Systemic barriers, stigma and discrimination preventing people living with viral hepatitis or HIV accessing care

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Author: Levinia Crooks

Australia enjoys international acclaim for its revolutionary response to HIV, and most recently, hepatitis C. And rightly so. Not only are we the only country in the world to offer universal access to new, highly effective hepatitis C cures, but our willingness to embrace the latest research – and build evidence-based responses founded on multisector collaboration – are the envy of the world.

Yet despite these successes, stigma and discrimination by the health workforce threaten to prevent us from optimising these achievements.

It is the responsibility of all health professions, including junior doctors, to educate themselves and take the time to understand the needs of these diverse and often vulnerable populations.

Barriers to care

The Australian Government and all jurisdictions have adopted National Strategies to help combat HIV, hepatitis B and hepatitis C. This suite of strategies also includes a sexually transmissible infections (STI) strategy and Aboriginal and Torres Strait Islander Blood Borne Viruses and STI Strategy. Stigma and discrimination were identified as leading causes for missed diagnoses of HIV and viral hepatitis and for the failure of people living with these conditions to engage with the health system and seeking timely care.

“about 40% of people referred into (the tertiary hospital) from community based clinics, AMS, and community health, fail to attend their hospital appointment. This is for a host of factors including structural issues like the cost and time to travel, parking fees and previous negative and stigmatising experiences in hospitals.”

Tertiary consultant physician Australasian Viral Hepatitis Conference 2016

HIV and viral hepatitis are about sex and drugs. It is all too easy for value judgements to compromise the fundamental Hippocratic principles of quality, compassionate and unbiased health care.

The discrimination can take many forms, including denial of care, inferior care, unjust barriers to service provision and lack of respect. It might be as simple as the terminology used on patient documentation, or the language used when communicating with colleagues.

The impact is considerable, not just for the individual involved, but to efforts to reduce disease prevalence.

Hepatitis C
In Australia, hepatitis C is most commonly transmitted by injecting drug use, an area where stigma is profound. Once in the health system people who are viewed as “drug-users” can experience suboptimal treatment, or be viewed as untrustworthy or even criminal. There are also established beliefs that all injecting drug use are associated with chaotic behaviour rendering people who inject drugs unreliable, and consequently unable to meet dosing treatment schedules. In cases where medication is costly - as it is with hepatitis C - people have argued that it is a waste to treat people who are likely to become reinfected. But these views are old fashioned and stereotyped.

The introduction of new, direct acting antivirals to the PBS has resulted in tens of thousands of Australians being cured of hepatitis C in the space of a few short months. The evidence shows us that people who inject drugs comply with dosing treatment schedules and have outcomes comparable to non-injecting drug users. In addition to the benefits to the individual there is also a strong public health argument in favour of treating this population to reduce the amount of circulating HCV in the community.

**Hepatitis B**

Hepatitis B is endemic in a number of regions and communities around the world, including Indigenous Australians, and in many Asian countries with significant migration to Australia such as Vietnam. Vaccination is the most effective way to reduce chronic HBV, but that needs to be done at birth and so the impact is delayed. In the meantime, many people carrying the disease require health care. In Australia, it is estimated that 220,000 people have chronic HBV, yet although these numbers are increasing, 50 per cent of people with the disease remain undiagnosed. And amongst those diagnosed, many are not in care.

There are a number of competing factors responsible for this. New migrants and refugees often have competing health demands and are dealing with adjustment to a new country. Previous negative experiences in seeking health care and/or fear of disclosure also contribute to poor uptake. Progressive HBV disease is largely asymptomatic, and can lack a sense of urgency, but the health impact is severe: significant liver damage, including liver cancer potentially leading to death or highly costly procedures such as liver transplants. Structural facilitators as well as the removal of discriminatory practices and redressing concerns around disclosure are required.

**HIV**

HIV stigma has been fuelled from the first identification the Acquired Immune Deficiency Syndrome (AIDS) and the initial terming of the condition Gay Related Immune Deficiency Syndrome (GRID). This set the precondition for discrimination against a sub-population of the community that was already stigmatised, namely gay men. The Grim Reaper Campaign of the 1980’s was fuel on the fire, and fear permeated the health system, schools and other services. This still has a residual impact today, with people living with HIV afraid that disclosure will result in discrimination or exclusion.

The reality is that globally, more women than men are living with HIV and while infection patterns differ around the globe, HIV is transmitted by risk behaviours, not risk-groups.
Attempts to protect people living with HIV from discrimination have resulted in processes and systems in some jurisdictions which keep HIV off the health record or which require data about HIV to be coded. While these may have been necessary when HIV was first being identified in the 1980s contemporary privacy arrangements should provide adequate protection. Today, these processes can result in a more complex service delivery system and mean that clinicians cannot access data and information which might contribute to decisions about care. So conversely, these measures introduced to protect, can actually be a barrier to care.

What ASHM is doing

ASHM is working with Colleges, Professional Societies and Associations on a two-year project to address stigma, discrimination and structural barriers to accessing health care and prevention services. The resulting training programs and policies will be designed to be taken up across different health services and settings and will provide clinicians in training with the skills to identify and address stigma and discrimination in their own practices and in the systems in which they work. At present, the focus is on general practitioners, sexual health services, tertiary hospitals and community clinics. This will allow ASHM to pilot interventions in different settings to make sure that they are hitting the mark.

While the project focuses on the health system, it is commonly recognised that stigma in the community also impacts negatively on people’s health seeking behaviour. Effort will be devoted to providing front-line staff with strategies and resources to encourage resilience in their patients and service users and to encourage an open environment for consumer feedback about services.

Barriers to care, stemming from stigma and discrimination must end. It is incumbent on junior doctors to make sure that patients are not denied care because of the discriminatory practices of their institutions. Instead, as you enter your careers in the digital age, you can take advantage of easy-to-access information, tools and emerging techniques that will enable you to personalise and tailor patient management. By treating your patients as individuals, and offering them respect and quality care, you can have a significant impact not only on their health, but on the health of the population.

References

2. Australian Government 3rd National Sexually Transmissible Infections Strategy
3. Australian Government 4th National Aboriginal and Torres Strait Islander Blood Borne Viruses and STI Strategy
endemicity.


9. MMWR Epidemiologic Notes and Reports Pneumocystis Pneumonia --- Los Angeles June 5, 1981 / 30(21);1-3

10. MMWR A Cluster of Kaposi’s Sarcoma and Pneumocystis carinii Pneumonia among Homosexual Male Residents of Los Angeles and Orange Counties, California June 18, 1982 / 31(23);305-7

11. Associated Press Eve Van Grafhorst


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