

FIRST EPISODE PSYCHOSIS AND TREATMENT DELAY – CAUSES AND CONSEQUENCES

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SUMMARY

Introduction: According to the clinical perspective, early diagnosis of the prodromal phase and early treatment provision in the first episode of psychosis (FEP) is able to prevent or reduce morbidity. The main aim of this study is to inventory and analyze the most important causes of treatment delay from the perspective of patients, families and healthcare providers. The secondary aim is to point out the most important consequences of treatment delay.

Subjects and methods: The study was conducted on 28 patients hospitalized for FEP of a schizophrenia spectrum disorder in the Psychiatry Clinic of Timisoara and Day-care center 2009. The corresponding sample of relatives consisted of 25 relatives, and the sample of health care providers of 10 general practitioners and 11 psychiatrists. A semi-structured interview with open-ended questions was used.

Results: Data analysis generated the following themes: society's beliefs and attitude about mental illness; fear of stigma and labeling, insufficient information, lack of infrastructure from the perspective of the professionals, and modified threshold for treatment initiation.

Conclusions: Efforts at the level of Communities as well as efforts at the level of psychiatry specialists could help individuals and their families to overcome the illness situation and improve their quality of life.

Key words: first episode psychosis - treatment delay - duration of untreated psychosis

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INTRODUCTION

There is a growing interest in early psychosis among psychiatric researchers. From the clinical perspective, early diagnosis (early recognition of the prodromal phase) and early treatment provision may be able to prevent and/or reduce morbidity. From the research perspective the study of early illness course provides the opportunity to identify various bio-psychosocial variables that cause or result from the decline in general functioning.

Early treatment in FEP is one of the few available points of intervention to improve prognosis. Duration of untreated psychosis (DUP) is defined as the time interval between the onset of the first psychotic symptoms and the initiation of adequate treatment. Short DUP has been associated with an earlier and better level of remission, a greater chance of recovery, lower relapse rates, less cognitive deterioration, less positive and negative symptoms and better social functioning. All studies agree that long DUP is associated with poorer outcomes. Early detection and treatment of FEP have been developed with the aim of reducing DUP. All efforts in this direction focus on reducing delay in help-seeking and delay in referral in order to reduce treatment delay. Norman et al. (2004) described two types of delay; delay caused by patients and delay caused by services, after the first contact has already been made. Brunet et al. (2007) even described three

components of delay: delay in help-seeking, delay in referral and delay in recognition by health-care providers. Key persons and family members could also represent an important part of the delay. The treatment and intervention in psychosis study (TIPS, Johannessen 2001), clearly demonstrated the impact of community and family education in increasing referrals and reducing treatment delay (Corcoran et al. 2007). On the other hand, there are several studies that point out the importance of stigma associated with mental illness. Fink et al. (1992) stated that the impact of stigma on patients and their families' vision represent a source for treatment delay. Collateral beliefs about mental illness are other causes for the delay. Wrigley et al. (2005) stated that negative social consequences associated with the above conditions may result in a reluctance to acknowledge mental health problems, which may have direct implications for help-seeking behaviour. Some authors suggested that stigma may cause barriers, which in turn may result in treatment delay. McGorry and Killackey (2002) state that societal stigma and self-stigmatisation may act as barriers to treatment initiation for both individuals and families.

The main aim of this study is to inventory and analyze the most important causes of treatment delay by the patients and their families and also from the health care providers point of view. The secondary aim is to point out the most important consequences of treatment delay.

SUBJECTS AND METHODS

The study was conducted on 28 patients hospitalized for FEP of a schizophrenia spectrum disorder (according to ICD-10) in the Timisoara Psychiatric Clinic and Day-Care center in 2009 as well as on their relatives who have initiated contact with the mental health services.

A semi-structured interview with open-ended questions was used to detect the potential determinants of treatment delay. The interviews revealed a list of recurrent themes and subthemes which were included in

the results. DUP was defined as the number of weeks from the onset of positive psychotic symptoms until first hospital admission. Positive psychotic symptoms were analyzed by using PANSS. A separate list of problems related to delayed recognition was given to health-care providers (general practitioners and psychiatrists) who were asked to depict the three most important problems.

RESULTS

Patients sample characteristics: the sample consists of 28 patients (Table 1).

Table 1. Patients sample characteristics

Gender	Male 67.28% (18)	Female 35.72% (10)
Age (mean ± SD)	28.5 (9.4)	22.5 (14)
Education	General 35.71% (10) Highschool 46.42% (13) University 17.85% (5)	
Employment	Employed 60.71% (17) Unemployed 39.29% (9)	
Living situation	With partner 17.85% (5) With family 57.14% (16) Alone 25% (7) Urban 75% (21) Rural 25% (7)	
Family psychiatric history for psychoses	Yes 89.29 % (25) No 10.71 % (3)	
Diagnostic classification (ICD-10)	Schizophrenia 17.85 % (5) Schizo-affective 7.14 % (2) Acute psychotic disorder 42.85% (12) Persistent delusional disorder 10.71% (3) Affective disorder with incongruent delusions 21.42 % (6)	
Median DUP	22.5 weeks (range 0-839)	
PANSS Score (Mean and SDs)	Total 105.7 (10.5) Positive 27.0 (6.3) Negative 22.9 (5.1)	

Family member characteristics: family members must have a regular recent contact with the patient and are the key contact persons. Investigation could be performed only on 25 relatives (Table 2).

