

Hepatitis medical care coordinators: Comprehensive and seamless support for patients with hepatitis

Hiroshi Isoda^{1,*}, Yuichiro Eguchi^{1,2}, Hirokazu Takahashi¹

¹Liver Center, Saga University Hospital, Saga, Japan;

²Loco Medical General Institute, Ogi, Saga, Japan.

Abstract: Chronic liver disease, especially viral hepatitis, is an urgent issue in Japan. Human resource management is important to promote appropriate care for patients with chronic liver disease in medical institutions and in the community. In 2011 the Ministry of Health, Labour and Welfare in Japan started training hepatitis medical care coordinators (HMCCs). Various medical professionals (such as public health nurses, general nurses, and clinical technicians), patients, and ordinary citizens are certified as HMCCs by the prefectural government after learning about liver diseases in a training program. The training program can be optimized in accordance with the regional circumstances and basic knowledge and skills of the applicants. HMCCs encourage residents and patients to undergo a hepatitis screening test, after which positive patients undergo detailed examination, treatment, and follow-up. HMCCs contribute to the expansion of knowledge about hepatitis in their workplace and community. By 2018, there were HMCCs in all 47 prefectures of Japan. There were 20,049 HMCCs in 2019. The most common professions of HMCCs were public health nurses, followed by general nurses, hospital pharmacists, laboratory technicians, and medical social workers. After certification, the activities of HMCCs vary; to ensure that HMCCs are adequately used in medical institutions, the supervisor and physicians must recognize the importance of HMCCs and generate opportunities for HMCC activity. The training and effective utilization of HMCCs is a promising way to decrease the prevalence and mortality of chronic liver diseases in Japan.

Keywords: hepatitis, coordinators, chronic liver disease, screening, treatment, follow-up

Introduction

The national survey of Japanese citizens conducted by the Ministry of Health, Labour and Welfare (MHLW) in 2011 revealed that approximately 50% of Japanese citizens had been screened for viral hepatitis (1). According to research supported by the Health and Labour Sciences Research Grant, the number of Japanese people who underwent detailed examination at a medical institution from 2014-2016 following a positive result in a screening test for viral hepatitis was estimated to be 0.53 to 1.2 million (2).

In 2009, the MHLW published the Basic Act based on Hepatitis Measures as a national action plan for addressing viral hepatitis. The Basic Guidelines on Hepatitis Measures was then issued in 2011 and revised in 2016. All measures and policies against hepatitis reflect these guidelines, which aim to reduce the number of patients with progression to cirrhosis and liver cancer. The guidelines recommend the spread of basic knowledge about hepatitis among the general population and relevant professionals, and promotion of screening tests for viral hepatitis, detailed examination after screening and

continuing appropriate treatment. The guidelines state that it is important for individuals with positive hepatitis screening test results at regional medical health check-ups and medical institutions to receive appropriate information and referral to a hepatologist for further detailed examination and treatment.

Along with these comprehensive measures and guidelines against hepatitis, there is a need for human resource personnel who support the decision-making and actions of the general population and hepatitis virus-positive population. Nationwide training of such human resource personnel started in 2009, and the training of hepatitis medical care coordinators (HMCCs) was promoted under a MHLW project from 2011. The revised Basic Guidelines issued in 2016 defined fundamental roles of HMCCs as: spreading awareness of hepatitis in their community or workplace, encouraging people to get screened for hepatitis, and following up with people who receive a positive hepatitis screening result (3-6). The name "hepatitis medical care coordinator" was proposed by the MHLW. The word "coordinator" was used in the name because the expected role of HMCCs includes collaboration with medical institutions, government

agencies, and other relevant parties in the community and workplace. The director of the Health Services Bureau (HSB) of the MHLW issued a notification stating that training of HMCCs should be promoted in a nationwide effort as part of a plan to implement measures to support patients with hepatitis (7). Various medical professionals, patients and citizens are eligible to be HMCCs. The training course consists of an education program about hepatitis, hepatitis management, and public medical services.

