

## Methodological challenges in the use of focus groups with people with severe mental illness

Desafios metodológicos para o uso de grupos focais com pessoas com doença mental grave

Desafíos metodológicos para el uso de grupos focales con personas que sufren enfermedades mentales graves

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### Abstract

*This study addresses the practical, methodological and ethical challenges that were found in three studies that used focus groups with people with severe mental illness, in the context of community mental health services in Brazil. Focus groups are a powerful tool in health research that need to be better discussed in research with people with severe mental illness, in the context of community mental health facilities. This study is based on the authors' experience of conducting and analyzing focus groups in three different cities – Campinas, Rio de Janeiro and Salvador – between 2006-2010. The implementation of focus groups with people with severe mental illness is discussed in the following categories; planning, group design, sampling, recruitment, group interview guides, and conduction. The importance of connecting mental healthcare providers as part of the research context is emphasized. Ethical issues and challenges are highlighted, as well as the establishment of a sensitive and empathic group atmosphere, wherein mutual respect can facilitate interpersonal relations and enable people diagnosed with severe mental illness to make sense of the experience. We emphasize the relevance of the interaction between clinical and research teams in order to create collaborative work, achieve inquiry aims, and elicit narratives of mental health users and professionals.*

*Mental Disorders; Community Mental Health Services; Focus Groups; Qualitative Research*

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## Introduction

In the past three decades, we have observed a growing interest regarding service users' perspectives to better understand medical systems, public health policies, as well as the illness experiences of users and their needs <sup>1,2,3,4</sup>. This change has been accompanied by an increasing acceptance of qualitative methods in social and human sciences applied to healthcare, either informed by interpretive or critical paradigms of research <sup>5,6,7,8</sup>.

A wide range of techniques has been used in qualitative health research as methodological strategies for gathering data. These include participant observation; document analysis; life history interviews; open-ended or semi-structured individual interviews; group interviews and focus groups <sup>7,8,9</sup>. Focus groups are considered a modality of group interview that enables researchers to access meanings, perceptions, opinions and interactions in a shared atmosphere <sup>6,10</sup>. Focus groups can be carried out either in qualitative or mixed methods studies and are considered a powerful tool in health research <sup>10,11,12,13,14,15</sup>.

Many authors identify the origins of focus groups in the 1940s, with the studies of the sociologist Robert Merton, who researched the reactions to advertisements and radio transmission during the Second World War <sup>1,2,3,4,5,6,7,8,9,10,11,12,16</sup>. Some years later, focus groups began to be used in marketing research because of their relatively low cost and speed in providing reliable data. In Brazil, focus groups were also of great use to the "dialogic research method," a method employed by the educator Paulo Freire, who was interested in giving voice to the marginalized groups through knowledge production "with" people and not "about" people <sup>7</sup>.

Focus group consists in a group interview wherein participants discuss a certain topic, usually chosen by the researcher <sup>14</sup>. They have been widely employed in health research, aiming to illuminate the subjective and intersubjective experiences of people that suffer from some kind of distress. Focus groups function through interactions among the participants, and provide them with a forum for discussion centered on the subject investigated through conversations conducted by the researcher, playing the role of group moderator. Participants speak about their experiences and listen to each other. This setting allows the narratives to mutually illuminate participants, rendering a deeper and shared exploration of the topic discussed, producing the empirical material in a different way when compared with an individual interview. Focus groups are also used in exploratory research to generate hypotheses, build measures or complement the findings of quantitative studies <sup>12</sup>, and to give voice to groups often silenced <sup>17</sup>. Focus groups are not only about joining people to exchange ideas, but require certain objectives, management skills, guidelines, organization and procedures to function <sup>10,11,12</sup>.

Patton <sup>18</sup> highlights that focus group is a technique of data collection that provides quality control for the data, as participants' interactions contribute to the control and balance of opinions among them, reducing, therefore, the possibility of false or radical opinions. The group interaction allows the researcher to observe how a controversy comes about and see how problems are solved <sup>13</sup>, evidencing different levels of consensus and divergences <sup>19</sup>.

