Experienced stigma in severe mental illness

Exploring experienced stigma in severe mental illness – contributing to validation of a psychometric instrument

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Acronyms

CASS – Clinician Assessment of Schizophrenic Syndromes

CAT – Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment

CESQ – Consumer Experiences of Stigma Questionnaire

CFA – Confirmatory Factor Analysis

CI – Confidence interval

CRPD – Convention on the Rights of People with Disabilities

DISC – Discrimination and Stigma Scale

DSSS – Depression Self-stigma Scale

EDS – Experiences of Discrimination Scale

EFA – Exploratory Factor Analysis

FBS – Frankfurter Befindlichkeits-Skala

GAF – Global Assessment of Functioning

GAS – Global Assessment Scale

HIV/AIDS – Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome

HSRS – Health Sickness Rating Scale

HSS – Stigmatisation Scale

ICCPR – International Covenant on Civil and Political Rights

ICD – International Classification of Diseases

ISE – The Inventory of Stigmatising Experiences

ISMI – Internalised Stigma of Mental Illness

KMO – Kaiser-Meyer Olkin statistic

M – Mean

MIDUS – MacArthur Foundation Midlife Development in the United States

MSA – Measures of sampling adequacy

MSS – Maristan Stigma Scale

NAMI – National Aliiance for Mentally Ill

PA – Parallel Analysis

PAF – Principal Axis Factoring

PANSS – Positive and Negative Syndrome Scale

PCM – Polychoric correlation matrix

PDD – Perceived devaluation and discrimination scale

PD-S – Paranoid-Depresivitäts-Skala

QOLI – Quality of Life Interview

RES – Rejection Experiences Scale

RMSEA – Root mean square error of approximation

SD – Standard deviation

SESQ – Self-esteem and Stigma Questionnaire

SFS – Social Functioning Scale

SLDS – Satisfaction with Life Domains Scale

SRER – Self Reported Experiences of Rejection

SS – Stigma Scale

SSMIS – Self-stigma of Mental Illness Scale

UDHR – Universal Declaration of Human Rights

WHO – World Health Organization

WLSMV – Means and Variance adjusted weighted least square

1Introduction

1. 1About stigma

1. 1. 1Why to focus on stigma?

Stigma is defined as a sign of disgrace or discredit. Authors agree it is a powerful negative attribute, having its impact on all social relations.

Stigma is present everywhere in our society. It affects different characteristics in people, ranging from sexual orientation to HIV/AIDS, several medical disorders, gender, race, unemployment or obesity. However, it is in mental health disorders that stigma has its most devastating impact, although not always obvious.

Discrimination, the enactment of stigma, appears closely associated to it. While stigma lies at the base of discrimination, discriminatory practices also promote and reinforce stigma. Discrimination is also about the conditions in which patients live, mental health budgets and the priority which we allow these services to achieve. [1] In other words, stigma and discrimination lead to social exclusion – a triad that is a key determinant of mental health.

Stigma and discrimination are violations of human rights. Intention and commitment to fight stigma are present in the spirit of legally binding treaties such as the Universal Declaration of Human Rights (UDHR) [2] , International Covenant on Civil and Political Rights (ICCPR) [3] , International Covenant on Economic, Social and Cultural Rights (ICESCR) [4] and Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) [5] , and are explicitly mentioned on the Convention on the Rights of People with Disabilities (CRPD) [6] .

CRPD actually demands that signatories ‘ take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise’, and to ‘ adopt immediate, effective and appropriate

measures ... to combat stereotypes, prejudices and harmful practices relating to persons with disabilities ... in all areas of life'. [6]

From the part of the World Health Organization, tackling stigma, discrimination and social exclusion is a major concern of the General Assembly, with of the General Assembly, with reflection in the WHO Mental Health Action Plan 2013-2020 [7] .

At regional level, in European Union, commitment to fighting stigma and discrimination is a consequence of signing treaties like European Convention on Human Rights, European Social Charter, European Convention on the Prevention of Torture and Inhuman or Degrading Treatment or Punishment and, specifically, Recommendation Rec(2004)10, of the Committee of Ministers to member states, concerning the protection of the human rights and dignity of persons with mental disorder.

Still at regional level, and in line with WHO Mental Health Action Plan, stigma and discrimination is one of the main action areas of European Mental Health Action Plan. [8]

At national level, fighting stigma, discrimination and social exclusion is a component of policies, plans and programs worldwide.

