Patients' relatives delayed help seeking after a first psychotic episode

Demora na procura por tratamento pelos familiares de pacientes após um primeiro episódio psicótico

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Abstract

Objective: Recent studies show that proper treatment after the first psychotic episode may be delayed for a long time. Some patients remain without care even while exhibiting serious symptoms. The objective of the study was to understand the reasons why patients' relatives waited at least 6 months to look for psychiatric counseling and treatment. Method: Qualitative analyses of semi-structured interviews with 15 relatives (of patients with first psychotic episode) who have waited more than six months before seeking psychiatric treatment were applied. The interviews were recorded; transcribed and relevant portions were codified and grouped, forming terms, concepts or categories. Results: These family members referred to individuals with mental problems in other families in a stereotyped fashion, citing negative aspects such as violence and criminality. They used softer terms when referring to their family members. Not knowing that their sick relative to be a case of mental illness, relatives classified certain observed behaviors as coming principally from spiritual problems and drug use. The initial delay in seeking medical help for the sick person was influenced by: 1) stereotyped misconceptions used by relatives to understand mental problems; 2) explanatory models elaborated to try to understand the sick person's behavior; 3) fear of psychiatric treatment; and 4) negative experiences with psychiatric services. Conclusions: Cultural aspects are present at all levels of this elaboration process. Their proper understanding by physicians can considerably diminish relatives' pain and suffering.

Keywords: Psychiatry; Psychotic disorders; Qualitative research; Patient care; Social environment

Resumo

Objetivo: Estudos recentes demonstram que o início do tratamento apropriado após o primeiro episódio psicótico pode ser adiado por um longo tempo. Alguns pacientes permanecem sem atenção profissional mesmo apresentando sintomas graves. O objetivo deste estudo foi o de compreender as razões pelas quais os parentes dos pacientes demoram pelo menos seis meses para procurar aconselhamento e tratamento psiquiátricos. Método: Foram realizadas análises qualitativas de entrevistas semi-estruturadas com 15 parentes (de pacientes em seu primeiro episodio psicótico) que demoraram mais de seis meses para buscar tratamento psiquiátrico. As entrevistas foram gravadas; as partes transcritas e relevantes foram codificadas e agrupados, formando termos, conceitos ou categorias. Resultados: Os familiares referiram-se aos indivíduos com problemas mentais de outras famílias de forma estereotipada, citando aspectos negativos, tais como violência e criminalidade. Utilizaram termos menos graves para se referir aos seus próprios familiares. Não sabendo que seu parente doente era um caso de doença mental, os parentes classifica-ram certos comportamentos observados como provenientes, principalmente, de problemas espirituais ou do uso de drogas. A demora inicial em buscar auxílio médico para a pessoa doente foi influenciada por: 1) conceitos equivocados e estereotipados utilizados pelos parentes para entender os problemas mentais; 2) modelos explanatórios elaborados para tentar entender o comportamento da pessoa doente; 3) medo do tratamento psiquiátrico; e 4) experiências negativas com serviços psiquiátricos. Conclusões: Estão presentes aspectos culturais em todos os níveis desse processo de elaboração. A compreensão adequada desses aspectos pelos clínicos pode diminuir consideravelmente a dor e o sofrimento dos familiares.

Descritores: Psiquiatria; Transtornos psicóticos; Pesquisa qualitativa; Assistência médica; Meio social

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Introduction

Recent studies have brought out the existence of a notable delay before the start of psychiatric treatment following a first psychotic episode, which may lead to a worsened clinical outcome in schizophrenia and related disorders.[1-3]

These studies use the DUP (*duration of untreated psychosis*) parameter, that is, the period from the first appearance of psychotic symptoms up to the start of adequate psychiatric treatment.

Reduced duration of untreated psychosis has been correlated with improved disease evolution and clinical outcome in some studies.[4-6] Other studies[7-8] have not demonstrated these relationship between duration of untreated psychosis and evolution of schizophrenia, therefore this finding is still controversial.

Being so, most mental health professionals consider that starting treatment as soon as possible is important to diminish biological, social and psychological damage to the patients.

