Measuring Behavioral Health Stigma as a Complex Adaptive System

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***Abstract*- Social labeling of people with behavioral health disorders falls under the umbrella of "stigma". Behavioral health stigma, one of the leading causes of population health disparities and inequalities in the world, has been widely explored and shown to play a leading role in limiting the access to behavioral healthcare. This article (a) frames behavioral health stigma as a complex adaptive system, (b) demonstrates the content validity of the Stigma Index – General Population (SI - GP) survey at measuring behavioral health stigma among the general population, (c) examines the application of the SI survey in policy decision-making processes, and (d) identifies the lack of a standard scalable analytics approach to monitoring and measuring stigma consistently over time. The article concludes with the discussion of the need for developing the Stigma Index, a shared measurement system that can provide data-driven insights on stigma and assist decision-makers in improving both the health of populations and the patient experience of care.**

Keywords—Stigma Index; Complex Adaptive Systems; stigma, behavioral health; behavioral health disorders; measuring scales; Consumer Sentiment Index, policy decision-making.

Introduction

Behavioral health is "a state of mental/emotional being and/or choices and actions that affect wellness" ("Substance Abuse and Mental Health Publications| SAMHSA Store", 2016). It is how people feel about themselves, others and their lives. It's about their resilience to meet and handle the demands of life with appropriate coping skills. Behavioral health is increasingly becoming a worldwide public health matter. The well being of societies continues to be a major challenge and an essential component of the overall global development.

About half of Americans will meet the criteria for a behavioral health disorder sometime in their life with the first onset usually occurring during childhood or adolescence years (Kessler et al., 2005). In fact, one in five adults in the United States experience a behavioral health disorder in any given year ("NAMI: National Alliance on Mental Illness", 2016). This is equivalent to approximately 43.8 million Americans of which 10 million live with a serious behavioral health condition such as schizophrenia, major depression or bipolar disorder. Statistics about the prevalence of behavioral health disorders by diagnosis suggest that 18.1 percent of Americans living with a behavioral health disorder suffer from anxiety disorders (e.g. posttraumatic stress disorder, obsessive-compulsive disorder and specific phobias), 6.9 percent

suffer from major depression, 2.6 percent suffer from bipolar disorder, and 1 percent of them suffer from schizophrenia ("NAMI: National Alliance on Mental Illness", 2016).

Behavioral health disorders can affect everyone regardless of their culture, race, ethnicity, gender or sexual orientation. According to the National Alliance on Mental Illness, American Indians/Alaska native adults (AI/AN) is the cultural/ethnic group the highest percentage of behavioral health disorders (28.3 percent); followed by White adults (19.3 percent), Black adults (18.6 percent) and Hispanic adults (16.3 percent). In 2014, more than half of the 43.8 million American adults (aged 18 and older) who experienced a behavioral health disorder in year 2013 did not receive any behavioral healthcare. White and AI/AN adults use healthcare services twice as often as Black and Hispanic adults and three times as much as Asian adults ("NAMI: National Alliance on Mental Illness", 2016).

Behavioral health illnesses include serious psychological distress, suicide, and mental disorders. They constitute thirteen percent of the global burden of disease and are projected to be fifteen percent by the year 2020 (Raymont, 2001). One suicide occurs every thirteen minutes in the United States, of which more than ninety percent actually suffer from at least one treatable or temporary behavioral health disorder ("American Association of Suicidology", 2016). Adults aged between 18 to 25 years old constitute the highest percentage of people who have serious thoughts about committing suicide (7.4 percent) ("CDC Works 24/7", 2016). While females are more likely than males to have suicidal thoughts, and males constitute 77.9 percent or the total number of adults who commit suicide ("American Association of Suicidology", 2016; Palmer, Pankratz, & Bostwick, 2005; Raymont, 2001). Suicide costs an estimated $51 billion to the healthcare system ("CDC Works 24/7", 2016).

The U.S. Surgeon General and the World Health Organization state that stigma is one of the key barriers to successful treatment engagement, including seeking and sustaining participation in services, employment opportunities and access to social support activities (Corrigan, 2004; Corrigan et al., 2001; National Institute of Mental Health, 1999; World Health Organization, 2000). Many do not seek behavioral healthcare because they are afraid to be socially disgraced or stigmatized based on their conditions, and internalize stigma as shame or guilt (Kessler, Mickelson, & Williams, 1999; Regier et al., 1993). About seventy percent of individuals who have behavioral health disorders choose not to seek behavioral health treatments (Regier et al., 1993; United States Department of Health and Human Services, 1999). Research shows that a large number of them avoid behavioral health service treatments in fear of being labeled by the general public ("American Association of Suicidology", 2016; Corrigan, 2004; "World Health Organization", 2001). They internalize stigma as shame or guilt because of their fear to be socially disgraced or stigmatized (Kessler, Mickelson, & Williams Regier et al., 1993; United States Department of Health and Human Services, 1999). Of those who actually seek treatment, a large portion end up dropping their treatments as means to avoid being labeled by the general public ("CDC Works 24/7", 2016; Corrigan, 2004; World Health Organization, 2001). Stigma is therefore a clinical risk factor that is likely to delay consumers' treatment seeking behaviors that would aggravate their behavioral health symptoms and fuel the vital cycle of stigma.

