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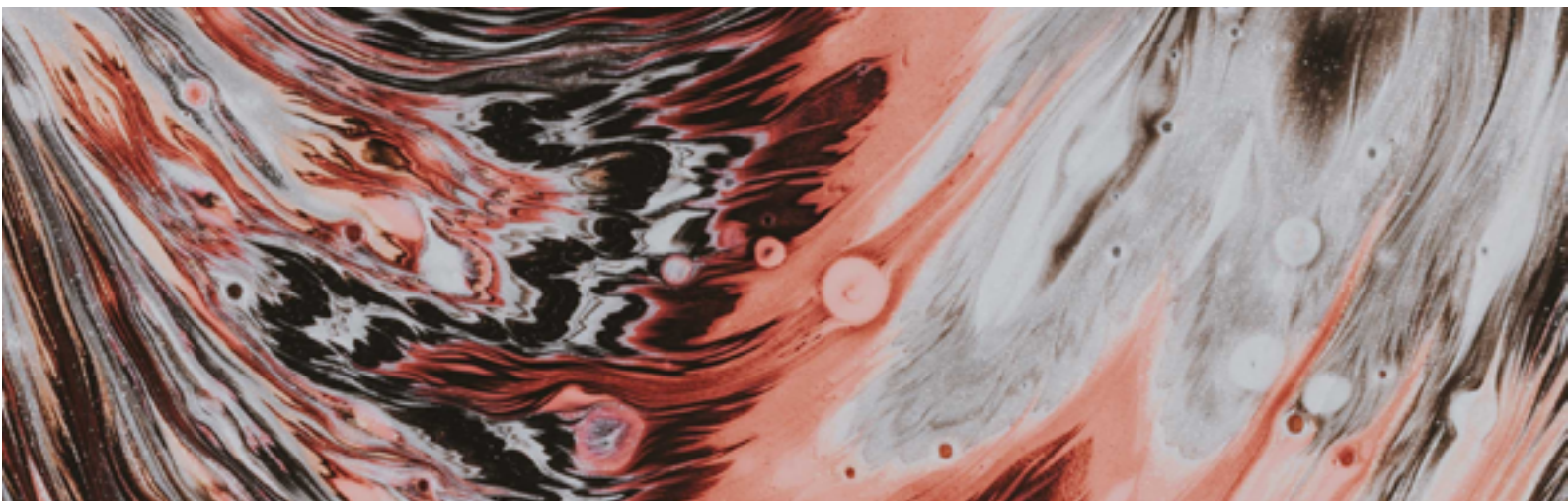
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**DEAR COLLEAGUES,**

I am pleased to introduce the third issue of the journal *Consortium Psychiatricum* in 2021. This is a thematic issue devoted to individuals' first psychotic episode. The articles included in this issue cover biological, social, and clinical issues connected with the first episode of psychosis.

In the editorial article, Professor Heinz Katschnig shares his experiences of organizing a family school to learn how to live with schizophrenia that has been functioning in Vienna for 35 years. It is a good example of the development of independent living skills and autonomy of young patients who faced psychosis.

The problem of compliance and factors that mediate drug compliance in patients after their first psychotic episode are explored in the research article by colleagues from St. Petersburg. Clinical features of manifest psychoses in patients admitted to the "First episode psychosis clinic" in 2020 and 2019 are described by colleagues from Moscow. A fundamental article on lipid biomarkers in schizophrenia, as written by a group of scientists from Skolkovo in collaboration with clinicians from the leading mental clinics in Moscow, shares findings about ceramide species' alterations that might be specific to patients with schizophrenia.

The historical review of research in social psychiatry conducted at the Moscow Research Institute of Psychiatry and the implementation of results in clinical practice was written by authors from the Department of Social and Biological Research of the Institute.

Articles on the organization of community mental care have come from India and Mexico.

I wish you pleasant reading.

**George Kostyuk,**

*Editor-in-Chief, Consortium Psychiatricum*

# Late ‘Early Intervention in Psychosis’: A Family School for Learning How to Live with Schizophrenia

Запоздалое «Раннее вмешательство при психозе»: школа жизни с шизофренией для детей и их родителей

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Editorial

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## ABSTRACT

The paper describes a family school for learning how to live with schizophrenia, which was founded in 1986 in Vienna, Austria, and is still running today. It was established in cooperation between professionals and the Austrian self-help association HPE of the relatives of persons with mental disorders. It addresses the needs of 10 families at a time, in cases where a son or a daughter was diagnosed with schizophrenia and had already experienced one or several episodes of the illness. The course lasts one and a half years and is organized according to the model of a weekly boarding school, where 10 children, the “residents”, stay in the school overnight from Sunday evening to Friday and take part in a structured program on cognitive, social and practical life skills. Ambulatory psychiatric treatment is taking place concurrently outside the school through local routine services. On weekends residents stay with their parents since the school is closed. Parents visit the school regularly to take part in joint activities with the residents. They also undertake night shifts in the school and attend a weekly parents’ group. In the regular encounters during everyday activities in the school, “learning by doing” occurs – parents get to know the daughters and sons of other families and can learn to distinguish between disease-related and personality-related behavior. Residents can have similar learning experiences in relation to the parents of other residents. The main aim of the school is that parents learn to provide “protected autonomy” for the daughters or sons in question, in order to assist them after the end of the course in leading a life characterized by as much autonomy as possible after the end of the school.

## АННОТАЦИЯ

В статье описывается основанная в Вене в 1986 году и действующая по сей день семейная школа, обучающая жить с шизофренией. Данная школа является результатом совместной работы специалистов в области психического здоровья и австрийской ассоциации взаимопомощи HPE, учрежденной родственниками людей, страдающих психическими расстройствами. В школе могут проходить обучение до 10 семей одновременно, при условии, если у ребенка диагностировали шизофрению и уже случались один или нескольких приступов заболевания. Курс обучения длится полтора года, он составлен по модели школы-интерната с недельным проживанием, в которой 10 «воспитанников» проживают в школе с вечера воскресенья по пятницу и в течение

этого времени проходят структурированную программу обучения когнитивным, социальным и прикладным жизненным навыкам. Одновременно с этим за пределами школы оказывается и амбулаторное психиатрическое лечение. На выходные школа закрывается, и дети возвращаются к своим родителям. Родители регулярно посещают школу и вместе с детьми принимают участие в совместных занятиях. Они также дежурят по ночам в школе и посещают еженедельные группы для родителей. При регулярных встречах во время повседневных занятий проводится «обучение на практике» — родители знакомятся с детьми из других семей и учатся различать, какие из особенностей поведения связаны с болезнью, а какие — с его личностью. Аналогичный опыт получают и пациенты, знакомясь и проводя время с другими родителями. Основная цель школы — научить родителей предоставлять детям с шизофренией «автономию с подстраховкой», чтобы после окончания курса они могли оказывать своим детям поддержку, и в то же время их ребенок мог вести максимально возможный самостоятельный образ жизни.

**Keywords:** *schizophrenia; family; vulnerability-stress-coping model; working with families; school; early intervention in psychosis*

**Ключевые слова:** *шизофрения; семья; модель «уязвимость-стресс-преодоление»; работа с семьями; школа; раннее вмешательство при психозе*

## **INTRODUCTION**

In international guidelines, family involvement in mental health services is an essential component in the treatment of schizophrenia, but its routine implementation in the services themselves is underdeveloped.<sup>1</sup> In this paper we report on a model of involving families as an external add-on activity to an ongoing treatment in local routine psychiatric services. It was founded jointly by professionals and a family self-help organization in Vienna (Austria) in 1986 and is still operating today. It addresses families with a child diagnosed with schizophrenia in late adolescence or early adulthood, where — after one or several clinical episodes — it has become clear that, contrary to initial hopes, the problem will not go away. It offers a one-and-a-half year learning experience in a weekly boarding school setting for 10 families at a time. We (1) discuss the motives for the establishment of the school, (2) explain the framework of the boarding school setting and (3) present the learning objectives, before (4) describing the working of the school in detail. Finally, (5) a discussion section, which also addresses limitations, concludes the article. Some illustrative data are included as Supplementary materials, which can be accessed electronically.

## **WHY A FAMILY SCHOOL FOR LEARNING HOW TO LIVE WITH SCHIZOPHRENIA?**

### **A diagnosis of schizophrenia leaves the family in despair — but hope exists**

When in late adolescence or early adulthood a child is diagnosed with schizophrenia, the life of a family

is fundamentally changed. Strange behavior might have occurred already some time before a professional diagnosis is received and treatment initiated.<sup>2</sup> However, since the typical age of onset of schizophrenia coincides with the challenging transition period of a young person to adult life, parents might have wondered whether this was just a sign of a ‘delayed puberty crisis’ or due to drug use. Mental health literacy in the general population is poor and stigma and discrimination of people with mental disorders, especially with schizophrenia, are widespread.<sup>3</sup> This makes it extremely demanding for parents and their child to accept the diagnosis of schizophrenia, which is often perceived as a virtual death sentence. Typically, a long and thorny grief process ensues, involving alternatively denial, depression and anger (akin to the processes proposed for the confrontation with one’s own death),<sup>4</sup> before it becomes clear that there is a problem that will not go away. Parents often do not easily give their child away to psychiatry, but, eventually, perhaps only after several hospitalizations and with substantial delay, the diagnosis of schizophrenia and the necessity of treatment will usually be accepted. Psychiatrists themselves may play a role in the delay since they might hesitate to communicate the diagnosis.<sup>3,5</sup>

Contrary to the public stereotype<sup>3,6,7</sup> there is abundant evidence from long-term follow-up studies of young people diagnosed with schizophrenia for a wide spectrum of outcomes, ranging from full recovery to a chronically deteriorating course, with many patterns in between. The respective results of early studies in Switzerland



and the US in the 1970s and 1980s<sup>8-10</sup> were confirmed by more recent research.<sup>11-15</sup> Variations in course and outcome may actually be consequences of the very imprecision of the diagnosis of schizophrenia (whose definition is still debated today),<sup>16,17</sup> which has probably led to including heterogeneous groups of patients in these studies. The findings of these studies suggest that there is always hope that the course of the disorder in people diagnosed with schizophrenia early in life may not automatically be devastating and that recovery or a somewhat milder course are possible. Knowing of this possibility counteracts the self-fulfilling prophecy mechanism of assuming a chronically deteriorating course, where it is supposed that nothing can be done. The aim of the family school described in the present paper is to motivate and assist parents who are willing to care for their child diagnosed with schizophrenia, to find the appropriate way of dealing with the difficult situation and provide an optimal environment which enhances the chances of positive developments.

### **Roles ascribed to parents of a child diagnosed with schizophrenia**

Probably ever since psychiatry has existed, parents of young people diagnosed with schizophrenia have been in the role of informants for psychiatrists about what had happened before the patient was admitted to hospital (as is the case in paediatrics where a child cannot speak for him/herself). After providing the information they often were (and still are today) left alone and excluded from the care process. In addition, the idea that schizophrenia was inherited gave parents an uneasy feeling and induced them to search their family trees for potential cases of schizophrenia.

When deinstitutionalization started in the 1960s and 1970s, hospital beds were reduced and patients diagnosed with schizophrenia were increasingly living near or with their families, new attention was given to parents by either blaming them for causing schizophrenia through their behavior or seeing them as victims of the disease<sup>18</sup> (Box 1).

Following earlier psychoanalytic theories about the 'schizophrenogenic mother'<sup>19</sup> the 1960s and 1970s saw a rise of accusations that parents were causing schizophrenia in their children by their own 'pathological' behavior, both in widespread 'antipsychiatric' publications<sup>20</sup> and in popular films (e.g., Ken Loach's

#### **Box 1: Role of the parents of daughters or sons diagnosed with schizophrenia as experienced in their contacts with psychiatry (1-3), as seen by themselves (4), and from the perspective of an active participant in solving problems (5)**

1. Informant for psychiatrists – like a parent of a sick child in paediatrics
2. Genetic cause of schizophrenia – the biological root of the disorder
3. Blamed as being the behavioral cause of schizophrenia – a perpetrator
4. Victim of the disorder – burdened by the disease
5. Active partner of professionals in solving problems – “positive resignation”

*Family Life*, 1971). The concept of 'treating' the whole family with psychoanalytic or systemic approaches was promoted and feelings of guilt were induced or increased in many parents. The attitudes of professionals toward parents were often ambiguous or even rejecting and it was not uncommon that the separation of parents and their sick children was advocated.

With the decrease of psychiatric hospital beds, the burden of care fell increasingly on parents who were helpless in addressing daily life problems and increasingly saw themselves as victims of the disease. The burden on families came to public attention 50 years ago in England, when the father of a son who had been diagnosed with schizophrenia and discharged from hospital (in the then ongoing deinstitutionalization movement in England) published an article in the *London Times* describing the family's experience of caring for their son and the associated burden.<sup>21</sup> The article resonated greatly with families in a similar situation, leading to the foundation of the 'National Schizophrenia Fellowship' (later renamed 'Rethink'; [www.rethink.org](http://www.rethink.org)) as a self-help and advocacy organization for family members and carers of people suffering from schizophrenia.<sup>22</sup> Over the following years the idea spread to other countries and similar associations were founded elsewhere; the earliest was in 1978 in Vienna/Austria ([www.hpe.at](http://www.hpe.at)), which the authors of the present paper helped to develop (other examples are NAMI in the United States; [www.nami.org](http://www.nami.org) and EUFAMI which covers numerous European family associations; [www.eufami.org](http://www.eufami.org)).

## Box 2: Burden on parents of a daughter or son diagnosed with schizophrenia

- Financial burden (e.g., giving up a job, in order to care for the patient at home)
- Health problems
- Fear of stigma, leading to...
- Social isolation
- Burn-out, depression
- Not knowing how to distinguish between “bad” and “mad” behavior of the daughter/son
- Not knowing how to react to cognitive disturbance, inactivity, delusions, hallucinations
- Impossible to get reliable information on the causes of schizophrenia
- Confusion about what the “correct” treatment is (medication? psychotherapy?)
- Helplessness with regard to reacting to aggressive and suicidal behavior

The problems and the burden identified in the early days were wide-ranging and left families in despair and disarray (Box 2) — and are still the same today.<sup>23</sup> It is not only empathy for the parents which should be a motivation to assist the family, but it can also be assumed that a family in disarray cannot be a beneficial environment for a person suffering from a mental disorder characterized by cognitive, emotional and communication problems.<sup>24</sup>

### ‘Working with families’: families as active partners in solving problems

In the 1980s, so-called ‘psychoeducational programs’ for families were developed and evaluated. They provided information and support to families in order to better understand and cope with the illness, including information on symptoms, prognosis and treatments of the diagnosed condition.<sup>25,26</sup> Families were not seen as causing schizophrenia, but were regarded in some approaches as responsible for relapses and needing, for instance, interventions in relation to their potential ‘high expressed emotion’ (high criticism, hostility and overinvolvement—the latter often fuelled by a mixture of anxiety and guilt) in order to avoid relapses. Results of these and similar studies on ‘family care’ in schizophrenia were promising.<sup>27-29</sup>

Inspired by these approaches and a nearly decade-long cooperation between professionals and the Austrian family self-help organization HPE, the ‘Family School for Learning How to Live with Schizophrenia’ was founded in 1986.<sup>30</sup> The School (as we refer to it hereafter) combines professional knowledge and interventions with the potential of self-help resources of the families. It anticipated some elements of later developments in mental healthcare, such as attention to the early stages of schizophrenia in young people,<sup>31</sup> the hope implied by the recovery concept,<sup>32</sup> the idea of a triadology,<sup>33</sup> quality of life issues<sup>34</sup> and the concepts of autonomy, inclusion and empowerment as advocated by the UN Convention on the Rights of Persons with Disabilities (CRPD).<sup>35</sup>

The approach applied in the School is not called ‘family therapy’ (where the family becomes the object of treatment), but ‘working with families’.<sup>18</sup> Once having accepted the diagnosis and having arrived at a kind of ‘positive resignation’ (Box 1 (5)) families work in partnership with the staff to find solutions to their problems, with families being seen as having needs as well as strengths.<sup>36</sup> Working with families comprises a range of different components on a spectrum (Figure 1) extending from the pure ‘professional pole’ to the pure ‘self-help pole’, with several kinds of ‘mixed activities’ in between,<sup>18,37</sup> which are specific for the School. Working

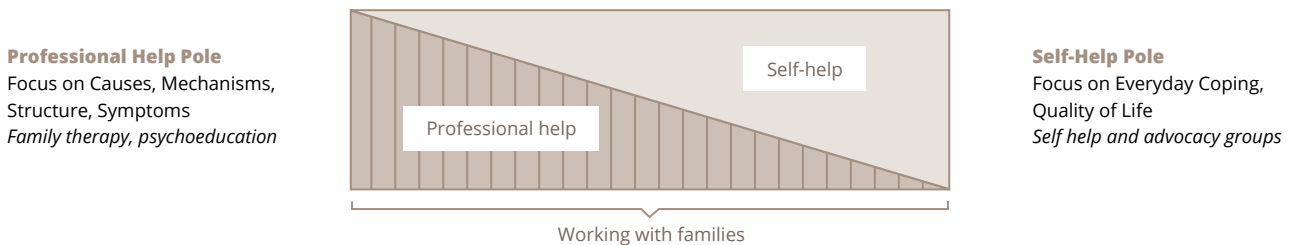


Figure 1. Working with families in relation to professional help and self-help

with families in the School follows Carl Rogers' principle of 'showing unconditional positive regard' for all family members, as well as being warm, empathic and genuine.<sup>38</sup>

Since many patients diagnosed with schizophrenia become socially unattractive and have difficulties in building and keeping social relationships, parents who want to care and are willing to learn about the optimal way of doing so may be the best source of support for many patients. Parents who are members of a self-help organization usually have these characteristics, which was an important motivation for establishing the School.

Children of families participating in the program are probably at a later stage in the disease process than those usually targeted by most Early Intervention in Psychosis (EIP) programs<sup>31</sup> and may have surpassed what has been called the 'critical period' for early intervention.<sup>39</sup> Nevertheless, it is still early enough in life so that, considering the potentially long life ahead, 'learning how to live with schizophrenia' makes sense. This is the reason for the peculiar title we have chosen for this paper.

### **THE GENERAL SETTING OF THE SCHOOL: A NEUTRAL LOCATION AND A NEUTRAL TIME IN A SMALL BOARDING SCHOOL PROGRAM**

During the planning process of the School several decisions were taken jointly by professionals and members of the self-help organization. First, it was decided that the School should function as a weekly 'boarding school' and that it should be established outside psychiatric services, in a 'neutral' location. Second, it was understood that enough time must be available for the learning process to take place concerning the complex needs of families, and the duration of the course was set at one-and-a-half years. Finally, it was suggested that the number of participating families should be small, to allow for the development of enduring personal contacts and mutual support. After some searching, a location was found for rent which allowed 10 families to participate simultaneously in the course.

#### **A neutral location: the School as a 'theater stage' for practising new behaviors**

Young people diagnosed with schizophrenia who are eligible for the School mostly live with their parents, for whom it is difficult to maintain the delicate balance between caring and letting autonomy grow (which is expected to increase at that stage of life). It was therefore

regarded as essential that the children (hereafter 'residents') live in their own space while participating in the course. This was also regarded as providing some relief for the parents. The School was therefore set up as a weekly boarding school, where the residents would stay from Sunday evening to Friday afternoon and go home for weekends and public holidays. The residents therefore live at a 'neutral location' rather than at one of the usual two places of hospital (the 'territory' of psychiatry) or parental home (the 'territory' of parents). Each 'territory' has its own rules determined by its 'owner', but in the neutral territory of the boarding school, neither of these 'owners' dominates. Residents have their own rooms, reflecting an important aspect of autonomy (e.g., when parents visit, they have to knock at the resident's door). Parents regularly visit and take part in routine activities (also explicitly involving children of other parents). We use the image of a theater stage, where new behaviors can be 'playfully' practised without serious consequences. Residents can, without pressure, practise small steps of autonomy and parents can practise how to let autonomy happen and how solutions to problems can be found.

#### **A neutral time: the School as 'journey' and a pause in life**

It was first regarded as necessary for the program to run for two full years (including a few weeks of absence for 'vacation') to arrive at substantial changes. However, it was argued that this would deter potential residents, who would perhaps prefer to stay just one year, because they and their parents might still aim for 'success' in life, such as finishing school or getting a job. Finally, a compromise of one-and-a-half years was chosen, which has stayed the same over the last 35 years.

Overall, it is stressed already in the selection process of families that participating in the program means a pause in life and that the focus is on the learning process, which is made easier away from the pressure of the relentless progress of 'real' everyday life. It is quite difficult to convey the idea of a break in life, in which no important life changes should happen. It has proven helpful to use the image of a 'journey' among a tourist party. A journey has a preparatory stage, where in the beginning the members of the tourist party get to know one another. During the main part of the journey, the main program takes place. For the final section, 'back



### Box 3: Learning objectives for both residents and parents

- Understanding the “vulnerability-stress-coping model”, “walk on a tightrope”, understanding the role of medication in reducing vulnerability
- Learning the optimal way of communicating (listening skills, communication of positive and negative feelings, making requests) and aiming at simplicity, clarity and continuity in communication
- Structuring daily activities
- Keeping aims realistic
- Networking with other families/residents

### Box 4: Specific learning objectives for parents

- Creating a non-critical, accepting environment (“protected autonomy”, “intimacy at a distance”)
- Attempting to keep behavior as a family consistent
- Creating optimal stimulation – no over-/under-stimulation (assisting a resident’s “walk on a tightrope”)
- Learning to cope with fluctuating insight and unpredictable behavior, with hallucinations and delusions
- Learning to cope with underactivity and low motivation (distinguish symptoms from “personality”)
- Optimal use of professional help, accepting that sometimes no “absolutely correct” professional solution is possible
- Getting reward from daughter’s/son’s presence
- Learning how to take care of one’s own needs

to real life’ is the issue, with perhaps some sadness that the journey is over. During a journey, away from everyday life at home, usually no important life changes take place.

The long duration of one-and-a-half years allows families to experience potential changes in the clinical picture in their own and others’ children. Occasionally, hospital admissions may occur, but also improvements in the clinical condition can be observed and both processes can prompt discussions about the possible reasons. One anticipated effect of the long duration was (and has proven to be correct) that some families will develop ties to one another, which facilitates mutual support after the end of the School. In fact, we have observed that families still meet one another after the end of the course and some have even set up shared flats where they continue caring for their children following the principles learned in the school.

