

Summary of QI Share & Learn: Nutritional Health – Thursday 9th May

Presentations & Case Studies

Nutritional health and body image in the modulator era: a paediatric perspective

Jacqueline Lowdon (Clinical Specialist Paediatric Dietitian, Co-Chair of CF BDA group), Leeds Children's Hospital

- CF is changing: In paediatric CF care, traditionally, there has been a lot of focus on weight gain and high fat diets, both of which allow for a preoccupation with body image.
- Children with CF, specifically teenagers, may be more prone to a negative body image and/or developing eating disorders when they start gaining weight rapidly on modulators. Reduced compliance with pancreatic enzymes and/or modulators is a risk.
- It can be challenging for CF professionals to adapt advice they were giving for years, especially when not every patient will gain weight on modulators and when there remains a proportion of patients who cannot benefit from modulators. There is a lack of guidance on optimal management of high BMI in CF and a lack of experience in dealing with overnutrition.
- Changing dietary advice is also a challenge for parents, who may be asked to make changes contrary to advice they had before.
- Learning and recommendations:
 - Supporting teenagers to improve body satisfaction may help to increase adherence to medications as well as quality of life.
 - CF professionals need to build new skills, adapt communication and provide anticipatory advice.
 - Work with others in the CF team, such as psychologists, to explore issues around body image and disordered eating.

A collaborative approach to supporting patients with body image concerns

Kerry-Lee Watson (Clinical Lead CF Specialist Dietitian, Co-Chair of CF BDA group) & Rachel Massey-Chase (Clinical Psychologist, Co-Chair of UKPPCF group), Adult CF Service, King's College Hospital NHS Foundation Trust

- The CF community experiences a lot of sub-threshold disordered eating and complex issues around body weight and shape, which has been complicated by modulators.
- One of the biggest challenges in adults with CF who have started modulators in the last few years is changing life-long eating habits.
- Acceptance of body shape and size is important and the team at King's now use body composition instead of weight and focus on nutritional health and wellbeing.
- The CF multidisciplinary team (MDT) is needed to support complex cases, as these can be multi-faceted and require a holistic approach with appropriate input from several professions.
- Nutritional advice and interventions to support patients should adapt around the patient and their unique needs, e.g. dietitian provides bespoke nutritional advice, psychologist support with eating behaviours and perception of body image, physiotherapy advice to increase physical activity and build muscle mass, social work support to access nutritious food etc.
- Learning and recommendations:
 - A holistic MDT approach is strongly recommended.
 - Have open consultations about nutritional concerns with patients: what are their concerns / do we have any concerns? Open questions and collaborative approach.
 - Refocus conversations away from weight/BMI and towards nutritional health and wellbeing.

Mindful Eating in CF – Are mindfulness-based practices helpful in supporting nutritional health and body image in CF?

Helen Eagan (Professor in Health Psychology), Birmingham City University

- Mindfulness can be a useful tool to support self-regulation, and while traditionally seen as separate to medical regimens, it can be highly complementary.
- Mindful eating techniques can include paying attention to the sensory experience of eating (the smell, taste etc.), not doing anything else while eating.
- A less well understood aspect of mindful eating is a non-judgemental awareness of thoughts and feelings when eating and considering how you think about food if your appetite or weight has changed.
- Initial results from research with a group of adults with CF showed that most wanted to eat more healthily and more than half wanted to lose weight, but that people with CF also have a lot of anxieties around eating and weight.
- For people with CF, some elements of mindful eating can be tricky, for example focusing on a sense of smell and taste is tricky for those with sinus issues, and the approach should be adapted for the individual.
 - Clinicians must consider the risk of negative consequences of mindful eating, as it can draw more attention to food and eating, which may be unhelpful for some.
- Learning, recommendations and further research:
 - People with CF need support to be able to interpret what their body is telling them and how this might change with modulators.
 - In terms of body acceptance, mindfulness can be transformational for some people due to its focus on non-judgemental reflection on thoughts and feelings when eating.
 - Further research is ongoing to adapt mindfulness scales on eating habits for people with CF. Adults with CF can find out more and join the study here: <https://bcu.questionpro.eu/t/AB3uywVZB3vmy2> (There is a £10 Amazon voucher available at each part of the study, on completion of stage 1 (eating behaviours scales), and again at stage 2 after using the practices for two weeks.)

Notes from the Q&A and open discussion

- Are we in a particularly complex time right now, in the 2020s, and might things become a little less complex as more patients come through who would have started modulators in their early years?
 - This is a unique period, with some unique challenges, but nutritional health will remain a focus in CF care, and patients will continue to face challenges with their weight, body image and eating, which CF teams must be equipped to support with.
 - For example, there is evidence of an increased risk of eating disorders in people on treatments that allow them to regulate their weight, which is the case in CF.
 - In paediatric care, clear advice on a high calorie diet used to be given very early on, but now individual circumstances, such as future eligibility for modulators, should be considered and nutritional advice for parents of newly diagnosed children should be adapted – this will remain the case in future, as the CF population continues to diversify.
- Some adults with CF who have gained weight and are now overweight/obese are actually reluctant to lose weight as they feel the additional weight is protective for them – how can we best advise these individuals, who may be reluctant to try to lose weight if indicated?
 - Change is difficult for everyone, and advice provided to people with CF for many years is changing, which some will struggle with, i.e. more weight gain or maintaining a higher BMI is no longer necessarily the goal – it is now about maintaining a healthy body and optimal nutritional status.

- Instead of focusing on weight and BMI, could try to reframe the conversation to focus on physical activity, exercise and/or nutritional health.
- Need to consider and explain the evidence of the impact of sustained overweight/obesity, including evidence from the general population, which is now relevant to people with CF on modulators.
- In paediatric care, it is difficult to shift the focus away from weight as weighing is vital to monitor development. How can we move our patients further towards these more functional goals with food, when as clinicians we are so focused on weight? Do you still work towards weight or BMI goals in underweight patients - if so, do you still aim for 50% BMI percentile?
 - As clinicians we need to evolve as well, moving away from the 'every clinic, every contact' spirit with weighing and focus on other elements of nutritional health, such as discussing diet and the benefits of different foods.
 - Weighing remains important in paediatric care, but body composition – rather than weight – could be a more helpful way to discuss the data, for example focusing conversations on support to increase muscle mass. However:
 - it was acknowledged that not all CF teams have access to equipment to determine body composition during weighing and there are limitations to interpreting the results in children.
 - some noted concerns that body composition, particularly a focus on fat percentages, could also be unhelpful, so these data also need to be framed carefully, and for some patients it may be preferable to shift the conversation entirely away from weight/BMI to focus on diet or physical activity – there is an opportunity to be proactive and preventative with diet advice with the younger population.
- Some of the eating behaviours in paediatric patients come from parents struggling to "drop" the high calorie meals as a result of the message given in the child's early years. Others can come from eating behaviours of the whole family.

If you have any questions or comments, please contact QI@cysticfibrosis.org.uk