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## **PSYCHOSOCIAL DIFFICULTIES EXPERIENCED BY PEOPLE DIAGNOSED WITH SCHIZOPHRENIA – BARRIERS TO SOCIAL INCLUSION**

### **Abstract**

Schizophrenia as mental illness is defined in terms of diagnostic criteria which do not include the full range of psychosocial difficulties that shape the lived experience of persons with this diagnosis and affect their quality of life. The biopsychosocial approach found in the World Health Organization's International Classification of Functioning, Disability and Health – ICF seems to be promising solution. The psychosocial difficulties (PSDs), as defined in it, are impairments, activity limitations and participation restrictions. Impairments and activity limitations are components of a person's health state. Participation restrictions go beyond the health state – they are restrictions in a person's functioning in his or her actual environment. Quality of life, on the other hand, is the subjective appraisal of impairments, activity limitations and participation restrictions. In the most recent systematic literature review the most relevant PSDs associated with schizophrenia are: cognitive functions and emotional functions, relationships with others, employment, participating in social activities. The themes from the patients' narratives indicate the same ones. The effective mental health services provision, as well as implementation of adequate social interventions should help users to overcome these difficulties. The idea of the training which focuses on common understanding regarding psychosocial difficulties as barriers to social inclusion, and guidance for future research seems to be obligatory in postgraduate curricula for mental health providers.

### **Introduction**

The personal, social and economic costs of brain disorders have been underestimated for decades because of the lack of valid and acceptable information (Andlin-Sobocki et al., 2005) and the reviews of such studies (Wittchen & Jacob, 2005). This is because these disorders are defined in terms of diagnostic criteria which, though invaluable in identifying the underlying health problem and its etiology, do not include the full range of psychosocial difficulties that actually shape the life experience of persons with these disorders and affect their quality of life.

The aim of this paper is to share with academics and mental health providers ideas on psychosocial difficulties (PSDs) with regard to the biopsychosocial approach found in the World Health Organization's International Classification of Functioning, Disability and Health – ICF (WHO, 2001).

Although, up until now the application of the ICF in psychiatry (Alvarez, 2012) and social sciences was rather limited it can serve as a basis for creating instruments comprehensively assessing psychosocial outcomes in mental disorders that could be of use in both research and clinical praxis – more effective training interventions, and monitoring their impact over time in terms of what really matters to patients and

caregivers. It might be also useful in terms of mental health providers' postgraduate education aiming at users' empowerment and social inclusion.

*Biopsychosocial (BPS) model*

The term “biopsychosocial model” is associated with the name of George Engel, the internist, psychiatrist, and psychoanalyst. His background in medicine and psychoanalysis inclined him to look for cross-links among illness, personal development, and life situation. His model responds to three problems in medical thinking that he considered as the causes for dehumanizing care: the dualistic nature of the medical model, with its separation of body and mind; the materialistic and reductionist orientation of medical thinking; the influence of the observer on the observed. The author provided a rationale for including the human dimension of both the clinician and the patient for a comprehensive treatment as well as for a scientific study – clinical formulations based on the BPS model give equal weight to the clinical data in the biological, psychological, and social spheres. All dimensions of the clinical domain function interdependently and reciprocally (Engel, 1997; White, 2005). Since Engel's publication (1997) the biopsychosocial model was put on the undergraduate and postgraduate teaching agenda in medical schools across the world and on the educational programme of residency training in psychiatry and psychology in many places.

*The International Classification of Functioning, Disability and Health – ICF*

The International Classification of Functioning, Disability and Health (ICF) published by the World Health Organization (WHO) in 2001 is based on the biopsychosocial model (BPS) of health and disability. It was developed as an international language to describe the consequences of health conditions at the individual and societal levels.

Psychosocial difficulties arise from the interaction of the psychological and the social factors – hence are not direct consequences of the health condition alone but are outcomes of the interaction between the health condition and contextual factors. They are not the factors that produce an intrinsic decrease in functioning, but also in terms of the physical, social and attitudinal environment that gives the true measure of the impact of brain disorders on people's lives. This social and attitudinal environment, especially in the case of mental illness, includes barriers such as misunderstanding, stigma and discrimination, as well as the absence of social policies to accommodate people with brain disorders in the workplace and in society (WHO, 2001). The absence of such environmental factors is a concurrent reason of functioning decrement – hence social exclusion.

The psychosocial difficulties, as defined in the International Classification of Functioning, Disability and Health – ICF (WHO, 2001), are impairments, activity limitations and participation restrictions. Impairments and activity limitations are components of a person's health state. Participation restrictions go beyond the health state to include restrictions in a person's performance of actions, tasks and behaviors in his or her actual environment. Quality of life, on the other hand, is the subjective appraisal of impairments, activity limitations and participation restrictions (Cieza et al., 2008).

*Psychosocial difficulties (PSDs) experienced by people with schizophrenia – literature review*

Schizophrenia is consistently demonstrated to have a major negative impact on quality of life (Marwaha et al., 2008; Thornicroft et al., 2004; Ritsner & Gibel, 2007), linked with disempowerment (Kilian et al., 2003; Longden, 2010) and social exclusion (Marwaha & Johnson, 2004; Meesters et al., 2010).

Several literature reviews analyzed various aspects of psychosocial difficulties in schizophrenia, such as psychopathological symptoms (Mäkinen et al., 2008) or impairments of basic cognition (Szöke et al., 2008), social cognition (Penn et al., 2008), emotional experience (Cohen & Minor, 2010), social functioning (Meesters et al., 2010), vocational functioning (Marwaha & Johnson, 2004) and quality of life (Eack & Newhill, 2007) but failed to systematically synthesize the data across the entire breadth of psychosocial problems experienced by people with this disease since there is lack of consensus how to define psychosocial outcomes (Figueira & Brissos, 2011).

In accordance with the ICF framework, psychosocial difficulties associated with schizophrenia can be characterized as impairments of mental functions (such as emotional functions) activity limitations, and participation restrictions in such domains as work, family life and leisure activities. Environmental factors such as stigma, a supportive family as well as personal factors, such as confidence in one's ability to overcome difficulties, can have a positive or negative impact on PSDs.

The systematic literature review (Świtaj et al., 2012) confirms that psychosocial problems encountered by people with schizophrenia in their daily lives are very diverse. The most frequently addressed PSDs were related to the areas of psychopathology, overall disability and functioning, relationships with others, cognitive functions, emotional functions, quality of life and wellbeing, employment, and energy and drive. This pattern of findings well reflects the common understanding of unfavorable schizophrenia course and outcome as a socially excluding disease manifesting itself by positive, negative, cognitive, mood and motor symptoms, variable degrees of functional, social and occupational impairments, and marked worsening of both objective and subjective indicators of quality of life.

*Psychosocial difficulties (PSDs) experienced by people with schizophrenia – lived experience*

A qualitative study using focus group methodology (Lehoux et al., 2006; Rees et al., 2007) was conducted in Warsaw to identify and explore the significance of the PSDs experienced by people with lived experience of schizophrenia. The recruitment of participants and data collection were performed by health professionals: one psychiatrist, one psychologist at the clinical centre. A maximum variation strategy regarding age, gender and severity of the health condition was used to ensure a wide range of views and perspectives. Eight patients, one moderator and an assistant discussed the themes, which were initiated by the moderator: *What are your difficulties in everyday life? Which of these difficulties trouble you most? How these difficulties affect your life? When did they start to be a difficulty? Why do you think this difficulty started? Have you notice any changes in regards these difficulties over the time? Why do you think these difficulties get worse or better, come and go?*

The main themes concerning the determinants of PSD included the illness itself, lack of public knowledge and understanding, the media's contribution to unhelpful

negative public image, negative or ignorant attitudes of mental health service workers, lack of continuity and long term view and limited resources. The PSDs identified were stigma, marginalization *...when I got schizophrenia my world changed! It was like a life sentence of rejection and poverty. I became instantly different, omitted, excluded and vulnerable. The challenges include not only the illness itself, but also other people's fear and ignorance...*, discrimination, social withdrawal, disengagement, loneliness *...even my closest friend disappeared when I told him about my illness...*, fear, despair and helplessness, problems with relationships and interpersonal skills (affecting family, intimate and occupational relationships), frustrations with mental health services *...being in hospital is really traumatic, there is always the fear of involuntary commitment, you can't talk freely, so you tell them what they want to hear and wait to be rescued. I think all health professionals should be taught listen more carefully and give clear information about what they think is the matter with you...*, problems with self-esteem and overprotection, un-met needs for social reciprocity, constancy, hope and understanding, problems with finding and keeping work *...I suppose I know now that I will never work and achieve what I originally wanted to do in life, I lost my first job because people eventually found out I was ill. I feel helpless but I am trying to accept it. I would really like find a proper job. I heard from a friend that supported-employment programmes can work ... and a place to live.*

For mental health providers and planners, relating these life experiences to clinical one can provide a tool for facilitating deeper levels of understanding between them and their clients, working towards a common understanding of the issues that really matter to those experiencing schizophrenia. This has the potential of informing research development, public attitudes as well as services provision and social inclusion.

#### *Psychosocial difficulties and empowering strategies*

Now in management, education (Kellerl & Dansereaul, 1995; Boomer, 1982), and mental health (Anczewska & Wciórka, 2007) empowerment is understood as a complex concept. It encompasses a number of phenomena relating to changing the intra-psyche and behavioral dimensions of people themselves. It fosters personal growth (gaining a sense of control and self-efficacy, self-awareness and self-acceptance, self-regulation); skills development; better understanding and utilisation of one's social role. The ideology applied to the individual equips him/her with an instrument of self-determination, provides competency awareness, strengthens self-esteem and increases stress resilience. It combines both process and outcome. The key issue seems to be that empowerment as a growth process of an individual should be supported and encouraged by the group structure within which he or she is working to promote learning. Engaging people with schizophrenia experience in structured organized activities that link them to each other and to institutions enhances their self-awareness and social achievement, improves mental health and reduces possible social exclusion. Empowering them (both intrapersonally and interpersonally) to take control to lead functional and fulfilling lives help them meet their needs for power and belonging, enables to pursue their goals and personal development.

## Conclusions

The paper illustrates the broad scope and diversity of psychosocial difficulties, as framed by the biopsychosocial approach in the World Health Organization's International Classification of Functioning, Disability and Health – ICF, found in the literature and in the qualitative users' narratives.

The effective mental health services provision, as well as implementation of adequate social interventions should help users to overcome these difficulties – hence to gain control of their lives and instil in them motivation to reclaim their position in the community.

The idea of the training which focuses on common understanding regarding psychosocial difficulties as barriers to social inclusion, better intervention targeting and guidance for future research seems to be obligatory in postgraduate curricula for mental health providers.

When planning longitudinal or cross-national research the psychosocial difficulties from the patients' perspective should be implemented.

## Acknowledgements

The paper is worked out within the scope of the EU funded project “Psychosocial fActors Relevant to brAin DISorders in Europe (PARADISE)” (<http://paradiseproject.eu/>). The project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under grant agreement n° 241572.

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