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# Existential questions in schizophrenia: perception of patients and caregivers

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## ABSTRACT

**OBJECTIVE:** To examine existential questions in the daily life of people with schizophrenia and their caregivers.

**METHODS:** Qualitative study with focus groups. 146 people with schizophrenia (55% men) and 80 caregivers (75% women) participated. They came predominantly from primary and secondary health services of Argentina, Brazil, Chile, Spain, England and Venezuela. Each group had between six and ten participants. The data was explored through a content analysis process.

**RESULTS:** Four omnipresent existential themes were identified from the discussions: the need for personal development and to find meaning in life; the need to be respected and not suffer discrimination or stigma; the conflict resulting from the loss of autonomy; the importance of understanding the illness and recognizing it as an illness. The existential questions were closely associated with objective needs, such as the lack of occupational opportunities and employment, which generally result in a life without meaning.

**CONCLUSIONS:** It is necessary to develop a new type of health care in which both the consideration for the person with schizophrenia and their subjectivity are as important as biological treatment. Health promotion strategies need to combat stigma and use mechanisms of occupational inclusion.

**DESCRIPTORS:** Schizophrenia. Schizophrenic Psychology. Health Knowledge, Attitudes, Practice. Existentialism. Qualitative Research.

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## INTRODUCTION

Although new research streams have added to the growing knowledge about mental health, the cure and normalization model continues to predominate. Psychopharmacological treatment, a paradigm of this model, has undoubtedly supported the development of improved health status, especially since the middle of the 20th century.<sup>7</sup> Nonetheless, this is insufficient, especially for populations that suffer severe functional incapacities such as schizophrenia. In addition to requiring diagnosis and appropriate pharmaceuticals, these individuals need to understand and manage the suffering caused by the illness.

Mental disorders such as schizophrenia limit social life and negatively impact self-esteem. Isolation, loneliness, anxiety, sense of emptiness and difficulties to find and maintain employment are almost constant themes. It is very difficult for patients to face the stigma that imposes daily constraints of all kinds and limits their social and employment lives.<sup>23</sup>

What should the patient do to manage these problems? How do they understand their existence as a person with a chronic illness that causes dramatic

life changes and for which there is no cure? Where can they find space to discuss their anxieties, since the health system does not commonly listen to them? Health professionals are not accustomed to thinking that people with schizophrenia have other demands besides psychotic symptoms. Van Meer<sup>23</sup> (2003) reports that patients frequently want to discuss subjective experiences with their doctors, but doctors consider such issues irrelevant.

In the 1960s, Fromm<sup>6</sup> (1966) described a crisis in traditional science. It became dehumanized, more concerned in the classification and control of individuals. Before Fromm, in the 19th century, Kierkegaard<sup>10</sup> (2003) already questioned the pretense of science in supposing that reality can be condensed and completely explained by concrete systems and frameworks. Kierkegaard argued that a system is incapable of accounting for human reality, since individuals are singular and have very particular differences and existences.

This article aimed to describe the subjectivity that makes each person with schizophrenia a singular being. In this sense, the study attempted to listen to what is usually ignored or forgotten: the existential themes and issues in the daily life of people with schizophrenia and their caretakers.

## METHODS

Focus groups were used to gather qualitative data. The participants had the following characteristics:

1. People with schizophrenia and other psychotic disorders with long evolution (F20-29), according to the International Classification of Diseases;<sup>14</sup> from both sexes; older than 15 years; and without hospitalization in the last three years - at least 60% of this time - due to mental health reasons, with good capacity for self-expression.
2. Informal caregivers: individuals connected to the patient; recognized by both the patient and themselves as the primary caregiver; and without formal contracts as a caregiver.

The participants were predominately from primary and secondary public health care services from the following cities: Buenos Aires, Rosario and La Plata (Argentina); Caracas (Venezuela); Concepción (Chile); Granada (Spain); London (England) and Porto Alegre (Brazil). The study concluded in November of 2005.

At each site, four focus groups of people with schizophrenia and two of informal caregivers were held. Each group had between six to ten participants. In total, 146 patients with schizophrenia (55% men) and 80 caretakers (75% women) participated. Mental health experts were trained to lead focus groups. A thematic

guide assisted the coordinator to guide the discussion. The discussions were taped and later transcribed.

Data were explored through a content analysis process.<sup>4</sup> To increase reliability, some parts of the transcripts were individually coded by different team members and subsequently compared. Discrepancies in coding were discussed and resolved through consensus. The process of coding data was performed with the program, Qualitative Solutions and Research – Non-numerical Unstructured Data Indexing (QSR NUD\*IST 4.0).<sup>18</sup> The dominant themes in the discussions lead to the categories analyzed.

