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

#O-10

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Introduction

- epNEC is a rare, aggressive malignancy associated with poor prognosis and limited treatment options[1]
- Diagnosis can be challenging because of disease rarity, nonspecific symptoms, and the need for biopsy and evaluation by a specialist, potentially resulting in a prolonged diagnostic journey[2,3]
- As a result, care partners play a critical role in supporting patients with epNEC, yet evidence describing their experiences, burden, and unmet needs remains limited
- This study sought to provide a comprehensive assessment of the caregiving journey and burden among care partners of patients with epNEC

epNEC, extrapulmonary neuroendocrine carcinoma

Objective

- This study aims to characterize the journey and burden, and identify unmet needs of US care partners of adults with epNEC, including experiences related to diagnosis, caregiving responsibilities, QoL, and work productivity

QoL, quality of life, US, United States

Methods

- A cross-sectional online survey of US adults who had cared for an individual with epNEC within the previous 12 months was conducted in February 2026
  - A care partner was defined as a family member or friend who, without pay, helps a person because of their diagnosis of epNEC
  - Care partners were recruited through national patient advocacy organizations
  - Eligible care partners were aged ≥18 years, resided in the US, and reported caring for an adult with a diagnosis of epNEC or MiNEN/MANEC with a NEC component
- Survey domains included diagnosis and referral, caregiving responsibilities, QoL, work productivity, and unmet needs
  - Caregiving burden was assessed using the CarGOQoL questionnaire; scores range from 0–100, with higher scores indicating better QoL
  - Care partner work productivity and activity impairment was assessed using the WPAI:CG questionnaire, with higher percentages indicating more impairment
- This study was exempt by the Pearl IRB under 45 CFR 46.104(d)(2)

CarGOQoL, CareGiver Oncology Quality of Life; CFR, Code of Federal Regulations; IRB, Institutional Review Board; MANEC, mixed adenocarcinoma neuroendocrine carcinoma; MiNEN, mixed neuroendocrine non-neuroendocrine neoplasm; NEC, neuroendocrine carcinoma; WPAI:CG, Work Productivity and Activity Impairment: CareGiver

Participants

- A total of 102 eligible care partners completed the study (**Table 1**)
  - Median age was 34 years, 43% were male, 56% were White, 12% lived in a rural area, 65% were college educated or above, and 72% were employed (20% full-time, 30% part-time, and 22% self-employed)
  - More than half of care partners (52%) were the care recipient's child
- Care recipients had a median age of 64 years, 52% were male, 58% were White, and the most common tumor locations were gastrointestinal (67%) and hepatopancreatobiliary (16%) (**Table 2**)

Diagnostic and Caregiving Journey

- Approximately 60% of care recipients took more than 1 month to seek medical care after noticing symptoms, with common delays attributed to personal (48%) and financial (41%) factors
- Around half (41%) of care recipients received an epNEC diagnosis confirmation more than 1 month after their initial contact with healthcare providers (37% within 1–3 months and 4% after 3 months)
- Most care partners (90%) began providing care before treatment initiation, including 35% who started providing care when the care recipient experienced symptoms, 27% when they initially sought help from healthcare providers, and 28% after they received their epNEC diagnosis but before treatment initiation
- Common responsibilities performed by care partners included discussions with clinicians during visits (75%), accompanying care recipients to appointments (69%), communicating with medical teams outside of in-person appointments (57%), and assisting with medical-related care (48%) (**Figure 1**)
- Among care partners who frequently accompanied patients to appointments (93%), 37% reported delays in receiving care due to transportation issues

Key Findings and Conclusions

- Care partners became involved early and played a central role throughout the epNEC diagnostic and treatment journey, while experiencing substantial emotional, physical, and work productivity-related burden
- Improved access to specialist care and care partner support resources may help address unmet needs and enhance support for this under-served population
- These findings underscore the importance of recognizing and addressing care partner needs as an integral component of comprehensive epNEC care

Table 1. Care partner characteristics

Characteristic	Overall (N=102)
Age in years, mean (median)	37.0 (34.0)
Gender, n (%)	
Male	44 (43.1)
Female	57 (55.9)
Other/non-binary	1 (1.0)
Race/ethnicity, n (%)†	
White or Caucasian	57 (55.9)
African American/Black	25 (24.5)
Hispanic or Latino	11 (10.8)
Native American or Alaskan Native	7 (6.9)
Asian or Pacific Islander	6 (5.9)
Residence area, n (%)	
Urban	64 (62.7)
Suburban	26 (25.5)
Rural	12 (11.8)
Highest level of education, n (%)	
Less than high school	0 (0.0)
High school graduate	9 (8.8)
Some college	27 (26.5)
College graduate/bachelor's degree	56 (54.9)
Graduate degree (e.g., Master, PhD, MD)	10 (9.8)
Employment status, n (%)	
Full-time	20 (19.6)
Part-time	31 (30.4)
Self-employed	22 (21.6)
Homemaker	13 (12.7)
Unemployed	14 (13.7)
Retired	2 (2.0)
Relationship of care partner to care recipient, n (%)	
Child	53 (52.0)
Other family member	24 (23.5)
Spouse/partner	22 (21.6)
Friend/neighbor	2 (2.0)
Parent	1 (1.0)
When care partner started providing care due to epNEC, n (%)	
When the care recipient experienced symptoms	36 (35.3)
When the care recipient initially sought help from healthcare providers/conducted tests for diagnosis	27 (26.5)
After the care recipient received epNEC diagnosis but before treatment	29 (28.4)
When the care recipient began treatment for epNEC	9 (8.8)
After the care recipient began treatment for epNEC	1 (1.0)

