COMMENTARY

Individuals to Systems: Methodological and Conceptual Considerations for Addressing Mental Illness Stigma Holistically

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Abstract

Mental illness stigma is a complex public health issue that creates barriers for clients needing access to quality mental health services. Most research focuses on interpersonal stigma with emerging research examining intrapersonal and structural stigma in the healthcare setting. This commentary focuses on how to address the gaps in the existing research to elicit greater organizational/structural change in healthcare systems and positive health outcomes. It describes key components of a 5-year multiphase study that aims to explore and address multiple levels of stigma holistically among stakeholders including physicians, nurses, protective services staff, and patients/families in an emergency department setting. Unique to this study is the inclusion of a patient research partner who will be positioned as a co-designer throughout the project. The goal of this study will be to explore, address, understand, and evaluate interventions that mitigate stigma in healthcare at both the individual and structural/organizational levels.

Keywords Stigma · Healthcare · Mental illness · Mental health · Emergency department

Background

Despite tremendous gains in stigma reduction over the past century in relation to gender, race, sexual orientation, religion, and medical diagnoses (e.g., HIV), mental illness-related stigma remains prevalent (Abbey et al., 2011). Stigma is a well-documented obstacle for people with mental illnesses (Liggins & Hatcher, 2005) including reduced life expectancy for those diagnosed with schizophrenia, bipolar disorder, schizoaffective disorder, depressive disorder, and substance use disorder (Chang et al., 2011;

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Hennekens et al., 2005). Mental illness-related stigma creates housing and employment difficulties, adverse economic effects, and serious barriers to access and quality health-care, including delayed treatment and early treatment discontinuation (Sharac et al., 2010). Stigma is also a major concern for healthcare practitioners and can impact help-seeking behaviors for themselves, which can negatively impact their work environment (Knaak et al., 2017).

A growing body of evidence is revealing the various ways that mental illness stigmatization is showing up in healthcare environments and among healthcare professionals. In a recent review of burnout among healthcare workers, physical and mental exhaustion were identified as significant issues requiring organizational and cultural change to support healthcare providers' ability to cope with work-related stress and the stigma associated with seeking help for mental health-related issues (Leo et al., 2021). Stigmatization manifests as negative attitudes and stereotypes, prognostic negativity, diagnostic overshadowing, insufficient skills of healthcare providers (HCPs), discriminatory behaviors, perceptions of unfair treatment among those receiving mental health services, and inequitable distribution of resources (Henderson et al., 2014). Furthermore, research with patients seeking help for mental illnesses describes experiences of feeling stigmatized, devalued, and dismissed by HCPs in emergency settings (Knaak et al., 2017). At a structural level, mental health/mental illnesses are chronically underfunded. As an example, in Canada, federal funding for mental health/mental illnesses is approximately 7% of the healthcare budget, yet other comparable countries spend over 10% (Bartram, 2017; Centre for Addiction and Mental Health [CAMH], 2017). It is also important to note the intersectional nature of stigma, that is, the many ways that stigma related to mental illnesses intersects with other marginalized statuses such as homelessness and LGBTQ2+ which can create additional barriers to accessing necessary social and structural supports and intensify stigma experiences (Jackson-Best & Edwards, 2018; Livingston, 2020).

Stigma in the healthcare system, particularly stigma towards people with mental illnesses, can create barriers to accessing health information, services, and protective resources; lead to substandard treatment of patients; and can engender patient mistrust of the healthcare system and further exclusion from it (Public Health Agency of Canada [PHAC], 2019). The stark mortality gap in high-income countries between people with severe mental illnesses and the general population—20 years for men and 15 years for women—has been argued to be at least partly related to the problem of stigmatization (Wahlbeck et al., 2011), suggesting that several important quality-of-care concerns exist, including access for people with mental illnesses (Knaak et al., 2015).

In addition, family members of people with mental illnesses often report negative effects in areas of their lives including time, energy, emotions, daily activities (Statistics Canada, 2015), and financial impacts (Sharac et al., 2010). Mental illness stigma has also contributed to the devaluation of HCPs working in these areas, leading to recruitment challenges in psychiatry and other mental health professions (Abbey et al., 2011).

