Addressing systemic barriers, stigma for people living with viral hepatitis a

For all the work done to create access to healthcare, there are as many barriers which bring their own set of issues.

Some of these barriers are created by health services at an institutional or policy level, while others originate from stigmatising attitudes of staff within facilities. Still others come from health consumers themselves who have past experience of, or are influenced by, stories about discrimination in the health service. Each of these factors can reduce health outcomes, impede quality of life and ultimately result in adding to the cost of providing healthcare if health seeking behaviour is delayed. An exciting new initiative funded by the Commonwealth Department of Health is seeking to introduce system changes, particularly in relation to healthcare for people living with hepatitis B, hepatitis C and HIV. The project is run by the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) and APNA is a valued partner.

The Australian Government and all jurisdictions have adopted national strategies[1] to help combat HIV, hepatitis B and hepatitis C. The suite of strategies also includes a *National Sexually Transmissible Infections Strategy*[2] and *National Aboriginal and Torres Strait Islander Blood-borne Viruses and Sexually Transmissible Infections Strategy*[3].

Stigma and discrimination have been 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 seek timely care. This is one of a number of projects running over the next two years to facilitate the implementation of the national strategies.

APNA's involvement means APNA members will benefit from the outcomes of the project whilst giving APNA direct input into how the project is developed; Jane Henty is representing APNA on the Project Advisory Committee. A component of the Education and Career Framework that APNA is currently developing will describe the expectations around what primary health care nurses can do in their role to limit the impact of stigma and discrimination and how they can address systems-level issues to improve access to care.

An overview of HIV, HCV and HBV in health settings

Literature review and community consultations have been conducted to help inform the project. 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.

HIV

HIV stigma has been fuelled from the first identification the acquired immune deficiency syndrome (AIDS)[4] and the initial terming of the condition Gay Related Immune Deficiency (GRID)[5] syndrome. This set the precondition for discrimination against a sub-population of the community, a subgroup which was already stigmatised, namely gay men. The Grim Reaper campaign was designed to shock the community and prime them to heed public health promotion education and information. Fear permeated the health system, schools[6] and other services, and we still experience the consequences of this in residual discriminatory practices and fear by people living with HIV that disclosure will result in discrimination or exclusion in some form. This largely came about because it was easy to attribute HIV to a sub-population rather than to a virus and specific practices which would facilitate its transmission. Globally more women than men are living with HIV[7] 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.

Hepatitis C

A similar chain of events has occurred in hepatitis C which is readily transmitted through contaminated injecting or surgical equipment and contaminated blood and blood products. Recreational injection drug use, where injecting equipment is shared with a person living with hepatitis C is a common route of infection. Hepatitis C can also be transmitted sexually, particularly where there is the potential for blood to blood transmission, and through other skin penetration procedures such as tattooing with contaminated equipment. While periods of injection drug use may be sporadic or short lived, chronic hepatitis C infection is lifelong unless treated. The stigma associated with current or past drug use makes it difficult for many people to come forward for testing. 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 is considerable evidence that people who inject drugs can comply with dosing treatment schedules and this is evidenced through compliance with methadone and other opiate substitution programs,[8] and a number of drug trials among people who are injection drug users.[9] A strong public health argument in favour of treating injection drug users is to reduce the amount of circulating HCV in the community.[10]

Hepatitis B

Hepatitis B is endemic in a number of regions and communities worldwide,[11] including in the Australian Indigenous population which can be identified back many thousands of years,[12] 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 impact is not realised until subsequent generations. In Australia it is estimated that 240,000 people have chronic HBV, but while it is increasing only 50% of these have been diagnosed.[13] Many people who have been diagnosed are not in

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care and it is thought that a number of competing factors are responsible for this. For example new migrants and refugees often have competing demands on health and are dealing with adjustment to a new country. It is thought that poor uptake of health services may be a result of previous negative experience in seeking healthcare and/or fear of disclosure. Progressive HBV disease is largely asymptomatic, and significant liver damage, including liver cancer can result, leading to death or highly costly procedures such as liver transplant. Structural facilitators as well as the removal of discriminatory practices and redressing concerns around disclosure are required.

With so many priorities why is this important?

As nurses you manage competing demands. Inviting more people into an often overcrowded health service can sound counterintuitive. But projects such as this one are aimed ultimately at reducing the health system burden: getting people tested early allows timely treatment initiation and averts new infections; task shifting, particularly to the community at earlier stages of disease progression, can avert more costly tertiary care as well as improve quality of life in people living with a chronic condition.

Systems-based approaches to prevention, testing, diagnosis, monitoring and treatment can reduce reliance on outmoded assumptions about infection demographics. We are all committed to delivering high quality services, and this can only be done if those services are delivered free from stigma and discrimination. Stigma and discrimination is not a one off concern, nor is it restricted only to the conditions covered by this project. We hope that by focusing on principles, as well as exploring specific initiatives, over the next two years we will, with APNA, be able to develop durable resources to assist nurses respond to these issues within our services. We see this as being important for new and emerging health service managers and those in training, as well as for those of us with established careers.

What will we actually see come from this project?

We aim to develop a number of online learning modules that will assist nurses to identify areas of concern in their services. We will also make available online tools, checklists and resources to help nurses put in place workplace strategies, policies and procedures.

The project is also working with the Royal Australian College of General Practitioners (RACGP) to develop training and resources. APNA will look at providing opportunities for primary health care nurses to discuss the issues raised in the review and to think critically about what steps should be taken. This may involve challenging some established opinions about health service access.

In early 2017 the Australian Healthcare and Hospitals Association (AHHA) will conduct a simulation for the project, bringing together a range of health service partners, collaborators, implementers and consumers to finalise a program of activity for the project through 2017–2018.

ASHM is committed to being transparent. Project resources and processes will be made available on the ASHM project website as well as key resources being made available through the APNA website. We also hope to see presentations submitted for the APNA conference and through presentations at other APNA forums and webinars.

Any enquiries about this work can be directed to SandDProject@ashm.org.au.

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