Management of Really Sick Patients under 18 with Anorexia Nervosa: Where to now??

Dr Dasha Nicholls
d.nicholls@ucl.ac.uk
Overview

• History of the MARSIPAN reports
• Overview of its content and purpose
• Some wider context
• Where now for Junior MARSIPAN
Care changes after anorexia death

A new eating disorders service has been set up in Norfolk after a teenager died following delays in her care.

BBC News, 6 Oct 2009

The coroner agreed “it would have been inappropriate to detain her under the Mental Health Act and to effectively force feed her”
History: BAPEN 2008 “Feeding Size Zero”

- EC: 17 year old young woman, BMI 10.4
- 3 year h/o restricting AN. First admission
- Referred by Local Adolescent IP unit
- Major family disagreements and problems
- NG fed with a struggle (no MHA)
- Sabotaged feed, exercised
- Weight fell → ICU, Pulmonary oedema
BAPEN Case EC: Outcome

• That evening, the Friday before Xmas, the family collected around the bedside – the only show of unity we had seen. They washed her hair and gave her her favourite teddy bear and said their goodbyes. EC died quickly.
Step 1: Creation of MARSIPAN

• November 2008: Paul Robinson approached consultant in charge of patient EC, who was very keen to prevent a repetition

• They started to collect group members (n=27)

• Consultant psychiatrists (adult and child) in EDP

• Physicians in nutrition
  – Gastroenterology
  – Intensive care
  – Paediatric nutrition

• Dietitians: ED, Gastro

• Pharmacist

• GP (advisory)

• Carers (advisory)
Junior MARSIPAN

• DN was approached by PR to join MARSIPAN discussion
• DN concluded that although the issues were similar, care for young people sufficiently different to merit separate guidance

• Key differences:
  – Definition of high risk in YP controversial
  – Admission of YP to paediatric wards is common
  – Most YP are not treated in Specialist Eating Disorders Units (SEDU’s) in the UK

• Teamed up with paediatric and dietetic colleagues – started work on Jnr MARSIPAN Jan 2010
Step 2: Collect case histories

- Failure to use the Mental Health Act
- Physician and GP apparently providing palliative care for severe Anorexia Nervosa
- Psychiatry seems to disappear from the scene...
- Failure to control eating disordered behaviours can be fatal.
- Collapse of local ED services
- Shortcomings in medical management
- Failure to recognize refeeding syndrome
- Overcautious refeeding
- Self induced Refeeding Syndrome
- Fatal refeeding syndrome induced at 15 kcal per kg per day
- Poor cooperation between NHS and private sector
- Differences of approach between CAMHS and adult services
- Taking carer’s concerns seriously
- Discharge of a deteriorating patient due to DNA
- Nobody is in charge of the patient: ‘somebody else’s responsibility’, ‘not my problem’
YOUR COUNTRY NEEDS YOU
Paediatrics and the Eating Disorders
NICE guidelines

• The involvement of a physician or paediatrician with expertise in the treatment of medically at-risk patients with anorexia nervosa should be considered for all individuals who are medically at-risk.
In children and adolescents with eating disorders, growth and development should be closely monitored. Where development is delayed or growth is stunted despite adequate nutrition, paediatric advice should be sought.

Healthcare professionals should ensure that children and adolescents with anorexia nervosa who have reached a healthy weight have the increased energy and necessary nutrients available in their diet to support further growth and development.
American Psychiatric Association
Eating Disorder Guideline

• For children and adolescents, the recommended treatment model is the team approach.
• In this interdisciplinary management approach, general medical care clinicians manage general medical issues, such as nutrition, weight gain, exercise, and eating patterns, whereas the psychiatrist addresses the psychiatric issues.
• In unusual circumstances, psychiatrists may be qualified to act as the primary provider of comprehensive medical care.
What did the underlying problems seem to be?

