

Survivorship care model for patients with metastatic neuroendocrine tumor

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Introduction

The oncology landscape is changing and there are many more patients living with cancer as a chronic illness.

An example of this are patients with metastatic neuroendocrine tumors.

Neuroendocrine tumors are rare often indolent tumors.

Approximately 22% of patients present with metastatic disease at diagnosis and many more patients may develop metastatic disease over time. The overall survival for these patient's may range from years to decades

These patients often don't identify as cancer survivors and don't meet the criteria for care in traditional survivorship clinics

Aim

To develop, implement and evaluate a multidisciplinary neuroendocrine wellness clinic

To address the unique survivorship/holistic needs of patients living with metastatic neuroendocrine tumors

Methods

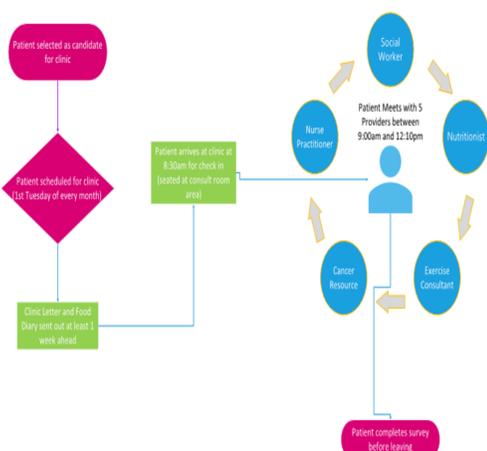
Patients from the NorCal CarciNET/UCSF patient support group were recruited to participate in a focus group assessing the need for and interest in attending a Neuroendocrine wellness clinic

Based on positive feedback, a Multidisciplinary neuroendocrine wellness clinic was established.

The Multidisciplinary wellness clinic included an oncology dietician, oncology nurse practitioner, social worker, cancer resource specialist and exercise counsellor

Logistics of neuroendocrine wellness clinic is depicted in graphic below.

NET Wellness Clinic Patient Flow



Results

Patients in the support group overwhelmingly agreed with the need for holistic care.

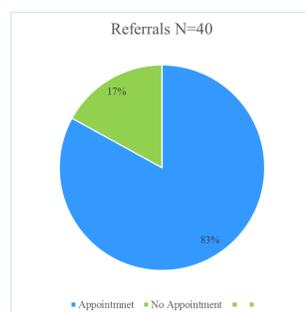
Patients identified with the term **Wellness** rather than survivorship

Patients were supportive of meeting with the multidisciplinary providers on one day to decrease the financial burden of transportation and time off work.

A referral was developed in the electronic medical record

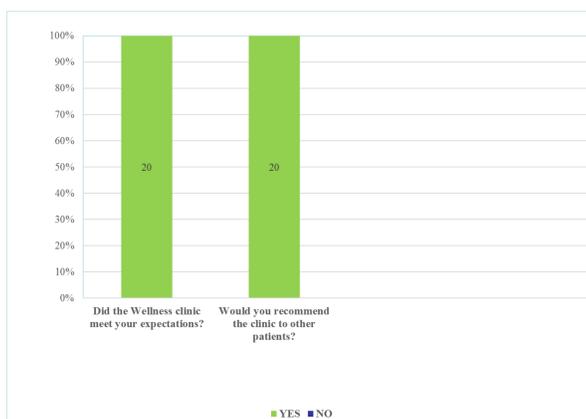
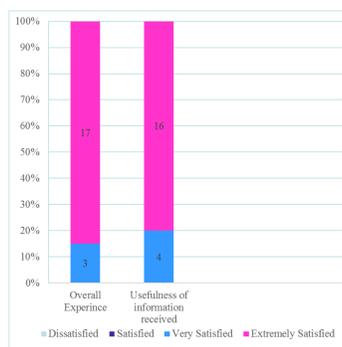
Patients were referred to the wellness clinic from the neuroendocrine oncology clinic.

At completion of the clinic visit a post-clinic survey was offered to patients and results are summarized below



Over the course of 16 months 40 patients were referred to the NET Wellness clinic. Of those 40 patients 83% complied with the referral and presented to the NET Wellness Clinic

Sixty percent of patients completed the post-clinic survey. 85% of patients were extremely satisfied with the overall experience and 80% of patients were extremely satisfied with the information received



On the post-clinic survey, 100% of patients who completed the survey stated that the wellness clinic met their expectations and would recommend the clinic to other patients

Results

Patient Comments

Did the Wellness clinic meet your expectations?

- It was above and beyond
- The clinic went beyond my expectations
- Informative and concise
- I had no idea what to expect- it was pretty amazing!

Would you recommend this clinic to other patients?

- Yes, this is helpful for someone living with carcinoid for several years and I believe even more so for those just diagnosed
- The information has resources that will improve and lengthen your life
- I wish I knew about this years ago

Conclusion

The multidisciplinary neuroendocrine wellness clinic achieved its goal of meeting the holistic needs of this unique patient population.

The implementation of the neuroendocrine wellness clinic demonstrated that the project was feasible and it was met with high levels of patient satisfaction

Acknowledgements

Northern California CarciNET community (NorCal CarciNET) <https://norcalcarcinet.org/>