Dual Diagnosis: Identifying Limitations in Current Models of Care

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Dual diagnosis (DD) is a term used to describe patients with concurrent developmental disabilities and mental illnesses. It is estimated that around 40% of individuals with a developmental disability also have a comorbid mental illness (KPMG, 2012). Independently, these conditions are universally recognized with accessible and well-evidenced treatment practices in place (Lunsky & Puddicombe, 2005); however, these methods are often ill-equipped to handle the unique needs of the dually diagnosed. Due to inadequate services and the challenging behaviours DD patients exhibit, they are often excluded from and do not respond well to conventional treatments, resulting in poorer health outcomes and a lower quality of life (KPMG, 2012). The immense challenges patients face in accessing necessary services are compounded by the fact that professionals often feel ill-equipped to treat them—further straining provision of care (Lunsky, Gracey, & Gelfand, 2008). Minimal research in this field also exacerbates issues for DD patients, as a lack of evidence-based strategies yields inconsistent care practices between healthcare providers—ultimately preventing a consensus on best practice (Lunsky & Puddicombe, 2005).

These problems are apparent within every setting of DD care: the inpatient environment, the outpatient environment, and during the transition between them. This literature review will address the issues associated with this continuum of care—focusing on the inadequacies of current practices and examining novel methods for providing specialized care to DD patients.

Inadequacies in Inpatient Care

Shortcomings in the continuum of DD care were outlined in a report by Lunsky and Puddicombe (2005), which surveyed the responses of Ontario psychiatric healthcare

professionals to current DD treatment practices, with aims of identifying critical areas of concern. Their feedback highlighted limitations to optimal care which result from inadequacies in current systems—namely, the adverse effects of overreliance on inpatient services, and the difficulties that DD challenging behaviours present to treatment provision.

In hospital, the complexity of DD patients demands unique care from professionals specially trained to address their comorbid diagnoses. Lunsky and Puddicombe's (2005) report reveals that specialized psychiatric facilities tailored towards dual diagnosis patients have a very limited number of beds, many of which are inaccessible to in-need, severely-debilitated DD patients because of 'bed blockers'—inpatients who no longer require hospitalization but remain institutionalized. To explain this, their report suggests that scarce outpatient options cause many DD patients to spend unnecessarily long durations in hospital. Lunsky et al. (2006) further explored DD-induced stress on the capacity of inpatient facilities through analysis of 3927 randomly collected mental health patient cases from nine Ontario psychiatric facilities. Their study found that despite recommended levels of care being generally higher for populations with concurrent developmental disabilities, only a few DD patients actually required inpatient psychiatric hospital support—the rest would benefit most from specialized community residences and other outpatient resources (Lunsky et al., 2006). Given that these non-institutional resources are sufficient, Lunsky et al. (2006) suggested that specialized psychiatric hospitals should invest in research to develop better methods for triaging incoming DD patients to ensure high-risk, high-need patients have priority access to beds.

Even if these facilities could accommodate the high patient demand, herding DD patients into hospitals is often counterproductive to their habilitation. After analyzing all CAMH patients with autism spectrum disorder between 1998 and 2004, Palucka and Lunsky (2007) deemed the

hospital experience—specifically the lack of food, varying personnel, noise, disruption to routine, and limited access to outdoor space—especially aggravating to patients' conditions, and to unfavourable behaviours. They noted locked seclusion rooms and mechanical or pharmaceutical restraints had to be used in 69% of cases. To avoid using these interventions, the study suggests that DD inpatient experiences should be limited as much as possible to avoid exposure to triggering hospital stimuli—primarily by trying to keep them situated in the community. However, this approach may not always be possible. In a qualitative study focused on Ontarian psychiatric care, Puddicombe and Lunsky (2007) found that aggression was the main barrier to discharge for DD patients, ultimately contributing to further inpatient facility stress. Balogh et al. (2017) documented that within a cohort of 66,484 patients with intellectual disabilities, DD individuals had increased hospital readmission rates post-discharge due to outpatient program inadequacies and exacerbation of caregiver burnout by challenging behaviours. Participants surveyed by Lunsky and Puddicombe (2005) agreed with this finding, also suggesting that high readmission rates resulted from the actions of poorly trained staff who provided insufficient care to DD patients.

