Cognitive Behaviour Therapy for Chronic Fatigue Syndrome in Adolescents

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Aims

- To describe the evidence for CBT in CFS in adults and adolescents
- To give an overview of CBT and what it entails

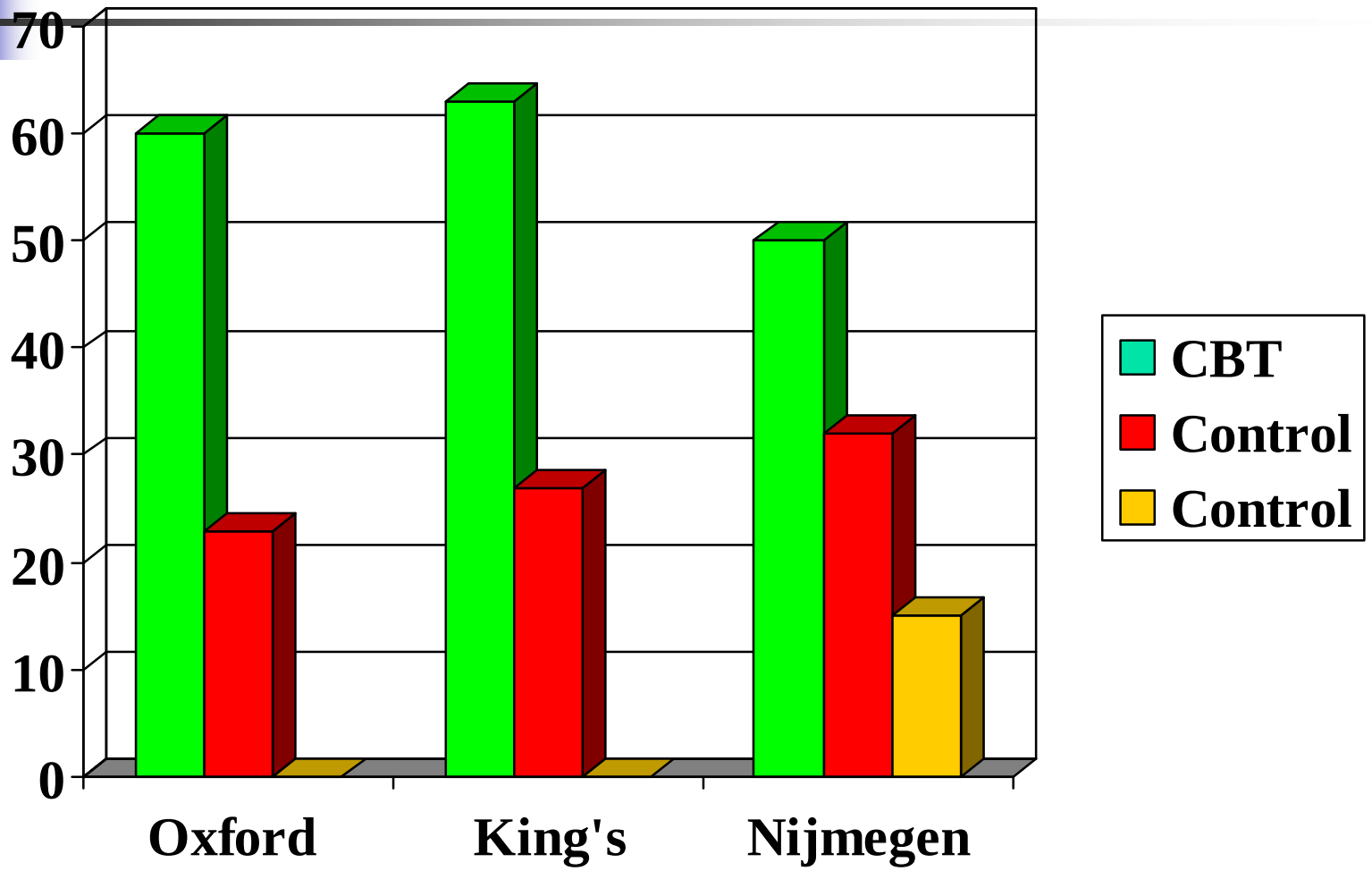
Our model of understanding CFS

- We distinguish between precipitating and perpetuating factors:

- Precipitated by:
  - virus or stress
- Perpetuated by:
  - Fear of making things worse
  - Doing less and getting into all or nothing behaviour driven by trying to prevent a worsening of fatigue
  - Symptom focusing
  - De-conditioning

(Wessely, David, Butler & Chalder 1989)

Percentage improved with CBT



What changed in our RCT?

