Original Article

The effect of mental illness on the activity of daily living: a challenge for mental health care*

Vida cotidiana após adoecimento mental: desafio para atenção em saúde mental

Vida cotidiana después de la enfermedad mental: desafío para la atención en salud mental

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ABSTRACT

Objectives: To investigate the effect of mental illness on the activity of daily living among individuals living in the community and to examine the options of those individuals for social inclusion. **Methods:** This qualitative study was guided by Agnes Heller's conceptualization of daily life. The sample consisted of 13 individuals who received care in a psychiatric hospital and 9 of their family members. Data were analyzed through content analysis. **Results:** Mental illness affected an individual's social participation and his or her activities of daily living. Although there were less opportunities for social inclusion, individuals with mental illness continued to be able to find other social possibilities. **Conclusions:** Mental health services valued the importance of daily life activities, which can promote autonomy and a place in society. It is important to recognize the challenges of individuals with mental illness for inclusion in the job market and interpersonal relationships.

Keywords: Mental health; Hospitals, psychiatric; Mental health services; Mentally ill persons

RESUMO

Objetivos: Procurou-se investigar como a doença mental afetou a vida cotidiana do paciente que está convivendo na sociedade e analisar as possibilidades de inclusão social encontradas pelos sujeitos da pesquisa. **Métodos:** Utilizou-se a metodologia qualitativa para abordar este tema e o conceito de cotidiano de Agnes Heller como fundamento da pesquisa. Foram realizadas 13 entrevistas com pacientes de um hospital psiquiátrico e 9 com familiares, e o material coletado foi submetido à análise do discurso. **Resultados:** Após o adoecimento mental há menos opções sociais e o rompimento com as atividades que esta população costumava realizar; porém, os pacientes encontram outros afazeres e novas possibilidades sociais, apesar de ainda serem necessários investimentos para inclusão social desta população. **Conclusões:** Indica-se que os serviços substitutivos valorizem as pequenas atividades da vida cotidiana, que geram autonomia e iniciam um processo de construção de um lugar social, sem esquecer os grandes desafios como a inclusão no mercado de trabalho e os relacionamentos afetivos.

Descritores: Saúde mental; Hospitais psiquiátricos; Serviços de saúde mental; Pessoas mentalmente doentes

RESUMEN

Objetivos: Se procuró investigar cómo la enfermedad mental afectó la vida cotidiana del paciente que está conviviendo en la sociedad y analizar las posibilidades de inclusión social encontradas por los sujetos de la investigación. **Métodos:** Se utilizó la metodología cualitativa para abordar este tema y el concepto de cotidiano de Agnes Heller como fundamento de la investigación. Se realizaron 13 entrevistas con pacientes de un hospital psiquiátrico y 9 con familiares, siendo sometido al análisis de discurso el material recolectado. **Resultados:** Después de la enfermedad mental hay menos opciones sociales y la ruptura con las actividades que esta población acostumbraba realizar; sin embargo, los pacientes encuentran otras ocupaciones y nuevas posibilidades sociales, a pesar de que aun sea necesario hacer inversiones para la inclusión social de esta población. **Conclusiones:** Se indica que los servicios sustitutivos deben valorizar las pequeñas actividades de la vida cotidiana que generan autonomía e inician un proceso de construcción de un lugar social, sin olvidar los grandes desafíos como la inclusión en el mercado de trabajo y las relaciones afectivas.

Descriptores: Salud mental; Hospitales psiquiátricos; Servicios de salud mental; Enfermos mentales

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INTRODUCTION

The present article refers to a study of the routine of mental patients that spent a period of time outside the psychiatric hospital but were admitted again after their social reinsertion failed. The focus was on the everyday lives of patients between hospital stays.

It is important to acknowledge that despite this reality of several admissions of mentally ill patients, the current context and the guidelines in mental health recommend mental health care that leads to the return of patients to community life, avoiding new admissions to psychiatric hospitals.

