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**OPTIMISM ABOUT TREATING  
SEVERE AND ENDURING ANOREXIA NERVOSA  
(SE-AN)**

**Hubert Lacey**

**Professor Emeritus, St George's, University Of London  
Medical Director, Newbridge House**



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**A CLINICAL REVIEW AND A PRACTICAL,  
EVIDENCE-BASED TREATMENT**

**Hubert Lacey**

Professor Emeritus, St George's, University Of London  
Medical Director, Newbridge House





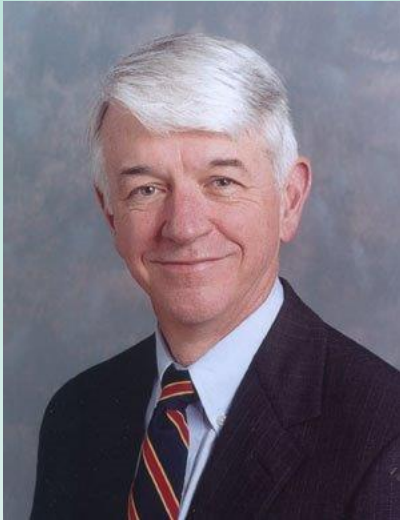
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**PART 1**  
**A CLINICAL REVIEW**

**Hubert Lacey**

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“Steinhausen’s (2002) assertion that the outcome of anorexia nervosa did not improve substantially in the last half of the 20<sup>th</sup> century likely applies equally to the first decade of the 21<sup>st</sup>.”

*Tim Walsh, 2016*

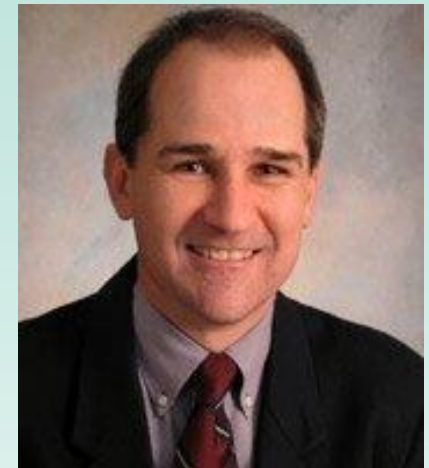
# Maudsley Family Based Treatment (M-FBT)



Prof. James Lock



Prof. Ivan Eisler



Prof. Daniel Le Grange

# Enhanced Cognitive Behavioural Therapy for Eating Disorders (CBT-E)



Prof. Christopher  
Fairburn

“It is critical to emphasise that the factors that sustain anorexia are likely distinct from those that contributed to its beginning. Hence it is useful to consider the stages of development of AN and to adjust treatment methods accordingly”

*Tim Walsh, 2016*

# Severe and Enduring AN (SE-AN)

20–25% of patients with AN do not remit over the long term:

- Chronic
- Treatment-resistant
- Non-responsive

*Ciao, Accurso and Wonderlich, 2016*



# Severe and Enduring AN (SE-AN)

- Few are going to recover
- Recovery Model is the wrong model
- Rehabilitation model should be pursued

*Arkell & Robinson, 2008*

# SE-AN: A Distinct Clinical Population?

“...while there appears to be theoretical consensus that SE-AN is a distinct clinical population in need of tailored treatment approaches, there is little empirical information to support this claim.”



*Ciao, Accurso and Wonderlich, 2016*

# SE-AN: A Distinct Clinical Population?

“It is thus crucial for clinicians and researchers to collaborate on developing an empirically-informed operational definition for SE-AN to facilitate future research.”

“...treatments can be further tailored to target mechanisms that sustain a severe and enduring course.”



*Ciao, Accurso and Wonderlich, 2016*



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## **PART 2**

### **DIFFICULTIES CLINICIANS HAVE IN DEFINING SE-AN**

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# SE-ED - Robinson

Should be defined by

- chronicity – 10 years
- clinical severity (clinical vignettes)

*Severe & Enduring Eating Disorder (2009) Wiley-Blackwell*

# SE-AN - Yolán

- Clinical Severity (difficulty in maintaining regular functioning)
- Treatment Failure (failure to reach sustained improvement)
- Chronicity

*Yolan, 2013 Journal of Eating Disorders 1:19*

# SE-AN – Tierney & Fox

- Delphi Study
- 53 ED specialists
- Sought to obtain a definition of SE-AN
  - Entrenched pattern of behaviour
  - Identity entwined with AN
  - Low weight BMI less than 17.5

*Tierney & Fox 2009 Int. J ED 42:62-67*

# Understanding SE-AN

“...the symptoms are utterly improbable, incomprehensible. Not only are they odd, and once formed they are difficult to arrest. But more perplexing is this insistence that, not only does the behaviour sustain their “safety” and well-being, it constitutes it. In AN, illness rises to the level of selfhood: it becomes, in effect, a consciousness unto itself.”

