PEER SUPPORT SERVICE FOR CALD PEOPLE LIVING WITH HEPATITIS B- THE EFFORTS, THE RISKS AND THE BENEFITS

Enaam Oudih
Manager BBV programs - RASA

Project team - Karshen Low, Sumbo Ndi, Namam Salih, Emma Williams,

---

We acknowledge this Land as the Traditional Lands of the Kaurna People and we respect and support their Spiritual, Physical, Economical, Intellectual and Emotional relationship with their Country.

We also acknowledge the Kaurna people as the custodians of the Adelaide Region and their inherent Cultural and Spiritual beliefs continue to sustain the living Kaurna People today.

Outline

- Overview of PEACE multicultural services
- Our journey of developing Peer Support work
- Key learning from the
    1. people with lived experience
    2. service providers
    3. literature review
- Hypotheses for a sustainable hepatitis B peer support model
- Conclusion

PEACE Multicultural Services

Personal Education And Community Empowerment

- We provide the Multicultural BBV and STIs services funded by SA Health
- We are all CALD and have different roles, collectively we:

1. Provide community education
2. Build community resources and capacity
3. Work with communities to eliminate stigma and discrimination
4. Provide counselling and case management services
5. Present the voice of Multicultural communities

Our Journey started when:

We experienced the power of people with lived experience mainly within the mental health, gambling help, HIV and viral hepatitis fields

- ✓ We observed the strengths, passion and the positive influence that people with lived experience have on others
- ✓ All accreditations, funding bodies and mainstream organisations have huge interest in having CALD people with lived experience participating in policy and service delivery

Relationships Australia
SOUTH AUSTRALIA

PEACE
Multicultural Services

So we began……

- ➢ Talking to CALD people who are involved in public speaking about their lived experience of living with HIV, hepatitis B, mental health and gambling problems
- ➢ Empowering people to recognise their strengths and the role they might play through education and support services
- ➢ Seeking their expression of interest and offering necessarily training
- ➢ Providing opportunities for them to contribute in any capacity they see relevant to them

Relationships Australia
SOUTH AUSTRALIA

PEACE
Multicultural Services

Soon after we began……

- People who expressed interest, raised their concerns about the harm this have already or may have caused them
- We learnt that:
  1. Our processes were not culturally appropriate
  2. People were reluctant to raise their complaints
  3. We could not simply take a mainstream approach and apply it to a CALD context
  4. We did not have enough knowledge about incorporating CALD people with lived experience into the services we offer

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

We had to enquire further…..

- An internal working group was established
- Learnt about co-design and co-production (attended training, obtained relevant articles and spoke to experts in the field of lived experience)
- Conducted literature review
- Ongoing consultation with CALD people who have a lived experience and with service providers

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

Our learning from the lived experience publication/experts…..

- This is not a new idea (Historically people have shared and used their lived experience in so many ways)
- In recent decades many social movement started to use their lived experience to advocate for a change
- There is a requirement now to have consumers involved into services that are being offered

"Nothing about us without us"

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

Our learning from the lived experience publication/experts…..

The lived experience is often related to:

1) issues associated with stigma and vulnerability (precisely the issues that they want to escape from)

2) Issues associated with recovery, living well and ability to overcome challenges (what if they don't??, what if they got sick again?? …etc

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

Our learning from the lived experience experts…..

- The way that lived experience is viewed and reduced causes harm
- Unrecognised and/or dismissed spiritual pain crushes people
- This isn't 'safe' work
- It can be lonely …
- Where do people with lived experience belong?
- Power imbalance is the elephant in the room

Ellie Hodges (May 2018)

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

Our learning from the lived experience experts…..

