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Theses of the Doctoral Dissertation

The Subjective Experience of People Coping with Mental Illness

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Chapter 1: Foreword and Overview

Coping with mental illness is often chronic, characterized by relapses and risks for one's health and safety (Sartorius et al., 1993). Suffering is a common experience, resulting from the realization of all the losses the illness brings into ones' life (Kaite et al., 2015). Thus, accepting that one has a mental illness and adjusting to it is a process, often a lengthy and painful one (Birley, 1991). Therapeutic approaches, however, have mainly focused on symptom reduction rather on subjective elements and patients' suffering. Only in the 1980s, as the movement towards deinstitutionalization of patients with mental illness began, realization grew that successful treatment must address broader issues including efforts to improve the well-being and quality of life of patients (Lambert & Naber, 2004). Treatment focused on rehabilitation, mainly by skills learning (Appelo et al., 1993). Over time, these efforts triggered more interest in patients' internal experience in coping with mental illness. Early efforts to examine patients’ experience highlight its magnitude by calling it a traumatic loss, as symptoms of Post-Traumatic Stress Disorder (PTSD) were evident after hospital discharge among patients with psychosis (McGorry et al., 1991). Later on, "post psychotic depression" was coined to describe the occurrence of depression as a psychological reaction to a major life event - the mental illness itself (Birchwood et al., 2005). Despite recent progress, research is still lacking on other elements in patients’ experience and other possible emotional reactions to mental illness. Any such research also needs to take into consideration the social meaning of mental illness, since it is one of the most stigmatized conditions in society (Byrne, 2000). Stigma has a harmful impact on patients’ emotional and social functioning, being a significant barrier to adherence to medical and psychological treatment (Cinculova et al., 2017; Corrigan, 2004).

The losses associated with mental illness, despite being clinically documented as a primary experience of patients (Appelo et al., 1993; Wittmann & Keshavan, 2007), have been largely neglected by researchers. The typical emotional reaction following any loss experience, grief, has been almost completely neglected. These reactions are crucial to investigate, mainly due to their known negative impact on physical and mental health in the non-clinical population (Miles, 1985; Moore et al., 1988). In the mental health field they were documented as common experiences of relatives of people coping with mental illness, having negative consequences for their own well-being and physical health (Godress et al., 2005). Surprisingly, while efforts have focused on family members, almost no efforts have been made to address the experience of loss and grief among the people affected the most by mental illness, the patients themselves. This dissertation focuses on elements in patients' experience such as stigma, loss and grief, and their influence on recovery will be investigated. This dissertation is also the first to examine the possible impact of loss and grief on non-adherence to medications, one of the most common and severe problem in mental health. Furthermore, it is valuable to examine these elements in Hungary, as such research is lacking (Evans-Lacko et al., 2014) and a lack of mental health and stigma research is known to be related to higher stigma in such countries (Lasalvia et al., 2013; Thornicroft et al., 2009). Moreover, such research is crucial considering the country's lack of a formal plan for mental health promotion and anti-stigma programs (Fernezelyi et al., 2009). Hungary has been found to have the lowest knowledge level on mental illness diagnosis (Olafsdottir & Pescosolido, 2011), the most negative attitudes towards people coping with mental illness and the most negative views regarding seeking professional help, compared to other countries (Coppens et al., 2013). Above all, this dissertation aims to initiate and facilitate a more profound body of research in Hungary and globally, focusing on the experience of people coping with mental illness. The hope is to improve treatment plans, care and quality of life for those struggling with mental health disorders.

Chapter 2: General Introduction: Living with Mental Illness

Treatment non-adherence. One of the most common ways to treat mental health conditions is with psychiatric medications (Gilbert et al., 1995). Despite the significant role of treatment adherence in symptom reduction and rehabilitation (Lee et al., 2006), non-adherence among people with mental illness is disturbingly high. Non-adherence is prevalent among those with a wide range of mental health diagnoses (e.g. schizophrenia, bipolar and depression) (Semahegn et al., 2020) and has been found to be related to worsening of symptoms and re-hospitalization, relapse, suicidality, reduced quality of life among patients, and to increased economic burden through high costs of healthcare usage, and unemployment (Ernst & Goldberg, 2004; Puschner et al., 2009; Svarstad et al., 2001). Research has been devoted to the examination of the possible factors underlying non-adherence, and the focus of attention has been mostly on objective factors (such as medication side effects, lack of insight and demographic factors)(Velligan et al., 2009). Recently however, studies have shifted attention towards more subjective factors related to patients' inner experience in coping with mental illness, (Ho et al., 2017; Yang et al., 2012). This has led to a line of research aiming to understand the meaning that mental illness has in the society and the changes it brings into people's lives.

Mental illness stigma. Despite the fact that every year approximately 38% of the European population experience mental illness (Wittchen et al., 2011), stigma towards mental illness is still surprisingly highly present (Cechnicki et al., 2011). Studies on mental illness stigma often classified it into two components: Public stigma (the negative stigmatic attitudes held by members in the society (Corrigan et al., 2006)) and internalized stigma (the experience of people coping with mental illness who internalized mental illness stereotypes and adopted them into their identity (Corrigan & Watson, 2002)). Over the years, much of the research on stigma was focused on public stigma and the prevalence in the society of negative attitudes towards mental illness (Vrbová et al., 2014). To examine and address stigma, research has mainly used the measure of social distance (Bogardus, 1925). Research findings show that despite the public's becoming more knowledgeable about mental illnesses over the years, attitudes have not improved and the desire of the public for social distance from people with mental illness has remained stable over recent years (Schomerus et al., 2012). As a result, efforts were dedicated to the establishment of anti-stigma intervention programs (through education and increasing familiarity with mental illness) (Corrigan et al., 2012; Griffiths et al., 2014). Only little research attention was devoted to internalized stigma (Brohan et al., 2010).

