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Author:
Holt, Martin; Treloar, Carla

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Martin Holt & Carla Treloar

National Centre in HIV Social Research, University of New South Wales, Sydney, NSW 2052, Australia

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Corresponding author: Dr Martin Holt, National Centre in HIV Social Research, University of New South Wales, Sydney, NSW 2052, Australia

Email: m.holt@unsw.edu.au

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Abstract

Aims: Although mental health problems are common among drug treatment consumers, little is known about how mental health issues are discussed by service providers or understood by clients within treatment settings. We analysed how co-occurring drug and mental health problems are discussed in treatment settings, specifically the use and understanding of clinical terminology (e.g. 'comorbidity' or 'dual diagnosis'). Method: 77 drug treatment consumers and 18 service providers in Australia were interviewed about barriers and incentives to treatment for people with co-occurring drug and mental health problems. Findings: Consumers had low levels of understanding of clinical terminology for co-occurring drug and mental health problems, except for those who had accessed literature or participated in programs developed by drug user organisations. Service providers recognised low levels of consumer mental health literacy, and advocated a client-centred approach that avoided the use of clinical terminology. Conclusions: Providers should encourage consumers to discuss mental health problems, and should not avoid using clinical terminology

as this may undermine the development of mental health literacy among consumers. Treatment services may benefit from working with drug user organisations to develop resources aimed at improving awareness and understanding of mental health problems among drug treatment consumers.

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Mental health problems are highly prevalent among those diagnosed with problematic drug use (Hall et al., 1999; Merikangas et al., 1998; Teesson et al., 2000) and are even higher among drug treatment populations (Callaly et al., 2001; Hickie et al., 2001; Ross et al., 2005; Teesson et al., 2005). Co-occurring drug and mental health problems pose significant challenges for people seeking treatment and for health professionals in both the drug treatment and mental health sectors. Comorbid conditions are more difficult to treat and manage than single drug or mental health problems, and are associated with poorer treatment outcomes (Greig et al., 2006; Hall, 1996; Havard et al., 2006; Siegfried, 1998).

There have been a number of studies and reviews attempting to identify best practice in the care and treatment of those with co-occurring drug and mental health problems (e.g. NSW Health, 2000; Teesson & Burns, 2001; Teesson & Proudfoot, 2003; Siggins Miller Consultants, 2003). The majority of these studies emphasise service provider and health professional perspectives on the challenges posed by comorbidity within drug treatment and psychiatric settings. Service user, client or consumer perspectives have been less prominent in these reviews, despite a recognition that '[r]esponses that don't include consumers

and carers will fail' (p. 143, Manns, 2003) and 'growing evidence that user involvement results in improved access, retention and client outcomes' (p. 1, National Treatment Agency for Substance Misuse, 2006).

Our study sought to bring client perspectives on drug treatment and mental health to the foreground, focusing on the ways that common mental health problems (anxiety and depression) are incorporated or not within treatment for illicit drugs. To allow a contrast between client and provider perspectives, we also sought the opinions of service providers on the management of comorbidity within drug treatment services. In this paper we discuss what we believe is a neglected area in research on comorbidity management within drug treatment – the ways that co-occurring drug and mental health problems are discussed with clients in treatment settings, and specifically the role of clinical terminology (particularly terms as 'comorbidity' or 'dual diagnosis') in discussions between clients and service providers. We explore how co-occurring mental health and drug problems are discussed with drug treatment clients and the impact this may have on mental health literacy among a group of consumers who experience a range of barriers to treatment (Treloar et al., 2004).

