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## Witnessing Life with Schizophrenia and Anosognosia: A Qualitative Research Study

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### Abstract

**Introduction:** Discharge of patients with schizophrenia from mental-health-hospital units without prior assessment of their competence to make informed medical decisions is a problem in the USA and beyond. Upon discharge, patients with schizophrenia and anosognosia are left on their own without capability to know that they have a disease that reduces brain tissue.

**Aim:** To identify what social workers have witnessed in terms of the living conditions and well being of those with untreated schizophrenia and signs of anosognosia.

**Method:** Narrative analysis with critical qualitative elements. The participants were social workers practicing in Ohio. Interview questions were asked to explore their experiences.

**Results:** This study found poor life conditions among this population, no evidence of assessment of the individual's capacity to make informed medical decisions, inconsistent follow-up in the community, and unlicensed personnel performing functions of case managers.

**Discussion:** Assessment to determine executive functioning and to rule out anosognosia is essential and ethical. In the event of psychosis with anosognosia, the most appropriate action is to include the family in the decision process.

**Implications for Practice:** Healthcare professionals must ensure that patients are assessed for anosognosia and executive functioning to ensure that patients have appropriate support system upon discharge.

**Keywords:** Schizophrenia; Human rights; Legal issues; Political issues; Families; Advocacy; Anosognosia

### Introduction

Reducing hospitalization for the mentally ill remains an important social and economic problem. Participation in community-mental-health centers lowered the number of hospitalizations by 82%, except in cases of schizophrenia and bipolar disease [1]. In those cases, patients' multiple re-hospitalizations are still, the reality. In cases of schizophrenia spectrum disorder, McQuade and Gromova [1] found 80% increase in re-hospitalization, compared to cases of major depressive disorders. One factor that might be leading to re-hospitalization is the lack of appropriate assessment for cognitive impairment prior to the patient's discharge from the hospital, especially assessment for anosognosia. Patients with schizophrenia and anosognosia have a delusion of health; they are sure that they do not have the mental illness. This cognitive impairment leads to refusal of treatment. Logically, persons who are sure of their own good health would not take medications to treat a disease that they do not have; as a result, the psychosis remains uncontrolled.

Patients' are being discharged from hospitals' mental-health units without prior assessment of their competence to make informed medical decisions is a problem in the USA and beyond. Emmett, Poole, Bond, and Hughes [2] found the same problem in the UK; health professionals claim to be familiar with the legal standards for assessment of capacity, but these standards are not followed routinely. Rosenbaum [3] alerted that psychiatrists' professional judgement leading to under treatment is arbitrary and could be considered negligence. Psychiatrists need to assess the competence of the individual to make informed medical decisions, specifically to rule out anosognosia, before honoring the patient's will. If anosognosia is verified through objective assessment, the next of kin should be contacted independently of consent and be involved in the decisions.

### OPEN ACCESS

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Schizophrenia causes a reduction in brain tissue and an increase in cerebral spinal fluid; these changes are worse in the frontal lobe [4]. The cerebral frontal lobe is the region responsible for high cognitive functions, such as inhibition, memories, problem solving, plans, emotional expression and communication [5]. The right frontotemporal hemisphere presents less volume than in the left hemisphere, which is consistent with cases of lack of awareness of illness (anosognosia) [6]. The changes in the brain of persons with untreated schizophrenia explain the substantial personality modification. The good news is that 80% of those treated with antipsychotic medication from the first episode of psychosis achieve remission [7]. Other type of medication may control the disease for the remaining 20% [7]. However, a definite factor leading to relapse and poor outcome on subsequent years is non-compliance with treatment [7]. Plasma level of antipsychotic was undetected or sub therapeutic in 34% of patients diagnosed with treatment resistance, suggesting the need for increased compliance with treatment and for plasma-level study before determination of medication resistance [8]. Quality of life for those with schizophrenia correlates to their adherence to medication [9]. However, approximately 60% of those suffering from schizophrenia lack the capability to know that they are ill [10], leading to treatment refusal.