Internalized stigma. Having a diagnosis of mental illness is known to influence the individual's inner experience and identity (Roe & Davidson, 2005)**.** Research reports that internalized stigma is common among various mental diagnoses (schizophrenia, bipolar, substance abuse disorders, depressive disorders, anxiety disorders and personality disorders) (Kamaradova et al., 2016). Internalized stigma has been strongly related to non-adherence to medical and psychosocial treatment (Cinculova et al., 2017; Fung et al., 2007), lower self-esteem, self-efficiency, empowerment, hope, social support and quality of life (Corrigan et al., 2006; Lysaker et al., 2007).

Shame. A major reaction of people who internalize the stigma of mental illness is shame (Schmader & Lickel, 2006), which despite being described as highly prevalent among people with mental disorders and affecting negatively patients' self-esteem and quality of life (Rüsch et al., 2007), has been mostly neglected (Link et al., 2004).

The specific importance of shame is related to its association with depression, suicide, social withdrawal and its influence on relationships and treatment avoidance (Hastings et al., 2000).

The experience of loss. Mental illness often means patients feel an immense sense of loss, resulting from multiple losses in crucial aspects of life (Mauritz & van Meijel, 2009). The losses involved in mental illness often include symbolic and less visible losses, such as loss of dreams, plans and hopes for the future (Ozgul, 2004). However, the main contributor for the lack of public recognition and acceptance of patients' loss is believed to be the stigma towards mental illnesses. This stigma also contributes to the lack of support usually provided to individuals coping with other, less stigmatized types of losses (Young et al., 2004).

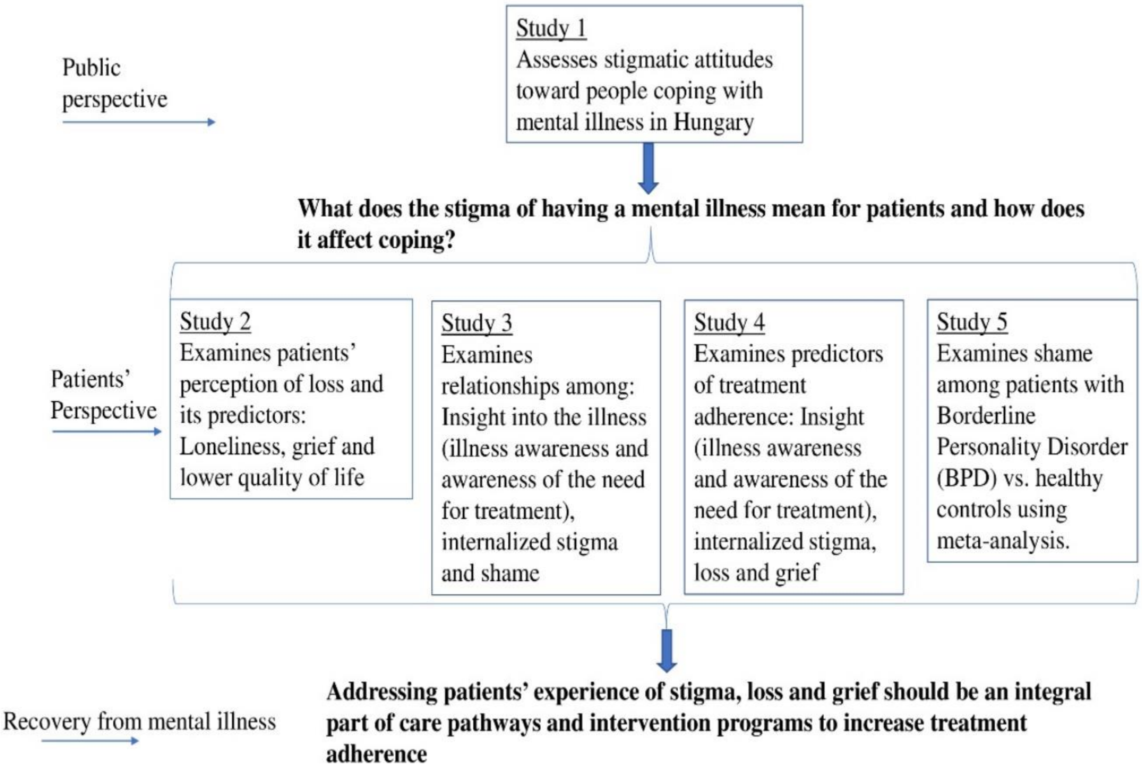
Despite the implications of loss for the person who is coping with mental illness, the study of loss in mental health has been focused on the loss experienced by family members (Solomon & Draine, 1996). Only recently the study of loss among patients has undergone significant progress following the development of the Personal Loss from Mental Illness scale (PLMI) (Stein et al., 2005), which supported the significance of the experience of loss, as it was found to be related to loneliness, increased symptoms, lower well-being (Stein et al., 2005) and lower quality of life (Potokar, 2008).