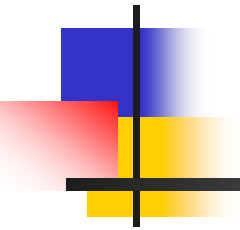
- The ***belief*** that exercise should be avoided and that doing less helped fatigue CHANGED

- Belief in the physical nature of CFS DID NOT CHANGE

(Deale, Chalder & Wessely 1998)

Long term outcome of CBT v relaxation for CFS: a 5 year follow up (Deale, Husain, Chalder & Wessely 2001)

- Setting: Medical out patient clinic
- Design: Longitudinal follow up
- Patients: 53/60 patients who took part in RCT
- Results: 24% who received CBT were completely recovered; 71% of those who received ANY CBT 5 years later rated themselves as much better; 18% of those receiving relaxation were much better.
- Conclusions: CBT produces long term benefits but some waning of effects at 5 years. Booster sessions would help maintain gains



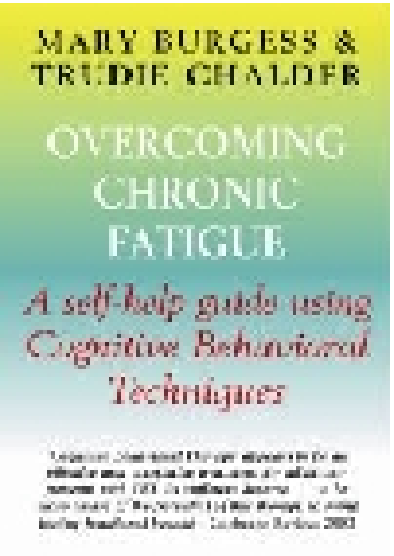
Is telephone treatment effective?

YES

- An open pilot study indicated that one face to face assessment appointment plus 13 fortnightly telephone appointments resulted in improvements in fatigue and disability

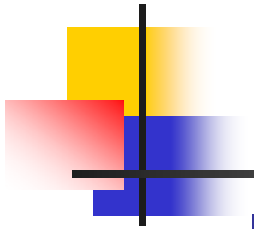
  (Burgess & Chalder 2001)
- In a RCT of face to face v telephone appt's (initial assessment face to face), fatigue and physical functioning improved in both groups
- There appears to be some evidence that telephone treatment is as effective as face to face

  (Burgess et al submitted)



Does it work in real life?

- Outcomes from RCTs have rarely been compared with those in clinical practice
- We compared outcomes on 30 patients who took part in our RCT and 384 patients who received treatment as part of the everyday clinical practice
- Results were similar in both groups up to discharge from treatment
- At 6 months FU those in the RCT did better
  - (Quarmby, Rimes, Deale, Wessely & Chalder. BRAT; 2007)



Is it possible to prevent chronic fatigue after infections?

Risk factors for development of fatigue following viral infections

- Serious infections can trigger long term fatigue
  - i.e. Infectious mononucleosis;

    (White et al 1997)
- Common viruses (URTI's) do not trigger long term fatigue

  (Wessely, Chalder, Hirsch et al 1995)
- Lengthy convalescence, being less fit or active and psychological co-morbidity predicts chronic ill health

  (Candy, Chalder, cleare, Wessely, White & Hotopf 2002)

