International Journal of Health Sciences
September 2015, Vol. 3, No. 3, pp. 33-43
ISSN: 2372-5060 (Print), 2372-5079 (Online)

Published by American Research Institute for Policy Development
DOI: 10.15640/ijhs.v3n3a4
URL: http://dx.doi.org/10.15640/ijhs.v3n3a4

Life Experience of Mothers Who Have Children with Schizophrenia in Turkey: Desperation, Pain and Anxiety

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Abstract

The aim of this paper is to reveal life experience of mothers with children with schizophrenia in Turkey. The study has been conducted by using qualitative research methods. The qualitative data has been collected from 10 mothers who live with their children with schizophrenia in Community Mental Health Center via in-depth interview. This research provides an account of, mothers' life experiences before and during the process of illness, their future expectations and concerns, as well as the information they received about illness. It was understood that children with schizophrenia vary premorbidly such as introverted, jealous, inability of socializing and failure at school. For mothers, onset period of the illness is quite painful and troubled. Mothers' basic idea about the cause of their children's illness is physical violence. The most important effect of the illness on the mothers is anxiety about the future of their children.

Keywords: Schizophrenia; person with schizophrenia; mothers of person with schizophrenia; mothers' life experience

1. Introduction

Schizophrenia does not only affect the patient negatively but also the patient's family. Because of schizophrenia's negative symptoms and especially cognitive destruction, most of the patients cannot sustain self-care and they need to be given care by someone else (Bora et all. 2009; Alataş and et all. 2009; Doğan, 2001). Therefore a family giving care to a schizophrenia patient is affected negatively in a psycho-social way (Godress et al. 2005; Çoban, 2008).

Most schizophrenia patients spend most of their lives in their homes because they are isolated from society. In families with a schizophrenia patient, one person becomes the caretaker (Milliken, 2001). In most families middle aged or older women take the responsibility of primary care and most of these women are mothers (Milliken, 2001). Therefore, illness leaves more effective marks on mothers and their lives are shaped with the conditions of care for the person with schizophrenia and the person's needs. There are studies that addressed mother's experience of adult children with schizophrenia (Ryan, 1993; Greenberg et al, 1993; Milliken, 2001). In a study of Ryan's (1993) mothers with schizophrenic children, mothers' lives have two main components: Disruption and loss. Disruption is experienced in mothers' own lives and their relationships with the ill child. Mothers' experience of 'loss' has two dimensions: The loss of child's potential to sustain a normal life and mother's loss of freedom in her own life. There are also studies that focused on the experience of fathers of adult children with schizophrenia (Howard, 1998; Pfeiffer, 2001; Wiens & Daniluk, 2009). Studies that have specifically addressed the experience of mothers of adult children with schizophrenia provide a springboard for questions about the experience of fathers (Wiens & Daniluk, 2009: 87).

In Turkey, schizophrenia patients' caregivers are primarily their mothers, and the information on mothers' experiences of illness and how they manage it is limited. There isn't any qualitative study about experience of mothers of adult children with schizophrenia in Turkey.

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Aiming to fill this gap in the literature, in this study, experiences of schizophrenia patients' caregivers are explored from the perspective of mothers. The main purpose of the study is to understand mothers who are caregivers of individuals with schizophrenia and to analyze the process and problems they go through in a multidirectional way. Therefore within this context, life experiences of mothers who give care to patients with schizophrenia are studied in deep around the issues addressed below: Personal knowledge of mothers, knowledge of life before the illness, information on the illness, experiences of illness process, expectations and fears about future.

2. Methods

In this study, qualitative research method is used. Strauss and Corbin (1990) defines qualitative research as "a process for producing information in order to understand lifestyles, stories, behaviors, organizational structures of people and social change". Another definition says it is "a research where qualitative data gathering techniques like observation, interview and document analysis are used and a qualitative process is followed in order to present perceptions and incidents in their natural environment in a realistic and wholesome way" (Yıldırım and Şimşek, 2006: 39). Qualitative research is an approach that prioritizes researching and understanding the social facts within their environments with an understanding that takes 'building theory' as the base.

