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Therapeutic follow-up in hospitalization: social inclusion, recovery of citizenship and respect for individuality

O acompanhamento terapêutico na internação hospitalar: inclusão social, resgate de cidadania e respeito à singularidade

Acompañamiento terapéutico en la internación hospitalaria: inclusión social, rescate de ciudadanía y respeto a la singularidad

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ABSTRACT

This study was carried out in a psychiatric crisis hospitalization unit, with the aim of drawing up a proposal for implementing therapeutic follow-up as part of the therapeutic program at this unit. The concept of therapeutic follow-up was envisaged as an important resource to be included in psychosocial rehabilitation projects, with the following goals: linking users with extra-hospital services, avoiding re-hospitalization and achieving inclusion in social networks. The study consisted of an exploratory-descriptive case study with a qualitative approach to data. Participant observation and a field diary were the techniques used for gathering and recording data. The difficulties experienced were correlated with the spheres of social networks, family, institutional relationships and society. The results included heeding the patient's and the family's suffering and including users in social networks, extra-hospital services and community organizations.

Key words: Mental health. Mental health services. Therapeutic follow-up. Rehabilitation. Social Inclusion.

RESUMO

Esta pesquisa foi realizada em unidade de internação psiquiátrica de crise, com objetivo de elaborar proposta de implementação do acompanhamento terapêutico (AT), para compor o programa terapêutico dessa unidade. Trabalhou-se com a concepção de acompanhamento terapêutico como recurso importante para integrar projetos de reabilitação psicossocial, tendo as seguintes finalidades: vincular o usuário em serviço extra-hospitalar, evitar as reinternações hospitalares e inclusão na rede social. A pesquisa constituiu um estudo de caso exploratório-descritivo, com abordagem qualitativa dos dados. Como técnica de coleta e registro dos dados, utilizou-se a observação participante e o diário de campo. As dificuldades vivenciadas relacionaram-se com esfera das redes sociais, família, relações institucionais e sociedade. Os resultados incluíram: acolhimento do sofrimento do portador e da família; inclusão dos usuários em redes sociais; serviços extra-hospitalares; e organizações comunitárias.

Palavras-chave: Saúde mental. Serviços de saúde mental. Acompanhamento terapêutico. Reabilitação. Inclusão social.

RESUMEN

Esta investigación se realizó en una unidad psiquiátrica de crisis, con objeto de elaborar propuesta de implemento de acompañamiento terapéutico (AT), para componer el programa terapéutico de esta unidad. Se ha trabajado con la concepción de acompañamiento terapéutico como recurso importante para integrar proyectos de rehabilitación psicosocial con las siguientes finalidades: vincular al usuario en servicio extra-hospitalario, evitar las internaciones repetidas en el hospital y en la red social. La investigación constituye un estudio de caso exploratorio-descriptivo con datos aproximados de calidad. Como técnica de colecta y registro de los datos se ha utilizado la observación participante y el diario de campo. Las dificultades afrontadas se relacionan con la familia, redes sociales e institucionales. Los resultados incluyen: acogida del sufrimiento del portador y de la familia, inclusión de los usuarios en redes sociales, servicios extra-hospitalarios y organizaciones comunitarias.

Palabras clave: Salud mental. Servicios de salud mental. Acompañamiento terapéutico. Rehabilitación. Inclusión social.

INTRODUCTION

The movements towards the psychiatric reform that originated in Western Europe and the United States half a century ago reached Brazil about thirty years ago. Despite the undeniable progress achieved so far, we still face a scenario in which ethically oriented goals aimed at abolishing asylum-like treatments are far from being fully implemented in Brazil (Amarante, 1995).

During our work and research in the field of mental health we observed problems in the implementation of the psychiatric reform's guidelines. According to these, the main objective of actions and services in mental health is to replace the hospital-focused model and create treatment opportunities in the community. However, what we have seen is the development of a process in which the mental disease is actually prolonged. This process emerged in the very services created with the mission to replace the asylum facility and which, in reality, dispense with hospitalization. Therefore, we observe some problems with a group of patients who experience an important increase in the number of their hospitalizations.

