

**PhD Thesis**

**THE ILLNESS REPRESENTATION OF SCHIZOPHRENIA AND  
STIGMATIZATION**

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## I. Aims and Topic of Dissertation

Contemporary Hungarian clinical psychology research is hardly concerned with the psychology of the more serious psychiatric disorders. Mainstream research considers these diseases as mostly biologically determined, and examination and healing of them is nearly exclusively remitted to the expertise of medical psychiatry, in spite of the lot of evidence proving psychological approach is also needed to understand and help people living with schizophrenia. One of the little researched phenomenon in psychology in our country concerning the lives of people with schizophrenia is stigma and discrimination inherent in them. Understanding stigmatization and discrimination due to mental illness, and reducing the problem requires an interdisciplinary approach. Stigma research can be efficiently completed by research tools of personality and social psychology as well as clinical psychological knowledge.

The problem of stigmatization of people living with schizophrenia is approached from the clinical psychological viewpoint in the dissertation. In addition to introducing currently dominant points of views the historical development of schizophrenia disease approach is presented, and summarization of the most important results and comments of foreign and Hungarian literature and research on the stigma of mental illness is attempted. Various aspects of stigma are described (such as public and self-stigma, discrimination, structural discrimination etc.), latest approaches of stigma and discrimination are introduced, such as Corrigan et al.'s four-stage progressive model about the occurrence of self-stigma, as developing during the interaction of the stigmatized person's subjective experience with the social environment. Possibilities of stigma testing and measurements are outlined. On the basis of international research results harms caused by stigma are introduced and the importance of the topic is argued.

Jones and colleagues (1984) used the term „mark” when clarifying the concept of stigma. The “mark” in this meaning is a descriptor that encompasses a range of characteristics and conditions that are seen as deviant by the society and that might set up the process of stigmatization. Stigma occurs when someone is marked through attributional processes with those undesirable characteristics, and the person gets devaluated, discredited by it in the eyes of others. Six dimensions of stigma were identified: *Concealability* refers to how easily detectable, obvious is the characteristic to others. *Course* refers to whether the stigmatized characteristic changes over time, may be reversible or not, may worsen in time. The

*Disruptiveness* of the stigmatized characteristic refers to what extent it may strain or obstruct personal interactions. *Aesthetics* refers to how much a characteristic is attractive or repulsive, containing the kind of automatic affective reactions people respond to it with. *Origin* describes what the perceiver believes how the condition came into being, may think that the person is responsible for it or not, and what causes might be considered when thinking about it. The last, sixth dimension, *Peril* indicates the threat, how much the stigmatized characteristic induces feelings of fear, how much people think and feel they are in danger either physically or in a way that we ought to face uncomfortable feelings. (Jones és mtsai, 1984; Sztancsik és Pék, 2014).

Conceptualising mental illness stigma the above dimensions' role have not been studied much. Feldmann and Crabdall's (2007) research is an exception. According to that, people may wish to keep a greater distance from the mentally ill if they think that they are responsible for their condition (origin), and when they think, that the person in question is dangerous (peril), and in addition if they believe that it is a rare illness or condition. According to their results, these later three factors explain the 60% of the variance of stigma.

Link and Phelan (2001) drew attention to the fact, that former stigma concepts would locate the problem in the individual, the external perceivers viewpoint and cognitive information processes were emphasized, and discrimination, segregation, and the subjective experience of the stigmatized people themselves were less taken into consideration.

According to their above mentioned model stigma is defined as something occurring when the following interrelated components are present at the same time. These components are labelling (labelled by any socially important characteristic), stereotyping (mostly negative characteristics linked to the label), separating (self or "us" from "them" via labelling), and status-loss and discrimination (as devaluating, discrediting, discriminating the stigmatized in a negative way). Link and Phelan added when these elements co-occur in a power situation stigma is created, and stigma is dependent on power. It refers to the phenomena that is always the less powerful who are stigmatized by those who are more powerful. Later their conception of stigma was completed with emotional reactions (Link, Yang, Phelan, Collins, 2004). Emotional reaction connected to stigma are not negligible because emotional responses (as mostly expressed via non-verbal channels) are detected by the stigmatized themselves, they perceive, recognize them and may take it as a statement of the others of themselves as persons. Viewing the problem from the other side our behaviour towards the stigmatized groups or people will be influenced by emotions via attributional processes (Weiner, 1986)

