

Needs assessment of people with viral hepatitis – China

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CEVHAP

Coalition to Eradicate Viral Hepatitis in Asia Pacific



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It is not the disease that is scary;
it's the response that is scary.

(Guangzhou 4)



Executive Summary

Viral hepatitis is a significant health issue for China with an increasing social and health burden related to the infections. For people with hepatitis B and hepatitis C, the impact of the infection is not only physical, but has significant social and economic implications, which for some participants were of greater importance and priority than the clinical manifestations.

● People with viral hepatitis reported:

- A variety of processes in which they were tested and diagnosed with hepatitis, with most participants diagnosed through educational institutions or workplaces rather than by health services. This essentially affects how and why people are tested, and how they respond to the infection. The primary rationale for testing was not for the benefit of the person tested, and few of the testing procedures reflected a systematic and effective process in which the individual or social consequences of the infection could be reduced.
- Few participants reported being provided with accurate information about viral hepatitis when they were diagnosed, and several reported significant misunderstandings about the virus. These misunderstandings ranged across the natural history of the infection, from how people assumed they were infected through to understanding viral hepatitis health promotion interventions, and information about clinical management including treatment options.
- Hepatitis B infection in China occurs within a familial context in which hepatitis has often had a significant intergenerational impact. This impact is reflected in sometimes several family members being infected, or having died as a result of hepatitis related liver disease, and with some families having extensive experience in relation to living with, and reducing the harm associated with viral hepatitis.
- The economic impact of being diagnosed, particularly with hepatitis B was often catastrophic for people and their families. There were several reasons for this including:
 - ▼ The diagnosis of one person in the family often led to the diagnosis of several others in the family, requiring clinical management, and sometimes pharmaceutical treatment, of numerous members of the one family. This occurs within a context of limited economic opportunities and inadequate treatment reimbursement.
 - ▼ The lack of specialist clinical services in rural areas meant that several participants relocated to cities where clinical specialists were available.
 - ▼ The lack of adequate reimbursement for effective pharmaceutical treatments.
 - ▼ Several of the participants were the only children of parents living in lower social economic rural areas. There were significant sacrifices made by these parents in ensuring their children were educated. The diagnosis of viral hepatitis within this context was devastating for both individuals and their families.

- While regulations reducing access to a broad range of education and employment opportunities for people with viral hepatitis were repealed in 2009, discrimination and stigma still affected the everyday life of many of the participants. This stigma is exacerbated in a context where there is a lack of, or inaccurate, knowledge about the infections among the general community, and where medical services lack appropriate regulation and provide alarmist information about viral hepatitis including advertising unproven cures.
- In spite of the economic impact and the variable knowledge of people with hepatitis about the virus, most of the people with hepatitis B were being regularly monitored for their infection. While just under half of the participants were recruited through clinical settings, most of the other participants were also being monitored with some regularity. All of the participants with hepatitis C were recruited through clinical services, and had been hospitalised as a result of the infection or treatment related issues.
- Decisions about the use and choice of pharmaceutical treatment for viral hepatitis are largely dictated by economic rather than clinical circumstances. This meant that many of the participants with hepatitis B were using, or had used, sub-optimal treatments where viral resistance can have a critical impact. None of the people with hepatitis C mentioned the use of direct acting antivirals as a treatment option.
- While there is a significant amount of literature describing the clinical and epidemiological impact of hepatitis B, and to a lesser degree of hepatitis C, there is limited research describing the lived impact of the infections including the social consequences and policy implications of the infection.

Reducing the individual, social and health burden of viral hepatitis in China will require a range of interventions including:

- The broadening of government policy, which currently largely focuses on reducing the transmission of hepatitis B, to include addressing issues related to chronic hepatitis B and hepatitis C infection. Given the significant social implications of the virus, primarily resulting from regulations that sought to reduce the access for people with viral hepatitis to a broad range of education and employment opportunities, this policy will need to include the development of partnerships across government ministries, clinical services, non-government organisations, researchers, and importantly people with viral hepatitis.
- The unsystematic nature of testing and diagnosis of viral hepatitis and liver disease in China and the broad range of non-health related agencies conducting this screening has resulted in people being diagnosed without the systematic provision of effective education or support about their infection. The development and implementation of nationally standardised testing protocols will assist in reducing the burden of viral hepatitis by ensuring that people with the infection are aware of their clinical and social options resulting from the infection.
- There is a need for accurate, accessible and useful information for people with viral hepatitis. While this needs to include information about the natural history of the infection, it also needs to address transmission, disclosure, family relationships, clinical management access, the impact and expectation of Traditional Chinese Medicine and folk remedies, health promoting information, employment and educational access, and other aspects of living with the infection.





*Xiao Shan gets her
one year old son, Cha
Li, ready for his final
hepatitis B vaccination.
Shaanxi, China*

- The cost of pharmaceutical treatment, both for people with viral hepatitis but also their families is an essential barrier to its access. Reducing the economic barriers to treatment will improve access. Several participants in the assessment indicated that they relocated as a result of having viral hepatitis to access specialist clinical services. This issue needs to be addressed with the development of effective models of care that can be instituted outside of tier one cities and in rural areas.
- While repealing discriminatory regulations affecting people with viral hepatitis is a vital step in reducing the stigma associated with viral hepatitis, it needs to be supported with interventions to reduce discriminatory activity from educational and workforce institutions. These interventions could include public awareness campaigns where hepatitis is framed as a chronic condition requiring regular monitoring. The prevalence of viral hepatitis within the Chinese community as whole can provide the rationale for ensuring that learning about the infection occurs within a broad range of educational settings.

Background

Rationale

Viral hepatitis has been described by the World Health Organization (WHO) and the United States Department of Health & Human Services as a “silent epidemic”.⁽¹⁻³⁾ With an increasing burden related to the infections, the asymptomatic nature of the infections, and the lack of a comprehensive public policy response to viral hepatitis ensures that the mortality and morbidity related to these infections will continue to grow.

It is estimated that up to 150 million people in China are infected with chronic viral hepatitis - 93 million people with chronic hepatitis B⁽⁴⁾ and between 13 and 44 million people with hepatitis C. ⁽⁵⁻⁸⁾ Reducing the global impact of viral hepatitis requires reducing the burden of infection in China. One-third of the global population infected with chronic hepatitis B live in China, with around 300,000 people dying each year from hepatitis B-related complications, including liver cancer and cirrhosis.⁽⁹⁾ China has the highest number of new cases of liver cancer as a result of hepatitis B and around 55% of global liver cancer deaths occur in China.^(10, 11)

Deaths among people with chronic hepatitis B and the number of cases of hepatitis B-related liver cancer are rising despite improvements in antiviral therapy. ⁽¹²⁾ Hepatitis B virus is difficult to eradicate and while treatments are increasingly able to control replication of the virus and reduce liver disease

progression, only a small proportion of people with chronic hepatitis B receive treatment.⁽¹³⁾ The Chinese government has made a significant impact in reducing new cases of chronic hepatitis B through the implementation of an expanded vaccination program,⁽¹⁴⁻¹⁶⁾ but the burden of mortality related to hepatitis C continues to increase.⁽¹⁷⁾

Increasing hepatitis C incidence has recently led the Chinese government to declare hepatitis C an urgent public health issue with the infection recognised as playing an important role in the development of liver cancer. The modes of transmission for hepatitis C in China differ significantly from that of hepatitis B with the blood supply and inadequate infection control within health care settings playing a significant role in the transmission of hepatitis C, particularly for people living in rural areas.

A significant gap in research supporting the development and implementation of effective interventions to reduce the burden of chronic viral hepatitis in China is the systematic documentation of how people with chronic viral hepatitis experience and respond to their infection. This type of investigation uncovers a perspective that provides the policy and health workforce with evidence of systemic gaps and barriers that are often invisible in more clinical or epidemiological research. The identification of these gaps can then form the basis for the development of relevant interventions to address the needs identified by people with chronic viral hepatitis.



Methodology

A needs assessment is a “systematic process to acquire an accurate, thorough picture of a system’s strengths and weaknesses, in order to improve it and meet existing and future challenges.” Several of the investigators for this Needs Assessment were involved in the development of the Australian National Hepatitis B Needs Assessment which was the first systematic research describing the lived experience of people with hepatitis B and was instrumental in raising the profile of hepatitis B with federal and state/territory governments in Australia. The study supported significant policy change within government and non-government agencies throughout Australia, including the development of the first national strategic response to address chronic hepatitis B. Given the Australian experience of the needs assessment, China-based clinical specialists sought the support of the Coalition to Eradicate Viral Hepatitis in Asia Pacific to develop a Chinese needs assessment of people with viral hepatitis.

This needs assessment aims to document the personal impact of infection with viral hepatitis, and identify the issues arising for people in responding to the infection. These data can be used to contribute and improve policies and programs seeking to reduce the burden of infection on people infected with hepatitis B and/or hepatitis C in China by identifying gaps in knowledge, education, support, access and infrastructure.

The scope of the population affected by chronic viral hepatitis, both numerically and geographically in China provides a challenge to the research and it is acknowledged that there are clear limits to the representativeness of the findings of the research. What this research does is to use qualitative methodology to systematically identify and document the lived experience of people with viral hepatitis.

This needs assessment was conducted in two stages. Stage 1 consisted of interviews with 13 key stakeholders across China with specialist clinicians, including one nurse, working in viral hepatitis (n=6), policy officers (n=3), pharmaceutical company representatives (n=1) and community advocates (n=3) to document the policy, health and social contexts in which people with viral hepatitis in China live.

Stage 2 consisted of interviews with 46 people with viral hepatitis. These included 13 women and 33 men with most participants having hepatitis B (n=41), and being under the age of 35 years.

The age range of participants was as follows:

Age range	Number of people
20-25 years	9
25-30 years	13
30-35 years	10
35-40 years	4
40-45 years	2
45-50 years	3
50-55 years	2
55-60 years	2
Over 60 years	1

Face to face interviews with people were held in Guangzhou (n=15), Dong Guan (n=2), Shanghai (n=11), and Beijing (n=17) with one telephone interview in Chongqing. Twenty of the participants were recruited through clinical services in Beijing and Guangzhou, and the remainder (n=26) through a non-government organisation in Guangzhou and contacts made through this organisation. All five people with hepatitis C were recruited solely through specialist clinical services in Beijing and Guangzhou, and all were over the age of 40 years.

The assessment used a methodology involving semi-structured individual interviews with data collected in a qualitative form. A semi-structured interview

guide was used with the following prompts:

- How did you find out you had hepatitis B or hepatitis C?
- Who told you that you had viral hepatitis, and how were you told?
- What information were you given when you were told you had hepatitis B/hepatitis C?
- Are you seeing a doctor for your hepatitis B/hepatitis C infection?
- Has finding out that you have hepatitis B or hepatitis C changed your life? How?
- What information would have been useful for you when you found out you had viral hepatitis?

- What other information do you need to help you deal with having hepatitis B/hepatitis C?

The electronically recorded interviews were conducted in Mandarin through an interpreter, with questions asked in English, interpreted, and responded to in Mandarin and then interpreted into English. Three interviews were conducted in English with specific words or concepts interpreted when requested. The length of the interviews ranged from 25 to 90 minutes. The interviews were initially transcribed in English by the lead investigator and all Mandarin responses translated using an independent translation service. The responses were then analysed based on grounded theory principles using Nvivo 10 (QSR International Pty Ltd, VIC, Australia).

Below: Everyone in this family photo is either currently living with, or has already died from liver diseases. In China, approximately 10% of the population over the age of 20 are chronically infected with hepatitis B.



Viral Hepatitis in China - the Context

The broader context for the lives of people with viral hepatitis in China includes:

- A significant increase in life expectancy over the past 30 years, the “meteoric economic development” (18) of the country as a whole, and the movement of people from rural to urban centres. This is reflected in a rapidly ageing population whose life expectancy has increased from 46 years of age in the 1950s to almost 75 years in 2010 (19) and with an estimated 51.5% of the population living in cities by 2015. (20) Poverty in China has substantially declined from 85% of people living below the poverty line of US\$1.25 per day in 1981 to 13.1% living below the poverty line in 2008. (21)
- Changes in health service delivery in China over the previous 40 years have been significant with communicable diseases no longer being the leading cause of death as they were in the late 1940s. Health services have changed from commune or locally based health workers through to the development of a three tier health service infrastructure. This infrastructure includes a referral network from “village through commune to county levels, with supervision in the reverse direction” (18) and where “minor illness (is) treated in the grassroots institution, serious disease in hospital.” (20) The market-oriented reform, introduced in the 1980s, has led to the rapid development of tertiary care accompanied by a weakening of primary care, and with the most recent (2009) health reforms seeking to re-strengthen primary care.
- The government aims to have one community health centre for each community of between 30,000 and 100,000 residents, and one government-run hospital in every township. Between 2000 and 2008, the number of general hospitals in China increased by 23%, and a doubling of specialist hospitals during this period. The total number of general hospitals with over 800 beds increased nearly 5-fold between 2000 and 2008. (22)
- Township hospitals are generally called township health centres, and are the rural equivalent to urban community health centres. With urbanisation, many rural township hospitals have been transformed into urban community health centres.
- The Chinese government note “unbalanced, uncoordinated and unsustainable issues” in the area of health sector development (19) with significant gaps occurring between urban, rural, regional and population settings in health service allocation, utilisation and health outcomes.
- The change from a planned to a market economy starting in 1978 had a significant impact on health service access with responsibility moving from the central to local governments, also described as “policy centralisation with financial decentralisation.” (23) At the same time, within a context of rapid economic growth, rural cooperatives disbanded with families losing health insurance previously obtained through these cooperatives. This caused a sharp decline in health insurance coverage from nearly universal levels in 1978 to 7% in 1999, with an implication of fee for service charges for uninsured patients. (24)
- Essential changes have occurred with the funding of health services within a context of market reforms including funding from and for local level services and a reduction in central funding particularly during the 1980s. While local level jurisdictions are responsible for health care financing they do not have responsibility for raising revenue and this provides the incentive for the use of curative care within hospital settings. (20)
- While governments reduced contributions to hospital budgets, policies were developed that enabled hospitals to make up their loss through user charges. Low consultation fees were established, with compensation for higher profit margins for selling drugs and high technology services. This also means that unlike in many countries, there is

no separation between prescribing and dispensing with hospitals able to fundraise by selling drugs, including Traditional Chinese Medicines (TCM).

- Regulations related to the delivery of public health and health services are poorly enforced and monitored, including those relating to the use of TCM. (20)
- While preventative health interventions were a strong focus of the health system prior to the 1980s, and included the eradication of smallpox in 1960 and polio from 1994 (20), these preventative interventions lost priority with a “laissez faire attitude to preventive health” (18) from the government and an increasing focus on hospital-based care.
- Health sector reforms commencing from 1997 included reforms to the insurance system. Three major health insurance programs cover specific groups with varying coverage rates - rural residents (94% coverage), urban employees (67%) and unemployed urban residents (60%) with insurance coverage for rural residents increasing from 13 to 92% from 2003 to 2008. This insurance provides for the reimbursement of various costs which is determined by the program and the location of the program with 41% of inpatient expenses being reimbursed. (22) Insurance is based on where you are registered, as opposed to where you reside.

As a health policy issue, viral hepatitis falls under the responsibility of the China central (or “national-level”) Center for Disease Control and Prevention (CDC) within the National Health and Family Planning Commission. The CDC works with the central government to coordinate the country’s public health system at the provincial, municipal (prefecture), and county (district) levels. Reducing the population prevalence of chronic hepatitis B to equal or less than 6.5% by 2015, is one indicator of the “Twelfth Five-Year Plan for the Health Sector Development.” (19)

In the 2013 Global Policy Report on the Prevention and Control of Viral Hepatitis, (25) from the World Hepatitis Alliance and the WHO national governments self-report hepatitis related activity with the Chinese government reporting:

- The Western Pacific World Health Organisation region, the region in which China is located,

accounts for 48% of global liver cancer cases among men and 62% among women.

- National coordination of viral hepatitis in China includes a written national strategy or plan that focuses exclusively on the prevention and control of hepatitis B and includes raising awareness, surveillance, vaccination, prevention in general, prevention of transmission via injecting drug use, prevention of transmission in health-care settings, and treatment and care.
- The government collaborates with civil society groups to develop and implement its viral hepatitis prevention and control programme including with the Wu Jieping Medical Foundation and the Chinese Foundation for Hepatitis Prevention and Control.
- Establishing a goal of eliminating hepatitis B by 2012, and that nationally 91% of newborn infants received the first dose of hepatitis B vaccine within 24 hours of birth and 94% of one-year-olds (ages 12–23 months) in a given recent year received three doses of hepatitis B vaccine.
- Testing for both hepatitis B and hepatitis C is confidential although not free of charge for all individuals.
- Publicly funded treatment is available for hepatitis B, but not for hepatitis C, with no information provided on who is eligible or the amount spent by the government on such treatment.
- The drugs included on the national essential medicines list or subsidised by the government for hepatitis B are interferon alpha, pegylated interferon, lamivudine, adefovirdipivoxil, entecavir, telbivudine and tenofovir, and for hepatitis C, ribavirin.

