

# Cognitive Behavioural Therapy for Chronic Fatigue Syndrome in A 15 Year-Old Girl; A Case-Report

Vahdet GÖRMEZ

MD, MRCPsych, DipCBT Department of Child and Adolescent Psychiatry, Bezmialem Vakıf University, Istanbul

## Abstract

Chronic Fatigue Syndrome (CFS) is a relatively common clinical condition that can cause sufferers to experience significant disability and distress, which may be further exacerbated by a lack of understanding from others, including health professionals. Cognitive behaviour therapy (CBT) has been widely researched and reported to be an evidence-based effective treatment approach for CSF. Cognitive-behavioural theory of CFS aims to describe how certain cognitions and behaviours could account for the symptoms, distress, and disability that maintain the illness. In this case study, a successful application of CBT in a 15-year-old young person with a twelve-month-history of disabling CFS is presented. We argue that for a clinical success, a non-judgemental approach to address the parental role in maintenance of the sick role is necessary. (**Journal of Cognitive Behavioral Psychotherapy and Research 2015: 97-103**)

**Key Words:** Cognitive behavioural therapy, adolescence, fatigue, chronic fatigue syndrome

## Özet

### Kronik Yorgunluk Sendromu ile başvuran 15 Yaşındaki bir Hastada Bilişsel Davranışçı Terapi ile Başarılı Sağaltım: Vaka Raporu

Göreceli olarak sık görülen bir hastalık olan Kronik Yorgunluk Sendromu (KYS) önemli oranda yeti-yitimi ve işlevsellikte bozulma oluşturabildiği halde sağlık çalışanları da dahil olmak üzere toplum tarafından yeterince anlaşılammıştır. Bu durumun hastalığın seyri üzerine olumsuz etkileri belirgindir. Kronik ve yıkıcı semptomları hastanın bilişsel, emosyonel ve davranışsal tepkileri modelinde açıklayan bir kurama dayanan Bilişsel Davranışçı Terapi (BDT), KYS için bilimsel verilerle desteklenmiş başarılı bir tedavi yaklaşımı sunmaktadır. Bu vaka raporunda bir yıl süre ile devam eden KYS ile başvuran 15 yaşındaki bir ergen kızda başarı ile uygulanmış BDT uygulaması sunulmaktadır. (**Bilişsel Davranışçı Psikoterapi ve Araştırmalar Dergisi 2015: 97-103**)

**Anahtar kelimeler:** Bilişsel Davranışçı Terapi, ergenlik, yorgunluk, kronik yorgunluk sendromu

## INRODUCTION

The chronic fatigue syndrome (CFS) was initially termed encephalomyalgia or myalgic encephalomyelitis due to its essential clinical features having an encephalitic element (manifesting as cognitive difficulties) and a skeletal muscle component (manifesting as chronic fatigue). However; more recently, the US Institute of Medicine (IOM) proposed the condition to be renamed as “systemic exertion intolerance disease, (SEID)” to better reflect the condition’s hallmark defining symptom, post-exertional malaise (Clayton 2015). CFS is characterized by severe fatigue and a

combination of symptoms that prominently feature self-reported impairments in concentration and short-term memory, sleep disturbances, and musculoskeletal pain (Holmes et al. 1998). For clinical diagnosis, the fatigue state should persist for at least 6 months and not to be the result of a medical condition or ongoing exertion (Crawley and Sterne 2009). Diagnosis of chronic fatigue syndrome can only be made after alternative medical and psychiatric causes of chronic fatiguing illness have been excluded (Fukuda et al. 1994). CFS is thought to affect up to 1% of the general population (Wessely 1995); however the preva-

lence rates is much lower in the community samples of children and adolescents at 0.06% and 0.1-0.5%, respectively (Malouff et al. 2008). Sufferers experience significant disability and distress, which may be further exacerbated by a lack of understanding from others, including health professionals (Edmonds et al. 2004, Cairns and Hotoph 2005 ). They tend to be markedly disabled and many are unable to work or go to school, to do house chores, or to socialize. Because the disorder is often considered to be dubious by friends and family members, individuals with the syndrome may receive little social support (Malouff et al. 2008).

National Institute for Health and Clinical Excellence (NICE) (2007) recommends that either cognitive behaviour therapy (CBT) or graded exercise therapy (GET) should be offered to patients with mild to moderate CFS, as these are the two interventions for which there is currently the clearest research evidence of benefit.

Cognitive-behavioural theory of CFS aims to describe how certain cognitions and behaviours could account for the symptoms, distress, and disability that constitute CFS. Cognitive and behavioural components of the therapy are well depicted in the book edited by Strauss SE. (1994), which we re-phrased and summarized in the table below (Table 1).

