The Families Point of View

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Talk Map

- My history in ED
- The cognitive interpersonal model.
- Translation into treatment.
MY HISTORY IN EATING DISORDERS
THE FIRST PSYCHOTHERAPY TREATMENT TRIALS FOR ANOREXIA NERVOSA

Family therapy versus individual therapy for relapse prevention following inpatient care
(Russell et al 1984, 1989.)
Maudsley Anorexia Nervosa Treatment Trial 1980’s

Family vs. Individual therapy
To prevent relapse after inpatient treatment

Patients randomised according to age & stage:
1. < 18 y, Early < 3 years
2. < 18 y, Enduring > 3 years
3. Adults
What is the essence of FBT (Maudsley)

- Agnostic on cause
- Externalisation of illness
- Initial focus on symptoms
- Food is medicine
- Non authoritarian stance.
FBT superior only in <18 yr and <3 years of illness

Stratified randomisation
Duration of illness moderates the response
The first example of personalised medicine in ED
What does the evidence say about Family therapy approaches for anorexia nervosa?
Fisher CA et al 2018- Cochrane Review

Limited amount of low-quality evidence that family therapy > treatment as usual.
(Based on two small trials with potential bias).
The three-legged stool of evidence-based practice in eating disorder treatment: research, clinical, and patient perspectives

Carol B. Peterson¹ ², Carolyn Black Becker³, Janet Treasure⁴, Roz Shafri⁵ and Rachel Bryant-Waugh⁶
FBT DOES NOT WORK FOR ALL TYPES OF ANOREXIA NERVOSA

• FBT = INDIVIDUAL THERAPY (< 18 years old & >3 years ill; long duration of untreated illness). (recovery low in both).

• FBT = INDIVIDUAL THERAPY > 18 years old (recovery moderate in both).

Russell et al 1987, Eisler et al 1997
What is acceptable for patients and their families?
What do the patients and carers say?
Parents question the core principles of MFT/FBT (Wufung et al 2019)

- Allocating responsibility to parents for re-feeding and weight restoration with an adversarial framework (parents vs externalised ED).
- Psychological distress (depression, OCD, ASD, social anxiety etc) deferred until the final phase.
Researchers question the core principles of MFT/FBT

- Should we continue to be agnostic about aetiology?
Over 40 years we have come a long way in what we know and what we do not know now.
What do Carers ask for?

Information and knowledge about eating disorders (Haigh & Treasure, 2003)

Help and support around how best to perform their role (Whitney et al., 2005)
What do carers and patient say is a problem?
Rebecca: Asked to sum up my experience of anorexia nervosa in one sentence - actually, I can do it in just one word - isolation.

McKnight et al 2009 - BMJ personal journey
Carers isolated and walled off

Sorry.
Nothing we can do. It's a question of confidentiality.

Go away!
I do not want you involved.
Developing the cognitive interpersonal model: predisposing factors

Schmidt & Treasure 2006; Treasure & Schmidt 2013
Antecedent Social Phenotype (AN)

• Loneliness, shyness and inferiority in childhood and adolescence (*Fairburn et al 1999)*.
• Reduced social aptitude (*Rhind et al 2015*).
• Social anxiety (*Penas Iledo et al 2010*).
• Solitary activities (*Krug et al 2014*).
• Submissive and striving behaviours (*Connan et al., 2003, 2007, Troop et al., 2008, Troop et al., 2003*).
• Social Problems *Cardi et al 2019*
• ↓ friend functioning. Loneliness ↑3X (*Mehl et al 2019*)
Developing the cognitive interpersonal model: maintaining factors

Schmidt & Treasure 2006; Treasure & Schmidt 2013
Chronic Stress: Brain on fire
Sensitisation to threat
Damage to hippocampus (↓ new learning/neurogenesis)
Attention to social expressions

AN > BN
Related to early Trauma
Chronic Stress

Harrison et al 2012; Cardi et al., 2013, 2015
Interpretation of Ambiguous social scenarios

As you walk in to a group of people, they stop talking because they were talking about...

Cardi et al., 2016, 2017
The implications for carers if there is a sensitisation to negative social cues such as:

Attentional focus towards threat
An interpretation focused on the negative
Brain needs 500 Kcal/day - deficits with malnutrition.  
2% of body mass but 20% of energy 
• The social brain hypothesis: Brain Size @Social Network (Dunbar).