Grief. Grief, according to Freud (1917), is a normal reaction to any loss experience, which can be the death of a loved one, the loss of any physical possession or loss of an ideal. Although grief is an important part of coping and accepting new reality, prolonged grief has been found to have serious mental and physical implications such as higher risk for psychological problems and reduced physical health (Miles, 1985; Moore et al., 1988). Grief following mental illness has been reported as a common reaction among families and parents of an individual coping with mental disorder (Godress et al., 2005; Miller et al., 1990). Furthermore, grief in families was found to be related to increased emotional distress, reduced psychological well-being and poorer health status (Godress et al., 2005). Few studies investigated grief in people who are coping themselves with mental illness; most of them are case studies and only one evaluated it empirically by qualitative measures (Mauritz & van Meijel, 2009). Grief in patients was manifested as shock, denial of the diagnosis, denial of their need for treatment and denial of the need for new adjustments to be made in their lives (Mauritz & van Meijel, 2009). Coming to terms with the illness occurred after recognizing their illness and their loss as a fact and accepting it. Acceptance was related to medication adherence, a decrease in symptoms and receiving information about the diagnosis (Mauritz & van Meijel, 2009). These preliminary findings suggest that grief might have negative influence on health, well-being and on actual coping with the illness such on medication-taking behavior.

Aims and research questions

The overarching goal of this dissertation was to examine understudied elements in the internal experience of patients with different diagnoses, and to emphasize their significance to the study of treatment non-adherence and patients' quality of life. To achieve this goal, five empirical studies were conducted to examine: 1. the significance and possible determinants of public stigma towards mental illness over a 15 year period in Hungary; 2. the experience of loss among people with different mental diagnoses; 3. insight and its relationship to internalized stigma and shame in patients with different diagnoses; 4. the impact of patients' internal experience of loss and grief on treatment non-adherence and quality of life; 5. the experience of shame among the group known to suffer from it the most, i.e those coping with Borderline Personality Disorder (BPD) (Ritter et al., 2014; Rüsch et al., 2007; Scheel et al., 2014; Unoka & Vizin, 2017).

Summary of the aims of the five presented studies:



Study 1
Assesses stigmatic attitudes toward people coping with mental illness in Hungary

What does the stigma of having a mental illness mean for patients and how does it affect coping?

Study 2
Examines patients' perception of loss and its predictors: Loneliness, grief and lower quality of life

Study 3
Examines relationships among: Insight into the illness (illness awareness and awareness of the need for treatment), internalized stigma and shame

Study 4
Examines predictors of treatment adherence: Insight (illness awareness and awareness of the need for treatment), internalized stigma, loss and grief

Study 5
Examines shame among patients with Borderline Personality Disorder (BPD) vs. healthy controls using meta-analysis.

Addressing patients' experience of stigma, loss and grief should be an integral part of care pathways and intervention programs to increase treatment adherence

Chapter 3: Study 1. Social rejection towards mentally ill people in Hungary between 2001 and 2015: Has there been any change?

Aims

This study examined the existence, significance and possible determinants of the previously unexamined problem of public stigma towards mental illness in Hungary (Evans-Lacko et al., 2014). This is especially important since such studies coming from Central and Eastern Europe are lacking, and since there is preliminary evidence from other new market economy countries of significantly higher stigma when compared to western countries (Winkler et al., 2015).

Materials and methods

Participants. Data were analysed from large, representative epidemiological surveys conducted in Hungary in 2001, 2003, 2007 and 2015 (Elekes and Paksi, 2003; Paksi, 2001; Paksi et al., 2009, 2017). The samples across different years are similar in terms of age (*M*=35, *SD*=10) and gender (50% females). The age range of 18-53 years was used (n=7605).

Materials

Socio-demographic questionnaire. Gender, age, and education level were assessed.

Social Distance was assessed with one question from the Social Distance Scale (SDS;Bogardus, 1925) asking about the acceptance of mental ill people as neighbours**.** Acceptance preferences were indicated using five-point scale (1=would object; 5=would welcome) and a "don't know" category. Participants were also asked to report on their willingness to interact with other minority groups in the society (such as those in prison, Roma people, and people with AIDS).

Familiarity with mental illness was assessed with the question: "Is there someone in your family who has/had been treated due to mental illness?" Participants chose from the following options: 0-no one, 1-mother, 2-father, 3-mother+father, 4-other, 5-mother+other, 6-father+other, 7-mother+father+other, and 9-don't know.

Statistical analyses. Time trend analysis using Chi-squared tests to assess attitudinal change. Logistic regression was performed to identify possible predictors including socio-demographic variables (age, gender and education) and familiarity with mental illnesses.

Results

Changes in the desire for social distance. Despite a significant trend in public preferences of more accepting attitudes during the years of 2001-2015 (χ^2=6.49, *p*<0.05), the effect size was very small (0.05) and the 2015 rejection level was still high (57%). Moreover, people with mental illness were found to be among the three most rejected groups (with only users of alcohol and drugs being more rejected).

Determinants of social distance. Lower familiarity with mental illnesses, female gender, and education below high school level were significant predictors. Familiarity with mental illness was found to be the strongest predictor. The prediction model was significant and explained 4.2% of the variance of social distance.

Discussion

As found in other countries, attitudes towards people with mental illness have not changed in Hungary, and overall rejection levels are still high. More effort is needed to understand better and overcome social rejection concerning mental illness.

Chapter 4: Study 2. Perceived loss among people living with mental disorders: Validation of the Personal Loss from Mental Illness Scale (PLMI)

Aims

Study 2 examined the experience of loss following mental illness, which despite its central role in patients' lives and in recovery (Wittmann & Keshavan, 2007), has been mostly investigated among relatives of patients. Importantly, rather than focusing solely on schizophrenia as was mostly done previously, this study focused on wide range of mental diagnoses. The construct validity of the PLMI (Stein et al., 2005) in a non-English speaking sample was examined using CFA. Possible covariates of loss were examined, and the predictive power of grief was empirically investigated for the first time.

