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Needs of relatives of patients with schizophrenia under crisis situations

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SUMMARY

Objective

This article presents the main crisis situations faced by relatives of schizophrenic patients, as well as their needs in psychiatric care at moments of crisis.

Method

Qualitative study. A discussion group of eight parents of patients with schizophrenia was formed. The group sessions were recorded and transcribed to analyze the information later on. In addition, the information was complemented with individual interviews with the relatives.

Results

Parents emphasized three main crisis situations: 1. a first psychotic crisis, 2. family crisis facing the diagnosis and in the process of acceptance of the disease, and 3. subsequent relapses. 4. Deficiencies in care crises and 5. needs of families in crisis situations are also detailed.

Conclusions

According to the narratives shared by the relatives in the discussion group, we can conclude that it is necessary to provide information to the family, the patients and the general population, so that there is a knowledge of the main characteristics and symptoms of schizophrenia. This should be carried out with the purpose of obtaining an early detection that facilitates treatment and prevents later crisis interventions, as well as creating a social support network in the community.

Key words: Needs, crisis, schizophrenia, family, qualitative study.

RESUMEN

Objetivo

Identificar y analizar las principales situaciones de crisis que enfrentan los familiares de pacientes con esquizofrenia, así como sus necesidades en la atención psiquiátrica en momentos de crisis.

Método

Con metodología cualitativa de recolección y análisis, la técnica utilizada fue la creación de un grupo de discusión con ocho familiares de pacientes con esquizofrenia. Las sesiones grupales se grabaron y transcribieron para analizar posteriormente la información. Además, se realizaron entrevistas individuales a cada familiar.

Resultados

Los familiares destacaron tres principales situaciones de crisis: 1. La crisis psicótica; 2. La crisis familiar ante el diagnóstico y en el proceso de aceptación de la enfermedad; 3. La crisis ante las recaídas subsecuentes. También se detallan: 4. Las deficiencias en la atención en situaciones de crisis y 5. Las necesidades de los familiares en estas situaciones.

Conclusiones

Desde la narrativa de los familiares se puede destacar la experiencia de una falta de información tanto a familiares y a pacientes como a la población en general, para que se conozcan los principales rasgos y síntomas que caracterizan a la esquizofrenia, para lograr con ello una detección temprana que facilite el tratamiento y la prevención de crisis posteriores. Es conveniente desarrollar intervenciones en los momentos de crisis y establecer una red social de apoyo en la comunidad.

Palabras clave: Necesidades, crisis, esquizofrenia, familia, estudio cualitativo.

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INTRODUCTION

The World Health Organization (2010) estimates that some 29 million people globally suffer from schizophrenia. Although its incidence is low (3 per 10,000), its prevalence is high due to the chronicity of the illness.[1] It is calculated that one in every four people will be affected by mental illness at some point in their lives. This implies that for every 10 people with serious mental disorders, there are 2.5 carers.[2] Caring for a person suffering the disorder brings a series of important challenges to the family environment. The carer's support is essential for the stability of the person with schizophrenia, as it can help to prevent possible psychotic crises and contribute to improving their level of global functioning and following treatment. Furthermore, one out of every two families of people with schizophrenia is at risk of having an emotional, physical, or psychiatric disorder related to the role of being the primary informal carer in the family.[3]

The concept of a crisis has various connotations and tends to be associated with a break in balance or "normality", or with the appearance or sudden reappearance of a disorder.[4] This changing situation implies a challenge and a reorganization in order to deal with the events that triggered it.

Vírseda[5] defines crisis as a psychological state resulting from the family dealing with events perceived as dangerous, accompanied by feelings of inability to resolve the situation efficiently with the resources available at that time.

There are studies on the intervention and prevention of crises in patients with schizophrenia,[6-8] on the role of the family in treatment, and on the consequences caused by schizophrenia in those who suffer the illness.[9-18] However, few studies take into account the problems faced by families when they need help in moments of crisis.

The aim of the present article is to provide knowledge of the experience and the narrative of primary crisis situations faced by families of patients with schizophrenia, as well as their needs in psychiatric care at times of crisis.

