BACKGROUND

The Healing NET Foundation (HNF) is interested in optimizing care for NET patients. One way to do this is to inspire NET centers to expand their expertise and services based on identified components that contribute to care excellence. HNF built a survey to help neuroendocrine cancer programs at American medical centers self-assess against the criteria for the ENETS Center of Excellence (CoE) designation.

METHODS

the ENETS CoE requirements and presented key components to the 60-member faculty of NET experts. The ARS response to the presentation was that 85% would consider trying to become an "Advanced NET Center" and 76% preferred an external audit to self-study for the designation.

Based on that feedback, HNF developed a survey around the ENETS CoE criteria in partnership with Thomas O'Dorisio, MD, of the University of Iowa, the only American center to be designated an ENETS CoE. The HNF survey was sent to Summit faculty representing twenty-five US medical centers offering NET care. Nineteen centers completed surveys between October 2018 and May 2019.

RESULTS

A majority of surveyed centers claimed to meet ENETS criteria in some basic measures, such as enough new GEP-NETs patients yearly, NET expertise in necessary disciplines, and regular tumor board meetings. A majority of centers report falling below ENETs criteria in new patients discussed in tumor board, standard operating procedures across disciplines, and patients enrolled in clinical trials.

CONCLUSION

Because details vary from center to center, a possible future HNF project is to develop an online profile of centers listing key measures, such as are outlined in this survey, that are voluntarily provided by centers as a resource for patients seeking advanced care and as a resource for centers striving to improve care.

CARE EXCELLENCE: A SURVEY

of American NET Centers for Self-Assessment by Established Criteria

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NEW PATIENTS

GEP-NETs

17 > 80 per year (threshold to be considered for CoE)

NON-GEP-NETS

9 > 50 per year

6 20-50 per year

3 < 20 per year

TOOLS & TREATS

Widely Available

19 NETSPOT (Ga-68 dotatate PET), CT, MRI, liver-directed therapies, advanced endoscopy

18 Octreoscan, Lutathera®/
PRRT/interventional radiology

Other Tools/Treatments

Individual centers additionally report: Radio-guided surgery, SBRT, MIBG, I131 MIBG, molecular profiling (DNA sequencing)

NET EXPERTISE & SPECIALIZATION

Medical Specialties with NET Expertise

19 Specialized Surgery (pancreas, liver, GI), Pathology, Radiology, Nuclear Medicine, Interventional Radiology

18 Thoracic Surgery, Gastroenterology

17 Medical/Pediatric Oncology, Nutritional Support

16 Medical Genetics

14 Pulmonology, Endocrinology, Cardiology

Dedicated Nurse

Is there a dedicated oncology nurse or nurse coordinator for GEP-NETs?

14 Yes (One center additionally has nurse for Pheo/Para and for GI Oncology)

3 No

1 Actively recruiting

1 Maybe

NET Specialist

19 Have a physician or physicians recognized as neuroendocrine specialists committed to providing care for NET patients

TUMOR BOARD CHARACTERISTICS

New Patients Discussed at Tumor Board

6 90-100% of new NET patients are discussed initially in tumor board

13 < 90% of new NET patients are discussed initially in tumor board

Medical Specialties at Tumor Board

19 Radiology, Surgery

17 Pathology, Medical/ Pediatric Oncology

16 Nuclear Medicine

11 Gastroenterology

Endocrinology

9 Medical Genetics

6 Dietitian/Nutritionist

Additional Specialties Attending Tumor Board

Individual centers additionally report: Interventional Radiology (4), Radiation Oncology (2), Nephrology, Pharmacy, Nurse Navigator, Hepatobiliary Surgery, and bringing in specialists for specific cases

MULTIDISCIPLINARY CARE

Administrative Support

Do administrative policies support the integration of care?

12 Yes

5 No

1 Don't know

1 "Yes in theory"

Interdisciplinary Interaction

How do the multi-discipline specialists interact? (Summary of respondent descriptions)

12 Listed tumor board

9 Cited personal communication (email, phone, text, in person)

7 Mentioned same day and/or same campus or clinic

3 Identified navigators/navigation

Also mentioned: Agreed upon general principles of care; shared medical record and one quarterback; integration also at institutional level through established pathways and quality protocols

Treatment Algorithm

How quickly is the treatment algorithm built? (Summary of respondent descriptions)

5 within a week or at weekly meeting (several mentioned weekly meeting to confirm algorithm)

4 same day or very quick

ADMINISTRATIVE POLICY & PRACTICES

Standard Operating Procedures

Does each discipline have SOPs codified in center policy?

5 Yes

12 No

2 Don't know

Patient Satisfaction Measures

Mechanisms in place for measuring patient satisfaction?

16 Yes

3 No

Communication Ratings

If yes on measuring patient satisfaction, are there high ratings on communication?

13 Yes

2 Communication not separated out

2 Don't know

CONNECTIONS BEYOND THE CENTER

Clinical Trial Participation

6 10-50% of new patients participate

13 <10% of new patients participate

Education Provided

Is there a commitment to educating patients & physicians outside the NET center setting?

17 Yes

2 No

Collegiality

How do you find connecting with NET colleagues (scholarly and clinical level)?

8 Very easy

9 Easy

2 Neither easy nor difficult

HURDLES ADDING TO EXISTING PROGRAM

Summary of Hurdles Identified

6 Funding/budget limitations

4 Gaps in staffing (specialists in specific disciplines, support staff)

3 Institutional bureaucracy

3 Issues with insurance

