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A description of the interpersonal impact of an eating disorder on family members
an examination of whether cultural, kin ship factors and specific ED behaviours contribute to carer's distress and the maintenance of the illness.

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King's College London

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A description of the interpersonal impact of an eating disorder on family members. An examination of whether cultural, kin ship factors and specific ED behaviours contribute to carer's distress and the maintenance of the illness.

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The high risk and the intrusive nature of ED symptoms can elicit emotionally driven reactions such as high expressed emotion (criticism, hostility and over protection) and behaviors (accommodation) from close others (Anastasiadou et al., 2014). These responses form one facet of the set of maintaining behaviours which may affect symptoms and duration of illness according to the cognitive interpersonal model on AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). However, less work has been carried out to examine the impact of bulimia and binge eating disorder on family members (parents, siblings and partners) and how their distress and caregiving style will affect the treatment outcome.

The first section of the thesis focuses on parental experiences, examining whether intrafamilial factors that are described by the cognitive interpersonal maintenance model, could be manifested in Greek parents of people with eating disorders (BN, AN, BED) and examines any differences in caregiving behaviours between Greek and English parents of people with Anorexia and Bulimia Nervosa in terms of psychological distress, expressed emotions and accommodating behaviors. The next part of the thesis focuses on exploring the impact of eating disorder on marital and sibling's relationship and comparing caregiving styles between siblings and spouses of adult patients with eating disorders and people with T1 and T2 Diabetes Mellitus. Cross sectional studies were then conducted to examine the caregivers' experiences in terms of psychological distress, expressed emotions and accommodating behaviors. The third part includes one longitudinal study, examining the applicability of the interpersonal maintenance model on patients with bulimia and binge eating disorder.

The findings of this thesis provide further evidence of experiences of all types of carers (parents, siblings, spouses) of people with all forms of eating disorder, (Bulimia Nervosa and Binge Eating Disorder and Anorexia Nervosa) and the applicability of the interpersonal maintenance model on caregivers and patients with Bulimia Nervosa and Binge Eating Disorder. Moreover, findings highlight the role of cultural differences in family functioning which may affect carers' reactions to illness (particularly expressed emotions and accommodation).

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Most of all I want to thank my beloved husband, my precious daughters, my mother for their patience and support throughout, and particularly towards the final stage of my PhD. I would like to dedicate this thesis to the “strong” Greek family ties and values, to all families of people with eating disorders in Greece. I hope this PhD project will help families to find their strength to struggle with eating disorder.

List of abbreviations

AESED - Accommodation and Enabling Scale for Eating Disorders

AN -Anorexia Nervosa

APA – American Psychological Association

BN -Bulimia Nervosa

BED- binge eating disorder

CC- Criticism

DASS-21 Depression, Anxiety, and Stress Scales (21-item version)

DM T1- Diabetes mellitus type 1

DM T2- Diabetes Mellitus type 2

DSM - Diagnostic and statistical manual of mental disorders

ED- Eating Disorders

EDNOS eating disorder not otherwise specified

EOI -Emotional Overinvolvement

FQ- Family Questionnaire

GR-Greece

M -Mean

Mdn - Median

p. critical value of statistical significance

SD- Standard Deviation

SE -Standard Error Mean

SPSS -Statistical package for the social sciences

TAU -Treatment as usual

UK- United Kingdom

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Presentations associated with the thesis

Poster presentations:

Eating Disorders in Greece: An examination of parents' distress, attitudes and behaviours. European Association for Psychotherapy, Athens, 2015

Aspects of caregivers' experiences in eating disorders: comparison between Greek and English parents. Eating Disorders International Conference, London, 2016

Declaration of candidate's role

All studies were carried out by myself and another individual. I carried out the design, data collection, data analysis, interpretation and write-up of all chapters. Except, the analysis of study 4 was conducted from a statistician due to the complicated nature of the structural equation model.

Chapter one

Introduction

1.1. Chapter aims

The aim of this introductory chapter is to provide an overview of eating disorders and to provide the context for this thesis. It will begin by considering the nature of eating disorders, their classification, epidemiology, and co-morbidity with other mental illnesses. A summary of risk factors and a presentation of familial role in maintenance of eating disorders according to the cognitive interpersonal maintenance model of eating disorders, more specifically the final aspect of the model that provides the theoretical background to this thesis will be described. The next section of this chapter illustrates the rationale of selection of familial members of people with diabetes as comparison group as well as a brief presentation of diabetes impact on families.

1.2 Eating Disorders: Overview

Eating disorders are characterised by disturbances of eating behaviours and a core psychopathology of overvaluation of shape weight and their control. Early reports of an anorexia nervosa-like illness date to the 1600s (Silverman, 1983) and anorexia nervosa as a diagnostic entity was described first in 19th century medical reports (Gull, 1874; Lasegue, 1873). Additional insights into predisposing and precipitating socioemotional factors for eating disorders emerged by Hilda Bruch in 1977, in her writings of AN stated that women with AN “*suffer from definite deficits in the way in which they interpret human relationships and think of their own role in life*” (Bruch, 1977). In contrast, bulimia nervosa and binge eating disorder were not widely discussed until the 20th century. This disorder was first described in medical terms in 1903 in “*Obsessions et la Psychasthenie*”, where Pierre Janet presents Nadia, a woman who engaged in secretly compulsive binges. Later in 1979, Gerald Russell described BN as a variant of AN and provided a rich, clinical description of this variant of ED which allowed other clinicians to detect such cases in their own practice (Palmer, 2004). Since then, the facade of eating disorders has changed dramatically. It is understood today that eating disorders have multiple and complex causes. In 2009, the Academy for

Eating Disorders (AED) defined eating disorders as biologically brain based, serious mental illnesses (BBMI), more specifically Klump et al. (2009) described an eating disorder as “a condition that current medical science affirms is caused by a neurobiological disorder of the brain, significantly impairs cognitive function, judgment, and emotional stability, and limits the life activities of the person with the illness” (p. 98).

1.2.1 Diagnostic Criteria

Current diagnostic schemes identify three main eating disorders, including anorexia nervosa, bulimia nervosa, and binge eating disorder (APA, 2013). Anorexia nervosa is defined by symptoms that include self-imposed or maintained weight loss such that the person is underweight (for age and height) and associated overvaluation of shape and weight. Two subtypes of anorexia nervosa are specified: restrictive type (with or without compulsive exercise); and binge eating/purging type, with binge eating (uncontrolled overeating) and purging (vomiting, laxative or diuretic misuse). Severity is specified according to BMI (kg/m^2) status. Bulimia nervosa and binge eating disorder are both defined in the DSM-5 by having regular and sustained binge eating episodes. People with bulimia also experience overvaluation of body weight or shape and engage in weight loss behaviour, such as extreme caloric restriction, excessive exercise, and forms of purging (for example, misuse of laxatives or diuretics, or self-induced vomiting). However, these behaviours are in compensation for episodes of objective binge eating, defined as overeating with an accompanying sense of loss of control. These binge episodes can trigger negative mood states (such as shame, guilt, or anxiety) and are often a source of body image disturbance. Hence, an individual with bulimia nervosa may be entrapped in a vicious cycle of binge eating, negative appraisal of weight/body shape, and extreme weight loss behaviours (Fairburn, Cooper, & Shafran, 2003). In contrast to anorexia nervosa, individuals with bulimia nervosa are overweight or within the normal weight range (Masheb & White, 2012). The most prevalent of three, is binge eating disorder (Hudson, Hiripi, Pope, & Kessler, 2007) which involves regular episodes of objective binge eating that are distressing to an individual, body image disturbance such as overvaluation of body weight or shape may also be experienced, but is not a diagnostic criterion (Mond, Hay, Rodgers, & Owen, 2007). The distinguishing feature of binge eating disorder however is the absence of

compensatory weight loss behaviour. As a consequence, although it is not a criterion of the disorder, binge eating disorder is often associated with being overweight or obese (Smith et al., 1998).

1.2.2 Onset, Prevalence and Life Course of Eating Disorders

Regarding prevalence and incidence of EDs, AN is the third most common chronic disease with an adolescent onset, with a lifetime prevalence of 1% for women and < 0.5% for men and the peak age of onset in early to mid-adolescence but may occur at any age, including childhood (Keski-Rahkonen et al., 2007; Madden et al., 2009). In turn, BN has a lifetime prevalence of 2% for women and 0.5% for men, with an average age of onset in later adolescence (Stice et al., 2013). In addition, BED is more likely a mid-life disorder with a much more even gender frequency, occurs among 3.5% of women and 2.0% of men (Hudson et al., 2007). However, a recent Australian study on adults showed that the 2014 and 2015 3-month prevalence of eating disorders are characterised: anorexia nervosa-broad 0.4% to 0.5%; bulimia nervosa 1.1% to 1.2%; ARFID 0.3%, BED-broad 1.5%; Other Specified Feeding or Eating Disorder (OSFED) presents predominantly atypical anorexia nervosa 3.2%; and Unspecified Feeding or Eating Disorder (UFED) 10.4% that is described by having recurrent binge eating without noticeable distress (Hay et al., 2017). In adolescent population, evidence shows that 22.2% meet criteria for any DSM-5 diagnosis in Australia (Mitchison et al., 2018). Moreover, other studies indicate that the global prevalence is 21% for early adolescents (Hammerle et al., 2016) and sits between the prevalence estimates of 19 and 37% reported by Micali and colleagues for 14 and 16-year-olds, respectively (Micali et al., 2015). However, binge-eating disorder is the most common of all eating disorders and occurs more equally across men and women than other eating disorders (Mustelin et al., 2016). The population prevalence of clinical BED is <1%–3.5% (Kessler et al., 2013; Mustelin et al., 2015; Smink et al., 2014; Mustelin et al., 2016), but up to 15% of adolescents and young adults report some loss of control or binge eating (Abebe et al., 2012; Goldsmith et al., 2015; Sonnevile et al., 2013).

1.2.3 Impact of Eating Disorders on Physical and Mental health

The course and outcome of eating disorders may cause an important deterioration of the individual's physical and mental health, often irreversible, persistent and life-threatening (Klein & Walsh, 2004); including electrolyte abnormalities, hypokalemia, hyponatremia and cardiac arrest (Mitchell & Crow, 2006), kidney damage, infertility, depression and anxiety. Furthermore, eating disorders have the highest mortality rates of all mental illnesses (Smink et al., 2012), with anorexia having one of the highest suicide rates of any psychiatric disorder (NIMH, 2018). Additionally, eating disorders pose adverse effects on cognitive and emotional functioning of the individuals suffering from them. Among them, it is important to underline the difficulties in social cognition (Caglar-Nazali et al., 2014; Oldershaw et al., 2011), problems in emotional intelligence (Hambrook, Brown, & Tchanturia, 2012), high levels of social anhedonia (Tchanturia et al., 2012), reduced emotion expression (Claes et al., 2012; Davies et al., 2011), and poor social functioning (Harrison, Mountford, & Tchanturia, 2014; Tchanturia et al., 2012). These severe impairments have a detrimental impact on interpersonal relationships, treatment outcomes and prognosis (Ridout, Thom, & Wallis, 2010; Anckarsater et al., 2011). Eating disorders also frequently co-occur with other mental health disorders, particularly anxiety disorders and depression (Hudson et al., 2007). Therefore, eating disorders are associated with notable quality of life impairment and impact on home, work, personal, and social life (Jenkins et al., 2011; Mitchison et al., 2012; Mond et al., 2012). This highlights the serious implications of eating disorders and indicates that people who care and support people with eating disorders could play an important role in recovery (Eisler et al., 2000).

1.3 Risk Factors of ED

The term “risk factor” refers to a measurable characteristic that precedes the onset of a disorder (Kraemer et al., 1997). Eating disorders are complex illnesses and research to date reveals a range of biological, genetic, psychosocial, and socioenvironmental factors that contribute to the illness onset and maintenance (Jacobi et al., 2004).

1.3.1 Genetic and Biological Factors

In all eating disorders there is an increased genetic heritability and frequency of a family history. Individuals with EDs are thought to have genetic predisposition that is activated by environmental (e.g., sociocultural, psychosocial) factors, which is also known as a gene-environment interaction (Jacobi et al., 2004). Twin, genetic and family-genetic studies confirm that EDs are strongly heritable (Thornton, Mazzeo, & Bulik, 2010; Klump & Culbert 2007; Scherag, Hebebrand, & Hinney 2010; Trace et al., 2013). Moreover, numerous physiological factors such as perinatal factors, puberty, excess body fat, and significant weight fluctuations are linked to ED onset (Goodman et al., 2014; Veses et al., 2011; Veses et al., 2014; Hilbert et al., 2014). On the other hand, brain imaging studies revealed that people with eating disorders may have altered brain circuitry that contributes to eating disorders (Kaye et al., 2011; Kaye, 2008). For instance, differences in the anterior insula, striatal regions, and anterior ventral striatal pathway as well as dysregulation of central serotonergic and dopaminergic systems have been discovered (Kaye et al., 2011; Kaye et al., 2013; Smith & Robbins, 2013; Xue et al., 2012).

1.3.2 Psychological Factors

There is established support for an association between certain temperament and personality traits and eating pathology. For instance anxiety, reward insensitivity, altered interoceptive awareness, and cognitive inflexibility and rigidity are common traits in individuals with the restrictive type of AN (Anderluh et al., 2003; Cassin & von Ranson, 2005; Fassino et al., 2004; Harrison et al., 2010; Kaye et al., 2004; Lilenfeld, 2011; Lilenfeld, Wonderlich, Riso, Crosby, & Mitchell, 2006; Wagner et al., 2006). On the other hand, people with BN tend to be impulsive, seek out new experiences and display a lack of inhibitory control, lower self-directedness and less cooperativeness (Raymond et al., 1999; Cassin & Von Ranson, 2005; Kaye, 2008; Bulik et al., 1995). In addition, eating, weight, and shape overconcern, and low self-esteem are considered as risk factors that are associated to ED onset and maintenance, especially during adolescence into young adulthood (Allen, Byrne, Oddy, & Crosby, 2013; Jacobi et al., 2011). Hence, many psychiatric disorders including attention deficit hyperactivity disorder (ADHD), mood, anxiety, substance use disorders, and obsessive

compulsive disorder among others, have been shown to co-occur with EDs (Micali et al., 2011; Mitchell et al., 2012; Seitz et al., 2013; Steinhausen et al., 2015).

1.3.3 Socioenvironmental Factors

Numerous sociocultural and interpersonal factors within an individual's social network influence the ED risk. The internalization of a thin ideal and perceived pressure to be thin are considered to be one of the major sociocultural risk factors for ED onset and maintenance, especially in adolescent girls (Stice, Marti, & Durant 2011; Rohde, Stice & Marti, 2014). Further, a history of being bullied specifically related to body weight and shape and traumatic events such as physical, emotional or sexual abuse sometimes indicate potential ED risk (Machado, Goncalves, Martins, Hoek, Machado, 2014; Inniss, Steiger, & Bruce, 2011; Reyes-Rodriguez et al., 2011). Additionally, a family history of affective disorders and sibling history of AN were strong predictors of AN in probands (Steinhausen et al., 2014). With regard to familial interaction patterns and stressors Machado et al. (2014) revealed that familial criticism about appearance and eating and negative attitude toward child's shape and weight are predictors of ED. Also, family overeating, parental absence or death, and familial disruption or deprivation in the home environment have been shown to confer risk for BED (Hilbert et al., 2014).

1.4 Familial Role in Maintenance on Eating Disorders

1.4.1 Familial Functioning on Eating Disorders, a Historical Perspective

The familial role on the development of ED was underlined from 19th century. Taking as an example the work of Gull (1874) and Charcot (1889), families were traditionally blamed for their children's disease and were considered an obstruction to recovery. At the same time, French psychiatrist Charles Lasague observed how the home environment shapes eating disorder pathology, as well as triggering emotional stress.

During the 1970's, new theoretical model suggested that family system with specific characteristics may function as risk factor for ED onset. In 1975, Salvador Minuchin, one of the founders of systemic family therapy, introduced the concept of the "psychosomatic family" which is characterized as being either enmeshed with overly

diffused boundaries or disengaged with overly rigid boundaries and overprotection (Minuchin et al., 1978). He argued that these familial interaction patterns trigger and maintain child's illness. Moreover, he believed that child symptomatology served to act out family conflict. In the same line, Selvini-Palazzoli (1974) added that these communication patterns among family members, lead to treatment resistance. However, others have argued that this model was considered implausible and poorly supported by empirical evidence (Eisler, 2005; Vandereycken, 2002).

Later in the 1990's, the model of 'psychosomatic family' was redefined (Dare et al., 1994) and a new paradigm originated in the field of family therapy on eating disorders redirecting attention away from family blaming models (Dare et al., 1995; Schmidt & Treasure, 2006; Le Grange et al., 2010). This paradigm highlighted the importance of familial role as a potential resource in recovery (Eisler, 2005). Moreover, the necessity for family involvement is substantiated by research indicating that family factors can contribute to the maintenance of eating disorders. For example, high levels of expressed emotion, misinterpretations about the illness and enabling methods of engaging with the symptoms of the ED can moderate the ED and treatment outcome (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013).

As more research is done on the diverse risk factors that have been discussed above, it becomes more and more clear that family is not the cause of their child's eating disorder. On the contrary, some familial interactive patterns may actually develop as a response to a family's struggle with an eating disorder rather than as precursors to an eating disorder (Hoste et al., 2011; Sim et al., 2009; Stern et al., 1984). In 2010, the Academy of Eating Disorders (AED) released a position paper that clarifies the role of the family in the acquisition of eating disorders. The paper points out that there is no data to support the idea that eating disorders are caused by a certain type of family dynamic or parenting style (Le Grange et al., 2010). Alternatively, there is strong evidence that families play an integral role of being part of the solution to the recovery process rather than the "problem" (Treasure et al., 2007).

1.4.2 Cognitive Maintenance Model (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013)

The cognitive-interpersonal maintenance model of EDs was initially developed in 2006 (Schmidt & Treasure, 2006) and was recently updated to include information from neuroscience (Treasure & Schmidt, 2013). This model provides another conceptualization of the aetiology and maintenance of EDs that integrates intra- and interpersonal factors and highlights the role of socio-emotional processing in combination with specific emotional responses and behaviours in close others that contribute to the vicious cycle of AN. The above four key components are posited as maintaining factors (illustrated in Figure 1):

‘Thinking style’. Specific cognitive patterns, OCD traits and a neuropsychological profile is depicted by poor set- shifting and weak central coherence (Roberts et al., 2007; Tchanturia et al., 2012; Lang et al., 2014) that manifests as poor cognitive flexibility and strong attention to detail (Lopez, et al., 2008); these factors are related to the development, maintenance and recovery of AN (Merwin et al., 2011; Treasure & Schmidt, 2013; Kidd & Steinglass, 2012).

‘Emotional and social style’. Social emotional difficulties have been shown to be present before the development of the disorder (e.g. comorbidity with personality disorder) (Godt, 2008) including deficits in recognizing facial expression emotions, (Oldershaw et al., 2011), inhibited emotional expression (Davies et al., 2011), and lower emotional awareness and deficits in emotion regulation (Gilboa-Schechtman, Avnon, Zubery, & Jeczmiern, 2006).

‘Pro-anorexia’. A set of positive beliefs about starvation and the valued nature of illness offers a sense of success and control (Borzekowski, Schenk, Wilson, & Peebles, 2010) that makes them feel more attractive and special (Branch & Eurman, 1980) which in turn contributes to ambivalence towards recovery (Gale, Holliday, Troop, Serpell, & Treasure, 2006).

The interpersonal relationships’, component proposes that maladaptive patterns of interaction with others develop in response to the manifestation of AN and then play a

role in illness maintenance (illustrated in Figure 2). Three mechanisms in this domain may contribute to perpetuation of AN: firstly, high levels of expressed emotion, particularly criticism and emotional over involvement; secondly, behaviours that either facilitate or disregard ED behaviours (accommodating and enabling behaviors) (Treasure et al., 2007); thirdly, compulsivity, rigidity and attention to detail, are shared common traits among AN patients and their caregivers which reinforce additional controlling behaviours in the home environment (Goddard et al., 2013). Therefore, carers' unhelpful behaviors and emotions characterized by high levels of EE, accommodating and enabling behaviors or unhelpful coping mechanisms, may increase distress in carers and in turn, allow ED symptoms to flourish (Figure 3).

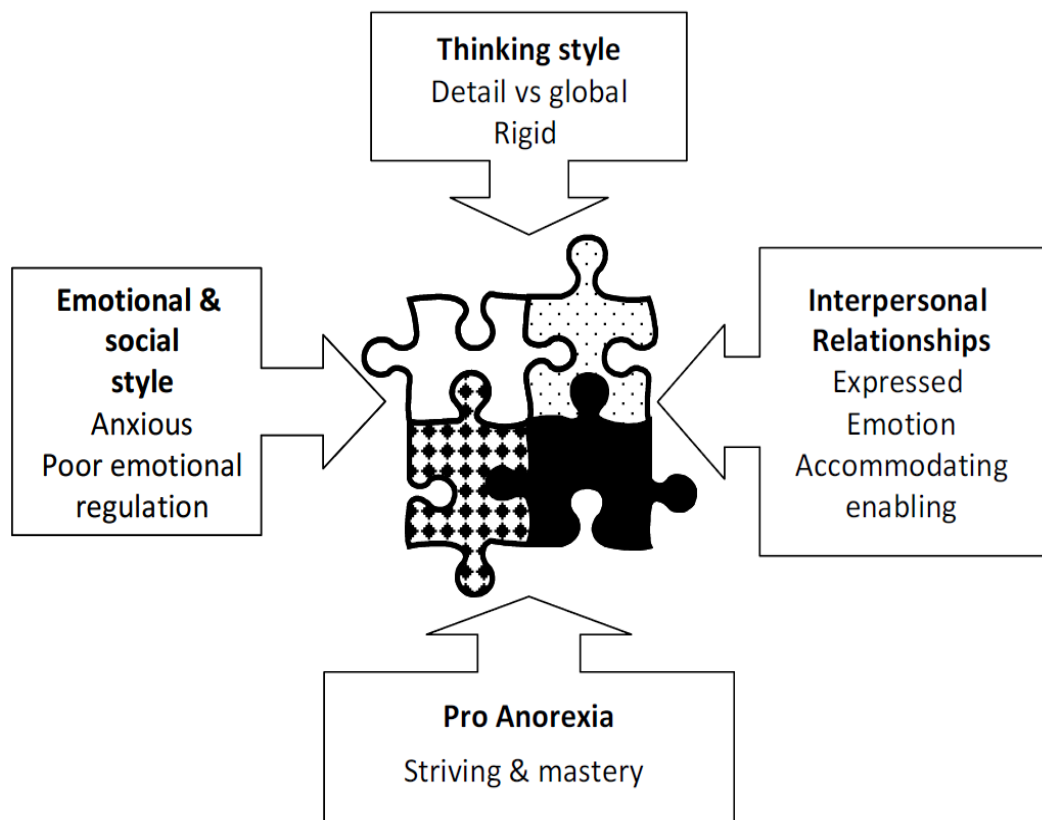


Figure 1.1. The cognitive-interpersonal maintenance model of EDs (Treasure & Schmidt, 2013)

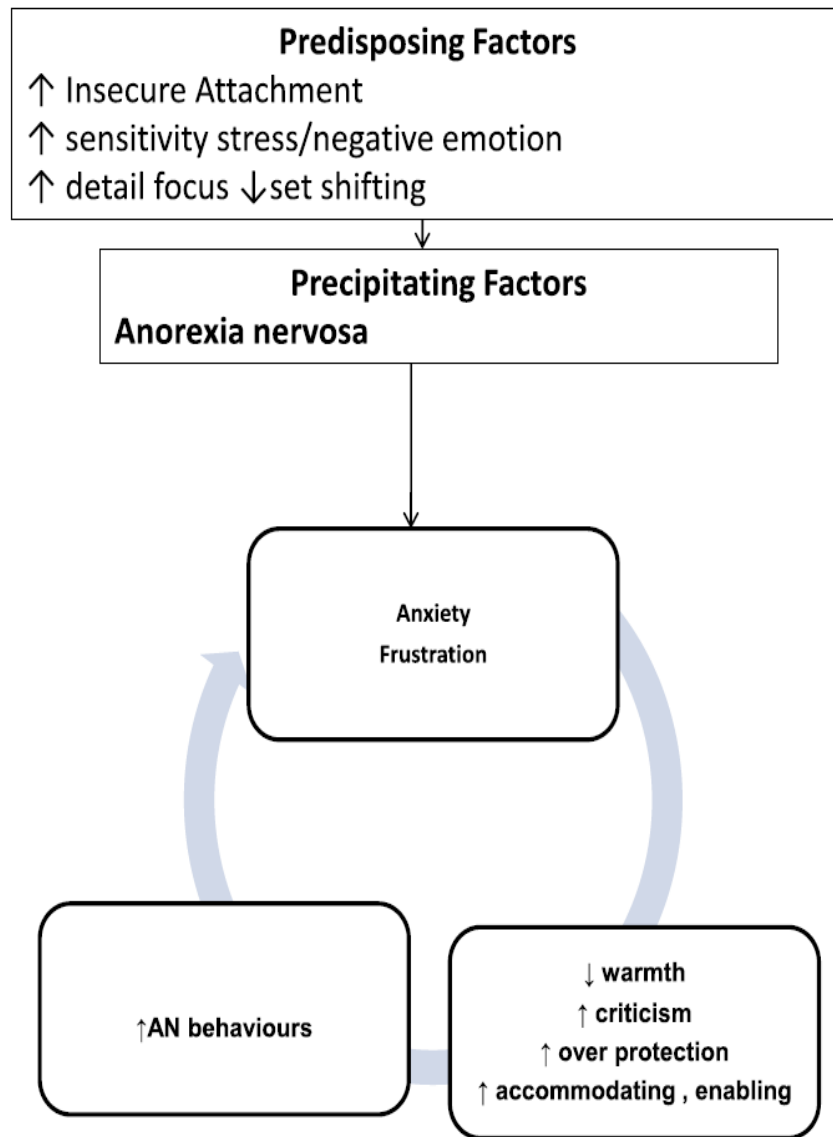


Figure 1.2. An interpersonal perpetuating cycle: Diagrammatic formulation of carers involvement within the maintenance of an ED (from Treasure & Schmidt, 2013).

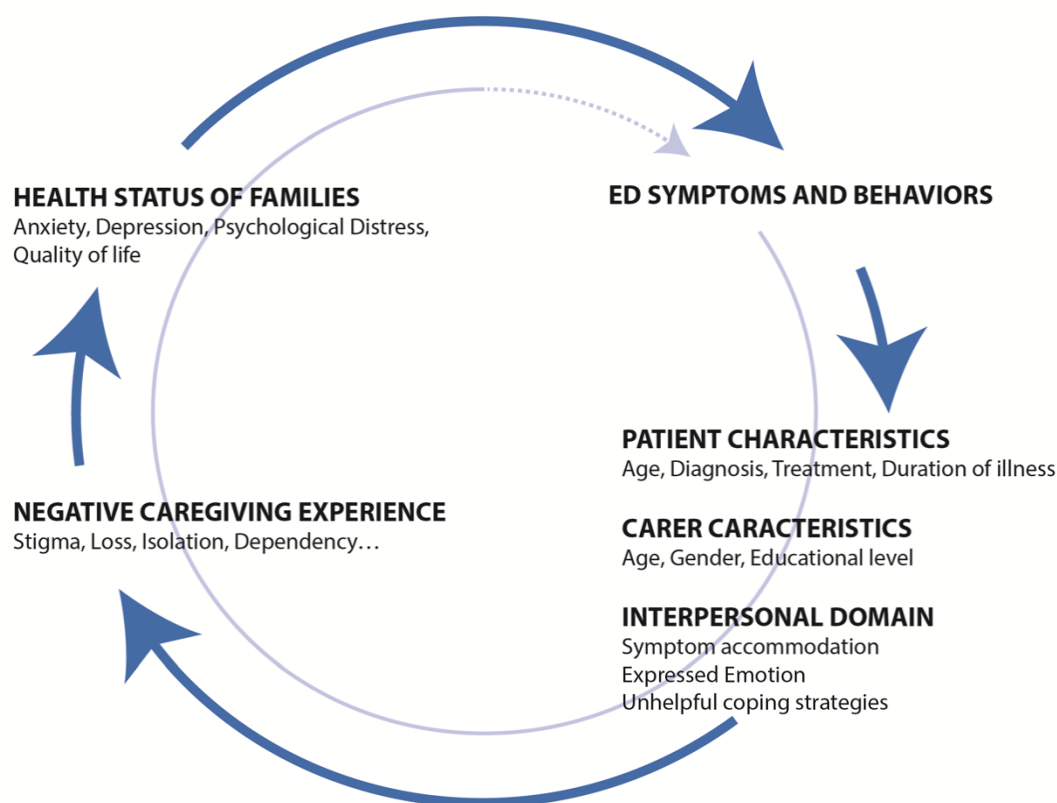


Figure 1.3. The interpersonal maintenance model in EDs (Schmidt & Treasure, 2006)

1.4.2. Evidence Supporting the interpersonal Component of Model

This model is also supported by current studies examining the negative aspects of care giving experience with eating disorder. These aspects have been summarized in a systematic review (Zabala et al., 2009) which has been recently updated (Anastasiadou et al., 2014). High perceived burden, and low care giving efficacy, are common and are associated with clinical levels of depression and anxiety which in turn are linked with highly expressed emotion such as criticism, hostility and or overprotection (Zabala et al., 2009; Kyriacou, Treasure, & Schmidt, 2008a; Goddard et al., 2013). Overprotection is associated with fear of the negative consequences of AN, and criticism is associated with erroneous illness appraisals about BN (Duclos et al., 2014; Kyriacou, Treasure, & Schmidt, 2008b). Furthermore, high levels of accommodation are linked with carer's distress due to the family's entrapment into a vicious cycle of the patient's eating, shaping and control behaviours (Goddard et al., 2013; Treasure et al., 2008). In addition, these features are associated with some socio

demographic and clinical characteristics of carers (such as gender of carer, educational status, contact time and eating problems) and patients (such as diagnosis, the severity of eating disorder symptoms, co-morbidity, and illness duration) (Anastasiadou et al., 2014; Duclos et al., 2013; Sepulveda et al., 2010; Zabala et al., 2009). In addition, empirical evidence of model's trans-diagnostic application suggests that dysfunctional interactions within the family are associated with more negative family caregiving (Goddard et al., 2011; Goddard et al., 2013; Sepúlveda et al., 2010; Winn et al., 2007) and poor treatment outcome (Rhind et al., 2016; Salerno et al., 2016).

1.4.3 Familial Expressed Emotions

Expressed emotion (EE) refers to the construct of key aspects of interpersonal relationships and has traditionally been used to describe relatives' attitudes and behaviors toward an ill family member (Brown & Rutter, 1966; Vaughn & Leff, 1976) in five dimensions (i.e., critical comments (CC), positive remarks (PR), hostility (H), warmth (W), and emotional overinvolvement (Brown, Birley, & Wing, 1972). Familial members that score above certain cut-offs on these three components are considered high on EE, whereas those who do not are classified as low on EE (Leff & Vaughn, 1985). The majority of EE research has been conducted with patients with schizophrenia or depression suggesting that relatives with high EE tend to have higher expectations of patients and may become more frustrated and controlling when patients do not live up to their expectations (Hooley, 2007), whereas those with low EE tend to believe that undesirable symptoms result from a genuine disorder that is not under the patient's control (Barrowclough & Hooley, 2003; Leff & Vaughn, 1985). Moreover, EE has also been measured in patients with eating disorders (EDs), two systematic reviews (Zabala et al., 2009; Anastasiadou et al., 2014) found that carers present high levels of expressed emotion, especially in relation to critical remarks and emotional over involvement. More specifically, Zabala, Macdonald, and Treasure (2009) identify that high levels of EE are found mostly among carers of older sufferers with longer duration of illness whereas Anastasiadou, Medina-Pradas Sepulveda & Treasure's (2014) review of twenty-nine studies indicated that percentage of high levels of familial criticism is fluctuated from 29% to 73.2%, whereas high levels of emotional overinvolvement varied from 27% to 89.3%. However, the majority of studies explored predominantly AN caregiving experiences and further studies measuring the levels of

EE of all forms of eating disorders on all familial members (i.e., siblings and spouses or partners) are limited.

1.4.4 Factors Modulating Expressed Emotions Levels

Evidence showed that familial EE is influenced by a number of variables, including the caregiver's socio-demographic characteristics, the clinical characteristics of the patient's illness (i.e., diagnosis, age, illness severity and duration). In terms of diagnosis, a significant association was found between higher levels of EOI among AN caregivers and higher levels of criticism among BN caregivers (Zabala et al., 2009). From the gender perspective, mothers of patients with AN and BN expressed more emotional over-involvement and critical comments than did fathers. Fathers expressed more emotional over-involvement toward patients with BN than patients with AN (Kyriacou, et al., 2008b; Zabala et al., 2009). Furthermore, high parental criticism is found to be associated with low social status in a mixed sample of AN and BN (Szmukler, Eisler, Russel, & Dare, 1985). In terms of diagnosis, a significant association was found between higher levels of EOI among AN caregivers and higher levels of criticism among BN caregivers (Zabala et al., 2009). However, later findings indicated that EE levels are not different among AN and BN parents (Duclos et al., 2013; Sepulveda et al., 2010). Moreover, high caregiver's EE was associated with large number of face-to-face hours with the patient, supervising his/her eating habits and medical health status (Winn et al., 2007). In two studies, the age of patients was linked with high levels of paternal criticism (Hoste, Labuschagne, Lock, & Le Grange, 2012; Szmukler et al., 1985). Even fewer studies have considered caregiver's EE and illness characteristics; one study showed that carers' higher levels of EE are associated more with purging behaviors rather than binge eating (Sepulveda et al., 2013). Finally, in regards to illness duration, higher levels of EE have been found among caregivers of patient with longer illness duration (Hoste et al., 2010; Sepúlveda et al., 2010; Szmukler et al., 1985).

1.4.5 Predictive Value of EE on Treatment Outcome

The literature review of Expressed Emotions (EE) in psychiatry found that family's level of expressed emotions such as overprotection, criticism (CC), and hostility affect adherence to treatment and moderate the outcome in psychiatric illness,

including eating disorders (Butzlaff et al., 1998). In families of patients with AN, high parental EE has been implicated as a prognostic indicator in adolescents with AN (Le Grange et al., 1992) and has been associated with a longer duration of illness (Hoste et al., 2012) and greater rates of treatment dropout (Szmukler et al., 1985), whereas parental warmth has been found to predict good treatment outcome (Le Grange et al., 2011). In adult women with eating disorders, parental criticism is associated with greater eating disorder symptomatology (Medina-Pradas, Navarro, Lopez, Grau, & Obiols, 2011). In spite of the fact that families of patients with eating disorders have lower rates of high EE than those with schizophrenia (Vaughn & Leff, 1976a), EE nevertheless seems to play an important role in accordance with the interpersonal maintenance model in AN, where high levels of EE are considered as a key maintaining factor for AN due mainly to the “negative aspect” of parental critical EE (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013; Zabala, Macdonald, & Treasure, 2009). Therefore, negative carer’s emotional reactions to the illness can generate a cycle of negative interactions that may hinder treatment outcome. Improving negative family interactions associated with EE may improve the prognosis of people struggling with an eating disorder (Treasure & Schmidt, 2013).

1.4.6 Accommodating and Enabling Behaviors

Accommodating and enabling refers to an over protective caregiving style that accepts core patient’s symptoms and behaviours in an attempt to alleviate family conflict and stress (Sepulveda et al., 2009). According to Treasure (2010) families accommodate into three domains of symptomatic behaviors. First, the family obeys patient set rules around food-related activities such as dinner time, food preparation, and grocery shopping. Often, meal times change into a nightmare for the entire family and the kitchen table becomes a battleground dominated by the bullying voice of the ED. Second, carers allow safety behaviors (such as exercise, vomiting, fasting) and sometimes enable by walking for hours with patient or by cleaning up bathrooms after purging. Third, they adhere to obsessive-compulsive behaviors such as reassurance seeking about shape or checking food ingredients. ED becomes the vital focus for the family and familial life becomes reorganized around it (Whitney et al, 2005; Kyriacou et al., 2009). Consequently, families become trapped into a vicious cycle of patient’s eating, shaping and control behaviors and they can inadvertently reinforce or ‘buffer’

some of the negative consequences which allows the ED behavior to persist (Treasure et al., 2008).

Several qualitative studies investigating the caregiver experience have referred to accommodation responses and note that carers display difficulties implementing limits in response to difficult behaviours. Honey and Halse (2007) report accommodation in the most detail, describing how carers ‘willfully’ endure difficult behaviours or interact with the individual with AN cautiously to avoid confrontation. Highet, Thompson, and King (2005) described how increased AN severity elicited carer distress and carers’ experience of despair and powerlessness over the ED (e.g., Honey & Halse, 2007; Huke & Slade, 2006). Subsequently, some partners in Huke and Slade (2006) describe ‘stepping back’ and ‘walk on egg shells’ out of fear for intensifying symptoms. Similarly, siblings use escape/avoidance coping strategies especially during meal preparation or mealtime (Honey et al., 2006).

In 2009, the first measurement scale, the Accommodation and Enabling Scale for Eating Disorders, was designed to assess the extent of such behaviors in carers (Sepulveda, Kyriacou & Treasure, 2009). Parental levels of accommodation in AN increase with illness duration (Sepulveda et al., 2009), carer’s contact time (Goddard et al., 2013), and if the carer has a personal history of ED (Stefanini et al., 2018). Mothers display higher levels of accommodation than fathers (Rhind et al., 2016). Salerno et al. (2016) suggested that carers’ high levels of accommodation are correlated with symptom severity and poor treatment outcome in AN. Carers’ accommodating behavior to people with BN and BED has not been measured.

1.5 ED Impact on Family Members

The families of people with ED encounter several problems such as reluctance of ED patients to admit their illness, medical complications and social stigmatization (Treasure et al., 2008b; Perkins et al., 2004a). Furthermore, the daily battles around the table, person's disrupted behavioral patterns, and mood alterations often monopolize family life (Treasure, 2010). These impact on the coping resources of carers leading to psychological distress (Perkins et al., 2004; Winn et al., 2004).

1.5.1 Parents

The general caregiving experience in eating disorders has been summarised in systematic reviews (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Zabala, Macdonald, & Treasure, 2009). The majority of studies in this field have applied quantitative and qualitative methodology, predominantly focusing on carers (especially parents) of those with anorexia nervosa and not to other forms of eating disorders. However, it is well established that the caregiving role in eating disorders is a substantial source of stress, which generates not only physical health problems but also significant psychological distress and burden compromising carers' quality of life and psychosocial well-being (Dimitropoulos, Carter, Schachter, & Woodside, 2008; Kyriacou, Treasure, & Schmidt, 2008b; Sepulveda et al., 2009; De la Rie et al., 2005). Further, a number of factors have been identified in relation to carer burden and psychological distress, including, among others, social isolation, stigma and role strain (Highet, Thompson, & King, 2005; McMaster, Beale, Hillege, & Nagy, 2004). Carers report high levels of subjective burden, low sense of caregiving efficacy and high levels of unmet needs for both information and other forms of support (Graap et al., 2008; Haigh & Treasure, 2003). Indeed, some authors have found that family caregivers of AN patients have higher levels of anxiety, depression, and perceived caregiving burden compared to caregivers of BN patients (Santonastaso et al., 1997; Graap et al., 2008) or those with other psychiatric illnesses (Treasure et al., 2001). However, another study of Winn et al. (2004) indicated that carers of adolescents with BN display similar levels of distress to the AN carers in the Haigh and Treasure (2003) study, with just over one half of the BN carers experiencing some mental health difficulties and a small proportion reporting significant distress. Moreover, parental low self-efficacy produces high expressed emotion and accommodating behaviors which in turn contribute to high levels of distress and burnout (Sepulveda, Kyriacou, & Treasure, 2009). Other variables are also caregiver's socio demographic characteristics (such as gender of carer, educational status, carer-patient contact time), and the severity of eating disorder's symptoms such as purging, co-morbidity, and illness duration (Kyriacou et al., 2008; Dimitropoulos et al., 2008; Winn et al., 2007; Sepúlveda et al., 2009; Anastasiadou et al., 2015).

1.5.2 Siblings

The impact of illness on siblings has received limited attention (Vandereycken & Van Vreckem, 1992). Qualitative studies focusing specifically on siblings of anorexia patients reveal that they perceive themselves to be left out and neglected both by parents and mental health system and they lack information about illness (Latzer, Katz & Berger, 2015; Garley & Johnson, 1994; Abrams, 2009). Many aspects of their lives are often significantly impacted by the eating disorder symptoms, mostly during adolescence (Areemit et al., 2010; Halvorsen et al., 2013). For instance, siblings of ED patients report higher levels of depression and negative sibling relationship compared to a control group (Latzer, Katz & Berger, 2002). Their sibling's illness has a negative impact on their quality of life including school work and leisure time (Halvorsen, Ro & Heyerdahl, 2013; Areemit, Katzman, Pinhas & Kaufman, 2010). Many experience contradictory feelings such as fears and worries, jealousy, empathy, shame, and guilt (Areemit et al., 2010). In situations where the illness becomes chronic and family resources are depleted, some siblings may participate in caregiving activities by adopting the role of intermediary and protector, which can limit expression of their own needs, potentially leading to overextension (Dimitropoulos et al., 2009). Due to previous equal relationship between the siblings, healthy siblings often have a great sense of responsibility assuming a more parent-like role (Abrams, 2009; Dimitropoulos, Klopfer, Lazar & Schacter 2009; Honey et al., 2009; Whitney et al., 2005). There is little research into the impact of siblings of people with Bulimia and Binge Eating Disorder on their co- siblings.

1.5.3 Spouses and Partners

For ED patients who are adults, their romantic partners may be their primary carer (Heavey, Parker, Bhat, Crisp, & Gowers, 1989; Highet, Thompson, & King, 2005). The current literature focuses mostly on the potential negative impact of an eating disorder on the couple's relationship such as the unwillingness of ED patients to accept their illness and other features of ED such as secrecy, lack of emotional and sexual intimacy, and communication problems that cause difficulties (Newton, Boblin, Brown, & Ciliska, 2006; Pinherio et al., 2010; Van den Brouke, Vandereycken, & Vertommen, 1995; Highet et al., 2005; Huke & Slade, 2006). These affect the dynamics of couple relationship which in turn may hinder adaptive dyadic coping, and generate a difficult

interpersonal environment for the AN patient (Lyons, Mickelson, & Sullivan, 1998). Partners become isolated from others (Highet et al., 2005; Huke & Slade, 2006; Leichner, Harper, & Johnston, 1985) and are often excluded from the treatment process, and unsupported (Bulik, Baucom & Kirby, 2012). Moreover, they report feelings of isolation, guilt, frustration and anger (Leichner et al., 1985). Partners encounter many difficulties concerning coping with patient's secrecy, attributing blame and responsibility, feelings of powerless over their partner's actions and emotional swings, and engaging in sexual activities due to the difficult images that they had seen, such as purging (Huke & Slade, 2006).

1.6 Caregiving Experiences of people with Diabetes Mellitus

1.6.1 The rationale for using Diabetes as comparison group

The decision to include T1 and T2 DM carers (particularly siblings and partners) as a comparison group was based on the fact that both EDs and DMs are life-threatening chronic illnesses with adolescent onset (especially T1DM). Also, both conditions involve complex changes in food and diet lifestyle which can impact on physical health and psychological well-being. These common factors impact on family functioning (Dimitropoulos et al., 2008; Kyriacou, Treasure, & Schmidt, 2008b; Sepulveda et al., 2009; De la Rie et al., 2005; Rintala, Jaatinen, Paavilainen, Astedt-Kurki, 2013; Malerbi, Negrato, & Gomes, 2012; Haugstvedt, Wentzel-Larsen, Rokne, & Graue, 2011) and can impact on management and prognosis.

Nevertheless, there are drawbacks from using people with diabetes as a comparison group. For example, there may be confounding of the two conditions as the prevalence of eating problems in people with Type 1 diabetes mellitus is twice that in people without diabetes (Sarwar et al., 2010). Also in research in T2DM 10–40% of individuals may meet the criteria for an eating disorder (Herpertz et al., 1998; Kenardy et al., 2011), binge eating disorder (BED) being the most common eating disorder, followed by BN (Meneghini, Spadola & Florez, 2006; Papelbaum et al., 2005). Moreover, the age of onset in the two conditions is not totally analogous in that there is a greater variation in diabetes. For instance, type 1 diabetes may present at any age, but most typically presents in early life between 6 and 12 years old (CDC, 2011) with a peak around the

time of puberty (Patterson et al., 2009); while type 2 appears to have a wider age onset ranging from childhood to elderly (CDC, 2014). In terms of gender, many studies showed no significant difference in the occurrence of T1D between genders (Berhan et al., 2011; Dabelea et al., 2014; Dahlquist et al., 2011; Everts et al., 2009). However middle-aged males are at significantly higher risk of diabetes than women (Sarwar et al., 2010).

1.6.2 Diabetes impact on familial members

While family members can influence the self-management of diabetes that requires daily blood-glucose monitoring, insulin injections, exercise and strict diet control, the diabetes of one family member also influences other members of the family (Bowes, Lowes, Warner, & Gregory, 2009; Pendley et al., 2002) by diminishing their quality of life (Awadalla, 2006), producing high levels of distress and eliciting emotional responses such as criticism and emotional over involvement (Viner et al., 1996; Forsander et al., 2000; Thompson et al., 2001). More specifically, parents of children with diabetes describe that their life has completely changed after diagnosis and their role has become more difficult and challenging, with overconcern about the future (Marshall, Carter, Rose, & Brotherton, 2009). These emotional responses persist several years after diagnosis (Wennick and Hallström, 2007). Family members perceive diabetes as a more serious illness than those suffering from diabetes themselves (White, Smith, & O'Dowd, 2007). They perceive diabetes to be a burdensome illness that one cannot control (August, Rook, Parris Stephens, & Franks, 2011), and a constant concern for the health (Stodberg, Sunvisson, & Ahlstrom, 2007) and future of the person with diabetes (Lohri-Posey, 2006). Fisher et al. (2002) indicated in their study that female partners of persons living with type 2 diabetes experienced even higher levels of psychological distress than the persons with diabetes themselves. The change or creation of new family routines that are related to diabetes care and management, produces distress to well sibling (Wennick & Huus, 2012). Younger siblings may be at increased risk because of poor adaptation possibly due to fewer coping mechanisms (Sleeman et al., 2010), others find that older siblings are more aware of changes within the family, which contributes to poorer adjustment (Ferrari, 1984; Jackson et al., 2008). Therefore, including the family in the treatment plan and providing them with

support and education plays an important role in the successful management of diabetes (White et al., 2007).

1.8 Chapter summary

This chapter provides a brief overview of eating disorders including their prevalence, incidence, co-morbidities, risk and familial role on maintenance of ED based on the interpersonal component of the cognitive maintenance model on Anorexia Nervosa. Significant progress has been made in the past few decades in understanding how carers (mostly parents) respond to illness and the illness's impact on them. Moreover, empirical evidence has been found to support the model. Despite these important advances, limited research has focused on the theoretical framework underlying the interpersonal component and even fewer studies have empirically tested this theoretical model on Bulimia Nervosa and Binge Eating Disorder carers (parents, siblings and spouses). Therefore, the next chapter of this thesis will introduce the sociocultural background in family structure and kinship in Greece in comparison to Southern European countries.

1.9 Thesis aims

This thesis includes five studies, which are designed to examine the transdiagnostic applicability of cognitive interpersonal maintenance model of anorexia nervosa to people with BN and BED. The aims of these studies: (i) a comparison of caregiving styles of people with anorexia nervosa and bulimia nervosa between Greek and English parents; (ii) a comparison of caregiving styles between siblings and spouses of adult patients with eating disorders and people with Diabetes Mellitus; (iii) to test the applicability of the interpersonal component of this model in people with BN and BED requiring outpatient/intensive treatment and whether these familial factors influence the course of illness.

1.9.1 Structure of Thesis

Chapter 2: Family structure and role of kinship in Greek culture

This chapter presents the literature review, exploring how family structure and role of kinship affects family interaction with mentally ill person in Greek culture.

Chapter 3: Eating disorders in Greece: An examination of carers' distress, attitudes and behaviors.

This chapter presents the results of a study conducted on a Greek sample of parents. The aims of the study were firstly to examine whether the theoretical model that has been generated in the UK and mainly in people with AN and their parents, could be applicable in another culture and in parents of patients with bulimia nervosa (BN), binge eating disorder (BED) and anorexia nervosa (AN) and secondly to explore their care-giving experience regarding anxiety, depression, stress and expressed emotions and accommodating behaviors.

Chapter 4 :Aspects of parental experiences in eating disorders: comparison between Greece and United Kingdom.

This chapter uses data from Greece and UK to examine how two groups of carers cope practically and emotionally with caring for individuals with eating disorders. Psychological distress, expressed emotions and enabling and accommodating practices were examined in a sample of parents from Greece and UK.

Chapter 5: Impact of an eating disorder in healthy adult siblings in comparison with those of Diabetes Mellitus I and II.

This chapter presents the results of a study conducted on a small sample of siblings of people with eating disorders in comparison of those of people with Diabetes Mellitus. This study aimed to assess (i) the applicability of the interpersonal model of AN on a small sample of adult non-affected sibling of people with eating disorders (BN, AN and BED) (ii) the impact of ED on siblings of individuals with ED, more specifically from the perspective of gender (iii) the differences between adult siblings of people with ED and those siblings of people with Diabetes in terms of depression, anxiety, and stress, as well as their expressed emotions and accommodating behaviors, (iv) sibling-patient characteristics would be predictors of high levels of psychological distress , expressed emotions and accommodating behaviors.

Chapter 6: Partners' experiences of people with Bulimia Nervosa and Binge Eating Disorder in comparison with those of people with Diabetes Mellitus I and II.

This chapter describes the findings of a study that examined (i) the applicability of the cognitive interpersonal maintenance model of ED to Greek partners of people with bulimia nervosa and binge eating disorder (ii) partners' experiences of people with BN and BED (iii) whether the impact of BN and BED on spouses is different from a chronic illness such as Diabetes type 1 and 2 which also includes food concerns.

Chapter 7: An examination of the impact of care giving styles (expressed emotions and accommodation) on the six-month outcome of adults with Bulimia Nervosa or Binge Eating Disorder: Testing the postulations of the cognitive interpersonal model in Bulimia Nervosa and Binge Eating Disorder.

This chapter presents the results from a study that empirically tested the application of the cognitive interpersonal maintenance model on patients with Bulimia Nervosa and Binge Eating Disorder.

Chapter 8: Discussion

An overview of research findings, strengths, limitations and implications for further research will be presented.

Chapter two

Family structure and the concept of kinship in Greece

This chapter will focus on cultural differences between Greece and Southern European countries in terms of family structure and kinship. Although current studies and theories have clearly focused on the effect of an eating disorder on the family functioning (and vice versa), there are other factors that play an important role in family interaction, such as the cultural norms of each society and country (Bhugra & McKenzie, 2003). However, the potential influence of culture and kinship in family and patient's interaction has received limited attention in the eating disorder literature.

2.1 Differences in patterns of Family structure and the concept of kinship between Greece and Southern European countries

There are considerable differences in terms of family ties between Southern and Northern European countries. Strength and weakness of family ties, defined as “cultural patterns of family loyalties, allegiances and authorities” also help explaining living arrangements and geographical mobility of young generations (Giuliano, 2007; Reher, 1998), larger fractions of family firms across countries (Bertrand & Shoar, 2006) and cross-country heterogeneity in employment rates (Algan & Cahuc, 2007).

2.1.1 The Mediterranean family system

One of the main differences between Southern European countries and other nations of the conservative regime type, both labelled by Esping-Andersen (1999) as ‘familialistic’, is the extent to which they have explicit family policies. Moreover, the literature indicates that Southern European nations (Spain, Italy, Greece and Portugal) exhibit similar features which include various aspects of structure and function of family, social networks and the nature of care regimes (Viazzo, 2003). The centrality of the family in these nations and a strong sense of solidarity within the extended family that is dominant within these societies has, of course, significant implications for the ways in which social needs are dealt with and hence upon the structuring and functioning of welfare states. In particular, the existence of strong family support networks and an acceptance of care responsibilities by family members (primarily women) lessen the pressure upon states to deal with diverse needs (Andreotti et al., 2001). The importance of the family enables welfare states to rely on the family as an alternative to the state and market and thereby limit, or deflect, state spending on services and benefits intended to deal with specific needs (Graselli, Montesi, &

Lannone, 2006). More specifically, in these three countries parents support their children mainly through prolonged co-residence and children are expected to leave the family of origin only after completing their educational career, finding a stable job and marrying (Kohli, Künemund, & Lüdike, 2005a). However, if adult children achieve all the above, they still choose to live close to their parents or to have frequent contacts with them (Kohli et al., 2005a; Tomassini et al., 2004). Moreover, when they get economically distressed as a consequence of divorce or widowhood, they are expected to move back to the parental home (Hank, 2007; Kohli & Albertini, 2008). Thus, these common features are derived from the cultural norms that form a particular family structure with lower levels of geographical mobility, younger and older people who tend to gravitate around the family nest and larger family size as an effect of that.

