DOCTORAL (PhD) DISSERTATION

TZIPI BUCHMAN-WILDBAUM

# THE SUBJECTIVE EXPERIENCE OF PEOPLE COPING WITH MENTAL ILLNESS

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EÖTVÖS LORÁND UNIVERSITY
FACULTY OF EDUCATION AND PSYCHOLOGY

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# The subjective experience of people coping with mental illness

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## Acknowledgements

Five years ago, when I started my PhD studies, I decided that I want to make a difference. I wanted to give a voice to the ones that have being silenced for years by society, only because of their mental illness. My past work experience with people coping with mental illness has made it clear to me that individuals are mainly coping with a life changing event, that is often times not being acknowledged or properly addressed by current methods of care. Five years ago, I went on a journey to investigate the perspective of the individual and experience of having a mental illness, a topic which was unfortunately not very popular or well-studied. In many respects, it has meant that this journey that I planned, was not always easy; it was long, challenging, and frustrating at times, but it all brought me here to this point in time where I can confidently say that it was worth it. The journey was also fulfilling, fascinating, enriching and helped me grow as a researcher, a therapist, and a person. It mainly allowed me to bring into the light the lived experience of people who are coping with mental illness, and this is the thing I'm proud of the most. However, I couldn't make this journey alone, and luckily, I was surrounded by remarkable people who helped and supported me along these years.

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## List of Publications that the Dissertation is Based Upon

| Study | Publication | Status | Impact factor |
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*Note.* Each co-author has granted permission for the given publication to be included in the current dissertation.

# Chapter 1: Foreword and Overview

*"My illness is a journey of fear, often paralyzing, mostly painful. If only someone could put a bandaid on the wound…but where? Sometimes I feel I can't stand it any longer. It hurts too much, and I'm desperate to feel safe, comforted" (McGrath, 1984, p. 638).*

Developing a mental illness brings into one's life a great amount of struggle, suffering, and disruption to functioning. Coping with mental illness is often chronic, characterized by relapses and risks for one's health and safety (Sartorius et al., 1993). Thus, it is not surprising that after learning that one has a mental illness, accepting and adjusting to it is a process, often a lengthy and painful one (Birley, 1991). It has been described by many as "a descent to hell" (Noiseux & Ricard, 2008, p.1152). Suffering is a common experience, resulting from the realization of all the losses the illness and symptoms have brought into their life (Kaite et al., 2015).

The understanding of and therapeutic approach toward mental illnesses have undergone changes over the years. Whereas in the field of physical illnesses, improving the care and quality of life of patients has long been investigated, such investigation in the psychiatric field has been lagging behind (Lambert & Naber, 2004). Only in the 1980s, with the beginning of the movement towards deinstitutionalization of patients with mental illness, which moved provision of care from long stay psychiatric residences to community living, a shift has occurred. From focusing solely on symptom reduction, a realization has grown that successful treatment must address broader issues, especially due to the chronic nature of such disorders. Thus efforts to examine and improve the well-being and quality of life of patients living in the community were initiated (Lambert & Naber, 2004; Lehman, 1983; Malm et al., 1981). This interest was renewed later on following the development of atypical antipsychotic medications, and patients' quality of life was an important outcome measure and important goal (Lambert & Naber, 2004). Treatment focused on rehabilitation, mainly by skills learning. However it seems that rehabilitation plans were constructed based on a general perception of normality (such as eliminating "strange" symptoms and maintaining normal behavior and paid employment), while less attention was given to the subjective perception and suffering of patients (Appelo et al., 1993). The meaning of having a mental illness and the emotional consequences of the significant changes and losses it brings to people lives were largely neglected (Appelo et al., 1993).

Over time, however, the shift of attention away from reduction of symptoms 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. McGorry and collaborators (1991) found that months after discharge from hospital, 36%-46% of patients who had been coping with psychosis in the past 2-3 years experienced symptoms of Post-Traumatic Stress Disorder (PTSD) according to the DSM-III criteria. The possibility that patients might experience post trauma as a reaction to their illness was later supported by Morrison et al. (2003). Later on, Birchwood et al. (2005) examined the experience of having mental illness, and developed the concept of "post psychosis depression" to describe depression as a reaction to coping with psychosis, with its meaning for individuals of feeling socially inferior because of the illness and the losses it brings. The depression, rather than being part of an illness' symptoms, was regarded as a psychological reaction to a major life event - the mental illness itself (Birchwood et al., 2005). In their research they stressed the importance of patients’ own experience. Patients who attributed the cause of the illness to themselves, perceived greater loss because of the illness and believed that the illness led them to a humiliating and inferior position in society which they are not able to change, were significantly more likely to show depression than those with a less pessimistic perception (Birchwood et al., 2000).

Despite recent progress, research is still lacking on other elements in patients’ experience and other possible emotional reactions to mental illness. Any such research however cannot be conducted without taking into consideration the social meaning of mental illness. Mental illness is considered to be one of the most stigmatized conditions in society (Byrne, 2000; Corrigan & Penn, 1999). The impact of the stigma has been found to be brutal on patients’ emotional and social functioning, linked to depression, shame, low quality of life, and has been found to be damaging for one's social functioning and recovery, being a significant barrier to adherence to medical and psychological treatment (Cinculova et al., 2017; Corrigan, 2004; Fung et al., 2007; Lysaker et al., 2007; Rüsch et al., 2006; Staring et al., 2009).

The harmful implications of the stigma attached to mental illness for people’s lives not only stress the importance of addressing it, but also emphasize the importance of investigating the internal experience of patients, who are not only coping with the symptoms of a chronic illness but also with their "new" ranking in society and their devaluated identity. Importantly, the study of stigma may provide only a glimpse into the fuller picture of the stormy and emotionally complex world of people coping with mental illness. Therefore, there is a need for better understanding of the broader elements in the experience of people for whom their lives were completely changed because of the illness and its meaning for their own life story. As mental illness more than anything is known to interrupt people's lives (Kaite et al., 2015), there is a need to shed light on what it means for patients. Although the most salient manifestation of interruption to living, the losses following the illness, have been clinically documented by health professionals (Appelo et al., 1993; Lewis, 2004; Ozgul, 2004; Wittmann & Keshavan, 2007), they have been largely neglected from research eyes. The typical emotional reaction following any loss experience, grief, has been almost completely neglected as well. 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; Porritt & Bartrop, 1985). Supporting evidence for the need to investigate loss and grief among patients comes from studies which identified their importance in the mental health field. This body of research chose to focus on the losses and grief of family members due to their relative's mental illness, and documented their manifestations and negative consequences for their own well-being and physical health (Godress et al., 2005; Miller et al., 1990). Surprisingly, while efforts were 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. Besides being highly informative by itself, it raises questions and demands critical thinking about the real scope of the problem of stigma and its possible discriminatory influence also on mental health research itself, emphasizing the clear need to investigate these elements among patients. As such, this dissertation will focus on elements in patients’ experience such as stigma, loss and grief. Their relevance and influence on recovery will be investigated while this dissertation will tackle one of the most common and severe problem in mental health - non-adherence to medications. By doing so, this dissertation will also be the first to examine the possible impact of loss and grief on non-adherence to medications. As well, cultural background cannot be detached from such investigation, and thus the thesis' examination of these elements in Hungary, where such research is particularly lacking (Evans-Lacko et al., 2014) is valuable. This is especially important as lack of mental health and stigma research is often known to be related with higher stigma in such countries (Lasalvia et al., 2013; Thornicroft et al., 2009). Hungary's communist background has been assumed to affect the perception and treatment of mental illnesses, as it was historically believed that there were no social problems in the country, and people coping with mental illness were referred, housed and treated in large shelters away from the community (Bajzáth et al., 2014). Furthermore, compared to physical health, mental health was and still is underfinanced (Dlouhy, 2014). The "hospital law" announcing on a reduction of 25% of psychiatric beds and the subsequent closure of the country's largest psychiatric center resulted in a further reduction of available treatment options for patients (Kurimay, 2010). With limited mental health support remaining, Hungary did not execute any formal plan for mental health promotion and anti-stigma programs, despite the World Health Organization's (WHO) recommendations and previous in-country intentions (Fernezelyi et al., 2009). Furthermore, despite WHO's recommendations on community psychiatry, no plan regarding how to initiate such a paradigm has established in Hungary (Fernezelyi et al., 2009). This atmosphere is well reflected in studies that found Hungary to have the lowest level of knowledge about mental diagnoses (Olafsdottir & Pescosolido, 2011), the most negative attitudes towards people coping with mental illness and the most negative views regarding seeking professional help, compared to Germany, Ireland and Portugal (Coppens et al., 2013). In light of this, further research on stigma and patients' coping with mental illness in Hungary might be especially needed to shed light and address elements which have been unspoken for years, and which have affected the lives of millions who are coping with mental illness.

Above all, this dissertation aimed to initiate and facilitate a more profound body of research in Hungary and globally, which will focus on the experience of people coping with mental illness with the hope of improving treatment plans, care and quality of life for those struggling with mental health disorders.

# Chapter 2: General Introduction: Living with Mental Illness

The main goal of this chapter is to review the literature on the subjective experience of people coping with mental illness, and more specifically to examine elements in patients' experience which despite their significance have been largely understudied. Moreover, the goal of this chapter is to present patients' internal experience as one which cannot be underestimated, ignored, or detached from research aiming to improve illness symptomology and recovery. Firstly, this chapter will present the well-known problem in the mental health field of non-adherence to medical treatment, known for its destructive impact on recovery and coping. Then the chapter will introduce the problem of stigma towards mental illness, and by adopting change in perspective, will focus on patients' internal experience rather than on objective factors which have been mostly the focus of research aiming to increase adherence. This chapter will give a glimpse into the life of people coping with mental illness to gain a better understanding regarding the inhibitory factors in treatment adherence which also undermine recovery. As such, the chapter will focus on the experience of stigma, loss and grief.

## Treatment non-adherence in the mental health field

Coping with mental illness is a lifelong process. The chronic nature of mental illnesses means that constant care and monitoring are often required. 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 (Corrigan, 2004; Lee et al., 2006), non-adherence among people with mental illness is disturbingly high.

Adherence is “the extent to which a person’s behavior- taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care professional” (World Health Organization, 2003, p. 3). Adherence behavior is not considered to be defined based on strict classification of complete adherence and complete non-adherence, but is regarded as a behavioral range from complete adherence to partial adherence and complete non-adherence (Julius et al., 2009).

Non-adherence constitutes a serious problem in the mental health field due to its devastating consequences and its high prevalence, which are considered to be higher than for people who are coping with physical illnesses (Fenton et al., 1997; Keck et al., 1996; McDonald et al., 2002; Scott & Pope, 2002). Non-adherence is prevalent among those with a wide range of mental health diagnoses, with non-adherence rates by diagnosis of 56% for schizophrenia, 44% for bipolar,  and 50% for adherence to antidepressants (Semahegn et al., 2020). Some have even reported on non-adherence rates as high as 65% and 70%  (Alekhya, Sriharsha, Priyadarsini, et al., 2015; Alekhya, Sriharsha, Ramudu, et al., 2015; Banerjee & Varma, 2013; Cramer & Rosenheck, 1998) and 57% in those with anxiety disorders (Julius et al., 2009). The implications of non-adherence are severe both for the patients and society as a whole. Non-adherence has been found to be related to worsening of symptoms and re-hospitalization, relapse, suicidality, reduced quality of life among patients, and is related to increased economic burden through high costs of healthcare usage, as well as unemployment and loss of income for patients (Ernst & Goldberg, 2004; Farooq & Naeem, 2014; Perkins, 2002; Puschner et al., 2009; Sajatovic et al., 2004; Svarstad et al., 2001).

Over the years, different methods have been developed to measure adherence and understand non-adherence better. These can be largely classified into objective and subjective methods. Objective measures include medical records, pill counts, electronic monitoring and blood/urine samples, while subjective ones are based on patient and clinician self-reports (Ljungdalh, 2017). Despite the variety in measurement methods, it seems that agreement is lacking regarding the best one to use to measure adherence, as each of them carries its own limitations in terms of accuracy, high cost, and administration (Velligan et al., 2006). As a result, studies utilizing different methods pose challenges to adherence research, especially as there is low accord among methods (Velligan et al., 2009). Different studies also differ in the way they define non-adherence, which can range from consuming 50% to 90%  of prescribed medication (Semahegn et al., 2020; Velligan et al., 2006). Still, in the study of adherence there is a significant reliance on self-report scales of patients and clinicians to assess adherence (Ljungdalh, 2017; Velligan et al., 2006). Despite being criticized for overestimating adherence (Velligan et al., 2009) and being affected by social desirability, memory, and patients’ manner of understanding the questions

(Farmer, 1999), it still constitutes the easiest measure to administer due to being non-intrusive and low investment, and being constructive in terms of providing valuable knowledge about how specific individual difficulties undermine adherence efforts (Fialko et al., 2008).

In efforts to address treatment non-adherence, 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. These can be classified into three main categories: Patient, environment and medication related factors. Patient related factors include demographic factors, negative attitudes towards medications, shorter illness duration and having poor insight into the illness. Treatment related factors include different types of medications and side effects, whereas environment related factors include social support and living conditions (Gaebel et al., 2010; Kampman et al., 2002; Perkins et al., 2008; Velligan et al., 2009). Recently however, studies have shifted attention towards more subjective factors related to patients' inner experience in coping with mental illness, aiming to gain a better understanding regarding the willingness of the person to adhere or not to the treatment (Ho et al., 2017; Tranulis et al., 2011; 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

Every year it is estimated that 38% of the European population cope with mental illness, which means there are 164.8 million people yearly who experience mental health issues (Wittchen et al., 2011). For many of them, the "living with mental illness journey" does not end with managing their symptoms and struggles, but they also have to cope with the stigma, stereotypes and misconceptions about mental illness held by the public, including even health providers themselves (Corrigan & Watson, 2002; Knaak et al., 2017). Stigma towards mental illness is still surprisingly highly prevalent, despite the remarkable statistics of people affected by mental illness, and is considered to be in many instances as having more harmful influence on the life and well-being of people than the mental diagnosis itself (Cechnicki et al., 2011).

Stigma can be defined as "an attribute that is deeply discrediting and lessens a person from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3).

Studies on mental illness stigma often classified it into two components: Public stigma and internalized stigma. Public stigma refers to the negative stigmatic attitudes held by members in the society (Corrigan, Watson, et al., 2006). Internalized stigma refers to 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). This research mainly includes stereotypes, prejudice and discrimination (Corrigan et al., 2009). Stereotypes towards mental illness mostly include beliefs that people with mental illness diagnoses are dangerous, unpredictable, and violent (Angermeyer & Dietrich, 2006). Prejudice is peoples' agreement with stereotypes about mental illness, which leads to negative emotional reactions (Hilton & von Hippel, 1996). Discrimination is behavioral reactions that can be manifested in loss of opportunities (job positions, living possibilities), social avoidance (Corrigan & Watson, 2002), coercion (such as perceiving the person as unable to make a decision for himself and thus authorities should make it for him, for example belief that treatment should be forced on people coping with schizophrenia (Pescosolido et al., 1999)) and segregation in the form of separating people with mental illness from the population into institutions (Brockington et al., 1993; Farina et al., 1992). As a result of the stigma, people who are coping with mental illness often face unemployment (Sharac et al., 2010), avoid care (Corrigan et al., 2014), experience limited social interactions and isolation (Rössler, 2016), have increased rates of suicide (Schomerus et al., 2015) and show reduction in their perceived health condition (Alvarez-Galvez & Salvador-Carulla, 2013). Stigma in mental illness is highly prevalent and spread around the world (e.g. Asia (Thara et al., 2003), Africa (Alem et al., 1999), Latin America and the Caribbean (de Toledo Piza Peluso & Blay, 2004), Southwest Asia (Al-Krenawi et al., 2004), and does not exclude any diagnosis; schizophrenia, mood disorders, anxiety disorders and eating disorders, are all largely stigmatized (Gerlinger et al., 2013; Griffiths et al., 2006, 2008, 2011; Mond et al., 2006). Considering the scope and the consequences, public stigma constitutes a significant problem in the mental health field.

The study of public stigma has mainly used the measure of social distance to examine and address stigma (Bogardus, 1925; Link et al., 1987). Social distance can be defined as one's desire to avoid contact with a given group of people in different forms of everyday contact (Jorm & Oh, 2009), and to express discriminatory behavior and rejection of specific groups of people. Research has shown that public desire for social distance is higher towards people coping with mental illnesses compared to people who are presenting normal behavior (Eker, 1989; Ingamells et al., 1996; Nieradzik & Cochrane, 1985), people with minor struggles (Link et al., 1999; Martin et al., 2007) or physical diseases (Breheny, 2007; Martin et al., 2007; Phelan, 2005) and other disorders (Falk, 2001). Among the different mental illness diagnoses, those with schizophrenia have been found to be more stigmatized than those with depression and anxiety disorders (Angermeyer & Dietrich, 2006; Rössler, 2016). Furthermore, findings from trend analysis studies reflected a grim reality; 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). In some instances it even got worse (Angermeyer et al., 2013). In an effort to understand better the underlying factors for social distance preferences, studies have looked at personal characteristics and found that factors such as older age, lower education, and less contact and familiarity with people with mental illness were all related to higher social distance (Jorm & Oh, 2009). Gender on the other hand did not yield consistent findings, as some studies found no impact for gender (Angermeyer et al., 2003; Jorm et al., 2012; Jorm & Oh, 2009), some found female gender to be related to greater social distance (Franke et al., 2019; Gaebel et al., 2008; Lauber et al., 2004), and others found males to express greater desire for social distance (Jorm & Griffiths, 2008; Jorm & Wright, 2008; Yoshioka et al., 2014). However, over the years too few studies using trend analysis have been conducted to allow more conclusive statements and suggestions regarding how to address the issue. Contributing to this difficulty is the fact that most of the studies on stigma were conducted in Western countries (Angermeyer & Dietrich, 2006). Furthermore, in Europe itself the distribution of stigma studies is mostly centered in Northwestern countries, whereas data from other parts of Europe, especially from Central and Eastern Europe is limited (Clarke et al., 2007; Evans-Lacko et al., 2014). This information might have a special importance as, according to the evidence, stigma is presumed to be higher in countries where research is lacking (Lasalvia et al., 2013; Thornicroft et al., 2009). Some support for this was found in a study that compared stigmatic attitudes towards patients with mental illness in the Czech Republic to those in England and found higher stigma in the Czech Republic (Winkler et al., 2015). The authors connected the characteristics of the country, with its new economy market and communistic background, to the difference that was found, especially the lack of sufficient budget devoted to mental health, low awareness of the public to mental illnesses and elevated rates of institutionalization. According to these investigators, their findings may reflect a bigger problem that might be prevalent in other Central and Eastern new market economy countries and may need further research. These findings also emphasize that stigma is widely prevalent in different countries and cultures, even if there is no declared awareness or recognition of it, and sometimes even specifically because of having no research on this topic, as previous studies show.

In light of the magnitude of stigma and its high prevalence around the world , the World Health Organization identified it as a global problem and also determined that actions against it should be taken (World Health Organization, 2013). As a result, research focus and efforts were dedicated to the establishment of anti-stigma intervention programs, most of which were focused on educating the public and refuting stereotypes, increasing familiarity with mental illness (Corrigan et al., 2012; Griffiths et al., 2014), and using mass media to protest against discrimination and increase awareness (Clement et al., 2013; Corrigan & Penn, 1999). These programs were found to be generally effective in reducing the stigma, but their effect was found to be small overall (Clement et al., 2013; Griffiths et al., 2014) and there is a need for further research to address it properly. While this focus on public stigma and efforts to reduce it in the general public are important, another important if not crucial topic, the stigma experience of those who cope with mental illness themselves, has received only little research attention (Brohan, Slade, 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; Yanos et al., 2010). Internalized stigma often considered to be a result of public stigma, starts early on when people develop certain belief systems about mental illness based on the cultural perception they were exposed to from childhood, which in many societies include many negative stereotypes. These all become relevant when the person herself or himself develops a mental illness. Internalized stigma can be defined as a multi-stage process: 1. Stereotype awareness, when the person is aware of the negative attitudes that exist in society regarding mental illness; 2. Stereotype agreement, when the person perceives these negative attitudes as true and valid; 3. Self-concurrence, when the person believes that these accurate negative attitudes apply to her/himself and represent who she/he is; 4. Self-esteem reduction, when the person's self-esteem decreases following the application of negative attitudes on one's self (Corrigan, Watson, et al., 2006). The end result of this process is individuals who lose their identity and adopt a new and stigmatized one (Yanos et al., 2010). Research reports that internalized stigma is widely common, as a third of people coping with mental illness exhibit elevated levels of internalized stigma (Brohan, Elgie, et al., 2010; Yanos et al., 2011). Internalized stigma is considered to incorporate different elements: cognitive (negative self-perception), affective (shame, anger, sadness) and behavioral (avoidance)(Brohan, Elgie, et al., 2010). As such, it is not surprising to find that internalized stigma is related to a long list of negative outcomes, some resulting from efforts to avoid being labeled as "mentally ill" and stigmatized, and some resulting from its relatedness to avoidant coping (Lysaker et al., 2007, 2009; Yanos et al., 2008). These effects of internalized stigma have severe implications for treatment delays and are strongly related to non-adherence to medical and psychosocial treatment (Cinculova et al., 2017; Corrigan, 2004; Fung et al., 2007), as was very much evident among various mental diagnoses (schizophrenia, bipolar, substance abuse disorders, depressive disorders, anxiety disorders and personality disorders) (Kamaradova et al., 2016). Among other negative consequences of internalized stigma are lower self-esteem, self-efficiency, empowerment, hope, social support and quality of life (Corrigan, Larson, et al., 2006; Corrigan, Watson, et al., 2006; Lysaker et al., 2007; Pearl et al., 2017; Werner et al., 2008).

### Shame

A major reaction of people who internalize the stigma of mental illness is shame

(Birchwood et al., 2007; Hinshaw, 2007; Rüsch et al., 2006; Schmader & Lickel, 2006), which despite being described as highly prevalent among people with mental disorders (Rüsch et al., 2007; Swan & Andrews, 2003) and affecting negatively patients’ self-esteem and quality of life (Rüsch et al., 2007), has been mostly neglected (Link et al., 2004). While a high degree of shame is prevalent in mental illnesses in general, there is evidence pointing to diagnostic differences, suggesting that people coping with borderline personality disorder (BPD) are especially prone to experience higher levels of shame (Ritter et al., 2014; Rüsch et al., 2007; Scheel et al., 2014; Unoka & Vizin, 2017).

The specific importance of shame is related to its destructive association with depression, suicide, social withdrawal and its influence on relationships and treatment avoidance (Hastings et al., 2000; Leenaars et al., 1993; Tangney, 1993; Tangney & Dearing, 2002). Shame, a self-conscious emotion, is usually experienced as a result of self-perception influenced or controlled by negative evaluation (Lewis, 1971) and is associated with feelings of inferiority and worthlessness (de Hooge et al., 2010). The examination of shame might be important as well in understanding the underlying mechanism affecting internalized stigma and its negative consequences, mainly treatment avoidance (Rüsch et al., 2006).

The interplay between shame and internalized stigma recently has been suggested to explain an interesting phenomenon mentioned in the scientific literature named "insight paradox" (Belvederi Murri et al., 2016; Lysaker et al., 2007). Insight, one's awareness of having a mental disorder, is a well-studied factor, mainly due to the high prevalence of people coping with various mental illness and lacking proper insight (Ghaemi et al., 2000; Pini et al., 2001). Lack of insight carries negative implications for recovery and well-being such as lower treatment adherence, worse clinical outcomes and clinical impairments (Aleman et al., 2006; Mohamed et al., 2009; Yen et al., 2005). However, paradoxically, accumulating findings have indicated that having insight might not always be positive, as it was found to be related to depressive symptoms, low self-esteem, lower quality of life and a sense of less meaning in life (Belvederi Murri et al., 2016; Ehrlich-Ben Or et al., 2013; Lysaker et al., 2003; Mintz et al., 2003; Moore et al., 1999; Staring et al., 2009). Internalized stigma was found to explain this paradox. Stigma carries for the person who internalized it negative meaning which attached to the recognition of having a mental illness. Thus, among these persons, insight might be accompanied and contaminated by stereotypical beliefs which make the individuals more vulnerable to adverse consequences (Lysaker et al., 2007; Staring et al., 2009). In that respect, shame was found to play significant role in making insightful individuals prone to internalize the public stigma, as it was found to mediate the relationship between insight and internalized stigma (Hasson-Ohayon et al., 2012). Thus, study of shame should be promoted and addressed, as it might play a significant role in interventions aiming to reduce internalized stigma and treatment avoidance and it might facilitate good insight which is not accompanied by negative self-beliefs.

As the study on stigma shows, coping with mental illness might be an emotionally painful process. While internalized stigma is a well-studied factor, research on the broader internal experience of people coping with mental illness is generally understudied. Understanding better and uncovering additional elements in patients' experience of coping with mental illness is important in gaining a better understanding regarding barriers to recovery and strategies to improve quality of life and wellbeing.

### The experience of loss

The experience of loss is a well-known reaction to different major life changes and events, with death of a loved one being the most clear example, but it can also include divorce, loss due to a natural disaster (Harvey et al., 1995) and the development of chronic physical illness (Harvey, 2002; Kelley, 1998; Stroebe & Schut, 2001). Although loss can be experienced following different life events and in differing intensity, it has been found to encompass common features (Harvey & Miller, 1998; Papa et al., 2014; Parkes, 1972). Loss has been defined as reduction in resources, whether they are concrete or abstract, which have a significant emotional importance for the affected individual (Harvey, 1996). Living with mental illness often means coping with a chronic health condition which poses difficulties and challenges, and which requires adjustments and can be emotionally demanding (Birley, 1991). Coping with mental illness often means for the patients an immense sense of loss, resulting from multiple losses in crucial aspects of life starting from loss of functioning in performing the most basic daily activities, to the loss of aspects of emotional and cognitive functioning, friendships, romantic relationships and educational and employment opportunities (Mauritz & van Meijel, 2009). The realization of having a mental illness has even been described as a psychological disaster, a crisis, due to its dramatic consequences for a person's daily life and future (Mauritz & van Meijel, 2009; Wittmann & Keshavan, 2007). Despite this, the experience of loss in mental illness has been neglected by research and society, partly because of the fact that the loss involved in mental illness is less evident or less visual as compared to the physical loss which is involved in physical illness and the death of a loved one (Baxter & Diehl, 1998; Young et al., 2004). 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, which also contributes to the lack of support usually provided to individuals coping with other, less stigmatized types of losses (Young et al., 2004). Decades ago, it was already claimed that the loss involved in mental illness is one that "cannot be openly acknowledged, socially validated, or publicly mourned" (Doka, 1989, p. xv), mainly as the acknowledgment of having a mental illness diagnosis usually carries self-blame, inferiority and helplessness (Young et al., 2004). Thus, loss following mental illness was named "ambiguous loss" due to the lack of public recognition or "ritualization" (Boss, 1991). Furthermore, while stigma contributes to the lack of public awareness of the loss, it can also intensify and contribute to higher sense of loss. Stigma can lead others to avoid contact with people coping with mental illness (Overton & Medina, 2008) and so fears from stigma and being labeled can lead to efforts to hide the illness, which can lead to an increase in symptoms and can slow recovery (Johnstone, 2001) creating more isolation, fewer opportunities, and thus further losses. Stigma also diminishes opportunities in terms of career and housing (Overton & Medina, 2008), which can intensify feelings of loss.

The loss following mental illness has been claimed to be different and unique in nature compared to other types of loss, as it is the chronic nature of the illness itself, its being periodic and unpredictable in terms of ending, which contributes further to the complexity of coping with mental illness (Olshansky, 1962).

Surprisingly, despite the meaningful 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, rather than by the individuals themselves coping with mental illness. Families' sense of loss was mostly related to the manifestations of mental illness; its symptoms and effect on functioning and the consequent losses experienced by their loved one in differing areas of life (Farina, 2000; MacGregor, 1994; Solomon & Draine, 1996). These studies however, did not purely focus on the perception of loss itself but investigated one of its most common outcomes, the reaction of grief (Davis & Schultz, 1998; Miller et al., 1990; Solomon & Draine, 1996), which found to be prevalent in these families. These studies reported over the years that family members, parents in particular, are grieving the losses brought into their relative's life by mental illness, and especially the loss of potential for their child to live a "normal life" (Ryan, 1993; Stein & Wemmerus, 2001).

The need to address and examine the question of what it is exactly that is lost in patients' lives following mental illness led a new line of studies to examine specifically the perception of loss among people coping with mental illness. A study which focused on the experience of loss of people coping with schizophrenia found that loss appears to be a core experience of patients who described it as "overwhelmingly painful" (Mauritz & van Meijel, 2009, p.26). Their experience of loss was acknowledged as important to address in order for them to reach an acceptance of their illness and to improve their coping (Mauritz & van Meijel, 2009). Another study found that patients' most prevalent and apparent loss in their lives was the loss of relationships, emphasizing this as an area of importance that should be addressed to improve recovery (Baker & Procter, 2015). The field of study of personal loss among patients underwent significant progress following the development of the Personal Loss from Mental Illness scale (PLMI) (Stein et al., 2005), which measures the perception of loss among people coping with mental illness. The scale was found to have good psychometric properties and to include four factors that reflect different loss areas: "Loss of Roles and Routines", "Loss of Former Relationships", "Loss of Former Self" and "Loss of Future" (Stein et al., 2005). The sense of loss among patients was found to be related to loneliness, increased symptoms, more problem drinking and lower well-being, stressing its impact on coping and recovery (Stein et al., 2005).

A number of studies using the PLMI supported the association between higher sense of loss and increased loneliness (Stein et al., 2013), and found loss to be related to low motivation for higher education (Stein, 2005), negative religious coping (Phillips & Stein, 2007) and to affect negatively recovery and quality of life (Potokar, 2008). These preliminary findings and the already known role of loss in recovery (Davis et al., 1998; Harvey et al., 1990; Neeld, 1990) target loss as an important aspect in the process of coping with mental illness which requires further research. This is especially important considering the common grief reaction, which usually follows perception of loss, and which also has not received much attention to date in investigations of coping with mental illness.

## 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. Grief is known to include denial of the loss, anxiety, restlessness and physiological symptoms, effort to search for the lost person, anger and guilt until acceptance of the loss and the new reality appears (Freud, 1917; Lindemann, 1944). Moreover, intrusive thoughts about the loss and emotional distress can be present, as well as avoidance of any reminders of the loss and difficulty in accepting the loss (Bruce et al., 1996; Davis & Schultz, 1998; Hansson et al., 1993; Horowitz et al., 1981; Miller et al., 1990).

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; Porritt & Bartrop, 1985).

As with loss, the examination of grief following mental illness has been relatively lacking. Grief in that aspect has been called "disenfranchised grief", as it is not acknowledged by society, in contrast to obvious grief following the death of a loved one (Doka, 1989). Worden (2009) even described this grief as including loss which is "socially negated" (p. 3) meaning that society perceives this grief as not involving "real" loss. This might not leave any place for people affected by mental illness to cope and work through their grief. As with the experience of loss, the studies which did focus on grief examined it in families. Olshansky (1962) was the first to imply that families are experiencing grief as a response to their child’s mental illness. He phrases it "chronic sorrow" and claimed that parents feel a significant sense of loss due to their child’s illness and react with a prolonged and recurring sadness. Chronic sorrow was also perceived to be a normal reaction to the complicated loss following mental illness, loss which was described as including multiple and never-ending losses, real and symbolic.

Since Olshansky's first claim, grief has been reported as a common reaction among families and parents of an individual coping with mental disorder (Atkinson, 1994; Bruce et al., 1994; Godress et al., 2005; Miller et al., 1990). Their grief has been described as complicated, as it has no clear loss object, and is considered to involve losses in which their representations and meaning continue to change and evolve over the years and meaningful landmarks in life. This makes it difficult for families to completely comprehend the loss and cope with their grief (Bruce & Schultz, 1992; Ozgul, 2004). Research on grief among families supports the known reported grief manifestations such as continuing emotional distress, preoccupation with their ill relative, struggles to adjust and accept the loss, intrusive thoughts about the illness and the loss and avoidance of reminders of the illness and the loss (Godress et al., 2005).

