Measuring Structural Stigma in Health-Care Settings from the Perspective of Service Users

Heather Stuart, PhD, FRSC, C.M.
Queen's University, Kingston, Ontario

Abstract

This report is one component of a larger Mental Health Commission of Canada initiative examining structural stigma in health-care settings. It reviews measurement approaches that could be used to monitor the extent to which health-care settings offer caring cultures, person-centred care, or recovery-oriented care. These dimensions were identified as important to service users in an in-depth qualitative study of structural stigma.

Health Canada   Santé Canada

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Introduction

In 2019, the Mental Health Commission of Canada (MHCC) undertook a multi-year project to examine structural stigma in health care settings. Structural stigma was conceptualized as the accumulated activities of social organizations and other social structures that deliberately or inadvertently create and maintain social or health inequalities. The aim was to better understand how health-care structures create and maintain stigma toward people with mental health and substance use disorders.

This report builds on one component of this larger project: a qualitative study of 20 individuals who had experienced structural stigma in health-care settings.[1] The dimensions of care that the study found stigmatizing are used as a jumping-off point for locating potential tools that health-care organizations could use to identify and monitor progress on reducing structural stigma in service users' areas of concern. Monitoring these structural stigma experiences is one aspect of a more comprehensive quality improvement framework that would include multiple sources of data and a range of data collection approaches (see Livingston, 2021).[2]

Study recap

The original qualitative study[3] set out to

- gain a better understanding of the potential role health-care organizational practices have in creating and maintaining structural stigma
- identify the constructs that could inform the development of a generic framework to depict the nature of structural stigma in health-care settings
- inform the development of an audit tool that could be used to assess and monitor the occurrence of structural stigma in health-care settings.

Qualitative data were collected from 20 individuals (representing a broad cross-section of people in Canada), who had experienced structural stigma due to a mental health or substance use disorder, including youth, Indigenous peoples, mental health advocates, clinical care workers, and peer support workers.

Participants had no difficulty identifying structural stigma within health-care settings and related a broad range of experiences with a similarly broad range of outcomes. Their stories painted a grim picture of the detrimental effects of structural stigma. Among them were significant psychosocial and health impacts, including increased morbidity and premature mortality.

Qualities of an ideal client-centred measurement instrument
When focus group participants were asked to consider metric tools to monitor aspects of structural stigma in health-care settings, they emphasized the importance of having input from people with lived experience in their development and testing.[4] They recognized that most tools had been developed either without their input or with token input. They also identified the need to measure outcomes that are relevant and meaningful to people with lived experience and their family members, rather than exclusively focus on employee perceptions or processes of care, as many audit instruments do.

In this context, characteristics of an ideal measurement tool would include being

- **grounded** — measures should be developed and tested based on meaningful input from clients and family members, so that scale items are important to service users
- **client directed** — service users and family members, rather than health professionals, should complete the measures so that care experiences are assessed from the perspective of the person with a mental health or substance use disorder
- **holistic** — measures should reflect the client's experience of their overall care experience, rather than individual care processes
- **person-centred** — measures should address the extent to which the care environment meets clients' needs and is empowering, affirming, and recovery oriented
- **generalizable** — measures should apply to a broad range of health and mental health settings to ensure that the physical, social, and mental health needs of clients are met in supportive environments across the full spectrum of the health-care system — ranging from primary care practices, to emergency rooms, to tertiary mental health services
- **psychometrically sound** — tools must have undergone rigorous psychometric testing to ensure their reliability, validity, and sensitivity to change.

Domains of interest

Three measurement domains were identified from the qualitative data provided by focus group participants: (1) the overall culture of care, (2) the extent to which services were person oriented and provided person-centred care, and (3) the extent to which recovery principles were reflected in the care provided.

The culture of care

In this context, the culture of care reflected the entire health-care experience: the visible facade of physical spaces, care processes, and the associated behaviours of staff, including their shared ways of thinking and patterns of communication. These were the taken-for-granted aspects of organizational life — the "way things are done"— including the most visible manifestations of the culture (e.g., physical layout of services, observable patterns of behaviour), the beliefs and values of staff (e.g., respect for patient autonomy and dignity), and the shared assumptions about such things as the nature of the caring role, respect for the knowledge and perspectives of patients and their relatives, assumptions about power differentials, etc.[5] Focus group participants described the overall culture of care as being broken. They described instances where staff behaviours and care processes were experienced as demeaning, dehumanizing, robotic, "out of whack," punitive, traumatic, and prison-like.[6]

