Author/s:
Leyden, J;Pavlakis, N;Chan, D;Michael, M;Clarke, S;Khasraw, M;Price, T

Title:
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Date:
2018-06-01

Citation:
Leyden, J., Pavlakis, N., Chan, D., Michael, M., Clarke, S., Khasraw, M. & Price, T. (2018). Patient-reported experience of the impact and burden of neuroendocrine tumors: Oceania patient results from a large global survey. Asia Pacific Journal of Clinical Oncology, 14 (3), pp.256-263. https://doi.org/10.1111/ajco.12785.

Patient-reported experience of the impact and burden of neuroendocrine tumors: Oceania patient results from a large global survey

Running title: Neuroendocrine Tumor Burden in Oceania

John LEYDEN,[1] Nick PAVLAKIS,[2] David CHAN,[2] Michael MICHAEL,[3] Stephen CLARKE,[2] Mustafa KHASRAW[2] and Timothy PRICE[4]

[1] The Unicorn Foundation, Mosman, New South Wales, [2] Department of Medical Oncology, Royal North Shore Hospital, St Leonards, New South Wales, [3] Peter MacCallum Cancer Centre, Melbourne, Victoria, and [4] Queen Elizabeth Hospital and University of Adelaide, Adelaide, South Australia, Australia

Correspondence: John Leyden, The Unicorn Foundation, P.O. Box 3913, Mosman, NSW 2088, Australia. Phone: +61 417 697 912; Fax: +61 2 9904 1929. Email: john.leyden@unicornfoundation.org.au.

Conflicts of interest: JL has received travel support from Novartis Pharmaceuticals Corporation. NP has received honoraria and travel support from and sits on advisory boards for Novartis Pharmaceuticals Corporation and Ipsen. DC has received honoraria from Ipsen and travel support

from Novartis Pharmaceuticals Corporation. SC has received travel support from Ipsen. MM, MK and TP have no conflicting interests to disclose.

Abstract

Aim: Despite the considerable impact of neuroendocrine tumors (NETs) on patients' lives, the patient journey is not well documented. The aim of this survey was to identify the impact and burden of NETs from the patient perspective.

Methods: This was a self-reported global survey regarding NET knowledge/awareness, disease impact/management, interaction with medical teams and desired improvements. One hundred thirty-eight patients (7% of the global study) in the Oceania region answered closed-ended questions using graded descriptors on their experience of living with NETs.

Results: The personal lives of patients were negatively impacted by NETs, including overall energy levels (72%, 99/138), emotional health (66%, 91/138) and finances (56%, 77/138). Eighty-one percent (22/27) of patients not currently working stated their NET was the reason they were not employed. Of those still working, taking days off work (64%, 39/61), working reduced hours (44%, 27/61) and stopping work for a period of time (31%, 19/61) were the most frequently reported outcomes of having a NET. Although most patients felt supported by their medical team (53% [73/138] reported being extremely or very supported by healthcare professionals in general), patients also identified areas for improvement in patient care. Better access to NET-specific treatments (58%, 80/138), more awareness about NETs (58%, 80/138) and materials to help patients better explain their condition (52%, 72/138) were indicated by patients as ways to help them live better with their disease.

Conclusion: The survey demonstrated a considerable burden of NETs on patients' lives and identified areas for improvements in long-term management.

Key words: burden of illness; neuroendocrine tumors; quality of life

INTRODUCTION

Neuroendocrine tumors (NETs) are a diverse group of malignancies that originate in neuroendocrine cells that naturally produce hormones to regulate bodily functions.[1–3] Although NETs are uncommon, incidence rates are rising, partly due to increased awareness and improvements in diagnosis.[3] In the United States, NET incidence has increased 5-fold over the past 30 years, and in 2004 it was reported that 5 out of 100 000 people are diagnosed with NETs every year.[3] Globally, NET incidence rates are also rising,[4–6] highlighting the need to increase awareness and improve disease management. Despite the substantial effect this disease has on patients' lives, the NET patient experience has rarely been documented, and only a few qualitative studies have been published to date.[7,8]

