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Neuroendocrine Tumour (NET) Dietary Education Programmes - Do They Work? : Analysis of Validated Patient Questionnaires

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Introduction: Group education has been proven to be beneficial in diabetes. Currently for NET patients there is an unmet need for group education. At Sheffield ENETS Centre of Excellence, we created a bespoke education programme. This was a pilot study delivered by multidisciplinary specialists. **AIMS** To establish if group education is an acceptable model to NET patients and if this has lasting health benefits. **METHOD** 15 stable NET patients were chosen from the Sheffield ENETS database (10 small bowel NETs and 5 non-functioning pancreatic NETs). The education session was split into 3 sections. 1. A comprehensive outline of NETs, 2. NET medical treatments and management 3. Nutrition and dietary advise delivered by 3 specialist NET dietitians. Prior to the 4 hour in person education session all participants completed the validated EORTC QLQ-C30 questionnaire and then either QLQ – GINET21 or QLQ-PAN 26 questionnaire depending on primary NET. Then 6 weeks and then 6 months post educational intervention the questionnaires were repeated. The likert scale dataset was then analysed using Excel in terms of descriptive statistics. **Results:** From the pre-course EORTC QLQ-C30 questionnaire for the small bowel NET group 30% of participants felt they were not limited in doing either their work or other daily activities in the past week. This improved to 56%, 6 months post intervention. With respect to the GI NET 21 questionnaire several positive findings were found at 6 months post intervention. This included: 100% of participants did not experience any heartburn or acid indigestion (baseline was 80%); 56% did not experience any bloating compared to 30% at the start; 56% stated their illness or treatment had not at all been distressing to those close to them (baseline was 30%). With respect to the pancreatic NET group the PAN 26 questionnaire found that pre-intervention 40% of participants experienced no side effects from their treatment. At 6 months post intervention this increased to 60%. **Conclusion:** This pilot study has demonstrated how patients find group education helpful and improved several aspects of quality of life. This initiative could be repeated on a larger scale in specialist NET centres to further assess benefit, including a hybrid or online format. Moreover, this style of group education can also be expanded across endocrinology fields to include adrenal insufficiency and sick day steroid rules. Finally, the health economic benefits look promising and could be further analysed to look at substantial long-term savings. The opportunities are limitless.

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