

Real-world management and patient perspectives on QOL with neuroendocrine tumors: An ANZ perspective

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1 | INTRODUCTION

Prof Michael Michael

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Neuroendocrine tumors (NETs) arise from the diffuse neuroendocrine system. The most common anatomical sites for NETs are the gastrointestinal tract (especially the small bowel, stomach, and appendix) and pancreas, which account for over 50% of cases and as a group are referred to as gastroenteropancreatic NETs (GEPNETs).¹ The age-standardized incidence rate in Australia has nearly doubled in the period between 1982 and 2020, from 8.9 cases per 100,000 population to an estimated 17 cases per 100,000 population.² This reflects the increased availability of diagnostic cross-sectional imaging and endoscopy,³ leading to increased identification of incidental lesions,⁴ and the diagnostic impact of somatostatin receptor imaging (⁶⁸Ga-DOTATATE positron emission tomography).⁵ Prognosis is dependent upon the primary site, disease extent, and histological grade

(based upon World Health Organization 2017 classification).¹ Diagnosis is often delayed by several years,⁶ the delay compounded by the patient consulting several medical disciplines, with little experience of managing NETs, prior to receiving a diagnosis.

NETs are characterized as functioning or nonfunctioning. Functioning tumors secrete various hormones and have associated clinical syndromes. The classical examples include small bowel NETs secreting serotonin resulting in the carcinoid syndrome (flushing, diarrhea, mesenteric fibrosis, and cardiac valvular disease) and pancreatic NETs (insulinomas, gastrinomas, and glucagonomas).⁷ Nonfunctional tumors present nonspecific symptoms related to mass and subject to the location of the primary tumor and metastases. The spectrum of these symptoms have a profound impact on patient health-related quality of life across several domains of functioning and interaction.⁸ Unlike other more common malignancies, patients with GEPNETs, even with metastatic disease, demonstrate a prolonged median survival, for example, 56 months for small bowel NETs of all grades.⁹ Hence, the NET-related symptoms can negatively impact patients over a very prolonged period of time.

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Treatment is based on histological grade, disease extent, the presence of secretory syndromes, and the rate of progression as well as institutional/regional resources. Treatment options include (1) observation with a “watch and wait” strategy,¹⁰ (2) somatostatin analogues (SSAs) (Sandostatin LAR [octreotide] or Somatuline Autogel [lanreotide]), for their antisecretory and antiproliferative effects,^{11,12} (3) peptide receptor radionuclide therapy,¹³ (4) molecular targeted agents (everolimus¹⁴ and sunitinib¹⁵) and chemotherapy.¹⁶ Given the rarity of these diseases, optimal management should include discussions within specialist NET centers.

There are several areas of unmet need in the management of patients with GEPNETs, including complexities in diagnosis and treatment, long-term management, and QOL issues. These issues formed the basis for the interactive Australian webinar entitled: “NET 2020: Real-World Management and Patient Perspectives on Quality of Life,” held on September 2, 2020. Presenters included medical oncologists with specialist expertise in NETs (Dr Lorraine Chantrill, Prof Tim Price, and Dr David Chan) and staff of NeuroEndocrine Cancer Australia (NET Patient Support Nurse Ms Kate Wakelin and Clinical Research Associate [CRA]/Project Officer, Ms Meredith Cummins).

The topics included:

- First-line treatment of patients with metastatic functional GEPNETs, and the approach in refractory disease: A case study presentation. Dr Lorraine Chantrill.
- Timing of first-line SSA treatment in patients with asymptomatic nonfunctional GEPNETs: Debate: When to watch & wait and when to treat nonfunctional GEPNETs and Group recommendation for treatment of nonfunctional GEPNETs. Prof Tim Price and Dr David Chan.
- Defining the QOL impact of GEPNETs in the Australian population: QOL issues in NET patients and eSHINE (Sandostatin LAR Home Injection Program) QOL survey findings. Ms Kate Wakelin.
- Defining the health information needs of patients with GEPNETs and their health care providers: How the clinical community can better support quality of life for patients with NETs. Ms Meredith Cummins.

