

Parent Education Model for Child & Adolescent Onset Psychosis

Elisha Agee, Jaquelyn Spezze, and Justin Underwood
Pepperdine University

Although history has shown that the onset of psychotic disorders typically begins in early adulthood, recent research has identified a specific population of children and adolescents who develop psychotic disorders at a young age. Children and adolescents who develop psychotic disorders typically have a more complex course and worse prognosis than adult onset. For this reason, early intervention can be crucial. Having parents and family members who actively participate in the treatment of patients experiencing psychosis greatly reduces the likelihood of relapse symptoms, while improving the quality of life of the patient and the family. This proposed model actively engages parents and other family members of children or adolescents diagnosed with a psychotic disorder in different contexts. In the model, families will participate in consultations with the primary treatment provider, giving and receiving valuable information about the best possible treatments. Parents will participate in caregiver psychoeducation/support groups for additional support from other parents and caregivers with similar challenges and needs. Families will also participate in family therapy as a whole in order for the family to improve communication, enhance problem-solving skills, and learn how to support the family's unique needs. Having the family involved in these different contexts of a child or adolescent living with a psychotic disorder will not only aid in the treatment of the disorder but also improve the quality of life for the entire family.

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Current treatment models available for child and adolescent onset psychosis are insufficient and do not take a multimodal approach. When addressing gaps in the literature in regard to treatment, it is first critical to explore and identify theoretical ideas and models to ensure that new ideas are philosophical-sound before a new program is actualized. Thus, the purpose of this manuscript is to develop a novel treatment program based on scientific literature that would assist clinicians in treating child and adolescent onset psychosis. The proposed treatment program is novel because the multiple modalities and components of other treatments that have been integrated in the model have been found to be efficacious. This integration was done in an effort to create a single feasible comprehensive program that eliminates many of the research and clinical gaps found in single component treatment modalities.

Early-Onset Psychosis

Prevalence & Etiology

Psychotic disorders such as schizophrenia or

schizoaffective disorder are serious mental illnesses that are often pervasive, life long, and crippling. Such disorders occur in approximately 1% of the population worldwide and affect not only individual patients, but also their family, friends, and community (Courvoisie, Labellarte, & Riddle, 2001). The onset of psychotic disorders usually occurs between the ages of 16 and 30, typically emerging much earlier in men than women (McGlashan & Johannessen, 1996; Virginia Commission on Youth, 2010). However, with a growing body of research, child and adolescent onset psychosis is increasingly recognized as a distinct phenomenon. Furthermore, approximately 39% of men and 23% of women who develop a psychotic disorder will experience their first psychotic episode before they turn 19 (Davis & Schultz, 1998; Gearing & Charach, 2009; Sharma, 2005).

Child-onset schizophrenia (COS) is extremely rare and refers to a child who begins displaying symptoms of psychosis prior to the age of 13 years old (Virginia Commission on Youth, 2010). There has been variability in the prevalence of COS. However, research typically agrees that COS occurs in approximately 0.1-1% of the individuals who develop any psychotic disorder (Courvoisie et al., 2001; Sharma, 2005; Virginia Commission on Youth, 2010). Adolescent-onset schizophrenia refers to when the first psychotic episode occurs between the ages of 13 and 17, and manifests in approximately 4% of

Correspondence concerning this article should be addressed to: Elisha Agee, Pepperdine University, Graduate School of Education & Psychology, 6100 Center Drive, Los Angeles, CA, 90045, USA. Email: elisha.agee@gmail.com.

individuals with any psychotic disorder (Sharma, 2005). Although still rare, with the onset of puberty the incidence of psychosis rises steadily (Anjum, Gait, Cullen, & White, 2010). However, other research has noted that adolescent-onset psychosis is “fairly common” (Courvoisier et al., 2001, p. 2). When referring to an individual who had their first psychotic episode or was diagnosed with a psychotic disorder during either childhood or adolescence, the term early-onset schizophrenia (EOS) is used, implying that the illness developed prior to the individual turning 18 years old (Courvoisier et al., 2001). For the purpose of this paper the term ‘early-onset’ will be used to indicate the emergence of a psychotic disorder prior to age 18. Additionally, the term ‘psychosis’ or ‘psychotic disorder’ will be used instead of schizophrenia, schizoaffective disorder, or another specific type of a psychotic disorder. The term psychosis is generally used to represent a category of disorders. Thus this paper will refer to a category of psychotic disorders, instead of the various subgroups and specific illnesses (Joshi & Towbin, 2002).

It is not uncommon for individuals to experience depressive symptoms concurrently with their first psychotic episode and symptoms of early onset affective psychoses are very similar to early onset nonaffective psychosis, causing a notable amount of misdiagnoses (Schothorst, Emck, & van Engeland, 2006). However, the literature on child and adolescent onset mood disorders with psychotic features is scarce, and much more research has been focused on early onset psychosis, without a specific relationship to mood symptoms (Ledda, Fratta, Pintor, Zuddas, & Cianchetti, 2009). Consequently, this paper will focus primarily on early onset-psychosis without the presence of mood symptoms.

The rarity of early onset psychosis (EOP) does not reduce the need for researchers and clinicians to focus on comprehensive and effective treatment protocols. Currently, no interventions have been tailored exclusively for children, adolescents, or the families affected by EOP (Gearing, 2008). In fact, using current treatments for child and adolescent psychosis, less than 25% experiencing psychoses fully recover (Gearing & Charach, 2009). Thus, there is a great need to develop a comprehensive treatment

program that will increase recovery rates for EOP.

There are many stressors and issues associated with psychotic disorders due to its devastating and distressing course, which creates a significant amount of burden on the caregivers and social support of individuals suffering from such illnesses. Additionally, hospitalizations often cost a significant amount of money, both for the families of those who are hospitalized, and for society at large (Goldberg, 1991). Adolescents experiencing psychotic episodes often require hospitalizations ranging from 25 to 45 days in length (Gearing & Charach, 2009). Costs associated with psychiatric hospitalizations related to schizophrenia are in the tens of billions of dollars annually. It is reasonable to assume that if hospitalizations associated with all types of psychosis were taken into account, this number would increase (Gearing & Charach, 2009).