Mental health literacy is a specialisation of the more generic term 'health literacy' (Nutbeam, 2000) and has been defined as:

> 'knowledge and beliefs about mental disorders which aid their recognition, management and prevention. Mental health literacy includes the ability to recognise specific disorders; knowing how to seek mental health information; knowledge of risk factors and causes, of self-treatments, and of professional help available; and attitudes that promote recognition and appropriate help-seeking.' (p. 182, Jorm et al., 1997a)

The growing body of work on 'mental health literacy' suggests that the poor recognition of the symptoms of mental health problems, a lack of understanding about treatment options, and the continuing stigma attached to mental illness, create barriers to help-seeking and adversely affect treatment outcomes (Burns & Rapee, 2006; Jorm et al., 1997a; Jorm et al., 2006; Thompson et al., 2004). Advocates suggest that encouraging mental health literacy among the public in general, and specific treatment populations in particular, is desirable because it will encourage people to take action to improve their mental health when problems arise (Jorm, 2000; Jorm et al., 2006).

The gap between professional and lay understandings of mental health is a particular concern of researchers of mental health literacy. Although non-specialist doctors and clinicians do not necessarily have comprehensive knowledge of mental health themselves (e.g. Goldman et al., 1999), existing research suggests that public knowledge and beliefs about mental health problems often differ quite markedly from professional opinions about best

practice. For example, consumers often see medication as unhelpful or harmful in mental health treatment, tend to prioritise social and environmental causes of mental health problems over biological ones, and perceive lay and self-help strategies to be as useful as professional treatment (Carder et al., 2003; Goldney et al., 2001; Goldney et al., 2002; Holt, 2007; Jorm, 2000; Jorm et al., 1997a; Jorm et al., 1997b; Pound et al., 2005).

As far as we are aware, there is little or no current published work on mental health literacy among drug treatment consumers, or the ways in which service providers approach the discussion of common mental health problems with clients within drug treatment settings. In this paper, we will outline both client and provider perspectives on the use of clinical terminology to describe comorbidity and dual diagnosis. In doing so, we will show how drug treatment clients appear to have a poor understanding of the ways in which co-occurring drug and mental health problems are described by clinicians. The accounts of service providers contain contradictory attitudes about the use of clinical terminology with clients, and about clients' ability to talk about their mental health problems. Although lay understanding of professional terminology is only one part of what we might understand by mental health literacy, we believe focusing on this issue illustrates broader problems in drug treatment clients' understanding of mental health conditions. A lack of consumer mental health literacy as well as contradictory service provider attitudes may present

additional barriers to clients fully engaging in treatment for co-occurring drug and mental health problems.

Method

The interview material presented here was collected as part of an Australian qualitative study of barriers and incentives to drug treatment for people with both illicit drug and mental health problems. Approval for the conduct of the study was granted by the University of New South Wales Human Research Ethics Committee and local ethics committees in all of the jurisdictions where recruitment took place.

Recruitment

Participants were recruited from Brisbane (Queensland), Perth (Western Australia) and Sydney and Bathurst in New South Wales. The sites were chosen to reflect a range of metropolitan and regional areas in Australia. Details of service user recruitment have been published elsewhere (Holt, 2007). Recruitment of service users was achieved using peer recruitment (employing local drug treatment clients to find eligible people through their social networks), word-of-mouth, and advertising in local drug treatment centres and drug user organisations. Participants had to be able to give or withhold consent, be aged 18 or over, report a history of illicit opiate or stimulant use, have current or recent experience of formal drug treatment (within the previous two

years), and report a clinical diagnosis of (or treatment for) a common mood or affective disorder, such as depression or anxiety, during the previous two years.

Interviews were semi-structured, focusing on drug use history, experiences of drug treatment, mental health background and experiences of mental health treatment. Interviews lasted up to one hour and were tape-recorded. Participants received AU$20 expenses for taking part in the study.

Service provider participants were recruited by identifying key staff in drug treatment services, mental health facilities, drug user groups and related support organisations in the four recruitment sites. In particular, staff who worked with consumers with comorbid drug and mental health problems or who had responsibility for comorbidity-related services were identified. The selected providers were invited to participate by letter. Invitation letters were followed by up by email or by phone. Providers who wished to participate contacted the research team to arrange an interview and to return consent forms.

