



Evaluation of Ongoing Participation of People with Schizophrenia in a Mutual Support Group as a Complementary Intervention to Outpatient Psychiatric Treatment

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Abstract

This study aims to evaluate a group of people with schizophrenia undergoing outpatient treatment and who participate in a mutual support intervention, compared to another group of people with the same diagnosis, but attending only the usual outpatient treatment. This is a prospective study, with two measurements between six months. The mutual support group was initially composed of 16 people and the treatment as usual group was composed of 15 people. Clinical (medication adherence and functioning) and Recovery (hope, well-being, recovery and internalized stigma) outcomes were assessed. Nonparametric tests were used to verify differences in measurements between groups and between two moments. A higher level of internalized stigma and a decrease in the adherence to drug treatment in the treatment as usual group were verified. When comparing the pre-post difference between groups, there was a greater increase in adherence to drug treatment in the mutual support group. Our data point to more favorable results in the mutual support group, showing that ongoing participation in these groups is an important tool for the recovery process and for the treatment itself.

Keywords Mental health · Recovery · Peer support · Support groups · Schizophrenia

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Introduction

Recovery process in severe mental disorders has been central to mental health policies, especially in English-speaking countries [28, 30]. Recovery has been defined as a personal and relational process, of rediscovering a new sense of identity, self-determination and personal empowerment to live, participate and contribute to the community [1]. Studies and literature reviews have pointed out that recovery can occur through five main processes, gathered in the acronym CHIME: connection with others, hope and optimism for the future, development of an identity beyond the disease, meaning and purpose in life, and empowerment [15]. Although the recovery process is individual and can occur regardless of treatment, care practices and health services can build a context that supports it. These practices seek to promote hope, autonomy and self-determination, supported by collaborative relationships and partnerships between professionals and users [14].

One of the main recovery-oriented practices is peer support. In this type of intervention, people diagnosed with a mental disorder, called peers, share, in a systematic and standardized way or not, their lived experiences and strategies for illness coping and management with other people in the same situation. In the literature, peer interventions have been usually divided into three main types: (1) Mutual support groups, where relationships are considered to be mutually reciprocal, even in the case in which some of the participants are viewed as more qualified or experienced than others; (2) Peer support services, in which support is mainly unidirectional, with at least one clearly defined peer, supporting one or more program participants, divided or added to the standard care available at the mental health service; (3) Mental health workers or peer service providers, mainly consisted of persons who have been users of mental health services, currently employed as members of professional teams and providing standard care by a service [4, 10, 17].

In recent years, a growing number of studies have evaluated the impact of peer support interventions. The effects on clinical variables, such as hospitalization rates and symptoms, have shown significant heterogeneity in the structure and typology of the interventions, in addition to several methodological limitations. On the other hand, the effects on recovery measures, including hope and empowerment, consistently points to positive impacts, in the short and medium term [4, 16]. However, most of these studies in recent years have focused on peer support services and interventions offered by peer workers, using structured and manualized activities. A smaller part of them is focused on mutual support groups, which usually consist of unstructured meetings and focused only on developing links between their participants [16, 19]. They can be defined as groups in which their participants share the same problem, meet regularly, exchanging information, receiving and offering support to each other [16, 22]. This type of group is based on what occurs naturally among people with mental health problems, with the proposal of promoting realistic hope, sharing experiences and exchanging coping strategies in problematic situations of daily life. [31].

Although mutual support groups play a secondary role in current developments in research on peer intervention, these groups are the most common and traditional ones in the mental health field [13, 22]. Previous research indicate that these groups may have effects equivalent to group interventions offered by professionals regarding clinical and well-being outcomes, despite a lack of methodological rigor [13, 22, 31]. Mutual support groups are usually offered and organized through associations or Non-Governmental Organizations (NGO), aimed at family members and people with specific serious mental disorders [13]. The participants of these groups also attend outpatient psychiatric treatment, and the group ends up being an informal complement to their treatment. Many people participate in these

groups for long periods, in which studies investigating the real contribution and benefits in continuing to participate in mutual support groups as a complement to outpatient treatment are scarce. Thus, this study seeks to fill this gap, evaluating a group of people with schizophrenia attending outpatient psychiatric treatment, and have also been participating for some time in a mutual support group of an NGO (serving family members and people with schizophrenia), compared to another group of people with the same diagnosis, who only attend the treatment as usual.

