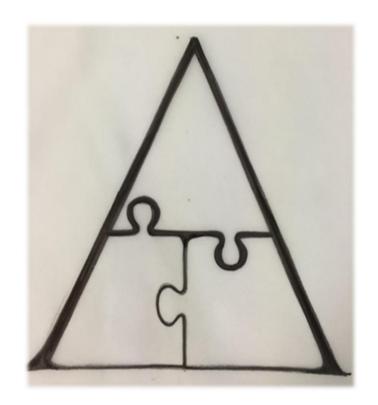
Empowering Carers



Prof. Janet Treasure







"Beat Delaying for Years"

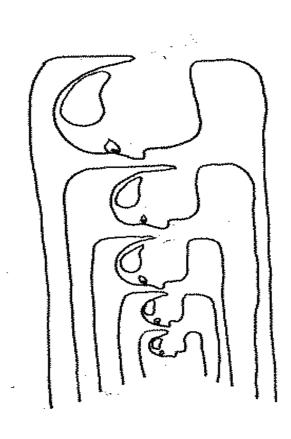
- Carers feel disempowered, alone and distressed when supporting someone with an eating disorder, and their physical and mental health is negatively affected.
- It is therefore important for services to empower and support carers.



Talk map

- We are no longer agnostic about the aetiology of eating disorders.
- How we can moderate some of the secondary interpersonal maintaining factors.
- How we can bridge from the anorexic voice to the recovery identity through social support.

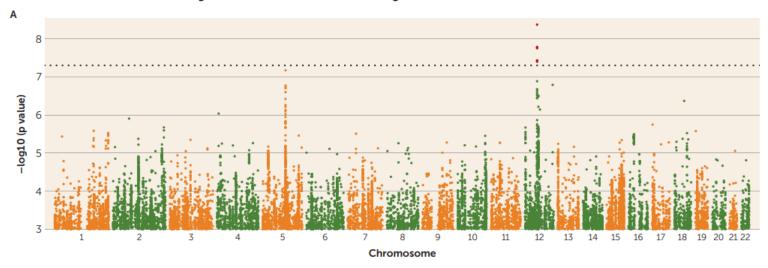
What do we know about heritability of Eating Disorders?



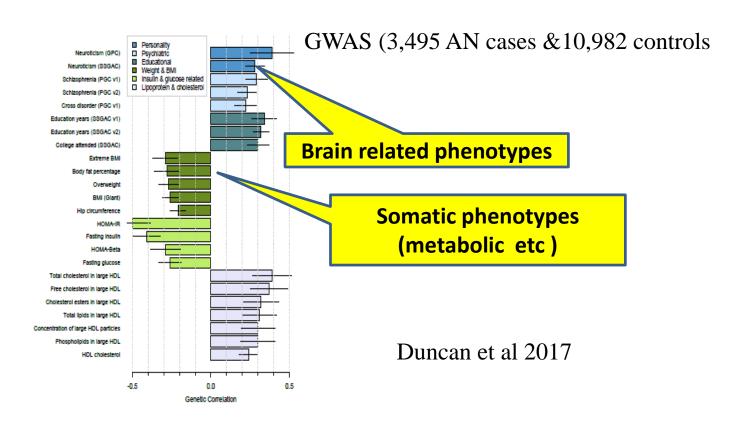
We know about some of the genes involved

- Heritability –58%-88% (Bulik et al., 2000)
- Genome wide significant locus on

FIGURE 1. Manhattan Plot and Regional Plot of the Genome-Wide Significant Locus for Anorexia Nervosa^a



Genetic correlations between AN and diverse phenotypes





- Please write using your non dominant hand
- "I am writing with my non dominant hand"
- How did you do and how did that feel?

Non Dominant Hand

ANY REFLECTION?



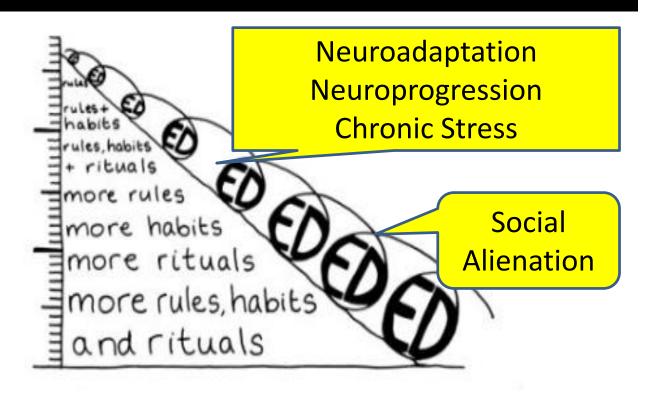
What are the mechanisms underpinning maintenance

