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## **Users' Perspective on the Evaluation of Mental Health Services**

### **Experience from a Discharge Program in Argentina**

*Abstract: Introduction: The inclusion of mental health service users' perspective in the evaluation of the services contributes both to its validity and to the protection of rights of individuals with mental illness. While the development of evaluations that take into account users' views is increasing, the practice still lacks diffusion in real-life settings, that is, incorporation in everyday service management practices, especially in developing countries. Objective: Describe and analyze users' perspective on a discharge program for women in Argentina, with emphasis on the strategies that facilitate the inclusion of their perspective on service evaluation in real life settings in a developing country. Methods: A qualitative study was carried out with fifty-six users of a discharge program associated with a psychiatric hospital in the southern zone of Greater Buenos Aires, from 2011 to 2012. The qualitative methodologies used were participant observation, records analysis, questionnaires, and*

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*focus groups. Results: The participative feature of the program, mental health workers' use of narrative language, and the focus on users' "everyday life" concerns emerged as variables that promote the inclusion of users' perspective. Conclusions: Results raise a discussion about the concept of "care" in contrast to "health care." Consequently, further development of the care component in community mental health services evaluations is proposed.*

Mental health service user's inclusion in the decision-making process regarding their own treatment has been increasingly emphasized in the past decades, and service evaluation is one important aspect in which their participation seems especially crucial. Services' awareness of the gap between their responses and the users' needs, increased public knowledge about what to expect from quality services, and acknowledgement of the human rights of individuals with mental illness are aspects that have contributed to the increasing interest in this topic [1]. From an international perspective, the World Health Organization (WHO) has highlighted the benefits of user participation in mental health services evaluations for over twenty years [2, 3], pointing out that users offer a unique perspective on the "reality" of services—in contrast to the "ideal" view of many administrators—and contribute to the definition of results. Further, the inclusion of users is not only an indicator of quality care but also a right, in light of the fact that the views of individuals with mental disorders have been historically devalued [4, 5, 6].

Despite general acceptance of users' inclusion in mental health services evaluations, its concrete implementation has been limited [7, 8]. Studies published on this topic emerged during the 1990s, and the majority of research today still comes from European countries. Articles analyzing users' perspective about psychiatric care reform—the movement from hospital to community-based care—also appeared in the 1990s, representing a low proportion of the published studies about the psychiatric reform. While interest in the topic has increased in the last decade, more discussion, as well as investigations into services in different contexts, such as from developing countries, are needed. Based on this lack of information from certain regions of the world, a study to describe and analyze users' perspective on a discharge program for women in Argentina was conducted, with particular emphasis on the strategies that facilitate the inclusion of the users' perspective on service evaluations.

In Argentina, psychiatric reform is not yet completed, as there is still a mixed model of care, with large asylums coexisting with community-based care. Nevertheless, a national law that promotes reform was approved in 2010 [9], and it is currently being implemented. While the delay in reform is due in part to the destruction of community-based care experiences during the last dictatorship (1976–1983), there have also been other obstacles, such as

corporate and union interests, and the reduced culture of management tools use within services.

The selected program—Programa de Rehabilitación y Externación Asistida (assisted discharge and rehabilitation program)—is one of the oldest currently running community-based care experiences in Argentina, functioning since 1999, and probably the oldest in Greater Buenos Aires, the urban agglomeration that is home to 9.9 million people [10].

The program provides services to support the discharge of individuals with mental illness who remain hospitalized for years for reasons not directly related to their medical condition, such as lack of family support and poverty. Patients willing to be discharged are aided with the provision of housing, continuity of care, and various supportive daily activities. Work with the participants in the program begins by teaching them the skills needed to live in a community, and more broadly, on encouraging their recovery as persons, which was lost during the long-term hospitalization [11]. Patients then move to state-supported group homes, where there is a team in charge of follow-up and providing support. The program also has a community center, open to the entire neighborhood, offering cultural and educational activities in which users may choose to participate.

The program's name, Assisted Discharge and Rehabilitation Program, is based on the assumption that mental health service users are individuals whose continued care is needed and depends on the availability of resources to exercise their rights while living in the community. The program is supported by the Ministry of Health of the Province of Buenos Aires, and although initially it was intended to be implemented in all of the Province's public institutions with prolonged psychiatric hospitalizations, the only successful implementation in line with the original guidelines is in a public psychiatric hospital for women, where this research was conducted.

