The impact of COVID-19 on patients and carers with severe anorexia nervosa
Janet Treasure and team
Talk Map

• The TRIANGLE trial
• Intervention: Digital resources and support
• The impact of COVID on Carers and patients


Rationale for TRIANGLE

• Relapse rate post admission for adult inpatient treatment is approximately 30%.

• Feasibility and pilot studies: psychoeducation & skills for carers reduced length of stay (LOS) & relapse with a decrease in care giver burden & increase caregivers & patients well being (Hibbs et al 2017; Magill et al 2018).

• Therapy targeting collaboration between carer givers & patient reduced LOS & relapse rate (Adamson et al 2019).

• Reach: Geographical separation
TRIANGLE- a multicentre NHS trial targets social factors

Collaborative, Social, Approach: Workbook & online workshops

Patients past/present

Supporters past/present

Professional team
Protocol of the TRIANGLE study

- **Participants:** Patients (>16 years) admitted for inpatient care & carers (aim N=385; final n=371) due to COVID

- **Intervention:** Online digital platform, collaborative recovery approach, workbooks & seminar style group workshops for patients and caregivers (single & combined).

- **Outcome:** Wellbeing of patient & carer, patient symptoms (BMI, ED psychopathology), Carer-carer skills. Health economics, LOS, relapse rate, Number of bed days after 12 & 18 months

- **COVID:** Pandemic (WHO) 11th March 2020 (n= 338 dyads) by 16th March (UK lockdown date) n=344 dyads (93%). Recruitment started July 2017 stopped July 2020 (n=371)
Process Study:
Qualitative Interviews April 2020

• Semi-structured interviews AN (n = 21) and their carers (n = 28)
• Questions related directly to the impact of lockdown and COVID-19 were analysed using thematic analysis.
• **Results:** Four broad themes were identified for patients and carers separately and core issues interlinked.
Themes

(i) disruption/change to ED service provision,

(ii) practical constraints of lockdown on ED recovery & increased pressure on carers.

(iii) adverse effects on the wellbeing of patients

(iv) perceived positive outcomes & increased patient & carer self-efficacy.
Patient themes

**Reduced access to ED services**
- Disparity in access to ED services
- Reliance on remote support from professionals
- Premature discharge from services

**Disruption to routine and activities in the community**
- Coping with changing routine and structure
- Disrupted transitions into community living
- Reduced motivation for recovery

**Heightened psychological distress and ED symptoms**
- Concerns over access to food and focus on exercise
- Increased fear and anxiety

**Increased attempts at self-management in recovery**
- Experiences of increased self-efficacy
- Seeking alternative practical coping strategies and resources

It was so unplanned...it was my second admission and I’d only been in four and a half weeks so obviously I hadn’t been there that long and weren’t anticipating discharge because there wasn’t a plan in place...

...so it kinda just makes me think ‘oh what’s the point of even trying to recover?’ if that makes sense, because I’m not doing anything

I think the media being ‘ooh you’ll gain weight...’ is quite difficult because then you think ‘that’s it, I’m gonna gain weight’ and I think that’s one thing I’ve really struggled with actually..

I’m quite motivated at the minute because...to put things into perspective, like your immune system is really weakened because of an eating disorder and for me, I don’t want that any more so I’m feeling really motivated to kind of improve my physical health.
Carer themes

Concern over provision of professional support for patients
- Fears over premature discharge of patients from services
- Change in delivery of support for patients

Increased practical demands placed on carers in lockdown
- Managing patient and family needs in lockdown
- Curtailment of normal activities and lack of routine
- Challenges around shielding and social distancing

Managing new challenges around patient wellbeing
- Increased displays of anxiety
- Reporting new food-related triggers

New opportunities
- Gratitude for increased time at home
- Noticing increased self-efficacy
- Utilising adaptive perspectives and approaches

... outpatient care changed a lot. Suddenly expectation to weigh self... very, very scary.

You just want some time apart and going to work does that ... and you need to have that break as a carer sometimes, don’t you?

“Oh your sleeve just touched that bit of packaging so you’d better change your top now because it might be on your sleeve” .... I feel her pain.... ... but it’s different anxiety

He’s now volunteering to help out with delivery of food to vulnerable people and he’s absolutely loving it, absolutely loving it.
Adverse Event Reporting

(n=371, recruitment began July 2017 closed July 2020)

• **Respiratory related (COVID)-Mild**
  4 (1%), all 4 post 11/03/2020.

• **Organ related (GI, renal, Cardiovascular)**
  3 (0.5% total cohort) with 2 reported post 11/03/2020.

• **Deaths**
  6 (1.6% total cohort), with 1 reported post 11/03/2020.

