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# A Journey Through Schizophrenia

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## 1. Introduction

Schizophrenia rolls in like a slow fog, becoming imperceptibly thicker as time goes on. At first, the day is bright enough, the sky is clear; the sunlight warms your shoulders. But soon, you notice haze beginning to gather around you, and the air feels not quite so warm. After awhile, the sun is a dim lightbulb behind a heavy cloth. The horizon has vanished into a gray mist, and you feel a thick dampness in your lungs as you stand, cold and wet, in the afternoon dark. (Saks, 2007, p. 35).

The positive and negative symptoms and the prodromal, acute, and residual phases of schizophrenia are described in this chapter using the personal accounts of Elyn Saks and other professionals who have made public their personal struggles with schizophrenia. Psychologists, psychiatrists, and other professionals have disclosed their stories in the professional literature and their own biographies. These professionals believe there is a need for the general public and those with serious mental illnesses to hear stories of those who are leading successful lives after surviving the fire of the illness and its treatment (Bassman, 1997; Baxter, 1998; Breeding, 2008; Deegan, 1993; Deegan, 2003; Freese, Knight, & Saks, 2009). The successes reported by these professionals are not anomalies. Longitudinal studies report a large number of people with schizophrenia seeing improvement in their condition over time (Davidson, Schmutte, Dinzeo, & Andres-Hyman; 2008; Ellison, Russinova, Massaro, Lyass, 2005; Siebert, 2005). These individuals also make the case for the need of those with schizophrenia and other mental illnesses to be heard by professionals who offer understanding, hope, and support and listen with an understanding heart rather than from an uncaring, objective perspective (Brooks, 2011; Chadwick, 2006; Deegan, 1993; Frese et al., 2009; Frese & Davis, 1997).

## 2. Prodromal phase

Saks is the Associate Dean, Chaired Professor of Law, Psychology, and Psychiatry & Behavioral Sciences at the University of Southern California Gould School of Law; Adjunct

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Professor of Psychiatry at the University of California, San Diego, School of Medicine; and Assistant Faculty, the New Center for Psychoanalysis. Saks began to notice changes in her behavior at age eight. She became very obsessive about lining up the shoes in her closet before she could go to bed at night. She kept her bedroom light on until all the books on the shelves were organized just right. At times, she would wash her hands one, two and, three times to make sure they were clean. These noticeable changes might have been preceded by even earlier events that went unnoticed. Ms. Saks developed a fear that someone was lurking outside her window at night. Ms. Saks became fearful of being alone, the darkness, and the nighttime. She began to recognize her limitation in controlling her fears and emotions. Delusional perceptions are very common in the early stages of schizophrenia (Fanous & Kenler, 2008; Gourzi, Katrianous & Beratis, 2002; Maddux & Winstead, 2012; Maxmen, Ward, & Kilgus, 2009). Saks describes her sense of hopelessness when trying to influence her environment and organize it; thus the title for her book, *The Center Cannot Hold: My Journey Through Madness*.

Carol North (1987) is currently the Chair in Crisis Psychiatry and Professor in the Departments of Psychiatry and Surgery/Division of Emergency Medicine/Section on Homeland Security at The University of Texas Southwestern Medical Center in Dallas. She is also Director of the Program in Trauma and Disaster at the VA North Texas Health Care System. She was only six years old when she found herself seeing frightening hallucinations of killer bees, murderers, and potential kidnappers on her way to school every day. When she heard voices talking to her in school, it did not occur to her that others did not hear the voices, too. Later those voices became very intrusive, so loud in fact that she often wondered if others could hear them, too. Gene Deegan, Psy.D. (2003), a Research Fellow at the Center for Psychiatric Rehabilitation, Boston University was diagnosed with “ambulatory schizophrenia” (p. 369) at age 17 but it was not until the time of his college graduation the he felt his sense of identity disintegrating with unusual sensations and terrible anxiety causing him to believe his very existence was precarious at best.

The majority of individuals who suffer from schizophrenia first experience prodromal or early symptoms such as social withdrawal, impaired functioning, flat affect, unusual perceptions, odd thinking, rambling speech, or preoccupation with overvalued thoughts (Gourzi, Katrianous & Beratis, 2002; Maddux & Winstead, 2012; Maxmen et al., 2009). Approximately one-fourth of those suffering from schizophrenia first experience an abrupt onset (referred to the acute phase) experiencing delusions, hallucinations, disorganized speech, or grossly disorganized or catatonic behavior. For those who experience prodromal symptoms following an acute phase, these symptoms are referred to as the residual phase. During these prodromal or residual phases, individuals are generally looked on as odd or referred to as “strange”.

### 3. Diagnostic criteria

According to Kaplan (2008), a Swiss psychiatrist, Eugene Bleuler, first used the term schizophrenia in 1908, as a description for a condition first described by a German

psychiatrist, Emil Kraepelin, who referred to the condition as dementia praecox. Bleuler defined schizophrenia as a disease best understood as a type of alteration of thinking and feeling and relating to the external world (Kuhn, 2004). Today, both the American Psychiatric Association's (2000) *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, text revised (DSM-IV-TR), and the World Health Organization's (1993) *International Classification of Diseases*, 10th revision (ICD-10) include in their descriptions the positive symptoms of delusions, hallucinations, disorganized speech, disorganized or catatonic behavior, and the negative symptoms of flat affect, reduced speech, lack of ability to experience joy or pleasure, lack of interest in forming relationships, and lack of ability to become motivated. To receive a diagnosis of schizophrenia, the DSM-IV-TR requires three diagnostic criteria be met: (a) two or more of the following characteristics present for a significant period of time for at least a month: delusions, hallucinations, disorganized speech (manifesting from a formal thought disorder), disorganized or catatonic behavior, or negative symptoms; (b) social or occupational dysfunction that is significantly below what was seen prior to the onset of the disturbance, and (c) of significant duration: i.e. continuous signs persisting for at least six months.

The DSM-IV-TR contains five sub-classifications of schizophrenia: (a) paranoid type (delusions or auditory hallucinations are present, but thought disorder, disorganized behavior, or affective flattening are not); (b) disorganized type (a thought disorder and flat affect are present together), (c) catatonic type (almost immobile or movement that is agitated and without purpose), (d) undifferentiated type (psychotic symptoms but the paranoid, disorganized, or catatonic symptoms are not met), and (e) residual (positive symptoms are present but only at a low intensity). The ICD-10 describes two additional subtypes: (a) post-schizophrenic depression: (depression arising in the aftermath of a schizophrenic illness with possible schizophrenic symptoms still present, and (b) simple schizophrenia (development of negative symptoms of schizophrenia with no psychotic episodes).

#### 4. Acute phase

The acute phase of schizophrenia usually manifests during adolescence or early adulthood, a time when social interactions and identity development can be seriously affected by the symptoms of schizophrenia. Many of those suffering from schizophrenia find they are less able to engage in social interactions after the onset of the disease, intensifying their anxiety (Lysaker & Lysaker, 2010). Elyn Saks (2007) describes her experience:

Place yourself in the middle of the room. Turn on the stereo, the television, and a beeping video game, and then invite into the room several small children with ice cream cones. Crank up the volume on each piece of equipment, then take away the children's ice cream. Imagine these circumstances existing every day and night of your life. (p. 229).

Saks received the diagnosis of chronic paranoid schizophrenia with acute exacerbation following involuntarily admission to the Yale Psychiatric Institute (Saks, 2007). However,

from the late 70s to early 80s, following graduation from Vanderbilt, Saks attended Oxford University, returning to the United States in 1982. While at Oxford Saks experienced both the positive and negative symptoms of schizophrenia. After arriving in England, she found it difficult to interact with others increasing her isolation; she found herself depressed along with feelings of self-hatred and a sense of paranoia. When the positive symptoms of schizophrenia appeared, she believed her neighbors were listening in on her conversations, that entities in the sky were going to harm her, and believed she was being commanded to harm herself. Hospitalization led her to employ the services of a psychoanalyst. The relationship with the psychoanalyst and her regimented schedule allowed her to develop friendships and engage more frequently in social interactions. Saks completed her degree at Oxford despite recurrent psychotic episodes.

Saks remained in England the year following her graduation, returning to the United States following admission to Yale Law School. Unfortunately, she had to leave behind the friends she had made, the routine she had developed, and the relationship with her psychoanalyst. Two weeks after classes began, Saks experienced visual hallucinations, psychotic thoughts, and disorganized speech. During a study session with her students, she invited them to accompany her to the roof of the library where she engaged in behavior that concerned those around her.

Carol North (1987) continued hearing voices into her adolescence but also began to experience visual hallucinations: colored lines wove around and moved occasionally in sync with the normal sounds of someone sneezing or a door slamming, eventually creating the illusion of seeing sounds. The voices did not explain to her what she was experiencing. Convinced she was on the verge of something big, she awoke one night to the sounds of someone calling her name and saw Jesus standing next to her bed. While in college, her hallucinations continued, resulting in the first of many hospitalizations.

Frederick J. Frese, Ph.D., a psychologist who has worked extensively with patients and families who are consumers of mental health, was diagnosed with schizophrenia at age 25. Frese (2000) writes, “When you are going into a schizophrenic break, in your mind you are behaving in a proper manner, but generally you also pick up from others that they are having problems with the way in which you are acting” (Frese, p.1417). His description of his second psychotic break shows an example of what he describes above, an individual believing he or she is behaving in a proper manner.

The Sunday before I was to fly with them to Nashville, I experienced my second psychotic break, while attending a religious service at the large Jesuit Gesu Church. For some reason during the service, without invitation, I proceeded to the altar. I began to assist the priest as he said the Mass. After this admittedly bizarre behavior, I passed out. While I was unconscious, someone apparently arranged for me to be taken to Milwaukee’s large public psychiatric hospital. When I awoke, I found I was strapped down to a bed in another padded, psychiatric seclusion room. I was very delusional. (Frese, 2010, p. 377).

## 5. The path and the stumbling blocks to recovery

A description of schizophrenia based on a discussion of the symptoms of the disorder would be incomplete without a discussion of the recovery processes and what these individuals view as significant in both helping and hindering this recovery process. Fortunately, the professionals discussed in this chapter, Frese, Saks, North and Degan, along with Wendy Walker Davis (Frese & Davis, 1997), Ron Bassman (1997), Al Siebert (1994), and Pat Deegan (1993) have brought their stories forward. The common themes in their stories of recovery and the common roadblocks to those recoveries provide valuable insights for those working in the mental health field.

### 5.1. Stigma

Many of the professionals cited in this chapter (Bassman, 1997; Deegan, 1993; Frese, 2000; Frese et al., 2009; Saks, 2007) discuss in their professional writings the significance of the stigma associated with schizophrenia. These professionals have described this stigma as a very serious matter, the consequences of the stigma sometimes worse than the symptoms of the disorder. How many mental health professionals and non-professionals are afraid to even discuss recovery because the resulting stigma would be harmful to them? Many who do disclose their experiences are told they do not, in fact, have schizophrenia, but were misdiagnosed. With the symptoms of schizophrenia and the stigma both entities to overcome, how has this stigma manifested itself in the lives of those who have chosen to go public?

