

HOW DO WOMEN EXPERIENCE FIBROMYALGIA IN FAMILY CONTEXT?

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ABSTRACT

HOW DO WOMEN EXPERIENCE FIBROMYALGIA IN FAMILY CONTEXT?

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The present study aimed to gain an in-depth understanding of how women experience fibromyalgia syndrome (FMS) in the family context. There were two main research questions in the study; (1) how do married female fibromyalgia patients with child(ren) experience pain, and (2) what is the association between these patients' pain experience and their family relationships? To answer these research questions, semi-structured interviews were conducted with six married women with children that were officially diagnosed with fibromyalgia. The transcriptions of the interviews were analyzed using interpretative phenomenological analysis (IPA). The analyses revealed four superordinate themes entitled as: (1) The features of fibromyalgia, (2) Fibromyalgia: A syndrome triggered by familial dynamics, (3) Fibromyalgia: A psychological phenomenon, and (4) Fibromyalgia as a triggering factor of change. The findings of the study were discussed in the light of the literature including the models that focus on family context.

Keywords: Fibromyalgia Syndrome, Interpretative Phenomenological Analysis, Chronic Pain, Familial Dynamics

ÖZ

KADINLAR AİLE ORTAMINDA FİBROMİYALJİYİ NASIL DENEYİMLER?

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Bu çalışma kadınların aile ortamında fibromiyalji sendromunu nasıl deneyimlediklerini derinlemesine anlamayı hedeflemektedir. Bu çalışmanın iki temel araştırma sorusu vardır; (1) evli ve çocuğu olan kadın fibromiyalji hastaları ağrıyı nasıl deneyimler? ve (2) evli ve çocuğu olan kadın fibromiyalji hastalarının ağrı deneyimleri ile aile ilişkileri arasındaki bağ nasıldır? Bu sorulara yanıt bulabilmek için evli, çocuğu olan ve resmi olarak fibromiyalji teşhisi almış altı kadınla yarı yapılandırılmış görüşmeler yapılmıştır. Görüşmelerin yazı dökümleri yorumlayıcı fenomenolojik analiz yöntemi ile analiz edilmiştir. Analiz sonucunda dört tema ortaya çıkmıştır. Bunlar, (1) Fibromiyaljinin özellikleri, (2) Fibromiyalji: Ailesel dinamiklerle tetiklenen bir sendrom, (3) Fibromiyalji: Psikolojik bir fenomen ve (4) Bir değişim aracı olarak fibromiyalji. Bu çalışmanın sonuçları aile ortamına odaklanan modeller dahil ilgili literatür ışığında tartışılmıştır.

Anahtar Kelimeler: Fibromiyalji Sendromu, Yorumlayıcı Fenomenolojik Analiz,
Kronik Ağrı, Ailesel Dinamikler

To Everyone in My Life

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CHAPTER 1

INTRODUCTION

1. 1. Pain and Chronic Pain

Pain is one of the most prevalent reasons to apply primary care (Disorbio, Bruns, & Barolat, 2006). Also, it is the most common complaint accompanied with other diseases (Madenci, Herken, Yağız, Keven, & Gürsoy, 2006). Correspondingly, it is universally accepted as an indicator of diseases (Hanoch Kumar & Elavarasi, 2016). On the one hand, pain can be a symptom of a psychiatric disorder; on the other hand, it could be a physical problem caused by a psychological problem (Kara & Abay, 2000). That is, there is a bidirectional relationship between pain and psychiatric disorders.

Pain is conceptualized as “whatever the experiencing person says it is, existing whenever s/he says it does” by McCaffery in 1968 (as cited in Berry, Katz, Covington, Miaskowski, & Dahl, 2005). That conceptualization stresses the subjective nature of the pain and the importance of self-report as a pointer of pain that exclude objectivity (Berry et al., 2005). The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or is described with such damage” (Merskey & Boğduk, 1994). That definition highlights that pain consists of different dimensions; therefore, it is a complicated experience (Berry et al., 2005).

It is asserted that pain means disease and suffering for the patients, a symptom for doctors and a feeling associated with signals starting with receptors and ending with brain cortex for the physiologists (Swieboda, Filip, Prystupa, & Drozd, 2013). Not

only the meaning of the pain differs for different roles, but also the experience of pain changes from person to person. In other words, pain is a subjective experience.

Pain alerts the body against the injuries; therefore, pain has a survival value for the living being (Swieboda et al., 2013). On the other hand, it has some negative consequences like reducing the quality of life or changing a person's life in a nonconstructive direction (Swieboda et al., 2013).

There is more than one way to categorize the type of pain. In terms of the duration, pain can be classified as acute or chronic (Berry et al., 2005). Acute pain has an important biological role which is a signal to show that there is an injury (Mosier, 2011). If the injury is cured, the pain disappears; however, if it is not cured, it can be transformed to chronic pain (Mosier, 2011). Compared to chronic pain, time for healing of tissue is shorter for acute pain (Berry et al., 2005). Also, compared to acute pain, there is not a biological value of the chronic pain, instead it can be seen as a disease state (Swieboda et al., 2013).

It is indicated that if pain persist at least for three months, it is called chronic pain (Bridges, 2011; Swieboda, 2013). On the other hand, some sources specify that to be considered as chronic pain, pain should continue at least for six months (Ahmad & Talaei, 2002; Merskey & Bogduk, 1994). Some studies pointed out that if it persists at least three or six months, it can be called as chronic pain (As cited in DiLorenzo, Pillai Riddell, & Holsti, 2016; Yazıcı, Tot, Biçer, Yazıcı, & Buturak, 2003). These shows health professionals did not have a common decision about when pain would be called chronic pain which is related to subjectivity of pain in terms of duration.

People diagnosed with chronic pain are not seen as a homogenous group. That is, people having chronic pain can differ in terms of physical, psychological and social conditions (McCracken, Spertus, Janeck, Sinclair, & Wetzell, 1999). For example, the severity of pain can change for people or they can have different emotional problems and their functionality can be affected differently (McCracken et al., 1999).

People with chronic pain can face some health problems like sleep problems, problems related to managing stress, and reduction in the activity level (Skevington, Carse, & Williams, 2001; Weering, Vollenbroek-Hutten, Kotte, & Hermens, 2007). At the same time, losing job, having social and family problems are some other problems (Duenas, Ojeda, Salazar, Mico, & Failde, 2016). Also, there is high comorbidity between psychological problems and chronic pain. For example, depression is the most common psychological problems of the people diagnosed with chronic pain (Tütüncü & Günay, 2011). Additionally, anxiety disorders, somatoform disorders, personality disorders and post-traumatic stress disorder are other commonly seen psychological problems being comorbid with chronic pain (Tütüncü & Günay, 2011). All of these problems have an adverse effect on the people's quality of life (Ahmad & Talaei, 2002).

1. 2. Fibromyalgia

One type of a chronic pain is fibromyalgia syndrome (FMS) characterized by widespread muscle and skeleton pain and physiological and psychological symptoms (Dönmez, & Erdoğan, 2009; Sevinç, 2013). Fibromyalgia is a word in Latin (Sevinç, 2013). 'Fibre' means the fiber, 'mys' means the muscle, 'algos' means the pain and 'ia' means the situation (Sevinç, 2013). Sir William Gowers used the word 'fibrositis' for the first time (Morris, 2011). He choosed to use that word because he thought that pain of muscles and sensitivity of muscle and skeleton occur due to inflammation (Morris, 2011). Also, the term of fibrositis refers to the "regional musculoskeletal" pain (İnanıcı, & Yunus 2004). Then, in 1972, the term of Fibromyalgia Syndrome was introduced by Hugh Smythe (Morris, 2011). When he introduced that term, he implied the widespread pain and points of tender (Morris, 2011).

In 1990, diagnostic criteria for FMS was built by The American College of Rheumatology (ACR) (Wolfe et al., 1990). According to the first criterion, chronic pain which is not related to one region of the body instead it is widespread and it should persist at least for 3 months. That is, there must be pain both on the left and

right side of the body, above and below the waist, and axial skeletal pain for a period of time. According to second criterion, there must be a pain at least 11 of 18 tender points.

In 2010, the diagnostic criteria for FMS were revised by ACR (Wolfe et al., 2010). According to first criterion of that revision, one should take 7 points or above from Widespread Pain Index and 5 or above from Symptom Severity Score or ones should take a point between 3 to 6 and 9 or above from and Symptom Severity Score. The other two criteria are that people should have symptoms for at least three months and they should not a have another disorder explaining their complaints. For the Widespread Pain Index (WPI), people choose which areas of their body throbbing with pain last week. There are 19 areas of the body, which are shoulder girdle left, shoulder girdle right, upper arm left, upper arm right, lower arm left, lower arm right, hip (buttock, trochanter) left, hip (buttock, trochanter) right, upper leg left, upper leg right, lower leg left, lower leg right, jaw left, jaw right, chest, abdomen, upper back, lower back, neck. For Symptom Severity, people consider fatigue, waking unrefreshed, and cognitive symptoms; and give each of them a score according to their last week. Scores are “0” for no problem, 1 for mild problems, 2 for moderate level problems, and 3 for severe level problems. Also, people consider somatic symptoms and give score 0 for no symptom, 1 for few symptom, 2 for moderate symptoms and 3 for a lot of symptoms.

The etiology of FMS is not known completely (Kolahi, Fakhari, Hajaliloo, Khabbazi, Dizaj, & Hemati, 2014). According to Dr. Philippe-Gaston Besson, who is the writer of a book about FMS, due to there is no any physical, laboratory, and/or radiological test to detect FMS, diagnosis of FMS is not easy (2003). Also, patients who have FMS look like being in the form, which means that FMS is not understood by appearance. Additionally, there are not any device that can measure the pain and fatigue of patients. It is indicated that after 3 to 5 doctors see patients, FMS is diagnosed and to be diagnosed with FMS, nearly five years pass.

Since there is any measurement to the diagnosis for FMS, possible existence of organic reasons of the disease is questioned (Kolahi et al., 2014). Due to the questions related to organic natures of FMS, it can be seen as a psychosomatic problem (Nordahl & Stiles, 2007). Also, FMS patient's behaviors related to pain are not correlated with tissue injuries, instead it is related to patient's psychological conditions like depressive, anxious, and somatic symptoms. Therefore, FMS could be considered under the title of psychosomatic problems (Sevinç, 2013). In Diagnostic and Statistical Manual of Mental Disorders (DSM), the word of "psychosomatic" corresponding to Somatoform Disorders in DSM-IV was replaced with Somatic Symptom and Related Disorders in DSM-5 (Grover & Ghosh, 2014). The main characteristics of that disorder are somatic symptoms that could lead to so extensive stress or an important disruption in daily functioning (Grover & Ghosh, 2014). Also, exaggerated and unreasonable thoughts, feelings and behaviors accompany somatic symptoms (Grover & Ghosh, 2014). Although some characteristics of FMS and somatoform disorders overlap, they are not similar (Hauser & Henningsen, 2014).

It is indicated that FMS is one of the most commonly seen disorders, specifically the second most prevalent disorder after osteoarthritis (Clauw, 2014). The prevalence rate of the FMS is estimated 4.2% in the world (Bulduk & Biral, 2015). Toptaş, Güleç, and Can (2004) examined the prevalence rate of FMS in Turkey and they look at the woman aging between 20 and 64. They found the prevalence of FMS nearly 4 per cent of women. Similarly, another study found the prevalence of FMS as 5.6 per cent among the woman in Turkey (Çakırbay, Cebi, Cebi, Karkuçak, & Çapkın, 2013).

It is asserted that women are diagnosed with fibromyalgia more than men. Similarly, it is found that more than 80% of patients who are diagnosed with fibromyalgia are women (Dönmez & Erdoğan, 2009). Another study supports this finding which specifies that FMS is seen 9 to 10 times in women (McBeth & Jones, 2007). There are some other findings done different countries found nearly similar results related to gender ratio. For example, when looking at the United States, it is seen that the

percentage of women diagnosed with FMS changes between 3 to 5 percentage; on the other hand, men's percentage changes between 0.5 to 1.6 (Kolahi et al., 2014). Similarly, in another study done in the United States, it was found that 3.5% is for women and 0.5% for men (Wolfe, Ross, Anderson, Russell, & Hebert, 1995). Although FMS is seen in every age, its incidence increases with age (Wolfe et al., 1995). FMS is seen rarely before the age of 20, and it reaches the peak level between the ages of 70 and 80 (Besson, 2003). There is a study comparing people with different ages (Wolfe et al., 1995). The results showed that although only 1% of females ranging between the ages of 18-29 diagnosed with FMS, this rate increases with increasing age; the rate of FMS diagnosis in females between the ages 70 and 79 is 7%. Another study done in Turkey found that the prevalence of FMS is 0.9% for women whose age ranged from 20 to 29; however, this rate increases to 3.6% for the women aging between 29 and 64 (Topbaş et al., 2005).

Although there is any information about FMS's etiology, it is known that some psychological disorders can be seen in that population. Some studies indicated that depression or psychosocial stress factors are related to beginning and continuation of FMS (Nordahl & Stiles, 2007; Şengül, Ateş, Şengül, Okay, Dilbaz, & Karaaslan, 2008). Other disorders seen in FMS patients before or after they got that diagnosis are somatization and anxiety disorders.

There are many studies investigating the relationship between FMS and depression (Altunören, Orhan, Nacitarhan, Özer, & Karaarslan, 2011; Pattern, 2001; Robinson, Birnbaum, Morley, Sisitsky, Greenberg, & Wolfe, 2004; Şengül & Akkaya, 2014). The rate of depression increases in people with physical problems (Şengül & Akkaya, 2014). This association was supported by the studies indicating that having a physical problem is a risk factor to develop depression (Pattern, 2001). Similarly, it was found that between 22% to 45 % depression accompanies FMS (Robinson et al., 2004). Also, a study done in Turkey found that nearly 55 per cent of FMS patients are diagnosed with depression during their life (as cited in Balcı Şengül & Akkaya, 2014). Another study reached the conclusion that 37.3% of FMS patients are also

diagnosed with major depression according to DMS-IV TR criteria (Altunören et al., 2011).

There are other studies suggesting that having low social-economic status, having a low education level, being women, being divorced, and having a disability are risk factors for the FMS (Topbaş et al., 2005). Although disability is a risk factor for developing FMS, it also develops with FMS. According to World Health Organization (2008), fibromyalgia is one of the most prevalent type of the chronic pain, where disability is highly probable. According to a study, 25% of female and 27% of the male participants could not work anymore after being diagnosed with FMS and other participants of the study indicated that FMS affects adversely their working life (as cited in Besson, 2003). Not only patients' work life is affected by FMS, but also their daily life is affected by symptoms of FMS (Henriksson, 1995). Since they are mostly tired and every action of them require more time, patients' daily life roles and activities negatively affected by FMS (Henriksson, 1995).

1. 3. Theoretical Perspectives

In 1977, psychiatrist George L. Engel, asserted that disease, illness and health are the results of gathering and influencing by biological, psychological, and social factors (as cited in Hatala, 2012). This argument is the main assumption of the Biopsychosocial Model which is widely accepted today (Hatala, 2012). Until the emergence of that model, the Biomedical Model was commonly used where the disease and illness are treated separately from the person and the environment (Deep, 1999). On the other hand, the Biopsychosocial Model asserts that recovery from illness and disease is associated with psychosocial factors (Deep, 1999). From this point of view, family and social environment are the part of diseases. This means that family and social environment affect the development of diseases and they are affected by them. The models that focus on family and social environment, and models focusing on the family context will be covered in the scope of this study. Specifically, there are models that specify ways that chronic pain in a family member has an impact on the whole family (Kern & Otis, 2003; Lewandowski, Morris,

Draucker, & Risko, 2007). These models are Family Systems Model, Operant Mechanisms Model, Cognitive-Behavioral Transactional Model, which are handled in detail below.

1. 3. 1. Family Systems Model

Family Systems Model is influenced by different theorist and theories which are Ludwig von Bertalanffy who developed General Systems Theory, Murray Bowen who developed Bowen Family Systems Theory, Salvador Minuchin who developed Structural Family Therapy, and Virginia Satir who is the founder of transformational Systematic Therapy (Helm, 2016). Unlike these models, Family Systems Model is a comprehensive model that provides a framework to understand chronic pain in family context (Kerns & Otis, 2003; Lewandowski et al., 2007).

In the light of this model, it is asserted that pain has certain roles in the family systems in terms of psychological functioning (Kerns & Otis, 2003).

Dysfunctionality in the family is the keyword to understand that roles. That model proposed that if there is a dysfunction in one part of the family, it will cause dysfunction in other parts, too (Lewandowski et al., 2007). Similarly, if there is a change in one part, there will be a change in the entire family system (Lewandowski et al., 2007). In other words, each member of the family affects the entire family and vice versa (Kerns & Otis, 2003).

It is claimed that when a family has a member having a chronic pain, this indicates that there is conflict and/or emotional problems which are covered (Lewandowski et al., 2007). These families have problems to handle with and they focus on the one who has pain. Even these families can reinforce the pain sufferer complaints instead of solving their problems (Lewandowski et al., 2007). Also, this reinforcement can occur to keep family stability (Lewandowski et al., 2007). The model says that the family tries to reach homeostasis, which is achieved by family rules; on the other hand, pain is a way of maintaining family homeostasis, which is a way of not violating the rules of the family (Roy, 1985). Similarly, chronic pain, which is

accompanied by disability, can be a way to be seen as a solution for interpersonal problems between family members (Lewandowski et al., 2007). For example, a woman can receive care from her husband because of her pain and disability. In this example, despite the fact that she could not demand care from her husband she could get care even without asking for it. As observed, pain can be used as a communication tool in the family (Lewandowski et al., 2007).

It was showed that chronic pain sufferers depend on other family members too much (Lewandowski et al., 2007). That is, there is a need for dependency for pain sufferers and this need is met through having pain. This dependency can prevent pain sufferers to recover from their pain and develop separated identity from their family (Smith & Friedemann, 1999). It was proposed that when a person could not have an individuated identity, then the person could be confused to differentiate emotional and physical problems (Lewandowski et al., 2007). The situation reminds the concept of alexithymia that has commonly seen in the chronic pain patients (Lumley, Asselin, & Norman, 1997; Cam Çelikel, & Saatçioğlu, 2006). Alexithymia was defined as not having the ability, perceive and show emotions that correspond to situations (Turk, Flor, & Rudy, 1987). It was indicated that instead of recognition and expression of emotion, pain sufferers focus on their pain sensations (Turk, Flor, & Rudy, 1987).

It was asserted that families use four different strategies to work (Smith & Friedemann, 1999). One of them is system maintenance which includes processes to keep the family in equilibrium. The other one is coherence which consists of methods to enable bonding between the members of the family. System change is another one and it contains strategies to change as a family. The last one is individuation that permits family member to exist outside of the family. On the other hand, these strategies do not work properly in the family if there is a member with chronic pain. Especially, because these families mainly focus on the pain, system maintenance and coherence strategies built around it. Moreover, family members try to help the pain sufferer and they use their time and energy for that person; therefore, they involve too much to the family but they alienate from the outside world

(Friedemann & Smith, 1997). This process prevents FMS patient from becoming individuated from the family.

1. 3. 2. Operant Mechanisms Model

According to the Operant Mechanism Model, chronic pain is dependent on principles of learning (Kremer, Sieber, & Atkinson, 1985). Therefore, it could be testable and it is easy to be supported empirically (Kremer et al., 1985). On the other hand, the principles of learning are affected by social responses especially by spouses' responses (Lewandowski et al., 2007). Pain is not directly understood from outside (Lewandowski et al., 2007). On the other hand, there are some pain behaviors that are from observed by others like seeking help or facial expression related to pain (Kerns & Otis, 2003). These pain behaviors could be reinforced by family members even when they are not showed (Kerns & Otis, 2003; Kremer et al., 1985). Although all family members could unintentionally give those reinforcements, it is asserted that it may mostly be given by spouses (Kerns & Otis, 2003; Lewandowski et al., 2007).