Focus groups consider the phenomenon studied in its "naturalistic" context, that is, in the social and cultural context where the phenomenon studied occurs, rather than in experimental research settings <sup>14,20,21</sup>. They can be used as a single technique or combined with other techniques <sup>22</sup>, and have been shown as a useful technique in evaluation studies to understand the complexity of participants' life <sup>21</sup>. Frequently, focus groups are applied to health service evaluations based on the constructivist paradigm that inspired the fourth-generation evaluation studies <sup>23</sup>. This perspective assumes that reality is plural, socially constructed by actions and interactions, by different social groups <sup>7,23</sup>.

Focus groups can provide an atmosphere of mutual support. Because of that, they have been increasingly used with people living with disabilities, historically stigmatized. In this sense, focus groups have gained popularity in the field of disability research <sup>7</sup> due to their openness, flexibility and potential benefits, such as empowering vulnerable groups, strengthening mutuality and enabling the constitution of social identities <sup>20,24</sup>. Powell & Single <sup>25</sup> suggest that focus groups have potential benefits, once it enables researchers to access a wide range of perspectives held by the participants.

Although there are supposed benefits, focus groups also have some disadvantages. Comparing with in-depth interviews, focus groups are most likely to access participants' experiences in a

superficial way<sup>25</sup>, and they also demand considerable effort for organization and logistics, requiring more time<sup>15</sup> and availability<sup>26</sup>. Sometimes the discussion goes in an unwanted direction, bringing difficulties for the moderator, who may bias the results by giving cues or inducing responses<sup>27</sup>. Moreover, focus groups require complex methods of analysis, considering the interactional context, and the small number of respondents can limit the transferability of findings to other contexts<sup>15,25</sup>.

In the last ten years, focus groups have been increasingly used in mental health research<sup>20,28,29,30</sup> to investigate different themes, such as: the illness experience and the recovery process<sup>30,31,32,33,34,35</sup>; social stigma<sup>26,30,36,37</sup>; evaluation of psychosocial services/interventions<sup>28,38,39,40</sup>, of primary care services<sup>41</sup> and training programs<sup>42</sup>, for developing measures<sup>43,44</sup> or validation of structured questionnaires<sup>21</sup>. However, few studies discuss focus group potentials and limitations when conducted with people with psychosocial disabilities.

This technique presents additional advantages when conducted with mental health service users, once it refers to a population with less contractual power, whose knowledge about their own experiences are not socially legitimated<sup>10</sup> a priori, the group setting can create an ambience of mutual support and recognition. It also permits more freedom for eliciting narratives and can minimize the verticality that usually exists in the relation between researcher and participants, as characterized by the individual interview setting, increasing the reliability of empirical data<sup>45,46</sup>. Furthermore, it allows participants to feel more comfortable, even stimulating the participation of those who have more difficulties to speak about themselves<sup>10</sup>.

Because it is a promising technique to elicit narratives and to empower service users in health research, it is necessary to deepen the discussion about what are the challenges, possibilities and limitations we face by conducting focus group with people with serious mental illness<sup>14,26,47,48,49,50,51,52</sup>, a group that suffer from stigmatization and that finds unique ways of telling their life story.

This study presents the practical, methodological and ethical challenges that were found in three studies that used focus groups with people with severe mental illness, in the context of community mental health services in Brazil.

## Mental health in Brazil and the context of the studies

During the last two decades, the mental health paradigm has changed from hospitals settings to a community and person-centered model in Brazil. The transformations in the mental health care started in the late 1970s, with the Brazilian Psychiatry Reform: a social and political movement that fought for the rights of people with mental health problems. This movement is known to have included the participation and engagement of service users and their families in the health system<sup>53,54</sup>.

From the 1990s to the 2000s, the Brazilian Psychiatric Reform gained more representativeness and legitimacy boosted by *Caracas Declaration*. The launching of the Brazilian mental health law (*Law n. 10,216/2001*) and financial reinforcement of public policies have contributed to the development of mental health system<sup>53,54,55</sup> through the implementation of Psychosocial Care Centers (CAPS)<sup>56</sup>. This paradigm shift changed the way researchers evaluate mental health services, increasing the value of diverse perspectives, including users' perspectives.