The Chinese government reported viewing viral hepatitis as an urgent public health issue and that while a specific strategy for the prevention and control of hepatitis B and/or hepatitis C is in place, no designated individual leads the implementation of this strategy nationally. Issues addressed in the 2006-2010 National Hepatitis B Prevention and Control Plan (2006) while largely focussing on hepatitis B prevention, also includes advocacy, prevention, screening, testing, surveillance, service evaluation, treatment, and multisectoral collaboration. Government-funded public awareness



campaigns for hepatitis B and/or hepatitis C are reported to have taken place in the past five years. Prevention has been included in the annual National Vaccination Day campaign since 2002. Action to reduce stigma experienced by, and discrimination against people who have hepatitis B and/or hepatitis C has also been taken by the government including the Infectious Disease Prevention Law (2004) and employment regulations which protect the rights of people with hepatitis B.

Data on viral hepatitis is collected through the China Information System for Disease Control and Prevention, and has what is described as a ‘well-developed infrastructure for viral hepatitis surveillance’. (26) This web-based, real-time reporting system covers 37 diseases across all areas of China and was developed in response to the severe acute respiratory syndrome (SARS) crisis in 2003. (27)

In 2008, the Chinese Government funded research with around RMB3 billion (US\$390 million), mainly against hepatitis B and related diseases, over the following decade. In 2013 alone, the Ministry of Science and Technology invested 300 million RMB (AU\$50 million) on research for the eradication, clinical treatment, surveillance and intervention of viral hepatitis, including hepatitis C and liver cancer. (9, 28)

Hepatitis B is a blood-borne and sexually transmitted virus which is transmitted either through percutaneous (puncture of skin) or mucosal exposure to contaminated blood or body fluids. Serum, semen, and saliva have been shown to be infectious for hepatitis B. Hepatitis B transmission occurs:

- perinatally (from mother to infant at or around birth)
- from and between children
- through sexual contact
- in health care settings, including contaminated needles or blood products
- through the unsafe sharing of injecting equipment

The risk of hepatitis B transmission from mother to infant during delivery is approximately 90% if the mother is HBsAg+ (surface antigen positive or has a chronic infection) and higher still if the mother is both HBsAg+ and HBeAg+ (hepatitis B e antigen positive). The risk of transmission is significantly reduced with the



After her husband's funeral, Mrs. Wang stands with her children. At age 34, Mr. Wang died of liver cancer caused by hepatitis B—one of almost 300,000 Chinese killed every year from hepatitis B-associated liver cancer and cirrhosis. Henan, China

administration of Hepatitis B Immunoglobulin (HBIG) and birth dose vaccination within 12 hours of delivery.

The natural history of hepatitis B is dependent on several factors, the major one being the age when a person is exposed. The vast majority of infants who become infected through perinatal exposure develop chronic hepatitis B (95%), while only a minority of people exposed at an older age progress to chronic infection (5%).

Chronic hepatitis B occurs when infection with the hepatitis B virus persists and is marked by ongoing serological evidence of infection and variable liver inflammation with persistence of HBsAg (surface antigen) for longer than 6 months traditionally defining chronic hepatitis B. The natural history of chronic hepatitis B is highly variable, marked by alternating stages of disease inactivity and activity, and by the lack of linearity in disease progression.

In literature relating to China and hepatitis B, there are a variety of ways in which the infection is described with differences in understandings in both refereed and grey literature of the definition of ‘chronic’ and ‘carrier’. In this report, people with hepatitis B are

described as having a chronic infection (surface antigen positive/HBsAg), with a proportion of these people having active viral replication (e-antigen positive, or previously known as having chronic active hepatitis). The term ‘carrier’ is used in various ways in refereed and grey literature but for simplicity and accuracy, is not used in this report unless within a direct quote.

Hepatitis C is a virus transmitted by blood and, without treatment, becomes a chronic or lifelong infection for 75% of people exposed. (29) The natural history of the infection generally progresses slowly, with limited liver disease in the first 10–15 years of infection with mortality and morbidity associated with the infection largely determined by direction of the infection and age. (30) Estimates for disease progression of hepatitis C to cirrhosis range from between 4 and 24%, with a population based cohort finding 7% of the sample of people with hepatitis C having cirrhosis after 20 years of infection. (31) Factors associated with further progression of liver disease, particularly liver cancer include older than 55 years, high levels of alcohol use and being male. (32) Hajarizadeh et al note that reducing the burden of hepatitis C related disease at a population level requires the removal of barriers to hepatitis C education, screening, evaluation and treatment. (33)

The vast majority of data available about viral hepatitis, both clinical and social in China focuses on hepatitis B.

Epidemiology

China is described by WHO as having an ‘intermediate’ prevalence of hepatitis B infection. Hepatitis B virus infection is a serious health problem in China, causing a substantial burden of acute and chronic liver disease (34) and with 40% of global deaths attributed to hepatitis B occurring in China. (35)

A total of 1,317,982 viral hepatitis cases were reported in China in 2010, with hepatitis B accounting for 80% of all cases (36) and almost 300,000 people dying per year as a result of the infection. (4, 16) China is the country with the largest absolute number of people infected with hepatitis C. (33)

In 1992, the China national hepatitis seroepidemiological survey found that almost 10% of

the population aged between 1 and 59 were chronically infected with hepatitis B, with up to 12% of children under the age of 5 years being chronically infected. (7) Based on the results of this survey, it has been estimated that in China, 120 million people have chronic hepatitis B infection with 20 million people being e-antigen positive or experiencing active viral replication. (9)

A national viral hepatitis prevalence survey conducted between 1992 and 1995 found a hepatitis C prevalence of 3.2% among the general population, (37) while a sero-epidemiological study in 2006 reported a national prevalence of 0.43% among people between 1 and 59 years. (16) In 2007, a special epidemiological survey conducted in six provinces reported an overall prevalence of 0.58%. (37) There are significant geographic variations in prevalence, with a 2006 survey of oesophageal cancer conducted among patients from Henan Province finding 0.9% of the samples were hepatitis C positive, (38) while the prevalence in the general population was found to be 2.1% in Fujian province, (39) 9.6% in Henan province, (40) and 25% in a rural community of elderly people. (41) The provinces of Henan, Guangdong, Guangxi, Xinjiang and Jilin account for almost 44% of all hepatitis C cases in China. (17)

Higher hepatitis C prevalence is found among people who inject, haemodialysis patients and former blood plasma donors particularly in Henan, Shanxi, Shandong and Anhui provinces. A systematic review and meta-analysis of entrants to methadone maintenance treatment clinics in China found a pooled national prevalence of HIV being 6%, while hepatitis C prevalence was 60% and HIV-hepatitis C co-infection was 4.6%. (42) A pooled prevalence of hepatitis C among people who inject in China was 61% with a greater prevalence in Hubei, Yunnan, Guangxi, Hunan and Xinjiang. No significant difference in prevalence was found among men or women who inject, with ethnic minority Chinese who inject being more likely to be infected, and those with a longer duration of injecting and infection with HIV. (43)

China has the highest age-adjusted incidence of liver cancer primarily resulting from hepatitis B infection with 24,536 new cases and 22,255 deaths from liver cancer in 2009. (10) Around 55% of all liver cancer deaths worldwide occur in China and liver cancer is the fourth most common cancer, and the second most common cause of cancer death in China in urban settings. (44, 45) There is a higher prevalence among men, and in rural areas, with an increasing liver cancer burden over time.



(10) As occurs in many countries, most patients with liver cancer present with advanced disease, reducing treatment opportunities. (12, 45) Most of these deaths are men between the ages of 30 and 65 years and up to 9.5% of Chinese women of childbearing age have hepatitis B. Viral hepatitis was the primary factor in 17% of all cancer deaths, and 13.2% of all cancer cases in China in 2005. (46, 47)

Prevention

In the “2006–2010 National Hepatitis B Prevention and Control Plan”, the Chinese Ministry of Health established a national goal of achieving a chronic hepatitis B prevalence of less than 7% by 2010 for the whole population and less than 1% for children under 5 years.

Perinatal transmission is the primary form of hepatitis B transmission in China. The vaccination program in China is recognized by WHO as a success story in preventing hepatitis B through universal infant vaccination. (48) The Western Pacific Regional Office, of which China is a member, was the first WHO region to set a time-bound goal of reducing chronic hepatitis B infection rates to <2% among 5-year-old children by 2012.

The implementation of the vaccination program in China occurred in stages. In 1992, the Ministry of Health recommended hepatitis B vaccine as a routine immunisation of infants, with parents having to pay for the vaccine and its administration. This payment resulted in higher vaccine coverage in urban and high socioeconomic areas and lower in rural and lower socioeconomic areas. (14, 16, 49, 50) In 1999, a National Expanded Programme on Immunization (EPI) review showed that immunisation coverage varied between 7.8% in Tibet to 99% in Beijing (16, 49) with a follow-up survey among children born in 2001 showing continued disparities in western provinces and rural counties. (16, 49) In 2002, China integrated the hepatitis B vaccine into the Expanded Program on Immunisation (EPI) and while payment for the vaccine was not required, an administration fee of up to \$1.10 per dose was permitted. (16, 51)

In 2002, the Chinese Government/Global Alliance on Vaccine and Immunization (GAVI) project provided \$US76 million funding to purchase hepatitis B vaccine and auto-disable syringes for all children born in western and poorer central provinces (49, 52, 53). In 2005, the State

Council issued the “Regulation on Vaccine Circulation and Immunization Management” eliminating all vaccination associated charges, so that infants born after 1 June 2005 would be provided with hepatitis B vaccine for free. (50, 54) From 2009 to 2011, the government provided the vaccine free of charge to all children under 15 who had not been vaccinated, and program coverage remains a challenge with lower vaccine coverage in rural areas and in western regions. (14, 49)

The impact of the vaccination program in reducing the prevalence of hepatitis B has been profound. In 2006, the Ministry of Health estimated that there were 93 million people chronically infected with hepatitis B with a decrease in the prevalence of chronic infection for people between 1–59 years from 9.8% to 7.2% between 1992 and 2006, and only 1.0% of children aged <5 years having a chronic infection. (16, 55) On an individual level, this has resulted in the prevention of between 24 and 30 million hepatitis B infections, and 4.3 million deaths among children born after 1992. (4, 49) Five challenges related to the vaccination program have been identified including that China still having the largest annual number of perinatal hepatitis B infections; no national policy on safe injection of vaccines; high risk adults and health care workers not covered by the program; hepatitis B surveillance needing to more accurately monitor acute hepatitis B and an effective treatment program for people with chronic infection. (56)

Other viral hepatitis prevention interventions in China include public health education campaigns, the screening of blood donors and high risk populations, and promoting safe injections and other medical procedures, (54, 57) and the one child policy. (16) Post transfusion hepatitis occurred in up to 50% of all transfusions in the 1960s with the routine screening of blood being introduced in the early 1980s. (4)

The first needle and syringe distribution program in China was initiated in 2000 by the Chinese Academy of Preventive Medicine (the predecessor of the Chinese Center for Disease Control and Prevention). By 30 June 2010, NSEPs had been established in 20 provinces and autonomous regions providing services to, on average, more than 36 000 people who inject per month. (58) China launched pilot MMT programs in 8 clinics serving 1,029 drug users in 2004 when community MMT program was implemented with the program expanding to 738 clinics serving 344,254 drug users by the end of 2011. (59)

Clinical management

The clinical management of people with viral hepatitis is primarily conducted in China by Infectious Diseases physicians in public hospitals (60, 61) with the overall treatment objectives being to suppress or clear the hepatitis virus; to reduce and prevent complications including cirrhosis, liver cancer and other liver disease; to improve quality of life, and prolong survival. Clinical management guidelines used in China have been developed by the Chinese Society of Hepatology and Chinese Society of Infectious Diseases in 2005. (61)

Three standard interferons (alpha 1b, 2a and 2b), two pegylated interferons (alpha 2a and 2b) and four nucleotide analogues (lamivudine, adefovir, entecavir and telbivudine) have been licensed and used in China for hepatitis B. Apart from the pegylated interferons, all of the antiviral agents are manufactured in China under patent. (54, 61-63) Tenofovir is not registered for use in China for hepatitis B, although is available free of cost for people with HIV, including for people with HIV and hepatitis B coinfection. Hepatitis C treatments recommended in China are pegylated interferon and ribavirin, (64) with patients with hepatitis C from China recording higher rates of hepatitis C clearance as a result of the IL28 gene. (7, 65)

Clinical management for hepatitis B infection consists of monitoring and when required, the provision of pharmaceutical treatment. While treatment is widely available, it is reported that only 19% or 6 million people with hepatitis B, (66) and around 1.6% of people with hepatitis C have accessed treatment, (67) largely as a result of the costs involved and the limited reimbursement. (9, 13, 51, 63) The use of lamivudine and adefovir is widespread as a hepatitis B treatment, and while recognised as causing viral resistance, is cheaper than other medications. (63)

A study of over 4000 outpatients from 10 hospitals in western China with viral hepatitis found more than 63% of the patients had hepatitis B and 35% had hepatitis C, with more women than men infected with hepatitis C who were also of an older age. Of the hepatitis B patients, 52% had received adefovir and 40%, lamivudine and the authors of this study found a

range of gaps in clinical management and suggested better routine screening, more thorough management interventions and the use of better treatments. (68)

In terms of monitoring, adherence is poor with one report of 77% of 3257 hepatitis B patients not following up after referral. (69) The authors described the challenges to monitoring in China include lack of income, self-paid health care costs for outpatients, rising health care costs, “drug kickbacks” to providers, fragmented services and free choice of physician.

There is widespread use of TCM in the clinical management of viral hepatitis with many TCM hospitals in large or medium sized cities and many general hospitals having TCM departments. (28) Over 300 herbal medicines have been officially registered and approved for treating hepatitis over the past two decades, and while there are concerns of the quality of controlled trials of TCM, medicinal herbs have been shown to normalise liver enzymes and modify hepatitis B markers. (70)

It has been estimated that approximately 25% of in- and outpatients receive TCM treatment, and that 73% of physicians only use Chinese herbs to treat chronic hepatitis B. (51) A study of over 4000 patients found that 56% had used TCM for their infection. (68)

Hepatitis B has been described as an economically catastrophic illness, with the direct costs of hepatitis B and its related diseases exceeding 40% of household annual income in China, with this cost increasing in line with the natural history of the infection. (71) The costs are significant for people with hepatitis from rural areas where it is estimated that less than 5% of patients can afford treatment for one year compared with approximately 40% of patients in more developed areas. Further, these costs are in addition to initial diagnostic tests needed to confirm a diagnosis of hepatitis B. (13) A survey on disease burden carried out in Shanghai in 2001 revealed that the annual direct and indirect medical costs for each patient with chronic hepatitis B were US\$3000, while the cost for a patient with compensated or decompensated liver cirrhosis were US\$5100 and US\$5200, respectively, with a per capita GDP at that time of around US\$1000 per annum. (66)

While direct costs to patients essentially affect access to treatment, other economic issues affect the provision



of care to people with viral hepatitis. Initially and essentially affecting access to clinical management, systematic testing for hepatitis B and hepatitis C is not available given the cost. (72) Other economic issues include a comparison of insurance schemes and the length of hospital stay for patients with hepatitis B finding that people insured under the urban employee scheme received a 2½ time longer length of stay than people insured under other schemes. (73) At the same time hospitals in urban settings with specialists services more often see inpatients with greater severity of disease. (74) Another health care access difference occurs between hepatitis B, hepatitis C and HIV/AIDS where clinicians spend an average of 33 minutes in an initial consultation with an HIV/AIDS patient, compared to 10 minutes for the initial consultation of hepatitis B and hepatitis C patients. (75)

In spite of its prevalence in China, research shows inadequate understandings among health workers about viral hepatitis. (66, 76, 77) A study of 120 physicians found that while most (90.9%) were aware of the Chinese consensus recommendations on hepatitis B, only 51.8% correctly identified the indications for the treatment of chronic hepatitis B, and 42.5% correctly described the end-points in treating HBeAg-positive or HBeAg-negative chronic hepatitis. (78) Another study of 250 health care workers attending a hepatitis conference, found that 34% did not know that chronic hepatitis B infection is often asymptomatic and 29% did not know that hepatitis B confers a high risk of cirrhosis, liver cancer, and premature death. (79) In a reflection of issues related to confidentiality, stigma and discrimination, 38% of the respondents informed chronic hepatitis B results to a patient's employer while 25% reported positive results to a patient's school. In both studies there was a relationship between poor knowledge about hepatitis B and health care workers who were located in rural areas. In relation to hepatitis C, in a web-based survey of physicians, 11% incorrectly reported transmission routes and a low awareness of testing or screening, 71% thought hepatitis C was incurable, and almost 50% reported no effective treatments for hepatitis C. (77)

Gaps in knowledge about the infection by people with the viruses have also been found, with almost 50% of patients with hepatitis B, and over 20% of patients with hepatitis C being unable to identify the likely cause of their infection. (68)



Above: Wang Dage's father and children stand next to his ID card. Approximately 100-120 million Chinese are infected with the hepatitis B virus, yet due to a lack of resources and the social stigma that has been associated with the disease, people are unaware of the severe public health risk it poses. Henan, China

Social implications of infection

There are significant social implications of being infected with viral hepatitis in China particularly relating to discrimination and stigma, (9, 76, 80) with the social implications of the infection surpassing that of the infection itself. (57) These are said to stem from responses to a significant hepatitis A outbreak in Shanghai in the late 1980s, where over 300,000 people or 4% of the population were infected, resulting in 47 deaths. (81-83) This event received extensive media attention, with subsequent confusion occurring among the general public between the different types of hepatitis. (80)

Discrimination

In this report, the use of the term 'discrimination' refers to regulatory interventions that reduce access to services or employment for people with viral hepatitis, while stigma relates to attitudes or beliefs affecting people with viral hepatitis.