CALD people living with Hepatitis B are often confronted with issues related to their migration and settlement experiences including:

- ✓ Language barrier
- ✓ Low health literacy and understanding the health system
- ✓ experiences of trauma
- ✓ Financial issues
- ✓ Stigma and discrimination
- ✓ Isolation or low level of supportive network
- ✓ Chronic illness can be viewed as a disability

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

CALD Service Providers perspectives

The initial interest of CALD People living with hepatitis B to become involved in any role that requires them to use their lived experience may originate from:

- ✓ worker's authoritativeness
- ✓ fear of losing current support if rejecting the offer
- ✓ A desire to repay the 'debt' as one client informed the service provider

PEACE Worker

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

CALD Service Providers perspectives

Power imbalance

- ➢ The power hierarchy changes depending on the context (*Seniority, knowledge, higher education, achievements or authority)*

  Gender and age play huge factors

"There is a positive correlation assumption that CALD people usually gain more power, knowledge, achievements and authority with age"

Worker from Asian background

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

CALD Service Providers perspectives

- How seniority and authority is perceived within a particular culture can heavily influence the effectiveness of the peer support if not even causing harm for the person involved

"The peer supporter can alter their story, can be selective of the words they use and also they can be heavily interrogated adding more to the stigma"

Worker from the Middle East

Relationships Australia
SOUTH AUSTRALIA

PEACE Multicultural Services

CALD Service Providers perspectives

All service providers agreed that:

1. the daily challenges experienced by people living with hepatitis B cause many barriers such as adopting to a new culture (Acculturation), seeking help and even reluctance to receiving and providing peer support.
2. People are worried about the shame they may bring
3. We need to be able to assess clients' readiness to be involved
4. There is no clarity about the framework of incorporating services by people with lived experience such as peer support

Relationships Australia
SOUTH AUSTRALIA

PEACE Multicultural Services

Literature Review

Peer support programs has been widely accepted to assist people with chronic conditions by improving their ability to self-manage, self-efficacy, treatment adherence, and well-being.

Blackberry, Walker, Moore, and Furler (2015)

Not much literature is available about peer support and hepatitis B

Relationships Australia
SOUTH AUSTRALIA

PEACE Multicultural Services

Literature Review

- Peer Support is the " Social emotional support, frequently coupled with instrumental support that is mutually offered" or "a system of giving and receiving help founded on key principles of respect , shared responsibility and mutual agreement"
- The implementation of peer support in health care context have had been provided positive results to both peer supporters and peer support recipients

Relationships Australia
SOUTH AUSTRALIA

PEACE Multicultural Services

Literature Review

Benefits of peer support

- Gaining personal growth which promotes confidence in their capabilities, empowered, increased sense of hope and coping skills with the illness (Solomon, 2004), ability to address feelings of stigma (Salzer, 1997 as cited in Solomon, 2004), and gaining a boost in self-confidence and self-esteem through a feeling of appreciation from the approval of others (Salzer & Shear, 2002)
- Professional growth such as developing job skills, and progressing forward in achieving long-term career goals by gaining helpful experience and knowledge were also an extensive benefit of peer support participation (Salzer & Shear, 2002).

Literature Review

STIGMA = "a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society".

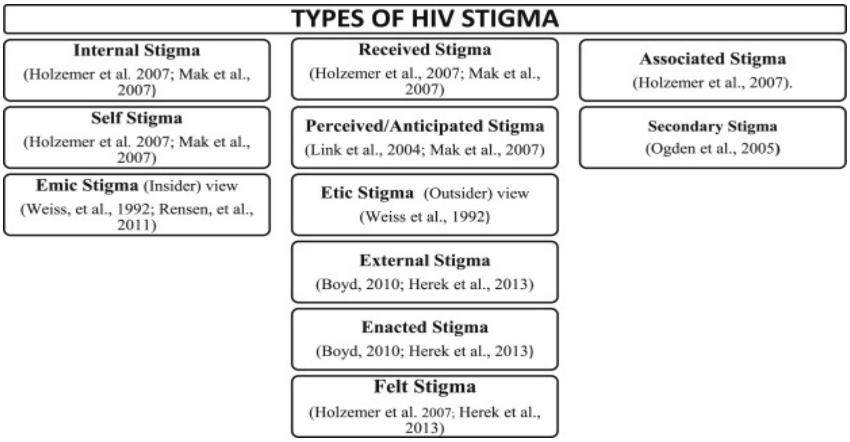
World Health Organisation (2001)

The impact:

Stigma worsens the situation and leads people to be reluctant to seek and/or accept support and assistances. Their significant others are also affected by it influencing their help seeking behaviour and disclosure issues too

(WHO, 2018)

Literature Review



TYPES OF HIV STIGMA

Internal Stigma
(Holzemer et al. 2007; Mak et al., 2007)

Self Stigma
(Holzemer et al. 2007; Mak et al., 2007)

Emic Stigma (Insider) view
(Weiss, et al., 1992; Rensen, et al., 2011)

Received Stigma
(Holzemer et al., 2007; Mak et al., 2007)

Perceived/Anticipated Stigma
(Link et al., 2004; Mak et al., 2007)

Etic Stigma (Outsider) view
(Weiss et al., 1992)

External Stigma
(Boyd, 2010; Herek et al., 2013)

Enacted Stigma
(Boyd, 2010; Herek et al., 2013)

Felt Stigma
(Holzemer et al. 2007; Herek et al., 2013)

Associated Stigma
(Holzemer et al., 2007).

Secondary Stigma
(Ogden et al., 2005)

H. Christa Chidrawi, Minrie Greeff, Q. Michael Temane, Colleen M. Doak (2015)

Literature Review

For some Hepatitis B is viewed as a disability = a burden to self, family, the society, and anyone who are important to them.

Disability in all its forms is a highly stigmatised issue within CALD communities because of attitudes and misconceptions

The Australian Human Rights and Equal Opportunity Commission (2000, p. 9)

People who prone to stigma and discrimination can develop a mental health issue

(Prasad-Ildes & Ramirez, 2006),

Literature Review

Acculturation = “is the process of social, psychological, and cultural change that stems from blending between cultures”

(Wikipedia 2018)

Acculturation distress occurs when adaption is unsuccessful or the journey of adopting to a new culture is too difficult

(Koneru, Weisman de Mamani, Flynn & Betancourt, 2007; Sakamoto, 2007)

Relationships Australia
SOUTH AUSTRALIA

PEACE
Multicultural Services

Literature Review

Collectivist culture
is one that's based on valuing the needs of a group or a community over the individual. Individuals in a collectivist culture are likely to value what is good for the whole over what is good for one person.

Study.com website (2018)

- If peer support is going to bring shame to the family and other significant others they will not participate

Relationships Australia
SOUTH AUSTRALIA

PEACE
Multicultural Services

Literature Review

- Collectivism may prevents people to manoeuvre around the support effectively. Within this environment the severity of the condition might be the main trigger to seeking help

- CALD people are more likely to seek help if they have the opportunity to discuss their condition with people around them such as family, friends, settlement services, and church leaders

Prasad-Ildes and Ramirez (2006)

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

Literature Review

Issue of Effort-Reward Imbalance (ERI)

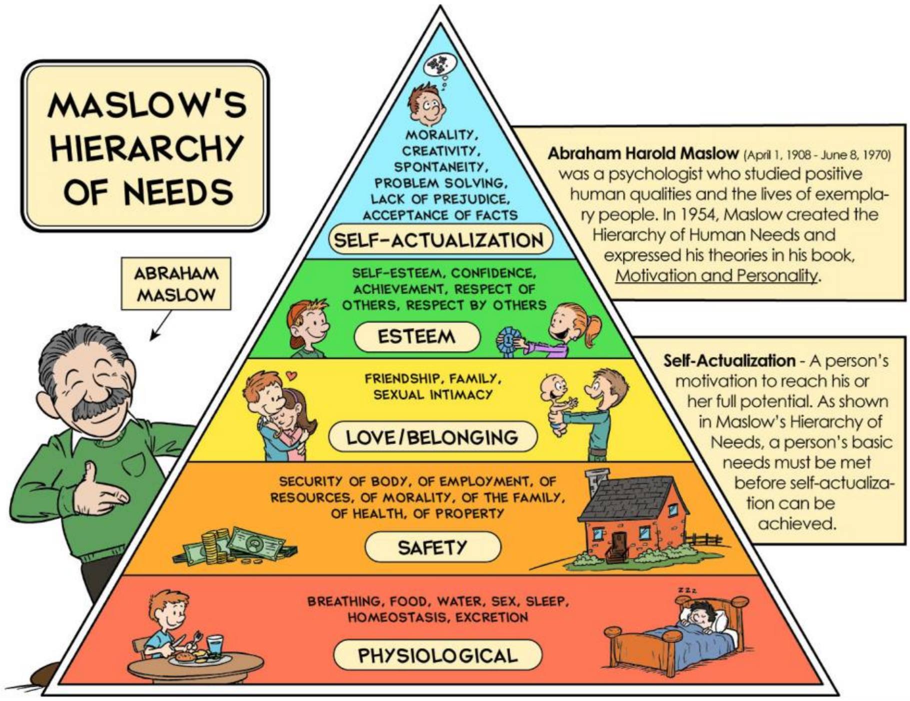
ERI model mentioned individuals that worked hard without receiving adequate reward may experience strain reactions- stress, demotivation, and burnout.

