THE SOCIAL EXCLUSION/INCLUSION OF USERS OF A PSYCHOSOCIAL CARE CENTER IN EVERYDAY LIFE

Mariana Moraes Salles, Sônia Barros

ABSTRACT: The present article aimed to identify the daily life experiences of users of a Psychosocial Care Center related to processes of social exclusion and inclusion. A qualitative approach was adopted as the research methodology. For data collection, semi-structured interviews were held with the service users and people from their social network. Discourse Analysis was used for analyzing the data. As results, it was found that the users experience situations in which they are excluded, especially in experiences related to discrimination and prejudice. There are also, however, opportunities from the context which favor inclusion, such as the inclusive attitude taken by people from service user’s social network and participation in the Psychosocial Care Center or in other places in the community. It is concluded that the processes of social exclusion/inclusion occur as everyday life unfolds, in the smallest and most subtle day-to-day occupations and relationships.

INTRODUCTION

In the mental health field, a process of transformation is occurring in the model of care for people with mental illnesses. In this regard, there has been growing reflection on questions of how people should relate to people with mental disorders, as there has been an increase in the number of services substituting the psychiatric hospitals. The concept of Psychosocial Rehabilitation (PR) has been used as a framework for the theory and practice in the mental health field.

PR is determined by variables: the micro-variables, related to private life and to affectivity, and macro-variables related to collective and social organizations. PR can be thought of as a set of strategies guided so as to increase the opportunities for exchanging resources and emotion, being a process which makes possible the “opening of spaces of negotiation for the patient, for their family, for the surrounding community and for the services which occupy themselves with the patient”. PR focusses on the person with mental illness and their particular needs, always articulating the singular therapeutic project with the social context in which the person finds themself, seeking to construct and make use of the community’s opportunities.

Integration into the community, however, remains a challenge for people with mental illnesses. The persistence of the association between mental illnesses and dangerousness results in stigma and isolation of those people who receive a psychiatric diagnosis. When a person receives the label of having a severe mental illness, a process of social exclusion can begin; in spite of the struggle against prejudice, the person still experiences discrimination, and opportunities and rights which in general are guaranteed to other people in society, who do not present mental problems, are denied to him or her. Thus, prolonged mental illness is associated not only with suffering, but with loss of liberty, autonomy and their access to material and social resources.

The fact that a person with mental illness lives in the community does not mean that he or she is included and is part of that community. For social inclusion to be constituted, the reconstruction of a meaningful and satisfactory life is necessary, in which one has access to opportunities related to the different activities and social roles which are considered important.

Social exclusion can be presented as a set of characteristics in the life of an individual, such as lack of contact and social support, unemployment, exclusion from participation in community organizations (like churches and clubs), discrimination, a reduced social role and few economic possibilities.

In addressing the issue of the social exclusion/inclusion of the person with mental illness, to a dialectical process is referred to, which takes into account the quality of the inclusion, the roles, the social relationships and everyday life’s subjectivities.

The social exclusion/inclusion dialectic is neither a state nor a thing: it is a process which involves the individual as a whole and his relationships with others, in the capitalist system. There is no single form, and it’s not a flaw in the system to be combatted as something which disturbs the social order – on the contrary, it is a product of the functioning of the system. The excluded person is not on the edges of society, but replaces and supports the social order, in this process experiencing social inclusion.

In this regard, it is important to understand the concept of social exclusion/inclusion within the context and logic of the mode of production of the capitalist system, reflecting on the current situation in which the people experiencing the process of social exclusion and inclusion find themselves.

In a capitalist society, the most decisive exclusion is that which occurs through the logic of capital, that is, through incorporation in the job market. Social integration is always directed at issues of infrastructure of the market of work and income.

Nevertheless, the process of social exclusion/inclusion is not characterized by insufficiency of material resources and work alone; other aspects, such as social relationships, are also of extreme importance. It is possible for there to be social inclusion even for those who do not work, it being necessary to reflect on other forms of inclusion, such as integration.