Maintaining factors are still in action

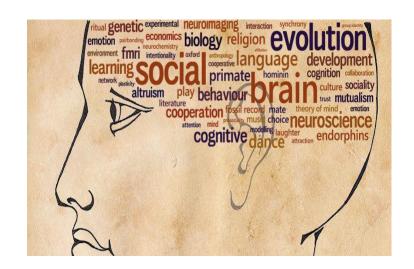
Many forms of talking treatment

target maintaining factors

What Happens over time in Anorexia Nervosa



Treasure et al 2014, Walsh 2013, Steinglass and Walsh 2016



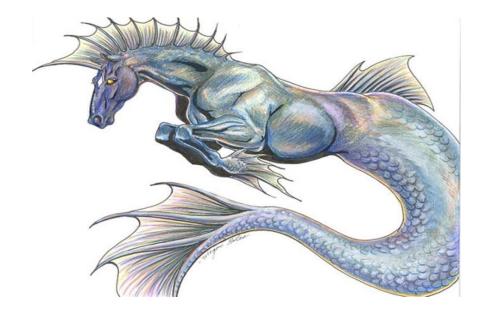
Brain needs 500 Kcal/day- deficits with malnutrition.

2% of body mass but 20% of energy

• The social brain hypothesis: Brain Size @Social Network (Dunbar).

NEUROPROGRESSION





Chronic Stress: Brain on fire Neuro adaptation: Emotion learning Damage to hippocampus (↓ new learning/neurogenesis)

Problems in Social Cognition



Caglar-Nazali et al Neuroscience and Biobehavioral Reviews (2013)

Domain	Effect
Negative self evaluation	2.2
Lack facial affect	2.0
Attachment insecurity	1.3
Sensitivity to social ranking	1.1
Alexithymia	0.66
Avoidance emotion	0.44
Low parental care	0.55
Reduced agency	0.39
Parental overprotection	0.29

Problems in Social Cognition



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A meta analysis of reactivity to interpersonal threat (Monteleone et al 2018)

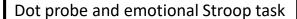


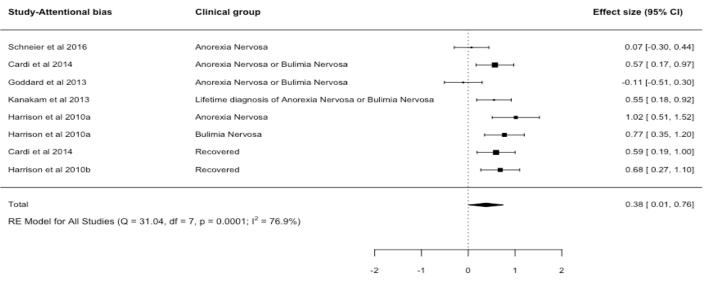












Reduced attention bias in clinical group compared to controls

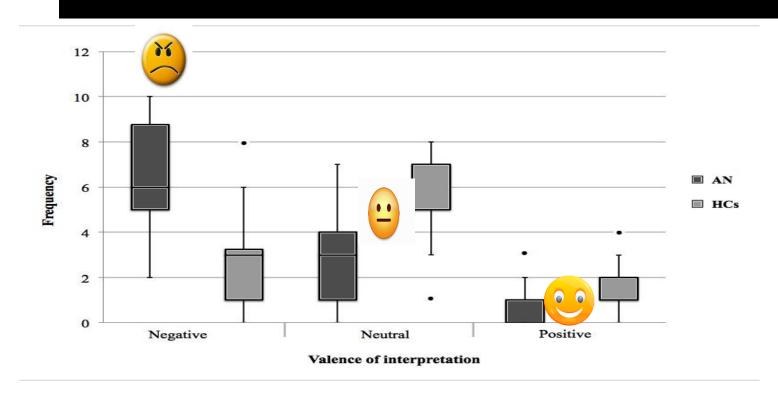


Increased attention bias in clinical group compared





Interpretation of Ambiguous scenarios





SOCIAL CUES: ATTENTION FOCUS THREAT INTERPRETATION FOCUS ON NEGATIVE

ANY REFLECTION?



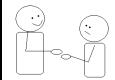
Problems in Social Cognition



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Reduced facial expressions in acute state



- Acute AN: large
 +ve/medium-ve
 ↓expression.
 Adult>Adolescent.
- Recovered AN: 个 positive emotions.

