

<p>Institution: King's College London</p>
<p>Unit of Assessment: UoA4 - Psychology, Psychiatry & Neuroscience</p>
<p>Title of case study: 16: An evidence based skills training intervention for carers of people with eating disorders improves care</p>
<p>1. Summary of the impact Eating disorders affect 5-10% of young people and in many cases persist into adulthood. At their most severe they can evoke intense emotional responses from those closest to the person. King's College London (KCL) research established that the response from others, combined with personal factors and beliefs, were key maintaining factors in the disorder. As a result, KCL researchers developed self-help materials that reduced distress and improved carers' ability to manage the person they were helping. This intervention programme has been adapted into a workshop, a self-help book, a DVD and a clinical handbook. The programme has been adopted by two of the largest UK eating disorder charities (BEAT and SUCCEED) and is recommended by the USA-based international charity FEAST and forms the basis of local NHS and international services including in the USA and Australia.</p>
<p>2. Underpinning research Eating disorders occur in 5-10 % of young people, who are most often cared for by their parents. Early research into these carers, led at Institute of Psychiatry, King's College London (KCL) by Prof Janet Treasure (1989-present, Professor of Adult Psychiatry), Prof Ulrike Schmidt (1995-present, Professor of Eating Disorders) and Dr Ana Sepulveda (2008-2010, Visiting Lecturer), found that 25-30% had clinical levels of depression and anxiety and over 90% wanted more information about the illness and how they might help their children.</p> <p>KCL researchers show carer-involvement in precipitating factors for eating disorders While there are several types of eating disorders, restricting anorexia nervosa, where weight loss is mainly through starvation, can evoke intense emotional responses from others. In 2006, KCL researchers proposed a unique model of restricting anorexia that proposes that carer anxiety is mirrored by patient anxiety, which in turn produces more eating disorder symptoms. Here, symptoms are maintained by the person's beliefs about the positive function of the illness (e.g. the feeling of control over their body) and by both positive (e.g. greater levels of caring) and negative (e.g. through criticism) responses from close others. People with restricting anorexia are particularly vulnerable because of emotional avoidant and/or obsessive-compulsive personality traits and unknown biological factors. This model does not emphasise the role of weight and shape-related factors in anorexia maintenance (1). From this model, KCL researchers predicted that recovery is most likely to involve empathic action and a reduction of expressed emotion from carers as these can help reduce pro-anorexic beliefs and avoidance of emotions. There had been no previous measures to examine the specific impact that someone with an eating disorder has on family life so in 2008, KCL researchers, with help from carers, developed the Eating Disorders Symptom Impact Scale (EDSIS). This is a 24-item scale with four factors: nutrition, guilt, dysregulated behaviour and social isolation that they, and others, have used since to investigate the benefit of carer interventions (2).</p> <p>The KCL model is turned into a workshop to help carers Following from their model, KCL researchers developed a series of workshops to equip carers with the skills and knowledge needed to help the person with an eating disorder break free from the traps that block recovery and to reduce expressed emotion. This became known as 'The New Maudsley Method' or 'Collaborative Care Skills Training.' Here, carers are introduced to the model of change and the principles of motivational interviewing. They learn how to use reflective listening to reduce confrontation and how to sidestep resistance (3). In a study of the development of this intervention, 35 carers participated in six, 2 hour workshops, delivered over 3 months. The level of carer distress, general care giving burden and specific difficulties caused by eating disorder symptoms all fell after the intervention and were maintained at 3 months (4). KCL researchers also evaluated levels of expressed emotion and found that while at baseline 55% of a group of 47 carers had high ratings, following workshop participation high expressed emotion fell to 24%, accompanied by an overall reduction in levels of distress and caregiving burden (5). Another key finding was that patients held positive attitudes towards involving carers in their care and that the skills training approach had positive effects on adult anorexia nervosa inpatients (6).</p>