#### LEARNING OBJECTIVES

In the program, schizophrenia is understood as a disorder following a ‘diathesis-stress’ or ‘vulnerability-stress-coping model’.<sup>40,41</sup> This implies a shift of emphasis from a fixed diagnostic entity to a dynamic process, where it is suggested that in a vulnerable individual, a stressor

may trigger clinical phenomena which are characteristic of a diagnosis of schizophrenia and where interventions may reduce vulnerability or improve coping with stressors. Based on such a dynamic conception of schizophrenia in the community, the English psychiatrist John Wing suggested a list of factors which are potentially under the control of parents.<sup>42</sup> The list was partly derived from research findings, showing that environmental factors can influence the course of schizophrenia - such as poor environmental stimulation enhancing passivity and withdrawal,<sup>43</sup> while life events,<sup>44</sup> ‘high expressed emotion’ and a critical atmosphere in families<sup>24</sup> can trigger schizophrenic episodes. Based on this list, we have defined learning objectives and guidelines for working in the School, divided (though they partly overlap) into those relevant for the whole family (Box 3), those specific to parents (Box 4) and those specific to residents (Box 5). These objectives are mostly self-explanatory and we will only comment on a few of them here.

Given the ‘environmental reactivity’ of schizophrenia, John Wing (who was also a cofounder of the English self-help organization described above) introduced the image that a person suffering from schizophrenia and living outside hospital has to perform a ‘walk on a tightrope’ between under- and over-stimulation, and that one can

### Box 5: Specific learning objectives for residents

- Improving self-management
- Improving cognitive performance in daily life
- Improving daily living skills necessary for an autonomous life (cooking, cleaning, laundering, grocery shopping, handling finances...)
- Improving social and communication skills
- Learning controlled withdrawal if overstimulation looms
- Managing self-medication
- Meaningfully organizing free time ("structure")
- Learning about the problems inherent in alcohol and drug use

attempt to 'create an optimal degree of stimulation'. Too much stimulation may facilitate a psychotic relapse with 'positive' or 'plus' symptoms; ambiguous and complex communication with lack of clarity and consistency is regarded as such a stressor. Many learning objectives for parents listed in Box 4 can be subsumed under this topic. Too little stimulation may end in passivity and withdrawal (called 'negative' or 'minus' symptoms in psychopathology).

The clear and concrete message of the image of the 'walk on a tightrope' has been found to be especially useful in working with families and it is frequently advocated as a general guideline in the School. The vulnerability-stress-coping model introduces the idea that one can also work on reducing vulnerability. It allows, for instance, to understand the role of prophylactic antipsychotic medication (an often controversial topic)<sup>45</sup> as a means of reducing vulnerability (or increasing resistance to stress); such framing may increase acceptance of antipsychotic medication. Also, the emphasis in the School on structuring one's daily life fits into the idea of reducing vulnerability to stress. Given the cognitive and emotional disturbances in schizophrenia, learning how to create and maintain a structure in daily life is one of the objectives, which goes hand-in-hand with creating an optimal stimulation. Taking part in the course provides in itself the experience of a structure in everyday life, as will be detailed below.

The learning objectives for parents include how to properly react to specific types of psychopathological phenomena, such as hallucinations, delusions, cognitive disturbances, underactivity and lack of motivation. While difficult to apply in concrete situations, it is suggested to parents that they try to react without devaluing the resident's experiences, but also without plainly accepting

them (e.g., in case of delusions: 'I accept that you see it like that, but please accept that I do not see it like that'). One of the more difficult situations for parents is to react to underactivity or low motivation. Distinguishing between disease-related underactivity, controlled withdrawal to avoid stress and 'laziness' (is the child 'mad' or 'bad?') is often not possible and understanding the impossibility of a correct reaction is helpful as such.

Finally, perhaps the most important topic is how, at that specific stage in life when young people in general are leaving their families for an autonomous adult life, the appropriate balance can be found between 'protection' and 'letting loose', called here 'protected autonomy'. The Viennese sociologists Rosenmayer and Köckeis<sup>46</sup> coined the term 'intimacy at a distance', which is used in the School and well understood.

While residents are in ambulatory psychiatric treatment in local routine services, the program of the School focuses on increasing skills of daily living, improving cognitive performance, learning how to avoid specific stressors (e.g., sidestepping discussions on topics related to the resident's delusional ideas) and controlled withdrawal if the environment is getting too stressful. One of the basic learning objectives is introducing structure into one's daily life.

### THE SCHOOL IN PRACTICE

In the present paper, we are looking back on the experience gained from 23 completed courses over the last 35 years, during which the working of the School has not substantially changed.

### Location, staff and financing

The School is located on the second floor of a traditional Viennese four-storey residential building near the city

center, in which (on other floors) other parties are living — so it is literally located 'in the community'. It has the name 'Pension Bettina' written on its entrance, taken from the earlier function of the flat as a small hotel. We have kept this name, by which the School is well known at the local psychiatric services. The size is 340 square meters, including rooms for residents (the former hotel guest rooms) and functional rooms (living room and dining room which can also be used as a room for group activities, kitchen, bathrooms, etc.). The staff consist of four part-time psychologists, among them the head of staff (there have only been two heads of staff in 35 years, guaranteeing continuity of concept and implementation). The staff work in the School during the day from Monday to Friday following a detailed schedule, contained in a set of guidelines and working forms. Night duties during the week are carried out by parents and psychology or medical students. The School is closed on weekends. Each family is assigned a personal staff member, who acts as a case manager throughout the whole course and develops intimate knowledge about the weaknesses, strengths and needs of the family, and helps to find individual solutions. The staff receive regular psychotherapeutic supervision, not least to be able to maintain the delicate balance between professional and self-help. Finance is provided by local social service departments together with a small co-payment by the families. The legal organization running the School is a small NGO.

### **Selecting families**

Families are referred for potential participation in the program by local psychiatric services, where the children are in treatment after one or several schizophrenic episodes have occurred. The referring services are aware of and agree with the principles of the program and inform and motivate the families to contact the School. Families are seen by School staff and are shown the rooms, including those where the residents would stay during the week. The learning objectives and methods are explained to families, as well as the concept of a long journey meaning a pause in life. While the School is focused on the whole family, it also attempts to provide a structure for assisting the residents to improve their everyday communication and social skills. However, it is stressed that the purpose of the School is not to cure the disease, but to improve the coping processes. The

staff get an impression of the families, their willingness and capacity for intensive involvement and enduring cooperation. A practical issue to consider is that the travelling distance of the parents from their home to the School should not be too long, since they are required to be regularly present. Repeated visits are sometimes necessary before everyone agrees that participation is desirable and possible.

Once a decision has been made, a contract is signed by the future residents, the parents and the head of staff. From the very beginning, this introduces an element of structure and planning into the whole process. The contract contains detailed duties of everyone in the process of participating in the program (including detailed house rules). One item says that ongoing psychiatric outpatient treatment is required, detailing that the program is offered in addition to ongoing treatment in the local routine psychiatric services. The first month of the program is classed as the preparatory stage, in which important discussions take place and decisions are made which determine to some extent the work to be carried out over the following 17 months. In four out of every five participating families, the resident is a son; mothers predominate (in a few cases, both mothers and fathers are involved). The average age of the residents is around 25 years. These characteristics have not substantially changed over the decades.

### **The time structure of the program**

The time structure of the course has *per se* an educational purpose, since it communicates that structure as such is essential. After the preparatory month, a warm-up phase of approximately three months follows; after all, moving into the School is a substantial change in the life routine of all participants. The main learning period runs for approximately 10 months and is followed by several months in which the main purpose is finalizing planning for life after the end of the course. The number of months for each phase is not fixed, but the sequence of the phases communicates a structure (using the image of a journey as discussed above). Throughout the whole course there is a repetitive weekly structure from Monday to Friday, with the School closed on weekends and on public holidays. Finally, there is a daily structure, with activities mainly taking place in the morning and mainly free time in the afternoon.

**Box 6: Essential activities in the school according to proximity to the professional and the self-help pole** (see Figure 1)

**a) Activities near the professional pole – “psychoeducational” activities**

- For residents: groups for day and weekend planning, cognitive training, music therapy
- For each individual family: six sessions of communication training during the midterm
- For parents as a group: Occasionally an external expert provides information in the weekly parents’ group

**b) “Learning by doing” activities – organized, task oriented routine activities with joint participation and encounters between residents and parents of different families, as well as staff, for practicing new behavior (“in vivo learning”, “vicarious learning”)**

- Each morning three parallel household chore groups
- Weekly excursion
- Night shift by parents (being alone in the school with all residents)

**c) Activities near the self-help pole – free time to be structured by residents and families themselves**

- For residents: free time in the afternoons and evenings (Monday through Thursday)
- For residents and parents: free time on weekends and public holidays
- For parents: weekly parents’ group for sharing information and mutual support

**Essential activities**

The different activities taking place each week from Monday to Friday and those expected to take place on weekends when the School is closed are listed in Box 6 and described below. To understand how the School works, it is important to explain these activities in detail. In line with the concept of ‘working with families’ they are classified into three groups, considering the degree of professional involvement (Figure 1). Everyone is repeatedly reminded to show unconditional regard for one another in all activities, emphasizing existing strengths of the other person and cautiously communicating identified weaknesses. All activities where residents are involved are organized in such a way that they are short and that frequent breaks are possible.

**a) Activities near the professional pole: ‘psychoeducational’ activities**

**For residents (participants: residents and staff)**

Most residents suffer from negative and cognitive symptoms, which are known to be related to deficits in communication and social skills in everyday functioning.<sup>47</sup> Several group activities with residents addressing these issues take place routinely during the week. They are somewhat similar to programs of psychiatric day services and also convey the idea of a structure and the need for planning one’s activities. Each morning, a planning group for the day is run by a staff member; on Friday early afternoon, a similar group takes place for planning the

weekend. Once a week in the afternoon, rules of living together in the School are discussed in a ‘house meeting’. In addition, once a week, a cognitive training session takes place using the ‘Integrated Psychological Therapy’ (IPT) program that combines neurocognitive and social cognitive interventions with social skills approaches.<sup>48</sup> Finally, once a week, the whole group of residents attends a music therapy session outside the School.

**For individual families (participants: resident, his/her parent(s) and staff)**

The staff member assigned to a family holds training sessions on communication skills with each individual family by using modules developed by Falloon and colleagues.<sup>41</sup> Topics include, among others, listening skills, making positive requests and communication of positive and negative feelings. Altogether, six training sessions are held during the midterm of the course, i.e., at a time when the specific problems of each family are well known to the staff, especially to the assigned staff member responsible for the family.

**For parents as a group (participants: parents, staff, external expert)**

Occasionally the parents’ group, taking place on Tuesday evenings (see (c) below), is attended by an invited expert providing information on specific topics, mainly medical and psychiatric and discussing questions of the parents.

**b) 'Learning by doing' activities: organized, task-oriented routine activities with joint participation and interaction between residents, parents and staff, to practise new behavior ('in vivo learning'; 'vicarious learning')**

One of the main features of the program is that the structure permits and facilitates interactions between residents and parents from different families in tasks such as grocery shopping, cooking, cleaning and laundering, on joint excursions and in the evenings when a parent is on night duty. The crucial issue is that parents also meet and interact with a child from a different family and thereby learn to distinguish better between behavior related to the disease and related to the personality. This gives them a frame of reference to better understand the behavior of their own child. Such contacts occur frequently during the one-and-a-half-year program. In the weekly parents' group (see (c) below) information is shared on observations made in these activities, often with surprising insights. For example, a mother experiencing her son as inactive on weekends at home may be astonished to hear the positive feedback from another mother who worked with the son in a cooking group during the previous week, thereby getting a feeling for the relevance of situational and environmental factors for specific behaviors. It becomes apparent how the long common history of children and parents can shape behaviors or can colour the perception of each other's behavior. What is true for parents is also true, *mutatis mutandis*, for residents, since they can experience cooperating and communicating with other parents, which provides a new perspective on their own parental relationship.

**Household chore groups with a few residents and a parent (participants: residents, parents, staff)**

These groups take place each morning from Monday to Friday and provide a unique opportunity for residents to cooperate with other residents on concrete tasks (the composition of the groups is changed every week). When a parent is available, there is also the opportunity for different residents and parents to cooperate and communicate with one another. The tasks include cleaning public rooms (for residents with cognitive disturbances, clear instructions are detailed in a note on the wall in each room), grocery shopping for meals (learning how to handle money and payments) and cooking meals (simple recipes have been compiled in a cookbook, with

an emphasis on cheap and healthy food to prevent later resorting to fast food). The household chore groups also enable residents to learn self-management and thereby achieve more autonomy after leaving the School.

**Night shifts (participants: residents, a parent or a student)**

There is a special room in the School where a parent stays once a month for a night shift. No staff are present at night, but there is always a staff member on call. Letting parents make night shifts has two purposes. First, it lets them experience responsibility not only for their own child, but also for others' children. In the beginning some fears exist, but parents gradually become less fearful and experience an increase in confidence in their own decision capabilities. Second, parents arrive in the early evening and mix with residents which leads to experiences of interaction with different residents enabling 'vicarious learning'. Since there are more than 20 night shifts necessary per month and only 10 participating families, psychology and medical students take the remaining shifts. Through their interaction with residents, they introduce an element of normality into the School. Residents appreciate the presence of students to a large degree (*see Supplementary materials*).

**Weekly excursion (participants: residents, parents, staff)**

Once a week, on Wednesday afternoon, an excursion takes place with the whole group. Residents and parents participate in the planning process. In summer, outdoor activities prevail (e.g., going to an open-air swimming pool) and in winter, indoor activities dominate (e.g., visits to a museum or cinema). Again, residents and parents of different families can experience each other's behavior in a normal routine setting.

**c) Activities near the self-help pole: free time to be structured by residents and families**

Residents and families are purposely given abundant free time during the program. They are encouraged and 'nudged' by the staff to learn how to structure free time on their own and avoid withdrawal of the residents, which is always a potential problem in schizophrenia. Once the course finishes, it will be necessary to maintain a structure, hopefully in meaningful activities, e.g., in schooling, occupational training, or a job. However,



this may often not be possible immediately and how to have a day structure needs to be learned, to uphold the optimal balance between under- and overstimulation. This is continuously encouraged by the staff during the whole course and the free time provides opportunities to practise how to structure one's time. Ideas and examples of how this can be achieved are discussed in other activities of the School. It has repeatedly become apparent how creative families can be if they have space and the time to develop and practise new ideas.

### **Free time for residents in the afternoons and evenings (Monday to Thursday)**

Residents have free time after lunch until around 5 pm, when specific group activities take place (see (a) above). The staff encourage residents to carry out activities during that free time, preferably outside the School and with other residents. Often, however, especially in the first months of the course, residents withdraw to their rooms and rest. This withdrawal is initially accepted by the staff, as the morning household chore groups can be quite demanding. Over time, staff increasingly encourage residents 'to do something' and the understanding of 'withdrawal' as a time-limited strategy against overstimulation (called 'controlled withdrawal') is emphasized. In the evenings, residents are encouraged to go out (e.g., to a cinema or to meet friends), preferably with other residents. This happens more frequently with the passing of time.

### **Free time for residents and parents on weekends and public holidays**

Since the School is closed and staff are not available on weekends and public holidays, residents and parents are on their own. At the beginning of the course, parents report that many residents stay inactive and sleep during the day. This can initially be interpreted as recovery from the strain of taking part in the weekly program. Over time, some residents may meet one another for common activities, parents do the same and a resident may even stay overnight in another resident's home. The closing of the School on weekends also keeps parents involved so that the transition at the end of the course is less complicated. In the event that any crisis intervention is needed on weekends, families must call the available local emergency services (and thus learn how these services work). Finally, every time residents

return to the School on a Sunday evening (this occurs at least 70 times during the program) they are learning how to leave home. For some, this is an exercise for potentially living autonomously after the program. In addition to weekends and public holidays, families are encouraged to take a vacation of 15 working days with their child.

### **Weekly parents' group (participants: parents, staff; occasional external experts)**

This group takes place once a week on Tuesday evenings between 7:30 and 9 pm. Tuesday was chosen so that parents can report on their experiences with the residents from the preceding weekend. The purpose is to share information, give feedback and provide mutual support. A wealth of topics is discussed (as listed in Boxes 1–5), particularly experiences of cooperation and contacts with residents of other parents in the organized activities during the week. An important function of the group is the experience of not being alone with the challenge of having a child with schizophrenia. Showing comfort for and helping each other is a powerful factor for helping oneself. Friendships may develop and may remain after the end of the course. One other important feature is that parents give feedback to one another about what they can do for themselves, instead of completely sacrificing themselves for their children. The group is always attended by two staff members, who avoid direct interference but, when appropriate, provide remarks on specific topics and behaviors in the sense of a 'guided discovery' approach, i.e., helping parents to become aware of certain aspects of their behavior. On several occasions, a psychiatrist joins the group to provide information on medical issues, especially on medication, which is always a hot topic (this is a psychoeducational component of the program; see (a) above). The group session often tends to run beyond 90 minutes and it may occur that parents continue the discussion in a pub. Given the many sensitive topics discussed, it is agreed that all information received about other families remains in the group.

### **DISCUSSION AND LIMITATIONS**

Due to a lack of resources and scepticism among professionals, the involvement of families is not yet routine in psychiatric services, as a recent review has shown.<sup>1</sup> The authors conclude that the involvement of families may require a cultural and organizational

shift, since family work can only be implemented if it is considered a shared goal of all members of a clinical team or mental health service. The approach of the School is one possibility of providing — as an add-on component — assistance to families with a child diagnosed with schizophrenia in late adolescence or early adulthood, who is in treatment in routine psychiatric services which are unable but nevertheless value the opportunity to provide systematic assistance to families.

While the School applies several known professional and self-help approaches, its unique feature is that it uses the format of a boarding school, i.e., of a neutral territory, to provide learning experiences over the long period of one-and-a-half years. Frequent encounters at the School between parents and residents from different families provide the opportunity of 'experimenting' with and learning new behaviors and skills, mainly through 'learning by doing' and 'vicarious learning'. Since a group of 10 families begin the course at the same time, relationships of mutual support can develop and often remain after the end of the program. The main objective is that parents learn to keep the delicate balance between caring and letting their child live in autonomy (a concept called 'protected autonomy') and to assist residents in developing skills for an autonomous life after the School.

The School has seen around 230 families finish the course since its foundation in 1986. Since it was not set up as a research project, no continuous evaluation was performed, but there are a few illustrative data. A three-year follow-up study on the first five courses (1986 to 1994) showed large improvements in the well-being and living situation of ex-residents and parents on several parameters. An anonymous assessment of the four most recent courses (2015-2021) by parents demonstrates high satisfaction with what they have learned (for details and references, see Supplementary materials).

In practice, there are several limitations. First, the School is not suited for all families. When parents work full-time, participation is not possible, since at least one parent has to come to the School regularly. Second, both the potential residents and the parents have to agree (and sign a contract) to participate, and this agreement is carefully evaluated by the staff. Over the last 35 years, around one in five families dropped out during the first few weeks of the program and were replaced by families

on the waiting list. The most frequent reason for dropping out was that the residents did not want to continue since they regarded the program as too burdensome and ended their participation by simply not returning to the School after a weekend. Another reason for dropping out was that residents, contrary to before entering the School, suddenly feared a delay in obtaining a degree or missing out on a training or a job opportunity. Severity of the disease in terms of positive, negative or cognitive symptoms could be an exclusion criterion, but not necessarily so. In contrast to the ideal picture of daily routine drawn above, it is often the case that limitations arise in coordinating 10 families for the program. While keeping to the basic philosophy of the School, the staff have to be extremely flexible and willing to compromise, e.g., in cases where parents cannot come to the School for an agreed activity or where residents cannot participate in a planned activity because of an outside medical or psychiatric appointment. In rare instances, a short hospital admission might become necessary during the program, but in these cases the place is kept open for the resident. In recent years, the risk of using drugs has been increasing in young people diagnosed with schizophrenia, which often leads to difficult decisions about whether or not to admit a family.

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### Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:DOI:10.17816/CP99

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# Revisiting Drug Compliance: The Need for a Holistic Approach in the Treatment of Severe Mental Disorders

К проблеме медикаментозного комплайенса: необходимость целостного подхода в терапии тяжёлых психических расстройств

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Original article

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## ABSTRACT

**INTRODUCTION:** The limited practice of depot antipsychotics and psychoeducation use, recommended for overcoming the noncompliance of patients with severe mental disorders, is linked to a high incidence of treatment violation. Therefore, the development of personalized mental healthcare approaches is a crucial healthcare task.

**AIM:** To describe and differentiate the role of clinical, social and psychological factors that lead to different level of treatment engagement of psychiatric inpatients.

**METHODS:** Secondary analysis of findings from 91 inpatients, based on the Treatment Motivation Assessment Questionnaire and Medication Compliance Scale, as well as the Scale of Internalized Stigma of Mental Illness and Perceived Discrimination and Devaluation Scale. Factorial analysis, cluster analysis and analysis of variance with p-level=0.05 and the calculation of the effect size (ES) according to Cohen's d and Cramer's V were used.

**RESULTS:** The nature of therapy compliance in various categories of patients is mediated differentially, including: the severity of negative symptoms (ES=0.29), the global level of functioning and work maladjustment (ES=0.23–0.26), various motivational and behavioral styles (ES≥0.74) and the intensity of psychiatric stigmatization (ES≥0.88).

**CONCLUSIONS:** Consideration of the clinical, social and psychological factors should empirically determine the strategies for the personalized use of prolonged antipsychotics and socio-psychotherapeutic interventions when developing an individual treatment plan for psychiatric in-patients.

## АННОТАЦИЯ

**АКТУАЛЬНОСТЬ:** Ограниченная практика применения депо-антипсихотиков и психообразования, рекомендуемых для преодоления некомплайенса пациентов с тяжелыми психическими расстройствами, сочетается с сохраняющейся высокой частотой нарушений режима лечения. Это определяет разработку персонализированных подходов психиатрической помощи в качестве актуальной задачи здравоохранения.



**ЦЕЛЬ:** Дифференцированное описание роли клинических и социально-психологических факторов, соучаствующих в формировании разной включенности пациентов психиатрического стационара в терапию.

**МАТЕРИАЛ И МЕТОДЫ:** Вторичный анализ данных 91 пациента психиатрического стационара с верификацией оригинальной кластерной модели включенности в лечебный процесс на основании данных Treatment Motivation Assessment Questionnaire, Medication Compliance Scale, а также Scale of Internalized Stigma of Mental Illness и Perceived Discrimination and Devaluation Scale. Используются факторный, кластерный и дисперсионный анализы с  $p\text{-level}=0.05$  и расчетом размера эффектов (ES) по Cohen's d и Cramer's V.

**РЕЗУЛЬТАТЫ:** Характер сотрудничества в терапии у разных категорий пациентов опосредован дифференцированно: выраженностью негативной симптоматики (ES=0.29), глобальным уровнем функционирования и трудовой дезадаптацией (ES=0.23-0.26), различными мотивационно-поведенческими стилями (ES $\geq$ 0,74) и интенсивностью психиатрической стигматизации (ES $\geq$ 0.88).

**ВЫВОДЫ:** Учет комплекса клинических и социально-психологических факторов эмпирически обуславливает стратегии персонализированного применения пролонгированных форм антипсихотиков и социо-психотерапевтических интервенций при разработке индивидуального плана лечения пациентов психиатрического стационара.

