

Multidisciplinary Care

Multidisciplinary Reference Centers: The Care of Neuroendocrine Tumors

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Abstract

The purpose of this study was to review the need for and benefits of multidisciplinary care in patients with cancer, to describe our experience setting up a multidisciplinary reference center (MRC) dedicated to the treatment of the uncommon cancer neuroendocrine tumors (NETs), and to present the perspective of a patient seeking treatment at our center.

The literature was searched to review the outcomes of patients with cancer treated by a multidisciplinary team.

Multidisciplinary care for patients with more common cancers has been associated with improvements in diagnosis, treatment planning, survival, patient satisfaction, and clinician satisfaction. Similar benefits have been seen in patients with NETs receiving treatment at a specialty center. The establish-

ment of our NETs MRC allows us to offer integrated care, providing surgical oncology and medical oncology disciplines; nurses well experienced in the treatment of NETs; and the expertise of endocrinology, diagnostic radiology, and interventional radiology specialists. Since our clinic was established, we have increased our availability to see patients and have received positive feedback from those attending.

MRCs have been associated with improved patient outcomes. As providers at a dedicated NETs MRC, we feel that these centers have a positive effect on both patient and provider experience. The creation of specialty centers with a focus on improving outcomes and quality of care should be a goal of health care systems and are especially important for patients with NETs and other rare cancers.

Introduction

Multidisciplinary care is ideal in the management of patients with complex conditions such as cancer. This style of patient care requires a team approach to health care that involves all relevant medical and allied health disciplines.¹ Multidisciplinary care for patients with cancer has been associated with improvements in diagnosis, treatment planning, survival, patient satisfaction, clinician satisfaction, and financial efficiency.^{2,3} Recognizing the potential benefits of treatment at a multidisciplinary reference center (MRC), this review will highlight the need for MRC care in rare cancers by using the example of neuroendocrine tumors (NETs). In addition, we describe our experience in establishing an MRC at Sunnybrook Odette Cancer Center (OCC) in Toronto, Canada.

Elements and Benefits of MRCs

MRCs dedicated to caring for patients with cancer are often considered the gold standard of health care delivery.¹ There is no single, universal model of multidisciplinary care, but most MRCs aim to facilitate multiple consultations during a single patient visit. MRC care also requires robust and continued communication among the health care team, typically facilitated by the case conference or tumor board, in which health care providers of different specialties gather to review and discuss the next steps in a patient's treatment.

MRCs have traditionally focused on treating more common cancers such as breast cancer and have achieved favorable out-

comes.² In a study of women with breast cancer treated 1 year before or 1 year after the opening of a multidisciplinary breast cancer clinic at Henry Ford Hospital, Detroit, MI, those who received MRC care had significantly decreased time between diagnosis and the initiation of treatment (42.2 days *v* 29.6 days; $P < .0008$) along with increased patient satisfaction.⁴ Among women with breast cancer treated in Yorkshire, United Kingdom, better survival rates were achieved by women under the management of clinicians who saw > 30 new patients per year with access to a multidisciplinary setting.⁵ High-volume centers appear to yield better management and survival.

Survival benefits associated with MRCs have also been seen in other common malignancies. Among patients with inoperable non-small-cell lung cancer treated at the Royal Infirmary Glasgow, United Kingdom, those treated after the introduction of multidisciplinary team care were significantly more likely to receive chemotherapy and achieved significantly lengthened median survival time compared with those who received treatment before this care was introduced.⁶ In a retrospective database study of patients with head and neck cancer treated in the south and west of England, care at a multidisciplinary clinic led to significantly improved 2-year survival.⁷ Finally, a study of women with ovarian cancer found that care at a multidisciplinary clinic led to a significant survival advantage ($P < .001$) that remained significant after adjusting for different rates of chemotherapy use ($P < .01$).⁸

Rationale for Establishing MRCs for Patients With Rare Cancers

The successful outcomes in patients with cancer treated at MRCs, along with the frustration experienced by patients with NETs, inspired our center to establish an MRC dedicated to the treatment of this uncommon cancer. In rare cancers, knowledge may be confined to certain practicing physicians and/or centers where patients with these diseases are seen in higher volumes. Creation of a dedicated MRC can lead to more informed treatment management decisions for those presenting with a rare condition. In support of this idea, a study evaluating patients with the rare disease soft tissue sarcoma found that treatment at a high-volume center was associated with a significantly lengthened median survival and was an independent predictor of improved survival.⁹

