

Nursing care for patients with cirrhosis

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Summary

Cirrhosis represents a major cause of morbidity and mortality, leading to a marked impairment in the quality of life of patients and their caregivers, and resulting in a major burden on healthcare systems. Currently, in most countries, nurses still play a limited role in the care of patients with cirrhosis, which is mainly restricted to the care of patients hospitalised for acute complications of the disease. The current manuscript reviews the established and potential new and innovative roles that nurses can play in the care of patients with cirrhosis. In the hospital setting, specialised nurses should become an integral part of interprofessional teams, helping to improve the quality of care and outcomes of patients with cirrhosis. In the primary care setting, nurses should play an important role in the care of patients with compensated cirrhosis and also facilitate early diagnosis of cirrhosis in those at risk of liver diseases. This review calls for an improved global liver disease education programme for nurses and increased awareness among all healthcare providers and policymakers of the positive impacts of advanced or specialist nursing practice in this domain.

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Introduction

In recent years, nurses have played an increasingly important role in patient care.¹ Changes started way before the COVID-19 pandemic but have been highlighted by the pandemic, with the shortage of nurses causing major problems in many countries and having a marked negative impact on patient care.² Nurses play important roles in many areas, having significant autonomy in the care of patients with acute and chronic conditions, both in hospital and primary care settings, and the ability to prescribe medications under certain circumstances in countries where this is permitted by law.³ However, these changes are heterogeneous in terms of their application in geographical areas due to differences in both nurse education programmes and local legislation.

In this context, chronic liver diseases have emerged as a very important challenge worldwide due to their high prevalence, marked mortality rates, and the very significant burden they place on healthcare systems.^{4,5} Nevertheless, in contrast to other chronic conditions, such as diabetes mellitus, heart failure, and chronic obstructive pulmonary disease, the role of nurses in the care of patients with liver diseases is less well developed in many countries.⁵ Furthermore, the extent of nurse-led research in liver diseases is markedly low compared to other chronic diseases.⁶ This is unfortunate because involvement of nurses in interprofessional teams would improve the overall care of patients with liver disease and could also help reduce the burden of liver diseases worldwide. There have been some initiatives to advance the role of nurses in this field, but there is a need for further international development.^{7,8}

This review addresses some established roles as well as new potential roles nurses can play in the care of patients with cirrhosis, both in the outpatient and inpatient contexts, including clinical care as well as counselling for patients and their caregivers. Moreover, nurses may also participate in early identification of individuals at a high risk of cirrhosis in the community. This could be achieved by implementing protocols of fibrosis assessment using non-invasive markers, such as FIB-4 (fibrosis-4 index) or APRI (aspartate aminotransferase-to-platelet ratio index), in individuals with risk factors for liver fibrosis, particularly patients with type 2 diabetes, obesity, and/or high alcohol consumption, so that preventive measures can be applied successfully before decompensated cirrhosis develops.^{5,9}

Nursing care of patients with compensated cirrhosis

Compensated cirrhosis is the asymptomatic phase of cirrhosis, namely cirrhosis in the absence of ascites, variceal bleeding, or hepatic encephalopathy.⁹ Currently, the diagnosis is typically made by transient elastography or magnetic resonance elastography carried out as follow-up of abnormal liver biochemistry or low platelet count, or incidentally on abdominal cross-sectional imaging. Although patients do not show specific complications of liver disease in this phase, nurses have an important role to play in counselling/education, as outlined below. This can either be in the primary care or hospital setting, depending on the characteristics of the specific healthcare systems.

Keywords: liver diseases; hepatic diseases; clinical nurse specialist; disease stigmatization; liver fibrosis; advanced care practitioner.

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Key points

- Nurses should play an important role in the care of patients with compensated cirrhosis as part of interprofessional teams, both in primary and hospital care.
- In primary care, nurses should play a role in early identification of liver fibrosis among individuals with risk factors for liver diseases.
- There is an urgent need for standardised and improved education programmes for nurses focused on the specific care of patients with liver diseases, particularly cirrhosis.