2.1.2 The concept of kinship in Greece

In the early 60's Triandis (1989) and Vassiliou (1990) defined Greek culture as collectivist ie the values of in the group include those shared with members of the extended family and friends who express affection and support. The ultimate aim is the success of the group rather individual success (Georgas, 1989). However, after the Second World War, the Greek family experienced many changes due to immigration to urban centers in Greece and abroad. These undergoing processes have affected many aspects of family life, leading families to adopt a nuclear structure with a child-centered focus (Georgas,1999; Georgas, 2000; Kataki, 1998; Papadiotis & Softas-Nall, 2006). Specifically, the Greek family appears to be nuclear but it functions as an extended family; this type of family has been called “*extended urban family*” whereas the children usually prefer to live within very close proximity to their original family, they are in daily communication and individual problems are considered family issues to be solved collectively (Georgas, 2000). Hence the role of kin remains very powerful in comparison to other Northwestern European countries (Georgas, 1999). In the same line evidence shows that Greeks present more collectivist values in comparison to those of Dutch people (Inglehart & Welzel, 2005) by giving great emphasis to traditional values (Georgas, 1989; Hofstede, 1980; Triandis, 1989). Moreover, social interaction and pleasure is interwoven with close relationships with family and friends and community events in Greece while, in the UK, wider social relationships may be more important (Kafetsios, 2006). Finally, the Greek family system integrates individualistic

components into collectivistic values by keeping strong ties and endorsement with family norms (Papadopoulos, 1988; Verkuyten & Pouliasi, 2002).

2.1.3 Patterns of Communication among Familial Members

The familial function is defined as extended; as a result the interpersonal constructs are based on conservatism, hierarchy (Hofstede, 2001; Rosenthal, Bell, Demetriou, & Efklides, 1989; Schwartz, 1994) and close human relationships. The interaction patterns include indirect style of conflict resolution, adoption of process-oriented coping strategies rather than outcome-oriented, increased emotional expression, expanded communication, and uninhibited self-disclosure and intense familial involvement (Francis & Papageorgiou, 2004; Hofstede, Hofstede, & Minkov, 2010). A pattern of overinvolvement may be considered to be the norm characterized by an intrusive style of relating which is considered a central component of family interaction; for example, mothers assume that they can intervene in their children's lives for prolonged periods of time (Vassiliou & Vassiliou, 1979). One explanation is that "mothers are assigned and assume a primary role concerning child-rearing. It is as if mothers compete with other potential sources of child-rearing (fathers, grandparents, other relatives, teachers, etc.) in order to perform it exclusively" (Vassiliou & Vassiliou, 1979, p. 440). These patterns of interaction contribute to the preservation of kin and close friends' network, and provide the psychological and financial support for family members (Kataki, 1998; Nassopoulos, 2003).

2.1.4 Parental style and attitudes

Parenting style is comprised of attitudes and behaviours towards the upbringing of their children (Darling & Steinberg, 1993) and it is based on two components: first is the level of demandingness that relates to parental control over children's actions and behaviors and second the responsiveness that is associated with parental ability to take into consideration the child's point of view and feelings (Baumrind, 1971; Baumrind, 1989). These dimensions are used to categorize three parenting styles, the authoritarian, authoritative and the permissive. However, Greek parents were categorized into four types: authoritative, authoritarian, permissive and strict (Antonopoulou & Tsitsas, 2011; Maridaki-Kassotaki, 2009). The strict style includes components from the authoritarian and the authoritative styles. For example, strictness is characterised by

high criticism, discipline and punishment which is also a feature of authoritarian parenting style. Indeed, this type of parenting is highly demanding, moderately responsive, with a lot emphasis on the critical nature of family rules (Maridaki-Kassotaki, 2009). This is due to traditional Greek culture that enhances family loyalty, adherence to group norms and maintenance of harmony in relationships with group members (Zervides & Knowles, 2007). Therefore, this type of familial value system is linked to severe and controlling child-rearing practices (Rosenthal, 1984), underlying the importance of conformity and obedience to parental rules (Papps, Walker, Trimboli, & Trimboli, 1995; Szapocznik & Kurtines, 1993; Triandis, 1989). In contrast, Anglo cultures are predominantly individualistic, tending to value personal needs and achievement; the parenting style is authoritative or permissive and child-rearing practices focus on raising autonomous and independent children (Hofstede, 1980).

2.1.5 Living arrangements in Greece

A core characteristic of Mediterranean families is that young adults stay longer in their family of origin in comparison to northern European families (Giuliano, 2007). In Greece, 68% of younger people lived with their parents (Vaggelis, 2005) due to high rates of unemployment, and absence of the welfare support. In addition, the coexistence of two or three generations is a common phenomenon in Greek family (Walker, 1998) acting as a care giving and social support resource for young adults and the aged (Kaldi-Koulikidou, 2007). The interaction of three generations (grandparents, parents and children) helps to maintain traditional values (Kaldi-Koulikidou, 2007; Walker, 1998). This might be a reason that Eurobarometer Flash (2000) shows that Greek people endorse the highest levels of traditional values in 15 European countries.

2.2 The role of Kinship on family and mental ill patient's interaction across cultures

The emotional interaction between family and ill family members may be modified by the cultural norms of each society. Interaction patterns between psychiatric patients and their families reveal interesting findings across countries (Bhugra & McKenzie, 2003). Specifically, western societies consider some of the components of EE (such as emotional over involvement and criticism) as pathological because they interfere in individual's autonomy and dignity; whereas, collectivist societies in which

extended kinship plays an important role, consider them as acceptable components of interpersonal relations (Heresco-Levy et al., 1990; Okasha et al., 2004). A systemic review of the literature by Bhugra & McKenzie (2003) indicated that the interaction between expressed emotion and patient's treatment outcome is complex because of the dissimilar attributions of EE across different cultures. For example, Kamal (1995) found that Egyptian patients with schizophrenia are more tolerant of higher levels of criticism before relapsing than patients in Western countries. One explanation is that interpersonal criticism is an indication of concern in this culture (Okasha et al., 2004). In another study, it has been found that criticism predicted relapse for Anglo-American patients with schizophrenia, but not for the Mexican-American patients (Lopez et al., 2004). However, the role of culture, kinship relationships and emotional interaction and outcome has received limited attention in the eating disorders literature.

2.3 Attitudes towards mental illness in Greece

Authoritarian and socially restricting attitudes towards mental illness remain prevalent within the Greek culture. Little research has been conducted for the examination of the prevalence of stigma among people from the Greek culture. A national survey conducted by Economou et al. (2009) in Greece revealed that self-reported levels of desired social distance increased as the level of hypothetical closeness of social situations increased. This again indicates that proximity and personal experience may be an important moderating factor of stigma. Studies by Mouzas et al. (2008) and Arvanity (2008) – conducted in different areas in Greece – revealed that Greeks held high levels of negative attitudes towards the mentally ill. The most recent study by Papadopoulos et al. (2012) revealed that UK-based Greek/ Greek Cypriots display significantly higher levels of stigmatizing attitudes compared with UK-based white- English and American samples. However, several studies suggest that collectivistic cultures (i.e., Greek) are more likely to hold stigmatizing attitudes towards mental illness, because people who have a mental problem are conceived as a deviation from the norm, being more visible to the community due to higher surveillance levels and the existence of numerous connections among people. As a consequence, families are more likely to try to hide the existence of a member who has a mental health problem, and are therefore less likely to attempt to access the appropriate services (Galletly and Burton 2011; Papadopoulos et al., 2012; Pettigrew & Tropp 2008; Wolff

et al., 1996). Therefore, kinship plays an important role on people behavior, values and attitudes towards mental illness (Papadopoulos, Foster & Caldwell, 2012).

2.3.1 Impact of mental illness on families in Greece

In Greece, the family is considered a pillar of society, and thus, problems are expected to be solved by the whole family (Georgas, 2000). In this regard, illness in one family member may affect family dynamics and result in substantial burden for the entire family due to stigma, social isolation and denial of illness in many cases (Madianos et al., 1997; Madianos et al., 1999). Moreover, families of people with long-term mental illness experience hopelessness and adopt unhelpful coping strategies eliciting high level of distress which adversely impacts their health and quality of life (Bibou-Nakou et al., 1997). Furthermore, evidence suggests that carer's gender, duration of illness as well as severity of symptoms predicts parental distress levels of patients with chronic schizophrenia (Mitsonis et al., 2012). Although the influential role of the family in the outcome of chronic mental illness is well documented, there has been limited research on the intrafamilial relationships in terms of expressed emotions and how these are related to the course of patient's illness and the risk of relapse in Greece (Koutra et al. 2014a). Two studies of Koutra et al. (2015; 2016) suggest that caregivers' high levels of criticism and burden have a significant impact to the course of psychosis, whereas high levels of emotional over- involvement and psychological distress were not found to be associated to patient's relapse.

2.3 Summary

There is strong empirical evidence suggesting that families from different cultures and countries can adopt some common and some different culture-specific family values and goals, according to which they develop appropriate parenting styles which influence family interaction, especially parental behaviors. Despite the growing interest in the caregivers' experiences on eating disorders, few studies have examined the above issue among European countries, whereas there are no comparative data for Northeastern and Mediterranean countries. In particular, Greece has a different family structure and kinship which include specific sociocultural elements which in turn may affect the family climate and familial responses to ED patient. Nevertheless, the impact of other psychiatric illnesses including eating disorders on carers has never been

investigated in Greece although there has been an increasing number of studies on family caregiving on EDs in Spain and Italy. More specifically, Spanish studies suggest that caregivers of ED patients present high levels of psychological distress, which are higher than those caring for a family member with depression or schizophrenia (Martín et al., 2015). Higher levels of distress is linked to carer's characteristics such as responsibility for patient's nutrition (Sepulveda et al., 2012), being divorced, or display symptoms of anxiety or depression and have lower educational level (Padierna et al., 2013). Mothers tend to have more emotional reactions and experience more difficulties than fathers who use more avoiding strategies in their relationship with a patient with AN (Las Hayas et al., 2014). Other predictors of low health-related quality of life among caregivers (especially mothers) of patients with an ED include the presence of patient's purging behaviors and carer's psychological distress (Sepulveda et al., 2014). Furthermore, another cross-sectional comparative study showed that carers of people with ED and substance-related disorder display higher levels of emotional overinvolvement, negative caregiving experience and poorer quality of life than the healthy control group (Anastasiadou et al., 2016). In terms of accommodation, two Italian studies showed that mothers report less avoidance coping strategies (Fiorillo et al., 2017) and high levels of accommodation and enabling behaviours are associated to carer's personal history of ED and being the primary carer of a person with anorexia (Stefanini et al., 2018).

Chapter Three

Study 1 (a)

Eating Disorders in Greece: An examination of parents' distress, attitudes and behaviours.

3.1 Abstract

Objectives: The aims of the present study were to examine whether intrafamilial factors that are described by the cognitive interpersonal maintenance model, could be

manifested in Greek parents of people with eating disorders (BN, AN, BED) and explore patient - parent characteristics that predict high levels of parental distress, expressed emotion, and accommodation.

Method: A cross-sectional design (N=112) was used to assess caregiving psychological distress (Depression Anxiety Stress Scale), expressed emotions (Family Questionnaire) and accommodating and enabling behaviors (The Accommodation and Enabling Scale for Eating Disorder).

Results: Parental distress was associated with high levels of expressed emotions (especially with emotional over involvement), reassurance seeking behaviors and illness related traits. Moreover, expressed emotions were linked to parent-patient characteristics. Symptomatic behaviors predicted parental accommodating behaviors. However, no significant associations were revealed between parental distress, EE, accommodating behaviors and the type of ED, carer- patient contact time, carer's marital status and own eating difficulties.

Conclusions: The cognitive interpersonal maintenance model fits some of the processes observed in Greek families of people with ED. Therefore, interventions focusing on reducing psychological distress, expressed emotions and accommodating could prove beneficial in order for parents to become more effective in support recovery from the illness.

Keywords: Carers, Eating Disorders, Anorexia nervosa, Bulimia Nervosa, psychological distress, expressed emotion, Accommodation, Enabling,

3.2 Introduction

Eating Disorders (ED) are serious and potentially life- threatening illnesses that affect the physical, emotional, and social development of those suffering from the condition. However, eating disorders have negative impact on families such as physical and mental health problems, poor quality of life and interpersonal difficulties (Hight, Thompson, & King, 2005; Nielsen & Bara-Carril, 2003). For example, caregivers are often exposed to factors such as unwillingness of ED patients to accept their illness, the

outward signs of malnutrition and resulting social stigmatizations, the daily struggles at meal times that often occur with EDs (Treasure, 2010). Such stresses can generate considerable stress and strain on family functioning including a number of dysfunctional changes in the family organization and interactions (Coomber & King, 2013; MacDonald, Murray, Goddard, & Treasure, 2010) which contribute to the problems that may arise in the relationship between the caregiver and the ED patient, which in turn worsen the symptoms related to the ED (Anastasiadou et al., 2014; Treasure & Schmidt 2013; Sepúlveda et al., 2012).

The literature suggests that the carer's role can aid recovery. Therefore, evaluating carer's distress and caregiving style will be relevant for the treatment in ED (Treasure et al., 2007). Schmidt and Treasure have developed an interpersonal model of AN maintenance, according to which the quality of the caregiver-cared person relationship may affect the symptoms and duration of the disease (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). This model is also supported by a systematic review (Zabala, Macdonald & Treasure, 2009) which has been recently updated (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014). High perceived burden, and low caregiving efficacy, are common and are associated with clinical levels of depression and anxiety which in turn are linked with high expressed emotion such as criticism, hostility and overprotection (Zabala et al., 2009; Kyriacou, Treasure, & Schmidt, 2008a; Goddard et al., 2013). Overprotection is associated with fear of the negative consequences of AN, and criticism is associated with erroneous illness appraisals about BN (Duclos et al., 2014 ; Kyriacou, Treasure, & Schmidt, 2008). Emotional overinvolvement is also associated with both parental anxiety and depression (Kyriacou, Treasure, & Schmidt, 2008). High levels of accommodation can be linked with carer distress due to the family's entrapment into a vicious cycle of illness behaviours (Goddard et al., 2013; Treasure et al., 2008).

The aforementioned aspects of caregiving are associated with socio demographic and clinical characteristics of carers (such as gender of carer, educational status, contact time and eating problems) and patients (such as diagnosis, the severity of eating disorder symptoms, co-morbidity, and illness duration) (Zabala et al., 2009; Anastasiadou et al., 2014; Duclos et al., 2013; Sepulveda et al., 2010). More specifically, the evidence indicates that gender has a great impact on parental

functioning. For instance, mothers of patients with AN and BN express more anxiety and depressive symptoms, and more feelings of distress and burden than fathers (Martin, et al., 2013; Raenker, 2011; Whitney & Eisler, 2005); whereas fathers show a more behavioral response to the illness, centered on unhelpful enabling and accommodating behaviors (Whitney & Eisler, 2005). From the perspective of Expressed Emotion, mothers of patients with AN and BN expressed more emotional over-involvement and less criticism than fathers (Duclos et al., 2013). Furthermore, caregivers who live together or spent more time together with the patient present significantly higher accommodation (Sepulveda et al., 2009). Carers' education level and personal history of eating disorder predict higher levels of stress, expressed emotions, accommodation and enabling of the ED (Sepulveda et al 2010; Stefanini et al., 2018).

In terms of illness aspects and patient's details, evidence suggests that carers of people with longer illness duration display higher levels of psychological distress, burden, expressed emotions (Szmukler et al., 1985; Hoste et al., 2012) and accommodation (Sepulveda et al., 2012). However, the impact of the type of ED is not clear, as a number of studies present contradictory results. Indeed the majority of studies are predominately on AN carers, and there is little evidence about bulimia and binge eating carers' experience, (Kyriacou et al., 2008b; Whitney et al., 2007; Winn et al., 2007). Specifically, one study of Winn et al. (2007) indicated that the majority of BN caregivers had been experiencing some mental health difficulties and considerable distress, similar to those of people with anorexia. A recent study reveals that the levels of distress and expressed emotions are similar among carers of people with AN and BN, although AN carers display higher levels of accommodation, particularly in the areas of avoidance, reassurance seeking and total score of accommodation and enabling scale (Stefanini et al., 2018). It is noteworthy, that the expected significant association between higher levels of emotional overinvolvement among caregivers of people with anorexia and higher levels of criticism among BN caregivers that is found in the study of Santonastaso et al. (1997), has not been established from two recent studies (Duclos et al., 2013; Sepulveda et al., 2010).

In summary, given the broad and complex range of symptoms and behaviours associated across EDs and their severity, and the associated different manifestations of

caregiver distress and response to illness, further research examining the impact of Bulimia Nervosa, Binge Eating disorder and Anorexia Nervosa is warranted. This study explores parental experiences of people with ED in the Greek population and considers whether the interpersonal domain of cognitive interpersonal model is applicable.

The overall aims of this study were to: (i) examine parental distress, emotional responses and behaviors; (ii) to consider whether the associations among these factors fit with the cognitive interpersonal model in AN; (iii) identify correlations between patients' clinical characteristics, relatives' socio- demographic characteristics and the above intrafamilial factors.

Our hypotheses were i) Greek parents of people with ED would exhibit psychological distress, high levels of EE and accommodating behaviors; ii) parents' psychological distress would be associated with high levels of emotional over involvement (EOI) and accommodating and enabling behaviors; iii) parent-related characteristics (a) gender, (b) own eating difficulties, (c) educational/occupational status and (d) marital status, (e) carer-patient contact time and patient's related characteristics (a) diagnosis, (b) eating symptomatology and (c) age of illness onset, are associated with parental distress, expressed emotions and accommodating behaviours.

3.3 Methods

3.3.1 Participants

The subjects were 112 parents of people with an eating disorder participating in this study and were recruited over a period of 1 year (April 2013–2014) from the Hellenic Centre of Eating Disorders. This provides outpatient care support to ED patients and their families. All of these parents had a child who had been diagnosed with an ED according to the Diagnostic and Statistical Manual of Mental Disorders-V (American Psychiatric Association, 2013) by professionals from our clinic. The sample of 112 parents was 73 mothers (65.2%) and 39 fathers (34.8%) with an average age of 55.45 years ($SD=8.89$). The patients had been diagnosed with an ED by a standard clinical interview following criteria of the Diagnostic and Statistical Manual of Mental Disorder, fifth edition, (American Psychiatric Association, 2013). They were interviewed in the ED unit by a qualified psychologist after one of their treatment sessions.

The patients had been diagnosed with an ED by a standard clinical interview following criteria of the Diagnostic and Statistical Manual of Mental Disorder, fifth edition (American Psychiatric Association, 2013). They were interviewed in the ED unit by a qualified psychologist after one of their treatment sessions. 81 patients were 93.8% females with a mean age of 25.85 ($SD = 6.5$) years. 28.4% were diagnosed with anorexia nervosa (AN), (54.3%) bulimia nervosa (BN), 16% binge eating disorder (BED) and 1% with atypical anorexia nervosa (A-AN). In addition, the mean illness duration of people with ED was 8.80 years ($SD=6.14$). Socio-demographic details of participants are presented in **Table 3.1**.

Table 3. 1 Demographic and clinical data of carers and patients

Patients	
	Mean (SD) / N (%)
Age	25.85 (6.50)
Gender	
Female	76 (93.8%)
Male	5 (6.2%)
Mean Duration of illness (years)	8.80 (6.14) (Median: 8.0)
Diagnosis	
Bulimia Nervosa	44 (54.3%)
Anorexia Nervosa	23 (28.4%)
Binge Eating Disorder	14 (19.75%)
Parents	
	Mean (SD) / N (%)
Age	55.45(8.89)
Gender	
Female	73 (65.1%)
Male	39 (35.9%)
Carer type	
Mother	73 (65.2%)
Father	39 (34.8%)
Living with patient:	
Yes	70 (66.7%)
No	35 (33.3%)
Face to face contact	
High (> 21 hours per week)	48 (42.8%)
Low (< 21 hours per week)	64 (57.2%)
Employment status	
Full time	64 (57.1%)
Part time / student	6 (5.4%)
Housewife / retired	41 (36.6%)
Other	1 (0.9%)
Marital status	
Married / living together	90 (88.2%)
Single/divorced /separated/widowed	12 (11.8%)

3.3.2 Measures

3.3.2.1 Clinical and demographic questions

Caregivers completed a demographic questionnaire that included details about themselves (including age, gender, marital status, employment status and education level) and the patient (diagnosis, age, gender, onset and duration of the illness ED

diagnosis, and co morbidity). Also, treatments and aspects of care giving experience (e.g. whether the carer was living with patient and the average duration of one-to-one contact) were asked.

3.3.2.2 Psychological Distress

The DASS-21 (Lovibond & Lovibond 1995b) is an instrument designed to measure the dimensions of depression, anxiety, and stress. It consists of 21 questions, seven for anxiety and seven for depression and seven for stress on a four-point Likert scale (range 0–3). It was translated into a Greek version and validated in a clinical sample and in a general population sample with similar reliability (Lyrakos, Arvaniti, Smyrnioti, Kostopanahiotou, 2011). The Cronbach alpha coefficient was $\alpha = .941$. Higher scores indicate a greater level of anxiety or depression and stress.

3.3.2.3 Expressed Emotions

The Family Questionnaire (FQ) (Wiedemann, Rayki, Feinstein, Hahlweg, 2002) is a 20-item self-report questionnaire measuring expressed emotions in carers. The FQ includes two subscales with 10 items each: emotional over-involvement (EOI) and critical comments (CCs). EOI includes unusually over-intrusive, self-sacrificing, overprotective, and over-identification with the patient. CCs are unfavorable comments on the behaviour or the personality of the ill individual. Scores are given on a 4-point Likert scale ranging from 1 (*never/very rarely*) to 4 (*very often*) and a higher total score indicates higher expressed emotion. In the current study, Cronbach α . coefficient was .82

3.3.2.4 Accommodation and Enabling Scale for Eating Disorders

The *AESED* (Sepúlveda, Kyriacou & Treasure, 2009) is a 33-item scale measuring accommodating and enabling behaviors in carers. It derives a total score falling between 0 and 132. A higher score indicates higher levels of accommodation of the eating disorder symptoms by the carers. The AESED consists of five sub- scales: avoidance and modifying routine; reassurance seeking; meal ritual; control of family; ‘turning a blind eye’. The reliability for the scale in this sample was high ($\alpha = .817$).

3.3.3 Procedure

Parents were given an information sheet about the study, a consent form and the questionnaires. Their participation was voluntary, and carers did not receive incentives for their participation. To be eligible for this study, the caregivers had to be from 35 to 70 years old and caring for a person with an ED, aging 13-50, had to have sufficient knowledge of Greek language, written and spoken and had to be currently living with a person with an ED or directly involved in the care of their child with an eating disorder. This study was approved by the Iatriko hospital Ethics Committee (1094/1-4-2013).

3.3.4 Adaptation process of Family Questionnaire and Accommodation Enabling Scale for Eating Disorders in Greek.

All the measurements were translated into Greek except the DASS 21 questionnaire that was validated within the Greek context (Lyrakos et al., 2011). While the other scales (FQ, AESED) had not been validated in a Greek population, we conducted the process of adaptation which consisted of four stages. The first stage in adaptation was the forward translation. Two bilingual translators whose mother tongue was the target language produced the two independent translations in a written report. In this way, the translations could be compared and discrepancies that may reflect more ambiguous wording in the original or discrepancies in the translation process could be noted. Poorer wording choices were identified and resolved after a discussion between the translators. The second stage was the synthesis of translations in which the two translators and a recording observer synthesized the results of the translations. Working from the original questionnaire as well as the first translator's (T1) and the second translator's (T2) versions, a synthesis of these translations was first conducted (producing one common translation), with a written report carefully documenting the synthesis process, each of the issues addressed, and how they were resolved. The third phase was back translation. Working from the T-12 version of the questionnaires and totally blind to the original version, a translator then translated the questionnaire back into the original language. Each measurement had two back translations which are produced by two persons with the source language (English) as their mother tongue. The one translator had not been aware or been informed of the concepts explored, and had not any medical background. The fourth phase was testing of the prefinal version

in ten caregivers from our clinical setting. Each subject completed the questionnaires, and was asked about what he or she thought was meant by each questionnaire item and the chosen response.

3.3.5 Data analysis

Data were analysed using Statistical Package for the Social Sciences (SPSS). version SPSS version 21. In order to assess the psychometric properties of the Greek version of the scales, an Exploratory Factor Analysis (EFA) was estimated using a principal component analysis (PCA) and Varimax rotation. We chose Varimax rotation because we did not expect one general factor or high correlations between the factors. In general, factor loadings are considered meaningful when they exceed 0.40 (Floyd & Widaman, 1995). Eigenvalues 41 were used to select items for each of the domains (if loadings were 4.0). The Kaiser–Meyer–Oklin (KMO) measure of sampling adequacy and Barlett’s Test of Sphericity are reported for assessing factorability of the data. A screeplot and Monte Carlo technique after PCA for parallel analysis were also conducted to determine the number of factors to retain.

With regard to the reliability analyses of the Greek version of the FQ and AESED. internal consistency was established using Cronbach’s alpha coefficient for the total scale and each subscale. It is suggested that a coefficient of 0.70 or higher could be considered “acceptable” (Nunnally & Bernstein, 1994). Convergent and discriminant validity was established by correlating the AESED-S with the five factors scores and DASS-Depression and FQ-CC and FQ- EOI, using Pearson correlation.

Descriptive statistics were used for reporting the means and standard deviations/medians and range for demographic, clinical and caregiving variables. Cronbach alpha (α) was computed for all scales to assess internal consistency. Descriptive statistics and analysis of variance, after appropriate assumptions testing, were used to examine the effects of all categorical variables on the main outcome measures. When assumptions were not met the equivalent non-parametric Mann-Whitney and Kruskal-Wallis tests respectively were applied. Correlations between the DASS dimensions (Depression Anxiety and Stress) and scale variables were assessed with the Pearson correlation coefficient.

The effects of diagnosis, eating disorder symptoms, illness onset, contact time, as well as parent's demographic details such as age, gender, educational level, marital status, occupation, living together and contact time were examined on all subscales of the administered questionnaires. Dimensions of the FQ and AESED questionnaires were also included in the multiple regression analysis model regarding DASS 21 and based on diagnosis (BN, AN, BED). Statistically significant factors were determined after checking the effects of all possible interactions between main effects and statistical significance was set at a p-value <0,05.

3.4 Results

3.4.1 Construct Validity and psychometric characteristics of the Family Questionnaire Accommodation Enabling Scale of Eating Disorders

3.4.1.1 Factorial structure of the Family Questionnaire

A two -factor structure of the FQ after applying the PCA emerged as shown in **Table 3.2**. This solution was composed of 20 items, accounting for 40.5 % of the total variance. Mostly almost all the factor loadings were above the criteria of 0.40 (range 0.01–0.85). This supported the stability of the questionnaire structure in this sample. In the case of Item 6 “I have to try not to criticize him/her” the factor loading was 0.37. and item 18 “ I have to insist he/she behave differently” was 0.38 which is below the meaningful threshold of 0.40 (Floyd and Widaman. 1995). However, as Item 6 and 18 loaded very closely to the suggested threshold and its frequency distribution (suggesting clinical relevance) was also satisfactory, we decided not to omit these items. Nevertheless, as these results indicated a high coincidence with the item loadings from the original factors, the author decided to keep them the same as the original instrument (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002). In addition, both Bartlett's test of sphericity [$\chi^2_{(528)} = 727.649$ p < .001] and the KMO index (0.79) confirmed the suitability of the correlation matrix for carrying out this analysis. An inspection of the screeplot revealed a clear break after the fourth component supporting the two -factor structure of the correlation matrix. The results of the Monte Carlo PCA showed two components with eigenvalues exceeding the corresponding criterion values. The percentage of explained variance was (EOI :20.9% and CC: 19.6%).

3.4.1.2. Reliability of the FQ

Regarding internal consistency, the Cronbach's alphas for the two subscales were acceptable. The Cronbach's alpha coefficients for the subscales were 0.808 (Emotional Overinvolvement) and 0.83 (Criticism), indicating high reliability.

Table 3.2 Principal component factor analysis with varimax rotation for a 2-factor solution of Family Questionnaire

Item	<i>Criticism</i>	<i>Emotional Overinvolvement</i>
1.I tend to neglect myself because of him/her	.187	.586
2. I have to keep asking him/her to do thing all the time	.404	.007
3. I often think about what will happen with him/her	.265	.567
4. He/She irritates me	.829	.026
5. I keep thinking about the reasons that caused his/her illness	.205	.645
6. I have to try not to criticize him/her	.372	.317
7. I cannot sleep because of him/her	.141	.679
8.It is difficult for us to agree on things	.513	.382
9.When something about him/her bothers me. I keep it to myself	-.079	.461
10.He/She does not appreciate what I do for him/her	.477	.339
11.I consider my needs less important	.169	.539
12.He/She sometimes gets on my nerves	.846	.106
13.I worry a lot about him/her	.275	.726
14.He/She does some things out of envy	.632	.055

15.I thought I would get ill myself	.307	.397
16.It bothers me when he/she always wants something of me	.656	.200
17.He/She is an important part of my life	-.097	.543
18.I have to insist he/she behave differently	.385	.333
19.I had to forget important things in order to be helpful to him/her	.015	.609
20.I am often angry with him/her	.799	.016
Eigenvalue	5.779	2.336
Percentage Variance explained	20.968	19.608
Cumulative percentage variance explained	20.968	40.576

3.4.1.3 Factorial structure of Accommodation Enabling Scale for Eating Disorders

Table 3.3 shows that the factor analysis of the AESED item scores in 112 parents of patients with an ED yielded five factors with eigenvalues greater than one, accounting for 56% of the cumulative variance. Both Bartlett's test of sphericity [$\chi^2_{(528)} = 1685.786$ $p < .001$] and the KMO index (0.726) confirmed the suitability of the correlation matrix for carrying out this analysis. The first factor gave an eigenvalue of 7.862 and explained 12.99 % of the total variance, which includes the main item loadings that correspond to the factor Meal ritual in the original version (with a loading of 0.40). All of the items from this factor correspond to the original version.

The second factor obtained an eigenvalue of 3.4 explaining of 12.52% the total variance. The principal item loadings in this factor corresponded to the subscale Reassurance seeking. The eight items coincided with the original version, except item 10 'Your relative with an ED involves a family member in repeated conversations about self-harm', which did not present a factorial loading greater than 0.4 in any factor. This could be due to the fact that, as indicated in the sample description, only 5.5% of the patients were displaying the symptom of self-harming. In the same line, the item 17 'accommodation of the exercise routine of the relative with eating disorder' was 0.384,

marginally close to 0.4. This score was very close to the Spanish version (Quiles Marcos et al., 2016).

The third factor presented an eigenvalue of 2.89, explaining 12.02% of the total variance and included the items that evaluated 'Avoidance and modifying routine'. The ten items coincided with the original version. Nevertheless, item 32 'Has your relative become distressed when you have not help him/ her?' and 33 'Has your relative become angry/abusive when you have not helped him/her?' appear to also be components of the Reassurance domain. These findings may be explained by the specific socio-cultural context of the Greek sample in which the denial of assistance from family and friends is highly associated with lack of reassurance and support than in the sociocultural context of the British sample.

The fourth factor presented an eigenvalue of 2.29, explaining 10.85% of the total variance and included the items that evaluated Control of family. The four items coincided with the original version. The fifth presented an eigenvalue of 2.29, explaining 10.85 % of the total variance and included the items that corresponded to the subscale of 'Turn a Blind Eye' which all coincided with the original version.

Regarding the factor structure, the analysis of the principal components confirms the existence of the five main scale factors in which the total variance was found to account for a similar variance (slightly lower) as compared to its original British counterpart (Sepulveda et al., 2009).

3.4.1.4 Reliability of the AESED

The internal consistency for the five subscales was high, ranging from .74 to .868. The Cronbach's alpha coefficients for the subscales were 0.803 (Avoidance & Modifying Routine), 0.867 (Reassurance Seeking), (Meal Ritual) 0.868 (Control Family) 0.808 and (Turning a Blind Eye) 0.742 indicating high reliability.

Table 3.3 Principal component factor analysis with varimax rotation for a 5-factor solution of AESED

Item	<i>Meal Ritual</i>	<i>Reassure Seeking</i>	<i>Avoidance & Modifying Routine</i>	<i>Control Family</i>	<i>Turning a Blind Eye</i>
1.Control the choices you make in the food you buy?	-.019	.019	.223	.764	.085
2.Control what other family members do in the kitchen and for how long?	.179	.073	.083	.648	.024
3.Control the cooking practices and the ingredients you use?	.183	.212	.229	.713	-.045
4.Control what other family members eat?	.195	.142	-.055	.692	.127
5.Constant questioning for reassurance whether he/she will get fat?	.009	.724	-.051	.377	.049
6.Constant questioning whether it is safe or acceptable to eat certain food?	.274	.642	.079	.495	.088
7.Constant questioning for reassurance whether he/she looks fat in certain clothes?	-.021	.675	-.054	.438	.203
8.Constant questioning about ingredients and amounts in food prepare	.038	.573	-.112	.576	-.017
9.Constant conversations about negative thoughts and emotions	.201	.685	-.018	.047	-.036
10.Constant conversations about self- harming	.042	.192	-.094	-.030	.161
11.Accommodating to what crockery is used?	.786	-.021	.044	.074	-.061
12.Accommodating to how crockery is cleaned?	.845	-.049	-.059	.126	-.012
13.Accommodating to what time food is eaten?	.630	.279	.333	.139	-.076
14.Accommodating to what place food is eaten?	.665	.166	.188	-.097	-.250

15.Accommodating to how the kitchen is cleaned up?	.773	.072	-.068	.111	.229
16.Accommodating to how food is stored?	.777	.138	.016	.125	.224
17.Accommodation of the exercise routine of the relative with an eating disorder?	.306	.386	.154	.279	.077
18.Accommodation of routines of checking their body shape or weight?	.308	.586	.199	.225	.092
19.Accommodating to how the house is cleaned and tidied?	.585	.315	.006	.196	.008
20.Ignore food missing	-.110	-.031	.103	.082	.516
21.Ignore if money is stolen	.030	<u>-.289</u>	-.051	.060	.263
22.Ignore kitchen left in a mess	.072	.165	.186	.058	.876
23.Ignore bathroom left in a mess	.123	.183	.101	.069	.864
24.To what degree would you say that the relative with and ED control your family and everyday life?	.168	.260	.528	-.178	.061
25.How often did you participate in behaviours related to your ...?	.226	.345	.451	.192	-.198
26.How often did you assist your relative in avoiding things that could make him/her more anxious?	.064	.285	.420	.176	-.249
27.Have you avoided doing things. going places or being with people ...?	.067	-.247	.721	-.076	.110
28.Have you modified your family routine because of your relative's ED symptoms?	-.072	.016	.781	.104	.140
29.Have you modified your work schedule because of your relative's needs?	-.008	-.104	.746	.385	.041
30.Have you modified your leisure activities because of your relative's needs?	-.045	-.041	.774	.318	.026

31.Has helping your relative in the previously mentioned circumstances caused you feel anxious?	.153	.281	.496	-.016	.329
32.Has your relative become distressed when you have not help him/ her?	.063	.468	.430	-.183	.278
33.Has your relative become angry/abusive when you have not helped him/her?	.081	.574	.413	-.115	.159
Eigen value	7.862	3.457	2.891	2.297	1.958
Percentage Variance explained	12.995	12.529	12.026	10.850	7.554
Cumulative percentage variance explained	12.995	25.524	37.550	48.401	55.955

3.4.1.5 AESED-S subscale correlations

All AESED-S subscales intercorrelated with each other, with significant and positive correlations ranging between .228 and .790. Results are shown in **Table 3.4**.

Table 3.4 Accommodation Enabling Scale of Eating Disorders Subscale Correlations

	Avoidance and modifying routines	Reassure seeking	Meal ritual	Control of family	Turning a blind eye
Avoidance and modifying routines	1				
Reassure seeking	.365**	1			
Meal ritual	.322**	.44**	1		
Control of family	.296**	.48**	.33**	1	
Turning a blind eye	.228*	.21	.38**	.82	1
Total AESED	.756**	.790**	.641**	.653**	.387**

Note: AESED-S, Spanish version of the Accommodation and Enabling Scale for Eating Disorders. * $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$.

3.4.1.6 External evidence of validity

This section presents the evidence concerning the relationships between the measurements provided by correlating the scores from the five AESED-S subscales with the level of depression, anxiety and stress measured by the DASS, and the level of expressed emotion measured by the FQ. The results are presented in **Table 3.5**.

Significant and positive correlations were found between ‘Avoidance & Modifying Routines’ subscale and depression, anxiety, stress subscales, criticism and EOI. Moreover, ‘Reassure seeking’ subscale showed a significant correlation with anxiety, and emotional overinvolvement subscales, ‘Meal Ritual’ subscale was positively associated with criticism and emotional overinvolvement and the ‘Turning a blind eye’ subscale showed a significant correlation with criticism. However, the ‘Meal ritual’ subscale did not show correlations with the DASS or FQ subscales.

Table 3.5. Correlations (Pearson) between the AESED subscale scores and DASS, and FQ

	Avoidance Modifying Routines	Reassure Seeking	Meal Ritual	Control of Family	Turning a Blind Eye
DASS					
Depression	.26**	.09	.06	.025	.06
Anxiety	.42**	.29 **	.05	.068	.05
Stress	.35**	.13	-.05	-.008	.10
FQ					
Criticism	.43**	.11	.19*	.05	.28**
Emotional Over involvement	.51**	.22 **	.22*	.09	.10

Note: AESED, Accommodation and Enabling Scale for Eating Disorders; DASS, Depression Anxiety and Stress Scale; FQ, Family Questionnaire; CC, criticism EOI, emotional over-involvement.

*Correlation is significant at the .05 level (2-tailed).

**Correlation is significant at the .01 level (2-tailed).

3.4.2 Clinical details of carers distress and caregivers' style

In regard psychological distress, parents reported high levels of depression, anxiety and stress (individual and combined subscales). Nearly half (46.3%) of parents scored at or above the suggestive threshold on the depression subscale, 41.7% scored at or above the suggestive threshold on the anxiety subscale and 39.8% scored at or above the threshold on stress subscale. High levels of expressed emotions were present in the parental group. Half of parents (50%) reported high levels of emotional over involvement (using the cut- off score of 27) and (36.6%) high levels of criticism (using the cut-off score of 23). Moreover, parents displayed high levels of accommodation with total score 42.99. The carers' average score for each subscale of the DASS-21, the Family questionnaire and accommodation and enabling scale for eating disorders, according to the diagnosis are illustrated in **Table 3.6**.

Table 3.6. Carers' Distribution of DASS 21, Family Questionnaire and AESED by diagnostic criteria

	Bulimia Nervosa			Anorexia Nervosa			Binge Eating Disorder		
DASS-21	N	Mean	SD	N	Mean	SD	N	Mean	SD
Depression	55	9.96	8.524	34	11.53	8.001	15	8	6.761
Anxiety	55	6.98	8.379	34	6.88	6.212	15	4.4	4.421
Stress	55	13.60	9.973	34	13.12	8.197	15	12.4	6.642
FQ									
Criticism	57	21.7	5.867	36	21.25	5.862	15	22.13	5.330
Emotional Overinvolvement	57	26.98	5.808	36	28.14	5.452	15	26.00	4.293
AESED									
Avoidance Modifying Routine	57	19.96	8.718	34	20.24	9.32	15	14.13	6.781
Reassure Seeking	56	10.66	6.929	33	10.52	7.624	15	7.0	4.071
Meal Routine	56	2.77	4.752	32	4.81	6.072	15	4.0	6.000
Control of Family	57	7.72	4.229	32	7.91	4.035	15	5.47	4.086
Turning a Blind Eye	55	3.60	3.804	29	2.24	2.459	15	2.73	2.712
Total Score	55	44.76	19.209	27	47.30	21.370	15	33.33	15.31

Note: AN, Anorexia Nervosa; BN, Bulimia Nervosa; BED, Binge Eating Disorder; M, mean SD, standard deviation; DASS-21, Depression Anxiety Stress Scale, possible score ranges for each subscale of 0-42; FQ, Family Questionnaire, possible score range of 10-40 for each subscale; AESED, Accommodation and Enabling Scale for Eating Disorders, possible score range of 0-132

3.4.3 Associations between Carer Distress with Caregiving Style and Eating Behaviours

We adjusted the predictive multiple regression models of depression, anxiety and stress (three dimensions of DASS21) by using the two dimensions of FQ and total AESED score, including the five subscales. In addition, we used patients' details (diagnosis, ED symptoms, age of illness, onset etc) as well as socio-demographic

details of parents. We were able to verify whether or not depression, anxiety and stress shared the same predictors. The final models are summarized in **Table 3.7**.

Anxiety, depression and stress levels yielded significant and mostly positive correlations with the one dimension of the FQ, the emotional over involvement (EOI). Higher EOI levels indicated higher scores in depression ($\beta=0.36$; $p=0.022$), anxiety ($\beta=0.34$; $p=0.022$) and stress ($\beta=0.67$; $p=0.000$). Further, there was a significant correlation between the anxiety and reassurance seeking behaviors as recorded in the AESED ($\beta=0.24$; $p=0.018$), in that parents reported higher levels of anxiety when they accommodated to reassurance seeking behaviors. Regarding the relationship between psychological distress and carer- and patient- related characteristics; a positive correlation was found between anxiety ($\beta=-2.662$; $p=0.051$), stress ($\beta=-2.907$; $p=0.080$) and gender, in that mothers displayed higher anxiety and stress than fathers. Furthermore a significant association was observed between anxiety ($\beta=8.879$; $p=0.002$), stress ($\beta=11.818$; $p=0.002$) and one eating behavior variable, 'Stealing food/money in order to binge', meaning that parents of patients who presented this behavior exhibited higher levels of anxiety and stress. No significant associations were found between psychological distress and type of diagnosis.

Table 3.7 Multiple regression analysis of ED symptom and caregiving experiences (FQ and AESED) as predictors of caregivers' psychological distress (DASS-21).

	Unstandardized Coefficients		t	Sig.	95,0% Confidence Interval for B	
	Beta Coefficient	Std. Error			Lower Bound	Upper Bound
Depression						
Emotional Overinvolvement	0.36	0.154	2.335	0.022	0.053	0.667
Anxiety						
Stealing food/money in order to binge	8.879	2.77	3.206	0.002	3.367	14.391
Emotional Overinvolvement	0.343	0.151	2.276	0.026	0.043	0.643
Reassurance Seeking	0.243	0.101	2.418	0.018	0.043	0.444
Gender	-2.662	1.351	-1.971	0.051	-5.341	0.017
Stress						
Emotional Overinvolvement	0.672	0.169	3.983	0.000	0.336	1.007
Stealing food/money in order to binge	11.818	3.644	3.243	0.002	4.572	19.064
Gender	-2.907	--.153	-1.767	0.08	-6.169	.355

3.4.4 Associations with care giving behaviours and aspects of illness

The multiple regression analysis of variables that are associated with Expressed Emotion are presented in **Table 3.8**. Regarding the relationship between emotional over-involvement (EOI) and carer-and patient-related variables, two significant associations were observed between emotional over-involvement and aspects of illness. High parental EOI scores were associated with patients' age of illness onset ($\beta=0.421$; $p=0.004$) and over exercising ($\beta=2.589$; $p=0.031$) which means that parents of people that are engaged in over exercise and have longer duration in illness, display higher levels of emotional overinvolvement.

In relation to criticism, two variables presented an association with high levels of criticism, the parental employment status and another trait of illness “eating secretly”; in which retired parents ($\beta=0.527$; $p=0.030$) presented higher criticism score than full time working parents, and parents of patients who eat secretly, showed high level of criticism ($\beta=2.723$; $p=0.017$). However, there were no significant correlations between Expressed Emotions and patient diagnosis or parental gender.

Moreover, findings showed that there are significantly negative differences between eating disorder symptoms and parental accommodating behaviours regardless of diagnosis (**Table 3.9**). Specifically, higher scores on meal ritual subscale were associated with the non-vomiting group of patients ($p=0.010$). Moreover, higher scores on the ‘Turning a blind eye’ subscale were associated with the “no restriction food intake” group ($p=0.011$) and higher scores on Control of Family subscale were associated with the ‘not eating in secret’ group ($p=0.004$). However, no significant differences were found in the area of avoidance modifying routine and reassurance seeking.

Table 3.8 Multiple Regression analysis of variables associated with expressed Emotions

	Unstandardized Coefficients				95.0% Confidence Interval for B	
	Beta Coefficient	Std. Error	t	Sig.	Lower Bound	Upper Bound
Emotional Overinvolvement						
Age of Illness Onset	0.421	0.142	2.956	0.004	0.138	0.704
Exercising excessively	2.589	1.18	2.194	0.031	0.247	4.931
Criticism						
Eating in secret	2.723	1.127	2.415	0.017	0.488	4.958
Carer's Employment status	0.527	0.239	2.205	0.03	0.053	1.001

Table 3.9 Multiple Regression analysis of variables associated with Accommodation and Enabling Behaviors.

	Unstandardized Coefficients		t	Sig.	95,0% Confidence Interval for B	
	Beta Coefficient	Std. Error			Lower Bound	Upper Bound
Meal Ritual						
Vomiting after meals	-2.755	1.046	-2.635	0.010	-4.830	-.681
Control of Family						
Eating in secret	-2.381	.801	-2.973	0.004	-3.969	-.793
Turning a Blind Eye						
Restricting food intake	-1.827	.701	-2.606	0.011	-3.218	-.435

3.5 Discussion

The aim of this study was to examine the experience of caring for someone with an ED and its impact on caregivers in Greece, by examining the interpersonal factors based to the cognitive-interpersonal maintenance model in AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) and explore whether patients' clinical characteristics, relatives' socio- demographic characteristics would be associated with the above intrafamilial factors. The first and second hypotheses were supported. Our findings indicated that intra familial factors, as predicted by the model, are present across the trans-diagnostic spectrum of eating disorders (BN, AN, BED) in Greek families. Greek parents presented high levels of psychological distress, expressed emotions and accommodating in accordance with previous findings (Anastasiadou et al., 2014; Zabala et al., 2009).

We also found that carers' high levels of distress were correlated with high levels of emotional over involvement (overprotective reactions) and accommodating behaviors, particularly in the area of reassurance seeking. Particularly, parental anxiety was found to be associated with patients' reassurance seeking behaviours, meaning that parental anxiety increases when they engage in reassurance seeking behaviors that related to weight, shape or food ingredient checking. These findings were consistent with other research suggesting that psychological distress of caregivers to the ED of a loved kin (characterised by high levels of stress, anxiety and depression) are associated with their responses to dysfunctional disease (high expressed emotions—overprotection and hostility—and adaptive behaviors to the symptoms—accommodation and enabling) (Goddard et al., 2013; Kyriacou, Treasure, & Schmidt, 2008a; Schmidt & Treasure, 2006; Treasure, 2010; Treasure & Schmidt, 2013; Treasure et al., 2005; 2008b;).

Our third hypothesis that some characteristics of carers and patients may affect parental levels of psychological distress, emotional responses and behaviors (expressed emotions and accommodation), was partially supported. In terms of parental characteristics, our results revealed two carer's variables that are associated to psychological distress and expressed emotions. Firstly, gender was found to be associated to high parental anxiety and stress; mothers displayed higher anxiety and

stress than fathers. This result indicated that the demands of caring for a child with ED may take a greater toll for mothers in accordance with previous studies among ED samples (Anastasiadou, Cuellar-Flores, Sepulveda, & Graell, 2016; Martin, et al., 2013; Raenker, 2011; Whitney & Eisler, 2005). Secondly, the occupational status of parent was related to high levels of criticism; retired parents presented more criticism in comparison to those working full-time. Thus, it seems that if parents stay at home and spend more time with patient, they feel more responsible for controlling patient's illness through critical remarks. This might be related to parenting style, which is more directive and controlling in Mediterranean families (Pilch, 1993).

Parental distress, emotional reactions and accommodation were associated with different aspects of the illness. Regarding caregiver's psychological distress, one eating behavior was linked to high parental anxiety and stress; specifically, parents of patients that are stealing food/money in order to binge, exhibited higher levels of anxiety and stress. The rationale may be that parents feel overwhelmed or embarrassed from the antisocial/intrusive nature of this behavior which has a negative impact on the rest of family. Enabling behavior may result in that parents may replace the stolen food or money in order to avoid any potential conflict between patient and other members of family (Treasure, 2010).

Furthermore, expressed emotions were found to be associated to illness traits; age of illness onset and exercising excessively was linked to highly emotional overinvolvement while "eating in secret" eating disorder behavior was associated with high levels of parental criticism. Parents of people that have a longer duration of illness and present the symptom of over exercising, become more overprotective due to fear of the enduring illness and negative consequences of excessive exercising, whereas parents of people that eat in secret react with high criticism and hostility, indicating a lower tolerance towards this ED symptom. Probably, high criticism could reflect parental failure to understand the mechanisms underpinning their children's symptom. On the other hand this behavior may have chronic nature which make relations in daily life more complex. Finally, greater levels of EE have been associated with parents attributing the patient's behaviour to internal factors, controllable by the patient, rather than external ones (Wendel, Miklowitz, Richards, & George, 2000) and studies of other mental illnesses (Perlick et al., 1999; Whitney et al., 2007) have found that when

caregivers feel that the patient is responsible for his/her illness, as opposed to external factors, the caregivers tend to report a more negative caregiving experience.

Regarding parental accommodation and enabling behaviors, three different domains of accommodating behaviors were associated with patients' ED. Firstly, parents of people without purging (particularly self-vomiting) showed higher levels of accommodation to meal ritual including issues of cleanliness in kitchen, food storage and control of the family's meal time. One plausible explanation is that non-purging patients have a more obsessive-compulsive temperament and tend to control meals and food, inevitably parents can be more easily be entrapped into patients' checking behaviours. Second, no food restriction was positively associated to parental acceptance of dysfunctional behaviours as reported in the 'Turning a blind eye' scale, implying that parents whose child does not restrict her/his food intake (probably overeating), allow unacceptable children's behaviors like bathroom or kitchen mess or food and money disappearing. Apparently, parents perceived no food restriction as safety behavior; as a result, they ignored these behaviors in order to avoid continuous conflict between the person with the ED and the family members (Sepulveda, Kyriacou, & Treasure 2009; Treasure, 2010). Third, patients' symptom "eating in secret" was negatively associated with parental responses in the control family scale: the less the patient eats in secret, the more the parents enable the patient's control of cooking and food ingredients or choice.

The type of eating disorder diagnosis was not found to be a predictor of parental distress, expressed emotions and accommodation in the current study, in accordance to findings of distress and expressed emotions in carers of people with ED (Di Paola, Faravelli, & Ricca, 2010; Stefanini et al., 2018; Duclos et al., 2013; Sepulveda et al., 2010). However, the lack of difference between eating disorder type and accommodation was in contrast to Stefanini et al. (2018) study in which carers of people with anorexia score higher in the areas avoidance, reassurance seeking and total score of AESED. It is possible that levels of accommodation may be higher among carers of people with AN than BN at the early stages of illness, while accommodation maybe in analogous levels among carers of people with chronic eating disorder. Furthermore, neither carer-patient contact time nor carer's personal ED history, education and marital status were found to link with any of intrafamilial factors. In contrast to Sepúlveda et al. (2009) findings, in this study contact time between carer and patient was not linked

to any parental variables (distress, emotional reactions and unhelpful behaviors). This may have been influenced by the older age of our sample or by the choice of the cut-off (21 h/week), which might have been unsuitable to highlight existing differences. In fact, some studies report a greater number of hours as having the most influential impact on the carers' distress (Gonzalez, Padierna et al., 2012).

3.6 Limitations

One limitation of our study is that, given the cross-sectional nature of our study, we cannot make any statements about causation. Another limitation was that factors other than caring for a person with an eating disorder contribute to the level of psychological distress reported by the participants. For instance, work-related demands, or the financial crisis in Greece may impact upon the level of psychological distress reported by the carer. Furthermore, the absence of a control group limits any conclusions that can be drawn regarding specific factors of caregivers of patients with ED and suggests the use of clinical and non-clinical comparison groups in future research. An additional limitation was that we did not examine for additional factors that may account for variations in parents' experience of psychological distress.

3.7 Clinical Implications

The findings of this study suggest the powerful consequences for parents who find themselves in the position of caring for a child with an ED. The fact that family members suffer from distress, anxiety and depression, suggests that they would merit treatment in their own right. One way to do this would be family interventions that offer support and psychoeducation. The understanding of the variables that are associated with carer distress and poor prognosis for patients such as illustrated by the cognitive interpersonal model might allow carer interventions to be designed to reduce the level of psychological distress and expressed emotion and reliance on maladaptive coping strategies.

3.8 Conclusion

In conclusion, the results of this study add evidence in support of the significant and aversive impact of caregiving for individuals across the spectrum of eating disorders. There are two novel aspects of this study. Firstly, this was the first study in Greece and secondly, it was a first study that presents a diagnostically mixed sample in which approximately 65 percent of participants are parents of adult people suffering from Bulimia and Binge Eating Disorder and highlights the association between illness aspects and traits and carer's demographics.

Chapter Four

Study 1(b)

Aspects of caregivers' experiences in eating disorders: comparison between Greek and English parents.

4.1 Abstract

Objective: To examine any differences in caregiving behaviours between Greek and English parents of people with Anorexia and Bulimia Nervosa in terms of psychological distress, expressed emotions and accommodating behaviors.

Method: Parents of people with eating disorders from Greece (n=89) and Britain (n=89) were assessed on psychological distress (Depression Anxiety Stress Scale), expressed emotions (Family Questionnaire) and accommodating and enabling behaviors (The Accommodation and Enabling Scale for Eating Disorder).