Primary sociability is defined as a system of rules which link the members of a group based on their “family, neighborhood and work belonging, and which weave networks of interdependence without the mediation of specific institutions”, these networks of relationships accompany the principal social roles and allow the transmission of learning and the reproduction of social existence. In the face of the fact that it is frequent for difficulties to occur in the process of primary integration, the term exclusion is defined as a break in relation to the primary integration networks.
The process of social exclusion/inclusion is multidimensional, as, in the same way that everyday life is heterogeneous, the process of social inclusion also takes place in different spheres of life, such as work, leisure, friends, family, housing, income, political activity, access to services and others. This process of social exclusion/inclusion develops based on how personal relationships are established, from the activities undertaken by the individual and from the relationship between the private and the collective.

Thus, reconstructing daily life after a period of illness does not mean living with the side effects of the medications or other treatment options; rather, it involves dealing with attitudes and reactions of the public in relation to mental illness.\(^1\)

In this context, the present article intends to contribute towards the social inclusion of people with mental illnesses, driving forward the debate and reflection on the subject, and proposing actions which make this population’s inclusion possible. The article’s objective was to identify the experiences of everyday life of people with mental illnesses, related to their processes of social exclusion and inclusion.

**METHODOLOGY**

The qualitative approach was used as the research methodology. This proposes that the meaning, as something arising from the human construction, is central to analysis of the social constitution.\(^1\) The context was considered in its complexity, reflecting on how the people in question live their lives, referring to the historical process in which they develop their base material, their social relationships, and their ideology.

As analytical categories, the concepts of Psychosocial Rehabilitation and Social Exclusion/Inclusion were used in this work, as described in the introduction.

The subjects of this investigation were people with mental illnesses who were users of a Psychosocial Care Center (CAPS) II in the West region of São Paulo, who were living in the community and facing the challenges of social inclusion and of constructing a meaningful life. Each service user interviewed was requested to indicate a person from their social network of relationships to participate in the research, the CAPS technical team being excluded from this. Family members, people from institutions (such as hostels and churches) and neighbors were indicated. As an ethical criteria, the only pre-requisite for the inclusion of these people in the study was to agree to participate in the research.

A total of 29 interviews was held, 17 with service users (identified in the results with the letter ‘U’) and 12 with people from their network of social relationships (identified with the letter ‘R’), as four service users did not want to indicate a person (or asserted that they had nobody to indicate). One person indicated, linked to the user’s social network, declined to participate in the research.

The CAPS, the study’s setting, was informed of the study’s objectives, the goals and the methodological procedures, and agreed with the carrying-out of the research in the locale. The project was also approved by the Ethics and Research Committee of the Municipal Health Department, which authorized the undertaking of the research (Decision n. 143/08). The interviewees signed the Terms of Free and Informed Consent, authorizing the use of the data collected in the above-mentioned research, with confidentiality of the interviewees’ identities being guaranteed.

The researcher was presented to the service users at the end of the social inclusion workshops which these participated in, and informed them of the research’s aims. Prior to data collection, the volunteers (CAPS service users and people who are part of their social networks) were informed about the study’s interests and reasons in a general meeting at the CAPS. The semi-structured interviews took place in the months of August and September 2008, in the CAPS or in places in the community, in line with the interviewees’ availability.

Two interview scripts were prepared, one for the service users and one for the people from their social network. The interviews investigated the interviewees’ conceptions on social inclusion, the service users’ daily lives, their material conditions, the places they went, the activities they carried out, the relationships they established with people around them and their social support network. In this way it was sought to ascertain how the process of exclusion/inclusion of people with mental problems happens. It was also intended to investigate the role of CAPS in the service users’ daily lives and in the perspective of social inclusion.