The usage of the word stigma began with the Greek practice of branding slaves who were caught while attempting to escape (Funk, 1950). The brand was the letter F, for fugitive and the word for such a mark was stigma. Since then, the meaning of stigma developed to include any sign for apparent or inferred condition(s) of divergence from social norms. Jones et al stated, "the bearer of a 'mark' … defines him or her as deviant, flawed, limited, spoiled, or generally undesirable" (Jones, 1984). Currently, in the context of mental health, the term stigma refers to several different aspects of people's attitudes and behaviors towards people with mental health problems. Most explicitly, it is defined by Goffman as "the situation of the individual who is disqualified from full social acceptance" and as an "attribute that is deeply discrediting" (Goffman, 1963). Goffman describes stigma as a social process that can be experienced or anticipated and that is reflected by the exclusion, rejection, and blame or devaluation of a person or group. Stigma occurs when the power of societies labels a person as different or deviant based on what is considered to be the closest to "norm". Thus, for someone to be stigmatized, he or she must have a physical character and/or behavioral attitude perceived or anticipated by society as an undesirable quality, deviant from the social norm.

People who have behavioral health disorders are often victims of human right violations, stigma and discrimination. Stigmatizing attitudes can vary among individuals, families, ethnicities, cultures, and across countries and communities (Abdullah & Brown, 2011). One reason for the inconsistency of the stigmatization process across societies is the "cultural divide" between communities of different social, cultural and economic structures. These different backgrounds can result in different beliefs regarding the origins and nature of behavioral health disorders and lead to differences in the attitudes and behaviors directed towards people with behavioral health disorders

Stigma as a Complex Adaptive System

It is important to identify both the local and global manifestations of stigma when quantifying it. STRIVE is an example of a research consortium that aims at investigating the social norms driving the HIV/AIDS epidemic (Stangl, Brady & Fritz, 2012). While this research mainly aims at exploring stigma towards HIV/AIDS, it highlights on the importance of measuring stigma in three different populations: the general population, healthcare workers and people living with a concealable stigmatized identity.