Materials and methods

Participants. 200 adults (Females=133, 66.5%), aged 18-65 (*M*=44.2, *SD*=11.8) with different mental illness diagnoses (schizophrenia=26.5%, mood disorders=29.0%, stress- related disorders=44.5%, personality disorders=5.0, disorders due to psychoactive substance use=1.0%) recruited from an outpatient mental health unit in Budapest, Hungary.

Materials

Socio-demographic questionnaire. Gender, age, previous hospitalizations, education, occupation, diagnosis, and marital status were assessed. Different diagnoses of the patients were assigned to ICD-10 diagnostic categories (World Health Organization, 1992).

Loss was assessed using the PLMI (Stein et al., 2005) comprising 20 items concerning the losses that individuals with mental illness experience. Participants rate the degree to which they agree with each statement on a 5-point Likert scale (1=strongly disagree; 5=strongly agree).

Loneliness was measured using The UCLA Loneliness Scale (Version 3) (Russell, 1996), with 20 questions on the frequency of respondents' feelings on a 4-point Likert scale (1=never; 4=always).

Grief was measured using the Mental Illness Version of the Texas Inventory of Grief (MIV-TIG) (Miller et al., 1990), comprised of 16 items assessing current grief using a five-point scale (1=completely false; 5=completely true).

Quality of life was measured using the Manchester Short Assessment of Quality of Life (MANSA) (Priebe et al., 1999), a 16-item self-report scale containing two question types: objective questions (four items) which are answered 'yes' or 'no', and subjective questions (12 items) asking individuals to rate on a 7-point scale their satisfaction from life overall and from specific life domains (1=couldn't be worse; 7=couldn't be better.

Statistical analyses. CFAs were used to assess the factor structure and item performance of Hungarian version of PLMI scale in the sample. Degree of fit for the comparative fit index (CFI) and Tucker-Lewis Index (TLI) had to be close to 0.95, and the model should be rejected when these indices are <0.90 (Brown, 2006). Root mean squared error of approximation (RMSEA) below 0.05 indicates excellent fit, a value around 0.08 indicates adequate fit, and a value above 0.10 indicates poor fit (Browne & Cudek, 1993).Next, a CFA with covariates was performed to test the association between loss and age, gender, previous hospitalizations, marital status, loneliness, grief, and quality of life.

Results.

Confirmatory factor analysis with covariates. The inspection of correlation matrix showed that one item (Item 13: *"I don't enjoy being around other people who have a mental illness"*) did not correlate significantly with any of the other 19 items, therefore it was removed from the further analyses. The original four-factor model of the PLMI scale did not fit closely to present data (χ^2=297.2, Df=146, CFI=0.879, TLI=0.858, RMSEA=0.072, C fit of RMSEA=<.0001, SRMR=0.059). One-factor model was further investigated and yielded acceptable degree of fit (χ^2=253.0, Df=148, CFI=0.916, TLI=0.903, RMSEA=0.060, C fit of RMSEA=0.102, SRMR=0.054). The factor loadings of the one-factor model ranged between 0.29 and 0.74. The mean item loading was 0.56.

Covariates of loss. The bivariate correlations show that mood disorder diagnoses were significantly related to higher perception of loss (*r*=0.18), while stress-related diagnosis was associated with less perceived loss (*r*=-0.20). The multivariate analysis shows that higher loneliness (β=0.36, *p*<.001), higher reaction of grief (β=0.36, *p*<.001), and lower quality of life (β=-0.25, *p*<.001) were significantly related to higher perception of loss.

Discussion

Study 2 supported a one-factor model over the previously proposed four-factor model, which might be due to cross-cultural differences that exist in stigma towards mental illness (Abdullah & Brown, 2011) and a greater exposure to stigma in Hungary (Buchman-Wildbaum et al., 2018) compared to the US, where the original study was conducted (Stein et al., 2005). The results support the construct validity of perceived loss, its significance to recovery, and the need to address loss in different diagnostic groups, as some might be more vulnerable than others.

Chapter 5: Study 3. The paradoxical role of insight in mental illness: The experience of stigma and shame in schizophrenia, mood disorders, and anxiety disorders.

Aims

This study focused on insight into having mental illness and its paradoxical implications for the lives of people coping with mental illness, mainly due to the impact of internalization of stigma. The study examined the construct validity of the Birchwood Insight Scale (BIS)(Birchwood et al., 1994), among people coping with different mental diagnoses. Investigation of insight has been limited and has yielded inconsistent findings (Birchwood et al., 1994; Cleary et al., 2014). Moreover, it is important to study various diagnostic categories, as the BIS has mostly been used with patients with schizophrenia and psychosis (Cleary et al., 2014). Poor insight has been found to be common also among those with other diagnoses (Ghaemi et al., 2000; Michalakeas et al., 1994). Finally, possible predictors of insight were examined, as well as the reported negative meaning it entails for patients, such as internalized stigma and shame.

Materials and methods

Participants. Same as in study 2.

Measures

Socio-demographic questionnaire. Same as in study 2.

Insight was measured using the BIS comprising eight items that assess three dimensions of insight into mental illness (illness awareness, need for treatment, and re-labeling of symptoms). Each item contains a statement offering three response options: *agree, unsure,* or *disagree*. Insightful responses are scored 2, unsure responses are scored 1, and responses which reflect poor insight are scored 0.

Internalized stigma was measured using the Self-Stigma of Mental Illness Scale SSMIS;)(Corrigan, Watson, et al., 2006), which includes four subscales: (i) awareness of the existence of stigmatic views regarding mental illness, (ii) agreement with the stigmatic views, (iii) adopting stigmatic views and projecting them into the self-identity, and (iv) self-esteem reduction. Each subscale contains ten statements to which participants can respond on a nine-point Likert scale of agreement (1=strongly disagree; 9=strongly agree).

