



Experiences of Persons with Schizophrenia Participating in a Recovery-Oriented NGO Project in Brazil

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Abstract This study aimed to understand the process of recovery from the perspective of people with schizophrenia and caregivers participating in a cultural and artistic project of a Non-Governmental Organization in São Paulo, Brazil. Five users with schizophrenia and their caregivers were interviewed by the first author, who had lived experience perspective and training in mental health research. A semi-structured interview guide was adopted (user and caregiver versions), designed to understand their knowledge, experiences, and perceptions of recovery from mental health problems. An Interpretative

Phenomenological Analysis was adopted to explore how each participant interpreted their own experiences. Respondents reported that friendship and social interactions emerged as an element of change in the cultural and artistic project working groups, which workshops helped in the development of personal skills, providing motivation for everyday life. Caregivers linked such changes more directly to the project activities than users with schizophrenia. This study was the first to investigate recovery-oriented activities promoted by Non-Governmental Organizations. Our findings suggest that such activities might

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be a valuable tool to promote recovery in contexts where this process is not yet officially incorporated in mental health policy.

Keywords Mental health · Recovery · Qualitative research · Interpretative phenomenological analysis · Interview

Introduction

Recently, the recovery movement in mental health has progressively expanded in different countries, especially in Europe and North America. The World Health Organization has promoted it based on implementing a more person-centered care and focused on personal development in the mental health system (Saxena, Funk and Chisholm, 2013; World Health Organization, 2021). In Latin American countries, such as Brazil, there are traditions that fall under the premises of recovery approach; however, it has not been comprised of clear recovery-oriented plans and guidelines. Additionally, a recovery-oriented approach is still not systematically embedded in mental health policies. Despite this, Brazil adopts assistance driven by human rights and focused on community mental health services, the so-called CAPS (Centers of Psychosocial Attention). There is an influence of the Italian deinstitutionalization process, from the perspective of Franco Basaglia, focused on promoting citizenship and psychosocial rehabilitation (Vera San Juan et al., 2021b; Onocko Campos et al., 2017).

The work of users' associations and recovery-oriented NGOs might be even more important in settings such as Brazil, where the approach is not systematically established. The typical recovery-oriented activities offered by these NGOs can be illustrated by partnerships with mental health services, through workshops and courses in various areas. This can occur particularly in the creative context, including artistic-cultural one, as has been done by the Brazilian Association of Friends, Relatives and Persons with Schizophrenia (ABRE). ABRE was established in 2002, inspired by the international project "Open the Doors" of the World Psychiatric Association (WPA), which was launched in more than 20 countries in 1999. This project generated actions to reduce stigma associated with schizophrenia (Gabel and

Baumann, 2003). ABRE's mission is to improve the quality of life of people affected by schizophrenia and their families, through support, information, and psychoeducation, embracing human rights and struggling against the stigma associated with mental disorders.

Within a movement that later became associated with the promotion of recovery, ABRE established several projects, some of which had already been the focus in previous studies (de Miranda, de Almeida Pimentel and Villares, 2014; Orsi et al., 2021b, Villares, 2015; Weingarten et al., 2021). Among these projects, the main one is "Casa Azul Creation Laboratory" (Laboratório de Criação Casa Azul—LACCA). This project was created in 2016 and is the only one that had not been associated with any study yet. The term "Casa Azul", within the acronym LACCA, was originally the studio of the Mexican painter Frida Kahlo. LACCA workshops aim to enable participants to expand their creation abilities and the enjoyment of art and culture expression, opening a space for working with different artistic modes, by providing interaction and participation in recreational activities in a welcoming and including environment.

Since its establishment, hundreds of users with schizophrenia have attended LACCA workshops. In partnership with the Schizophrenia Program (PROESQ) and held in the facilities of Paulista School of Medicine, at the Federal University of São Paulo (UNIFESP), LACCA provides workshops such as: fine arts, writing, philosophy, information technology, English, music, mindfulness, Taichi, theater, yoga, among others. These workshops were given by highly competent and distinguished professionals, who were volunteers at LACCA. There were also workshops led by users, such as writing, philosophy, and English. The workshops were offered on a semester basis and anyone, users, caregivers and everyone else could attend it.