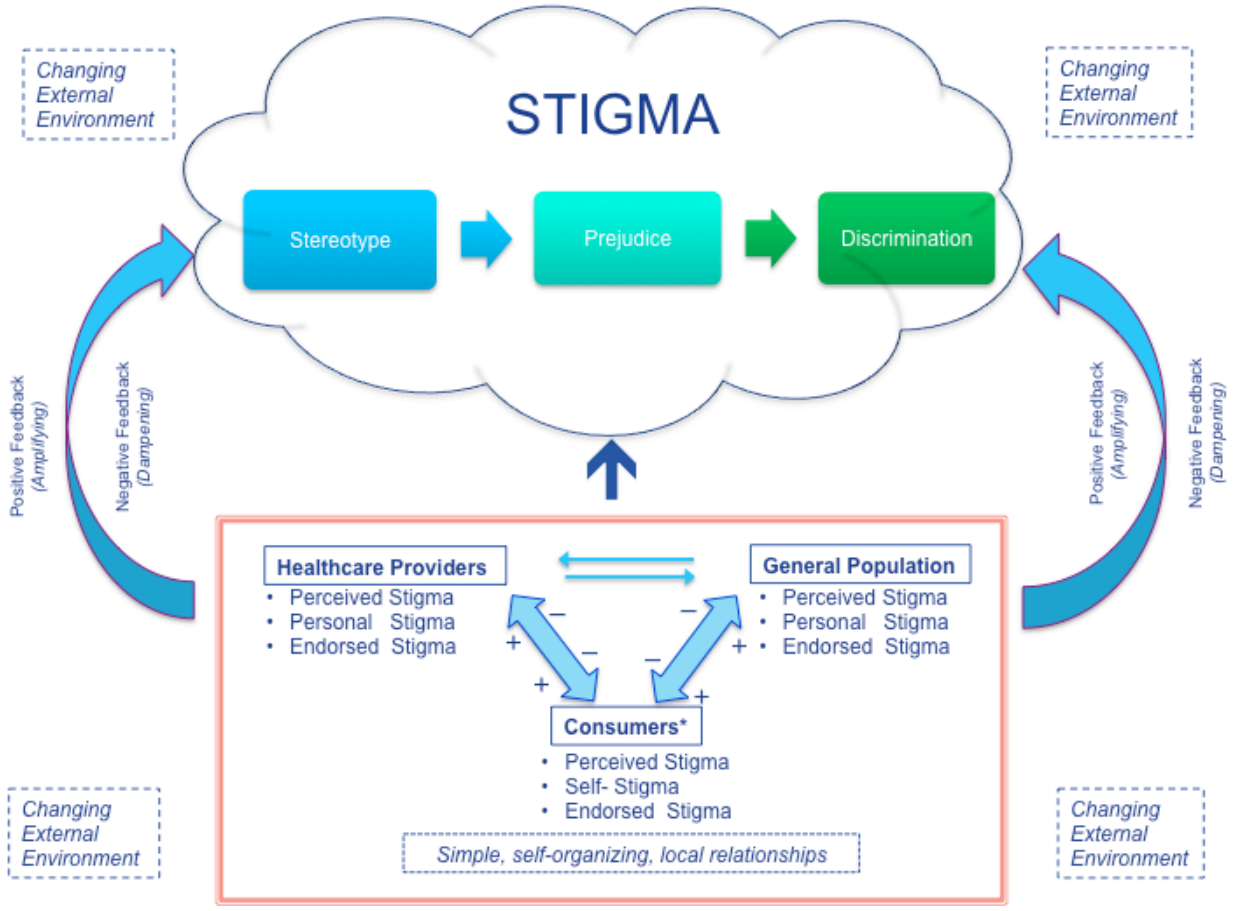

Fig. 1 Stigma as a Complex Adaptive System framework

Behavioral health stigma is a three-step structural process that begins with the initiation of stereotypic views and ends with discrimination. Stereotypes are "fixed, over generalized beliefs about a particular group or class of people" (Brockington, Hall, Levings C., & Murphy, 1993). They can be learned and applied on individuals who have observable or behavioral characteristics that cue them as deviant from the mainstream "norm" (Brockington, Hall, Levings C., & Murphy, 1993; Corrigan, 2004; Holmes & River, 1998; Pryor, Reeder, Yeadon, & Hesson-McInnis, 2004). Prejudice, the second step of the stigmatization process, occurs when a person endorses stereotypic views. It is often accompanied by common responses such as a reflexive disgust (Corrigan et. al, 2001; Holmes & River, 1998; Sadow, Ryder & Webster, 2002). People's expectation from a social interaction is what defines the extent to which they are likely to have prejudicial attitudes (Van Brakel, 2006). Prejudice shapes behavioral responses and ultimately leads to the third aspect of stigma, discrimination. Discrimination can take the form of social distancing, social exclusion and/or policies that treat individuals with a concealable behavior unfairly (Corrigan et. al, 2001; Lebel, 2008). For instance, individuals who believe that being in contact with a stereotyped group of people would lower their social levels and make their identities less ideal are more likely to discriminate against that group (Van Brakel, 2006).

Behavioral health stigma is an outcome of perceived or inferred attributions that define stigmatizing reactions towards consumers such as anger and pity (Corrigan et. al, 2001). It is driven by the social decisions that individuals make when locating a new idea or situation on their mental attitude scale after having incorporated past experiences with present circumstances (Griffin, 2012; Sherif, 1963). People's attitudes change depending on whom they meet, whom they know and where they live. The stigmatization process is therefore an embedded Complex Adaptive System (CAS) within a changing external environment. It can be defined as the collection of diverse interconnected independent components that self-organize and evolve over time without the presence of a one central controller. Thus, looking at one agent or target group as the only central planner cannot explain stigma. Figure 1 frames behavioral health stigma in the context of a CAS and illustrates three independent population groups that play key roles in its emergence: healthcare providers, the general population and consumers. The individual agents interact and collectively form self-organizing, local micro social relationships that generate the non-linear and overall global pattern of stigma. For the purpose of this study, consumers are defined as individuals who have a behavioral health disorder.

Quantifying stigma is complex because it exists in a constantly changing social structure where no local centralized force is responsible for its emergence. Stigma is an example of a dynamic process and global behavior pattern that emerges from the collective interactions of individual components that interact and create local relationships at the simple level and have the ability to adapt to the environment where they belong. For example, the stigma level of a member in a community is impact to self-stigma internalized by consumers. Similarly, the stigma level among healthcare providers varies based on their different clinical experiences treating consumers. In addition, the stigma level exerted by healthcare providers and members of the general population would likely impact how likely consumers self-stigmatize themselves and choose not to disclose their behavioral health disorders in public and avoid seeking treatment.

Agents' interactions are based on a set of internalized rules that define their level of stigma. There are four main stigma dimensions: perceived, personal, endorsed, and self-stigma. Perceived stigma is a reflection of a person's perception of the public stigmatizing attitudes that are present towards a labeled group. This stigma dimension is found to correlate with health services seeking behavior (Cooper, Corrigan, & Watson, 2003; Eisenberg, Downs, Golberstein, & Zivin, 2009; Griffiths, Christensen, & Jorm, 2008; Kessler, Mickelson & Williams, 1999). It can be captured from the point of view of the one who stigmatizes and the stigmatized one. Perceived stigma represents the discrimination that consumers fear or perceive to be present in a community, which has a great effect on their willingness to seek treatments (Corrigan, 2004; Sirey et. al, 2001). For instance, a higher level of perceived public stigma was shown to be linked to a lower treatment adherence (Cooper, Corrigan, & Watson, 2003). Personal stigma is an individual's own discriminatory attitude towards consumers after having perceived the stigma present in public (Caltaux, 2003; Eisenberg, Downs, Golberstein, & Zivin, 2009). Endorsed stigma is an individual expressed agreement with stereotypic, prejudicial and discriminatory behavior towards the labeled group. Consumers's incorporation of public expressions of stigma into their own beliefs about themselves is known as self-stigma. It is "the product of internalization of shame, blame, hopefulness, guilt and fear of discrimination associated with a behavioral health disorder" (Corrigan, Watson, & Barr 2006; Sirey et. al, 2001). Large proportions of consumers who don't seek treatment internalize negative attitudes expressed by

