Schizophrenia: The Patient Journey

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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 inventory of needs and treatment opportunities using focus group sessions, expert interviews, consumers' input, and 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 reduction 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

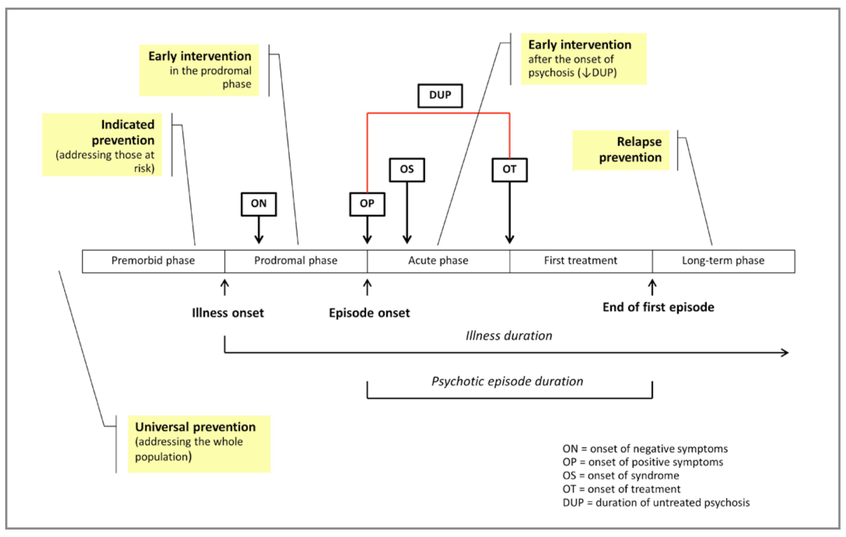

Figure 1: **Intervention strategies early in the course of schizophrenia**

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 psychosocial 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 counselling, 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 not leading to severe adverse consequences. The objective is to bring people back to their own environments out of the inpatient setting and keep them out of hospitals by preventing relapse.

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, referral, 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:

Brohan, E, et al. 2010. Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN-Europe study. Schizophr. Res; De Hert, M, et al. 2015. The use of continuous treatment versus placebo or intermittent treatment strategies in stabilized patients with schizophrenia: A systematic review and meta-analysis of randomized controlled trials with first- and second-generation antipsychotics. CNS Drugs; Gustavsson A, et al. 2011; Cost of disorders of the brain in Europe 2010. Eur Neuropsychopharmacol; Murru A, et al. 2016. Duration of untreated illness as a key to early intervention in schizophrenia: A review. Neurosci Lett; Owen MJ, et al. 2016. Schizophrenia. Lancet; Schultze-Lutter F, et al. 2015. EPA guidance on the early detection of clinical high risk states of psychoses. Eur Psychiatry; Sommer IE, et al. 2016. Early interventions in risk groups for schizophrenia: what are we waiting for? NPJ Schizophrinia; Stafford MR, et al. 2013. Early interventions to prevent psychosis: systematic review and meta-analysis. BMJ; Winkler P, et al. 2016. Deinstitutionalised patients, homelessness and imprisonment: Systematic review. Br J Psychiatry; Winkler P, et al. 2017. A blind spot on the global mental health map: a scoping review of 25 years' development of mental health care for people with severe mental illnesses in central and eastern Europe. Lancet Psychiatry.

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Schizophrenia: The socio economic impact of early intervention (EI) programmes

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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-incorporated in mental health policies of some countries, such as the United Kingdom (Garety et al., 2006; NICE, 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; Hastrup et al., 2013; McCrone et al., 2010; Mihalopoulos et al., 2009; Valmaggia et al., 2009). In other countries of Central and Eastern Europe (see 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, 2016b). Current mental health care reforms in the CR region are focused on deinstitutionalization 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 not available yet, but they 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 (Euros; 2016 values). Relevant epidemiological, probabilities and economic data were sourced from published literature *(Nielsson et al 2008, Home Office, 2005, Vallmagia et al. 2009) (Bond et al 2015; McCrone et al. 2009; https://www.gov.uk/national-minimum-wage-rates ONS 2016; Randall et al, 2016; Home Office, 2005; 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 hospitalization 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; Vallmagia et al. 2009; Randall et al. (2015b); Craig et al., 2004; Park et al., 2016; NHS, 2016; Garety et al., 2006; Power et al., 2007; Nordentoft 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 homicide prevented). In the short term at two years after treatment, it can generate the potential cost-savings of 187,605 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 looking at variations in the probabilities of being employed in standard care and costs of accused crime events.

In CR, (Indicated prevention and EI programmes): 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 were about 5,500 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 changes1-2-3 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.

