

Stigma, Discrimination and Hepatitis B

A review of current research

2013

Jeanne Ellard and Jack Wallace



Australian Research Centre in Sex, Health & Society (ARCSHS)

Faculty of Health Sciences

La Trobe University

A body politic and corporate

ABN 64 804 735 113

ARCSHS operates from within the academic environment of La Trobe University.

La Trobe University is a Statutory Body by Act of Parliament.

Level 2

215 Franklin Street

Melbourne 3000

Franklin St Campus

Telephone (+61 3) 9479 8700

Facsimile (+61 3) 9479 8711

Email arcshs@latrobe.edu.au

Online <http://www.latrobe.edu.au/arcshs>

Monograph series no. 93

ISBN: 9781921915468

Suggested citation: Ellard, J and Wallace, J. (2013) Stigma, discrimination and hepatitis B: A review of current research (ARCSHS Monograph Series No. 93), Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University. ISBN: 9781921915468

The Summary Report and Full Report are available at <http://www.latrobe.edu.au/arcshs/publications>

Contents

| | |
|--|-----------|
| EXECUTIVE SUMMARY | 2 |
| RECOMMENDATIONS | 4 |
| INTRODUCTION | 6 |
| METHOD | 10 |
| FINDINGS | 11 |
| Australian Research | 11 |
| International Research - North America | 14 |
| International Research – China, Singapore and Taiwan | 16 |
| Gaps in current research and future directions | 18 |
| REFERENCE LIST | 20 |

Executive summary

Australia's first National Hepatitis B Strategy 2010-2013 notes that "Stigma and discrimination continue to be unfortunate responses to BBVs" (blood borne viruses) (p.19).(1) The Strategy supports gathering evidence to reduce the impact of any possible hepatitis B related stigma and discrimination, and to better inform nationally coordinated responses. This community brief identifies current knowledge of hepatitis B related stigma and discrimination by reviewing Australian and International research and recommends future research directions for Australia.

The negative consequences of stigma and discrimination on the health and wellbeing of affected individuals and communities in relation to the Human Immunodeficiency Virus (HIV) and hepatitis C are well documented.(2-5) There are essential differences between hepatitis B and other blood-borne viruses, in particular hepatitis C and HIV which influence the extent and nature of hepatitis B related stigma and discrimination.

Current research indicates that concerns about discrimination and experiences of stigma may be greater among people from particular culturally and linguistically diverse (CALD) communities as a result of attitudes and discriminatory practices in their country of origin. The scope and degree of stigma and discrimination appears to vary between affected communities and it is therefore important not to assume that these issues are present in all communities affected by hepatitis B.

Evidence suggests that when stigma and discrimination are associated with people with chronic hepatitis B it is primarily related to a poor understanding of prevention and transmission, and not linked to concepts of moral deficit that characterise HIV and hepatitis C related stigma and discrimination. The small body of available research indicates that higher levels of knowledge about the prevention, transmission and clinical management of hepatitis B reduces the impact of stigma and discrimination and improves health outcomes.

There is no indication from Australian research that hepatitis B related discrimination per se is a significant issue at the health care provider level. There is evidence that communication between patients and health-care workers is not always optimal, with

this having the potential to negatively impact on knowledge and understanding about the transmission and clinical management of hepatitis B.

While there is little evidence of widespread discrimination specifically related to hepatitis B, many of the individuals and communities most affected by hepatitis B including specific CALD communities, Indigenous Australians, people who inject drugs and gay and bisexual men are marginalised, and experience a form of stigma and discrimination on the basis of race, illicit drug use and/or sexuality. These broader issues of stigma and discrimination may negatively influence the engagement of some individuals and communities with hepatitis B prevention and clinical management.

Recommendations

Further research is needed to enable a better understanding of the non-clinical factors that facilitate and act as barriers to hepatitis B testing, vaccination and clinical management including a better understanding of the extent and influence of stigma and discrimination across the different affected communities in Australia. Priority areas for future research in relation to hepatitis B stigma and discrimination include:

- Investigating the prevalence and nature of hepatitis B stigma and discrimination in the Australian context
- Exploring any intersection between racism, social and economic inequality, and the experiences of migration on the hepatitis B health outcomes of migrants, including refugee populations in Australia
- Developing an understanding of any relationship between levels and quality of knowledge about hepatitis B, and stigma and discrimination
- Investigating whether discriminatory attitudes and practices towards people affected by hepatitis B in their country of origin affect their health seeking behaviour in Australia
- Identifying hepatitis B related knowledge gaps among health care providers, particularly among people working with communities that experience a high prevalence of hepatitis B
- Investigating whether the availability of a preventive vaccine for hepatitis B influences levels of stigma and discrimination in health care settings
- Investigating hepatitis B knowledge gaps among Indigenous Australians and their health and social services providers to identify barriers to testing, vaccination and clinical management, including the role of stigma and discrimination
- Identifying or developing standardised stigma and quality of life measures for inclusion in survey based research. The use of standardised measures across research studies will increase opportunities for comparison of findings between different populations and contexts
- Investigating the social and cultural meanings of stigma for different individuals and populations affected by hepatitis B.