the community and perceive themselves as less adequate and more inferior than others (Bathje & J. Pryor, 2011; Corrigan, 2004; Link & Phelan, 2001; Link, Cullen, Struening, Shrout, & Dohrenwend, 1989; Taylor & Dear, 1981). Measuring self-stigma can be used as a tool to predict the extent to which consumers internalize public stigma (Johns, 2010; Link, 1987).

While each agent is capable of individually responding to local social events, they self-organize themselves to collectively produce the stigma behavior. The non-linear continuous stigma emergence is the result of agents interacting such that a small change in the mental models of agents at the simple level is able to lead to a larger difference in the outcome of stigma at the global level. This impact can be the result of either a positive or a negative feedback. The only way to understand the global pattern and predict the overall quantity of stigma is to study the complexity of the stigma outcome from the simplicity of its agents interacting.

New Contribution to Measuring Stigma

Despite the presence of a large body of research that aim at studying behavioral health stigma, the behavioral healthcare field still lacks a unified standardized scale that can quantitatively measure stigma across different cultural and social contexts. The exhaustive number of scales and the variety of questions used to gauge the presence of public and consumer stigma makes the comparison of stigma level from one community to another a difficult task.

The aim of the current study is to create a measure of stigma that includes a minimal set of questions that measures behavioral health stigma as described above The motivation behind such work is to build the foundation for developing a computational simulation model that provides the behavioral healthcare field with a Stigma Index indicator able to quantify and monitor the change in stigma over time.

The closest example of such a research is the Consumer Sentiment Index (CSI) (“Surveys of Consumers”, 2016). While the CSI is a statistical measure of consumers' attitudes towards the overall economy in the United States, it is based on a survey that consists of only five main questions, conducted every month by the Survey Research Center at the University of Michigan. Public data collected is used to generate an aggregate of people's attitudes regarding the current and expected conditions of the economy in the United States. The succinct number of questions in the CSI survey makes it easy to administer and help with offsetting the response burden. The development of a similar survey to the CSI in terms of its limited number of questions that reflects the overall stigma present in a community would provide important data-driven insights to policy makers, healthcare facilities and community activists on ways to reduce stigma and improve the health of individuals in the United States.

Methods

Research carried out in this study was approved by the Institution Review Board (IRB) for research with human subjects at the University of North Carolina at Charlotte.

The Stigma Index - General Population (SI-GP) survey was first piloted at the University of North Carolina, Charlotte. It was available to participants electronically through the Department of Psychology Research Signup system. The later is run by the SONA system, an experiment management system for online research study participation for recruiting students in universities. Data collection was completely anonymous as there were no personal records about the participants. Prior to completing the survey, all participants were presented with a consent that describes the aim of the study. It was not until after they have read and provided their informed consent that they were allowed to proceed with completing the survey. Participants were college students enrolled in General Psychology courses and received research credits applied towards their program of study upon completing the survey.

The tested version of the SI-GP survey included demographic questions and a scale consisting of thirty three items that were developed using an adaptation of the Explanatory Model Interview Catalogue (EMIC) and the Participation domains of the International Classification of Functioning, Disability and Health (Weiss et.al, 1992; World Health Organization, 2001). The scale covered stigma components related to relationships (collegial, social, friendship, family, marriage, etc.), respect and employment opportunities.

A total of nine hundred and one participants were recruited to participate. Students who completed the survey in less than four minutes were removed from the study, leaving a total sample size of eight hundred and twenty four participants. Since the focus of the study is mainly to evaluate stigma from the perspective of non-consumers, participants who disclosed currently being treated for a behavioral health disorder were not included in the study, leaving the total sample size to six hundred and nineteen participants. On average, participants took approximately eight minutes to complete the survey ($M = 7.77$, $SD = 4.60$).

Table 1 presents the demographic characteristics of the total sample. The majority of participants were unmarried (95.3%), White Americans (66.4%), aged between 18 and 22 years old (88.9%) and completing their undergraduate studies (99.2%). The majority of them indicated “Christianity” to be their practicing religion (72.1%). Out of the total sample size, 30.2% indicated they have a family member who is a consumer, 37.9% indicated they have a friend who is a consumer and 15.2% indicated they have a colleague who is a consumer. While the majority of participants indicated they would not fear for their safety if they are near someone who has a behavioral health disorder (88.5%), 11.5% indicated they would.