• Systemic issues
  – Lack of training
  – Lack of communication
  – Difficulties with physical+behavioural+family+staff issues
  – Joint paediatric/mental health working – unclear responsibilities
  – Discontinuity of care

• Specific issues
  – Risk assessment
  – Admission? Where?
  – Renutrition
    • Refeeding syndrome
    • Underfeeding syndrome
  – Consent
  – Transitions
  – Management of ED behaviours
Risk Assessment - adults

• BMI: Hi risk <13
• Phys exam:
  – CVS, muscle power (SUSS test)
• Bloods: Electrolytes, LFTs, Glucose
• ECG
Young People: risk assessment framework

- Body mass
- Cardiovascular Health
- ECG abnormalities
- Hydration Status
- Temperature
- Biochemical Abnormalities
- Disordered eating behaviours
- Muscular weakness
- Activity and exercise
- Engagement with management plan (YP and family)
- Self harm and suicide
- Other mental health concerns
- Other (medical)
<table>
<thead>
<tr>
<th>BODY MASS</th>
<th>RED (High risk)</th>
<th>AMBER (Alert to high concern)</th>
<th>GREEN (Moderate risk)</th>
<th>BLUE (Low risk)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage Median BMI (see section A1 for calculation of %BMI) &lt;70%</td>
<td>Percentage Median BMI 70-80% [Approximates to between 2nd and 0.4th BMI centile]</td>
<td>Percentage Median BMI 80-85% [Approximates to between 9th and 2nd BMI centile]</td>
<td>Percentage Median BMI &gt;85% [Approximates to above 9th BMI centile]</td>
<td></td>
</tr>
<tr>
<td>Recent loss of weight of 1kg or more/week for two consecutive weeks</td>
<td>Recent loss of weight of 500g-999g/week for two consecutive weeks</td>
<td>Recent weight loss of up to 500g/week for two consecutive weeks</td>
<td>No weight loss over past two weeks</td>
<td></td>
</tr>
</tbody>
</table>
Admission to hospital

• How sick is the patient? (physical examination and risk assessment)
• Where is the best place for the patient to be?
• In adult cases, a Specialist Eating Disorder Unit is the most appropriate placement
  – less clear for young people
• Where is an available bed (and funding)?
• What can be done to cope while a suitable bed is arranged?
Specialist ED Units/beds

- SEDU’s are standard care in adult ED services, albeit high threshold for admission. Use of medical beds very rare.
- SEDU’s rare in CAMHS, lower threshold for admission. Use of paediatric beds common.
- We chose (after much debate) to use the term specialist eating disorders beds (SEDB) to refer both to SEDUs and to generic units specifically equipped for managing YP with AN.
What SEDU/SEDB’s should (in our view) offer

- NG insertion and feeding
- Daily biochemistry
- Frequent nursing observations
- Prevention of symptomatic behaviours (e.g. water drinking, absconding, exercising etc).
- Daily (reported) ECGs
- Sedation of a resisting patient
- Treatment of pressure sores
- Immediate cardiac resuscitation
- Use of appropriate legal frameworks including the MHA
- Safe restraint techniques, and paediatric psychopharmacology
- Access to advice from paediatricians and paediatric dietitians
What *Paediatric* services should (in our view) offer (in addition to the above)

- IV infusions
- Artificial ventilation
- Cardiac monitoring
- CVP lines
- TPN
- Paediatric “Crash” team
- Treatment of serious medical complications.
Location of care for YP

• In most cases, YP with severe AN should be cared for in a Specialist Eating Disorders Bed (SEDB), with support from paediatric services when needed. For children age 12 and under, this should be a unit that is suitable for younger patients.

• If a SEDB is unavailable, location will depend on the quality of liaison between paediatrics and CAMHS, and the experience of generic CAMHS unit, as well as risk assessment

• Near home to enable parental involvement if possible
Key tasks of the in-patient paediatric/medical team are to

a) safely re-feed the patient, avoiding re-feeding syndrome due to too rapid re-feeding, and underfeeding syndrome due to too cautious re-feeding;

b) manage, with the help of the CAMHS staff, the behavioural manifestations of AN secondary to the fear of weight gain, for example compulsive exercise;

c) occasionally treat young people under compulsion (using parental consent, the Children Act or the Mental Health Act, depending on the setting, age and capacity);

d) arrange transfer of the young person to appropriate CAMHS care as soon as it is safe to do so.
Management of Refeeding

• NICE guidelines on nutritional support advise very low starting calories to avoid Refeeding Syndrome.

