

HAVING METASTATIC CANCER AS A YOUNG ADULT: A QUALITATIVE
EXAMINATION OF SELF-DISCREPANCY

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ABSTRACT

HAVING METASTATIC CANCER AS A YOUNG ADULT: A QUALITATIVE EXAMINATION OF SELF-DISCREPANCY

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The main purpose of this study was to investigate the self-concept and discrepancy between different types of selves of young adult metastatic cancer patients. For this purpose, eight female metastatic cancer patients whose ages ranged between 27 and 38 years old formed the sample of the study. Semi-structured interviews were conducted with each participant, and the transcripts of the interviews were analyzed by the Interpretive Phenomenological Analysis method. According to the results, there were 4 superordinate themes: ‘Compulsory Changes in Self-Concept with Ambivalent Evaluations’; ‘New Ideals not in the Agenda of a Healthy Young Adult’; ‘Others’ So Called ‘Minimalist’ Expectations’; ‘My Body is a Cage: “I Feel Like My Soul Stuck in My Body”’. The results were discussed within the framework of the related literature, and the results were interpreted in terms of clinical implications.

Keywords: Self-concept, Self-discrepancy, Metastatic Cancer, Young Adulthood, Interpretive Phenomenological Analysis

ÖZ

GENÇ YETİŞKİN OLARAK METASTATİK KANSERE SAHİP OLMAK: BENLİK FARKLILIKLARININ NİTELİKSEL OLARAK İNCELENMESİ

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Bu çalışmanın temel amacı metastatik kanser tanısı alan genç yetişkinlerin benlik kavramlarının ve benlik türleri arasındaki farklılıklarının incelenmesidir. Bu sebeple, çalışmanın örneklemi 27-38 yaş arası metastatik kanser tanısı almış sekiz kadından oluşmaktadır. Katılımcılarla yarı-yapılandırılmış görüşmeler gerçekleştirilmiştir ve görüşmeler Yorumlayıcı Fenomenolojik Analiz yöntemi ile analiz edilmiştir. Analiz sonuçlarına göre, 4 üst-temaya ulaşılmıştır: ‘Benlik Kavramında Çelişkili Değerlendirmelerle Meydana Gelen Zorunlu Değişimler’; ‘Sağlıklı Genç Yetişkinlerin Gündeminde Olmayan Yeni İdealler’; ‘Diğerlerinin ‘Küçük’ Görünen Beklentileri’; ‘Vücudum Bir Kafes: “Ruhum Bedenime Sıkışmış Gibi Hissediyorum”’. Sonuçlar, ilgili alanyazın çerçevesinde tartışılmış ve klinik etkileri açısından yorumlanmıştır.

Anahtar Kelimeler: Benlik Kavramı, Benlik Farklılıkları, Metastatik Kanser, Genç Yetişkinlik, Yorumlayıcı Fenomenolojik Analiz



To my family...

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CHAPTER 1

GENERAL INTRODUCTION

Cancer, the uncontrolled division of body cells, causes many psychological and physiological impacts in one's life. The incidence of cancer diagnosis is becoming more and more common in Turkey as it is the case worldwide. Although it was once known as "older people disease", cancer rates exhibit an accelerating pattern especially among younger adults (children, older and younger adults) (Sung, Siegel, Rosenberg, & Jemal, 2019; Young et al., 2015). Young adulthood is an important life period in which important decisions are made and new roles and responsibilities are taken (Erikson, 1959). Getting cancer diagnosis during this life period may lead to different effects than diagnosed in older ages. The fact that cancer is less expected for that age and the inability of the person to meet the requirements of the developmental period after the diagnosis may negatively affect the person. Considering that the prevalence is on the rise for younger generations (Kaatsch, Steliarova-Foucher, Crocetti, Magnani, Spix, & Zambon, 2006), it is of utmost importance examining the effects of cancer on young patients' life in terms of psychological health and well-being. Self-concept is one aspect of well-being that is affected by a cancer diagnosis.

Self-concept has been a subject that has been explored by psychologists for many years. Although its definition varies, the widely accepted definition includes that self-concept is about one's thought about themselves. Majority of researcher agrees that self-concept is multidimensional and has a dynamic structure. One framework that examines the different constructs of self-concept is the self-discrepancy theory. Self-discrepancy examines different aspects of the self such as actual-self, ideal-self, and ought-self, and also examines the relationship between these self-constructs (Higgins, 1989a).

This study aims to examine the self-concept and discrepancy between different types of selves of young adult metastatic cancer patients. In this section, firstly, the prevalence and psychological effects of cancer diagnosis will be explained. Next, the self-concept will be introduced briefly, and then the theory of self-discrepancy will be clarified. Later, the effects of cancer on self-concept will be described. Finally, the purpose and importance of the study will be explained.

1.1. Cancer

Cancer is one of the most life-threatening diseases among all kinds of illnesses (Bhattacharjee, 2013; Shirzadfar & Khanahmadi, 2018), and it is quite common as the life expectancy becomes greater. While there were 14 million cancer patients in 2012, this number is expected to increase to 19.3 million in 2025 (World Health Organization, 2015). Cancer is generally defined as the uncontrolled and abnormal growth of cells as a result of DNA damage caused by various reasons (Kumar, Cotran, & Robbins, 2003), and there are more than 200 types of cancer (Coller, 2014). In 2018, 1 out of 6 deaths were reported to be caused by cancer. Besides, approximately 70% of deaths are reported from middle and low-income countries (WHO, 2018). Consistent with these findings, in Turkey, cancer is the second most common cause of death, as well (TÜİK, 2015). It is expected that the rate of cancer diagnosis and the number of deaths due to cancer will increase. The most important reasons for this are thought to be a long life span, sedentary lifestyle, the prevalence of cigarette consumption, and overweight problems (Torre, Siegel, Ward, & Jemal, 2016). However, only 10% of cancers are caused by genetic factors (Shirzadfar & Khanahmadi, 2018).

There are two essential factors while understanding prognosis of cancer; type and stage. Some common types of cancer differ between genders. The most common cancers among women are breast, lung, and cervical cancers. However, the most common cancer types in men are gastric, prostate, and liver cancers (Asthana, Chauhan, & Labani, 2014). The stage of cancer is an important factor in determining the treatment and the course of the disease. The stage of the disease is determined by considering the size of the tumor and the presence of metastasis (Brierley,

Gospodarowicz, & O'Sullivan, 2016). Metastasis is the spread of the cancerous cell to surrounding tissues and other organs (Lazebnik, 2010; Tarin, 2011). It is associated with most of the cancer-related deaths (Chaffer & Weinberg, 2011; Steeg, 2016) and treatment failures (Qiu, Huang, Shi, Xia, Zhao, & Cao, 2016).

1.1.1. Treatment Process of Cancer

The diagnosis of cancer causes the patient to be exposed to treatment methods that are severe and negatively affect ones' daily functioning. Surgery, chemotherapy, and radiotherapy are the most widely used treatment methods (Greenwald, 1997) which might be applied either alone or combined. Surgery is the first and most effective treatment method for many cancer types. The idea of mechanical cleaning of the disease-causing area relieves many patients although adaptation of the person to the results and impacts of the surgery may vary depending on the operated area and its meanings for the person (Guex, 2005).

Chemotherapy uses chemical drugs to treat the disease (Arruebo et al., 2011) or to slow down cell division in the body. However, these drugs affect not only cancerous cells but also healthy cells, as well (Münstedt, Manthey, Sachsse, & Vahrson, 1997). All types of treatment methods could have some side effects on the patients' bodies. Nevertheless, chemotherapy is associated with numerous toxic side effects both physiologically and psychologically (Schirmacher, 2017). These side effects can be mild, moderate, severe, and life-threatening, according to WHO's classification. Some side effects can be seen rapidly on the skin and hair, in the gastrointestinal tract and kidneys. Also, side effects can occur in vital organs such as the heart, brain, and lung (Schirmacher, 2019). Nausea, vomiting, diarrhea, memory impairment, headache, renal dysfunction, and early menopause are some of the side effects of chemotherapy (Smith & Prewett, 2019). Besides, researches show that chemotherapy has a negative effect on sexual interest/function and cognitive functioning, as well (Avis, Crawford, & Manuel, 2004; Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998).

Radiotherapy consists of applying X-ray, gamma, alpha, and beta waves to the cancerous areas. It usually prevents cancer from growing and spreading through damaging the cells (Shirzadfar & Khanahmadi, 2018). Radiotherapy is a safer method when compared with chemotherapy, and it has a low risk of damaging healthy tissues (Guex, 2005). The prominent side effect of radiotherapy is skin damages (Wong et al., 2013). However, sometimes there may be some chronic side effects such as fibrosis and permanent scars (Pastore, Romano, Rese, Conte, Iorio, & Mosiello, 2019).

Hormone therapy is another method used in cancer treatment. Hormone therapy is the use of drugs or hormones to slow down the growth of cancer cells particularly in certain types of cancer. It is also called hormonal therapy, endocrine therapy, or hormone replacement therapy (Sturdee & MacLennan, 2003). Still, it is not free from severe side effects such as vomiting, hot flashes, pain, fatigue (Mouridsen, 2006).

Apart from the elementary physical and psychological difficulties of diagnosing cancer, all these treatment methods have more or less negative physical and psychological effects on the persons' life. Such effects may be more pronounced in the life of younger who have multipleroles and more active social lives rather than the older people (Ahles et al., 2010; Mattsson, Ringner, Ljungman, & von Essen, 2007).

1.1.2. Cancer in Young Adulthood

Young adulthood has been defined cover different age ranges depending on the respective developmental theories. One of the most widely accepted theories is Erik Erikson's psychosocial developmental stages. Erikson emphasized the importance of culture and social environment in identity development. He defined 8 developmental periods and each period has its own conflicts to resolve. Accordingly, 18-40 years old is described as young adulthood. The central conflict of this period is the intimacy against isolation meaning that spousal, friendship and family relations are of great importance during this period. The ability to establishing a close relationship with other people ensures that the conflict of this period is resolved adaptively, and the person feels intimacy (Erikson, 1958).

Cancer diagnosis and cancer deaths are mostly seen in people over 60 years old (National Cancer Institute of Canada, 2006). The comanlity of cancer in old ages mainly explained by the fact that old peoples' stem cells losing the defensive power (Shirzadfar & Khanahmadi, 2018). Although cancer is relatively rare in youngsters, it is one of the most important causes of death in young adulthood and is, therefore, seen as an essential health problem (Bleyer, O'leary, Barr, & Ries, 2006; Bleyer & Barr, 2009). In the 20-39 age group, cancer causes more deaths than many diseases, such as heart diseases and diabetes (Jemal et al., 2005). According to The National Cancer Institute (Howlader et al., 2019), the rates of cancer diagnosis among young adults (20-39 years) between 2012-2016 are 0.0042% for women (425.2 per 100.000 women) and 0.0025% for men (251.2 per 100.000 men). Especially in women, death due to cancer is much higher than other causes (Bleyer & Barr, 2009). Although cancer types in this age group differ, testicular cancer, breast cancer, sarcoma, melanoma, leukemia, and female genital tract malignancy are the most common types (Bleyer & Barr, 2009). Being diagnosed with cancer before the age of 30 cannot be explained mainly by genetics or exposure to carcinogens (Bleyer, Viny, & Barr, 2006). While the cause of cancer is mostly environmental factors in elderly patients, it is thought to be prenatal and congenital in children. Young adulthood cancers are thought to be a spontaneous mutation not related to environmental factors or hereditary (Bleyer & Barr, 2009).

Lifelong developmental theories posit that psychological development is a lifelong process (Baltes, Reese, & Lipsitt, 1980; Elder, Johnson, & Crosnoe, 2003). As such, an essential event like cancer diagnosis definetly affects people in some way or another, depending on the specific developmental phase of life (Albritton, Barr, & Bleyer, 2009). Particularly, being diagnosed with cancer as a young adult might imply some unique challenges due to multiple roles and tasks aimed to be realized during this period. The unique difficulties mostly stem from the fact that deadly diseses like cancer are not usually associated with such young ages which might have nagetive implications on the particular developmental tasks of young adulthood (Albritton et al., 2009; Bleyer, 2007). Young adults are busy with establishing family, having children, maintaining a stable career and engaging in intimate relationships. The

primary duties of this period mainly cover taking persons' own responsibility and gaining social and economic independence, and juggling multiple roles in family system (Arnett, 2000; Buchmann & Kriesi, 2011). However, in the treatment process of cancer, people have to get help to perform their daily tasks and to maintain self-care due to the deterioration in their physical functionality. Therefore, they become dependent on others (Luoma & Hakamies-Blomqvist, 2004). In addition, this process could harm people's future plans and goals due to a possible death threat (Melin-Johansson, Ödling, Axelsson, & Danielson, 2008). Considering the importance of autonomy, independence, and future plans in young adulthood, it is important to examine the effects of diagnosing cancer in this period.

1.1.3. Physical and Psychological Effects of Cancer

The physical effects of cancer are usually experienced due to both illness and treatment related process. Physical effects can be seen in many areas such as pain, weight gain, weight loss, neurological troubles, gastrointestinal problems, nausea, memory losses, distraction, physical functionality deterioration, early menopause (Odo & Potter, 2009; Phillips-Salimi & Andrykowski, 2013; Zebrack, 2011). Neuropathy and physical weakness are amongs other symptoms that can be seen during and after the treatment (Stein, Syrjala, & Andrykowski, 2008). The effects of cancer on a persons' life are not only physical but also psychosocial. The experience of cancer is frequently described with unpredictability, uncertainty, exhausting treatment process, and continuing anticipatory threats, hence being diagnosis of cancer and its treatment are greatly stressful for patients (Gurevich, Devins, & Rodin, 2002).

Extensive research has shown that cancer patients are prone to experience many psychological problems when compared with non-cancer counterparts (Carlson, 2010; Zhang, Xiao, & Chen, 2017). Besides, illness and treatment related physical symptoms such as pain, fatigue, sleep problems and nightmares (Smith, Redd, Peyser, & Vogl, 1999) increase the probability of experiencing higher levels of psychological distress (Bennett, Goldstein, Lloyd, Davenport, & Hickie, 2004; Stone & Minton, 2008). Patients often report that they feel fear, anxiety, and helplessness after being diagnosed

with cancer (Smith et al., 1999). Depression is also common among cancer patients. In a meta-analysis study, the rate of depression of in-patients was found to be ranging from 4% to 14%, while it is between 5% and 16% for out-patients cancer patients, and 7% and 49% for palliative patients (Walker et al., 2013). Reduced concentration, memory impairment, and change in sexual functionality are other psychological problems due to cancer diagnosis which are further complicated by the uncertainty of disease and treatment process (Caruso, Nanni, Riba, Saboto, & Grassi, 2017). Cancer also has debilitating consequences on perception of self, others and the world after the diagnosis. Coupled with the side effects and uncertainty of the disease process, many cancer patients suffer from low self-esteem, low sense of control and instability of intimate relations (Martins et al., 2019).

Although the afformentioned psychological impacts might be evident across patients of different ages, youngsters with cancer seem to experience some particular challenges in consistent with their developmental conflicts and responsibilities (Zebrack & Isaacson, 2012). Accordingly, young adult with cancer feel they fall behind their ages since disease and treatment process compromise their autonomy, decision making process and quality of work and family relationships. They usually felt distress as the physical and psychological threats associated with prognosis prevent them from living their life fully as their peers (Eiser & Kuperberg, 2007; Zebrack et al., 2013). Besides, establishing and maintaining social ties is an important developmental task for young adults. Yet, young cancer patients have to maintain their treatment which prevent them to participate social events like their peers. Thus, many young cancer patients feel alienated and isolated because they cannot do many things that their peers do because of cancer, such as going to school / work, getting married, acting independently, or having children (Zebrack, Hamilton, & Wilder-Smith, 2009). Another factor affecting the social relationship can be the change in body perception. Changes in bodily appearance such as hair loss, weight loss, which often appear as side effects of the treatment process, can affect people's perception of the body. Their images are important to young adults because they ask for their peers' approval (Bleyer, 2007). Due to changes in body appearance, people may perceive themselves less attractive (Rudberg, Carlsson, Nilsson, & Wikblad, 2002). Change in social life

has a dual effect. One dimension is that the changes people experience due to cancer negatively affect social life. The other dimension is the deterioration in social life negatively affects the psychological well-being. Social relations have an important role in identity development in young adulthood. Thus, the absence or deterioration of social relationships have negative effects in young adulthood (Tindle, Denver, & Lilley, 2009).

Romantic relationships and sexuality are also fundamental of defining self during young adulthood. Cancer diagnosis and treatment process can negatively affect a person's romantic relationships and sexuality as well as social relationships due to chronic pain, fatigue, early menopause, and instability of hormones (Evan, Kaufman, Cook, & Zeltzer, 2006; Fobair, Stewart, Chang, D'Onofrio, Banks, & Bloom, 2006). Sexuality is a criterion of quality of life, and therefore any deterioration is important. This effect can be short and long term: such as sexual reluctance to infertility. Deterioration in sexuality and intimacy can cause stress in people and to reduce this stress, it is recommended that individuals develop a 'new normal' definition for sexual activity and intimacy (Bolte & Zebrack, 2008). Changing even the definition of normal can reflect how much the lives of people have changed due to cancer.

These negative effects that occur in social life, romantic relationships and sexual life can negatively affect the general psychological well-being. According to the literature, young people compared to the older group have more anxiety and depression (Linden, Vodermaier, MacKenzie, & Greig, 2012), more difficulty in adapting to the diagnosis of cancer (Kornblith et al., 2007), higher stress levels (Christensen et al., 2009; Kornblith et al., 2007; Mertz, 2012) and increased risk of breakdown of the quality of life (Howard-Anderson, Ganz, Bower, & Stanton, 2012; Reed, Simmonds, Haviland, & Corner, 2012; Wenzel et al., 1999). The deterioration of their future plans, as well as the deterioration of their roles and responsibilities, are considered as some of the causes of the stress that they experience (Dunn & Steginga, 2000). For example, they may have fear about being parent. Young cancer patients may not want to have a new child due to the fear of recurrence of cancer (Senkus et al., 2014) or they may feel anxiety about became infertile due to treatment (Kent, Parry, Montoya, Sender, Morris,

& Anton-Culver, 2012). In addition, the difference between the fact that they become more dependent on others due to the cancer and the desire to be independent in accordance with the development period becomes an important source of tension (Kent et al., 2012).