*Touyz and Strober, 2016*

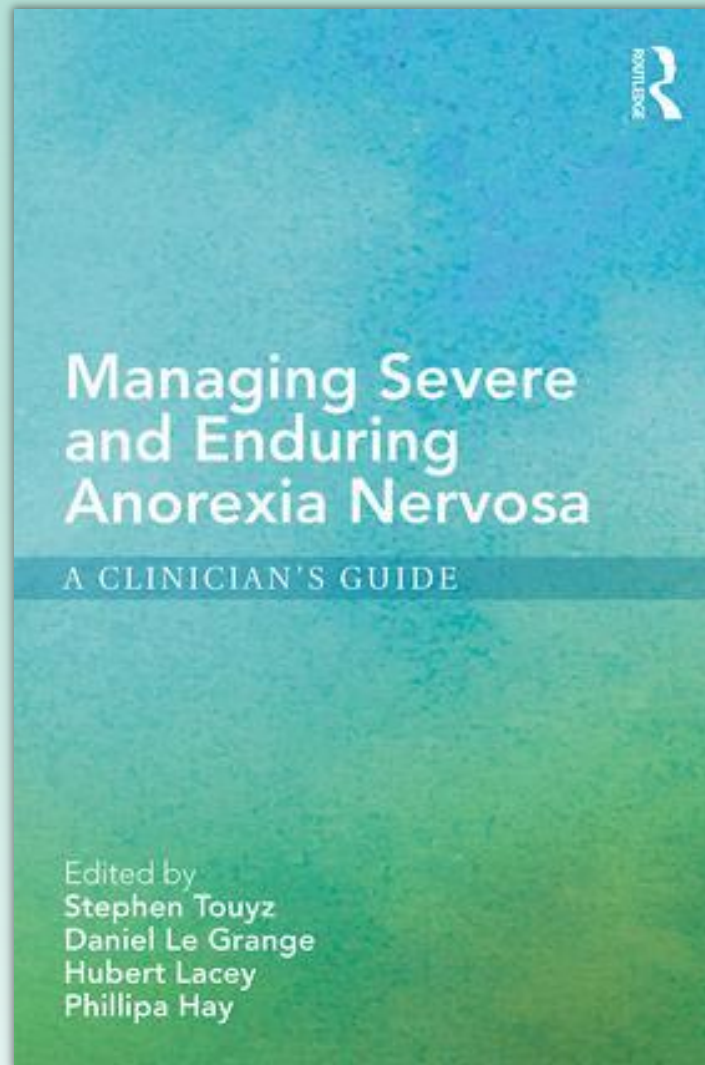


# What is Chronic, or Severe and Enduring Anorexia Nervosa (SE-AN)?

- There is no generally accepted definition of what constitutes ‘chronicity’ in AN (Tierney & Fox, 2009).

# What is Chronic, or Severe and Enduring Anorexia Nervosa (SE-AN)?

- There is no generally accepted definition of what constitutes ‘chronicity’ in AN (Tierney & Fox, 2009).
- There is no agreement on a specific number of years of illness – particularly as the likelihood of people recovering reaches a plateau and fails to reach zero. (Robinson)
- Some evidence suggests that the plateau does not appear until 10–20 years after the onset of the disorder (Steinhausen).



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**PART 3**  
**DIFFICULTIES IN DIAGNOSING SE-AN**

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# Severe & Enduring Anorexia (SE-AN) – Lacey

- Diagnosis
- 6 concepts

# Severe & Enduring Anorexia (SE-AN) – Lacey

- Diagnosis
- 6 concepts of which
  - 3 shared with acute anorexia
  - 3 reflect chronicity

# Severe & Enduring Anorexia – 1st

- Behaviours Aimed at Weight Loss

# Severe & Enduring Anorexia – 1st

- Behaviours Aimed at Weight Loss
  - Restriction
  - Over-activity
  - Purging

# Severe & Enduring Anorexia – 2nd

- Endocrine Disturbance
- Menstrual Disturbance
- Loss of Sexual Drive
- Immaturity



# Severe & Enduring Anorexia – 3rd

- Pathognomonic Psychopathology
  - Phobia of being at a Normal Body Weight
  - Pursuit of Thinness

# Severe & Enduring Anorexia – 4th

- Persistent
  - No periods of Remission
  - If fluctuating behaviourly, the psychopathology – phobia of normal body weight – remains

# Severe & Enduring Anorexia – 5th

- Resistant to Treatment
  - Must have been treated
  - Untreated patient can not have SE-AN
  - Broad spectrum of therapies
  - A number of therapists

# Severe & Enduring Anorexia – 6th

- Severity
  - Measurement is not by questionnaire alone
  - Social isolation
  - Co-morbid features
    - addictive behaviour
    - self-damaging behaviour

# Severe & Enduring Anorexia 6th and Enduring Anorexia Nervosa

- Severity
  - Ambivalence about change  
(phobia of normal body weight)
  - Ego-synchronously attached to low weight



# Severe & Enduring Anorexia

- High unemployment

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- Multiple medical complications

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- High use of social & welfare services



# Severe & Enduring Anorexia Nervosa

- Blighted Life
- Thwarted Achievement
- Disrupted Families



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**PART 4**  
**DIFFICULTIES & BARRIERS IN TREATMENT**

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# Severe & Enduring Anorexia

- Highly resistant to treatment, often having repeated treatment 'failures'

# Severe & Enduring Anorexia

- Highly resistant to treatment, often having repeated treatment ‘failures’
- Direct inpatient costs exceed that of schizophrenia (Rieger *et al.*, 2000)
- SE-AN has the highest mortality rate of all mental illnesses
  - 20% after 20 yrs (Steinhausen *et al.*, 2000)

# SE-AN refuse treatment

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# Reasons for SE-AN refusing treatment

- Rigid inflexibility leads to denial of reality
- Strong feeling they can deal with their own difficulties.