Link and Phelan (2001) define the stigma associated with mental illness in terms of the labeling, stereotyping, loss of status, and discrimination that can occur when one group exercises power over another. Ritsher and Phelan (2004) discuss the concept of internalized stigma, that often results in inner psychological harm and the authors see this internalized stigma as resulting in the belief that one does not belong in any social groups. The stigma associated with a mental illness affects the individual's self-esteem and adaptive social functioning outside the family, and influences the willingness of outpatients to take the medications that their psychiatrists prescribe (Link & Phelan, 2001; Lysaker, Tsai, Yanos, & Roe, 2008; Perlick, 2001; Ritsher & Phelan, 2004). Furthermore, family members are also affected by the stigma. They experience a type of stigma just from being the relative of a person with schizophrenia. Because the wellbeing of family influences the individual with schizophrenia, the family's response to the stigma can affect the person with the illness.

Pat Deegan (1993) was told at 17 that she had a disease like diabetes and if she continued taking neuroleptic medications, she might be able to cope. Rather than being seen as a precious human being, Deegan describes being told she was a schizophrenic, with family and friends referring to her as "a schizophrenic" (p. 9). Saks (2008) believes she was given a grave prognosis that she describes as a death sentence; she would never live or work on her own. Frese et al. (2009) discuss the pessimistic view of recovery that permeates the mental health profession and Frese and Davis (1997) describe how the limitations put on the person

with the illness by professionals and others eventually become the limitations of the person themselves. It becomes a common practice to encourage individuals to lower their expectations regarding potential personal accomplishments and to assume a full life is just not possible. Ronald Bassman (1997) writes:

Having experienced both sides of the treatment model, I have the dubious privilege of seeing the discrimination, stigmatization, and devaluation that permeate both the mass media and the mental health system. I see good professionals unwittingly underestimating potential and overvaluing diagnosed weaknesses while inadvertently limiting precious hope; in so doing, they make it difficult for other much-needed recovered role models to come forward. (p. 240).

## 5.2. Recovery

What are the components of recovery that many of these professionals agree on? What have researchers uncovered that appears to significantly influence the recovery from schizophrenia in a positive way? First, is the belief put forth by many that recovery is a process, not a destination that will occur after a long series of events (Deegan, 1993; Frese et al., 2009; Frese & Davis, 1997). Symptoms often require continual management, but it is possible to manage symptoms effectively and live happy, successful lives. Bassman (Frese et al, 2009) lists the factors of continuing to have hope, safe havens, natural supports, belief in himself, family reconciliation, and meaningful work as significant factors. Deegan (1993) admits using the hospital when she needs to, taking medications, receiving support from friends, work, physical exercise, and time in nature as ways she manages her symptoms. Feeling empowered in a recovery process that is strength based, with peer support, that works to reduce stigma, exhibits respect from professionals, includes an educational component, and allows a place for hope to reside are all factors that seem to repeat themselves in the writings of those who are recovering (Cavelti, Beck, Kvrjic, Kossowsky, & Vauth, 2012; Frese, et al., 2009, Freese, 2000). The important role that meaningful work can play should not be overlooked (Ellison et al., 2005; Honkonen, Stengård, Virtanen, & Salokangas; 2007; Tandon, Nasrallah, & Keshavan; 2010; Ventura et al., 2011). Eack, Greenwald, Hogarty, and Keshavan (2010) and Tandon et al. (2010) view cognitive work as helpful with Tandon et al. seeing family psychoeducation, social skills training, and active community involvement as significant as well.

## 6. Summary

What we offer those who experience the symptoms of schizophrenia should be based on not only an accurate understanding of schizophrenia, but an appreciation of what is possible in the recovery of that disorder; and an appreciation of what supports the likelihood that an individual experiencing these symptoms will be limited not by internalized or externalized stigma, a treatment team caught in the limitations of the diagnosis, or a vacant and seemingly uncaring environment that can develop from family, friends, and professionals

who see only limitations and not possibilities. The mental health field owes a debt of gratitude to the professionals who have come forward with their stories, telling what was required for them to overcome not only the illness but many times overcoming the people treating the illness as well. May the mental health field use these experiences from those who have been both doctor and patient to improve the quality of treatment to those who must respond to schizophrenia, viewed as one of the most challenging of mental illnesses.

## Author details

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