• **Overdose and self-Harm**
  4 (1% total cohort), with 0 reported post 11/03/2020.

• **Severe Weight deterioration (>2.5kg/m)**
  108 (29% total cohort) with 48 reported post 11/03/2020.
Conclusion

• Difficulty with sudden disruption of treatment – especially if OCD, & depressive, anxiety comorbidity.

• Lockdown reduced many patients’ ability to reintegrate following discharge, apart from those connecting through COVID-19 related work.

• Carers felt increased responsibility for the wellbeing of loved ones.

• Some cases with adaptive mindsets and self-efficacy, supporting others, making the most of support offered and reaching out to alternative self-management resources.

• The collaborative, shared approach increased mutual empathy & in some cases connected citizens.
Acknowledgements

TRIANGLE research and clinical team

Our participating research sites

Our collaborators
How COVID-19 and confinement are affecting our adolescent patients and their families at UCSF

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Department of Psychiatry and Behavioral Science, UCSF Weill Institute for Neuroscience
University of California, San Francisco, CA
Emeritus Professor of Psychiatry & Behavioral Neuroscience
The University of Chicago, IL

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A little bit about the US context

Inpatient Treatment

- Influx of cases followed by barriers to access specialized care post discharge. Challenge to help families understand this is a crisis and they need to act now, but they are unable to access FBT/specialized care.

- "COVID story AN" = short-hand for those who were fine until March, decided to 'eat healthier' and had the opportunity to start exercising and then became medically unstable as a result of malnutrition.

- Along the way a fear of weight gain and body image concerns developed - for many, this was not present prior to weight loss.

- Many parents recognize concerns sooner than they might have if their kid was off socializing with friends all day or at school.

- Fewer males - many were often flagged with bradycardia when completing sports physicals.
School

- Less opportunities to find “natural consequences” for noncompliance with nutrition/restfulness – usually no school, but that’s largely not happening. Not being able to log on to online school is not the same.

- Increased burden for parents in supervising their children during school hours.

- Sudden opportunity to return to in-person school a few days a week, families are more reluctant to hold kids back because they've been so desperate for a sense of 'normal.' Meal supervision is more complicated with restrictions of who can come on to campus and wanting to protect staff from being around someone with a mask off while eating.

- Scared to return to school - slowing down pace of life and increasing supervision felt safe. Returning to school in person, even for 2 days/wk feels daunting. Parents: "Do you think she is ready?!!" Clinician: “Yes, she is ready to have more stimulus in her life, to fill time with things other than thinking about food. But COVID had shrunk their world and almost seemed to cause them to over-pathologize the ED.
Outpatient Treatment - FBT

- Social isolation at a time when spending time with peers is critical – now managing peer relationships via social media (exclusively).

- For those who struggle with eating out/social eating - it has taken much more intentional effort to have opportunities to practice that.

- Several patients who were doing relatively well and on track to wrap up treatment had very significant set-backs with the loss of structure, uncertainty, and ‘weirdness’ of the pandemic.

- Patients with comorbid diagnoses - difficult to figure out how impairing their symptoms are right now. Are they not going out for a walk because they are depressed? Anxious about contracting COVID? Hard to observe functioning in some kids.
Outpatient Treatment - FBT

- Ability to connect with healthy identity factors (e.g., sports, friends, clubs), has been hindered, which has made the lure of the ED more powerful. Many teens have needed to have parents increase supervision because their own motivation to fight the ED is lower.

- On the flip side, some introverted patients like not being at school and it has led to decrease social comparison and emphasis on looks.

- One adolescent felt that "everything was out of control" when shelter-in-place began, a feeling that spanned her academic, sport, and social life. Taking control of her food was a means to resolve that discomfort with all of the uncertainty she experienced.

- Increased anxiety and challenges with tolerating an incredible amount of uncertainty.

- Loss of sense of safety in people and the world, especially for children for whom the loss of structure and normalcy feels traumatic.
Some Challenges

- How do you weigh the patient?
- What if they don’t want to join the family?
- What if they join, but sit behind the computer monitor?
- Stable Wi-Fi, charged devices, social anxiety on camera?
Some Benefits

- Not traveling

- Being able to join from separate locations

- Caregivers can work from home, meal supervision is more feasible

- Teen patients are less exhausted and overextended for the most part
Translating evidence-based treatment for digital health delivery: A protocol for family-based treatment for anorexia nervosa using telemedicine

A. Hambleton, D. Le Grange, J. Miskovic-Wheatley, S. Touyz, M. Cunich and S. Maguire

*Journal of Eating Disorders* 2020 8:50

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Assessment of Impact of COVID-19 confinement in ED and factors associated with resilience

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Special issue on COVID19 and ED (28 6)