Yamanashi Prefecture used to have the highest mortality rate for liver cancer in Japan. In 2009, the Yamanashi prefectural government started training human resource personnel referred to as "liver disease coordinators" who contributed to a prefectural primary measure to decrease the regional mortality rate. A total of 23 liver disease coordinators were certificated in the first round of the training program. The liver disease coordinators of Yamanashi Prefecture were later recognized as performing unique and important activity that fits the national measures against hepatitis, and this inspired similar training programs of HMCCs in other prefectures across Japan.

Chapter 5 of the revised Basic Guidelines on Hepatitis Measures asked individual prefectures to follow the basic roles of HMCCs as defined in the Guidelines (5). Subsequently, a document compiling recommendations for the training and utilization of HMCCs was drafted at the 19th annual meeting of the Council for Promotion of Hepatitis Measures organized by the MHLW. This document was called the "Notification Regarding Training and Utilization of Hepatitis Medical Care Coordinators" and was issued to prefectural governments by the director of the HSB of the MHLW on April 25, 2017 (MHLW HSB Notification No. 0425-4) (7). This document also defined the roles and activities of HMCCs, which should be flexibly optimized to fit the regional circumstances regarding hepatitis care. This optimization should reflect feedback from stakeholders such as municipal government officials, healthcare professionals at regional core centers for liver disease care and other institutions, and patients with hepatitis; even the name "HMCCs" can be modified. Moreover, the training program and contents can be optimized depending on the placement and occupation of the HMCCs. Each individual prefecture should update the roles, activities, and training of HMCCs in accordance with the changes in the regional measures against hepatitis. By 2018, HMCCs were available in all 47 prefectures of Japan. This review summarizes the current state and issues of HMCCs and discusses further utilization of HMCCs based on related documents, measures, literature and survey results.

Role of HMCCs as coordinators

Role of HMCCs in the community

The constitutive network of professionals such as primary care physicians, public health nurses and medical workers in the community and workplace is important to promote screening for hepatitis, detailed examination after screening, and treatment with appropriate antiviral therapy. The primary role of HMCCs involves direct engagement with residents and patients with hepatitis in the community. HMCCs working at medical institutions are also expected to collaborate with those working at government agencies. The extensive engagement of HMCCs across communities and workplaces is effective in increasing public understanding of hepatitis and is expected to reduce the discrimination and prejudice against patients with hepatitis that impedes the smooth transition through screening, detailed examination after screening, treatment, and follow-up.

Role of HMCCs for individuals

The most important role of HMCCs is to support patients with hepatitis and their family members to promote a seamless transition through the four stages of measures against hepatitis (screening, detailed examination, treatment, and follow-up). Depending on the placement and profession of the HMCC, the roles of HMCCs are divided into: *i*) offering advice to patients with hepatitis and their family members through counseling, *ii*) referring people to government agencies and regional core centers for liver disease care, *iii*) encouraging people to undergo a screening test for viral hepatitis, *iv*) encouraging people with positive screening test results to undergo detailed examination at a specialized medical institution, and *v*) providing information about medical expenses and other relevant programs (Figure 1). HMCCs activities engage medical workers such as public health nurses, general nurses, pharmacists, clinical technicians and nutritionists, medical administrators, general citizens, and patients with hepatitis. Therefore, the activities of HMCCs vary depending on their site of placement in a medical institution or screening organization, public health center or municipal government agency, or health service section in a private company or health insurance company. Recruiting people with various professions and backgrounds as HMCCs contributes to covering the entire activity and concept of HMCCs. Table 1 shows the roles of HMCCs as suggested by the MHLW.

The activity of HMCCs is basically voluntary work in addition to or concurrent with their original job tasks in the medical profession. HMCCs expertly support people and patients affected by hepatitis. Legal compliance related to the background quantification and workplace should be maintained throughout any HMCC activity. Private information should be protected in accordance with the relevant laws.

