

SYNTHESIS

NEED: UNMET HEALTH-RELATED NEEDS ASSOCIATED WITH PSYCHOTIC DISORDERS



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■ FOREWORD

Psychotic disorders like e.g. schizophrenia or delusional disorder affect a substantial share of the population, and have a major impact on those who suffer from them. Aside from the typical symptoms of the disease, like hallucinations or impaired reasoning, these patients frequently struggle with other complaints like fatigue, stress, anxiety or depression.

Many patients also report a negative impact on employment, social inclusion and quality of life, and the disease also impacts their nearest and dearest. In other words, the care for persons living with a psychotic disorders goes well beyond purely medical considerations, and may also need to include social and psychological support.

To what extent do our healthcare system, our welfare sector and our society in general succeed in meeting the needs of people with psychotic disorders? In this NEED report, we worked directly with them to identify their unmet needs, with the underlying aim of triggering actions to better respond to those needs. Over the last few years, many policy initiatives have been taken for the benefit of people with mild to moderate mental health problems, like e.g. an improved access to primary care psychologists. The results of this report clearly show that such initiatives could also be taken to improve the care and support for this group with more serious issues.

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■ SYNTHESIS

1 BACKGROUND

1.1 About NEED^a

The NEED initiative (short for “Needs Examination, Evaluation and Dissemination”) aims to identify unmet health-related needs to support the transition to a more needs-driven healthcare policy and innovation system. It relies on an innovative, evidence-based methodology to **systematically identify and assess the health-related needs** of patients living with a specific disease (in this case, psychotic disorders) across health, healthcare, and social domains, as well as the unmet needs of society that relate to the disease. The resulting evidence is integrated in a central database and can be used to inform healthcare providers, policymakers/public funders, patient organisations, research institutes, and pharmaceutical and medical device companies **on tailoring services, interventions and R&D strategies to better support this population.**

1.2 Psychotic disorders

Psychotic disorders are a heterogeneous group of **mental health disorders characterised by psychotic symptoms** like hallucinations, delusions, and disorganised behaviour. Common diagnoses include schizophrenia, schizoaffective disorder, delusional disorder, and schizophreniform disorder^b. Schizophrenia, one of the most common psychotic disorders, has an approximate **prevalence** of 4/1 000 population. Psychotic disorders represent a major public health concern with substantial unmet needs affecting patients, caregivers, and society at large.

Symptoms typically appear in late adolescence or early adulthood, a period where they can interfere with important stages of personal and social development. Aside from the psychotic symptoms mentioned above (the so-called “positive symptoms”), patients often experience negative symptoms (e.g. loss of motivation, loss of emotional expression, reduced sense of pleasure) and cognitive symptoms (e.g. issues with memory, attention, learning or reasoning). Some will only ever experience one single episode and make a substantial or full recovery. In others, the disorder will be **chronic or recurrent** and cause persistent symptoms and difficulties in many areas of life.

Primary psychotic disorders (those that do not result from another disease or from substance use/abuse) are the result of multiple, complex and interacting **causes**, like genetic vulnerability, environmental exposures, neurodevelopmental factors and early psychosocial trauma. This makes **preventing** the disease altogether (primary prevention) particularly challenging, and current strategies mainly focus on early detection and intervention as well as avoiding further acute episodes in known patients (secondary prevention).

Diagnosis relies on clinical assessment, as there are currently no effective diagnostic tests to identify or categorise psychotic disorders, though tests can sometimes be performed to exclude other diagnoses. **Treatments** include medication (particularly antipsychotics), which mainly targets positive symptoms, and psychosocial interventions to improve functioning. **Limited illness awareness** is common in patients with psychotic disorders and is associated with delayed access to care and diagnosis, reduced treatment adherence and poorer prognosis.

^a For more information on the NEED initiative and its methodology, please refer to the previous publications available through the dedicated website: <https://health-needs.eu/index.php/en/> (select “publications” in the “research” menu).

^b This study covers all psychotic disorders as defined in the DSM-V, including bipolar disorder with psychotic features, but excluding psychotic disorders due to another medical condition (secondary psychotic disorder).

Psychotic disorders can create a **self-reinforcing cycle of exclusion**. Vulnerable populations (e.g. persons with a migration background or facing socioeconomic difficulties) are known to be at higher risk and may experience more difficulties to access the care they need. On the other hand, these diseases can have a profound impact on patients' ability to work and function in daily life and cause stigma, exclusion and socioeconomic struggles.