Key issues related to discrimination and hepatitis B:

- Discrimination was initially regulated in 1981 with the Technical School Student Admissions Medical Test Standards and Implementing Regulations, promulgated by the State Labour Bureau and the Ministry of Health, mandating that no one diagnosed with chronic hepatitis could be hired. (81)



- On the 30 October 1995, the Food Hygiene Law of the People's Republic of China regulated that "no sufferers of dysentery, typhoid, viral hepatitis ... (including carriers of the pathogen) ... may engage in work with ready-to-eat foods" (Article 26). These public places included the food industry, pharmaceutical, health products, water supply and education sectors.
- Medical tests were required for civil servants from 1994, and while these tests stated that if "acute hepatitis is cured for one year and persistent hepatitis is cured for two years, persons carrying the hepatitis virus but having normal liver function may be employed." In reality, these guidelines were not effectively followed.

Several events motivated changes to these regulatory barriers, including the stabbing of two government staff members and the murder of one in 2003 by a 22 year old university graduate, rejected from a position as a civil servant on the basis of his hepatitis B status. (84, 85) While this caught the attention of the media and the public, over the following few years many more people with hepatitis B sued and won against employers for discriminatory employment practices. This included China's first hepatitis B discrimination case in 2003 where a graduate filed a lawsuit against the Wuhu Bureau of Human Resources, arguing that its actions in not accepting his employment as a result of having hepatitis B had "deprived him of his eligibility to act as a public servant, discriminated against a person with HBV, and violated his lawful rights and interests." (81, 84, 85) Other examples of discrimination include:

- 24% of people with hepatitis B reported losing jobs as a result of their infection. (86)
- 74 students enrolled at Yunnan Provincial Advanced Technology School who had hepatitis B were expelled in 2007. (84)
- In March 2006, 20 three-year-old toddlers in Hangzhou were denied admission to kindergarten because they had hepatitis B. (84)
- October 2006, 19 Uyghur students who received a positive hepatitis B test were expelled from Urumqi public schools. (84, 87)
- 58 students enrolled at Shandong Medical and Pharmaceutical School were expelled on the basis of their hepatitis B status.
- 11 September 2009, 31 students with chronic hepatitis B infection were excluded from schools as they were "not suitable for collective life." (88)
- Employers routinely screen prospective employees with hepatitis B tests as a condition of employment. (89)
- 31% of 100 kindergartens in 2012 reported not enrolling children with hepatitis B. (90)

Significant changes have occurred in educational and employment access of people with hepatitis B since 2003 where the China Ministries of Health and of Personnel announced that people with hepatitis B must not be discriminated against when seeking employment and education. (91-94) Other key changes include:

- On 17 January 2005, the Ministries of Personnel and Health issued the (Trial) General Standards for Medical Tests in Civil Service Hiring, which removed hepatitis B markers from the Medical Test Table attached to the General Standards.
- On 18 May 2007, the Labour and Social Security Bureau and the Ministry of Health issued an administrative regulation providing for the protection of the employment rights and right to privacy of people with hepatitis B and requiring employers not to use chronic hepatitis B infection as a reason to refuse to hire or to terminate the jobs of employees.
- In February 2010, the Ministry of Human Resources and Social Security, Ministry of Health and the Ministry of Education jointly issued a notice which required the cancellation of compulsory hepatitis B tests in employment and school enrolment. (93, 95) The notice states that while hepatitis B screening should not occur, liver function tests including ALT are permitted.
- In the *Guidelines on Hygiene and Care in Nurseries and Kindergartens* released in May 2012, people with hepatitis B were allowed to work in nurseries and kindergartens provided that they do not keep long fingernails. (95)
- The *Law on Food Safety* requires employees should not be rejected to work in the food industry based on their hepatitis B status and calls on the cancellation of compulsory hepatitis B test for chefs and waiters working in hotels and restaurants. (96)



- The *Health Check Standards for Civil Servant Recruiting* released in 2012 provides for people with hepatitis B to be employed as civil servants, except for special policemen. (97)
- It is estimated that each year 30-40% of new military recruits are rejected because of a positive hepatitis B status. The rationale for the restriction is that recruits train and live together and they may be subject to injuries and traumas which would impose danger of hepatitis B transmission in close contact. (98)
- Students with hepatitis B have the same rights as other students to study and choose schools. (95)
- People with hepatitis B have the right to get married although a partner with negative hepatitis B surface antibody is required to receive vaccine before marriage. (93)

While these regulatory changes have reduced legislative barriers, discrimination still remains a significant issue for people with hepatitis B. One report notes that a year after the regulatory change, 61.1% of state-owned enterprises still explicitly sought hepatitis B testing for employment purposes. In a survey carried out in 2008, 84%, or 80 of 96 multinational corporations operating in China required applicants to be tested for hepatitis B, with 44% specifically rejecting people with hepatitis B from employment. (99) There are systemic challenges to responding to this discrimination with no clear or comprehensive definition of discrimination, with this being particularly important in terms of the China Labor Law. (84, 85, 87)

A 2010 report from a Beijing-based non-government human rights service for people with hepatitis B, (81) noted how people with hepatitis B subvert regulatory or other barriers to employment. These strategies included asking people without hepatitis B to take a medical examination in their stead, using personal connections, or identifying prospective employers who do not require or conduct testing. The report also noted the poor understanding of employers about hepatitis B and/or the immunological markers of the infection. In responding to a child found to have hepatitis B, one mother reported that she “had to make a fake physical examination record for my son to enter a kindergarten.” (90)

Quality of life

Research has found that people with hepatitis B experience a lower quality of life in China than in other countries including United States, Canada, United Kingdom, Spain and Hong Kong due to stigma and discrimination and its impact on employment, marriage and education in China. (100) The impact of the infection has mental and emotional consequences with people with hepatitis B reporting greater levels of anxiety, depression and nervousness and more negative life events than people without hepatitis B. People with hepatitis B in China report lower quality of life than other people, and in spite of a range of interventions being conducted, one study of people with hepatitis B found no significant changes in scores about health concerns, psychological trends toward hostility, doctor support, and the sense of being discriminated against. (101) In relation to hepatitis C, a psychological questionnaire conducted with patients with hepatitis C found that 50% were depressed, which the authors reported occurred as a result of social stigma and discrimination resulting from the infection. (102)

A survey found that parents of children with hepatitis B were significantly more stressed than parents who children did not have hepatitis B. (103) While the article notes the existence of a ‘special health kindergarten’ for children with hepatitis B, parents of children with hepatitis B had less social support, were socially isolated from close friends and the community and had less perceived meaning in life. The article notes that in 1992 there were 3 “special” kindergartens for children with hepatitis B compared to 500 ordinary kindergartens, meaning that only 2.8% of children with hepatitis B attended kindergarten compared to 97.2% of children without hepatitis B.

Stigma

Stigma against people with hepatitis B in China is supported by ignorance and misunderstandings of how the virus transmitted, with many people believing that they can be infected through casual contact with people with hepatitis B including eating with people with hepatitis B. There is a significant lack of understanding about viral hepatitis within the broader community in China with one survey of over 60,000 people visiting hepatitis themed online forums believing that hepatitis B can be transmitted through kissing (40%), having meals with a person with hepatitis B (30%) with 5%

thinking that handshaking and hugging could transmit hepatitis B. (86) A study of rural residents showed that accurate knowledge of hepatitis B could be predicted by age, educational levels, occupation and marital status, with the main source of information being television, newspapers and magazines, broadcasts and relatives. (104) In this study, only half of the participants were aware that hepatitis B can cause liver cancer.

In qualitative interviews with 40 people without hepatitis B, most lacked basic knowledge about hepatitis B including over half believing that hepatitis B could be transmitted through saliva, shared eating utensils, eating together, kissing, skin contact and shared towels. (81) Most people reported getting their knowledge about hepatitis B from advertising or word of mouth.

Further, the stigma associated with viral hepatitis infection is exacerbated by pharmaceutical companies and hospitals exploiting the prevalence of hepatitis B to sell alleged cures and remedies. (80) People with hepatitis B have noted that the poor understanding of the public occurs as a result of false advertising claims about hepatitis B and possible cures from poorly regulated clinical services; the lack of government supported education and awareness campaigns about hepatitis B; an over-supply of labour, meaning that people with hepatitis B could be excluded from the workforce, and acceptance of discrimination as affecting their social environment in relation to hepatitis B. (81, 87)

The internet in China plays a major role for people with hepatitis B in gaining social, emotional and physical support. (93) An analysis of 1,607 messages from an online support group revealed multiple barriers including institutional discrimination, relationship difficulty, alcohol-drinking social norms, limitations of the health care system and pharmaceutical market, and financial constraints. Major coping behaviours were identified as seeking health and reproductive advice, avoiding disclosure and discrimination, protecting legal rights, preventing transmission, and outreaching support behaviours.

Unlike its approach to hepatitis B, China has been reported to have made solid progress in developing policies and programs to address HIV related stigma and discrimination. It is one of the few countries globally where top leaders took a public stand to eliminate stigma associated with people with HIV at an

early stage of the epidemic. China has also developed numerous policies to protect the rights of people with HIV to retain their jobs without discrimination. (105)

While the vast majority of research about the impact of stigma and discrimination specifically refers to hepatitis B, stigma and discrimination related to hepatitis C is increasingly recognised as a social problem, with people with hepatitis C experiencing discrimination when attending school, looking for a job and when they marry. In 2007, 80 people with viral hepatitis took part in a psychological questionnaire survey, 50.0% of whom were evaluated to have depression as a result of social stigma and discrimination. (106) A study of hepatitis C related stigma and discrimination in patients from Guangzhou in 2010 found that 75.6% of patients had been denied a job, 56.1% felt being discriminated against, and 26.8% had ever been rejected by a date, based on their hepatitis C status. (107)

Key stakeholder interviews

Interviews were held with thirteen key stakeholders across China including clinicians, researchers, advocates, and representatives of non-government organisations providing health and social services to people with chronic hepatitis B or hepatitis C to detail, from their perspective, the needs of people with viral hepatitis.

Several stakeholders noted the primary focus of the government being on implementing the hepatitis B vaccination programme, and while this implementation has largely been successful there was still a need to support people with viral hepatitis to reduce the morbidity and mortality associated with the infection. Two stakeholders noted that there was no single government agency in China identified with responsibility for reducing the burden of viral hepatitis. Advocacy about hepatitis was limited to professionals, with people with the infections generally unwilling to publicly disclose their infection.

One key contextual issue noted by the majority of stakeholders was the lack of education, information and awareness of the general public about viral hepatitis, and the fundamental impact this has on the social support of people living with the infections. Much of the misinformation within the general public



related to confusion about the different hepatitis viruses, and further exacerbated by misinformation disseminated through the media in advertisements for fake treatments and cures through private, and sometimes public medical services. One impact relating to the lack of knowledge of the infection, particularly by people living with the viruses was their motivation to undertake regular monitoring of the infections, and a reliance on specialists to provide this information.

The lack of knowledge about the infections was also noted as affecting a broad range of health care workers, and was enhanced by a lack of continuing education or interest in conducting clinical research by medical professionals.

Three stakeholders noted the lack of systematic testing, screening or diagnosis of people with viral hepatitis with people more likely to have been diagnosed when they have a family history of the infection, live in larger cities and those with higher education.

One key barrier to clinical services described by each key stakeholder was the cost of accessing clinical services, and the lack of reimbursement for people in accessing treatments. As one specialist clinician noted, *“if you don’t earn money, then you cannot pay, then you do not get diagnosed and you don’t get treatment. It is as simple as that.”*

The costs associated with clinical management essentially limited the types of medication being used, what tests are used, and the continuation of lifelong treatment. The lack of knowledge about the infections, including by people with the infections, affects access to clinical services, particularly in the context where the infections are largely asymptomatic. Key hepatitis drugs, such as tenofovir for hepatitis B are not included in the essential medicines list, and drugs that are not used overseas such as Lamivudine are used in China because they are cheaper.

The issue of fake treatments and cures and the poorly implemented regulations overseeing private medical services was noted by several stakeholders as not only enhancing poor understanding of hepatitis by the general public, but also affecting the trust of the public and people with viral hepatitis in clinical services.

The use of TCM is widespread, and is widely acknowledged by clinical specialists. The use of TCM is

not uncomplicated, with these treatments being able to normalise liver function testing while not having an anti-viral effect – the consequence being that people with normal liver function will not necessarily access clinical services until experiencing symptoms, and often very late in the disease progression.

The pervasive stigma associated with viral hepatitis reduces the willingness of people to access clinical services. Two clinicians noted people with viral hepatitis preferred to pay for treatment from their own pocket rather than risk the possible social consequences of seeking reimbursement from their insurance provider. Another clinician described stigma supporting the use of fake treatments given an unwillingness of people to access appropriate clinical services where successful treatments were available.

A range of interventions were suggested, including:

- A greater priority by the government in responding to hepatitis, including the development of a comprehensive strategic response.
- More equitable access to clinical services, including pharmaceutical treatment trials in rural and remote areas.
- Increased reimbursement of pharmaceutical treatments to improve the affordability and reduce barriers to treatment access.
- Provision of government funding to increase the community awareness and knowledge about viral hepatitis. Interventions included mass awareness campaigns for the general public, including people living with viral hepatitis to reduce the fear and stigma associated with the infections, and for people with hepatitis to know that treatments are available. It was acknowledged that there was a challenge involved in highlighting the impact of hepatitis while not increasing levels of stigma.
- The development of systematic policy and processes for the provision of a positive hepatitis diagnosis.
- Better implementation of the regulations covering the operation of medical services including hospitals, health centres and other medical clinics.
- An increase in, and consistency across the country for the reimbursement of pharmaceutical treatment, and increasing access to effective treatments.

Assessment findings

The findings of this assessment are described using the sequence in which people with viral hepatitis experience the infection. The following section outlines key findings from the interviews and uses quotes to illustrate key themes and issues emerging from the analysis of the interviews.

Many of the participants used the term “the big/small three” in the interviews to describe their stage of hepatitis B related liver disease, and that they or others with hepatitis B, were described as being ‘carriers.’

For the sake of clarity and accuracy, several China (n=10) based clinicians and people with hepatitis B were asked to define these descriptions. There was general agreement that having the big three meant that a person was positive for hepatitis B surface antigen, hepatitis B e-antigen and anti-core antibody (anti-HBc). This means that they had high levels of the virus, or using the natural history models, this could be seen as a person being in the first two phases of the infection - the Immune Tolerance or Immune Clearance phases. Having the small three was described as being surface antigen positive, hepatitis B e-antibody (anti HBe) and anti-HBc positive, representing stages 3 and 4 or in the Immune Control and Immune Escape phases of the natural history models. None of the clinicians noted the use of HBV DNA or ALT levels as an inclusion factor in defining either stage. Several participants noted that they understood that being e-antigen negative meant that their viral load was less, and this had fewer social implications.

A person is described as being a ‘carrier’ when they are surface antigen positive or have a chronic infection, and their ALT levels are within normal range, or as one clinician noted is in the first stages of the natural history model, i.e., the Immune Tolerant or Immune Control stages. Prof JiaJidong provides further detail by noting:

while the inactive HBsAg carrier is defined as the HBsAg carrier without active viral replication and significant

liver disease, the chronic HBV carriers are defined as HBsAg carriers with active viral replication but normal serum amino transaminase levels. The latter is a very important category of chronic HBV infection in China, where early life infection is common and immune tolerance phase lasts for decades. (61)

Testing

Many opportunities exist for a person to be screened, tested and diagnosed with viral hepatitis in China. Participants reported testing for viral hepatitis occurring through all levels of the educational system from kindergarten to university and including military school, workplace testing, testing prior to vaccination and when donating blood. While participants in this study with hepatitis B reported a variety of ways that they were tested, all participants with hepatitis C reported testing for this infection solely occurring through hospital based testing.

