

Stigmatization on the way to recovery in mental illness. The factors associated with social functioning

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Summary

Persons with mental disorders often experience stigmatization. There is a number of social factors that may affect the process of recovery and at the same time, in certain circumstances, could be a source of stigma. Mentally ill may find strength in themselves to fight against the disease or the opposite – can internalize the negative attitudes of the society and become self-stigmatized. The patient's family, on the one hand, is often the only source of social support, on the other hand, can experience a destructive influence of courtesy-stigma. Mentally ill have to face social reluctance which is reinforced by stereotypical media coverage of mental disorders. The social network of patients is poor and often limited to a family system. Negative views about persons diagnosed with mental illness are most visible in the labour market. Patients experience many types of discrimination at work, have lower employment rates and lower mean wages than healthy ones. Structural discrimination is a form of stigma which is revealed in underfunded and inefficient system of mental health care. All the social factors mentioned above are necessary for recovery (positive stimulation of functioning), but can also increase stigma and become a significant barrier in the recovery of psychiatric patients. This paper highlights the complex and ambiguous nature of the relationship between social factors and the recovery of the mentally ill basing on the data from the literature.

Key words: stigmatization, recovery

Introduction

Stigmatization of the mentally ill is a multistep process leading to the rejection of the individual, his discrimination and exclusion from the various areas of social functioning. A number of social factors that affect the process of recovery were identified. Public perception, media coverage of the illness, patient's social network, attitude and functioning of the family, professional career and finally the patient himself – may

contribute to or be an obstacle to recovery. The aim of this study is to highlight the complex and ambiguous nature of the relationship between social factors and the recovery of mental health on the basis of data from the literature.

Public perceptions of the mentally ill

A significant part of the society holds a negative attitude towards the mentally ill and this attitude has not changed for years. This happens despite the popularization of knowledge about mental illnesses (especially on the biological model) and despite a growing acceptance of psychiatric treatment [1]. Mentally ill are usually identified with the dangerous, aggressive and unpredictable individuals. That is why the vast majority of respondents admit that they prefer to maintain social distance towards them [2, 3]. In a study of public opinion it was especially emphasized that the patients are noticeably different from the general population [4]. Bizarre behaviour and appearance may be a result of the illness or pharmacotherapy (dyskinesia, dystonia, akathisia, obesity). Two large studies published in 2000 and 2008 (by Wciórka and Wciórka) show that the percentage of positive attitudes in Polish society towards mentally ill decreased from 71% in 1999 to 65% in 2008. It is still very common (more than 60% of affirmative answers) that the mentally ill are described in an offensive way [4]. Negative public perceptions of the mentally ill are also confirmed by the results of an unusual study of Schomerus et al. The respondents (German adult population) admitted that if they were to decide on budget cuts in the health sector, they would most probably limit the budget for patients with mental disorders [5].

The mass media play the major role in forming public opinion about mental illnesses. The media could educate the public and provide reliable information about mental illnesses, but in fact they fulfil this role only in relation to depressive disorders, suicides or substance addiction. Among surveyed psychiatric patients, 23.8% believe that the media maintain the most negative view of the patients [6]. In the print media, most articles on mental health reflect a reluctance to patients and it seems that the patients with psychotic disorders are stigmatized the most. Although in the British newspapers there has been a significant decrease in the number of articles that stigmatize mental illnesses, this trend can be applied only to depression. Descriptions of schizophrenia remain largely negative [7]. The analysis of media coverage of mental health brings a clear conclusion: the mentally ill are associated with the use of violence, are dangerous and should be avoided. To make matters worse, the negative image of the mentally ill is also maintained by the TV programs for children, thus raising the next generation that will stigmatize psychiatric patients [8].

Self-stigma

In the process of recovery the role of personal involvement of the patient in regaining control over his life and resisting stigma has been pointed out. In the process of empowerment a mentally ill may find strength in himself to fight against the disease [9]. However, patients often think about mental illnesses stereotypically. It is worth