This supplement provides summaries of each of these presentations, which we believe will be of great interest to the wider medical community.

2 | FUNCTIONAL NEUROENDOCRINE TUMOR CASE STUDY

Dr Lorraine Chantrill

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Neuroendocrine tumors (NETs) can be complex to treat and require an individualized treatment approach. We present a case study for interest. The patient, a 72-year-old woman presented with pelvic symptoms of abdominal pain and discomfort, and flushing. She had a distant history of breast cancer and melanoma of the skin. Imaging performed by her general practitioner showed liver lesions, and a liver

biopsy indicated that she had an intermediate grade NET with a Ki-67 of 10%.

A baseline serum chromogranin A (CgA) (416 ng/ml) rose to 1366 ng/ml at follow-up. A ⁶⁸Ga-DOTATATE positron emission tomography (PET) computed tomography scan in March 2019 showed a possible primary tumor in the small bowel with lymph node and liver metastases. An ¹⁸F-fluorodeoxyglucose (FDG) PET scan showed no FDG uptake in the liver, though there was some focal uptake at the ileocecal junction, which was most likely physiological.

Treatment with the somatostatin analogue, Sandostatin LAR (octreotide) 30 mg monthly was commenced. In the past, patients often initiated therapy with short-acting octreotide; however, it is now common practice to start treatment with the long-acting analogue, as they are more effective and convenient.

After the commencement of treatment, the patient's symptoms quickly resolved. She kept a diary to record episodes of diarrhea and flushing. Patient diaries are useful in the first few months of treatment as they provide an objective measure of treatment effects, and the clinician can demonstrate to the patient the impact of the treatment on their NET. Diaries are also useful in identifying if a patient starts to develop resistance to the drug.

Cardiac assessments should be routinely performed for any patient with symptoms of carcinoid syndrome as it can lead to cardiovascular issues, in the form of right-sided valvular and endomyocardial fibrosis. This patient had minor mitral and tricuspid regurgitation and a sclerotic aortic valve, which is considered unrelated to carcinoid syndrome. The patient had normal right heart chambers.

The resolution of symptoms unfortunately only lasted approximately 6–8 months after commencing treatment and the patient developed diarrhea again in October 2019. CgA levels were taken every 3 months and these started to increase again (from 150 to 167 ng/ml). A second ⁶⁸Ga-DOTATATE PET/CT scan in April 2020 (12 months after the initial scan) showed evidence of disease progression. There was a rapid increase in CgA levels between April 2020 and July 2020, with levels exceeding 300 ng/ml. As the patient had persistent symptoms and disease progression, she was referred for peptide receptor radionuclide therapy with ¹⁷⁷Lu-DOTATATE. After discussion within a multidisciplinary NET team meeting, the patient was recommended for ¹⁷⁷Lu-DOTATATE therapy as a single agent—though some NET centers combine this with chemotherapy. The patient continues to be monitored and treated.

3 | NEUROENDOCRINE TUMORS: THE CASE FOR “WATCH AND WAIT”

Prof Timothy Price

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“Watch and wait” or active monitoring of patients who do not require immediate treatment is a form of management that has been practiced for many years across medical disciplines. This approach may be suitable for patients with nonfunctional, low-volume, and low-grade (Ki-67 < 2%) neuroendocrine tumors (NETs) with no negative

prognostic factors. The benefits of delaying treatment with somatostatin analogues (SSAs) include delaying monthly clinic attendance for injections, and reduced costs to the patient and the community. Further, while treatments are generally well tolerated, patients may avoid treatment side effects, particularly diarrhea and flatulence, and the potential for long-term risk, such as gall stones.