Thirty years ago, I was diagnosed with hepatitis A ... I was hospitalised for around two months ... When I was discharged, I was found to have hepatitis C.

(Male, 60-65yo, hepatitis C, Beijing31)

I had a heart operation, and had a transfusion, and in 1990 found out I had hepatitis C

(Female, 55-60 yo, hepatitis C, Beijing34)

Opportunities for screening hepatitis B commence in China at a very early age. School based screening for viral hepatitis was conducted within what several participants described as being a routine health check. The testing itself occurred within the school, and when a positive result was found several people were told to attend the hospital.

In primary school, year 5 there was a check-up. Another girl and myself were called up and



our teacher said please get your parents to take you to the hospital for a further check-up

(Female, 25-30 yo, hepatitis B, Chongqing28).

When I was 6 years old, when I was in kindergarten, every student was asked to do the body check, and at that time I got to know that I was carrying the hepatitis B virus

(Female, 30-35 yo, hepatitis B, Guangzhou10).

Back during my school days, I found out after going to a hospital for a health check-up. (I was) around 14 or 15 years old

(Male, 20-25yo, hepatitis B, Beijing38).

Various processes were described with university based testing for hepatitis B, with some people being tested and diagnosed at the university, or in several cases immediately referred to a hospital as a result of the testing for further investigation.

During the university entrance health-check, my teacher handed me a report and asked me to have a further virus count test for hepatitis B. That was the time when I knew that I was a hepatitis B carrier... I didn't know how serious hepatitis was

(Female, 20-25yo, hepatitis B, Shanghai20).

For one participant, becoming an adult provided them with the opportunity for donating blood, and it was through this process that they were diagnosed with hepatitis B.

I decided to give blood and before you give blood you have a test. The medical worker told me that there was something wrong with my blood and I may be infected with hep B virus ... I went to the hospital and got screened, and the doctor told me that I was infected with hep B. I just gave blood to celebrate my 18th birthday

(Female, 20-25yo, hepatitis B, Beijing40).

The familial nature of hepatitis B transmission was reflected by many participants, with the motivation

for testing occurring as a result of other family members being diagnosed with hepatitis B.

My mother was sick and went to the hospital for a check-up. The result turned out that she had liver cancer... so all my family members decided to have a check-up... (I was) around 12, 13 years old

(Male, 25-30yo, hepatitis B, Beijing43).

At first it was my daughter who got sick with hepatitis B, and ... the professor (at the hospital) told me: "Your daughter has hepatitis B, it's better for the parents to have a check-up as well." ... So both me and my wife had a check-up ... and were diagnosed with hepatitis B. I had hepatitis B E-positive, my wife had E-negative, my daughter was also E-positive

(Male, 35-40yo, hepatitis B, Guangzhou7).

Workplace testing for hepatitis B variously occurred prior to employment or as part of regular health checks being conducted by the workplace.

After graduating in 2002, I had been working for a company for half a year when the company conducted a welfare health-check, that's when I found out that I had hepatitis B

(Male, 25-30yo, hepatitis B, Beijing42).

(I was tested at a) health check centre. I wanted to be a pastry chef and I was required to have a "Personal health check record", and the issuing authority told me about it

(Male, 30-35yo, hepatitis B, Shanghai25).

None of the participants being tested for viral hepatitis as a result of their employment were working in industries where there was significant risk of them transmitting hepatitis to others, with several mentioning their office based work role.

I applied for the public relations manager for a very big factory, and everyone had to do the blood tests, especially for hepatitis

(Male, 30-35yo, hepatitis B, Guangzhou1).

The repetitive nature of testing for viral hepatitis in China, the restrictions on people living with the viruses, and the stigma related to the infection provides the context in which people with viral hepatitis reported undermining testing processes. Several participants reported processes in which they avoided being tested, particularly in relation to testing through educational and workplace institutions.

When I applied for post graduate study, I had to go through a health check-up which tests hep B. Even the government had banned this type of hep B health check, but there's still one conducted. So I asked someone to do it for me

(Male, 25-30yo, hepatitis B, Beijing39).

There were many ways that were described by participants in which they avoided being tested. A process mentioned by several participants was to ask friends to take the test in their stead.

I needed to keep this job ... I asked a very good friend of mine to do the blood test for me, to fake the result

(Male, 30-35yo, hepatitis B, Guangzhou1).

There was one time where the recruitment notice listed the requirements and prerequisites, so in order to get in I asked my friend to do the blood test for me, to cover up the fact that I have the disease

(Female, 20-25yo, hepatitis B, Guangzhou5).

While regulations providing for testing of viral hepatitis in relation to accessing education institutions and workplaces were amended in 2008, liver function testing is still permitted and was reported to still occur. For people with viral hepatitis, testing for liver function as opposed to screening for hepatitis remains problematic and several participants noted their continuing need to subvert these processes. For example, one person explained:

Before 2008, they already stopped the testing ... and when I started university, my mother

found a relative's child who is studying in the same university to help us do the test

(Female, 25-30yo, hepatitis B, Chongqing28).

Other processes for avoiding being tested included using connections within health services. The following quote highlights the essential nature of needing to receive a negative result to the hepatitis test, and the impact that this has on a person with viral hepatitis.

My parents happened to know the hospital personnel who conducted the health check in my high school, so that person changed my health check result from hepatitis positive to negative. So I was given a chance to rebuild myself

(Male, 25-30yo, hepatitis B, Beijing43).

Another participant described how he tried several options to avoid being tested within a workplace setting:

There was ... a company which I wanted to seek a position in, so I tried to bribe the doctor. The doctor who, was quite a righteous man, told me that I need to be responsible for my tests results and wouldn't help me with that. I ended up asking his colleagues, another doctor, to get through. The third time, I asked my friend to take the tests for me

(Male, 25-30yo, hepatitis B, Guangzhou4).

One participant was very clear in his advice to other people with viral hepatitis in relation to employment based testing:

Don't worry too much about the country's policy, if you have a good job offer, you just need to cheat or use connections to get you through

(Male, 25-30yo, hepatitis B, Beijing43).



Being diagnosed

Participants noted being variously informed that they were infected with viral hepatitis by their parents, teachers, and medical staff. A summary table describes the breakdown of the agencies involved in informing participants that they were infected with viral hepatitis. All the participants with hepatitis C were informed of their infection within a clinical setting.

Informed of infection by:	Numbers
Blood donation	3
High School	4
Hospital	12
Junior high school	5
Medical check-up	4
Parents	7
Primary school	3
University	6
Workplace	2

The majority of participants reported receiving very little information at the time of diagnosis, with many having limited prior knowledge about the infection or the implications of being infected.

I had never come in contact with (hepatitis) before, so I didn't know anything... The doctor said: "A lot of people are hepatitis carriers, but as long as the symptoms are under control and there's no relapse, there should be no problem"

(Male, 25-30yo, hepatitis B, Beijing38).

I was in junior high school, year 1 in 2000. There's a health check conducted by the school, and I found out that I was a hep B carrier. But at that time, neither the teacher nor the students had any knowledge about this disease, and my family also knew nothing about it

Male, 25-30yo, hepatitis B, Shanghai22).

Several participants described being shocked to find out that they were infected with viral hepatitis; *"it was like I was struck by lightning"* (Male, 35-40yo, hepatitis B, Guangzhou4).

Given the familial nature of transmission of the infection, several participants had known all of their lives that they were infected with hepatitis, and that as a result of their infection felt they needed to live in ways that were different from other people.

I was still a little child; my mother didn't tell me bluntly what I had, she just ... told me not to do intense exercise, even though I did like running and other sports a lot

(Female, 20-25yo, hepatitis B, Shanghai27)

Since my earliest recollection, I knew I had hep B. In my family, my parents don't have it, just me

(Female, 25-30yo, hepatitis B, Beijing45)

One principal theme resulting from the data gathered from participants is that hepatitis is not only a health or clinical issue for people in China, but has substantial social, emotional, economic and familial impacts. The impact of viral hepatitis on access to educational institutions, particularly before the 2008 regulatory change, was recognised by one medical professional in their provision of a diagnosis

At the time, the doctor said this was very serious, you need treatment; if you do not treat you may not go to university. And the whole family got very anxious about the whole thing

(Male, 25-30yo, hepatitis B, Beijing39).

As noted previously, people were tested and diagnosed with hepatitis in a variety of ways. That variety means that often participants received the diagnosis from teachers or through workplace human resource personnel. This means that the initial, and sometimes subsequent, impact of hepatitis is related to other issues than a person's health status. As one man from Beijing with hepatitis B described:

I had been working for a company for half a year when the company conducted a welfare health-

check, that's when I found out that I had hepatitis B. ... Because my company didn't have any privacy protection measures, the reports were there for everyone to see... I was quite worried about it because I thought it might cost me my job

(Male, 25-30yo, hepatitis B, Beijing42).

me to go to the hospital. He just told me that I had this disease, well, strictly, carrier is not equal to having the disease. He just told me: "You have hep B." and that's it. I didn't know what risks this disease would have on my health

(Female, 30-35yo, hepatitis B, Guangzhou2).

The breadth of agencies conducting testing for hepatitis meant several participants noted being repeatedly diagnosed and there were a variety of ways in which the diagnosis was provided to the participant.

During the university health check-up, I was really worried that the teacher and classmates would find out I have the disease. What happened was that the health check results were released in a way that only the name of the students who don't have hepatitis were announced, so no one paid attention to whose name was missing

(Male, 25-30yo, hepatitis B, Beijing43).

While information was provided at the point of diagnosis for several participants, sometimes the information needed is not necessarily around clinical markers, but about how to address the emotional impact of the infection.

It was a health check-up prior to the university entrance exam, so I was informed by my teacher. She told me point blank that I had hepatitis B. She also told me that only my surface antigen was positive, but the rest of the result such as liver function and HBV level were normal. I didn't know much about it, all I knew was it's a scary disease

(Male, 30-35yo, hepatitis B, Beijing46).

There was (a test) before going to high school, during which I was found to be a hepatitis B carrier... the teacher posted the health check results on the classroom wall ... so individual students could go and check what sort of problems they had, for example, short-sightedness

(Female, 25-30yo, hepatitis B, Shanghai27).

The psychological and emotional impact on some participants was severe, and several described leaving their educational institution for a period of time after being diagnosed, to seek time to address both the physical and the psychological impact of the diagnosis.

(The school) told me that if I had abnormal liver function and big three. I needed to withdraw from school ... because of this I had to withdraw from school for half a year

(Male, 30-35yo, hepatitis B, Shanghai21).

One participant was unaware that he had chronic hepatitis B until informed by the university he was attending when he went to get vaccinated.

When I was queuing up with a couple of my classmates for the vaccine, we were told that we were exempt and could go home, as people with hepatitis B should not be injected

(Male, 25-30yo, hepatitis B, Beijing41).

I took one year off university. The school suggested that I receive treatment because my liver function's not normal ... Not much information was given to me, I was just told that I needed treatment. They told me to come back to university when I recover

(Male, 30-35yo, hepatitis B, Shanghai24).

For most participants, the diagnosis was provided with little information about how to respond effectively to the infection.

(The doctor) just gave me a report saying I was a hep B carrier. E-negative, and that's it. Because it's just a general health check, so he didn't ask

Other participants described being informed that they were diagnosed with viral hepatitis as part of a group. For several, this process did not include the provision of information or recognition of any emotional impact,



while for others the way in which the diagnosis was provided was remembered several years after the event.

The teacher asked five of us, all girls, to go outside of the classroom, and all five of us were found to have hep B. She delivered the news with a smile, and told us that our situation's not very bad, and she specifically offered some words of comfort to me, probably because back then I was a cry baby

(Female, 25-30yo, hepatitis B, Beijing44).

In grade 3, 9 years old, I was dragged into a room ... 15 – 18 of us were invited into another room, and said that "yes, you guys are hepatitis B carriers"

(Male, 30-35yo, hepatitis B Guangzhou1).

Most people interviewed for the project were being clinically monitored for their infection. One participant noted that instructions about this came at the point of diagnosis.

They said there was no need to get medicine and they told me this kind of disease, you cannot be cured but you live like normal people, and there is no obvious symptoms you just like others, but you go to the hospital every six months to have a test and make sure that everything is ok

(Female, 20-25yo, hepatitis B, Beijing40).

A couple of participants reported processes in which they were diagnosed that were positive experiences for the provision of bad news.

My teacher ... told me that I was a hepatitis carrier... (and) that the hepatitis virus was not scary, and that around 10% of the world's population had it, so I didn't need to worry. ... She provided me with counselling and cited a lot of examples that a lot of other people also had it, too. For example Andy Lau, (celebrity) had it as well, but he'd been living normally

(Male, 30-35yo, hepatitis B, Guangzhou6).

While there can be benefits related to knowing that you have an infection, one participant was clear of his regret at being diagnosed.

I feel that I am very unhealthy, I can't really put my finger on how uncomfortable I feel. There is a big difference between my health condition before getting the disease and the health condition after I got the disease. I feel miserable

(Male, 35-40yo, hepatitis B, Guangzhou7).

The process of diagnosis occurs within a broader context of a person's life and the implications of being diagnosed were more complex than just being told they have a virus, and as one man noted:

Physically, the impact I experienced is minimal, because everything's normal as long as I take care of myself, but psychologically, the impact is huge

(Male, 25-30yo, hepatitis B, Beijing43).

Another participant stated "it's not the disease that is scary; it is the response that is scary"

(Male, 35-40yo, hepatitis B, Guangzhou4).

Familial context of infection

Most participants with hepatitis B, while reporting that they lacked knowledge about the infection, noted a family context in which hepatitis had already had a significant impact.

I had a certain level of knowledge about the disease because my mother had it as well. My knowledge about it was, it's a virus, and the transmission route was mainly through blood ... I knew it could be transmitted from mother to the baby... I have 2 brothers, and all three of us had 'small three'

(Male, 55-60yo, hepatitis B, Beijing37).

My father died at the age of 50 because of liver cancer. It was back in 2006. I have an elder brother, but he doesn't have hepatitis. My mother sort of had e-antigen negative. I was diagnosed with e-positive

(Male, 25-30yo, hepatitis B, Beijing38).

My mother transmitted that disease to my father when they got married ... my uncle also



has it ... besides that my grandmother has it ... and my grandmother's elder sisters

(Female, 20-25yo, hepatitis B, Shanghai27).

While several participants noted the deaths of family members as a result of hepatitis and liver cancer, for some participants with hepatitis B, having family members who were infected was seen as unexceptional and reduced any anxiety related to being infected with viral hepatitis.

I thought it was just one of the common diseases... in my family there were a few relatives who had this type of disease, so they think it can be treated... my mother has it, my father was a carrier, but was cured before I was born

(Male, 20-25yo, hepatitis B, Guangzhou15).

For other participants, one person being diagnosed, particularly with hepatitis B had a significant impact on their families given the familial nature of transmission and which meant that the trajectory of their lives would fundamentally change.

My father took me to the hospital for a check-up, and I was diagnosed as E-positive, though the level was not very high, and my family had check-ups as well, and my father was found out to have it as well, but he didn't care at all. My younger brother had a fatty liver, but my mother was very healthy. After I was diagnosed with hep B, my father tried to keep his distance with me

(Female, 25-30yo, hepatitis B, Beijing44).

My parents have it, my relatives on my mother's side have it, two of my mother's siblings. My mother's younger sister and younger brother and younger brother's daughter have it. My father died of liver cancer when I was around 16 years old

(Male, 25-30yo, hepatitis B, Guangzhou11).

The disclosure of infection to family members also occurs within a broader social and political context in China with the implementation of the one child policy in 1979. For a family with one child, the diagnosis of this child with a chronic infection is particularly significant.

*I am the first generation of the only child.
Good for Ma and bad for me at the same time
...my mother really condemns herself*

(Male, 30-35yo, hepatitis B, Guangzhou1).

The impact of the implementation of the vaccination program essentially affected who within their family was infected.

In Guangdong Province, hep B is very common, basically people from my generation, 7 out of 10 of them have hep B. My older and younger sister and I all have it. There are five children in my family and the oldest three children were all born in the 1980s and all have it. But my younger brother and the youngest sister who were born later don't have it. Because at that time, the vaccine was available

(Female, 30-35yo, hepatitis B, Guangzhou2).

Infection with hepatitis B has significant social, economic and health implications. Several participants reported members of their families choosing not to be tested as a result of the economic implications of the infection and access to treatment.

I don't know whether my parents have it or not because I asked them to go for a check-up, they didn't go. They just told me they didn't have it ... Because we are from a rural village and we didn't have much financial capacity, so they were probably afraid of the expense. You know, if you were rich, you could go for a check-up anytime you want. But my family had financial difficulties

(Male, 20-25yo, hepatitis B, Guangzhou12).



Economic Impact

Being infected with viral hepatitis had a significant economic impact on most participants. This economic impact can be seen throughout the trajectory of the personal experience of living with viral hepatitis.

