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Developing Clinical Guidelines for Dietitians Treating Young People with Anorexia Nervosa - Family Focused Approach Working Alongside Family Therapists

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Abstract

Introduction: Family therapy for the treatment of Anorexia Nervosa (AN) in an outpatient setting is the evidenced based model of care. Nutritional intervention is an essential component in the treatment of AN particularly in adolescent who pose an increased risk due to high energy requirements relating to pubertal growth. The NHS England transformation strategy for mental health (2015) outlined targets to improve clinical skills specifically to meet the needs of young people with AN. Our aim was to develop clinical guidelines for dietitians working alongside family therapists treating young people with AN, ensuring evidence-based standardisation of care amongst providers of eating disorder services across England.

Method: Expert stakeholder meetings were held to formulate content of the dietetic component of the eating disorders national training, ensuring alignment with the family therapy treatment model. In 2017, the national training was delivered at key hub sites across England. Post national training an expert working group was established, comprising of eating disorders clinicians recruited from specialist interests groups to expand on the content delivered at national training and develop clinical guidelines for dietitians.

Result: Twenty specialist eating disorders clinicians contributed to the guidelines, formatted into three treatment phases to reflect family therapy models of care. The clinical guidelines have been endorsed by the British Dietetic Association.

Discussion: These guidelines provide best available evidence-based practice for dietitians treating young people with AN with a family focused approach. Working in conjugation with the therapy team will ensure appropriate challenging of AN behaviors and optimise nutritional intake.

Introduction

Nutritional intervention is an important component in the treatment of eating disorders and the dietitian is therefore an essential member of the multidisciplinary team, especially when in the presence of other co-morbidities such as coeliac disease, food allergies and Type 1 diabetes mellitus [1]. Dietitians should not treat eating disorders as sole practitioners and must work within a multidisciplinary team [2].

The peak onset for AN diagnosis in females in the United Kingdom is between 15 and 19 years with an incidence rate of 0.2% of the population [3]. The timing of the peak onset during adolescents is problematic in that it is also a time when energy requirements essential for pubertal growth are at their peak. The combination of high energy requirements, nutritional restriction and excessive exercising lends itself to a rapid deterioration in health, at a time of vulnerable periods of brain development and physical growth, resulting in potentially permanent physical and psychological consequences [4].

Although inpatient and day patient treatments are generally effective in weight restoration of patients with AN, they are also disruptive to family, social and educational life. Family Therapy for Anorexia Nervosa (FT-AN) is an intensive outpatient treatment where parents play an active and positive role. Family focused treatment is the evidenced based model of care for treating young people with eating disorders [5,6]. Parents are a resource in treatment, developing methods to restore their malnourished adolescent's weight [7]. The expectation is that parents take a lead in managing their child's eating in the early stages of treatment.

With the therapist, families are encouraged to explore how the eating disorder and the interactional patterns in the family are entangled and how this entanglement has made it difficult for the family to revert to their normal developmental course. When deciding whether day patient or inpatient care is most appropriate a number of factors need to be considered including: the young person's weight; the rate of weight loss; the medical status; and crucially whether the parents can support them and keep them from significant harm as an outpatient. In some cases outpatient treatment is not an option, due to the presence of overt systemic issues or risky AN cognitions and behaviours [8].

The availability of dedicated community eating-disorder services

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improves outcomes and cost effectiveness. If a young person starts their treatment in a general Child and Adolescent Mental Health Service (CAMHS), they are more likely to be admitted to an inpatient service than those treated in specialist eating disorders setting. Services need to be able to respond to the broader needs of families as well as the young person with an eating disorder. This might include supporting the family with techniques to help manage eating disorders in young people, and information about additional support services or expert advice ("NHS England. Access and waiting time standards for child and young people with eating disorders: commissioning guide," 2015) [9].

NHS England transformation strategy for mental health outlined targets to ensure improved clinical and management skills specifically to meet the needs of children and young people with an eating disorder, and the needs of their family. This is vital to providing a viable service that focuses on continuous improvement and therefore £30 million of recurrent funding (announced in the Autumn Budget 2014) was promised to transform services in England for the treatment of children and young people with eating disorders up to the age of 18 years ("NHS England. Local transformation plans for child and young people's with mental health and wellbeing: guidance and support for local areas," 2015) [10].

Providers of eating disorder services will be required to demonstrate that they deliver evidence-based, high-quality care. This can be supported through the membership of a national quality improvement and accreditation network to produce transparent and accessible data for all stakeholders. This will enable providers to assess and continue to improve the quality of care they provide, and ultimately become accredited services. To address this provision of high quality care across England we aimed to develop clinical guidelines to provide a practical approach to the dietetic complexities of young people with AN, which would support and reflects the FT-AN model of care.

