Schizophrenia: The Patient Journey

Mohr P1, Leven A2, Arteel P3, Boyer P1, Golderisi S1, Karkkainen H1, Wasserman D1, Guldemond N4, Gaebel W1

1European Psychiatric Association (EPA); 2EUFAMI; 3GAMIAN Europe; 4 The Institute of Health Policy & Management (iBMG), Erasmus University.

Background
Schizophrenia is a severe mental disorder which affects 0.8-1.5% of the population. It is a clinically heterogeneous illness with highly variable course, typically episodic. Frequent relapses contribute to neurobiological impairment, functional and social decline, and poor treatment response. Schizophrenia has a substantial impact on patients, their families, caregivers, and society in general. It is one of the top 25 leading causes of disability worldwide, affecting negatively all the aspect of a person’s life. Schizophrenia can be effectively managed: in most cases recovery and social reintegration through adequate treatment and care is possible. However, currently more than 50% of people with schizophrenia do not receive appropriate, timely, and adequate treatment. The patient journey is a description of how patients experience a disease or condition from their first awareness of symptoms through all stages of the illness. It represents an alternative view on mental illness, based on person’s individual experience, highlighting the fact that the daily life experience of patients is diverse. The patient journey aims to identify key issues in the care for schizophrenia patients that have to be improved.

Methods
We analysed the care pathway of schizophrenia patients to identify major barriers preventing patients with schizophrenia from receiving timely and adequate treatment and we proposed recommendations on how to overcome them. The journey is based on a literature review.

The focus was on three highly relevant patient pathways (Fig. 1):

1. Indicated prevention for individuals at risk of developing schizophrenia
2. Early intervention and education of the duration of untreated psychosis (DUP) for patients not yet diagnosed with schizophrenia
3. Relapse prevention for patients after first episode of schizophrenia, and patients with episodic course of the illness

Treatment Gaps and Unmet Needs
Care pathway analysis identified the following barriers to optimal treatment:

Health care services: missed or delayed detection/diagnosis: The current systems do not provide appropriate prevention for patients at risk and early intervention services. Other contributing factors include lack of disease awareness among patients, families, and public; lack of information, training and education among primary care providers; stigmatizing attitudes and beliefs about schizophrenia.

Limited access to timely and adequate treatment: The current model does not provide optimal management of schizophrenia due to the poor collaboration among health and social care professionals and lack of continuity of the antipsychotic treatment. Furthermore, there is a lack of cooperation between care providers and patients and their families, inadequate utilisation of pharmacological and psychoeducational interventions, and proper patient monitoring.

Non-adherence to treatment: A major factor causing non-adherence, in addition to illness-related factors (lack of insight), is that patients are often not well informed on the medications’ side effects and/or how to manage them.

Limited availability of rehabilitation programmes: Social and vocational rehabilitation (employment services, money management counseling, cognitive remediation, social skills training) helps people with schizophrenia to improve overall functioning and social reintegration, to participate fully in their communities.

Low implementation of deinstitutionalization: Deinstitutionalization has been demonstrated to be beneficial to the patients while low implementation of deinstitutionalization:

- Poor collaboration among health and social care professionals
- Lack of continuity of the antipsychotic treatment
- Limited access to timely and adequate treatment
- Non-adherence to treatment
- Limited availability of rehabilitation programmes
- Low implementation of deinstitutionalization

Recommendations
Main Recommendations
Invest in research to continue developing new treatments that can improve quality of life, functioning and reduce associated direct and indirect costs.

Promote prevention and early intervention programmes, which have beneficial socio-economic impact.

Raise awareness of the public and medical professionals and fight stigma.

Support patients and groups of caregivers for information, expertise, sharing experiences, and advocacy.

Build partnerships and cooperation with other stakeholders, e.g., the media organisations (local, regional, national, European and academic institutions), trade unions, pharmaceutical industry, governments, regulatory bodies and insurers.

Complementary Recommendations
Support advocacy and peer group community and empower them to voice their needs within the treatment alliance and in the discussions with healthcare professionals.

Train healthcare professionals and look into incentive systems to promote a timely diagnosis, treatment, and care.

Conclusions
Most people with schizophrenia need a lifelong treatment; however, they can live their own life if they receive timely and proper treatment. In general, we found that the provision of early detection and early intervention programmes is of great importance for an effective management of the illness. Optimal management requires a paradigm shift in the focus of schizophrenia treatment, from symptom control, achieving and maintaining remission, to the emphasis on recovery. Changing the paradigm requires challenging adaptations of health and social care moving away from fragmentation to a seamless care model. For this purpose, effective mental health policies are needed.