COVID19 and ED: Implications and recomendations

COVID-19 Confinement and Consequences in ED

- Patients with Eating disorders (ED) represented a vulnerable group.
- Symptomatic deterioration such as restriction, purging, binging and exercise has been reported.
- Moreover, the physical sequel of the disorders such as weight loss in anorexia nervosa (AN), electrolyte imbalance in bulimia nervosa (BN), or cardiovascular risk in binge eating disorder (BED) amplify the risk.
- Emotional distress in the face of environmental changes is another triggering factor.
- Restrictions placed on movement may have limited adaptive strategies in the face of these difficulties with reduced access to support.
COVID-19 Confinement and Consequences in ED

New Cases in Spain

14th March to 11th May 2020

14th March to 11th May 2020
The sample was constituted of 74 adults, with female predominance (71 patients, 95.9%) and a mean age of 32.12 (±12.84) years old. **25.6% worse**

<table>
<thead>
<tr>
<th>Concerns</th>
<th>n</th>
<th>%</th>
<th>p</th>
<th>df</th>
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<td>Adaptive reactions: Sport</td>
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<td>7.7</td>
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<td>Adaptive reactions: Routine</td>
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<td>Adaptive reactions: Work/studies</td>
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<td>Non-adaptive reactions</td>
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<td>Anxiety: Motor</td>
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<td>Depression</td>
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<tr>
<td>Other situations</td>
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<td>50</td>
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</table>

**FIGURE 1** Path diagram with the standardized coefficients. Note. Continuous line: significant coefficient. Dash line: non-significant coefficient.

*Bold: significant comparison.
*Bold: effect size into the range mild-moderate (df > 0.50) to high-large (df > 0.80).
COVID-19 Outbreak in Spain
COVID-19 Confinement Impact in ED: Assessment measure

The three last scales are answered on a five-point Likert scale. Sections 2 and 3 consider two moments of time: before confinement and now, the present (CIES Scale and translated in 19 languages)

Cronbach alpha values ranged from good to excellent.
COVID-19 Confinement Impact in ED: Assessment measure
COVID-19 Confinement Impact in ED: Assessment measure

Evaluation of Telemedicine between the groups

<table>
<thead>
<tr>
<th>Anorexia (AN)</th>
<th>Bulimia (BN)</th>
<th>OSFED</th>
<th>Obesity</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 55</td>
<td>n = 18</td>
<td>n = 14</td>
<td>n = 34</td>
</tr>
<tr>
<td>Mean</td>
<td>Mean</td>
<td>Mean</td>
<td>Mean</td>
</tr>
<tr>
<td>25.58</td>
<td>28.61</td>
<td>29.50</td>
<td>28.97</td>
</tr>
<tr>
<td>SD</td>
<td>10.40</td>
<td>6.46</td>
<td>9.53</td>
</tr>
<tr>
<td>7.25</td>
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</tbody>
</table>

Pairwise comparisons: $p$ | $|d|$ |
Anorexia vs bulimia: .218 | .35 |
Anorexia vs OSFED: .148 | .39 |
Anorexia vs obesity: .047* | .38 |
Bulimia vs OSFED: .782 | .11 |
Bulimia vs obesity: .891 | .05 |
OSFED vs obesity: .853 | .06 |

Abbreviation: OSFED, other specified feeding eating disorder.
Conclusions and Take-home message

• Regarding the effects of confinement, positive and negative impacts of the confinement depends on the ED subtype, being the OSFED patients those who endorsed an increase in eating symptomatology and in psychopathology.
• Low Self-directedness was associated with an aggravation of ED and general psychopathology during confinement.
• ED worsening was linked to less-adaptive coping strategies in confinement situation with a resulting weight increase.
• AN patients expressed the greatest dissatisfaction and accommodation difficulty with remote therapy when compared with the previously provided face-to-face therapy.
• CIES Scale has adequate goodness-of-fit for the confirmatory factor analysis, and Cronbach alpha values ranged from good to excellent.
Management challenges and usefulness of e-health strategies during the COVID-19 pandemic

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AED Webinar, 10.11.2020
COVID-19 and mental health

COVID-19
- Uncertainty
- Isolation
- Disruption to standard care and routine

Use of unhelpful behaviours to cope with stress*

Clinical need
- From face-to-face to online services

*Worsening of eating disorder symptoms during COVID-19:
  Schlegl et al., 2020 (Germany), Branley-Bell and Talbot, 2020 (UK),
  Termorshuizen et al., 2020 (US and the Netherlands)
E-health strategies: from choice to necessity

Use of telemedicine to:
“reinforce or establish web-based and other telemedicine platforms to provide direct clinical services and provide clinical decision support”
E-HEALTH: POSITIVES*