Counselling about healthy diet and lifestyle

Regardless of the cause of cirrhosis, nurses should counsel patients with compensated cirrhosis to eat a healthy diet, with high protein, low fat, low/moderate sodium, and increased fibre content.¹⁰ Diets should be adjusted to the specific needs of patients. Patients with obesity or malnutrition should ideally be managed together with a dietitian and engaged in specific multidisciplinary primary care programmes, if available.^{10,11} Moreover, the holistic approach provided by nurses may be helpful to address psychosocial factors related to alterations in nutritional status.¹² Finally, nurses should also advise patients to avoid hypomobility and perform moderate exercise, whenever possible, because increased physical activity prevents/ameliorates sarcopenia and may have beneficial effects on the evolution of cirrhosis.^{13,14}

Education about cirrhosis and its potential complications

Education of patients and caregivers about liver disease, and potential complications, is important due to the low level of knowledge about cirrhosis in the general population. Education about the disease may help patients/caregivers to seek medical attention at an early stage should complications arise. Among the different complications of cirrhosis, variceal haemorrhage can be prevented effectively with the use of beta-blockers or endoscopic variceal band ligation (see below).

Assisting in treating the cause of cirrhosis

Removal of the cause of cirrhosis, whenever possible, is associated with decreased risk of decompensation and increased survival.¹⁵ Nurses can play an important role in helping the patient to reach this goal. In patients with alcohol-related cirrhosis, nurse interventions in primary care may help patients to achieve abstinence and maintain adherence to specific pharmacotherapy for alcohol dependence, as shown in a randomised-controlled trial on acamprosate.¹⁶ However, other studies assessing the impact of nursing interventions in the management of alcohol-related liver disease in primary care have not been positive.¹⁷ Nevertheless, because of its central position in care, brief counselling and psychosocial support by primary care nurses is likely important for some patients and caregivers. Moreover, nurses should also coordinate with alcohol treatment facilities and address the social stigma associated with alcohol use.¹⁸ In patients with non-alcoholic (or metabolic) fatty liver disease, the major role of nurses should be to encourage weight loss and identify perceived stigma associated with being overweight.¹⁹ To encourage and maintain weight loss, calorie restriction with 30% energy reduction, a Mediterranean/plant-based diet, minimisation of refined carbohydrate/high-fructose corn syrup intake, and an aerobic

exercise plus resistance programme are recommended.^{10,20} Achieving weight loss of greater than 10% is ideal to reduce hepatic steatosis, inflammation, and hepatic fibrosis.

Screening for gastroesophageal varices and hepatocellular carcinoma

In addition to activities aimed at preventing hepatic decompensation by acting on the cause of cirrhosis, nurses' role in patients with compensated cirrhosis should include prevention of variceal bleeding and screening for hepatocellular carcinoma (HCC).^{8,15} The nursing role in prophylaxis against variceal bleeding includes scheduling screening and surveillance endoscopies. The first endoscopy should be performed at the time of initial diagnosis. If there are no varices on the first endoscopy, a repeat endoscopy should be scheduled in 3 years. If there are small varices, a repeat endoscopy should be scheduled in 1 to 2 years. Non-selective beta-blockers should be prescribed in selected patients with small varices and in all patients with large varices, assuming no contraindications. Nurses have an important role to play in educating patients regarding monitoring beta-blocker therapy, such as recording of resting heart rate and blood pressure.^{8,15} Moreover, patients should also be made aware of side effects of beta-blockers like hypotension, dizziness, and cold extremities. Meanwhile, twice yearly surveillance for HCC with ultrasonography is mandatory in patients with compensated cirrhosis.

Immunisations

An additional nursing role involves the issue of immunisations in cirrhosis, particularly reviewing individual immunisation history and scheduling required immunisations. Mandatory vaccines include COVID-19, pneumococcal pneumonia, influenza, and tetanus. Serologic testing for hepatitis A and B should be performed to assess previous exposure, and respective vaccines should be given if the patient is negative for anti-HAV and anti-HBc antibodies.