In this research, we address the authors' experiences of developing three different studies (Table 1), informed by the theoretical framework of the Brazilian Psychiatric Reform<sup>54,57</sup> and the interpretative paradigm<sup>7,9</sup>, in which focus groups were conducted with people with severe mental illness in community mental health services in three Brazilian cities: Campinas (São Paulo State), Rio de Janeiro and Salvador (Bahia State). The themes studied were the evaluation of community mental health services, and their integration with primary care, as well as the subjective experiences of users and their rights. These themes still need innovative ways of analysis and evaluation<sup>57</sup>.

The aims of the studies were:

(1) Study 1: to evaluate models of healthcare, management, and professional formation in the CAPS network<sup>38</sup>, performed in 2006-2007 with two focal groups of users diagnosed with severe mental illness, in Campinas.

**Table 1**

Studies conducted by the authors using focus groups with people with severe and persistent mental disorders.

Study	Research question	Aim	Subjects of the study and inclusion criteria	Number of groups and composition
(1) <i>Evaluation of the Network of Psychosocial Care Centers: Between Collective and Mental Health</i> (Onocko Campos et al. 38)	Do the institutional aspects of the Brazilian Psychiatric Reform in the CAPS context show relations within intersubjectivity, management, professional qualification, and clinical aspects?	To evaluate the assistance, management and workers' education models of CAPS network	Subjects: CAPS users. Criteria: (i) to be, for six months or more, in the function of/enrolled at CAPS; (ii) to accept to participate in the research; (iii) to accept to participate in the research; to be in treatment at a community mental health service (specifically for users).  n = 12 each group	Total: 20 focus groups with users (n = 2)
(2) <i>Evaluation of Innovative Strategies in Primary Health Care Organization</i> (Onocko-Campos et al. 58)	How does the implementation of FHS function through the incorporation of specialists (pediatrics, gynecologists, and dentists) and the inclusion of innovative organizational arrays that aim to modify the traditional medical-centered model?	To compare the performance of primary care units according to the implementation of new arrangements and strategies in primary care and mental health	Subjects: primary care users with severe mental illness. Criteria: (i) to be more than 18 years old; (ii) to have used the primary care center at least three times in the last six months.  n = 12	Total: 9 focus groups with users (n = 3)
(3) <i>Experience, Narrative and Knowledge: The Perspective of Users and Psychiatrists</i> (Serpa Junior et al. 59)	How is the illness experience of people diagnosed with schizophrenia? How is the experience of psychiatrists formulating the diagnosis and treatment? Can the users' illness experience illuminate the psychiatrists' technical knowledge and vice-versa?	To understand how the illness experience of people diagnosed with schizophrenia can inform psychiatrists technical knowledge and vice-versa	Criteria: (i) self attribution of common experiences related to psychotic conditions identified by watching a docudrama produced by the research team, based on self-reports selected from the <i>Schizophrenia Bulletin</i> (first person criteria); (ii) to be diagnosed with schizophrenia spectrum disorder by the community mental health service clinical team and – to meet MINI Plus criteria for psychotic disorders (third person criteria); (iii) to accept to participate in the research; (iv) to be in treatment at a community mental health service.  4-8 participants each group	Total: 25 focus groups with users (n = 25).  Users from the same service in each city (Campinas – 7, Rio de Janeiro – 9, and Salvador – 9)

CAPS: Psychosocial Care Centers; FHS: Family Health Strategy.

(2) Study 2: to evaluate the mental health assistance provided by primary care centers situated in high social-vulnerability regions<sup>58</sup>, performed in 2007-2008 with three focal groups of users, in Campinas. (3) Study 3: to analyze if the experience of people diagnosed with schizophrenia can inform the technical knowledge of psychiatrists and if the technical knowledge of psychiatrists can inform the experience of people diagnosed with schizophrenia<sup>59</sup> performed in 2009-2010 with 25 focus groups, in Campinas, Rio de Janeiro and Salvador.

Despite the historical and cultural particularities, as well as differences related to population number and urbanization process, the cities mentioned are large urban centers (metropolis) in which the psychosocial network has been implemented since the 1990s.

