

Schizophrenia and the Family Burden during the Pandemic

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Abstract: *This article focuses on the issue of the burden that families with people with schizophrenia in care are confronted with. The pandemic caused significant disruption to the family dynamics of people caring for individuals with schizophrenia due to their higher risk of infection and worse outcomes.*

Families with patients with schizophrenia should pay close attention to detect both respiratory and psychiatric symptoms as early as possible. They may need health care professional support, guidance and help to prevent COVID-19 infection among people diagnosed with schizophrenia. However, the issue of the difficulties that families with people diagnosed with schizophrenia face remains a serious matter.

Keywords: *family burden; pandemic; schizophrenia.*

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Introduction

The phrase *family burden* is associated with how relatives perceive their own emotional and physical health, social life and financial status resulting from their care for a sick relative (Sales, 2003). The symptoms of schizophrenia affect the family members who care about the diagnosed person.

The family of individuals with schizophrenia should think about changes that occurred as a result of the disease.

The strange symptoms of schizophrenia and the unpredictability of the diagnosed patient's behavior lead to feelings of uncertainty in traditional families, the disease being often seen as an undeserved punishment (Rhee & Rosenheck, 2019).

Discussions

Specialized studies divide this burden into two categories: objective and subjective (Lippi, 2016).

The subjective burden of a family with a person diagnosed with schizophrenia is the result of permanent feelings of worry, pain, despair due to the behavior with increased potential for aggression of the sick person, his limited capacity for autonomy and self-control, but also the feeling of insecurity for the sick person, family members and society (Manao & Pardede 2019).

Moreover, the emergence of the pandemic brings an additional cause for concern, fear or panic for these people. The parents of persons with schizophrenia or those who care about them often express their concern about the future and the trajectory of the individual's life after their death (Chen et al., 2019).

Patients in this category, already in a constant struggle with the depressive mood due to the "burden" of carelessness, may now face a growing feeling that no one really understands them and can help them, in addition to them already feeling powerless, socially isolated and stigmatized (Luca et al., 2020).

The objective burden of families in this category also consists of two aspects. The first one includes neglect of other family members, the occurrence of intra-family conflicts and secondly, the deterioration of family and marital relationships, especially of social relationships due to loss of contact with close relatives and friends.

Family members of people diagnosed with schizophrenia feel ashamed of the sick person's symptoms and behavior and avoid inviting other people home.

The self-stigmatization of family members is also present, often in the case of the sick person.

Social distancing measures can be an additional factor in increasing family conflict situations due to additional mental pressure and the fact that they have to stay together most of the time (Ciubara et al., 2015).

Social isolation and the lack of community support are other real problems that have existed even since the pre-pandemic period, which may be now felt more strongly (Lupu et al., 2017).

The caregivers of an individual with schizophrenia are required to find out from reliable sources about the vulnerability of the loved one suffering from schizophrenia, given that the classic medical consultation has been replaced by telemedicine (DeLuca et al., 2020).

An additional complication is the way they have to explain to the patient what a pandemic is, knowing that suspicion, over- or mis-interpretation and delusional ideation are part of the psychopathological picture of schizophrenia, therefore the risk of exacerbation of symptoms is increased.

Another problem is the constant concern for the patient to comply with additional hygiene measures, given that the ability to understand, the elements of psycho-cognitive impairment and negligence of personal hygiene of a patient with schizophrenia is often diminished (Chirita et al., 2012). They may have difficulties in understanding the explanation of the need and obligation to wear a protective mask, given that the volitional function and the anchoring in reality of patients with schizophrenia are also frequently present.

The reactions of relatives to schizophrenia symptoms are based on the way the family interprets them. Families often attribute negative symptoms, outbursts of anger and behavioral manifestations to the sick person; other family members sometimes feel that the individuals with schizophrenia intend to provoke and even make them feel upset (Ciobotea et al., 2016). Most often, family members are not aware of the symptoms and the role of this medical condition and tend to accuse the sick person of bad will (flattened affect, ambivalence, lack of pleasure in life, lack of personal motivation and aptitude deficit are misinterpreted by family members). It is difficult for them to accept situations like this or they may even forget that these attitudes are consequences of the disease (Ciubara et al., 2016).

In addition, parents, spouses and relatives are often unable to manage their individual or family needs due to the fact that their attention is focused on the sick person and the consequences of this condition.

On the other hand, there are situations in which the family with a diagnosed with schizophrenia person tends to overprotect them, or not to insist due to the fear of reaction of the sick person (Ornell et al., 2020).

There is a risk that the relatives themselves may neglect, reducing their vigilance regarding their own health and delaying the referral to specialists even if they do not feel well.

These families may also be in a permanent state of stress at the thought that someone in their family might get Covid-19.

Belonging to a family with patients with schizophrenia also means facing constraints in carrying out relaxation activities. These difficulties can lead to states of exhaustion or overwork during this period.

Job loss or declining incomes, rising absenteeism from work, and the occurrence of financial problems caused by medical expenses were pre-pandemic problems exacerbated by the pandemic (Fonseca et al., 2020).

Nowadays, the objective burdens mostly felt by families of individuals with schizophrenia are financial obligations related to medical costs, transportation to mental health care providers, procuring the necessary prescriptions and medication, and providing basic necessities for a decent living.

Families of people diagnosed with schizophrenia experience feelings of increased concern or frustration during this period, in close connection with the limitations and restrictions imposed on them and on the sick person.

The whole family, both relatives and people with schizophrenia may be concerned about the current situation and the occurrence of relapses given that accessibility to psychiatric hospitals is limited on the grounds that there is a great number of infections in hospitals.