Methods

This is a prospective study with two measures between six months, which evaluated ongoing interventions, offered independently from the research.

Participants

This study comprised a non-probabilistic sample of people with schizophrenia spectrum disorders. People of both sexes, over 18 years old, who were in outpatient psychiatric care, with regular use of medication at the time of the research, diagnosis of schizophrenia, schizotypal disorders and other delusional disorders (F20-F29, according to the International Classification of Diseases—ICD-10), certified by a public or private mental health service, and that had cognitive ability to understand and participate in the data collection, as assessed by the interviewer, were included in the study.

Study participants were recruited from two different groups. One of them worked as a treatment as usual group and was formed by people treated in a university outpatient psychiatric service and taking medication. This group was formed by a convenience sample comprised by 15 people, appointed by a service professional to participate in the study. The other group originally included all 17 people who, in addition to the standard outpatient treatment, participated in a mutual support group, carried out by a NGO managed by people with schizophrenia, their families and friends. However, one of them did not accept to participate in the study and the remaining 16 were included in the study.

Interventions

Treatment as Usual Group

Psychiatric consultations were held at a university service that offers specialized and multidisciplinary outpatient treatment for people with schizophrenia spectrum disorders. This service claims to value an open dialogue between patients, family members and the multidisciplinary team. At the beginning of each consultation, the professional seeks to assess the patient's mental state, receiving complaints from the patient and the family, as well as actively asking about psychiatric symptoms. Social, routine and lifestyle aspects are also evaluated. The environment also allows a screening of non-psychiatric clinical issues, which receive appropriate guidance.

The provision of psychoeducation on the disease and treatment is another component of assistance. The frequency and duration of psychiatric care vary according to the needs of each patient. Usually, consultations take place at intervals of 30 days, which can be

anticipated, in case of clinical worsening or other risky situation, or postponed, in case of stability. The duration of each consultation, on average, is between 30 and 60 min, depending on patient's clinical status.

Mutual Support Group

The mutual support group was started in May 2005. Initially, this group proposed to make visits to the homes of people with schizophrenia, who were confined at home, to get them out of this morbid condition of isolation and reintegrate them socially. Subsequently, it was concluded that this service format was not the most appropriate, since it would be little productive, expensive and with doubtful effectiveness. Thus, it was concluded that the most practical and feasible way to achieve this objective would be to promote weekly meetings, in sessions that last initially, at most, an hour. The mutual support group accepts anyone under psychiatric care, whatever it may be. The only requirement is that they are diagnosed with schizophrenia or schizoaffective disorder, associated with the NGO and clinically stabilized. In addition to participating in the mutual support group, all members also attend usual psychiatric outpatient treatments, including medication use, whether from the public network or even by private professionals. The group was initially coordinated by two mental health professionals and had two or peers as facilitators. Over the years, the group has grown, and, at the request of the participants, the duration has increased to 1:30 h.

With the advances in technology, a parallel online group was created through a social network (WhatsApp), with a user as moderator, which aggregates all participants. In this virtual discussion forum, people, just as they did in the face-to-face activities of the mutual support group, exchange information and interact with each other, exchanging life experiences and eventual difficulties they face daily. It is worth mentioning that, over time, the format of the mutual support group was changing and evolving, and in 2016, the group's coordination was transferred from a mental health professional to one of the facilitator's peers.

As already mentioned, the mutual support group does not have a therapy or self-help format, being a group of mutual support, and the meetings are free, with no pre-defined themes or guidelines. Each participant simply poses a topic, spontaneously, and this is discussed by the group, with a moderator's management, seeking to give voice to all the demands of each participant. Therefore, the group consists of an opportunity for its participants to socialize, to have an experience with other people with the same psychiatric diagnosis, who know the daily difficulties. Over time, the group also started to organize itself through a genuine friendship network, external meetings in parks, malls, cinema, food meetings, and celebrations, which have become traditions such as birthdays and Christmas at the end of the year. It should be noted that at the last meeting of each month, a fraternization between participants was established in the last half hour. In this way, there is a regular social interaction between the participants beyond the regular meeting.