In the last two decades there has been increasing interest in cultures of care, both as a way to explain health-care failings (such as medication errors or safety concerns), and as a way to implement performance improvements. Cultures of care have been described as too often being task based when they should be person based. The priority in this area is to establish cultures that will allow health-care organizations to provide high-quality care.[7] The management of organizational cultures is increasingly considered to be a key aspect of health-system reform.[8]

This reshaping of health-care cultures to improve outcomes has generated a need for measurement instruments that can assess organizational cultures in various health-care contexts. One important challenge has been the lack of consensus on operational definitions (over 300 exist).[9] For the most part, however, the term "caring cultures" has been used to reflect health-care settings in which high-quality health care can flourish based on dimensions such as effective management and leadership, staff engagement and empowerment, teamwork and collaboration, and patient centredness.[10] Within this context, it is not surprising that diverse measurement approaches have also emerged — again, with little consensus on the optimal procedure. These have ranged from structured questionnaires to unstructured, qualitative assessments, though the predominant approach has been self-reported questionnaires. Rarely, have these approaches undergone any extensive testing, validation, or structural confirmation.[11]

The bulk of tools designed to measure health-care cultures has been directed to the self-reports of employees (rather than clients) in relation to organizational structures and practices. For example, a 2004 review[12] identified five major dimensions that were measured via staff self-reports, though not consistently across every scale. These included leadership, group behaviours and relationships, communications, quality of worklife, and health-care worker outcomes. In 2009, Scott and colleagues[13] conducted a detailed evaluation of 13 instruments, each of which examined employee perceptions. The authors deemed all the instruments to have limitations in terms of their scope, ease of administration, and scientific properties. Another study by Jung and colleagues[14] reviewed instruments to measure organizational culture. While the review identified 70 instruments with some psychometric data available for 48 of them, none had robust reliability and validity data, and none took the perspective of the client or family member.

One notable exception is the Schwartz Center Compassionate Care Scale,[15] which was designed to measure the extent to which those who received care experienced it as "compassionate." In this context, compassionate care was defined as a process that involved recognition, understanding, emotional resonance, and empathetic concern. This measure was developed for use in hospital settings for patients receiving physical health care. It followed a rigorous process that was heavily grounded in the experiences of service users. After several rounds of psychometric testing (including exploratory and confirmatory factor analysis[*]), 12 items were retained (see Table 1). The items were scored on a scale of 1 to 10, with 1 reflecting *not at all successful* and 10, *very successful*. While the focus was assessing the doctor-patient relationship, rather than the entire health-care experience, this scale is one example where items could be made more generic (to apply to any health-care setting) and rendered more appropriate for people with mental health and substance use disorders across the range of structural stigma experiences they are likely to encounter. It also provides a road-map for an exemplary development process.

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[*] These are statistical analyses that are used to uncover and then confirm the dimensional structure of the data. Ideally scales should have all questions (items) correlating highly on a single factor, making them uni-dimensional.

Table 1. The Schwartz Center Compassionate Care Scale [16]

Compassionate care involves relating well to patients and families and recognizing and addressing their concerns or distress. Health professionals' compassionate care is essential to high quality medical care. Please answer the following questions with regard to the doctor who was in charge of your care during your recent hospitalization.

1   Express sensitivity, caring and compassion for your situation?

2   Strive to understand your emotional needs?

3   Consider the effect of your illness on you, your family, and the people most important to you?

4   Listen attentively to you?

5   Convey information to you in a way that was understandable?

6   Gain your trust?

7   Always involve you in decisions about your treatment?

8   Comfortably discuss sensitive, emotional or psychological issues?

9   Treat you as a person not just a disease?

10   Show respect for you, your family and those important to you?

11   Communicate test results in a timely and sensitive manner?

12   Spend enough time with you?

From "Can Compassionate Healthcare be Measured? The Schwartz Centre Compassionate Care Scale," by B. A. Lown, S. J. Muncer, and R. Chadwick, 2015, *Patient Education and Counseling, 98*(8), p. 1008 (https://doi.org/10.1016/j.pec.2015.03.019). Copyright 2015 by The Schwartz Centre for Compassionate Healthcare.

