COVID-19 Mental Health Working Group concept paper series

Topic – Stigma

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The COVID-19 pandemic has affected us all. However, the effects on mental health have not been universal. Therefore, the road to recovery after COVID-19 is complex. This series of papers engages experts across multiple disciplines, addressing digital engagement and the need for information, and the unique mental health recovery challenges experienced by students, carers, older adults as well as stigmatised or marginalized communities. Each of the papers in this series is structured as follows: What we know, what we don't know and what we can do to map a nuanced path to effective creative recovery.

What We Know

Stigma is born out of existing stereotypes, biases, prejudices, and various forms of oppressive and discriminatory attitudes towards individuals and/or communities of people. As early as 1963, Erving Goffman identified people living with disease as having spoiled or tainted identities which justifies prejudicial responses against them. Stangl et al., (2019) provide us with a framework to better understand stigma and ways to reduce this within health care policy and practice. For instance, stigma is a strong feeling of disapproval that people in a society have about social groups, practices and conditions especially when they are poorly understood, and outcomes are not clear.

The current COVID-19 pandemic has provoked social stigma and discriminatory behaviours against people from some cultural backgrounds, people who are unwell with COVID-19 and those that treat them (Elias, 2020). Health workers have been verbally and physically attacked because they were construed to be caring for people who are ill with COVID-19. These feelings and behaviours have been extended to anyone perceived to have been in contact with the virus, such as recent travellers or healthcare workers. Such attitudes can negatively affect those with COVID-19 or those who may have been in contact with COVID-19, as well as their caregivers, family, friends and communities.

If stigma is experienced by members of the community during the COVID-19 pandemic it may hinder people from disclosing symptoms which will add to continued spread. Therefore, it is crucial that we recognise how the stigmatisation of people affected by COVID-19 will be fundamental to the delivery of high-quality health care, including mental health. For instance, suicide is three times more prevalent in the LGBTIQ community than in the rest of the population during 'normal times', and a staggering seven times more prevalent in members of our first nations communities. It is unknown how the stress and anxiety induced by a lethal pandemic may further interact with existing risk to suicide in such vulnerable and stigmatised groups.   After all, stigma and shame are closely related to each another as they both seek to socially disqualify individuals and communities from acceptance, access and equality. Stigma can also be attached to a person such as a family member or health care worker via association with the person who is impacted by a disease or a diagnosis.

There are lessons to learn about how stigma can affect the lived experience and health outcomes of people affected by COVID-19 from community, media and health care reactions to HIV/AIDS as well as previous pandemics (Hargreaves & Davey, 2020). For instance, stigma was one of the main drivers of the HIV crisis in the 1980s and 1990s and obstacles to enacting effective health promotion and disease prevention. As a result, the insidious impact of stigma associated with HIV/AIDS permeated throughout the LGBTQ+ community, healthcare system, society in general and to this day and continues to exacerbate structural and social determinants of health disparities amongst sexual and gender minorities (Sontag, 1989).

When people do not understand or fear how a virus is transmitted or whether it can be treated, they may blame, shame and ostracise people who they deem responsible for a disease, or even belittle the reasons for their illness or death. It is therefore important that we take a community approach to improve awareness of the stigma experienced during the COVID-19 pandemic, and that we understand how stigma operates at personal, cultural and political levels to prevent the ostracisation and stigmatisation of people directly affected by infectious diseases including COVID-19 (Burke, 2020).

For instance, is anticipated that COVID-19 will likely fall hardest among older people and vulnerable groups including the disabled, people living with mental illness, first nations people and women and children experiencing domestic violence (Hargreaves & Davey, 2020; Schultz & Jackson, 2020). Media accounts of deaths as a result of COVID-19 have also stressed that older people have died as a result of existing underlying comorbidities (Guardian staff, 2020). This narrative devalues the lives of people who have died from COVID-19, and the lives of people who are living with chronic health conditions. A discussion of how stigma has operated during the COVID-19 pandemic needs to be more widely understood throughout the community and across media platforms.

What We Don't Know

We are in the early days of COVID-19 and do not know how the social repercussions of the pandemic will play out over time and whether we will see the mass stigmatisation of people directly affected by COVID-19 in coming months and years.

We have also yet to see the long-term impact of the social isolation and shutdown we all experienced as a result of the COVID-19 pandemic, or whether the social restrictions and incidence of COVID-19 will fuel stigmatisation across the community.

We do not know how social isolation and misinformation will affect the most vulnerable individuals in stigmatised groups such as those in refugee or first nations communities even without a global pandemic and additional stressors.

What We Can Do

We draw here on lessons learnt from the HIV epidemic and outline how we can educate and engage a wider community approach to diminish stigma (Preciado, 2020). It is most important that we engage the wider community to respond with a whole of community approach to counter stigma experienced during the COVID-19 pandemic and to provide support to people directly affected by

the coronavirus. Otherwise, we run the risk of people not disclosing symptoms and compromising their health by not seeking medical help and infecting others with COVID-19.

Health professionals and health legislators who are working on the frontline of the COVID-19 crisis have a responsibility to reduce health disparities experienced by patients and communities. There are lessons to learn from community, media and health care reactions to HIV/AIDS and previous pandemics (Hargreaves & Davey, 2020; Burke, 2020), especially when people were scapegoated, ostracised and stigmatised as a result of their health status (UNAIDS, 2016). It is therefore important to identify the experience and outcomes of previous pandemics and how they shaped community reaction to those who acquired infection.

It is also important to explore the impact of COVID-19 on how the community views health professionals and how health workers view themselves. Health professionals have continued to work in settings that will expose them to risk of infection and these are the group of people who have greater risk of infection, adverse outcomes and death. We can reduce the potential stigmatisation of individuals and groups of people affected by COVID-19 by challenging negative language used to describe people with an actual or possible COVID-19 diagnosis. It is therefore important that the community, social care and health care sectors develop strategies and actions to diminish stigma arising from COVID-19.

The public presentation of narratives of people directly affected by COVID-19 will extend our understanding of the lived experience of those who have recovered from COVID-19, and those that have cared for people who have been ill from, recovered or died as a result of the coronavirus. Knowledge of the lived experience of COVID-19 will educate about the complexity of living with this illness, as well as responding to the disease. This is a vastly different experience to living through the shutdown conditions of the pandemic, which has affected communities through multiple dimensions, including social and physical isolation, loss of employment, remote working and learning and the reduction in live entertainment, cultural and recreational activities.

Artistic responses to the stigmatisation of people affected by HIV/AIDS by artists such as Gran Fury (US), David McDiarmid (Australia) and David Wojnarowicz (US) raised awareness about the impact of stigma on the lived experience of HIV. There are also many artworks which address the impact of the shutdown of cities and the work of essential workers during the CIVID-19 pandemic. However, it will also be important to see artworks which respond to the complexity of COVID-19, including issues connected to stigma.

Furthermore, the media has a critical role to play by refraining from language, misinformation and assumptions that could lead to the stigmatisation of people directly affected by COVID-19.

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Authors:

Associate Professor Phil Maude, Associate Professor Keely Macarow (RMIT) and

Matiu Bush (Clinical Lead, Hotel Quarantine program, Victoria State Government, Department of Justice and Community Safety).

RMIT contact:
Associate Professor Phil Maude: phil.maude@rmit.edu.au

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