

Mental illness-related stigma in healthcare: Barriers to access and care and evidence-based solutions

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Abstract

Mental illness-related stigma, including that which exists in the healthcare system and among healthcare providers, creates serious barriers to access and quality care. It is also a major concern for healthcare practitioners themselves, both as a workplace culture issue and as a barrier for help seeking. This article provides an overview of the main barriers to access and quality care created by stigmatization in healthcare, a consideration of contributing factors, and a summary of Canadian-based research into promising practices and approaches to combatting stigma in healthcare environments.

Introduction

Mental illness-related stigma, including that which exists in the healthcare system and among healthcare providers, has been identified as a major barrier to access treatment and recovery, as well as poorer quality physical care for persons with mental illnesses. ^{1–5} Stigma also impacts help-seeking behaviours of health providers themselves and negatively mediates their work environment. ^{6–9} What follows is a consideration of the literature on the main sources of personal and interpersonal stigma in healthcare, impacts for both patients and providers, and evidence-based solutions that can be implemented to improve patient-provider interactions and quality of care.

What are the main sources of stigma in healthcare?

Developed from Goffman's pioneering work, 10 stigma is conceptualized as a complex social process of labeling, othering, devaluation, and discrimination involving an interconnection of cognitive, emotional, and behavioural components. 11,12 Stigmatization occurs on multiple levels simultaneously intrapersonal (eg, self-stigma), interpersonal (eg, relations with others), and structural (eg, discriminatory and/or exclusionary policies, laws, and systems). 11-13 It is also keenly recognized that only powerful social groups can stigmatize. 11 Such an understanding is helpful for appreciating how stigmatization occurs on multiple levels throughout the healthcare sector, including structural (eg, investment of resources, quality of care standards, organizational culture), interpersonal (eg, patient-provider interactions, discriminatory behaviours, negative attitudes), and intraindividual (eg self-stigma, patient reluctance to seek care, provider reluctance to disclose a mental illness and/or seek care). 12,13

Research has identified a number of issues contributing to stigmatization in healthcare, which have direct and indirect impacts on access and quality of care for persons living with mental illnesses. These have been described as "key learning needs,"¹⁴ acknowledging that they are specific concerns that can be changed through targeted initiatives.

Negative attitudes and behaviours

People with lived experience of a mental illness commonly report feeling devalued, dismissed, and dehumanized by many of the health professionals with whom they come into contact. 15–21 Key themes include feeling excluded from decisions, receiving subtle or overt threats of coercive treatment, being made to wait excessively long when seeking help, being given insufficient information about one's condition or treatment options, being treated in a paternalistic or demeaning manner, being told they would never get well, and being spoken to or about using stigmatizing language. 15-21 While research also highlights many positive patient experiences (eg, Clark et al. 19 Barney et al. 20 and Connor et al.²¹), the pervasiveness with which negative interactions are reported suggests the problem is not isolated to a few insensitive providers but is more systemic in nature—that it is a problem with how healthcare culture prioritizes and perceives persons with mental illnesses. 1,4-7

Research with healthcare providers is consistent with this idea, finding that stigmatizing attitudes and behaviours towards persons with mental illnesses exist across the spectrum of healthcare.^{2,5–7} Also, patients with certain disorders, such as personality disorders, tend to be particularly rejected by healthcare staff and are often felt to be difficult, manipulative,

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and less deserving of care.^{6,22–24} A Canadian qualitative study¹⁴ articulated stigmatization among health providers to be, at least in part, related to a tendency "see the illness ahead of the person," which can contribute to a failure to use personfirst language and/or a tendency to engage in behaviours that may be experienced as dismissive or demeaning. Burnout and compassion fatigue have been identified as exacerbating concerns.^{2,14}

Lack of awareness

Another issue is a lack of awareness and unconscious biases, which acknowledge the power of hidden beliefs and attitudes that can underlie stigma-related behaviour. 14,25–28 Qualitative research has found that for many healthcare providers, it is only through the experience of receiving anti-stigma training that they become aware of the subtle and unintended ways certain beliefs and behaviours may have been contributing to stigmatizing experiences among their patients (Knaak et al. 14 see also Sukhera et al. 25 and Horsfall et al. 28)

Therapeutic pessimism

Research consistently demonstrates that healthcare providers tend to hold pessimistic views about the reality and likelihood of recovery, which is experienced as a source of stigma and a barrier to recovery for people seeking help for mental illnesses. ^{2,6,7,12,29} Research also suggests that pessimism about recovery for some providers is associated with a sense of helplessness, leading them to believe that "what they do doesn't matter." ¹⁴