In their proposal of case conceptualisation model for CFS, Deary and Chalder reported that by identifying the predisposing and precipitating factors, the client could begin to make a sense of what made them vulnerable to developing the illness. To the extent that some of these factors are within their control, we can also provide them with tools and insight to protect

them against relapse in the future. By identifying the maintaining factors that are keeping the client stuck in an illness cycle, we provide them, again, with insight and tools to begin to modify their life and move forward. The authors concluded that ‘the key is to use the framework to understand what it is that has led this person sitting in front of you, to where they are today’.

## CASE SUMMARY

### Biographic data/background history

T.A. is a 15-year-old girl, who lives with her mother and their three dogs. Her parents had separated around three years previously; however she continued to have frequent contact with her father, who was also the training coach for the football team that T.A. had played for until she became ill. She had two older half siblings, who were married and lived elsewhere. At the time of her first presentation to us, T.A. was a student on a part-time reduced timetable ‘due to her illness’. She met developmental milestones at expected age and was reported to have always been popular in her peer group. She had experienced a brief and transitory separation anxiety in the preschool and during transition to primary school. She had no significant personal or family history of past medical or psychiatric illnesses.

### *Presenting symptoms*

Her predominant symptoms had initially been persistent fatigue, joint ache, a hoarse voice and hypersomnia. Reportedly, she initially tried to carry on with her daily chores; however then became significantly disabled in the following 3 months, therefore had to

**Table 1.** Cognitive and behavioural components addressed in therapy sessions

Cognitive components	Behavioural components
Providing psycho-education about the nature of CFS and the relevance of cognitions to its perpetuation	Starting with gradual increase in activities consistent with patient’s short term goals
Reducing excessive concern about activity-induced symptoms	Carrying out planned activities at regular intervals, regardless of the occurrence of symptoms
Adopting a socratic approach to challenge distorted cognitions, and attitudes; such as all-or-nothing attitude, perfectionistic beliefs about standards and responsibilities, striving for functioning at pre-morbid levels	Relaxation techniques
Guidance to deal with life problems, and teaching problem-solving techniques	Planned rest

make significant adjustments to her daily routine. As a keen and talented synchronised swimmer she had trained seven times a week, which included getting up at 5 am twice a week for swimming sessions and often not finishing until around 10 pm. She said she had long struggled to keep up with this extremely busy and demanding schedule and indicated that the viral infection was somewhat “a relief”. She then returned to her swimming squad by coaching and training younger children but in a more flexible and relaxed manner. She had difficulty getting up in the mornings and was therefore consistently late for school, which she said got her into trouble with teachers. She struggled to sustain concentration in the lessons however reported that her energy levels and concentration were at their highest on her return from school. She slept up to 14 hours a night and also during the day on the weekends and holidays. Alongside CFS symptoms she also experienced episodes of low mood, which she attributed to getting frustrated with her condition and strained relationship with her parents. She followed a healthy diet and had no history of alcohol or substance use.

## Case Conceptualisation

### *Vulnerability factors*

T.A has a perfectionistic and competitive personality and a typical ‘all or nothing’ attitude. She sets standards high and becomes highly self-critical of her perceived below par achievements, which she regards as a clear failure. A typical example was her ‘failed’ attempt to return to the swimming competitions, where she did not come in the first group. Her interpretation of this ‘failure’ was in a catastrophic manner and she quickly jumped to the conclusion that she could never do the same as before. Having previously played football for 60 minutes in the team coached by her father, she declined her father’s offer to stay on the pitch for 10 minutes to help her make a gradual return as leaving the pitch after 10 minutes meant for her that she let her team-mates down.

Despite having some close friends, she never disclosed her problems to them, due to fear that her ‘sporty and strong’ image, which she believed to be the main attribute that made her popular and likeable, would get demolished. The statement that ‘no-one would like me if I am weak’ appeared to be one of her main rules of living.

Clearly, T.A. had an extremely active lifestyle prior to developing the illness. Her attempts to return to the same level of activity after the onset of the illness resulted in being physically deconditioned rapidly. She

gradually experienced symptoms of pain and fatigue at lower levels of activity. This then created the vicious cycle of ‘more rest and more deconditioning’.

