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Improving patient-centered care for HIV and mental illness: exploring hospital and community integration through education

Deanna Chaukos [a,b], Sandalia Genus [b,c], Lesley Wiesenfeld[a,b], Robert Maunder [a,b] and Maria Mylopoulos [d,e]

[a]Department of Psychiatry, Temerty Faculty of Medicine, University of Toronto, Toronto, Canada; [b]Department of Psychiatry, Sinai Health System, Toronto, Canada; [c]Department of Anthropology, University of Toronto, Toronto, Canada; [d]Department of Pediatrics, University of Toronto, Temerty Faculty of Medicine, Toronto, Canada; [e]The Wilson Centre, University of Toronto, Toronto, Canada

ABSTRACT

Current models of care delivery are failing patients with complexity, like those living with HIV, mental illness and other psychosocial challenges. These patients often require resource-intensive personalized care across hospital and community settings, but available supports can be fragmented and challenging to access and navigate. To improve this, the authors created a program to enhance integrated, trauma-informed care through an innovative educational role for a HIV community caseworker embedded in an academic HIV Psychiatry clinic, called the Mental Health Clinical Fellowship. Through qualitative interviews with 21 participants (patients, physicians, clinicians and Mental Health Clinical Fellows) from October 2020–March 2023, the authors explore how implementation of this program affects patient experiences and satisfaction with care. Patients described their care experiences as less stigmatizing, more accessible, holistic and coordinated. They often attributed this to the integration between fellow and psychiatrist, and specifically the accessible stance of community organizations embedded within a hospital, which helped build trust. Interchangeable and integrated support by caseworker and psychiatrist improved patient engagement in psychiatric management and patient satisfaction with their care. Cross-context and cross-disciplinary care provision that includes providers from community and hospital working directly together to deliver care can improve care for patients with significant complexity.

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HIV; mental illness; psychiatry; complexity; integrated care; collaborative care

Introduction

Current models of care delivery are failing patients with significant complexity, like those living with HIV and mental illness (Durbin et al., 2016, 2017; LeGrand et al., 2015; Moore et al., 2015; Orellana et al., 2015). HIV infection has wide-ranging medical and psychosocial impacts, including many neuropsychiatric complications (Bekele et al., 2018; DiMatteo et al., 2000; Maunder et al., 2021; Nel & Kagee, 2013). HIV often affects psychosocially vulnerable people, and its effects are amplified for those with mental illness and/or substance use disorders (Abrahams et al., 2008; Maunder et al., 2016). HIV is eight times more prevalent amongst people with mental illness than in the general population (Rosenberg et al., 2001). Moreover, having HIV increases the risk for substance use disorders, with addiction having a lifetime rate of up to 84% (Durvasula & Miller, 2014). Syndemics of these conditions compound their complexity (Brezing et al., 2015). These issues are poorly addressed by current evidence-based treatment pathways and a medical system reliant on standardization, best suited to address single diseases, acute care visits, or uncomplicated chronic management (Baird et al., 2013; Corazza et al., 2019). This failure to manage complexity leads to excessive emergency room visits, a lack of follow-up, poor retention in care, and other negative outcomes (Choi et al., 2016).

People living with HIV, mental illness and other psychosocial challenges often require resource-intensive personalized care (Ojikutu et al., 2014). When care is distributed across hospital and community settings it may become fragmented and challenging to access and navigate (Koester et al., 2014; Noest et al., 2014; Powers et al., 2017). One way to bridge this fragmentation is through integrated care (Sockalingam et al., 2016; Youssef et al., 2020). Integrated care is a systems-based

CONTACT Deanna Chaukos deanna.chaukos@sinaihealth.ca Department of Psychiatry, Mount Sinai Hospital, Joseph & Wolf Lebovic Health Complex, 600 University Avenue, Toronto, Ontario M5G 1W7, Canada

healthcare delivery model that consists of an interprofessional process for communication and decision making, which brings together the shared and separate skills and knowledge of different providers (Baird et al., 2013; Sockalingam et al., 2020; Youssef et al., 2020). An example of integrated care is the Assertive Community Treatment model for patients with severe and persistent mental illness. It is a formalized interprofessional collaboration that adjusts access to social services, case management, and primary and psychiatric care depending on patient need (Katon et al., 2010; Phillips et al., 2001; Verhaegh et al., 2009; White et al., 2014). Often, informal collaborations across hospital and community settings are necessary to meet the needs of specialized medical populations, including those living with HIV and mental illness.