Davies et al., 2016 Neurosci Biobehav Rev

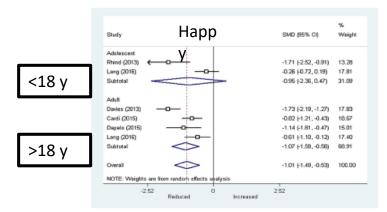




Fig. 2. Forest plot of the meta-analysis for facial emotional expression in response to positive affect in patients with AN.

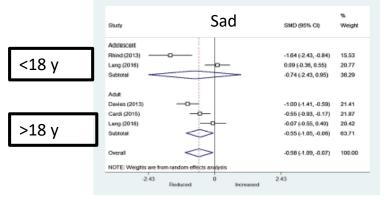
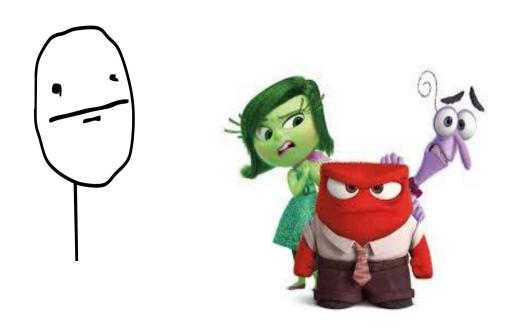


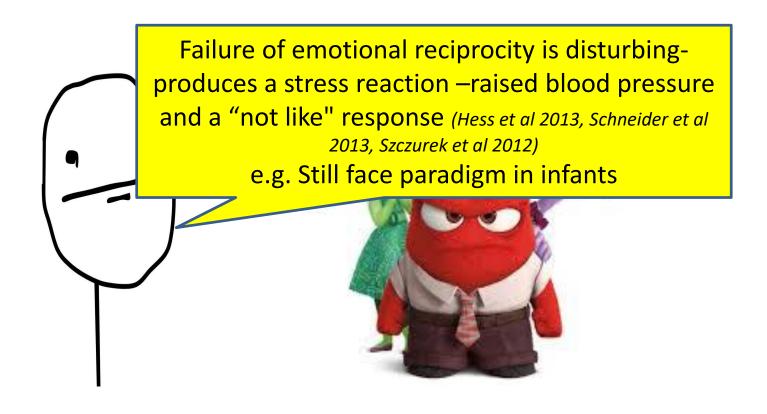


Fig. 3. Forest plot of the meta-analysis for facial emotional expression in response to negative affect in patients with AN.

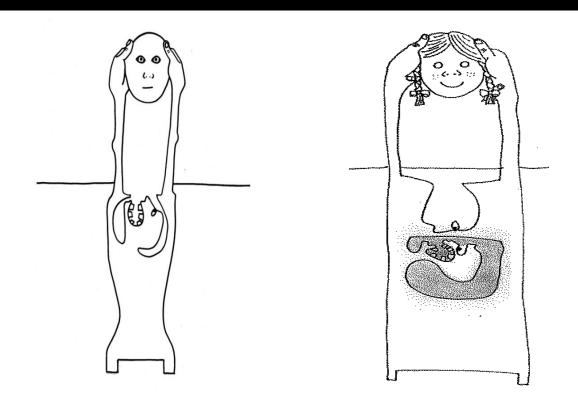
Typical interpersonal relationship with AN



Disruption of interpersonal relationship

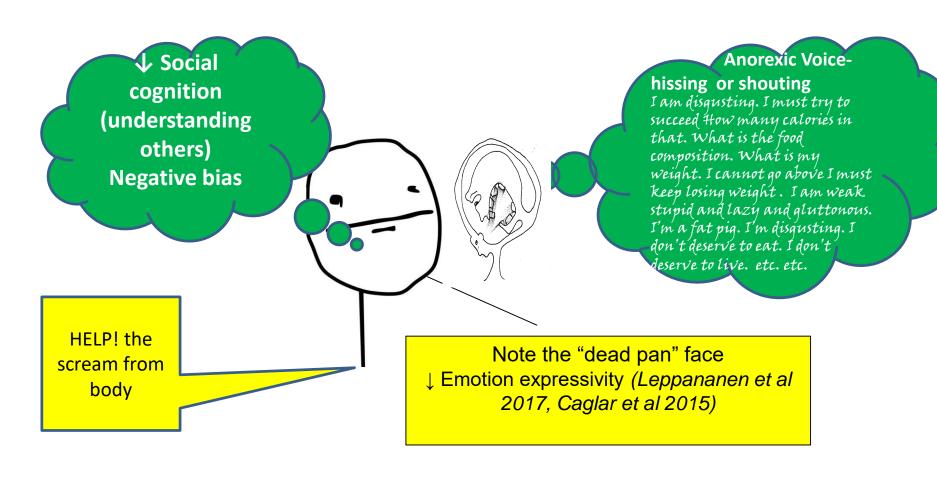


Social communication inhibited: A blank mask or fake pleasing



Davies et al., 2011, 2013; Dapelo et al., 2016; Lang et al., 2016; Leppanen J. et al. (2017)