In addition, future research exploring stigma and discrimination in relation to BBVs including hepatitis B should clearly describe how the concepts of stigma and discrimination are defined within the research study.

Introduction

An estimated 218 000 people were living with chronic hepatitis B in Australia in 2011 reflecting an estimated prevalence in Australian of 1.02%.⁽⁶⁾ Most people with chronic hepatitis B in Australia were born in the Asia-Pacific region (38%), and while Indigenous Australians make up 2.3% Australian population ⁽⁷⁾ an estimated 10% of people from these communities are infected with chronic hepatitis B.⁽⁶⁾

Australia's National Hepatitis B Strategy 2010-2013 ⁽¹⁾ identifies hepatitis B disproportionately affecting people born in countries with high rates of chronic infection – these are primarily due to high levels of mother-to-child and early childhood transmission due to inadequate vaccination programs. Hepatitis B prevalence estimates within specific culturally and linguistically diverse communities (CALD) in Australia are assumed to be consistent with prevalence in countries of origin with the top three countries of birth of people with hepatitis B in Australia being China, Vietnam and the Philippines.⁽¹⁾ The Australian Government provides funded vaccination programs for infants and children, with immunisation recommended for other at-risk individuals including the sexual partners and household contacts of people with acute and chronic hepatitis B.⁽⁸⁾

Chronic viral hepatitis is a major contributing factor for the development of primary liver cancer. This type of cancer is experiencing the fastest increasing incidence of cancer, and is the fastest rising cause of cancer mortality.^(9, 10) While pharmaceutical treatment for hepatitis B is available, it is estimated that there are high levels of undiagnosed chronic hepatitis B in Australia.⁽¹¹⁾

To increase the uptake of testing, vaccination and clinical management and reduce the social and economic health burdens associated with chronic hepatitis B and associated liver cancer, research is needed to better understand the barriers and facilitators to health seeking behaviours. The National Hepatitis B Needs Assessment ⁽¹²⁾ noted the dearth of knowledge and insight into the non-clinical factors that influence uptake of hepatitis B testing and clinical management in Australia.

The negative consequences of stigma and discrimination on the health and wellbeing of affected individuals and communities in relation to the Human Immunodeficiency

Virus (HIV) and hepatitis C has been well documented.(2-5) For example, higher levels of HIV stigma have been associated with lower levels of social support and poorer physical health (2) while people who have experienced, or are concerned about experiencing discrimination or stigmatisation are less likely to be tested for HIV or hepatitis C.(3) This experience of stigma and discrimination in relation to other blood borne viruses (BBV) and its impact raises concerns as to whether hepatitis B also attaches stigma to particular behaviours, identities and communities and if so whether this negatively influences health outcomes.

The first National Hepatitis B Strategy 2010-2013 details the national public health response to hepatitis B and notes that stigma and discrimination “continue to be unfortunate responses to BBVs” (blood borne viruses) (p.19).(1) One activity within the strategy is to gather evidence on the influence that hepatitis B related stigma and discrimination have on public health interventions, to better inform nationally coordinated responses.

There are two major ways in which stigma and discrimination are associated with BBV - these can be related to perceptions about the modes of transmission of the BBV, and about the communities predominantly affected by BBVs. For example, stigma and discrimination in relation to HIV and hepatitis C have been strongly associated with the sexual and drug use practices that transmit them and with the populations’ most affected namely gay and bisexual men, and people who inject drugs.(4, 5)

There are significant epidemiological differences in the populations and communities most affected by hepatitis B, and those affected by HIV or hepatitis C. While hepatitis B can be transmitted through sexual contact and through shared injecting equipment, these are not the primary routes of transmission, particularly for people experiencing a chronic or lifelong infection. In Australia gay and bisexual men are the population predominantly affected by HIV, with people who inject drugs being the population most affected by hepatitis C. In contrast these two populations represent only a minority of those affected by chronic hepatitis B.(12)

Gay and bisexual men and people who inject drugs are significantly less likely to develop chronic hepatitis B (5%) compared to people infected at birth or in infancy 90%. (12) With most people living with hepatitis B in Australia being from CALD backgrounds, if hepatitis B does elicit stigma and discrimination in the Australian

context, it is more likely to be associated with race and cultural difference as opposed to issues of sexuality, sexual practice and drug use.