A study by Lunsky, Gracey, and Gelfand (2008) created focus groups consisting of psychiatric staff from emergency rooms (ERs), including psychiatrists, nurses, and social workers from 6 hospitals in Toronto, Ontario. The study examined issues that DD patients faced from the perspectives of the ER staff. They reported a general lack of knowledge, training, and available services among ER inpatient care and caregiver outpatient care. ER staff were also uncomfortable with the aggressive behaviours that DD patients frequently exhibited during visits, which often led to distress among the staff. The study included suggestions made by the staff, highlighting that better communication was needed between the hospital and outpatient

services. The ER staff often found that they were not given enough information about DD patients upon admittance into the hospital, thus making it more difficult for them to know how to treat these patients. The ER staff also suggested that better access to DD experts was needed to alleviate stress when dealing with psychiatric crises among the DD population. Hunter, Gardner, Wilkness, and Silverstein (2008) would suggest psychiatric care practitioners adopt new approaches to best address DD behaviours—notably, the Multimodal Functional Model (MFM) for patient interactions. Their paper outlines the use of this methodology through various case examples—all which emphasize the practitioner's identification of a patient's individualized vulnerability factors, and avoidance of their aggravation through selective practices. They describe the method as 'best practice' and stress its successful implementation in various U.S. facilities.

Another study conducted by While and Clark (2014) in the United Kingdom (UK) focused on developing and testing the effectiveness of a competency assessment for nurses who work with intellectually disabled patients, including DD patients. These researchers administered their competency assessment tool on focus groups of experienced, trained nurses at a local hospital. When interviews of trained nurses were conducted, the nurses reported that they had a very limited understanding of the roles that were expected of them when providing care for this patient population. Thus, the researchers advocated for a competency assessment to evaluate the knowledge and skills of the nurses who care for DD patients. This tool would provide a framework for understanding the skills nurses have, as well as determine whether core educational programs for healthcare staff need to be altered.

Complexities of the Inpatient to Outpatient Transition

Accessing and receiving appropriate care from community-based resources can oftentimes be challenging for DD patients due to a variety of systemic factors. Durbin, Sirotich, Lunsky, and Durbin (2017) examined data from 2611 adults in community mental health programs and found that DD patients were more likely to have unmet personal care, transportation, basic education, and treatment information needs than individuals with only a developmental disability. While these findings suggest that improvements to the quality of specialized DD patient services are necessary, other studies indicate that an increase in the overall quantity of these resources is also warranted. A national study by Lunsky, Garcin, Morin, Cobigo, and Bradley (2007) looking at mental health services for individuals with developmental disabilities found that patients face difficulty accessing appropriate psychiatric care in their communities because there is an absence of specialized health services available for DD patients, particularly in rural regions. In regard to existing resources, the current supply of community-based resources is insufficient—evidenced by numerous DD patients who reported waiting over three months to receive much needed healthcare services (Lunsky et al., 2007). As a result of the long waiting lists for these services, McMorris, Weiss, Cappelletti, and Lunsky (2013) found that the responsibility of providing care to these individuals often remains with families and contributes to caregiver burnout. Furthermore, their qualitative study which surveyed families and outpatient staff noted that community-based resources have generally taken a reactive, rather than proactive approach in dealing with DD patients—meaning that individuals and families are only connected with these services after a crisis has occurred (McMorris et al., 2013).

The absence of a robust continuum of care that guides individuals before, during, and after their psychiatric crises means that DD patients have difficulty navigating community

resources. In times of need, these individuals resort to seeking care in hospital ERs. Weiss, Lunsky, Gracey, Canrinus, and Morris (2009) conducted a qualitative study based on the perspectives of caregivers and found that the escalation of challenging behaviours and the lack of appropriate community resources for dealing with mental health crises were the predominant causes of ER visits by individuals with developmental disabilities. The study also noted that although only a small portion of individuals with developmental disabilities visited the ER for psychiatric purposes, those who did access it were frequent visitors. Lunsky, Tint, Robinson, Khodaverdian, and Jaskulski (2011) suggest that these individuals return to the ER because problems from prior visits remained unresolved. Furthermore, many of these patients were sent home without follow-up appointments or knowledge about available resources for future crises, signaling the need for a formalized procedure to connect families and caregivers to community services (Lunsky et al., 2011). Research by Spassiani, Abou Chacra, and Lunsky (2017) reinforces the idea that ERs are ill-suited environments for supporting DD patients and points to the demand for liaison workers to bridge the gap between hospital and community care by ensuring follow-up and successful implementation of crisis plans.