Confusing Social Signaling



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

I was known as the "**ice queen**" at Uni



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

They did not know what was going on inside.

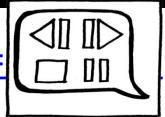
Davies et al 2013, 2014, 2016, Cardi et al 2014, Rhind et al 2014, Ambwani et al 2016

ANY REFLECTION?



The Still face paradigm

https://www.youtube.com/watch?v=
 9w2g



- In adults dislike and autonomic arousal when interact with still face (Gross et al 2003).
- Also this is recognised in robots as the "uncanny valley effect".

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)
- Negative bias attention and interpretation (Cardi et al 2017)





Problematic Interpersonal Relationships

Problems in social cognition in part developmental but become stronger in later stages a feature of neuroprogression (Caglar et al 2015)

 Problems in social cognition impact on the therapeutic alliance and family& peer relationships.



ANY REFLECTION?



Increasing isolation



- "I was recently 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)
- "It's the loneliness that will get you. Not the hunger, or the worrying, or the rituals, or the paranoia. Not even the fear of getting fat. It's the loneliness that's the real killer. The longer you're ill, the worse it is." Melissa

Social difficulties accumulate over time in families and friends

Honeymoon phase –maybe initial praise .

Families and social networks the start to become organised around the symptoms: accommodate, enable or become angry & frustrated or withdraw because of interpersonal difficulties



Isolation is Maintaining factor. Carer Skill Therapy to improve interpersonal relationships and increase social network



Magill et al 2016; Hodsall et al 2017



I do not need help- go away.

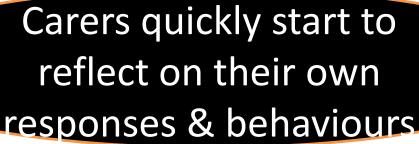
HELP!!!!

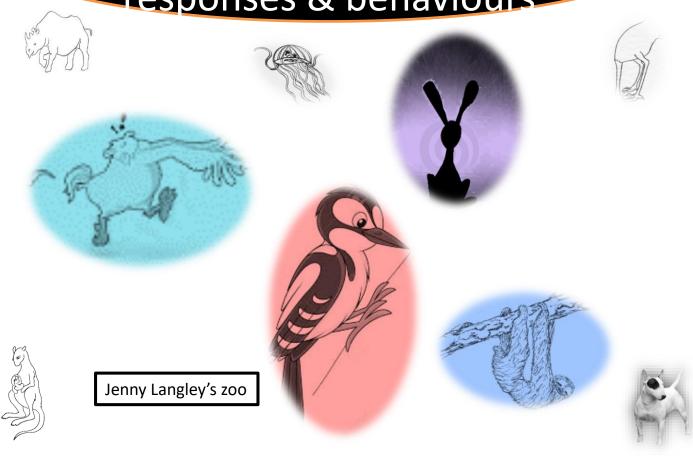
Disrupted interpersonal factors

- Living with or caring about someone with AN is exhausting, relationships can rupture.
- Carers swing from being bullied
- "I really want you to come out to dinner with us, so we'll make sure we go somewhere that serves plain salad" (Accommodating)
- or exasperated
- "You're being ridiculous and ruining everyone else's meal by being so demanding". (Hostile)

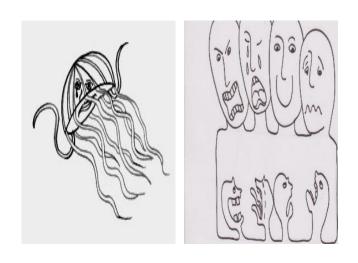




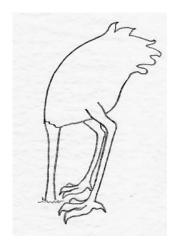




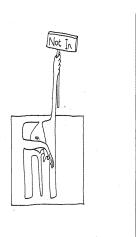
Tension with carer's emotional responses.