Outcomes

The following clinical and recovery outcomes were used:

Clinical outcomes

For the evaluation of functioning, the Social and Personal Performance Scale (PSP) was used, which was applied by two psychiatrists through individual interviews. All other

instruments were applied collectively in each group and filled by the participants themselves. The PSP Scale is scored in four main areas, namely: A. Socially useful activities, including work and study; B. Personal and social relationships; C. Self-care; D. Inconvenient and aggressive behaviors. Each area has its own definition of the severity levels and the final score of the instrument is given by means of a decimal score, which ranges from 0 to 100, and another final score, which indicates the final number / index of this assessment [6, 21].

Adherence to drug treatment was assessed using the Brazilian version of the Medication Adherence Rating Scale—MARS-BR [20, 29]. Ten questions are asked about how the research participant takes his psychiatric drugs and what they think about them, each with two options (Yes / No). The higher the score, the greater the level of adherence.

Recovery outcomes

Four measures related to recovery were evaluated, all using instruments in their version adapted to the Brazilian context: hope, well-being, recovery and internalized stigma. The level of hope was measured using the Herth Hope Scale—EEH (Herth Hope Index), consisting of 12 items. [2]. Well-being was measured using the World Health Organization Well-Being Index (WHO-5), in which participants answer five questions related to the general level of well-being [3, 11]. The recovery process was assessed using the Brazilian version of the Recovery Assessment Scale (RAS-BR)—brief version, with 24 items, which is the most used instrument internationally to assess this variable [8, 27]. Internalized stigma was assessed using the Brazilian version of the Internalized Stigma in Mental Illness scale (ISMI-BR), which is a questionnaire consisting of 29 items [24, 25].

Procedures

Participants meeting the study inclusion criteria were contacted and invited to participate voluntarily, being informed about the purpose and content of the research. Upon participation acceptance, they signed an informed consent form. The first application of the assessment instruments and interviews with psychiatrists took place between August and September 2019. All participants in both groups were already participating in their respective evaluated interventions, both the mutual support and treatment as usual groups. It is worth mentioning that, at the time of the first assessment, the participants in the mutual support group were restarting meetings in the second half of the year, after a brief interruption regarding the winter vacation period (July). The second evaluations and interviews with psychiatrists took place six months after the beginning of the first collection, between February and March 2020.

Data Analysis

Data were analyzed using the Statistical Package for Social Sciences (SPSS) for Windows, version 21. The first analyses were descriptive, with calculations of means, standard deviations and percentages, to verify the distribution of sociodemographic and clinical variables, in addition to the scores of the outcome instruments used. For the inferential analyses, non-parametric tests were chosen, given the small sample size. To verify the difference in the scores of clinical measures and recovery between the mutual

support group and the usual treatment group in the moments of pre and post-test, separately, the Mann–Whitney test was used. This statistical test was also used to compare the difference between the pre and post-test of the instrument scores between the mutual support group and the usual treatment group. To verify the changes in these scores between the pre and the post-test in each group, the Wilcoxon test was used. Finally, Spearman's correlation between the time of participation in the mutual support group and the score of the instruments that showed some significant result in the other tests was verified. In both tests, a significance level of $p < 0.05$ was used.

Results

Out of the 31 participants initially recruited for the study, who responded to the pre-test, only 28 completed data collection in the post-test. In the mutual support group, one participant gave up his participation in the study, due to lack of interest in continuing the research, while in the treatment as usual group, one participant also refused to continue, due to a disagreement as to the time and place for the application of the instruments, and another was not able to answer the questionnaires in the post-test, as he is very functionally disorganized. The sociodemographic and clinical characteristics of the participants are described in Table 1, for the total sample and for the two groups separately. In total, there was most male participants (64.5%), single (90.3%), with an average education of 13.0 (3.4) years, with income (51.6%), living accompanied (87.1%) and without children (87.1%). As for the clinical data, the mean age of onset and the mean time of treatment were 23.2 (8.7) years and 15.8 (8.8) years, respectively. Most received additional treatment to the psychiatric one (51.6%). There was a predominance of oral medication (90.3%), taking the medication alone (93.3%), having previous psychiatric hospitalization (64.5%), performing regular physical activity (70.0%) and with an average outpatient treatment time of 12.2 (7.2) years.