Aim

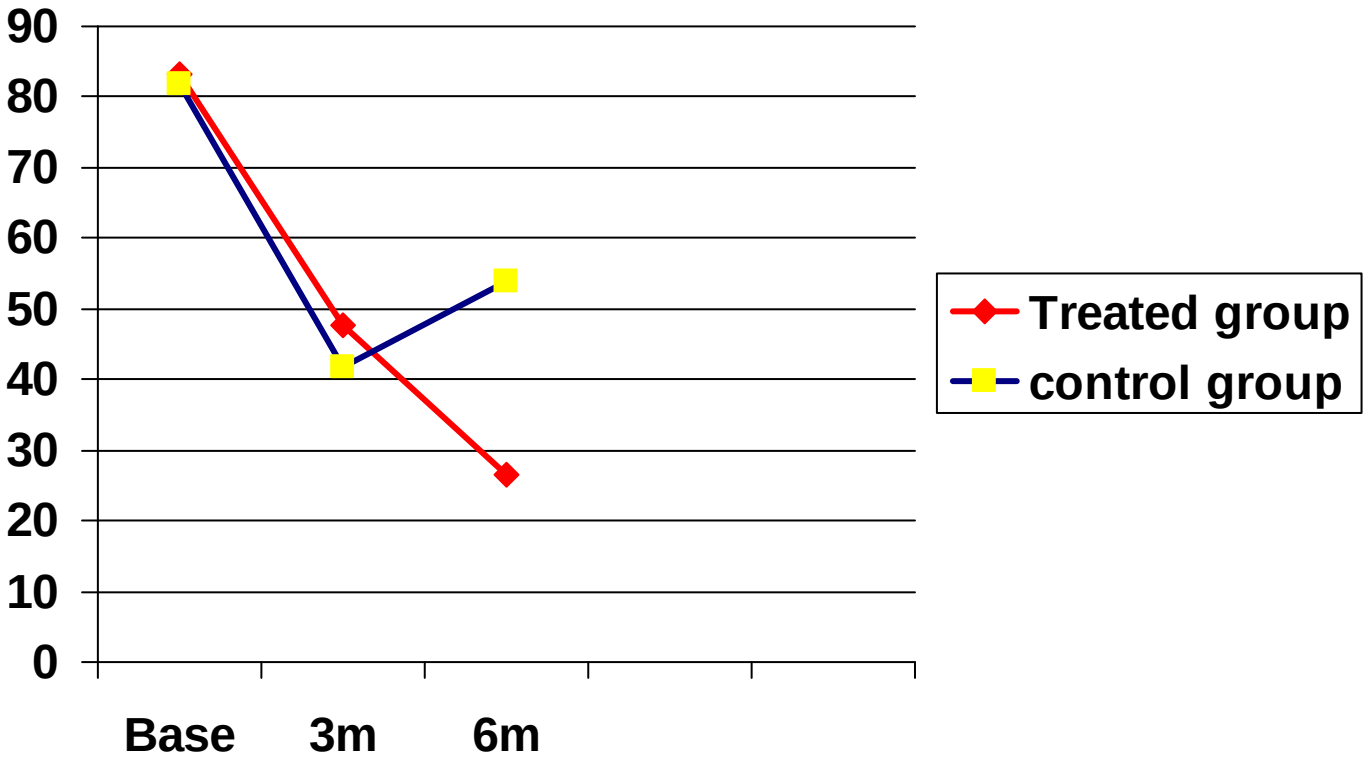
- To test the hypothesis that a brief psycho-educational package, administered by a research nurse shortly after onset of GF would reduce fatigue symptoms by 6 months

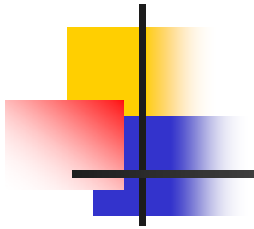
Intervention

- One session “face to face” followed by 2 telephone sessions 2 weeks apart with nurse
- Sessions reinforced with a booklet
- Concentrated on “lifestyle management” – advice to return to work, gentle grading of activity, and planned rest
- Sessions recorded and supervised

Prevention of Chronic Fatigue in Glandular Fever

(*Candy, Chalder, Cleare, Wessely & Hotopf 2005)*





Is it possible to reduce fatigue associated with chronic diseases i.e. cancer?

Design & subjects

- Randomised controlled trial of 3 sessions of behaviourly oriented psycho-education with a nurse versus usual care

