ARTICLE

Peer Reviewed

Re-Thinking Concurrent Disorder: Exploring Ethical Issues in Conducting Research with the Concurrent Disorder Patient

Michelle C. Danda MN MPN RN CPMHN(C)
PhD Candidate, Faculty of Nursing, University of Alberta,
Edmonton, Alberta, Canada

Abstract

Mental health researchers are leaders in collaborative research partnerships between academics and those with lived experience in mental health services. Collaboration allows for newly established ethical imperatives to support understanding and acceptance that those whom the research is for also have a stake in how the research is done. Ethical issues arise within the challenging context of adherence to principles of inclusion of those with lived-experience in survivor-led and survivor-controlled research within institutional and structurally controlling settings. The focus of this discussion is to explore ethical issues that emerge when conducting research on inpatient acute mental health settings with individuals identified as living with concurrent disorders (a combination of mental health and substance use disorder). Ethical tensions are exacerbated by the constraints of an inherently oppressive inpatient acute care service structure operating within a medical model. Researchers engaging patients living with both mental health and substance use issues admitted to inpatient mental health settings must consider the perspectives from which problem substance use are defined. There are unintended risks posed in identification of the combination of mental health and substance use disorder including further stigmatizing a subpopulation of substance users amongst all inpatient acute mental health service users. The "outing" of individuals as substance users within a stigma-laden system may result in a clinician's negative moral judgement and punitive measures under the guise of control and safety. Lack of consistent terminology used to describe people living with mental health and substance use issues poses additional challenges for robust inclusion. Navigating these issues can lead to meaningful inclusion of people with mental health and substance use issues in ethically responsible research that is aligned with a recovery approach.

Key words: mental health, concurrent disorder research, dual diagnosis research, ethical research

Mental health researchers lead the movement of collaborative research partnerships between academics and those with lived experience in mental health services (Rose, 2014). The collaborative research relationship produces a newly established ethical imperative resulting from understanding and acceptance that those whom the research is for also have stake in how the research is done (Rose, 2014). This paper explores ethical issues that emerge when conducting research on inpatient acute mental health settings with individuals identified as living with concurrent disorders (a combination of mental health and substance use disorder; other countries sometimes use the term "dual diagnosis"). The ethical issues arise because of aspiring to adhere to principles of inclusion of those with lived-experience in survivor-led and survivor-controlled research in all aspects of the research process. There are further challenges to inclusion because of the constraints of an inherently oppressive inpatient acute care service structure built and continuing to exist within a medical-driven model (Velleman & Baker, 2008). Risks are posed to potential participants of concurrent disorder research when identifying the combination of mental health and substance use disorder; a subpopulation of substance users (especially those who are admitted involuntarily) may experience further stigmatization and "outing" as a substance user within an inpatient system that may react with moral judgement and punitive measures. Ethical issues related to use of the term "concurrent disorder" must be considered to ensure ethically sound research that accomplishes goals of inclusion, collaboration, and empowerment.

Background

Some ethical issues stem from the medical model approach of pathologizing mental health issues, in contrast with more newly established guidelines from the perspectives of other health disciplines like nursing, social work, and psychology, as well as peer-based groups, that emphasize the concept of recovery as best practice (Brekke, Lien, Davidson, & Biong, 2017; Guest & Holland, 2011; Tilsen & Nylund, 2008). This reconceptualizing of mental illness has resulted in less emphasis on diagnostic criteria and problem-based approaches (Barker, 2017). To successfully engage those in the inpatient mental health setting living with both mental health and substance use issues, researchers must consider the perspective from which notions of problem substance use are defined.

Lack of consistency of terminology used to described people living with mental health and substance use issues poses ethical challenges related to who is included in so-called concurrent disorder research and why.