China has experienced significant economic structural changes over the past 40 years, with an increasing middle class, industrialisation and the movement of people from rural to urban centres. Several of the participants reported having strong emotional and psychological responses to finding out that they were infected with hepatitis, particularly when it occurs within a context of significant family sacrifice resulting from increasing or consolidating their economic status.

I came from a rural area, and I was the only one in my family to have the chance to go to university, my mother was a single mother who brought me up, the reason I went to university was because I wanted to find a decent job. I had no idea how I managed to walk out of the hospital. It's like I was hit by lightning. I didn't dare to tell my mother

(Female, 30-35yo, hepatitis B, Guangzhou13).

This incident had a great impact on my parents because my parents were peasants; their only hope in their lifetime was for me and brother to go to university

(Male, 25-30yo, hepatitis B, Shanghai22).

My health condition placed me under a lot of pressure ... I couldn't cope with a heavy workload ... my studies lagged behind ... I had to ask my family to support me financially, so I felt I betrayed their expectations

(Male, 25-30yo, hepatitis B, Beijing41).

The diagnosis of hepatitis B in one person in the family was reported to have led to the diagnosis of several family members for several participants. For one man who moved cities to access treatment, which required him to find casual work when possible, the economic impact was devastating.

It placed a huge financial pressure on me as my whole family had the same disease, the pressure was unbearable ... my wife has to take medication, I have to take medication, my daughter has to take medication

(Male, 35-40yo, hepatitis B, Guangzhou7).

For several participants, testing for viral hepatitis limited the scope of the employers available to them and their choice of employment:

I am working in a small factory ... I was forced to work in the small one, because large factories conduct health checks, so I can't enter ... To enter big factories, I might need to bribe the staff by giving them a couple thousand RMB. Basically, to buy my way in

(Male, 35-40yo, hepatitis B, Guangzhou3).

In China (people with viral hepatitis) cannot join the military, and my childhood dream was to be a soldier

(Male, 30-35yo, hepatitis B, Shanghai26).

Infection with viral hepatitis was reported to essentially affect employment choices and the location where one participant chose to live.

I can only find jobs with which I am not totally satisfied. The reason I came to Beijing to seek jobs was because I thought Beijing's policy was more flexible

(Male, 25-30yo, hepatitis B, Beijing43).

Several participants reported losing continuous employment as a result of being infected with viral hepatitis.

In 2009, I joined a company and ... applied to be a clerk in the warehouse. During this period they asked to do a check-up and then go on probation. After probation, they looked at the (medical results) and said they cannot, you need to resign because the result is positive

(Female, 25-30yo, hepatitis B, Beijing45).

The change of regulations reducing workplace testing for viral hepatitis, particularly in state



owned enterprises was reported by one participant as having no impact on their job seeking.

I went to a state owned enterprise; the interview went all right, but then the person in charge said they need to do a medical check-up. I know that nowadays, when you medical check-up it will be all right because I can pass the liver function test no problem. It is hep B; got rejected as a result of disclosing hep B

(Female, 25-30yo, hepatitis B, Beijing45).

The emotional and economic burden of the infection, particularly in relation to treatment access, including continuing treatment, was noted by several participants, particularly those having moved from more economically challenged rural areas.

I desperately want to get rich, because I am so poor...if I have money, I can receive the best treatment... my parents are frustrated right now, and they want me to stop taking medication, but I don't dare to... they suffer because of me

(Male, 20-25yo, hepatitis B, Guangzhou12).

(My) parents didn't come up to me and tell me, it's was me who approached them because I sensed that they were acting a bit weird. I still remember vividly what happened that day, I came home and my father lying on the ground crying, and he said: "Son, I am sorry, I don't have money for your treatments!" So I asked him what was going on, and that's the time he told me

(Male, 20-25yo, hepatitis B, Shanghai19).

For one man, a man with hepatitis B who lived in a rural farming area and who had been hospitalised with cirrhosis, the impact of infection was emotional, economic and fundamentally affected his standing within the household:

I cannot be the head of the household anymore and my wife has become head of the house, because the disease has harmed me... (I) don't want to treat because it is not easy to treat

(Male, 50-55yo, hepatitis B, Beijing36).

Psychological impact

Many participants described being scared of the infection as a result of either their own lack of information or of societal attitudes to people with hepatitis.

I am an X-man but without any super power. That is really like a branded mark in my heart, that I feel bad about myself... in my childhood I had been told I am a lethal weapon

(Male, 30-35yo, hepatitis B, Guangzhou1)

I was very scared. Most of the time people with hep B are like a vampire movie - we cannot go into the sunshine, and you cannot let people know who you really are. There is always some wall between you and others

(Female, 20-25yo, hepatitis B, Beijing40).

This fear and lack of information about viral hepatitis among people with the infections, and within the community as a whole, affected people within educational settings and in workplaces.

My teacher, who bought the school catering business, told the whole class not to go outside the school for meals as we would have higher chances of getting hepatitis, and that universities won't accept those who have hepatitis. This comment had a great impact on me because it meant I couldn't go to university

(Male, 25-30yo, hepatitis B, Beijing43).

People say it's very harmful, and can do huge damage to your body, and could get everybody in the factory killed. That's what they had this rumour circulated in the factory...I was very depressed, I was very concerned about this situation, I was even totally believed that I could get everybody transmitted including the people who had a close relationship with me

(Male, 30-35yo, hepatitis B, Guangzhou1).



In a reflection of a previous quote, several participants noted isolating themselves and withdrawing from contributing in the wider community:

It is scary because if you have it you cannot socialise ... if you lose an arm, the most you cannot do is don't shake hands with people

(Male, 25-30yo, hepatitis B, Beijing 41).

You're different. You're a carrier ... when people talk about hep B... you should get away from the people with hep B. I was silent, I didn't talk too much

(Male, 30-35yo, hepatitis B, Guangzhou1).

I hide myself

(Female, 25-30yo, hepatitis B, Guangzhou5).

I carry a burden

(Male, 30-35yo, hepatitis B, Shanghai21).

I even thought about suicide. I hid from people for several months

(Female, 20-25yo, hepatitis B, Beijing40).

While most people interviewed noted a significant emotional response to viral hepatitis, several reported that the lived experience of infection with viral hepatitis differed markedly from the perceived experience or from what they or others expected.

For the general public it might be a scary disease but for me, who has it, I feel like I am just a normal person like everyone else

(Female, 20-25yo, hepatitis B, Guangzhou5).

Not much impact, I eat normally, drink normally, go for holidays, climb mountains, overseas for holidays, no difference

(Female, 50-55yo, hepatitis C, Beijing34).

Assumptions of transmission

While the assumed evidence of hepatitis B transmission in China is occurring from mother to child, there were a variety of assumptions made by participants about how they were infected. The question was not one that was initially asked given the lack of relevance to the aim of the assessment, but the variety of answers are worth reporting given their conflict with common epidemiological or transmission understandings. The table below lists the self-reported routes of hepatitis transmission.

Transmission route	No. of people reporting (hepatitis B)	No. of people reporting (hepatitis C)
Airborne transmission	1	
Alcohol use	1	
Blood transfusion	1	1
Dentist		1
Ex-wife (who experienced cancer)	1	1
Health care service	2	
Mother to child	8	
Reuse of vaccination needle	8	
Sharing food/utensils	3	
Sharing toilet	1	
Don't know	5	

Four of the people with hepatitis C were asked how they thought they were infected. One reported not knowing, while the others variously reported the infection occurred through a dentist, blood transfusion, and one man reported being infected by his ex-wife.

I suspect I got infected by my ex-wife ... She died at the end of 2012 because of liver and gallbladder cancer. That's just my guesswork, of course there's no way I could find out

(Male, 45-50yo, hepatitis C, Guangzhou9)

While some responses appear to reflect a lack of accurate knowledge, they don't necessarily reflect a broader ignorance about the infection by the individual participant. The participant reporting being infected

with hepatitis B as a result of airborne transmission was tertiary educated and was particularly knowledgeable about viral hepatitis clinical management including the rationale for monitoring. One person, while being very clear and accurate in their understanding of how hepatitis B was transmitted also reported that their infection occurred through the sharing of food utensils. Of two participants reporting being infected through the vaccination program, one acknowledged that their mother was also infected with hepatitis B, while the mother of the other participant had died of liver cancer.

One young woman noted:

I guess it was from mother to child, I am not sure... I grew up in the rural countryside so I wasn't exposed to an unsanitary environment, but strangely enough my mother doesn't have hepatitis B

(Female, 20-25yo, hepatitis B, Guangzhou5).

Knowledge of identifying how a person was infected was also hampered by families being unwilling to be tested for the infection. This lack of willingness occurred for a range of reasons including the lack of options available to them if they should be diagnosed with the infection.

Maybe from mother to child. My mother didn't have a test, so I am not quite sure. Another possibility could be from an injection. Because I grew up in the village, and the syringes we used were not one-off syringes, they're made of glass, so I might have been transmitted by that.

(Female, 20-25yo, hepatitis B, Shanghai 20).

Disclosure

The social implications of being infected with viral hepatitis in China are significant, and several participants noted the predicament they were in when wanting to disclose to others that they had the infection.

I'm in a dilemma. One way you want people to accept you, and under the condition that they know that you have this disease, but on the other side I am afraid to tell them because I am afraid I will be rejected. You won't be accepted totally, but I am still not brave enough to tell others

(Female, 20-25yo, hepatitis B, Beijing40).

One person with hepatitis C noted a Chinese cultural norm acting as a motivator for disclosing to others:

In China we want 'face'. I don't want ... a person to say to me that you have an infectious disease, why you never tell me, so I tell people ... I am responsible for myself and I am responsible for you as well, we respect each other

(Male, 55-60yo, hepatitis C, Beijing48).

The process of disclosure for several participants was done over time, with one person describing a need for emotional safety before being able to disclose:

I tell people gradually when I feel safe and comfortable I will have the courage to tell people about this

(Female, 20-25yo, hepatitis B, Beijing40).

The stigma related to viral hepatitis essentially affects how and to whom people with viral hepatitis disclose their infection to, and is an essential barrier to disclosure.

I don't like to tell, because I feel inferior because I am sick, and also about how society treats you if you have hepatitis B or hepatitis C

(Male, 45-50yo, hepatitis C, Guangzhou 9).



I only tell my close friends, of course within them there are some who still feel uncomfortable with it, but just a couple of them, not many. But the others, when they mention hepatitis in casual conversation, they seem to be very scared about it

(Female, 20-25yo, hepatitis B, Guangzhou 16).

Most participants reported disclosing to a small number of people. These included family members, friends and, for some, workplace colleagues.

Family

The protection of participants' families was described by several as being the motivation for informing them of the infection.

Not many people know my condition. I am afraid that if I tell them, they will distance themselves from me ... I told some of my relatives and people who are very close to me ... I told my relatives because I want to prevent them from getting the same disease as me, so I told them the things they should be aware of

(Male, 20-25yo, hepatitis B, Guangzhou12).

Another form of protection of the family was described by another participant who had not disclosed his infection to his family given their response to his brothers' disclosure of the infection.

They don't know I have it. My parents had tests done and found out that they too had hepatitis... I don't want them to worry about me because my family was very worried when they found out about my brother's disease

(Male, 25-30yo, hepatitis B, Beijing42).

An essential issue in China is the lack of accurate information about viral hepatitis among people most affected. For one participant, who had been tested and diagnosed through school based testing, meant that they had only disclosed their infection to their parents until the possible infection of their children had become an issue.

In 2008, when my older sister had her first baby. She's also a hep B carrier, and her new born must have the

vaccine within 24 hours. I just realized that I was in the same situation so if I had a baby, I need to do the same thing. That's also why my family found out

(Female, 30-35yo, hepatitis B, Guangzhou2).

Even with the familial nature of hepatitis B infection, families were not necessarily supportive of participants. One man with hepatitis B who was diagnosed when he was 6 or 7 years of age reported the response of his relatives to his diagnosis:

My relatives were afraid of getting infected and asked me not to go to their home again

(Male, 35-40yo, hepatitis B, Guangzhou3).

Friends

The lack of accurate information about viral hepatitis had an impact on several participants in terms of the number of people and their relationship with the people whom they had assumed were at risk as a result of their infection.

I told my flatmates and that we shouldn't share eating utensils ... I begged them not to tell others, because I do not live close to others I think it will do no harm to them and I do not want to cause trouble to myself. The less people know the better

(Female, 20-25yo, hepatitis B, Beijing40).

I told people who are close to me and whom I used to share food with, as I don't want to get them infected. Some of them are not worried because they know it isn't transmitted that way but the rest of them are still a bit worried. When we have meals together, they will serve me food to prevent me from touching the food

(Female, 20-25yo, hepatitis B, Guangzhou16).

The nature of a late diagnosis provided the context in which it was impossible for one participant to keep his infection secret:

More than a dozen of my friends knew. Because I was admitted into hospital and my university mates came to visit me

(Male, 25-30yo, hepatitis B, Beijing39).



Several participants reported leaving school for up to 12 months when they were diagnosed. The implications of this process included a form of disclosure: "I had to withdraw from university, so everyone knew"

(Male, 20-25yo, hepatitis B, Shanghai30).

Within educational settings, selective disclosure was one strategy used, where an acknowledgement was made of having hepatitis, although being discrete about the type of hepatitis:

I didn't tell them specifically what type of hepatitis I had, I just told them it is hepatitis. They didn't ask me in detail anyway.

(Male, 20-25yo, hepatitis B, Guangzhou15).

I told them I had alcoholic hepatitis... most people think that alcohol hepatitis is not infectious

(Male, 45-50yo, hepatitis C, Guangzhou9).

Work

Various participants described a variety of processes in which they disclosed or made the choice not to disclose within workplaces.

In the past, because of work, when you have to tell others, I would tell others. But in total, I only told two people from work. I think this is problematic, because it infringed my privacy, and I was asked to provide a health certificate, so I had to tell them

(Male, 25-30yo, hepatitis B, Guangzhou11).

While there have been significant changes in the employment regulations affecting people with viral hepatitis since 2007, the social implications of the infection and the poor knowledge about viral hepatitis among the broader community meant that for one participant there was a need to keep silent about her infection.

Just like the people in my current workplace, they don't know that I have hepatitis B. I can cover up this fact as there's no health-check for e-positive or e-negative hepatitis. My colleagues would sometimes say something like "don't dine out, beware of catching hepatitis", or something like that

(Female, 20-25yo, hepatitis B, Guangzhou5).

When it comes to work, I think I still lack the courage to tell the interviewer that, you know, "I have hep B, will you hire me still" or something? I don't have the courage to do this. I think it's an expression of honesty. I think it's just, like for example, you want to get married with someone, I think you must tell them the truth. With work, I think, you should be loyal to your employer

(Female, 25-30yo, hepatitis B, Beijing40).

Even if a person with viral hepatitis is accepted within the workplace, if they are diagnosed and disclose having the big three, which is thought to have greater infectiousness, they can face further issues of alienation. One factory worker noted:

If your colleagues find out you have the big three, they seem to look at you differently, very scared of you

(Female, 25-30yo, hepatitis B, Dong Guan17).

There were fears of significant ramifications for people, particularly for one participant working alongside the food industry, even with no opportunity for transmission:

I am afraid of telling my colleagues as I am working in a catering business. I am a food delivery man - would you order food from me? ... This job is my meal ticket

(Male, 30-35yo, hepatitis B, Shanghai25).

One issue of the multiple processes for testing people for viral hepatitis, particularly outside of medical services, is the issue of confidentiality of these test results, particularly for an infection with such important social consequences.

The way the company deals with the complementary health check is no good. For example when the report comes back, it goes through the HR department, and maybe the HR department are not very professional and they read and tell other people about it. This is not ideal

(Male, 25-30yo, hepatitis B, Beijing42).



One participant, working within a factory noted that while there had been a change in testing patterns over the previous two years, there was still a need to be discrete in relation to disclosure within workplaces.

Not many of my colleagues know because people with an old mind-set show their fears once they hear 'e-positive' or 'e-negative'. They are afraid of being infected

(Female 25-30yo, hepatitis B, Dong Guan17).

For another participant, there were very clear boundaries set within one of the workplaces in which they were employed for people with viral hepatitis.

You guys should eat in one corner, because all the hep B carriers assembled together to eat share their food at the one table. You are not allowed to eat with other people

(Male, 30-35yo, hepatitis B, Guangzhou1).

Health promoting behaviour in response to being infected with viral hepatitis also provided an opportunity, if not for full disclosure of being infected, at least an indication of difference with the need to modify some behaviours.

When I dine out with my colleagues, they usually order fried food, which I can't eat. I really want to eat it; it's hard to withstand the temptation because I really like deep-fried food ... So there are a lot of inconveniences in my daily life. I also need to pull myself away from alcohol

(Female, 25-30yo, hepatitis B, Dong Guan17).

For most participants, having viral hepatitis required an investigation of the human resources processes instituted within potential employers. One participant, concerned at starting employment at a new company, questioned the human resources division about the viral hepatitis testing in the workplace. His concerns about disclosing in the workplace were misplaced given that the hierarchy and many of his colleagues within the workplace were infected with viral hepatitis.