All participants were asked personal, perceived and endorsed stigma items. They were asked to indicate their level of agreement with each of the items. The order of the items in the survey was randomized. A 5-point Likert scale was used ranging from 1 to 5 (1= Strongly agree, 2= Agree, 3= Neutral, 4= Disagree, 5= Strongly disagree). Personal stigma statements begin with “I …” followed by an example of discriminatory behavior. Statements measuring perceived stigma begin with "Most people …” or “In my community/family…” followed by an example of

discrimination. Statements measuring endorsed stigma consists of general stereotypic statements such as “Having a behavioral health disorder is a problem for a person to get married”. The scale consists of 11 items addressing “personal stigma”, 17 items addressing “perceived stigma” and 8 items addressing “endorsed stigma”.

Table 1
Participant demographic information.

	N = 619
Gender (%)	
Female	58.7
Male	40.9
Age (%)	
18-22	88.9
23-27	7.8
28-32	2.3
>32	1.1
Race (%)	
White	66.4
Black	19.9
Hispanic	4.7
Asian	3.2
Other	5.8
Education(%)	
Undergraduate	
Freshman	45.2
Sophomore	24.6
Junior	17.8
Senior	11.6
Graduate	
Graduate degree	0.2
Other	0.6
Religion (%)	
Christianity	72.1
Islam	1.3
Judaism	1.0
Agnosticism	5.5
Atheism	4.5
Hinduism	0.3
Prefer not to say	9.5
Other	5.8
Marriage Status (%)	
Unmarried	95.3
Married	2.1
Other	2.6
Have a family member with a behavioral health disorder (%)	
Yes	30.2
No	69.8
Have a friend with a behavioral health disorder (%)	
Yes	67.9
No	32.1
Fear of someone with a behavioral health disorder (%)	
Yes	11.5
No	88.5

Results

All item statistics are shown in Table 2. Prior to entering items into the factor analysis, all items were screened for appropriate item endorsement rates (items means) and variability (standard deviation). Six items were removed from the item pool because their means were lower than 2.2, but the rest of the items had moderate means (between 2.2 and 4 on the 5-point Likert response scale). In order to assess item discrimination for the retained items, their corrected item-correlations were computed. A total of five items showed to have a weak correlation with r_{IT} values below 0.2 and therefore were eliminated. One of the items that aimed at measuring stigma present at employment places was removed as 21.3% of participants indicated they were not employed at the time of completing the survey.

An exploratory factor analysis was conducted to evaluate the factor structure underlying the retained set of items, and to aid in selecting the items to be included in the final scale. Stopping rules were followed in conducting the analysis and interpreting the results. In order to allow for the factors to correlate, maximum likelihood extraction with an oblique rotation was used.

The initial extraction revealed five factors with an eigenvalue above 1.0, which indicates the presence of fewer than five factors. Given that four factors were required to account for at least 47% of the total item variance and the list of eigenvalues showed a clear "elbow" suggesting the possibility of the existence of three factors in this model, the degree of simple structure of two separate exploratory factor analyses specifying three and four factors were evaluated. Based on this analysis, the three-factor model was selected as the best fitting model. The four-factor model was rejected because multiple items had significant non-conceptual cross loadings. Within the three-factor model, one item was removed as it had a lower factor loading and another one was removed as it conceptually loaded on the wrong factor. This resulted in a model that had a minimum of four items loading on each of the three factors. Definitions of the stigma measures are summarized in Table 2. A total of twenty one items were retained: five items loaded on "personal stigma", eight items loaded on " perceived stigma" and eight items loaded on "endorsed stigma".

Table 2
Stigma measures and definitions.

Stigma Measures	Definition
Personal Stigma	Own personal discriminatory behavior towards consumers
Perceived Stigma	The perception of stigma towards consumers in the community
Endorsed Stigma	The endorsement of stereotypic statements towards consumers

Following the initial factor analysis and in order to create a final SI-GP scale that was relatively short but retained sufficient content validity, the three items within each factor that have the highest factor loadings were selected. The aim was to create a scale that consists of a minimal set yet sufficient total number of items required to reduce respondent fatigue. A total of nine items

were retained with each factor having three items. The nine items demonstrated acceptable discrimination with r_{IT} values of more than 0.3 (Nunnally & Bernstein, 1994). The internal consistency for the overall scale composed of the nine items was acceptable (David, 2003) with a Cronbach's alpha of 0.73. All exploratory factor analysis statistics of the retained items are shown in Table 3. The complete wording of the nine items scale is shown in the appendix.

Table 3
Exploratory factor analysis and item-total correlations for retained items (Cronbach's alpha = 0.73).