In order to facilitate the patient's access to treatment following a first psychotic episode, we need a better knowledge of the reasons underlying the delay before starting psychiatric treatment.

One way to study the route followed by an individual until reaching psychiatric treatment is to examine the "pathways to care", which can be defined as the sequence of contacts with individuals and organizations carried out by individuals with mental illness or their relatives when seeking treatment, as well as the care provided as a result of this search.[9]

We consider help and treatment seeking actions as social and cultural processes, and thus, the pathways to care cannot be taken out of the cultural and social context encompassing the illness. Attitudes, values and belief systems transmitted by the family and other social agents influence the way the individual perceives, defines and responds to his/her symptoms and crises. Culture not only influences the perception of the problem, but also the ways they are dealt with, determining the direction and duration of the pathways.[9-10] Beliefs about diseases, the behavior of sick people, treatment expectations and the health system itself are aspects of social reality.[11] They can be seen as cultural constructions, with distinct formats in different societies and different social strata of the same society.[12-13]

Angel and Thoits[14] observed that individuals inherit a vocabulary of health and illness from their culture. The vocabulary achieved delimits possibilities for symptom interpretation and determines options of help seeking. The processes and cultural references, through which individuals perceive physical and emotional changes, determine how the individuals will classify these changes (i.e. physical or psychological, serious or insignificant) and what actions are to be taken.

Anthropological studies have demonstrated that the influence of cultural factors pervades the schizophrenic experience, defining symptom perception, the search for help and treatment, and the course and evolution of this illness.[15-18] Some of these studies reveal that culturally constructed beliefs concerning mental illness define a social place for the sick individual, a place that can be either one of special inclusion in the family and society or one of exclusion, both of which influence disease prognosis.[17-18]

In an ethnographic study with relatives of Mexican patients diagnosed with schizophrenia, Jenkis found that Mexicans elaborate the disease through the use of the *"nervios"* concept.[18] Some Mexican conceptions about mental illness can be very extreme, involving a notion of complete loss of reason and control, which is deemed a virtually incurable condition; as a result, they avoid considering a family member to be mentally ill. The importance of family bonds leads to a preference for a category that includes the patient in the family, in that the problem of *"nervios"* happens to everyone. The use of this term decreases stigmatization of the ill family member and involves a prospect of cure for the condition.

Based on a study of disease conceptions among the relatives of patients diagnosed with schizophrenia in Brazil, Villares showed that they construct a more benign and agreeable concept of their relative's illness through the use of categories such as *"nervoso"*, problems of the "head" and spiritual problems.[19]

In a study of the religious and cultural construction of the first psychotic episode of 21 young inhabitants of the outskirts of São Paulo, Redko found that religion has a series of symbols and representations that equip patients to give meaning to their psychotic experience.[20] Religious references are useful for naming or describing what the youths are experiencing, and are used as a strategy for dealing with the psychosis. These references are necessary for reassuring patients and providing grounds to a feeling of belonging. According to the author, "religion helps to communicate, elaborate and transform the experience of psychosis."

According to Kleinman, changes in biological and psychological processes are quite distinct in experience and meaning for each individual, constituting unique processes.[12] Studying them as being explanatory models that clinicians and their patients construct in order to understand the illness, the initial ones based on their cultural accoutrements of the medical establishment and the following based on lay cultural baggage. These explanatory models are defined as notions about an episode of the illness that are used by everyone involved in a given clinical process. They provide explanations for the illness, guide choices concerning therapies and available therapists and introduce personal and social meaning to the experience of the disease.

Illness perception, understanding, and help and treatment seeking, always place the distinct explanatory models of the physician and the patient in opposition. In this light, we can now see the doctor-patient relationship as a negotiation between these two explanatory models, which are not static, as both sides are in a process of transformation through experience and new information.

An understanding of the main components of this relationship between specialist and patient takes place, therefore, in the arena of social relations, functioning on the levels of: 1) appearances, which include the gamut of sense and perceptual phenomena and their rationalizations and 2) essences, the profound motives and true reasons that invisibly move people (level of cultural functioning).[21]

The research question answered by this study was: Why delays of more than 6 months, to seek psychiatric counseling, are a common practice for relatives of persons having suffered a first psychotic episode, in the Greater Sao Paulo area?