The Brazilian process of Psychiatric Reform began in the end of the 1970's, inserted into a political and social picture of redemocratization. This movement questioned the conditions of patient care and the hegemony of private hospitals, demonstrating the need for investing in the public sector.

The aim was to overcome the belief that psychiatric hospitals were the only place to treat mental disorders and replacement services were proposed which used an open system approach, respecting and increasing the rights of patients for social and family reinsertion.

In this context, the focus of treatment is no longer the symptom but the singularity of each patient – their history, culture, and daily lives – pointing out for a process that makes it easier for individuals to practice autonomy and their functions in the community, enhancing their possibilities with a personalized strategy[1].

However, nowadays, there are still some psychiatric hospitals that keep residues of the asylum model, existing together with replacement services such as the Psychosocial Care Centers and the day-hospitals.

A great difference between the hospital based model and the proposal against the hegemony which denies the classical model, is the attempt for social inclusion of mentally ill patients, with treatment in replacement services and also new social relations and spaces for life[2].

When social exclusion occurs, it is usually associated with individuals having to leave the job market, being socially weak, and unable to perform their citizenship. To build the social inclusion, individuals have to be able to lead their own history[3].

We can identify that people with mental problems are still among the ones most excluded from society. In the complex relationship between social exclusion and mental illness, many of the characteristic elements from social exclusion (such as unemployment, low income, and lack of social network) are, at the same time, causes and consequences of mental illness[4].

Thus, the present study was conducted to contribute to the care of psychiatric patients, supporting their social insertion. To that end, the specific objectives were to investigate how mental illness affected daily lives of patients that are living in society, and to assess the possibilities of social insertion found by the individuals of the study.

METHODOLOGY

The qualitative approach was used in the methodology of the present study in an attempt to understand the social relations in the field of health. Some aspects were essential such as "the relationship between individuals and society; between action, structure and meanings; between subject and object; between the fact and value; between reality and ideology, and the possibility of knowledge, according to the view of some sociological trends"[5].

According to this view on health and qualitative methodology, we based this investigation on Agnes Heller's concept of the everyday life, which is a critical analysis of the real working as a base to understand the social practice of concrete historical subjects.

Being inserted into a society is to organize a daily life that leads to continuity, interacting with others around you and with the society mode of production[6].

Individuals are inserted into society, understanding and taking part in the every day life of the community. Individuals' every day activities are related with everyday activities of their families, friends, workmates, thus, forming a network of social relations connected with these different activities. In this network, individuals may appropriate their reality in their own way, printing the mark of their personality, keeping their singularity, and building a life inserted in society[6].

The concept of psychosocial rehabilitation was used as an analytical category in the present investigation to establish the best negotiations between patients' needs and the opportunities of the context[1].

To sum up, we may infer that the assumptions of Psychosocial rehabilitation are: the construction of a new form of autonomous life inserted in society; the process of empowering users developed in the habitat, market and work, which are considered as places for exchange; and the reference to micro and macro variables of the social context determining the results of Psychosocial Rehabilitation.

The bases of the concept of everyday life relates with the assumptions of Psychosocial Rehabilitation, when it states that mentally ill individuals can build a life in society connected with the different levels?, without losing their uniqueness. Both concepts also discuss social insertion, mode of social production and the web of relations.

Place of Study

The research was conducted in 2004, in a Psychiatric inpatient hospital founded in 1958. This hospital is in the

city of São Paulo - SP. It is a private hospital with an agreement with the Single Health System (SUS), at the time of the study, there were 440 beds divided into different physical spaces called "wards".

The hospital has a routine for patients with pre-established times that must be met. The routine of the hospital is: to wake up, make the bed, take a shower, take the morning medication, have breakfast, wait in the yard or in the hallways for the ward to be cleaned, have lunch, take again the medication (if prescribed), stay in the yard or watch TV, have dinner, and take the night medication.