References:

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Background

Early intervention (EI) services were developed to provide support before and after the onset of psychosis. These services are currently well-entrenched in mental health policies of some countries, such as the United Kingdom (Gosset et al., 2006; NICCE, 2016) where they appear to be cost-effective in a longer period of time, especially because of the reduction of both, in-patient stay and lost productivity (Andrew et al., 2012; Hastie et al., 2013; McConnie et al., 2016; Minabe et al., 2019; Valmaggia et al., 2009). In other countries of Central and Eastern Europe (e.g. Czech Republic), these services are mostly unavailable and mental health care systems are predominantly hospital-based leading to excessively long hospitalizations, and unmet needs (Winkler et al., 2017, 2018b). Current mental health care reforms in the CR region are focused on deinstitutionalisation as it has been demonstrated to improve the quality of life of people with severe mental illnesses while not leading to homelessness, criminality or suicides (Kunitoh, 2013; Winkler et al., 2016a). EI services could therefore be developed within these reforms and enable people with incipient psychosis to stay in the community rather than in the psychiatric hospitals. The objective of this economic analysis was to assess the socio-economic impact of EI programmes in two separate healthcare systems in Europe: UK where EI are already available, and Czech Republic, where EI are not yet available but could be developed within the current mental health care reform.

Methods

Decision trees were used to model the economic impact of adopting and/or scaling up EI services in two countries chosen to represent both old and new EU member states. All model structures and parameter choices were agreed with a panel of experts.

In the United Kingdom (UK): We assessed the economic value of providing EI before the onset of psychosis (individuals with prodromal symptoms) and after the onset of psychosis (individuals with first episode psychosis in secondary care) compared with usual care in the countries. EI model adopted here is based on Valmaggia et al (2009) and the costs were calculated on the basis of services used following referral and the impact on employment, criminal justice and housing at national level (2016 values). Baseline epidemiological, probabilities and economic data were sourced from public literature (Nelson et al., 2008, Home Office, 2008; Valmaggia et al., 2009; Bond et al., 2015; McConnie et al., 2019; https://www.gov.uk/national-minimum-wage-rates ONS 2016; Randall et al., 2016; Home Office, 2008; Blood et al., 2016). Short (1-2 years), medium (2-5 yrs) and long-term (>5 yrs) time frames were considered. Discount rate of 3.5% was applied as needed.

In Czech Republic (CR): The Czech economic model estimated the incremental value of adopting indicated prevention for people at high risk of psychosis and EI services for people with the first episode of psychosis (defined as those with first hospitalisation for psychosis). Healthcare and employment costs were calculated for the annual costs of the programme. While appropriate probabilities were sourced from the literature, epidemiological and economic data were based on Czech registers and unit costs (Unpublished, NIMH CZ; HIS, 2017; Fusar-Poli et al., 2012; van der Gaag et al., 2013; Valmaggia et al., 2009; Randall et al., 2018b; Craig et al., 2018).公园 et al., 2016; NHS, 2014; Gosset et al., 2006; Power et al., 2007; Nordenfelt et al., 2008; Petersen et al., 2005).

Results

In UK: EI programme (assuming about 15,800 people in UK have prodromal symptoms): In the short-term (1-2 years) EI was more costly than usual care due to an additional cost incurred in health care services (more than 39m Euros extra cost).

In the medium (2-5 yrs) to the long-term (>5 yrs): EI may generate cost-savings due to reduced inpatient care costs, improved employment and crime costs (20m – 32m Euros saving respectively).

In UK: EI programme: EI was less costly (and more effective) than usual care in terms of:
- Employment costs (and probability of being employed). In the short-term (2 years): it can generate a potential cost-savings of 50,372 Euros.
- Crime costs (and number of homicides prevented). In the short-term at two years after treatment, it can generate the potential cost-savings of 187,606 Euros.
- Housing costs (and probabilities of spending at least 1 day in supported housing). In the medium term (5 years): it can generate cost-savings of 133,000 Euros.

The findings were still robust in a series of sensitivity analyses which demonstrated robustness of the results across settings.

In CR, (indicated prevention and EI programme): The economic model demonstrated that costs associated with care as usual for people with the first episode of psychosis were about 46 million Euro each year (knowing - based on national registers - that there are about 5,000 people with psychotic disorders hospitalized for the first time at an outpatient psychiatrist in CZ (2015).

>It is estimated that these costs could be reduced by 25% if only Indicated prevention services were adopted (policy change 1), 33% if only Indicated prevention services were adopted (policy change 2) and 40% if both, Indicated prevention and EI services were adopted (policy change 3) in the country. This means an annual cost savings of about 2,000-2,800-3,300 Euro per patient when introducing policy changes 1-2-3 respectively.

These estimates are very conservative in terms of that only health care costs and costs associated with reduced work productivity and do not include costs associated with other sectors, e.g. social care, informal care, criminal justice, housing arrangements.

Conclusions

Overall, the UK economic analyses showed early detection and early intervention services for people with early psychosis had the potential for cost savings from a societal perspective. Our results suggest that adopting indicated prevention and EI services in the Czech Republic would be highly cost saving due to decrease in hospitalizations and better employment outcomes of people with psychoses. Uncertainty was tested in multiple sensitivity analyses which demonstrated robustness of the results across settings.