**Key words:** *treatment adherence and compliance; patient engagement; motivation; mental disorders; stigma*

**Ключевые слова:** *приверженность лечению и комплаенс; вовлеченность пациента; мотивация; психические расстройства; стигма*

## INTRODUCTION

The traditional approach to achieving high adherence to treatment in patients with severe mental disorders is the widest possible use of depot antipsychotics. However, despite the general consensus on the described strategy,<sup>1</sup> the practice of using prolonged-release antipsychotics in various healthcare institutions remains inconsistent and, even taking into account the greater cost, is unreasonably limited.<sup>2</sup>

Among the barrier factors for the widespread use of depot drugs in clinical work are organizational factors (a limited number of drugs paid for from insurance funds due to a high cost for depot antipsychotics), the doctors' attitude (difficulties in dose control, subjective perception of the appointment as coercion of the patient, established clinical practice), or factors related to the patient, such as a fear of painful injections, lack of information or perception of depot therapy as a coercive measure.<sup>3</sup> At the same time, an analysis of the frequency of prolonged-release antipsychotics use indicates their predominant prescription in situations of clinical uncertainty: among 37.8% of patients with polypharmacy,<sup>4</sup> as well as among those with increased aggressiveness<sup>5</sup> and those who

rarely seek in-patient care.<sup>6</sup> At the same time, the question remains unclear whether such categories of patients benefit the most from the depot therapy. On the contrary, some clinical recommendations indicate the validity of using depot drugs not only for the treatment of severe patients, but also as a choice for routine anti-relapse therapy.<sup>7</sup>

It is noteworthy that psychiatrists themselves are often biased towards prolonged-release antipsychotics, and in a hypothetical situation of their own treatment they would prefer taking oral drugs.<sup>8</sup> This prejudice associated with changing patterns of behavior is believed to be one of the key markers of the stigmatization process.<sup>9</sup> Stereotyping attitudes towards patients and strategies for choosing drug therapy can determine cognitive biases. Then, in order to increase adherence to treatment, depot therapy is prescribed algorithmically and without considering recommendations on the need to combine prolonged-release antipsychotics with psychoeducation programs to achieve the desired level of compliance.<sup>10</sup>

There is solid evidence that different categories of patients demonstrate significantly different rates

of treatment adherence, even with depot antipsychotics, depending on their motivation for treatment and attitude to the disease.<sup>11</sup> At the same time, in addition to the patient's own motivation for treatment, the perceived external pressure from the patient's environment is an independent factor in increasing involvement in the therapeutic process, acting along with the factors of distress and insight on the disease.<sup>12</sup>

From this review of the literature, it follows that the task of forming a high adherence to antipsychotic therapy in severe mental disorders is intractable in the case of a mechanistic prescription of depot drugs to the most severe patients. On the contrary, the benefits of therapy with prolonged-release antipsychotics could be available to a larger number of patients through the development of personalized rehabilitation programs that include, along with the individualized selection of medical therapy, taking into account the socio-psychological conditions of a mental disorder development and the patient's own motives for therapy.

The purpose of the study is a differentiated description of the role of clinical and socio-psychological factors involved in the formation of different levels of in-patient engagement in the treatment process. The hypothesis of the study was based on the assumption that the level of involvement of patients with mental disorders in therapy is available for instrumental analysis and can be increased through rehabilitation strategies addressed to morbid (biological), motivational (psychological), and socio-behavioral factors specific to different types of patients. The implementation of the study was carried out through a sequential completion of tasks:

- 1) verification, based on the objectively observed behavior of patients during treatment and their therapeutic alliance, of the original cluster model of involvement in the treatment process, based on an instrumental assessment of therapeutic motivation and the structure of compliance
- 2) description of targeted strategies to increase adherence to treatment, depending on the main clinical, psychological and behavioral parameters: severity of symptoms, characteristics of the course of the disorder and attitude to the disease, and the therapeutic alliance, in each of the selected types of patients.

## METHODS

A sample of 91 patients of the V.M. Bekhterev National Research Medical Center for Psychiatry and Neurology was studied, clinical and experimental psychological data were subjected to secondary analysis in February 2020, after identifying the typology of patients based on their motivation for treatment and profile of drug compliance. A detailed description of the examined respondents is presented in Table 1. The study protocol was implemented in accordance with the principles of the Declaration of Helsinki, GCP and approved at a meeting of the Independent Ethics Committee at the V.M. Bekhterev National Research Medical Center for Psychiatry and Neurology No. EK-I-105/18 (25.09.2018).

To identify the reasons for the motivation of patients included in the study, as well as to operationalize their drug compliance, the original psychometric instruments were used. The Treatment Motivation Assessment Questionnaire (TMAQ) was applied, based on the Treatment Motivation Scale developed in the Department of Integrative Pharmacology-Psychotherapy.<sup>13</sup> Therapeutic motivation is described quantitatively – through the total indicator of its intensity, and also qualitatively – when comparing the parameters of individual sections with those standardized for six levels or four factors of the questionnaire. It has demonstrated good internal consistency (Cronbach's alpha 0.842), and its external as well as meaningful validity has been established previously.<sup>13,14</sup>

To assess the multifactorial nature of patient compliance, the Medication Compliance Scale (MCS)<sup>15</sup> was used, which is answered by a doctor based on complete clinical information and medical history of the patient. Individual MCS items include the study of the patient's clinical condition according to the Brief Psychiatric Rating Scale (BPRS),<sup>16</sup> the Negative Symptom Rating Scale (SANS),<sup>17</sup> and the Global Assessment of Functioning (GAF).<sup>18</sup> In addition to the original psychometric instruments, the Internalized Stigma of Mental Illness (ISMI) scale<sup>19</sup> and the Perceived Discrimination and Devaluation Scale (PDD)<sup>20</sup> were used.

The data obtained were statistically analysed using the SPSS 16.0 software package. The principal component method with varimax rotation was used to factorize the data. The k-means cluster analysis was used. Analysis of variance was performed using ANOVA and the Student's t-test for parametric data, Kruskal-Wallis H-criterion

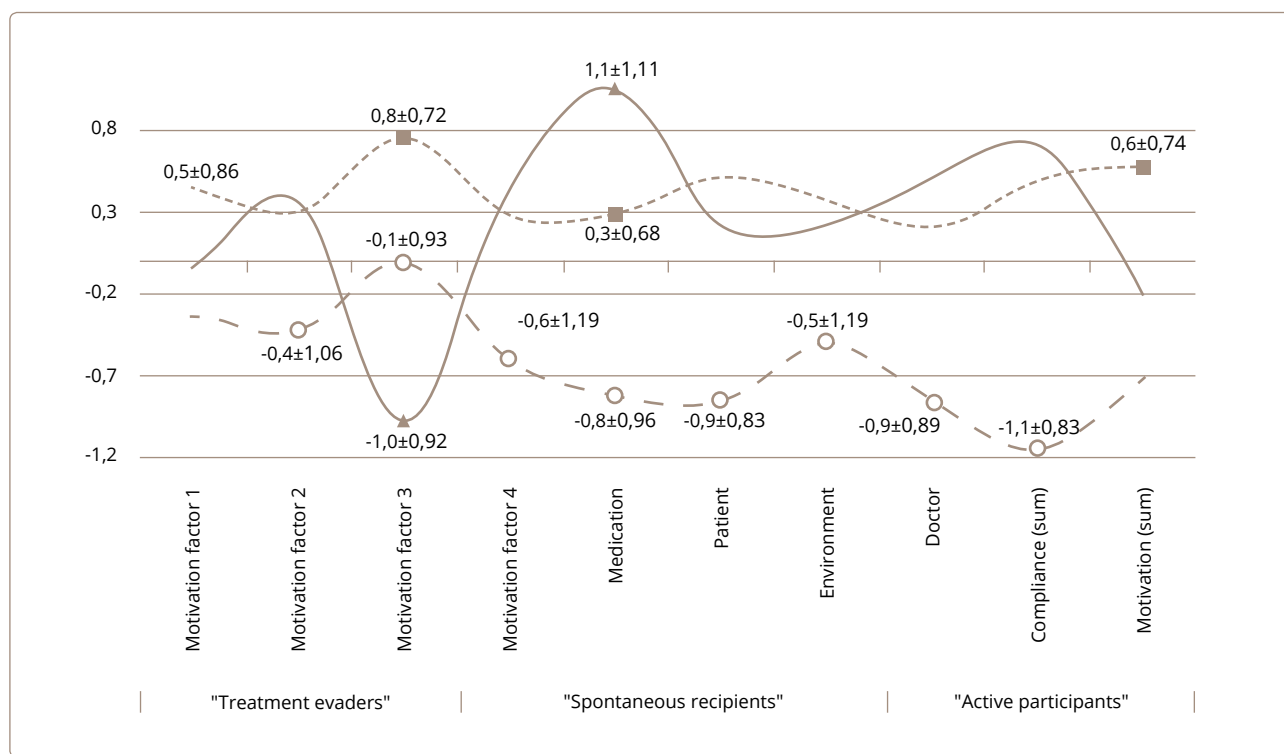
and Mann–Whitney U-criterion for nonparametric data and Pearson Chi-square for rated values. The data distribution was assessed using the Kolmogorov-Smirnov z-criterion. For descriptive statistics of revealed significant differences, we used the calculation of the size of effects according to the Cohen's d and Cramer's V criteria.

### Study procedures

Enrolment in the study was carried out after obtaining voluntary informed consent. The inclusion criteria were: 1) being in in-patient treatment in the department of integrative pharmaco-psychotherapy of patients with mental disorders, 2) readiness and ability to undergo psychometric examination in accordance with the protocol, and 3) fluency in Russian. Noninclusion criteria:

the severity of the positive symptoms or cognitive impairments, which determines the patient's inability to correctly answer the questions of the original psychometric instruments. The exclusion criterion was the withdrawal of consent to participate at any stage of the study.

The most typical options for the involvement of in-patients in the treatment process were established in the cluster analysis of psychometric data: standardized indicators of the compliance scale subscales and four factors of the motivation assessment questionnaire.<sup>21</sup> The selected groups of patients had the most similar structures of motivation for treatment and drug compliance within the cluster, but they differed maximally when compared with each other (Figure 1).



**Figure 1. Typology of patients depending on the prevailing structure of treatment motivation and the corresponding profile of medication compliance (means and standard deviations of questionnaires standardized indices)**

**Footnote.** Parameters of the Treatment motivation assessment questionnaire (TMAQ): factor 1 – the psychoeducative component of the internal disease picture, factor 2 – the insight into the necessity of the treatment, factor 3 – the insight into the psychological mechanism of the morbid social maladjustment, factor 4 – the willingness to an active participation in the treatment process, motivation – the sum total of TMAQ. Subscales of Medication Compliance Scale (MCS): medication – the attitude to medication, patient – factors referring to the patient, environment – factors referring to the environment of the patient, doctor – factors referring to the therapist, compliance – the sum total of the MCS. Marked standardized indices with significant intergroup differences, Cohen's  $d \geq 0.74$ ;  $p \leq 0.05$ .

## RESULTS

Patient clusters, differing in the degree of involvement in therapy, were numerically comparable (Table 1) and did not differ in the main socio-demographic and clinical characteristics (gender, age, education, marital status and children, nosology, duration of the disease, frequency of hospitalizations, severity of productive symptoms), as well as the frequency of taking antipsychotics of the 1<sup>st</sup> or the 2<sup>nd</sup> generations, antidepressants and mood stabilizers.

The fundamental difference was in the behavior of patients assigned to different clusters during drug treatment and in their therapeutic alliance (Table 2).

The proportion of patients in cluster 1 was overwhelming among respondents with a low therapeutic alliance (MCS 4.1). Often, they were unable to maintain

drug compliance on their own. The adherence disorder for these “evading” patients was stable throughout the whole available medical history (MCS 1.5). Patients in this cluster included those with more frequent use of nonrecommended drugs and / or irregular use of recommended medications. The search for factors involved in the formation of low adherence to treatment in cluster 1 revealed the most pronounced morbid changes in this group of patients. They suffered from negative symptoms, and, compared to patients in cluster 3, were more socially maladjusted (Table 1).

Cluster 2 included half of the subgroup of respondents with a high therapeutic alliance, as well as 19% of patients who needed external control of medication and 30% who were self-medicating at the time of the current hospitalization. Nevertheless, this cluster included the

**Table 1. Sociological and clinical features of patients after clusterization**

		Cluster 1 N=29	Cluster 2 N=23	Cluster 3 N=39	p-level of differences
<b>Sex</b>	Male	15	8	11	≥0.05
	Female	14	15	28	
<b>Mean age, years, M [S.D.]</b>		30.7 [9.8]	36.1 [12.5]	35.1 [13.2]	≥0.05
<b>Occupation</b>	employed	5	9	20	p=0.046
	unemployed	23	12	17	
	disability pension	1	2	2	
<b>Marital status</b>	married	9	11	10	≥0.05
	single	20	12	29	
<b>Education</b>	primary	11	4	8	≥0.05
	secondary	8	7	5	
	higher	10	12	26	
<b>Diagnosis (ICD-10)</b>	F2	24	15	30	≥0.05
	F3	2	4	2	
	F4+F6	1	3	5	
	F0	2	1	2	
<b>Illness duration, years, M [S.D.]</b>		8.9 [9.5]	10.4 [11.0]	8.1 [8.0]	≥0.05
<b>Inter hospitalization rate, months, M [S.D.]</b>		24.0 [13,4]	34.3 [27.5]	25.7 [21.6]	≥0.05
<b>BPRS (positive symptoms)</b>	≥60 points	12	6	7	≥0.05
	40-60 points	14	12	24	
	≤40 points	3	5	8	
<b>SANS (negative symptoms)</b>	≥60 points	13	5	5	p=0.004
	30-60 points	13	8	14	
	≤30 points	3	10	20	
<b>GAF (global functioning)</b>	≤40 points	13	6	4	p=0.015
	40-60 points	13	11	28	
	≥60 points	3	6	7	

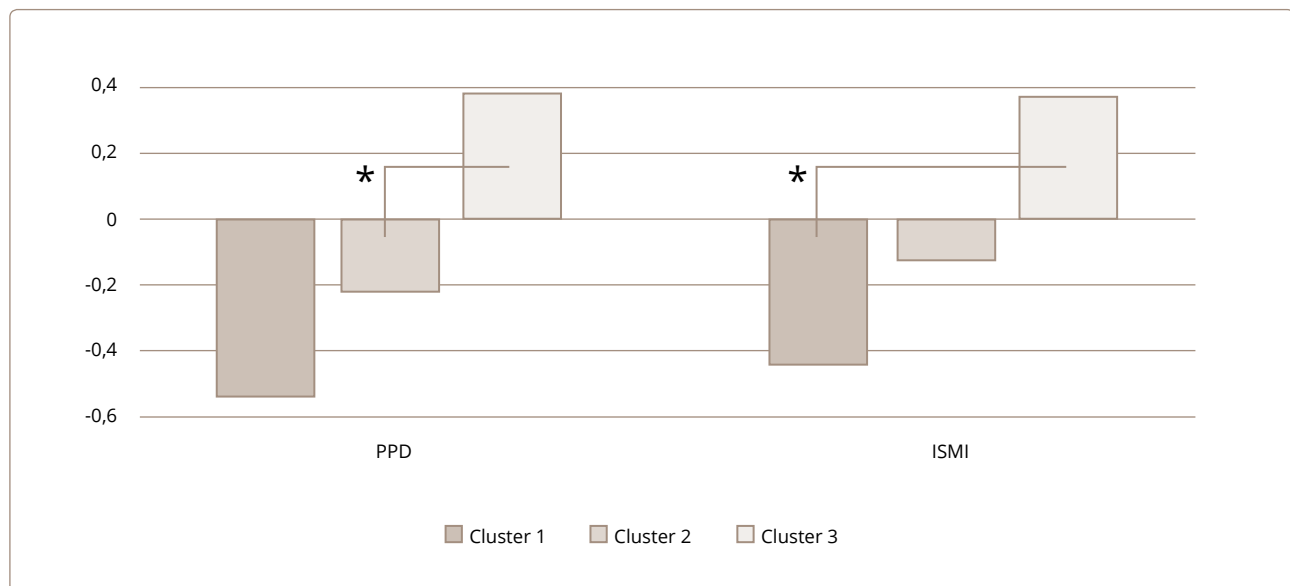
rarest history of drug compliance violations (Table 2). Interestingly, such “recipients of therapy” were more inclined to discriminate against other mentally ill patients than in cluster 3 (Figure 2).

In cluster 3, with the maximum indicators of the intensity of therapeutic motivation, the most common

was the average level of therapeutic alliance and attitude to medication. Unexpectedly, this group included half of the patients who have arbitrarily discontinued drug therapy in the past. It is important to note separately that the respondents here were inclined to actively resist psychiatric stigmatization (Figure 2).

**Table 2. Differences in the prevalence of compliance violation history between groups of patients after clustering**

Predominant behavioral pattern in medication compliance scale	Behavior occurrence			Criterion of differences
	Cluster 1	Cluster 2	Cluster 3	
<b>1.1 Behavior during medication</b>				
Evasion of medication intake	3	0	0	p=0,0001; $\chi^2=23.4$ , df=4, Cramer's V=0.51
Externally controlled drugs intake	18	6	8	
Self-controlled drugs intake	8	17	31	
<b>1.5 Noncompliance history</b>				
Nonrecommended drugs intake	5	1	2	p=0,002; $\chi^2=24.1$ , df=8, Cramer's V=0.52
Self-discontinuation of medication	14	5	19	
Irregular intake of medication	4	0	2	
Self-reduced dosage	0	4	4	
Absence of noncompliance	3	13	12	
<b>4.1 Therapeutic alliance</b>				
Low	15	0	1	p=0,0001; $\chi^2=41.1$ , df=4, Cramer's V=0.67
Medium	13	12	28	
High	1	11	10	



**Figure 2. Standardized scores for psychiatric stigmatization in patients from different clusters (means and standard deviations)**

**Footnote.** PDD — Perceived Discrimination and Devaluation Scale (low scores reflect higher external stigmatization); ISMI — discrimination resistance subscale of Internalized Stigma of Mental Illness; Cluster 1 — patients «avoiding treatment»; Cluster 2 — «passive recipients» of treatment; Cluster 3 «active treatment participants». \*p<0,05



## DISCUSSION

The study confirmed the hypothesis of the complex nature of the phenomenon of long-term adherence to drug therapy in psychiatric in-patients. The fact of a high intensity of motivation for treatment, without its nature assessment, does not allow for predicting a favourable attitude towards medication and a high therapeutic alliance in patients with severe mental disorders. The data obtained demonstrate that, in addition to the factor of insight into the disease described earlier in the literature,<sup>11</sup> the processes of psychiatric stigmatization play a significant role in the formation of adherence to therapy in hospital patients with severe mental disorders.

Long-term adherence to antipsychotic therapy is critical for the decrease of productive symptoms and the prevention of maladjustment in schizophrenia patients.<sup>22</sup> Based on the data of the analysed sample, it was revealed that among patients with impaired functioning, unfavourable social and labour status and the most pronounced negative symptoms, low drug compliance is associated with impaired motivation for treatment. Thus, the patients most in need of stable drug treatment did not have sufficient psychological resources to maintain a therapeutic alliance and adherence to treatment. The prevalence of the irregular use of drugs in such "difficult" patients determines the rationale that 32% of the examined patients should be treated with prolonged-release antipsychotics in combination with the active formation and maintenance of a therapeutic alliance, their family should be involved in psychoeducation and training in the supervision of the patient's medication.

Only one fourth of the sample showed long-term adherence to therapy. Adherence was supported by a moderate intensity of motivation for treatment, which became an illustration of the applicability of the "law of optimum" in relation to therapeutic motivation in patients with severe mental disorders.<sup>23</sup> However, patient compliance is not the only barrier to the use of long-acting antipsychotics. Since they discriminated against other psychiatric patients and showed a relative decrease in the motivation for treatment, it is legitimate to judge the limited self-identification of "recipients of therapy" as patients in need of psychiatric care. Thus, it is more important for this category of patients to prevent the formation of a semantic connection between the depot as a therapeutic option and the risk of limiting

their freedom in choosing a treatment strategy, rather than ensuring the constant receipt of the antipsychotic in the form of a depot.

A significant (43%) part of the sample (highly functioning patients with no signs of severe abulia) were active in opposing discrimination. This is consistent with literature data on the multidimensional relationship between motivational processes, internal stigma, and disease outcome.<sup>24</sup> Active and purposeful actions of patients within the therapeutic program are not only a reflection of their overall high level of functioning, but also an indirect effect of overcoming self-stigmatization affected by their involvement in the rehabilitation system. Probably, among the "active participants" of therapy, the motive of resistance to stigmatization had an expansive subjective interpretation in the form of distancing from the doctor (middle-level therapeutic alliance) and, thus, was associated with a medical history aggravated by therapy discontinuation. These findings highlight the potential for the increased use of long-acting antipsychotics also in patients who demonstrate an active stance during treatment, when combined with rehabilitation interventions aimed at correcting dysfunctional beliefs about illness and medication.

A potential limitation of the study is the nosological heterogeneity of the sample. However, a significant part of the social and psychological factors that determine involvement in the therapeutic process is the same in various mental disorders. Therefore, samples mixed by diagnosis are widely represented in studies addressed to the psychology of the treatment process.<sup>25,26</sup> Our sample of patients reflects the naturalistic nosological profile of patients with mental disorders seeking for in-patient care. In addition, there were no statistically significant nosological differences between the identified clusters of patients with different levels of inclusion in therapy. Thus, the objective of the study did not depend on bias in the selection of patients.

## CONCLUSION

Verification of the original cluster model has demonstrated the applicability of instrumental assessments of motivation to treatment and drug compliance to determine the types of treatment involvement of patients with mental disorders. Analysis of the differences between the identified clusters of "active participants", "passive recipients" and patients

that “avoided therapy” helps to objectively assess the multifactorial nature of patients’ behavior during the treatment process. The level of compliance of patients with severe mental disorders is mediated by the severity of negative symptoms and social maladjustment, various motivational and behavioral styles, and the intensity of psychiatric stigmatization. Taking these factors into account empirically determines the strategies for the personalized use of prolonged forms of antipsychotics when developing an individual treatment plan for psychiatric in-patients.

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**Conflict of interests:** The authors report no conflicts of interest.

**Authors' contribution:** N.G. Neznanov, M.Yu. Sorokin — concept and design of the article; M.Yu. Sorokin — literature searches; M.Yu. Sorokin — writing the manuscript; N.B. Lutova, V.D. Wied — comments on the draft paper; N.G. Neznanov, N.B. Lutova — revising the manuscript; N.G. Neznanov, N.B. Lutova, V.D. Wied — approval of the final version.

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# Clinical Features of First-episode Psychoses During the COVID-19 Pandemic

Клиническая картина манифестных психотических состояний в период пандемии COVID-19

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Original article

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## ABSTRACT

**INTRODUCTION:** The pandemic of the new coronavirus infection has become one of the most significant global social shocks in the past decade. It influenced the lifestyle of many people, including those with mental disorders.