Method

Referencing anthropological theory is an appropriate mode for investigating these subjects. Therefore a qualitative approach was used in this study. Information concerning the experience of family members of the ill person when seeking help and treatment was gathered. We evaluated how relatives mentally work out these issues, and what are the successive attempts for understanding and for perceiving connections in the sense of understanding and managing the reality. The study was approved by the Universidade Federal de São Paulo's ethics committee (process n. 0769/02).

1. Location

The study took place at the Psychotic Episode Program (PEP), an outpatient service of the Department of Psychiatry at the Universidade Federal de São Paulo created in 1999 with the objective of treating and accompanying patients in their first psychotic episode.

2. Patient selection

We decided to carry out the study with families who had one member at the PEP, justifying this criterion by the need to obtain coherent histories and intelligible, non-fragmentary discussions, which would not have been possible if the discussant were the patient him/herself. Patients whose families participated in the study were selected from among those in care at the PEP at that time.

Inclusion criteria for patients whose relatives were evaluated:

1) Having begun treatment due to a first psychotic episode defined by the presence of at least one of the typical symptoms, to wit, delusions, thought disorder, catatonic symptoms;

2) Having a time of untreated psychosis longer than six months defined as the interval between the start (as perceived by the family) of psychotic symptoms and the start of proper treatment;

3) Between 14 and 45 years;

4) Living with at least one family member.

Exclusion criteria:

1) Having had proper psychiatric treatment, defined as the use of a sufficient quantity of antipsychotic medication, (dose equivalent to 5mg of haloperidol), for sufficient time (minimum of three months) according to Larsen's criteria;[22]

2) Exhibiting an organic mental disorder;

3) Selection of relatives.

Relatives were a crucial aspect of the study, because they, for the most part, are the ones who decide to seek or not to seek medical treatment.

For family members, the inclusion criteria were:

1) Being at least 18 years old;

2) Living with the patient or in frequent contact with him/her;

3) Accepting to sign a consent form.

3. Data collection

Relatives were heard in in-depth interviews lasting between 45 minutes and 1 hour 50 minutes. A checklist was used containing subjects concerning: 1) perception of the first symptoms or behavioral changes in their sick relative; 2) how these were dealt with; 3) how they were understood, and if help was sought, what this help was and what difficulties they faced in getting it.

The study included 15 valid interviews with family members of 9 patients from June 2002 to July 2003. All of the interviews were recorded and later transcribed.

4. Analysis

Analysis was preceded by the organization of common passages in the interviews, which were grouped and classified, as per research needs, in terms of categories, concepts and notions, in the sense outlined by Kant, in his Critique of Pure Reason, that became the basis of scientific thought, according to Lalande.[23] Roughly, these terms correspond to decreasing levels of abstraction, as found in language.

Analysis, as such, involved discovering meaning nexuses, formulated or suggested, for each group of ideas identified in the interviews.[24-26] This methodological procedure of classification and analysis is common in the Social Sciences and is based on the theoretical principals of anthropologists like Lévi-Strauss[21] and Oliveira;[24] our field data collection procedures and techniques came from Martinelli[27] and Enelow.[28] The main explanatory categories were: relatives' conceptions about mental disorders, conceiving of the problem in cultural terms, and responsiveness to the psychiatric treatment and related services.

We sought to bring out the reference system used by the patient's relatives in their effort to understand and explain the patient's actions and ideas. Texts were trimmed of idiosyncratic interpretations, keeping only actions, facts and opinions common to at least two people and capable of revealing an underlying analytic reference.

Quotations from informants are identified with fictitious names.

Results
1. Characteristics of patients and relatives

The 9 patients who participated in the study aged between 20 and 29 years, were single, 6 (67%) were men and 3 (33%) were women. As regards years of education, 2 (22%) had not finished primary school, 5 (56%) had not finished secondary school and 2 (22%) had finished secondary school. Concerning religion, 3 (33%) were Catholics, 4 (44%) Evangelists, 1 (11%) Jewish and 1 (11%) belonged to a sect (Universo em Desencanto).

