Lived experiences of Australians with mental health and AOD comorbidity and their perspectives on integrated treatment

Despite growing evidence about integrated treatment, people with mental health and alcohol or other drug use comorbidity can find themselves on a 'comorbidity roundabout'. This study collated the perspectives of people with lived experience of these issues to better understand how mental health and AOD services can better address their experiences and treatment needs.

The top causes of disease burden among Australians are dominated by mental health and alcohol or other drug use (AOD) disorders. Of significant concern is the common co-occurrence (i.e. comorbidity) of mental health and AOD disorders. It is estimated that almost one in five Australians with a mental health disorder also have a co-occurring AOD disorder (Teesson et al. 2009). Conversely, between 47-100 per cent of people in AOD treatment in Australia have co-occurring mental health disorders (Kingston et al. 2017). This common comorbidity remains a major cause of disability, poor quality of life, early mortality and poses a significant challenge for the Australian health system.

Increased awareness and public concern about comorbidity has led to major government initiatives (Australian Institute of Health and Welfare 2005; NSW Department of Health 2008; National Mental Health Commission 2013).

In the *2013 National Report Card on Mental Health and Suicide Prevention*, the National Mental Health Commission recommended that individuals with co-occurring mental health problems and AOD use 'must be responded to in a comprehensive, integrated way wherever they present' (National Mental Health Commission 2013).

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Research demonstrates that integration of mental health and AOD treatment is key to enhancing outcomes for individuals with comorbidity and preventing them from falling through the gaps (Deady et al. 2015; Leung et al. 2016). However, despite the growing evidence and governmental responses regarding integrated treatment, individuals experiencing comorbidity continue to receive disparate care targeting either their mental health or AOD disorder. Individuals can find themselves on a 'comorbidity roundabout', moving from one service to another and navigating a complex range of factors in attempt to access treatment (Kay-Lambkin et al. 2004). The National Mental Health Commission has acknowledged these significant barriers, including 'siloed structures, inadequate funding, or constraints on professional development and supervision'. Furthermore, the Commission called for innovative and non-discriminatory responses encouraging the integration of services, and for funding and policy to facilitate these actions.

In response to the increasing need to better address mental health and AOD comorbidity, standardised toolkits were developed in the United States to improve comorbidity competency among treatment services (Substance Abuse and Mental Health Services Administration 2011a & 2011b).

The Dual Diagnosis Capability in Mental Health Treatment (DDCMHT) and Dual Diagnosis Capability in Addiction Treatment (DDCAT) toolkits are designed for mental health treatment services and AOD treatment services, respectively, to assess capability of addressing comorbidity across seven dimensions: program structure, program milieu, assessment, treatment, continuity of care, staffing, and training.

Guided by the toolkit scoring criteria, services are rated on each of these dimensions and the sum of these ratings indicates whether services are i) addiction/mental health only, ii) dual diagnosis capable, or iii) dual diagnosis enhanced, and provide guidance as to how to improve.

Studies in the US and Australia have demonstrated effective implementation of these toolkits and associated improvements in comorbidity competency ratings (McGovern et al. 2014, Matthews et al. 2011, Western Australian Network of Alcohol and other Drug Agencies 2011). However, no study to date had examined the perspectives of people with lived experience of comorbidity in relation to the utility of these resources. The perspective of these individuals is critical to informing the implementation of these toolkits in Australia and for enhancing comorbidity competency of Australian treatment services.

As such, this mixed methods study sought to examine the perspectives of Australian adults (N=19) with lived experience of mental health and AOD comorbidity. Information regarding experiences with comorbidity, treatment experiences and their impressions of the DDCMHT and DDCAT was collated via an online survey in November-December 2017. Consistent with international guidelines for anonymising data, direct identifiers (e.g.,names) and quasi-identifiers (e.g., demographics) are not reported (Emam et al. 2015).