Stigma, including self-stigma, is also experienced by HCPs who are unwilling to seek help for their own mental health issues, and whose workplace culture may penalize those who experience mental health problems (Adams et al., 2010; Wallace, 2012). Rates of mental illness and suicide are higher in medical students, residents, and staff physicians compared to the general population (MacLean et al., 2016; Schernhammer, 2005; Schernhammer & Colditz, 2004). In general, when stigma is internalized (i.e., self-stigma; Corrigan et al., 2006), it can be a barrier to help-seeking and interfere with recovery from mental illnesses (Knaak et al., 2017).

More recently, HCPs have been identified as a high-risk group for negative mental health outcomes related to the COVID-19 pandemic given the unique challenges of their work under outbreak conditions (Lai et al., 2020; Maunder et al., 2008). While a few interventions have been proposed to support the mental health of HCPs during this pandemic, no mention is made of the impact of stigma on their help-seeking behaviors (Leszcz et al., 2020; Wu et al., 2020).

Defining Stigma

Contemporary definitions describe stigma as a process where human differences are labelled and attached to negative stereotypes, which leads to separation from the stigmatized group resulting in unequal and negative outcomes (e.g., prejudice and discrimination). In particular, Link and Phelan's (2001) definition not only places the burden of stigmatization on the stigmatizer; their definition also describes stigmatization occurring at separate levels. Broadly, mental illness stigma has been described within the context of three levels: intrapersonal, interpersonal, and structural (see Knaak et al., 2017; Livingston, 2020).

Structural stigma refers to the accumulated activities of organizations that create and maintain social inequalities for people with lived experience of mental illness and/or substance use in terms of access and quality of care. This includes the underfunding of addictions and mental healthcare (Livingston, 2020; McGinn & Grimminck, 2019), as well as policies, practices, and models of care that systematically create and maintain inequities in both access to and quality of care for people with mental illnesses or substance use problems (Knaak et al., 2020; Livingston, 2020).

Stigma is also perpetuated at the interpersonal level and known as public stigma. Public stigma refers to the stereotypes and negative attitudes individuals hold themselves or that are perceived to exist in the public (Corrigan et al., 2012). These biases and beliefs may result in stigmatizing practices by health professionals (Allan & Smylie, 2015; Bailey et al., 2017; White Hughto et al., 2015). A lack of mental health training including gaps in traditional cultural approaches to healing may contribute to such biases and further perpetuate stigma at the interpersonal level (Alencar Albuquerque et al., 2016; Allan & Smylie, 2015; James, 2010; Nyblade et al., 2019; White Hughto et al., 2015). Beyond attitudes and stereotypes, the language used, particularly labels (i.e., addict, junkie, schizophrenic), can also negatively impact people experiencing mental illnesses and addictions (Reynaert & Gelman, 2007). This stigmatizing language is hurtful and can lead to prejudice and discrimination and can influence HCPs' perceptions of patients (Kelly & Westerhoff, 2010; White Hughto et al., 2015). These types of labels restrict identities and overshadow other qualities that the person possesses (CAMH, 2005).

When public stigma is internalized (i.e., self-stigma; Corrigan et al., 2006), it can be a barrier to help-seeking and interfere with recovery from mental illnesses (Knaak et al., 2017). Stigmatization at an intrapersonal level can affect both patients and HCPs. For example, a systematic review of qualitative and quantitative research on barriers to help-seeking found that health professionals, as well as ethnic minorities, youth, men, and those in the military, were disproportionately deterred by self-stigma (Clement et al., 2015). The authors also found that health professionals were more likely than other groups to report disclosure/confidentiality concerns, shame/embarrassment, and negative social judgement as barriers to help-seeking.

