



## **SCHIZOPHRENIA**

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THE ROLE  
OF CAREGIVERS  
IN FOSTERING  
COOPERATION

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Schizophrenia is one of the most debilitating and stigmatizing mental illnesses, which sometimes follows a pretty turbulent course. The signs and symptoms of this disease usually raise serious problems regarding a patients' functioning and, in consequence, result in their isolation and social exclusion. Schizophrenia requires a long-term and comprehensive treatment with antipsychotic drugs. Even so, it is all too often the case that the outcomes of the administered therapy do not bring any expected results. Despite intensive treatment, patients are unable to return to the sense of wellbeing felt before the outbreak of the disease, while their level of performance remains below their starting capabilities over a long period of time.

Schizophrenia is a tough experience also for patients' close relatives, given that it is them on whom the burden falls to provide care. Estimates show that as much as 10 persons in a schizophrenic patient's immediate environment are directly affected with disease consequences, including constant stress, life destabilization due to disease recurrences, significant welfare loss in the area of mental health, deterioration of mutual relations within a family, and stigma associated with caregivers that leads to their discrimination and social exclusion.

The provision of assistance to patients also generates high costs related to the organization of life and the need for care provision with simultaneous burden on caregivers in an employment sphere, which leads to reduction in their working hours. The presented report "Schizophrenia. The Role of Caregivers in Fostering Cooperation" shows, among others, the findings of a survey conducted in order to identify a typical profile of Polish caregivers supporting schizophrenic patients and their key role in a therapeutic process. In Poland, schizophrenic patients are usually cared of by their parents or spouses – professionally active persons who take care of patients for 34 hours per week, on average. It represents nearly 90% of working hours of another full-time job.

Throughout the entire period of disease, family members and close relatives from a patient's immediate environment play an important role, as it is crucial to diagnose

schizophrenia at its early stage and initiate treatment as soon as possible. Caregivers should always be taken into account when planning a treatment strategy and included in psychoeducation activities due to the fact that assistance provided in a patient's natural environment, in addition to medication, represents a significant part of any therapy. Families involved in a therapeutic process are a great help in achieving a satisfactory level of cooperation with a patient, observing therapy principles, avoiding disease recurrences and re-educating a patient in the field of social skills. Caregivers act as a pillar of a schizophrenic patient treatment system.

Among modern criteria for improvement, remission and recovery in schizophrenia, the level of psychosocial performance, the return to the fulfilment of social roles and the ability to regain autonomy are key factors for evaluating the efficacy of a schizophrenia treatment. Modern therapy should be comprehensive and focused on the improvement of a patient's functioning and their life quality, as well as the reduction of adverse effects of the disease on a patient and their family.

The growing interest in various aspects of everyday life of schizophrenic patients seen in recent years is also due to a great deal of hope that we place in the development of new medicinal products. Atypical antipsychotics contribute to a large extent in regaining ability to fully participate in social life, returning to employment or education, and performing other roles. The most modern methods of pharmacological treatment include long-acting atypical drugs administered in form of injections (long-acting injections, LAIs) that are not yet widely distributed, thus, their availability on the Polish market is considerably limited. These products allow for the improvement of a patient's cooperation with medical staff that, on a general note, leads to reduction in the burden on caregivers and their concerns whether the patient adheres to medical recommendations. Modern antipsychotic drugs improve the life quality of families of schizophrenic patients by simplifying treatment scheme. Patients do not have to be convinced and reminded about the need to take medication on a daily basis, thus, the stress and anxiety felt by caregivers is reduced.



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It is often said that schizophrenia is one of the most common and severe mental diseases. The risk of developing this disease during a lifetime is estimated at approx. 1%. According to the statistical data provided by the National Health Fund (NFZ), there are nearly 190,000 persons with diagnosed schizophrenia who are provided with medical assistance on an annual basis. There is also a group of persons who have experienced an episode of this psychosis, but do not use medical care for various reasons, which is however difficult to estimate.

Nevertheless, it is too rarely noted that schizophrenia is a burden also on the immediate environment of a patient, in particular their closest relatives. This burden may last with various intensity for many years. Assuming that there are 10 persons per one patient with diagnosed schizophrenia who are directly affected with disease consequences, the total number amounts to nearly 2 million affected people. This number illustrates a real social significance of schizophrenia, which might not be noticeable on an everyday basis.

The problems of families and caregivers of schizophrenic patients are presented in the report “Schizophrenia. The Role of Caregivers in Fostering Cooperation”. The findings of a survey conducted among hundreds of caregivers of schizophrenic patients shown in this report are very interesting. They illustrate a profile of a Polish caregiver, often one of a patient’s parents or their spouse/partner, usually living with a patient under the same roof. They provide a patient with assistance for 34 hours per week, on average. Therapists often emphasize the great importance of participation and engagement of families and caregivers in a treatment process.

The report rightly draws attention to long-term consequences of a difficult and burdensome role played by caregivers of patients suffering from mental disorders. According to the survey results, fulfilling this role represents the greatest source of stress in a life of caregivers. Another adverse factor is still a stigma for persons with mental illnesses that also affects their caregivers.

We know that the improvement of a situation of mentally ill patients and their caregivers requires an increase in public expenditures on mental healthcare and reform of psychiatric healthcare in accordance with the guidelines of the National Mental Health Protection Programme. Only a nation-wide community-based psychiatric care model is an opportunity for providing effective assistance to patients suffering from mental disorders close to home and relevant support for their families and caregivers within local mental healthcare centres. The increase in expenditures on the requested 5% level of expenses on healthcare, following other European Union countries, will make it possible to implement a modern healthcare model and to improve access to effective medicines, particularly to second-generation antipsychotic drugs in form of long-acting injections. Such a therapy improves treatment results and cooperation with medical staff, as well as reduces the burden on caregivers. Therefore, several times lower percentage of patients taking antipsychotic drugs in form of long-acting injections in Poland, compared to other European Union countries, must raise many concerns. If we want to discuss modern psychiatric care, this situation also has to change.



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**REV.**  
**ARKADIUSZ NOWAK**

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President of the Foundation  
Institute for Patient's Rights  
and Health Education

In many countries, recent years have seen an increase in interest in mental health and intensification of efforts for its improvement. Lifestyle changes, aging society and social factors that are unfavourable for mental health will make mental illnesses an increasing challenge for Europe in the 21st century.

Mental disorders currently affect one in five persons all over the world, representing the second cause of death after communicable diseases. According to the forecasts of the World Health Organisation (WHO), in the coming years, mental illnesses, such as schizophrenia, will become one of the major health issues leading to social malfunction of many people.

In 2013, in response to the above-mentioned worrisome forecasts and data showing that the problem of mental illnesses is often disregarded compared to other non-communicable diseases, the World Health Organisation (WHO) adopted two strategic documents: Global Comprehensive Mental Health Action Plan and European Action Plan, aimed at improving mental health prophylaxis and supporting patients suffering from mental illnesses.

Nevertheless, in Poland, mental health is still underestimated and given lower priority compared to other non-communicable diseases. The social situation of such patients has remained unchanged for years. Schizophrenic patients are still too often excluded from social life, whereas the burden to provide care falls mainly on a patient's family members who bear the financial, emotional and social consequences of this disease. As it follows from the data presented in this report, there are approximately 10 persons from a patient's immediate environment who are directly affected with disease consequences. However, it should be borne in mind that schizophrenia affects relatively young people and, due to its chronic nature, it constitutes a multi-year burden on families, having an impact on the health of caregivers.

The recovery of a patient suffering from mental disorder is a long-term and complex process, in which it is crucial to apply a comprehensive approach including not only pharmacological treatment, but also psychoeducation, psychotherapy and activity-based therapy or a take-up of employment. Such changes are expected by all communities acting for the good of patients with mental disorders, thus, also public health and social policy should move towards this direction.

# WHAT IS SCHIZOPHRENIA

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**SCHIZOPHRENIA IS A SEVERE MENTAL DISORDER WHICH AFFECTS PATIENTS' PERCEPTION OF THE WORLD, THEIR ABILITY TO THINK CLEARLY, EXPRESS EMOTIONS OR MAKE DECISIONS, AS WELL AS THEIR RELATIONS WITH OTHER PEOPLE. THIS DISEASE IS OBSERVED MAINLY IN YOUNG PEOPLE WHOSE CONNECTION WITH REALITY IS SERIOUSLY DISTORTED. SYSTEMATIC TREATMENT BASED ON SUCCESSFUL COOPERATION WITH PHYSICIANS AND CAREGIVERS HELPS MANY PATIENTS RETURN TO A NORMAL LIFE.**

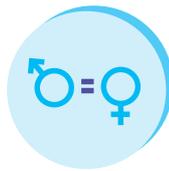
Schizophrenia is a chronic disease which affects more than 50 million people world-wide. The causes of this psychosis have not yet been fully explained yet, however, there are many theories suggesting that it results from complex interactions between various factors of hereditary, individual (e.g. ability of coping with stress) and environmental (e.g. emigration, big city life, tough experiences, addictions) origin. <sup>[1]</sup>

The underlying cause of schizophrenia is a biochemical imbalance of neurotransmitters in the brain (primarily the disturbed functioning of dopaminergic pathways in the brain) which is manifested through compromised perception of reality and, thus, misperception of the world. Untreated schizophrenic patients isolate themselves from the society and their environment which is reflected in the loss of friends, education possibilities, professional opportunities and the deterioration of effective communication skills. According to the World Health Organization (WHO), schizophrenic patients usually have well-preserved level of awareness and intellectual abilities, although there is a risk of occurrence of some cognitive deficits as time goes by. <sup>[2]</sup>

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**SCHIZOPHRENIA IS CHARACTERISED BY MANY SYMPTOMS WHICH MAY DEVELOP DIFFERENTLY AND OCCUR WITH VARIABLE INTENSITY IN EACH PATIENT. PSYCHIATRISTS RECOGNISE SCHIZOPHRENIA AS A DISEASE WITH HIGHLY INDIVIDUALISED SYMPTOMS – EACH PATIENT SUFFERS FROM „THEIR OWN SPECIFIC CONDITION”.**

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The incidence of schizophrenia in men and women is comparable. The disease occurs at similar rates in all ethnic groups around the world.



Schizophrenia is a multi-factorial disease of both genetic and environmental origin. It is impossible to predict who will or won't develop schizophrenia.

**REMEMBER – NO ONE IS TO BLAME FOR BEING SICK.**



Studies show that schizophrenia may be caused by an imbalance of chemicals in the brain. Scientists believe that schizophrenia, like many other conditions, may result from a combination of genetic and environmental factors.



As compared to other known diseases, schizophrenia leads to a development of permanent disability in a greater number of young people.

<http://www.invegasustenna.com/about-schizophrenia>

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Schizophrenia is most likely caused by dopamine secretion disorders - its surplus or deficiency.



The most common form of hallucinatory sensations are auditory hallucinations - patients hear voices.



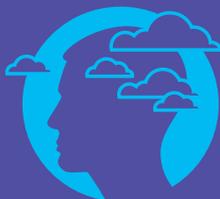
Schizophrenic patients strongly believe that their thoughts are heard by all other people or that someone has put these thoughts directly into their heads.



Their speech and expressions become tangled, confused and non-communicative. This results in disorganised thinking.



**Paranoid delusions** - false beliefs about reality which are inconsistent and sometimes absurd.



Patients lose touch with reality and live in their own world.

Schizophrenia is not a single disease, but a whole array of concomitant conditions referred to as schizophrenic psychoses. In clinical practice, the diagnosis of schizophrenia is based on the occurrence of schizophrenic symptoms which persist for at least 1 month and include:

#### POSITIVE SYMPTOMS

e.g. delusions, thought disturbances, sensations of a hallucinatory nature

#### NEGATIVE SYMPTOMS

e.g. communication difficulties, avolition, inaction, shallow emotions, a loss of interest in social relationships, decreased motivation, limited ability to experience joy, apathy, slow movement, not taking care of oneself

#### SYMPTOMS OF MENTAL DISORGANISATION

e.g. difficulties in understanding the environment, human behaviour and expression<sup>[3]</sup>

The below-listed categories are not completely separate forms of this disease as the only difference between them is the prevalence of a specific group of signs and symptoms. Furthermore, the below-described types of schizophrenia may blend into one another in the case of a multi-annual course of disease.<sup>[4]</sup>

DEPENDING ON THE INTENSITY AND PREDOMINANCE OF INDIVIDUAL SYMPTOMS, THERE ARE 6 DIFFERENT TYPES OF SCHIZOPHRENIA:



#### SIMPLE

no positive symptoms; slow, but progressive deterioration of everyday functioning of a patient, depression, sense of loneliness



#### PARANOID

characterised with a prevalence of hallucinations and delusions; the sense of being persecuted or conspired against



#### HEBEPHRENIC

characterised with a prevalent sense of being inadequate and symptoms of disorganisation: unpredictable behaviour, childishness, distracted speech



#### CATATONIC

characterised with a prevalence of slow movement; the patient does not take up contact with the environment and remains extremely motionless



#### RESIDUAL

characterised with a prevalence of, so called, chronic residual symptoms of stable and low intensity

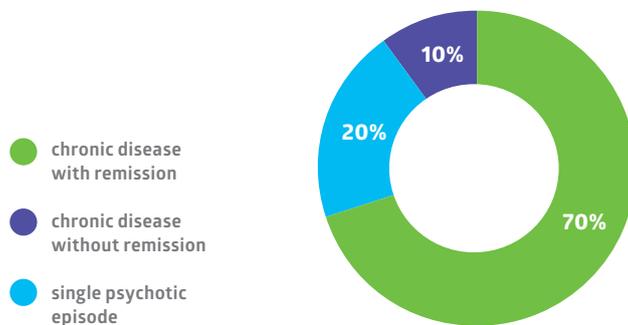


#### UNDIFFERENTIATED

characterised with a lack of prevalence of any symptoms and their volatility

**Diagram 1.**  
**Percentage of patients with a given type of schizophrenia course**

Falkai 2005; Wright 2008<sup>[5, 4]</sup>



In most cases, the symptoms of schizophrenia are recurrent and periodical disease exacerbations are preceded by improvements in the patient's condition. In some patients, the symptoms resolve almost entirely between different periods of disease, whereas in other patients the disease has a chronic and progressive course, with periodical exacerbations. The diagnosis of schizophrenia does not equal a chronic disease lasting many years for all patients. Approximately 20% of schizophrenic patients may experience only one acute episode of this psychosis (cf. Diagram 1).<sup>[4]</sup>

#### SYMPTOMS:



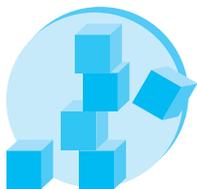
problems with differentiating  
between reality and own  
hallucinations or delusions



thought  
disturbances



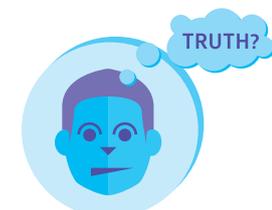
emotional  
disturbances



disorganised  
behaviour



hallucinations



delusions

The natural course of schizophrenia includes the following four phases of disease development: acute psychotic episode, remission, relapse and late stabilisation. In approximately 60-70% of diagnosed patients, the phase of acute psychotic episode occurs before the age of 30. In such case, the symptoms of disease develop very quickly and reach full progress in only six months.