Person-centred care

Person-centred care is one component of a caring culture that focuses on creating a positive relationship between health-care staff and service users. But it does not capture the overall feel of current health-care environments and processes of care. Our focus group participants described staff relationships that were cold, uncommunicative, demeaning, and sterile. Staff were seen as relating to patients according to diagnostic labels rather than as people. Relationships were experienced as disempowering, patronizing, and stigmatizing.[17]

As with caring cultures, there is no universally agreed upon operational definition of person-centred care. However, there is broad recognition that a person-centred health system is one that helps people make informed decisions about their care and supports them in managing their own health and health care. Achieving these aims requires health-care services to work in partnership with clients to deliver care that is responsive to their needs, individual abilities, preferences, lifestyles, and personal goals.[18]

In 2014, the Health Foundation in the U.K. sponsored an extensive review of measurement tools that could be used to assess person-centred care.[19] Researchers found that the largest proportion (two-thirds) of studies on person-centred care were conducted in hospital contexts using instruments developed by academic researchers who had worked with health service teams (rather than clients) as part of a quality improvement initiative. Just over half of the 503 studies reviewed measured person-

centred care as a broad holistic concept. The remainder measured one or more specific processes of care (e.g., choice, compassion, integration, privacy, respect, rights, trust, advocating, assessing needs, engagement, goal planning, listening, participating, self-care support, or transitions). Eighteen of the holistic measures were directed to service users or family members.

Yet, none of the holistic measures cited would be appropriate for measuring person-centred care across a range of health-care settings. Most were specific to a target group of patients (e.g., those in a nursing home or receiving endometriosis care) and focused on specific processes of care (e.g., being given adequate information or having coordinated care). While no instrument stands out as entirely appropriate for our needs, Table 2 illustrates the Dimensions of Person-Centred Care instrument to be used in frail elderly populations.[20] For our purposes, it provides some insight into important dimensions of person-centred care and how these might be operationalized.

Table 2. Dimensions of Person-Centred Care Instrument [21]

Dimension of Care	Item
Personalization	o The doctors understood fully what I was going through. o I was made to feel at home very quickly. o By the time I left I felt the staff were my friends not just staff members. o The service was designed more for the convenience of staff than for patients.
Empowerment	o I felt as though the staff and I were partners in the whole process of my care. o Nobody asked me what I thought about my treatment. o The nurses didn't seem to listen to what I said. o The nurses always listened attentively to what I said.
Information	o At times I felt the doctors did not want me to ask questions. o I wish the doctor had given me a fuller explanation of my condition. o I was sometimes left waiting, not knowing what was going on. o The doctors should have given me more information about my treatment.
Approachability/ Availability	o I was often unable to locate nurses for assistance. o Sometimes I felt a bit abandoned by the staff while in hospital. o I would have liked to speak with the nurses more often. o I would have like to speak to the doctors more often.
Respectfulness	o Sometimes the staff stood near me talking about me as if I wasn't there. o The staff were very concerned about my privacy.
Miscellaneous	o I had plenty of choice in the food they provided. o While in hospital I was waited on hand and foot.

From "Measuring Person-Centred Care in a Sub-acute Health Care Setting," by S. Davis, S. Byers, and F. Walsh, 2008, *Australian Health Review, 32*(3), p. 500 (https://doi.org/10.1071/ah080496). Copyright The Author(s) 2008 Open Access.

Recovery-oriented care
The lack of a recovery perspective was another aspect of the broader health-care culture identified by our focus group participants as stigmatizing. Treatments were considered to be too narrowly focused on symptom remission, ignoring the broader determinants of health such as poverty, homelessness, and unemployment. In the substance use field, a lack of harm reduction opportunities and an emphasis on total abstinence were found. Participants also described a clear power differential between staff and

those receiving care. Staff who were recovery oriented were easily recognizable, as they spent more time outside of the "fishbowl" and were more communicative with clients about the processes and outcomes of care. They were able to instil hope.[22]

Outside of the mental health system, person-centred care has gained currency as a model that is influencing policy and practice. Within the mental health system, a parallel development has been the emergence of the recovery paradigm. Both models value people, respect them as individuals, and organize care to meet their needs. Both models require health-care professionals to appreciate the totality of the individual, practise person-centred care, and engage clients as partners in the health-care process.[23] However, recovery-oriented systems go beyond this to redefine the very nature of what it means to live in recovery with a mental health or substance use disorder. Recovery is conceptualized as a personal journey toward meaning, a fulfilling life, and a positive sense of identity and empowerment, regardless of the presence of symptoms or use of medications.[24] In its most general sense, a recovery-oriented service refers to the extent to which it facilitates personal recovery for clients.[25]

The growing policy imperative to support personal recovery by providing recovery-oriented services has developed in advance of clear evidence of what makes a service recovery oriented.[26] While guidelines for providing recovery-oriented care are beginning to emerge (e.g., MHCC, 2015),[27] there is still no consensus on the dimensions that could be used to identify a recovery focus in mental health service delivery or elsewhere in the health system. A number of recovery instruments have been developed, though none meet even minimal standards for psychometric assessment. For example, in a systematic review of personal recovery measures, Shanks and colleagues[28] identified 13 recovery measures, noting that none had been subjected to "a *substantial and robust* psychometric evaluation" (p. 977, emphasis added). In addition, all of the measures in the study addressed the client's recovery journey rather than the elements of the service delivery environment that promoted recovery. Burgess and colleagues[29] reviewed instruments that addressed the domains of recovery relevant to the orientation of services. Of the eight instruments identified as service-level measures, three were not considered feasible for routine monitoring of clinical care, as they contained more than 100 items. Only two were developed with consumer input, and both of these lacked psychometric testing and had not been published in the scientific literature.