• However, they also say they do not apply to patients with eating disorders (although many experts say that they do!)

• Initial feeding rate
  – ED settings 20 kcal/kg/day
  – Medical settings 5-15 kcal/kg/day
    • Increase within 2 days to avoid UnderFeeding Syndrome
Liaison Psychiatry

• Regular staff meetings need to be held to ensure a consistent approach and minimize the risk of splitting (such as playing some staff off against others).

• Produce an A4 sheet of straightforward guidelines on medical management of low weight patients aimed primarily at junior medical staff.

• A similar brief guide for nursing and medical staff on supporting patients and families.
Compulsory Care

• AN is potentially “sectionable”
• Feeding is “treatment”
• Consultants must escalate if not satisfied
• Responsible Clinician (not medical consultant) must now be appointed [in English/Welsh law]. They cannot be a paediatrician.
Behavioural Management of EDs in Medical settings

• Med/Psych/EDS consultation
  • Initial treatment plan
  • Regular review

• Special nurses trained to recognize and deal with ED behaviours

• Role of parents!

• MHA/other legal framework if necessary
‘Parents are best considered partners in the process of recovery, and appropriate involvement agreed as clearly as possible. For example, a ‘trial and error’ process may be necessary to establish whether parental involvement in feeding on the ward is helpful or not. It is inevitable that nursing staff will be better able to feed the patient in some instances, by virtue of their emotional distance. This is not evidence of parental inadequacy. Trials of transfer of responsibility for feeding to parents or to the young person should be made as soon as possible, since this will determine the length of stay and level of ongoing treatment need. Providing opportunities to practice in different contexts (e.g. off the ward, at home) will help clarify the level of support the young person needs to eat and from whom’.

• i.e. assessment of treatment need
Drug management of agitation and resistance

- Drugs: Benzodiazepines, neuroleptics
- Routes: Oral, IM, IV
- Monitor: Respiration, BP, Conscious level
- Staff: Psychiatrist, anaesthetist, ICU physician
- Location
  - Depends on physical risk of ED + medication
  - Psych ward/SEDU, Medical Ward, Medical ICU
The Junior MARSIPAN report provides guidance on:

- Risk assessment, physical examination and associated action
- Location of care and transition between services
- Compulsory treatment
- Paediatric admission and local protocols
- Management of refeeding
- Management of eating disordered compensatory behaviours in a paediatric setting
- Management in primary care and paediatric outpatient settings
- Discharge from paediatric settings
- Management in specialist CAMHS inpatient settings
Paediatrics and CAMHS in Partnership

• Every hospital into which a young person with severe anorexia nervosa is likely to be admitted should identify a consultant paediatrician with the interest, training (or willingness to be trained) and expertise to coordinate paediatric care for junior MARSIPAN patients in that setting. This includes admission to psychiatric units as well as acute hospitals.

• Every hospital into which a patient with severe anorexia nervosa is likely to be admitted should identify a consultant psychiatrist and team with the training and expertise to coordinate care and with whom a working relationship can be built to support an acute admission.
Health commissioners should

• ensure that robust plans are in place for the care of young people with anorexia nervosa, including adequately trained and resourced paediatric, nursing and dietetic staff in the acute services and appropriately skilled staff in specialist mental health services.

• support joint working between services (e.g. funding for CAMHS nursing staff whilst the patient is in an acute hospital)

• be aware of gaps in local resources and be willing to support referral to national centres for advice or treatment when necessary
Endorsed by

- Royal College of Psychiatrists
- B-EAT (Eating Disorders charity)
- Young People’s Special Interest Group (YPSIG) of the RCPCH
- Nutrition Group of the RCPCH
- BSPGHAN
- British Paediatric Mental Health Group
Where to now?

