

## **Feedback summary on the study about informal carer's lived experience of caring for people diagnosed with bipolar and substance use disorders**

This study aimed to use qualitative methods to better understand the experience and needs of people who provide informal support to a friend, partner, or parent diagnosed with both bipolar and substance disorder (carers). The research project was carried out as part of a Masters Degree and conducted by Zoe Gruneska under the supervision of Dr Lesly Berk and Associate Professor Tess Knight, at Deakin University. Six in-depth interviews were conducted with carer participants across rural and metropolitan Australia and two participants submitted a written account of their experiences. The eight transcripts were analysed using the systematic method described by Thomas (2006). This allows for the identification of themes and categories directly from the raw data. Key themes/categories and sub-themes included:

### 1. Challenges reported by carers:

*Initial confusion:* Participants reported feeling very alone and at a loss about how to understand and deal with their new situation. It was difficult for example, to recognise that the challenging behaviour and mood instability of the person with bipolar and substance use disorders (referred to as "person") was part of a mental health condition. Most carers reported dissatisfaction, lack of trust and helplessness over the variety of prior diagnoses received by the person and delays in appropriate diagnosis and treatment.

*Uncertainty and unpredictability:* Even after the initial stages, most participants reported needing to be constantly hypervigilant. They did not know what bipolar disorder mood and especially what alcohol/drug related risky or aggressive behaviour, they may need to deal with next.

*Mental health crises:* Times when the person was at risk of harming or killing themselves were particularly challenging for carers, and they felt overwhelmed by the responsibility of trying to keep the person safe. Carers reported that one of the most emotionally distressing and guilt-inducing experiences was being required to call the police to intervene in a crisis.

*Inconsistent care and support:* To some extent carer's experience of challenges appeared to be related to perceptions of the quality of care and support provided to them and the person. Some carers reported that although health professionals and services assisted the person in a crisis, the person was not adequately followed up afterwards. Those living in rural/remote areas were especially disadvantaged by the lack of accessible health services, even when the person was experiencing a mental health crisis. Furthermore, although carers were usually the person's main source of informal support, they were rarely included in discharge planning. Instead carers were left to deal with the person's ongoing illness-related challenges alone.

### 2. Personal impact on carers

There were reports from participants of feeling "burnt out" and experiencing symptoms of anxiety, depression and stress-related disorders. They encountered a number of conflicting feelings (e.g. anger vs protectiveness towards the person) and felt guilty about actions that they sometimes needed to take to set limits with the person's challenging substance-use related behaviour, or in the interests of the person's welfare. They reported that the lack of family inclusive practice of health services/professionals led them to feel undervalued, overlooked and overwhelmed with their vital informal role at times. Furthermore, it was common for carers to need time off work when the person was very symptomatic, or in some cases they were required to cease work, with financial implications.

Feelings of isolation and loneliness related to:

- The withdrawal of people in their social network. Others did not seem to understand the carer's situation, grew tired of its chronic nature or judged the person or carer negatively. Participants considered that some of the negative judgement occurred in response to the person's substance-use related behaviours. This was particularly intense in rural/ remote areas and small communities.
- The deterioration of their social relationship with the person. In some cases, there was a striking association between the person's aggressive behaviour when intoxicated and relationship deterioration.

### 3. Adjusting to their informal supportive role

Despite these challenges, certain factors were associated with carer's positive adjustment to their role such as:

*Awareness:* Carers suggested that it takes time and experience to become aware of the complexity of the person's condition, how their substance use interacts with their bipolar disorder and their illness patterns. This awareness was viewed as potentially empowering carers to stand back and find ways to cope proactively with challenges.

*Coping and self-care:* Some carers expressed that much of their time centred on the person and they tended to feel guilty about their own needs (e.g. need for space or to do enjoyable activities or hobbies). Some experienced carers however, found positive ways to take care of themselves as well (e.g. accessing psychotherapy, or exercising).

*Acceptance:* A certain amount of acceptance of the person's condition by both the person and carer was recommended, especially if this was accompanied by a collaborative commitment between the carer and the person to work towards wellness.

*Support from health professionals/services:* All carers expressed a need to be provided with information/literature about the person's comorbid conditions and supports when they initially engaged with health services. Experienced carers considered that this would have made it much easier to adjust to their vital informal role. Participants emphasised that this input needed to come from health services / professionals who really understood dual diagnosis and practical ways to deal with it. Appropriate care and support of the person and carer at various stages along the illness trajectory (e.g. in a crisis and community follow-up) was highlighted as a way to improve outcomes for people with bipolar and substance use disorders and their families.

*Peer support:* Privacy and confidentiality were viewed as barriers to participation in peer support groups when carers lived in small communities. Another barrier to engaging in support groups for some experienced carers was concern over taking on another carer role. Indeed, some experienced carers expressed the need for peer interaction that focused on what they had in common beyond their carer role.

In summary, there is very little information about the experiences and needs of carers of people with both bipolar disorder and substance use problems, which is surprising given that these conditions commonly occur together (Berk et al 2013, Cleary et al 2008). Our study suggests that these carers may experience considerable ongoing distress and objective burden over and above that encountered in acute bipolar depressive/manic episodes. This may be particularly related to the challenge of dealing with substance-use related behaviour that can place additional strain on the carers emotional wellbeing, relationships, career, finances and general quality of life.

Furthermore, the literature highlights the negative effect of comorbid substance use on treatment response and course of illness in bipolar disorder (Mazza et al, 2009, Jaworsky et al., 2011). Thus, carers may eventually be faced not only with problematic and unpredictable behaviour related to the person's intoxication, withdrawal and need to access drugs/alcohol, but with increased bipolar episode frequency, severity and mood instability.

Although this study is limited by its small sample size and the generalizability of the results are uncertain, the in-depth reports from carers themselves provide valuable insights into the experience and needs of family and friends who support a person with bipolar and substance use disorders. The study flags the need to better educate health professionals and services to enhance the care and support of people and families affected by these comorbid disorders, and for more research in this area. It suggests that there is a vital need for better services and accessible information for all those affected by bipolar and substance use disorders, and informal carers play a significant but unrecognised supportive role. As a result of these findings, we hope to add an information resource to [www.bipolarcaregivers.org](http://www.bipolarcaregivers.org) with strategies specifically to assist carers of people with bipolar and substance use disorders in the Australian context.

#### References

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