While there have been studies comparing “watch and wait” with active treatment in the setting of low-grade non-Hodgkin’s lymphoma, no such studies have been conducted in NETs. In the absence of such trials, it is informative to consider the progression-free survival (PFS) of the placebo groups in two large trials of SSAs: the PROMID¹² and CLARINET¹¹ trials.

PROMID was a randomized, double-blind, placebo-controlled study of the effect of octreotide LAR on the control of tumor growth in patients with metastatic neuroendocrine mid-gut tumors. Eighty-five treatment-naïve patients were enrolled, mainly with low-grade NETs (95% with Ki-67 \leq 2%).¹² The study showed a strong signal for an antiproliferative effect of octreotide LAR (median time to progression of 14.3 months in the octreotide LAR arm compared with 6.0 months in the placebo arm). There was 88% crossover from the placebo group and no overall survival difference has been seen between the study arms. However, despite the PFS results, the imbalances in the treatment arms should be noted: median time since diagnosis was 7.5 months for patients in the octreotide LAR arm compared to 3.3 months in the placebo arm, and patients with longer duration from diagnosis to treatment may have had more indolent disease. Approximately 25% of patients in the placebo arm had not progressed at 12 months, raising the question of whether the same proportion of patients in the octreotide LAR arm could have waited 12 months or more before starting treatment.

The randomized, double-blind, placebo-controlled CLARINET study of lanreotide enrolled 204 patients with nonfunctional, pancreatic, mid-gut, unknown, and hind-gut NET. Most patients had low-grade NETs (70% with Ki-67 \leq 2%). About 95% of patients had not progressed in the previous 6 months prior to study entry. Similar to the PROMID study, there was a strong signal for an antiproliferative effect of lanreotide. There has also thus far been no difference in the overall survival. Approximately 50% of patients in the placebo arm had not progressed at 18 months, hence again, could these patients have waited?

Overall, in both trials, there was a group of patients in the placebo arms who did not progress during the trials, and who may be suitable for a “watch and wait” strategy.

Patients suitable for a “watch and wait” approach are those with asymptomatic, nonfunctional, low-volume and low-grade (Ki-67 < 2%) disease, no negative prognostic factors, and a NETPET grade¹⁷ of 0 or 1. A new tool of tumor growth rate score prior to treatment (TGR₀) may also be useful with < 4% per m² growth over the prior 6 months predictive of indolent activity.¹⁸

Importantly, a “watch and wait” strategy is not appropriate for all patients with NETs. It is unlikely to be suitable for patients with pancreatic NETs, which tend to be more aggressive than small bowel NETs. Also, careful discussion with patients is required to ensure they agree with the approach, as quality of life is reduced if they

“watch and worry.” Other possible downsides of the “watch and wait” approach include the potential to miss symptoms of progression, and an increased burden of disease monitoring. Patients must commit to undergoing regular monitoring with 3–6 monthly computed tomography scans, NETest liquid biopsy,¹⁹ and PET scans. Chromogranin A (CgA) testing may also be performed, and the 3-month tumor growth rate (TGR_{3m}) could also be used and would ideally remain less than 0.8% per month.

There is clearly a proportion of patients who could enjoy the quality of life benefits from delaying the start of treatment with SSAs without negative clinical consequences, making “watch and wait” a valid management strategy for some selected patients with NETs.

4 | NEUROENDOCRINE TUMORS: THE CASE FOR TREATMENT

Dr David L. Chan

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All clinicians would agree that there are some patients for whom “watch and wait” is a suitable strategy and some for whom early initiation of somatostatin analogue (SSA) therapy is recommended. The question is then: how can a clinician appropriately select the subtypes of patients with neuroendocrine tumors (NETs) for whom a “watch and wait” strategy is reasonable? Conversely, what percentage of patients would warrant routine initiation of SSA therapy on diagnosis?