Drawing on Different Perspectives

I am a mental health nurse. My career began in the Lower Mainland, British Columbia in the late 2000s, on a "concurrent disorder" inpatient unit. Mental Health inpatient programs in the Lower Mainland were then, and continue to be, organized under the umbrella term of psychiatric services. There has been deliberate work done to foster a culture shift away from a medical model based on pathology towards a person-centered, recovery-focused, and holistic wellness-driven approach. For example, in 2019 the British Columbia Children's Hospital changed the name of the building that housed their mental health programs and resources to the *Healthy Minds Centre* (Provincial Health Services Authority, 2019). The name change occurred after engaging patients, families, and clinicians in a contest to suggest names that could change the understanding of mental health care, a strategy intended to reduce stigma. However, inpatient policies and practices continue to lag.

Specialized concurrent disorder programs aimed at providing integrated services for those living with complex mental health and substance use issues, though designed from a perspective of holistic, strengths-based care, remain heavily influenced by medical models prioritizing formal diagnosis (Schütz et al., 2013; Manley, Gorry, & Dodd, 2008). The wide spectrum of people identified as concurrent disordered, coupled with the challenge of applying a diagnosis or labelling someone with a substance use disorder (a label with which they may not agree) complicates the process of asking someone to engage in a research project based on their labelling. In the inpatient mental health setting where most patients are admitted against their will [greater than 50% in British Columbia (Johnston, 2017)] there may be a tendency to overattribute the nature of a patient's substance use as problematic, and to what end?

The Challenge of Terminology

Ethical dilemmas arise from the challenge of defining a "concurrent disorder" and

understanding the social construction of the term. The need to re-think mental health terminology that is rooted in medical model language is not a new debate. According to the Mental Health Commission of Canada (2009), “there is no single, comprehensive definition of recovery and well-being that is shared by everyone,” indicating the need for individualized approaches that explore the unique context of the patients in establishing their wellness goals (pp. 27). To philosophically align mental health and substance use research with the Mental Health Commission of Canada’s understanding that each person's path of recovery, “is necessarily different, as they draw on their own unique set of resources, strengths, and relationships to confront the specific challenges they face,” (pp. 27) the language used to talk about the person recovering must be deconstructed.

Recovery is aimed at helping individuals alleviate symptoms of a diagnosis and move towards establishing holistic health goals and improving quality of life (Mental Health Commission of Canada, 2009). The term “dual diagnosis” is inadequate because the complex relationship between mental illness and substance use (and misuse) involves a multitude of psychosocial factors that cannot be simply explained by a descriptor of an individual having two co-existing disorders (Guest & Holland, 2011). That terminology is no longer helpful from a clinical perspective, nor a quality of life perspective. From a research perspective, the term “concurrent disorder” may be best suited to help differentiate nonsubstance-using from substance-using mental health patients.

Dual Diagnosis

The term “dual diagnosis” gained increased popularity in the 2000s, as evidenced by multiple journals using the term in their title and increasing numbers of research articles using the term. Some researchers have called for a re-evaluation of the term (Smith & Morris, 2010). In the United Kingdom and Australia, debates have emerged surrounding the term “dual diagnosis”. In recent years, academic researchers have increasingly re-thought the term because of the lack of specificity in providing useful information for clinical use, oversimplification of often multiple complex issues, and conflation of all mental health and substance use issues into two broad categories (Hamilton, 2014). In the United Kingdom, the term “dual diagnosis”, though perhaps initially helpful to shift understanding of substance use away from judgement of people as moral failures, today causes the unintended harm of further pathologizing and stigmatizing individuals (Barker, 2017; Guest & Holland, 2011).

The intended goals of 'mainstreaming' individuals living with mental health and substance use issues in order to decrease stigma, increase access to services, increase capacity of services, and provide better care, have failed to actualize (Guest & Holland, 2011). In their re-thinking of the term "dual diagnosis" Guest and Holland (2011) questioned whether the term "dual diagnosis" can be applied to those living with mild to moderate co-existing difficulties who are able to function within, and contribute to, society. They argued that the term "dual diagnosis" promotes a medicalized concept, but potentially limits a nuanced understanding of co-morbidity thereby restricting its application to those living with severe mental illness. In Canada, the same concern can apply to the concept of "concurrent disorder" because the term refers to simultaneously meeting DSM-5 (Diagnostic and Statistical Manual of Mental Disorders) diagnostic criteria for mental health and substance use disorders.