I was very worried in the beginning...Before I started my current job, I asked HR specifically

whether hepatitis is part of the health check and they said no... it only checks your liver function but not hepatitis ... some of my colleagues, including my supervisor and my boss from upper management level, also have hepatitis

(Male, 30-35yo, hepatitis B, Beijing46).

Educational institutions

The testing and disclosure processes in educational institutions have the potential for significant and long term impact on people with viral hepatitis.

I am an intern and my company is planning to arrange an internal group health check for hepatitis in July... I am very worried that if the results showed that I had it, the company may ask me to leave or something... I heard that there's a medication which can temporarily turn the result from positive into negative. ... There seems to be no other way

(Female, 20-25yo, hepatitis B, Guangzhou16).

These often inadequate processes affected some participants from a very early age.

For each health check I was singled out by the teacher to redo the test. I was the only one of the whole class who was asked to do so, so my classmates asked me what had happened... I was around 7 years old

(Female, 20-25yo, hepatitis B, Guangzhou5).

Given the lack of accurate information and the stigma related to the infections, confidentiality of test results becomes an important issue. For one participant, the breaching of confidentiality within an educational institution occurred as a result of poor delegation.

In China, sometimes the teacher would ask the class rep to manage student profiles, so some of the student representatives found out about my situation and would talk behind my back and during my third year of high school, whenever I went for a swim there was always 4 or 5 students who refused to swim in the same swimming pool. They knew I had hepatitis B

(Female, 20-25yo, hepatitis B, Guangzhou5).



Relationships

Over half of the participants with hepatitis B interviewed for this study were under the age of 35 years and discussed the challenges of having viral hepatitis and developing intimate relationships. Many participants noted the difficulty of disclosing to partners or potential partners that they had viral hepatitis.

It's hard for me to find someone because I have hepatitis. Because people generally are scared by it and personally I feel that even if I find someone, I would feel awkward telling her about my condition... there's a girl I met on an online dating website who I had feelings for, but after I told her that I had hepatitis she turned me down

(Male, 25-30yo, hepatitis B, Beijing42).

For one young woman, this meant not engaging with romantic relationships at all:

I am not prepared to tell (a boyfriend) because I think you will get refused and I am afraid to be hurt

(Female, 20-25yo, hepatitis B, Beijing40).

Various strategies were used for disclosing, including disclosing before emotional involvement had developed, or after a significant period of time within the relationship where there was more to lose. Several participants waited until they felt it was an appropriate time for them to disclose.

I had two boyfriends in the past, I told my first boyfriend at the beginning of our relationship that I had hep B, and I don't think he loved me, I think he stayed in the relationship out of pity, so we broke up eventually. My second boyfriend didn't care and we got along well, he introduced me to his parents during Duanwu (Sticky rice cake) Festival, and his parents firmly opposed our relationship. His parents were so determined to separate us, to the extent where they were willing to disown their son if he choose to be with me

(Female, 25-30yo, hepatitis B, Beijing45).

I told her after 3 or 4 months after our first date. She was surprised, and she only asked

"am I going get that very easily?" I said no because ... you're vaccinated already

(Male, 30-35yo, hepatitis B, Guangzhou1).

The process of finding a partner was challenging for several of the participants, as the following quote illustrates:

Recently I have been looking to start a relationship. I have met 4 or 5 boys but because of this disease, I was rejected by them all

(Female, 25-30yo, hepatitis B, Shanghai20).

Within China, a couple of participants reported that the disclosure of a viral hepatitis status to a partner or potential partner was a disclosure to the rest of their family:

In China when two people get married, it is the business of two big families. When you want to get married, you have to consider whether the whole of the extended family of the other party will affect their condition

(Female, 30-35yo, hepatitis B, Guangzhou13).

My girlfriend's family didn't want us to be together any more after they found out about my condition. They told my girlfriend to break up with me. But my girlfriend insisted on staying with me

(Male, 25-30yo, hepatitis B, Beijing39).

Every time I have a boyfriend, and we get close and I tell them I have hepatitis B, but when he told his parents, they were so afraid

(Female, 35-40yo, hepatitis B, Guangzhou10).

One participant, for whom having viral hepatitis was generally not of significant importance still found the issue of romantic relationships vexing:

Generally I am not worried about it. But I don't know how to deal with this matter when I am in a relationship

(Male, 30-35yo, hepatitis B, Shanghai29).



One participant, who at the time of the interview had not disclosed his infection to his girlfriend and felt guilty about this lack of disclosure, explained his rationale for not disclosing resulted from a concern about her lack of knowledge about the infection:

I have a girlfriend, she's a very nice person, so I feel really guilty being with her. I don't know how. (Did you tell her?) No. We are from the village, and we didn't receive a lot of education, because we don't have much knowledge, we tend to think that people with diseases are no good. If I tell her, she might break up with me

(Male, 35-40yo, hepatitis B, Guangzhou 3).

While most participants noted the difficulty in disclosing their infection, one highlighted that there had been a change in attitude within the general public in recent years, stating that “some people may think it is a big deal, but others think it is acceptable” (Male, 30-35yo, hepatitis B, Beijing46). This participant also noted that an increase in government activity had reduced the level of stigma related to the infection, making it easier to get peer support.

In recent years, people have gained an insight into this disease and think of it as less scary and there are government funding health check in rural villages now... so people who have the same disease feel liberated to discuss it.

Further on in the interview though, this participant noted that in spite of a change in attitude about the infection within the broader community, he still worried about disclosing to friends as “this disease might jeopardise friendship and communication.”

Information about viral hepatitis

The provision of accurate information about hepatitis supports a person living with the virus in reducing the physical, emotional and social burden of the infection.

This disease had caused me a lot of problems and stress but as I gradually learned to accept it, and I kept gaining knowledge about it, I can say that I am fine with it now

(Male, 35-40yo, hepatitis B, Guangzhou4).

Wang Dage's sister grieves at her brother's gravesite. Hepatitis B has been called the “silent killer” because it strikes without warning. There are usually no symptoms until the cancer is very advanced.



The lack of information or general knowledge about viral hepatitis comes in a context where there is seen to be a lack of accurate information for people with viral hepatitis, or within the community in general. This was noted as a result of a lack of activity from the government in providing accurate information.

The government hasn't done enough to promote public awareness about hepatitis ... Even though the risks of being infected are very small; the public still fears this disease

(Male, 25-30yo, hepatitis B, Beijing42).

A critique was made of one government-supported awareness raising campaign that, for this participant, was unsuccessfully targeted and had little impact.

There's one infomercial produced by the Department of Hygiene, was endorsed by Andy Lau ... It didn't mention transmission routes ... (like) you won't get infected by just having a meal together, and it didn't mention that there should not be discrimination against the disease either. All it said was "show your care to hepatitis patients" ... the content was cryptic and obscure

(Male, 30-35yo, hepatitis B, Shanghai29).

The non-government health industry in China is lightly regulated and this provides the opportunity for the development and advertising of hospitals providing fake treatments that claim to cure hepatitis. Promotional material supporting these services are often alarming, and many participants noted the provision of skewed knowledge or information about hepatitis to both the general public and people living with viral hepatitis.

Back in 2008, my brother took me to a hospital which was advertised on TV. The treatments weren't very effective and they cost a lot, so I only received treatment there for one month. Afterwards ... (at) another hospital, I went there for a few injections. But after going there for two weeks I found out that all these hospitals were not all they were hyped up to be. They were scams. It's not possible to cure my disease

(Male, 25-30yo, hepatitis B, Beijing41).

I learned about the negative side from TV commercials, they advertised that hepatitis B in serious cases can lead to liver cancer etc., and they'd brag about how good their medication was

(Female, 25-30yo, hepatitis B, Shanghai 20).

I hate those misleading TV or radio commercials about hepatitis, they reinforced people's fear and deepen their misunderstanding about hepatitis. This is also the reason I am afraid of telling others about my disease as some people may be biased by these commercials and develop a misconception, once I tell them, they will think that it is a very scary disease

(Male, 30-35yo, hepatitis B, Beijing46).

Some of the concerns about these claims were also related to location, particularly in smaller Chinese cities.

There are still many ... fake medical advertisements, they are ... broadcasting fake drugs, fake treatment, fake everything. And nowadays there are many clinics in the second and third tier cities that are making loads of money by producing fake drugs

(Male, 30-35yo, hepatitis B, Guangzhou1).

Several participants, diagnosed through an educational institution, noted the lack of information or education in those settings about public health generally or hepatitis specifically:

There's no public health information in the educational system

(Female, 25-30yo, hepatitis B, Chongqing28).

I was in the one of the best primary and high schools ... no-one came to our school to talk about hepatitis. Nobody came to tell us why you are a hepatitis B carrier, and how it was transmitted, how you got the disease and how you can tell the others to have a better life, to protect your liver

(Male, 30-35yo, hepatitis B, Guangzhou1).

The lack of information was also seen to affect health care workers, and several of the participants



noted that they had better knowledge about the infection than health care workers.

The doctors ..., who work in county level clinics, might not always provide accurate information. As a patient, I have a lot of opportunities to exchange opinions with others on social or community occasions, plus I always go to hospitals, so I can surely say that those doctors probably had less knowledge about hepatitis than me, a hepatitis patient

(Male, 30-35yo, hepatitis B, Beijing46).

In the past, doctors would prescribe medication and stuff once you were diagnosed as e-positive, but recently no doctor does that anymore. They just tell you there's no effective medication, that you just need to refrain from eating deep fried and oily food and refrain from staying up all night

(Male, 25-30yo, hepatitis B, Dong Guan18).

My father is a specialist in kidney in one of the best hospitals in China, but his knowledge in hepatitis is very limited

(Male, 30-35yo, hepatitis B, Guangzhou1).

Many of the participants described a lack of confidence in their knowledge about their infection or how to judge what information was correct.

There is some information, but I don't know how to work out which information is right or wrong

(Female, 25-30yo, hepatitis B, Chongqing28).

One young woman, highly educated and otherwise knowledgeable about hepatitis B, described inconsistent responses to the infection within the family.

They do not ask me to eat separately... we use the same towels, we sleep together, and nothing is special. But my aunt will prepare a bowl for me, and when we've finished she will get the bowl and chopsticks and put them in the microwave oven because she thinks that saliva or other liquids from your body can transmit through these channels... I also I think there is some risk (of transmission through saliva) even although

the research and the medical people said it won't be transmitted through these channels ... I think it is safer

(Female, 25-30yo, hepatitis B, Beijing 40).

Many participants described using the internet and other electronic discussion forums as a means of getting information about living with the virus, getting peer support for the infections, and making friends and connecting with others living with viral hepatitis.

I am thankful that I get access to the internet, because I am able to add other 'battle mates' with hep B to my QQ group (Online social network). They told me not to drink alcohol and have regular check-ups ... after learning about hep B, I have been keeping regular hours, avoiding oily deep-fried food and stopped drinking alcohol even in social gatherings

(Female, 25-30yo, hepatitis B, Beijing44).

Web-based communication processes were reported by key informants as being used to provide health promotion information to people with viral hepatitis, including reminders for monitoring. The internet groups also provide information that is not provided by clinical services, or provides information in a more accessible manner that clinical services are able to do.

In the QQ group, there are people, 'hep B battle mates', who answer your questions. When I first got the hep B five indicator test results, I didn't know how to read it. You know, many doctors today don't give you a detailed explanation, they simply go straight to prescribing anti-virus meds for you to take ... Some 'senior battle mates' or some hep B patients, who have learnt a lot about the disease through being long-time sufferers, and they have become experts in this field and helped me by explaining the situation

(Female, 25-30yo, hepatitis B Beijing 44).

Internet based services also provide a level of emotional safety – an important resource for a person with an often stigmatised health condition.

I tried to find a boyfriend through social media, so I have joined some QQ groups in order to have a chat with others. I might not be able to find someone I like immediately, but

online I feel that everyone's the same, we are equal, and I feel comfortable and happy

(Female, 25-30yo, hepatitis B, Beijing45).

Other forms of internet based information and support included individual blogs from specialists, two of which were specifically mentioned.

While most of the participants with hepatitis C reported less need for information, in one case they knew less about the hepatitis they were infected with than other hepatitis viruses, "I know hep A and hep B but nothing about hepatitis C" (Male, 40-45yo, hepatitis C, Beijing47).

Health promotion

Various harm reduction strategies to reduce the impact of infection with viral hepatitis were described by participants. At a simple and accessible level, several participants reported the following health promoting interventions being used:

- Not staying up late (Shanghai 19, 24, 29, 30, Dong Guan 18, Beijing 41, 48, Chongqing 28, Guangzhou 16)
- Not getting tired (Beijing 48, Shanghai 22)
- Physical exercise (Shanghai 19, 29)
- Avoidance of fried food (Shanghai 19, 26, 30 Guangzhou 5, 15 Dong Guan 17)
- Avoidance of alcohol (Shanghai 19, 22, 24, 26, 29 Guangzhou 5, 12, 15, 16, Beijing 46, 48)
- Avoidance of spicy foods (Dong Guan 18, Chongqing 28, Guangzhou 16)

Other interventions included: not eating barbecued chicken or lamb; eating protein powder and calcium; eating 'soft food' – porridge, noodles, bean curd; eating 'lighter' food; not over-eating or getting angry; not smoking, and eating plenty of fruit.

The asymptomatic nature of the infection, alongside the lack of accurate information for people with the viruses has a significant impact on how people respond to physical implications of the infection.

I am confused about how you really deal with hep B, because sometimes I feel that I cannot deal with it because I struggle in my heart and my mind and how to deal with right and wrong

(Female, 25-30yo, hepatitis B, Beijing40).

Several participants talked of the need to negotiate through the unregulated medical system, including identifying credible treatment services. One mentioned their experience operating within a context of fear resulting from the original hepatitis B diagnosis.

They were very anxious and worried, and they would like me to have the disease treated as soon as possible. So they bought a lot of medication from that hospital, and I took them for a while, but the results of the test didn't show any improvement. Then, we switched to another hospital, so in total we spent around two years visiting hospitals for my treatments. I was 14 years old. So that lasted from 14 to 16, 17 years old. In hindsight, all the treatments were useless, they were all fake medications. None of the medicines were anti-viral

(Male, 25-30yo, hepatitis B, Beijing 39).



Clinical Management - Monitoring

Of the 46 people with viral hepatitis interviewed for the assessment, 17 were recruited through clinical services, including all five of the people with hepatitis C. The majority of all participants were having their infection clinically managed, as shown in the following table. The categories used are not mutually exclusive, meaning several participants are counted in more than one category.

Type of clinical management	No. of people with hepatitis B	No. of people with hepatitis C
Not reported	1	1 (1st hospital visit)
No clinical management	3	
Monitored (irregular)	3	
Monitored (annual or more)	22	
Antiviral treatment	14	
Hospitalised	5	4

There were few barriers identified by participants related to monitoring their hepatitis B infection:

The hospital in Beijing asks you to check ALT levels if you told them you are a carrier

(Male, 25-30yo, hepatitis B, Beijing 39).

I have regular check-ups on my liver function but not to see if I am e-positive or e-negative

(Female, 20-25yo, hepatitis B, Guangzhou5).

For one man, diagnosed through an educational institution, regular monitoring was the motivating factor in ensuring that his viral load was low enough to allow him to continue his education:

All I know ... I have to do the blood test twice a year, because to make sure that my virus load is ... low enough for me to share together with other

classmates. That's the only one thing that I can remember from my childhood, and my youth

(Male, 30-35yo, hepatitis B, Guangzhou1).

One participant noted that their monitoring of viral hepatitis occurred as a result of the health checks conducted with all students conducted at their university:

Every year the school organises the health check. Everybody has a liver function test – this is only a small part of the whole check-up

(Male, 20-25yo, hepatitis B, Guangzhou15).

The changes in the regulations providing for the testing of employees or potential employees for viral hepatitis was noted by participants as having an impact on their monitoring of the condition:

(The) change in testing policy means that you are not tested as often

(Male, 20-25yo, hepatitis B, Shanghai19).

Several barriers existed in the process for some of the participants in being monitored for viral hepatitis or seeking further information about the infection including hospital overcrowding.

If there were a lot of people waiting in line for an ultrasound or something, I would simply skip that. I was too careless, I admit that I didn't take it seriously

(Male, 55-60yo, hepatitis B, Beijing37).

The silent asymptomatic nature of hepatitis infection was noted by a couple of participants as reducing the levels of monitoring:

I had a check-up in 2010 or 2011, and since then I haven't had any more tests. On one hand, even if I had experienced minor discomfort, generally, my condition was still quite normal. On the other hand, I became less concerned about it when I tried to maintain a good mood. Even though sometimes it still bothers me, I no longer treat it as an important issue

(Male, 25-30yo, hepatitis B, Beijing41).



My last check-up was 18 months ago, and I am too busy

(Female, 25-30yo, hepatitis B, Chongqing 28).