KCL researchers turn the workshop into a self-help intervention

As workshops are limited by the number of participants who can be accommodated and the need for travel, a self-help intervention named 'Expert Carers Helping Others (ECHO)' was designed to be delivered via a book and DVDs. The implementation demonstrated that whether the intervention was delivered with (n = 73) or without (n = 80) telephone or email support from a clinician it reduced carers' distress, with improvement in carers' status and perceived improvements in patients. This was associated with reductions in expressed emotion and in accommodating and enabling behaviours (7). Further development included a web-based version of the intervention plus support called 'Overcoming Anorexia Online.' Compared to usual support from a patient and carer organisation (n = 30), carers who received this intervention (n = 33) showed significantly reduced anxiety and depression (8).

3. References to the research

1. Schmidt U, Treasure J. Anorexia nervosa: valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *Br J Clin Psychol* 2006;45(Pt 3):343-66. Doi: 10.1348/014466505X53902 (185 Scopus citations)
2. Sepulveda AR, Whitney J, Hankins M, Treasure J. Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders. *Health Qual Life Outcomes* 2008;21;6:28. Doi: 10.1186/1477-7525-6-28 (24 Scopus citations)
3. Treasure J, Sepulveda AR, Whitaker W, Todd G, Lopez C, Whitney J Collaborative care between professionals and non-professionals in the management of eating disorders: a description of workshops focussed on interpersonal maintaining factors. *Eur Eat Disord Rev* 2007;15:24-34. Doi: 10.1002/erv.758 (38 Scopus citations)
4. Sepulveda AR, Lopez C, Todd G, Whitaker W, Treasure J. An examination of the impact of "the Maudsley eating disorder collaborative care skills workshops" on the well being of carers: a pilot study. *Soc Psychiatry Psychiatr Epidemiol* 2008;43(7):584-91. Doi: 10.1007/s00127-008-0336-y (28 Scopus citations)
5. Sepulveda AR, Todd G, Whitaker W, Grover M, Stahl D, Treasure J. Expressed emotion in relatives of patients with eating disorders following skills training program. *Int J Eat Disord* 2010;43(7):603-10. Doi: 10.1002/eat.20749 (14 Scopus citations)
6. Goddard E, Macdonald P, Treasure J. An examination of the impact of the Maudsley Collaborative Care skills training workshops on patients with anorexia nervosa: A qualitative study. *Eur Eat Disord Rev* 2010;19(2):150-61. Doi: 10.1002/erv.1042 (6 Scopus citations)
7. Goddard E, Macdonald P, Sepulveda AR, Naumann U, Landau S, Schmidt U, et al. Cognitive interpersonal maintenance model of eating disorders: intervention for carers. *Br J Psychiatry* 2011;199(3):225-31. Doi: 10.1192/bjp.bp.110.088401 (12 Scopus citations)
8. Grover M, Naumann U, Mohammad-Dar L, Glennon D, Ringwood S, Eisler I, et al. A randomized controlled trial of an Internet-based cognitive-behavioural skills package for carers of people with anorexia nervosa. *Psychol Med* 2011;41(12):2581-91. Doi: 10.1017/S0033291711000766 (4 Scopus citations)

Grants

- 2007-13. PI: U Schmidt. National Institute of Health Research; £1,998,296: Treatment of Anorexia nervosa: Translating experimental neuroscience into clinical practice
- 2009-11. PI: J Treasure. South London and Maudsley (SLaM); £25,000: Charitable Funds Training Carers to be telephone coaches
- 2011-14. PI: J Treasure. National Institute of Health Research; £249,582: Expert carers helping others

4. Details of the impact

Work at King's College London (KCL) led to the development of a skills training intervention for carers of people with an eating disorder that has been shown to have a positive impact on anxiety and depression. Depending on delivery methods, this is known as Collaborative Care Skills Training, The New Maudsley Method or Expert Carers Helping Others.