Thus, based on work developed in this unit we have witnessed problems presented by some patients that hindered their treatment processes, which were related to the impact of the disease and the fragility of patients with mental disorders and their families in the disease process. Additionally, patients presented a series of social difficulties, which in general, led to their exclusion from social inter-relationship spheres. Other problems were coupled with these, which became important obstacles to the maintenance of a minimum level of quality of life of individuals with mental disorders: breakup with social networks and non-adherence to outpatient treatment, in addition to a lack of treatment resources, especially medication, in outpatient mental health services.

Based on consensus reached among the mental health services in the city where this research is carried out, and under the oversight of the local manager, hospital-discharged patients were referred to a mental health outpatient service or facility to proceed with their psychiatric treatment. However, these services did not offer any other therapeutic resources in addition to medication (or they were very limited). Thus, patients would only attend medical visits with no other therapeutic alternative whatsoever beyond consultations. Users of these services frequently abandoned treatment with consequent relapses of psychotic crisis and new hospitalizations.

In the face of these problems, we perceived the importance of providing more individualized care to these patients, which would at least point to a chance of recovering important aspects that enable material production in their lives, new forms of care delivery, social inclusion and the avoidance of the vicious cycle of recurrent hospitalizations and prolonging the disease process.

Given the increased number of hospitalizations evidenced in the hospitalization unit, the failure of some treatments for users at the outpatient level and context, where they are disconnected from social networks, we thought that a therapeutic follow-up (TF) would be a privileged tool to work in the delivery of care to patients with mental disorders and who were facing these problems. Because TF is a clinical practice that can be developed out of hospital facilities and traditional environments and be carried out in public areas or in the patients' social and domiciliary environments, it represented an important strategy to allow us to be closer to the families' problems and existent difficulties. Additionally, because TF is individualized care, it could enable, through the creation of a therapeutic bond, the development of a more efficient elaboration of suffering and also affective relationships more significant to patients. It also could be a potential strategy to include patients in social networks and movements of social inclusion.

Therefore, this study's main objective was to develop a proposal for the implementation of therapeutic follow-up to integrate with the therapeutic program of the hospitalization unit.

The chosen methodology was an exploratory-descriptive case study with qualitative data analysis. Participant observation was used for data collection and a field diary to record data. Participant observation was carried out in ten TF consultations with users appointed by the technical team from the hospitalization unit, based on clinical meetings.

The TF consultations were performed by the researchers in and out of the hospital unit, accompanying patients out on the street, in their homes, in outpatient services (Psychosocial Care Center II-CAPS II, outpatient hospitals and mental health outpatient clinics in the city and region) and in the city's social organizations such as: the House of Culture of the Ribeirão Preto city council, Commerce Social Service (SESC), Industry Social Service (SESI), the Vocational Training Center of the Ribeirão Preto city council and a public school. These consultations were recorded in the field diary, and the records contain both the description of events during these consultations and our impressions that resulted from the established inter-relational bond and experience through the inter-subjective interaction of the involved partners, that is, user and therapist.

The psychiatric hospitalization unit, in which the study was carried out, integrates a state psychiatric hospital with the public health network in Ribeirão Preto, SP, Brazil, which is the reference center for 25 cities that compose the administrative region, whose center is Ribeirão Preto. The facility has a group of residents who implement the project of therapeutic houses in partnership with the city and one crisis stabilization unit, whose male ward hosted the study.

Hospitalization in this unit is indicated for cases that present some level of risk to the patients' physical integrity or of people close to them. Patients have to be referred by the public and mental health network of the region and city and pass through the office that regulates the availability of vacancies.

In recent years, however, an increase in the number of re-hospitalizations has been verified, which has pointed to a new process in which the disease condition has been extended, after the construction of services that were supposed to replace the hospital-focused model.