As noted previously, additional resourcing for hospitals and doctors comes prescribing and selling treatments, including TCM. The link between treating physician, the prescribing and purchasing of treatments was noted by several participants as reducing their willingness to participate in monitoring given possible exploitation by medical staff

If it's just liver function test, there's not any problems. But some hospitals prescribe medication for you and once they do that, the medication usually costs 1000, 2000 RMB ... Both TCM and western medication, depends on which hospital you go to

(Female, 25-30yo, hepatitis B, Dong Guan 17).

At the same time, few participants reported an economic burden related to monitoring, with the costs being minimal, "100 RMB (Aus\$20) to monitor" (Male, 30-35yo, hepatitis B, Guangzhou6).

Clinical Management - Pharmaceutical treatment

The cost of treatment was an essential barrier noted by each of the key stakeholders and most participants with viral hepatitis.

I didn't receive treatment right away because I didn't have enough money

(Male, 35-40yo, hepatitis B, Guangzhou 4).

The economic burden arising from the lack of full reimbursement for treatment essentially affected the choice of pharmaceutical drugs used by participants, with an economic rather than clinical outcome being the priority. As one man noted, "if he was rich he could have the best treatment in the world" (Male, 20-25yo, hepatitis B, Guangzhou 12), while others reported:

I need to think about my financial situation when I make decisions. I need to compare the price, especially when I need to choose between long-

term medication and short-term medication, but on the other hand, I need to find out whether expensive medication is more effective than cheaper ones. I need to take all these into consideration

(Male, 30-35yo, hepatitis B, Beijing46)

I found a senior professor ... after seeing my results, he recommended ... anti-viral treatments. He asked me about my family's financial situation and what type of treatment I could afford. I told him my family's financial situation's not very good, so he recommended me to have Lamivudine

(Male, 35-40yo, hepatitis B, Guangzhou4).

There was a cascade of treatment availability based on financial resources for people with viral hepatitis described by one participant:

If you have 3 million RMB (Aus\$615,000) or you have 300,000 (Aus\$61,500) you can treat. 30,000 (Aus\$6,150), 3,000 (Aus\$61.50) you can also treat. If you have 3,000, you can do TCM, you can go to the village - they have a special formula

(Male, 45-50yo, hepatitis B, Beijing33).

Economic decisions not only affected the choice of drugs but also the length of time that people were required to use treatment.

At first, my parents took me to a hospital in Wuhan in the hope of treating my disease, but the doctor told us that the medication we need is going to cost around 20,000 to 30,000 RMB (Aus\$4,000 - \$6,000). Back then, it was a relatively heavy financial burden on my family. I was around 13 years old and was still in junior high school. I had one course of treatment and had some improvement

(Male, 25-30yo, hepatitis B, Beijing43).

The pharmaceutical treatment process has many stresses, some of which are informed by economic related issues, while others reflect concerns expressed by other people with hepatitis B.

There are a few things that worry me, one is my financial status, and the second one is the effect of



the treatment... Back in 2008, when I just started pegylated interferon, it cost me around 100,000 RMB (Aus\$20,000) a year. This figure daunted me ... I used pegylated interferon for about a year which didn't work, so I switched to entecavir. The reason I use tenofovir now was because I planned to start a family ... And the yearly costs of tenofovir are definitely cheaper than pegylated interferon, it's about 1,200 RMB (Aus\$245) per month

(Male, 30-35yo, hepatitis B, Beijing46).

Treatments are reimbursed with the amount dependant on the health insurance scheme and the locality in which a person is registered for insurance. One participant, a PhD student reported the following in terms of the cost of treatment:

I still need to pay. I need to pay 30%. ... Entecavir costs around 1,000 RMB (Aus\$200) a month, 30%, 300 RMB (Aus\$61.00)

(Male, 25-30yo, hepatitis B, Beijing39).

For another participant, the vagaries of reimbursement policies and his relocation as a result of employment opportunities required him to travel almost 3,000 kilometres and spend up to a day in a liver clinic each month to seek a rebate for their treatment.

When I had pegylated interferon, I had to fly back to Hangzhou, where my medical insurance was registered, to lodge a claim for the pharmaceutical rebate. I used to fly back each month and spend a day in the hospital because of the long queue

(Male, 30-35yo, hepatitis B, Beijing46).

Several participants were not using treatment as a result of the cost of treatment, particularly when other financial burdens were being prioritised.

Because I came from a village and my family didn't have much money, they were already experiencing financial hardship sending me to university, so I decided to delay treatment and wait and see how things would turn out

(Male, 35-40yo, hepatitis B, Guangzhou4).

Physical access to treatment services appears uncomplicated in locations where the services exist. Nineteen of the participants were recruited to the study through hospital based services, nine of whom were in-patients. Several of these participants noted the expense related to being an in-patient which were significant and out of the range of people without substantial financial resources.

In terms of finance, when I had hepatitis, I could afford the medical expenses, but when it developed into cancer, the medical insurance policy the country introduced can't help much. Take Beijing for example, if you had a major disease and were admitted into hospital, the maximum amount you could claim is around 300,000 RMB (Aus\$61,400) a year, and for outpatients, it's 20,000 RMB (Aus\$4,100). Since I was admitted into hospital in July, the costs for basic treatments per month have been up to 100,000 RMB (Aus\$20,500) per month. That includes having keyhole surgery twice

(Male, 55-60yo, hepatitis B, Beijing37).

The need for effective communication between medical professional and patient was noted by one 27 year old man, who was hospitalised as a result of treatment resistance occurring after stopping pharmaceutical treatment. This occurred as a result of poor communication, and also due to previous experiences in using traditional medicines.

I went to the hospital for the check-up and the doctor prescribed ... Entecavir, I was told it was an anti-virus medication which should be taken for a long period. Somehow I didn't pay much attention to that comment, so I took it for 3 months and stopped for 4 months. After stopping medication for 4 months, I started to experience tiredness, pain in part of my body and jaundice. ... I wasn't told about the consequences of stopping the medication because in the past I only needed to take medication for a few months each year to lower ALT level

(Male, 25-30yo, hepatitis B, Beijing38).

This experience had not only physical but also economic ramifications, with a possible alternative being liver transplant; "if I was asked to have a liver

transplant, then of course I can't afford it. It costs more than one million RMB (Aus\$205,000).⁴⁸ In spite of the cost, two opportunities presented themselves but given a lack of cash he was unable to access a liver transplant.

The first time was when I got diagnosed and asked to have a liver transplant. My elder brother and others chipped in some money and I borrowed some from friends, but when the hospital asked me to pay the cash up front, I simply couldn't pay by lump sum, so I failed to do it and the liver was taken by someone else. The second time was ... (when) my sister-in-law told me that Chaoyang Hospital just called and said they had a liver, but when I was about to put my clothes back on and leave, the hospital called again saying that the liver could not be used.

While most participants were infected with hepatitis B, people with hepatitis C also reported issues with accessing pharmaceutical treatment. One man with hepatitis C was hospitalised because of the higher reimbursement available for hospitalised patients. He noted that:

If I go to the hospital as an outpatient, the maximum money I can claim is 20,000 RMB (Aus\$4,100), and one injection's more than 10,000RMB (Aus\$2,000), 1,000RMB (Aus\$205) per week, maximum 20,000 RMB (Aus\$4,100) reimbursement, you do the maths, how many injections can I have? ... I have no savings, all these years I have to have medication, and I earn very little but need to pay extra expenses every month. I only have one child, and it's a lot of pressure on them.

(Male, 55-60yo, hepatitis C, Beijing⁴⁸)

Two of the participants mentioned moving cities to access treatment given greater clinical expertise in these cities in comparison to the localities where they were from.

The (local) hospital told him that his condition's very serious and there's nothing the doctors could do, and recommended that he go to one of the big hospitals. But his family, the children, were afraid that going to a big hospital is just in vain because he was too ill

(Male, 45-50yo, hepatitis B, Guangzhou⁸).

Shi Dage waits on a hospital bed to receive a liver exam. Without appropriate monitoring or treatment, one in four people infected with chronic hepatitis B will die from liver cancer or liver failure. Henan, China



While monitoring was being adhered to by many participants, being informed that your infection was moving to a different stage did not necessarily equal accessing treatment services, particularly where there is confusion and assumptions about terms used to describe hepatitis B natural history.

Every year I do routine a check-up ... and it changed to E-positive last year. Even though I am not very concerned because I know about it, the doctor recommended that I receive treatment. But anyhow I didn't follow that advice, because I am a carrier, and I know that there's no treatments for being a carrier, what's really important is for me to have a balanced diet, moderate exercise and sufficient rest

(Female, 30-35yo, hepatitis B, Guangzhou2).

concerned about it, though they found me a sort of a folk medicine practitioner. I had another health check in my 3rd year of high school and ... the result came back saying that I was e-positive. I was so sad. I believed I was cured

(Female, 20-25yo, hepatitis B, Guangzhou16).

No participant could clearly state the ingredients within the secret recipe, although a range of other traditional interventions were noted, and described as being able to cure hepatitis.

Take some drugs, as weird as frogs penis, snakes kidney, or something that is really good for your liver, you can come together with the one drug, you can totally get the virus out of your body

(Male, 30-35yo, hepatitis B, Guangzhou1).

Traditional Chinese Medicine

A range of experiences regarding the use of Traditional Chinese Medicines (TCM) in response to viral hepatitis were noted by the majority of participants. These included treatments used in response to the initial diagnoses through to medicines and experiences with clinical services purporting to cure hepatitis. Several participants described using a 'secret recipe' that was used within their families in response to a diagnosis of hepatitis B: "every family tend to have some secret recipe for TCM treatment" (Female, 25-30, hepatitis B, Dong Guan17).

I used some folk remedy. To convert me to negative. They put some herbs on me. In total I had four marks on me, but two disappeared one year ago. My mother believed in it, I didn't want to receive that treatment, but my mother insisted on taking me there

(Male, 20-25yo, hepatitis B, Shanghai19).

The use of traditional medicines provided a false sense of security for several participants.

I had a health check in my second year of high school and afterwards I got feedback saying that I was suspected to be carrying the virus ... I told my family about it. They didn't seem very

Cultural norms and the impact of viral hepatitis infection was noted by one participant who had recently given birth:

Even when I was in confinement after the birth of my baby, I couldn't drink 'yellow liquor,' a traditional alcoholic drink in my hometown for women after delivering a baby ... Generally, people in rural areas do not have much knowledge about the disease, so even if the woman has hepatitis, she'd still drink a lot of yellow liquor during confinement

(Female, 25-30yo, hepatitis B, Dong Guan17).

While families were described as the source for secret recipes, physicians within public hospitals were also reported as prescribing traditional medicines for hepatitis.

After visiting this so-called 'Army Hospital,' I was prescribed some traditional Chinese patent medicine, a medicine which is to be taken after being mixed with boiling water. After a few courses of this treatment I didn't find it particularly effective, but I spent a lot of money on it, so I thought this hospital might just be a sham. I calmed myself down and thought about it and I decided that I should stop going to this type of hospital

(Male, 35-40yo, hepatitis B, Guangzhou4).



*I'm using a liver protector, through the hospital
– not expensive after reimbursement*

(Male, 45-50yo, hepatitis B, Beijing33).

Given the lack of a 'cure' provided for hepatitis B by western medicine, the use of traditional medicines was seen to be a viable option:

With my family's support, I have tried traditional Chinese medicine together with other medication for a few years, but none of them worked

(Female, 25-30yo, hepatitis B, Dong Guan17).

One participant understood use of traditional and western medicine and within the context of long term treatments that TCM offered something that western medicine was unable to provide.

Many hospitals are profit-oriented. The disease sort of gave me an opportunity to learn, and now I have a fairly good level of knowledge of Chinese medicine. It's Chinese medicine which gave me hope

(Male, 25-30yo, hepatitis B, Beijing41).

Several participants described their liver as being 'hot' or having fire in their liver.

There is something wrong in the liver, because there is too much fire in the liver, so we have to put out the fire in the liver by taking the TCM. It's nothing to do with the virus

(Male, 30-35yo, hepatitis B, Guangzhou1).

The use of Baijiu, a white wine with an alcohol percentage of up to 60% by volume, was one cure for hepatitis B noted by one participant:

Just based on rumour, if you can drink up 500 gms of the Baijiu ... you can be diagnosed as hepatitis negative

(Male, 30-35yo, hepatitis B, Guangzhou1).

While there were several claims of traditional medicine curing hepatitis, several participants also reported using traditional medicine to restore liver function.

This is of particular significance in a context where there is more employment based testing for liver function rather than antigen or antibody testing.

I heard that there's a medication which can temporarily turn the result from positive into negative. I found that information online, but I don't know what kind of medicine it actually is

(Female, 20-25yo, hepatitis B, Guangzhou16).

When I went back to school later on, there's a medicine called 'Bifendatum' which was said to be able to lower ALT level, I was not sure about whether my liver function's normal, but having this medicine guaranteed me to pass health check

(Male, 30-35yo, hepatitis B, Shanghai21).

Discrimination

The comprehensive nature of how discrimination affected many participants was reflected in the following comments and the ingrained nature of the issue within Chinese society:

There's no vaccination to discrimination ... it is always there. There is no way you can tell a granny at the age of 80 that you shouldn't discriminate (against) people with the hep B, it all starts from a very young age ... and there's no way you can turn things around

(Male, 30-35yo, hepatitis B, Guangzhou1).

The stereotype is deeply rooted in people's mind, the discrimination has been going on for such a long time so it will take a long time to change people's mind set

(Female, 20-25yo, hepatitis B, Guangzhou5).

The pervasive and devastating nature of the experience of discrimination relating to viral hepatitis was reported by one participant as the rationale for not informing their family of their infection:

*The more you know, the more you get hurt.
The less you know, the less you fear*

(Female, 25-30yo, hepatitis B, Shanghai20).



Several participants noted that the needs assessment interview was the first time they had disclosed the social and personal impact of having viral hepatitis as the quote below illustrates:

The public are generally still ignorant about the disease, they think it is easily transmitted, it is a serious disease. I'm happy to tell you, because I've never told anyone before

(Female, 25-30yo, hepatitis B, Chongqing28).

Discrimination was reported to have a lasting and damaging psychological impact:

Having have been discriminated against since I was a child has impacted on my personality and character. I was afraid to tell people about it and I was quite timid

(Female, 20-25yo, hepatitis B, Guangzhou5).

The process of discrimination, on an individual level commences with disclosure. As noted previously, many of the participants had not disclosed their infection to others, and for one this meant that they didn't experience discrimination related to the infections.

I thought that it's a shameful disease and I should not tell other people because the public would be alarmed and feel scared ... maybe no one would want to be your friends ... I hide myself

(Male, 20-25yo, hepatitis B, Shanghai19).

One barrier to accessing medical services as a result of viral hepatitis lies with the social implications of the infections:

I saw one of my classmates (at the hospital), but I didn't have the courage to say hello to her. I think we were both afraid to bump into an acquaintance. We usually would choose to go to some remote place

(Female, 25-30yo, hepatitis B, Shanghai20).

The issue of self-stigmatising was described by one participant who noted that while information needed to be provided to the public about viral hepatitis, and that this would support reducing discrimination, people with viral hepatitis, "need to change their own mind-set towards the disease, and how to adopt a positive attitude towards it, instead of putting their heads in the sand" (Male, 35-40yo, hepatitis B, Guangzhou4).



Since his father's death, Xiao Wang has been taken to school by his grandfather. A safe and effective vaccine exists that stops the transmission of hepatitis B, but poor access to the vaccine, inadequate education and a social veil of silence have resulted in as many as 400 million people worldwide living with hepatitis B. Henan, China

Summarising the needs of people with viral hepatitis

Viral hepatitis in China, for people with the infection, is as much a social as a clinical issue. The individual, social and political responses to the infection occur within a dynamic context where vast social, cultural and economic changes have occurred over the past two decades in China. Individual responses to being infected with viral hepatitis primarily occur as a result of a range of non-clinical agencies conducting significant health and clinical related activities for which they are often untrained and unskilled to conduct.

The following section highlights the issues raised by people with viral hepatitis framed in the trajectory that they experienced being infected with hepatitis.

Being diagnosed

A variety of processes were described in which people with viral hepatitis were screened or tested and subsequently diagnosed with viral hepatitis. These processes have significant implications.

People with viral hepatitis reported being **tested for hepatitis by a range of non-health/clinical** related services. This means that people with viral hepatitis are not necessarily tested or diagnosed by professionals with the skills to conduct this diagnosis and where the primary purpose of testing is not of the primary benefit for the person being tested.

The variety of processes in which a person with viral hepatitis is diagnosed means that **there is little consistency or quality control in providing this diagnosis across the different professions**

conducting this testing. How a person with viral hepatitis is informed of their diagnosis is pivotal in their attitude towards being infected and how they respond to the infection. Data from the needs assessment found that people were diagnosed in a broad range of ways, with only a couple of people expressing that their diagnosis event provided them with the information and skills to respond effectively to the diagnosis.

