

Faculty of Eating Disorders

## NEWSLETTER

@rcPsychEDFac

April 2024 Spring Issue "It is the long history of humankind (and animal kind, too) that those who learned to collaborate and improvise most effectively have prevailed."

Charles Darwin



## What to expect

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## Introduction

## By Dr David Coyle & Dr Louise Johnston

We want to begin with an apology. It has been a while since you have received a copy of the Faculty Newsletter. Louise and I took over as Communications representatives on the Faculty Executive Committee in 2023 and it has taken us some time to find our footing and produce this document. We are delighted to bring it to you now.

As a body of professionals we find ourselves in a challenging era, challenges that exist in concentric circles but each impacting on all of us and on the individuals that we seek to treat. Underfunding and threadbare commissioning profiles mean that we are all struggling to do the best that we can with what we have got. Yet day and daily we see examples of innovation and brilliance from people, from teams, who are driving forward despite the obstacles they face. The Royal College of Psychiatrists was designed to support Psychiatrists to be the best versions of themselves, upholding a core set of values: courage, innovation, respect, collaboration, learning and excellence.

Courage to speak up, but also courage to listen.

Innovation within the clinical field, improving outcomes and patient experience.

Respect for one another, and for the diverse viewpoints we hold.

Collaboration with service users and their families, and with the many disciplines with whom we work.

Learning, from evidence and from experience.

Excellence to strive for the best within ourselves and within our practice.

Although we all aspire to hold these values, the lens through which they are put does not always result in precisely the same opinions or ideas. If anything this approach would stymie development as it is the kaleidoscope of knowledge and experience that paints a better picture for the future. We hope that this newsletter captures a snapshot of those colours for all of you taking the time to read it, and encourages others to come forward with thoughts and ideas of their own.

## Spotlight: personal Professor Ulrike Schmidt

A huge congratulations to our colleague Professor Ulrike Schmidt for being awarded an OBE in the New Year Honours 2023.

Dr Schmidt, MD PhD FMedSci FRCPsych FAED, is Professor of Eating Disorders and Director of Centre for Research in Eating and Weight Disorders (CREW) at King's IoPPN. She is a Consultant Psychiatrist at South London and Maudsley NHS Foundation Trust and she leads the Eating Disorders and Obesity Theme at the NIHR Maudsley Biomedical Research Centre. After completing her medical studies at the University of Düsseldorf, Ulrike went on to train in psychiatry at the Maudsley Hospital, and has been a consultant in the Eating Disorders Service there since 1998, and Professor of Eating Disorders at the IoPPN since 2006.

Ulrike's research spans the spectrum of EDs and their biopsychosocial underpinnings. She has pioneered many influential treatment innovations. She was the first to introduce guided self-help interventions (initially book-based, later web-based) for bulimic EDs, translating specialist treatment into scalable formats. This approach is now recommended by NICE as a first-line treatment. Ulrike also led the development of MANTRA, the first anorexia-specific psychotherapy for adults, which is now also NICE-recommended. She developed FREED, an evidence-based early intervention programme which transforms young people's lives, with dramatic improvements in outcomes and large cost-savings. FREED was adopted for national roll-out in the NHS (2020) and now is available across all of England. Ulrike has also pioneered novel, highly targeted treatments, such as non-invasive brain stimulation. She leads a large, cross-disciplinary UKRI-funded research consortium on early intervention in EDs (£3.8m), developing more personalised interventions, especially for under-served and minoritised groups. This unique programme spans neuroscience, informatics and arts and is co-produced with young people.

Ulrike has produced 500+ peer-reviewed papers and many other publications. Her H-index (google scholar) is 108. Ulrike's research leadership has been recognised through multiple awards, most prominently an

NIHR Senior Investigator Award, an Academy for Eating Disorders Research Leadership Award and a Fellowship from the Academy of Medical Sciences. She has supervised 45+ doctoral students and multiple early-stage researchers, many of whom now work in academia or NHS leadership roles. Her dedication to her students was recognised by a King's supervisory excellence award. Ulrike has also led/contributed to national and international policy initiatives, improving training and clinical practice. She leads national training for adult ED teams, MANTRA and FREED.

We are incredibly fortunate within the field of Eating Disorders to have a mind of this calibre working so tireless to improve the lives of individuals who suffer, helping to educate and inspire peers and lead the way for future generations.

# Spotlight: Clinical



# Patient knowledge about prescribed medication for comorbidities in adolescent patients in eating disorder service.



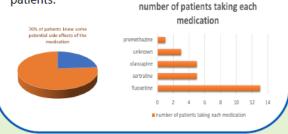
The aim of this pilot study was to inform the team about how much the young people in the eating disorders service understand about the medication they are taking. We hypothesized that they might not be well informed, and that compliance and effectiveness of medication could be improved with more knowledge. In the UK the most accessible resource is found at the website of a mental health charitable organisation YoungMinds.<sup>1</sup>

#### **Background:**

We wished to understand what young people could recall about their medication as opposed to their parents or carers. Knowledge young people have about their medication could inform practitioners whether we need to change information giving practices. Higher of satisfaction with medicines levels information are associated with higher levels of reported adherence, and lower levels of satisfaction are associated with stronger concerns about the potential adverse effects of medicines. We decided to measure what the young person knew rather than their satisfaction with the received information due to the ego-syntonic nature of eating disorders and ambivalence about treatment. Therefore we chose not to use the Satisfaction with Information about Medicines Scale (SIMS)<sup>2</sup> which is not validated for children and is a longer questionnaire.

#### Results:

21 questionnaires were completed by young people aged 12 to 17 years. 24% of respondents were not able to comment about possible side effects of the medication they were taking. All but three patients knew the name of their medication and why this was prescribed and two of the three who struggled were younger patients.



#### Methods: The content of the questionnaire: A questionnaire (six 🛓 brief questions) filled in by young people in person when attending appointments. All participants were patients within the Eating Disorders CAMHS Oxfordshire. The answers were collected over the period of January to March 2023. What young people told us about how the medication helps them: reduces intrusive thoughts I became calmer, especially when having fear foods or eating in public. I am happier. helps to feel less low it makes emotions less heightened, as well as helping me to eat. eases some anxieties and obsessive thoughts Conclusions: Most young people knew why their medication was prescribed and their knowledge about that medication was mostly correct. However, there were differences between clinician rational for prescribing and perceived symptom improvement. This could be an area of opportunity for improvement of care. Research shows that when considering medication in mental health, young people highlighted perceived lack of involvement in decision-making as being particularly detrimental to their well-being.3 Explicit reminders about target symptoms and offering medication leaflets again in follow up appointments might support young people better in understanding their medication. While researching literature and current support websites for this

pilot study we noted that there is limited information about medicines used in mental health disorders that is written for teenagers. This is something that RCPsych could lead on and link with organisations that do have this information, like YoungMinds.

rerence: https://www.youngminds.org.uk/young-person/medications last accessed October 2023 Home R, Hankins M, Jenkins R. The Satisfaction with Information about Medicines Scale (SIMS): a new measurement tool for sudt and netearch, Qual Holath Care. 2020 Sept103/133-00 Sana S. McMillan, Bethany Wilson, Helen Stapieton & Annanda J. Wheeler (2022) Young people's experiences with mental health medication: A narrowite version of the qualitative interture. Journal of Mental Health, 31-2, 281-285

Contact information: Dr Ewa Posner, Specialty Doctor, <a href="mailto:ewa.posner@oxfordhealth.nhs.uk">ewa.posner@oxfordhealth.nhs.uk</a>. Dr Caz Nahman, Consultant Child and Adolescent Psychiatrist, <a href="mailto:caz.nahman@oxfordhealth.nhs.uk">caz.nahman@oxfordhealth.nhs.uk</a>.

## The creation of a MEED Score Calculator to aid MEED

Author - S HAYWARD, Junior Clinical Fellow, Sowenna, CAMHS inpatient unit, Cornwall

#### Quality Improvement Project

#### INTRODUCTION

The Medical Emergencies in Eating Disorders (MEED) guidelines include a scoring system, the MEED Score, which is an all-age risk assessment of the physical safety and risk to life of patients with eating disorders<sup>(1)</sup>. Accurate MEED Scores are therefore fundamental for patient safety. However, MEED Scores can be timely and confusing for unfamiliar professionals.

The MEED Score Calculator is a spreadsheet consisting of a colour-coded table with each MEED Score category. Red, Amber and Green are selected based on the described parameter and totals are automatically calculated.

Additional "Background and Instructions" and "Medical Management" pages explain how to use the calculator and how to manage medical issues arising from MEED Scores. MEED Scores can be simply copy and pasted into electronic notes/referrals.