The majority of service providers were interviewed over the telephone, with a small number conducted face-to-face in Sydney. All interviews were tape recorded. Interviews were semi-structured and focused on the participant's experiences of working with people with drug and mental health problems, the ways in which their service addressed comorbidity, and barriers and incentives to drug treatment for people with common mental health problems. Interviews

lasted up to one hour. Service providers were not reimbursed for taking part in the study.

Analysis

After being transcribed verbatim, service user interviews were coded according to main areas of interest (e.g. experiences of substitution therapy, relationships with doctors, mental health background) and entered into NVivo qualitative analysis software. Analysis proceeded by taking each main area of coding in turn and looking for patterns of consistency and points of difference, drawing on core procedures common to both discourse analysis and grounded theory (Glaser & Strauss, 1967; Potter & Wetherell, 1987). Points of connection (or contradiction) between coded areas were also identified.

Service provider interviews were transcribed verbatim. Transcripts were read and re-read by the second author, looking for patterns, consistencies, and points of difference. This identified topics and experiences of particular interest to service providers in relation to the treatment of people with both drug and mental health problems, and contrasted provider accounts with the themes identified in the service user analysis.

The difficulties service users had in discussing mental health, and their understanding of terms such as comorbidity, were identified as areas warranting further attention and provided the starting points for the analysis presented here.

Service provider accounts were then examined to see how providers thought consumers discussed mental health issues, and to explore provider's opinions on the use of clinical language within consultations. All given participant names are pseudonyms and other identifying details have been removed or changed.

Participants

77 consumers of drug treatment services were recruited across the four sites. The mean age of service users was 37 years with an equal representation of men (n=39) and women (n=38). The majority of participants were Australian born (n=63) and 12 reported Aboriginal or Torres Strait Islander heritage. All service users had sought drug treatment after problems with illicit opiate or stimulant drugs, particularly heroin and amphetamines. Nearly all the participants (n=70) had received or were receiving substitution treatment, and a similar number (n=73) had received a diagnosis of depression during their treatment history. Less than a third of service user participants (n=22) had received a diagnosis of anxiety. Nearly all those diagnosed with anxiety (18 of 22) also reported experiences of depression during their treatment history.

18 service providers took part in the study (seven from Sydney, five from Perth, and three each from Brisbane and Bathurst). The majority of service provider participants worked for drug and alcohol treatment services (n=10), including one dual diagnosis coordinator. The other participants were four staff members from drug user organisations, two mental health practitioners, one general

practitioner specialising in drug and alcohol issues and a manager from a non-governmental support organisation.

Results

Service user accounts

Although drug treatment service users often struggled to articulate their experience of mental health problems, with encouragement some could describe their experiences of anxiety or depression:

> 'My mental health background is I suffer from depression. I have my good days, my bad days. I can go good for a couple of weeks and then some weeks I can just, something will just set me off and I can just plummet for a while. I'll have four or five bad days and yeah I just, mostly I don't want to go anywhere, I don't want to meet anyone, don't want to talk to anyone, I literally just shut myself in the house and if somebody comes around I don't even answer the door, even though my friends know I'm there.' (Mike, 35 years old)

> 'I've always been an anxious person, I've always had – for quite some time – anxiety attacks. I didn't know what they were – I've always had that stuff where I'd get that sick feeling and my heart would be racing and I just would be really… yahh! You know? I was always one of those people who has been "highly-strung"' (Melanie, 37 years old)

As is illustrated in Mike and Melanie's accounts, when service users described the impact of mental health problems, they typically used colloquial speech to describe symptoms and the ways that anxiety and depression affected their lives. Mike, for example, focuses on the way that depression makes his mood "plummet" and how he becomes socially isolated when he is depressed. Melanie's description of panic attacks focuses on feeling sick and having a "racing" heart. Although service users could generally remember the name of the condition with which they had been diagnosed, and evidence of symptomatology could be inferred from their accounts, it was noticeable that service users rarely described their experience of mental health problems with direct reference to clinical terminology, discrete symptoms or diagnostic criteria.