In the phase of the acute psychotic episode, patients experience a variety of symptoms, such as: hallucinations, delusions, anxiety, thought disorders, disorganised action, agitation or weakness, apathy, decreased motivation, the loss of vigour and initiative. It is the patient's family and their closest relatives who has a crucial role to play in this period – **it is therefore vital to ensure early diagnosis and the fastest possible initiation of treatment.** Unfortunately, in Poland, the implementation of schizophrenia treatment is usually significantly delayed. In more than half of schizophrenic patients, the time taken between the occurrence of the first symptoms and the initiation of treatment is usually about one year. In this period of time, the symptoms of disease are significantly aggravated and the efficacy of pharmacological treatment is lower. <sup>[4, 21]</sup>

Long waiting periods for a psychiatric consultation may lead to the escalation of symptoms and, in consequence, the patient's hospitalisa-



SCHIZOPHRENIA REQUIRES A LONG-TERM TREATMENT WHICH USUALLY TAKES MANY YEARS AND WHICH IS MOST EFFECTIVE WHEN INITIATED IN THE EARLY STAGE OF DISEASE DEVELOPMENT. THE QUICKER IS THE TREATMENT INITIATED AFTER THE OCCURRENCE OF THE FIRST SYMPTOMS, THE FASTER CAN A PATIENT RETURN TO NORMAL LIFE.

tion. The phase of acute psychotic episode is followed by remission which consists in a significant improvement of the patient's state of health. The disease symptoms manifest to a lesser extent, they are milder or do not occur at all, so the functioning of the patient is remarkably improved. The relapse of disease is, unfortunately, observed in most patients. Symptoms

which occur in the relapse phase do not differ from those which are observed in the first psychotic episode, however, their severity and duration may vary.<sup>[4]</sup> Each subsequent relapse causes further deterioration of a patient's condition and considerably reduces the level of a patient's functioning in the society (which is well illustrated in Figure 2 and reflected by the green part of the graph). Most recurrences are observed within the period of five years from the first episode of schizophrenia – the cumulative frequency reaches the level of 82% – and the resignation from medication is recognised as the major cause of disease relapse.<sup>[7, 8]</sup> The last phase of schizophrenia is late stabilisation during which the course of the disease becomes milder. According to scientific findings, this phase occurs mainly in patients who are over 50 years of age.<sup>[4]</sup>

The duration of individual periods is conditional upon the patient's attitude, their family and approach towards treatment.<sup>[3]</sup> The lack of disease awareness, disbelief in treatment effects, excessively critical or emotional approach towards the patient and overprotection on the part of the patient's relatives result in the non-adherence to medical recommendations and increase in the level of stress suffered by the patient and their caregivers.<sup>[11, 12]</sup>

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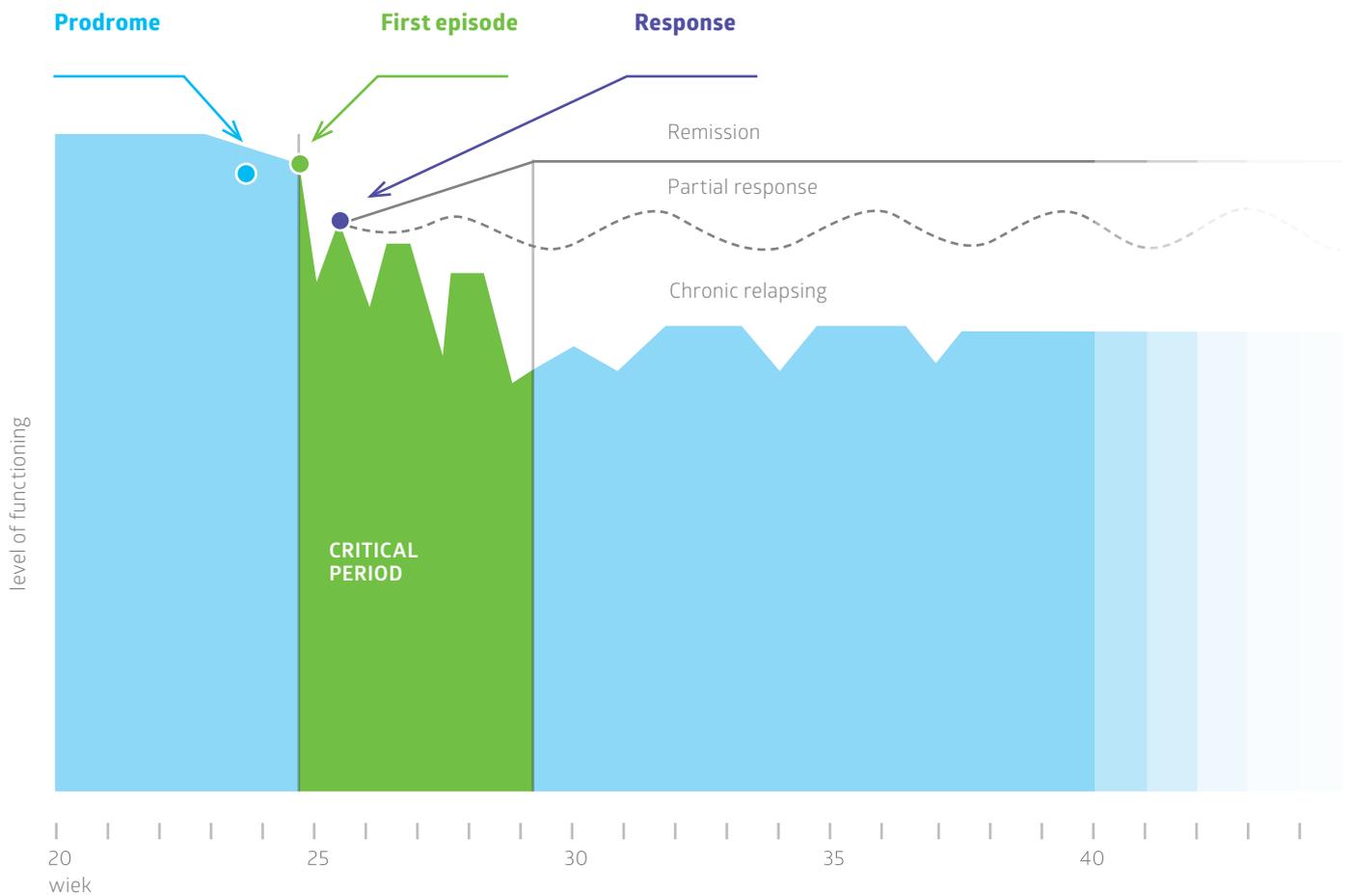
**THE IDEAL TREATMENT**  
IS A THERAPY WHICH COMBINES PHARMACOLOGICAL  
TREATMENT WITH PSYCHOTHERAPY, LEADING TO  
A CONSIDERABLE REDUCTION OR ELIMINATION  
OF SYMPTOMS, RELAPSE PREVENTION,  
AND ENABLES PATIENTS TO RETURN  
TO NORMAL FUNCTIONING IN THE SOCIETY.

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**Figure 2.**  
**Diverse response to treatment**

Based on Birchwood 1998

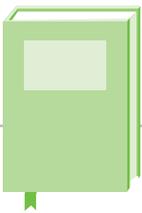
Effective symptom control from the first episode can result in patients becoming reintegrated into families, social, educational and occupational systems



In consequence, it triggers an acute relapse of psychosis, depression or even suicide in a patient.<sup>[11]</sup> According to estimates, suicide remains a cause of death in 5 out of 10 schizophrenic patients, whereas the key risk factors include the sense of hopelessness, depression and the number of hospital admissions.<sup>[13, 14]</sup> Both the deteriorating condition of patients and the need for a long-term provision of care have an impact on the mental state of caregivers who, as a result, may experience depression or neuroses requiring even hospital treatment.<sup>[12]</sup>

An adequately selected therapy - which should not be confined solely to pharmacological treatment, but also embrace psychotherapy, psychoeducation, rehabilitation, activity - based therapy and support for the patient's caregivers - is the key prerequisite for a therapeutic success.

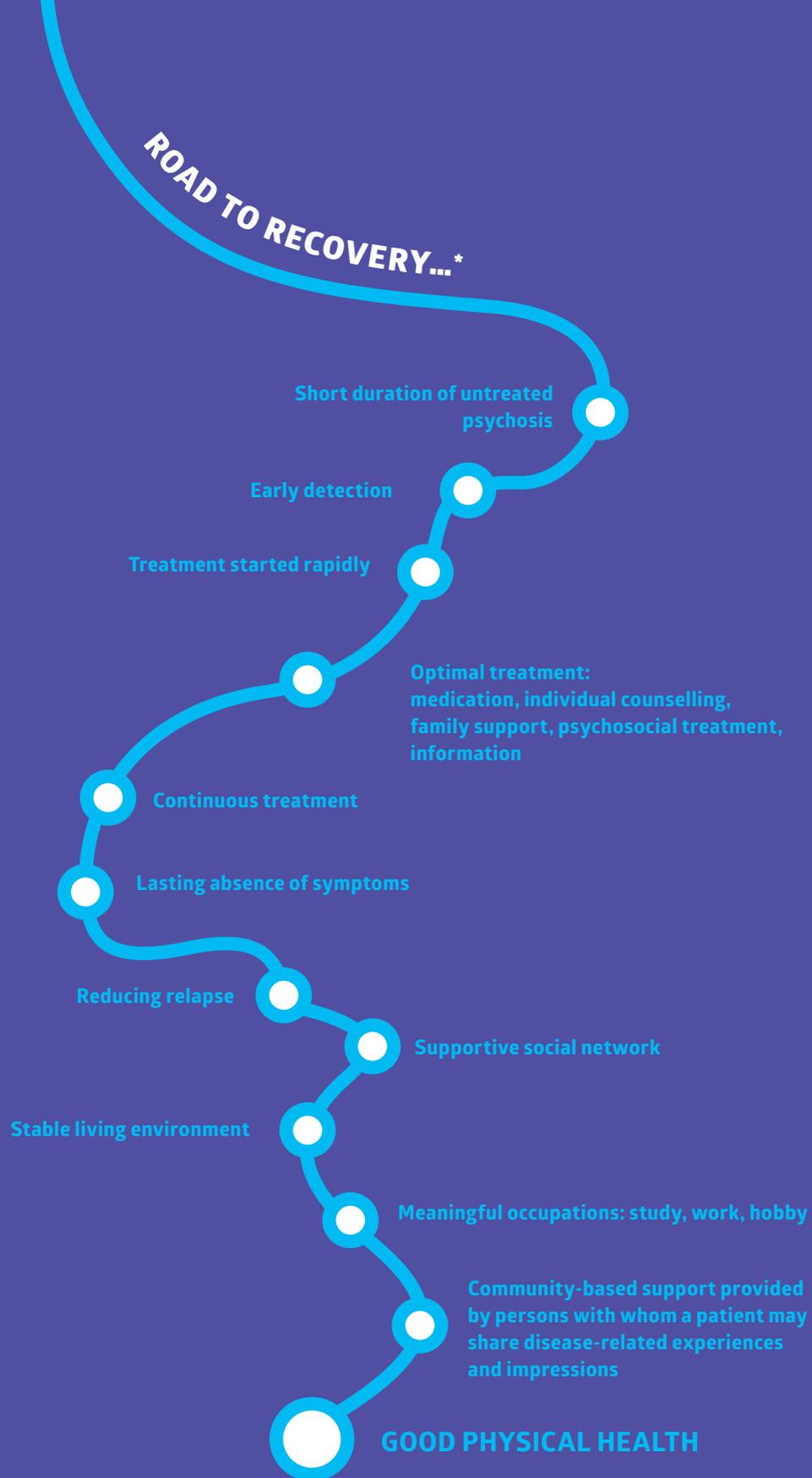
The earlier are the patients and their relatives offered such a form of assistance, the higher are the chances of successful treatment and the patient's return to normal functioning in the society. An innovative treatment is streamlined and comprehensive. Its main objective is the improvement of the patients' functional abilities and their life quality, as well as the reduction of an adverse impact of the disease on the patients and their families.



#### SCIENTIFIC FINDINGS:

SCHIZOPHRENIA LEADS TO THE SHORTENING OF LIFE EXPECTANCY BY 10-20 YEARS. THE PATIENTS SUFFERING FROM THIS DISEASE ARE OVER 2.5 TIMES MORE EXPOSED TO THE RISK OF DEATH COMPARED TO HEALTHY POPULATION, MAINLY DUE TO 12 TIMES HIGHER RISK OF SUICIDE AND INCREASED RISK OF DEVELOPING CARDIOVASCULAR OR RESPIRATORY DISEASES.

Source: Chesney 2014<sup>[15]</sup>, Saha 2007<sup>[16]</sup>



## REALISTIC EXPECTATIONS AND HOPE FOR THE FUTURE

\* Full recovery is observed in approximately 1 in 4 patients, whereas in a majority of other cases it is possible to achieve a significant reduction in the intensity of symptoms and improved wellbeing at various levels.