Regarding the research mentioned, we performed thirty focus groups conducted with the participation of community mental health service users, who had been diagnosed with severe mental illnesses, such as schizophrenia and mood disorders. The number of participants in the groups ranged from four to twelve people that met the following inclusion criteria: to be enrolled in the referred service for the past six months; to be diagnosed with persistent and severe mental illness, and to have given informed consent to participate. No participant had a previous clinical relationship with any of the researchers. The three studies had approval from ethics committee (approval letters – Study 1: n. 396/2004; Study 2: n. 562/2007; and Study 3: n. 87 Liv-02). In all cases, focus groups were developed in the context of the community mental health services, in each city, and were specially created for research purposes. Further details about the studies are found elsewhere<sup>28,48,59</sup>.

## Method

This study is based on the authors' experiences of conducting and analyzing focus groups with people with severe mental illness to produce an analytical report that could help other researchers to face the challenges and limitations of this data collection technique. For this purpose, methodological and ethical challenges related to implementing focus groups with the target-population were identified through the research process. We used observation and field reports as techniques for producing information. The groups were audio recorded and transcribed. Data analysis was based on thematic analysis model<sup>60</sup>, and included fluctuant reading, codification and categorization. In all cases, two researchers (one that conducted the group and other that did not conduct focus group) read the transcripts independently, and performed the codification process. Data were grouped and organized in the following categories: planning; guide construction; recruitment, and management of the focus groups. We will discuss the changes that we found necessary to introduce to the classical focus group technique to achieve the specific goals of each study dealing with groups of participants. All participants signed the informed consent form.

## Findings and discussion

### On focus group planning

When comparing the focus groups performed with users of the same service with those that included users from different services, we found that same service groups were more welcoming. They created a familiar atmosphere in a short period, facilitating the participation and interaction among participants. We perceived that the participation and the interaction increased when the group sessions were conducted with the same members. Developing more than one focus group with the same participants also appeared to be useful, that is, it enhanced the considerations and insights of the participants and provided a more detailed description of the illness experience and treatment.

Depending on the author, past research establishes the total number of participants for focus groups between 4 and 12<sup>11,61,62</sup>. However, according to our experiences, it was beneficial to have groups with 3 or 4 participants when the research was exploring subjective experiences of people whose accounts could be very moving. This is especially true when the participants presented difficulties

with comprehension and/or speech, or when the disorder was an object of social stigma<sup>24</sup>, as it is the case of people with severe mental illness in the Brazilian context. As many invited users could have psychic or physical health destabilization, which may prevent them from attending the invitation, it was very important to invite more participants than the minimum necessary, to fulfill a minimum of participants in the focus group session.

In Brazil, there is still a gap in social justice, and severely ill mental health users are often affected by inequalities and multiple stigmas, related to poverty, to the lack of education, to mental illness and/or racial discrimination. That is why the planning of focus groups must consider all these barriers in order to facilitate the participants' attendance in group sessions (e.g., conducting focus groups near their homes or healthcare services, giving them financial compensation for public transportation, and offering them a snack have shown to be very important strategies). We did not give any other type of compensation (monetary or otherwise) to the participants. It was also important to carefully plan all these costs as part of the research budget.

### **On recruitment: accessing participants**

The access of participants to the groups required careful consideration and time to be successful; often there was a need to get in touch again with the participants before the beginning of the group<sup>63,64</sup>. These moments, usually forgotten in the literature, were of fundamental importance to the success of the research. The reliance established with the CAPS' teams in relation to the object of study and the researchers, as well as the reliability of the focus group participants, was key for the focus groups to take place.

Discussing the research with the mental health team and planning each activity altogether were necessary conditions for successful research and for the facilitation of access to users. Furthermore, the preliminary meetings with the participants and service teams before the focus groups were strategic elements for the recruitment process. When it was necessary to cancel the focus group for any unexpected reason, for example, the researchers remained in the service establishing contact with CAPS clinical team and with the users to maintain contact with the service.

Morgan<sup>12</sup> recommends recruiting participants that have never met previously, so it is not recommended to use pre-existing groups as research focus groups. Due to the difficulties in recruiting people suffering from mental illness, Owen<sup>24</sup> and Koppelman & Bourjolly<sup>64</sup> decided to use groups that already existed in the services they used for their research. In our investigation, we did not use pre-existing groups; however, in some cases, the focus group participants were treated at the same service and already knew each other. This condition, with the fact that the location where some focus groups were performed was the same where participants were being treated, contributed to a non-invasive atmosphere in a way that facilitated the interaction among participants. It would probably have been different if the group was functioning in an unknown place or with unfamiliar people; this could possibly increase some persecutory feelings, which are not rare among these participants.