NETs

NETs are considered an uncommon form of cancer. However, because of a rapidly increasing incidence (rising five-fold since 1973)¹⁰ and increased prevalence, patients with NETs are becoming progressively more common in cancer clinics. NETs provide a clinical challenge because they comprise a heterogeneous group of malignancies with a wide range of morphological, functional, and behavioral characteristics.¹¹ NETs can display various growth patterns, from slow to explosive. In addition, as neoplasms produced from endocrine glands, NETs have the ability to hypersecrete hormones with a wide range of clinical manifestations including carcinoid syndrome, which is characterized by flushing and diarrhea.¹² An effective diagnosis of NETs requires a multimodal approach that combines evaluation of clinical symptoms and hormone levels, radiological and nuclear imaging, and histological confirmation.¹³ Furthermore, because of its rare nature, many physicians may lack experience with or education about this disease, resulting in misdiagnosis and delayed diagnosis.¹⁴ This creates a compelling rationale for centralized multidisciplinary care in NETs.

NETs and Multidisciplinary Care

An NET-carcinoid summit organized in 2007 by the National Cancer Institute determined that there is: (1) a lack of access to sensitive and specific imaging to diagnose NETs, (2) variable local resources and expertise in treatment, and (3) a paucity of high-quality clinical trials. The consensus was to encourage the development of regional MRCs and to establish multicenter clinical trials.¹⁴ To meet this need, the European Neuroendocrine Tumor Society (ENETS) has recently taken the initiative in establishing criteria for NET Center of Excellence (CoE) certification throughout Europe. The newer, sister organization of ENETS, North American Neuroendocrine Tumor Society (NANETS), has recently taken a slightly different approach to standardize care throughout North America by producing its first set of original treatment guidelines, in which multidisciplinary care is highlighted as the most effective treatment strategy.¹⁵ However, development of treatment guidelines is distinct from the development of MRCs that deliver integrated care.

There has been evidence of improved survival in patients with NETs treated at specialty centers. In a retrospective study describing evolving trends in treating patients with metastatic NETs in the North West Adelaide Health Service, Australia, Townsend et al¹⁶ found significant differences in outcomes achieved by patients treated at a medical oncology unit (MOU) compared with those treated with standard care. Among these, in patients treated at an MOU, median survival was 112 months versus 32 months for patients treated at another specialty service. In addition, 79% of patients who attended an MOU received treatment with octreotide LAR (the mainstay of medical therapy) compared with only 10% of patients referred to a different type of specialist. In octreotide LAR-treated patients, median overall survival was 112 months versus 53 months in patients who did not receive octreotide LAR ($P = .021$). Ten-year survival was 40% and 22%, respectively. Studying the outcomes of 146 patients with metastatic midgut NETs treated by the MRC at H. Lee Moffitt Cancer Center, Tampa, FL, between 1999 and 2003, Strosberg et al¹⁷ report a median survival of 103 months and a 5-year survival rate of 75%. The authors state that the prolonged duration of survival found in their specialist center compares favorably with historical data and possibly reflects the impact of improved use of somatostatin analogs and other medical treatment advances.

Clinical Trials

Because there are a limited number of approved therapies for the treatment of patients with metastatic NETs, clinical trials are necessary to evaluate new therapeutic options. However, the rarity of NETs is often cited when discussing the lack of clinical trials in this disease.¹⁴ The establishment of MRCs has been clearly associated with increased recruitment rates in clinical trials in patients with cancer.^{18,19} In 2008, a study found that efforts by a multidisciplinary team to increase patient awareness of appropriate clinical trials significantly increased trial screening rates and may improve recruitment.²⁰ MRCs dedicated to NETs will not only further research in the area of NETs by facilitating enrollment in large randomized trials, but also have the added benefit of providing patients with new treatment options that would not be available in a non-MRC setting.

Establishing an NETs MRC

We decided to establish an MRC because many patients with NETs who presented to our center were frustrated with the medical system, having had difficult and prolonged experiences in either diagnosis or treatment of their disease (Fig 1). This may have been exacerbated by access barriers to integrated care for patients with NETs. In Ontario, patients with NETs often face complex treatment plans, including chemotherapeutic, hormonal, and surgical strategies that require coordinated management. We felt that this would be best delivered in a single, integrated clinic setting (Fig 2). In addition, the resources available in our tertiary care center were optimal for the development of the NETs MRC at the OCC (Fig 3).

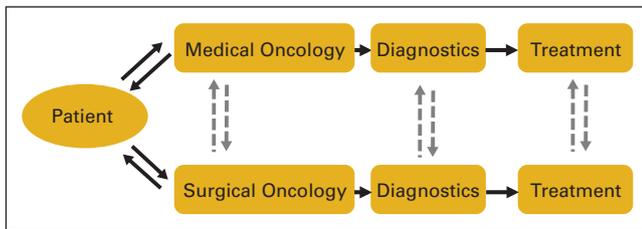


Figure 1. Typical flow of care for a patient with neuroendocrine tumors without integrated care. The patient flows through individual disciplinary arms, which may or may not involve collaboration. It is possible that a patient will never present to certain units or may undergo duplicate testing and possible contradictory decision making in each arm.