When consumers were directly asked about the clinical terminology used to describe co-occurring drug and mental health problems ('dual diagnosis' and 'comorbidity'), they often showed little recognition or understanding of these terms, and often had to guess their meaning. The term dual diagnosis was recognised slightly more than comorbidity:

> 'I've heard of dual diagnosis but I just can't remember like, in where or who said it but I've heard it.' (Helen, 24 yrs old)

> 'Oh, dual diagnosis. I think I've heard that on TV.' (Daphne, 42 yrs old)

'No [I] haven't heard of comorbidity, sounds like, like two people wanting to go off and die together' (Hanna, 51 yrs old)

'…comorbidity is um after you're dead.' (Terry, 44 yrs old)

'Is that like when you're using more than one drug? No?' (Francis, 38 yrs old)

'…it sounds like two people dying together. What the fuck does that mean – comorbidity?' (Perry, 41 yrs old)

Although responses like Hanna's and Perry's were delivered with some humour, frustration was also expressed by consumers when trying to interpret what comorbidity was supposed to mean. Some service user participants were concerned that use of the term comorbidity would increase the stigma of those in drug treatment and discourage people from accessing services:

'Yes, I think it [the terminology] scares a lot of people from asking or accessing or even just being involved or having anything to do with it [treatment] because it automatically tells them that it is, "you have got a problem and it's a serious fucking problem, it's a serious word." Mental, comorbid… to me it just sounds [like] "shit, I don't need another label."' (Martin, 39 yrs old)

As we will see in the following section, service providers often shared the concern that clinical terminology might increase the burden of stigma of those in treatment. However, other service user participants suggested that terms like comorbidity may not have been used or explained to them because of a perception on the part of drug treatment staff that service users were not capable of dealing with technical knowledge or complex problems:

> '…they might have thought I was too stupid because I'm a junkie' (Richard, 35 yrs old)

The idea that consumers did not have the capacity to understand clinical terminology was challenged by the accounts of those who had learnt about comorbidity and dual diagnosis by reading drug user organisation literature or by participating in peer education programs. In fact, the only service user participants to have a solid understanding of terms like comorbidity were those who had engaged in peer education activities or accessed drug user organisation literature. Service users did not describe any activities designed to improve their mental health literacy being undertaken by drug treatment services or other organisations:

> '[Comorbidity] means that I have a drug problem and I have psychiatric issues as well. I've just completed a course through [my local drug user

organisation] and it's specifically designed for dual diagnosis people.' (Jane, 37 yrs old)

'Well dual diagnosis is familiar to me. Comorbidity I'd never heard of until we did this [the interview]... But most of that jargon people have no clue. The only ones, the only people that do have a bit of a, are people that read the magazines [from drug user organisations].' (Kate, 44 yrs old)

Service users who understood the relevance of terms like comorbidity to their own drug and mental health problems represented a small minority of participants. This perhaps reflects the limited availability of education programs aimed at increasing mental health literacy among drug treatment clients, whether that be through education programs, literature or other sources. Accounts like Jane and Kate's emphasised that drug treatment service users did have the capacity to understand clinical terminology and could use it productively to increase their knowledge of co-occurring drug and mental health problems.

Service provider accounts

Service providers were asked about their use of clinical language, particularly terms like comorbidity, when they had discussions with drug treatment clients. Providers from drug treatment and mental health services often said that they tried to avoid using clinical terminology with clients and emphasised the use of lay or client centred language:

> 'When I'm talking to people, I tend to talk as much as possible in their own language… I think generally you hear people use comorbidity or dual diagnosis as a clinical term; it's not necessarily something that's used when you're talking to people.' (Mental health provider, Perth)

> 'Oh, we'd never say "Oh, mate, we think you've got a dual diagnosis" – no, no, no… well, some people come and actually say the words, use that language, but it's all really about meeting people where they're at, y'know? And if somebody is obviously paranoid about being mad then we won't talk about it all and we'll just talk about the doctor wanting to talk to them… we'll just talk about "your health". So we won't put them through any more trauma than they need to be put through' (Drug treatment provider, Sydney)

Service providers like the drug treatment provider quoted above were concerned that using clinical terminology could stigmatise and alienate drug treatment clients, who were recognised as an already marginalised and

disadvantaged group of consumers. Providers were worried that terms like comorbidity would provoke client anxieties about being labelled mentally ill, or simply be confusing when trying to discuss mental health problems with clients.