Training and education of HMCCs

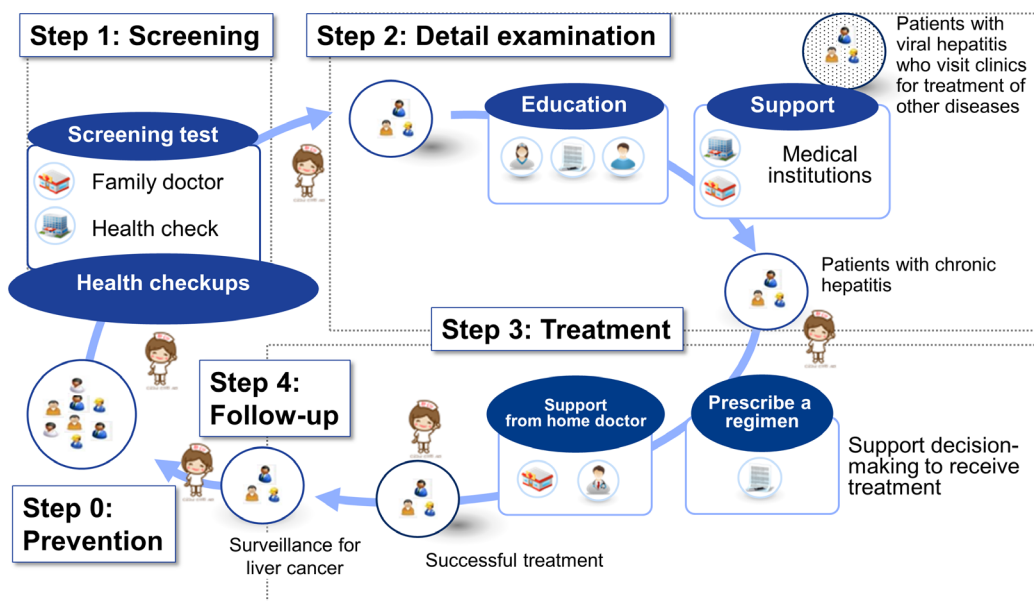


Figure 1. Hepatitis medical care coordinators (HMCCs) activity at each step of hepatitis care. HMCCs promote hepatitis screening tests (step 1), detailed examination (step 2), treatment (step 3), and follow-up after treatment. HMCCs also promote the prevention of liver disease and hepatitis virus infection (step 0).

Training of HMCCs

Prefectural governments are primarily responsible for the training of HMCCs. Training seminars and qualification examinations are organized in collaboration with the regional core center. Individuals are certified as HMCCs and registered on the official list. Although the eligibility requirements for HMCCs vary among prefectures, several prefectures do not require HMCCs to be qualified experienced medical workers. The common topics included in the HMCC training program are described in Table 2. The contents of the program are designed to be flexible and to be optimized in accordance with the regional circumstances and differences in the baseline knowledge and experiences of applicants. The program may also include upcoming topics that might be associated with the roles of HMCCs in the future.

Certification of HMCCs

Most prefectures issue HMCC certificates signed by the prefectural governor or the director of the government department responsible for measures against hepatitis. An increasing number of prefectures also issue a badge that is worn on the professional uniform to identify the wearer as a HMCC. Recently, several prefectures have begun to require periodical renewal of HMCC certification, and provide advanced programs for further learning (8). Several prefectures ask the institutions where HMCCs work to submit periodic reports about HMCC activities.

Continuous education of HMCCs

Following changes in hepatitis care such as drug development and amendment of measures, it is important for HMCCs to update their knowledge. Opportunities for HMCCs to learn the newest information should be provided. Sharing the experiences of HMCC activities, especially successful activities, encourages HMCCs and increases their motivation. Interdisciplinary collaboration among HMCCs and other professionals will extend the possibility of HMCC activities. Joining patient group meetings provides different viewpoints and thoughts of patients with hepatitis and their family members. Prefectures and regional core centers organize various lectures, meetings, and educational events for HMCCs. In many prefectures, these opportunities are available and open to all people involved in hepatitis care.