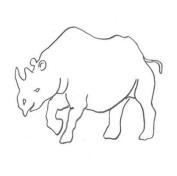
High intensity emotion-jelly fish



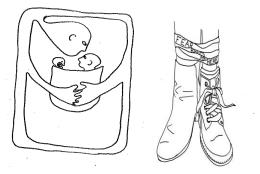




The see saw of emotionally driven behaviours.









Push towards growth Rhino & terrier

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

See Saw produces Splitting



- Within individuals
- Within families
- Within treatment teams
- Within friends
- Between families and treatment team

Collaborative approach within Families & Between Families & Treatment team





Fathers play an important role in treatment



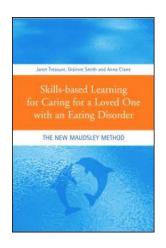


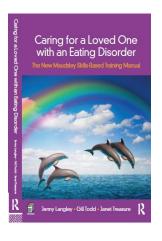
Non Dominant Hand

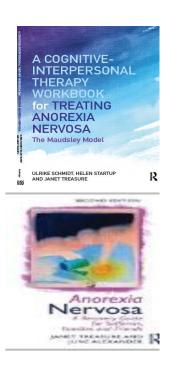
- Please write using your non dominant hand
- "I am writing with my non dominant hand"
- Your partner needs to have no empathy for your disability and has no patience and should get you to hurry. Also they may be critical of your efforts.

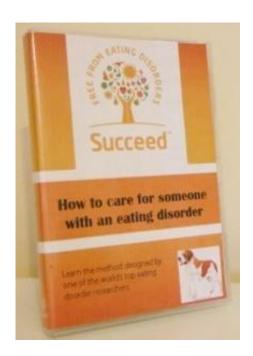
ANY REFLECTION?











Materials used for guided task sharing with carers (lay and professional). Skills to reduce interpersonal maintaining factors

The evidence base from IOPPN

RESEARCH ARTICLE

A Pilot, Multicentre Pragmatic Randomised Trial to Explore the Impact of Carer Skills Training on Carer and Patient Behaviours: Testing the Cognitive Interpersonal Model in Adolescent Anorexia

John Hodsoll¹, Charlotte Rhind², Nadia Micali^{3,4}, Rebecca Hibbs², Elizabeth Goddard², Bruno Palazzo Nazar^{2,5} Ulrike Schmidt² , Simon Gowers⁶, Pamela Macdonald², Gillian Todd², Sabine Landau¹ & Janet Treasure²*

⁵Department of Biostatistics, King's College London, Institute of Psychiatry, Psychology & Neuroscience, London, UK Department of Psychological Medicine, Section of Eating Disorders, King's College Landon, Institute of Psychiatry, Psychology & Neuroscience, Landon, UK

*Bahavioural and Brain Sciences Unit. University College London, Institute of Child Health, London, UK

Department of Psychiatry, Icahn School of Medicine at Mount Sinai, New York, NY, USA mathute of Psychiatry, Federal University of Rio de Janeiro (IRUB-UFRI), No de Janeiro, Brazil

⁶Adolescent Psychiatry, University of Liverpool, Chester, UK

Aim: The aim of the study is to establish the acceptability, feasibility and approximate size of the effect of adding a carer intervention

Experienced Congivers Helping Others (ECHO) to treatment as usual (TAU) for adolescents with anorexia mercoa.

Methods: The stary is a pike trachemister large comparing TAU (m = 90) ashore TAD pairs ECHO with (m = 90) technologies. The stary is a pike trachemister large comparing TAU (m = 90) ashore TAD pairs ECHO with (m = 90) technologies. Results Albough engagement with ECHO was poor (only 30% of cares in the ECHO go per and our 50% of the body, there were markers disturements finderes in the ECHO group read our 50% of the body, there were markers disturements fidelity, in that caregivers in the ECHO group showed a moderate increase in care skils (ES = 0.1 at 22 months and a reduction in accommodating and enabling behaviour at 6 months (ES = 0.17). In terms of efficacy, in the ECHO group, cares spent less time care gring (ES = 0.0.1) = 0.0.01 at 1 year, and patients had a minor advantage in body mass indice (ES = 0.17), fever advantage in body mass indice (ES = 0.17). In terms of the end of the en

nissions, decreased peer problems (ES = -0.36) and more pro-social behaviours (ES = 0.53). The addition of telephone guidance to duced little additional benefit. Conclusions: The provision of self-management materials for carers to standard treatment for adolescent anorexia nervosa shows ben-