Family members caring for people diagnosed with schizophrenia assume guilt for not recognizing the symptoms earlier, and can feel it even more profoundly during this pandemic period when psychiatric hospitals are operating differently, and hospitalizations are made only in an emergency.

There is a higher risk of recurrence, given the emotional suffering of those diagnosed with schizophrenia due to the fact that they are already vulnerable to the onset of the pandemic, their limited access to community and the risk of discontinuation of medication.

The exhaustion of relatives, caused by the behavior of individuals with schizophrenia, the occurrence and management of psychotic symptoms

and the lack of treatment compliance of people diagnosed with schizophrenia associated with pandemic problems could be increased.

The need to seek medical and social services is certainly increased during this period. In addition to the early detection of the first signs of exacerbation of psychiatric symptoms, the relatives of the individuals who suffer from schizophrenia also care for the detection of respiratory symptoms and careful monitoring of the general condition of health of patients with schizophrenia.

Another problem that these families frequently face is the increase of the workload within the household, especially in the conditions in which it is possible that all family members are permanently at home. On the other hand, the relatives must find alternatives for spending their free time in a family-friendly way.

The obligation to accompany the sick person outside the house is now cumulated with additional worries due to protection and hygiene measures that the individuals with schizophrenia can hardly accept.

The COVID-19 pandemic may have consequences for the quality of care for families with patients with schizophrenia.

Specialized research conducted before the outbreak of the pandemic shows that families caring for a person with schizophrenia face stronger feelings of burden than those caring for people diagnosed with other chronic diseases.

Negative experiences and their dissatisfaction, feelings of anxiety, fear, stress or shock, confusion, lack of control, despair and frustration are feelings that these people face more intensely.

The caregivers often choose not to talk about the burden and exhaustion they feel, and the specialists they address have difficulty in establishing an effective therapeutic relationship, gaining the trust of these people so that they can express themselves, be able to explain the emotional states they go through, so that specialists understand the impact that this burden has on them. Personal skills and the application of the principles of psychoeducation by mental health specialists and those in social work play the role of helping their relatives to express feelings and recognize the importance and meaning of the psychopathological signs. Explanations accessible to everyone's understanding can lead to both self-knowledge and understanding behavior and drama of the loved one in the family, diagnosed with schizophrenia. The expression of emotions is closely related to their management, prevents the experimentation of negative feelings of sadness, frustration, helplessness, anger, guilt, despair.

Understanding the depression, frustration, difficult situation of the person diagnosed with schizophrenia is closely correlated with optimizing the family environment and thus the well-being of all members of the family

The need for the family members to confess have always existed, although their defense and adaptation mechanisms led them to be reserved about their personal lives.

One of the reasons for the reduced capacity for communication and self-disclosure could be the internalization of the stigma associated with the diagnosis of schizophrenia of a loved one, but also of social stigma and labeling (Untu et al., 2015).

These people may not feel support from social psychiatric services in the conditions in which there were no centers before the pandemic period specialized in managing family crises, support groups or therapy sessions for both them and the sick, and the restrictions imposed by the pandemic make it difficult to set them up.

The uncertain course of the disease, disturbing behavior, self-stigma, loneliness, lack of help from outside or other family members, lack of reciprocity from the sick person and fear of unpredictable changes in behavior, reduced ability to adapt to new situations and last but not least, suicide risk are identified by families with individuals with schizophrenia as problems they face which may be added to the insecurity of the pandemic (Sher, 2020).

The importance of involving members in the healing process of a sick person is recognized, but their task to manage the continuous care of a person is extremely difficult in the conditions imposed by the pandemic.

Recent pandemic studies show that patients with schizophrenia include a higher risk of infection and poorer recovery outcomes, especially if they have clinical comorbidities (Fonfana et al., 2020).

They are also vulnerable to exacerbation of psychoticism and relapses due to fear of illness, stress and boredom associated with compulsory isolation.

The caregivers need to be helped to find internal resources but also financial support to be able to adapt to the pandemic situation, in order to be able to manage the burden of schizophrenia care.

Psychoeducational programs help families improve their problem-solving, communication and coping skills (Ciubara et al., 2015). Provided in the format of multifamily groups, psychoeducation sessions help families develop social support. Both the diagnosed person and family members feel the need for psychological support, counseling and guidance by the psychiatrist, psychologist or social worker to regain their lost social status with label-

ing and stigmatization (Valcea et al., 2016). Once they regain confidence due to their own strengths, those people are more likely to implement actions that lead to the optimization of social integration.

On the one hand, there is the need for people to confess, although their defense and adaptation mechanisms have led them to be hesitant concerning their personal lives.

On the other hand, awareness of the *de facto* reality can lead to the possibility of finding viable solutions and increasing the motivation to act constructively in order to manage one's own feelings in a different way and to improve the relationship with the sick person.

Changing the perspective on mental health could have the immediate effect of supporting the person diagnosed with schizophrenia in finding their own anchors and mobilizing them to succeed in socio-professional rehabilitation.

Nowadays, the recovery of people diagnosed with schizophrenia is the subject of social action to promote mental health. There are institutions all over the world, organizations and specialists who make considerable effort to tackle with the psycho-social reintegration of patients diagnosed with schizophrenia.

However, the issue of the difficulties of families with patients with schizophrenia remains a challenge.

Conclusions

Mental health and addiction concerns affect a great number of people around the world.

They are the leading cause of the global burden of disease and are the leading causes of disability worldwide.

The pandemic could be an opportunity to improve mental health and social care services, to create a multidisciplinary monitoring, intervention and care system of psycho-emotional, socio-professional and financial support networks.

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