# 01

# EPIDEMIOLOGY OF SCHIZOPHRENIA

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**SCHIZOPHRENIA IS A MENTAL ILLNESS WHICH CONCERNS EVEN 1 IN 100 PEOPLE WORLDWIDE. ACCORDING TO ESTIMATES, SCHIZOPHRENIC PATIENTS REPRESENT BETWEEN 0.7% AND 1.0% OF THE ENTIRE EUROPEAN POPULATION, WHEREAS, EACH YEAR, APPROXIMATELY 15 IN 100,000 PATIENTS ARE DIAGNOSED WITH SCHIZOPHRENIA. SCHIZOPHRENIA MAY AFFECT ANYONE, HOWEVER, THIS DISEASE IS MOST FREQUENTLY OBSERVED IN YOUNG PEOPLE (MORE THAN HALF OF THE PATIENTS DIAGNOSED WITH SCHIZOPHRENIA FELL SICK BEFORE THE AGE OF 30) AND IT HAS COMPARABLE PREVALENCE IN BOTH MEN AND WOMEN. [1, 17, 18]**

**In Poland, no epidemiological studies of schizophrenia have been conducted so far. There is also no central register of schizophrenic patients, thus, based on various sources, it is estimated that their number falls between 335,000 and 385,000, the half of which are non-diagnosed patients who, therefore, receive no adequate medical care.**

These estimates are consistent with the most recent data concerning the number of patients diagnosed with schizophrenia (F20) extracted from the registers of the National Health Fund (NFZ) for the years 2010-2014. In 2010, as much as 180,809 patients diagnosed with schizophrenia received benefits funded by the National Health Fund (NFZ). In subsequent years, the number of schizophrenic patients slightly fluctuated, whereas the number of patients diagnosed with schizophrenia (F20) and treated jumped by 3.4% to 187,021 within 5 years. Simultaneously, during the period considered, there was also observed a decline in the number of hospital admissions of schizophrenic patients - this number dropped by nearly 10% from 57,930 to 52,387 hospitalizations settled by the National Health Fund (NFZ).<sup>[19]</sup> The above-mentioned decline in the number of hospital admissions might have been caused by a gradual transformation of the Polish mental healthcare system, in particular, the transition from treatment carried out in large, independent psychiatric hospitals to the model of community-based psychiatry. In this new model, great emphasis is attached

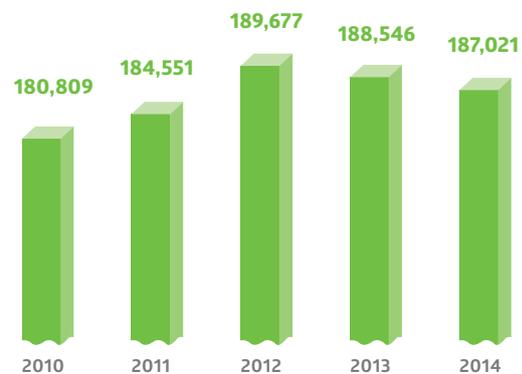
to the shifting of the treatment of mental disorders from hospitals to community-based care provided within a patient's family and working environment, where the patient functions on a daily basis.<sup>[18]</sup>

#### The number of people diagnosed with schizophrenia in Poland per year:

Source: own study based on the IPIN 2009 data



**Diagram 2.**  
Number of patients diagnosed with F20 disease and treated under contracts with National Health Fund (NFZ)



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**Prevalence of schizophrenia against other diseases (data concerning Poland):**

187,000 SCHIZOPHRENIA

60,000 HEPATITIS C

60,000 MULTIPLE SCLEROSIS

5,000 CROHN'S DISEASE

2,000 CYSTIC FIBROSIS

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The number of schizophrenic patients is relatively high as compared to the number of patients affected by other known chronic diseases. Low public awareness, as well as growing stereotypes and prejudices, results in the social stigma of mental disorders and, in consequence, lead to the discrimination and social exclusion of patients and institutions providing assistance in coping with mental illnesses.

In Poland, there are several thriving organisations which bring together schizophrenic patients and their families, effectively provide assistance on local level and significantly influence the everyday life of patients. Unfortunately, these organisations still remain unnoticed by decision-makers. Schizophrenic patients, who seem to be lost in life, are not as active and mediagenic in fighting for their own rights or greater investments in new drug development as, for instance, patients with multiple sclerosis or cystic fibrosis.

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**Schizophrenia  
is a chronic disease  
affecting more  
than **50 mn**  
people  
worldwide.**

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# 02

# SCHIZOPHRENIC PATIENT CARE

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**ANY DISEASE AFFECTING IMMEDIATE FAMILY MEMBERS IS A SOURCE OF TOUGH EXPERIENCES, NOT ONLY FOR PATIENTS, BUT ALSO FOR THEIR FAMILY MEMBERS WHO MOST FREQUENTLY TAKE THE BURDEN OF CARING FOR PATIENTS. PATIENTS' FAMILIES HAVE TO BEAR THE FINANCIAL, EMOTIONAL AND SOCIAL CONSEQUENCES OF THE ILLNESS, AND USUALLY INCREASES THE PSYCHOLOGICAL BURDEN WHICH RESTS WITH THEIR MEMBERS (STRESS, DEPRESSION, NEUROSES). [11] IF A GIVEN ILLNESS IS A CHRONIC MENTAL DISORDER, THE BURDEN ON THE FAMILY IS EVEN GREATER.**

## CHARACTERISTICS OF CAREGIVERS

**A caregiver of a schizophrenic patient is usually a family member, a person involved in the therapeutic process of a patient or a person providing a patient with various kinds of assistance, i.e. financial help, supervision over the treatment process or helping out with daily chores.**

In order to define the profile of Polish caregivers and describe their crucial role in the process of treating schizophrenic patients, the survey entitled "Taking Care of Close Relatives with Diagnosed Schizophrenia" has been carried out amongst 100 caregivers of schizophrenic patients. The survey revealed that, in most cases, the role of the primary caregiver lies with women (78%) at an average age of 51 years. According to its results, the patient's family has a significant role to play in the care of patient, whereas the primary caregiver is the patient's parent (46%) or the patient's husband / wife / partner (26%). In most cases, due to a high degree of kinship, caregivers live with a patient (81%) under the same roof. The vast majority of these people are professionally active persons (68%) who spent on average 34 hours per week taking care of a patient, i.e. as much as 85% of another full-time employment. <sup>[21]</sup> These results correspond to data available in other research studies conducted both in Poland and on a global scale. <sup>[22-24]</sup>

# 78%

OF CAREGIVERS  
ARE WOMEN



# 51

YEARS AVERAGE  
AGE OF A CAREGIVER

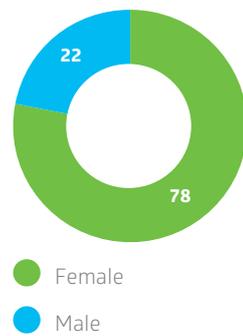
ACCORDING TO SOME SCIENTISTS, THE PROCESS WHICH TAKES PLACE IN FAMILIES WITH SCHIZOPHRENIC PATIENTS IS SIMILAR TO THE PROCESS TRIGGERED BY THE REACTION TO AN EXTENDED MOURNING. SCIENTISTS DEEM THAT CONTACT WITH A DEAR AND LOVED PERSON WHO IS STILL ALIVE, BUT WITH WHOM IT'S IMPOSSIBLE TO COMMUNICATE, LEAVES THE PATIENT'S IMMEDIATE FAMILY MEMBERS IN AN EXTREMELY PAINFUL SENSE OF LONELINESS.

Source: Chuchra 2009 <sup>[20]</sup>

**Diagram 3.**  
**Characteristics of a Polish caregiver based on the findings of a survey entitled „Taking Care of Close Relatives with Diagnosed Schizophrenia”**

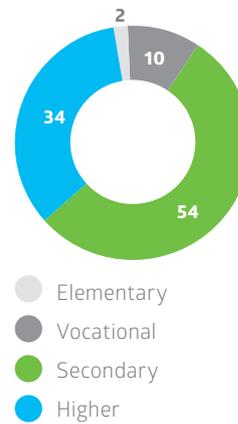
**Sex of a caregiver (%)**

What sex is the caregiver?



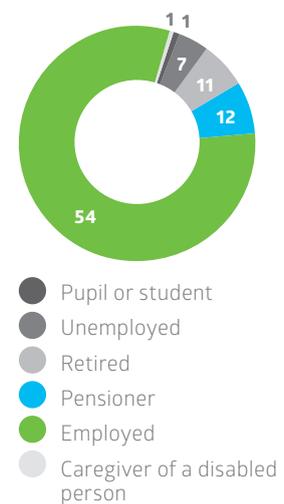
**Educational background of a caregiver (%)**

What is the educational background of the caregiver?



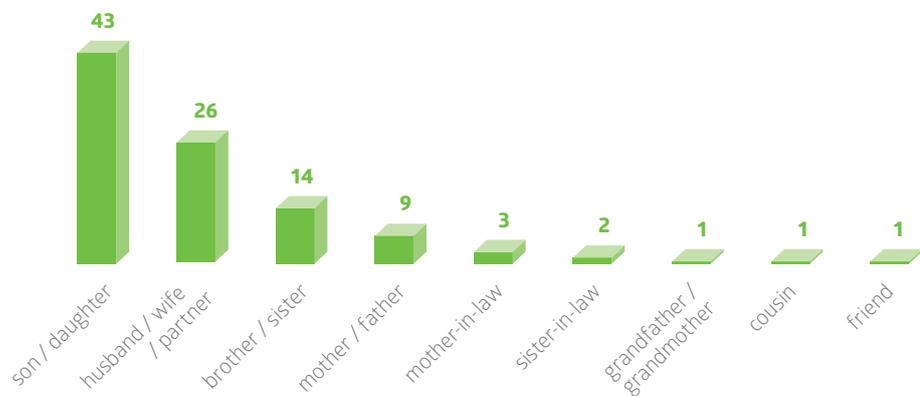
**Employment status of a caregiver (%)**

What is the employment status of the caregiver?



**Diagram 4.**  
**Relationship between a patient and a caregiver (%) based on the findings of „Taking Care of Close Relatives with Diagnosed Schizophrenia”**

Who is the patient for the caregiver?



## BURDEN ON CAREGIVERS

**Persons, who are involved in the care of patients with mental disorders, often suffer from adverse implications of the performed supervision. These consequences have both an objective (e.g. additional financial burden resulting from the fact of being a caregiver) and subjective dimension related to a psychological discomfort and lower quality of life.**

According to the survey "Taking Care of Close Relatives with Diagnosed Schizophrenia", in professional sphere, the objective burden affects as much as 25% of caregivers who were forced to reduce the number of working hours by one-third on average due to the performed role. <sup>[21]</sup> Furthermore, taking care of a patient is connected with high costs (on average PLN 568.00 per month) which significantly increase the financial burden with respect to the reduced number of working hours. <sup>[21, 22]</sup>

A considerably higher percentage of presenteeism cases is also observed amongst caregivers compared to persons non-taking care of any patient (30% and 17.5%, respectively). <sup>[26]</sup> Caregivers also experience remarkable deterioration in their health condition. The number of hospital admissions and visits to hospital emergency departments is considerably higher in this group. <sup>[21, 22]</sup>



### BURNOUT SYNDROME

IS A STATE OF PHYSICAL AND MENTAL EXHAUSTION WHICH RESULTS FROM A PROLONGED PRESENCE OF NEGATIVE FEELINGS. THE HIGHEST EXPOSURE TO THE RISK OF A BURNOUT SYNDROME IS OBSERVED IN THE GROUP OF PEOPLE WHO ARE INVOLVED IN A LONG-TERM PROVISION OF ASSISTANCE (PHYSICIANS, THERAPISTS, NURSES, AND CAREGIVERS).

The subjective aspect of caring for a patient is, however, the most burdensome for caregivers. Taking care of a chronically sick person requires a lot of engagement, commitments and sacrifices, and is often connected with great fatigue and constant life under stressful conditions which, in consequence, may lead to the development of a burnout syndrome with simultaneous considerable aggravation of associated symptoms of depression and anxiety. <sup>[27]</sup>

There is a remarkable decline in life quality, mainly in terms of mental health and social functioning, observed in caregivers. [28, 29] Approximately 12%-18% of caregivers are on the verge of depression, whereas the factors behind increased risk of its development are as follows: young age, low educational status of a caregiver and exacerbation of disease symptoms. [30]

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### IF YOU ARE A PHYSICIAN OF A SCHIZOPHRENIC PATIENT...

ASK THE PATIENT'S CAREGIVER ABOUT THEIR HEALTH CONDITION AS THEY MIGHT HAVE ALREADY EXPERIENCED THE FIRST SYMPTOMS OF DEPRESSION. CAREGIVERS ARE „SILENT PATIENTS” WHO REPORT NO SYMPTOMS AND WHOSE MEDICAL APPOINTMENTS ARE USUALLY LIMITED TO ACCOMPANYING THE PATIENT.