In a time when quality mechanisms tend to be implemented into healthcare systems, there is also a trend to develop parts of quality standards that have statements on fighting stigma at a local level. NICE quality standards are a good example [9] . To implement stigma into quality standards is, by itself, a

strategy to fight it, by turning each service user in a potential advocate, as Byrne noted [1] .

Therefore, there is the need to foster development of indicators that can be used regarding mental illness stigma.

1. 1. 2Evolution of the concept

Stigma is a word that has its reminiscences in the Greek civilization. Stigma were body marks that were intentionally applied to individuals- the stigmatized – that carried unacceptable moral or individual traits, as compared to standards in that society. Christians absorbed the concept, adding two other meanings to those body marks – to indicate a holy grace or to indicate a sign of deformity/physical disease.

Anyway, even in early days of Christianity, stigma implied, from the social point of view, firstly, “ imputing a meaning into something” even if it did not have that meaning, and, secondly, dealing with deviations to a social norm.

Goffmann [10] was the first author to theorize stigma. To Goffmann, stigma is the result of a gap between perceived attributes and stereotypes. It is a matter of perspective, not reality. it is “ in the eye of the beholder”. Stereotypes are selective perceptions that categorize people, and that exaggerate differences between groups (‘ them and us’) in order to obscure differences within groups. [11]

He defines three types of attributes:

- Body(physical) – e. g. visible deformities in the body, deformity caused by physical disease
- Character (personal) – e. g. mental illness, criminal conviction
- Tribal (Social) – e. g. stigma of one group against another.

Goffmann also distinguishes between “ discredited” and discreditable”.

Those concepts were further developed by Jones et al. [12] , who proposed six dimensions of stigma:

- Concealability indicates how obvious or detectable the characteristic is to others.
- Course indicates whether the stigmatizing condition is reversible over time. Irreversible conditions provoke more negative attitudes than others.
- Disruptiveness indicates the extent to which a mark blocks or diminishes interpersonal interactions.
- Aesthetics reflects what is attractive or pleasing to one’s perceptions. When applied to stigma, it means whether a mark provokes a reaction of disgust.
- Origin refers to how the condition came into being. Perceived responsibility on the conditions will carry more negative attitude.
- Peril, refers to feelings of danger or threat induced in others. This can mean physical threat (as in “ contamination”) or simply uneaseness.

According to Byrne, stigma is connoted with a few negative attributes. Shame is its first expression, resulting from perception as indulgence or as a weakness, despite centuries of knowledge, media campaigns and “ the decade of the brain”. Blame is also an attitude that appears associated to

shame. [1] Maintaining secrecy is the maladaptive way some people find to cope with shame, but it can lead to deleterious consequences.

1. 1. 3Development of stigma

Negative attitudes towards people with mental illness, according to Byrne [1] , exist since playschool and extend into early adulthood. This is suggested by several studies: Weiss [13] examined a cohort of children of elementary school age and confirmed the prejudices eight years after; Green [14] compared attitudes between several studies using the same measures, that ranged over 22 years, and found consistent results indicating community had the same negative attitudes. This objects the common belief that with increased scientific knowledge about mental illness, stigma would tend to disappear.

1. 1. 4Different concepts of stigma

Stigma concept has evolved in the last fifteen years.

Link and Phelan have added discrimination to Jones' original dimensions. [15] Still, in 2001 the same authors present two major challenges for the concept of stigma.

The first challenge is that researchers who research stigma do so from their own vantage point, giving priority to their scientific theories and research techniques rather than words and perceptions about people they study, which lead to misunderstanding of the experience of people being stigmatized and to perpetuation of assumptions that are unsubstantiated.

The second challenge is about individualization of stigma and the fact that in research it tends to be considered as an attribute or a mark of the individual rather than a designation or tag that others affix to a person.

Thus, Link and Phelan propose a definition of stigma based on a convergence a few components:

- Distinguishing and labelling human differences – oversimplification of salient differences between human beings occurs, with further labelling of individuals.
- Associating human differences to negative attributes – Labels previously mentioned are associated to negative sterotypes, as previously described by Goffmann. Categories and stereotypes are often “ automatic” and facilitate “ cognitive efficiency”.
- Separating “ us from them” – Social labels connote a separation between the group that stigmatizes (“ us”) and the group that is being stigmatized (“ them”). For example, some people talk about people who have schizophrenia as being “ schizophrenics”.
- Status loss and discrimination – stigma leads to loss of status in social hierarchy, and to discrimination, both at individual and at structural levels.