### **On the focus group guide**

The thematic guide to be discussed in the focus group is composed by a set of open-ended questions that focus on the research subject and theme of interest, for example, users' perceptions about the service, illness, and recovery experiences. This guide, usually elaborated according to the research objectives and theoretical framework, should be brief and clear<sup>65</sup>, and works as a guide for the group moderator<sup>13</sup>. Considered more of a discussion and not a group interview, the guide should be flexible. There is no rigid sequence of topics. Often they can emerge spontaneously during the discussion or can be introduced by the moderator, who will connect one topic to the other and explore the questions discussed.

The guide planned for a unique focus group session may not be integrally addressed during the first meeting because of the participants' peculiar narratives: nonlinear narratives organize themselves; meanwhile, associative pathways are not explained to the others. In this way, the participants may answer some topics even when they seem to betake to apparently peripheral subjects, demanding more time and flexibility from the focus group moderator.

The most important subjects should not be left until the end of the session, because it is necessary to have time to discuss all the subjects <sup>66</sup>. People with severe mental illness usually have difficulties in maintaining concentration for long periods, sometimes because of their medications, so it is very important for the guide construction to be brief and clear and to have enough time to complete the guide's objectives.

### **Focus groups management**

All focus groups were conducted by at least two researchers: the moderator and the observer who took notes. The role of the moderator was to conduct the discussion and to enable participation of the focus group members. The role of the observer was to take notes of the participants' reports, body language, context clues, parallel speech, commentaries, and all forms of non-verbal manifestations. These notes helped in the transcription of the audio-recorded material and further codification, thematic analyses, and interpretation.

Seeking to capture the whole process of the groups and fieldwork, all the information was registered in a field diary <sup>24</sup>. The reports included the position of each participant in the setting and the group duration. The feelings and perceptions of the researchers related to the development of the groups, its contexts and the situation of each participant at the end of the group were also registered.

To effectively prioritize the voice of people who do not have their voice valued, we recommend awareness to not incur in any segregating and/or directive attitude. We also suggest having a flexible research design in order to enable necessary changes in the group trajectory. To conduct research with people diagnosed with severe mental illness means that, most of time, the research team will have to adapt itself to the group functioning and dynamic with the mental health team, as well as to the daily life and users' singularity and idiosyncrasies. Cancelling groups due to service contingencies (no room availability, emergencies, and others), or the impossibility of developing them because of the absence of service users (barriers of access to the service, emotional instability, crisis) are situations that must be considered in research design.

Apart from these challenges, the lack of concentration, the reduced self-esteem, self-confidence, and emotional and/or hallucinatory states are some of the other difficulties faced by researchers when accessing participants' perceptions and experiences. Owen <sup>24</sup> also found these aspects in his study with women with severe mental illness.

Thus, it is difficult to estimate the number of groups necessary for data saturation and have spending time to create a welcoming atmosphere that allows the participant to experience mutuality and to feel comfortable speaking about what his/her thoughts and feels.

Respect, empathy towards participants, knowledge and familiarity to the theme discussed, listening and communication skills, good capacity to control personal opinions and preconceptions, sense of humor, and capacity to deal with unexpected situations are some of the necessary moderator qualities and characteristics highlighted by Krueger & Casey <sup>11</sup>. These abilities are necessary to cope with some difficulties, such as participants who refuse to share their experiences, opinions, and thoughts or even those who find it difficult to express their feelings, to follow social rules practiced in the group and to respect the confidentiality. All these issues can be intensified in people with severe mental illness <sup>62</sup> and we, therefore, highlight the need for a very well trained research team.

It is also necessary not to tire the participants out. Therefore, the focus group duration in our studies varied from one to one and a half hours, and sometimes, the participants themselves asked to conclude the discussion. This shows the establishment of a welcoming and open atmosphere, allowing for spontaneity and flexibility <sup>64</sup> and considering the possibility of not covering all the topics proposed to be discussed in the group session.