The cost hospitalization is not only financial. Secondary effects also occur as the child or adolescent is not in school, and consequently may have educational impairments. As a result, there may be a discrepancy between the need for, and the availability of, treatment interventions for parents and families managing EOP in children and adolescents.

The term *psychotic* refers to the presence of a pre-determined set of symptoms, such as delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behavior (APA, 2000). Negative symptoms may also be present, and reflect the disappearance of certain abilities and emotions normally present (APA, 2000; Green, 2001). Examples of negative symptoms include, flat or blunted affect, alogia, and avolition (APA, 2000). More generally speaking, it may refer to alterations in typical thought processes or disruptions in thinking accompanied by the symptoms previously mentioned (Joshi & Towbin, 2002). According to the Diagnostic & Statistical Manual, 4th Edition, Revised (DSM-IV-TR), the criteria for EOP (in schizophrenia in particular) is synonymous with the adult criteria for the disorder and can reliably be used for children and adolescents (APA, 2000). The only (yet very important) difference is that children and adolescents may fail to meet expected social or academic milestones. By contrast, the criteria for adults include deterioration in functioning (Sharma, 2005).

Although there are variations of terms describ-

ing similar psychopathologies, such as psychotic, psychotic disorder, and psychosis, for the purposes of this manuscript the term ‘psychosis’ will be used. The Diagnostic & Statistical Manual, 5th Edition, was recently published and includes changes to two primary psychotic disorders that relate to the idea of psychosis described in this paper. The following changes have been made to the schizophrenia category. First, the special attribution of bizarre delusions and Schneiderian first-rank auditory hallucinations were removed. Second, an individual must have at least delusions, hallucinations, or disorganized speech in order to be diagnosed (APA, 2013b). Regarding schizoaffective disorder, once Criterion A has been met there is no longer a requirement that a major mood episode must be present for the majority of the disorder’s total duration (APA, 2013b). Due to the recency of its publication and the fact that research has not yet begun to study the new categories in depth, this paper focuses primarily on diagnostic criteria and research associated with DSM-IV-TR criteria for psychosis.

Although the DSM-IV-TR and multiple studies have identified the presentation of EOP as closely resembling adult psychosis, the clinical picture of EOP deviates from adult onset in a variety of ways (APA, 2000). A significant difference is that the earlier the onset of psychosis, the more severe the symptoms and prognosis appear to be (Anjum et al., 2010; APA, 2013a; Krausz & Muller-Thomsen, 1993). EOP also seems to be paired with a higher prevalence of negative symptoms (APA, 2013a; Schothorst, Emck, & van Engeland, 2006). Negative symptoms are often difficult to differentiate from depressive symptoms. However, negative symptoms often seen in prodromal psychosis include reduced drive, attention problems, and anergia, and not affective symptoms such as depression, or suicidality (McGorry, Yung, Phillips, 2002).

Children and adolescents experiencing psychosis may present cognitive impairments such as impaired concentration and ability to focus, diminished interest, incoherent speech, and confused thinking (Joshi & Towbin, 2002; Larson, McGlashan, & Moe, 1996; Sharma, 2005). Child and adolescent psychosis may also include extreme moodiness such as high levels of anxiety, poor emotional control, bizarre and/or stereotypy behaviors, and severe problems

with building and maintaining friendships (Sharma, 2005). Delusions and hallucinations may be more difficult to assess in children and adolescents perhaps due to a reluctance to disclose or the more active imaginations typically seen during development, but they are often present, along with paranoia, “a preoccupation with inner thoughts” (p.1), vivid and bizarre thoughts and ideas, or an inability to distinguish dreams from reality (Sharma, 2005). Furthermore, delusions and hallucinations may be elaborate, with visual hallucinations being much more common in children than in adults (APA, 2013).

As mentioned earlier, the onset of psychosis typically occurs between the late teens and mid thirties. Although onset prior to adolescence is rare, there have been cases of psychosis documented in as young as 5- or 6-year olds (APA, 2000). There are numerous etiologic possibilities and the etiology of many cases of EOP is multifactorial. It is believed that the cause of psychotic disorders most commonly relates to the interaction of genetic influences, biological factors, family influences, and environmental factors (Joshi & Towbin, 2002; Sharma, 2005). Individuals may also experience psychosis as a result of brain or metabolic disorders. There may also be some causes that are still unknown. Genetic deficits, prenatal viral infections, obstetric complications, and marijuana use during adolescence, have also been associated as risk factors and have predictive value for the onset of psychosis (Anjum et al., 2010). Recent research has indicated that youths who experience psychotic episodes prior to puberty have an increasing number of brain abnormalities and their brains may have diminished brain tissue volume (Commission on Youth, 2010).

Developmental, environmental, and cognitive influences may play an even greater role in EOP than in adult onset psychosis (Joshi & Towbin, 2002). In fact, it has been estimated that in up to 90% of EOP cases there are also behavioral and or developmental abnormalities present, such as social withdrawal, disruptive behavioral disorders, academic problems, speech and language delays, and abnormal brain growth (McClellan & Werry, 2001; Virginia Commission on Youth, 2010). Also, research has indicated that in children under the age of 12, early language deficits and motor impairments may precede the first psychotic episode.

It thus appears that the age of onset of psychosis may have both pathophysiological and prognostic significance. Individuals with EOP appear to have poorer premorbid adjustment, lower educational achievement, and more evidence of brain abnormalities (APA, 2000). Further, aside from the strong inverse relationship between age of onset and prognosis, those with earlier onset of psychosis are more often males with prominent negative symptoms, cognitive impairment, and markedly impaired social functioning (APA, 2000; Gearing, 2008; Sharma, 2005).