## Methods

### *Procedures*

The users' perspective of the program was explored through four strategies: (a) *Participant observations* at the community center, recorded and sent periodically to two experts for feedback; (b) *Analysis of discharge notebooks*, a record tool developed by the program to create a communicative channel between the staff and the users (each with his or her own notebook) while the users were preparing for discharge; (c) A *questionnaire* composed of twenty-five items answered by users regarding their perception of the program, the help they felt they were receiving from the program, and ways to evaluate

the program; and (d) *Focus groups*, based on discussion topics drawn from the analysis of the questionnaire.

The questionnaire was administered to fifty-six users. It was built specifically for this research, being reviewed by other researchers and by team members of the program in order to check the content and language used. It had open-ended questions followed by close-ended questions about the same topic. In order to review the reliability of the open-ended questions, a local researcher who works on similar topics, unaware of the results, was asked independently to categorize the answers to two questions given by twenty users. Both researchers arrived at the same categories, indicating a solid inter-rater reliability. In those questions that referred to external factors, specifically housing and work questions, a complete coincidence with the participants' answers was observed, indicating questionnaire validity.

Three focus groups were conducted with selected users, and each one had a different topic: housing, work, and social networks. These themes are also the three main areas in which, according to Saraceno [12], psychosocial rehabilitation is organized. Each focus group had four components: introduction (duration and purpose), discussion of highlighted phrases arising from the questionnaires, help that should and should not be provided by the program, and evaluation indicators for each topic. The entire process was conducted between 2011 and 2012.

### *Sample*

All existing *discharge notebooks* ( $n = 46$ ) were analyzed. They were written between 2001 and 2005 when, for unknown reasons, the use of discharge notebooks was discontinued. While the *questionnaire* should have been applied to all current users of the program who were discharged during the course of the study ( $n = 62$ ), it was answered by 90 percent ( $n = 56$ ). Those who did not complete the questionnaire were in a crisis episode and hospitalized ( $n = 3$ ); lived independently (not in group houses) and only attended the program for medication support ( $n = 2$ ); or were about to be discharged from the program and refused to participate ( $n = 1$ ). The total number of persons discharged by the program since its initiation is seventy-five, meaning that 75 percent of all persons ever discharged from the program were included in the study.

With regard to the fifty-six individuals who were interviewed, 89 percent ( $n = 50$ ) lived in group homes and 11 percent ( $n = 6$ ) lived independently (with friends, with relatives, or alone). The period that the users had been part of the program was calculated by the time that elapsed between discharge and the moment of the study. Fifty-nine percent ( $n = 33$ ) of the sample had been in the program for five years or longer, while only 5 percent ( $n = 3$ ) had

been involved for less than a year. Additionally, 53 percent ( $n = 30$ ) reported having had only one hospitalization in their lifetime, although the time they were hospitalized was over five years for 54 percent ( $n = 39$ ) of the sample. In terms of age, 45 percent ( $n = 25$ ) were between fifty-one and sixty years old, and 27 percent ( $n = 15$ ) were older than sixty, signifying that the sample was conformed mostly by middle-aged, followed by elderly women. The educational level of the sample was similar to that of the general population of that area of the Province of Buenos Aires, with 38 percent ( $n = 20$ ) having completed secondary school or higher, and only 4 percent ( $n = 2$ ) with no schooling. Finally, the primary psychiatric diagnosis was psychotic disorders for 68 percent of the sample ( $n = 38$ ), followed by mood disorders, personality disorders, and mental retardation with 7 percent ( $n = 4$ ) for each one of these diagnoses.

Each *focus group* was made up of ten service users. The sampling aimed to achieve heterogeneity in the groups, based on responses to the questionnaires [13]. The groups that focused on “housing” and “work” had eight assistants, and the “social networks” group had four. The study was first presented to the participants through a bimonthly assembly in which staff and users discuss issues and problems related to the program. Then the study was explained in detail to each potential participant and written informed consent was obtained.