Recently, the association between grief and well-being was supported as well with regards to grief following mental illness, as among these families, their grief over their child’s illness was found to be related to increased emotional distress, reduced psychological well-being and poorer health status (Godress et al., 2005). Most importantly, studies on grief among families not only support its presence but also emphasize its magnitude, as shown by findings indicating that grief among families as a result of mental illness is similar to the grief of families who have lost their loved one (Miller et al., 1990). This grief, moreover, was found to be higher and more intense than the grief which was experienced by families who lost a child, or who have a child with head injury (Atkinson, 1994). According to Miller et al. (1990) grief involved in mental illness is delayed compared to grief involved in death, due to the progressive nature of mental illness; mental illness brings more losses and pain over time, which can only be completely and clearly grasped years after the initial diagnosis (Miller et al., 1990). While these studies uncovered remarkable findings regarding the impact of mental illness on families, surprisingly there is a lack of studies examining the impact of mental illness in terms of the grief it brings to those who are coping themselves with mental disorders. People who are coping with mental illness are not grieving for the loss of another person, but might be grieving the loss of their past identity and the person they used to be (Wittmann & Keshavan, 2007). The few studies that investigated grief in patients focused on schizophrenia, and only one of these evaluated it empirically by qualitative measures (Mauritz & van Meijel, 2009). Case studies did refer to the losses patients with schizophrenia are experiencing (e.g. to social life, functioning, educational and occupational), which in order to accept them, patients must go through a grieving process (Appelo et al., 1993; Wittmann & Keshavan, 2007). In their qualitative study Mauritz and van Meijel (2009), were able to document and support the manifestations of grief in patients as well, as patients coping with schizophrenia reported on a grieving process following the discovery of their illness. They discovered that grief  was initially manifested as a shock reaction, which they described as "psychological disaster" (p.255), which later on was followed by patients' denial of their 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). Denial was one of the ways patients could avoid feeling the grief and emotional pain. One of the patients even described it as being "so painful, a kind of paralyzing sadness. That is what I run away from. I don't want to face it. I prefer not to talk about it" (Mauritz & van Meijel, 2009, p. 255). Patients' grief was manifested by different emotions such as anger and desperation, and by behavioral avoidance and withdrawal from others. Their grief was also found to increase the experience of loss, such as in cases when denial of the need for treatment lead to non-adherence to medications, which resulted in worsening of symptoms and further obstacles to daily functioning and contacts with others. Eventually patients reported on coming to terms with the illness, which occurred after recognizing their illness and their loss as a fact and accepting it, together with the limitations and adjustments it brings to their lives. According to Mauritz and van Meijel (2009) acceptance was related to medication adherence, a decrease in symptoms and receiving information about the diagnosis. Finding new meaning to life and having hope were mentioned as successful means to cope with the grief (Mauritz & van Meijel, 2009).

To build on these findings, further exploration of the impact of grief on patients is needed. This is especially important considering the literature on grief among families, connecting it to a reduction in health and well-being. Preliminary studies on grief among patients might even propose that it has a negative influence on actual coping with the illness such on their medication-taking behavior. As grief does involve denial and avoidance coping, the examination of grief might uncover and contribute new knowledge to the study of coping with mental illness and ways of improving adherence. Furthermore, investigating the coping process using a grief lens might contribute significantly to a better understanding of patients' experience, and could have meaningful therapeutic implications. If grief is addressed, therapies could be directed towards achievement of acceptance and adaptive coping (Appelo et al., 1993). Use of a grief lens might also help in understanding better the phenomenon of patients' lack of insight into their mental illness. It might be that what was considered to be poor insight is a simple reflection of active grieving.

## Overreaching research questions

While there are still many open questions left about the exact manifestations of loss and grief among patients, this dissertation aimed to focus on the larger picture of the internal experience of patients coping with mental illness, emphasizing its significance also to the study of treatment non-adherence and patients' quality of life. The number of studies focusing on patients' experience, especially of loss and grief, is limited. Moreover, most of the studies in this field were focused on those with a schizophrenia diagnosis, neglecting other chronic mental diagnoses. Thus, knowledge in this field is sparse. As such, this dissertation adopts a global perspective into looking at different elements of patients' experience, with the main aim of examining the experience of patients with different diagnoses and its possible impact on their lives and adherence to treatment. By doing that, a secondary goal of this dissertation is to contribute new knowledge to the study of patients' experience worldwide, in countries which this study is especially limited, by translating and validating existing English language questionnaires into Hungarian. Similar findings of patients' experience in different cultures and countries might show a shared experience among people coping with mental illness and emphasize the importance of examining and addressing it. By presenting a global picture of patients' experience and its crucial significance to coping and recovery, this dissertation aimed to raise awareness and facilitate further and more specific research on elements and mechanisms in patients' experience. This is needed to contribute knowledge and address existing gaps regarding the study of mental illnesses when compared to physical illnesses, and especially to improve patients' coping and quality of life.

## Specific research questions related to the five studies

*Study 1* aimed to initiate the examination of patients' experience firstly by examining the existence and significance of the problem of public stigma towards mental illness, and more specifically in a country where such examination is lacking. As such, the study aimed to examine for the first time in Hungary the attitudinal trends towards people coping with mental illnesses. Examining stigma in Hungary is especially important considering the lack of studies coming from Central and Eastern Europe, and considering preliminary evidence from other new market economy countries of a worrisome picture of significantly higher public stigma when compared to western countries (Winkler et al., 2015). This study used a social distance measure to investigate trends of stigma over a 15 year period among nationally representative samples. Furthermore, the study also evaluated the possible determinants of stigma towards people coping with mental illness. Even though improvement over the years in public attitudes was expected due to Hungary stronger relationship with European values after joining the EU in 2004, this improvement was expected to be only moderate, consistent with findings from other countries with similar communist background (Winkler et al., 2015), and due to the country’s underfinanced mental health system and lack of national anti-stigma programs (Dlouhy, 2014; Fernezelyi et al., 2009). Based on the literature it was also expected that older age, lower education level and lower familiarity with mental illness would significantly predict higher preferences for social distance from people coping with mental illness.

*Study 2* moved on to focus solely on the internal experience of people coping with mental illness diagnosis. More specifically, this study aimed to focus on the experience of loss following mental illness, which despite its central role in patients' lives and in recovery (Appelo et al., 1993; Davis et al., 1998; Lewis, 2004; Neeld, 1990; 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 people coping with wide range of mental diagnoses.

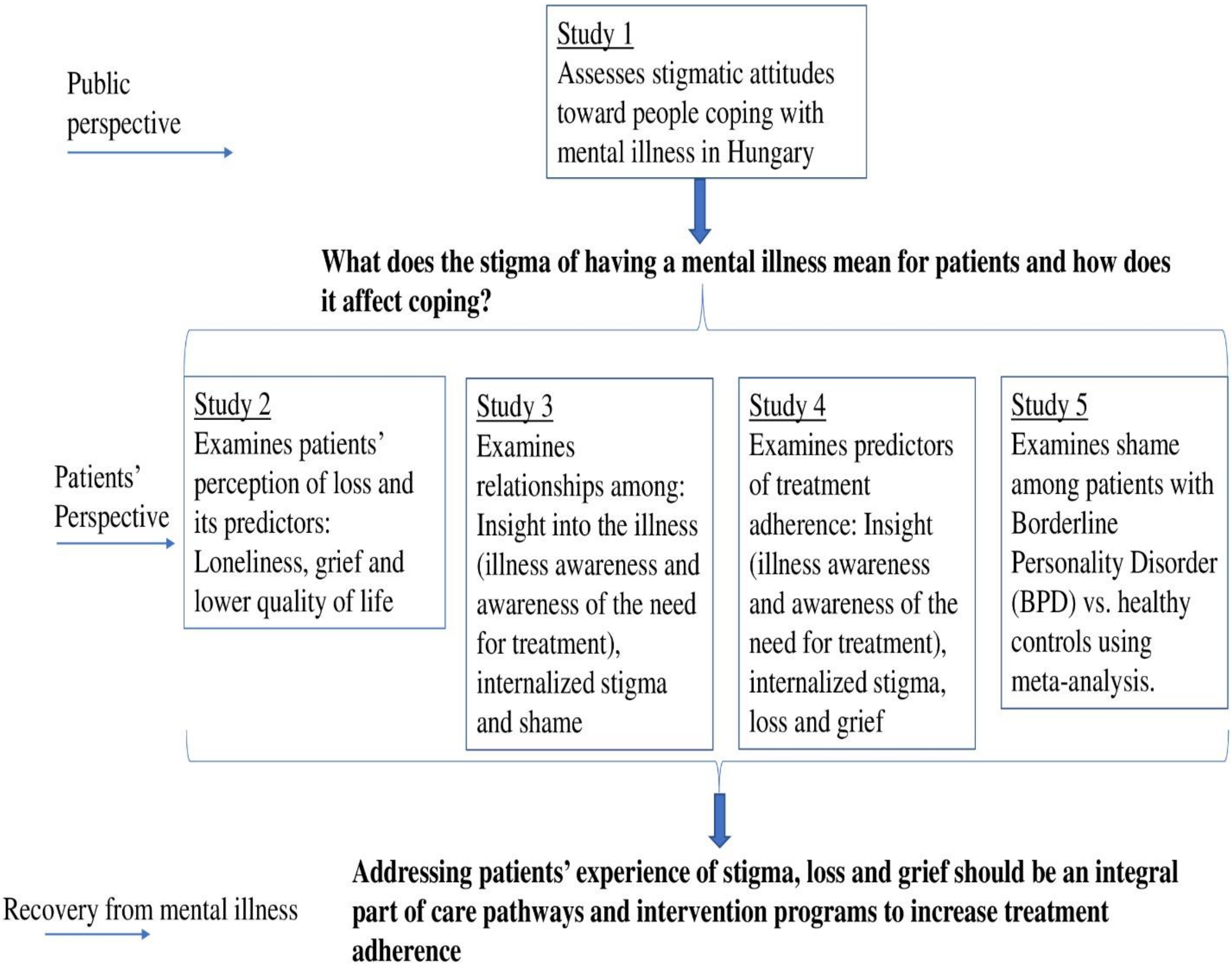
Furthermore, this study aimed to examine the construct validity of the relatively new Personal Loss from Mental Illness scale (PLMI) (Stein et al., 2005) in a non-English speaking sample using confirmatory factor analysis (CFA). Based on the literature, possible covariates of loss were examined as well, while the predictive power of grief was empirically investigated for the first time. It was expected that older age, previous history of hospitalizations, loneliness, grief, and lower quality of life would be significant predictors of higher perception of loss.

*Study 3* proceeded to examine further the experience of patients, and 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. This study aimed firstly to examine the construct validity of one of the most commonly used insight scales, the Birchwood Insight Scale (BIS)(Birchwood et al., 1994), among an Hungarian sample of people coping with mental illness diagnoses. Examining the factor structure of the BIS is important especially since such investigation has been limited and has also yielded inconsistent findings (Birchwood et al., 1994; Cleary et al., 2014). Moreover, focusing on different diagnostic categories is important, mainly as the BIS was mostly used with patients with schizophrenia and psychosis (Cleary et al., 2014), and poor insight has been found to be common also among those with other diagnoses (Eisen et al., 1998; Nassir Ghaemi et al., 2000; Michalakeas et al., 1994; Peralta & Cuesta, 1998). Subsequently, possible predictors of insight were examined, as well as the reported negative meaning it entails for patients, such as internalized stigma and shame. It was expected that insight would be a significant predictor of high levels of internalized stigma and shame.

*Study 4* 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 aimed to examine the factor structure of the Medication Adherence Rating Scale (MARS) (Thompson et al., 2000) among Hungarian patients with different diagnoses. As with insight and the BIS, the MARS was mainly used among those with schizophrenia, and 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; Lingam & Scott, 2002; Melfi et al., 1998), it calls for a wider examination. Furthermore, the possible predictors of treatment adherence were examined as well, and for the first time, patients' experiences such as loss and grief were examined as possible predictors. The negative impact of non-adherence on patients' lives was investigated as well. It was expected that lower insight, increased internalized stigma, loss and grief would be significant predictors of treatment non-adherence. Lower adherence was expected to be related to lower quality of life.

*Study 5,* due to the suggested relatedness of shame with internalized stigma and its suggested impact on adherence, aimed to focus on the experience of shame among the group known to suffer from it the most, that is people coping with Borderline Personality Disorder (BPD) (Ritter et al., 2014; Rüsch et al., 2007; Scheel et al., 2014; Unoka & Vizin, 2017). The study aimed to stress the prevalence and significance of shame by conducting the first meta-analysis comparing self-reported shame among patients with BPD to a healthy control group. Although studies reporting shame to have negative impact on self-esteem, quality of life, and core BPD symptoms (such as unstable relationship patterns and anger and hostility) (Rüsch et al., 2007; Unoka & Vizin, 2017), and as one of the leading factors for suicidal tendencies (Lester, 1997; Linehan, 1993), research on shame among those with BPD specifically and with other groups in general, has been neglected. Such investigation is needed to understand better the prevalence and significance of shame in this population. It was expected that patients with BPD would report on experiencing higher shame compared to healthy controls.

**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: Social rejection towards mentally ill people in Hungary between 2001 and 2015: Has there been any change? (study 1)

Note. The article has been accepted for publication and the final pre-published version is presented in this thesis. The final published version is available in: https://doi.org/10.1016/j.psychres.2018.05.051

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## Abstract

Despite the improving mental health literacy of the public over recent years, people's attitudes towards people with the diagnosis of mental illness do not appeared to have changed. Long-term studies are scarce and mainly limited to Northwestern Europe. Given that no study has ever been carried out in Hungary, the present study examined attitudinal trends towards mentally ill people in the country, and evaluated its determinants using one item of the Social Distance Scale to assess social rejection towards others. National representative surveys of Hungarian adults were conducted in 2001, 2003, 2007 and 2015 (*n*=7605). By means of interview and a self-administered questionnaire, socio-demographic information, preferences for social distance, and familiarity with mental illnesses were assessed. Trend analysis demonstrated that no meaningful change had occurred in the desire for social distance over a period of 15 years. Being a woman, having low education level, and lower familiarity with mental illnesses were all related to higher preferences for social distance. However, the explanatory power of these factors was very small (4.2%). As found in other countries, attitudes towards mentally ill people have not changed in Hungary. More effort is needed to understand better and overcome social rejection concerning mental illness.

**Keywords:** Mental illness; Stigmatization; Social distance; Trend analysis; Public attitudes; Anti-stigma programs; Mental health promotion

## 1. Introduction

Annually, up to one-third of Europeans suffer from at least one mental disorder meaning that approximately 164.8 million people in Europe are affected by mental illnesses (Wittchen et al., 2011). In addition to their symptoms, people diagnosed as being mental ill must cope with the stigma surrounding these disorders (Caldwell & Jorm, 2000; Gureje et al., 2005; Jorm et al., 1997; Link et al., 1999). They often perceived as strange, frightening, unpredictable, aggressive, lacking self-control, violent and dangerous (Crisp et al., 2000; Link et al., 1999; Phelan & Link, 1998). These beliefs, often conceptualized as 'public stigma', constitute one of two stigma dimensions and should be differentiated from 'internalized stigma', the internalization of stigmatizing beliefs by the stigmatized individual (Corrigan & Watson, 2002). In any of the dimensions, attitudes concerning stigma can have a severe impact on people' lives because they experience psychological distress, have difficulties with personal relationships, experience delays in seeking help, and have decreased opportunities in achieving educational and vocational goals (Corrigan, 2004; Link et al., 1997; Wells et al., 1994).

The most frequently used variable to assess stigma is social distance and can be used to assess the desire to avoid contact with mentally ill people (Jorm & Oh, 2009). Studies have consistently reported that despite the improving mental health literacy of the public (Angermeyer & Matschinger, 2005; Jorm et al., 2006), social distance preferences concerning mentally ill people have not changed over the last 20 years (Schomerus et al., 2012) and in some cases have even increased (Angermeyer et al., 2013). Long-term studies are important in this respect because the knowledge they contribute serves as a reliable starting point for intervention programs. However, the number of studies using trend analysis is scarce and mainly limited to wealthier countries because such studies are both costly and time intensive . Consequently, most studies to date have been carried out in North Western Europe (Evans-Lacko et al., 2013; Makowski et al., 2016; Mirnezami et al., 2015) whereas data from Central and Eastern European countries (Clarke et al., 2007) –especially from countries with new market economies–is lacking (Evans-Lacko, Courtin, et al., 2014). This is of significant importance especially because greater stigma towards the mentally ill has been found in countries with less research on the topic (Lasalvia et al., 2013; Thornicroft et al., 2009). For instance, Winkler et al. (2015) reported significantly higher rates of stigma towards mentally ill people in the Czech Republic when compared to those in England. They concluded that their findings might indicate a larger societal problem related to mental health in the countries with new market economies in Central and Eastern Europe and that more research should be conducted in these regions (Winkler et al., 2015).

Given this background, the main aim of the present study was to examine– for the first time in Hungary – public attitudes towards mentally ill people. Hungary, a country with new market economy, was governed by communist propaganda, according to which there were officially no social problems in the society, and that people with mental illness were systematically excluded and housed in large asylums (Bajzáth et al., 2014; Höschl et al., 2012). Even though Hungary joined the EU in 2004, it is still greatly lagging behind other EU countries in terms of mental health (Bitter & Kurimay, 2012). Mental health care in Hungary is underfinanced when compared to physical health (Dlouhy, 2014) and the dominant mental health approach is largely biological rather than social and psychological (Dlouhy, 2014).

Furthermore, while the World Health Organisation (WHO) gathered its recommendations in 2005 for implementation of anti-stigma programs and mental health promotion in Europe, no progress was made in Hungary concerning these issues (Fernezelyi et al., 2009).

In 2007, Hungary’s largest psychiatric treatment, teaching and research institute was closed. This happened as a consequence of the 2006 "Hospital Law" (Kurimay, 2010) which decided there was to be a reduction of 25% of acute psychiatric beds in the country. Since then, other psychiatric services (including outpatient services) have reduced. Well established care pathways have also been disrupted leaving many patients temporarily or on a long-term basis without or with reduced psychiatric care. Furthermore, the hospitalization rate of psychiatric patients has increased rather than decreased (Bitter & Kurimay, 2012). Despite finalising the document of the first National Programme for Mental Health in Hungary in 2009 (a program initiated to implement WHO recommendations) by an expert group, it has never become an official government program or received financial support (Bitter & Kurimay, 2012).

Community psychiatry, one of the fundamental elements of WHO initiatives, which aimed to move mental health resources from hospitals to the community and to integrate mental health services into primary care, is still in its infancy in Hungary. In fact, there is no actual plan about how this new paradigm will be introduced and realized (Fernezelyi et al., 2009). Despite the fact that Hungary acknowledges mental health issues and considers these as a priority, the lack of consensus among Hungarian psychiatrists about the direction of mental health reforms is a serious obstacle for further development (Dlouhy, 2014).

This climate is well reflected in the problematic picture arising from the few studies carried out on the Hungarian population. For instance, when compared to other European countries, Hungary has the lowest level of schizophrenia recognition from a vignette describing schizophrenia symptoms (Olafsdottir & Pescosolido, 2011), and has the most negative attitudes towards mentally ill people and towards openness to seeking professional help, compared to Germany, Ireland and Portugal (Coppens et al., 2013).

Despite these concerns, to the best of the authors' knowledge, no in-depth study has ever examined stigmatic attitudes toward people living with a mental disorder in Hungary. Consequently, the present study investigated stigma towards the mentally ill by analysing the trends of preferences for social distance over a period of 15 years using nationally representative samples. Using these data, the study also evaluated the determinants of social distance in an effort to help to understand the factors underlying negative attitudes. Previous studies have found that older age, lower education level, and lower familiarity with mental illness are related to a higher preferences for social distance (Jorm & Oh, 2009). Findings regarding gender are less consistent as most of the community samples show no significant gender difference (Angermeyer et al., 2003; Whatley, 1959) although some studies have shown greater social distance among female participants (Gaebel et al., 2008; Kirmayer et al., 1997) and male subjects (Jorm & Griffiths, 2008; Jorm & Wright, 2008). It was assumed that with Hungary's joining the EU in 2004 and the stronger relationship with European values, that this might have a positive effect on attitudes concerning mentally ill people during the past decade. However, considering Hungary's underfinanced mental health system and the lack of national anti-stigma programs, only a moderate (positive) change was expected. Furthermore, it was expected that older age, lower education level, and lower familiarity with mental illnesses would be significant predictors of higher preferences for social distance. Due to conflicting evidence in the psychological literature regarding the impact of gender, no hypothesis on this variable was formulated.

## 2. Methods

### 2.1. Participants

The present study analysed data from large epidemiological surveys that were conducted in Hungary during the years of 2001, 2003, 2007 and 2015 (Elekes & Paksi, 2003; Paksi, 2001; Paksi et al., 2009, 2017). The sampling was random stratified according to settlement size, region and age, except in 2001, when in Budapest, countryside stratification was applied. Weights were used to compensate for over- or under- represented groups. The samples of all years, except 2003, comprised 18-64 years old Hungarian citizens, whereas in 2003 the age range for participation was 18-53 years. In order to examine the trends in social distance level during the different years, all samples were used and compared, using the common age range of 18-53 years (socio-demographic characteristics of the samples can be found in Table 1). A total of 7605 individuals were included in the analysis. More specifically 1869 (in 2001), 2476 (in 2003), 2118 (in 2007), and 1142 (in 2015). In order to examine the prediction model of social distance, data from the updated and most recent sample of 2015 were used, including the whole sample (age range 18-64 years). A total of 1490 participants were included in the latter analysis.

### 2.2. Procedure

Household surveys were conducted using similar protocols over the four time points. The participants were contacted and interviewed by trained interviewers. After being presented with information about the study and giving informed consent verbally, participants completed the research questionnaires. The questionnaires were answered utilising a mixed technique. For the socio-demographic information and social distance scale, data were collected via interview. For sensitive questions, namely personal familiarity with mental illnesses, participants completed the questionnaire on their own. All questions were presented in Hungarian.

## 2.3. Materials

### 2.3.1. Socio-demographic questionnaire

Gender, age, and education level were assessed. The education level categories were merged into three categories (0=below high school, 1=high school with diploma, and 2=academic).

### 2.3.2. Social Distance

Social distance was assessed using a single item from the Social Distance Scale (SDS;Bogardus, 1925). The SDS was originally developed to assess participants' willingness to have social contact with members of diverse groups in different situations in a progressive order of intimacy (ranging from marriage to entrance to the country). In the present study, the willingness to interact with mentally ill people was assessed with one question from the SDS asking about the acceptance of such individuals as neighbours. This was done to reduce the length of the questionnaire and to avoid excessive demands for the participants who were presented with large number of questionnaires. Using a five-point scale ranging from 1-5 and a "don't know” category (1 = would object, 2 = would rather not, 3 = would depend, 4 = would not disapprove, 5 = would welcome), participants indicated their acceptance preferences.

In the present study, social distance level was found to have a skewed distribution, therefore responses were grouped together by means, so "would object" and "would rather not" responses were merged constituting a "would object" response (an indication of attitudes of social rejection towards mentally ill people), and "would depend", "would not disapprove" and "would welcome" were merged constituting a "would accept" response (an indication of attitudes of social acceptance towards mentally ill people). In the statistical analyses conducted in this study, social rejection responses were coded as 0, and social acceptance responses were coded as 1.

As mentally ill individuals were not the main interest of the epidemiological study, 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 (Gypsies), people with alcohol use disorders, people with large families, people with AIDS, drug users, homosexuals, migrants, and Jews. This study was originally interested in public attitudes specifically towards substance use disorders. Consequently, findings showing that many members of the lay pubic cannot correctly recognize mental disorders as such (Angermeyer & Dietrich, 2006), and that substance use disorders are less commonly regarded as a mental illness (Schomerus et al., 2011), were taken into consideration. For this reason, alcohol and drug users were placed as separated categories. Social distance towards all minority groups was also used and compared in order to put into context the social distance level towards mentally ill people.

### 2.3.3. Familiarity with mental illness

In order to investigate the familiarity of the participants with mental illnesses, a self-administered question was included: "Is there someone in your family who has/had been treated due to mental illness?" Participants had to choose their answer 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. These options were then merged into: yes-1, no-2, 8-invalid, and 9-don't know.

### 2.4. Statistical analyses

To test the effect of time on the two combined social distance response categories (indicating rejection or accepting attitudes towards mentally ill people), Chi-squared tests were used. To examine the prediction model of social distance, data from the recent sample of 2015 were used and analysed. Logistic regression was performed to identify the predictors of social distance including socio-demographic variables (age, gender and education) and familiarity with mental illnesses. SPSS 22 version was used for the analyses.

## 3. Results

### 3.1. Descriptive statistics

The percentages, means, and standard deviations (SDs) of study variables for the different samples over the four different time points (which were used for the trend analysis) can be found in Table 1. The samples across the different years are similar in terms of age and gender, while in terms of education, there was a slight tendency towards a higher level of education. It  also appears that there was a tendency to report less on personal familiarity with mental illnesses.

Table1. Descriptive statistics of data used for trend analysis and years comparison

| | YEAR | | | | **Statistical comparison $\chi^2$ or $F$ (*p* value)** | **2001 and 2015 comparison (*p* value) (*ES*)** |
|---|---|---|---|---|---|---|
| | **2001** | **2003** | **2007** | **2015** | | |
| | | | | | | |
| ***N*** | 1869 | 2476 | 2118 | 1142 | | |
| **Gender** | | | | | | |
| *Female % (n)* | 50.9 (951) | 50.2 (1244) | 49.7 (1053) | 53.4 (610) | $\chi^2$=4.48 | |
| **Age** | | | | | | |
| *Mean (SD)* | 35.6 (10.6) | 35.6 (10.6) | 35.3 (10.3) | 36.1 (10.0) | $F$=1.64 | |
| **Education level** | | | | | | |
| *Below high school % (n)* | 51.0 (951) | 49.1 (1215) | 44.0 (930) | 41.2 (470) | $\chi^2$=46.39*** | |
| *High school with diploma % (n)* | 34.5 (644) | 37.2 (921) | 38.4 (812) | 42.5 (484) | | |
| *Academic % (n)* | 14.5 (271) | 13.7 (338) | 17.6 (373) | 16.3 (186) | | |
| **Familiarity with mental illness** | | | | | | |
| *Having a family member who is/was treated due to mental illness % (n)* | 9.0 (156) | 13.8 (314) | 11.7 (217) | 10.4 (103) | $\chi^2$=25.58*** | |
| **Social distance**[a] | | | | | | |
| *People with mental illness% (n)* | 61.7 (1139) | 64.3 (1578) | 59.2 (1245) | 57.0 (634) | | $\chi^2$=6.49*<br>*ES*=0.05 |
| *Drug users % (n)* | 83.3 (1536) | 82.2 (2019) | 78.3 (1649) | 83.6 (931) | | $\chi^2$=0.08<br>*ES*=0.01 |
| *People with alcohol use disorders %* | 77.7 (1442) | 75.7 (1865) | 72.3 (1527) | 72.9 (815) | | $\chi^2$=8.61**<br>*ES*=0.05 |

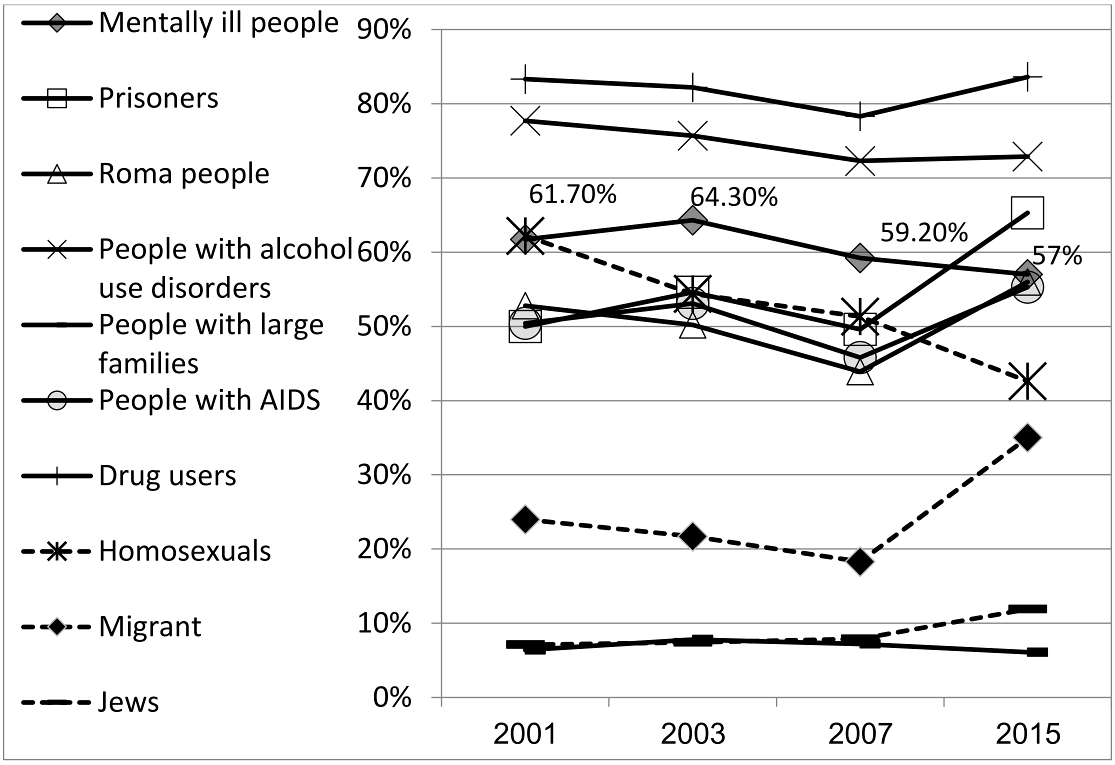
| | | | | | | |
|---|---|---|---|---|---|---|
| *(n)* | | | | | | |
| *Homosexuals % (n)* | 62.2 (1140) | 54.4 (1336) | 51.3 (1077) | 42.6 (472) | | $\chi^2$=107.40***<br>*ES*=0.19 |
| *Roma people % (n)* | 52.8 (980) | 50.2 (1233) | 43.9 (924) | 56.0 (627) | | $\chi^2$=2.79<br>*ES*=0.03 |
| *People with AIDS % (n)* | 50.4 (918) | 53.1 (1292) | 45.8 (964) | 55.3 (611) | | $\chi^2$=6.50*<br>*ES*= 0.05 |
| *Prisoners % (n)* | 50.0 (917) | 54.6 (1339) | 49.6 (1043) | 65.3 (731) | | $\chi^2$=65.95***<br>ES=0.15 |
| *Migrants % (n)* | 24.0 (445) | 21.7 (533) | 18.3 (385) | 35.0 (388) | | $\chi^2$=41.86***<br>*ES*=0.12 |
| *Jews % (n)* | 7.1 (132) | 7.4 (181) | 7.9 (166) | 11.9 (132) | | $\chi^2$= 19.40***<br>*ES*=0.08 |
| *People with large families % (n)* | 6.4 (119) | 7.8 (192) | 7.2 (151) | 6.1 (69) | | $\chi^2$=0.10<br>*ES*=0.01 |

[a]%=More likely to **object** as a neighbour; *ES*=effect size (Cramer's V); ***$p<0.001$; **$p<0.01$; *$p<0.05$.

### 3.2. Changes in the desire for social distance

Overall, Chi-square tests indicated a significant (positive) trend in public preferences for social distance towards more accepting attitudes during the years of 2001-2015 (Table 1). However, closer examination reveals that the effect size was very small (0.05) and the 2015 rejection level was still high (57%) compared to over 60% in both 2001 and 2003. In fact, when comparing the public rejection levels towards mentally ill people to other minority groups in the Hungarian society (see Figure 1) it is evident that mentally ill people are among the three most rejected groups (with only alcohol and drug users being more rejected).

