Chronic Fatigue Syndrome in Adolescents

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Aim of lecture

- To give an overview of a model of understanding and treating Chronic Fatigue Syndrome in adolescents
Operational Criteria (consensus criteria) Sharpe et al 1991

Persistent physical and mental fatigue present for at least 50% of the time

- Of definite onset – not lifelong of at least 6 months duration
- Other symptoms usually present e.g. myalgia, sleep disturbance
- 50% reduction in activities
- Symptoms made worse by activity
- No other condition present which would produce fatigue as main symptom

Prevalence

- Prevalence rates:
  - Self report chronic fatigue was 0.57
  - CDC criteria for CFS was 0.19
  - Parental report was 0.04

- The risk factors for chronic fatigue and CDC criteria for CFS were older age and anxiety disorders.

- Parental report of ME or CFS was associated with maternal distress on the GHQ

  (Chalder et al 2003; BMJ)

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Demographics, impairments and disability

- Majority are female
- No association with social class or ethnicity
- Prognosis better than for adults
- Marked disability associated with fatigue
  - Of 211 children with CFS/ME, 62% attended 40% of school or less
  - Only 5% children attended school F/T in 2nd care RCT

(Crawley & Sterne 2008: Archives of Disease in Childhood; Chalder et al 2009, Psych Med)
Psychiatric Co-morbidity

- Anxiety, depression and conduct disorder associated with new onset fatigue in community (Rimes et al 2007)

- Case control study in hospital care (CFS v emotional disorders {EM}).
  - High levels of co-morbid emotional disorders in children with CFS (72%)

- CFS group had fewer pre-morbid psychological problems and less psychiatric co-morbidity than the ED group (Garralda & Rangel 2005)
Vulnerability factors
Personality (adolescents)

- Using the Personality Assessment Schedule children with CFS are more introspective, sensitive, conscientious, rigid and hypochondriacal (anankastic), or aloof, shy and eccentric than normal controls
  (Garralda & Rangel)

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High expectations relate to activity and symptoms

- Children under-estimated current levels of activity & voiced a desire to achieve higher levels of activity in the future than they expected to achieve (Fry & Martin 1996)

- CFS adolescents under-estimated the level of fatigue they expected to experience compared to healthy controls (Garralda & Rangel 1999)
High expectations related to performance

- 28 children with CFS and 29 age sex matched healthy controls

- Measures:
  - Child and parent perception of adolescents intelligence based on norms in the population
  - AH4 group test of general intelligence (Heim 1970)

- Results: Parents over-estimated the child’s actual IQ. Discrepancy between actual IQ and perception was greater than age gender matched controls

- (Godfrey et al 2009, J of Psychosomatic Res)
Precipitating Factors
Role of Infectious Mono in CFS

- In adults GF, hepatitis, meningitis Q fever trigger fatigue

- Six, 12, and 24 months after infectious mononucleosis, 13%, 7%, and 4% of adolescents, respectively met the criteria for CFS

- All 13 adolescents with CFS were female (Katz et al 2009)
Other reported triggers

- Stress
  - Transitions e.g. change of school, starting exam work
  - Life events e.g. parental separation
  - Chronic stress e.g. bullying
Misattribution

- Symptoms of stress not recognised as such

- Fatigue attributed to an unspecified disease: ME (has aetiological implications)
From Fatigue to CFS: Pathways to chronicity

- They or their parents NOT recognising they are stressed and pushing themselves too hard
  OR

- Deliberately withdrawing from school etc for fear of failing
Failure to link symptoms with circumstance & therefore failure to take appropriate action

Lack of appropriate advice

Ongoing unresolved stress

Lack of support or belief in symptoms
Maintenance Factors
The Role of Behaviour

- Seeking an explanation for symptoms, repeated consultations, tests
- Symptom focusing (increasing worry)
- Resting/sleeping too much (to try and recover)
- Over doing activity, alternating with resting too much (boom & bust approach, symptom led behaviour)
Maintenance Factors
Role of Fear and Emotion