Method

The development of clinical guidelines for dietitians treating young people with AN stems from the government's transformation strategy to provide high quality care and equality of service across England. Great Ormond Street Hospital and the South London and Maudsley NHS Trust were successful in their joint bid to provide the eating disorders national training to commissioners across England, which instigated the development of a dietetic education package, to support the eating disorders training. For the first time the dietetic education program was to be formatted to support the phased approach adopted by Family Therapy for AN (FT-AN).

Stage 1

Once a successful bid for the National Eating Disorders Training was secured it was necessary to devise a dietetic education section to support the overall eating disorders training program. Numerous expert stakeholders meetings were held with specialist eating disorders dietitians from around the United Kingdom who work in both adults, and CAMHS. The purpose of the meetings was to discuss the content and format of the dietetic training session, ensuring a consensus in a field with limited research. A thorough review of available evidence was therefore essential, one that would draw upon expert clinical experience and practice.

Stage 2

The National Training for Eating Disorders was delivered throughout 2017 at key hub sites (London, Manchester, Peterborough and Bristol); the training took eight days, which was spread over several months. The teaching sessions focused on aetiology, medical risk assessment, in-depth assessment, treatment (family focused) and multi-disciplinary teamwork. The nutritional section consisted of a 1hr lecture, followed by four hours of workshops, which focused on how to practically incorporate key points from the lecture [8,11,12]. Inadvertently, the national training highlighted a disparity in dietetic care and was a catalyst for the development of clinical guidelines. Throughout the training, various contacts were made with specialist eating disorder dietitians who voiced their commitment to expanding the dietetic teaching session in to clinical guidelines working towards standardisation of care.

Stage 3

On completion of the National Training for Eating Disorders an expert working group was formed recruiting specialist eating disorders *via* the National Dietitians' Mental Health Group and from links made during the training. The final authors are practicing pediatric and adolescent specialist eating disorders dietitians from England, Republic of Ireland and Northern Ireland. Additional advice was sought from family therapists, psychiatrists and a pediatrician. Each author focused on their specialist area of interest.

A final draft was sent to the expert working group to comment on overall content and structure. Amendments were made and a final face-to-face regional expert stakeholders meeting was held. Each phase within the guidelines was discussed through a point-by-point basis to finalise content and to ensure the importance of multi-disciplinary team working was conveyed.

Results

Nineteen specialist eating disorders dietitians and a consultant family therapist and a paediatrician directly contributed to the clinical guidelines with numerous other professionals assisting and supporting the development of the guidelines from regional specialist dietitian meetings. The final format supports and follows a similar structure to FT-AN – namely a phased approach.

Phase 1

The first phase of the clinical guidelines heavily focuses on dietetic engagement, development of therapeutic alliance and restoration of the young person's weight. Universally, dietetic practice has shifted over time to a client-focused approach. This is an improvement over the traditional medical approach, in which the clinician is regarded as the expert. Family focused eating disorder treatment is a two-way process i.e. looking at how clinicians can be both client and family focused.

The dietitian's primary focus early in treatment is to assist parents in managing challenges to the renourishment process. Whilst providing nutritional expertise, dietitians should keep in mind how they can implement an FT-AN aligned approach; the treatment philosophy is critical to providing coherent multi-disciplinary care with particular focus on:

- Increasing parental alignment
- Increasing parental renourishment confidence
- Externalising the illness from the young person
- Maintaining an agnostic stance [13].

Additionally, within this first phase a detailed initial assessment sets out the ongoing therapeutic relationship and the role of the dietitian. There is a clear assessment against norms and the resulting problems brought about by dietary restriction, which are identified, and explained to the young person and their parents. Often the effects of under eating are not associated with common symptoms and the parents may still be looking for an alternative medical explanation for these symptoms. Furthermore, the assessment outlines key points in eliciting information from diet history and interpreting biochemistry specific to AN. Other topics addressed in the first phase include: energy requirements throughout the renourishment process with specific reference to the metabolic state and biochemistry; when to use a prescriptive meal plan and the use of oral nutritional supplements.

Phase 2

The second phase of treatment focuses on encouraging the parents to help their child to take more control over eating in an age-appropriate manner and expands on the importance of a balanced diet with particular focus on bone health. This needs to be approached with caution, being mindful that giving too much nutritional information to the younger patients who may not have developed an extensive understanding of calories/ fat may be detrimental. Furthermore, this phase provides practical guidance on challenging feared foods, promoting healthy eating and ascertaining whether the family and young person understand their nutritional needs to optimise catch-up growth and healthy development.

Of note, some young people may adopt a socially acceptable dietary exclusion as part of the development of their eating disorder, such as plant-based diet or veganism, the young person's rational being to protect the environmental or ethical reasons. In line with a FT-AN approach the dietitian should assess the family's beliefs around this. It is the dietitians' role to educate the family about the risk linked to veganism within the context of AN compared to the general population, so they can fully understand the relevance of a restriction in their child's diet.