**AIM:** To compare the psychopathological structure of psychotic states in young patients (up to 40 years old) with first-episode psychosis before the COVID-19 pandemic and during the COVID-19 pandemic.

**METHODS:** The research was conducted at the First psychotic episode clinic of the Mental-health clinic No. 1 n.a. N.A. Alexeev, Moscow, Russia. In total, 66 patients were enrolled, who met the inclusion criteria: first-in-life admission to a mental healthcare unit that occurred during the spring of 2019 (control group) or spring 2020 (experimental group), diagnosis on admission that belonged to the group “Acute and transient psychotic disorders” (F23.XX) of ICD-10. Patients with a disability or concurrent somatic or neurologic conditions were excluded from the study. Assessment of clinical and psychopathological characteristics with the allocation of the leading syndrome within the psychotic state, psychometric assessment according to the PANSS scale was carried out, the above indicators were compared between the experimental and control group.

**RESULTS:** We observed statistically insignificant increase in the rates of affective and catatonic subtypes of psychoses, a decrease in the rate of the delusional subtype of paranoid syndrome. PANSS scores differed significantly for different clinical subtypes of psychoses, although the differences between the experimental and control groups showed no statistical significance. Additionally, in spring 2020, a considerable decrease in the total number of hospitalizations was revealed.

**CONCLUSIONS:** The differences in the clinical and psychopathological structure of psychotic states revealed during the COVID-19 pandemic were statistically insignificant. Additional results of the study may indicate a decrease in the availability of mental healthcare for patients with psychoses, which requires further investigation.

## АННОТАЦИЯ

**АКТУАЛЬНОСТЬ:** Пандемия новой коронавирусной инфекции стала одним из социально значимых потрясений всемирного масштаба в последнее десятилетие. Она оказала существенное влияние на уклад жизни многих людей, в том числе на больных с психическими расстройствами.

**ЦЕЛЬ:** Сравнить психопатологическую структуру манифестных психотических состояний у пациентов молодого возраста (до 40 лет) до пандемии COVID-19 и во время пандемии COVID-19.

**МАТЕРИАЛ И МЕТОДЫ:** Работа выполнена в клинике первого психотического эпизода, подразделения ГБУЗ «ПКБ №1 им. Н.А. Алексеева» ДЗМ. Всего в исследование включены 66 пациентов, отвечавших критериям включения — первичная госпитализация в ПКБ№1 весной 2019 (группа сравнения — 45 пациентов) или 2020 (основная группа — 21 пациент) года, диагноз из рубрики F23, отсутствие инвалидности, сопутствующей соматической или неврологической патологии, которая затрудняла обследование или требовала дополнительных лекарственных назначений. Проведена оценка клинко-психопатологических характеристик с выделением ведущего синдрома в рамках психотического состояния, психометрическая оценка по шкале PANSS, вышеуказанные показатели сопоставлены между основной группой и группой сравнения.

**РЕЗУЛЬТАТЫ:** Выявлено статистически незначимое увеличение доли аффективно-бредовых и кататонно-бредовых состояний, а также уменьшение доли параноидных состояний за счет бредового их варианта. Результаты психометрической оценки по PANSS достоверно различались между пациентами с разными клинко-психопатологическими вариантами психозов, однако значимых различий между основной группой и группой сравнения обнаружено не было. Дополнительно было обнаружено уменьшение общего количества госпитализаций весной 2020 года.

**ВЫВОДЫ:** Выявленные в ходе исследования различия клинко-психопатологической структуры манифестных психотических состояний в период пандемии COVID-19 не продемонстрировали статистической значимости. Побочные результаты исследования могут указывать на изменение доступности психиатрической помощи для пациентов с манифестными психотическими состояниями, что требует дальнейшего изучения.

**Keywords:** *COVID-19; psychosis; first-episode psychosis; acute and transient psychotic disorders; PANSS*

**Ключевые слова:** *COVID-19; психоз; первый психотический эпизод; острые и преходящие психотические расстройства; PANSS*

## INTRODUCTION

The pandemic of the new coronavirus infection is undoubtedly one of the most significant shocks of recent decades. Besides an immediate “biological” impact on the human body, the COVID-19 pandemic and widespread antiepidemic measures which have been introduced have fundamentally affected the mode of life of many people, including those suffering from mental disorders.<sup>1,2</sup> Large-scale quarantine measures (“lockdown” or “self-isolation”) have especially affected social contacts and lifestyle habits, that together with economic instability and contradictory information about the pandemic increased psychological distress.<sup>3-5</sup> Thus, a global psycho-traumatic situation has been formed, which affects

human mental well-being.<sup>6,7</sup> During the pandemic period, an increase in the incidence of reactive mental disorders has been noticed, including those on the psychotic register.<sup>8</sup> Besides the influence on the population as a whole, some authors point to the possibility of the infection negatively influencing patients with a history of mental disorders<sup>9</sup> and, moreover, exacerbation of symptoms in patients with schizophrenia.<sup>10,11</sup> In recent studies, there are sporadic indications of a change in the clinical representation of psychiatric disorders under the influence of the coronavirus infection or antiepidemic measures.<sup>12</sup> Despite achievements in recent decades in the sphere of studying psychic disorders as a whole and their clinical peculiarities, various questions

concerning diagnostics and the clinical picture of manifest psychotic states during large-scale social shocks remain unsolved.<sup>13</sup> Little is known about the association between the COVID-19 pandemic and manifest psychotic states. A number of clinical cases of acute psychoses were described in patients who have experienced a new coronavirus infection<sup>14-16</sup> or psychoses whose development could be associated with the psychological impact of an unfavourable epidemic situation.<sup>17,18</sup> Special attention is attracted towards dangerous and potentially lethal cases of catatonia<sup>19</sup>, associated with disease itself<sup>20,21</sup> as well as its psychosocial impact.<sup>22,23</sup> Meanwhile, Russian researchers have mainly studied various aspects of the pandemic impact on the incidence of nonpsychotic mental disorders.<sup>24-26</sup> Thus, there is a need to consider fundamentally important questions concerning the prognosis and psychopathological characteristics of psychoses manifested during the coronavirus pandemic.

**The goal of this research** was to compare the psychopathological structure and syndrome severity of manifest psychotic states in young patients (under 40 years old) before the COVID-19 pandemic and during the COVID-19 pandemic.

**Hypothesis.** The psychopathological structure of manifest psychotic states and syndrome severity changed during the COVID-19 pandemic. These changes can be attributed to an increase in the incidence rate and severity of catatonic syndrome.

## METHODS

The research was carried out in the First psychotic episode clinic of the Mental-health clinic No. 1 n.a. N.A. Alexeev of Moscow Healthcare Department.

The inclusion criteria were as follows: diagnosis F23 according to ICD-10; hospitalization between March 1 and May 31 2019 or 2020; absence of disability or comorbid physical or neurological pathology that would make medical examination difficult or would require additional drug prescriptions. The choice of the enrolment time period in 2020 for experimental group was determined by introduction of the most radical antiepidemic measures (The Decree of the President of the Russian Federation "On Measures to Ensure Sanitary and Epidemiological Welfare of the Population on the Territory of the Russian

Federation Owing to the Spread of a New Coronavirus Infection (COVID-19) of April 2, 2020"), which, to our understanding, could have had the greatest impact on the mental state of our patients. The control group included patients hospitalized in the clinic in the same period of the previous year.

The research sample comprised 66 patients (27 men and 39 women), who had received in-patient treatment due to manifest psychotic states in spring 2019 or 2020. The research participants were divided into two groups: the experimental group (2020,  $n=21$ ) and the control group (2019,  $n=45$ ). All participants in the experimental group were COVID negative at the time of experiment. Two patients had a confirmed diagnosis of COVID-19 infection 4 to 8 weeks prior to the experiment.

A comparison of the main sociodemographic indices (sex, average age, education level and employment status) was performed to evaluate the comparability of the groups according to social parameters. Evaluation of the mental state was carried out using a clinical psychopathological method, singling out the dominating syndrome. Patients were divided into subgroups according to the leading syndrome type.

The Russian version of PANSS (Positive and Negative Syndrome Scale) 27 was used to evaluate the severity of mental symptoms at the point of hospital admission. Our psychometric examination included an additional evaluation using the "catatonia subscale" (N1-4, N6, G1-3, G5-7, G11, G13, G15 and G16 point scores),<sup>28,29</sup> conditionally labelled by the letter "C", with a maximum total score 105.

The statistical analysis of the received frequency data was performed using Pearson chi-squared  $\chi^2$  test. The Fisher's angular transformation  $\phi$  was used in cases where application of  $\chi^2$  test was impossible. Student's t-criterion was used to compare the average duration of the initial psychosis phase and PANSS scores in the sample groups. The mean (M) was used to evaluate the central tendency, and data scattering was used to evaluate the standard deviation (SD). Value of  $p \leq 0.05$  was accepted as statistically significant.

The research was conducted in accordance with the Declaration of Helsinki regarding issues of medical ethics, and the participants' rights, interests and personal dignity were protected at all times. All the patients examined gave their informed consent prior to participating in the research.



**Table 1. Clinical and sociodemographic characteristics of patients**

Parameter	2019 (n=45)		2020 (n=21)		Statistical significance indices
	n	%	n	%	
Women	25	55.6	14	66.6	$\chi^2=0.706$ ; df=1; p=0.403
Men	20	44.4	7	33.3	$\chi^2=0.719$ ; df=1; p=0.396
<b>Education level at the time of the medical examination</b>					
Secondary education	5	11.1	6	28.6	$\varphi=1.7$ ; p<0.05
Specialized secondary education	6	13.3	2	9.5	$\varphi=0.4$ ; p>0.05
Incomplete higher education	6	13.3	2	9.5	$\varphi=0.4$ ; p>0.05
Higher education	28	62.3	11	52.4	$\varphi=0.7$ ; p>0.05
<b>Employment status at the time of the medical examination</b>					
College student	3	6.7	1	4.8	$\varphi=0.3$ ; p>0.05
University student	4	8.9	1	4.8	$\varphi=0.6$ ; p>0.05
Specialist (skilled job)	3	6.7	1	4.8	$\varphi=0.3$ ; p>0.05
Unskilled labour	7	15.5	2	9.6	$\varphi=0.7$ ; p>0.05
Unemployed	28	62.2	16	76.2	$\varphi=1.2$ ; p>0.05

## RESULTS

### Sociodemographic characteristics

The experimental group (2020) consisted of 14 women (66.6%) and 7 men (33.3%), and their average age was  $28.2 \pm 7.3$  years. The control group (2019) comprised 25 women (55.6%) and 20 men (44.4%), with an average age of  $27.3 \pm 5.6$  years. The groups of patients were comparable in terms of sex and sociodemographic characteristics at the time of medical examination (Table 1).

### PSYCHOPATHOLOGICAL CHARACTERISTICS

The duration of the initial phase of the manifest psychotic state (the period immediately preceding development of psychosis, during which the non-psychotic disorders or transitory psychotic symptoms were observed) varied significantly:  $4.8 \pm 4.6$  weeks in the experimental group versus  $14.6 \pm 11.1$  weeks in the control group ( $p=0.03$ ).

Three variants of manifest psychotic syndromes were determined on the basis of the prevailing psychopathological symptomatology: affective-delusional, paranoid and catatonic, each of them was additionally divided into subvariants.

**Affective-delusional syndrome** ( $n=25$ ) was characterized by prevalence of the changed affect in combination with acute sensory delusions, in the absence of delusions of perception and psychic

automatisms. This variant of psychotic states was represented by manic-delusional, depressive-delusional and mixed affective-delusional states depending on the dominating pole of affect.

Manic-delusional states ( $n=7$ ) were accompanied by the dominating elevated mood, often with irritability, that corresponded with delusions of grandeur, special abilities and messianism, always followed by ideas of persecution. The structure of the depressive-delusional states ( $n=3$ ) was represented by an anxiety-depressive affect with delusional ideas of guilt, sinfulness, contagion and apprehension of imminent, inevitable punishment.

The mixed affective-delusional states ( $n=15$ ) were characterised by unstable affect, with elements of symptoms of each affective pole, episodes of intensive panic, mental disorganization, confusion, staging phenomena and delusions of special significance.

**Paranoid syndrome** ( $n=22$ ). The leading psychopathological symptoms were acute hallucinations or psychic automatisms together with persecutory delusions.

The hallucinatory variant ( $n=9$ ) was characterized by a high intensity of hallucinations, which designated the delusional content and patients' behavior.

In the delusional variant ( $n=13$ ), in the absence of hallucinations or their low intensity, the condition

was defined by pronounced mental automatisms (usually represented not only by ideational but also by motor or sensory types), as well as by delusions of influence or capture syndrome.

**Catatonic syndrome** ( $n=19$ ). The psychotic states in this group were united by a prevalence of catatonic symptomatology (psychomotor agitation, stupor, catalepsy, mutism, negativism, speech and motor stereotypies, echolalia or echopraxia).

In catatonic-delusional states ( $n=15$ ), the catatonic symptomatology was accompanied by hallucinations, mental automatisms, delusions of persecution or of influence.

States exclusively represented by catatonic symptomatology were rare ( $n=4$ ). Such conditions corresponded to the definition of "lucid" catatonia and were characterized by a predominance of hypokinetic motor disorders in the form of stupor or substupor.

The prevalence of patients' leading psychopathological syndromes is represented in Table 2.

The prevalence of affective-delusional, paranoid and catatonic syndromes did not differ significantly in 2019 and 2020.

### PSYCHOMETRIC EVALUATION USING PANSS

Statistically significant differences were found between clinical subgroups in PANSS total scores ( $p=0.04$ ), and in pair-wise comparison of C subscale score between

**Table 2. Prevalence of psychotic syndrome types in 2019 and 2020**

Syndrome	2019 ( $n=45$ )		2020 ( $n=21$ )		Statistical significance indices
	n	%	n	%	
Affective-delusional syndrome	16	35.5	9	42.9	$\chi^2=0.328$ ; df=1; $p=0.567$
Paranoid syndrome	16	35.5	6	28.6	$\chi^2=0.302$ ; df=1; $p=0.583$
Catatonic syndrome	13	29	6	28.6	$\chi^2=0.001$ ; df=1; $p=0.9736$

the catatonic subgroup and affective-delusional and paranoid subgroups ( $p=0.02$ ). Statistically significant differences in psychopathological structure of psychosis were not found between the experimental group and the control group (Table 3).

### DISCUSSION

Despite our hypothesis that COVID-19 pandemic from the very beginning could have influenced the mental state of the patients with psychotic spectrum disorders, we did not manage to find any statistically significant differences between experimental and control groups.

Patients with the affective-delusional syndrome demonstrated a higher score on the PANSS P scale (2019: 26; 2020: 24.6) than on the N scale (2019: 23.4; 2020: 23.8) in both groups. The catatonia scale score was moderately

**Table 3. PANSS scores (M±SD) in the clinical subgroups according to the leading syndrome type**

PANSS Scale	Leading psychopathological syndrome					
	Affective-delusional syndrome		Paranoid syndrome		Catatonic syndrome	
	2019 ( $n=16$ )	2020 ( $n=9$ )	2019 ( $n=16$ )	2020 ( $n=6$ )	2019 ( $n=13$ )	2020 ( $n=6$ )
P	26±4.8	24.6±6.3	24.3±5.2	24.2±3.6	26.8±6	28±5.3
N	23.4±6.1	23.8±4	22.9±5.2	24.3±6	29±7.4	33.8±11.5
G	49.1±8.8	49.2±6.1	45.1±7.3	47.3±7.9	60.5±12.7	64.5±13.5
C	41.7±9.5	42.2±9.5	40.1±6.2	42.5±8.5	53.8±13.1	57±14.4
Σ	107.4±16	105±12.8	99.8±18.1	102.6±18.2	126.1±27.1	135.2±31.3

Footnote. P is the positive symptomatology scale; N is the negative symptomatology scale; G is the general psychopathological symptomatology scale; C is the catatonia scale; Σ is the total score.

high (41.9 and 42.2 in 2019 and 2020, respectively), the total PANSS score was intermediate, compared to other groups (2019: 107.4; 2020: 105).

Patients with paranoid syndrome had lower total PANSS scores (2019: 99.8; 2020: 102.6) and lower scores on P scale (2019: 24.3; 2020: 24.2), with slightly higher scores on the N scale (2019: 22.9; 2020: 24.3), while the scores on the catatonia subscale did not differ from those of the affective-delusional syndrome subgroup (2019: 40.0; 2020: 42.5).

The most severe psychopathological disorders were observed in patients with catatonic syndrome according to PANSS total score (2019: 126.1; 2020: 135.2). Scores on the P scale were slightly higher than in other groups (2019: 26.8; 2020: 28), negative syndromes according to N scale score were more pronounced comparing to other subgroups (2019: 29; 2020: 33.8). Higher scores were also noted on the catatonia subscale: 53.8 and 57 in 2019 and 2020, respectively.

It should be noted that a number of factors could have affected the results of the research. Firstly, verification of statistical significance was essentially limited by a small sample size. Secondly, we noticed that the total number of patients hospitalized with F23 diagnoses was significantly higher in 2019 (45 patients) than in 2020 (21 patients). This observation corresponds with data showing a decrease in the total number of hospitalizations in Mental-health Clinic No.1 named after N.A. Alexeev for the period studied (2152 hospitalizations in spring 2019; 1597 hospitalizations in spring 2020). A probable decrease in the availability of psychiatric help could influence the characteristics of the sample in 2020. Thirdly, of the examined patients, few had received a confirmed diagnosis of the COVID-19 infection, thus, in the experimental group only the psychosocial impact of the pandemic, but not the virus infection itself could have any impact on the course of psychotic disorders.

## CONCLUSIONS

During the first months of the COVID-19 pandemic no difference was observed in the psychopathological structure of manifest psychotic states of in-patients. Therefore, it is necessary for further (extensive) research to be carried out to examine the impact of the COVID-19 pandemic on the manifestations of psychotic conditions.

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**Authors' contribution:** V.A. Zyablov — concept and design of the article; V.S. Chizhikov — reviewing publications, obtaining data for analysis; M.A. Gusev — reviewing publications, obtaining data and data analysis, drawing conclusions. All authors participated equally in the discussion.

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# Ceramides: Shared Lipid Biomarkers of Cardiovascular Disease and Schizophrenia

Церамиды: общие липидные биомаркеры сердечно-сосудистых заболеваний и шизофрении

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Original article

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## ABSTRACT

**INTRODUCTION:** Schizophrenia, although a debilitating mental illness, greatly affects individuals' physical health as well. One of the leading somatic comorbidities associated with schizophrenia is cardiovascular disease, which has been estimated to be one of the leading causes of excess mortality in patients diagnosed with schizophrenia. Although the shared susceptibility to schizophrenia and cardiovascular disease is well established, the mechanisms linking these two disorders are not well understood. Genetic studies have hinted toward shared lipid metabolism abnormalities co-occurring in the two disorders, while lipid compounds have emerged as prognostic markers for cardiovascular disease. In particular, three ceramide species in the blood plasma, Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1), have been robustly linked to the latter disorder.

**AIM:** We aimed to assess the differences in abundances of Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1) in the blood plasma of schizophrenia patients compared to healthy controls.

**METHODS:** We measured the abundances of Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1) in a cohort of 82 patients with schizophrenia and 138 controls without a psychiatric diagnosis and validated the results using an independent cohort of 26 patients with schizophrenia, 55 control individuals, and 19 patients experiencing a first psychotic episode.

**RESULTS:** We found significant alterations for all three ceramide species Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1) and a particularly strong difference in concentrations between psychiatric patients and controls for the ceramide species Cer(d18:1/18:0).

**CONCLUSIONS:** The alteration of Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1) levels in the blood plasma might be a manifestation of metabolic abnormalities common to both schizophrenia and cardiovascular disease.

## АННОТАЦИЯ

**АКТУАЛЬНОСТЬ:** Шизофрения является не только психическим заболеванием, но и влияет на физическое здоровье людей. Одними из основных сопутствующих соматических заболеваний, связанных с шизофренией, являются сердечно-сосудистые заболевания, считающиеся одной из основных причин повышенной смертности у пациентов с диагнозом шизофрения. Хотя общая предрасположенность к шизофрении и сердечно-сосудистым заболеваниям хорошо известна, механизмы, связывающие эти два расстройства, недостаточно изучены. Генетические исследования указали на общие аномалии липидного обмена, сопутствующие этим двум расстройствам, в то время как липидные соединения были идентифицированы как прогностические маркеры сердечно-сосудистых заболеваний. В частности, три представителя церамидов, определенной группы липидов, в плазме крови, Cer (d18: 1/16: 0), Cer (d18: 1/18: 0) и Cer (d18: 1/24: 1), были ассоциированы с риском сердечно-сосудистых заболеваний.

**ЦЕЛИ:** Мы оценивали различия в содержании Cer (d18: 1/16: 0), Cer (d18: 1/18: 0) и Cer (d18: 1/24: 1) в плазме крови больных шизофренией по сравнению с контрольной группой.

**МАТЕРИАЛ И МЕТОДЫ:** Мы измерили содержание Cer (d18: 1/16: 0), Cer (d18: 1/18: 0) и Cer (d18: 1/24: 1) в когорте из 82 пациентов с шизофренией и 138 человек из контрольной группы без психиатрического диагноза и, далее, подтвердили результаты анализа в слепом исследовании независимой когорты из 26 пациентов с шизофренией, 55 человек из контрольной группы и 19 пациентов, перенесших первый психотический эпизод.

**РЕЗУЛЬТАТЫ:** Мы обнаружили значительные изменения для всех трех видов церамидов Cer (d18: 1/16: 0), Cer (d18: 1/18: 0) и Cer (d18: 1/24: 1). Среди этих соединений Cer (d18: 1/18: 0) показал наиболее сильные наибольшую разницу между пациентами и контрольной группой.

**ВЫВОДЫ:** Изменение уровней Cer (d18: 1/16: 0), Cer (d18: 1/18: 0) и Cer (d18: 1/24: 1) в плазме крови может быть проявлением метаболических аномалий, общих для как шизофрении, так и сердечно-сосудистых заболеваний.