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- Mistrust of interpersonal relationships
- Extreme apprehension about a loss of control
- Distorted thinking which adversely impacts on decision-making abilities
- Mood disturbance exacerbated by the metabolic changes of starvation and malnutrition.
- Clinician's doubts regarding the long-term outcome of the disorder.

*(adapted from Anderson & Stewart, 1883 and Goldner, 1989)*

# In absence of guidance or evidence...

“Clinicians often modify treatment, target co-morbid complicating disorders, switch to intermittent supportive treatments, or intensify treatments with higher levels of care, all of which are based on clinical decision making with a minimal of scientific guidance” (p. 467).

*Minimizing and treating chronicity in the eating disorders:  
A clinical review (Wonderlich et al., 2012).*

# Factors to consider...

- The longer the duration of illness both patient and clinician view the treatment experience as negative and as failure (Woodside, 2004).

# Factors to consider...

- The longer the duration of illness both patient and clinician view the treatment experience as negative and as failure (Woodside, 2004).
- Both patients and clinicians experience a sense of hopelessness about the possibility of change (George et al, 2004)



# Factors to consider...

- Globally, treatment programmes are limited in their capacity to treat these patients and it is not uncommon for *non-specific medical palliation* to become the default care (Lopez *et al*, 2010; Strober, 2009).

# Factors to consider...

- **Given the choice of palliation...and taking the challenges and complexities of treatment... a *different paradigm* is needed.**
- (Robinson, 2009; Goldner, 1989; Yager, 1992; Vitousek et al, 1998; Strober, 2004; Williams et al, 2010; Lacey & Sly, 2013)

# Factors to consider...

- Such a *paradigm* must reflect:
  - the severe and enduring nature
  - the weight phobia at its core
  - the avoidance of treatment
  - dropout.

(Strober, 2009; Williams *et al*, 2010; Lacey, 2013)

# Factors to consider...

- Any treatment for SE-AN must *intrigue* patients by offering something other than weight gain. (Lacey & Sly, 2013)

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- Any treatment for SE-AN must *intrigue* patients by offering something other than weight gain. (Lacey & Sly, 2013)
- Most importantly SE-AN patients wish to address their *quality of life and mood*. (Touyz *et al*, 2013)

# Factors to consider...

- Any treatment for SE-AN must *intrigue* patients by offering something other than weight gain. (Lacey & Sly, 2013)
- Most importantly SE-AN patients wish to address their *quality of life and mood*. (Touyz *et al*, 2013)
- Patients must want to stay in treatment because it is *clinically meaningful to them*.

# Factors to consider... and Enduring Anorexia Nervosa

- **Rather than recovery, treatment needs to focus on:**
  - Retention in treatment
  - Improved Quality of Life
  - Harm minimisation
  - Avoidance of failure





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**PART 5**  
**BRIEF SUMMARY OF EVIDENCE BASE**  
**OF TREATMENT**

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# International team

## Treatment site 1: Sydney

**Stephen Touyz** (site supervisor); Rebecca Smith (project coordinator); Carla Evans (therapist); Monica Ward (therapist); Liz Rieger (supervisor); Phillipa Hay (medical consultant)

## Treatment site 2: London

**Hubert Lacey** (site supervisor); Bryony Bamford (therapist); Vicki Mountford (supervisor); Amy Brown (research assistant); Sam Scholtz (medical consultant)



## Data management site: Chicago

**Daniel le Grange** (site supervisor) Colleen Stiles-Shields (data management)

# Two approaches, if adapted, have promise

- A modified Cognitive Behavioural Therapy (CBT-AN) (Pike *et al*, 2003) has documented efficacy for relapse prevention
- A modified Specialist Supportive Clinical Management (SSCM), (McIntosh *et al*, 2010: McIntosh *et al*, 2006) a treatment that has shown efficacy in adults

# Differences in treatment

CBT	SSCM
Patients receive <b>Motivational Enhancement Therapy</b>	<b>Psycho-educational material</b> is given and discussed to increase patient motivation.
Treatment and sessions are <b>highly structured</b> and largely <b>therapist directed</b> .	Treatment and sessions are <b>less structured</b> and <b>patient directed</b> .
Eating behaviours are directly <b>challenged</b> through use of behavioural experiments and cognitive strategies.	Changes to eating behaviours are <b>encouraged</b> using advice and education around nutrition.
Patients are given <b>homework</b> in each session which relates to session content and is <b>always followed up</b> in the next session.	<b>No homework</b> is ever given. Patients may be sent away with educational material, but it is not necessarily raised in the next session.

# Aims of this RCT

To establish the first effective outpatient treatment for SE-AN by:

- comparing the capacity of CBT and SSCM to
- improve quality of life and to reduce depression and social isolation
- reduce core eating-disorder pathology
- and to investigate whether the reduction in chronicity translates to a reduced burden on medical services