KCL research led to worldwide use of the Collaborative Care Skills Training Workshop

Impact case study (REF3b)

The Collaborative Care Skills Training Workshop is recommended and used both nationally and internationally. The 2013 NHS England 'Standard Contract for Specialised Eating Disorders (Adults)' says in its Best Practice Guideline that both in- and outpatient services should include provision of "expert family interventions specifically focused on the eating disorder." Here the 'Maudsley Collaborative Care Skills Model' was the only named example of this approach (1a). Most directly, this intervention forms the basis for current practice at the South London and Maudsley (SLaM) NHS Foundation Trust which offers help in both in- and outpatient settings. Around 80 carers a year participate in this workshop (1b). The Collaborative Care Skills Training approach is also the basis for Empowering Families workshops, set up by and for carers by the charity BEAT (the largest UK eating disorder charity) (1c) and run by local carer groups throughout the UK, for example, by the eating disorder charity First Steps in Derbyshire (1d).

This form of family work is also used in international centres. For instance, in 2012 the Center for Eating Disorders at Sheppard Pratt in Baltimore, Maryland, USA introduced the Collaborative Care Skills Training workshops, saying that "family members and caregivers of our patients will be provided with an additional level of support and engagement in the recovery process" (1e). Additionally, following training by the KCL/SLaM team, researchers at Deakin University in Geelong, Australia, provided the Collaborate Care Skills Training workshops to a group of carers and examined their utility. As part of their assessments they used the KCL-developed Eating Disorders Symptom Impact Scale measure and found the workshops to be "effective in reducing carer distress and burden as well as modifying unhelpful emotional interactional styles when caring for family members with an eating disorder" (1f).

The New Maudsley Method book disseminated and used by many charities and services

In 2007, KCL researchers adapted the intervention to a self-help book for carers called 'A Skills-based learning for caring for a loved one with an eating disorder. The New Maudsley Method.' As of July 2013, nearly 16,000 copies of the paperback version of this book have been sold (2a). This was followed in 2010 by a clinician's guide that describes the model and interventions. This has so far sold nearly 1,500 copies (2b). These books are on the reading list of a large range of services both nationally and internationally and are recommended by a number of user groups. For instance, the **London Carer's Group says the book "is a great resource for carers**, giving them an insight into some of the skills needed when caring for someone with an Eating Disorder." It is also recommended by NHS Eating Disorders Services in South Yorkshire, Oxford and Cambridgeshire. **In the USA, the book is recommended by the Webster Wellness Professionals Centre** in St. Louis, Missouri and the Eating Disorders Recovery Centre of Western New York, who say it holds "easy-to-understand guidelines and tips for parents and carers about facilitating and supporting recovery" (2a).

This Webster Wellness Professionals Centre also provides a link to the KCL-developed website detailing The New Maudsley Approach and containing tools for families and for professionals working with families (2c). A downloadable 'Toolkit for Carers' is also provided by SLaM (2d), with a version also provided by F.E.A.S.T., an international organisation based in the USA set up by, and for, parents and caregivers to help loved ones recover from eating disorders (2e,f). Scenarios from the carer's book have also been turned into easily-accessible cartoons available through YouTube. Two of the videos – 'modelling support' and 'modelling effective parenting' – have received 1,151 and 2,727 views respectively (2g). Additionally, KCL researchers have developed training DVDs for carers with SUCCEED, an eating disorders charity that promotes the dissemination of evidence based treatment and prevention. These are subtitled with several languages (Chinese, Spanish, Greek, Italian, French) (2h).

Public Dissemination

In addition to publications, the results of KCL research have been disseminated via plenary lectures and workshops to international professional and carer meetings. For instance, in May 2013 Prof Treasure spoke at an Australian conference with over 200 carers (3a). KCL work and researchers have also appeared on the radio, e.g. on Radio 4's All in the Mind (3b) and in newspapers, e.g. in The Times Magazine (3c), that have helped the general public in their understanding of eating disorders and the role of carers.