Because poor insight may lead to a faulty self-evaluation of the living conditions of those with untreated schizophrenia, there is a need for an independent assessment. The purpose of this research study was to identify what social workers have witnessed in their practice regarding the living situation of individuals suffering from schizophrenia presenting anosognosia signs that refused or were non-compliant with medical treatment. This research study examined the social resources used by this population and whether their basic economic and non-economic needs were met. The significance of this research rests in the juncture where human rights, psychiatry, and law intersect. All these three areas must concur to ensure persons with schizophrenia presenting anosognosia have their needs met while living in the community.

## Theoretical Framework

The Social-Resources Theory was used as framework for this study. It was first developed by Uriel G. Foa in 1971 [11]. Resources are reserves available for social action. This study focused on resources considered indispensable for the survival and well-being of those experiencing psychosis while living in the community. Social-Resources Theory explores how individuals access social resources to meet their goals. On the other hand, personal resources (non-economical) are resources belonging to the individual, such as strength, health, and familial resources. Different groups have different access to capital resources. Social workers can determine if the resources available are enough to allow individuals with schizophrenia and signs of anosognosia to function independently as competent community members. This ability to function well in the community is impaired if either the economical or non-economical resources reach a level below the acceptable minimum for survival with dignity [12]. In such cases, the individual will require interventions that will help them secure appropriate resources. Structural constraints and social interaction dynamics may limit the capital of disadvantaged groups; finding ties outside that disadvantaged group generates better resources [13]. Familial ties are examples of strong personal resources. This type of ties has shown to increase schizophrenia treatment compliance in 82% (Amador & David, 1998).

## Methods

The method used for this study was narrative analysis with critical qualitative elements. Critical qualitative elements arise from the emphasis placed on human rights where disciplines intersect [14]. The innovation of this study consisted in the investigation of social conditions through the report from social workers working with persons with schizophrenia presenting signs of anosognosia in the course of their professional practice, instead of based on reports from those directly affected by the health issue. This specific aspect of the design was used to prevent interference from a cognitive impairment distorting reality, which is a common occurrence in schizophrenia. Studies that reported the views of those with a diagnosis of schizophrenia might not be accurate if the possibility that participants had impaired perception of reality was not ruled out through assessment.

Social workers practicing in Ohio were invited to participate in this study through email with a link to the interview questions. The data was collected in an online platform. Those who consented to participate were asked to write narratives following open-ended and targeted questions to explore their experiences. The interview was structured and conducted online. Text narrative was used as source of data.

The data was analyzed by direct approach to content analysis. The framework of the interview led to a prediction of the coding. Keywords throughout the text were identified and coded. The goal of the study was to capture the essence of what was perceived by social workers while working with families and with individuals suffering from schizophrenia with signs and symptoms of anosognosia who refused medical treatment or were non-compliant with it. Table 1 lists the interview prompts.

## Sample and Demographics

The method of sampling chosen was purposive. The participants were self-selected members of the Ohio Chapter of the National Association of Social Workers. The administration of the Chapter forwarded to the Chapter members the investigator's email containing the invitation to participate in the research study and a link to the interview prompts. The participants' characteristics were collected through a demographic questionnaire.

The results of the demographic questionnaire revealed that the participants were active in the profession, representing eight Ohio counties in the USA: Cuyahoga, Muskingum, Coshocton, Wood, Clermont, Butler, Hamilton and Ashtabula, totaling 22 participants. It was not possible to determine the number of participants who actually received the email, declined to participate, or dropped out of the study because the only existent records were from those who submitted their responses. The theoretical point of saturation was achieved; that was the point where no new information was introduced. Gathering examples from interviewees' written narratives was the method used to establish the trustworthiness of the study. The demographics collected revealed that 83% of the respondents had a master's degree; the remaining had a baccalaureate degree. Fifty-six percent were licensed-independent social workers. Seventy percent of the respondents had five years of recent experience or more. The study did not include inquiries about age, ethnicity and gender.