There is evidence that communities in different countries have divergent responses to hepatitis B.(12-14) The endemic and intergenerational nature of hepatitis B in many South East Asian countries could mean that the infection is often normalised within families and affected communities. Further, the predominant mode of transmission, i.e. from mother to infant, and the availability of a vaccine to prevent transmission may protect against the forms of stigma and discrimination experienced by people affected by HIV and hepatitis C. On the other hand in China and the Philippines, systemic and regulated hepatitis B discrimination has and still exists in relation to employment, education and access to healthcare.(12, 15, 16)

This community briefing seeks to identify the current knowledge about the nature and scope of hepatitis B related stigma and discrimination by a review of Australian and International research of contemporary understandings and knowledge about hepatitis B related stigma and discrimination. In addition the paper recommends future research directions in relation to hepatitis B stigma and discrimination in the Australian context. The overview, discussion and recommendations for future research are intended to inform and influence the work of practitioners in the field of hepatitis B health promotion, policy, research and clinical practice. The paper may also be useful for individuals and organisations working more broadly with affected populations including people from CALD communities, Indigenous health services and relevant peak bodies.

Stigma is characterised by experiences and/or feelings of shame, social exclusion, rejection, blame and adverse social judgements about an individual or group. The definition of stigma used in this briefing is as a conceptually complex social and individual process, associated with 'deviations from the normal' (p. 441).(17) Scrambler describes these adverse judgments as:

... an enduring feature of identity conferred by a health problem or health-related condition, and the judgement is in some essential way medically unwarranted. In addition to application to person or a group, the discriminatory social judgement may also be applied to a disease or designated health problem itself with repressions in social and health

policy. Other forms of stigma, which result from adverse social judgements about enduring feature of identity apart from health-related conditions (e.g. race, ethnicity, sexual preferences), may also affect health... (p. 441-442).

Stigma can consist of overt discriminatory actions by individuals or institutions sometimes described as 'enacted stigma,' or manifest as something that the stigmatised person feels, such as shame or expectations that they will be excluded or discriminated against in some way (4, 17) sometimes termed 'felt stigma.'(17)

Discrimination involves actions by individuals or institutions to explicitly treat individuals or groups with particular characteristics in an unequal or adverse manner with denying someone employment or access to health care on the basis of race or sexuality as key examples.(18)

Method

A literature search was conducted of the major sociological, psychological and medical databases, including:

- Annual Reviews
- Anthropology Plus
- Australian Public Affairs Full text
- Health & Society database
- HIV/AIDS database
- Medline
- Science Direct
- Sociological Abstracts
- Social Science Citation Index.

An internet search for published monographs, community reports and policy documents was also conducted for publications between the years 2000-2013. Relevant articles, monographs community reports and policy documents were identified using combinations of the following keywords, phrases and subject headings:

- Hepatitis B/HBV/chronic hepatitis B/CHB stigma and discrimination
- Attitudes towards hepatitis B/HBV/chronic hepatitis B/CHB
- Knowledge and understandings of hepatitis B/HBV/chronic hepatitis B/CHB
- Experiences of living with hepatitis B/HBV/chronic hepatitis B/CHB

While focussing on hepatitis B related stigma and discrimination, broader issues of hepatitis B knowledge and education were canvassed given the potential interconnection between knowledge and understandings of a particular health issue and stigma and discrimination. For example, misconceptions about transmission or lack of knowledge about clinical management options can play a role in stigmatising and marginalising people affected by hepatitis B.

Findings

Only a small amount of research currently addresses stigma and/or discrimination in relation to hepatitis B. Contemporary research indicates that stigma is present within some CALD communities in Australia, Canada and the USA, but it is less clear what underpins this stigma and its impact on health outcomes and the everyday lives of people affected by hepatitis B. There is clear evidence of widespread institutional discrimination in several jurisdictions in South East Asia including China and the Philippines.(14, 15, 19)

Australian Research

A hepatitis B needs assessment published in 2007 (12) noted that populations affected by hepatitis B come from a diverse cross-section of ethnic and social backgrounds – and that these communities are often marginalised from generalist health services (p. 21). The needs assessment found divergent experiences and responses to hepatitis B. For example, people who inject drugs were noted as a population who did not always complete vaccination as a consequence of social marginalisation, while some participants from CALD backgrounds proposed that the intergenerational nature of hepatitis B made disclosure straightforward and did not feel that being infected with hepatitis B was associated with shame (p. 31). In contrast, other participants in the needs assessment perceived hepatitis B to be shameful and avoided disclosing their infection to others. It is less clear whether these attitudes relate to the particular CALD communities these participants came from or reflect individual differences.