NEUROPROGRESSION
Social communication:
lack of mirroring facial expressions

- Acute AN: large ↓ expression. Adult > Adolescent.
- Recovered AN: ↑ positive emotions.

Davies et al., 2016 Neurosci Biobehav Rev
Social communication inhibited: A blank mask or fake pleasing

Davies et al., 2011, 2013; Dapelo et al., 2016; Lang et al., 2016; Leppanen J. et al. (2017)
REACTIONS OF OTHERS TO ANOREXIA NERVOSA
Lack affect & interpersonal relationships
I was known as the "ice queen" at Uni

No reciprocity to warmth, a frosty, "aloof" response.

Tutors would get annoyed as they thought I did not care.

They did not know what was going on inside.

Problems in Social Perception

- Difficulty detecting intimacy (Costanzo & Archer, 1993)
- Respond coldly to warm feedback (Ambwani et al 2016)
- Less appropriate social problem solving (Sternheim et al., 2012)
THE IMPACT ON RELATIONSHIPS
First do no harm: iatrogenic Maintaining Factors in Anorexia Nervosa

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Abstract

The aim of this paper is to reflect on the way that we as clinicians may play an inadvertent role in perpetuating eating disordered behaviour. This is considered within the theoretical framework of Schmidt and Treasures’ maintenance model of anorexia nervosa (AN). The model includes four main domains; interpersonal factors, pro-AN beliefs, emotional style and thinking style. Interpersonal reactions are of particular relevance as clinicians (as with family members) may react with high expressed emotion and unknowingly encourage eating disorder behaviours to continue. Hostility in the form of coercive refeeding in either a hospital or outpatient setting may strengthen conditioned food avoidance and pessimism may hamper motivation to change. Negative schema common to eating disorders, for example low self-esteem, perfectionism and striving for social value may augment existing or initiate new eating disorder behaviour. Services can become a reinforcing influence by providing an overly protective,
Confusing Social Signaling

↓ Social cognition
Negative bias
↓ Emotional management

HELP! the scream from body

A “dead pan” face

Anorexic Voice-hissing or shouting
I am disgusting. I must try to succeed. How many calories in that. What is the food composition. What is my weight. I cannot go above. I must keep losing weight. I am weak. I am stupid. I am lazy. I am gluttonous. I’m a fat pig. I’m disgusting. I don’t deserve to eat. I don’t deserve to live. etc. etc.

AN behaviour:
Rejecting food—ignoring the distress of others. Lying, cheating, secrecy.
Animal metaphors to describe unhelpful interpersonal styles

INTERPERSONAL RELATIONSHIPS AT HOME MIRROR THOSE IN HOSPITAL
High anxiety and frustration
Eventually accommodate or enable or withdraw from illness
Problems in social cognition impact on the therapeutic alliance and family & peer relationships.

- They can be modified
Isolation: a modifiable maintaining factor

- Solution: ↑ Connection

- Repair relationship ruptures and ↑ connection.
Isolation: a modifiable maintaining factor

- Solution: ↑ Connection

- Repair relationship ruptures and ↑ connection.
Carers Needs

Skill sharing solutions to provide windows & doors in the wall.
Windows & doors in walls: Knowledge & Skill Sharing between non/professional carers

- Shared formulation
- Listening with motivational interviewing skills.
- Solution based/positive psychology frame.
- Coaching emotional regulation.
- Experiential learning from habit change (accommodating, enabling)
- Remediating extreme cognitive styles with flexibility and big picture thinking.
- Coaching behaviour change techniques

Treasure et al 2011. First do no harm, Treasure & Nazar 2016, Cardi et al 2018
Experienced Carers helping Others (ECHO)
A carers – self management intervention.
PPI involvement at every phase

Working Together
Collaboration

Step out of Eating
Disorder Traps

Provide Skills for
↑ Change

Shared
Understanding
Shared Skills

Regulate emotion
Care for self.
↓ accommodation
↓ over protection
↓ hostility & criticism
↓ disagreement & division

Compassion
Positive communication
Behaviour Change Skills
Share information about risk and maintaining factors. Consequences of starvation on the brain

Shared Understanding
Shared Skills

Regulate emotion
Care for self.
↓ accommodation
↓ over protection
↓ hostility & criticism
↓ disagreement & division

Compassion
Positive communication
Behaviour Change Skills

Working Together
Collaboration

Step out of Eating Disorder Traps

Provide Skills for ↑ Change
DESCRIBING HOW RISK AND MAINTAINING FACTORS MAKE CHANGE DIFFICULT
Experienced Carers helping Others (ECHO)

A carers – self management intervention

PPI involvement at every phase

Provide Skills for ↑ Change

Step out of Eating Disorder Traps

Share information about impact on close others

Working Together Collaboration

Regulate emotion
  Care for self.
  ↓ accommodation
  ↓ over protection
  ↓ hostility & criticism
  ↓ disagreement & division

Compassion
  Positive communication
  Behaviour Change Skills

Shared Understanding
Shared Skills
ITS MY CHILD THAT HAS GOT TO CHANGE NOT ME!
When we are no longer able to change a situation – we are challenged to change ourselves.