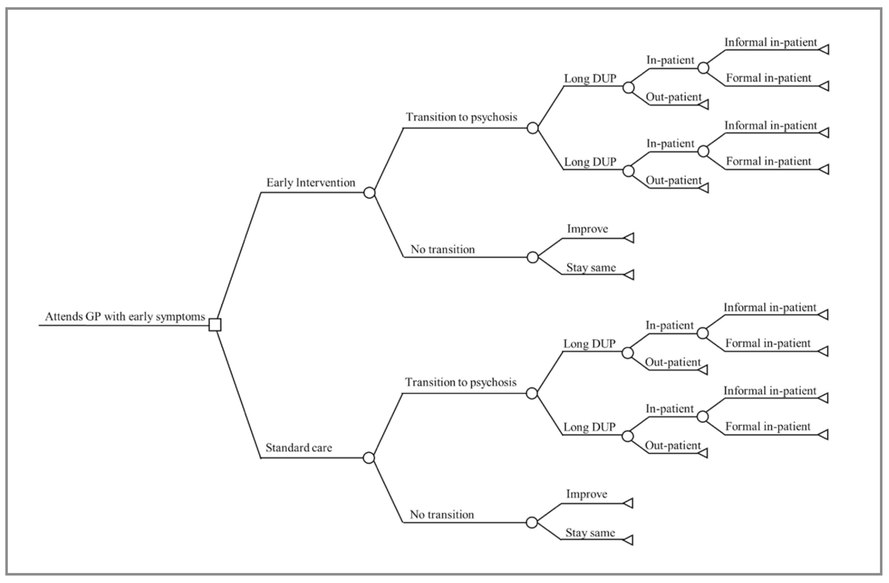

Figure 1: **UK - EI model**

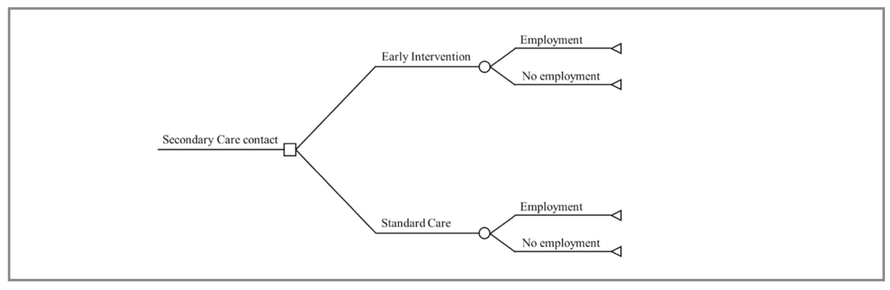

Figure 2: **UK - EI model for employment**

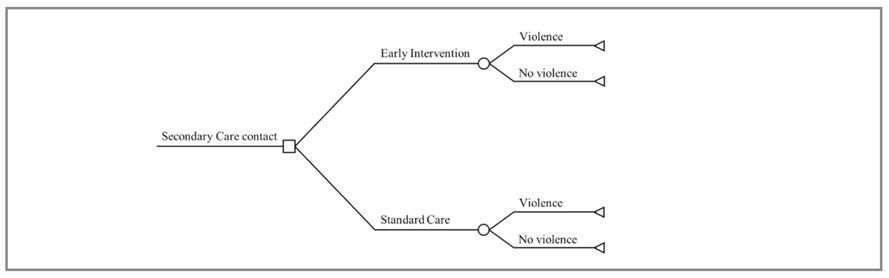

Figure 3: **UK - EI model for crime**

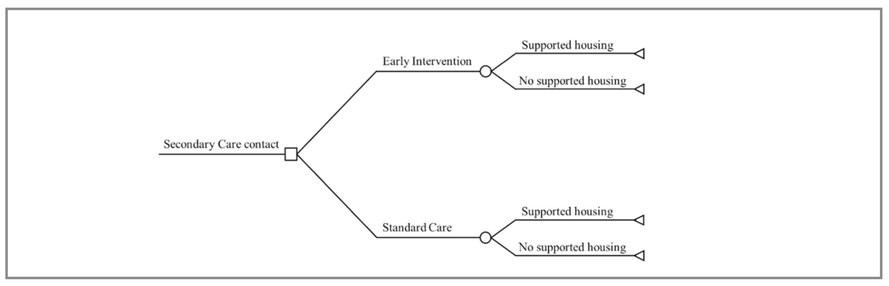

Figure 4: **UK - EI model for housing**

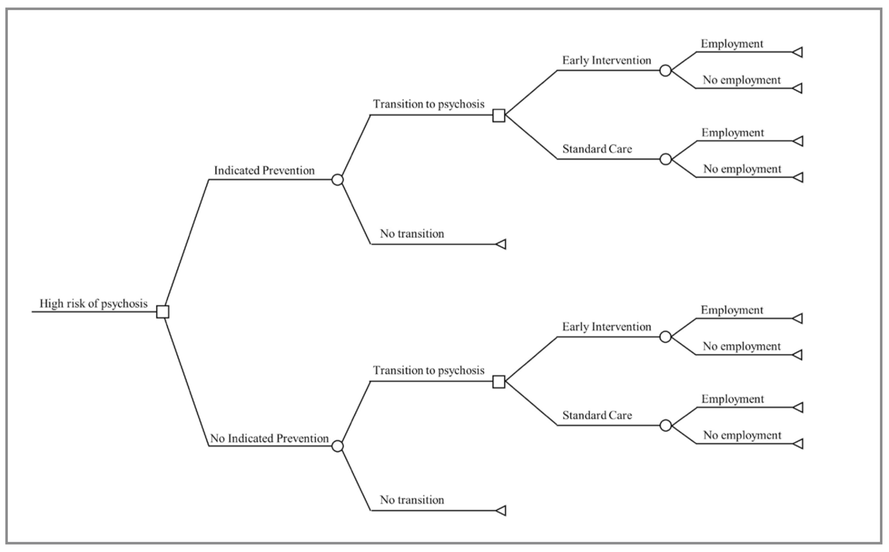

Figure 5: **CR – Indicated prevention & EI model**

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