There are studies that showed when spouses give a positive attention to pain expression of pain sufferer, pain, pain behaviors, and observed pain behaviors are reported at a higher rate (Block, Kremer, & Gaylor, 1980; Kremer et al., 1985). Also, there is an increase in disability in this case (Flor, Turk, & Rudy, 1989). On the other hand, when the spouses are less responsive to pain expressions, the rate of depressive symptom severity and other affective distress increases (Flor, Turk, & Rudy, 1989).

Like all other behaviors, couples give some responses to pain behaviors, too. These responses could be paying attention or showing sympathy to pain expression of pain sufferer, or indirectly encouraging pain sufferer to avoid her responsibilities or undesirable activities (Lewandowski et al., 2007). Due to those responses, pain behaviors are reinforced and they open the door for later exhibition of pain behaviors, even when these responses are not shown (Lewandowski et al., 2007). These couples try to handle problems that are seen in all marriages. On the other

hand, they also try to cope with the problems related to chronic pain (Lewandowski et al., 2007). It was argued that because there could be a decrease in the marital problems on the occurrence of pain behaviors or the focus could change from the marital problems to pain behavior, pain sufferer may be conditioned to show pain behaviors to escape or not to confront with the marital problems (Newton-John, 2002).

Although social support is seen as a positive factor in the traditional perspectives, this is not the case for Operant Conditioning Model (Lewandowski et al., 2007). That model proposed that although pain sufferer evaluates attention given to pain behavior positively, they could have devastating effects on that person, such as fostering pain and disability (Lewandowski et al., 2007). The model suggested that attention from others could be evaluated positively only when there are behaviors that are beneficial for the pain sufferer, such as compliance to the treatment plan (Lewandowski et al., 2007).

It was asserted that to escape household tasks and other tasks in the family, pain behaviors could be promoted (Lewandowski et al., 2007). Family members could do tasks of the pain sufferer due to the pain behaviors which could perpetuate the exhibition of the pain behaviors (Nicassio & Radojevic, 1993). It could be speculated that if family members don't do a task for pain sufferer, there could be decrease on pain behaviors; however, there is inconsistent result between the aversive responses of family members to pain behaviors and decrease in pain behaviors (as cited in Lewandowski et al., 2007).

1. 3. 3. Cognitive-Behavioral Transactional Model

Cognitive-Behavioral Transactional Model is another theory examining chronic pain in the family context (Williams, 2010). This model is a more holistic model compared to Operant Mechanisms Model (Lewandowski et al., 2007), since it was developed after seeing the limitations of Operant Mechanisms Model (as cited in Kerns & Otis, 2003). That model shed light on maintenance of health and

management of chronic pain (Lewandowski et al., 2007). Also, the model suggested that social environment, specifically family, is a context where adaptation or maladaptation occurs in the terms of pain experience (Kerns & Otis, 2003.).

The model suggested that experience of pain depends on the interaction between people's prior biological, behavioral, cognitive, and affective susceptibility and their unique challenges, and stresses of the situation where they experience pain (Kerns & Otis, 2003). Also, the model suggested that this interaction occurs in a social context, specifically in a family context, which could support coping strategies and result in a positive outcome like ideal pain management or result in a negative outcome like disability (Kerns & Otis, 2003).

The model proposed that family members, more specifically couples, appraise any situation related to painful situations to understand whether their resources are sufficient to that situation (Leonard, Cano, & Johansen, 2006). Then, they decide whether the situation should be perceived as stressful or not (Leonard et al., 2006). Through that appraisal, the family tries to understand their positive and negative sides and family members' competency level according to coping strategies (Kerns & Otis, 2003). After these, family members start to think about whether their reactions are accurate and/or which different reactions they can give to any stressful situations (Kerns & Otis, 2003). It is asserted that both coping strategies and reactions of the family members are so important that they can aggravate or reduce the level of stress (Leonard et al., 2006).

According to this model, the family has schemes, which are fixed set of beliefs about every concept, such as illness and health, and their reactions to them that are seen accurate or not (Kerns & Otis, 2003). Actually, these schemes develop by family members and they continue their existence through the family's existence. The model suggested that the family and the member of the family are programmed to think about the pain with these enduring schemes (Kerns & Otis, 2003). Also, both family and pain sufferer respond to pain depending on this schemes, and eventually their appraisals of pain are determined by schemes (Kerns & Otis, 2003). On the other hand, family's flexibility in terms of finding new ways to think about the pain

has a role in appraising the process related to pain and management the situations regarding pain. Also, these processes have an effect on the future situations related to pain (Lewandowski et al., 2007).

The theory postulated that the response of the family to pain sufferer's expression has as a positive effect on the person's experience of pain like preventing depression; on the other hand, at the same time it also has a negative effect on the person like promoting disability (Lewandowski et al., 2007; Kerns & Otis, 2003).

1. 4. The Aim of the Study and Research Questions

Although these theories provide a point of reference, the proposed study is not specifically bound to any of the theories mentioned above. The present researcher wants to see how pain is experienced in the context of family in Turkish culture. Therefore, the aim of the study is to gain an in-depth understanding of how women experience fibromyalgia in the family context. There are two main research questions in the study. These are (1) how do married female fibromyalgia patients with child(ren) experience pain and (2) what is the association between these patients' pain experience and their family relationships?

CHAPTER 2

METHOD

In this section, the methodological framework, sampling method and participants, procedure, data analysis, and trustworthiness of the study will be mentioned.

2. 1. Methodological Framework

2. 1. 1. Qualitative Approach

Pain is a subjective and dynamic experience which makes it difficult to measure and study. Moreover, it is influenced by different contextual factors, i.e., spiritual, social, cultural, cognitive and biological determinants (Osborn & Rodham, 2010). This multi-factorial nature of pain does also make it difficult to understand. Due to these reasons, pain researchers try to use different techniques to study pain.

Due to subjective, dynamic and multifactorial characteristics of pain, studying pain by using quantitative approaches is difficult (Osborn & Rodham, 2010). On the other hand, qualitative approaches use open-ended questions to gather information from participants, which allows gaining rich answers (Carter & Little, 2007). Also, those approaches focus on the unique experiences of individuals and try to make sense of those experiences (Osborn & Rodham, 2010; Schwandt, 2001). Additionally, the aim of using these approaches is not to generalize particular results to general populations, instead the researchers are aware that the investigated phenomenon can only be shared with other people who have similar contextual factors (Osborn & Rodham, 2010). Due to these reasons, the use of qualitative approaches seems to be more useful to understand the pain.

One of the qualitative approaches, interpretative phenomenological analysis (IPA), was chosen for the present study, because it could reveal the most comprehensive answers to questions asked at the beginning of the study. Besides that, this approach has advantages compared to the other approaches. It enables to gain in-depth and detailed materials related to the investigated phenomenon and opens the door to unexpected results (Barker, Pistrang, & Elliott, 2002): Thus, IPA was chosen since it served the purpose of the study.

2. 1. 2. Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) has several characteristics, that led the present researcher prefer it among the other qualitative approaches.

IPA aims to investigate how people make sense of their individual life and the world (Smith & Osborn, 2007). Also, by using IPA, researchers try to understand how people make sense of certain things like experiences and situations (Smith & Osborn, 2007). IPA enables researchers to interpret the interpretations of the participants (Howitt, 2010; Smith, 2004). All of these show that this analysis method is much more interested in the subjective side of the experiences instead of the objective side (Smith & Osborn, 2007). In other words, like other methods in psychology, it is not suitable to generalize the results of the IPA from a specific population to another group of people or society. Instead, the researchers using IPA are interested in the in-depth analysis of individual's interpretations related to the way they see things around to them. Attaining that, there are researchers who understand the experiences of people from their own point of view. Although the researchers are not capable of understanding other people's experiences in a direct way, by the help of this method they get as close to it as possible.

This method of analysis aims an in-depth analysis of people's perception and experience. Therefore, interviews are done with small sample size (Smith & Osborn, 2007). Also, the purposive sampling is used for that approach (Smith & Osborn, 2007). That means, people who share similarities like sharing the same socio-

economic status are chosen for that approach. Moreover, small sample size is used in IPA, because the analysis is done deeply and requires too much time (Pietkiewicz & Smith, 2012). Also, the size of the study is changed according to depth and richness of the case, the way the researcher wants to look at the similarities and differences between cases, and the number of participants that will be pragmatic for the researcher (Pietkiewicz & Smith, 2012). It should be added that the depth of the study is more important for IPA than the breadth of the study (Pietkiewicz & Smith, 2012).

IPA has some important features. First of all, it is an idiographic approach; it is interested in a case and it is a way to talk about the case (Smith & Osborn, 2007). After a case is analyzed in detail, another case can be analyzed with the same process. On the other hand, the method does not allow to talk about probability and/or generalizations related to a group or the population (Smith & Osborn, 2007; Howitt, 2010). Secondly, it is an inductive approach; IPA uses a broader research question that enables participants to give rich contents (Smith, 2004). Also, it does not try to reach a specific verification of hypothesis. Instead, it is open to coming up with unexpected themes during interviews and analyses (Smith, 2004). Lastly, IPA is an interrogative approach. It contributes to the mainstream literature through its research and discussion methods that benefit from existing psychology literature and challenge it (Smith & Osborn, 2007).

As data collection method, semi-structured interviews are used in IPA (Smith & Osborn, 2007). Unlike structured interviews, the order of questions is not important, probes can be used and questions can be changed in the semi-structured interviews (Smith & Osborn, 2007). Also, establishing an alliance with participants is important in semi-structured interviews (Smith & Osborn, 2007). Moreover, active listening, including listening actively, understanding what participant say and negotiating meaning with the participant, is one of the essential features of the researcher (Pietkiewicz & Smith, 2012). Another thing that has to be mentioned about semi-structured interviews is that it allows the participant to talk about their world. Due to these advantages, semi-structured interviews provide richer data (Smith & Osborn,

2007). Being value-laden, containing technical words, and closed questions are not preferred by IPA that may restrict the richness of the participant's answers (Smith & Osborn, 2007).

Although the researcher interprets what participants say, IPA is not solely based on that interpretation. Instead, it is recommended to keep some questions that may lead to self-reflexive thought in his/her mind both during the interview and during the examination of the transcriptions. These questions are "What is the person trying to achieve here? Is something leaking out here that was not intended? Do I have a sense of something going on here that maybe the participants themselves less aware of?" (Smith & Osborn, 2007).

There are also some points that should be kept in mind during the interviews. For example, the location of the interview is important. Since people are more comfortable in their personal space, the interview can be done in the home of the participants. Also, the interview must not be interrupted by some external factors. Thus, a quiet place must be preferred. (Smith & Osborn, 2007). Lastly, during the interview, being alone with the participant is important (Smith & Osborn, 2007).

2. 2. Sampling Method and Participants

2. 2. 1. Sampling

Researchers using IPA try to understand people's understanding and perception in an in-depth way; therefore, the interviews are done with a small sample size (Smith & Osborn, 2007). Also, interviews continue until "data saturation" is reached, which gives an opportunity to grasp the investigated topic comprehensively (Francisa et al., 2010). Also, the purposive sampling is used for that approach (Smith & Osborn, 2007). This means that people who share similarities like same socioeconomic status are chosen for that approach instead of randomly chosen people. The aim is to reach context specific information, which is "local, provisional, and situation dependent"

(Madill, Jordan, & Shirley, 200). As mentioned above, small sample size is used in IPA, because the analysis is done deeply and required too much time (Pietkiewicz & Smith, 2012). It should also be restated that the depth of the study is more important for IPA than the breadth of the study (Pietkiewicz & Smith, 2012).

2. 2. 2. Participants

The purposive sampling procedure was used for the study and interviews were performed with individuals, who share some similarities. The common features of the participants are being women, being married, having at least one child, and receiving treatment for FMS. Also, they had at least high school graduation and they belonged to middle or upper SES groups. The age range of participants was determined as 25 to 45 years. However, it was difficult to find participants between that age ranges; upper limit of age range was increased from 45 to 55. The primary criterion for the participants was being officially diagnosed with fibromyalgia syndrome. The participants were those who receive treatment from the Department of Algology in Gazi Hospital and were willing to participate in the study. Protecting the confidentiality of participants, alphabetically ordered letters were used according to an order of interview, instead of using participants' own names.

2. 3. Procedure

The semi-structured interview was used as the data collection method. The questions in the interview were determined by researcher and they were discussed with the researcher's supervisor Prof. Dr. Özlem Bozo and a research assistant of the department Dr. Yağmur Ar. Then, the last version of questions was formulated (see Appendix A). Although, there were questions asked to the participants whenever they talk about freely, they were not stopped by the researcher, instead they were encouraged.

The interviews were conducted with FMS patients, who came to the Algology Department of the Gazi Hospital. Before obtaining approval from the ethics

committee, the researcher met the head of the algology department in Gazi Hospital. After the doctor's approval, the researcher submitted the proposal to the committee of research ethics for the approval. The approval was given by METU Human Subjects Ethics Committee (see Appendix B). The researcher accompanied doctors while they saw their patients in the clinic. When there was a FMS patient, the researcher gave information about the study and if they met the criteria, she invited them to the study.

Interviews were done in a room at the algology department. There were only the researcher and the participant in the room. Before each interview, the informed consent form was given (see Appendix C). The duration of interviews varied from 61 to 133 minutes. A recorder was used during interviews. Then the records were transcribed. During the transcriptions, all demographic information of participants was changed with anonymous statements so that they could not be recognized.

2. 4. Data Analysis

It is important to be familiar with the data of the study (Howitt, 2010). Through the interviews and transcribing process, that familiarity was gained. Also, as recommended, the researcher read the transcription over and over again (Howitt, 2010; Pietkiewicz & Smith, 2012). The researcher used left side column in the text of transcription to take notes with a few words (Howitt, 2010). After the researcher became familiar with the data and took notes, the preliminary themes were constituted with a few words that were constituted by higher level abstraction, and they were written on a different page (Smith & Osborn, 2007; Pietkiewicz & Smith, 2012). After this process was applied to the whole text, the titles and the notes were written to another page and similar themes were clustered (Smith & Osborn, 2007). Some themes, which were not relevant to the structure, were dropped in that stage (Pietkiewicz & Smith, 2012). Then, superordinate and subordinate themes were created (Howitt, 2010). The name of the superordinate themes covered its subordinate themes (Smith & Osborn, 2007). Then all of these processes were applied to other cases, and at the end, the themes of the first and second cases were

compared in terms of their similarities and differences and this process was applied to other cases, as well (Howitt, 2010). During that process, repeated themes were detected and superordinate and subordinate themes were determined accordingly. Then, the research assistant, Yağmur Ar, independently analyzed a transcription and superordinate and subordinate themes were also formed by her. At the end, the researcher separately discussed the themes with the research assistant and the thesis' supervisor. Finally, the researcher revised the superordinate and subordinate themes according to the suggestions made during those discussions.

2. 5. Trustworthiness of the Study

Unlike quantitative studies, the researcher has more or less an impact on the phenomena which is investigated in qualitative studies. That is, qualitative research has a subjective nature. At this point, “reflexivity” emerges, which is the term to understand the role of the researcher on the process of research and data analysis (Willig, 2001). Personal characteristics of the researcher like their demographic information (gender, age etc.), biases, beliefs, attributions, political stances, and attitudes towards to the participants are particularly important for the researcher (Berger, 2013). The researcher is positioned according to those personal characteristics; therefore, the researcher should be aware of her personal characteristics and how they possibly affect the research (Patton, 2002). There is a version of reflexivity called as “hermeneutic reflection” (as cited in Maunders, 2010). According to it, the researcher has a central role in the study. The results of the study are based on the researcher preconceptions and assumptions, because these are the basis of the researcher's way of grasping the world (Maunders, 2010). On the other hand, the researcher should be aware of them and keep them out of the research (Maunders, 2010). Also, the term of “double hermeneutic” refers to the interpretation depending on two different sources (Fischer, 2009). Firstly, the participant makes sense of the world through her/his lenses and then the researcher interprets the participants' making sense of the world (Fischer, 2009). The aim of the researcher is trying to understand the participants' experience from the participants' perspective (Pietkiewicz & Smith, 2012). To sum up, the researcher's contribution to the study is

important. Therefore, the next section is composed of a personal statement that will give information about the researcher.

2. 5. 1. Self-Reflexivity

I am a 27-year-old single woman and I have lived in a town until the age 18. Then, I studied psychology at Middle East Technical University (METU) for 5 years. After I graduated from METU, I started a master's program on health and social psychology, which is predominantly on aging. After two years of education in that program, I started to Clinical Psychology master's program at METU. During the study, I was a student on Clinical Psychology M.Sc. Program at Middle East Technical University. As an internship, I provided therapy to the clients under the supervision of Ph.D. students at the AYNA Clinical Psychology Support Unit at METU.

My interest in pain started nearly three years ago when I had a pain that did not go on my right shoulder and it had continued approximately a year. That pain was not severe but it was constant. After I did some physical exercises, the pain disappeared. Yet, when I stopped doing the exercises for a while, it just came back. After I started the Clinical Psychology Master's Program, I became curious about the bidirectional relation between mind and body. As a starting point, I decided to write my thesis on pain experience.

CHAPTER 3

RESULTS

3. 1. Participant Knowledge and Participant Observation

In this section, the basic information on the participants and the themes that were often repeated by the participants will be mentioned briefly. Also, observations and interpretations of the researcher about participants will be mentioned at the end of each section.

3. 1. 1. The Interview with A

The duration of the first interview, done with A, was 128 minutes. She was 43 years old. She was graduated from university and she was working as a teacher when the interview was held. At the beginning of the interview, she talked about her work where she faced with many problems. When she was diagnosed with fibromyalgia, approximately 7 months before the first interview, she also has started to experience problems at work. After she talked about the problems she had at work, she spontaneously gave some information about her family. She had an arranged marriage that had been going on for 15 years. Her husband was reluctant to take responsibility for household chores. Instead, he only wanted to watch TV. She described her husband as a classic Turkish man who does not share domestic responsibilities.

She had two children; her daughter was 12 and her son was 8 years old. Her daughter wanted her mother to do her staff instead of herself, leading to problems between them. Her husband and daughter were criticizing her, because she was bringing work to home. Unlike them, her son was helping her. She said that she had always tried to

meet others' needs both at home and work. Yet, instead of appreciating her, her husband and daughter made complaints about her. So, she was angry with them, constantly questioning why she kept supporting them. At the end of the interview, she started to cry while she was talking about her disappointment at her husband.

During the interview and transcription process, I became aware that I was angry with the A's husband. I questioned why she got married him and she was not divorced yet. Additionally, I thought that her daughter was imitating the father's attitude towards her mother, mimicking his attitudes while dealing with her.

3. 1. 2. The Interview with B

The duration of the second interview performed with B was 133 minutes. She was 54 years old. She was graduated from high school. She worked as a public servant and she retired in 2007. At the beginning of the interview, she talked about her problems about her family. She said that her mother had a surgery because she had cancer. She was always with her, but her sister and brother were not there. She told, they judged her but she did not deserve those judgments. During the surgery, they argued with each other on the phone. Since then, she has drawn border between herself and her family members. Since that argument, she had not been talking to her sister and she had contacted with her brother less than she had before. In the meantime, although she had kept suffering from pain for 6 or 7 years, she was diagnosed with fibromyalgia 13 months ago.

She had been married for 28 years. Through her marriage, she wanted her husband to defend her against his family but he did not. She thought that she developed fibromyalgia, because she is a sensitive person. Also, she stated that she always said "you're right" to others, without any attempt to object and dispute with them. So, she developed this illness. Moreover, she said that she always tried to meet others' needs, especially her mother's and her sister's; yet she could not do that anymore.

During the interview and transcription process, it was obvious to me that B had tried to change some of her personality traits, which were according to her the reason of her fibromyalgia and the cause of aggravation of symptoms. I thought that she was trying to get rid of things that she has complained throughout her life by using fibromyalgia as an excuse.

