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Being autonomous: what do mental health services indicate?

Ser autônomo: o que os serviços de saúde mental indicam?

Ser autónomo: ¿qué indican los servicios de salud mental?

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ABSTRACT

Objective: To build qualitative outcome indicators in psychosocial care regarding autonomy from the perspective of users and their families.
Methodology: This is an evaluative case study based on the dialectical hermeneutics theoretical framework, conducted at a mental health community service, in the state of Rio Grande do Sul, Brazil. The first stage of data collection occurred between February and July 2014, and consisted of constructing indicators based on qualitative data analysis of the two evaluative studies conducted at this same service. The second stage, between August and September 2014, consisted of validating the indicators constructed through the focus groups with nine users and nine family members.
Results: The users and relatives stated three qualitative indicators related to their autonomy resulting from their insertion in the service. The indicators were better self-management of income, improved everyday activities, and greater bargaining power.
Conclusion: The methodology proved appropriate to create qualitative indicators, from the perspective of the participants, and revealed that the service helps users achieve autonomy.
Keywords: Personal autonomy. Mental health. Evaluation. Qualitative research. Indicators.

RESUMO

Objetivo: Construir indicadores qualitativos de resultado na Atenção Psicossocial relacionados à autonomia na perspectiva dos usuários e familiares.
Método: Estudo de caso avaliativo, com referencial teórico hermenêutico-dialético em um Centro de Atenção Psicossocial no Rio Grande do Sul, Brasil. A primeira etapa da coleta de dados, fevereiro-julho/2014, consistiu na construção de indicadores a partir da análise dos dados qualitativos de duas pesquisas avaliativas neste mesmo serviço. A segunda etapa, agosto-setembro/2014, validou os indicadores construídos por meio de grupos focais com nove usuários e nove familiares.
Resultado: Os participantes apontaram três indicadores qualitativos relacionados à sua autonomia como resultado da inserção no serviço, sendo eles, melhora na autogestão da renda, melhor desenvolvimento das atividades do cotidiano e maior poder de negociação.
Conclusão: A metodologia utilizada mostrou-se adequada para criação de indicadores qualitativos na perspectiva de usuários e familiares, bem como apontou que o serviço auxilia no processo de conquista da autonomia.
Palavras-chave: Autonomia pessoal. Saúde mental. Avaliação. Pesquisa qualitativa. Indicadores.

RESUMEN

Objetivo: Construir indicador cualitativo de resultado en la Atención Psicosocial relacionado con la autonomía desde la perspectiva de los usuarios y familias.
Metodología: Estudio de caso evaluativo, realizado en un Centro de Atención Psicosocial del Rio Grande do Sul, Brasil. La primera etapa de recopilación de datos, febrero-julio/2014, consistió en la construcción de indicadores a partir del análisis de los datos cualitativos a partir de dos investigaciones de evaluación en este mismo servicio. La segunda etapa, agosto-septiembre/2014, validó los indicadores construidos a través de grupos focales con nueve miembros y nueve familiares.
Resultados: Los usuarios y familias mostraron tres indicadores cualitativos relacionados con su autonomía como consecuencia de la entrada en lo servicio: mejora de la auto-gestión de los ingresos, mejor desarrollo de las actividades diarias y aumento de la capacidad de negociación.
Conclusión: Lo servicio ayuda en el proceso de desarrollo de la autonomía.
Palabras clave: Autonomía personal. Salud mental. Evaluación. Investigación cualitativa. Indicadores.

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INTRODUCTION

In the context of the Brazilian Psychiatric Reform, the conquest of autonomy of users of mental health centres is expanding as the object of the collective and shared process between users, health workers, family members, and the community, permeated by the daily, singular, and subjective experiences of the service users(1).

Autonomy is the bases of deinstitutionalisation and, in relation to users of mental health services, the comparison of efficiency and effectiveness are not pertinent. The focus here is new possibilities of expression and participation in all the varying degrees(2).

When it comes to mental health, specifically psychosocial care centres, the focus tends to be change and strengthening the groups and individuals, making them important devices to create autonomy and social reintegration(3). Achieving autonomy and empowering the subjects is one the main expected outcomes of the practice in this context.