The coordination of care providers around patient needs is one element of patient-centered care. Patients view their care as "patient-centered" when they feel listened to, understood, accepted, supported and when needs and preferences are recognized (Le et al., 2022; Youssef et al., 2020). Patient-centered care from nonjudgmental and accepting providers can reduce barriers to accessing care by increasing trust and overcoming patients' negative self-perception (Youssef et al., 2020). Additionally, discussion between patients and providers encourages patients to share challenges, gain confidence, seek knowledge, and develop skills to manage physical symptoms and improve health outcomes (Le et al., 2022; Youssef et al., 2020). High-quality integrated care is hypothesized to better achieve patient-centered care; however, there is little empirical knowledge to support this (Youssef et al., 2020).

To improve and increase capacity for care of patients living with HIV and mental illness, we developed a program to enhance integrated, trauma-informed care by creating an innovative educational role for a HIV community outreach caseworker embedded in an academic HIV Psychiatry clinic. Termed the Mental Health Clinical Fellowship (hereafter, "the fellowship"), this experience was designed to provide intensive training in behavioral health treatments for caseworkers, enhance the clinic's case-management capacity for patients living with HIV and mental illness, bridge hospital and community care, and create bi-directional learning, all with the intended aim of improving patient outcomes and increasing retention in care. Beyond task-sharing, the fellowship emphasized perspective exchange and dialogue between providers (Boyd et al., 2022), including development of an integrative care skillset applied across contexts and disciplines. We have written previously about the fellowship from the educational perspective of health care providers (Chaukos et al., 2022). Here, we explore the fellowship from the patient perspective. Through qualitative interviews, we examine how implementation of this program affects patient experiences and satisfaction with care.

Materials and methods

Context

This research was conducted at the Clinic for HIV-related Concerns in the Department of Psychiatry at Sinai Health, Toronto, Canada, which offers psychiatric assessment, psychotherapy and psychopharmacologic management. Clinic staff supervise residents, trainees from other disciplines, and medical students. Patients seen at the clinic are living with HIV, have diverse gender and sexual identities, and diverse racial and cultural backgrounds, including new immigrants and refugees. Most have significant trauma experiences.

Intervention

The fellowship is a one-year secondment for a frontline case manager or mental health worker employed at an AIDS Service Organization (ASO). The fellow returns to the ASO after the fellowship. Throughout the fellowship, the fellow works one day per week at their ASO to facilitate continuity and knowledge translation. Funding ensures the fellow's position at their ASO is backfilled.

The fellows must have a degree in a clinical discipline, good standing in a relevant regulatory college, and a commitment to frontline community work with people living with HIV and mental illness. Fellows have had diverse training backgrounds, making it important that the learning objectives be tailored to a fellow's expertise, goals and experience. Overall, the fellow acquires knowledge about psychiatric management while working as part of a team to provide patient care. Fellows observe and participate in psychiatric assessment and follow-up care, have opportunities to develop psychotherapy skills through direct supervision, engage in reflective practice about challenges of providing care to complex patients, and learn about psychiatric resources in a hospital setting and how clients in the community access them. Assisting with patient engagement, fellows identify and collaborate with clinic staff to improve patient access to hospital care. Fellows are community knowledge facilitators, sharing their expertise about community contexts and services that aim to improve care for people living with HIV and mental illness. By creating opportunities for skills and perspectives sharing, as well as cross-discipline collaboration, the fellowship aims to traverse the silos of hospital and community.

Participants

Study participant criteria included: (a) patients of the clinic who work with the fellows; (b) the fellows; (c) clinicians in the clinic (seven psychiatrists, one occupational therapist and one social worker, all with experience in multidisciplinary settings). The most complex patients who received care in the clinic were identified to work with fellows. All patients had (1) HIV, (2) a DSM5 diagnosis of anxiety, mood, trauma-related, or psychotic disorder and (3) one or more of substance use disorder (active use or in remission); lifetime trauma or adverse childhood experiences; and/or a social, economic, cultural, interpersonal context that complicates assessment or treatment.

Data collection

This study was approved by the Mount Sinai Hospital Research Ethics Board (reference number: 19-0085-E). Participants provided written or recorded verbal informed consent for the semi-structured interviews. Data collection occurred during the fellowship program (October 2020–March 2023). Patients were interviewed once, several months into working with the fellow. Fellows and clinicians were interviewed at the beginning and end of each year of the fellowship program. Interviews were conducted by an experienced qualitative researcher (SG).