- Consecutive patients receiving cytotoxic treatment on an out-patient basis

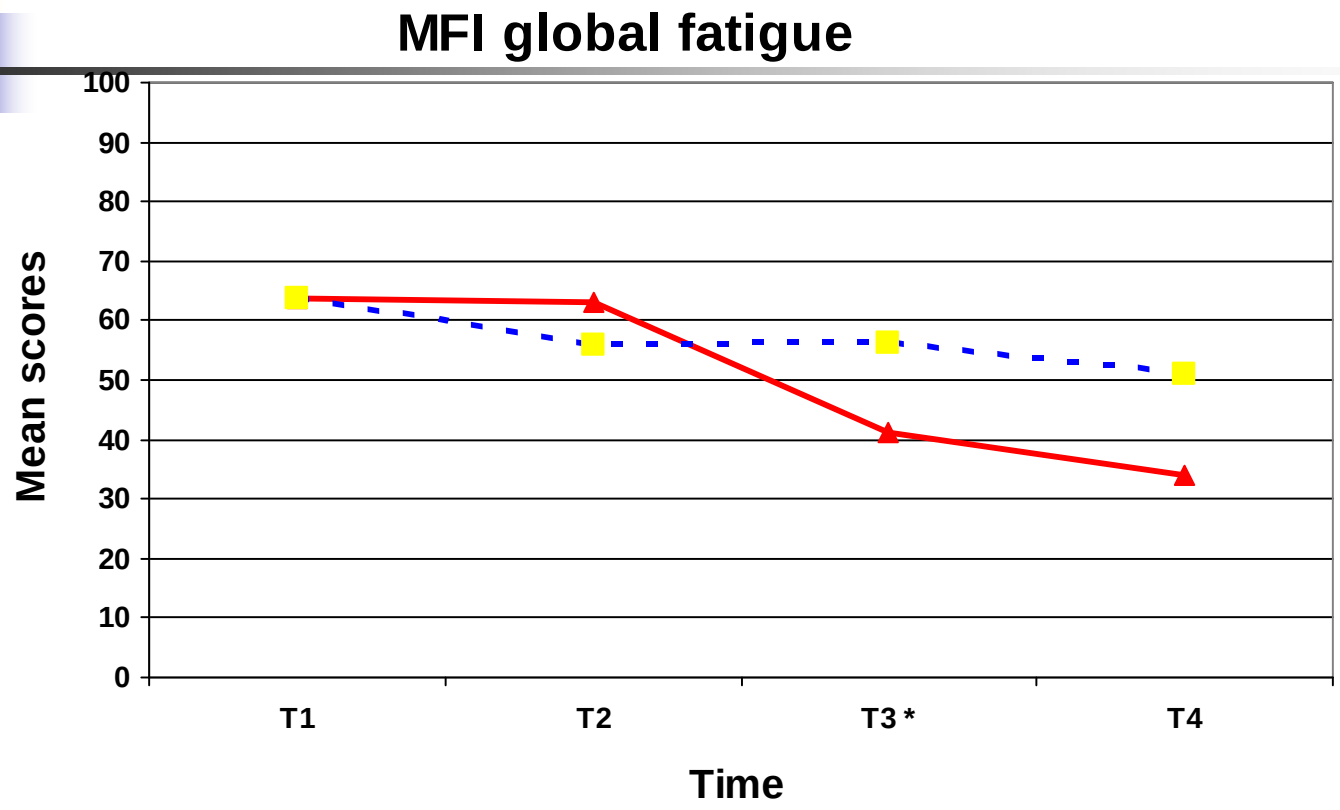
Armes, Chalder, Addington-Hall & Hotopf. (2007) Cancer

Psycho-educational intervention for Cancer related fatigue

Three one hour sessions over 9-12 weeks with nurse

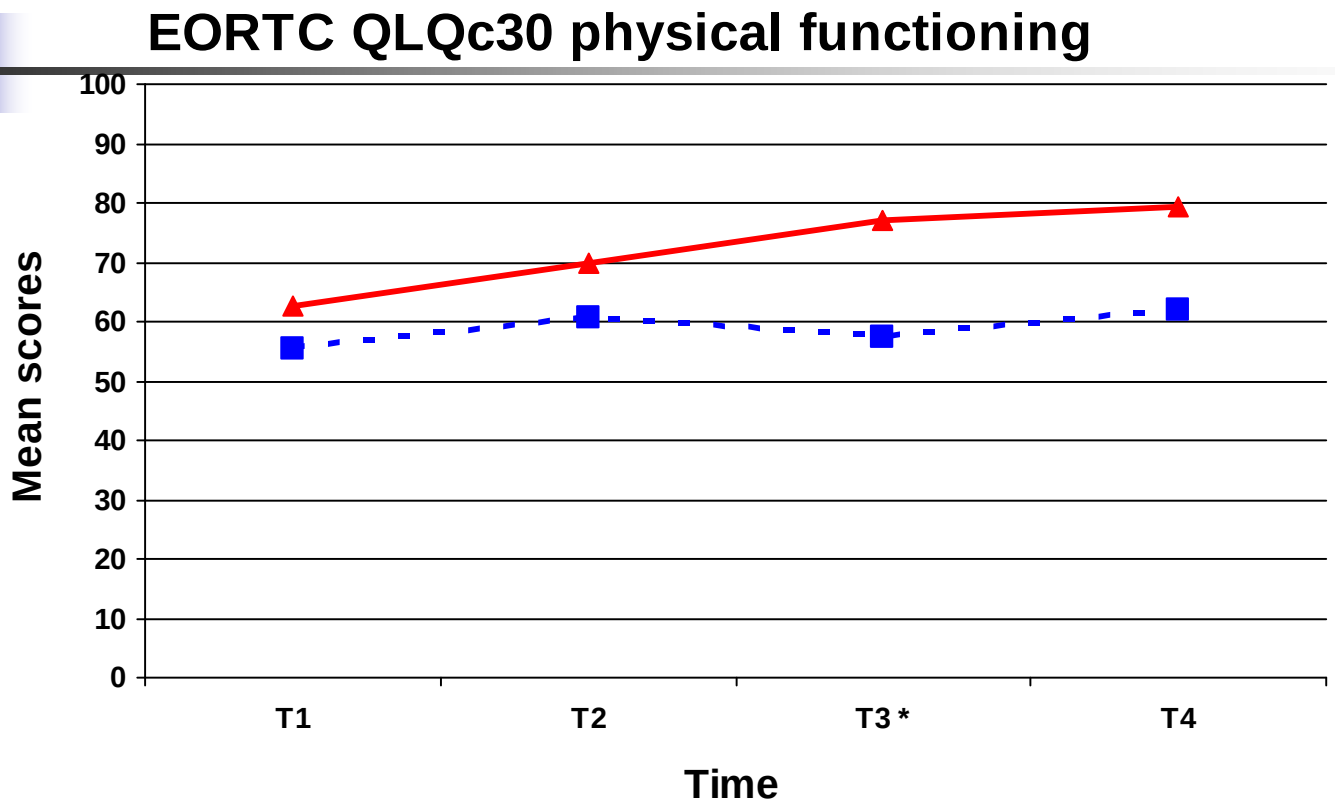
- Session 1: Assessment
- Session 2: Activity planning
  Sleep management
- Session 3: Increasing activity
  Dealing with negative thoughts