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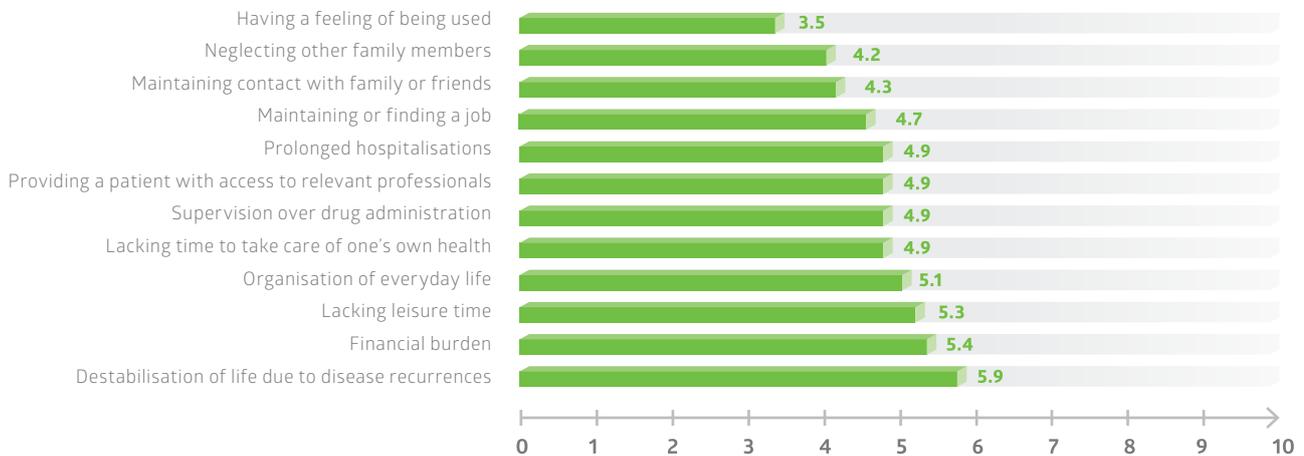
Worrying about the patient and encouraging them - i.e. the need for motivating and mobilising the patient to perform everyday activities - are also identified by caregivers as a burden. [22] The social stigma of caregivers also poses a major problem and constitutes an additional source of stress, leading to the discrimination and social exclusion of caregivers. [28, 30]

In the survey entitled “Taking Care of Close Relatives with Diagnosed Schizophrenia”, caregivers declared that schizophrenia suffered by their close relatives is the greatest source of stress in their life and many of them experience the social stigma associated with this disease. A long-term care for a schizophrenic patient - which takes an average of 9 years and, in most cases, begins with an emergence of the first symptoms (52%) - reinforces negative feelings in caregivers. Most schizophrenic patients are single persons with difficulties in establishing and maintaining social contacts. Their caregivers are usually the only persons with whom such patients maintain an ongoing relationship. Furthermore, the vast majority of caregivers lives together with their patients and remains constantly exposed to stressful situations. Due to the burden connected with taking care of a schizophrenic patient, nearly 25% of all the survey respondents have sought the assistance of a psychiatrist or a psychologist in order to better address the growing difficulties and problems. Caregivers recognised the following issues as the most burdensome aspect of the performed role: life destabilisation due to disease recurrences requiring hospitalisation, financial burden, the lack of leisure time and the need to re-organise everyday life (cf. Diagram 5). [21]

**Diagram 5.**  
**Factors affecting the burden on caregivers**

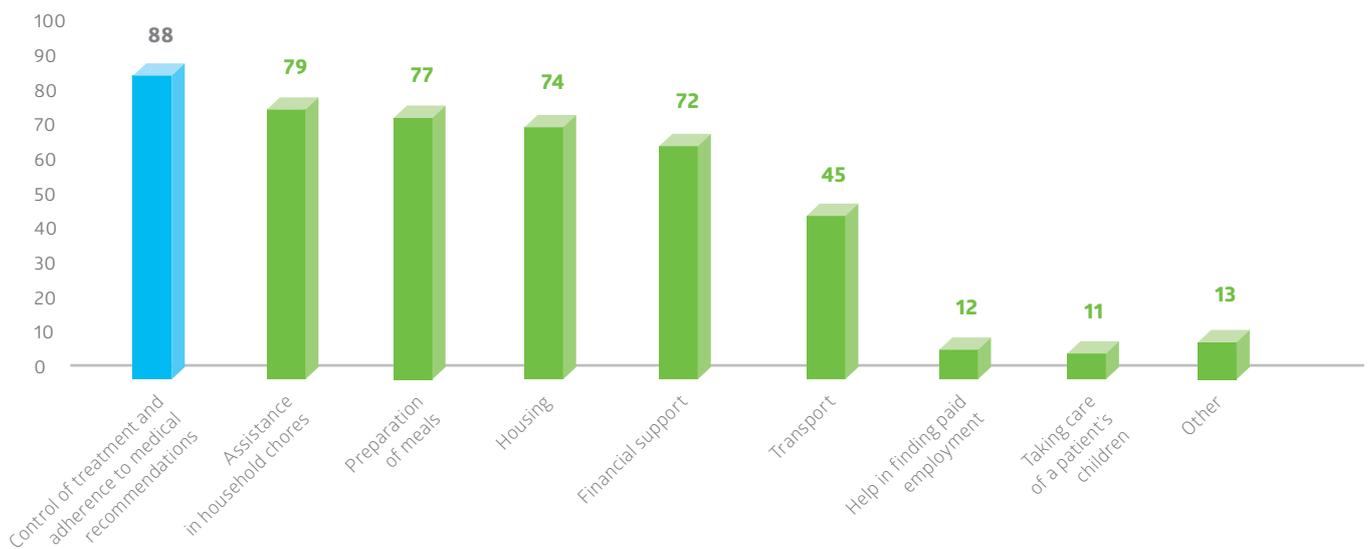
Survey question: When taking care of schizophrenic patients caregivers often encounter various tasks, problems and difficult issues. Please rate on a scale from 0 to 10, how burdensome they are for you.

Average rating on a scale from 0 to 10



**Diagram 6.**  
**Types of support provided to patients (%)**

Survey question: What type of support do you provide to the patient?



## ROLE OF CAREGIVERS IN TREATING SCHIZOPHRENIC PATIENTS

**Next to pharmacological treatment and psychoeducation, the provision of care in the patients' natural environment is the key element of their treatment. According to many experts, the family and caregivers of a schizophrenic patient should always be considered when planning the best possible treatment strategy and included in the process of psychoeducation and therapy.**

Families involved in therapeutic processes become a great help in terms of adherence to the therapeutic recommendations, relapse prevention and patients' re-education in the field of social skills and competences. They constitute a pillar of the system of treating schizophrenic patients.<sup>[31]</sup>

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### BEST TREATMENT RESULTS ARE CONDITIONAL UPON EFFICIENT COOPERATION BETWEEN PATIENTS, DOCTORS AND FAMILIES.

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Acceptance, respect and emotional support are crucial in overcoming the sufferings related to the disease and strengthening the patient's motivation to enter or continue treat-

ment. Viewed in this way, the family becomes an intermediary between the patient and the physician. Families support both therapeutic measures undertaken by the physician and shape the patient's active approach towards therapy. The best treatment results are achieved only if all the parties - the patient, the physician and the patient's family - cooperate for the successful treatment. A trilateral, solid cooperation based on mutual trust considerably facilitates an effective fight against the disease and better understanding of the course of disease which, in turn, affects the patient's and the family's quality and comfort of life.<sup>[32]</sup>

The importance of the caregivers' role in improving the cooperation of schizophrenic patients has been confirmed by many scientific studies, according to which family support in drug administration and stable life situation increase the level of adherence to medical recommendations.<sup>[33]</sup> The results of a country-wide survey conducted in Poland indicate that caregivers are highly involved in the therapeutic process of patients. Besides, the role of caregivers consists in supervising treatment and compliance with medical recommendations (88%), as well as providing assistance in daily chores (79%), meal preparation (77%), housing support (74%) and financial aid (72%) (cf. Diagram 6).<sup>[21]</sup>



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**Per one schizophrenic patient there are 10 persons in their immediate environment affected by the disease consequences. Possible negative effects include worsened relations, difficulties in making decisions necessary to provide patient with care, greater burden and stress due to the current disease situation.**

Source: Schizofrenia. Poradnik <sup>[29]</sup>

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# 03

# COOPERATION IN TREATMENT

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**THE ESTABLISHMENT OF MUTUAL UNDERSTAND WHERE TWO PARTIES ARE INTELLECTUALLY AND EMOTIONALLY INVOLVED IN THE TREATMENT PROCESS AND JOINT AGREEMENT ON THE GOALS OF COOPERATION BUILD A BASIS FOR GOOD RELATIONSHIP BETWEEN A PETIENT AND A PHYSICIAN.**

## ROLE OF A PATIENT-PHYSICIAN COOPERATION IN TREATMENT

**The key aspect of treating schizophrenia is the achievement of satisfactory level of cooperation with a patient as treatment results are often more dependent on whether and how the patient uses medication than on the treatment effectiveness. Adherence to medical recommendations is the most important aspect in treating schizophrenia and the key prerequisite for successful therapy.**

The foundation of a good relationship between the patient and the physician is finding a common ground in communication with both parties being intellectually and emotionally involved in the treatment process, as well as the establishment of mutual cooperation goals.

The prevailing factors affecting the level of collaboration between the schizophrenic patient and the physician include: **the patient's demographic portrait** (age, sex, socio-economic status, education level), **disease characteristics** (diagnosis and the course of disease, severity of symptoms, clinical picture of schizophrenia, alcohol abuse, memory and cognitive functions, the patient's insight into illness, well-being and other beliefs of the patient), **treatment** (the personality and the attitude of the physician, the medication used, hospitalisation, high costs of treatment, high frequency

of medication doses, the complexity of medical procedures) and **environmental factors** (social support, practical barriers such as: the lack of money or means of transport, the education of the patient and their family).<sup>[34, 35]</sup>

As regards schizophrenia, the lack of cooperation is not due to the patients' laziness or any negligence on the part of their caregivers, but may be connected with a nature of the disease. Patients suffering from cognitive disorders, attention and memory deficits, have difficulties in understanding what is expected from them and may forget how to use drugs. The lack of understanding of the disease with simultaneous non-acceptance of the diagnosis and fear of being stigmatised leads to a situation where patients no longer see the need for taking drugs, as they perceive it as a manifestation of weakness and dependency. This helps in shutting out any thoughts about the disease.<sup>[33, 36]</sup>

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AS REGARDS SCHIZOPHRENIA,  
**THE LACK OF COOPERATION IS NOT DUE TO THE PATIENTS' LAZINESS OR ANY NEGLIGENCE ON THE PART OF THEIR CAREGIVERS, BUT MAY BE CONNECTED WITH A NATURE OF THE DISEASE.**

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## PATTERNS OF NON-COMPLIANCE WITH MEDICAL RECOMMENDATIONS

Proper adherence to therapeutic recommendations involves such stages as: understanding and accepting medical recommendations obtained from the physician, purchasing the prescribed medicines in a pharmacy, entering and continuing treatment.

Any of the above-described stages may pose difficulties and result in the non-compliance with therapeutic recommendations. Such difficulties include: the failure to purchase the prescribed medication, non-commencement or delayed commencement of therapy, deliberate or unintentional skipping of doses, dose adjustment, periodical administration of reduced/increased doses, discontinuation of drug administration, shortening of treatment, and non-adherence to dietary recommendations or lack of physical activity.

A frequent problem encountered in mental disorders is the non-acceptance of diagnosis or insufficient motivation to initiate treatment, which leads to a situation where the prescribed medication is not even purchased in a pharmacy. Furthermore, even the purchase of medication does not guarantee the initiation of treatment. Some patients abandon medication, for example, after having read the patient information leaflet or due to its volume.<sup>[37]</sup>



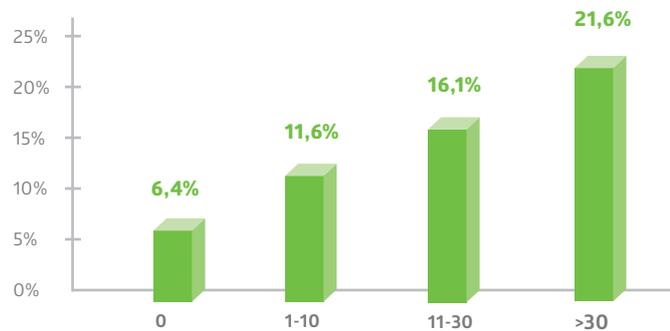
## CONSEQUENCES OF NON-COMPLIANCE WITH MEDICAL RECOMMENDATIONS

**Any failure to comply with therapeutic recommendations causes a number of adverse or even fatal consequences. Ignoring therapeutic recommendations directly results in an ineffective treatment and progression of the disease.** <sup>[37]</sup>

Patients who do not adhere to medical recommendations, so called non-cooperating patients, experience the aggravation of disease symptoms. The abandonment of therapy or its improper use is often associated with further deterioration of the patients' social functioning and their contacts with close relatives. Non-cooperation results from the patient's increased aversion to treatment and is one of the grounds for a development of such an aversion. Patients, who do not take drugs or use them on an irregular basis, are often admitted to the psychiatric care department on an emergency basis. The number and the duration of hospitalization have increased which, in turn, results in higher actual costs of therapy and care provided to patients in this group. <sup>[33, 38]</sup> According to study findings, a few days of break (1-10 days annually) in using drugs for schizophrenia causes an almost twice increase in the risk of disease recurrence and renewed hospitalization (cf. Diagram 7). <sup>[39]</sup>

**Diagram 7.**  
Percentage of hospitalised patients

Source: Weiden 2004 <sup>[32]</sup>



Non-acceptance of treatment [days/year]

### IT'S WORTH TO KNOW THAT...

IN 2003, THE WORLD HEALTH ORGANISATION (WHO) RECOGNISED THE NON-COMPLIANCE WITH MEDICAL RECOMMENDATIONS AS ONE OF THE MOST SERIOUS HEALTH ISSUES FOR THE HUMANITY AND ONE OF THE MAIN BARRIERS TO SUCCESSFUL THERAPY.\*

Source: Sabate 2003 <sup>[40]</sup>



**ONE MISSED**  
TABLET PER  
WEEK MAY  
RESULT



**50** IN  
**DAYS**  
OF DISCONTINUED  
TREATMENT PER YEAR.

ACCORDING TO SOME REPORTS,  
CERTAIN PATIENTS DO NOT TAKE  
DRUGS EVEN FOR

**110** DAYS  
A YEAR.

Information prepared on the basis of the study by Mahmoud 2004: the observation period was one year and the study population included patients with schizophrenia or schizoaffective disorders, treated with atypical antipsychotic drugs administered orally.

**AS MUCH AS 62% PATIENTS,**  
WHO HAVE HAD A RELAPSE WITHIN TWELVE  
MONTHS AFTER THE FIRST PSYCHOTIC EPISODE,  
DID NOT USE MEDICATION IN LINE WITH  
THE MEDICAL RECOMMENDATIONS.

Source: Morken 2008 <sup>[43]</sup>

## SCALE OF THE PROBLEM OF NON-COOPERATION

**A significant part of schizophrenic patients shows cooperation problems during the first 50 days of treatment, whereas 15-25% of patients abandon the use of medication during the first 7-10 days after having been discharged from the hospital. Another crisis is observed after six months from the stabilisation of the disease.**

These short intervals are, however, not surprising. In everyday clinical practice, renewed hospitalization soon after the hospital discharge (i.e. within 30 days) is common in patients from schizophrenia spectrum and affects approximately 25% of persons suffering from this disease.<sup>[41]</sup> As much as 75% of patients do not adhere to medical recommendations within two years after having been discharged from the hospital.<sup>[42]</sup>

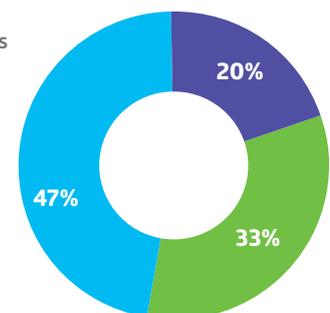
However, it is hard to precisely determine the number of schizophrenic patients who do not comply with medical recommendations, particularly in a long-term horizon. Psychiatrists have to rely on very little reliable information gathered during interviews with patients and their caregivers. Fearing potential consequences, patients and their families often mislead the physician and intentionally do not admit how, in fact, the observance of therapeutic recommendations look alike in their everyday life.