Despite the improvements and attempts for humanization, we can still see in this hospital traces of an asylum model which is marked by a strong institutional rule structure.

Study participants

The subjects of the present study were people with mental illness admitted to the psychiatric hospital described and their families, these patients, who were discharged from hospital and had to face the challenge of living in the community, had to build a routine outside the institution and had to continue the treatment in another care model different from that of hospital care.

Patients were selected according to the following criteria: patients admitted longer than a month (who had the possibility of overcoming the acute phases of the disease); patients admitted again to hospital in a period smaller than six months (that is, who had lived in society for a period of time, but whose life was impracticable and therefore were admitted again); aware patients, with orientation regarding time and space, able to keep a conversation, without moderate or severe cognitive deficit (able to answer questions and take part in the interview) and that accepted to take part on the study. Selection criterion for relatives was accepting to take part on the research.

As most hospital beds were for males, 12 men and one woman were interviewed, with ages ranging from 20 to 51 years old, with a total of 13 patients interviewed. Nine interviews were performed with relatives of these patients and four relatives did not agree to take part in the study; relatives were women, usually mothers and caregivers from 45 and 73 years old. These interviews were performed in the hospital.

The semi structured interview was geared to life history, emphasizing a certain stage or sector of personal life or an organization. In the present study, we assessed? the stage of patients' personal lives in the period between admissions[5].

The hospital was informed about the objectives, purposes and methodology of the study and the research project was approved by the hospital's Teaching and Research commission. The research project has also been approved by the Ethical Research Committee of the Nursing School at the University of São Paulo. Patients and relatives gave their written consent and confidentiality of their identity was assured.

Data analysis

Discourse analysis was used to interpret and understand the reality supported by the material collected, in order to "understand the mode of working, the organization principles, and the forms of social production of meaning"[5]. The discourse is produced within institutions, groups of a certain social context from a historical construction.

Discourse analysis sees "language as a necessary mediation between men and the natural and social reality" assessing the relationship established by language among individuals that speak and the situations where saying is produced[7].

The analyst sets out, separates, and links the bits said, organizing them for analysis. From the heterogeneity of the text, a thematic path is built, based on the bits said[8]. In the process of analysis, boundaries and cuts are designed and concepts and theories are resumed[7].

Rereading the several emerging themes, similarities among them were searched for, in an attempt to identify the empirical categories from the discourse. In the present article the focus will be on the category "everyday life", emphasizing the changes that occurred after mental illness and the patients' possibilities for the future.

RESULTS

In patients and relatives' discourse analysis, everyday life was one of the themes approached, and subjects made a relevant observation of the break caused by their illness, talking about a routine before the illness and another afterwards. Themes such as expectations and desires were also mentioned despite the mental illness.

In the statements analyzed, the past is related with greater possibilities of activities and social inclusion. There is a rupture with the "before the illness", when there were greater probabilities and more options of work, leisure and more friends.

P* 10 – *I lost interest in my career, my girlfriend, the married life.*

P 9 – *Now I don't do anything. After I got sick.*

P 3 – *It's been a year since I last worked. Since I got sick.*

PR 8 – *There were some friends, but this was long ago, then*

* The abbreviations "P", "PR" refer, respectively to the patients' discourse and their relatives. For example, in "P 13" and "PR 13", patients 13 and his relative are the interviewees. In only one case there is the statement of two relatives, the mother ("R1 P1") and the sister ("R2 P1").

they left. So now there aren't any. I have no friends.

The interruption of life is marked, the activities, the relations, and the social place individuals had are suspended because of the illness. There is a comparison between the everyday life "before" getting sick and the present life. Admission is seen as a mark of this break in everyday life.

Patients reported they found it difficult to keep their social network of friends and work and the illness was associated with depression and lack of hope. The illness carries a void to patients' lives.

However, although these breaks are reported, patients performed several activities during the day, presented as useful chores and enabling social contact, opposite to the apathy caused by mental illness.