- Alternative to decreased access to in-person treatment (proved efficacy to reduce eating disorder symptoms and comorbid anxiety or depression for binge eating) and potential wide reach
- Strong public demand; particularly helpful for stigmatized psychiatric conditions
- Appropriate to deliver evidence-based psychological therapies, e.g. CBT
- Offers opportunities for self-monitoring, self-management, regular check-ins, prompt delivery of interventions, social connection (including carers’ involvement)

*Editorials: Fernandez-Aranda et al., EEDR 2020; Weissman, Bauer and Thomas, IJED 2020; Waller et al., IJED 2020; Murphy et al., The Cognitive Behaviour Therapist 2020
E-HEALTH: CHALLENGES

Reach

Uptake and persistence

Management of risk

Taylor et al., IJED 2019; Ambwani, Cardi, Treasure, 2014
E-health strategies: Reach

Health care iniquities and “postcode lottery”

- Need for a coordinated “international mental health response”
- Collaborative work for cultural adaptation of online resources

McGorry; Touyz, Lacey, Hay, 2020; Branley-Bell and Talbot, 2020
E-health strategies: uptake and persistence (1)

Results from the SHARED trial:
Online guided self-help for patients with anorexia nervosa mentored by recovered individuals, carers or psychology graduates
(Cardi et al., 2015; Cardi et al., 2019; Cardi et al., 2020; Albano et al., in prep.)

• Drop-out 18% (therefore comparable to drop-out from face-to-face therapies)
• Early alliance with mentor delivering online guidance predicts lower drop-out
• Greater verbal synchronicity with “peer mentors” compared to mentors, which predicts alliance

Further evidence for:
• Importance of multimedia channels to produce superior outcomes (Barak et al., 2019)
• Early symptom improvement related to later alliance quality (Graves et al., 2017)
Guided self-help associated with lower drop-out from study protocol compared to control condition
(Albano et al., 2019)

<table>
<thead>
<tr>
<th>Study or Subgroup</th>
<th>Experimental Events</th>
<th>Total</th>
<th>Control Events</th>
<th>Total</th>
<th>Weight</th>
<th>Peto Odds Ratio Peto, Fixed, 95% CI</th>
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<td>10</td>
<td>41</td>
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<td>8</td>
<td>50</td>
<td>17.4%</td>
<td>1.47 [0.54, 3.98]</td>
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<td>34</td>
<td>4</td>
<td>37</td>
<td>4.3%</td>
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<td>72</td>
<td>15</td>
<td>70</td>
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<td>0.47 [0.19, 1.14]</td>
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<td>24</td>
<td>3</td>
<td>17</td>
<td>5.7%</td>
<td>0.67 [0.12, 3.80]</td>
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<tr>
<td><strong>Total (95% CI)</strong></td>
<td></td>
<td>435</td>
<td></td>
<td>436</td>
<td>100.0%</td>
<td>0.63 [0.41, 0.95]</td>
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<tr>
<td><strong>Total events</strong></td>
<td></td>
<td>43</td>
<td></td>
<td>63</td>
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</tbody>
</table>

Heterogeneity: $\chi^2 = 7.05$, df = 6 ($P = 0.32$); $I^2 = 15\%$
Test for overall effect: $Z = 2.20$ ($P = 0.03$)
E-health strategies challenges: Risk

Risk (e.g. weight or mood deterioration)
- TRIANGLE and SHARED Trials: Total of 558 patients with anorexia nervosa. No adverse events associated with participation in online therapy
- Online guided self-help associated with reduced anxiety and greater confidence in own ability to change at 6 weeks (end of intervention)

Possible strategies to enhance risk management
- Carers’ involvement
- Use of video calls
- Weight check conducted by GPs
E-health strategies: notes of caution

• E-health strategies cannot substitute human contact

• Spending time online might imply greater exposure to triggering messages

• Online support might be perceived as “second best” attempt to care
When the whole sort of COVID lockdown started we utilized the forum of that week just to sort of talk about how everyone was feeling rather than ....it still all related back but it was quite a nice sort of space, whereas they could have just gone ‘let’s just ignore that and just do what we were supposed to’, but no, I’ve always felt included. I’ve never felt excluded and I’ve never felt like I have to participate. I’ve never felt that anything that I’ve said has been wrong. I’ve never sort of witnessed them saying anything along those lines, so it’s always been really positive... it’s helped me sort of keep going with recovery, I think.”

“...having the opportunity to have the [TRIANGLE] forums, I think, is a really good thing, especially now with no outpatient services...”

“...the bits about transitioning away from hospital and the experiences people have had, that’s obviously quite relevant to me now... and it just so happens that I was discharged at the beginning of Coronavirus and so it’s quite good to have that material available now.”
Thank you!

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