Cancer has not only negative but also positive psychological effects. Many studies confirm that cancer survivors show some positive life changes (Bellizzi, 2004; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Sears, Stanton, & Danoff-Burg, 2003). Since an undesirable and robust life event in a person's life changes one's assumptions about past and future so that any improvement in their life style or life opinion defined as positive effects (Tedeschi & Calhoun, 1996). For example, the appreciation of life as what she/he has and re-evaluation of her/his priorities are considered as positive effects of cancer (Casellas-Grau, Ochoa, & Ruini, 2017).

Cancer also has an effects on self-concept. Since the focus of this study is on the self-discrepancies of young adult cancer patients, information about self-concept will be given in the following section.

1.2. Self-Concept and Self-Discrepancy Theory

The term 'self' or 'self-concept' is a notion that has been studied in psychology for many years. (Allport, 1943; Rosenberg, 1979; Schlenker, 1985; Smith, 1980). However, there is no single agreed on definition of self-concept due to the multidimensional structure of the construct. Self-concept, in its most general form, can be referred as the person's perception, feelings, attitudes, and behaviors in relation to the construct of self (Marshall, 1989; Plucker & Stocking, 2001; Rosenberg, 1979; Shavelson, Hubner, & Stanton, 1976; Oyserman, 2001).

Many researchers have identified different dimensions of the self and their relationship to psychological well-being (e.g., James, 1890; Freud, 1914/1957; Rogers, 1954). In general, conceptualization of self consists of social, emotional, and physical aspects (Ackerman & Wolman, 2007; James, 1890). William James (1890), the first theorist who highlighted the multidimensional structure of self suggested that self has two main

dimensions, which are 'I' and 'Me'. These selves are distinguished as the self acting and the self that realizes that person is doing the action. The first one called as 'I' part and 'self as knower'; however, the other one called 'me' part and 'self as known'. In one, the person is the subject, and in the other, the person is the object. These reflect two aspects of the self, and they form integrity together. That is, 'me' self is closely related with self-consciousness (Blanke & Metzinger, 2009; Dainton, 2016). Accordingly, the person is considered as the subject as a person who acts, evaluates and thinks, and also as an object who is thought, evaluated and affected by the perception of others (Bandura, 1978). Later, Baldwin (1897) widens conceptualization of self and posited the 'socius' or 'social-self' dimension. In this definition, it was emphasized that the self has a social and cultural dimension. As similar to James's 'me' self, Cooley (1902) developed the 'looking-glass self.' With this term, he describes the process by which the individual's self-opinions are influenced by how others see and perceive him/her. All these explanations support the evidence that self-concept cannot be captured comprehensively without understanding multiple dimension contributing self-concept.

Rogers (1954), who is also the founder of client-focused psychotherapy, made notable contributions to the study of self-concept. He identified the different structures of the self and their relationship to psychological comfort. According to Rogers, self-concept consists of two main parts which are real-self (actual-self) and ideal-self, respectively. Real self is all about who and what the person is while ideal self refers to features that the person wants to have ideally. These characteristics tried to be attained might be related to physical, psychological and social traits. Yet, when the diversion between characteristics of real self and ideal self is too wide, incongruence occurs which is close related with many psychological problems. Accordingly, if real self and ideal self are similar to each other, the person will be psychologically healthy. However, if the difference between the two types of self is large, the person will experience psychological problems such as anxiety, depression, and lack of self-confidence (Rogers, 1954; Rogers, 1961).

Furthering Rogers's theory, Higgins (1987) developed a comprehensive approach, called as Self-Discrepancy Theory (SDT), to identify the incongruence between the various dimensions of the self-concepts and their impacts on psychological health. SDT defines how people perceive themselves, their ideals and responsibilities. According to this theory, self has three essential domains, namely, actual self, ideal self, and ought self. Actual self refers to the traits that someone believes he/she actually owns. Basically, it covers responses given to the question of 'who you are?'. By contrast, ideal-self represents the traits that someone ideally would like to be (i.e., hopes and wishes) and covers basically responses given to the question of 'who you would like to be?'. Finally, ought-self refers to the traits that someone believes he/she should/ought to own. These "should be own" characteristics are in close relation with duties, responsibilities, moral standards. In otherwords, ought self comprises of answers given to 'who you should be?'. Accordingly, ideal-self and ought-self are considered as self-guides. These self-guides are basically compared to current self, and they can use to assessment discrepancy (Higgins, 1987).

The classification of ought-self is one of the essential points that distinguishes Higgins's theory from Rogers' theory. Moreover, Self-Discrepancy Theory has some fundamental aspects that distinguish itself from other self-related theories. According to Higgins (1987), this theory has three primary objectives. Firstly, the theory distinguishes different types of annoyance that people with contradictory beliefs may experience. Secondly, the theory associated different discrepancies with different types of emotions. That is, three self-types will create different types of discrepancies and each discrepancy will lead to a different emotional vulnerability. Last but not least, it emphasizes that different self-discrepancies exist and accessible when trying to determine what kind of discomfort people often experience. Basically, this theory emphasizes that one will experience different negative results depending on the type of discrepancy between the selves and that it will be important to understand what the person is experiencing.

The Self-Discrepancy Theory not only defines different dimensions of the self, but also different standpoints in the perception of self concept. Accordingly, self-concept

includes both perception of an individual' regarding oneself and the perception of significant others (e.g., parents, siblings, romantic partner, friends) about themselves (Higgins, 1989a). In other words, the importance of significant others while forming different structures of self-concept has been emphasized for different types of self and self-perceptions. Therefore, a total of six selves are conceptualized including ones' own perceptions and others' perceptions and named as actual-own, actual-other, ideal-own, ideal-other, ought-own, and ought-other selves (Higgins, 1989). Unless a balance is established among self-guides, discrepancies would develop resulting in certain negative emotions. Discrepancies between actual-self and ideal-self is associated with dejection related emotions (e.g., sadness, disappointment etc.) due to feeling of inability to reach something wished to be attained (Higgins, 1987; Strauman, Lemieux, & Coe, 1993). A mild discrepancy usually causes sadness, while an advanced discrepancy results in depression. Nevertheless, the discrepancy between actual-self and ought-self leads to agitation-related emotions (e.g., worry, anxiety, guilt) due to the inability of someone to do what she/he feels to do (Higgins, 1987). The mild level of this type of discrepancy is related to the feeling of nervousness, while the higher level is related to generalized anxiety. Reversely, SDT claims that when actual/ideal self match, one will experience emotions like happiness, and when actual/ought self match, one will experience emotions like calm (Higgins, 1987).

The emotional consequences of the difference between self shaped by ones' own perception (Higgins, 1999) and self originated from others' perception (Moretti & Higgins, 1999a-1999b; Moretti, Holland, & McKay, 2001) have been the subject of various research. In a study with high school students using four self types, the results were consistent with the emotional vulnerability proposed by the theory. They test actual/own-ideal/own; actual/own-ideal/other; actual/own-ought/own; and actual/own-ought/other discrepancies and results showed that actual/ideal discrepancies were associated with dejection-related emotions and actual/ought discrepancies are related with agitation related emotions regardless of the standpoints (Higgins, Klein, & Strauman, 1985). Although these results are supported many studies (Strauman, 1989-1992; Strauman & Higgins, 1988), there are also some studies where particular discrepancy is not found to be related to specific emotions (Heppen

& Ogilvie, 2003; Ozgul, Heubeck, Ward, & Wilkinson, 2003; Phillips & Silvia, 2005). Furthermore, in some studies, anxiety and depressive emotion were confirmed to be related to specific discrepancy (Higgins, 1987; Higgins, Klein, & Strauman, 1985; Moretti & Higgins, 1990; Scott & O'Hara, 1993), but no supportive results have been found for other emotions like shame and guilt (Tangney, Neidenthal, Covert, and Barlow, 1998).

Higgins (1999) agreed that the relationship between the type of self discrepancy and the emotional vulnerability may not always be observed. Thus, he suggested that in this relationship “the magnitude of a self-discrepancy, the accessibility of a self-discrepancy, the applicability and relevance of a self-discrepancy in a current context, and the importance of a self-discrepancy to the person” are have moderator effect. Accordingly, as the effect of the four moderators' increases, the likelihood of discrepancy related emotions increases, as well (Higgins, 1999). It is suggested that the current location (e.g., for academic wishes being the university or a café) (Boldero & Francis, 1999) and self-awareness (Philips & Silvia, 2005) have a moderator effect on this relation. These discrepancies are also related with differences in the motivational aspect of an individuals' life. While actual/ideal discrepancy is associated with discouragement, actual / ought discrepancy is usually associated with cautiousness (Higgins, 2012).

The impact of self-discrepancy has been in relation to various psychological problems, as well. The relationship between social anxiety (performance and social interaction anxiety) and self-discrepancy was examined, and the results confirmed that there is a significant relationship with actual – ought discrepancy and social interaction/performance anxiety (Johns & Peters, 2012). A meta-analysis study examining 70 studies also support that there is a relationship between self-discrepancy and psychological well-being. The study found that the extent of the relationship between self-discrepancy and psychopathology varied between mild-moderate, and actual-ideal discrepancy had a stronger relationship with anxiety and depression than actual-ought discrepancy (Mason et al., 2019). These results were also valid for people with chronic pain. A study with patients having chronic low back pain suggested that

higher self-discrepancy results in increased stress and depressive symptoms (Waters, Keefe & Strauman, 2004). Studies show that there is a positive relationship between negative psychological conditions such as anxiety and depression and self-discrepancy. However, there is a negative relationship between the purpose of life and self-discrepancy (Stanley & Burrow, 2015). These findings suggested that increasing self-discrepancy negatively affects the psychological health of the person.

Self-concept is considered as a dynamic structure that is affected by the persons' experiences and social environment (English & Chen, 2007; Sarbin, 1952). Cancer diagnosis, which is an important life event in a persons' life, also has effects on self-concept. For this reason, information about cancer disease will be given in the following section. The self-concept changes over time, especially it changes after events that cause changes in one's daily routine (Demo, 1992).

1.3. Cancer Diagnosis and Self-Concept/ Self-Discrepancy

There might significant changes in the self-concepts of cancer patients in multidimensional aspects due to diagnosis itself and treatment process. Yet, self-concepts of cancer patients have been exclusively investigated in relation to body image, self-esteem, or self-efficacy (e.g., Mock, 1993; Pintado, 2017; Vas, Povey, & Clark-Carter, 2019). To illustrate, alopecia, thinning of or losing hair, is a common side effect during cancer treatment. which has devastating impacts on a patient's body image and self-esteem (Münstedt, Manthey, Sachsse, & Vahrson, 1997; Lemieux, Maunsell, & Provencher, 2008). Similarly, body related concerns lead to many psychological problems particularly among women with breast cancer. As breasts and reproductivity are perceived as symbols of femininity (Fang, Lin, Chen, & Lin, 2015) those women usually suffer from greater levels of depression and anxiety due to profound body related changes (e.g. loss of breasts, infertility) resulted from treatment protocols (Begovic-Juhant, Chmielewski, Iwuagwu, & Chapman, 2012; Chua, DeSantis, Teo, & Fingeret, 2015; Pintado, 2017). A recent study provided further support to the relationship between self-concept changes and psychological distress. This study highlighted that palliative care patients suffer greater deterioration in their

body regardless of gender. Particularly, a strong commitment to before the disease body images increased the distress further which compromises use of functional coping strategies, coping skills (Vas et. al., 2019).

Although self-concept has social, psychological and cultural dimensions, only a few studies examined changes in self perception of cancer patients in relation to aspects other than body perception. Existing studies indicated that a positive self-concept during disease prognosis mediate the relation between anger and resilience among adolescent cancer patients (Wu, Chang, Tsai, & Liang, 2018). It seems that intrapersonal and interpersonal changes aroused from disease process encourage some patients to revise their identity and the norms they are living with. If revision process is experienced positively, it increases sense of control and autonomy (Kumar & Schapira, 2012).

There are a limited number of studies examining the self-discrepancy of cancer patients. According to a quantitative study in which self-discrepancy of elderly women with cancer were compared with older women without cancer, no difference was found between the two groups in terms of self-discrepancy. However, cancer patients were found to have lower ideal-self scores. Because of these results, it was interpreted that cancer patients keep their self-discrepancy at the normal level by lowering their ideal self. The ideal self is reduced as a compensation for the possible change occurring in the actual self due to cancer (Heidrich, & Ward, 1992). This change can be considered as important for the protection of psychological health. Another study with cancer patients has been found that high levels of self-discrepancy are associated with high depression, low psychological health, and low life purpose regardless of the severity of symptoms. Furthermore, it was found that self-discrepancy has a moderator effect between one's perception of health status and depression, life purpose and good relations. Thus, Self-discrepancy of cancer patients will be related to their adaptation to the disease (Heidrich, Forsthoff, & Ward, 1994). However, the average age of the participant is 62 of that study. So, self-discrepancy has not been studied for young adult cancer patients, and studies about psychosocial dimensions are limited.

1.4. The Aim of the Thesis

Diagnosing metastatic cancer is challenging for all patients, but its effect may vary depending on the persons' developmental period. However, young adulthood could be considered as more vulnerable to severe effects of metastatic cancer. Because, normally, physically the most energetic times of life is young adulthood and at that time people take important steps for their lives (Charmaz, 1983). Furthermore, it is a rare and shocking experience to be diagnosed with cancer in young adulthood. Since they are at a young age and are diagnosed with a life-threatening disease, young people with any metastatic diagnosis tend to experience psychological problems (Dunn & Steginga, 2000). Thus, this focus group need special examination to really understand what they experience after diagnosis. For this purpose, this study aimed to examine what young adults experience when they are diagnosed with metastatic cancer, by focusing on self-concepts and discrepancy between different aspects of selves.

In the literature, some changes in self-concept are reported after cancer diagnosis. However, studies on self-concept mostly focus on physical and bodily changes. There is no study which examines the self discrepancy between different selves of cancer patients to the best of our knowledge. However, self-discrepancy has been found to be associated with physical health and psychological functionality in cancer (Heidrich, 1999). Thus, this study, aimed to contribute to this gap in the literature.

Considering all these factors, a detailed examination of the self-concept and discrepancy between selves of young adult women would be critical in determining the psychological needs and correct psychological interventions of this group.

The following research question has been investigated:

1. How did metastatic cancer diagnoses affect the self-concept of young women in terms of the discrepancy among different aspects of selves?

CHAPTER 2

METHOD

In this section, the theoretical background of the method used in the current study was explained, then information about the participants, data collection process and data analysis would be provided.

2.1. Methodological Background

2.1.1 Qualitative Researches

Qualitative studies are different from quantitative research in terms of their goals/hypotheses, researcher's position and investigation of experience (Lefevre, Moro & Rachel, 2019). While quantitative research tests the accuracy of a predetermined hypothesis, qualitative methods are mainly concerned with the meaning created by data itself. In qualitative studies how a person interprets a subject and how it is experienced is examined with all its subjectivity. In other words, the nature of the experience itself is examined in detail (Pietkiewicz & Smith, 2012). Thus, the main purpose of qualitative studies is to investigate how an event, situation or concept is experienced and expressed by individuals (Mays & Pope, 2000).

Qualitative studies are carried out by obtaining in-depth information regarding a particular phenomenon with smaller number of participants. Thus, thickness of data is enriched through in-depth theoretical investigation (Mays & Pope, 2000). There are many qualitative research methods such as Grounded Theory, Discourse analysis, Phenomenology, Narrative Analysis, Interpretative Phenomenological Analysis (Smith 2008; Willig 2008; Camic, Rhodes & Yardley, 2003). These methods differ in terms of the nature of research questions, sampling procedures and analytic strategies.

Only Interpretative Phenomenological Analysis (IPA) methodology was explained in the following section as it was employed in the present study.

2.1.1.1 Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) provides an extensive understanding of how a person lives a specific experience (Smith, 2008) and how they make sense of it (Taylor, 1985). IPA has three fundamental principles which are phenomenology, hermeneutics, and ideography. Firstly, IPA is mainly a phenomenological method meaning that it aims to understand basic parts of a phenomenon or experience that is unique to the individual, separating it from others' (Pietkiewicz & Smith, 2012). That is, its purpose is to investigate core of the subject rather than to reduce it to the predefined categories. Secondly, IPA employs hermeneutics method, the method of interpretation, through which not only experience itself but also how the experience is expressed get an importance. In other words, IPA not only defines what the experience is but also examines how the situation, event or concept is experienced in a detailed and inclusive way with an interpretation. In fact, IPA is particularly defined as a double hermeneutic method. In double hermeneutic method, the participant initially explains the experience with their perception and interpretation. Later, the expressed experience is reinterpreted with the subjectivity of the researcher (Smith & Osborn, 2007). Thirdly, IPA is ideographic meaning that IPA focuses on a particular subject and examines it in detail for each individual to the point when a detailed and rich knowledge is available for that specific group (Smith, Flowers, & Larkin, 2009). This means that the researcher "focuses on the particular rather the universal" (Smith, Harré, & Van Langenhove, 1995). Therefore, all cases are analyzed separately without relying on a general statement (Pietkiewicz & Smith, 2012). So, IPA researcher starts analysis with the first case and after finishing its detailed examination, proceed through the analysis of the second case with the same attention until the last participant (Pietkiewicz & Smith, 2012).

IPA have been applied in many fields, especially in health and clinical psychology. This method is generally recommended to study relatively little researched topics

(Smith, Jarman, & Osborn, 1999). This thesis research aimed to provide an understanding of the experience of young adult metastatic cancer patients' self-concepts and discrepancy between selves in depth. As far as it is known, studies on this subject are limited and there is no study with young adults. Since other studies are conducted by quantitative method, it is important to investigate patients' experiences in detail in this context. In particular, a detailed understanding of the shaking effect of diagnosing metastatic cancer in young adulthood is necessary for possible treatment and interventions. For this purpose, IPA is the best methodological background because it is mainly used to investigate how people make sense of major life events (Smith, et al., 2009). It gives the chance to investigate participants' appraisal, perception, and emotion in detailed. In other words, it makes it possible to understand participant words as much as possible. Therefore, IPA is best methodology for this study, which has never been thoroughly investigated qualitatively.