Link and Phelan also emphasize that stigma is a matter of power – certain groups in the society have the power to stigmatize. Stigma is also a matter of degree – there is a continuum between its existence and its absence.

Corrigan [16] , has an opposing view, focused on cognitive and behaviour features of mental illness. He proposed a model in which stigma was categorized either as public or self stigma.

Public stigma is defined as the reaction that the general population has to people with mental illness. Self stigma is the prejudice which people with mental illness turn against themselves.

In each of the categories, stigma is broken down into three elements: stereotypes (cognitive knowledge structures) prejudice (cognitive and emotional consequence of stereotypes) and discrimination (behavioural consequence of prejudice) [17] .

Thornicroft et al. [18] , elaborate on this framework, stating that stigma is composed of problems at three levels: Knowledge, Attitudes and Behaviour.

Mental health knowledge is also known in the literature as mental health literacy. A study by Jorm et al. in Australia has shown better knowledge was correlated with better recognition of the features of depression, and better compliance with help seeking or medication and/or psychotherapy compliance. [19] Nevertheless, by citing contradicting evidence, Thornicroft [18] states that “ an increase in knowledge about mental illness does not necessarily improve either attitudes or behaviour towards people with mental illness.”

Negative attitudes, also known as prejudice, is the most studied component. According to Thornicroft, it can predict more strongly actual discrimination than do stereotypes. Attitudes have been widely researched. There are

studies regarding both public, healthcare practitioners (and medical students) and caregivers.

Thornicroft emphasizes the importance of studying actual behaviour, stressing that most of the studies have focused on attitudes towards hypothetical situations, rather than actual stigmatizing and discriminative behaviour. Thornicroft proposes a shift from research focused on stigma to research focused on discrimination. [18]

1. 1. 5Correlates and consequences of stigma

Stigma can have profound impact both at individuals with mental illness and their relatives.

Rüsch et al. [17] list four negative consequences of public stigma:

- Everyday life discriminations encountered in interpersonal relations and depictions in media
- Structural discrimination – inequity in the access to opportunities in private and public institutions.
- Self-stigma (versus empowerment)
- Fear of stigma as a barrier to use health services.

About self-stigma and empowerment, Rüsch et al. comment, firstly, that self-stigma and empowerment are on the same continuum of self-esteem. They also remark that people may have different reactions to public stigma – while some people react with low self-esteem (self-stigmatized), some people might react with anger or indifference. They point out a possible explanation for this resides both within group identification with public stigma and

perceived legitimacy of it. They also point the issue of self-disclosure – a person who considers mental illness is a part of his/her identity will more likely reveal his/her condition to others.

Secondly, Rüsch et al. comment on the relationship between stigma and service use. People decrease usage of psychiatric services in order to overcome public stigma. This is supported by evidence showing associations of this lack of usage with negative reactions from family members and poorer social status.

Lack of usage of psychiatric services is intrinsically linked to decreased treatment compliance and, therefore, poorer prognosis. [20, 21]

Personal stigma has shown to be associated with variables at different domains, in a systematic review and meta-analysis conducted by Livingston and Boyd.

In the psychosocial domain, stigma has been negatively associated with hope, self-esteem, empowerment/mastery, self-efficacy, quality of life and social support/integration, both at group and individual levels. [22–24]

In the psychiatric domain, stigma has been positively associated with symptom severity and negatively with treatment adherence [22] . There are mixed results regarding association of stigma to diagnosis, illness duration, hospitalizations, insight, treatment setting, functioning and medication side effects, with most of the studies failing to show any statistically significant association.

Regarding socio-demographic variables, both gender, age, education, employment, marital status, income and ethnicity have failed to show any consistent results. [22] We should note, however, that some studies have shown significant associations, both positive and negative, regarding each of the variables, with stigma.

1. 2Stigma research

Wahl et al., in 1999, mention four types of stigma research:

- Research that involves self-reports from general public.
- Research using vignettes or profiles of individuals and study participants' ratings of people described.
- Analogue behaviour studies,(" experimental studies") in which people are led to believe they are dealing with a person with mental illness.
- They note, however, there was, at the time, few research focused on mental health consumer, and his personal experiences of mental stigma. [25]

The paradigm changed and nowadays there is a relatively large number of instruments to measure personal experiences of mental stigma.