However, some service providers thought the lack of mental health literacy among drug treatment consumers, including a familiarity with clinical terminology, was problematic within treatment settings. Providers noted that drug treatment clients struggled to articulate their mental health experiences within consultations, had little understanding of what mental health treatment might involve (as opposed to drug treatment), and therefore were poorly equipped to participate in or influence mental health treatment decisions:

> 'I don't think there's as much of an understanding or a confidence or… what is the word I'm looking for? A sense of sort of ownership and power over what it [mental health] means, [what] all the sort of different medications or treatment might mean in the mental health area as much as drug treatment.' (Drug treatment provider, Sydney)

The lack of 'ownership' of mental health experiences among drug treatment clients was thought by some service providers to lead to a fear of discussing mental health within clinical settings, further exacerbating the development of consumer mental health literacy, and making treatment decisions more difficult for both providers and clients:

> ‘So if you try and talk to somebody about the fact that you’re experiencing mental health problems, they’re more likely to say “Look, I don’t want to know about this; just leave me alone”. So people learn very quickly not to talk about it because nobody wants to know. The consequences of that are often that they [consumers] don’t develop the language, they don’t develop a positive and lucid way of talking about their mental health experiences because of this cut-off and not being allowed to.’ (Mental health provider, Perth)

Among service providers, there was a recognised need for drug treatment clients to develop ‘positive and lucid’ ways of talking about mental health to improve treatment outcomes. The account above suggests that the lack of understanding among consumers about mental health issues and the inability to discuss mental health problems were seen as mutually reinforcing issues; without talking about mental health problems with clinicians clients were unlikely to develop a better understanding of mental health issues, and without an understanding of those issues, clients were reticent to discuss their mental health with providers.

Discussion

Our findings have a number of potential implications. One reading would suggest that service providers are correct to avoid clinical terminology and focus on client-centred language when discussing mental health with clients. Clients

appear to have limited understanding of clinical terminology and use lay discourse to describe the effects of common mental health problems on their lives. Some clients are also concerned by the potentially stigmatising effects of having a mental health diagnosis when they are likely to already be stigmatised as former or current illicit drug users. Service providers could therefore be encouraged to find out the ways that clients talk about their mental health, and incorporate these meanings within consultations as part of a patient- or client-centred approach to treatment (Bauman et al., 2003; Lewin et al., 2001; Mead & Bower, 2000). Identifying the fears and concerns of drug treatment clients about mental health labels and terminology with a view to countering stigma and reassuring clients could also be a useful part of a client-centred approach.

However, we should remember that, although few in number, some drug treatment clients were clearly able to understand and use clinical terminology about comorbidity. These consumers had either participated in peer education programs designed to increase literacy about co-occurring drug and mental health problems, or had accessed educational materials and articles on similar topics produced by drug user organisations. These accounts show that drug treatment clients can have the capacity to understand clinical terminology and relate it to their own circumstances. This suggests that within drug treatment settings avoiding discussion of mental health concepts or clinical terminology may be misguided. If consumers have the capacity to understand clinical

terminology, this should be encouraged to improve their mental health literacy and their ability to participate in treatment. Avoiding the discussion of clinical diagnoses, mental health terminology or the ways in which comorbidity is understood or conceptualised misses an opportunity to recruit clients as active participants in their treatment, and therefore undermines the development of client-centred approaches where joint decision-making is valued (Bauman et al., 2003; Lewin et al., 2001; Mead & Bower, 2000).

