O-10

Care Partner Experiences and Burden in Extrapulmonary Neuroendocrine Carcinoma: Findings from the VOICE Survey

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BACKGROUND

Care Partners (CPs) play a critical role in supporting patients with Extrapulmonary Neuroendocrine Carcinoma (epNEC), yet evidence describing their experiences and unmet needs remains limited. This study characterized the caregiving journey and burden among CPs of individuals with epNEC.

METHODS

A cross-sectional survey was conducted among US adults who had cared for an individual with epNEC within the previous 12 months. Participants were recruited through patient advocacy groups (PAGs) in February 2026. Survey domains included diagnosis and referral, caregiving responsibilities, quality of life (QoL), work productivity, and unmet needs. Care partner burden was assessed using the CareGiver Oncology Quality of Life tool (CarGOQoL; range 0-100; higher scores indicate better QoL) and the Caregiver Work Productivity and Activity Impairment (WPAI:CG; higher percentages indicate more impairment).

RESULTS

A total of 102 CPs completed the survey (mean age, 37 years; 56% White; 12% Rural; 65% college educated or above; 72% employed), with most being the care recipient's child (52%). Care recipients had a mean age of 60 years, were 52% male, 58% White, and 82% had gastroenteropancreatic-NEC. Approximately 60% of care recipients took >1 month to seek medical care after noticing symptoms, with common delays attributed to personal (48%; e.g., lack of awareness of symptoms) and financial (41%) factors. Most CPs (90%) began providing care before treatment initiation; common responsibilities included participating in discussions with clinicians (75%) and accompanying care recipient to

appointments (69%), while assistance with daily hygiene (26%) was reported as the most burdensome task.

Emotional distress, depression, and anxiety were reported as the most significant impacts of diagnosis on CPs' day-to-day lives. CarGOQoL scores demonstrated notable burden in psychological well-being (mean: 51), private life (mean: 59), and physical well-being (mean: 61). Mean activity impairment attributable to epNEC was 51%. Among employed CPs, overall work impairment was 58%, including absenteeism of 22% and presenteeism of 51%.

Oncologists were the primary source of information regarding epNEC management (70%), followed by PAGs (52%) and other healthcare professionals (51%). Interestingly, 41% of CPs reported utilizing artificial intelligence as a source of information. CPs identified care partner support groups, specialists offering novel therapies, and greater involvement in treatment decision-making as their highest unmet needs.

CONCLUSIONS

CPs play a central role throughout the epNEC diagnostic and treatment journey and experience substantial emotional, physical, and work productivity-related burden. Improved access to specialist care and caregiver support resources may help address unmet needs and enhance support for this underserved population.

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