Health and Quality of Life Outcomes



Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders

Ana R Sepulveda*1, Jenna Whitney2, Matthew Hankins2,3 and Janet Treasure1

Address: 'Department of Psychological Medicine, King's College of London, Institute of Psychiatry, London, UK, 'Department of Psychology, King's College of London, Institute of Psychiatry, London, UK and 'Division of Primary Care & Public Health, Brighton & Sussex Medical School University of Brighton, Falmer, UK Email: Ana R Sepulveda* - a sepulveda@ion.kcl.ac.uk: Jenna Whitney - i.whitney@ion.kcl.ac.uk: Matthew Hankins - m.c.hankins@bsms.ac.uk

* Corresponding author

Published: 21 April 2008

Health and Quality of Life Outcomes 2008, 6:28 doi:10.1186/1477.7525-6-28 This article is available from: http://www.hqlo.com/content/6/1/28

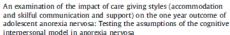
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Journal of Affective Disorders 19I (2016) 230-236



Journal of Affective Disorders

journal homepage: www.elsevier.com/locate/jad



Laura Salemo **, Charlotte Rhind b, Rebecca Hibbs b, Nadia Micali c,d, Ulrike Schmidtb, Simon Gowers*. Pamela Macdonaldb. Elizabeth Goddardb. Gillian Toddf. Gianluca Lo Coco *, Janet Treasure b

* librarily of histon, Department of Psychology and Educational Science, Polerone, Edy.

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RESEARCH ARTICLE

Two-year Follow-up of a Pragmatic Randomised Controlled Trial Examining the Effect of Adding a Carer's Skill Training Intervention in Inpatients with Anorexia Nervosa

Nicholas Magill¹, Charlotte Rhind², Rebecca Hibbs², Elizabeth Goddard², Pamela Macdonald², Jon Arcelus^{3†}, John Morgan⁴, Jennifer Beecham⁵, Ulrike Schmidt², Sabine Landau¹ & Janet Treasure^{2*}

Biosacistics Department, KIPPN, London, UK

*Department of Psychological Medicine, King's College, IoPPN, London, UK

School of Sport, Exercise and Health Sciences, Loughborough University, Loughborough, UK

forlishine Centre for Eating Disorders, Leeds Partnerships NHS Foundation Trust, Leeds, UK London School of Economics and Political Sciences, London, UK

Background: Active family engagement improves outcomes from adolescent inputient care, but the impact on adult anorexia nervosa is

Aim: The aim of this study was to describe the 2-year outcome following a pragmatic randomised controlled trial in which a skill training intervention (Experienced Caregivers Helping Others) for cares was added to inpatient care.

Method: Patient, caregiver and service outcomes were measured for 2 years following discharge from the index inpatient admission.

Results: There were small-sized/moderate-sized effects and consistent improvements in all outcomes from both patients and carers in the Experienced Caregivers Helping Others group over 2 years. The marked change in body mass index and carers' time caregiving following. inpatient care was sustained. Approximately 20% of cases had further periods of inpatient care.

Conclusion: In this predominately adult amore is nervous suspece, enabling carest to provide active support and management skills may improve the benefit in all pyraptom domains that gradually follow from a period of impatient care. Copyright 0 2013 John Wiley & Sons,



Cognitive interpersonal maintenance model of eating disorders: intervention for carers

Elizabeth Goddard, Pamela Macdonald, Ana Rosa Sepulveda, Ulrike Naumann, Sabine Landau, Ulrike Schmidt and Janet Treasure

Carers of people with eating disorders report high levels of Carries of piopie with eating disorders report night levels or distress. In addition, carrier, responses to the illness may perpetuate eating disorder symptoms. A cognitive interpersonal maintenance model of eating disorders is proposed and interventions for carers may improve well-being in both carers and patients.

To examine an interpersonal maintenance model of eating disorders, using a self-help intervention for carers.

A pre-test-post-test design was used with carers randomised

Carers' distress reduced and secondary outcomes improved. Carors' distress reduced and secondary outcomes improve improvement in carers' status and percelved improvement in patients were associated with reductions in expressed emotion and in accommodating and enabling behavious. Self-help and guided self-help versions were comparable.

Conclusions
Charges in maintenance factors from the theoretical model were associated with a reduction in carers' distress and improvement in perceived patient functioning, Interventions which specifically target maintaining factors may be of

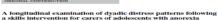
A pre-test-post-test deligin was used wen cares randomized fine self-neigh capital self-neigh, which included the Popular Caress Heiping Others RCHOI intervention. Cares' distress, which being, proposed mainternance factors, and care reports on the status of the patient were miseaured.

