Bulletin of the *Transilvania* University of Braşov
Series VII: Social Sciences • Law • Vol. 18(67) No. 1 – 2025
https://doi.org/10.31926/but.ssl.2025.18.67.1.1

NAVIGATING STIGMA: VOICES OF INDIVIDUALS WITH SCHIZOPHRENIA

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Abstract: *Using interviews of six people diagnosed with paranoid schizophrenia, the study identifies how stigmatization is perceived at different levels by the respondents. Five themes are presented, focusing on public stigmatization, stigma within the healthcare system, in professional life, in close relationships, and self-stigmatization. Examples of participants' views are offered in order to understand their perspectives better and to plead for more education for the public and greater tolerance.*

Key words: *schizophrenia, stigmatization, mental health, qualitative research.*

1. Introduction

While individuals diagnosed with schizophrenia represent a numerical minority, psychological inquiry prioritizes their experiential realities over statistical representation. What is most salient is not their prevalence, but the pronounced risk of social stigmatization they endure as a result of being identified through the symptomatic markers of mental illness. Using stigma and discrimination are ancient habits, and their fundamental purpose remains the same from past to present: to avoid individuals considered dangerous. Thus, society categorizes what is different as something to be feared and either avoided or attacked. But is this fear justified, or is it simply a lack of information?

Part of the answer to this question lies in the perspective of those who are stigmatized, in their experiences with stigma. This study aims to explore the perspective of vulnerable populations, helping to understand the perspectives of patients with schizophrenia.

2. Literature Review

Schizophrenia, a severe chronic illness recognized under this name since 1908, did not achieve its status as a serious pathology due to high frequency but rather the opposite. With a lower prevalence compared to other mental illnesses, the severity of this condition lies in the symptoms that profoundly affect the quality of life as well as life expectancy. According to DSM-5 (American Psychiatric Association, 2013), the

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symptoms of schizophrenia include delusional ideas, hallucinations, or disorganized speech, and impaired relational skills. The average age of symptom onset is 25, with the first hospitalization occurring after the age of 32 (Carey, 2000).

Stigmatization is defined as a collective behavior manifested in social structures by devaluing a distinctive characteristic. Tajfel et al. (1971) explain this phenomenon as a cognitive consequence—a natural need to classify and understand the surrounding environment in the absence of other orienting indicators. Valery & Prouteau (2020) demonstrate in research on public stigma that schizophrenia is associated with the most negative mental representation. Public stigma and discrimination against individuals with schizophrenia occur through labeling them as different from the majority population, possessing undesirable, problematic, and blameworthy traits (Dickerson et al., 2002; Violeau et al., 2020).

In the general population, individuals suffering from this condition are perceived as incompetent, violent, and dangerous. Jankowski et al. (2023) cite alarming statistics indicating that between 1996 and 2018, in the United States, there was a 10% increase in the prevalence of the belief that patients diagnosed with schizophrenia pose a danger.

Zhang and collaborators (2021) identified six sources of stigma, namely physical, tribal, moral, servile, emotional, and associative. Regardless of the source, stigma produces negative consequences felt by individuals on personal, social, and professional levels.

An interesting perspective on stigmatization is offered by Bogart, Rosa, & Slepian (2018), who describe in their research the difference in stigma between cases where individuals were born with a pathology and those who developed a pathology later in life. A person born with a disability is more easily stigmatized by the population than someone who developed a disability over the course of their life. By extrapolation, this theory suggests that a person diagnosed with a condition like schizophrenia, which typically appears in adulthood but has significant genetic implications, is more often marginalized when individuals focus on the inherited gene. Conversely, they are more easily accepted by society when environmental influences are seen as the cause of illness.

Statistics indicate no differences in the desire for social distancing between the general population and medical staff when interacting with individuals diagnosed with schizophrenia. However, beliefs about danger, incompetence, and poor prognosis are not as intense among professionals as in the general population (Valery & Prouteau, 2020). Other studies have shown that individuals without pathologies may distance themselves from stigmatized individuals to avoid "contamination" (Zhang et al., 2021).

In a study aimed at analyzing the stigmatization of this pathology in Romanian media, Calo and Băban (2013) demonstrated that in over 80% of cases, crimes committed by a person with schizophrenia were presented to the public by emphasizing the individual's dangerousness.