According to the results of a wide-ranging ADHES survey conducted both among psychiatrists, nurses and caregivers of schizophrenic patients, approximately 53% of patients belong to the group characterised by a difficult cooperation between the patient and the physician, including 20% of patients who continuously fail to cooperate. According to psychiatrists, even 1 in 5 patients entirely ceases treatment without consulting medical staff (cf. Diagram 8). As a rule, it is assumed that nearly 85% of patients, who continuously fail to cooperate with the physician, experience an exacerbation of the disease, whereas only 30% of patients in this group are able to recognise the non-compliance with medical recommendations as a reason for such disease relapse. However, according to medical staff, it is the patient's family or persons directly taking care of patients who should assume responsibility for the supervision over the compliance with medical recommendations. On the other hand, caregivers who are well aware of their responsibilities indicate that it is one of the most difficult roles that they have to perform when taking care of patients.<sup>[44-46]</sup>

**Diagram 8.**  
**Cooperation between physicians and patients**

Source: ADHES study<sup>[44-46]</sup>

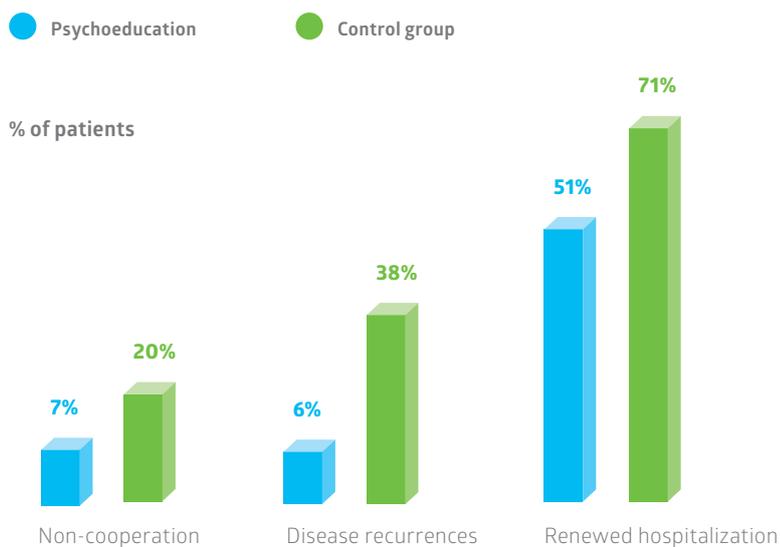
- Cooperating patients
- Patients with difficulties in cooperation
- Patients persistently failing to cooperate



## AWARENESS AND PSYCHOEDUCATION

Insufficient cooperation often results from the lack of understanding and acceptance of the disease both by patients and their caregivers. Upon the diagnosis, the patient usually treats a disease as a sentence, seeing no point in entering treatment and often gives up to the disease, which is mainly due to the lack of knowledge on schizophrenia and possible positive effects of treatment.

**Diagram 9.**  
Role of psychoeducation in improving patients' cooperation, reducing disease recurrences and renewed hospitalization



Building awareness amongst patients and persons belonging to their immediate environment by expanding their knowledge on the disease, its treatment and functioning in various areas related to disease treatment is the factor influencing the quality of cooperation. Psychoeducation constitutes a form of measure aimed at changing the patient's attitude and behaviour during the therapy.<sup>[34]</sup>

The patient participating in an educational programme is more likely to adhere to medical recommendations and less likely to experience disease recurrences which usually have a milder course and the hospitalization itself is usually shorter.<sup>[47]</sup> Participation in psycho-educational activities positively influences the general and social functioning of patients, their life quality and satisfaction from the mental healthcare services (cf. Diagram 9).<sup>[47]</sup>

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**It is hard to estimate the number of patients using oral antipsychotic drugs and showing the lack of cooperation or only partial cooperation, which prevents the complete diagnosis of a problem.**

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# 04

# SCHIZOPHRENIA TREATMENT

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**COMPREHENSIVE TREATMENT  
OF SCHIZOPHRENIA USUALLY  
TAKES THE ENTIRE LIFE OF A PATIENT  
AND ALSO INCLUDES PSYCHOEDUCATION,  
PSYCHOTHERAPY AND ACTIVITY-BASED  
THERAPY, NEXT TO PHARMACOLOGICAL  
TREATMENT.**

## EFFICACY OF LONG-ACTING ANTIPSYCHOTIC INJECTIONS

**Treatment of such disorders as schizophrenia - having a complex picture and high impact on the life of affected persons - requires a multi-dimensional approach, both with respect to strictly medical treatment and rehabilitation.**

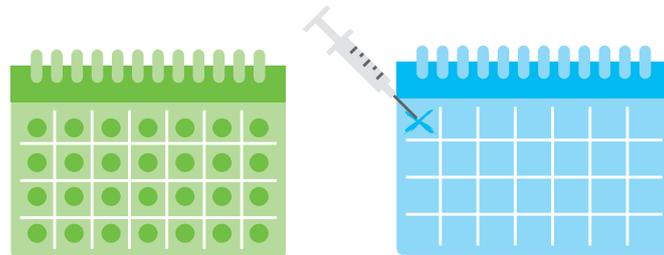
Therapy of schizophrenic patients encompasses the treatment of disease exacerbations, as well as long-term maintenance therapy. The main purpose of therapy is to prevent disease recurrences, reduce the intensity of symptoms and improve the quality of life.

From a broader perspective, effective treatment which enables a patient to return to normal life also helps in reducing the DALY (Disability-Adjusted Life Year) ratio, i.e. the measure of social burden caused by disease which is expressed in units of time. One DALY means the loss of one year of healthy life resulting from the disability or early death. According to the WHO data, in 2010 alone, more than 92,000 years of life (DALY) were lost in Poland due to early death or health impairment caused by schizophrenia.

The disability alone constituted the primary social burden. In order to reflect the impact of schizophrenia on the Polish society, one should imagine a complete health loss experienced by the residents of such cities as Słupsk, Jaworzno or Grudziądz. The impact of schizophrenia on the health of the population is increasing over the subsequent years.<sup>[48]</sup>

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There are different ways to take schizophrenia medication, including



### PILLS

Taken by mouth on a daily basis, sometimes multiple times a day. They must be taken as directed to be effective.

### LONG-ACTING OR SHORT-ACTING INJECTABLES

Administered by injection by a trained healthcare professional. Long-acting medication may be given once or twice a month. Between injections, medicine is released gradually in the body so it lasts over time. Injections must be given on schedule to be effective.

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## Development of antipsychotic drugs

Source: Juckel and Morosini, 2008<sup>[49]</sup>



## AVAILABLE FORMS OF DRUG THERAPY

The currently available psycho-pharmacological measures include both antipsychotic drugs with proven efficacy (conventional drugs, first-generation drugs), which have been in use since the middle of the 20th century, as well as new substance of slightly different mechanism of action (atypical drugs, second-generation drugs).

Conventional drugs, which significantly block the dopamine receptors, have limited efficacy in controlling negative symptoms and their use is connected with a high degree of risk of adverse extrapyramidal symptoms, including:

- dystonic reactions consisting in strong muscle tensions and bending of different parts of the body which often cause an unnatural posture,
- seizures during which a patient stares at one single point for a long time,
- drug-induced parkinsonism with symptoms resembling the Parkinson's disease,
- involuntary movements, pulsation of muscles, muscle tremors.

These medicinal products are used mainly in disease exacerbations and in long-term treatment in aggressive patients who suffer from hallucinations and delusions.

The most common drugs used currently in the treatment of schizophrenia are atypical drugs. The anti-dopamine effect of these medications is weaker and their mechanism of action involves an additional blockage of receptors of neurotransmitters' routes (serotonin, muscarinic, histamine receptors). Compared to first-generation drugs, **atypical drugs ensure better control of negative and affective symptoms, higher impact on cognitive disorders and decreased risk of adverse extrapyramidal symptoms which, in turn, helps in avoiding the deterioration of cooperation between the patient and the physician and, in consequence, reduces the risk of disease relapse.** <sup>[50, 51]</sup>

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### THE LACK OF COOPERATION

OR ONLY PARTIAL COOPERATION BETWEEN THE PATIENT AND THE PHYSICIAN IN TREATING SCHIZOPHRENIA IS THE MOST COMMON PROBLEM REGARDING THE USE OF ORAL ANTIPSYCHOTIC DRUGS.

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**Two categories of antipsychotic drugs used in schizophrenia treatment:**

#### **FIRST GENERATION (conventional)**

Available in the form of pills, intramuscular injections and long-acting injections.

#### **SECOND GENERATION (atypical)**

Available in the form of pills, intramuscular injections and long-acting injections.

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## PROLONGED-RELEASE INJECTIONS

**Beside the oral preparations of the above-described medications, their prolonged-release equivalents are also used and administered in form of intramuscular injections once or twice a month (so called LAIs or long-acting antipsychotic injections). The use of long-acting drugs is an important option in treating schizophrenia.**

At the same time, the common belief, according to which the use of LAIs is reserved exclusively for patients non-cooperating with the physician, seems to be misleading. In the first place, it should be noted that the use of long-acting medication ensures a **stable level of active substance in the body**, thus, guaranteeing higher efficacy of antipsychotic treatment. It helps in avoiding any fluctuations in the drug level in the body which allows for a long-term clinical improvement.

The administration of long-acting antipsychotic injections also facilitates treatment thanks to the use of **the lowest possible medication doses** which, in turn, may minimise the risk of the occurrence of adverse effects during therapy. The use of long-acting antipsychotic injections also **reduces the risk of a sudden discontinuation of treatment or overdose**, and enables the patient to break the routine of a daily administration of a specific number of tablets.<sup>[52]</sup> In the light of the foregoing, the

administration of drugs only once or twice per month may extend the remission period which, in turn, results in a full social inclusion of the patient, reduced disability level, return to work and reduced risk of suicide.<sup>[53-55]</sup>

Obviously, it is equally important to **improve the patient's cooperation with healthcare professionals** which, in a broader perspective, also leads to the **reduction of anxiety in the patient's environment and concerns as to whether the patient adheres to medical recommendations.**<sup>[50]</sup> This is partly due to the fact that administration of long-acting antipsychotic injections requires a visit to an outpatient care department which allows for a direct contact between the patient and the medical staff, and - even more importantly - **allows a distinction to be drawn between the lack of response to a specific medication and the lack of response caused by a non-systematic daily use of oral medications.** A caregiver is simultaneously absolved from their obligation to remind the patient of adhering to medical recommendations on a daily basis and is no longer obliged to negotiate the administration of another dose of medication with a patient.<sup>[21]</sup>

In the light of the foregoing, the administration of long-acting antipsychotic injections in all groups of schizophrenic patients, including patients after the first psychotic episode, is more and more often considered in the clinical practice guidelines, whereas the only prerequisite for such practices is a planned and relatively long treatment period.<sup>[56]</sup>

## PROVEN EFFICACY OF LONG-ACTING ANTIPSYCHOTIC INJECTIONS

The efficacy of long-acting antipsychotic injections has been proven in multiple randomized clinical studies and in everyday clinical practice.<sup>[57]</sup>

Long-acting antipsychotic injections, especially the second-generation ones (atypical drugs), as compared to orally administered drugs:

- **may lead to the reduction of symptoms and, thus, mitigate the course of disease;**<sup>[58, 59]</sup>
- **improve the general functioning of patients**<sup>[60]</sup>, in particular patients with a newly diagnosed disorder,<sup>[61]</sup>
- **reduce the risk of hospitalization.**

According to the systematic review in which only pre-post studies were analysed (which are recognised by experts as more relevant to the actual clinical practice), switching from oral treatment (pre) to long-acting injections (post) allows for the **reduction of the hospitalization risk by more than 60%** and, therefore, significantly reduces the number of hospital admissions in schizophrenic patients.<sup>[62]</sup> At the same time, the administration of atypical drugs in form of long-acting injections enables the reduction of the percentage of hospi-

talized patients by nearly 27% in comparison to patients treated with oral medications<sup>[63]</sup>;

- they are **well tolerated** by patients and have **an advantageous safety profile**<sup>[64-66]</sup>
- they positively influence the cooperation with physicians and increase the observance of medical recommendations; in addition, **it is necessary to amend treatment or increase the dosing in a smaller number of patients;**<sup>[67, 68]</sup>
- they may **improve the life quality of caregivers** of schizophrenic patients - the treatment regime is simplified and the patient does not have to be encouraged and reminded of taking drugs every day, thus, the level of stress and anxiety sensed by caregivers is reduced.

It is necessary to consider that long-acting antipsychotic injections are atypical drugs which allow to achieve the above-standard objectives of treating schizophrenia - i.e. the restoration of pro-social and cognitive functions with simultaneous anti-depression effect. They serve as an exceptionally advantageous form of antipsychotic treatment due to the combination of benefits of both long-acting and second-generation medications.<sup>[51]</sup>

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THE TREATMENT WITH  
PROLONGED-RELEASE DRUGS  
REDUCES THE BURDEN BORNE BY CAREGIVERS.

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## ACCESS TO LONG-ACTING MEDICATIONS FROM THE POLISH PERSPECTIVE

**In Poland, amongst the currently available antipsychotic drugs of prolonged release, the reimbursement is possible with regard to conventional drugs (haloperidol, zuclopenthixole, flupenthixole) and atypical drugs (risperidone, olanzapine).**

DESPITE THE PROVEN THERAPEUTIC BENEFITS, THE USE OF ATYPICAL ANTIPSYCHOTIC DRUGS OF PROLONGED RELEASE IS CURRENTLY NOT VERY COMMON IN CLINICAL PRACTICE, WHICH IS DIRECTLY CONNECTED WITH THE LIMITATIONS OF DRUG REIMBURSEMENT POLICY.