Figure 1. Social distance towards mentally ill people versus other minorities*



*%=More likely to **object** as a neighbour

## 3.3. Determinants of social distance

A logistic regression analysis was performed to predict the levels of social distance (Table 2). The results indicated that this prediction model was significant and explained 4.2% from the variance of social distance. Lower familiarity with mental illnesses, female gender, and education below high school level were significant predictors, while familiarity with mental illness was found to be the strongest predictor in the model. Education level in general and age were not found to be significant predictors of social distance.

Table 2. Prediction model for social distance[a] towards people living with mental disorders in 2015

| Predictor variables | Odds ratio [95% confidence interval] |
|---|---|
| Familiarity with mental illnesses | |
| Yes | 3.02 [2.06-4.43]** |
| No | Reference group |
| Gender | |
| Men | 1.30 [1.03-1.64]* |
| Women | Reference group |
| Age (years) | 1.00 [0.99-1.01] |
| Education level | |
| Below high school | 0.71 [0.50-0.99]* |
| High school with diploma | 0.78 [0.55-1.09] |
| Academic | Reference group |

[a] More likely to **accept** as a neighbour; Social acceptance was coded 1 and social rejection was coded 0 in the present analysis. ***$p<0.001$; **$p<0.01$; *$p<0.05$. Cox & Snell $R^2$=0.031; Nagelkerke$R^2$=0.042.

## 4. Discussion

The present study indicated that attitudes of social rejection towards mentally ill people in Hungary are relatively high, and there were no meaningful changes observed in public attitudes over a 15-year period. These results are consistent with other trend analysis studies from the few international studies which found no evidence of a substantial increase in the public's acceptance of people with mental illness over the last decade (Angermeyer et al., 2013; Mirnezami et al., 2015; Schomerus et al., 2012).

The results also indicated that over the 15-year period, while relatively high rejection towards minorities such as prisoners, people with AIDS, and Roma people are still evident, mentally ill people are among the three most rejected groups in Hungarian society (with those having alcohol and drug use disorders being the two highest). Moreover, while it seems that there is a general trend of higher rejection over the years towards most of the minority groups in the society, these groups appear to arouse an independent pattern of stable and high rejection. These findings highlight the need to examine more in-depth the core beliefs of the Hungarian public towards mentally ill people, because it might imply that these groups share common beliefs, which have not been addressed at a national level to date. Some insights regarding this were found in a study examining public beliefs toward depression in four European countries (Coppens et al., 2013). Results demonstrated that in Hungary more than any other country, the most common beliefs were that "people with depression are weak and dangerous" and that "depressive people could snap out of their situation if they really wanted it" (Coppens et al., 2013). The existence of these beliefs may reflect the tendency to see individuals with mental disorders unrelated to substance use, as dangerous and ones who should be blamed for their condition, similar to that regarding drug users and people with alcohol use disorders (Schomerus et al., 2011). While this rejection ranking of people with alcohol use disorders, drug users, and people with mental disorders unrelated to substance use has been found in other studies (Corrigan et al., 2010; Schomerus et al., 2011), such findings also stress the need to conduct more thorough examinations of the prevalent beliefs in all countries. The findings also suggest that an effective anti-stigma intervention should be tailored more specifically on a country-by-country basis because differences may appear even within a Western context and in countries who at least (in theory) are thought to share similar notions about mental illness (Kleinman, 1977).

Examination of the different predictors of social distance in the present study also support this. While there is a relative consistency in previous research regarding the impact of age on social distance, where rejection of others is associated with being older (Jorm & Oh, 2009), in Hungary it appears that age does not play an important role in attitudes of social rejection. In general, education was not a significant predictor – as found in other studies (Jorm & Oh, 2009) – but in Hungary it appears that the most important group to target is individuals without high school education. Moreover, it appears that women are the ones who report the greatest rejection from mentally ill people, and not men as found in several population studies conducted in Germany, Czech Republic, England, and the U.S (Angermeyer & Matschinger, 1997; Corrigan & Watson, 2007; Evans-Lacko, Corker, et al., 2014; Winkler et al., 2015).

In line with the study hypotheses and the international literature (Jorm & Oh, 2009), familiarity with mental illnesses was found to be a significant predictor of lower social rejection. Furthermore, it appeared that familiarity was the most important predictor for attitudes of social rejection and indeed, it also stands at the heart of many of the existing anti-stigma programs (Corrigan et al., 2012; Griffiths et al., 2014). These programs reduce stigma by creating interpersonal contact with people with mental illness (Corrigan et al., 2012) and has been found effective in reducing attitudes of social rejection (Griffiths et al., 2014). Protest (against discrimination, for example in the mass media) and education programs with the intention of increasing knowledge concerning mental illnesses, are the other two prevalent elements that have been the focus of intervention programs until now (Corrigan & Penn, 1999). While mass media intervention has been found to have a small to moderate effect on stigma

(Clement et al., 2013), education programs have been found to be successful (Corrigan et al., 2012). However, the most successful programs appear to be the ones that combine educational and social contact elements (Evans-Lacko et al., 2013). Nevertheless, it is important to keep in mind that – overall and in general – the effect of existing programs appears to be small. Thus, further research is needed in order to gain more knowledge about the determinants of stigma and attitudes of social rejection and how they can be targeted so that more effective interventions can be developed (Griffiths et al., 2014). This need also arises from findings in the present study, because the explanatory power of the different predictors was very small. Additionally, from the literature it is evident that for interventions to be effective they should be targeted towards specific populations, be delivered locally, and involve contact with people who have successfully managed mental illness (Corrigan, 2011). It is also important that such initiatives are long-term and ongoing, perhaps integrated into routine care (Grausgruber et al., 2009).

The results of the present study mostly emphasize the problematic reality of mentally ill people in Hungary. In the presence of strong public rejection for more than a decade, no national plan to tackle mental illness stigma has been introduced and research in that topic is considerably lacking. The social rejection ranking of mentally ill people, people with alcohol use disorders and drug users found in the present study, highlights that the Hungarian population still do not perceive substance-related disorders as "mental illness' and mental health literacy programs are especially required. Given that Hungary has one of the highest rates in the world of alcohol-related mortality and morbidity (Kurimay, 2010), better education is especially important in Hungary, and can improve public attitudes and care of people with substance use disorders. Furthermore, allocating resources to mental health research in Hungary would provide important insights regarding the high rates of social rejection. Xenophobia in Hungary was always highly prevalent and according to new reports, it has increased during recent years (Simonovits et al., 2016). The most socially rejected groups are mostly disadvantaged groups such as people with disabilities, low educational background, those living at the countryside, pensioners, living in Eastern counties, or unemployed (Fábián & Sík, 1996). Mentally ill people are also one group that were highly stigmatized during the history of Hungary. They were socially excluded and discriminated in the labor market, resulting in unemployment and homelessness which only increase the social rejection (Bányai, 2015). Whether this social rejection is a unique and specific problem, a reflection of poor mental health system and policies, and/or a part of a wider xenophobia phenomenon that arises from this research, is something that should be investigated further in order to address this issue better.

Given that the study's main aim was to specifically examine stigma in a country with new market economy, the investigation appears to have been justified by the results found. During the era of communism, the government in Hungary officially considered all social problems to be either the consequences of capitalism or a result of the activities of 'anti-government elements'. Mental illnesses were perceived as individual problems, unrelated to the society, and people with mental illness were marginalized, socially excluded and hospitalized in large psychiatric asylums (Bajzáth et al., 2014; Höschl et al., 2012). It is possible that the communist heritage is still present in the public minds, and can supply explanation, even if partial, to the high rate of social rejection in Hungary. As such, although it cannot be confirmed from the present study's findings alone, the high prevalence of social rejection in Hungary may be indicative of a bigger problem in countries with new market economies compared to other parts of Europe. This assertion is supported by findings from another country with new market economy, the Czech Republic (Winkler et al., 2015), where a high level of stigmatization towards the mentally ill was found, a level which appears similar to the one in Hungary and which was significantly higher than compared to England. As such, it is possible that this problem represents a bigger problem in countries with new market economies in Europe. Because there has been little published research from this region of Europe (Evans-Lacko, Courtin, et al., 2014), the present study raises and stresses the need to examine public attitudes in other countries with new market economies in Europe.

This present study is not without limitations. First, as the study is a part of a larger epidemiological research project utilising self-report data where the focus was not mental illness stigma, and the examination of attitudes toward stigma was only partial. Only one item from the Social Distance Scale (SDS) was used and an expanded examination of stigmatic beliefs and attitudes is needed, especially as social distance is just one component of stigma. Other components such as the stereotypes of dangerousness or unpredictability as well as the tendency to blame people with mental illness as responsible for their disorder are also important to assess. This is especially important considering that this is the first study to be conducted in Hungary on attitudes of stigma toward mentally ill people. The use of self-report methodologies (in this case interviews and self-completion questionnaires) also has well known biases (most notably memory recall and social desirability).

Second, as familiarity with mental illness was found to be an important factor, there might be a need to examine it in a more in-depth way so that it includes other familiarity levels rather than family members. Having a close friend with mental illness or having a mental illness diagnosis, can all have significant impact on preferences for social distance. Third, it is important to mention that the examination of the two main study variables (i.e., social distance and familiarity), was assessed using only one item, which should be considered when interpreting the findings. Forth, while this study examined attitudes towards mentally ill people in general, distinguishing between different mental illness diagnoses is also needed. This is important, especially as it was found that the level of attitudes towards stigma and social distance tend to vary across different diagnoses (Parle, 2012) and over the years. As decreases in preferences for social distance towards depression was found over the years (Reavley & Jorm, 2012; Silton et al., 2011), it is possible that examining attitudes towards different diagnoses will highlight different trends. This may increase the application and generalization of the results to different mental illness diagnoses and increase the effectiveness of anti-stigma programs. Finally, it is important to note that the different samples during the years differed in level of education, as tendency towards greater education in more recent years was found. Thus, consideration should be made when interpreting the results.

### 4.1. Conclusions

Despite the aforementioned limitations, the present study has many strengths including a longitudinal time span of 15 years and robust nationally representative data. As the first ever study of this kind in Hungary, the findings provided insights into attitudes of the Hungarian population towards mentally ill people. By doing so, this study contributes insights into the public’s attitudes toward stigma in general and strengthens international efforts in combating mental illness stigma. Most importantly, these efforts should facilitate and stimulate a more profound examination of the underlying factors of stigmatization, which is highly prevalent and disturbingly persistent in Hungary and other countries.

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

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## Abstract

*Objective:* The development of mental illness often leads to pervasive losses in different areas of people's lives. However, previous research has tended to focus on the loss experienced by families while the examination of the loss experienced by individuals who are themselves coping with mental illness has been neglected. The present study tested the factor structure of the Hungarian version of the Personal Loss from Mental Illness (PLMI) scale, and analyzed its associations with age, gender, previous hospitalizations, marital status, loneliness, grief, and quality of life. *Methods:* Mentally ill patients (N=200) with different diagnoses were recruited from a mental health center in Hungary, and completed self-report questionnaires. Confirmatory factor analysis (CFA) with covariates was conducted. *Results:* CFA analyses rejected the previous four-factor structure and suggested a single factor structure to be superior. Higher loss perception was predicted by higher loneliness, grief, and lower quality of life. Patients with mood disorders reported higher loss as compared to patients with other psychiatric diagnoses. *Conclusions:* The present study stresses the magnitude of loss and raises the need to examine further the role of loss in coping and recovery. Asking patients about their feelings in clinical practice is of high importance.

**Keywords:** Schizophrenia spectrum disorders; Mood disorders; Stress disorders; Grief; Quality of life; Stigma

## 1. Introduction

Adaptation to one's mental illness can be a long-lasting and emotionally draining process (Birley, 1991). Living with a diagnosis of mental illness often means experiencing multiple losses in many essential aspects of life such as the loss of emotional and cognitive abilities, social bonds and relationships, employment and/or educational opportunities, and even in performance of simple daily activities (Mauritz & van Meijel, 2009). While loss commonly occurs and is well recognized in many life changing events such as the death of a loved one or the development of physical disorders, the losses caused by mental illness are typically less visible (Young et al., 2004) and have been conceptualized as being more vague and frequently neglected by the public eyes (Baxter & Diehl, 1998). The stigma of mental illness is mainly considered to blame in minimizing the public acknowledgement of patients' loss, as well as minimizing the provision of support usually offered to individuals affected by other, less stigmatizing life changing events in their social environment (Young et al., 2004).

Studies on personal loss imply that different loss experiences share common features regardless of type of loss (Harvey & Miller, 1998; Papa et al., 2014; Parkes, 1972). While it can differ in intensity, loss has been generally defined as reduction in resources, which can be both concrete or more abstract, in which an individual is greatly emotionally invested (Harvey, 1996). The loss resulting from mental illness can be enduring and complex in nature involving both actual losses (e.g., losses of functioning and abilities) and symbolic losses (e.g., loss of hopes and dreams for the future). Furthermore, unlike the loss that occurs following the death of a loved one, these losses are mainly unpredictable as to when they may end (Olshansky, 1962).

Despite the clinical evidence demonstrating that loss is a central experience of patients (Appelo et al., 1993; Lewis, 2004; Wittmann & Keshavan, 2007; Young et al., 2004), the study of personal loss has tended to focus mainly on the loss experienced by family members of mentally ill patients (e.g., Davis & Schultz, 1998; Miller et al., 1990; Ozgul, 2004)). However, these studies – while describing the various losses that family members experience –do not focus specifically on the individual's perception of loss, but rather on their emotional and cognitive reaction to loss, which typically refers to grief (DeSpelder & Strickland, 1992). Family members, in particularly parents, are found to grieve the (i) objective losses caused by the development of the illness itself (e.g., cognitive and emotional abilities), and (ii) psychosocial losses resulting from these objective losses and changes in functioning, which eventually manifests in denied access to meaningful social roles (MacGregor, 1994; Solomon & Draine, 1996). Very often, parental grieving is related, maybe more than anything, to their child's loss of potential to live a “normal life” (Ryan, 1993; Stein & Wemmerus, 2001).

While previous studies have emphasized the magnitude of the reactions of families to the experience of loss following mental illness, few studies have explored the loss experienced by the ones who are coping with mental illness themselves. A qualitative study among schizophrenia patients reported loss to be a profound, central, and “overwhelmingly painful” experience (Mauritz & van Meijel, 2009, p.26). Their feelings of loss were noted as being important in helping patients coming to terms with their illness and improving their coping (Mauritz & van Meijel, 2009). Another qualitative study reported that the loss of relationships was the most dominant theme among patients, highlighting this as an important issue in the recovery process (Baker & Procter, 2015).

To help researchers empirically investigate loss among mentally ill patients, the Personal Loss from Mental Illness (PLMI) scale was developed that (i) assesses loss perception of patients, and (ii) focuses on perception of loss *per se*, creating a distinction between loss and grief reaction (Stein et al., 2005). Previous factor analysis of the PLMI scale delineated four different factors: ‘Loss of Roles and Routines’, ‘Loss of Former Relationships’, ‘Loss of Former Self’ and ‘Loss of Future’ (Stein et al., 2005). The PLMI scale has demonstrated satisfactory psychometric properties (for detailed information see: Stein et al., 2005)). Initial studies using the scale found individuals' loss to positively related to low ambition and motivation to study in college (Stein, 2005), increased loneliness (Stein et al., 2013), and negative religious-coping (Phillips & Stein, 2007), and to be negatively related to recovery and quality of life (Potokar, 2008). Patients' personal characteristics were also found to be related to loss, where older age, higher number of previous hospitalizations, and lower number of jobs held by patients were found to be related to increased perception of loss (Stein et al., 2005).

Given the major role of loss in recovery (Davis et al., 1998; Harvey et al., 1990; Neeld, 1990), and considering its significant role in mentally ill patients' lives, examining loss following mental illness is of high clinical importance and therefore more studies on loss are warranted. Consequently, the further examination of the construct validity of the PLMI scale is also important in a non-English speaking context. Therefore, the present study validated the factor structure of the Hungarian version of PLMI scale using confirmatory factor analysis (CFA). In addition, and based on contemporary literature, possible covariates of loss were chosen (e.g., personal characteristics such as age and previous hospitalizations, loneliness, and quality of life) to investigate the nomothetic network of the loss construct. It was hypothesized that older age, previous hospitalizations, increased perception of loneliness, and decreased quality of life would be significant predictors of higher loss. Based on the strong evidence from the literature associating grief with loss, grief reaction was also examined for the first time in the present study. It was hypothesized that increased grief reaction would be significant predictor of increased loss.

## 2. Methods

### *2.1. Participants*

Participants comprised 200 adults with mental illness diagnoses recruited from an outpatient unit of mental health center in Budapest, Hungary. The inclusion criteria were: (i) having a psychiatric diagnosis according to the ICD-10 (World Health Organization, 1992), (ii) taking psychiatric medications, (iii) being inpatients or outpatients in any type of psychiatric care, (iv) being patients who had not been abusing illicit substances and alcohol for at least two weeks at the time of the assessment, (v) being aged between 18 and 65 years, and (vi) being able to complete the questionnaire according to the patient's psychiatrist. The exclusion criteria were (i) having an acute phase of illness, (ii) having a diagnosis of an organic brain disorder, dementia, and/or mental retardation, and (iii) not having the mental competency and/or ability to complete the self-report questionnaire or give informed consent.

### *2.2. Procedure*

Patients who were eligible to participate in the study were identified and contacted by the psychiatrists who were treating them. Those who agreed to participate received an information sheet about the goals of the study and signed an informed consent form. Participants then completed a self-report questionnaire. All questionnaires were translated from English to Hungarian and back translated from Hungarian to English. The possible discrepancies between the original and back-translated version were solved. Ethical approval was granted by the ethics board of the regional hospital responsible for the patients' welfare.

### *2.3. Measures*

#### 2.3.1. Socio-demographic questions

Gender, age, previous hospitalizations (yes/no), education (finished high school/did not finish), occupation (employed/unemployed), diagnosis, and marital status (married/divorce/widow/single) were assessed. Marital status was dichotomized into single (divorce/widow/single) and married categories in the further analysis. Different diagnoses of the patients were merged and divided into six categories according to the ICD-10 codes categorization (World Health Organization, 1992): (i) schizophrenia spectrum disorders (e.g., schizophrenia, schizotypal and delusional disorder), (ii) mood disorders (e.g., major depressive disorder, bipolar and manic disorder), (iii) stress-related disorders (e.g., phobic anxiety disorders, obsessive- compulsive disorders, somatoform disorders), (iv) behavioral syndromes associated with physiological disturbances (e.g., eating disorders), (v) personality disorders (e.g., borderline personality disorder, avoidant personality disorder), and (vi) disorders due to psychoactive substance use.

#### 2.3.2. Personal loss from mental illness

The Personal Loss from Mental Illness (PLMI) scale is self-report instrument that assesses perceptions of personal loss due to mental illness (Stein et al., 2005). The scale comprises 20 items concerning the losses that individuals with mental illness experience. Participants rate the degree to which they agree with each statement using a 5-point Likert scale ranging from 1 ('strongly disagree') to 5 ('strongly agree'). Higher scores reflect more personal loss due to mental illness.

#### 2.3.3. Loneliness

The UCLA Loneliness Scale (Version 3) (Russell, 1996) is the most commonly used self-report instrument by both researchers and clinicians to assess feelings of loneliness. The scale comprises 20 questions asking participants to rate the frequency of their feelings on a 4-point Likert scale ranging from ‘never’ to ‘always’. The score for each item is summed together to generate an overall loneliness score. A higher score indicates a greater degree of loneliness. The scale was found to have high internal consistency (coefficient alpha ranging from 0.89 to 0.94) and the test-retest reliability over a one-year period was also good ($r$=0.73) (Russell, 1996). The scale was also found to have good reliability among schizophrenia and bipolar patients (Stein et al., 2013) as well as in the present sample ($\alpha$=0.93).

### 2.3.4. Grief

The Mental Illness Version of the Texas Inventory of Grief (MIV-TIG) (Miller et al., 1990) is an adaptation of Texas Revised Inventory of Grief (TRIG) (Faschingbauer et al., 1977). The TRIG assesses reactions of grief following the death of a family member whereas the MIV-TIG assesses grief among family members following their relative's mental illness and the loss of that person due to the mental illness (Miller et al., 1990). Grief manifestations in this scale are enduring emotional distress, preoccupation with the lost person, and an inability to accept the loss. The MIV-TIG includes 24 items. The first eight items assess initial grief and the remaining 16 items assess current grief. In the present study only the final 16 items were administered. Because the present study intended to examine the grief reaction of patients themselves, a minor adaptation of the items was carried out with a simple modification of pronoun (e.g., *“I am preoccupied with the thoughts of how I could have been if not for the illness”*) as was also done in a previous study (i.e., (Patterson et al., 2005)). Participants respond on a five-point scale ranging from ‘completely true’ to ‘completely false’ with higher score indicating greater grieving (Miller et al., 1990). The reliability of the second part of MIV-TIG is high ($\alpha$= 0.92) (Miller et al., 1990). High internal consistency was also observed in the present sample ($\alpha$=0.95).

### 2.3.5 Quality of life

The Manchester Short Assessment of Quality of Life (MANSA) (Priebe et al., 1999) was developed as a shortened version of the Lancashire Quality of Life Profile (LQLP) (Oliver et al., 1997). The MANSA is a 16-item self-report scale containing two differing question types: objective questions (four items) which are answered ‘yes’ or ‘no’, and subjective questions (12 items) asking individuals their overall satisfaction from life and from specific life domains. Each of the 12 questions is scored on a seven-point rating scale of satisfaction, ranging from 1= ’couldn't be worse’ to 7= ’couldn't be better’. The total score is the average of the 12 question scores. A higher score indicates a better quality of life. The measure has satisfactory internal consistency and is highly correlated with the scores on the LQLP (Priebe et al., 1999). Very good internal consistency was also found in the present study ($\alpha$=0.87).

### *2.4. Statistical analyses*

In the first step of the analysis, confirmatory factor analyses (CFAs) were used to assess the factor structure and item performance of Hungarian version of PLMI scale in the sample. In CFA, acceptable degree of fit requires the comparative fit index (CFI) and the Tucker-Lewis Index (TLI) to be close to 0.95, and the model should be rejected when these indices are <0.90 (Brown, 2006). The next fit index was root mean squared error of approximation (RMSEA). 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). In the next stage, 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. The CFA with covariates technique was chosen for the present study because it can best estimate the effect of indicators and grouping variables or other continuous variables on latent variables at the same time. All analyses were performed with MPLUS 8.1 (Muthén & Muthén, 1998).

## 3. Results

### *3.1. Descriptive statistics*

The percentages, means, and standard deviations (SDs) of the study variables are shown in Table 1. The majority of the sample were women, graduated from high school, were currently employed, and had one diagnosis (where the most common were stress-related disorders). Almost half of the sample had previous hospitalizations, and 39.5% were currently married. The participants had a wide age range with a mean of 44.2 years (SD=11.8).

Table 1. Descriptive statistics of the study sample

| | |
|---|---|
| Gender (female) *N* (*%*) | 133 (66.5) |
| Age, mean (*SD*) | 44.2 (11.8) |
| Education, graduated high school *N* (*%*) | 157 (78.5) |
| Occupational status, employed N (*%*) | 112 (56.0) |
| Marital status, married *N* (*%*) | 79 (39.5) |
| Previous hospitalizations*N* (*%*) | 89 (44.5) |
| Diagnosis | |
| Schizophrenia spectrum disorders *N* (*%*) | 53 (26.5) |
| Mood disorders *N* (*%*) | 58 (29.0) |
| Stress-related disorders *N* (*%*) | 89 (44.5) |
| Personality disorders*N* (*%*) | 10 (5.0) |
| Disorders due to psychoactive substance use *N* (*%*) | 2 (1.0) |

| | |
|---|---|
| Behavioral syndrome associated with physiological disturbances *N* (*%*) | 2 (1.0) |
| Only one diagnosis *N* (*%*) | 188 (94.0) |
| Two diagnoses | 10 (5.0) |
| Three diagnoses | 2 (1.0) |

Note: The total sample *N*=200.

### *3.2. Confirmatory factor analysis with covariates*

Before all analyses, the reversed items were re-coded in order to assess the desired direction such as higher loss. Furthermore, 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 (see Table 2). After inspection of the modification indices and the content of the items, the allowing of three-error covariances between items yielded fit indices close to adequate fit. However, the correlations among factors were higher than *r*=0.86 and furthermore a correlation larger than 1.00 between 'loss of roles and routine' factor and 'loss of future' factor indicated a problem with the model specification (see Table 3). The strong correlations implied that the four factors did not capture different meanings. Therefore, the unidimensionality of the loss construct was further investigated. Also tested were the one-factor model and a second-order factor model in which one second-order factor is assumed to explain the correlations among the primary factors. The problem with model estimation remained in the case of second-order factor model, therefore the one-factor model was further investigated and which yielded acceptable degree of fit if three error covariances were allowed between semantically close items such as: *"I haven't really changed very much because of having a mental illness"*(reversed item) and *"Having a mental illness has really changed who I am"*; *"I miss the friends that I had before I became ill"* and *"I have lost a lot of friends because of being mentally ill"*; and finally *"Having a mental illness has taken away my normal daily routine"* and *"I liked myself better before I became mentally ill".* This measurement model was also supported with exploratory factor analysis, in which the eigenvalue of the first factor (7.06) was almost five times higher than that of the second factor (1.44). The factor loadings of the original four-factor model and the accepted one-factor model are presented in Table 3. The factor loadings of the one-factor model ranged between 0.29 and 0.74. The mean item loading was 0.56. The internal consistency was also excellent (Cronbach $\alpha$=0.90).

To identify the covariates of loss, CFA with covariates analysis was performed. The bivariate correlations between the explanatory variables and the latent construct are presented in the supplemental materials (i.e., supplementary table). Mood disorder diagnoses were significantly related with higher perception of loss ($r$=0.18), while stress-related diagnosis was associated with less perceived loss ($r$=-0.20). No other diagnostic categories were significantly related to loss. Loneliness and grief were also positively associated with loss ($r$=0.76 and 0.71 respectively). However, better quality of life was associated with lower level of perceived loss ($r$=-0.73).

In the multivariate analysis, only the significant correlates of loss were entered. Higher loneliness ($\beta$=0.36, $p$<.001), higher reaction of grief ($\beta$=0.36, $p$<.001), and lower quality of life ($\beta$=-0.25, $p$<.001) were significantly related with higher perception of loss. No other variables were significantly associated with loss. The lack of the association with mood and stress-related diagnoses in the multivariate analysis can be explained by the large comorbidities between these two categories ($r$=0.50).

Table 2. Fit indices of the alternative measurement models of Personal Loss from Mental Illness scale.

| | | $\chi^2$ | *Df* | *CFI* | *TLI* | *RMSEA* | *C fit of RMSEA* | *SRMR* |
|---|---|---|---|---|---|---|---|---|
| Model 1* | One-factor model | 253.0 | 148 | 0.916 | 0.903 | 0.060 | 0.102 | 0.054 |
| Model 2 | Four first-ordered factors | 297.2 | 146 | 0.879 | 0.858 | 0.072 | <.0001 | 0.059 |
| Model 2a* | Four first-ordered factors with error covariances | 231.4 | 142 | 0.928 | 0.914 | 0.056 | 0.212 | 0.052 |
| Model 3* | Second-order factor model | 235.4 | 144 | 0.927 | 0.913 | 0.056 | 0.202 | 0.053 |

Notes: *N*=199. *Four error covariances were allowed (between "I haven’t really changed very much because of having a mental illness" (reversed item) and "Having a mental illness has really changed who I am"; between “I miss the friends that I had before I became ill"; and "I have lost a lot of friends because of being mentally ill"; between "Having a mental illness has really changed who I am" and “People who knew me before would hardly recognize me now.” and finally between “Having a mental illness has taken away my normal daily routine" and "I liked myself better before I became mentally ill"). Specification error occurred during the analysis. All analyses were performed with the exclusion of Item 13.

Table 3. Confirmatory factor analysis of Personal Loss from Mental Illness scale: Factor loadings

| | Four-factor model* | | | | One-factor model* |
|---|---|---|---|---|---|
| | Loss of roles and routine | Loss of former relationships | Loss of former self | Loss of future | Perceived loss |

| | | | |
|---|---|---|---|
| Y1 "Chances are good that I will get married and have a family"** | 0.30 | | 0.29 |
| Y2 "I will probably never be able to own my own house" | 0.32 | | 0.33 |
| Y3 "It is hard for me to find a good reason to get out of bed" | 0.69 | | 0.69 |
| Y4 "I have things that I like doing everyday"** | 0.43 | | 0.42 |
| Y5 "I doubt that I will have the same future as others my age" | 0.59 | | 0.59 |
| Y6 "The plans I make for each day often do not get done" | 0.68 | | 0.68 |
| Y7 "Having a mental illness might stop me from getting/keeping a good job" | 0.74 | | 0.74 |
| Y8 "I miss the friends that I had before I became ill" | | 0.71 | 0.68 |

| | | | |
|---|---|---|---|
| Y9 "I have lost a lot of friends because of being mentally ill" | 0.67 | | 0.62 |
| Y10 "Having a mental illness has kept me from being an important member of my family" | 0.69 | | 0.65 |
| Y11 "I liked myself better before I became mentally ill" | 0.56 | | 0.53 |
| Y12 "People who knew me before would hardly recognize me now" | 0.64 | | 0.62 |
| Y14 "I haven’t really changed very much because of having a mental illness"** | | 0.41 | 0.36 |
| Y15 "Having a mental illness has really changed who I am" | | 0.72 | 0.68 |
| Y16 "Having a mental illness has taken away my normal daily routine" | | 0.82 | 0.74 |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| Y17 "I feel that I don’t have the kind of friends that other people my age have" |  |  |  | 0.70 | 0.70 |
| Y18 "I don’t plan for the future but I do have hopes for what I would like to happen"** |  |  |  | 0.32 | 0.33 |
| Y19 "Other people often tell me not to plan too far into the future" |  |  |  | 0.44 | 0.43 |
| Y20 "My future is as bright now as it was before becoming ill"** |  |  |  | 0.70 | 0.70 |
| Correlations of the latent factors |  |  |  |  |  |
| Loss of former relationships | 0.91 |  |  |  |  |
| Loss of former self | 0.91 | 0.86 |  |  |  |
| Loss of future | 1.03(!) | 0.93 | 0.86 |  |  |

Notes: N=199. Item 13 was excluded due to close to zero factor loading on its respective factor. *: The error covariances between item 8 and item 9. item11 and item 16. item15 and item14, and item15 and item12 are freed. **: Reversed items. All reversed items were recoded before the analyses. (!): The higher than 1.00 correlation indicates the untrustfulness of this model specification and shows that the latent factors cannot be distinguished statistically. The correlation larger than 1 is a result of the model estimation and a clear sign that we had to reject this model.

## 4. Discussion

The main goal of the present study was to investigate and validate the Personal Loss from Mental Illness (PLMI) scale in a relatively large and diverse sample of Hungarian adults with mental disorder diagnoses. The PLMI scale is a psychometric instrument that assesses patients' perception of loss following mental illness (Stein et al., 2005). The present study supported a one-factor model over the previously proposed four-factor model. Based on the results, mentally ill patients do not differentiate between different aspects of loss, but do possess a general perception of loss. It is possible that the different factor structure found in the present study may be due to cross-cultural differences that exist in stigma towards mental illness (Abdullah & Brown, 2011). For example, previous studies have suggested that in particular areas in Europe, such as countries in Eastern and Central Europe, higher stigma might be especially present due to the communist history and the deficiency in mental health reforms that exist in these countries (Buchman-Wildbaum et al., 2018; Winkler et al., 2015). A recent Hungarian study found that stigmatic attitudes were highly widespread among the Hungarian public and remained constant over a 14-year period (2001-2015) (Buchman-Wildbaum et al., 2018). As such, it is possible that compared to the sample in the original PLMI scale study which was conducted in the US (Stein et al., 2005), patients in Hungary are more exposed and affected by the stigma, and thus their losses are perceived as a general sense of intense loss. Interestingly, this possibility may indicate that the pattern of perceived loss may be distinctive in different countries. However, further studies are needed to examine the factor structure of the PMLI scale (and its' possible association with stigma) so a more definitive conclusion can be formulated.