The two landmark randomized trials in NETs, PROMID¹² and CLARINET²⁰ (described in the previous summary), demonstrated no definitive evidence in terms of the impact on overall survival based on early initiation of treatment after allowing for crossover, though the population in the CLARINET trial was relatively indolent. SSAs are well tolerated by the vast majority of patients. An option for patients concerned about the potential of side effects is to initiate them on a short-acting formulation prior to administration of the long-acting depot. This is generally not necessary in practice as stated above. We note that withdrawal due to side effects in the trials was relatively low (PROMID 5/43 patients and CLARINET 3/101 patients) and that adverse events were not severe.^{11,12}

There are three types of patients who may derive less benefit from an SSA if there is a delay in treatment initiation. The first group of patients are those with poor hepatic reserve due to high-volume liver disease, who may have worsened outcomes with a delay in treatment. SSAs are cytostatic and do not generally produce significant regression of disease. Thus, in patients with impaired hepatic reserve, further disease progression may lead to hepatic impairment and worsened functional status. The second group is patients with aggressive clinical disease who cannot afford to lose time with a “watch and wait” strategy. The final group of patients are those with poor performance status, where further progression of their illness would significantly diminish their ability to tolerate systemic treatment.

Another factor that may influence a recommendation for early SSA initiation is that of predicted NET biological behavior, whether through histopathology or nuclear medicine findings. Positron emission

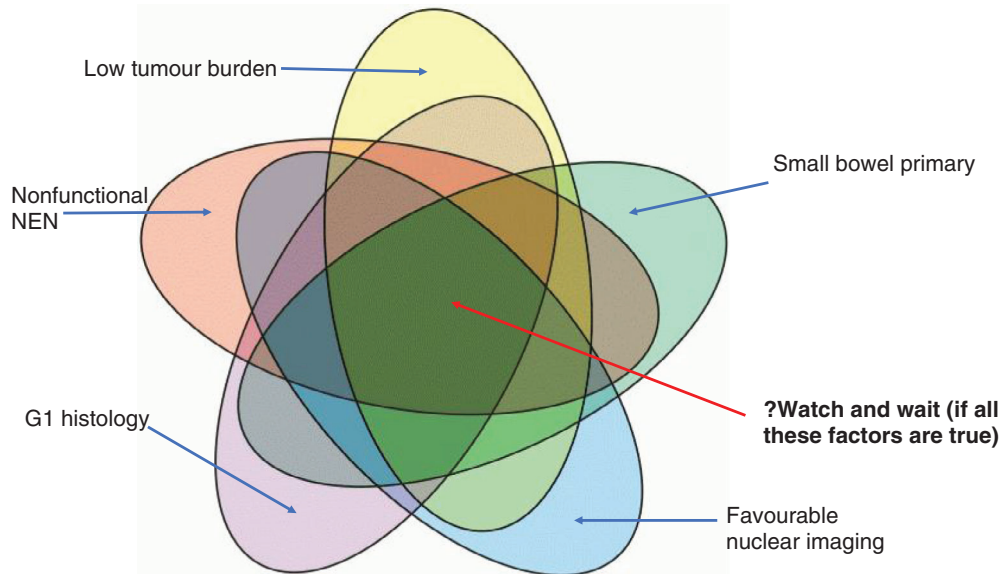


FIGURE 1 Venn diagram of the watch and wait strategy

tomography (PET) scans may be able to predict disease biology and has relevance especially in the Australian context to guide clinical decision making. Recent research has demonstrated that high fluorodeoxyglucose (FDG) avidity on PET is a marker of increased disease aggressiveness, and that high metabolic tumor volume on ^{18}F -FDG PET is also a poor prognostic factor.^{5,21} A particularly poor marker of prognosis is the existence of ^{18}F -FDG avid, ^{68}Ga -DOTA-octreotate nonavid disease (a NETPET score of 5).¹⁷ A “watch and wait” strategy would not be suitable for these patients. While histopathology remains the gold standard for grading NETs, it is susceptible to sampling error. A biopsy may have sampled a relatively benign part of the tissue, but not metastases that may harbor a more aggressive histology. PET imaging may be able to highlight these areas without having to biopsy many different hepatic lesions, which would not be feasible or safe.