Guirgis and colleagues conducted two studies in the southern suburbs of Sydney. In the first, (20) they investigated General Practitioners' (GPs) knowledge and management of viral hepatitis in CALD populations. The authors reported that 54% of GPs agreed that there was stigma attached to the diagnosis of either hepatitis B or hepatitis C, and that this stigma was a barrier to health care. The study did not identify any potential differences relating to stigma associated with infection with either hepatitis B or hepatitis C or clarify the factors influencing stigma.

The second study explored the barriers faced by people from CALD backgrounds in attending a specialist outpatients hepatitis clinic in the southern suburbs of

Sydney.(21) Interviews were conducted with 60 participants who reported cultural barriers to accessing healthcare including fear of discrimination, a culture of silence within their communities and concerns about privacy and confidentiality. The study identified that some participants were concerned about stigma and discrimination, but it did not provide detail of why participants feared discrimination nor did this study differentiate between hepatitis B and hepatitis C.

In another Australian study, researchers conducted qualitative interviews with 26 GPs with an interest in, or with a high hepatitis B case load about their knowledge and management of hepatitis B.(22) The study reported some evidence of stigma and discrimination associated with hepatitis B with several participants suggesting that some patients preferred to attend a GP practice rather than a specialist Liver Clinic to protect their anonymity and with one GP noting that stigma made patients unwilling to disclose their status. Several participants thought that stigma was related to notions of cleanliness and lack of understanding of transmission routes, particularly among people born in South East Asian countries. Two GPs noted a reluctance of some of their colleagues in treating people with hepatitis B as they would not want their practice labelled as a place that treated 'Aboriginals' and/or 'refugees.' However, most GPs interviewed did not describe stigma as a significant issue in relation to hepatitis B given the infection being common within particular communities.

A qualitative study exploring the perspectives of people living with chronic hepatitis B in Australia (23) found some evidence of stigma, with participants reporting selective disclosure of their infection to other people to protect themselves and other members of their family from negative responses. The authors identify the need for further investigation to determine the extent and impact of stigma and discrimination on people living with hepatitis B.

A recent qualitative research study (2013) conducted with members of the Chinese community in Victoria,(24) noted that while participants typically said there was no stigma attached to hepatitis B, they were nonetheless unsure as to whether if they had hepatitis B they would disclose their infection as they believed people with hepatitis B experienced difficulties. Some participants expressed concerns about how a person with hepatitis B should be treated in social contexts, particularly those involving the sharing of food. While the research identified a range of potential barriers to testing including a perception that hepatitis B was less problematic in Australia than in China;

that there was no treatment for hepatitis B, and that hepatitis B would be symptomatic and that symptoms would be the best indicator of a need for testing, it was less clear whether stigma and discrimination played a role in relation to testing.

A survey of hepatitis B knowledge, testing and vaccination among Chinese and Vietnamese born adults in Australia, found a marked difference in the rate of self-reported hepatitis B. While Vietnamese respondents self-report rates were similar to current estimates of prevalence in Australia, the self-report rates were much lower among the Chinese respondents. The authors speculate that this difference may in part reflect an unwillingness of some Chinese respondents to disclose their hepatitis B infection given a fear of discrimination and stigma, but they also note that there is no apparent reason why this factor might differentially influence disclosure by Chinese compared with Vietnamese respondents.(25)

Aboriginal and Torres Strait Islander populations are disproportionately affected by hepatitis B compared to the general population and are identified in the National Hepatitis B Strategy 2010-2013 as a priority population for prevention and clinical management.(1) The negative impact of colonisation, racism and economic inequality on the health and well-being of Indigenous Australians is well documented.(26-28) It is less clear whether Aboriginal and Torres Strait Islanders experience any specific form of stigma or discrimination related to hepatitis B.

Two recent studies have been conducted in the Torres Strait, the first investigating how health service providers respond to chronic hepatitis B (29) and the second looking at the knowledge and understanding of Torres Strait Islander people with hepatitis B.(30) Qualitative interviews conducted with health care providers in the Torres Strait did not reveal significant issues associated with stigma and participants suggested that the inadequate knowledge and awareness of hepatitis B reduced any possible hepatitis B related stigma.(29) Several participants raised concerns that the possible framing of hepatitis B as a sexually transmitted infection may lead to cultural shame. Consistent with Wallace et al., 2011, a study looking at knowledge and understanding among Torres Strait Islander people living with hepatitis B found low levels of knowledge about the infection and a lack of awareness of important health protective behaviours, including moderation of alcohol use. However, the study did not identify hepatitis B related stigma or discrimination as factors in this population. (30)

International Research - North America

The majority of international peer-reviewed research focuses on studies conducted in North America with different Asian-American communities. Similar to Australia, hepatitis B prevalence is higher among Asian-born communities in the United States and Canada with several studies identifying attitudes in participants' country of birth as underpinning concerns about stigma.