3. 1. 3. The Interview with C

The duration of the third interview done with C was 61. She was 48 years old. She was graduated from high school. After the graduation, she had worked for the tax administration until she got married. She said that she suffered from pain in different parts of her body for 5 to 6 six years, but she was diagnosed with fibromyalgia 3 to 4 years ago. At the beginning of the interview, she said that her sister died 1.5 years ago because of cancer. They were four sisters and C was the eldest one. She was talking about her sisters as if they were her children. She mentioned that after her sister died, her fibromyalgia symptoms got worse.

She said that her spouse's family made pressure on her but her husband didn't support her in the past. She mentioned that both family pressure and her spouse's attitudes affected her negatively. Additionally, she said that both she and her husband are angry; and therefore, their discussions last long. On the other hand, she said that she started to use antidepressants, which enabled her to change her attitudes towards her husband; so, their discussion began to last shorter. Also, her son was 24 years old and daughter was 18 years old now. After their children turned to be grown-ups, they did not allow them to argue, too. She said that she had been married for 26 years. She stated that although her expectations from marriage were not met, her relationship with her husband had been getting better as compared to the past. She reported that in the past, she tried to do all the housework and she described herself as a perfectionist; as a result, she thought that she developed fibromyalgia.

At some point of the interview, she described an unrealistic relationship with her husband; she evaluated their relationship as perfect. At that point, I thought that she

employed defense mechanisms. Also, although her sister's death had an adverse effect on her fibromyalgia symptoms; on the other hand, this traumatic experience did not prevent her from develop effective coping strategies for her relationship with her husband.

3. 1. 4. The Interview with D

The duration of the fourth interview conducted with D was 120 minutes. She was 51 years old. She was graduated from high school and she had never work. She got married 34 years ago. Her husband's mother died when he was too young; therefore, her husband and his siblings were very fond of each other. Through the interview, she mostly talked about her spouse's family who were constituting the main problem for her marriage. She said that especially one of the sisters of his husband, who was the most influential person in her husband's family, treated her badly.

She had 2 children who were 33 years old daughter and 31 years old son. Her daughter married with an Azeri man. Her daughter's mother-in-law treated her daughter badly. Throughout the inter view, D mentioned several times that her daughter's mother-in-law was not right.

She had started to suffer from the symptoms of fibromyalgia 30 years ago. Although she was diagnosed with fibromyalgia those times, she did not follow the treatment plan. Then, she came to the department of algology 3 months before the interview and she was starting to follow the treatment.

Through the interview, D mentioned her husband's sister and her attitudes and behaviors toward her that she actually did not deserve so many times. Similarly, she stated many times that her daughter's mother-in-law was not right. As D's discourses showed that both her husband's sister and daughter's mother-in-law are still important figures for her; they keep being the major stress factors in her life.

3. 1. 5. The Interview with E

The duration of the fifth interview performed with E was 86 minutes. She was 51 years old. She was graduated from high school and she had never worked. She has been suffering from pain for 6 years and she was diagnosed with fibromyalgia at that time but she did not follow the treatment. Last year, she started to follow the treatment for fibromyalgia.

She mentioned that her mother was not close to her; therefore, she was in need of intimacy. She said that both she and her husband were helping an old woman living alone; she could satisfy her need for closeness which was not satisfied by her mother. On the other hand, her mother was jealous of that woman and both her mother and her sister argued with her about issues related to that old woman. Since these arguments, she had not been communicating with her sister. However, she discovered that the old woman said negative things about herself to her husband. Then, she took this woman out of her life.

She said that her relationship with her spouse was bad for 4 years; he was not supportive anymore, and she was negatively affected by him. At those times, her husband had problems at work and he behaved differently than he did in the past. On the other hand, both before and after those 4 years their relationship started to get better and the husband turned out to be a good supporter of her.

She had two daughters who are 11 and 17 years old. She mentioned them only when I asked questions related to her children. On the other hand, she mainly talked about her husband, her mother, sister, and the old woman. She described them as the source of problems in her life. She was trying to get them out of her life. The only person she talked positively about was her husband but she also highlighted that she lost her trust to him. She cried several times during the interview. I became upset for her and I thought that she did not deserve all of these things. On the other hand, I realized that her construction related to her life events was built around how right she was and she gave examples which were so convincing about her rightfulness.

3. 1. 6. The Interview with F

The duration of the sixth interview conducted with F was 72 minutes. She was 33 years old. She was graduated from university and she was working as a manager in a school. She began to suffer from pain 6-7 years ago and she was diagnosed with fibromyalgia at that time but she didn't follow the treatment. Last year, she came the algology department and she started to follow the treatment for fibromyalgia.

She had an arranged marriage and she has been still married at the time of the interview. At the beginning of her marriage, she had some troubles with her spouse's family. Her husband was not supporting either his family's or his wife's side, although she wanted him to defend herself against his family. Even though he did not do this, she wanted him at least tell her that she was the right in these disputes. She said that her pain started after she was married, because she experienced lots of stress and many troubles after getting married; and she thought that fibromyalgia is a psychological disorder. Also, she mentioned that she did not care about her husband's family as she did in the past. She said, she would not be affected negatively if she could get divorced.

During the interview, she talked too much about his spouse's family. Although she talked about the events which happened in the past, she became angry and frustrated as if they were occurred in a short time ago. Also, based on what she said, it was clear that her husband didn't meet her expectations and she was unhappy with her marriage.

3. 2. Superordinate and Subordinate Themes

Interpretative Phenomenological Analysis of the six semi-structured interviews about how women experience fibromyalgia in family context resulted in the emergence of four superordinate themes and fifteen related subordinate themes (see Table 1).

Table 1

Superordinate and Subordinate Themes

Superordinate Themes	Subordinate Themes
1. The Features of fibromyalgia	<ul style="list-style-type: none">1.1. Endless pain1.2. Severity of the pain varying from situation to situation1.3. Pain in different parts of the body1.4. Symptoms other than pain1.5. Different experiences related to the diagnosis and treatment process of fibromyalgia
2. Fibromyalgia: A syndrome triggered by familial relationships	<ul style="list-style-type: none">2.1. The family of a fibromyalgia patient as a trigger2.2. The family of the spouse as a trigger2.3. The spouse of the patient as a trigger2.4. Children of the patient as a trigger
3. Fibromyalgia: A psychological phenomenon	<ul style="list-style-type: none">3.1. Personality traits and fibromyalgia3.2. Emotions and fibromyalgia3.3. Others' view of illness and fibromyalgia
4. Fibromyalgia as a triggering factor of change	<ul style="list-style-type: none">4.1. Positive change in self4.2. Change in relationships with others4.3. Change in daily activities

3. 2. 1. First Superordinate Theme: The Features of Fibromyalgia

This superordinate theme aimed to capture the features of fibromyalgia symptoms that were experienced by participants. It seemed that pain is endless, its severity varies from situation to situation, and it is experienced in different parts of the body. Although the pain was the most predominant symptom of fibromyalgia, there were many other symptoms, too. Also, it was understood that there were different experiences related to the diagnosis and treatment process of fibromyalgia.

3. 2. 1. 1. Endless Pain

Four participants described the pain as endless. For example, A said that:

I have no idea when it began; it began suddenly and it never stops... I know that the pain is always there...

A said that she didn't know how her pain started; however, she said that the pain was always there. B said that her pain did not prevent her from meeting her needs:

I cannot say that the pain is so severe that it restricts my life. But, I feel like that it is kind of carving, harming and damaging me softly. You know it happens slowly. But, the pain is always just right there.

She especially highlighted the word "slowly", which corresponds to the severity of pain. She also used "carving", "leaving damage" and "harming" for that slow pain.

Like other participants, C did also mention her endless pain:

The pain is not very intense but it is chronic. As it is a constant pain, I got used to feel the pain continuously... I just know that it is because of my fibromyalgia, it is something that I have to live with. Likewise, if someone has an allergy, s/he admits that they have to live with the medications to suppress it. I will live like this but the pain never stops.

She said that her pain was not severe, but it was chronic. Due to her chronic pain, she got used to live with it. She added that when people have pain, they think about it; however, since she knows that her pain is the result of fibromyalgia, she does not

mind it. Although she could repress her pain with medication, she said that the pain would never disappear.

Four of the participants said that their pain will not go away; instead they stated that pain is always with them. As C stated, some of the participants saw their pain as a part of their identity because of a never-ending nature of it.

3. 2. 1. 2. Severity of Pain Varying from Situation to Situation

All participants stated that they do not suffer from constant pain. Instead, they said that their pain severity changes. According to all participants, their pain changed according to the physical fatigue caused by housework. For example, F mentioned about how housework affected her pain:

Especially, while I am doing housework, the pain increases much more. When it comes to cleaning, each of my joints and all my body aches.

Similarly, some of the participants mentioned that if they do not do housework and rest during the day, they do not feel so much pain. Thus, housework, a kind of physical activity, resulted in increased pain; however, resting was seen as a way of feeling less pain.

Some participants talked about the daily activities that caused physical fatigue, which in turn, results in increased pain. For example, D talked about climbing stairs:

Whenever I walk, my both legs and all of my bones ache. For example, if I climb up ten stairs, I feel like that there is no more energy in my legs. That's why I rest a lot. I rest on stairs like the elder do.

She said that her bones ache when she walks. Also, when she climbs up stairs, her legs become tired and she rests as older people. This example showed that similar to doing housework, other daily activities like walking and climbing stairs do also affect their pain severity. The common point between them was physical fatigue. In other words, physical activity that caused physical fatigue resulted in increased pain.

Some participants talked about the timing of the change of their pain severity during the day. For example, F said that her pain increased at nights:

But I feel more pain when I go to bed. Not when I am up and while moving during daytime, I feel it more when I go to bed. Especially, in my hip.

She said that she does not feel pain when she moved, but she felt it when she went to her bed to sleep. Similar to F, D said that:

Whenever I am surrounded by lots of people, I do not realize that there is pain. However, I am convulsed with pain at nights. Then, during daytime, I do not even realize how the time passes with my granddaughters/sons. I am happy that lose the track of time when I am with them. Maybe, everything affects me psychologically. When I am alone, I feel everything more intensely. I don't know...the crowd, the rush...with the kids you have a different agenda.

She said that when there are people around her, she is not aware of her pain. Although she felt pain at nights, she forgets it when her grandchildren are around during the day. She also added that maybe psychology has an effect on everything. As she said, she focused on her pain when she was alone, but she had other agendas when there were other people and/or events.

Actually, both B and D mentioned that they feel their pain when they are alone. The only time to be alone is sleeping time for them; therefore, they focus on their pain and they realize that there is an increase in the intensity of their pain.

The participants did also mention the effect of weather conditions on their pain severity. They said that their pain severity increases especially due to wind and cold. For example, B said that:

Reluctance...I don't want to go out. If I go out, I will feel the wind, I will get cold. The pain hits as soon as I go out when it is cold outside. Like a piece of ice was put my back. First, the pain feels cold.

As they said that both cold and wind result in an increase in pain severity. These factors were also the reason of why they are not willing to go outside to walk.

This subordinate theme showed that physical fatigue caused by daily activities including housework, walking, and climbing stairs lead to an increase in the pain severity. Also, the pain was felt the most severely at nights when participants were alone. Moreover, weather conditions including wind and cold air resulted in an increase in the severity of their pain.

3. 2. 1. 3. Pain in Different Parts of the Body

Participants described pain in different parts of their bodies. For example, F mentioned that:

On my shoulder, especially on my scapular, I have too much pain.

F said that she had so much pain on her shoulder and scapula. Also, D said that all of her joints were in pain:

I am saying sometimes all my joints. Even my toe joints and all my body ache. My arms, my flesh, my shoulders, my neck, my back ache immensely. My legs, as I said, my calves ache more, my feet ankles ache.

D indicated that even joints of her toes radiate pain. Also, her arms, flesh, shoulder, neck, waist, calves, ankles were in pain. B referred to the pain areas as:

But lately, for the last 6 years, there have been extreme ache in my shoulders and arms. My head aches. My hand and feet ankles have been aching terribly lately. I mean especially my hand and feet ankles.

B had suffered from an extreme pain on her shoulders for the last six years. She also said there was pain in her arms and head. She said that recently there was too much pain on the wrist of her hands and feet's ankles. Unlike the others, D didn't mention any specific bodily parts:

My whole body aches from time to time. I feel the pain in all of my joints for the last two months.

D said that her whole body suffers periodically. For example, in the last two months all of her body including her joints had pain. E said that she could not indicate specific regions of her pain:

The worst part is that I can't even make people understand that I am suffering from pain. Because, one day my arm ached, the next day my leg ached, then my head, then my face. I can say that this pain is like traveling within my body. As the pain is not just in one area, I cannot even describe it to the people around me. How can I explain it to the doctor? If I go to the doctor, s/he might say that I have a disorder, but the pain location changes the next day. It feels like that it is traveling within my body. It is the only word that I can describe it.

E said that there was a constantly changing pain in different regions of her body. To describe it, she named it as "traveling pain". Like other participants, she indicated that different regions of her body have pain but those regions change day by day.

All participants mentioned more than one part of their body that had pain. Also, they especially talked about their joints. It was noteworthy that one participant talked about traveling pain rather than pain in a fixed area.

3. 2. 1. 4. Symptoms Other than Pain

Although all participants indicated pain as the main symptom of fibromyalgia, they described other symptoms, too. Like two of the participants, F described how she was reluctant to do anything:

The pain bothers me and decreases my life quality. For example, I don't want to do anything or housework. I don't even care if it is untidy, I already have the pain and I get too tired. When I clean the room, I don't feel like myself. I don't want to do anything and I don't want to go out. For example, the doctor, who is very popular, suggested me to take my time for a walk or an exercise. But I don't even start for a walk. For example, I love shopping but believe me I don't even feel like going shopping. I just want to stay at home and sit all the time. It decreases my life quality constantly. I am aware of that. I don't feel energetic.

Like most of the other participants, C talked about her sleep problems:

You don't understand why. You don't have the pain but you don't sleep all the night. You just can't sleep. It distorts your sleep. When you can't sleep, you wake up tired. Even if you sleep, you wake up tired. Even if you sleep for

twenty-four hours, you are still tired. Everybody sleeps well and they wake up spry in the mornings, but you wake up tired; tired and unhappy in the mornings. How it does relate I don't know but the oxygen does not reach to the muscles in this disease.

Like other participants, B talked about fatigue:

The pain begins with weakness. It is like a headache but not like a sudden headache. Let say I forgot my medicine today. My pain is coming right away and it is intense. But there is no signal for the pain. It is just like weakness, tiredness; more like tiredness extreme tiredness. Like I said before, I was like carrying stones on my back, did all housework and consumed my whole energy. It is this kind of pain. Weakness.

Half of the participants mentioned their unwillingness to do anything during the day. Also, most of the participants said that they had problems with sleep; even when they sleep, they could not wake up as if they rested. Moreover, two of the participants talked about their fatigue.

3. 2. 1. 5. Different Experiences Related to the Diagnosis and Treatment Process of Fibromyalgia

Three of the participants mentioned that they were diagnosed with fibromyalgia in the past when they suffered from pain but they did not follow the treatment. For example, D described that process like below:

They diagnosed it as fibromyalgia, but as I said before, I didn't have a detailed treatment. I think it was 30 years ago or something. Maybe I was not really aware of it. But I had unbelievable pain in those times in my body. After that, nobody did anything about my treatment, just nothing... It was my first time in this department. I was trying to comply with using pain killers on my own for years.

Although there were patients diagnosed with fibromyalgia when their complaints start, there were also participants who had not received that diagnosis immediately. For example, C described the process of fibromyalgia diagnosis like this:

I had fibromyalgia almost for five or six years but of course I did not have diagnosis. I was always going to see doctors but they did not diagnose my illness. If my back was aching, I was going to see the doctor of physical therapy.

I went to different doctors for all the pain I have in different parts of my body like in my legs, waist, and back. I had separate physical therapies for all but the pain did not go away. After a while, again and again, I have become a hypochondriac. Then, a doctor diagnosed it as fibromyalgia... It has been three years, three or four years.

She said that her symptoms of fibromyalgia started 5 or six years ago. Whenever she had pain in any part of her body, she went to the doctor; however, they could not diagnose it. Then, she was diagnosed with fibromyalgia 3 or 4 years ago.

There were people who were diagnosed with fibromyalgia when the symptoms of fibromyalgia started for the first time but they did not follow the treatment plan. After the time passed, they were diagnosed with fibromyalgia again and they started to follow the treatment plan. On the other hand, there were people who were not immediately diagnosed. These people went to different units of different hospitals to get a diagnosis. After a certain period, they were diagnosed with fibromyalgia.

3. 2. 2. Second Superordinate Theme: Fibromyalgia: A Syndrome Triggered by Familial Relationships

This superordinate theme represented the effect of familial dynamics on participants' symptoms of fibromyalgia. It was shown that the family of participants, the family of their spouses, participants' spouses and children could trigger their symptoms or exacerbate them.

3. 2. 2. 1. The Family of a Fibromyalgia Patient as a Trigger

According to five participants, their family members caused exacerbation of symptoms of fibromyalgia. Four of the participants mentioned how their relationship with their family members negatively affected their symptoms. E described her argument with her sister and how she was affected by it:

...I told my sister not to shout but she was yelling at the top of her voice. My mother-in-law's home was upstairs and she came to our home because of the noise. Anyway, my sister left home and I did not see her about seven months. However, my mother and my sister were seeing each other and I think they

affected each other's thoughts about my mother-in-law. My mother-in-law loves me and cares about me and I love the way she treats me. My mother feels envy towards her because she cannot show her warmth to me in the same way. I can say that my disease must have started at that time. After all, I have begun to suffer from severe pain. I remember that a couple days after that day the surface of my tongue split and bled.

Other three participants did also give examples for arguments they had with their family members and eventually, their pain increased. All of them highlighted that they saw themselves as innocent and right; therefore, they did not deserve their reactions. Moreover, three of them seemed to be angry when they talked about this issue. Those who became angry about those issues talked with the researcher as if she was one of their family members with whom they argued.

C said that her pain increased after her sister's death:

... But at that time I did not have any kind of pain. Now, my pain has increased. I suppose after my sister's death it increased much more.

Although there were not any other examples related to loss of a family member, this example shed light on how a family member's death could affect pain experience.

There was another example which was given only by one participant:

While I took my mom to the hospital I was always tired. I was going home exhausted and without enough rest I was coming back to the hospital. In the hospital, I was standing for hours and when I came to home I was feeling just like a collapsed balloon. I did not want to do anything at home. I had to care my mother in the hospital because it was my duty and there was nobody to do so.

B talked about the time when she was a caregiver to her mother. Although she became exhausted after that care, she thought that it was her duty as a child. That example brought up the issue of how caregiving affects pain experience of fibromyalgia patients.

In this subordinate theme, there was only one shared topic that was how participant's pain exacerbated by arguments with their family members. Only one of the

participants mentioned how her pain increased after she lost her sister and another participant expressed that due to her caregiver role to her mother, her symptoms of fibromyalgia got worse.

3. 2. 2. 2. The Family of the Spouse as a Trigger

In the current study, the analyzed interviews revealed the important role of the spouse's family in the fibromyalgia patient's life and pain experience. The following extract gave an example how spouse's family sees F:

Those people are ignorant and hidebound. They treat me as if I am their servant, not their son's wife. Actually, they tried to have me to do everything they want to. They expected that I would do anything that they ordered to me. However, if I tell them they treated me in that way, they would never admit it. For example, in my family, if my father wants to drink water he gets his water himself; I mean he does not ask for water from someone else. But in this family, my father-in-law asks for water from my mother-in-law even if the water-bottle is in front of him.

F described her spouse's family as old-fashioned. For example, even if there was water on the table, her father-in-law asks her to give him a glass of water. This example demonstrated that spouse's family expected services from herself. Also, this example showed that they gave the role of the service provider that showed the pattern of their relationship. The service provider role was shared by other three of the participants, too. All of them were reluctant about that role but they behaved according to that role. Also, all of them said that their fibromyalgia symptoms get worse when they do too much work of their spouse's family.