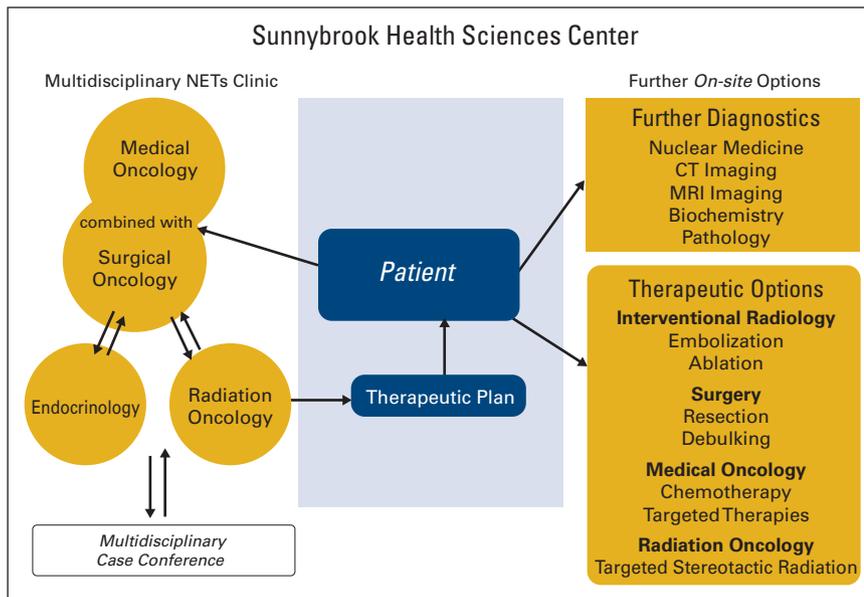


Figure 2. Patient-centered flow of care in the multidisciplinary neuroendocrine tumors (NETs) clinic. The patient is at the center of decision making. In contrast to Figure 1, there is consistent assessment by multiple arms of care, improved coordinated decision making, and a reduced chance of duplicated tests and/or contradictory plans of care.

Structure and Operation of Our MRC

All patients with NETs are directly triaged to the NETs MRC and are scheduled to be seen by physicians from both the medical and surgical oncology departments at the same initial visit. In addition, they are seen by the same dedicated and experienced nurses from both medical and surgical oncology staff each time they visit the clinic, which provides consistent patient information, education, and support and ensures a high level of care continuity. The clinic also provides a valuable educational opportunity for trainees as well as early exposure to multidisciplinary care.

The clinic addresses the needs of both new and follow-up patients with NETs. Medical information, including diagnostic imaging, is reviewed in advance by both medical and surgical oncology teams to formulate a coordinated plan. For each patient, a multidisciplinary discussion takes place, which can include input from the endocrinology, diagnostic radiology, and interventional radiology teams, with the objective of developing

an integrated, individualized management plan for discussion with the patient. Treatment recommendations are always conveyed to and discussed with the referring doctor. For patients who do not live locally, treatment plans generated from the integrated clinic can be customized for coordinated implementation at their nearest institution. Furthermore, video conferencing with satellite sites across Ontario has been established to facilitate patient care.

Provider Perspective: How We Did It

The establishment of the NETs MRC at OCC required the input, consent, and support of multiple partners. At the planning stage, community physicians were informally consulted to ensure that adequate need existed and to obtain opinions on how the MRC might be best structured from both a patient and a provider perspective. A series of discussions with members of the pathology department was essential to ensure their involvement in both consistent synoptic reporting as well as diagnostic and research components of the MRC. Support from the heads of medical and surgical oncology was obtained by emphasizing that the NETs MRC would be an extra clinical endeavor in addition to (rather than instead of) the current workload of the physicians involved. Not to be overlooked, we have benefited greatly from the support of our partner nurses, who after working with many patients with NETs, have first-hand understanding of the importance of the NETs clinic and have expressed enthusiasm in participating. Nursing administration has been supportive of this unique initiative by allowing our partner nurses to make the NETs MRC a priority.