2.2. Participants and Sampling Method

In IPA, participants are selected purposively to create a homogeneous sample in an attempt to obtain detailed information on the interest subject (Smith, Flowers, & Larkin, 2009). Consistently, the inclusion criteria were determined as follows (1) being a young adult between the ages of 20 and 39 (2) being a female metastatic cancer patient (3) being aware of the current diagnosis and (4) going through active treatment at the time of the study. As the main aim of this study was to understand self-related conceptualizations of young adults with metastatic cancer, age range was determined according to Erikson's description of young adulthood stage (Erikson, 1963). Besides, only patients with metastasis and in active treatment were selected since both metastatic cancer and related treatment experiences are associated with more profound life style changes among young adults (Lo, Lin, Gagliese, Zimmermann, Mikulincer & Rodin, 2010; Kroenke, Rosner, Chen, Kawachi, Colditz & Holmes, 2004). Even though no criteria regarding the relationship status had been determined, all participants were single. Being a mother was also determined as an exclusion criterion as it might compromise the homogeneity of the sample.

Accordingly, current sample was composed of eight female metastatic cancer patients whose ages ranged between 27 and 38 years old. These patients were receiving active treatment at Hacettepe University Oncology Hospital. Although one patient was not diagnosed with metastatic cancer, she was included to the present study as her disease (i.e. glioblastoma) affects more than one area of her body and was regarded as metastatic. Researcher invited participant either through face-to-face invitation at treatment room or by phone. There was only one patient who met the eligibility criteria yet did not agree to participate in the study. Six of the participants were living with their family (e.g. Asya, Fatma, Emel, Seda, Oya, Ayşe) both prior to and after the diagnosis. One patient (Canan) was living alone and the other (Derin) moved to her family after the diagnosis. Some demographic and diagnostic information of participants was presented in Table 1. The primer diagnoses of the participants were written and the areas with metastases were indicated in brackets. The name of the participants was distorted to assure confidentiality.

Table 1 *Demographic and Diagnostic Information of Participants*

Name	Age	Marital Status	Education	Treatment	Diagnosis	Time Since Diagnosis
Asya	27	Single	University	Chemotherapy	Throat (Air Tube & Lung & Liver)	6 years, 11 months
Derin	33	Single	University	Chemotherapy	Colon (Lung & Liver)	9 months
Fatma	38	Single	University	Chemotherapy	Breast (Lung & Liver)	5 years, 2 months
Emel	27	Single	University	Chemotherapy	Glioblastoma	4 years, 5 months
Seda	27	Single	University	Chemotherapy	Soft Tissue (Lung & Uterus)	2 years, 1 months
Canan	30	Single	University	Hormone Therapy	Adenoid Cystic (Lung & Bone)	9 years 10 months
Oya	36	Single	University	Chemotherapy	Stomach (Ovary)	7 months
Ayşe	37	Single	University	Chemotherapy	Soft Tissue (Lung)	1 year

2.3. Procedure

Before data collection process, ethical permission was obtained from the Human Subject Ethics Committee of METU (see Appendix A). Since data would be collected from Hacettepe University Oncology Hospital, an application was also made to the hospital management and additional permission was obtained (see Appendix B). Since the researcher was working as a clinical psychologist in this hospital, she talked about

the purpose of the study to the participants who met the criteria and invited them to the study. Appropriate patients were screened from the hospitals' information system. While some patients were invited to face-to-face while they were receiving treatment in the hospital, others were contacted via the telephone numbers received from the system and invited to the study. Face to face semi-structured interviews were conducted with the people who agreed to participate in the study voluntarily. The interviews were held in a room where the participant and the researcher were left alone. Interviews were made in the clinical psychologist' room with the outpatients and in the patient's room with the inpatients. Only one interview was held with each participant and interviews lasted between 35 to 85 minutes. All participants were informed about the purpose of the study and audio recording, and then their written consent was obtained subsequently (see Appendix C).

The data was collected through semi-structured interviews as it is generally used and recommended in IPA analysis (Smith, 2008). Questions are predefined, open-ended, and far from directions. The interview questions were developed by the research team to examine the changes in the self-concept of the participants after being diagnosed with metastatic cancer (see Appendix D & E). Also, the researcher encouraged the participants to speak freely in order to express their true experiences with all their subjectivities.

The data collection process took seven months (December 2018 to June 2019). A pilot interview was conducted to test the suitability of the questions for the study. In the pilot interview, there were no questions that were not understood, so; no changes were made of the question list. After the first interview was analyzed and the results shared with the research team, other interviews were conducted. All interviews were included in the analysis.

2.4. Data Analysis

Analysis of data was carried out in a rigorous process based on subjectivity without being restricted by previous theoretical knowledge as much as possible. In other words,

an inductive perspective was employed consistent with IPA rationale (Pope, Ziebland, & Mays, 2000; Smith & Osborn, 2003). As recommended analyzes of the participants' accounts were performed in an order (Smith et al., 2009). First of all, a word by word transcript was prepared from the audio recording of the first interview and read twice. This re-read process was crucial to familiarize with data well, and to think about possible themes about overall of the interview (Smith et al., 2009). Then, the transcript of the first interview was coded according to its content, language, and interactional context. The codes were grouped consistent with their conceptual relation. In this way, a list of sub and super-ordinate themes had been determined. The findings of the analysis for the first case were shared with the research team and organized within the framework of their conceptual feedbacks. Then the same analytic process was repeated for the second interview. Cross-case comparison was made between the theme lists of first and second interviews and a common theme list was developed. The same process was repeated exactly for the analysis of all remaining interviews one by one. After each analysis, a comparison was made with the last common theme list. Previous analyzes were re-examined for new themes emerging in the following sessions. Throughout the analysis process, results were shared with the research team periodically.

All transcription was made by the researcher. The analysis of the first interview was made with the research team, after that, the remaining analyzes were done by the researcher and the feedbacks of the research team was received. During all interviews and throughout the analysis process, the researcher took notes about her feelings and thoughts because subjectivity is an important component of the IPA analysis. These notes were used in the analysis phase.

2.5. The Trustworthiness of the Study

The reflexivity of the researcher is an important part of the IPA since it shapes the interpretation of results (Willig, 2008). Therefore, in IPA studies, it is recommended to write the reflexivity section, where the researcher specifies the characteristics that

may affect the way she/he formed the research question and interpreted the data. So, in this section, background information about the researcher was presented.

“I am 28 years old, female, and clinical psychologist. My research interest on this topic stems from my work experience as a clinical psychologist in an oncology hospital. I worked in the same hospital for three years and was making psychotherapy sessions with cancer patients and their relatives. I have observed people have difficulties in accepting the diagnosis and adjusting changes in their lives after a cancer diagnosis. Patients often stated their confusion due to cancer diagnosis, chemotherapy or radiotherapy process by saying ‘I cannot take it’ (“*kendime konduramıyorum*”); ‘I was a person with decent strength but now I cannot even perform my job’ (“*güçlü kuvvetli biriydim şimdi çalışamıyorum*”), ‘I was not a person who gets sick easily, now I cannot understand how I got this illness’ (“*ben hiç hasta olan biri değildim nasıl böyle bir hastalığa yakalandım anlamıyorum*”). In brief, patients often state their confusion about their perception of self and the possible change of this perception. Such sentences in sessions make me curious about this topic and constitute the main motivation to conduct this study.

One of the important things I noticed during the analyzes was that before my work experience, cancer disease meant for me that it caused me to lose my grandmother. And, I realized that I never knew exactly what she thought, what she felt, what she lived, even though I was with her during the treatment process. Although the sample of the study consists of a different age group, I think this personal experience may have affected my research interest. While presenting my thesis study proposal, I said that I tend to focus on the positive aspects of patients' experiences. Now, I think that this tendency may be related to my personal experience. During the analysis, I tried to realize the impact of this tendency as much as I could.

I experienced emotional difficulty to listen to the patients' experiences with all their emotional dimension, both during my work experience and during this research. I had felt anxious especially in the part when doing the transcription of the audio recordings. At these times and when I felt intense negative emotions during the analysis, I took a

break in order not to harm the process. In this process, I thought that if I continued analysis with intense anxiety, it might affect the process negatively. For this reason, I shared my feelings with my clinical psychologist colleague during the analysis process in order to this emotional difficulty not to affect the analysis. I also tried to understand why this emotional difficulty was caused.

However, I believe that my professional experience as a clinical psychologist and personal experiences as a the relative of the patient make it easier to establish relationships with the participants in the interviews. Establishing a good relationship is essential so that people can express themselves more accurately and comfortably.”

CHAPTER 3

RESULTS

In this study, self-concepts of female young adult cancer patients were examined. For this purpose, interviews of eight participants were analyzed according to the guidelines of Interpretative Phenomenological Analysis (IPA). As a result of the analysis, four super-ordinate themes; (1) Compulsory Changes in Self-Concept with Ambivalent Evaluations, (2) New Ideals not in the Agenda of a Healthy Young Adult, (3) So Called ‘Minimalist’ Expectations from Others, and (4) My Body is a Cage: “I Feel Like My Soul Stuck in My Body (See Table 2) emerged. In this section, the super-ordinate themes and their subthemes were explained with quotations from the interviews in order to make the process transparent.

Table 2. *Themes of Interpretative Phenomenological Analysis of Young Adult Metastatic Cancer Patients in terms of Self-Concepts*

1. Compulsory Changes in Self-Concept with Ambivalent Evaluations
1.1. Overvaluation of being Strong: Pushing the Limits
1.2. Justification of the Characteristics of Self after Cancer
1.3. Ambivalent Emotions about the Loss of Developmental Characteristic of Young Adulthood: Laughing while Losing
1.4. Feeling Isolated from the Peers
2. New Ideals not in the Agenda of a Healthy Young Adult
2.1. Normalcy is Becoming the New Ideal
2.2. Need for an Omnipotent Self to Beat Cancer
3. Others’ So Called ‘Minimalist’ Expectations
3.1. Expectations-Centered Only around Survival
3.2. Restrictions due to Others’ Pressure of being Strong
3.3. Feeling Guilty because of Cancer Burden Imposed on Family
4. My Body is a Cage: “I Feel Like My Soul Stuck in My Body”

3.1. Compulsory Changes in Self-Concept with Ambivalent Evaluations

This superordinate theme was about how participants perceived themselves after cancer diagnosis and how they emotionally reacted to these perceptions. In particular, it covers the effects of mandatory changes due to metastatic cancer diagnosis on the self-perception of the participants. Almost all participants reported loss of some part of their identity, while some mentioned positive and negative characteristics that had become evident after the metastatic cancer diagnosis. Interestingly, patients had a tendency to report these changes with ambivalent emotions and their feelings fluctuated fast during reporting their experiences. There is an ambivalence in their self-perceptions arising from being faced with a metastatic cancer diagnosis at such a young age. On the one hand, they over-emphasized strength with positive emotions and even denied their physical limitations. On the other hand, they expressed a feeling of weakness, loss and grief. In summary, this superordinate theme reflected the complex effects of ‘struggling’ with the diagnosis of metastatic cancer as a young adult and its impact on self-evaluations.

3.1.1. Overvaluation of being Strong: Pushing the Limits

The first theme was over valuation of being strong. This sub-theme represented the “extreme efforts” our patients spent in order not to cry and seem weak during disease process. They just tried a lot to continue their life as same as before cancer diagnosis. This theme also covered acting “as if” there hadn’t been any physical or psychological losses. Participants believed that such an attitude made them “different” from other patients. It seems that young metastatic cancer patients tried to remain strong and motivate other patients. Besides, being strong was perceived to be an important necessity to beat cancer. Although forcing themselves to catch up normal helped them psychologically, it was also evident that they denied the extent of their physical symptoms. For example, Asya felt proud of herself since she continued working in spite of her doctors’ recommendations. Although she enjoyed the positive comments of her colleagues about her perseverance for working, her physical difficulties were also evident between the lines:

“Güçlü derler onu çok duydum. ‘Çok güçlüsün biz- ben senin yerinde olsam böyle düşünemezdim’ gibi onu diyebilirler ... çok sıkıntılı nefes alamıyorum yürüyemiyorum falan ama o zorluklarla 4 ay işe gittim. Mesela iş arkadaşlarımdan haberleri vardı hani sıkıntıdan. Ben söyleyince bana çok hayran kalıyorlardı. ‘Nasıl yapabiliyorsun’ – bir de düşüncelerimde öyle şey yoktu hani ‘niye bana oldu?’ falan – çok pozitif insanımdır yani”

“They say ‘strong’, I heard it a lot. They say it like ‘You are so strong – We- I couldn't think like that if I were in your shoes’ ... I was not able to breathe easily, I couldn't walk, but I went to work with those difficulties for 4 months. For example, my colleagues aware of my disease. When I talked about the disease, they were very impressed by my efforts. ‘How can you do it’ they asked - there was no such thing in my thoughts, such as ‘Why did it happen to me?’ Or something like that - I am a very positive person.”

As can be seen, “behaving like a healthy young adult “and receiving praises for being strong increased the morale of our patients. It was like they felt like a healthy young adult with pushing their limits. Yet, it seems that they denied the presence of the physical limitations, which might also compromised their physical health. For example, Ayşe continued her normal life after the illness and even increased the amount of exercise she did before the cancer diagnosis. She admitted that this was a way to deny the realities of the disease and feel like healthy:

“Kemoterapiye yeni başladım, kemoterapi ilacına. Yani işte bir 3 doz alacağım yani 3 alacağım 1 kürünü aldım. Onu aldığım ilk gün hani kusma falan oldu yani o 3-4 gün biraz tabi sersemlik oluyor ama işe gittim yani şey değildi. Rapor almadım... Gerek duymadım yani. Yani işten- iş yerinde belki kafam biraz meşgul olur diye düşünüyorsunuz ama gerçi olmuyor yani. Hani ciğerlerimde evet bir şey var ama ben bunun şeyini hissetmiyorum şu anda. Ben bunu hissetmiyorum belki de 2 ay sonra çıkmayacak bir şey diye düşünüyorum. Hep bu tarafından bakmaya çalışıyorum. Çünkü yürüyorum hatta daha ağırlık verdim atıyorum 6 km yürüyorum falan kendimi zorluyorum nerede acaba bir sıkıntı yaşatacak bana diye ... ben aslında kendimi zorlayarak ‘ben sağlıklıyım aslında bir şey yok’u hissetmeye çalışıyorum yani. Yememe içmeme dikkat ediyorum hep böyle okuduğum şeylerden yine ıı iyi gelecek ne varsa onları yapmaya gayret ediyorum.”

“I just started chemotherapy, chemotherapy medicine. So I would take 3 doses, that is, I would take 3 cycles. The first day I received the treatment, I was vomiting, I was dizzy but I went to work so it wasn't something big. I did not get a medical report for resting... I did not need it. I mean, you think that my mind will be busy at at work, but it doesn't work that way. . Yeah, there's something in my lungs, but I don't feel it right now. I don't feel it, maybe, I believe, nothing will happen in my lungs in the next 2 months. I always try to think like this. Because I am walking, I even gave more weight, I am walking 6 km, I am forcing myself to see at which point I am going to have a problem. I am pushing my limits by convincing myself ‘I am healthy’.

I pay attention to my eating and drinking, and I always try to do whatever I need to do becoming healthy.”

Not surprisingly, participants also seem really cheerful and positive during the interviews. Somehow, they like to surprise others with their cheer and joy although they were suffering from debilitating impacts of the treatment. This mission of delivering cheer and being strong also extended to other patients and their families. Our young participants felt special and stronger as long as they increased the morale of others. So, they behaved as if there was nothing wrong in being treated for metastatic cancer at a young age. To illustrate, Derin, describes herself as a really cheerful person who laughed no matter what the conditions were. She said that she responded by laughing when others were “pitying” her because of her being diagnosed with a metastatic cancer condition at such a young age:

"Neşe sanırım ya ben sürekli gülüyorum her koşulda yani. Yani burada çünkü hastaların da dikkatini çekmiş mesela gelip bana ‘vah vah tüh tüh’ diyen hastalar oluyor böyle ya da yakınları oluyor ‘çok gençsin, yazık sana’ falan diyen. Ben gülüyorum mesela ‘sağ olun, size de geçmiş olsun, olsun bitecek, herkes atlatacak’ ben yanımdaki hastalara da moral veriyorum mesela sürekli.”

“I think its joy/laughter, I laugh all the time in every circumstances. You know here, there are some patients coming and saying to me ‘what a pity! (Because of her being young) There are people like this or their relatives saying ‘you are too young, pity you’ or something like that. For example, I laugh to this reactions, I say "thank you, get well soon, it will end, everyone will survive". I also give morale to the patients around me.”

Although, behaving as if nothing had changed was perceived as helpful while coping with the disease, this attitude leads our participants to develop unrealistic expectations about the treatment process. That is, that is optimistic attitude made them vulnerable as they were psychologically not prepared for negative outcomes. Particularly, this attitude resulted in a psychological collapse as the disease level progressed. For example, Oya said, she tried not to be negatively affected by physical consequences of the disease. Yet, she experienced a collapse when she learnt the operation was not successful:

“O başlarda diyorum ya çok çok iyiydim. Hiçbir şey moralimi bozmuyordu. Düzelecek edecek hiçbir sıkıntı yok. Ama sonradan işte ne olduysa

ameliyattan sonra oldu..... Ondan sonra psikolojim tamamen darmaduman oldu işte. Hiç kimseyle konuşmak istemedim, hiçbir şey yapmak istemedim, televizyon izlemek istemedim..... ameliyata çok büyük şeyler bağladım. O da yemek yemede sıkıntılarım hala devam edince herhalde düzelmeyecek deyip kendimi kapattım diye düşünüyorum.”

“Like I said, I was really upbeat from the beginning I was very, very good. Nothing made me uncomfortable like There was no trouble to fix. But everything falls after the operation... After that, my psychology was completely dismal. I didn't want to talk to anyone, I didn't want to do anything, and I didn't want to watch TV... I had expected from so much things from the surgery... I did not want to interact with anyone, I shut down myself when my eating difficulties had continued; believing that I nothing wil improve I would never be recovered when I still have difficulties in eating.”