In the present study, patients' perceived loss was positively associated with loneliness and negatively associated with quality of life, supporting the construct validity of perceived loss. These results are consistent with the study hypotheses and with findings from previous literature, confirming the major role and impact of loss in patients' lives (Potokar, 2008; Stein et al., 2005). Conversely, patients' personal characteristics (e.g., age, gender, marital status, previous hospitalizations) did not have a statistically significant role in perception of loss. These results are in contrast with the results of Stein et al. (Stein et al., 2005), who found that age and hospitalizations were associated with loss. However, other results reported here were in accordance with their findings regarding the non-significant correlation between loss, gender, and marital status. Consequently, these results may stress the prevalence and magnitude of loss in patients' lives irrespective of their personal characteristics.

Educational and occupational status significantly correlated with loss, supporting the construct validity of perceived loss. Therefore, higher perceived loss was related to unemployment and lack of high school education. This is in accordance with the fact that mental illnesses usually develop in early adulthood (Kessler et al., 2007), and causes difficulties in getting diploma and further acquiring and maintaining a job (Stein, 2005). Stein et al. (2005) also found occupation to be significantly negatively related to loss, but did not find any association between education and loss. It might be that the larger sample included in the present study allowed higher statistical power, leading to differences in the results yield by the two studies. In light of the preliminary nature of this study, further studies are needed to formulate more robust conclusions.

The present study is the first to quantitatively examine the experience of grief among a relatively large sample of mentally ill patients, and the first to examine its association with the perception of loss. While the literature on grief following mental illness was limited to the experience of families, reporting significant grief levels among parents, caregivers, and siblings of mentally ill patients (Atkinson, 1994; Davis & Schultz, 1998; Godress et al., 2005; Miller et al., 1990; Olwit et al., 2015; Titelman, 1991), the present study is the first to not only find that mentally ill patients themselves also grieve, but that higher loss perception because of their illness, is related with higher grief. Grief following mental illness is described in the literature as prolonged, compatible with the chronic nature of mental illnesses, and brings evolving challenges (Godress et al., 2005). While grief is a vital process on the way to acceptance and recovery (Worden, 2001), prolonged and unresolved grief has been found to be a risk factor for psychological problems, poor physical health, and suicidality (Miles, 1985; Moore et al., 1988; Porritt & Bartrop, 1985; Szanto et al., 2006). Among families of mentally ill patients, grief has been associated with emotional distress, lower health status, and poorer psychological wellbeing (Godress et al., 2005). In the present study, correlations were found between higher grief, higher loneliness, and lower quality of life, emphasizing the need to target loss in therapeutic settings and to explore further grief in patients, to get better understanding of its manifestations and its possible role in coping and recovery.

Another novel finding of the present study (although this was not the main focus) was that loss was experienced differently by patients with different diagnoses, because the mood disorders group reported higher levels of loss, while the stress-related disorders group reported lower level of loss. Although any mental illness brings challenges and losses, these might be more prominent in the mood disorders group, compared to stress-related disorders which are considered as having less severe and chronic manifestation (Jorm & Wright, 2008; Wood et al., 2014; Yoshioka et al., 2014). Individuals with mood disorders often experience affective relapses (Schaffer et al., 2006), alternating periods of mania, and depressed mood, sometimes with severe episodes that may also contain delusions and hallucinations (Goodwin & Jamison, 2007). Inevitably, these characteristics affect and compromise individuals' psychosocial functioning, leading to difficulties in creating and maintaining social contacts, obtaining and maintaining employment, and diminishing their self-esteem and quality of life (Blairy et al., 2004; IsHak et al., 2012).

Furthermore, stigma surrounding mental illness might also affect loss perception among different patients. Public stigma (i.e., negative stereotypes held by members of the society towards mental illness; (Corrigan et al., 2006)) although affecting all patients, is known to be more destructive for those with more severe illness manifestation (Farina, 1981; Oliveira et al., 2015), such as mood disorders (Ellison et al., 2013; Wood et al., 2014). Moreover, these patients, compared to people with stress-related disorders, demonstrate higher levels of internalized stigma (Chang et al., 2016; Pal et al., 2017). Internalized stigma describes the process whereby stigmatized individuals themselves internalize and adopt stigmatic beliefs into their own identity (Corrigan & Watson, 2002). Known to have harmful consequences, internalized stigma has been found to be destructive to individuals with mood disorders as well in terms of reducing their social functioning (Perlick et al., 2001), impairing functioning in the workplace (Haslam et al., 2005), and leading to loss of life opportunities resulting in unemployment, lack of opportunities to establish a family, and lack of social network (Elgie & Morselli, 2007; Michalak et al., 2006).

It should also be noted that no significant difference in perceived loss was found between the schizophrenia spectrum disorders group and the other groups. Because this patient group is also affected by stigma to an even greater extent (Brohan et al., 2010, 2011; Holzinger et al., 2003) and characterized by more severe illness manifestation leading to many losses (Wittmann & Keshavan, 2007), differences might have been expected. One possible reason for this may be the categorization chosen in the present study of different disorders into this group, which may have affected the results. Another possible reason may be the study inclusion criterion of patients who had the capacity to answer the study questionnaire, which might have excluded patients with more severe manifestation of schizophrenia spectrum disorders. Because there might be differences between actual losses and perception of losses, it is also possible that these patients do not perceive their losses to the same extent as they actually are. Schizophrenia spectrum disorders are characterized by prolonged course, including a sequences of relapses, remissions, and very often re-hospitalizations, which result in a consequent disruption to their functioning, goals they are trying to achieve, and the life they are trying to construct (Ozgul, 2004). Consequently, individuals tend to experience many losses which are sometimes very difficult for them to completely comprehend their meaning and/or what they symbolize, because they continue to change and evolve over the years (Ozgul, 2004). Therefore, it is possible that these patients are overwhelmed by loss and do not perceive the enormity of it. This misperception can also be interpreted as denial, a defense mechanism used in the face of overwhelming and anxiety-provoking reality of losses (McGlashan & Carpenter, 1981; McGlashan & Carpenter, 1976; McGorry & McConville, 1999; Moore et al., 1999). Finally, it is also possible that the schizophrenia spectrum disorders patients included in the present study were less insightful regarding their illness and the losses it brings into their lives than the other patient groups. According to the literature, as a result of the illness process (Cuesta & Peralta, 1994), 50%-80% of schizophrenia spectrum disorders patients are at least partially unaware of their illness (Amador & Gorman, 1998), and that poor insight is a prevalent feature of schizophrenia, not only among patients in acute psychosis, but also among outpatients in stable state (Coursey et al., 1995; Dickerson et al., 1997). In fact, Amador et al. (1994) found that a range of illness awareness deficits are more severe and extensive among these patients compared with those with major depressive disorders with or without psychosis. Other studies have found that patients with schizophrenia have poorer awareness of social consequences of their illness than patients who have major depression with psychotic features and bipolar patients (Braw et al., 2012; Pini et al., 2001)**.** As all these options are possible, and considering the limitation of the grouping of patients or labeling them with a diagnostic category used in the present study together with the preliminary nature of the findings, more research is needed to investigate the perception of loss among these patient groups.

The present study has important clinical implications. First, and despite the limitation of grouping of patients, the findings emphasize the importance of the internal experience of mentally ill patients irrespective of their diagnoses because these were controlled for in the multivariate analysis. Irrespective of how much or little insight mental patients may consider to have (Michalakeas et al., 1994; Pini et al., 2001), the present study demonstrated that patients were well aware of changes in their lives due the losses following their illness. Their awareness is ever-present, leading them to grieve for their old self, and compromising their feelings of belonging to others and their quality of life. However, in practice, the focus of rehabilitation protocols is mainly on helping patients to acquire skills with the goal of activation and integration in the community, while addressing and recognizing the losses encountered by patients is being neglected (Appelo et al., 1993; Young et al., 2004). Acknowledging the losses patients are experiencing, helping them to accept them, coming to terms with the fact they are ill, and finding new goals and meaning in life, should be an integral part of interventions and treatments offered to mentally ill patients (Appelo et al., 1993; Young et al., 2004). Educating patients, normalizing their experience, and encouraging them to share their experiences with others with similar experiences can also be important in decreasing feelings of loneliness (Young et al., 2004). This has been found to be a risk factor for a wide range of health problems and death (Luo et al., 2012). Proper treatment might also reduce grief and improve a patient's quality of life. Second, because the present study indicates that there might be differences in the way different patients perceive their illness, loss might be especially important to address among patients with mood disorders.

The present study is not without limitations. First, as the study mainly explored the loss experience of patients with any psychiatric diagnoses without focusing on specific diagnoses, and to avoid the extra burden on patients, their diagnoses solely relied on the assessment conducted by their treating psychiatrist, and were not based on additional systematic assessments (such as structured interviews). Furthermore, for pragmatic reasons due to the sample size, patients were classed into broad diagnostic sub-groups because participants had so many different diagnoses. Therefore, a wide range of diagnoses were sometimes treated as one sub-group, making it difficult to identify differences which might exist within these sub-groups. Consequently, and considering the lack of research on the topic, the study results should be interpreted and applied with caution. Further research is needed to examine and clarify differences which might exist in loss perception of patients with different diagnoses.

Given that the severity of illness symptoms (i.e., severity of depressive symptoms or symptom levels in schizophrenia) was not assessed and controlled for, there is a possibility that the degree of illness symptoms may have impacted the associations between diagnoses, loss, grief, loneliness and quality of life.

While the number of previous hospitalizations can be an important indicator for illness severity, the present study only assessed the presence or absence of them. This may possibly have affected the participants' responses in relation to impact on loss. However, the number of previous hospitalizations also has limitations and can be biased. Asking participants about the number of previous hospitalizations may be affected by recall difficulties and social desirability (due to the self-reported nature of the data), and may also be confounded with age because the number of previous hospitalizations might be higher among older patients. The convenience sample used in the present study also compromises the generalization of the results. However, it provides insight into the planning of further research on this subject. Finally, due to the cross-sectional nature of the study, causality between variables cannot be assumed. Future studies with a larger sample size are needed to examine the factor structure of the PLMI scale. This would also help clarify whether the poor psychometric fit of Item 13 which was unique to the sample in the present study, or whether it represents more profound problem with the Item content. It might be that Item 13 ("*I don't enjoy being around other people who have a mental illness*") reflects an internalized negative attitude towards mental illness rather than a perceived loss. Future studies might also examine loss among more specific patient groups with a larger sample size.

### 4.1. Conclusions

Despite the limitations outlined, the present study provides important insights into the loss experience of mentally ill patients and important implications for health professionals. First and foremost is the need to examine patients with different diagnoses about their sense of loss and to better understand how to provide interventions that will address their feelings, helping them come to terms with their illness and improving their lives. Future research should also investigate the impact of loss on the adjustment of patients in different and more specific illness groups. Additionally, the role of perceived loss in non-adherence with medication and psychotherapeutic treatment – a highly prevalent problem in the psychiatry field – should also be examined.

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Supplementary Table*:* Correlations between the variables in the CFA with covariates analysis.

| | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. |
|---|---|---|---|---|---|---|---|---|---|---|
| 1. Loss | | | | | | | | | | |
| 2. Age | -0.13 | | | | | | | | | |
| 3. Gender | 0.03 | 0.12 | | | | | | | | |
| 4. Hospitalizations | 0.03 | 0.10 | -0.07 | | | | | | | |
| 5. Marital status | -0.14 | **0.23** | 0.09 | -0.13 | | | | | | |
| 6. Schizophrenia | 0.03 | -0.05 | **-0.20** | **0.37** | **-0.17** | | | | | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| spectrum disorders | | | | | | | | | | |
| 7. Mood disorders diagnosis | **0.18** | 0.13 | 0.12 | 0.01 | -0.09 | **-0.37** | | | | |
| 8. Stress-related disorders diagnosis | **-0.20** | -0.01 | 0.06 | **-0.35** | **0.24** | **-0.50** | **-0.50** | | | |
| 9. Loneliness | **0.76** | **-0.24** | -0.03 | 0.02 | **-0.25** | -0.02 | 0.15 | -0.15 | | |
| 10. Quality of life | **-0.73** | 0.10 | -0.07 | 0.05 | 0.16 | 0.16 | **-0.21** | 0.08 | **-0.74** | |
| 11. Grief | **0.71** | -0.01 | 0.10 | -0.04 | -0.07 | -0.05 | **0.17** | **-0.17** | **0.57** | **-0.57** |

Notes: $N$=173. The boldfaced correlations are significant at least at $p$<0.05. Due to missing values, correlation between loss and occupation was calculated separately and resulted in $r$=0.18 $p$<0.03. Similarly, in case of education, the correlation is $r$=0.18, $p$=0.020.

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

## (study 3)

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## Abstract

This study examined the factor structure of the Hungarian version of the Birchwood Insight Scale (BIS) and analyzed its association with socio-demographics, diagnosis, internalized stigma, and shame using confirmatory factor analysis (CFA) with covariates. Mentally ill patients (N=200) completed self-report questionnaires. CFA supported two-factor structure. While previous hospitalizations and diagnosis were associated with insight, insight predicted higher internalized stigma and shame. Efforts to increase insight should be matter of importance in the wider spectrum of mental diagnoses. However, such efforts should be conducted with special care as further research is needed to understand the impact of insight on wellbeing.

**Keywords**: Internalized stigma; The Birchwood Insight Scale (BIS); Confirmatory factor analysis (CFA); Awareness of illness; Intervention programs

## Introduction

Having insight, or awareness of having a mental illness diagnosis is a crucial step in successful coping and recovery (Frese, 2000; McEvoy, 2004). Insight has been defined as including three different but overlapping dimensions: (i) individuals' acknowledgment of having a mental illness diagnosis; (ii) the recognition that treatment is necessary to control the illness, and (iii) the ability to re-label the experienced symptoms as abnormal and part of the illness (David, 1990). Unfortunately, individuals with various different mental disorders often possess poor insight (Ghaemi, Boiman, & Goodwin, 2000; Pini, Cassano, Dell'Osso, & Amador, 2001). Lack of insight has been found to be an important predictor of adverse clinical outcomes, treatment non-compliance, and increased cognitive impairment (Aleman, Agrawal, Morgan, & David, 2006; Mohamed et al., 2009; Yen et al., 2005). However, conflicting findings implying that having insight is not necessarily associated with positive outcomes, contribute much to the complexity of the insight construct, and were consequently coined as the "insight paradox" (Lysaker, Roe, & Yanos, 2007).

More specifically, it has been found that having high insight is associated with depressive symptoms, low quality of life, low self-esteem, and less meaning in life (Ehrlich-Ben Or et al., 2013; Lysaker, Lancaster, Davis, & Clements, 2003; Mintz, Dobson, & Romney, 2003; Moore, Cassidy, Carr, & O'Callaghan, 1999; Staring, Van der Gaag, Van den Berge, Duivenvoorden, & Mulder, 2009). Recently this paradox was explained with the internalization of stigma, a psychological process that occurs when individuals agree with the stigma that is present in society, internalize the stigma, and adopt a stigmatized identity (Corrigan, Watson, & Barr, 2006). According to this assertion, the meaning that is attached to the recognition of having a mental illness is important, and individuals who demonstrate high insight together with high levels of internalized stigma are more prone to experience adverse outcomes (Lysaker et al., 2007; Staring et al., 2009). What makes insightful people adopt a stigmatized identity is a question which was investigated by Hasson-Ohayon et al. (2012), who found that the experience of shame mediated the relationship between insight and internalized stigma. Therefore, shame should be regarded as an important factor which – when accompanied by insight – affects the susceptibility to internalization of stigma.

Over the years, efforts to assess insight has taken different approaches. Among these are the assessment of insight utilizing a one-item measure to detect overall insight level (Lincoln, Lüllmann, & Rief, 2007). However, this is an approach which is not considered to be sensitive enough to the specific and different dimensions of insight (Baier, 2010). Consequently, different scales were developed in order to take into consideration the multi-dimensional nature of insight (Amador et al., 1993; Beck, Baruch, Balter, Steer, & Warman, 2004). However, most of the existing scales are based on clinicians observation (Young, Campbell, Zakzanis, & Weinstein, 2003) and might also require some training in how to administer the scales (Sanz, Constable, Lopez-Ibor, Kemp, & David, 1998). Furthermore, some instruments are very long, which might be an obstacle for patients with limited mental and/or psychological capacities (Cleary et al., 2014).

The Birchwood Insight Scale (BIS; Birchwood et al., 1994), is an eight-item self-report measure, which was developed to offer an easy and brief alternative to assess the three insight dimensions. The BIS is a reliable and valid tool to assess insight, and is sensitive enough to assess individual differences and changes in insight which might occur over time (Birchwood et al., 1994). Despite being increasingly used in psychiatric research (Cleary et al., 2014), very few studies have examined the scale's psychometric properties and/or factor structure, and their findings are inconsistent. Birchwood et al. (1994) reported on the same three-factor structure which was previously found by David (1990).

However, other researchers have reported that a one-factor structure yielded the best fit among a sample of patients experiencing a first episode of psychosis, and a mixed sample of chronic patients with psychotic and mood disorders (Cleary et al., 2014). Additionally, because studies investigating insight in the psychiatric field have mainly focused on individuals with schizophrenia and psychosis (Ghaemi, 1997), the BIS has mainly been used among these patient groups (Cleary et al., 2014). Consequently, the generalizability of the BIS to other patient populations is unclear. While poor insight is a main symptom of schizophrenia and psychosis in general (Amador et al., 1994; Carpenter, Bartko, Strauss, & Hawk, 1978; Pini et al., 2001), there is increasing empirical evidence that it also occurs in many other disorders such as bipolar disorder, mood disorders without psychotic symptoms, and anxiety disorders (Amador et al., 1994; Eisen et al., 1998; Ghaemi et al., 2000; Michalakeas et al., 1994; Peralta & Cuesta, 1998; Pini et al., 2001).

The main goal of the present study was to examine the factor structure of the BIS using a relatively large sample of patients experiencing a wide range of mental diagnoses. Moreover, as all the previous studies were conducted among English-speaking populations, the present study examined the functioning of the BIS factor structure among a non-English speaking sample. Furthermore, the secondary goal of the study was to examine the possible predictors of insight including socio-demographic factors, diagnosis, and previous hospitalizations. Given the relationship between insight and internalized stigma and the latter's negative impact on recovery, the ability of insight to predict both internalized stigma and shame was also investigated. It was hypothesized that a high degree of insight would be a significant predictor of high levels of internalized stigma and shame. Due to the high prevalence of poor insight among patients with diverse diagnoses, and its' meaningful implications (both positive and negative) for recovery, insight constitutes a major concern in the mental health field. Consequently, acquiring more precise knowledge regarding the different predictors and outcomes of insight on their different facets can meaningfully contribute to the improvement of the lives of people coping with mental illness and is of high clinical importance.

## Methods

### *Participants*

A sample of 200 adults with a mental illness diagnosis were recruited from an outpatient unit of mental health center in the Hungarian capital of Budapest. The inclusion criteria were: (i) having a psychiatric diagnosis according to the ICD-10 (World Health Organization, 1992), (ii) taking psychiatric medications, (iii) being inpatients or outpatients in any type of psychiatric care, (iv) being patients who had not abused illicit substances and alcohol for at least two weeks at the time of the assessment, (v) being aged between 18 and 65 years, and (vi) being able to complete the questionnaire following the judgment of their psychiatrist. The exclusion criteria were (i) having an acute phase of illness, (ii) having a diagnosis of an organic brain disorder, dementia, and/or mental retardation, and (iii) not having the mental competency and/or ability to complete the self-report questionnaire or give informed consent.

### *Procedure*

Patients who met the study inclusion criteria were contacted via their treating psychiatrists. Upon agreement to participate, patients received an information sheet about the study's goals and signed an informed consent form. Participants then completed a self-report questionnaire. All questionnaires were translated from English to Hungarian and back-translated from Hungarian to English using accepted translation protocols (Beaton, Bombardier, Guillemin, & Ferraz, 2000). The possible discrepancies between the original and back-translated version were resolved. Ethical approval was granted by the ethical board of the regional hospital accountable for the patients' welfare.

### *Measures*

Socio-demographic questions included those relating to gender, age, previous hospitalizations (yes/no), education (finished high school/did not finish high school), occupation (employed/unemployed), diagnosis, and marital status (married/divorce/widow/single). Patients were divided into six categories according to the ICD-10 codes categorization (World Health Organization, 1992): (i) schizophrenia spectrum disorders (e.g., schizophrenia, schizotypal and delusional disorder), (ii) mood disorders (e.g., major depressive disorder, bipolar and manic disorder), (iii) stress-related disorders (e.g., phobic anxiety disorders, obsessive-compulsive disorders, somatoform disorders), (iv) behavioral syndromes associated with physiological disturbances (e.g., eating disorders), (v) personality disorders (e.g., borderline personality disorder, avoidant personality disorder), and (vi) disorders due to psychoactive substance use.

#### Insight

The Birchwood Insight Scale (BIS; Birchwood et al., 1994) is an eight-item self-report instrument that assesses three dimensions of insight into mental illness (illness awareness: Items 2 and 7; need for treatment: Items 3,4,5 and 6; and re-labeling of symptoms: Items 1 and 8). Each item contains a statement offering three response options: *agree, unsure,* or *disagree*. Each response is scored on the basis of the insight level it reflects, where insightful responses (agree/disagree) are scored 2, unsure responses are scored 1, and responses which reflect poor insight are scored 0.

Because the sample of the present study included patients who were not hospitalized, a minor change was made in Item 4 assuming hospitalization (*"My stay in the hospital is necessary"* was adapted to *"The treatment in the institution is necessary"*). The scale has good internal consistency and reliability (α=0.75 and test-retest reliability=0.90) (Birchwood et al., 1994). In the present study the BIS had moderate internal consistency (α=0.64).

### Internalized stigma

The Self-Stigma of Mental Illness Scale (SSMIS; Corrigan et al., 2006) is a self-report instrument that assesses internalization of stigmatic views that exist in society. The scale includes four subscales reflecting the four stages process of stigma internalization as proposed by Corrigan et al. (2006): (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 to on a nine-point Likert scale ranging from 1 (*strongly disagree*) to 9 (*strongly agree*). The total score of each subscale ranges between 10-90, where higher scores reflect increased adoption of stigma as indicated by the specific subscale. Good internal consistency was found in the present study (stigma awareness: α=0.92, stigma agreement: α=0.90, stigma internalization: α=0.83 and self-esteem reduction: α=0.84)

### Shame

The Experience of Shame Scale (EES; Andrews, Qian, & Valentine, 2002) is a 25-item instrument that assesses three aspects of shame: (i) *characterological shame* (experiencing shame because of personal habits, behavior with others, the kind of person, and because of self-capabilities), (ii) *behavioral shame* (experiencing shame when doing and saying something wrong and due to failure in competitive situations), and (iii) *bodily shame* (experiencing shame because an individual considers their body or its parts unacceptable). In the assessment of each aspect, there are three items addressing the following: (i) *experimental component* (with a direct question about feeling shame), (ii) *cognitive component* (such as concerns regarding the opinion of others), and (iii) *behavioral component* (questions regarding efforts to hide or avoid situations). For each item, participants are asked to respond based on their feelings over the past year on a four-point Likert scale ranging from 1 (*not at all*) to 4 (*very much*). Scores are calculated by summing up the items to produce a total score ranging between 25-100. The Hungarian validated version of this scale (Vizin, Urbán, & Unoka, 2016) was used in this study, and had excellent reliability (α=0.97).

### *Statistical analyses*

First, a series of confirmatory factor analyses (CFAs) were used to assess the factor structure and item performance of the Hungarian version of the BIS in the sample. Unlike previous studies, items of the Birchwood Insight Scale were treated as ordinal and used the mean- and variance- adjusted weighted least squares (WLSMV) estimator. In CFA, acceptable degree of fit requires the comparative fit index (CFI) and the Tucker-Lewis Index (TLI) to be close to 0.95, and the model should be rejected when these indices are <0.90 (Brown, 2006). The next fit index was root mean squared error of approximation (RMSEA). 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). The measurement invariance of the BIS was also tested in groups having or not having a schizophrenia diagnosis. After establishing measurement invariance, 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. The CFA with covariates technique was chosen for the present study because it can best estimate the effect of indicators and grouping variables or other continuous variables on latent variables simultaneously. Finally, the association between the insight factors, internalized stigma, and shame was investigated. All analyses were performed with MPLUS 8.1 (Muthén & Muthén, 1998).

## Results

### *Descriptive statistics*

The percentages, means, and standard deviations (SDs) of the study variables are shown in Table 1. The majority of the sample were women, graduated from high school, and were diagnosed with stress-related disorders. Almost half of the sample had previous hospitalizations. The age range of the sample was wide (32 to 56 years), with a mean of 44.2 years (SD=11.8).

Table 1. Descriptive statistics of the study sample (N=200)

| | |
|---|---|
| Gender (female) *N (%)* | 133 (66.5) |
| Age – mean (SD) | 44.2 (11.8) |
| Education, graduated high school – *N* (%) | 157 (78.5) |
| Previous hospitalizations – *N* (%) | 89 (44.5) |
| Diagnosis | |
| *Schizophrenia spectrum disorders – N* (%) | 53 (26.5) |
| *Mood disorders – N* (%) | 58 (29.0) |
| *Stress-related disorders – N* (%) | 89 (44.5) |
| *Personality disorders – N* (%) | 10 (5.0) |
| *Disorders due to psychoactive substance use – N* (%) | 2 (1.0) |
| *Behavioral syndrome associated with physiological disturbances – N* (%) | 2 (1.0) |
| *Only one diagnosis- N (%)* | 188 (94.0) |
| *Two diagnoses- N (%)* | 10 (5.0) |
| *Three diagnoses- N (%)* | 2 (1.0) |

*Confirmatory factor analyses of the Birchwood Insight Scale*

As a first step, the one-factor model (Model 1) was tested which yielded excellent fit (see Table 2). However, the inspection of the factor loadings revealed that Item 1 (*"Some of my symptoms are made by my mind"*) did not load significantly on this factor. The three-factor model was also tested as suggested in previous research. This model also yielded excellent fit (see Table 2). 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 (see Table 3). Because of the large correlation between *"awareness of illness"* and *"re-label of symptoms"*, they were merged, and a two-factor model was tested with exclusion of Item 1. This model also yielded an excellent degree of fit (see Table 2). This two-factor model with seven items was also contrasted with the one-factor model with seven items. Since the two-factor model showed superior fit to data, this model 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 correlation between the two factors was strong (*r*=0.75).

Because this scale was tested primarily with patients suffering from psychosis, the measurement invariance between patients diagnosed with schizophrenia and not diagnosed with schizophrenia was also checked. Applying the increasing constrains did not worsen the model fit significantly therefore the measurement invariance was supported (see details in Table 2).

Table 2. Fit indices of the alternative measurement models of the Birchwood Insight Scale

| | | $\chi^2$ | *Df* | *p* | *CFI* | *TLI* | *RMSEA* | *Cfit of RMSEA* |
|---|---|---|---|---|---|---|---|---|
| Model 1 | One-factor model (8 items) | 30.1 | 20 | 0.0675 | 0.973 | 0.962 | 0.050 | 0.465 |
| Model 2 | Three-factor model (8 items) | 18.6 | 17 | 0.3538 | 0.996 | 0.993 | 0.021 | 0.794 |
| Model 3 | One-factor model (7 items)* | 25.3 | 14 | 0.0320 | 0.970 | 0.955 | 0.063 | 0.259 |
| Model 4 | Two-factor model (7 items)* | 15.0 | 13 | 0.3059 | 0.995 | 0.991 | 0.028 | 0.709 |
| Multigroup analysis: Invariance testing of the two factor model# | | | | | | | | |
| | Configural invariance (freely estimated factor loadings and thresholds) | 29.3 | 26 | 0.2991 | 0.992 | 0.987 | 0.036 | 0.612 |
| | Metric invariance model (equal factor loadings)** | 30.9 | 31 | 0.4702 | 1.000 | 1.000 | 0.000 | 0.784 |
| | Scalar invariance (equal factor loadings, and equal thresholds)*** | 39.7 | 36 | 0.3079 | 0.991 | 0.989 | 0.032 | 0.673 |

Note: *N*=200. *Item 1 was removed due to non-significant factor loading. Comparison of model fit of Model 3 and Model 4 was performed with difftest procedure implemented in Mplus 8.1. Model 4 yielded significantly closer fit to the data ($\Delta\chi^2=6.73$, $\Delta df=1$, $p<0.01$).#: The grouping variable was having or not having schizophrenia diagnosis, **:The difftest between configural and metric invariance model is nonsignificant ([$\Delta\chi^2$=2.95, $\Delta$df=5*p*=0.7074]. ***: The difftest between metric and scalar invariance model is nonsignificant ([$\Delta\chi^2$=10.25, $\Delta$df=5*p*=0.0685]).