Challenges in Establishing Our Center

The establishment of our MRC required us to overcome certain challenges. Initially, barriers to our program included a lack of awareness regarding both the nature of NETs and the need for a separate MRC within the context of OCC. The leadership team at OCC also had concerns regarding the use of space and resources. For example, the potential for an increased demand for chemotherapy—which is already over capacity at our center—was expressed, requiring us to convince decision makers that most patients who need systemic therapy will receive it at their referring institution. In addition, because of the space constraints on the creation of an open clinic at OCC, the physical space in which to locate our clinic was obtained by the hospital administration through a plan of compromise with our colleagues. Representing our MRC initiative as an opportunity to be expert in an underserved field and perform important research allowed us to win support of the administration and proceed with the creation of our MRC.

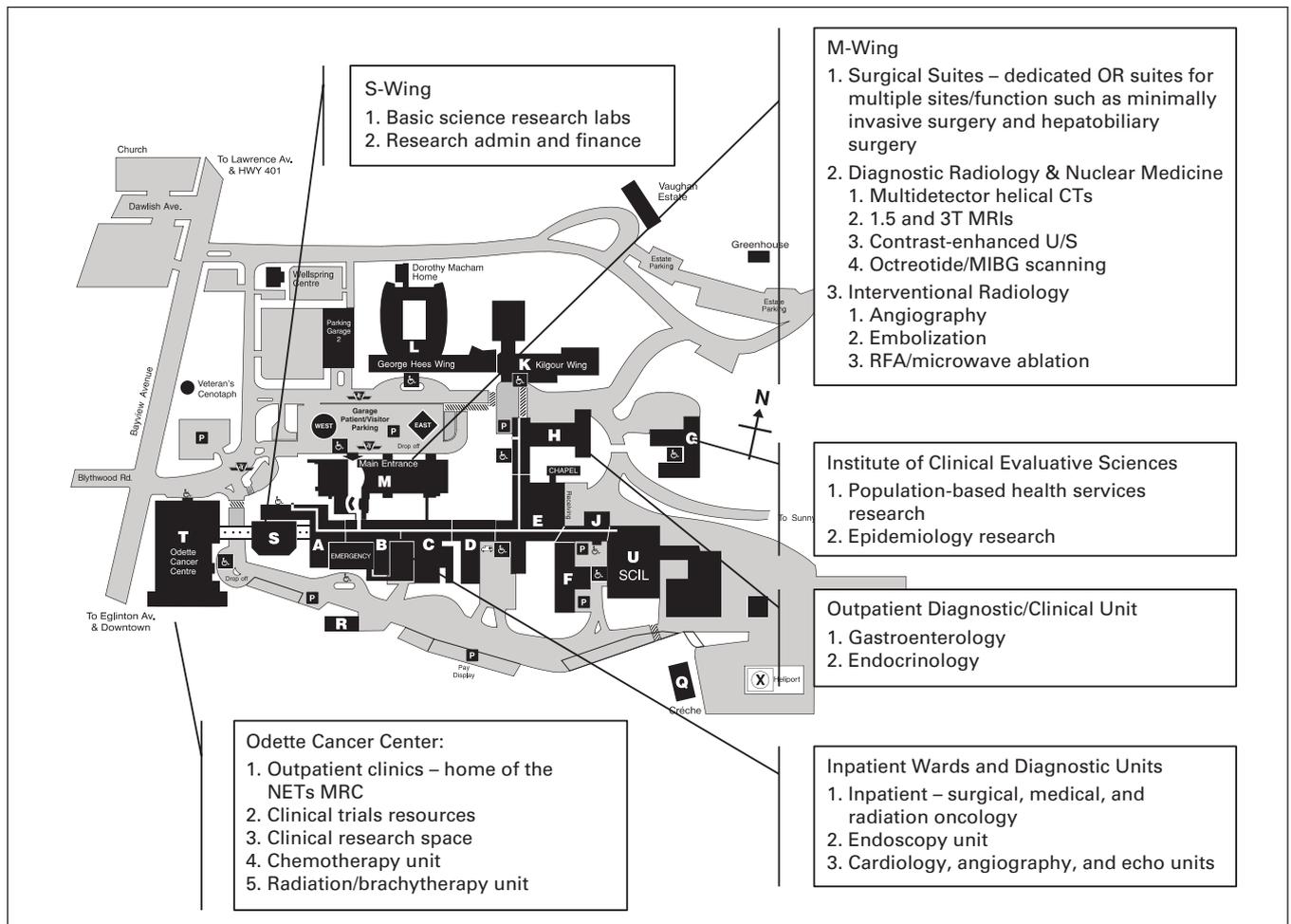


Figure 3. Structural plan of the campus where the Odette Cancer Center neuroendocrine tumors (NETs) multidisciplinary reference center (MRC) is situated, showing the location of all services available on one site. admin, administration; OR, operating room; CTs, computed tomography scans; MRIs, magnetic resonance images; U/S, ultrasound; MIBG, (iodine-131-metaiodobenzylguanidine) scintiscan; RFA, radio frequency ablation.

