Refresh: Patient experience of an online healthy eating webinar designed specifically for adults with Cystic Fibrosis on CFTR modulators



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Objective & Method

Since the introduction of Elexacaftor/Tezacaftor/Ivacaftor (ETI) many patients with CF have experienced weight gain. In response to an increasing number of patients' BMI rising above 25Kg/m2, more patients requesting weight loss advice and dietitians recognising a lack of healthy eating knowledge, a healthy eating webinar (and supporting handouts) was developed and delivered to patients at a regional CF Centre between May 2021-Febuary 2022. Patients who stated they wanted to lose weight or those who had a BMI ≥25Kg/m2 were invited to attend via a telephone call or during CF clinic appointments.

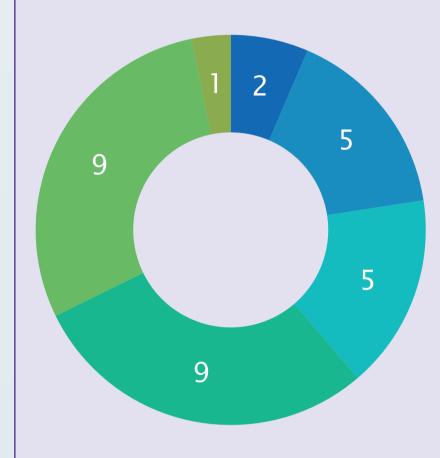
The healthy eating webinar known as "Refresh" covered topics including; changes in the CF diet and the effect of CFTR modulators, energy balance, developing new eating habits, a review of the UK's Eat Well Guide and all food groups, where to start with healthy eating, considerations when changing your diet with CF. All presented by a CF dietitian online and followed by a question and answer section.

An online survey was used to evaluate webinar attendance and attendees' views on the session (including; usefulness, knowledge gained and dietary changes they would consider as a result of the webinar). This was sent via email to all patients who attended the online webinar.

Results

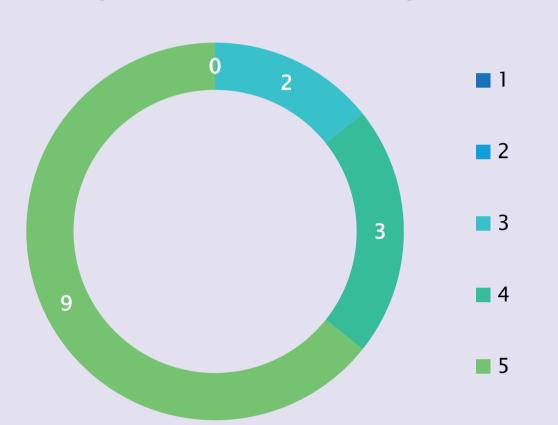
- 23 patients attended the webinar and 14 provided feedback (out of a full cohort of 353)
- Attendees included; 11 male, mean age of 39 years and mean BMI of 28.8Kg/m2
- 21 were taking ETI, one taking Ivacaftor and one post-transplant

Reason for attending the webinar

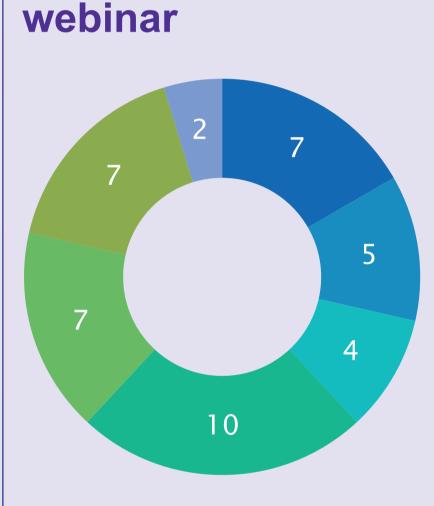


- Just intrested to learn more
- Aiming to become healthier overall
- Improve overall diet
- Prevent weight gain
- Lose weight
- Other Better manage weight and importance of exercise

Usefulness on a scale of 1-5 (5 = most useful)



Changes attendees would consider after attending



- Increase fruit and vegetable intake
- Develop regular eating habits
- Choose more wholegrains
- Reduce overall fat intake
- Reduce sugar intake
- Aim for balanced diet
- Reduce snacks and alcohol Other • Explore different approaches to help me feel more energised and feel generally more healthy

11/14 attendees reported they learnt something new (summarised below):