From this perspective, TF seemed to be an important tool to identify the difficulties faced by patients and their families and answer problems experienced in the disease process through the offering of new possibilities so as to facilitate users to make their own lives. According to Porto and Sereno (1991) and Barretto (1998) this practice is a process of intervention in the lives and daily routines of patients, with the production and construction of events, of new forms of subjectivity and reconstruction of personal history. However, in our case, we did not have long periods of time to carry out the intervention because the period of hospitalization in the unit was relatively brief. Thus, the TF had the following objectives: to welcome the suffering process through listening and support, ease social-family re-adaptation, establish more efficient bonds with society, connect the patient with outpatient services, include them in social networks and avoid the process of prolonging the disease process. In addition to the proposal to implement the therapeutic follow-up in this hospitalization unit, which was our main objective, the study had the following specific objectives: to characterize the patients undergoing therapeutic follow-up, know the factors that motivated the team to indicate these patients to the TF and identify the difficulties during this activity.

therapeutic follow-up: a strategy to include people who are in psychic suffering

Because therapeutic follow-up is a practice aimed to recover the right to enjoy public life for people who have been systematically excluded from such spaces, it is a form of care delivered to the individual who recovers the ability to circulate in the social world, an ability that was interrupted by the disease. This practice intensifies social exchange with a view to connect spheres of material and symbolic production in life and the search for spaces in culture in which particular forms of psychotic existence find expression, value and legitimacy (Carvalho, 2004).

In this way, we saw an important connection between TF and the reflections of some authors (Costa- Rosa, 2000; Saraceno, 1999) on rehabilitation and psychosocial care.

Psychosocial rehabilitation is understood as a set of strategies that, instead of qualifying suffering individuals through normalizing actions, presents them with paths in which they can produce social value and meaning based on the recovery of their ability to produce their own life through citizenship. Thus, it recommends actions that focus on recovering one's ability to recreate life in culture, through actions acknowledged and legitimated in the world and that include oneself in systems of social exchange (Saraceno, 1999).

Costa-Rosa (2000) analyzes two care modes in mental health through the concept of alternativity, in which a given reality is opposed to another, in the form of a contradiction: the asylum-like and the psychosocial. These two contradictory care modes are also alternative because their essential constitutions are opposed to each other. The author compares these two models and underscores some characteristics of the psychosocial mode as an alternative in health care because it views the human being in its biopsychosocial diversity, positions the individual as producer and transforming agent, includes him/her in social life, organizes horizontal institutions, bases itself on interdisciplinarity and permits the social participation and individualization of the individual. According to the author, the psychosocial model attributes the whole importance to the individual, mobilizing him/her as the main agent of his/her own treatment aiming at self-management. The psychosocial model replaces the technical-scientific dimension, which is typical of the asylum model. It is based on a dimension that privileges the ethical-aesthetic view, in which projects are based on interdisciplinary knowledge, focusing the symbolic dimension (psychic and sociocultural) as opposed to the organic model in the asylum mode.

Still, according to Costa-Rosa (2000), the psychosocial mode is noted as that which permits new forms of sociability, supported by dialogical interaction. Clients leave their condition of being banned, silent and immobile in which they are tutored by technicians, and assume interlocution, free transit and position themselves as subjects in a subjective, sociocultural and historical dimension.

If we refer to events that are given priority in TF, we discover that the objectives, principles and goals are very similar to those described in the field of strategies of psychosocial rehabilitation.

Porto e Sereno (1991) stresses that TF is an intervention that re-connects the subject with the social cycle, aligns the psychotic world with culture and enables the discovery of spaces in which individuals in psychic suffering can express their idiosyncrasies. TF also allows the reconstruction of a personal history in which individuals are active agents and exert their potential.

Barretto (1998) highlights the fact that therapeutic follow-up triggers a process in which

suffering individuals can inscribe their subjectivity on the world and, in this way, re-create their personality through the development of a creative and nonadaptive existence in relation to culture.

TF is a practice in which social exchange is the basis of events constructed during consultations. In the same way, it is an interdisciplinary practice without territorial boundaries of knowledge or excess of identities as pointed out by Saraceno (1999). TF promotes health in the most open environments, walks through the city and appropriates it as a place of habitation and collective coexistence, a field of negotiation and exercise of social contractual and citizenship (Marinho, 2006).

TF is, in our perspective, an important instrument for integrating projects focused on a psychosocial care mode because both: establish practices opposite to asylum-like practices and are aligned with the proposal of psychiatric reform; compose actions intended to recover citizenship; represent care modes that are based on the subject's individualization to the extent it involves the individual in his/her subjective, sociocultural and historical dimensions; are practices in which social exchange is the basis of construction and potential events and are interdisciplinary practices without territorial boundaries and fragmentation of knowledge and practice (Fiorati, 2006).