Patients were asked about their experiences receiving care from the clinic psychiatrist and fellow, prior care experiences, and their understanding of high-quality mental health care. Fellows and clinicians were asked about their work in the clinic, including with each other, and about facilitators to providing high-quality care for people living with HIV and mental illness. Interviews were recorded and professionally transcribed. Data collection and analysis happened in parallel, so themes identified through analysis informed ongoing data collection.

Data analysis

Transcripts were thematically analyzed (Braun & Clarke, 2014) by DC and SG and themes were discussed with RM and MM. Qualitative research occurs in context and is influenced by perspective. DC is a consultation/liaison psychiatrist, and the Associate Program Director of the Psychiatry Residency Program at the University of Toronto. SG is the research coordinator for this project, in the Department of Psychiatry at Sinai Health, with expertise in thematic analysis and qualitative research. RM is the head of research for Psychiatry at Sinai Health, with expertise in attachment research and medically complex patients. MM is a senior scientist at The Wilson Centre, with expertise in adaptive expertise and qualitative research. Using a constructivist analytical framework, interview data were iteratively coded through the generation of open codes. Using NVivo (Version 12, QSR International Pty Ltd., Victoria, Australia), codes were grouped into different categories and sub-categories, capturing themes that were identified using a deductive and inductive approach (Braun & Clarke, 2006). From October 2020 to March 2023, team meetings were held to analyze data and develop a coding framework. Throughout the coding process, an audit trail was created, and the analytical framework used in this study was developed iteratively.

Results

Of twenty-one study participants, nine patients were interviewed, all who worked with a psychiatrist and the fellow in the clinic. Three fellows and nine clinicians (seven psychiatrists, one occupational therapist and one social worker) completed pre- and post-interviews. The 33 interviews conducted ranged from 45 to 90 min in length.

Prominent themes in the data include patient perceptions of quality mental health care, experiences facilitating access to mental health care through clinical integration, and the benefits of team-based health care provision.

Perceptions of quality mental health care: bridging barriers

Participants described a need for mental health care to help them manage mental and physical health issues. They explained that they look for mental health providers to help them traverse barriers to accessing care. Participants spoke about stigma, and intersectional factors that compounded stigma, impacting their comfort with seeking care:

> knowing the stigma of mental health, my HIV status, and drug usage. To some degree, it played on my mind, in terms of who's going to know, how many people are involved [in care] … . It kept me away from seeking proper help because [of] the stigma.

Participants described a need for more holistic care:

> I need someone who's not going to be all clinical, just telling me you need meds, you need this. No, I need more of a holistic approach.

Though participants described more availability of mental health supports in the HIV sector, their

experience was that resources lacked integration of their multiple problems.

> due to past advocacy, people [who are] HIV positive have access to mental health care much easier than a lot of people … . But … it's kind of appalling how hard it is for the majority of us to get … access to treatment. Nobody seems to know … where to send you. If you're talking to your family doctor, they're not a mental health expert … . [I]t's very difficult to get access to the proper mental health care that you need … . I've encountered psychiatrists who [are] good on gay issues but horrible when it comes to HIV. There is access to care out there. Whether the care is good is another question. The good care is very, very hard to get.

Integration of the community and hospital stance: overcoming stigma

Participants described their experiences with the psychiatrist and fellow team, noting that they felt less stigmatized in this care setting, and often attributed this to the fellow – their experience in the community sector and non-judgmental stance – and how the fellow's involvement helped them access psychiatric treatment.

> I didn't feel like I was walking into a mental health clinic or a HIV clinic. So, I didn't feel any stigma associated with it.

Participants discussed how the fellow role, including a more casual frame (more common in community-based work), with increased accessibility, helped build trust and effectively implement psychiatric management plans:

> they try to keep things open and honest and encourage me to be honest without any judgement. Which is not something that I've always felt easy to do … with every other clinician. There are other clinicians where I would talk about substance use and probably make myself look better than I actually was, because I felt guilty about it, or I felt stigma, or I was embarrassed or ashamed.

As part of integrated care plans, the fellow supported patients to meet basic needs like housing and access to food, which allowed for further engagement in psychiatric treatment.

> when it came to housing and immediate support … , [the fellow] was there to give me information to help me and [the psychiatrist] was the one assessing my mental state and seeing what he can do … to help me mentally to progress, to thrive, to function.

Later they said,

> [the fellow] knows the neighbourhood … . I would not even know how to, because … I don't use a computer … . [The fellow] showed up to come with me, because I would never do that on my own … . She came on the bus, and … put housing in for me. She got in touch with a friend of hers because she's very well-connected in the … gay community – I'm not.