A Canadian study (14) examining the sociocultural factors potentially affecting hepatitis B prevention and treatment in Chinese Canadians found that while stigma was not a health care access barrier, two thirds of participants believed they were stigmatised as a result of hepatitis B; 31% were ashamed of their illness; 47% were unwilling to discuss the issue with friends and family and that 52% of participants incorrectly believed that hepatitis B could be transmitted by sharing food. The authors suggest that the association between sharing food and transmission may contribute to feelings of stigma and shame, with fears of transmission leading some to either avoid disclosure or self-exclude from important social events. The authors also suggest that fears around disclosure and feelings of shame in relation to hepatitis B may stem from the systematic discrimination of people with hepatitis B in China.(14)

A study investigating the impact of hepatitis B knowledge and stigma on screening in Canadian Chinese found hepatitis B related stigma associated with reduced rates of hepatitis B screening.(31)The study found that as with other infectious diseases such as HIV, perceptions of contagion and an overestimated risk of transmission through casual contact play a role in the development and perpetuation of hepatitis B related stigma. Consistent with other Canadian research,(14) a common misconception among participants was that hepatitis B could be transmitted through the sharing of food. The authors observe that this issue is particularly significant within Chinese communities where sharing food is used to establish and strengthen social bonds, and that as a consequence people with hepatitis B may avoid disclosing their status to others, and those who are at risk of infection may avoid screening for fear of diagnosis and subsequent social isolation.

A study from the United States (13) looked at correlates of hepatitis B knowledge and health behaviour framework collected data from four Asian-American migrant groups - Vietnamese, Hmong, Korean and Cambodian. The study found that hepatitis B awareness varied across the four groups and ranged from 45% within the Hmong to

79% among Korean Americans. While most respondents in all four groups correctly identified that hepatitis B could be transmitted through sharing needles and in childbirth, large proportions of all groups incorrectly believed it could be transmitted by coughing, and sharing food, drink and eating utensils. Thirty-eight percent of Vietnamese respondents believed that people with hepatitis B were avoided compared to 70% of Cambodian respondents, indicating variable levels of stigma across communities. The researchers did not find a relationship between increased knowledge about hepatitis B and perceived susceptibility, perceived severity, awareness of stigma and a belief in the efficacy of testing across the four groups.

Another study from the United States looking at knowledge transfer from health care providers to pregnant women, with the aim of identifying poor adherence to standard hepatitis B preventive practices among clinicians, found that stigma was a factor. (32) Qualitative interviews were conducted with 16 obstetricians and 17 perinatal nurses in a high hepatitis B prevalence area in southern California. All participants described themselves as important sources of hepatitis B information and while most believed they were responsible for providing education, especially to patients with hepatitis B, they consistently expressed low self-efficacy in their ability to conduct this education and that their lack of knowledge and training was a barrier to this education. A sub theme of stigma emerged consistently throughout interviews with participants perceiving a hepatitis B related stigma and that this made patients reluctant to receive information and/or to encourage their sexual contacts and family members to be tested for hepatitis B. Several participants described difficulties in discussing hepatitis B with a patient if a partner or family member was present at the appointment and one participant was asked by a patient not to discuss their hepatitis B infection in front of their partner. This study illustrates the need for better hepatitis B clinical education and resources to assist health care providers in addressing issues of disclosure and stigma.

A study of Chinese immigrants in an urban Chinatown in Chicago (19) sought to formally evaluate stigma through the development of a hepatitis B stigma instrument. The authors reported that the stigma items used in the study showed a high degree of reliability with stigma rated across a number of domains, including 'fear of contagion', 'guilt' and 'social isolation.' The study found that stigma was greatest in the fear of contagion domain with 60% of respondents indicating a belief that people with hepatitis B could put others at risk and should avoid close contact with others. Limited

stigma was identified in the social isolation or healthcare neglect domains and the study found that having a family member with hepatitis B, and greater knowledge was associated with lower degrees of stigma. The authors noted that a history of institutional discrimination in schools and the workplace in some Asian countries poses another barrier to testing among high prevalence populations and may contribute to low rates of vaccination. Another US study among people with hepatitis B developed and validated a disease-targeted quality of life instrument with the research finding that among people with hepatitis B, concerns of infecting others and being stigmatised negatively impacted on the quality of life of people living with hepatitis B.(33)