The few studies on the topic of recovery in Brazil have focused mostly on how this concept is present in the reports of service users with schizophrenia (Lopes et al., 2012; Ricci et al., 2021). Studies focusing on the participation of these people in interventions and activities explicitly oriented towards recovery are even more scarce (Vera San Juan, 2021a). It is also worthy to mention that studies in this context should also include the perspectives of relatives or informal caregivers. This is due to the Brazilian and Latin-American sociocultural

aspect of long-lasting affective and financial reliance on family and the importance of family members for the recovery process, which has been pointed by previous authors (de Oliveira et al., 2021; Ricci et al., 2021; Vera San Juan, 2020).

Despite WHO recommendations to incorporate recovery-oriented practice in the clinical routine (World Health Organization, 2021), the practical application of its principles has occurred more easily through the activities of NGOs than through official policies (Slade, Amering and Oades, 2008). Usually, mental health professionals, even if they are technically qualified and trained, face strong difficulties in adapting to the recovery approach due to their clinical experience predominantly rooted in the biomedical model (Read, Bentall and Roar, 2009; Sartorius, 1998). In addition, there is also the difficulty of health systems in incorporating paradigm shifts into routine clinical practice. On the other hand, NGOs involved in health care, having less training and clinical training, are usually more flexible, allowing an approach that can be more coherent with the philosophies of self-determination and risk-taking (Rose, 2018; Slade, Amering and Oades, 2008). In this sense, the role played by users' associations and NGOs stands out, especially those collaboratively managed by mental health professionals, family members and users with severe mental disorders. Such NGOs, based mainly on volunteer work, encourage the role of work toward the promotion of peer-support, a practice in line with the principles of recovery among the various forms of recovery-oriented practices. Initiatives such as peer support have been on the spot, based on the lived experience of people with severe mental disorders (Thara and Patel, 2010).

Within this context, the objective of this study is to learn users' recovery process through the collection of reports from users with schizophrenia and their caregivers. This was achieved using a structured interview guide, as to understand how LACCA contributes to and supports their process of recovery and empowerment. To our knowledge, this is the first study investigating recovery experiences in the context of NGO artistic and cultural activities using this approach.

Methods

This study followed a major inter-institutional research project between a Brazilian and a British university, with the aim of contributing to how people with mental disorders understand, conceive, and perceive terms and experiences related to the recovery approach in the Brazilian and Latin American context (Vera San Juan, 2020). The present study was approved by a Brazilian Ethics Committee Board.

Participants

From the initial eight mental health service users with schizophrenia, selected by a convenience sampling, participants of LACCA workshops, together with their respective caregivers, only five pairs of each were included in the study. The reason for the refusal by the remaining three users with schizophrenia and their caregivers was mainly lack of time and no interest in participating in the interviews. The inclusion criteria were people of any gender, over 18 years old, receiving psychiatric outpatient care at the time of the research, and diagnosed with schizophrenia, schizotypal disorder, or other delusional disorders (F20-F29, according to the International Classification Diseases—ICD-10). Exclusion criteria included those who were unable to answer the questions in the interview guide, due to clinical or cognitive conditions. User group was comprised of three male and two female users, whose ages ranged from 29 to 42 years, and age of illness onset ranging from 15 to 31 years. Caregivers were only female, aged from 47 to 61 years.

Study Setting

ABRE's mission, through LACCA, is to encourage people with lived experience, especially those with severe mental disorders, to act as protagonists, through cultural and educational actions. LACCA offers workshops in partnership with a Brazilian University Schizophrenia Program. Such program provides its physical space for conducting ABRE cultural and artistic activities, open to the community. This initiative was inspired by the Brazilian psychiatrist and educator Dr. Nise da Silveira, who adopted art in

her work with users in Brazil, throughout the 1940's and 1970's (Almeida, Pedrosa and Rotolo, 2021; Guimarães and Saeki, 2007).