#### AIMS

1) Increase **confidence** amongst healthcare professionals completing MEED Scores

2) Increase **efficiency** of completing MEED Scores

#### METHOD

 A preliminary survey questioning MEED Score confidence and efficiency was sent to healthcare professionals who complete MEED scores (including psychiatric and paediatric doctors, GPs and Eating Disorder team members

 The MEED Score Calculator was created using Microsoft Excel

 Upon completion of the survey, the MEED Score Calculator was distributed via email

 Three months later, the 2<sup>nd</sup> survey was sent to users, focusing on calculator use and the impact on MEED Scoring efficiency and confidence

 Upon reviewing results, the MEED Calculator Version 2 was created

 The 3<sup>rd</sup> survey was sent to users again, focusing on efficiency and confidence

Results of this survey were then
analysed

#### RESULTS

 28 participants completed the preliminary survey

Only 15% of participants completed MEED scores as often as they would like

1<sup>st</sup> Cycle

11 participants completed the 2<sup>nd</sup> survey
 Only 9% prefer not using the calculator (36% haven't completed a MEED Score since having Calculator access)

- 55% of respondents report increased
- confidence completing MEED Scores

 80% of respondents report reduced time spent completing MEED Scores

2<sup>nd</sup> Cycle

6 participants completed the 3<sup>rd</sup> survey
67% of respondents now use the MEED Score

- Calculator when completing MEED Scores
- 100% reported improved confidence compared to Version 1
- 80% reported improved efficiency compared to Version 1

 100% reported increased confidence in managing medical issues raised on MEED Scores \*Surveys remain open to complete

CONCLUSIONS

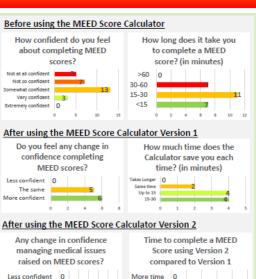
The MEED Score Calculator increases confidence and efficiency of MEED scoring amongst healthcare professionals, achieving both aims.

Furthermore, due to positive feedback from eating disorder professionals, the MEED Score Calculator was included in the Kernow Local Medical Committee newsletter to raise awareness amongst Comwall GPs. It is also due to be added to local clinical referral guidelines for GP referrals to eating disorder services.

The calculator has also been shared across the Emergency Department in the Royal Cornwall Hospital and with psychiatric doctors across Cornwall at a CPD event. Further afield, it has been shared with the CAMHS eating disorder teams in Cheshire and Wirral partnership and spoken about at a Paediatrics Mental Health conference in Oxford.

We aim to make further improvements to the Calculator based on user feedback.

We hope for knowledge of this simple tool to spread throughout relevant primary and secondary care settings, making MEED Scoring more accessible and quicker for healthcare professionals. We anticipate that with this, we will see improvement in the robustness of physical monitoring and the quality of referrals. Thus, reducing risk of adverse physical health outcomes in this vulnerable cohort.



The same

1 2 3

Less time



Partly condensed example of a completed MEED Score on the MEED Score Calculator (Version 2)

#### REFERENCES

1. Medical Emergencies in Eating Disorders: Guidance on Recognition and Management [Internet]. Royal College of Psychiatrists. 2022 May [cited 202AD Sep 1]. Report No.: CR33. Available from: https://www.repsych.ac.uk/mproving-care/campaigning-for-bettermental-health-policy/college-reports/2022-college-reports/cr233

#### CONTACT INFORMATION

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The same 0

0 1 2 3 4 5 6

More confident

Contact for more information and access to surveys and the MEED Score Calculator

## Reimagining Care; Effectiveness of Modifying an Adolescent Eating Disorder Intensive Service

Ellen Hayes, Nicola Tweedy, and Dr Victoria Chapman Specialist Child and Adolescent Eating Disorder Service, Royal Free Hospital, London

#### Introduction

- Approximately 20% to 30% of patients with anorexia nervosa will require intensive care over the course of their liness for medical or psychological stabilization (1).
   Although often necessary, the benefits of inpatient care for adolescents beyond medical stabilization is disputed, as the risk for readmission and relapse is high (2).
- Display, as up has not readmand and reapper is high (2).
  Alternative intensive treatments can often higher levels of care while allowing the young person to remain within their social, family and educational context (3).
  In studies reporting on adjoiscent esting disorder intensive services there are high variations in the approach that they take. There is variability in the amount and length of treatment that is offered and
- the expected outcomes.
- · Although literature concerning this treatment increasing, there is still no clear unified approach to adole scent intensive treatment (1).

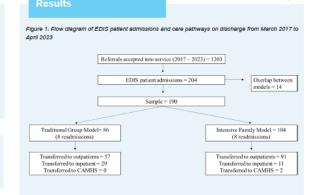
- · An evidence-based agreement on the most important elements of intensive treatment in adolescent
- esting disorders is needed to foster treatment programs which are most helpful to improve outcomes. The aim was to evaluate the effectiveness of the Royal Free Eating Disorder Intensive Service (EDIS) of a modification in treatment from a group-based programme to an intensive family treatment.

- The Eating Disorder Intensive Service (EDIS) was developed in 2013 following evidence from the
   TOUCAN trial (4), with the aim of reducing the number of admissions to Specialist Eating Disorder Units.
- FOUCAN that (4), with the slim of reducing the humber of admissions to Specialist Ealing Disorder Units. EDIS is a community based treatment that is truly integrated with the outpatient service. Patients who were not progressing with outpatient treatment or at immediate risk of hospitalization were offered a day service treatment at the same site as their outpatient care. In 2020, the Covid-19 pandemic necessitated a change to the EDIS treatment model, as it was previously ran as a traditional group model. The below table demonstrates how the service was previously run as a traditional day programme, to how it is run now as an intensive family model with a rationale for the change.

| Traditional Model  | Intensive Family Model   | Rationale   |
|--|--|---|
| Meal support sessions in a<br>group, without the family<br>present                                       | Individual family meal support,<br>on-site or online.  | Families gain confidence to<br>transfer meal support skills to<br>home                            |
| Young people in a group with<br>other patients during the day.<br>Family attends only for FT-AN<br>input | Patients attend with family for<br>meal support and key<br>sessions, and remain separate<br>from other EDIS users. | Meal support continues to be<br>family based, strengthening the<br>FT-AN approach                 |
| Young people educated on site<br>in a group by specialist<br>teachers.                                   | Young people supported by<br>team to attend school whilst<br>also attending EDIS.                                  | Remaining within school &<br>community maintains<br>connections                                   |
| Young people admitted to<br>psediatric ward if they're at risk<br>of re-feeding or need<br>NG feeding.   | Monitoring for re-feeding on-<br>site with psedistricians. NG<br>feeding by nurses within<br>EDIS.                 | Less burden on paeds wards.<br>Lengthy ward and tier 4<br>admissions more likely to be<br>avoided |

#### Description of sample

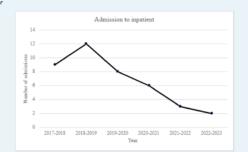
- · Retrospective chart review with patients aged between 10-18 years old who had accessed EDIS between March 2017 - April 2023. The sample was split in two groups; those in EDIS from March 2017 to March 2020 when it was run as a
- Intractional day patient freatment (N = 86), and from April 2020 to April 2023 when the service was
  modified following the Covid-19 pandemic as an intensive family-based treatment (N = 104).
   Outcomes from the traditional group model were compared to the new intensive family model, namely
  length of admission, %mBMI difference, and transfers to inpatient services.



 No significant differences were found in %mBMI of patients on admission or discharge from EDIS between the groups. The change in %mBMI from admission to discharge from EDIS between groups was also not significant.

#### Transfer to Specialist Inpatient Unit

- transfer to Specialist Inpatient Unit I in the traditional group model 29 out of 86 EDIS patients were transferred to a specialist esting disorder unit over the three years (33.72%). In the Intensive family group model 11 patients out of 104 were transferred to an inpatient service (10.58%) over the three years. A Mann Whiteny U best showed a significant difference in the number of patients that were transferred to inpatient services (U = 5392.00, p <.01).
- Figure 2. Graph demonstrating the number of transfers to Specialist Eating Disorder Units from EDIS by year



Length of admitsion • Mean length of treatment in the traditional model group was 143.19 days (SD = 100.11), and in the intensive family model group was 97.2 days (SD = 53.43). • Mann Whithey U tast indicated that there was a significant difference in the duration in EDIS between each group (U = 5559.00, p <.01)

#### Conclusions

- Transforming our adolescent intensive eating disorder service from a group-based programme to an intensive family treatment has improved patient outcomes. Changing our treatment approach significantly lowered the length of admission to the intensive service and resulted in significantly less patients being transferred to inpatient services.
- . Previous studies have raised concerns that the treatment of adolescent eating disorders in a group setting could lead to comparison, competition and social contagion (5). Group based therapy may lead to the development of unhelpful alliances and competition between young people. Clinical observations along with the preliminary findings of this paper may
- echo these previous results and may explain why the modification in our service approach significantly approved patient outcomes. An evidence-based agreement is needed on the most important elements of intensive treatment to improve the quality and standardization of care, especially as intensive services for adolescent eating disorders continue to be set up within the NHS.