At times, there will be the possibility of encountering a moderator that does not integrate well into the research team, who does not have a specific formation, and certain intersubjective abilities, such as knowing how to listen to the participants who do not get involved in the discussion <sup>11,12</sup>. In our research, the professionals that conducted the focus groups had fieldwork and research experience as well as clinical experience with mental health service users. This allowed us to be aware of the study object and objectives, as well as to reflect on the group dynamic and the interaction between

participants and researchers. A group setting where the researcher does not consider the clinical aspect could interfere with the quality of data produced<sup>65</sup>.

In order to manage and address clinical issues resulting from the discussion in the group, sometimes we also included a mental health team member to provide “clinical support”, being inside the group without any research responsibility, but only in case of any destabilized user in the group context. These clinical supporters never were somebody with clinical responsibilities towards any of the focus group participants. Similar attitudes were outlined by Owen<sup>24</sup> and Koppelman & Bourjolly<sup>64</sup> in focus groups developed for women with severe and persistent mental disease. As Owen<sup>24</sup> highlighted, we also observed the importance of other arrangements of permanent care, such as discussing periodically with the service teams topics regarding research and clinical issues related to focus group conduction and treatment.

The group moderation needs to be flexible, to balance possible asymmetries between the users' participation and to include all voices, even the accounts that are apparently out of focus<sup>67</sup>. Management of time and the interaction among participants and the creation of a dialogic atmosphere that allows the emergence of different perspectives about the theme discussed permitted not only the emergence of consensus, but also dissent. This avoids having only an apparently homogeneous view regarding a certain subject<sup>68</sup>.

In our experience, the mutuality produced in the group with people with severe mental illness resulted much more from the fact that the narratives elicited were coproduced by the participants, the researchers, and the context. That is, mainly from intersubjectivity, rather than from a common trace of identity.

In one study, the focus group constituted for research a regular activity in the service after the study. On the other hand, implementing the group inside the service contributed to raising narratives centered on the symptoms<sup>69</sup>, on medication and complaints about the service.

It was common that participants addressed demands related to treatment, therapeutic plans, and even information about the psychiatric diagnosis to the group moderator. In such circumstances, it was explicit that the line between research and care was blurred. Such situations did not happen only because the research activities were developed in the treatment setting, but because we inquired about participants' experiences. The questions asked by the researchers might elicit narratives and reflections referred to the illness-wellness process, giving a new meaning to the experience itself.

The researchers addressed ethical questions resulting from the blurred line between research and care, such as when and in what circumstances should community mental health teams be informed by the demands and complaints directed by the focus group participants to the researchers? Alternatively, what if the researchers perceive a participant is in a psychiatric crisis that requires clinical care? How can the researchers be sensitive to the participants' clinical conditions while respecting, at the same time, the users, and the ethical principle of confidentiality?

## Conclusion

In this study, the authors considered their vast experience in conducting focus groups with people with severe mental illness. The reflections from this experience are the strength of the article, since they allowed us to make some recommendations to other researchers about the need to modify the design and planning of the research when working with this population. Flexibilizations of the classical technique, such as reduction of group duration, establishment of a collaborative work with clinical team, reduction of the number of participants, allowed reaching the studies' objectives through a respectful and ethical manner.

Joining different researches that used focus groups for different purposes could be considered a weakness of this article. Nevertheless, we hope that this study can stimulate other researchers to use focus groups with this population and thus contribute to give voice to an often-silenced group, as well as to reinforce the legitimacy of mental health users' participation in evaluative research, overcoming the stigma.

Participative research strategies used with people diagnosed with severe mental illness lead us to look for alternative ways of operationalizing focus groups and to face approaching ethical and



methodological challenges. In this sense, we recommend that the research design and tools should be flexible enough to consider the experiences and engagement of users and professionals involved. In this manner, the planning of the focus group should consider the characteristics of the place where they will be developed, the characteristics of the participants, and the time and resources needed to work in the field.

Considering the clinical aspect in this type of group is an ethical imperative. A connection must be established among the research team, clinical staff and the users. This is essential for the development of the focus group, for the quality of narratives elicited and the exchanges produced. In this sense, focus group must be beyond the setting. Planning the conduction of focus group, the time required for work field and the number of meetings are important tasks to deepen group discussions and to pursue research objectives.