Table 3. Confirmatory factor analyses of Birchwood Insight Scale: Three measurement models

| | One-factor model | Three-factor Model | | | Modified two-factor model | |
|---|---|---|---|---|---|---|
| | Insight | Awareness of illness | Need for treatment | Re-labeling of symptoms | Awareness of illness | Need for treatment |
| Item 1: Some of my symptoms are made by my mind | 0.12ns | | | 0.16ns | | |
| Item 2: I'm mentally well | 0.54 | 0.63 | | | 0.62 | |
| Item 3: I do not need medication | 0.86 | | 0.89 | | | 0.89 |
| Item 4: The treatment in the institution is necessary | 0.41 | | 0.43 | | | 0.44 |
| Item 5: The doctor is right in prescribing medication for me | 0.66 | | 0.68 | | | 0.68 |
| Item 6: I do not need to be seen by a doctor or | 0.81 | | 0.82 | | | 0.82 |

| | | | | | | |
|---|---|---|---|---|---|---|
| psychiatrist | | | | | | |
| Item 7: If someone said I have a nervous or mental illness, they would be right | 0.59 | 0.69 | | | 0.68 | |
| Item 8: None of the unusual things I am experiencing are due to an illness | 0.51 | | | 0.66 | 0.58 | |
| Factor correlations | | | | | | |
| Need for treatment | - | 0.73 | | | 0.75 | - |
| Re-labeling of symptoms | - | 0.86 | 0.66 | - | - | - |

Note: Standardized factor loadings. ns = non-significant

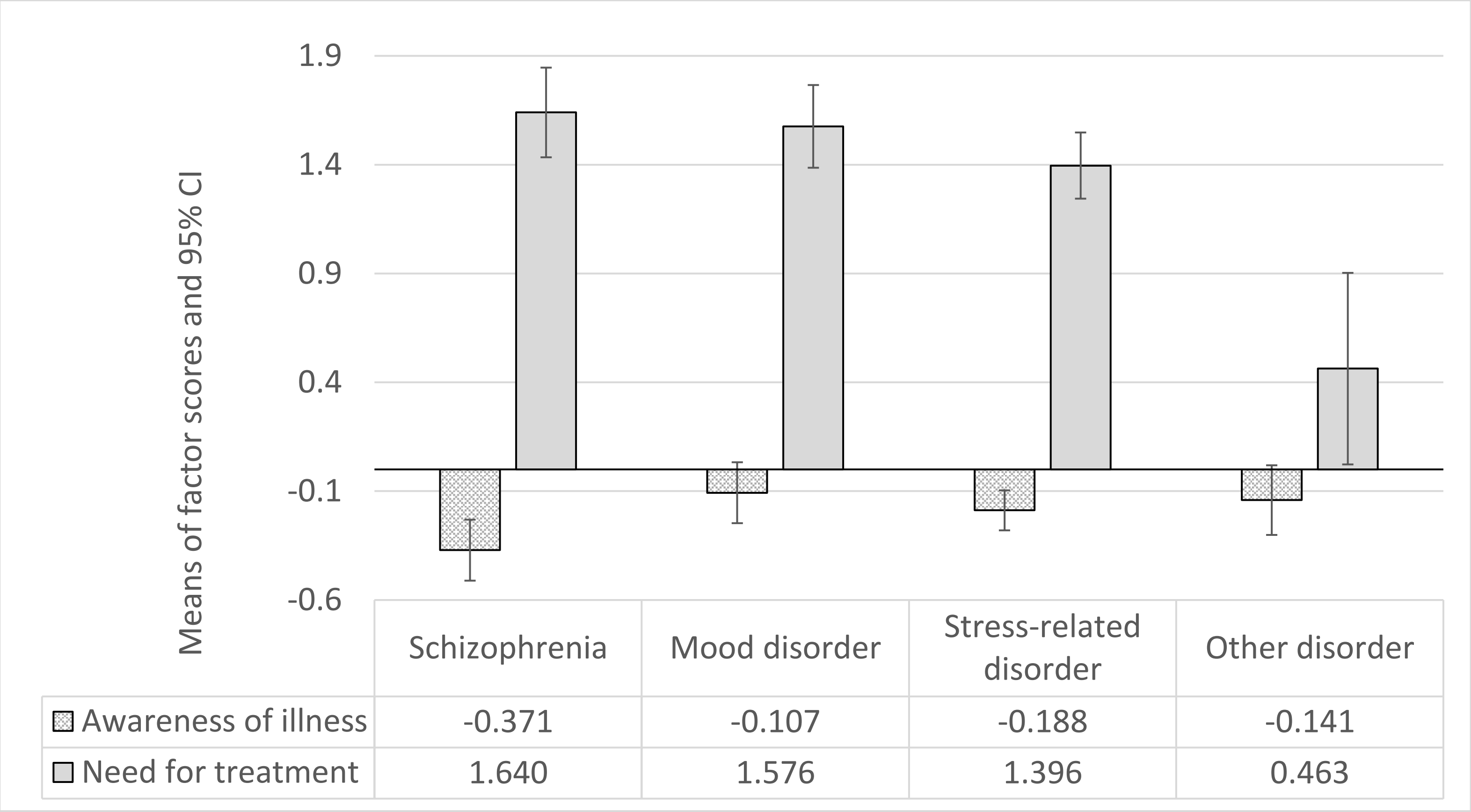
*Differences of insight among patients with different diagnoses*

After establishing the measurement model of insight, comparison of patients with different diagnosis along the factor scores of two insight dimensions was made. Figure 1 shows the means and 95% confidence intervals of factor score of awareness of illness and need for treatment factors among patients with schizophrenia spectrum disorders, mood disorders, stress-related disorders, and other disorder diagnosis (such as personality disorders, disorders due to psychoactive substance use, and behavioral syndrome associated with physiological disturbances). A significant main effect was found in the awareness of illness factor (F(3, 192)=2.86, *p*<0.05). Tukey HSD post-hoc test showed that only schizophrenia spectrum disorders and mood disorders groups differed significantly (*p*<0.03). The effect size of the difference was medium sized (Cohen *d*=0.52). Although the statistical test did not reach the level of significance, the effect size of the group difference is not negligible. For example, the difference between schizophrenia and stress-related groups was also medium sized

(Cohen *d*=0.40), and that between mood disorders and stress-related disorders group was small (Cohen d=0.17). In the case of the need for treatment factor, a significant main effect was also 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 according to Tukey HSD test.

The schizophrenia spectrum disorder patients had the highest score for need for treatment but it differed significantly only from the other diagnosis group. However, the effect size of difference between schizophrenia and stress-related group was not negligible either (Cohen *d*=0.35), but it did not reach statistical significance due to the low statistical power because the required sample size would be 260 (if the power was 0.80) in this case. The difference between schizophrenia and mood disorder group was negligible (Cohen *d*=0.09).

*Figure 1*. Comparison of two insight factors across mental conditions.



| | Schizophrenia | Mood disorder | Stress-related disorder | Other disorder |
|---|---|---|---|---|
| ▨ Awareness of illness | -0.371 | -0.107 | -0.188 | -0.141 |
| ☐ Need for treatment | 1.640 | 1.576 | 1.396 | 0.463 |

*Note:* Factor scores are estimated from the CFA model. CI=confidence interval.

*Predictors of insight: gender, age and hospitalization*

Table 4 presents the result of bivariate correlation analyses and the CFA with covariates analysis. Correlation analysis showed that awareness of illness correlated positively with hospitalization and negatively with schizophrenia spectrum diagnosis. Being hospitalized associated with higher awareness of illness. Having a schizophrenia spectrum diagnosis also associated with lower awareness of illness. Age, gender, and other diagnosis were not related with awareness of illness. Need for treatment correlated positively with age, schizophrenia, and mood disorders diagnoses. Therefore, older age, schizophrenia, and mood disorders diagnoses associated with higher recognition of need for treatment. Hospitalization was associated with the recognition of higher need for treatment.

In a multivariate analysis, the predictors of the two insight factors with CFA with covariates model were tested. Covariates were gender, age, and hospitalization. Because previous analysis found associations between insight and diagnosis, here the impact of diagnosis was controlled for. Only hospitalization significantly 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, $\beta$= 0.254 $p$<0.05).

*Table 4.* Predictors of the two factors of insight: CFA with covariates analysis

| | Awareness of illness | | Need for treatment | |
|---|---|---|---|---|
| | *R* | *β* | *r* | *β* |
| Age | -0.076 | -0.099 | **0.175*** | 0.104 |
| Gender | -0.047 | -0.069 | -0.020 | -0.020 |
| Hospitalization | **0.199**** | **0.254*** | **0.208**** | 0.135 |
| $R^2$ | | 8.7% | | 10.7% |

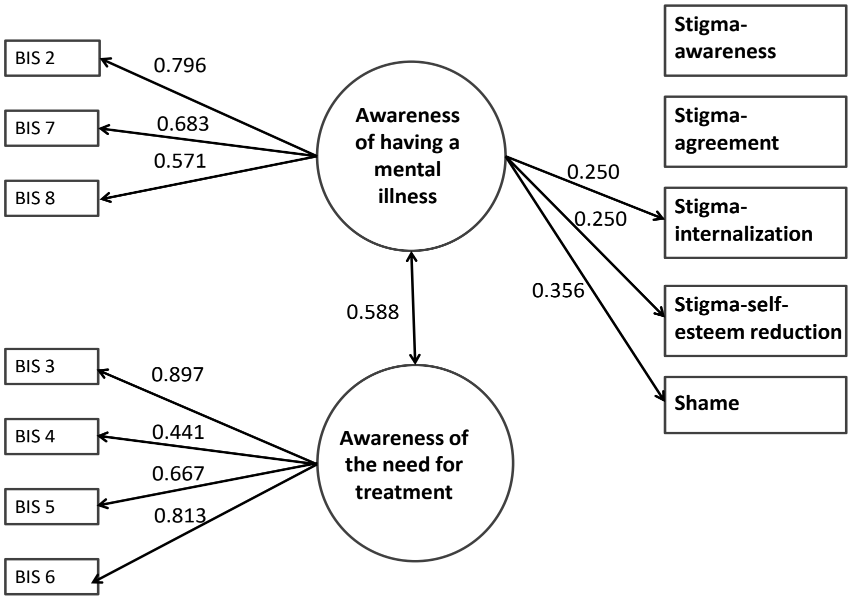
*Note*: *N*=191. *r*=bivariate correlations between factor scores and the explanatory variables. Hospitalization coding: 1=hospitalized and 0=non-hospitalized. Diagnoses were controlled for in the model. *β*=standardized regression coefficients. Boldfaced coefficients are significant at p<0.05. **p<0.05; **p<0.01; ***p<0.001.*

*The impact of insight on shame and stigma*

In order to estimate the impact of insight on shame and stigma, the correlation matrix between the two latent factors and four factors of the Self-Stigma of Mental Illness Scale and the shame score were estimated. The awareness of illness factor correlated significantly with the score of internalized stigma in self-identity (*r*=0.34 *p*<.001), the score measuring the self-esteem reduction due to stigma (r=0.36, *p*<.001), and the shame score (*r*=0.53 *p*<.001). The awareness of illness factor did not correlate with the awareness of stigmatic views and the agreement with stigmatic views (*r*=0.11 and 0.04, respectively). The need for treatment factor did not correlate with the four factors of stigma or with the shame score.

A multivariate model within a structural equation modeling framework was tested (see Figure 2). 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 in the analysis. The awareness of illness factor significantly predicted shame (β=0.36, *p*<.001), internalized stigma (β=0.27, *p*<.01), and self-esteem reduction (β=0.25, *p*<.01), therefore they had unique shared variance with awareness of illness.

Figure 2: Structural equation modeling of insight, internalized stigma and shame



Note: Only the significant (p<.05) paths are presented. The path coefficients and factor loadings are standardized.

## Discussion

The main goal of the present study was to examine the factor structure of the Birchwood Insight Scale (BIS) among non-English speaking individuals with different psychiatric diagnoses. The study results indicated that the two-factor structure have the best fit and– if not the poor functioning of Item 1 – also validates the factor structure which was reported originally (Birchwood et al., 1994). While the previous validation study of Cleary et al. (2014) also reported on the poor functioning of Item 1 their findings of a one-factor structure are in contrast to the present study's results and the original study of Birchwood et al. (1994). Furthermore, by including different diagnostic groups, the present study confirms the applicability of the BIS not only in patients with psychosis but also in patients with a wider range of diagnoses. This is also supported by the measurement invariance testing between patients having or not having a schizophrenia diagnosis.

Further studies should consider the elimination of Item 1 from the BIS or adding a new item to the 're-labeling symptoms' subscale so the scale will reflect the three known insight dimensions which have been reported in the literature (David, 1990). Cleary et al. (2014) proposed that the poor functioning of Item 1 might be because of the confusing meaning of the words "made by my mind" which can have different meanings in different cultures and can be open to different interpretations by the participants. Other sources for difficulties in interpretation might be related to the words "some of my symptoms" and not "all of my symptoms" (Cleary et al., 2014). As none of these options were tested, studies should consider all these options when using the scale.

As part of examining insight among the wider patient population groups, the present study also compared the different diagnostic groups in terms of their insight levels. The group comparison revealed that schizophrenia spectrum disorder patients had the lowest level of awareness of illness compared to the mood disorders, stress-related disorders, and other disorder group. The effect sizes were medium-sized when schizophrenia spectrum disorders were compared with mood disorders and stress-related disorders. However, the effect size of the difference between patients with mood disorder and stress-related diagnosis were small. The mood disorders group had the highest illness awareness. This finding is in contrast with a study indicating that stress-related disorders patients had higher insight compared to bipolar patients and patients with depression (Ghaemi, Boiman & Goodwin, 2000), and supports the need to examine insight among individuals with different and less severe mental illness diagnoses, especially because such research is lacking. The finding that schizophrenia spectrum disorder patients had the lowest illness awareness levels is in line with other research indicating that schizophrenia patients specifically have poorer awareness of having mental illness compared to other mental disorders (Amador et al., 1994; Braw et al., 2012; Pini et al., 2001; Ramachandran, Ramanathan, Praharaj, Kanradi, & Sharma, 2016), but in contrast with David et al. (1995) who found that the diagnosis of schizophrenia is not specifically associated with poor insight, and with Arduini et al. (2003) who found no significant differences in illness awareness when comparing schizophrenia and bipolar patients.

The discordant findings across studies regarding the different diagnoses probably depends on how the researchers operationalized the insight measure. A frequently used way of assessing insight is based on expert rating such as the Scale to Assess Unawareness of Mental Disorder (SUMD; Amador et al., 1994). However, the method in the present study was based on patients' self-report. It is important to note that the present study supported the sensitivity to assess lower insight in schizophrenia with self-report, which is a more cost-effective way to assess insight compared to structured diagnostic interviews. Nevertheless, and regardless of group comparisons, schizophrenia spectrum disorders in the present study were found to be significantly associated with low illness awareness, which emphasizes that schizophrenia patients are sensitive and prone to deficiencies in their awareness of having mental illness. This finding supports existing knowledge concerning illness manifestations which describe poor insight as the main illness feature (Cuesta & Peralta, 1994), with 50%-80% of patients experiencing insight deficits to differing degrees (Amador & Gorman, 1998). In contrast with illness awareness, schizophrenia patients did not differ significantly from mood disorder and stress-related disorder patients in the need for treatment factor which might imply that their awareness in terms of need for treatment is not lower than other diagnoses. In fact, schizophrenia patients had the highest awareness in the need for treatment, a finding which in a larger sample and more powered study might have reached a statistically significant level. This finding is in line with the different manifestations of the disorders and the continuous need for treatment control which exists– especially among schizophrenia spectrum disorders (American Psychiatric

Association, 2006) compared to other disorders. Interestingly, while these patients appear to be the most aware of the need for treatment, treatment non-compliance is highest among this patient group (Cramer & Rosenheck, 1998; Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010), which might imply that it is not necessarily the lack of awareness leading them not comply to treatment, but that there might be other underlying factors. However, considering the discordant findings across studies, more research in needed to clarify differences in insight between patients with different diagnoses, especially because studies examining different insight dimensions are lacking.

The present study also examines the possible predictors of insight and its different consequences. From the study results it appears that socio-demographic factors such as age and gender are not significant predictors of insight. These results are in line with previous studies (David, Buchanan, Reed, & Almeida, 1992; Goldberg, Green-Paden, Lehman, & Gold, 2001; Marková & Berrios, 1992; McEvoy, Aland, Wilson, Guy, & Hawkins, 1981). On the other hand, patients' previous hospitalizations found to be an important factor in the prediction of insight as it significantly predicted illness awareness. This finding is in accord with previous studies which found positive associations between hospitalization and insight (e.g., Tariku, Demilew, Fanta, Mekonnen, & Abebaw Angaw, 2019) because hospitalization may provide opportunity for the patients to learn about their specific condition and diagnosis. However, the patients included in the present study were stable and already under treatment, therefore this result is not applicable for those patients who are unstable and who are chronically hospitalized (Harvey, Loewenstein, & Czaja, 2013). However, interesting to note that while the presence of previous hospitalizations predicted insight in terms of awareness into the illness, it did not predict patients' awareness in the need for treatment. It is important to mention that this finding might be the result of multicollinearity among the different variables in the study, because hospitalizations were found to be positively associated with awareness for the need for treatment, an association which disappeared in the multivariate analysis. However, this association was weak to moderate in size. Still, this finding is important to consider for further research, because it implies the opposite to the commonsense perception of being hospitalized in order to receive a treatment, and thus might mean that hospitalizations in the context of mental health might be more meaningful to patients' self-definition and to an illness identity, rather than to their perception of receiving necessary treatment.

This possibility is in line with findings from stigma research, stating that the acknowledgement of having a mental illness is associated with negative self-definition such as perceiving the whole self and one's identity as ill and ruined (Yanos, Roe, & Lysaker, 2010), rather than, for instance, perceiving the disorder as separate from the self, as a health condition that might be controlled by proper treatment. Williams (2008) claims that having the awareness that one has mental illness often initiates a process which changes the way individuals perceive themselves, leading them to adopt a new identity. Unfortunately, this new identity, in many instances, appears to be affected by mental illness stigma, incorporating negative stereotypes which exist in the society.

The results of the present study regarding the consequences of insight further support the possibility that illness awareness is accompanied by negative interpretations, as the only insight aspect which predicted negative outcomes was the awareness of having a mental illness, and not the recognition of the need for treatment. In fact, the awareness of having a mental illness was found to have a negative impact most specifically on self-related aspects, and predicted higher internalized stigma and lower self-esteem. This was not associated with the other lesser self-related stigma aspects, such as awareness to social stigma and agreement with the stigma. Similarly, having a higher awareness of the illness also predicted higher experience of shame. These findings reinforce the accumulating studies reporting on an “insight paradox”, meaning that having insight into one’s illness is not always positive, and in the context of mental illness, it might even be detrimental. It might be present in particularly societies where especially high stigma is present, such as Hungary, because high and persistent stigmatization has been reported in Hungarian society towards mental patients (Buchman-Wildbaum et al., 2018).

Among the insight aspects, the present study targeted the “awareness of having mental illness", because this insight aspect is potentially hurtful having negative aspects. These findings reinforce previous studies reporting the same conclusion. Using the BIS Norman, Windell, Lynch, and Manchanda, (2011) found the illness awareness aspect to be the only insight aspect which was consistently associated with depression, anxiety, anger, hostility, and engulfment (a process describing one's acceptance of the patient role as their main self-definition). Similarly, Hasson-Ohayon et al. (2012) found illness awareness was the only insight aspect to be related to higher feelings of shame. Staring et al. (2009) reported more specific differentiation between the insight aspects in terms of their individual contribution to different negative outcomes. In their sample, among individuals with high internalized stigma, the awareness of having mental illness was found to have the most influential impact on negative self-esteem, while the need for treatment aspect was found to have the largest negative impact on depressed mood and quality of life.

Because treatment for mental illness mainly includes medication, which often has an element of chronicity, involves limitations, and require adaptations, it is plausible to speculate that awareness to the need for treatment will mainly influence individual's mood and quality of life, and will be less related to stable beliefs of self-worth, self-definition, or self-esteem *per se*. However, further study is needed in order to shed light on the complexity of the insight construct and to draw more solid conclusions, especially as studies focusing on its specific aspects are limited.

The results of the present study have several clinical implications. Firstly, the study results, consistent with other findings, might imply that in the mental health field, insight and internalized stigma might be two intertwined factors that together produce negative consequences. Besides the aforementioned negative effects on individual's self-perception, internalized stigma has also been related to treatment non-compliance (Gerlinger et al., 2013; Kamaradova et al., 2016), a widespread problem within the mental health field, which can have severe consequences (Lacro, Dunn, Dolder, Leckband, & Jeste, 2002; Sajatovic, Davies, & Hrouda, 2004). Therefore, paradoxically, it might be that in some cases, having high awareness into the illness, will interfere with patients’ willingness to ask for help and engage in treatment, although they might be aware of the need for treatment.

Consequently, although not examined in this study, rather than assuming full responsibility to lack of insight, internalized stigma should be taken into consideration when facing difficulties with treatment compliance. The experience of shame should also be addressed, especially as it might make individuals more vulnerable to the internalization of stigma (Hasson-Ohayon et al., 2012). As such, this mainly implies that there is a need to formulate intervention programs which will aspire to improve insight while empowering patients simultaneously, in a way that their awareness of having a mental illness will not be accompanied with negative self-definition.

Psychoeducation programs which supply knowledge concerning mental illness, the treatment, and focus on refuting stereotypes might be helpful. However, the impact of such programs on insight remains unclear. There is evidence that these programs increase knowledge (Lincoln, Wilhelm, & Nestoriuc, 2007) but it is not clear if the patients use such knowledge in their everyday life and struggles (Kemp & David, 1995; Sevy, Nathanson, Visweswaraiah, & Amador, 2004). A promising intervention which was found to increase insight (Yanos, Roe, West, Smith, & Lysaker, 2012) and reduce internalized stigma (Hansson, Lexén, & Holmén, 2017) is Narrative Enhancement and Cognitive Therapy (NECT) (Yanos, Roe, & Lysaker, 2011). Intervention programs aiming to increase insight should keep in mind that although having awareness to any life struggle is an important step in recovery, in the mental health field, not only might this not be enough, but it might also be contaminated with stigmatic and self-devaluing beliefs. Therefore, internalized stigma and shameful feelings should be an inseparable part of any intervention or treatment plan offered to individuals coping with mental illness.

Secondly, the study results may also stress the need to examine and address insight among patients with different diagnoses instead of focusing solely on those with schizophrenia. While the BIS in this study was found to be applicable to patients with different diagnoses, future research might benefit from the development of insight scales which are tailored to specific diagnoses. A promising step in this direction is the Mood Disorders Insight Scale (MDIS), a modified version of the BIS, that is suitable specifically for mood disorders (Sturman & Sproule, 2003).

Third, the present study stresses the complexity of insight and the need to differentiate between different aspects of insight. As such, efforts to increase awareness of the illness itself without taking special care, might not always be the best practice, especially among individuals who are affected by stigma. On the other hand, the fact that awareness concerning the need for treatment was not associated with stigma or shame, might be highly informative for clinicians and for the development of intervention programs aimed at improving treatment compliance. However, as previous studies (i.e., Staring et al., 2009) reported that awareness concerning the need for treatment can be associated with other negative consequences (which were not examined in this study), additional research is needed, especially because studies examining the different aspects of insight and their outcomes are lacking.

The present study also has several limitations. First, since a wide range of diagnoses were included in the study for simplification purposes, patients with different diagnoses were grouped together into a larger diagnostic category. This compromised the ability of this study to identify differences which might exist between patients in the same groups. Future studies should examine insight in more specific diagnostic groups, and among a larger sample. Second, a convenience sample used in the present study which also compromises the generalization of the results to the wider population. Third, because the study was cross-sectional, causality between variables cannot be inferred. Moreover, because insight can fluctuate over time (Wiffen, Rabinowitz, Lex, & David, 2010), longitudinal studies are especially needed. Finally, as cultural differences exist in stigma towards mental illness (Abdullah & Brown, 2011), cross-cultural studies would be valuable in shedding more light on the impact of insight and its relatedness to internalized stigma and negative outcomes.

## Conclusions

Despite the limitations, the present study contributes important knowledge concerning the study of insight in the psychiatric field. The results support the construct of insight and also the use of the BIS among non-English speaking patients with different diagnoses. In clinical practice, practitioners should keep in mind that poor insight might be commonplace among patients with different psychiatric diagnoses, and is not just limited to patients with schizophrenia. Therefore, efforts to increase insight should be directed towards different patient populations, including schizophrenia patients. However, these efforts should be implemented cautiously, with careful consideration of stigma, and the negative meaning it has for individuals coping with mental illnesses. Further research is needed to better understand the complexity of insight and how its promotion can be directed towards individual growth and recovery.

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# Chapter 6: Targeting the problem of treatment non-adherence among mentally ill patients: The impact of loss, grief and stigma (study 4)

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## Abstract

The present study examined the factor structure of the Hungarian version of the Medication Adherence Rating Scale (MARS) and analyzed its association with socio-demographics, insight, internalized stigma, and the experience of loss and grief as a result of the mental illness diagnosis, using confirmatory factor analysis (CFA) with a series of one covariates at a time. Mentally ill patients (N=200) completed self-report questionnaires. CFA supported the original three-factor structure although one item was moved from its original factor to another. Lower insight, higher internalized stigma, loss, and grief were significant predictors of lower treatment adherence. Lower adherence was found to be significantly associated with lower quality of life. No difference in adherence was found between different diagnostic groups, which stresses the need to examine non-adherence in the wider spectrum of mental diagnosis. The study also stresses the importance of patients’ subjective experience in promoting better adherence, and raises the need to address the experience of stigma but also of less studied experiences, such as patients‘ feelings of loss and grief. Integrating these experiences in intervention programs might have meaningful implications for the improvement of treatment adherence and patients’ quality of life.

**Keywords:** Insight; Internalized stigma; Medication Adherence Rating Scale; MARS; Quality of life; Factor structure; Intervention programs; Recovery

## 1. Introduction

Psychiatric medications are often the first line of treatment offered to mentally ill patients (Gilbert et al., 1995) due to their fundamental contribution to symptom relief and to patients' rehabilitation (Corrigan, 2004; Tsang et al., 2006). However, despite its advantages, non-adherence is highly prevalent among mentally ill patients. In fact, compared to patients who are receiving treatment for physical conditions, mental patients are the least likely to adhere their medication regimen (Fenton et al., 1997; Keck et al., 1996; McDonald et al., 2002; Scott and Pope, 2002).

Adherence is "the extent to which a person's behavior-taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care professional" (p.3, World Health Organization, 2003). Additionally, adherence should be regarded as a range of behaviors from complete adherence to medication, through partial adherence, to complete non-adherence (Fialko et al., 2008). Non-adherence to psychiatric medications is known to have detrimental consequences for both patients and society, including increased symptom severity, relapses, re-hospitalizations, suicides, and reduced quality of life (Ernst and Goldberg, 2004; Perkins, 2002; Puschner et al., 2009; Sajatovic et al., 2004; Svarstad et al., 2001; Weiden and Olfson, 1995). Its consequences for society is mainly through the loss of income of patients and the high costs of healthcare (Weiden and Olfson, 1995).

In order to assess medication non-adherence, a variety of methods have been utilized. Among them are "subjective methods" such as patient and clinician reports, and "objective methods" such as pill counts, electronic monitoring, and serum level measures (Velligan et al., 2006). However, it appears that there is no clear consensus regarding which method is preferable because each of them has its' particular shortcomings (Velligan et al., 2006). Patients' self-reports have been criticized for being influenced by memory deficits and social desirability bias (Sajatovic et al., 2010; Yang et al., 2012). However, patient self-reports are considered to be the most efficient due to (i) their non-intrusive and easy to administer nature, (ii) the low investment in terms of cost which is required to use them, and (iii) them being considered highly informative regarding individual adherence problems (Fialko et al., 2008).

The Medication Adherence Rating Scale (MARS) (Thompson et al., 2000) is a useful self-report scale that was developed to assess adherence among psychiatric populations. With the goal of developing more reliable, valid, and comprehensive tool for assessing adherence, including behavior and attitudes, Thompson et al. (2000) used two well-established self-report scales, the 30-item Drug Attitudes Inventory (DAI) (Hogan et al., 1983) and the four-item Medication Adherence Questionnaire (MAQ) (Morisky et al., 1986), to construct the MARS. The scale score ranges from 0 (*low likelihood of medication adherence*) to 10 (*high likelihood of medication adherence*) reflecting the continuous nature of adherence (Fialko et al., 2008). Previous exploratory factor analysis suggested a three-factor structure: (i) medication adherence in terms of behavior, (ii) medication adherence as reflected from ones attitudes, and (iii) individuals' attitudes towards psychiatric medications and their negative side-effects (Thompson et al., 2000). This structure was also supported by an additional validation study (Fialko et al., 2008).

When examining non-adherence, understanding its underlying factors is vital in order to properly address it. Among the leading factors concerning non-adherence are poor insight, shorter illness duration, negative attitudes toward medication, lack of social support, and medication side-effects (Diaz et al., 2004; El-Mallakh, 2007; Lacro et al., 2002; Olfson et al., 2006). Internalized stigma – the adoption of stereotypes by mental patients themselves (Corrigan et al., 2009) – is another well-studied factor compromising adherence (Hajda et al., 2016; Livingston and Boyd, 2010; Yılmaz and Okanlı, 2015) because it makes patients ashamed and individuals would rather not take their medication than being labeled as "mentally ill" (Corrigan, 2004).

Grief (which although being commonplace among patients) and its impact on adherence, has never been previously examined. Grief can be experienced as a result of the mental illness due to many different types of loss (e.g., loss of functioning, relationships, sense of self, and dreams for the future) (Appelo et al., 1993; Lewis, 2004; Mauritz and van Meijel, 2009; Stein, 2005; Stein et al., 2005; Wittmann and Keshavan, 2007). Examining grief as a consequence of mental illness is meaningful especially as grief is known to be related to reduced psychological wellbeing, physical health, and suicidality (Miles, 1985; Moore et al., 1988; Porritt and Bartrop, 1985; Szanto et al., 2006) and was recently found to be associated with loneliness and lower quality of life, specifically among mentally ill patients (Buchman-Wildbaum et al., 2020). Most importantly, grief which is known to include behavioral avoidance, negative cognitions, and emotional reactions to loss (Horowitz et al., 1981), is thought to negatively affect adherence. For example, previous research involving individuals with schizophrenia reported difficulties in accepting the diagnosis and the need for treatment, avoidant behaviors, and distress (Mauritz and van Meijel, 2009). Therefore, the possibility that it impacts and hinders patients' medication-taking, requires further research.

The first main goal of the present study was to further examine the factor structure of the MARS among a non-English speaking psychiatric population. Although non-adherence is prevalent in the wider spectrum of mental diagnosis (Colom et al., 2005; Gilmer et al., 2004; Lingam and Scott, 2002; Melfi et al., 1998), previous studies using the MARS have mostly been conducted among schizophrenia patients (Fialko et al., 2008; Jaeger et al., 2012; Thompson et al., 2000). Therefore, examining its measurement model among patients with other psychiatric diagnoses is needed.

The second main goal was to examine the possible predictors of non-adherence in order to gain a better insight regarding the different ways by which it can be reduced or avoided. More specifically, the present study focused mainly on insight, internalized stigma, loss, and grief. It was expected that lower insight, increased internalized stigma, loss, and grief would all be significant predictors of non-adherence. The impact of non-adherence on patients' lives was also examined, and it was expected that lower adherence would be associated with lower quality of life.

## 2. Methods

### *2.1. Participants*

The present study's sample comprised 200 individuals with a diagnosis of psychiatric disorder who were receiving routine mental care in an outpatient division of a mental health center in Budapest, Hungary. The inclusion criteria were: (i) having a mental health diagnosis according to the ICD-10 (World Health Organization, 1992), (ii) being consumers of psychiatric medications, (iii) being inpatients or outpatients in any form of psychiatric care, (iv) being patients who had not been abusing illicit substances and alcohol for a period of at least two weeks at the time of evaluation, (v) being in the age range 18 to 65 years, and (vi) having (based on their psychiatrist's view) the capability to answer the questionnaire. The exclusion criteria were (i) being at a severe (i.e., acute) phase of the illness, (ii) being diagnosed with an organic brain disorder, dementia, and/or mental retardation, and (iii) not having the mental capability and/or capacity to answer the self-report questionnaire or provide informed consent.

### *2.2. Procedure*

The psychiatrists at the mental health center contacted and invited eligible patients to participate in the study. They supplied important information about the study, including the study's goals which were communicated both verbally and in writing. Patients who agreed to participate in the study were asked to sign an informed consent sheet and then to complete a self-report questionnaire. The study questionnaires were all translated from English to Hungarian and back translated from Hungarian to English. Any possible inconsistencies between the original and back-translated version were addressed and solved. The present study was given ethical approval by the ethical board of the regional hospital accountable for the patients' welfare.

### ***2.3. Measures***

#### *2.3.1. Socio-demographic questions*

In the present study, different factors were evaluated such as the participant's gender, age, education (finished/did not finish high school), employment status (employed/unemployed), psychiatric diagnosis, marital status (married/divorced/widowed/single) and history of former hospitalizations (yes/no). Patients were allocated into six diagnostic groups based on their diagnosis and following the ICD-10 codes classification (World Health Organization, 1992): (i) schizophrenia spectrum disorders (e.g., schizophrenia, schizotypal and delusional disorder), (ii) mood disorders (e.g., major depressive disorder, bipolar and manic disorder), (iii) stress-related disorders (e.g., phobic anxiety disorders, obsessive-compulsive disorders, somatoform disorders), (iv) behavioral syndromes associated with physiological disturbances (e.g., eating disorders), (v) personality disorders (e.g., borderline personality disorder, avoidant personality disorder), and (vi) disorders due to psychoactive substance use.

#### *2.3.2. Adherence*

The Medication Adherence Rating Scale (MARS) (Thompson et al., 2000) is a 10-item scale that encompasses three adherence elements; (i) adherence in terms of behavior (Items 1-4), (ii) adherence in terms of attitudes (Items 5-8), and (iii) attitudes towards psychiatric medications and their negative side-effects (Items 9 and 10). The scale includes ten yes/no items, and the scoring depends on whether the individual indicates adherence or non-adherence; those responses implying adherence are coded as 1, while those responses implying non-adherence are coded as 0. The scores of the ten items are summed up to produce total score which ranges from 0 (low likelihood of medication adherence) to 10 (high likelihood of medication adherence) (Fialko et al., 2008). In the present study the scale found to have adequate internal consistency (Cronbach $\alpha$=0.61).