Ethical Implications

To explore ethical implications of conducting mental health research from a person-centered, strengths-based perspective it is essential to question the utility of a catch-all term used to identify and label those living with mental health and substance use issues. Division persists between medicalization based on neurobiological pathology for diagnostic purposes (Szerman et al., 2013) and alternative descriptors aimed at aligning with a person-centered, recovery-oriented approach that helps distance persons from pathology. Though useful for operationalizing research variables and categorizing patients, terms like "dual diagnosis" and "concurrent disorder" are focused on the simple qualification of a person meeting diagnoses or disorder criteria rather than focusing on the needs and wants of the individual, and attendant problems affecting their quality of life (Hamilton, 2014; Selick & Wiktorowicz, 2016).

Ethical issues continue to arise when the context and story of the individual are ignored, erased, or sacrificed for the sake of collecting quantifiable, discrete data. In 2008, Velleman and Baker (2008) discussed the importance of recognizing that mental health services and research could be enhanced by the adoption of a broad, inclusive term to recognize a diversity of co-existing problems, as a means to avoid medicalized terminology such as 'dual diagnosis' or 'co-morbidity'. Their argument was rooted in an understanding that a term inclusive of 'mental health' and 'substance use

problems' was consistent with an individualized, case formulation driven approach. Adoption of such a term could enhance practitioners' confidence in the detection, assessment, and treatment of co-existing problems. The term "concurrent disorder" can be extended to a wide range of individuals living with mental health and substance use problems, but is also ultimately inadequate.

Pathology of Mental Illness and Addiction

Traditionally, research in mental health has been dominated by a medicalized approach, favouring empirical research and distancing the researcher in the role of expert, resulting in an "us versus them" approach (Beresford & Boxall 2013; Hamilton, 2014; Marrow & Weisser, 2012). Research in mental health has largely been constructed from the perspective of developing diagnostic criteria that are used to identify a mental illness (Regler, 2018). Diagnostic criteria can be helpful in explaining problems in mental health functioning, and may also help the diagnosed individual understand their mental health issues (Regler, 2018). However, in recent years there has been increased questioning of the utility of mental illness diagnoses insofar as they distance the person from the context in which experience of their symptoms exists (Regler, 2018). Questioning of the traditional medical and psychological model has led to alternative explanations, understandings, and research on mental health and mental illness.

Re-Thinking the Concept of Pathology: The Example of the Hearing Voices Movement

The Hearing Voices Movement (HVM) research has recently been used as a guide for research and practice innovation in mental health in England and the Netherlands to promote the need and perspective of people experiencing voices to be understood as experts in their experience (Corstens, Longden, McCarthy-Jones, Waddington, & Thomas, 2014). Researchers must ethically weigh how to best include voice-hearers in their research, for example, using qualitative and narrative methods to capture the lived-experience (Corstens et al., 2014). The goal of the research is to construct and conceptualize voice hearing and the "voice hearer" as an alternative, liberating and empowering act and agent in contrast with the traditional psychiatric pathologizing of psychosis (Corstens et al., 2014). Researchers identified that the empowering process normalizes voice-hearing in contrast to the disease-based model that pathologizes the experience, stigmatizes the person, reduces self-esteem,

and prioritizes eliminating the experience (Corstens et al., 2014). As the HVM grew, research from an empirical perspective gained popularity and was conducted in collaboration with those within the HVM along with academic and clinical allies; this sparked debate about the role of formal and traditional research. Key components of research involving those of the HVM are participation and collaboration, in accordance with the "nothing about us without us" principle. We need to respect the rights of those marginalized by their experiences to participate meaningfully in the decision-making related to them (Charlton, 2000).

