International patient survey of physical, emotional and informational challenges when living with NETs: understanding the unmet needs

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Introduction

Although a number of countries, treatment centers and organizations have a variety of patient resources which have evolved over the last decade, the usefulness of information sources used by patients with neuroendocrine tumors (NETs) is rarely explored.

Aims

This survey set out to achieve the following:

• Understand the physical, informational and emotional challenges facing patients before, at, and after their diagnosis of NET
• Identify the key challenges that patients face
• Understand where patients get the information and support to deal with these challenges, the channels they use, and whether their needs are being met

Methods

• Patients associated with the Association Des Patients porteurs de Tumeurs Endocrines Diverses (APTED: http://www.apted.fr/), The Carcinoid Cancer Foundation (CCF: https://www.carcinoid.org), and Netzwerk Neuroendokrine Tumoren (NeT) e.V. (http://www.glandula-net-online.de), as well as non-members of these organizations, completed the online survey (SurveyMonkey) after its dissemination via the following channels:
  – News article on APTED, CCF and Netzwerk NeT e.V. websites
  – Posts and tweets on social media profiles
  – Banners on home pages
  – Space in regular email newsletters
  – ‘Last chance’ email
• Each survey comprised the same 12 questions with multiple-choice answers, some of which included an option for free-text entry, thereby allowing additional information to be captured
  – All questions were checked and approved by the respective organizations
  – All questions were phrased in French, English or German, according to the country in which the survey was done.

The survey was conducted over the following periods in 2015:

France
15th October–5th November
USA
2nd August–September
Germany
1st September–30th September

Results

• 745 online surveys were completed in the USA (n=248), Germany (n=240) and France (n=257).
• A diagnosis of NET had been made in 26% (France), 66% (USA), and 65% (Germany) of respondents, 15 years prior to the survey period
• Before diagnosis, patients often experienced multiple symptoms
  – The most common symptoms were diarrhea, flushing, bowel or bladder habit changes (including incontinence), and persistent pain (Fig. 1)
  – Other symptoms included chest/abdominal pain, wheezing and breathing difficulties, edema, nausea/vomiting, and anemia

• Although a relatively small proportion felt empowered by their diagnosis as it allowed them to have a group of the condition and take back control, a distinctly larger proportion reported relief upon being diagnosed, possibly for similar reasons (Fig. 2)

• Patients living with NETs reported fatigue, diarrhea, disturbed sleep, and pain and discomfort as being their greatest challenges (Fig. 3)

• A high degree of variability between approaches to seeking information was observed between patients from France, the USA, and Germany; the internet and search engines were most frequently used overall (Fig. 4)
• Patient association websites and patient brochures or information booklets were most commonly used by French and German patients, perhaps specializing in NET information; patient brochures, and patient editions were published by Netzwerk NeT e.V. in Germany
• Patients’ perceptions may well have overlapped with what constitutes a patient association website and a NET/carcinoid support group
• NET/carcinoid disease awareness websites and support groups, and general cancer websites were used most often by American patients.
  – Similarly, it is possible that an overlap exists between what patients regarded as being a patient association website and a NET/carcinoid disease awareness website

• Information sources regarded as being the most useful were (data not shown):
  – France: Patient association websites, government/health authority websites, brochures
  – USA: NET/carcinoid disease awareness websites, NET/carcinoid support groups, general cancer websites
  – Germany: patient association websites, brochures

Conclusion

Tailored access to information resources may help patients to face negative emotions, which may be exacerbated by untreated physical symptoms

Gastric ulcer
Persistent cough or hoarseness
Headache
Jaundice
Abnormal bleeding or discharge
Lumps
Skin rash
Persistent pain
Diarrhea
Flushing
Bowel or bladder changes
Nausea or vomiting
Dizziness
Weight gain or loss
Loss of appetite
Flushing
Weight gain
Other
France
Germany
USA
Responders (%)
90
80
70
60
50
40
30
20
10
0

Figure 1. Symptoms experienced before receiving NET diagnosis

Figure 2. Emotions experienced after receiving NET diagnosis

Figure 3. Greatest challenges of living with NETs

Figure 4. Sources that patients use to seek information about NETs

Figure 5. Formats in which patients would like to receive information about illness

Conclusions

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