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Shared Care Model (SCM) in the Management of Neuroendocrine Neoplasms (NENs)- Patient Perspective

Spencer Fansolato¹, Jackie Herman², Weera Seddiq¹, Enrico Mandarino², Radhika Yelamanchili³.

¹Michael G. DeGroot School of Medicine, McMaster University; ²CNETS Canada, Cornwall, Ontario, Canada; ³Niagara Health System, St. Catharines, Department of Oncology, McMaster University.

BACKGROUND

Rural-urban disparities in NEN incidence and outcomes have been previously noted. Multidisciplinary expert management of NENs is consolidated to urban centers. SCMs can bring expert care closer to home. SCMs have been studied in cancer survivorship, but not in NENs. Patient perspectives on the current landscape, including their attitudes towards primary NEN care (PNC) versus NEN specialty centers (NSC), are pivotal to designing an optimal SCM.

METHODS

An anonymous 43 question survey developed on SurveyMonkey was reviewed initially by a patient focus group. It included multiple choice, select-all, and open responses. Domains included demographics, clinical characteristics, PNC vs NSC details and factors affecting patient satisfaction. The Canadian Neuroendocrine Tumour Society (CNETS) patient advocacy group's electronic mailing list was used for distribution during 2023-2024. Spearman's Regression was used for analysis.

RESULTS

96 Canadian NEN patients participated in the first round, predominantly female (73%) and >60yrs (70%). 56% identified their PNC provider as a NEN specialist. 36% have been referred to NSC, mostly for PRRT or second opinion. 50% report financial toxicity, 55% drove >4hrs, 70% took time away from work/activities, and 42% reported expenses >\$200/appointment to attend NSC. Despite this, 61% reported improved patient experience due to NSC involvement, whereas 84.5% were satisfied/somewhat satisfied with their PNC.

There was a significant ($p < 0.05$) association between increased financial toxicity and younger age, lower household income, more time spent away from work/activities attending NSC appointments, and high burden of physical symptoms. Factors valued in NSC included knowledge/skills and resource availability whereas ease of access, care closer to home, and continuity of providers were valued in PNC; Tumor board review significantly improved satisfaction with both ($p < 0.05$). Higher symptom burden correlated positively with NSC satisfaction, but negatively with PNC ($p < 0.05$). Most patients (74%) identified ability to access NSC as needed, while continuing with primary NEN care as the key to SCM.

CONCLUSIONS

To our knowledge, this is the first patient survey focusing on variables that rationalize the need for and determine the success of NEN SCM. We demonstrated the relative pros/cons of both PNC and NSC, including time and financial toxicity. Future SCMs should bring NSC expertise/resources closer to home by increasing knowledge/experience of PNCs, coordination between providers, and NEN tumor board access. Our sampling methods incurred bias towards well-connected CNETS patients. Hence, next steps in survey expansion to increase generalizability by targeting more diverse patient population via social media, clinics and patient support programs are underway.

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