Most of the participants mentioned their spouse's family as a stress factor. Also, they did not want to spend time with them; however, due to their husband, they spent time with them. For example, F explained that she had a problem with her spouse's father:

... This pregnancy...after I gave birth, I experienced many big problems. My father-in-law turned me out of the house. But in that case, I was definitely sure that I was right. My husband also supported me. My husband and I left the house, my father-in-law's house. When we had a problem with my father-in-law I always tried responding him in a calm way and I always affirmed his

claims. However, when I responded him and did not behave as the same way that I used to, he turned me out of the house, because they did not get used to this way. Now, we have a good relationship again, we solved our problems and they hold me in high regard. However, these wear down me. I have fibromyalgia now. All my pains begin after my marriage because of stress and despair.

As F said that before she got married, she didn't have any pain; on the other hand, after she got married she was diagnosed with fibromyalgia and she suffered from pain. Although there was a good relationship between the spouse's family now, she lost her health due to stress she experienced in her marriage. She lost her health that was replaced with fibromyalgia and pain.

Three of the participants said that they behaved according to rules of their spouse's family. C talked about this:

... We do not live our lives by ourselves. We are pushed to live the life in a way that someone else wanted from us; in a way that your spouse's family expects from us. I do not feel free. This family is a traditional family. I had self-confidence, I was freer and I was doing whatever I wanted to do. After marriage, I have felt pressure on me. Actually, they do not put pressure on me. But somehow I felt like I had to behave in a certain way so that they would like our relationship. I had to treat them nicely even though I did not want to do it. All of this wore me down.

C and other two participants highlighted that their spouse's family were traditional families who restricted themselves and they started to live in accordance with their wishes. Because they depend on them, they feel pressure on themselves, which is one of the sources of their stress. As a result of their stress, their symptoms of fibromyalgia got exacerbated.

3. 2. 2. 3. The Spouse of the Patient as a Trigger

In that subordinate theme, the focus point is "husbands" of fibromyalgia patients. All of the participants, except E, had arranged marriages. On the other hand, all the participants said that their expectation from the marriage was not meet. For example, C said:

I thought that I would always be happy and I would have a peaceful marriage. I got married an educated person who had a career and a good position. On the other hand, in Turkey men and marriages are not similar to what I expected. My husband is not sensitive enough towards me. He has an angry manner; I have the same manner, too. As usual, women are affected negatively much more than men do. He is healthy and has no problem. What happened to me?

Although C married her husband, due to her husband's qualifications he could not meet her needs in the marriage. Also, during the interview, she accused her husband as the reason of her fibromyalgia. Although other participants did not mention their husband as the cause of their fibromyalgia, all of them felt disappointed about their marriage. Two of them said that they did not recommend marriage to young people because marriage is not similar with people's fantasies about marriage.

All of the participants thought about divorce in the past or were thinking about it at the time of interview but they showed their children as the reason for not getting divorced. For example, C said:

... When you face a problem, sometimes you cannot see the solution and think about the divorce. But then you think about your children. When you divorce, what will children do? With these questions, you try to be patient. Every time there can be a solution but the fact is you wear down.

Although they could not divorce, they were aware that they were negatively affected by the marriage.

A said these about non-divorce:

No, why would he want it? He has me and he gets anything he wants. He lives in a luxury, cleaning of the house is done, meals are done, his laundry is done etc. He uses the house just like a hotel. Is there any reason for him to leave such a life? I thought that I experience so many negative things. But when it is about children and when you feel those emotions related to them, then you give up your thoughts.

A mentioned that since she does all the housework, her husband does not want to get divorced. Similar to A, other participants also expressed that they do all the housework. However, four of them said that their husbands do not help them. Although two of the participants had a job and one of them got retired approximately 10 years ago, they also said that their husbands expected housework from them. On

the other hand, all of the participants said that when they do housework, their pain get worse.

Three of the participants mentioned that their husbands are under the influence of their family. For example, D said that:

My spouse was under the effect of his family. Now, we are happy because no one from his family is with us. However, I could not tolerate some of my experiences. It was not a marriage that I expected.

Not only C, but also two other participants added that they could not tolerate their husband's position between them and their family. Although they expected that their husband supported them in front of their family, they did not; instead, they stand by their family. One of the participants said that she still argues with her husband because of the past events where her husband did not support her.

Although some of the participants said that their husband had an indirect effect on their pain but another said that they had a direct effect. For example, E said:

My relationship with my husband is good now and my pain is less severe. It makes me feel better to know he loves me. It is good to feel his care. When I feel sad or when I become upset about something related to him I definitely feel the pain in that process. But as I said before, if I am happy and if I feel his care I have less pain or no pain at all.

Like E, most of the participants described their husband as the most influential person in their life. Therefore, they could affect their pain and other symptoms of fibromyalgia both negatively and positively.

All of the participants said that their expectations from their husband and marriage were not met and they were disappointed about their marriage. All of them had thoughts of getting divorced in the past; some of them still think about divorce. All of the participants had the role of a service provider at home, 4 of them said that their husband usually do not help them. Also, three of the participants said that their husbands do not support them in front of their family. Some of the participants mentioned that their husbands have an indirect role in the increase of their pain but

others said that they have a direct role. Actually, these findings indicate how patients' husbands impact on the patients' pain. For most of the participants, spouses had a negative effect on them, which resulted in an increase in pain and other symptoms.

3. 2. 2. 4. Children of the Patient as a Trigger

In that subordinate theme, examples related to the role of participant's children in the symptoms of fibromyalgia were given. For example, A questioned her role in her family:

I am upset. I don't know my status at that house. As I said my daughter always expects something from me. She does not say "mom, I love you" even once without expecting anything. I feel sad. I am upset because I continuously ask myself whether they will still love me if I do not give something to them or if I do not help them. Sometimes I expect appreciation from them just because of the fact that I am in their lives. But I do not know. Life is difficult, very difficult.

She said that her daughter always wants something from her. Her daughter says "I love you" only when she does something for her. She said that her family members express their love to her only when she does something for them. After she talked about this, she said that life is hard.

B talked about her daughter's situation:

I get stuck. I do not like that guy. I do not like his family too. I told my daughter, this is not going to work well. The only thing that matters is my daughter. However, my daughter does not seem to be sure. I don't know what is going to happen. Nowadays, I have lots of pain in my arms and shoulders. It occurs again; all of these that I experienced triggered the pain.

She described a situation that she wanted her daughter to get divorced, but her daughter was not sure about it. She said that due to the uncertainty about her daughter's divorce she became upset. She had pain on her shoulder and arms triggered by her daughter situation.

D indicated that she was tired in the last 5 years:

Think that he and everybody around me also know that I was exhausted in last 5 years. My son and daughter got married. Their spouses' families came and stay in my house for 20 days. I cooked all the food and did all the work by myself.

She said that her son and daughter got married and she did a lot of stuff during that period. As a result, she got tired a lot. D also talked about her daughter's unhappy marriage:

Whenever my daughter was sad or despair, I felt myself really bad. When I feel like this, the pain becomes more severe.

She said that when her daughter was unhappy and sad, she also felt worse emotionally, which in turn, increased her pain.

E mentioned how she becomes tired:

Every weekend my daughters and my husband want to go out. Even if I have pain, I go out with them. Actually, I make a sacrifice in order not to upset them. However, I became really exhausted.

Her daughters and husband want to go outside every weekend. She goes with them even if she has pain, because she does not want to hurt or upset them; on the other hand, she becomes so tired.

In this subordinate theme, most of the participants stated that since their children want to engage in leisure activities as a family and since they do not want to upset them, they participate in those activities. As a result, they become physically tired. One of the participants said that her daughter's uncertainty about getting divorced had a triggering effect on her pain. Another participant stated that two of her children got married and she felt exhausted then. Also, she indicated that when her daughter was unhappy due to problems in her marriage, her pain increased. It can be suggested that their children's important life events like their marriages or their contemplation about getting divorced negatively influence their pain. Also, it can be stated that problems of their children had a negative effect on their pain.

3. 2. 3. Third Superordinate Theme: Fibromyalgia: A Psychological Phenomenon

This superordinate theme aimed to portray the association between psychological issues and fibromyalgia. Accordingly, personality traits, emotions, and others' view of illness were covered in that superordinate theme.

3. 2. 3. 1. Personality Traits and Fibromyalgia

In this subordinate themes, participants' personality traits that were seen as causes of developing fibromyalgia were covered. For example, four of the participants said that they were altruistic people. For example, C stated that:

I am an altruistic person since I know myself. I think what happened to me is the results of this characteristic. I am responsible for almost everybody' needs around me like my mother, my father, my brother etc. I try to solve all their problems as if they are mine. I have never thought to stay behind to not to solve their problems or I have never expected a solution from someone else. Yet, if I could not feel well or could be sick then I could expect someone else's help.

C mentioned that she had been altruistic all the time. According to her, being altruistic refers to doing something for others. She also said that her altruistic characteristic was one of the reasons why she had fibromyalgia. On the other hand, she said that she could expect altruistic behaviors from others, only if she becomes ill.

Like C, three other participants also described themselves as altruistic. Being altruistic basically meant to them to be in the role of thinking about others and not herself, and doing something for others. On the other hand, these three participants were concerned that they were altruistic a lot for others, and others were not treating them in the same way. Also, they stated that while they are altruistic individuals, they are negatively affected by this personality characteristic. More precisely, the fact that other people led them to think about their altruistic behaviors and make negative attributions about this characteristic.

Three of the participants described themselves as sensitive, fragile, caring, and minding. For example, D mentioned about her characteristics that provided the basis for fibromyalgia:

Think that your husband treats you badly and makes you unhappy. I feel it. I am a sensitive person. If I were a person who is reckless and ignorant, maybe it would not be like that. But I am very sensitive and fragile. So, this illness has come up. Pain showed up without any reason. Pain began in different parts of my body. I tried to find out the reasons of my pain and here it is the answer: fibromyalgia.

She referred to the negative effects of the relationship with his husband on her. But she put the focus on her caring and minding characteristic. She said that because she had these characteristics, she had problems with her husband; as a result, she had an unknown pain. Through the discourses with D, it was understood that she attributes her fibromyalgia to her caring and minding character.

Just like D, two other participants portrayed themselves as sensitive, fragile, caring, and minding. They all indicated these characteristics as the cause of their fibromyalgia.

B said that she judged herself in the past:

What relieves my pain is Cymbalta. I told that “I judge myself” to my doctor and he prescribed me Cymbalta. I have begun to judge myself about my mother’s illness. Why am I doing this? Why am I doing like this... What I have done to deserve all of these? When I ask these questions the doctor prescribed Cymbalta. After taking this medication, I felt relieved.

B told the doctor she judged herself because of fibromyalgia, so the doctor prescribed a kind of antidepressant. She said that she started to judge herself less after using the medicine, so she felt relieved.

Although B said that she judged herself because she had fibromyalgia, other participants judged themselves due to their personality characteristics. For example, A said that:

I do not want to see my unhappy marriage or this or that as a reason of my disease. Of course, they might partly affect my disease. However, it is more about my personality/my character. If I were more relaxed, maybe I would experience more positive things in my life.

It was obvious that she thought that she had fibromyalgia due to herself but not due to the problems in her marriage.

Just as B, the majority of participants talked about various factors that had a role in the occurrence and severity of fibromyalgia. On the other hand, at one point of the interviews, they mentioned that they had that syndrome due to their personalities. In this regard, A's statements were as follows:

Why do I have this disease? I think it is because of my personality. I am very sensitive, fragile, and touchy. When I did research about fibromyalgia, I found that this disease is more common in people who have some similar characteristics. It is more frequent among women who are perfectionist. I was aggressive and under stress, and I was not happy in my marriage. Actually, it was not a peaceful marriage.

According to A, people, who have similar personality traits with her develop fibromyalgia. She said that she did research on it and reached that conclusion.

In this subordinate theme, it was seen that participants described themselves as altruistic, sensitive, fragile, caring, and minding. Also, it was mentioned that they judged themselves due to these characteristics of themselves. Moreover, they said that these characteristics are the reason of developing fibromyalgia.

3. 2. 3. 2. Emotions and Fibromyalgia

The emotions shown by the participants during the interview were presented in this section as observations. Additionally, participants provided some information about what kind of emotions they experience in their daily life. The first predominantly experienced emotion was anger that was shared by five participants. For example, B said that:

I was so angry and so aggressive, because I was feeling myself like a stress ball and everyone in the family and around me were treating me in that way. Whenever someone feels bad, s/he tries to calm her/himself down by treating me in a bad manner. I think I was too naive and people get advantage of it.

Other participants mentioned that they showed their anger toward people. On the other hand, it was observed that some of them feel guilty when they talked about their anger. For example:

I feel guilty. Maybe I was not good enough to fulfill my husband's needs. On the other hand, I am angry with him, because he was not with me during the process. I could not fulfill each and every responsibility of the house. Why was he not with me? How I could handle all of the problems by myself. What if she needs to make her toilet? My husband did not find a solution but complained. He did not take any responsibility and I am angry at him because of his behaviors.

A said that she did not spend enough time with her daughter when her son was born; so she felt guilty. After she briefly mentioned it, she started to talk about her anger towards her husband. As it was seen in this example, the participant experienced both anger and guilt.

In addition to cases where the anger was directed towards the others, there were also cases where the participants directed their anger to themselves. This was observed during the interviews, but only A directly talked about it:

Of course. I need help for that moment... Then I became angry with myself, too. I wish I would not be with my daughter all the time. I wish I had told them to go to the park without me so that I could have stayed at home alone to clean the house. I possessed my daughter so much that I did not let her father spend time with his daughter.

She said that she was angry with herself because she did not take care of herself as she wanted. Immediately after that, she used expressions of regret. For A, being angry to herself, regret, guilt, and anger were all in the same process and complementing each other. But it could be an extreme interpretation to say this for other participants.

Another emotion that was experienced by most of the participants was sadness. For example, E said that:

Actually I feel it more when I am upset. It is more triggered when I feel sad. Severity of the pain doubles itself and its threshold become lower when I am sad.

When participants had intense emotions, they used different methods to cope with them. It was understood that two of the participants yell at people when they are angry. One participant said that she expresses her anger through her movements. Two other participants stated that they cry when they are sad.

Moreover, two participants said that they use antidepressants under the psychiatrists' supervision and so they feel calmer. For example, E said that:

Actually the problems are still there. I am using medications and these medications make me feel calmer. Although the problems exist, I become unresponsive. I experienced some problems with my family. After that I felt myself bad. I cried so much. I became an angry person. At home, I easily get angry. I immediately react to everything with anger. Of course there are still problems, there are still things that make me sad or break my heart but thanks to medications I have borne it until this time.

E stated that she felt bad about a situation she experienced. She also said that she has cried from time to time and she was sad and aggressive at that time. She told that although that situation is not resolved, she found relieve in medicine.

Most of the participants did also mention the pain they experienced in some parts of their body when they talked about their emotions. E spoke about her pain and emotions:

So I felt nervous, sad, bored, and as a result, pain appears. For example, I had headache just because I was angry or aggressive. It had it, since I felt angry.

What E said was like a summary of the feelings mentioned above. As E said, most of the other participants stated that when they experienced negative emotions, they either began to experience pain or the severity of their pain got increased.

In conclusion, the participants talked about and expressed their anger during the interviews. When expressing their anger, some participants referred to situations where they felt guilty, and some participants mentioned situations where their anger was directed to themselves. Two participants said that they yell at people in the case of anger and one participant said that she expresses her anger with her movements. Participants did also talk about sadness. Two participants stated that they cry when they become sad. Participants said that all these abovementioned emotions are followed by emergence of or increment in pain.

3. 2. 3. 3. Others' View of Illness and Fibromyalgia

This subordinate theme included other people's attributions about fibromyalgia. For example, it was interesting what C said:

C: When looking from outside, it seems that I am okay. That is why nobody believes that I have a disease. I do not have a visible disease but I cannot make people understand that I am unwilling to do anything because of the disease.
Interviewer: Does nobody believes it?

C: No. They do not believe it. I tell the people, who do not believe me, that I searched on the Internet, that they may watch the videos by spending half an hour in order to understand the nature of the disease. But they keep on not believing me. When I tell them about the disease it seems like I am lying because it is chronic pain. They think that there cannot be any pain that lasts for years. According to them, for example, your kidney may ache because you have kidney calculi; or your stomach may ache but it will be okay soon. But in this disease, everyday one of your body parts ache. Every day you are unhappy. I think it is perceived as I am pretending or I feigning reluctance.

Interviewer: Who does perceive it like this?

C: For example, my husband. He never believes me. He said that "every day, every single day one part of your body aches. There is not any single day that you have not any kind of pain. It is like a chorus in your mouth.

C said that people do not believe her because she does not seem to be ill. She even suggested doing research about fibromyalgia to people who do not believe her. She also said that her husband does not believe her. At one point of the interview, she said that it could be enough for her if he only believed her about her illness. She also wanted to be supported by her husband.

Regarding this issue, E said that:

So, I mean that I want everyone, who has a fibromyalgia patient around him/herself, be sensitive towards them and their disease. They should be aware of the disease. That is what I can tell to those people. Because what they are saying or how they behave may affect the patient negatively. They may think that those patients exaggerate their pain or are hypochondriacs. Sometimes, we, as fibromyalgia patients, do not feel any pain in the morning but it may get worse at night or vice versa. People around us do not want to experience this scene but they should keep in mind that it is actually us, who do not want to suffer from this pain. Pain makes me exhausted. Pain might decrease my energy suddenly while I feel very energetic. But it is real and it is happening. This is all I what to say.

E stated that other people see her as a hypochondriac person and they said that she exaggerates her condition. In fact, just like C, she said that others do not believe her illness. She also stated that she is negatively affected by these. E said that her husband complained about her pain in the past:

There was no husband who supported me. He did not even listen to me. For example, when I was going to say something, he said that he is busy. I remember a time when once we went to hospital and he told to me that he got bored with my illness and pain. After that incidence, I could not tell him anything when I was in pain.

Although E's spouse complained about her illness, B's husband complained indirectly by saying that she is always in the hospital:

Interviewer: While you are experiencing these; while you suffer from pain; how is your relationship is affected by all of these?

B: My husband told me that "every day you are in hospital"

Interviewer: How did he tell that?

B: He said that "Now you are a professor!"

In addition to the participants who gave information about others' view of the disease, F said that her husband does not support her and she is alone in deal with fibromyalgia:

He didn't help me while I was trying to cope with it. I used medications... We did not do anything to solve problems together. I went to a doctor. I became ill. I started to use medications that helped me to calm down.

In that subordinate theme, two participants said that others do not believe their illness. One of them said that her husband made a complaint about her illness and another participant's husband complained about her frequent visits to hospitals. Also, four participants stated that they were alone in coping with fibromyalgia.

3. 2. 4. Fourth Superordinate Theme: Fibromyalgia as a Triggering Factor of Change

This superordinate theme aims to present the extent to which the participants experienced a process of change after the diagnosis of fibromyalgia. It seems that they experienced change in self, relations with others, and daily activities.

3. 2. 4. 1. Positive Change in Self

In this subordinate theme, participants expressed that they were no longer satisfied with some of their characteristics after they developed fibromyalgia. For example, F said that she does not want to feel sorry anymore:

Why do I feel bad about this? But I did. I have only one life to live. I am not here to upset myself for the others. I do not care. I do not want to feel sad anymore. I do not want to make myself upset or wear out.

F said that she was obsessed with something in the past but she implied that she was not like that anymore. Also, she said that she does not want to be upset. Immediately after that, she said that she does not want to upset herself. It was understood that she was upset and worn out; on the other hand, she underlined that she does not do these anymore.

C indicated this:

I think one begins to know oneself when having an illness. When you know about yourself and your disease, you know what would be better for yourself. And you try to behave or live accordingly.

C said that fibromyalgia was a way to understand herself. After she knew both herself and her illness better, she behaved accordingly not to aggravate her symptoms. C also mentioned that:

Self-esteem, caring for yourself, spending some time by yourself etc. These are good things for my disease. In the past, I was caring for my children, my husband, and my home much more than I was caring for myself. I used to wear out myself. I used to make myself exhausted.