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# Opinions

#### Lived Experience Perspective

Hi my names Leah, I'm 19 and my favourite colours blue. I like the feel of courdoroy, the smell of lemon and I love teddies! I also happen to have an eating disorder. I didn't want to start with that as it's taken a long time, but I have very much realized that ED is a part of me, I am not a part of him; for context I will be using ED and he/him pronouns to portray my eating disorder. Disclaimer: I will not be using any specifics that I think may be deemed triggering in this piece, please seek professional help if you or someone you know may be struggling with an eating disorder.

I'm going to start from 2020 when lockdown began and ED crept in.

I don't remember much from this time just that I would never go back to that period; I used to be a competitive swimmer, I'd never struggled with body image or any kind of food related issues up to this point, however I was a pescatarian as I hadn't liked meat since I was young. I went into a great panic even we went into an indefinite lockdown; this was much expected as at the time I had undiagnosed autism and have struggles with OCD from a young age. Of course none of us could train in the pool so we did online land sessions twice a week; on top of this I began to work out daily and go on long walks to maintain fitness. It got to the point extremely quickly where I would get up at 5am, do all my school work (as I was preparing for my GCSE's the next year) and have done 3 work outs by 12pm. I became vegan started only eating wholemeal carbs, and eating lunch by 2pm- yes Lunch at 2pm!! I was known to CAMHS and had been in therapy from a very young age within 3 months of the noticeable onset of ED children's eating disorder services or CEDS, yes this confuses me too as adult eating disorder services is also CEDS- the 'C' being community) diagnosed me with anorexia nervosa.

I'm going to skip forward to 2022 now as yes those 2 years imbertween were no doubt important it wasn't anything I feel could help others; it was a constant battle with trying to recover and failing and battling with myself and my parents and it stayed this way pretty much constantly until the summer of 2022.

This was when things got extremely difficult for me and I couldn't cope with the thoughts of ED any longer. I absconded January of 2022 and shortly after had my second admission to a children's psychiatric facility. This specific unit wasn't for eating disorders however had good resources to help and many patients there did suffer with disordered eating. They helped my to become more flexible with foods and how to portion food without measuring which was the first time I'd done this in years. They transitioned my slowly from having meal support 1:1 to having

meals and snacks independently, then my parents supporting me when I went home on the weekends later on in the 3 month admission. I was introduced to yoga and light exercise to help me get stronger not smaller. All in all I was the best I'd been in the time I'd lived with ED. I met my boyfriend of a year and a half there and this pushed me to keep going and I had even more support not only from my family but from his family. During this admission I also got diagnosed with autism, FINALLY; after my 3rd assessment which was something that's had a really positive impact on my life as it's given me better understanding of myself and allowed me more resources in the community.

If all of this sounds too good to be true... it was. In the September of that year I turned 18 which wasn't long after being discharged from hospital. As I said I suffer with other mental health and was referred to AMS- adult community mental health services. My team was lovely but with no psychologist and this was the first time I hadn't had therapy in probably about 9 years. I was also referred to CEDS that's October and rejected as, at the time, I wasn't physically unwell. Me and my mum have had many conversations since this time and both agree that therapeutic eating disorder input may have maintained not only my physical health, but all the mental progress too. After being declined by this service I tried my best but was extremely oblivious to the deterioration of my health over the next several months. Was now an adult with no ED support. I was distracted by the business of life, I'd started a support work job for adults with additional needs. Therefore I was out of the house a lot, it was nice being free and going out more but I didn't know at this point how well I was becoming. By June with my second referral and acceptance into CEDS I was almost immediately sent the A&E. I was in the local general hospital for 6 weeks which was a strange period as I didn't know how all of this had happened. It was a time of reflection but great confusion; I was then accepted into an adult ED inpatient unit. It was very different from the adolescent wards I've been on, very regimented but this suited me well as I have autism. It not only got me out of the danger zone Physically but really helped me to have a more positive mindset to life. It helped us come together more as a family and brought me, my family and my boyfriend's family much closer too. I met some of the most remarkable and inspiring people I know on that ward, they made my stay a lot more bearable. As well as an amazing team of staff who I couldn't have got through it without.

This brings us to now. I'd like to end here, like a story book where the girl is free of ED and takes a bite into a delicious slice of chocolate cake laughing with her friends...but that's not real life and that would not be true to me. I still have my struggles, it's very early days and I'm all honestly writing this makes me feel a bit vulnerable, but in a positive way. It helps me to reflect and think about what things I've learned from my experiences and what I want to take forward with me; also what I think may benefit others in their journey.

So now that you know a bit about me I'd like to share some things that I think could help you. •weight does not determine how unwell you are. You cannot see an eating disorder. This affected me a lot at the beginning as I thought I wasn't "sick enough" (which is not a thing), not to say EDs don't detriment your health but you can die from an eating disorder at any weight, and will if you don't seek help. Yes it may be tempting to get so unwell that people start intervening. But even if it's not a professional, please seek help from a trusted adult.

#### start recovery now!

It was daunting to me that the average recovery time for an eating disorder is 7 years and left me feeling a bit hopeless. But if you don't start recovery now you will live with ED for longer and those 7 years (though it is different for everyone) will become further away! It's never too early to start getting better and letting go of ED.

#### -nobody who has fully recovered from an eating disorder regrets it.

People used to say this to me, and to be honest I thought they were chatting absolute nonsense! Because I wasn't better then. And I'm not saying that means you will love your body and never have any dislikes or other struggles, but there won't be limits (other than allergies) and I can guarantee you won't regret it.

#### even you're recovered you will still have other stresses.

I'm in no way fully recovered but, as weird as it sounds, I'm lucky enough to get to worry about other things in life now. Random arguments with my sister about who get to sit in the front seat of the car, finances, and the nitty gritty bits of life which seem to dissolve when I was deep in my eating disorder. Because even without ED people have worries, and that's okay!

#### recovery does not happen over night.

There are some days that I wake up and wish I could just be better, but even in these thoughts you have to keep going. Because what's the alternative? Stay stuck? Making steps in the right direction puts you on that path and even though it may feel tedious you have the little wins along the way and happy moments. Recovery is not linear it will challenge you in more ways than you can possibly imagine, but the life you get after will be so incredibly worth it. There may not be a lightbulb moment and you won't just wake up and don't have an ED, but the voice will slowly but surely quieten . So please make those steps in your own way; at your own pace and don't be too disheartened by setbacks. Allow people in to help you. Recovery is long, yes…but the life after is even more beautiful with recovery.

#### Iastly, (and not everybody agrees) I believe everybody can overcome an eating disorder.

Nobody's life pre and post ED is the same, it's all individual. It doesn't matter how long you have struggled, you deserve your best life. However recovery has to come from you; you need to grasp onto any small incrim of motivation and hope, no matter what it is and use it to help you. You have to want to get better. At first, you may even be doing it for a loved one or a friend, anything that helps you in tough moments....Remember, you are valid and you can do this! Thank you for reading if you have managed to get through this piece I've written. I hope you have found it helpful and can take even one thing from this. Please believe in yourself because I believe in you.

#### Lived Experience Perspective: Listening to lived experience

In recent months, there have been an increasing number of conversations across many platforms around difficult subjects relating to ways we understand and respond to those with severe and/or longstanding eating disorders. On the one hand, emotive stories have been shared on social media and with the press in relation to patients' poor experience of care, or the withdrawal of care, which is often inaccessible and insufficiently resourced in the first place. On the other hand, we have seen academic papers attempting to define a cohort of patients with a new brand of psychiatric terminal illness (Guadiani et al., 2022), attempts to dismantle such constructs from patients, clinicians and academics, including myself in the Lancet Psychiatry and elsewhere (Downs et al., 2023; Downs, 2023).

In this short article, I don't want to restate the arguments I have made elsewhere about the flaws in defining patients as having "terminal" or "enduring" illnesses. Instead, I want to emphasise the importance of listening to each others perspectives with a degree of courage, compassion and confidence that I am concerned is not always present in sufficient quantity to allow us to work together on the creation of knowledge, policy and care - rather than pulling apart. It is only in coming together on the basis of shared vision and values that we will minimise harm and maximise the opportunities to transform the field of eating disorders for the better.

The bringing to light of tensions around how best to care for those experiencing longstanding and severe illness is surely a good thing, as to have conversations behind closed doors, without the inclusion of representation from patients and carers, would be to fall short of the values we share as members or workers within the College. It is surely better to be prepared to talk openly about clinical challenges and seek to address shared difficulties than to grapple with them without dialogue or collaboration. A tendency I have witnessed, however, in the discussion of such difficult subjects, is the generation and perpetuation of opposing "sides" that can often forget that we all share the same goals - to help patients, and to treat them in effective ways that lead to recovery. Worse still, people can feel shut down, silenced, attacked, or in some other way fearful of those who may disagree with them, which does little to lead to an enhanced understanding based on a synthesis rather than divergence of ideas.