Starting from the concept that not all stigmas have the same intensity, Zhang et al. (2021) conducted research in which they analyzed and included general characteristics influencing stigmatization and discrimination, regardless of the domain of manifestation. Disruptiveness, centrality, and lack of control over behaviors generate stronger stigma.

All the above suggest that patients with schizophrenia are at risk of being stigmatized with negative consequences on their social and psychological function.

3. Methods

3.1. Objectives

The main objective of this study, which is part of broader research on the impact of a schizophrenia diagnosis, is to identify the forms of stigmatization perceived by people with schizophrenia. As a result, we asked: How is social stigma perceived by people diagnosed with schizophrenia? while considering various contexts – within close relationships, the professional environment, medical services, and, more broadly, in society.

In this research, we used a qualitative design based on semi-structured interviews. This approach allows the collection of deep and detailed information, revealing a comprehensive perspective on the participants' experiences with stigmatization. The answers were analyzed using thematic analysis, information units relevant to the themes were extracted and coded. The researchers utilized deductive coding techniques while also adopting an inductive strategy by supplementing the subcategories after reviewing the raw data. As a result, descriptive codes (phrases, titles that describe the information) were generated for each selected unit of information. Five themes emerged, each with codes and subcodes, supported by quotes that reflect the respondents' perspectives.

3.2. Instrument and participants

The semi-structured in-depth interview method was chosen, as it provides the necessary flexibility for a thorough exploration of the participants' experiences and individual perceptions. It consisted of 17 questions and lasted approximately 30–60 minutes. During the interviews, topics such as personal experiences of stigma and rejection, barriers within the healthcare system, and strategies to combat stigma were addressed. For this article, we focus only on aspects highlighting the presence of stigma related to psychiatric diagnosis. Additionally, great attention was paid to non-verbal communication, noting participants' significant reactions. The participants were beneficiaries of a social services center, and the interviews were conducted in one of the center's rooms, in a safe, comfortable, and familiar space for the participants. It is also worth mentioning that the participants and the main interviewer had a trust-based relationship built over two years of weekly activities aimed at personal development, activities carried on voluntarily. All participants were informed about the purpose of the study, and they agreed to be interviewed, knowing that they could always withdraw from the study.

Participants’ selection was intentional based on the psychiatrist’s established schizophrenia diagnosis. Depending on the researcher’s prior experience with the beneficiaries, individuals with a higher level of functionality were chosen. The studied sample consisted of six people, five males and one female. Five of the six participants lived with their families, while one lived alone but maintained an active relationship with their family and received help when needed. Five participants were aged between 41 and 56, with one participant being 23 years old. The average age at the onset of the illness was 25 years. Only one respondent had higher education, which may be influenced by the late age at which the illness developed, being the only participant whose onset occurred after the age of 35.

4. Results

By analyzing the answers provided by the six participants, both similarities and differences can be observed in how they perceive stigmatization and in their experiences with this diagnosis. Five themes were identified in relation to stigma: broader social context, healthcare system, workplace, interpersonal relationships, and even the intrapersonal level. For each theme, there are categories illustrated with quotes.

4.1. Public stigma

Public stigma includes broad social interaction or interaction with people who are not acquaintances of the participant, exposing discrimination and abusive behavior.

Rejection

This category exclusively includes discriminatory behaviors experienced by participants from individuals with whom they had no prior relationship. It is important to emphasize that the "perpetrators" did not have detailed information about the victims of the stigma.

"I've been to institutions before. Once at the gas company, the guard there treated me poorly. Another time at City Hall. I went to submit documents for heating aid, and I didn't know which counter to go to. A security guard grabbed me by the arm like this (laughs) and pushed me a little."

One participant describes the view society holds about people with schizophrenia, stating that they are to be avoided and unpredictable: *"It's better to avoid us or that we are to be avoided because you never know what to expect from us."*

Labelling

The labels mentioned by the participants include insults they have experienced throughout their lives following the onset of their illness. *"There are expressions like 'leave him, he's in his own world'".*

Other mentions by participants include curses, avoidance behaviors, or even a sense of superiority. *"It seems to me that sometimes people put labels on us, labels like 'they're crazy,' or they curse you, or they ignore you. They avoid you or mock you—I don't know if I'm saying this right—they push you aside like that."* One participant pointed out that people are unaware that during treatment, the illness is under control. *"They know you're crazy, so to speak, insane—not that I have a diagnosis, and it doesn't manifest; they think I'm insane."*

Mass-media

"In the media, you hear all kinds of news about mentally ill patients, and they're not exactly pleasant."