An evaluation of a San Francisco initiative addressing the high hepatitis B rates among Asian Americans in San Francisco (34, 35) found that a partnership approach was successful in increasing awareness about hepatitis B among Asian and Pacific Islanders communities. The campaign aimed to create public and health care provider awareness about the importance of testing and vaccination for members of the Asian-American community; promote routine testing and vaccination within the primary care medical community, and to ensure access to treatment for chronically infected individuals. The evaluations included information derived from interviews with community leaders about their perceptions of the effectiveness of the campaign and annual reports of activities from members of the partnership. Key informant interviews indicated that the project had been successful in changing community views of hepatitis B by successfully de-stigmatising and de-personalising hepatitis B (34) and that participants noted that shifting stigma among the American-born was easier than among participants born overseas. Annual reporting from participating organisations indicated that a partnership approach had been successful in increasing awareness of hepatitis B and promoting routine testing and vaccination although they could not determine whether this increased awareness had resulted in higher levels of testing and vaccination. (35)

International Research – China, Singapore and Taiwan

Research conducted among Taiwanese university students (36) compared knowledge, health beliefs and self-efficacy toward hepatitis B prevention among students and found that most students (regardless of their hepatitis B status) reported that they would be afraid to tell friends if they were infected with hepatitis B. It is not clear, from the published data from this study, whether these fears are associated with stigma or concerns about discrimination. Further, the study found that most students

also reported that they would be afraid of being infected if their friends had hepatitis B, which suggests at least some confusion in relation to transmission and prevention.

A qualitative study conducted in Singapore (37) investigating barriers identified by physicians in managing hepatitis B in primary care settings identified fear of stigmatisation as negatively impacting on disease monitoring. Eight focus groups were conducted with 43 primary care physicians in Singapore with most participants identifying that people with hepatitis B had a poor understanding of the infection. Some focus group participants suggested that the public perceptions of people with hepatitis B as being a “contagious individual” (p.335) led to some people with hepatitis B to enter a state of denial, hide their status and not monitor their infection. The authors note that while participants recognised such barriers, they did not appear to see their own role as primary care physicians as central to improving patients understanding of hepatitis B or increasing patient interest in follow-up monitoring.

A study looking at hepatitis B and liver cancer knowledge among healthcare and public health professionals in China (15) where regular testing occurs within many workplaces, found that 18% of the health professionals said that they do not report a positive hepatitis B result directly to the patient while 38% reported positive results to the person’s employer and 25% reported to a patients school. The study found that health professionals who only reported positive results to employers and schools had less overall hepatitis B knowledge than those who only reported results to patients – and supporting the idea that hepatitis B related stigma and discrimination can be mitigated by effective hepatitis B education. The authors conclude reporting policies in China reflect underlying prejudice against people with hepatitis B and may deter people at-risk from being screened and subsequently receiving the vaccine or being monitored for liver cancer. A 2011 commentary published in *the Lancet* about hepatitis B discrimination in China (16), notes that while the Chinese government has taken legislative action in 2007 to eliminate discrimination against people living with hepatitis B in the areas of employment and education, the authors argue that the enforcement of these regulations has been limited, and that discrimination continues. The authors call for large-scale dissemination of scientific knowledge about hepatitis B to eliminate the ‘ingrained fear that leads to discrimination’ (p. 1059).(16)

Gaps in current research and future directions

While the small body of research looking at hepatitis B stigma and discrimination offers important insights and directions for future research, it has clear limitations. Much of the research makes a range of assumptions and does not provide definitions of how stigma and/or discrimination are being conceptualised within the research. Some research does not distinguish between hepatitis B and hepatitis C, even while the manifestations of stigma and discrimination are essentially very different between these infections. In most cases, research investigating CALD populations affected by hepatitis B in Australia, the US or Canada does not identify whether participants were recent arrivals, well established or indeed second or third or fourth generation migrants. The experiences and knowledge of hepatitis B may be very different for recently arrived migrants compared to individuals or communities who are well established.

Few studies investigate the nature of stigma and discrimination within particular contexts and communities. In Australia, the US and Canada there is little research examining attitudes and behaviours of health care providers toward individuals and communities affected by hepatitis B and little research exploring the experiences of people with hepatitis B with their health care providers.

While the populations and communities affected by HIV, hepatitis C and hepatitis B vary, a fundamental difference between the infections is that a preventative vaccine exists for hepatitis B. There is currently no research that investigates the influence that the availability of a preventive vaccine has in relation to stigma and discrimination within different contexts including health care settings.

A key point arising from the literature is that people from particular countries where discrimination is evident, for example China and the Philippines (14, 15, 19) may be less likely to seek medical treatment in Australia as a result of a fear of discrimination. Further research is needed to better understand how discriminatory practices in countries of origin influence engagement with testing, vaccination and clinical management in the Australian context.