In the researches designed with qualitative method, there is an effort to reach a deep comprehension about the subject studied. In this study the purpose of using qualitative research method is the effort to account for and understand the experiences and lives of mothers who give care to their adult children with schizophrenia. This study does not aim to generalize. Experiences of mothers who give care to individuals with schizophrenia are accounted for and analyzed through qualitative study.

2.1. Data Collection Technique

In the research, semi-structured interview technique is used as data collection method. According to Seidman (1991:3) the main purpose in using an interview technique is usually not to test a hypothesis, in contrast it is trying to understand the experiences of other people and how they put a meaning in them. Main purpose in the studies where interview technique is used, the information acquired from the studied sample is not to generalize it to the universe but to the studied individuals (Türnüklü, 2000). Therefore the focus is the stories of other people, descriptions and thoughts. The purpose of using an interview technique in this study is to try to understand the experiences of participating mothers and how they put a meaning in them. A semi-structured interview form is brought together with questions aiming to reveal the life experiences of participating mothers. Semi-structured interview form consists of 5 categories. These are:

1. Personal information (Age, marital status, education, employment, information about other members of the family)
2. Life information before schizophrenia. (How life before diagnosis was, what kind of a child the patient was, interaction between family members before the diagnosis, if the child with schizophrenia had different developmental features than others of his/her age before the diagnosis).
3. Information about the disorder (Span of the disorder, frequency of hospitalization, existence of disorder in close relatives, patient's thoughts about the cause of the disorder).
4. Post-diagnosis experiences (Responses to the disorder, problems faced during the disorder, coping methods, physical and spiritual support received during disorder, relations and interaction between family members after the disorder).
5. Expectations and anxieties of participating mothers about the future (Anxieties and expectations about the child's life, anxieties and expectations about her own life).

2.2. Participants

The research was conducted at Aşır Aksu Community Mental Health Center, a division of Antalya Education and Research Hospital. Sample of the research consists of 10 mothers who live with and give care to individuals with schizophrenia, registered at Community Mental Health Center. In this study, purposeful sampling method is used. In order to select participating mothers for purposive sampling, a specific criterion is set (Yıldırım and Şimşek, 2006). It is out of the question to generalize the results of this kind of sampling universally.

In selection of the sample, instead of statistical represent ability, the sample is to be analyzed deeply and as a whole in its context (Patton, 1990; Rubin and Rubin, 1995; Türnüklü, 2000). Participants of the research are selected among the mothers of individuals with schizophrenia, registered to Antalya Community mental Health Center. At the time of the research, number of registered patients at the center was 176 and almost all of them suffered from schizophrenia. Only 93 of the individuals with schizophrenia lived with their parents. The criterion to be selected for the research is that the mother lived with her adult child with schizophrenia and she volunteered to participate. At the beginning of the research the houses of the individuals with schizophrenia registered at the center who were regulars were called, mothers were informed about the research and were invited to the center for an interview. Only 10 mothers applied to the center and accepted to participate in the research. The research was conducted with 10 participating mothers. As the results of the research were not to be generalized universally, the tendency was to analyze the life experiences of the participating mothers in deep.

Two of the participating mothers are aged between 45 and 50; six of them are between 50-60 and two of them are over 60. Six of the mothers are married, three of them are widows. Two of the participating mothers have two children, two have three children, four have four children, one has five children and one has six children. When the education of mothers is examined it is seen that two of them have never gone to school but they later learned to read and write at Public Education Centers. Six of them are primary school graduates, one is middle-school graduate and one is a retired teacher graduated from education institute. Seven of the mothers are housewives, the other four are retired. Al the mothers except the retired ones stated that they worked at various short term jobs for financial reasons. And these jobs are cleaning, tea serving (at the offices), cooking, sewing, working as a doctor's assistant, running grocery store.

Five of the participating mothers' adult children with schizophrenia are male, five of them are female. Individuals with schizophrenia are aged between 27 and 41. The age of disorder emergence for males is between 17 and 24 whereas it is 15 to 24 for females. Considering the present ages of the patients, the most recent case has had schizophrenia for nine years; the oldest has had it for 17 years. Therefore the mothers have been giving care to their children with schizophrenia for 9 to 17 years.