Within the healthcare system, stigmatization occurs on multiple levels simultaneously (as shown in Fig. 1), and the levels are interconnected with bidirectional impact. For example, training requirements and resource allocation (structural) can influence providers' attitudes and level of comfort in working with people with mental illnesses (interpersonal). Discriminatory behaviors and attitudes in healthcare settings (interpersonal) can influence providers' view of their own mental health (intrapersonal) and vice-versa. Given the interconnectedness of the different levels of stigma, attendance to all levels is required for a thorough understanding of the problem of stigmatization, as well as for designing strategies to effectively address it.

Research Gaps

Stigma within the healthcare system has been addressed to some extent, but important limitations remain. It is clear in the literature that mental illness stigma at the structural level impacts patients and those seeking help negatively, whether it is negative help-seeking experiences, poor treatment, or poorer health outcomes (see Livingston, 2020 for a review). Of key concern, however, as noted in a review by Henderson et al. (2014), is that few studies address more than one level of stigma and that future research should address multiple levels of stigma and the relationship between them. For example, there has been considerable research on understanding the problem of stigma at the interpersonal level and identifying effective approaches and key ingredients for anti-stigma interventions (e.g., see Henderson et al., 2014; Knaak et al., 2014). Similarly, in Rao et al.'s (2019) review of multi-level stigma interventions, they conclude that the research literature has examined stigma at the interpersonal and intrapersonal levels, given prior focus of the literature and ease of implementation, but little or no work has incorporated structural stigma within multilevel studies. In examining the literature, Livingston (2020) also indicated that there is little focus on structural stigma within the mental illness stigma domain beyond addressing attitudes of healthcare practitioners. Given this lacuna in the literature, mental illness stigma researchers should focus on multilevel research beyond the intra- and interpersonal levels, as well as examine structural stigma interventions beyond changing attitudes in HCPs (e.g., focus on policy change). Furthermore, the implementation

Fig. 1 Stigma at multiple levels
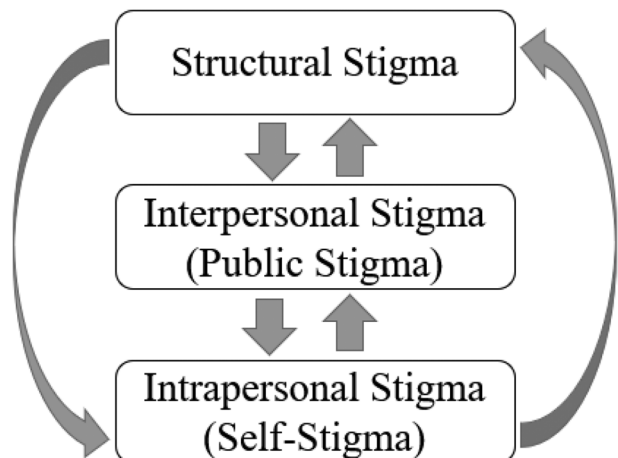
of interventions—and how implementation factors might hinder broader and long lasting structural or organizational level change to the delivery of care—is also lacking (Gronholm et al., 2017; Hatzenbuehler, 2016; Knaak et al., 2020). This type of research would go a long way in addressing structural stigma and its impact on patient experiences and health outcomes.

As well, qualitative or quantitative studies are commonly undertaken by stigma researchers, with considerably fewer utilizing mixed methodological approaches. Rao et al. (2019) suggest a multi-pronged approach to measurement of stigma reduction interventions, including how they are related across levels of analysis and how they reciprocally affect one another.

For some, mental illness stigma manifests as shame, isolation, and silence (Corrigan & Rao, 2012). The visibility of patient research partners (PRP) can break down some of those barriers by creating a safe space for sharing. While many studies include participant narratives of lived experience, there has been relatively little emphasis on the utilization of patient research partners in the research process, despite the fact that meaningful inclusion and participation of people with lived and living experience have been identified as an important mechanism for stigma reduction (Knaak et al., 2020; Manafo et al., 2018; Nyblade et al., 2019). Including PRP ensures that the voices of patients and their families are heard, respected, and represented and that a focus on patient-identified priorities and outcomes are maintained (Canadian Institutes of Health Research [CIHR], 2017).