#### *2.3.3 Insight*

The Birchwood Insight Scale (BIS) (Birchwood et al., 1994) is a brief eight-item self-report measure which assesses three dimensions of insight into mental illness: illness awareness (Items 2 and 7), need for treatment (Items 3,4,5 and 6), and re-labelling of symptoms (Items 1 and 8). Each item contains a statement with three response options (i.e., agree, unsure or disagree). Participants' responses on each item is scored depending on the insight level it indicates, where responses indicating good insight (agree/disagree) are scored as 2, unsure responses are scored 1, and responses which indicate poor insight are scored as 0. In the present study two changes were made. First, because the study participants were not hospitalized, a minor modification was made in the item presuming hospitalization (Item 4) ("My stay in the hospital is necessary" was amended to "The treatment in the institution is necessary"). Second, in light of findings in a previous validation study from Hungary reporting on two-factor structure ('illness awareness' and 'need for treatment') (reference blinded for peer review purposes) the present study only examined these factors. The BIS in the current sample found to have moderate internal consistency (Cronbach $\alpha$=0.69; illness awareness: Cronbach $\alpha$=0.54; need for treatment: Cronbach $\alpha$=0.64).

### *2.3.4 Internalized stigma*

The Self Stigma of Mental Illness Scale (SSMIS) (Corrigan et al., 2006), assesses the four stages process of stigma internalization suggested by Corrigan et al. (2006), and included them as subscales: (i) individual's awareness of stigma concerning mental illness held by the society, (ii) individual's agreement with these stigmatic beliefs, (iii) individual's adoption of these beliefs into their own personal identity, and (iv) resultant decrease in an individual's self-esteem. Participants rate their agreement with 10 statements included in each one of the four subscales on a nine-point Likert scale ranging from 1 (*strongly disagree*) to 9 (*strongly agree*). Each subscale includes a total score ranging between 10-90, and higher scores indicates greater acceptance of stigma as indicated by the specific subscale. The scale was found to have good internal consistency in the present study (stigma awareness: Cronbach α=0.92; stigma agreement: Cronbach α=0.90; stigma internalization: Cronbach α=0.83; self-esteem reduction: Cronbach α=0.84)

### *2.3.5 Grief*

Grief was assessed using the Mental Illness Version of the Texas Inventory of Grief (MIV-TIG) (Miller et al., 1990). The MIV-TIG is an adapted version of Texas Revised Inventory of Grief (TRIG) (Faschingbauer et al., 1977) which is used to assess grief reaction to the death of a loved one. The MIV-TIG was modified to assess grief as a result of a relative's mental illness and the loss of that individual as s/he was before the development of mental illness (Miller et al., 1990). The scale includes the different known expressions of grief such as persistent emotional distress, being constantly occupied with the lost person, and difficulties and unwillingness to acknowledge and accept the reality of the loss. The MIV-TIG comprises eight items evaluating initial grief and 16 items evaluating current grief (i.e., 24 items in total). The present study only utilized the 16 items focusing on current grief. Furthermore, as the present study assessed grief of mental patients themselves and not of their relatives, a minor adjustment of the items was made, manifested in first account statements (e.g., *"I am preoccupied with the thoughts of how I could have been if not for the illness"*) similar to previous modifications (Patterson et al., 2005). Participants were asked to respond to the items based on a five-point Likert scale ranging from 'completely true' to 'completely false'. Item scores are summed up into a total score, where higher scores reflect higher grieving (Miller et al., 1990). Excellent internal consistency was found in the present study (Cronbach $\alpha$=0.95).

### *2.3.6. Perceived loss as a result of mental illness:*

The Personal Loss from Mental Illness (PLMI) Scale was developed to assess individuals' perception of loss resulting from their mental illness (Stein et al., 2005). Four factors in the scale structure have been identified: 'loss of roles and routines', 'loss of former relationships', 'loss of former self' and 'loss of future' (Stein et al., 2005). The scale comprises 20 items asking about respondents' agreement with statements regarding the losses experienced by individuals with mental illness. Participants agreement levels can range from 1 (*strongly disagree*) to 5 (*strongly agree*). Item scores are summed up to generate subscale and total scores, where higher scores indicate higher perception of loss. Excellent internal consistency of the scale was found in the present study (Cronbach $\alpha$=0.90).

### *2.3.7. Quality of life*

The Manchester Short Assessment of Quality of Life (MANSA) (Priebe et al., 1999) is shortened version of the Lancashire Quality of Life Profile (LQLP) (Oliver et al., 1997). The MANSA comprises 16 questions, with four categorized as "objective" (asking about facts such as being accused for a crime) answered dichotomously (yes/no), and 12 categorized as "subjective" (asking about life satisfaction in general and specific different aspects of life) answered on a seven-point rating scale of satisfaction, ranging from 1 (*couldn't be worse*) to 7 (*couldn't be better*). Total scale score is the mean average of the 12 question scores, where higher scores indicate a better quality of life. The scale had very good internal consistency in the present study (Cronbach α=0.87).

### *2.4. 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 confirmatory factor analyses (CFAs) were conducted. MARS items were regarded as categorical and used the mean-adjusted and variance-adjusted weighted least squares (WLSMV) estimator. In CFA, an appropriate degree of fit means that the comparative fit index (CFI) and the Tucker-Lewis Index (TLI) should be close to 0.95, whereas model indices of <0.90 means that the model should be declined (Brown, 2006). The next fit index used was root mean squared error of approximation (RMSEA). RMSEA lower than 0.05 implies excellent fit, a value around 0.08 implies adequate fit, and a value above 0.10 implies poor fit (Browne & Cudek, 1993). After calculating the factor scores, a comparison for statistical difference in factor scores between groups with different diagnosis were 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. This approach was chosen due to its ability to prevent the problem of multicollinearity. Finally, the association between the adherence factors and quality of life was investigated. All analyses were performed with MPLUS 8.1 (Muthén & Muthén, 1998).

## 3. Results

### *3.1. Descriptive statistics*

Table 1 presents the percentages, means, and standard deviations (SDs) of the different variables used in the present study. The current sample was dominated by women and high school graduates. The predominant mental illness diagnosis was stress-related disorders, and almost half of the participants had previous hospitalizations in their history. The sample was diverse in terms of age (ranges from 32 to 56 years), with a mean of 44.2 years (SD=11.8).

Table 1. Descriptive statistics of the sample

| | |
|---|---|
| Gender (female) *N* (%) | 133 (66.5) |
| Age – mean (SD) | 44.2 (11.8) |
| Education, graduated high school – *N* (%) | 157 (78.5) |
| Previous hospitalizations – *N* (%) | 89 (44.5) |
| Diagnosis | |
| *Schizophrenia spectrum disorders – N* (%) | 53 (26.5) |
| *Mood disorders – N* (%) | 58 (29.0) |
| *Stress-related disorders – N* (%) | 89 (44.5) |
| *Personality disorders – N* (%) | 10 (5.0) |
| *Disorders due to psychoactive substance use – N* (%) | 2 (1.0) |
| *Behavioral syndrome associated with physiological disturbances – N* (%) | 2 (1.0) |
| *Only one diagnosis* | 188 (94.0) |
| *Two diagnoses* | 10 (5.0) |
| *Three diagnoses* | 2 (1.0) |

### *3.2. Confirmatory factor analysis of the Medication Adherence Rating Scale (MARS)*

A series of confirmatory factor analysis with items as categorical indicators and WLSMV estimator were performed. The first model including only one factor yielded unacceptable degree of fit. The second model was the original three-factor model which had close to acceptable degree of fit (see Table 2 note). Inspecting the factor structure, modification indices and the content of the items, Item 5 was removed ("*I take my medication only when I am sick*") from the adherence attitude factor to the adherence behavior factor. The error covariance between Item 1 ("*Do you ever forget to take medication?*") and Item 2 ("*Are you careless at times about taking your medication?*") was allowed. The size of the correlations between the uniqueness of these two factors was large (r=0.76). These modifications yielded excellent degree of fit in all fit indices. The factor loadings of the original (Model 2) and modified (Model 3) measurement models are presented in Table 2. The means of factor loadings of each factor in the modified model were 0.63, 0.62, and 0.87 respectively. Internal consistencies of the factors were: behavior: Cronbach α=0.64, attitude: Cronbach α=0.44, side-effects: Cronbach α=0.61.

Table 2. Confirmatory factor analyses of The Medication Adherence Rating Scale: Factor loadings of measurement models

| | Original three-factor Model* | | | Modified three-factor model** | | |
|---|---|---|---|---|---|---|
| | Adherence: Behavior | Adherence: Attitude | Adherence: Medications side effects | Adherence: Behavior | Adherence: Attitude | Adherence: Medications side effects |
| Item 1: Do you ever forget to take medication? | 0.53 | | | 0.54 | | |
| Item 2: Are you careless at times about taking your medication? | 0.29 | | | 0.31 | | |
| Item 3: When you feel better, do you sometimes stop taking your medication? | 0.83 | | | 0.82 | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| Item 4: Sometimes if you feel worst when you take the medication, do you stop taking it? | 0.78 | | | 0.78 | | |
| Item 5: I take my medication only when i am sick | | 0.99 | | 0.72 | | |
| Item 6: It is unnatural for my mind and body to be controlled by medication. | | 0.46 | | | 0.53 | |
| Item 7: My thoughts are clearer on medication. | | 0.38 | | | 0.76 | |

| | | | | | | |
|---|---|---|---|---|---|---|
| Item 8: By staying on medication, i can prevent getting sick. | | 0.33 | | | 0.56 | |
| Item 9: I feel weird, like “zombie“ on medication. | | | 0.90 | | | 0.92 |
| Item 10: Medication makes me feel tired and sluggish. | | | 0.82 | | | 0.81 |
| Factors correlations | | | | | | |
| Adherence Behavior | - | 0.62 | 0.58 | - | 0.24ns | 0.53 |
| Adherence Attitude | - | - | 0.33 | - | - | 0.27ns |

Note: Standardized factor loadings. ns = non-significant. *: Fit indices: $\chi^2$=55.9, df=31, *p*<.004; CFI=0.907, TLI=0.866; RMSEA=0.065 Cfit of RMSEA=0.174. **: Fit indices:

$\chi^2=38.6$, df=31, $p<.1646$; CFI=0.972, TLI=0.959; RMSEA=0.036 Cfit of RMSEA=0.731.

### *3.3. Medication adherence in different diagnostic groups*

After calculation of factor scores, adherence dimensions were compared across three diagnostic groups, and no significant main effect was found (see Table 3). However, comparison between the schizophrenia spectrum disorders group and the other two groups together, showed that schizophrenia patients reported higher score of adherence behavior than the other groups together (see Table 3 note). The same analyses with the attitude and side-effects resulted in much smaller difference.

*Table 3. Comparison of adherence dimensions across diagnostic groups.*

| Dimensions of adherence* | Schizophrenia spectrum disorders *N*=51 | Mood disorders *N*=56 | Stress-related disorders *N*=84 | *F* | *p* | Effect size *F* |
|---|---|---|---|---|---|---|
| Behavior | 0.03 (0.31) | -0.07 (0.34) | -0.08 (0.37) | 1.77 | 0.1737 | 0.08 |
| Attitude | 0.01 (0.31) | -0.03 (0.33) | -0.04 (0.34) | 0.38 | 0.6843 | 0.04 |
| Side effects | -0.06 (0.57) | -0.12 (0.54) | -0.12 (0.59) | 0.21 | 08134 | 0.04 |

*Note:* *Factor scores were used in the calculation. *f:* effect size index, An f = 0.10 is a small effect and an f = 0.25 is a medium effect (Cohen, 1988). f values for group comparisons: *Behavior*: Schizophrenia versus Mood disorder: *f*=0.06; Schizophrenia versus stress-related disorder: *f*=0.08; mood disorder versus stress-related disorder *f*=0.01. *Attitude*: Schizophrenia versus Mood disorder: *f*=0.03; Schizophrenia versus stress-related disorder: *f*=0.04; mood disorder versus stress-related disorder *f*=0.01. *Side effects*: Schizophrenia versus Mood disorder: *f*=0.03; Schizophrenia versus stress-related disorder: *f*=0.03; mood disorder versus stress-related disorder *f*=0.00.
Comparison between the schizophrenia spectrum disorders group and the mood and stress-related disorders together, showed that schizophrenia patients reported higher score of adherence behavior than the other groups together (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 effect size estimates (Cohen's d=0.16 and 0.11 respectively).

### *3.4. Covariates of medication adherence: Single covariate models*

The predictors of the dimensions of adherence were tested in a series of CFAs with single covariate models. In these models, only one predictor was entered in each model. The standardized regression coefficients are presented in Table 4. Covariates were gender, age, insight, internalized stigma, loss, and grief. Higher insight ("need for treatment factor") predicted significantly higher adherence (adherence behavior and attitude). Higher stigma predicted significantly lower adherence. Especially adopting stigmatic views into self-identity and self-esteem reduction were associated with lower adherence behavior, attitude, and lower tolerance of side-effect. Furthermore, awareness of (and agreement with) stigmatic views were associated with lower tolerance of side-effects of the treatment. Similarly, higher loss and higher grief were associated with lower adherence in terms of lower tolerance of side-effects.

*Table 4. Covariates of medication adherence: single covariate models*[#]

| | Dimensions of medication adherence | | |
|---|---|---|---|
| Covariates | Behavior | Attitude | Side effect |
| Age | 0.15 | 0.10 | 0.08 |
| Gender | 0.04 | -0.05 | -0.21 |
| Grief (MIV-TIG) | -0.10 | -0.01 | **-0.45*** ** |
| Internalized stigma | | | |
| *Awareness of the stigmatic views* | -0.14 | 0.10 | **-0.22*** |
| *Agreement with the stigmatic views* | -0.09 | -0.04 | **-0.23*** |
| *Adopting stigmatic views into self-identity* | **-0.35***** | **-0.19*** | **-0.24*** |
| *Self-esteem reduction* | **-0.30**** | **-0.27*** | **-0.21*** |
| Personal loss (PLMI) | -0.16 | -0.02 | **-0.29**** |
| Insight | | | |
| *Illness awareness* | -0.10 | 0.08 | -0.12 |
| *Need for treatment* | **0.30**** | **0.49***** | 0.09 |

*Note*: [#]: CFA with single covariate models include only one covariate, therefore each line of the table represents one model. Standardized regression coefficients. Medication adherence dimensions are used as latent variables and covariates are used as observed variables. **p*<.05; ***p*<0.01; ****p*<.001.

### *3.5. Correlations between adherence and quality of life*

Adherence was expected to be associated with quality of life. Due to the medium-sized correlations among adherence factor and possible multicollinearity, instead of the traditional regression analysis to predict quality of life, the focus was only on the correlations of the construct. Increased behavior and tolerance of side-effect aspects of adherence correlated significantly with increased quality of life (*r*=0.24 *p*<.01 and *r*=0.25 *p*<.01, respectively). 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).

## 4. Discussion

The present study confirmed the three-factor structure of the Medication Adherence Rating Scale (MARS) (Fialko et al., 2008; Thompson et al., 2000) among non-English speaking patients with different diagnoses. However, a minor modification was required, namely Item 5 (“I take my medication only when I am sick”) should be removed from the ‘attitude’ factor and added to the ‘behavior’ factor. In addition to the psychometric considerations, the content of this item also warranted this change. Similar change was proposed in a validation study of the Taiwanese version of the MARS (Kao and Liu, 2010). However, in the Taiwanese study, the MARS was found to have two factors (adherence behavior and subjective response to medications), which reinforce the need for further examination of the scale among different populations from different cultural backgrounds.

The present study also examined possible differences in adherence among different diagnoses. Participants from the three major diagnostic categories did not differ in the three adherence scores. However, based on the results, it is possible that the sample size was not large enough to allow the detection of small differences among diagnostic groups. This finding conflicts with the literature claiming that the problem of non-adherence is especially higher among those with schizophrenia (Cramer and Rosenheck, 1998; Sajatovic et al., 2010; Taj et al., 2008; Tesfay et al., 2013). However, this finding might be also the result of the inclusion of participants who were not hospitalized and in a stable state, and therefore cannot be generalized to the wider schizophrenia patient population.

The findings of the present study also provide important new knowledge about the less frequently studied predictors of adherence. The present study is the first to find that patients’ experience of loss and grief significantly (negatively) influenced their adherence to treatment. Although loss and grief were reported as the main experiences of patients by mental health professionals over the years (Appelo et al., 1993; Lewis, 2004; Wittmann and Keshavan, 2007; Young et al., 2004), this body of research was neglected and instead research interest was devoted mainly to the loss and grief experienced by family members of individuals with mental disorders (e.g., Davis and Schultz, 1998; Miller et al., 1990; Ozgul, 2004). Only recently was this important topic revived with the development of the Personal Loss from Mental Illness Scale (PLMIS) (Stein et al., 2005) and novel findings associating the experience of loss with higher loneliness, lower recovery rates, and lower quality of life (Buchman-Wildbaum et al., 2020; Potokar, 2008; Stein et al., 2005).

A recent study also confirmed the association between loss and higher grief among patients with mental disorders (Buchman-Wildbaum et al., 2020). That study was also the first to examine grief among patients themselves, and the first to report that it is associated with higher loneliness and lower quality of life. Grief might interfere with medication-taking due to its nature, including emotional distress regarding the loss, behavioral avoidance, and denial of the new reality and the adjustments that need to be taken (Horowitz et al., 1981). Furthermore, a previous study reported that among schizophrenia patients, grief manifested in difficulties in accepting the existence of the diagnosis and need for treatment and in withdrawal and avoidance (Mauritz and van Meijel, 2009). The taking of medication might be a painful and troublesome daily reminder of their status of "mentally ill", the losses they experienced, who they used to be before the illness, and all their previous dreams for the future. Under the influence of grief and the strong difficulty to accept the fact that they have an illness, acceptance of the need to take medications might be comprised. It is interesting to note that in the present study, both loss and grief were specifically related to the adherence aspect affected by negative attitudes regarding the side-effects of medications. While it is possible that more significant results regarding adherence aspects might be more likely to have found among a larger sample, this finding is highly informative. Out of the adherence aspects, this aspect of the influence of medications might be the most concrete and vivid reminder for their illness and therefore it is specifically and strongly associated with grief. Previous studies have already reported that side-effects of medications negatively influencing individuals' adherence behavior (Perkins, 2002; Perlick, 2004; Robinson et al., 2002; Sajatovic et al., 2011). Furthermore, Mauritz and van Meijel (2009) found that the negative influence of medications was related to feelings of loss and grief in schizophrenia.

The findings of the present study may contribute to the extant literature by implying that it is not necessarily the actual side-effects of medications but the grief and the difficulty to accept their illness and the need in medications, which is associated with higher tendency to perceive medications as having negative influence, irrespective of medications having more or less side-effects. This in turn might reduce their probability of adherence. However, due to the preliminary nature of the present study, more research is needed on the topic of loss and grief in mental health and its influence.

The present study also found that insight into mental illness is a significant predictor of better adherence, in line with previous literature (e.g., Beck et al., 2011; David et al., 1992; Kao and Liu, 2010) and with the proposition that better insight leads to better understanding of the need for treatment and to better adherence (Beck et al., 2011; Droulout et al., 2003; Kozuki and Froelicher, 2003; Lysaker et al., 2018; Misdrahi et al., 2012; Mohamed et al., 2009; Yen et al., 2005). The present study found that only the insight aspect of ‘awareness of the need for treatment’ was significantly associated with adherence (as manifested in patients' behavior and their attitudes) while ‘awareness of the illness’ aspect did not predict any dimensions of adherence. This is in line with studies reporting that awareness of the need for medication leads to better adherence (Kao and Liu, 2010; Misdrahi et al., 2012; Mutsatsa et al., 2003; Rocca et al., 2008) but in contrast with previous findings reporting positive associations between illness awareness and adherence (Misdrahi et al., 2012; Mutsatsa et al., 2003; Rocca et al., 2008). Interestingly none of the insight aspects predicted adherence in terms of negative attitudes and medications side-effects. This finding was also found by others (e.g., Misdrahi et al., 2012; Mutsatsa et al., 2003) and might mean that for patients with insight, possible side-effects will not play significant role in adherence because they understand and prioritize the positive consequences that treatment has.

The present study also found that internalized stigma predicted lower adherence in accordance with previous findings (Hajda et al., 2016; Livingston and Boyd, 2010; Yılmaz and Okanlı, 2015). This is especially important considering the high rates of individuals with mental illness that experience internalized stigma (Brohan et al., 2010). Interestingly, adherence was also found to be negatively affected even if patients do not necessarily internalize the stigma. However, even the simple recognition of the existence of negative stereotypes in the society towards mental illness or the agreement with these stereotypes predicted lower adherence. More specifically, they were both predictors of the adherence aspects related to negative attitudes regarding medication side-effects. This might be the reflection of the high stigma exists towards psychiatric medications and their impact, perceiving them as unnatural with harmful impact irrespective of its accuracy (Angermeyer et al., 1993; Croghan et al., 2003; Horne, 1999; Mojtabai, 2009). The importance in examining adherence was also validated in the present study because non-adherence was found to be significantly associated with lower quality of life, which also supported by previous findings (Hayhurst et al., 2014; Puschner et al., 2009).

The present study might have some important clinical implications. Perhaps the most significant one is the need in understanding that patients' subjective experience such as of stigma, loss, and grief while coping with any mental illness is important, if not crucial in targeting treatment adherence. As such, there is a need for an intervention plan which will address such painful experiences. An example of an intervention which has been found to increase insight (Yanos et al., 2012), reduce internalized stigma, and improve patients quality of life (Hansson et al., 2017; Roe et al., 2010) is Narrative Enhancement and Cognitive therapy (NECT) (Yanos et al., 2011). As the first step in coping with grief is to accept the existence of loss (Worden, 1982), acknowledging patients' experience and defining it as a normal reaction of grief, can facilitate patients' acknowledgment and acceptance of their experiences, illness, and perhaps also the need in treatment routine (Young et al., 2004). Finding new meaning to life can also have healing impact and reduce grief (Young et al., 2004). Another important implication is that the study of grief might shed insight concerning another critical and common problem in the psychiatry field – the lack of insight (Pini et al., 2001). It is possible that what appears in many instances as lack of insight might be a clear manifestation of grief (Appelo et al., 1993; Mauritz and van Meijel, 2009; Young et al., 2004), which has important implications for the treatment offered. Furthermore, the present study provided support for the application of the MARS to the broader spectrum of mental diagnoses, and the need for examining treatment adherence in diagnoses other than schizophrenia. However, it might also raise the need to develop an illness-specific adherence scale, especially because different diagnoses may carries specific barriers to adherence (Velligan et al., 2010, 2009).

Importantly, the study findings are limited here in several aspects. First, because the sample of the present study was diverse in terms of diagnoses, patients were divided and grouped into main diagnostic groups. Therefore, the detection of differences which might exist between diagnoses in the same groups was not possible. Moreover, this specific grouping might compromise the generalization of the results to these diagnostic groups. This should be addressed in future studies by examining adherence in more specific and larger diagnostic groups. Another factor which might limit the generalization of the study results is the convenience sample utilized and the inclusion of a relatively stable and functioning sample. Second, as the present study was cross-sectional, cause and effect patterns between variables cannot be verified, and the impact of third variables cannot be excluded. Finally, adherence was assessed by patients' self-report, which is known for inaccuracies (Sajatovic et al., 2010). However, other measurements are also known for their inaccuracies (Velligan et al., 2006), and focusing on patients’ perspectives was preferable for the present study in examining patients’ subjective experience.

In spite of the limitations presented, the present study offers valuable insights to the study of medication adherence. These mainly include the importance of examining non-adherence in a broader range of diagnoses and of focusing on patients’ grief and loss while tackling adherence problems. This might be especially important in order to help patients come to terms with their illness, the need for treatment, and in finding new meaning and goals for life, which will facilitate adherence, healing, and a better quality of life.

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# Chapter 7: Shame in borderline personality disorder: Meta-Analysis. (study 5)

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## Abstract

Shame has been found to be a core feature of borderline personality disorder (BPD). To date, there is no existing systematic review or meta-analysis examining shame in BPD as compared to healthy controls (HCs). A meta-analysis of 10 studies comparing reported shame in BPD to HCs was carried out. Demographic and clinical moderator variables were included to see if they have a relationship with the effect size. Results showed that those with BPD had more reported shame than healthy controls. In addition, in BPD and HCs, higher education level was related to lower reported shame. In HCs, it was found that those who were younger reported a higher level of shame. Finally, among BPD patients, there was a relationship between levels of reported shame and elevated PTSD symptomology. These findings emphasize the clinical relevance of shame in BPD and the need to formulate psychotherapeutic strategies that target and decrease shame.

**Keywords:** Shame; Borderline personality disorder; BPD; Meta-analysis; Review

# Introduction

Borderline personality disorder (BPD) is a debilitating mental disorder, known to carry serious consequences for the lives of those affected due to elevated levels of disease and death rates, especially from suicidality (Lieb et al., 2004). Symptoms of BPD include non-suicidal self-injury, suicidal ideations, increased occurrence of suicidal acts as compared to other disorders, impulsive behaviors, and an insecure sense of self. This pattern of instability is largely evident in social relations, in individuals' emotional state and in the manner they perceive and evaluate themselves (American Psychiatric Association, 2013). Though not a core criterion in the diagnosis of BPD, accumulating evidence coming from both clinical practice (Lieb et al., 2004), and research (Brown et al., 2002; Nathanson, 1994; Rüsch, Lieb, et al., 2007), has found that shame is a core, dominant theme in those experiencing BPD symptoms.

Shame has been described as emotionally difficult, as the result of a strict judgment of one's own personality as negative (e.g., having flaws or being damaged) (Lewis, 1971; Tangney et al., 1996). Shame is known to be an internal experience that occurs mainly when an individual perceives him or herself as inferior. This devaluating perception often triggers efforts to minimize the risk of further harm, such as avoiding social situations and/or withdrawing while interacting with others (Gilbert, 1998). Although experienced internally, shame can be shown externally, such as through blushing, not engaging in conversation, and decreased eye contact as well as an immediate desire to move away from the situation producing shame (Gilbert, 1998; Tangney et al., 1996; Tracy & Matsumoto, 2008).

Current research has parsed shame into two types: a) shame proneness, or the predisposition to feel shame in a diverse range of circumstances, and b) state shame, or shame that is situation dependent and temporal (Rüsch, Lieb, et al., 2007). Considering this, studies mostly have utilized methods that distinguish between shame proneness and state shame, and between explicit and implicit shame (Rüsch, Lieb, et al., 2007; Unoka & Vizin, 2017). Explicit shame refers to shame, which is conscious and evaluated by direct questioning, indicated by the individual in the form of self-report scales, whereas, implicit shame refers to shameful responses, which arise automatically, unconsciously, and are evaluated by indirect methods (Lewis, 1971; Ritter et al., 2014). Furthermore, certain studies noted different types of shame, such as between characterological, behavioral, bodily shame, cognitive and existential shame (Scheel et al., 2014; Unoka & Vizin, 2017)

To date, shame has been identified by clinicians and researchers as one of the emotions most associated with persistent suicidal tendencies (i.e., self-harming acts, rage) and impulsive behaviors in people with BPD (Lester, 1997; Linehan, 1993a). Patients with BPD report significantly elevated levels of shame (proneness and state shame/explicit and implicit/ among all different types of shame) relative to the general healthy population and as compared to other mental disorders (e.g., social phobia, major depression, narcissistic personality disorders, ADHD and non-personality disorders)(Ritter et al., 2014; Rüsch, Lieb, et al., 2007; Scheel et al., 2014; Unoka & Vizin, 2017). Moreover, shame in BPD has been found to have a negative association with a patient’s self-esteem and quality of life, but a positive association with increased anger-hostility and unstable interpersonal relationships, a core symptom of those with BPD (Rüsch, Lieb, et al., 2007; Unoka & Vizin, 2017).

Though the clinical relevance of shame in BPD has been recognized by scientists and clinicians through research and practice, respectively, to date, no quantitative review of the literature has been undertaken. Taking this into consideration, the current paper presents a meta-analysis of self-reported shame in those with BPD in order to elucidate the magnitude. Moderator variables such as age, gender, education, and other clinical variables were also assessed. Based on the literature, we hypothesized that BPD patients would report higher levels of shame as compared to healthy controls and clinical and socio-demographic moderator variables would have an impact on reported shame in both BPD patients and healthy comparison controls.

## Methods

### Data collection

#### *Overall Literature Search*

Our search was conducted using both PubMed and PsychINFO with the search terms "borderline personality disorder" OR "BPD" AND "Shame" AND "controls" OR “healthy controls.” The search was limited to papers in English published between 1980 and March 2020 on human participants. In addition, we looked at the references from other articles and reviews on the same subject. The studies were discussed and reviewed by four of the authors (T.B.W, Zs.U., G.V., and M.J.R) and 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). All potential shame questionaires were considered as shame is many things and we looked at an aggregate variable.

The search initially generated 35 studies for potential inclusion in the study. Once we looked at these 35 studies, 10 articles were included (see Table 1). We excluded articles for the following reasons: a) lack of control group (N= 15), b) shame paradigm instead of a questionnaire (N= 7), and c) a lack of BPD diagnosis but instead just BPD symptomatology (N= 3). We chose to do a meta-analysis with a control sample for a calculation of the Cohen´s d, which we explain further in the methods section.

Table 1. Studies which were used in the meta-analysis

| **Study name** | **Shame scale(s)** | **Scale description** |
|---|---|---|
| Bach 2018 | Young Schema Questionnaire 3-short form (YSQ-S3) - defectiveness/shame | Measures shame as manifested by shameful beliefs about oneself. |
| Dyer 2015 | Body Image Guilt and Shame Scale (BIGSS)-shame | Measures shame related to body image |
|  | Modification of the survey of body areas (SBA)-shame | Measures shame related to body areas. |
| Gadassi 2014 | Experience Sampling Diary-mood assessment (response to social proximity) (from 0-4)-shame | Measures shame in response to social proximity |
| Ritter 2014 | Experiential Shame Scale (ESS)-German translation | Measures state shame |
|  | Test of Self-Conscious Affect (TOSCA-3)-German translation | Measures shame proneness based on individual's respond to different scenarios |
| Rüsch 2007 | Test of Self-Conscious Affect (TOSCA-3)-short version, German translation. | Measures shame proneness based on individual's respond to different scenarios |
|  | Experiential Shame Scale (ESS)-German translation | Measures state shame |
| Unoka 2017 | The experience of Shame Scale (ESS) | Measures different manifestations of shame: Character, Behavioral and Bodily. |

| | | |
|---|---|---|
| Wiklander 2012 | The Test of Self-Conscious Affect (TOSCA) first version-shame, Swedish translation | Measures shame proneness based on individual respond to different scenarios |
| Scheel 2014 | SHAME (a scale developed by authors) | Measures different manifestations of shame: Bodily, cognitive and existential. |
| Chan 2005 | Internalized Shame Scale (ISS)-total score | Measures trait shame |
| Mneimne 2017 | Experience Sampling Methodology-shame reports (from 1-6-extremely)-average score for 14 days | Measures experience of shame in response to different interpersonal events |

### *Categorical Moderator Variables*

We searched the articles for clinical moderator variables of co-morbid mental health diagnoses (i.e., post-traumatic stress disorder, major depressive disorder, anxiety disorder), drug-use, medication use, and demographic variables of gender (i.e., percentage of sample that was male), education (i.e., mean years), mean age, and marital status. However, due to lack of inclusion of all these variables in all of the studies, we could only include gender, education, mean age, and co-morbid post-traumatic stress disorder as continuous moderator variables. When a significant effect for heterogeneity emerged, categorical moderator analysis of variables was performed. Mean age and gender (i.e., male sample percentage) were considered continuous moderator variables.

## Data analysis

Our meta-analysis was executed with Comprehensive Meta-Analysis, version 3.0 software (Borenstein et al., 2005). Cohen's d values were calculated from the difference in scores between BPD patients and HCs on checklists and questionnaires of shame. The Cohen’s d was analyzed by using two means (BPD group and healthy comparison group) divided by standard deviations (SD). In accordance with Cohen (1998), the effect sizes were divided by level of magnitude of small ($d = 0.2$), medium ($d = 0.5$), or large ($d \geq 0.8$) (Cohen, 1988) . 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. Though our objective was to look at disparities between types of shame as well as the conclusions of different shame questionnaires, there was not enough data in the literature to provide calculation of the effects of such moderators.