## Ethical Considerations

Cleveland State University Institutional Review Board in Ohio,

**Table 1:** Interview Prompts.

•	What is the quality of life (living conditions, health, family situation, etc.) of those with untreated schizophrenia or who were non-compliant with treatment?
•	Are specific tests used to determine the competence of clients with schizophrenia who refuse treatment?
•	Is the family called to be in the hospital at the time the patient is discharged from the locked unit even in the absence of patient consent?
•	Do social workers follow up on the discharged patient to assess life conditions, ability to use money and provide for oneself. If yes, what is the procedure? If not, are there any risks for the mentally-ill persons to be left on their own?
•	How could you assist the family in their wish to help the person with untreated schizophrenia to improve the client outcome?
•	Do social workers provide education, support, and/or guidance to the family of the client with untreated schizophrenia on how to cope with the situation?
•	Are case managers parts of the healthcare team? Explain the difference between your services and the case managers' services.
•	Are there obstacles to providing the services you consider most appropriate and beneficial for your client?
•	Do you monitor the status of your clients to ensure that their basic needs are met?
•	Include important issues not addressed in the other items.

USA, approved this project. Informed consent was obtained from the participants. The participants' individual identifiable information that could connect them to the text narrative was not collected. The investigator did not establish any relationship with the participants prior to conducting the study and did not know who they were or what they knew about the researcher because the study was anonymous. Participants could skip questions that they did not want to answer or did not apply to them and withdraw at any time before submitting their answers by closing their computer browser.

## Data

The narratives were collected online. There was neither an interviewer nor facilitator; there were just impersonal online questions. This innovative system was used to prevent bias, assumptions, and other types of interference. There is not a way to know if there was anyone else present at the time the participants were responding to the prompts (Table 1). There were not field notes per se; the participants wrote their own notes or answers. No audio or video recording was used. The responses were not timed. There was only one questionnaire; no repeated interviews were carried out. This study was not piloted beforehand. Because the participants typed their own responses, transcripts for comments were not considered. Through open-ended questions, participants had opportunity to offer meaningful responses. The researcher was the only data coder. The coding was non-hierarchical; there were not sub-code levels.

## Results

Three themes were identified prior to data collection: life situation, assessment of ability to make informed medical decisions and patient follow-up in the community. Two other themes derived from the data: difference between case managers and care managers and unmet expectations. The results demonstrated consistency with the data. Qualtrics was the software used for data collection and management.

### Life situation

Most of the respondents (89%) described the quality of life of people suffering from schizophrenia with signs of anosognosia as poor. The exception was in cases where the family supervised the person with the illness. The following themes developed as possible factors leading to poor quality of life: lack of medication-management skills, non-compliance with treatment, limited housing options or homelessness, lack of family support, stress, declining health, and hopelessness. Two representative statements from different participants were:

*Participant #7: I worked with clients who suffered from*

*schizophrenia while working at a community mental health center doing case management and intake assessments. Those clients who were not taking their medication often had very chaotic lives and living situations. Often, they had unstable living situations and strained family relationships. They often were not very physically health conscious (smoking, poor diet, etc.).*

*Participant #18: The experience I have is working specifically with the veteran population and child welfare. On the child welfare end, we had many cases of neglect and abuse among this group. The homes were often cluttered and in disarray. Very few took care of their physical health. Many family members who had a long history with the schizophrenic family member rarely intervened because they did not want to deal with the consequences of the erratic behavior. Just to keep the peace, they said, and did hardly anything to assist with parenting. With veterans, I am seeing a history of homelessness. Both groups are either underemployed, unemployed, on or seeking assistance from the county (cash, medical and food assistance) or social security disability from the federal government. Family involvement is almost non-existent due to burning bridges for various reasons.*

### Assessment of ability to make informed medical decisions

The second topic referred to the assessment of the individual's ability to make informed medical decisions regarding one's own brain disease. Except for two participants, who mentioned cases of forensic evaluation in criminal court cases, the participants were not aware of any assessment or test applied to clients to determine the competence or capability of persons with schizophrenia to make informed medical decisions regarding their illness. Two illustrative statements follow.