noting that even before the onset of the illness the patient grows up in a society that is prejudiced to the mentally ill. Probably that is why, after being diagnosed with a mental disorder, they easily become self-stigmatized and internalize negative social attitudes [10]. Cechnicki et al. studied 202 patients with schizophrenia or schizophreniform syndromes. Among them, 58% anticipated the discrimination in the field of interpersonal contacts, and 55% of those surveyed patients – in the area of employment. Experience of stigma in the form of rejection by others was confirmed by 87% of respondents, and 50% of respondents have had an interpersonal contact broken-off [11]. According to Uçok, the majority of the mentally ill expect negative reactions from the society (e.g. fear or discrimination). This does not necessarily coincide with the experienced discrimination. Self-stigma, called in the literature “a second disease”, results in reduced self-esteem and is a major obstacle in keeping the social roles at work and in personal life. In the INDIGO study 64% of patients with schizophrenia anticipated discrimination and, as a consequence, stopped themselves from applying for work, training or education [12]. In the study conducted by Link et al. 74% of patients believed that employers discriminated the mentally ill [13]. Pessimism about personal life was revealed in a lack of faith in the ability to establish and maintain closer relationships. Among patients 81% of respondents expected rejection in intimate relationships [13]. It is worth noting that in that study group only 36% of patients had a diagnosis of paranoid schizophrenia. In the study conducted by Karidi et al. 79.3% of respondents with schizophrenia did not believe that anyone would want to marry them [6]. The vast majority of patients with schizophrenia (72%) feel that they should conceal their diagnosis. Moreover, this group is dominated by the young and better educated people [12, 14]. Anticipation of discrimination is more common in those who have never experienced discrimination [12]. Goffman claimed that “stigma is a product of expectations rather than reality.”[15] It turns out that a younger age of onset of the illness predisposes to internalize and develop a self-stigma. Patients feel less accepted in the period immediately after the diagnosis of mental illness. Those who have been ill for a longer time are more likely to actually experience stigma in their lives and bear most of the social consequences of stigma. Males are more susceptible to the social consequences of mental illness [6]. Moreover, self-stigma positively correlated with the severity of disease symptoms, but negatively with patients’ compliance [16].

Self-stigma is a self-reinforcing process which develops unfavourable defence mechanisms. Patients with more self-stigma accept discriminatory attitudes of the society which further reduces their self-esteem, leading to the avoidance of any social challenges (e.g. applying for a job). Particularly alarming is how self-stigma affects young people, after the first episode of illness, who at the beginning of their way to recovery, instead of developing hope and empowerment, internalize the negative stereotypes.

Family and caregivers of the mentally ill

After being diagnosed with mental illness the patient is usually surrounded only by a small group of relatives, who support him. In fact, patient's family often becomes a victim of stigmatization. This phenomenon is called a courtesy stigma. Along with the diagnosis of mental illness patient's relatives – often parents – must find themselves in a new situation and deal with a number of its consequences. Suddenly they become responsible for all the basic needs of the patient and have to provide him with accommodation, care, food and economic resources. In addition, they have to face often incomprehensible symptoms of the illness. Illness of a family member becomes their major financial burden. In this case, the family may experience strong feelings of fear, anger, frustration or shame [17, 18]. Stigmatization of the family may have its source in either a sense of shame for having an ill, “different” family member, or a sense of guilt and responsibility for his illness, or may be a result of labelling the whole family with a status of “mental illness” [18, 19]. Blaming the family (directly or indirectly) for the mental illness of their relative is still a potent source of stigma. The factors that contributed to this include already outdated concept of “schizophrenogenic mother” and the anti-psychiatry movement, which accused the parents of treating patients instrumentally. Parents may not only feel responsible for causing the child's illness, but also for inefficient help or for causing psychiatric hospitalization. The feeling of shame for mental illness of a family member coexists with a sense of injustice for social rejection. On the other hand, siblings and children – in the defence reaction – may reject and sneer at a mentally ill member of family [20]. The ambiance of the family has an effect on the healing process. It has been proved that the risk of recurrence of psychosis is lower when the family has friendly and empathetic approach to the patient [18]. Long-term care of the mentally ill, however, often result in the development of neurotic and depressive disorders [21]. Magaña et al. studied Latino families of the mentally ill, and found that 40% of the caregivers had depressive symptoms (≥ 16 points at CES-D score). In addition, the higher level of patients' mental illness symptoms was associated with greater severity of depressive symptoms in the closest caregiver [22]. It might seem that understanding of mental illness would reduce the negative consequences of stigma and would help to accept the existing situation. The study conducted by Hasson-Ohayon et al. showed that the greater insight into the illness had a family, the more stigma they experienced [23]. Angermeyer et al. reported that nearly two-thirds of surveyed caregivers (mothers of patients were the majority of them) had experienced stigma in interpersonal interactions (social exclusion, loss of friends, being ignored by the medical staff, being blamed by the others for the mental illness of a relative). The experience of structural discrimination by 27.7% of respondents was also an important factor contributing to the courtesy stigma [24]. The family feeling guilt and shame becomes more self-stigmatized, stops seeking professional help and becomes socially excluded. Zendjidjian and Caqueo-Urizar confirm that caregivers of people with mental disorders, in addition to complaints about the reduced quality of life, report the experiences of social isolation –simi-