Lack of skills

Inadequate skills and training seem to be associated with stigmatization in two ways. First, it is believed to lead to feelings of anxiety or fear and a desire for avoidance and social/clinical distance among practitioners, which can negatively impact patient-provider interactions and quality of care. 6,29–31 Second, it can lead to less effective treatment and poorer outcomes. 2,6,32

Stigma in workplace culture

Importantly, the problem is not just outward facing—mental illness-related stigma also permeates the healthcare sector as a workplace. It has been described as a problem of culture, where staff are often discouraged to talk openly or seek help for psychological problems. ^{1,6,8,9} Research with healthcare providers in Canada indicates that the level of stigma regarding their own willingness to disclose and/or seek help for a mental illness is consistently higher than their level of stigma for other dimensions such as negative attitudes and preference for social distance. ³³ Also, within the workplace context, people with mental illnesses are perceived as less competent, dangerous, and unpredictable and that work itself is not good for people with mental illnesses. ³⁴

Consequences of stigma for access and quality care

These issues create barriers through such pathways as delays in help-seeking, discontinuation of treatment, suboptimal therapeutic relationships, patient safety concerns, and poorer quality mental and physical care. 1-2,12,35-37 For example, anticipated stigma from healthcare providers has been identified as a factor in people's reluctance to seek help for a mental illness. 12,15,19 Compromised patient-provider relationships and early termination of treatment are also consequences. 2,5,15,16,38,39 A survey conducted by the Canadian Psychiatric Association found that 79% reported first-hand experiences of discrimination towards a patient and 53% observed other medical providers, discriminating against a patient from psychiatry. Stigma also has consequences for patient safety. 16,40 A recent Canadian study identified stigma as a barrier to patient safety through factors such as staff attitudes and institutional culture and the accepted marginalization of mental health patients that occurs through stigmatization.⁴⁰

Poorer physical care for persons with mental illnesses is another consequence of stigmatization. Persons with lived experience of a mental illness commonly report barriers to having their physical care needs met, including not having their symptoms taken seriously when seeking care for non-mental health concerns. S,15-16,19 Studies also demonstrate that persons with mental illness histories receive poorer quality care for their physical health problems. Physical to occur largely through a process of diagnostic and treatment overshadowing, whereby physical symptoms are misattributed to a patient's mental illness, creating delays in diagnoses and treatment options.

Stigmatization also has inward-facing impacts for health professionals' own willingness to seek help or disclose a mental health problem, which can result in an over-reliance on self-treatment, low peer support—including ostracization and judgment from co-workers if disclosure does occur—and increased risk of suicide. 1,6,8,9,43 Given that mental illnesses are related to presenteeism and productivity losses in the workplace (eg, Dewa et al. 44), it's even more important to consider the impact of stigma in this context. For example, initial reluctance to seek help may result in decreased productivity, which may lead to confirmation of stereotypes and additional stigma by co-workers resulting in further reluctance to seek help.

Removing barriers to access and care through stigma reduction

The deleterious impacts of stigma in healthcare have promoted increased calls to action for health organizations to take leadership roles in tackling the problem. ^{1,18,26,27,45–47} A growing body of Canadian research has identified promising strategies for stigma reduction in healthcare settings. For example, qualitative and theoretical models emphasize the importance of approaching stigma reduction with the goal of culture change, a

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dedication to taking a sustained, integrated approach to target stigma from both outward- and inward-facing perspectives (avoiding the temptation to employ one-off programming), and committing to strong leadership support. ^{14,27} Implementation models also emphasize mandatory and/or incentivized participation, as well as the incorporation of stigma reduction metrics into hospital and other accreditation processes as a key measure for quality of care. ^{3,14}

Key ingredients for effective stigma reduction in healthcare contexts have also been identified.⁴⁸ It is believed the effectiveness of these ingredients lies in the extent to which they are able to address the sources of stigma describe above. 14 These include teaching skills that help healthcare providers know "what to say" and "what to do," ensuring program facilitators are modelling person-first behaviours and making ample use of social contact. 48 Social contact generally refers to hearing firstvoice testimonies from people with lived experience of a mental illness who are trained to speak about their experiences of illness and recovery, as well as their experiences within the healthcare system, and is a key strategy for interprofessional educational approaches to stigma reduction in healthcare. 48-50 It is a qualitatively different kind of contact from typical provider-patient interactions. In social contact approaches, people with lived experience of a mental illness are seen not as patients but as educators. 45,50-52 Social contact has been shown to disconfirm stereotypes, diminish anxiety, heighten empathy, make personal connections, and improve understanding of recovery. 50-52

Two other key ingredients have also been identified. The first is providing interventions that include myth busting or a transformative learning focus to target unconscious biases and correct false beliefs that may be negatively impacting care. ^{25,27,48} The second is demonstrating/emphasizing recovery from a mental illness and showing ways in which healthcare providers play an impactful role in that process. ⁴⁸ More fulsome implementation of person-centred recovery-oriented models of care is also believed to be important. ^{53–55}