NETs are graded according to mitotic count and proliferative index,[9] and are classed as functional or nonfunctional based on whether they produce hormones or not. Hormonal production may lead to symptoms such as wheeze, flushing, and diarrhea: the so-called "carcinoid syndrome".[2,10] NET symptoms are often nonspecific or absent until advanced stages of disease,[1,2,11] which can impact diagnosis.[2,11] Diagnosing a NET can take several years, with symptoms reportedly persisting for up to 9 years prior to diagnosis.[2] Many patients are seen by numerous medical specialists and often undergo duplicate diagnostic tests as a result of the nonspecific nature of their symptoms. This can lead to different, and potentially conflicting, treatment recommendations and long delays in diagnosis.[12]

Patient-reported outcomes and documentation of the patient experience are becoming increasingly important in oncology. The Institute for Healthcare Improvement introduced the “Triple Aim” initiative to help address inadequacies in healthcare and optimize healthcare system performance. The goals of the “Triple Aim” are: (1) improve the patient experience of care; (2) improve the health of populations and (3) reduce the per capita cost of healthcare.[13] In order to achieve reforms in healthcare, it is believed that these goals must be addressed simultaneously.[13] As cancer management moves towards more patient-centered care, the perspective of patients and their families are required to enable clinicians to better understand the NET patient experience and provide personalized treatment plans.

The International Neuroendocrine Cancer Alliance (INCA) is a network of 18 independent organizations and patient groups from 15 countries, aiming to be the global voice supporting people living with NETs. In collaboration with Novartis Pharmaceuticals Corporation, INCA conducted the first large, global survey that collected data on the NET patient experience from multiple countries. The aim of the survey was to increase understanding of the views and experiences of patients with NETs, with a focus on patient needs and challenges with regards to diagnosis and management of NETs, interactions with medical teams, knowledge and awareness levels of the disease, information sources and desired improvements.

Increased knowledge concerning NETs from a patient perspective may help to identify areas required to improve patient care, thus providing benefits to healthcare systems.[14] The previously published global survey comprising 1928 patients in >12 countries demonstrated a significant impact of NETs and their symptoms on patients’ work and daily lives.[15] The survey also showed that NETs placed a significant burden on society through enhanced healthcare resource utilization. This manuscript discusses the results of the survey obtained specifically from patients in the Oceania region regarding the impact and burden of NETs on patients’ lives.

MATERIALS AND METHODS

Study design and participants

Patients self-reported as being diagnosed with NET were predominantly recruited online using e-mail, social media channels, website postings and flyers of the INCA member organizations/patient advocacy groups. Key questions and survey domains were created at a round table meeting of the INCA leadership held during the 10th annual European Neuroendocrine Tumor Society (ENETS) conference in Barcelona, Spain (March 2013). Direct input into question development was made by 14 NET patient health consumer groups within INCA, and the final questionnaire was reviewed and edited by all INCA members and Novartis between May and October 2013. The research organization Hall & Partners was employed to develop a detailed survey which assessed the NET patient experience based on the meeting discussions and a review of the NET literature. This anonymous survey was intended to be primarily conducted online, although paper copies were also generated and distributed via patient advocacy groups and healthcare professionals to reach patients without Internet access. The estimated time for completion was 25 minutes, based on survey length. Surveys were available in eight languages: Bulgarian, Dutch, English, French, German, Japanese, Norwegian and simplified Chinese. The survey was designed and conducted as an equal collaboration between INCA and Novartis Pharmaceuticals. For transparency, the Novartis logo was clearly displayed on all materials and patients were notified that the INCA patient group partners or Novartis may use the data for disease awareness purposes. Hall & Partners facilitated conduction of the survey from February to May 2014 and analyzed the results.