Key findings

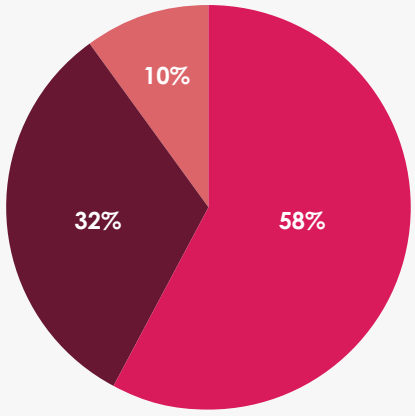
Participant mental health and AOD characteristics

All participants reported experiencing mental health problems and AOD-related problems at some point in their lifetime. Their first such experience occurred, on average, at ages 18 (SD=8.99) and 27 (SD = 9.67), respectively. Most participants (89.5 per cent) had been diagnosed with a mental health disorder by a professional, of which the most common was depression (94 per cent), followed by post-traumatic stress disorder (PTSD) (65 per cent), generalised anxiety disorder (41 per cent), social anxiety (29 per cent), eating disorder (24 per cent), bipolar disorder (24 per cent), obsessive compulsive disorder (OCD) (12 per cent), panic disorder (6 per cent) and borderline personality disorder (6 per cent). More than half (68 per cent) had been diagnosed with an AOD disorder and, among those diagnosed, alcohol was the main drug of concern (53.8 per cent), followed by amphetamines (38.4 per cent), other opiates (30.7 per cent), heroin (23 per cent), benzodiazepines (23 per cent) and cannabis (15.3 per cent).

Lived experiences with comorbidity

As depicted in Figure 1, over half the sample reported that their mental health problems had impacted their lives to a greater extent than their AOD use. Only 10 per cent reported that their AOD use impacted their lives to a greater extent than their mental health problems.

Figure 1. Proportion of people describing the extent to which their mental health problems or AOD use impacted their lives



When discussing their experiences with comorbidity, a number of participants noted the inter-related nature of mental health and AOD problems, for example:

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"I find that I use alcohol to escape feeling the fear and loss of control over my own mind. When I'm drunk it's almost like I have a rest and my brain recovers and I can be again safe at my grandma's place without a worry in the world. I would be loved again and I would be worth something not just the scraps of who I used to be."

Another participant reflected on experiences of comorbidity and the impact of trauma:

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"Often people use drugs to relieve their mental health problems or memories of trauma. They are isolated and scared. Everyone wants to be included in life."

All participants described experiencing stigma and discrimination because of their mental health and AOD use. The majority had encountered situations where they heard others say offensive things about people with AOD use problems (95 per cent) and about people with mental health problems (90 per cent). Almost two-thirds (63.1 per cent) felt they were treated as less competent by others upon revealing their mental health issues and almost all (95 per cent) had avoided stating their AOD issues on written applications (e.g., for jobs, licenses, housing etc.) for fear it would be used against them. Others (47.4 per cent) perceived they had been turned down for a job for which they were qualified when their health issues were revealed. On a similar note, when asked about the most significant challenges faced, one participant remarked:

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"People thinking that I'm weak for taking medications, family thinking that all I need is a job, or to do something better, or that I have caused it myself, or that I just need to get over what happened to me and to stop playing the victim."

Participants also provided solutions on how stigma and discrimination associated with mental health and AOD use might be reduced. These included educating the public and health professionals about comorbidity and more funding to support integrated treatment and comorbidity initiatives. One participant stated that:

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"Providing education through visual means to the community regarding the causes and triggers for these issues and the struggles faced by individuals living with mental health and or AOD issues is crucial. Using all available channels such as social media, radio and television so that people are more understanding and equipped to better handle situations where a friend or loved one may need help and support."

Others highlighted the importance of empowering people with lived experience and implementing integrated treatment approaches:

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"Empowering those suffering from it and helping them to set boundaries to protect themselves from social media and others who abuse them. Educating the victims of mental health problems and having a more integrated or holistic approach when treating them, which will allow for educating their families and support systems."

Mental health and AOD treatment experiences

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Almost all participants (95 per cent) had received some form of treatment for their mental health in their lifetime (i.e., 89 per cent outpatient counselling, 56 per cent inpatient treatment, 44 per cent peer recovery support) and just over half the sample (58 per cent), had received treatment for their AOD use (91 per cent detoxification, 82 per cent peer support, 64 per cent outpatient counselling, 55 per cent maintenance therapies, 18 per cent residential rehabilitation). The ages at which these individuals first sought treatment for their mental health problems and AOD use were 25 years (SD=6.3) and 29 years (SD=7.69), respectively.