Cancer related fatigue (RCT)



Linear regression at T3 (Corrected for T1)
B = -15.9, 95% CI = -30.2, -1.7, P = 0.030

Results: Secondary outcome



Linear regression at T3 (Corrected for T1)

B = 15.2, 95% CI = 5.3, 25.1, P = 0.003

Family focused CBT for CFS in adolescents: an open pilot study

- Aim: to examine the efficacy of family focused CBT based on our model for 11-18 year olds with CFS
- 23 patients offered treatment
- 83% improved according to our pre-determined criteria: <4 fatigue & attendance at school at least 75% time

2 RCTs

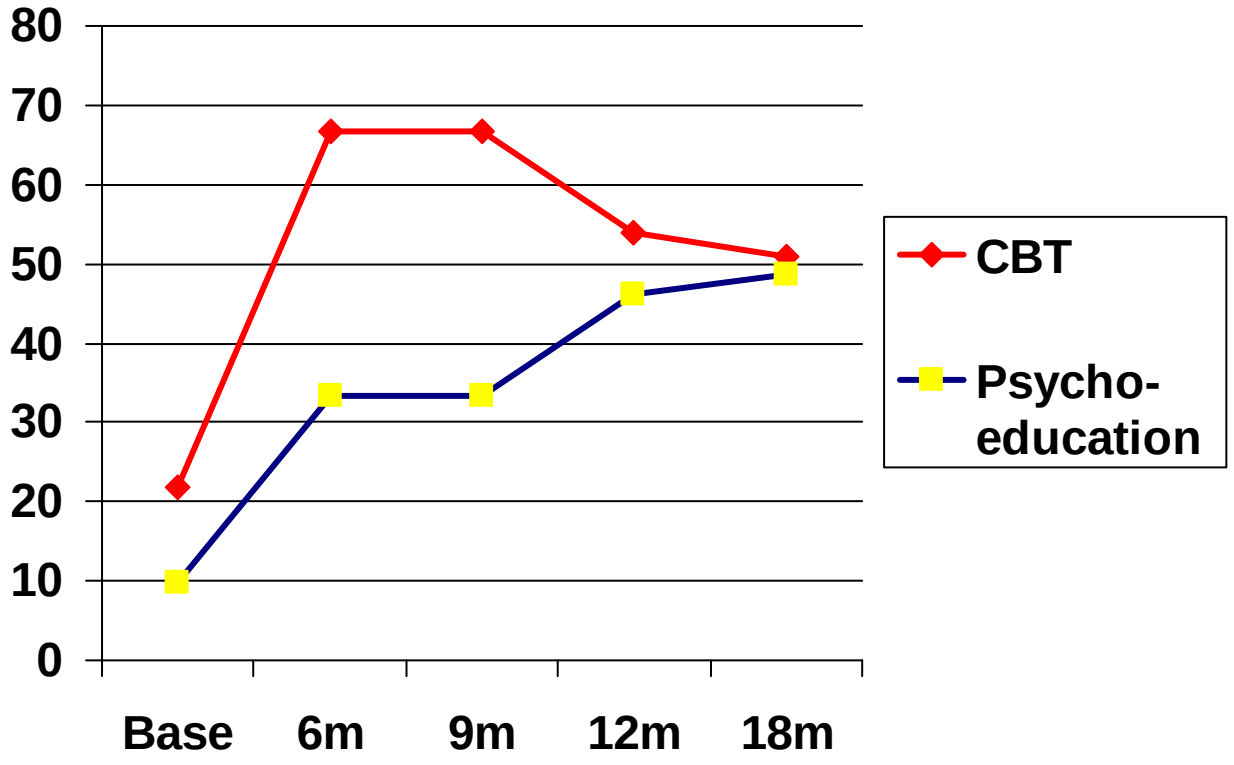
- Dutch study: compared CBT with W/L; In the CBT group, children were less fatigued and symptomatic, were functioning better, were attending school more (58% v 29%) at 5 months