• More guidance for some of the gaps
  – Son of Junior MARSIPAN – the ‘ADEPT’ papers
    1. Bones – Jane Whittaker (Manchester)
    2. Puberty – Simon Chapman (Kings)
    3. Assessment of healthy weight – Francine Verhoeff (Liverpool)/Graeme O’Connor (GOSH)
  – A&E, Early recognition etc.
# Table of Contents

- Key Guidelines ........................................... 4
- Eating Disorders ........................................ 4
- Important Facts about Eating Disorders .......... 5
- Presenting Signs and Symptoms ..................... 6
- Early Recognition ....................................... 7
- A Comprehensive Assessment ....................... 8
- Refeeding Syndrome .................................. 12
- Goals of Treatment ..................................... 14
- Timely Interventions .................................. 15
- Ongoing Management .................................. 16
- About the Academy for Eating Disorders ........ 17
Where to now?

• Education and training
  – MARSIPAN training course @ UCL
    • [www.ucl.ac.uk/medicine/teaching/profdev](http://www.ucl.ac.uk/medicine/teaching/profdev)
  – FACE RISK assessment tool

• Research
  – RCT two rates of refeeding in severe AN – O’Connor et al
  – Short vs long admission in paediatric ward – Madden et al
Other suggested next steps

• Validation of the risk assessment framework
• Audit of the impact of Junior MARSIPAN on skills and practice
  – Aim is to avoid deaths, but also reduce trauma and anxiety
  – Subject of a CQUIN for Manchester
  – User and parent perceptions of acute care (based on experience of running RCT)
HES data for 0-14 year olds
1998-2012

- F50.0 Anorexia nervosa
- F50.1 Atypical anorexia nervosa
- F50.2 Bulimia nervosa
- F50.3 Atypical bulimia nervosa
- F50.5 Vomiting associated with other psychological disturbances
- F50.8 Other eating disorders
- F50.9 Eating disorder, unspecified
AN only 0-14 years
The role of paediatrics in ED care
in Nov 2000
arrived in Stanford University, California to do some thinking
New anorexia therapy makes patient's family a key to recovery

BY KRISTIN WEIDENBACH

Due to attention in the popular press, the public knows more than ever about eating disorders such as anorexia nervosa. But among child and adolescent psychiatrists who typically treat patients with the disease, there are many more questions than answers about the cause of the condition and the best form of treatment. Stanford physicians are hoping that the family-focused treatment program they are testing will help patients conquer the illness before it causes long-term physical problems.

"This is a field with a lot of opinions, but not a lot of actual research," said James Lock, MD, PhD, assistant professor of psychiatry and behavioral sciences and medical director of the comprehensive pediatric care unit at LPCH. "There have been only eight randomized, controlled clinical trials in psychotherapy for anorexia," said Lock. He aims to enroll 86 patients and their families in his trial, making it the largest psychotherapy study yet of adolescents with anorexia.

The family-based treatment plan that Lock and his colleagues are using was pioneered in England, where Lock worked with Christopher Dare, MD, a psychotherapist at the Maudsley Hospital in London, to learn Dare's approach to the problem.

The clinical trial being conducted at Stanford and LPCH is the first U.S. study of this family-therapy plan. What makes the approach different from the traditional treatment plan for anorexia is that it attempts to address a patient's eating problems first before tackling any underlying psychological problems. The reasoning behind the approach is that a patient's behavior is usually so severe, and his or her thought processes so distorted, that any attempts to address the psychological issues first will likely fail. "We don't really know what causes the illness, but the approach usually advocated is that it's a family and/or a psychological development problem," said Lock. "This turns that idea on its head -- the perspective is reversed."

In traditional family and individual therapy, Lock explained, therapist and patient talk about issues of adolescent development, focusing on childhood, upbringing and family life. The therapist will ask the patient how she feels about herself and her family (90 to 95 percent of anorexia patients are girls), in the hope that the eating disorder will be solved by resolving underlying conflicts. The psychiatrist looks to address problems within the family in the hope that the patient's behavior will change as a result, said Lock.

The new therapy approach looks upon the family primarily as a resource for treatment, not as a cause of the disorder. "We tell them, 'We don't know what causes it but you know her best and can be a resource to her as she's fighting an illness that's really not her anymore,'" said Lock. "The whole tone is different. The illness is seen as an external factor -- the family's not to blame and neither is the adolescent. The initial emphasis is on the hazards of the illness and the need to address it."