Clinical characteristics (e.g., NET type, years since diagnosis, functional status), sociodemographic characteristics (e.g., age, sex) and information on burden of NETs on daily life and work, desired improvements and information sources were self-reported by patients with NET. The questions covered patient awareness of NETs, the diagnosis process, the burden of NETs, ongoing disease management, interactions with healthcare providers, experience with and access to different NET treatments and resources used for education about NETs. Questions were categorized as follows: (1) initial screening; (2) patient's current status; (3) diagnosis; (4) quality of life; (5) NET management; (6) NET treatment; (7) NET education and (8) demographics (the full survey is located in the **Supporting Information**). The majority of survey questions were closed-ended (i.e., participants were provided options from which to choose), with the exception of certain open-ended questions collecting numerical data (e.g., age, number of visits per year to a NET specialist center). Patients were asked to answer graded questions; responses included the graded descriptors "not at all", "somewhat", "very" and "extremely", and when asked the degree to which they (dis)agreed with a particular statement, the descriptors "strongly" and "somewhat" were added to response choices.

Data analyses

The survey software package MERLIN (Merlinco) was used for data analysis. The data were analyzed for Oceania as a whole as well as by subgroups, including primary site of tumor, time since diagnosis and whether the patient was visiting a specialist NET treatment center. Descriptive statistics, including means, medians and percentages, were used to summarize survey responses. The z-test was used to determine statistical significance for percentages, and the t-test for means, with a 95% confidence interval level ($P < 0.05$). For some questions, responses are presented as the top two responses (e.g., "somewhat" agree/"strongly" agree; a moderate amount/a lot).

RESULTS

Patient characteristics

Oceania patients represented 7% (138/1928) of the total number of patients who participated in the global survey. Of these, 97% (134/138) lived in Australia (88%, 122/138) or New Zealand (9%, 12/138); the remaining 3% (4/138) originated from unspecified smaller islands.

Patient-reported sociodemographic parameters and clinical characteristics are summarized in Table 1. The median patient age was 56.0 years and 68% (94/138) of respondents were female. The most common primary NET sites were gastrointestinal (GI; 49%, 67/138), the pancreas (21%, 29/138) and the lungs (9%, 13/138). Fifty percent of patients reported having functional disease (69/138). Most patients were diagnosed with a low-grade (grade 1) NET (36%, 49/138). However, a large proportion of patients reported that their physician did not give their NET a grade (28%, 39/138) or describe/discuss their grade (12%, 17/138). The median time since diagnosis of NET was 3 years. Nearly two-thirds of patients (62%, 86/138) were diagnosed <5 years ago and 54% (74/138) reported having metastases at diagnosis. The majority (64%, 89/138) of patients had a caregiver to help them with their daily lives, although at the time of the survey 44% (61/138) were employed.

Patient feelings regarding NET

Many patients reported that having a NET induced feelings of apprehension, including concern (51%, 70/138), uncertainty (46%, 63/138) and anxiety/worry (43%, 59/138). Despite this, some patients also reported feeling hopeful (31%, 43/138) and optimistic (25%, 34/138). At the time of diagnosis, most patients reported feeling shocked (71%, 98/138), scared (69%, 95/138) and uncertain (61%, 84/138), while only a few reported feeling relieved (17%, 23/138) and hopeful (14%, 19/138). Patients felt that

NET specialist centers were beneficial, as those who visited specialist centers ≥1 time a year were significantly less stressed (15% [9/59] *vs* 34% [27/79]) and less shocked (5% [3/59] *vs* 19% [15/79]) than those who did not visit one. Patients who were diagnosed >5 years ago were more frustrated (50% [26/52] *vs* 33% [28/86]) and angry (33% [17/52] *vs* 12% [10/86]) than those diagnosed more recently; however, they also reported being more confident (15% [8/52] *vs* 2% [2/86]).