Shame was measured using the Experience of Shame Scale (Andrews, Qian, & Valentine, 2002) comprising 25 items on each of which participants rate on their feelings on a four-point Likert scale (1=not at all; 4=very much). The Hungarian validated version of this scale (Vizin et al., 2016) was used in this study.

Statistical analyses. First, a series of CFAs were used to assess the factor structure and item performance of the Hungarian version of the BIS in the sample. The measurement invariance of the BIS was also tested in groups having or not having a schizophrenia diagnosis, and groups with different diagnosis were compared for statistical differences in factor scores. Next, a CFA with covariates was performed to test the association between insight and age, gender and previous hospitalizations, while diagnosis was controlled for. Finally, the association between the insight factors, internalized stigma, and shame was investigated.

Results

Confirmatory factor analyses of the Birchwood Insight Scale. As a first step, a one-factor model (Cleary et al., 2014) was tested which yielded excellent fit (χ^2=30.1, Df=20, p=0.0675, CFI=0.973, TLI=0.962, RMSEA=0.050, Cfit of RMSEA=0.465). However, the inspection of the factor loadings revealed that Item 1 did not load significantly on this factor. The three-factor model was also tested as suggested in previous research (M. Birchwood et al., 1994) and yielded excellent fit (χ^2=18.6, Df=17, p=0.3538, CFI=0.996, TLI=0.993, RMSEA=0.021, Cfit of RMSEA=0.794). However, the third (*"re-labeling of symptoms"*) factor has only one significantly loading item, and Item 1 did not load significantly on this factor either. Because of the large correlation between *"awareness of illness"* and *"re-label of symptoms"*, they were merged, and a two-factor model was tested excluding Item 1. This model also yielded an excellent degree of fit (χ^2=15.0, Df=13, p=0.3059, CFI=0.995, TLI=0.991, RMSEA=0.028, Cfit of RMSEA=0.709). This two-factor model with seven items was also contrasted with the one-factor model with seven items, and showed superior fit to data ($\Delta\chi^2$=6.73, Δdf=1, $p<0.01$), thus it was retained in further analysis. The factor loadings in this model ranged between 0.58-0.68 in the *"awareness of illness factor"* and between 0.44-0.89 in the *"need for treatment"* factor. The measurement invariance of the BIS between patients diagnosed with vs. not diagnosed with schizophrenia was supported.

Differences of insight among patients with different diagnoses

Awareness of illness factor: A significant main effect was found (F(3, 192)=2.86, $p<0.05$). Only schizophrenia spectrum disorders and mood disorders groups differed significantly (Tukey HSD post-hoc test $p<0.03$), meaning that patients with schizophrenia had lower illness awareness. The difference was of medium effect size (Cohen d=0.52). The effect size of the group difference for schizophrenia vs stress-related groups did not reach significance but is not negligible (Cohen d=0.40).

Need for treatment factor: A significant main effect was found (F(3,192)=5.05 $p<0.01$). However, only the group with other diagnosis differed significantly from schizophrenia ($p<0.01$), mood disorders ($p<0.01$), and stress-related disorders ($p<0.05$) groups, having lower treatment awareness according to Tukey HSD test. Patients with schizophrenia had the highest score for need for treatment but it differed significantly only from the other diagnosis group. The effect size of difference between schizophrenia and stress-related group was not negligible (Cohen d=0.35), but it did not reach statistical significance due to low statistical power.

Predictors of insight: gender, age and hospitalization. Only hospitalization predicted the awareness of illness (i.e., those patients who were previously hospitalized were more aware of their illness) (unstandardized B= 0.324; SE=0.142, β= 0.254 $p<0.05$).

The impact of insight on shame and stigma. A multivariate model within a structural equation modeling framework was tested. In this model the paths between the need for treatment and the outcome variables were fixed to zero due to the lack of bivariate correlations. Age and gender were controlled for. Higher awareness of illness predicted higher shame (β=0.36, *p*<.001), internalized stigma (β=0.27, *p*<.01), and self-esteem reduction (β=0.25, *p*<.01).

Discussion

Results of study 3 indicated that the two-factor structure shows the best fit and, except for the poor functioning of Item 1, it also validates the factor structure which was reported originally (Birchwood et al., 1994). Furthermore, it also confirms the applicability of the BIS not only in patients with psychosis but also in patients with a wider range of diagnoses. Diagnostic differences were found in insight levels, stressing the importance of examining insight in patients with different diagnoses rather than schizophrenia alone. Lastly, the study emphasizes the importance in understanding the complexity of insight, and the need to address it with careful consideration of stigma, and the negative meaning it has for individuals coping with mental illnesses.

Chapter 6: Study 4. Targeting the problem of treatment non-adherence among mentally ill patients: The impact of loss, grief and stigma.

Aims

This study aimed to examine the connectedness and impact of patients' internal experience on one of the most the most common problems in the mental illness field, treatment non-adherence. Firstly, the study examined the factor structure of the Medication Adherence Rating Scale (MARS) (Thompson et al., 2000) among patients with different diagnoses. The MARS has mainly been used to measure treatment adherence among those with schizophrenia. Since previous findings have reported that non-adherence is commonplace among a wider spectrum of mental illness (Colom et al., 2005; Gilmer et al., 2004; Melfi et al., 1998), it calls for a wider examination. Furthermore, possible predictors of adherence were examined, as well as the impact of non-adherence on patients' lives.

Materials and methods

Participants. Same as in study 2.

Measures

Socio-demographic questionnaire. Same as in study 2.