**Keywords:** *ceramide; schizophrenia; cardiovascular disease; lipid; blood plasma*

**Ключевые слова:** *церамиды; шизофрения; сердечно-сосудистые заболевания; липиды; плазма крови*

## INTRODUCTION

Schizophrenia (SCZ) is a debilitating mental illness affecting the individual's thinking, perception, emotional response, as well as daily functioning, in general. Individuals diagnosed with schizophrenia are also

at increased risk of somatic comorbidities, such as cardiovascular disease (CVD), type 2 diabetes, and obesity.<sup>1,2</sup> It has been estimated that patients with schizophrenia show a two-fold increase in mortality compared to the general population.<sup>3</sup> Most of this excess



mortality can be attributed to physical illnesses, with CVD being one of the leading causes of death.<sup>3-5</sup>

Understanding the mechanisms of CVD development in individuals with schizophrenia is of extreme importance for the management and treatment of the disorder. While lifestyle and antipsychotic medication can affect the risk of CVD,<sup>5</sup> there seems to be an intrinsic and complex relationship between this physical disorder and schizophrenia. Genetic pleiotropy has been reported for schizophrenia and cardiometabolic abnormalities,<sup>6-10</sup> implying shared genetic risk factors for CVD and SCZ. Stratification by genetic susceptibility to cardiometabolic abnormalities has also been proposed to separate SCZ patients into subgroups with differing metabolic profiles.<sup>11</sup> At the same time, even though genetic studies show hints of a shared susceptibility towards both SCZ and CVD, the mechanisms linking these two disorders are difficult to untangle from genetic information alone. In this respect, quantifying metabolic profiles of compounds associated with CVD in individuals diagnosed with SCZ can deepen the understanding of this connection by identifying the abnormalities common to the two disorders. Lipids, in particular, have been shown to undergo substantial alterations in schizophrenia.<sup>12</sup> Further, genetic variants exhibiting pleiotropic effects in SCZ and CVD are particularly enriched in genes involved in lipid metabolism.<sup>9,10</sup>

While classical lipid measurements, such as low-density lipoproteins (LDL), high-density lipoproteins (HDL), and total triglycerides, are well known to be associated with both CVD<sup>13</sup> and SCZ,<sup>14-16</sup> advances in lipidomics have provided the opportunity to expand the scope of metabolic profiling and deepen our understanding of lipid alterations in disease. Ceramides, a class of lipids that consist of a sphingosine backbone connected by an amide bond to a fatty acid (FA) chain of varying length have been shown to predict cardiovascular events more effectively than classical lipid measurements.<sup>17</sup> In particular, three lipid species, Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1), have been proposed as promising biomarkers of CVD.<sup>18</sup> To assess whether disruption in the metabolism of these ceramides is also characteristic of patients with SCZ, we investigated the levels of these three lipids in 82 patients diagnosed with SCZ in comparison to 138 control (CTL) individuals without a psychiatric diagnosis. We further validated the results on an independent dataset of 26 SCZ patients, and

55 CTL patients, as well as 19 patients exhibiting a first episode of psychosis (FEP).

## METHODS

### Main sample cohort

Subjects included in this cohort were inpatients recruited from the Mental Health Research Centre, Moscow. The cohort included adult (18 or more years of age) participants with a diagnosis of SCZ ( $n=82$ ; age  $31.2\pm 8.4$ ; 23% female). SCZ status was determined based on the International Classification of Disease (ICD-10). The exclusion criteria were being less than 18 years old, severe somatic and neurological illness, recent surgery, pregnancy, history of substance and alcohol abuse, acute heart failure, severe chronic heart failure, and a diagnosis of CVD. Sample collection was performed at the Neuroimmunology Laboratory of the Mental Health Research Centre, Moscow. The control group ( $n=138$ ; age  $29.5\pm 8.3$ ; 22% female) consisted of healthy volunteers from the Mental Health Research Centre who were showing no signs of psychiatric disorders and met the same exclusion criteria at above (less than 18 years of age, family history of any psychiatric disorder, severe somatic and neurological illness, recent surgery, pregnancy, substance and alcohol abuse acute heart failure, severe chronic heart failure, a diagnosis of CVD). Patients and healthy participants were evaluated by board-certified psychiatrists from the same centre, whilst somatic condition was assessed by internists of the respective specialties. The study was approved by the local ethics committee of the Mental Health Research Centre (Protocol No. 281; 05/05/2016). Informed consent was obtained from all participants. The entire study was conducted in line with the World Medical Association Declaration of Helsinki formulating ethical principles for medical research involving human subjects.

### Validation sample cohort

Participants included in the validation cohort were inpatients diagnosed with a first episode of psychosis (FEP,  $n=19$ , age  $27\pm 7$ , 53% female) and schizophrenia (SCZ,  $n=26$ , age  $35\pm 12$ , 58% female), as recruited at Mental Health Clinic No. 1, named after N.A. Alexeev.

Exclusion criteria for patients were being less than 18 years of age, having a serious medical or surgical illness, any previous episodes of psychosis due to substance abuse, acute heart failure, severe chronic heart failure,

and psychotic symptomatology within a clearly diagnosed affective or borderline personality disorder. For healthy controls, the exclusion criteria were being less than 18 years of age, having a current or previous psychiatric disorder, a family history of any psychiatric disorder, head trauma, neurological illness, serious medical or surgical illness, or a history of substance abuse. SCZ status was determined based on the International Classification of Disease (ICD-10). Patients were evaluated using a structured interview for the Positive and Negative Syndrome Scale (PANSS), including the PANSS positive, PANSS negative, and PANSS general psychopathology subscales. The average total PANSS was determined to be  $98 \pm 24$  for women and  $91 \pm 22$  for men. The Russian version of PANSS, with acceptable validity and reliability, was used to evaluate the severity of the symptoms of psychosis in the schizophrenia patients in this study.<sup>19</sup>

The control group (CTL,  $n=55$ ; age  $32 \pm 8$ , 35% female) consisted of healthy volunteers who had no apparent signs of any psychiatric disorders and met the same exclusion criteria (aged less than 18 years old, family history of any psychiatric disorder, severe somatic and neurological illness, recent surgery, pregnancy, history of substance and/or alcohol abuse, acute heart failure, severe chronic heart failure).

CTL and SZ had no addictions including  $<80$  mg of ethanol equivalent per week and  $<10$  cigarettes per day. Informed consent was obtained from all participants. The protocol for this study was approved by the Interdisciplinary Ethics Committee, Moscow (Protocol No.1, 22/07/2017).

### Lipid measurements

Plasma was obtained from peripheral venous blood in the morning from individuals that had undergone an overnight fast. Plasma samples were collected in 4 ml Vacutainer tubes containing the chelating agent ethylenediaminetetraacetic acid (EDTA) (BD Vacutainer, Franklin Lakes, NJ, US). Tubes were centrifuged at  $4^{\circ}\text{C}$  at 1100g for 15 min. The supernatant was stored immediately in 500  $\mu\text{l}$  aliquots at  $-80^{\circ}\text{C}$ . We collected the blood plasma samples from the main cohort comprising 82 SCZ and 138 CTL individuals (SCZ: age  $31 \pm 8$ , 23% female; CTL: age  $30 \pm 8$ , 22% female). We further collected a validation cohort including samples from 26 SCZ, 19 FEP, and 55 CTL individuals (SCZ: age  $35 \pm 12$ , 58% female; FEP: age  $27 \pm 7$ , 53% female; CTL:

age  $32 \pm 8$ , 35% female). Studies on the validation of the data obtained were conducted using the blind method, i.e., during the measurement of the lipid profile, the experimenter did not know which sample (patients or controls) he/she was measuring. We randomized the plasma samples with respect to the diagnosis and extracted lipids from them following the same standardized extraction procedure. We then measured lipid abundances using liquid chromatography coupled with mass spectrometry (LC-MS) in negative ionization mode for the main dataset and validation dataset in two distinct experimental runs. Sample processing, LC-MS measurements, and data preprocessing were performed as described elsewhere.<sup>48</sup> We determined the molecular ions corresponding to Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1) based on their initial molecular ion masses, chromatography retention time, and their fragmentation profiles (LC-MS<sup>2</sup>) by the presence of characteristic sphingoid base fragments.

To simplify the normalization of lipid abundances between the main and validation datasets, 20 demographically representative reference samples from the main dataset were remeasured together with the validation dataset. The mean abundances of these samples in the validation and main datasets were used to normalize the abundances in the validation dataset: for each lipid, the differences between these means were subtracted from the abundances of each sample in the validation dataset to produce normalized abundances.

### Statistical analysis

Statistical tests were performed on the base-two log transformed abundances to ensure normal distribution. The Welch t-test of unequal variance was used to assess statistical differences. However, bar plots were visualized on the original scale.

Analysis, including statistical analysis, performance calculation for naïve classifiers, and logistic regression, was performed using the publicly available python libraries "scipy" and "sklearn". The prediction models were trained using the main dataset, and tested on both the main and validation datasets.

## RESULTS

The statistical analyses of the lipids extracted from main cohort SCZ and CTL samples demonstrated that all three ceramides of interest, Cer(d18:1/16:0), Cer(d18:1/18:0),

	Ceramide spices	Cer(d18:1/16:0)	Cer(d18:1/18:0)	Cer(d18:1/24:1)
<b>p-values</b>	SCZ vs CTL, main	<0,001	<0,001	<0,001
	SCZ vs CTL, validation	0,44	0,001	0,16
	FEP vs CTL, validation	0,012	<0,001	0,02
<b>Fold-changes</b>	SCZ vs CTL, main	1,17	1,63	1,21
	SCZ vs CTL, validation	1,08	1,76	1,08
	FEP vs CTL, validation	1,22	1,55	1,12
<b>ROC AUC</b>	SCZ vs CTL, main	0,67	0,81	0,66
	SCZ vs CTL, validation	0,57	0,73	0,61
	FEP vs CTL, validation	0,68	0,81	0,67

Table 1. p-values, fold-changes, and ROC AUC values for the comparisons between the psychiatric and CTL groups.

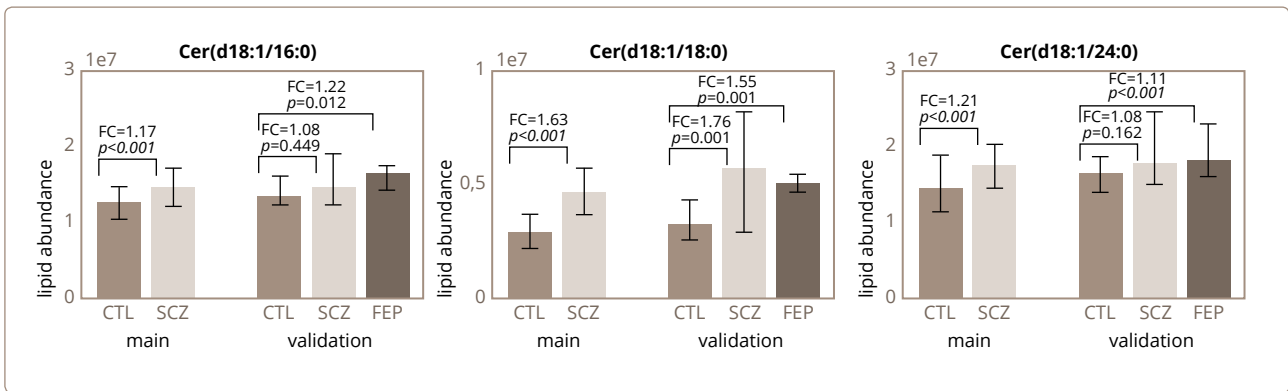


Figure 1. The median and interquartile ranges in sample groups for each of the ceramides' abundances: Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1). The median abundances in each sample group correspond to the bar heights, and the interquartile range is indicated by the error bars. For each of the ceramide, sample groups are indicated on the bottom, from left to right: CTL main cohort, SCZ main cohort, CTL validation cohort, SCZ validation cohort, FEP validation cohort. The p-values of the Welch t-test and the fold-changes in abundances for the comparisons between the psychiatric and CTL groups are indicated on the plots.

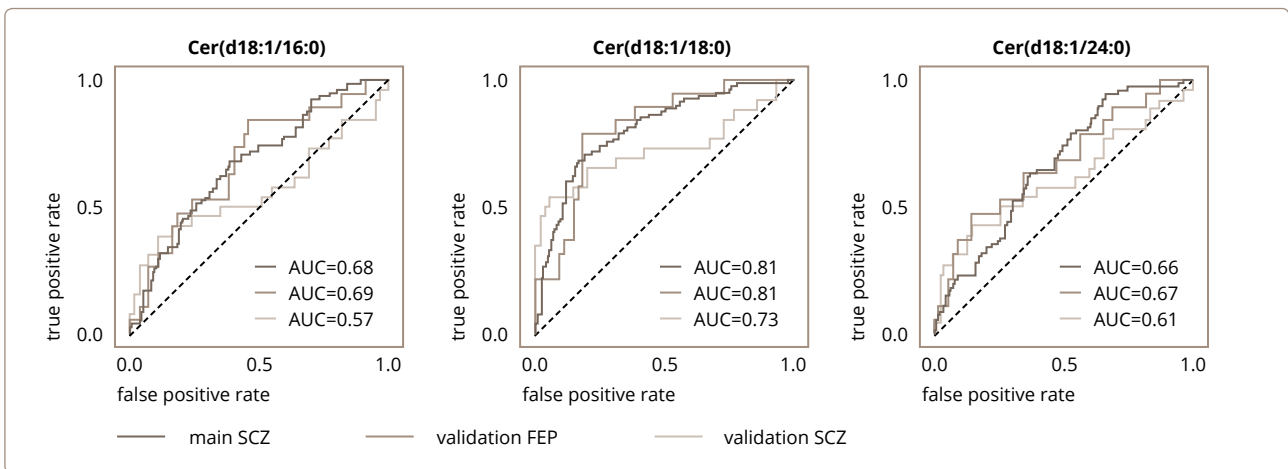


Figure 2. The receiver operating characteristic (ROC) curves for the naïve classifiers that were based on each of the ceramides' abundances: Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1). Each ceramide species, in conjunction with an abundance threshold, represents a naïve classifier, with individuals with abundances higher than the cutoff threshold classified as the psychiatric patient group, and individuals with abundances lower the cutoff – as CTL group. For each ceramide, the ratio of the true positive classifications is plotted against the ratio of false positive classifications for the different cutoff thresholds. Colours correspond to the different classification tasks: main cohort SCZ vs. CTL (dark red), validation cohort FEP vs. CTL (red), validation cohort SCZ vs. CTL (orange). The corresponding areas under the curves (AUCs) are indicated on the plots.

and Cer(d18:1/24:1), displayed statistically significant differences in abundance between the SCZ and CTL groups, with all three compounds showing a higher abundance in SCZ (Welch t-test,  $p < 0.0001$ ) (Figure 1; Table 1). Similarly, the intensities of all three ceramides were elevated in SCZ and FEP patients compared to CTL individuals in the validation cohort. Further, despite reduction in statistical power due to smaller sample size, abundance of all three ceramides differed significantly between FEP and CTL samples (Welch t-test,  $p = 0.0125$ ,  $0.000005$ , and  $0.0255$ , respectively), as well as for Cer(d18:1/18:0), between the SCZ and CTL samples (Welch t-test,  $p = 0.0012$ ; Figure 1; Table 1).

We then tested the possibility of being able to discriminate between the two groups of individuals, psychiatric patients and controls, based on the abundances of each of the three ceramides. The abundances of each compound, in conjunction with an abundance threshold, represented a naive classifier, with individuals with abundances higher than the cutoff threshold classified as the psychiatric patient group, and individuals with abundances lower than the cutoff as the CTL group. To assess the predictive power of these naive classifiers, we used Area Under the Curve of the Receiver Operator Characteristic (AUC ROC), which reflects, for the different cutoff thresholds, the relationship between the ratio of false positive and true positive classifications. A large AUC (with a maximum of 1) corresponds to a classifier for which, with an appropriate cutoff threshold, the ratio of true positives is higher, while the ratio of false positives remains low. Of the three ceramides, Cer(d18:1/18:0) showed best performance, as indicated by the fact that it had the highest ROC AUC score (Cer(d18:1/16:0): AUC = 0.68; Cer(d18:1/18:0): AUC=0.81; Cer(d18:1/24:1): AUC=0.61; Figure 2; Table 1). We then assessed the performance of these same classifiers when applied to the classification of psychiatric patients versus CTL in the validation cohort. For the three ceramides, the separation of SCZ and CTL was slightly worse than in the main cohort (Cer(d18:1/16:0): AUC=0.57; Cer(d18:1/18:0): AUC=0.73; Cer(d18:1/24:1): AUC=0.61; Figure 2; Table 1). The classification of FEP versus CTL individuals, however, displayed no decline in accuracy compared to the main cohort performance (Cer(d18:1/16:0): AUC=69; Cer(d18:1/18:0): AUC=81; Cer(d18:1/24:1): AUC=67; Figure 2; Table 1), indicating the good generalization capabilities of the separation models.

We next used the abundances of the three ceramides together to construct a logistic regression model separating psychiatric patients from CTL individuals. The model trained on the samples from the main cohort showed a similar accuracy to the best-performing individual ceramide, Cer(d18:1/18:0), but its accuracy in the validation dataset was, in fact, higher (main cohort, SCZ vs CTL: AUC=0.82; validation cohort, SCZ vs CTL: AUC=0.81; FEP vs CTL: AUC=0.83).

## DISCUSSION

Schizophrenia (SCZ) is burdened by a range of metabolic abnormalities. In this work, we have assessed the abundances of three ceramide species, Cer(d18:1/16:0), Cer(d18:1/18:0), and Cer(d18:1/24:1), in the blood plasma of patients suffering from SCZ and in control individuals with no psychiatric diagnosis. These ceramide species were chosen on account of their emerging role as biomarkers of cardiovascular disease (CVD).<sup>18</sup> Our results demonstrate that ceramide alterations might be an abnormality common to both SCZ and CVD.

While CVD progression can be affected by environmental factors such as lifestyle, weight, and smoking,<sup>5</sup> there is evidence for a genetic basis of CVD.<sup>19</sup> There are also reports of shared genetic risk factors for both SCZ and CVD,<sup>6-8</sup> with lipid-related genes being highlighted in the literature.<sup>9,10</sup> Likewise, while ceramides can be affected by lifestyle, diet, and other environmental factors, the human plasma lipidome, and ceramides in particular, were found to have a marked genetic component.<sup>20-22</sup> The identifications of genes, such as *SPTLC3*, that show association with both CVD and blood plasma ceramide levels,<sup>20</sup> but that were also reported in connection to SCZ,<sup>23,24</sup> demonstrates the possibility of an intrinsic connection between SCZ, CVD, and ceramide metabolism abnormalities beyond the superficial influences of environmental factors.

Ceramides are structural elements of eukaryotic cell membranes. They also have signalling functions, being involved in processes such as apoptosis and inflammation.<sup>25,26</sup> Moreover, ceramides are enriched in neural tissues and are vital for the normal functioning of brain cells, in particular.<sup>27-29</sup> While the exact role of ceramides is not fully elucidated, perhaps the most convincing evidence of their important functional role is the numerous reports of ceramide alterations in various disorders besides CVD, such as diabetes, insulin resistance,

neurodegenerative disorders, and multiple sclerosis.<sup>30,31</sup> In a similar manner to CVD, specific ceramide lipid species quantified in blood plasma, including the Cer(d18:1/18:0) compound assessed in this study, have been proposed as biomarkers of depression.<sup>32</sup> In schizophrenia, ceramide alterations have been reported in the brain,<sup>33</sup> and mechanisms linking metabolic abnormalities and SCZ through sphingolipids have been proposed.<sup>12,34</sup>

While ceramides in blood plasma have been extensively studied as biomarkers of depression,<sup>32</sup> surprisingly, we have not been able to find any studies that explicitly focused on ceramides in the blood plasma of SCZ patients. Nevertheless, alterations in the blood plasma of SCZ patients were investigated and reported for other lipid classes.<sup>35-47</sup> In our work, we demonstrated that the abundance of one particular ceramide previously reported as a reliable depression and CVD biomarker – Cer(d18:1/18:0)<sup>18,32</sup> – was sufficient to distinguish SCZ from CTL with an AUC higher than 0.8, where this result was further reproduced in an independent cohort of first psychotic episode patients. We also found that the discriminatory power of the other two assessed ceramides, Cer(d18:1/16:0) and Cer(d18:1/24:1), was lower, but the associated differences in abundance between the SCZ and CTL groups was nonetheless statistically significant. We found that the combination of the abundances for the three ceramides in a single model produced moderate improvement in the classification performance compared to the single compound Cer(d18:1/18:0). The model performance achieved in this study is not, however, the best reported for SCZ and CTL group separation – models based on other lipid classes allegedly reached AUC=0.98,<sup>43</sup> indicating extensive disruption of lipid metabolism in SCZ.

The limitation of this study was that only three ceramides were identified, whereas there are several hundred different kinds of lipids in an organism. Environmental factors such as lifestyle, weight, and smoking were also not taken into account. This will be pursued in following studies, where more patients will be recruited, and more lipids will be investigated.

## Conclusion

The interplay between SCZ and metabolic abnormalities, such as CVD, remains poorly understood. Genetic studies have hinted at a connection between these disorders through common lipid metabolism alterations.<sup>9,10</sup> Specific

ceramide species have been proposed as biomarkers of CVD, and we found these same ceramides to be altered in SCZ as well. While the mechanism of ceramide alterations in disease is not clear, the systematic study of lipid and other metabolic disruptions that co-occur with SCZ and CVD might help elucidate the connection between these disorders in the future.

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# Comprehensive Clinical and Social Research at the Moscow Research Institute of Psychiatry: Translation into Clinical Practice

Комплексные клинико-социальные исследования в Московском научно-исследовательском институте психиатрии: трансляция в клиническую практику

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Historical article

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## ABSTRACT

The article is devoted to the work of the Moscow Research Institute of Psychiatry to improve psychiatric care for patients with psychotic disorders. An important feature of this work was an integrated approach, in which the clinical picture of the disease was assessed in close connection with the patient's personal and psychological characteristics, social conditions of his life, therapeutic opportunities, rehabilitation potential and organizational structure of care. The article reflects the results of many years of work of the department of outpatient psychiatry and the organization of psychiatric care under the guidance of Professor I.Ya. Gurovich. The results of scientific research carried out by the staff of the institute in a traditional humanistic manner are presented. The translational nature of the research is emphasized by its inextricable link with clinical and social approaches.

As a result of many years of work, a concept was developed to provide assistance to various groups of patients, starting with the first manifestations of the disease and ending with cases of long-term chronic disorders with a pronounced level of social maladaptation. As a result, a whole spectrum of new organizational forms of psychiatric care was proposed, such as departments (clinics) of the first psychotic episode, medical rehabilitation departments, assertive community treatment departments, designed for the most difficult patients. These organizational forms were fixed in the regulatory documents of the Ministry of Health and Social Development of the Russian Federation. To date, the above departments have been established in psychiatric institutions in many regions of the Russian Federation. Further development of this area is associated with neurobiological research to identify complex biomarkers of psychotic spectrum disorders.

Thus, the research carried out at the present time preserves the tradition of an integrated clinical and social approach to the study of mental disorders. It is shown that an important advantage of this approach is their translational nature.

## АННОТАЦИЯ

Статья посвящена работе Московского научно-исследовательского института психиатрии по совершенствованию психиатрической помощи пациентам с психотическими расстройствами. Важной особенностью этой работы являлся комплексный подход, в котором клиническая картина заболевания оценивалась в неразрывной связи с личностными и психологическими характеристиками пациента, социальными условиями его жизни, терапевтическими возможностями, реабилитационным потенциалом и организационной структурой помощи. В статье приводятся результаты многолетней работы отдела внебольничной психиатрии и организации психиатрической помощи под руководством профессора И.Я.Гуровича. Представлены результаты научных исследований, выполненных сотрудниками института в традиционном гуманистическом ключе. Трансляционный характер исследования подчеркивается неразрывной связью с клиническими и социальными подходами.