In my own experience of this discourse, I have shared some of my own experiences of care which have been less than optimal, and been met by eating disorders professionals telling me that this is unhelpful. I can understand their perspective - that it may be demoralising to hear negative experiences, for both patients and those working in the field. As previously intimated, my own perspective is that these difficulties are better brought into the light, as that is where they can be grappled with, and worked to be changed. If such failures in care are happening anyway, they are neither made unreal or improved by ignoring them. I have the general view that if patients have trusting relationships and experience their care as good, then this will not be undermined by hearing the experiences of others that are less positive. At least, this has been my own experience when engaged in effective care. I have felt sorry for those whose stories I have heard that fall short of the care I have been lucky to receive.

"Shooting the messenger" who conveys their negative experiences, and only privileging positive feedback, risks missing valuable opportunities to improve services. It could also render a degree of "invalidity" on those who've had poor care, which can mirror other, harmful experiences and relationships in their lives. I

have been very concerned recently to have learnt that I have been described as "spreading misinformation" about services that causes harm to patients, when my only intention is to speak from my own experience only, in order to identify gaps in care that can be resolved for the benefit of others. This can only happen if we are open about these problems in the first place.

These interactions also highlight the complexities and advanced levels of reflexivity required when working in lived experience roles - something I am not always sure is as widely appreciated as it could be. On a personal level, it is frustrating to be seen through a very limited lens, especially when the identity of patient is constraining in the first place. Even within this, it has been difficult when my comments perceived as "negative" have overshadowed the many hours of work sharing positive examples of best practice and creating new knowledge about eating disorders and their treatment through constructive, collaborative research.

I share these thoughts not out of a sense of personal victimhood or a need for sympathy, neither of which I require, but for those working in arenas where patients share their experiences and feedback to have a greater understanding of the value and role of expertise gained by personal experience. Whilst one can only speak for one's own subjective experiences, there are common care pathways and features of services that many patients share. We have the best opportunity to learn from patients when we are willing to - and welcoming of - them sharing *any* of their experiences that *they* feel may be useful for others to learn from. In my own work facilitating other patients to share their experiences, I believe that it is the patients themselves who are the best judge of what is useful to be shared, and heard. The job of those being *shared with* is to listen, with curiosity and courage, and to leave room for all experiences to be appreciated as valid - the good, bad, and - frankly - the ugly. In doing so, there is so much that can be learnt.

The phenomenology of eating disorders as experienced by individuals in their uniquely situated positions in the world - including experiences of treatment settings - can shed light on problems that can only be solved if we bring them into the light, without fear, and with compassion for all involved. After all, we are in this together, and we need to constantly seek to come together when discussing complexities around how to provide care for those with longstanding and severe eating disorders - not to pull apart, or pull each other apart. This is essential for the benefit not only of patients and their carers, but for the professions that seek to help them.

#### **James Downs**

#### **References on request**

# Projects

#### Update from Dr Benjamin Geers

I am really grateful to have received one of the annual research bursaries from the Faculty of Eating Disorders. Our project's broad aims are to assess patterns of help seeking in children and young people with possible eating problems, and to investigate the link between disordered eating and medical diagnosis of eating disorders. We have completed our initial analysis of the Mental Health of Children and Young People 2017 (MHCY 2017) data, and I have recently submitted this for presentation at the RCPsych International Congress, which this bursary will help support me to attend. I am also submitting this project for presentation at the Faculty of Eating Disorders Spring Meeting. We are currently writing up the full manuscript of our analysis for publication. Additionally, we are also planning Patient and Participant Involvement work, which the bursary will help fund, before undertaking analysis of the Avon Longitudinal Study of Parents and Children (ALSPAC) dataset. I would once again like to extend my thanks to the faculty for their support and for this incredible opportunity.

## Scottish Personality Disorder- Eating Disorder Pathway Update

As inpatient consultant on the North East Scotland Regional Eating Disorders Unit in Aberdeen, I have seen a rise over the past few years in patients being admitted with comorbid Eating Disorders and Personality Disorder. I have noted the apparent increase in the complexity of these patients; the high levels of patient distress caused by admissions; and the fact that, in my experience, specialist staff on the Eating Disorders Unit often do not feel sufficiently upskilled to look after patients with Personality Disorder. As a result, I began to have conversations locally about developing a pathway, to identify the aspects of care that were both helpful and unhelpful in this patient group. I soon found that these conversations had been replicated both regionally, and nationally, and, together with colleagues, we began to think about pathway development on a wider scale. Our first meeting was in April 2022, and focussed on Borderline Personality Disorder. This soon broadened out to the full range of personality disorders, and comorbid eating disorders.

Over the passing months, we have met regularly, taking time to establish the scope of the groups and the desired outcomes. We have tried to ensure a comprehensive coverage of clinicians from across Scotland, and from across disciplines, as well as representing the full age range. We have taken into account diversity of patients and have approached patient and carer representatives, as well as clinicians from General Practice and Medicine.

We decided that our desired outcome would be a pathway document. Given the limited evidence base, this would initially identify current practice across Scotland, and examine the available literature. We would hope to suggest what good practice would look like, and how this could be delivered in a Scottish context. The

hope would be that this would provide a baseline for future service development and be useful in planning and securing funding for this.

Early on in the process, we met for an afternoon workshop, where teams brought case vignettes. This allowed us to think about the commonalities and differences in patients that are being seen, but also in how the services respond. It was reassuring to experience far greater commonality than difference, and to learn from alternative perspectives.

This workshop will help us write anonymised case vignettes to be used in the document, to ensure that this is a "live" clinically relevant document, rather than simply prescriptive theory.

We have now divided into three work streams look at different aspects of the comorbid disorders. We are meeting regularly to discuss, write and edit. Speaking personally, there is huge benefit in these meetings on their own, as the shared experience and learning is significant.

We have links with the Scottish National Personality Disorder Improvement Plan, and aim to be represented in that.

We have also linked in with Dr Tony Winston, who is involved in similar work in England, and has been very helpful. It is also useful to have my involvement on the Faculty Executive Committee, so that we can link in with UK wide guidance and best practice, as well as national patient and carer representatives.

We have committed a significant amount of time to this project to date, and I feel that this is a worthwhile investment, from a clinician, patient and carer perspective.

Any queries and comments appreciated.

## Louise Johnston

## **ESSAY WINNERS**

In this era of highly increasing numbers of patients with eating disorders, what new ideas and innovations would you like to bring to the field of Eating Disorders which can help our patients and their carers?

#### From Dr Florence Tilling: Essay Prize Winner 2023

#### Introduction

700,000 people in the UK are estimated to suffer from eating disorders (EDs), with subthreshold and unreported EDs likely to further raise this statistic. 90% of those affected are women.<sup>1</sup> Young adults and adolescents have the highest risk of onset.<sup>2,3</sup> All EDs, including subthreshold and atypical, have medical complications affecting every organ system.<sup>4</sup> Of these, anorexia nervosa affects between 2-4% of women and has the highest mortality rate of all psychiatric conditions; up to 5% higher than that of the general population.<sup>1,2,3,5</sup> The best prognosis in anorexia nervosa is for young people with a short duration of illness; up to 60% of adolescents with early specialist intervention reach full recovery.<sup>5,6</sup> Furthermore, age at assessment has been shown to be a significant predictor of mortality.7 This highlights the importance of early intervention, diagnosis and management of EDs in young people.<sup>4,6,7</sup>

A major factor preventing patients from presenting early is difficulty disclosing problems due to stigma and embarrassment around EDs,<sup>8,9</sup> with many never seeking professional help.<sup>10</sup> This is particularly true in children and adolescents for whom the first step might be a discussion with their parents or carers, which many find difficult, and depending on carers' attitudes, can reduce likelihood of seeking help.<sup>9</sup> This is usually followed by seeing a GP and a referral process before seeing a psychiatrist and finally beginning a treatment journey. Each of these steps includes being asked personal questions and discussing sensitive topics with another person, often strangers, which can increase psychological distress. Many young people will avoid discussing psychological concerns with their GP as they are dubious of the utility of doing so and fear embarrassment.<sup>11,12,13</sup> Furthermore, the delay between booking an initial GP appointment and beginning a treatment plan could be as long as 6 months,<sup>14</sup> likely increasing mortality.<sup>7</sup> It would therefore be beneficial to harness technology to expedite the way patients access specialist assessment and care. In the era of mobile phones, when adolescents use their phones for a vast proportion of communication with peers and services, young people are likely to feel empowered to discuss personal issues over text.<sup>15,16</sup> It may be that a platform such as a mobile phone application, or app, which could connect young people via text or video chat to a mental health professional without any complicated, anxiety inducing steps or face-to-face interactions, would encourage them to engage and seek help for EDs.