Three of the patients have never been hospitalized, they were treated at home. One patient was hospitalized numerous times. The other patients were hospitalized once or twice.

When it comes to other members of the family with disorders, it is seen that two of the patients have a bi-polar sibling; one patient has a sibling who also has schizophrenia; and one patient's father has schizophrenia too.

2.3. Data Collecting Process

"Ethical Approval" was given to the research by Ministry of Health Public Hospitals Authority Turkey, Antalya Provincial General Secretary of the Association of Public Hospitals, Antalya Education and Research Hospital Clinical Research Ethics Committee. In addition, participants were informed about the name, period, method of the research and they signed an approval form that they were given necessary information and they volunteered, before the interviews. The participants who could not read were informed by the researcher and their approval was taken. All the interviews were recorded with a voice recorder.

The research started on the 13th of June, 2013 at Antalya Education and Research Hospital Aşır Aksu Community Mental Health Center and was completed in 3 months. The last interviews were held on the 8th of November, 2013. Each interview lasted approximately 40 minutes.

2.4. Analyzing the data

The data acquired in the research are analyzed with content analysis method. Content analysis is generally a method used to analyze written and visual data. Basic purpose of content analysis is to reach concepts and relations which can explain the collected data (Yıldırım and Şimşek, 2006:227). Therefore, the data collected with this purpose has to be conceptualized first. Then it has to be organized logically according to the concepts emerged and the themes that explain the data has to be determined (Straus and Corbin, 1990). Accordingly, first the data collected was conceptualized, then it was organized according to the emerged concepts and the themes that explain the data are determined.

The data collected from the interviews with the participants is first transcribed from the voice recorder and transferred to computer. Then the answers of the mothers who give care to individuals with schizophrenia are classified under headings according to the frequency. The questions asked to participants are coded as main themes, opinions about the main themes and sub-themes; and they were analyzed under the categories created.

3. Results

Findings related to the study are categorized according to interviews with mothers as "mothers' knowledge of life before illness, life during illness period, experiences of illness period and the effects of these periods on mothers".

3.1. Life of Person with Schizophrenia before Illness Diagnosis: Introversion, Jealousy and Insufficiency of Social Circle and Academic Failure

Studies of patients who are diagnosed with schizophrenia state those patients with schizophrenia show calm, introverted and schizoid characteristics. It is stated that especially girls show passive and over sensitive behaviors whereas boys show unexpected and unpleasant behaviors. They have a few or no friends during their childhood, they cannot participate in social activities or team sports and their academic success is low (Işık, 2006; Erol, 2007).

In the study, mothers are asked about their children's early ages. Main focus of these questions are to find out what their life was like pre-illness, if there are any differences between the child with schizophrenia and the healthy siblings related to their periods of growing up and the quality of communication between family members. Interviews with the mothers show childhood characteristics of children diagnosed with schizophrenia are more crystallized and their child with illness differentiates from their other children. Characteristics which become clearer in children diagnosed with schizophrenia are introversion, jealousy, insufficiency of social circle and academic failure.

3.1.1. Introversion, Jealousy and Insufficiency of Social Circle

Some of the mothers state that there are developmental differences between their children. They say children diagnosed with schizophrenia have introverted jealous, stubborn, aggressive behaviors. One of the mothers interviewed, stated that her son, seemingly with no physical or mental challenge could not run or play ball like other boys. A mother of six expressed the differences of her child as follows:

Have I seen any difference? My schizophrenic child's nature was a bit different from my other kids. A bit introverted a bit stubborn. Maybe it was a sign even when he was little, that he would have a problem.

Another mom expressed her daughter's introverted behaviors during her school years as follows:

Here is how I thought: My daughter has never had any friends, she always drew herself back. For example, she never wanted to play on the street. Because she said she cannot. My daughter experienced such things all through her childhood. Also at school. She was always by herself.

Another mother tells about her son's childhood:

Around that time something violent happened between my children, two siblings. I think the source of it was my sick child. My son wanted to protect me. He always says he was jealous and he never wanted to share me with anyone else.