Impact of NETs on patients' personal lives

Patients with NETs reported a considerable impact on their personal life (Figure 1A). The majority of patients (71%, 98/138) felt that NETs had a large or moderate negative effect on their overall quality of life and 38% (53/138) reported fair/poor health. Most patients also reported a negative impact of NETs on their overall energy levels (72%, 99/138) and emotional health (66%, 91/138). Patients who visited a NET specialist center were less likely to report that their relationships with their friends had been negatively affected (27% [16/59] *vs* 44% [35/79]), and respondents diagnosed ≥5 years ago were more negatively affected with regards to their attitude towards daily life than those who were diagnosed <5 years ago (65% [34/52] *vs* 48% [41/86]). Patients with GI NETs were more likely to report that their social life had been negatively affected by their NET: GI NETs, 64% (43/67); pancreatic NETs, 41% (12/29) and lung NETs, 23% (3/13). Patients with functional disease were more likely to report a moderate or greater impact of their NET on their life (81% [56/69]) compared to patients with nonfunctional (65.4% [17/26]) or asymptomatic disease (54% [13/24]). All patients with grade 3 NET reported a moderate or greater impact of their NET on their life (4/4), whereas 71% (35/49) and 61% (17/28) of patients with grade 1 or grade 2 NET, respectively, reported this.

Patients reported making several changes to their lifestyles as a result of their NET (Figure 1B), including dietary changes (61%, 84/138) and spending a lot of time (60%, 83/138) and money

(57%, 78/138) on travel to and from medical appointments. Additionally, patients who visited specialist centers ≥1 time a year were less likely to cut back on leisure purchases than nonvisitors (32% [19/59] *vs* 49% [39/79]). Just 7% (9/138) of patients reported having to make no lifestyle changes at all.

Impact of NETs on patients' work lives

NETs affect a relatively younger age group than most advanced cancers,[3,16] and thus have the potential to impact work with follow-on effects on family and the community. Having a NET negatively affected patients' work lives (Figure 2), including having to take days off work because of their NET (64%, 39/61), having to work reduced hours (44%, 27/61), stopping work altogether for a period of time (31%, 19/61) and asking employers to make accommodations (25%, 15/61). The majority of unemployed patients or patients unable to work because of a medical disability (81%, 22/27) also indicated that their NET was the reason they stopped working. Of patients who had retired, 30% (11/37) stopped working earlier than planned due to their NET.

Support provided to patients with NETs

Patients generally felt well-supported by their medical team, with 53% (73/138) of patients stating that the level of support provided by healthcare professionals in general was either very or extremely supportive. Nurses (87%, 27/31), oncologists/hematologists (82%, 89/108) and nuclear medicine specialists (82%, 50/61) were the most supportive, while lung specialists (56%, 5/9) and nutritionists (44%, 4/9) were the least supportive (Table 2). However, these results may be affected by a small base number.

Improvements to NET patient care

When asked what would help patients to live better with their NET (Figure 3), the most common desired improvements were better access to NET-specific medical treatments (58%, 80/138), more awareness about NETs to make it easier to communicate openly about their condition (58%, 80/138), materials to help patients better explain their condition to their family and friends (52%, 72/138) and access to a NET medical team (48%, 66/138). Many patients lacked access to treatments they know exist (Table 3). In all cases, the percentage of patients with knowledge of particular treatment options was greater than the percentage of patients with access to those options.

DISCUSSION

NETs are a difficult cancer to both diagnose and treat. Despite the slow-growing, asymptomatic nature of the majority of NETs, negative effects are experienced by many patients. Published data on the experiences and perspectives of patients with NETs are lacking, due to difficulties associated with collecting patient-reported data and the rarity of this disease. This survey reports findings for NET patient experiences in Oceania within the first, large global study reporting the impact of NETs from the patient perspective.

NETs have a substantial negative impact on patients living in the Oceania region. Consistent with the global survey, patients' emotional and physical well-being and social interactions were greatly affected by their NETs.[15] Importantly, both in Oceania and globally, patients with functional NET were more likely to report a moderate or greater impact of their NET on their life (Oceania 81%; globally 82%) compared with nonfunctional (Oceania 65%; globally 73%) or asymptomatic disease

(Oceania 54%; globally 49%). These findings are consistent with a survey conducted in the United States, which demonstrated that among patients with NET, those with current NET and carcinoid syndrome reported the greatest burden in terms of health-related quality-of-life measures (the Short Form-36 and the Patient-Reported Outcomes Measurement Information System [global health and −29]), with >4 bowel movements per day and the presence of any flushing episode over a 2-week period causing a statistically significant reduction in quality of life.[16,17] These data collectively demonstrate the importance of controlling functional tumor symptoms from the patient perspective and the detrimental impact that symptoms of diarrhea or flushing have on a patient's social, occupational and role functioning.