In addition to her overly active and committed life style, T.A. was also going through a stressful time prior to developing chronic fatigue. She had long been stressed out with preparations for a major competition to be selected to the national team and it seems that her (and her mother’s) high levels of worry and anxiety had long preceded the “down with the virus” end, which -as stated earlier- came as a ‘relief’ and somewhat a *dénouement* to this seemingly never ending demands “from within and without”. Her mother’s overprotective, overinvolved and enmeshed parenting style since her divorce also deserves special attention in the case formulation. T.A.’s responsibilities had quite often been taken over by her mother’s goodhearted efforts.

### *The critical incident*

T.A. was reportedly told “by the doctors” that the investigations carried out were “normal” and that she “just had a viral infection”. This clearly meant for T.A that she was not taken seriously. She was referred by her General Practitioner to a paediatric neurologist; however was advised to “take a rest” in the meantime. It is likely that this ill-advised rest had contributed to the length of her fatigue as it is evident from research that a graded reintroduction of physical activity at the very early stage promotes better outcome in the long term.

At initial assessment, T.A and her mother presented with a firm belief ( a somewhat jargon statement) that “the initial viral infection remains dormant in the body and can get re-activated with stress”. She had therefore concluded that it was better to stay on the safe side and not to put pressure on herself, i.e. rest as much as possible.

### *Maintaining factors*

Avoidance: T.A.’s high levels of fatigue were maintained by low levels of activity, which then led to general loss of fitness. This resulted in a sharp and dramatic shift from a non-stop daily routine to staying in bed for prolonged hours. This is likely to have caused loss of muscle strength and subsequently experiencing pain even after minimal activities. She also reported feeling guilty due to not being able to walk their dogs.

Excessive sleep: T.A. reported constant feelings of tiredness and need for sleep “to catch up”. Slee-

ping occupied most of her day on the weekends and holidays. She had catnaps at odd times during day. She was mostly late for the school in the mornings despite up to 14 hours of night-time sleep. Excessive sleep made her more tired and struggle to do daily routines.

Beliefs about the illness: T.A. believed that she would end up “in bed for days” had she carried out activities outside of her current ‘routine’, which consisted of minimal daily chores and erratic school attendance. At school she would sit in the classroom avoiding most activities. She believed that increased activity would make her stressed, which in turn “re-activates the dormant virus” and make her more fatigued. Although rather vague and confused about her beliefs she was worried that the initial ‘damage’ caused by the viral infection might get worse if she ‘pushes too much’.

To avoid the feared catastrophe, she would start preparing days before any event outside her routine, such as a scheduled family occasion or a gathering activity with friends. As part of her preparation rituals she would stop all activities and start “storing energy” by resting and sleeping. If she thinks that she had not prepared well, she knows ‘from the experience’ that she would be in bed aching for days after the event. She described a “hoarse and croaky” voice as the typical early indication of a relapse. She reported feeling frustrated about the uncertainty about the cause of her fatigue and with herself that she was not able to enjoy time with friends. Her pleasant and happy pre-morbid mood has changed into an “always on edge, irritable and short-tempered” one, according to her mother.

#### *Rating scales and standardised measures*

1. Chalder Fatigue Scale (Chalder et al. 1993); This 11-item questionnaire measures the severity of fatigue. Four response options range from “less than usual” to “much more than usual”. Bimodal scoring gives a range of 0–11 and yields a cut-off for “caseness” or excessive fatigue at 4 or over. The Likert system for scoring is used (0, 1, 2, 3), with a total possible score ranging from 0–33. A higher score indicates more fatigue.

2. Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983); This is a 14-item scale that measures anxiety and depression symptoms experienced in the past week. Responses are scored on a scale of 0-3, with 3 indicating higher symptom frequencies. Score for each subscale (anxiety and depression) can range from 0-21 with scores categorized as follows:

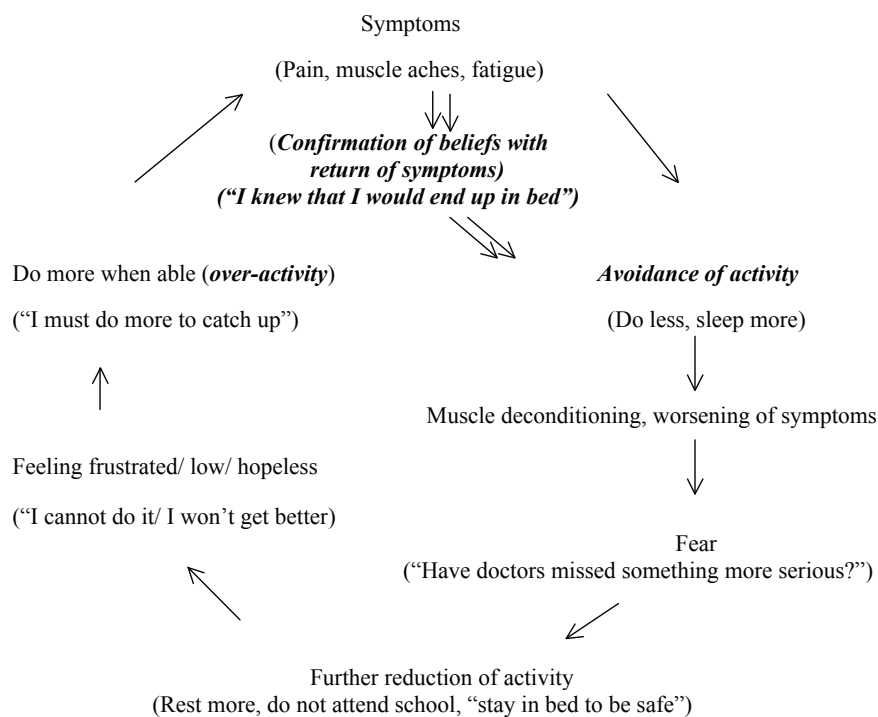
normal (0-7), mild (8-10), moderate (11-14), severe (15-21). Scores for the entire scale (emotional distress) range from 0-42, with higher scores indicating more distress.

#### *Course of the therapy*

T.A had 16 sessions over the course of a six-month period. A typical session structure consisted of the following items; mood check, homework review, setting a mutually agreed agenda, conducting collaborative work on the agenda items, setting new homework, providing a brief summary of the session and eliciting feedback. In addition to a long list of short and mid-term targets she identified the following long term, end-of-treatment goals; to attend school trips; to enjoy playing football and swim without fear of becoming ill again. (It is important to note that she emphasized that she did not intend to go back to competitive swimming again). Case-conceptualisation is the starting point in cognitive-behavioural therapy, and the clinical compass that needs to be readily present throughout the journey, in which the therapist guides the client. The maintenance formulation, which is presented below in Figure 1, is a collaborative answer that we (VG and T.A) drafted together for the question, ‘what is it that has kept me ill for so long?’.

Cognitive components of the therapy started with psycho-education about CFS in the first two sessions. In order to explore her mother’s (and also T.A’s) belief that ‘dormant viral infection gets re-activated’ and its impact on the safety behaviours displayed by T.A., her mother was invited to the psychoeducation session.

T.A was introduced to the basic concept of CBT that the cycle of our thoughts, feelings and bodily reactions are inter-related and continuously affect each other and that they subsequently determine and maintain our actions, which in turn confirm our beliefs about the problem behaviour. She was then guided throughout the therapy to question the validity of her related beliefs. One of her negative automatic thought was ‘If I do more I will be in bed aching for days’. She was therefore asked to keep a thought diary and illustrate them in the hot cross bun model of CBT cycle. The aim was to empower her to understand and challenge the impact of the “boom and bust” attitude on fatigue and pain. An activity and rest diary was also introduced to demonstrate the relationship between excessive rest or overactivity and pain/fatigue. The vicious cycle illustrated in Figure 1 was always kept on the table and re-visited each time when dis-



**Figure 1.** Vicious cycle of fatigue maintenance

cussing her thought and activity diaries. Her prolonged rest/inactivity and subsequent diminished muscle strength were discussed as the possible maintaining factors of her longstanding worries. The following alternative explanation had initially to be provided by the therapist due to T.A.'s reluctance to challenge her previously reported beliefs about the illness: "I feel fatigued because I am not used to exercise, but I will be able to do more with practice" She said she gets muscle/joint aches 'even following light exercises', but then tentatively agreed to carry out behavioural experiments to test out this alternative view. Impact of the 'boom and bust' attitude (excessive activities to go back to the same level of training and then taking long rests due to pain and fatigue) on the maintenance of her illness was shared with her and then included in the figure illustrating maintenance cycle.

Her perfectionistic attitude leading to setting standards high and subsequent frustration when standards not met was challenged and its impact on her mood and bodily symptoms was addressed. She initially objected to the planned activity of playing football with friends 'only' for 10 minutes as she said walking off the pitch after 10 minutes means that she let her friends down. She said she would therefore end up staying on the pitch for longer and then become ill again. She was worried that she would not get invi-

ted again, had she left the pitch early. She rated that she 80 % believed this would happen (i.e. she would not get invited again). However T.A was encouraged to get support for the team coach (her father) and to disclose to her friends that she was advised to make a gradual return to team-play hence could only do it for 10 minutes to start with. The strength of her belief gradually dropped as she received an understanding and supportive reception from her friends instead of her fear of rejection. She then gradually increased the time she spent on the pitch. She was encouraged not to catastrophise any setbacks and be prepared to drop her activities to the previous level if needed. In order to monitor activity levels T.A. was asked to keep activity diary, which enabled her to be self-conscious of signals of reaching her activity limit. She was instructed to reduce daily activities and have some rest in between when she felt the fatigue was coming up.