3.1.2. Justification of the Characteristics of Self after Cancer

This theme was about the patients’ overvaluations of the positive self-related changes brought by cancer. Our participants believed that they improved a lot “thanks to cancer”. Having being diagnosed with cancer, they learned to “stay in the moment”, “not to mind little things” and appreciate life more. Yet, it took researchers’ attention that some participants perceived every personal change “positive” without elaborating their emotions about the losses they had suffered. They even reported to feel “lucky” for having metastatic cancer because they were now aware their goals in life. In can be inferred that they tried to minimize or even to deny hurtful consequences (e.g. being close to death, losing organs or body parts) of metastatic cancer to cope with the imminent death at such a young age. For example, Seda reported to feel really grateful for having cancer by stating that:

“Aslında bütün özelliklerimin değişmesi bence iyi oldu çünkü çok negatif bir insandım ben öncesinde. Hani niye yaşıyorum ki diye sorgularken şu an kesinlikle yaşamalıyım diyen birisi haline geldim. Yani bence iyi ki değişmişim ya da bu süreç bence iyi ki kanser olmuşum yani çok söylenir mi bilmiyorum ama bence olmuşum evet zor ama bence güzel olmuş. Çünkü şu an ben olamazdım şu anki fikirlere ulaşamazdım”

“Actually, it was good for me to completely change as a person all my because I was a very negative person before cancer. I was questioning why I am living this life, Now I became someone who says I have to live! So I think it's good that I have changed.. I hesitate to say but thanks God I have cancer it's really good to have cancer, yes, it's hard but I think it's great. Otherwise, I wouldn't be the person now I am without cancer”

Similarly, Emel said that she was lucky to have a cancer because everyone would die and at least her diagnosis was clear to her.

“Herkesin bir ölüm tehlikesi var. Benim sadece adı konmuş hani hastalığımın. Aslında bir tık dün düşündüm bunu aslında bir tık benim avantajım var. Benim teşhisim konulmuş durumda, ama sağlıklı bir insanın meçhul yani ne olacağım benim de meçhul tabii ki ama benim en azından teşhisim var. O şekilde düşünüyorum. Tabi günden güne değişiyor düşüncelerim.”

“Everyone carries the risk of of death. Mine is just nominated through my disease. Actually, I thought yesterday, actually its my advantage. My diagnosis is made, but a healthy person’s future is unknown, what I will be is unknown as well, but at least I have a diagnosis. I think that way. Of course, my thoughts are changing day by day. ”

Similarly, Derin reported that she had improved herself because she had realized that she would die at any time due to metastatic cancer. For example, she stated her change not to feel sorry for the unimportant things and learnt to live the moment after a cancer diagnosis.

“Mesela ne oldu- kendimi saçma sapan şeyler için üzmemeyi öğrendim. Yani ne kadar olur bilmem ama gene de elimden geldiğince saçma sapan şeyleri dert etmemeyi- diyorum ya en basiti insanları kırmamayı da şey yapıyorsun... Hayata karşı anın tadını çıkartmayı öğreniyorsun çünkü ölümün ne zaman geleceği belli değil yani.”

“For example what happened - I learned not to upset myself for nonsense. So, I don't know how, but still don't worry about the absurd things as I can – as I say, basically you do something not to hurt people... You learn to enjoy the moment against life because it is not certain when will the death come. ”

3.1.3. Ambivalent Emotions about the Loss of Developmental Characteristic of Young Adulthood: Laughing while Losing

This theme was about expression of conflicting emotions while mentioning cancer related losses as a young person. Our participants acknowledged that they had lost a lot due to metastatic cancer diagnosis. They felt profoundly weak and suffered many physical ailments because of chemotherapy. They believed they could not marry, socialize like before or rise in a career. Besides, they felt isolated from their peers because of their weakened strength and treatment challenges. Yet, almost all of them

mentioned those losses with laughter. They even made jokes and ridiculed themselves while telling physical impairments brought by cancer.

For example, Derin explained while laughing that she could not walk without someone's support due to her body becoming extremely weak during the treatment process and that she fell one day while trying to act alone:

“Kemoterapiden sonra işte önce hastanede yatarken de şeydim- hatta düştüm yani kemoterapi aldıktan sonra duştan çıkarken kendim hareket etmeye çalıştım küt diye yere yapıştım ondan sonra da (güler). Çünkü vücudum çok güçsüzleşmişti, aşırı zayıflamıştım, başım dönüyordu sürekli yani bacaklarım güçsüzdü. Kimseden destek almadan yürüyemiyordum bile yani. Birileri koluma giriyordu sürekli benim.”

“After chemotherapy, I was in the hospital first - I even fell after chemotherapy., I mean I tried to move myself when I got out of the shower, I stuck to the ground (laughing). Because my body was very weak, I lost a lot of weight, my head was constantly dizzy, so my legs were weak. I couldn't even walk without any support. Someone was in my arm all the time.”

Likewise, Seda heard that a doctor was explaining her parents that she would die due to cancer. And, she immediately found this sentence ridiculous and funny.

“...doktor da tepki olarak ‘zaten senin kardeşin ölecek’ gibi saçma bir cümle kullandı ... Yani garip, komik geldi hani yani o insana güvenemeyeceğimi burada tedavim olamayacağını düşündüm.”

“...the doctor used a ridiculous sentence like "your sister will die"... So it sounded strange, funny, so I thought I couldn't trust that person (doctor), and I couldn't have a cure here”

Some patients were much more aware of their ambivalence regarding feeling strong and weak at the same time. For example, Ayşe who was proud of her emotional stamina admitted that she felt incompetent and worthless. Although she was known for her resilience throughout her life, she just felt powerless as she did not have a minute not ruminating about disease:

“...Bir de güçlü olduğumu söylerler genelde yani olaylar karşısında. Ama aslında güçlü değilmişim demek ki diye düşünüyorsunuz yani.

Şu an güçsüz hissediyorum aslında kendimi. Beni ele geçirmiş durumda çünkü yani çünkü kafamdan atamıyorum hala. Dediğim gibi geleceğe yönelik

bir şey düşünemiyorum, sürekli hani öldüğüm zaman öteki tarafı çok düşünür oldum acaba gerçekten var mı? Falan diye. Bu düşüncelerden kurtulamadım ya kabullenemedim yani ‘tamam ya bu olay benim başıma geldi artık e tedavimi de alıyorum 2 ay sonra bakacağız tekrardan’ demeyi isterdim de bir türlü diyemiyorum yani.”

“People say that I am strong, in general, in response to events. But I start to think that I am not that strong.

I feel weak now. Cancer has taken over me because I mean I still cannot get it out of my head. As I said, I cannot think anything but my cancer and future. I start to think about after death life frequently. Is it real? Things like that.... I could not get rid of these thoughts, I could not accept it. I wish I could say, "okay, this event happened to me, now I am going to take my treatment; 2 months later, we will look at it again." However, I could not say this.”

3.1.4. Feeling Isolated from the Peers

This theme reflected the social isolation experiences of the participants due to disruptions resulted from metastatic cancer. This disruption was mostly caused by the restrictions due to chemotherapy, such as not being able to go out or attending activities. Sometimes, the changing nature of the relationships lead to social isolation, as well. To exemplify, Canan felt her discomfort upon her friends treating her differently after cancer. She believed her friends did not share developments in their lives in an attempt not to upset her. Although her friends were well-intentioned, their behavior was negative for her since she felt isolated due to oversensitivity of others. It seems that young patients felt alienated from their social circle, as their healthy counterparts were embarrassed to share the things that our participants were missing. Canan expressed this situation as follows:

“Yani şöyle oluyor insanlar genelde size odaklanıyorlar ve kendilerinden çok bahsetmiyorlar. Bunu hala yaşıyorum ben 11 örneğin sevgilisiyle yaşadığı sorunu anlatacak bana arkadaşım ki arkadaş gruplarında yani arkadaşlarımla oturduğumuzda konuşacağımız 3-5 konudan biri zaten budur. Ama anlatmak istemiyor bilinçaltında muhtemelen şeyi düşünüyor işte onun bir sürü derdi sorunu var zaten hani bunu mu dinleyecek ya da işte bunu mu anlatayım ben ona diye ben bunu birkaç kez dile getirdim hani benimle her şeyi konuşmanızı istiyorum her şey kaldığı gibi devam etsin istiyorum, olduğu gibi- eskiden olduğu gibi. Ama çok olmuyor öyle yani hani genelde ‘nasılsın? sağlığın nasıl? Her şey yolunda mı?’ gibi konulardan konuşuyoruz. Sonrasında ben günlük hayatımdan belki yaşadığım kişilerin sorunlarından vs bahsediyorum. Ama onlar yani yakın arkadaşlarımda bu özellikle oluyor. 11 çok bahsetmek istemiyorlar galiba.”

“So it's like people usually focus on you and they don't talk about themselves much. I am still experiencing this, for example, my friend will tell me about the problem she had with his boyfriend, which is one of the 3-5 topics we will talk about in groups of friends. But she does not want to tell me this anymore, she might think so subconsciously, ‘she has a lot of problems she should not listen my problems’. I have mentioned this several times, I want them to talk to me everything, I want everything to continue as it remains, as it is - as before. But it doesn't happen much, we talk just like ‘how are you doing? how is your health?’. Then I talk about my daily life, maybe the problems of the people I live with, etc. But this is especially the case with my close friends. I guess they don't want to talk a lot.”

Some participants express the deterioration in relationships as a natural consequence of cancer since cancer is a long-term disease. For example, Asya stated that she had no friends because she was in a difficult situation due to cancer.

“Yani normal arkadaş zaten şimdi şey olunca hani ciddi hastalık olunca bir de uzun süreli olunca. Uzun süreli arkadaşlık da normal kız arkadaşlık o da zaten olmuyor. Düşünce yanında hiç kimse kalmıyor. Bir bir herkes gidiyor zaten. Arkadaşım yok.”

“I mean when there is a serious situation like life-threatening disease, even it is a long-term disease. Long-term friendships I mean normal friendships are broken. Nobody stays with you when you in a bad situation. Everybody leaves you one by one. I do not have any friends.”

Impairment in social relationships are important for patients. For example, Emel stated that she needed social support when she had diagnosed with cancer.

“Şu an hani diyorum ya psikolojik olarak inişlerde çıkışlardayım mesela ilk teşhis konulduğunda diyordum ki ‘niye arkadaşlarım yanıma gelmiyor işte niye yanımda destekçi değiller, yarım elma gönül alma çiçek bari yollasalar’ falan diyordum.”

“I am now saying that I have ups and downs psychologically. For example, when I was diagnosed, I was saying, “Why do not my friends come to visit me? Why they are not here to support me? At least they could send me flowers.””

3.2 New Ideals not in the Agenda of a Healthy Young Adult

This superordinate theme depicted the changes in the ideals, dreams and wishes of young cancer patients. Young adulthood is a period of time where there supposed to be dynamic developmental changes. In this period, people mostly dream about the

future, work romantic relationships and having children. The goals are really colorful and diverse. However, there seems to be significant transformation in ideals and dreams of young adults with metastatic cancer. This reflected newly developed the impacts of which might be artificial.

3.2.1. Normalcy is Becoming the New Ideal

This theme was about how young cancer patients' ideals and priorities had changed and "being normal" became an ideal after metastatic cancer diagnosis. They had gone through profound changes in their lives including physical losses, and fear of imminent death. While normalcy was taken for granted before the cancer diagnosis, it became an ideal to be attained throughout treatment process. Although all these examples show that people miss their old routines, Canan emphasized 'normal life' and being a normal person' was what she was longing for by stating that "... But what I want is that I want to be a person who only has an academic career and has a happy relationship. So I want to be an ordinary person with an ordinary life." "... Ama ne istiyorum ben yani aslında sadece akademik kariyer yapan bir, mutlu bir ilişkisi olan bir insan olmak istiyorum yani. Yani herhangi bir insan olmak istiyorum normal bir hayatı olan.". Likewise, when Asya was asked what her dreams were as a young adult, she longed for ordinary tasks she had performed before cancer and grueling treatment:

"İşe gitmek isterdim- yani hani sağlığım engel olmasa işe gitmek isterim en büyük şeyim o. İ- hani şu an mesela hiç bir şey – temel ihtiyaçlarım haricinde yapamıyorum. Gezmek isterim, dışarı çıkmak isterim. Bütün yapamadıklarımı yapmak isterim."

"I wish I went to work, I mean if my health did not restrict me....My biggest wish is going to work if my health is well. For now, for example, nothing at all - I am not able to do anything except for my basic physical needs. I want to travel, I want to go out. I want to do all the things that I can't do right now"

Similarly, Emel felt out of life due to her illness. When asked about her wishes and desires, she said doing things that were normally performed every day was her main dream:

“Sağlıklı. Ve 11 hayatın içinde olmayı özledim. Özellikle hani tek değil de mesela değişik değişik giyinmeyi özledim. Şu an ha- hareketlerim kısıtlı olduğu için rahat neyse onu giymek durumundayım. Bir de kemoterapi aldığım için vücudumda kanama olmaması gerekiyor; dar bir şey giyemiyorum mesela. Eskisi gibi neyi canım istiyorsa onu giymek istiyorum. Makyaj yapmayı özledim. Öyle. Görselliğe çok fazla dikkat eden bir insanım.”

“Healthy. And I miss being in the middle of the life. In particular, I missed to dressed varied, not only one type. Now I have to wear whatever is comfortable because my movements are lrestricted. Also, since I have received chemotherapy, there should be no bleeding in my body; for example, I can't wear anything tight. I want to wear whatever i want like before. I miss doing makeup. Because I am a person who really cares how she looks to others”

3.2.2. Need for an Omnipotent Self to Beat Cancer

This theme represented young cancer patients’ desires to be a different person after such a transformative experience. They believed that they had to make necessary changes in their personality, feelings and thoughts in order to reach remission. Their old personality characteristics were held responsible for the development and recurrence of cancer. That is why they spent a great effort to reach an ideal personality full of positive attributes putting cancer at bay. Yet, development of these new ideals traits- to be temporary as they had been abandoned them whenever they entered into remission. For example, Fatma expressed her regret by stating that “I had survived through a transformative experience, I tried to be completely different (after first remission); yet when I started to feel concern for ordinary life hassles, my cancer had metastasized to my lungs”. Besides, our participants believed they had power makee necessary personality changes which was associated with a glorified sense of control since changing personality traits was a difficult task. Some patients idealized a sense of control because of their desire to control cancer. Accordingly, Seda thought that “her control” was the most important factor in the occurrence and disappearance of the disease. She stated that her personality traits caused the disease and she could recover from disease by controlling and modifying those traits now.

“Seda: Yani ben hala o şeyde kesin katılıyorum bence hastalıkları yapan zihin çünkü o zaman hastalıklı bir zihnim vardı ki ben şu an bu süreçteyim. Görüşmecisi: Peki bu size nasıl hissettiren bir şey oluyor? ‘hastalığı ben yaptım’ gibi bir düşünce.

Seda: Demek ki iyileştirebilirim de aslında oluyor. Hani onu yapıyorsa beyin bence onu da yapabilir. Bu şey gibi ıı işte buradan canınız acıdığında belki acımayacak ama komut veriyorsun nöronlar çalışıyor ve acı hissediyorsun. Belki onu mesela ben şu aralar şey deniyorum damar çok a- damar yolu çok acıyor bende ben hiçbir şey düşünmeyip kendimi sürekli telkin ediyorum ‘her şey yolunda, her şey yolunda’. Ablam o an hani kan alırken şey diyor ‘niye sırtıyorsun?’ ‘her şey yolunda çünkü’ diyorum. Hani böyle artık telkin etmeye başladım.”

“Participant: So I still agree on that thing, I think the mind that makes diseases. Because I had a sick mind, I am in this process right now.

Interviewer: So how does this make you feel? A thought like "I made the disease".

Participant: So, I can actually heal the the disease by my control. If the brain can make the disease so, I think the brain can recover it, as well. Like this thing, well, maybe it won't hurt when you hurt, but you command the neurons work and you feel pain. Maybe, for example, I am trying something right now. For example, the vascular path hurts so much and I try to say ‘everything is okay, everything is okay’ to myself. My sister says something at that moment when she takes blood, 'why are you grinning?' I say 'because everything is fine'. I started to preach like this now.”

Similarly, Ezgi thinks she is able to overcome the disease by this strong sense of control. She also stated that she would become healthier by matching negative events with positive thoughts.

“Önceden mesela ‘şuram ağrıyor; acaba şundan mı? Kalbim sıkışıyor; acaba bundan mı?’ diye kendimi olumsuzla çekiyordum. Şimdi olumluyorum. Mesela kafamda ağrı varsa ‘iyileşiyor ya onun belirtileri’ ne bileyim kulağımdan kıtır kıtır sesler geliyor ‘iyileşiyor ya, yok oluyor ya onun sesleri’ ya direkt olumlama yapıyorum. Mesela baş parmağımda tırnak düşmesi oldu; benim ilk teşhis konulduğunda yine böyle tırnağımda çıkacak gibi bir şey oldu- oynadı. Dedim ‘böyle başladı, böyle tamamen vücudumu terk edecek’ hani düşmesini bile olumlayarak. Yani bu pollayanacılık değil, gerçekten böyle düşünüyorum.”

“Previously, mostly I was negative. For example, if any part of my body hurts, I was thing its due to a bad thing. I am positive now. For example, if I have headache I think it’s a sign of healing. Also, when I heard something in my ears I consider it as a sound of getting better, its disappearing. For example, the nail of my thumb falls off. When I was diagnosed, something like that would happen on my nail again. I said, "It started like this, it will completely leave my body the same way it started". So it's not exacerating, I really think that.”

3.3. Others' So Called 'Minimalist' Expectations

This superordinate theme was about others' expectations imposed on young adults in relation to responsibilities and duties they were supposed to do after metastatic cancer diagnosis. Our participants felt the pressure that they did not have any responsibilities and duties apart from surviving cancer. In other words, although the number of expectations seems to decrease, one important and overwhelming task was still present: managing cancer and staying alive. Additionally, participants thought the life of others (e.g. parents and family members) around them also became much more difficult after cancer. This thought leads them to feel profound guilt which seem to accentuate impacts of others' expectations of being strong and healthy.

3.3.1. Expectations-centered Only around Survival

This theme represented the perception that “nothing expected from me, apart from becoming healthy”. Still, these patients felt the heavy burden of trying to stay alive since recovery was not completely under their control. Although cancer seems to free them from any ordinary responsibilities, their one and only duty to stay alive and healthy was the most difficult one. In fact, this might be why defeating cancer was not perceived as a desire, but as a responsibility by our participants. For example, Derin stated that:

“İyileşmek zorunda hissediyorum kendimi zaten en basiti herkese karşı sorumluluğum aslında En büyük sorumluluğumu iyileşmek üzerine hissediyorum şu anda”

“I feel like I have to recover, like it is simply my responsibility towards everyone...
.... I I feel that my biggest responsibility is to recover right now.”