В результате многолетней работы была разработана концепция оказания помощи различным группам пациентов, начиная с первых проявлений заболевания и заканчивая случаями длительно протекающих хронических расстройств с выраженным уровнем социальной дезадаптации. В результате были предложены целый спектр новых организационных форм психиатрической помощи, таких как отделения (клиники) первого психотического эпизода, медико-реабилитационные отделения, отделения интенсивного оказания психиатрической помощи, предназначенные для наиболее тяжелого контингента пациентов. Данные организационные формы были закреплены в нормативных документах Министерства здравоохранения и социального Развития Российской Федерации. На сегодняшний день вышеперечисленные отделения созданы в психиатрических учреждениях в многих регионах РФ. Дальнейшее развитие данного направления связано с нейробиологическими исследованиями по выделению комплексных биомаркеров расстройств психотического спектра.

Таким образом, исследования, осуществляемые в настоящее время, сохраняют традицию комплексного клиничко-социального подхода к изучению психических расстройств. Показано, что важным преимуществом данного подхода является их трансляционный характер.

**Key words:** *translational psychiatry; psychosocial rehabilitation; biological research*

**Ключевые слова:** *трансляционная психиатрия; психосоциальная реабилитация; биологические исследования*

## INTRODUCTION

Russian psychiatry from the beginning of its establishment as a scientific discipline was characterized by a holistic approach to the mental healthcare provision. An important characteristic of this approach was comprehensive consideration of clinical, psychological and social aspects, personality of the patient, along with the organization of treatment and rehabilitation issues. The clinical manifestation of the disease was assessed together with the patient's personality, psychological traits and social conditions, therapeutic opportunities, rehabilitation potential and organizational structure of care. Typical of Russian psychiatry as a whole, this approach has formed the basis of the scientific and practical activities of the Moscow Research Institute of Psychiatry (MRIP) since it came into being. The clinical approach has definitely been the "carte-de-visite" of the MRIP across the entire period of its existence and remains such at the present time.

Professor Lev Markovich Rozenstein, one of the first directors of the MRIP, is known as a major theorist of psychiatric care organization and an active adept of the rehabilitation approach in psychiatry. He was a brilliant clinician and a sophisticated diagnostician, developing concepts for the prevention of mental disorders, based on a deep understanding and the practical application of K. Jaspers' phenomenological method.<sup>1</sup> His statements that hospitalizations alone cannot solve the problems of mental patients sound surprisingly modern. In his view, it is necessary to go beyond hospital psychiatry, especially since the majority of psychiatric patients will always remain in the community. The preventive approach in psychiatry, inextricably associated with outpatient psychiatric care, according to L.M. Rozenstein, was based on a comprehensive assessment of the patients' condition (and not only the sum of certain symptoms of the disease) and a subtle analysis of the actual disease manifestations

together with dynamics of the patient's personality in a social environment.

L.M. Rozenstein's ideas were reflected in the concept of social and vocational rehabilitation of patients with schizophrenia, which was actively developed in Russian psychiatry between the 1950s and the 1970s. Here we can highlight the studies of Professor Dmitry Evgenievich Melekhov,<sup>2</sup> in which special attention was paid to the concept of "defect", understood as persistent, post-psychotic manifestations not limited by negative symptoms, but rather possessing a certain structure, clinical features and dynamics.

D.E. Melekhov was the head of the MRIP in the 1950s and is one of the founders of the vocational rehabilitation system in the Soviet Union. Understanding the working capacity prognosis in his studies is inextricably associated with clinical indicators, using both static and dynamic characteristics (systematics of schizophrenia forms according to the "cross section" and "longitudinal section"), as well as post-psychotic states.<sup>2</sup>

In this regard, D.E. Melekhov singled out the period of defect development at the active disease stage, the period of formation and stabilization of the defect, as well as the period of the formed and compensated defect. At the same time, even in the latter case, the defect was not considered as being stiff condition, on the contrary, the dynamics of the formed, defective conditions in the guise of episodic, short-term inadequate mood and activity fluctuations, reactive states and the pathological development of the post-psychotic personality were indicated. Moreover, possibility of the compensation, subcompensation (labile and incomplete compensation) and defect decompensation were discussed. The need to distinguish between reactions developing during the active course of the disease and the reactions that generate new symptoms of the disease from truly compensatory reactions, were emphasized.

Based on the peculiarities of the clinical picture and the dynamics of the defect (which is much broader than negative disorders sometimes synonymously used in these cases), the tactics of social and labour recovery of patients were established. Indeed, it is important to distinguish between the restoration of social functioning, due to the symptoms regression in the active stage of the disease and the patient's adjustment due to the defect compensation in the post-psychotic period. At the same time, the importance of purposeful activity

of the individual and the significance of the environment in the compensation of defect were emphasized.<sup>2</sup>

**The purpose** of this article is to review the clinical and social research conducted at the Moscow Research Institute of Psychiatry, and implementation of their results in clinical practice.

## **NEW APPROACHES TO THE MENTAL HEALTHCARE IN THE COMMUNITY**

Professor Isaac Yakovlevich Gurovich also used an integrated approach to the rehabilitation of patients with mental illnesses. In 1978 as the head of the Outpatient Psychiatry and Organization of Mental Healthcare Department, he placed this clinical approach at the forefront of organizational healthcare in psychiatry. New organizational forms of mental care were filled in with clinical content; they were based on the understanding of the dynamic nature of psychiatric diseases, that determines the patients' social functioning.<sup>3</sup>

The system of treatment in day hospitals using step-wise approach and continuity of care was developed in the department. The development of the treatment approaches for subacute, subpsychotic conditions, the so-called "outpatient exacerbations" appeared to be a significant achievement.<sup>4</sup> The dissertation researches performed in the department formed the basis for the Regulation on day hospitals, which laid the foundation for the further development of the psychiatric service, with a shift to outpatient care, and for the organization of new forms of care provision within the service. A detailed development of clinical and social indications and contraindications for the admission, significantly increased the scope of conditions that can be treated in day hospitals and enabled patients with psychotic disorders, who maintain socially acceptable behavior and have the support of their family,<sup>5</sup> to receive treatment there. Other substitute forms of hospital care have been developed, such as home inpatient care.<sup>6</sup>

The essential role of psychosocial therapy and psychosocial rehabilitation as an obligatory component of psychiatric care at any stage of its provision including a day hospital,<sup>7</sup> was emphasized together with the importance of adequate and intensive psychopharmacotherapy. An important administrative decision — the introduction of social workers into the staff of psychiatric institutions and their subdivisions (psychiatric hospitals, day hospitals, neuropsychiatric

dispensaries), enshrined in the corresponding order of the Ministry of Health, was the logical result of this work and significant achievement of the department. This laid the foundation for comprehensive, polyprofessional healthcare for mentally ill. An important aspect of this approach was the consideration of psychosocial interventions not only as a tool to facilitate social adjustment, but also as an effective method of treatment.

The work of outpatient psychiatric facilities has significantly changed and their services have been tailored to the needs of the patients. The modern management of psychiatric patients in the dispensary was laid, the criteria for dispensary observation and the indications for withdrawal from it were developed and implemented.<sup>8</sup>

One of the research directions of the department were the issues of social adjustment and the rehabilitation of patients with chronic schizophrenia, which made up a significant part of the dispensary contingent. The features of clinical manifestations and social adjustment of patients with schizophrenia were studied at the stage of disorder stabilization, in an outpatient setting. As a result, a close relationship was highlighted between the clinical manifestations of the disease, forms of social adjustment and the conditions conducive to successful rehabilitation.<sup>9,10</sup>

It should be emphasized that all studies put the clinical approach at the forefront, based on a subtle diagnostic assessment of the patient, including both psychopathological analysis and the dynamics of the disease, as well as personality, psychological and social characteristics. For the first time in Russian psychiatry, the concept of quality of life was introduced into the analysis of the patients' condition; its features were described in various groups of patients, as well as its importance for social adjustment and psychosocial treatment and rehabilitation.<sup>11</sup>

The pharmacoepidemiological and pharmaco-economic aspects of the psychiatric care for patients with schizophrenia were studied for the first time.<sup>12</sup>

The Russian-Canadian disability program (1997–2007), which was organized by the staff of the Department of Outpatient Psychiatry and Organization of Mental Healthcare of the MRIP and the Department of Community Rehabilitation and Disability Studies at the University of Calgary (Canada) was the next step in the development of the clinical and social directions

in psychiatry. The principles of psychosocial therapy and rehabilitation, the interprofessional team management of patients, as well as individual case management were developed within the framework of the Russian-Canadian program. The staff of the Department scientifically substantiated the efficiency of methods, widely known abroad such as psychoeducation, compliance therapy and the training of social and cognitive skills.

The long-term cooperation of the Department with the University of Calgary facilitated the development of joint educational programs, a large number of specialists from the regions of Russia were trained in psychosocial therapy and the rehabilitation of patients, including internships in Canada. Together with the Moscow State Social University (MSSU), the course for social workers, "Social work in psychiatry", was developed.

### **CARE SYSTEM FOR SPECIAL PATIENT GROUPS**

A further development of the concept of psychosocial therapy and rehabilitation led to the study of clinical and social characteristics and the identification of the special needs of various groups of patients with schizophrenia. One of the most important areas of research was the study of the initial stages of psychotic spectrum disorders and, on this basis, the development of scientifically-grounded practical approaches to organizing care for patients with newly emerging psychotic conditions. Along with detailed descriptions of the clinical picture and therapeutic approaches in care, considerable attention was paid to the clinical and organizational aspects. As a result, the principles underlying the work of first episode psychosis departments (clinics), were established. After a series of educational seminars, similar clinics were opened in more than 30 regions of the Russian Federation. In fact, a reference system of mental healthcare at the initial stages of psychotic spectrum disorders was developed, including not only inpatient and day hospital treatment, but also the long-term follow up of patients. Its efficiency was proved, both from a clinical point of view and the social recovery of patients.<sup>13-15</sup>

Along with the first psychotic episode, considerable attention was paid to the study of the clinical features and the social functioning of patients with a chronic course of the disease, frequent and prolonged hospitalizations, as well as those who had lost social ties.<sup>16,17</sup> The efficiency of the complex community therapy of schizophrenic

patients, discharged after long-term hospitalizations, has been demonstrated, which, along with active pharmacotherapy, should include the psychoeducation of patients and their relatives, as well as training in self-care and independent living skills.<sup>18,19</sup> The efficiency of special rehabilitation programs was investigated using the example of the "Club House" model.<sup>20</sup> Various groups of patients with schizophrenia and schizophrenia spectrum disorders, receiving care as outpatients, were studied. The principles of complex community-based psychosocial therapy and rehabilitation were developed and implemented for each of these groups.<sup>21-23</sup>

An important element of the department's scientific activity was the study of socially vulnerable groups of patients with schizophrenia, and the development of adequate organizational forms of mental healthcare, tailored to their needs. These groups included patients with unstable social and labour adaptation, with frequent and very frequent hospitalizations, as well as lonely patients.<sup>24-28</sup>

The work was carried out in two directions: on the one hand, the psychological components surrounding the issues of loneliness, the disability of patients with schizophrenia and the stigma of mental illness were investigated and the main "targets" of psychosocial interventions for these patients were identified;<sup>29,30</sup> on the other hand, the efficiency of psychosocial work with this group of patients was demonstrated with the involvement of community resources, namely, the integrated social services centres.<sup>31</sup> The study of the social environmental factors and the immediate surroundings of patients with schizophrenia made it possible to develop and put into practice the methods of work with the family of patients with mental illnesses, known as compliance therapy.<sup>32</sup>

An important milestone in the development of community-based psychiatry was the organization of Russia's first association of psychiatric care consumers and their relatives, called "New Choices", with branches in more than 50 regions of the country.<sup>33</sup> This organization is now known as the All-Russian Public Organization of People with Mental Disabilities.

Such forms of transdisciplinary collaboration of psychiatric institutions, social protection services and public institutions, aimed at the re-integration of patients with mental illnesses into society, are now an essential part of community-oriented psychiatry.

## CONCLUSION

Thus, as a result of longstanding work, the concept of care for various groups of patients was developed, starting with the first manifestations of the disease and ending with cases of long-term, chronic disorders with a pronounced level of social maladjustment. As a result, a broad spectrum of new organizational forms of mental healthcare was proposed. In addition to the aforementioned first episode psychosis clinics,<sup>34</sup> medical rehabilitation departments (operating both within a hospital and in the community) were proposed and put into practice. Staffing, objectives, indications for referral and the methodology of work were developed. Furthermore, a completely new form of care for Russian psychiatry — intensive care departments for patients with the most severe symptoms, receiving care in a day hospital — was introduced.<sup>35-37</sup> These organizational forms were statutory enshrined in the Order of the Ministry of Health and Social Development of the Russian Federation No. 566n, "On approval of the procedure of medical care provision for mental and behavioral disorders", dated May 17th, 2012. To date, the aforementioned departments have been established in psychiatric services in many regions of the Russian Federation.

All these new organizational forms of psychiatric care are characterized by a significant proportion of psychosocial therapy and rehabilitation within the treatment course. This approach is based on a thorough study of psychosocial intervention targets and their therapeutic mechanisms. In this regard, the study of cognitive impairments in psychotic spectrum disorders, which play a decisive role in the social functioning, is essential.

The features of neurocognitive deficit and its dynamics were described in detail among patients with schizophrenia and schizophrenia spectrum disorders at different stages of the disease, and depending on the course type.<sup>38-41</sup> Much attention has been paid to the studies of social cognitive functions, resulted in development of the whole range of new pathogenetic-oriented approaches to psychosocial therapy.<sup>42,43</sup> An investigation into the negative symptoms of schizophrenia and their relationship with cognitive functioning has been carried out; new tools are being validated to assess social cognitions and negative symptoms.<sup>44,45</sup> The latest forms of cognitive remediation are tested in clinical units



(first episode psychosis clinic, medical rehabilitation department). Methodological developments in this direction have contributed to the introduction of a number of modern training programs into the practice, such as training on cognitive and social skills,<sup>46</sup> motivational training for patients with schizophrenia<sup>47</sup> and metacognitive training for patients with psychosis.<sup>48,49</sup>

The further development is associated with neurobiological studies, aimed at the identification of complex biomarkers for diagnostics and determination of biopsychosocial intervention tactics. This refers to the study of evoked potentials,<sup>50,51</sup> in particular, the study of facial expressions,<sup>52-55</sup> the study of oculomotor alterations in patients with schizophrenia spectrum disorders<sup>56</sup> and autoimmune disorders in newly emerging psychotic states.<sup>56-59</sup> In general, the task is to carry out a network analysis of the identified disorders.<sup>60-62</sup>

Thus, the research carried out at the present time preserves the tradition of an integrated clinical and social approach, on the basis of which organizational models of psychiatric services are proposed. An important advantage of this approach is the applicability of its results in healthcare practice, that is, the translational nature of scientific studies.

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# Community-Based Mental Health Services in Mexico

## Амбулаторная психиатрическая служба в Мексике

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### Short Communication

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### ABSTRACT

**AIM:** This article describes the general characteristics of community-based mental healthcare in Mexico.

**METHODS:** Data from national surveys, special studies and statistics from the national information system during the period 2001–2017 are used. Available information on health systems, new regulations and the innovations implemented are reviewed, as well as research on psychosocial interventions conducted within the country.

**RESULTS:** Data show a fragmented health system with services for workers and those without social security or private care. This is a treatment system essentially based on tertiary healthcare and not integrated into the general health system, with a significant treatment gap and delay in relation to the first treatment. At the same time, a slow but steady increase in the level of care provided at primary healthcare level and in specialized community services has been observed. This trend has been accompanied by an increase in the number of medical doctors, psychologists and, to a lesser extent, psychiatrists, incorporated into the primary healthcare services. At the same time, no new psychiatric hospitals have been built; there has been a proportional reduction in psychiatric beds but no increase in mental health services or beds allocated to first contact hospitals. Research initiatives have analysed the barriers to reform, and efficient interventions have been developed and tested for the community and for primary healthcare; special interventions are available for the most vulnerable but no formal efforts have been to facilitate their implementation.

**CONCLUSIONS:** Evidence is available regarding the implementation of the transition from reliance on tertiary healthcare to reinforced primary care. At the same time, parity, financial protection, quality and continuity of care remain major challenges.

### АННОТАЦИЯ

**ЦЕЛЬ:** В статье описываются общие характеристики амбулаторной психиатрической службы в Мексике.

**МАТЕРИАЛ И МЕТОДЫ:** Используются данные национальных опросов, специальных исследований и статистические данные из национальной информационной системы за период 2001–2017 гг. Приводится обзор доступной информации о системе здравоохранения, новых нормативных документах и внедренных инновациях, а также данные исследований психосоциальных интервенций.

**РЕЗУЛЬТАТЫ:** Данные отражают фрагментированность системы здравоохранения, с услугами для работников и для тех, кто не имеет социального обеспечения или частной помощи. Система медицинской помощи при психических расстройствах является в основном третичной помощью и не интегрирована в общую систему здравоохранения. Наблюдается отсутствие преемственности между первичной и специализированной помощью и задержка в оказании специализированной помощи. В то же время наблюдается медленное, но неуклонное повышение качества первичной медико-санитарной помощи и специализированной амбулаторной психиатрической помощи. Эта тенденция сопровождается увеличением числа врачей, психологов и, в меньшей степени, психиатров в службах первичной медико-санитарной помощи. При этом новых психиатрических больниц не построено; количество койко-мест в психиатрических больницах уменьшилось, но при этом не увеличилось количество психиатрических служб или койко-мест в больницах общего профиля. В рамках исследовательских инициатив были проанализированы препятствия на пути реформ, и были разработаны и протестированы эффективные вмешательства при оказании психиатрической помощи по месту жительства и для первичной медико-санитарной помощи; для наиболее уязвимых пациентов предусмотрены специальные меры, однако каких-либо формальных усилий по их внедрению не предпринималось.

**ВЫВОДЫ:** Имеются данные о реализации перехода от третичной психиатрической помощи к усиленной первичной медико-санитарной помощи. В то же время основными проблемами остаются обеспечение равенства при оказании помощи, финансовой защиты, качества и непрерывности медицинской помощи.

**Key words:** *mental disorders; treatment; community services; primary care; psychosocial interventions*

**Ключевые слова:** *психические расстройства; лечение; службы по месту жительства; первичная помощь; психосоциальные вмешательства*

## INTRODUCTION

The inclusion of mental health in the UN Sustainable Development Goals and the universal health coverage commitment adopted by countries, re-opened the debate on best practices in terms of closing the treatment gap between needs and the demand covered. This challenge posed in Alma Ata in 1978, namely, universal health coverage through primary care,<sup>1</sup> has not been met around the globe<sup>2</sup> and Mexico is no exception. The prevailing treatment paradigm, based on tertiary healthcare has failed and there is a large treatment gap in relation to both primary and specialized care (for example, only 19% of people with a mental condition and 49% of people with a substance use dependency have access to any care).<sup>3,4</sup> This situation is compounded by the fact that those who are most at risk from mental health problems are usually those with the least access to services (i.e., families living in poverty, children exposed to abuse or neglect,

minority groups or elderly people). Accordingly, a significant proportion of the population is excluded from mental healthcare.<sup>5,6</sup>

## GENERAL HEALTHCARE SYSTEM IN MEXICO

The Mexican healthcare system comprises two sectors: public and private. Public services include social security institutions, which provide services for workers in the formal sector of the economy (IMSS) and the government (ISSSTE, PEMEX and others), and institutions that deliver services to those without social security. The private sector provides services for those with the capacity to pay.

Social security institutions are financed by government, employer and employee contributions, covering both employees and their families; students from public institutions, from 7th grade to postgraduate level receive free health services from these institutions.<sup>7</sup> Services for the general population, not affiliated to any labour



insurance, including freelance workers, those working for the informal economy, the unemployed, etc.), were funded by federal and state governments through the Popular Insurance Scheme, established in 2003. This scheme provided services for 40% of the population without medical insurance;<sup>8</sup> a small contribution was paid by users when receiving care (recovery fees depending upon the income level).<sup>7</sup> This system was substituted in 2019 by a new Institute of Health for Wellbeing (INSABI), which is still in the development stage. The private sector is financed through payments made by users when they receive care and through private health insurance premiums.<sup>7</sup>

The last available national health survey<sup>9</sup> reported that 61% of outpatient consultations were provided by the public sector and 38.9% by the private sector, whereas only 17% of users of inpatient hospital services benefitted from services at private hospitals.

A recent report on Public Health and Primary Care,<sup>10</sup> shows that despite significant reforms, key challenges remain. The National Health Survey<sup>9</sup> showed that 21% of the population had no insurance, while a subsequent survey revealed that 87% of the population from the lowest socioeconomic level lacked access to health services. It has also been estimated that 49% of health expenditure is private and that over 90% corresponds to out-of-pocket expenses, mainly for outpatient care and medicines.

### **THE HISTORY OF MENTAL HEALTH SERVICES**

Mental health services have been provided at psychiatric institutions since 1566. For many years, treatment was based in psychiatric hospitals, with little investment in rehabilitation or community care.<sup>11</sup> Mexico was one of the few countries to participate in the World Mental Health Survey,<sup>12</sup> which demonstrated that it is one of the countries with more people seen at the tertiary care level than at the primary care level.<sup>13</sup> Thus, latency in receiving care is high: 14 years for depression as opposed to one year in Spain.<sup>14,15</sup>

Primary care services for mental health also have a long history. The Mexican Institute of Social Security (IMSS) recognized the need for family doctors in 1954, however, it was not until 1971 that the specialization of family medicine was created, with a focus on primary care (86% of its services). Psycho-affective disorders are among the 10 leading reasons for consultation.<sup>16</sup>

For persons not affiliated to the IMSS, primary care services were formalized in 1959 after the Ministry of Health established the General Directorate of Neurology, Mental Health and Rehabilitation. This, in turn, created the Mental Hygiene Services, incorporated into primary care centres in Mexico City, with preventive actions and first contact care, and a referral system to specialized services. The staff was multidisciplinary with a psychiatrist, psychologist, and social worker. This initiative was not widespread and by 1964 only 16 such services had been established, 10 in Mexico City and six in various states. In the 1980s and 1990s, the federal authorities overhauled the health sector, reducing the budget and the range of services, including mental healthcare.<sup>17,18</sup>

The Ramón de la Fuente National Institute of Psychiatry, a national health institute with research, education and clinical services was inaugurated in 1979. Research into the epidemiology of mental disorders, neurosciences, as well as clinical and psychosocial aspects led to culturally adapted interventions. Emphasis was placed on the more vulnerable and new models were tested in communities, primary care and specialized services.<sup>19,20</sup>

Mental health was included in the Popular Insurance Scheme via payment to each state, depending on the local quota per affiliated family. In 2007, prevention (e.g., early detection and brief advice for addictions), screening and treatment (pharmacological and psychotherapeutic) for various mental health disorders were included. The number of disorders covered increased over time and by 2018, the scheme covered autism, depression and other mood disorders, as well as psychosis.<sup>21</sup> Unfortunately, this was not fully implemented as a primary care referral to tertiary level was required, among other reasons, with limited hospitalization days and a re-referral to primary care for the continuity of care; care for severe depression was only provided in general hospitals, but the institutions were not ready to identify or treat those with mental disorders; as a result the provision for mental disorders was poor. The health budget in 2017 was \$2.586 million pesos or just over \$1.00 per capita, while in high-income countries it was, on average, \$58.73.22 When the Popular Insurance Scheme was established, public expenditure on mental health increased from 0.3% to 0.7%, then declined continually to a level of 0.3% by 2017. Although the new government has announced the implementation of a new program



to replace the former Popular Insurance Scheme and has committed to universal coverage, there has been a significant reduction in the health budget since 2019. However, patients with mental disorders, who receive treatment in public institutions, are beginning to have access to free medication (<https://ciep.mx/presupuesto-para-salud-mental-relevancia-ante-la-covid19/>).