According to Lock, the percentage of patients that die from psychiatric or medical consequences is greater for anorexia than for any other psychiatric illness. Heart disturbances and suicide are the most common causes of death, but serious medical problems include bone breakage, infertility, depression, and a specific kind of low blood pressure. Most anorexia patients are female, in part because of a cultural preoccupation with female body image, and also because diagnostic indicators such as cessation of menstruation mean females are more likely to be officially diagnosed, said Lock. However, males also can develop the disorder. Boys may actually suffer from the underlying psychological aspects of anorexia for longer than girls do before medical problems appear because -- due to basic differences in physiology -- males can tolerate a more severe reduction in body fat for longer periods.

The family-based therapy, like any anorexia treatment plan, aims to help and ultimately cure the patient before the medical effects of the disease take their toll. "We don't have any drugs for anorexia. The only medication is food - food really does change your state of mind," said Lock.

Lock has written a reference book about the technique so that other psychotherapists can adopt it. The book, "Treatment Manual for Anorexia Nervosa -- A Family Based Approach," published by Guilford Publications, was released in October. W. Stewart Agras, MD, emeritus professor of psychiatry and behavioral sciences is a co-author. According to Lock, it is the only existing manual for treatment of anorexia nervosa in adolescents.

Lock is still looking for volunteers to take part in the Stanford clinical trial, which is supported by funding from the National Institute of Mental Health. Participants must be 12 to 18 years old and have been diagnosed with anorexia nervosa. Patients will be randomly assigned to a six-month or 12-month treatment program. Some of the 30 patients currently in the study have already completed their treatment but overall results will not be revealed until the trial is complete, which is expected to be in 2002. Those interested in participating should call (650) 723-5473. SR

NOVEMBER 15, 2000  STANFORD REPORT  7
TREATMENT MANUAL
for
Anorexia Nervosa
A Family-Based Approach

JAMES LOCK
DANIEL LE GRANGE
W. STEWART AGRAS
CHRISTOPHER DARE
Paediatric comprehensive care unit, Stanford
specific to needs of patients
main purpose is refeeding
Paediatric comprehensive care unit

2-3 week admissions for medical stabilisation

OP treatment + academic centre

Child Psych

Adolescent medicine

Regular outpatient review

Network of community therapists

Residential unit for treatment resistant cases
Comprehensive ED service with paediatric and mental health staff, providing continuity of care across outpatient, intensive outpatient and inpatient treatment, delivering evidence based stepped care tailored to patient need.
Pros and cons of a medical model

- underlines medical seriousness
- limits likelihood of death
- clear framework for admission and discharge
- ? more appropriate to evoke medical than psychiatric authority
- Helps externalise problem and minimise blame (‘brain disorder’)

- revolving door admissions
  - play off between length of stay and frequency of readmission
- limited parental involvement
- model ‘mirrors the power structures that are implicated in causal models’ i.e. disempowers patient (and parents)

COST?
EFFECTIVENESS?
Anorexia nervosa is the third commonest chronic illness of adolescence\(^1\)...  

[obesity and asthma are 1\(^{st}\) and 2\(^{nd}\)]

\(^1\)Lucas et al. AM J Psychiatry 1991;148;917
Thank you!

Dasha.Nicholls@gosh.nhs.uk
Acknowledgments

**Eating Disorder Psychiatrists**
Dr Agnes Ayton, Staffordshire
Dr Jane Whittaker, Royal Manchester Children’s Hospital
Dr Paul Robinson, St Ann’s Hospital, London

**Dietitians**
Graeme O’Connor, Great Ormond Street Hospital
Sarah Le Grice, Manchester Children’s Hospital

**General practitioners**
Dr Rob Barnett, Liverpool

**Paediatricians**
Dr Damian Wood, Nottingham University Hospital
Dr Gail Moss, Sheffield Children’s Hospital
Dr Francine Verhoeff, Alder Hey Children’s Hospital, Liverpool
Dr Lee Hudson, University College, London and GOSH
Dr Barbara Golden, University of Aberdeen

Dr Colin Michie, Chair of RCPCH Nutrition group
Dr R. Mark Beattie, President of BSPGHAN