METHOD

Qualitative study based on the experience of discussion groups[19] of families of people with schizophrenia. The sample was a convenience sample of type cases. Invitations were made to families who attended public health institutions in Mexico City. The inclusion criteria was to have a family member with schizophrenia with whom they lived day to day; and the people with schizophrenia were receiving integrated treatment (psychiatric and psychosocial) at the time of the study.

Cooperation was voluntary, anonymous, and confidential. Informed consent was obtained from the participants, according to which they agreed to participate in the group sessions in the knowledge that these would be recorded. The study was previously passed by an ethics committee and met international regulations for bioethics.

The research consisted of creating a space for constructed dialogue in each session and allowing the flow of information that not only went into depth on the subjects raised, but also widened the background information through the effect of synergy and the interrelation of the group.[20]

The narrative theory that examines how people attribute feelings to their experience and existence was taken into account.[21] This theory suggests that integrating the subjective and objective of research strategies results in a more complete comprehension of schizophrenia. Each one of the family members was also interviewed to complete the information.

Procedure and information analysis

The group sessions for the present study were guided by a series of aspects that allowed various subjects to be approached, such as: the meaning of schizophrenia, and the experience and primary needs of families in crisis situations they may have faced during the process of the illness. The process of analysis was carried out from transcriptions of the two group sessions. Primary categories were firstly obtained of analysis or theme. Secondly, certain fragments of the families' narratives were selected which were considered representative of the theme of the present study, in order to finally articulate the information through theoretical content.

RESULTS

Demographic description of the families

The group was made up of eight family members (seven females and one male), of which there were six mothers, one sister, and one father, with an average age of 59.44 years. Some 44.4% had a partner and the remaining 55.6% did not; 33.3% had high school education and 55.6% studied for one or more years at university. At the time of the study, 77.8% had paid work and 22.2 were unpaid (working in the home). Some 44.4% of the family members lived with their sick relative all day, and the rest (55.6%) saw them for periods during the morning, afternoon, or evening. In terms of relapses with hospitalization of the patients, 33.3% had not relapsed, 22.2% had had at least one relapse with hospitalization, 33.3% had relapsed twice, and 11.2% had relapsed three times.

The first psychotic crisis

Family members who participated in the discussion group considered that the appearance of these behaviors in their relatives was perceptible before they were diagnosed with schizophrenia, and in the majority of cases, this phase coincided with adolescence.

One family member even mentioned that they confused the first symptoms exhibited by their son with typical teenage behavior:

> F7: "*As it presented around age 19 or 20, I thought it was a teenage thing; that laziness that teenagers have.*"
>
> F5: "*[…] He started to isolate himself when he finished high school, he started thinking that people who came to see him wanted to hurt him […] and I saw him be absent, his eyes would blink suddenly and they would look blank, or very strange. I would say to him, "what's wrong?" …I didn't understand.*"
>
> F1: "*My son, suddenly, he was working, he used to be very capable, in work and everything. Then there was an accident […]. Later, he was climbing some stairs and he fell; I was so scared and I spoke to the doctor […] and I asked, what's wrong with him? The doctor said to me, we suspect that your son may have a mental problem […] and I didn't understand […].*"
>
> F2: "*I was totally ignorant, but thank God I have information now, they diagnosed him and I felt I could breathe again, but I spent a lot of time feeling desperate […].*"

It has been shown that specialized mental healthcare services are used little, and that general doctors, family members, friends, and/or religious leaders are used instead. It has also been shown that an important percentage of the population that relapses to primary care levels has mental health disorders, but that these are rarely detected, and even less so referred in a timely manner.[22] As a consequence, family members go from place to place and pass through many institutions before receiving the help they need. The following excerpt is an example of this situation:

> F2: "*[…] at first I found it very difficult to manage the situation, because I never had any direct information. First I started seeing the psychologist at my son's school, because he had gotten into fights on two occasions, and on the third he had assaulted the teacher. The psychologist suggested family therapy; I didn't go to family therapy. […] That psychologist sent me to a psychiatrist. […] He never said to me, "we're going to do a study, we're going to so an investigation", never! He did do an encephalogram […] and the thing is, the whole time, I never heard the word schizophrenia.*"