Material and Procedures

Interviews were conducted with five users with schizophrenia and their caregivers, adopting a semi-structured interview guide, available in two versions: one for users and another for caregivers. The interviews were conducted by the main author of this study at the facilities of the Brazilian Schizophrenia Program, where this project was held, and at users and their caregivers' homes. These interview topic guides were adapted from those used in the above-mentioned major inter-institutional research project. Details around guideline development can be found in Vera San Juan (2020). The interview guides were designed to understand the knowledge, experiences, and perceptions of recovery from mental health problems. Questions were added whenever each respondent mentioned a topic that needed further clarification, and attention was paid to focusing on assessing participants' personal experience, as well as to avoid stereotyped responses. Lived experience was emphasized when participants' answers referred only to medical concepts or definitions provided by health services and personal knowledge.

Interview guides started with the following information topics: (1) introduction; (2) user or caregiver information; (3) background, including the individual notion of recovery, with questions such as how caregivers describe users' process since their mental problems started, whether this is related to or compliant with users' answers, how caregivers define being well or not being well and what it means to be well. These were followed by (4) 19 dimensions of recovery with questions such as: how relevant users or caregivers consider that the dimensions of recovery identified in previous literature are to their understanding of well-being (Agrest et al., 2021; Orsi, 2021b; Vera San Juan, 2021a). These dimensions were: connection, empowerment, hope and optimism for the future, identity, meaning in life, and resilience. A list of words and their definitions was shown to verify how user or caregiver felt about them, relating them to their personal experience and explaining the words that could be unclear; and (5) Closing.

Table 1 presents the initial nineteen recovery themes and dimensions that drove the interview guides, both in user's and caregiver's versions:

All participants were interviewed by the first author, who had a previous experience with schizophrenic users through a professional interaction in another psychosocial work performed by ABRE, which was the mutual support group, evaluated in another study (Orsi, 2021b). The interviewer came to this work from a lived experience perspective and training in mental health research at the proponent NGO, where he holds a position of Director since 2007. In this regard, due to this previous approach, the researcher used the bracketing procedure, excluding the context and any underlying assumptions to analyze data in its purest form.

Participants were initially contacted by telephone and interviewed face-to-face at their homes or in the facilities where LACCA activities were conducted. Written informed consent was obtained from all participants before the interviews. The ten interviews had an average length of 40 minutes each. When a user had multiple caregivers, the primary one was selected to participate in the study. To analyze the content of the responses, the interviews were audio recorded, duly authorized by the participants, as part

Table 1 Recovery themes and dimensions

1	Mental disorder
2	Diagnosis
3	Changes and positive impacts
4	Resilience
5	Identity
6	Hope and optimism
7	Sense of life
8	Life projects
9	Empowerment
10	Sense of belonging
11	The process of recovery
12	Goals and dreams
13	Personal achievement
14	Self esteem
15	Connection
16	Work and paid activity
17	Family
18	Costumes and traditions
19	Leisure and free time

of the Informed Consent Form. Then, reports were transcribed and stored in electronic files with access restricted to the responsible researchers. The semi-structured nature of the interviews provided a space in which participants' responses largely determined their course.

Data Analysis

The Interpretive Phenomenological Analysis (IPA) was adopted to generate emerging themes from the initial ones. This approach enables working with small samples as done by other similar studies (Ali et al., 2023; Atapattu et al., 2022; de Wet et al., 2015; Rácz et al., 2017), and all responses may be analyzed in detail. Despite the initial 19 themes and dimensions given in the interview guide that were used as a basis for the analysis, the inductive approach characterizing IPA was used to explore how each participant interpreted their own experiences. Therefore, transcriptions were conducted from the spontaneous expression that each theme evoked in the participants, allowing the generation of the emerging themes (Eatough and Smith, 2008; Pincus et al., 2016; Smith, 2009).