For a detailed comparison of the impact of NETs on patients in the global vs Oceania region see the **Supporting Information.** Patients in the Oceania region reported a considerable impact of NETs on their working lives, comparable to results seen in the global survey.[15] The average age and employment status of Oceania patients were similar to the overall global survey population. Many of these patients had to stop working altogether, and more patients in Oceania than in the global population had to take days off work (64% *vs* 49%) or reduce their working hours (44% *vs* 24%), highlighting the additional financial burden of NETs on the individual and the community in terms of lost revenue and increased government funding for medical care and social support services. The survey also identified areas for improvement to help patients live better with their NETs. Consistent with the results of the global survey, many patients did not know or had not been told their tumor grade, suggesting a lack of communication between patients and physicians.[15] Patient-reported gaps in patient care included better access to NET-specific treatments, greater awareness of NETs and understanding how to manage treatment- and disease-related symptoms, which can be improved by increasing access to NET specialist centers. While NET centers of excellence in Europe have been undergoing a rigorous process of accreditation by ENETS since 2007, NET specialist centers in the

Oceania region are lacking, with only a few centers of expertise and local hospitals with a clinical interest in NET. Therefore there is a substantial difference in care delivery in the Oceania region compared to the US or European healthcare environment for NET. Collaboration between centers in Oceania that focus on NET care may help further improve and unify patient care and research in the region. Centers of excellence in the US have been associated with improved patient outcomes compared to standard care, including prolonged overall survival.[3,18] This may be due to improved treatment availability in specialist centers. However, in terms of treatment availability, this survey demonstrated that more patients in the Oceania region reported having access to PRRT (39% *vs* 28%) or were currently receiving PRRT (29% *vs* 17%) compared to globally. Furthermore, more patients in Oceania reported having access to drug therapy other than chemotherapy (62% *vs* 56%) or were currently receiving this treatment (53% *vs* 47%) compared to global rates.

Limitations of this survey include a potential for recall bias, the lack of a standardized, validated health-related quality of life assessment tool and the fact that the respondent population may not be fully representative of a heterogeneous NET population. Most patients were recruited online and through patient advocacy groups and are therefore likely to be highly motivated individuals. Furthermore, 68% of the respondents were women, which differs from the equal sex distribution expected of patients diagnosed with NETs.[3] Additionally, over one-third of participants had a minimum education level of a bachelor's degree.

Despite these limitations, the survey findings directly reflect patients' perspectives on NETs. The ability to understand how patients experience their disease is extremely important, and these data provide critical information that allows healthcare organizations to move toward patient-centered care. Patient-reported outcomes and data regarding patients' experience are becoming increasingly useful in identifying gaps in knowledge and improving the quality of patient-centered care.

CONCLUSION

This survey highlights the considerable impact and burden NETs have on patients' lives, identifying unmet needs which patients felt would help them to live better with their NETs. The results provide valuable insights into NET patient perspectives, and suggest changes that may reduce the burden of NETs on healthcare systems and ultimately improve the patient journey in this difficult disease.

ACKNOWLEDGMENTS

The authors thank the patients who participated in this survey and our patient advocacy partners throughout Oceania who contributed to this project, including Australia, The Unicorn Foundation; New Zealand, Unicorn Foundation NZ. Hall & Partners fielded the survey and analyzed the results. Data collection and analysis were supported by Novartis Pharmaceuticals Corporation and conducted as an equal collaboration between the International Neuroendocrine Cancer Alliance and Novartis. Medical writing assistance was provided by Renee Gordon, PhD, and Harleigh E. Willmott, PhD, CMPP (ApotheCom, Yardley, PA) and was funded by Novartis Pharmaceuticals Corporation.