# Design

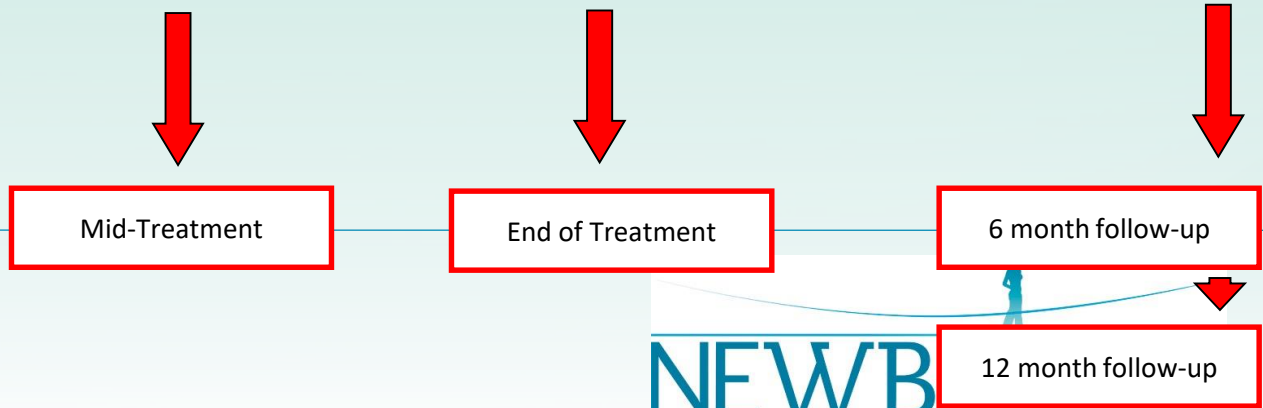
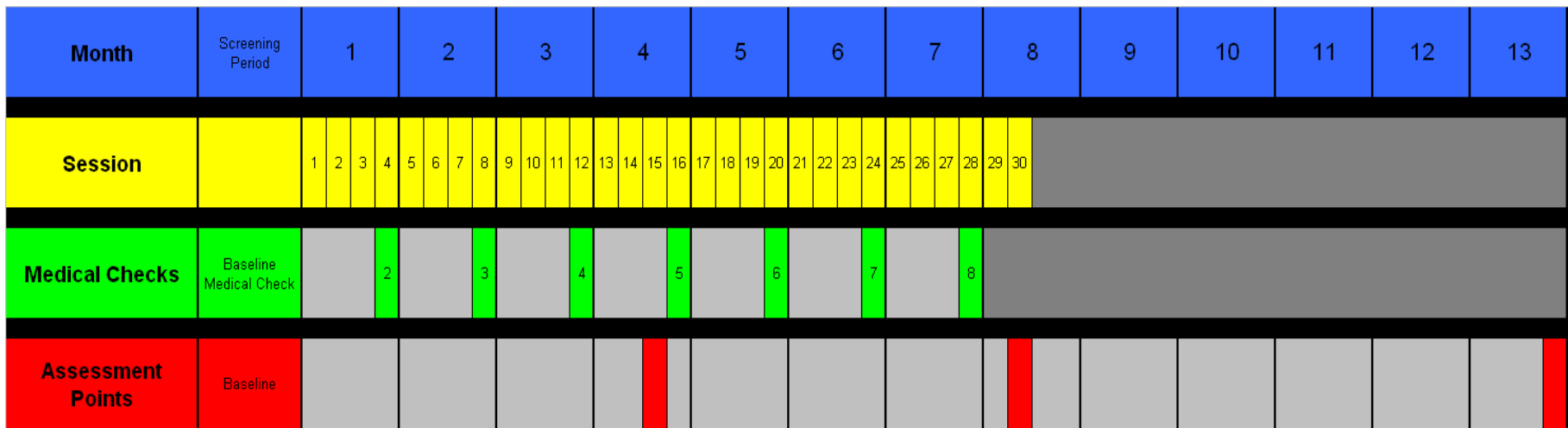
- **Primary Outcome: mental Health related Quality of Life; mood disorder and social adjustment**
- **Secondary Outcome: weight; eating disorder symptoms; motivation to change and health care burden**

# Design

- **8 months of treatment**
- **27.5 contact hours of therapy**
- **33 = 50 minutes sessions**
- **Contact hours identical in each model of therapy.**



# Participant Timeline



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# Patient Characteristics

- Mean Age 33.4yrs
- Mean Duration of illness 16.6yrs
- Restricting sub-type 74%
- Taking Psychotropic drugs 41%
- Medical Concern 86%

# Patient Characteristics

- Unemployed 61%
- College Degree 74%
- Never had emotional relationship 51%
- Consensual intercourse 15%

**Treating severe and enduring anorexia nervosa:  
a randomized controlled trial**

**S. Touyz, D. Le Grange, H. Lacey, P. Hay, R. Smith,  
S. Maguire, B. Bamford, K. M. Pike and R. D.  
Crosby**

**Psychological Medicine *May 2013, pp 1 - 11*  
*DOI: 10.1017/S0033291713000949,***

# Treatment Outcome

- Both treatments acceptable
- Very low drop-out
- Both treatments effective
- All patients gain weight
- Positive changes continue

# Treatment Outcome

- *Both treatments acceptable*
- *Very low drop-out*
- Both treatments effective
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- Positive changes continue

# Acceptability of Treatment

- 87.3% completed treatment
- 85.7% completed at least one post treatment assessment



# Acceptability of Treatment

- No sig. differences between the two treatment groups in follow-up completion rates.