Of the 15 relatives interviewed, 8 (53%) were mothers, 1 (7%) a father and 6 (40%) siblings, while 10 (67%) were women and 5 (33%) men. Regarding age, 6 (40%) aged between 20 and 39 years and 9 (60%), between 40 and 59, while 6 (40%) were single, 6 (40%) were married, 2 (13%) were divorced or separated and 1 (7%) was a widower.

Concerning years of education, 7 (47%) had not completed primary school, 1 (7%) had finished only primary school and 7 (47%) had completed at least secondary school. Regarding religion, 8 (53%) were Catholics, 5 (33%) Evangelists and 2 (14%) were Jews.

2. Guidelines to elaborate analytic categories

Based on interview analysis, we observed that the search for help and treatment was influenced by: 1) the relatives' stereotyped misconceptions about mental illness; 2) models constructed to understand the patient's problem; 3) fear of psychiatric treatment; 4) a bad experience with psychiatric services.

3. Popular conceptions concerning mental illness

Many relatives reported that when they first perceived behavioral changes in the patient, they did not see it as an illness, a psychiatric problem. The understanding of the problem as an illness developed slowly during the process of seeking help and treatment.

However, before their relative got sick, they had had some notions about mental disturbances, but this was not associated with the common idea of disease.

Some relatives used the terms "*loucos*" (crazy) and "*malucos*" (lunatics) to refer to individuals with mental disorders, with whom they had had very little contact. The conceptions presented concerning crazy individuals were quite prejudiced and derogatory.

"For me, lunatics tear up money, throw rocks at people […] Curse at people, you know, for me that was crazy. You know, I didn't have this business of a head problem, you know, get upset by something, say things that don't… I had no idea what that was."

For the interviewed relatives insanity was something distant that they knew about vaguely. Crazy people were not a part of their daily life; they were people you ran into on the street from time to time. They confounded them with drunks, beggars, the homeless, that is, with outcasts, people excluded from society. The crazy were insignificant people, outside their universe of relationships and rarely thought about.

The idea they had of insanity was also strongly tied to violence and lack of control. Crazy people were seen as dangerous, as having lost the "brake" that controls impulses and allows social interaction; they would be capable of any act, including violence. Therefore, they were threatening, caused fear and had to be watched and contained.

"Uh, on television it's terrible, you know, it shows the worst examples, people who are completely, make no sense, people lose their reason […] Because, I don't know, the person can get a knife, hurt himself, hit someone else, can attack someone."

For relatives these stereotypes of insanity, that they had before treatment started, did not explain what had happened to their relative, who was not seen as crazy. It was impossible to compare him with these lunatics on the streets: drunks, beggars, or with the crazy people you learn about in the newspapers or on television, out of control, aggressive, and threatening.[29]

4. Problem elaboration and classification

In as much as their previous experience was not useful for understanding the present condition of the ill person, relatives were obliged to understand and fit the patient's problem into a category of known ideas. The main explanation expressed by relatives was to deny its importance. One of them summarized this well: "It's nothing".

Initially people tried to understand their relative's problem as a passing stress, a crisis characteristic of the age or the heightening of some personality traits, an eccentricity. Symptoms were discounted, considered irrelevant and insignificant.

1) Drug problems

On perceiving the first behavioral changes and psychotic symptoms, some relatives thought they were a result of drug use. When they were able to confirm the fact that the youth used drugs, everything came to be explained as a drug effect, especially of cannabis, as this quotation expresses:

"The first thing that came into my head is that he was using drugs, because a behavior like that, he talked to himself in the bathroom, cursed the neighbors from the bathroom…"

Drug use is associated with lack of character, a departure from family values. In these cases relatives expressed their disappointment, as if the patient had betrayed them and had failed to return the investment they had made on him. This was a family shame, something you did not tell other people about, in that there was fear of discrimination against the patient and family.