Medication counselling

Nurses also play an important role in reviewing medications and improving medication adherence, not only at first visit but also in follow-up visits, either in-person or via telehealth approaches.^{8,15} During their first visit, patients should be advised to avoid the use of non-steroidal anti-inflammatory drugs (NSAIDs) and aspirin as pain relievers. Acetaminophen (paracetamol) should be used as an alternative, at doses of a maximum of 2 g daily. Patients with active alcohol use should also be advised that they may be at greater risk of liver toxicity when taking paracetamol. Fluoroquinolones, penicillins, and

cephalosporins are generally acceptable as prescribed antibiotics. Statins at lower doses are acceptable, as are oral hypoglycaemic agents or insulin in patients with diabetes.

Caring for comorbidities

Nursing care for patients with compensated cirrhosis should also focus on comorbidities that are frequently associated with liver disease. Comorbidities may include features of the metabolic syndrome, namely obesity, diabetes, hypertension, and cardiovascular disease.²⁰

The role of nurses in the care of patients with compensated cirrhosis is summarised in Fig. 1.

Role of nurses in the care of patients with decompensated cirrhosis

The development of at least one complication such as ascites, gastrointestinal bleeding, or hepatic encephalopathy indicates the transition to decompensated cirrhosis. As a result, life expectancy significantly decreases to a median of 2 years.⁹ The demands on disease management increase because of the dynamic and unpredictable trajectory of this disease stage, with high hospitalisation rates leading to increased costs. Treatment strategies are concentrated on managing and preventing complications, referring patients for liver transplantation or discussing supportive or even end-of-life care in very advanced cases with contraindications for transplantation.^{9,21,22} The main roles of nurses in the care of patients with decompensated cirrhosis are outlined below. These are generally performed in the hospital setting.

Holistic patient-centred approach

For patients and their relatives, the development of decompensated cirrhosis represents a turning point, with a need for

increased levels of support and information. For those patients previously diagnosed with compensated cirrhosis, they are confronted with a different situation, experience multiple, often co-occurring symptoms, and perceive increased morbidity and decreased quality of life which can be difficult to self-manage.^{9,21,23,24} Patient's ability to cope with the illness can be disrupted and their self-management may be impaired. Moreover, because of patients' cognitive and physical limitations, their dependence on healthcare professionals and caregivers increases.^{25,26}

Irrespective of whether the patients are hospitalised or not, a holistic patient-centred approach is essential and nurses have expertise in exploring patients' experiences of illness and identifying potential needs for: i) information and education; ii) practical help; iii) physical symptom relief; iv) care work; and v) psychological support.²⁷ This task is of great importance to facilitate an improved understanding of the disease among patients and caregivers.

Assessment of frailty and risk of falls

Frailty is common in patients with decompensated cirrhosis and has been associated with faster disease progression, poor quality of life, and decreased survival.²⁸ Of the different methods reported to assess frailty in cirrhosis, the liver frailty index, which includes three tests – grip strength, chair stands, and balance – seems to be the most frequently used.²⁸ Frailty should be measured at the time of hospital admission and repeatedly after discharge to evaluate changes. Main measures to reverse/improve frailty are adequate nutritional intake as well as moderate physical exercise. Nurses have an important role to play in encouraging these lifestyle improvements. An important consequence of frailty is an increased risk of falls, which is also related to the presence of covert hepatic encephalopathy, a common complication in patients with decompensated cirrhosis.²⁹ Nurses should identify patients at a higher risk of falls so that preventive strategies can be discussed with patients and caregivers.