3.1.2. Academic Failure

In the interviews with mothers, another point emphasized about childhoods of children with schizophrenia is the academic failure of schizophrenia patients. With the exception of one, all mothers stated that their children fail at school.

When we have a look at the education levels of individuals with schizophrenia; one is a university graduate, four are high school graduates, four are middle school graduates and one is primary school graduate. Academically, there is no low rate of success. But mothers of the individuals with schizophrenia usually say their children are challenged at school, their children are never successful, they are usually mediocre. Except one, all the mothers expressed that their children experienced learning difficulties and they went through academic negligence.

A mother who says her child learned to read and write later than his classmates expresses difficulties she had gone through: "If we had left it to his teacher, he would never learn to read. I taught him to read and write. Because his teacher said 'This one is not fit for class. He distracts other kids…"

The mother who could not accept that her son could not learn to read and write. And she taught her child, with determination and patience, using different methods. With the attention of the mother the child first graduated from primary school, and then took a diploma in hairdressing from apprentice school. But despite all the efforts related to his education this person who is 30 now, has never been able to have a job experience.

3.2. Life during Illness: Despair

The studies show schizophrenia emerges between 15 to 25 ages in men and 25 to 35 in women (Salem and Kring, 1998; Frangou and Murray,2008; Angermeyer et all. 1990; Köroğlu, 2009; Işık,2006). When the illness first emerges, possible signs and symptoms include weakening of judgment, deterioration of impulse control, extreme selfishness, the desire to fulfill his own requests, lying and aggression (Çoban, 2008). First attack phase of schizophrenia is a period when delusion, hallucination, severe thought disorder and corruption in functionality and other negative symptoms rise violently. And also patient may lose self-care ability (Işık, 2006). Because of this, first psycho-attack of a schizophrenia patient is an unexpected and usually frightening experience both for the patients and the families (Üçok, 2007). The onset of mental health problems in a young person raises many issues around parents' views of their parenting role that both reinforce and challenge the nature of this role (Harden, 2005:209) and is associated with a great deal of emotional distress and life disruption for the identified sufferer and the family (Godress et all. 2005).

In the interviews with the participants, all the mothers' state that emergence period of the illness was very painful. They emphasize that they did not know what to do and they had problems figuring out whom to ask for help. The children's symptoms were unusual behavior like aggression, bad temper, introversion, shutting down communication with family members, paranoia, running away, insufficient self-care (no bath for 6 months, no change of clothes for long periods). Mothers state that they could not persuade their children to ask for psychiatric help. Some of the mothers express that it took a long time for them to accept the illness. And they also say some fathers do not acknowledge their children's illness despite the years-long treatment they have been getting and multiple stays in psychiatry clinics.

The mothers interviewed say they had difficulty accepting the change of behavior in their children at first. Then they only took them to a hospital for an inspection only when they face something important. And this waiting period delays the start of treatment.

One of the participants expresses the reason she took her daughter to a psychiatrist for the first time:

My daughter started to cry and I could not console her. I definitely could not. Then something insignificant happened and she started to laugh. When she started laughing I slapped her so that she would come to herself. Then laughing sickness started. She was laughing all the time. She was talking to herself and laughing. I was frightened. And then we decided to take her to a doctor.

Another mother tells about the incident that required the hospitalization of her daughter:

She overreacted to even small things we said like 'Honey come sit here'. She screamed, got angry, got nervous. Her older sister came from work. When my sick daughter started acting weird, her sister said 'What are you doing? She rushed to the kitchen and came back with a knife. When we saw she was running toward her sister we held her and did not let her go. After that we put her in a hospital.

Delusions caused by schizophrenia are wrong beliefs in which perceptions and life experiences are misinterpreted (Tandon et al. 2013). Imagining evil can be seen in various matters like delusions of reference, body, religion and grandeur. Delusions of reference make people believe people's actions or references in books, newspapers, song lyrics are directed towards them (Köroğlu, 2009). Words of a mother who experienced this kind of delusions in her child are very important:

My son was just back from his father's. TV was on. He said 'Turn off the TV. Everybody is listening to us'. Then I suddenly hugged him and I said 'What happened to you my son? He neither laughed nor talked. He didn't say anything else.