- Fear that HURT = HARM : leading to avoidance of activity
- Frustration, demoralisation, low mood
- Loss of confidence in own abilities
- Embarrassment ("I should be able to cope with this", "People think it’s all in my head")
Maintenance Factors
Role of Significant Others

- Sceptical reactions and lack of support from health professionals, family & friends, ("I don’t believe in ME")

- Gradual loss of social contact leading to isolation and anxiety about socialising

- Fears reinforced by family/friends leading to overprotection

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Maintenance Factors
Fears about school work

Fear of making mistakes due to reduced concentration & memory
- Fear of failure
  Leading to:
  - Driving self too hard to prove that you can
  - Saving energy for school work and ‘crashing out’ at evenings and weekends
  OR
- Avoiding homework commitments
- Avoiding school
- Booming and busting

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Symptoms of CFS/ME are distressing and debilitating and therefore patients will often pay much attention to them.

Focusing on symptoms may lead to an exacerbation of symptoms and further avoidance.
LIFE STRESS AND LOW MOOD

- Ongoing life stresses and problems may further exacerbate CFS/ME
  Stressors may include: difficulty studying, social isolation, other illnesses, etc.

- Frustration about their illness and effects may lead to helplessness, loss of control which can lead to low mood/depression

- The above may further reduce the desire to be active
Clinical Implications of the Model

- Address fearful cognitions, behavioural avoidances and symptom focusing
- Make activity symptom independent
- Gradually increase activity which changes cognitive and attentional processes
- Offer support
- Address high standards
3 RCTs

1) 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)

2) 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 2010)
Psycho-education

CFS has a **good prognosis** in adolescents

- Present a model of CFS that **distinguishes predisposing, precipitating and maintaining factors**
- Introduce the concept of **symptom management** – that the way we manage our physical symptoms can make a difference to the outcome
- Give advice on **pacing and consistency** of activity and rest, in order to break the vicious circle of symptom lead behaviour
- Give advice on **sleep management**
- Convey the message that **hurt does not equal harm** – increased symptoms do not mean more pathology
- Advise adolescent to **gradually build up activity** over a period of months.
Long term follow after CBT

- 44 participants took part
- Primary outcome: at least 70% school attendance – 90% CBT v 84% psycho-education
- Recovery: 79% CBT v 64% psycho-education
- Those in CBT group reported sig better emotional and behavioural outcomes using SDQ (Lloyd, Chalder & Rimes BRAT 2012)

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Predictors of Outcome after CBT

- 28% of mothers reported severe fatigue at baseline.
- Greater baseline fatigue in mother predicted poorer treatment outcome for adolescents after CBT.

(Knoop et al 2008)
3) FITNET CBT (Nijhof et al, The Lancet 2012)

- Design: Internet based CBT v TAU
- 12-18 year olds (n=135); tertiary care; primary outcomes were fatigue, school attendance and physical functioning
- Fitnet resulted in better outcomes at 6 months: school attendance 75% fitnet v 16% TAU
Additional treatment evidence

- Qualitative study: The Lightening Process; young people reported positive and negative experiences (Reme et al 2012)

- Non randomised cohort with no treatment baseline: Telephone CBT (face to face assessment + 6 telephone treatments) resulted in improved fatigue, social adjustment and school attendance (Lloyd et al 2012)
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
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

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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
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

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Helping parents to set limits

- Addressing unhelpful behaviours
- What to do when teenagers act out
- Discuss positive reinforcements
- Adolescent and parent to spend set amount of time together when appropriate and convenient for both parties (not in the middle of the night)
Specific Characteristics of Family Work

- Circular/systemic questions – eg “who do you think is most worried”; “what do you think your mother 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  Trudie Chalder 2010
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
- Encourage mum to find new interests / work
Predictors of Outcome after CBT

- RCT in Netherlands
- 28% mothers reported severe fatigue at baseline
- Greater baseline fatigue in mother predicted poorer treatment outcome for adolescent (Knoop et al 2008)
- Baseline perfectionism predicted poor school attendance at 6 mfu after telephone CBT (Lloyd et al 2012)
http://www.kcl.ac.uk/projects/cfs

Chronic Fatigue Syndrome – a guide for young people” (Chalder & Husain 2003)

Blue Stallion Publications