Adherence was measured using the MARS which has 10 yes/no items encompassing three elements of adherence: (i) adherence in terms of behavior, (ii) adherence in terms of attitudes, and (iii) attitudes towards psychiatric medications and their negative side-effects. The scoring depends on whether the responses implying adherence (coded as 1), or non-adherence (coded as 0).

Insight was measured using the BIS as in study 3.

Internalized stigma was measured using the SSMIS. As in study 2.

Grief was measured using the MIV-TIG as in study 2.

Loss was measured using the PLMI as in study 2.

Quality of life was measured using the MANSA as in study 2.

Statistical analyses. In order to assess the factor structure and item performance of the Hungarian version of the MARS in the current sample, a series of CFAs were conducted. After calculating the factor scores, a comparison for statistical difference in factor scores between groups with different diagnosis was conducted. Next, a series of CFAs with single covariate models were performed to examine the associations between adherence, sociodemographic factors, insight, internalized stigma, grief, and loss. Finally, the association between the adherence factors and quality of life was investigated.

Results

Confirmatory factor analysis of the MARS. The original three-factor model was examined and yielded close to acceptable degree of fit (χ^2=55.9, df=31, *p*<.004; CFI=0.907, TLI=0.866; RMSEA=0.065 Cfit of RMSEA=0.174). Inspecting the factor structure, modification indices and the content of the items, Item 5 was removed from the adherence attitude factor to the adherence behavior factor. The error covariance between Item 1 and Item 2 was allowed. These modifications yielded excellent degree of fit in all fit indices (χ^2=38.6, df=31, *p*<.1646; CFI=0.972, TLI=0.959; RMSEA=0.036 Cfit of RMSEA=0.731). The means of factor loadings of each factor in the modified model were 0.63, 0.62, and 0.87 respectively.

Medication adherence in different diagnostic groups. No significant main effect was found. However, comparison between the schizophrenia spectrum disorders group and the mood disorders and stress-related disorders groups together, showed that schizophrenia patients reported higher score of adherence behavior (t[186]=1.93, p=0.055, Cohen’s d=0.33). The same analyses with the attitude and side-effects resulted in much smaller difference (Cohen’s d=0.16 and 0.11 respectively).

Covariates of medication adherence: Higher insight into the need in treatment predicted higher adherence (adherence behavior; $\beta=0.30$, $p<0.01$, and attitude; $\beta=0.49$, $p<.001$). Higher stigma predicted lower adherence. Especially adopting stigmatic views into self-identity (adherence behavior; $\beta=-0.35$, $p<.001$, attitude; $\beta=-0.19$, $p<.05$, and lower tolerance of side-effect; $\beta=-0.24$, $p<.05$) and self-esteem reduction (adherence behavior; $\beta=-0.30$, $p<0.01$, attitude; $\beta=-0.27$, $p<.05$, and lower tolerance of side-effects; $\beta=-0.21$, $p<.05$). Higher loss and higher grief predicted lower adherence in terms of lower tolerance of side-effects (loss; $\beta=-0.29$, $p<0.01$, grief; $\beta=-0.45$, $p<.001$).

Correlations between adherence and quality of life. Increased adherence correlated significantly with increased quality of life (adherence behavior; $r=0.24$ $p<.01$ and tolerance of side effects; $r=0.25$ $p<.01$). When the correlations between behavior and side-effect aspects of adherence ($r=0.535$) were controlled for, the remaining partial correlations were still significant ($r=0.132$, $p<.05$ and $r=0.145$, $p<.05$, respectively).

Discussion

The study confirmed the three-factor structure of the MARS (Fialko et al., 2008; Thompson et al., 2000) among non-English speaking patients with different diagnoses. The study supports the need to examine and address adherence issues in patients with different diagnoses, and mostly emphasizes the importance and significance of patients' internal experience on actual coping and recovery.

Chapter 7: Study 5. Shame in borderline personality disorder: Meta-Analysis.

Aims

This study aimed to focus on the experience of shame among the group known to suffer from it the most, that is people coping with BPD (Ritter et al., 2014). The study conducted the first meta-analysis comparing self-reported shame among patients with BPD to a healthy control group (HC). Understanding better the prevalence and significance of shame in this population is important, especially considering studies reporting shame to have negative impact on self-esteem, quality of life, and core BPD symptoms (Rüsch et al., 2007; Unoka & Vizin, 2017), and as one of the leading factors for suicidal tendencies (Linehan, 1993).

Materials and methods

Data collection. A literature search was conducted, limited to papers in English published between 1980 and March 2020. The studies had the following inclusion criteria: a) used questionnaire or checklist measures of shame in those with BPD, b) included a healthy comparison group, and c) had statistical values that allowed the calculation of an effect size (Cohen's d). The search initially generated 35 studies for potential inclusion but only 10 articles were included (3543 participants; HC=2,283, BPD=1,260).

Categorical Moderator Variables. We searched the articles for relevant moderator variables. We included gender (percentage of males), education, mean age, and percentage of the sample with co-morbid post-traumatic stress disorder as continuous moderator variables.

Data analysis. The Cohen's d was analyzed by using two means (BPD group and HC group) divided by standard deviations (SD). The confidence intervals (CI) and z-transformations were done to see whether the Cohen's d values were statistically significant. In regarding homogeneity of the effect sizes across studies for shame, we used the Cochran *Q*-statistic (Hedges & Olkin, 1985). When we discovered heterogeneity with the *Q*-statistic, we used a random-effects model for a significant level of the mean effect sizes. To test publication bias, we used a funnel-plot and the tests developed by Begg and Mazumdar (1994) and Egger et al. (1997).