With the new form of mental health care planning, it is important to assess the community services of the network to reveal their weaknesses and potentialities(4). Based on this understanding, methodological development and the results of this study give rise to a tool that signals, through indicators, potential and expected outcomes of mental health actions in line with real psychosocial rehabilitation from the precepts of psychosocial care.

In an attempt to evaluate mental health actions, the Ministry of Health has been working to create projects and indicators and include them in the primary care information system. However, these indicators, although useful, are still unable to fully indicate essential elements of the reality of Brazilian healthcare or the results of actions for users of mental health centres(5).

Indicators are defined as a synthesis-measure constructed on previously collected information to accompany, monitor, and assess useful strategic health actions that can resolve several issues of this field(6).

This study is sustained on a participative and qualitative assessment and arises from the need to produce qualitative outcome indicators that can support the analysis of expected outcomes in a mental health service.

Thus, this study intends to answer the guiding questions: What are the qualitative outcome indicators of autonomy from the perspective of users of a mental health service and their families?

To understand how the studied psychosocial service promoted the autonomy of its users, the aim of this paper was to construct qualitative outcome indicators in psychosocial care related to autonomy from the perspective of users and their families.

METHODOLOGY

This is an evaluative case study with a constructivist approach based on the dialectical hermeneutics theoretical framework with the aim of building qualitative outcome indicators for the subject matter autonomy in psychosocial care. It is the product of a master's thesis entitled, "*Indicadores qualitativos de Atenção Psicossocial a partir da avaliação de quarta geração*"(5). The study was conducted at a type II psychosocial care centre in the municipality of Alegrete, Rio Grande do Sul, Brazil.

In relation to the framework, the fourth generation evaluation, grounded in dialectical hermeneutics, is an alternative to the traditions ways of assessing services. According to this framework, the organisational focus of the service must arise from claims, concerns, needs, and issues of the interest groups, users, families, workers, and managers in a dialogical manner(7).

Research for this study was based on two prior studies conducted in southern Brazil, CAPSUL I in 2006 and CAPSUL II in 2011. These studies are characterised as evaluative research with a methodological path based on fourth generation assessment(7).

Data collection and the construction of qualitative indicators were divided into two stages. The first step occurred from February to July 2014, and consisted of resuming the qualitative database of the evaluation process of the studies CAPSUL I and CAPSUL II referred to above. This database comprises field journals, user interviews, and interviews with family members, totalling 46 documents. We started with a systematic analysis of these data to identify the statements of users and their families about how their lives changed after frequenting the studied service. These statements were used to build the assessment indicators of psychosocial care in CAPS. The statements were arranged in a matrix to form units of information. The analyses and interpretation of these statements were used to create twenty possible qualitative outcome indicators. The information units and their respective indicators were arranged in the matrix according to the homogeneity of their subjects to build provisional categories, namely Autonomy, Social Reintegration, Prejudice, and Satisfaction.

The second collection stage occurred from 18 August to 2 September 2014. It consisted of returning to the studied service for field observation and the forming of focus groups. First, the study was presented to the workers and users of the service. Then, invitations were sent to the family members and the users to attend and participate in the study. The criterion for inclusion of the users were primarily those who participated in the study CAPSUL I (2006) and CAPSUL II (2011), over 18 years of age, and users who attended or were attending the service in the intensive or semi-intensive modality. For the family members, the criteria were those who primarily participated in the study CAPSUL I and the study CAPSUL II, over 18 years old, and whose family members had attended or were attending the service in the intensive or semi-intensive modality. The first focus group had nine users, and the second focus group had nine family members, accompanied by three researchers who guided the discussions.

The preliminary indicators were presented to these groups for discussion and validation. The main target of the focus groups was for users and their families to discuss the preliminary indicators and state those that represented the main changes in their lives regarding autonomy and those considered important to assess the expected outcomes of a mental health service.

The interviews of the focus groups were recorded on audio and transcribed in full. The data were subjected to thematic content analysis. The data were interpreted with a review of literature on the concept of psychosocial care to identify fragments of meaning in the statements of the users and their families that could respond the question guiding the study. The outcomes were as follows: Better self-management of income, Improved everyday activities, and Greater bargaining power.