Discourse Analysis was used for examining the statements. This undertakes a reflection on the conditions of production and understanding of...
the meaning of the texts; with a view to “under-
standing the mode of functioning, the principles
of organization, and the forms of social produc-
tion of meaning”. Discourse Analysis sees
language as a necessary mediation between man
and the context. Language is understood as a way
of giving meaning, considering the production of
meanings as part of the life of humans, as subjects
and members of specific societies.12

In this work, following the collection of
data, the interviews were transcribed in full, con-
stituting a text for analysis. A thematic trajectory
was made, seeking to group the fragments of the
discourses by the issues to which they refer, bring-
ting together the similar thematic excerpts from
all the statements. Based on this theme, the text
was reviewed, with views to finding affinity and
connection between the themes, so as to define the
empirical categories inherent to the discourse. The
following empirical categories were identified: the
process of social exclusion/inclusion; social net-
works; and mental health care. The present article
refers to the process of social exclusion/inclusion
category; the other categories shall be dealt with,
in depth, in other articles.

RESULTS AND DISCUSSION

Processes of social exclusion

The interviewees gave various reports of sit-
uations in which they felt excluded and described
how they experience, in their day-to-day, the
process of social exclusion. The aspects reported
most as experiences of social exclusion were dis-
crediting and prejudice – experiences from daily
life which produce social exclusion and which are
in accordance with society’s conceptions about
mental illness, characterizing people with mental
illness as disabled and dangerous.

One of the ways in which service users ex-
perience prejudice is the impossibility of talking
openly about their illness, fearing being excluded
due to the stigma and the negative label which
mental illnesses carry.

The service users try to deal with the labels
related to mental illness by, for example, keep-
ing their illness secret or by withdrawing from
situations which produce stigma; these efforts,
however, frequently result in social isolation.13

I don’t say that I’m on medication... I tell people
I take medication for blood pressure, but I don’t say I
take psychiatric medications, because there’s a lot of
prejudice. They’ll think I’m crazy. And that’s not right,
for me to be hiding. Because I’d like to be open with
everybody (U6 phr 25).

Besides the prejudice, the interviewees men-
tioned various examples of situations in which
they had suffered discrimination, supporting the
literature and showing, yet again, the extent to
which the fact that a person has a mental illness
leads to a process of social exclusion.

All the interviewees – the service users and
the people from their social networks – reported
the experiencing of discrimination in the bus. The
special pass betrays that its carrier has a disability,
which, not being a visibly physical one, will prob-
ably be a mental one. This unanimity, in indicating
the bus as a place where discrimination takes place
in daily life, indicates that an intervention directed
at the interaction of people within public transport
might be a focus for combatting prejudice against
people with mental illnesses.

[...] the drivers all know me. So, when I get on...
I sit down, y’know, kind of ashamed, everybody looking
at me, because I’ve got the special pass (U6 phr 117).

Sometimes he goes out cheerful and comes back
sad, and says that he was on the bus and some guy was
looking at him in that way... But it’s over, and I said
‘It’s not important now’ (R17 phr 55).

In addition to this, people with mental
illnesses, in trying to participate in community
environments or socialization environments are
often physically excluded, both from public places
and from private ones, thus having their chances
of social participation limited by the label of being
mentally ill.

That people with mental illnesses must be
kept at a distance is part of passes for common
knowledge; thus, geographically speaking, the
service users still keep themselves segregated, in
spite of no longer being in institutions.14 The word
‘exclusion’ “expresses in a strong way a condition
of somebody who is outside, who is not an integral
part, who does not belong, for whom there is no place”.

[On discrimination] I’ve experienced it. I went
to a bar, when the guy there came over to say I was
doing treatment. They took me out of the bar, said I was
mad, and other stuff. They kicked me out of the bar. So
I left, y’know. I left, annoyed, but I left. It’s unpleasant
to hear these things (U11 phr 21).

In the Park, there was a time when they wouldn’t
let him go to the Água Branca Park. Nothing had
happened, because he doesn’t annoy anybody. The problem is, he’d be doing those yoga exercises, you know (R15 phr 57).

In this context, the experience of not going to different social spaces can be considered as an experience related to social exclusion and isolation. Mentally-ill people’s chances of circulating in society are reduced due to the relationship established with this population.

In the face of the lack of possibilities, of “having nowhere to go, nobody to talk to, and lacking a social network” the service users can spend the whole day at home, isolated and valuing less in the universe of social exchange, that is, having no contractual power. Thus, the psychosocial care clinic must “be guided by this complex function, of carrying out a set of actions which increase social circulation and avoid the isolation of the mentally-ill person”.