Activation of HMCC activity

Several prefectures do not track the activity of HMCCs after their certification. Our questionnaire-based self-evaluation survey found that approximately 60% to 70% of HMCCs were underutilized (9). Prefectures and regional core centers for liver disease care need to establish an implementation strategy for the better utilization of HMCCs. Possible approaches to increase the utilization of HMCCs include *i*) increasing the awareness of HMCCs and their activities among the general public and patients with hepatitis, *ii*) making the list of organizations with HMCCs available to the general public and patients with hepatitis, *iii*) creating badges or other items to identify HMCCs, *iv*) encouraging collaboration with other medical institutions and groups (including patient groups) to identify potential opportunities for HMCC activity,

Table 1. Roles of hepatitis medical care coordinators (HMCCs)

Segment	1) Regional core centers, medical institutions, and screening organizations	2) Public health centers and municipal government offices	3) Private companies or health insurers	4) Other organizations
Basic roles	Provide information, counseling, and support regarding health and lifestyle, and carry out follow-up to ensure that patients with hepatitis and people who test positive for hepatitis receive appropriate medical care; coordinate the collaboration between government agencies and workplaces to provide appropriate information and opportunities for patients with hepatitis.	Raise public awareness and disseminate information about all aspects of hepatitis prevention; coordinate with regional core centers and other related community organizations and occupational health-focused organizations to promote screening, detailed examination after screening, treatment, and follow-up through their agencies.	Promote hepatitis screening in the workplace and strive to create a work environment that allows patients with hepatitis to continue working comfortably as they undergo treatment.	Raise public awareness in their local community, serve as a source of advice for patients with hepatitis and their family members, and link patients to medical institutions and government agencies.
Specific examples of the job description	<ul style="list-style-type: none"> ✓ Explain information related to hepatitis care and direct people to hepatitis screening services ✓ Encourage people who screen positive for hepatitis to undergo detailed examination, and refer them to a specialized medical institution ✓ Explain the importance of continuing follow-up examinations (such as blood tests including tumor markers and ultrasonography) after antiviral therapy ✓ Offer lifestyle advice and guidance on medication use and nutrition to patients with hepatitis and their family members ✓ Explain public subsidy programs for regular testing expenses or medical expenses and the disability certificate program, or assistance from the appropriate government agency ✓ Direct people to resources for assistance with settlements from class-action lawsuits regarding hepatitis C and B ✓ Direct people to resources for assistance with working or parenting while receiving hepatitis treatment ✓ Organize workshops for medical institution staff 	<ul style="list-style-type: none"> ✓ Explain basic information about hepatitis and encourage people to undergo screening for hepatitis ✓ Refer people to medical institutions or organizations where they can be screened for hepatitis ✓ Refer people to regional core centers for liver disease care, consultation and support centers for liver disease, and specialized medical institutions ✓ Encourage people who screen positive for hepatitis to undergo detailed examination ✓ Direct people to follow-up programs run by the national government, or carry out independent follow-up (in the case of some prefectural governments) ✓ Direct people to subsidy programs to cover regular testing expenses or medical expenses and the disability certificate program ✓ Explain and direct people to programs for periodic immunization against hepatitis B and conduct outreach and educational programs to inform people about infection prevention ✓ Direct people to resources for assistance with settlements from lawsuits regarding hepatitis C and B ✓ Direct people to resources for assistance with working or parenting while receiving hepatitis treatment ✓ Participate in public awareness events in the community or workplaces and direct people to those events 	<ul style="list-style-type: none"> ✓ Provide information about hepatitis to business owners, management, and human resource departments ✓ Raise awareness among employees of the basic facts about hepatitis ✓ Direct people to hepatitis virus testing services and counseling resources ✓ Offer advice on how to continue working while receiving hepatitis treatment and accommodate patients in the workplace (e.g., direct them to counseling resources) ✓ Refer people to support and counseling services such as consultation and support centers for liver disease at regional core centers for liver disease care ✓ Explain subsidy programs to cover regular testing expenses or medical expenses and the disability certificate program, or direct people to resources for assistance from the appropriate government agency ✓ Participate in public awareness events in the community or workplace and direct people to those events 	<ul style="list-style-type: none"> ✓ Raise awareness among community members and facility residents of the basic facts about hepatitis ✓ Direct people to hepatitis testing ✓ Direct people to information sources about hepatitis and to the nearest consultation and support center for liver disease ✓ Participate in public awareness events in the community or workplace and direct people to those events