These outcomes resulted in the identification of fourteen outcome indicators validated within their categories, as shown in Chart 1.

Analytical Categories	Qualitative indicators
Autonomy	**- Better self-management of income** **- Improved everyday activities** **- Greater bargaining power**
Prejudice	- Empowerment to confront prejudice - Diminished prejudice
Social Reintegration	- Social participation - Existence of associations - Social network expansion - Return to work - Enhanced communication - Construction of friendship bonds - Improved quality of interpersonal relationships
Satisfaction	- Reduced need for psychiatric hospitalisation or no hospitalisation - Feeling or sense of well being

Chart 1 - Matrix of qualitative outcome indicators by consensus of the groups of users and their family members in Alegrete, 2014
Source:[5]

The discussions presented here address the qualitative indicators of the category Autonomy. The other categories and their corresponding indicators are discussed in later publications.

The names of the participants and the date of the statements were presented as follows: User 1 and year of interview, e.g. U1 2006, or U2 2011 or U3 2014, Family member 1 and year of statement, e.g. F1 2006, or F2 2011 or F3 2014. The project was submitted to the Research Ethics Committee of the Faculdade de Enfermagem e Obstetrícia da Universidade Federal de Pelotas, and approved with opinion No. 753.374. The entire database is stored and shall remain in the hands of the researchers for up to five years.

RESULTS AND DISCUSSION

The results of this study show the main changes in the lives of the users and their families after these users attended the community mental health service, that is, the CAPS. These participants formed two focus groups with nine users and nine family members.

The user group consisted of four women and five men, while the family group had five women and four men who were closely related or lived in the same houses as the users of the service. All the participants, users, and their families were previously contacted by telephone and invited to participate in the groups that would, in turn, participate in the discussions to validate the preliminary indicators.

The texts simultaneously contained their reports of the changes they experienced and the three indicators validated by users and family members related to one of the intrinsic aspects when it comes to psychosocial care: autonomy.

Indicator 1 - Better self-management of income

The self-management of income was one of the first indicators related to the theme autonomy. According to the reports, the users perceive their insertion in service as important for the acquisition of income and self-management, thus enabling them to use their income as they think best.

Nationwide efforts are required to strengthen the construction of an integrated health network that provides users with spaces for democratic participation, self-management, and inclusion in marketing and networking opportunities in society(8). In this study, self-management of income emerges as an important factor for the autonomy and sociality of users in their territory, as shown below.

> *[...] All the problems, from financial to family related, they , in the mental health service I got that, they are investing in me, they, right, helped me with my dreams that I had and now they are helping me with my dream to have my house, you understand... and, and when I need money they help me, they get me work to do, I do it, and I have my money, so the mental health service for me is more than a mother, it's a mother and a father at the same time for me [...]* **(U1 2006)**

> *[...] It's that day five, day three I get my money to pay for the light and water to help the mother house stuff, to go to the market. Right, day five, day three light and water and rent of the house [...]* **(U7 2014)**

> *[...] U1, so you get your and his (husband)? And you administer both?* **(Interviewer)**

> *I administer both (hers and her husband's). Mine and his that I get. I give it, I only get it and give it to him. Spending on food, water, light and buying a few more things here for the house. I, mine goes to the house, for my expenses, and there is nothing left. I have bills up to here [...]* **(U1 2014)**

Based on the analysis, we observed that income is an important issue for the users. The service was perceived as a point of support where users often requested help from the professionals who worked there. These practitioners, when requested by users, helped them pay for their bills on time, helped them organise invoices and payment receipts, accompanied the users to shops and the supermarket to buy their groceries, and sometimes accompanied them to the bank to solve outstanding issues.

The support provided by the service varies according to the limitations of users, as some do not read or write, while others are unfamiliar with bank notes. This support is important because it helps them organise their lives according to their limitations and the limitations of their income, and recognise their purchasing power and self-control, thus enabling autonomy.

The receptive assistance, connectedness, co-responsibility, and autonomy are essential for the care relationship between mental health workers and users from the perspective of psychosocial rehabilitation. Thus, health workers are required to recognise the freedom, dignity, and singularity of users to strengthen the user-worker bond(9).