The trend is shifting care delivery from psychiatric institutions to community-based services, and there has been a growing involvement of primary healthcare.<sup>23</sup> In 2012, 42 specialized medical units for ambulatory care were opened in 20 states. In 2018, before the COVID-19 pandemic, 51 units were operating in 22 of the 32 Mexican states.<sup>24</sup> Three hundred and ten centres were also opened for the prevention and treatment of substance use disorders, yet despite the common comorbidity,<sup>25</sup> mental healthcare was not included in their mandate initially;<sup>26</sup> however, in 2019 a reform mandated treatment of mental and substance use disorders in both systems. A third organization, Juvenile Treatment Centres (CIJ) for substance use disorders, with 120 community centres, also included mental health treatment. Today, the three organizations are united within a network that has amplified health coverage significantly.

Unfortunately, there is still no formal referral system for mental disorders among the different levels of care. Individuals seen at primary care level are often referred to the tertiary level without treatment. This is primarily because primary level medical consultations are usually brief and focus on treating somatic symptoms, making the detection and treatment of chronic disorders more difficult. This is compounded by the lack of collaboration between primary care staff (mainly general and family doctors, nurses, psychologists and social workers) and mental health specialists, and the lack of trained human resources to deliver mental healthcare, including psychiatrists.<sup>5,27</sup>

The country has also made significant progress in formulating laws, policies and programs to improve community mental healthcare, which comply with international human rights guidelines and are periodically reviewed. However, these have only been partially implemented. In this respect, the seventh chapter of the Mexican General Health Law stipulates the characteristics of mental healthcare. Likewise, certain states, including Mexico City, have a specific mental health law, stating

that the prevention and care of mental illness is a priority for the government. In recent years, various initiatives have been submitted to the Senate and the Chamber of Deputies to establish a National Mental Health Law, aimed at promoting community services, strengthening primary healthcare, outpatient care and coordination with hospitalization systems.

## **GENERAL CHARACTERISTICS OF THE MENTAL HEALTH SYSTEM**

Mexico allocates 2.2% of the total health budget to mental health services, eight times lower than the proportion of the global burden of disease, estimated for mental health disorders (16% of the total days lost for premature mortality and days lived without health; conversely, 80% is spent in the tertiary care sector).<sup>5,23,28</sup> To serve a population of 129.2 million inhabitants, there are 39 psychiatric hospitals in Mexico, 34 of which are funded by the Ministry of Health and five by the National Institute of Social Security. These psychiatric hospitals provide care for workers and families with mental disorders, with an organized referral system, yet characterized by significant treatment delays. Services for government workers provided by ISSSTE are delivered by the public sector and 89% of hospitals are located in major cities.

Psychiatric hospitals have extended outpatient services. Although patients can be referred by other hospitals or primary healthcare workers, they usually seek outpatient and inpatient care at psychiatric hospitals without a referral. Only 2% of the beds are in general hospitals. There are 1649 mental health community services, 467 of which were developed as part of the initiative to bring specialized outpatient services to the community, known as UNEMES, and 1169 primary care units within the mental health service.

In 2017, 3.3 million medical consultations were provided by the Ministry of Health for individuals without social security (1.2 million, nearly a third, were provided by the Popular Insurance Scheme) and for those with social security, as mental health services in this sector are limited. Of the total number of medical consultations by the Ministry of Health, 24.8% were provided in the outpatient services of psychiatric hospitals and 20.7% by other specialized hospitals, with a total of 45.5% being provided at tertiary care level. Approximately the same proportion (45.4%) was provided in outpatient mental health services (of which 28.4% were provided in general

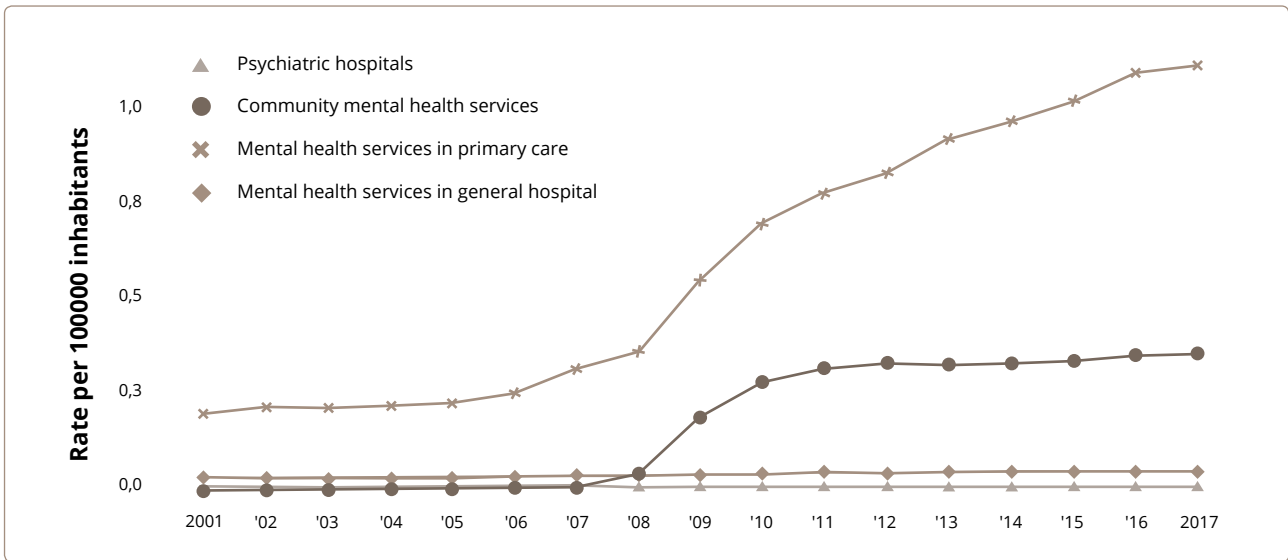


Figure 1. Trends in the availability of Mental Health Services

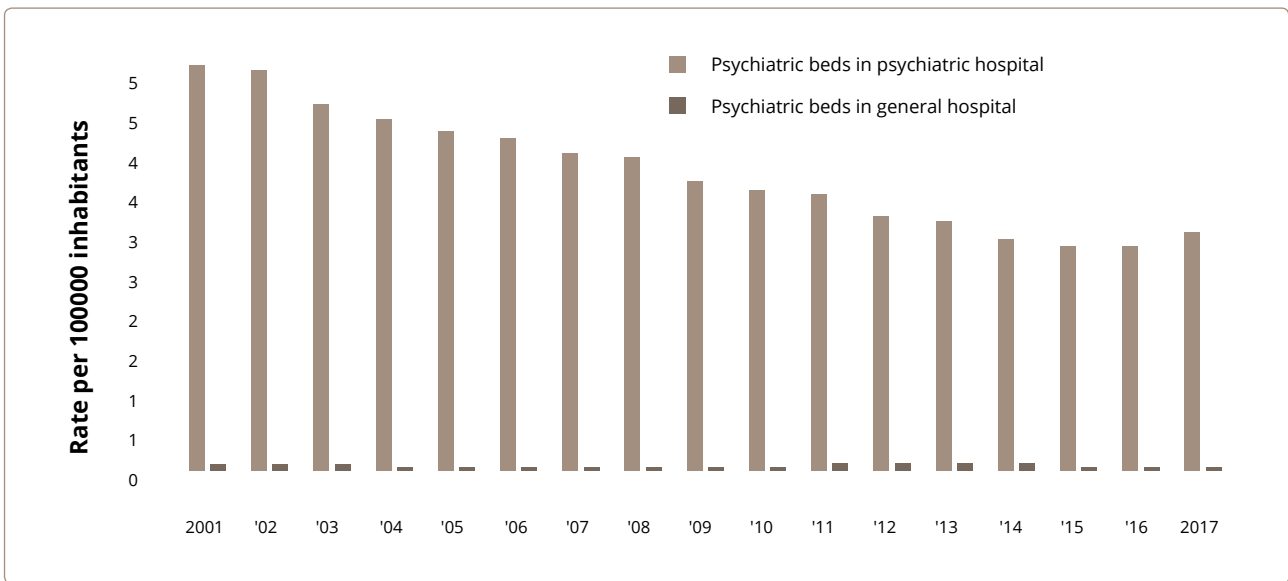


Figure 2. Trends in the distribution of beds and psychiatric services

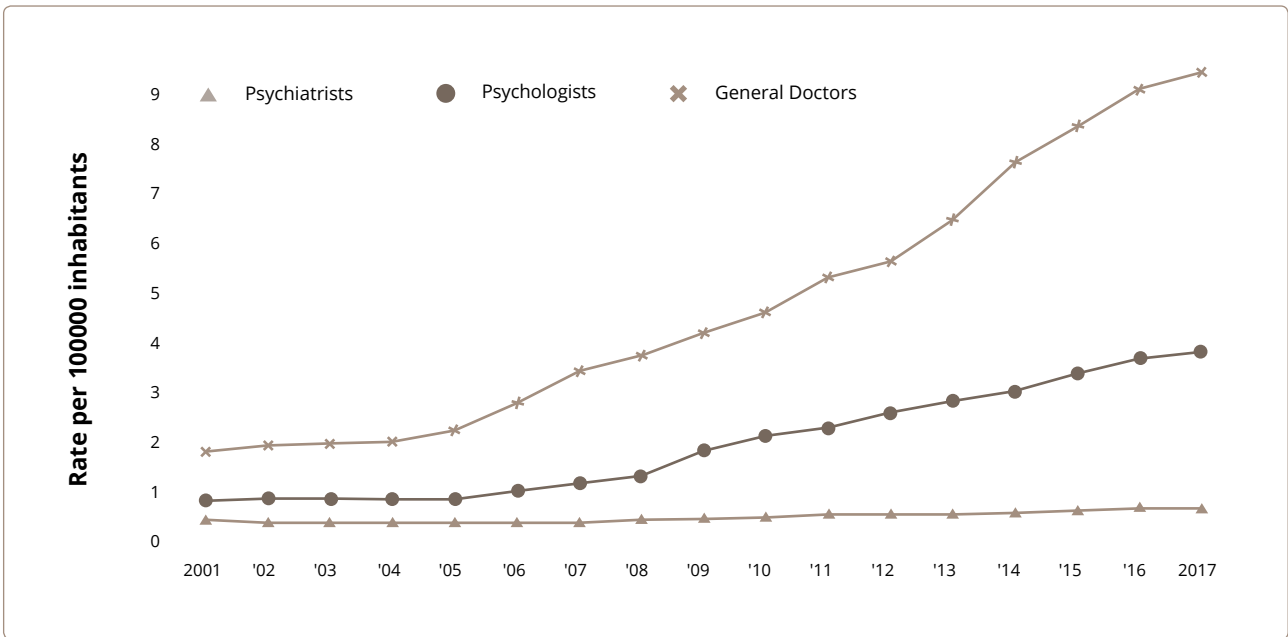
health centres with mental health services and 17% at outpatient mental health clinics), an important shift since 2010, when only 38.3% of medical consultations were provided by outpatient mental health services. In 2017, only 8% were provided in general hospitals with mental health services.

Trends in mental health services can be observed within the units run by the Ministry of Health. Data show a sustained increase in primary health units with mental health services (rising from 0.2 per 100,000 inhabitants in 2001, to 1.1 per 100,000 inhabitants in 2017). Since 2008, there has also been an increase in mental health

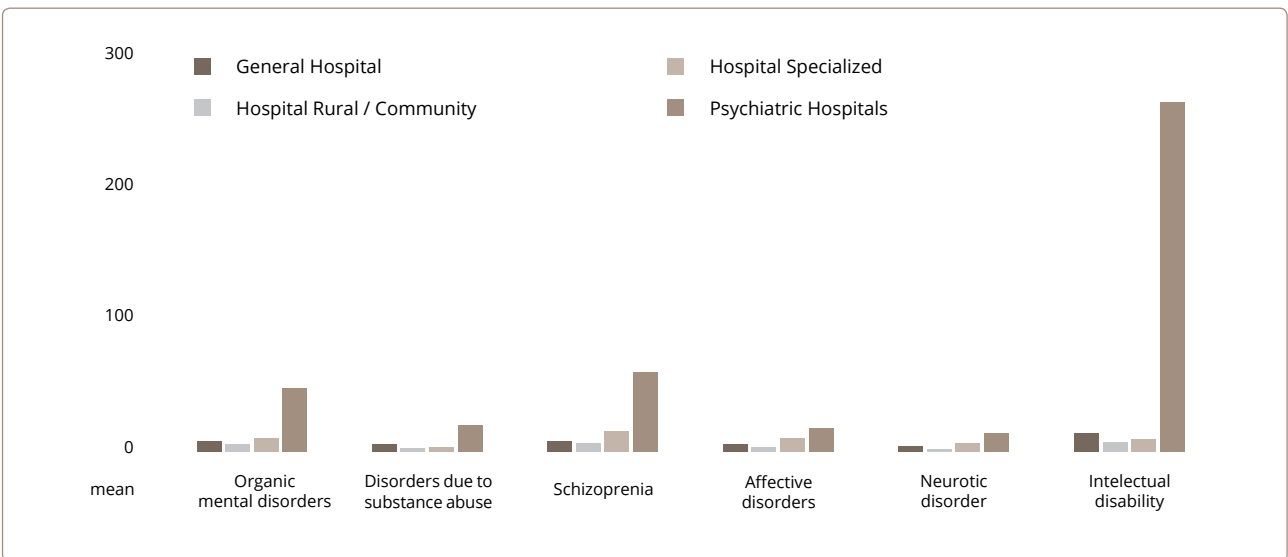
community services (from 0.1 per 100,000 inhabitants in 2008 to 0.4 per 100,000 inhabitants in 2017) (Figure 1).

The number of psychiatric hospitals has remained stable (with 0.03 hospitals per 100,000 inhabitants). Although the number of beds in psychiatric hospitals decreased from 5.07 to 2.98 per 100,000 inhabitants, psychiatric beds in general hospitals did not increase (Figure 2).

Coinciding with this trend in services, human resources have also increased. From 2001 to 2017, within the services coordinated by the Ministry of Health, the number of psychiatrists rose from 0.5 to 0.7 psychiatrists



**Figure 3. Human Resources in Mental Health Services**



**Figure 4. Average of inpatient days in hospital due to mental**

per 100,000 inhabitants; GPs working in mental health services increased fivefold (from 1.9 to 9.5), while the number of psychologists increased fourfold from 0.9 to 3.9 psychologists per 100,000 inhabitants (Figure 3).

From 2010 to 2017, outpatient mental health in primary care accounted for 38.5% of all outpatient consultations, reaching 45.4% in 2017 (primary care units within the mental health service rose from 22.5% to 28.4%, while community mental health units increased from 15.8% to 17.0%). Conversely, outpatient care at highly

specialized hospitals decreased from 21.5% to 20.7%, while outpatient care at psychiatric hospitals fell from 29.3% to 24.8% during this period.

More than half of all hospital discharges (62%), due to mental and behavioral disorders were from psychiatric hospitals, 24% were from general hospitals, 9.1% were from specialized hospitals and 4.4% from rural hospitals.

Inpatient care days varied according to the type of disorder and the characteristics of the care services. Psychiatric hospitals had the longest stays of all services

for all disorders, except for personality disorders, the duration of which was the same in psychiatric hospitals and specialized hospitals. Intellectual disability involved the lengthiest stays (from 263 days in psychiatric hospitals to 6.6 days in hospitals located in rural communities) (Figure 4).

### **GENERAL CHARACTERISTICS OF COMMUNITY-BASED MENTAL CARE IN MEXICO: INTERVENTIONS**

The delivery of community-based mental care takes place in schools, workplaces and through the families of the most vulnerable. The treatment developed and tested by the National Institute of Psychiatry (INPRFM) includes programs for those with mental disorders and their families,<sup>31</sup> on-line interventions for depressed females who have not sought help<sup>32</sup> (assistance) to reduce substance use and depression symptoms,<sup>33</sup> interventions for families with alcohol-related problems in indigenous populations,<sup>34</sup> prevention of violence among young people<sup>35</sup> survivors of violence, street children and youth, prison populations, sex workers, migrants, those living in unsafe communities, indigenous groups, as well as communities living in poverty.<sup>36</sup>

The principal, evidence-based psychological interventions that have proven to be effective in Mexico include cognitive-behavioral techniques (such as behavioral activation, relaxation training for anxiety and identification, and modification of automatic thoughts related to depression and anxiety), implemented in rural community health settings,<sup>37</sup> as well as problem-solving therapy,<sup>38,39</sup> stress reduction based on mindfulness training<sup>40</sup> and stress management for mental health professionals.<sup>41</sup>

There have also been local efforts to complement pharmacological and psychological interventions, designed to address the contextual sources or social determinants of mental health problems (such as underemployment, inadequate housing, food insecurity, and violence) through the collaborative work of primary care providers (PCP) and promoters (trusted community members, who deliver health-related services).<sup>42</sup>

Initiatives to help general practitioners overcome the barriers of lack of time and expertise, as well as the evaluation and management of common mental disorders observed in the primary care setting (i.e., depression, anxiety and unexplained medical symptoms) have been implemented and evaluated in Mexico (including very brief screening tools, training packages on

WHO-mhGAP guidelines and manualized psychological interventions).<sup>43,44</sup>

### **STRENGTHS, WEAKNESSES AND FUTURE DEVELOPMENTS**

It is true that public policies exist to guide actions designed to care for the community and that significant progress has been made in the development of community-based care services. However, although some progress has been observed in terms of a greater participation in primary care, the treatment for mental disorders remains within specialized services (tertiary care), specifically psychiatric hospitals. These hospitals remain responsible for a large proportion of outpatient care and nearly all hospitalizations. The shift towards a paradigm of more community than hospital care has been hampered by the lack of an integrated policy and an insufficient, poorly optimized budget.

A clear example of these conditions is the low availability of psychotropic drugs in primary healthcare, forcing people to buy them out of pocket, which either has a major impact on a family's finances and/or prompts the decision not to take the medication. Low priority is attributed to mental health because in many cases, it is still considered the exclusive domain of specialists in the mental health sector. Many patients with mild disorders, which are under control and can be treated in primary healthcare, are referred to psychiatric hospitals.

It is essential to allocate more financial resources and to distribute them more effectively to enhance community mental health. Likewise, care models with successful results should be promoted, taking into account the impact of social, cultural and environmental factors on mental illness.

One of the elements that has worked least well in Mexico is the participation of patients in the community. Self-management is rarely promoted, and actions taken by community members are not fully exploited, such as linking MH services with the population by recommending available social networks. It is necessary to promote actions to expand and coordinate the participation of community members and patients, encouraging them to take care of their mental health and helping them recognize when to seek services. The World Health Organization also recommends the participation of patients and family members in the planning and

implementation of policies, and the monitoring and provision of services.

Likewise, to improve the delivery of community services in Mexico and to achieve a model, such as that proposed by the WHO, it is essential to strengthen communication and collaboration between the various platforms<sup>45</sup> and to set up continuous monitoring systems. This link between the community and the health system will facilitate the identification of cases, care seeking and the timely referral to treatment.

One of the challenges is to achieve a paradigm shift whereby mental healthcare is not only the responsibility of psychiatrists and psychologists. The results of various investigations confirm that other health professionals (nurses, social workers) and even those from the same community could carry out mental health promotion activities, as well as the detection and care of certain mental disorders, with the appropriate training, supervision and continuous support from mental health specialists.

## CONCLUSIONS

A small but steady increase in services and human resources (more GPs and psychologists) in primary healthcare and specialized community services was observed. This shift is an important step towards reducing the treatment gap.

The challenge for the population that does not have a severe psychosocial disability, is to assess the scope of these actions to reduce the treatment gap for mental disorders, and to ensure the quality and continuity of care. We are convinced that Mexico can build a mental healthcare model that will improve the quality of life of the population, by integrating mental healthcare across the lifespan into the health system, with coordinated actions in various sectors, including civil society organizations.

No additional psychiatric hospitals have been built and the number of beds at these institutions has declined. Unfortunately, there has not been an increase in the number of beds or mental health services in general hospitals. A significant proportion of persons with mental disorders are in jail.<sup>46</sup> Those with a severe intellectual disability and to a lesser extent, schizophrenia and other psychoses, are abandoned in the isolation wards of long-stay psychiatric hospitals. This calls for an urgent program of deinstitutionalization to smaller units, with the necessary services to protect the human rights of this population, together with a new system to guarantee

continuity of care, housing and labour facilities, so as to integrate those with psychosocial disabilities into the community.

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# Community-Based Mental Health Services in India: Current Status and Roadmap for the Future

Внебольничные службы психиатрической помощи в Индии: текущее состояние и перспективы на будущее

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Short Communication

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## ABSTRACT

An estimated 197.3 million people have mental disorders in India, and majority of the population have either no or limited access to mental health services. Thus, the country has a huge burden of mental disorders, and there is a significant treatment gap. Public mental health measures have become a developmental priority so that sustainable gains may be made in this regard. The National Mental Health Program (NMHP) was launched in 1982 as a major step forward for mental health services in India, but it has only been able to partially achieve the desired mental health outcomes. Despite efforts to energize and scale up the program from time to time, progress with development of community-based mental health services and achievement of the desired outcomes in India has been slow. Public health measures, along with integration of mental health services in primary healthcare systems, offer the most sustainable and effective model given the limited mental health resources. The main barriers to this integration include already overburdened primary health centres (PHCs), which face the following challenges: limited staff; multiple tasks; a high patient load; multiple, concurrent programs; lack of training, supervision, and referral services; and non-availability of psychotropic medications in the primary healthcare system. Thus, there is an urgent need for a fresh look at implementation of the NMHP, with a focus on achieving sustainable improvements in a timely manner.