Possible occupation and background of a HMCC in each segment: 1) Medical professionals such as doctors, nurses, pharmacists, registered dietitians, clinical technicians, medical social workers, and other staff at medical institutions. 2) Public health nurses, public health professionals, and government agency staff. 3) Occupational health managers, human resource and labor relations managers, and labor and social security attorneys. 4) Patient advocacy group members, employees of pharmacies, welfare offices, or nursing care offices, and community association members.

Table 2. Topics commonly included in the hepatitis medical care coordinator (HMCC) training program

i) Expected roles and outlook of HMCCs	<ul style="list-style-type: none"> √ Learn to be cautious in giving information and advice to patients with hepatitis and people who test positive for hepatitis, and to be conscious of their role in linking these individuals to relevant institutions. √ Understand the general picture of prefectural goals for measures against hepatitis and the flow of screening, detailed examination after screening, treatment, and testing in their prefecture and understand their role and methods for coordination as determined by their site of placement or their profession. Ministry of Health, Labour and Welfare notifications state that it is important for local governments, medical institutions, and hepatologists in leadership roles to make concessions and ensure that HMCCs feel fulfilled in their work. These concessions were put into a guidebook and distributed to prefectures and regional core centers for liver disease care across Japan as part of a project funded by a Health and Labour Sciences Research Grant (9). √ Understand the feelings of patients, develop a compassionate mindset, and learn techniques for compassionate engagement. Understand how to protect patients' rights, prevent discrimination and bias, and handle personal information. Several prefectures organize opportunities for trainees to hear directly from patients and their family members during HMCC training.
ii) Basic knowledge of liver diseases	<ul style="list-style-type: none"> √ Have basic knowledge of topics such as infection prevention, pathology, testing (<i>e.g.</i>, perspectives on hepatitis testing and liver function testing), and treatment related to hepatitis B, hepatitis C, nonalcoholic steatohepatitis, cirrhosis, and liver cancer. Encourage people who screen positive for hepatitis to receive detailed examination and refer them to a specialized medical institution.
iii) Knowledge of local circumstances and public programs	<ul style="list-style-type: none"> √ Understand the epidemiology of liver disease in their prefecture, regional characteristics and challenges, and plans and targets for prefectural measures against hepatitis. √ Be familiar with periodic immunization schedules against hepatitis B, hepatitis screening programs in their prefecture or city, public subsidy programs for medical expenses associated with further testing after an initial diagnosis of hepatitis infection and periodic testing for hepatitis, and counseling services under the Act on Special Measures Concerning Hepatitis B and the Act on Special Measures Concerning Hepatitis C. √ Provide basic information about the High-Cost Medical Expense Benefit, policies to support people with disabilities, and social programs to support working while receiving treatment (<i>e.g.</i>, programs that allow patients to take time off, take a leave of absence from work, or to work reduced hours) and provide the contact information of places that offer counseling on these matters.
iv) Regional systems for the coordination of liver disease care	<ul style="list-style-type: none"> √ Know the roles and availability of regional core centers for liver disease care (liver disease counseling and support centers), specialized medical institutions, and hepatologists in their prefecture, and develop a system for coordination between primary care physicians and these institutions.
v) Specific tasks	<ul style="list-style-type: none"> √ Have knowledge of effective methods for encouraging hepatitis screening and detailed examination, methods for counseling and supporting patients with hepatitis and their family members, specific approaches for hosting educational sessions on liver diseases, patient support groups, and high-level case studies. √ New HMCCs are expected to acquire skills that enable them to respond flexibly to meet various needs in the field by learning from case studies of real-world challenges encountered by experienced HMCCs.