But I don’t go out, not ever. Not even with my nephew (U14 phr 35).

[On the subject of going to other places] no... I only come here [CAPS] (U16 phr 26).

Not all discrimination, however, is in exclusion from physical spaces or from the community in a broad way; discrimination was reported which takes place in personal relationships, either explicitly or implicitly. One should stress the strength of subtle exclusion caused by the distancing of friends and acquaintances, who stop spending time with the person with a mental illness, thus excluding them from their social environment.

I think that the silence, the lack of communication on the part of the people he used to be with, I think that’s a good example [of discrimination experienced by the service user]. He could count the people who have stayed in contact with him, out of the group of friends and people who we used to spend time with, in our day-to-day, on the fingers of one hand. And maybe that’s why he has this consideration for me, because I didn’t change, I carried on being his friend, as I always was, you know (R13 phr 46).

Sometimes, this isolation is also accompanied by the distancing of family members, which makes the feeling of loneliness and lack of support more acute. Because the family is a primary social network and a bond that tends to persist after the beginning of the mental illness, the lack of family support has a significant impact on the service users’ daily lives.

The family members are members of the general population, up until they experience the service user’s mental illness; as a result, they probably have the same knowledge of ‘common knowledge’ as other members of society, which can attain the level of disinformation and prejudice. The family members can feel lost in trying to understand what is happening, being unable to connect the experience of the mental illness with their own experiences, and may react by withdrawing from or attacking the service user.18

I stopped living with my sister, because unfortunately there was a brief argument with my brother-in-law... And in the heat of the moment, he told me to leave, and so I did (U16 phr 18).

Also identified in the discourses were phrases which express the experience of exclusion because of not participating in community activities, as the service users do not go to different social spaces (such as clubs, parks, libraries, workplaces and others) and do not have occupations which are meaningful to them. A meaningful occupation is different for each one and may be related to leisure activities, social activities, work or household chores, for example, depending on the person’s life history, their interests, and their social context. The lack of engagement and participation in occupations was considered a form of social exclusion.

In this context of lack of participation in activities, the service users report feeling an “emptiness”; as a result of their exclusion and lack of social participation, they experience anxiety and distress. With all the losses which occur concomitantly with the onset of the mental illness, it is difficult for the service users to achieve the feeling of self-realization.

Because I practically vegetate, I live inside the house, I don’t go out, I don’t go out. I believe I’m not included in society, I think I’m not (U10 phr 23).

I don’t know why, but I don’t like Sundays at all, I get anxious. Not anymore, because the medication helps not to have that immense emptiness, which I have on Sundays (U1 phr 24).

[On activities outside the CAPS] after I leave here, I feel an emptiness (U6 phr 73).

Even though the CAPS helps to fill this “emptiness” and find meaningful occupations in the routine of the institution, for some service users this is not enough for them to feel included. In this regard, social inclusion is an inclusion which must extend beyond the CAPS’s walls; it is participation in social activities and groups in the CAPS, but also outside the CAPS.
The role of the spaces reserved for the service users alone would change if these could circulate in other social environments as they would like to. The objective of social inclusion is for people to have a life which is not segregated, taking advantage of the social opportunities when and how they chose.14

[On whether he considers himself included in society] I think not, I don’t have a social life. I hardly go out. From CAPS home, from home back here, to the CAPS (U11 phr 12).

[On social inclusion] no. Only here at the CAPS, only through the CAPS (U11 phr 28).

In the experiences on social exclusion, another aspect stressed by the interviewees was the lack of income, as an issue for feeling themselves to be included. In a consumer society, those without purchasing power feel themselves to be excluded, that it has been made impossible for them to participate in social exchanges, that they lack the minimum material conditions for survival.

In addition to this, the service users’ financial limitations affect their ability to interact with their social network, and emphasize the image that they are different and the feeling of being excluded from society.19

[How society could help him] [laughs] writing off my debts [laughs]. I have debts with society in general, the world in particular and some very dear people (U4 phr 33).