The HVM highlights the importance of language and terminology used to describe people's experiences. Terms like "auditory" and "visual hallucinations", though deeply engrained as an objective way to describe the experience of the person hearing voices, are both pathologizing and stigmatizing because they seek biomedical explanations and are loaded with assumptions that voices are not real (Corstens, et al., 2014). Similarly, language use can be explored with respect to understanding and labelling the experience of someone who is living with mental health issues who also uses substances. In the inpatient acute hospital setting, there is pressure to label substance use as a disorder or problem in an objective way; unfortunately, these diagnostic criteria mask the lived contextual experience of the person. How can this be safely navigated when trying to identify those who qualify for meeting inclusion criteria for concurrent disorder research? Consideration must be given to how this can ethically fit with participant or survivor controlled and led research aimed at helping patients participate and improve the system to make it more recovery-oriented.

The Concept of Recovery

The concept of recovery in the Canadian context is changing. Recovery has been defined in many ways. The literature and discussion about recovery can be divided into three categories: recovery as a personal journey, research on the social aspects of recovery, and research which outright rejects the concept of recovery and the connection to sanism and medical pathologizing processes (Marrow & Weisser, 2012). There are critiques of the concept of recovery existing within a deeply entrenched medical model of mental health services.

Marrow and Weisser (2012) found that patients entrenched in the mental health system often have very little control over their own lives, which necessarily makes recovering difficult, even

impossible. Attempts to include those with lived experience within the traditional structure succumb to institutional pressures as evidenced by divides between employed peers (those with lived experience) with a perceived need to take on a professional demeanor and other service users (Marrow & Weisser, 2012). Similar processes may occur when those with lived experience are engaged in conducting research. For example, there may be pressures related to who is able to participate in research, favouring those who accept notions of recovery and a path that embodies concepts like hope, personal growth, and responsibility. What about those who reject or resist such ideas due to entrenchment within an oppressive and disempowering medical model?

How can space be made within mental health research to include the voices of those who actively reject the labels that the system is trying to impose? Health care research that includes acute inpatient mental health service users and invites them to share experiences and provide input into the terminology used to describe their unique situations is better quality research.

Conclusion

Mental health researchers need to re-think the term “concurrent disorder” and deconstruct the concept for the purpose of engaging in ethically sound, justice-oriented research that can empower both patient and researcher in a collaborative and emancipatory research process.

References

Barker, P. (2017). What is in a name? The search for appropriate and consistent terminology. In D. B. Cooper (Ed.), *Introduction to mental health: Substance use* (pp. 23-29). CRC Press.

Beresford, P., & Boxall, K. (2013). Where do service users’ knowledge sit in relation to professional and academic understandings of knowledge? In P. Staddon (Ed.), *Mental health service users in research: Critical sociological perspectives* (pp. 69-86). Policy Press.

Brekke, E., Lien, L., Davidson, L., & Biong, S. (2017). First-person experiences of recovery in co-occurring mental health and substance use conditions. *Advances in Dual Diagnosis*, *10*(1), 13-24.

Charlton, J. I. (2000). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.

Chorlton, E., & Smith, I. C. (2016). Understanding how people with mental health difficulties experience substance use. *Substance Use & Misuse*, *51*(3), 318-329.

Corstens, D., Longden, E., McCarthy-Jones, S., Waddingham, R., & Thomas, N. (2014). Emerging perspectives from the hearing voices movement: Implications for research and practice. *Schizophrenia Bulletin*, *40*(Suppl_4), S285-S294.

Faulkner, A. (2017). Survivor research and Mad Studies: The role and value of experiential knowledge in mental health research. *Disability & Society*, *32*(4), 500-520.

Guest, C., & Chrisp, T. A. (2015). Delivery of a mainstreaming treatment model towards co-existing difficulties: A brief exploration of practitioners' understanding, views and reported experiences. *Advances in Dual Diagnosis*, *8*(2), 102-115.

Guest, C., & Holland, M. (2011). Co-existing mental health and substance use and alcohol difficulties: Why do we persist with the term "dual diagnosis" within mental health services? *Advances in Dual Diagnosis*, *4*(4), 162-172.

Hamilton, I. (2014). The 10 most important debates surrounding dual diagnosis. *Advances in Dual Diagnosis*, *7*(3), 118-128.