	Factors					
Items	Personal Stigma	Perceived Stigma	Endorsed Stigma	M	SD	r_{IT}
5	0.55			3.10	0.90	0.40
3	0.54			2.61	0.81	0.36
10	0.50			2.22	0.77	0.42
18		0.69		2.35	0.77	0.54
28		0.66		2.68	0.91	0.55
16		0.64		2.42	0.80	0.46
23			0.59	3.00	0.91	0.38
27			0.59	3.58	0.85	0.47
22			0.49	3.28	0.85	0.42

Discussion

In this study, the SI survey was shown to be reliable at measuring behavioral health stigma among student members of the general population. It can be used to understand the influence of stigma on consumers' seeking behavior and access to behavioral healthcare. The scale is feasible to administer due to its limited number of items. The nine items of the scale relates to employment, respect and family relationships issues that consumers face because of their disorders. One limitation of the current study should be considered. The target population mainly consisted of students completing their undergraduate degree. Thus, there is a need to validate the scale in other population samples such as among non-student members of the general population, consumers and healthcare providers. Despite this limitation, results from this study suggest that the SI survey can bring a global overall score to the prevalence of stigma if conducted across different settings.

At the healthcare system level, the SI survey can be used to evaluate the delivery of high healthcare value to consumers and improve elements in processes of health institutions. Analysis of healthcare providers' stigma scores on the SI survey has the potential to drive healthcare policy decision-making processes and ensure improved health outcomes over time within healthcare facilities. Almost seventy percent of all healthcare visits are reported to be related to psychosocial disorders (“SAMHSA”, 2016). One strategy implemented by healthcare facilities to improve quality and access to behavioral healthcare is integrating behavioral health into primary care settings (“Behavioral Health in Primary Care / SAMHSA-HRSA”, 2016; Ivbijaro & Funk, 2008). This change can lead healthcare facilities and behavioral health programs to shift their

focus on training healthcare providers to use non-discriminatory evidence-based practices when communicating and screening patients for behavioral health disorders. Some healthcare providers perceive people with behavioral health disorders as less deserving of care, annoying and manipulative with suicidal urges (Lewis & Appleby, 1988). Even health professionals with behavioral health conditions agree that negative discriminatory attitudes towards consumers exist in the medical profession (Fabrega, 1995). The SI survey can be used to evaluate the stigma level among healthcare providers and ensure that consumers obtain compassionate respectful care that encourages them to follow up with their treatments.

One of the consequences for the presence of stigma in healthcare facilities is clinical "misdiagnoses", a phenomenon that can occur when one's physical symptom is interpreted as a behavioral health problem while in reality it may be due to a physical health illness. Comorbidity between mental and physical disorders is very common. More than 68% of consumers have at least one physical condition and 29% of the people who have a physical disorder have a comorbid behavioral health condition (Goodwall, Druss & Walker, 2011). Cardiovascular disease, respiratory disease, diabetes, obesity, and cancer are some of the main causes of death for people with serious behavioral health disorders (Corrigan & Penn, 2015; Finkelstein, Lapshin, & Wasserman, 2008). Using the SI survey to analyze the impact of stigma reduction within clinical settings on the rate of comorbidity is essential for the development of appropriate policy decisions that aim at optimizing the performance of behavioral healthcare.

At the community level, data results obtained from administering the SI survey to consumers and non-consumers can be used as incentives to promote the development of effective anti-stigma and discrimination initiatives. Testing the survey across different communities can help identify target populations and design local community-specific interventions to monitor changes of stigma over time. Currently, there are a number of anti-discrimination laws that cover psychiatric disorders in the United States such as the "Americans with Disabilities Act" and federal law that prohibits housing discrimination based on disability ("HUD/U.S.", 2016). Nonetheless, stigma and discrimination still prevents consumers from living a normal civic life.

The issue of community lodging is one important example to consider when examining the acceptance of stigmatized individuals. This method of assessment was adopted during the early American civil rights movement when it was clear that the same lodging rooms that are said to be available to potential White tenants are said to be unavailable to potential Black tenants. Similarly, research indicates that property-owners are significantly less likely to rent their houses/apartments to someone who has a behavioral health disorder than to someone who does not (Page, 1996). Refusing to accommodate people with behavioral health disorders is one example of socially excluding them based on their conditions, even with the presence of regulations that are meant to protect their rights to live a normal civic life. Socially excluding consumers would nurture the vital cycle of stigma and result in aggravating their mental health symptoms. If consumers are instead accepted and treated fairly like any other member of the society, stigma could potentially decrease over time. The only way to capture such findings is to develop a Stigma Index that can monitor the changes of stigma over time, and aid with uncovering the extent to which the general public abides by federal laws and regulations that aim to reduce stigma.

Conclusion

Until today, there is an absence of a shared measurement system that uses data to drive upstream patient-centered interventions and policies to reduce stigma and affect the behavioral health of populations. The SI survey is a starting point for the development of such a behavioral health stigma assessment model that measures stigma as a CAS. The complexity of stigma relies in the ability of the system agents to adapt and change with the environment based on past experiences that are embedded within social structures. "Contact" is an example to consider regarding how stereotypic views adapt over time. The degree to which members of the general public are in close social contacts with consumers is an important factor that influences stigma.

Future research work includes administering the SI survey to a diverse population to ensure measuring stigma as a complex adaptive system that is based on interconnections among responsible agents for its emergence. Such a process would drive decision makers to identify gaps within systems, set policy frameworks for healthcare and community organizations, and ultimately develop efficient systems capable of making a reduction in stigma over time.

Appendix

A. The final Stigma Index scale with the retained nine items

Dimension	Item
Personal Stigma	I would recommend a friend or a family member who has a behavioral health disorder for a job working for someone I know (Item 3 of original scale)
	I wouldn't mind renting a room in my home to someone who has a behavioral health disorder (Item 5 of original scale)
	I wouldn't mind working on the same job with someone who has a behavioral health disorder (Item 10 of original scale)
Perceived Stigma	In my community, a person who has a behavioral health disorder is treated with respect (Item 16 of original scale)
	Most people in my community would accept a friendship relationship with someone who has a behavioral health disorder (Item 18 of original scale)
	People in my community would think less of a person if he/she has a behavioral health disorder (Item 28 of original scale)
Endorsed Stigma	A behavioral health disorder causes problems in the family (Item 22 of original scale)
	Having a behavioral health disorder is a problem for a person to get married (Item 23 of original scale)
	Having a behavioral healthcare disorder can cause problems in an on going-marriage (Item 27 of original scale)

B. The tested version of the Stigma Index scale

Dimension	Item
Personal Stigma	I would introduce a friend or a family member who has a behavioral health disorder to a young man/woman I know
	I would recommend a friend or a family member who has a behavioral health disorder as a caretaker of the children of someone I know
	I would recommend a friend or a family member who has a behavioral health disorder for a job working for someone I know
	I would avoid moving to a new home if I will have a neighbor who has a behavioral health disorder
	I wouldn't mind renting a room in my home to someone who has a behavioral health disorder
	I would feel comfortable being seen in public with a person who is known to have a behavioral health disorder
	I would be willing to visit someone who has a behavioral health disorder
	I wouldn't be willing to invite a person who has a behavioral health disorder to my house
	I would accept as a friend someone who has a behavioral health disorder
	I wouldn't mind working on the same job with someone who has a behavioral health disorder
Perceived Stigma	People in my community would invite someone who has a behavioral health disorder to their houses
	People in my community would avoid building a friendship with someone who has a behavioral health disorder
	People in my community would allow having someone who has a behavioral health disorder be a caretaker of their children
	People in my community would engage in a social activity with a person who has a behavioral health disorder
	In my family, a person who has a behavioral health disorder would be treated with respect
	In my community, a person who has a behavioral health disorder is treated with respect
	In my community, healthcare providers treat a person who has a behavioral health disorder with respect
	Most people in my community would accept a friendship with someone who has a behavioral health disorder
	The place of my employment would be open to employing someone who has a behavioral health disorder
	People in my community would think less of a person if he/she has a behavioral health disorder
	In my community, having a behavioral health disorder is associated with shame and embarrassment
	In my community, a family would choose not to disclose to friends and co-workers if one of its members had a behavioral health disorder
	People in my community consider someone who has a behavioral health disorder as dangerous
	People in my community would feel sorry for a person who has a behavioral health disorder
Endorsed Stigma	Someone who has a behavioral health disorder is more likely to harm others than someone who does not have a behavioral health disorder
	The opinion of someone who has a behavioral health disorder should not count in family discussions
	A behavioral health disorder causes problems in the family
	Having a behavioral health disorder is a problem for a person to get married
	A family member of a person who has a behavioral health disorder has difficulty getting married
	A friend of a person who has a behavioral health disorder has difficulty getting married
	A person with a behavioral health disorder has difficulty to get hired for a job
	Having a behavioral health disorder can cause problems in an on-going marriage
	It is easy to tell if a person has a behavioral health disorder

C. The Stigma Index survey

Information Sheet

Evaluating Stigma towards Behavioral Health

You are being asked to participate in an evaluation of stigma towards behavioral health because your opinion matters.

Farah Tokmic, a doctoral student at UNC Charlotte, will be conducting the study. In this study, you will be asked to answer survey questions, which would take on average 5-10 minutes to complete. There are no risks for you in this study and your participation in this study is voluntary. There will be no cost to you. Although you may not receive direct benefit of this study, your participation is key to improve behavioral healthcare access. There will not be any identifiers collected. The survey is anonymous and the data collected will be securely stored and accessible only to the researchers administering the study. Findings in this study will not identify individual participants and will serve to better measure stigma towards behavioral health. If you have any questions or concerns related to this study please contact the principle investigator, Farah Tokmic, Ph.D Student at 704- 446-7508 or you may contact the project consultant Oleg Tcheremissine, M.D at 704-446-7504 or the project advisor Mirsad Hadzikadic, Ph.D at 704-687-8643.

I have read the above information. I understand what I will be asked to do. I agree to be in this study and understand that the completion of the survey constitutes my consent to participate in the project. I may keep a copy of this information sheet.

In this survey:

(1) A **behavioral health disorder** is a **mental health disorder** such as **anxiety**, **depression**, **bipolar** and **schizophrenia** disorders, but **not alcohol or substance abuse**.

(2) A **healthcare provider** can be **any** of the following: **primary care physician**, **psychiatrist**, **psychologist**, **nurse practitioner**, **registered nurse**, **counselor**, **social worker**, and all **students** in those disciplines.

Part 1: Please indicate how much you agree with each of the following statements:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I would introduce a friend or a family member who has a behavioral health disorder to a young man/woman I know	☐	☐	☐	☐	☐
I would recommend a friend or a family member who has a behavioral health disorder as a caretaker of the children of someone I know.	☐	☐	☐	☐	☐
I would recommend a friend or a family member who has a behavioral health disorder for a job working for someone I know	☐	☐	☐	☐	☐
I would avoid moving to a new home if I know I will have a neighbor who has a behavioral health disorder	☐	☐	☐	☐	☐
I wouldn't mind renting a room in my home to someone who has a behavioral health disorder	☐	☐	☐	☐	☐
I would feel comfortable being seen in public with a person who is known to have a behavioral health disorder	☐	☐	☐	☐	☐
I would be willing to visit someone who has a behavioral health disorder	☐	☐	☐	☐	☐
I wouldn't be willing to invite a person who has a behavioral health disorder to my house	☐	☐	☐	☐	☐
I would accept as a friend someone who has a behavioral health disorder	☐	☐	☐	☐	☐
I wouldn't mind working on the same job with someone who has a behavioral health disorder	☐	☐	☐	☐	☐
People in my community would invite someone who has a behavioral health disorder to their houses	☐	☐	☐	☐	☐
People in my community would avoid building a friendship with someone who has a behavioral health disorder	☐	☐	☐	☐	☐

People in my community would allow having someone who has a behavioral health disorder be a caretaker of their children	☐	☐	☐	☐	☐
People in my community would engage in a social activity with a person who has a behavioral health disorder	☐	☐	☐	☐	☐
In my family, a person who has a behavioral health disorder would be treated with respect	☐	☐	☐	☐	☐
In my community, a person who has a behavioral health disorder is treated with respect	☐	☐	☐	☐	☐
In my community, healthcare providers treat a person who has a behavioral health disorder with respect	☐	☐	☐	☐	☐
Most people in my community would accept a friendship with someone who has a behavioral health disorder	☐	☐	☐	☐	☐
The place of my employment would be open to employing someone who has a behavioral health disorder	☐	☐	☐	☐	☐
The opinion of someone who has a behavioral health disorder should not count in family discussions	☐	☐	☐	☐	☐
A behavioral health disorder causes problems in the family.	☐	☐	☐	☐	☐
Having a behavioral health disorder is a problem for a person to get married	☐	☐	☐	☐	☐
A family member of a person who has a behavioral health disorder has difficulty getting married	☐	☐	☐	☐	☐
A friend of a person who has a behavioral health disorder has difficulty getting married	☐	☐	☐	☐	☐
A person with a behavioral health disorder has difficulty to get hired for a job	☐	☐	☐	☐	☐
People in my community would think less of a person if he/she has a behavioral health disorder	☐	☐	☐	☐	☐
In my community, having a behavioral health disorder is associated with shame and embarrassment	☐	☐	☐	☐	☐
In my community, a family would choose not to disclose to friends and co-workers if one of its members had a behavioral health disorder	☐	☐	☐	☐	☐
People in my community would feel sorry for a person who has a behavioral health disorder	☐	☐	☐	☐	☐
It is easy to tell if a person has a behavioral health disorder	☐	☐	☐	☐	☐
Someone who has a behavioral health disorder is more likely to harm others than someone who does not have a behavioral health disorder	☐	☐	☐	☐	☐
People in my community consider someone who has a behavioral health disorder as dangerous	☐	☐	☐	☐	☐
Having a behavioral health disorder can cause problems in an on-going marriage	☐	☐	☐	☐	☐

Part 2: Demographic Information

1. Please provide your birthdate (mm/dd/yyyy)

2. What is your gender?
1= Female
2= Male

3. What race or ethnicity do you consider yourself to be?
1= White
2= Black
3= Hispanic
4= Asian
5= Other

4. What is your sexual orientation?
1= Heterosexual
2= Homosexual
3= Bisexual
4= Other

5. What is your marriage status?
1= Unmarried
2= Married
3= Other

6. What is your religious affiliation?
1= Judaism
2= Christianity
3= Islam
4= Hinduism
5= Agnosticism
6= Atheism
7= Other
8= Prefer not to answer

7. What is your current education level?
1= Freshman
2= Sophomore
3= Junior
4= Master
5= Graduate degree

8. What is your current residential ZIP Code?

9. In what country where you born?

10. In what state where you born?

11. In what city where you born?

12. In what country did you start elementary school?

13. In what state did you start elementary school?

14. In what city did you start elementary school?

15. Do have a child with special needs at your household?
1= Yes
2= No

16. Have you been ever been diagnosed with a behavioral health disorder
1= Yes
2= No

17. Are you currently being treated for a behavioral health disorder?
1= Yes
2= No

18. Do you have a family member diagnosed with a behavioral health disorder?
1= Yes
2= No

19. Do you have any friend who has a behavioral health disorder?
1= Yes
2= No

20. Do you know of any colleague working with you who has a behavioral health disorder?
1= Yes
2= No

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