Inadequacies in Outpatient Care

Following the transition from a hospital setting, outpatient care also presents significant complications. Recently, Baldacchino et al. (2011) have noted a shift from institutionalization to community-based care in an attempt to reduce patient confinement. However, this shift has proven unsuccessful, with current literature revealing issues in outpatient staff perceptions of DD patients, staff training, and care practices.

Caregivers from rural communities reveal an overwhelmingly negative perception of dual diagnoses among outpatient staff. Through a qualitative study interviewing outpatient caregivers and DD patients, Kreitzer, McLaughlin, Elliott, & Nicholas (2016) demonstrated the trepidation evoked by the mere label of a 'dual diagnosis'. This stigma stems from a lack of training as the outpatient service providers stated they possessed neither the "expertise [n]or the staff resources" to work with DD patients (Kreitzer et al., 2016). Furthermore, caregivers noted a lack of recognition for experienced staff in the field and a lack of specialized training for inexperienced staff (Kreitzer et al., 2016).

Through a retrospective cohort study, Balogh et al., (2018) discovered that DD patients are admitted to ERs at nearly double the rate of patients with a mental illness, suggesting severe inadequacies in both discharge planning and outpatient follow-up. Furthermore, qualitative research from DD patients, family members, and ER support staff revealed that despite these frequent visits, DD patients faced immense discrimination from hospital workers who often denied them care altogether by refusal of admission into hospital facilities (Spassiani et al., 2017). DD patients are therefore subject to inadequate resources in the community, leading to a cyclical process of inadequate care in the ER setting. To prevent the cyclical process of frequent ER visits, swift discharge, and subsequent readmission, Spassiani et al. (2017) suggest significant changes to discharge practices and care by emergency department staff, including increased awareness of dual diagnosis and formal training for outpatient staff.

Outpatient care models require engaging programming to improve patient outcome. However, qualitative interviews of adults with a dual diagnosis and their caregiving parents demonstrate that this need is unmet and families are forced to fill the gap themselves (Nicholas et al., 2017). Vocational activities provide the opportunity for patients to develop social skills and

introduces a sense of purpose into their lives (Nicholas et al., 2017). When vocational needs were not met, DD patients relied more heavily on their families, resulting in decreased self-sufficiency (Nicholas et al., 2017). Because of this subsequent inability to care for themselves, families of DD patients were concerned for the quality of life of these patients (Nicholas et al., 2017).

New Directions and Innovations in Care

Alterations to treatment practices will enhance the quality of care that patients receive. Part of this process involves increasing familial and patient involvement in care. Family members are crucial because they navigate the system, advocate for patients, address system deficits, and play a significant role in patient care—for example, in assisting patients in adhering to their medications (Nicholas et al., 2017; Tan et al., 2015). However, a study conducted by Nicholas et al. (2017) discussed how family members of DD patients, despite being their primary caregivers, felt unwelcomed, belittled, or dismissed by the clinicians treating the patient.

Research has shown that additional input from the patients themselves has also been beneficial to care. Because it can be difficult to evaluate DD patients' responses to questions, self-reporting (for those who are able to articulate their responses unhindered by cognitive defects) was a valuable tool for resolving this issue (Scott & Havercamp, 2018). There are specific questionnaires designed for self-assessing mental health in people with developmental disabilities, such as the Glasgow Depression Scale for People with a Learning Disability, Glasgow Anxiety Scale for People with an Intellectual Disability, and the Glasgow Depression Scale–Carer Supplement (Sullivan et al., 2018).

In addition to involving families and patients in the treatment process, large-scale changes in caregiving have been created and implemented in regions of Canada and the United

States. For example, the Flexible Assertive Community Treatment (FACT) program in the Ottawa region is a novel model of care, focusing on improving the skills mix of staff involved in treatment, communication between staff members, and vocational and occupational support for patients (Farrell & Pow, 2016). On the other hand, the Systemic, Therapeutic, Assessment, Resources and Treatment (START) model of care, which focuses on improving prevention and intervention services in communities, is used in 19 American states and has improved service experiences while reducing challenging behaviours and emergency psychiatric service use in patients (Beasley, Kalb, & Klein, 2018). In addition, new guidelines published by *Canadian Family Physician* to better support DD patients emphasize the importance of working with an interdisciplinary clinician team and involving family members in care (Sullivan et al., 2018).