# Acceptability of Treatment

Low dropout rates in this study may be attributed to the fact that therapists worked on areas that the patient herself deemed important, in particular areas associated with quality of life, which improved engagement and motivation

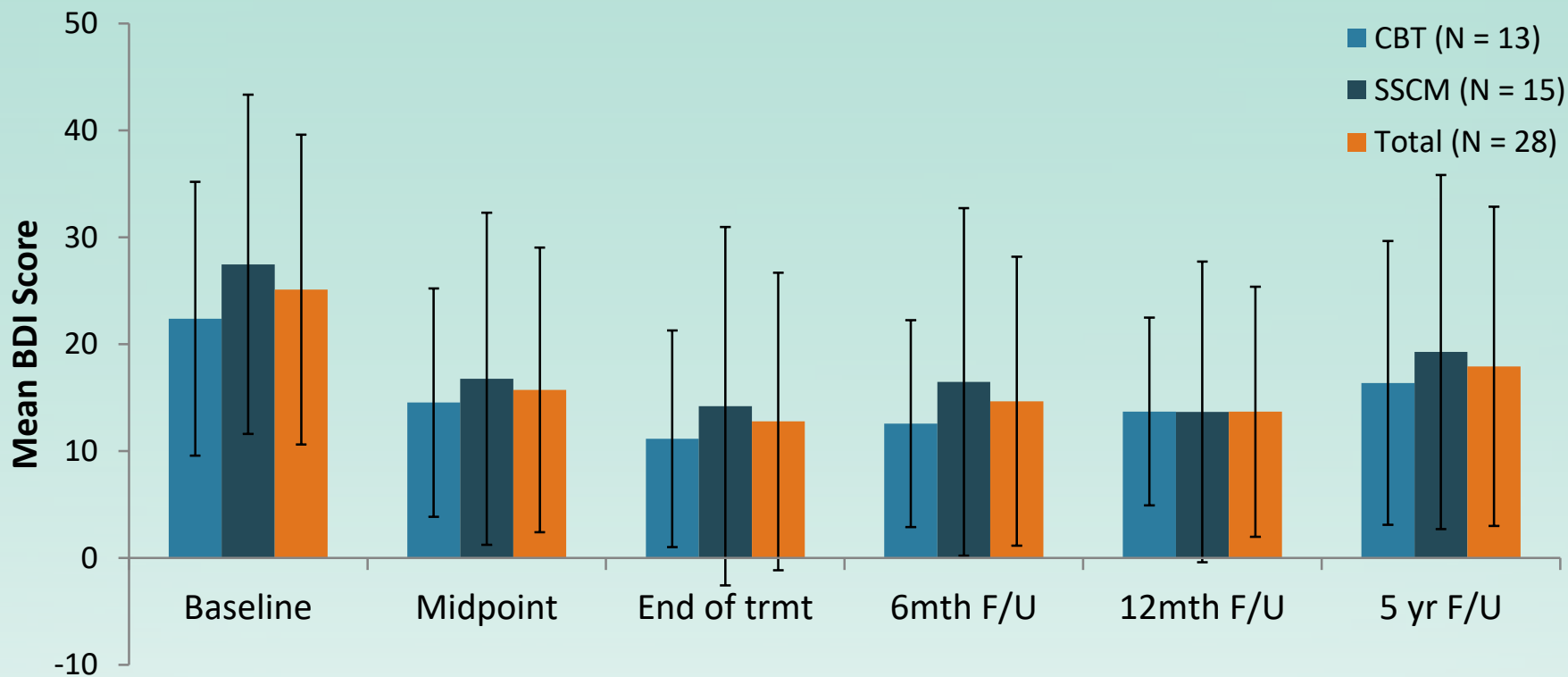
# Treatment Outcome

- Both treatments acceptable
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# Treatment Outcome

- *Both* treatment groups reported significant improvement on *all* primary and secondary measures
- Primary Outcome: mental health Quality of Life, mood disorder symptoms, and social adjustment, ALL improved

# 5 year follow-up: Beck Depression Inventory



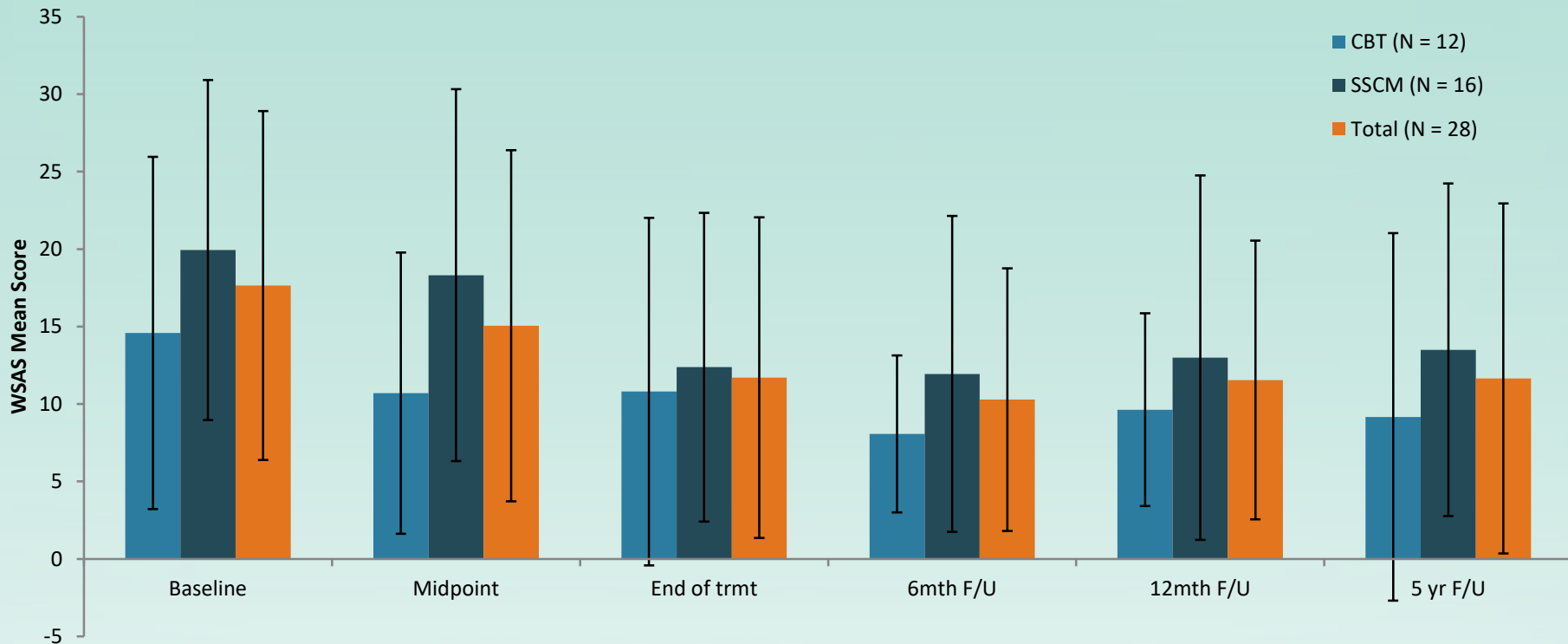
**Note:** Combined sample at 5yr mean BDI is significantly lower than baseline but significantly higher than at end of treatment. Error bars = Standard Deviation. Lower score denotes reduction in depression symptoms.