Challenges in Coordinating the Work of Multiple Colleagues

Coordinating the involvement of all specialties was also challenging initially. For example, radiologists were reluctant to participate because of time constraints and the fact that not all presenting patients required interventional radiology procedures. However, in recognition of the fact that interventional radiologists can play an important role in the treatment of patients with NETs, an agreement was reached in which an interventional radiologist visits the clinic at one point during the day to discuss all possible cases requiring their involvement. This plan has been well received. In addition, our center has the capability for video conferencing to facilitate collaboration with physicians in any location in Ontario. Moreover, this enables the center to both receive and transmit live diagnostic and pathology imaging.

Other colleagues unaffiliated with but affected by our MRC also require ongoing consultation. Potential conflicts between our colleagues are actively avoided by emphasizing that the NETs clinic will not require their involvement. We also readily relocate our MRC from one wing of the OCC to another to remain con-

siderate of the physical space required by our colleagues, and take advantage of all empty hospital space during our MRC clinics.

Finally, our MRC requires a great personal commitment from the founding physicians, as the time and work devoted to this practice is beyond that compensated by our secured research funding. In our Canadian Academic Tertiary Cancer Center, all care is publicly funded, and the federal and provincial regulations prevent any privately funded care delivery. Accommodations were made by all participants, as remuneration was different for each team member. Medical oncologists and nursing staff are remunerated on a salary basis, whereas surgeons and radiologists still function on a fee-for-service basis. Balancing this situation required that all participants had a high level of personal commitment to running this MRC. Currently, there is no official governance, and all decisions are made by consensus between the founding physicians and nursing partners.

Future Outlook

We initiated our MRC in June 2009 as a once-a-month clinic and we have now increased its frequency to twice a month. Looking forward, we hope to expand our MRC in terms of the

number of patients treated and number of research opportunities, including clinical trials. One of our goals was to ensure that patients leave the center with a well-constructed plan for their treatment as well as an understanding of their disease. We believe that we have reached this goal and are currently conducting a qualitative study to assess this. The success of the NETs clinic has created positive momentum such that other specialties, including radiation oncology, have expressed interest in collaborating with us as part of our NETs MRC.

Patients' Perspectives

Because our clinic was established recently, robust data on patients' perspectives have not yet been obtained. However, a qualitative study aiming to gain insight into the experience of patients diagnosed with NETs and treated at OCC has completed data collection and the results are currently being analyzed. A mixed-methods study using in-depth individual patient interviews was performed. After every three interviews, responses were analyzed and the interview questions adjusted slightly to address common themes. Our ultimate goal was to use patients' feedback to improve the design of our clinic and our care of patients. To date, unsolicited patient feedback has been favorable. An example follows:

After several misdiagnoses and many months of anxiety and waiting, I was finally diagnosed with a midgut NET and carcinoid syndrome. I was referred to an oncologist in a cancer center who decided that I was a good candidate for chemotherapy. After three sessions, a computed tomography scan showed that the tumors had grown. I was given the choice of entering a drug trial or going home to "wait and see." I did not fare much better at the second cancer center I attended. I was offered a treatment that was outdated, with no data published in a reputable journal.

Finally, I was fortunate to be able to attend the new MRC at Sunnybrook. At each visit, I see a medical oncologist, a surgeon and their respective nurses. Decisions about my care are made with a team approach. I am a well-informed consumer and often attend visits with journal articles in hand. All providers were open to my needs. At my last visit, innovative options were discussed, which indicated collaborative thinking at the highest level. I feel listened to, appreciated, and respected. By seeing all providers at one time, I am saved multiple visits. Not only is

everyone on the same page, but everyone is reading from the same book!

MRCs are the gold standard of cancer care delivery in many national health systems. Patients with cancer who attend MRCs have achieved improved outcomes, including a reduction in the time between diagnosis and treatment and longer survival time, alongside provision of a greater number of therapeutic options. As providers at a dedicated NETs MRC, we feel that these centers have a positive effect on both patient and provider experience. Although establishing our MRC at OCC required the input, consent, and support of multiple parties, including that of peers, administrators, nursing staff, and decision makers, initial resistance to our undertaking was resolved with practical compromise and an appeal to the shared desire of establishing a leading center in an underserved field, in which important health care delivery and research could be performed in this uncommon cancer. The creation of specialty centers with a focus on improving outcomes and quality of care should be a goal of health care systems and are especially important for patients with NETs and other rare cancers.

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