As for the clinical and recovery outcomes, Table 2 shows the differences between the mutual support and treatment as usual groups in the pre and post-test, separately, using the Mann–Whitney test. There was no significant difference between the groups in the pre-test in relation to any of the verified measures. In the post-test, only the ISMI scale showed a significant difference between the groups, with a higher level of internalized stigma in the treatment as usual group.

Table 3 shows the differences between the pre and post-test measurements for each of the groups, using the Wilcoxon test. The only significant difference was found in the usual treatment group, with respect to the MARS scale, in terms of a decrease in the level of adherence to drug treatment.

Table 4 shows the comparison of the difference in the pre and post-test of the instrument scores between both groups, according to the Mann–Whitney non-parametric test. Only the MARS scale showed a significant difference from the pre to the post-test between the groups during the study period, with a greater improvement in the level of adherence to psychiatric medication in the mutual support group. The Spearman correlation test was also used to assess the relationship between the time of participation in the mutual support group and the difference between the pre- and post-test scores on the MARS and ISMI scales, which were the only ones that showed any significant results in the other analyses. This was done in order to verify whether this variable could work

Table 1 Description of the sociodemographic variables and history of the disorder

Variable	Mean (Standard Deviation) or Percentage—n (%)			p
	Total sample (N = 31)	Mutual support group (N = 16)	Usual treatment group (N = 15)	
Gender				
Male	20 (64.5%)	12 (75%)	08 (53.3%)	0.21
Female	11 (35.5%)	04 (25%)	07 (46.7%)	
Age (years)	41.2 (8.4)	39.8 (7.4)	42.7 (9.4)	0.26
Marital Status ^a				—
Single	28 (90.3%)	15 (93.8%)	13 (86.7%)	
Married	2 (6.5%)	0 (0.0%)	02 (13.3%)	
Widow/divorced	1 (3.2%)	01 (6.3%)	0 (0%)	
Education (years)	13.0 (3.4)	13.1 (3.4)	12.9 (3.6)	0.68
Own income				0.21
No	15 (48.4%)	06 (37.5%)	09 (60%)	
Yes	16 (51.6%)	10 (62.5%)	06 (40%)	
Housing ^a				—
Alone	4 (12.9%)	04 (25%)	0 (0%)	
Accompanied	27 (87.1%)	12 (75%)	15 (100%)	
Children				0.94
No	27 (87.1%)	14 (87.5%)	13 (86.7%)	
Yes	4 (12.9%)	02 (12.5%)	02 (13.3%)	
Age of illness (years)	23.2 (8.7)	24.2 (6.9)	22.1 (10.5)	0.29
Treatment time (years)	15.8 (8.8)	15.2 (9.0)	16.5 (8.8)	0.47
Number of medications	2.7 (1.7)	2.9 (2.2)	2.6 (1.1)	0.80
Type of medication ^a				—
Oral	28 (90.3%)	13 (81.3%)	15 (100%)	
Oral + injectable	3 (9.7%)	03 (18.7%)	0 (0%)	
Take medication alone?				1.00
No	02 (6.7%)	01 (6.7%)	01 (6.7%)	
Yes	28 (93.3%)	14 (93.3%)	14 (93.3%)	
Did not answer	01 (—)	01 (—)	0 (—)	
Psychiatric hospitalization				0.81
No	11 (35.5%)	06 (37.5%)	05 (33.3%)	
Yes	20 (64.5%)	10 (62.5%)	10 (66.7%)	
Regular physical exercise				0.24
No	09 (30.0%)	03 (18.7%)	06 (42.9%)	
Yes	21 (70.0%)	13 (81.3%)	08 (57.1%)	
Did not answer	01 (—)	0 (—)	01 (—)	