Not surprisingly, not only people around them but also patients themselves expected from themselves to defeat the metastatic cancer. Canan responded very quickly when asked what she expected from herself by reporting that “Yani, tabii ki iyileşmek (gülerek)” “So, of course healing (while laughing).”

Sometimes, participants are not clearly aware of this burden. For example, even though she is expected to be healthy, when Fatma is asked about the expectations from her she said ‘nothing’. “Ya onlar benden pek beklentileri yok yani sağlıklı olayım, iyi olayım hani...” “They do not expect much from me, they just want me to be healthy and sound.”

3.3.2. Restrictions due to Others’ Pressure of being Strong

This theme was particularly about the expectations of others (e.g., family members, doctors, friends) not to be sorry and not to cry during cancer treatment. Our patients seem to read an implicit message behind those expectations. This implicit message was cancer diagnosis could only be beaten through staying strong and positive. This expectation of others imposed burden upon our patients and made them reluctant to share their real thoughts and feelings. To illustrate, Derin stated that she cried when she learned that she was diagnosed with cancer and her doctor told her not to cry.

“X Hoca çok iyi davrandı mesela şöyle sa- ben ağlayınca sarıldı bana ‘ağlama kızım ben’ dedi ‘zaten’ dedi ‘üzülüyorum hani genç hastaları görünce’ dedi. ‘Ama’ dedi ‘yeneceğiz’ dedi ‘sen güçlüsün bak gülüyorsun hep’ dedi”

“Dr X. behaved very well towards me, for example, when i cried, he hugged me and said, 'Don't cry my dear,' he said 'already,' he said, 'I'm sad when I saw young patients going through this.' "But," he also said, "we'll beat," he said, "you're strong, look, you're always laughing."

Although others’ desire of not seeing patients while crying was widely expressed, the impact of this expectation seem to differ across patients. Some patients had said that being expected to remain tenacious created strain which also lead them to feel that their situation had not been appreciated: As Ayşe said;

“Ayşe: Olumlu olmamı istiyorlar.

Görüşmeci: Bu nasıl hissettiriyor size böyle bir beklentinin olması herkes tarafından?

Ayşe: O benim üzerimde bir yük gibi oluyor bazen yani çünkü yani şey diye düşünüyorsunuz onlar benim yerimde değil yani acaba beni yerime-benim yerimde olsalar olumlu olabilirler mi?”

“Ayşe: They want me to be positive.

Interviewer: How does this make you feel, everyone having such an expectation?

Ayşe: It is like a burden on my shoulders, because I mean you think that they are not in my shoes, I mean, will they be able to remain positive if they were in my place?"

Ayşe added that such expectancy prevented her from sharing her real thoughts and feelings comfortably. Although cancer was the most central issue in her life, she was not able to talk about it because of others unfair expectations.

"E kolay bir şey değil yani olumlu olmamı istedikleri için şey de yapamıyorum yani hani çok üzüldüğüm zaman bu sefer konuşmak istemiyorum konuşursam çünkü yani nasıl anlatsam ya hastalıkla ilgili rahat konuşamıyorum yani onlarla benim hep olumlu olmamı istedikleri için ben şimdi mesela size cenazemden bahsediyorum her türlü kötü şeyden bahsediyorum. Onlara bunlardan bahsedemem yani. Asla bahsedemem. Hemen çünkü saçmalıyorsun da bilmem ne falan böyle büyük tepkiler alıyorum yani. aklıma gelen her şeyi söylemiyorum, hastalıkla ilgili konuşmuyorum. Bazen artık dayanamıyorum hani ağlama şeyim geliyor sadece ağlıyorum onda da gene konuşmuyorum yani sadece ağlıyorum. 'inşallah düzeleceğim' diye ağlıyorum."

"It is not easy I mean I can't do anything because they want to see me be positive, so even when I feel very sad, I don't want to talk this time, I am not able to talk comfortable about my disease since they want me to be positive all the time.... Now, I am talking to you about my funeral, I'm talking about really bad things to you. But I can't tell them about these. I can never talk about. When I say something about these, I received intense reactions, they say 'you are being silly...I'm not saying everything that comes to my mind, I'm not talking about the disease. Sometimes, I feel I can't take it anymore, I want to cry. I just cry without saying anything, so I'm just crying and saying "I hope I will be okay"'"

Similarly, Oya did not share her thoughts about death with her family even though she believed it was normal to think death when diagnosed with metastatic cancer disease. She just felt the pressure of keeping death related thoughts as a secret in order not to upset her family:

"Yani ilginç değil, ölümü daha yakın hissediyorsun. Hani bir daha evime gidebilecek miyim sağlıkla ya da nasıl gideceğim bilmiyorum. Bunu da size söylüyorum ilk kez. O gün ameliyattan sonra kontrole gittik. Çankaya Belediyesi Cenaze Aracı yazıyordu arabayla giderken önümden geçti dedim ki 'acaba beni Sivas'a böyle bir şeyle mi götürecekler yoksa yürüyerek mi gideceğim'. Onu düşünüyorum. Yoksa ölüm herkese yakın da bana daha yakın gibi hissediyorum. Bunu annem, babam diğerleriyle paylaşmak istemiyorum üzmemek adına ama hep aklıma geliyor ne yalan söyleyeyim."

“I mean, it is natural, you feel closer to death. I do not know whether I will return to my home healthy or how I will return. You are the first person I share. That day, we went to check-up after surgery. I saw a Funeral Vehicle which passed by me. And I think that "Will they take me to Sivas with such a thing, or will I go just walking?" I am thinking about it. Otherwise, everyone feels close to death so it is for me, as well. , and. I do not want to share this with my mother, father, and others, but I always think of it”

3.3.3. Feeling Guilty because of Cancer Burden Imposed on Family

This theme was related to feelings of guilt felt by our participants as their disease not only a burden upon them, but others as well. They acknowledged that their families’ life became more difficult due to cancer related problems which made them to express profound guilt. Unfortunately, this guilt seems to be another reason for acting like happy almost all the time: For example, Emel thought that she had worn her family because of the cancer diagnosis that completely changed her own life, as well. She tried to show herself better than she really was in an attempt to compensate the guilt she was experiencing:

“Emel: Bu süreçte gerçekten yine bahsettiğim gibi ailemi çok yıprattım, kendi elimde olmadan.

Görüşmeci: Sizin elinizde değil, aynen.

Emel: Ailem de bunun farkında. Bana hatta kızıyorlar. Bundan dolayı suçluluk hissettiğim için kızıyorlar. Onun için iyileştiğimde, daha iyi hissettiğimde daha güzel vakit geçirmek. Şu an mesela başım ağrıyorken kalkıp oynuyorsam, onları mutlu ediyorsam, onları gülümsetiyorsam, espri yapıyorsam rahatsız olmama rağmen baya bir ağır geçiriyorum çünkü bu süreci ona rağmen hani hissettirmemeye çalışıyorsam iyileştiğimde daha güzel olmasını hani hayalimden öte olmasını istiyorum.”

“Emel: In this process, as I have mentioned earlier, I have worn my family out too much, independent of my control.

Interviewer: Without your control, exactly.

Emel: My family is also aware of this. They even get angry at me. So they get angry because I feel guilty. That is why I want to have a better time when I get better. For now, for example, if I get up and dance when I have a headache, it is to make them happy, to make them smile, make a joke, even if I feel quite ill. I want our lives to be beautiful more than I imagine when I am recovered.

3.4. My Body is a Cage: “I Feel Like My Soul Stuck in My Body”

This superordinate theme relates to the fact that young cancer patients had many plans that they wanted to do, but these plans had been blocked by cancer. Young adulthood is a period in which new steps are taken in terms of career, relationship and social life but getting cancer diagnosis in this period destroyed all plans of patients. Although they wanted to live like any young adult, they felt their soul had stuck in to their sick body which seems to increase feeling of helplessness. Asya expressed her feelings of being stuck by using a metaphor;

“İlk zamanlar zor oluyor tabi hani yani ruhum vücudumun içine sıkışmış gibi hissediyorum. Çıkmak istiyorum ama vücudum izin vermiyor (güler). Zor oluyor ama mecburum başka çarem yok. Sürekli- başka çarem yok yani.”

“It has been difficult at first, so I feel like my soul is stuck in my body. I want to go out, but my body does not allow (Laughing). It is difficult, but I have no other choice. Always - I have no choice.”

Just like Ayşe, Oya used a metaphor to express the dilemma between having a sick body and a young soul. As life progressed in a routine way, she described the cancer as a wall that she suddenly faces it and hit it quickly.

“Her şey allak bullak oldu. Beklentilerim her şey değişti. Hayatta birden bire tosladınız duvara. Her şey değişti. Düzenli giderken birden duvara toslamış gibisiniz.”

“Everything got messed up. My expectations, everything have changed. You hit the wall suddenly in life. Everything has changed. You are like hitting the wall suddenly while everything going on a regular basis.”

Duygu said that her romantic relationship and business life, which are the two most important concerns in a young adult's life, are affected by the disease.

“Benim bütün planlarım alt üst oldu. Düğünüm olacaktı, düğün planım alt üst oldu.... İşimden – şu anda mesela şey düşünüyorum acaba sözleşmeliyiz biz çünkü sağlık bakanlığı sözleşmeli atadı bizi diyorum ki acaba sözleşmeme son verebilirler mi gibi şeyler de şu anda kafamda var mesela ama ben nasıl diyeyim- bir başkasına muhtaç olmak her zaman bana zor geldi.”

“All my plans have turned upside down. I was planning to make a wedding but my wedding plan turned upside down... I am concerning about the possibility of losing my job. Because there is no guarantee to continue my job as same as before cancer. It is always difficult for me to be in need of someone else”



CHAPTER 4

DISCUSSION

The main aim of this study was to investigate self-concepts and discrepancies between selves of female young adult metastatic cancer patients. To the best of our knowledge, there has not been any study particularly examining aspects of self and its discrepancies among young metastatic cancer patients. Thus, eight young adult women diagnosed with metastatic cancer were examined in the context of dimensions of self-concept. According to the Interpretive Phenomenological Analysis (IPA), four superordinate themes emerged. These were ‘Compulsory Changes in Self-Concept with Ambivalent Evaluations’; ‘New Ideals not in the Agenda of a Healthy Young Adult’; ‘Others’ So Called ‘Minimalist’ Expectations’; ‘My Body is a Cage: “I Feel Like My Soul Stuck in My Body”’. In this section, the results of the analysis were discussed within the framework of the relevant literature.

4.1. Compulsory Changes in Self-Concept with Ambivalent Evaluations

The first super-ordinate theme was ‘compulsory changes in self-concept with ambivalent evaluations’. This theme was related to how participants perceived themselves and responded to the changes in their life as a young adult with metastatic cancer diagnosis. Although having emotional stamina to cope with cancer related changes is not something new in psycho-oncology literature (Brandão, Schulz, & Matos, 2018; Lent, 2007; Marroquín, Czamanski-Cohen, Weihs, & Stanton, 2016), our participants seem to be torn between the need to stay strong and grieve for cancer related losses as a young person with metastatic illness. They were living between two worlds since they encountered death while being full of life. As they reported, “cancer is like a cage” preventing their body and soul function to the fullest. A possible explanation for this extreme emphasis on staying strong might be closely related with

the developmental stage our patients were in. Young adulthood is a period in which important life decisions and changes are made. In this period, being diagnosed with cancer inevitably affects central plans related to establishing a family, having children and rising through a career. (Avis, Crawford, & Manuel, 2004; Baucom, Porter, Kirby, Gremore, & Keefe, 2006; Roberts, Severinsen, Carraway, Clark, Freeman, & Daniel, 1997). It was evident that both patients themselves and their families expected them to behave like a young person while dealing a metastatic cancer diagnosis. Accordingly, young patients had a tendency to push their physical and psychological limits which sometimes lead them to overlook realities brought by a metastatic cancer diagnosis.

The first sub-theme, ‘Over-Valuation of Being Strong: Pushing the limits’, was related to the investment that our patients made to seem strong. The basis of this theme was that patients had a visible need to define themselves as 'strong' and to be able to perceive themselves in a better place from other patients. The relationship between the term of ‘inner strength’ and quality of life is emphasized in cancer literature (Dingley & Roux, 2014; Gonzalez, Nuñez, Wang-Letzkus, Lim, Flores, & Nápoles, 2016; Jenkinson, & Cantrell, 2017; Moloney, 1995; Raphael, Frey, & Gott, 2019). Inner strength is defined as the internal capacity that enables people to deal with stressful experiences such as cancer. Accordingly, inner strength helps to perceive events as challenging rather than traumatic. Thus, the emphasis of the participants on being strong can be interpreted as 'inner strength', from one perspective. In a qualitative study conducted with older women it was found that strength was associated with 3 factors. These are surviving, finding strength in everyday events, and gathering and sharing the memories (Moloney, 1995). Consistent with these findings, in current study, the survival of young cancer patients despite challenging treatment can be seen as a basis for their emphasis of being strong. In fact, despite physical difficulties, continuing their daily routines by forcing themselves might be a way to pursue their young adult life. Nevertheless, it was also apparent that this insistence to pursuit youth without evaluating physical limitations also impeded processing losses various losses brought by cancer, which seem to create an extra burden on our participants.

The second sub-theme was ‘justification of characteristics of self after cancer’. The participants believed that they had improved themselves thanks to cancer. It is common for cancer patients to think that ‘after cancer self’ is a better version of themselves (Antoni et al., 2001; Lechner, Zakowski, Antoni, Greenhawt, Block, & Block, 2003). Positive changes are often defined as giving more importance to relationships with family and friends, changing priorities in life and being a more tolerant person (Antoni et al., 2001). Such attitudes have been usually described as ‘benefit finding’ (McFarland & Alvaro, 2000; Tedeschi & Calhoun, 1996; Tomich & Helgeson, 2004). Accordingly, benefit finding is considered as a coping mechanism which might or might not have functional implications. There are different results in the literature regarding the effects of benefit finding during such life threatening conditions. Some studies have found benefit finding is related with positive adjustment (Helgeson, Reynolds, & Tomich, 2006; Kvillemo & Branström, 2014). Others, by contrast, emphasized the negative aspects of extremely positive evaluations. For example, benefit finding might sometimes lead individuals to ignore severity of their disease or to suppress distress. In those conditions, remaining strong might result in low quality of life as people are not realistically prepared to face with process of metastatic illness (Tomich & Helgeson, 2004). In that regard, first two sub- themes were reported as functional coping mechanisms for our metastatic cancer patients. Although these efforts might be considered positive at first glance, focusing only goodness and positivity, seems also bringing other hardships. Between the lines, it was apparent that participants’ mind seesawed between psychological strength and physical limitations. Although such insistence has been also observed among other cancer patients (Chavan, Kedia, & Yu, 2017; Cordova, Giese-Davis, Golant, Kronenwetter, Chang, & Spiegel, 2007), young adults might feel more obligated to remain strong and consequently deny physical limitations due to the dilemma resulting from dying at such a young age.

The third sub-theme was ‘Ambivalent Emotions about the Loss of Developmental Characteristic of Young Adulthood: Laughing while Losing’. Interestingly, our patients described physically disabling situations usually with humour and sarcasm. In other words, they reacted emotionally incompatible with the content they described.

It is known that humour can be used to alleviate intense emotional burden during stressful times. Also, people even use laughing as a coping strategy because there is nothing they can do other than laughing in an uncontrolled situation (Stevenson, 1993). In this context, sarcasm and ridiculing death might be considered as coping mechanism since they had little control over the situations. Yet, functional emotional regulation is of utmost importance for psychological health particularly during periods of serious illness (Conley, Bishop, & Andersen, 2016). Based on our observations during interviews, this mechanism was also over used to the point that young patients denied disease and treatment related realities. Hence, over use of this mechanism runs the risk of not processing negative emotions associated with various losses as a young person. Accordingly, over-valuation of being strong, justifications of new characteristics, and ambivalent emotions might also be indicators that young cancer patients might deny the disease, and their emotions. Although tendency to deny has been usually studied among older cancer patients (Jerant et al., 2018; Vos & Haes, 2007) there is limited knowledge about how denial and avoidance operates at such a young age for metastatic cancer patients. The findings of the current study suggested that young adults might be using denial frequently throughout the disease process and this over use might be closely related with facing such a life threatening situation at such a young age. All in all, being stuck in a young body and soul while dying seem to create a unique emotional toll for our patients.

The last sub-theme was 'feeling isolated from peers'. This theme included patients deteriorating social relationships due to restrictions of illness and treatment. Also, others' 'very sensitive' behaviour make our patients angry as they did not want be remembered with their illness. Findings related with deterioration in social relations and need for social support are in line with the existing findings literature (Kent et al., 2012; Kim, & Gillham, 2013; Warner, Kent, Trevino, Parsons, Zebrack, & Kirchhoff, 2016). However, it has been known for many years that social isolation is a risk factor associated with higher mortality (Reynolds & Kaplan, 1990). A recent meta-analysis study also supported the effect of the quality of social relations on mortality (Holt-Lunstad, Smith, & Layton, 2010). In cancer patients, social isolation has been associated with increased negative effects of treatment, as well (VanCleave & Fall-

Dickson, 2019) and mortality as it can make it difficult for people to reach care (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). Strong social relationships have a positive effect on long-term psycho-social well-being and physical functionality in cancer patients (Thompson, Rodebaugh, Pérez, Schootman, & Jeffe, 2013). Therefore, social support is thought to be an important need of our patients, both for practical and psychological reasons such as maintaining treatment and providing emotional support.

4.2. New Ideals not in the Agenda of a Healthy Young Adult

This theme was about changes in young adults' ideals and desires after metastatic cancer diagnosis. The first sub-theme was 'Normalcy is Becoming the New Ideal'. This theme basically refers to the fact that ultimate ideals of young adults was only returning to 'old normal' after metastatic cancer diagnosis. Having been asked about their desires, they longed for the things that they had granted before cancer diagnosis like being healthy, working, and wearing dresses without any concern. In fact, this finding was consistent with studies with different samples in psychooncology literature (Kyngas, Mikkonen, Ryttilähti, Seppanen, Vaattovaara, & Jamsa, 2001; West, Bell, Woodgate, & Moules, 2015; Woodgate, 2006). Metastatic cancer diagnosis takes every part of life out of 'normal' disrupting ones' perception of normality and leading to the development of a new normality about self and future (Bury, 1982; Garrard, Fennell, & Wilson, 2017; Tolbert, Bowie, Snyder, Bantug, & Smith, 2018). Accordingly, our participants yearned for the old normal since treatment procedures and unpredictability of the disease process disrupted their usual plans as a young adult. Although such a longing might also be relevant to older cancer patients, it might be a much more pressing concern for young adults as their life is supposed to be full of dynamic roles and tasks due to their developmental stage.