Mental illness stigma can be characterized by the above mentioned dimensions and components. This phenomena cannot be avoided by mental health professionals, because

people living with mental illness, struggling with psychological problems, may not seek help because of the fear of being stigmatized if doing so. It may hinder treatment, it can influence cooperation and the progress of recovery (Thornicroft, 2006).

The treatment of psychiatric disorders and the stigma attached to it have effects not only upon people living with serious mental illness, but those recovering or recovered, their surroundings, family members, mental health professionals and more or less, directly or collaterally the whole society. Direct effect of it is when in case of a close relative's (sibling's, parent's) mental illness the marriage or relationship of a couple is discouraged (even though they were healthy). Indirectly the whole society is affected by the question: whether we can experience social care and solidarity when get in a difficult situation or not?

Corrigan and others have pointed out that mental illness stigma does affect at least two ways the life of those living with mental illness, as self-stigma (internalized stigma) and as public stigma (as the stigma of the wider society, and the public views) (Corrigan és Watson, 2002; Corrigan, 2004,2007; Corrigan, Kerr, Knudsen, 2005; Wahl, 1999).

An overview of the results and experience of anti-stigma programmes abroad and the few local research and professional activities examining or proposing to reduce mental illness stigma is provided in the dissertation.

The thesis aims to draw attention to the importance of starting systematic research in the field in Hungary, in order to plan national anti-stigma campaigns in the light of research. Investigation has been started in eastern Hungary, Debrecen. Public stigma and self-stigma of those affected should be studied in context of one and the other, as emphasized.

Fundamental questions of the research are, whether the diagnosis of schizophrenia is a stigma in Hungary too? What psychological tools are adequate to measure the phenomena? What kind of views of the disorder may play an important role in the evolution of stigma and stigmatization?

## I. Hypotheses group

1. The fact of a psychiatric illness calls for a less positive perception of personal characteristics compared to a situation when perceivers do not know about such disorder of the assessed person. This effect is even more specific, when the diagnosis of schizophrenia is also present.
2. Perceivers relate to a person's childbearing plans less supportive when the perceived person is mentally ill compared to a person otherwise with the same characteristics without the illness. This effect is even more specific when the diagnosis of schizophrenia is also present.
3. The above answers are in connection with the desirable social distance.
4. These effects are independent from the age, gender and education of the respondents, but may be interrelated with the knowledge of a person with the mental illness in question.
5. When the diagnosis of schizophrenia is given, different causes are emphasized to play important roles in the development of the mental illness, different outcome and prognosis is assumed by perceivers. (Different from the case when diagnosis is unknown.)
6. Perception of the dangerousness of a person living with schizophrenia is in connection with the less positive perception of personal characteristics, i.e. is a key-factor in the process of stigmatization.
7. The presence or absence of schizophrenia diagnosis and the assessment of the mentally ill person's dangerousness, as a stigma, may influence the willingness to seek help in an imaginary similar situation.

## II. Hypotheses group

1. The Hungarian translation of the Self-Stigma of Mental Illness Scale – Short Form, (SSMIS-SF) is an appropriate and reliable measurement tool to assess self-stigma and results of it support Corrigan et al.'s measure results and theoretical model.
2. The more severe self-stigma is associated with lower level of general well-being.
3. The volume and nature of the experience of discrimination is related to the severity of self-stigma, but the absence of discriminatory experience does not necessarily mean the lack of it.
4. The severity of self-stigma is connected with the causes, outcome and prognosis of the disorder test persons assume.

### III. Hypotheses group

1. People living with the diagnosis of schizophrenia perceive the other person with the similar diagnosis generally more positive, and relate to this person's childbearing plans more supportive than a non-patient layman.
2. This effect is related to the desirable social distance.
3. Due to their experience people living with schizophrenia are more aware of the multifactorial determination of the disorder and the possibilities of treatment, than non-patient laymen, though in both groups biomedical approach to the disorder is dominant.