Spending time cleaning and organizing the house was frequently mentioned by patients, they were concerned with the place they lived which demonstrates responsibility and ability to be independent.

P 11 – *I do the dishes, I mop the floor, I clean the bathroom.*

P 7 – *Then I go back home, do the laundry, and clean the house.*

The family pointed out household chores as a way to value the abilities of patients and associate this ability to a stage where the disease is stable. Doing the household chores is a way of being included and accepted in the family.

PR 11 – *He is so helpful. Sometimes someone is taking up the trash and he helps. Sometimes someone is cleaning the lobby and he asks if he can help. He is very helpful.*

PR 11 – *He is so calm, you should see. I find the apartment clean, the bathroom clean, the kitchen impeccable. He is very neat. But when he is in a crisis he gets unrecognizable.*

Household chores encourage individuals to adjust to the social, transforming the routine into action that can be classified, guiding the practical routine of men and legitimizing the social order[9].

Being able to take care of the house is one of the first steps to achieve independence and to live in society without requiring daily support from people.

Additionally to household chores, there are other activities patients perform at home that connect them to the shared world such as leisure activities. Leisure is a personal choice; it arises from a private interest, from an individual desire, as leisure activities are opposite to mandatory activities.

Patients mentioned several activities that were attractive and pleasant for them, such as watching television, listening to music, reading the newspaper. Most activities are done at home, they can be shared activities but they are solitary actions, individual ones. These are accessible activities, which are a resource for patients with tendency to retreat themselves, but which connects them to the external world since television and music are part of the social space.

P 8 – *I really like listening to music, I like listening to rock'n roll and reggae.*

P 4 – *(About leisure activity) Just going to the beach once in a while, looking at the beach, the sea, walking on shorts and that's ok.*

P 3 – *I like playing soccer and reading comics.*

The leisure activities oppose to the apathy, providing the patients with subjects that can be shared. Choosing a leisure activity shows initiative and a personal pursuit. Overall, they are important for life satisfaction, for feeling well where you are and with what you are doing.

Patients have also reported other activities that were part of their daily lives such as religious activities, practicing sports, walking around the neighborhood, and social contact. Patients and relatives tended to depreciate these activities and to not make patients responsible for other tasks which are considered more important. Thus, the losses reported by patients due to the illness are reiterated.

In patients' discourse, their desires and projects for the future have also been identified. Opposed to the apathy, paralysis and feeling of loss experienced by patients when they refer to the past, to "before the illness", the expectations for the future are promising and lively.

The main perspective is to live better, including to form a family, to expand and intensify relationships, to work and to be free from hospital stay as a form of treatment.

The desire to have a relationship with others is presented as something relevant, and the expectation of dating and building a family is stressed, to build a stable connection, to have someone to count on, to establish an affective relationship. The relational deprivation represents social exclusion, loss of roles and social interaction developed before the process of getting ill[10].

P 11 – *(I would like to) Date, go to the movies, take my girlfriend home, have children.*

P 10 – *(I would like to) Build a family; build a life, because I've already suffered a lot.*

P 8 – *I would like to be happy, find a place for myself, get married and have children.*

Another essential issue was work expectation. Entering the job market is a milestone in adult life, in the formation of a social network, and in the acknowledgment that one is capable.

Work is a way to achieve a place for social integration, as well as a place where human beings can reproduce their material (eat, drink, wear) and social (leisure, living together and freedom) lives[11].

P 10 –*Who knows, maybe I can get better, right? Maybe I can get a job, right? And... That is interesting, and that can help me out in life, right? That I can dress well, with money, buy myself a wallet, some machines, something for my house, right? And what I think about is to help my mother.*

P 8 – *I would change...I would get a job, a formal job, permanent for my whole life, until I get very old.*

P 4 – *(I would like to) work, of course. Work, work on my own.*

Pleasure with small things in life also appears, like wandering, eating something special, hanging out with friends, going to the beach, having a religion. They seem to be details, but it is from the constitution of small parts, pleasant and meaningful moments that one approaches to well being and to the construction of one's life.