v) promoting understanding of HMCC activity by hepatologists and providing an environment where HMCCs can work effectively, and vi) asking the administrators of individual institutions to support the activities of HMCCs (9). The Hepatitis Information Center shares case studies about HMCC initiatives and methods to support HMCCs (10).

Maximization of the advantages based on the professional backgrounds of HMCCs

HMCCs can be placed at regional core centers for liver disease care, specialized medical institutions that employ hepatologists, other general medical institutions, public health centers and municipal government offices, screening organizations, pharmacies, disability welfare and nursing care offices, private companies and organizations, health insurers, patient groups, and others. To promote referral to hepatitis specialists when needed, it is important that HMCCs are placed at general clinics without a hepatologist (*e.g.*, ophthalmology clinics, orthopedic surgeries, and obstetric clinics) that

commonly perform screening for viral hepatitis, as well as at specialized medical institutions with hepatologists that provide hepatitis treatment. Patients with hepatitis and their family members can become HMCCs and can offer support based on their own personal experience as a person affected by hepatitis. Engagement of HMCCs across local communities and workplaces is expected to reduce discrimination and bias against patients with hepatitis and to increase public understanding of hepatitis. It is important that an individual coordinator does not have to take on all roles, but rather utilizes the advantages of their field and collaborates with others to promote appropriate hepatitis care. In accordance with the regional implementation of measures against hepatitis (8), many prefectures have a defined policy for HMCC placement and have specific targets for the number of HMCCs and the number of medical institutions with HMCCs.

Current HMCCs in Japan

By 2018, there were HMCCs in all 47 prefectures of

Japan. There were 20,049 HMCCs in 2019 (Figure 2) (11). According to a survey by the Hepatitis Information Center, more than 3,800 HMCCs were trained at 50 of the 71 regional core centers (12). In Hiroshima Prefecture and Saga Prefecture, more than 1,000 HMCCs were trained by 2017 (13). In 2018, the most common professions of HMCCs were general nurses and were available in 46 prefectures (98%), followed by

public health nurses (45 prefectures, 96%), laboratory technicians (38 prefectures, 81%), hospital pharmacists (37 prefectures, 79%), and medical social workers (36 prefectures, 77%) (Figure 3) (14). Enomoto *et al.* conducted a questionnaire survey about the placement and degree of activity of HMCCs at 17 regional core centers in 2019 (15). The total number of HMCCs was 480, and the number of HMCCs at each center