Early Intervention & Primary Treatment

Understanding the course of psychosis is crucial for recognizing and distinguishing the early warning signs of psychosis. The first stage of the illness is referred to as the prodromal stage, and is indicated by the slow and gradual development of a variety of signs and symptoms prior to development of a full psychosis (Subotnik & Nuechterlein, 1988; Morrison et al., 2004). These symptoms consist of dysfunctional premorbid development such as social withdrawal and isolation, academic difficulties, deterioration in hygiene and grooming, loss of interests, shyness, outbursts of anger, idiosyncratic preoccupations and behaviors, and disturbances in social behavior (APA, 2000; Joshi & Towbin, 2002).

The next stage is called the active stage, sometimes referred to as the acute stage. The active stage often consists of explicit delusions or hallucinations, strange or idiosyncratic behaviors, functional deterioration, and formal thought disorder (Virginia Commission on Youth, 2010; Moukas, Stathopoulou, Gourzis, Beratis, & Beratis, 2010). Hallucinations and delusions may be less detailed or complex in nature for EOP than those observed in adults. Visual hallucinations may be more common in EOP (APA, 2000).

The recovery phase follows the acute phase and describes the time in which symptoms remit and dissipate. In the phase, there may be some ongoing symptoms of psychosis along with confusion, disorganization, dysphoria, and lability in mood (Virginia Commission on Youth, 2010; Moukas, et al., 2010). The last stage of psychosis usually consists of the residual phase, in which positive psychotic symptoms are minimal but nega-

tive symptoms may still be present, such as apathy, lack of motivation, social withdrawal, or flat affect.

It is critical that caregivers are educated to recognize the early warning signs of relapse into another episode of psychosis and to understand the course of the illness. This will allow them to start treatment with their child or adolescent as early as possible. If the early warning symptoms of a relapse are recognized and early assistance and interventions are implemented, the long and disheartening course of the illness and substantial burden on the family can be minimized (Kennedy et al., 2008).

EOP relapse rates are understudied, but it has been indicated that they closely parallel adult relapse rates (Gearing, 2008). Current numbers reveal that 33% of EOP patients are readmitted to a psychiatric hospital within the first year of experiencing psychotic symptoms, 44% relapse within 2 years, and 58% relapse within 5 years of their first psychotic episode (Gearing, 2008). These hospitalizations take a toll emotionally on both the youth and the family. They also impose a financial burden on the family and the health care system. Utilizing therapeutic supports outside hospital settings reduces the financial burden to the family and is overall more cost-effective (Goldberg, 1991; Weiden & Olfson, 1995). Thus, the proposed intervention is a good fit for the EOP population and useful to society as a whole.

Consequently, there is a substantial need for parent education and solid treatment interventions for children or adolescents diagnosed with EOP in order to minimize the possibility of a relapse. Furthermore, there is a great need for broader education about the risk of EOP, since approximately 39% of men and 23% of women who develop a psychotic disorder will experience their first psychotic episode before the age of 19 (Davis & Schultz, 1998; Sharma, 2005). Research has found that caregivers and families with ongoing contact with mental health professionals are more likely to better cope and recover from the crisis of having a child or adolescent diagnosed with a mental illness. The child or adolescent also has a better overall prognosis (Ambikile & Outwater, 2012). Therefore, this parent education model focuses on interventions for individuals experiencing EOP and their families. It serves the purpose of in-

creasing their caregiver's and family's knowledge of the illness, its course, and treatment. In this way, this proposed model seeks to help children or adolescents with psychosis by assisting their caregivers and family, which will in turn assist the child or adolescent.

Current Theoretical Models of Treatment

Family Consultation Theoretical Model

Family consultation is brief, flexible, and utilized per the request of the family that has a child or adolescent experiencing their first episode of psychosis (Lepage, 2005). Consultation is "asking the advice or opinion of an expert and as deliberating together" (Marsh, 2001, p.46). Usually, the first intervention the family of a child or adolescent with EOP experiences is family consultation. Sometimes it is the only intervention the family encounters that is specifically for the family. Family consultations range from one to five sessions and typically occur during or after a crisis, child or adolescent inpatient treatments, hospitalizations, and/or family transitions. Families are then referred to long-term treatment (e.g., family therapy, couples therapy, National Alliance of the Mentally Ill, and/or individual therapy; Dausch et al., 2012; Marsh & Lefley, 2003). Mental health professionals perform family consultations, which are first implemented at initial diagnosis or first hospitalization of the youth (Lepage, 2005). Both the family members and the youth (if possible) are present in the consultation and the intervention is collaborative in nature.

The purpose of family consultations after a child or adolescent experiences psychosis for the first time is to provide information, expert advice, support, and empathy to the family, as well as to improve family coping skills and assist in identifying and prioritizing the family's needs (Marsh, 2001). Family consultations provide the means to assist the family in formulating a family service plan, addressing illness-related questions and concerns, and making the most informed decision about their child or adolescent and family as a whole (Marsh & Lefley, 2003). The consultation also provides a systems oriented assessment of the family's current needs, concerns, strengths, and resources (Marsh, 2001). Furthermore, the family consultation is focused on problem res-

olutions and is goal oriented. Topics of the consultation may include discussing the youth's substance abuse disorder (if one is present), long-term treatment planning, living arrangements, and psychoeducation about the course of the illness (Marsh, 2001).

The consult also emphasizes the family as the primary agent of decision making regarding their child or adolescent and also as responsible for implementing those decisions. Research has shown that when a family and/or the child or adolescent is informed about early psychosis and about the possible medical and psychosocial interventions, they make better informed decisions about treatment and follow-up care (Lepage, 2005). Therefore, family consultations appear to be extremely important to include into the proposed parent and family education program. Furthermore, it is suggested that family consultations increase the family members' self-efficacy in caring for their child or adolescent with psychosis (Solomon, Draine, Manion, & Meisel, 1996).