The management of the focus group acquires even more importance, requiring empathy, expertise in managing groups, and data saturation. Intersubjective skills, such as listening and moderating without making personal evaluations and/or prejudices, and the capacity to deal with unexpected situations are also needed.

Placing intersubjectivity at the center of attention and accessing participants' lived experience requires multiple precautions that converge into a common objective: to create a time and space where it is possible to coproduce narratives. This acquires particular importance when considering people with severe mental illness, who still suffer the consequences of prejudice. To approach narratives of people with severe mental illnesses as valuable testimony means to recognize their legitimacy. It is about an ethical position. By considering ethics, we hope to contribute to improving community mental health services, making them more porous to incorporating other values, and looking for flexible mental health services, that is, sensitive to users' voices.

## Contributors

R. T. Onocko-Campos, E. M. Leal and O. D. Serpa Junior participated in the design, development and data analysis of the project, in the writing, critical review and final approval of the version to be published, in addition to being responsible for all the aspects of the study and ensuring the accuracy and completeness of any part of the research. A. R. G. Díaz and C. M. Dahl participated in the development, data collection and analysis of the project, in the writing, critical review and final approval of the version to be published, in addition to being responsible for all the aspects of the study and ensuring the accuracy and completeness of any part of the research.

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## Resumo

O artigo trata dos desafios práticos, metodológicos e éticos identificados em três estudos que utilizaram grupos focais com pessoas com doença mental grave, no contexto dos serviços comunitários de saúde mental no Brasil. Os grupos focais são uma ferramenta poderosa para a pesquisa em saúde que merece uma discussão ampliada nos estudos com portadores de doença mental grave, no contexto dos serviços comunitários de saúde mental. O estudo tem como base as experiências dos autores na realização e análise de grupos focais em três cidades – Campinas, Rio de Janeiro e Salvador – entre 2006 e 2010. Discute-se o uso de grupos focais com pessoas com doença mental grave, de acordo com as seguintes categorias: planejamento, formato do grupo, amostragem, recrutamento, roteiro de entrevista em grupo e condução. O artigo destaca a importância de envolver os profissionais de saúde mental no contexto da pesquisa. Os achados enfatizam as questões e os desafios éticos, além da criação de um ambiente sensível e de empatia dentro do grupo, onde o respeito mútuo facilite as relações interpessoais e permita que as pessoas com diagnóstico de doença mental grave possam construir sentidos para a sua experiência. Os autores destacam a relevância da interação entre as equipes clínicas e de pesquisa para fomentar a colaboração, alcançar as metas da pesquisa e evocar as narrativas dos usuários e profissionais de saúde mental.

Transtornos Mentais; Serviços Comunitários de Saúde Mental; Grupos Focais; Pesquisa Qualitativa

## Resumen

El artículo trata sobre los desafíos prácticos, metodológicos y éticos, identificados en tres estudios que utilizaron grupos focales con personas con una enfermedad mental grave, en el contexto de los servicios comunitarios de salud mental en Brasil. Los grupos focales son una herramienta poderosa para la investigación en salud, que merece una discusión ampliada en los estudios sobre pacientes con enfermedades mentales graves, en el contexto de los servicios comunitarios de salud mental. El estudio tiene como base las experiencias de los autores en la realización y análisis de grupos focales en tres ciudades -Campinas, Río de Janeiro y Salvador- entre 2006 y 2010. Se discute el uso de grupos focales con personas con una enfermedad mental grave, de acuerdo con las siguientes categorías: planeamiento, formato del grupo, muestra, reclutamiento, guía de entrevista en grupo y ejecución. El artículo destaca la importancia de involucrar a los profesionales de salud mental en el contexto de la investigación. Los hallazgos enfatizan cuestiones y desafíos éticos, además de la creación de un ambiente sensible y de empatía dentro del grupo, donde el respeto mutuo facilite las relaciones interpersonales y permita que las personas con un diagnóstico de enfermedad mental grave puedan dar sentido a la experiencia. Los autores destacan la relevancia de la interacción entre los equipos clínicos y de investigación para fomentar la colaboración, alcanzar las metas de la investigación y evocar las narrativas de los usuarios y profesionales de salud mental.

Trastornos Mentales; Servicios Comunitarios de Salud Mental; Grupos Focales; Investigación Cualitativa

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