Another participant mother talks about her son's delusion: "He says 'Mom. I started seeing people as monsters on the bus. I started seeing them differently." Parents say they decide to take their children to a psychiatrist after the child's different behavior keeps repeating or something important enough to affect other family members happens. After examination of the doctor, treatment starts but the families express serious difficulties in sustaining the treatment. A mother talks about this period: He stopped taking the medicine after some time. He did not accept it from my hand either. When I tried to put the medicine in his food he didn't want meals from me. He scrambled eggs and only ate them.

Schizophrenia, unlike some illnesses, obligates a lifelong treatment. The point where treatment is stopped, the patients start to have episodes. This hurts both the patient and his environment. Eventually he has to be hospitalized. Because of these, mothers say they have difficulty sustaining the children's treatment, and also persuading them. They try various ways for solutions but sometimes they are just helpless.

3.3. Thoughts about the Cause of the Illness: Physical Violence and Socio-Economic Difficulties and Spell

In the interviews, mothers who have spent every minute with their children since they were born were asked about their thoughts related to the cause of the illness. It was seen that participant mothers had some ideas about the cause of the illness. Among these are lack of peace at home, violence from the father against the wife and the kid, genetics, sibling rivalry, death of a loved one (father), socio-economic difficulties and spells! Findings from the interviews are important in how mothers find a meaning in their children's illness and their view point of the illness's cause.

3.3.1. Physical Violence and Socio-Economic Difficulties

Frangou and Murray (2008), states that emphasize of life experiences in schizophrenia depend on two hypotheses: These incidents whether nice or not are "full of stress" and schizophrenic patients are especially subject to stress. It is stated that psychological problems cause schizophrenia to emerge. Unreliable environments, bad life conditions without social support, being under threat function as triggers for emergence of schizophrenia. A life with stress increases the risk of schizophrenia and social conditions are also important in its emergence (Çoban, 2008; Ertuğrul, 2007).

The most striking finding from the study is that mothers' expressions of domestic violence. Interviewees are asked about their domestic lives before the illness. In the first two interviews mothers mention the lack of peace at home and the effects of violence from their husbands on themselves and their children. When stories of violence were received in the third interview, like the first two, the focus of information was settled. Therefore questions in the rest of the interviews were in this direction. Seven of the ten interviewed mothers stated that their husbands used violence against them and their oldest child. An interviewed mother said she herself inflicted violence against her children. Mothers were asked which children were subject to violence and if there were differences in terms of violence inflicted on between the children with schizophrenia and healthy children. The result is children subjected to domestic violence are the oldest and these oldest children have schizophrenia.

An interviewed mother said her husband used physical and verbal violence against all the members of the family. The oldest daughter was diagnosed with schizophrenia and she was the child who was subjected to violence most. So the mother had his daughter marry at the age of 18 thinking it was the only way for her to be saved from violence. "Because it was something very severe, my daughter could not handle it. So I had my daughter marry immediately. I took her from school. It was to save her from her father's violence". Another mother talks about the violence her child was subjected to: "When my husband was angry he hit around. My daughter could not serve his father like I could. Then he hit my daughter. I was keeping silent. I wasn't saying anything. Though he hit me from time to time he did not beat me up much".

A mother whose oldest child has schizophrenia, talks about the violence she and her child faced:

Childhood of my son was very painful. The father was alcoholic. Because he beat me up a lot he grew with a fear of father till he was 12. Yes he beat me up very much, very harshly. My son was my oldest. He did not hit my daughter. I and my son lived through all that violence.

Another mother expresses that the reason for her child's schizophrenia is the violence her husband inflicted upon her and the child. And also because of the social and economic insufficiencies: I have an idea about the reason of the illness; Dysfunctions of the family and rage of the father. As it can be understood from the interview process and mothers' statements, "physical violence" is a common characteristic in both mother's and the child's experiences. In this context, violence inflicted on the first child and the first child having the illness makes a point. It is important in thinking physical violence as the trigger of the illness.