If it is considered desirable to encourage mental health literacy among drug treatment consumers, the question then becomes one of how best to achieve this, whether through peer education or resources developed by drug user organisations, contact with clinicians or other means. Attempts to improve mental health literacy have generally focused on educational awareness-raising campaigns for the public or local populations (Jorm, 2000; Jorm et al., 2005). Clear, non-judgmental education campaigns and resources raising awareness of the links between drug use and mental health and the availability of treatment may therefore be of value to drug treatment clients. Collaborative arrangements between treatment services and drug user organisations may be a productive avenue to pursue, if supported by adequate resources, in order to maximise consumers' access to peer-led education and clinical expertise. We are deliberately advocating for the involvement of drug user organisations in the development of education programs and outreach aimed at improving the

mental health literacy of drug treatment clients. Previous research suggests that professional contact with doctors or other clinicians for common mental health problems like depression is not associated with increased mental health literacy (Goldney et al., 2002) and informal contact with friends and family may have more of an influence on mental health beliefs (Jorm, 2000). Peer-led approaches may therefore be more effective in bridging the professional/lay divide for drug treatment consumers and service providers.

As Jorm (2000) acknowledges, the concept of mental health literacy assumes that professional knowledge of mental health conditions and treatments is superior to lay beliefs. An alternative approach to breaching the professional/lay divide is for doctors and other service providers to gain a better understanding of lay beliefs about mental health in general (and those of their patients in particular), and to incorporate this understanding into treatment policies and provider/client discussions (Rogers & Pilgrim, 1997). Communication incorporating the client's world view is generally recognised as a key part of a patient- or client-centred approach that can involve clarifying client concerns, taking account of the client's life situation, better orienting treatment plans to client priorities and skills, and fostering joint decision making about treatment options (Bauman et al., 2003; Lewin et al., 2001; Mead & Bower, 2000).

This paper should not be read as describing the full range of consumer and service provider experiences of mental health and drug treatment. Qualitative research is best employed when the topic under investigation is sensitive, novel or outside the personal experience of the researchers. Qualitative research of this type does not claim to be statistically representative but uses purposeful sampling procedures to collect data to a point where 'theoretical saturation' can be reached: the point where no new insights can be drawn from additional data collection (Glaser & Strauss, 1967). We assessed the interview data generated with service user participants to have reached this point. However, we cannot speak confidently of the application of our results to consumers not included in the study, such as those from culturally and linguistically diverse backgrounds, those primarily engaged in drug treatment other than substitution treatment (e.g. residential rehabilitation) or those experiencing psychotic-spectrum disorders. As consumers cannot be seen as a homogenous group, neither can service providers or treatment services. The service provider accounts gathered in this study were included to provide a contrast to service user perspectives. We cannot claim that the views of service providers here reached saturation or, indeed, speak to the very few services which expertly manage co-occurring drug and mental health problems.

Given those caveats, our findings suggest there is an opportunity for drug treatment service providers to work with clients and drug user organisations to

improve knowledge and awareness of mental health problems among drug treatment consumers, and to improve consumer engagement in mental health treatment. We are not naive to the challenges this may pose to both service providers and consumers. Drug treatment services are often overstretched and poorly resourced to handle high prevalence mental health problems like anxiety and depression. Service providers may lack training, expertise and ongoing support to undertake mental health care (Kavanagh et al., 2000; Siegfried et al., 1999; Siggins Miller Consultants, 2003; Treloar et al., 2004).

On the consumer side, drug user organisations are rarely well enough resourced to undertake additional peer education or resource development activities. Drug treatment consumers are socially marginalised and may be fearful of additional stigma due to mental illness. Negative perceptions and beliefs that drug treatment clients lack skills or are psychologically deficient may lessen the chances of consumers effectively participating in treatment (Treloar & Holt, 2006). Yet the capacity of some drug treatment clients to absorb and use complex knowledge about mental health problems and comorbidity should not be overlooked. We think that most drug treatment providers are committed to addressing common mental health problems with their clients. Based on our findings, initiating open and honest discussions with consumers about their mental health, and not shying away from clinical discourse, would be a good place to start.

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