Results: Greek and British parents did not differ in terms of psychological distress. Criticism (CC) from the Family Questionnaire was higher in the Greek parents. Moreover, Greek parents scored higher in total accommodation score and the Avoidance and Modifying Routine, meal ritual and Control of Family subscales in comparison to English parents. Meal Ritual domains from the accommodation scale, were higher in Greek parents, particularly in the group with a higher level of contact (>21 hours per week).

Conclusion: These differences in emotional reactions and accommodating behaviors between Greek and English parents, may represent cultural factors that may need to be differentially targeted in treatment in order to make family interventions more effective.

4.2 Introduction

In the past two decades, there has been a rise in the number of studies that investigate the experiences of caregivers with an eating disorder (ED) and explore the association between the maintenance of eating disorders (EDs) and family dynamics and interaction (Treasure et al., 2007; Highet, Thompson, & King, 2005). According to two systematic reviews, eating disorders have a great impact on family functioning. Carers experience low care giving efficacy with high levels of distress, expressed emotions and accommodation (Anastasiadou, Sepúlveda, Medina-Pradas, Treasure 2014; Zabala, MacDonald, & Treasure, 2009). Moreover, these reactions vary depending to aspects of patient's condition such as diagnosis, eating symptoms and carer's characteristics (contact time, educational status etc) (Winn et al., 2007; Raenker et al., 2013). Furthermore, the interpersonal model of AN maintenance describes how these family reactions may have an impact on a person with an eating disorder as vicious cycles can be set up that perpetuate the illness (Schmidt & Treasure 2006; Treasure & Schmidt, 2013).

Within these studies that have focused on the effect of an eating disorder on the family functioning (and vice versa) however, little attention has been given to quantitative research on ED caregiver experiences from different sociocultural context and how these experiences are influenced by the cultural norms of each society, whereas several studies have examined this with other forms of mental illnesses (Bhugra & McKenzie, 2003).

4.2.1 Differences in patterns of Family structure and the concept of kinship between Greece and Southern European countries

There are noticeable differences in terms of family structure, kinship and childrearing practices across Europe. Countries have been designated as those with “weak family ties” (the Scandinavian European countries) and those with “strong family ties societies” (the Mediterranean group) (Reher, 1998). South European countries (Greece, Italy, Spain, Portugal) share common cultural norms for the critical role of mothers' presence and care in early childhood years, strong family ties and a high dependence on the extended family for supporting childcare needs (Saraceno, 2010). Moreover, a network of people including a close relative, friends or neighbours

cooperate in meeting these childcare needs. Social networking is a fundamental component of Greek social structure and the family care system is defined as “familism” (Doumani,1990). More specifically, a culture of familism underlining that parent-child relationship and allegiance to the family system plays a key role for obtaining social solidarity (provision of carer and support) and productivity (economic activity within family business) (Giuliano, 2011).In order to keep strong ties and endorsement with family norms, childrearing practices are directive, demanding and based on control over children’s actions and behaviors, expecting conformity and obedience and diminishing child’s motive for autonomy and independence (Papps et al., 1995; Szapocnik & Kurtines, 1993; Triadis, 1989). Overall the Greek family functions as extended which is characterized by cohesiveness and tight bonds and interactions (Georgas,1999; Georgas, 2000; Kataki, 1998).

4.2.2 Impact of family and patient’s interaction in Greece

Evidence indicates that Greek families of people with long-term mental illness, encounter psychosocial problems such as stigma and illness denial (Madianos, Madianou, Vlachonikolis, & Stefanis, 1987; Madianos, Economou, Hatzianeou, Papageorgiou & Rogakou, 1999). Furthermore, one cross-cultural study indicates that Greek families display more burden than Dutch and British families due to lack of social support and public mental services (Magliano et al., 1998). Another study on Greek patients from patient’s perspective (obsessive-compulsive disorder) indicates that parental responses are characterized by overprotectiveness, rejection and less emotional warmth (Ehiobuche, 1998). These rejecting and controlling parenting styles have been described as authoritarian parenting type which is associated with a variety of forms of psychopathology, including depression, schizophrenia, anxiety disorders, substance abuse and eating disorders (Gerlsma, Emmelkamp, & Arrindell, 1990; Parker & Asher, 1987; Rapee & Heimberg, 1997).

To conclude, our understanding of the role of culture in family reactions and attitudes in eating disorders remains limited, due to lack of cross-cultural research in this area. Moreover, most studies have been carried out in UK or the United States, which limits the application of their results in other contexts, as burden, expressed emotions and accommodating behaviors are likely to be influenced by sociocultural factors, such as

culture, kinship and parenting style.

Therefore, the overall aim of this study was to identify any difference in the psychological distress, expressed emotions and accommodating behaviors among Greek and British families of people with eating disorders. We hypothesized that Greek parents would report higher levels of psychological distress, expressed emotions (more criticism), accommodation and enabling behaviors than English parents. In addition, it was hypothesized that the contact time with patient would be associated to the psychological distress and less adaptive behaviours (accommodating behaviours and expressed emotion) within parental groups.

4.3 Methods

4.3.1 Subjects

Data from 178 parents of patients suffering from eating disorders from two countries, Greece and England were included, i.e. 89 parents from each country. The Greek sample was taken from study 1(a) and UK sample originated from preexisting data of published studies from the Institute of Psychiatry, Psychology and Neuroscience, section of eating disorders. All of these parents had a child who had been diagnosed with an ED according to the Diagnostic and Statistical Manual of Mental Disorders-V (American Psychiatric Association, 2013) by professionals from our clinic or psychiatric settings in UK.

Socio-demographic details and clinical details of Greek and English parents of people with an eating disorder are outlined on **Table 4.1**. There were eighty-nine parents in each group. In the Greek sample, the mean parental age was 55.6. Over a half lived with the patient, and (43.6%) had of more than 21 hours per week contact time. The majority of children (61.8%) were suffering from bulimia nervosa (BN) and (38.2%) from anorexia nervosa (AN). In UK sample mean of parents' age was 56.37. The majority (86.5%) lived with the patient and over a half had over 21 hours of contact time. Their children were diagnosed with anorexia nervosa and their illness duration was almost five years and the majority were female.

Table 4.1 Demographic and clinical details of parents and patients

Carers	Greek	English
Age	55.6 (9.28)	56.36 (6.8)
Female : Male patient	86 : 3 (93.3% female)	83 : 6 (96.6% female)
Carer type		
Mother	55 (61.8%)	55 (61.8%)
Father	34 (38.2%)	34 (38.2%)
Living with patient: Yes/no	54:30(64.3% Yes)	77:12(86.5% Yes)
Face to face contact		
High(>21 hours per week)	38 (43.6%)	46 (51.7%)
Low (<21hours per week)	49 (56.4%)	42 (48.3%)
Employment status		
Full time	50 (56,8%)	42 (47.2%)
Part time / student	4 (4.5%)	18 (20.2%)
Housewife / retired	34 (38.7%)	19 (21.3%)
Other		10 (11.3%)
Marital status		
Married / living together	71 (87.7%) 10 (12.3%)	72 (80.9%) 17 (19.1%)
Single/divorced / separated/widowed		
Patients	Greek	English
Age	26.05 (6.68)	22.21 (4.83)
Female: Male (N)	86:3(96.6%female)	83:6(93.3% female)
Mean Duration of illness (years)	5.12 (3.67) (Median: 4.5)	4.46(4.93) (Median: 3.0)
Diagnosis		
BN	55 (61.8%)	1 (1.1%)
AN	34 (38.2%)	88 (98.9%)

4.3.2 Measures

Caregivers completed a demographic questionnaire that included details about themselves (including age, gender, marital status, employment status and education level) and the patient (diagnosis, age, gender, onset and duration of the illness, ED diagnosis, and co morbidity). Also, treatments and aspects of care giving experience (e.g. whether the carer was living with patient and the average duration of one-to-one contact) were recorded.

Depression and Anxiety: The short version of the Depression, Anxiety & Stress Scale (DASS-21) (see study 1). In the current sample Cronbach α coefficients was 0.84.

Expressed Emotions: The Family Questionnaire (FQ) (see study 1). In the current sample, Cronbach α coefficient was 0.81.

Accommodating and Enabling Behaviors: The Accommodation and Enabling Scale for Eating Disorder (AESED) (see study 1). The reliability for the scale in the current sample was high ($\alpha = .85$).

4.3.3 Procedure

We conducted a cross-sectional study with a descriptive and comparative design. The carers were matched according to their gender, age and educational level.

4.3.3.1 Greek Sample (please see Study 1)

Ethical committee approval was obtained by Iatriko hospital (1094/1-4-2013)

4.3.3.2 Adaption process of scales (please see study 1)

4.3.4 Data analysis

General Linear Models under the univariate approach were used to assess statistically significant differences between Greek and English carers for all the dimensions of the questionnaires DASS 21, FQ and AESED. The carers were matched according to age,

sex and educational level and were controlled for the effect of contact time and type of diagnosis (AN, BN). Logistic regression was applied to examine differences between the two groups of carers and the recorded ED symptoms. All effects were again controlled for confounder variables (contact time and type of diagnosis). Statistical significance was set at 0.05. All analyses were carried out with the use of SPSS v.21.

4.4 Results

4.4.1. Clinical Details and Caregiving Behaviors

High levels of psychological distress were present in both groups of carers. In the Greek group, (45.5%) carers of people with BN and (55.9%) of people with AN reported mild to severe levels of depression. The English group displayed (46.1%) mild to severe levels of depression. On the anxiety scale, the Greek parents showed high levels of anxiety (AN 44.1%; BN parents 41.8%) and the English sample (21.3%). On the stress scale, the Greek group showed high stress (AN parent 35.3 %, BN parents 40%) and the English 34.8%. Moreover, high levels of criticism and emotional over involvement were present in the Greek and English group. In the Greek group (32.4%) of AN carers and (34.5%) of BN carers reported higher levels of CC (using the cut- off score of 23) than English carers (21.3%). Also, the Greek group AN carers (58.8%) and BN carers (49.1%) showed higher levels of emotional overinvolvement (using the cut-off score of 27) compared with the English (42.7%) group. In terms of accommodating and enabling behaviors, the overall score of accommodation and enabling scale for eating disorders (AESED) in parents was 46.07 (SD=19.86) in Greece and 37.05 (SD=22.62) in UK.

4.4.2_Examination of parental experiences of people with eating disorders (Greek versus English)

The measures of parental distress (DASS) and caregiving style (FQ and AESED) are shown on **Table 4.2**. No significant difference was found between parental groups in depression ($p=0.693$), anxiety ($p=0.371$) and stress subscales ($p=0.580$) with regard to the caregivers' gender, age and educational level, and the effect of the contact

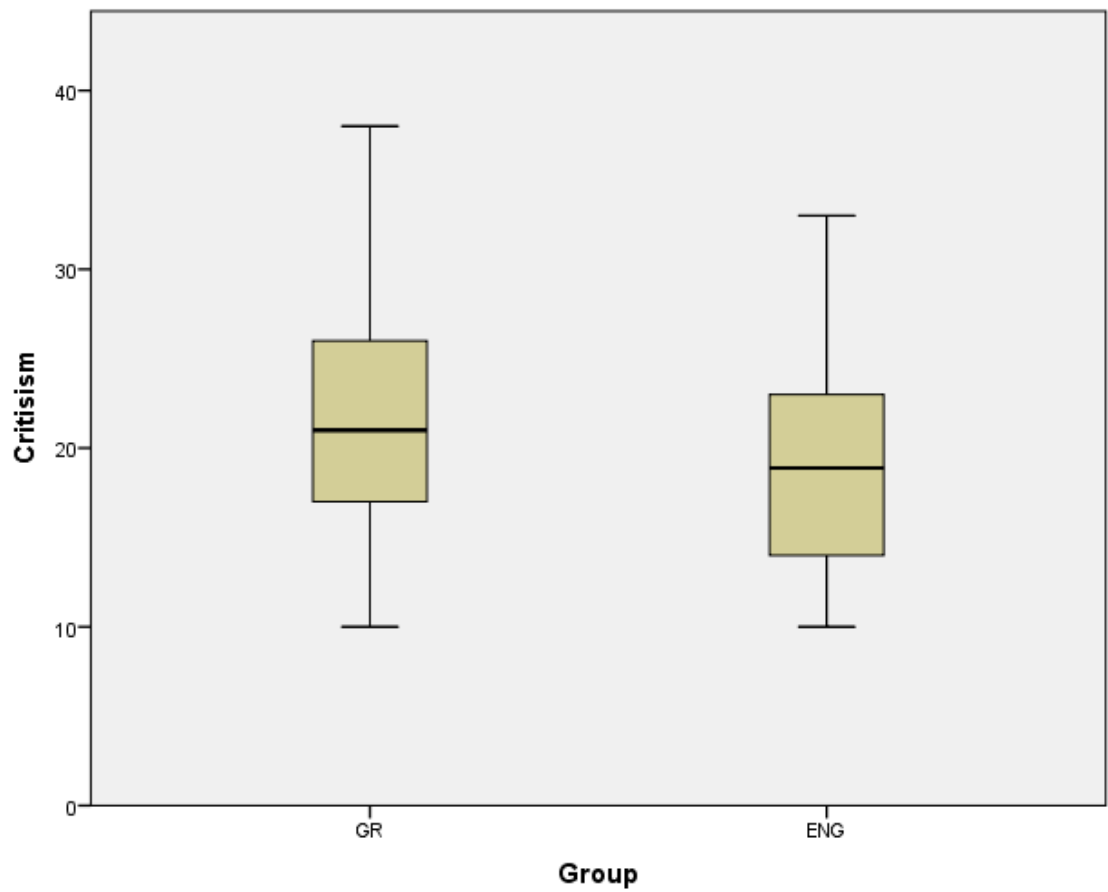
time (Depression $p=0.146$, Anxiety $p=0.298$, Stress $p=0.331$) and type of diagnosis (Depression $p=0.482$, Anxiety $p=0.754$, Stress $p=0.755$).

Graph 4.1 illustrates the significant difference in criticism (CC) values between the groups, Greek parents scored higher on Criticism ($p=0.011$) than English. This outcome was independent of diagnosis ($p=0.49$) and contact time ($p=0.72$). However, there was no significant difference between Greek and British parents in emotional over involvement ($p=0.19$), in terms of contact time ($p=0.81$) and diagnosis ($p=0.32$).

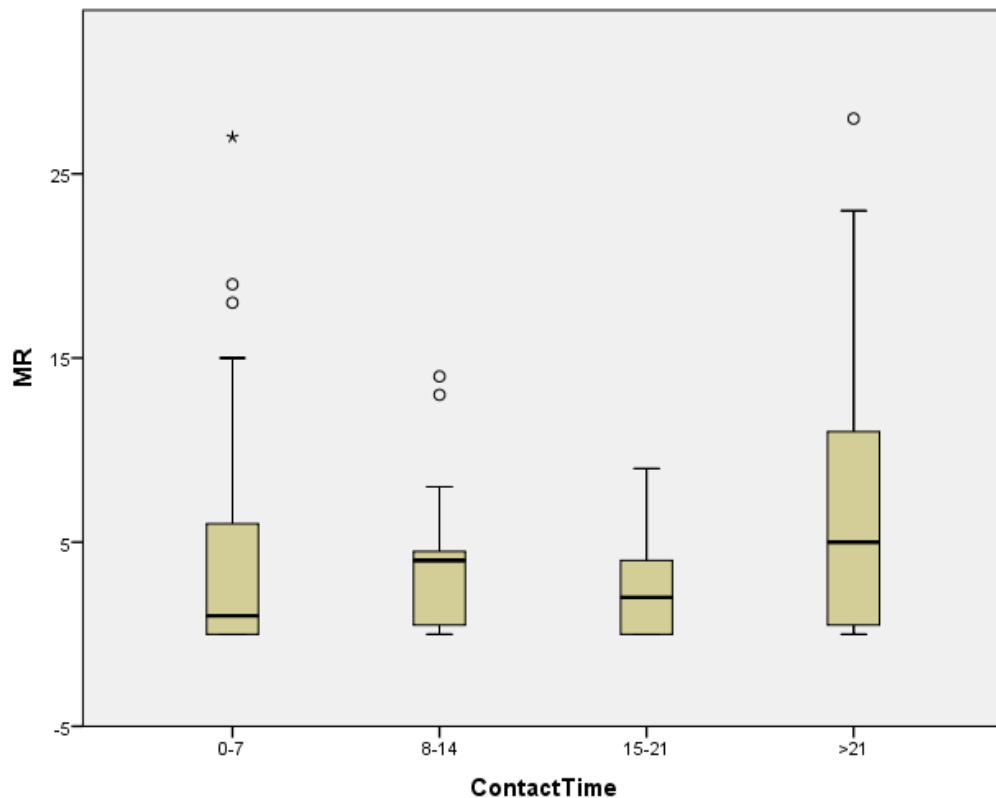
Greek parents scored higher on total score of accommodation ($p=0.042$), than English, regardless of contact time ($p=0.164$) and type of diagnosis ($p=0.678$). In the five subscales of accommodation Greek parents score higher on the Avoidance & Modifying Routine (AMR) ($p<0.0001$), on the meal ritual subscale ($p=0.006$) and on the Control of Family (CF) subscale ($p=0.044$) in comparison with the English group. However, there was no significant difference within groups in the Reassurance Seeking and Turning a Blind Eye subscale ($p=0.885$) regardless of the type of diagnosis ($p=0.198$) and contact time ($p=0.314$). Similarly, no significant difference was found on the (MR) meal ritual subscale ($p=0.104$) between the groups regardless of the type of diagnosis ($p=0.212$). Nevertheless, a significant effect of contact time was observed on meal ritual (MR) subscale ($p=0.006$) within groups. After accounting for multiple comparisons with the Bonferroni tests correction, data showed that parents with high contact time (more than 20 hours per week) score higher in meal ritual subscale than those with low (0-7 hours per week). **Graph 4. 2** shows the pairwise comparison between levels of contact time and meal ritual subscale of accommodation and enabling scale.

Table 4.2. Measures of distress (DASS) and caregiving style (FQ and AESED) between Greek and English parents

			Mean	Standard Deviation	P-value
DASS21					
Depression	Group	GR	10.56	8.32	0.693
		UK	10.47	9.74	
Anxiety	Group	GR	6.94	7.59	0.371
		UK	4.94	7.99	
Stress	Group	GR	13.42	9.29	0.580
		UK	13.91	9.81	
Family Questionnaire					
Criticism	Group	GR	21.48	5.67	0.011
		UK	18.88	5.40	
Emotional Overinvolvement	Group	GR	27.53	5.59	0.190
		UK	26.70	4.82	
Accommodation & Enabling Scale					
Avoidance &Modify Routine	Group	GR	20.24	8.79	0.001
		UK	12.58	7.57	
Reassurance Seeking	Group	GR	10.87	7.13	0.696
		UK	9.80	7.00	
Meal Ritual	Group	GR	3.60	5.39	0.106
		UK	6.75	6.76	
Control of Family	Group	GR	7.91	4.03	0.044
		UK	6.25	4.19	
Turning a Blind Eye	Group	GR	3.09	3.38	0.885
		UK	2.25	3.07	
AESED Total Score	Group	GR	45.71	28.72	0.042
		UK	37.05	22.62	



Graph 4.1 This boxplot shows the levels of criticism between Greek and English group



Graph 4.2. Within groups comparison of levels of contact time on the area of meal ritual of accommodation scale.

4.5 Discussion

The purpose of this study was to examine any differences between Greek and British parents of a patient with Bulimia and Anorexia Nervosa in terms of psychological distress, expressed emotions and accommodating behaviors. Our findings indicated that Greek parents demonstrate similar levels of psychological distress but higher levels of criticism and accommodation than English group. Also, these results were not significantly different to the effect of patient's diagnosis and carer-patient contact time. Therefore, our first hypothesis that Greek parents would report higher levels of psychological distress, expressed emotions (particularly criticism) and accommodation than English parents, was partially confirmed. Moreover, the second hypothesis that any difference among groups would be associated to the contact time, was not substantiated.

In our sample, no significant difference was found between the two parental groups in terms of psychological distress. This finding is in contrast with the study by Magliano et al (1998) who found that Greek families of people with mental illness report higher psychological distress than Dutch and British families. This finding needs confirmation in larger studies due to the cross-sectional nature of the present study.

As expected, Greek parents reported significantly higher levels of criticism than English. This finding was consistent with other studies suggesting that criticism is considered a usual component of interpersonal interaction in collectivist societies with extended kinship (Heresco-Levy, Greenberg, & Dasberg, 1990; Okasha, et al 2004). This fits with child-rearing practices which instill control and obedience in children (Triandis, 1989; Ruggiero, 2004). In addition, intrusiveness which is in the form of “making repeated attempts to establish contact or to offer unsolicited (and frequently critical) advice” (Cole & Kazarian 1988, p.393), appears to be prevalent element of parental style of communication in Greece (Francis & Papageorgiou, 2004). Together, these studies reflected that EE is influenced by cultural differences in familial structure.

In terms of caregivers' accommodation and enabling behaviors, our findings confirmed the hypothesis that Greek parents would have higher levels than the English. Greek parents reported higher total score on accommodation scale and on three out of five subscales including carers' modification of daily schedule, due to time involved in rituals, and endured more to controlling behaviors. These findings were closely linked to the suggestion in the literature that families react overprotectively to patient's behaviors concerning food and body issues (Winn et al., 2007; Whitney and Eisler, 2005; Treasure, Whitaker, Whitney, & Schmidt, 2005).

However, these significant differences were not correlated with the contact time, unlike earlier studies that suggested the form of eating disorder had a significant impact to different areas of accommodation (Sepúlveda et al., 2009). Moreover, Greek parents presented more accommodation and enabling behaviors despite the fact of having less contact time than the English group. This may be explained in that accommodation in Greek family may act as a form of control or intrusiveness to their child, suggesting the detrimental impact of authoritarian parenting style. Moreover, the finding that parents with higher level of contact time (more than 21 hours weekly) endorse more to patient's

meal rituals was in line with studies that accommodation is associated to carer's contact time (Anastasiadou et al., 2014).

Neither hours of contact with the patient, when included in the analyses as covariate, had a significant effect on these variables, which might suggest that differences in the family functioning may be explained by differences in family structure that distinguish Greek families from English families.

4.6 Limitations

Several methodological limitations need to be mentioned. Firstly, the Greek sample came from a single treatment center whereas the British sample of carers were recruited from various eating disorder services in London. Thus, our findings may not be as representative of the population as a whole. A second limitation was that we assessed caregivers at only one point in time, which did not allow us to observe changes in caregiver burden, expressed emotions and accommodation over time or make any statements about causation. Thirdly, the absence of normal control or clinical comparison group limited any conclusions that can be drawn regarding cultural factors influence caregiving aspects in ED.

4.7 Clinical Implications

This study provides new insights into considering the role of culture and family structure on the impact of ED on family members. The comparison between Greek and English families may be relevant to the effectiveness of treatments that were developed in the UK. Further research is needed to explore caregivers' expressed emotion in culturally diverse groups, and the impact this has on outcomes for individuals diagnosed with eating disorders. The question of what might constitute a 'normative' level of EE within a particular family or cultural group, and whether this is relevant to understanding how familial factors may influence treatment outcome, needs to be addressed. Further research is also required into the cultural sensitivity and appropriateness of measurements used in these types of studies. Therefore, healthcare providers need to be mindful of the cultural context and family interventions may need to be adapted to the cultural context in order to help carers to get more skills for coping effectively to the illness.

4.8 Conclusion

These findings demonstrate the impact of eating disorders on Greek and English parents in terms of psychological distress, expressed emotions and accommodation. Greek parents demonstrated higher levels of criticism and accommodating behaviors than English; these differences may relate with the cultural context. Moreover, these findings have clinical implications, highlighting the importance of supporting and empowering caregiver with skills to tackle the negative consequences of illness. Additionally, we hope that future family interventions may be more adapted to cultural background. This was the first study that explored ED families from two different sociocultural contexts.

Chapter Five

Study 2

Experiences Among Non -affected Adult Siblings of People with Eating Disorders and Those of people With Diabetes.

5.1 Abstract

Objective: The aim of the study was to examine the impact of illness in terms of psychological distress, expressed emotions and accommodation among healthy siblings of individuals with eating disorder and to compare these reactions to those seen in siblings with diabetes mellitus.

Method: Fifty participants (females N=32, male=18, 18- 60 years old) with a sibling with an ED (n=25 study group) or with DM (n=25, comparison group) were assessed for psychological distress and expressed emotions and accommodation towards their ill sibling.

Results: Siblings of people with ED reported less depression and stress but higher levels of criticism and higher accommodation (particularly on reassurance seeking and control of family) than the siblings of people with diabetes. Sibling's age (older) had an effect on distress, expressed emotions and accommodation. Sibling's gender (females more impacted) was associated with anxiety and accommodation in the ED group.

Conclusion: Siblings are negatively impacted by both diabetes and eating disorders. The siblings of people with an ED patient have higher levels of criticism and accommodation than siblings of people with DM.

Keywords

eating disorders, diabetes, siblings, psychological distress, expressed emotions, accommodation

5.2 Introduction

The lives of both eating disorder patients and their families are impacted by the illness. Caring for someone with an ED can generate significant stress and strain on family functioning which in turn may have negative consequences on the family

organization and interaction (Coomber & King, 2013; MacDonald et al., 2010). Two systematic reviews have underlined the negative effects on quality of life and wellbeing of all family members and high expressed emotion and accommodating and enabling behaviours in relationship to the ill member (Anastasiadou et al., 2014; Zabala, Macdonald, & Treasure, 2009). Indeed, some authors have found that caregivers of ED patients have higher levels of anxiety, depression, and perceived caregiving burden than caregivers of patients with other psychiatric illnesses (Treasure et al., 2001; Graap et al., 2008; Zabala et al., 2006). Most research exploring family members' experiences of living with a person with an ED has focused on parents (Vandereycken & Van Vreckem, 1992), while siblings' experiences have been studied less (Dimitropoulos et al., 2013).

5.2.1 Siblings and Eating Disorders

The available evidence suggests that eating disorders can impose a substantial burden on siblings; for example some are asked to participate in family based treatments in order to reduce burden and responsibility (Dimitropoulos, Klopfer, Lazar, & Schacter, 2009; Honey & Halse, 2007; Vandereycken & Van Vreckem, 1992). Siblings report silently worrying that the ill sibling might die and they feel forgotten or invisible as parental attention is focused on the ill sibling's needs (Halvorsen, Ro, & Heyerdahl, 2013; Latzer, Ben-Ari, & Galimidi 2002; Garley & Johnson, 1994; Areemit, Katzman, Pinhas, & Kaufman, 2010). Their relationship with their sibling changes as does their role in the family (Dimitropoulos et al., 2012). Many adopt an undemanding child role (Areemit, Katzman, Pinhas, Kaufman, 2010) and/or engage in caregiving activities (Dimitropoulos et al., 2009). Their common coping strategies include escape/avoidance especially during meal preparation or mealtime (Honey, 2008), externalization of the problem (Dimitropoulos et al., 2009) with increased knowledge about AN. Most studies in this area have focused on the siblings of adolescent patients with anorexia nervosa rather than the other forms of eating disorder (BN or BED).

5.2.2 Siblings and Diabetes

Research regarding the influence of a child's illness or disability on other family members (McLinden, Miller, & Deprey, 1991) has shown that healthy siblings who are living in the shadow of the illness, experience social isolation (Taylor et al., 1980),

emotional deprivation (Kramer, 1984), disturbed peer relationships (Iles, 1979), increased responsibility (Gallo, Breitmayer, & Zoeller, 1991), and greater health fears (Menke, 1987). The impact of sibling ill health depends on age, gender, personality and illness duration, with females reporting more distress than males, and adolescents showing the poorest adjustment compared to other age groups (Alderfer et al., 2009).

Siblings of people with diabetes have been observed to show social withdrawal and shyness (Tritt & Esses, 1988) and adjustment problems such as difficulties in self-concept, school, and social competencies (Ferrari, 1987) with unmet personal needs, intense negative emotions and loss of normality in their relationship with the affected sibling. In the case of T1DM, family dynamics are affected as care of the chronically ill youth dominates the family's schedule. As a consequence, sibling relationships can be altered, especially if the typically developing sibling must take on a caretaker role (Graff et al., 2012). Loos and Kelly (2006) found that nine of the sixteen siblings they interviewed contributed to the care of the youth with T1DM, both physically and psychologically. Wennick and Huus (2012) reported siblings assisted with blood glucose monitoring and motivating the youth with T1DM to follow their diabetes management regimen when their brother/sister "needed a break from testing." Siblings in Herrman's (2010) study discussed the need to watch the youth with T1DM for signs of hypoglycemia and intervene accordingly. Therefore, the sibling relationship becomes parentified, showing overprotectiveness with this burden persisting into adulthood (Smith, 2007).

The decision to include diabetes as comparison group was based on the fact that there are some contextual similarities (and differences) to the sibling's experiences of people with eating disorder and diabetes. Both conditions are life threatening chronic illnesses with an adolescent onset and involve complex changes in food and diet lifestyle which can impact on physical health and psychological well-being. If left untreated, both problems can have serious physical complications, placing an extraordinary burden on the patient and family members. A main difference is based on the stigmatization and level of societal acceptance towards serious mental illness such as eating disorders (Stewart, Keel, Schiavo 2006; Roehrig & McLean 2010; Crisp, 2005). It therefore could be argued that people with diabetes are more positively accepted in society than people with eating disorders. This difference is reflected in many ways, one of which is the

level of public health services and supports available to them whereas persons with an eating have far few services available, especially in Greece. Moreover, the multifactorial etiology of eating disorders and the varying and often contradictory treatment approaches encountered by families of people with eating disorder, contribute to stress in its own right, leading to a frustration and self-blame, not experienced by families with diabetes. In addition, families of people with ED may hold false attributions that the patient has some personal control over their eating disorder symptoms, which can lead to high levels of criticism and frustration and accommodation to eating disorder's symptoms (Treasure & Schmidt, 2013). This is the first study that examines ED siblings functioning in comparison to another clinical group exploring the interpersonal component of cognitive interpersonal maintenance model (Treasure & Schmidt, 2013) and specifically how psychological distress can lead to a caregiving style that can maintain the illness with expressed emotion, and accommodating behaviours.

The aims were to achieve the following: (1a) to compare experiences of unaffected adult siblings of people with ED (AN, BN, BED) with those of people with DM (T1 & T2 DM) in terms of psychological distress, expressed emotions and accommodation and (1b) to identify the patient- siblings characteristics that mostly expose well siblings to high levels of stress, anxiety, depression, and expressed emotion, favoring the accommodation, (2a) to examine the caregiving experiences of siblings of people with an ED according to interpersonal maintenance model in ED, (2b) to examine these aspects from gender perspective. (2c) to investigate whether sibling – patients details (age, educational status, illness duration, diagnosis, patient-carers' contact time) has an impact on the levels of psychological distress, expressed emotions and accommodation.

On the basis of the empirical studies discussed previously, we developed the following hypotheses:

1. Significant differences will be found between the study and comparison groups in the levels of psychological distress, expressed emotions and accommodation. ED siblings would report higher levels of psychological distress, expressed emotions and accommodation than DM siblings.

2. Factors such as age, gender, educational status, diagnosis, interaction time, illness duration, would have an impact on burden, emotional responses and accommodation.
3. The distress of siblings of people with ED might be associated with expressed emotion and accommodation and enabling behaviors (a hypothesis of the interpersonal component of cognitive maintenance model in AN (Treasure & Schmidt, 2013)).

5.3. Method

5.3.1 Participants

Fifty siblings of outpatients with an ED or DM participated in this study. The ED sample (N=25) consisted of participants recruited from our clinic. These had a sibling with an ED, diagnosed by mental health professionals at the clinic. The average sample age was 36 years (SD = 7.9), 36% were male and 64 % female and 44% of the siblings were spending more than 21 contact hours per week with the patient. Most sisters described themselves as primary carers (68.7%), whereas the majority of brothers described themselves as secondary carers (89.9%). Definition of primary and secondary carer was subjective but was related to the level of dependence by the patient and number of hours of contact.

The patients had been diagnosed with an ED by a standard clinical interview following criteria of the Diagnostic and Statistical Manual of Mental Disorder, fifth edition (American Psychiatric Association, 2013). They were interviewed in the ED unit by a qualified psychologist after one of their treatment session. The patients were 92% females with a mean age of 34.7 (SD = 8.9) years. 48 % were diagnosed with anorexia nervosa (AN), 40% bulimia nervosa (BN), 12% binge eating disorder.

The DM group consisted of siblings with type 1 and 2 diabetes recruited from the diabetic department of Iatriko Hospital in Athens. These had a sibling with an DM diagnosed by the diabetic department of Iatriko Hospital in Athens. The average sample age was 40.5 years (SD = 14.3), 36% were male and 64 % female and 100% of the siblings were spending more than 21 contact hours per week with the patient.

The DM patients were 68 % females with a mean age of 39 (SD = 15.3) years. 76 % were diagnosed with Type 1 (DM I), 24 % Type 2 (DM II).

Socio-demographic details of the non - affected siblings and clinical details of their siblings with eating disorder or T1 &T2 Diabetes are outlined on **Table 5.1** and **5.2**. There were twenty-five adult siblings (16 females and 9 males) in each group.

5.3.2 Measures

Demographic Questionnaire: These established details such as age, sex, marital status, occupation of the non- affected sibling, and core clinical information about the ill sibling (symptoms, age, and co-morbidity, treatment) and social condition (e.g. whether the siblings cohabited and time spent with one-to-one contact).

- The short version of the *Depression, Anxiety & Stress Scale* (DASS-21) (please see study 1), in the current sample Cronbach was $\alpha=0.925$.
- *The Family Questionnaire* (FQ), (see study 1). In the current sample Cronbach was $\alpha= 0.815$.
- *The Accommodation and Enabling Scale for Eating Disorder* (AESED) (see study 1). In the current sample Cronbach was $\alpha =0.854$.

5.3.3 Procedure

A cross-sectional study with a descriptive and comparative design was conducted. Siblings of a person with ED were recruited over a 1-year period (October 2016 to October 2017). Then, a summary of the study was provided to ED patients, asking them to inform their siblings about research. For the ED group 25 siblings were included in the study by providing a written informed consent. The inclusion criteria for the unaffected siblings were as follows: adult siblings 18- 65 (male, female) of a diagnosed person with an eating disorder with sufficient knowledge of the Greek language, written and spoken. Siblings were excluded if they were diagnosed with an eating disorder, were acutely suicidal or if they had a diagnosis of psychosis, learning disability, neurologic diseases or diseases affecting metabolic regulation (i.e. diabetes).

The DM group consisted of siblings with type 1 and 2 diabetes recruited from the diabetic department of Iatriko Hospital in Athens (old and new admissions) and were matched for age and gender with ED group. First, permission from hospital board was obtained, as well as from doctors. Then, a summary of the study was provided to DM patients, asking them to inform their siblings about research. Finally, 25 out of 30 siblings provided their informed consent (five siblings refused to participate because of lack of time and/or expressed distrust regarding confidentiality of their personal information). The inclusion criteria for the unaffected siblings were as follows: adult siblings 18-65 years old (male, female) of people diagnosed with Diabetes Mellitus (type I and II) with sufficient knowledge of the Greek language, written and spoken. Siblings were excluded if they were diagnosed with an eating disorder, were acutely suicidal or if they had a diagnosis of psychosis, learning disability, neurologic diseases or diseases affecting metabolic regulation (i.e. diabetes).

The full set of questionnaires was sent to all participants, along with an information and consent sheet and a prepaid return envelope. Participants were not offered any incentives for participation.

5.3.4 The adaptation process of instruments (please see study 1).

5.3.5 Statistical Analyses

The collected data were described as means and standard deviations when measured on a scale, and as frequencies and percentages in the case of categorical variables. The participants in each group were matched for age and gender. The relationships between the three measurements and their subscales were examined with the Pearson's correlation coefficient. The Pearson's correlation coefficient was also used to examine the relationship of the questionnaires and age, onset and illness duration, while the Independent samples t- test and the one -way ANOVAs under Tukey's multiple comparisons tests, where appropriate, were used to assess statistically significant differences across the levels of categorical variables such as gender, educational level, contact time or diagnosis. These univariate results, were then used in regression analysis to adjust the differences in the outcomes relating to gender and

diagnosis by the remaining potential confounders that were recorded. The SPSS v 22.0 was used for the analysis and statistical significance was set at 0.05 in all cases.

5.4 Results

5.4.1 Clinical details of siblings' distress and relationship style

Siblings of people with an Eating Disorder

The siblings of the patients with ED were adults and 15 out of 25 have identified themselves as primary caregivers. Nearly half lived with the patient, and 12% had of more than 21 hours per week contact time. In many cases the illness of their (mainly female) siblings had been protracted. Eight percent of siblings scored at or above the suggestive threshold on the depression subscale and 12% scored at or above the suggestive threshold on the anxiety subscale. High levels of criticism and emotional over involvement were present, 56% reported high levels of critical comments (CC) (using the cut- off score of 23) and 12.5 % showed high levels of overprotection (EOI) (using the cut-off score of 27) from the family questionnaire.

Siblings of people with Diabetes

The siblings of the DM patients were slightly older. Over the half lived with the patient and all had less than 21 hours of contact time. Their siblings with diabetes had also had a protracted illness. About a third of patients were male. Over one of third of siblings scored at or above the suggestive threshold on the depression subscale and 12.5% scored at or above the suggestive threshold on the anxiety subscale. High levels of criticism and emotional over involvement were present, eight percent reported high levels of critical comments (CC) (using the cut- off score of 23) and 16 % showed high levels of overprotection (EOI) (using the cut-off score of 27) from the family questionnaire.

Table 5.1 Demographic details of sibling groups (carers) with ED and DM

Carers	Eating Disorders	Diabetes Mellitus
	Mean (SD) / N (%)	Mean (SD) / N (%)
Age	36.0 (7.9)	40.5 (14.3)
Female	16 (64.0%)	16 (64.0%)
Male	9 (36.0%)	9 (36.0%)
Living with patient:		
Yes/no	11:14 (44% Yes)	13:12 (52% Yes)
Face to face contact		
High (>21 hours per week)	22 (88%)	25(100%)
Low (<21hours per week)	3(12%)	
Employment status		
Full time	16 (56%)	12 (48%)
Part time	0	5 (20%)
Student	9 (36%)	3 (12%)
Unemployed	2 (8%)	2 (8%)
Other		3 (12%)
Educational level		
Primary school		
High School		2 (8%)
Senior high school	10 (40%)	13 (52%)
University	8(32%)	7 (28%)
Master degree	7 (28%)	3 (12%)

Table 5.2 Sociodemographic of the ill siblings

Eating Disorder	Diabetes Mellitus

	Mean (SD) / N (%)	Mean (SD) / N (%)
Age	34.7 (8.9)	39.0 (15.3)
Female:		
Male (N)	23:2(92%female)	17:8 (68% female)
Diagnosis		
Anorexia Nervosa	12 (48.0%)	
Bulimia Nervosa	10 (40.0%)	
Binge Eating Disorder	3 (12.0%)	
T 1 Diabetes		19 (76%)
T 2 Diabetes		6 (24%)
Mean Duration of illness (years)		
Anorexia Nervosa	10.75 ± 9.26	
Bulimia Nervosa	15.00 ± 7.04	
Binge Eating Disorder	25.00 ± 11	
T1 Diabetes		13.00 ± 9.64
T2 Diabetes		11.83± 7.11

M, Mean ; SD, Standard Deviation

5.4.2 An examination of experiences of non-affected siblings of people with eating disorders in comparison with those of people with T1DM and T2DM.

5.4.2.1 Preliminary Analysis

The independent samples t-tests confirmed that there were statistically significant differences for the two groups of siblings. Siblings of people with diabetes had higher levels of depression and stress, whereas the siblings of people with eating disorder had higher levels of criticism (CC) and scored higher in accommodating behaviours particularly in the areas of reassurance seeking and control (AESED) than siblings with diabetes. Results from the analysis are presented in **Table 5.3**.

Table 5.3 Measures of sibling distress (DASS) and interpersonal reactions (FQ and AESED) in siblings of people with ED and DM

	Diagnosis	N	Mean	SD	SE	p-value
Depression (DASS)	ED	25	3.16	3.223	.645	.002
	DM	25	7.12	4.944	.989	
Anxiety (DASS)	ED	25	2.75	3.068	.626	.251
	DM	25	3.88	3.615	.738	
Stress (DASS)	ED	25	6.13	3.180	.649	.002
	DM	25	9.32	3.660	.732	
Criticism (FQ)	ED	25	24.16	4.089	.818	.003
	DM	25	20.52	3.991	.798	
(FQ)	ED	25	19.83	5.181	1.058	.325
Emotional	DM	25	18.40	4.899	.980	
Overinvolvement						
Avoidance &	ED	24	16.29	9.101	1.858	.680
Modify	DM	25	17.32	8.225	1.645	
Routine						
Reassurance	ED	25	13.74	5.924	1.359	.000
Seeking	DM	25	5.20	3.606	.721	
Meal Ritual	ED	25	3.52	4.114	.823	.067
	DM	25	1.48	3.549	.710	
Control of Family	ED	22	7.25	5.076	1.036	.009
	DM	25	3.84	3.508	.702	
Turning a Blind Eye	ED	25	3.17	4.141	.864	.329
	DM	25	2.20	2.582	.516	
Overall score	ED	25	41.76	21.724	4.345	.023
AESED	DM	25	30.04	11.777	2.355	

SD, Standard Deviation; SE, Standard Error mean; ED, eating disorder; DM Diabetes Mellitus; DASS-21 Psychological Distress FQ-EOI, Family Questionnaire Emotional Over- involvement; FQ-CC, Family Questionnaire Criticism; AESED, Accommodation and Enabling Scale for Eating Disorders; Independent t -test at $p < 0.05$. Bold values indicate statistically significant differences between ED and DM group of siblings.

5.4.2.2 Regression Analysis

In order to examine how carer's age, gender, own eating or weight problems, contact time, cohabitation with patient as well as type of diagnosis (eating disorder versus diabetes) and age of illness onset, may influence distress, expressed emotions and accommodation, data were analyzed using multiple regression analysis. The dependent variables were psychological distress (depression, anxiety, stress) in the first analysis, expressed emotions (criticism, emotional overinvolvement) in the second analysis, and accommodation (five subscales) in the third analysis. Results revealed significant main effects of sibling -patient aspects to carers' groups.

Psychological Distress

The regression equation examining the predictors of siblings' distress, showed that type of diagnosis is significant. Graph 5.1 and 5.2 shows that sibling' diagnosis has a significant effect on depression and stress subscale. Siblings of people with DM displayed higher levels of depression $F(1,33) = 7.508$, $p = 0.010$ and stress $F(1,32) = 9.156$, $p = 0.005$ than those of people with ED. No other independent variables were significant in psychological distress.

Figure 5.1 This block box shows the impact of diagnosis to siblings' levels of depression

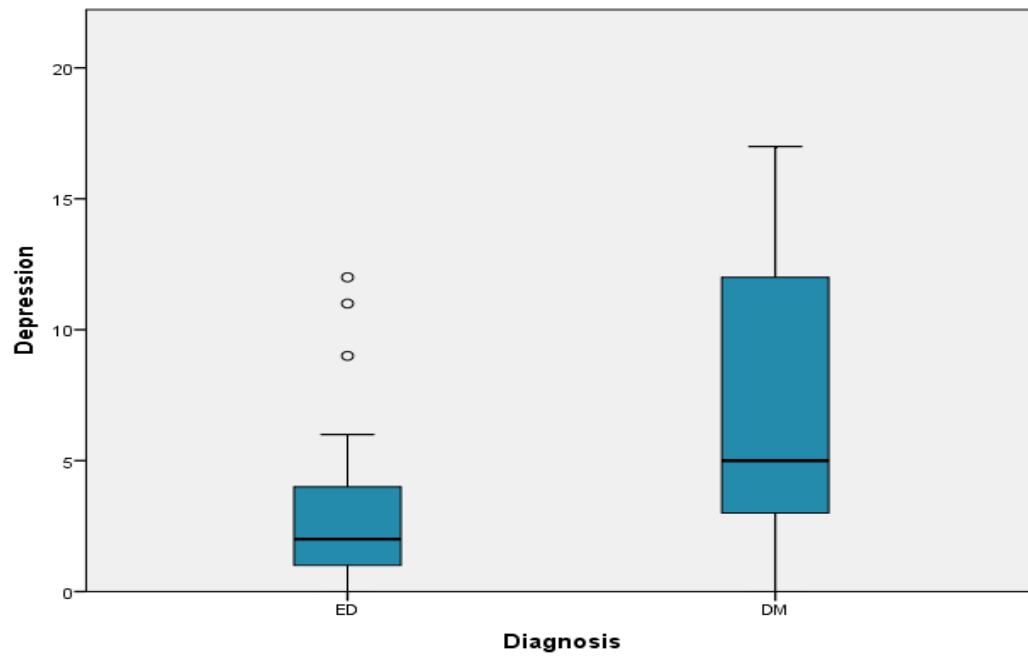
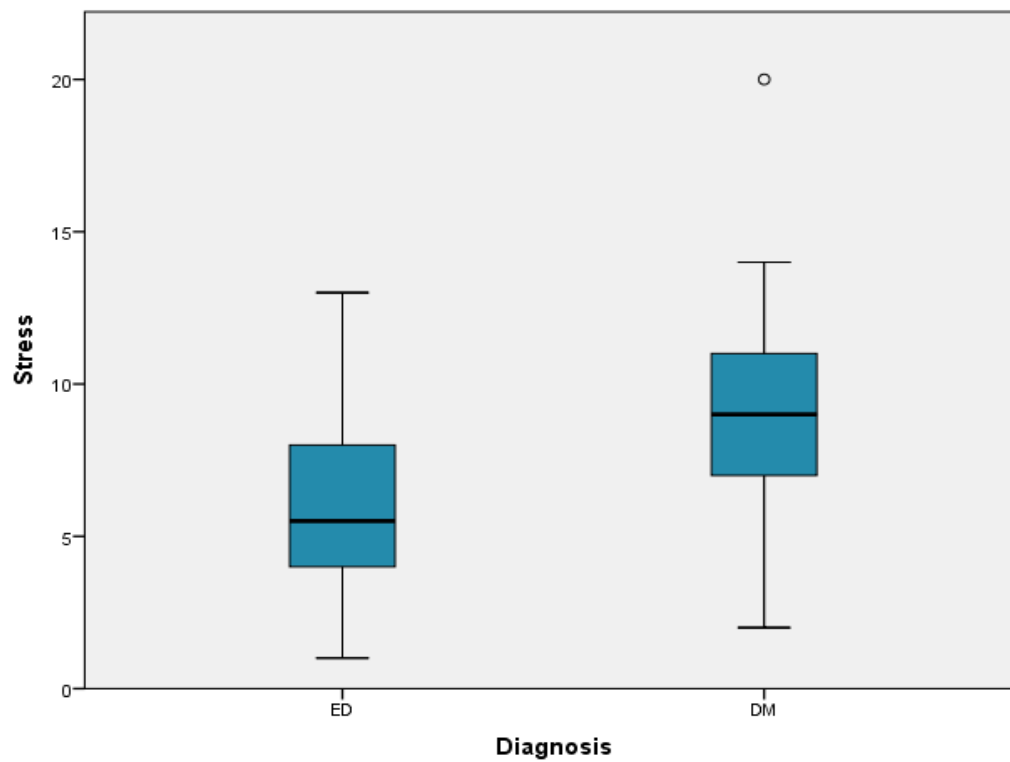


Figure 5.2 The effect of diagnosis on siblings' levels of stress



Responses to Illness

The hypothesis that the siblings of people with eating disorder would have higher interpersonal emotional reactions (expressed emotions) was confirmed in part in that diagnosis is significant predictor of criticism $F(1,33) = 5.386, p = 0.027$ but not overinvolvement ($p = 0.834$) (figure 5.3). Sibling's age had a significant main effect on criticism $F(1,33) = 4.575, p = 0.040$ (see figure 5.4) with older siblings displaying higher levels of criticism. Also, patient's age of illness onset had an impact on criticism $F(1,33) = 5.760, p = 0.022$ (figure 5.5). Siblings of an individual with an earlier age of illness onset, (often associated with a longer duration of illness) expressed more criticism to their affected sibling.

Figure 5.3 This block box presents the impact of diagnosis to the levels of criticism between groups

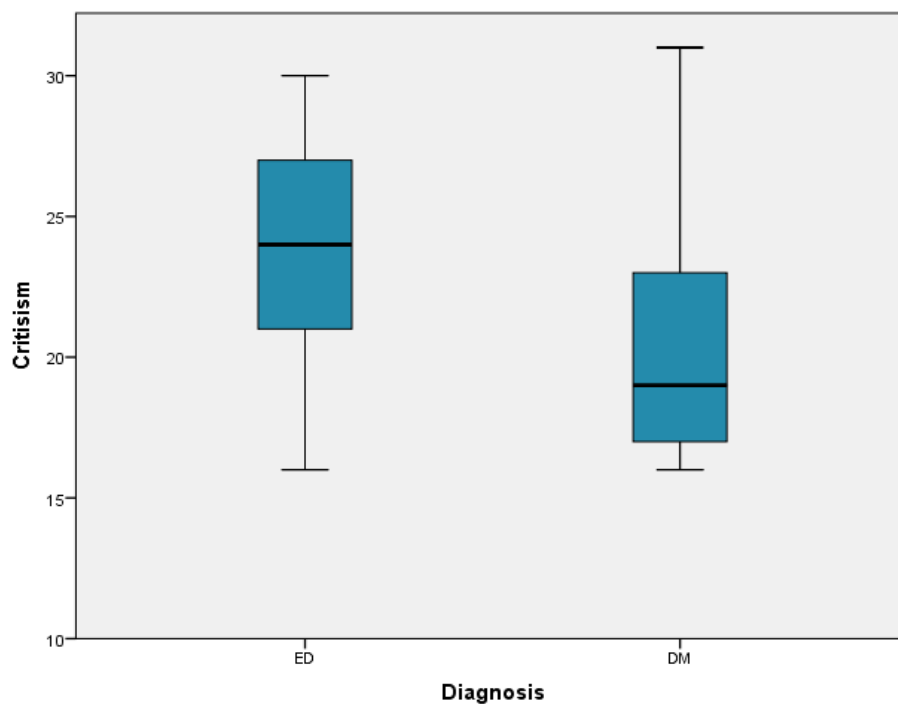


Figure 5.4 The impact of carer's age to the levels of criticism within groups

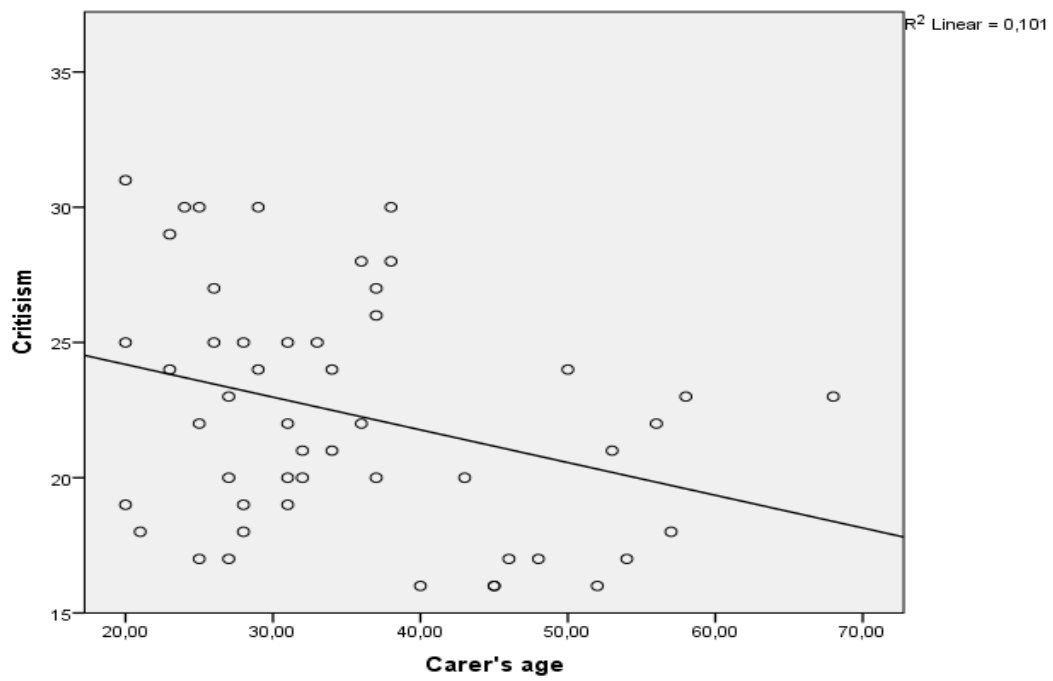
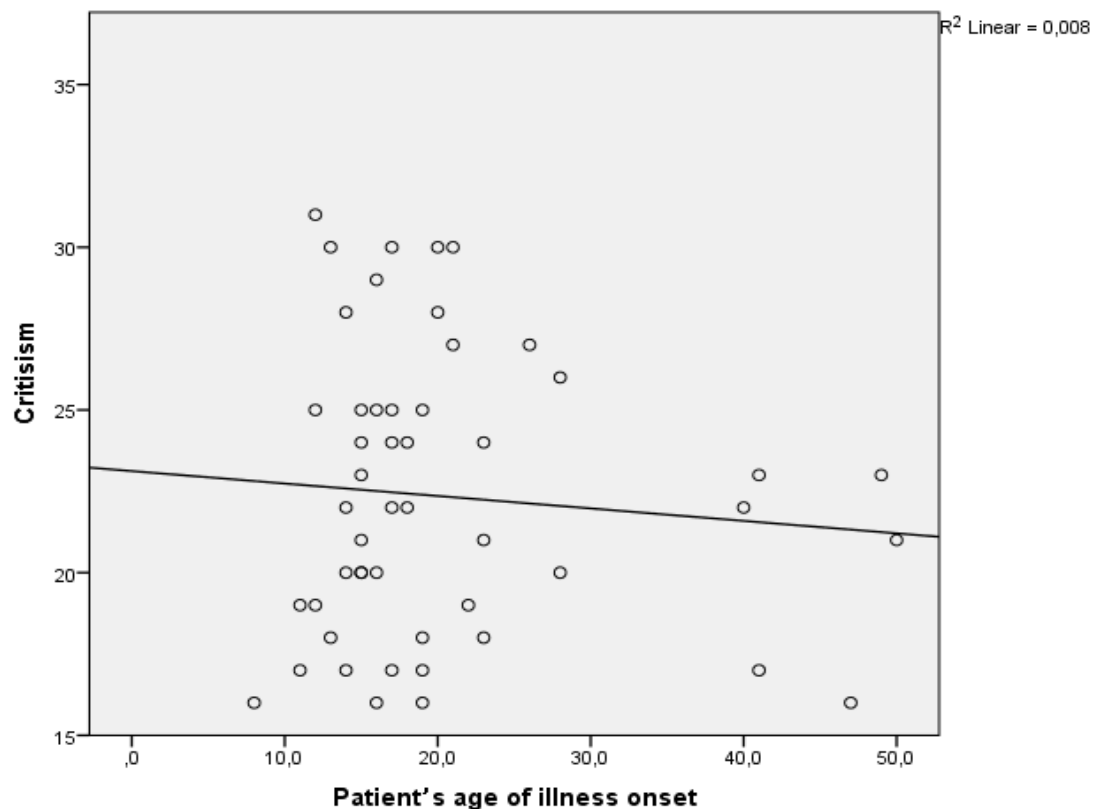


Figure 5.5 The effect of patient's age of illness onset on the levels of criticism within groups



In regard to the accommodation and enabling behaviors, siblings' demographic details and aspects of illness had significant main effects. Gender had a significant impact to the area of avoidance and modify routine $F(1,32) = 11.346$, $p = 0.002$ as female siblings admitted to higher levels of avoidance (modifying routine) than males (figure 5.6). Also, cohabitation had a significant effect on avoidance modifying routine $F(1,32) = 5.513$, $p = 0.025$ (figure 5.7) and overall score of accommodation and enabling scale, $F(1,33) = 6.165$, $p = 0.018$ (figure 5.14).