Stigma research often tends to focus on the experiences or outcomes of a single participant group within a particular healthcare setting (e.g., health providers or service users), as opposed to examining the experiences of both cross-disciplinary HCPs and patient groups within the system simultaneously. As such, research that aims to gain a more comprehensive understanding of stigma reduction interventions within a particular healthcare setting or context will add value to the research (Nyblade et al., 2019).

While stakeholder engagement is gaining traction in the health field, a relatively small number of research papers refer to stakeholder engagement or the utilization of multiple stakeholder groups. Boaz et al. (2018) explained how the engagement of stakeholders, who have a direct interest in the process and outcomes of a project, research, or policy endeavor, is being increasingly promoted within public health research as an important pathway to achieving impact.

To address these gaps, the remainder of this paper describes key methodological and conceptual elements of a 5-year research project that aims to understand mental illness-related stigmatization in emergency care. As described in more detail below, the study utilizes a holistically orientated, mixed methods, longitudinal research methodology to capture and address the multiple levels of stigma (intrapersonal, interpersonal, structural) and the needs of multiple stakeholder groups.

Research Study

The Exploring Mental health Barriers in Emergency Rooms (EMBER) study is funded by the Calgary Health Foundation (CHF) in Alberta, Canada. The EMBER study focuses specifically on stigma within an Emergency Department (ED) setting at a major hospital in Alberta, Canada, and explores how mental illness-related stigma impacts patients, families,

physicians, nurses, and protective services staff. The study is unique in that it takes a holistic view of stigma and aims to address multiple levels of stigma simultaneously.

The exploration includes investigating stigma at the intrapersonal level, including self-stigma and the willingness to seek help, the interpersonal level in patient-provider interactions, and structurally within organizational policies and procedures. Additionally, the study aims to develop evidence-based interventions, implementation strategies, and knowledge translation activities to mitigate stigma and discrimination in hospital EDs across these different levels.

The study has seven main objectives:

1) Identify gaps in our understanding of mental illness-related stigma and discrimination experienced by patients and families in EDs, utilizing a PRP
2) Complete a policy review of hospital and health authority-based organizational protocols, procedures, and policies to identify ways that structural stigma and discrimination may exist and affect the delivery of care for patients and families in the ED setting
3) Examine the experiences and attitudes of professional staff who receive mental health patients in the ED (including ED physicians and nurses, ED psychiatric physicians and nurses, as well as protective services staff) and any potential links to further stigmatization of patients and families
4) Develop and implement multiple stigma-reducing interventions for professional ED staff (physicians, nurses, protective services)
5) Evaluate the impact of stigma-reduction interventions on patient access and quality of care, patient experience, and ED staff attitudes and behaviors, with attention to impacts at all three levels of stigma
6) Evaluate the shift in patient and professional staff perceptions of mental illness stigma and discrimination in EDs over time (i.e., longitudinally)
7) Develop a stigma reduction curriculum including resources for scale and spread

The study objectives will be accomplished in five distinct phases over five years (see Tables 1 and 2).

First, throughout all phases of the study, our interest is in understanding and addressing stigma at multiple levels. To this end, the measures we will use—including the evaluation of implemented interventions—will not just assess individual level change (through pre and post surveys) but will also examine the extent to which interventions may lead to sustained organizational changes within the ED. Strategies for assessing these larger structural shifts will be co-developed with our PRP, participant groups, and invested stakeholders and will include focus groups, ethnographic interviews, an assessment of implementation fidelity, embedded client satisfaction surveys, and/or provider follow up surveys. Also, a longitudinal component will be embedded into the methodology to support the ability to assess change over time.

