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Identifying Care Processes Promoting Person-Centred Care for Patients Diagnosed With Neuroendocrine Tumours (NETs)

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BACKGROUND: Patient-centred care (PCC) involves partnering with patients to co-design and deliver care. PCC delivery often focuses on the clinical encounter and provider-patient relationship which have inter and intra-provider variability. However, standardizing the care environment with a focus on processes that will promote patient engagement is a critical enabler to PCC. Providing PCC for NETs entails unique challenges due to rarity, complexity, and misinformation. Previous work indicated that the majority of NETs patients prefer taking a more passive or shared but leaning passive role in shared decision-making (SDM). Care processes underpinning PCC and participation in SDM according to this preferred role are unknown. We aim to identify processes for achieving PCC in terms of engagement in their care.

METHODS: We will use a narrative interview approach with a semi-structured, open-ended, interview guide; through story-telling, participants will be prompted to share their experiences, rather than abstract belief statements. Patients from NETs clinics in Canada, Australia, and the United States will be included. A purposive sampling strategy will be used to enroll approximately 10 patients per centre, for a total of 60 patients.

RESULTS: Data analysis will be iterative and inductive, framed by the adapted Donabedian framework for PCC. Data coding will establish major and minor patterns and themes in the data. Data collection and analysis will start in Fall 2020 and continue until theoretical saturation.

CONCLUSION: This study will identify how to best engage patients in SDM according to their preferred role and how to provide PCC adapted to the unique challenges of NETs. We will focus on actionable care processes to provide structure where there might be intra and inter-physician variation. Multi-institutional perspectives will be sought to learn from different systems, and ensure usability across health systems.

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