In the area of reassurance seeking, the type of diagnosis $F(1,28) = 19.789$, $p = 0.000$, patient's age of illness onset $F(1,28) = 7.781$, $p = 0.009$ and sibling's age $F(1,28) = 6.047$, $p = 0.020$ have statistically significant effects (see figures 5.8, 5.9, 5.10). Siblings of people with eating disorders reported higher levels of giving reassurance than those of people with diabetes. Moreover, siblings who are older in age and have an affected sibling with a longer duration of illness, engaged more in reassurance behaviors.

In the domain of control of family, diagnosis $F(1,32) = 10.756$, $p = 0.003$, patient's age of illness onset $F(1,32) = 4.550$, $p = 0.041$ and cohabitation $F(1,32) = 14.370$, $p = 0.001$ are relevant as the siblings of people with an eating disorder, with an earlier age of illness onset and living together reported being more controlled (Figures 5.11, 5.12 and 5.13)

However, meal ritual and turning a blind eye, were not significantly related to any of the covariates.

Figure 5.6 The effect of sibling's gender on the levels of avoidance modifying routine within groups

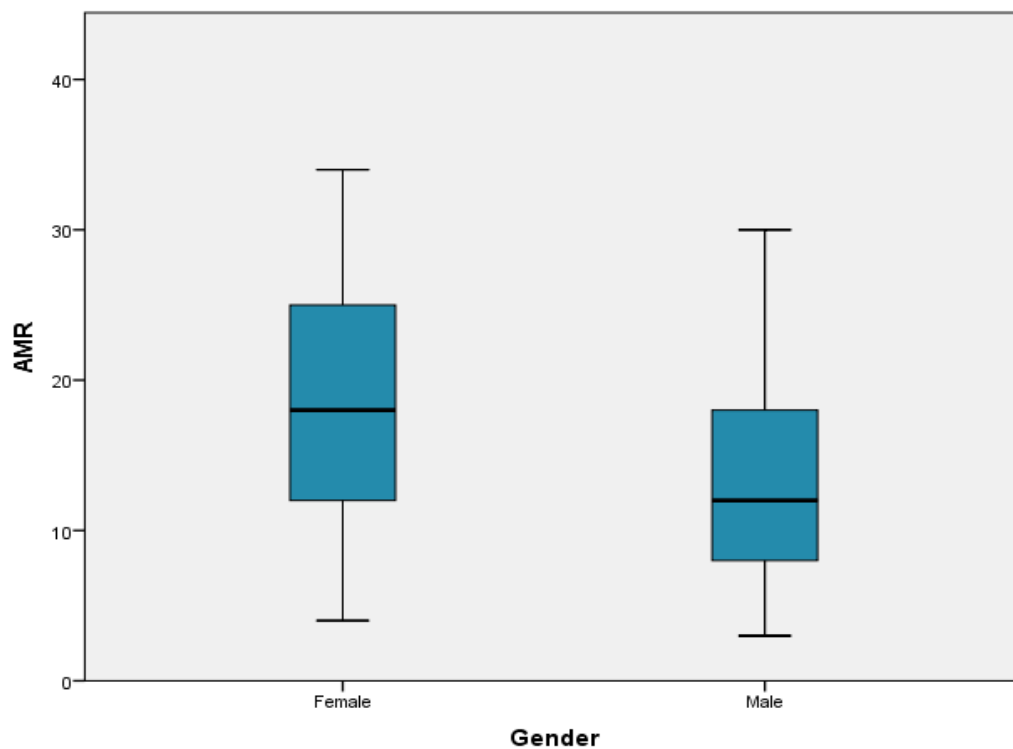


Figure 5.7 The effect of cohabitation on avoidance modifying routine within groups

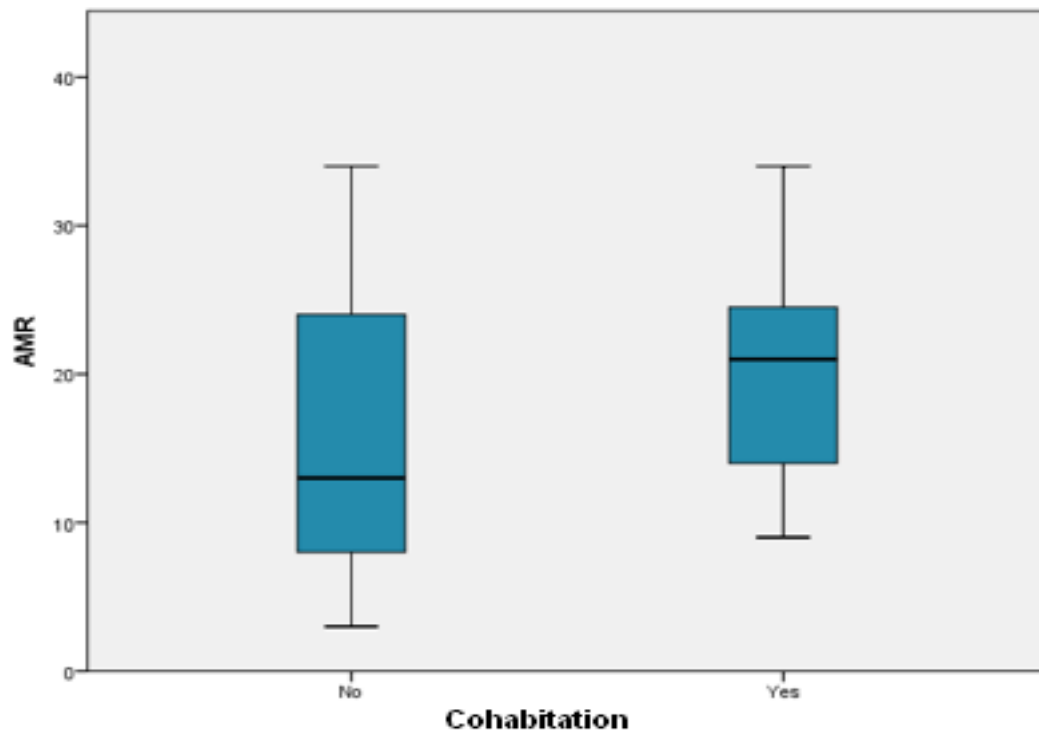


Figure 5.8 The impact of diagnosis to the area of reassurance seeking behaviors

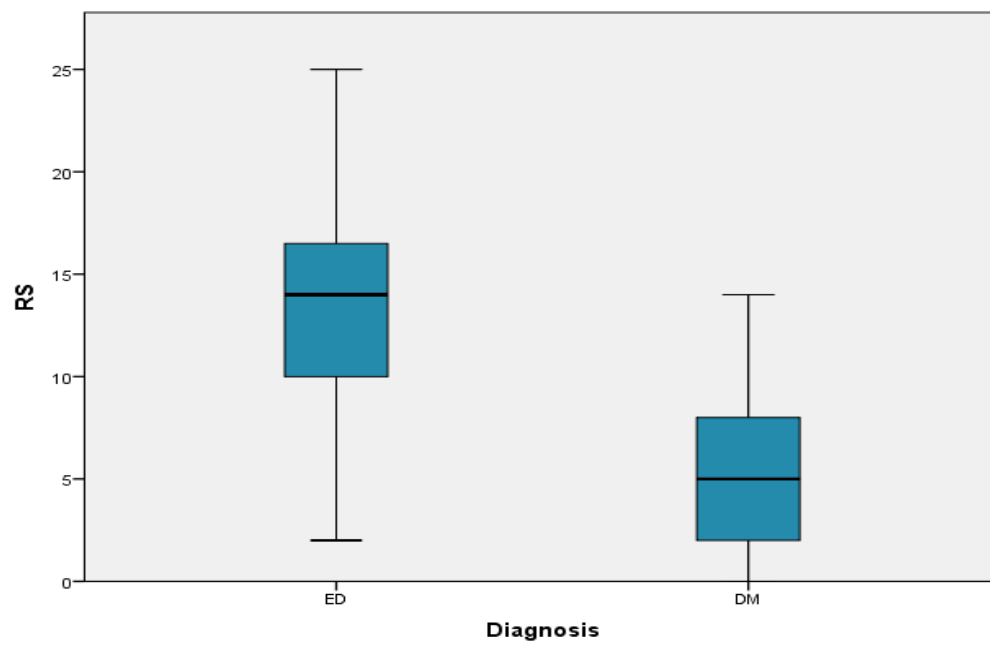
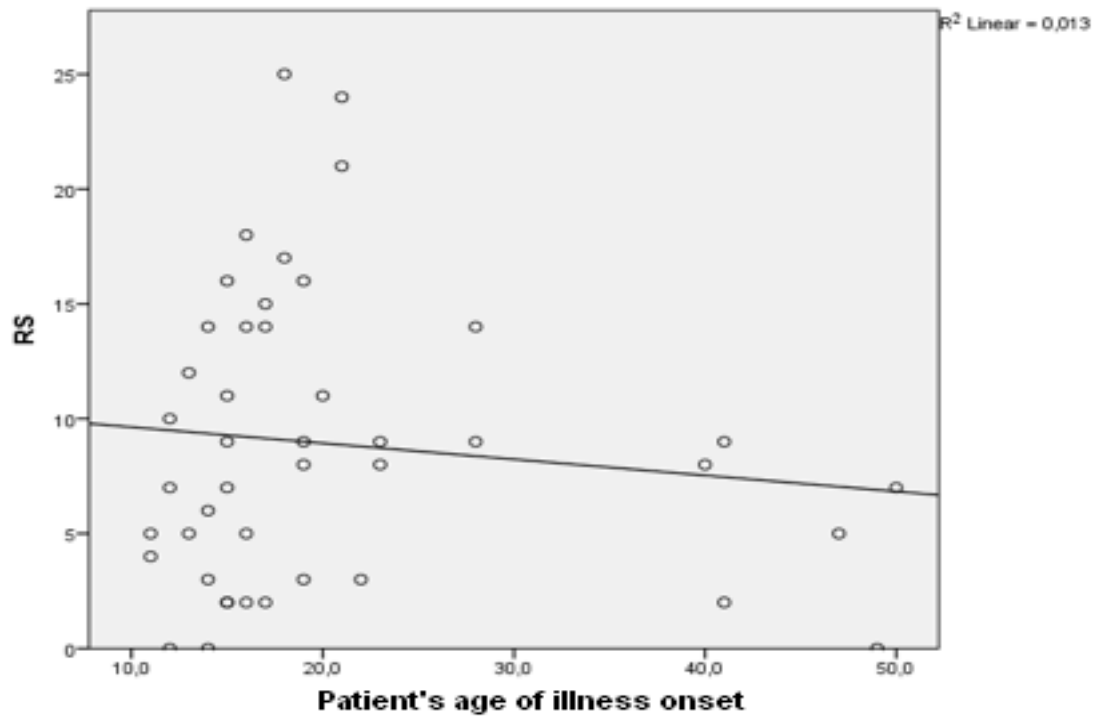
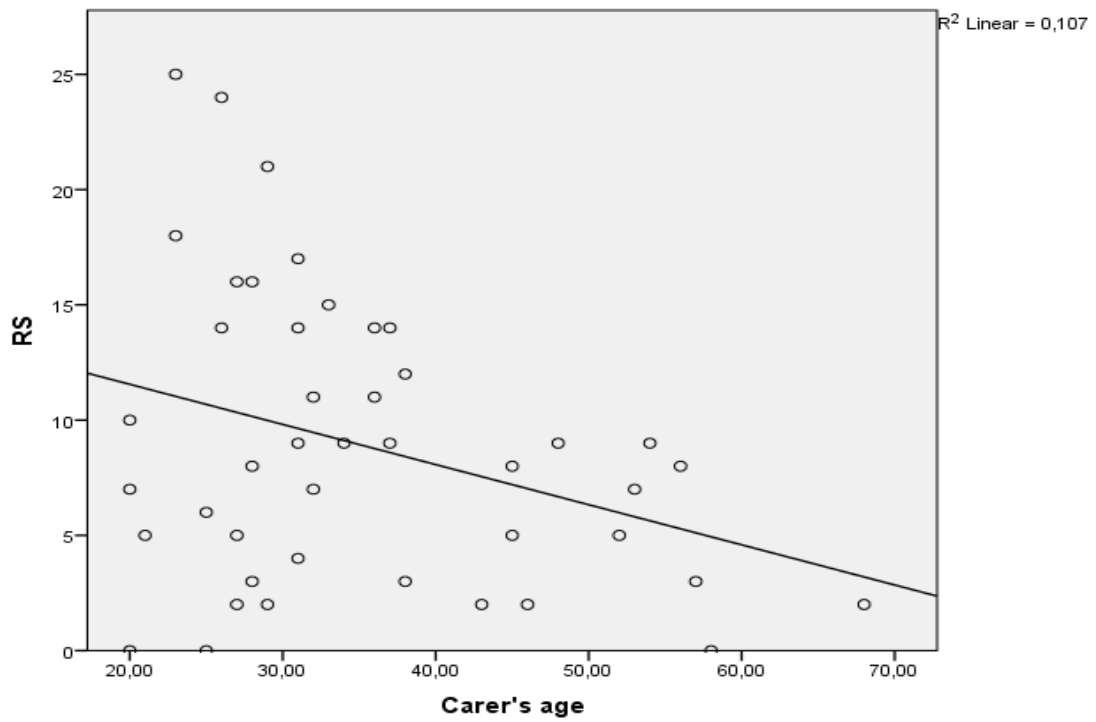


Figure 5.9 The impact of patient's age of illness onset to the area reassurance seeking behaviors within groups



Note: RS, Reassurance Seeking subscale of accommodation scale; R2 Linear, R square linear regression

Figure 5.10 The impact of carer's age to the area of reassurance seeking behaviors



Note: RS, Reassurance Seeking subscale of accommodation scale; R2 Linear, R square linear regression

Figure 5.11 The impact of diagnosis to the area of control of family

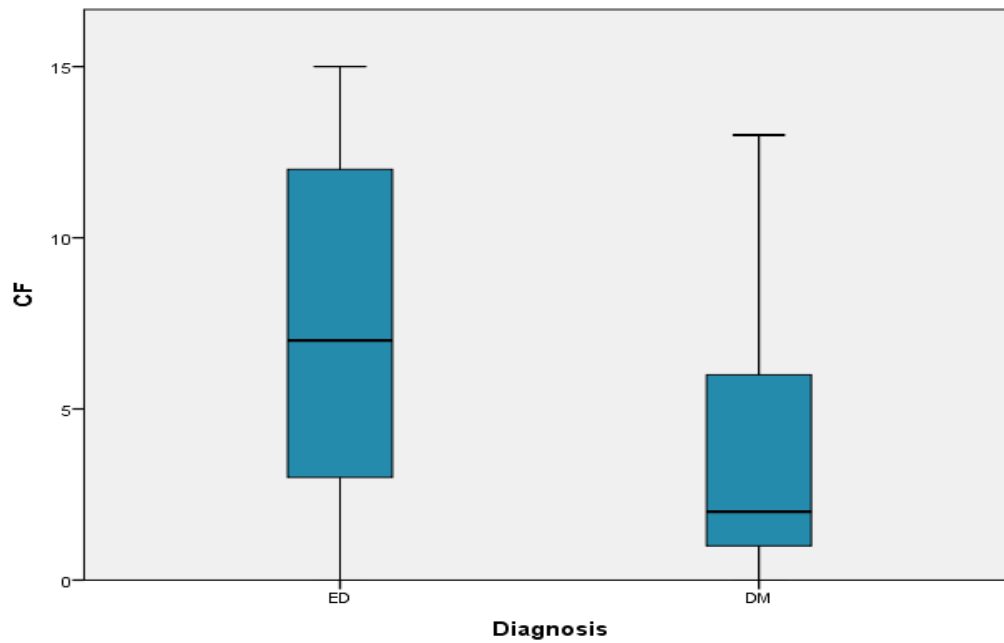
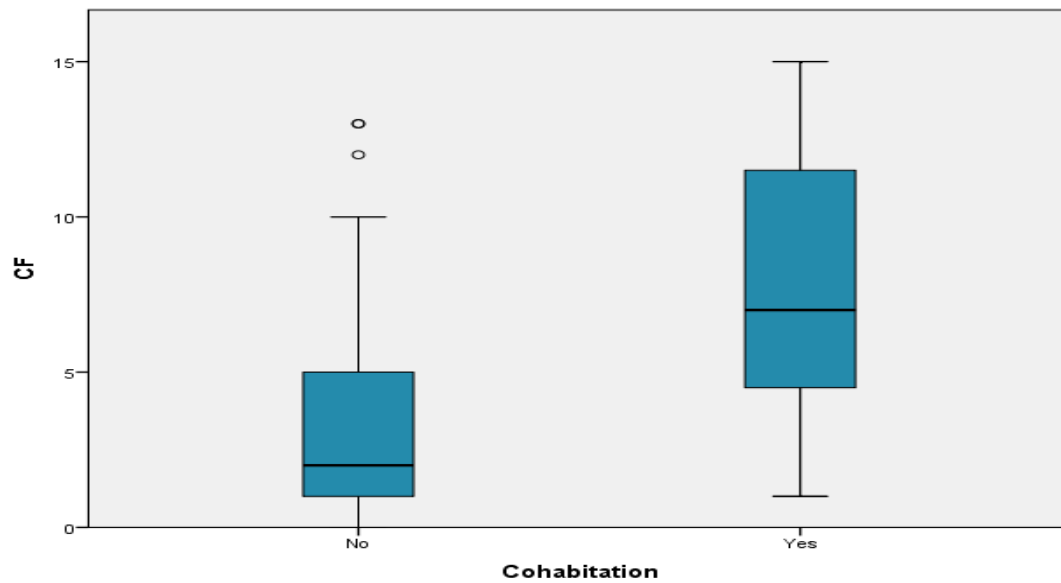
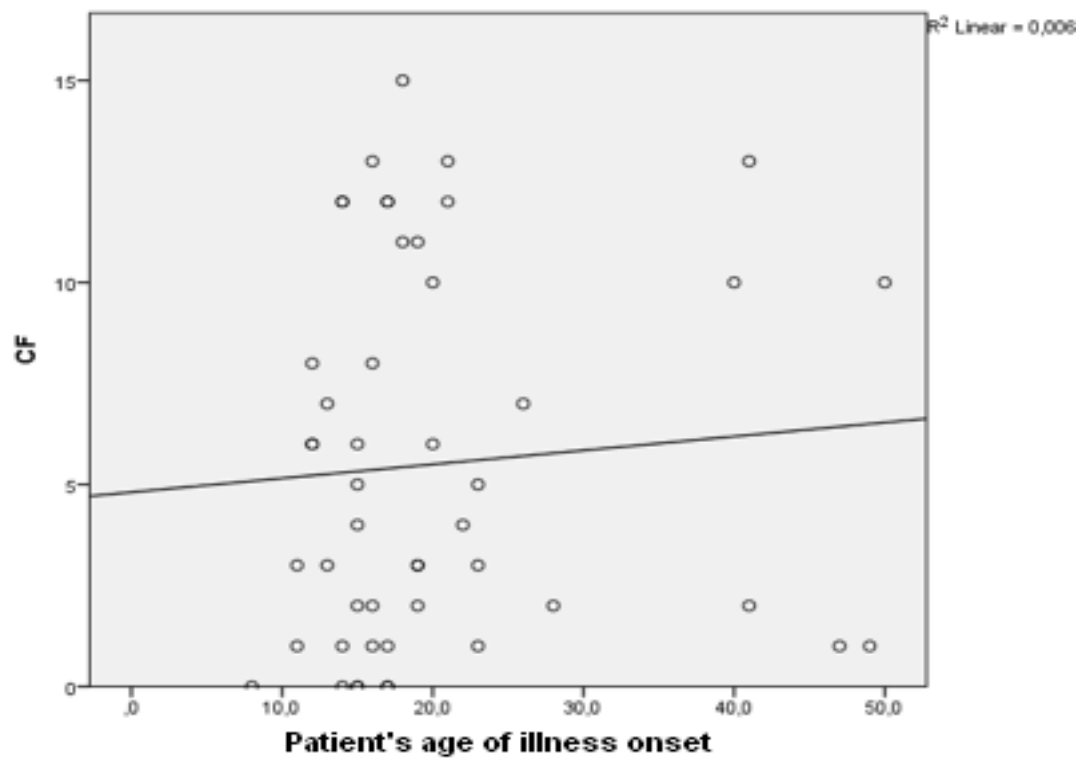


Figure 5.12. The impact of cohabitation to the area of control of family



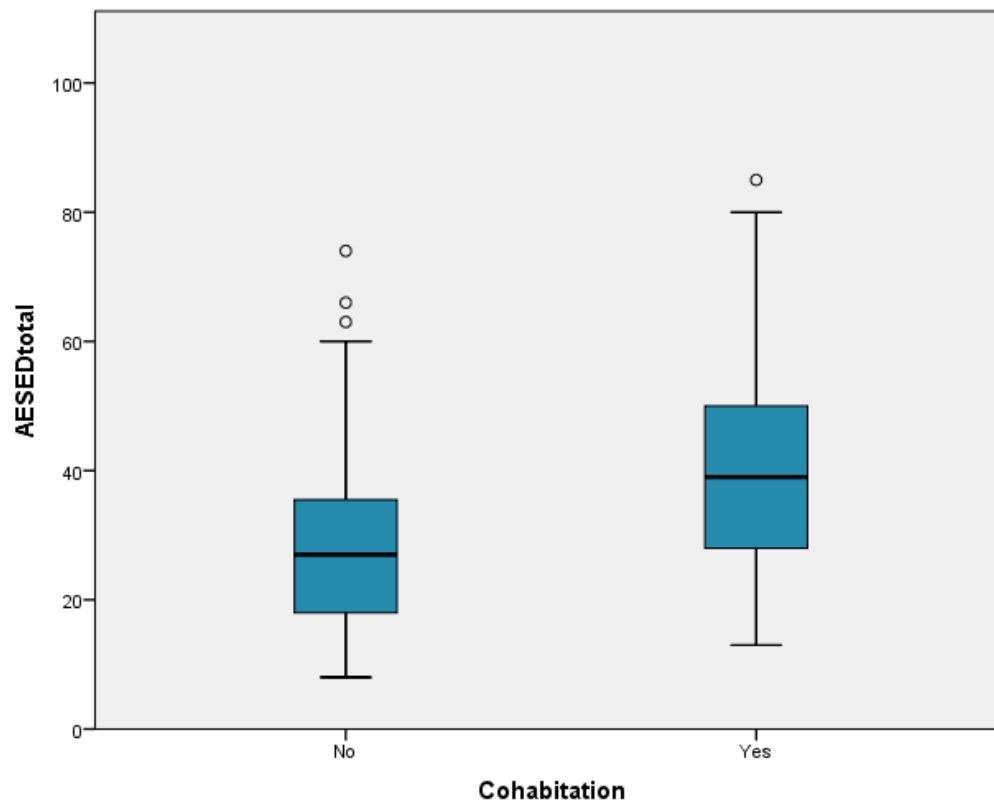
Note: CF, Control of Family subscale of accommodation scale

Figure 5.13 The impact of patient's age of illness onset to the area of control of family



Note: CF, Control of Family; R2 Linear, R square linear regression

Figure 5.14 The impact of cohabitation to the overall score of accommodation and enabling scale



5.4.3 Examination of siblings' distress and relationship style across the form of eating disorder diagnosis

The siblings' average score for each subscale of the Distress Anxiety Stress Scale (DASS-21), the Family questionnaire and accommodation and enabling scale for eating disorders, according to the form of the eating disorder diagnosis are illustrated in **Table 4**. One result revealed that siblings of people with anorexia score higher on criticism($p=0.029$) than those of people with Binge Eating Disorder. No significant differences were found between siblings' factors.

Table 5.4 Measures of sibling distress (DASS) and reactions to illness (FQ and AESED) in siblings of people with ED by diagnosis

		N	Mean	SD	SE	p-value
Depression (DASS-21)	AN	12	4.42	3.605	1.041	.161
	BN	10	2.20	2.658	.841	
	BED	3	1.33	1.528	.882	
Anxiety (DASS-21)	AN	12	3.67	3.143	.907	.219
	BN	9	2.33	3.122	1.041	
	BED	3	.33	.577	.333	
Stress (DASS-21)	AN	12	7.67	3.114	.899	.052
	BN	9	4.56	2.920	.973	
	BED	3	4.67	.577	.333	
(FQ) Criticism	AN	12	26.25	3.137	.906	.029
	BN	10	22.70	4.084	1.291	
	BED	3	20.67	4.041	2.333	
(FQ) Emotional Overinvolvement	AN	12	20.83	5.167	1.492	.648
	BN	9	19.00	5.745	1.915	
	BED	3	18.33	4.163	2.404	
Avoidance& Modify Routine (AESED)	AN	12	20.17	8.548	2.467	.067
	BN	9	11.00	6.928	2.309	
	BED	3	16.67	11.930	6.888	
Reassurance Seeking (AESED)	AN	9	16.33	6.305	2.102	.192
	BN	7	11.71	5.469	2.067	
	BED	3	10.67	2.887	1.667	
(AESED) Meal Ritual	AN	12	5.33	5.105	1.474	.077
	BN	10	1.40	1.897	.600	
	BED	3	3.33	1.155	.667	
(AESED) Control of Family	AN	11	9.82	4.355	1.313	.059
	BN	10	4.70	4.877	1.542	
	BED	3	6.33	4.933	2.848	
(AESED) Turning a Blind Eye	AN	12	2.92	4.889	1.411	.669
	BN	8	4.13	3.758	1.329	
	BED	3	1.67	.577	.333	
Overall AESED score	AN	12	51.17	22.631	6.533	.097
	BN	10	31.40	17.258	5.457	

BED	3	38.67	20.599	11.893

Note: Univariate analysis; AN, Anorexia Nervosa; BN, Bulimia Nervosa; BED, Binge Eating Disorder; M, mean *SD*, standard deviation; DASS-21, Depression Anxiety Stress Scale, possible score ranges for each subscale of 0-42; FQ, Family Questionnaire, possible score range of 10-40 for each subscale; AESED, Accommodation and Enabling Scale for Eating Disorders, possible score range of 0-132. **Bold values indicate statistically significant differences between groups of siblings. Correlation is significant at the 0.05 level (two-tailed)**

5.4.3.1 Associations between siblings' distress and reactions to illness

Pearson's correlations were applied to identify associations between psychological distress, expressed emotions and accommodating behaviors with confounder variable the type of eating disorder. **Table 5. 5** presents the associations between siblings' distress and reactions to illness. Results show that high levels of anxiety in siblings of people with eating disorder is associated with higher scores in the area of reassurance seeking ($p=0.050$).

Distress was associated with accommodating behaviours (AESED). **Figure 5.15** displays the negative correlation between DASS and AESED on siblings of people with anorexia nervosa; the lower levels of depression are correlated with higher scores of control family subscale ($p=0.009$); whereas in siblings of people with bulimia, **figure 5.16** shows a positive correlation between DASS and AESED that higher levels of anxiety are correlated with higher scores of avoidance modification routine ($p=0.012$). No other significant correlations were found between DASS and FQ in terms of diagnosis in ED group. However, Pearson's correlations were not applied to identify associations between BED diagnosis and psychological distress, expressed emotions and accommodating behaviors, due to small sample ($N=3$) of siblings.

Table 5.5 Correlations between psychological distress and reactions to illness

Eating Disorders		Depression	Anxiety	Stress
Criticism (FQ)	Pearson Correlation	.311	.325	.275
	Sig. (2-tailed)	.130	.121	.193
	N	25	24	24
Emotional Overinvolvement (FQ)	Pearson Correlation	.074	.079	.265
	Sig. (2-tailed)	.732	.713	.210
	N	25	25	25
Avoidance & Modify Routine (AESED)	Pearson Correlation	.207	.358	.220
	Sig. (2-tailed)	.331	.08	.303
	N	25	25	25
Reassurance Seeking (AESED)	Pearson Correlation	.009	.456	.067
	Sig. (2-tailed)	.971	.050	.786
	N	25	25	25
Meal Routine (AESED)	Pearson Correlation	.229	.285	.197
	Sig. (2-tailed)	.271	.177	.356
	N	25	25	25
Control of Family (AESED)	Pearson Correlation	-.305	-.077	-.042
	Sig. (2-tailed)	.147	.727	.850
	N	25	25	25
Turning a Blind Eye (AESED)	Pearson Correlation	.260	.295	.362
	Sig. (2-tailed)	.230	.183	.098
	N	25	25	25
Overall score of AESED (AESED)	Pearson Correlation	.082	.309	.194
	Sig. (2-tailed)	.696	.142	.364
	N	25	25	25

Figure 5.15 Association of anxiety and reassurance seeking behaviors in AN sibling

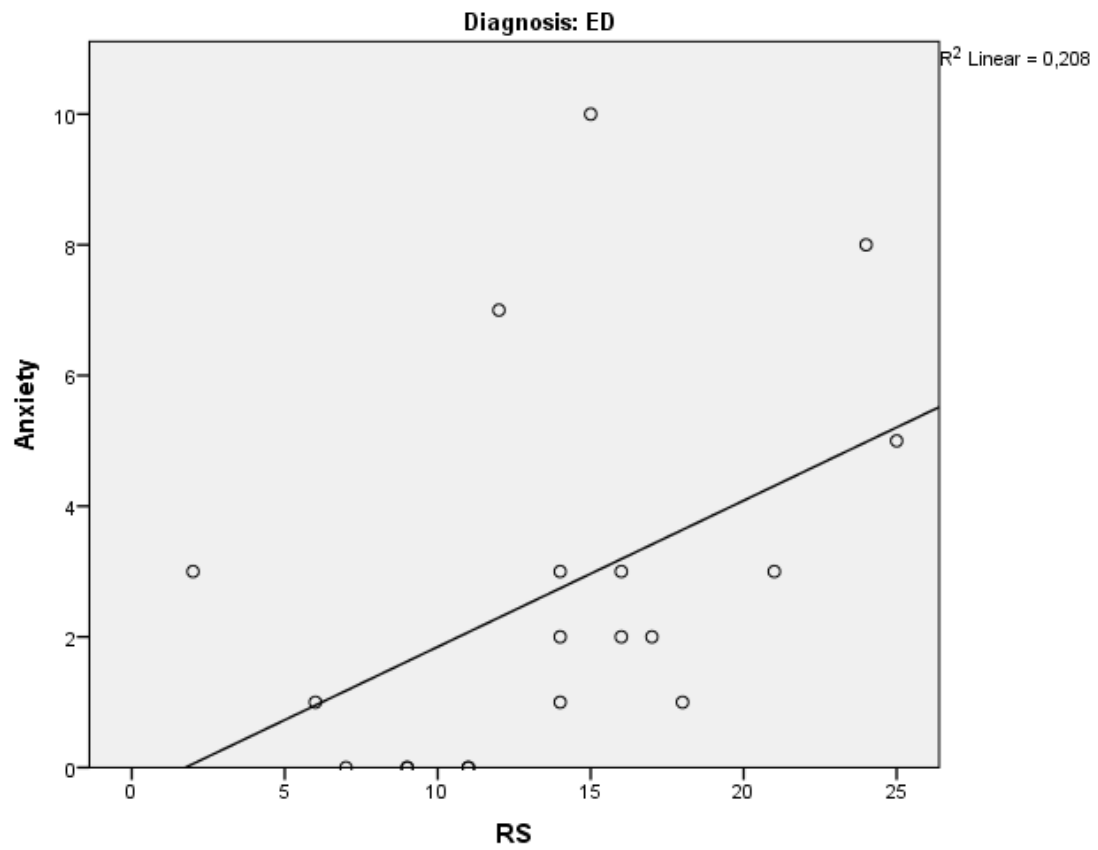
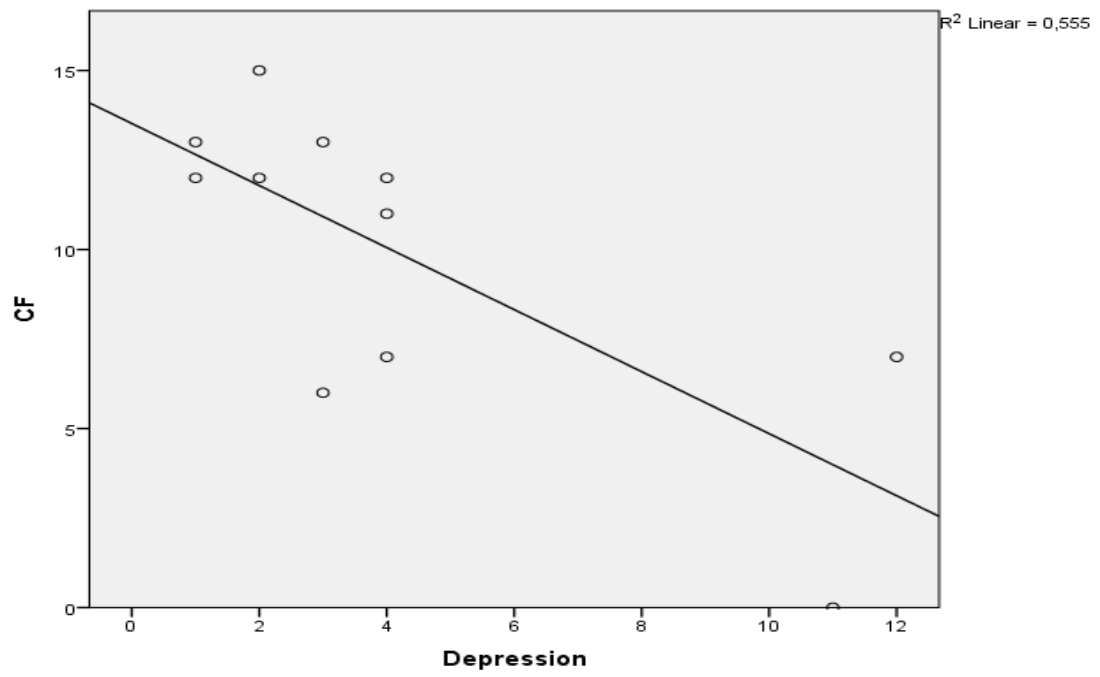


Figure 5.16 Association of depression and control of family behaviors in siblings of BN people



Note: CF, Control of Family; R2 Linear, R Square Linear Regression

5.4.3.2 Gender differences in siblings functioning as a reaction to eating disorder

The results of independent sample t-tests revealed significant differences among female and male siblings in distress and accommodation subscales of measures. **Table 5.6** shows that female siblings display higher levels of anxiety ($p=0.013$) in the area of avoidance modification routines ($p=0.021$) and reassurance seeking ($p=0.031$) than male siblings.

Table 5.6 Mean and standard deviations of psychological variables for the total sample and comparisons between sisters and brothers

Gender		N	Mean	SD	SE	P
Depression (DASS)	Female	16	3.63	3.739	.935	0.347
	Male	9	2.33	1.936	.645	
Anxiety (DASS)	Female	16	3.63	3.324	.831	0.013
	Male	9	1.00	1.414	.500	
Stress (DASS)	Female	16	6.75	3.296	.824	0.179
	Male	9	4.88	2.696	.953	
Criticism (FQ)	Female	16	24.25	4.420	1.105	0.887
	Male	9	24.00	3.674	1.225	
Emotional Overinvolvement (FQ)	Female	16	20.06	4.626	1.156	0.767
	Male	9	19.38	6.479	2.291	
Avoidance Modify&Routine (AESED)	Female	16	19.25	8.161	2.040	0.021
	Male	9	10.38	8.331	2.946	
Reassurance Seeking (AESED)	Female	16	15.92	5.632	1.626	0.031
	Male	9	10.00	4.619	1.746	
Meal Ritual (AESED)	Female	16	4.25	4.058	1.014	0.245
	Male	9	2.22	4.116	1.372	
Control of Family (AESED)	Female	16	8.38	5.252	1.313	0.127
	Male	9	5.00	4.106	1.452	
Turning a Blind Eye (AESED)	Female	16	3.00	3.525	.910	0.790
	Male	9	3.50	5.372	1.899	
Overall AESED	Female	16	48.00	18.787	4.697	0.053
	Male	9	30.67	23.189	7.730	

Note: Independent samples t- tests; M mean, SD standard deviation, SE standard error mean; DASS-21, Depression Anxiety Stress Scale, possible score ranges for each subscale of 0-42; FQ, Family Questionnaire, possible score range of 10-40 for each subscale; AESED, Accommodation and Enabling Scale for Eating Disorders, possible score range of 0-132 Bold values indicate statistically significant differences between groups of siblings. Correlation is significant at the 0.05 level (two-tailed)

5.4.3.3 Sibling- patient details' effect on psychological distress and relationship style

One way-ANOVA analysis was conducted to examine the influence of six independent variables (gender, sibling's contact time with patient, educational level, age, diagnosis and patient's age of illness onset) on each subscale of the three measurements (DASS-21, Family Questionnaire and Accommodation and Enabling Scale). Siblings' educational level included three levels (Senior high school, Bachelor degree, Master or Doctorate), contact time consisted of five levels (<7h, <14h, <21h, >21h, other), sibling's age, patient's diagnosis consisted of three types (Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder), the age of illness onset (ranged from 10-30 years old).

Results indicated that diagnosis has a significant effect to the levels of criticism, siblings of people with AN showed higher criticism ($p=0.029$) than those of people with BED ($p=0.029$) regardless of sibling's gender. Moreover, sibling's contact time with eating disorder patient had an impact to the area of meal ritual subscale of accommodation and Enabling Scale; siblings with higher contact time (>21 hours) with patients show higher accommodation to the area of meal ritual ($p=0.031$). The Pearson's correlation coefficient indicated that patient's illness duration was marginally positively correlated to criticism ($p=0.050$), siblings showed higher levels of criticism towards patients with longer illness duration. The results did not indicate any significant effect of gender to the above-mentioned variables. No other significant differences were found based on diagnosis and distress, emotional overinvolvement and accommodation.

5.4.3.4 Regression analyses

Furthermore, general linear models were applied to adjust for confounders (sibling's age, gender, contact time, educational level, type of diagnosis and age of illness onset) to the noticed differences to siblings for each dimension of the research instruments used.

In regard to siblings' psychological distress, our results revealed that diagnosis $F(2,13) = 4.447$, $p = 0.034$ and carer's age $F(1,13) = 53.266$, $p = 0.022$ has an impact to the depression subscale; siblings of people with anorexia and siblings older in age show higher levels of depression. Moreover, the effect of gender $F(1,12) = 7.756$, $p = 0.017$

had a significant effect to the anxiety subscale, female siblings displayed higher levels of anxiety than male ones (figure 4). Finally, diagnosis $F(2,12) = 9.754$, $p = 0.011$ and carer's age $F(2,12) = 9.994$, $p = 0.008$ had a significant impact on stress subscale, siblings of people with anorexia and older in age siblings showed higher levels of stress. In regard to expressed emotions, none of the aforementioned variables had a main effect.

Gender had a large impact on accommodation and enabling behaviors (figure 5 & 6), female siblings accommodated by avoidance /modifying routine $F(1,12) = 8.449$, $p = 0.013$ and were also more involved in giving reassurance $F(1,7) = 6.215$, $p = 0.041$ than males. Moreover, carer's age had a great impact on accommodation, older in age siblings accommodated by avoidance/modifying routine $F(1,12) = 5.581$, $p = 0.036$, endorsed to Control of family $F(1,12) = 12.688$, $p = 0.004$ as well as they scored higher on the overall score of accommodation and enabling scale for eating disorders, $F(1,13) = 7.4398$, $p = 0.017$. No significant differences were found on the area of meal ritual and turning a blind eye in carer -patient variables.

Figure 5.17 Gender Effect on the levels of anxiety

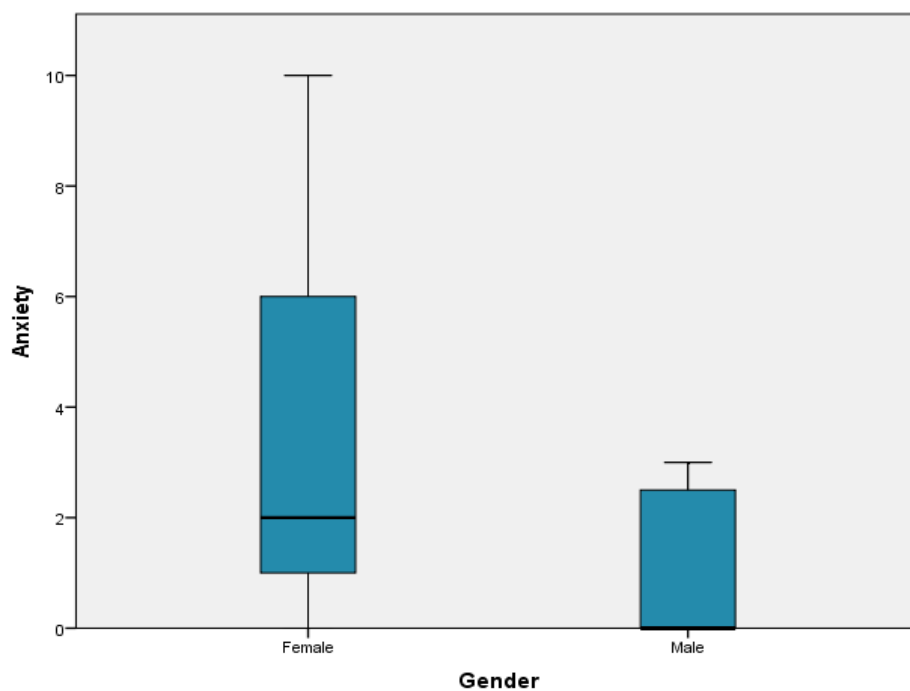


Figure 5. 18 Gender Effect on the area of Avoidance Modifying Routine

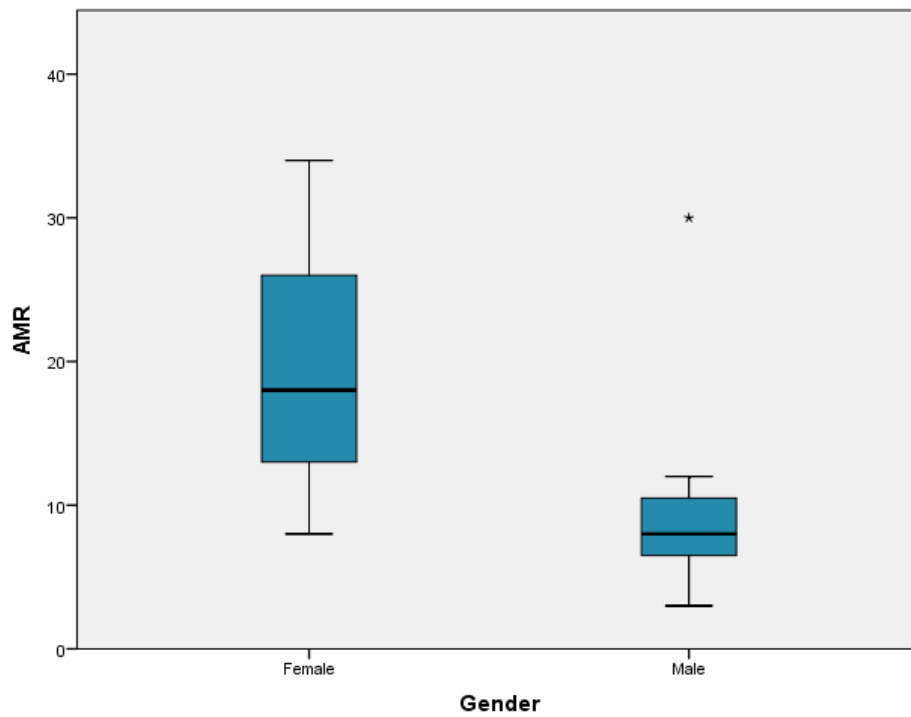
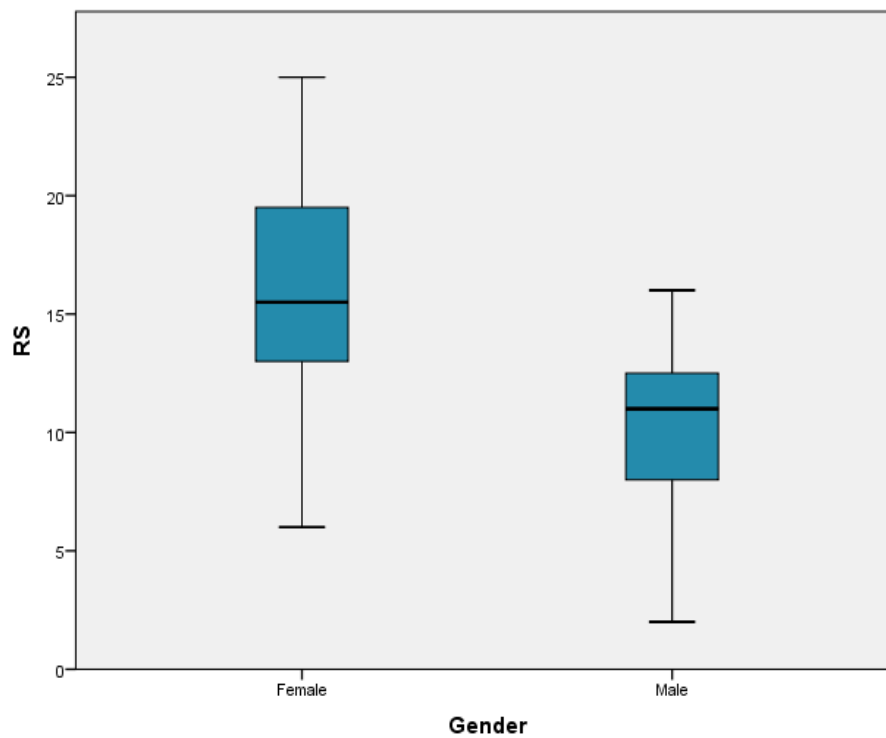


Figure 5. 19 Gender Effect on the area of Reassurance Seeking



Note: RS, Reassurance Seeking subscale of accommodation scale

5.5 Discussion

The first aim of this study was to (i) identify whether siblings' distress and emotional, behavioral responses to illness differ between those of adults with ED, and those of adults with DM, and (ii) to explore whether carer-patient factor predict siblings' factors.

5.5.1 Siblings' Functioning: ED versus DM group

The first hypothesis that siblings of people with ED would report higher levels of distress and higher levels of maladaptive interpersonal behaviours such as criticism, emotional overinvolvement and accommodation, was partially supported.

There were surprising similarities as well as anticipated differences between siblings of people with ED and those with DM. Our hypothesis that the siblings of people with ED would have higher levels of depression and stress was not confirmed in that it was the siblings of people with DM with significantly higher distress. Moreover, no difference was found between ED and DM siblings on levels of anxiety and emotional overinvolvement. As expected, levels of criticism and accommodation was higher in ED group that showed higher levels of criticism and accommodation to patient's illness behaviors than DM.

These findings contrast with studies suggesting that families of people with mental illness show greater emotional distress than families with physical illness due to stigma (Anderson & Bury 1988; Sim et al., 2009). It is also possible that there is a degree of stigma or familial criticism also associated with Type 2 diabetes which is thought to result from lifestyle factors and family's perception about the causation of disease. For instance, people may identify type 2 diabetes as a more self-inflicted disease than type 1. Thus, illness attributions associated with factors controllable by the patient, rather than external ones, may lead to stigma and distress (Wendel et al., 2000). In the case of ED, relatives may also hold causal attributions linked to external factors such as family problems (Whitney et al., 2007).

The role of sibling accommodation to the illness has, to our knowledge, never been previously explored in these forms of illness. ED siblings engaged in more

accommodation such as joining in with reassuring seeking and allowing control over the family. This finding is in accordance with those studies reporting familial (mainly parental) accommodation (Stefanini et al., 2018; Sepulveda, Kyriacou & Treasure, 2009). Most of the domains of accommodation related to food, body and shape issues, generally symptoms which are more dominant in people with eating disorders rather than diabetes.

The siblings of people with diabetes also showed accommodation to the illness. This is a natural response to the sick role of others and many of these behaviours aim to support their affected sibling.

5.7.1.1 Carer-patient demographic factors as predictors on siblings' functioning

The third hypothesis, that sibling's age, gender, eating own problems, cohabitation, contact time and patient's age of illness onset would predict sibling's distress, expressed emotions and accommodation beyond groups, was partly confirmed.

The most influential factors on siblings' relationship style were the age of siblings, cohabitation with patient and patient's age of onset. In terms of psychological distress, none of the above variables had an impact. In regard to criticism we found older siblings and a longer duration of illness expressing higher levels. In terms of accommodation, female siblings, living with the patient were most involved. A possible hypothesis behind the gender difference in these emotionally driven behaviours is the fact that sisters tend to use less effective coping styles, such as emotion-focused coping rather than problem-solving strategies (Dimitropoulos et al., 2013). Older siblings with an affected sibling with a longer duration of illness, are more likely to part in reassuring behaviors and allow the illness to control family behaviors. As it might be expected, the siblings who live together with patient, endorse more accommodating and enabling behaviours. One possible explanation of this finding is that older siblings may adopt more of a caregiver role during the course of the illness (Areemit et al., 2010; Wennick & Huus, 2012).

Factors such as living with patient and illness duration have been found to be associated with high levels of familial accommodation in previous studies with other clinical

samples such as anxiety, obsessive compulsive disorder and eating disorders (Storch et al., 2007; Lebowitz, 2017; Anastasiadou et al., 2014).

5.5.2 Eating disorder's impact on non-affected siblings

The second aim of this study was to examine whether interpersonal factors described by the cognitive interpersonal maintenance model, could be manifested in siblings of people with eating disorders (BN, AN, BED), (i) explore these sibling experience from gender perspective, (ii) examine if other sibling-patient factors predict psychological distress, expressed emotions and accommodation and enabling behaviors. Although this sample was limited in size and potentially not representative, the findings revealed similar relationships styles in response to the illness in both parents and siblings (Anastasiadou et al., 2014; Treasure et al., 2007; Dimitropoulos et al., 2008; Graap et al., 2008).

5.5.2.1 Eating Disorder 's impact on siblings

Siblings displayed distress and anomalies in their relationships to their ill sibling, marked by high expressed emotions and accommodating behaviours. In particular adult siblings experienced low levels of distress and responded to illness with high levels of criticism and accommodation. However, the levels of psychological distress among siblings of the present study were lower than those reported in previous studies in parents (Anastasiadou et al., 2014; Zabala et al., 2009). Moreover, comparable levels of criticism and accommodation were found to previous studies among ED carers' samples (Goddard et al., 2011; Gísladóttir & Svavarsdóttir, 2011; Nilsson, 2014; Merwin, Zucker, & Timko, 2013; Anastasiadou et al., 2016; Stefanini et al., 2018).