3.3.2. Spell

It is very meaningful that a mother who is a teacher says the cause of the illness is "a spell by her mother-in-law". Participant mother expresses herself in these words: My children were normal till that day. I sent my daughter and son to stay with their grandmother (on father's side). After they came back from her they stopped calling me 'mom'. They suddenly drifted away from me. I started beating up the kids. And they stopped coming near me. I made their beds, put a blanket on but they did not respond. I could not reach my kids. I asked my neighbor what it could be. She said 'Yes, it can be a spell'. There were no problems till then in our family. The spells are very common in our neighborhood.

3.4. Experience of Illness Period: Pain

The studies state there are 6.3 years between the emergence of schizophrenia and hospitalization. As the "illness without treatment period" between emergence of first symptoms and the start of the treatment or hospitalization gets longer, response to treatment is more limited and episodes are more frequent (Üçok, 2007). The diagnostic process can be very distressing and protracted, and lead to parents feeling disenfranchised (Harden, 2005:212).

The interviews with the mothers exhibit that the emergence of the illness and the time course that comes after is painful. Family members start to recognize the changes in the patient in the onset of the illness. Family members are concerned and they cannot know what to do in the face of these weird actions of the patient. Family members experience shame, fear, guilt, hopelessness, anxiety, rage and despair when they encounter the illness (Junk, 2000; Bademli, 2013).

In all the interviews with mothers, participants became sad and could not stop their tears from falling when they were telling their traumatic life stories, especially when they remember the time of the diagnosis. Because of this, tissues were kept ready in the interview room. One of the mothers said she could not cry anymore after all the difficult years she had been through and she does not need the tissues. But it was observed that while she was telling about the time when her daughter was diagnosed, she could not stop her tears. While one of the interviewed mothers said she was very sad when her daughter was diagnosed with schizophrenia and she taught about suicide, another mother expressed herself with these words: I had never heard of schizophrenia before. I conducted research and learned that it is such a bad and difficult illness where you hurt yourself and others. How could I respond? It happened to us and I was so sad. I even cried at the doctor's. My doctor hit his hand on the wall and said 'Do you see this wall? You have to be strong like it. If you want to help your child, you have to be strong for yourself and for him.

3.5. Problems Encountered During Illness and Ways to Cope with: Anxiety

Schizophrenia illness is defined as "a disorder that goes with symptoms of deprivation (negative) like delusions of various frequency and intensity, scattered speech and behaviors, symptoms of excess behavior like catatonia (positive) and poor thoughts, decrease of will, loss of pleasure, shallow or blunted affect" (Yıldız, 2011). Along with it is emphasized that the illness hurts communication between people, causes the individual to hinder personal care, obstructs professional success, handicaps productivity and creativity, corrupts family relations and friendships and destructs individual's memory and attention functions.

Families of children with serious mental illnesses go under a huge burden in the periods when they undertake all the care of their child (Osborne and Coyle 2002). These families are deprived of basic resources and they experience insufficiencies of time and information (Milliken and Northcott, 2003).

"Family burden" is an important term in schizophrenia. Families encounter various difficulties at every phase of the illness and they have to face it on their own (Provencher and Mueser, 1997; Grandon et all, 2008; Gülseren 2002; Gülseren et al. 2010).

In family studies with individuals who have mental illnesses in the family, subjective responsibility is defined according to emotional states of the family like stigmatization, loss, fear and anxieties that emerge while dealing with mental illnesses, giving care and emotional challenges (Greenberg et al. 1993). Within the scope of the study, it is found out that biggest problem mothers experience start after they persuade the children to accept treatment. A mother whose daughter did not follow the treatment and did not use the medicine tells an incident: When my daughter ran away we could not find her for 4 days. She slept in olive gardens, under trees. She drank water from the mosque. We looked everywhere. Hospitals, morgues. We called the police. We gave her pictures to the newspapers. We put her pictures on utility poles. We let the *mukhtar* [local governor] know, had announcements made from mosques. Then she was found lying on an empty field. A little girl saw her. She called out to her mother and said 'Someone's dead here'. When they touched her she jumped up. They took her home and brought her to the mukhtar. As we had already informed the mukhtar he called us. And we went to take her with a convoy of cars. As if we were going to take a bride.