- Swapping from high fat to low fat this does not mean less calcium
- Grate cheese instead of slices
- Portion sizes for each food group
- Learnt about good choices and ideas of healthier snack options
- Leant own areas for improvement e.g. alcohol / snacking Not the only one struggling with weight
- Avocado has healthy fats for taking modulators
- Reminder of salt intake and ideas for reducing tablet intake
- What foods to eat to maintain lung health Could be more useful to use Carbs and Cals app more
- Ways to increase fruit and vegetable intake e.g. smoothies

Interest in other Healthy Eating Webinars

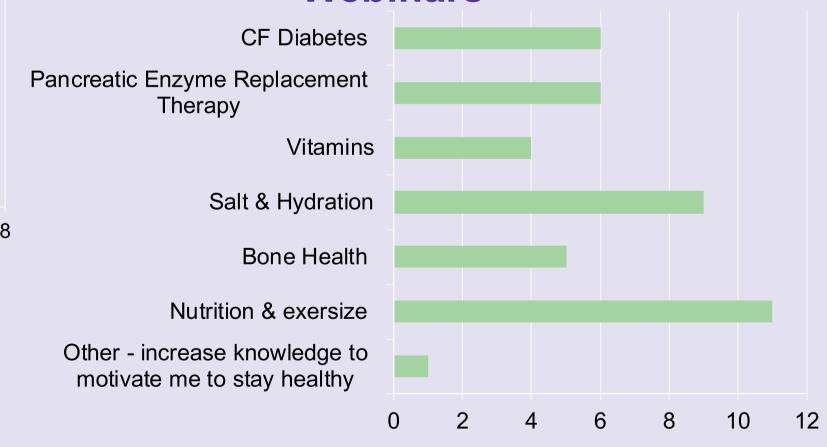


Other Topics suggested were:

- Healthy but tasty alternatives to snack bars
- Reduced sugar pudding ideas
- More wider menu choices that are easy to prepare
- Whilst one of those who selected other stated "I believe you have given the tools required in this session"

Webinars CF Diabetes

Interest in other Nutrition Education



Introduction of CFTR 🬟 Refresh Developing New Habits Noticing hunger & fullness cues Regular Eating Avoiding "Caveman Cravings" Informed decisions Refresh Carbohydrates 'Starchy Foods' Carbohydrates are our main energy 🤎 They also provide: Fibre, vitamins & minerals 1/3 of your diet — include with each meal Eat with each meal Choose WHOLEGRAINS Refresh Foods & Drinks High in Fats & Sugars Refresh Changing your Diet with CF

The Evolution of the CF Diet?

Introduction of enteric coated **Pancreatic Enzymes**

Low Fat

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Discussion

- The webinar clearly had a positive influence on patient's knowledge and readiness to change their eating behaviour. Patients reported they gained new knowledge about healthy eating behaviours and many were considering making dietary changes following attending the webinar.
- Attendees found it particularly useful for identifying eating behaviours and food choices they wanted to change
- Clear interest was shown for further education on healthy eating and other CF specific nutrition topics, indicating that attendees were interested in increasing their nutrition knowledge and that the online format was acceptable to them. However, as only 50% of attendees provided feedback this could be biased by attendees who were more motivated to make dietary changes.
- Delivering 'bitesize' education online is more accessible to patients as they do not need to travel to the centre and can to join from
- home, work, college etc. It also provides the opportunity for them to share their experience and learn from peers without the risk of cross infection.
- The main challenge to this project has been limited engagement / attendance. This contrasts to the number of patients who had requested weight management and healthy eating advice during virtual clinical consultations.
- Attendance rates reduced further following the lifting of national COVID-19 restrictions. Reasons for this were not explored during this study though could be due to patients not being ready to make changes as they were still adjusting to the effects of ETI therapy, preferring face to face education, or having less time as life returned back to normal following COVID-19 restrictions. Engagement with online education in CF is an area of interest for further research.

Conclusion

Patients found this healthy eating webinar useful, often learnt something new and felt motivated to consider making dietary changes. Most of these webinars were delivered during the COVID-19 pandemic. Since national restrictions have ceased, patient engagement with the webinar has reduced. In response to this reduced engagement, the webinar has been made available online on demand (heartlandscf.org). Patient engagement with this will be evaluated and barriers/facilitators to engagement with online education will be explored.