Despite the positive opinion of the Transparency Council, there are two types of new generation long-acting antipsychotic injections - paliperidone and aripiprazole - which have not yet been included in the list of reimbursed drugs.<sup>[69, 70]</sup> The experts from the Polish Psychiatric Association emphasize that no new psychotropic drug has been added to the list of reimbursed drugs in recent years.<sup>[71]</sup> Moreover, only conventional long-acting injections are reimbursed in a wide variety of indications, i.e. in mental disorders or mental retar-

dation, whereas the access to second-generation reimbursed drugs in form of long-acting injections is very limited. Only a narrow group of patients previously treated with oral medications, who experienced the relapse of the disease due to a documented, persistent lack of cooperation, is entitled to reimbursement.

According to the national consultant of psychiatry, the documented persistent lack of cooperation shall be understood as the patient's conduct which lasts at least 4 weeks and is persistent despite attempts to change the patient's behaviour: non-adherence to the medical recommendations regarding drug administration, dose adjustments, discontinued treatment, failure to appear at medical appointments.<sup>[72]</sup> The situation is additionally complicated by the fact that it is hard to assess the actual level of the patient's cooperation. The most objective method would be the monitoring of drug serum concentration, however, such blood tests are very expensive and burdensome for the patient. Other methods - such as counting tablets or packages, or electronically registered opening of packages - are too subjective and unreliable.<sup>[50]</sup>

At the same time, experts emphasize the usefulness of long-acting injections in the first, critical period of the disease, i.e. after the first episode of schizophrenia and in the first years after having fallen sick. Thus, the limitation of their use only to patients with chronic schizophrenia who suffer from significant functional deficits and do not cooperate during treatment presents a considerable barrier to access to therapy for young people. According to experts, this group of patients would draw the greatest advantage and obtain a chance to continue work and education. The use of long-acting injections would help in limiting the recurrences of the disease, mainly through the expected high degree of cooperation, and would allow for the reduction in indirect costs related to the disease, such as incapacity to work or pensions. <sup>[56, 71, 73-76]</sup>

*„The Polish mental healthcare system is in the process of a gradual transition from treatment carried out in large, independent psychiatric hospitals to the model of community-based psychiatry.”*

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TO PROVIDE PATIENTS AND PHYSICIANS WITH A BROADER ACCESS TO VARIOUS FORMS OF PHARMACOLOGICAL TREATMENT WHICH WOULD ENABLE THE INDIVIDUALISATION AND OPTIMISATION OF TREATMENT, IT IS NECESSARY TO INTRODUCE ALTERNATIVE LONG-ACTING DRUGS WITH POSITIVE RISK-BENEFIT BALANCE ONTO THE MARKET.

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# 05 COSTS OF SCHIZOPHRENIA

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**SCHIZOPHRENIA WAS RANKED 4<sup>TH</sup>  
AMONG ALL DISEASES CAUSING  
INABILITY TO WORK AND GENERATING  
THE HIGHEST EXPENSES FOR THIS  
KIND OF INABILITY IN 2013.**

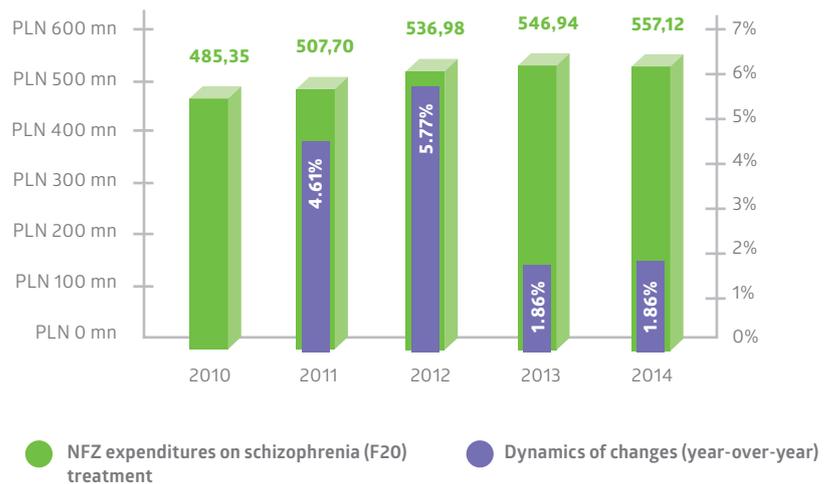
## DIRECT COSTS

In 2012, the amount of investment spent on healthcare in Poland was PLN 107.8 billion which represented 6.8% of the country's GDP. It should be pointed out that this percentage was much lower than the average value calculated for the OECD countries. The state expenditures exceeded 70% of the overall expenses with more than 28% share of private costs. [77, 78]

The expenditures for medical services related to the treatment of patients with diagnosed schizophrenia are on the rise every single year. Between 2010 and 2014, they jumped by nearly 15% from PLN 485.34 million to PLN 557.12 million, respectively. In 2014, the costs of treating schizophrenic patients amounted to 0.98% of the overall value of all contracts signed by the National Health Fund (NFZ) with health care providers. [79, 80]

The medical care for schizophrenic patients is financed from a wide range of medical benefits. In 2014, the highest expenditures were recorded in the field of mental healthcare services and addiction treatment (PLN 554,386,115.00) as well as care benefits and allowances (PLN 2,586,109.00).

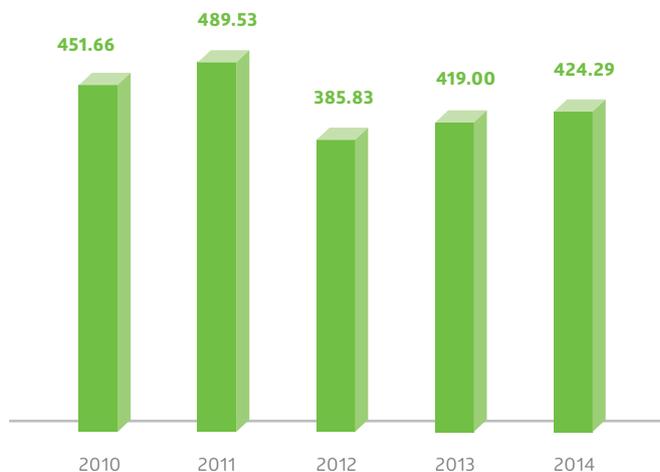
Diagram 10. Expenditures on the National Health Fund (NFZ) services related to the treatment of schizophrenic patients and the growth dynamics over the years 2010-2014<sup>[81]</sup>



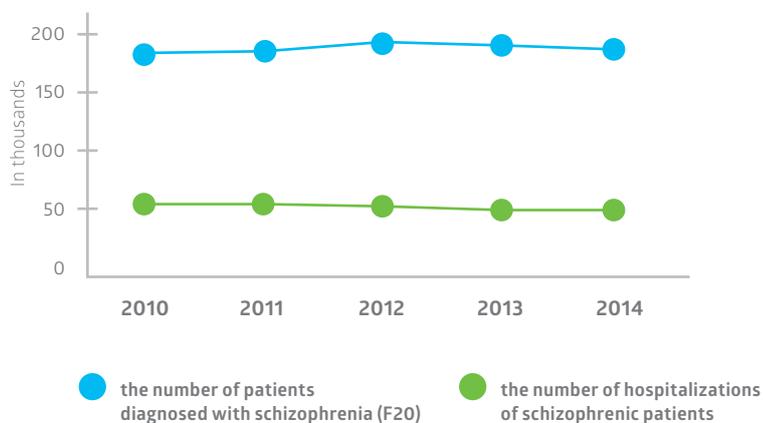
### THE LOW RATE OF CONTINUED TREATMENT

WITH ORAL ANTIPSYCHOTIC DRUGS, WHICH RESULTS FROM LOW COMPLIANCE WITH MEDICAL RECOMMENDATIONS, LEADS TO FREQUENT RELAPSES AND RENEWED HOSPITALIZATIONS, AND IS RELATED TO PERMANENT DETERIORATION OF THE PATIENT'S FUNCTIONING. THE MOST EXPENSIVE COMPONENT OF DIRECT MEDICAL COSTS ARE FREQUENT, RENEWED HOSPITALIZATIONS.

**Diagram 11.**  
Expenditures on the reimbursement of drugs used  
in the treatment of schizophrenia and the bipolar affective disorder  
over the years 2010-2014 (PLN mn)



**Diagram 12.**  
Number of patients and hospitalizations of patients  
diagnosed with schizophrenia (2010-2014)



The costs of the reimbursement of drugs used in the treatment of schizophrenia and the bipolar affective disorder exceeded PLN 424 million in 2014. In 2011, there was an upward trend in the National Health Fund (NFZ) expenditures on the drug reimbursement, but in 2012 the drug refund value fell dramatically (by more than PLN 103 million), which was probably due to the adoption of Drug Reimbursement Act and the application of sanctions against physicians for any malpractice regarding the prescription of reimbursed drugs. Over the years 2010-2014, there could be observed a drop in the National Health Fund (NFZ) expenditures on the reimbursement of drugs used in the treatment of schizophrenia and the bipolar affective disorder by more than PLN 27 million (cf. Diagram 11).

In 2014, there were more than 187,000 schizophrenic patients treated in Poland. At the same time, the National Health Fund (NFZ) financed 52,387 days of hospitalization related to this condition. Between 2010 and 2014, the number of schizophrenic patients and the number of hospitalizations of these patients were similar (cf. Diagram 12). Between 2010 and 2013, the average duration of patient hospitalization (data for ICD-10: F20-F29) increased by 12.6 days and equalled 34.8 days in 2013<sup>[82]</sup> (cf. Diagram 13).

The costs related to the treatment of patients with diagnosed schizophrenia vary greatly in different voivodeships which is, undoubtedly, connected with the number of patients who reside in a given region or have entered treatment in

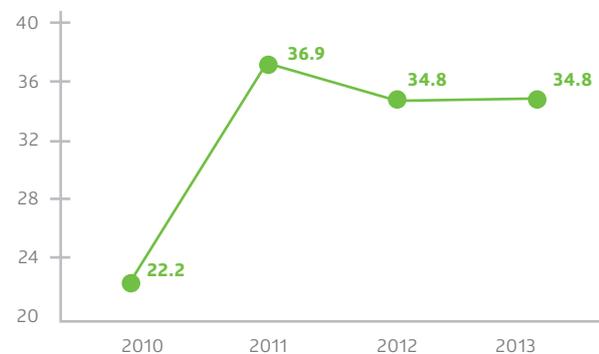
a given area (in 2014, 13.4% of all the schizophrenic patients were treated in the territory of Masovian Voivodeship, 11.64% in the Silesian Voivodeship and 9.26% in the Lesser Poland Voivodeship). In 2014, the highest costs of treating schizophrenia were recorded in the Masovian Voivodeship and in the Silesian Voivodeship (which amounted to PLN 87.01 million and PLN 73.69 million, respectively). These costs represented, correspondingly, 15.62% and 13.23% of the total expenditures incurred by the National Health Fund (NFZ) for the treatment of schizophrenia. The lowest expenditures were generated by the treatment of patients in the Warmia and Mazury Voivodeship and in the Świętokrzyskie Voivodeship (2.84% and 2.77%, respectively).

Given the nature of the data and the manner of settling certain medical services (e.g. services performed within primary care are settled on the basis of a per capita rate), it is hard to estimate costs related to treatment and, thus, it may be assumed that the actual medical costs of treating patients with diagnosed schizophrenia are much higher than presented in this report.

It should be pointed out that, beside the costs incurred by the National Health Fund (NFZ) for the treatment of schizophrenia, in Poland, there is also the National Mental Health Program which is mainly focused on improving access to various forms of psychiatric care and enhancing the therapeutic offer.

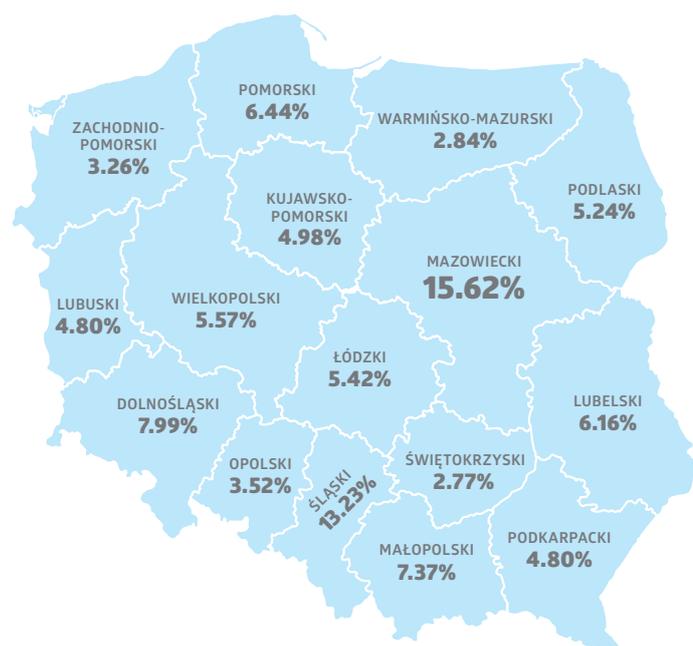
**Diagram 13.**  
Average number of hospitalization days of patients with psychoses, including schizophrenia, over the years 2010-2013

\*this data concerns patients diagnosed with ICD-10: F20-F29



**Share of direct costs incurred for the treatment of schizophrenic patients in individual Voivodeship Branches of the National Health Fund (NFZ) in 2014**

Source: Own study



The programme is financed from the state budget, by the local government entities and the National Health Fund (NFZ). In 2014, in accordance with the programme conditions, the expenditures on the implementation of individual tasks amounted to nearly PLN 330 million, whereas the recommended expenditures for the years 2011-2015 were calculated in the financing schedule at the level of PLN 1.27 billion.<sup>[83]</sup>

## SOCIAL BENEFITS PAID OUT IN RELATION TO SCHIZOPHRENIA

**In 2013, the expenditures incurred by the Social Insurance Institution (ZUS) due to schizophrenia (ICD-10: F20) exceeded the amount of PLN 1.11 billion which represented 3.4% of overall expenditures incurred for all the diseases (ICD-10: A00-Z99).<sup>[84]</sup>**

In the ranking of diseases causing an incapacity to work, generating the highest expenditures on benefits related to such an incapacity in 2013, the schizophrenia took the 4th place, after the obstetric care due to conditions related mainly to pregnancy (O26), chronic ischaemic heart disease (I25) and disorders of nerve plexus and nerve roots (G54).