Parent Support Group Theoretical Models

Current treatments for EOP often include multiple components, with each component contributing a valuable feature to overall management of the psychosis and its impact on the individual and their family. For example, interventions such as day care treatment centers may bring relief to parents by creating a break from caregiving and creating valuable time for parents to accomplish other responsibilities. Also, providing parents time away from caregiving allows them to take part in their own income generating activities, which can directly help the management of their child's illness due to the staggering costs of hospitalizations, emergency room visits, and medications (Ambikile & Outwater, 2012). Group interventions for parents are also commonly used and have been found effective.

The Family Centered Program is an intervention consisting of a family focused group for youths with schizophrenia (Kennedy et al., 2008). The model consists of 6 weeks of intensive 2-hour group sessions followed by six monthly booster sessions. The first hour of each session involves the family meeting together to learn and practice specific skills pertinent to living with a child or adolescent with psychosis. The skills taught focus on anger management, stress man-

agement, and strategies for coping with problems at school and at home. The second hour consists of the family being broken up into smaller groups, such as parents and caregivers, and siblings of the individual experiencing the mental illness. Each group discusses topics that are relevant to their role in the family. For example, the parents' group focuses on mutual support and provides education about schizophrenia, symptom management, enhanced family communication, and relapse prevention.

The Psychoeducational Multiple Family Group (PMFG) is an approach that is made for various models and settings, and is used for integrating caregivers and family into treatment (Gearing, 2008). It is a semi-structured intervention that is flexible and focuses on competencies, not deficits, thus directly supporting the family. It combines psychoeducation and therapeutic processes to enable patients to engage in behavioral change for the family and the child or adolescent with psychosis. PMFG focuses on improving communication, medication adherence, problem solving, use of crisis intervention, symptom management, and establishment of social support and coping skills (Gearing, 2008). The format consists of 5-8 families attending a closed group over a period of time ranging from 2 months to 2 years.

Family Psychoeducation Theoretical Model

Psychotic disorders are not completely treatable by medication and almost always require adjunctive therapies (McFarlane, Dixon, Lukens, & Lucksted, 2003). Families that participate in such treatment can have a significant effect on their relative's outcome. Successful treatment of a psychotic disorder often includes families and significant others involved in caring for the patient. They may serve many roles and fulfilling these roles can burden the patient's support system, increasing burnout. This burnout often has negative effects on the patient's treatment as well as the patient's and family's well-being (Adamec, 1996; Cochrane, Goering, & Rogers, 1997). However, if families are provided with education about the nature of schizophrenia and possess coping skills specific to the patient, they can fulfill the above mentioned roles while increasing their overall well-being (Cuijpers, 1999; Shi, Zhao, Xu, & Sen, 2000).

Family psychoeducation provides them with useful information on the nature of psychosis, its course, and successful treatments. It teaches and enhances each family member's ability to cope with their relative's confusing illness. Psychoeducation aims to encourage families to analyze their behavior toward their relative with psychosis, adjust their behavior to compensate for their deficits, coordinate the roles of everyone involved in the treatment and rehabilitation, and ensure that they are all attempting to achieve the same goals in a supportive relationship.

Practitioners help families create and maintain helpful relationships within the family unit. Training family members to maintain helpful relationships with their relative and to form stable support systems is emphasized. The role of the family as directly involved in the treatment of symptoms is deemphasized, leaving that within the scope of the relative with psychosis and his or her treatment team. A family's focus on progress and symptom reduction could impede successful treatment, whereas a family focused on support could have a very positive effect on the patient's rehabilitation (McFarlane et al., 2003).

Families may also require support and a therapeutic environment where they can process, grieve, and grow. Practitioners provide empathetic engagement with the family, addressing their unique stressors and concerns and providing the continued education and ongoing support that is often necessary for families (McFarlane et al. 2003). The intervention with the family also focuses on the enhancement of problem solving skills and improving communication skills to aid the rest of the family as a unit. Programs that successfully accomplish these goals reduce hospitalizations of the patient, and decrease the patient's positive and negative symptoms, particularly if the intervention lasts for at least three months (Dyck et al., 2000; McFarlane et al., 2003; Pitschel-Walz, Leucht, Baumi, Dissling, & Engel 2001).

Relapse Prevention Theoretical Model

Serious mental illnesses, specifically psychosis, have periods of remission or times when there are few symptoms present and other times when the symptoms are worse or exacerbated (Marsh, 2001). Relapse of a psychotic episode is the reoccurrence

or exacerbation of psychotic symptoms, which eventually leads to interference and impairment in the individual's daily living (Levy, Pawliuk, Joobor, Abadi, Malla, 2012; Addington, Addington, Patten, 2007; Moller & Murphy, 1997). Relapse can be associated with an increased risk of re-hospitalization, feelings of hopelessness, fatigue, and a loss of pleasure (Marsh, 2001). However, research has found that approximately 93% of family members can identify the warning signs of a relapse in their relative with a psychotic disorder and approximately 80% of relapses can be prevented (Amenson, 1998). Relapse prevention can significantly reduce the disruption of the family's lives and also decrease the risk of re-hospitalization of the relative with psychosis (Marsh, 2001). Many variables affect relapse, which include the child or adolescent (e.g., prior functioning, coping strategies, substance use, treatment adherence), family (e.g., expressed emotion, level of support), and illness (e.g., treatment responsiveness, symptoms) (Amenson, 1998). Although there are many variables that affect the likelihood of relapse, many of these variables can be modified to develop a relapse prevention plan.