Secondly, an examination of mental health-related policies will be a central component of the current research. Even though policy review has been identified as an emerging topic of interest in relation to organizational stigma, there is a scarcity of research that has examined policy change implications for stigma reduction in healthcare settings (Livingston, 2020; Rao et al., 2019). One Canadian study conducted in a primary healthcare setting found that changes as a result of policy reviews, in conjunction with anti-stigma interventions, reduced stigmatizing attitudes among HCPs (Khenti et al., 2019). Similarly, a set of

Table 1 EMBER study phases, milestones, and objectives

Phase and timeline	Brief description	Milestones	Objectives
Phase 1: Needs assessment *Year 1*	Understanding all three levels of stigma, including participant experiences, attitudes, and behaviors.	• study design • research ethics • sample design • recruitment • focus groups, interviews, and surveys	Objectives 1 and 3
Phase 2a: Structural policy review *Years 1 and 2*	Collaboration with hospital and health authority stakeholders' team to review and evaluate mental health policies in ED settings.	• structural policy review • dissemination of results	Objective 2
Phase 2b: Research team refinement of recommended stigma reduction interventions and developing an implementation and evaluation framework *Years 1 and 2*	Identify inward and outward facing stigma reduction interventions to ensure stigma is addressed at all three levels. Engage focus groups to adapt interventions and understand implementation considerations. Finalize implementation and evaluation framework for intervention delivery.	• suitability of identified interventions (focus groups) • adaptations to interventions • development/adaptation of implementation and evaluation framework and measures	Objective 4
Phase 3: Piloting and evaluating interventions *Years 2 and 3*	Pilot stigma reduction interventions among ED staff groups. Evaluate at baseline, immediate follow up, and 1, 3, 6, and 12 months. Engage patients and families in focus groups regarding their perceptions of the piloted interventions and implementation.	• facilitator training • participant recruitment, scheduling, and promotion • pilot interventions • assess efficacy of interventions • qualitative research patients and families-implementation	Objectives 4 and 5
Phase 4: Data synthesis and recommendations for broad dissemination *Years 3 and 4*	Analyze data from the interventions, focus groups, and policy review. Synthesize results, disseminate findings, and provide recommendations.	• synthesize data and evaluation outcomes • qualitative feedback from patients and families • final report and recommendations	Objectives 5 and 6
Phase 5: Knowledge translation and mobilization *Years 2–5*	Engage in collaborations and partnerships with ED and beyond to disseminate findings and successful interventions. Develop a stigma reduction curriculum and resources.	• integrated knowledge translation • end of grant knowledge translation • scale and spread	Objective 7

Table 2 Research gaps addressed by EMBER study

Research gap addressed	Phase of project
Understanding and addressing stigma at multiple levels	All phases
Examination of mental health-related policies	Phase 2a
Multi-stakeholder engagement	All phases
Patient research partner	All phases
Stigma reduction implementation strategies	Phase 2b and 3
Mixed method methodology and conceptual framework	All phases

interventions to reduce HIV stigma in a Vietnamese hospital setting improved attitudes towards patients with a HIV diagnosis (Pulerwitz et al., 2015). Like these initial studies, the current research will examine mental health-related policies within the ED, make recommendations for change, and measure the impacts of those changes via various methods including patient and staff perceptions, stigma reduction, and behavioral outcomes (Rao et al., 2019).

Third, the research team will engage with multiple partners including policy advisors, organizational leaders, provincial addiction and mental health standards teams, patient advisory committees, and the Mental Health Commission of Canada. Multi-stakeholder engagement will be utilized in this project to create an iterative process with the aim of soliciting knowledge and experience from individuals with a broad range of direct interest in our research (Deverka et al., 2012).

Fourth, patient engagement in research involves patients undertaking roles beyond those of traditional study participants (Hamilton et al., 2018) to ensure a focus on patient-identified priorities and outcomes, and health research findings that are more responsive to the needs of service users (CIHR, 2017). To this end, our study team will include a PRP who will participate as an equal member of the research team, involved in all aspects of design, data collection, analysis, and writing (CIHR, 2014, 2017). Additionally, the PRP will help to synthesize data and share results with intended audiences (i.e., patients and families) during the knowledge translation phase. The PRP will also act as a role model using their lived experience and voice to educate others.