Counselling about healthy lifestyle, diet, and self-management

Education about healthy lifestyle and diet is key, as already mentioned for patients with compensated cirrhosis. However, nutritional counselling is more important here due to the frequent existence of sarcopenia and frailty, as well as the need to reduce sodium intake in patients with ascites and/or oedema. The participation of a multidisciplinary team is essential to help reach the goals of adequate calorie and protein intake.¹⁰

Self-management is defined as “patient's ability to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of a disease”.³⁰ The goals of self-management support are a better understanding of the disease, the ability to set individual goals, to make informed choices and to increase self-efficacy. Nurses play an important role in delivering these aspects of care via appropriate verbal and written education. This task is particularly important in liver diseases because of the poor education and awareness of patients about such diseases. Nurses can work with patients and their caregivers to teach them how to recognise changes early, how signs and symptoms are connected with or related

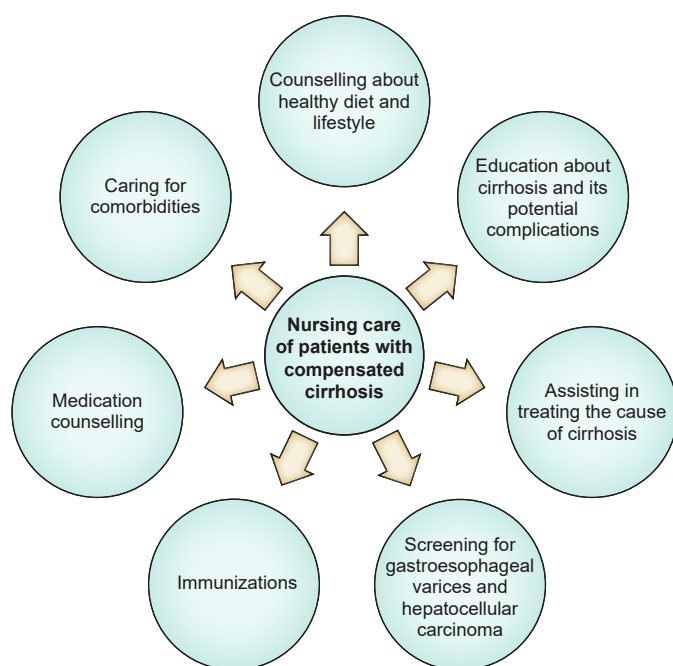


Fig. 1. Roles of nurses in the care of patients with compensated cirrhosis.

to treatment, how to get in contact with healthcare professionals, how to prevent further complications and how to initiate and maintain healthy lifestyle behaviours. Consequently, patients can identify their priorities and preferences regarding care, which is a prerequisite for active involvement in collaborative treatment planning and in defining goals of care.²¹ The inclusion of nurses in interprofessional teams facilitates the early involvement of allied healthcare professionals, such as dietitians, physiotherapists, and social workers, and can spur the introduction of further service providers, such as counselors or palliative care specialists, if required.

Nursing role in management of complications of cirrhosis

The role of nurses in the care of hospitalised patients with decompensated cirrhosis is very important and has been discussed extensively elsewhere.⁸ A comprehensive assessment includes observing the signs of decompensation (e.g. accumulation of fluid, bleeding, changes in mental status, jaundice), risk prevention (e.g. delirium, malnutrition, falls), and assessment of further symptoms that place additional stress on the patient. In addition to specific signs of the disease, patients may have other symptoms, such as pain, breathlessness, difficulties sleeping, and/or anxiety that should be identified by nurses.³¹ It is important to understand these experiences from the patients' perspective, including their severity, factors that exacerbate or relieve symptoms, and their impact on everyday life.³² Moreover, psychosocial factors should be explored to identify additional needs related to an increased dependency on assistance with personal care, fears about dying, or the cessation of unhealthy choices, among others.²²

The role of specialist nurses in liver diseases

In recent years, nurses with advanced skills in liver diseases have been incorporated into the teams caring for patients with cirrhosis in some countries, usually in large university hospitals. Although their roles may vary between centres, they are mainly focused on outpatients and usually have significant autonomy to deliver care. Moreover, they can support ward nurses with discharge planning, which is a key element of an integrated care model.^{21,33} The job titles and formal education requirements of these nurses differ between countries, but for the purpose of this paper all non-ward nurses who have extended roles in the care of patients with cirrhosis are referred to as advanced practice nurses (APNs). APNs are part of the nursing team, but usually have additional training, in general a master's or PhD degree, that enables them to provide expert care in a specific clinical population.^{7,34} In some countries, such as the UK, there are specialist nurses who have training in a specific area without a master's degree. In some countries, nurses are legally permitted to undertake non-medical prescribing