Her sleep pattern was erratic at the start of therapy. Strategies to set some routines; such as getting up at the same time including on the weekends; cutting daytime naps and avoiding to go to bed early even when feeling tired were incorporated into agenda. Her sleep pattern gradually improved and despite occasional slip-ups she managed to re-establish a routine with intensive support from her mother. Her mother could not attend most sessions due to work commitments;

however a regular link was maintained with her over the phone.

**Planning activity and rest:** She was encouraged to have the same amount of activity followed by periods of resting for a planned week. These activity periods were then gradually increased with rest periods being reduced. Having achieved a regular pattern of activity and rest, she was encouraged to go out with friends for social activities on the weekends i.e. going to town centre or cinema. She at times struggled to follow the planned activity program, in terms of either 'overdoing' activities or ignoring to take a rest. Psycho-education about the 'boom and bust' activity style and the importance of graded increase in activity levels with rest were regularly re-visited in the sessions.

The last three sessions focused on relapse prevention work. She gradually became more able to generate constructive thoughts when faced with challenges i.e. a physical illness (i.e. her positive attitude to a flu that she experienced during therapy course) rather than catastrophising it as the indicator of a relapse. Her premorbid life style as a potential risk factor for relapse and therefore the need for adopting a more balanced and relaxed daily routine was debated. She was able to demonstrate that she could anticipate a fatiguing activity and therefore take some rest to prevent an unwanted outcome rather than resorting to "safety behaviours". She displayed skills to generate cognitive alternatives to support these behavioural changes and was able to set weekly or fortnightly activity programs for future events/targets at the end of therapy.

Both T.A. and her mother considered her progress as "very much improved" and 100% believed that T.A was on her way to a complete recovery, rating for which was initially only 20% for T.A and 10% for her mother. Clinical improvement was also reflected in the self-rated measures such as Chalder Fatigue Scale (CFS), and Hospital Anxiety and Depression Scale (HADS). Total CFS score dropped from 27 to 5; and HADS total score dropped from 25 to 7.

Most of the treatment goals set in the Session 1 were either mostly of fully met at the end of therapy. T.A. was no longer catnapping during day; she established a regular sleep pattern; was able to get to school in time, do regular physical activities and socialise with her friends. During the course of the therapy she successfully managed to attend a school trip and had prolonged periods of football activities with friends on several occasions, towards the end of therapy.

## DISCUSSION

In this case study, a successful treatment of an adolescent with Chronic Fatigue Syndrome using Cognitive Behavioural Therapy was presented. The CFS treatment protocol proposed by Deary and Chalder and the protocol outlined in the book edited by Strauss (1994) was adopted and the PACE (Cox et al. 2004) materials were used when needed. Therapy consisted of 16 sessions over the course of six months. The client was accompanied by her mother in sessions 1, 2, 6 and in last three sessions. The mother was also seen alone for 15 minutes after each session she attended. Her mother's role was initially that of a co-patient due to her clear role in the maintenance of T.A.'s illness; however she quickly progressed to taking an active and positive role in helping T.A to successfully apply between-sessions assignments.

CBT for CFS targets changing cognitions and aims to help client to build up regular daily activities. Adopting an empirically supported and structured therapy model can explain the success of this particular case. Other important factors that might have contributed to the success can be speculated as the follows; establishing a trusting therapeutic relationship with the client; helping mother gain insight into her role in the maintenance of the illness and enabling mother to progress from being part of the illness cycle to become a co-therapist; maintaining regular contact with mother over the telephone to ensure on-going support; keeping the "busy-and-cannot-attend" father in the loop via the mother; and the client's positive attitude.

It is important to note that despite presence of some symptoms of depression and anxiety (both indicating moderate severity before treatment) medications were not used for treatment. As expected, improvement in fatigue symptoms led to similar improvement in depression and anxiety symptoms. One of the main advantages of CBT over medication is the long term maintenance of gains. The main downside of this case study is lack of follow up assessment to evaluate whether such therapeutic gains and improvement were maintained. This was due to the therapist's re-location to a different geographical area.

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*Yazışma adresi/Address for correspondence:*

e-mail: [vahdetgormez@gmail.com](mailto:vahdetgormez@gmail.com)

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