For patients receiving care from the psychiatrist and fellow, time to build trust and support meeting basic needs were an important foundation for engagement in psychiatric treatment. Patients experienced this integration as holistic and patient-centered care.

Shared mission and team-based care: cohesive purpose

Patients spoke about the benefits of team-based, integrated care, including noticing the coordination and communication amongst team members, and how different roles contributed toward a cohesive purpose and psychiatric management plan.

> when I see both a psychiatrist and a mental health clinician and they speak to each other and collaborate, or collaborate with other professionals, I think that that has been the best approach to care that I've had.

Patients described the team as a cohesive and interchangeable unit, that the teamwork between the psychiatrist and fellow was validating their needs.

> I got you guys and I'm grateful, so happy. I have a team of caregivers. I have [the fellow] and I have [a psychiatrist]. I feel special. I can get things going.

> it was completely inviting, completely wonderful, and they're looking for solutions … . [T]hank goodness for these two because I wasn't in a good spot.

Discussion

Patients living with HIV, mental illness and other forms of complexity require intensive case-management and care coordination for frequent appointments at both community and hospital settings. Yet, there are few hospital-based care models that integrate community providers and resources while simultaneously providing opportunities for clinicians to collaborate. Even in systems where community and hospital providers frequently refer to and rely on each other, providers understand little of the work done in different contexts, and thus true integration is difficult (Chaukos et al., 2022, 2023). We developed the fellowship to provide more integrated care to patients with complexity, and to create educational opportunities for providers to acquire a cross-context and cross-discipline integrative care skillset. Though this care model may not be feasible in all contexts, the lessons learned about patient-centered care – specifically that clinical integration

occurred when psychiatrists and community caseworkers collaborated to construct and implement care plans together – can have broad possible application.

Patient participants shared that quality mental health care includes safe, non-stigmatizing and holistic care. But stigma, negative self-perception and structural barriers, including compounded barriers due to intersecting marginal identities, make affordable, coordinated and integrated care extremely difficult to access (Koch et al., 2015; Vogeli et al., 2007). Further, patients described how the fellowship program combined the accessible stance of community organizations with the psychiatric assessment and treatment required for their mental illness, and how integration across hospital and community allowed for patients to feel cared for and listened to. Patients reported that the program improved access to psychiatric care and mitigated fragmentation. Participants in our study received patient-centered care – they felt cared for, they were active collaborators in their care, and their providers personalized their care to address their needs (Youssef et al., 2020).

Notably, in this care model, multiple levels of integration were necessary (Valentijn et al., 2015). For example, clinical integration at the micro level (patient care level) required fellow and psychiatrist to engage in perspective exchange, not simply task sharing. Patients recognized that psychiatrist and fellow were interchangeable, i.e., the care provided by each was well-known by the other. Knowledge, respect, and trust of the care provided by the other, and a shared understanding of how the expert skills of the other contributed to a shared mission, was essential at the meso level (i.e., day-to-day operations of the clinic) for professional integration. Formalized partnerships across community and hospital organizations, as well as educational opportunities that aim to impart collaborative skill sets that emphasize integration, can impact the quality of integrated care and thus patient-centeredness.

Through this unique educational model, patients were provided with holistic care and treatments that addressed their unique care needs and were connected to additional care services when needed. These are hallmarks of patient-centered care, an outcome of quality integrated care (Youssef et al., 2020). Overall, the fellowship highlighted systemic barriers to care for patients and helped dismantle those barriers at an individual level, while mitigating fragmentation and reinforcing that integrated care models work for patients to better access psychiatric care.

Our study has limitations. These results are preliminary, based on the first three years of the program, in one hospital. As such, further study is necessary, with more candidates and in more diverse clinical settings. Secondly, it is challenging to distinguish the benefits of the educational and integrative aspects of the role from the benefits of adding another care provider to the clinic. Thirdly, this study only involved 21 participants, which is a small sample and the study included only 9 patient participants. The patient population of the clinic experienced barriers to accessing health care, including trauma and ongoing chaotic life experiences, and some patients were unable to participate.

To conclude, we argue that cross-context and cross-disciplinary care that includes providers from community and hospital engaging in perspective exchange (such that they are interchangeable team members) improves patient-centered and integrated care for patients with complexity. We are piloting the third year of the fellowship.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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ORCID

Deanna Chaukos http://orcid.org/0000-0001-5813-697X
Sandalia Genus http://orcid.org/0000-0002-7508-8348
Robert Maunder http://orcid.org/0000-0001-9309-3899
Maria Mylopoulos http://orcid.org/0000-0003-0012-5375

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