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Table 1 Summary of patient-reported sociodemographics and clinical characteristics

	Patients (*N*=138)
Patient-reported sociodemographics	
Age, mean, years	53.9
Age, median, years	56.0
Age distribution, years, %	
18–49	33
50–59	28
60–69	30
≥70	9
Female, %	68
Educational level, %[†]	
Not university-educated	61
Bachelor's degree or higher	39
Caregiver, %	

Yes	64
No	35
Prefer not to answer	1
Work status, %	
Employed full-time	22
Employed part-time	13
Self-employed	9
Not employed, but looking for work	2
Not employed and not looking for work	3
Retired	27
Medical disability	14
Student	2
Homemaker	7
Clinical characteristics	
NET type, %	
Gastrointestinal	49

Pancreas	21
Lung	9
Thymus	2
Other	10
Site unknown/I don’t know	10
Tumor grade, %[‡]	
Low (grade 1)	36
Intermediate (grade 2)	20
High (grade 3)	3
Unknown/don’t remember	41
Functional status, %[§]	
Functional	50
Nonfunctional	19
Asymptomatic	17
Not discussed/don’t remember	14
Time since diagnosis, mean, years	5

Time since diagnosis, median, years	3
Time since diagnosis, years, %	
≤1	26
2–3	27
4–9	34
≥10	13
Metastatic disease at the time of diagnosis, %	54

[†] *N*=122; information about education level was available only for the patients from Australia. [‡] Grade 1: NETs are relatively slow growing, Ki-67 index ≤2%; grade 2: NETs have a less predictable, moderately aggressive course, Ki-67 index 3 to 20%; grade 3: NETs can be highly aggressive, Ki-67 index >20%. [§] Functional NET: produce symptoms caused by the secretions of hormones (e.g., flushing, diarrhea, wheezing, cramping); nonfunctional NET: do not secrete hormones, but they may cause symptoms caused by the tumor's growth (e.g., pain, intestinal blockage, bleeding). NET, neuroendocrine tumor.

Table 2 Support provided by healthcare professionals to patients with NETs

Group	Very/extremely supportive	Somewhat supportive	Not supportive at all
Nurse/nurse practitioner (*n*=31)	87%	6%	0%
Oncologist/hematologist (*n*=108)	82%	12%	6%
Nuclear medicine specialist (*n*=61)	82%	16%	0%
Surgeon (*n*=48)	73%	21%	4%
General practitioner/primary care physician (*n*=102)	68%	28%	3%
Physician assistant (*n*=3)†	67%	33%	0%
Gastrointestinal specialist (*n*=24)	67%	21%	8%
Endocrinologist (*n*=37)	62%	35%	3%
Lung specialist (*n*=9)†	56%	33%	11%
Nutritionist (*n*=9)†	44%	56%	0%

Base: All Oceania respondents (number varies by category).

Question: Which of the following best describes the level of support you receive from each of the following in helping you deal with your NET?

†Small base. NET, neuroendocrine tumor.

Table 3 Availability of NET Treatments

	Treatments I have heard of, n (%)[*]	**Treatments I have access to, n (%)**[†]	**Treatments I have received/am currently receiving, n (%)**[‡]
Surgery	123 (89%)[†‡]	108 (78%)	95 (69%)
PRRT	113 (82%)[†‡]	54 (39%)	40 (29%)
Drug therapy other than chemotherapy	113 (82%)[†‡]	85 (62%)	73 (53%)
Chemotherapy	111 (80%)[†‡]	63 (46%)[‡]	35 (25%)
Observation (eg, watch and wait)	99 (72%)[†‡]	72 (52%)[‡]	54 (39%)
Interventional radiology	86 (62%)[†‡]	35 (25%)[‡]	15 (11%)
Other/none of the above	13 (9%)	8 (6%)	9 (7%)

Base: All Oceania respondents (*N*=138)

Question: This is a list of available NET treatments. Please select those you have heard of, those you have access to (meaning they are available to you), and those you have received/are currently receiving for the treatment of your NET.

[*†‡]Indicate significant differences, $P<0.05$, between the % in the specified column and the % given in the other column.