Description

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Eur Child Adolso: Psychiatry (2016) 25:1337-1347 DOI 10.1007/s00787-016-0859-9

ORIGINAL CONTRIBUTION



Received: 29 January 2016 / Accepted: 23 April 2016 / Published online: 9 May 2016 © Springer-Verlag Berlin Heidelberg 2016

Clinical effectiveness of a skills training intervention for caregivers in improving patient and caregiver health following in-patient treatment for severe anorexia nervosa: pragmatic randomised controlled trial

Rebecca Hibbs, Nicholas Magill, Elizabeth Goddard, Charlotte Rhind, Simone Raenker, Pamela Maddonald, Gill Todd, Jon Arcelus, John Morgan, Jennifer Beecham, Ulrike Schmidt, Sabine Landau and Janet Treaure

Treaches with caregivers in the 6-bits group had induced earning.

Copyright and sivage:

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BMC Health Services Research



Development and validation of the Accommodation and Enabling Scale for Eating Disorders (AESED) for caregivers in eating disorders

Ana R Sepulveda*1, Olivia Kyriacou2 and Janet Treasure1

Address: "Department of Psychological Medicine, Section of Eating Disorders, King's College London Institute of Psychiatry, London, UK and

Department of Psychology, Institute of Psychiatry, King's College London, UK Email: Ana R Serubvela* - a serubvela@ton kel acuk: Olivia Kiriacou - o kiriacou@ton kel acuk: lanet Treasure - tireasure@ton kel acuk * Corresponding author

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RMC Health Sentre: Research 2009 @171 | doi:10.1186/1477-6963-9-171

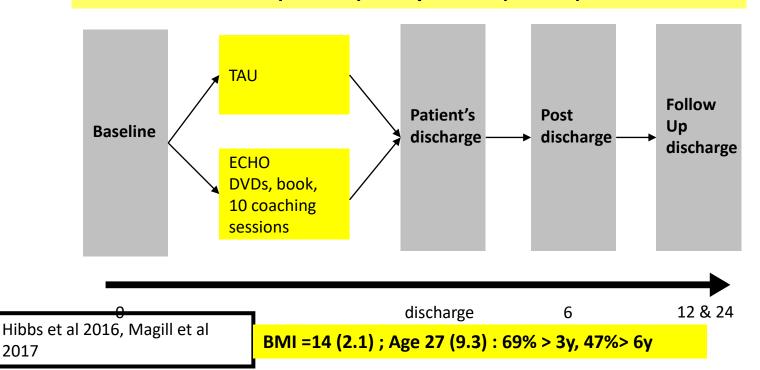
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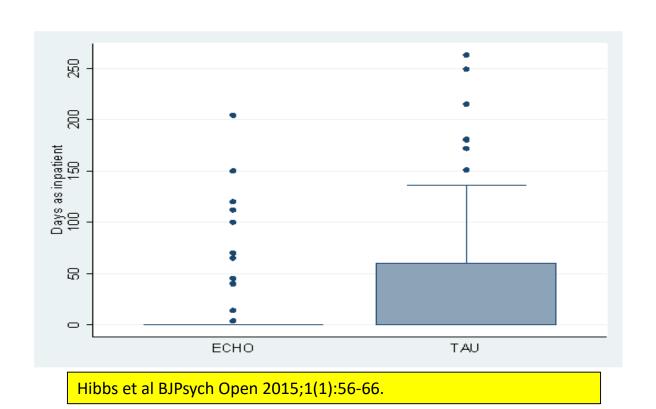
Does ECHO improve outcome from inpatient care for patients with severe enduring anorexia nervosa?

Assessment carer (n= 267) and patient (n=178)

2017

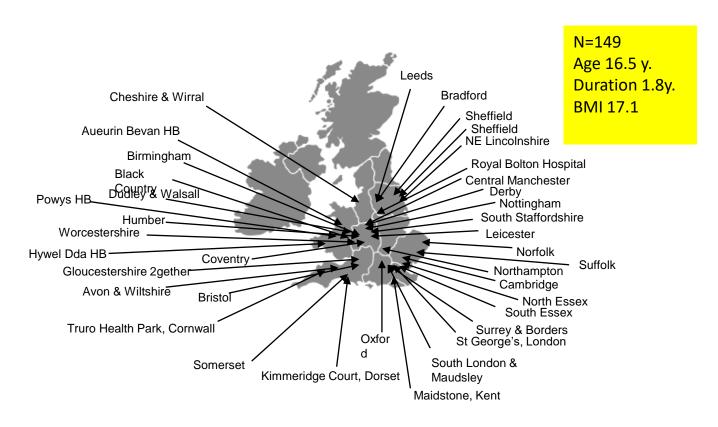


Adult: Bed Usage in first 6 months after admission



Multi centre RCT for outpatients under 21 years (Hodsall et al 2017)