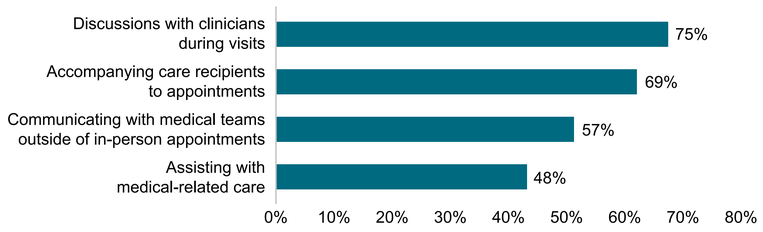
†Categories are not mutually exclusive

Table 2. Care recipient characteristics

Characteristic	Overall (N=102)
Age in years, mean (median)	59.6 (64.0)
Gender, n (%)	
Male	53 (52.0)
Female	49 (48.0)
Race/ethnicity, n (%)‡	
White or Caucasian	59 (57.8)
African American/Black	23 (22.5)
Hispanic or Latino	13 (12.7)
Native American or Alaskan Native	6 (5.9)
Asian or Pacific Islander	5 (4.9)
Primary location, n (%)	
Gastrointestinal	68 (66.7)
Hepatopancreatobiliary	16 (15.7)
Gynecologic	11 (10.8)
Genitourinary except prostate	7 (6.9)
Time from first noticed symptoms to first healthcare provider visit, n (%)	
<2 weeks	9 (8.8)
2 weeks to <1 month	32 (31.4)
1 month to <3 months	35 (34.3)
3 months to <6 months	25 (24.5)
≥6 months	1 (1.0)
Reason for time elapsed, n (%)‡,§	**N=61**
Personal issues (e.g., time burden, lack of awareness about symptoms)	29 (47.5)
Financial issues (e.g., lack of healthcare insurance coverage)	25 (41.0)
Cultural issues (e.g., cultural stigma against cancer, language barrier)	18 (29.5)
Waiting for symptoms to resolve on their own	17 (27.9)
Geographic issues (e.g., lack of transportation)	16 (26.2)
Relationship issues (e.g., lack of understanding from other family members)	16 (26.2)
I don't know	1 (1.6)
Time between initial contact with healthcare providers and epNEC diagnosis confirmation, n (%)	
<2 weeks	18 (17.6)
2 weeks to <1 month	40 (39.2)
1 month to <3 months	38 (37.3)
3 months to <6 months	3 (2.9)
≥6 months	1 (1.0)
I don't know	2 (2.0)

‡Categories are not mutually exclusive. §Asked among care partners who reported ≥1 month between care recipient's first symptoms and first healthcare provider visit

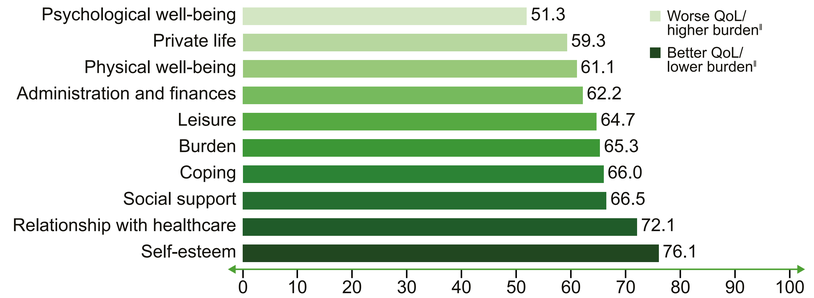
Figure 1. Common responsibilities performed by care partners



Impact of epNEC on Care Partner QoL, Functioning, and Work

- Emotional distress, depression, and anxiety were reported as the most significant impacts from receiving a diagnosis on the care partners' 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) (**Figure 2**)

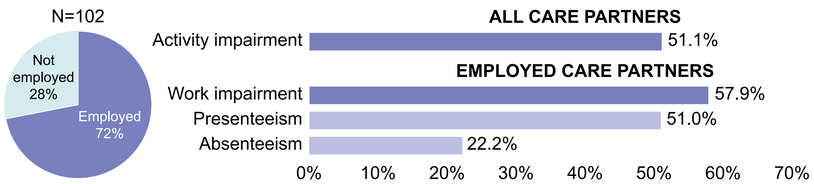
Figure 2. CarGOQoL – mean scores‖



‖All domain scores were measured on the 0–100 scale. A higher score indicates better QoL. The scores reflect the care partner's QoL over the past 4 weeks (recall period: 4 weeks)

- Based on the WPAI:CG, epNEC was associated with, on average, a 51% impairment in the care partners' ability to perform regular daily activities (**Figure 3**)
- Among employed care partners (72% of the sample), overall work impairment was 58%, with absenteeism (work time missed) at 22% and presenteeism (impairment while working) at 51%

Figure 3. WPAI:CG¶



¶Work impairment reflects productivity loss due to both presenteeism (reduced productivity while working) and absenteeism (work time missed). The scores reflect the care partner's work impairment over the past 7 days (recall period: 7 days)

Care Partner Support and Unmet Needs

- Oncologists were the primary source of information for epNEC management (70%), followed by patient advocacy groups (52%), and other healthcare professionals (51%). Interestingly, 41% of care partners reported utilizing artificial intelligence as a source of information
- The most common reported unmet needs included access to care partner support groups and specialists offering new/novel therapies, and greater involvement in decision-making alongside healthcare providers

Limitations

- Findings may not be fully generalizable to the broader population of care partners of patients with epNEC, as the care partners of patients with more advanced illness may have been less likely to participate
- Only the care partners of patients with a confirmed diagnosis were included. As a result, this limitation may lead to an underestimation of the barriers encountered by care partners during the patient journey
- Patient experiences were reported by care partners and may therefore be subject to recall bias

References

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