An analysis of each topic proposed by the semi-structured interview guides was performed through the completion of the following steps by the first author: (1) The transcripts were read and revised to obtain a general idea of each participant's speech. Participants' emerging reports were noted, as well as the particularities of each ones; (2) Transcripts were reviewed, focusing on the topics raised, allowing a focus on the original reports and speeches of each participant; (3) The emerging reports, grouped into pre-established topics, were observed and condensed to obtain the essence of each participant's lived experience; (4) Groups of related topics were identified and mentioned in the transcripts, which generated a list of main themes of users with schizophrenia and their caregivers; and (5) The final recovery dimensions obtained from this analysis were checked and revised by two other authors of this study. A selection and refinement of the most representative reports were made for each theme and recovery dimension, to ensure that the analysis corresponded to the main objective in each participant's speech. The strategy for dealing with saturation was obtained when there

was repetition of ideas and answers during the reading of the semi-structured interview guides.

Results

All 19 original recovery themes and dimensions from the guide were grouped into eight topics after the interview (see Table 2), based on their similarity, to make the analysis and results presentation easier.

The results obtained for each topic are presented and discussed below. For each one, there is at least one report, selected as the most representative.

Mental Disorders and Diagnosis

Users: Most users with schizophrenia considered people with mental disorders are just like everyone else, but with diverse kinds of suffering and different experiences. Mental disorders were even seen as bad luck, expressed mainly through the diagnosis, but which needed to be faced by them in their daily lives.

Suddenly, a person with a mental illness, whether it is schizophrenia or bipolar disorder or schizoaffective disorder, is a person just like the rest of us. In the beginning, we felt very bad luck, terrible luck and that is it. One must face it, as the saying goes in Spain: 'take the bull by the horn and push'. (User 2).

Caregivers: expressed how the visibility of their family member's mental disorder affects the caregiver, in addition to a connection between this caregiver and the way the family member feels.

Yes, because of the following, my coworkers knew very well when M. was not well because

Table 2 Grouped recovery themes and dimensions

1	Mental disorders and diagnosis
2	Changes, positive impacts, and resilience
3	Identity, connection and sense of belonging
4	Hope and optimism
5	Meaning and life project
6	Empowerment, work and paid activity
7	The recovery process, goals, and dreams
8	Personal achievement and self-esteem

I was not well either. So, they used to say: ‘M. is not doing well today, is he?’ And I said, ‘No, he is not.’ They noticed it and when he improved, they said: ‘he got better.’ So, that was all the colleagues who worked with me. It was a constant. So, they knew. And as I saw that he got better, so did I. I felt happier and I let go, giving him independence. (Caregiver 1).

Changes, Positive Impact, and Resilience

Users: Optimism and willpower were listed as key factors for resilience to overcome problems related to mental disorders, as an outcome of the participation in these workshops.

You need to have that inner strength, right? To be able to overcome the issues that come to your life, and happen in your everyday life, you need to have this optimism, this willpower and I basically, I particularly, I feel like a very resilient person. Strong enough to withstand the face that life imposes on me, right? This is also important for recovery. (User 3).

Caregivers: the relevance of structuring a daily routine was mentioned, taking one day at a time regarding facing obstacles, with the aid of LACCA activities. Also, aspects related to resilience were linked to trusting in the physician and the perspective of improving and overcoming mental illness.

What is resilience? That is what I said, today you are not well, but tomorrow maybe the doctor will switch the medicine, I will get better. I am going to do something I like the most. I am feeling very tired during the day, so I must rest more. It has to do with resilience. (Caregiver 2).

It is good, because the workshops provide contact with other things, right? [...] She has access to an art class, which she likes, she has access to a computer class, she has a welcoming setting. [...] These are supportive things, right? As not let the... have a routine, a normal life within everything she can have. She does not have to have limitations; she must be supported to go up the steps that she will climb. (Caregiver 5).

Identity, Connection, and Sense of Belonging

Users: connection was identified as a relationship with oneself, through a process of continuous interaction with external activities, like those provided by LACCA workshops. In this sense, identity was mentioned as an individual and personal feature, in evolution, facing life’s adversities and being a particularly important element for overcoming them. The context in which a person lives was also reported as very important. Interaction, friendship, and partnership created among participants during the activities were also emphasized as a way of expressing a sense of belonging.