However, the line between the support for users and the control of subjects is thin, and requires workers to promote the active autonomy of users to avoid reproducing paternalistic care.

Teams with a paternalistic attitude prevent or hinder the social rehabilitation of users, and can hinder the autonomy of the users(10).

Another issue is the importance of income and purchasing power to include users in different areas of the community. When users also play the role of consumers, with the potential to choose and buy, society starts to see them differently and any stigma or bias starts to wane.

Indicator 2 – Improved everyday activities

The second indicator reveals the importance of conducting comprehensive and personalised activities based on individual resources, family counselling, and intersectoral work with the community, to expand the autonomy, social reintegration, and sense of citizenship of users(11).

Corroborating with this observation, the interviewed users perceive the service as a device for personal appreciation insofar as the activities support the development of daily activities and increase their power of autonomy, as mentioned below:

> *[...] Look, now that I am doing this treatment inside the CAPS with the orientation of a doctor, psychologist, nurses, my whole life is feeling normal, of course with my medication, without, without excess of overdoing it, not stopping, nothing, the guidance of the doctor, but I'm leading a normal life, doing my things as a housewife, the market, I go*

> *to the bank, I get my benefit, so you know, everything I do, I'm doing the best I can, of course I'm not going to say that, that I do not feel a pain here and there like any person feels, a normal person and I feel that I went back to what I was before, but with the whole team with me, doctor, nurse, CAPS mental health, everyone [...]* **(U10 2006)**

> *[...] Now I moved and got my own home there. The person who really got all this for me was my lawyer. Yes, she's the one who did it. Now I take care of my house, do laundry, clean the house, cook and everything. I am married right now with my husband, and he is hardworking right, he is out now working [...]* **(U6 2014)**

Among other purposes, mental health services have to promote social reintegration and conviviality with the family and other members of the community. The service should also expand the possibilities of users to participate in various social spaces(12).

The results of this study reveal the positive influence that everyday activities have on autonomy, as shown in the statements of the family members below:

> *[...] They do everything here, but even you know, more activities, it also helps, right, but I am really happy here, I have nothing to complain about, it's the teacher, last year she was in a bad way! The pencil she wouldn't hold it in her hand, nothing, now she does. I mean, it's a process like kindergarten, now she does some scribbles and stuff, but she holds then pen, and now the teacher they have there, she roots for her pulls it for her and she comes here, she did know how to cut a steak, you know [...]* **(F6 2006)**

> *[...] A year ago she came here she didn't talk. This family never provided the treatment. No medical treatment, or anything and I don't think they ever taught her, the things that, she was like that, slow, like a child. When she came to live with me, three years ago ... she didn't even know how to have a bath, she didn't know we went to the bathroom and had to wash, not even that... "How quickly she is learning"!, I said to a teacher. Bah, she even works in the vegetable garden, everything, and she, everybody knows ... she didn't speak! They come in the morning, they have all their meals here, they have meals, they attend class with the teacher, participate in the vegetable garden, capoeira, physics, and they have the psychologist there, too... they get medication, too... even when she came here now, it's been two years since she came here, but she didn't speak at all, nothing, nothing. Everyone there knows, that when she came here I had to take her to the cafeteria, I had to take her to the bathroom, I had to serve her, I had to cut the meat, everything. Now she's speaking, participates in everything [...]* **(F6 2011)**

The family members perceive the positive influence bonding has on the users at the service. The statements also indicate the exercise of freedom. The family members express their happiness and satisfaction when they mention the initiative of users to do what they want and practice their leisure activities without assistance. The "power to choose" and "manage to do things" in the life of any human being translates into freedom.

Other accounts of the family members emerged from the discussion on improving everyday activities, as shown below:

> *[...] Before I had to change everything, his shoes, his clothes for him to have a bath, towel, reach everything, bathroom, sometimes I have to help him buckle his shoe, things like that we had to do but now he does everything alone. He showers, he chooses the clothes he wants to wear, I just wash and iron and put the clothes in the closet and he chooses what he wants to do. Sometimes he asks, "Little sister, do I put this on?" But he's doing it alone so I'm enjoying it very much. He's acting that way, he's doing things on his own, managing to realise that he can really do it, so at home he didn't want to sweep a patio, didn't want to help me in anything, he wanted to watch television... Not now, he gets up, makes his bed, he helps me sweep the yard. He asks, "Sis, you want me to sweep for you?" It's all good, but he feels like doing things, he feels like coming right away. He says, "Sis, I'm going to have a shower to go see my friends, do the workshop," so he has improved a lot since he started here. A major improvement [...]* **(F2 2014)**

In this new model of care, the family becomes a highly relevant resource to be exploited for the reintegration of users, the therapeutic process, and the inclusion of actions for this public.