5.5.2.2 Associations between siblings' distress and reactions to illness in terms of diagnosis

Our hypothesis that siblings' high levels of distress would be associated with expressed emotions and accommodation, was only partially substantiated. Our main finding revealed that high levels of anxiety in siblings of people with eating disorder was associated with higher scores in the area of reassurance seeking. Surprisingly, our results showed a differentiation in terms of ED diagnosis; when the cared person suffers

from anorexia nervosa, siblings score significantly higher in the areas of control of family when their levels of depression are lower. This contrasts with data suggesting that family accommodation might increase caregiver (mainly parental) burden and distress (Treasure & Schmidt, 2013; Whitney, Haigh, Weinman, & Treasure, 2007; Whitney, Currin, Murray, & Treasure, 2012). This difference may be a result of the different intra family roles or a result of the long duration of illness in our sample. Siblings of people with bulimia experience higher levels of anxiety when they modify their personal routine (work schedule, leisure activities, and family relations) to fit around the patients' symptoms. This finding fits with the evidence that carers of patients suffering from Bulimia Nervosa rate themselves as scoring higher in the “avoidance and modifying routine” (Stefanini et al., 2018).

5.5.2.3_Gender differences on siblings functioning

Our hypothesis that sisters would display higher levels of distress and accommodation, was confirmed. Sisters appeared to be more affected and demonstrated higher levels of anxiety, and engaged more in avoidance modification routine and reassurance seeking than brothers. These results were consistent with those of ED studies in which female caregivers (mothers) exhibited more caregiving burden compared with male ones (Kyriacou et al., 2008a). Also, sisters were more involved in a caregiving role and hence drawn into unhelpful enabling and accommodating behaviors. Brothers showed lower accommodation, possibly due to their detached attitude to illness and family issues (Jungbauer, Heibach & Urban 2015).

5.5.2.4 The effect of sibling-patient factors on distress and relationship style

Other carer-patient characteristics had a significant impact in the aspects of sibling functioning. Levels of depression and stress were higher in siblings of people with AN than those of people with BED, in accordance with the many studies which have examined carers (mainly parents) of patients suffering from anorexia nervosa, most of which observed high levels of psychological distress and burden (MacDonald et al., 2014; Goddard et al., 2011; Kyriacou et al., 2008a). The impact of sibling's age may be confounded by a longer duration of illness which in turn leads to higher levels of psychological distress. This finding implies that with increasing age the sibling moves from secondary to primary carer.

Siblings' emotional responses particularly criticism is influenced by type of diagnosis and patient's illness duration. Siblings of people with anorexia respond with more criticism than those of people with binge eating disorder. This finding is inconsistent with a previous review of Zabala et al. (2009) which reported that AN carers (mainly parents) present higher levels of overinvolvement whereas bulimia carers respond with criticism. One possible explanation of this different perspective is that a sibling with anorexia nervosa can monopolize family life, limiting parental attention to the other siblings who may experience anger towards their sibling for this relative neglect (Garley & Johnson, 1994).

Gender and sibling's age have a large impact on accommodation to ED symptoms. The sisters accommodated more by avoidance modifying routine and were also more involved in reassurance giving than brothers. This finding resonates with previous studies which have found that sisters of people with eating disorders use avoidance, in an effort to avoid conflict and tension within family and alleviate patient's distress (Garley & Johnson, 1994). Also, older siblings managed ED symptoms by avoidance and felt more entrapped within the eating disorder rules over cooking practices and choices over what and where family members are eating or doing. This agrees with the similarly significant tensions reported during mealtime by siblings (Dimitropoulos, 2012) which in turn led them to buffer these ED behaviors in order to preserve the peace within family (Treasure et al., 2007). Additionally, older siblings may have a more pronounced parenting role with high expectations and demands within the family, including incompatible allegiances to their parents and siblings which in turn may exaggerate their levels of accommodation (Garley & Johnson, 1994; Areemit et al., 2010). Siblings that spend more time (>21 hours per week) with the ED patient accommodate more to meal ritual which includes how kitchen, house and crockery is cleaned, how food is stored or what time the food is served. This in line with a similar relationship between the time carers spent with caregiving and their levels of accommodation in parental carers (Sepulveda et al., 2009).

5.6 Limitations

The present study had several limitations. The first was the small sample size of 50 participants, which made it difficult to perform complex statistical analyses and therefore limited the significance of the findings. The second was the current cross-

sectional design that does not allow for distinguishing problems as antecedents or responses to the sibling's illness, rather it only offered a description of siblings functioning after a protracted illness in many cases. These results did not allow us to differentiate between siblings whose apparent psychological distress and symptoms were due to coping with the ongoing presence of EDs, from those who had psychiatric problems, or counterproductive patterns of functioning independently from this problem. Longitudinal designs aiming at examining family factors following the onset of the eating disorder would permit us to specify the direction of these relationships. Second, it would be beneficial to replicate this research in the future with larger sample size and other populations such as siblings with different cultural background and with other psychiatric disorders to enhance its generalizability. A third limitation was that the comparison was predominately between patients with anorexia and bulimia and the T1DM control group. The sample of participants with BED and T2DM had too little power to detect significant differences. However, the inclusion of both type 1 and type 2 (both acute and long term) was problematic due to different aetiology and prognosis. For example, the risk of acute hypoglycemia and the associated mortality at a young age is higher in Type 1. Therefore, a larger sample would also be desirable in order to compare siblings of patients AN with Type 1 and BN or BED with Type 2 diabetes. The fourth limitation was that the instrument used to detect accommodating or enabling behaviours (AESED) was developed specifically to address the areas of accommodation on carers of people with eating disorders, and there may be additional areas associated with metabolic control that were not included for DM carers. The final limitation was that the accommodation scale may be more relevant in those who cohabit and less relevant in older adults.

Despite these limitations, the information generated by this study provides insight into the experience of unaffected siblings living with either an ED or DM patient. Exploring the patient's understanding of their relationship with the unaffected sibling would have added another perspective.

5.7 Clinical implications

This was the first study, to our knowledge, which has examined sibling experiences of people with eating disorder (AN, BN, BED) compared with those of people with diabetes. The overall findings of this study have considerable implications

for supporting the non-affected siblings. With respect to family interventions, the focus is typically on how the parents (and other carers) can respond in ways that may promote behavioral changes in the affected individual (Lock et al., 2001; Treasure et al., 2007). However, family-based treatments (adolescents) identify how to help siblings improve their relationship with their ill sibling encouraging greater discussion among the affected person and their siblings about the illness. As it has been established by this research, the appearance of an ED or DM has a substantial impact on siblings of patients and more specifically their emotional and behavioral reactions to illness. Our results seem to reinforce the idea that sibling's responses are more adaptive and generic rather dysfunctional whilst sibling's response to ED is not very different from response to physical illness. Therefore, interventions should be targeted specifically on siblings with emphasis on their behavioral, cognitive and emotional responses, following the genesis of the disorder, which may be adapted to each relationship style and to the differential perceptions that sisters and brothers have about illness. Siblings who are often excluded from treatment decisions and are thought over as a "neglected" group, should always be included in clinical research and practice.

5.8 Conclusion

This study has collected valuable data about the relationship style of non-affected adult siblings of people with eating disorders and those with diabetes. Overall, these findings indicate how siblings' factors and/or aspects of illness may influence their relationship style with their affected sibling. To our best knowledge, this has been the first study investigating specific aspects of sibling burden and coping strategies as depicted by the interpersonal maintenance model in AN (Treasure & Schmidt, 2013). In addition, this study indicated several sibling-patient variables that have highly significant impact on sibling's distress and caregiving behaviors. The current study suggests that siblings do not notably differ from parents of people with ED in terms of their relationship style although they do favor similar strategies which could be counterproductive if they are not connected with information about EDs and self-care. Considering that many siblings report that they feel incapable of helping with the illness, it is possible that a specific sibling's treatment intervention may benefit them to adopt new communication strategies that may help them in the face of their sibling's illness and may in turn improve the outcome of patients with severe ED.

Chapter Six

Study 3

Partners' experiences of Bulimia Nervosa and Binge Eating Disorder: comparison with spouses of patient with Type 2 Diabetes Mellitus.

6.1 Abstract

Background: Eating disorders impact on carers' quality of life and psychosocial well-being by producing high levels of psychological distress and burden. According to the cognitive interpersonal model (Treasure & Schmidt, 2013) these emotional reactions might contribute to the maintenance of the illness, e.g. through high levels of over-involvement and criticism (Expressed Emotions) and/ or accommodating and enabling behaviors.

Aims: To examine the applicability of the interpersonal component of cognitive interpersonal maintenance model in spouses and compare the caregiving experience between partners of people with Bulimia Nervosa, Binge Eating Disorder and those of people with Diabetes Mellitus II.

Method: Spouses and partners of people with Bulimia Nervosa, Binge Eating Disorder (n=17) and Type 2 Diabetes Mellitus (n=16) were assessed on psychological distress (Depression Anxiety Stress Scale), expressed emotions (Family Questionnaire) and accommodating and enabling behaviors (The Accommodation and Enabling Scale for Eating Disorder).

Results: Spouses of patients with Bulimia Nervosa or Binge Eating Disorder displayed high levels of psychological distress, expressed emotions and accommodation. Moreover, the comparison between eating disorder and diabetes mellitus partners suggested that partner groups present similar profiles of depression, stress, emotional overinvolvement, criticism and accommodation. However, ED spouses showed lower levels of anxiety and scored higher in the area of avoidance modify routine to the accommodation and enabling scale than DM group.

Conclusion: Living with someone with bulimia or Binge Eating Disorder presents many challenges for partners, who experience high levels of distress, expressed emotion and accommodating behaviors. These aspects of partners' caregiving experiences are similar to the experiences of partners of patients with Type 2 Diabetes. Partners may be a useful resource to improve the management of these conditions but

may be benefitted from active inclusion to improve their understanding about how to provide a helpful role.

Keywords: Partners, Eating Disorders, Bulimia Nervosa, Diabetes Mellitus psychological distress, expressed emotion, Accommodation, Enabling,

6.2 Introduction

Caregivers of patients with anorexia nervosa (AN) or bulimia nervosa (BN) frequently report distress related to various aspects of living with a chronic illness, such as worries about the patient's future and communication problems leading to conflicts (Whitney & Eisler, 2005; Graap et al., 2008). Two systematic reviews appraising the literature relating to caregiving burden, found evidence for psychological distress and high expressed emotion (EE) in families of people with EDs, (Zabala, Macdonald, & Treasure, 2009; Anastasiadou et al., 2014). These difficulties may contribute to problems in intrafamilial relationships which may hinder rather than help the resolution of ED behaviours. This is a core element of the cognitive interpersonal maintenance model of anorexia nervosa (AN) (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Specifically, this model proposes that carers' emotional reactions such as high levels of anxiety and depression, psychological distress, as well as their dysfunctional responses to the illness, in the form of high expressed emotion and accommodation to symptoms, can act as maintaining factors of an ED. However, the impact of eating disorders on spouses and partners have received minimal attention, especially on those who care about a person that suffers with bulimia nervosa or binge eating disorder. (Highet et al., 2005; Huke & Slade, 2006; Perkins et al., 2004).

6.2.1 Romantic Relationships and partners' experiences of people with ED

According to the literature on the impact of eating disorders on partnerships, intimacy is a problem for women with bulimia nervosa or binge eating disorder. Women with these disorders report difficulties experiencing closeness with a partner and report low levels of satisfaction in relationships (Evans & Wertheim, 1998); they express a fear of closeness (Pruitt, Kappius, & Gorman, 1992) and report avoidance of interpersonal relationships (Thelen, Farmer, MacLaughlin-Mann & Pruitt, 1990) and

experience poor sexual functioning (Rothschild, Fagan, Woodall, Anderson, 1991). Moreover, partners of people with bulimia nervosa or Binge Eating Disorder are demanding and challenging. Partners experience high levels of distress and lack of support, with social isolation due to their partners social withdrawal (Highet et al., 2005; Huke & Slade, 2006; Leichner, Harper, & Johnston, 1985; Perkins et al., 2004; Winn et al., 2004). Emotional and sexual intimacy is reduced in part due to negative body image (Highet et al., 2005; Huke & Slade, 2006). Hence, some partners want to terminate the relationship but feel guilty in doing so (Highet et al., 2005). Partners are conflicted with feelings of powerlessness in the face of the illness and sense of responsibility for the wellbeing of their partner (Hugh & Slade, 2006; Perkins et al. 2004; Van den Broucke & Vandereycken, 1998; Van den Broucke et al., 1995). These complex interpersonal emotional reactions may perpetuate BN symptoms as depicted by cognitive interpersonal maintenance model in AN.

6.2.3 Type 2 Diabetes Mellitus: Partners' Perspective

Diabetes is a chronic illness which, like eating disorders, involves food management as part of illness. Food-related issues are identified as challenging. This affects patient's psychological wellbeing and quality of life, family social relationships and lifestyle (Choi, 2009; Gerstle, Varenne, & Contento, 2001; Trief et al., 2003).

People living with a spouse with DM share a focus on food management in the context of a protracted course of illness. It is well established that spouses of people with type 2 diabetes often develop psychological problems and interpersonal conflict (Trief et al., 2003). Partners experience fear, uncertainty about the patient's future (Lohri-Posey, 2006), high levels of psychological distress (August et al., 2011; Fisher et al., 2004; Franks et al., 2012) and worries about the risks connected with diabetes (Stodberg et al., 2007). Living with diabetes produces chronic stress which may lead to increased marital dissatisfaction (Iida et al., 2013). Spouses' emotional reactions and behaviors are perceived negatively as nagging or arguing (Beverly, Miller, & Wray, 2006; Trief et al., 2003), and criticism (Sabone, 2008). Overprotection (Hagedoorn et al., 2006) or lack of support may occur. In turn these relationship problems may affect the ability of the person with diabetes to maintain good glycemic control and self-care (Trief et al. 2006; Hagedoorn et al., 2006). Therefore, the style of interaction may be similar to that seen in eating disorders.

The aims of this study were to explore partners' experiences of people suffering from Bulimia Nervosa (BN) or Binge Eating Disorder (BED) and compare them with those of people with Type 2 Diabetes. Finally, we were interested if the cognitive maintenance model was relevant (Treasure & Schmidt, 2013).

Our main hypotheses were (1a) Spouses of people with Bulimia or Binge Eating Disorder would display high levels of distress, expressed emotion and accommodation and enabling behaviors (1b) Spouses' distress was positively related to their emotional responses such as emotional overinvolvement and criticism and accommodation (2) partners of people with Bulimia, Binge Eating Disorder would show similar levels of psychological distress and expressed emotions but more accommodation and enabling behaviors than those with T2 Diabetes Mellitus.

6.3 Materials and Methods

6.3.1 Design

This was a cross-sectional study using self-report questionnaires to examine psychological distress, expressed emotion and accommodating behaviors in partners of people with BN and BED in comparison to the partners of people with Diabetes Mellitus II.

6.3.2 Participants

The sample of the current study consisted of 33 spouses of persons diagnosed with bulimia nervosa (BN), binge eating disorder (BED) or type 2 diabetes (DM2). The ED sample (N=17) consisted of participants recruited from our clinic. The average sample age was 43 years ($SD= 7.16$), 88.25% were male and 11.75 % female. The patients had been diagnosed with an ED by a standard clinical interview following criteria of the Diagnostic and Statistical Manual of Mental Disorder, fifth edition (American Psychiatric Association, 2013). The patients were 88.2% females and 8.8 % males with a mean age of 38.6 ($SD= 11.7$) years. Among patients 58.8 % were diagnosed with bulimia nervosa (BN), 41.2% binge eating disorder (BED) and mean illness duration was 17.7 ($SD= 8.86$) years.

The DM spouses consisted of patients with type 1 and 2 diabetes recruited from the diabetic department of Iatriko Hospital in Athens. The average sample age was 53.7 ($SD= 4.77$) years, 37.5 % were male and 62.5 % female. The DM2 patients were 37.5 % females and 62.5 % males with a mean age of 52 ($SD= 6.3$) years with mean illness duration 15.7 ($SD= 12.86$) years. More socio-demographic details of spouses and clinical details of their partners with eating disorder or T2 Diabetes are outlined on **Table 6.1**.

6.3.3 Carers' Measures

Caregivers completed a demographic questionnaire that included details about themselves (including age, gender, marital status, employment status and education level) and the patient (diagnosis, age, gender, onset and duration of the illness ED diagnosis, and co morbidity). Also, treatments and aspects of care giving experience (e.g. whether the carer was living with patient and the average duration of one-to-one contact) were recorded.

Psychological Distress

The short version of the *Depression, Anxiety & Stress Scale* (DASS-21) was used to measure depression and anxiety (for details please see study 1). In this sample, Cronbach α coefficient 0.92.

Expressed Emotions

The Family Questionnaire (FQ) (for details please see study 1). In this sample, Cronbach α coefficients was 0.835.

Accommodating and Enabling Behaviors

The Accommodation and Enabling Scale for Eating Disorder (AESED) (for details please see study 1). The reliability for the scale in the Greek sample was high ($\alpha = .82$)

6.3.4 Procedure

Eating Disorder Partners

ED spouses were selected on the basis of being a partner for a new intake adult patient diagnosed with bulimia nervosa (BN) or binge eating disorder (BED) in our clinic. Spouses or partners were included in the study if they provided written informed consent and the patient for whom they were caring also agreed to participate. At the time of recruitment for this project, 20 spouses of patients showed interest and willingness to participate. The inclusion criteria for partners were between ages 20 to 70, currently living with a patient with Bulimia Nervosa or Binge Eating Disorder, with sufficient knowledge of Greek language. Three spouses were excluded because their responses were incomplete. The final sample consisted of 17 spouses.

Comparison group Type 2 Diabetes Mellitus

Spouses or partners of patients suffering from T2 Diabetes Mellitus were ascertained from the Diabetic Department of Iatriko Hospital that provides outpatient care to patients suffering from Diabetes or various metabolic problems. First, permission from hospital board was obtained, as well as from doctors. Then, a summary of the study was provided to DM patients, asking them to inform their partners about the research. At the time of recruitment for this project, 20 spouses of patients who under medical care during this period, showed interest and willingness to participate. The inclusion criteria for partners were between ages 20 to 70 currently living with a patient with T2 DM, with sufficient knowledge of Greek language. Four spouses were excluded because their responses were incomplete. The final sample consisted of 16 spouses.

Ethical approval (Please see study 1)

The full set of questionnaires was sent to all participants, along with an information and consent sheet and a prepaid return envelope. There were not any incentives for participation.

6.3.5 Adaptation of scales (Please see study 1)

6.3.6 Data analysis

Data were analyzed using SPSS version 21. Descriptive statistics were used for reporting the means and standard deviations/medians and range for demographic, clinical and caregiving variables. Cronbach alpha (α) was computed for all scales to assess internal consistency.

General Linear Models under the univariate approach were used to assess statistically significant differences between ED and DM spouses for all the dimensions of the questionnaires DASS 21, FQ and AESED. It should be noted that the initial design was a matched comparison in terms of age, gender and educational level within groups. However, the two samples were systematically different, concerning gender and age, due to the differences of DM and ED patients. Therefore, we modeled all outcomes standardizing the results of the observed differences in these three factors.

6.4 Results

6.4.1 Demographic and clinical information

Demographic and clinical information is presented in **Table 6.1**. There was an equal sex distribution of patients with DM, whereas the BN/BED patients were mainly women as this gender difference accounts for difference in vocational functioning. Although the duration of illness was similar in both sets of patient groups, the ages of both the patient and carer groups were different given that the usual age of onset of BN/BED is in adolescence or early adulthood. Therefore, the matching of groups in terms of gender and age was not possible though, the educational and social level was similar in both groups of partners.

6.4.2 Clinical Details and Caregiving Behaviors

6.4.2.1 Eating Disorder group

Approximately one of fourth of ED spouses had moderate to severe levels of psychological distress (depression 23.6% and anxiety 11.8%). One of third spouses presented (29.4%) high levels of emotional overinvolvement (EOI) and (41.2%) high

levels of criticism (CC) and overall score 46.53 ($SD= 21.02$) on accommodation and enabling scale (AESED).

6.4.2.2 Diabetes Mellitus group

Over a third of DM spouses reported high levels of psychological distress, depression (31.3%), anxiety (18.8%) and (12.5%) stress. In terms of expressed emotion, spouses display high levels of emotional overinvolvement (6.3%) and (18.8 %) of CC respectively. The overall score of accommodation was 42.56 ($SD= 15.01$)

6.4.3 Partners reactions to illness between groups

The continuous scale was used for testing statistical differences between groups. The results are outlined in **Table 6.2**. Overall, the groups' mean scores were low and below the cut off of the normal upper value in DASS 21 subscales. In the Diabetes group, anxiety levels were higher and there was a trend for the stress level to be higher. There was no overall difference in accommodating & enabling behaviors, although carers of people with eating disorder group scored higher on the Avoidance & Modifying Routine scale.

Table 6.1 Demographic and clinical details of spouses and patients.

	Eating Disorder	Diabetes Mellitus
Carers	Mean (SD) / N (%)	Mean (SD) / N (%)
Age	43.06 (7.16)	53.7 (4.77)
Female	2(11.75%)	6(37.5%)
Male	15(88.25%)	10(62.5%)
Carer type		
Spouse	13 (76.5%)	13 (81.3%)
Partner	4 (23.5%)	3 (18.7%)
Employment status		
Full time	16(94.1%)	6 (35.5%)
Part time / student	1(5.9%)	3(18.8%)
Housewife / retired	0	7(43.8%)
Other	0	0
Educational level		
Primary school	0	1(6.25)
High School	1 (5.8%)	1(6.25)
Senior high school	6(35.3%)	8(50%)
University	8(47.0%)	5(31.8%)
Master degree	3(17.7%)	1(6.25%)
Patients		
Age	38.6 (11.71)	57.2 (6.30)
Female: Male (N)	15:2(88.2%female)	6:10 (37.5% female)
Duration of illness (years)	17.7 (8.86)	15.7 (12.86)
Diagnosis		
Bulimia Nervosa	10 (58.8%)	
Binge Eating Disorder	7 (41.2%)	
Type 2 Diabetes		16 (100%)

Table 6.2 Measures of caregivers' distress (DASS) and caregiving style (FQ and AESED) between ED and DM group.

				Mean	Standard Deviation	P- value
<i>DASS-21</i>						
Depression	Group	ED	5.71	5.16	0.231	
		DM	7.75	4.38		
Anxiety	Group	ED	2.88	3.31	0.028	
		DM	7.00	6.53		
Stress	Group	ED	7.06	3.31	0.056	
		DM	10.50	6.28		
<i>Family Questionnaire</i>						
Criticism	Group	ED	21.59	5.52	0.101	
		DM	18.31	5.60		
Emotional Overinvolvement	Group	ED	23.12	6.16	0.625	
		DM	22.25	5.49		
<i>Accommodation & Enabling Scale</i>						
Avoidance &Modify Routine	Group	ED	19.53	9.06	0.022	
		DM	14.44	8.28		
Reassurance Seeking	Group	ED	10.53	5.97	0.367	
		DM	8.63	5.98		
Meal Ritual	Group	ED	6.12	4.94	0.899	
		DM	6.38	6.57		
Control of Family	Group	ED	8.00	4.61	0.567	
		DM	8.94	4.69		
Turning a Blind Eye	Group	ED	2.35	3.27	0.127	
		DM	4.19	3.44		
AESED Total Score	Group	ED	46.53	21.02	0.536	
		DM	42.56	15.01		

Note: ED, eating disorder; DM, Diabetes Mellitus.

6.4.4 Association of Spouses' Distress with Expressed Emotions and Accommodation

We adjusted the predictive Pearson correlation of depression, anxiety and stress (three dimensions of DASS-21) by using the two dimensions of Family Questionnaire (FQ) and Accommodation and Enabling Scale (AESED) the total score, including the five subscales. Results are shown in **Table 6.3**.

6.4.4.1 *Eating Disorder Group*

Anxiety and stress levels yielded significant and mostly positive correlations with both dimensions of the FQ, the emotional over involvement (EOI) and criticism (CC) in ED group. Higher emotional involvement (EOI) levels were associated with higher scores in anxiety ($p=0.033$) and stress ($p=0.024$). Further, higher levels of criticism (CC) were correlated with higher scores in anxiety ($p=0.008$) and stress ($p=0.001$).

6.4.4.2 *Diabetes Mellitus Group*

In the DM group, there was a significant correlation between the depression, criticism, avoidance modify routine, reassurance seeking and stress with “turning a blind eye” behaviors and overall score of accommodation and enabling scale. Specifically, lower levels of depression were linked with higher levels of criticism ($p=0.026$) and higher levels of Reassurance Seeking behaviors ($p=0.008$), whilst higher levels of depression were associated with higher levels of avoidance modify routine practices ($p=0.034$) and higher levels of stress were linked with higher scores in the area “turning a blind eye” behaviors ($p=0.03$) and overall score ($p=0.045$).

Table 6.3 Correlations in ED and DM partners' psychological distress (DASS-21) and caregiving style (FQ & AESED)

		ED Spouses			DM spouses		
	<i>DASS-21</i>	Pearson Correlation	Sig. (2-tailed)	N	Pearson Correlation	Sig. (2-tailed)	N
Family Questionnaire							
<i>Emotional Overinvolvement</i>	Depression	.237	.359	17	.348	.187	16
	Anxiety	.518	.033	17	.172	.523	16
	Stress	.542	.024	17	.222	.409	16
<i>Criticism</i>	Depression	.374	.140	17	-.555	.026	16
	Anxiety	.620	.008	17	-.380	.146	16
	Stress	.725	.001	17	-.009	.975	16
Accommodation and Enabling Scale							
<i>Avoidance & Modifying Routine</i>	Depression	-.053	.841	17	.533	.034	16
	Anxiety	.302	.239	17	.057	.835	16
	Stress	.435	.081	17	.273	.306	16
<i>Reassurance Seeking</i>	Depression	.170	.515	17	-.638	.008	16
	Anxiety	.351	.167	17	-.280	.294	16
	Stress	.442	.076	17	-.004	.990	16
<i>Meal Ritual</i>	Depression	.170	.513	17	-.209	.437	16
	Anxiety	.191	.462	17	.124	.647	16
	Stress	.221	.394	17	.216	.421	16
<i>Control of Family</i>	Depression	-.247	.339	17	.235	.380	16
	Anxiety	-.037	.888	17	.254	.342	16
	Stress	-.070	.790	17	.333	.207	16
<i>Turning a Blind Eye</i>	Depression	-.208	.423	17	.223	.405	16
	Anxiety	.194	.456	17	.115	.670	16
	Stress	.131	.617	17	.691	.003	16
<i>AESED Total</i>	Depression	-.021	.936	17	.073	.788	16
	Anxiety	.297	.247	17	.080	.768	16
	Stress	.370	.144	17	.507	.045	16

Note: ED eating disorder; DM Diabetes Mellitus; Bold values indicate statistically significant differences <0.05

6.5 Discussion

The aim of this study was to explore the experiences the partners of people with Bulimia or Binge Eating Disorder. We confirmed our first hypothesis in that we found that a quarter of partners of people with Bulimia Nervosa, Binge Eating Disorder reported a high-level of psychological distress (particularly depression) and high levels of expressed emotion (particularly criticism) and accommodating behaviors (particularly avoidance modify routine). The percentage of ED spouses who showed high levels of expressed emotions was similar to the levels found in systematic reviews which predominantly consisted of parental carers (Anastasiadou et al., 2014). However, the levels of accommodation in ED spouses was higher (Goddard et al., 2011; Grover et al., 2011; Sepulveda et al., 2009).

Furthermore, we confirmed our secondary hypothesis in that we found that spouses' distress was positively related to emotional overinvolvement and criticism. This suggests that the cognitive interpersonal maintenance model in AN is applicable for BN and BED carers. The interpersonal component of the model postulates that carers' emotional reactions are characterized by high levels of anxiety and depression, psychological distress, as well as their emotional and behavioural responses to the illness in the form of expressed emotions or accommodation to symptoms (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013).

The second aim of this study was to compare the levels of distress, expressed emotion and accommodating behavior between spouses of people with Bulimia Nervosa and Binge Eating Disorder and spouses of people with T2 Diabetes Mellitus. Our hypothesis was confirmed as results showed no differences in the levels of expressed emotions, depression and stress; however, levels of anxiety were higher in the DM spouses. The ED spouses had higher levels of Avoidance Modifying routine subscale of the accommodation and enabling behaviors scale although the total score was similar across both groups.

Although this is the first study to compare distress and caregiving style (expressed emotions and accommodation) in spouses of patients with Bulimia Nervosa and Binge Eating Disorder with those of patients with a type 2 DM, we expected that spouses would show similar outcomes on these variables. This is due to the fact that previous

studies have shown that spouses respond in similar ways to these two illnesses (Highet et al., 2005; Huke & Slade, 2006; Leichner et al., 1980; Perkins et al., 2004; Winn et al., 2004; August et al 2011; Fisher et al., 2002; Franks et al., 2010). However results suggested that spouses of people with ED display lower levels of anxiety than DM, which fit to previous findings in DM spouses which indicate high levels of psychological distress (August et al 2011; Fisher et al., 2002; Franks et al., 2010) and worries are associated to the life threatening complications connected with diabetes (Stodberg et al., 2007). Furthermore another difference was found to ED spouses that show higher accommodation to the area of avoidance modifying routine than DM group. This was an interesting finding implying that ED spouses may favor to change their daily routine in order to avoid constant arguments, which could make the relationship unbearable.

These findings suggest that spouses of people with eating disorder and those of people with type II diabetes, share similar emotional responses and patterns of accommodation.

6.6 Limitations

Certain limitations should be considered. First of all, it was a cross-sectional study with all the limitations this implies in testing causal effects (i.e., the strong possibility of reverse causation). Second, our sample was small and heterogeneous and it was difficult to match for age, when we chose to match for similar illness duration. Limited resources meant that we were unable to match for gender. Third, the Accommodation Enabling Scale for Eating Disorders was developed specifically to address the accommodation and enabling behaviors of carers of people with eating disorders, and there may be additional difficulties posed by Diabetes Mellitus that were not included. Fourth, we did not examine additional factors that may account for variations in caregivers' consequences, such as the severity of patients' symptoms because we did not have a common instrument to assess severity of symptoms across the eating disorders and diabetes mellitus.

6.7 Clinical Implications

This study provides evidence that living with a partner with Bulimia Nervosa and Binge Eating Disorder & Diabetes Mellitus impacts on the relationship in a variety

of ways. More comparative research on ED, using both healthy and clinical control groups, is needed to substantiate the findings reported here. Furthermore, there is a need to evaluate other illness specific factors which were not considered in this study. For example, the medical costs of illness, everyday partner's involvement in food preparation, exercise and health monitoring, may be of relevance.

Nevertheless, these findings suggest that the needs of spouses should be considered in the assessment of patients with Bulimia, Binge Eating Disorder and diabetes as both illnesses have a significant impact on the partners of patients and may result in physical, mental or emotional overload (Anastasiadou et al., 2014; Ridge et al., 2014; Houston-Barrett & Wilson, 2014). Our results support the idea that interventions should be related to the characteristics and interpersonal maintenance factors, which are specific to the illness, and the spouses should be involved in the treatment process (Treasure & Schmidt, 2013; Bulik, Baucom, Kirby, Pisetsky, 2011).

From a clinical perspective, we encourage clinicians to always involve spouses or partners in the treatment of bulimia and binge eating. The simplest way is to spend some time with spouses and patients together, explaining in extend the impact of illness on couple relationship. The second step could be explaining the negative reinforcement that accommodating behaviors exert on bulimic symptoms and teaching them how to progressively stop accommodating behaviors. This psychoeducational approach is highly appreciated from patients and family members and can be applied even when CBT is not used.

6.8 Conclusion

These findings demonstrate the impact of Bulimia and Binge Eating Disorder particularly on male spouses. These partners experience high levels of psychological distress, expressed emotions, accommodating behaviours; moreover, they display similar patterns with spouses of people with T2 DM. Supporting partners in helping them moderate emotional responses such as criticism, emotional over involvement and less adaptive behaviours, such as accommodation, may help them cope better with the caregiving role and also improve the outcome for the person with BN or BED.

Chapter Seven

Study 4

An examination of the impact of care giving styles (expressed emotions and accommodation) on the six-month outcome of adults with Bulimia Nervosa or Binge Eating Disorder: Testing the postulations of the cognitive interpersonal model in bulimia nervosa

7.1 Abstract

Objective: A cognitive interpersonal maintenance model of anorexia nervosa (AN) was first proposed in 2006 and updated in 2013 (Schmidt and Treasure, 2006; Treasure and Schmidt, 2013.). The aim of this study was to test the interpersonal component of this model in people with BN and BED requiring outpatient treatment.

Method: Dyads(n=65) consisting of patients with Bulimia nervosa and Binge Eating Disorder and their primary carer were included in the study. Caregivers completed the Depression Anxiety Stress Scale, Family Questionnaire and the Accommodation and Enabling Scale at intake. Patients completed the Eating Disorders Examination Questionnaire at intake and after six-month interval. Structural equation modeling was used to examine relationships among these variables.

Results: Carers' anxiety was significantly related to carers' emotional overinvolvement, which in turn, was positively related with accommodation and negatively related with patients' symptoms change. Also, high levels of criticism were found to predicted change on eating symptoms in patients.

Discussion: The cognitive interpersonal maintenance model of eating disorders (EDs) was partially confirmed. It follows that interventions targeting interpersonal maintaining factors may need to take into consideration the sociocultural background of family's normative level of expressed emotions.

Key words: carers, patients, BN, BED, cognitive interpersonal maintenance model

7.2 Introduction

The differences and similarities between anorexia nervosa (AN) and bulimia nervosa (BN) have been an important issue for both clinicians and researchers (Fairburn et al., 2008). The personality traits of people with BN or BED differs from that with AN; for example patients with Bulimia (BN) have noticeable difficulties with impulsivity, distress tolerance and emotional regulation particularly in terms of identifying, experiencing, and accepting various emotional states (Anestis et al., 2010; Lavender et al., 2012). However, individuals with BN or BED experience analogous difficulties in emotional regulation as those in AN (Kittel, Brauhardt, & Hilbert, 2015) which in turn contribute to perpetuation of eating disorder symptoms.

In addition, social difficulties may be a risk factor or appear as the illness develops including impaired social cognition such as difficulties in recognizing specific emotions in facial expressions and social avoidance which is characterized by social detachment, poor social skills, and interpersonal difficulties (Kessler, Schwarze, Filipic, Traue, & von Wietersheim, 2006; Legenbauer, Vocks, & Ruddel, 2008; Kuhnpast, Gramann, & Pollatos, 2012; Dapelo, Surguladze, Morris & Tchanturia, 2017). Moreover, BN patients show a delayed help seeking behavior, meaning that ask for professional help after 4–5 years from illness onset (Turnbull, Ward, Treasure, Jick, & Derby, 1996; Hoek & van Hoeken, 2003). Even with professional support only about 40% of individuals treated for BN experience lasting remission (Stice & Bulik, 2008). The protracted and disabling course of the disorder can have a profound interpersonal impact on the family (Anastasiadou et al., 2014; Zabala, Macdonald, & Treasure, 2009).

Eating disorder symptoms are persistent and intrusive into the family life, and interpersonal relationships can be entrapped into disorder's vicious cycle. Moreover, the intrusive nature of the symptoms of an eating disorder can elicit emotional reactions such as high expressed emotion (criticism, hostility and over protection) and accommodating and enabling behaviors that collude with illness by organizing the family around eating disorder rules, disregarding or covering up the negative consequences of eating disorder symptoms (Sepúlveda, Kyriacou, & Treasure, 2009; Anastasiadou et al., 2014; Treasure & Schmidt, 2013).

These emotional responses and behaviours form one facet of the set of maintaining behaviours which are described in the interpersonal domain of cognitive interpersonal model in AN which explains how these dysfunctional responses to the illness and behaviours may be reinforcing as they reduce anxiety and distress in the short term but they can allow the symptoms to persist and hinder recovery (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Explicitly, intrafamilial communication with high levels of expressed emotions (EE) including criticism (CC) and emotional overinvolvement (EOI) reflect an aspect of an unhelpful communication style (Vaughn, 1989) may be a key element in the maintenance of ED symptoms (Schmidt & Treasure, 2006). The studies of two systematic reviews (Zabala, Macdonald, & Treasure, 2009; Anastasiadou et al., 2014) display that high levels of expressed emotions (EE) among families of patients with eating disorders are associated with caregivers' distress and anxiety, severity of ED symptoms, the age of the patient, duration of illness and type of the ED (Rienecke et al., 2015; Goddard et al., 2013; Kyriacou et al., 2008b; Duclos et al., 2014; Hoste et al., 2012; van Furth et al., 1996; Anastasiadou et al., 2015). However, regarding the impact of the type of eating disorder on the level of caregivers' expressed emotions, Duclos, Vibert, Mattar & Godart (2012) indicate to their systematic review on expressed emotions that it remains uncertain whether anorexia or bulimia has more significant impact on familial expressed emotions because of the contradictory study findings.

Furthermore, accommodation was included as a maintaining factor in the revised interpersonal cognitive maintenance model (Treasure & Schmidt, 2013). According to the model enduring or permitting the symptoms of the eating disorder that constantly increase patient's entrapment within the vicious cycle of weight and shape-controlled behaviors, contributes to the perpetuation and maintenance of symptoms. Family accommodation was first noted in relatives of adults with obsessive compulsive disorders and anxiety (Calvocoressi et al., 1995). Furthermore, empirical evidence supports that family accommodation in OCD is associated with increased symptom severity (Lebowitz, Storch, MacLeod, Leckman, 2014; Storch et al., 2012). Therefore, as in OCD and anxiety disorders, family accommodation in eating disorders is manifested in many forms. For example, certain groceries are not bought because of the patient's distress in having these foods in the house. Family members may engage

in constant reassurance about the patient's weight and shape, or follow the patient's rigid schedule of meal times or to meal-preparation rituals (Treasure et al., 2010). Family accommodation is associated with an increase in caregiver burden (Anastasiadou et al., 2014; Sepulveda et al., 2009; Anastasiadou et al., 2016). Family accommodation is higher in caregivers who spend more time with the patient, or have personal experience of an eating disorder and high levels of anxiety and their relative has a longer duration of the disorder (Anastasiadou et al., 2014; Sepulveda et al., 2009; Stefanini et al., 2018; Rhind et al., 2016).

Furthermore, empirical evidence supports this model, suggesting that high EE of caregivers of AN patient impacts the course of the disorder and treatment response (Goddard et al., 2013; Rienecke et al., 2015; van Furth et al., 1996). Moreover, another study on caregivers of adolescents with AN suggests that parental accommodation predicts a change in symptoms (Salerno et al., 2016).

Research into what it is like to care for an individual with BN and BED is meagre (Anastasiadou et al., 2014). BN caregivers are thought to experience similar level of distress and emotional difficulties as carers of people with AN (Winn et al., 2007). There are practical and relational difficulties related to bulimic symptoms; for example, blocked drains from purging, depletion of food stocks, and behavioral difficulties. These symptoms generate feelings of frustration and disgust in caregivers and these negative emotions may have an adverse impact on outcomes. (Perkins et al., 2004). Drawing a hypothesis from the cognitive interpersonal model, it is possible that these caregivers' negative experiences might impact on the treatment outcome of the individuals with BN and BED.

The aim of this study was to empirically test the application of the cognitive interpersonal maintenance model on people with Bulimia Nervosa and Binge Eating Disorder. Our main hypothesis was that caregivers' emotional and behavioral reactions (caregivers' distress, emotional reactions and accommodating and enabling behaviors) would influence treatment outcome in terms of rate of symptom change over 6 months. Our secondary hypothesis was that carers' anxiety would be positively associated with expressed emotion and accommodating and enabling behaviors (see Fig. 1). Contact

time, patient's age, illness duration and age of illness onset would be confounding variables.

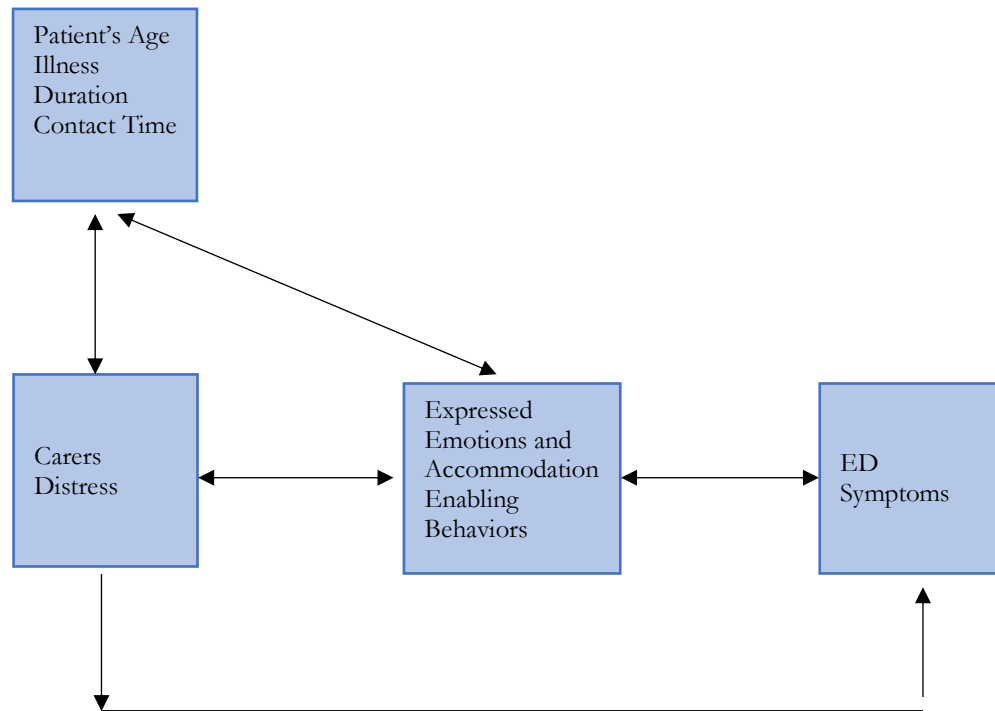


Figure 7.1 A cognitive interpersonal maintenance model of eating disorders. Carer's expressed emotions, and accommodation and enabling, are the proposed maintaining factors.

7.3 Methods

7.3.1 Design

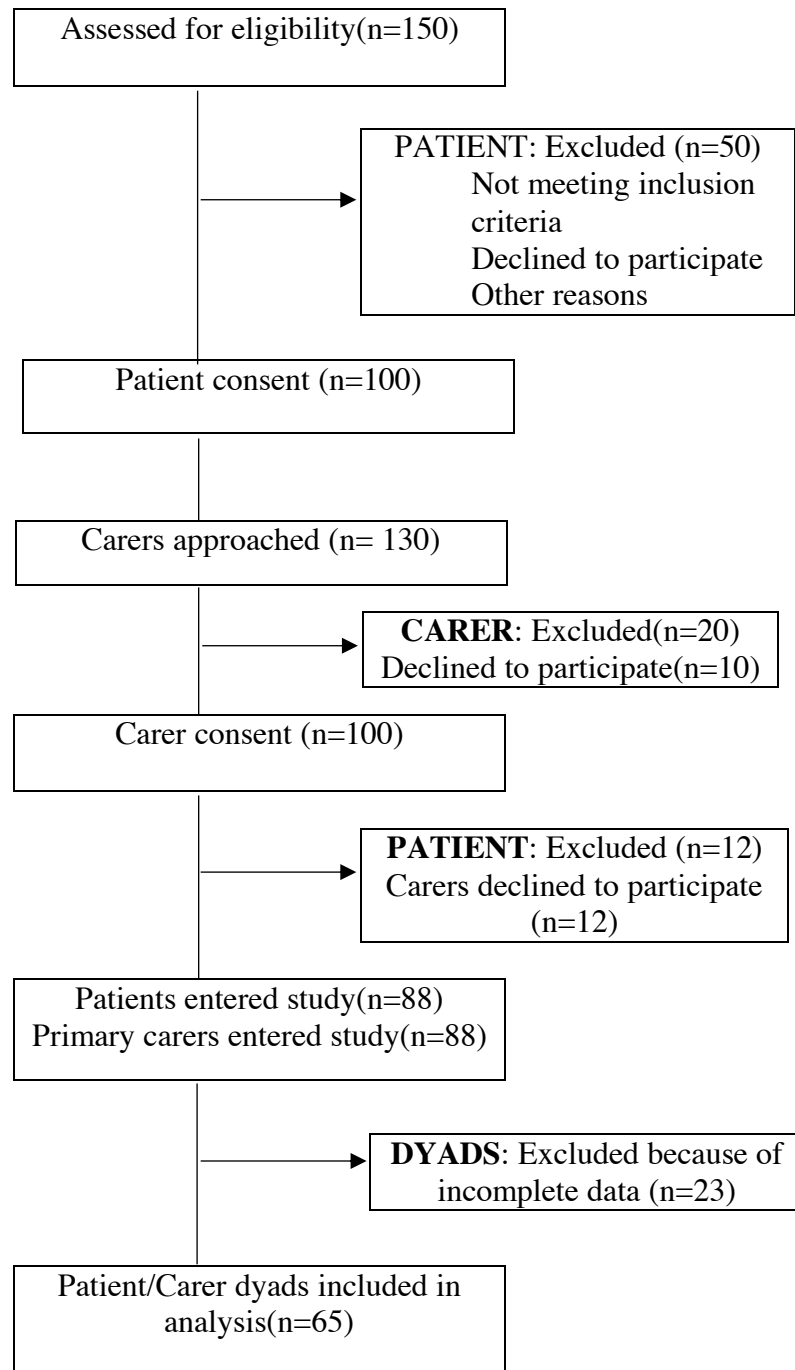
The design of this study was longitudinal. Data was collected as part of the baseline assessment of patients presenting to the Hellenic Centre For Eating Disorders. The sample (n = 65 patient/carer dyads) included adults (age 18-55 years) with BN or OSFED – BN subtype and binge eating disorder (BED) according to the DSM- V criteria (APA, 2013).

Patients and their primary carers completed the initial assessments at intake (T1). Patients were then entered into treatment. The form of treatment was not constrained experimentally but followed usual clinical procedure. Treatment duration varied from patient to patient. After 6 months, patients completed the self-report measure of eating psychopathology (EDE-Q) (T2).

7.3.2. Participants

Sociodemographic details of participants are presented in Table 7.1. The sample of dyads (patient-carer) was recruited from clinic. The majority of carers were mothers (53.1%) and spouses/partners (35.9%). One third of the carers self-reported lifetime eating difficulties. The patients reported an illness onset at the age of 17 but their diagnosis was made 6 years later (age of 24) and they had presented at the specialized clinic for treatment 3 years after being diagnosed.

Figure 7.2 Diagram of Participant Flow.



7.3.3. Assessment measures

At baseline caregivers completed a demographic questionnaire (age, ethnicity, marital/living/employment status, years in education, contact time with relative) and clinical information (illness duration, number of previous admissions, diagnosis, height and weight) by self-report as part of the baseline assessment and the following self-report questionnaires:

7.3.3.1 Caregivers' evaluation

Psychological Distress

The Depression, Anxiety, and Stress Scale, DASS-21 (described on Study 1) and Cronbach's α in the current sample was 0.83.

7.3.3.2 Carer's response to the illness

The Accommodation and Enabling Scale for Eating Disorders (described on Study 1) and Cronbach's α in the current sample was 0.92.

The Family Questionnaire (described on Study 1) and Cronbach's α in the current sample was 0.815.

7.3.3.3 Patients' evaluation

At baseline and over six months patients completed a demographic questionnaire and the following self-report questionnaire:

The Eating Disorder Examination – Questionnaire (EDE-Q) is a self-report measure assessing ED symptoms over the previous 28 days on a 6-point Likert scale (Fairburn & Beglin, 1994). The total score is used in the present study (maximum score = 6). This instrument had good reliability and validity in ED samples and had good internal consistency in the present sample ($\alpha = 0.87$).

7.3.4 Procedure

Patients with a primary diagnosis of BN or OSFED - BN subtype ED or BED were offered the opportunity to participate in the study upon admission to clinic. A carer was defined as someone who provided unpaid help and support to a child, partner,

relative, friend, or neighbor. A minimum of one carer per patient was recruited, although all close carers were encouraged to take part. They were identified as carers by the patient and were currently living with or were in a close relationship with them. Patients were asked to indicate who they considered as a primary carer. Patients were aged 18 or over and spoke Greek. Exclusion criteria was severe comorbidity at time of admission (e.g., severe learning disability, psychosis). See Figure 2 for details of participant flow. The final sample comprised 65 patients and their primary carers who completed all the items of questionnaires.

Main ethics approval was granted by the Iatriko Hospital Ethics Committee in Athens (11/H0725/4).

7.3.5 Statistical Analysis

All measured scales were described with the use of means and standard deviations and the relationships between them were initially assessed with the help of bivariate correlations. After evaluation of assumptions for parametric data, skewed distributions were found for age as well as for all three dimensions of carers' distress therefore square root transformation was applied to the measurement of carers' distress and log trans-formation was conducted for age. Maximum likelihood estimation was used to examine the fit of models of their respective observed variance-covariance matrices. The overall goodness of fit model was assessed using a variety of global fit indices: C/MIN statistic (χ^2/df), comparative fit index (CFI), non-normed fit index (NNFI), and the root-mean-square error of approximation (RMSEA). Multivariate non-normality was evaluated using Mardia's index (1.74). Bias corrected confidence intervals (C.I.) were computed using 5,000 bootstrap resamples for indirect effects.

7.4 Results

7.4.1 Clinical Details and Caregiving Behaviors

The clinical descriptive data and caregiver behaviors are presented in Table 2. Patients had a high level of psychopathology in terms of EDEQ (Total score=4.0, SD=1.45). The majority of carers exhibited low levels of psychological distress. However, approximately one caregiver in ten showed at least mild symptoms of depression (17%), anxiety (15.39%), and stress (7.69%). Almost half of the carers

reported high levels of over-emotional involvement (44.62%) and high levels of criticism (40%). In addition, carers showed high accommodation, with a mean total score 50 ($SD=25.19$) of the Accommodation Eating Scale for Eating Disorders questionnaire.

Correlations between carer and patient variables are reported in Table 7.3. Carers' anxiety was positively correlated with patient age, and depression whereas carers' stress was positively associated to carers' depression and anxiety. In regard to expressed emotions, carers' emotional overinvolvement was negatively associated with illness duration and patient's age while emotional overinvolvement was positively correlated to depression, anxiety and stress. Moreover, carers' criticism was associated to stress and emotional overinvolvement. A significant positive correlation was found between carers' accommodation and psychological distress and expressed emotions. Finally, patients' eating disorder symptoms were positively correlated with illness duration.

Table 7.1 Demographic data of patients and their primary carers

Patient	Mean (SD) /N (%)
Age	29.5 (9.31)
Female: Male (N)	60:5 (92.3% female)
<i>ED Diagnosis</i>	
Bulimia Nervosa	40 (61.5%)
EDNOS-BN type	8 (12.3%)
BED	17 (26.2%)
Medication	14(21.5%)
Lowest lifetime BMI (kg/m ²)	20.0 (5.13)
Mean Duration of illness (years)	8.95 (7.8)
Age of illness onset	16.95 (4.45)
Age of Diagnosis	23.81 (8.09)
<i>Marital Status</i>	
Married/living together	25 (39.1%)
Single	39 (60.9%)
Level of Education	
High School	3 (4.7%)
Secondary School	18 (28.6%)
University Degree	33 (52.4%)
Postgraduate Degree	9 (14.3%)
Primary Carers	
Age	50.14 (10.1)
Female: Male	38:27 (58.5% Female)
Carer type	
Mother	34 (53.1%)
Father	3 (4.7 %)
Partner/spouse	23 (35.9 %)
Other relative	4 (6.3%)
Living with patient: Yes	47(72.3%)
Face to face contact	
High (> 21 h per week)	35 (53.8%)
Low (< 21 h per week)	30 (46.2%)
<i>Employment status</i>	
Full time	32 (49.2%)
Part time	5 (7.7%)

Unemployed/housewife/retired/sick leave	26 (40%)
Other	2 (3.1%)
Marital status	
Married/living together	52 (80%)
Single/divorced/separated/widowed	13 (20%)
Problem with eating or weight	20 (30.8%)

BN: Bulimia Nervosa; BED binge eating disorder EDNOS-BN: eating disorder not otherwise specified bulimic subtype; BMI: body mass index; ED: eating disorder. M: mean; SD: standard deviation.