There is also a growing body of program-based Canadian evaluation research with healthcare providers. 25,31,45,52,56-64 Effective models include workshop-based interventions, skillsbased interventions, and intensive social contact interventions. One workshop program showing promising results is a 2-hour face-to-face delivered program called Understanding Stigma developed by the Ontario Central Local Health Integration Network. 56,57 This program includes educational elements designed to increase knowledge, skills, and awareness, "action-oriented" elements aimed at behaviour change, and one or more social contact elements. It has been evaluated in numerous settings with different healthcare audiences using a pre-post follow-up design and the 15-item Opening Minds Scale for Health Care Providers (OMS-HC) scale, developed specifically to measure attitudes and behavioural intentions of healthcare providers towards persons with mental illnesses.³³ Evaluation results show significant pre-post improvements in all 3 factors of the OMS-HC, with changes being sustained at

3- and 6-month follow-up with the implementation of a booster session. 56,57

Another program demonstrating encouraging evaluation results using the OMS-HC is a web-based accredited on-line continuing medical education program called "Combating Stigma," 58,59 freely available at www.mdcme.ca. Participant observation, human factors, and design thinking were primary methods informing the curriculum design, as the key objective was to address the challenge that stigma is a largely unperceived learning need for many health providers with denied limitations in quality of care. 59 While designed primarily for physicians, evaluation data show that over half of the program's participants are nurses and allied health professionals. 59 A similar program for nurses titled "De-Stigmatizing Practices and Mental Illness" is now available on the www.mdcme.ca site.

The Working Mind (TWM) is a promising inward-facing program being used in healthcare settings. ⁶⁴ Developed from the Department of National Defence's Road to Mental Readiness Program, ⁶⁵ the primary objectives of TWM are to reduce the stigma of mental illnesses, increase resiliency, and promote early help seeking in program participants. ^{47,64,65} Preliminary evaluation results indicate the program is effective at improving attitudes, encouraging people to seek help, and increasing readiness to deal with stress and challenging events, ⁶⁴ and is currently being adapted for resident doctors and physicians.

Skills-based training also holds promise as a model for reducing stigma. Skills-based interventions focus on behaviour change by aiming to improve confidence, comfort, and understanding of mental illnesses as being inherently treatable and manageable. 14,48 One example is the Adult Mental Health Practice Support Program developed in British Columbia. 30,31,60,64 The program teaches self-management cognitive behavioural tools to family physicians and other frontline healthcare providers for patients with mild to moderate depression and anxiety. It aims to reduce stigma through improved patient-provider interactions and improved confidence and competence in working with patients with mental illnesses. 30

An evaluation of this program in British Columbia found that physicians reported decreased reliance on prescribing antidepressant medications, felt their patients were better able to stay or return to work, and reported improved patient care. A randomized control study of this same program in Nova Scotia found robust improvements in confidence and skills compared to treatment-as-usual (TAU) and also a significant reduction in social distance. Researchers also found significantly lower Patient Health Questionnaire (PHQ)-9 depressive ratings among patients at 6-month follow-up and significantly lower levels of anti-depressant prescribing compared to TAU. 64

Another important model is that of intensive social contact, where health providers meet at multiple time points with a person with lived experience of a mental illness living in recovery in order to learn about that person's life and

experiences. 45,52,63 Evaluations using the OMS-HC have shown this model to be effective at improving attitudes and behavioural intentions and sustaining those improvements over time, and qualitative research suggests the personal and cooperative nature of the social contact can provide a powerful and positively transformative learning experience for both providers and client educators. 45,63

Conclusion

The primary focus of this article was to identify barriers to access and quality care created by stigmatization processes at the level of personal and interpersonal stigma and to identify solutions that can be implemented within existing structures. A key limitation of the evidence described in this article is that many anti-stigma interventions are evaluated using provider-based outcomes—typically attitudes and behavioural intentions of health providers. There is a need for more research that targets the impacts of stigma reduction initiatives on patient experiences and specific care practices. As well, many programs are implemented and evaluated as "one-off" interventions. Longitudinal research using mixedmethod designs that track the implementation of more sustained stigma reduction efforts within healthcare organizations and setting would be of benefit.

An organizational culture that promotes staff health and well-being and is committed to combating stigma in patient care is likely to have a positive impact on staff and patient safety as well as the financial bottom line. Approaching the problem of stigmatization from an organizational culture perspective and a quality of care perspective—and developing and implementing relevant stigma reduction metrics and targets into health and safety (eg, Canadian Standards Association 66) and accreditation standards—would likely be an effective way to target the personal and interpersonal components of stigma described above and would also begin to address the structural aspects of stigma embedded in the health system.

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