Unmet needs in the management of neuroendocrine tumours: A global survey involving patients, patient advocates and healthcare professionals


INTRODUCTION

• Neuroendocrine tumours (NETs) are neoplasms arising from the endocrine system which can form in various locations in the body2

• NETs are an uncommon disease with incidences varying from 1.51 to 6.98 per 100,000 annually4

• The incidence of NETs has been rising over the past 30 years which may be due to earlier and improved diagnosis3

• Receiving a NET diagnosis is often still a difficult and long process6

• Patients and advocates have similar disease characteristics (Table 1)

2. Informational needs

• 84% of HCPs felt they were able to provide sufficient information to patients/families

• However, a much smaller amount of patients/families and advocates thought that the patient’s needs were mostly/fully met (Fig. 1)

3. Diagnosis and treatment needs

• Gallium-68-DOTATATE/DOTATOC PET/CT and PRRT were, reportedly, only available for a limited number of patients (Fig. 2 and 3)

• The most common reason for unavailability of treatment was due to the healthcare system of the patient’s country (Fig. 4)

4. Care needs

• Only 66% of patients reported having access to a multidisciplinary team, which was overestimated by advocates (84%) and HCPs (70%)

• For 66% of patients contact needs with their multidisciplinary team were mostly/fully met

5. Research needs

• The majority of participants felt that patient involvement in research was important (patients: 68%; advocates: 62%; HCPs: 46%) (Table 2)

• However, in practice, most patients (84%) had never participated in a clinical trial and if they had, their experience was mostly limited to a single trial (76%)

CONCLUSIONS

• There is an urgent need for further research and improved collaboration between patients, advocates and HCPs to lighten these gaps and improve the access to and quality of information, care and research worldwide

REFERENCES


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