Interviewed mothers were not only late to start treatment but also were delayed in sustaining it. The reason for this delay is that the family does not accept the illness and does not recognize its importance. Acceptance of the illness only happens after the problems and difficulties that the children with schizophrenia cause other members of the family. These problems are running away from home, aggressive behavior against family members and trying to hurt him/her. Mothers express the most important problems they have with their children as follows: I think I did my best. Would you believe if I said I went everywhere after my son? I was grabbing my younger son and following him. One day he said he was going at 11.30 at night and left. He came to the end of the cliff. I remember going there to take him walking over the wall. I prayed to God I could get back without falling.

This mother says the biggest problem with the illness is the idea of her son hurting himself. She believed she could protect her son by following her day and night. Another mother with a daughter thinks only about protecting her child from sexual tendencies. This is important on how the study shows that sex of the child with schizophrenia determines the ways the parents are worried about them. My daughter came of age and she started to show interest in boys. I don't want her to go out because I fear that she might see a man and finds him attractive. Her interest in the opposite sex is too much. She thinks about them all the time and insomnia begins. She starts talking out of the blue. I worry that insomnia will cause stroke or trigger her illness. My first job is to stop her from having a child. Because she will definitely come back home. What if her child is ill too? And what will happen to them if I die?

This mother with a schizophrenic daughter states that she has concerns about her future. She says the biggest problem is her daughter's possible affection for a man and the situations that can be caused by her sexual relations. Because she is concerned that her child may carry the same mental illness. She is also worried that a negative experience she might have with a man can trigger her illness and she would have an episode. The methods she has developed against these problems are not to let her daughter out on her own, stop her from communicating with other people on the Internet, get to know all the strangers in her daughter's life and try to keep them away from her daughter and isolate herself and the daughter from life. Another participant mother with a schizophrenic child was going through the same kind of concerns and expressed herself this way: My biggest problem is to keep asking myself if my daughter did something wrong, if she was deceived by someone, if something happened to her. I do not want her to be on her own. I want someone to be with her all the time. I am scared that something may happen to her. She is a girl and she can get pregnant. The environment is bad. I don't want her alone.

This mother, like the previous one says she cannot leave her child alone and on her own. She believes she can protect her this way. As it can be seen in the interviews, the most important problem for mothers with daughters is their children's "sexual life" and fear that their children will get pregnant afterwards. To manage this course they develop special methods of protection.

The pictures painted by the interviews with mothers reveal that mothers experience anxiety about their children more than themselves. Problems like insufficient self-care, unemployment, financial insufficiency, impossibility of building a home of their own, cause's mothers to be anxious about their children with schizophrenia. Mothers give all the care to their children.

Although their children are adults, mothers do the everyday jobs for them like giving a bath, preparing meals, doing laundry, ironing, cleaning the house and shopping. Therefore mothers have intense anxiety about who will be giving the children the care they need if something happens to them.

They do not trust their healthy children and husbands about it. It has been observed that mothers serve as armor by taking over all the problems related to schizophrenic children so that other members of the family are not affected and the problems do not multiply. In the interviews mothers' thoughts about the future of themselves and their children with schizophrenia are brought to daylight. Whatever their incapability is, it has been found out that all the mothers' anxiety of future are the same. Mothers who are responsible for the care of their children stated that they are anxious of the possibility that if something happens to them, their children cannot take care of themselves. A participant with a daughter said: My only wish from God is, how can I put it, should he take my life first or her life? Or both of us at the same time? I beg God, this is my only wish. I am worried about how she will end up. Nothing else. I only think about what will happen to her if I die.

Families with a child who has a mental illness lose their enthusiasm and hope related to their children's future (Osborne and Coyle, 2002). Most of the children whose mothers we interviewed are single, with no experience of marriage or employment. Like all other mothers who have healthy children, mothers who participated in our study are deeply sad about their children's inability to build a family and experience parenthood. Not only because of the inability to get married, love and be loved but also because of unemployment, unproductivity, inability to work and earn money, they feel hopeless about future. A mother expresses herself in these words: "I am disappointed. My dreams are shattered. My expectations were never fulfilled. I was dreaming of getting my kid married. All my dreams were about giving them an education and make their homes".

Findings of the study have similarities to Ryan's (1993) study with mothers of schizophrenic children. Especially anxieties of mothers about their children in their own lives are alike. As it was mentioned before, one dimension of the loss experienced by mothers is "the child's loss of his potential to sustain a normal life". Moving from this point, in the interviews with mothers it was found out mothers' general anxiety is generally about their children's inability to sustain a normal life ever.

3.6. Things Mothers Want to Change in their Lives

It is stated that negative effects like poor living conditions, incidents of a stressful life trigger schizophrenia and cause it to emerge. The mothers we have interviewed throughout our study often expressed that they have experienced socio-economic insufficiencies and they were along with their children were subjected to violence. Mother who faces intense physical violence from her husband says she would change these if she could turn back time: What I would do? I would leave the husband then. Then I would raise my children somewhere nice. I do not know, its ignorance, I do not know (cries). Then honour was important, I really do not know. We had no idea about anything. It is Ok now but it is too late.

It has been expressed by mothers that domestic violence affects the relationships and interactions of family members and it causes discomfort at home. These negative patterns within the family did not fade although the violence ended. They rose with the emergence of the illness. All these negative situations caused mothers to struggle desperately and lose their hope about future. Mothers' ideas about their own lives are shaped around their "children". Although they have their own lives "motherhood" may cause a mother to postpone or neglect her own life. Another point mothers emphasize about their living area is about area of freedom. Especially the mothers' wishes if they could turn back time they would "live apart from their husbands" is about their self-confidence and their area of freedom. Thus as stated in Ryan's study, other component of the loss mothers experience is the loss of "mother's freedom in her own life".

4. Discussion

Schizophrenia has been the subject of many researches with different angles but it still preserves a lot of unknown aspects. Every research starts with the hope of contributing to unveil these unknown no matter how small or big the contribution is. In this study carried out to hear mothers who give care to their children with schizophrenia in Turkey, life experiences of mothers are tried to be exhibited. Human life is a long process from birth to death.

In these study experiences of mothers who have a child with schizophrenia and how they are affected are accounted for since the patient's childhood. The study is believed to be of great importance in this aspect. Most important of the findings of the study is the existence of physical violence against individuals with schizophrenia by their mothers and fathers, during their childhood. Majority of the mothers expressed that both they and their children -especially the oldest child who is diagnosed with schizophrenia- were subject to intense physical violence.

When the matter is studied from this angle domestic violence does not only affect the family. It is an important issue that causes more serious social problems affecting the whole society. Another important outcome of this study is the effects of the illness on mothers who spend a life time with their schizophrenic children. First of all is despair. In the first time course when the illness emerges, first symptoms are seen mothers had difficulty making sense of it and they did not know where to turn to. This caused mothers to struggle helplessly. Another affect is affliction, the pain mothers go through both at the emergence and the course of the illness. This pain turns chronic because there is a starting point of the illness but there's no point where it stops. Watching their children with no hope of getting better and the thought that any negative situation can trigger the child's illness and turn worse is a never ending agony in mothers. Another effect is intense anxiety about the future of their children. At a point where they start thinking the child will be independent and their responsibilities will end they face the fact that the child might never be independent. These mothers are naturally anxious about how their children will sustain their self-care without them in future. Mothers cannot leave a child who requires a lifelong treatment to someone. They think any situation can trigger the illness. So they are crushed under the load and the responsibility of the illness. And they keep deferring their own lives for the sake of their children's.

There are similar findings with the studies that focused on the experience of mothers and also fathers (Howard, 1998; Godress et all.2005; Pfeiffer, 2001; Junk, 2000). They demonstrated that parents of children with a mental illness experience significant levels of grief (pain) and despair. In the Pfeiffer's study (2001) fathers reported that the early phases of the illness were the most difficult. Fathers reported ongoing concerns about child's everyday well-being, as well as fears about their child' future. The most important limit to this study in the number of samples. When approached from this angle, though the number of mothers interviewed is small, very important findings are obtained about mothers' lives. With these limitations in mind, it will be important for researches to learn more about the experiences of mothers who have children of all ages with schizophrenia.

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