2 METHODS

In line with the NEED methodology, the research team explored the unmet health-related needs associated with psychotic disorders through various means, including an online survey and individual semi-structured interviews with patients or their legal representatives, a clinical expert questionnaire, and existing sources such as databases and scientific literature. The study included both patients who had been diagnosed recently, and patients diagnosed a long time ago, and who may have been in remission or in an acute or subacute phase of the disease.

3 RESULTS

It would be impossible to adequately report the wealth of insights yielded by the NEED study in this brief summary and the accompanying fact sheet, which focus on the most striking and most actionable results. Full results are available in the scientific report.

Overall, the findings call for comprehensive, patient-centred, and socially sensitive policies to better support individuals with psychotic disorders and their families.

3.1 Health burden

Psychotic disorders cause a **substantial overall health burden** in Belgium, with high disability, loss of quality of life and significant premature mortality, resulting both from the disease itself and from treatment side-effects.

Psychological symptoms – including depression or sadness, anxiety, concentration problems, and stress – were widely reported and often perceived as highly burdensome and they were also linked to challenges in daily life and social functioning.

Fatigue is the only **physical symptom** of psychotic disorders that stands out in our survey. However, weight gain is a very common side-effect of antipsychotic treatments, affecting 80% of patients. **Comorbidities** like endocrine or metabolic diseases, bone and joint issues, etc. were also frequently reported.

3.2 Healthcare challenges

Surveyed patients experienced substantial **delays** both in asking for help and in receiving a diagnosis. As mentioned above, lack of illness awareness can play a role; moreover, initial symptoms can be subtle and easy to misinterpret. The request for help may come from people around the patient, highlighting the importance of mental health awareness in the general population.

Overall **treatment effectiveness** is limited because current approaches remain mainly symptomatic rather than disease-modifying. Medication focuses heavily on controlling positive symptoms but does little to improve negative and cognitive symptoms, which might even be compounded by side effects like affective blunting or brain fog. Its effectiveness is lower in some groups, and particularly in patients who are also faced with other diseases or socioeconomic challenges. Quality of life is sometimes improved by a combination of pharmacological, psychosocial and other interventions, but symptoms can persist or reappear despite treatment, side effects are substantial, and treatment resistance can be an issue. This often results in complex treatment trajectories, with frequent adjustments in medication or dosage.

Treatment availability and accessibility is hampered by issues like disorganisation of the psychiatric care leading to long waiting lists for psychiatric consultations, the absence of reimbursement for some non-pharmacological therapies or the lack of structural funding for specific early diagnosis and early intervention (youth-friendly) services. A lot has been done over the past few years to improve access to care for mild to moderate mental health conditions, but there is still a gap to be filled for patients with more severe issues like psychotic disorders.

Surveyed patients are generally satisfied with the way their routine care is organised, and most of them typically see the same healthcare professional, ensuring good continuity of care. **Coordination of care** across different settings and providers appears considerably more challenging. Patients frequently lack support when transitioning from inpatient to outpatient care, and report that the burden of navigating the healthcare system falls largely on them.

The majority of patients report limited **participation** in treatment decisions and, while not all of them want to be more involved and shared decision-making is not always possible (e.g. during acute psychosis), this is nonetheless an attention point. Some gaps also need to be addressed in the **information** provided to patients, including clearer explanations on the disorder, treatment rationale and side-effects, as well as longer-term and future-oriented topics, including family planning. Finally, it is important to keep in mind that both participation and information needs can evolve over time or fluctuate with the severity of the disorder.

3.3 Social and societal challenges

Family and friends often play a crucial role in offering emotional and practical support, but many persons living with psychotic disorders still feel **misunderstood or even stigmatised**. The profound impact of the disease often results in strained relationships with others, but also in a **considerable burden for informal carers**, who frequently report a substantial impact on their own health, social life and productivity. Social **isolation** is frequent, especially early on, but patients report becoming more engaged in social activities (including (volunteer) work and peer support groups) as they stabilise.

Unsurprisingly, psychotic disorders also have a highly disruptive impact on **education**, given the young age at presentation, **and on work participation**. Many patients report having to interrupt their studies or even abandon them altogether. Similarly, long or permanent absences (often several years) from the work sphere are common, and many patients who remain employed need to reduce their workload or struggle with productivity issues and fatigue. Financial difficulties are common as a result, as patients frequently rely on sickness or disability insurance benefits.



■ RECOMMENDATIONS^c

To the Belgian Federal Minister for Social Affairs and Public Health and the ministers of the federated entities responsible for health

1. **Consider ways to better organise and finance early detection and early intervention programs for people with psychotic disorders in the early phases of the condition.** Such programs could improve engagement with care, reduce relapses and strengthen a range of clinical and functional outcomes compared with usual care.
2. **Devote specific attention to the early phases of psychotic disorders in the development of clinical care pathways.** The combination of high symptom burden, increased suicide risk, educational or work disruption, and loss of social roles during these phases necessitates early, intensive, and tailored interventions. In view of the frequent chronic and relapsing course of these conditions, structured and sustained follow-up over the longer term is essential. Particular attention must also be paid to the diagnostic process to ensure its quality and to the monitoring of clinical practice guidelines. Existing care pathways for chronic conditions (e.g. diabetes, chronic kidney disease) could serve as a source of inspiration.
3. **Guarantee continuity of care during transitions,** particularly from inpatient hospitalisation to outpatient services, through structured discharge planning and coordinated follow-up before the exit. The guide to good practices "Somatic care for people with severe psychiatric disorders" is, in this respect, a useful tool to support this coordination and strengthen the quality of follow-up in the front line.
4. **Strengthen support services to informal caregivers and families** of people with psychotic disorders. Caregivers provide substantial unpaid support and experience high health burden.

To the Belgian ministers of the federated entities responsible for education and adult education

5. **Guarantee reasonable educational adjustments and provide supported return-to-education programs.** Psychosis often disrupts education at critical developmental stages, leading to lasting disadvantages. Maintaining or restoring educational trajectories improves long-term employment prospects and social participation. Academic adaptations should be considered, such as the possibility of taking classes at home, the possibility of spreading out studies over more years, the possibility of continuing to receive financial aid despite several consecutive failures, etc. Initiatives in this direction, such as BedNet or ClassContact, must be supported.

To the Belgian Federal Minister for Social Affairs and Public Health and RIZIV – INAMI

6. **Strengthen financial access to long-term psychological care for people with psychotic disorders** Patients report experiencing difficulties accessing longer-term psychological care due to waiting times to see a psychologist acceding to the agreement on national tariffs (so-called conventioned psychologist) and reimbursement issues.

^c The KCE has sole responsibility for the recommendations.



To the Belgian Federal Minister for Social Affairs and Public Health, the Federal Minister of Employment, Economy, and Agriculture and the ministers of the federated entities responsible for health and employment

7. **Promote stay-at-work and return-to-work policies**, e.g. by increasing supported employment programmes such as individual placement and support. More than half of respondents reported having stopped working due to their health condition. Legislation intended to facilitate return to work for individuals on long-term leave must be implemented prudently and adapted to the particular circumstances of this group of already vulnerable patients.
8. **Strengthen cross-sectoral collaboration between health, education, and employment authorities** in line with the *Health in All Policies* approach and existing interfederal health objectives, as well as the ongoing development of regional objectives. Given the multifaceted impact of psychotic disorders, such coordination is essential to ensure effective prevention, treatment, and educational, social and occupational reintegration, with particular attention to individuals in vulnerable situations.

To researchers, research funders and the industry

9. **Direct research funding towards pharmacological interventions that improve functional outcomes and quality of life** for people with psychotic disorders. Particular attention should be given, among other things, to side effects, negative and cognitive symptoms, and treatment resistance.
10. **Direct research funding also towards non-pharmacological interventions that improve the quality of life of people with psychotic disorders.**

To groups of health professionals, healthcare providers, and academic health departments

11. **Strengthen shared decision-making and information provision, adapted to the phase of illness, the clinical insight of the patient and individual preferences.** Many patients report insufficient information and limited involvement in decisions, undermining empowerment and adherence.
12. **Promote the use of the guide to good practices "Somatic care for people with severe psychiatric disorders", this tool is useful to strengthen patient involvement and promote good information exchange in the front line.**
13. **Promote research on organizing acute care modalities.** Patients described hospitalisation as ambivalent and sometimes traumatic, particularly during first admissions, citing a lack of humanity and personalised attention. Research is needed to identify how acute care can be organised in more secured, person-centred, humane, and less destabilising ways.

To the Belgian Federal Minister for Social Affairs and Public Health, to the ministers of the federated entities responsible for Health, and to patient organisations and support groups for psychosis

14. **Develop and/or continue initiatives aiming to increase public and professional awareness of psychotic disorders to reduce stigma and improve mental health literacy.** Stigma and low mental health literacy delay help-seeking, accurate diagnosis and initiation of treatment, reduce the quality of care – particularly at first contact – and worsen social outcomes of patients with psychotic disorders.



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