

Disclosure of hepatitis B and experiences of stigma among a sample of Chinese people living with hepatitis B in Australia

Dr Elena Cama



UNSW
SYDNEY



Centre for Social Research in Health

Background

- Decisions of whether to disclose a stigmatised health condition are complex and have ramifications for affected populations, including affecting their ability to present themselves authentically and receiving help or support from others.
- Where people do disclose, who they choose to tell, and the responses of those people (whether negative or supportive) will have varying impacts on health outcomes [1].
- Stigma a key factor in decisions to disclose [3]: People living with hepatitis B often do not disclose their status (e.g., to family, acquaintances) due to concerns about experiencing stigma [3-6], with some people who do disclose subsequently expressing regret for doing so [5].
- Limited knowledge of disclosure practices among people living with hepatitis B in health care contexts.

Our research

- Aim: Identify practices of / specific concerns around disclosure, access to care, and stigma among a sample of Chinese people living with hepatitis B.
- 65 Chinese people living with hepatitis B recruited through ECCQ.
- Online survey measuring disclosure practices, concerns around disclosure, perceived and experienced hepatitis B-related stigma, negative treatment by health workers, reduced access to care due to stigma, personal wellbeing, and frequency of check-ups.
- Non-parametric correlations used to measure relationship between concerns around disclosure and other variables.

Disclosure

N=65	N (%)
Lifetime disclosure	
Immediate family	56 (87.5)
Sexual/intimate partners	48 (75.0)
Doctors	42 (65.6)
Other health workers	12 (18.8)
Friends	18 (28.1)
Other relatives	15 (23.4)
Social workers/support service workers	3 (4.7)
Work colleagues	7 (10.9)
Concerns around disclosure	
Being isolated by friends/family/colleagues because of having hepatitis B	31 (48.4)
Being a burden to my family or an employer	13 (20.3)
Losing your job or study placement (or not being considered in the first place)	13 (20.3)
Being rejected by sexual/intimate partners	11 (17.2)
Being blamed for getting hepatitis B	7 (10.9)
Being rejected by my community	7 (10.9)
Having your visa rejected or making it harder with Australian migration	8 (12.5)

Note: Valid percentages are reported. Items were not mutually exclusive.

Perceived and experienced stigma

	N (%)
Perceived and experienced stigma (% agreement)	
People I care about stopped talking to me after learning I have hepatitis B	1 (1.6)
I have received a lot of support from people after I told them I have hepatitis B	9 (14.8)
Most people are uncomfortable around someone with hepatitis B	25 (41.7)
Some people avoid touching me once they know I have hepatitis B	22 (36.1)
Some people avoid sharing food with me once they know I have hepatitis B	31 (51.7)
People's attitudes about hepatitis B make me feel worse about myself	8 (13.3)
People with hepatitis B are treated like outcasts or rejects	7 (11.7)
Telling someone I have hepatitis B is risky	30 (49.2)
I feel ashamed because I have hepatitis B	6 (10.0)
I have lost friends, family, or intimate partners by telling them I have hepatitis B	1 (1.7)
Reduced access to care due to stigma (% any)	
Not gone for a health check-up appointment	11 (17.7)
Looked for alternative health services	9 (14.5)
Delayed seeing other health care providers	9 (14.3)
Not told health workers about their hepatitis B status	9 (14.3)
Delayed going to the doctor	9 (13.8)

Note: Valid percentages are reported. Items were not mutually exclusive.

Correlations and Conclusions

- Greater stigma associated with having more concerns around disclosure of hepatitis B ($\tau_b = .424, p < .001$) and poorer personal wellbeing ($\tau_b = .199, p < .05$).
- Negative treatment by health workers associated with lower frequency of check-ups ($\tau_b = -.264, p < .05$) and reduced access to care ($\tau_b = .242, p < .05$).
- Greater frequency of check-ups associated with higher personal wellbeing ($\tau_b = .234, p < .05$).
- Findings highlight that disclosure decisions are tied to concerns of social isolation and rejection, and these concerns may be shared by perceived and experienced stigma.
- Stigma continues to impact access to care, with interventions needed to address stigma in both the community and in healthcare settings.

Acknowledgements

This work is supported by the Commonwealth Department of Health and NSW Ministry of Health.

Thanks to the Advisory Group comprised of the Hepatitis and Multicultural Organisations and researchers in each state and territory.

Thank you to all the people involved in this study, but most especially to our researchers of Chinese background, Simin Yu and Eric Wu.

The rest of the team includes: Loren Brener, Robyn Horwitz, Timothy Broady, Elena Cama, and Carla Treloar

References

- [1] Quinn DM. When stigma is concealable: The costs and benefits for health. In: Major B, Dovidio JF, Link BG, editors. The Oxford handbook of stigma, discrimination, and health. Oxford University Press; 2018. <https://doi.org/10.1093/oxfordhb/9780190243470.013.19>
- [2] 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 Res Notes. 2011 Mar 3;4:45. <https://doi.org/10.1186/1756-0500-4-45>
- [3] Adjei CA, Stutterheim SE, Naab F, Ruiter RAC. "To die is better than to tell": reasons for and against disclosure of chronic hepatitis B status in Ghana. BMC Public Health. 2020 May 12;20(1):663. <https://doi.org/10.1186/s12889-020-08811-5>
- [4] Freeland C, Farrell S, Kumar P, Kamischke M, Jackson M, Bodor S, Block TM, Frasso R, Cohen C. Common concerns, barriers to care, and the lived experience of individuals with hepatitis B: a qualitative study. BMC Public Health. 2021 May 28;21(1):1004. <https://doi.org/10.1186/s12889-021-11093-0>
- [5] Huang J, Guan ML, Balch J, Wu E, Rao H, Lin A, Wei L, Lok AS. Survey of hepatitis B knowledge and stigma among chronically infected patients and uninfected persons in Beijing, China. Liver Int. 2016 Nov;36(11):1595-1603. <https://doi.org/10.1111/liv.13168>
- [6] Taheri Ezbarami, Z., Hassani, P., Zagheri Tafreshi, M., & Alavi Majd, H. (2017). A qualitative study on individual experiences of chronic hepatitis B patients. Nursing open, 4(4), 310–318. <https://doi.org/10.1002/nop2.100>