I am not included in society. Because I have no purchasing power, I can’t buy anything, I don’t have an income (U16 phr 8).

Investment in the direction of social inclusion means working in a broad way on the impacts which mental illnesses can have on people’s lives – including the impact of losing one’s job, interrupting schooling and losing contact with friends and family. It also includes dealing with the feeling of isolation caused by other people’s attitude in relation to mental illness.20

It is also necessary to remember that the process of social exclusion/inclusion is not focused on the individual alone, but is a process of an individual who lives in a specific society.

Possibilities for social inclusion

At the same time that society excludes the person with a mental illness, there are also reports of experiences in which people from the service users’ social co-existence have an inclusive attitude.

Social inclusion is not just a theory or concept, it is something lived and experienced by people.21 The attitude of neighbors, family members and professionals who are in contact with the service users – of accepting them as they are, accepting their difficulties and differences – is an attitude of inclusion. The attitude taken by the people in the service users’ networks – of relating to the person rather than the illness – facilitates social inclusion, allowing the service users to belong to the environment in which they live. This is how the community experiences the inclusion of the person with mental illness.

The experience of social inclusion does not mean fitting into society and being accepted as a “normal” person; this would be like asking a person in a wheelchair to walk again if he wants to be respected. Social inclusion of people with mental illnesses means including the experience of madness as part of our society, valuing these people and recognizing the contributions which they can make.14

So everybody, my friends and relatives and family members, everybody co-exists very well with L. Maybe because he’s a really good guy, he doesn’t make problems with anybody. So what’s needed is for people to understand, to know that there’s nothing bad, nothing frightening about a person who is different (R12 phr 50).

The service users report, as experiences of social inclusion, the fact of their being welcomed by others, of being welcomed by people with whom they co-exist. In contradiction to the experiences of distancing from family members, this welcome and acceptance were mentioned as occurring principally with family members, an environment in which the service users can feel included.

The encouragement of people close to the service user can make all the difference in the process of social inclusion, with a welcoming family being a positive indicator in this process.22

[On social participation] it was when I went to live with my sister, at the beginning of the year. I went there and was well-received, they were having a barbecue... and everybody was happy because I was arriving, and I felt really good (U16 phr 17).

[On the situation of social inclusion] I participate in the environment inside my own home. When my sisters have birthdays, they invite me (U10 phr 36).

In contradiction to the experiences of social exclusion in different spaces in the city, the service users also report chances for participating and cir-
culating in social spaces. They make use of opportunities in the context, circulating in locales in their neighborhood and other neighborhoods, valuing the opportunities that a big city offers, and not just the possibilities offered by their established geographical territory. In this regard, one can point to the need to take advantage of the opportunities to circulate, and the offer of cultural and leisure activities, for those who live in a metropolis.

“The fact of going out onto the street, talking to people, and seeing life in motion is itself a way of being inserted in the community, and represents participation in the shared world”.

These co-existences in the public spaces represent experiences in the scenarios of habitat and market: they are exchange spaces.

[On places frequented] there’s the São Paulo Cultural Center, in Vergueiro (U1 phr 32).

I go into the city, to Bom Retiro. I go to the supermarket, I’ve got friends there, and talk with the girls, buy something and return home (U5 phr 62).

[In the Água Branca Park] I have a cup of sugar-cane juice, eat a hot dog, and do things that are good for my well-being (U15 phr 36).

The fact of being received well in the places they frequent is an experience of social inclusion; of feeling accepted and able to interact with others in a relationship of equality. Thus, the chance to frequent spaces which are not exclusive for mentally-ill people is an important way of experiencing social inclusion.

Social insertion takes place in microcosm in the service users’ spaces for circulation in the neighborhood and in the city. It is a collective process in which the participation of the person with mental illness can only be defined by the person herself.

But he was always in some other place with people who didn’t have mental problems. Cinema, a party... he participated. I think this is as important in the life of a mentally-ill person as the treatment is. Not to be segregated, to be there, to participate, to be with others who do not have this illness (R4 phr 21).