This would also benefit parents and carers who have concerns about a young person, for whom the first hurdle is persuading them to see a medical professional. Presenting the young person with a phone chat or video call may ease this struggle. A substantial number of appointments are not attended by patients despite carers' attempts. This wastes valuable NHS time and resources, with estimates of up to 650,000 monthly appointment slots resulting in 'did not attend' appointments across the NHS.17 This is for a variety of reasons including transportation difficulties and cost of getting to appointments, forgotten appointments and difficulty arranging time off work to attend; all of these would be reduced by utilising remote consultations. Furthermore, for carers, for whom supporting a young person with an EDs is often stressful, isolating and traumatic, 18,19 a multimedia app would allow them quick access to advice and guidance on recognising dangerous behaviours, how they can help, and when to seek urgent care.

#### **Technology and Eating Disorders**

Introducing new technologies into the field of EDs is a controversial topic. This is largely due to the correlation between increased social media use and the increase in ED diagnoses in young people.<sup>20,21</sup> Though this is difficult to prove beyond a statistically significant correlation, it is understandable that researchers are attempting to find causes for the 90% rise in hospital admissions for EDs in the past five year period.<sup>22</sup> And there is no doubt that there are online communities which are having a detrimental effect on ED sufferers and susceptible young people,<sup>23</sup> with TikTok being the most recent to face criticism in the media.<sup>24</sup> However, mobile phone usage is not declining. Reported average time on mobile phones for 16 year olds in 2021 was 3.8 hours a day.<sup>25</sup> and the age of first acquiring a phone is decreasing, with a recent report finding that the majority of seven-year-olds now own a phone.<sup>26</sup> Therefore, attempting to remove or limit phone usage to decrease exposure to negative messaging and dangerous trends would likely be unsuccessful. Instead, using the same medium to spread a combative positive message, psychoeducation and to provide evidence-based help may be more effective.

#### **Eating Disorder Apps**

Apps to help with mental health are no longer a new idea but an exploding market. Worldwide it is estimated that there are between 10,000 and 150,000 mental health apps available today.<sub>27,28</sub> These range between apps providing meditation tips, mood-tracking and apps designed to connect people with registered therapists.<sub>2728,29</sub> With so many available and with so little regulation or evidence available about such apps,<sup>30</sup> it is understandable that many clinicians are wary of their usage. It is difficult to know if the information provided is correct and there are reports of apps containing erroneous crisis numbers.<sub>31,32</sub> The non-profit, OneGuidePsyberguide, has been set up to help navigate this complex field based on; credibility, user experience and transparency.<sub>33</sub> This has been found to be useful for primary care providers<sub>34</sub> and may improve confidence in these apps. However, there are still many drawbacks to online apps and cyber-security remains a concern. A study of the top twenty mental health apps highlighted 145 vulnerabilities which could allow malicious access to sensitive information.<sub>35</sub>

There are pre-existing apps designed for those with EDs. A 2021 study showed that of the 28 available, four apps have 96% of the monthly active users.<sup>36</sup> All of these apps were found to include elements of evidence-based treatments; this is a great improvement on the 2015 study into apps for EDs which concluded that none available at that time used evidence-based principles.<sup>37</sup> The four ED apps (in descending order of monthly active users) were found to be; "Mental Health Tests", "RR Eating Disorder Management", "Rise Up: Eating Disorder Help" and "Psychiatry Pro-Diagnosis, Info, Treatment, CBT & DBT".<sup>36</sup> Of the four apps, two focus on diagnostic questionnaires and psychoeducation, and two which have primary features of symptom and meal tracking. The app with the most evidence-based elements was Psychiatry Pro, however, the researchers commented that many of these elements are accessible in long pdf. documents which are not particularly user-friendly.

The most comprehensive app was RR Eating Disorder Management. The most prominent feature is a log for tracking; meals and snacks, feelings, a photo option, and a thought diary. It also has options to 'check-in' with many further parameters including binge or purging behaviours, food exposures and triggers. These are analysed into insights and comparisons between inputs in the form of charts. There are a range of goals and challenges to input or choose from, with reminders and rewards when these are completed. The weekly skills and goals offer psychoeducation and CBT-based tips and there is a meditation section with guided meditations and breathing exercises with visual imagery. Furthermore, there is a community section including an activity feed, community coping skills and an option to 'pair up' with other RR users to share progress, encouragement and virtual gifts. Importantly, the app also allows for connection with a clinician and a paired clinician app for viewing patient progress and for sending messages and documents between patient and clinician.<sup>38</sup>

This app is rated 4.8 stars on GooglePlay with 8,420 reviews, however, according to Psyberguide it has a 'user experience' rating of 2.8/5. It appears that though many have a positive experience of the app, others find the reminders and ability for clinicians to see and comment on the log obstructive to recovery.<sup>39</sup> Clinicians display a similar inconsistency, with some finding the access to patient data useful as sessions can be planned in advance, whilst others found that the use of the app allowed patients to become more passive while they

themselves felt an expectation to check patient logs regularly and comment on them.<sup>40</sup> Furthermore, Psyberguide gives the app a transparency rating of 'unacceptable' due to a privacy policy which does not state that the app/server encrypts/de-identifies the data nor disclose whether user information is stored locally.<sup>33</sup>

## Method - an NHS eating disorder service app

This review of existing apps gives a backdrop for development of a comprehensive NHS ED app. It is clear that the technology and demand for an initiative such as this is present. Outlined in Table 1 are the proposed features of this app and the NICE guideline they relate to.

|   | Proposed Application Features   | Does this exist in<br>currently existing<br>applications? | NICE<br>Guideline |
|---|---|---|-------------------|
| 1 | A comprehensive screening<br>questionnaire on signing up for the<br>app, including mood, thoughts,<br>behaviours and co-morbidities,<br>allowing for those in crisis to be<br>identified and triaged to appropriate<br>specialist care for assessment<br>immediately, this would be flagged to<br>redo at recommended intervals to<br>monitor progress. Those who are not | No  | NG69 1.2.6        |

|   | identified to be at high risk would still<br>be able to use the features of the app<br>but will not be recommended to<br>request an appointment with a<br>healthcare professional.   |     |  |
|---|--|-----|--|
| 2 | Information available regarding local<br>teams, crisis numbers and support<br>groups. If appropriate this would also<br>include the patient's named<br>psychiatrist and date of next<br>appointment as well as other<br>members of the team such as<br>dieticians and psychologists and<br>options to request appointments,<br>video chats and direct messenger<br>appointments. | No  | NG69 1.5.10  |
| 3 | Psychoeducation delivered in a<br>digestible and engaging manner   | Yes |  |
| 4 | Self-tracking features in a wide range<br>of parameters which can optionally<br>be shared with healthcare<br>professionals, with the understanding<br>that they are unlikely to comment or<br>direct message about these outside<br>of sessions/appointments unless<br>otherwise arranged with that clinician  | Yes | NG69 1.5.2   |
| 5 | A CBT based set of skills and goals<br>with in-app rewards. Potential for<br>further developments such as<br>meditation.   | Yes | NG69 1.3.5<br>and 1.3.16<br>NG69 1.5.5<br>and 1.5.10 |
| 6 | A community section in which users<br>could connect with other users to<br>share motivation, encouragement<br>and support. This would be done  | Yes |  |

|  | anonymously with moderation to<br>remove and prevent a competitive<br>environment or potentially<br>detrimental material.  |    |  |
|--|--|----|--|
| 7                                      | A secondary or partner app for<br>parents and carers which allows for<br>connection with their caree's app.<br>Appointment times and reminders<br>would display on both apps and there<br>would be an option for the patient to<br>share their logs with their carer who<br>could in turn comment or 'like'<br>activity. The carer app would also<br>include psychoeducation and<br>important information on eating<br>disorders and local teams and crisis<br>numbers. Furthermore, carers could<br>connect to other carers for support,<br>advice and encouragement. There<br>would also be scope for family<br>therapy to be delivered remotely via<br>video calls. | No | NG69 1.3.12<br>NG69 1.3.16<br>NG69 1.5.6 |
| Table 1- Proposed application features |  |    |  |

Furthermore, it allows for a secure privacy policy in line with NHS sensitive information

governance; this removes the risk posed to young people when using mental health apps.<sub>33,35</sub> It would also save the NHS time and money by reducing the number of missed appointments as, when suitable, appointments could be over call or video chat and when in-person appointments are required these would be displayed on the app with reminders prior to the appointment for both patient and carer. Many practitioners may find the app to be useful as it allows them to check-in with high-risk patients between appointments, and monitor their logs if they have been shared. It would also level out some of the inequality in accessibility of mental health services in different areas<sub>42</sub> as waiting lists could be shared between areas to even out waiting times.