The project was approved by the Research and Ethics Committee of the Hospital Materno-infantil Presidente Vargas, Porto Alegre Municipal Health Department (Process number 05-02, 3 April 2002).

## ANALYSIS OF RESULTS AND DISCUSSION

### Need for personal development

This category is related to the search for meaning in existence. It is strongly linked to the employment issue and ability to be productive. Due to the symptoms or the stigma, difficulty in finding work is almost a rule for people with schizophrenia. Without performing an occupational activity, these people experience a sense of uselessness, feel unproductive, dependent and therefore inferior to others.

*I would like to earn a good salary, have a home, children... but I am always tired, without energy to work... if I did not have this illness, I could be a doctor... (Man with schizophrenia, Brazil).*

Many participants reported experiencing immense disillusionment due to the realization that all their childhood friends have an organized life, employment, a partner and children, while they have no significant accomplishments.

*My mother used to tell me “when your father and I are dead you will wait for your siblings with lunch, with clothes, in an organized home”... Then that was the last thing I wanted, learn how to cook and wait for my siblings for when they arrive from work!... How so? Because I have schizophrenia I will have to stay put in the house, by myself, without children. (Woman with schizophrenia, Chile).*

For some participants, a possible solution for these problems would be the availability of occupational therapeutic resources. In Latin America especially, there is a marked deficiency in this type of service. Performance of occupational activities decreases the sense of emptiness, increases self-esteem and contributes to treatment adherence. Nonetheless, even in contexts where such

resources are available, some participants questioned if people that enroll in the activity would have anywhere to apply the knowledge gained, since there is a lack of work opportunities.

*...it is a shame I do not have a job. I do have the assistance, but my job ended... it is not the same... my studies are over, they are over...* (Man with schizophrenia, Argentina).

Frankl<sup>5</sup> (1978), when reflecting upon people who did and did not survive following the Second World War, concluded that people with projects they felt necessary, appeared to have improved chances of survival than those who lost meaning in life. Frankl was convinced that if someone does not have reason to live, the person tends to give up on life even if his or her other needs are satisfied. This theory helps us to understand why suicide is so common among people with schizophrenia.<sup>20</sup> The employment issue is central to understanding this problem. The majority of participants do not perform a formal or informal job, independent of socioeconomic context. This has a dramatic impact on self-esteem.

*The main motive that maintains may day to day is to do something with my time. If you have structure in your day, you're not worried, but if you reach a point where you stop and do not know what to do, it can leave you vulnerable.* (Man with schizophrenia, England)

This is the reason for including mechanisms for employment inclusion in any health care strategy that seeks to improve the lives of people with schizophrenia. Without such mechanisms, it is probable that patients follow a pattern of social exclusion, including marginalization in many contexts.

### **Discrimination and the need for respect**

The existential anxiety present in discussions of participants with schizophrenia is in part explained by the reality to which they are submitted. In addition to facing all sorts of adversity, there are emotional consequences to having such a highly stigmatized illness.

*... the difficulty is revealed when they ask my daughter "what do you do with your life?", "with what do you work?". How can someone respond? Naturally, the tendency is to hide the real situation or what you desire, due to shame.* (Caregiver, England)

The behavior of the patient following the outbreak is often difficult to understand for people that live with them. Problems with lack of motivation are interpreted as laziness. In some sites, bizarre behavior is understood as a manifestation of evil. The sick person is often seen as potentially violent.

*If I tell a neighbor that I have this illness, they would tell me: "this child is crazy" and reject me or feel bad*

*for me... and I don't want anybody to feel bad for me... I prefer that somebody hates me but don't feel sorry for me...* (Women with schizophrenia, Chile)

It is also common that the family is embarrassed to have a special member. Many families feel like victims of a cruel destiny. Abandonment can occur. In Argentina and Venezuela, institutionalization still happens. In England a large part of people with schizophrenia live in protected apartments.

*She is our only daughter and we have a long marriage. We were unlucky.* (Caretaker, Argentina)

Stigma is one of the most important obstacles to the personal development of people with mental illness.<sup>21</sup> Difficulties to find work, maintain affectionate relationships, to share housing and rejection and fear by the community are common aspects of life for those who suffer stigma. The word schizophrenia is constantly used in the mass media as a metaphor for negative personal character.<sup>2</sup> Even child television programs have references about mental illness, the majority of a disdainful nature, which can contribute to the development of segregation behavior in young viewers.<sup>25</sup>

In our study, participants from Latin American countries also considered inadequate investment in health services by political bodies as an expression of stigma, especially the low availability of professionals, consultations and pharmacists.