Relapse occurs in stages, called the Stages of Relapse Model. The five stages of the relapse model are: stability, early warning signs, relapse, symptom remission, and recovery (Amenson, 1998). In stability (Stage 1) the symptoms are controlled and there is a good quality of life for the child or adolescent. The stage of stability can be maintained if family members and child or adolescent notice and respond to the early warning signs (Stage 2) before relapse occurs (Stage 3; Marsh 2001). Early warning signs include an increase in symptomatology, a change in the child's or adolescent's behaviors, and alterations in biological rhythms (Amenson, 1998). Families can help monitor the symptoms, triggers, and warning signs they notice in their child or adolescent and also provide support and a low stress environment (Marsh, 2001). In relapse (Stage 3) the child's or adolescent's symptoms are severe and require assistance from the family to obtain immediate interventions with their mental health care provider (Marsh, 2001). During relapse it is important for the family to maintain a sense of hopefulness for the child or adolescent. In symptom remission (Stage 4) the child or adolescent has to follow the treatment

regimen given by the treating mental health provider and usually appears to be quiet and sometimes dazed from the aftermath of the relapse and trauma of relapsing (Marsh, 2001). The child or adolescent is at a high risk for relapse during symptom remission and also during recovery (Stage 5; Amenson, 1998). During recovery the family should focus on healing and reintegration of their child or adolescent. Furthermore, the family should monitor risk factors, manage symptoms and triggers, and also enhance protective factors (Marsh, 2001). Therefore, this program entails increasing knowledge and skills, and changing attitudes throughout the treatment process.

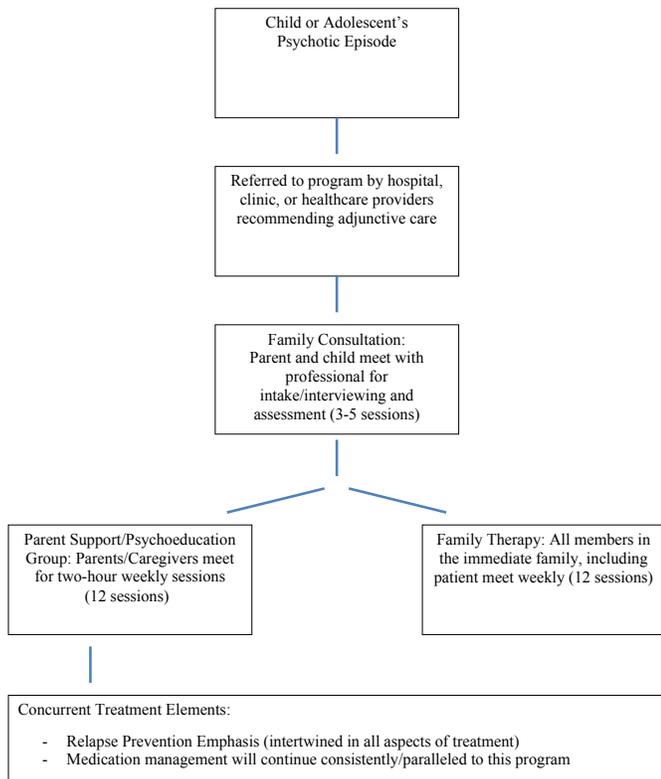
The Program

Description

The proposed model (presented in Figure 1) utilizes a multimodal approach for parents and caregivers of children or adolescents with early onset psychosis. Parents and caregivers receive support and learn skills in several different contexts. First, parents and guardians will participate in family consultations with their child or adolescent's primary treatment provider. Parents and caregivers collaborate about their child or adolescent's individual treatment, providing and receiving important information about the treatment of the psychotic symptoms. Second, parents and caregivers participate in parent support/psychoeducation groups where they learn the unique skills needed to aid in their child's recovery while providing a safe space to process the difficulties and frustrations inherent in being a parent or caregiver of a child or adolescent exhibiting psychotic symptoms. Third, parents will attend family therapy with their child or adolescent with EOP and any other siblings or caretakers of the child. Family therapy allows the family to learn communication and problem solving skills as the family learns to function supportively and address the needs of all its members. Last, relapse prevention interventions and techniques will be interwoven and emphasized throughout all the aforementioned interventions.

The program will last about 3 months, consisting of 12 weekly sessions of parent groups and family therapy, and approximately 3-5 family consultations.

Figure 1. Description of Proposed Program



However, all services will be available for follow-up or “check-in” sessions due to the complexity and longevity of the disorder. Parents and caregivers will continue in their role as consultants throughout the duration of their child’s treatment. The target population for this treatment model is parents or caregivers of children or adolescents with psychosis who are currently under psychiatric care. This treatment model also seeks to assist with the child’s or adolescent’s transition from acute inpatient treatment to outpatient treatment. Referrals will be made by treating psychiatrists or psychologists for adjunctive care.

A primary targeted behavior of this treatment model will be minimization of psychotic symptoms and reduction of the risk of relapse. This will be accomplished by having all components of this program focusing on symptom management. EOP is comprised of the presence of positive symptoms, such as hallucinations and delusions, negative symptoms

such as alogia and apathy, and behavioral outbursts, which often put the safety of the child and others at risk. Many parents and guardians have reported that the presence of such symptoms affects multiple aspects of their lives, including when these behaviors negatively impact individuals outside the family, such as neighbors, classmates, and community members. (Ambikile & Outwater, 2012). Additionally, family support is crucial in the growth and development of their children, and is related to whether their child receives mental health services. Therefore, by integrating family consultations, parent psychoeducation and support, family therapy, and relapse prevention, the child or adolescent’s treatment plan will be tackling symptom management from several different angles.

The developmental needs of children and adolescents will be addressed in the proposed parent education model in various manners. The therapeutic approach would vary depending on the child and adolescent’s developmental stage and the interventions would be tailored for the child’s or adolescent’s developmental stage. For example, in family therapy the interventions and interactions will incorporate play therapy for younger children, while with adolescents interventions will be based on talk therapy. In addition, psychoeducation for the child and adolescent will be provided to the child or adolescent in a manner that is understandable to them based on their developmental stage (such as language abilities, abstract thinking capacity, and so forth).