larly to their mentally ill relatives [25, 26]. In the study conducted by Struening et al. 43% of caregivers thought that families of the mentally ill were devalued [27]. Loneliness of the families and the lack of psychological support make the family itself an insufficient support for the mentally ill. Failure of care may cause exacerbation of mental illness, and as a consequence lead to hospitalization or admission to social welfare centres [21].

Social functioning and discrimination

Chronically mentally ill patients often present the lack of autonomy and dependence on others, loss of social roles and no significant interpersonal relationships. Difficulties in social functioning may be associated with the course of the disease, may also result from stigma and discrimination experienced in everyday life. The social network of patients plays a crucial role in their proper social functioning. Greater social network and social support result in better insight into illness and higher subjective satisfaction with life and with treatment [28, 29]. Unfortunately, according to data obtained from environmental rehabilitation programs, the social network of the chronically mentally ill is very poor and mostly limited to closest family members and therapists and patients met at the rehabilitation centres. Least likely members of support systems are the neighbours, which only confirms the isolation of patients in their place of residence and shows reluctance of their closest environment [30]. Non-familial network is particularly important because its size positively correlates with less severe psychopathological symptoms and better outcomes in the social functioning [29, 31]. The difficulty in establishing and maintaining deeper emotional relationships keeps patients in isolation. Bronowski et al. studied the social functioning of chronically ill persons involved in environmental support programs. 75% of respondents were single and did not have regular partners. The dominance of passive leisure activities was pointed out (most of socio-cultural activities have been carried out in the community centres) which are not in favour of making personal contacts. The ability to communicate with people at “rather easy” level was confirmed by less than one third of patients [32]. On the other hand, social withdrawal of patients may be due to fear of rejection or condemnation [12, 14]. As public confidence in relation to the mentally ill is very poor, patients have very limited access to perform social roles and this further pushes them to the margins. Although the respondents surveyed by CBOS (Public Opinion Research Centre in Poland) would agree to have a mentally ill neighbour, they would protest against entrusting them socially responsible roles as teaching, child care, treatment, or acting as a deputy or mayor [4]. Although it was noted that the mentally ill are more often detained or arrested by the police than healthy controls, Steadman suggests that this may be due to excessive suspicion of public services directed against the patient [33]. In the study conducted by Schulze and Angermeyer patients admitted that sometimes they were unjustly accused of various offenses and crimes [34]. Their discrimination is also expressed in blocking the access to health facilities –psychiatric patients are often dismissed by staff and sent back to other centres. Somatic complaints reported

by patients are ignored and justified by the mental illness [34]. In some countries patients have limited civil rights in the areas of voting, parenting, remaining married and serving jury duty [35].

