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International Patient Survey of Physical, Emotional, and Informational Challenges when Living with Neuroendocrine Tumors: Understanding the Unmet Needs

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BACKGROUND: The usefulness of information sources used by patients with neuroendocrine tumors (NETs) is rarely explored. Patient surveys that gather information about disease burden and its impact on daily living, including emotional impact, may be key to optimizing care. This survey aimed to: understand the physical, emotional, and informational challenges facing patients before, at, and after NET diagnosis; identify information sources, preferred format, and any unmet needs.

METHODS: The Carcinoid Cancer Foundation, Netzwerk Neuroendokrine Tumoren (NeT) e.V., and L'Association des Patients porteurs de Tumeurs Endocrines Diverses approved questions. The online survey was disseminated via respective websites, social media, and email (for patients registered with an organization). Each survey comprised 12 questions with multiple-choice answers and/or free-text entry.

RESULTS: 741 surveys were completed in the USA (n=428), Germany (n=240), and France (n=73) over 6 weeks in 2015. Diagnosis was made ≤5 years prior to

the survey in ≥65% patients. Prior to diagnosis, the most commonly reported symptoms were diarrhea (40% of responders [min]–47% responders [max]) and flushing (13–45%). Other common symptoms included changes in bowel or bladder habits, and persistent pain. After diagnosis, the most common emotion was anxiety (52–67%). Patients living with NETs reported fatigue (38–66%), diarrhea (20–53%), and sleep disturbance (35–38%) as their greatest challenges. The most frequently used sources patients used to seek information about NETs included disease awareness websites, search engines, patient association websites, and patient brochures. The most favored format for information about the illness was "patients-like-me" case studies (62–89%). Preferred information sources and formats differed among countries. There was an unmet need for simple and accessible explanations relevant to circumstantial, physical, and/or emotional difficulties.

CONCLUSION: Patients with NETs seek reliable, personally relevant, easily understood information to help face negative emotions, which may be exacerbated by physical symptoms.