Table 7.2. Descriptive data for patient details, ED symptoms and caregiving styles

	Mean	SD	Skewness	Kurtosis
Illness Duration(in years)	8.95	7.80	1.07	0.76
Patient's age (in years)	29.49	9.31	0.76	0.06
Depression (Carers)	5.35	4.95	1.13	0.22
Anxiety (Carers)	3.62	4.48	1.73	2.34
Stress (Carers)	7.71	4.47	0.48	0.12
Emotional Overinvolvement (Carers)	26.13	5.84	-0.11	-0.81
Criticism(Carers)	21.80	6.01	0.29	-0.48
Accommodating and Enabling (AESED;0–132) (Carers)	50.37	25.19	0.60	-0.10
ED symptoms (EDEQ) (Patients)	-0.88	1.45	-0.58	-0.48

Table 7.3 Correlations between carer and patient variables

	1	2	3	4	5	6	7	8	9
Illness Duration	-	-	-	-	-	-	-	-	-
Patient's Age (in years)	.496**	-	-	-	-	-	-	-	-
Depression (Carers)	-.070	-.063	-	-	-	-	-	-	-
Anxiety (Carers)	-.224	-.263*	.792**	-	-	-	-	-	-
Stress (Carers)	-.039	-.079	.695**	.713**	-	-	-	-	-
Emotional Overinvolvement (Carers)	-.261*	-.304	.404**	.446**	.503**	-	-	-	-
Criticism (Carers)	.041	.082	.116	.017	.381**	.498**	-	-	-
AESED(Carers)	.026	-.143	.336**	.309*	.470**	.647**	.408**	-	-
EDEQ Change (Patients)	.258*	-.019	-.138	-.194	-.169	-.066	.220	.097	-

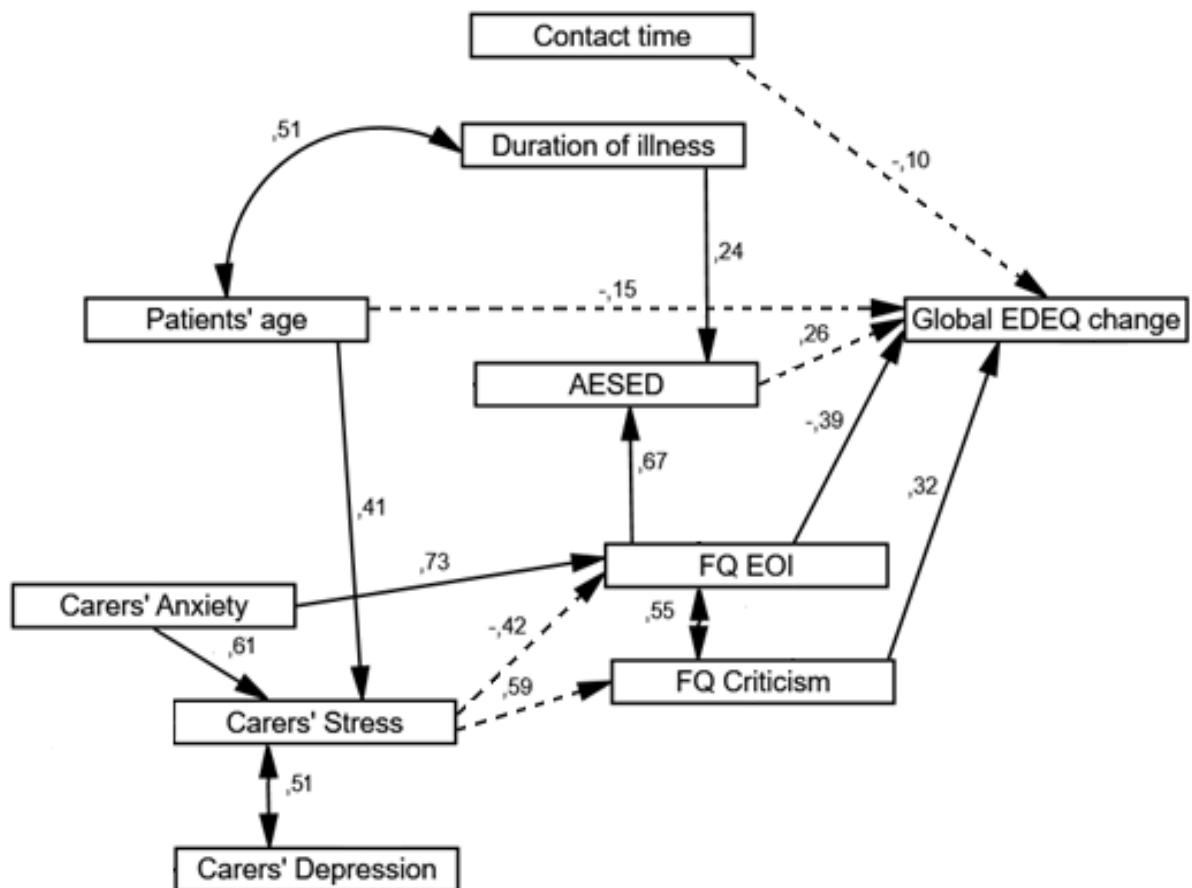
Note: DASS: depression, anxiety, and stress scale; FQ: family questionnaire, emotional overinvolvement, criticism ; AESED: accommodating and enabling scale for eating disorders; EDEQ: eating disorder examination questionnaire. *p < 0.05. **p < 0.01.

7.4.2 Structural Equation Model testing the cognitive interpersonal maintenance model of eating disorders

Figure 3 displays a structural equation model of the interpersonal maintenance model of EDs (contact time, patient's age, illness duration and age of illness onset were entered as confounders). Eating Disorders Examination Questionnaire score represents ED psychopathology. All fit indices suggested that the model fits the data well ($\chi^2 = 32.30$; $\chi^2/df = 1.16$; CFI = 0.98; RMSEA = 0.04; absolute standardized residual < 1.96). The standardized parameter estimates presented in Figure 3 showed that carers' anxiety was significantly related to stress and emotional overinvolvement. However, carers' anxiety had a significant effect on accommodation (standardized indirect effect value = 0.49, $p < 0.05$) through Emotional Overinvolvement. Furthermore, carers' stress and depression were found to be related each other, but no significant correlations were found between stress, criticism and emotional overinvolvement. Moreover, carers' emotional overinvolvement was directly and positively linked with accommodation but no correlation was found between criticism and accommodation. In regard to patient's details, results showed that patient age is positively associated with carers' stress and illness duration is directly and positively correlated with caregivers' accommodation.

In regard to the impact of caregivers' emotional and behavioral reactions on symptom change, we failed to support the hypothesis that carers' distress was directly connected to symptom changes (EDEQ). Generating indirect effect indices through effect decomposition, it became apparent that only carers' anxiety has a significant effect on symptoms change through Emotional Overinvolvement (standardized indirect effect value = 0.28, $p < 0.05$). In line with our hypothesis, we found that expressed emotions (emotional overinvolvement and criticism) were significantly related to each other and had a direct effect on ED symptoms change. The standardized regression coefficients were 0.39 and 0.32 respectively showing that higher criticism scores are related to lower changes in the ED symptoms (EDEQ); while in contrast to our hypothesis higher levels of emotional overinvolvement were related to more changes in ED symptoms (clinical improvement). Contrary to our hypothesis, accommodation and enabling was not significantly associated with patient's symptoms change ($p = 0.127$). Neither carer-patient contact time nor patients' age was significantly correlated to the ED symptoms changes.

Figure 7.3 Structural equation model testing the cognitive interpersonal maintenance model of eating disorders



DASS: depression, anxiety, and stress scale; FQ: family questionnaire, EOI: emotional overinvolvement; AESED: accommodating and enabling scale for eating disorders; EDEQ: eating disorder examination questionnaire

Note: Carers', expressed emotions and accommodating and enabling are the proposed maintaining factors. Confounding variables are patient's age illness duration and carer's contact time with patient. Standardized coefficients are presented in the diagram. To be classed as significant a minimum of $p < 0.05$ was used. Significant parameters are presented by solid lines whereas nonsignificant ones by dashed lines. Errors were omitted from the diagram.

7.5 Discussion

The aim of the present study was to test the application of interpersonal maintenance model in a sample of individuals entered for treatment of Bulimia Nervosa, other specify feeding and eating disorders bulimia subtype and Binge Eating Disorder in Greece. The specific research questions were to examine whether caregivers emotional and behavioral reactions (caregivers' distress, emotional reactions and accommodating and enabling behaviors) influenced treatment outcome in terms of rate of symptom change over 6 months. We partially confirmed our first hypothesis in that we found that carers' anxiety was indirectly related to patients' ED symptoms change though emotional overinvolvement. Whereas carers expressed emotions were directly associated with eating disorders symptoms. However, the hypothesized relationship between accommodation and change of eating disorder symptoms was not supported. We found partial support for the second hypothesis in that carers' anxiety would be positively associated with expressed emotion and accommodating and enabling behaviors. On the other hand, we found that caregivers' anxiety was directly and positively associated with emotional overinvolvement which in turn was associated with accommodation. In regard to the confounding variables, contact time had no significant effect on change of eating disorder symptoms and carers' reactions and behaviors while patient age increased carers reported higher stress and illness duration was associated with accommodation.

These findings are consistent with the interpersonal cognitive maintenance model which argues that carers' responses to the illness are associated with change of eating disorders symptoms (Schmidt & Treasure 2006; Treasure & Schmidt, 2013). Carer's anxiety did not have a direct relationship with eating disorder symptom change but it was mediated through carers' emotional overinvolvement. Expressed emotions were related directly with eating disorder symptoms. For example, the higher the level of criticism the worse the patient's outcome and the converse was associated with low levels of criticism. However, the finding that highly emotional overinvolvement in carers was associated with clinical improvement in eating disorder symptoms and the reverse was related to low levels of emotional overinvolvement, was unexpected.

This deviation could be explained along cultural lines (Bhugra & McKenzie, 2003), as emotional overinvolvement is considered to be a “destructive force among kin and a

failure to preserve culturally appropriate boundaries among self-systems.’’ (Jenkins 1992, p. 217). Additionally, emotional over- involvement is arguably the most culture-dependent construct of the four in the assessment of high expressed emotions (EE) (Singh, Harley, & Suhail, 2013) and evidence indicates that the role of emotional over-involvement in treatment outcome is inconsistent across cultures. In some studies, findings suggested that caregivers’ emotional overinvolvement can be beneficial for treatment outcome. For example, the study of King and Dixon (1996) in young adults with schizophrenia indicated that carers’ emotional overinvolvement contributed to the improvement of patient’s social adjustment. Similarly, a Greek study on carers of people with psychosis showed that higher levels of criticism predicted illness course or rate of relapse rather than the emotional over-involvement (Koutra et al., 2015). Plausibly, high levels of EOI could be considered a sociocultural response to a chronic eating disorder (i.e., high values for family and parental responsibilities) as an attempt on the part of caregiver to assist the patient to manage more effectively with eating symptoms whereas lower levels of EOI may be perceived from patients as a lack of interest and support which in turn have comparable effect with high criticism. It should be noted that the majority of studies that have tested the applicability of the model indicated that emotional and behavioral responses influence the treatment outcome, including samples of carers-patients with anorexia nervosa from UK. Therefore, any differences found in the prevalence and impact of EOI in non-UK settings could merely be an artifact of a culturally inappropriate operationalization of emotional overinvolvement in that cultural context (Lopez et al., 2009). Moreover, this is the first study on eating disorders that tested the applicability of model outside UK, so it is not possible to compare our findings to analogous studies from another cultural context. Furthermore, it is possible that the effect of high emotional overinvolvement may be accompanied by the presence of high warmth which included sympathy, concern, positive comments, interest in other as a person, and expressed enjoyment in mutual activities (Brown, Birley, & Wing 1972; Brown, Monck, Carstairs, & Wing 1962; Rienecke, 2018).

Balancing overprotection and lack of support is challenging when living with ED patient. Thus, emotional responses described throughout in negative terms such as dysfunctional or over protective, may in fact be supportive and helpful in terms of ED outcome. Moreover, this finding leads to the question of whether emotional

overinvolvement is functional or dysfunctional and appears to be a very valuable indicator of reforming our vocabulary for how we think and talk about familial responses. Focusing treatment in ED on enhancing the positive aspects of EE may be just as important as reducing the negative aspects of EE. Further research and modification is needed to the model which might differ across diagnoses.

In the current study, accommodation was not found to be significantly associated with change of eating disorder symptoms, in consistency with Goddard et al. (2013) study but in contrast to Salerno et al. (2016) study in which it was suggested that carers' accommodating and enabling behaviours is a maintaining factor.

Moreover, the finding that caregivers' anxiety was associated with emotional overinvolvement is consistent with Kyriacou, Treasure and Schmidt (2008a) study in AN carers, indicating also that caregivers' self-sacrificing, overprotective and intrusive behaviors, may entail a type of anxious caregiving in bulimia and binge eating patients. Furthermore, high levels of EOI were found to be related to high levels of accommodation; this finding is in accordance to the cognitive interpersonal model that describes how caregivers' high overprotection leads to higher accommodation to the illness (Treasure et al., 2008). Carers' accommodation to symptoms and enabling behaviours (AESED) was observed to present a positive relationship with illness duration, which is consistent to the findings of the systematic review of Anastasiadou et al. (2014).

7.6 Limitations

There are also some limitations to this study. First, the sample of the study was small and our results require replication, ideally with a larger sample. Second, the model has been tested at the intake of carers' pattern of accommodating behaviours and emotional responses predicted patient outcome. Models to examine the mediating as well as moderating role of these processes will be of interest. Third, the outcome data were measured by using a self-report instruments and therefore they are subject to the limitations inherent in this method, including bias and socially desirable responding. Fourth, the population of patients and caregivers were from a single catchment area in Athens and hence, generalizability of results may be limited. Fifth, the patients included in this study predominantly had a long illness course and a high

severity. Therefore, these findings may be limited in the extent to which they can be generalized to patients with duration of illness less than 9 years.

7.7 Clinical Implications

This was the first study, to our knowledge, which has tested the assumptions of the cognitive interpersonal model in a sample of individuals entered for treatment for Bulimia Nervosa, OSFED bulimia subtype and Binge Eating Disorder in Greece. The overall findings of this study have considerable implications for supporting caregivers, mainly in terms of enhancing the repertoire of family interventions in bulimia and binge eating disorder. Understanding the cascade of processes that mediate the impact of family function on caregivers' psychological distress through their emotional responses (emotional overinvolvement or critical attitude toward the patient) and behaviors which in turn may help or hinder recovery, is crucial in developing more effective family interventions, aiming to improve familial patterns of interactions by promoting awareness of family dynamics, which in turn may indeed reduce the burden and improve the emotional well-being of family caregivers.

7.8 Conclusion

In conclusion, the present findings provide an empirical evidence of the applicability of interpersonal maintenance model in carers and patients with Bulimia and Binge Eating Disorder. Carers' anxiety impact eating disorders symptom and accommodation through the mediation of emotional overinvolvement whereas emotional responses had an impact to treatment outcome in terms of rate of symptom change over 6 months. Therefore, the findings of the current study are promising and seem to support the complex interactions between BN and BED patients and carers which are portrayed in the cognitive interpersonal maintenance model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013), but further attention is needed on sociocultural background of families of people with eating disorders, specifically to the aspect of expressed emotions that varies across cultures. Further, data suggested that caregivers need more support in adopting strategies through interventions that help them to cope more effectively by targeting potentially maintaining processes and fostering helpful responses.

Chapter Eight

Discussion

8.1 Introduction

The aim of this final chapter is to synthesise the findings and implications of this study. A brief overview is given and the main research findings are described before a synopsis of the limitations, clinical implications and areas for further research are discussed.

8.2 Overview

The literature base provides substantial evidence that family members experience high levels of psychological distress and intense emotional reactions, such as anger, shame, anguish, frustration and guilt (Graap, et al., 2008; Haigh & Treasure, 2003; Kyriacou, et al., 2008a; Whitney, et al., 2007; Winn et al., 2007). There is also evidence that suggests that these responses can lead carers to become stuck in unhelpful reactions and attitudes that maintain the illness (Salerno et al., 2016; Goddard, et al., 2011; Kyriacou, et al., 2008b; Sepulveda, et al., 2009; Anastasiadou, et al., 2014). According to the Interpersonal Maintenance Model of Anorexia Nervosa, these dysfunctional patterns of communication can allow eating disorder symptoms to flourish. This model suggests that expressed emotions (criticism and emotional over involvement) and accommodating and enabling behaviours can perpetuate the illness and impact on treatment outcome and the course of the illness (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Nevertheless, the majority of studies in this area have focused on the caregivers (mainly parents) of people with Anorexia Nervosa, while less work has been carried out to examine the impact of bulimia and binge eating disorder on family members (parents, siblings and partners) and how their attitudes and responses may influence treatment outcome.

Moreover, there is considerable evidence to suggest that cultural factors can play an important role in the family's response to a mentally ill family member, because of differences in family structure, interaction and emotional expression which can vary from culture to culture. Mediterranean families have different parental attitudes and family structure than families from Northern Europe. Therefore, the interpersonal reaction to living in close contact to someone with an eating disorders may differ in Greek culture, which is the setting of the studies undertaken for this PhD.

The main aim of this thesis was examining the transdiagnostic applicability of cognitive interpersonal maintenance model of anorexia nervosa to people with BN and BED. The studies included the following design: a comparison of caregiving styles of people with anorexia nervosa and bulimia nervosa between Greek and English parents; a comparison of caregiving styles between siblings and spouses of adult patients with eating disorders and people with T1 and T2 Diabetes Mellitus. Finally, the last study examined whether caregiver's distress, emotional and behavioral responses influence the treatment outcome in people with Bulimia and Binge Eating Disorder.

8.3 Main research findings

8.3.1. Study 1(a)

Eating disorders in Greece: An examination of parents' distress, attitudes and behaviours.

- Emotionally driven intra familial responses are, as predicted by the model, present across the trans-diagnostic spectrum of eating disorders (Bulimia Nervosa, Anorexia Nervosa, Binge Eating Disorder) in Greek families.
- Greek parents reported high levels of psychological distress, expressed emotions and accommodating behaviours. Moreover, carers' high levels of distress were correlated with high levels of emotional over involvement (overprotective reactions) and accommodating behaviors.
- Parental distress, emotional reactions and accommodation were associated with different aspects of the illness.
- Some parental demographic characteristics and illness aspects and traits predicted parental levels of psychological distress, emotional responses and behaviors (expressed emotions and accommodation).

8.3.2 Study 1(b)

Aspects of caregivers' experiences in eating disorders: comparison between Greek and English parents

- Greek parents demonstrated similar levels of psychological distress but higher levels of criticism and accommodation particularly in the area of avoidance & modifying routine, meal ritual and control over the family than English parents.

8.3.3 Study 2

Experiences Among Non -affected Adult Siblings of People with Eating Disorders and Those of people With Diabetes.

- Siblings of people with eating disorders showed lower levels of depression and stress but higher levels of criticism and accommodation (particularly reassurance seeking and control of family) than the siblings of people with diabetes.
- Age of sibling, illness duration, cohabitation and gender predicted high levels of emotional reactions and behaviors to illness (eating disorder and diabetes)
- High levels of anxiety in siblings of people with eating disorder was associated with higher scores in the area of reassurance seeking. In regard to the type of diagnosis, siblings of people with anorexia nervosa showed that lower levels of depression are linked to higher accommodation on the area of control of family.
- High levels of anxiety in siblings of people with bulimia were associated with more modification and adaptation of their personal routine (work schedule, leisure activities, and family relations) to fit around the patients' symptoms.
- Sisters appeared to be more affected and demonstrated higher levels of anxiety, and engaged more in avoidance modification routine and reassurance seeking than brothers.
- Sibling-patient characteristics had a significant impact on aspects of sibling functioning (diagnosis, patient's age of illness onset, sibling's age, gender, contact time).

8.3.4 Study 3

Partners' experiences of Bulimia Nervosa and Binge Eating Disorder: A comparison with spouses of patient with Type 2 Diabetes Mellitus.

- A quarter of partners of people with Bulimia Nervosa and Binge Eating Disorder reported high levels of psychological distress (particularly depression) and high levels of expressed emotion (particularly criticism) and accommodating behaviors (particularly avoidance and modification of routines).
- Spouses' distress was positively related to emotional overinvolvement and criticism.
- The comparison between eating disorder and diabetes mellitus partners showed similar profiles of depression, stress, emotional overinvolvement, criticism and accommodation. Spouses of people with bulimia and binge eating disorder reported lower levels of anxiety but higher accommodation especially in avoidance and modifications of routine than the spouses of patients with diabetes.

8.3.5 Study 4

An examination of the impact of care giving styles (expressed emotions and accommodation) on the six-month outcome of adults with Bulimia Nervosa or Binge Eating Disorder: Testing the postulations of the cognitive interpersonal model in Bulimia Nervosa and Binge Eating Disorder

- Carer's anxiety did not have a direct relationship with eating disorder symptom change but was mediated through carers' emotional overinvolvement.
- Carers' anxiety was directly and positively associated with emotional overinvolvement which in turn was linked to accommodation.
- Carers' expressed emotions were directly associated with eating disorders symptoms change. Specifically, the higher the level of criticism the worse the patient's outcome and the converse was associated with low levels of criticism. However, unexpectedly, we found that carers emotional overinvolvement was

associated with an improvement in eating disorder symptoms and the reverse was related to low levels of emotional overinvolvement.

- Carers' levels of accommodation were not significantly associated with change in eating disorder symptoms.
- Contact time had a minimal effect on change of eating disorder symptoms and no connection with carers' reactions and behaviors. Patient age was positively correlated with carers' stress. Illness duration was linked with accommodation.
- These findings suggest that targeting carers criticism may improve the outcome of BN and BED.

8.4 Strengths

The novelty of this thesis is based on examining experiences of all types of carers (parents, siblings, spouses) of people with all forms of eating disorder (Bulimia, Binge Eating Disorder and anorexia nervosa). The applicability of the interpersonal maintenance model on caregivers and patients with bulimia and binge eating was tested for the first time. Moreover, study 2 and 3 were the first to examine sibling and spouses' experiences and compare them with a clinical group which has a similar impact on eating behavior (diabetes). This comparison made it possible to identify factors that can impact carers' distress, emotional and behavioral reactions, such as carer's age, gender, illness duration, and type of eating disorder among others. Finally, study 1(b) and 4 highlight the role of cultural differences in family functioning which may affect familial reactions to illness (particularly expressed emotions and accommodation).

8.5 Limitations

The main limitations of each study were presented throughout the thesis in the relevant chapters. The following highlights the main shortcomings of the project as a whole.

8.5.1 Participants and Generalizability

First, in order to further improve the generalizability of the present findings, more care should be taken to achieve a more homogeneous sample in terms of age and gender of carers. The participants are not representative and generalizable to the general

population of ED carers as the majority of carers were recruited from one clinic in Athens.

The participants in Study 2 and Study 3 were recruited from the diabetic department of Iatriko Clinic. It is therefore possible that this group of carers is not representative of all carers in the area of DMs, in that they actively and voluntarily engaged and were involved with services and support networks.

An additional potential bias lies in the fact that, specifically for the parental, siblings' and spouses' sample, the diagnosis for each patient as well as a description of illness-related symptoms and behaviors (used in Study 1,2,3) was collected through a self-report survey completed by carers. Thus, a weakness regarding the reliability of carers' reports about clinical features of the illness was added.

The index of patients had a protracted duration of illness therefore these findings may be limited in the extent to which they can be generalized to patients with duration of illness of less than 9 years.

8.5.2 Correlation, not causation

The cross-sectional design of the studies (1a,1b, 2 and 3) does not allow us to draw unidirectional conclusions regarding the relationship between the variables studied. For example, in the first four studies, it has been found that aspects of illness (ED symptoms and behaviors) may provoke relatives' adverse emotional and behavioral responses to the illness, which in turn, may make the caregiving experience more burdensome. However, the assumption that patterns of relatives' responses may not fuel specific ED symptoms cannot be rejected.

8.6 Clinical implications

The following is a synopsis of the clinical implications overall. Again, these have been discussed in relevant chapters but in the closing section, it is important to reiterate and expand where necessary.

The results from all studies provide evidence for transdiagnostic applicability of interpersonal component of the cognitive maintenance model of eating disorders

(Schmidt & Treasure, 2006; Treasure & Schmidt 2013), for carers of people with Bulimia Nervosa and Binge Eating Disorder.

Therefore, these findings justify the need for carer interventions that may lead to better treatment outcomes. Current guidelines support the involvement of family members in treatment process (National Institute for Health and Care Excellence, 2018; Wilson & Shafran, 2005), as they are seen as part of the solution and possibly the best resource for sustaining their relative's recovery (Downs & Blow, 2013; Eisler, 2005). The findings from this thesis underline the impact that living with an ED has on multiple aspects of family functioning in Greece.

Carers are found to benefit from information about the genetic and neurobiological contributions to eating disorder risk and the perpetuating factors that are included in the cognitive interpersonal maintenance model (Treasure & Schmidt, 2013; Schmidt & Treasure 2006), and advanced later by Treasure, Rhind, Macdonald, and Todd (2015). The first caregivers' manual named New Maudsley Collaborative Care Skills (Treasure, Smith, & Crane, 2007) was transformed into skill-based workshops and more recently as web-based materials (Grover et al., 2011), or workbooks/DVDs (Goddard et al., 2011; Hibbs et al., 2015). Outcomes from interventions following these protocols reveal a significant reduction of burden and distress among caregivers (Grover et al., 2011; Hibbs et al., 2015; Hoyle, Slater, Williams, Schmidt, & Wade, 2013; Marcos, et al., 2013) and also increased patient satisfaction and adherence to treatment (Gisladdottir, Treasure, & Svavarsdottir, 2017; Magill et al., 2016; Salerno et al., 2016). Therefore, it would be helpful to apply and test the effectiveness of these carers' interventions in Greece.

Most notably of clinical relevance, the present thesis findings have demonstrated for the first time that family interventions might need to take into consideration the cultural issues that arose in Study 1b and 4, regarding the role of expressed emotion across cultures. Although it seems clear that in previous studies more attention has been drawn to intra-familial and individual aspects of family caregiving in EDs (i.e., coping strategies, sociodemographic characteristics), there is limited available research about the role of emotional over-involvement in treatment outcome across cultures. Therefore, it would be interesting for future research to consider cultural differences

between carers regarding their emotional experiences of caregiving when developing and carrying out family-based interventions.

8.7 Suggestions for future research

The work presented in this thesis has highlighted numerous avenues for future research to take. A number of suggestions and recommendations are discussed below.

In regards to furthering our understanding of familial functioning, future research should examine BN and BED caregiving aspects in comparison to clinical and control groups. Larger samples of carers are needed. Further examination of the relationship between these aspects of caregiving (e.g. distress, expressed emotions and accommodating behaviours) and patient's symptom change using longitudinal data, will enable the direction of these relationships to be substantiated. In addition, further examination of the caregiving role and related behaviours in fathers, brothers and partners of people with an eating disorder may be useful. Finally, longitudinal cross-cultural studies from Mediterranean area will be useful to understand further the role of expressed emotions in the field of eating disorders.

8.8 Conclusion

Overall this thesis provides further evidence showing that carers of adult people with bulimia and binge eating disorder (parents, siblings, spouses) have high levels of caregiving distress, criticism, emotional overinvolvement and engage in patterns of behaviour (accommodating behaviours) theorised to maintain illness according to the interpersonal cognitive maintenance model on anorexia. This thesis highlights that cultural factors can play an important role in the family's response to an individual with an eating disorder due to differences in family structure, interaction and emotional expression. Additionally, thesis finding suggest: (i) that the caregiver's response is adaptive rather than dysfunctional, and that it is a generic response rather than one specific to mental illness (ii) that overprotection promotes recovery, and (iii) the amendment of interpersonal maintenance model including other forms of ED and sociocultural variations of familial responses.

Chapter Nine

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APPENDICES

Appendices

Ethical approval Study Material

Appendix A: Ethical Approval



**ATHENS MEDICAL
GROUP**

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4 April 2013

Ms. Maria Tsiaka

Director and Founder of Hellenic Center for Eating Disorders

Kipon 40 & Chelidonous, Kifissia ,14564
Athens, Greece

Dear Ms. Tsiaka

Hospital approval: 1094/1-4-2013 **"A description of the interpersonal impact of an eating disorder on family members. An examination of whether cultural, kin ship factors and specific ED behaviours contribute to carer's distress and the maintenance of the illness."**

On behalf of the Committee, I am pleased to confirm the approval for the above research on the basis described in the application form, protocol and supporting documentation. This research PhD project consists four studies that would be conducted in Greece:

Study 1: Eating disorders in Greece. An examination of carers' distress, attitudes and behaviors.

Study 2: Impact of an eating disorder in healthy adult siblings in comparison with those of diabetic patients in Greece.

Study 3: Investigating the experiences of partners of people with Bulimia and BED in comparison to partners of people with diabetes.

Study 4: An examination of the impact of care giving styles (expressed emotions and accommodation) on the six-month outcome of adults Bulimia Nervosa and Binge Eating Disorder: Testing the postulations of the cognitive interpersonal model in anorexia nervosa.

I wish you every success with this research project

Yours sincerely

Menelaos Kalogeris

MD, Scientific Director of Iatriko Hospital in Faliro, Athens
Ethics Committee President

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CONSENT FORM STUDY 1

Explanation of research

We are being invited to participate in this research study. Your participation in the study is voluntary, if you don't wish to take part, simply let researcher to know. Your participation requires your understanding about the purpose of this study and if you wish to take part, please read carefully the following information and sign the following consent form. If you have any questions or concerns about any aspect of this project, please ask the researcher.

Why are you doing this study?

The purposes of this study is to examine whether intrafamilial factors (such as psychological distress, emotional responses and behaviors to illness) that are described by the cognitive interpersonal maintenance model, could be manifested in Greek parents of people with eating disorders (Bulimia Nervosa, Anorexia Nervosa, Binge Eating Disorder). Also, this study data would be compared with preexisting data of English parents of people with anorexia. Our expectation is a deeper understanding of illness's impact on carers which in turn help us to design carers' intervention that promote caregivers' adaptive coping styles may reduce their caregiving burden and improve their interaction with patient.

Why are you selected?

You have been chosen you to participate in this study as being a parent of a person suffering from eating disorder. Participation in this study is voluntary. You do not have to answer any question you do not want to answer. If at any time and for any reason, you would prefer not to participate in this study, please feel free not to. If at any time you would like to stop participating, please tell me. We can take a break, stop and continue at a later date, or stop altogether. You may withdraw from this study at any time, and you will not be penalized in any way for deciding to stop participation. If you decide to withdraw from this study, the researchers will ask you that any information collected from you will not be used if the participant decides to withdraw before finishing the study.

- If you agree to take part, you will be asked if you would like to participate in future studies, how your participation in this study will not be affected if you choose not to participate in future one.

What will I do if I choose to be in this study?

If you agree to participate in this project, you will be asked to complete the demographics details as well as some information about your child 's symptoms and an anonymous set of questionnaires about psychological distress, expressed emotion and accommodating

and enabling behaviors. These responses are concerning your reactions to your affected child. The battery of questionnaires would be sent either electronically or by post and when you have completed it, please send it back to researcher.

What are the possible risks or discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

What are the possible benefits for me or others?

Taking part in this research study may not benefit you personally, but we may learn new things that will help others.

How will you protect the information you collect about me, and how will that information be shared?

Results of this study may be used in publications and presentations. Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. To minimize the risks to confidentiality, your data will be coded and encrypted and manuscripts are stored in a locked cabinet. Only the researcher would have access to the data.

We may share the data we collect from you for use in future research studies or with other researchers – if we share the data that we collect about you, we will remove any information that could identify you before we share it.

Study's results

All the collected information will be analyzed by PhD student Maria Tsiaka, Institute of Psychiatry, King's College, London. Participants will be able to learn about the results of the study on the website, www.eatingresearch.com or if they are requested to be mailed. Any data and information published in scientific journals will also be available to participants upon request.

Who can I contact if I have questions or concerns about this research study?

If you have questions, you are free to ask them now. If you have questions later, you may contact the researchers at King's College with Prof Janet Treasure, Department of Academic Psychiatry, Section of Eating Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Consent

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form.

Consent for use of contact information to be contacted about participation in other studies

Initial one of the following to indicate your choice:

_____ I agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

_____ I do not agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

Participant's Name (printed)

Participant's Signature

Date

Consent Form of Study 1 in Greek

ΕΝΗΜΕΡΩΤΙΚΟ ΔΕΛΤΙΟ ΕΡΕΥΝΑΣ

Πρόσκληση για συμμετοχή στην ακόλουθη ερευνα:

Θα θέλαμε να σας προσκαλέσουμε να συμμετάσχετε σε αυτό το ερευνητικό έργο. Θα πρέπει να συμμετέχετε μόνο εάν το θέλετε. Επιλέγοντας να μην λάβετε μέρος δεν θα αποβεί σε βάρος σας με κανένα τρόπο. Προκειμένου να αποφασίσετε την συμμετοχή σας, είναι σημαντικό να κατανοήσετε τον λόγο για τον οποίο διεξάγεται η συγκεκριμένη έρευνα και τι συνεπάγεται η συμμετοχή σας. Αφιερώστε χρόνο για να διαβάσετε τις ακόλουθες πληροφορίες προσεκτικά και συζητήστε το με άλλους εάν το επιθυμείτε. Ρωτήστε μας αν υπάρχει κάτι που δεν είναι σαφές ή χρειάζεστε επιπλέον πληροφορίες.

Ποιος είναι ο σκοπός της μελέτης:

Μας ενδιαφέρει να μάθουμε κατά πόσο η ψυχολογία (σε επίπεδο άγχους, κατάθλιψης και στρες) των γονιών ατόμων με Διατροφικές Διαταραχές όπως Νευρική Βουλιμία ή Ανορεξία επηρεάζεται από την ασθένεια, καθώς και να αξιολογήσουμε ποια συναισθήματα τους είναι κυρίαρχα απέναντι στο άτομο που πάσχει από την διαταραχή και ποιες συμπεριφορές υιοθετούνται για να αντιμετωπίσει της ασθένειας.

Τα δεδομένα της έρευνας θα συγκριθούν με προϋπάρχοντα δεδομένα γονιών ατόμων με Διατροφικές Διαταραχές όπως Νευρική Βουλιμία ή Ανορεξία από την Μεγάλη Βρετανία για να διερευνήσουμε τυχόν διαφορές που υπάρχουν εξαιτίας των διαφορών στη δομή της οικογένειας και της κουλτούρας.

Αναμένουμε ότι η βαθύτερη κατανόηση των συνεπειών της ασθένειας σε συγγενείς ατόμων με Διατροφικές Διαταραχές θα μας βοηθήσει να αναπτύξουμε επιπλέον θεραπευτικά μοντέλα για την ουσιαστική υποστήριξη της ελληνικής οικογένειας και του ασθενή που πάσχει από Δ.Δ.

Γιατί έχετε επιλεγεί:

Σας έχουμε επιλέξει για πιθανή συμμετοχή σε αυτή τη μελέτη γιατί εσείς είστε γονιός ατόμου που πάσχει από διατροφική διαταραχή (Νευρική Ανορεξία, Νευρική Βουλιμία, Αδηφαγική Διαταραχή και άτυπες μορφές). Εξαρτάται απόλυτα από εσάς αν θα λάβετε ή όχι μέρος. Εάν αποφασίσετε να λάβετε μέρος, θα σας δοθεί ένα αντίγραφο του παρόντος φύλλου πληροφοριών και θα σας ζητηθεί να υπογράψετε ένα έντυπο συγκατάθεσης. Εάν αποφασίσετε να συμμετάσχετε μπορείτε οποιαδήποτε στιγμή να αποχωρήσετε από τη μελέτη χωρίς να δώσετε εξηγήσεις για αυτό.

- Εάν συμφωνήσετε να λάβετε μέρος, θα ερωτηθείτε αν θα θέλατε να συμμετάσχετε και σε μελλοντικές έρευνες. Η συμμετοχή σας στην παρούσα μελέτη δεν θα επηρεαστεί σε περίπτωση που επιλέξετε να μην λάβετε μέρος σε μελλοντικές.

Τι θα σας συμβεί αν λάβετε μέρος:

Εάν αποφασίσετε να συμμετάσχετε σε αυτό το έργο, θα σας ζητηθεί να συμπληρώσετε 4 ερωτηματολόγια (χρόνος συμπλήρωσης περίπου 25 λεπτά). Όλα τα δεδομένα προστατεύονται από κωδικοποιημένο σύστημα και παραμένουν ανώνυμα.

Ποιοί είναι οι πιθανοί κίνδυνοι από την συμμετοχή:

Δεν προβλέπεται κανένας κίνδυνος από την συμπλήρωση των ερωτηματολογίων, πέρα από το συνηθισμένο που διατρέχουμε στην καθημερινότητα μας.

Ποια είναι τα πιθανά οφέλη/ πλεονεκτήματα από τη συμμετοχή:

Μερικοί φροντιστές ανακαλύπτουν ότι συμπληρώνοντας τα ερωτηματολόγια τους βοηθά να προβληματιστούν για τους εαυτούς τους ή τις εμπειρίες τους ως φροντιστές και αυτό από μόνο του είναι χρήσιμο. Επιπλέον, συμφωνώντας να λάβετε μέρος σε αυτή την μελέτη συνεισφέρετε στην έρευνα για τη βελτίωση και προσαρμογή καλύτερων μελλοντικών παρεμβάσεων και ελπίζουμε ότι θα βοηθήσει τους φροντιστές να αντιμετωπίσουν καλύτερα τη κατάσταση στην οποία βρίσκονται.

Η συμμετοχή σας στη μελέτη θα παραμείνει εμπιστευτική!

Τα δεδομένα που συλλέγουμε είναι ανώνυμα και η ταυτότητα σας προστατεύεται από κωδικοποιημένο σύστημα. Οι πληροφορίες που συγκεντρώνονται είναι εμπιστευτικές μεταξύ εσάς και του ερευνητή. Τα αποθηκευμένα δεδομένα προστατεύονται από ένα κωδικό

πρόσβασης και τα χειρόγραφα φυλάσσονται σε κλειδωμένο ντουλάπι. Μόνο ο ερευνητής έχει πρόσβαση στα δεδομένα. Είστε ελεύθεροι να αποχωρήσετε σε οποιοδήποτε σημείο μέχρι την σύνταξη των δεδομένων.

- ο Μπορείτε να αποσύρετε τα δεδομένα σας ανά πάσα στιγμή μέχρι τη μεταγραφή τους για χρήση στη τελική αναφορά.
- ο Εάν αποφασίσετε να λάβετε μέρος θα σας δοθεί το παρόν έγγραφο πληροφοριών και θα σας ζητηθεί να υπογράψετε έντυπο συγκατάθεσης.
- ο Καθώς η συμμετοχή είναι ανώνυμη δεν είναι εφικτό να αποσύρετε τα δεδομένα σας μετά την ολοκλήρωση της έρευνας..
- ο Τα αποτελέσματα της έρευνας θα παρουσιαστούν σε συνέδρια επιστημονικά η θα δημοσιευθούν σε διεθνή επιστημονικά περιοδικά
- ο Τα δεδομένα της έρευνας μπορεί να τα μοιραστούμε με άλλους συνάδελφους για την διεξαγωγή άλλων ερευνών , η ανωνυμία σας είναι διασφαλισμένη.

Τι θα γίνουν τα αποτελέσματα της έρευνας:

Όλες οι συγκεντρωμένες πληροφορίες θα αναλυθούν και συνταχθούν από την υποψήφια Διδάκτορα, Μαρία Τσιάκα Institute of Psychiatry, King's College, London. Οι συμμετέχοντες θα μπορούν να μάθουν για τα αποτελέσματα της έρευνας στην ιστοσελίδα, website www.eatingresearch.com ή εφόσον ζητηθεί να σταλούν ταχυδρομικώς. Οποιαδήποτε δεδομένα και πληροφορίες δημοσιευθούν σε επιστημονικά περιοδικά θα είναι επίσης διαθέσιμα στους συμμετέχοντες κατόπιν αιτήματος.

Επικοινωνία για περισσότερες πληροφορίες:

Εάν η μελέτη σας έβλαψε με οποιοδήποτε τρόπο μπορείτε να επικοινωνήσετε με το King's College London χρησιμοποιώντας τα ακόλουθα στοιχεία για διευκρινίσεις και πληροφορίες: **Prof Janet Treasure**, Department of Academic Psychiatry, Section of Eating Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Παρακαλούμε δώστε την συγκατάθεσης σας υπογράφοντας την παρακάτω συναινετική φόρμα. Παρακαλούμε κρατείστε το έντυπο ενημέρωσης για εσάς.

ΣΥΝΑΙΝΕΣΗ ΣΥΜΜΕΤΟΧΗΣ ΣΤΗΝ ΕΡΕΥΝΑ

Έχω διαβάσει το παραπάνω ενημερωτικό έντυπο της έρευνας .Μου δόθηκε η ευκαιρία να θέσω ερωτήσεις και οι απαντήσεις μου απαντήθηκαν. Αν έχω επιπλέον ερωτήσεις, Γνωρίζω που να απευθυνθώ. Συμφωνώ να συμμετάσχω στην ερευνητική μελέτη που περιγράφεται παραπάνω και θα λάβω αντίγραφο αυτής της φόρμας συγκατάθεσης.

Συγκατάθεση για τη χρήση των πληροφοριών για να επικοινωνήσουμε σχετικά με τη συμμετοχή σας σε άλλες σπουδές

Αρχικό από τα παρακάτω για να δηλώσετε την επιλογή σας:

_____ Συμφωνώ να επιτρέψω στους ερευνητές να χρησιμοποιήσουν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για να επικοινωνήσουν μαζί μου σχετικά με τη συμμετοχή σε μελλοντικές έρευνες.

_____ Δεν συμφωνώ να χρησιμοποιούν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για τη συμμετοχή σε μελλοντικές έρευνες.

Όνομα και Επώνυμο Συμμετέχοντος

Υπογραφή

CONSENT FORM STUDY 2

Explanation of research

We are being invited to participate in this research study. Your participation in the study is voluntary, if you don't wish to take part, simply let researcher to know. Your participation requires your understanding about the purpose of this study and if you wish to take part, please read carefully the following information and sign the following consent form. If you have any questions or concerns about any aspect of this project, please ask the researcher.

Why are you doing this study?

The purposes of this study are to examine the impact of illness in terms of psychological distress, expressed emotions and accommodation among healthy siblings of individuals with eating disorder and to compare these reactions to those seen in siblings with diabetes mellitus.

Our expectation is a deeper understanding of illness's impact on siblings which in turn help us to design carers' intervention that promote sibling's adaptive coping styles may reduce their caregiving burden and improve their interaction with patient.

Why are you selected?

You have been chosen you to participate in this study as being an unaffected adult sibling of a person suffering from eating disorder or diabetes mellitus. Participation in this study is voluntary. You do not have to answer any question you do not want to answer. If at any time and for any reason, you would prefer not to participate in this study, please feel free not to. If at any time you would like to stop participating, please tell me. We can take a break, stop and continue at a later date, or stop altogether. You may withdraw from this study at any time, and you will not be penalized in any way for deciding to stop participation. If you decide to withdraw from this study, the researchers will ask you that any information collected from you will not be used if the participant decides to withdraw before finishing the study.

- If you agree to take part, you will be asked if you would like to participate in future studies, how your participation in this study will not be affected if you choose not to participate in future one.

What will I do if I choose to be in this study?

If you agree to participate in this project, you will be asked to complete the demographics details as well as some information about your sibling's symptoms and an anonymous set of questionnaires about psychological distress, expressed emotion and accommodating and enabling behaviors. These responses are concerning your reactions to affected child. The battery of questionnaires would be sent either electronically or by post and after completion sending it back to the researcher.

What are the possible risks or discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

What are the possible benefits for me or others?

Taking part in this research study may not benefit you personally, but we may learn new things that will help others.

How will you protect the information you collect about me, and how will that information be shared?

Results of this study may be used in publications and presentations. Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. To minimize the risks to confidentiality, your data will be coding and encrypted and manuscripts are stored in a locked cabinet. Only the researcher would have access to the data.

We may share the data we collect from you for use in future research studies or with other researchers – if we share the data that we collect about you, we will remove any information that could identify you before we share it.

Study's results

All the collected information will be analyzed by PhD student Maria Tsiaka, Institute of Psychiatry, King's College, London. Participants will be able to learn about the results of the study on the website, www.eatingresearch.com or if they are requested to be mailed. Any data and information published in scientific journals will also be available to participants upon request.

Who can I contact if I have questions or concerns about this research study?

If you have questions, you are free to ask them now. If you have questions later, you may contact the researchers at King's College with Prof Janet Treasure, Department of Academic Psychiatry, Section of Eating Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Consent

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form.

Consent for use of contact information to be contacted about participation in other studies

Initial one of the following to indicate your choice:

_____ I agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

_____ I do not agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

Participant's Name (printed)

Participant's Signature

Date

Consent Form of Study 2 in Greek

ΕΝΗΜΕΡΩΤΙΚΟ ΔΕΛΤΙΟ ΕΡΕΥΝΑΣ

Πρόσκληση για συμμετοχή στην ακόλουθη έρευνα:

Θα θέλαμε να σας προσκαλέσουμε να συμμετάσχετε σε αυτό το ερευνητικό έργο. Θα πρέπει να συμμετέχετε μόνο εάν το θέλετε. Επιλέγοντας να μην λάβετε μέρος δεν θα αποβεί σε βάρος σας με κανένα τρόπο. Προκειμένου να αποφασίσετε την συμμετοχή σας, είναι σημαντικό να κατανοήσετε τον λόγο για τον οποίο διεξάγεται η συγκεκριμένη έρευνα και τι συνεπάγεται η συμμετοχή σας. Αφιερώστε χρόνο για να διαβάσετε τις ακόλουθες πληροφορίες προσεκτικά και συζητήστε το με άλλους εάν το επιθυμείτε. Ρωτήστε μας αν υπάρχει κάτι που δεν είναι σαφές ή χρειάζεστε επιπλέον πληροφορίες.

Ποιος είναι ο σκοπός της μελέτης:

Μας ενδιαφέρει να μάθουμε κατά πόσο επηρεάζεται η ψυχολογία (σε επίπεδο άγχους, κατάθλιψης και στρες) των ενήλικων αδελφών (άντρες, γυναίκες) που δεν έχουν νοσήσει από διατροφική διαταραχή, ατόμων με Διατροφικές Διαταραχές όπως Βουλιμία η Ανορεξία η ατόμων που πάσχουν από Διαβήτη τύπου 1 και 2.

Καθώς και να αξιολογήσουμε ποια συναισθήματα σας είναι κυρίαρχα απέναντι στο άτομο που πάσχει από την διαταραχή και ποιες συμπεριφορές υιοθετείτε για να αντιμετωπίσετε την ασθένεια.

Η σύγκριση μεταξύ ενήλικων αδελφών ατόμων με Βουλιμία η Ανορεξία και Διαβήτη τύπου 1 και 2 αποσκοπεί στην διερεύνηση των κοινών και διαφορετικών επιπέδων του αντίκτυπου που έχουν οι δύο ασθένειες στα αδέλφια.

Αναμένουμε ότι η βαθύτερη κατανόηση των συνεπειών της ασθένειας σε αδέλφια ατόμων με Διατροφικές Διαταραχές ή Διαβήτη τύπου 1 και 2. Έτσι θα μας βοηθήσει να αναπτύξουμε επιπλέον θεραπευτικά μοντέλα για την ουσιαστική υποστήριξη των αδελφών ατόμων με διατροφική διαταραχή είτε Διαβήτη τύπου 1 και 2.

Γιατί έχετε επιλεγεί:

Σας έχουμε επιλέξει για πιθανή συμμετοχή σε αυτή τη μελέτη γιατί είστε αδελφός η αδελφή κάποιου που πάσχει από διατροφικές διαταραχές (Ανορεξία, Βουλιμία) είτε Διαβήτη τύπου 1 και 2.

Εξαρτάται απόλυτα από εσάς αν θα λάβετε ή όχι μέρος. Εάν αποφασίσετε να λάβετε μέρος, θα σας δοθεί ένα αντίγραφο του παρόντος φύλλου πληροφοριών και θα σας ζητηθεί να υπογράψετε ένα έντυπο συγκατάθεσης. Εάν αποφασίσετε να συμμετάσχετε μπορείτε οποιαδήποτε στιγμή να αποχωρήσετε από τη μελέτη χωρίς να δώσετε εξηγήσεις για αυτό.

- ο Εάν συμφωνήσετε να λάβετε μέρος, θα ερωτηθείτε αν θα θέλατε να συμμετάσχετε και σε μελλοντικές έρευνες. Η συμμετοχή σας στην παρούσα μελέτη δεν θα επηρεαστεί σε περίπτωση που επιλέξετε να μην λάβετε μέρος σε μελλοντικές.

Τι θα σας συμβεί αν λάβω μέρος:

Εάν αποφασίσετε να συμμετάσχετε σε αυτό το έργο, θα σας ζητηθεί να συμπληρώσετε 4 ερωτηματολόγια (χρόνος συμπλήρωσης περίπου 25 λεπτά). Όλα τα δεδομένα προστατεύονται από κωδικοποιημένο σύστημα και παραμένουν ανώνυμα.

Ποιοί είναι οι πιθανοί κίνδυνοι από την συμμετοχή:

Πιθανόν η διαδικασία συμπλήρωσης των ερωτηματολογίων να είναι κάπως δύσκολη με κάποιο τρόπο, ίσως να την βρείτε κουραστική.

Ποια είναι τα πιθανά οφέλη / πλεονεκτήματα από τη συμμετοχή;

Μερικοί φροντιστές ανακαλύπτουν ότι συμπληρώνοντας τα ερωτηματολόγια τους βοηθά να προβληματιστούν για τους εαυτούς τους ή τις εμπειρίες τους ως φροντιστές και αυτό από μόνο του είναι χρήσιμο. Επιπλέον, συμφωνώντας να λάβετε μέρος σε αυτή την μελέτη συνεισφέρετε στην έρευνα για τη βελτίωση και προσαρμογή καλύτερων μελλοντικών παρεμβάσεων και ελπίζουμε ότι θα βοηθήσει τους φροντιστές να αντιμετωπίσουν καλύτερα τη κατάσταση στην οποία βρίσκονται.

Η συμμετοχή σας στη μελέτη θα παραμείνει εμπιστευτική!

Τα δεδομένα που συλλέγουμε είναι ανώνυμα και η ταυτότητα σας προστατεύεται από κωδικοποιημένο σύστημα. Οι πληροφορίες που συγκεντρώνονται είναι εμπιστευτικές μεταξύ εσάς και του ερευνητή. Τα αποθηκευμένα δεδομένα προστατεύονται από ένα κωδικό πρόσβασης και τα χειρόγραφα φυλάσσονται σε κλειδωμένο ντουλάπι. Μόνο ο ερευνητής έχει πρόσβαση στα δεδομένα. Είστε ελεύθεροι να αποχωρήσετε σε οποιοδήποτε σημείο μέχρι την σύνταξη των δεδομένων.

- Μπορείτε να αποσύρετε τα δεδομένα σας ανά πάσα στιγμή μέχρι τη μεταγραφή τους για χρήση στη τελική αναφορά.
- Εάν αποφασίσετε να λάβετε μέρος θα σας δοθεί το παρόν έγγραφο πληροφοριών και θα σας ζητηθεί να υπογράψετε έντυπο συγκατάθεσης.
- Καθώς η συμμετοχή είναι ανώνυμη δεν είναι εφικτό να αποσύρετε τα δεδομένα σας μετά την ολοκλήρωση της έρευνας.
- Τα αποτελέσματα της έρευνας θα παρουσιαστούν σε συνέδρια επιστημονικά ή θα δημοσιευθούν σε διεθνή επιστημονικά περιοδικά
- Τα δεδομένα της έρευνας μπορεί να τα μοιραστούμε με άλλους συνάδελφους για την διεξαγωγή άλλων ερευνών, η ανωνυμία σας είναι διασφαλισμένη

Τι θα γίνουν τα αποτελέσματα της έρευνας;

Όλες οι συγκεντρωμένες πληροφορίες θα αναλυθούν και συνταχθούν από την υποψήφια Διδάκτορα, Μαρία Τσιάκα Institute of Psychiatry, King's College, London. Οι συμμετέχοντες θα μπορούν να μάθουν για τα αποτελέσματα της έρευνας στην ιστοσελίδα, website www.eatingresearch.com ή εφόσον ζητηθεί να σταλούν ταχυδρομικώς. Οποιαδήποτε δεδομένα και πληροφορίες δημοσιευθούν σε επιστημονικά περιοδικά θα είναι επίσης διαθέσιμα στους συμμετέχοντες κατόπιν αιτήματος.

Επικοινωνία για περισσότερες πληροφορίες:

Εναπόκειται σε εσάς να αποφασίσετε αν θα λάβετε μέρος ή όχι. Εάν αποφασίσετε να συμμετέχετε μπορείτε να αποχωρήσετε οποιαδήποτε στιγμή χωρίς εξηγήσεις.

Εάν η μελέτη σας έβλαψε με οποιοδήποτε τρόπο μπορείτε να επικοινωνήσετε με το King's College London χρησιμοποιώντας τα ακόλουθα στοιχεία για διευκρινίσεις και πληροφορίες: **Prof Janet Treasure**, Department of Academic Psychiatry, Section of Eating Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Παρακαλούμε δώστε την συγκατάθεση σας υπογράφοντας την παρακάτω συναινετική φόρμα. Παρακαλούμε κρατείστε το έντυπο ενημέρωσης για εσάς.

ΣΥΝΑΙΝΕΣΗ ΣΥΜΜΕΤΟΧΗΣ ΣΤΗΝ ΕΡΕΥΝΑ

Έχω διαβάσει το παραπάνω ενημερωτικό έντυπο της έρευνας. Μου δόθηκε η ευκαιρία να θέσω ερωτήσεις και οι απαντήσεις μου απαντήθηκαν. Αν έχω επιπλέον ερωτήσεις, Γνωρίζω που να απευθυνθώ. Συμφωνώ να συμμετάσχω στην ερευνητική μελέτη που περιγράφεται παραπάνω και θα λάβω αντίγραφο αυτής της φόρμας συγκατάθεσης.

Συγκατάθεση για τη χρήση των πληροφοριών για να επικοινωνήσουμε σχετικά με τη συμμετοχή σας σε άλλες σπουδές

Αρχικό από τα παρακάτω για να δηλώσετε την επιλογή σας:

_____ Συμφωνώ να επιτρέψω στους ερευνητές να χρησιμοποιήσουν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για να επικοινωνήσουν μαζί μου σχετικά με τη συμμετοχή σε μελλοντικές έρευνες.