Table 1 (continued)

Variable	Mean (Standard Deviation) or Percentage—n (%)			p
	Total sample (N = 31)	Mutual support group (N = 16)	Usual treatment group (N = 15)	
Participation in additional activities of NGO ^a	No	0 (0%)	14 (93.3%)	--
	Yes	16 (100%)	01 (6.7%)	
Time of participation in the reception (years)	--	4,8 (4,9)	--	--

^aThe analysis was not performed when one of the cells has a value of zero

* $p < 0,05$

Table 2 Comparison of instrument scores between the mutual support group and the usual treatment group, before and after the test, according to the Mann–Whitney non-parametric test

Phase	Instrument	Mutual support group		Usual treatment		P
		Mean (standard deviation)	Average posts	Mean (standard deviation)	Average posts	
Pre-test	MARS	8.06 (1.73)	15.44	8.33 (1.63)	16.60	0.71
	EEH	3.,94 (6.74)	17.31	35.60 (6.17)	14.60	0.40
	WHO-5	55.75 (20.58)	16.16	54.40 (20.33)	15.83	0.92
	RAS	94.25 (11.06)	17.28	90.67 (12.67)	14.63	0.42
	ISMI	63.38 (13.17)	14.41	68.07 (13.39)	17.70	0.31
	PSP	75.44 (13.73)	18.59	62.60 (16.49)	13.23	0.10
Post-test	MARS	8.67 (1.34)	16.97	7.46 (1.90)	11.65	0.08
	EEH	35.67 (5.18)	13.87	36.77 (6.65)	15.23	0.66
	WHO-5	54.67 (21.73)	15.07	48.31 (23.35)	13.85	0.69
	RAS	94.33 (12.17)	16.70	8800 (11.07)	11.96	0.13
	ISMI	62.93 (11.29)	11.30	70.92 (11.32)	18.19	0.03*
	PSP	73.40 (15.35)	1.,40	68.46 (1304)	13.46	0.53

MARS: Medication Adherence Rating Scale; EEH: Herth Hope Scale; WHO: World Health Organization Welfare Index; RAS: Scale for Assessing the Ability to Overcome Patients with Schizophrenia; ISMI: Internalized Stigma Scale in Mental Disorder; PSP: Social and Personal Performance Scale

* $p < 0,05$

Table 3 Comparison between the scores of the instruments evaluated between pre and post-test in the mutual support group and usual treatment groups, according to the Wilcoxon nonparametric test

Group	Instrument	Pre-test/Mean (standard deviation)	Post-test/Mean (standard deviation)	Average Posts		p
				Positive	Negative	
Mutual support group	MARS	8.06 (1.73)	8.67 (1.34)	5.00	3.00	0.08
	EEH	36.94 (6.74)	35.67 (5.18)	5.79	9.94	0.27
	WHO-5	55.75 (20.58)	54.67 (21.73)	8.06	7.93	0.80
	RAS	94.25 (11.06)	94.33 (12.17)	6.35	11.30	0.84
	ISMI	63.38 (13.17)	62.93 (11.29)	11.50	5.67	0.61
	PSP	75.44 (13.73)	73.40 (15.35)	6.00	6.00	0.18
Usual treatment	MARS	8.33 (1.63)	7.46 (1.90)	4.50	5.06	0.02*
	EEH	35.60 (6.17)	36.77 (6.65)	6.20	3.50	0.31
	WHO-5	54.40 (20.33)	48.31 (23.35)	5.50	7.50	0.64
	RAS	90.67 (12.67)	88.00 (11.07)	5.33	8.43	0.34
	ISMI	68.07 (13.39)	70.92 (11.32)	7.57	5.00	0.27
	PSP	62.60 (16.49)	68.46 (13.04)	6.44	8.25	0.38

MARS: Medication Adherence Rating Scale; EEH: Herth Hope Scale; WHO: World Health Organization Welfare Index; RAS: Scale for Assessing the Ability to Overcome Patients with Schizophrenia; ISMI: Internalized Stigma Scale in Mental Disorder; PSP: Social and Personal Performance Scale