Professional functioning

Having a job has an important impact on the functioning in the society and determines independence of the individual. Having a job correlates with positive outcomes in terms of illness severity, quality of life, self-esteem and social functioning [36]. Most European studies reported that the employment rate for people with schizophrenia was between 10% and 20%. For example, in the UK the last decade of 20th century brought little change in this respect, in contrast to the increase in the employment rate in the general population and among people with physical disabilities [37]. The benefits for people with mental disorders account for 40% of all the benefits for people with disabilities [38]. The Polish study of people with schizophrenia, 15 years after the first hospitalization, found that adapting to work presents the biggest difficulty for them. 60% of patients in productive age did not work, only 28.2% of respondents worked, including only 17.6% on a full-time basis, 19% have not taken any job for 15 years [39]. Similar results were reported by Cechnicki. After 20 years of having schizophrenia 31% of respondents had jobs, but only 25% of the respondents worked in the open market [40]. Barriers to finding a job can be: disease deficits (cognitive impairment), negative symptoms (low levels of motivation and social skills, impaired task performance), the impact of symptoms on self-presentation, positive symptoms or side effects of pharmacotherapy. Social skills and cognitive functions are independent predictors of job functions, despite the existence of a strong relationship between them [41]. In literature it is noted that positive symptoms may not necessarily be a barrier to employment; it is likely that negative symptoms play a greater role (regardless of any connection with the psychotic process) [36]. There was a great disparity between the declared willingness to work and the real abilities of patients. In most studies, patients say they want to work [32, 36]. Schulze and Angermeyer say that for people with schizophrenia stigma is a major barrier to employment [34] and this was confirmed by the attitudes of employers [42]. People with mental illness experience numerous examples of discrimination at work. Many employers find them incapable of work [43]. The mentally ill have lower employment rates compared with somatic patients and healthy controls. It was found that they also have lower average wages compared to healthy subjects or patients with somatic disorders. These differences can only partly be explained by limitations in functioning resulting from the illness or medication. A study conducted in the U.S. shows, however, that a significant part of discriminatory attitudes of employers is related to the prejudice and stigmatization of the mentally ill, not from low efficiency of their work. Among the surveyed patients with anxiety, affective, adaptive and psychotic disorders, the latter ones had the lowest rates of employment and wages [44].

Having employment has both economic (a chance for financial independence and a way out of poverty) and psychological function for patients (provides the structure

and rhythm of the day, gives a sense of efficacy and favours development of social relations). Job is regarded both by the patients [45, 46], and physicians as an important factor contributing to recovery [47].

Structural Discrimination

On the way to recovery the patient should be supported by the appropriate organization of mental health care and by access to modern medical treatment. In this area, the mentally ill are clearly discriminated. Patients complain about the inefficient mental health care system and draw attention to the need to shift the burden of inpatient care for outpatient preventive measures [34]. In Poland there was great hope in the National Mental Health Programme (NPOZP). The report on the implementation of NPOZP in 2011 concluded that the involvement of most of the institutions in its realization is insignificant. Local governments entrust the tasks to incompetent people, convinced of the optional nature of NPOZP, focused on short-term remedial actions. Small financial commitment of the implementers cannot guarantee the proper introduction of the Programme and is an example of structural discrimination against the mentally ill [48]. Structural discrimination is also reflected by the distribution of system resources for mental health care. In Poland in 2010, the expenses for this purpose accounted for 3.29% of the entire health budget, which, in light of the increasing prevalence of mental illnesses, is a drop in the ocean [49]. For comparison, in Western European countries for the same purpose shall be allocated from 6% to 10% of the health budget. Undervalued pricing of mental health services, inadequate allocation of funds and restrictions on refund of psychotropic drugs directly affect the possibility of effective treatment of patients [49].

Recapitulation

For many years there has been a general opinion that the mentally ill are dangerous and should be avoided. Maintaining social distance towards them results in their low self-esteem. This leads to social withdrawal and reinforcement of already existing social isolation of patients. Under these conditions, the patient, unless he receives a comprehensive psychological support (in addition to adequate medical treatment), has little chance to develop faith in the possibility of recovery and full return to society. The closest family usually provides him with basic care. However, the family experiencing destructive influence of courtesy stigma is usually not able to offer more. It seems that the most important social factor determining the recovery is having job. Having a job, economic independence and daily opportunities for personal development are perceived, both by patients and by clinicians, as favourable on the way to recovery. In the literature, however, the attention is drawn to the low availability of professional activation programs, as well as the inefficient environmental model of mental health care, which would provide patients a better chance for social reintegration. A reason for this is the structural discrimination of mental health care, expressed in the chronic underfunding from the state budget.

Conclusions

1. A person with mental illness on the one hand should find the strength to fight the stigma, but on the other hand, can also internalize stigmatizing attitudes of the society. Self-stigma is a significant barrier in keeping and fulfilling social roles.
2. The family of the patient is often his only and crucial source of social support, on the other hand, the family may stay under the destructive influence of courtesy stigma. A family deprived of a comprehensive psychological support is often unable to be a sufficient support for the patient.
3. Social functioning of patient is limited (in addition to symptoms of the illness) by his poor social non-familial network and by social discrimination.
4. The most visible and impeding gaining the autonomy manifestation of stigmatization of the mentally ill is their unreasonably low position in the labour market.
5. Structural discrimination against the mentally ill is a barrier to recovery and a source of stigma. The current structure of mental health care and its chronic underfunding favours the persistence of stigma.

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