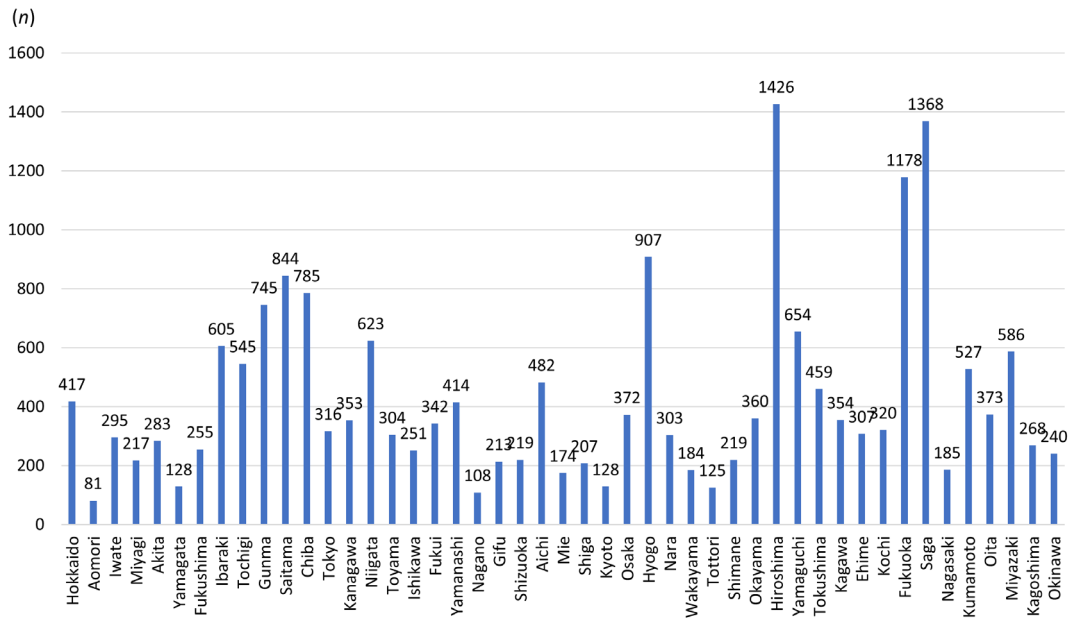


Figure 2. Number of hepatitis medical care coordinators (HMCCs) in Japan. In 2019, there were a total of 20,049 HMCCs in 47 prefectures. All prefectures had started training HMCCs by 2018.

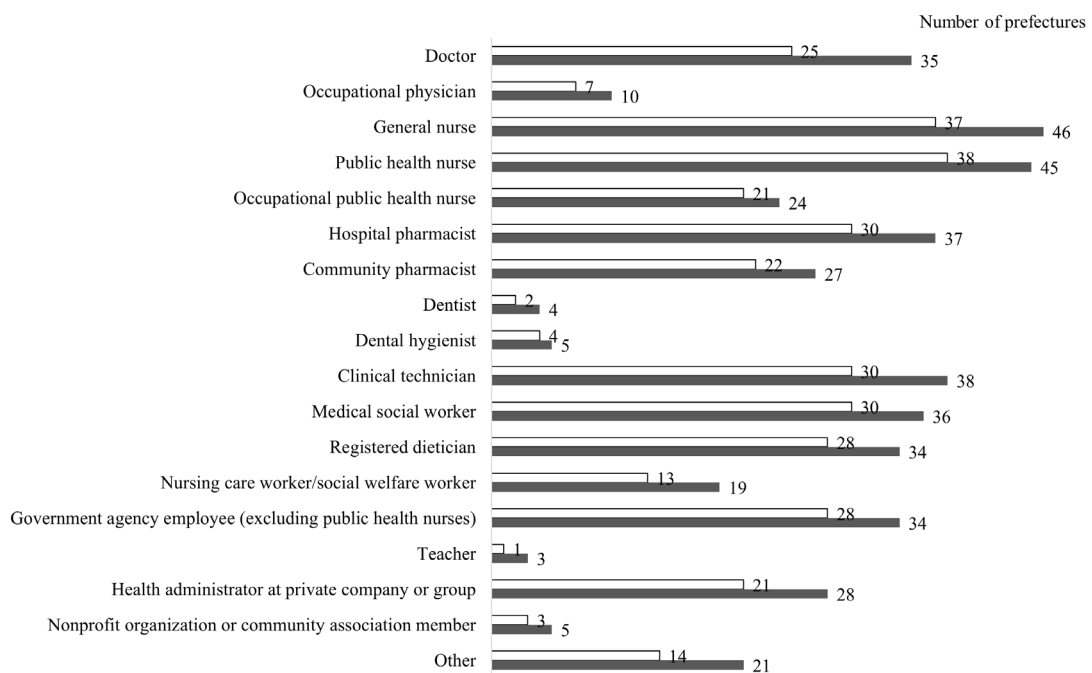


Figure 3. Professions of hepatitis medical care coordinators (HMCCs). The bar graph shows the number of prefectures that trained people from individual professions as HMCCs. The open bars and gray bars represent the number of prefectures in 2017 and 2018, respectively.