(sometimes requiring a completion of a formal educational qualification; see below). This enables APNs to start or modify the dose of some of the drugs used in patients with decompensated cirrhosis, particularly diuretics and beta-blockers. Despite limited data, there are studies encouraging the integration of APNs or specialist nurses into care models for patients with cirrhosis. For example, in Australia, case management by specialist nurses with enhanced education resulted in an increased quality of care and improved attendance at outpatient clinics.³⁵ A study from the UK showed that a dedicated nurse-led follow-up had a positive impact on care coordination and quality of life in patients.³⁶ Moreover, data from the US shows that APNs closely working with hepatologists/gastroenterologists improved quality of care and patient outcomes.³⁷ Finally, a study from Italy showed that a multidisciplinary team of physicians, general practitioners, and specialist nurses caring for patients with decompensated cirrhosis discharged from hospital was able not only to reduce readmissions to hospital but also increase survival.³³ These findings highlight the importance of team approaches with APNs or specialist nurses in the management of patients, facilitating effective high-level decision-making and addressing complex needs with appropriate interventions (Table 1). However, data are still scarce, and more studies are needed on optimal healthcare in decompensated cirrhosis.

A summary of nurses' roles in patients with decompensated cirrhosis is provided in Fig. 2.

Differences in nursing roles across countries and their potential impact on the care of patients with liver diseases

Globally, nursing practice is applied differently according to the healthcare funding models, geography, and cultural perspectives of each country.³⁸ Whilst an aging population and diminishing numbers of registered nurses are common factors, the levels and scope of practice, and educational requirements, differ considerably. For example, in the World Health Organization (WHO) European regions only 32.5% (13/40) of countries provide initial nurse education at degree level and 17.5% (7/40) of countries educate nurses exclusively at diploma level.³⁹ The level of nurse education is of the utmost importance because it impacts on the scope of professional practice and 'extended roles' that can be undertaken. The medicalisation of nurses' roles has expanded against the backdrop of a growing population of older patients (many with long-term chronic conditions), increasing health service costs, fewer medical doctors and a need to reduce doctors' working hours.^{3,40} Of 95 countries globally surveyed by the WHO, 53% (50/95) report having nurses who can work in an advanced capacity and undertake activities that are traditionally considered to be medical, such

Table 1. Examples of effective interventions of specialised nurses in the care of patients with advanced cirrhosis.

Nurse intervention	Outcome	Country (reference)
Chronic disease management model	Increased quality of care and better attendance to outpatient clinics	Australia ³⁰
Supportive care of liver nurse specialist	Improved care coordination	UK ³¹
Coordination with hepatologists/gastroenterologists	Improved quality of care, higher rates of screening for varices and HCC, and patients outcomes	USA ³²
Coordinated care with physicians after discharge	Lower readmission rate and improved survival	Italy ²⁴

