Family responses to a child with schizophrenia: An Indonesian experience

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A B S T R A C T

Indonesian culture puts a high value on family bonding. Therefore, support and encouragement for each family member is high that any problems are the responsibility of the whole family. This paper explores the implications of the phenomena whether is a schizophrenic child in the family affected the parental relationship in Indonesian family and trying to find out the implication of parental relationship on medication adherence. This was a cross-sectional study which involved 180 parents of children with schizophrenia and parents with aged matched non-schizophrenic children as a control group; consisting of 45 parents of children with schizophrenia and 135 parents of non-schizophrenic children. The parental relationship was examined by using the Indonesian version of Family Adaptability and Cohesion Evaluation Scale IV (Indonesian version of FACES IV). Our study revealed that 75.6% of children with schizophrenia experienced a healthy parental relationship compared to 94.80% in the parents of non-schizophrenic children group. The most prevalent of unhealthy relationship among parents of children with schizophrenia was chaotic disengagement. Parental adherence to give medication for their child with schizophrenia was better if they had a healthy parental relationship. In conclusion, a small number of Indonesian parents with schizophrenic children experienced an unhealthy parental relationship. Therefore, psycho-education and supportive psychotherapy still needed to facilitate those families to express their emotion adapt and cope.

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1. Background

In Indonesian culture, family bonding is a strong factor in daily living. Every family member has a close relationship, taking care and being responsible for each other. The extended family is still the usual lifestyle for most Indonesian families even in urban cities, thus an intergenerational parenting style is prevalent. The supportive system of the extended family works through optimal emotional expression. It means that the whole family manages their problems and reduces the burden as a whole. Therefore, Indonesian families have better coping strategies and are more able to adapt to environmental changes, have less psychosocial stress and more effective problem solving skills (Kraeger and Schröder-Butterfill, 2008). These families have a better parental relationship and offer more support and understanding for their children especially in carrying out their daily functions (Olson and Gorall, 2006).

Several studies have shown that children with schizophrenia affect parental relationships by interrupting the balance of the family system, leading to poor communication and high emotional expression which leads to unhealthy relationships. Parents with unhealthy relationships are much more fragile and defensive; the parent’s energy is depleted and the family is weakened and the unity of the system is threatened (Olson, 2011; Whittingham et al., 2013). Healthier family systems induce better ways for parents to adapt and cope with their child with schizophrenia (Doane et al., 1981; Asarnow et al., 1988; Yee and Sigman, 1998; Hamilton et al., 1999; Nayeli et al., 2010; Otero et al., 2011).

Family systems can be assessed via three variables: cohesion, flexibility, and communication. Cohesion is an emotional bond between family members. Flexibility is a quality and expression reflected in leadership and organization, adaptable role, and rules

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on relating and negotiating. The third dimension is communication that refers to positive communication skills used in families or couples. Instability in cohesion, communication, and flexibility triggers an unhealthy family system and parental relationship. A balanced family system leads to a healthier family and provides for the satisfaction of each family member (Olson, 2000; Olson, 2011; Breitkreuz et al., 2014).

Childhood schizophrenia is a severe mental illness. The prevalence of the disorder varies among countries. In the US, this condition occurs in less than 1 per 40,000 children (Gochman et al., 2011). The exact prevalence rate in Indonesia is still unknown. Even with a relatively low prevalence rate, the impact of this condition is significant for both the child and their family. According to guidelines for childhood schizophrenia management, the target of therapy should focus on patient’s functional capacities, such as, mastery of developmental tasks according to the child’s age. Any interventions designed to reduce difficulties and negative outcomes should involve parents as much as possible (AACAP, 2012; Yee and Sigman, 1998).

The current study focused on identifying parental relationships among Indonesian families who had a schizophrenic child, and trying to answer whether the Indonesian family system which has demonstrable supportive family relationships was affected by having a child with schizophrenia. The hypothesis was that children with schizophrenia affected the Indonesian parental relationship even though it had strengths. The goal was to gain information on the importance of having a child with schizophrenia as a stressor on the parental relationship. The data can be important for implementing a management system empowering parents and the family system.