Williams and colleagues[30] deliberately set out to find measures that assessed the contribution of mental health services to personal recovery, with a version that was rated by service users, and for which at least one psychometric paper was available. Thirteen measures were identified, yet only six met the eligibility criteria. Excluded measures either had no published psychometric data, assessed recovery competencies of staff, needed trained assessors, did not provide quantitative data, or were unpublished and not available. The six measures considered eligible for review were based on different conceptualizations of recovery and ranged in length from seven to 50 items. None had undergone complete psychometric assessment. Only one — the Recovery Self-Assessment (RSA) measure — had adequate internal consistency (with alphas ranging from .70 to .90), but key aspects of validity (construct, criterion, test/re-test, and responsiveness) had not been evaluated. Table 3 provides examples of the items on this measure, which can be oriented to be given to program providers, staff, clients, or family members. Items are rated on a six-point agreement scale, ranging from *strongly disagree* to *strongly agree* (with *not applicable* included). A full psychometric analysis of the RSA for

hospital providers found good-to-excellent internal consistency and reasonable convergent validity.[*] It also distinguished between providers in a state hospital and those in community support programs.[31]

Table 3: Examples of Items from the Recovery Self-Assessment Measure [32]

Dimension of Care	Item
Life Goals	o Staff actively assist people in recovery with the development of career and life goals that go beyond symptom management and stabilization. o Staff routinely assist individuals in the pursuit of educational and/or employment goals.
Involvement	o People in recovery work alongside agency staff on the development and provision of new programs and services. o People in recovery are regular members of agency advisory boards and management meetings.
Diversity of Treatment Options	o Criteria for exiting or completing the agency are clearly defined and discussed with participants upon entry to the agency. o This agency activity attempts to link people in recovery with other persons in recovery who can serve as role models or mentors by making referrals to self-help, peer support, or consumer advocacy groups or programs.
Choice	o People in recovery have access to all their treatment records. o Agency staff do not use threats, bribes, or other forms of coercion to influence a person's behaviour or choices.
Individually-Tailored Services	o This agency offers specific services and programs for individuals with different cultures, life experiences, interests, and needs. o All staff at this agency regularly attend trainings on cultural competency.

From "From Rhetoric to Routine: Assessing Perceptions of Recovery-Oriented Practices in a State Mental Health and Addiction System," by M. O'Connell, J. Tondora, G. Croog, A. Evans, and L. Davidson, 2005, *Psychiatric Rehabilitation Journal, 28*(4), p. 381 (https://doi.org/10.2975/28.2005.378.386). Copyright 2005 by the American Psychological Association.

Recovery-oriented measures are most appropriate for mental health services. But because structural stigma occurs in all areas of the health-care system, they are not useful for measuring structural stigma where the many, most egregious examples occur. For example, none specifically address the problem of diagnostic overshadowing,[†,33] or coercive care experienced in emergency rooms. Thus, to be useful, recovery measures will need to be augmented by measures that assess broader climates of care.

Summary

To date, most measurement tools have been developed by researchers and for researchers, with little input from people with lived experience and their families.[34] Measures that focus on clients' own

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[*] Convergent validity occurs when the new measure correlates well with an existing measure that is assessing a similar construct.

[†] That is, the process by which a person with a mental health or substance use disorder receives inadequate or delayed treatment for a physical condition because it is misattributed to the underlying mental health or substance use disorder.

perceptions of their care experience are rare. When available, they typically focus on a single provider-patient relationship (e.g., doctor-patient), a single location in the health system (e.g., a family practice clinic), or a specific clientele (e.g., cancer patients or elderly people in care homes). Evidence in support of validity and reliability is largely lacking. This review did not uncover a single example that met all the hoped-for criteria of an ideal psychometrically tested measurement instrument described at the outset of this report.

What is needed now is a new, standardized, and psychometrically tested instrument (or set of instruments) that quantifies the personal experiences of people with mental health and substance use disorders who have encountered structural stigma in a variety of health-care settings.

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