Conversely, in an already stretched NHS, the creation of a new service and the resources required to create an app could be perceived as a waste of funds. In addition, though models of apps connecting clients to therapists have been shown to be effective in preliminary research,<sup>43</sup> it is not proposed to replace in-person appointments, which are recommended for accurate assessment of those with EDs.<sup>44</sup> Clinicians may have some reservations; all current available apps are in the private sector, therefore connecting patients to professionals who may have a smaller client pool, thus, more time available to review patient progress online and engage in more frequent remote consultations at patient request than would ever be possible within the limitations of the NHS workforce. Another concern is that the suggestion of working from home and a new online service may raise problems with confidentiality as patients and healthcare professionals would need to ensure they are in a secure location and cannot be overheard when they engage in virtual appointments or telephone consultations.

On balance, it is evident that a new technology of mental health apps, including apps for those with EDs, is an expanding market. These apps appear desirable to those seeking help and are likely to be used whether endorsed by the NHS or not. In line with patient-centred care, it would be pragmatic to accept that such apps are likely to be used, and that there is an argument for creating one in which evidence-based methods, correct information and adequate privacy policies can be ensured. In an ideal system with abundant resources, such an innovation would elevate the quality of care and allow increased connectivity between patients, carers and health-care professionals. However, a comprehensive app with all features displayed in Table 1 may not be realistic within the NHS at present and clinicians may oppose some suggested features. However, a simplified version could be created then developed and updated over a longer period. This would not only allow for a smaller initial budget, but for improvements to be made in line with user feedback. A starting point for such an app would be a portal for patients and carers to access information about EDs, local teams, upcoming appointments and documents. In a digital age, it is time for mental healthcare to embrace the technologies we take for granted in every other aspect of life.

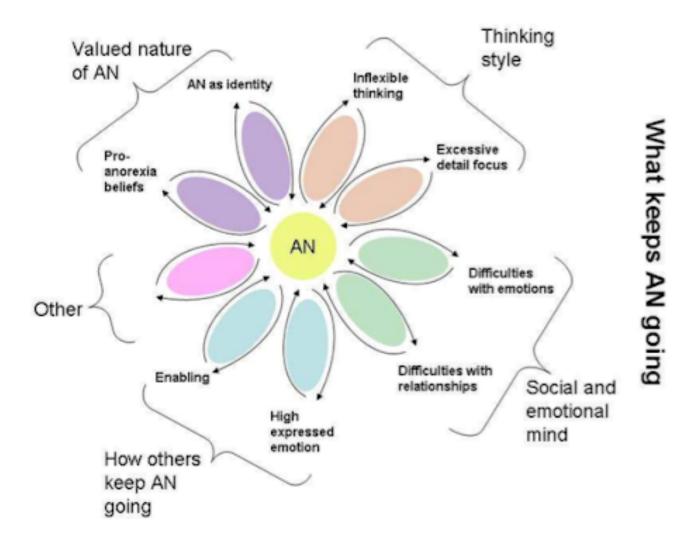
#### **References on request**

#### From Dr Syed Ahmad: Essay Prize Runner-up 2023

#### Introduction

In an era characterised by the relentless pursuit of an idealised body image, the prevalence of eating disorders has emerged as a critical public health concern in the United Kingdom. These multifaceted and often-debilitating conditions are thought to affect up to 1.25 million people in the UK1, with mortality rates twice as high that the general population, and with low recovery rates for illnesses like Anorexia Nervosa (AN) and Bulimia Nervosa (BN) of which 54% and ~50% respectively will never fully recover2. Moreover, recent research shows that eating disorders have been significantly exacerbated by the onset of COVID-193, thought to be caused by diminished access to healthy coping mechanisms, and diminished treatment access. However, the dynamic field of eating disorders has many new research programmes that are being established and this essay is intended to outline how pharmacologically assisted psychotherapeutic uses of psychedelics could serve as a groundbreaking innovation in patient and carer outcomes.

The most common conditions under the umbrella of eating disorders are BN, AN and Binge-Eating Disorder (BED). These conditions are distinct, but have a few shared characteristics such as a predilection towards rigid thinking4, emotional dysregulation5 & negative affectivity6, identity dysfunction7 and a sense of detachment4. Taking the condition of AN as an example, the 'Vicious flower' model of AN8 (Fig.1) lists some of the maintaining factors behind AN as being AN identity formation, inflexible thinking and difficulty with emotion. Different eating disorders have also been shown to be connected to other psycho-social issues, with AN linked with OCD and social issues, and BN linked with ADHD.



## Fig.1

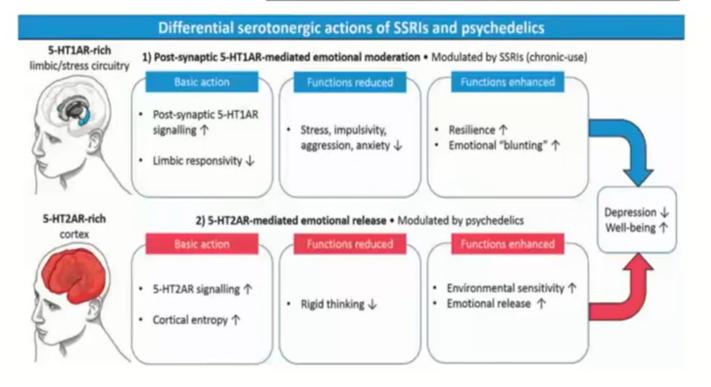
#### **Psychedelics**

Psychedelics such as psilocybin and lysergic acid diethylamide, are commonly used recreational drugs in the UK that are known to have profound effects on cognition, perception and emotions. Spiritual and meaningful experiences are often reported when taking these drugs, and they have been perennially used as medications with cross-cultural origins. These drugs, however, following unethical and covert usage in the 1960s became banned substances in the 1967 UN Convention on Drugs, leading to a long-term drought of research and academic interest, hardened by socio-political attitudes by Western powers about the "war on drugs". Despite this, psychedelics, in the modern day, present an interesting transdiagnostic therapeutic avenue, especially for the treatment of eating disorders, potentially linked to many of the aforementioned shared traits of those disorders. Brain imaging studies of individuals with AN observed 5-HT alterations, and specifically lower 5-HT2A binding in parts of the frontal, parietal and occipital cortices9. In psychedelic drugs, the 5-HT2A receptor signalling that occurs is thought to be the cause of lowered rigid thinking, and greater emotional release, inducing a

positive mood and combatting detachment and emotional dysregulation, as well as increasing neuroplasticity (Fig.2). This serves in contrast to SSRIs, for example, which primarily use 5-HT1A receptor signalling to decrease anxiety, but also increase emotional blunting, potentially maintaining the emotional withdrawal and sense of detachment experienced by patients. Although these both induce positive mood and wellbeing, comparing the side effect profiles, the length of treatment and the emotional blunting of SSRIs with the emotional release of psychedelics, the psychedelic drugs present a safer, and possibly more effective alternative. This is especially the case in the treatment of BN, where SSRIs are occasionally used. Furthermore psychedelic drugs have been known to cause a phenomenon named "ego-dissolution" whereby the distinction between self-representation and object representation is blurred, which is known to have profound effects on identity formation, key in the maintenance of AN. Patients with AN frequently report that their self-image is intimately intertwined with the diagnosis/state of anorexia, and their anorexic identity gives them meaning and purpose. Psychedelics may exert the pivotal force in shifting to a broader, depersonalised viewpoint from this intricately interwoven identity, which could potentially lead to the disruption of this cognitive association. In the burgeoning psychedelic literature, this phenomenon is named "REBUS", meaning relaxed beliefs under psychedelics

### The therapeutic potential of psychedelic drugs

RL Carhart-Hamis and GM Goodwin



#### Fig.2

Psychedelics could also have an impact on carers, who routinely report emotional

distance & intimacy as being among the toughest issues to manage. One carer said, "We used to have a really close relationship and now all of a sudden I can't have that relationship with her, and that really hurts. I find that very sad."

Psychedelics have the potential to remediate this element of the carer's relationship with their ward, through heightened emotional release which has been shown to facilitate extraversion, social openness and the fostering of social bonds. Furthermore, psychedelics could facilitate family-based therapy modalities by increasing cognitive flexibility in patients and thereby making the patient more suggestable, amenable to advice and positive encouragement.