*Participant #16: The only time it [ability to make informed medical decisions regarding treatment for mental illness] appears to be assessed is if they are having a psychotic episode and are involuntarily held at a psychiatric hospital. If they are oriented to person, place, time and situation, they are usually declared competent enough and no further tests or evaluations are conducted.*

*Participant #11: Regarding making medical decisions, this is a sticky area. Many of the consumers that we serve have no advance directive for health care, which is very disheartening. It places the consumer at a very unfair position in relation to autonomy. They have the right to refuse any services, but this means that they will not be able to receive assistance.*

### Patient follow-up in the community

The third topic was on following up the discharged patient to



evaluate this person's life conditions, ability to manage money, and ability to provide for oneself. Some of the issues reported by the participants were lack of effective discharge follow-up of patients, unlicensed care managers performing the role of case managers, and persons with serious mental health issues living in the community without a support system. Three representative statements by different participants are reproduced. The third one refers to an intervention, which has not been used widely.

*Participant #6: In my recent experience, an older adult man who was depressed (lived alone, was admitted to a local inpatient unit, and later discharged) was not followed up by anyone from the hospital or the local mental health center where he had an appointment set up. He simply did not attend that follow up appointment, and that was where it was left, unfortunately. I felt like he had fallen through the cracks.*

*Participant #17: Often those with schizophrenia do not want to sign releases of information for outside agencies. This makes it difficult to get some needs met.*

*Participant #8: A lot of the time, it is frustrating that we see patients cycling into the hospital many consecutive times. It is so clear that we are not able to give them follow-up resources that will be actually helpful or usable for them [...].*

*Participant # 3: Hospital social workers, in my 21 years of experience, do not follow up on the discharged clients. That is why connecting with the client's outpatient workers are so crucial to helping the client be successful. There are many risks for mentally-ill clients to be left to themselves. They often revert right back to the downswing that landed them in the hospital.*

### **Difference between case managers and care managers**

The fourth topic emphasizes the interchangeability of the following two terms: case managers and care managers. The following participants' statements help to clarify the use of both terms. First, three selected statements illustrating the role of the case manager are included below.

*Participant #4: Case managers are often the most important part of the team. They are the ones who work in the community with the client and are often able to connect with family members and help clients build support. I work as a team with case managers to provide wraparound care to clients and families. I direct the treatment, and case managers implement much of the treatment. They coach the clients in daily living situations.*

*Participant #4: Case managers assist with money management, helping connect the client with other programs and services, finding housing, and teach/coach daily living skills. We have had case managers take clients to meet with landlords, coaching them how to interact with them. They have taken them to food banks and helped them learn to use public transportation. They have worked in the homes on behavior management.*

*Participant # 17: I am a housing LISW-S case manager. I provide housing support, transportation, referrals for payees or fiduciaries, referrals to community providers for utility, food, and rent assistance. I deal directly with the housing authority and landlord. I see my clients at minimum monthly or based on acuity. Hands-on budgeting assistance is something I would like to provide in the future.*

The next two statements reveal the role of care managers and the corresponding issues.

*Participant 10: Unfortunately, many times, different agencies forward the case to a care manager. Many of them are not social workers and, even more disturbing, they have no license. People still think that care managers are social workers [...] many are not! They are not properly educated as a licensed social worker [...]. This only further hurts any mental health consumer because of severe lack of appropriate care once the consumer has been discharged from a hospital setting.*

*Participant 11: I have observed the care managers here at this agency, they are not well educated on mental health and many are not licensed, many don't even have a degree. This is my honest answer; it puts the consumer at a total disadvantage. It is also not helpful for the consumers' mental health needs or stability.*

### **Unmet expectations**

The fifth and last topic alerts to unmet expectations and difficult circumstances, such as the impact of the schizophrenia symptoms on children living with parents who have the disease.

*Participant #6: Stated: "Often times, families wish that doctors, professionals, courts, etc. could do more to assist them with their loved one's situation".*

## **Discussion**

### **Poor living conditions and wellness**

While studies conducted in various countries that investigated the subjective views of individuals with schizophrenia revealed that they were satisfied with their quality of life in the community, still, there are many basic needs that have not been met [15-18]. The present study confirmed the findings of Chia-Huei, and Chin-Yu [19]: those living with schizophrenia have poor quality of life. McCreadie [20] studied a factor that has affected the health and quality of life of patients with schizophrenia, meaning their dietary habits. The results showed that patients with schizophrenia make poor dietary choices, even worse choices than those made by the poorest members of the general population [20]. The life expectancy for persons with schizophrenia is 20 years less than that for the general population [21]. The Schizophrenia Commission [22] was established in England to study the situation of schizophrenia. The Commission [22] used the word "scandal," referring to the poor physical health of those with severe mental illness and "shameful," referring to the poor quality of care available to those with schizophrenia, especially considering the recent scientific advancements. The situation is not better in the USA for those with schizophrenia and anosognosia. The present study confirmed the findings of those studies regarding the poor health situation of this population.