The idea of replacement services is to favor ill patients, so they can experience the illness as a unique experience. The technical team starts to take into account the sick person, their history, their habits, social environment, the way they live life. The proposal is to help them deal with their difficulties, giving conditions and possibilities so they can take part in the social game[12].

P 10 – *Sunday, I want to eat "feijoada", there is a waterfall I can go.*

P 8 – *I would like to go out on Friday, go to a bar e have a beer. That is what a miss.*

P 4 – *I intend to live in my house on the beach, and then visit my mother in her place in the city, in São Paulo.*

PR 4 – *I think he needed to do something; a skill would be good, I think he would feel better; he would not be so troubled.*

What patients want for their future is to take part in socially accepted activities, which are part of the everyday life for the common sense: love, work, leisure, health and money.

DISCUSSION

The reports of mentally ill individuals show that mental illness causes a break in the everyday lives of these people which is marked by material and affective losses. Subjects relate the illness with lack of will, inaction, restricted possibilities and abilities. The statements confirm this lack of possibilities, the situation where they have no interest, a monotonous routine, and a life of isolation.

The social ties are lost, showing the difficulty in including them in the primary social network of relatives, friends and neighbors. Additionally, the disease also shows the difficulty of inclusion through work, decreasing patients' possibilities.

Corroborating the results of other studies[10- 11,13], the present study reinforces the devastating consequences of mental illness which makes people with a mental disorder be depreciated and excluded from their social context.

However, despite the depression cause by comparing what they could do "before the disease", investigating the everyday lives of this population showed that there are several activities on their present daily lives that give them a social place.

When the everyday life is looked more closely, within what is considered as "there is nothing to do", there are several small possibilities of activities and social inclusion. These occupations are usually depreciated, if they are, for example, compared to work, enhancing the idea of emptiness and disconnection with the shared world.

However, patients are still optimists regarding their expectations for the future, they present the desire to change the inertia, the lack of work, and the lack of a relationship.

Reinforcing the results of the research in the field of social inclusion, expecting a better life works as an anchor, stabilizing the current life, giving it meaning, and an optimistic view. For individuals' rehabilitation, it is essential that they have hope and believe in themselves[13].

The process of Psychosocial Rehabilitation refers to the possibility of patients perform their citizenship and achieve autonomy, professional education, social capacity, and material goods. It is the ability of people to fulfill completely their rights, with access to value, and towards emancipation.

Patients are the ones that can, in their system of relations, develop new forms of autonomy even if their mental illness does not present remission, affective ties may decrease the vulnerability and enable the creation of social connections[14].

When everyday life is not isolated, individuals live their lives in a conscious relationship with the private and the collective; they are responsible for their reality, imposing the mark of their personality[15].

FINAL CONSIDERATIONS

As presented by the interviewees, what they want and expect for the future is rehabilitation. Patients' discourse and the proposals of Psychosocial Rehabilitation converge. Individuals suffering mental illnesses refer they want to treat themselves, take care of their health, build a family, have friends, and work, they want a routine inserted into the community, they want a successful rehabilitation process. The challenge in life for mentally ill patients and their plans for the future are similar to the purposes of Psychosocial Rehabilitation.

When patients reported their daily lives, on one hand they indicate ways that enable the construction of a socially inserted life, with the performance and appreciation of the small activities of daily life, such as leisure, sports and household chores. On the other hand, there are great barriers that they cannot usually go through such as inclusion in the job market and affective relationships.

Thus, these aspects should be treated by the mental health services that aim at social insertion of patients, including in the practices of mental health teams paying attention to small daily activities that lead to autonomy and start a process of construction of the social place, and also to the major challenges such as the inclusion in the job market and the affective relationships.

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