Figure Legends

Figure 1 A) Negative impact of NETs on different aspects of life. B) Lifestyle changes caused by having a NET.

Base: All Oceania respondents (*n*=138).

Question (1A): How much has each of the following areas of your life been negatively affected, if at all, by your NET? Top 2 results shown (a moderate amount/a lot).

Question (1B): Since you were diagnosed with your NET, have you had to make any of the following changes? Please select all that apply.

NET, neuroendocrine tumor.

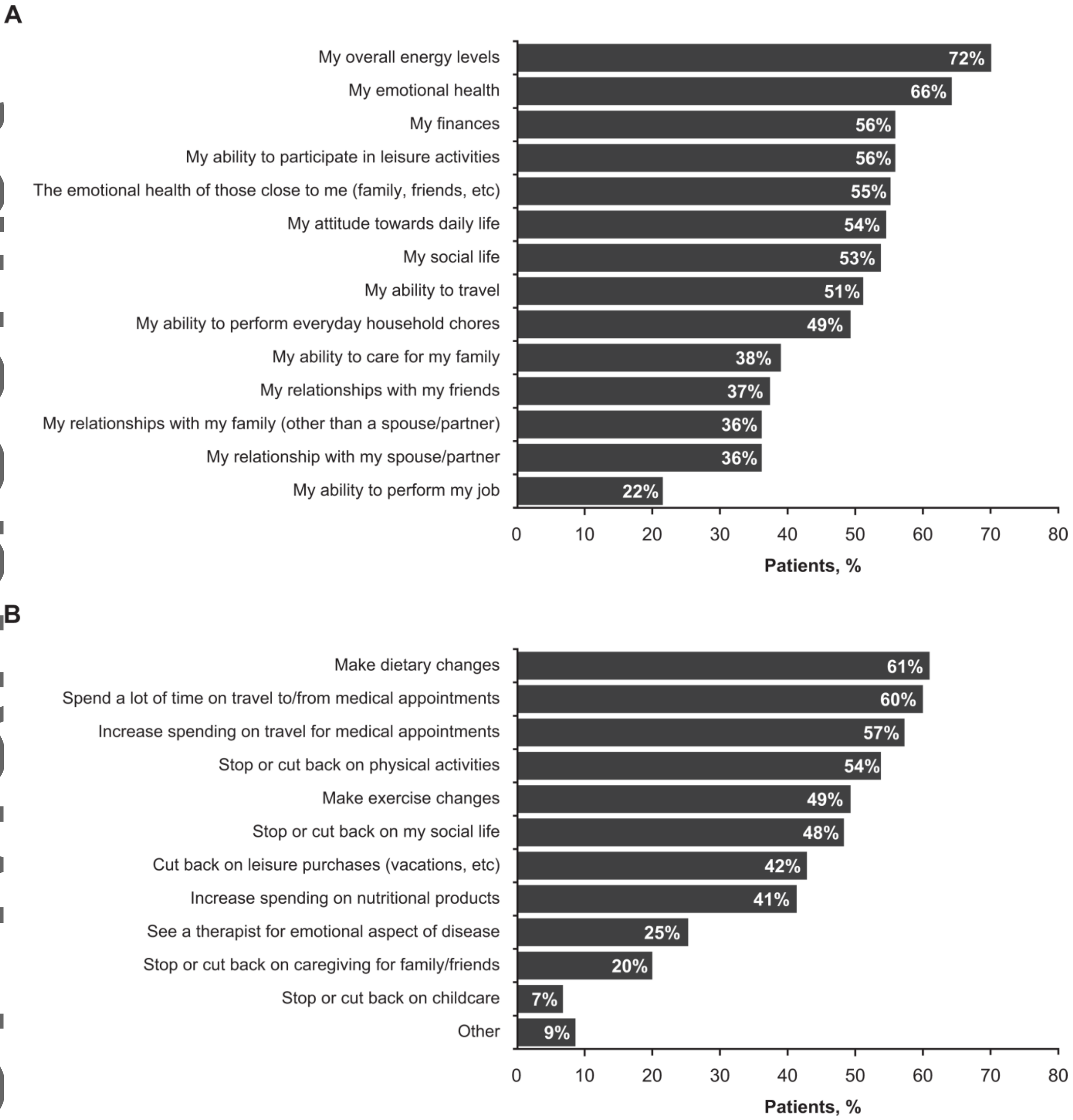
A
My overall energy levels 72%
My emotional health 66%
My finances 56%
My ability to participate in leisure activities 56%
The emotional health of those close to me (family, friends, etc) 55%
My attitude towards daily life 54%
My social life 53%
My ability to travel 51%
My ability to perform everyday household chores 49%
My ability to care for my family 38%
My relationships with my friends 37%
My relationships with my family (other than a spouse/partner) 36%
My relationship with my spouse/partner 36%
My ability to perform my job 22%
0
10
20
30
40
50
60
70
80
Patients, %
B
Make dietary changes 61%
Spend a lot of time on travel to/from medical appointments 60%
Increase spending on travel for medical appointments 57%
Stop or cut back on physical activities 54%
Make exercise changes 49%
Stop or cut back on my social life 48%
Cut back on leisure purchases (vacations, etc) 42%
Increase spending on nutritional products 41%
See a therapist for emotional aspect of disease 25%
Stop or cut back on caregiving for family/friends 20%
Stop or cut back on childcare 7%
Other 9%
0
10
20
30
40
50
60
70
80
Patients, %