  (Stulemeijer et al 2005; British Medical Journal)

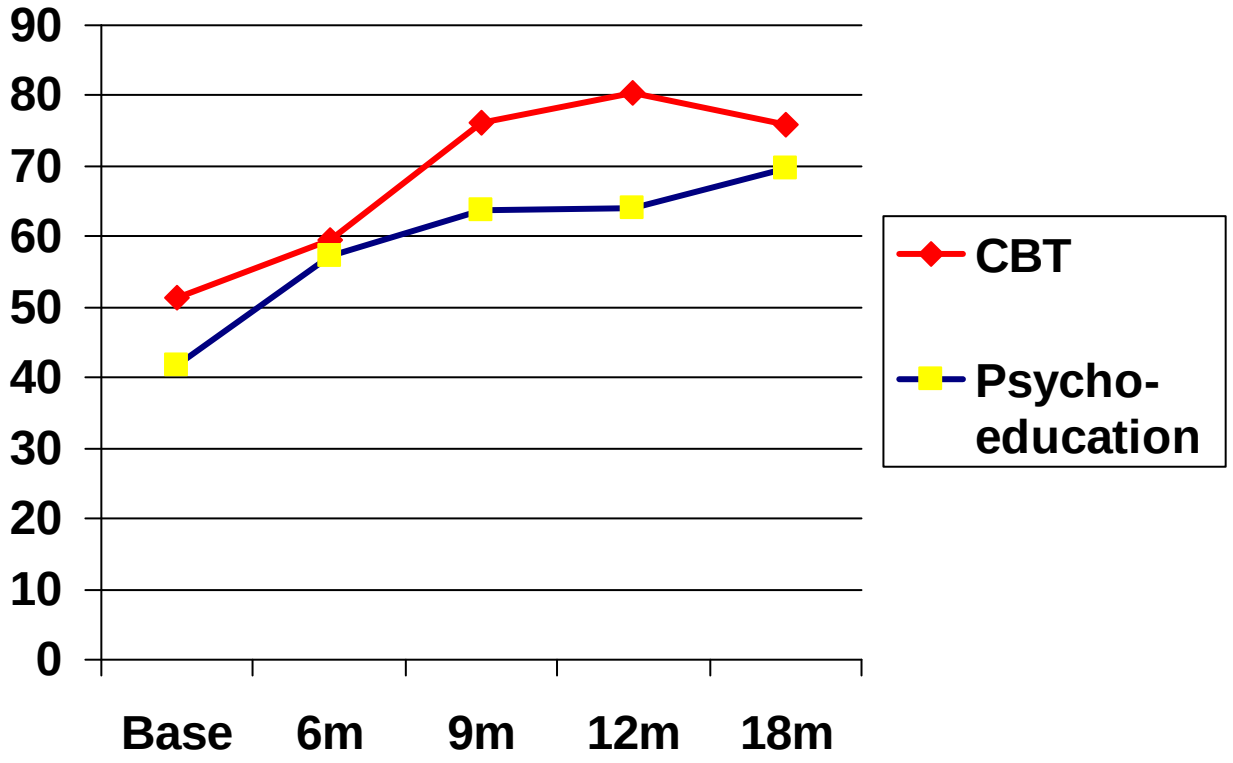
- We compared 13 sessions of family focused cognitive behaviour therapy with 4 sessions of psycho-education (advice on rehabilitation) over 6 months

  (Chalder, Deary, Husain & Walwyn. Psychological Medicine, in press)