## II. Methods Applied

Public stigma, assumptions of the 1st Hypotheses group were examined in an experimental setting, using vignettes and questionnaires amongst non-patient laymen. Participants were randomly chosen to take part in one of the two experimental or the control group. As an independent variable they read either an experimental or a control vignette about the same fictive person, who was a psychiatric patient with the diagnosis of schizophrenia (1), a psychiatric patient without diagnosis (2), or was not a patient (3). Following the reading, attributed personal characteristics, relation to the childbearing plans of the person described in the vignette, and the desirable social distance to the person were assessed in all groups. The vignettes in the 1<sup>st</sup> and 2<sup>nd</sup> test groups contained a short description of a psychiatric illness onset, the difference was only the absence or presence of the part "*a form of schizophrenia was diagnosed*", in these test groups the inventory also assessed what potential causes, triggers and maintaining factors are attributed to the fictive person's disease. What are the treatment options, prognosis presumed? Is the disease considered to be dangerous with or without treatment? Is the impersonated woman in the vignette seen as capable of independent living? Uniquely designed scales were used to assess these beliefs.

The research conducted among people living with schizophrenia was designed to examine the assumptions of the 2nd Hypotheses group, subjective self-stigma and experienced discrimination. To study these phenomena the author translated and applied the validated Self-Stigma of Mental Illness Scale – Short Form (SSMIS-SF) into Hungarian. WHO general Well-Being Index short form (WBI-5) and Discrimination and Stigma Scale version 12 (DISC-12) were applied in addition, scales that have been adopted and validated in international research

already. Participants living with schizophrenia also filled in the 1<sup>st</sup> test group's full test inventory of the previous research of layman.

The 3<sup>rd</sup> group of hypotheses is investigating the differences of answers through equivalent test materials of the two research groups: differences similarities of opinions and attitudes about the disorder between people living with schizophrenia and non-patient layman.

SPSS has been applied for hypothesis verification and statistical analysis.

### **III. Results, Theses**

Deductible conclusions of the first research, based upon the responds of laymen (lay in terms of their psychiatric, clinical knowledge) are as follows

- The fact of a psychiatric illness and even more the diagnosis of schizophrenia is likely to call forth less positive personality assessment and attributions – in spite of the fact that the sample was otherwise highly educated.
- The experimental setting and the uniquely developed scales proved to be adequate measures to detect the attitude and attribution modification effect of the “mental illness” and the “schizophrenia diagnosis” labels.
- The free decision of bearing a child is less supported by respondents when the person on the vignette has a mental illness (either with or without the diagnosis) even under the same conditions.
- The social distance scale alone is not an appropriate device for detecting the above differences. Those, whose primal style of responding is more “distant” and who are more cautious when scoring personal characteristics, are not all stigmatizing, some of them would let closer relationship, when mental illness is present. Their attitude can be called benevolent. The other group of cautious scorers are those who would keep a greater distance in case of psychiatric illness, they can be those who admit their less positive attitude and they would be test people worth involving in testing anti-stigma interventions' efficiency.
- The *label of schizophrenia* does modify causal attributions of the disease towards a genetically determined, inborn neurodevelopmental disorder, and it does not change to what extent people think it is also determined by social interactions or the communication style of the family one lives in.

- Schizophrenia is seen as a chronic disease with relapses, as a disease that needs medical treatment, and can also be treated by psychotherapy. Generally respondents think it cannot be cured definitively. If the disorder is not treated, people believe the mentally ill person is more dangerous to self and others when the schizophrenia diagnosis is given.
- The assessment of dangerousness (peril) is a key factor in developing less positive opinion about a mentally ill person.
- When the diagnosis of schizophrenia is given, respondents are more prone to think they would seek help in a similar situation. According to this result the diagnosis, as a “label”, will not hamper help-seeking, it would rather facilitate it.
- Most of respondents believe that the person living with schizophrenia introduced in the vignette is able to fulfil independent living, and they do not think the disease and its prognosis is determined biologically exclusively.