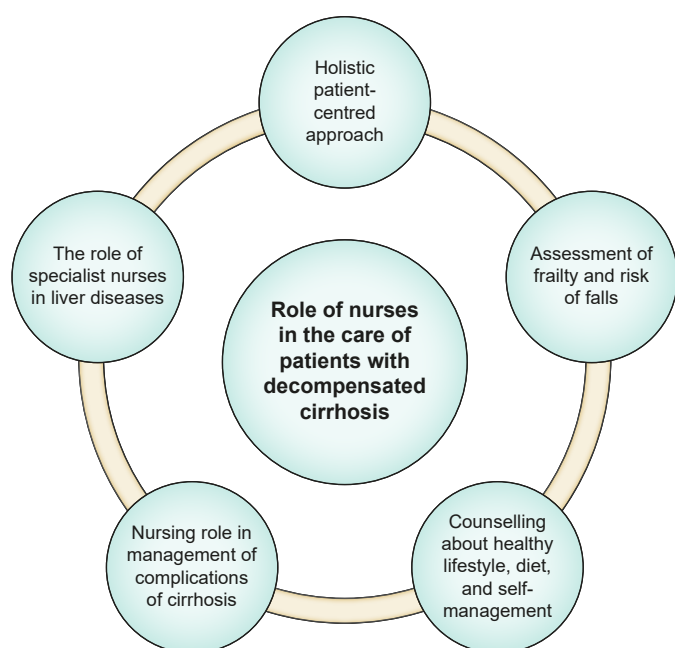


Fig. 2. Roles of nurses in the care of patients with decompensated cirrhosis.

as taking a patient history, making diagnostic decisions, ordering and interpreting blood tests, X-rays, ultrasound scans, prescribing and monitoring long-term progress, and making decisions to admit or discharge patients from hospital.³ This figure falls to just 30% of European countries having access to APNs.³ It is often agreed that access to a master's degree

postgraduate qualification is necessary to underpin nurse-led advanced practice, particularly for a formal APN qualification although less so for specialist nursing activity, but this is not an option in all countries, with 9/40 WHO European member countries not providing this level of education.³ There is ongoing work by the International Council of Nurses to characterise the scope of APNs and specialist nurses in different countries, but the differences in educational requirements and legislative policy continue to hamper progress. However, a review of 39 countries in 2016 identified that 11 had considerable task shifting from physicians to nurses, 16 countries enabled a lesser degree of task shifting, and 12 countries did not permit these roles (Fig. 3).⁴¹ The intention is not for nurses to replace physicians, but to facilitate improvements in the process of care, such as access to protocol-driven interventions in a timely manner, within an interprofessional team. In England, a crucial interprofessional blurring of boundaries occurred in 1992 between nursing and medicine when a legal framework that permits non-medical prescribing was first introduced.⁴² This has expanded globally and as of 2019, 13/39 countries surveyed reported changes to legislation to enable nurses to prescribe; Cyprus, Denmark, Estonia, Finland, France, Ireland, Netherlands, Norway, Poland, Spain, Sweden, Switzerland (only in the Canton Vaud region), and the UK.⁴³

Patients with liver disease in the UK have benefited from these changes to nurses' roles. As an example, nurse-led day case paracentesis services are increasing in the UK.^{43–48} These services reduce hospital admissions and may improve cost-effectiveness of some procedures. There have been no adverse safety events reported and patient experiences are highly favourable. Nurses' extension into the advanced practice



Fig. 3. A map of task shifting from physicians to nurses in the European region. Countries shown in green have enabled significant task shifting, those in yellow moderate task shifting and those in red have not permitted task shifting.

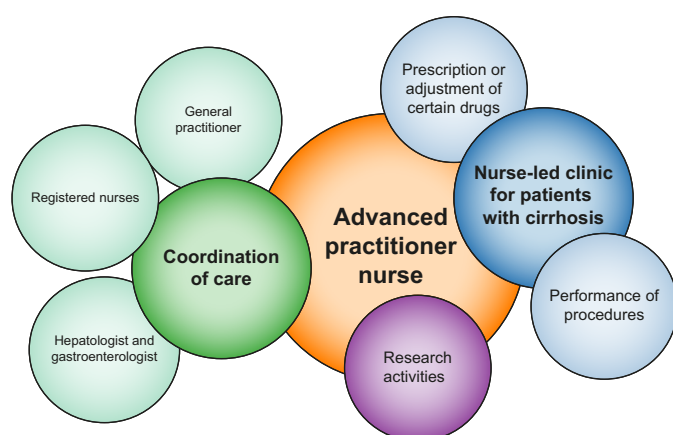


Fig. 4. Roles of advanced practitioner nurses in clinical care.