2. Method

The study used a cross-sectional design. One hundred and eighty eight parents were divided into two groups. The first group consisted of 45 parents of children with schizophrenia, and the second group included 135 parents of non-schizophrenic children as a control group. The ages of the schizophrenic and control children in the families ranged from 12–18 year of age. The parents were comparable on a number of demographic variables.

The diagnosis of schizophrenia was based on the Diagnostic and Statistical Manual for Mental Disorder-IV–TR (DSM-IV–TR) criteria for schizophrenia. The diagnosis of schizophrenia was made by the child psychiatrists at the Child and Adolescent Psychiatry Outpatient Clinic, Cipto Mangunkusumo General Hospital, Jakarta. Meanwhile, the degree of severity was assessed after the research subjects enrolled into the study by using the clinical global impression for severity scale (CGI-S) by different child psychiatrist. The non-schizophrenic children were defined as children without any mental illness or chronic physical illness. The non-schizophrenic children were selected by psychiatry residents and using the MINI Kid as a guideline for interviewing. Children who had mental retardation were also excluded from the study.

The research subjects were selected by using a consecutive sampling method at the Child and Adolescent Psychiatry Outpatient Clinic, the Pediatric and Dentistry Outpatient Clinic at Cipto Mangunkusumo General Hospital (RSCM), Jakarta. RSCM is one of the national referral hospitals in Indonesia and acts as the tertiary level of hospital in Jakarta. The exclusion criteria for parents were having mental retardation or having other chronic physical or mental illnesses, and being a single parent. All parents signed an informed consent before participating in the study.

2.1. Instrument

This study used the Family Adaptability and Cohesion Evaluation Scale IV (FACES IV) to assess the parental relationship. FACES IV consists of 42 items and contains six scales that have 7 items in each scale. Olson and Gorall (2006) developed FACES IV, as a self-report questionnaire starting in the year 2000. Each item in the scale uses a five-point Likert scale: (1) strongly disagree/very dissatisfied; (2) generally disagree/somewhat dissatisfied; (3) undecided/generally satisfied; (4) generally agree/very satisfied; and (5) strongly agree/extremely satisfied (Olson, 2000). Hursepuny (2006) validated the FACES IV in the Indonesian language. The validity and reliability yielded a Cronbach’s α coefficient of 0.935 (Hursepuny, 2006).

Both parents were asked to fill in the Indonesian version of FACES IV. The results of FACES IV in this study were categorized into a healthy parental relationship that had a mean circumplex total ratio ≥1, and an unhealthy parental relationship that had a mean circumflex total ratio of less than one. Based on the circumplex ratio model, there were six categories of parental relationship (Olson, 2000):

(i) Balanced (circumplex total ratio = 1.31–2.5): a healthy functional level and lower level of problems. This category of relationship is the best in handling stressors and having stronger relationships while facing challenges from time to time.

(ii) Rigidly balanced (circumplex total ratio = 1.01–1.3): this relationship has a high degree of emotional cohesion and a high level of rigidity, however, there is difficulty in adapting to changes because of the high rigidity.

(iii) Mid-range (circumplex total ratio = 0.82–0.99): this relationship has a low level of both balanced and unbalanced attributes.

(iv) Flexibly unbalanced (circumplex total ratio = 0.75–0.81): this is a dysfunctional relationship, however, these parents are still capable of handling problems if really necessary.

(v) Chaotically disengaged (circumplex total ratio = 0.38–0.74): represents a dysfunctional relationship with low emotional cohesion and problems in adapting to change.

(vi) Unbalanced (circumplex total ratio = 0.24–0.37): this type of relationship has many problems in all aspects of family functioning and does not offer any protection or strength for family members.

Demographic data, such as, educational level, socioeconomic status, ethnicity, and medication adherence were also collected. All data were analyzed using SPSS version 16.0 for Windows. Chi-Square analysis was applied for statistical analysis with a p-value of <0.05 which was considered statistically significant in this study. The Ethics Committee of the Faculty of Medicine University of Indonesia approved the protocol for this study on 17th April 2012.

3. Results

The mean age for fathers and mothers was 49.09 and 44.38 year, respectively, in the group with a schizophrenic child. In the group of non-schizophrenic children, the mean age for fathers and mothers was 46.59 and 42.09 years, respectively. The majority religion for parents was Muslim. Most of them had Javanese (51.11%) and Betawinese ethnicity (46.67%). Parent’s educational background was quite similar in both groups.