The final section in phase 2 focuses on exercise and activity level, which remains a contentious issue in young people with AN who have previously used exercise to control their weight or shape. It is important to remember that healthy exercising has many benefits, not least its cathartic value [14] along with strengthening of muscles, management of mood and improved bone health [15-18]. Once the team has deemed exercise to be safe based on engagement with therapy, cardiovascular health, bone mineral density and percentage median body mass index (usually over >85%mBMI), then low-level activity can be introduced. The guidelines provide practical information on establishing healthy exercise.

Phase 3

The final phase is usually initiated once the adolescent is able to maintain a healthy weight (3 regular menses or if pre-menarche/ or male >95%mBMI) and focuses on establishing a healthy age-appropriate relationship with parents. This can be the most rewarding phase for clinicians, the young person and family as it is a time when control of their AN becomes noticeable and should be encouraged and challenged in a guided manner - it is important not to push too hard even if the young person wants to move faster.

During this phase you can challenge rigid calorie counting by recommending eating out at new restaurants without calling ahead to check the menu; or by advising the young person to buy new products and brands without checking calories. The guidelines provide practical advice on managing common nutritional deficiencies and addresses veganism/ vegetarianism [19,20].

The FT-AN approach places parents in control, which further limits the normal adolescent development. Parents can be encouraged to support age appropriate adolescent independence away from eating and meals if the young person continues to rely primarily on parents regarding food choices. Be mindful that parents may feel socially isolated and lose sight of what normal adolescent development is and what the young person's peers are doing.

Once eating issues and weight/ shape concerns are no longer the primary problem, families need to be encouraged to deal with age-appropriate decisions around negotiating adolescent issues, which include education, socialising, exercising, flexible thinking and risk taking. The role for the clinical team is not to make those decisions but to support the family to make decisions by encouraging communication and modelling problem solving techniques.

The dietitian could be involved in thinking about meals out of the home, social events that involve food and alcohol, dealing with trips away from the family, cooking independently, vegetarianism and planning for future issues. It is useful to help parents distinguish between adolescent and anorexic thinking concerning food, eating patterns and alcohol.

In light of the low self-esteem which invariably accompanies AN it is essential to address the risks of alcohol and drug misuse; coping strategies and healthy general recommendations might need to be discussed, with an emphasis on risky behaviour associate with adolescents with AN.

British Dietetic Association Endorsement - The clinical guidelines have been endorsed by the British Dietetic Association (BDA) from 2019 to 2022. The BDA endorsement provides quality assurance that the information is accurate and evidence based.

Discussion

The best available evidence from the literature relating to nutrition and eating disorders was used to develop clinical guidelines for dietitians treating young people with AN: family focused approach. These guidelines stemmed from the National Eating Disorders Training, an initiative from NHS England, which highlighted the gap in standardised dietetic management within eating disorders. Numerous expert stakeholder meetings were organised involving specialist dietitians and clinicians. The working group was formed by systematically recruiting specialist dietitians during the national training and from the dietitians' expert mental health group.

A consensus regarding content within phases was achieved providing a practical approach to the dietetic complexities of young people with AN - other eating disorders are alluded to within the guideline, but not in depth. Throughout the guidelines, recommended competencies emphasise key learning points within sections ensuring the dietitian can focus their understanding. Although these guidelines focus on the dietitian's role in treating and managing AN the dietitian must align with the multidisciplinary team [21].

FT-AN is the evidence-based treatment model for young people with AN and therefore dietitians should be focusing their treatment programs to align with FT-AN. Dietitians working in eating disorders must have an understanding of the underlying dynamics and be aware of their professional boundaries when treating these complex patients. Furthermore, dietitians should appreciate the changeable energy requirements seen in this complex patient group and therefore regularly recalculate energy requirements throughout the treatment period. Additionally, a concise well-structured meal plan can provide parents with the confidence needed to engage with FT-AN, opening the opportunity to promote weight gain, avoid hospitalisation; shedding light on the unique skills of the specialist eating disorders dietitian.

Conclusion

Working in conjunction with the therapy team will guide the dietetic treatment, ensuring appropriate challenging of anorexic behaviours, whilst optimising nutritional intake and minimising the long-term physical complications associated with AN. Dietitians should be mindful of the synergy between psychological and nutrition; without psychological understanding and support, nutritional rehabilitation is likely to be ineffective. Conversely, malnutrition will negatively influence cognitive function and behaviour.

Comprehensive, structured and practical clinical guidelines were developed for dietitians treating young people with AN with a family focused approach. Incorporating the best available evidence and expert opinion with regards to nutritional support in this group. Providing a consensus for a standard of care across the United Kingdom and Republic of Ireland.

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