Johnston, L. (2017, November). *Operating in darkness: BC's Mental Health Act detention system*. Community Legal Assistance Society. Retrieved from https://d3n8a8pro7vhmx.cloudfront.net/clastest/pages/1794/attachments/original/1527278723/CLAS_Operating_in_Darkness_November_2017.pdf?1527278723

Khan, S. (2017). Concurrent mental and substance use disorders in Canada. Statistics Canada Health Report, 28(8), 3-8.

Manley, D., Gorry, A., & Dodd, T. (2008). Dual diagnosis-developing capable practitioners to improve services. *Advances in Dual Diagnosis*, *1*(1), 20-26.

McCarthy-Jones, S., Castro Romero, M., McCarthy-Jones, R., Dillon, J., Cooper-Rompato, C., Kieran, K., Kaufman, M., & Blackman, L. (2015). Hearing the unheard: an interdisciplinary,

mixed methodology study of women's experiences of hearing voices (auditory verbal hallucinations). *Frontiers in Psychiatry*, *6*, 181.

Mental Health Commission of Canada. (2009). *Towards recovery & wellbeing: A framework for a mental health strategy in Canada.* Retrieved from https://www.mentalhealthcommission.ca/sites/default/files/FNIM_Toward_Recovery_and_Well_Being_ENG_0_1.pdf

Morrow, M., & Weisser, J. (2012). Towards a social justice framework of mental health recovery. *Studies in Social Justice*, *6*(1), 27-43.

Pascal, J., & Sagan, O. (2018). Cocreation or collusion: The dark side of consumer narrative in qualitative health research. *Illness, Crisis & Loss*, *26*(4), 251-269.

Provincial Health Services Authority. (2019). *Introducing the healthy minds centre.* Retrieved from http://www.bcchildrens.ca/about/news-stories/stories/introducing-the-healthy-minds-centre

Reedy, A. R., & Kobayashi, R. (2012). Substance use and mental health disorders: Why do some people suffer from both? *Social Work in Mental Health*, *10*(6), 496-517.

Regler, R. (2018). Formulating the efficacy of using diagnosis to conceptualise distress. *Journal of Mental Health and Aging, 2*(1), 36-39.

Rose, D. (2014). Patient and public involvement in health research: Ethical imperative and/or radical challenge? *Journal of Health Psychology*, *19*(1), 149-158.

Rush, B., Fogg, B., Nadeau, L., & Furlong, A. (2008). On the integration of mental health and substance use services and systems: Main report. *Canadian Executive Council on Addictions*.

Russo, J. (2012). Survivor-controlled research: A new foundation for thinking about psychiatry and mental health. *Forum: Qualitative Social Research, 13*(1).

Schütz, C., Linden, I. A., Torchalla, I., Li, K., Al-Desouki, M., & Krausz, M. (2013). The Burnaby treatment center for mental health and addiction, a novel integrated treatment program for patients with addiction and concurrent disorders: Results from a program evaluation. *BMC Health Services Research*, *13*(1), 288.

Selick, A., & Wiktorowicz, M. (2016). Co-occurring mental health and addiction disorders: The elusive path to integrated care. *International Journal of Noncommunicable Diseases*, *1*(3), 97.

Smith, G. L., & Morris, P. (2010). Dual diagnosis: What does it mean? *Mental Health and Substance Use: Dual Diagnosis*, *3*(2), 162-165.

Szerman, N., Martinez-Raga, J., Peris, L., Roncero, C., Basurte, I., Vega, P., Ruiz, P., & Casas, M. (2013). Rethinking dual disorders/pathology. *Addiction Disorder Treatment, 12*(1), 1-10.

Tilsen, J., & Nylund, D. (2008). Psychotherapy research, the recovery movement and practice-based evidence in psychiatric rehabilitation. *Journal of Social Work in Disability & Rehabilitation*, *7*(3-4), 340-354.

Velleman, R., & Baker, A. (2008). Moving away from medicalised and partisan terminology: A contribution to the debate. *Mental Health and Substance Use: Dual Diagnosis*, *1*(1), 2-9.

Acknowledgements: none

Competing Interests: none

Address for Correspondence: danda@ualberta.ca

Publication date: May 10, 2020