In Australia, Indigenous Australians are disproportionately affected by hepatitis B, however there is currently no research that indicates particular issues of stigma and discrimination associated with hepatitis B. Future research in the field of hepatitis B

should endeavour to better understand the experiences of and understandings of hepatitis B among Indigenous Australians to identify specific issues that negatively impact on the prevention and clinical management of hepatitis B.

While hepatitis B in and of itself may not attract stigma and discrimination, broader issues of identity, cultural difference, racism and inequality may play a role in shaping the health outcomes of individuals and communities affected by hepatitis B.(38, 39) Some CALD communities may be reluctant to be identified with hepatitis B as a result of wider fears that it will confirm media driven perceptions in the wider Australian community that migrants and in particular asylum seekers are vectors of disease and burdens on the health system. Ongoing experiences of racism by people from CALD backgrounds, Indigenous Australians and refugees may contribute to low rates of hepatitis B testing, treatment and vaccination and this should be explored further.

Finally, the small body of available research suggests that when stigma and discrimination are attached to people with hepatitis B it is predominantly associated with poor understandings of transmission rather than linked to concepts of moral deficit in the ways that have characterised HIV and hepatitis C related stigma and discrimination. Improving the quality of hepatitis B education among health providers and affected communities, developing culturally appropriate resources, and strengthening the communication skills of health care providers so that they can effectively provide accurate and accessible information about hepatitis B to the diversity of affected individuals and communities will significantly reduce stigma and discrimination related to hepatitis B.

Reference list

1. **Australian Government Department of Health and Ageing.** National Hepatitis B Strategy 2010 - 2013. Canberra: Commonwealth of Australia; 2010.
2. **Logie C, Gadalla T.** Meta-analysis of health and demographic correlates of stigma towards people living with HIV. *AIDS Care.* 2009;21(6):742-53.
3. **ASHM, NCHSR.** Stigma and Discrimination around HIV and HCV in Healthcare Settings: Research Report. Sydney: ASHM;2012.
4. **Slavin S, Brener L, Callander D, de Wit J.** The HIV Stigma Audit. Sydney: National Association People Living with HIV;2012.
5. **Hopwood M, Treloar C, Bryant J.** Hepatitis C and injecting related discrimination in New South Wales, Australia. *Drugs: Education, Prevention and Policy.* 2006;13(1):61-75.
6. **MacLachlan J, Allard N, Towell V, Cowie B.** The burden of chronic hepatitis B virus infection in Australia, 2011. *Australian and New Zealand Journal of Public Health.* 2013; online.
7. **Australian Bureau of Statistics.** Population Distribution, Aboriginal and Torres Strait Islander Australians. Canberra: Commonwealth of Australia; 2006.
8. **National Health and Medical Research Council.** The Australian Immunisation Handbook: 10th Edition. Canberra: Commonwealth of Australia; 2013.
9. **Australian Institute of Health and Welfare.** Cancer incidence projections: Australia, 2011-2020. Canberra: 2012.
10. **Tracey E, Kerr T, Dobrovic A, Currow D.** Cancer in New South Wales: Incidence and mortality report 2008. Sydney: Cancer Institute NSW;2010.
11. **Amin J, Law M, Bartlett M, Kaldor J, Dore G.** Causes of death after diagnosis of hepatitis B or hepatitis C infection: a large community-based linkage study. *The Lancet.* 2006;368(9539):938-45.
12. **Wallace J, McNally S, Richmond J.** National Hepatitis B Needs Assessment. Melbourne: Australian Research Centre in Sex, Health & Society, La Trobe University;2007.
13. **Maxwell A, Stewart S., Glenn B, Wong W, Yasui Y, Chang C.** Theoretically informed correlates of hepatitis B knowledge among four Asian groups: The health behaviour framework. *Asian Pacific Journal of Cancer Prevention.* 2012;13(4):1687-92.