arena has enabled timely access to interventions and supported the medical profession during the challenges associated with a significant shortage of doctors.⁴⁹

Nevertheless, there is an urgent need for a standardised and improved education programme for nurses globally with respect to the specific care of patients with liver diseases. A coordinated effort is needed between scientific societies, universities, and national healthcare systems to set up specific programmes of education for nurses in the care of liver diseases. While waiting for a global standardisation of nursing studies, which will be difficult to achieve and will take time, scientific societies, particularly hepatology and digestive disease societies, in coordination with nursing societies, may play an important role in setting up specific programmes for education of nurses in liver diseases. Potential roles of an APN or specialist nurse in the care of patients with cirrhosis are summarised in Fig. 4. We propose that nurses specialised in the management of cirrhosis should be present in hospitals treating a significant volume of patients with decompensated cirrhosis.

Other potential roles of nurses in liver diseases

Recent evidence indicates that chronic liver diseases can be diagnosed early during the process of chronic liver inflammation and fibrosis development.⁹ This period is asymptomatic and usually very long, more than 20 years on average. Therefore, the early stages of disease provide a long diagnostic window. One strategy that has been proposed consists of using non-invasive markers of liver fibrosis in individuals with risk factors for liver diseases, such as increased alcohol con-

sumption, diabetes mellitus, obesity, or other factors related to metabolic syndrome.⁵⁰ Some of the non-invasive markers for liver fibrosis include serological scores such as FIB-4, APRI, or NAFLD fibrosis score.⁵¹ Other non-invasive tools with higher accuracy, such as transient elastography, can also be used but, unfortunately, they are uncommonly available, particularly in primary care.⁵² The existence of nurse-led chronic care clinics either in hospital care or in primary care provides a unique opportunity to identify individuals with risk factors for chronic liver diseases and to assess non-invasive serologic markers of fibrosis in these higher risk individuals. A population of particular interest is patients with type 2 diabetes, due to the high frequency of liver fibrosis/cirrhosis in this population.⁵³ Primary care nurses could identify individuals with risk factors for chronic liver diseases and recognise those with high likelihood of liver fibrosis, referring them for specialised care and providing counselling to improve lifestyle factors and reduce risk factors for liver disease.

Conclusions and future directions

In conclusion, a greater involvement of nurses in the care of patients with cirrhosis is needed, both in hospital and primary care. In the hospital setting, nurses should play a key role not only in the care of patients admitted with acute complications of cirrhosis but also as APNs or specialist nurses in the coordination of care between hospital and primary care; moreover, nurses should also be part of interprofessional teams, including physicians, nutritionists, psychologists, physical therapists, and social workers, to improve the quality of care of patients with decompensated cirrhosis, to prevent frequent readmissions and to improve outcomes. In primary care, nurses should participate in the care of patients with compensated cirrhosis by providing educational counselling to patients and caregivers, improving self-management, screening for varices and HCC, assessing and updating pharmacotherapy and immunisations, and treating the aetiological factor(s) of cirrhosis; furthermore, nurses should also play a role in identifying patients with early hidden fibrosis or cirrhosis to help guide lifestyle modifications. Finally, important efforts should be made to increase research on the nursing care of liver diseases in general, and specifically in cirrhosis. Nursing research is particularly relevant to improve the level of care in areas that are not covered by standard medical research. All these potential roles for nursing care will require important educational activities and increased awareness of the importance of cirrhosis among nurses, but also other healthcare providers and policymakers.

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Abbreviations

APNs, advanced practice nurses; APRI, aspartate aminotransferase-to-platelet ratio index; FIB-4, fibrosis-4 index; HCC, hepatocellular carcinoma; WHO, World Health Organization.

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Conflicts of interest

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Please refer to the accompanying ICMJE disclosure forms for further details.

Authors' contributions

NF, PKH, AO, KJ and MC all participated to the conception and design. All the authors contributed to drafting the article and revising it critically for important intellectual content and gave the final approval of the version to be published.

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Supplementary data

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