Although not the primary focus of this paper, a critical aspect of this program entails close communication and active involvement with the child’s psychiatrist to ensure sufficient medication adherence and management, should medication be warranted. The Food and Drug Administration has approved the use of some antipsychotic medications in children and adolescents with severe emotional disorders such as psychosis (Harrison, Cluxton-Keller, & Gross, 2012). Both the research regarding medication and the prevalence of medication use among children and adolescents experiencing their first psychotic episode is growing, and minors are increasingly being prescribed antipsychotic medications as part of treatment (Cooper et al., 2006; Harrison, Cluxton-Keller, & Gross, 2012). This change is critical since psychotropic med-

ications, particularly antipsychotics, are almost always a component of, and by some are viewed as the foundation of, treatment for psychosis (Seligman & Reichenberg, 2007; Zipursky, 2002). Due to the fact that children and adolescents with psychosis are a part of a highly vulnerable population that is still growing and developing, psychiatrists would need to obtain baseline measures before initiating antipsychotic medications (e.g., body mass index, liver functioning, blood pressure, lipids) and would need to continue to monitor medically while receiving such medication (Harrison, Cluxton-Keller, & Gross, 2012).

Since the majority of individuals prescribed antipsychotic medication for psychosis are only partially adherent to their prescribed medication regimen, there is an even greater need for this treatment program to address and include ways to assess, maintain, or increase, adherence to medication as needed (Leucht & Heres, 2006). Studies have indicated that poor adherence to medication is one of the major predictors of readmission to the psychiatric hospital, making individuals three times more likely to be admitted than those who are adherent to their medication treatment (Gearing & Charach, 2009). Within the proposed treatment protocol, medication management would be monitored by the child's or adolescent's psychiatrist. However, psychoeducation about medication, benefits, side effects, and risk factors, would be incorporated into all aspects of treatment, starting with the initial consultation, and continuing in both family therapy and the parent/guardian support group. Collaboration with the psychiatrist would also be incorporated throughout the program, to further benefit from the establishment of a cohesive treatment team or wraparound program.

Structure of Program

Family Consultation Intervention

The structure of the family consultation in the presented parent program is empirically supported by research. However, it will be modified to specifically accommodate families with children or adolescents that have recently experienced EOP. The literature on family consultation focuses on families with a relative that recently experienced their first episode of psy-

chosis, but it is not specifically geared toward families of children or adolescents. As mentioned, the majority of first episode psychosis occurs from between the ages of 16 and 30 and the incidence of childhood onset of psychosis is extremely rare. Therefore, most resources for parents or caregivers are not geared for children or adolescents (under the age of 18), highlighting the necessity of this treatment model.

The family consultation will range between one and five sessions. Since this intervention is flexible and adaptive, if it is determined that the family needs more consultations due to re-hospitalizations and/or a crisis, the program can adapt to the needs of the family. The first session of the family consultation usually occurs shortly after the initial diagnosis or during the hospitalization of the child or adolescent. There will usually be more than one consultation because many times the family will be too overwhelmed in the initial consultation to retain all the information the consultant offers the family and/or the child or adolescent (Lepage, 2005).

The first consultation will include interviewing and assessing the family members and the child or adolescent (if present). The first consultation, and all other consultations, will be adjusted to be developmentally sensitive, such as interviewing the family more when the client is younger and using interviews that are developmentally appropriate. The first consultation seeks to gather information about the child or adolescent, understand what preceded the hospitalization, and describe the warning signs the family and/or child or adolescent may have noticed before the first episode of psychosis (Lepage, 2005). In addition, the first family consultation assists in engaging the family or caregiver and the child or adolescent into treatment during a difficult time in order for them to become committed to continue further treatment.

In the first consultation, the mental health care provider will respond to the family and child or adolescent's most urgent concerns and needs. The consultant will assess the impact the first episode of psychosis and hospitalization had on the child or adolescent and the family, their current knowledge of psychosis, existing coping skills and social support, strengths and weaknesses, and whether or not there were any apparent preexisting family stressors (e.g.,

life cycle transitions, separation/divorce; Lepage, 2005). Even in the first consultation, the consultant seeks to offer knowledge, advice, and skills to assist the family in helping their child or adolescent recover from psychosis. Specifically, the consultant will offer education to the family and/or child or adolescent in order to reduce blame and guilt (Lepage, 2005). The first consultation provides referrals and resources to the family or caregiver and child or adolescent, such as information for a case-manager, in order to address transportation or insurance issues.

The second through fifth consultations will vary according to the needs of the child or adolescent and their family. In this program, the consultations may also include extended family members. If the child or adolescent has siblings, the siblings will be given age appropriate information and education regarding their sibling's diagnosis, hospitalization, and treatment plan. Furthermore, parents and siblings will be given a tour of the child inpatient facility in order to better inform them and ease their fears about how their family member is being treated. In the later consultations the child or adolescent and all family members will identify potential relapse signs and behaviors, and will also develop a detailed crisis plan. In addition, the family, child or adolescent, and consultant will create a discharge plan to transition the child or adolescent from inpatient to outpatient treatment. There will also be scheduled follow-up consultations after the child or adolescent has been discharged from the hospital at week one, month one, and as needed.

Parent/Caregiver Psychoeducation & Support Group

One component of the proposed parent education model is a parent and caregiver psychoeducation and support group. Psychotic disorders place a significant burden on family and caregivers due to their frequent onset during late adolescence and their lifelong course (Kennedy et al., 2008). Typically, parents and primary caregivers are ill prepared for their child's or adolescent's diagnosis of a psychotic disorder and may not know how to manage the disorder (Gearing, 2008). Therefore, parent groups can help counter this ill preparedness and increase caregivers' awareness of available resources while also incorporating caregivers

into treatment (Kennedy et al., 2008). Also, involving parents of children or adolescents with psychosis in the treatment plan enhances medication adherence and overall prognosis (Gearing, 2008). Such an intervention has been shown to be effective in the past, and the proposed psychoeducation and support group integrates various topics present in past efficacious parent groups (Kennedy et al., 2008). Previous models have had various durations, such as 6 and 8 weeks. The proposed group, however, will meet for 12 weeks (Gearing, 2008; Kennedy et al., 2008).