Nowadays, the interval of time between the first diagnosable symptoms of schizophrenia through to the moment when the patient is actually diagnosed generally oscillates between one year and two.[23,24] There is also the additional delay before treatment starts. From there, it is important to provide better training for general practitioners and psychologists to enable them to take advantage of tools that ensure early diagnosis and direct the patient to mental health care in a timely fashion.[24]

Families frequently do not seek help until the patient is in a psychotic crisis, present very strange attitudes, shows violent behavior that is difficult to control, or is in at-risk situations. All of the above generates a conflict because most of the time, these characteristics lead the patient to be hospitalized.[25]

> F7: "*At the beginning, I thought it was puberty, but it was complicating things. Until one day, a colleague spoke to me and told me that I might not have realized my son was doing dangerous things and that was when we started to worry, because he started to talk and say things to people, ideas and things that were out of place; he walked across the street with his arms wide open; very strange things. So […] we went straight to a psychiatrist […].*"

Lack of information causes patients and their relatives to go to the doctor until a crisis or first psychotic episode happens; the moment in which the impact is greater and management is more complex, instead of seeking psychiatric attention in a prodromal phase when symptoms can serve to prevent a crisis. In this sense, the importance of promptly detecting and treating patients with a first psychotic episode lies in preventing the development of neurobiological alterations which complicate the prognosis.[26]

It should be considered that as well as generalized misinformation about schizophrenia, there are other aspects that delay the pursuit of professional help. On the one hand there is the stigma around psychiatric patients being associated with "being crazy"; and on the other, there is the denial of illness and the impact on families caused by the diagnosis, which can be considered another type of crisis, as we will see shortly.

Family crisis in regards to the diagnosis and the process of accepting the illness

Family relationships and dynamics are altered when the requirement for psychiatric care is introduced. One of the family members in the group described schizophrenia as "a family disorder":

> F7: "*The family is dragged into it [schizophrenia].*"

Schizophrenia can represent a twofold problem: on the one hand, dealing with the problems of the illness itself, and on the other, overcoming the adverse social conditions that are caused around it. Schizophrenia arising transforms the family dynamic, and most of the time it is difficult to accept the fact that a family member is suffering from a mental illness:

> F1: "*[…] You often say 'it won't happen to me'; in that moment, you reject it.*"
>
> F7: "*[…] When the psychiatrist told us that it was very serious, I never imagined how much, until after he said it was schizophrenia, and as my husband also has a sister who has it, I said 'No, it can't be, no!'*"
>
> F6: "*I was aware that there was a problem, but no way did I accept that he had that; I mean, I didn't even know even though the doctor explained it to me, until he used mimes and gestures. I said to the other doctor, the psychiatrist, 'it's not true, it's not true, it's not true'.*"

Initially, the patient and their families deny the illness, because the diagnosis has a significant impact and real ten-

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sion, which very often also makes it difficult to adhere to treatment.[27]

> F1: "*[…] You don't accept why… it's difficult to accept that a family member – in my case, my son – has this illness. When, for some reason, family members find out, the first reaction is to deny it: 'no! How can you think that?'*"
>
> F4: "*I think another obstacle is the family itself, who don't accept the illness, they say it's blackmail, that the person isn't really ill, so that's also really difficult.*"

The experience of facing a diagnosis without sufficient information causes anxiety and desperation on the part of the family, and much uncertainty as to the treatment and life expectations of the patient. Care is therefore necessary because the diagnosis causes emotional damage:

> F6: "*We can't be isolated and alone when facing a diagnosis that damages us. It damages us emotionally, because my son cannot have that […] I am angry with everyone and I need help, I just have a family member who has this problem.*"

The doctor must bear in mind that the diagnosis generates an emotional block in families which stops them clearly hearing the initial explanations. Therefore, it is necessary to set up further meetings with questions to make sure that the family has understood. Although it may be tedious for the doctor – and possibly costly for the institutions – the time invested in these initial sessions will be fruitful over the course of treatment, because doing so avoids many mistakes and misinterpretations.[28]

The process of accepting the illness and the way in which each family member is involved in the patient's treatment are different according to the type of relationship they have with the patient, and the way in which they cope with the situation.[13] Some family members have to leave work in order to take care of the patient, while others simply do not support the family situation and avoid living with them, as in the following example:

> F7: "*Even my daughter went to England, running away from the family situation, and she always told me that my son was useless, that he was no good for anything. That hurt me a lot, but she was right to express what she felt, because I always saw him in bed, not continuing with school or finding a job.*"

In studying family carers, it was found that more than half (58.8%) had some psychiatric disorder, within which depression was particularly notable among women, and alcohol dependency among men.[3] This may be a consequence of the constant stress the family is under due to schizophrenia and the fact that some family members neglect personal care due to caring for, and overprotecting, the sick relative. Some studies have reported that one in every three family members have high levels of anxiety or depression linked to the role of carer.[29] The following excerpt sheds light on the consequences faced by a mother due to her total dedication towards the patient:

> F3: "*For two years I carried on like that – bam! And when I got past the anger by letting it go, it came back to me, and suddenly […] it had to come back to me because I was terribly depressed.*"

Subsequent relapses and continuous crises

Some 66.6% of the group participants had the experience of relapses in their family members.

Lader[30] defines relapse as the return of an illness after total or partial recovery. Relapse in patients with schizophrenia can be assessed by means of symptomatic, phenomenological, and behavioral levels, and it is detected by the appearance or resurgence of psychotic symptoms such as delirium, hallucinations, strange behaviors, or disordered thinking.

Some studies have observed that 80% of patients diagnosed with a first episode of schizophrenia or schizoaffective disorder have an average of two relapses in the first five years of the condition's development.[31] The reasons why a patient might relapse are very diverse, although it has been reported that the index of relapse is greater in patients who only receive pharmacological treatment in comparison with those who received psychological and psychosocial treatment in conjunction with pharmacological treatment.[15] However, it has also been seen that in spite of receiving medication in prescribed doses, many patients with schizophrenia still have relapses.[27]

Relapses mentioned by the family members participating in the group were provoked by bad medication management or stopping medication.

> F8: "*[…] she had only had two admissions when she was diagnosed, and when she got arthritis and it was the same, they stopped the medication and she relapsed […] she went to the doctor, they cut the dose almost in half, and within two weeks my sister had relapsed.*"
>
> F5: "*There was one problem which was the only relapse my son has had throughout his whole illness, which was when they admitted him […] The other day the medication failed, [the doctor] took all the medication away, just like that […].*"

There are studies that establish that the primary variable in relapse is suspension of treatment, given that with removal of medication, 67% of patients relapse within a year.[26]

There are also recent works focused on Expressed Emotion (EE) in the family, considered the best predictor of relapses currently known for people with schizophrenia, and which could be characterized as a family communicative style with the patient that influences the course of the illness.[24]

The family environment and basic attitudes towards the patient have a powerful influence on their perceived quality of life, even above other variables like psychopathology.[17,32,33] As such, patients whose families have high EE are up to four times more likely to relapse than those whose families have low EE.[24]

The prediction of relapses in schizophrenia is an important component to consider, because there is evidence that almost half of the 78% of patients with schizophrenia have had repeated episodes and experienced a progressive deterioration in functioning after each successive relapse.[34]

A relapse is considered to be a crisis because it is a serious and unforeseen situation where there is a radical change in the patient's behavior (due to the appearance of symptoms) which means decisions have to be made. Furthermore, very often a risk situation can lead to suicide attempts or acts.

After a look at the various crisis situations that are faced by family members, we will examine the differences and care needs.

Deficiencies in help in crisis situations

All participants agreed that there is a series of deficiencies in care from the emergency services. One of the problems they mentioned was that faced with the level of demand, appointments with the psychiatrist are very far apart, and that when ill family members have a crisis or relapse before an appointment, they have to attend the emergency room. According to their experience, care received there has been deficient, due to the lack of trained staff with sufficient experience because they are in training. It is also paradoxical that the most highly-trained psychiatrists do not attend to those patients in crisis who need urgent attention.

> F8: "*I can't go to the emergency room because the resident does not have the judgment and the general practitioner is coming out of their first year […] she wasn't even admitted […] I think they are lacking a lot […].*"
>
> F4: "*I worry a lot that my son will require hospitalization and there won't be a bed for him.*"

As we have previously seen, a crisis is an unexpected and sudden situation that rarely coincides with the exact date of a psychiatrist appointment. As such, in moments of crisis, patients almost always have to go to the emergency room for treatment.