### ***Data Analysis***

Notes in the discharge notebooks were categorized into those made by the staff and those made by users. Analysis was centered on the written interaction between staff and users, and the users’ notes were analyzed qualitatively by searching for emerging categories [14]. In addition, one of the original creators of the discharge notebooks was interviewed to explain the purpose of the notebook as part of the discharge process. The questionnaires were also analyzed qualitatively, using, as starting categories, the questions themselves and then identifying emerging themes. As previously stated, the focus groups sought to analyze deeply three of the emerging themes from the questionnaires: housing, work, and social networks. Finally, the data arising from the different strategies—discharge notebooks, questionnaires, interview, focus groups, and observations—were triangulated.

## **Results**

### ***Discharge Notebooks***

Of the forty-six notebooks reviewed, only twelve users had written in them (26 percent). This may be related to the fact that long-term hospitalizations

reduce initiatives to practice reading and writing skills, a situation that can be described in terms of functional illiteracy. The notes made by the twelve users were organized into six categories: (a) answering a question made by a staff member, (b) asking the staff a question, (c) referring to an experience related to the discharge process, (d) explaining how they feel, (e) thanking the staff, and (f) commenting on the care they received and making suggestions for improvement. The last two categories could be labeled as elements related to the users' perspective of the program and the care received.

The notebooks also showed that the language used by the staff tended to be in the first person (e.g., "seems to me"; "we observe"), conditional (e.g., "is possible"; "would be"), and prioritizes questions over claims. In their notes, the users indicated that they liked knowing how they were seen by the staff, and that these views helped them in their discharge and recovery process.

### *Questionnaires*

Users' responses to the questionnaire were also organized into six categories: 1) significance of the program for the user; 2) program objectives; 3) participation in community activities offered by the program; 4) perceptions about the help provided by the program; 5) expectations when entering the program and the extent to which they were fulfilled; and 6) participation in the program's evaluation. This article will focus on describing the last three categories.

Answers related to category 4, the users' perceptions about the help provided by the program, were divided into two main areas: the first, the most discussed topic, referring to the assistance and support users received to leave the hospital and to continue living in the community; and second, regarding their recovery process, including how they "came alive again," their right to live in freedom, and how they learned to live again in the community. The users also highlighted the program support with obtaining housing, finding and obtaining a job, and reforming familial relationships and/or creating a new family. Finally, the users were asked if they received help from sources apart from the program. Answers touched on support from family, housemates, and the users themselves. It is especially noteworthy that 13 percent of participants named specific workers and professionals of the program as "other things besides the program that had helped them."

Regarding category 5, expectations the users had before entering the program, 11 percent of the participants responded that they did not have any prior expectations. For the remaining 89 percent who entered with expectations, the most common expectation was obtaining housing (21 percent), gaining freedom (14 percent), finding a job (13 percent), and "getting their family back" or forming a new one (11 percent). Thus, 61 percent of the participants

stated that their expectancies had been met, even though they felt that there were certain aspects they still needed to achieve (e.g., find a job, reform ties to their families, live independently from the program). For the final category—participation in the program’s evaluation—when the users were asked if they had the opportunity to give their opinions about the program 43 percent ( $n = 20$ ) of the respondents considered that they would raise their opinion about the program, 21 percent ( $n = 12$ ) answered that they cannot do so, and 36 percent ( $n = 20$ ) did not respond to the question. Some users explained that they could not give their opinion because they were not familiar with other programs upon which to base a comparison, or that they were not able to comment about the program due to their illness. Those who answered that they could give their opinion said that the questionnaire itself was an example, that they felt free to say what they thought, and that they felt listened to, exemplified by the fact that they were being asked about how they felt. Some of the users highlighted the group meetings as a place and time in which they could give their opinions, and specifically in the general assembly. Nevertheless, some considered that it was difficult to speak in a group meeting, and that they felt more comfortable just listening.

### ***Focus Groups***

In terms of the types of support that should and should not be given by the program, the participants valued the program’s responsiveness to the special needs and abilities of each user, as certain activities were needed by some users but not all. In this sense, the participants recognized some things as their own responsibility: building a home, keeping the job the program helped them obtain, maintaining their relationship with neighbors, and dating. The discussion revealed that users felt that evaluation indicators were more of a professional domain, considering that only professionals have the expertise to know if the provided support is adequate. Nevertheless, the users also felt that their emotional wellbeing—mainly indicated by “feeling fine”—was a subjective aspect that could serve as an evaluation indicator; and professionals could only inquire on it by simply and directly asking to users how they feel.