varied from eight to 77. The overall mean percentage of active HMCCs in all facilities was 78% (374/480), and this varied from 7.9 to 100% among the facilities. The most common occupations of the HMCCs were nurses (50%), followed by clinical laboratory technicians (11%), pharmacists (8.0%), nutritionists (8.0%), and doctors (3.5%); 29.3% of the nurses were assigned to the department in charge of liver disease.

Challenges in HMCC work

The current state of HMCC activity and issues were surveyed by qualitative interviews with HMCCs, working supervisors and colleagues of HMCCs in 2018 (12). A total of 124 healthcare professionals were interviewed and various issues were recognized. We then conducted a quantitative self-evaluation survey in all 47 prefectures. HMCCs were divided into four segments in accordance with their degree of activity as a HMCC and degree of self-awareness as a HMCC. Regardless of the self-awareness as a HMCC, HMCCs with professions and backgrounds showed high activity levels. We generated a movie of their activities (16) and compiled the important points into a reference book (17). The survey also revealed several issues regarding underutilization in the segments with low activity caused by no opportunity for HMCC activity, not knowing what they can do as an HMCC, not having the knowledge and methods for HMCC activity, and being denied permission for HMCC activity by the institution. The degree of activity tended to be low when the HMCC activity was not recognized by the prefectural government, supervisor, and physicians. In contrast, active HMCCs were well recognized and appreciated by supervisors, hepatologists, and patients in their institutions, and were given further opportunities for HMCC activity. These results suggest that recognition of HMCCs by others is associated with increasing activity of HMCCs. Our research group created leaflets for each prefecture to help supervisors and patients understand the importance of HMCC activity (18).

Overseas expansion of HMCCs

Similar to Japan, Mongolia has a high mortality rate of liver cancer, and the major etiology of liver cancer is chronic hepatitis C (19,20). It is estimated that 52,500 patients need anti-hepatitis C therapy (21). The total number of medical workers in Mongolia is insufficient, and the individual medical workers have inadequate knowledge about hepatitis C (22). Therefore, there is a need for an awareness program for patients with hepatitis and an educational program for medical workers. Since 2016, we have been exchanging opinions and information about viral hepatitis with the members of the Ministry of Health in Mongolia. In December 2018, we educated 150 medical workers as the first HMCCs in

Tuv province, Mongolia. The HMCCs training program was officially supported by the Mongolian government. To our knowledge, there is no similar human resource development program like the HMCCs training program supported by government in other countries except in Japan and Mongolia. Further training sessions were scheduled in other provinces of Mongolia in 2020. However, it was postponed due to the recent COVID-19 pandemic. We are planning to support the Mongolian HMCCs training activity on the web. Overseas expansion of the Japanese HMCC training program will contribute to improve the hepatitis care system and decrease the mortality rate of liver cancer in Mongolia and other countries.

Conclusion

There have been marked developments in the diagnosis and treatment of viral hepatitis, cirrhosis, and liver cancer. In accordance with the World Health Organization's target of hepatitis C elimination by 2030 (23), there has been a worldwide expansion of hepatitis screening tests and encouragement of patients with positive results to undergo treatment. The training and effective utilization of HMCCs in Japan is a promising way to decrease the prevalence and mortality of liver disease.

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- *Address correspondence to:
 Hiroshi Isoda, Liver Center, Saga University Hospital, 5-1-1 Nabeshima Saga, Japan
 E-mail: e6140@cc.saga-u.ac.jp