The second sub-theme was 'Need for an Omnipotent Self to Beat Cancer'. This theme was related to the emphasis of the participants the need to develop a new personality to beat cancer. The characteristics of this new personality was usually contrasting with the features before the cancer diagnosis. Through attaining those ideal traits, our

patients believed that they would be able to put cancer at bay. This finding partially supports the previous findings emphasizing patients' sense of control decreases after cancer diagnosis (Kim, & Gillham, 2013; Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano, & Balaguer, 2016; Wicks, & Mitchell, 2010). The sense of control is important in predicting health behaviour and psychological effects of diseases (Mystakidou, Tsilika, Parpa, & Galanos, 2015). In chronic diseases, the focus of internal control has been found to be an important contribution to adaptation and coping (Cvengros, Christensen, & Lawton, 2005). Also, it is known that high control perceptions of individuals are advantageous in compliance with stressful medical and surgical procedures and chronic diseases (Wallston, 1992). This new omnipotent self believed to beat cancer might be functional in terms of increasing young patients' sense of control over their treatment process. Nevertheless, such an effort might be equally disappointing as it might lead to unrealistic expectations about disease outcomes. Current literature does not provide robust evidence regarding impact of personality on cancer development and recovery (Amelang, 1997; Härtl, Engel, Herschbach, Reinecker, Sommer, & Frieze, 2010). Unfortunately, various genomic dynamics beyond the control of the patients seems to operate in the prognosis this disease. Hence, mental health professionals are better be cautious about such idealistic attitudes and help patients develop cautious optimism.

4.3. Others' So Called 'Minimalist' Expectations

This theme reflects the changes in young adults' perception about their obligations and responsibilities as being a young metastatic cancer patient. The sub-themes were in close relation with the expectations of patients' relatives and their impacts on patients' mental health. The first sub-theme was 'Expectations-centered Only around Survival'. This theme was about the pressure that participants felt to reach full remission. Recovery was perceived like an imperative that their families had imposed on them. Although they also mentioned to be free from all other life responsibilities, they still felt the heavy burden of surviving as they were aware that disease progression was not completely under their control. The second-sub-theme was closely related with the first sub-theme, which was 'Restrictions due to Others' Pressures of being Strong'.

This theme was also about families' high expectation from patients to be strong, and happy independent of up and downs of the process. Accordingly, participants admitted their reluctance to share their real feelings and thoughts in close relation with the losses and fears they experienced. Not only the patients' relatives, but also the healthcare staff had demanded that our young patients not cry and to stay strong. Although expectancy for enduring strength might be a coping strategy through life threatening conditions (Gilbar, Or-Han, & Plivazky, 2005; Schou, Ekeberg, & Ruland, 2005), these expectations might have been amplified due to young age of our participants. All in all, no parent or young adult associates young adulthood with a metastatic cancer. In that sense, both patients themselves and families might have expected the morale, strength and persistence shown by young adults. Yet, such a perseverance might not be possible all the time due to debilitating impacts of the disease and treatment process. That is to say, the expectation that patients should never cry or feel sorry did not coincide with the reality of the patients' situation. And such a high expectation might prevent young cancer patients from sharing their real sadness and troubles, which might, in turn, increase their emotional burden (Austenfeld, & Stanton, 2004; Brandao et al., 2016; Giese-Davis et al., 2006; Hilton, 1994; Zhang, & Siminoff, 2003).

The last sub-theme was 'Feeling Guilty because of Cancer Burden Imposed on Family'. Disease itself and treatment process significantly affected the life of the patient and their relatives and that is why metastatic cancer has been defined as a "family illness. Patients might sometimes feel guilty because they disturb the usual life for those around them. Therefore, they felt the pressure to get rid of cancer for their relatives. Guilt can be experienced among cancer patients for different reasons: such as thinking that the cause of the disease because of their past experiences (Oliveri, Scotto, Ongaro, Triberti, Guidi, & Pravettoni, 2019) or guilt could have been caused by the recovery called as survivor guilt (Perloff, King, Rigney, Ostroff, & Johnson Shen, 2019). In this study, the reason of guilt seems to be conceptually different. Participant felt guilty because of the negative effects on the other people lives, due to their diagnosis and treatment. Such negative feelings might be abounded in our sample from a life transition perspective, as well. Throughout young and middle adulthood, adult offspring usually provide emotional and tangible support to their parents

(Evandrou, Falkingham, Gomez-Leon, & Vlachantoni, 2018; Schwarz, Trommsdorff, Kim, & Park, 2006). So, once again, a life-threatening disease like cancer, might have disrupted these usual reverse role taking. This might be why our patients might have perceived themselves as a burden since it should have been their time to take care of others.

4.4. General Discussion

This study had attempted to identify the changes in young adult female metastatic cancer patients' perception of themselves after the diagnosis. The emerged themes pointed out to different aspects of the self and their relation to each other. Individuals are expected to establish different self-aspects due to interaction between expectations of themselves and others throughout their lives. According to the Self Discrepancy Theory, the person would eventually experience more psychological problems when the difference between the different structures of the self is greater (Higgins, 1987). Thus, people usually attempt to balance these differences to restore their psychological balance. However, life-threatening diseases, such as metastatic cancer diagnosis, inevitable affects the constellation of different selves as a result of the changes in physical appearance (Dropkin, 1999), functionality (Spelten, Sprangers, & Verbeek, 2002) and psychological attributes (Park, Zlateva, & Blank, 2009). Although such a re-organization might be more challenging for young persons, there has been no study in the literature regarding self-discrepancy experiences of young metastatic cancer patients. Only one study has been found investigating challenges aroused from the difference between ideal and actual self among elderly cancer patients (Heidrich, & Ward, 1992).

When the findings of the current study are examined within the framework of the Self-Discrepancy Theory, it can be inferred that there are dynamic changes almost in all aspects of self due to incompatibility between nature of youth and cancer disease. It can be said that although the actual selves of young adult cancer patients have been affected by the difficulties and limitations caused by cancer, their desire to appear strong is dominant which seems to stem from both their own and others' expectations.

However, being unable to continue their business life, social relationship, and physical mobility are important changes in their actual self. Their ideals had also been affected by metastatic cancer. Their desires had changed profoundly from establishing a successful career, being an active part of the community, developing a to ordinary activities such as 'dressing as they want', and 'just going to work'. Considering that young adults' ideals would have been different without such a dreaded diagnosis, these inevitable changes seem to create a conflict between remaining young and living in a diseased body. The fact that the discrepancy between the actual-ideal self would lead people to experience dejection-related emotions (Higgins, 1987) might have explained why our patients refrained to express their grief and sadness throughout the interviews. The regression in the actual self may be compensated by the regression in the ideal self, by this way the discrepancy may have been kept in balance. Although the participants in this study stated that their expectations and responsibilities decreased quantitatively, they had a qualitatively heavy responsibility of 'to surviving'. Due to their young age, both themselves and their families expected them to push their limits in spite of the realities brought by metastatic cancer. Therefore, it can be inferred that their actual-ought self-discrepancy may be high as their young soul is fighting with an elderly disease. In other words, the increase in the ought self while the actual self regressed can be interpreted as the increase of this discrepancy. Actual-Ought discrepancy is known to be associated with agitation-related emotions (Higgins, 1987). In the current study, the only emotion that emerged as a theme was guilt. This may be related to the fact that young adult metastatic cancer patients' actual-ought discrepancy difference is excessive.

4.5. Interpretation of the Results with an Interview

In this section, the themes that emerged during an interview with a participant (Ms. Oya) would be explained in detail to consolidate the integrity of the results.

At the beginning of the interview, Oya explained how strong she was when she learned the disease and started to treatment process. She said that she did not break her spirits at first, had no trouble and strongly believed that she would recover because she was young and full of life. She reported to have been greatly satisfied with her life before

cancer, and all she wanted to end this and return to her old normal. She then continued that she wanted to be strong and fight the disease because everyone expected it from her. She then stated that the thought of death came to her mind even in small plans about the future in her life. Moreover, she said that she was sharing her concerns about death for the first time in this interview as she suppresses these thoughts in order not to burden her family. And at the end of the session, she explained that she felt like 'hitting to a wall' with this disease and how much her life had changed. These themes were all representing the main four themes of results of the analysis. All themes interacted with each other indicating the common and unique challenges that young adult cancer patients might experience due to their developmental stage. The image of a strong person who is not affected from cancer and the desire to return to her old life as soon as possible are expressed simultaneously. Also, being expected to be strong and not being able to share her death anxiety, due to this expectation, are also related with each other. These are expressions might be conceptualized as challenges aroused from changes among actual, ideal and ought self of a young person after a metastatic cancer diagnosis.

4.6. Limitations and Directions for Future Studies

One point to be specified as a limitation in the study was to have one-time meetings with the participants. This limitation can be considered in two dimensions. Firstly, it was an advantage to have more than one interview with the same participant in order to obtain detailed information in qualitative studies (Smith et al., 2009). However, since the sample requires reaching to metastatic cancer patients, it was difficult to interview some participants due to their physical problems. On the other hand, meeting with the same participants at different stages of the disease would also be an important contribution to observe the change in self-discrepancies. In addition, only participants without children were included in this study to ensure homogeneity. It was thought that the role of 'motherhood' may have a different effect on this process. Therefore, it may be important to conduct a similar study with young adults who have child.

4.7. Clinical Implications

This study has valuable results for psycho-oncology literature and also for practitioners working with young adults diagnosed with cancer. Results provided a detailed explanation of self-concept of young adult metastatic cancer patients and the changes experienced throughout the process. Study also reflects basic areas where patients have difficulties such as expectations and necessities. Furthermore, it also gives information about the coping mechanism that young adults use against life threatening situations. Accordingly, the current study provides a preliminary basis for intervention programs specifically designed for young adults with metastatic cancer diagnosis. The existing intervention programs mainly focus on alleviating psychological symptoms such as anxiety and depression. However, understanding young patients' priorities in the reorganization of self seems to be an important issue throughout this process. Some coping mechanisms (e.g. being optimistic, pushing physical limits) might seem functional at the first glance. Yet, these coping mechanisms might be grounded on unrealistic expectations due to young ages of the participants. In other words, being a young adult might inflate responsibilities of metastatic cancer although disease related realities are not compatible with their developmental life span. Hence, careful attention should be paid to process losses and new appraisals simultaneously taking into account developmental trajectories of those patients. In that respect, family members of young cancer patients might also be included to intervention program in order to make sense of experience of being a parent of a young but dying child. In addition, the family's expectations such as 'looking strong and not crying' make it difficult for young adult cancer patients to express themselves. In this regard, informing the family can also facilitate the process for patients.

4.8. Conclusion

The aim of this study was to investigate the self-concept and discrepancy between selves of young adult metastatic cancer patients. There is no study in this context as far to the authors' best knowledge. For this reason, besides contributing to the literature, important results have been obtained that will be useful in working with

young cancer patients in practice. It has been seen that there are important changes in the person's actual, ideal and ought self. Basically, there are difficulties due to the emphasis on being strong and conflicting emotions. While evaluating these people in terms of their psychological well-being, it is important to pay attention to the desire to look strong and also, to create a space for emotional expression.



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APPENDICES

A: APPROVALS OF METU HUMAN SUBJECTS ETHICS COMMITTEE

UYGULAMALI ETİK ARAŞTIRMA MERKEZİ
APPLIED ETHICS RESEARCH CENTER

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25 Haziran 2018

Konu: Değerlendirme Sonucu

Gönderen: ODTÜ İnsan Araştırmaları Etik Kurulu (İAEK)

İlgi: İnsan Araştırmaları Etik Kurulu Başvurusu

Sayın Prof.Dr. Tülin GENÇÖZ

Danışmanlığını yaptığınız doktora öğrencisi Özlem KAHRAMAN'ın "Kanser Hastalarında Benlik Kavramı" başlıklı araştırması İnsan Araştırmaları Etik Kurulu tarafından uygun görülerek gerekli onay 2018-SOS-126 protokol numarası ile 26.06.2018 - 30.12.2019 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
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Dr. Öğr. Üyesi Pınar KAYGAN
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T.C.
HACETTEPE ÜNİVERSİTESİ
Tıp Fakültesi Dekanlığı
İç Hastalıkları Anabilim Dalı Başkanlığı
Medikal Onkoloji Bilim Dalı

Sayı : 90611621-000
Konu : "Kanser Hastalarında Benlik Kavramı"

ONKOLOJİ HASTANESİ BAŞHEKİMLİĞİNE

İlgi : 15/10/2018 tarihli ve 282844 sayılı yazı.

Klinik Psikolog Özlem KAHRAMAN ERKUŞ'tan alınan "Kanser Hastalarında Benlik Kavramı" ile ilgili yazısı incelenmiş olup, çalışmanın bilim dalımızda yapılmasında bir sakınca görülmemiştir.

Gereği için bilgilerinize sunulur.

e-imzalıdır
Prof. Dr. Saime Ayşe KARS
Bilim Dalı Başkanı

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C: INFORMED CONSENT FORM

Gönüllü Katılım Formu

Bu çalışma, Orta Doğu Teknik Üniversitesi Psikoloji Bölümü Klinik Psikoloji Doktora Programı öğrencilerinden Uzm. Psk. Özlem Kahraman tarafından, öğretim üyesi Prof. Dr. Tülin Gençöz danışmanlığında yürütülmektedir. Çalışmanın amacı, kanser tanısının ve tedavi sürecinin kişinin benlik kavramı üzerindeki etkisinin araştırılmasıdır. Çalışmaya katılmayı kabul ettiğiniz takdirde sizinle ses kaydı alınarak yüz yüze bir görüşme gerçekleştirilecektir. Görüşmenin yaklaşık 90 dakika sürmesi beklenmektedir. Ses kaydı sırasında sizden kimliğinizi belirleyecek hiçbir bilgi istenmeyecektir.

Bu çalışmaya katılım gönüllülük esasına dayanmaktadır. Görüşme soruları içerisinde, katılımcılara rahatsızlık verecek sorular bulunmamaktadır. Ancak, görüşme sırasında herhangi bir sebepten dolayı rahatsızlık hissederseniz görüşmeyi yarıda bırakabilirsiniz. Bu çalışma süresince toplanan veriler gerçek kimlik bilgileriyle eşleştirilmeyecektir. Elde edilen bilgiler yalnızca bilimsel ve profesyonel amaçlı yayınlarda kullanılacaktır.

Araştırmayla ilgili daha fazla bilgi almak isterseniz, araştırmacı Uzm. Psk. Özlem Kahraman'a (e-mail: ozlem.kahraman@metu.edu.tr) ulaşabilirsiniz.

Yukarıdaki bilgileri okudum ve bu çalışmaya tamamen gönüllü olarak katılıyorum
(Formu imzaladıktan sonra araştırmacıya geri veriniz).

Ad Soyad

Tarih

İmza

D: THE INTERVIEW QUESTIONS (TURKISH VERSION)

1. Kanser tanısı alma sürecinizi anlatır mısınız? (Tanıyı nasıl öğrendiniz?)
 - a. Tanıyı ilk duyduğunuzda neler hissettiniz?
 - i. Bu duyguyla başa çıkmak için neler yaptınız?
 - b. Kanser tanısı almak size/hayatınızı nasıl etkiledi?
 - c. Tedavi süreci size/hayatınızı nasıl etkiledi?
2. Kendinizi nasıl biri olarak anlatırsınız?
 - a. En temel özellikleriniz neler?
 - i. Hastalık sürecinde bu özelliği nasıl deneyimlediniz?
 - b. Çevrenizdekilere göre sizin en temel özellikleriniz neler?
 - i. Hayatınızda fikrine görüşüne önem verdiğiniz kişiler kimlerdir? Onlara göre en temel özellikleriniz neler?
 - c. Kendinizden beklentileriniz neler?
 - i. Sizin için en önemli rolünüz nedir? O role göre kendinizden beklentileriniz nelerdir?
 - ii. Bunlardan hangilerini karşıladığınızı düşünüyorsunuz?
 - iii. Bunlardan hangilerini karşılamadığınızı düşünüyorsunuz? Neden?
 - d. Çevrenizdekilerin sizden beklentileri nelerdir?
 - e. Kendinizi yapmak zorunda hissettiğiniz şeyler nelerdir?
 - f. Bunlarda değişimler oldu mu?
 - i. Nasıl başa çıkıyorsunuz?
 - ii. Değişmesinden memnun olduğunuz özellikleriniz var mı?
 - iii. Değişmesinden memnun olmadığınız özellikleriniz var mı?
3. Tanı ve tedavi sürecinde size yardımcı olan özellikleriniz nelerdir?
 - a. Sizin için durumu zorlaştıran özellikleriniz nelerdir?
 - b. Şu anda sahip olmadığınızı düşündüğünüz ama sahip olsanız size yardımcı olacak özellikler nelerdir?

E: THE INTERVIEW QUESTIONS (ENGLISH VERSION)

1. Could you tell about your cancer diagnosis process? (How did you learn the diagnosis?)
 - a. How did you feel when you first heard about the diagnosis?
 - i. What did you do to deal with this feeling?
 - b. How did cancer diagnosis affect you / your life?
 - c. How did the treatment process affect you / your life?
2. How would you describe yourself as a person?
 - a. What are your main features?
 - i. How did you experience this feature in the disease process?
 - b. What are your main features according to those around you?
 - i. Who are the people you care about in your life? What are your main features according to them?
 - c. What are your expectations from yourself?
 - i. What is your most important role for you? What are your expectations from yourself according to that role?
 - ii. Which of these do you think you met?
 - iii. Which of these do you think you did not meet? Why is that?
 - d. What are the expectations of those around you from you?
 - e. What are the things you feel you are obligated to do?
 - f. Have there been any changes in these?
 - i. How do you cope?
 - ii. Do you have any features that you are pleased to change?
 - iii. Do you have features that you are not satisfied with the change?
3. What are your characteristics that help you in the diagnosis and treatment process?
 - a. What are your features that make the situation difficult for you?
 - b. What are the features that you think you do not currently have, but if you have them, what will help you?