Viktor E. Frankl
Carer’s emotional responses (too much, too little).

- High intensity emotion-jelly fish
- Avoidant Emotional Response
Carer’s emotionally driven behaviours (too much push or too much pull).

Push towards growth
Rhino & terrier

Pull to perfect safety/nurture
-kangaroo, accommodating, reassuring
Accommodating

Families accept:
- Food & meal rituals.
- Safety behaviours (exercise etc.)
- OCD behaviours with reassurance.
- Calibration and competition with other family members.

I will not eat
I would prefer to die
I have to have different crockery for preparing and cooking my meals. They are kept separately.

Edi sometimes comes down in the morning and says she dreamed about eating a chocolate mousse. She will then keep asking throughout the day- I did not eat a mousse did I? She goes on and on.

“She stands over me when I am cooking to ask whether I have put oil in the food and checks throughout the meal. I am the only one who can cook for her.

Edi will ask me a hundred times a day whether she ate too much at her last meal.

She will only drink from a new bottle of water. The fridge is stocked with her water.

No one can go in the kitchen when she is there.
The vicious circle of accommodating AN mode:

AN impacts on relationships

Family very concerned & make exceptions for AN

Parents may have high anxiety and walk on egg shells.

AN becomes stronger

AN symptoms increase

Become less flexible
The trap of Accommodation

- Participating in ED behaviours eg food rituals (part of response illness behaviour).
- Avoiding triggers (eg following rules, time of eating, what to buy, how to store, what implements to use etc).
- Accommodating ↓ distress.
- Not accommodating ↑ distress and aggression (verbal & physical), pestering, badgering and emotional blackmail (e.g., accusing the caregivers of not loving or caring/suicide threat), extinction burst.
All the family need to be involved

Small amounts of accommodation in other family members keeps illness going.

(Salerno et al 2015)
The trap of enabling

Carers remove the negative consequences of an eating disorder and/or turn a blind eye.
They clean up mess in kitchen or bathroom.
They cover up for lost food.
They give money for food

Emotions: Fear, Guilt, Anxiety, shame
Enabling ED. Avoidance & modify routine

Covering up for:
- Plumbing toilet problems
- Stealing (food and money)
- Mess
- Social & family
“If I go down to the kitchen and find that she has finished off all the cereal I have to go off and drive to the supermarket so that the others can have breakfast.

“I know that money has gone from my purse so I take more care to hide it but my husband does not take as much care- so I am sure she is taking his money.

• Her car was out of action, so I drove her to the supermarket at 11.0 pm. I did not want her to go locally as it is expensive and people know us.

• I have to clean up the toilets; it’s not nice for the rest of the family.
The trap of enabling

- Binge & purging can become fixed like addictive habits.
- Removing the negative consequences and/or providing money or food enables binge/purge behaviours to become fixed habits.
WHAT ACCOMMODATING AND ENABLING BEHAVIOUR HAVE YOU SEEN?
She often buys cream cakes etc. that she makes me eat even when I do not want them.

Every time I go up/down any stairs she then has to go up/down them twice as many.

She gives her younger sibling money to go to the tuck shop every day. She opens the cupboard door that contain snacks to tempt my other daughter when she comes home.

She does not like it when I buy healthy foods for me to eat.

Edi has to see me eat every night before she will eat anything and judges what she eats by the type of food and amount I have eaten that night.
REACTION TO REACTIONS
The vicious circle of Fragmentation

Starved AN mode: impacts on relationships visible & via ↓social cognition

AN voice the only friend Isolation

Fragmentation lack trust

Terror drives extreme reaction

Tricking Cheating, lying etc
Interpersonal factors

- Burn out and fragmentation can occur
Division vs Consistency & Co-operation

Divide and Rule
- Parents take polarised positions.
- Tension between total nurture & growth.