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# 5 year follow-up: WSAS



**Note: Error bars = Standard Deviation**

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# Treatment Outcome

Secondary Outcome measures similarly improved in *both* treatment groups:

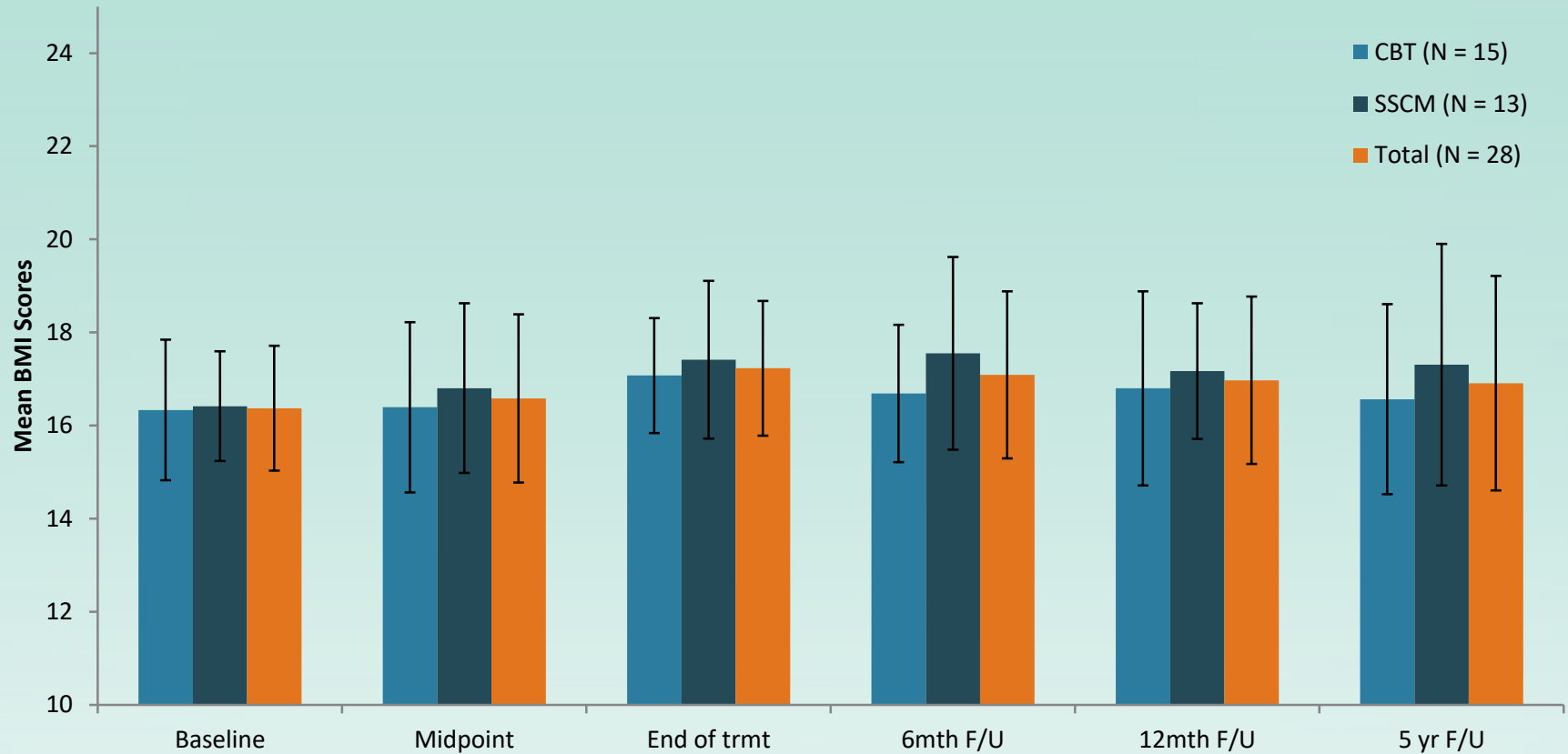
- eating disorder symptoms, motivation for change, and health care burden.