### **Previous Clinical Research on Psychedelics**

Preliminary data on the abuse potential of self-administration of psychedelic drugs show that the abuse liability is negligible 11, and therefore could present a safe alternative to current offerings, such as the high dose SSRIs occasionally used in BN management. With respect to other mental health conditions, MDMA has already shown promising results in the treatment of PTSD, with 2 doses of MDMA and psychological support found to have lasting benefits 6 months after treatment. Psilocybin has been shown in a 2021 study to be at least as effective as escitalopram in treating major depressive disorder 12 (MDD). In the two-arm double-blind placebo controlled trial one group was given a typical dose of 6 weeks daily escitalopram, and the other was given just two doses of psilocybin, with the side effect profile being significantly better in psilocybin. In an analysis of a previous 2016 study published in the Lancet, psilocybin was found to be the most efficacious single dose treatment ever 13, which in an era of chronic antidepressant prescriptions, offers a much needed alternative. The growing evidence for transdiagnostic efficiency with conditions such as depression, anxiety, PTSD and addiction, shows promise for psychedelics' extensibility into the domain of eating disorder, especially BN and AN given their proven link with depression 14. Although the specific evidence for eating disorders and psychedelics is in its infancy, the results of a recent pilot study have been published, showing 25 mg psilocybin and psychotherapy in patients with AN leading to a significant reduction in the Eating Disorder Examination (EDE) scale from 3.5 to 0.8 after 84 days, as well as global reductions in anxiety and depression up to 84 days after 15, supported by another study showing reduction in depressive symptoms, and increases in wellbeing after 2 weeks (Fig.3). Three more clinical trials on the effects of psilocybin on anorexia and binge eating disorder are ongoing, with one being completed recently.

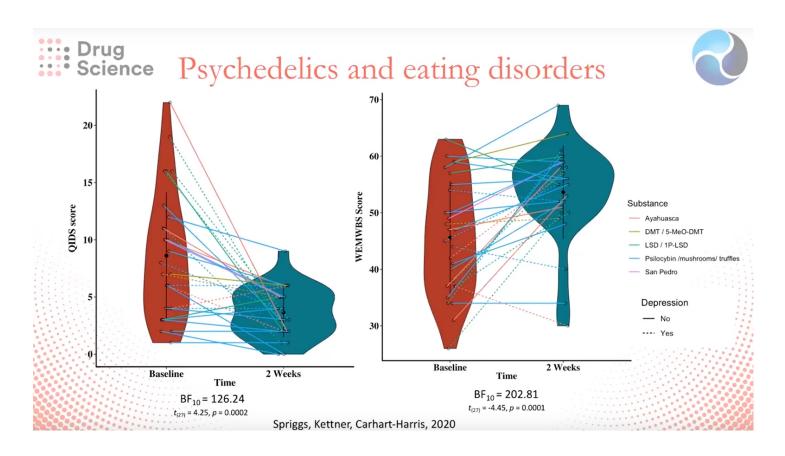


Fig.3

### Logistical Factors for Widespread Uptake of Psychedelics

Practically, there are many positive factors which underscore the amenability of psychedelics to being a new paradigm-shifting innovation in the field of eating disorders. The psychedelic research cited thus far have been most published in one of two leading research centres; John Hopkins, in the USA, and Imperial College London in the UK, with both currently undertaking clinical trials on eating disorders and psychedelics. Furthermore psychedelics are becoming a hot-bed of venture investment with the reputable companies Usona and COMPASS pathways providing funding for the ongoing research. This shows that there is a level of academic and industrial interest in therapeutic pathways for psychedelics, and that funding opportunities are available, which will facilitate new projects getting off the ground. Psychedelic assisted therapy is the name under which most psychedelic treatments are being explored, Roseman et al. comments on this that, "psychedelic therapy may be more appropriately thought of as a distinct form of (drug-assisted) psychotherapy than as a pure pharmacotherapy," in this way, psychedelics can be seen as a bridge between pharmaco-therapeutic and psychotherapeutic treatment modalities, and foster bridge building between the two disciplines, encouraging greater future integration.

As well as this it's important to note that in contrast to the medications like antidepressants, sedatives and anti-psychotics that are used as pharmacological treatment for eating disorders, psychedelics have a ancient, cross-cultural, history of widespread use in many societies, and as such natural variants of psychedelics, should pose significantly less long-term health risks. Psychedelics have been an enduring feature of human existence across a plentitude of cultures and continents ; Siberians in Asia, Ancient Romans in Europe, the Amazonians in the Americas, as well as the Bwiti people from Gabon, Africa, to name a few11. This is the inverse of the synthetically produced pharmaceuticals produced in modern times, which have not been steeped in the same history or cultural webs of meaning. It is also worth mentioning that there is invariably a stigma attached to psychedelic use stemming from the reputation of the drug's use amongst certain subcultures in the 1950s and 60s. This would need to be tackled through the government transforming their educational stance on psychedelic use, and the dissemination of teaching materials to professionals in the field of mental health. Marketing psychedelic drugs through other names such as psycho-active drugs or serotonergic hallucinogens could also be useful in uncoupling the negative connotations from these drugs.

#### Legal Obstacles

Caveating the immense success psychedelic drugs have found in preliminary research, they are still a Schedule 1 banned substance under the 2001 Misuse of Drugs Regulations in the UK, and as such, are notoriously difficult and expensive to acquire for clinical trials. In this aspect the UK is lagging behind other pioneers of psychedelic therapy; the US, Canada and Australia all allow pathways for psychedelics to be therapeutically prescribed, with psychedelics being on the equivalent of Schedule 2 in Australia. However, the pharmaceutical licencing body in the UK, Medicines and Healthcare products Regulatory Agency (MHRA) has sanctioned several phase II clinical trials in the last year on psychedelics and mental health disorders, and the Advisory Council on the Misuse of Drugs (ACMD) has recommended, following a letter co-signed by the Royal College of Psychiatrists themselves, to extend Schedule 2 status for research purposes to all Schedule 1 drugs 16. With all this in mind, the legal viability for and the accessibility of widespread clinical trials to further test and establish the safety, efficacy and trans-diagnostic therapeutic potential of drugs seem to be on the horizon.

#### Conclusion

With the increasingly widespread prevalence of eating disorders, the prospect of psychedelic-assisted therapy represents a potentially ground-breaking new innovation that could reinscribe the treatment pathways of many such disorders, and lead to a paradigm shift, with cooperation between pharmaco-therapeutic and psychotherapeutic modalities. Although further legal action is needed to facilitate research and prescribing, the success of this in the near future is probable, and seems inevitable given the trajectory of other countries. The factors of safety in lack of abuse liability, transdiagnostic efficacy, one-off dosage method, plausible multi-model levels of action, institutional and venture capital funding, and empirical success in preliminary clinical trials, all point to psychedelics being a very promising innovation in the field of eating disorders, with widespread interventions on the horizon.

#### Endnotes

## From Dr Edwin Birch: Essay Prize Runner-up 2023

#### Ethical Challenges of Harm Reduction in severe Anorexia Nervosa

#### Overview

The treatment of a subset of patients with Anorexia Nervosa (AN), most recently referred to as "severe and enduring anorexia nervosa" (SE-AN), present particular therapeutic and ethical challenges to the treating psychiatrist. Often characterised as being non-responsive to multiple cycles of treatment and placing a high burden on services, the field has sought new strategies to support these patients as best as possible within the resources available. So called "harm reduction" approaches, adopted from addiction treatment, aim to give patients more autonomy over their specific treatment goals which may not include the traditional recovery-focussed goals of existing treatment modalities. Whilst an attractive proposition, this commentary will highlight three ethical concerns in this approach and consider whether harm reduction will nonetheless emerge in the context of overstretched and under-resourced eating disorders service in the UK.

#### Introduction

Practitioners in the field of AN in 2024 will be all too familiar with the reductive maxim quoted in textbooks as to the trajectory of recovery: 1/3 making a full recovery, 1/3 a partial recovery and 1/3 progressing to a chronic form of the illness[i]. This final third of patients has received considerable attention in the literature, not least because these refractory patients require the most intensive use of resources in their treatment[ii].

Various monikers have been given to an even smaller small percentage of these chronic patients whose symptoms remain intractable and severe over a number of years, variously being described as "chronic-intractable", "enduring and serious", "end-stage" and more recently in British scholarship, "severe and enduring anorexia nervosa" (SE-AN)[iii].

Alongside this myriad of terminology, there is no clear consensus on exactly how long symptoms should persist until we ascribe patients as belonging to this category. Tumba and colleagues recently suggested a diagnosis of >10 years along with severely low BMI and multiple failed attempts at treatment, whilst Bianchi et al cite a 6 year threshold[iv],[v].

Whichever definition one chooses to adopt, there is an appreciation that SE-AN may require a more nuanced strategy than a conventional AN patient. One such approach that has been gaining traction is one of harm reduction, which is summarised by Tumba et al[vi] as an approach that:

"should help the patient maintain a weight that balances quality of life but is below ideal weight range and still associated with medical risks"

They, amongst others, posit that harm reduction is a more ethical pathway than the alternative which often

involves progression to involuntary treatment methods.