Conclusion

The literature cited in this paper specifically suggests that insufficiencies in outpatient resources have placed a significant amount of pressure on hospitals to deliver care to DD patients. However, inpatient settings are suboptimal for treating this population and should be reserved for high-risk patients. For the majority of DD patients, a lack of formal procedures connecting individuals from the hospital to community-based services has rendered current transition processes ineffective. In addition to recommendations for improvements to the continuum of care, current literature on DD patients investigates innovative models of care that may introduce novel treatment practices. However, the recommendations presented are limited, as advances in care for DD patients suffer from a lack of research surrounding this comorbidity. Furthermore, the majority of existing research in this area relies on administrative data or the perspectives of families, caregivers, and hospital staff. While it was mentioned that a patient's

perspective is an extremely valuable tool in treatment, the inability of certain patients to clearly articulate their viewpoints prevents researchers from gathering conclusive evidence that fully encompasses the preferences of this diverse patient population. Nevertheless, current research outlines major systemic issues in the continuum of care for DD patients and provides a clear direction for stakeholders, such as healthcare professionals and policymakers, to invest in treatment and programming efforts that will improve the quality of life and care for these individuals.

References

Baldacchino, A., Greacen, T., Hodges, C. L., Charzynska, K., Sorsa, M., Saias, T., . . . Baeck-Moller, K. (2011). Nature, level and type of networking for individuals with dual diagnosis: A European perspective. *Drugs: Education, Prevention and Policy, 18*(5), 393-401. doi: 10.3109/09687637.2010.520171

Balogh, R., Lin, E., Dobranowski, K., Selick, A., Wilton, A. S., & Lunsky, Y. (2018). All-cause, 30-day readmissions among persons with intellectual and developmental disabilities and mental illness. *Psychiatric Services, 69*(3), 353-357. doi:10.1176/appi.ps.201600534

Beasley, J. B., Kalb, L., & Klein, A. (2018). Improving mental health outcomes for individuals with intellectual disability through the Iowa START (I-START) program. *Journal of Mental Health Research in Intellectual Disabilities, 11(*4), 287-300. doi: 10.1080/19315864.2018.1504362

Charlot, L., & Beasley, J. B. (2013). Intellectual disabilities and mental health: United states–based research. *Journal of Mental Health Research in Intellectual Disabilities, 6*(2), 74-105. doi: 10.1080/19315864.2012.715724

Durbin, A., Sirotich, F., Lunsky, Y., & Durbin, J. (2017). Unmet needs of adults in community mental health care with and without intellectual and developmental disabilities: A cross-sectional study. *Community Mental Health Journal, 53*(1), 15-26. doi: 10.1007/s10597-015-9961-6

Farrell, S., & Pow, J. (2016). *Improving outcomes in dual diagnosis specialized care* [Powerpoint slides]. Retrieved from https://www.cfhi-fcass.ca/sf-docs/default-source/on-call/on-call-presentation-dual-diagnosis-5-dec-2016-e.pdf?sfvrsn=dac3d444_4

Gentile, J. P., & Jackson, C. S. (2008). Supportive psychotherapy with the dual diagnosis patient: Co-occurring mental illness/intellectual disabilities. *Psychiatry, 5*(3), 49-57.

Hunter, R. H., Wilkniss, S., Gardner, W. I., & Silverstein, S. M. (2008). The multimodal functional model-advancing case formulation beyond the "diagnose and treat" paradigm: Improving outcomes and reducing aggression and the use of control procedures in psychiatric care. *Psychological Services, 5*(1), 11-25. doi:10.1037/1541-1559.5.1.11

KPMG. (2012). *Provincial review of dual diagnosis programs*. Toronto: Author.