I think the person needs to have what I call a personality, right? A person needs to know who they are, where they came from, where they are and where they are going, right? In life, we must have this concept, so as not to hesitate and stray from the path, right? And I think that this part of identity is also very important to overcome... We must look for things that bring meaning to our lives, right? (User 3).

It is about interaction we are talking here all the time, right? The more you interact, the more conditions you will have for a more common social life or the closer to normality. So, the connection is very important, you create spaces, where you start to attend [the workshops] and have contact with people, even from the professional aspect as well. I think that, depending on the person, they must aspire to get a job. Nowadays there are work classifications, there are people with disabilities, disabled patients. So, even the work itself, as far as possible, is a connection and this connection is very important for recovery. (User 3).

Connection. You connect with yourself first, to the point where you are an emotionally independent person, and then you interact, because then you will relate because you feel good, not because you need another person. This is a connection with yourself, with your deep self. This is essential. This is very important. (User 1).

Caregivers: LACCA workshops were seen as promoting a strong increase in connection and sense of belonging among participants.

[...] The person connects more with life, with things, with people, right? Just like he is here, in a very good connection of experiences, right, with people here. [...] I think it is very good, very good! He has improved a lot with these workshops. [...] It was the best thing that happened in his life, it helped him a lot. (Caregiver 3).

Hope and Optimism

Users: hope and optimism were often seen with some skepticism, within a more realistic context for facing life. However, these elements seem to have significant importance to them.

You must be hopeful and not complain about things, right? Be an optimistic person, because the more positive you think, the more conditions you will have to be able to get out of a certain difficult situation. (User 3).

Caregivers: hope was seen as a fundamental element in recovery, as a crucial factor in overcoming mental illness.

Hope always, right? Because we know that, through medicine, what they say about this is that there is no cure, but we must have faith and hope to be able to always expect improvement, right? And that is what is happening to him. I hope he gets better even more each day. (Caregiver 3).

Meaning and Life Project

Users: LACCA workshops helped in the development of personal skills, providing motivation for everyday life.

Arts, I have a goal that helps me to draw better, to have a broader experience to draw better. I have Art classes with C. And J., it helps me to practice writing, so I have new ideas to write better things, because I want to draw and write good things. (User 1).

Caregivers: LACCA activities gave new meaning to users' lives, providing new motivation and improving family relationships.

I see he lives; he has a little life. He has life! [...] He is very ethical. Of all activities, Arts are the only thing he shows me, that he can share with me. Then, the other activities are therapeutic, they are almost like a therapy, and he has amazing ethics. Sometimes I ask: 'who coordinated today?' And he says: 'J was the same...' and I am happy. (Caregiver 2).

Empowerment, Work, and Paid Activities

Users: empowerment was seen as being productive, especially regarding paid work. Work and paid activity were viewed as a major step in the recovery process of a person with serious mental illness, and they were usually represented as one of the main assets of the recovery process, that is, the main achievement of sense of belonging and protagonism in society.

What is empowerment anyway? We go back to the same line, work, just as it is. Now, it would be important for Brazil to implement a decent benefit for schizophrenics. If we talk about working, most of them cannot bear the business environment and so, we must have at least a decent livelihood from the State, you know? Anyway. (User 2).

It can be a paid or even unpaid activity, or even a job as a volunteer, etc. I think work dignifies a man, right? It brings a complement to life that no other function can bring you, right? It is a journey that you complete daily and that has a fundamental importance in our lives as human beings. (User 3).

Caregivers: being part of a peer group in LACCA workshops was seen as something that promotes and encourages a sense of belonging and empowerment. Work and paid activity were reported as giving a new meaning to life, providing a new routine, even if the activity initially starts through volunteering.

She is what she has, sometimes I see more... sometimes she feels empowered with something when she is nearby... That is what I said, when she is with her schizophrenia group, with those from the group, I realize that she has self-esteem, empowerment, but when she is out there in society, she shrinks, she hides. (Caregiver 4).