* $p < 0,05$

Table 4 Comparison of the difference in the pre and post-test of the instrument scores between the mutual support group and the usual treatment group, according to the Mann–Whitney non-parametric test

Instrument	Mutual support group		Usual treatment		<i>p</i>
	Mean (standard deviation)	Average posts	Mean (standard deviation)	Average posts	
MARS	0.60	18.37	-0.69	10.04	0.006
EEH	-2.27	12.63	1.15	18.65	0.20
WHO-5	-2.67	15.30	-3.08	13.58	0.59
RAS	-0.40	15.73	-1.61	13.08	0.41
ISMI	1.27	13.87	2.23	15.23	0.68
PSP	-3.60	12.13	1.77	17.23	0.11

MARS: Medication Adherence Rating Scale; EEH: Herth Hope Scale; WHO: World Health Organization Welfare Index; RAS: Scale for Assessing the Ability to Overcome Patients with Schizophrenia; ISMI: Internalized Stigma Scale in Mental Disorder; PSP: Social and Personal Performance Scale

* $p < 0,01$

as a possible factor linked to these results, but there was no significant correlation for either of the two variables.

Discussion

Many users participate in mutual support groups for long periods, without a clear definition of the real benefit of continuing in participating in these groups, as a complement to outpatient treatment. An assessment was made of a group of people with schizophrenia who are undergoing outpatient treatment and have also been participating in a NGOs mutual support group for at least a month, which has had a tradition of serving family members and people with this mental disorder since its foundation, in 2002, compared to another group of people with the same diagnosis, but who only attend the usual outpatient treatment.

It was possible to verify from the results: a) a higher level of internalized stigma in the treatment as usual group in the post-test, compared to the mutual support group; b) a significant decrease in the level of adherence to drug treatment in the treatment as usual group; c) regarding the comparison of the pre-post change in the measures analyzed between the groups, only adherence to drug treatment showed a significant difference, with a greater increase in the mutual support group, compared to the treatment as usual group. Therefore, although there is no significant improvement between the pre and post-test in the mutual support group regarding clinical and recovery outcomes, the data point to a possibility of more favorable results in this group.

These findings are compatible with those presented in effectiveness studies [4, 16]. As in this study, the evidence is not very strong, but points only to a benefit of the peer groups, which varies from small to moderate, mainly in the clinical variables and, in a greater proportion, in outcomes related to recovery. A recent review suggests that more specific and manual based peer support interventions tend to have more positive effects on clinical outcomes, while more generic and less structured interventions, such as the mutual support group, tend to have more heterogeneous outcomes [4].

In this study, a clinical variable, represented by adherence to drug treatment, and a recovery variable, internalized stigma, were the only ones that showed any significant difference. Adherence to medication seems to be a novelty pointed out by this study. However, there is positive evidence of more specific and structured peer interventions and mutual support on this outcome [5, 12, 18, 26], but not in the case of unstructured groups, as in this study. In addition, it should be emphasized that this is not an effectiveness study, but a six-month assessment of existing groups, in which all its components have been undergoing outpatient treatment with medication for some time.

Regarding internalized stigma, there is evidence of positive effects on this outcome, both from more structured interventions [7, 23] and from mutual support groups [9, 31]. However, none of the investigated measures showed a significant difference between the groups in the pre-test, which may indicate a lack of consistency in the results over time. This may also have occurred because the study started in the period of resuming the activities by the mutual support and treatment as usual group (which occurs in a university service) after a vacation break.

Another possible positive finding in favor of the mutual support group was that, since the beginning of this research it presented data of less clinical vulnerability and better sociodemographic condition, when compared to the people of the usual treatment. On the other hand, this may also be something pre-existing regardless of the effects of participation in the mutual support group, since even with this difference, in the treatment as usual group, only the most cognitively trained people accepted and were able to participate in the research.