In other parts of the interview, she said that she used to spend too much effort for others in the past, and as a result, she wore out her body. Just like F, C also used the following expressions:

Well, now I learned not to be obsessed with anything. Life is too short to be obsessed with things. It was not worth to become upset for anyone.

B said that:

In order not to make others upset, I kept upsetting. All the sadness that I experienced has turned into a disease. I used to internalize all the problems and sorrows. I made myself invaluable in others' eyes. I did not set my own rules; I did not set boundaries in my relationships. But now, I do it. I feel relieved. I have boundaries and it means other people cannot make me upset if I do not let them. I did not know it before.

B ignored herself in the sake of others, but eventually, this made her sick. Just like the other participants, B underlined that she will not allow anyone to upset her anymore.

Also, E said that:

When I was 35, I was so sick that I could not get up from the bed. Even my psychiatrist had told me that I had too many responsibilities. At that time, I decided to let them go. I mean, I have cared for them all the time, now it is their turn to take care of me. I decided that I should not be that much altruistic. I think being altruistic is a part of the human nature but now I am trying to lessen it. I mean I stay back from people, and from everything.

It was obvious that E mentioned that she was an altruistic person in the past. But at the time of the interview she was trying to be less altruistic.

The common point of the participants was they pay too much attention to others but they forgot and ignored themselves. After they developed fibromyalgia, they became aware that this harmed to them and then they entered in a process of change. Also, they highlighted that they didn't want to be like that anymore.

3. 2. 4. 2. Change in Relationships with Others

This subordinate theme represents changes in relationships with others. For example, it seemed that C experienced a change in two different areas. First, she said that now she can ask for help from her children and husband for housework:

In the past, when there was work to be done, I was the first one who runs and does it. I was doing all the works. Now, I know that when I am exhausted, my disease gets worse. But I was not aware of that before. I was working and working...I was getting exhausted and this used to make me angry. I was unaware of the negative effects of my anger on my symptoms. But I did not know that this could harm me. Now, because I am more aware of it, I try not to make myself exhausted, and I do not do that much work. I ask others to do works.

C used to do all the housework by herself, but she realized that doing so increases her pain severity. This means that she is not spending so much time and effort to do housework anymore and that she can ask for and gets help from others. C also said that she used to have some expectations from her husband but not anymore:

Expectations make people unhappy. When I was young I used to have expectations and I often felt unhappy. For example, I expected my husband to buy me flowers for my birthday. I expected him to buy a present or flowers to me. And when he did not, I became upset. Now, I do not expect anything. I do all the things by myself. I could have done them before, too. However, I expected from others to do them even before I told them. But now, I have learned not to expect anything from others and I am happier...

She stated that although she had those expectations, they were not met by her husband; therefore, she became unhappy. So, she indicated that she does not have any expectations from her husband anymore.

For A, after the pain, the problems in her life became unimportant. Also, she started to talk to her friends to solve her problems at work:

I had some problems about my work place. I still have them Yes, there were problems and they are still there. However, I do not care about those problems due to my pain. Or since I have pain I try to solve problems at work more than before by talking to my colleagues. I begin not to be interested in problems anymore.

Problems occurred at work when A's pain started for the first the time. Along with the entrance of the pain into her life, other problems in her life became insignificant and she sought solutions for them. She even tried to solve problems at work by talking to her friends. So, A started to get help from others just like C.

F said that she was thinking too much about her husband and his family but she quitted that habit:

Yes, it happens now, too. I do not care about as much as I did in the past. I cared too much before. Now, I do not. I do not have any expectations, as well. I do not care about anything. If I care, I am getting angry and I argue with my husband. We are always arguing/ fighting. As I said, for now, I do not care, and I may get divorced. His father or mother, I do not care about them.

She said that she does not have any expectation from her husband she does not care about him and his family anymore. As a result, she stated that she and her husband did not argue as much as before. It was seen that both F and C had expectations from their husband in the past, but now they do not.

B mentioned that she set a boundary between her family and herself and she is not communicating with them like she did in the past:

Now, I had enough with the problems especially during and after my mother's operation. I really had hard time; I was nervous... I was already losing my patience. Others' manner, attitudes, and behavior towards me... I began to destruct the walls that were put against me. I am telling others why I am exposed to these. I am not nice to others anymore. But they are nice to me now. They are aware of that I am broken, something is broken between us, I am not the same person, I am not the same B as I was before and I have the walls

against them. I would call them, but I did not. I am still like that. Yet, I am pleased with this period. So pleased.

B suffered from pain for 6-7 years, but 13 months ago she received the diagnosis of fibromyalgia. That coincided with her mother's operation and her caregiving period. F stated that she was downtrodden by her family both in past and when her mother was in hospital. She said, although she was altruistic to her family members, they were not. On the other hand, she said that she did not deserve this. As a result, after her mother's surgery, she stood back from her family and communicated less than she did in the past.

Four of the participants stated that after they were diagnosed with FMS, they entered a process of change in terms of relationship with other people. Two of the participants said that they could ask for help now. Also, two of them said that they do not have any expectations from their husband. Moreover, one of the participants individuated from her family.

3. 2. 4. 3. Change in Daily Activities

This subordinate theme contained changes in daily activities that were happened after participants received the diagnosis of fibromyalgia. For example, A said that she added physical exercise to her daily life, as it was recommended by her doctor:

Because my doctor told me that my muscles are weak and I should do sports to strengthen my muscles, now I have physical activities to do every day. I hope I will be healthier.

B said that she wanted to take part of some activities:

I want to join some activities. I want to swim. I want to do sports. Two years ago, I heard about a painting workshop in Dikmen. I decided to go there, but I could not start. However, I do want to do something, I do want to make some effort. Staying at home became a habit for me... If I do not want to go, I do not go and I stay at home.

She said that she often spend her time at home; however, she wants to attend new activities that requires her to go outside.

C said that she tried to spend some time for herself:

I try to have time to rest more. When I get rested, I feel better. Now I spend time with myself, I have brakes. I am trying to treat myself well. I have hobbies; I spend some time for my hobbies. I do needle work at home; I made ceramics for a while. My hobbies make me feel good. My friends make me feel better. I want to do anything which is good for me. I want to spend time with people who make me feel better. I want to stay away from negative people. I try to walk.

C expressed that she devoted time to herself to rest, engage in her hobbies, and spend time with her friends. She also expressed that she kept the things that were good for her in her life but removed things from her life that were not good for her. It seemed that after she developed fibromyalgia, her main focus became her well-being.

E explained what she has been doing for a while in order to not experience the same pain again in the future:

I have not done so many things so far, but from this point on I will start doing. As I said before, I came here to this center, I have already used my medications, I have physical treatment. I will begin to walk. Until now, I did not do any of them, because I was exhausted and I did not feel myself strong enough to go to have a walk. But now, even when I feel exhausted, I take the walk regularly. I have some neighbors and we accompany each other while walking. I decided to stay away from people who make me upset. I struggle for a higher life quality. I am searching for a solution which terminates my disease and pains completely. I wish I never had this disease. I do not want experience it again. Because it is difficult.

E also stated that she followed the treatment and she started to walk. Like C, E said that she tries to keep distance from people who caused her to feel bad.

In this subordinate theme, it was realized that the participants put themselves in the center of their life and they did things that were good for their health. It was seen that they do various activities that they did not in their past including physical exercises. In addition, two participants said that they do not spend time with people who make them not to feel good, but they see people who make them feel good.

CHAPTER 4

DISCUSSION

The present study aimed to gain an in-depth understanding of how women experience fibromyalgia syndrome (FMS) in the family context. There were two main research questions in the study. The first one was related how married female fibromyalgia patients with child(ren) experience pain, and the other one was about the association between pain experience of these patients and their family relationships. To answer these research questions, semi-structured interviews were conducted with six married women with children that were officially diagnosed with fibromyalgia. The transcriptions of the interviews were analyzed using interpretative phenomenological analysis (IPA). The analyses revealed four superordinate themes titled as: (1) The Features of fibromyalgia, (2) Fibromyalgia: A syndrome triggered by familial dynamics, (3) Fibromyalgia: A psychological phenomenon, and (4) Fibromyalgia as a triggering factor of change.

In this chapter, findings of the study will be discussed in the light of models introduced in the first chapter and the existing literature related to the findings. Also, the strengths and limitations of the current study, clinical implications of the current findings, and suggestions for future studies will be presented in this chapter.

4. 1. The Features of Fibromyalgia

One of the main questions of the study was “how do married female fibromyalgia patients with child(ren) experience pain?” It seemed that the first superordinate theme of this study is as an answer to that question.

All the participants of this study mentioned their pain as “endless”. This was similar to existing fibromyalgia literature, where it is characterized by chronic and widespread pain (Jahan, 2011; Plazier, Ost, Stassijns, Ridder, & Vanneste, 2015; Wolfe, 1995). Also, participants of this study indicated that their pain is subjected to change depending on different situations. They reported that when they do something leading to physical fatigue, their pain severity increases. On the other, when they rest, their pain severity decreases. According to a report from the U.S. Food and Drug Administration, fibromyalgia patients experience intense pain when they do physical activities like cleaning their home (2014). Although physical activity is particularly recommended for those patients, most of the patients fail to adapt physical activities to their lives due to the aggravation of their symptoms (Bush et al., 2011).

Some of the participants indicated that their pain increases when it is cold and windy. According to the literature, there are controversial findings about the effect of weather conditions on the symptoms of fibromyalgia (Blecourt, Knipping, Voogd, & Rijswijk, 1993). There is limited evidence about the effect of weather on this syndrome (Smedslund et al., 2014), but many studies asserted that weather conditions do not influence fibromyalgia symptoms (e.g., Blecourt, 1993; Bossema, Middendorp, Jacop, Bijlsma, & Geennenn, 2013).

According to the American College of Rheumatology (ARC), for the diagnosis of fibromyalgia there should be pain in at least 11 of 18 tender points (Wolfe, 1990). The participants of this study mentioned some of these tender points. Also, one of the participants described her pain as “traveling pain” that pain called as “transient” pain in a study (Wolfe et al., 1995). Moreover, one of the participants highlighted that her entire body suffers from pain. On the other hand, most of fibromyalgia patients do not have pain in their whole body or they do not have pain in at least 11 tender points (Clauw, 2014). In the current study, most of the participants’ description of fibromyalgia met the new diagnostic criteria of fibromyalgia.

There is a study that was conducted with women living in Turkey whose age ranged between 20 and 54. That study found that after pain, the most common symptoms of fibromyalgia are weakness, fatigue, paresthesia in hands or feet, headache, morning stiffness, non-restorative sleep, a change in natural color of hands and/or feet in the cold, and chest pain (Topbaş, Güleç, & Can, 2004). Another study carried out with a fibromyalgia patients reported that subjective swelling, paresthesia, stiffness, sleep disturbance, fatigue, and irritable bowel syndrome are found in fibromyalgia patients when the pain ceases (Wolfe et al., 1995). Another study highlighted pain, fatigue, and mood disorders as the most commonly seen symptoms of fibromyalgia (Plazier et al., 1995). Similar to these findings, in addition to pain, participants of this study mentioned reluctance, sleep problems, and fatigue.

In the literature, it was reported that it may take years to be diagnosed with fibromyalgia (Besson, 2003; Cymet, 2003). Similarly, some participants of the current study indicated that they received the diagnosis of fibromyalgia many years after they began to seek medical advice in several branches of medicine. Although some of the participants were diagnosed with it immediately, they did not comply with the treatment plan, which mostly consisted of only medications. It was indicated that medications are the most commonly used treatment method for fibromyalgia but some patients cannot benefit from them much; therefore, they may be unwilling to comply with the treatment (Briones-Vozmediano, Vives-Cases, Ronda-Perez, & Gil-Gonzalez, 2013). Actually, the treatment literature of fibromyalgia recommends multidisciplinary care that contains medications, physical exercise, psychotherapy, and other alternative therapies, such as acupuncture and yoga (Angst, Verra, Lehmann, Brioschi, Aeschlimann, 2009; Goldenberg, 2009).

This theme was a descriptive theme that explained how participants described their pain, how their pain increased and decreased according to different situations, how other symptoms differed from pain, and how their treatment process was. As a result, it was understood that participants had an endless pain that could increase due to physical fatigue and weather. In addition to pain, they had reluctance, sleep problems, and exhaustion. Also, although participants' symptoms could not fit the old version of the diagnostic criteria for fibromyalgia, they fit to the new version.

Moreover, it was understood that receiving the diagnosis of fibromyalgia could take time and a holistic treatment is the best treatment for fibromyalgia.

4. 2. Fibromyalgia: A Syndrome Triggered by Familial Relationships

One of the starting points of this study was the present researcher's question in her mind that how women experience fibromyalgia in the family context; in other words, how familial dynamics impact on the fibromyalgia related experiences of the participants.

During the interviews all of the participants automatically mentioned their husbands before the researcher asked questions about them. Actually, they mostly talked about their spouses. It is understood from the interviews that the most influential person in the lives of participants are their husbands. In the literature, it was claimed that spouses are critical figures in terms of emotional and social support, and they have considerable impact on patients' health behaviors and treatments (Butterfield & Lewis, 2002). It was also indicated that coping and chronic pain adjustment skills of the patients are mostly influenced by their spouses (Flor, Turk, & Rudy, 1987). This means that husbands of patients can affect patients' health condition in positive or negative ways. In other words, spouses directly or indirectly can increase or decrease the severity of symptoms of fibromyalgia patients. As Cognitive-Behavioral Transactional Model indicated, coping strategies and reactions of spouses are so important; that is, they can aggravate or reduce the level of stress, resulting in positive or negative effects on pain experiences of their wives. (Leonard et al., 2006).

One of the most important findings of the current study is that all the participants expressed that their expectations from marriage are not met. That is, they were disappointed. This brings one of the claims of family systems model to the mind. According to the family systems model, if there is a family member with chronic pain, this may be an indication of presence of uncovered conflicts and/or emotional problems among family members (Lewandowski et al., 2007). Unsatisfied expectations from marriage reported by the participants pointed that there might be at

least some conflicts in these marriages. Furthermore, all of the participants stated that they have thought about getting divorced at least once, and some of them were still considering divorce at the time of the interview. These statements can be evaluated as the signs of the problems in the marriages of the participants.

In the literature, it was stated that divorce and widowhood are risk factors for women to be diagnosed with chronic pain (Vieira et al., 2012). Also, the prevalence of chronic pain has increased among divorced/widowed women. This is associated with social/emotional support, which is assumed to be less for these women; which in turn, thought to trigger the development of chronic pain (Vieira et al., 2012). In the current study, although the participants were still married, they could not receive sufficient support from their husbands; and they were thinking about divorce. Although divorce is a risk factor for developing chronic pain, it seems that, at least for one participant, “C”, marriage has been the reason of fibromyalgia:

“I thought that I would always be happy and I would have a peaceful marriage... As usual, women are affected negatively much more than men. He is healthy and does not have any problem. What happens to me?”

All participants stated that their pain increases when they do housework. Also, most of them indicated that they have always been doing housework alone without any help from their husbands. As Operant Mechanisms Model claimed that patients report more and more pain or they exhibit more pain behaviors to escape from their responsibilities (Lewandowski et al., 2007), which is called secondary gains (Pawl, 2013). However, the current participants indicated that even their pain level is aggravated with housework, they continue to do them because nobody do these works for them. This situation is parallel to another assumption of Operant Mechanisms Model. Accordingly, when spouses or other people do not support the patients, and do not offer help and do the things them, patients’ pain behaviors tend to extinguish, or at least decrease (Nicassio & Radojevic, 1993). That is, even the participants exhibit pain behaviors, they cannot get support from others; thus, these behaviors seemed not to be reinforced by their husbands. Moreover, this model

suggested that when the patients cannot get help from their spouses, there may be a decrease in pain behaviors (Lewandowski et al., 2007). Considering the findings of the current study, there is no evidence for this suggestion of Operant Mechanisms Model.

According to the literature, there is an association between having a supportive spouse and experience of pain. In the perceived presence of the spousal support, patients tend to rate their pain as more intense compared to the patients who have non-supportive spouses (Kremer et al., 1985). For this study, it is not possible to attain any conclusion about that kind of association, because the participants of this study indicated that they do not receive support from their husbands. On the other hand, it was obvious that the marital satisfaction of the participants was low due to their unsupportive spouses. Although there is no direct link between severity of the pain and unsupportive husbands in this study, there may be indirect effects of their spouses on their pain severity.

One of the inclusion criteria of participants was having at least one child. Although all of the participants talked about their spouses before the interviewer asked a question about them, most of them talked about their children when the interviewer posed questions. Three of the participants indicated that they mostly spend time with their children when they want to do something as a family. They state that effort of spending time with their children makes them tired, but they did not want to disappoint their children with not attending those activities. In a study, it was reported that nearly half of the participants do not attend social or familial activities due to chronic pain (Moulin, Clark, Speechley, & Morley-Forster, 2002). In another study, it was found that people with chronic pain are less in touch with their family members (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). As it is seen, having pain is an element that can affect the interactions among family members. This is an instance about one of the main arguments of Family Systems Model (Kerns & Otis, 2003). It was asserted that each member of the family affects the entire family and vice versa (Kerns & Otis, 2003). That is, although fibromyalgia patients' symptoms can be aggravated by family members, they can also negatively

affect other family members to a certain extent. On the other hand, although their symptoms may worsen, it is noteworthy that half of the participants in this study ignored themselves to meet their children's wishes. While their symptoms are aggravated by their participation to familial activities, it can be said that these activities do also have a positive effect on their family relationships.

Another point mentioned by participants is that their symptoms of fibromyalgia, especially their pain, were triggered by their children's stressful life events. When there is a stress factor in the family, this may exceed the available resources of the family (Preece & Sandberg, 2005). Due to the fact that there is not enough familial resource to cope with stressful situations, people with fibromyalgia try to use their resources to cope with those stressful events, which in turn, give rise to overloading and worsened symptoms (Preece & Sandberg, 2005). It was found that fibromyalgia patients have high levels of stress (Jahan, Nanji, Qidwai, & Quasim, 2012). Also, it was stated that perceived stress level is the most significant predictor variable to explain aggravation of fibromyalgia symptoms (Murray, Murray, & Daniels, 2007). Taking these into account, it makes sense that symptoms of fibromyalgia patients, including the current participants, worsen when their children face with stressful events.

"A" stated that her daughter constantly expects "A" to do something for her and she says "I love you" only when A does something for her. Similarly, she indicated that her spouse expects "A" to do all the housework and child care by herself. Although other participants have not explicitly mentioned this issue, most of them specified their "service provider" role at home. This means that their role is just doing housework, meeting other family member needs, caring for both their children and husbands. The participants, however, complained about this role. This role made the researcher think that patients could not meet their needs in the family, like getting sufficient support from their family members. Similarly, in a study, it was found that women with fibromyalgia perceive less support from their family members (Shuster, McCormack, Pillai Riddell, & Toplak, 2009). In the same study, it was found that there is a significant relation between less perceived support and both anxiety and

depression. Consequently, it can be stated that perceived support may have a substantial impact on the well-being of fibromyalgia patients.

The starting point of this study was the effect of spouses and children on patients and their condition; however, during the study it was found that the families of spouses and the families of fibromyalgia patients do also have negative impacts on them. This was not anticipated by the researcher; therefore, they can be considered as unexpected results.

The literature has started to focus on the impact of interpersonal relations on chronic illnesses including chronic pain (Leonard et al., 2006). This study had the same focus. Accordingly, it was found that relationships with family members affect the lives of participants, including their health condition. Although familial relationships can be a source of support for participants, it seems that these relationships can also be a source of stress for the current participants. Similar to the findings of the present study, in a study, nearly half of the chronic pain patients stated that they have had a supportive family but others stated the opposite (Jamison & Virts, 1990). The ones, who did not have supportive families reported more pain and required more medications compared to the ones with supportive families (Jamison & Virts, 1990). Thus, the present findings are parallel to the relevant literature. Parallel to the studies in the literature, the current findings revealed that having extended families worsens the pain experiences of fibromyalgia patients. As Cognitive-Behavioral Transactional Model postulated that family context have impacts on pain experiences of patients both in positive and negative ways (Kerns & Otis, 2003). For the participants of the study, it seems that spouses, children and extended families of patients have had limited positive effects on their pain experiences. However, all the family members have worsening effects on fibromyalgia symptoms of patients.

