

Self-Management Among Chinese People With Schizophrenia and Their Caregivers: A Qualitative Study

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This study explores the practice of self-management in Chinese people with schizophrenia and their caregivers. Twenty-one patients and 14 caregivers were interviewed. Four themes were identified, reflecting the practice of self-management from both the patients' and caregivers' perspective: managing medication, monitoring and dealing with symptoms, maintaining social relations, and seeking health information and maintaining medical appointments. In general, self-management practices among Chinese people with schizophrenia were not optimal. This study highlights the importance of developing and implementing family-based self-management programs for Chinese people with schizophrenia and their family in order to enhance their self-management abilities and improve care outcomes.

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ACCORDING TO CLARK *et al.* (1991), living with a chronic illness, including schizophrenia requires self-management to facilitate well-being, to decrease the effects of the illness and to limit disease progression. Several studies have demonstrated that if people with chronic disease avoid self-management and are not actively involved in their own care, positive clinical outcomes are difficult or impossible to achieve (Marks, Allegrante, & Lorig, 2005).

Although some researchers have questioned the self-management ability of people with schizophrenia, most recent studies published in Western literature have revealed that significant proportions of people with schizophrenia can successfully manage their conditions. They not only have the ability to make decisions about taking medicine, but also have a great capacity to manage psychotic symptoms (Kampman *et al.*, 2002; Marland & Cash, 2005; Onken, Craig, Ridgway, Ralph, & Cook, 2007; Shepherd *et al.*, 2010).

In China, it was estimated that the prevalence of schizophrenia was 0.49% (Xiang *et al.*, 2008). Previous studies demonstrated several characteristics related to experiences and treatment among

Chinese people with severe mental illness, which include schizophrenia.

First, the mental health service system in China is under-developed. Unlike Western countries, psychiatric hospitals remain the major service providers to the mentally ill in China. However, according to Zhang's (2003) data, China has only 575 psychiatric hospitals and 110 thousand beds for its population of 1.3 billion, and most of them are located in large and mid-sized cities. Besides that, China lacks qualified mental health professionals (Hu, Higgins, & Higgins, 2006). There are only 1.3

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psychiatrists and 2.1 psychiatric nurses per 100,000 people in China. Generally, psychiatric services in China are not easily available or accessible (Tang, Sevigny, Mao, Jiang, & Cai, 2007).

Second, patients face severe stigma. Almost half of Chinese people with schizophrenia reported having been laid off, and 42.1% of patients reported that their friends distanced themselves after finding out about the patient's illness. Stigma from parents and other close relatives was frequent. For example, more than half of patients felt disliked or despised by family members; 59.6% indicated that family members wanted to conceal the presence of a psychiatric patient in the family from others. In terms of their partner relationships, one third reported that their partners broke up with them because of their mental illness. The perception of stigmatization caused emotional distress among Chinese people with schizophrenia. Over half felt that they were worthless because of their illness; 40.6% deliberately avoided most social contacts and 43.8% had thought of ending their lives (Lee, Lee, Chiu, & Arthur, 2005).

Third, the treatment rate among Chinese people with severe mental illness is low. According to Ran et al.'s (2003) study, only 5.9% of people with schizophrenia accepted antipsychotic drug treatment; more than one third of participants in his study never accepted any treatment (Ran et al., 2003). A disturbing finding was based on Shen et al.'s (2006) study that 80.2% of those with moderate and severe mental illness did not receive 12-months of treatment, even in Beijing and Shanghai (Shen et al., 2006). Inaccessibility to and/or unavailability of psychiatric services was the most common barrier to seeking psychiatric treatment among Chinese people with severe mental illness. In addition, severe mental illness is often accompanied by social stigma in China, leading to the possibility that patients and their families hide the problem and avoid proper professional treatment (Tang et al., 2007). Besides the reasons mentioned above, lack of knowledge of mental illness was also a barrier for people with severe mental illness seeking treatment. In Ran et al.'s study, almost half of the relatives of people with severe mental illness did not know what problem the patients had; 7.9% insisted that the abnormal behavior was caused by ghosts or gods and 2.0% believed that the patients suffered from physical illness (Ran et al., 2003).

Fourth, patients have poor clinical outcomes. In a recently published study, only 23.7% of people with schizophrenia had good insight and merely 5% showed improvement over the 1-year follow-up, which demonstrated that impaired insight, was very common among readmitted Chinese people with schizophrenia (Xiang et al., 2012a,2012b). In terms of symptoms, studies showed that 75.6% of untreated people with schizophrenia continued to experience marked symptoms, and 6.4% experienced a further deterioration in their illness (Ran et al., 2003). Social functioning was damaged severely. Chinese people with severe mental illness were more likely to have severe or extreme difficulty in understanding and communicating, getting along with people, life activities, and participation in society. Approximately 8% of people reported severe or extreme difficulty in self-care (Li et al., 2011). The relapse rate is also high according to one study. The 1-year relapse rate varied from 12 to 39.9% (Xiang et al., 2011). A 2005 study demonstrated that poor medication adherence was significantly associated with a higher frequency of relapse in Chinese people with schizophrenia (Chen et al., 2005). People with schizophrenia experienced distressing psychiatric symptoms and were also stigmatized because of their illness and poor employment opportunities. These distressing factors lead to a decreased quality of life (Xiang et al., 2012a,2012b). According to Xiang et al.'s study, people with schizophrenia living in community had significantly poorer scores in the physical and psychological quality of life domains when compared with the general Chinese population (Xiang et al., 2012a,b).

Because of the characteristics mentioned above, severe mental illness causes enormous burdens to Chinese patients, their families and society. It is not surprising to see that schizophrenia and other mental illnesses will account for one fifth of the total disease burden in China by 2020 (Lu, Frank, Liu, & Shen, 2009).

In order to increase patient compliance, prevent relapse and improve their social functioning, many Chinese researchers have designed and conducted interventions for Chinese people with schizophrenia and their families, such as psychoeducation, family therapy, social skill training, etc (Chan, Yip, Tso, Cheng, & Tame, 2009; Ran, Xiang, & Huang, 2001; Xiang, Ran, & Li, 1994; Xiong et al., 1994). However, little data exist regarding self-

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