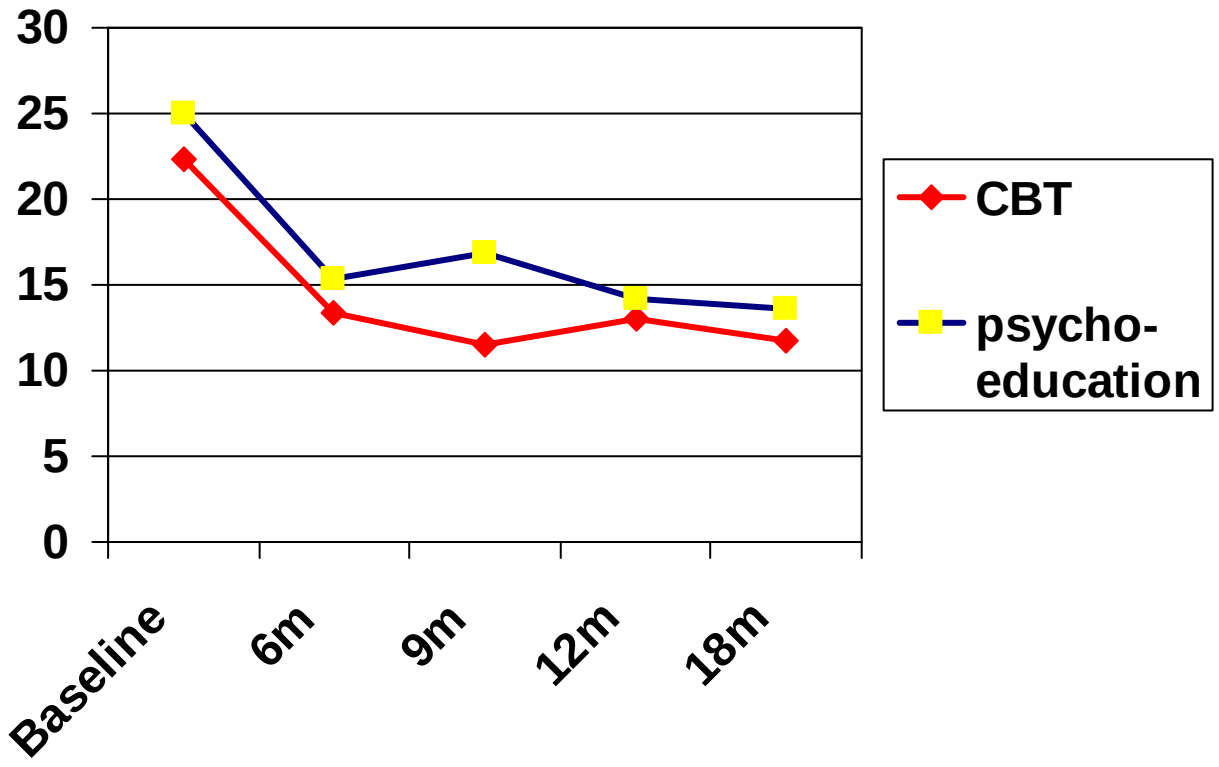
Percentage of time at school



Physical functioning



Fatigue



Cook book approach on how to do it

Assessment: goals

1. Promote engagement
2. Socialise family to therapeutic model and orientation
3. Develop a shared understanding of the condition
4. Provide an explanation for symptoms
5. Identify precipitating and maintaining factors.

Assessment

- Important: take time, and let the youngster/family tell their story
- Be careful with question sequence: begin with symptoms
- Impact of symptoms on daily life (details of activity, rest, sleep disturbance, modifications, restrictions, avoidances)
- Typical day
- Impact on mood
- Onset & fluctuations: lifestyle prior to onset; advice, beliefs and management at onset

Assessment

- Previous investigations, referrals and treatments (allow discussion/ventilation of unsatisfactory encounters
- What has helped and what hasn’t
- Families own understanding of the illness, beliefs about symptoms and their management
- Beliefs and attitudes of others
- Developmental history including family and own attitudes to health and illness and medical history
- Goals and expectations

Engagement

- Be empathic and explicit in conveying belief in reality of physical symptoms
- Shift focus from “cause” to “symptom management”
- Avoid physical versus psychological discussions
- Use physical illness analogies to illustrate approach
- Challenge therapeutic nihilism/room for optimism
- It is possible to recover