One of the starting points of this study was how familial dynamics impact on the fibromyalgia related experiences of the participants. To understand that question comprehensively, the models that focus on family and social environment, and the models focusing on the family context mentioned in the first chapter. These were

Family Systems Model, Operant Mechanisms Model, and Cognitive-Behavioral Transactional Model. Although some assumptions of these models were in line with the experiences of the current participants, it seemed that these models were inadequate to explain the whole picture about the experiences of women with FMS in the family context. These models especially focused on spouses and children of patients, and also, on the bi-directional relationships between them. However, the families of spouses and the families of fibromyalgia patients are not included in these models, but it was revealed in this study that they also have an impact on participants FMS experience. Shortly, it seemed that spouses, children and extended families of the current participants had limited positive effects on their pain experiences; in contrast, all the family members had worsening effects on fibromyalgia symptoms of patients.

4. 3. Fibromyalgia: A Psychological Phenomenon

In this superordinate theme, it was seen that participants defined themselves with some common personality traits like altruistic, sensitive, fragile, caring, and minding. Also, some of them made a causal attribution between these personality traits and their illness. They said that they developed fibromyalgia due to these characteristics. On the other hand, it was seen that the important issue was not their characteristics. Instead, their expectations from people that were not met in their relationships were the real issue. The patients having these characteristics, such as being sensitive and caring, could not receive the same attitude in turn from their family members. Participants respectively mentioned their spouse, spouse's family, their own family in which they were grown up and their children when they talked about their personality characteristics. This could be interpreted as when they interact with those people with an attitude of expecting "sensitiveness" from them in return, they experience disappointment, which in turn, negatively affected their health. In other words, although the participants had these "good characteristics" and they treated people accordingly, they did not respond in the same way. As a result, they felt disappointed and they blamed themselves for having these personality characteristics.

In the literature, there is not any specific personality pattern matching with fibromyalgia patients (Malin & Littlejohn, 2012; Torres et al., 2013). In other words, there is no personality trait found in the literature that makes individuals more prone to develop fibromyalgia. On the other hand, some personality characteristics were associated with that population. One of them is having unrealistic expectations regarding oneself and others (Magnusson, Nias, & White, 1996). In the current study, E stated that she has searched for a solution that will terminate her disease and pains completely. As it is seen that she has an unrealistic expectation regarding fibromyalgia. Also, high level of demands from others is another characteristic of that population (Amir, Neumann, Bor, Shir, Rubinow, & Buskila, 2000). For example, “C” mentioned that she expects others to do things for her even before she tells them to do so. As a matter of course, her unspoken demands were not met and she experienced disappointments.

Also, as mentioned above, participants thought that their personality characteristics were one of the reasons of why they developed fibromyalgia. This explanation sounds like a defense mechanism called “turning against the self”. It is defined as “directing aggressive thoughts or behaviors toward oneself” (Zoccali et al., 2007). In the literature, this defense mechanism is associated with depression (McWilliams, 2010). Moreover, although none of the participants said that they were diagnosed with depression, some of them used antidepressant medications and they benefitted from them. The use of this defense mechanisms and antidepressant medications both by the present participants and people diagnosed with depression brings to mind that if there is an association between fibromyalgia and depression. Studies indicated that there is a high comorbidity between fibromyalgia and depression (Aparicio et al., 2013; Tütüncü & Günay, 2011; Vespa et al., 2015). This is explained by a common mechanism found both in fibromyalgia and depression that are the effect of genetic, environment, and interaction between them (Gracely, Ceko, & Bushnell, 2011).

It is indicated that anger is one of the negative emotions mostly seen in fibromyalgia patients (Okifuji, Turk, & Curran, 1999; Van Middendorp, Lumley, Jacobs, Bijlsma, & Geenen, 2010). Also, it is reported that anger has an important role in the

development and continuation of fibromyalgia (Tütüncü & Günay, 2011). Similarly, participants of this study mentioned their anger towards other people and themselves. It was seen that when some participants talked about their anger, they started to talk about their guilt, as well. Moreover, for some participants, it can be assumed that separation from other people might lead to the feeling of guilt.

The participants did mainly talk about sadness they experienced. Sadness is predominantly associated with depression (McWilliams, 2010); the prominent experience of this emotion by FMS patients might be explained by the comorbidity between fibromyalgia and depression. Furthermore, some participants were yelling and using body language during anger, and crying during sadness. These reactions are ineffective ways for coping with emotions. Thus, as it was indicated in the literature, fibromyalgia patients may benefit from emotional disclosure and expression interventions (Geenen, Ooijen, Lumley, Bijlsma, & Middendorp, 2012).

Fibromyalgia cannot be detected by any objective examination; therefore, both doctors and ordinary people may tend to reject fibromyalgia as a syndrome (Bernstein, 2016). Similarly, participants of this study indicated that others are not convinced that they have an illness. Although they talked about “others”, it was seen that they mostly mentioned their husbands. Because others were not believing in them, they seemed like they struggle to cope with fibromyalgia alone.

This theme covered how participants defined their personality and how they attributed their illness to those personality traits. On the other hand, it seemed that they expected “sensitiveness” from others in return to their “positive” personality traits. When this did not happen, they experienced disappointment and they blamed themselves; as a result, their health was affected negatively. Also, the theme revealed that participants had unrealistic expectations both from themselves and others. Additionally, participants mentioned their anger towards other people and themselves. For some participants, speaking about anger accompanied with speaking about guilt. Moreover, it was understood that “sadness” was one of the predominant emotions experienced by participants. They used “turning against the self” as a

defense mechanism, and they benefited from antidepressant medication. Thus, these could be explained by the comorbidity between fibromyalgia and depression. Furthermore, it was seen that other people do not believe that the participants really suffer from an illness; as a result, the participants felt that they have to cope with fibromyalgia alone.

4. 4. Fibromyalgia as a Triggering Factor of Change

This superordinate theme was one of the unexpected findings of the current study. It captured that some of the participants neglected themselves for the sake of their relationships with others and daily activities; which in turn, made their symptoms worse. In order not to be affected adversely by others, it was seen that they entered into a period of change. In the literature, that period called as post-traumatic growth, which briefly refers to a positive change occurring after negative life experiences (Chun & Lee, 2008). These positive changes may be related to self-concept, relations with others, and priorities in life (Moreira-Almeida & Koenig, 2008). It can be suggested that participants of this study realized that their first priority in life is their health; therefore, they started to build their life around the things that can be good for their health. Although some participants in the current study looked like experiencing post traumatic growth, the relationship between pain and post-traumatic growth was investigated only by few studies; therefore, further studies are required to depict this association (Min, Lee, Lee, & Chae, 2013).

Some of the participants started to adopt new attitudes and behaviors that makes them less altruistic, caring etc., and revised their interpersonal relations and began to treat everyone as they deserve, and some of them had an intention to adopt new physical activities to their life. Although they had the intention to do physical activities, they had not started their intentions to carry into effect. In the literature, it was indicated that intention to adopt a new behavior is not the best predictor of change (Schwarzer, 2008). Moreover, even they could start to practice new behaviors, it is not easy to maintain them (Bouton, 2014). As mentioned before, most of the participants were unwilling to do physical exercise due to its worsening effect

on pain, although it is recommended for fibromyalgia patients (Bush et al., 2011). It can be suggested that if people understand the rationality behind how physical exercise have a positive outcome on pain, they would adopt those behaviors more easily to their life. Thus, this patient group might benefit from interventions that include psychoeducation modules.

This theme revealed that participants' priority was others in the past; so, they were neglecting themselves. After they were diagnosed with fibromyalgia, their priorities have started to change from others to themselves and their own health. Moreover, although they had not started to practice, it was seen that some of the participants had an intention to do physical activities.

4. 5. Reflection on the Study

The researcher had pain a few years ago. Those times, she started to be curious about the concept of pain. As a result, she decided to investigate how women experience fibromyalgia in the family context. Although the researcher expected the effects of spouses and children on the experiences of fibromyalgia patients, she did not expect to find that both the families of spouses and families of fibromyalgia patients have an effect on their experiences. The researcher is not married; therefore, she might fail to notice the influence of extended families on married women in Turkish culture.

The researcher thought that the process and content of interviews are affected by her gender and "psychologist" role. Specifically, these could enable that interviewees feel comfortable during the interviews and easily disclose their experiences related to fibromyalgia; as a result, the interviews included rich contents.

Moreover, the professional identity of the researcher, her therapy-related knowledge and experience, might had an influence on the nature of the relationship between her and interviewees, the quality of questions asked to them, and her attitudes during the interviews. Furthermore, the analysis of data was affected by her professional identity, too. It can be assumed that if other people who have different professional

identities had conducted the interviews and/or interpreted the data, the result would be different than the current results.

4. 6. The Strengths and Limitations of the Current Study

There are many quantitative studies that focused on women with fibromyalgia; however, they only focused on some limited aspects of it. Qualitative methods like IPA, however, can obtain an in-depth understanding of how women experience fibromyalgia. Thus, its methodology is one of the most important strengths of the current study. Also, this study revealed how fibromyalgia is experienced by women, how their symptoms are influenced by familial dynamics. Additionally, the association between fibromyalgia and psychological issues was shown and how fibromyalgia could trigger change was approached in this study. Moreover, although fibromyalgia is not considered as an illness by some people, this study showed how fibromyalgia patients experience the illness itself and the associated difficulties with it.

Although using IPA was one of the strengths of the present study, it also constitutes one of the fundamental limitations of the study. Although one of the transcriptions was analyzed by a research assistant and the researcher discussed the themes of the study with this research assistant and her supervisor, all stages of the analysis were conducted according to the researcher's interpretation. That is, this study includes subjectivity like other studies conducted with IPA. Thus, the generalizability of the results is limited.

Purposive sampling was used for this study. The inclusion criteria were as follows: being a woman, being married, having at least one child, having at least high school degree, being in the age range of 25-55, being officially diagnosed with fibromyalgia, and receiving treatment for fibromyalgia. Additionally, all of the participants were members of middle socio-economic group. Due to these inclusion criteria, generalizability of the findings is further limited.

4. 7. Clinical Implications of the Current Study and Suggestions for Future Researches

This study provided valuable insights for people who have similar experiences and for health professionals to understand unique experiences of fibromyalgia patients. Also, the study revealed different themes about experiences of women who are diagnosed with fibromyalgia. Future studies can investigate these themes in a more detailed way. Also, future studies may be conducted not only with fibromyalgia patients but also with their family members to understand their experience of living with a fibromyalgia patient. This would enable a comprehensive understanding related to experiences and perspectives of fibromyalgia patients and family members.

In this study, it was shown that how women with fibromyalgia are affected by their spouse, children, spouse's family, and their family of origin. The participants reported that they are not supported in some of those relationships. Instead, they depicted a picture where they saw those relationships as an important stress factor. Especially, some participants stated that they could not get support from their husbands and their expectations from marriage were not met. Thus, it can be suggested that when clinical psychologists have fibromyalgia patients, they should focus especially on family dynamics and how fibromyalgia patients are affected by them. Also, fibromyalgia patients whose symptoms are aggravated due to their children and/or spouse may benefit from the family and/or couple therapies. Moreover, if cognitions, emotions, attributions, and behaviors of fibromyalgia patients related to family members are determined as one of the subjects of the therapy, fibromyalgia patients might further benefit from psychotherapy.

This study revealed that participants could not express their emotion effectively. Clinical psychologists who work with fibromyalgia patients should focus on the patients' emotions, the way they express and cope with them. As Geenen et al. (2012) indicated that fibromyalgia patients may benefit from emotional disclosure and expression interventions.

Some of the participants of this study indicated their intention to do some activities that include physical exercises. It was indicated that although physical activities are recommended to fibromyalgia patients, they are unwilling to do them (Bush et al., 2011; Mannerkorp, 2005). However, it was stated that intention is not the most important determinant of behavioral change (Schwarzer, 2008). It is important that both clinical psychologists and fibromyalgia patients should have knowledge about how and why physical activities are beneficial for fibromyalgia patients and how physical activities can be adopted to those patients' daily routine. Thus, it is recommended that clinical psychologists find ways to motivate fibromyalgia patients to adopt physical activities; or they can collaborate with health psychologists.

The findings of this study revealed that fibromyalgia could be a triggering factor for people to change their life in a positive way. Parallel to strength based approaches, these positive changes can be identified during therapy sessions and they might be encouraged to strengthen and sustain these changes. Also, they may be used to reach treatment goals more easily.

The result of the study suggested that the collaboration between psychologists and other health care professionals is important. A good team work would make FMS patients benefit more from their treatment.

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APPENDICES

APPENDIX A: QUESTIONS FOR SEMI-STRUCTURED INTERVIEW

1- Can you please describe the pain you have been experiencing?

(Prompts: How does the pain begin? Exactly in which parts of your body does it arise? How do you feel during that time? How is the severity of the pain? Does the severity of the pain change? If it changes, what are the circumstances that cause it to change?)

2- How long have you been experiencing this pain?

(Prompts: When did you get the diagnosis? (If the patient delayed to see a doctor: What was the reason of your delay to see a doctor?)

3- What do you think about the reasons of these complaints/illness?

(Prompts: What triggered your complaints/symptoms?)

4- How is your relationship with your partner?

(Prompts: If you think about beginning, development and current phases of your relationship with your partner, how was the courses of events? How do you describe your partner?)

5- How does your relationship with your partner affect your pain?

(Prompts: Do you think that it has negative impacts on your pain? Do you think that it has positive impacts on your pain?)

6- How does your illness affect your relationship with your partner?

(Prompts: Do you think that it has negative impacts on your relationship with your partner? Do you think that it has positive impacts on your relationship with your partner?)

7- Do you have difficulties in your relationship/marriage?

(Prompts: If yes, what are the subjects that you have difficulties in? How do you cope with these difficulties? How does your partner cope with these difficulties? How do you and your partner together cope with these difficulties?)

8- Can you please describe the relationship with your child/children?

(Prompts: How is your relationship? Do you have difficult times/subjects in your relationships with your child/children? How do you deal with these difficulties?)

9- What do you do to cope with the pain you have been experiencing?

(Prompts: What are the things/circumstances that make it difficult for you to cope with the pain you have been experiencing?)

APPENDIX B: ETHICS COMMITTEE APPROVAL

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07 HAZİRAN 2017

Konu: Değerlendirme Sonucu

Gönderen: ODTÜ İnsan Araştırmaları Etik Kurulu (İAEK)

İlgi: İnsan Araştırmaları Etik Kurulu Başvurusu

Sayın Doç. Dr. Özlem BOZO;

Danışmanlığını yaptığımız Felek YOĞAN'ın "*How do Women Experience Fibromyalgia in Family Context*" başlıklı araştırması İnsan Araştırmaları Etik Kurulu tarafından uygun görülerek gerekli onay 2017-SOS-019 protokol numarası ile 07.06.2017 – 31.12.2017 tarihleri arasında geçerli olmak üzere verilmiştir.

Bilgilerinize saygılarımla sunarım.


Prof. Dr. Ş. Halil TURAN

Başkan V


Prof. Dr. Ayhan SOL

Üye


Prof. Dr. Ayhan Gürbüz DEMİR

Üye


Doç. Dr. Yaşar KONDAKÇI

Üye


Doç. Dr. Zana ÇITAK

Üye

BULUNAMADI
Yrd. Doç. Dr. Pınar KAYGAN

Üye


Yrd. Doç. Dr. Emre SELÇUK

Üye

APPENDIX C: INFORMED CONSENT FORM

ARAŞTIRMAYA GÖNÜLLÜ KATILIM FORMU

Bu araştırma, ODTÜ Psikoloji Bölümü Yüksek Lisans öğrencisi Felek Yoğan tarafından Doç. Dr. Özlem Bozo danışmanlığındaki yüksek lisans tezi kapsamında yürütülmektedir. Bu form sizi araştırma koşulları hakkında bilgilendirmek için hazırlanmıştır.

Çalışmanın Amacı Nedir?

Araştırmanın amacı, fibromiyalji tanısı almış kadın hastaların fibromiyaljiyi aile ortamında nasıl deneyimlediklerini derinlemesine anlamaktır.

Bize Nasıl Yardımcı Olmanızı İsteyeceğiz?

Araştırmaya katılmayı kabul ederseniz, sizden bir görüşmeye katılmanızı beklenmektedir. Yaklaşık olarak 60 dakika ile 180 dakika arasında sürmesi beklenen bu görüşmede size açık uçlu sorular yöneltilecek ve sizin bu sorulara yanıt vermeniz beklenecektir. Görüşme ses kayıt cihazı ile kaydedilecektir ve daha sonra içeriği araştırmacı tarafından analiz edilecektir.

Sizden Topladığımız Bilgileri Nasıl Kullanacağız?

Araştırmaya katılımınız tamamen gönüllülük temelinde olmalıdır. Görüşme süresince verdiğiniz bilgiler görüşmeyi yapan kişi, ODTÜ Psikoloji Bölümü'nde araştırma görevlisi olarak çalışan bir kişi ve tez danışmanı tarafından incelenecektir. Verdiğiniz bilgiler eğitim amacıyla ve/veya bilimsel yayınlarda kimlik bilgileriniz verilmeden kullanılacaktır.

Katılımla ilgili bilmeniz gerekenler:

Görüşme genel olarak kişisel rahatsızlık verecek sorular içermemektedir. Ancak, katılım sırasında sorulardan ya da herhangi başka bir nedenden ötürü kendinizi rahatsız hissederseniz görüşmeyi yarıda keserek çıkmakta serbestsiniz. Böyle bir durumda görüşmeyi yapan kişiye görüşmeden çıkmak istediğinizi söylemeniz yeterli olacaktır.

Araştırmayla ilgili daha fazla bilgi almak isterseniz:

Görüşmenin sonunda, bu çalışmayla ilgili sorularınız cevaplanacaktır. Bu çalışmaya katıldığınız için şimdiden teşekkür ederiz. Çalışma hakkında daha fazla bilgi almak için ODTÜ Psikoloji Bölümü yüksek lisans öğrencisi Felek Yoğan (E-posta: felekyogan@gmail.com) ile iletişim kurabilirsiniz.

Yukarıdaki bilgileri okudum ve bu çalışmaya tamamen gönüllü olarak katılıyorum.

(Formu doldurup imzaladıktan sonra uygulayıcıya geri veriniz).

İsim Soyisim

Tarih

İmza

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APPENDIX D: TURKISH SUMMARY / TÜRKE ÖZET

KADINLAR AİLE ORTAMINDA FİBROMİYALJİYİ NASIL DENEYİMLER?

BÖLÜM 1

GİRİŞ

1.1. Ağrı ve Kronik Ağrı

Ağrı birinci basamak sağlık kuruluşlarına başvurunun birincil sebeplerinden biridir (Disorbio, Bruns ve Barolat, 2006). Ayrıca, ağrı diğer hastalıklara eşlik eden en yaygın şikayet sebebidir (Madenci ve ark., 2006). Bunlara paralel olarak, ağrı evrensel olarak bir hastalık göstergesi olarak kabul edilmiştir (Hanoch Kumar ve Elavarasi, 2016). Bir taraftan ağrı psikiyatrik bir problemin bir semptomu olabilirken, diğer taraftan psikolojik problemlerin yol açtığı fiziksel bir sorun da olabilir (Kara ve Abay, 2000). Başka bir deyişle, ağrı ile psikiyatrik sorunlar arasında çift yönlü bir ilişki vardır.

