Living With Mentally Ill Parents: The Child Perspective

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Bu çalışma I. Uluslararası V. Ulusal Psikiyatri Hemşireliği Kongresi'nde (2011, İSTANBUL) sözel bildiri olarak sunulmuş ve Sözel Bildiri Üçüncülük Ödülü almıştır.

ABSTRACT

This study investigated the emotions, thoughts and experiences of children who live with parents have a mental disorder. Phenomenological method was chosen and the study sample included 15 children. Written statements of the participants were collected with a structured questionnaire form. Five main themes emerged: "everything has changed", "do you call mine a life?", "milestone", "these days too shall pass", "mother, come to your senses and pull yourself together already!!" Results suggest that children living with mentally ill parents have a need to be acknowledged, professional help and reinforcement of their coping mechanisms.

 $\textbf{Key words:} \ \text{living with mentally ill parents, children of mentally ill parents, parental mental illness, psychiatric nursing, qualitative research$

Bu çalışma Akdeniz Üniversitesi Bilimsel Araştırma Projeleri Yönetim Birimi tarafından desteklenmiştir (Proje No: 2010.01.0122.002)

ÖZET

Amaç: Ruhsal hastalığa sahip ebeveynin çocuğu olmak oldukça zorlu bir yaşamı beraberinde getirmektedir. Buna karşın ruhsal sorunu olan ebeveyne sahip çocukların neler yaşadıklarına dair toplumda ve sağlık çalışanlarında farkındalığın az olduğu bilinmektedir. Ülkemizde de ruhsal bozukluk tanısı almış ebeveynlerin çocuklarının duygu, düşünce ve deneyimlerini açıklaştırmak ve bu hastalıkların çocukların psikososyal gelişimi üzerindeki etkilerini tanımlamak amacıyla yapılmış çalışmalara gereksinim duyulmaktadır. Bu çalışmanın amacı, çocukların, ruhsal hastalık tanısı almış ebeveynle yaşamaya ilişkin duygu, düşünce ve deneyimlerini belirlemektir.

Yöntem: Bu çalışmada fenomenolojik yöntem kullanılmış ve katılımcı sayısı, "veriye doyma" ilkesine göre belirlenmiştir. Buna göre örneklem 15 çocuktan oluşmuştur. Araştırmanın verileri soru kağıdı ile toplanmıştır. Çocukların yazılı ifadelerinden elde edilen veriler, Colaizzi'nin(1978) önerdiği veri analizi yöntemine göre analiz edilmiştir.

Bulgular: Araştırmaya katılan çocukların dokuzu kız, altısı erkek olup, beşi ilköğretimde, onu lisede eğitimine devam etmektedir. Çocuklardan 3'ünün annesi, ikisinin ise her iki ebeveyni de hastadır. Çocukların duygu, düşünce ve deneyimleri beş tema grubu altında toplanmıştır: "Dönüm noktası", "Herşey değişti", "Anne kendine gel ve toparlan artık!", "Benimki de yaşantı mı?", "Bugünler de geçecek".

Sonuç: Çalışmanın sonucunda, ruhsal hastalığı olan ebeveynle yaşamanın, çocukların aile içi ilişkilerini ve okul yaşamlarını olumsuz yönde etkilediği, çocukların bunlarla baş etmek için sürekli bir çaba içinde olduğu bulunmuştur. Buna göre ruhsal hastalığı olan ebeveynlerin çocuklarını ve diğer aile üyelerini bilgilendirecek, baş etme becerilerini güçlendirecek, mevcut hizmetlere ulaşımı kolaylaştıracak bir dizi müdahale programının oluşturulmasına ve bu programları yürütecek özel bir insan gücünün yetiştirilmesine gereksinim bulunmaktadır.

Anahtar sözcükler: "Ruhsal hastalığı olan ebeveynle yaşamak", "Ruhsal hastalığı olan ebeveynin çocukları", "Ebeveynin ruhsal hastalığı"

INTRODUCTION

Mental illness in parents can alter family life in various ways and cause children to experience serious social, physical and emotional problems (Pretis & Dimova 2008, Mason et al. 2007, Knutsson et al. 2007, Singleton 2007, Foster et al. 2005, Mowbray et al.

2006, Mordoch & Hall 2008). Children of parents who have been diagnosed with mental illness carry more risk of developmental and psychological disorders than those in the general population because of genetic and environmental factors, the change in the parental role and the fact that they are directly exposed

to the symptoms of illness. Due to the difficulties they face, these children have become the focus of research and application (Foster et al. 2005. Trondsen 2012).

Research on children of parents who were diagnosed with mental illness indicates that these children experience destructive and painful childhoods, are diagnosed with depression during puberty, present with symptoms of psychological illnesses, exhibit behavioural problems and experience isolation. hey are unprepared for the changes undergone by their parents. They sense that their own parents are unlike parents of other children and feel that their parents have become completely different people than who they used to be. They have to look after their parents, are not privy to information about the illness and they try to understand it. They do not feel safe at home, they distance themselves from their friends and rarely go out. It is also indicated that they want to openly discuss their feelings and experiences, and that they suffer economic difficulties (Pölkki et al. 2004, O'Connell 2008, Mowbray et al. 2004, Aldridge 2006, Mordoch & Hall 2008).

In a study which systematically reviews 13 qualitative studies on children living with mentally ill parents, it was concluded that the children share common dramatic experiences which reduce resilience against strenuous life events, and which could negatively impact mental health (Buldukoğlu et al. 2011). Furthermore, in a study examining the effects of mental illness from the points of view of mental health professionals, it was reported by mental health workers that mental illness in parents negatively affects parent-child interaction and that the children experience behavioural, emotional and social problems as well as a depletion of educational accomplishments (Aldridge & Becker 2004).

Considering the fact that many aspects of the lives of these children are extremely influenced by the mental illness of their parents, it is important to identify their needs, support the family unit as a whole, attach importance to primary protection, and to provide early intervention (Foster et al. 2005). Siegenthaler et al. (2012) conducted meta-analysis of 13 randomized controlled trials administered for

this purpose, concluded that interventions in such children may be effective and recommended that further studies be conducted. Mordoch (2010) suggested that mental health professionals can present opportunities to relieve the anxiety of these children, and stressed the need for teamwork in addressing the problems of such highly vulnerable children.

As members of mental health teams, psychiatric nurses need to approach the needs and strengths of individuals, family units, groups and the community holistically. They should encourage optimal mental and physical health and participate in preventive action. (ISPN, 2006).

Be it in the context of community mental health nursing or of providing holistic care for individuals with mental illness, there is an essential need for the implementation of family focussed mental health nursing practices in order to benefit parents with mental illness, their offspring and the community. In planning for such implementation, it is necessary to first identify the experiences of children of mentally ill parents. Even if a satisfactory level of research on this topic can be found in international literature, there is need in Turkey for research conducted for the purposes of expounding the emotions, thought processes and experiences of the offspring of parents diagnosed with mental illness and defining the effects of such illness on the psychosocial development of these children. The aim of this study is to identify the emotions, thought processes and experiences of children whose parents have been diagnosed with mental illness.

Materials and methods

The phenomenological method was selected for this study in order to better understand the emotions, thoughts and experiences of offspring of parents diagnosed with mental illness (Streubert & Carpenter 1999, Aksayan & Emiroğlu 2002). This exploratory study was conducted from February 2010 to February 2011. Ethical approval for the study was obtained from XXX University Faculty of Medicine Ethical Committee. Institutional permission was obtained from XXX University Hospital management.

A pilot study was conducted with five children who satisfied the selection criteria. At the conclusion of the pilot study, it was found that there was no need to make any changes in the open-ended questions. Data from the pilot study was not included in the analysis.

In order to acquire accounts most consistent with experiences related to being children of parents with mental illness, purposive sampling techniques were used. The study sample consisted of 12-18 year olds who volunteered to take part in the study and were living with parents diagnosed with mental illness currently undergoing inpatient treatment at a hospital. The study sample was determined by data saturation as applicable in qualitative studies and consisted of 15 children. The data saturation is accomplished when it is not possibly to gather new information from participants' responses anymore.

Before inviting the children to participate in the study, parents who are hospitalized were informed about the research. The interviews with the children were conducted in the homes of the children who met the study selection criteria following parental approval. The purpose of the data collection at home is to provide a non-threatening environment which protects them against stigmatization. The children took the survey after they were informed about the study, and their written consent was obtained. The children completed the survey in 20-30 min, though they were allocated more time.

The children filled out an eight-question survey assessing the age, gender, educational status, place of residence, family structure, the parent that was sick, duration and the diagnosis of the parent's condition. In addition to the eight survey questions there were also five open-ended questions where the children were asked to write freely about their emotions, thoughts and experiences of parents diagnosed with mental illness without any restrictions or reservations. A separate sheet of paper was provided for each open-ended questions. The questions were:

- 1 How would you compare your life now with that before the unset of your mother/father's illness?
- 2 Please write down how your mother/fat-

- her's illness has affected your life and the kind of changes you have been experiencing.
- 3 If you had the chance to tell your mother/father about what you are going through because of his/her sickness, what would you like to say?
- 4 What is your life like in comparison to the lives of other children whose mother or father does not have this sickness?
- 5 What steps are you taking to resolve the difficulties you are experiencing due to your mother's/father's illness?

Data analysis

The data obtained the end of the survey was analyzed by Colaizzi's (1978) constant comparative method (Streubert & Carpenter 1999). According to the process, the responses were examined by each resercher who independently reached an opinion of the experiences of children whose parents have a mental illnes. Next, respond the questions were reviewed and discussed by the researchers as a group, and common and meaningful statements were identified. These common expressions are formulated under five major themes. Then, all the original expressions in each group of themes were crosschecked for accuracy. Finally, each participant was asked to read and comment on the results of the study to make sure that the findings accurately reflected their perceptions. Validity as a result of the search, analysis of any situation affecting not occur.

RESULTS

In the current study, it was revealed that the children who had parents with mental illness shared similar dramatic experiences and that the parents' mental illness had a considerable impact on the lives of the children. Demographic data about the parents and the children who participated in the study are displayed in Table 1. The thematic analysis of the data collected from the participants shows that the experiences of children whose parents have mental illness can be grouped under five main themes. These themes are; "everything has changed" [n=14 (93.3%)], "do you call mine a life?" [n=13 (86.6%)], "milestone" [n=12 (80%)], "these days too shall pass"

TABLO: Participant characteristic (n=15).							
Age	Sex	Education	Place	Family Type	Parent	Parent's illness	Duration of Parent's Illness
13	Female	Primary school	Country	Extended	Mother	Schizophrenia	'Since I was a little girl'
13	Female	Primary school	Country	Nuclear	Mother&Father	Depression with psychotic features	1-2 years
18	Female	High school	Country	Nuclear	Mother	Conversion disorder	'Since my childhood'
13	Female	Primary school	Country	Nuclear	Mother	Depression with psychotic features	1 year
16	Female	Primary school	Country	Nuclear	Mother	Depression with psychotic features	1 year
15	Female	High school	Town	Extended	Mother	Depression	'Since I was born'
17	Male	High school	Country	Nuclear	Mother	Depression/ Suicide attempt	10 years
17	Male	High school	Country	Nuclear	Mother	Depression	10 years
14	Female	High school	Country	Nuclear	Mother	Schizophrenia	'Before I was born'
15	Male	High school	Country	Nuclear	Mother&Father	Bipolar Disorder	1 year
16	Male	High school	Town	Nuclear	Mother	OCD/ Depression	2 years
14	Female	High school	Country	Nuclear	Mother	Psychotic Disorder	6 years
13	Male	Primary school	Country	Nuclear	Mother	Depression	5 years
16	Female	High school	Town	Nuclear	Mother	Depression/ OCD	7 years
15	Male	High school	Country	Nuclear	Mother	Depression	1 year

[n=11 (73.3%)] and "mother, come to your senses and pull yourself together already!!" [n=8 (53.3%)]

Theme 1: "Everything has changed"

Almost all the children have expressed that their lives have changed a great deal after their parents became ill. The children had to do the housework themselves and their schoolwork was affected by this.

The dimensions of the change that the children experience covered a wide spectrum as stressed in their discourse: a negative turn in the physical conditions in the home, especially relationships and roles in the family; decline in their school performances, constant concern over the sick parent and related mental exhaustion, alienation from the family, isolation and loneliness. A personal account related to this is as follows: "Everything is bad in the house. No cleaning is done, no meals are cooked. My father mistreats us when my mother is hospitalized. I developed bad habits (alcohol, smoking) and a constant urge to pick fights. My mother took me out of school so I won't fight (Male, 17 years). Only one of the children stated that the illness has had a positive effect on the family interrelationships, that following the unset of the illness, his/her parents interacted better with each other and started paying more attention to him/her.

Theme 2: "Do you call mine a life?"

The contents of the second theme of our study reflects expressions used by children in their efforts to make sense of the changes in their lives. In this content, it is apparent that the children think that their lives are shaped by the illness, that they are tired of living like this and that they are rebelling against the situation. One of them verbalised this as follows: "Children in my class can share things with their mothers, I cannot. Their mothers come to PTA meetings, mine doesn't. They are

happy to have their mothers by their side, I am saddened (female, 13)

It is shown in the expressions used by the subjects within the framework of this theme, that having an ill parent negatively affects self-image and that they experience low self-worth. This was articulated by one of the children as follows:

"I feel like I am second hand goods while other children are top of the range." (male, 15)

Theme 3: "Milestone"

In comparing their lives before and after the unset of a parent's illness, the participants describe the event as a milestone in their lives. The sentence: "The world existed before my mother's illness, but came to an end when she got sick." by a 17 year old male participant conveys the unset of illness as virtually a new era in his life. The salient common point of the statement by 12 subjects was that they saw the illness of their parents as something that divided their lives into two eras of "before the illness and after the illness". The fact that the children used some interesting metaphors in their statements drew the attention of the researchers. In this aspect, one salient expression used was: "I see my life as an orange. When my mother is well, I feel it is like a ripened, sweet orange, and when she is not, it feels like a rotton one." (13 year old male).

Theme 4: "These days too shall pass"

This theme covers the coping mechanisms of the children. Despite all the obstacles, the participants hope for the recovery of their parents, believe that it will all pass one day and make efforts themselves toward that end. It has been found that these efforts often reach dimensions that surpass what is expected of a child's life experience and individual resilience, and that they often try to act with the composure possessed by adults. The statements of a children in relation to this issue is as follows:

"I take my mother to doctors and soothsayers in the hope that she will recover. I pray that she gets better, and believe that she will. She will get better and come back to us." (16 year old female)

In addition to this, it has been noticed that two children used the unusual coping method of avoiding their mother and the rationalization coping mechanism. This is expressed well in one's statements:

"I worry. I don't approach children who are with their mother. I try not to think of my mother." (13 year old female)

Theme 5: "Mother! Come to your senses and pull yourself together already!"

It has been seen that the statements of the participants strongly reflect a yearning for healthy and competent parents. In this context, they part rebel against, part implore their mothers/fathers, as illustrated by the following statement:

"Mother! Come to your senses and pull yourself together already! Things aren't how you think! Everyone live their own lives." (14 year old female)

In our study, it has been found that some children have had candidly articulated their awareness of the effect the illness of their parents on their lives. This is plainly reflected in the following statement:

"Because she didn't fulfill her duties towards us as a mother, I used to tell her that I wish she had never brought me into this world... That way, my younger sibling and I would never have had to face the difficulties of being the children of a sick mother. That way, we would not have had to take care of our own selves wherever we were, at whatever time." (14 year old female)

In short, our research results indicate that children of parents with such illnesses have poignant and pathetic life.

DISCUSSION

As far as the authors are aware, this study is the first conducted in Turkey with the participation of children of mentally ill parents, and one which focuses on the life experiences of such children. There are similarities between this study's findings and the findings of other available studies that document the perceptions of children living with parents have a mental disorder.

According to the observations made in this study, when a parent becomes ill, the family itself becomes off-kilter and from the point of view of the children, the illness signals the

end of the good days and the beginning of the bad ones. It also causes them to develop the belief that nothing will ever be the same again. It was construed from the accounts given by the participants that the illness of a parent burdens them with weighty emotional, physical and social responsibilities including care-giving to the ill parent, house-work, caring for younger siblings, thus undertaking duties usually performed by the parent. Performance at school and educational life of every participant was negatively affected. There are similar observations in current literature indicating that offspring of mentally ill parents avoid their friends, undertake the responsibility of doing the housework as well as looking after their siblings and their ill parents, and that this has an effect on their performances at school (Mowbray et al. 2006, O'Connell 2008, Mordoch & Hall 2008, Garley et al. 1997, Webster 1992). Such experiences tend to deprive the child of parental care and nurture at a time most needed. In fact, such children are forced to look after the parents who cannot look after their own children. In a study by O'Connell (2008) such situations are described as 'mothering one's mother.'

Studies indicate that children of mentally ill parents are unprepared for the consequences of the changes undergone by their parents, that they conceive their parents as totally transformed human beings, and that they do not feel safe at home (Chien 2008, Mowbray et al. 2006, O'Connell 2008, Mordoch & Hall 2008, Garley et al. 1997, Webster 1992). Our study revealed no such accounts by the participants but indicated that such children will, rather than fear their parents will fear for them, that they express longing for the parent that they used to have before the illness struck. At the same time, the participants did not see themselves as members of normal families and perceived their selves as being strained and mentally imbalanced. Various research shows that in comparison to other children, those of mentally ill parents are at risk of mental health problems (Hung et al. 2009, Foster et al. 2005, Yöntem 2011). Similarly, our study indicates that having mentally ill parents will constitute a negative effect on the bio-psychosocial development of children

and that many are forced to live under difficult conditions without outside support (Pölkki et al. 2004, Pretis & Dimova 2008, Mason et al. 2007).

These children are developmentally at an age where their sense of identity still continues to be established. This development is primarily qualitative, but is in a sense quantitative because personal identity is getting stronger and beliefs are getting more rigid. The environment they live in both contributes to and determines the solutions for the developmental crisis they experience (Miller 2008). The basic interaction in this environment is the child's relationship with the parent and other family members. In this context, it has been reported that individuals who have chronic mental illness have difficulties in coping with child rearing (Pehlivan 2006). At the same time, other family members also focus on the illness of the parent, rendering the children invisible. The needs and problems of the children are often denied under such circumstances. Indeed. there is a study reporting that the children cannot find anyone to talk to about their feelings about the parent's illness within or outside the family (Trondsen 2012). It is reported in studies by Garley et al. (1997) and Riebschleger (2004) that such children's relationship with their parents have changed after the illness, that they do not speak to anyone all day long, become intraverted and long to go back to their life before the illness. In this context it can be deduced that a healthy identity development process is at risk in children who participated in the study (Garley et al. 1997, Riebschleger 2004).

The data of the current study show that children who are being raised with parents with mental health problems retain the hope that such days will pass and await the recovery of their parents, despite being emotionally vulnerable and sensitive. They have expressed reverting to self-devised mechanisms including trying not to interrupt their studies, attempting to talk to their friends and relatives, focusing on entertaining activities and trying to be optimistic. Other studies also report that children with similar experience are indulging in hobbies to pass time, acquiring information about the illness, seeking professional help and maintaining positive thoughts. It is also stressed that these children transcribe what they experience onto paper, share with people they trust, talk to their friends, meet with other children who have similar issues, write letters to their parents, talk to the healthy parent and seek social support from friends, neighbours and grandparents. Other efforts to cope include physical or emotional distancing, watching television, reading books and doing sports (Pölkki et al. 2004, Knutsson et al. 2007, O'Connell 2008, Garley et al. 1997, Beardslee & Podorefsky 1988, Valiakalayil et al. 2004). In our study, two of the participants have indicated that they have strayed from home, another has started using alcohol and drugs. It was also determined that children who have difficulty coping with the challenging life events caused by the sickness of the parent feel and experience problems such as loneliness, alcohol use, suicide attempts, anorexia nervosa, embarrassment by the parent's illness, self isolation, distress and frequent crying (Pölkki et al. 2004, Knutsson et al. 2007, Handley et al. 2001, Kinsella et al. 1996). An interesting behaviour encountered in the current study is avoiding friends with healthy parents. It is thought that this is an outcome of their efforts to cope with feelings of worthlessness resulting from not having a healthy mother.

Hence the children's struggles are bordering at a level that can affect their own mental health and they should not be left to their own means. Pursuant to this issue, Siegentheler et al. (2012) have found that therapeutic approaches focusing on improving resilience, informedness and understanding of the parents' illness can be effective in adolescents.

All of the study participants have a mother who is sick while two of them also have a sick father. It is for this reason that a theme predominantly reflecting the longing for a healthy mother i.e. 'mother pull yourself together already' has emerged. The children are complaining about not having a mother's care available to them as needed. They have expressed their belief that the mother would recover if she works hard at it so that they could have back their healthy home-maker mother who takes care of her children It can be seen that the illness means lack of functio-

nality and this can be attributed to lack of information about the illness and its treatment. In a similar study, it is reported that children's understanding of mental health includes reduced physical health, social behaviour and a reduction in the functionality of the parent (Mordoch & Hall, 2008). Hence it can be seen that the children are in need of information about their parents' illness.

This study shows that children whose parents have a mental disorder need to be handled by a multidisciplinary team with a specialized approach that covers domestic and external relationships of these children. In Turkey, children who fall under this category can only get a chance to interact with a psychiatric clinical nurse or a Public Mental Health Center Nurse. Much as the nurses are not officially expected to take charge of these children, they can provide some support within the context of their job descriptions (Regulation of Nursing 2010). In the process of structuring this support, it is imperative to understand what the children in this category are experiencing, making sure that they are not neglected, that they are acknowledged, and that the nursing interventions for enhancing their coping abilities, increasing their endurance be integrated into training and practice of psychiatric nursing as an important first step. It has been determined that interventions providing a combination of crisis management, psychoeducation and peer support by children who have had similar experiences do indeed improve coping skills in children of parents with mental illness (Orel et al. 2003).

CONCLUSION

As a result of this phenomenologic research, it was found that living with a parent who has a mental disorder has a negative effect on the inter-family relationships and school performance of the children and that they are in constant struggle to cope with this. With this study, we believe we were able to assess what the feelings, thoughts and experiences of the children were in regards to living with parents diagnosed with mental illness, and determine the basics elements of the supporting care to be offered to them.

Pursuant to the results of our study, it is recommended to:

- conduct observational studies, focus groups or individual sessions with the view of understanding such children in depth.
- develop intervention programs aimed at informing the children of parents with mental illnesses and other family members about the illness, enhancing their coping skills and facilitating their access to available services.
- train specialized personnel who will be qualified to run intervention programs that are developed to help children of parents with mental disorder.

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