There is no national standard for how viral hepatitis testing is to occur, or training for people conducting the testing. The impact of the lack of standards means that people are inadequately informed that they are infected, and what they could do to respond effectively to this infection.

There are three major explanatory clinical models that are used to explain hepatitis B to people living with the virus: the 4 phase natural history model, the big/small three or the 5 tests. The three descriptions have utility although what each lacks, the other provides. The four phases of natural history, while reflecting current natural history understandings, is inaccessible to most people without a specialist understanding, including many health care workers. The big/small three and the five tests are simple statements that provide for an easy understanding and permits a person with hepatitis B to feel engaged with their infection. More research is needed to **identify an effective explanatory model for chronic hepatitis B infection** that is not only accurate but accessible and understandable to people living with the infection.

There are a range of expectations, standards and ethical frameworks that operate within health services. These frameworks have been developed to ensure the physical and psychological safety of health services clients and patients and do not necessarily operate in educational institutions or in workplaces, the sites in which a large number of people with viral hepatitis are diagnosed. There are a range of workplace practices that are implemented within health services, such as confidentiality that are not implemented within other



sectors. This means that **the provision of a diagnosis is not necessarily provided in ways that respect or support good health, but is provided in ways that are relevant to the institution conducting the testing.** This does not promote good health either for the person being diagnosed or within the health system generally.

Teachers and human resources staff have become defacto health staff by becoming responsible for diagnosing and informing a person with an infection that often has significant health outcomes. These staff have not been trained, do not necessarily have the knowledge and should not be responsible for conducting these processes.

The specific diagnostic event, or how an individual is informed that they have viral hepatitis is pivotal in how they frame their understanding and respond to the infection. This framing is affected when agencies whose primary purpose for testing is not for the benefit of the person being tested, but in a misguided attempt to reduce further transmission.

The cost of treatments reduces the willingness of people who are at risk of chronic infection being screened for the infection. Two participants described their families being unwilling to be tested for viral hepatitis as they were unable to afford to respond to the infection as a result of the cost of the treatment.

Reducing the burden of viral hepatitis requires people with viral hepatitis in China to be provided with **consistent, confidential and accurate information** about the infections including standardised pre and post-test information for people conducting tests, and for people being tested for viral hepatitis detailing the risks involved in being tested, and the roles and responsibilities of the testing authorities. The information needs to be relevant to the person and include information about:

- Natural history about the infections, and reducing the impact of the infection through clinical management.
- How and to whom to disclose including to relevant friends, family colleagues and partners.
- Accurate information about reducing further transmission of viral hepatitis.

- Legal rights and responsibilities, particularly in terms of employment.
- Support information including to web-based information.
- To support these processes, a **specific national diagnosis policy** describing the tests required, how the tests should be performed, the information and support provided to people being tested and the development of what constitutes best practice in providing a diagnosis for a person with viral hepatitis needs to be developed.

Hepatitis B and hepatitis C are not casually transmitted. There is no justification for any agency to conduct testing outside of health services, and to decline services or employment to people with viral hepatitis as a result of their infection. While many agencies have stopped testing for chronic hepatitis B or to identify people with e-antigen positive infection, the use of liver function testing as a proxy cannot be justified.

Familial context of infection

The repercussions of a positive diagnosis for viral hepatitis were often substantial, not only for the individual being diagnosed, but for many within the immediate and sometimes extended family. Many participants described **their diagnosis as essentially changing their and their family's lives**, with several members of their immediate family also finding out they had hepatitis, and requiring clinical intervention as a result of this diagnosis. For several participants, this fundamentally changed their lives from one in which hepatitis had little impact, to where it became the focus of their life, to the point of relocating to access better treatment services.

Even when family members were not themselves infected, the impact was often substantial with participants noting the economic impact of the infection, particularly for people from rural areas seeking to strengthen their economic standing. For other participants, **the diagnosis caused an additional and sometimes severe stress on the family dynamics.**

The familial context also encompasses an acknowledgement that **for many people with viral hepatitis, the infection has always played a significant part in their lives.** This comes about as a result of deaths within their family of liver cancer resulting from viral hepatitis. This relationship between their personal infection, and the experience of the infection within their family could be further investigated, particularly in determining the psychological impact of these experiences and their effect on accessing clinical services for the infection.

Several participants described families of origin using 'secret recipes' in response to their diagnosis. This use of a traditional form of healing supports a hypothesis that there is a reservoir of knowledge about viral hepatitis or liver disease within families who are more affected by the infections. **This knowledge, while not using a bio-medical based understanding of viral hepatitis, is part of the context in which people with viral hepatitis live.** This knowledge needs further investigation to understand how it can be used to engage with people with viral hepatitis and promote their health through reducing barriers to clinical services.

Information about hepatitis

In spite of the millions of people with viral hepatitis in China, there were inconsistent and sometimes essentially inaccurate understandings of people with viral hepatitis about their infection and options for its management. At one point, the researcher was asked by a person within a clinical setting whether there was a treatment for viral hepatitis. **The variety of assumptions about how people thought they were infected reflects the lack of consistent information provided to people at the point of diagnosis, and which occurs throughout the trajectory of their infection.**

A large proportion of participants use the Internet as an authoritative source of information. This information not only translated the bio-medical aspects of the infection into practical application, but was also used as a source of peer education where discussions

about living with hepatitis occur. While there were concerns that there was inaccurate information on the Internet, the breadth and personalised nature of the information played an important role.

The inadequately regulated medical care system provides opportunities for the provision of **alarmist and inaccurate information about viral hepatitis** to the general population, including people with viral hepatitis. For people with viral hepatitis, this ensures unwarranted anxiety about the infection; unrealistic expectations about treatment or clinical management, and with the poor quality of the infection provided, a lack of support within the general community for people with viral hepatitis.

The implications of being tested, particularly with the social or economic implications resulting from a positive test result meant that **several participants noted subverting the testing processes.** Several reported this subversion having a psychological impact, and that they felt that they had disappointed their personal ethical standards.

The provision of **information to people with viral hepatitis needs to acknowledge the psychological and emotional impact of being diagnosed.** The age range in which people were diagnosed, with participants reporting being 6 or 7 years of age when they found out they had viral hepatitis highlights the need for information to be available that is relevant and accessible to a broad range of people. This implies the development of a breadth of resources including how these resources are produced about viral hepatitis that acknowledge different ages, literacy, social and cultural implications of the infection.

Several participants highlighted the balance between recognising hepatitis as a serious illness, and ensuring that this seriousness did not worsen relationships between people with viral hepatitis and the broader community.

The lack, or poor quality, of information about viral hepatitis was not only experienced by people with viral hepatitis, but also by health care workers. Given the prevalence of viral hepatitis across the Chinese community, **there is a need to ensure that all health care workers are cognisant of the infections and are equipped to effectively respond.**



Clinical management

Given that one of the recruitment strategies included the use of clinical services, most people interviewed for the assessment were in regular contact with clinical services and reported having their infection regularly monitored. In spite of this, there were a range of barriers to accessing clinical services, including accessing pharmaceutical treatment. **The primary barrier was economic, which essentially reduces access to pharmaceutical treatments,** and to the choice and likely clinical outcomes associated with the use of specific treatments. It means that the choice of treatment is not clinically, but economically based. Drugs that are not recommended for use in other countries as a result of the development of drug resistance are used in China given that they are cheaper to use.

The economic decision about which pharmaceutical treatment to use is also informed, particularly in relation to hepatitis B, as a result of the mostly lifelong nature of the treatment. **Several participants were risking viral resistance as a result of stopping treatment because of their economic circumstances.**

The economic sacrifices some participants and their families were making were substantial, within some of these sacrifices related to unnecessary bureaucratic structures relating to reimbursement policies and where a person was registered. Several of the participants noted significant personal and familial disturbance in relocating to different cities to access specialist clinical services.

The bio-medical response of using pharmaceutical treatments to reduce viral activity and inflammation, does not address psychological needs of several of the participants. Several participants noted clinicians selling 'liver protectors', or capsules containing herbal treatments through public hospitals. **These herbal treatments were cheaper and therefore more accessible** to the people using the treatments.

Many of people interviewed reported using traditional forms of healing including TCM, which was reflected in comments from key stakeholders. There was an expectation by two participants that their use of traditional forms of healing had cured them of viral hepatitis, and it was only after the development of symptoms that clinical intervention was sought. There were instances in which **lessons learned from the use of these modalities affected the understanding of participants about the use of pharmaceutical treatments, and of expectations about these treatments were able to achieve.** For one of the participants, these expectations led to liver failure.

Traditional Chinese Medicine plays an important role in terms of providing people with viral hepatitis treatment options, and while not able to cure hepatitis, can affect liver function and provide an important psychological role to people living with a chronic infection. This importance, along with the reality of the widespread nature of the use of TCM, needs to be acknowledged within clinical guidelines, with patients provided with information about what it is that they can expect from the use of TCM.

Hospital barriers, particularly where given the poor monitoring of regulations and the relationship between doctors, hospitals and profit making as a result of prescribing, means a lack of faith in the medical profession and their advice. This lack of faith is also affected by the inadequately regulated private medical system providing a context in which the advertising of 'cures' for viral hepatitis, particularly hepatitis B are promoted. **The nature of the advertising of these cures is alarmist** and not only add to the misinformation and fear about viral hepatitis within the broader community but confuses treatment decision making for people with viral hepatitis.

There were a range of ways in which people with hepatitis sought to reduce the impact of the infection, some of which, given current knowledge of the infections, were not based on the best available data. This provides a rationale for developing accurate and accessible information for people with viral hepatitis where they are provided with information that actually reduces the individual burden of the infection.

Stigma and discrimination

The history of systematic discrimination of people with viral hepatitis from workplace and educational institutions affects the day-to-day lives of people with viral hepatitis in a range of ways. In spite of regulations that reduce discriminatory activity including limiting access to education, employment, and services, people with viral hepatitis report experiencing reduced access, particularly to employment opportunities.

There is still discrimination that operates within workplaces, but rather than being related to viral hepatitis infection it is related to people having abnormal liver function test results. The use of **these tests essentially targets many people with viral hepatitis** and continues to exclude them and compromise their human rights.

The **lack of accurate information within the general community** about hepatitis affects the willingness of people with viral hepatitis to disclose their infection to friends, colleagues, and for some, their families. This will essentially affect a person's willingness to participate in monitoring or treating their infection.

Further, many people with viral hepatitis are scared of disclosing when developing intimate relationships with others.

Contextual environment

More than in most other countries, a policy to reduce the burden of chronic viral hepatitis in China needs to involve a range of government and non-government agencies given the **significant social, economic, clinical and cultural implications** for people with viral hepatitis. A comprehensive national response to the infection needs to address the social as much as the clinical aspects of the infection.

This needs assessment has limitations which need to be taken into account, one of which is the lack of people with hepatitis C who provided their experience to the assessment. This reflects **the comparative lack of information and research related to hepatitis C** as opposed to hepatitis B. There is a need to ensure that a national research agenda, specifically for hepatitis C, is developed and implemented.

The depth into which this assessment could investigate specific issues was limited, and there remains a need to include further **research into the social impact of the infection**, including how the social implications of the infections affect access to clinical services and reducing the individual burden of viral hepatitis infection.



Conclusion

The individual stories of people with viral hepatitis are often full of fear, despair, isolation and grief. This study shows that, while there is a significant prevalence of viral hepatitis within China, responding to the impact of the infection requires more than a purely clinically based response.

The success of the implementation of the vaccination program in China is a significant global public health event. China is the single country in the world that experiences the greatest burden of viral hepatitis infection. While the vaccination program reduces the number of people infected with hepatitis B, the impact on the health system and the community will not be fully expressed for several decades. In the meantime, over 10% of the population experience a chronic hepatitis infection, the burden of which will continue to increase over the next five or six decades unless significant intervention is made.

The impact of viral hepatitis affects the whole Chinese population:

- with a prevalence of over 10% in people over the age of 20, most people in China will be acquainted with or know someone who is living with hepatitis;
- people with chronic viral hepatitis are at an age of high productivity and form an important part of the workforce;
- the morbidity and mortality related to the infection essentially affects the health system and the community as whole

Given the prevalence of the infection in China, and the visible and silent impact of the infection upon the population, the lack of, or inconsistent, understanding about the infection is striking. This deficit also carries over into the general population and therefore affects the social environment in which people with viral hepatitis live. The need for significantly improved levels of accurate

understanding about viral hepatitis is imperative.

Looking at viral hepatitis in China through a bio-medical or clinically based framework alone excludes the reality of the familial context of the infection for the vast majority of people experiencing the infection. People in China have lived with viral hepatitis for generations and there is much knowledge about the infections which is evidenced by the use of traditional and familial medicine. It is important that research is conducted to investigate current forms of knowledge about the infection, so that culturally appropriate and engaged health promotion information about viral hepatitis is developed and disseminated.

The health system in China is well placed to address the physical needs of people with viral hepatitis, with few adjustments. The barriers to clinical management include issues that are far broader than hepatitis, but nevertheless need to be addressed. The treatment choices for people with viral hepatitis are largely determined by economic rather than clinical means. This means that cheaper treatments widely used in China are not used in most other countries given their clinical outcome limitations including the development of viral resistance. Access to effective clinical management is largely determined by geography, and better access for people out of tier one cities to clinical services needs to be developed.

People with hepatitis are tested, diagnosed and informed by a variety of sources including medical professionals, educators, workplaces and parents. Within each of these sources, a range of experiences and expertise informs the process of diagnosis. Many of the sources of testing have not been trained to conduct this health-related activity and should not be expected to provide what, for the majority of people infected with hepatitis, will be a life changing piece of information.

While hepatitis is primarily understood as a clinical condition and there are significant social implications resulting from the condition, it should be the responsibility of trained and knowledgeable medical professionals to provide information at the point

of diagnosis. Expecting workplaces or educational institutions to conduct this process neglects to acknowledge the physical implications of the infection and the need for people with hepatitis, particularly hepatitis B to maintain lifelong monitoring of the infection. The social implications of viral hepatitis demands significant attention, as they essentially affect the role of people with viral hepatitis within the broader community, and reduce the willingness of people with viral hepatitis to participate fully within the community.

While discriminatory regulation has been repealed, most people with viral hepatitis participating in this needs assessment report significant stigma related to the infection. This primarily affected them in terms of employment choices and personal relationships.

There are a range of issues influencing the social status of people with viral hepatitis including a poor understanding of the infections by the general public and health care workers, the unregulated nature of medical services who frame hepatitis as an issue of personal risk, and the range of professions that conduct testing and diagnosis of viral hepatitis.

The World Health Organisation's *Framework for the Prevention and Control of Viral Hepatitis* provide four axes that can be used by national governments to develop public health responses to the infections. This needs assessment provides suggestions for elements that could be incorporated into a national action plan using these axes and is provided in the table on the next page.

Wang Dage's mother grieves at her son's gravesite. Since the virus has a dormancy rate of between three and four decades, most people infected in childhood die of liver cancer in their thirties and forties. Henan, China



WHO Axis	Action Plan Priority in China
1 Raising awareness, promoting partnerships and mobilising resources	<ul style="list-style-type: none"> ● Develop a series of authoritative information campaigns targeting general public, health care workers and people with viral hepatitis. ● Facilitate a national roundtable of key stakeholders including academics, clinical specialists, advocacy organisations and people with viral hepatitis to develop and inform the implementation of a national action plan. This plan would coordinate action to reduce the morbidity and mortality associated with viral hepatitis. ● Ensure that all health care workers are provided with professional development in viral hepatitis including management and support.
2 Evidence-based policy and data for action	<ul style="list-style-type: none"> ● Identify priorities for epidemiological, clinical, public health and social research. ● Develop a comprehensive national plan to reduce the burden of viral hepatitis and that acknowledges and addresses the social implications of hepatitis infection ● Investigate the enablers and barriers to clinical management services, including the role of family as enablers, and stigma as a barriers to management ● Conduct further assessments of people with viral hepatitis in specific locations, and addressing the needs of people with hepatitis living in rural and remote areas ● Conduct a comprehensive economic analysis determining the costs of not responding effectively to viral hepatitis, and of the costs to families of not testing or being managed.
3 Prevention of transmission	<ul style="list-style-type: none"> ● Continue to monitor and report on the national hepatitis B vaccination program, addressing gaps when evident. ● Continue to develop and implement infection control processes. ● Conduct professional development of all health care workers about viral hepatitis, including transmission routes.
4 Screening, care and treatment	<ul style="list-style-type: none"> ● Develop and implement a national viral hepatitis testing/diagnosis policy prioritising the needs of people at risk of infection and acknowledges the breadth of agencies conducting this testing. ● Identify barriers to poor clinical monitoring rates and address these barriers. ● Ensure treatment choices are determined by clinical rather than economic issues ● Increase treatment reimbursement rates ● Develop treatment guidelines that acknowledge and address issues related to the use of TCM ● Improve access to treatment for people in rural and remote areas ● Broaden the treatments available to people with viral hepatitis

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