Engagement

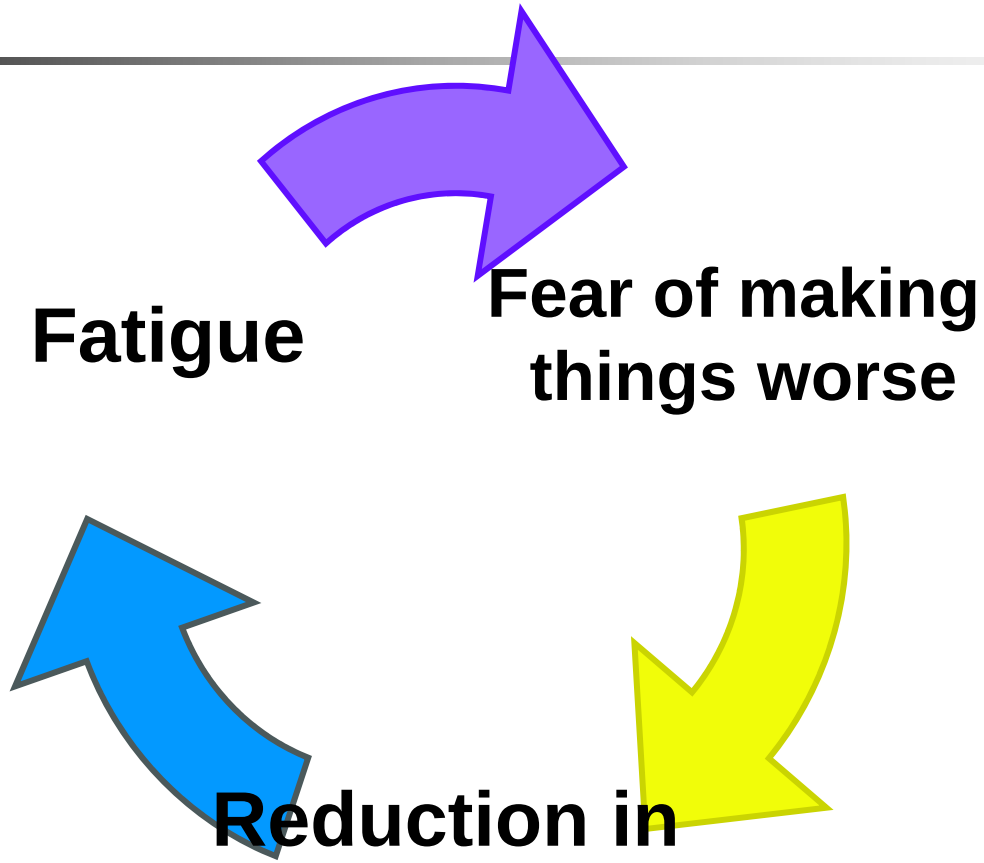
- Use language which the patient can relate to
- Avoid using the term depression unless absolutely necessary
- Use terms which the patient is comfortable with i.e. stress
- Integrate physiological and behavioural explanations to describe mechanisms of fatigue i.e. the effect sleep disturbance has on muscles or how jet lag causes fatigue and the importance of routine

- Highlight sacrifices which family will have to make to participate in treatment
  - i.e. attending consultations, discussing difficult issues openly, carrying out homework, preparing for setbacks, potentially learning to live with ongoing residual difficulties,

Offering a Rationale

- Fit the model to the individual's history
- Use a three systems model to explain the link between physiological, cognitive and behavioural responses
- Distinguish between triggering and maintaining factors
- Explain the effects of rest in an acute and chronic condition - the differences
- Describe vicious circle of fear / avoidance

Vicious Circle



Principles of activity and rest for those who are disabled

- Establish a base-line – look for inconsistencies
- Negotiate goals based on current levels of activity
- Spread activity and rest evenly throughout the day
- Do not increase activities at first
- Focus on consistency
- Increase activities and rest slowly

Words of warning

- Be prepared for a temporary worsening of symptoms with each increase in activity
- It may be weeks / months before level of fatigue reduces
- Goal is to break association between symptoms and stopping activity
- Symptoms will wax and wane

Sleep Management

- Sleep diary
- Reduce daytime sleep / rest rather than sleep
- Introduce idea of bed restriction
- Stick to a routine bedtime / up time
- Stimulus control if awake at night
- Worry time

Questioning beliefs

- Reviewing evidence for and against beliefs
- Identifying thinking errors
- What is the effect of believing this?
- What would happen if I changed my belief?
- Is there an alternative explanation?
- What is the worst that could happen?
- What is the best that could happen?
- What is most likely to happen?
- Behavioural experiments

Specific Characteristics of Family Work

- The condition is de facto systemic – beliefs, behaviours and symptoms distributed. All family invited
- Importance of engaging parents
- Distinguishing anxiety in parents from anxiety in children
- Generally enabling family differentiation as often there is fair degree of enmeshment

Specific Characteristics of Family Work

- Circular/systemic questions – eg “who do you think is most worried”; “what do you think your dad thinks about that”
- Addressing young person directly
- Them as main focus of treatment – modelling effect?
- Peer group concerns
- Under those big hats they are listening
- More directive/educative at first
- Quicker response time than adults

Specific Characteristics of Family Work

- Working with schools
- Identifying if school culture is maintaining factor
- Getting school to take condition seriously
- Negotiating academic help/home tuition
- Negotiating changes in curriculum
- Negotiating changes in year
- A lot of letters

Specific Characteristics of Family Work

- Ending treatment
- Improvement coinciding with maturation and differentiation
- Allowing parent to allow child to take risks
- Again identifying where anxieties lie
- Brokering compromise deals
- Loss of roles and new roles for parents

Conclusions

- CBT or a modified form of CBT is an effective treatment for fatigue syndromes in a variety of settings
- Engagement is crucial
- Important to assess both fatigue and physical functioning as primary outcomes
- Important to be hopeful! EVIDENCE suggests!