2) Spiritual side

A search for spiritual explanations is *de rigueur* in Brazilian culture.[20,30-31] In interviews only one relative failed to produce this kind of explanation. Pentecostal religions were those most mentioned. Even people who did not practice Evangelical religions sought them out to deal with the patient's problem. There was also an interest in "witchcraft", "blessings" or communication with spirits. Informants spoke with a certain reticence, saying they did not really believe in these things, but sought them out as yet another attempt at cure and a possible explanation.

One of the ways of understanding psychotic symptoms is to consider the patient as possessed by a spiritual entity, most frequently the devil. The influence of a malign force[32] is a commonplace explanation for a person presenting behavioral changes, euphoria and saying lots of meaningless or weird things.

"I thought, it must be somebody who died and I don't know…invaded his body, his soul, beats me…[…]. That's what I thought, that somebody had died like that, because there was no way he could have invented so many things, talking so much about things that had never happened in his life."

The dark force responsible for the patient's disturbance is identified with the devil, a pervasive figure in the daily life of Pentecostals, in that he is the incarnation of all evil, source of illness, conflicts, unemployment, vices like gambling, alcohol and drugs.[20,32-33]

The devil can act when someone commits a sin or when they go to services of other religions, especially Afro-Brazilian cults.[32-33]

However, for the people interviewed there had been sin or attendance to some other religion. Some relatives explained what happened through the idea of "cursed".

In a curse, when an individual commits some mistake, normally related to Afro-Brazilian religions (practicing *macumba*, participating in *umbanda* or making a pact with the devil), God allows the devil to act and influence later generations (five or ten generations). Thus, the evil a person is carrying now is a consequence of the mistakes of his ancestors, a kind of spiritual inheritance.

"That's the way it is, suddenly someone in my family, from my ancestors who were involved in something, black magic or something, that goes on from generation to generation. So for three or four generations nothing happens, but suddenly in the fifth generation something can happen,[...] First the people from the church said that this came from my mother's womb, and could have been anyone, even more so the last daughter, so it came out in her. So it's like that, if some family goes into something wrong, or black magic, it may not come out in that generation, but in future generations; someone can, I don't know, get sick or have an attack and die."

The illness is understood as an imbalance that can be manifested at various levels: body, soul and spirit. According to the relatives, the spiritual are the things of God, the soul is mind, thoughts and feelings and diseases of the body fall to the physician. As a result, seeking out religious help in most cases does not exclude medical treatment and these are considered complementary, acting on different levels.

However, in two cases relatives saw the patient's problem as exclusively spiritual and concerned themselves solely with the spiritual question for a period of one to three years.

5. Conceptions about psychiatry

Some relatives delayed a long time in seeking psychiatric care; but others sought it out right from the beginning but did not follow the indicated treatment.

The search for psychiatric treatment was often delayed because relatives were afraid of psychiatric services. The practices of psychiatrists were considered aggressive, authoritarian, and could even make the patients worse. Interviewed relatives talked about fear of excessive medication and its effects, of entering into a psychiatric hospital, the use of electroshock therapy and straightjackets.

"My neighbors [...] said: "Carlos isn't right in his head and if you put him in a hospital, he's going to end up out there among the lunatics, they'll give him shock, I don't know what will happen, they'll dope him, tie him up in a straightjacket"[...]. So I got scared, I mean really scared."

A good part of these ideas and images concerning psychiatric treatment in public knowledge are vestiges of the old insane asylums and mental hospitals, where practices were not always praiseworthy and were often cruel and inhuman.

"Once on television I saw it, they went to some insane asylum or other, but it was on television, they were all put together there, all kind of imbalanced, dazed, walking around and all the family rejects put together in there, you know. So I said my son isn't going to end up in a place like that, no way."

Relatives generally had no reference or experience with psychiatric treatment involving more positive connotations.

However, some of the interviewed looked for treatment earlier but did not follow the recommendations. In these cases, treatment was not followed due to structural questions of mental health care services (there were difficulties to get initial care, consultations were brief and there were considerable delays in scheduling return visits) and due to difficulties in the doctor-patient relationship.

"So time passed, so the health system wasn't working out, it wasn't working. [...] The doctor looked at me like this, handed me the medications and said to come back in three months. You know it just wasn't right?"