At its core, the clinician reaches an agreement with the patient on a personal treatment goal, which may avoid the need for aforementioned invasive measures, thus in theory preserving a greater degree of patient autonomy and prioritising quality of life.

However, the remainder of this essay will identify three ethical issues which arise when harm reduction is held up as the answer for managing SE-AN patients.

### 1. Are we truly reducing harm? The physiological consequences of malnutrition

Harm reduction arose from addiction treatment in the 1980s[vii], whereby it was recognised that for many patients the destructive trail of drug-seeking behaviour, especially for opioids, could be offset to a degree by medically supervised provision of drugs. A similar parallel has been drawn to AN, whereby we can mitigate some of the social cost of repeated inpatient admissions and medical complications by accepting, in conversation with the patient, a lower BMI target. However, recent work has shown that the model may not be readily comparable for SE-AN[viii], most pertinently because there is a misplaced assumption that a lower BMI target will offset the harm of malnutrition as well as social harm.

Unfortunately it is well described that malnutrition to any degree is *actively* harmful and may lead to irreversible end organ damage across both the short and long term[ix],[x]. Every organ system is affected, most alarmingly the cardiovascular complications which pre-dispose patients to fatal arrhythmias, and the effects of malnutrition on bone density, which if allowed to persist as in a harm reduction strategy would compound over the long term[xi].

As such, harm reduction in these patients may be a slight misnomer. Granted we may avoid admissions in the short term, but we cannot untangle the harm physiologically that will remain and create complications in the long term, even at marginally higher baseline BMI targets.

## 2. To consent or not to consent- an over-reliance on preserved patient capacity

Another major ethical barrier to harm reduction as a strategy is the issue of capacity on the part of these patients. Every proponent of harm reduction speaks to the importance of allowing the patient to give informed consent before pursing the approach, and there is a default assumption that patients with SE-AN retain capacity for such decisions[xii].

However as eloquently summarised by Geppert amongst others, when dealing with SE-AN, we must call into question the validity of this consent regarding their treatment[<u>xiii</u>]. It has already been provisionally established that at the most severe levels of disease (encompassing all SE-AN patients) cognitive abilities are affected and we must challenge whether these patients can truly consent to this approach to treatment[<u>xiv</u>].

And while the question of consent remains contentious, harm reduction will not be ethically sound in the framework set out by those who support its implementation in modern practice.

#### 3. Is harm reduction an admission of futility?

Harm-reduction approaches are by definition closely aligned to the concept of futility in psychiatry, which remains a highly controversial area[xv]. In one sense, by abandoning the traditional treatment aims, we are

implicitly acknowledging that these aims are not obtainable, ie. to pursue them is futile.

This logic will lead into a host of ethical issues which are more traditionally levelled at the even more loaded topic of palliative care in AN and physician assisted dying (PAD) for SE-AN patients[xvi]. Some such ethical criticisms are that examples exist of recovery from AN even at late stages or severe levels of disease. Additionally there is a large grey area between treatment failure and treatment engagement, with some commentators arguing that SE-AN patient's "treatment failure" is actually a failure to *engage* with treatment[xvii],[xviii]. It quickly becomes a blurry line in harm reduction between alleviating suffering and being complicit in the patients' psychopathology.

We must also be reticent that for many patients recovery is a continuous process, which may take years. Creating a binary narrative that patients are either recovered or refractory (and therefore futile) could be counterproductive for how we think about this subset of patients.

#### Closing remarks

Whilst portraying itself as a humane and progressive alternative to more restrictive and invasive measures, we must be cognisant of the ethical issues of harm reduction highlighted above which still only scratch the surface of this ongoing debate. Unfortunately as demand for eating disorders services continues to rise, harm reduction may become more widespread and we should be honest about the fact that some SE-AN patients require a level of support for their recovery beyond the scope of local resources. This should however, not preclude our attempts to provide this support and care; going forward we must be mindful of the danger of harm reduction replacing recovery as the gold standard in SE-AN.

#### **References on request**

# Events

#### **Conference Programme**



## Faculty of Eating Disorders Spring Conference

**Date:** Wednesday 29 May 2024 **Venue:** Online via EventsAir

| Time                 | Session  |  |
|----------------------|--|--|
| 09.15am              | <b>Welcome address</b><br>Dr Ashish Kumar, Chair of the Eating Disorders Faculty, RCPsych,<br>Clinical Director, CAMHS, Mersey Care NHS Foundation Trust, and Dr<br>Agnes Ayton, Vice Chair of the Eating Disorders Faculty, RCPsych |  |
| 09.30am              | Plenary 1: Inpatient psychotherapy and transition<br>Chair: Dr Ashish Kumar, Chair of the Eating Disorders Faculty,<br>RCPsych, Clinical Director, CAMHS, Mersey Care NHS Foundation<br>Trust  |  |
| 09.30am              | <b>Long-term outcome</b><br>Dr Riccardo Dalle Grave, <i>Director Department of Eating and Weight</i><br><i>Disorders, Villa Garda Hospital, Garda, Italy</i>   |  |
| 09.50am              | Stepped care to prevent relapse after discharge<br>Dr Agnes Avton, Vice Chair of the Eating Disorders Faculty, RCPsych   |  |
| 10.10am              | Transitions<br>Dr Maria Livanou, <i>Kings College London, London</i>   |  |
| 10.30am              | Q&A  |  |
| 10.45am -<br>11.15am | Break  |  |
| 11.15am              | Plenary 2: Pathways into eating disorder care and outpatient<br>psychotherapy<br>Chair: Dr Hubertus Himmerich, <i>Kings College London, London</i>   |  |
| 11.15am              | Pathways into eating disorder care<br>Professor Alessio Monteleone, University of Campania "Luigi<br>Vanvitelli", Largo Madonna delle Grazie, Naples, Italy  |  |

| Viennese model of outpatient treatment of adolescent anorexia<br>nervosa based on the new Maudsley model<br>Professor Andreas Karwautz, Medizinische Universität Wien, Vienna,<br>Austria       |
|---|
| Balancing evidence-based with evidence-generating: extending<br>cognitive behavioural therapy for eating disorders<br>Dr Karina Allen, South London and Maudsley NHS Foundation Trust<br>(SLaM) |
| Q&A   |
| Lunch   |
| Plenary 3: Working with young people and novel developments<br>Chair: Dr Lisa Mukherjee, Great Ormond Street Hospital for Children,<br>London   |
| Towards understanding how single- and multi-family therapy for<br>anorexia nervosa work<br>Dr Julian Baudinet, South London and Maudsley NHS Foundation<br>Trust (SLaM)                         |
| Day programmes for adolescents eating disorders-current<br>practices and future directions<br>Dr Mima Simic, South London and Maudsley NHS Foundation Trust<br>(SLaM)                           |
| Transdiagnostic and personalised diagnosis and treatment of<br>eating disorders<br>Professor Christina Ralph-Nearman, University of Louisville, United<br>States of America                     |
| Early life appetite: a risk factor for later ED symptoms<br>Professor Clare Llewellyn, University College London  |
| Q&A   |
| Break   |
| Plenary 4: Update from the Faculty's research bursary winners,<br>Highlights and Discussion from the day  |
|   |

|        | Chair: Dr Ashish Kumar, Chair of the Eating Disorders Faculty,<br>RCPsych, Clinical Director, CAMHS, Mersey Care NHS Foundation<br>Trust  |  |
|--------|---|--|
| 3.35pm | <ul> <li>Update from the Faculty's research bursary winners</li> <li>Passent Helal - Can gut microbial diversity predict the prognosis of AN</li> <li>Wendy Yuepeng Wang - A qualitative study into the unmet training needs of psychiatry trainees with respect to delivering care of people with eating disorders – trainee and trainers' perspective</li> <li>Mrityunjai Kumar - A Workforce survey to evaluate perspective about Eating Disorder Psychiatry posts and their training needs</li> </ul> |  |
| 4.05pm | Reflections from the day<br>Dr Ashish Kumar, Chair of the Eating Disorders Faculty, RCPsych,<br>Clinical Director, CAMHS, Mersey Care NHS Foundation Trust  |  |
| 4.30pm | Meeting Close   |  |



We at the Royal College Eating Disorder Faculty want to hear from you!

As you can see from the Newsletter the content we seek to promote is varied, so we welcome any submissions for future editions. That might include, but not be limited to:

• Clinical papers

- Posters
- Essays
- Lived experience accounts
- Innovations and service developments
- Quality Improvement Projects
- Promotions for relevant upcoming events

We cannot guarantee inclusion, at least not in the next immediate edition, but please do not let that stop you. Bear in mind that our goal is to promote excellence, to inspire others and to instil a message of hope.

Any submissions can be emailed either to Dr Louise Johnston Iouise.johnston3@nhs.scot or Dr David Coyle david.coyle@belfasttrust.hscni.net

Thank you,

David & Louise

| Editors                              | X Account     | Contact  |
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