METHODOLOGICAL PATH

Studies mainly focusing on human beings and involving procedures, processes and relationships that refer to the subjective universe of human existence, productions and events that occur inside certain realities and social networks and are included in certain historical contexts, are developed in a field of inter-subjectivities characterized by a relation of communication between cultural universes, shared by the researcher and the researched. This inter-subjective field of constant exchange conditions the process of knowledge and therefore cannot be measured through quantitative techniques (Costa, 2002).

The type of study we developed fits this case and therefore our methodological choice was the exploratory-descriptive case study with qualitative data analysis. Participant observation was used to collect data and a field diary to record data. The choice of a qualitative approach met the need to explain human reality inside a universe that cannot be grasped through quantitative data, in quantified and objectified reality, not taking into account values, meanings, beliefs, idealizations and others that mediate the whole process of knowledge construction (Minayo, 1992).

Another key aspect we considered because it involves human beings, was the ethical posture in which we based the whole process, especially the consultations that are the main focus of this study.

The project was submitted to and approved by the Ethics Research Committee at the University of São Paulo at Ribeirão Preto, College of Nursing and also submitted to the technical team of the hospitalization unit at the Psychiatric Hospital that hosted the study and was approved by its Clinical Directory. Patients were invited to participate in the consultations and study in a meeting between mental patients and respective families and the team in which the first were informed about the objective of the consultations and ensured of their right to participate or not in the study with no harm whatsoever and an absolute guarantee of anonymity.

Data collection was carried out through the participant observation technique during consultations. Observation enabled us to immerse in the cultural and daily universe of the studied individuals and grasp elements of the inter-subjective relation established through consultations. Collected data were recorded in a field diary in which events were historically arranged as well as subjective impressions that resulted from the therapeutic process.

The unit's technical team referred these patients to the therapeutic follow-up, who we cared for in the hospital itself during their hospitalization and after hospital discharge (homecare). Consultations were held in the hospital facility, in the users' households, on the streets and in areas open to the public.

Data analysis was based on content recorded in the field diary. Through careful and successive readings, we designed some elements that integrated the set of information treated in light of specific objectives: the characterization of the patients under TF, knowledge of factors that led these patients to be indicated as suitable for TF and identification of difficulties experienced in the process.

DISCUSSION OF DATA AND RESULTS

Ten users were attended between December 2004 and July 2005. Because the study was carried out in a male unit, all participants were men with severe mental disorders, between 30 and 50 years old, and who had been submitted to long treatment processes in the public mental health network. These were marked by a biography filled with social ruptures, repeated hospitalizations, failed treatments and brief stays in mental health day-hospital facilities. Their interpersonal relationships were fragmented, marriages were either broke up or had never been initiated. These people were disconnected from social relationship networks, they did not have any intimate relationships, friends or any spontaneous interpersonal connection. The mother was the figure who maintained support, though weary in some cases. The patients under TF had interrupted their educational process or professional occupation due to the mental disease and were not involved in any productive activity. Although the patients' files reported paranoid schizophrenia and bipolar disorder (depressive episode), what mattered for our purpose was the existential process marked by suffering experienced by these people.

The factors that led the team to select these users for TF were: lack of social ties and exclusion from areas where exchanges take place; lack of support and non-adherence to the outpatient treatment; conflicts and family rejection and lack of guidance concerning the patient's management; many re-hospitalizations; severity of the psychopathological condition, and intention to prevent the process in which the disease condition is extended.

The main difficulties perceived during the research process are related to the difficulties experienced by the mental patient himself and those related to the social networks, family, institutional relations and society.

In relation to social networks, we found that all the patients under TF were disconnected from any organized dimension of the social network, starting with the family to which the patient belonged. Patients had marginal roles in relation to their families' daily and ordinary routines. Similarly, they had no connection with any organized social group in the community, were excluded from social exchange, both in relation to social exchange systems and life production spheres. In our perspective, this fact is a consequence of the

process to which patients are subjected, which is the endless extension of the psychotic process, that is, life is marked by an incurable diagnosis, which oftentimes, is considered the verdict, leading patients to find themselves progressively distanced from other social actors (Fiorati, 2006).