Team work essential
A network of support.
Experienced Carers helping Others (ECHO)

A carers – self management intervention

PPI involvement at every phase

Provide Skills for ↑ Change

Step out of Eating Disorder Traps

Working Together Collaboration

Skills in: Communication – Motivational interviewing

Emotional regulation

Behaviour change

Shared Understanding

Shared Skills

Regulate emotion
Care for self.
↓ accommodation
↓ over protection
↓ hostility & criticism
↓ disagreement & division

Compassion
Positive communication
Behaviour Change Skills
WHAT IS THE EVIDENCE?
ECHO: a collaboration of Parents (Partners), and Professionals (2 P’s).

WORKBOOK
Focus on illness maintaining factors and goal planning

VIDEO CLIPS
Expert by experience: Expert by knowledge

GUIDANCE
ECHOMANTRA: a collaboration of Parents (Partners, Peers) Patients and Professionals (3 P’s).

- Shared Digital Resources coproduced by 3 P’s.
- Anonymous shared peer and patient/carers and workshop/groups facilitated by psychology graduates.

(Adamson et al 2019, Int Rev Psych)
MRC framework for complex interventions

2010
ECHO
Experienced Carers Helping Others
Phone & digital for parents and partners
Setting: inpatients

2015
MANTRA
Maudsley Model of Treatment for Adults with Anorexia Nervosa
Therapy for parents and partners
Setting: outpatients

2016
ECHOMANTRA
Individual workshop for patients, parents & partners
Setting: inpatients

2017
ECHOMANTRA TRIANGLE platform
Integrated online workshop for patients, parents and partners

Materials used for guided task sharing with carers. Skills to reduce interpersonal maintaining factors
The addition of ECHO to TAU as aftercare for AN inpatients (CASIS). (Hibbs et al 2016; Magill et al 2017)

15 Collaborating sites

Queen Elizabeth Hospital
Darwin Centre
Kinver Centre
Coventry
STEPS, Bristol
Cotswold, Marlborough
Haldon Unit
Highfield Unit
Cotswold House
Seacroft Hospital
Cheadle Royal Hospital
Brandon Unit
St Vincent’s
St George’s
Bethlem

N=178
Age 25.8 y.
Duration 7.7 y.
BMI 14.4.
ECHO ↓ carer and service burden

- ↓ Carers’ burden (ES: 0.5)
- ↓ Emotional behaviours (ES: 0.3-0.5)

- ↓ Length of admission (148 vs 168 days)
- ↓ Re-admission rate (27% vs 32%; p=0.04)

Hibbs et al 2016; Magill et al 2017
Improvements for parents & partners

It has given me hope and a focus. I can see positive change when I walk alongside my daughter. I nudge her in the right direction like the dolphin metaphor. I have learnt to challenge some anorexic behaviours.

- ↓ Carers’ burden (ES: 0.5)
- ↓ Emotional behaviours (ES: 0.3-0.5)
It was a turning point for my recovery. It was the first time we have been **offered support as a couple** and involved both of us in my treatment.

Not just focusing on weight and food. Give you **skills to cope with different aspects of life** as you “re-enter” it.
Improvements for public

↓ Length of admission
1. 1.148 vs 168 = 20 day ↓ reduction.
2. 88 vs 111 = 29 day ↓ reduction.

↓ Rescue Readmission
1. 27% vs 32% (p=0.04) = 500 day ↓
2. 12% vs 16% NS = 400 day ↓

↓ Waiting list

NHS saving:
↓ LOS (£10,000-14,500/case)
↓ Rescue (£2000-2,500/case)
Conclusion

- Isolation is a core problem for people with anorexia nervosa and their family and is one of the key maintaining factors in the cognitive interpersonal model.
- It is possible to modify isolation by improving social connection.
- Co-operation and collaboration with carers is part of this process.
- This approach can make services more cost effective.
Collaborative caring involves triangulating care

It involves empowering individuals through disseminating information and sharing skills

It involves supporting carers to build resilience, knowledge of the illness and communication skills which allow them to respond differently to the illness
References to evidence of collaborative care


- Videos to show how to undertake exercises
- [www.youtube.com/watch?v=S6YMdosgAkE](http://www.youtube.com/watch?v=S6YMdosgAkE)
- Eg exercise 1.5 in the training manual
- Readiness Ruler for Carers.
- [www.thenewmaudsleyapproach.co.uk](http://www.thenewmaudsleyapproach.co.uk)
- For Worksheets