Fifth, given the gap in stigma reduction implementation strategies in healthcare settings, robust implementation strategies will be given key considerations in this study to ensure uptake and sustainability. Through the utilization of focus groups with patients, families, and our various service provider groups we hope to gain increased understanding in areas including: (a) the perceived fit between proposed training and identified learning needs; (b) the suitability of intervention content for different learner groups; (c) intervention length; (d) format of delivery; (e) size of training groups; (f) mix of professionals within groups; (g) incentives for participation; (h) sustainability; (i) support for reinforcement of training over time; (j) anticipated implementation challenges and how to address them; and (k) expected or desired outcomes. An implementation strategy will be developed alongside the intervention(s) and assessing implementation will be part of the evaluation framework.

Sixth, a mixed method methodology will be use to explore multiple perspectives, positions, and standpoints in relation to mental illness stigma in ED settings (Johnson et al., 2007). Qualitative and quantitative research design will help ensure a more holistic and comprehensive capturing of multiple participant perspectives (e.g., patient/families, HCPs, protective services) including the policies that inform the delivery of mental

health services. The combination of quantitative and qualitative methods supports a shared commitment to understanding and improving the human condition, a common goal of disseminating knowledge for practical use, and a shared commitment for rigor, conscientiousness, and critique in the research process (Reichardt & Rallis, 1994). A mixed method approach will help to capture quantitative results and qualitative findings, and for this project, will reflect the experiences of patients and families, healthcare providers, and protective services, as well as the policies that inform the delivery of mental health services. It is expected that the combining of research methods will create aspects of triangulation where qualitative and quantitative methods may be both complementary and/or conflictual. In essence, it is our hope that the triangulation within mixed methods will help to capture the richness and complexity of human behavior (mental health stigma) by studying it from more than one standpoint. The specific statistical analyses used will be determined based on the measurements and interventions chosen, taking into account feedback from participants in the first phases of the project. In the needs assessment phase of the project (phase 1), quantitative analysis will be primarily descriptive. In the intervention phase of the project (phase 3), we will be examining the effectiveness of interventions across groups and at multiple timepoints on various outcome measures. The type of inferential statistics that will be used to analyze the data will be based on the selected intervention, outcome measures, number of groups, and other relevant variables (e.g., demographic variables). We anticipate methods such as mixed model analysis of variance or multivariate analysis of variance will best fit the data gathered.

The ORBIT model will be used as a conceptual framework to support the cross-disciplinary approaches used by the research team to explore: clinical and public health policy needs (phases 1 & 2); multiple intervention strategies (phase 3); targeted changes in health behaviors related to mental health stigma; and the potential of behavioral treatments to affect health outcomes (phases 4 & 5; Mensah & Czajkowski, 2018). Critical features of the ORBIT model include a flexible and iterative process, pre-specified clinically significant milestones for forward movement, and a return to an earlier phase for refinement in the event of suboptimal results. In essence, the ORBIT model will support the research team's exploration of rigorous methods to test the efficacy of multi-level stigma interventions, including the evaluation of, and reciprocal relationships between, interventions and across levels of analysis (Rao et al., 2019).

Summary and Conclusions

In summary, the ubiquitous nature of mental illness stigma in healthcare has deleterious outcomes for patients and families attempting to access treatment and services. This study will fill a gap in the stigma research using rigorous methodological and conceptual approaches to multi-level stigma interventions, stigma policy, and stakeholder partnerships. Unique to this study will be the utilization of a patient research partner, alongside cross-disciplinary HCPs and patient groups, to explore mental illness stigma that is embedded in the healthcare system. Ultimately, the goal of the research is to create sustainable interventions for the mitigation of mental illness stigma in healthcare settings and to enhance policies, patient-provider interactions, and health outcomes related to access and quality of care.

Declarations

Conflict of Interest Author ECC was the named fellow on a grant from Janssen Inc., Canada, with the funds being used to contribute to support for research assistants involved in participant recruitment and database maintenance.

Ethics Approval This study has been approved by the University of Calgary's Conjoint Health Research Ethics Board (REB20-1639).

Consent to Participate and Consent for Publication N/A.

Competing Interests Authors ACHS and SK are guest editors for the International Journal of Mental Health and Addiction, Special Issue on Stigma, Mental Illness, and Substance Use. Author SK is an associate editor for the International Journal of Mental Health and Addiction. All other authors declare no competing interests.

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