Regardless of the patient’s histological and imaging characteristics, it is vitally important to understand the patient’s perspective and where they are on the spectrum of wanting to start treatment. Some patients need reassurance regarding possible side effects, whereas others are very keen to start treatment even though they may be suitable for a “watch and wait” management strategy. In this case, if the treatment has a low incidence of side effects, then patient preference can be an important consideration (Figure 1).

Finally, some large studies have shed light on general predictors of early progression in patients with advanced NETs. The GETNE-TRAGSU²² study was a real-world study of 535 patients from the Spanish Group of Neuroendocrine and Endocrine Tumors Registry (R-GETNE) with grade 1–2 gastroenteric pancreatic primary tumors treated with first-line SSAs. This study was validated in the United Kingdom. A nomogram developed to predict progression-free survival found predictors for rapidly progressive disease included a high Ki-67 index, the primary tumor site (gastric and pancreatic NET tumors), high liver involvement, a high neutrophil-to-lymphocyte ratio, and metastases in the peritoneum or bone. Patients who have indicators of

rapidly progressing disease should be considered for early initiation of therapy in order that they have the opportunity to be exposed to as many different lines of efficacious therapy as possible.

In summary, the patients who are truly suitable for a “watch and wait” strategy are those with nonfunctional neuroendocrine neoplasms with grade 1 histology, without FDG avidity, perhaps a small bowel primary tumor, a low tumor burden, and indolent disease. The absence of any of these factors may drive the clinician to recommend early initiation of SSAs, and thus statistically many patients may end up being commenced on SSAs as a result. A group discussion after the debate had confirmed this recommendation and emphasized the role of the patient’s wishes in the decision process.

5 | QUALITY OF LIFE IN PATIENTS WITH NEUROENDOCRINE TUMORS

Ms Kate Wakelin

NET Patient Support Nurse, NeuroEndocrine Cancer Australia, Melbourne, Victoria, Australia

Neuroendocrine tumors (NETs) are relatively uncommon making them difficult to diagnose, and most often occur in the gastrointestinal tract or bronchopulmonary tree.²³ Treatment is complicated and can have debilitating side effects impacting on the patient’s quality of life (QOL). The incidence and prevalence of NETs is steadily increasing in Australia.² Current projections indicate that nearly 5000 Australians will be diagnosed with NETs in 2020, representing 3.4% of all new cancer diagnoses.² The 5-year survival rate has also increased from 20% in 1987 to 48% for the period 2012–2016.²

eSHINE is a home injection and patient support service, which commenced in 2009, for people living with NETs or acromegaly receiving long-acting octreotide (octreotide LAR) treatment.²⁴ Patients prescribed octreotide LAR initially attend a hospital clinic for monthly

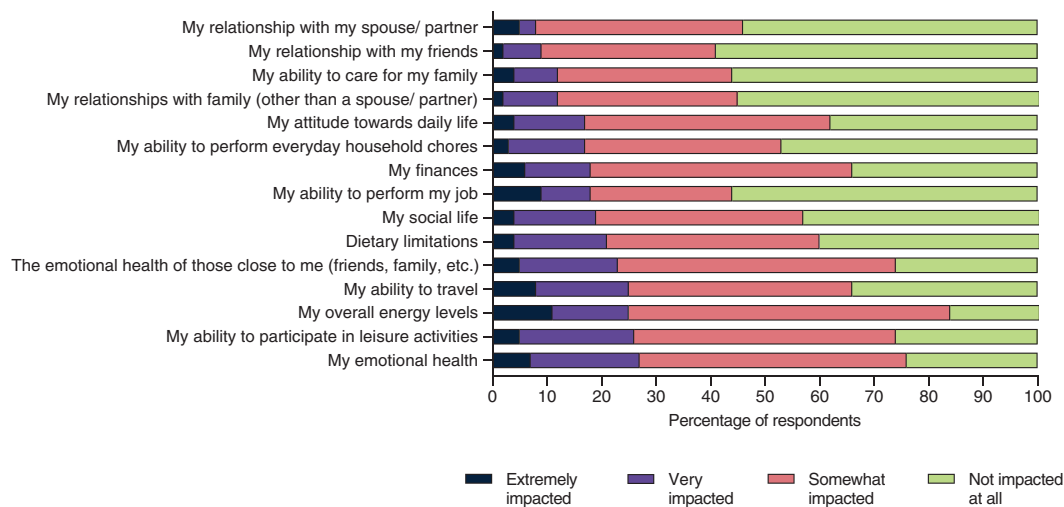


FIGURE 2 Impact of neuroendocrine tumors on respondents to the eSHINE patient survey (N = 133)

injections and ongoing education and support. Patients can be referred to eSHINE by their treating clinician once their condition has stabilized.²⁴ The eSHINE service is provided by doctors and nurses, removing the need and added burden of monthly hospital visits.²⁴ This study aimed to increase our understanding of the impact of NETs on a patient's QOL, and to assess the benefit of the eSHINE program.

Consented patients from the eSHINE mailing list (N = 267) were invited to participate in an electronic, self-reported survey comprising 29 questions. These questions covered clinical characteristics, diagnosis, patient sociodemographic factors, the impact of living with NETs, and the perceived benefits of the eSHINE program.

There was a 54% (n = 144) response rate with 129 (48%) respondents answering all questions. Respondents were almost evenly split in relation to both gender (female 52.1%; male 47.2%) and geographic distribution (metropolitan 51.4%; regional 48.6%). Most respondents were aged over 65 years (59%) and were retired (56.3%).

Seventy-three (50.7%) of the respondents had a primary diagnosis of gastrointestinal NETs and 83 (57.6%) had been diagnosed more than 5 years ago. Respondents reported that living with NETs had negatively impacted many aspects of everyday living (Figure 2). The factors most affected were energy levels (84%), emotional health (76%), and reduced ability to participate in leisure activities (74%). These findings support those from a similar study of patients with NETs in Oceania.²⁵ Access to a supportive network to manage and treat their NETs was extremely important to participants. Over 80% of participants were satisfied or extremely satisfied with the eSHINE program, and more than 85% reported a positive impact on their QOL. Benefits included time and cost savings due to reduced hospital travel, treatment flexibility around own schedule, reduced stress/worry due to visit by trained healthcare professionals, choice of support services, and reduced carer burden. The most helpful aspects of the eSHINE program were found to be having a healthcare professional to administer treatment at the patient's home. This was followed by reimbursement for Chromogranin A testing and ⁶⁸Ga-DOTATATE PET scans.

Our results show that people living with NETs experience multiple negative impacts on their QOL. However, the eSHINE program was seen as valuable for several reasons, including the support gained from healthcare professionals. These findings are important due to the increased survivorship of people living with NETs. Further, the COVID-19 pandemic has illustrated the importance of home-based healthcare delivery programs, such as eSHINE, in keeping vulnerable patients out of hospital, reducing both exposure and transmission to nosocomial infections, such as coronavirus.²⁶

6 | HOW THE CLINICAL COMMUNITY CAN BETTER SUPPORT QUALITY OF LIFE FOR NEUROENDOCRINE PATIENTS

Ms Meredith Cummins

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Neuroendocrine tumors (NET) frequently result in chronic disease that is described by many patients as a "rollercoaster ride" that impacts many aspects of their lives.

Neuroendocrine cancer is a heterogenous cancer, and the presenting symptoms are often nonspecific (Figure 3). Prediagnosis can be a challenging time for patients, with misdiagnoses and delayed diagnosis having a huge impact on their quality of life (QOL). Patients often go through multiple investigations, and by the time the diagnosis is made, many patients with NETs have advanced disease.

The eventual delivery of the diagnosis frequently results in patients having to deal with a myriad of emotions. In addition, medical tests, travel-related expenses, and specialist visits are common cost burdens,²⁷ and patients with NETs may also experience job loss or early retirement due to their disease.

There have been several recent studies conducted focussing on the impact of NETs on QOL.

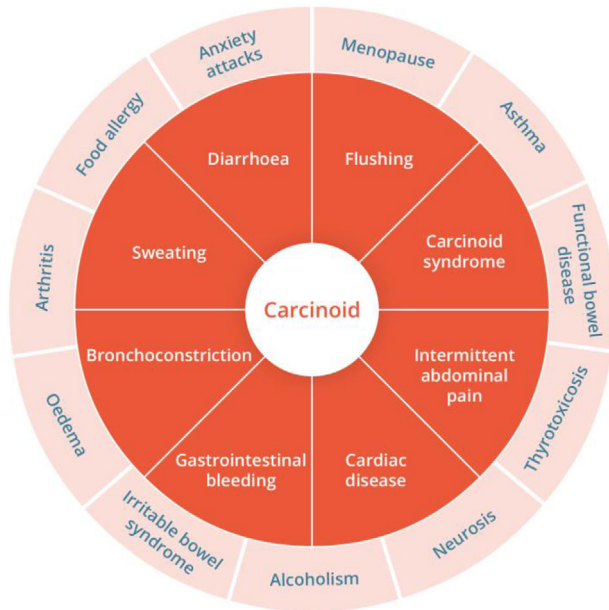


FIGURE 3 Symptom wheel for neuroendocrine tumors--the nonspecific, vague nature of the symptoms and signs (inner circle) results in diagnostic error (outer circle) of other disorders or delay in correct diagnosis

- A 2018 survey of 138 people with NETs in the Oceania region (7% of the global study)²⁵ found that NETs had a negative effect on the patients' overall energy levels (72%), emotional health (66%), and finances (56%). There was also an impact on work life, with many people working reduced hours (44%), taking days off work (64%), or stopping work for a period of time (31%).
- A 2019 integrative literature review found patients with NETs experience fatigue, nausea/vomiting, pain, dyspnea, and sleep disturbance, and that anxiety, higher rates of depression, and stress negatively impact health-related QOL.⁸
- A 2019 observational study of symptom tracking using a mobile application (app) revealed a large symptom burden for people with NETs that varied daily and had a negative impact on mental, physical, and social QOL.²⁸ Weekly symptom tracker averages correlated well with validated health-related QOL and symptom questionnaires, and daily app-based journaling may also reduce recall bias and give more detail on the daily lived experience.

When asked about improving management, patients report wanting better local access to NET-specific medical treatments; more awareness and understanding about NETs, including how to manage disease- and treatment-related symptoms, materials to better explain their condition, and access to a multidisciplinary medical team. The top three factors providing the most "peace of mind," reported by patients on the eShine support program, were having a supportive and knowledgeable medical care team, having a home injection service provided by a trusted and trained healthcare professional, and having access to the latest information about their disease.

Collaboration between centres to improve and unify patient care and research, provision of best practice information and fact sheets, and the development of NET optimal care pathways are important in building for the future.

6.1 | QOL enhancement through education and information

NeuroEndocrine Cancer Australia (NECA) is developing educational modules for general practitioners entitled "Not your usual suspects – How to identify neuroendocrine cancer when it's not part of the typical line-up." These interactive modules are accredited by The Royal Australian College of General Practitioners (40 continuing professional development points) and aim to improve the understanding of NETs to enable earlier diagnosis, streamline processes for referral to NET Centres of Excellence, improve knowledge of treatments, and promote QOL for patients.

In addition, NECA, in collaboration with NET specialist clinicians from around Australia, has launched the PLANET Registry. The purpose of the registry, the first NET registry in the world, is to:

- collect data on patients with NETs from Australian hospitals;
- identify the medical needs of patients with NETs;
- determine resource needs to treat patients; and
- provide a platform to aid with planning of medical research.

There is also a smart phone application (app) for patients recruited to the PLANET registry to record patient-reported outcomes thus becoming a living diary. The current data collected are:

- QOL data (through European Organisation for Research and Treatment of Cancer quality of life questionnaire [QLQ]-C30 and QLQ-GINET21 questionnaires)
- Bristol Stool Scale data;
- Height, weight, and body mass index data; and
- Eastern Cooperative Oncology Group performance status data.

Early introduction for patients to NECA, by healthcare professionals, can help enhance the QOL of patients with NETs, through the provision of booklets, fact sheets, and introduction to support networks. An improved understanding of the symptoms and management of this chronic, complex, disease among healthcare workers is also key to improving patients' QOL. Clinicians should refer patients to state-based NET Centres of Excellence and practice collaborative care, irrespective of metropolitan, regional, or rural locations.

7 | CONCLUDING SUMMARY

Prof Michael Michael

Consultant Medical Oncologist, Co-Chair Neuroendocrine Unit, a European Neuroendocrine Tumor Society (ENETS) Centre of Excellence Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia

This meeting underscored the importance of discussing the unmet needs of patients with neuroendocrine tumors (NETs) in a multidisciplinary environment. With over 300 Australian attendees, the meeting explored key questions relating to the treatment and management of patients with NETs. An online survey immediately preceding the presentations highlighted increased prescribing of somatostatin analogues (SSAs) for both functional and nonfunctional pancreatic and small bowel NETs, as well as increased awareness of the impact of disease-related symptoms on health-related quality of life (HRQOL).

SSAs inhibit endocrine and exocrine secretions and have antiproliferative and proapoptotic effects.²⁹ SSAs, such as Sandostatin LAR (octreotide) and Somatuline Autogel (lanreotide), are considered first-line therapies of choice in controlling GEPNETs secretory syndromes.³⁰ A profound response to SSA therapy is generally achieved in patients with carcinoid symptoms, with biochemical response ranges up to 50%.¹⁵

The phase III PROMID and CLARINET trials have demonstrated that SSAs delay tumor growth in patients with both mid-gut NETs and GEPNETs.^{11,12} Treatment choices for patients who develop secretory syndromes or radiological disease progression, despite standard dose SSAs, include increasing SSA dose intensity.^{31,32} The other alternative is peptide receptor radionuclide therapy, the efficacy of which was confirmed in the NETTER-1 phase III trial.³³

Delaying the start of SSA treatment and avoiding the need for monthly injections can be beneficial for some patients with nonfunctioning grade 1 tumors, with low-volume and indolent disease. However, not all patients are suitable for this “watch and wait” strategy, especially patients with poor hepatic reserve, grade 2 or higher disease, poor performance status, and patients with pancreatic NETs who have a poorer prognosis. Careful discussion with patients is required to ensure that QOL is not compromised by anxiety about the strategy (“watch and worry”) or by the burden of disease monitoring.

There is a large unmet need in HRQOL of patients with NETs. Home-based administration of SSA by a healthcare professional was identified in the eSHINE study as being valued by patients and the service improved patient HRQOL and reduced stress.²⁴ Patient QOL can also be better supported by addressing the health information needs of patients with GEPNETs and their health care providers. NeuroEndocrine Cancer Australia (NECA) plays an essential role in advocacy for patients with NETs by linking patients to specialist NET centers, providing NET information to patients, running general practitioner education services, developing national NET guidelines, and overseeing the innovative development of the PLANET registry.

In conclusion, the *Real-world management and patient perspectives on quality of life with neuroendocrine tumours: an Australian and New Zealand perspective* webinar provided an excellent forum to discuss patient and clinician perspectives. The utility of SSAs as a first-line treatment for patients with functional and nonfunctional GEPNETs was highlighted as was the QOL concerns and unmet needs of patients with NETs.

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