14. **Wu H, Yim, C, Chan A, Ho M, Heathcote J.** Sociocultural factors that potentially affect the institution of prevention and treatment strategies for hepatitis B in Chinese Canadians. *Canadian Journal of Gastroenterology*. 2009;23(1):31-6.
15. **Chao J, Chang E, So S.** Hepatitis B and liver cancer knowledge and practices among healthcare and public health professionals in China: a cross-sectional study. 2010;10(1):98.
16. **Yang T, Wu, M-C.** Discrimination against hepatitis B carriers in China. *The Lancet*. 2011;378(1059).
17. **Scambler G.** Health-related stigma. *Sociology of Health & Illness*. 2009;31(3):441-55.
18. **Giddens A, Duneier M, Appelbaum R, Carr D.** *Introduction to Sociology*. New York: W. W. Norton & Company; 2009.
19. **Cotler SJ, Cotler S, Xie H, Luc B, Layden T, Wong S.** Characterizing hepatitis B stigma in Chinese immigrants. *Journal of Viral Hepatitis*. 2011; 19:147-152.
20. **Guirgis M, Yan K, Bu Y, Zekry A.** General practitioners' knowledge and management of viral hepatitis in the migrant population. *Internal Medicine Journal*. 2012;42(5):497-504.
21. **Guirgis M, Nusair F, Bu Y, Yan K, Zekry A.** Barriers faced by migrants in accessing healthcare for viral hepatitis infection. 2012;42(5):491-496.
22. **Wallace J, Hajarizadeh B, Richmond J, McNally S.** *Investigating general practice and hepatitis B*. Melbourne: Australian Research Centre in Sex, Health & Society, La Trobe University; 2012.
23. **Wallace J, McNally S, Richmond J, Hajarizadeh B, Pitts M.** Managing chronic hepatitis B: A qualitative study exploring the perspectives of people living with chronic hepatitis B in Australia. *BMC Research Notes*. 2011;4(45).
24. **Adamson E, Haynes K, Murphy M.** *Perceptions of liver cancer and hepatitis B in the Victorian Chinese community*. Melbourne: Cancer Council of Victoria; 2013.
25. **Vu L, Gu, Z, Walton J, Peet A, Dean J, Dunne M. & Debattista J.** Hepatitis B Knowledge, Testing, and Vaccination Among Chinese and Vietnamese Adults in Australia. *Asia Pacific Journal of Public Health* 2012;24(2):374-84.
26. **Larson A, Gillies M., Howard P, Coffin J.** It's enough to make you sick: the impact of racism on the health of Aboriginal Australians. *Australian and New Zealand Journal of Public Health*. 2007;31(4):322-9.
27. **Eades S.** Reconciliation, social equity and indigenous health. *Medical Journal of Australia*. 2000;172:468-9.
28. **Henry H, Houston S, Mooney G.** Institutional racism in Australian healthcare: a plea for decency. *Medical Journal of Australia*. 2004;180:517-20.

29. **Wallace J, Pitts M, McNally S, Ward J, Nakata Y.** Situational Analysis of Hepatitis B in the Torres Strait: we nab them and then we let them go, just like fish. Melbourne, Victoria: Australian Research Centre in Sex Health & Society; 2011.
30. **Preston-Thomas A, Fagan P, Nakata Y, Anderson E.** Chronic hepatitis B - Care delivery and patient knowledge in the Torres Strait region of Australia. *Australian Family Physician.* 2013;42:225.
31. **Li D, Tang T, Patterson M, Ho M, Heathcote J, Shah H.** The impact of hepatitis B knowledge and stigma on screening in Canadian Chinese persons. *Canadian Journal of Gastroenterology.* 2012;26(9):597-602.
32. **Yang E, Cheung C, So S, Chang E, Chao S.** Education and Counseling of Pregnant Patients with Chronic Hepatitis B: Perspectives from Obstetricians and Perinatal Nurses in Santa Clara County, California. *Asian Pacific Journal of Cancer Prevention*2013;14(3):1707-13.
33. **Spiegel B, Bolus R, Han S, Tong M, Esrailian E, Talley J, et al.** Development and validation of a disease-targeted quality of life instrument in chronic hepatitis B: The hepatitis B quality of life instrument, version 1.0. *Hepatology* 2007;46(1):113-21.
34. **Yoo G, Fang T, Zola J, Dariotis W.** Destigmatizing hepatitis B in the Asian American community: Lessons learned from the San Francisco Hep B free campaign. *Journal of Cancer Education.* 2012;27(1):138-44.
35. **Bailey M, Shiau R, Zola J, Fernyak S, Fang T, So S, et al.** San Francisco Hep B Free: A grassroots community coalition to prevent hepatitis B and liver cancer. *Journal of Community Health.* 2011;36(4):538-51.
36. **Wang W-L, Wang C-J, Tseng H-F.** Comparing Knowledge, Health Beliefs, and Self-Efficacy Toward Hepatitis B Prevention Among University Students With Different Hepatitis B Virus Infectious Statuses. *Journal of Nursing Research.* 2009;17(1):10-9.
37. **Tan N, Cheah, SL.** What barriers do primary care physicians face in the management of patients with chronic hepatitis B infection in primary care? *Singapore Medical Journal.* 2005;46(7):333-9.
38. **Viruell-Fuentes E, Miranda PY, Abdulrahim S.** More than culture: Structural racism, intersectionality theory, and immigrant health. *Social Science & Medicine.* 2012;75(1):2099-106.
39. **Grove N, Zwi, AB.** Our health and theirs: Forced migration, othering, and public health. *Social Science & Medicine.* 2006;62(8):1931-42.