Because, in this case, he should have an activity, but not necessarily... Another meaning that an individual should make is a new meaning for money, because at that time I taught M. a lot that it was important he had an activity, in fact it was a philanthropic activity, which was... That not only those who earn money are important... (Caregiver 1).

The Recovery Process, Goals, and Dreams

Users: the recovery process was seen as essentially related to the acceptance of their mental disorder and adapting themselves to face daily challenges.

There is no doubt it is possible. Now, for a person, it is essential to overcome this emotional maturity of accepting life, accepting things as they are. From that moment on... it is funny! From the moment you accept the illness, your life starts to normalize and improve. It is amazing! Yeah!... It is essential, because if you do not accept it, you do not take the necessary steps to normalize. For me, recovery is living in peace and happiness. (User 2).

Personal Achievement and Self-Esteem

Users: self-esteem and personal achievement were mostly reported as individual characteristics, intrinsically related to each one's journey of recovery. In this sense, life project must be rebuilt, supported by willpower, and nurtured by resilience.

I feel fulfilled because I accepted the frustration! I have accepted all the frustration and I no longer care about the typical achievement society expects from a person. What does society expect? Work, study, college, etc. Today I do not go through that." [...] "I became more sociable, calmer, more understanding and more communicative. (User 2).

Caregivers: mental illness was mentioned as something that undermines self-esteem and, as such, occupational activities, like those developed at LACCA, become especially important for the process of regaining values and meaning in life.

At this moment of her life, she is now looking for other things, I think she has already set-

ted this part of the treatment, it is the part... What is missing is the financial part, right? It is on path because I think it is something that, for people with disabilities, people with special needs, like this one, a minimum survival rate should be established. Should be provided. Why? Because a person can follow their treatment, have some flexibility to be able to do their own things. From the moment they are unable to survive, they will not be able to continue treatment... (Caregiver 5).

However, fomenting independence, daily activities and routines, family support and self-esteem were seen as fundamental elements for coping with and overcoming mental illness.

The independence itself... The independence he acquired... First, there is a lot of family support. Support must be given without being invasive. Got it? It is kind of like that, just go, if it does not work, you can come back. So, if he has this support and the thing is, self-esteem, he must develop self-esteem, because a very famous psychiatrist that I had the pleasure of meeting, said: 'the flagship of mental illnesses is self-esteem'. (Caregiver 1).

Discussion

Through the analysis of the interviews' transcripts, several themes emerged about the recovery dimensions included in the guide, which were regarded as the factors associated with participants' experience of recovery. One difference between the reports of users with schizophrenia and their caregivers is that the first ones generally did not associate the changes and improvements that occurred in their lives directly with their participation in LACCA. This explicit association of gains and improvements with participation in this project was more present in family members' reports. One of the reasons could be that family members have an external role, as spectators and a third party. Users with schizophrenia, being personally involved, and facing their experiences more directly, had more difficulty in making this association. Although the topics differed by themes, users' and their caregivers' speeches became intertwined in the different topics, with one referring to the other,

and even though interview guide was structured with previously determined topics, the participants ended up dispersing in their speeches and covering different subjects within the same one.

For most users, people with mental disorders were viewed just like everyone else, but with different suffering and life experiences. Friendships and social interactions were mentioned as an element of change in LACCA working groups. For caregivers, the relevance of structuring a daily routine was supported by LACCA activities, which were able to give new meaning to users' lives, providing new motivation and improving family relationship. Independence, daily activities and routines, family support and self-esteem promoted by these projects were also reported as fundamental elements for coping with and overcoming mental illness. Occupational activities developed in LACCA became very important for the process of regaining values and meaning in life. LACCA workshops were seen as promoting to its participants a strong increase in connection and sense of belonging, which could be verified and attested by their families.

Despite being the first study on recovery reports in the context of NGO-led activities, these results confirm findings from previous studies on recovery experiences. For instance, a recent systematic review on mental health service users with schizophrenia and informal caregivers' perspectives showed that, while users emphasize social aspects of acceptance and connection with others, their caregivers emphasize aspects of symptoms (Vera San Juan, 2021a). This result should be expected, as the review included studies inside a treatment and service setting, where families and professionals usually emphasize a clinical recovery perspective. In our study, developed in a non-clinical context, both emphasized social aspects, with family members focusing more on the impacts of interactions with other people in the recovery occupational activities.