F: CURRICULUM VITAE

PERSONAL INFORMATION

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EDUCATION

Degree	Institution	Year of Graduation
BA	Hacettepe Un. Psychology	2013
MS	Hacettepe Un. Clinical Psychology	2015
PHD	METU Clinical Psychology	2020

WORK EXPERIENCE

Year	Place	Enrollment
2019- Present	Baskent Un. Department of Psychology	Lecturer
2016-2019	Hacettepe Un. Hospitals	Clinical Psychologist

FOREIGN LANGUAGES

Advanced English

PRESENTATIONS

1. **Kahraman Erkuş, Ö.** (2018). The relation between depression and anxiety levels with sleep and appetite status of cancer patients. 20th National Congress of Psychology, Ankara, Turkey.

2. **Kahraman, Ö. & Soygüt Pekak, G.** (2017). The Comparison of the Forced Migrants Families and Non-Migrant Families in the Context of Schema Therapy Model. *15th European Congress of Psychology, Amsterdam, The Netherlands.*

TEACHING EXPERIENCE

General Psychology (2019-2020) – Lecturer
Health Psychology (2019-2020) – Lecturer
Psychopathology II (2019-2020) – Lecturer
Psychotherapy Supervision (2019-2020) – Lecturer
Psychotherapeutic Interview (2019-2020) –Lecturer

G: TURKISH SUMMARY / TRKE ZET

BLM 1

GENEL GİRİŞ

Kanser, tanı alan kişinin hayatında fiziksel ve psikolojik pekok zorluęa yol aar. Gemişte ‘yaşlı hastalığı’ olarak düşünlen kanser, ocukları ve zellikle gençleri de etkilemektedir (Sung et al., 2019; Young et al., 2015). Genç yetişkinlik hayatta nemli kararların alındığı, yeni rol ve sorumlulukların edinildiğı kritik bir yaşam dnemidir (Erikson, 1959). Bu sebeple, bu dnemde kanser tanısı almak, yaşamın dięer dnemlerinden farklı bir etkiye sahip olmaktadır. Genç yetişkinlerde kanser tanısı oranının artması (Kaatsch et al., 2006) sebebiyle bu yaş grubu iin kanserin etkilerinin incelenmesi nem kazanmaktadır. Kanser tanısından etkilenen zelliklerden biri de benlik kavramıdır. Benlik kavramı, zerinde ok alışılan ve farklı tanımlar yapılan bir kavram olmasına rağmen ok boyutlu bir yapısı olduęu ve kişinin deneyimlerinden etkilendiğı zerinden hemfikir olunan konulardır. Bu alışmada genç yetişkin metastatik kanser hastalarının benlik kavramları ve farklı benlik trlerş arasında oluřan farklılıkların incelenmesi hedeflenmektedir. Bu sebeple, ilk olarak kanser hakkında genel bilgiler verildikten sonra benlik kavramı aıklanacak ve ardından benlik farklılıkları teorisi aktarılacaktır.

1.1. Kanser ve Tedavi Sreci

Kanser tm hastalıklar ierisinde yaşamı en fazla tehdit eden hastalıklardan biri olarak grlmektedir (Bhattacharjee, 2013; Shirzadfar & Khanahmadi, 2018) ve tanı sıklığı gittike artmaktadır. Kanser temel olarak hcrelerin kontrolsz ve anormal bir şekilde bymesi olarak tanımlanmaktadır ve ikiyzden fazla kanser eşidi vardır (Coller,

2014). Dünya Sağlık Örgütü (2018) raporuna göre, 2018’de her altı ölümden biri kanser dolayısıyla meydana gelmektedir. Benzer bir şekilde Türkiye’de de ölümün en yaygın ikinci sebebi kanserdir (TÜİK, 2015).

Yaygın kanser türleri cinsiyetlere göre farklılık göstermektedir. Kadınlarda meme, akciğer ve servikal kanserler yaygın olarak görülürken erkeklerde mide, prostat ve karaciğer yaygın olarak ortaya çıkmaktadır (Asthana ve ark., 2014). Metastaz kanserin çevredeki doku ve organlara yayılması olarak tanımlanmaktadır (Lazebnik, 2010; Tarin, 2011) ve tedavideki başarısızlıklarla ilişkili en önemli faktör olarak görülmektedir (Qiu ve ark., 2016).

Kanser tanısının yanı sıra tedavi için uygulanan yöntemler de kişinin hayatında önemli bozucu etkilere yol açabilmektedir. Ameliyat, kemoterapi ve radyoterapi en yaygın kullanılan tedavi yöntemlerindendir (Greenwald, 1997). Ameliyat pekçok kanser türü için ilk uygulanan ve oldukça etkili olan bir tedavi yöntemidir. Kanserli bölgenin kanser hücrelerinden temizlenmesi pekçok hasta için rahatlamaya yol açsa da kanserin bulunduğu bölgeye ve o bölgenin kişi için anlamına göre psikolojik etkiler değişiklik göstermektedir (Guex, 2005). Kemoterapi tedavi için kimyasal ilaçların kullanılmasıdır (Arruebo ve ark., 2011). Ancak, ilaçlar sadece kanserli hücreleri değil sağlıklı hücreleri de etkilemektedir (Münstedt ve ark., 1997). Bu sebeple, kemoterapi diğer yöntemlere göre daha fazla fiziksel ve psikolojik yan etki ile ilişkilidir (Schirmacher, 2017). Radyoterapi ise X-ray, gama, alfa ve beta dalgalarının kanser hücrelerinin yayılmasını veya büyümesini önlemek için kanserli bölgeye uygulanmasıdır (Shirzadfar & Khanahmadi, 2018).

Uygulanan tüm yöntemlerin az ya da çok fiziksel ve psikolojik etkiye yol açabileceği söylenebilir. Bu etkinin, daha aktif sosyal hayatı olan ve daha karmaşık rollere sahip olan genç yetişkinlerde daha fazla belirgin olduğu düşünülmektedir (Ahles ve ark., 2010; Mattsson ve ark., 2007). Genç yetişkinler aile kurmak, kariyer edinmek, yakın ilişkiler geliştirmek ve bağımsızlık gibi önemli gelişimsel aşamalardan geçmektedirler (Arnett, 2000; Buchmann & Kriesi, 2011). Ancak, kanser tanısı ve tedavi süreci kişilerin günlük işlevlerini yeri getirirken dahi yardım almalarını gerektirecek yan

etkilere sahip olabilmektedir. Bu da kişilerin bağımsızlıklarını kaybetmelerine yol açmaktadır (Luoma & Hakamies-Blomqvist, 2004). Ayrıca, kanser tanısı bir ölüm tehditi olarak görüldüğü için kişilerin gelecekle ilgili planlar yapmalarını engellemektedir (Melin-Johansson et al., 2008). Bu gelişim döneminde özerklikliğin, bağımsızlığın ve gelecek planlarının önemi düşünüldüğünde, bu yaş grubu için kanserin etkilerinin incelenmesi önem kazanmaktadır.

1.1.1. Kanserın Fiziksel ve Psikolojik Etkileri

Kanserın etkileri hastalığın kendisi ve alınan tedavi yöntemi dolayısıyla oluşabilmektedir. En sık görülen fiziksel etkiler ağrı, kusma, kilo değişimi, bellek problemleri, fiziksel kayıplar ve erken menapozdur (Odo & Potter, 2009; Phillips-Salimi & Andrykowski, 2013; Zebrack, 2011). Ayrıca, kanser tanısı ve tedavi süresi kanserin çoğunlukla beklenmedik olması ve sürecin belirsizliği dolayısıyla hastalar için stresli bir dönemdir (Gurevich ve ark., 2002). Kanser hastalarının kanser tanısı almayan kişilere göre psikolojik problemler yaşama olasılığını daha yüksek olduğu bilinmektedir (Carlson, 2010; Zhang ve ark., 2017). Hastalar çoğunlukla kanser tanısından sonra kaygı, korku ve çaresizlik hissettiklerini belirtmektedirler (Smith ve ark., 1999). Genç yetişkinleri ise farklı psikolojik zorlukları vardır. Sosyal ilişkilerin ön planda olduğu bu gelişim döneminde kişilerin sosyal hayatında dışında kalmaları izolasyon ve yabancılaşma hissetmelerine yol açmaktadır (Zebrack ve ark., 2009). Romantik ilişkiler ve cinsellik bu yaş grubu için önemli olan durumlardır ve hastalığın yol açtığı ağrı, bulantı, hormonların değişimi gibi durumlar dolayısıyla kişiler bu alanlarda da zorluk yaşamaktadırlar (Evan ve ark., 2006; Fobair ve ark., 2006). Bunların etkisiyle genç yetişkinlerin daha yaşlı gruba göre daha fazla kaygı ve depresyon belirtisi yaşadıkları bilinmektedir (Linden ve ark., 2012).

1.2 Benlik Kavramı ve Benlik Farklılıkları

Benlik genel olarak kişinin algı, duygu, düşünce, tutum ve davranışlarının bütünü olarak tanımlanır (Marshall, 1989; Plucker & Stocking, 2001; Rosenberg, 1979; Shavelson, Hubner, & Stanton, 1976; Oyserman, 2001). Benliğin çok boyutlu yapısı

pekçok teorisyen tarafından kabul edilmiştir. Rogers (1954), farklı benlik tipleri ve bunların psikolojik iyilik haliyle ilişkilerini tanımlamıştır. Rogers'ın kuramına göre gerçek benlik ve ideal benlik olmak üzere iki benlik türü vardır. Gerçek benlik kişinin kim olduğuyla ilişkili iken ideal benlik kim olmak istediği ile ilişkilidir. Higgins (1987), Rogers'ın kuramına zaruri benliği de ekleyerek genişletmiştir. Zaruri benlik kişinin yapmak zorunda hissettiği ve kendisini sorumlu gördüğü özelliklerini içermektedir. Higgins'in bir diğer önemli katkısı benlik türleri arasındaki farklılıkların kişiyi farklı duygusal problemlere yatkın hale getireceğini söylemesidir. Bu yönüyle, Higgins'in teorisi 'Benlik Farklılıkları' teorisi olarak adlandırılmıştır. Buna göre, kişinin gerçek benliği ve ideal benliği arasındaki fark büyürse kişi üzüntü ile ilişkili duyguları deneyimlemeye daha yatkın hale gelir. Gerçek benlik ve zaruri benlik arasındaki farkın büyümesi ise kaygı ve suçluluk gibi duygularla ilişkilidir. Bu sebeple, kişiler benlikleri arasındaki farkları belirli bir seviyede tutarak rahatsız edici duyguları deneyimleme olasılıklarını düşürdükleri önerilmiştir (Higgins, 1987).

Benlik kavramı dinamik bir kavramdır; kişinin deneyimlerinden ve sosyal çevresinden etkilenir (English and Chen, 2007; Sarbin, 1952). Kanser tanısı sonrası da tanının anlamları ve tedavi sürecinin zorlayıcılığı dolayısıyla kişilerin benlik kavramlarında değişimler olduğu bilinmektedir. Ancak, kanser hastalarının benlik kavramları çoğunlukla benden imajı, öz-yeterlik ve öz-saygı çerçevesinde incelenmiştir (e.g., Mock, 1993; Pintado, 2017; Vas et al., 2019). Kanser hastalarının benlik farklılıklarını inceleyen çalışma sayısı kısıtlıdır. Yaşlı kanser hastası kadınların benlik farklılıklarının kanser hastası olmayan kadınlarla niceliksel olarak karşılaştırıldığı bir çalışmaya göre iki grup arasında benlik farklılıkları açısından bir fark bulunmamıştır. Ancak, kanser hastalarının ideal benliklerinin kontrol grubuna göre daha düşük olduğu görülmüştür. Bu sonuç, kanser hastalarının benlik farklılığını azaltmak amacıyla ideal benliklerini düşürdükleri şeklinde yorumlanmıştır (Heidrich, & Ward, 1992). Kanser hastaları ile yapılan başka bir çalışmada ise benlik farklılıklarının yüksek depresyon ve düşük psikolojik iyilik haliyle ilişkili olduğu ve bu ilişkinin semptomların ciddiyetinden bağımsız olduğu bulunmuştur (Heidrich ve ark., 1994). Ancak iki çalışma da yaşça ileri bir grupta yapılmıştır ve benlik değişiminin niteliği ile ilgili bilgiye ulaşamamaktadır.

1.4. Tezin Amacı

Genç yetişkinlik kişinin normal şartlarda fiziksel olarak en aktif olduğu ve geleceğiyle ilgili önemli adımlar attığı bir dönemdir (Charmaz, 1983). Bu dönemde, kanser tanısı almak nispeten daha nadirdir ve kişiler için sarsıcı bir etki yaratmaktadır (Dunn & Steginga, 2000). Bu yüzden bu grubun, kanser tanısının yarattığı etkiler açısından özel olarak incelenmesi önemli görülmektedir. Literatürde kanser tanısı sonrası benlik kavramında meydana gelen bazı değişimler rapor edilmiştir. Ancak, bu değişimler çoğunlukla fiziksel ve bedensel değişimlerle ilişkilidir. Bilindiği kadarıyla genç yetişkinlerin benlik farklılıklarına ve benliğin psiko-sosyal boyutlarına odaklanan bir çalışma bulunmamaktadır. Bu sebeple, bu çalışmada genç yetişkin metastatik kanser tanısı alan kadınların benlik kavramları farklı boyutlara odaklanılarak ve bu boyutlar arasındaki farkları inceleyerek araştırması hedeflenmiştir.

Araştırma sorusu:

- 1) Metastatik kanser tanısı genç yetişkin kadınları benlik kavramı ve farklı benlik türleri arasındaki farklılıklar açısından nasıl etkilemiştir?

BÖLÜM 2

YÖNTEM

2.1. Yorumlayıcı Fenomenolojik Analiz

Bu çalışmada nitel araştırma yöntemlerinden biri olan Yorumlayıcı Fenomenolojik Analiz (YFA) yöntemi kullanılmıştır. Nitel araştırmalar, araştırmanın amacı, araştırmacının konumu ve deneyimin incelenmesi açılarından nicel çalışmalardan farklılık göstermektedir (Lefevre, Moro & Rachel, 2019). Nitel çalışmalar genellikle daha az katılımcı ile derinlemesine analiz yapılması için kullanılır. YFA belirli bir deneyimi kişilerin nasıl yaşadığı (Smith, 2008) ve onu nasıl anlamlandırdıklarını

(Taylor, 1985) incelemek amacıyla kullanılır. YFA'da kişinin algısı ve yorumları incelenirken araştırmacının yorumlama biçiminin süreci etkileyebileceği göz ardı edilmez (Smith & Osborn, 2007). Bu yöntemde genel bilgiye ulaşılmaktansa kişinin incelenmesi hedeflenir (Smith, Harré, & Van Langenhove, 1995). Bu sebeple tüm katılımcılar ayrı ayrı ve teorik bilgilerden olabildiğince etkilenmeden tüm öznellikleri ile incelenir. Bu sebeple, YFA'nın özellikle az araştırılan konularda kullanılması önerilir (Smith, Jarman, & Osborn, 1999). Bu çalışmada, genç yetişkinlerin metastatik kanser tanısı deneyimleri benlik kavramları ve benliğin farklı boyutları arasındaki farklılıklar açısından inceleneceği için YFA'nın iyi bir metodolojik temel sunduğu düşünülmüştür. Genç yetişkinler için oldukça sarsıcı olan bu deneyim bilindiği kadarıyla bu bağlamda çalışılmamıştır. YFA'nın kişilerin ne hissettiği, ne düşündüğünü ve bir deneyimi nasıl yorumladıklarını anlama fırsatı sunması bu çalışmanın temel hedefleriyle örtüşmektedir.

2.2. Katılımcılar ve Örneklem Yöntemi

YFA çalışmalarında, çalışmanın amacına uygun homojen bir örneklem kullanılması tavsiye edilmektedir (Smith, Flowers, & Larkin, 2009). Bununla tutarlı olarak bu çalışma için 20-39 yaş arası, kadın, metastatik kanser tanısı almış ve tanıyı tam olarak bilen, tedavi süreci devan eden, çocuğu olmayan ve üniversite mezunu katılımcıların örneklemi oluşturması planlanmıştır. Bu kriterleri sağlayan 8 kadın hasta çalışmaya dahil edilmiştir. Katılımcıların yaşları 27 ile 38 arasında değişmektedir. Ayrıca, hepsi bekar, üniversite mezunu, bir kişi hariç hepsi kemoterapi tedavisi alan metastatik kanseri olan kadın hastalardır. Çalışma içerisinde gizliliğin korunması için katılımcıların isimleri değiştirilmiştir.

2.3. İşlem

Araştırmanın verileri toplanmadan önce Orta Doğu Teknik Üniversitesi Etik Kurulundan ve Hacettepe Üniversitesi Onkoloji Hastanesinden gerekli izinler alınmıştır. Araştırmacı Hacettepe Üniversitesi Onkoloji Hastanesinde klinik psikolog olarak çalıştığı için verilerin tamamı o hastaneden toplanmıştır ve araştırmacı tüm

katılımcıları kendisi araştırmaya davet etmiştir. Katılımcılarla yüz yüze yarı-yapılandırılmış görüşmeler gerçekleştirilmiştir. Görüşmeler 35 ile 85 dakika arasında sürmüştür. Tüm görüşmelerin ses kayıtları katılımcıların onayı ile alınmıştır.

2.4. Veri Analizi

Verilerin analizleri YFA çalışmalarında önerildiği üzere sırayla yapılmıştır. İlk olarak, ilk katılımcının görüşmesinin transkripti çıkartılmıştır ve analiz edilmeye başlanmadan önce veriye aşina olmak amacıyla (Smith ve ark., 2009) iki kez okunmuştur. Daha sonra görüşme içeriğine, kullanılan dile ve ilişkisel anlamlarına göre kodlanmıştır. Ardından, kodlar ilişkilerine göre gruplandırılmıştır. Bu şekilde oluşturulan tema listesi araştırma ekibiyle paylaşılmış ve ardından onların önerileri çerçevesinde düzenlemeler yapılmıştır. Daha sonra, ikinci görüşme için aynı analiz süreci yürütülmüştür ve ikinci görüşmenin tema listesi birinci görüşmenin tema listesi ile karşılaştırılarak ortak tema listesi belirlenmiştir. Tüm süreç, her yeni görüşme için aynı şekilde ve sırayla devam etmiştir.