Parents and caregivers will meet once per week for 2 hours while their child or adolescent attends their typical day program, outpatient treatment, or daily routine of therapy and doctors' appointments. Caregivers will have their experiences normalized, receive support from people who can relate to those experiences, and hear about other caregivers' problems that they have not experienced but might anticipate. The psychoeducational aspect of the parent group is crucial as such interventions for parents and families have consistently been correlated with improved outcomes and a reduction in relapses and hospitalizations. Family psychoeducational interventions have been found to be more effective in preventing relapse than individual treatment or medication (Gearing, 2008). The support aspect of the parent group will not be separate from, but rather, intertwined with the psychoeducational aspect. The integration of support groups and psychoeducation groups is not frequently seen, but the need for support is not isolated from the other aspects of the illness or the distress being caused by the illness. Therefore, by incorporating support into the psychoeducation group, an optimal environment will be fostered to promote understanding and self-care, and allow for experiences to be normalized by other group members while learning about the specifics of the illness. The group will be open to parents with children of all different ages. The goal is that bringing together parents raising children and youth of different ages may provide perspective and offer further support to parents from those who have gone through similar experiences, both in terms chronological development and in the course of the psychiatric illness.

The parent group will have a different topic and

theme for each session. The attendees will learn about the scheduled topic, and then share their experiences and thoughts related to the theme. The following is a brief summary of some of the main topics that will be covered in the parent group, and the various aspects of each theme that will be emphasized.

The topic of ‘Grief’ will be one of the first themes covered in the parent group. Primary caregivers often go through the stages of grief when their child or adolescent is diagnosed with a psychotic disorder. Parents often worry about the future life of their child or adolescent, and grieve the consequences the diagnosis may have on their long-term goals for their child, such as working full-time, getting married, and having children, often recognizing that such a future is now unlikely (Ambikile & Outwater, 2012). It will also explore the presence of grief in relation to accepting their child’s or adolescent’s diagnosis.

Parents and caregivers will also be taught about the symptoms, course, and treatment of psychosis. The opportunity to learn and increase knowledge about psychotic disorders and share experiences with other parents who also have a child or adolescent suffering from a psychotic disorder empowers parents (Gearing, 2008; Kennedy et al., 2008). Educational material will cover recognition of early symptoms of relapse, symptom management techniques, medication, de-escalating aggressive behavior, and communicating with paranoid or psychotic youth.

The topic of ‘Emotional Coping’ is another crucial theme that will be covered in the parenting group. Significant stress and a spectrum of emotions often occur as a result of caring for a child or adolescent with psychosis. Parents may feel sadness, bitterness, guilt, anxiety, fear, anger, and helplessness (Ambikile & Outwater, 2012; Gearing, 2008). Coping skills will be taught to help parents manage their own emotions and reactions. The specific tools that will be taught and practiced include relaxation and stress management techniques, and changing negative thoughts.

Children and adolescents in general thrive on structure and boundaries, but maintaining structure and strict rules is even more essential when raising a son or daughter with psychosis. Since children or adolescents experiencing psychotic symptoms have impaired judgment they may cause serious harm to

themselves or others. Consequently support and safety are primary considerations (Joshi & Towbin, 2002). Although the hospital is a last resort, parents need to be able to recognize when their child or adolescent is extremely stressed and acutely symptomatic, and they must be willing to hospitalize their child with keeping their child’s best interest in mind. Thus the parent group will also teach parents how to set boundaries and the importance of creating and maintaining structure, because such an environment is beneficial for managing psychotic symptoms, particularly upon discharge from the hospital (Kelly, 2005).

Other topics of the parent group will consist of social support and strategies for maintaining a social life, coping with stigma, managing economic challenges, problem solving and communication skills training, and the development of realistic expectations.

Family Therapy

Although information and skills can be crucial for successful treatment and significantly improve the quality of life for all involved, families have found it difficult to access resources and information (Adamec, 1996; Marsh, 1992; Marsh & Johnson, 1997). Therefore, family therapy can effectively involve the entire family unit and draw upon the family psychoeducational theoretical model. Interventions will vary according to the child’s or adolescent’s stage of development. For example, families with children may utilize elements of play while families with adolescents may utilize more traditional talk or dialectic approaches. This mode of the treatment is less structured to allow the family to direct therapy in ways that would be most beneficial to meet their needs and provides flexibility to adapt to these needs. This allows the family’s cultural values to be honored and respected. The family’s values may help create coping skills and fulfill unique roles specific to the family that has shown an increase in overall well-being of those with psychosis and their families (Cuijpers, 1999; Shi, Zhao, Xu, & Sen, 2000).

In these culturally syntonic ways, all family therapy should include some common elements. Education about psychosis, its treatment, and guidelines to the most successful outcomes should be provided from the onset in order to disseminate import-

ant information through the entire family. Caregivers and siblings will learn about the common symptoms and courses of psychotic disorders to help them understand what they might expect. They will also understand how the disorder is treated and what some of the most effective treatments look like. Families should create a crisis plan so that all members know their roles and responsibilities in emergency situations. Planning for emergency situations ahead of time can reduce stress during times of crisis and help alleviate fears by normalizing the expectation of the unexpected (McFarlane et al., 2003).