If there was heterogeneity, moderators were assessed with the *Q*-statistic. The demographic moderator variables (i.e., age, gender, education level, percent of sample with co-morbid PTSD) were examined with meta-regression methods as continuous variables.

Results. A large effect size (N= 3543, d = 1.44) with significant heterogeneity (Q_B [20] = 271.332, p< .0001) was revealed.

Publication Bias. The funnel plot was asymmetric and the Begg (p = .0005, 1-tailed) and Egger (p = .0001, 1-tailed) tests were significant, suggesting a possible "file drawer" problem. For the publication bias detection, fail-safe N calculation revealed that 4,970 "null" studies would need to be found and integrated in the meta-analysis to refute our findings. Therefore, the current findings represent the current literature of self-reported shame in BPD vs. HC groups.

Moderator Analyses

Demographic variables. While the BPD group had no significance (Z= .81, p= .41), analysis showed a significance for age in the HCs (Z= -5.80, p=.0001), showing that as age increased, self-reported shame decreased. As education level decreased, self-reported shame increased in both groups (BPD: Z= -2.53, p=.01; HC: Z= -1.54, p=.02).

Clinical variables. Significance was found between co-morbid PTSD with BPD (Z= 2.48, p=.01). As the percentage of those co-morbid PTSD in the sample increased, reported shame increased.

Discussion

The study results emphasized the high prevalence of shame among people with BPD diagnosis, and offers an important contribution to understanding patients' experience and to detecting those who are at a higher risk to experience shame. It also stresses the need to formulate intervention programs that will target shame in people with BPD diagnosis.

Chapter 8: General discussion

This dissertation added new findings to the limited stigma research in Hungary, and also presented a worrisome picture of high and persistent rates of rejection towards people with mental illness. This finding can contribute to a better understanding of some of the other results of the dissertation, mainly the internalized stigma, shame, loss and grief found among Hungarian adults coping with mental disorders. By focusing on such elements in patients' experience, this dissertation sheds light on factors which were largely understudied, and emphasizes their magnitude with regard to important aspects of living, such as loneliness and lower quality of life, and, ultimately, to recovery, by negatively affecting treatment adherence. Furthermore, this dissertation contributed knowledge by translating and validating English language scales into Hungarian and supporting their applicability to different patient populations in a different culture. Lastly, this dissertation was the first to conduct a meta-analysis on the experience of shame among people coping with Borderline Personality Disorder (BPD), and to document a significantly high level of shame in this group when compared to the healthy population.

The stigma towards mental illness. As has been reported around the world (Schomerus et al., 2012), Hungary shows relatively consistent and high levels of social rejection towards people coping with mental illness over a 15-year period (Buchman-Wildbaum et al., 2018). Moreover, people with mental illness constitute the most rejected group in Hungarian society compared to other minority groups. While a trend of high rejection has been reported around the world, there may be contributing factors specific to Hungary or to other nearby countries, such as its communist background, which was found to be associated with higher stigmatization towards people with mental illness (Winkler et al., 2015). Supporting evidence shows Hungary to have the most negative attitudes towards mental illness when compared to other European countries (Coppens et al., 2013; Olafsdottir & Pescosolido, 2011). The communist background may also help explain the continuing lack of formal governmental programs or reforms to educate the public and address specifically the stigma in the mental health field (Fernezelyi et al., 2009). The dissertation findings yield recommendations for intervention programs stressing the importance of culture in formulating such programs. In contrast with other countries (Jorm & Oh, 2009; Winkler et al., 2015), in Hungary low education and female gender were related to high levels of rejection towards people coping with mental illness. Familiarity with mental illnesses, which was also found to have meaningful influence on stigma (Jorm & Oh, 2009), was found to be the most important issue to address in Hungary.

Insight and internalized stigma. Results from the studies in this dissertation contribute to a better understanding of the "insight paradox" reported in the literature (Lysaker et al., 2007). The dissertation findings imply the need to differentiate among aspects of insight. Awareness of the illness aspect itself was destructive for one's self as it was related to internalized stigma, low self-esteem and shame, while awareness of the need for treatment was not (Buchman-Wildbaum, Váradi, et al., 2020b). On the other hand, awareness of the need for treatment was related to better treatment adherence (Buchman-Wildbaum, Váradi, et al., 2020a).

The experience of shame. This dissertation shows that shame among people coping with BPD is highly prevalent compared to the healthy population and contributes more specific information about shame in this group. Individuals with low educational background and co-morbid PTSD are more prone to experience higher shame. While shame is a common reaction to internalized stigma, it is important to consider other elements that might contribute to shame specifically in this group of patients, such as previous history of trauma and abuse (which is especially high in this group compared to the population) (Zanarini et al., 2002).

Loss and grief following the development of mental illness. One of the most important findings of this dissertation is the loss and grief it revealed in people coping with mental illness. The documentation of manifestations of grief is an especially important finding, due to the lack of such research in this group of people. Furthermore, this dissertation (Buchman-Wildbaum, Richman, et al., 2020) supported for the first time the association between perception of loss and grief and the previously documented negative impact that loss has on individuals' life, linked to loneliness and lower quality of life (Potokar, 2008; Stein et al., 2005). The most striking finding of this dissertation was to witness the possible impact of loss and grief on treatment non-adherence, a possibility which has never been examined before. Good direction in explaining this association is the well-known involvement of distress, denial and avoidant behaviour in grief (Horowitz et al, 1981). This might be supported by Mauritz and van Meijel (2009), who found that grief among patients was manifested in difficulties accepting their illness and the need for treatment. Medications and their side effects might be the ultimate daily reminder of their illness and everything they have lost. This dissertation also provides support for the importance of maintaining adherence to treatment, as lower adherence was found to be related to lower quality of life among patients (Buchman-Wildbaum, Váradi, et al., 2020a).