One of the main limitations of our study was the small sample size. Also, there may have been a bias in the results due to data collection, since the application of scales and questionnaires was done collectively, due to logistical conditions and the physical facilities of the place for the interviews, with huge difficulty in getting an individualized time schedule for each person. The fact that they are already existing interventions, the short period of the study and the lack of an experimental research design do not allow us to reach a conclusion about this. Finally, another limitation faced by the research was that the study period was short, that is, only six months, and, thus, the next studies could take a longer time.

Conclusions

Despite the modest results and the numerous limitations presented, the interpretation of data from our study indicates that the mutual support group has been an important instrument for socializing and reintegrating their participants into daily activities, touching and promoting fundamental aspects and experiences in the recovery process, both clinical and social.

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

Declarations

Ethics Approval The project was approved by an Ethics Committee on Human Research (protocol number: 3.225.681), with all participants providing informed consent.

Consent to Participate All participants completed written informed consent.

Conflict of Interest RAB has received honoraria for speaking and chairing engagements from Janssen, Torrent, Ache and Sanofi-Aventis outside this manuscript. He has also received personal fees and non-financial support from Janssen, personal fees from Pfizer, Torrent and Sanofi-Aventis outside this manuscript. The other authors declare that they have no conflict of interest.

References

1. Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosoc Rehabil J*. 1993;16(4):11–23.
2. Balsanelli, ACS, Grossi, SAA, Herth, KA. Cultural adaptation and validation of the Herth Hope Index for Portuguese language: study in patients with chronic illness. *Texto contexto - enferm*. [Internet]. 2010 Dec [cited 2020 Nov 16]; 19(4): 754–761. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072010000400019&lng=en.
3. Bech P. Measuring the dimensions of psychological general well-being by the WHO-5. *QoL Newsletter*. 2004;32:15–6.
4. Bellamy C, Schmutte T, Davidson L. An update on the growing evidence base for peer support. *Ment Health Soc Incl*. 2017;21(3):161–7.
5. Boardman G, McCann T, Kerr D. A peer support programme for enhancing adherence to oral antipsychotic medication in consumers with schizophrenia. *J Adv Nurs*. 2014;70(10):2293–302.
6. Brissos S, Palhava F, Marques JG, Mexia S, Carmo AL, Carvalho M, Dias C, Franco JD, Mendes R, Zuzarte P, Carita AI, Molodynski A, Figueira ML. The Portuguese version of the Personal and Social Performance Scale (PSP): reliability, validity, and relationship with cognitive measures in hospitalized and community schizophrenia patients. *Soc Psych Psych Epid*. 2012;47(7):1077–86.
7. Corrigan PW, Larson JE, Michaels PJ, Buchholz BA, Del Rossi R, Fontecchio MJ, Rüsich N. Diminishing the self-stigma of mental illness by coming out proud. *Psychiat Res*. 2015;229(1–2):148–54.
8. Corrigan PW, Phelan SM. Social support and recovery in people with serious mental illnesses. *Community Ment Hlt J*. 2004;40(6):513–23.
9. Corrigan PW, Sokol KA, Rüsich N. The impact of self-stigma and mutual help programs on the quality of life of people with serious mental illnesses. *Community Ment Hlt J*. 2013;49(1):1–6.
10. Davidson L, Chinman M, Kloos B, Weingarten R, Stayner D, Tebes JK. Peer support among individuals with severe mental illness: A review of the evidence. *Clin Psychol-Sci Pr*. 1999;6(2):165–87.
11. de Souza CM, Hidalgo MPL. World Health Organization 5-item well-being index: validation of the Brazilian Portuguese version. *Eur Arch Psy Clin N*. 2012;262(3):239–44.
12. Druss BG, Zhao L, von Esenwein SA, Bona JR, Fricks L, Jenkins-Tucker S, Lorig K. The Health and Recovery Peer (HARP) Program: A peer-led intervention to improve medical self-management for persons with serious mental illness. *Schizophr Res*. 2010;118(1–3):264–70. <https://doi.org/10.1016/j.schres.2010.01.026>.
13. Kelly JF, Yeterian JD. Mutual-help groups. In: O’Donohue WT, Cummings NA, editors. *Evidence-based adjunctive treatments: Practical Resources for the Mental Health Professional*. Burlington: Academic Press; 2008. p. 61–105.
14. Le Boutillier C, Leamy M, Bird VJ, Davidson L, Williams J, Slade M. What does recovery mean in practice? A qualitative analysis of international recovery-oriented practice guidance. *Psychiatr Serv*. 2011;62(12):1470–6.
15. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal Recovery in mental health: systematic review and narrative synthesis. *Br J Psychiatry*. 2011;199(6):445–52.
16. Levy LH. Self-help groups. In: Rappaport J, Seidman E, editors. *Handbook of community psychology*. New York : Kluwer Academic; 2000. p. 591–613.
17. Lloyd-Evans B, Mayo-Wilson E, Harrison B, Istead H, Brown E, Pilling S, Kendall T. A systematic review and meta-analysis of randomised controlled trials of peer support for people with severe mental illness. *BMC Psychiatry*. 2014;14(1):39.