Patients in crisis who attend the ER and whose cases are serious enough are hospitalized, while those who do not merit admission are sent home without receiving the care they require, nor adequate information for family members to know what to do if another crisis happens. This situation is difficult, because on one side, the family seeking help in crisis is worried about their family member needing hospitalization.

> F8: "*…she went to the doctor, they cut the dose almost in half, and within two weeks my sister had relapsed. I went to the emergency room, and the resident said to me 'no, the doctor is overrun, the ER is full, your sister is not that bad'. They didn't even look her over, didn't even take her off the gurney, they gave me a receipt and said 'take her to the doctor'. But we went in March and the appointment isn't until May!*"

On the other hand, family members agreed that some doctors lack tact, empathy, and care in emergency situations to detect possible relapses.

> F2: "*[The doctor] doesn't answer, on one or two occasions I have called up to 15 times over three or four days and not managed to speak to her. So I get demoralized, I am so disappointed I feel like I'm starved of attention. Because I don't have anyone else to talk to, because no-one else knows [my son] as she is his doctor.*"

Needs of family members in crisis situations

Now knowing the various crisis situations families are facing, it is relevant to take into account their needs in such situations mentioned by group participants.

Need for information, professional and institutional help with crisis management

The family members agreed that there is a lack of information for the general public about mental disorders in order for people to know the primary symptoms and be able to detect it early in order to prevent later crises (Figure 1).

> F2: "*First it was very difficult for me to manage the situation because I never had any direct information.*"
>
> F6: "*There is no clear information, there is no timely information.*"
>
> F2 "*Information for people to know where to go in a crisis. This information should be on a massive scale, because you never know who could have a psychotic crisis and it is very difficult to know what to do.*"

It is also important for information to be broadcast through the media about different institutions and hospitals that deal with mental disorders, where to seek help when there is not adequate information to make a decision in a crisis situation, and above all, if it is the first time that psychotic symptomatology is present.

When the patient already has a diagnosis of schizophrenia, the information provided must be more specific and detailed, both for the family members as well as for the user, to understand what schizophrenia is, how it is treated, what consequences it has, what the prognosis is, etc. This lack of knowledge brings various complications that make it difficult to manage the illness, such as: self-perception of a limited capacity to deal with crises, inadequate establishing of clear expectations and objectives, and these expectations not being met by the patient.[15]

> F6: "*The illness has an impact on the family member, and when that person does not have information […] I think they explain more to cancer patients than they do to schizophrenia patients. So if the illness is so impactful for the family, why are we treated this way? With no information – we need clear information […]*"

It is vital that different mental health institutions systematically provide and distribute information around the symptoms, etiology, and treatment of schizophrenia, with the aim of improving understanding and behaviors associated with the illness. As such, it is sought to diminish the rate of relapse and improve the patient's quality of life.[10]

Just as the family is a very important factor in treating schizophrenia, they need to receive attention beyond information and training, because all family members are

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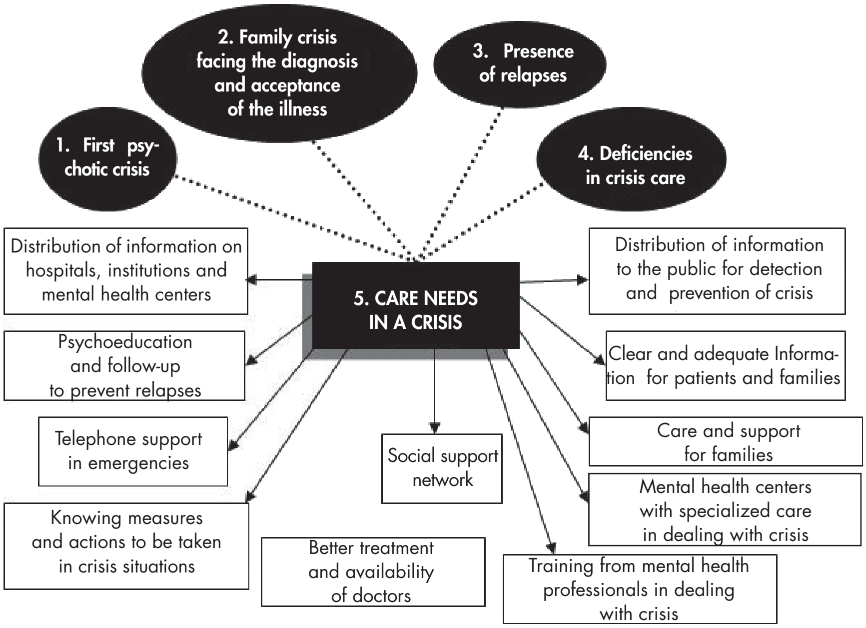

