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

Hubert Lacey

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Medical Director, Newbridge House
A CLINICAL REVIEW AND A PRACTICAL, EVIDENCE-BASED TREATMENT

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PART 1
A CLINICAL REVIEW

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

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
“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.”

*SE-AN: A Distinct Clinical Population?*

*Ciao, Accurso and Wonderlich, 2016*
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)

SE-AN - Yolan

- 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*
“...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).
Managing Severe and Enduring Anorexia Nervosa

A CLINICIAN’S GUIDE

Edited by
Stephen Touyz
Daniel Le Grange
Hubert Lacey
Phillipa Hay
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-synchronically attached to low weight
Severe & Enduring Anorexia

- High unemployment
Severe & Enduring Anorexia

- High unemployment
- Multiple medical complications
Severe & Enduring Anorexia

- High unemployment
- Multiple medical complications
- Repeat hospital admissions
Severe & Enduring Anorexia

- High unemployment
- Multiple medical complications
- Repeat hospital admissions
- High use of GP/Family services
Severe & Enduring Anorexia

• High unemployment
• Multiple medical complications
• Repeat hospital admissions
• High use of GP/Family services
• High use of social & welfare services
Severe & Enduring Anorexia Anorexia Nervosa

- Blighted Life
- Thwarted Achievement
- Disrupted Families
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
Reasons for SE-AN refusing treatment

- Rigid inflexibility leads to denial of reality
- Strong feeling they can deal with their own difficulties.
Reasons for SE-AN refusing treatment

- Rigid inflexibility leads to denial of reality
- Strong feeling they can deal with their own difficulties.
- Mistrust of interpersonal relationships.
- Extreme apprehension about a loss of control.
Reasons for SE-AN refusing treatment

- Rigid inflexibility leads to denial of reality
- Strong feeling they can deal with their own difficulties.
- 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.
Reasons for SE-AN refusing treatment

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

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

<table>
<thead>
<tr>
<th>Month</th>
<th>Screening Period</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
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</thead>
<tbody>
<tr>
<td>Session</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
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<td>10</td>
<td>11</td>
<td>12</td>
<td>13</td>
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<tr>
<td>Medical Checks</td>
<td>Baseline Medical Check</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
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<td>9</td>
<td>10</td>
<td>11</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>Assessment Points</td>
<td>Baseline</td>
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</tbody>
</table>

- **Mid-Treatment**
- **End of Treatment**
- **6 month follow-up**
- **12 month follow-up**
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
- All patients gain weight
- 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
- Very low drop-out
- Both treatments effective
- All patients gain weight
- Positive changes continue
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.
5 year follow-up: WSAS

Note: Error bars = Standard Deviation
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

- Baseline
- Midpoint
- End of trmt
- 6mth F/U
- 12mth F/U
- 5 yr F/U

Mean BMI Scores

- CBT (N = 15)
- SSCM (N = 13)
- Total (N = 28)

Note: Error bars = Standard Deviation
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
• 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
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
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

0121 580 8362
www.newbridge-health.org.uk
enquiries@newbridge-health.org.uk
Therapy

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

- Keep the focus of work small and varied ‘realistic expectations’.
- Explore adaptations and changing values (what was important, what is now).
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.
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.
Thank you!

Questions and clarifications
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