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Breakthrough Symptoms Remain an Unmet Need in Symptomatic Patients with Neuroendocrine Tumors



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BACKGROUND: Internet-engaged NET patients surveyed about symptom control.

METHODS: U.S. NET patients from two online communities, experiencing at least one symptom, completed a 64-item questionnaire: April 29-May 23, 2020.

RESULTS: One hundred patients participated: 73% female, 75% age 56 - 75, 93% Caucasian. Primary tumor distribution: GI NET (N=55), PNET (N=33), Lung NET (N=11), other NET (N=13).

All patients were currently on somatostatin analogue, experiencing breakthrough symptoms: diarrhea, flushing, or other (13% experienced one, 30% two, 57% greater than two). Over one-third of treated patients experience symptoms daily.

Table 1. Percentage of Breakthrough Symptoms

	GI NETs	pNET	Lung NET
Diarrhea (n)	49	29	7
Daily (%)	39%	17%	14%
Several times per week (%)	10%	21%	25%
Fecal Incontinence (n)	49	29	1
Daily (%)	14%		
Several times per week (%)	10%	14%	100%
Flushing (n)	42	19	6
Daily (%)	14%	37%	33%
Several times per week (%)	17%	5%	17%

Thirty-three percent experience “Other” NET symptoms (N=71) daily.

Of 100 patients, 45% have anxiety or depression, trouble exercising (65%), and sleeping (57%). 54% said NETs affected employment. Depending on medication between 59% (N=79) and 65% (N=51) identified triggers as a major factor in decreased quality of life. 43% said maintaining friendships has been impacted.

Only 40% of patients surveyed have rescue treatment available.

Communicating via Internet with other patients for NET information is common. For 60 patients seeing NET specialists, 47% called web-based resources the best for NET information. For 21 patients seeing general oncologists: 52% believe web-based is best.

CONCLUSION: Breakthrough symptoms remain an unmet need, even in treated patients with NETs. While traditionally patients relied on their physicians, patients now, also depend on the Internet. Improved awareness of optimal somatostatin analogue use may improve syndrome control.

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