Only 16 per cent of those who had received mental health treatment said they were made aware and could access services for their AOD use. On the other hand, 60 per cent of those who had accessed AOD treatment were made aware of services to support their mental health problems. Two-thirds (64 per cent) of the sample reported that they would prefer to work on their mental health and AOD use in an integrated way, with 27 per cent preferring to work on the AOD use prior to their mental health problems and 9 per cent wanting to work on their mental health problems first. Participants explained that their preference for integrated treatment was because they viewed their mental health and AOD problems as interlinked. For example, one participant noted that:

"Both MH and AOD issues went hand in hand for me. I think I would have started healing and growing much faster [if they had been treated in an integrated way]".

Close to three-quarters (73 per cent) of participants would prefer to have the same therapist working on both issues. Having different therapists for these issues was seen as a barrier to establishing a connection and developing rapport with a treatment provider. For example, one individual stated that:

"It's hard enough to open up to people and get a good connection. Only explaining yourself once would be fantastic".

Another participant reflected on their experience of the 'comorbidity roundabout':

"In my experience it is difficult to see which one came first, but sitting in my shoes, it does not matter, it needs to be treated together, not sending me from mental health services to AOD services, back and forth. It needs to be treated holistically, and people need not give up on me because I have not ceased my drug use, or I relapse."

Impressions of the DDCMHT and DDCAT toolkits

As depicted in Table 1, all participants rated the DDCMHT and DDCAT toolkit dimensions as being extremely important for evaluating whether a treatment service is competent in addressing comorbidity (all mean ratings > 9 out of 10).

Table 1. Ratings of importance of each dimension of the toolkits

Toolkit Dimensions	Rating out of 10 (mean, SD)
Program structure	9 (1.52)
Program milieu	9.47 (0.96)
Assessment	9.47 (0.77)
Treatment	9.68 (0.58)
Continuity of care	9.47 (1.02)
Staffing	9.52 (0.09)
Training	9.89 (0.31)

In relation to previous experiences of mental health treatment, between 42-58 per cent of participants indicated that the dimensions had not been adequately addressed to respond to their comorbidity. Some remarked that 'assessment is not often done thoroughly enough' and they've 'never been asked about comorbid health issues'. Others described the impact of disparate care in the following way:

"As soon as mental health services see AOD issues, they either refuse support or refer out. Mental health services do not do dual diagnosis well."

"I had to go to so many different services and practitioners to find help. It took many years to and a lot of hard work and time by me to finally get on the right track."

A slightly smaller proportion (between 32-58 per cent) reported that the toolkit dimensions were not adequately addressed in their previous AOD treatment experiences. Participant reasons included that there are *'not enough workers and funding'*, it is a *'difficult system to navigate'* and there is *'no acknowledgment of dual diagnosis'*.

A number of participants discussed other important factors they thought were not covered by the toolkits. These included employing workers with lived experience in treatment facilities and the importance of building a rapport with the treatment provider. Additionally, trauma informed care and support services for families and carers of individuals with co-occurring disorders were highlighted as important considerations.

Individuals can find themselves on a 'comorbidity roundabout', moving from one service to another and navigating a complex range of factors in an attempt to access treatment.

Research demonstrates that integration of mental health and AOD treatment is key to enhancing outcomes for individuals with comorbidity and preventing them from falling through the gaps.

Conclusions

This study collated the perspectives of people with lived experience of mental health and AOD use comorbidity. Most participants indicated that their mental health problems had a greater impact on their lives than their AOD use and all had experienced stigma and discrimination in relation to both issues. Despite experiencing their mental health and AOD problems as inter-related, the majority of participants reported receiving disparate care and recognised that services did not adequately address their comorbidity. Most participants also indicated they would prefer integrated treatment that is delivered by the same therapist.

Consistent with existing literature, the DDMHT and DDCAT were endorsed by participants as critically useful tools in determining how well mental health and AOD services could work towards better addressing their experiences and treatment needs for comorbidity. Not captured by these tools were the inclusion of peer workers with lived experience, and specific strategies for incorporating trauma and family member/carers into the treatment experience. This valuable feedback will be used to inform the implementation of the DDCMHT and DDCCAT in Australian mental health and AOD treatment services. These toolkits have the potential to significantly improve the standard of care for many Australians living with comorbidity, an urgent priority.

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