The participants of this study brought up issues regarding healthcare providers' conformity with the desire of the patients to refuse treatment without assessing their capability to make healthcare decisions regarding their mental illness. Anosognosia prevents those patients from recognizing their own illness and their need for medical treatment, rendering them unable to be considered informed. The delusion interferes with the person's ability to process the information provided by the psychiatrists and other healthcare professionals. Unawareness of the disease is common in schizophrenia and in other diseases involving the right hemisphere brain volume reduction [6]. The exercise of autonomy to make informed medical decisions is directly dependent on the mental capability to make those decisions. Therefore, the most appropriate action in cases of anosognosia would be to contact a family member and allow this person to participate in

the medical decisions if existence of a medical power of attorney is unknown.

The present study revealed that many individuals living with schizophrenia and anosognosia who refused or were non-compliant with treatment were struggling to obtain the basics in life. Most had modest financial resources and, many times, were unable to hold a job, manage their money and medications in addition to dealing with stress, hopelessness, and impulsiveness. These factors add to the suffering of those experiencing such a serious and debilitating disease. The more advanced the disease process, the poorer the quality of life of those living with schizophrenia [23,24].

England's expenditures with schizophrenia reach £11.8 billion per year [22]. In the USA, the direct cost is \$16.3 billion [25,26]. The indirect costs of schizophrenia could arrive at double that amount, which includes social services agencies, housing, criminal justice system, and so on, while expenditures with treatment are reasonable, about four-to-six percent of the direct cost specified above [27]. A cost-effective, lawful, and humane recommendation is to ensure that assessment to determine whether the patient has the capability to make informed medical decisions is conducted (to rule out anosognosia), and that healthcare professionals have knowledge of applicable laws regarding limited competence (to properly deal with cases of anosognosia). Limited competence in cases of anosognosia means that a person may have legal competence to practice all acts of daily life except those related to the delusion of health. Those persons need to have a guardian with limited powers to participate in medical decisions, usually the next of kin. Limited guardianship is a legal resource available in all states in the USA except in Mississippi [28].

### Timing of care and family involvement

The American Health Insurance Portability and Accountability Act (HIPAA) is the law that regulates the release of medical information. This law has an exception to the non-disclosure of protected health information that applies to cases of schizophrenia with anosognosia: when the disclosure of private information prevents or lessens a serious threat to health or safety [29]. This exception applies to this population because the delay in the treatment of schizophrenia has a harmful effect in the brain tissue and cognitive functioning of the person [30]. The short time between a first episode of psychosis and the administration of antipsychotic medication has been widely recognized in the scientific literature as essential for best outcomes and preservation of the cognitive function of patients with schizophrenia [31-35].

Health professionals too often accept as valid the decision to decline treatment from a cognitively-impaired person who cannot recognize his or her own disease (anosognosia). Such acceptance places this person at an unfair position, as participant #7 asserted. Every nurse and physician has the responsibility to ensure that the patient has competence to make informed medical decisions. The Teach Back method has been used in most inpatient hospital units. This method has shown improvement in self care and reduction in hospital readmission, promoting understanding of the disease process and treatment adherence [36]. Although this method is not specifically for competence assessment, it facilitates the identification of the problem by pointing to the need for focused assessment. Under the Teach-Back method, a person who believes to be healthy while having a serious chronic disease would not be discharged home to live independently. Before the discharge, a responsible person (usually, the next of kin) would have to be contacted and educated on the

disease and on the care that the person would need at home. It is equally important to include anosognosia assessment in psychiatric areas, using a valid and reliable method (e.g., [37]) to ensure the patient is aware of the disease and its effects in the brain. Further, the alienation of the family based on the inaccurate understanding of patient privacy and autonomy and, ultimately, the withholding of treatment from this vulnerable population without appropriate consent could be classified as social-structural violence because current policies supporting these actions go against the law. Further, those actions could be considered malpractice and abuse.