*...I speak openly about what I have... because I consider it an obligation to myself, and it is an obligation given the situation in this country. Because they do not give us the level of care that they provide to a person with a kidney illness... For them dialysis is never unavailable.* (Woman with schizophrenia, Venezuela)

Stigma causes existential suffering and has a negative impact on self-esteem. It is a vicious cycle, since low self-esteem is probably connected to worse health status.<sup>12</sup> Studies indicate that patients who report feeling more stigmatized have more severe symptoms and are in a worse condition.<sup>3</sup>

*Depression, anxiety, pain, discrimination, does not only come from family members; it is more from friends and acquaintances or strangers. One person feels dependent, one does not have a way to go out, one has a blocked mind, it is a very terrible thing.* (Man with schizophrenia, Brazil)

### **Autonomy**

Autonomy is related to the possibility of independence, not being subject to somebody else's will. In addition, we can include the subjective sense of satisfaction from an individual feeling a reasonable amount of internal coherence. People with schizophrenia generally

have problems with autonomy. At least when they are symptomatic, they are constrained by the illness and have difficulty rationalizing and making decisions that are good for themselves and others. Even when stable, they may remain limited by the demands of treatment.

The caretaker becomes the main support for the maintenance of these people's lives. In Latin American countries, it is the families, especially mothers that assume this responsibility. In England, public services, represented by health and social professionals, usually perform this task.

*I feel that something that would really improve my quality of life would be to make me more responsible for my issues and to not depend so much on the judgment of my caretakers for what is or is not good for me... I need to finally resolve this in order to be an adult again. I feel that having been in the mental health system has kept me in a child's role.* (Man with schizophrenia, England)

Some schizophrenic participants in Latin American countries protested that they, if allowed, they could adequately to respond to a series of situations, but they are considered incapable. They accused the caretakers of not allowing them to perform such easy tasks as taking care of their own food. People do not trust their abilities, and therefore they are not stimulated and end up worsening.

On the other hand, while they regret not having freedom to make their own decisions, many patients also reported feeling incapable and unmotivated to perform them. Also, while a large part of caretakers thought their children were too dependent, they did not stimulate them to develop their abilities for daily life. This uncertainty reflects the insecurity patients experience. Protective behaviors by both sides limit the exercise of autonomy.

*People believe they are not capable. In my case I am overprotective... I say do this and that and... In the afternoon, my son stays alone since I work and then he becomes motivated, makes his milk, bathes; on the other hand I am on top of him "come, put your jacket on, do not go out"... I want to manage him as if he was still a baby. I lack confidence that he can.* (Caretaker, Argentina)

The problem related to the autonomy of patients with chronic mental health disorders is even more complicated under current circumstances. In the developed countries and the large urban centers, family support is decreasing. In addition, there is great emphasis on the individual and their material attainment. These are ideals that people with schizophrenia generally cannot meet. In schizophrenia, the patient loses the internal ability to perform the roles that society demands. This may be a reason that the evolution of schizophrenia is apparently better in less fortunate sociocultural contexts.<sup>9</sup> In these contexts there is more emphasis on

the collective and less on individuals. This may result in less existential suffering, since it reduces the social pressure to become "successful" and "normal".

Our findings also suggest that reduced capacity to manage life leads many schizophrenic patients to be unable to manage their treatment and identify their mental and physical problems. This can contribute to deteriorated health. Studies show that schizophrenic patients experience increased morbidity and mortality associated to an array of medical illness, which reinforces the hypothesis.<sup>15</sup>

To respond to this problem, professionals should have a preventive perspective in terms of anticipating this complaint (which often comes late in this population). According to the study participants, health services often view people with schizophrenia as frequently under psychosis: the patient and the illness are conflated. In result, there is no space for needs that are not objective and unrelated to psychotic symptoms. It is common that providers do not even listen to these symptoms. The subjectivity of the patient has traditionally been repressed from health care.

*There is a real need for more creative approximation and acceptance and to listen to the individual. Schizophrenia has various manifestations. Professionals should address this issue... The first thing they ask me is "Do you want to commit suicide? Do you think people hate you?" and such things. Until we are that level, we do not make any progress.* (Man with schizophrenia, England)

The patient ends up divided, not seen as a whole but only through their individual parts. Professionals assume responsibility for "urgent" issues (the symptoms), while they ignore subjectivity or attribute it to others (religious and societal, among others). This is also a protective measure. When we transform the illness into an object (the body, the symptoms), we decrease our responsibility and restrict demand. In a certain sense dehumanization is a way to protect ourselves from the burden of being a caregiver. This mechanism can be negative for patients, as the patients in our study attest.