Diagnostic difference. Patients with schizophrenia spectrum disorders had the lowest illness awareness but their awareness of the need for treatment and their adherence were no different than for those with mood disorders and stress related disorders (Buchman-Wildbaum, Váradi, et al., 2020a, 2020b). Interestingly, treatment awareness, but not illness awareness, was related to better adherence (Buchman-Wildbaum, Váradi, et al., 2020a). Furthermore, the experience of loss was not found to be related specifically to the diagnosis of schizophrenia (Buchman-Wildbaum, Richman, et al., 2020). Patients with mood disorders had the highest level of illness awareness and higher experience of loss. Higher experience of loss was found to be related to lower treatment adherence, to higher loneliness and lower quality of life (Buchman-Wildbaum, Richman, et al., 2020; Buchman-Wildbaum, Váradi, et al., 2020a). This might mean that in mental illnesses, which are highly stigmatized, the awareness itself might be harmful to coping, posing a barrier to adherence among highly insightful patients, such as those with mood disorders. Low illness awareness in patients with schizophrenia might be a protective factor, a possibility also supported by (Moore et al., 1999). While the lack of insight often noted in those with schizophrenia has been considered to result from neurological deficit (McGorry & McConville, 1999), the dissertation results suggest that psychological factors also impact illness experience. The fact that patients with schizophrenia had high treatment awareness, raises the possibility that they might well be aware of the illness. Schizophrenia is characterized by multiple losses, which might be too much to completely comprehend, and too painful to acknowledge. The finding of low illness awareness might also be seen as reflecting denial rather than pure lack of insight (Startup, 1996). Studies have shown that denial is used as a defense mechanism against the anxiety-provoking reality of the illness, which is the most stigmatized in society (Moore et al., 1999). This dissertation raises the idea that this low awareness, this denial, can be also part of a more complex process of grief, which is known to include denial and avoidance (Clayton, 1990).

Practical implications. This dissertation offers a glimpse into the full meaning of having a mental illness, encompassing the public's and the individuals' perspective, suggesting that these might go hand in hand. While educating the public about mental illness and fighting stigma is important, supporting those affected by mental illness is crucial. To improve patients' treatment adherence, the results highlight the need to address internalized stigma, loss and grief. This dissertation adds to existing knowledge and implies that interventions should aim to facilitate "healthy insight", promote awareness of medical need and facilitate illness awareness that is free of self-stigmatizing beliefs. In efforts to promote "healthy" insight, it might also be important to address feelings of shame, which were found to be associated with illness awareness, and which may contribute to internalized stigma and treatment avoidance (Hasson-Ohayon et al., 2012). While it is especially important to address loss among people coping with mood disorders, there is a need to formulate interventions based on the specific needs of people with various diagnoses, each carrying their own challenges and losses. Addressing perception of loss might provide support and reduce grief as well. If a patient’s grief is not recognized, it can be mistakenly perceived as a symptom of the illness and might be dismissed or pathologized, impeding recovery (Young et al., 2004). In therapy, efforts should be directed toward acknowledging the losses that the illness brings, as they are often left unrecognized (Doka, 1989). Naming their experience as grief and stressing it as a normal and healthy response to a major and often traumatic life event, might be healing in itself (Young et al., 2004). Understanding the role of internalized stigma, loss, and grief might change treatment perspectives and help therapists address with empathy important elements of subjective suffering,

Limitations and future direction. First, due to the lack of previous research on grief among people coping with mental illness, and the preliminary nature of this study, the results should be interpreted with caution. Although a scale to assess grief with mental illness has been developed for family members (Miller et al., 1990), there is a need for further research and perhaps for the development of a specific scale to assess grief among people coping with mental illness. A longitudinal research design could be beneficial, as grief in mental illness known to be continuous and fluctuating (Young et al., 2004). The other factors measured in this study, such as insight and adherence, might fluctuate with time as well (Wiffen et al., 2010). Second, while this dissertation offers insights regarding the experience of patients with different diagnoses, these are limited due to combining patients with different diagnoses into a larger diagnostic group. Important to mention as well is the convenience sample used in this dissertation and its specific characteristics, which included stable and relatively high functioning adults, engaging in outpatient services. Thus, the generalizability of the results to the broader patient population of those with schizophrenia/mood disorders/anxiety disorders might be compromised. Third, it is important to mention that factors not measured, such as symptom severity, may affect the associations explored. Fourth, the cross-sectional design used as part of this dissertation limits the ability to infer causality from the findings. Lastly, self-report measures have been criticized for their inaccuracies (Sajatovic et al., 2010). However, the researcher-rated format might also be biased (Young et al., 2003), and as the main aim of this dissertation was to stress the importance of patients' own experience, self-report measures were preferable. Future studies investigating patients’ internal experience should consider the possible impact of internalized stigma on perception of loss and grief. Cross-cultural studies might provide important insights regarding these associations and the mechanisms involved in treatment non-adherence. Possible differences among diagnostic groups with regard to shame, internalized stigma and grief should be examined in more depth in a larger sample.

Conclusions

This dissertation presents five empirical studies providing important insights to the study of coping with mental illness and treatment adherence. Maybe more than anything, this dissertation points to the need to adopt a more empathetic approach towards those whose lives have changed due to a chronic illness, and to understand their experience as a normal part of coping with a life changing event. As health professionals we should listen to clients without judgement or stigmatic attitudes and create a safe place for them to grieve. It might not only reduce their suffering but also improve their acceptance of the illness, willingness to adhere to treatment and improve their quality of life.

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