2.5. Çalışmanın Güvenirliği

YFA çalışmalarında araştırmacının öznelliğinin analizi etkilediği kabul edilmektedir. Bu çerçevede araştırmacının kendisini araştırmayı etkileyecek özellikleriyle tanıtması önemli görülmektedir (Willig, 2008). Bu çalışmada, araştırmacı süreç boyunca kendisini gözlemlemiş ve analizi etkileyebilecek özelliklerini ve duygularını olabildiğince fark etmeye çalışmıştır.

BÖLÜM 3

BULGULAR

Bu çalışmada genç yetişkin metastatic kanser hastalarının benlik kavramlarının incelenmesi amaçlanmıştır. Yapılan analiz sonuçlarına göre dört üst temaya

ulaşılmıştır. Analiz sonuçlarına göre, 4 üst-temaya ulaşılmıştır: (1) ‘Benlik Kavramında Çelişkili Değerlendirmelerle Meydana Gelen Zorunlu Değişimler’; (2) ‘Sağlıklı Genç Yetişkinlerin Gündeminde Olmayan Yeni İdealler’; (3) ‘Diğerlerinin ‘Küçük’ Görünen Beklentileri’; (4) ‘Vücudum Bir Kafes: “Ruhum Bedenime Sıkışmış Gibi Hissediyorum”’.

3.1. Benlik Kavramında Çelişkili Değerlendirmelerle Meydana Gelen Zorunlu Değişimler

Bu üst tema katılımcıların metastatik kanser tanısı aldıktan sonra kendilerini nasıl algıladıklarını ve bu değişime nasıl tepki verdiklerini yansıtmaktadır. Temel olarak, kişilerin hayatında meydana gelen zorunlu değişimlerin kendilerini algılamalarını etkilerini yansıtmaktadır. Katılımcıların büyük çoğunluğu benliklerinde meydana kayıplar olduğunu söylerken bir yandan pozitif kazançları olduğunu da vurgulamaktadırlar. Analiz sonuçlarına göre, genç yetişkinlerin metastatik kanser tanısından sonra güçlü görünmeye dair yoğun bir arzu duyguları ve bu sebeple kendi psikolojik ve fiziksel limitlerini zorladıkları görülmektedir. Bazen hiçbir şey değişmemiş gibi davranmaya çalıştıkları ve kanserden sonra değişim olumlu durumların değeri abarttıkları görülmüştür. Örneğin katılımcıların bir kısmı ‘iyi ki kanser oldum’ ifadesini kullanmıştır. Kanser sayesinde hayatlarını iyi yönde değiştirebildiklerine dair inançları vardır. Ancak bu pozitifliğin kanserin getirdiği kayıpları göz ardı ederek elde edildiği görülmüştür. Ayrıca, katılımcıların negative deneyimlerini pozitif duygularla ve gülerek anlattıkları gözlenmiştir. Son olarak, genç yetişkin olarak kanser dolayısıyla sosyal ilişkilerdeki bozulma bir tema olarak ortaya çıkmıştır. Bu bozulma bazen kişilerin sosyal etkinliklere katılamaması dolayısıyla oluşurken bazen de hastaların çevresindeki kişilerin fazla hassas davranmaları kişilere kendilerini izole hissettirmektedir.

3.2. Sağlıklı Genç Yetişkinlerin Gündeminde Olmayan Yeni İdealler

Bu üst tema genç yetişkin kanser hastalarının ideallerinde ve isteklerinde meydana gelen değişimleri yansıtmaktadır. Genç yetişkinlerin normal şartlar altında dinamik

gelişim özelliklerinin gerçekleştiği ve kişilerin kariyer, romantik ilişki gibi konularda çeşitli istek ve arzularının olduğu bir dönemdir. Ancak, metastatik kanser tanısından sonra kişilerin geçmişte normal olarak yaptığı günlük aktivitelerin yeni idealler haline geldiği görülmektedir. Örneğin; istediği gibi giyinmek, işe gitmek gibi. Bununla birlikte, genç yetişkinlerin kanseri yenmek amacıyla kişiliklerinde bazı değişimler yapmayı hedefledikleri ve kendilerinde bu gücün olduğuna inandıkları görülmektedir. Kendi düşünce ve kişiliklerini kontrol etme arzusu kanseri kontrol etme arzularının bir yansımasıdır.

3.3. Diğerlerinin ‘Küçük’ Görünen Beklentileri

Bu üst tema genç yetişkin metastatik kanser hastalarının hissettikleri sorumluluk ve görev algılarındaki değişimi yansıtmaktadır. İlk olarak, katılımcıların kendilerinden bir şey beklenmediğini ifade ederken sadece ‘iyileşmelerinin’ beklendiğini söylemektedirler. Aslında hastalardan hala çok büyük ve kişilerin kontrolünde olmayan bir beklentinin var olduğu görülmektedir. Bununla birlikte, hasta yakınları, arkadaşlar ve bazen doktorların hastaların güçlü görünmesini, ağlamamalarını ve pozitif olmalarını bekledikleri görülmüştür. Ancak, bu beklentilerin kişiler üzerinde bir duygusal yük oluşturduğu ve bu sebeple gerçek duygu ve düşüncelerini paylaşmalarını engelledikleri ortaya çıkmıştır. Son olarak, genç yetişkinlerin sahip oldukları kanser tanısının çevresindekilerin hayatını olumsuz etkilemesi sebebiyle kendilerini suçlu hissettikleri görülmüştür.

3.4. Vücudum Bir Kafes: “Ruhum Bedenime Sıkışmış Gibi Hissediyorum”

Bu üst tema genç yetişkinlerin içinde bulundukları gelişim dönemleri dolayısıyla hayatlarında önemli bir yeri olan ve yapmayı planladıkları durumların metastatik kanser tanısından etkilenmesini yansıtmaktadır. Pekçok katılımcı kendilerini ‘duvara toslamış’ gibi hissettiklerini ve hayatlarındaki evlilik planı, kariyerde ilerleme gibi önemli olayların olumsuz etkilendiğini söylemiştir. Özetle, katılımcılar genç olarak sahip oldukları enerji ile hasta bir vücudun içinde olmanın yarattığı çelişkiyi dile getirmişlerdir.

BÖLÜM 4

TARTIŞMA

Bu kısımda araştırma sonucu elde edilen bulgular ilgili alanyazın ışığında tartışılmıştır.

4.1. Benlik Kavramında Çelişkili Değerlendirmelerle Meydana Gelen Zorunlu Değişimler

Bu üst tema katılımcıların güçlü görünmeye yaptıkları vurguyu, kanserin negatif yönlerini görmezden gelme eğilimlerini ve çelişkili duygu ifadelerini yansıtmaktadır. Katılımcıların güçlü görünmeye yaptıkları vurgunun olası sebebinin içinde bulundukları gelişim dönemi olabileceği düşünülmüştür. Duygusal güçlülük kanser ile başa çıkmada önerilen yöntemlerden biri (Brandão, Schulz, & Matos, 2018; Lent, 2007; Marroquín, Czamanski-Cohen, Weihs, & Stanton, 2016) olsa da genç yetişkinlerin güçlü olmak ve genç yetişkin olarak metastatik kanser tanısının kayıplarıyla mücadele etmek arasında bölünmüş oldukları görülmektedir. Bu sebeple kendi psikolojik ve fiziksel limitlerini ‘kanser yokmuş gibi’ yaşamak için zorlasalar da bu durum onların yaşadıkları gerçek durumları görmelerini ve bunları fark etmelerini zorlaştırıyor gibi görünmektedir. Katılımcıların kanser sonrası elde ettikleri pozitif durumları vurgulamaları fayda bulma olarak yorumlanabilir (McFarland & Alvaro, 2000; Tedeschi & Calhoun, 1996; Tomich & Helgeson, 2004). Fayda bulma ve güçlü görünme çabası kişilerin yaşadığı zor durumlarla başa çıkmak için kullandıkları bir mekanizma olarak düşünülebilir (Helgeson ve ark., 2006; Kvillemo & Branström, 2014) ancak her zaman işlevsel olmayabilirler. Aynı şekilde, güçlü görünme arzusu, pozitif kazançların vurgulanması ve fayda bulma genç yetişkinlerin hastalığı ve hastalık dolayısıyla oluşan duyguları inkar etme eğiliminde oldukları şeklinde yorumlanabilir. Kanser hastalarının inkar eğilimi çoğunlukla daha yaşlı grupta çalışılsa da (Jerant et al., 2018; Vos & Haes, 2007) bu çalışmanın bulguları genç yetişkin kanser hastalarının inkarı sıklıkla kullandığını göstermektedir. Bunun temel sebebi, genç yaşta ölüm tehditi olan bir hastalık tanısı almanın başa çıkması zor bir durum olması düşünülebilir. Tüm bu çabalar ilk etapta olumlu olarak görünse de genç

kanser hastalarının durumun gerçekliğini fark etmelerini ve kendilerini olumsuz durumlara hazırlamalarını engelledikleri söylenebilir.

4.2. Sağlıklı Genç Yetişkinlerin Gündeminde Olmayan Yeni İdealler

Bu tema genç yetişkinlerin ideal ve isteklerinde meydana gelen değişimleri yansıtmaktadır. Normal hayata Özlem duyulması kanser hastaları için bilinen bir durumdur (Kyngas, Mikkonen, Rytlahti, Seppanen, Vaattovaara, & Jamsa, 2001; West, Bell, Woodgate, & Moules, 2015; Woodgate, 2006) ancak bunun genç yetişkin kanser hastaları için daha belirgin görüldüğü söylenebilir. Kişilerin kanser yenmek için kendilerinde tümgüçlü kontrol hissetmeleri, hastaların kontrol algılarında artış olması olarak yorumlanabilir. Kontrol algısının fazla olması kanser hastalarında başa çıkma ve hastalığa uyumunu arttırması açısından işlevseldir (Cvengros ve ark., 2005). Ancak, bu tutum hastaların hastalıkla ilgili gerçekçi olmayan beklentiler geliştirmesine yol açabildiğini için belirli bir düzeyden sonra işlevsiz olarak yorumlanabilir. Bu sebeple, sağlık çalışanları hastaların bu tutumlarına dikkat etmeli ve daha ılımlı bir pozitiflik geliştirmelerinde yardımcı olmalıdırlar.

4.3. Diğerlerinin ‘Küçük’ Görünen Beklentileri

Bu tema kişilerin hayatta kalmaya ve güçlü olmaya dair hissettikleri sorumluluk ile ilişkilidir. Genç yetişkinlik iken kanser tanısı almak hiç kimse için alışıldık bir şey değildir. Bu sebeple, bu yaş grubundaki kişilerin çevresinden güçlü olmaya dair daha fazla baskı hissettikleri söylenebilir. Güçlü görünmek başa çıkma stratejisi olarak görülmektedir (Gilbar, Or-Han, & Plivazky, 2005; Schou, Ekeberg, & Ruland, 2005) ancak bu çalışmanın bulgularına göre güçlü görünme beklentisi kişiler için bir sorumluluk haline gelmektedir ve gerçek duygu ve düşüncelerini paylaşmalarını engellemektedir. Duygu ifadesinin psikolojik iyilikle ilişkisi düşünüldüğünde kişilerin duygularını paylaşmamaları duygu yüklerini arttırmaktadır (Austenfild, & Stanton, 2004; Brandao ve ark., 2016; Giese-Davis ve ark., 2006; Hilton, 1994; Zhang, & Siminoff, 2003).

Su luluk kanser hastalarında farklı sebeplerle ortaya  ıkmaktadır. Bu  alıřmanın  rneklemini oluřturan gen  kanser hastalarında su luluęun kaynaęı kiřilerin  evresindekilerin d zenini bozduklarını d ř nmeleridir. Normal řartlarda gen  ve orta yetiřkinlik kiřilerin ebeveynlerine duygusal ve fiziksel olarak destek verdikleri bir d nem olduęu i in (Evandrou, Falkingham, Gomez-Leon, & Vlachantoni, 2018; Schwarz, Trommsdorff, Kim, & Park, 2006) bu d ng n n tersine d nmesi kiřilerin su luluęunun temel sebebi olarak yorumlanabilir.

4.4. Genel Tartıřma

Bu  alıřmanın sonu larına g re metastatik kanser tanısından sonra kiřilerin ger ek, ideal ve zaruri benlikliklerinde  nemli deęiřimler meydana gelmektedir. Benlik farklılıkları teorisini bu benlik tipleri arasındaki farklılıkların deęiřik olumsuz duygulara yol a tıęını  nermektedir (Higgins, 1987). Bu  alıřmaya g re gen  yetiřkinlerin  alıřma hayatlarına devam edememeleri, sosyal iliřkilerinin bozulması, fiziksel kısıtlamalarla karřılařmaları ger ek benliklerinde meydana gelen deęiřime  rnek g sterilebilir. Ayrıca, beklentilerinin kariyer ve iliřkilerde ilerleme yerine iře gitmek gibi g nl k aktivitelere d n řmesi ideal benliklerindeki deęiřim olarak yorumlanabilir. Benlik farklılıkları teorisine g re kiřilerin ger ek ve ideal benlikleri arasındaki farkın artması  z nt  ve depresyon gibi duyguları deneyimlerimelerine yol a maktadır (Higgins, 1987). Bu  alıřmadaki katılımcıların  z nt  ifadelerinin  ok kısıtlı olması ger ek bekliklerinde meydana gelen geriye gitmeyi ideal benliklerinde geri gitme ile telafi etmeleri ile a ıklanabilir.

Kiřilerin kendilerinden ve  evresindekilerin o kiřiden beklentileri zaruri benliklerini oluřturmaktadır. Bu  alıřmada gen  yetiřkinlerin hayatta kalmak ve iyileřmek řeklinde beklentiler dolayısıyla zaruri benliklerinin arttıęı s ylenebilir. Ger ek benlik ve zaruri benlik arasındaki farklılıęın artması kaygı ve su luluk gibi duygularla iliřkilidir (Higgins, 1987). Bu sebeple, bu  alıřmadaki katılımcıların ger ek benlikleri gerilerken zaruri benliklerinde artıř olması daha fazla kaygı ve su luluk hissetmeleriyle iliřkili olabilir.  alıřmanın temalarında ortaya  ıkan tek duygunun su luluk olması da bu durumla a ıklanabilir.

4.5. Çalışmanın Kısıtlılıkları ve Gelecek Çalışmalar için Öneriler

Bu çalışmada katılımcılarla sadece bir kez görüşme yapılmıştır. Nitel çalışmalarda birden fazla görüşme yapılması verinin zenginleşmesi açısından tavsiye edilmektedir (Smith et al., 2009). Bu çalışma kapsamında aynı kişiyle birden fazla ve özellikle farklı hastalık dönemlerinde görüşme yapılmış olmasının kişilerin benlik kavramları ve farklı benlik türleri arasındaki farklılık hakkında elde edilecek bilgiyi zengileştirmesi bakımından önemli olacağı düşünülmüştür. Ancak, katılımcıların metastatik kanser hastaları olması dolayısıyla pratikte birden fazla görüşme yapmak her zaman mümkün olmayabilir. Daha sonra yapılacak çalışmalarda buna dikkat edilmesi önemli olabilir. Bunun dışında bu çalışmada homejenliğin sağlanması amacıyla sadece çocuğu olmayan kadınlarla görüşme yapılmıştır. Aynı çalışmanın çocuğu olan kadınlarla tekrarlanması annelik rolünün bu süreçten nasıl etkilendiğinin incelenmesi açısından önemli olabilir.

4.6. Klinik Uygulamalara Dair Öneriler

Bu çalışmadan elde edilen bulgular genç yetişkinlerin metastatik kanser tanısında sonra benlik kavramlarında yaşadıkları değişimi detaylı olarak yansıtmaktadır. Bununla birlikte, kişilerin zorluk yaşadıkları temel alanlara da işaret etmektedir. Örneğin, beklentiler ve ihtiyaç duydukları şeyler. Ayrıca, genç yetişkinlerin bu süreçte kullandıkları bazı başa çıkma mekanizmaları hakkında bilgi sağlamaktadır. Bazı başa çıkma mekanizmaları (pozitif olma, sınırlarını zorlama gibi) ilk başta işlevsel gibi görünse de kişilerin gerçekçi olmayan beklentiler geliştirmelerine yol açmaktadır. Bu sebeple, genç yetişkinlerin psikolojik durumları değerlendirilken bu faktörlere dikkat edilmesi ve içerisinde bulundukları gelişim döneminin baskın özelliklerinin unutulmaması gerekmektedir. Ayrıca, müdahale programları temel olarak kaygı ve depresyon gibi semptomlara odaklanmaktadır. Ancak, bu duyguların arkaplanında yaşanan bu değişimlerin incelenmesi önemli görünmektedir. Bu sebeple, bulgular geliştirilebilecek müdahale programları için temel oluşturabilir.

4.7. Sonuç

Bu çalışma genç yetişkin metastatik kanser hastalarının benlik kavramlarını ve benlik türleri arasındaki farklılıkları incelemeyi amaçlamıştır. Literatürde bilindiği kadarıyla böyle bir çalışma bulunmamaktadır. Bu açıdan, literatüre katkısının yanısıra genç yetişkin kanser hastalarıyla pratikte çalışacak kişiler için de zengin ve önemli bilgiler sunmaktadır. Temel olarak kişilerin tüm benlik alanlarında değişimler olduğu ve güçlü olmaya yapılan çok baskın bir vurgu olduğu görülmektedir. Kişilerin güçlü olma arzusunun anlaşılması ve yorumlanması ayrıca duygu ifade için alan yaratılmasının önemli olacağı düşünülmüştür.



APPENDIX H: TEZ İZİN FORMU/ THESIS PERMISSION FORM

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Adı / Name : ÖZLEM

Bölümü / Department : PSİKOLOJİ

TEZİN ADI / TITLE OF THE THESIS (İngilizce / English) : HAVING METASTATIC CANCER AS A YOUNG ADULT: A QUALITATIVE EXAMINATION OF SELF-DISCREPANCY

TEZİN TÜRÜ / DEGREE: Yüksek Lisans / Master ☐ Doktora / PhD ☒

1. **Tezin tamamı dünya çapında erişime açılacaktır.** / Release the entire work immediately for access worldwide. ☒
2. **Tez iki yıl süreyle erişime kapalı olacaktır.** / Secure the entire work for patent and/or proprietary purposes for a period of **two years**. * ☐
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