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Lessons Learned From Research With Adolescents With Schizophrenia and Their Families

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A B S T R A C T

The purpose of this study is to present our experiences of conducting a randomized clinical trial of a self-management intervention for adolescents with schizophrenia and their families.
Challenges and strategies of recruiting subjects; engaging families in self-management intervention; tailoring interventions for this population were discussed. Participants' comments on their experience were presented. Adolescents and their families are poorly prepared to manage schizophrenia; therefore psychosocial interventions should address their needs. Impaired cognitive functioning in adolescents with schizophrenia should be a target for interventions and should be considered in planning interventions.

Schizophrenia, a major mental illness, often begins during adolescence and negatively impacts individuals due to personal suffering from psychiatric symptoms and impaired psychosocial functioning. Families of individuals with schizophrenia suffer as well because of ongoing comprehensive care (American Psychiatric Association, 2000; Clark & Lewis, 1998; Lieberman et al., 2001; Schmidt, Blanz, Dippe, Koppe, & Lay, 1995). Individuals with schizophrenia frequently experience relapse within 5 years of recovery from a first episode (Robinson et al., 1999); thus this early stage of illness—the first 5 years—is a critical period for implementing effective treatment to achieve desirable outcomes (Lieberman & Fenton, 2000; Lieberman et al., 2001; Onwumere, Bebbington, & Kuipers, 2011).

The literature consistently demonstrates the effectiveness of family intervention along with antipsychotic medication treatment in reducing relapse rates and family burden (Bustillo, Lauriello, Horan, & Keith, 2001; Falloon, 2003; Hogarty et al., 1986; Onwumere et al., 2011; Pharoah, Mari, Rathbone, & Wong, 2006; Pitschel-Walz, Leucht, Bauml, Kissling, & Engel, 2001). Family-centered interventions underline coping skills that are achieved through family problem solving. Contents of interventions include psychoeducation about mental illness, early warning signs of relapse, social skill training, communication skills, and specific skills to deal with stress (Falloon et al., 1985; Mueser, Glynn, & Liberman, 1994). Accordingly, family intervention is crucial to adolescents with schizophrenia because they experience a critical early stage of illness and families are often closely involved in the care of the adolescents. Parents find themselves faced with handling the illness affecting their adolescents (Schepp, 1992) in addition to the demands that a family typically places on them. The healthy siblings may feel neglected when the parents' attention is focused on the ill adolescent, and the parents may not have time for themselves if they need to vigilantly monitor the ill adolescent (McElroy, 1998).

The focus of many prior studies, however, is on interventions for groups other than adolescents, including adults with schizophrenia (Barrowclough et al., 2001; Dyck, Hendryx, Short, Voss, & McFarlane, 2002; Dyck et al., 2000; Farooq et al., 2011; Li & Arthur, 2005), first episode psychosis (Agius, Shah, Ramkisson, Murphy, & Zaman, 2007; Breitborde et al., 2011), or recent-onset schizophrenia (Grawe, Falloon, Widen, & Skogvoll, 2006; Lenior, Dingemans, Linszen, de Haan, & Schene, 2001; Lenior, Dingemans, Schene, Hart, & Linszen, 2002). Studies of siblings of adolescents with schizophrenia also have been limited (Friedrich, Lively, & Rubenstein, 2008).

The purpose of this paper is to discuss our valuable experiences of conducting and completing a clinical trial of self-management for adolescents with schizophrenia and their families (R01MH56580). This self-management program was a family-centered intervention in which adolescents were taught to recognize psychiatric symptoms and their aggravating factors, namely, symptoms of stress, in order to handle those symptoms; and families were taught to support and encourage adolescents to learn symptom awareness and skill acquisition. Although experienced research teams designed and implemented the clinical trial, there were unanticipated challenges in the process of the trial. Most reports of research studies focus mainly on the outcomes, such as effectiveness of interventions on health. Frequently encountered difficult challenges experienced in

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conducting the clinical trial are not always reported. By sharing our lessons learned from the challenges, nursing scholars who will conduct clinical trials for this adolescent population may take these challenges into consideration in advance and devise effective implementation plans to make clinical trials successful.

OVERVIEW OF SELF-MANAGEMENT THERAPY

The information regarding the original study, its demographic data, symptoms and stress, and coping skills have been previously reported elsewhere (Lee & Schepp, 2009; Lee & Schepp, 2011a, 2011b). The purpose of the study was a randomized clinical trial to test the effectiveness of a family-based self-management therapy on the psychosocial functioning in adolescents with schizophrenia and their families. Two theories, namely, the stress-vulnerability model of severe mental illness (Liberman, 1988; Nuechterlein & Dawson, 1984) and self-regulation theory (Kanfer & Gaelick-Buys, 1991) guided the intervention. The stress-vulnerability model that states an interaction between the biological basis of mental illness and environmental factors provides the rationale for stress reduction and relaxation in the intervention. The process of self-regulation includes symptom recognition, symptom evaluation, and symptom management through coping skills or strategies. The family-based self-management therapy was composed of 12 sessions (2 hours/each). The first hour of each session was for all participants (i.e., parents, adolescents with schizophrenia, and siblings) in a large group to learn about basic self-management skills and to practice the skills for an hour. The family members were then divided into smaller, more homogenous groups (i.e., parent group, adolescent group, sibling group) to practice skills for the second hour of the intervention. The group met once a week for six intensive sessions and then once a month for six reinforcement sessions.

CHALLENGES AND IMPLICATIONS FOR FUTURE STUDIES

Recruiting Subjects

Recruitment of eligible subjects is crucial to the success of clinical research. Recruiting subjects is always challenging but recruiting adolescents with schizophrenia, as well as their parents and siblings is an even greater challenge. The original study used professional referrals and advertisements to recruit subjects. Professional referral is a method to recruit subjects through referrals from mental health professionals who have already contacted and treated youth with mental illness. The advantage of professional referrals is that mental health professionals identify eligible subjects and are aware of needs for mental health resources for youth and their families in a community; therefore, they can provide a pool of potential subjects. To this end, we personally contacted mental health agencies, acute care inpatient psychiatric facilities, and professionals such as school nurses, counselors, and nurse practitioners to inform them of the study and ask for their support in recruiting adolescents with schizophrenia and their families. We, then, maintained the relationship by frequent communications via email, letter, or phone calls, and follow-up thank you for referrals. The disadvantages of this method are that it is very time consuming, to develop and maintain such relationships, and the researcher has to wait until referred contacts are available. Advertisements in local newspapers were also used, which resulted in large numbers of families seeking involvement in the study. The disadvantage was that many did not meet the study criteria, in particular, diagnosis criteria.

During the recruitment process, a total of 161 potential subjects were referred to the study; of these, 67% of 161 did not meet the inclusion criteria during a telephone screening process. Forty adolescents with schizophrenia, along with 108 adult family members (e.g., parents, grandparents) and 44 siblings, were enrolled. Professional referrals yielded 21 enrolled subjects (53%); thus this turned out to be an effective method to recruit subjects with schizophrenia and their families. Enrollees recruited from advertisement in newspapers and others (e.g., referral from other study) were 27.5 and 17.5% respectively. Of the enrolled, we retained 96% in the treatment group and 94% in the control group after completing all sessions.

Several strategies were implemented to recruit persons of diverse ethnic and cultural background. A research team included culturally competent professionals of Asian ethnic heritage to guide in recruiting and retaining minority families. The Asian American population is one of largest ethnic minority groups in the State of Washington; therefore, several subjects would be expected to be of Asian American ethnicity. With this effort, nine Asian adolescents (22.5%) and their families were enrolled and successfully retained in the study. Recruitment efforts also targeted minority communities. Subjects in an African American community enrolled in studies in which the second author and research teams were involved were informed about the study, and three African American adolescents (7.5%) were enrolled and retained in the study. We also utilized translation services for subjects whose second language is English; in our study, 11 families out of 40 (28%) indicated that English is not their fluent language.

Challenge

Despite our efforts, there were still challenges in recruiting subjects. Since adolescents were required to enroll with family members as a cohort (adult family member or adult care giver was required; sibling was not required), family members' commitment to participate in the study for approximately 13.5 months may have been a barrier to recruiting subjects. Time conflicts due to family work schedules affected the adolescents' involvements in interventions. Lack of motivation, a symptom of schizophrenia, could function as a barrier for the adolescents to participate in research. The lack of insight of many individuals with schizophrenia leads some adolescents to believe that they do not need to be involved in a symptom self-management intervention to learn how to manage an illness. Consequently, many families were hesitant to be involved if the adolescent refused to participate. For many families, the idea of participating in a randomized clinical trial (RCT) was new to them; they were not aware of what an RCT had to offer or what it was. They were also very reluctant to get involved in intervention studies due to negative experiences that families have had with others, such as being blamed for adolescents' illness, or anticipated rejection or misunderstanding from others, as prior studies have indicated (Perlick et al., 2011; Sherman, Fischer, Bowling, Dixon, Ridener, & Harrison, 2009). Participants commented as follows:

> It's tiring, frustrating, worrisome and lonely to have a mentally ill child. People who haven't experienced mental illness don't have a clue of what it's like. Physical illness produces sympathy; mental illness produces misunderstanding. (Parent)

> It's hard to have this type of illness when people around you don't understand. (Adolescent with schizophrenia)

Implications

As can be seen in our study, healthcare providers are in a position to initiate discussions regarding participation in clinical trials for subjects who are reluctant to access resources due to mental health stigma, and to direct eligible subjects to appropriate research teams. When professional referral is utilized, reducing the workload related to recruiting and reimbursing health care staff and clinicians for time spent on recruitment (Fletcher, Gheorghe, Moore, Wilson, & Damery,