Figure 1. Family members' experiences and needs in crisis situations.

affected by the illness, and most of the time they need to be listened to, to alleviate the impact and the tension produced by living with a sick family member.

Need for integrated care

The group participants also revealed the need for integrated care (pharmacological treatment; individual, group, and family psychotherapy; psychoeducation, etc.) given that they are included in the implications of the illness and they are affected by the responsibility that comes with caring for a sick family member.

> F6: *"the family needs integrated care – schizophrenia is not just isolated to my son, it is about his siblings, my wife, and me; and with our families. Schizophrenia is involved all around my son who is ill with it, it involves those who are around him and dealing only with the direct family members doesn't work, it doesn't solve the problem."*

There are studies on integrated treatment[15-17] that demonstrate a notable improvement in self-care, socialization, sticking to treatment, and improvement in family relationships that are normally altered in patients with schizophrenia.

The more that families have a space where they are informed, listened to, and receive adequate professional and paired support, the easier they will find it to contend with the illness in crisis situations.

> F7: *"We grow and strengthen ourselves to be able to cope with the situations that arise."*
>
> F4: *"To go to therapy, seek help, you know? From specialists, both for her and for the family. Inform the family as well."*

Beyond exclusive pharmacological treatment, the close follow-up of the patient which involves the family, along with active psychosocial intervention, has been shown to be effective in reducing the number of admissions and improving patients' welling.[30]

Need for support groups

The majority of family members in the group consider support groups important, where they can share their experiences and difficulties with other people who are in a similar situation:

> F7: *"I also feel that I need a group where I can be supported in understanding my son and myself; a group centered on my son's illness."*
>
> F6: *"We need groups […] we need the direction of psychologists and psychiatrists, we need groups where we can join together."*

These groups are very important to form social support networks among informed families. However, it is necessary for there to be a support on the part of professionals in the field of mental health to provide orientation and follow-up.

CONCLUSIONS

Being responsible for the care of patients in the community, families of people with schizophrenia are those who live and confirm the different types of crisis during the course of the illness. Based on that expressed by the family members, three primary crisis situations stand out: 1. *First psychotic crisis*: When the first symptoms appear in the prodromic phase, families are not familiar with what is happening, and as such, treating the patient is delayed because they do not know where to turn to obtain care; 2. *Family crisis after the diagnosis and in the process of accepting the illness*: when the illness appears, there is an impact on family members, for whom it is difficult to accept the diagnosis. Changes occur in the family dynamic due to living day-to-day with the patient, and stress on the carers increases, because they are dedicated full time to the sick family member without receiving any training; 3. *Subsequent relapses and continued crises*: Relapses, which have various causes, in particular the suspension of medication. Within numbers 4. *Deficiencies* and 5. *Care needs are also needs that the family members face in crisis situations: the need for information, professional and institutional support for crisis management, the need for integrated attention, and support groups*. What stands out is the lack of information on mental disorders for the general population and the management of discrimination towards patients with schizophrenia, which in itself creates a barrier to the process of accepting the illness. Furthermore, not having knowledge about the appropriate health institutions leads to difficulties in seeking timely attention. Family members require education in measures that should be taken into account in a crisis or relapse, as well as the need to have emergency services that function as real "crisis resolution centers" with trained staff. Furthermore, follow-up programs should be organized, which give more personalized care and prevent relapses. On the other hand, it is necessary to implement integrated care which combines pharmacological, psychological, psychosocial, and family treatment. In particular, psychoeducation[35] should be included to cover the needs of patients in the long term. Finally, adequate attention for the families is necessary to improve their quality of life.[16] It has been observed that family participation favors patients' development, given that continuity of treatment is more sustainable and makes the prognosis favorable.[6]

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