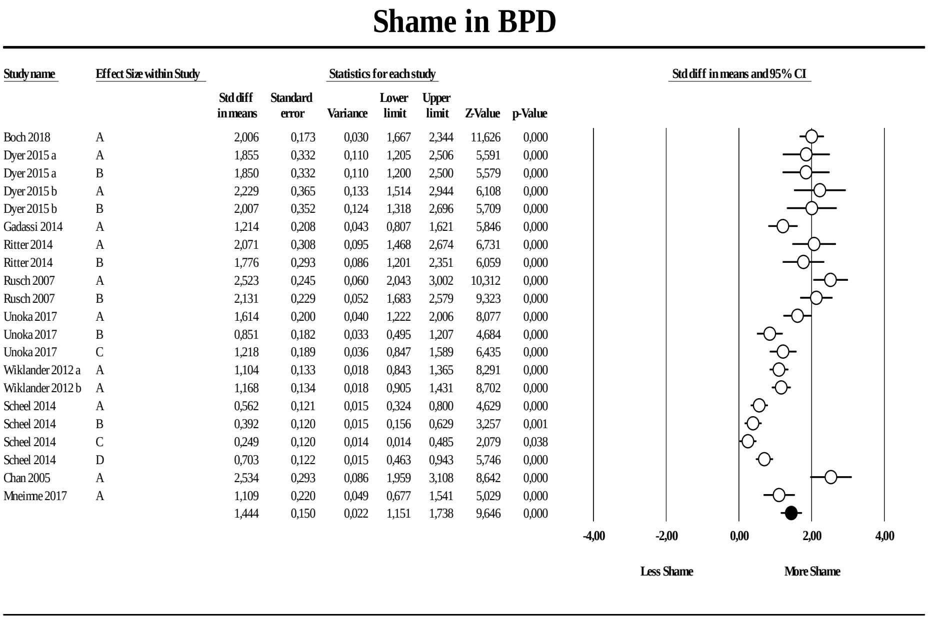
## Results

### *Overall*

Ten studies were included with 3543 participants (HC=2,283, BPD=1,260). Analysis of self-reported shame for the entire sample revealed a large effect size ($N$= 3543, $d = 1.44$) with significant heterogeneity ($Q_B$ [20] = 271.332, p< .0001).

Considering that there was potential variability in the effect sizes within healthy and patient groups that were more than just a sampling error, moderator variable analyses were performed. The results are depicted in Figure 1.

Figure 1. Shame as depicted in a forest plot. Effect sizes are depicted and subgroups within study are shown.



**Shame in BPD**

| Study name | Effect Size within Study | Statistics for each study | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Std diff in means | Standard error | Variance | Lower limit | Upper limit | Z-Value | p-Value |
| Boch 2018 | A | 2,006 | 0,173 | 0,030 | 1,667 | 2,344 | 11,626 | 0,000 |
| Dyer 2015 a | A | 1,855 | 0,332 | 0,110 | 1,205 | 2,506 | 5,591 | 0,000 |
| Dyer 2015 a | B | 1,850 | 0,332 | 0,110 | 1,200 | 2,500 | 5,579 | 0,000 |
| Dyer 2015 b | A | 2,229 | 0,365 | 0,133 | 1,514 | 2,944 | 6,108 | 0,000 |
| Dyer 2015 b | B | 2,007 | 0,352 | 0,124 | 1,318 | 2,696 | 5,709 | 0,000 |
| Gadassi 2014 | A | 1,214 | 0,208 | 0,043 | 0,807 | 1,621 | 5,846 | 0,000 |
| Ritter 2014 | A | 2,071 | 0,308 | 0,095 | 1,468 | 2,674 | 6,731 | 0,000 |
| Ritter 2014 | B | 1,776 | 0,293 | 0,086 | 1,201 | 2,351 | 6,059 | 0,000 |
| Rusch 2007 | A | 2,523 | 0,245 | 0,060 | 2,043 | 3,002 | 10,312 | 0,000 |
| Rusch 2007 | B | 2,131 | 0,229 | 0,052 | 1,683 | 2,579 | 9,323 | 0,000 |
| Unoka 2017 | A | 1,614 | 0,200 | 0,040 | 1,222 | 2,006 | 8,077 | 0,000 |
| Unoka 2017 | B | 0,851 | 0,182 | 0,033 | 0,495 | 1,207 | 4,684 | 0,000 |
| Unoka 2017 | C | 1,218 | 0,189 | 0,036 | 0,847 | 1,589 | 6,435 | 0,000 |
| Wiklander 2012 a | A | 1,104 | 0,133 | 0,018 | 0,843 | 1,365 | 8,291 | 0,000 |
| Wiklander 2012 b | A | 1,168 | 0,134 | 0,018 | 0,905 | 1,431 | 8,702 | 0,000 |
| Scheel 2014 | A | 0,562 | 0,121 | 0,015 | 0,324 | 0,800 | 4,629 | 0,000 |
| Scheel 2014 | B | 0,392 | 0,120 | 0,015 | 0,156 | 0,629 | 3,257 | 0,001 |
| Scheel 2014 | C | 0,249 | 0,120 | 0,014 | 0,014 | 0,485 | 2,079 | 0,038 |
| Scheel 2014 | D | 0,703 | 0,122 | 0,015 | 0,463 | 0,943 | 5,746 | 0,000 |
| Chan 2005 | A | 2,534 | 0,293 | 0,086 | 1,959 | 3,108 | 8,642 | 0,000 |
| Mneimne 2017 | A | 1,109 | 0,220 | 0,049 | 0,677 | 1,541 | 5,029 | 0,000 |
| | | 1,444 | 0,150 | 0,022 | 1,151 | 1,738 | 9,646 | 0,000 |

### *Publication Bias*

The funnel plot that 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. HCs.

### *Moderator Analyses*

***Demographic variables.*** Moderator analysis by gender showed no significance in either the BPD sample (Z= .28, p=.77) or the HC group (Z= .04, p= .96).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.

We found that as education level decreased, self-reported shame increased in both groups (BPD: Z= -2.53, p=.01; HC: Z= -1.54, p=.02). The mean education level was 13.5 for patients with BPD and 15.6 for healthy controls.

***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

Our findings revealed a large overall effect size (d= 1.44) when looking at self-reported shame in those with BPD as compared to healthy controls. Results revealed that individuals with BPD report considerably higher levels of shame levels as compared to HCs. These findings are in accordance with the literature (Ritter et al., 2014; Rüsch, Lieb, et al., 2007; Scheel et al., 2014; Unoka & Vizin, 2017) and are the first to be validated in a meta-analysis.

The current study also found that several moderator variables influence shame in BPD, such as education and co-morbid PTSD diagnosis. Age and gender on the other hand did not influence shame in BPD patients. These findings may stress the magnitude and understanding of shame as a widely experienced emotion not just parsed by gender. In the HC group too, gender was not found to influence shame, which is partially consistent with the literature, where some studies have reported gender differences (Ferguson & Crowley, 1997; Harvey et al., 1997) and others have not (Harder et al., 1992; Wright & O'Leary, 1989). As regards age in the HCs, we found that as age increased there was a significant impact on reported shame levels, which is in line with the human natural developmental pathway and with the maturity principle (Roberts et al., 2008). The maturity principle states that there is a positive development throughout life; that is, people are more likely to develop positive and socially contributing personal traits, such as pride as a function of increasing age. On the contrary, maladaptive traits, such as shame, are expected to decline as individuals mature (Roberts et al., 2008). A study which tracked individuals' levels of shame over the life span, provided further support for the maturity principle by finding decreasing shame levels with age (Orth et al., 2010). Our results contribute to the developmental literature of BPD by showing that in their adult development the ‘maturity principle’ is not valid at least in the area of shame (Cameron et al., 2019; Roberts & Damian, 2019). Education on the other hand, in both groups, was found to have a significant impact on shame. This contributes new insights to the existing body of literature as only a small number of studies have examined the relationship between shame and education. While one study, (Hasson-Ohayon et al., 2012) which examined shame reported no association, another study (Vizin et al., 2016) reported a positive relationship between education and shame in healthy and clinical samples. We hypothesize that the connection can be seen between higher levels of shame are due to ones social environment surrounding them while performing. This is in line with Stein and Kean (2000) who found that those who had social anxiety were more likely to have shame and therefore not be able to perform tasks in the education system (i.e., presntations, exams) (Stein & Kern, 2000). Further studies are needed to draw any conclusions about the association between shame and education.

Our findings supported our hypothesis that BPD patients are prone to report higher levels of shame as compared to HCs. Researchers and clinicians have found that traumatic incidents, neglect, and distress experienced both in early years of life and as adults put individuals with BPD at risk of experiencing higher levels of shame and should all be regarded as important in the occurrence of shame in BPD (Linehan, 1993a). Furthermore, it is also evident that the severity of these occurrences, in particular the severity of both sexual and verbal (Vizin et al., 2016) abuse and of neglect, have a substantial role in the appearance of shame (Karan et al., 2014). Being sexually abused contains aspects of manipulation, which have a devastating influence on individuals, leading them to perceive themselves as weak, feelings which produce pervasive shame (Karan et al., 2014). Being verbally abused is humiliating in itself, and if done by attachment figures their shaming messages are internalized and the internalized other became shaming (Unoka &Vizin, 2017). Being neglected emotionally may result in perceiving one's own desires and emotions as inappropriate in the eyes of others, which can also create feelings of shame (Karan et al., 2014). The association between trauma and shame was also supported by (Chan et al., 2005) who found a significant positive relationship, not only among patients with a BPD diagnosis but also among those without BPD. Taking into account that sexual abuse in women with BPD is more prevalent than in the general population (about 62.4%; Zanarini et al., 2002) can be informative in understanding the high prevalence of shame in individuals with BPD.

The high prevalence of shame among BPD patients can also be explained by the etiology of BPD itself. While a range of theories supplies a different explanatory framework for the development of BPD, they all agree that shame proneness is an inherent component of the disorder. The biosocial model posits an interaction between individuals' elevated emotional susceptibility and the impact of being raised in a neglecting and invalidating environment which is responsible for the appearance of BPD symptoms (Linehan, 1993a) . The reason for that is that in a harsh environment, a child's negative emotions are criticized and perceived as a source of shame. However, the more damaging a process occurs when the child begins to invalidate their own emotions, the more they may feel ashamed in reaction to emotional expression. This has a long-lasting effect, resulting in high shame-proneness in adult life (Linehan, 1993a). Enduring feelings of shame can be the result of the mutual impact of traumatic incidents with neglect and judgmental interactions occurring in one's close environment early in life, and personal traits connected to danger-related bodily systems, which will all determine the magnitude of reaction to these negative incidents (Andrews et al., 2002; Mills, 2005). The impact of these incidents facilitate in the creation of early maladaptive schemas (EMSs) (Young et al., 2003), which play a fundamental role in the individual identity structure (Pinto-Gouveia & Matos, 2011; Tomkins, 1963; Young et al., 2003). Moreover, object relations theory (Kernberg, 1984) explains the centrality of shame proneness in the presentation of a BPD diagnosis with particularly negative and split self-representations of individuals with BPD, which are absent from any constructive or favorable self-representations. Supporting evidence come from studies comparing shame levels in different diagnoses, reporting significantly higher levels of shame experienced by individuals diagnosed with BPD compared to individuals diagnosed with other affective disorders (Rüsch, Lieb, et al., 2007; Scheel et al., 2014). Shame levels in the face of negative affect have also been noted throughout the literature as significantly higher among the BPD group (Jacob et al., 2009). Moreover, not as with other negative emotions, the impact of shame specifically (when generated by the researchers) persist for a longer period of time among the BPD group as compared to the other diagnostic groups (Gratz et al., 2010). The perception that BPD by itself is characterized by amplified feelings of shame is reinforced and validated by the results of the current study comparing BPD patients to healthy controls.

The moderator analysis also provided essential insight into the current body of research regarding shame and BPD by targeting education as an important factor, as BPD patients with lower educational levels experienced significantly greater shame. This finding might contribute to the detection of patients who are specifically at risk and prone to more intense feelings of shame. Considering this, a more fitting psychotherapeutic intervention can be developed. Identification of patients who are prone to shame is important especially in the light of the findings. That is, higher shame levels were found to be among BPD patients who also suffer from PTSD. It was already found that PTSD is associated with shame (Andrews et al., 2000), and from this study, it seems that the comorbidity of BPD and PTSD is especially problematic.

The role of PTSD in the study results can be better understand through the role of shame in the etiology of PTSD. Shame is known to be a common reaction to trauma (Dahl, 1989) and a mediator between childhood abuse and trauma and psychopathology later in life (Andrews, 1995, 1997). According to this, shame is known to be a response related to defeat and submission which is often involved in abuse and attack, and is associated to a further psychopathology. More specifically, some have found shame to be related with biological reactions (which were suggested to be rooted in the social humiliation involved in traumas) that can provoke the fundamental biopsychosocial symptoms of PTSD (Tangney et al., 2007). Furthermore, the experience of shame is known to prevent integration of the memory of the trauma into one's life story and identity, and as a result impede recovery (Feiring et al., 1996; Sippel & Marshall, 2011; Wilson et al., 2006). The impact of shame known to be especially significant in chronic traumatic exposures (Herman, 1992). Importantly, there is a substantial support for the association between higher shame and PTSD (Saraiya & Lopez-Castro, 2016). The study result of the higher shame levels among BPD patients with co-morbid PTSD provides further support for the notion about the association between shame and PTSD, especially as the study conducted among population with high prevalence of trauma history. As such it might imply on an extra element of shame and suffering for BPD patients who also cope with PTSD. Thus, it also stresses the need for a further research about shame among this group, and its association and pathways to an added psychopathology. Nevertheless, this findings are meaningful by itself, as they were able to provide further support for the manifestation of PTSD in BPD and the key role of maladaptive emotions (Bolton et al., 2006), especially as previous study conducted among patients with BPD failed to do so (Rüsch, Corrigan, et al., 2007).

As studies report that BPD symptomatology decrease with age (Paris et al., 1987; Stone, 2001) suggesting that some symptoms "burn out", meaning that people learn how to live with them as they mature (Stevenson et al., 2003), it is interesting to find that shame in our sample was not. This might provide further support for studies reporting on a significant improvement of BPD symptoms which represent more acute manifestation of the disorder such as impulsivity, while temperamental symptoms such as anger found to be more persistent and long lasting (Zanarini et al., 2007). Considering the negative impact of shame, this finding of the current study might as well support the need to give temperamental symptoms such as shame, at least the same priority as other more acute symptoms, in the treatment of BPD. This is especially important as currently the main effective treatment modalities offered for BPD patients as Dialectical behavioral therapy (DBT)(Linehan et al., 1991) and mentalization-based therapy (Bateman & Fonagy, 2001), mainly address the acute symptoms of BPD (Zanarini et al., 2007). This need is supported further by the current study other results of higher shame among BPD patients with co-morbid PTSD, which might imply that shame represents a unique and complex experience among this patient's group which might not be properly addressed as part of the treatment of BPD. As such it stresses the need to examine shame, its manifestations, implications and treatment.

This study raises clinical implications in terms of treatment offered to patients with BPD. While shame has been overlooked in the study of BPD, it has been found to be a common experience of patients which also has negative implications for patients' lives  (Rüsch, Lieb, et al., 2007; Unoka & Vizin, 2017). It is especially crucial to have a high awareness of patients' experience of shame, as this might not be easy to identify, mainly as it involves avoidant behaviors and can be masked by other emotions, such as anger (Rüsch, Lieb, et al., 2007). Our findings stress the importance and need for formulating intervention programs that will target shame in patients with BPD diagnosis.

An item in DBT exposure-based interventions, opposite action, is another promising part of DBT therapy that has been shown to decrease levels of shame among individuals with BPD (Rizvi & Linehan, 2005). In opposite action, individuals learn to alter an undesirable emotion by recognizing that emotion when it appears, noticing the behaviors that their emotion automatically elicits (called "action tendencies") but eventually identifying and choosing a behavior that is opposite to those they initially sought out. The prevention of maladaptive behavioral tendencies and engaging in a new opposite one, reinforce the new response pattern while weakening the original emotional response (Linehan, 1993b).

While DBT, in general, has been known to have extensive empirical support (Kliem et al., 2010), it is its central component, mindfulness, which could be especially effective in reducing shame in BPD. Mindfulness, which is the ability to focus on ones' current experiences in the present with acceptance and without judgment (Keng et al., 2011), can help in reducing shame in different ways by allowing perceptional change (Shapiro et al., 2006), as it creates a distance between individuals and their experiences, providing opportunities to re-examine thoughts and feelings and perceive them not as constant or permanent, but as being psychological states which change (Keng & Tan, 2017). Mindfulness also has the potential of increasing acceptance for one's own adverse feelings (Baer, 2003). As mindfulness fosters acceptance of one's feelings rather than criticizing them, it has the potential also to reduce the difficult feelings that people with BPD have towards their own experience of shame (Schoenleber & Berenbaum, 2012) as well as their own views of themselves. According to empirical evidence, mindfulness has been found to successfully decrease shame in individuals with BPD characteristics (Keng et al., 2011) and considering our findings, it could be helpful to look at shame further within BPD patients.

This study has limitations. First, the studies included in this meta-analysis were cross-sectional and thus, causality cannot be assumed from the results. Second, the number of studies included in the analysis was relatively small due to the current literature. Due to the study being a meta-analysis with the comparison value being Cohen’s d, it did not include studies with just a BPD group, as a healthy control comparison group was required for inclusion in the study. While clinical comparison groups (i.e., dual diagnosis or other mental health disorders) could have been meaningful in contributing more insight about the prevalence and influence of shame among different diagnoses, the literature was limited in that aspect and thus we chose to focus on BPD alone. Finally, we only used papers that used self-report tests or questionnaires as there is currently not one widely used shame paradigm; however, this led to limited inclusion of papers. We also were interested in looking at this as compared to other clinical groups but were limited by lack of studies in the current literature.

In sum, our study provides the first meta-analysis to assess reported shame in BPD patients as compared to healthy controls. Variables such as education level and comorbidity of PTSD were found to moderate results. The paper highlights an important contribution to understanding the experience of BPD patients and to the detection of the ones who are at a higher risk to experience shame. Future studies should evaluate the influence of shame on the lives of individuals with BPD diagnosis, and the ability of different psychotherapeutic approaches to target and reduce shame successfully.

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# Chapter 8: General Discussion

Despite the general progress regarding awareness and knowledge about mental illness, mental disorders are still perceived differently than physical disorders and are highly stigmatized (Schomerus et al., 2012). This dissertation conducted in Hungary added new findings to the limited stigma research in Hungary, and mainly exposed a worrisome picture of high rates of rejection towards people with mental illness, which remained relatively consistent over a 15-year period. These findings can contribute to a better understanding of some of the other results of the dissertation, mainly the documented internalized stigma, shame, loss and grief found among Hungarian adults coping with various 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. Importantly, this also allowed for interesting findings regarding between diagnostic group variations in personal experiences. Lastly, and due to previously documented diagnostic variations in the experience of shame, 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 and support the significantly high level of shame which is especially present in this patient group when compared to the healthy population.

## Summary of findings: Studies 1 to 5

**Study 1.** Using a representative sample of Hungarian adults, this study reported on high social rejection towards people coping with mental illness, which was relatively consistent over a 15-year period. Moreover, rejection towards people coping with mental illness was found to be highest when compared to other minority groups in Hungarian society. Different personal characteristics such as female gender, lack of high school education, and lack of familiarity with illnesses were related to higher rejection towards people coping with mental illness. Familiarity levels, more specifically, were found to be the most significant in terms of predictive power.

**Study 2.** Including a sample of 200 Hungarian adults coping with different mental diagnosis, this study explored the perception of loss among patients and investigated the factor structure of the Personal Loss from Mental illness (PLMI) scale (Stein et al., 2005). The study supported a one-factor model over the previously found four-factor model. Furthermore, higher perception of loss among patients was related to such personal characteristics as unemployment and lack of high school education and to the experience of higher loneliness, lower quality of life, and, for the first time, to higher grief. Another novel finding of this study was that patients with different diagnoses differed in their perception of loss, as higher loss was found among people coping with mood disorders.

**Study 3.** This study investigated the factor structure of the Birchwood Insight Scale (BIS) and the paradoxical impact of insight on patients' lives. The study reported a two-factor structure for the Hungarian version of the scale, in contrast with the previously reported three-factor structure. Furthermore, a history of previous hospitalizations predicted higher illness awareness. Insight, more specifically peoples' illness awareness of having a mental illness, predicted higher internalized stigma and lower self-esteem, emphasizing the impact of acknowledging the influence of illness awareness on one's self. Supporting this, the study found that high illness awareness predicted higher shame. Importantly, people with different diagnoses differed in their insight, as those with schizophrenia spectrum disorder reported the lowest illness awareness compared to people coping with mood disorders or stress-related disorders. This was in contrast to patients’ levels of awareness of the need of treatment, where no significant differences between the groups were found.

**Study 4.** In an effort to tackle the problem of treatment non-adherence and to investigate its relation to patients' experience, this study translated and investigated the factor structure of the Medication Adherence Rating Scale (MARS). Different aspects common in patients’ experiences were examined as predictors of adherence. This study confirmed the three-factor structure reported in the literature with one item modification for one item. Furthermore, this study found for the first time that patients’ experiences of loss and grief were significant predictors of lower treatment adherence. Having insight into the need for treatment predicted higher adherence while internalized stigma predicted lower treatment adherence. The significant negative impact of stigma was apparent even in the face of a person’s simple awareness of the existence of stigma in society and agreement with it, regardless of their actual internalization of stigma. Importantly, while no difference in adherence was found among diagnostic groups, further analysis comparing a group of patients with schizophrenia to a combined group of patients with mood disorders and patients with anxiety-related disorders, showed that patients with schizophrenia had the highest treatment adherence.

**Study 5.** This study conducted a meta-analysis to investigate shame, the most reported experience of people coping with mental illness, which is known to be responsible for avoidant coping and non-adherence to treatment. This study was the first to focus on people coping with Borderline Personality Disorder, a diagnostic group which is especially known for high shame experienced, and compared their self-reported shame to that of a healthy control group. This study, which included 3543 participants, found that patients with BPD reported on significantly higher levels of shame compared to healthy controls, and emphasized the high prevalence of shame among this group of patients. Furthermore, lower educational background and higher PTSD symptoms were predictors of higher shame among patients with BPD.

## Discussion of general findings

### The stigma towards mental illness

Despite the passage of time, stigma towards mental illness is still highly prevalent. This dissertation supports this notion and provides new insights regarding the prevalence and magnitude of stigma in a country where such research has been limited. This dissertation in fact represents the first effort to uncover attitudinal trends of stigma toward mental illness in Hungary over a period of 15 years among a representative sample of Hungarian adults. As has been reported around the world (Angermeyer et al., 2013; Mirnezami et al., 2016; Schomerus et al., 2012), Hungary is no exception in showing 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, it was astonishing to discover that people with mental illness constitute the most rejected group in Hungarian society (including those having alcohol and drug use disorders) compared to other minority groups in the society. Despite a general pattern of higher rejection over the years towards other minority groups, it seems that the rejection towards people coping with mental illness has its own pattern, being relatively consistent and high. Studies from Hungary do show that xenophobia, which was always generally highly present, has increased over the recent years (Simonovits et al., 2016). As rejection has been directed towards the most disadvantaged groups in the society (such as people with disabilities, low educational background, and the unemployed)(Fábián, 1996), people with mental illness were no different, and were highly stigmatized over Hungarian history. They were discriminated in the labour market and were socially excluded, creating further unemployment and homelessness, which only amplified social rejection (Bányai, 2015). This dissertation reflects this reality and might also point to a specific problem which has not been properly addressed in Hungary. While supporting a similar trend of rejection that has been reported around the world, there might also be contributing factors which are specific to Hungary or to other nearby countries. It was already suggested that countries with a previous communist background might be especially prone to higher stigmatization and less acceptance of minorities in general, and people coping with mental illness more specifically (Winkler et al., 2015). The communist background and government perception of mental illness being an individual’s problem, disconnected from the society at large, pushed people coping with mental illness into the margins of society, into psychiatric centers (Bajzáth et al., 2014; Höschl et al., 2012). This reality can be manifested in previous findings regarding the public's low knowledge level about mental illness, the negative attitudes towards people coping with mental illness (perceiving them as dangerous and responsible for their condition), and towards mental illness treatment in Hungary. These attitudes were the most negative when compared to other European countries (Coppens et al., 2013; Olafsdottir & Pescosolido, 2011). The communist background can also provide some explanation for 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 absence of such programs may also indicate the presence and magnitude of stigma at the governing level as well. The dissertation findings yield recommendations for intervention programs stressing the importance of culture in formulating such programs as, in contrast with other countries (Jorm & Oh, 2009), in Hungary an individual's age was not a significant predictor of social rejection, while low education was. Furthermore, in Hungary, more so than in other countries women were found to express high levels of rejection towards people coping with mental illness (Angermeyer & Matschinger, 1997; Corrigan &

Watson, 2007; Evans-Lacko et al., 2014; Winkler et al., 2015). However, 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. This also supports the need for examining attitudes toward mental illness in different countries, even if they are assumed to have a similar Western context, background or attitudes towards mental illness (Kleinman, 1977).

### Insight and internalized stigma

Considering the grim reality of high social rejection that exists in Hungary towards people coping with mental illness, it is not surprising to find that for many Hungarian patients the acknowledgement of having a mental illness comes with high emotional price. In this dissertation it was found that high insight into having a mental illness was related to higher internalized stigma, lower self-esteem and higher shame, supporting previous findings (Hasson-Ohayon et al., 2012; Staring et al., 2009).

In addition to supporting previous results concerning the negative impact of insight, results from the different studies in this dissertation combined might provide valuable knowledge and contribute to a better understanding of the "insight paradox" reported in the literature (Lysaker et al., 2007). This paradox refers to conflicting findings regarding the consequences of insight. Insight has been found to be crucial for treatment adherence, but harmful in other respects, related to depression, low self-esteem and low quality of life (Mintz et al., 2003; Moore et al., 1999; Staring et al., 2009). While this paradox was known to be explained by internalized stigma and the negative meaning it dictates for one's own identity, the dissertation findings imply the need to differentiate between the different aspects of insight and might thereby shed more light on this issue. More specifically, this dissertation found that the awareness of the illness aspect itself was destructive for one's self as it was found to be 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, while awareness of having a mental illness was not (Buchman-Wildbaum, Váradi, et al., 2020a). These findings from separate studies might be informative in understanding better the insight paradox, targeting the illness awareness aspect which is prone to negative implications. This allows for a more precise knowledge about the concept of insight, which has multiple layers. Some are more affected by the influence of stigma than others. Thus, increasing some aspects of insight might be harmful, while increasing other aspects might be beneficial.

### The experience of shame

As the experience of shame is common among people with different mental disorders, and was also found to be a main barrier to seeking help and recovery, investigating shame is of high clinical importance. A group of patients that is known to experience an especially high level of shame is people who are coping with Borderline Personality Disorders (BPD). This dissertation constitutes the first meta-analysis to focus on shame among this group and to support the high prevalence of shame among this group compared to the healthy population. Moreover, this dissertation contributed more specific information about shame in this group, targeting individuals with low educational background and co-morbid PTSD as ones who are more prone to experience higher shame (Buchman-Wildbaum et al., 2021). While shame is a common reaction to internalized stigma, it is important to consider other elements which 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). In any case, this finding serves the first robust support for the magnitude of the problem of shame in this group, and stresses the importance of patients’ own experience in light of previous findings documenting the negative impact of shame on the lives of patients with BPD specifically, as shame is associated with low self-esteem, lower quality of life, higher anger and more unstable personal relationships (Rüsch et al., 2007; Unoka & Vizin, 2017). However, due to the lack of previous research on shame, additional research is still needed to investigate shame in this group and in other diagnostic groups as well as its negative influence.

### Loss and grief following the development of mental illness

One of the most important findings of this dissertation is the loss and grief documented by people coping with mental illness. By validating for the first time the Personal Loss from Mental Illness scale (PLMI) (Stein et al., 2005) among a non-English speaking sample, this dissertation supports the existence of loss perception among people coping with different psychiatric diagnoses (Buchman-Wildbaum, Richman, et al., 2020). Interestingly, variations in findings regarding the scale factor structure compared to the first validation study (Stein et al., 2005), might even indicate cultural differences in the experience of loss, as the experience is affected by the country’s atmosphere and attitudes towards mental illness. The one factor structure found in the current study might imply that peoples’ experience of loss is so intense and meaningful that they don’t distinguish between different elements of loss. It is already known that there are cultural differences with respect to mental illness stigma (Abdullah & Brown, 2011), and this finding can provide a window to some of the manifestations of these differences. The study’s chosen location serves as a very interesting and important one, as it can give a glimpse to the experience of patients in countries where such research is limited. It was proposed that there are specific areas in Europe which are more prone to higher stigmatization, especially countries in Eastern and Central Europe, due to the communist background and their management of mental health, from treatment to general perception (Winkler et al., 2015). Indeed, findings from this dissertation targeting people who are coping with mental illness as the most rejected group in Hungarian society for almost more than a decade, support this possibility (Buchman-Wildbaum et al., 2018). For people coping with mental illness and living in a country which generally possesses negative attitudes towards mental illness, it is reasonable to assume that this will affect their opportunities for social interactions, employment, their self-perception and might also trigger avoidant behaviours, all of which in turn might amplify their perception of loss. Accordingly, perception of loss in this dissertation found to be related to higher loneliness and lower quality of life (Buchman-Wildbaum, Richman, et al., 2020). Understanding that differences in perspectives, governmental programs and mental health reforms can have a crucial impact on the inner experience of patients is valuable. However, due to the preliminary nature of the study of loss and the initial usage of the translated PLMI scale, more studies need to be done locally but also globally to allow more firm conclusions.

Importantly, grief was documented as well among the sample that participated in the study, supporting the findings of Mauritz and van Meijel (2009), who were the first to examine grief empirically by utilizing qualitative measures and reporting on grief among patients with schizophrenia as a reaction to their illness. Despite being documented by health professionals (Appelo et al., 1993; Lewis, 2004; Wittmann & Keshavan, 2007; Young et al., 2004), the general scientific interest in patients' experience of grief over the years has been very minimal. While the grief literature creates a distinction between a "normal" grief reaction and complicated or prolonged grief, which is continuous (Shear et al., 2011), grief as a response to mental illness was thought to be a reaction which should not be pathologized due to the complex nature of such illnesses, being chronic and progressive (Olshansky, 1962). The study of grief following non-bereaved losses began by suggesting that grief can be experienced following any loss that affects and change aspects of life the person finds most valuable, such as losing a job or experiencing divorce (Carlson et al., 2000). Despite differences in possible loss experiences, some commonalities were also mentioned, such as having the perception of loss and experiencing reduction in resources, whether they are physical, psychological, or even symbolic. These commonalities can be seen in different experiences, from the death of a loved one to loss of employment, accidents, victimization through violence, and physical illnesses (Carlson et al., 2000). In fact, there are studies which found that it is the level of disruption an individual experiences to their daily life, social interactions, self-esteem and self-image which is related to grief intensity (Brown et al., 1996; Schulz et al., 2006), suggesting the personal subjective experience itself in coping with an event is an important determinant of reactions of grief. Following that, over the years grief was documented as a response to differing loss experiences, such as loss of job, divorce, natural disasters, head injury and physical illnesses (Marwit et al., 2008; Marwit & Kaye, 2006; Papa et al., 2014; Papa & Maitoza, 2013; Shear et al., 2011). Considering that mental illnesses are mainly known to lead to a massive sense of disruption to one’s life (Kaite et al., 2015) and to alterations in one's self perception and identity (Williams, 2008), it is only logical to assume that patients might be grieving because of their illness and grieving for their previous lives. This dissertation was able to support this notion by finding that patients do grieve, which in this study was manifested in negative emotional reactions to thinking about their old self before the illness and their future life as was always imagined to be before the illness, yearning for their old self, being preoccupied with the illness and thoughts about how they used to be and how they could have been if not for the illness, and difficulties to accept the illness and to stand any reminders of the illness. These are all typical and specific manifestations of grief, which can be differentiated from other emotional reactions such as depression (Ogrodniczuk et al., 2003). This dissertation also supports previous claims of Wittmann and Keshavan (2007) who, while describing three clinical cases, reported and elaborated on the different manifestations of grief in patients with schizophrenia; some grieve over the interruption caused to their life by the illness which "stole" the life they had planned for themselves, others were constantly searching for meaning and eventually found this experience as positive, while for others, the illness itself and its symptoms were a way to cope with the losses (Wittmann & Keshavan, 2007). Furthermore, besides documenting the appearance of grief among patients, this dissertation (Buchman-Wildbaum, Richman, et al., 2020) supported for the first time among patients with mental illness 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). Importantly, this dissertation provides the first support for the previously documented negative impact of grief following mental illness which until now was only studied among relatives of people coping with mental illness (Godress et al., 2005), and now has been found among patients themselves, related to loneliness and lower quality of life (Buchman-Wildbaum, Richman, et al., 2020).