In a Brazilian study with mental health service users with schizophrenia, different aspects were identified in the recovery process. Receiving mental health services was extremely helpful for participants, especially those feeling overwhelmed by symptoms, but not enough to help them regaining a meaningful life in their communities. Solidarity from friends and family members was recognized as an important recovery asset (Ricci et al., 2021). These findings

reinforce the potential role of non-clinical activities for the recovery process, like those provided by LACCA.

Regarding the limitations of this study, the first to be mentioned is the small sample size. Despite the extrapolation of results is not aimed in qualitative studies, a larger sample could make our findings more representative. Another limitation of the study might be related to the interview guide being adapted from a more general previous study that sought to apprehend the meaning of recovery for mental services users with schizophrenia and their caregivers in the Brazilian context, regardless of participation in any activity. However, this is also a strength due to the strict development of this original topic guide and validation through a focus group in the same setting of the current study (Orsi et al., 2021a).

In many reports, the role of LACCA workshops appeared in some of the themes. For example, in the last topic ("Work and paid activity"), users and their families highlighted the importance of LACCA activities, even if they are not remunerated. It is important to note that, despite being in separate dimensions in the analysis, work and paid activity, were often associated as one of the main forms of empowerment in the reports. A last strength to be highlighted is that this research used a service user perspective, following a rigorous analysis process, and to our knowledge it is the only study so far looking into this matter.

Conclusion

This study allows to raise a few questions regarding how much these recovery-oriented activities offered through NGO projects promote empowerment and protagonism, as pointed out by users with schizophrenia and their caregivers, thus impacting their recovery journey. There are numerous processes brought either by users and their caregivers, in the sense of belonging, friendship, daily and occupational activities, either paid or not. Although not explicitly mentioned as having been caused by LACCA activities, these processes seem to be natural results of LACCA workshops. These activities do not have a usual therapeutic approach, such as occupational therapy activities, but are rather focused mainly on a cultural and artistic way. Not depreciating occupational therapy work, but cultural

and artistic activities themselves seem to be a very valuable and add-on support to people in a stable mental health condition.

This study could also be labeled as a user-led mental health research, which has been encouraged in the field in the past decades. Although the first author of this study is directly involved in the NGO, we consider the results suggest that cultural and artistic activities, like the ones focused on this study, could have a very positive and promising impact on the people implied. This kind of workshops, conducted by NGOs, might work as a useful tool to promote recovery in contexts where this process is not yet officially incorporated in mental health policy, as is the case in Brazil.

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Author Contributions JAO designed, conducted the study and collaborated with data analysis and manuscript preparation. MCRA and WFO collaborated with the analysis, data interpretation and preparation of the whole manuscript. NVSJ developed and provided the main semi-structured interview guide of this study and collaborated with the data interpretation. CCV collaborated on the study design and the data interpretation. RAB collaborated on the study conduct and data interpretation. AG collaborated on the study design, data analysis and supervised the manuscript preparation.

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Data Availability The data sets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Conflict of interests RAB received personal fees from Sanofi, Ache, from institutional grants, personal fees and non-financial support from Janssen, outside the submitted work. Also received grants from the European Research Council, Medical Research Council (UK) and Cyted—Programa Iberoamericano de Ciencia y Tecnología para el Desarrollo, and grants from CNPq, FAPESP and CAPES (Brazil). The other authors declare that they have no conflict of interest.

Ethical Approval This study was approved by the Research Ethics Committee of UNIFESP, in accordance with Resolution CNS 466/2012, and registered at Plataforma Brasil, CAAE N. 2,394,928 (year 2019).

Consent to Participate Consent to Participate Informed consent was obtained from all individual participants included in the study.

Consent to Publish All participants provided informed consent to publish the images used in the photovoice project.

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