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Intensive Personalized Program for Living with NENs as a Chronic Disease



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Background: The Intensive Personalized Program for Daily Living with NENs is a pilot program transitioning patients and their primary carer to a new “normal”

METHODS:

Roles:

- Program Workshop Coach
- NEN Dietitian
- Scientific Advisor
- Nutritionist

Screening Criteria were used.

- The Patient Units attended a three day dedicated residential workshop called “ July 9 11 2019
- The Patient Units attended three video interviews with the NEN Dietitian followed by individualized recommendations
- The purpose of the workshop is to teach attitudinal techniques to live with Cancer as a Chronic Disease
- Techniques include CBT, NLP and Mindfulness

RESULTS:

- Four patients with GEP NENs completed adapted adult patient carer QoL questionnaires, and attended an initial virtual consultation with their carer, coach, and NEN Dietitian
- After completing a three day interactive workshop, four NENs patient carer couples were followed by a clinical NEN Dietitian and the workshop coach
- Patient reported outcomes using adapted adult patient and carer QoL questionnaires were analysed 1 An adapted research instrument based on the Carer Scoring Manual was also used for Patient Scoring
- At six months follow up, two patients retained the initial QoL score and two showed 17 29 score improvement Carer scoring showed one stable, two improvement of 14 28 and one showed a drop of 22
- All patients showed increased eating discipline and autonomy
- Carers reported increased independence to continue their personal activities
- Additionally, Patient Units documented increased understanding of each other's challenges, decreased expectations, and increased cooperation.

CONCLUSION: Preliminary data provide important insights on the major role of such an intensive personalized program in transitioning patients and carers to a “new normal”

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