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Implementation of a Patient Advisor Program for Neuroendocrine Tumor Patients: Acceptability, Benefits and Potential Challenges

Florence Bénard¹, Frédéric Mercier¹, Sandrine Huez², Marie-Pascale Pomey³.

¹Surgical Oncology, Department of Surgery, Centre Hospitalier de l'Université de Montréal (CHUM), Montréal, QC, Canada; ²Centre d'Excellence pour le Partenariat avec les Patients et le Public, Montréal, QC, Canada; ³Centre de recherche du Centre hospitalier de l'Université de Montréal (CRCHUM), Montréal, QC, Canada. Department of Public Health, Université de Montréal, Montréal, QC, Canada.

BACKGROUND

Multiple unmet needs of patients diagnosed with a neuroendocrine tumor (NET) have been described in the literature, especially informational and psychological needs. A multidisciplinary approach has been suggested to improve overall care of NET patients. Trained patient advisors (PA) could complement the healthcare team, by providing a personalized accompaniment to patients based on their experiential knowledge, therefore helping to bridge this current gap. The aim of this study was to explore the acceptability, perceived advantages and limits of a PA program for NET patients.

METHODS

For this mixed methods study, thirteen patients with a diagnosis of small bowel or pancreatic NET were recruited. Participants first completed an online questionnaire to collect sociodemographic data and information regarding their diagnosis. Semi-structured interviews were then conducted with patients alone, or accompanied by their spouse, to collect their opinions on the implementation of a PA program focused on NET patients. Questions explored the patients' interest in the program, the potential benefits and challenges perceived, as well as practical considerations for implementation. Interviews were transcribed verbatim and analyzed following principles of grounded theory.

RESULTS

A total of thirteen patients and four spouses were interviewed, with an average interview length of 64.5 minutes. The creation of a PA program was supported by 85% of the patients, who believed this resource could be an interesting source of information for NET patients, and could provide them with moral support, as well as a meaningful social network. Participants suggested that the possibility of being paired with a PA should be introduced at the moment of diagnosis, but the timing of the initial contact should be left to the patient's discretion. Patients should also be referred to a PA whose trajectory of care is as similar to theirs as possible. Anticipated challenges included incompatible personalities, discomfort and logistical considerations such as time and transport.

CONCLUSIONS

The implementation of a PA program would be positively received by NET patients. Envisioned benefits included access to experiential knowledge as a source of information, provision of moral support and creation of a social network, which could possibly address current unmet needs. Further studies are needed to evaluate the feasibility and concrete impacts of such a program on NET patients' trajectory of care.

ABSTRACT ID 21433