Humanized care, on the other hand, has a different effect. Patients with schizophrenia that receive care where conversation and listening are prioritized improve their quality of life.<sup>17</sup> Also, the active participation of the patient in their own treatment appears to improve self-esteem and overall health.<sup>8</sup>

### **Being conscience of the illness**

Being conscience of the illness involves understanding your own functioning, to know yourself. In populations with schizophrenia this process is complex. Since society has prejudice against the disease, it involves significant

pain to admit that you have it. Family members even feel shame and blame, which can lead to denial.

*I lost my memory, job and developed schizophrenia. I never wanted to see a doctor because I did not want to admit that I had developed schizophrenia (Man with schizophrenia, Chile)*

The lack of ability for insight (or to understand it as an illness) is very frequent in people with schizophrenia.<sup>1</sup> Some individuals have cognitive limitations, which decreases their capacity for understanding. Poor treatment adherence frequently results from this process. Remaining symptomatic may also be a way to escape from reality. Denial is a common defense mechanism in other illnesses. In oncological diseases, for example, the patient goes through several mental stages until accepting their illness (denial, search for magical solutions, anger).<sup>24</sup> Chronic diseases like diabetes, rheumatism and hypertension may even be denied on principal.<sup>11,16</sup>

*I suffered a lot when the psychiatrist told me I was crazy. They told me with gentler words, but it was a bomb... we were very ignorant about it. My friends were a little afraid, but not of me. They were afraid of the illness. They thought that I would do something to them. (Man with schizophrenia, Spain)*

Some participants reported that after accepting their mental illness, they began to suffer less. Studies suggest being conscience of the illness is associated with lower grade symptoms and better treatment management.<sup>13</sup> Likewise, lower adherence appears connected to lower levels of insight.<sup>19</sup> These data justify the implementation of psychoeducational strategies by service providers. The identification of tactics used by patients to control symptoms may help their treatment. The individual experiences must be appreciated.

*... I am not going to sit on the rooftop and say "Listen! I'm a psychiatric patient" because there is stigma outside. But if somebody comes and says "What's going on?", I explain the problem. The only way to make them understand is if people who suffer from the problem sit down and explain it. We are the best teachers there are. (Man with schizophrenia, England)*

There is a need to develop health promotion mechanisms based on patient experiences. This should begin with changes in communication between providers and clients. Frequently the professionals experience difficulty with this, including when divulging the illness to the patient. The illness of some participants was simply identified as an "illness of the nerves" for a long time.

*To me it seems very important that psychiatrists, in addition to using big words and approaching as from above, actually stop to explain what is happening because I still do not know. (Women with schizophrenia, England)*

Many participants reported it is necessary to be actively involved in gaining an understanding of the illness. This involves searching for information, studying, and participating in group therapy and associations. Understanding the illness and searching for information appears to promote citizenship.

*We have to know everything there is in the mental health system in order to stay alive. We need to know what they are doing to us, advocate around our illness, help increase our self-esteem. It seems to me that the current system is inadequate for us. (Man with schizophrenia, England)*

## FINAL COMMENTS

The loss of social connections and opportunities (especially employment) after the onset of illness is omnipresent in the lives of people with schizophrenia. Pain, depression and desire to die were expressed in the discussions. In fact, why would someone want to continue to live if their subjective experiences are not considered important and they do not have a partner, feel rejected, do not have personal projects, lack professional realization and depend on others? Actually it is surprising that in the midst of so much adversity, these individuals continue to find reasons to keep living.

Complex changes that appreciate each individual's reality are necessary. Strategies for employment inclusion are certainly very important and should be prioritized. Therapeutic workshops, development of protective laws and workplace quotas are fundamental for people with schizophrenia to reach improved quality of life and autonomy.

Fighting stigma is the other big challenge, since it requires changes in societal imagination. The development of means to increase access to information and knowledge about the illness may be the most viable way to obtain improvement. In particular, health education approached should be promoted.

It is also necessary to improve the quality of health care. The reality of the health services seems to encourage the maintenance of dehumanized care, more concerned with curing illnesses than with health promotion. Health promotion is an even greater challenge, especially in Latin American contexts where social and economic adversities play a critical role in quality of life. The very survival of some people is constantly threatened. They first must survive to later exist as a person with feelings and desires.

Changes do not occur while the most interested parties remain silenced. Participation and mobilization of patients are some of the most important impetuses for social transformation. A more pro-active posture is necessary to make patients exercise their citizenship. As one of the participants concluded:

*You need to overcome your illness by accepting it, going out every day and carrying on with your life because you can't let your life stop... it's important that everyone understands that we have to keep going and*

*do something for ourselves. We can't always blame the system. If you want to return to society, you have to accept certain things.* (Man with schizophrenia, England)

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