Discussion

1. Popular conceptions concerning mental illness

Before their domestic experience with their relative, the stereotyped conceptions of interviewed relatives about insanity were elaborated out of common knowledge, that is, they came out of traditional ideas, not from scientific objectivity or empirical evidence. Lunatics were seen as outcast individuals, scorned, excluded from society like drunks and beggars, to be censured, or else as potentially violent individuals, dangerous, who must be watched.

This stereotype system, although current, did not serve to family members when describing their sick relative. Interviewed family members understood and mentioned "lunatics on the streets" in a clearly differentiated manner than they mentioned their own sick relatives.

Analysis of the interviews confirmed two concepts present in other parts of outlying São Paulo, as reported by Quirino dos Santos,[27] which can, for the purposes of this study, be characterized as "our lunatics" and "the others' lunatics", with the distinction between these two classes being made possible by the affective and emotional warmth people have with their sick relative but not with the remaining ones.

The "others' lunatics" are receptacles of highly negative behavioral attributions such as violence, begging and criminality, strengthening an idea of social withdrawal. These others' lunatics are outside the daily life of the interviewed relatives, a desired separation, in that they are a threat, can be dangerous and, even worse, can show themselves to be like our own lunatics, making the distinction between the two categories slippery.

Despite exhibiting behavioral problems, "our lunatics" are understood in their own strange purposes. The behavioral changes they show are acceptable within the elastic notion of rationality and understood. Yes, they have problems but they make sense.

The mental illness of the "others", called lunacy by patient relatives, was mostly associated with violence.

The stereotype linking mental illness and especially schizophrenia to violence is common throughout the world.[34] Even studies showing a more tolerant public attitude concerning schizophrenia,[35] also reveal that the idea of danger from the mentally ill remains close to the surface, in popular consciousness, being one of the most important components of the stigma of schizophrenia.

When evidence showed that the model in vogue was inadequate, family members did not abandon it, they just separated their sick relative from it, asserting that he/she was not like the others. Even in the face of evidence to the contrary, they stubbornly carry on accepting tradition as a window to the world.

2. Problem elaboration and classification

Family members always need to understand what is happening with their relatives. They also need to classify serious changes in behavior exhibited within the categories available to them, and within their cultural milieu, in order to get an idea as how to deal with the situation, what attitudes to adopt, in essence, how to understand in order to act.

According to the interviews, at first, symptoms were not given importance, and considered just an adolescent crisis, thus viewing them as disturbances that would be solved without the need for treatment.

With the persistence and aggravation of the problem, successive explanations are found that can cover whatever the patient is doing. A psychotic picture reveals a situation of chaos and confusion, where the crucial question for the individual and his relatives is to use culturally available interpretations to organize the experience.[36]

Interviewed relatives attributed the patient's condition to a spiritual problem or drug use. In addition, they related each of these explanations to the understanding that the patient's problem was caused or set off by psychic or social factors.

In the cases studied, there is generally a tendency to explain a patient's problem as caused by external factors: suffering experienced by the patient, especially in childhood, led to fragility, making him/her more susceptible to factors outside the body, like spirits, pressure at work. As a result, this emotional fragility made it impossible to react successfully to external factors. In this sense, the patient is not held responsible for the illness, which just happened when the problem came out due to drug use.

Of particular importance was the attribution of psychotic symptoms to spiritual problems, an explanation used by almost all those we interviewed. Psychotic symptoms were seen as caused by spirits that took possession of the person or at least partially, as a result of a "spiritual element".[37]

3. Conceptions about psychiatry

Some questions concerning psychiatric care contributed to the delay in starting treatment, among which were: negative notions that relatives had about psychiatry and its practices and bad experiences with treatment, both in terms of the structural aspects of mental health services and due to problems in the doctor-patient relationship.

Conclusions

Cultural factors may influence the whole process of understanding and seeking help for a first psychotic episode.

Thus, mental health professionals should routinely evaluate cultural and social meanings that patients and relatives give for symptoms and illnesses. This will allow more inclusive evaluation of patients and their diseases and of their family's involvement. This will also make it possible to propose interventions that both respect and effectively mobilize particular family bonds available to the patients.[37]

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