5. Sources to corroborate the impact

1. Widespread Use of the Collaborative Care Skills Training Workshop

- a. NHS England: <http://www.england.nhs.uk/wp-content/uploads/2013/06/c01-spec-eat-dis.pdf>
- b. South London and Maudsley NHS Trust Eating Disorders Service: <https://www.national.slam.nhs.uk/wp-content/uploads/2011/06/Eating-Disorders-Service-booklet.pdf>
- c. Empowering Families workshop: <http://www.b-eat.co.uk/get-help/get-support/empowering-families/>
- d. First Steps: <http://www.firststepsderby.co.uk/eating-disorders/training/skills-carers-workshops>
- e. Center for Eating Disorders at Sheppard Pratt: <http://eatingdisorder.org/blog/2012/07/new-collaborative-care-programs-for-parents-caregivers-and-loved-ones/>
- f. Pépin G, King R. Collaborative Care Skills Training workshops: helping carers cope with eating disorders from the UK to Australia. *Soc Psychiatry Psychiatr Epidemiol* 2013;48(5):805-12. Doi: 10.1007/s00127-012-0578-6

2. Publication and dissemination of The New Maudsley Method

- a. Treasure J, Smith G, Crane A. Skills-based learning for caring for a loved one with an eating disorder. *The New Maudsley Method*. London & New York: Routledge; 2007.
 - Eating Disorders and Carers, London Carers Group: <http://eatingdisordersandcarers.co.uk/london-carers-group/>
 - South Yorkshire Eating Disorders Association: <http://www.syeda.org.uk/view/carers>
 - Cotswold House, Oxford, NHS Specialist Eating Disorders Service: <http://www.cotswoldhouse.nhs.uk/resources/books/>
 - Cambridgeshire and Peterborough NHS Trust, The Phoenix Centre: <http://www.phoenixcentre.nhs.uk/ForParentsCarers/FurtherReadingandLinks/tabid/1816/language/en-US/Default.aspx>
 - Webster Wellness Professionals Eating Disorder Treatment Questions and Answers: <http://www.websterwellnessprofessionals.com/questions-and-answers.html>
 - Eating Disorders Recovery Center of Western New York resources for carers: <http://www.nyeatingdisorders.org/eating-disorders-carers/>
- b. Treasure J, MacDonald P, Schmidt U. *The Clinicians Guide to Collaborative Care in Eating Disorders*. London & New York: Routledge Press; 2010
- c. The New Maudsley Approach: thenewmaudsleyapproach.co.uk/About_Us.php
- d. SLAM/KCL Toolkit for Carers: <http://www.kcl.ac.uk/iop/depts/pm/research/eatingdisorders/resources/TOOLKIT-FOR-CARERS-FEB3-09.pdf>
- e. F.E.A.S.T. advice for parents: <http://feast-ed.org/TheFacts/Parentingduringrecovery.aspx>
- f. Carer's Toolkit: http://feast-ed.org/Portals/0/Documents/Carers_Toolkit.pdf
- g. YouTube videos for patients and carers. C&M Productions
 - Modelling support: www.youtube.com/watch?v=I7rfZWGfIL8
 - Modelling effective parenting for eating disorders: http://www.youtube.com/watch?v=JhA_CSht7tU
- h. SUCCEED Carer DVD: <http://www.succeedfoundation.org/work/skillsforcarers>

3. Public Dissemination

- a. 1st Australian Eating Disorders Conference for Families & Carers: http://www.athomewitheatingdisorders.com/uploads/1/3/0/2/13022385/janet_treasure_workshop_flyer_final.pdf
- b. All in the Mind. Aired 11.5.2012: <http://www.bbc.co.uk/programmes/b010y000>
- c. The Times, 15.12.2012: <http://www.thetimes.co.uk/tto/magazine/article3626553.ece>