One participant believes that mass media is responsible for social stigmatization. They argue that overly violent stories about people with schizophrenia contribute to spreading a negative perception among consumers of psychiatric services. The participant admits to having met offenders with mental health conditions in the hospital but emphasizes that not all patients can commit such acts, and even healthy individuals can carry out these actions. They recount their experience with television, where they were interviewed and the positive aspects of their life were not aired. Another participant expresses dissatisfaction with the absence of informative programs about mental illnesses, claiming that the topic is only brought up when presented negatively. *"They exaggerate in the media. Well, there's no debate on this topic, but when certain things happen, this stigma is attached, like 'they were mentally ill' and stuff like that."*

4.2. Stigmatization and discrimination in the health system

Discriminatory behaviors within the healthcare system can have significant negative consequences for beneficiaries. These behaviors may reduce access to quality care, negatively impact the psycho-emotional aspect of patients, and lead to treatment discontinuation. Two participants described aggressive behaviors within the hospital, with one participant specifically recounting severe physical abuse from staff responsible for ensuring the facility's security: *"….the stretcher-bearers, the security guards … some resort to beating because they don't know how to handle certain patients. It happened to me too; I was beaten maybe because I wasn't behaving well due to the symptoms."*

4.3. Stigma in relation with professional life

Getting and securing a job

For individuals with mental health conditions, the range of jobs they can apply for is reduced, which is due to the skills that deteriorate because of the symptoms of illness. The presence of stigmatization can significantly decrease the number of available positions for them.

"Well, I once wanted to get a job. There was a position at City Hall, actually several positions at City Hall, for people with disabilities. And when the lady in charge found out that I had a mental illness, she didn't know how to get rid of me. I insisted, I kept insisting, and I got hired. I worked for two days, then the lady came and said, 'Oh, well, we need to do some additional tests for you, but we don't have money for tests, and you can't work at City Hall anymore."

Regarding retaining employment, one participant shares their experience of losing his job after falling ill: *"I lost my job where I was, at the Local Police, City Hall, and Local Police. I had to retire...due to illness, and now I work only four hours a day."*

Another experience recounted by a participant highlights that, when staff layoffs occurred, the participant was dismissed in the first wave of layoffs: *"When layoffs were made, they told me, 'That's it, you no longer have a job; look for something else, I don't know.' They were harsher, less...understanding."*

Interaction with employers and co-workers

Regarding the relationships that the participants have or have had with colleagues or supervisors, experiences involving discrimination were present for two of the six respondents: "*There, where I worked, at the job. They found out about the illness and all, and it's like they were scared... they wouldn't let me do certain things, certain work tasks."*

4.4. Interpersonal relationships

Isolation

"I was withdrawn and fearful of everyone."

Various discriminatory experiences can lead to individuals isolating themselves, excluding themselves from social interactions, and thus experiencing profound negative effects on their emotional and mental well-being. As a defense mechanism, stigmatized individuals tend to reduce their social interactions out of fear of rejection. *"I had doubts because I didn't really interact with people, mostly just with family... I haven't been in a community of people to socialize or spend time with them in a long time; I'm a rather solitary person."*

Another participant spoke about losing friends. The participant explained that people began to avoid them after learning about their diagnosis, leading to their self-imposed isolation. *"Gradually, I had no friends left. And I shut myself off; my friends knew I was ill and started avoiding me. And I didn't have friends anymore."*

Rejection

This category includes accounts of both avoidant attitudes from those around the participants as well as potentially aggressive, discriminatory behaviors.