## АННОТАЦИЯ

По оценкам, в Индии 197,3 миллиона человек страдают психическими расстройствами, при этом большинство населения страны или вовсе не имеет возможности обратиться к службам психиатрической помощи, либо его доступ к ним ограничен. Таким образом, в стране прослеживается колоссальное бремя психических заболеваний при наличии существенной разницы между общим числом случаев возникновения рассматриваемых расстройств и количеством людей, получающих необходимое лечение. Меры профилактики психических заболеваний среди широких масс населения стали приоритетным направлением развития, ввиду чего в данной области можно ожидать долгосрочных успехов. В 1982 году была запущена Национальная программа психического здоровья (НППЗ) – важный шаг вперед в области развития служб психиатрической помощи Индии, который, однако, лишь отчасти смог достичь желаемых результатов в соответствующей области. Несмотря на все усилия по ускорению и оперативному расширению программы, прогресс в развитии внебольничных служб психиатрической помощи в Индии оказался недостаточным, а желаемые результаты не были достигнуты. Меры общественного здравоохранения, наряду с внедрением служб психиатрической помощи в систему

первичной медико-санитарной помощи, предлагают наиболее устойчивую и эффективную модель с учетом ограниченных ресурсов специализированной психиатрической службы. Основным препятствием на пути такого внедрения является перегруженность центров первичной медико-санитарной помощи (ПМСП) и следующие проблемы, с которыми сталкиваются данные центры: ограниченное число персонала, чрезмерно широкий спектр задач, большое количество пациентов, одновременное проведение ряда различных программ, отсутствие профессионально подготовленных медицинских специалистов, надзорных и справочных служб и нехватка психотропных препаратов в системе первичной медико-санитарной помощи. Таким образом, существует острая необходимость в новом подходе к реализации НППЗ с фокусировкой на как можно более быстрое улучшение ситуации.

**Keywords:** *community psychiatry; India; low- and middle-income countries (LMICs); public health; mental health services*

**Ключевые слова:** *внебольничная психиатрия; Индия; страны с низким и средним уровнем дохода (СНСД); здравоохранение; службы психиатрической помощи*

## **INTRODUCTION**

Estimates made by the World Health Organization (WHO) suggest that mental and behavioral disorders account for around 12% of the global burden of disorders.<sup>1</sup> It has been suggested that this may be an underestimation, considering the interconnectedness between mental illness and other socioeconomic conditions, especially in low- and middle-income countries (LMICs), which account for almost three quarters of the global burden of mental and behavioral disorders.<sup>2,3</sup> An estimated 197.3 million people have mental disorders in India.<sup>4</sup> Additionally, there is a significant treatment gap present in both developed and developing countries, with the vast majority of patients in LMICs lacking any access to treatment facilities for mental and behavioral disorders.<sup>2</sup> Thus, public mental health measures have become increasingly important and should be a development priority, especially in LMICs, including India.<sup>5</sup> Progress in this regard can be assessed according to the following criteria: presence of an official mental health policy; programs or plans for mental health; budgetary allocations; a dedicated mental health workforce; availability of essential psychotropic medications in primary care; increased treatment coverage; reduced suicide rates; and protection of the human rights of those who are mentally ill.<sup>3</sup>

## **HISTORICAL PERSPECTIVES OF COMMUNITY MENTAL HEALTH IN INDIA**

Historically, in India, psychiatric patients have been cared for by family members in the community, in the absence of formal community psychiatric services. Community psychiatry barely existed in British India. The first psychiatric outpatient service, the precursor to present-

day general hospital psychiatric units (GHPUs), was set up at the R.G. Kar Medical College, Calcutta, in 1933, by Ghirindra Sekhar Bose. This was followed by similar set-ups in Bombay (1938) and Patna (1939). However, for both mental health and general healthcare, many people did not have access to Western medical institutions and relied either on the traditional sector or Western-trained private practitioners.<sup>6</sup>

The spread of community services can be traced back to the early 1950s in India. While there was a drive for deinstitutionalization in the Western world (based on the principle that humans have the right to be cared for in the community), institutionalization was not a major issue in India as there were few psychiatric beds available in hospitals.<sup>7</sup> Thus, an important difference between the West and India, regarding development of community services, was that in India, this approach was supported primarily to make up for inadequate hospital-based services, rather than out of concern for human rights per se.

One of the earliest experimentations in community care (in 1952, before the advent of formal services) involved making provision for family members to stay with patients in tents on hospital premises during treatment, due to a shortage of available beds for admission to mental hospitals (an initiative instigated by Dr Vidya Sagar in Amritsar).<sup>7</sup> In later decades, many new initiatives were introduced, which laid the foundations for community psychiatry in India. In 1964, a weekly community mental health service was started as part of the Comprehensive Rural Health Services Project (CRHSP), in Ballabgarh, by the All-India Institute of Medical Sciences (AIIMS), New Delhi. This was followed

by establishment of two important community mental health services in the late seventies. WHO funded the project at Raipur Rani in Haryana under the aegis of the Postgraduate Institute of Medical Education and Research (PGIMER), Chandigarh. Further community mental health services were introduced in Sakalwada, Karnataka, under the aegis of the National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore.<sup>7</sup> These programs were the forerunners of the National Mental Health Program (NMHP) in India, which now includes community clinics in primary health centres (PHCs), supported by mental health professionals at district level, training of medical and multipurpose health workers, school mental health initiatives, home-based follow-up services by nurses and organization of psychiatric 'camps'.

### **NATIONAL MENTAL HEALTH PROGRAM (NMHP)**

The National Mental Health Program (NMHP) was launched in 1982 as a major step forward for mental health services in India. It had three key objectives, including ensuring the availability and accessibility of a minimum level of mental healthcare for all, encouraging the application of mental health knowledge in general healthcare and promotion of community participation in the development of mental health services. Despite this being a ground-breaking initiative, the initial phases of implementation of the program were marred with difficulties. Various factors contributed to initial shortcomings like unrealistic targets; inadequate staff resources; inefficient administration; failure to develop indicators for addressing objectives; an inadequate emphasis on creating awareness among users; uncoordinated, fragmented efforts by various stakeholders; and inadequate budgetary support.<sup>7</sup> Notwithstanding these flaws, one of the important achievements of the program during its first decade was recognition of a district-based model for provision of mental health services, with satellite primary health centres (PHCs) providing mental health services (based in the Bellary district in Karnataka state).<sup>8</sup> This district model was subsequently expanded to cover four districts. The program was re-strategized in 2003 to include two schemes, namely 'Modernization of State Mental Hospitals' and 'Up-gradation of Psychiatric Wings of Medical Colleges/General Hospitals', to act as hubs, supporting mental health services in the community. The manpower development scheme (aimed at achieving mental health human-resource sufficiency) became

part of the program in 2009. Under the first scheme, 15 existing mental hospitals/institutes/medical colleges were upgraded to start/strengthen courses in psychiatry, clinical psychology, psychiatric social work, and psychiatric nursing. Under the second scheme, 39 departments in 15 government medical colleges/government mental hospitals were given support to start/increase their intake of students for postgraduate (PG) courses in mental health.<sup>9</sup>

### **DISTRICT MENTAL HEALTH PROGRAM (DMHP)**

The District Mental Health Program (DMHP) forms the core of the mental health services available at community level. The DMHP was launched as an extension of the NMHP in 1996, building on the success of the Bellary model in Karnataka, based on the realization that mental health services should primarily be dispensed through existing primary health facilities as creation of a parallel infrastructure for mental health was not immediately feasible, considering the prevailing (severe) limitations of mental health infrastructure and manpower. Thus, existing staff in these primary health centres (PHCs), like doctors and paramedical workers, were trained to provide mental health services. The National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru, provides medical officers with three months' training to equip them with the skills and knowledge necessary to treat psychiatric disorders at the primary level.<sup>10</sup> There is also provision for referral services so that patients suffering from severe mental disorders can be directed to district hospitals.<sup>7</sup> Table 1 lists the components of the DMHP.<sup>9</sup>

In the period up to 2002, the DMHP was gradually extended to 25 districts across 20 Indian states.<sup>11</sup> As of now, 241 districts (out of 718 districts in India)<sup>9</sup> are covered under the scheme, and it is proposed that the DMHP be expanded to all districts in a phased manner. The population of various districts in India is highly variable, with a range from 0.008 million (in the least populated) to 11 million (in the most populated).<sup>12</sup> The average population of districts in India in 2019 was 1.86 million (as per the Indian census).<sup>13</sup> The National Mental Health Survey (NMHS) 2015–16 found the overall weighted prevalence for any mental morbidity in India to be 13.7% over a lifetime (then averaging 10.6%) and that (at the time of the survey) there was a large treatment gap.<sup>14</sup> This translates into very high numbers of individuals requiring

**Table 1. Components of the DMHP**

<b>District Mental Health Program:</b>	
Service provision: provision of mental health outpatient and inpatient mental health services, with a 10-bed inpatient facility	
Outreach component	<ol style="list-style-type: none"> <li>1. Satellite clinics: four satellite clinics per month at community health centres (CHCs)/ primary health centres (PHCs) by the DMHP team</li> <li>2. Targeted interventions</li> <li>3. Life-skills education and counselling in schools</li> <li>4. College counselling services</li> <li>5. Workplace stress management</li> <li>6. Suicide prevention services</li> </ol>
Sensitization and training of health personnel (at district and subdistrict level)	
Awareness camps to promote awareness of mental illnesses and related stigma, through involvement of local Panchayati Raj Institutions (PRIs), faith healers, teachers, leaders, etc.	
Community participation	<ol style="list-style-type: none"> <li>1. Links with self-help groups, family and caregiver groups, and nongovernmental organizations (NGOs) working in the field of mental health</li> <li>2. Sensitization of enforcement officials regarding legal provisions for effective implementation of the Mental Health Act</li> </ol>

psychiatric services in these districts, which might be difficult to achieve even with universal coverage under the NMHP across all districts in India. Additionally, most of the population may have to bear the cost of out-of-pocket payments for mental health services as DMHP services with limited manpower may struggle to meet the mental health requirements of these populations, especially in overpopulated districts. Table 2 lists the manpower allocation for the DMHP.<sup>9</sup>

**NATIONAL MENTAL HEALTH POLICY**

A robust and comprehensive mental health policy is important to drive the growth of mental health services and systems.<sup>15</sup> The National Mental Health Program (1982) and the Mental Health Act (1987) provided the implicit policy directions for community and institutional mental healthcare in India until recently. India’s Mental Health Policy group was formed in May 2011. The National Mental Health Policy of India, entitled ‘New Pathways, New Hope’, was published by the Ministry of Health and Family Welfare, Government of India, in October 2014.<sup>16</sup> The policy is inclusive in nature and incorporates an integrated, participatory, rights- and evidence-based approach, encompassing both medical and nonmedical aspects of mental health. The strategic areas identified for action are as follows: effective

**Table 2. Manpower for the DMHP**

<b>S.No.</b>	<b>Manpower (on a contractual basis)</b>	<b>Number of positions</b>
1	Psychiatrist	1
2	Clinical Psychologist	1
3	Psychiatric Nurse	1
4	Psychiatric Social Worker	1
5	Community Nurse	1
6	Monitoring and Evaluation Officer	1
7	Case Registry Assistant	1
8	Ward Assistant/Orderly	1

governance and accountability; promotion of mental health; prevention of mental disorders and suicide; universal access to mental health services; enhanced availability of human resources for mental health; community participation; and research, monitoring and evaluation. It stresses delivery of mental health services within the existing healthcare system, using the primary healthcare approach, based on principles of universal access, equitable distribution, community participation,

intersectoral coordination and use of appropriate technology. It also recognizes that these services should be comprehensive and should address the needs of persons with mental illness, their care providers and healthcare professionals.

## **LEGISLATION**

Dedicated mental health legislation legally reinforces the goals of mental health policies and plans.<sup>17</sup> Legislation is also important to prevent abuse and violation of the rights of patients with mental illness. As early mental health legislation was primarily drafted to safeguard the public from dangerous patients (by isolating such patients), the welfare of the patients themselves was always a secondary consideration. As a paradigm shift has occurred globally, towards a more rights-based approach for persons with a disability, including a mental disability (e.g., UNCRPD, 2006),<sup>18</sup> the same principle is reflected in mental health legislation (i.e., the Mental Healthcare Act) (MHCA 2017), which superseded the Mental Health Act (MHA 1987). The new act is progressive and rights-based, but it mainly focuses on the rights of persons with mental illness during treatment in hospital, with limited discussion of the continuity of treatment in the community and the role of the family and community in management of individuals with mental illnesses.<sup>19</sup>

The MHCA 2017 has been criticized for failing to address Indian cultural sensitivities related to the involvement of families in treatment decisions.<sup>19</sup> Families are a key resource for management in Indian society due to the cultural tradition of interdependence, and treatment teams also depend heavily on the active involvement of family members.

Mental health legislation must engage and work in tandem with legislation for people with disabilities, e.g., the Rights of Persons with Disabilities Act, 2016<sup>20</sup> and the National Mental Health Policy of India (2014).<sup>16</sup> The Rights of Persons with Disabilities Act, 2016 includes mental illnesses, and it stresses full and effective participation and inclusion in society, nondiscrimination, accessibility, equality of opportunity and protection of the rights of individuals with disabilities.<sup>20</sup> In LMICs (including India) where most people live in poor socioeconomic conditions, greater benefits and welfare measures like job preservation and housing schemes for patients with mental illness are needed.

## **OTHER APPROACHES TO COMMUNITY MENTAL HEALTH IN INDIA**

Other significant approaches to community mental health in India include the camp approach, school mental health, NGO initiatives, media-based interventions, and telephone helplines.

There has been a long tradition of the camp approach for people living in remote areas with limited access to health services. The duration of these camps can vary, but most usually remain for a day in areas accessible by car or several days in places with limited access by road. The camp approach has been used to treat a range of mental health conditions (including addictions) and has also been utilized in times of natural disasters.<sup>7</sup>

Initiatives in school mental health have included a life-skills education program for children and adolescents, with sensitization training for schoolteachers, focused on mental health problems prevalent in children and adolescents.

Nongovernmental organizations (NGOs) have been engaged in delivering mental health services with innovative models, to address the needs of local populations. There is also provision within the National Mental Health Program (NMHP) for state governments to execute activities relating to mental health in partnership with nongovernment organizations/agencies.<sup>9</sup>

## **IMPACT OF COMMUNITY MENTAL HEALTH SERVICES**

The availability of studies considering long-term trends in prevalence rates of various psychiatric disorders in the Indian population is limited. These studies provide indirect and limited information about the performance of various mental health initiatives which have been implemented in the Indian population over previous decades. Early epidemiological studies in India reported variable prevalence rates for psychiatric conditions, thus impacting on planning, funding, and delivery of mental healthcare facilities.<sup>21</sup>

The National Mental Health Survey (NMHS) 2015–16 suggested that the overall weighted prevalence for any mental morbidity in India was 13.7% over a lifetime and 10.6% at the time of the survey.<sup>14</sup> It also found a very high treatment gap of between 70% and 92% for different disorders, including 85% for common mental disorders, 73.6% for severe mental disorders and 75.5% for psychosis, among others.<sup>14</sup> There have been suggestions



about an increase in the crude prevalence and disability-adjusted life-years (DALY) rate for depressive disorders, anxiety disorders, bipolar disorders and schizophrenia in India between 1990 and 2017, and a doubling of the proportional contribution of mental disorders to the total disease burden in India in the same period.<sup>4</sup>

Thus, despite the initiatives implemented to improve mental health services in India, minimal improvements have been seen at ground level. The factors contributing to this are the high treatment gap, poor implementation of mental health services, gender differentials in treatment and poor evidence-based treatments.<sup>22-26</sup>

## **ROADMAP FOR THE FUTURE**

### **Budgetary Considerations**

One of the primary reasons for the initial shortcomings following launch of the National Mental Health Program in 1982 was the shortage of allocated funds. Lack of a designated budget for mental health within a nation's health budget is a major impediment to service development.<sup>27</sup> Another major difficulty which has been seen in India is underutilization of allocated funds<sup>28</sup> because of multiple factors, ranging from difficulty in employing mental health manpower to an inability to execute infrastructure projects in a time-limited manner. 'Redtapism' and lack of a coordinating nodal agency can also be a major hurdle in the timely execution of projects.

Funds allocated to the NMHP have decreased significantly in recent years, and this is a matter of concern. The Union Budget of India 2021-22 set a corpus sum of 712.69 billion Indian Rupees (INR) for the health budget, including 5.97 billion INR for mental health. Only 7 percent of the allocated amount for mental health has been earmarked for the NMHP.<sup>29</sup> By way of comparison, the budget allocation for the NMHP in 2010 was 0.44% of the total budget allocated to the Ministry of Health and Family Welfare, but this was reduced to 0.06% in 2020. Moreover, another major cause for concern is that major cuts have been made in the revised NMHP budget estimates in recent years. For example, in 2018-19, the allocated amount of 500 million INR was slashed to 55 million INR, and in 2019-20, the allocated amount of 400 million INR was slashed to 50 million INR.<sup>30</sup> Thus, underfunding continues to be a major barrier, contributing to slow gains under the NMHP.

Hence, ring-fencing allocated funds to be used exclusively for mental health services, along with a nodal agency to ensure this, may go a long way towards ensuring proper utilization of funds allocated for mental health.<sup>31</sup>

### **Mental Health Service Delivery**

The recommendation to deinstitutionalize mental health and to adopt a primary health model for service delivery has been longstanding.<sup>32</sup> While institutionalization has been seen as a major challenge in the West since adoption of a rights-based approach to mental health, this has not been the case in India, along with other LMICs.<sup>7</sup> Direct adoption of the same approach in LMICs (including India) may not necessarily have similar desirable effects on overall service provision in these countries as they already have a dearth of mental health resources. However, existing mental hospitals and institutions can serve as referral centres in the management of patients with severe mental illnesses, especially where there is insufficient social support and for medicolegal cases,<sup>33</sup> while the transition to predominantly community-based services is being planned and implemented. The current policy of strengthening and upgrading existing mental hospitals to 'Centres of Excellence', along with provisions for strengthening of the mental health training being incorporated into the National Mental Health Program, will provide the essential building blocks for successful community-based services as envisioned.<sup>9</sup> However, periodic reappraisal of the goals set, achievement thus far and course corrections is essential, and the mechanisms ensuring this must be built into the program to prevent skewed development. In recent years, the overall scope of mental health services and a significant reduction in stigma have been achieved, but this comes with the caveat that these services are essentially concentrated around urban and semiurban areas.

### **Mental Health Workforce**

Factors contributing to the shortage of mental health professionals in LMICs (including India) are urban concentration, a preference for private practice and the brain drain.<sup>1,5</sup> There is an acute shortage of mental health professionals in India, with two mental health workers and 0.3 psychiatrists per 100,000 population, which is a major limiting factor when it comes to planning mental health services for communities.<sup>34</sup> Retaining mental health

professionals is an even greater challenge, along with ensuring their equitable distribution. Minimizing the brain drain and retaining professionals in the public sector must be afforded a high priority by means of financial incentives, favourable working conditions, and provisions for career advancement.<sup>35</sup> At the same time, efforts should be made to ensure that enhanced training capacities are adequately utilized by ensuring equal professional opportunities for trained personnel. It is envisaged that, in the District Mental Health Program, existing manpower will be trained in PHCs (like doctors and paramedical staff) and equipped with the skills and knowledge necessary to provide mental health services. Nonspecialist health workers contribute to service delivery and play an important role in detection, diagnosis, treatment, and prevention of common and severe mental disorders as part of a complex stepped-care approach. There should be better provision for their in-service training to enable them to deliver effective services to the general population.<sup>35</sup>

Another important approach to improving service provision for the general population is to improve psychiatry education and training at the level of undergraduate medical courses.<sup>31</sup> The ability to independently diagnose and treat mental disorders and make appropriate referral decisions will improve service provision on a much wider scale, with visible improvements.

### **Mobilization of Community Resource**

In many LMICs, including India, faith healers, religious leaders and practitioners of alternative systems of medicine are often the first point of contact for patients with psychiatric disorders, rather than mental health services.<sup>36</sup> Efforts must be made to educate and sensitize this subgroup of the population about the importance of seeking a professional diagnosis and undergoing appropriate treatment (with regular follow-up), supported by better delivery of mental health services in the community. Some services can be sought as time-limited interventions (like camp services), which can mobilize large numbers of people in a limited time, in remote areas. Community campaigns to increase awareness about psychiatric illnesses and decrease the associated stigma should also be prioritized as stigma and discrimination against people with mental health problems are important barriers to identification and treatment of mental disorders.<sup>37</sup> Family members

are essentially the primary caregivers in most LMICs, including India, and can contribute to detection, treatment-seeking, and management of family members with mental disorders.<sup>35</sup>

### **Integration with Primary Care**

Currently, integration of community mental health services with primary healthcare is the most viable method to provide mental health services in most LMICs, including India, but significant shortcomings still exist in terms of achieving this goal.<sup>38</sup> The main barriers to integration include the following: already overburdened PHCs with limited staff; multiple tasks; patient load; multiple concurrent programs; lack of training, supervision and referral services; and non-availability of psychotropic drugs in the primary healthcare system.<sup>32</sup> In this context, alternative mechanisms for program delivery, like the National Health Mission (which subsumed the National Rural Health Mission and National Urban Health Mission in India), should be considered. It has also been suggested that mental healthcare should be integrated with better performing services for other chronic conditions or, alternatively, with other systems like social care or education.<sup>39</sup>

### **Mental Health Research**

The WHO's Mental Health: Global Action Program envisages multidimensional research efforts in LMICs to improve the mental health situation.<sup>40</sup> There is a wide gap between research efforts focused on developed countries and those focused on LMICs (in terms of mental health), and this divide has not decreased over time.<sup>41</sup> Furthermore, research does not seem to have had an impact on the policy and practice of mental health due to a disconnect between researchers and communities.<sup>42</sup> Attention needs to be focused on a systemic approach in order to debate the relevance of research questions, with the involvement of all stakeholders at appropriate levels (including policymakers, practitioners, advocacy groups and the community at large), and to generate resources and funds for this.<sup>42-44</sup>

### **CONCLUSIONS**

Although progress has been slow in development of community-based mental health services and achievement of the desired outcomes in India, the importance of these cannot be understated. India has

a huge burden of mental disorders and a significant treatment gap.<sup>2,4</sup> Public health measures, along with integration of mental health services in primary health systems, offer the most sustainable and effective model for LMICs with few resources, including India. Despite the National Mental Health Program having been in effect since 1982, it has only been able to partially achieve the desired mental health outcomes.<sup>8</sup> It is important to continuously assess performance with independent audits and periodic reviews in order to identify problems at the earliest and initiate corrective measures.<sup>45</sup> Thus, there is an urgent need to take a fresh look at implementation of the program, with a focus on achieving sustainable improvements in a timely manner.

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