In 2013, the highest share in the Social Insurance Institution (ZUS) pay-outs due to schizophrenia belonged to pensions for incapacity to work and social pensions which represented 74.4% (PLN 827,785,000.00) and 22.7% (PLN 252,647,000.00) of the overall ZUS expenses on the schizophrenia, respectively (cf. Table 1).

**Table 1.**  
**Social Insurance Institution (ZUS) expenditures due to schizophrenia in 2013**

Source: Social Insurance Institution (ZUS) data

Type of benefits	Pay-outs [in million PLN]	Share in pay-outs due to schizophrenia
Incapacity to work pensions	827.79	74.352%
Social pensions	252.65	22.693%
Rehabilitation benefits	9.88	0.888%
Sickness absence	23.01	2.066%
Medical rehabilitation	0.02	0.002%
<b>TOTAL</b>	<b>1,113.34</b>	<b>100.0%</b>

## INDIRECT COSTS

According to the International Classification of Diseases (ICD-10), schizophrenia (F20) is a chronic disease with a tendency for relapse and exacerbation of symptoms. Relapse is commonly observed in 70-80% of all the cases of disease. The patients diagnosed with schizophrenia require continuous treatment and prophylaxis in the remission periods. The persons suffering from schizophrenia have difficulties in adapting to social life, including working environment. This disease is a factor behind the absenteeism and the reduction in professional activity.

Apart from direct costs, schizophrenia leads to lower productivity. The loss of productivity caused by the disease is due to the absence from work, reduced workforce productivity, the need for using state aid (pensions for permanent and temporary incapacity to work), early death, as well as informal care provided by third parties.

The data presented in this study are focused on the loss of productivity caused by the employee's absence from work due to sickness (short-term absenteeism) and related to the collection of pension for complete or partial incapacity to work by the employee (long-term absenteeism).

*„Despite its relatively low prevalence in the population due to its chronic nature and its impact on multiple aspects of social life of patients, schizophrenia constitutes a considerable challenge for health policy.”*

SCHIZOPHRENIA IS A CHRONIC DISEASE WITH RECURRENCES OBSERVED IN

**70-80%**  
OF PATIENTS.

**SCHIZOPHRENIA AFFECTS ALL THE ASPECTS OF THE PATIENT'S LIFE, COMPROMISES COGNITIVE FUNCTIONS, PREVENTS FULL SOCIAL LIFE EVEN IN A FAMILIAR ENVIRONMENT, LEADS TO DIFFICULTIES AT WORK OR EVEN UNEMPLOYMENT.**

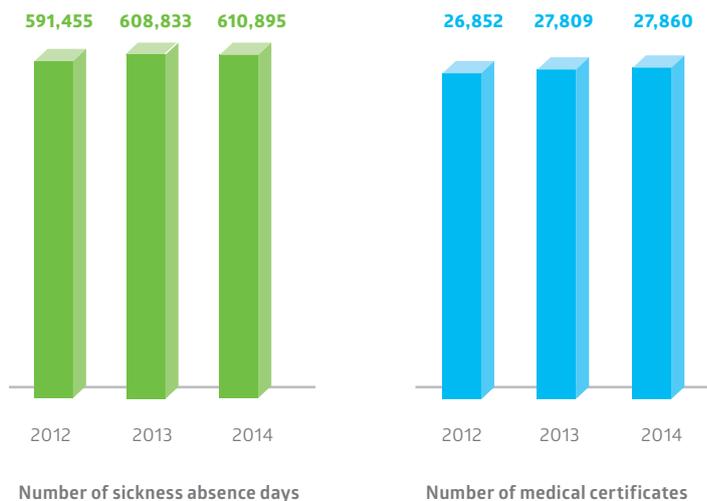
**Table 2.**  
**Sickness absence due to schizophrenia (F20) in 2014**

Source: Social Insurance Institution (ZUS) data<sup>[85]</sup>

	Number of sickness absence days	Number of medical certificates
F20 Schizophrenia	610,895	27,860

**Diagram 14.**  
**Sickness absence due to schizophrenia (F20) between 2012 and 2014**

Source: Own study based on the Social Insurance Institution (ZUS) data<sup>[85]</sup>



## SHORT-TERM INCAPACITY TO WORK

In 2014, the Social Insurance Institution (ZUS) issued more than 27,000 medical certificates concerning temporary incapacity to work due to schizophrenia which means that approximately 15% of diagnosed patients received at least one sick leave due to schizophrenia in the same year. The total number of sickness absence days exceeded 610,000. (cf. Table 2). Since 2012, the number of days of sick absence caused by schizophrenia has shown an upward tendency, just as the number of issued medical certificates (cf. Diagram 14).

In 2014, the average duration of leave due to temporary incapacity to work amounted to nearly 22 days. The majority of medical certificates (2,956) related to the absence from work due to schizophrenia was issued for the period of 14 days (cf. Diagram 15).

## LONG-TERM INCAPACITY TO WORK

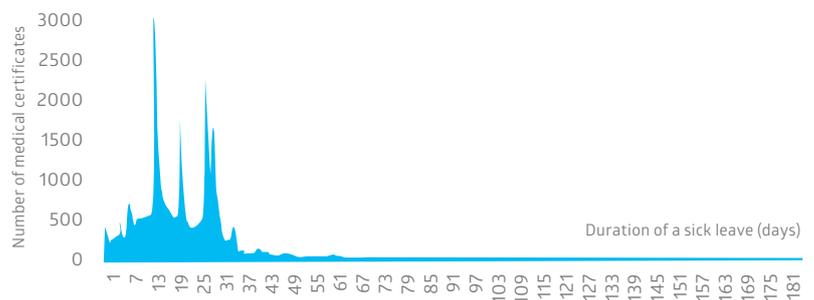
In 2014, as much as 15,800 persons with diagnosed schizophrenia were granted the right to pension for incapacity to work (partial or complete). There were 1,192 first-time medical certificates and 14,608 renewed medical certificates issued (cf. Table 3).

Most of them, i.e. more than half, were medical certificates confirming complete incapacity to work (cf. Diagram 16).

The number of first-time medical certificates issued in 2014 increased by nearly 11% compared to 2011. With regard to 2012 and 2013, the number of persons who were granted a pension due to schizophrenia for the first time was slightly lower in 2014. Likewise, similar drop was observed with regard to renewed pensions. In 2014, the number of granted medical certificates was lower than in previous years, except for 2010 when the highest number of renewed medical certificates was issued (cf. Diagram 17, Diagram 18).

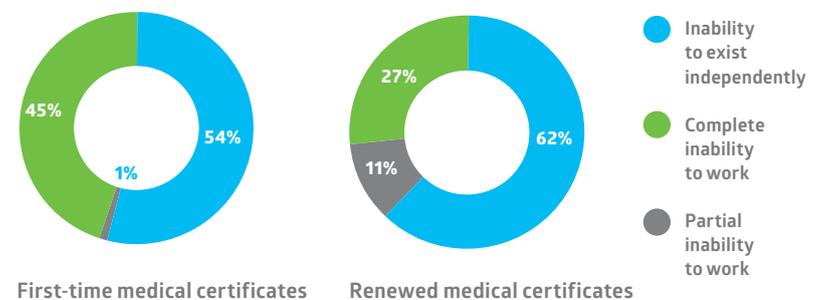
**Diagram 15.**  
Number of medical certificates issued due to schizophrenia (F20) according to the duration of a sick leave in 2014

Source: Own study based on the Social Insurance Institution (ZUS) data <sup>[85]</sup>



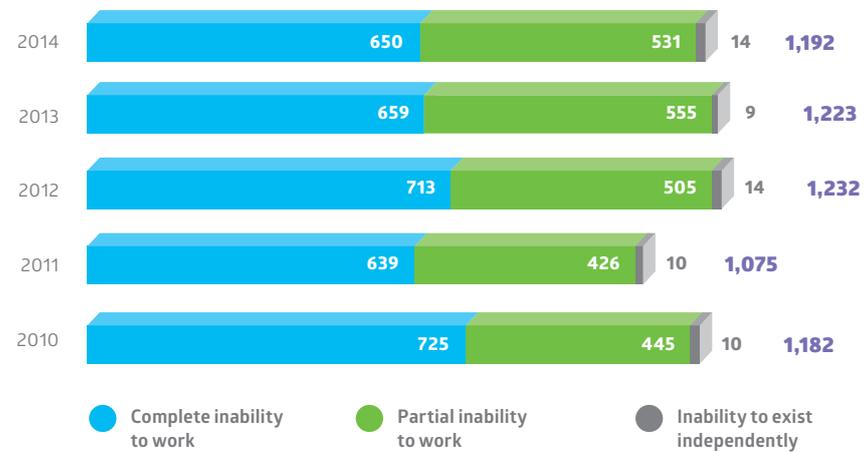
**Diagram 16.**  
Structure of first-time and renewed medical certificates issued for pension purposes due to schizophrenia in 2014

Source: Own study based on the Social Insurance Institution (ZUS) data <sup>[85]</sup>



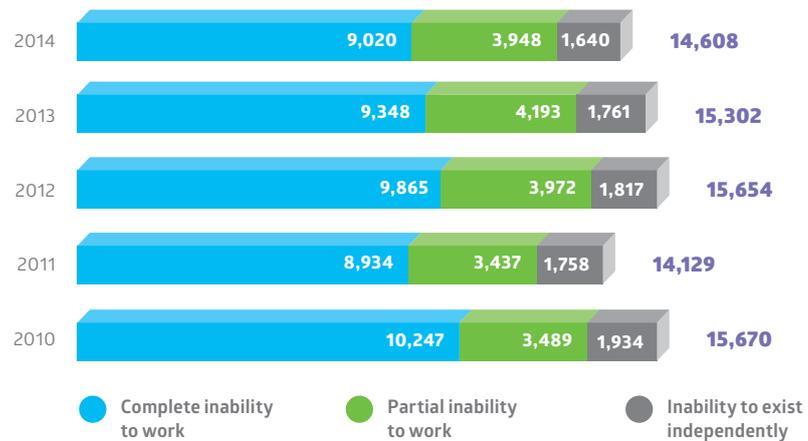
**Diagram 17.**  
Number of issued first-time medical certificates for pension purposes  
due to schizophrenia (F20) between 2010 and 2014

Source: Own study based on the Social Insurance Institution (ZUS) data [85]



**Diagram 18.**  
Number of issued renewed medical certificates for pension purposes  
due to schizophrenia (F20) between 2010 and 2014

Source: Own study based on the Social Insurance Institution (ZUS) study [85]



**Table 3.**  
**First-time and renewed medical certificates issue for pension purposes due to schizophrenia (F20) in 2014**

Source: Social Insurance Institution (ZUS) data <sup>[85]</sup>

	Inability to independent existence	Complete incapacity to work	Partial incapacity to work	Total
First-time medical certificates, including:	14	648	530	1,192
Definite medical certificates	14	639	518	1,171
Indefinite medical certificates	-	9	12	21
Renewed medical certificates, including:	1,640	9,020	3,948	14,608
Definite medical certificates	1,449	8,351	3,948	13,748
Indefinite medical certificates	191	669	321	1,181

**Table 4.**  
**Average age of pension retirement due to schizophrenia (F20) in 2014**

Source: Own study based on the Social Insurance Institution (ZUS) study <sup>[85]</sup>

Age [years]	First-time medical certificates			Renewed certificates		
	Inability to independent existence	Complete incapacity to work	Partial incapacity to work	Inability to independent existence	Complete incapacity to work	Partial incapacity to work
	40.93	38.19	38.85	50.67	46.04	44.98

**Table 5.**  
**Average duration of definite pension retirement due to schizophrenia (F20) in 2014**

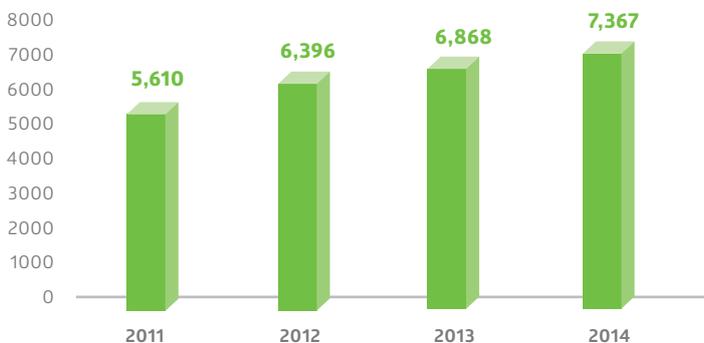
Source: Own study based on the Social Insurance Institution (ZUS) study <sup>[85]</sup>

Duration [months]	First-time medical certificates			Renewed certificates		
	Inability to independent existence	Complete incapacity to work	Partial incapacity to work	Inability to independent existence	Complete incapacity to work	Partial incapacity to work
	26.54	22.87	20.34	33.74	35.04	33.69

**SOCIAL PENSIONS ARE BENEFITS AWARDED TO ADULTS WHOSE STATE OF HEALTH DOES NOT ALLOW THEM TO TAKE UP ANY JOB. HOWEVER, THE DETERIORATION OF HEALTH MUST HAVE TAKEN PLACE BEFORE THE AGE OF 18 YEARS OR IN THE COURSE OF STUDIES BUT BEFORE THE AGE OF 25 YEARS, OR DURING DOCTORAL STUDIES. OTHERWISE, THE PENSION WILL NOT BE GRANTED.**

**Diagram 19.**  
**Social pension medical certificates due to schizophrenia (F20) between 2011 and 2014**

Source: Own study based on the Social Insurance Institution (ZUS) study <sup>[85]</sup>



In 2014, as much as 7,367 patients received social pension due to schizophrenia. Over the years 2011-2014, there was observed a continuous increase in the number of patients receiving such benefits (cf. Diagram 19). Schizophrenia affects many people at a relatively young age, even before they enter the labour market. Personal development and proper functioning in the society is inhibited by an emerging mental crisis which often leads to the exclusion from the labour market. Undoubtedly, this constitutes a tremendous financial burden both for the patient's family, as well as for the entire society.

In 2014, the patients suffering from schizophrenia received partial or complete pensions in the average age of 38 years. In the case of patients who were incapable to work and live independently, the average age of receiving first-time medical certificates was 41 years. Whereas the average age at which patients received renewed medical certificates was between 45 and 51 years (cf. Table 4). The first-time medical certificates were issued for an average period of 2 years, whereas the renewed medical certificates were issued for the period of almost 3 years (cf. Table 5).

## METHODOLOGY FOR ESTIMATING INDIRECT COSTS

Indirect costs are generated by short- or long-term absenteeism. They constitute a serious financial burden both for the state budget and for an individual patient. In this report, the costs related to the loss of production capacity due to sickness were calculated based on two methods: human capital approach (HCA) and friction cost approach (FCA).

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### FRICION COST APPROACH

The friction cost approach pays attention to the fact that, over the longer term, the „lost employee” may be replaced by another person who has been unemployed or by the reorganisation of work. In this method, the loss of productivity is calculated for a defined period of time - so called friction period - which is necessary to restore an adequate level of production.<sup>[11]</sup>

The calculations are based on the assumption that the friction period, i.e. the time needed to replace a given employee with another one, amounts to 3 months.

### HUMAN CAPITAL APPROACH

In the human capital approach, the social loss due to sickness means that the entire human capital of a given person cannot be any longer used by the society.

This loss is taken into account during the entire period of the sickness or decreased professional activity of the patient.

This method helps to determine the maximum loss of productivity.<sup>[10]</sup>

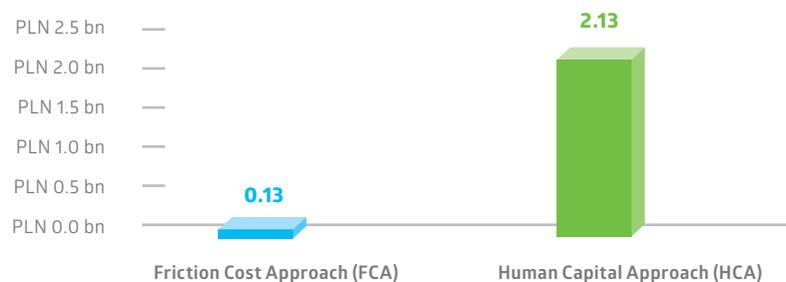
**Table 6.**  
**Indirect costs of schizophrenia**

Source: Own study based on the Social Insurance Institution (ZUS) and Main Statistical Office (GUS) data<sup>[85, 86]</sup>

Cost Category	Friction Cost Approach (FCA)	Human Capital Approach (HCA)
Short-term absenteeism	PLN 119,355,186.44	PLN 119,355,186.44
Long-term absenteeism (pensions)	PLN 13,426,338.60	PLN 2,011,157,859.14
<b>Total indirect costs</b>	<b>PLN 132,781,525.04</b>	<b>PLN 2,130,513,045.57</b>

**Diagram 20.**  
**Total indirect costs of schizophrenia**

Source: Own study based on the Social Insurance Institution (ZUS) and Main Statistical Office (GUS) data<sup>[85, 86]</sup>



In both approaches, the unit used to calculate the loss of productivity is the average monthly gross remuneration in the national economy which, according to the data obtained from the Main Statistical Office (GUS) amounted to PLN 3,659.40 in 2013.<sup>[86]</sup> The indirect costs are accrued until the moment of termination of professional activity by employees, i.e. until the retirement age has been reached by them. The analysis is based on the target retirement age of 67 years, according to the pension reform. In terms of pensions, it was also assumed that patients may not live long enough to reach the retirement age, thus, the results were adjusted to the life expectancy ratios based on the Polish Life Expectancy Tables of 2013 published by the Main Statistical Office (GUS).<sup>[87]</sup>

In 2013, the costs of absenteeism due to schizophrenia amounted to approximately PLN 119.36 million. Whereas, the costs of the productivity loss related to the granting of pension for incapacity to work due to schizophrenia, calculated with the use of friction cost and human capital method, amounted to approximately PLN 13.43 million and PLN 2.13 billion, respectively (cf. Table 6, Diagram 20).

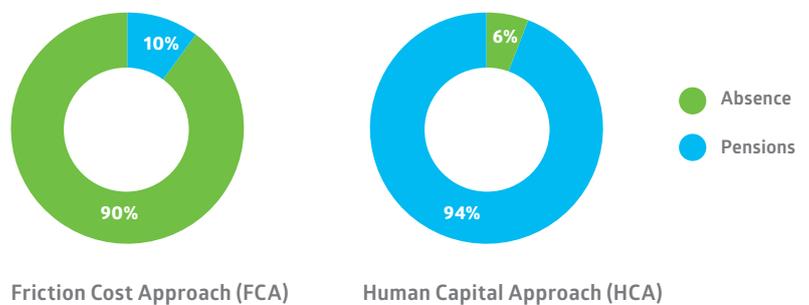
In the case of friction cost approach, there is visible a significant percentage of costs resulting from sickness absence (90%) with simultaneously low share of costs related to permanent or partial incapacity to work (10%). This results from the concept of friction cost approach - replacing an employee who is permanently incapable to work. The situation is different for costs estimated by means of a human capital approach (HCA) method. The costs of awarded pensions represent nearly 94% of the total costs (cf. Diagram 21).



**THE COSTS OF ABSENTEEISM HAS BEEN CALCULATED BY MULTIPLYING THE NUMBER OF DAYS OF SICK ABSENCE BY THE AVERAGE GROSS REMUNERATION IN THE NATIONAL ECONOMY. THE DATA PUBLISHED BY THE SOCIAL INSURANCE INSTITUTION (ZUS) CONCERN ONLY CALENDAR DAYS FOR WHICH THE MEDICAL CERTIFICATES ARE ISSUED. THUS, THE RESULTS ACHIEVED SHOULD REFERRED TO THE NUMBER OF DAYS WORKED DURING THE ENTIRE YEAR. ASSUMING THAT EACH EMPLOYEE WORKS FOR 250 DAYS IN A YEAR AND RECEIVED 26 DAYS OF PAID HOLIDAY LEAVE PER YEAR, IT HAS BEEN CALCULATED THAT IN 2013 THERE WERE 224 WORKING DAYS.**

**Diagram 21.**  
**Indirect cost structure of schizophrenia**

Source: Own study based on the Social Insurance Institution (ZUS) and Main Statistical Office (GUS) data<sup>[85, 86]</sup>



## COST SUMMARY

In 2013, the overall costs, i.e. the total direct and indirect costs related to the treatment of patients with diagnosed schizophrenia, amounted to PLN 1.1 - 3.1 billion depending on the adopted method of indirect cost estimation (friction cost approach and human cost approach respectively).<sup>1</sup> It should be emphasized that the estimated costs include also the costs incurred by the reimbursement of drugs used in the treatment of schizophrenia and bipolar affective disorder.

Apart from direct and indirect costs, there are presented the expenditures of the Social Insurance Institution (ZUS) incurred in relation to schizophrenia, which amounted to PLN 1.11 billion in 2013, and the expenditures connected with the operation of the National Mental Health Programme which equalled PLN 263.68 million (cf. Table 7).

In the case of schizophrenia, as well as many other chronic diseases, it is necessary to consider the burden resting with the persons who provide care for the patients with mental disorders. There is no doubt that the care of schizophrenic patients requires tremendous sacrifice and commitments. Caregivers often experience health deterioration, as well as suffer from stress and depression. They are usually the closest family members who invest their entire time in the care of patient, with no remuneration. It is not uncommon that persons involved in the care of a patient resign from work partially or entirely. In consequence, the indirect costs are incurred also in relation to the loss of production capacity of caregivers of schizophrenic patients. In fact, these costs are hard to measure as, according to the above analyses, the available data concerns only schizophrenic patients or, in some cases, all persons suffering from mental disorders in general. As a result, the calculation of schizophrenia costs rarely includes the losses incurred by the patient's caregiver or, in a broader sense, the patient's family due to the incapacity to perform regular work due to the provided care. The fate of non-diagnosed patients is also disregarded.

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SCHIZOPHRENIA IS ONE OF THE MOST COSTLY  
CONDITIONS DUE TO ITS EARLY ONSET, CHRONIC  
NATURE, HIGH MORBIDITY AND MORTALITY RATES.

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Despite its low prevalence in the society at the level of 0.5-1.0%, schizophrenia requires an investment of significant financial resources [88]. The reason for the high costs of schizophrenia lies in the nature of this disease. The treatment is continuous from the moment of diagnosis and usually takes years, whereas a typical onset of the diseases occurs in young age. As a chronic disease with high probability of relapse, it affects the patient's lifestyle and life quality, as well as impacts the patient's capacity to work. The adverse consequences of schizophrenia also affect the entire society as this disease leads to the loss of the patient's working time, both due to sickness leaves and temporary or permanent incapacity to work. The reduction in labour force and, thus, the loss of production capacity of the country negatively influence its economic growth. In terms of the loss of production capacity, the financial implications of this disease are particularly noticeable with regard to pensions, assuming that the capital of a given person cannot be further used by the society or replaced by another person. Moreover, approximately 1 in 3 schizophrenic patients makes suicide attempts, where 10% of such attempts results in death. [88] This also translates into higher costs from the broader view of entire society. Therefore, it is necessary to undertake measures aimed at minimising the costs related to schizophrenia.

**Table 7.**  
**Total costs related to the treatment of schizophrenic patients in 2013**

Source: Own study based on the Social Insurance Institution (ZUS) and Main Statistical Office (GUS) data [85, 86]

Cost Category	Friction Cost Approach (FCA)	Human Capital Approach (HCA)
Indirect costs (without drug reimbursement)	PLN 546,937,326.00	
Drug reimbursement costs*	PLN 419,003,464.00	
Total indirect costs	PLN 132,781,525	PLN 2,130,513,046
<b>DIRECT AND INDIRECT COSTS*</b>	<b>PLN 1,098,722,315.00</b>	<b>PLN 3,096,453,836.00</b>
<b>SOCIAL INSURANCE INSTITUTION (ZUS) EXPENDITURES</b>	<b>PLN 1,113,340,000</b>	
<b>EXPENDITURES FOR NMHP**</b>	<b>PLN 263,680,000</b>	

\*the summary includes drugs used in the treatment of schizophrenia and bipolar affective disorder

\*\*National Mental Health Programme

1) It should be noted that due to the character of available data and the manner of settling some medical services, it is impossible to conduct an accurate estimation of both indirect and direct costs, thus, the presented values should be considered approximate.

# 06

# CONCLUSIONS

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**SCHIZOPHRENIA IS THE MOST COMMON MENTAL DISORDER WHICH AFFECTS 1 IN 100 PEOPLE WORLDWIDE. DUE TO A RELATIVELY HIGH PREVALENCE IN THE POPULATION, ITS CHRONIC NATURE AND ITS IMPACT ON MULTIPLE ASPECTS OF SOCIAL LIFE OF PATIENTS, SCHIZOPHRENIA CONSTITUTES A CONSIDERABLE CHALLENGE FOR HEALTH POLICY.**

For the time being, an innovative pharmacological treatment together with a holistic rehabilitation approach enables to positively influence the course of a natural disease process, which leads to the reduction in the frequency of relapses, the reduction in the risk of intensification of stigmatising neurological deficits and the minimisation of somatic consequences of concurrent conditions.

Beside the positive effects on the patient's medical condition and functioning, the latest antipsychotics are also an economically viable option for the entire system. However, in Poland, the access to new generation drugs is significantly limited. Despite having included two state-of-the-art long-acting neuroleptics in the reimbursement lists, less than 4% of schizophrenic patients receive this form of treatment (cf. Table 8).<sup>[19, 89]</sup> Such limitation is mainly due to restrictive reimbursement conditions which, according to expert opinions, have all the characteristics of structural stigmatisation.<sup>[90]</sup> What makes the situation worse is that patient qualified for treatment with long-acting drugs of second generation are in the advanced stage of disease and often have already experience multiple relapses of psychosis, where each subsequent recurrence leads to the deterioration of social life and additional costs for payers.<sup>[19, 89]</sup> According to experts, the current situation could be improved with the classification of long-acting

second-generation drugs as first-line drugs in the treatment of schizophrenia, introduced to the treatment already after the first psychotic episode which is a key moment in the successful therapy. In such event, patients would have a better chance of normal development within the society and professional growth.<sup>[89]</sup>

**Table 8.**  
**Percentage of patients taking LAIs in different countries.**

Country/Region	Percentage of patients using LAIs
Australia	27%
Austria	50%
East Asia	15.3%
Belgium	21.5%
Finland	30%
Hong Kong	37%
Canada	6.5%
Germany	9%
New Zealand	15%
<b>Poland</b>	<b>4%</b>
Sweden	50%
USA	18-28%
Hungary	22%
Great Britain	29%

Apart from the significant role of pharmacological treatment in ensuring proper functioning of schizophrenic patients in the society, there are also other elements of healthcare system which are necessary, namely: access to outpatient care, efficient community care, support for caregivers and families, as well as employment support for patients. The treatment of mental disorders, including schizophrenia, requires an access to any and all treatment methods, including non-drug therapies. In Poland, it is possible by increasing the number of facilities providing professional assistance and counselling for persons exposed to the mental health disorders and their families. At the same time, it is necessary to popularise the community-based model of psychiatric healthcare, where professionals with diverse qualifications would treat and assist schizophrenic patients in their familiar environment.<sup>[91]</sup> Although these assumptions are included in the currently binding National Mental Health Programme, they have not been yet fully implemented.

It should be noted that the role performed by the family is extremely important in the patient's recovery process. According to experts, even the best therapy may not be successful without support from caregivers. Indicating such a significant role and responsibility of caregivers in the patient's convalescence and recovery, it would be simultaneously necessary to offer caregivers an additional psychological and educational support programme to mitigate the effects of stress which they continuously experience.

Therefore, apart from strictly medical measures, the proper care of schizophrenic patients should also focus on the psychological support of the patients - both through their family, their closest environment and their doctors. It is extremely important to keep caregivers in a good health condition as the burden of shaping the patient's will to fight the illness rests mainly with them.

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**It should be noted that the role performed by the family is extremely important in the patient's recovery process. According to experts, even the best therapy may not be successful without support from the caregivers.**

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