Thus, we observe that at the same time at which families gave up on their patients, health technicians are also distanced from them due to the difficulties inherent in the most complex cases – a condition that is included in the process of extending the illness that occurs in outpatient services, which, instead of replacing the hospital-focused model, reproduces treatments, aspects and characteristics typical of the asylum model and consequently excludes patients with mental disorders (Desviat, 1999).

In the face of the difficulties found in projects of rehabilitation, we sought alternatives to include these patients in social organizations in the community in addition to health services. It was useful to point out social alternatives to these people, however, it also exposed the omission of these services in relation to the integration of actions, a principle recommended by the Single Health System (SUS) and not complied with in such cases (Campos, 1992).

We went to non-governmental organizations, cultural associations, governmental bodies of culture and professional training, and to a public secondary school and included the participants in these organizations: computer courses, gardening, artistic design, hairdressing and halfway houses. However, at times, social impossibilities impeded desires that were incompatible with the rationality of a technology-dependent society. It can be illustrated by the case of one participant who dreamed of becoming an architect, but slowly developed the idea of getting enrolled in an artistic design course.

In relation to the family sphere *per se*, we observed they gave up on their members who became mentally ill, which led to a certain deterioration of the families' relationships. Family members reported they were overloaded with the care they had to provide, which increased their dismay in the face of difficulties that resulted from the lack of care and assistance they experienced. The only resource provided by the services was a return to medical visits; the services did not help in the management of patients so they would properly adhere to treatment.

We also observed a process in which families felt increasingly guilty, responsible for the disease and treatment failure, a guilt imputed by health technicians (Melman, 2001). This process is rooted in the very process of formation of the Brazilian modern family in the development of the Brazilian capitalist State. That is, a certain medical power in connection to the political objectives of the State imposing on families standards to the development of docile behavior needed to constitute a new affable demeanor required by the new political order (Costa, 1983). It is still currently observed as we see the technical-scientific orientation being imposed on families, without taking into account any political or anthropological dimension in which families are inserted.

The therapeutic follow-up was a very valuable resource for our practice because the consultations at home enabled us to be in close contact with families, which in turn facilitated welcoming these families' suffering and making new arrangements for the care of these individuals so as to minimize treatment abandonment.

In relation to institutional relations, we witnessed many asylum-like aspects entrenched in the way professionals treated and cared for patients. Even though we know that the therapeutic project of the hospitalization unit is aligned with the objectives of psychiatric

reform and with psychosocial care, these principles were not consensually and uniformly applied in this unit by the whole group of workers. We observed some workers neglecting individual care for patients due to some of the unit's rules of operation, that is, the facility's bureaucratic rules of operation overlapped the patients' individual needs. In this perspective, we also observed authoritarian and/or childlike practices to the detriment of therapeutic management, the recurrent use of physical and chemical restraining methods, and the lack of appropriate attire, which was changed only once a day.

In the face of the observed institutional barriers, TF also proved to be equally relevant because when we presented individual therapeutic projects we could contribute to discussions at several levels through our participation in team meetings and based on these discussions we reviewed many of these asylum-like practices. The team had several opportunities in which it could reformulate these actions. Additionally, when the intervention took the form of individualized care, inherent to TF itself, it took into account the patient's decision about the proposed treatment and the user's desires in the whole process. We also witnessed these same asylum-like aspects in the mental health outpatient services. In these services we observed that families and patients were blamed for already existent difficulties and treatment abandonment. Health technicians were not willing to take responsibility for complexities of the most difficult cases. We also observed coded links; crystallized and ritualized procedures in relation to patients' care; unshakable technical-scientific certainties in the territorializing of knowledge and an excess of professional identities; concentration of power in the medical action in a service still organized according to the medical-psychiatric model, and the absence of individual therapeutic projects. The process in which health technicians gave up in face of the difficulties, has in our view, two functions: to cover up their unwillingness to take responsibility in the construction of new forms of care and their therapeutic impotence in the face of the failure of the healing ideal of a model focused on the illness and not on the individual and his suffering.