# Treatment Outcome

- Both treatments acceptable
- Very low drop-out
- Both treatments effective
- *All patients gain weight*
- Positive changes continue



# 5 year follow-up: BMI



**Note: Error bars = Standard Deviation**

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# Treatment Outcome

- All patients gained weight
- 3 patients have had a baby

# Treatment Outcome

- Both treatments acceptable
- Very low drop-out
- Both treatments effective
- All patients gain weight
- *Positive changes continue*

# Treatment Outcome

- Positive changes continued at end of treatment & at 6 months and 12 month follow-ups
- Magnitude of change was from moderate (BMI) to large (readiness to recover)

# Baseline predictors of better outcomes

- Lower age, shorter illness duration, non-purging type, better social /work adjustment, not taking psychotropic medication
- Those with more severe symptoms, depression older age & purging subtype benefited more from CBT
  - Le Grange *et al.* BRAT 2014

# Within therapy predictors of outcome

- Therapeutic alliance (especially later in therapy)
  - Stiles-Shields *et al.*, *IJED*, 2013
- Improved eating disorder symptoms and BMI predicted current and future quality of life
  - Bamford *et al.* *IJED*, 2014

# Treatment Outcome

- Little evidence that specific therapy factors help in the short term
- More likely 'common' factors

# Treatment Outcome

- therapist competence
- the experience of support and encouragement
- raising of hope and patient expectations of improvement



# Treatment Outcome

- therapeutic alliance

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- Therapeutic alliance was a significant predictor of eating disorder symptomology at end of treatment and follow-up (ps less than 0.04) but not mood

Therapeutic Alliance in Two Treatments for Adults with Severe and Enduring Anorexia Nervosa

C Stiles-Shields, D Le Grange, P Hay, H Lacey, & S Touyz Int J of ED

# Treatment Outcome

These findings challenge view that SE-AN :

- Have little or no motivation to change
- Are unlikely to respond to conventional psychosocial treatments
- Have a high treatment drop-out

# Treatment Outcome

- Shows that SE-AN should be offered specialised treatment in ED clinics
- Should not be given non-specific palliative care only
- Should be offered more than generic treatment or care homes



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## PART 6

### ADAPTION OF SSCM FOR SE-AN A TASTER OF PRACTICAL ASPECTS

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# Treatment adaptations

- Main adaptations included:
  - Focus is on quality of life rather than weight restoration
  - Goals are smaller (improvement rather than cure) but you MUST have them
  - Motivational throughout therapy
  - Symptom (clinical) management
  - Increased focus on reassurance, consistency, encouragement, psycho-education and supportive advice

# Specialist Supportive Clinical Management

- Elements of clinical management and supportive psychotherapy.
- Clinical management
  - Education
  - Care
  - Support
  - Fostering a therapeutic relationship
  - Emphasizes the resumption of normal eating and restoration of weight

# Specialist Supportive Clinical Management

- Elements of clinical management and supportive psychotherapy.
- Supportive psychotherapy
  - Praise
  - Reassurance
  - Advice
  - Other therapy content is dictated by patient



# Primary Aim

- The **primary aim of SSCM therapy is to maintain a therapeutic relationship** that facilitates the return to more normal eating with some weight gain or at least prevents weight loss, and most importantly enables other life issues, that may impact on the eating disorder, to be addressed.

# Weight Requirement

- No target weight
- No weight loss – or treatment ended
- No requirement to gain weight
- Benefits of weight gain

# Techniques

- **Assessment**
- Motivation
- **Symptom management**
- **Quality of Life**
- Psycho-education
- Development of a therapeutic alliance

# Assessment

- What is the disorder
- *How* the disorder developed

# Assessment

- What is the disorder
- *How* the disorder developed
- *Why* it developed

# Assessment

Understand the patient

- within herself
- within her family
- within her society

# Assessment

- A graph of body-weight from pre-puberty to current age

# Assessment

- A graph of body-weight from pre-puberty to current age
- Below the weight-line: behavioural symptoms
- Above the weight-line: life events



# Assessment

- confirms the diagnosis
- reassures the patient that the problems are understood by the therapist
- it establishes the symptom focus as an essential part of therapy
- allows the establishment of an individualised Target Symptom Checklist

# Target Symptoms

The **Target Symptom Checklist** is designed to:

- provide structure
- ensure that the primary focus on eating patterns and symptoms of anorexia nervosa remains

# Assessment

- Determine QoL goals based on current and past history

# Assessment

- Leads to collaborative 'goal setting'

# At the beginning of Treatment

Goals follow Assessment

- Two to Five Goals

# At the beginning of Treatment

- Two to Five Goals
- Patient always works to these goals
- Never less than two goals
- At least one must be symptomatic and at least one be a quality of life goal
- Patient can develop mini-goals on route to a goal

# Sample Goals

- Restore normal eating
- Stop vomiting
- Restart voluntary work
- Restart the piano
- Have coffee with sister

# Techniques

- Assessment
- Motivation
- Symptom management
- Quality of Life
- **Psycho-education**
- Development of a therapeutic alliance



# Psycho-education modules

- What Is Anorexia Nervosa? (incidence / causes etc)
- Effects of Dieting / problems related to dieting
- Socio-cultural Influences on Eating Disorders
- Ineffectiveness of Dieting
- Ineffectiveness of Purging
- The Cycle of Disordered Eating
- Theories of Biological and Genetic Contribution to Weight Status and Body Shape (Set Point Theory)
- Effects of Starvation (Keys, Vitousek etc)
- Society's contribution to body image
- Exercise as Weight-Control
- What are the Scales Really Telling You? (weight fluctuations etc)
- Medical Consequences of Eating Disorders
- Nutrition and Recovery from Eating Disorders
- Bone Health

# Therapy

- Keep the focus of work small and varied ‘realistic expectations’.