Ağrıyı sınıflandırmanın birden fazla yolu vardır. Devam ettiği süre temel alınarak yapılan sınıflandırmaya göre akut veya kronik ağrı olarak sınıflandırılmaktadır (Berry ve ark., 2005). Akut ağrının biyolojik olarak bir rolü vardır; buna göre, ağrı bedende bir hasar olduğuna yönelik sinyal vermektedir (Mosier, 2011). Eğer hasar iyileştirilirse ağrı ortadan kalkmaktadır, fakat ağrı ortadan kalkmazsa kronik ağrıya dönüşme olasılığı vardır (Mosier, 2011). Ağrı eğer üç veya altı aydan uzun sürerse, bu durumda bu ağrı kronik ağrı olarak adlandırılmaktadır (akt., DiLorenzo, Pillai Riddell ve Holsti, 2016; Yazıcı ve ark., 2003).

1.2. Fibromiyalji

Bir kronik ağrı türü olan fibromiyalji sendromu, yaygın kas ve iskelet ağrısı ile fizyolojik ve psikolojik semptomlarla tanımlanmaktadır (Dönmez ve Erdoğan, 2009; Sevinç, 2013). 1990 yılında, Amerikan Romatizma Koleji tarafından, fibromiyalji sendromu ile ilgili tanı kriterleri oluşturulmuştur (Wolfe ve ark., 1990). Bu tanı kriterlerinin ilkinde göre, kronik ağrının vücudun bir bölgesine özgü olmaması gerektiği, aksine yaygın bir vücut ağrısı olması gerektiği ve bu ağrının en az üç ay süresince devam etmesi gerektiği ifade edilmiştir. Başka bir deyişle vücudun sağ ve sol bölgesinde, belin alt ve üst kısmında ve iskelet ekseninde bir süredir ağrı olması gerekmektedir. Belirtilen kriterlerin ikincisine göre ise, vücudun on sekiz hassas noktasının on birinde ağrı olmak zorundadır.

Öte taraftan bu kriterler, Amerikan Romatizma Koleji tarafından, 2010 yılında değiştirilmiştir (Wolfe ve ark., 2010). Bu yeni kriterlerin birincisine göre, Yaygın Ağrı İndeksi'nden 7 puan ve üzeri puan alınmalıdır veya Semptom Şiddeti Puanı'nın 3'ten 6'ya kadar bir değer olması ya da 9 ve üzeri bir değer olması gerekmektedir. Ayrıca, kişilerin en az üç aydır bu şikayetlere sahip olması ve bu şikayetlerini açıklayan başka bir hastalığa sahip olmamaları gerekmektedir.

Fibromiyaljinin etiyolojisi bütünüyle bilinmemektedir (Kolahi ve ark., 2014). Ayrıca bir kişi yaklaşık olarak üç veya beş doktora gittikten sonra ve yaklaşık olarak beş yıl süre geçtikten sonra fibromiyalji teşhisi alabilmektedir.

Kadınların erkeklere kıyasla daha fazla fibromiyalji teşhisi aldıkları öne sürülmüştür. Benzer bir şekilde, bir çalışma tarafından, fibromiyalji teşhisi almış kişilerin %80'inden daha fazlasının kadın olduğu tespit edilmiştir (Dönmez ve Erdoğan, 2009). Ayrıca, her ne kadar fibromiyalji sendromu her yaşta görülse de, yaş arttıkça görülme sıklığı da artmaktadır (Wolfe ve ark., 1995).

Fibromiyalji sendromunun etiyoloji tam olarak bilinmese de, bu teşhisi alan kişilerde bazı psikolojik sorunların görüldüğü bilinmektedir. Bazı çalışmalara göre, depresyon ve psikososyal stres faktörleri bu sendromun başlaması ve devam etmesiyle ilişkili

bulunmuştur (Nordahl ve Stiles, 2007; Şengül ve ark., 2008). Bu hasta grubunda görülen diğer psikolojik sorun ise somatizasyon ve kaygı bozukluklarıdır.

Depresyon ve fibromiyalji sendromu arasında bir ilişki olduğunu söyleyen birçok çalışma vardır (Altunöre ve ark., 2011; Pattern, 2001; Robinson ve ark., 2004; Şengül ve Akkaya, 2014). Depresyon oranının fiziksel problemleri olan kişiler arasında yüksek olduğu görülmüştür (Şengül ve Akkaya, 2014). Bu durum, fiziksel problemlerin depresyon geliştirmek için bir risk olduğunu söyleyen çalışmalar tarafından desteklenmektedir (Pattern, 2001). Benzer bir şekilde, fibromiyalji teşhisi almış kişilerin %22 ile %45'inin depresyon teşhisi de aldığı görülmüştür (Robinson ve arkadaşları, 2004). Bunlara ek olarak Türkiye'de yapılmış bir çalışma fibromiyalji teşhisi almış kişilerin %55'inin yaşamları boyunca en az bir kez depresyon teşhisi aldığını belirtmiştir (akt., Balcı Şengül ve Akkaya, 2014).

Düşük sosyo-ekonomik düzeye sahip olmanın, düşük eğitim durumunun, kadın olmanın, boşanmış olmanın ve bir engele sahip olmanın fibromiyalji geliştirmek için birer risk faktörü olduğu saptanmıştır (Topbaş et al., 2005).

1.3. Teorik Bakış Açılıarı

Psikiyatrist George L. Engel, 1977 yılında, sağlığın, rahatsızlıkların ve hastalıkların biyolojik, psikolojik, ve sosyal faktörlerden etkilendiğini ve onların bir toplamı olduğunu ifade etmiştir (akt., Hatala, 2012). Bu argüman günümüzde yaygın olarak kabul gören Biyopsikososyal Model'in bir varsayımıdır (Hatala, 2012). Bu modelden önce, Biyomedikal Model yaygın olarak kullanılmaktadır ve bu modele göre rahatsızlık ve hastalıklar kişilerden ve çevrelerinden bağımsız olarak ele alınmaktadır (Deep, 1999). Öte yandan, Biyopsikososyal Model, rahatsızlıklardan ve hastalıklardan iyileşmenin psikososyal faktörlerle ilişkili olduğunu ileri sürmektedir (Deep, 1999). Bu bakış açısına göre, aile ve sosyal çevre hastalıkların birer parçasıdır. Bu çalışma kapsamında aile ile sosyal çevreye odaklanan modeller ele alınacaktır. Bu modellere göre aile üyelerinden birinde bulunan kronik ağrı bütün aileyi etkilemektedir (Kern ve Otis, 2003; Lewandowski ve ark., 2007). Bu modeller

Aile Sistemleri Kuramı, Edimsel Mekanizma Modeli ve Bilişsel Davranışçı Transaksiyonel Modeli'dir.

1.3.1. Aile Sistemleri Kuramı

Bu kurama göre her bir aile üyesi tüm aileyi etkilemekte ve tüm aile her bir üyeyi etkilemektedir (Kerns ve Otis, 2003). Ayrıca, bu kurama göre, ağrı ailede dengeyi sağlamanın bir yolu olarak görülmektedir (Lewandowski ve ark., 2007). Son olarak, bu kurama göre, ailenin odağı kendi aralarındaki problemlere çözüm bulmak yerine ağrı hastasının şikayetleridir (Lewandowski ve ark., 2007).

1.3.2. Edimsel Mekanizma Modeli

Bu kuramın odak noktası aile üyelerinin ağrı ve ağrıyla ilişkili durumlara verdiklere tepkilerdir (Kerns ve Otis, 2003). Bu kurama göre, ağrı hastası olan aile üyesi, diğer aile üyelerinden istediği tepkileri alabileceği davranışların neler olduğunu öğrenir (Kerns ve Otis, 2003). Başka bir deyişle, aile üyeleri, ağrı hastasının ağrı davranışlarını pekiştirebilmektedir.

1.3.3. Bilişsel Davranışçı Transaksiyonel Modeli

Bu model Edimsel Mekanizma Modeli'ne göre daha bütüncül bir bakış açısı sunmaktadır (Lewandowski ve ark., 2007). Modelin odak noktası, ağrı ile ilişkili olarak, kişinin sağlığı ve hastalığını yönetme şeklidir (Lewandowski ve ark., 2007). Ayrıca, bu model ailenin inanışlarına, değerlerine ve başa çıkma stratejilerine odaklanmaktadır (Lewandowski ve ark., 2007).

1.4. Çalışmanın Amacı ve Araştırma Soruları

Bu çalışmanın amacı kadınların aile ortamında ağrıyı nasıl deneyimlediklerini derinlemesine olarak incelemektir. Bu çalışmanın iki temel araştırma sorusu vardır; (1) evli ve çocuğu olan kadın fibromiyalji hastaları ağrıyı nasıl deneyimler? ve (2)

evli ve çocuęu olan kadın fibromiyalji hastalarının aęrı deneyimleri ile aile ilişkileri arasındaki baę nasıldır?

BÖLÜM 2

YÖNTEM

Bu bölüm metodolojik çerçeve, örneklem yöntemi ve katılımcılar, prosedür, veri analizi ve çalışmanın güvenilirlięi kısımlarından oluşmaktadır.

2. 1. Metodolojik Çerçeve

2. 1. 1. Niteliksel Yaklaşım

Aęrı dinamik bir olgudur, bu yüzden bu konuyu niceliksel yöntemlerle çalışmak zorlayıcıdır (Osborn ve Rodham, 2010). Öte taraftan, niteliksel yaklaşımlar, katılımcılardan bilgi almak için ucu açık sorular sormayı içerir, bu durum da bahsi geçen yaklaşımların zengin içeriklere sahip olmasını sağlamaktadır (Carter ve Littler, 2007). Ayrıca bu yaklaşımlar kullanılarak yapılan çalışmalar beklenmeyen sonuçların çıkmasına olanak vermektedir (Barker, Pistrang ve Elliott, 2002). Bunlardan dolayı, bu çalışmada analiz yöntemi olarak yorumlayıcı fenomenolojik analiz kullanılmaktadır.

2. 1. 2. Yorumlayıcı Fenomenolojik Analiz

Bu yaklaşım, temel olarak, insanların kendi hayatlarına, yaşadıkları dünyaya, deneyimlerine ve durumlara verdikleri anlamları derinlemesine olarak anlamayı amaçlamaktadır (Smith ve Osborn, 2007). Bu analiz yöntemi, yukarıda belirtilenlerin, kişiler tarafından öznel olarak nasıl yorumlandığına odaklanmaktadır (Smith ve Osborn, 2007).

2. 2. Örneklem Yöntemi ve Katılımcılar

2. 2. 1. Örneklem

Bu yöntem derinlemesine analiz gerektirdiği için az sayıda kişi ile görüşme yapılmaktadır (Smith ve Osborn, 2007). Ayrıca, bu yöntem için benzer özellikler taşıyan kişiler katılımcı olarak seçilmektedir (Smith ve Osborn, 2007).

2. 2. 2. Katılımcılar

Bu çalışmada evli, en az bir çocuğu olan, 25-55 yaş aralığında olan, en az lise mezunu ve resmi olarak fibromiyalji teşhisi almış altı kadınla yarı yapılandırılmış görüşmeler yapılmıştır

2.3. Prosedür

Katılımcılarla yapılan görüşmeler Gazi Hastanesi Algoloji Birimi'nin bir odasında gerçekleşmiştir.

2. 4. Veri Analizi

Yapılan görüşmelere ait yazı dökümleri araştırmacı tarafından defalarca okunmuş ve temalar belirlenmiştir. Bu yazı dökümlerinden bir tanesi araştırma asistanı tarafından analiz edilmiştir. Sonrasında, araştırma asistanı ve tezin danışmanı ile birlikte, ayrı olarak, temalar üzerine tartışılmıştır ve bu tartışmanın sonucunda araştırmacı tarafından temalar oluşturulmuştur.

2. 5. Çalışmanın Güvenilirliği

Bu yöntem araştırmacının yorumlamasına dayanmaktadır ve bu öznel bir süreçtir. Araştırmacının, araştırdığı konuyu etkileyebilecek kişisel özelliklerinin (Berger, 2013), varsayımlarının (Maunders, 2010) ve dünyayı anlamlandırma şekillerinin (Maunders, 2010) farkında olması önemlidir.

BÖLÜM 3

SONUÇLAR

3. 2. Üst Temalar ve Alt Temalar

Bu çalışmanın sonucunda dört tane üst tema ve bunlara bağlı olan toplam on beş alt tema ortaya çıkmıştır.

3. 2. 1. Birinci Üst Tema: Fibromiyaljinin Özellikleri

Bu tema, katılımcılardan tarafından fibromiyaljinin nasıl deneyimlendiğini anlamayı amaçlamaktadır. Bu temaya göre, katılımcılar, hiç bitmeyen, şiddeti farklı durumlara göre değişiklik gösteren ve bedeninin farklı bölgelerinde görülen bir ağrı deneyimlemektedir. Her ne kadar katılımcılar temel olarak ağrı deneyimlese de, ağrı dışında da deneyimledikleri fibromiyaljiyle ilgili şikayetleri vardır. Bunlara ek olarak, katılımcıların fibromiyalji teşhisi ve tedavisi ile ilgili farklı deneyimlere sahip oldukları anlaşılmaktadır.

3. 2. 1. 1. Hiç Geçmeyen Bir Ağrı

Dört tane katılımcı ağrılarının hiç geçmediğinden bahsetmiştir. Katılımcı A ağrısının ne zaman başladığını bilmediğini fakat her zaman bir ağrısı olduğunu söylemiştir. Katılımcı B, her ne kadar ağrısı olsa da, bu ağrının ihtiyaçlarını karşılaması için bir engel olmadığını söylemiştir. Katılımcı C, ağrısının çok şiddetli bir ağrı olmadığını fakat kronik bir ağrı olduğunu ifade etmiştir.

3. 2. 1. 2. Farklı Durumlara Göre Değişiklik Gösteren Ağrı Şiddeti

Bütün katılımcılar sabit bir ağrıya sahip olmadıklarını, aksine ağrı şiddetlerinin değişiklik gösterdiğini ifade etmiştir. Bütün katılımcılar ev işlerinden kaynaklı

fiziksel yorgunluğun ağrılarını etkilediğini ifade etmiştir. Başka katılımcılar ise ev işi yapmak yerine dinlendiklerinde ağrılarının azaldığını ifade etmiştir. Bazı katılımcılar fiziksel yorgunluğa yol açan gündelik aktivitelerin ağrılarının artması ile sonuçlandığını ifade etmiştir. Katılımcılardan bazıları günün farklı zamanlarında ağrılarının şiddetinin arttığını ifade etmiştir. Örneğin, katılımcı F ağrılarının geceleri arttığını söylemiştir. Ayrıca bazı katılımcılar hava koşullarına bağlı olarak ağrı şiddetlerinin arttığını ifade etmiştir. Özellikle rüzgâra ve soğuğa bağlı olarak bu değişikliğin meydana geldiğini ifade etmişlerdir.

3. 2. 1. 3. Vücutun Farklı Bölgelerinde Ağrı

Katılımcılar vücutlarının farklı bölgelerinde ağrı betimlemiştir. Katılımcı F omuzlarında ve kürek kemiğinde ağrı olduğunu belirtmiştir. Katılımcı D, ayak parmaklarında bile ağrının dolaştığını söylemiştir. Katılımcı B omuzlarında, kollarında ve kafasında ağrı olduğunu ifade etmiştir. Katılımcı D, vücudunun her yerinin ağrıdığını söylemiştir. Katılımcı E ise, ağrıyan yerlerinin sürekli olarak yer değiştirdiğine değinmiştir.

3. 2. 1. 4. Ağrı Dışında Başka Semptomlar

Her ne kadar katılımcılar özellikle ağrıları olduğundan bahsetseler de, ağrı dışında da sahip oldukları semptomlar da bulunmaktadır. Katılımcı F bir şeyler yapmak için isteksizliğinden bahsetmiştir. Başka birçok katılımcı gibi, katılımcı C, uyku ile ilgili yaşadığı problemlere değinmiştir. Ayrıca, katılımcı B de, diğer katılımcıların çoğunda olduğu gibi yorgunluk yaşadığını belirtmiştir.

3. 2. 1. 5. Teşhis ve Tedavi Süreci ile İlgili Farklı Deneyimler

Katılımcıların üç tanesi her ne kadar geçmişte fibromiyalji teşhisi almış olsalar da tedaviye uymadıklarını ifade etmiştir. Öte taraftan, diğer üç katılımcı ise, şikâyetlerinin üzerinden yıllar geçtikten sonra fibromiyalji teşhisini alabildiklerini ifade etmiştir.

3. 2. 2. Fibromiyalji: Ailesel İlişkilerler Tetiklenen Bir Sendrom

Bu tema aile ilişkilerinin katılımcıların fibromiyalji semptomları üzerinde nasıl bir etkisi olduğuna işaret etmektedir. Bu temaya göre katılımcıların ailelerinin, eşlerinin ailelerinin, eşlerinin ve çocuklarının katılımcıların semptomlarını tetiklediği ya da onların kötüleşmesine yol açtığı bulunmuştur.

3. 2. 2. 1. Bir Tetikleyici Olarak Fibromiyaljili Kişinin Kendi Ailesi

Katılımcıların beş tanesine göre kendi aileleri fibromiyalji semptomlarının kötüleşmesine yol açmaktadır. Üç tane katılımcı aileleriyle tartışma yaşadıklarında ağrılarının nasıl arttığını ifade etmiştir. Katılımcı C kız kardeşi öldükten sonra ağrılarının arttığını söylemiştir. Katılımcı B ise annesinin hastalığından dolayı annesine hastanede eşlik ettiği zamanlarda ağrılarının bu durumdan olumsuz etkilendiğini belirtmiştir.

3. 2. 2. 2. Bir Tetikleyici Olarak Eşin Ailesi

Bu alt tema katılımcıların eşlerinin ailelerinin, katılımcıların yaşamları ve ağrıları üzerinde nasıl bir etkiye sahip olduğunu içermektedir. Katılımcıların dört tanesi eşlerinin ailelerinin kendilerinden hizmet beklediğini ve onlara hizmet ettiklerinde semptomlarının kötüleştiğini ifade etmiştir. Katılımcıların çoğu eşlerinin ailelerinin kendileri için birer stres faktörü olduğunu ifade etmiştir. Katılımcıların üç tanesi eşlerinin ailelerinin kurallarına göre yaşadıklarını belirtmiştir.

3. 2. 2. 3. Bir Tetikleyici Olarak Eş

Bu alt tema katılımcıların eşlerine odaklanmaktadır. Katılımcı E dışında, diğer tüm katılımcılar, görücü usulü evlendiklerini söylemiştir. Öte yandan, bütün katılımcılar evlilikten beklentilerinin karşılanmadığını belirtmiştir. Ayrıca, bütün katılımcılar geçmişte boşanmayı düşündüklerini ve/ya hala düşündüklerini fakat çocuklarından

dolayı boşanmadıklarını belirtmiştir. Katılımcıların üç tanesi eşlerinin kendi ailelerinin etkisi altında olduğunu söylemiştir. Bazı katılımcılar eşlerinin ağrılarını doğrudan etkilediğini söylese de, bazıları dolaylı olarak etkilediklerini ifade etmiştir.

3. 2. 2. 4. Bir Tetikleyici Olarak Çocuklar

Bu alt tema katılımcıların çocuklarının fibromiyalji semptomları üzerindeki etkilerine odaklanmıştır. Katılımcı B kızının boşanması ile ilgili durumun kendisinin ağrı deneyimini tetiklemesinden bahsetmiştir. Katılımcı D, son beş yıl içinde, kızının ve oğlunun evlendiğini ve bunların kendisini yorduğunu ifade etmiştir. Ayrıca, katılımcı D, kızının evliliğinde mutsuz olduğunu ve bu durumun kendisini kötü hissetmesine yol açtığını, neticede ağrılarının da arttığını ifade etmiştir. Katılımcı E, kızını üzmemek için, kızı ve eşiyle birlikte hafta sonları bir yerlere gittiğini ve bunun sonucunda yorulduğunu belirtmiştir.