1. 2. 1Instruments to measure stigma – categories and criteria for psychometric properties

In 2010, Brohan et al. [26] , reviewed systematically 75 studies with instruments to measure personal experiences of mental stigma. Quality criteria for health status questionnaires have been thoroughly reviewed by Terwee et al, [27] and are briefly described inTable 1.

Table 1 – Criteria for quality of psychometric instruments [26, 27]

Content validity	Clear description is provided of the measurement aim, target population, concepts that the questionnaire is intended to measure, and investigators or experts involved in item selection
Internal consistency	Factor analysis performed on adequate sample size (minimum of 100 subjects, 4 to 10 subjects per variable); Cronbach alpha between 0, 70 and 0, 95
Construct validity	Specific hypotheses should be assessed (e. g. expected correlations between measures or expected differences in scores between “ known” groups); at least 75% of the results are in correspondence with those hypotheses in a subgroup of at least 50 patients
Test-retest reliability	Intraclass correlation coefficients (ICC) or cohen’s Kappa ≥ 0, 70 in a sample of at least 50 patients
Floor-ceiling effects	Are considered to be absent if less than 15% of respondents achieved the lowest or the highest possible score.

Brohan et al. [26] considered instruments to measure personal experiences of stigma in three categories:

- Perceived stigma

- Self-Stigma
- Experienced stigma

The found fourteen measures, used in the studies, which are listed inTable 2, and that were, thus, grouped in each of those categories. Instruments used were also assessed as to their psychometric properties, according to criteria by Terwee et al. [27]

Table 2 – Scales assessing stigma experienced by people with experience of mental illness (Adapted from Brohan et al. [26])

Scale	Measures Perceived stigma	Measures experienced stigma	Measures self-stigma	Measures other
PDD – Perceived devaluation and discrimination scale [28]	Perceived discrimination (6 items) Perceived devaluation (6 items)	No	No	No
ISMI – Internalised Stigma of	No	Discrimination	Alienation	Stigma resistance

			(6 items) Stereotype endorsement	
Mental Illness [29]		experience (5 items)	(7 items) Social withdrawal (6 items)	(5 items)
SSMIS – Self-stigma of Mental Illness Scale [30]	Stereotype awareness (10 items)	No	Stereotype agreement (10 items) Stereotype selfconcurrence (10 items) Self-esteem decrement (10 items)	No
CESQ – Consumer	No	Experiences of	No	No

		stigma (9 items)		
Experiences of Stigma Questionnaire [25, 31]		Experiences of discrimination (12 items)		
RES – Rejection Experiences Scale [32]	No	Rejection experiences (11 items)	No	No
DSSS – Depression Self-stigma Scale [33]	Public stigma (4 items)	Stigmatizing experiences (6 items)	General selfstigma (9 items) Secrecy (9 items)	Treatment stigma (4 items)
	No	Rejection experiences (12 items)	No	No

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SS – Stigma Scale [35]	No	Discrimination (12 items)	Disclosure (11 items)	Positive aspects (5 items
ISE – The Inventory of Stigmatising Experiences [36]	Perceived stigma 2 items	Experienced stigma 2 items	Social withdrawal 1 item	Impact of stigma (5 item)
SESQ – Self-esteem and Stigma Questionnaire [37]	Feelings of stigmatisation (8 items)	No	No	Self-esteem (6 items)
HSS – Stigmatisation Scale [38, 39]	Perceived stigma (15 items)	No	No	No
MIDUS – MacArthur Foundation Midlife Development	No	Major discrimination	No	No

		(11 items) Day to day discrimination (11 items)		
in the United States [40]				
DISC – Discrimination and Stigma Scale [41, 42]	Anticipated discrimination (4-items)	Experienced discrimination (32 items)	No	No
EDS – Experiences of Discrimination Scale [43]	No	Has discrimination occurred (1 item) Specific settings of discrimination	No	Stressfulness of discrimination in specific settings (8 items)

		(8 items)		
Maristan stigma scale (MSS) [44, 45]	Health professionals (4 items)	No	Self-Stigma (4-items)	Informal Networks (11 items) Socio-institutional (12 items)

1. 2. 2Perceived stigma

Perceived or felt stigma, according to Scambler et al [46] original definition, refers principally to the fear of enacted stigma, but also encompasses a feeling of shame associated with the illness. Van Brakel et al [47] , however, remove the feeling of shame from that definition, considering research about perceived stigma as research in which " people with a (potentially) stigmatized health condition are interviewed about stigma and discrimination they fear or perceive to be present in the community or society".