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- Explore adaptations and changing values (what was important, what is now).

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- Allow them space to grieve for life losses and acknowledge reality of impact of anorexia.

# Therapy

- Keep the focus of work small and varied ‘realistic expectations’.
- Explore adaptations and changing values (what was important, what is now).
- Allow them space to grieve for life losses and acknowledge reality of impact of anorexia.
- Always work towards an ending.

# What SSCM is

- Therapeutic alliance is KEY
- Uses psycho-education, advice, support, encouragement, symptom monitoring,

# What SSCM does NOT involve

(from Fawcett et al.,1987)

No systematic focus on specific psychological techniques:

- Interpretations
- psychodynamic explanations
- cognitive distortions
- interpersonal relationships
- Regression.

# What SSCM is

- Flexible
- Treatment tailored to the individual patient
- Treatment tailored to specific needs and goals



# What SSCM does NOT involve

(from Fawcett et al.,1987)

No systematic focus on specific psychological techniques:

- Specific behavioural instructions (other than advice regarding eating/related issues).
- Systematic exploration of body image.

# What SSCM is

- A collaborative 'goal setting' treatment
- Focus on symptoms must be maintained throughout

# What SSCM does NOT involve

(from Fawcett et al.,1987)

No systematic focus on specific psychological techniques:

- Use of deliberate confrontation.
- Family therapy

# What SSCM is

- Active strategies can be suggested but not enforced

# Number of Sessions

- 20-30 sessions
- Initially twice a week (engagement)
- Always working on the ending

# Therapist Requisites

- Any professional background
- Experienced in working with ED
- Experienced in at least one therapeutic model
- High quality interpersonal skills

# Therapist Requisites

- Able to use relevant personal opinions
- Able to use personal experience
- Comfortable working with ‘patient as expert’

# Therapist Requisites

- Able to tolerate minimal change
- Able to tolerate the patient's entrenched defences



# Therapist Requisites

- Able to work flexibly according to patient style

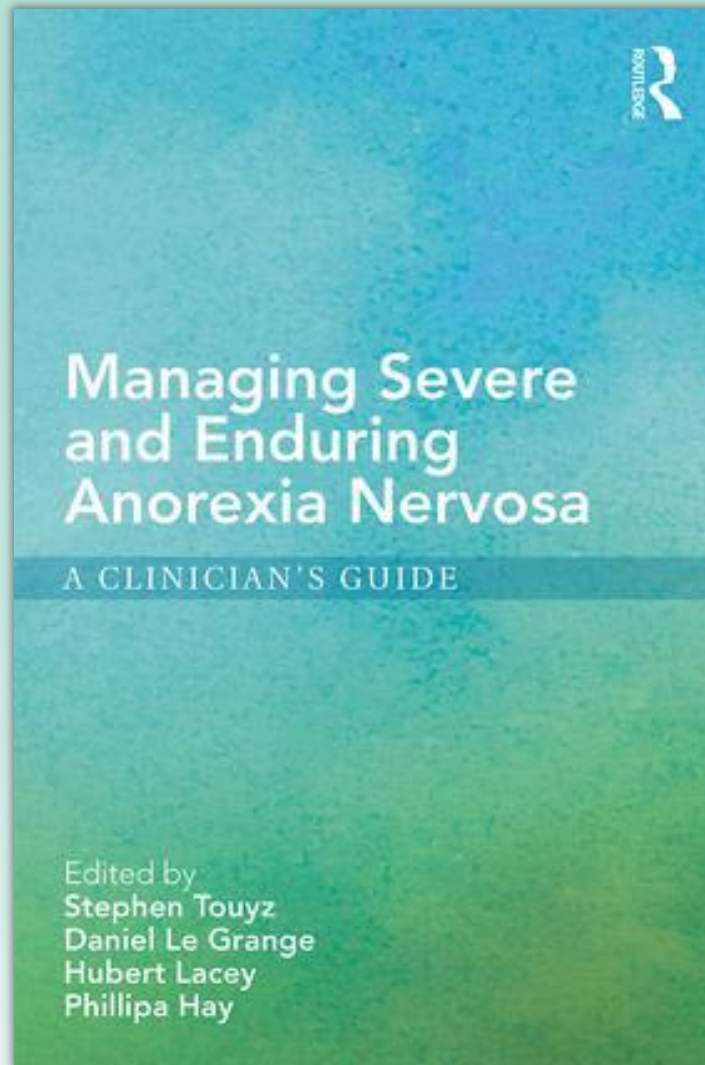
# Concluding remarks

Treatment of the chronically ill demands awareness of the related “customs” by which these patients insist they must live.

*Touyz and Strober 2016*

# Concluding remarks

It requires an understanding of why it is hazardous to ask patients with SE-AN to challenge their routines too soon, too forcefully.



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# Thank you!

## Questions and clarifications

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**OPTIMISM ABOUT TREATING SEVERE AND  
ENDURING ANOREXIA NERVOSA (SE-AN)**

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