Whereas the family was previously kept away from this process because it was considered the source of any mental disorder, in the proposal of deinstitutionalisation, it takes the leading role in care(13).

Given the proximity and co-responsibility of the families with the users, they often feel burdened with the extra care due to the high dependence of this population.

Their statements reveal that the bond with the studied services and the activities it offers help users perform daily tasks previously considered difficult, and relieves or diminishes the burden on the family members. This benefit (improved everyday activities) is an important outcome related to autonomy arising from psychosocial care.

Indicator 3 - Greater bargaining power

The psychosocial mode enables the horizontalisation of power relations, and the subjects' participation in the construction and development of their treatment and in decision-making relations with workers(14).

According to this study, the relations built in this service are based on negotiation, where the users can express themselves about conflicts and negotiate with the people involved. Bargaining power is perceived as the expression of autonomous subjects who manage to make decisions and place themselves in the care process, as shown in the statements below:

> *[...] Oh, sometimes I fight, you know, with worker 4, mainly because of my medication. I avoid taking certain medication, because they make my tongue curl so I don't want to take it [...]* **(U5 2006)**
>
> *[...] And how do you manage to solve this?* **(Interviewer)**
>
> *Talking to professional 8 he talks to the psychologist, then she talks to me, tells me what I need to take or he switches medication, to see which one will work [...]* **(U5 2006)**
>
> *[...] And if you have a problem with the medication, can you talk to the doctor? Does he listen when you want to change the medication?* **(Interviewer)**
>
> *Yes, I can [...]* **(U6 2014)**

The bargaining power presents itself as an exponent indicator, given that it only exists from the encounter of people who assume empathy for themselves and the appreciation of others. In the democratic scenario, we have people who feel jeopardised and recognise the power of their speech, while, on the other side, we have people who have the capacity to put themselves in the place of others and appreciate speech, resulting in the horizontalisation of power. The postures are antagonistic, on both sides, to the traditional psychiatric model.

For a real change to occur in mental health care today, it is not enough to merely knock down the walls of asylums; it is necessary to replace the entire culture that sustains violence, discrimination, and the imprisonment of madness, that is, this care must be accompanied with a different way of perceiving and acting in the face of madness(15). The interviews and discussions in this study shed light on the extreme importance of this theme to assess the real outcomes of psychosocial care.

FINAL CONSIDERATIONS

The aim of this study was to build qualitative outcome indicators with a focus on autonomy, resulting in the three aspects signalled by the users and the family members after attending the studied service, namely better self-management of income, improved everyday activities, and greater bargaining power.

The results shows that the users and professionals build a bond to drive autonomy, and the outcomes, rather than the actual users, address the processes that must be investigated with more depth in future evaluative studies.

Given the multidisciplinary and interdisciplinary composition of the teams at the mental health centres, the nurse emerges as one of the workers who can contribute to the provision of comprehensive care in the context of community mental health. Moreover, nurses are trained in several fields of knowledge, and have the potential to extend their scope of work to care for this population.

Traditionally, indicators used to assess and monitor healthcare are created by people who are considered academic or professional experts in a given subject or topic. However, the people who are potentially benefited or jeopardised by the practices of a service, that is, the users and their families, are often unaware of the process of creating these parameters.

A potentiality of this study, beyond the construction of outcome indicators, lies in the use of a participative methodological pathway primarily based on the participation of users and their families. According to this approach, the users and their families are the experts who are qualified to analyse and reflect on what is offered and their expectations in relation to the mental health service in terms of achieving autonomy. A limitation of this study was the scarcity of references found during the bibliographical search that could enable a more profound dialogue on the qualitative indicators of psychosocial care, thus stressing the need for further research on this subject.

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