The CAPS was also emphasized as a place in which the service users experience social inclusion, and feel welcomed, make friends and feel they belong to the environment. Although the experience of inclusion happens within the physical space of the CAPS, there are chances for interactions with users and professionals of the service, and with family members and people interested in the activities promoted by the CAPS. These possibilities for social interaction are also described as experiences of social inclusion.

[On the situation of social inclusion] the commemoration of those with birthdays that month. Because, because of that, they make a cake, people come from outside. And I feel I’m participating. There’s just that, but it’s through the CAPS, it’s here inside, through the CAPS, outside you don’t get this participation (U11 phr 25).

[On the situation of social inclusion] a few years ago, there was a poetry and music competition, in a library in the city center. And M. participated, along with other patients from other CAPS. It was a very beautiful party, because it wasn’t only mentally-ill people, people described as “normal” were there too. He got over this thing about being ill (R4 phr 24).

The majority of the service users do not have a comfortable financial situation, only one service user and one person from the support network reported the experience of having income as an experience of social inclusion. Nevertheless, for those who have the opportunity to have a stable and adequate income, this is an experience of inclusion because of the possibility for consuming and autonomy. An income allows the person to be seen not as a weight, or a burden that the family members have to carry.

Access to income is equally important to provide material resources, but also non-material resources, which equip the person in the emotional or instrumental dimension, like inviting somebody to a café or to the cinema.

I always took care of myself to have my own money. I never asked for money from my stepfather. I didn’t think it was right to be asking him for money, I always worked. And I felt good when I went to buy a pair of sneakers, to buy something. (U9 phr 43).

One should, however, be attentive such that social inclusion does not become a normative requirement. It is important to note the extent to which each individual desires to alter his or her level of inclusion; at some times in life, a person may wish for a moderate level of inclusion in certain aspects of her life, such as contact with extended family. Participation in society must not become a rule; social inclusion is a process of the individual’s choice on how to live her daily life.

CONCLUSIONS

The service users’ routine experiences of exclusion evidence that they remain in an under-privileged position, exemplifying a social injustice,
in that the same opportunities are not available to all. To confront social exclusion, the stigma in relation to mental illness must be the subject of social debate, as society needs to reflect on its attitude regarding this question.

Thus, campaigns could be created to combat the stigma in relation to mental illness, through varying means of communication, such as television and radio, or using publicity materials in places where discrimination occurs. One possibility for undertaking this campaign is that it could be structured and financed by the Ministry of Health, or by other governmental bodies. In the same way that there are campaigns for prevention of AIDS, or against prejudice in relation to AIDS, or campaigns for prevention of breast cancer, prejudice against people with mental health problems should also be treated as a health matter.

One important context for carrying out these campaigns is that of public transport, considering that the service users point out that use of this represents a time in which situations of exclusion of the person with mental illness occur. Hence, posters could be put up inside the bus against discrimination and in favor of respecting difference. In addition to this, to deal with discrimination, the attention of health professionals is important for empowering the service users, who can position themselves to guarantee their rights.

The technical team can also act, providing contractual powers to mental health service users, in making use of the respect for their technical knowledge in mediating conflicts which arise in everyday life. The CAPS professionals can facilitate contact between the person with mental illness and people in the community, seeking to avoid prejudice, discrimination and the failure to value these people.

The experiences reported in this research, as experiences favorable to the process of social inclusion, are advances, located in the routine of a population which is no longer confined in psychiatric hospitals but which is struggling to construct a life in society. Thus, it was possible to show that many of the processes of social exclusion/inclusion take place in everyday life, in the smallest and most subtle occupations and relationships of the day-to-day. In spite of there still being changes to be made, it is possible to perceive transformations, both in the service users’ lives and in how society relates to this population.

Transformations can be perceived in the dialectical of the processes of social exclusion and inclusion; before, people with mental illnesses disappeared from the social setting, being hospitalized in psychiatric hospitals; now, they have achieved visibility for the people from their social network, in the environments of mental health in the community, and have begun to participate in different social settings.

REFERENCES