(Johannes, 2012)

When individuals dealing with stigma and are exposed, the larger the gap between high efforts and low rewards could induce negative emotions and harm

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services



Abraham Harold Maslow (April 1, 1908 - June 8, 1970) was a psychologist who studied positive human qualities and the lives of exemplary people. In 1954, Maslow created the Hierarchy of Human Needs and expressed his theories in his book, Motivation and Personality.

Self-Actualization - A person's motivation to reach his or her full potential. As shown in Maslow's Hierarchy of Needs, a person's basic needs must be met before self-actualization can be achieved.

Building sustainable CALD specific Hepatitis B Peer Support Service

- **Meaningful services can only increase the opportunities for CALD people to participate in peer support**
- The quality of treatment and care can only be enhanced when we attempt to address issues as per the Maslow's hierarchy of needs
- This can only be achieved when we **work together** with everyone involved (service providers, family members and other significant others

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

Building sustainable CALD specific Hepatitis B Peer Support Service

- Consider what stigma actually means to the community, pick up unique cues of stigma

- Provide community education and build the capacity of the targeted community to:
    1. Address own Stigma
    2. Enhance understanding and meaning of seeking help
    3. Positively promote the role of people with lived experience

Relationships Australia
SOUTH AUSTRALIA

PEACE
Multicultural
Services

Building sustainable CALD specific Hepatitis B Peer Support Service

Employ a dedicated Peer Support Coordinator to address:

1. Power imbalance issues
2. Critically analyse the reediness of the individual and the efforts required vs rewards- (advocate for paid peer support positions too)
3. Provide clarity about the roles and responsibilities
4. Map the journey for the interested individual and help them grow into the role
5. Work collaboratively with significant others

Relationships Australia
SOUTH AUSTRALIA

PEACE
Multicultural
Services

Building sustainable CALD specific Hepatitis B Peer Support Service

The Peer Support Coordinator to also:

- Assess sense of security and safety before, during and after participation

- Work to build ongoing resilience to:
  1. Cope with changes
  2. Recognise cultural conflict and other ethical issues
  3. Have crises management and well-being plans

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

Building sustainable CALD specific Hepatitis B Peer Support Service

<u>We need skilled workforce</u>

The Australian Commission on Safety and Quality in Health Care states that:

1. The infrastructure, policies, processes, resources, people and relationships that make up the system, can have an impact on the way clients develop their literacy, respond and act
2. Everyone involved in providing care needs to be able to give and receive, interpret and act on information in a way that is meaningful to the client
3. When we collaborate we can improve the safety and quality of care and reduce disparities

Relationships Australia SOUTH AUSTRALIA

PEACE Multicultural Services

Conclusion

1. Peer Support is an extremely helpful approach but huge gaps still exist within the multicultural context
2. It can not exist without community development work
3. Incorporating the lived experience into service delivery requires us to dedicate resources, have a framework and a structure that allows us to minimise risks and efforts for the participants while increasing their sense of rewards and achievements
4. Further research is badly needed in this area

Relationships Australia®
SOUTH AUSTRALIA

PEACE™
Multicultural Services