### **Discussion**

In terms of aspects that promote users’ inclusion in the evaluation of mental health services, analysis of the discharge notebooks showed that the narrative language used is a fundamental facilitator of users’ participation. In theoretical terms, “narrative” language is opposed to the “technical-scientific” language typically used in professional records. Narrative language captures the par-

ticularities of experiences by including a temporal dimension and changing perspectives, while technical-scientific language, which produces general and abstract theories, is timeless and aims to define certainties [15].

For users, knowing how staff perceives them encourages them to share their own opinions. The sharing of perspectives, with the use of appropriate language, has been highlighted as a powerful tool in psychotherapy [16] and would be useful for services evaluation. This is especially important in the current global context, in which the WHO is promoting users' access to their own records as a crucial indicator of quality mental health care [17]. Another facilitator is the participative feature of the program, exemplified in the general assembly made up of both staff and users.

From the questionnaire results, it is possible to underline some aspects. First, according to users' perspective, part of the value of a community-based program is related to the fact that it focuses on their needs not only as "mental patients," but as persons: what it means to have a house, a job, and meaningful social relationships, which are everyday life concerns shared by everyone, not only recovering mental patients. This harmonizes with the proposal of shifting from rehabilitation to citizenship approach [12] in terms of users' needs and responses of the programs toward them. The second aspect present in users' answers refers to the importance of their relationship with the program care providers, which opens the discussion about the relations between formal and informal care processes. A usual division about care refers to who the provider is [18]. However, what could be inferred from users' responses is that formal care providers could be, at the same time, informal caregivers. This means that some care activities developed by formal providers are considered by users to be helping them precisely because they are not expected to be doing them.

The third issue that is especially interesting about these results is that they challenge the same idea of *expectancies* as a valid measurement for mental health services evaluation. Despite the fact that just 11 percent had any at all and 39 percent considered that the program did not fulfill their expectancies, the overall answers showed high satisfaction with the program. Finally, it is possible to hypothesize that users' ideas about their lack of ability to evaluate the program—which was observed both in the questionnaire and in the focus groups—related to their disempowerment as mental health patients. Accordingly, imagining a different role regarding the services' decision processes seems unthinkable to them.

In summary, the results of this research coincide with findings from other studies about aspects of community-based services evaluations that are valued by users: the idea of freedom [19], the ability to make an independent decision [20], the emphasis on personal relationships with the staff over professional relationships [21], and the staff's attitudes toward the users [22]. Given that this



research was conducted in the context of a developing country, with a cultural and psychological background distinct from the European and American settings in which most prior studies were based—with psychoanalysis being a mainstream approach in Argentina—it shows that there are common concerns and needs of individuals with mental illnesses who live in community settings. Additionally, it is important to emphasize that the sample of this study was completely female, which opens the debate about gender perspective in the field of community mental health services. Extensions of this research could compare the help needed and not needed in male and female samples regarding housing, work, and social network dimensions.

Evidence supports that understanding and evaluating how mental health services function require diverse types of analyses, among which qualitative studies about users' perspectives and experiences are an important methodological approach. Thus, the question to be answered is, What is the contribution of users' perspective, especially in terms of what cannot be achieved by other approaches? While some authors conceptualize this as a "soft" indicator [23], we prefer to link it with the theoretical development of the "care" dimension in healthcare [24, 25]. Care has been described as the dimension of healthcare that requires a human relationship and recognition of the "other" as a "fellow," and which is coupled with a technical dimension to enable quality assurance. Mental health services users are the most qualified to give an account of the care received in the services.

Finally, this research has the limitation, shared by many studies, of having a vulnerable population evaluate the program on which, in certain ways, they depend. In order to understand more fully the reasons why the program did not meet their needs, it would have been helpful to include in this study users who had left the program at different stages. Another limitation of this research is that the questionnaire used was built ad hoc.

## **Conclusions**

This study illustrates what users most valued when evaluating community-based services: freedom, choice, and appreciation as persons over patients, aspects framed as "care," a dimension in healthcare that is essential to achieve quality. In this sense, the users' perspective on services is unique, since they have the experience of knowing how healthcare is received and if care has been truly fulfilled. Users' participation in services evaluations is only possible if there is a context that allows it, and this context is, in part, provided by the language used by professionals when talking to and about users and by the participative opportunities offered by the services. When users realize that they have the right to evaluate the services they use, they will understand

that their involvement in the evaluation process is also an important duty they have as citizens.

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