18. Magura S, Laudet AB, Mahmood D, Rosenblum A, Knight E. Adherence to medication regimens and participation in dual-focus self-help groups. *Psychiat Serv*. 2002;53:310–6.
19. Mahlke CI, Kramer UM, Beckerc T, Bocka T. Peer support in mental health services. *Curr Opin Psychiatry*. 2014;27(4):276–81.
20. Moreira IC, Bandeira M, Pollo TC, Oliveira MS. Cross-cultural adaptation to Brazil of Medication Adherence Rating Scale for psychiatric patients. *J Bras Psiquiatr*. 2014;63(4):273–80.
21. Nasrallah H, Morosini P, Gagnon DD. Reliability, validity and ability to detect change of the Personal and Social Performance scale in patients with stable schizophrenia. *Schizophr Res*. 2008;161(2):213–24.
22. Pistrang N, Barker C, Humphreys K. Mutual help groups for mental health problems: A review of effectiveness studies. *Am J CommunPsychol*. 2008;42(1–2):110–21.
23. Pyle M, Pilling S, Machin K, Allende-Cullen G, Morrison AP. Peer support for internalised stigma experienced by people with psychosis: Rationale and recommendations. *Psychosis*. 2018;10(2):146–52.
24. Ritsher JB, Otilingam PG, Grajales M. Internalized stigma of mental illness: psychometric properties of a new measure. *Schizophr Res*. 2003;121(1):31–49.
25. Ronzani TM, Soares RG, Nery FC, Silveira PS. Adaptação transcultural brasileira da escala de estigma internalizado de transtorno mental - ismi-br. *Geraiis, Rev Interinst Psicol*. 2017;10(1):25–34.
26. Rosenblum A, Matusow H, Fong C, Vogel H, Uttaro T, Moore TL, Magura S. Efficacy of dual focus mutual aid for persons with mental illness and substance misuse. *Drug Alcohol Depen*. 2014;135:78–87. <https://doi.org/10.1016/j.drugalcdep.2013.11.012>.
27. Silva TR, Berberian AA, Gadelha A, Villares CC, Martini LC, Bressan RA. Validação da Recovery Assessment Scale (RAS) no Brasil para avaliar a capacidade de superação das pessoas com esquizofrenia. *J Bras Psiquiatr*. 2017;66(1):1–8.
28. Slade M, Leamy M, Bacon F, Janosik M, Le Bouillier C, Williams J, Bird V. International differences in understanding recovery: systematic review. *Epidemiol Psych Sci*. 2012;21(4):353–64.
29. Thompson K, Kulkarni J, Sergejew AA. Reliability and validity of a new Medication Adherence Rating Scale (MARS) for the psychoses. *Schizophr Res*. 2000;42:241–7.
30. van Weeghel J, van Zelst C, Boertien D, Hasson-Ohayon I. Conceptualizations, assessments, and implications of personal recovery in mental illness: A scoping review of systematic reviews and meta-analyses. *Psychiatr Rehabil J*. 2019;42(2):169.
31. Worrall H, Schweizer R, Marks E, Yuan L, Lloyd C, Ramjan R. The effectiveness of support groups: a literature review. *Ment Health Soc Incl*. 2018;22(2):85–93.

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