Figure 2 The impact of NETs on patients' work life.

Base: Oceania respondents who are currently employed (*n*=61).

Question: Has your NET impacted you at work in any of the following ways? Please select all that apply.

[†]For example: flexible work schedule, work from home, adaptive devices, opportunities for rest. NET, neuroendocrine tumor.

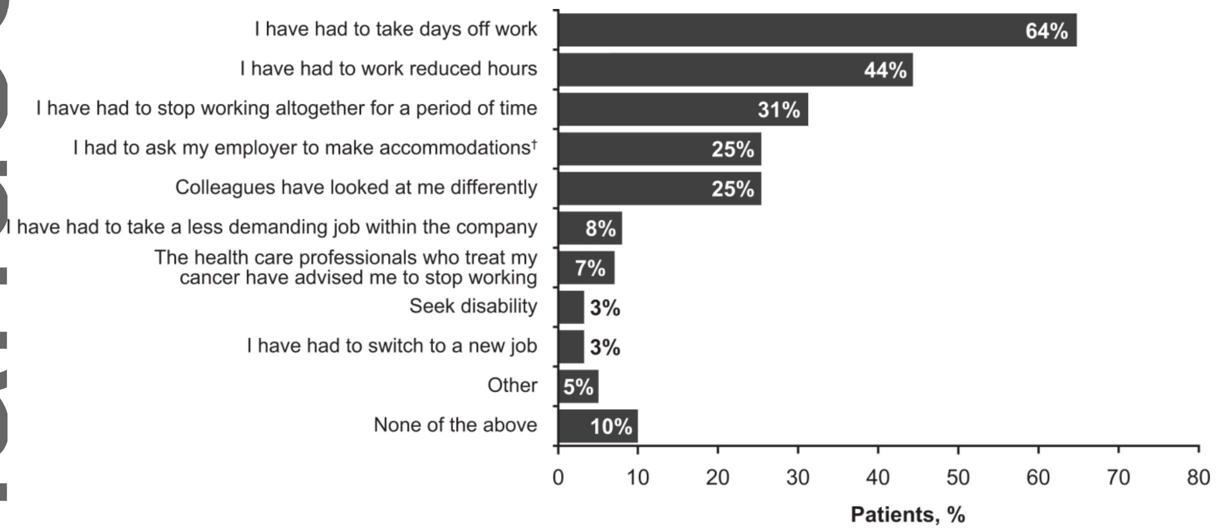

Figure 3 Desired improvements in NET patient care.

Base: All Oceania respondents (*n*=138).

Question: Which of the following, if any, would help you living with a NET?

NET, neuroendocrine tumor.