology Nurses interested in caring for patients with HCC.

Consensus guideline 5.2 addresses competency standard 3.

Consensus guideline 5.3: Provide ongoing education, support and leadership for health professionals involved in caring for people with, or at risk of, hepatocellular carcinoma

- Seek opportunities to contribute to, participate in and/or lead HCC education forums.
- Actively engage in own professional development activities to ensure knowledge currency.
- Provide expert information regarding the meaning of test results, the natural history of HCC and underlying liver disease, treatment options and appropriate referral to members of the MDT.
- Provide education and support for health professionals involved in caring for people with, or at risk of, HCC including, but not limited to, medical practitioners, primary health care workers, drug and alcohol workers, workers in the custodial setting, registered and enrolled nurses, midwives, multicultural health workers, community-based organisations, allied health professionals and health assistant workers.

Consensus guideline 5.3 addresses competency standard 2.

References

8 Carville, Cowie, op. cit.
13 Ibid.
14 Ibid.
15 Ibid.
24 Ibid.
27 Chih-Yi Sun, Sarna, op. cit.
29 Australasian Hepatology Association, op. cit.
32 Llovet, et al., op. cit.
36 Australasian Hepatology Association, op. cit.
39 Respecting Patient Choices, op. cit.
40 Australasian Hepatology Association, op. cit.
41 Ibid.
43 Australasian Hepatology Association, op. cit.
49 Australasian Hepatology Association, op. cit.
APPENDIX 1: QUESTIONNAIRE
MEASURING CONSENSUS

EXPERT REVIEW OF THE AHA CONSENSUS-BASED NURSING
GUIDELINES FOR THE CARE OF PATIENTS WITH HEPATITIS B/
HEPATITIS C/ADVANCED LIVER DISEASE/ HEPATOCELLULAR
CARCINOMA

The purpose of the expert panel review of the AHA Consensus-based Nursing Guidelines is to
validate the content of the document. You are asked to review the document and consider
whether the following criteria have been fulfilled.

Each criterion is rated on a 5-point scale ranging from 1 'strongly disagree' to 5 'strongly agree',
with two mid points: 2 'disagree' and 4 'agree', and one neutral point: 3 'neutral'. The scale
measures the extent to which a criterion has been fulfilled.

• If you are confident that the criterion has been fully met then you should answer 'strongly agree'.
• If you are confident that the criterion has not been fulfilled at all or if there is no information
available then you should answer 'strongly disagree'.
• If you are unsure that a criterion has been fulfilled, for example, because the information is
unclear or because only some of the content fulfils the criterion, then you should answer 'agree',
'disagree' or 'neutral', depending on the extent to which you think the issue has been addressed.

To tick the box, please click the box with the cursor (if using Microsoft Office Word 2007 or
later). If you are using an earlier version of Word, please highlight or **bold** your response.

There is a box for comments under each item. Please use this space to explain the reasons for
your response.

SCOPE AND PURPOSE

1. The overall objective of the AHA Consensus-based Nursing Guidelines for the Care of Patients
with Hepatitis B/Hepatitis C/Advanced Liver Disease/Hepatocellular Carcinoma (HCC) is
specifically described.

<table>
<thead>
<tr>
<th></th>
<th>1: Strongly disagree</th>
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2. The content of the AHA guidelines reflect the scope of the Hepatology Nurse's role in caring
for patients with hepatitis B/hepatitis C/advanced liver disease/HCC.

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3. The clinical issue (hepatitis B/hepatitis C/advanced liver disease/HCC) covered by the guidelines is adequately described in the background of the guideline document.*

- [ ] 1: Strongly disagree
- [ ] 2: Disagree
- [ ] 3: Neutral
- [ ] 4: Agree
- [ ] 5: Strongly agree

Comments:

4. The pivotal literature is referenced in the background of the guideline document.*

- [ ] 1: Strongly disagree
- [ ] 2: Disagree
- [ ] 3: Neutral
- [ ] 4: Agree
- [ ] 5: Strongly agree

Comments:

**RIGOUR OF DEVELOPMENT**

5. The methods used to formulate the guidelines are clearly described.*

- [ ] 1: Strongly disagree
- [ ] 2: Disagree
- [ ] 3: Neutral
- [ ] 4: Agree
- [ ] 5: Strongly agree

Comments:

6. A procedure for updating the guidelines is provided.*

- [ ] 1: Strongly disagree
- [ ] 2: Disagree
- [ ] 3: Neutral
- [ ] 4: Agree
- [ ] 5: Strongly agree

Comments:

* Questions 3, 4, 5 and 6 were not included in the questionnaire distributed in consultation round 5 to the members of the AHA who attended the Summit 2012.

**CLARITY AND PRESENTATION**

**Domain 1: Provision and management of nursing care for patients with or at risk of hepatitis B/hepatitis C/advanced liver disease/hepatocellular carcinoma**

7. The consensus guidelines and accompanying explanation in Domain 1 are specific and unambiguous.

- [ ] 1: Strongly disagree
- [ ] 2: Disagree
- [ ] 3: Neutral
- [ ] 4: Agree
- [ ] 5: Strongly agree

Comments:
8. The consensus guidelines and accompanying explanation in Domain 1 represent my understanding of the Hepatology Nurse’s role in providing nursing care for patients with hepatitis B/hepatitis C/advanced liver disease/HCC.

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Comments:

Domain 2: Interdisciplinary coordination and care for patients with hepatitis B/hepatitis C/advanced liver disease/hepatocellular carcinoma

9. The consensus guidelines and accompanying explanation in Domain 2 are specific and unambiguous.

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Comments:

10. The consensus guidelines and accompanying explanation in Domain 2 represent my understanding of the Hepatology Nurse’s role in interdisciplinary care and coordination for patients with hepatitis B/hepatitis C/advanced liver disease/HCC.

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Comments:

Domain 3: Non-discriminatory practice

11. The consensus guidelines and accompanying explanation in Domain 3 are specific and unambiguous.

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Comments:

13. The consensus guidelines and accompanying explanation in Domain 3 represent my understanding of the Hepatology Nurse’s role in non-discriminatory practice.

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<th>5: Strongly agree</th>
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Comments:
**Domain 4: Professional self-care and development**

14. The text in Domain 4 presents key review criteria for Hepatology Nurses to monitor their scope of practice.

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<th>5: Strongly agree</th>
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Comments:


15. The text in Domain 4 presents key review criteria for Hepatology Nurses to engage in reflective practice.

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Comments:


**Domain 5: Clinical and community leadership**

16. The consensus guidelines and accompanying explanation in Domain 5 is specific and unambiguous.

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Comments:


17. The consensus guideline and accompanying explanation in Domain 5 represents my understanding of the Hepatology Nurse’s role in clinical and community leadership.

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Comments:


**OVERALL ASSESSMENT**

Would you recommend the AHA Consensus-based Nursing Guidelines for the Care of Patients with Hepatitis B/Hepatitis C/Advanced Liver Disease/HCC for use in practice?

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<tr>
<th></th>
<th>1: Unsure</th>
<th>2: Would not recommend</th>
<th>3: Recommended (with alterations)</th>
<th>4: Strongly recommend</th>
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Comments:
FURTHER COMMENTS ON THE AHA CONSENSUS-BASED NURSING GUIDELINES FOR THE CARE OF PATIENTS WITH HEPATITIS B, HEPATITIS C, ADVANCED LIVER DISEASE AND HEPATOCELLULAR CARCINOMA

Comments:
