



Original article

A National network of schizophrenia expert centres: An innovative tool to bridge the research-practice gap



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ABSTRACT

Schizophrenia is probably the most severe psychiatric disorder with much suffering for the patients and huge costs for the society. Efforts to provide optimal care by general practitioners and psychiatrists are undermined by the complexity of the disorder and difficulties in applying clinical practice guidelines and new research findings to the spectrum of cases seen in day-to-day practice. An innovative model of assessment aimed at improving global care of people with schizophrenia provided by the French national network of schizophrenia expert centres is being described. Each centre has established strong links to local health services and provides support to clinicians in delivering personalized care plans. A common set of assessment tools has been adopted by the ten centres spread over the whole French territory. A web application, e-schizo[®] has been created to record data in a common computerized medical file. This network offers systematic, comprehensive, longitudinal, and multi-dimensional assessments of cases including a medical workup and an exhaustive neuropsychological evaluation. This strategy offers an effective way to transfer knowledge and share expertise. This network is a great opportunity to improve the global patient care and is conceived as being an infrastructure for research from observational cohort to translational research.

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1. Introduction

Schizophrenia is probably the most severe psychiatric disorder [40]. Patients with schizophrenia exhibit a wide range of symptoms from a variety of domains. The cardinal features are delusions, hallucinations, formal thought disorder, disorganized or abnormal motor behaviour and negative symptoms. In addition to these symptoms, the disorder is, to variable degrees, accompanied by a broad spectrum of cognitive impairments [27], which strongly reduces functional outcome [21,36] and to medical comorbid disorders, which require specific assessment and treatment [2]. The onset of the disorder occurs in adolescence or early adulthood, its course is usually chronic with different stages from early prodromes to chronic and severe handicap. In addition, up to 40% of people suffering from schizophrenia attempt suicide at least once, with estimates of about 5–15% for completed suicide [52]. Schizophrenia is the third most disabling illness of the central nervous system worldwide with a global cost of 23.7 millions disability-adjusted life years (DALYs) [14].

Despite treatment advances over the past decades, schizophrenia is still associated with a chronic relapsing course, marked functional impairment in a substantial proportion of patients, and remains often unrecognized or misdiagnosed leading to delayed treatments. Moreover, recent systematic reviews indicated that subjects suffering from schizophrenia have a reduced life expectancy of 15–20 years compared with the average general population, mostly because of increased medical comorbid diseases, as well as reduced access to medical treatment and to healthcare services [48,63].

Recent systematic reviews and practice guidelines have been proposed to optimize the pharmacological management of schizophrenia [24,25,46]. While, several studies have shown that psychosocial interventions such as cognitive behavioral therapy, cognitive remediation therapy, psycho-education programs, family intervention, social skills, training programs, and case management or assertive community treatment for people with schizophrenia, as an adjunct to medications can reduce psychotic symptoms and relapse risk and improve patients' long-term outcomes [32,61]. Particularly, neuropsychological assessment and rehabilitation have gained much interest in recent years, but very few patients have access to a comprehensive neuropsychological assessment. In addition, systematic assessment of comorbid medical disorder is required as well as management of diet and of physical activity in order to improve the overall prognosis.

Due to the heterogeneity of schizophrenia, as well as the evolution through successive stages [41], personalized medicine, based on individual data to determine treatment choices including pharmacological agents, psycho-social strategies, and lifestyle measures [51] need to be implemented. In addition, strategies to reduce duration of untreated psychosis (DUP) for people with first-episode psychosis are widely advocated as a plausible way in which patient outcomes and experience of services may be improved [46].

Unfortunately, due to inadequate training of psychiatrists, lack of systematic evaluation in clinical practice and/or limited availability and access to different models of effective treatments, the dissemination of the recommendations in usual practice within mental health services is slow and patchy [43]. This leads to elevated relapse rates (80% of patients relapse within 5 years) [35,60], long duration of untreated psychosis [39], high levels of adverse effects such as movement disorders, weight gain, cardiac and sedative problems, and increased risk of developing somatic diseases and early death [10].

In France, based on the above findings, the need to reduce DUP, to improve diagnosis and personalized treatment of schizophrenia led both the Ministry of Research and the Ministry of Health to

support the development of a national network of schizophrenia Expert Centres under the aegis of FondaMental foundation (<http://www.fondation-fondamental.org>), a scientific foundation created in 2007. This paper describes how the FondaMental foundation used this opportunity to introduce a new model to implement Expert Centre enabling systematic and standardized assessment of patients suffering from schizophrenia, and to enhance collaborations between Expert Centres and local clinicians (general practitioners and general psychiatrists) who provide the first point of contact with health services for most individuals with schizophrenia. The Expert Centres offer wide access for all schizophrenia subjects with few barriers for referral and no biases towards treatment-refractory cases. Their goals are to provide reliable systematic multi-dimensional assessments of subjects leading to personalized therapeutic recommendations, all shared with the patients, their relatives and the referring clinicians. These Expert Centres are also conceived as an infrastructure for research as they enable to follow-up large size cohorts, to build large and shared databases and biobanks, and to facilitate the implementation of research projects. The links between care and research also enable the efficient transfer of innovation into clinical practice and the implementation of the quality of care.

The following sections outline the rationale for the Expert Centres and include discussions of key elements of the assessment process.

2. Implementation and development of the Schizophrenia Expert Centres

2.1. Rationale

The national network of Expert Centres is envisioned as an innovative health and research care system composed of a network of specialized teams. Each team is composed of psychiatrists, psychologists, neuropsychologists and nurses, all specialised in care and research for schizophrenia that will support - but not replace - the existing health system. The Schizophrenia Expert Centres are required to first provide a comprehensive systematic assessment of patients with a probable diagnosis of schizophrenia, using a shared e-medical tool, to elaborate psychiatric and somatic diagnoses, to give advice on personalized treatment strategies, to monitor the evolution of the disorder through yearly follow-up consultations (Fig. 1) and last to propose to patients to participate to large collaborative research projects. This integrated approach aims to:

- accelerate access to specialists for all subjects suffering from schizophrenia, as well as subjects at risk;
- promote a personalized medicine approach by a systematic and thorough investigation of schizophrenia, to improve detection and prevention of somatic and psychiatric comorbidities, to offer personalized recommendations for pharmacological, psychosocial and lifestyle care, to prospectively evaluate the impact of treatments recommended for the individual and to identify risk factors for relapse;
- reduce delays between illness onset, accurate diagnosis and introduction of appropriate treatment;
- enhance concordance between evidence-based medicine guidelines and clinical practice;
- disseminate knowledge and skills on new diagnostic tools and therapeutic strategies.

Ten regional Expert Centres have been opened so far across France, and are widely distributed all over the country. Clinical team members from each centres have monthly meetings to

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