Four out of six participants reported experiences showing they were not accepted in social relationships over time due to their medical condition. The experiences vary, and regardless of the severity of actions, the impact also depends on the individual characteristics of each participant. *"Yes, I was badly insulted, and I told my father, 'Look, the neighbor next door spoke rudely to me, used vulgar language, insulted me.' She works as a vendor at a kiosk, and I bought something, and she gave me something else. When I told her she didn't give me what I needed, she cursed me out really badly."*

Another participant recounted an event that appeared to have significant emotional consequences. They spoke about a friend who rejected them after the illness, not believing them, and remembered a series of degrading words said by this friend: *"That my friend, my former friend, who I've now separated from, rejected me very harshly. How to say it, they misunderstood me deeply, and because of that, they made some very nasty conclusions. They didn't understand my illness well, didn't get it, thought I was a lazy good-for-nothing, that I couldn't make any progress, that I was just living on this earth for nothing."*

4.5. Self-stigmatization

During this study, participants disclosed self-stigmatization by underestimating themselves through behavior such as asking questions aimed at seeking confirmation from the interviewer: *"I don't know, did I go off-topic, maybe I'm just rambling?"*

Additionally, other mentioned negative self-perception: *"I was no longer seen in the same way, I no longer had that pleasure, that dignity,"* or mentioning physical complexes: *"Especially since I've also gone grey, and I have this eye that I can't see with anymore, I feel worse."*

5. Discussion

The present study aimed to identify types of stigmas that people with schizophrenia might experience. Public stigma and the implications of stigma in professional life exposed the media as promoting labeling people with mental disorders as unreliable and untrustworthy, displaying examples of avoidance in public spaces or within institutions. An alarming example uncovered discriminatory attitudes within state institutions. Such experiences can cause individuals suffering from mental illness to feel despair, a lack of support, and rejection from the society they live in. All stigma-related behaviors described by participants in this theme carry significant risks and implications for the psychological state and functionality of the individual. Participants' descriptions are in line with findings that society's image of schizophrenia is so distorted that this pathology is perceived as one of the most dangerous and unpredictable mental illnesses within the spectrum of 93 potentially stigmatizing conditions, including injectable substance abuse and a history of sexual abuse (Jankowski et al., 2023).

The second theme addressed was stigmatization within healthcare services. Dissatisfaction with Romania's healthcare system arose from experiences at healthcare facilities. Study respondents described brutal abuses within the hospital, aggressive behaviors from security staff. Violent acts can harm both the mental and physical health of psychiatric service beneficiaries. Hospitals need to promote a safe environment based on understanding, respect, empathy, and open communication. Otherwise, there is a risk of premature treatment abandonment, a fact confirmed by previous statistics according to which over 30% of patients diagnosed with schizophrenia do not benefit from mental health services due to fears stemming from stigma and discrimination (Jankowski et al., 2023).

Interpersonal relationships highlighted the discriminatory behavior that participants encountered in their interactions. Participants described multiple moments of rejection in close relationships due to their medical condition. The rejection they experienced from others promotes social and emotional withdrawal, which can have negative effects on the health of patients with schizophrenia.

Another category addressed was self-perception. For most participants, there were periods in which they could not accept their situation and engaged in self-stigmatization, as a consequence of social stigma (Valery & Prouteau, 2020). Negative feelings of shame, guilt, or inferiority, acquired because of stigmatization, can worsen psychiatric symptoms and lead to additional mental health problems, such as depression and anxiety (Degnan et al., 2021).

It is crucial to acknowledge certain limitations of this research. The main limitation arises from the small sample size. Additionally, the constraint to a single demographic region represents an obstacle to data generalization. Everyone's experiences are unique; those presented in this study may be specific to the selected sample. Another limitation is the lack of diagnostic diversity, as all study participants were diagnosed with paranoid schizophrenia. Participants may fail to recall, refuse to mention, or be influenced by the symptomatology of the illness by recounting certain experiences. Therefore, the results of this study should be treated with caution.

This research on stigma from the perspective of people with schizophrenia has highlighted both the complexity and severity of this phenomenon and underscored the fact that social stigma is far more devastating when viewed through the eyes of those stigmatized. The fear of discrimination and rejection by society drives them to isolation, to withdraw into groups exclusively made up of sick individuals who cannot judge them. All these factors make the lives of people diagnosed with schizophrenia harder, leading to a lower quality of life, worsening symptoms, and the loss of motivation to take treatment, be functional, and actively engage in society (Valery & Prouteau, 2020).

The results can serve as a valuable source of information for public education, as one of the positive endeavors necessary. Knowing the schizophrenic individuals' perspective helps to better understand and accept others. One sad finding of this study is that although the most common excuse for people who discriminate against mental illnesses is fear of individuals with pathologies, this research concludes that they are more afraid of us than we are of them.

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