### Patient discharge from hospital to the community

The participants in this study revealed the problems that have resulted from the discharge of adult patients with schizophrenia and signs of anosognosia from an acute locked unit to the community. Hospitals' psychiatric units have included the patient's family during the discharge, even without the patient's consent, but have failed to provide the family with information on the patient's situation.

Discharging a patient in the company of the family without providing caregivers information and education about the diagnoses, treatment, consequences from lack of treatment, risks, and resources places both family and patient at risk for harm. The caregiver has right to know especially if the patient is non-compliant with recommended treatment. A high percentage of persons with schizophrenia and low compliance with antipsychotic medication that live with parents commit parricide [38]. Common risk factors for parricide include self-imposed isolation in the home, depression, and prior violence against the parent [38,39]. Without any information about the patient's status, the family might be misled to think that the condition of the patient is not serious, and that there are not safety risks to consider before taking the patient home. This could be considered reckless endangerment of the family because healthcare providers' action could be considered as culpable disregard of foreseeable consequences [40-42].

Further, ensuring the patient's wellbeing and capability to perform activities of the daily living independently is essential to life in the community. The ability to plan, for example, is crucial in daily living, such as creating a budget and managing money, planning for obtaining meals or cooking, obtaining medication before running out of it, and planning for going to follow-up appointments. It is common for persons with schizophrenia to be unable to plan even simple things, such as plan to wear appropriate clothes for the weather condition. They may wear a coat on a summer day, which leads to dehydration, or wear a short-sleeve t-shirt on a freezing winter day. This difficulty with planning may occur because the disease affects the lateral prefrontal cortex, which is involved mainly in higher executive functions [5]. The patient's ability to plan and follow-through with daily activities must be tested as part of an evaluation of the patient's readiness for discharge to the community with appropriate support system and resources.

### Unlicensed workers in Ohio, USA

Participants expressed dissatisfaction regarding personnel with insufficient qualifications performing many of the functions of licensed case managers under the title of care managers. Because some unlicensed workers (care managers) are performing the function of social workers or nurses (case managers), patients may not receive adequate services. Patients and families may be misled in believing that the patients' care is being managed by a Registered Nurse or a Social Worker. The mentally-ill population is a vulnerable population

in the community and should be receiving, always, proper services from licensed personnel.

## Conclusion

Social workers provide services in the community to persons with schizophrenia. Therefore, they can report on the living conditions of those who live in the community with untreated schizophrenia, their wellbeing, whether their basic needs have been met, and whether their dignity has been maintained. Schizophrenia is a chronic illness, which can be controlled with proper treatment early in the disease process but does not heal when left on its own. Schizophrenia affects the brain by reducing brain tissue and should not be taken lightly.

This study confirmed the findings in McQuade and Gromova [1], showing the reduced effectiveness of community-mental-health clinics in cases of schizophrenia. The results pointed to factors that possibly have led to this low effectiveness, such as the patient's lack of treatment or less-than-the-expected compliance with the treatment, improper discharge from the hospital, and faulty patient follow-up in the community.

Study participants expounded on the chaotic living conditions of those with schizophrenia who are not consistent or refuse the treatment and their struggle to obtain the basics in life. In cases of anosognosia, the patients cannot recognize the disease in themselves (delusion of health), leading to refusal of treatment. Social workers reported on how families would like more to be done for their loved ones than it has been done. In many cases, this disease could be alleviated by proper treatment delivered in fulfillment of legal and ethical principles. Because of the severity of the diagnosis of schizophrenia and the possibility of anosognosia, psychiatrists should perform a focused assessment if the patient refuses treatment to determine the patients' competence to make informed medical decisions. Leaving persons with anosognosia and untreated psychosis on their own in the community is a social-structural violence. This action submits this population to unnecessary hardship and inflicts severe emotional distress in the family. This is the time and it is our duty to do more than it has been done for those suffering from schizophrenia and anosognosia. The reconciliation of psychiatry with the law is fundamental to the improvement of the life conditions of those suffering from this serious neurodevelopmental brain disease.

## Disclaimer

The opinions contained in this article are the author's own and do not reflect the view of this journal.

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