Kreitzer, L., McLaughlin, A. M., Elliott, G., & Nicholas, D. (2016). Qualitative examination of rural service provision to persons with concurrent developmental and mental health challenges. *European Journal of Social Work, 19*(1), 46-61. doi: 10.1080/13691457.2015.1022859

Lunsky, Y., Bradley, E., Durbin, J., Koegl, C., Canrinus, M., & Goering, P. (2006). The clinical profile and service needs of hospitalized adults with mental retardation and a psychiatric diagnosis. *Psychiatric Services, 57*(1), 77-83. doi: 10.1176/appi.ps.57.1.77

Lunsky, Y., Garcin, N., Morin, D., Cobigo, V., & Bradley, E. (2007). Mental health services for individuals with intellectual disabilities in canada: Findings from a national survey. *Journal of Applied Research in Intellectual Disabilities, 20*(5), 439-447. doi: 10.1111/j.1468-3148.2007.00384.x

Lunsky, Y., Gracey, C., & Gelfand, S. (2008). Emergency psychiatric services for individuals with intellectual disabilities: Perspectives of hospital staff. *Intellectual and Developmental Disabilities, 46*(6), 446-455. doi: 10.1352/2008.46:446-455

Lunsky, Y., Tint, A., Robinson, S., Khodaverdian, A., & Jaskulski, C. (2011). Emergency psychiatric service use by individuals with intellectual disabilities living with family.

Journal of Mental Health Research in Intellectual Disabilities, 4(3), 172-185. doi: 10.1080/19315864.2011.597540

McMorris, C. A., Weiss, J. A., Cappelletti, G., & Lunsky, Y. (2013). Family and staff perspectives on service use for individuals with intellectual disabilities in crisis. *Journal of Mental Health Research in Intellectual Disabilities, 6*(1), 14-28. doi: 10.1080/19315864.2011.606393

Nicholas, D. B., Calhoun, A., McLaughlin, A. M., Shankar, J., Kreitzer, L., & Uzande, M. (2017). Care experiences of adults with a dual diagnosis and their family caregivers. *Global Qualitative Nursing Research, 4*, 2333393617721646-2333393617721646. doi: 10.1177/2333393617721646

Ontario Mental Health Foundation. (2005). *Dual diagnosis in Ontario's specialty (psychiatric) hospitals: qualitative findings and recommendations*. Toronto: Author.

Palucka, A. & Lunsky, Y. (2007). Review of inpatient admissions of individuals with autism spectrum disorders to a specialized dual diagnosis program. *Journal on Developmental Disabilities, 13*(1).

Puddicombe, J., & Lunsky, Y. (2007). Aggression and dual diagnosis: Implications for Ontario's developmental services. *Journal on Developmental Disabilities, 13*(1).

Scott, H. M., & Havercamp, S. M. (2018). Comparison of self- and proxy report of mental health symptoms in people with intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities, 11*(2), 143-156. doi: 10.1080/19315864.2018.1431746

Spassiani, N., Abou Chacra, M. S., & Lunsky, Y. (2017). "Why are you here? Can't you cope at home?" The psychiatric crisis of people with intellectual disabilities and the community's

response. *Journal of Mental Health Research in Intellectual Disabilities, 10*(2), 74-92. doi: 10.1080/19315864.2016.1278290

Sullivan, W. F., Diepstra, H., Heng, J., Ally, S., Bradley, E., Casson, I., . . . Witherbee, S. (2018). Primary care of adults with intellectual and developmental disabilities. *Canadian Family Physician, 64*(4), 254.

Tan, X., Marshall, V. D., Balkrishnan, R., Patel, I., Chang, J., & Erickson, S. R. (2015). Psychotropic medication adherence among community-based individuals with developmental disabilities and mental illness. *Journal of Mental Health Research in Intellectual Disabilities, 8*(1), 1-22. doi: 10.1080/19315864.2014.959216

Weiss, J. A., Lunsky, Y., Gracey, C., Canrinus, M., & Morris, S. (2009). Emergency psychiatric services for individuals with intellectual disabilities: Caregivers' perspectives. *Journal of Applied Research in Intellectual Disabilities, 22*(4), 354-362. doi: 10.1111/j.1468-3148.2008.00468.x

While, A. E., & Clark, L. L. (2014). Development of a competency tool for adult trained nurses caring for people with intellectual disabilities. *Journal of Nursing Management, 22*(6), 803-810. doi: 10.1111/jonm.12002