The most striking finding of this dissertation was to witness the possible impact of loss and grief, experiences which were not previously the focus of research in general and of research on recovery more specifically. The problem of treatment non-adherence is one of the most investigated problems in the psychiatric field due to its destructive consequences for individuals and society (Puschner et al., 2009; Sajatovic et al., 2004; Svarstad et al., 2001; Weiden & Olfson, 1995). However, research was mainly focused on objective factors which might compromise adherence such as sociodemographic, medication side effects and poor insight (Diaz et al., 2004; El-Mallakh, 2007; Olfson et al., 2006), while more subjective factors, which might shed light on motivational processes in willingness to take mediations, have not received much research attention. The investigation of internalized stigma symbolises positive progress, as interest has begun into understanding the manner in which patients perceive themselves following social attitudes and in the manner their lives are affected by these attitudes. As found in the literature (Cinculova et al., 2017; Corrigan, 2004; Fung et al., 2007), this dissertation also found that higher levels of internalized stigma predict lower treatment adherence (Buchman-Wildbaum, Váradi, et al., 2020a). Importantly, it was not only the actual internalization of stigma which was related to lower adherence, but was also the simple awareness of the existence of stigma towards mental illness which compromised patients' adherence (Buchman-Wildbaum, Váradi, et al., 2020a).

The novelty of this research, however, is in shedding light onto other subjective experiences which might affect treatment adherence, and in finding for the first time that both higher loss and grief predicted patients' lower adherence to medications (Buchman-Wildbaum, Váradi, et al., 2020a). It is well known that grief involves withdrawal and avoidant behaviour. According to Horowitz et al. (1981), reactions that are typical for grief include experiencing distress in thinking or talking about the loss, or by reminders of the loss. Thus, avoidance is taking place, which can take place in the form of denial of the loss, the meaning or its consequences, behavioural avoidance and emotional numbness (Horowitz et al., 1981). All these reactions might serve to provide good direction in explaining why and how grief sabotages treatment adherence. Support for this idea was also found in a study by Mauritz and van Meijel (2009) reporting that among patients with schizophrenia, grief reactions were manifested in difficulties accepting their illness and the need for treatment. As they are already coping with intrusive thoughts and are preoccupied with their illness and the distress it brings as part of their grief (Horowitz et al., 1981), the need to take medications might be an additional, and the ultimate, daily reminder of their illness and everything they have already lost. Under the influence of grief, struggling with accepting their illness and with emotional distress in the face of illness reminders, their adherence might be compromised. Additionally, side effects, which are often prevalent in the intake of psychiatric medications, might be another and the most concrete reminder of their illness and the losses (such as physical changes involved in weight gain which is a common documented side-effect (Ashoorian et al., 2014)). This possibility might be supported by this dissertation’s findings that grief predicted the adherence dimension of having negative attitudes concerning medication side effects (Buchman-Wildbaum, Váradi, et al., 2020a). While it is possible that a larger sample would have yielded more significant findings regarding other adherence elements, the finding might indicate grief’s significance in patients’ experience. While medication side-effects are known to have a negative influence on adherence (Perkins, 2002; Perlick, 2004; Sajatovic et al., 2011), this study might contribute important information to the adherence literature by implying that it is not necessarily the side-effects themselves that compromise individuals’ willingness to adhere to medications, but the grief, the emotional pain and difficulty in accepting and acknowledging their illness and need for medications that are associated with higher tendency to perceive medications as having negative influence, irrespective of medications having more or fewer side-effects. This is in turn might reduce the probability of actual adherence. 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), as has also been found in previous studies (Hayhurst et al., 2014; Puschner et al., 2009).

### Diagnostic difference

Although it was not the dissertation's main goal, the presented results also provide important insights about possible differences in the experience of patients with different diagnoses. Taking together the results of the various studies included in this dissertation might provide an interesting framework, mainly about the different manifestations of illness awareness and its negative role in the mental health field. While patients with schizophrenia spectrum disorders had the lowest illness awareness, their awareness for the need for treatment and their adherence was no different than for patients with mood disorders and stress related disorders (Buchman-Wildbaum, Váradi, et al., 2020a, 2020b). If anything, although significant levels were not achieved, patients with schizophrenia had the highest awareness for the need for treatment, and highest adherence when compared to the two comparison groups combined. Moreover, the experience of loss was not found to be related specifically to the diagnosis of schizophrenia spectrum disorders (Buchman-Wildbaum, Richman, et al., 2020). On the contrary, patients with mood disorders had the highest level of illness awareness and higher experience of loss. Additionally, while it was found in the other dissertation results that treatment awareness was related to better adherence, illness awareness was not (Buchman-Wildbaum, Váradi, et al., 2020a). Similarly, 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 health conditions that are highly stigmatized, such as mental illnesses, the awareness itself might be harmful for ones' coping, and might be a specific barrier to adherence among highly insightful patient groups, such as those with mood disorders. In that aspect, it is possible that the low illness awareness found among patients with schizophrenia might be some sort of protective factor among this study group. This possibility is also supported by Moore et al. (1999) who found that unawareness of the illness among patients with schizophrenia was a protective factor against depression. This also supports the suggested multidimensional structure of insight (Michalakeas et al., 1994) and the importance of distinguishing among different insight aspects.  It is however important to remember that the study sample was composed of relatively well-functioning, non-hospitalized adults and thus direct conclusions regarding the wider range of patients with schizophrenia or mood disorders might be compromised.

Another interesting finding regarding the illness experience of different patients was the difference in loss perception, as patients with mood disorders reported the highest loss compared to those with stress related disorders. No significant difference was found in loss perception between patients with schizophrenia compared to those with other diagnoses. Generally, compared to stress related disorders, both mood disorders and schizophrenia spectrum disorders are considered to have a more severe manifestation and prognosis (Jorm & Wright, 2008; Wood et al., 2014; Yoshioka et al., 2014), tend to experience symptomatic relapses, and have a fluctuating mental state (Goodwin & Jamison, 2007; Schaffer et al., 2006; Wittmann & Keshavan, 2007). These difficulties might all be related to a lower level of functioning, both social and occupational (Blairy et al., 2004; IsHak et al., 2012; Mauritz & van Meijel, 2009), when compared to people with stress related disorders, and might trigger multiple losses. Mental health stigma was found to be higher as well towards diagnoses with more severe illness manifestations, such as mood disorders and schizophrenia (Ellison et al., 2013; Oliveira et al., 2015; Wood et al., 2014). Internalized stigma was found to be higher among these groups of patients compared to those with stress related disorders (Chang et al., 2016; Pal et al., 2017) and was found to have a negative influence on their lives, triggering further losses of employment opportunities, social interactions and chances to establish a family (Elgie & Morselli, 2007; Holzinger et al., 2003; Michalak et al., 2006). While it is reasonable that those with mood disorders would experience higher loss and higher illness awareness than those with stress related disorders, a question remined regarding why this was not the case in the group with schizophrenia. This is especially interesting considering the fact that schizophrenia is deemed to be more severe and stigmatized than the other disorders (Angermeyer & Dietrich, 2006; Wittmann & Keshavan, 2007). This finding can potentially provide interesting new knowledge regarding the study of insight in schizophrenia. On one hand this finding can be explained by the known problem of lack of insight which is especially present in those with schizophrenia, and considered to be the result of the illness process and the neurological deficit involved

(Cuesta & Peralta, 1994; McGorry & McConville, 1999). Thus, it is possible that the patients with schizophrenia in the sample were less aware of their illness and the losses it brought into their lives. This possibility might be supported by the dissertation results reporting that the patients with schizophrenia had the lowest illness awareness compared to the other groups (Buchman-Wildbaum, Váradi, et al., 2020b). However, other reported results might introduce another possibility. More specifically, while it was found that patients with schizophrenia had the lowest illness awareness, they also had the highest treatment awareness, which might be paradoxical, as awareness of having an illness is presumed to be necessary for being aware of the need for treatment. This might raise the possibility that despite being believed to be unaware of their condition, patients with schizophrenia might be well aware, which might point to underlying psychological factors in the coping process. As schizophrenia is characterized by a prolonged course, including relapses, re-hospitalization and thus disruption to one's life as well as multiple losses whose meaning keeps evolving, it is possible that these are often too much for those with schizophrenia to completely comprehend, and too painful for them to acknowledge. Thus, the lack of difference in perception of loss and the low illness awareness that were found might also be seen as reflections of denial rather than pure lack of insight. This possibility is supported by previous studies which reported on the use of denial as a defense mechanism against the anxiety-provoking reality of the illness, which is known to be the most stigmatized in the society (McGlashan & Carpenter, 1981; McGorry & McConville, 1999; Moore et al., 1999). This dissertation might support the involvement and impact of psychological factors in illness experience, in raising the attention that this low awareness, this denial, can be also part of a more complex process of grief. Clayton (1990) claims that in grief, coping might be stuck in the stage of denial, where the person is trying to avoid negative and painful emotions while being preoccupied with the losses. Although it is difficult to distinguish in schizophrenia between poor insight and denial, there is support for the fact that denial as well can contribute to what is seen as poor insight in people with schizophrenia (Startup, 1996). Mauritz and van Meijel (2009) found that grieving in patients with schizophrenia was characterized by denial and difficulty accepting the illness, although patients were insightful about the illness. Wittmann and Keshavan (2007) elaborated with case studies on the experience of grief among patients with schizophrenia who had difficulty accepting their illness, the losses it brings and their own "lost" identity. They mourned their previous self and previous life. For these patients, introducing the concept of grief and normalizing their experience as a reaction to loss reduced denial and improved their ability to accept their illness. This might also raise the possibility that current measures of insight might not be sensitive enough or might be too simplistic in gaining a fuller picture of patients' perception and acknowledgment of their illness. This possibility might be supported by the findings of Birchwood et al. (2000) according to which the assessment of insight into the illness was not enough to explain depression as a result of the illness in schizophrenia, where it was the wider perception of patients of their illness, the losses it brings and their pessimism level, which determined their emotional response to the illness. Examining patients' experience with a "grief lens" was already proposed by Young et al. (2004) to understand better patients' experience, symptoms, and behavior and to improve their coping. However, it is important to stress that this dissertation is limited in its ability to provide conclusive inferences as it is preliminary in its nature. Moreover, the study of grief in mental illnesses is in its infancy and much more research is needed, although these findings might provide a promising research direction.

Interestingly, while schizophrenia is especially known to be related to treatment non-adherence (Cramer & Rosenheck, 1998; Kamaradova et al., 2016; Sajatovic et al., 2010), in this dissertation patients with schizophrenia not only did not differ from the other patient groups, additional analyses even pointed to the possibility that their adherence was the highest. The fact that the individuals who participated in the study were stable and high functioning might allow for this interesting finding and might provide a window into different stages of coping among patients with schizophrenia living in the community, into their difficulty in accepting the illness and usage of denial. In that respect, it appears that the awareness of the need for treatment might be an important factor which could compensate and have a beneficial impact on treatment adherence.

### Practical implications

This dissertation provides several practical implications both locally and globally, as well. This dissertation offers a glimpse into the actual meaning that having a mental illness has, encompassing the public's perspective and the individuals' perspective, suggesting that these might go hand in hand. Any study in the mental health field should consider that mental illnesses are not without social meaning, meaning which in

Hungary seems to be especially and consistently negative. While educating the public about mental illness and fighting the stigma are important, supporting those who are affected by mental illness seems to be crucial. A good starting point in understanding patients' experience is to look carefully at the negative consequences that insight of having a mental illness is found to have, which for patients was related to higher internalized stigma, shame and low self-esteem. Interestingly, this illness awareness by itself is destructive, as other insight elements such as awareness for the need for medical treatment was not related to the above negative consequences. On the contrary, awareness of the need for medical treatment was positively related to higher treatment adherence. The negative connotation of mental illness and its harmful implications was found to be so powerful, as this dissertation discovered, that patients didn't actually have to internalize the stigma to be negatively affected, but even their simple awareness of the stigmatic attitudes that exist in society led to their lower adherence to medications. This is important to understand when approaching and formulating intervention plans for patients. While efforts to reduce the stigma on a social level are important, this might be a lengthy process, and this dissertation, maybe more than anything, points to the immediate need for formulating interventions at the individual level as well.

In terms of government policies regarding mental health, Hungary has conflicting forces at play. On one hand, efforts have been made to conform to European standards and expectations, but on the other hand, these efforts are often restricted by existing structures, operational mechanisms and economic constraints (Dlouhy, 2014). However, positive progress is present in the framework of two programs that took place in Hungary: the Suicide Prevention Programme in Regions with a very high suicide rate (Szanto et al., 2007) and a program which was part of the European Alliance against Depression (Székely et al., 2013), aiming to increase awareness of mental health, lower suicide rates, and improve the care of people coping with mental illness. Despite being effective, many more policies are needed, especially given the alarming numbers of suicides and alcohol-related mortality and morbidity in Hungary, which are among the highest not only in Europe but in the world (Kurimay, 2010; Rihmer & Akiskal, 2006). As this dissertation demonstrates, in Hungary and globally, interventions are needed also at the individual level, to increase resilience among people coping with mental illness themselves. In order to improve patients' treatment adherence, the presented results suggest that addressing internalized stigma, loss and grief are needed. Up until now, intervention programs to increase adherence included psychoeducational elements, educating patients about their illness and the importance of medications, elements of monitoring symptoms and addressing medication side effects, technology based services providing reminders, addressing adherence problems resulting from cognitive impairments and supporting daily intake, and elements from Cognitive Behavioral Therapy (CBT) addressing negative thought about medications (Velligan et al., 2009). This dissertation adds to the existing knowledge and implies that interventions should aim to facilitate "healthy insight", awareness of medical need should be promoted and illness awareness which is absent from any self-stigmatized beliefs should be facilitated. Such interventions can benefit from progress which has been made in the establishment of programs aiming to reduce internalized stigma. These have mainly adopted psychoeducational elements with the focus on increasing knowledge, refuting stereotypes and myths about mental illness and increasing illness acceptance. Most of them also combined additional elements such as CBT to target irrational self-concept and to provide social skills training, goal attainment programs and narrative therapy (Tsang et al., 2016). Generally, these all have been found to be effective in reducing internalized stigma (Tsang et al., 2016) and in improving quality of life, depression and anxiety symptoms (Xu et al., 2017). In efforts to promote "healthy" insight, feelings of shame, which were found to be associated with illness awareness, might also be important to address, especially due to their possible contribution to internalized stigma and treatment avoidance (Hasson-Ohayon et al., 2012; Rüsch et al., 2006). While addressing shame might be important among the general patient population, previous studies report that it might be especially important among people coping with Borderline Personality Disorder (BPD), as shame was found to be significantly higher in this group compared to those with other diagnoses, and was even suggested to be a core feature in their experience (Ritter et al., 2014; Rüsch et al., 2007; Scheel et al., 2014; Unoka & Vizin, 2017). The existence of high shame levels among this group was also supported by this dissertation comparing shame levels in BPD to the healthy population. As diagnoses differ in their severity and manifestation, they might also differ in the social reaction they trigger and thus it is possible that different patients are affected differently by stigma, while some might be more vulnerable to internalization of stigma than others (Rüsch et al., 2006). Having a severe illness manifestation (Lieb et al., 2004) and suffering to a higher degree from shame, it is possible that patients with BPD might be especially vulnerable to internalized stigma as well (Linehan, 1993), a possibility which was supported in a study comparing internalized stigma between patients with BPD and patients with social phobia (Rüsch et al., 2006). Accordingly, differences in internalized stigma were also found among those with other diagnoses, such as schizophrenia, depression, and bipolar, presenting higher internalized stigma than people coping with anxiety (Chang et al., 2016). It might imply that intervention programs should be formulated to the specific nature and characteristics of specific diagnoses. In BPD for example, special consideration must also be given to the vast history of trauma, abuse and neglect which is highly evident in this group, and is especially related to shame (Lewis, 1998; Zanarini et al., 2002) which might be further reinforced also by the experience of internalized stigma, adding an additional element of suffering. These however should be further examined by more specific research comparing internalized stigma and shame among different groups of patients.

The main practical contribution of this dissertation, however, is in shedding light into less studied illness experiences, suggesting that they provide an alternative way to understand patients' experience and symptoms, and stressing that these experiences should also be taken into consideration in efforts to improve adherence. Finding that patients are experiencing loss and grief because of their illness has a meaningful contribution, first to the perception of mental illness as a whole, in allowing a more empathetic understanding of people who have been diagnosed with mental illness. Mainly, by perceiving individuals separately from their illness, we place them in a "normal" context of individuals who experience a normal grief reaction to a major life event. Second, the findings also raise awareness of a new and a major piece in the investigation of barriers to adherence and recovery, and thus carry important implications to the formation of psychotherapeutic intervention and improvement of care. Assessing and addressing patients' perception of loss might be an important element in such programs and can also be empowering. Although the association between loss and internalized stigma was not examined in this dissertation, it is possible that these two factors are affecting and reinforcing each other, as higher loss because of the illness might perpetuate negative stereotypes and self-beliefs, which by itself might facilitate more avoidance, lower adherence, lower functioning and further losses. Thus, reducing patients' perception of loss might also reduce self-defeating beliefs and internalized stigma. The diagnostic difference in the perception of loss stresses the importance of addressing loss, especially among people coping with mood disorders, but mainly calls for the need to formulize interventions which are based on the specific needs of people who are coping with different diagnoses, especially as these can carry different challenges and losses. Addressing perception of loss might provide support and reduce grief as well. The importance of identifying grief in patients was mentioned also by Young et al. (2004) stressing that if unrecognized it can be mistakenly perceived as part of the symptoms of the illness and might be dismissed or pathologized, and might impede recovery. Appelo et al. (1993) offer that many emotional and behavioral symptoms in schizophrenia for example (such as anger, aggression and passivity), might also be reinterpreted as normal reactions to the illness reality, and as ineffective coping manners with the losses and grief. This understanding might change enormously the perspective behind offered treatment, emphasizing elements of subjective suffering and empathy, instead of criticizing or medicating some of these behaviors (Appelo et al., 1993). According to Lewis (2004) in efforts to address grief, it is important to pay attention to different phases of grief (documented among patients with schizophrenia): grieving all the losses following the illness and grieving due to the loss of symptoms of mental health such as delusions and hallucinations. Illness symptoms were suggested by Freud (1961) to actually be an effort to cope with the illness and create a new meaning to life, and new identity in the face of the illness. Losing one’s symptoms as part of recovery process can be a source of grief as well, as it might be experienced as diminished sense of worth or importance. As such, as part of efforts to reduce grief, increase acceptance and improve recovery, these issues should be acknowledged and addressed (Lewis, 2004). Furthermore, while grief has been described in the literature as occurring in stages (such as shock, disorganization, denial, acceptance and reintegration (Ramsay, 1977)), these were described as less useful in the case of grief following a mental illness, due to the ambiguous and enduring nature of the illness and the grief it brings (Young et al., 2004). Accordingly, individuals can move back and forth among different stages, as feelings of grief might re-emerge in different points in life, especially at meaningful milestones (Rando, 1993), contributing to the complex nature of grief work in coping with mental illness. The first task of therapeutic interventions aiming to reduce grief is to increase acceptance of the illness and the new reality (Worden, 1982). Thus, in therapy, efforts should be directed into acknowledging the losses that the illness brings, and making them real and valid, as they are often being unnamed and unrecognized (Doka, 1989). Asking about and exploring patients' lives before the illness, their identity and hopes for the future can be helpful in understanding the losses and validating patients’ experience about the differences between the past and current reality (Young et al., 2004). Naming their experience as grief, normalizing it and stressing it as a normal and healthy response to a major life event, which is often very traumatic as well, might be healing by itself (Young et al., 2004). In that aspect, educating patients about grief and about its possible manifestation in their symptoms, and its impact on their functioning and coping might be vital (Appelo et al., 1993). It is not only acceptance which is important to achieve but also integration, or finding a meaning to life, which can be achieved following efforts to locate individuals' experience within a context which makes sense to them (Young et al., 2004). Attachments to lost roles, social bonds, and positions might sabotage this process, and thus should be recognized and addressed as well (Appelo et al., 1993). Reconnecting with others is another important element in grief therapy which might be incorporated in offered treatment, and might be especially important among people who are coping with mental illness, who are often isolated and are alone with their pain (Young et al., 2004). Developing a mental illness is an individual but also a family crisis, and often times patients carry blame and guilt, feeling responsible for the losses and pain the illness brings to the family as well (Young et al., 2004). Thus, incorporating family members in therapeutic interventions and allowing patients and families to share their experiences in a safe environment might be empowering for patients and for the family system as a whole, and might facilitate empathy, understanding and acceptance.  Reconnecting with others who are also coping with mental illness, and sharing experiences which were largely ignored, such as losses and grief following the illness, could help in normalizing their experience, in alleviating their pain and reducing loneliness and in facilitating acceptance and an improved coping. Acknowledging their current lack of social or community support, which is usually present in the case or bereavement loss, might be helpful in normalizing their grief and in understanding its importance (Young et al., 2004). Understanding the spirituality, beliefs and values of patients is important, as these provide comfort and facilitate the exploration and achievement of a new meaning to life (Young et al., 2004). Elements from CBT, mainly of restructuring negative thoughts regarding low self-worth and hopelessness concerning the future, as with internalized stigma, might help as well in reducing symptoms of grief. Restructuring self-defeating thoughts and replacing them with more adaptive and rational ones, together with skills training, might facilitate the process of meaning-making and recovery (Appelo et al., 1993). Trauma focused therapy might be another treatment modality that can be utilized to address the traumatic losses and experience of grief involved in the development of mental illness, to increase integration of traumatic memories and experiences and increase acceptance and recovery. This might be especially important in light of earlier findings pointing to a high prevalence of patients who experience PTSD symptoms as a reaction to coping with mental illness (McGorry et al., 1991; Morrison et al., 2003) and on the negative influence of unprocessed traumas, including those related to previous psychiatric hospitalization, on treatment adherence (Lecomte at al., 2008; Tessier et al., 2017). Trauma focused therapy might be especially important among patients known to have a vast history of trauma such as patients coping with BPD (Zanarini at al., 2002). Known to be effective in reducing symptoms of PTSD (Slotema et al., 2019), trauma focused therapy might also be effective in reducing feelings of shame, which in this dissertation was found to be related to a higher prevalence of PTSD symptoms among patients with BPD (Buchman-Wildbaum et al., 2021).

The differences found in this dissertation among those with different diagnoses in terms of perceptions of loss call for the need to further examine the experience of grief among different diagnostic groups, and possibly to establish grief reduction programs based on the specific needs and manifestations of grief in the specific diagnostic groups. Furthermore, the difference among those with different diagnoses which was also found in insight levels and to some degree in adherence, is important and informative by itself, carrying practical implications not only for the treatment offered to patients but also for future research. It emphasizes that efforts to increase adherence to treatment should fit the needs of people coping with different diagnoses, which is especially important also as different diagnoses are found to carry unique barriers for adherence (Velligan et al., 2009). In schizophrenia for example, a combination of techniques such as Cognitive Remediation Therapy (CRT) can be helpful in improving the cognitive deficits that are often involved (Wykes et al., 2011), contributing to improvement in insight and quality of life (Garrido et al., 2013; Lalova et al., 2013). Furthermore, it also supports the need to examine and address prominent barriers to recovery in the mental health field in the broader spectrum of mental diagnoses rather than in schizophrenia alone. However, due to the preliminary nature of this dissertation, further research in these topics is needed.

## Strengths of the present dissertation

This dissertation as a whole includes several strengths.

First, it provides a significant contribution to the study of the internal experience of people coping with mental illness. It supports well documented findings regarding the negative meaning that mental illness might have for patients, and the negative impact that awareness to the illness has on self-related aspects (Hasson-Ohayon et al., 2012; Staring et al., 2009), findings which are especially important due to the previous consensus that insight into the illness in general should be always promoted. It mainly supports and emphasizes the complexity of insight when it comes to mental health, and contributes by suggesting that, unlike illness awareness, insight into the need for treatment might be important to promote in order improve adherence. The negative meaning that is attached to illness awareness, the internalization of stigma and its harmful influence on non-adherence is documented and supported as well. Besides supporting previous research, this dissertation contributes new knowledge to this body of research by investigating elements in patients’ experience which were largely understudied, like loss and grief. Moreover, this dissertation is the first to empirically investigate the experience of grief among patients, and to examine its relevance to recovery, stressing its importance and relatedness to one of the most common and severe problems in the mental health field. Thus, this dissertation stresses the importance of patients' internal experience and the need to incorporate subjective elements as well in efforts to improve treatment adherence. This dissertation offers that perception of loss, grief, internalized stigma and shame might all participate in destructive processes related to impeding recovery and reduced quality of life. Furthermore, this dissertation contributes new and important insights about the experience of individuals with different mental diagnoses, which is meaningful as current research is largely focused on the experience of people coping with schizophrenia spectrum disorders (Fialko et al., 2008; Ghaemi, 1997). This dissertation mainly stresses that problems which are common in the mental health field (such as poor insight and low treatment adherence) are not just schizophrenia problems, but are prevalent in other diagnoses as well, emphasizing that there is a whole spectrum of diagnoses and individuals who need support and better care. This was stressed as well by the results presented in this dissertation taken from a meta-analysis, emphasizing the magnitude of shame in patients with BPD, which was significantly higher compared to the healthy population. This represents another meaningful contribution of this dissertation as it constitutes the first meta-analysis to be conducted measuring self-reported shame among patients with BPD, a population which is specifically prone to experience high levels of shame.

Second, besides contributing new and valuable knowledge about the experience of patients, this dissertation adds important knowledge about the public perception regarding mental illnesses in Hungary. This dissertation contributes to the field by performing the first time-trend analysis in Hungary, examining attitudinal change over a 15-year period, and using a robust and representative sample of Hungarian adults. This is especially important as in order to address a problem, its extent and possible determinants should be fully studied, and in Hungary such research to this point was lacking. As such, it contributes meaningful knowledge about the social environment of people in Hungary who are coping with mental illness, providing a background for the better understanding of patients' experience. Moreover, it contributes new knowledge to the study of stigma in Hungary specifically and provides possible suggestions regarding to the formulation of intervention programs to combat the stigma.

Lastly, in the framework of this dissertation, new and also commonly used English language scales were translated into Hungarian and were validated for the first time (to the author's knowledge). The Personal Loss from Mental Illness scale (PLMI) (Stein et al., 2005) is a relatively newly developed scale, and its factor structure was examined for the first time among non-English speaking population. While supporting the presence of loss perception among patients and supporting its validity, it contributes valuable insights into this new body of research implying that there might be diagnostic and cultural difference in perceptions of loss. The commonly used insight and adherence scales, BIS (Birchwood et al., 1994) and MARS (Thompson et al., 2000), were also translated and validated for the first time in Hungary, supporting the use of these scales also among patients with different diagnoses rather than mainly in those with schizophrenia. Furthermore, the present work provides suggestions for minor modifications in the structure of these factors, implying possible cultural differences and a need for a further examination. This also constitutes a significant contribution to the research field in Hungary and to future research by facilitating the use of these validated Hungarian questionnaires.

## Limitations and future direction

Despite the mentioned strengths, this dissertation might include important limitations as well.

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 presented in this dissertation should be interpreted with caution. Despite the contribution of previous work to the study of grief among family members, and the development of a specific scale to asses grief following mental illness (Miller et al., 1990), there is much yet to discover about grief among patients themselves. While this study supports the usage of this scale among patients, there is a need for further research about the specific manifestations of grief among patients and across different diagnoses, and perhaps for the development of a specific scale to assess grief among people coping with mental illness. The exploratory qualitative study by Mauritz and van Meijel (2009) on grief in patients with schizophrenia can be a good starting point for future research. Any such research might benefit from adopting a longitudinal design, especially as grief in mental illness known to be continuous and fluctuating (Atkinson, 1994; Young et al., 2004). This might be especially important as the other factors measured in this study, such as insight and adherence, might fluctuate with time as well (Velligan et al., 2009; Wiffen et al., 2010), and their association in time might be important to assess. The preliminary nature of this dissertation and the lack of meaningful research about the experience of shame among patients limited as well the ability of this dissertation to compare shame levels among people with different diagnoses and to identify specific groups which might be especially prone to shame, a topic which should be addressed further in future research.

Second, while this dissertation offers insights regarding the experience of patients with different diagnoses, these might be limited mainly due to the categorization implemented. More specifically, as the sample included in this dissertation was diverse in terms of diagnoses, for simplification purposes patients with different diagnoses were classified together into larger diagnostic groups. This mainly affected the ability to detect differences which might exist among diagnoses grouped together, and might affect the generalization of the results to more specific diagnoses. 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, while contributing important insights regarding the experience of loss and grief, it is important to mention that other factors, such as symptom severity, were not measured, and as such, the possible effect of other factors on the association found cannot be ruled out.

Fourth, the cross-sectional design used as part of this dissertation limits the ability to infer causality from the findings.

Lastly, the assessment of factors such as adherence and insight was conducted by using self-report measures, which have been criticized for their inaccuracies due to reasons such as social desirability, memory deficits and ability to understand the questions (Sajatovic et al., 2010; Yang et al., 2012). Assessing insight with self-report might also be subject to limitations, mainly when considering the involvement of denial, patients' efforts to deny the existence of the illness in order to preserve positive self-esteem and not face the pain (Startup, 1996). However, this possibility might call for the need to examine further the concept of insight and its measurement, the objective measures as well, suggesting that current methodology might not be sensitive enough and might measure other constructs, such as denial, possibilities which were also supported by Mintz et al. (2003). Furthermore, as the researcher-rated format might also be biased as well (Young et al., 2003), and as the main aim of this dissertation was to focus and stress the importance of patients' own experience, implementing self-report measures was preferable. Their known advantages such as being easy to administer, fast, simple and being a valid indication for patients behavior and perception (Fialko et al., 2008; Jaeger et al., 2012) were supported in this dissertation as well. Future studies investigating patients’ internal experience should take into consideration the social meaning of mental illness and the possible impact and contribution of internalized stigma on perception of loss and grief, examination of which was outside of the scope of this dissertation. As there are cultural differences in stigma towards mental illness (Abdullah & Brown, 2011), cross-cultural studies might be especially important in providing valuable insights regarding these associations and the exact mechanism involved in treatment non-adherence. Possible diagnostic differences should be examined more precisely in a larger sample and with regard to shame, internalized stigma and grief as well.

## Conclusions

Despite the limitations outlined, and especially due to its preliminary nature, this dissertation presents five empirical studies providing important insights to the study of coping with mental illness and treatment adherence. This dissertation mainly emphasizes the need for a change in perspective, and for a shift from the substantial emphasis on objective factors as part of understanding coping and recovery. As expected from the public, researchers and health professionals as well are expected to see the individual first, rather than his or her illness. Maybe more than anything, this dissertation calls the need to adopt 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. This might also help in eliminating the possible influence of stigma on treatment and care pathways provided for people coping with mental illness. Allowing a better understanding of not only objective factors, but also subjective ones such as shame, stigma, loss and grief, might bring great relief for people who could not properly grieve their losses. As health professionals we should do a better job in listening to clients without judgement or stigmatic attitudes, and in creating 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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