Perceived stigma can refer both to what an individual thinks most people would believe towards a certain group of the society or what that individual thinks about him personally as a member of a stigmatized group. [48] Components of perceived stigma reported in the literature as measurable variables include stereotype awareness (perception by the individual of how individuals with mental illness are viewed by " most other people" in the society) [16] and personal expectations or fears of encountering stigma.

Perceived stigma is addressed in the vast majority (79%) of the studies reported by Brohan et al. Seven measures were used in the literature to measure it: PDD, SSMIS, ISE, HSS, SESQ, DSSS and DISC.

PDD [26, 28] is the most commonly used scale. It totals 12 items – its two subscales measure perceived discrimination and perceived devaluation – a way of measuring stereotype awareness. Perceived stigma is also measured in 10 item stereotype awareness subscale in SSMIS [30] . HSS investigates perceptions of how the person feels they have been personally viewed or treated by the society. In 2 of its items, DISC addresses the expectation of being stigmatized in various aspects of life – a concept called anticipated discrimination. Although in a specific setting and about a specific group, MSS [44, 45] " health professionals" subscale measures in our opinion perceived stigma regarding healthcare professionals, so it would fit in perceived stigma category.

Regarding psychometric properties, all of the measures above mentioned reported on content validity. PDD, SESQ and DSS did not report whether target population was involved in selecting items in the scale. DSSS and SESQ reported results on internal consistency. However, PDD; SSMIS, ISE and HSS, although have calculations for Cronbach's alpha, do not have factor analysis. SSMIS and SESQ have measured test retest reliability. MSS has been multiculturally tested, and its content validity was assessed. Cronbach alpha, internal consistency and test-retest reliability have been reported and meet criterion level.

1. 2. 3Self-Stigma

Self-stigma is considered, by Corrigan, the internalization of the public stigma. For Corrigan et al, there are three components in self stigma: negative belief about the self (e. g., character weakness, incompetence) – cognitive response, agreement with beliefs expressed by the public or the society and negative emotional reaction (e. g., low self-esteem, low self-efficacy) – affective response and behaviour response to prejudice (e. g., failing to pursue work and housing opportunities) [16, 49]

Self-stigma is assessed by ISMI, SSMIS, DSSS, SS and ISE.

Alienation, stereotype endorsement and social withdrawal subscales in ISMI, measure self-stigma, which correspond to its affective, cognitive and behavioural dimensions [50] . SSMIS measures self-stigma through three sub-scales: stereotype agreement; stereotype self-concurrence and self-esteem decrement [26, 30] . SS has a “ disclosure” subscale, which focus on the three dimensions already mentioned [26, 35] . ISE contains one item on social withdrwal [36] . DSSS addresses self-stigma through two subscales – general self-stigma and secrecy: general self-stigma measures personal stereotype awareness. Secrecy subscale can be comparable to social withdrawal subscale in ISMI and disclosure scale in SS [33] . MSS [44, 45] has a 4 item subscale on self-stigma.

According to Brohan, all the measures reported on content validity. DSSS did not report on target population involvement in item selection. SSMIS and ISE reported on partial criteria for internal consistency, reporting Cronbach’s

alpha calculation but not factor analysis. ISMI; DSSS and SS have full internal consistency analysis.

ISMI, SSMIS and SS have been reported to have measured test-retest reliability.

1. 2. 4Experienced stigma

According to Brohan and van Brakel, experienced stigma is the " experience of actual discrimination and/or participation restrictions on the part of the person affected" [26, 47] .

For the purpose of this definition, measuring experienced stigma can refer to measuring experiencing stigma in general or a report of experiences of stigma in specific situations or areas of life. [26]

By measuring experienced stigma, one can, thus, assess direct effects of public stigma on the stigmatized individual.

Measures of experienced stigma include ISMI, CESQ, SRES, DSSS, SRE, SS, ISE, MIDUS, DISC and EDS.

CESQ will b