Result of the experimental research with lay participants seems to prove that a person living with schizophrenia, when it is known, can expect less positive attributions and attitudes even in a setting without stakes. This result draws attention to the probably existing stigma worth dealing with in Hungary too! This experimental setting using a vignette method, and the measures applied, can be adequate tools to assess attitude differences even about a wider range of mental illnesses or, to detect the effect of an anti-stigma intervention when needed. Characteristics of lay-thinking about psychiatric disorders (in a wider representative sample of people) may point out themes worth dealing with by education, so that the most objective picture of mental illness could be drawn in a future anti-stigma campaign. Result of the research confirm international experience: there should be “dangerousness” and “recoverability” among these themes in case of schizophrenia disorders.

Research conducted with people living with schizophrenia showed:

- The Hungarian version of SSMIS-SF is a reliable tool to measure stigma experience of those living with the illness, results are consistent with international data and confirm the four-step progressive model of the development of self-stigma with the modification that three steps are likely to emerge instead. Those' self-respect, who apply stigmatizing stereotypes on themselves is likely to worsen in parallel with that (not in a next step).
- This research can be considered as a pilot study, raising awareness of a practically useful measure tool of mental illness self-stigma, worth validating, and which was translated and applied in a Hungarian sample first by the author of the dissertation.
- The more severe self-stigma is associated with deterioration of subjective well-being, this should be considered when therapy of the mentally ill is planned.
- According to results isolation may be the reason why people living with schizophrenia in Hajdú-Bihar County, Hungary do not report or hardly experience any discrimination.
- To measure the experience of subjective self-stigma SSMIS-SF is more applicable than DISC-12.
- Agreement with the disease being “dangerous” and “unrecoverable” was associated with more severe self-stigma among those living with schizophrenia. These results can confirm that these themes should be included and dealt with during anti-stigma programmes.
- Participant with more severe self-stigma are more likely to agree that a person living with schizophrenia needs permanent, continuous psychological support.

*Comparison of responses of the layman and the schizophrenic sample concerning schizophrenia confirm:*

- Those who experience the mental illness themselves, see another person in the same boat more positive than those who do not know the illness and its meaning from self-experience.
- Besides the biomedical approach to schizophrenia the importance and awareness of psychosocial factors (i.e. abuse, disturbances of familial communication) are also present in both groups, though even more emphasized in explanations of the illness among those people living with schizophrenia.

- The need for psychological and social support in case of schizophrenia is also more often indicated by people living with schizophrenia themselves, than those not ill laymen. Helping professionals should react to this signal as to a need, and make psychological support continuously available when needed, not only provide medical treatment for those living with schizophrenia.

Results confirm that in Hungary, Hajdú-Bihar County a person living with schizophrenia can expect “worse” assessment and judgement in several fields of life, worse than one with the same circumstances and characteristics without the illness. This negative attitude probably due to stigma may disseize them of opportunities and may worsen the quality of life, well-being of these people even more, besides the burden of the disorder itself. In the samples of participants of the research not the biomedical model is the exclusively dominant approach to schizophrenia, and the need for widespread social and psychological, psychotherapeutic support is also pronounced.

According to the research carried out the measure tools applied are adequate to study mental illness stigma in a wider sample of society. The need for more pronounced presence of the theme of mental illness stigma in local professional and social discourse, is empirically proven, so we could fight the harmful effect of stigma.

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### List of publications related to the dissertation

#### Hungarian book chapters (1)

1. **Sztancsik, V.**, Pék, G.: A mentális betegek és a megbélyegzés: az észlelt, a tapasztalt és a belsővé tett stigma jellemzői és vizsgálati lehetőségei.  
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2. **Sztancsik, V.**, Máth, J., Pék, G.: Stigmatization of psychiatric patients and schizophrenic people in Hungary.  
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#### Hungarian scientific articles in Hungarian journals (2)

3. **Sztancsik, V.**, Máth, J., Pék, G.: Szkitofréniával élők megbélyegzettségének mérése.  
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