Families should engage in enhancing communication and identifying and solving problems, focusing on the psychosocial rehabilitation in the child or adolescent and addressing the needs of the family. Families of children may focus on safety needs and who will be responsible for supervising the child, while families of adolescents may focus more on socialization and adaptive coping techniques. The therapist will aid the family in identifying strengths and needs of the family. They will then address and process issues that are most salient to them as they work together in learning to collaboratively solve problems. Family therapy can help repair dysfunction in the family unit and encourage growth as a unit as family members learn to communicate and collaborate together to address the challenges that face them both as individuals and as a family.

In this approach, emphasis is not placed so much on symptoms as it is on enhancing mutual support and increasing well-being and resiliency while providing a safe, calm environment that promotes rehabilitation. Specifically, families should seek to understand and reduce high levels of expressed emotion in order to help facilitate recovery and prevent relapse (Wasserman, de Mamani, & Guilia, 2012). Time should also be given to address feelings of loss and grief associated with a diagnosis of a psychotic disorder (McFarlane et al., 2003). Family therapists must balance the needs of the family as a whole with the specific challenges and needs of a child or adolescent with psychosis. McFarlane et al. (2003) gives helpful guidelines for therapists conducting the family therapy, suggesting that the therapist aid in coordinating all elements of treat-

ment to understand what goals everyone is working toward as they pay attention to the social and clinical needs of the child or adolescent. This is best done by exploring the family's expectations for family therapy and overall treatment and listening as partners in treatment planning and delivery. Families should also be encouraged to expand their social support networks to those who can be empathetic to the unique needs and challenges of families living with someone with EOP, such as the National Alliance for Mental Illness (NAMI) or other multifamily groups.

The main objective of family therapy is to help the family function as a unit, both to help facilitate the treatment of EOP as well as to provide the support needed for a family living with someone with EOP. The family's needs and solutions are addressed as a whole. Individual needs are framed as challenges for the family and solutions are generated in order to facilitate unity.

Assessment of Outcomes

In order to assess the parent education program the families will be given various measures to complete before, during, and after the proposed program. Measures will focus on quality of life, level of functioning of the family, level of expressed emotion within the family, and symptom reduction in the child or adolescent. Specifically, the family will be given the Level of Expressed Emotion scale (LEE), Family Environmental Scale (FES), and Quality of life Interview (QOLI) to assess the family's level of expressed emotion, family cohesion and conflict, and satisfaction with family relationships, respectively (Cole & Kazarian, 1988). Furthermore, the child or adolescent will be given the Symptom Checklist-90-Revised to measure psychotic symptoms in addition to several other symptom scales such as the Positive and Negative Symptoms Scale (PANSS) and Brief Psychotic Rating Scale (BPRS). In addition, the frequency and duration of hospitalizations will be monitored and tracked.

Critique of the Proposed Program

The parental educational program has several strengths not only for the parents or caregivers, but also for the child or adolescent with EOP. The first strength is that the program is extremely adaptable

and flexible to the needs of the family and the child or adolescent with psychosis. The program duration, content, consults, and sessions can be adjusted to the needs of the family and/or child or adolescent. By allowing for individual adaptation and deferring to the family's values, this program may be more culturally sensitive than many manualized treatments that do not allow for adaptability. Second, the program is multifaceted and offers a variety of treatment options that not only addresses the parents, but also incorporates the child or adolescent with a psychotic disorder, siblings, and extended family. Third, the program is developmentally appropriate and is composed of interventions that are targeted for families and their children or adolescents under 18 years old. Last, it was developed on the foundation of research supporting the current effective treatment components for working with a child or adolescent with EOP and their families.

The program also has some limitations and weaknesses. The intervention requires the entire family's participation and makes significant demands of their time and energy. It may be difficult to get the "buy in" of all the family members. For instance, existing family discord may make it difficult for members to cooperate and provide the necessary support. Families may also become defensive if they perceive that they are being blamed for their family member's illness. Some family members may take education and skills training as being critical of their role (i.e. judging their parenting style or viewing an older sibling as not protective enough). It is also possible that the family exhibits hopelessness in the face both of valid concerns and of stereotypes about serious mental illness. Stigma may also prevent some family members from wanting to be associated with psychiatric facilities or interacting with others who are actively psychotic. Additionally, adolescents may worry about losing autonomy when the family is involved with their treatment.

Furthermore, utilizing multimodal treatments requires cooperation and coordination between all parties. Families and children or adolescents must be flexible to meet several demands. But the providers must also coordinate treatment and maneuver their schedules to allow families to participate in treatment with multiple professionals. Participa-

tion of these professionals raises the cost for such treatments, both in paying the professionals and also the cost associated for transportation and work missed by parents. In addition, it should be noted that the model does not account for biological factors or psychosocial factors other than the family. Some patients' course may respond differently based on which of these components are present.

Conclusion

The diagnosis of a mental illness can be devastating for a child or adolescent and their family, particularly if the disorder is as pervasive, debilitating, and intrusive as a psychotic disorder. Currently, there are no treatment models focusing on EOP tailored exclusively for children or adolescents and their families. This gap may explain the high current relapse rate, which results in great financial and emotional costs. Consequently, there significant need for treatment interventions focusing on educating the family on the illness and its consequences, and strengthening family communication and functioning, both individually and systemically as a family unit. The proposed model seeks to address the need for such a parent education program.

The proposed model was developed on a strong foundation of effective treatment interventions indicated by research and utilizes a multimodal approach for parents and caregivers of children and adolescents with EOP. The model seeks to assist transition of the child or adolescent from acute inpatient treatment to outpatient treatment. Additionally, all components of this model allow for "follow-up" or "check-in" sessions after completion of the three-month program. Ultimately, the goal of this program is to minimize psychotic symptoms, reduce the risk of relapse, and increase overall family functioning. In sum, the implementation of this comprehensive parent education program model should be considered by all health care providers when working with a child or adolescent experiencing a psychotic episode. In the future, it is recommended that this treatment model be implemented and studied for its efficacy in children and adolescents with early onset psychosis.

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PARENT EDUCATION MODEL FOR EARLY ONSET PSYCHOSIS

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