However, these beliefs and values are the bases of these bureaucratic-institutional barriers. They do not occur in a vacuum, rather they find a fertile ground where they reproduce in society itself, a capitalist and globalized society, which creates values based on the possession and purchase of goods in which everything becomes merchandise, even values (Costa, 2004). In this perspective, patients with mental disorders are excluded from several social spheres because they do not produce, do not move goods and merchandise (only medication and treatment), and thus are generally destitute of value and socially excluded as citizens. At the same time, we see that patients are destitute in terms of daily life due to their unusual behavior, because their messages and affections are not understood under the cultural codes of this society and are thus relegated to the world of irrationality.

However, therapeutic follow-up was a very important strategy for the program of this hospitalization unit because in addition to implementing a more humanized and individualized practice, its actions were always directed towards the social inclusion of patients with mental disorders, so that it effectively enabled a better communication with the mental health network in the city and region and we were able to include some of the patients under TF in some outpatient services, which favored their permanence in the community and avoided re-hospitalizations. Additionally, as TF many times explored the patients' domiciliary environment, it allowed us to welcome the suffering of family

members, which directed new arrangements for care, consequently minimizing abandonment. Specifically with patients, the TF opened up possibilities to construct new forms of subjectivity and the elaboration of suffering as it also led them to be included in social networks and in cultural or training activities in social organizations in the community. This practice also created a fertile ground for institutional relations to become more democratic, an important element preventing the disease process from becoming prolonged and chronic.

Despite the noted difficulties, the development of TF with these users enabled the development of a proposal to implement TF in the therapeutic program in the hospitalization unit that hosted this study so as to treat acute crises of mental disorders, whose goals were: to help users who have any difficulty in being discharged from the hospital; offer elements to prevent the process through which the disease is prolonged; mobilize actions in order to avoid further hospitalizations; ease the permanence of patients in the community and favor outpatient treatment.

The technical team of the hospitalization unit forwards users who demand TF in the following situations: users who present problems in their family relationships and have difficulties in returning to social-family life; who are socially abandoned and/or socially isolated and need support to be included in social networks; who present a severe and persistent psychopathological condition; who already have a high number of re-hospitalizations and those who have a need to be included in mental health outpatient services or social organizations in the community. And also the manner in which this therapeutic activity is implemented is submitted to individual therapeutic projects, which is discussed case-by-case, jointly with the unit's therapeutic team and users. This activity will be available for supervised training of professionals or students from the health disciplines, highlighting the interdisciplinary characteristic that marks TF and its specificities and theoretical and practical properties.

Therefore, in our opinion, any health and mental health action, or any rehabilitation project should aim to include the construction of a routine in which the unusual and singular existences and idiosyncratic expressions of psychotic individuals may find value, inclusion and legitimacy.

FINAL CONSIDERATIONS

This project opened up a field of possibilities in respect to the benefits enabled by the implementation of a therapeutic follow-up with users included in this study. That is, this practice revealed rich resources that can be developed by rehabilitation projects and also in one-time actions, which present a series of difficulties that mark the most complex cases.

Much was discussed about the possibility of implementing TF in the public health system in the first meetings and encounters with therapeutic practioners held in the 1990s. Some professionals who exerted this therapeutic function asserted that the clientele attended in the public mental health services did not belong to the same symbolic universe of technical-scientific productions of therapists and their alternatives because they had other references of understanding of the public and private spheres.

Currently, we have examples of Brazilian public health services that already include TF practice in their therapeutic projects, such as: TF developed with children who have

problems with the law in a program from the city council of São Paulo[1] and a project developed by a team in the Institute of Psychology at the Federal University of Rio Grande do Sul, in partnership with the city council of Porto Alegre, offered therapeutic follow-up in outpatient services in the public mental heath network, among others (Palombini, 1998).

In our specific case, TF was a very useful and valuable resource developed jointly with the therapeutic program of this hospitalization unit for acute crisis of mental disorders that integrates the public network of mental health care.

Most of all, with regard to the actions that guided our interventions, these were always based in concern for and focused on rescuing and recovering individuals' ability to materially and symbolically produce their own lives, to develop a creative life through which they could inscribe their own personal mark on culture through constant action of life re-creation in the world and shared reality.

COLLABORATORS

The author Regina Célia Fiorati participated in all stages of the preparation of the article. The author Toyoko Saeki participated in the development of the article, its discussion and review. Toyoko Saeki also participated in the literature review, discussions and text review.

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