- Number of samples: 25
- Health-care providers: the group consisted of 21 persons.
- Ten general practitioners and 11 psychiatrists have been interviewed.

The following themes have been generated by the data analysis:

The following Societal beliefs and attitudes about mental illness were identified. These topics represented the participants' perceptions of society's reaction to the behavior of the ill persons and the families' perceptions. The patients state that "people make jokes"; "laugh"; "make critical comments"; "label me as crazy, strange"; "make distance"; "don't want to be around me"; "reject me". Labeling and social distancing emerge as being the most frequent and this even before a diagnosis has been given.

Table 2. Family members characteristics

Type of family member	Mother* 53.57% (15) Father 10.71% (3) Partner 17.85% (5) Brother / Sister 10.71% (3) Other 7.14% (2)
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*Mothers are more involved

The following were the family members' perception of society's reaction: -"don't fool with them"; "they don't treat them nice". Their own perspective is different from those held by society, possibly due to the physical and emotional proximity. The families' beliefs about the mental illness describe the family members' responses to the behavior of their relative ones experiencing early psychosis. The family members are not as negative as society, the most frequent topics being empathy and compassion. Only on rare occasions do anger, tension, conflict or blame appear. These reactions include observing but giving other explanations than illness (external attribution) – being burned out; finding other guilty parties (conflict with relatives, stressful life events); transcultural and religious explanations. Patients and families do not differ within this topic, but there is a predominance for the rural living condition and the general educational level. Mitigating the impact of the patients' behaviour (excusing the behaviour) in order to protect their ill relative from harm labeling, they would warn society by excusing the peculiar behavior of the ill relative. On the other hand keeping the illness a secret is also a method of coping (potentially for family with a high social standard).

Denial is also reported by family members. This includes observing nothing – not realizing the signs. This topic is mostly seen in the patients sample; only family members with quite a marked attitude of disengagement were allocated to this situation.

A raised threshold for the initiation of treatment - This topic refers to a situation when the patients demonstrated violent or suicidal behavior which overwhelmed familiar coping mechanisms and so treatment was initiated.

Health care providers group give the following most frequent explanation: General practitioners suggest an insufficient information and experience – including dissimulating attitudes of the patient and family, nonspecific complaints that could lead to a misdiagnosis, and difficulties in doctor-patient-family relations. Psychiatrists claim especially that they are missing the ambulatory infrastructure for early recognition.

DISCUSSION

Essential to research on help-seeking pathways is the attempt to understand delay to treatment of early signs and symptoms of psychosis and the factors involved in the decision to seek help. Treatment delay is a feature common to many clinical situations.

Uncertainty surrounding behavioural changes is an important factor contributing to delay. Although participants may recognize changes in themselves, they generally do not attribute them to a mental illness. Self-imposed isolation and withdrawal connected to critical or "joking" attitudes in society is a false coping pathway used.

Fear of stigma and negative labeling is also an important factor. Stigma was identified as a major concern that would affect both the individual and their family. Having a family history of mental illness also may shape the family's unique perspective. Positive family history is not always associated with a shorter delay in treatment. This may be due to tolerance for and denial or previous experience of stigma.

Parents also engage in ignoring, avoiding, hiding, giving other explanations, mitigating, which are an important source for treatment delay. There is also the possibility of significant others who have persuasive influence on key relatives. Corcoran et al. (2007) stated that the fear of labeling results in the adoption of certain coping mechanisms by family members (excusing secrecy, denial). The same attributes were also observed in the study of Judge et al. (2008) and Boydell et al. (2006). Link et al. (1991) stated that psychiatric labels are associated with negative societal reactions which exacerbate the course of the person's disorder.

The study has several limitations that should be acknowledged: quite a small sample that limit generalizability of the findings. Because of more complex variables that undoubtedly influence DUP, the model is by no means a comprehensive depiction of the treatment delay process, hence the model is more speculative in nature; only apparent associations among variables could be evaluated and not causal pathways. The approach remains an important area for further studies.

CONCLUSION

Individuals and family factors have been shown to be associated with a longer DUP. Treatment delay appears to be driven by a complex set of intersecting factors. Problems related to health-care providers were also a source for delay treatment, especially for general practitioners.

Educational programs could be developed with the aim of reducing the threshold at which treatment is established and ultimately decreasing DUP leading to improved outcome for individuals having this serious mental illness. Community-level effort linked with psychiatric specialist-level activities could help individuals and families to overcome the illness situation and improve their quality of life.

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