_____ Δεν συμφωνώ να χρησιμοποιούν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για τη συμμετοχή σε μελλοντικές έρευνες.

Όνομα και Επώνυμο Συμμετέχοντος

Υπογραφή

CONSENT FORM STUDY 3

Explanation of research

We are being invited to participate in this research study. Your participation in the study is voluntary, if you don't wish to take part, simply let researcher to know. Your participation requires your understanding about the purpose of this study and if you wish to take part, please read carefully the following information and sign the following consent form. If you have any questions or concerns about any aspect of this project, please ask the researcher.

Why are you doing this study?

The purposes of this study are to examine the impact of illness in terms of psychological distress, expressed emotions and accommodation among partners of individuals with Bulimia Nervosa and Binge Eating Disorder and to compare these reactions to those seen in spouses of people with Type 2 Diabetes Mellitus.

Our expectation is a deeper understanding of illness's impact on carers which in turn help us to design carers' intervention that promote caregivers' adaptive coping styles may reduce their caregiving burden and improve their interaction with patient.

Why are you selected?

You have been chosen you to participate in this study as being a spouse or a partner of a person suffering from Bulimia Nervosa and Binge Eating Disorders or Type 2 Diabetes mellitus. Participation in this study is voluntary. You do not have to answer any question you do not want to answer. If at any time and for any reason, you would prefer not to participate in this study, please feel free not to. If at any time you would like to stop participating, please tell me. We can take a break, stop and continue at a later date, or stop altogether. You may withdraw from this study at any time, and you will not be penalized in any way for deciding to stop participation. If you decide to withdraw from this study, the researchers will ask you that any information collected from you will not be used if the participant decides to withdraw before finishing the study.

- If you agree to take part, you will be asked if you would like to participate in future studies, how your participation in this study will not be affected if you choose not to participate in future one.

What will I do if I choose to be in this study?

If you agree to participate in this project, you will be asked to complete the demographics details as well as some information about your partner's symptoms and

an anonymous set of questionnaires about psychological distress, expressed emotion and accommodating and enabling behaviors. These responses are concerning your reactions to affected child. The battery of questionnaires would be sent either electronically or by post and after completion sending it back to the researcher.

What are the possible risks or discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

What are the possible benefits for me or others?

Taking part in this research study may not benefit you personally, but we may learn new things that will help others.

How will you protect the information you collect about me, and how will that information be shared?

Results of this study may be used in publications and presentations. Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. To minimize the risks to confidentiality, your data will be coding and encrypted and manuscripts are stored in a locked cabinet. Only the researcher would have access to the data.

We may share the data we collect from you for use in future research studies or with other researchers – if we share the data that we collect about you, we will remove any information that could identify you before we share it.

Study's results

All the collected information will be analyzed by PhD student Maria Tsiaka, Institute of Psychiatry, King's College, London. Participants will be able to learn about the results of the study on the website, www.eatingresearch.com or if they are requested to be mailed. Any data and information published in scientific journals will also be available to participants upon request.

Who can I contact if I have questions or concerns about this research study?

If you have questions, you are free to ask them now. If you have questions later, you may contact the researchers at King's College with Prof Janet Treasure, Department of Academic Psychiatry, Section of Eating Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Consent

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form.

Consent for use of contact information to be contacted about participation in other studies

Initial one of the following to indicate your choice:

_____ I agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

_____ I do not agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

Participant's Name (printed)

Participant's Signature

Date

Consent Form of Study 3 in Greek

ΕΝΗΜΕΡΩΤΙΚΟ ΔΕΛΤΙΟ ΕΡΕΥΝΑΣ

Πρόσκληση για συμμετοχή στην ακόλουθη έρευνα:

Θα θέλαμε να σας προσκαλέσουμε να συμμετάσχετε σε αυτό το ερευνητικό έργο. Θα πρέπει να συμμετέχετε μόνο εάν το θέλετε. Επιλέγοντας να μην λάβετε μέρος δεν θα αποβεί σε βάρος σας με κανένα τρόπο. Προκειμένου να αποφασίσετε την συμμετοχή σας, είναι σημαντικό να κατανοήσετε τον λόγο για τον οποίο διεξάγεται η συγκεκριμένη έρευνα και τι συνεπάγεται η συμμετοχή σας. Αφιερώστε χρόνο για να διαβάσετε τις ακόλουθες πληροφορίες προσεκτικά και συζητήστε το με άλλους εάν το επιθυμείτε. Ρωτήστε μας αν υπάρχει κάτι που δεν είναι σαφές ή χρειάζεστε επιπλέον πληροφορίες.

Ποιος είναι ο σκοπός της μελέτης:

Μας ενδιαφέρει να μάθουμε κατά πόσο επηρεάζεται η ψυχολογία (σε επίπεδο άγχους, κατάθλιψης και στρες) των συντρόφων και συζύγων ατόμων με Διατροφικές Διαταραχές όπως Βουλιμία ή Αδηφαγική Διαταραχή είτε από Διαβήτη τύπου 1 και 2. Καθώς και να αξιολογήσουμε ποια συναισθήματα σας είναι κυρίαρχα απέναντι στο άτομο που πάσχει από την διαταραχή και ποιες συμπεριφορές υιοθετείτε για να αντιμετωπίσετε την ασθένεια. Η συγκριτική έρευνα των συντρόφων ατόμων με Βουλιμία ή Αδηφαγική Διαταραχή και Διαβήτη τύπου 1 και 2 αποσκοπεί στην διερεύνηση των κοινών και διαφορετικών επίπεδων του αντίκτυπου που έχουν οι δυο ασθένειες στους συντρόφους.

Αναμένουμε ότι η βαθύτερη κατανόηση των συνεπειών της ασθένειας σε συντρόφους ατόμων με Διατροφικές Διαταραχές, Βουλιμία ή Αδηφαγική Διαταραχή είτε με Διαβήτη τύπου 1 και 2, θα μας βοηθήσει να αναπτύξουμε επιπλέον θεραπευτικά μοντέλα για την ουσιαστική υποστήριξη των συντρόφων και του ασθενή που πάσχει από Διαβήτη 1 ή 2.

Γιατί έχετε επιλεγεί:

Σας έχουμε επιλέξει για πιθανή συμμετοχή σε αυτή τη μελέτη γιατί εσείς σύντροφος φροντίζετε επί του παρόντος κάποιον που πάσχει από Νευρική Βουλιμία και Αδηφαγική Διαταραχή ή Διαβήτη 2. Εξαρτάται απόλυτα από εσάς αν θα λάβετε ή όχι μέρος. Εάν αποφασίσετε να λάβετε μέρος, θα σας δοθεί ένα αντίγραφο του παρόντος φύλλου πληροφοριών και θα σας ζητηθεί να υπογράψετε ένα έντυπο συγκατάθεσης. Εάν αποφασίσετε να συμμετάσχετε μπορείτε οποιαδήποτε στιγμή να αποχωρήσετε από τη μελέτη χωρίς να δώσετε εξηγήσεις για αυτό.

- Εάν συμφωνήσετε να λάβετε μέρος, θα ερωτηθείτε αν θα θέλατε να συμμετάσχετε και σε μελλοντικές έρευνες. Η συμμετοχή σας στην παρούσα μελέτη δεν θα επηρεαστεί σε περίπτωση που επιλέξετε να μην λάβετε μέρος σε μελλοντικές.
- Τα αποτελέσματα της έρευνας θα παρουσιαστούν σε συνέδρια και επιστημονικά περιοδικά
- Καθώς η συμμετοχή είναι ανώνυμη δεν είναι εφικτό να αποσύρετε τα δεδομένα σας εφόσον έχει ολοκληρωθεί η έρευνα.
- Τα δεδομένα της έρευνας μπορεί να τα μοιραστούμε με άλλους συνάδελφους για την διεξαγωγή άλλων ερευνών, η ανωνυμία σας είναι διασφαλισμένη.

Τι θα σας συμβεί αν λάβω μέρος;

Εάν αποφασίσετε να συμμετάσχετε σε αυτό το έργο θα σας ζητηθεί να συμπληρώσετε 4 ερωτηματολόγια (χρόνος συμπλήρωσης περίπου 25 λεπτά). Όλα τα δεδομένα προστατεύονται από κωδικοποιημένο σύστημα και παραμένουν ανώνυμα.

Ποιοί είναι οι πιθανοί κίνδυνοι από την συμμετοχή;

Πιθανόν η διαδικασία συμπλήρωσης των ερωτηματολογίων να είναι κάπως δύσκολη με κάποιο τρόπο, ίσως να την βρείτε κουραστική.

Ποια είναι τα πιθανά οφέλη / πλεονεκτήματα από τη συμμετοχή;

Μερικοί φροντιστές ανακαλύπτουν ότι συμπληρώνοντας τα ερωτηματολόγια τους βοηθά να προβληματιστούν για τους εαυτούς τους ή τις εμπειρίες τους ως φροντιστές και αυτό από μόνο του είναι χρήσιμο. Επιπλέον, συμφωνώντας να λάβετε μέρος σε αυτή την μελέτη συνεισφέρετε στην έρευνα για τη βελτίωση και προσαρμογή καλύτερων μελλοντικών παρεμβάσεων και ελπίζουμε ότι θα βοηθήσει τους φροντιστές να αντιμετωπίσουν καλύτερα την κατάσταση στην οποία βρίσκονται.

Η συμμετοχή σας στη μελέτη θα παραμείνει εμπιστευτική!

Τα δεδομένα που συλλέγουμε είναι ανώνυμα και η ταυτότητα σας προστατεύεται από κωδικοποιημένο σύστημα. Οι πληροφορίες που συγκεντρώνονται είναι εμπιστευτικές μεταξύ εσάς και του ερευνητή. Τα αποθηκευμένα δεδομένα προστατεύονται από ένα κωδικό πρόσβασης και τα χειρόγραφα φυλάσσονται σε κλειδωμένο ντουλάπι. Μόνο ο ερευνητής έχει πρόσβαση στα δεδομένα. Είστε ελεύθεροι να αποχωρήσετε σε οποιοδήποτε σημείο μέχρι την σύνταξη των δεδομένων.

- [44]. Μπορείτε να αποσύρετε τα δεδομένα σας ανά πάσα στιγμή μέχρι τη μεταγραφή τους για χρήση στη τελική αναφορά.
- [45]. Εάν αποφασίσετε να λάβετε μέρος θα σας δοθεί το παρόν έγγραφο πληροφοριών και θα σας ζητηθεί να υπογράψετε έντυπο συγκατάθεσης.
- [46]. Καθώς η συμμετοχή είναι ανώνυμη δεν είναι εφικτό να αποσύρετε τα δεδομένα σας μετά την ολοκλήρωση της έρευνας.
- [47]. Τα αποτελέσματα της έρευνας θα παρουσιαστούν σε συνέδρια επιστημονικά ή θα δημοσιευθούν σε διεθνή επιστημονικά περιοδικά.
- [48]. Τα δεδομένα της έρευνας μπορεί να τα μοιραστούμε με άλλους συνάδελφους για την διεξαγωγή άλλων ερευνών, η ανωνυμία σας είναι διασφαλισμένη

Τι θα γίνουν τα αποτελέσματα της έρευνας;

Όλες οι συγκεντρωμένες πληροφορίες θα αναλυθούν και συνταχθούν από την υποψήφια Διδάκτορα, Μαρία Τσιάκα, Institute of Psychiatry, King's College, London. Οι συμμετέχοντες θα μπορούν να μάθουν για τα αποτελέσματα της έρευνας στην ιστοσελίδα, website www.eatingresearch.com ή εφόσον ζητηθεί να σταλούν ταχυδρομικώς. Οποιαδήποτε δεδομένα και πληροφορίες δημοσιευθούν σε επιστημονικά περιοδικά θα είναι επίσης διαθέσιμα στους συμμετέχοντες κατόπιν αιτήματος.

Επικοινωνία για περισσότερες πληροφορίες:

Εναπόκειται σε εσάς να αποφασίσετε αν θα λάβετε μέρος ή όχι. Εάν αποφασίσετε να συμμετέχετε μπορείτε να αποχωρήσετε οποιαδήποτε στιγμή χωρίς να εξηγήσεις.

Εάν η μελέτη σας έβλαψε με οποιοδήποτε τρόπο μπορείτε να επικοινωνήσετε με το King's College London χρησιμοποιώντας τα ακόλουθα στοιχεία για διευκρινίσεις και πληροφορίες: Prof Janet Treasure, Department of Academic Psychiatry, Section of Eating

Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Παρακαλούμε δώστε την συγκατάθεσής σας υπογράφοντας την παρακάτω συναινετική φόρμα. Παρακαλούμε κρατείστε το έντυπο ενημέρωσης για εσάς.

ΣΥΝΑΙΝΕΣΗ ΣΥΜΜΕΤΟΧΗΣ ΣΤΗΝ ΕΡΕΥΝΑ

Έχω διαβάσει το παραπάνω ενημερωτικό έντυπο της έρευνας. Μου δόθηκε η ευκαιρία να θέσω ερωτήσεις και οι απαντήσεις μου απαντήθηκαν. Αν έχω επιπλέον ερωτήσεις, Γνωρίζω που να απευθυνθώ. Συμφωνώ να συμμετάσχω στην ερευνητική μελέτη που περιγράφεται παραπάνω και θα λάβω αντίγραφο αυτής της φόρμας συγκατάθεσης.

Συγκατάθεση για τη χρήση των πληροφοριών για να επικοινωνήσουμε σχετικά με τη συμμετοχή σας σε άλλες σπουδές

Αρχικό από τα παρακάτω για να δηλώσετε την επιλογή σας:

_____ Συμφωνώ να επιτρέψω στους ερευνητές να χρησιμοποιήσουν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για να επικοινωνήσουν μαζί μου σχετικά με τη συμμετοχή σε μελλοντικές έρευνες.

_____ Δεν συμφωνώ να χρησιμοποιούν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για τη συμμετοχή σε μελλοντικές έρευνες.

Όνομα και Επώνυμο Συμμετέχοντος

Υπογραφή

PATIENT 'S CONSENT FORM STUDY 4

Explanation of research

We are being invited to participate in this research study. Your participation in the study is voluntary, if you don't wish to take part, simply let researcher to know. Your participation requires your understanding about the purpose of this study and if you wish to take part, please read carefully the following information and sign the following consent form. If you have any questions or concerns about any aspect of this project, please ask the researcher.

Why are you doing this study?

The purpose of this study is to examine if any of your carer's emotional and behavioral reactions to your illness, will affect your change of symptoms after 6 months of treatment.

This study will help us to understand the cascade of processes that mediate the impact of family dysfunction on caregivers' psychological distress through their emotional responses (emotional overinvolvement or critical attitude toward the patient) and behaviors which in turn may hinder recovery, is crucial in developing more effective family interventions aiming to improve dysfunctional familial patterns of interactions by promoting awareness of family dynamics may indeed reduce the burden and improve the emotional well-being of family caregivers.

Why are you selected?

You have been chosen you to participate in this study as asking professional help to our unit and being diagnosed with Bulimia or Binge Eating Disorder. Moreover, we will be asked to define a person as your primary carer (parent, spouse, sibling, or a friend) who has your permission and agree to take part in this study. After six months, we will ask to complete the same questionnaire of eating disorders symptoms. Participation in this study is voluntary. You do not have to answer any question you do not want to answer. If at any time and for any reason, you would prefer not to participate in this study, please feel free not to. If at any time you would like to stop

participating, please tell me. We can take a break, stop and continue at a later date, or stop altogether. You may withdraw from this study at any time, and you will not be penalized in any way for deciding to stop participation. If you decide to withdraw from this study, the researchers will ask you that any information collected from you will not be used if the participant decides to withdraw before finishing the study.

- If you agree to take part, you will be asked if you would like to participate in future studies, how your participation in this study will not be affected if you choose not to participate in future one.

What will I do if I choose to be in this study?

If you agree to participate in this project, you will be asked to complete the demographics details as well as some information about previous treatment, diagnosis etc and an anonymous questionnaire about your eating disorders behaviors and symptoms the last 28 days. These responses are concerning your reactions to affected child. The battery of questionnaires would be sent either electronically or by post and after completion sending it back to the researcher.

What are the possible risks or discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

What are the possible benefits for me or others?

Taking part in this research study may not benefit you personally, but we may learn new things that will help others.

How will you protect the information you collect about me, and how will that information be shared?

Results of this study may be used in publications and presentations. Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. To minimize the risks to confidentiality, your data will be coding and encrypted and manuscripts are stored in a locked cabinet. Only the researcher would have access to the data.

We may share the data we collect from you for use in future research studies or with other researchers – if we share the data that we collect about you, we will remove any information that could identify you before we share it.

Study's results

All the collected information will be analyzed by PhD student Maria Tsiaka, Institute of Psychiatry, King's College, London. Participants will be able to learn about the results of the study on the website, www.eatingresearch.com or if they are requested to be mailed. Any data and information published in scientific journals will also be available to participants upon request.

Who can I contact if I have questions or concerns about this research study?

If you have questions, you are free to ask them now. If you have questions later, you may contact the researchers at King's College with Prof Janet Treasure, Department of Academic Psychiatry, Section of Eating Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Consent

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form.

Consent for use of contact information to be contacted about participation in other studies

Initial one of the following to indicate your choice:

_____ I agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

_____ I do not agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

Participant's Name (printed)

Participant's Signature

Date

Patient's consent form study 4 in Greek

ΑΣΘΕΝΗΣ ΕΝΗΜΕΡΩΤΙΚΟ ΔΕΛΤΙΟ ΕΡΕΥΝΑΣ

Πρόσκληση για συμμετοχή στην ακόλουθη έρευνα:

Θα θέλαμε να σας προσκαλέσουμε να συμμετάσχετε σε αυτό το ερευνητικό έργο. Θα πρέπει να συμμετέχετε μόνο εάν το θέλετε. Επιλέγοντας να μην λάβετε μέρος δεν θα αποβεί σε βάρος σας με κανένα τρόπο. Προκειμένου να αποφασίσετε την συμμετοχή σας, είναι σημαντικό να κατανοήσετε τον λόγο για τον οποίο διεξάγεται η συγκεκριμένη έρευνα και τι συνεπάγεται η συμμετοχή σας. Αφιερώστε χρόνο για να διαβάσετε τις ακόλουθες πληροφορίες προσεκτικά και συζητήστε το με άλλους εάν το επιθυμείτε. Ρωτήστε μας αν υπάρχει κάτι που δεν είναι σαφές ή χρειάζεστε επιπλέον πληροφορίες.

Ποιος είναι ο σκοπός της μελέτης:

Μας ενδιαφέρει να διερευνήσουμε πως τα άτομα που πάσχουν από Νευρική Βουλιμία ή Αδηφαγική Διαταραχή αντιλαμβάνονται τις συναισθηματικές αντιδράσεις των φροντιστών τους, και σε τι ένταση είναι τα συμπτώματα της Διατροφικής Διαταραχής στην έναρξη της θεραπείας. Επίσης πως αυτά τα συναισθήματα και οι συμπεριφορές που κυριαρχούν στη σχέση του άτομου που πάσχει από διατροφική διαταραχή και του αρχικού φροντιστή του μπορούν να επηρεάσουν την εξέλιξη της νόσου και την πορεία της θεραπείας μέσα στους επόμενους 6 μήνες.

Ότι αφορά τον φροντιστή που θα καθορίσετε ως πρωταρχικό, (γονείς, αδέρφια, σύντροφοι, φίλοι) εφόσον συναινείτε και συναινεί και ο ίδιος σε αυτό, να συμμετέχει μέσω συμπλήρωσης ερωτηματολογίων στην αρχή της θεραπείας σας. ο στόχος είναι να διερευνήσουμε κατά πόσο επηρεάζεται η ψυχολογία (σε επίπεδο άγχους, κατάθλιψης και στρες) καθώς και ποια από τα συναισθήματα τους είναι κυρίαρχα απέναντι στο άτομο που πάσχει από την διαταραχή και ποιες συμπεριφορές υιοθετούνται για την αντιμετώπιση της ασθένειας.

Η έρευνα θα μας βοηθήσει να αναπτύξουμε επιπλέον θεραπευτικά μοντέλα για την ουσιαστική υποστήριξη της ελληνικής οικογένειας και του ασθενή που πάσχει από Βουλιμία.

Γιατί έχετε επιλεγεί:

Σας έχουμε επιλέξει για πιθανή συμμετοχή σε αυτή τη μελέτη γιατί είστε ο πρωταρχικός φροντιστής που υπέδειξε το άτομο που ζήτησε θεραπεία από το Κέντρο μας. Εξαρτάται απόλυτα από εσάς αν θα λάβετε ή όχι μέρος. Εάν αποφασίσετε να λάβετε

μέρος, θα σας δοθεί ένα αντίγραφο του παρόντος φύλλου πληροφοριών και θα σας ζητηθεί να υπογράψετε ένα έντυπο συγκατάθεσης. Εάν αποφασίσετε να συμμετάσχετε μπορείτε οποιαδήποτε στιγμή να αποχωρήσετε από τη μελέτη χωρίς να δώσετε εξηγήσεις για αυτό.

[49]. Εάν συμφωνήσετε να λάβετε μέρος, θα ερωτηθείτε αν θα θέλατε να συμμετάσχετε και σε μελλοντικές έρευνες. Η συμμετοχή σας στην παρούσα μελέτη δεν θα επηρεαστεί σε περίπτωση που επιλέξετε να μην λάβετε μέρος σε μελλοντικές.

Τι θα σας συμβεί αν λάβω μέρος:

Εάν αποφασίσετε να συμμετάσχετε σε αυτό το έργο θα σας ζητηθεί να συμπληρώσετε 4 ερωτηματολόγια (χρόνος συμπλήρωσης περίπου 25 λεπτά). Όλα τα δεδομένα προστατεύονται από κωδικοποιημένο σύστημα και παραμένουν ανώνυμα.

Ποιοί είναι οι πιθανοί κίνδυνοι από την συμμετοχή:

Πιθανόν η διαδικασία συμπλήρωσης των ερωτηματολογίων να είναι κάπως δύσκολη με κάποιο τρόπο, ίσως να την βρείτε κουραστική.

Ποια είναι τα πιθανά οφέλη/ πλεονεκτήματα από τη συμμετοχή:

Δεν θα υπάρχει κάποιο άμεσο προσωπικό όφελος. Όμως, συμφωνώντας να λάβετε μέρος σε αυτή την μελέτη συνεισφέρετε στην έρευνα για τη βελτίωση και προσαρμογή καλύτερων μελλοντικών παρεμβάσεων και ελπίζουμε ότι θα βοηθήσει τους φροντιστές να αντιμετωπίσουν καλύτερα τη κατάσταση στην οποία βρίσκονται.

Η συμμετοχή σας στη μελέτη θα παραμείνει εμπιστευτική!

Τα δεδομένα που συλλέγουμε είναι ανώνυμα και η ταυτότητα σας προστατεύεται από κωδικοποιημένο σύστημα. Οι πληροφορίες που συγκεντρώνονται είναι εμπιστευτικές μεταξύ εσάς και του ερευνητή. Τα αποθηκευμένα δεδομένα προστατεύονται από ένα κωδικό πρόσβασης και τα χειρόγραφα φυλάσσονται σε κλειδωμένο ντουλάπι. Μόνο ο ερευνητής έχει πρόσβαση στα δεδομένα. Είστε ελεύθεροι να αποχωρήσετε σε οποιοδήποτε σημείο μέχρι την σύνταξη των δεδομένων.

- Μπορείτε να αποσύρετε τα δεδομένα σας ανά πάσα στιγμή μέχρι τη μεταγραφή τους για χρήση στη τελική αναφορά.
- Εάν αποφασίσετε να λάβετε μέρος θα σας δοθεί το παρόν έγγραφο πληροφοριών και θα σας ζητηθεί να υπογράψετε έντυπο συγκατάθεσης.
- Καθώς η συμμετοχή είναι ανώνυμη δεν είναι εφικτό να αποσύρετε τα δεδομένα σας εφόσον έχει ολοκληρωθεί η έρευνα.
- Τα αποτελέσματα της έρευνας θα παρουσιαστούν σε συνέδρια και επιστημονικά περιοδικά
- Τα δεδομένα της έρευνας μπορεί να τα μοιραστούμε με άλλους συνάδελφους για την διεξαγωγή άλλων ερευνών, η ανωνυμία σας είναι διασφαλισμένη.

Τι θα γίνουν τα αποτελέσματα της έρευνας:

Όλες οι συγκεντρωμένες πληροφορίες θα αναλυθούν και συνταχθούν από την υποψήφια Διδάκτορα, Μαρία Τσιάκα Institute of Psychiatry, King's College, London. Email: Maria.Tsiaka@kcl.ac.uk

Οι συμμετέχοντες θα μπορούν να μάθουν για τα αποτελέσματα της έρευνας στην ιστοσελίδα, website www.eatingresearch.com ή εφόσον ζητηθεί να σταλούν ταχυδρομικώς. Οποιαδήποτε δεδομένα και πληροφορίες δημοσιευθούν σε επιστημονικά περιοδικά θα είναι επίσης διαθέσιμα στους συμμετέχοντες κατόπιν αιτήματος.

Επικοινωνία για περισσότερες πληροφορίες:

Εναπόκειται σε εσάς να αποφασίσετε αν θα λάβετε μέρος ή όχι. Εάν αποφασίσετε να συμμετέχετε μπορείτε να αποχωρήσετε οποιαδήποτε στιγμή χωρίς εξηγήσεις.

Εάν η μελέτη σας έβλαψε με οποιοδήποτε τρόπο μπορείτε να επικοινωνήσετε με το King's College London χρησιμοποιώντας τα ακόλουθα στοιχεία για διευκρινίσεις και πληροφορίες: **Prof Janet Treasure**, Department of Academic Psychiatry, Section of Eating Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Παρακαλούμε δώστε την συγκατάθεσή σας υπογράφοντας την παρακάτω συναινετική φόρμα. Παρακαλούμε κρατείστε το έντυπο ενημέρωσης για εσάς.

ΣΥΝΑΙΝΕΣΗ ΣΥΜΜΕΤΟΧΗΣ ΣΤΗΝ ΕΡΕΥΝΑ

Έχω διαβάσει το παραπάνω ενημερωτικό έντυπο της έρευνας. Μου δόθηκε η ευκαιρία να θέσω ερωτήσεις και οι απαντήσεις μου απαντήθηκαν. Αν έχω επιπλέον ερωτήσεις, Γνωρίζω που να απευθυνθώ. Συμφωνώ να συμμετάσχω στην ερευνητική μελέτη που περιγράφεται παραπάνω και θα λάβω αντίγραφο αυτής της φόρμας συγκατάθεσης.

Συγκατάθεση για τη χρήση των πληροφοριών για να επικοινωνήσουμε σχετικά με τη συμμετοχή σας σε άλλες σπουδές

Αρχικό από τα παρακάτω για να δηλώσετε την επιλογή σας:

_____ Συμφωνώ να επιτρέψω στους ερευνητές να χρησιμοποιήσουν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για να επικοινωνήσουν μαζί μου σχετικά με τη συμμετοχή σε μελλοντικές έρευνες.

_____ Δεν συμφωνώ να χρησιμοποιούν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για τη συμμετοχή σε μελλοντικές έρευνες.

Όνομα και Επώνυμο Συμμετέχοντος

Υπογραφή

CARER'S CONSENT FORM STUDY 4

Explanation of research

We are being invited to participate in this research study. Your participation in the study is voluntary, if you don't wish to take part, simply let researcher to know. Your participation requires your understanding about the purpose of this study and if you wish to take part, please read carefully the following information and sign the following consent form. If you have any questions or concerns about any aspect of this project, please ask the researcher.

Why are you doing this study?

The purpose of this study is to examine if any of your emotional and behavioral reactions to patient will affect his /her change of symptoms after 6 months treatment.

This study will help us to understand the cascade of processes that mediate the impact of family dysfunction on caregivers' psychological distress through their emotional responses (emotional overinvolvement or critical attitude toward the patient) and behaviors which in turn may hinder recovery, is crucial in developing more effective family interventions aiming to improve dysfunctional familial patterns of interactions by promoting awareness of family dynamics may indeed reduce the burden and improve the emotional well-being of family caregivers.

Why are you selected?

You have been chosen you to participate in this study as being a primary carer (parent, spouse, sibling, or a friend) of a selected patient suffering from Bulimia Nervosa and Binge Eating Disorders who agree to take part in this study. Participation in this study is voluntary. You do not have to answer any question you do not want to answer. If at any time and for any reason, you would prefer not to participate in this study, please feel free not to. If at any time you would like to stop participating, please tell me. We can take a break, stop and continue at a later date, or stop altogether. You may withdraw from this study at any time, and you will not be penalized in any way for deciding to stop participation. If you decide to withdraw from this study, the researchers will ask you that any information collected from you will not be used if the participant decides to withdraw before finishing the study.

- If you agree to take part, you will be asked if you would like to participate in future studies, how your participation in this study will not be affected if you choose not to participate in future one.

What will I do if I choose to be in this study?

If you agree to participate in this project, you will be asked to complete the demographics details as well as some information about your cared one 's symptoms and an anonymous set of questionnaires about psychological distress, expressed emotion and accommodating and enabling behaviors. These responses are concerning your reactions to affected child. The battery of questionnaires would be sent either electronically or by post and after completion sending it back to the researcher.

What are the possible risks or discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

What are the possible benefits for me or others?

Taking part in this research study may not benefit you personally, but we may learn new things that will help others.

How will you protect the information you collect about me, and how will that information be shared?

Results of this study may be used in publications and presentations. Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. To minimize the risks to confidentiality, your data will be coding and encrypted and manuscripts are stored in a locked cabinet. Only the researcher would have access to the data.

We may share the data we collect from you for use in future research studies or with other researchers – if we share the data that we collect about you, we will remove any information that could identify you before we share it.

Study's results

All the collected information will be analyzed by PhD student Maria Tsiaka, Institute of Psychiatry, King's College, London. Participants will be able to learn about the results of the study on the website, www.eatingresearch.com or if they are requested to be mailed. Any data and information published in scientific journals will also be available to participants upon request.

Who can I contact if I have questions or concerns about this research study?

If you have questions, you are free to ask them now. If you have questions later, you may contact the researchers at King's College with Prof Janet Treasure, Department of Academic Psychiatry, Section of Eating Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Consent

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form.

Consent for use of contact information to be contacted about participation in other studies

Initial one of the following to indicate your choice:

_____ I agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

_____ I do not agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

Participant's Name (printed)

Participant's Signature

Date

ΕΝΗΜΕΡΩΤΙΚΟ ΔΕΛΤΙΟ ΕΡΕΥΝΑΣ

Πρόσκληση για συμμετοχή στην ακόλουθη έρευνα.

Θα θέλαμε να σας προσκαλέσουμε να συμμετάσχετε σε αυτό το ερευνητικό έργο. Θα πρέπει να συμμετέχετε μόνο εάν το θέλετε. Επιλέγοντας να μην λάβετε μέρος δεν θα αποβεί σε βάρος σας με κανένα τρόπο. Προκειμένου να αποφασίσετε την συμμετοχή σας, είναι σημαντικό να κατανοήσετε τον λόγο για τον οποίο διεξάγεται η συγκεκριμένη έρευνα και τι συνεπάγεται η συμμετοχή σας. Αφιερώστε χρόνο για να διαβάσετε τις ακόλουθες πληροφορίες προσεκτικά και συζητήστε το με άλλους εάν το επιθυμείτε. Ρωτήστε μας αν υπάρχει κάτι που δεν είναι σαφές ή χρειάζεστε επιπλέον πληροφορίες.

Ποιος είναι ο σκοπός της μελέτης;

Μας ενδιαφέρει να διερευνήσουμε πως τα άτομα που πάσχουν από Νευρική Βουλιμία ή αδηφαγική Διαταραχή αντιλαμβάνονται τις συναισθηματικές αντιδράσεις των φροντιστών τους, και σε τι ένταση είναι τα συμπτώματα της Διατροφικής Διαταραχής στην έναρξη της θεραπείας. Επίσης πως αυτά τα συναισθήματα και οι συμπεριφορές που κυριαρχούν στη σχέση του ατόμου που πάσχει από διατροφική διαταραχή και του αρχικού φροντιστή του μπορούν να επηρεάσουν την εξέλιξη της νόσου και την πορεία της θεραπείας μέσα στους επόμενους 6 μήνες. Το άτομο με διατροφική διαταραχή θα του ζητηθεί να συμπληρώσει ξανά το ερωτηματολόγιο των συμπτωμάτων για επαναξιολόγηση της πορείας του είτε συνεχίζει την διαδικασία της θεραπείας στο Κέντρο είτε έχει διακόψει.

Αυτή η έρευνα θα μας βοηθήσει να αναπτύξουμε επιπλέον νέα θεραπευτικά μοντέλα για την αντιμετώπιση της βουλιμίας.

Γιατί έχετε επιλεγεί;

Σας έχουμε επιλέξει για πιθανή συμμετοχή σε αυτή τη μελέτη γιατί έχετε αποφασίσει να κάνετε θεραπεία για την διατροφική διαταραχή στο Κέντρο μας. Εξαρτάται απόλυτα από εσάς αν θα λάβετε ή όχι μέρος. Εάν αποφασίσετε να λάβετε μέρος, θα σας δοθεί ένα αντίγραφο του παρόντος φύλλου πληροφοριών και θα σας ζητηθεί να υπογράψετε ένα έντυπο συγκατάθεσης.

- Εάν συμφωνήσετε να λάβετε μέρος, θα ερωτηθείτε αν θα θέλατε να συμμετάσχετε και σε μελλοντικές έρευνες. Η συμμετοχή σας στην παρούσα μελέτη δεν θα επηρεαστεί σε περίπτωση που επιλέξετε να μην λάβετε μέρος σε μελλοντικές.

Τι θα σας συμβεί αν λάβετε μέρος;

Εάν αποφασίσετε να συμμετάσχετε σε αυτό το έργο, θα σας ζητηθεί να συμπληρώσετε 4 ερωτηματολόγια (χρόνος συμπλήρωσης περίπου 25 λεπτά). Όλα τα δεδομένα προστατεύονται από κωδικοποιημένο σύστημα και παραμένουν ανώνυμα.

Ποιοί είναι οι πιθανοί κίνδυνοι από την συμμετοχή;

Πιθανόν η διαδικασία συμπλήρωσης των ερωτηματολογίων να είναι κάπως δύσκολη με κάποιο τρόπο ίσως να την βρείτε κουραστική.

Ποια είναι τα πιθανά οφέλη / πλεονεκτήματα από τη συμμετοχή;

Μερικοί φροντιστές ή θεραπευόμενοι ανακαλύπτουν ότι συμπληρώνοντας τα ερωτηματολόγια τους βοηθά να προβληματιστούν για τους εαυτούς τους ή τις εμπειρίες τους και αυτό από μόνο του είναι χρήσιμο. Επιπλέον, συμφωνώντας να λάβετε μέρος σε αυτή την μελέτη συνεισφέρετε στην έρευνα για τη βελτίωση και

προσαρμογή καλύτερων μελλοντικών παρεμβάσεων και ελπίζουμε ότι θα βοηθήσει τους ασθενείς και τους φροντιστές τους να αντιμετωπίσουν καλύτερα τη κατάσταση στην οποία βρίσκονται.

Η συμμετοχή σας στη μελέτη θα παραμείνει εμπιστευτική!

Τα δεδομένα που συλλέγουμε είναι ανώνυμα και η ταυτότητα σας προστατεύεται από κωδικοποιημένο σύστημα. Οι πληροφορίες που συγκεντρώνονται είναι εμπιστευτικές μεταξύ εσάς και του ερευνητή. Τα αποθηκευμένα δεδομένα προστατεύονται από ένα κωδικό πρόσβασης και τα χειρόγραφα φυλάσσονται σε κλειδωμένο ντουλάπι. Μόνο ο ερευνητής έχει πρόσβαση στα δεδομένα. Είστε ελεύθεροι να αποχωρήσετε σε οποιοδήποτε σημείο μέχρι την σύνταξη των δεδομένων.

- ο Μπορείτε να αποσύρετε τα δεδομένα σας ανά πάσα στιγμή μέχρι τη μεταγραφή τους για χρήση στη τελική αναφορά.
- ο Εάν αποφασίσετε να λάβετε μέρος θα σας δοθεί το παρόν έγγραφο πληροφοριών και θα σας ζητηθεί να υπογράψετε έντυπο συγκατάθεσης.
- ο Καθώς η συμμετοχή είναι ανώνυμη δεν είναι εφικτό να αποσύρετε τα δεδομένα σας μετά την ολοκλήρωση της έρευνας
- ο Τα αποτελέσματα της έρευνας θα παρουσιαστούν σε συνέδρια επιστημονικά η θα δημοσιευθούν σε διεθνή επιστημονικά περιοδικά
- ο Τα δεδομένα της έρευνας μπορεί να τα μοιραστούμε με άλλους συνάδελφους για την διεξαγωγή άλλων ερευνών , η ανωνυμία σας είναι διασφαλισμένη

Τι θα γίνουν τα αποτελέσματα της έρευνας:

Όλες οι συγκεντρωμένες πληροφορίες θα αναλυθούν και συνταχθούν από την υποψήφια Διδάκτορα, Μαρία Τσιάκα, Institute of Psychiatry, King's College, London. Οι συμμετέχοντες θα μπορούν να μάθουν για τα αποτελέσματα της έρευνας στην ιστοσελίδα, website www.eatingresearch.com ή εφόσον ζητηθεί να σταλούν ταχυδρομικώς. Οποιαδήποτε δεδομένα και πληροφορίες δημοσιευθούν σε επιστημονικά περιοδικά θα είναι επίσης διαθέσιμα στους συμμετέχοντες κατόπιν αιτήματος.

Επικοινωνία για περισσότερες πληροφορίες:

Εναπόκειται σε εσάς να αποφασίσετε αν θα λάβετε μέρος ή όχι. Εάν αποφασίσετε να συμμετέχετε μπορείτε να αποχωρήσετε οποιαδήποτε στιγμή χωρίς να εξηγήσεις.

Εάν η μελέτη σας έβλαψε με οποιοδήποτε τρόπο μπορείτε να επικοινωνήσετε με το King's College London χρησιμοποιώντας τα ακόλουθα στοιχεία για διευκρινίσεις και πληροφορίες: **Prof Janet Treasure**, Department of Academic Psychiatry, Section of Eating Disorders, 5th Flr, Thomas Guys House, Guys Campus, London SE1 9RT. Email: Janet.Treasure@kcl.ac.uk

Παρακαλούμε δώστε την συγκατάθεση σας υπογράφοντας την παρακάτω συναινετική φόρμα. Παρακαλούμε κρατείστε το έντυπο ενημέρωσης για εσάς.

ΣΥΝΑΙΝΕΣΗ ΣΥΜΜΕΤΟΧΗΣ ΣΤΗΝ ΕΡΕΥΝΑ

Έχω διαβάσει το παραπάνω ενημερωτικό έντυπο της έρευνας .Μου δόθηκε η ευκαιρία να θέσω ερωτήσεις και οι απαντήσεις μου απαντήθηκαν. Αν έχω επιπλέον ερωτήσεις, Γνωρίζω που να απευθυνθώ. Συμφωνώ να συμμετάσχω στην ερευνητική μελέτη που περιγράφεται παραπάνω και θα λάβω αντίγραφο αυτής της φόρμας συγκατάθεσης.

Συγκατάθεση για τη χρήση των πληροφοριών για να επικοινωνήσουμε σχετικά με τη συμμετοχή σας σε άλλες σπουδές

Αρχικό από τα παρακάτω για να δηλώσετε την επιλογή σας:

_____ Συμφωνώ να επιτρέψω στους ερευνητές να χρησιμοποιήσουν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για να επικοινωνήσουν μαζί μου σχετικά με τη συμμετοχή σε μελλοντικές έρευνες.

_____ Δεν συμφωνώ να χρησιμοποιούν τα στοιχεία επικοινωνίας μου που συλλέχθηκαν κατά τη διάρκεια αυτής της μελέτης για τη συμμετοχή σε μελλοντικές έρευνες.

Όνομα και Επώνυμο Συμμετέχοντος

Υπογραφή

Appendix B. Study Materials

Ερωτηματολόγιο για τους φροντιστές

Αυτό το ερωτηματολόγιο είναι για εσάς και το άτομο που υποστηρίζετε με την διατροφική διαταραχή.

Οι πληροφορίες που μας δίνετε σε αυτό το φύλλο θα αντιμετωπιστούν ως αυστηρά εμπιστευτικές και θα χρησιμοποιηθούν για να μας βοηθήσουν να καταλάβουμε πώς μπορούμε να βοηθήσουμε εκείνους με διατροφική διαταραχή και τους φροντιστές τους. Παρακαλούμε συμπληρώστε όσο μεγαλύτερο μέρος αυτού του ερωτηματολογίου μπορείτε.

Οι πληροφορίες επικοινωνίας θα αποθηκευτούν ξεχωριστά από τις απαντήσεις του ερωτηματολογίου σας. Αυτό θα διασφαλίσει την εμπιστευτικότητα των λεπτομερειών που παρέχετε.

Παρακαλούμε συμπληρώστε τα παρακάτω:

Όνομα:.....

.....

Διεύθυνση:

.....

...

.....

.....

Ταχυδρομικός κώδικας:.....

Τηλ. (Σπιτιού):.....Τηλ.

(Δουλειά):.....

Email:.....

.....

Όνομα του ατόμου για το οποίο νοιάζεστε

.....

Εάν είστε σύμφωνοι για να κρατηθούν τα στοιχεία σας σε μια ασφαλή εθελοντική βάση δεδομένων, παρακαλούμε υπογράψτε και γράψτε την ημερομηνία παρακάτω. Χρειαζόμαστε πάντα τους εθελοντές για να συμμετέχουν στην έρευνα έτσι ώστε να μπορούμε να έρθουμε σε επαφή μαζί σας για μελλοντικές μελέτες εάν συναινείτε, αν και δεν υποχρεούστε να συμμετέχετε.

Ναι, συμφωνώ να κρατήσετε τα στοιχεία μου σε μια ασφαλή εθελοντική βάση δεδομένων για να έρθετε σε επαφή μαζί μου σε μελλοντικές μελέτες.

Όνομα:.....

.....

Υπογραφή.....

Ημερομηνία.....

Παρακαλούμε συμπληρώστε το ακόλουθο ερωτηματολόγιο διαβάζοντας προσεκτικά την κάθε ερώτηση και απαντώντας σε κάθε μια από αυτές

Κώδικας και Ημερομηνία

1. **Κώδικας** (συμπληρώνεται από την ερευνητρια)

1.2 Σημερινή Ημερομηνία

$\overline{H}\overline{M}$ / $\overline{M}\overline{M}$ / $\overline{X}\overline{X}$

Δημογραφικές Ερωτήσεις

1 Ημερομηνία Γέννησης: $\overline{H}\overline{M}$ / $\overline{M}\overline{M}$ / $\overline{X}\overline{X}$

2 Φύλο: ☐ Θηλυκό ☐ Αρσενικό

3 Ποια είναι η τρέχουσα θέση απασχόλησης σας; (Σημειώστε ένα τετράγωνο)

☐ Πλήρης απασχόληση

- ☐ Μερική απασχόληση
- ☐ Άνεργος
- ☐ Φοιτητής
- ☐ Συνταξιοδοτημένος
- ☐ Με άδεια ασθένειας
- ☐ Νοικοκυρά / - Σύζυγος
- ☐ Άλλο

Διευκρινίστε για ό,τι άλλο

4 Ποιο είναι το υψηλότερο επίπεδο εκπαίδευσης που έχετε ολοκληρώσει;(Σημειώστε ένα τετράγωνο)

- ☐ Απόφοιτος Δημοτικού
- ☐ Απόφοιτος Γυμνασίου
- ☐ Απόφοιτος Λυκείου
- ☐ Πτυχίο Πανεπιστήμιου
- ☐ Μεταπτυχιακό
- ☐ Διδακτορικό
- ☐ Άλλο

Διευκρινίστε για ό,τι άλλο

5 Πόσα χρόνια εκπαίδευσης έχετε κάνει;

_____ χρόνια και _____ μήνες

6 Είναι τα ελληνικά η μητρική σας γλώσσα;

- ☐ Ναι
- ☐ Όχι

7 Ποια είναι η εθνικότητά σας;

8 Ποια είναι η οικογενειακή σας κατάσταση;

- ☐ Παντρεμένος/η
- ☐ Συζώ
- ☐ Εργένης
- ☐ Διαζευγμένος/η
- ☐ Εν διαστάσει
- ☐ Χήρος/α

9 Έχετε κόρη(ες);

- ☐ Ναι
- ☐ Όχι

10 Έχετε γιο(ους);

- ☐ Ναι
- ☐ Όχι

11 Εάν απαντήσατε ναι στις ερωτήσεις 9 και 10 γράψτε τις ηλικίες των παιδιών σας στον πίνακα

Παιδιά 1. Παιδί- ηλικία ηλικία 5 Παιδί- ηλικία Κόρη(ς) Γιος(οι)	2. Παιδί- ηλικία	3 Παιδί- ηλικία	4. Παιδί-

Λεπτομέρειες για το άτομο που φροντίζετε

12 Παρακαλούμε περιγράψτε την σχέση σας με το άτομο που φροντίζετε με τις ακόλουθες επιλογές: (Σημειώστε ένα τετράγωνο)

Αυτή / Αυτός είναι ο/η...

- ☐ Σύζυγος
- ☐ Σύντροφος
- ☐ Παιδί
- ☐ Αδελφός/η
- ☐ Γονιός
- ☐ Άλλος συγγενής

Διευκρινίστε για ό,τι άλλο

☐ Φίλος

☐ Άλλο

Διευκρινίστε για ό,τι άλλο

13 Ποια είναι η ημερομηνία γέννησης του/της;

$\overline{\text{H}}\overline{\text{M}}$ / $\overline{\text{M}}\overline{\text{M}}$ / $\overline{\text{X}}\overline{\text{X}}$

14 Ποια είναι η ηλικία του/της;

___ __ χρονών

15 Ποιο είναι το φύλο του;

- ☐ Θηλυκό
- ☐ Αρσενικό

16 Ποια είναι η οικογενειακή του/της κατάσταση; (Σημειώστε ένα τετράγωνο)

- ☐ Παντρεμένος/η
- ☐ Συζεί
- ☐ Ελεύθερος/η
- ☐ Διαζευγμένος/η
- ☐ Εν διαστάσει

☐ Χήρος/α

17 Ενδιαφερόμαστε να μάθουμε τι είδους διατροφική διαταραχή είχε/έχει το άτομο το οποίο φροντίζετε. Παρακαλούμε απαντήστε σε όλες τις συμπεριφορές και συμπτώματα που περιγράφουν τις διατροφικές τους δυσκολίες:

- ☐ Ναι *Σοβαρά ελλιποβαρής*
- ☐ Ναι *Περιορίζει την πρόσληψη τροφών*
- ☐ Ναι *Ασκείται υπερβολικά*
- ☐ Ναι *Κάνει εμετό μετά από γεύματα*
- ☐ Ναι *Δεν έχει έμμηνο ρύση για 3 μήνες ή περισσότερο*
- ☐ Ναι *Τρώει ασυνήθιστα μεγάλες ποσότητες φαγητού με μια φορά (υπερφαγία)*
- ☐ Ναι *Τρώει κρυφά*
- ☐ Ναι *Κλέβει φαγητό/λεφτά για να φάει υπερβολικά*
- ☐ Ναι *Σοβαρά υπέρβαρος*

Άλλες; Παρακαλούμε Διευκρινίστε

18 Έχει διαγνωστεί το άτομο το οποίο φροντίζετε , ποτέ με διατροφική διαταραχή από επαγγελματία ιατρικών υπηρεσιών;

- ☐ Ναι
- ☐ Όχι

Αν ναι, ποια ήταν η διάγνωση; (Μπορείτε να σημειώσετε περισσότερα από ένα εάν η διατροφική διαταραχή άλλαξε με τον καιρό)

☐ Νευρική ανορεξία

- ☐ Νευρική βουλιμία
- ☐ Αδηφαγική διαταραχή
- ☐ Δεν γνωρίζω
- ☐ Άλλο
- ☐ Διαβήτης Ι
- ☐ Διαβήτης ΙΙ

Διευκρινίστε για ό,τι άλλο

19 Σε ποιά ηλικία πρώτο-διαγνώστηκε με διατροφική διαταραχή το άτομο το οποίο φροντίζετε;

20 Σε ποιά ηλικία άρχισε να βιώνει διατροφικές δυσκολίες το άτομο το οποίο φροντίζετε;

21 Ενώ το άτομο το οποίο φροντίζετε υποφέρει από διατροφική διαταραχή, έχει επιπλέον προβλήματα; Παρακαλούμε απαντήστε σε όλες τις συμπεριφορές παρακάτω Παράδειγμα Αυτός/Αυτή:

- ☐ Ναι *Πίνει υπερβολικά*
- ☐ Ναι *Χρησιμοποιεί παράνομα ναρκωτικά*
- ☐ Ναι *Χρησιμοποιεί νόμιμα ναρκωτικά (π.χ.. υπνωτικά χάπια) παραπάνω από την συνιστώμενη ποσότητα*
- ☐ Ναι *Αυτοτραυματίζεται (π.χ. δαγκώνοντας, κόβοντας, καίγοντας τον εαυτό του/της)*
- ☐ Ναι *Κλέβει (συμπεριλαμβανόμενου και του φαγητού)*
- ☐ Ναι *Παίζει τυχερά παιχνίδια*

Άλλες; Παρακαλούμε διευκρινίστε

5. 11 Κατά μέσο ορό, πόσες ώρες προσωπική επαφή έχετε εβδομαδιαία με το άτομο που φροντίζετε;(Σημειώστε ένα τετράγωνο)

- ☐ 0 – 7 ώρες / εβδομάδα
- ☐ 8 – 14 ώρες / εβδομάδα
- ☐ 15 – 21 ώρες / εβδομάδα
- ☐ Περισσότερες από 21 ώρες / εβδομάδα
- ☐ Άλλο

Διευκρινίστε για ό,τι άλλο

5. 12 Κατά μέσο όρο, πόσες ώρες άλλης επαφής έχετε εβδομαδιαία με το άτομο που φροντίζετε; (π.χ. τηλέφωνο, μήνυμα, ηλεκτρονικό ταχυδρομείο)

- ☐ 0 – 7 ώρες / εβδομάδα
- ☐ 8 – 14 ώρες / εβδομάδα
- ☐ 15 – 21 ώρες / εβδομάδα
- ☐ Περισσότερες από 21 ώρες / εβδομάδα
- ☐ Άλλο

Διευκρινίστε για ό,τι
άλλο

Άλλα Θέματα

6.1 Είχατε ποτέ πρόβλημα με το φαγητό ή το βάρος σας;

☐ Ναι

☐ Όχι

Αν ναι, παρακαλούμε γράψτε σύντομες λεπτομέρειες για το διατροφικό σας πρόβλημα (π.χ. ανορεξία, υπερφαγία); και εάν έχετε διαγνωστεί ποτέ με διατροφική διαταραχή:

6.2 Είχε ποτέ κανένας άλλος στην οικογένεια σας πρόβλημα με το φαγητό ή το βάρος;

☐ Ναι

☐ Όχι

Αν ναι, παρακαλούμε γράψτε λεπτομέρειες για την σχέση τους με εσάς (π.χ. μητέρα ή ξάδελφος/η); το διατροφικό τους πρόβλημα (π.χ. ανορεξία, υπερφαγία); και εάν έχουν ποτέ διαγνωστεί με διατροφική διαταραχή:

6.3 Θα θέλατε να προσθέσετε κάτι άλλο;

DASS - 21

ΟΔΗΓΙΕΣ: Παρακαλούμε διαβάστε την κάθε δήλωση και μαρκάρετε ένα αριθμό 0, 1, 2, 3 που δηλώνει πόσο η δήλωση ίσχυε για εσάς την προηγούμενη εβδομάδα.
Δεν υπάρχουν σωστές ή λάθος απαντήσεις. Μην χρησιμοποιείται πολύ χρόνο στην κάθε δήλωση.