The mean age (SD) of the research subjects was 16.27 (1.86) years. The group of children with schizophrenia consisted of more
males than females (ratio 3:1). The age matched non-schizophrenic children group consisted of fewer males than females (ratio 2:3) (Table 1). The Clinical Global Impression Scale for severity (CGI-S) level among children with schizophrenia ranged from 1 to 6, and most of them had a severity level between 3 and 4 (57.8%). Ninety seven percent of the children with schizophrenia had been treated with atypical antipsychotic medications, such as, risperidone, aripiprazole, olanzapine, and quetiapine.

The study found that 75.6% of parents (Table 1) who had a child with schizophrenia perceived a healthy parental relationship compared to 94.8% in the group of parents with non-schizophrenic child (p < 0.05, Table 2). In the childhood schizophrenia group, 13.30% of parents experienced a chaotically disengaged relationship, meanwhile in the non-schizophrenic child group only one parent perceived a similar condition (Table 3). Most families who experienced a healthy parental relationship complied with the medication schedule for their child with schizophrenia compared to the unhealthy parental relationship group (82.40% vs. 17.60%, p > 0.05) (Table 4).

4. Discussion

This study found that 75.60% of parents with schizophrenic children had a healthy parental relationship pattern. This finding differed from previous studies. In Egypt, El-Shafie et al. (2008) found that 75.65% of families with mentally disturbed children had a poor parental relationship. Otero et al. (2011) found that 43% of families who had a child with juvenile onset psychosis experienced a poor family relationship. The explanation for the different finding in Indonesian family systems could be that the Indonesian family system is more collectivist, and supportive in maintaining a healthy parental relationship. Both parents felt secure in facing the stressor of having a child with schizophrenia, although some still struggled. In addition, symptoms of schizophrenia in our samples were relatively mild to moderate. All of the children with schizophrenia in this study could carry out their daily functions quite well, such as going to school, socializing, and having peer interaction. In addition, it could be said that mild symptoms of schizophrenia might account for the finding of good parental relationships.

However, this study also revealed that childhood schizophrenia was still a major stressor for a small number of parents and influenced the parental relationship. The supporting and encouraging system from other family members did not work optimally among this group, as parents of children with schizophrenia still perceived an unhealthy parental relationship categorized as chaotically disengaged. This type of relationship has low emotional attachment and problematic adaptation. Although we did not identify the family history of this condition, it could be understood that for these parents living with a child with schizophrenia might lead to a response of grief and feeling of sadness as schizophrenia is still a severe mental illness with stigma in the community, and there is the fear of loss of future potential for the child (Ghaemi and Pope, 1994; Osborne and Coyle, 2002; Saunders, 2003).

Another important finding in this study was that the parental adherence in delivering medication was higher in those families with a healthy parental relationship compared to an unhealthy one. Several studies have explained that adherence is closely related to positive attitudes toward the medication, the illness, and social support (Sayre, 2000; Verdoux et al., 2000; Verdoux et al., 2002; Bordenave-Gabriel et al., 2003). It is said that the higher support correlates with higher adherence, and decreased or poor social support is a predictor of non-adherence (Sayre, 2000). Low levels of schizophrenic severity based on the CGI-S scale more or less contributed to positive parental perception and insight toward their children with schizophrenia, while the unhealthy parental relationship triggered feelings of helplessness or hopelessness and the perception or reality of increased stress that negatively affected adherence (Saunders, 2003; Loffler et al., 2003).

5. Conclusion

The clinical implications of this study are that parental counselling and parental supportive psychotherapy was very important part of helping parents to cope and accept their child with schizophrenia. Therefore, management systems for childhood schizophrenia should not merely focus on medication. Various studies concluded that psychosocial intervention, family intervention, social skill training, and effective cognitive remediation when
given at the same time with drug treatment produced better outcomes (Falloon, 2003).

6. Limitations

This study had several limitations. It did not elaborate other factors that influenced parental relationships except for having a child with schizophrenia. Other factors that should be considered are parental personality traits, other psychosocial stressors, and other support systems in the family. However, this study was the first study in Indonesia that tried to understand the relationship among parents of children with schizophrenia. Future studies need to be done using a different design that could explain more cause–effect relationships.

References