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Pheo Para Alliance Patient Centered Research on Challenges for Those with Pheochromocytoma and Paraganglioma

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BACKGROUND

Patients with pheochromocytoma/paraganglioma (PPGL) often face difficulties in obtaining timely and accurate diagnosis, as well as in accessing experienced specialists. However, little is known about the experiences of patients in obtaining effective care.

METHODS

To address this gap and give voice to the patients, we invited potential participants, through social media, email, and the PheoPara Alliance (PPA) website, to complete a 20-min online survey, Survey of Challenges in Pheochromocytoma & Paraganglioma Experiences (SCOPPE).

RESULTS

The respondents included 270 participants who were mostly female (80.8%), US residents (78.9%), from urban/suburban areas (57.8%), generally well-educated (75.6% with at least some university) and self-identified as white (87.7%) with a median age of 52 years (SD=14.2). Interestingly, 77.8% of respondents had clinical genetic testing performed, and of those, 60% had a known susceptibility gene pathogenic variant, with *SDHB* (48.4%) and *SDHD* (27%) being most common.

Participants reported difficulties and delays in obtaining correct diagnosis and treatment. There was a median of 29 months (IQR 6-73.5) from their first symptom to diagnosis; 48.4% saw four or more health care professionals (HCP) before being diagnosed; and 49.3% received one or more initial misdiagnoses. Many reported lack of access to an experienced medical team (28.9%) and to relevant information (25.6%), as well as poor communication among specialists (28.9%).

More knowledgeable HCPs, better access to experts and medical centers, and better medical team coordination were rated as “very” / “extremely” important by at least 75% of participants. Most would prefer to make decisions about their care in partnership with their medical team (73.5%).

Participants reported inability to receive several recommended treatments, including surgery, PRRT, and MIBG. Approximately 23% had to travel more than 100 miles to be treated by a specialist.

CONCLUSIONS

Overall, delays, misdiagnoses, and treatment inaccessibility present significant risks to patients' health. It is important for HCPs to be aware of, and act to alleviate, these important difficulties identified by our participants. As such, the PPA has developed a program to recognize Clinical Centers of Excellence (CCE) and Clinical and Research Centers of Excellence (CRCE) to provide clear information for patients on where to gain valuable multi-disciplinary expert care. The program is ongoing, and to date, 12 centers (10 US, 2 UK) have been approved.

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