Η εκτίμηση είναι η ακόλουθη:

0 Δεν ίσχυσε καθόλου για έμενα

1 Ίσχυσε για έμενα σε κάποιο βαθμό ή κάποια στιγμή

2 Ίσχυσε σε μεγάλο βαθμό για έμενα, ή για μεγάλο χρονικό διάστημα

3 Ίσχυσε παρά πολύ για έμενα, ή τις περισσότερες φορές

1.	Δεν μπορούσα να ηρεμήσω τον εαυτό μου	☐ ☐ ☐ ☐
		0 1 2 3
2	Ένιωθα ότι το στόμα μου ήταν ξηρό	☐ ☐ ☐ ☐
		0 1 2 3
3	Δεν μπορούσα να βιώσω κανένα θετικό συναίσθημα	☐ ☐ ☐ ☐
		0 1 2 3
4	Δυσκολευόμουν ν' ανασάνω (π.χ., υπερβολικά γρήγορη αναπνοή, κόπηση της ανάσας μου χωρίς να έχω κάνει σωματική προσπάθεια)	☐ ☐ ☐ ☐
		0 1 2 3
5	Μου φάνηκε δύσκολο να αναλάβω την πρωτοβουλία να κάνω κάποια πράγματα	☐ ☐ ☐ ☐
		0 1 2 3
6	Είχα την τάση να αντιδρώ υπερβολικά στις καταστάσεις που αντιμετωπίζα	☐ ☐ ☐ ☐
		0 1 2 3
7	Αισθάνθηκα τρεμούλα (πχ στα χέρια)	☐ ☐ ☐ ☐
		0 1 2 3
8	Αισθανόμουν συχνά νευρικότητα	☐ ☐ ☐ ☐
		0 1 2 3
9	Ανησυχούσα για τις καταστάσεις στις οποίες θα μπορούσα να πανικοβληθώ και να φανώ ανόητος στους άλλους	☐ ☐ ☐ ☐
		0 1 2 3

10	Ένωσα ότι δεν είχα τίποτα να προσμένω με ενδιαφέρον	☐ ☐ ☐ ☐ 0 1 2 3
<i>Η εκτίμηση είναι η ακόλουθη:</i> 0 Δεν ίσχυσε καθόλου για έμενα 1 Ίσχυσε για έμενα σε κάποιο βαθμό ή κάποια στιγμή 2 Ίσχυσε σε μεγάλο βαθμό για έμενα, ή για μεγάλο χρονικό διάστημα 3 Ίσχυσε παρά πολύ για έμενα, ή τις περισσότερες φορές		
11	Βρήκα τον εαυτό μου να νιώθει ενοχλημένος	☐ ☐ ☐ ☐ 0 1 2 3
12	Μου ήταν δύσκολο να χαλαρώσω	☐ ☐ ☐ ☐ 0 1 2 3
13	Ένωθα μελαγχολικός και απογοητευμένος	☐ ☐ ☐ ☐ 0 1 2 3
14	Δεν μπορούσα να ανεχτώ οτιδήποτε με κρατούσε από το να συνεχίσω με αυτό που έκανα	☐ ☐ ☐ ☐ 0 1 2 3
15	Ένωσα πολύ κοντά στον πανικό	☐ ☐ ☐ ☐ 0 1 2 3
16	Τίποτα δεν μπορούσε να με κάνει να νιώσω ενθουσιασμό	☐ ☐ ☐ ☐ 0 1 2 3
17	Ένωσα ότι δεν άξιζα πολύ ως άτομο	☐ ☐ ☐ ☐ 0 1 2 3
18	Ένωσα ότι ήμουν αρκετά ευερέθιστος	☐ ☐ ☐ ☐ 0 1 2 3
19	Αισθανόμουν την καρδιά μου να χτυπάει χωρίς να έχει προηγηθεί σωματική άσκηση (ταχυπαλμία, αρρυθμία)	☐ ☐ ☐ ☐ 0 1 2 3
20	Ένωσα φοβισμένος χωρίς να υπάρχει λόγος	☐ ☐ ☐ ☐ 0 1 2 3

21

Ένωσα πως η ζωή δεν είχε νόημα

☐ ☐ ☐ ☐

0 1 2 3

ΟΙΚΟΓΕΝΕΙΑΚΟ ΕΡΩΤΗΜΑΤΟΛΟΓΙΟ

ΟΔΗΓΙΕΣ: Αυτό το ερωτηματολόγιο παραθέτει τρόπους με τους οποίους οι οικογένειες αντιμετωπίζουν προβλήματα της καθημερινότητας. Για κάθε στοιχείο παρακαλούμε δείξτε πόσο συχνά αντιδράσατε στον ασθενή με αυτόν τον τρόπο και συμπληρώστε το κενό που είναι το πιο ακριβές κατά την άποψη σας. Δεν υπάρχουν σωστές ή λάθος απαντήσεις. Το καλύτερο είναι να σημειώσετε την πρώτη αντίδραση που σας έρχεται στο μυαλό και να σημειώσετε μια απάντηση ανά ερώτηση.

		Ποτέ/ Πολύ Σπάνια	Σπάνια	Συχνά	Πολύ Συχνά
1	Τείνω να παραμελώ τον εαυτό μου εξαιτίας του/της	☐ 1	☐ 2	☐ 3	☐ 4
2	Του/της ζητώ συνέχεια να κάνει πράγματα	☐ 1	☐ 2	☐ 3	☐ 4
3	Σκέπτομαι συχνά τι θα γίνει με αυτόν/την	☐ 1	☐ 2	☐ 3	☐ 4
4	Με εξαγριώνει	☐ 1	☐ 2	☐ 3	☐ 4
5	Σκέπτομαι συνέχεια τους λόγους της αρρώστιας του/της	☐ 1	☐ 2	☐ 3	☐ 4
6	Πρέπει να προσπαθήσω να μη τον/την κριτικάρω	☐ 1	☐ 2	☐ 3	☐ 4
7	Δεν μπορώ να κοιμηθώ εξαιτίας του/της	☐ 1	☐ 2	☐ 3	☐ 4
8	Είναι δύσκολο για εμάς να συμφωνούμε σε πράγματα	☐ 1	☐ 2	☐ 3	☐ 4
9	Όταν με ενοχλεί κάτι σε αυτόν/την, το κρατώ για τον εαυτό μου	☐ 1	☐ 2	☐ 3	☐ 4
10	Αυτός/αυτή δεν εκτιμά ότι κάνω για αυτόν/την	☐ 1	☐ 2	☐ 3	☐ 4
11	Θεωρώ λιγότερο σημαντικές τις ανάγκες μου	☐ 1	☐ 2	☐ 3	☐ 4

12	Μερικές φορές μου την δίνει στα νεύρα	☐ 1	☐ 2	☐ 3	☐ 4
13	Ανησυχώ πολύ για αυτόν/την	☐ 1	☐ 2	☐ 3	☐ 4
14	Κάνει κάποια πράγματα από φθόνο	☐ 1	☐ 2	☐ 3	☐ 4
15	Σκέφτηκα ότι θα αρρωστήσω και εγώ	☐ 1	☐ 2	☐ 3	☐ 4
16	Με ενοχλεί όταν θέλει συνεχώς κάτι από έμένα	☐ 1	☐ 2	☐ 3	☐ 4
17	Είναι σημαντικό κομμάτι της ζωής μου	☐ 1	☐ 2	☐ 3	☐ 4
18	Πρέπει να επιμένω να συμπεριφερθεί διαφορετικά	☐ 1	☐ 2	☐ 3	☐ 4
19	Έπρεπε να αφήσω σημαντικά πράγματα για να τον/την βοηθήσω	☐ 1	☐ 2	☐ 3	☐ 4
20	Είμαι συχνά θυμωμένος-η με αυτόν/την	☐ 1	☐ 2	☐ 3	☐ 4

AESED

12.1 ΟΔΗΓΙΕΣ: Τα παρακάτω στοιχεία περιλαμβάνουν μια σειρά από δηλώσεις που ισχύουν συνήθως στα μέλη της οικογένειας που μένουν με συγγενείς ή φίλους με διατροφική διαταραχή. Θα θέλαμε να διαβάσετε κάθε μια και να αποφασίσετε πόσο συχνά έχει ισχύσει στα μέλη της οικογένειας σας τον τελευταίο μήνα. Είναι σημαντικό να έχετε υπόψη ότι δεν υπάρχουν σωστές ή λάθος απαντήσεις. Η πρώτη σας απάντηση είναι συνήθως η καλύτερη επιλογή.

12.2 Μένετε με τον άτομο το οποίο φροντίζετε ☐ Ναι ☐ Όχι

στοιχεία -Τον τελευταίο μήνα πόσο συχνά σκεφτήκατε για:
0 = ποτέ 1 = σπάνια 2 = κάποιες φορές 3 = συχνά 4 = κάθε ημέρα

12.3 Ελέγχει ο συγγενής σας...

	ποτέ	σπάνια	Μερικές φορές	συχνά	Κάθε μέρα

1.	τις επιλογές φαγητού που αγοράζετε;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2.	τι κάνουν τα άλλα μέλη στην κουζίνα και για πόση ώρα;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3.	Τους τρόπους μαγειρέματος και τα συστατικά που χρησιμοποιείται;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4.	τι τρώνε τα άλλα μέλη της οικογένειας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

12.4 Ο συγγενής σας συμπεριλαμβάνει κάποιο μέλος της οικογένειας σε συνεχείς διαλόγους...

		ποτέ	σπάνια	Μερικές φορές	συχνά	Κάθε ημέρα
5.	Ζητώντας επιβεβαίωση για το αν θα παχύνει;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6.	Για το αν είναι ασφαλές ή αποδεκτό να φάει κάποιο συγκεκριμένο φαγητό;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7.	Ζητώντας επιβεβαίωση για το αν δείχνει παχύς/ια με συγκεκριμένα ρούχα;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8.	Για συστατικά και ποσότητες, καθώς και πιθανά υποκατάστατα ανεπιθύμητων συστατικών;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9.	Για αρνητικές σκέψεις και συναισθήματα	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10.	Για αυτοτραυματισμό	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11.	Ποια σερβίτσια χρησιμοποιούνται;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
12.	Πως καθαρίζονται τα σερβίτσια;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

13.	Τι ώρα τρώνε φαγητό;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
14.	Σε ποιο μέρος τρώνε φαγητό;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
15.	Πως καθαρίζεται η κουζίνα;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
16.	Πως αποθηκεύεται το φαγητό;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
17.	Την άσκηση ρουτίνας για τον συγγενή με διατροφική διαταραχή;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
18.	Τον έλεγχο του συγγενή σας για το σχήμα του σώματος τους και το βάρος τους;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
19.	Πως το σπίτι καθαρίζεται και ταχτοποιείται;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

12.6 Επιλέγεται να αγνοήσετε τις πτυχές της διατροφικής διαταραχής του συγγενή σας που επηρεάζουν την ζωή της οικογένειας σας σε μια προσπάθεια να συμφιλιωθεί να καταστεί ανεκτή για το υπόλοιπο της οικογένειας όπως εάν...

		ποτέ	σπάνια	Μερικές φορές	συχνά	Κάθε ημέρα
20.	Εξαφανιστεί το φαγητό;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
21.	Κλαπούν χρήματα;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
22.	Η κουζίνα αφεθεί ακατάστατη;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
23.	Το μπάνιο αφεθεί ακατάστατο;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

24. Γενικά, σε πιο βαθμό θα λεγάτε ότι ο συγγενής με την διατροφική διαταραχή, ελέγχει την οικογενειακή ζωή και τις δραστηριότητες;

Καθόλου

Κατά το ήμισυ

Εντελώς

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		ποτέ	σπάνια	Μερικές φορές	συχνά	Κάθε ημέρα
25.	Πόσο συχνά συμμετέχετε σε συμπεριφορές που σχετίζονται με τους εξαναγκασμούς του συγγενή σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
26.	Πόσο συχνά βοηθάτε τον συγγενή σας να αποφύγει πράγματα που μπορούν να τον/την κάνουν περισσότερο ανήσυχος;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

στοιχεία

-Κατά τον τελευταίο μήνα πόσο συχνά έχετε σκεφτεί για:

0 = όχι 1 = ήπια 2 = μέτρια 3 = σοβαρά 4 = υπερβολικά

		όχι	ήπια	μέτρια	σοβαρά	υπερβολικά
27.	Έχετε αποφύγει να κάνετε πράγματα, να πάτε σε μέρη ή να είστε με άτομα εξαιτίας του προβλήματος του συγγενή σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
28.	Έχετε τροποποιήσει την καθημερινότητα της οικογένειας εξαιτίας των συμπτωμάτων του συγγενή σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
29.	Έχετε τροποποιήσει το πρόγραμμα της δουλειά σας εξαιτίας των αναγκών του συγγενή σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

30.	Έχετε τροποποιήσει τις ασχολίες που κάνετε τον ελεύθερο χρόνο σας εξαιτίας των αναγκών του συγγενή σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
31.	Σας έχει προκαλέσει άγχος το να βοηθάτε το συγγενή σας στις προηγούμενες περιπτώσεις;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
32.	Έχει υπάρξει αγχώδης ή ενοχλημένος ο συγγενής σας με την διατροφική διαταραχή όταν δεν τον βοηθήσατε;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
33.	Έχει υπάρξει θυμωμένος ή βίαιος ο συγγενής σας όταν δεν τον βοηθήσατε;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Ευχαριστούμε που συμπληρώσατε αυτό το ερωτηματολόγιο. Εκτιμούμε ιδιαίτερα την βοήθεια σας.

Questionnaire for Carers

This questionnaire is about you and the person who you are supporting with an eating disorder.

The information that you give us on this sheet will be treated as strictly confidential and will be used to help us understand how we can help those with an eating disorder and their carers. Please fill it as much of this questionnaire as you can.

Your contact details will be stored separately from your questionnaire responses. This will ensure the details you provide are kept confidential.

Please complete the following:

Name:.....

.....

Address:

.....

...

.....

.....

Postcode:.....

Tel (home):..... Tel

(work):.....

Email:.....

.....

Name of the person you are caring for:

.....

If you are happy and consent for your details to be kept on a secure volunteer database, please sign and date below. We always need volunteers to take part in research so we may contact you for future studies if appropriate although you are under no obligation to take part.

Yes, I consent to you keeping my contact details on a secure volunteer database for me to be contacted for future studies if appropriate.

Name:.....
.....

Sign: Date:
.....

Thank you very much for your help.

Please complete the following questionnaire by reading each question carefully and
answering every question.

Code and Date

1.1 Code (filled in by the research team)

1.2 Today's Date

$\overline{\text{DD}}$ / $\overline{\text{MM}}$ / $\overline{\text{YY}}$

Demographic Questions

1 Date of birth: $\overline{\text{DD}}$ / $\overline{\text{MM}}$ $\overline{\text{YY}}$

2 Gender: ☐ Female ☐ Male

3 What is your current employment status? (Tick one box)

- ☐ Full time employed
- ☐ Part time employed
- ☐ Unemployed
- ☐ Student
- ☐ Retired
- ☐ Sick leave
- ☐ Housewife / -husband
- ☐ Other

If other, please specify

4 What is the highest level of education you have completed? (Tick one box)

- ☐ No qualifications
- ☐ High school
- ☐ Senior School
- ☐ University degree
- ☐ Postgraduate degree
- ☐ Master
- ☐ PhD

If other, please specify

5 How many years of education have you received?

_____ years and _____ months

6 Is your first language English?

- ☐ Yes
- ☐ No

7 What is your ethnicity?

- ☐ Greek
- ☐ Other

8 What is your marital status?

- ☐ Married
- ☐ Living together
- ☐ Single
- ☐ Divorced
- ☐ Separated
- ☐ Widowed

9 Do you have a daughter(s)?

- ☐ Yes
- ☐ No

10 Do you have a son(s)?

- ☐ Yes
- ☐ No

11 If you have answered yes to question 4.9 and 4.10, please type in the ages of your children in the table.

<i>Children</i>	<i>1. child - age</i>	<i>2. child - age</i>	<i>3. child - age</i>	<i>4. child - age</i>	<i>5. child - age</i>
Daughter(s)					
Son(s)					

Details about the person you are caring for

12 Please describe your relationship to the person you are caring for with the following options: (Tick one box)

She / He is my...

- ☐ Spouse
- ☐ Partner
- ☐ Child
- ☐ Sibling
- ☐ Parent
- ☐ Other relative

If other, please specify

-
- ☐ Friend
 - ☐ Other

If other, please specify

13 What is her / his date of birth?

$\overline{DD}$ / $\overline{MM}$ / $\overline{YY}$

14 What is her /his age?

___ years

15 What is her / his gender?

- ☐ Female
- ☐ Male

16 What is her / his marital status? (Tick one box)

- ☐ Married
- ☐ Living together
- ☐ Single
- ☐ Divorced
- ☐ Separated
- ☐ Widowed

17 We are interested to know what sort of an eating disorder the person you care for has/had. Please answer to all the behaviours and symptoms below that describe their eating difficulties:

- ☐ Yes *Severely underweight*
- ☐ Yes *Restricting food intake*
- ☐ Yes *Exercising excessively*
- ☐ Yes *Vomiting after meals*
- ☐ Yes *Missing menstrual periods for 3 months or more*
- ☐ Yes *Eating unusually large amounts of food in one sitting (binge eating)*
- ☐ Yes *Eating in secret*
- ☐ Yes *Stealing food/money in order to binge*
- ☐ Yes *Severely overweight*

Others? Please specify

18 Has the person that you care for ever been diagnosed with an eating disorder by a health professional?

- ☐ Yes
- ☐ No

If Yes, what was the diagnosis? (You may tick more than one if the eating disorder has changed over time)

- ☐ Anorexia nervosa
- ☐ Bulimia nervosa
- ☐ Binge eating disorder
- ☐ I don't know
- ☐ Other

If other, please specify

19 At what age was the person you care for first diagnosed with an eating disorder?

20 At what age did the person you care for start to experience these eating difficulties?

21 While the person you care for is suffering from their eating disorder do she / he has any additional problems? Please answer to all the behaviours below. E.g. does she / he:

- ☐ Yes *Drink a lot of alcohol*
- ☐ Yes *Use illegal drugs*
- ☐ Yes *Use legal drugs (e.g. sleeping tablets) in excess of the recommended amount*
- ☐ Yes *Deliberately hurt themselves (e.g. by biting, cutting burning themselves*
- ☐ Yes *Steal (including food)*
- ☐ Yes *Gamble*

Others? Please specify

5. 11 On average, how many hours of face to face contact do you have with the person you care for each week? (Tick one box)

- ☐ 0 – 7 hours / week
- ☐ 8 – 14 hours / week
- ☐ 15 – 21 hours / week
- ☐ More than 21 hours / week
- ☐ Other

If other, please specify

5. 12 On average, how many hours of other contact do you have with the person you care for each week? (e.g. telephone, text, email etc)

- ☐ 0 – 7 hours / week
- ☐ 8 – 14 hours / week
- ☐ 15 – 21 hours / week
- ☐ More than 21 hours / week
- ☐ Other

If other, please specify

Other Issues

6.1 Have you ever had a problem with eating or weight?

- ☐ Yes
- ☐ No

If Yes, please give brief details of your eating problem (e.g. anorexia, over-eating); and whether you have ever been diagnosed with an eating disorder:

6.2 Has anyone else in your family ever had a problem with eating or weight?

- ☐ Yes
- ☐ No

If Yes, please detail their relationship to you (e.g. mother or cousin); their eating problem (e.g. anorexia, over-eating); and whether they have ever been diagnosed with an eating disorder:

DASS - 21

INSTRUCTIONS: Please read each statement and tick a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week.

There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much, or most of the time

1.	I found it hard to wind down	☐ 0	☐ 1	☐ 2	☐ 3
2	I was aware of dryness of my mouth	☐ 0	☐ 1	☐ 2	☐ 3
3	I couldn't seem to experience any positive feeling at all	☐ 0	☐ 1	☐ 2	☐ 3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	☐ 0	☐ 1	☐ 2	☐ 3
5	I found it difficult to work up the initiative to do things	☐ 0	☐ 1	☐ 2	☐ 3
6	I tended to over-react to situations	☐ 0	☐ 1	☐ 2	☐ 3
7	I experienced trembling (eg, in the hands)	☐ 0	☐ 1	☐ 2	☐ 3
8	I felt that I was using a lot of nervous energy	☐ 0	☐ 1	☐ 2	☐ 3
9	I was worried about situations in which I might panic and make a fool of myself	☐ 0	☐ 1	☐ 2	☐ 3
10	I felt that I had nothing to look forward to	☐ 0	☐ 1	☐ 2	☐ 3

The rating scale is as follows:

0 *Did not apply to me at all*

1 *Applied to me to some degree, or some of the time*

2 *Applied to me to a considerable degree, or a good part of time*

3 *Applied to me very much, or most of the time*

11	I found myself getting agitated	☐ ☐ ☐ ☐
		0 1 2 3
12	I found it difficult to relax	☐ ☐ ☐ ☐
		0 1 2 3
13	I felt down-hearted and blue	☐ ☐ ☐ ☐
		0 1 2 3
14	I was intolerant of anything that kept me from getting on with what I was doing	☐ ☐ ☐ ☐
		0 1 2 3
15	I felt I was close to panic	☐ ☐ ☐ ☐
		0 1 2 3
16	I was unable to become enthusiastic about anything	☐ ☐ ☐ ☐
		0 1 2 3
17	I felt I wasn't worth much as a person	☐ ☐ ☐ ☐
		0 1 2 3
18	I felt that I was rather touchy	☐ ☐ ☐ ☐
		0 1 2 3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	☐ ☐ ☐ ☐
		0 1 2 3
20	I felt scared without any good reason	☐ ☐ ☐ ☐
		0 1 2 3
21	I felt that life was meaningless	☐ ☐ ☐ ☐
		0 1 2 3

FAMILY QUESTIONNAIRE

INSTRUCTIONS: This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to the patient in this way and tick the box which is most accurate from your point of view. There are no right or wrong responses. It is best to note the first response that comes to mind, and make only one response per question.

		Never / Very rarely	Rarely	Often	Very often
1	I tend to neglect myself because of him/her	☐ 1	☐ 2	☐ 3	☐ 4
2	I have to keep asking him/her to do things	☐ 1	☐ 2	☐ 3	☐ 4
3	I often think about what is to become of him/her	☐ 1	☐ 2	☐ 3	☐ 4
4	He/she irritates me	☐ 1	☐ 2	☐ 3	☐ 4
5	I keep thinking of the reasons for his/her illness	☐ 1	☐ 2	☐ 3	☐ 4
6	I have to try not to criticise him/her	☐ 1	☐ 2	☐ 3	☐ 4
7	I can't sleep because of him/her	☐ 1	☐ 2	☐ 3	☐ 4
8	It's hard for us to agree on things	☐ 1	☐ 2	☐ 3	☐ 4
9	When something about him/her bothers me, I keep it to myself	☐ 1	☐ 2	☐ 3	☐ 4
10	He/she does not appreciate what I do for him/her	☐ 1	☐ 2	☐ 3	☐ 4
11	I regard my own needs as less important	☐ 1	☐ 2	☐ 3	☐ 4
12	Her/she sometimes gets on my nerves	☐ 1	☐ 2	☐ 3	☐ 4
13	I am very worried about him/her	☐ 1	☐ 2	☐ 3	☐ 4
14	He/she does some things out of spite	☐ 1	☐ 2	☐ 3	☐ 4
15	I thought I would become ill myself	☐ 1	☐ 2	☐ 3	☐ 4
16	When he/she constantly wants something from me it annoys me	☐ 1	☐ 2	☐ 3	☐ 4

17	He/she is an important part of my life	☐ 1	☐ 2	☐ 3	☐ 4
18	I have to insist that he/she behave differently	☐ 1	☐ 2	☐ 3	☐ 4
19	I have given up important things in order to be able to help him/her	☐ 1	☐ 2	☐ 3	☐ 4
20	I am often angry with him/her	☐ 1	☐ 2	☐ 3	☐ 4

AESED

12.1 INSTRUCTIONS: The following items contain a number of statements that commonly apply to the family members who live with a relatives or friends with an eating disorder. We would like you to read each one and decide how often it has applied to your family members over the past one month. It is important to note that there are no right or wrong answers. Your first reaction will usually provide the best answer.

12.2 Are you living with the person that you are caring for? ☐ Yes ☐ No

Items -During the past month how often have you thought about:
0 = never 1 = rarely 2 = sometimes 3 = often 4 = every day

12.3 Does your relative with eating disorder control...

		never	rarely	some- times	often	every day
1.	the choices of food that you buy?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2.	what other family members do and for how long in the kitchen?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3.	cooking practice and ingredients you use?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4.	what other family members eat?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

12.4 Does your relative engage any family member in repeated conversations...

		never	rarely	some- times	often	every day
5.	asking for reassurance about whether she/he will get fat?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6.	about whether it is safe or acceptable to eat a certain food?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7.	asking for reassurance about whether she/he look fat in certain clothes?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

8.	their ingredients and amounts, possible substitutes for ingredients?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
		never	rarely	some- times	often	every day
9.	about negative thoughts and feelings	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10.	about self-harm	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11.	what crockery is used?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
12.	how crockery is cleaned?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
13.	what time food is eaten?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
14.	what place food is eaten?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
15.	how the kitchen is cleaned?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
16.	how food is stored?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
17.	the exercise routine of the relative with an ED?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
18.	your relative's checking their body shape or weight?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
19.	how the house is cleaned and tidied?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

12.6 Do you choose to ignore aspects of your relative's eating disorder that impinge your family's life in an effort to reconcile or make it tolerable for the rest of the family such as if...

		never	rarely	some- times	often	every day
20.	food disappears?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
21.	money is taken?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
22.	the kitchen is left a mess?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
23.	the bathroom is left a mess?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
24. In general, to what extent would you say that the relative with an eating disorders controls family life and activities?						
None at All About Half Completely						
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐						

		0	1	2	3	4	5	6	7	8	9	10
								never	rarely	some- times	often	every day
25.	How often did you participate in behaviours related to the your relative's compulsions?	☐	☐	☐	☐	☐	☐	0	1	2	3	4
26.	How often did you assist your relative in avoiding things that might make her/him more anxious?	☐	☐	☐	☐	☐	☐	0	1	2	3	4
Items -During the past <u>month</u> how often have you thought about: <i>0 = no 1 = mild 2 = moderate 3 = severe 4 = extreme</i>												
								no	mild	mode- rate	severe	extrem e
27.	Have you avoided doing things, going places, or being with people because of your relative's disorder?	☐	☐	☐	☐	☐	☐	0	1	2	3	4
28.	Have you modified your family routine because of your relative's symptoms?	☐	☐	☐	☐	☐	☐	0	1	2	3	4
29.	Have you modified your work schedule because of your relative's needs?	☐	☐	☐	☐	☐	☐	0	1	2	3	4
30.	Have you modified your leisure activities because of your relative's needs?	☐	☐	☐	☐	☐	☐	0	1	2	3	4
31.	Has helping your relative in the before mentioned ways cause you distress?	☐	☐	☐	☐	☐	☐	0	1	2	3	4
32.	Has your relative with an eating disorder become distressed/anxious when you have not provided assistance?	☐	☐	☐	☐	☐	☐	0	1	2	3	4
33.	Has your relative become angry/abusive when you have not provided assistance?	☐	☐	☐	☐	☐	☐	0	1	2	3	4

Study material (Patient)

1. Section – Code and Date

1.1 Code (please put your initials)

1.2 Today's Date

DD / MM / YY

1.3 Date of admission

DD / MM / YY

1.4 Date of discharge

DD / MM / YY

2. Section – Introduction and Instructions

Thank you very much for taking part in our study. Please read the information sheet to get all the information about the project. Here are some notes that may guide you through the process.

Patient Questionnaire → Please return the questionnaire to the researcher after you have filled in every question. Please read the instructions given carefully and answer every question.

- a. Your Details
- b. Demographic Questions
- c. Other Issues
- d. Psychological Questionnaires

We appreciate you taking the time and spending the effort to support us in our research project.

4. Section “Demographic Questions”

4.1 What is your date of birth:

DD / MM / YY

4.2 What is your gender:

☐ Female

☐ Male

4.3 What is your current height (centimetres)?

_____ cm

4.4 What is your current weight (without clothes, in kilogram)

_____ kg

4.5 How old are you?

_____ years

4.6 What is the lowest weight you have ever been at your current height?

kg

4.7 What is your diagnosis? (e.g. Anorexia Nervosa)

4.7 In your view, how long have you had an eating disorder?

_____ years _____ months

4.8 How old were you when you first developed an eating disorder? _____
years

4.9 How old were you when you were first diagnosed with an eating disorder?
_____ years

4.10 Do you have a current diagnosis of anything other than an eating disorder? E.g. depression, OCD

☐ Yes

☐ No

If yes, please specify

4.11 Are you currently taking any medication?

☐ Yes

☐ No

If yes, please specify

4.12 Apart from this time, how many times have you been in treatment because of your eating disorder in the past? Please specify if they were general hospitals, or general psychiatric hospitals

Treatment type (e.g. ED specialist,Hospital)	Length of stay	Age

If you need more space, please feel free to attach another sheet of paper.

4.13 Do you have any siblings?

☐ Yes

☐ No

If Yes, how many?

Older brother(s) _____ Younger brother(s) _____

Older sister(s) _____ Younger sister(s) _____

If you have a sister or a brother, are you a twin? ☐ Yes ☐ No

4.14 What is your current or most recent occupation?

4.15 What is your current employment status?

- ☐ Full time employed
- ☐ Part time employed
- ☐ Unemployed
- ☐ Student
- ☐ Retired
- ☐ Sick leave
- ☐ Housewife / -husband
- ☐ Other

If other, please specify

4.16 What is the highest level of education you have completed? (Tick one box)

- ☐ No qualifications
- ☐ High school
- ☐ Seniorschool
- ☐ University degree
- ☐ Postgraduate degree
- ☐ Diploma / BTEC
- ☐ Other

If other, please specify

4.17 How many years of education have you received?

_____ years

4.18 Is your first language English?

- ☐ Yes
- ☐ No

4.19 What is your ethnicity?

- ☐ Greek
- ☐ Other

4.20 What is your marital status?

- ☐ Married
- ☐ Living together

- ☐ Single
- ☐ Divorced
- ☐ Separated
- ☐ Widowed

4.21 Do you have children?

- ☐ Yes
- ☐ No

4.22 If you have answered yes to question 4.14 , please type in the ages of your children in the table.

<i>Children</i>	<i>1. child - age</i>	<i>2. child - age</i>	<i>3. child - age</i>	<i>4. child - age</i>	<i>5. child - age</i>
Daughter(s)					
Son(s)					

Section 5 “Questions about your carer”

5.1 Who are your carer(s) to you? (You may tick more than one box)

She / He is my...

- ☐ Mother
 - ☐ Father
 - ☐ Step-Mum
 - ☐ Step-Dad
 - ☐ Sibling
 - ☐ Other relative
- If other, please specify
- _____

- ☐ Friend
 - ☐ Other
- If other, please specify
- _____

5.2 Do you currently live together with the carer(s)?

- ☐ Yes
 - ☐ No
- Details
- _____

5. 3 On average, how many hours of face to face contact do you have with the person who cares for you each week? (Tick one box)

- ☐ 0 – 7 hours / week
- ☐ 8 – 14 hours / week
- ☐ 15 – 21 hours / week
- ☐ More than 21 hours / week
- ☐ Other

If other, please specify

5. 4 On average, how many hours of other contact do you have with the person who cares for you each week? (e.g. telephone, text, email etc)

- ☐ 0 – 7 hours / week
- ☐ 8 – 14 hours / week
- ☐ 15 – 21 hours / week
- ☐ More than 21 hours / week
- ☐ Other

If other, please specify _____

Section 6 “Questions about your treatment”

6.1 Are you currently receiving treatment?

- ☐ Yes
- ☐ No

If yes, what sort of treatment is this?

If yes, how long have you been receiving this treatment?

6.2 How satisfied are you with the current treatment? (If no current treatment please consider the most recent one)

☐	☐	☐	☐	☐	☐
Very satisfied	Quite satisfied	unsure	Quite dissatisfied	Very dissatisfied	Never received treatment

6.3 Do you feel that you have been supported by mental health professionals?

☐	☐	☐	☐	☐
Nearly always	Often	Sometimes	Rarely	Never

6.4 What do you think that your carers need to know to help / support you more?

Section 7 “Thoughts of change”

INSTRUCTIONS: Please tick the number which best describes what you think.

- 1. Importance to change. Ask yourself the following questions: How important is it for you to change? What score would you give yourself out of 10?**

Not at all *Very Much*
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 6 7 8 9 10

- 2. What are your desires, reasons and needs for change?**

- 3. Ability to change. Ask yourself the following questions: How confident are you in your ability to change? What score would you give yourself out to 10?**

Not at all *Very Much*
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 6 7 8 9 10

- 4. How many people do you feel close to? It does not matter where they live or whether you have seen them recently. Please write number in the box.**

- 5. Please tell us how you would rate the practical and emotional support provided by the person closest to you using the 1-7 scale below.**

Never *Always*
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 6 7

- 6. Can you lean on and turn to the person closest to you in times of difficulty?”**

Never *Always*
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 6 7

7. Does he/she give you practical help?

Never ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ Always

0 1 2 3 4 5 6 7

Section 8 “EDE-Q”

INSTRUCTIONS: The following questions are concerned with the **four weeks BEFORE YOU WERE REFERRED TO CLINIC** (28 days). Therefore, please think about the time before you were admitted to hospital when answering them. Please read each question carefully and tick the appropriate box.

Please answer all the questions.

On how many days out of the <u>past 28 days</u> ...	No days	1-5 days	6-12 days	13-15 days	16-22 days	23-27 days	Every day
Have you been deliberately trying to limit the amount of food you eat to influence your shape or weight?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
1. Have you gone for long periods of time (8 hours or more) without eating anything in order to influence your shape or weight?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
2. Have you <u>tried</u> to avoid eating foods which you like in order to influence your shape or weight?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
3. Have you tried to follow definite rules regarding your eating in order to influence your shape or weight; for example, a calorie limit, a set amount of food, or rules about what or when you should eat?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
4. Have you wanted your stomach to be empty?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
5. Has thinking about food or its calorie content made it much more difficult to concentrate on things you're interested in; for example, read, watch TV or follow a conversation?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

On how many days out of the <u>past 28 days</u> ...		No days	1-5 days	6-12 days	13-15 days	16-22 days	23-27 days	Every day
6.	Have you been afraid of losing control over eating?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
7.	Have you had episodes of binge eating?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
8.	Have you eaten in secret? (Do not count binges)	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
9.	Have you definitely wanted your stomach to be flat?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
10.	Has thinking about shape or weight made it more difficult to concentrate on things you are interested in; e.g., read, watch TV or follow a conversation?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
11.	Have you had a definite fear that you might gain weight or become fat?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
12.	Have you felt fat?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
13.	Have you had a strong desire to lose weight?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Over the <u>past 4 weeks</u> (28 days)		None of the times	A few of the times	Less than ½ the time	Half the time	More than ½ the time	Most of the time	Every time
14.	On what proportion of times that you have eaten have you <u>felt guilty</u> because of the effect on your shape or weight? (Do not count binges)	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
15.	Have there been any times when you have felt that you have eaten what other people would regard as an unusually large amount of food given the circumstances?			0 ☐ No			1 ☐ Yes	
16.	How many such episodes have you had over the past four weeks?	_____ episodes						
17.	During how many of these episodes of overeating did you have a sense of having lost control over your eating?	_____ episodes						

	Have you had other episodes of eating in which you have had a sense of having lost control and eaten too much, but have <u>not</u> eaten an unusually large amount of food given the circumstances?							
	☐ Yes ☐ No							
18.	How many such episodes have you had over the past four weeks?				_____ episodes			
	Have you made yourself sick (vomit) as a means of controlling your shape or weight?							
	☐ Yes ☐ No							
20.	How many times have you done this over the past four weeks?				_____ times			
21.								
Over the <u>past 4 weeks</u> (28 days)...								
	Have you taken laxatives as a means of controlling your shape or weight?							
	☐ Yes ☐ No							
22.	How many times have you done this over the past four weeks?				_____ times			
23.								
	Have you taken diuretics (water tablets) as a means of controlling your shape or weight?							
	☐ Yes ☐ No							
24.	How many times have you done this over the past four weeks?				_____ times			
25.								
	Have you exercised <u>hard</u> as a means of controlling your shape or weight?							
	☐ Yes ☐ No							
26.	How many times have you done this over the past four weeks?				_____ times			
27.								
	Over the past 4 weeks (28 days)	Not at all		<i>Slightly</i>		<i>Moderately</i>		<i>Markedly</i>
28.	Has your weight influenced how you think about (judge) yourself as a person?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
29.	Has your shape influenced how you think about (judge) yourself as a person?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
30.	How much would it upset you if you had to weigh yourself once a week for the next four weeks?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

31.	How dissatisfied have you felt about your weight?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
32.	How dissatisfied have you felt about your shape?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
33.	How concerned have you been about other people seeing you eat?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
34.	How uncomfortable have you felt seeing your body; for example, in shop window reflections, while undressing or taking a bath or shower?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
35.	How uncomfortable have you felt about others seeing your body; for example, in communal changing rooms, when swimming or wearing tight clothes?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

PATIENT'S QUESTIONNAIRE IN GREEK

1. Ενότητα – Κωδικοί και ημερομηνία

1.1 Κωδικός (Παρακαλούμε γράψτε τα αρχικά σας)

1.2 Σημερινή ημερομηνία

Μέρα -- / Μήνας -- / Χρόνος --

1.3 Ημερομηνία έναρξης της θεραπείας

Μέρα -- / Μήνας -- / Χρόνος --

1.4 Ημερομηνία λήξης της θεραπείας

Μέρα -- / Μήνας -- / Χρόνος --

2. Ενότητα– Οδηγίες

Παρακαλώ μόλις συμπληρώσετε το ερωτηματολόγιο επιστρέψτε το στον θεραπευτή σας

→ Παρακαλούμε διαβάστε τις οδηγίες προσεκτικά και μετά απαντήστε στις ερωτήσεις.

- e. Προσωπικές πληροφορίες
- f. Δημογραφικές ερωτήσεις
- g. Ερωτήσεις για το άτομο για το οποίο φροντίζετε
- h. Άλλα θέματα
- i. Ερωτήσεις ψυχολογικού τύπου

4. Ενότητα “Δημογραφικές ερωτήσεις”

4.1 Ημερομηνία γέννησης: -- / M -- / M -- Έτος

4.2 Φύλο: ☐ Άρρεν ☐ Θήλυ

4.3 Ποιο είναι το ύψος σας ; _____ cm

4.4 Ποιο είναι το βάρος σας (υπολογισμένο χωρίς ρούχα) _____ kg

4.5 Πόσο χρονών είστε; _____ έτη

4.6 Ποιο είναι το χαμηλότερο βάρος που είχατε σε αυτό το ύψος; _____ kg

4.7 Τι διάγνωση σας έχει γίνει; (π.χ Νευρική ανορεξία)

4.7 Κατά την γνώμη σας πόσο καιρό έχετε διατροφική διαταραχή ;

_____ Χρόνια _____ Μήνες

4.8 Πόσο χρονών ήσασταν όταν εκδηλώσατε για πρώτη φορά διατρ. διαταραχή ;
_____ χρονών

4.9 Πόσο χρονών ήσασταν όταν διαγνωσθήκατε για πρώτη φορά με διατρ. διαταραχή;
_____ χρονών

4.10 Έχετε διαγνωσθεί με κάτι άλλο εκτός από διατρ. διαταραχή; π.χ κατάθλιψη,

☐ Ναι

☐ Όχι

Αν ναι, παρακαλώ αναφέρετε τι

4.11 Παίρνετε φαρμακευτική αγωγή ;

☐ Ναι

☐ Όχι

Αν ναι, παρακαλώ αναφέρετε τι

4.12 Εκτός από αυτή την φορά, πόσες άλλες φορές έχετε κάνει θεραπεία για την διατ. διατροφή ; Παρακαλώ αναφέρετε αν η θεραπεία που ακολουθήσατε ήταν εξειδικευμένη στις διατρ. διαταραχές ή ήταν γενική. Είχατε εισαχθεί στο νοσοκομείο;

Είδος θεραπείας/Νοσοκομείο	Διάρκεια	Ηλικία

Αν χρειάζεστε και άλλο χώρο παρακαλώ σημειώστε σε ξεχωριστό χαρτί

4.13 Έχετε αδέρφια;

☐ Ναι

☐ Όχι

Αν ναι, πόσα;

Μεγαλύτερο αδελφό(ους) _____ Μικρότερο αδελφό(ους)

Μεγαλύτερη αδελφή(ες) _____ Μικρότερη αδελφή (ες)

Είστε δίδυμοι; ☐ Ναι ☐ Όχι

4.14 Ποια είναι η τωρινή σας ή πιο πρόσφατη επαγγελματική σας απασχόληση;

4.15 Ποια είναι η επαγγελματική σας κατάσταση;

- ☐ Πλήρης απασχόληση
- ☐ Μερική απασχόληση
- ☐ Άνεργη
- ☐ Φοιτήτρια
- ☐ Συνταξιούχος
- ☐ Νοικοκυρά /Σύζυγος
- ☐ Άλλο

Παρακαλώ προσδιορίστε

4.16 Επίπεδο εκπαίδευσης (Σημειώστε μόνο μία κατηγορία)

- ☐ Λυκειακή εκπαίδευση
- ☐ Πανεπιστημιακή εκπαίδευση
- ☐ Μεταπτυχιακή εκπαίδευση
- ☐ Διδακτορικό
- ☐ άλλο

Παρακαλώ προσδιορίστε

4.17 Πόσα είναι τα συνολικά χρόνια εκπαίδευσης που έχετε λάβει ;
_____ χρόνια

4.18 Τα ελληνικά είναι η πρώτη σας γλώσσα;

- ☐ Ναι
- ☐ Όχι

4.19 Ποια είναι η εθνικότητά σας;

4.20 Ποια είναι η οικογενειακή σας κατάσταση;

- ☐ Παντρεμένη
- ☐ Συζώ
- ☐ Άγαμη
- ☐ Διαζευγμένη
- ☐ Σε διάσταση
- ☐ Χήρα

4.21 Έχετε παιδιά;

- ☐ Ναι
☐ Όχι

4.22 Αν απαντήσετε Ναι στην ερώτηση 4.14 , τότε γράψτε τις ηλικίες των παιδιών σας στον παρακάτω πίνακα please.

Παιδιά	1 Ηλικία	2. Ηλικία	3. Ηλικία	4. Ηλικία	5. Ηλικία
Κόρη (ες)					
Υιός (ιοι)					

Ενότητα 5 “Ερωτήσεις για αυτόν που σας φροντίζει (φροντιστής)”

5.1 Ποιος είναι ο φροντιστής σας? (μπορείτε να σημειώσετε περισσότερο από μία κατηγορία)

Είναι η/ο

- ☐ Μητέρα
☐ Πατέρας
☐ Μητριά
☐ Πατριός
☐ Αδέλφια
☐ Άλλος συγγενής

Παρακαλώ προσδιορίστε

- ☐ Φίλος
☐ Άλλος

Παρακαλώ προσδιορίστε

5.2 Ζείτε μαζί με τον φροντιστή σας;

- ☐ Ναι ☐ Όχι Λεπτομέρειες

5. 3 Κατά μέσο όρο πόσες ώρες περνάτε μαζί με τον φροντιστή σας κάθε εβδομάδα? (Επιλέξτε μία κατηγορία)

- ☐ 0 – 7 ώρες / εβδομάδα
☐ 8 – 14 ώρες / εβδομάδα
☐ 15 – 21 ώρες / εβδομάδα
☐ Περισσότερες από 21 ώρες / εβδομάδα
☐ Άλλο

Παρακαλώ
προσδιορίστε _____

5. 4 Κατά μέσο όρο πόσες ώρες (την εβδομάδα) περνάτε έχοντας επαφή μαζί με τον φροντιστή σας χρησιμοποιώντας άλλο μέσο; (Επιλέξτε μία κατηγορία)? (π.χ. τηλέφωνο, sms, email κλπ)

- ☐ 0 – 7 ώρες / εβδομάδα
☐ 8 – 14 ώρες / εβδομάδα
☐ 15 – 21 ώρες / εβδομάδα
☐ Περισσότερες από 21 ώρες / εβδομάδα
☐ Άλλο

Παρακαλώ
προσδιορίστε _____

Ενότητα 6 “Ερωτήσεις γύρω από την θεραπεία σας”

6.1 Είστε ήδη σε θεραπεία;

- ☐ Ναι
☐ Όχι

Αν ναι, τι είδους θεραπεία είναι;

Αν ναι, πόσο καιρό είστε σε αυτή την θεραπεία;

6.2 Πόσο ικανοποιημένη είστε από την συγκεκριμένη θεραπεία; (Αν δεν είστε τώρα σε θεραπεία παρακαλώ αναφερθείτε στην πιο πρόσφατη)

☐	☐	☐	☐	☐	☐
Πολύ ικανοποιημένη	Αρκετά ικανοποιημένη	Δεν είμαι σίγουρη	Αρκετά δυσανεστημένη	Πολύ δυσανεστημένη	Δεν έχω λάβει ποτέ θεραπεία

6.3 Νιώθετε ότι έχετε την υποστήριξη που χρειάζεστε από τους ειδικούς της ψυχικής υγείας;

☐	☐	☐	☐	☐
Σχεδόν πάντα	Συχνά	Μερικές φορές	Σπάνια	Ποτέ

6.4 Τι πιστεύετε ότι θα πρέπει να γνωρίζουν οι φροντιστές σας ώστε να μπορούν να σας βοηθήσουν/υποστηρίξουν περισσότερο;

Ενότητα 7 “Σκέψεις για την αλλαγή”

ΟΔΗΓΙΕΣ: Παρακαλούμε σημειώστε τον αριθμό που ανταποκρίνεται καλύτερα σε αυτό πιστεύετε

8. Η σημασία της αλλαγής. Ρωτήστε τον εαυτό σας τις εξής ερωτήσεις: Πόσο σημαντικό είναι για σας να αλλάξετε; Τι βαθμολογία θα δίνετε στην παρακάτω κλίμακα από το 0 μέχρι το 10;

Καθόλου

σημαντικό

Πολύ

σημαντικό

☐

☐

☐

☐

☐

☐

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☐

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0

1

2

3

4

5

6

7

8

9

10

9. Ποιες είναι οι επιθυμίες σας, οι λόγοι και οι ανάγκες σας για να αλλάξετε;

10. Ικανότητα για αλλαγή. Ρωτήστε τον εαυτό σας τις εξής ερωτήσεις: Πόσο σίγουρη είστε για την ικανότητα σας για αλλαγή. Τι βαθμολογία θα δίνετε στην παρακάτω κλίμακα από το 0 μέχρι το 10?

Καθόλου

σίγουρη

Πολύ

σίγουρη

☐

☐

☐

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10

11. Με πόσους ανθρώπους νιώθετε κοντά; Δεν έχει σημασία αν μένετε μαζί τους ή αν δεν τους έχετε δει πρόσφατα. Παρακαλώ σημειώστε το νούμερο στο τετράγωνο

12. Μπορείτε να μας πείτε πόσο βαθμολογείτε την ηθική και την πρακτική υποστήριξη που παίρνετε από το άτομο που είναι πιο κοντά σε εσάς (από το 1 μέχρι το 7).

Ποτέ ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 Πάντα

13. Μπορείτε να στηριχθείτε στο άτομο που νιώθετε πιο κοντά όταν είστε δύσκολα;

Ποτέ ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 Πάντα

14. Παίρνετε πρακτική υποστήριξη από το συγκεκριμένο άτομο;

Ποτέ ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 Πάντα

Ενότητα 8 “EDE-Q”

ΟΔΗΓΙΕΣ: Οι επόμενες ερωτήσεις αφορούν τις 4 εβδομάδες πριν μας επισκεφθείτε (28 ημέρες). Για αυτό σκεφθείτε αυτό το διάστημα πριν απαντήσετε στις παρακάτω ερωτήσεις. Παρακαλώ διαβάστε την κάθε ερώτηση προσεκτικά πριν απαντήσετε και σημειώστε την κατάλληλη κολώνα.

Παρακαλώ απαντήστε σε όλες τις ερωτήσεις.

Πόσες ημέρες τις τελευταίες 28 ημέρες	Καμία ημέρα	1-5 ημέρες	6-12 ημέρες	13-15 ημέρες	16-22 ημέρες	23-27 ημέρες	Κάθε ημέρα
36. Προσπαθήσατε να μειώσετε την ποσότητα του φαγητού με σκοπό να επηρεάσετε το βάρος σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
37. Μείνατε χωρίς φαγητό για πολλές ώρες (8 ώρες και περισσότερο) με σκοπό να επηρεάσετε το βάρος σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
38. Προσπαθήσατε να αποφύγετε φαγητά που σας αρέσουν με σκοπό να επηρεάσετε το βάρος σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
39. Προσπαθήσατε να ακολουθήσετε αυστηρούς κανόνες διατροφής με σκοπό να επηρεάσετε το βάρος σας; Π.χ περιορισμό θερμίδων, συγκεκριμένο είδος φαγητού	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
40. Θέλατε να έχετε άδειο στομάχι;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
41. Σκεφτόσασταν το φαγητό, το περιεχόμενο του φαγητού ή υπολογίζατε θερμίδες έτσι ώστε να	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

μην μπορείτε να συγκεντρωθείτε σε αυτά που σας αρέσουν και απολαμβάνετε π.χ τηλεόραση, διάβασμα ή να συμμετέχετε σε μία συζήτηση;							

Πόσες ημέρες τις τελευταίες 28 ημέρες...	Καμία ημέρα	1-5 ημέρες	6-12 ημέρες	13-15 ημέρες	16-22 ημέρες	23-27 ημέρες	Κάθε ημέρα
42. Φοβηθήκατε ότι θα χάσετε τον έλεγχο με το φαγητό;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
43. Είχατε επεισόδια υπερφαγίας ή συνεχούς τσιμπολογήματος;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
44. Φάγατε κρυφά; (Μην υπολογίσετε τα υπερφαγικά επεισόδια)	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
45. Θέλατε οπωσδήποτε το στομάχι σας επίπεδο;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
46. Σκεφτόσασταν τόσο έντονα το βάρος σας ή το σώμα σας που δυσκολευόσασταν να συγκεντρωθείτε στα πράγματα που σας ενδιαφέρουν π.χ να δείτε τηλεόραση ή να συμμετέχετε σε μία συζήτηση;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
47. Είχατε πολύ έντονο φόβο ότι πήρατε βάρος ή ότι είστε παχιά;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
48. Νιώθατε παχιά;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
49. Είχατε πολύ έντονη επιθυμία να χάσετε βάρος;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Τις τελευταίες 4 εβδομάδες (28 ημέρες)	Καμία φορά	Λίγες φορές	Λιγότερες από τις ½ φορές	Τις μισές φορές	Περισσότερες από τις ½ φορές	Τις περισσότερες φορές	Κάθε φορά
50. Πόσες φορές νιώσατε ενοχές γιατί νομίζατε ότι φάγατε κάτι που θα επηρεάσει το βάρος σας ή το σώμα	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

	σας; (Μην υπολογίζετε τα υπερφαγικά επεισόδια)						
51.	Υπήρχαν φορές που θεωρήσατε ότι φάγατε αυτό που θα έλεγαν και οι άλλοι "ασυνήθιστα μεγάλη ποσότητα φαγητού";	0 ☐ Όχι	1 ☐ Ναι				
52.	Πόσα τέτοια επεισόδια είχατε τις τελευταίες 4 εβδομάδες;	_____ επεισόδια					
53.	Σε πόσα από αυτά τα επεισόδια είχατε την αίσθηση ότι χάνετε τον έλεγχο γύρω από το φαγητό; (ότι δεν μπορείτε να σταματήσετε)	_____ επεισόδια					
54.	Είχατε άλλα επεισόδια κατά την διάρκεια των οποίων νιώθατε ότι χάνετε τον έλεγχο γύρω από το φαγητό αλλά δεν καταναλώσατε τόσο μεγάλη ποσότητα φαγητού; ☐ Ναι ☐ Όχι						
55.	Πόσα τέτοια επεισόδια είχατε κατά την διάρκεια των τελευταίων 4 εβδομάδων;	_____ επεισόδια					
56.	Κάνετε εμετό στην προσπάθειά σας να ελέγξετε το βάρος σας; ☐ Ναι ☐ Όχι						
57.	Πόσες φορές κάνετε εμετό την τις τελευταίες 4 εβδομάδες;	_____ φορές					
Τις τελευταίες 4 εβδομάδες (28 ημέρες)...							
58.	Πήρατε καθαρτικά με σκοπό να ελέγξετε το βάρος σας ή το σώμα σας; ☐ Ναι ☐ Όχι						
59.	Πόσες φορές το κάνατε τις τελευταίες 4 εβδομάδες;	_____ φορές					
60.	Πήρατε διουρητικά με σκοπό να ελέγξετε το βάρος σας ή το σώμα σας; ☐ Ναι ☐ Όχι						
61.	Πόσες φορές το κάνατε τις τελευταίες 4 εβδομάδες;	_____ φορές					
62.	Κάνετε υπεργυμναστική με σκοπό να ελέγξετε το βάρος σας ή το σώμα σας; ☐ Ναι ☐ Όχι						
63.	Πόσες φορές κάνετε υπεργυμναστική τις τελευταίες 4 εβδομάδες;	_____ φορές					

	Τις τελευταίες 4 εβδομάδες (28 ημέρες)	καθόλου		λίγο		Μέτρια		Σημαντικά
64.	Το πώς είναι το βάρος σας επηρεάζει το πώς κρίνετε τον εαυτό σας σαν άτομο;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
65.	Το πώς είναι το σώμα σας επηρεάζει το πώς κρίνετε τον εαυτό σας σαν άτομο;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
66.	Πόσο πολύ θα σας αναστάτωνε αν έπρεπε να ζυγίζεστε μόνο μία φορά την εβδομάδα για τις επόμενες 4 εβδομάδες;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
67.	Πόσο δυσαρεστημένη νιώθετε με το βάρος σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
68.	Πόσο δυσαρεστημένη νιώθετε με το σώμα σας;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
69.	Πόσο σας απασχολεί για το αν οι άλλοι θα σας δουν να τρώτε;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
70.	Πόσο δυσάρεστα νιώθετε όταν βλέπετε το σώμα σας? Π.χ. Στις βιτρίνες, ή όταν κάνετε μπάνιο ή όταν γδύνεστε;	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
71.	Πόσο δυσάρεστα νιώθετε όταν οι άλλοι βλέπουν το σώμα σας; Π.χ σε κοινά δοκιμαστήρια, στο κολύμπι ή όταν φοράτε κολλητά ρούχα	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6