3. 2. 3. Fibromiyalji: Psikolojik Bir Fenomen

Bu tema psikolojik konular ile fibromiyalji arasındaki ilişkiyi göstermeyi amaçlamaktadır. Bu tema içinde kişilik özellikleri, duygular ve diğerlerinin hastalığa bakışları ele alınacaktır.

3. 2. 3. 1. Kişilik Özellikleri ve Fibromiyalji

Bu alt temada, katılımcılar tarafından, fibromiyaljiye sahip olmalarının nedeni olarak görülen kişilik özellikleri ele alınmaktadır. Örneğin, katılımcıların dört tanesi fedakâr kişiler olduklarını ifade etmiştir. Bu katılımcılara göre fedakâr olmak, kendilerini düşünmek yerine diğerlerini düşünmek ve diğerleri için bir şeyler yapmak anlamına gelmektedir. Öte taraftan, katılımcıların üç tanesi diğerleri için kendilerini feda ederken, bu esnada kendilerini göz ardı ettiklerini ifade etmiştir. Ayrıca katılımcıların üç tanesi kendilerini, hassas, kırılğan, önemseyen ve bir şeyleri kafaya takan olarak betimlemiştir. Katılımcı B, kendisini geçmişte yargıladığını, bunu doktoruna söylediğinde, doktorunun kendisine antidepresan ilaç yazdığını ve

neticede rahatladığını ifade etmiştir. Her ne kadar katılımcı B fibromiyaljiye sahip olduğu için kendisini yargılasa da, diğer katılımcılar sahip oldukları kişilik özelliklerinden dolayı kendilerini yargıladıklarını belirtmiştir.

3. 2. 3. 2. Duygular ve Fibromiyalji

Bu alt temada katılımcıların görüşmeler sırasında ifade ettikleri ve sergiledikleri duygular ele alınmaktadır. Beş katılımcı tarafından temel olarak deneyimlenen duygu öfkedir. Her ne kadar katılımcıların çoğu diğerlerine öfkelenirse de, bazıları kendilerine de öfkelenmektedir. Bazı katılımcılar öfkelenedikten hemen sonra suçluluk duyduklarını ifade etmiştir. Üzüntü ise katılımcıların çoğunun deneyimlediği bir diğer duygudur. Katılımcılar duygularıyla baş ederken farklı yöntemler kullanmaktadır. İki katılımcı öfkeli olduğunda diğerlerine bağırıldığını, bir katılımcı öfkesini hareketleri ile belli ettiğini ve iki katılımcı üzüldüklerinde ağladıklarını ifade etmiştir. Tüm bunlara ek olarak iki katılımcı, psikiyatrist gözetimi altında antidepresan ilaç kullandıklarını ve neticede rahatladıklarını ifade etmiştir.

3. 2. 3. 3. Diğerlerinin Hastalığa ve Fibromiyaljiye Bakışı

Bu alt tema diğer kişilerin fibromiyalji ile ilgili atıflarını içermektedir. Katılımcı C, hasta gibi gözükmediği için, diğerlerinin kendisinin hasta olduğuna inanmadığını belirtmiştir. Katılımcı E, diğer kişilerin kendisini hastalık hastası olarak gördüğünü ve kendi durumunu abarttığını düşündüklerini söylemiştir. Katılımcı B, eşinin kendisine sürekli olarak hastanede olduğunu söylediğini belirtmiştir. Tüm bunlara ek olarak, katılımcı F, eşinin kendisine destek olmadığını, bunun neticesinde fibromiyalji ile yalnız başına baş ettiğini ifade etmiştir.

3. 2. 4. Bir Değişim Aracı Olarak Fibromiyalji

Bu tema, katılımcıların fibromiyalji teşhisi aldıktan sonra ne tür bir değişim sürecine girdiklerini içermektedir. Katılımcıların kendiliklerinde, diğerleriyle ilişkilerinde ve gündelik aktivitelerinde değişiklikler olduğu görülmektedir.

3. 2. 4. 1. Kendilikte Olumlu Bir Değişiklik

Bu alt temada katılımcıların fibromiyalji teşhisi aldıktan sonra sahip oldukları bazı özelliklerden memnun olmadıkları görülmektedir. Örneğin, katılımcı F, kendisini daha fazla üzgün hissetmek istemediğini ifade etmiştir. Katılımcı C, fibromiyaljinin kendisini anlamada bir araş olduğunu, bu teşhisi aldıktan sonra kendisini daha iyi tanımaya başladığını ve hastalığını kötüleştirmeyecek bir şekilde davranmayı öğrendiğini belirtmiştir. Ayrıca, geçmişte, diğerleri için çok çaba harcarken kendi bedenini yıprattığını söylemiştir. Ayrıca katılımcı E, geçmişte fedakar birisi olduğunu fakat artık daha az fedakar birisi olmaya çalıştığını ifade etmiştir.

3. 2. 4. 2. Diğerleriyle İlişilenmede Değişiklik

Bu alt tema katılımcıların diğerleriyle değişen ilişkilerini ele almaktadır. Katılımcı C, ev işleri için eşinden ve çocuklarından yardım istemeye başladığını belirtmiştir. Ayrıca, geçmişte tüm ev işlerini yalnız başına yaptığını fakat artık ev işlerini o kadar umursamamaya başladığını söylemiştir. Katılımcı A, ağrıları başladıktan sonra hayatındaki diğer şeylerin önemsizleştiğini ve iş arkadaşları ile iş yerinde yaşadığı problemleri çözüme kavuşturabilmek için konuşmaya başladığını ifade etmiştir. Katılımcı F, geçmişte, eşiyile ve onun ailesi ile ilgili çok fazla düşündüğünü, fakat artık bu alışkanlığını bıraktığını ifade etmiştir. Katılımcı B ise kendisi ile ailesi arasına bir sınır çektiğini ve onlarla geçmişteki gibi sıkça iletişim kurmadığını söylemiştir.

3. 2. 4. 3. Gündelik Aktivitelerde Değişiklik

Bu alt tema, katılımcıların fibromiyalji teşhisi aldıktan sonra gündelik aktivitelerinde meydana gelen değişiklikleri içermektedir. Katılımcı A, doktoru tarafından kendisine önerilen fiziksel aktiviteleri yapmaya başladığını söylemiştir. Katılımcı B vaktinin çoğunu evde geçirdiğini fakat katılmak istediği yeni aktiviteler olduğunu ifade etmiştir. Katılımcı C kendisine zaman ayırmaya başlamak istediğini söylemiştir.

Katılımcı E ise tedavi planına uyduğunu ve yürüyüş yapmaya başladığını söylemiştir.

BÖLÜM 4

TARTIŞMA

Bu bölümde, bu çalışma tarafından elde edilen bulgular ilk bölümde açıklanan modeller ve ilgili literatür ışığında ele alınacaktır. Ayrıca bu bölüm, çalışmayla ilgili düşünceleri, çalışmanın güçlü yönlerini ve sınırlılıklarını, çalışmanın klinik bulgularını ve sonraki çalışmalar için önerileri içermektedir.

4. 1. Fibromiyaljinin Özellikleri

Bu çalışmanın temel çıkış noktalarından bir tanesi fibromiyaljinin katılımcılar tarafından deneyimlenme şeklinin nasıl olduğudur. Bütün katılımcılar “hiç geçmeyen” bir ağrıdan bahsetmiştir. Benzer bir şekilde, literatürde de fibromiyalji kronik ve yaygın vücut ağrısı olarak geçmektedir (Jahan, 2011; Plazier ve ark., 2015; Wolfe, 1995). Ayrıca katılımcılar fiziksel yorgunluğa bağlı olarak ağrılarının arttığını belirtmişti, Amerika Birleşik Devletleri'nin yiyecek ve madde ile ilgili raporları tarafından desteklenmektedir (2014). Katılımcılar hava durumlarına bağlı olarak ağrılarının arttığını ifade etse de, literatürde bu konuyu destekleyen az sayıda çalışma bulunmaktadır (Smedslund ve ark., 2014). Bütün katılımcılar vücutlarının birden fazla noktasında ağrı olduğunu söylemiştir. Ayrıca, literatürde de belirtildiği gibi katılımcılar, ağrı dışında isteksizlik, uyku ile ilgili problemler ve yorgunluktan şikayetçidir gibi (Plazier ve ark., 1995; Topbaş ve ark., 2004; Wolfe ve ark., 1995).. Son olarak, her ne kadar bazı katılımcılar, şikayetleri başladığı sıralarda fibromiyalji teşhisi almış olsa da, bazı katılımcıların bu teşhisi alması yılları almaktadır (Besson, 2003; Cymet, 2003).

4. 2. Fibromiyalji: Ailesel İlişkilerler Tetiklenen Bir Sendrom

Bu çalışmanın bir diğer temel çıkış noktası kadınların aile ortamında ağrıyı nasıl deneyimlediklerini öğrenmektir. Katılımcıların tamamı eşlerinin doğrudan veya dolaylı olarak ağrılarının artmasında etkili olduğunu ifade etmiştir. Bilişsel Davranışçı Transaksiyonel Modeli'in ifade ettiği gibi, eşlerin tepkileri, ağrı hastalarının streslerinin artmasında veya azalmasında etken roldür ve bunun sonucunda ağrı deneyimi olumlu veya olumsuz bir şekilde etkilenmektedir (Leonard ve ark., 2006). Katılımcıların hepsinin evlilikten beklentisi karşılanmamıştır ve yaşamlarında en az bir kez boşanmayı düşünmüşlerdir. Bu durum akla Aile Sistemleri Kuramı'nı getirmektedir. Bu kurama göre ailede kronik ağrısı olan bir aile üyesi olduğunda, bu durum, orada üstü örtülmüş çatışmalara ve/ya duygusal sorunlara işaret etmektedir (Leonard ve ark., 2006). Katılımcıların çoğu çocuklarını kırmamak için ailenin tüm üyelerinin katıldığı aktivitelere katılmaktadır. Öte taraftan, bir çalışmada kronik ağrısı olan katılımcılarından yarısının sosyal aktivitelere katılmadığı görülmüştür (Moulin ve ark., 2002). Ayrıca, katılımcıların semptomlarının çocuklarının stresli yaşam olayları sonucu arttığı görülmüştür. Literatüre göre, ailedeki stres faktörleri kişilerin baş etme kaynaklarının üstüne çıkabilmektedir, bu durumda kronik ağrısı olan birey kendi bireysel kaynaklarını kullanmaya yönelmektedir ve bu durum semptomlarının kötüleşmesine yol açmaktadır (Preece ve Sandberg, 2005). Her ne kadar bu çalışmada üzerinde durulan nokta katılımcıların eşleri ve çocukları olsa da, bu çalışmada eşlerin ailelerinin ve katılımcıların kendi ailelerinin de fibromiyaljiyi deneyimleme şekilleri üzerinde etkisi olduğu ve bu etkilerin genellikle olumsuz etkiler olduğu görülmüştür.

4. 3. Fibromiyalji: Psikolojik Bir Fenomen

Bu tema içerisinde katılımcıların kendilerini fedakar, hassas, kırılğan, önemseyen ve bir şeyleri kafaya takan olarak tanımladıkları görülmüştür. Öte taraftan, literatürde, fibromiyalji ile eşleştirilen herhangi bir kişilik örüntüsü işaret edilmemiştir (Malin ve Littlejohn, 2012; Torres ve ark., 2013). Ayrıca, katılımcılar bu özelliklerini fibromiyaljiye sahip olmalarının nedeni olarak görmektedir; bu açıklama “kendine döndürme” isimli savunma mekanizmasını akla getirmektedir. Bahsi geçen savunma mekanizması, depresyon teşhisi almış kişiler tarafından sıklıkla kullanılmaktadır

(McWilliams, 2010). Literatürde öfke duygusunun fibromiyalji teşhisi almış kişiler tarafından deneyimlendiği belirtilmiştir (Okifuji, Turk ve Curran, 1999; Van Middendorp ve ark., 2010). Benzer bir şekilde bu duygu katılımcıların da sıklıkla deneyimlediği bir duygudur. Bazı katılımcıların öfke duygularından bahsederken, aynı zamanda, suçluluk duygularından da bahsettiği görülmüştür. Ayrıca katılımcılar üzüntü duygularından da bahsetmiştir. Bu duygu da depresyon teşhisi almış kişilerin de sıklıkla hissettiği bir duygudur. Kendine döndürme savunma mekanizması ile üzüntü duygusunun fibromiyalji teşhisi almış kişiler ile depresyon teşhisi almış kişiler tarafından deneyimlenmesi, fibromiyalji ile depresyonun birbirine eşlik eden iki hastalık olduğunu akla getirmektedir. Fibromiyalji herhangi bir objektif araçla saptanamadığı için, doktorların da içinde yer aldığı kişiler fibromiyaljinin bir sendrom olduğunu reddetme eğilimindedir. (Bernstein, 2016). Bununla paralel bir şekilde, bu çalışmanın katılımcıları, diğer insanların kendilerinin bir hastalıkları olduğuna inanmadıklarını ifade etmiştir. Bunun sonucu olarak fibromiyalji ile yalnız başlarına baş etmeye çalıştıklarını belirtmişlerdir.

4. 4. Bir Değişim Aracı Olarak Fibromiyalji

Bu tema, araştırmacı için beklenmeyen bir bulgu olmuştur. Bu temaya göre, katılımcıların diğerleriyle ilişkilerini ön plana koyarken hem kendilerini hem de gündelik aktivitelerini göz ardı ettikleri saptanmıştır. Diğerlerinden kötü bir şekilde etkilenmemek için bir değişim sürecine girmişlerdir. Bu durum literatürde “travma sonrası büyüme” olarak kavramsallaştırılmıştır ve olumsuz yaşam olaylarından sonra meydana gelen olumlu değişiklikler olarak adlandırılmaktadır (Chun ve Lee, 2008). Bu olumlu değişiklikler kendilikle, diğerleri ile ilişkilerle ve yaşamdaki önceliklerle ilgili olabilmektedir (Moreira-Almeida ve Koenig, 2008).

4. 5. Çalışmayla İlgili Düşünceler

Araştırmacı, katılımcıların aileleri ve eşlerinin ailelerinin, katılımcıların fibromiyalji deneyimleri üzerinde bir etkisi olacağını çalışmanın başında öngörememiştir. Araştırmacının evli olmaması, Türk kültüründe geniş aile üyelerinin kadınlar

üzerindeki etkisini görmesini engelleyen bir unsur olarak görülebilir. Ayrıca arařtırmacı, cinsiyetinden ve psikolog rolünden ötürü görüşme süreçlerinin ve içeriklerinin bunlardan etkilendiğini ve neticede katılımcıların kendilerini kolaylıkla açabildiklerini düşünmüştür. Bu durumun görüşmelerin zengin bir içeriğe sahip olmasına yol açtığı söylenebilir. Bunlara ek olarak arařtırmacının, terapi yapma bilgi ve deneyimini de içeren, profesyonel kimliği katılımcılarla arasında kurulan ilişkinin doğasını ve bulguların yorumlanmasını da etkilemiştir. Farklı profesyonel kimliklere sahip kişilerin bu görüşmeleri yapması ve/ya bu görüşmelerin bulgularını yorumlamasının, bulunan bulgulardan daha farklı bulguların elde edilmesine yol açacağı düşünülmüştür.

4. 6. Çalışmanın Güçlü Yönleri ve Sınırlılıkları

Bu çalışmanın yorumlayıcı fenomenolojik analiz yöntemini kullanması bu çalışmanın en güçlü yanlarından bir tanesidir. Bu yöntem sayesinde kadınların fibromiyaljiyi aile içinde nasıl deneyimledikleri ve bu deneyimlerin aile ilişkilerinden nasıl etkilendiği derinlemesine ele alınmıştır. Ayrıca, fibromiyalji ve psikolojik konular arasındaki ilişki ile fibromiyaljinin değişim sürecine girmeyi tetikleyen bir etken olması bu çalışma tarafından ortaya konulmuştur. Her ne kadar, fibromiyalji çoğunlukla hastalık olarak görülme de, bu çalışma katılımcıların fibromiyaljiyi ve ona eşlik eden güçlükleri deneyimlediklerini göstermiştir. Öte taraftan, bu çalışmanın sınırlılıklarından bir tanesi yorumlayıcı fenomenolojik analiz yönteminin kullanılmasıdır. Her ne kadar görüşmelerden bir tanesinin yazı dökümü bir araştırma asistanı tarafından analiz edilmiş olsa da ve arařtırmacı saptadığı temaları bu araştırma asistanı ve tez danışmanı ile tartıştıktan sonra oluşturmuş olsa da, bu çalışmadaki bulgular arařtırmacı tarafından yorumlanmıştır. Başka bir deyişle, bu çalışma öznellik içermektedir ve bu durum bu çalışmanın bulgularının genellenmesini sınırlandırmaktadır. Ayrıca bu çalışmanın örnekleme arařtırmacı tarafından belirlenen kriterlere bağlı olarak oluşturulmuştur, bu çalışmanın bulgularının genellenmesini sınırlandıran bir diğer durum da budur.

4. 7. Çalışmanın Klinik Bulguları ve Sonraki Çalışmalar İçin Öneriler

Bu çalışma katılımcılarla benzer deneyimlere sahip kişilerin ve sağlık alanında çalışan kişilerin fibromiyaljinin kadınlar tarafından nasıl deneyimlediği ile ilgili önemli farkındalıklar içermektedir. Ayrıca bu çalışma bu deneyimlerle ilgili farklı temaları içermektedir ve bu temalar bundan sonra yapılacak çalışmalar tarafından detaylı olarak ele alınabilir. Klinik psikologlar, fibromiyalji hastaları ile çalıştıklarında onların aile içe ilişkilerine ve bu ilişkilerden nasıl etkilendiklerine odaklanabilir. Ayrıca eşi ve/ya çocuklarından dolayı fibromiyalji semptomları tetiklenen kişiler çift ve/ya aile terapisinden faydalanabilir. Ayrıca, fibromiyalji hastalarının aile üyeleri ile ilgili bilişleri, duyguları, atıfları ve davranışları terapide çalışılırsa, bu kişiler terapiden daha fazla yararlanabilir. Fibromiyalji teşhisi alan kişilerle çalışan klinik psikologlar bu kişilerin duyguları ve bunları nasıl ifade ettikleri konusu ile ilgili çalışmalar yürütebilir. Bunların yanı sıra, klinik psikologlar, fibromiyalji hastalarının gündelik hayatlarına fiziksel aktivite katabilmeleri için onları motive edecek yollar bulabilir veya bu konuda sağlık psikologları ile iş birliği içinde çalışabilir. Tüm bunlara ek olarak, bu çalışma fibromiyaljinin değişim sürecine girmeyi sağlayan bir araç olduğu görülmüştür, klinik psikologlar olumlu olarak görülen bu değişiklikleri destekleyebilir ve böylelikle sürdürülebilir olmasını sağlayabilir. Son olarak bu çalışmanın bulgularından yola çıkarak, psikologlar ile diğer sağlık çalışanları arasındaki iş birliğinin çok önemli olduğu ve iyi bir takım çalışmasının bu hastalıktan muzdarip kişiler için maksimum fayda sağlayacağı söylenebilir.

APPENDIX E: TEZ FOTOKOPİSİ İZİN FORMU

ENSTİTÜ

Fen Bilimleri Enstitüsü

Sosyal Bilimler Enstitüsü

Uygulamalı Matematik Enstitüsü

Enformatik Enstitüsü

Deniz Bilimleri Enstitüsü

YAZARIN

Soyadı: YOĞAN

Adı : FELEK

Bölümü: PSİKOLOJİ

TEZİN ADI (İngilizce): How Do Women Experience Fibromyalgia in Family Context?

TEZİN TÜRÜ: Yüksek Lisans

Doktora

1. Tezimin tamamından kaynak gösterilmek şartıyla fotokopi alınabilir.

2. Tezimin içindekiler sayfası, özet, indeks sayfalarından ve/veya bir bölümünden kaynak gösterilmek şartıyla fotokopi alınabilir.

3. Tezimden bir (1) yıl süreyle fotokopi alınamaz.

TEZİN KÜTÜPHANEYE TESLİM TARİHİ: