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Lessons learned from research with adolescents with schizophrenia and their families

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Abstract

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.

Keywords

adolescents; schizophrenia; intervention

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 five years of recovery from a first episode (Robinson et al., 1999); thus this early stage of illness -the first five 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

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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 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 (Kaner et al., 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, 9 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 3 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 of 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 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 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 et al., 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, 2012) would aid in achieving successful recruitment for studies. To reduce the workload for professional referrals, a system where healthcare clinicians introduce research studies and direct potential subjects to research teams for study involvement information or the consent process would be helpful to recruitment as recommended in previous studies (Bell-Syer, Thorpe, Thomas, & Macpherson, 2011). A method of reimbursing staff for time spent on recruitment should be in accordance with ethical principles for human subject research. Alternatively, providing educational materials for patients or health care staff would be considered. Familiarity with clinical routines, such as group therapy sessions where a researcher can contact a clinician who runs group sessions for potentially appropriate subjects, would be an important source for successful recruitment as mentioned in a prior study (Hadidi, Buckwalter, Lindquist, & Rangen, 2012).

Other methods such as respondent-driven sampling and using social networking websites would be considered for future attempts to recruit this population. Respondent-driven sampling, in which a small referral incentive is provided to study participants who make referrals, has been used to recruit individuals with dual diagnoses (Jaffee et al., 2009; Wang et al., 2005). We did not use this method to recruit adolescents with schizophrenia and their family members, but it could be a useful method if it is in accordance with ethical principles. Social networking websites were used by Jones, Saksvig, Grieser, and Young (2012) in recruiting adolescents. Advertisements of research studies on social networking websites could be a useful approach to recruiting subjects in that people with mental illness may feel more comfortable accessing RCT from such websites. Contacting potential trial participants using a research registry should be considered.

Flyers, posters, or promoting family intervention using point-of-decision prompts at clinics or family access places (e.g., churches), or informational meetings at clinics regarding the general overview of RCTs and the benefits for patients need to be considered. These efforts would raise awareness of studies and their benefits and possibly increase health-seeking behaviors (Fletcher et al., 2012). Likewise, providing information for the families enrolled in an RCT control group, after the RCT is completed, on the intervention skills that were

taught would benefit the control group families and be helpful in future attempts to recruit subjects in the community.

Family participants appreciated our service location (i.e., a university) to preserve anonymity, which suggests that holding sessions at a place which does not indicate mental health service would allow families to access RCTs more comfortably. As we mentioned above, involvement of personnel with minority ethnic backgrounds as well as language competencies tend to be effective in recruiting and retaining minority subjects. Our study used weekday evening sessions with refreshments provided and transportation assistance to avoid time conflict, but younger siblings often felt tired in evening sessions. Flexibility in scheduling sessions, in particular, Saturday session, would be considered.

Engaging families in self-management intervention

Our rationale for engaging families is that the majority of adolescents with schizophrenia have just experienced the first episode of psychosis; families and adolescents are poorly prepared to manage the illness; therefore, they need to obtain knowledge, skills, and support to manage adolescents' illness. Such interventions through multi-family group involvement compared to single family group are of benefit to families because they receive mutual peer group support and the stigma often associated with the family of an adolescent with schizophrenia is reduced when they are among others with common issues and concerns (Barbato & D'Avanzo, 2000; Perlick et al., 2011). It was confirmed that family members learn best how to respond to their family member with schizophrenia when in the company of others experiencing the same situations. Participants commented:

These classes (symptom management) have been very helpful in sharing the concerns with other parents. We look forward to talking with the other families. I think our son enjoys being in an environment where he knows he's not the only kid to have experienced hallucinations and severe anxiety (Parent).

These classes (symptom management) really help me a lot; how to handle stress and knowing we are not the only ones who have these problems (Parent).

I haven't met anyone who's been through all of the same garbage that my brother, my family, or I (as his sister) have gone through. I identify most with friends who have siblings that are also two years younger. I kind of understand those friends who have lost their sibling because of death...I lost my brother too...except I got him back (Sibling).

After each larger group session, the family participants attended, smaller groups (i.e., parent group, adolescent group, or sibling group) where the content covered was addressed again. The adolescent group continued to practice stress reduction skills and identified target symptoms that they would manage. The sibling group carried out activities similar to the adolescent group, discussed their concerns, and provided support to each other. The parent group discussed their concerns and supported each other. The parent group also received any additional information in which they were specifically interested, such as management strategies or medication adherence.

All three groups appreciated the small group session for the support they received from the others in the group experiencing similar situations. Each family member addressed individual needs and concerns consistent with previous literature (Addington, Coldham, Jones, Ko, & Addington, 2003). For example, parents expressed a desperate need for education about this illness, particularly during the initial stages of schizophrenia, in order to learn how to manage the illness. Parents also reported that the stigma surrounding mental illness interfered with seeking treatment for their youth. Adolescents displayed various symptoms of schizophrenia and their need to learn coping skills.

Parent interaction is by far the best part of the program. Support of parents going through the same thing with a knowledgeable facilitator really is helpful (Parent).

I used to go to bed wearing clothes and shoes at night before I participated in this program because I had to run out of the house when my son was aggressive and irritable. I feel much better now. I am feeling peaceful because I know what to do when my son gets irritable (Parent).

Challenge

We observed that heterogeneous subject profiles such as age range, developmental level, acuity level of mentally ill adolescents, and education level functioned as challenges to receive the intervention within multifamily sessions. For example, for the adolescents with schizophrenia, information needed to be delivered in a simple, straight-forward, and clear manner in order to hold their attention but may be boring or redundant for those who learn quickly (e.g., siblings). Adolescents with schizophrenia tended to be shy and withdrawn in a total family group setting. We also should pay special attention to the sibling groups. Based on data from 40 siblings (mean age $\pm$ SD=16.38 $\pm$ 4.79), 7 siblings (17.5%) reported that they themselves have emotional/behavioral problems. In their own group sessions, siblings also expressed frustrations and fears of becoming mentally ill which were not discussed in the all family sessions; prior studies have noted this (Friedrich et al., 2008).

In high school, I broke down in tears and exhaustion about every three weeks it seemed. Now, I'm in college in a more stressful environment and teary breakdowns don't happen nearly as often nor last as long. I use many of the techniques we learned in the class to physically relax myself when my mind is racing like that (Sibling).

It's hard having a mentally ill brother. I'm always afraid now that the nightmare of having to see my brother sick, depressed, frustrated, hospitalized; will it happen all over again? It's a stress and while it has been a 'learning experience', I wish it had never happened to us or anyone else ever (Sibling).

It is hard having a mentally ill brother. You're always trying to stay out of his way so he won't get upset. You are always being extra nice (Sibling).

Implications

The length of time of multifamily session would be shortened, and small group sessions would be emphasized based on observations aforementioned. Further, small group sessions would be beneficial for adolescents with schizophrenia who were not actively involved in all family sessions. Although siblings need to learn how to work with their siblings with schizophrenia, they may also need psychosocial interventions to manage their own concerns. For example, education about schizophrenia and genetic counseling (Abrams, 2009; Hodgkinson, Murphy, O'Neill, Brzustowicz, & Bassett, 2001), would help to reduce fear for siblings of adolescents with schizophrenia. Ongoing communication between parents and healthy siblings would be helpful (Abrams, 2009) because unexpressed emotion regarding unmet needs could lead to psychological distress or feelings of isolation (Opperman & Alant, 2003).

Tailoring interventions to target population

There are few studies that identify the crucial elements of psychosocial interventions for adolescents with schizophrenia and their family. From studies of adults with schizophrenia (Kennedy, 1994; Leete, 1989; Lovejoy, 1984), we adapted the skills used to manage illness such as recognizing symptoms related to relapse and symptoms management. Therefore,

symptom identification, awareness and management, stress management, and coping skills, which were relevant to the adolescents as well as to the family members, were included in the intervention. Strategies to decrease stress for adults with schizophrenia were also adapted for use in our intervention. Examples included (a) allowing time for the adolescents to think when they were asked to give information so they don't become stressed when forced to respond in a hurried fashion; (b) helping the adolescents decrease stress by teaching them to structure their time and organize their activities throughout the day so they know what to expect; and (c) if they are susceptible to excess stimuli, helping them find ways to filter out background noises in their environment (Leete, 1989; Lovejoy, 1984).

We continued to question how to deliver meaningful and effective interventions to adolescents with schizophrenia. It has been established that schizophrenia is associated with cognitive impairment and such impairment contributes to poor social functioning, issues with work, and problems managing the illness (Fitzgerald et al., 2004; Sorensen, Mortensen, Parnas, & Mednick, 2006; Trotman, McMillan, & Walke, 2006). Therefore, the intervention was delivered based on two principles: simplicity and concreteness. Intervention sessions were simplified to deliver one or two main topics in a single session in order for the adolescents to engage in and understand the concepts being presented. Various activities were utilized. For example, in addition to group discussion, adolescents were asked to draw a picture of the symptoms they have when they are angry and then asked to draw a picture of them using the skills they learned to manage the anger symptoms. Once adolescents with schizophrenia attain the aforementioned skills and strategies, they will be able to learn more advanced skills (e.g., interpersonal skills) and receive different types of interventions. These interventions appeared to meet the families' needs.

I think this program helped train me as a caregiver so well that we have avoided the expense of hospitalization twice during the program - if these coping skills could be taught then insurance costs could be drastically reduced (Parent).

This program (symptom management) was very comprehensive. It is too bad we have had to waste time, energy, and money on medical care providers. You have been a much more comprehensive resource (Parent).

Challenge

As we expected, adolescents with schizophrenia exhibited relatively low cognitive functioning. Their cognitive functioning was assessed with the Symbol Digit Modalities Test (SDMT) in the 24 adolescent subjects in the treatment group before each session. SDMT involves matching 120 numbers with symbols in a 90-second time frame; the number of correct responses is the SDMT score (Smith, 1982). A higher number indicates that the individual is processing information more readily. The mean score of the SDMT score in the subjects of our study was 37.80 (SD=12.35; Range=18-58) which is much lower than individuals serving as non-psychiatric controls aged 15-20 (mean± SD=59.3±11.6) (Yeudall, Fromm, Reddon, & Stefanyk, 1986). Abstract concepts, wordy descriptions, and complicated homework were not useful for adolescents with schizophrenia.

Implications

We may use a cognitive function test to assess subjects' executive functioning and concentration to tailor content and delivery methods of an intervention to each subject's level of functioning. Brief written materials can be used to overcome cognitive impairment for this population. Combining psychosocial interventions with cognitive enhancement therapy would be considered for a future study. Impaired cognitive functioning should be a crucial target for therapeutic intervention and should be considered in developing interventions (Naismith et al., 2009). The following family quotes are worthy of note in

considering the content of interventions for this population for future research because few studies have paid attention to the issue of close interpersonal relationships and more studies need to be done to help this population and their family members.

I worry that he'll be stuck in a cycle of sickness/recovery for the rest of his life. I worry that he won't meet someone special to make his life fantastic. We'll never leave him, but I want him to have someone for himself (Sibling).

I read whatever I can about mental illness and schizophrenia, but there's always a feeling that I could learn more. Knowledge is power, but sometimes I feel powerless against this illness (Parent).

Conclusions

The present study provided a description of the challenges we experienced, and the strategies to consider for those implementing future studies engaging the families of adolescents with schizophrenia. Family interventions should be considered for adolescents with schizophrenia, as the benefits have been evident. Research recruitment requires sustained and innovative efforts in order to achieve adequate numbers of subjects. Multifamily group sessions and small group sessions are needed to provide the families of adolescents with schizophrenia with supportive interventions including (a) training for the families in the management of the patient's symptoms; (b) the management of healthy siblings' concerns and needs; and (c) the provision of information on the nature, course and outcome of a patient's disease. For adolescents with schizophrenia, the contents of an intervention should be simple and concrete. Homework or keeping records were not found to be effective with adolescents with schizophrenia because of the nature of their cognitive challenges. The social support felt by the families from having other families who were facing the same challenges available to share experiences with was a potent outcome of this RCT.

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