38 NHS ED services (17 CAMHS, 13 adult, 8 both)



Number of Hospital Admissions: Adolescents (Hodsall et al 2017)

Patient/carer Group	6 months	12 months
ЕСНО	12%	9%
TAU	16%	8%

THE IMPACT ON CARERS

- Skills 个
- Expressed emotion ↓
- Accommodate ↓
- Time caring ↓







The good news

- We can moderate interpersonal environment.
- Skills training for carers reduces the need for admissions and improves carer well being.



Goddard et al 2011, Hibbs et al 2015, Magill et al 2015, Hodsoll et al 2016

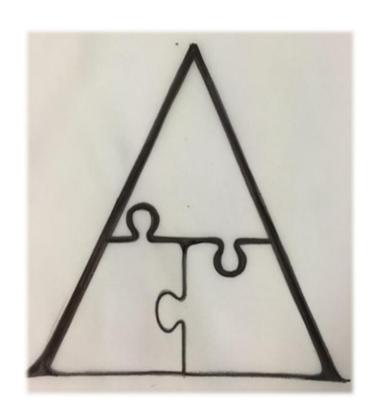
All providers of eating disorder services should:

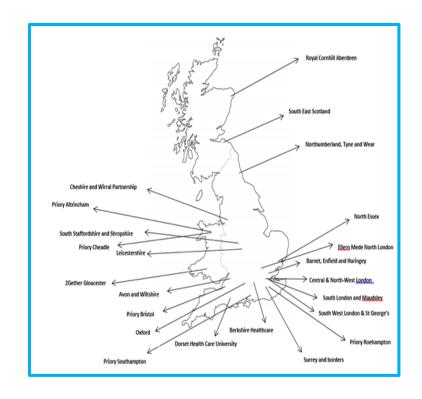
- 1. Have a policy that ensures family empowerment
- 2. Train all staff accordingly
- 3. Provide useful and comprehensive information
- 4. Offer all carers and siblings an assessment of their own needs.
- Offer all carers peer-to-peer support.
- Offer training to provide optimum support for their loved ones.
- Support carers when a loved one faces a transition between services.
- 8. Seek and act upon carers' input and feedback

BEAT consultation Document

TRIANGLE

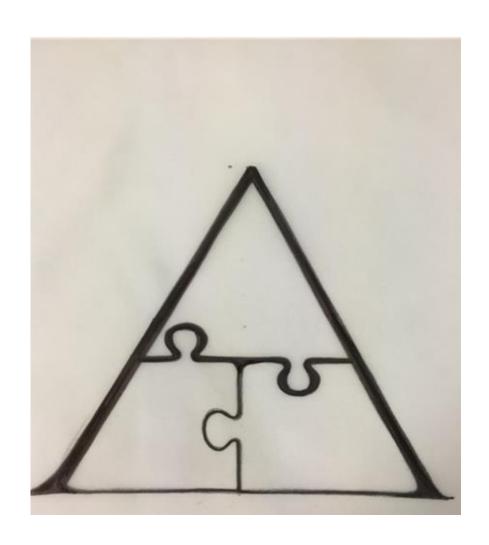
Transition care in AN: Through guidance online from peer and carer experts





Conclusions

- Historically families were excluded but they are now embraced as part of the team.
- Social isolation is a key maintaining factor that results from problems in all relationships (friend, family and therapist) and can be moderated.
- Carers can develop skills to target patient needs and improve carer and patient Interpersonal relationships.
- This can improve wider relationships.



Many thanks

- MHRN, CSOs and experienced carers who made all this possible.
- Rhind, C., Hibbs, R., Goddard, E., Macdonald, P., Gowers, S., Schmidt, U., Tchanturia, K., Micali, N., Yolanta Quiles. Maria Quiles, Maria Troiani, Maria Stephanis, G Pepin, R King, Maria Quiles, Yolanda Quiles, Ana Sepulveda, Laura Salerno, Le Coco, K Rowlands, V Aye, V Cardi, F Fernandez













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