

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

Mohid Khan,¹ Abdelali Majdi,² Grace Goldstein,³ Katharina Mellar,⁴ Rupert Watts⁵

¹University Hospital of Wales, Cardiff, UK; ²Ipsen, Boulogne-Billancourt, France; ³The Carcinoid Cancer Foundation, New York, USA; ⁴Netzwerk Neuroendokrine Tumoren (NeT) e.V., Nürnberg, Germany; ⁵Kanga Health Ltd, Congleton, UK.

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
- Patient surveys of disease burden/impact on daily living may be key to optimizing care but seldom address the emotional impact of a condition

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 L'Association des Patients porteurs de Tumeurs Endocrines

Diverses (APTED: <http://www.apted.fr/>), The Carcinoid Cancer Foundation (CCF: <http://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

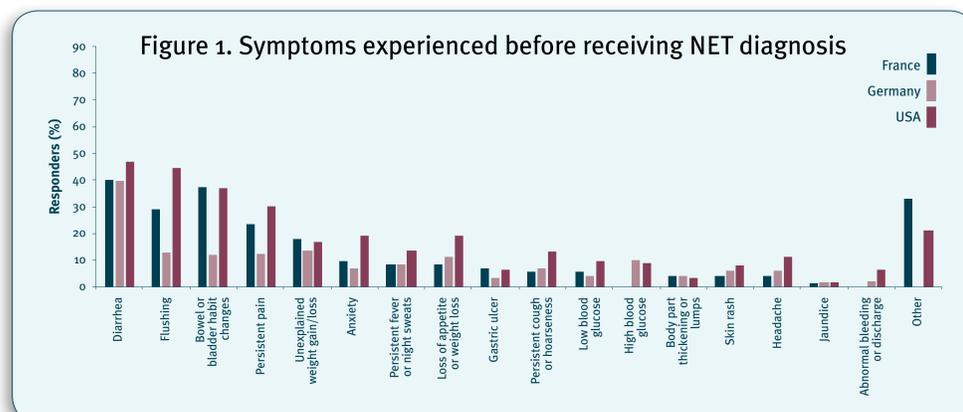
- Each survey comprised the same 12 questions with multiple-choice answers, some of which included an option for free-text entry, thereby allowing additional information to be captured
 - All questions were checked and approved by the respective organizations
 - All questions were phrased in French, English or German, according to the country in which the survey was done

The survey was conducted over the following periods in 2015:

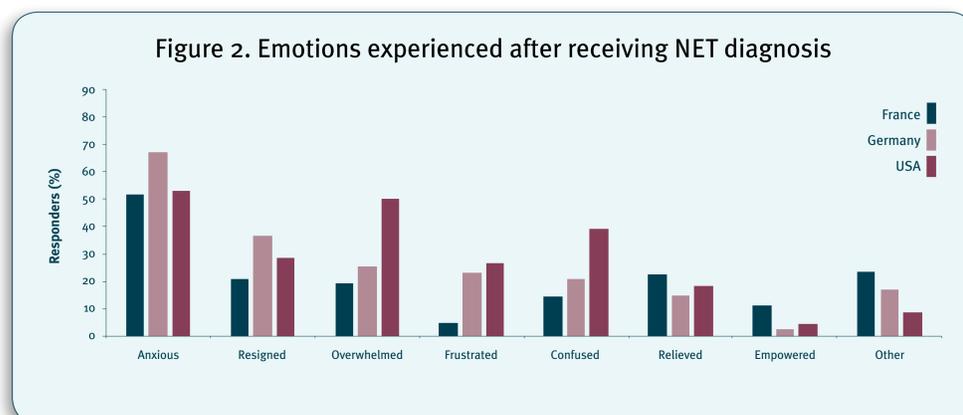
France	15th October – 9th November
USA	11th August – 2nd September
Germany	1st September – 30th September

Results

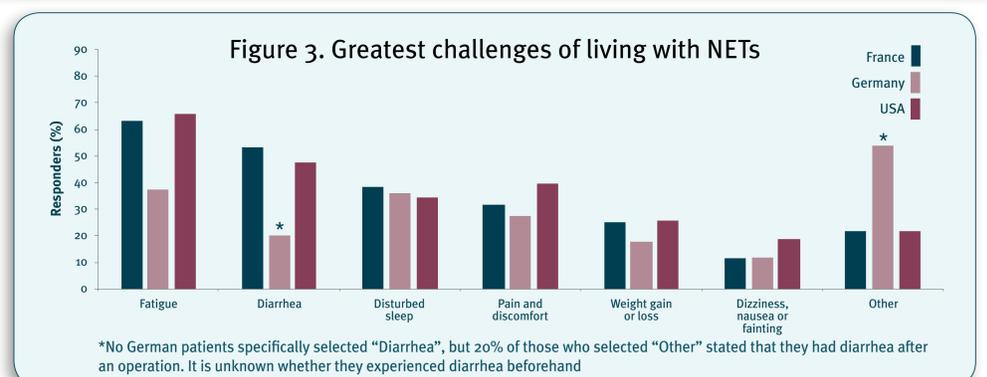
- 741 online surveys were completed in the USA (n=428), Germany (n=240) and France (n=73)
- A diagnosis of NET had been made in 76% (France), 66% (USA), and 65% (Germany) of respondents \leq 5 years prior to the survey period



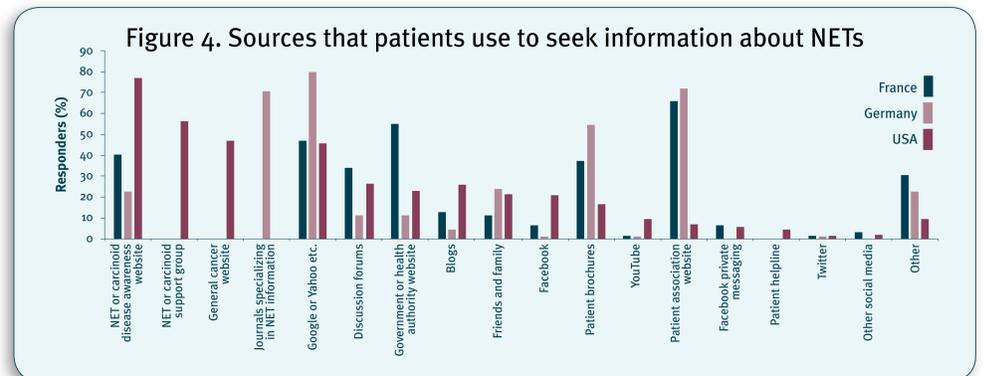
- Before diagnosis, patients often experienced multiple symptoms
- The most common symptoms were diarrhea, flushing, bowel or bladder habit changes (including incontinence), and persistent pain (Fig. 1)
 - "Other" symptoms included chest/abdominal pain, wheezing and breathing difficulties, edema, nausea/vomiting, and anemia



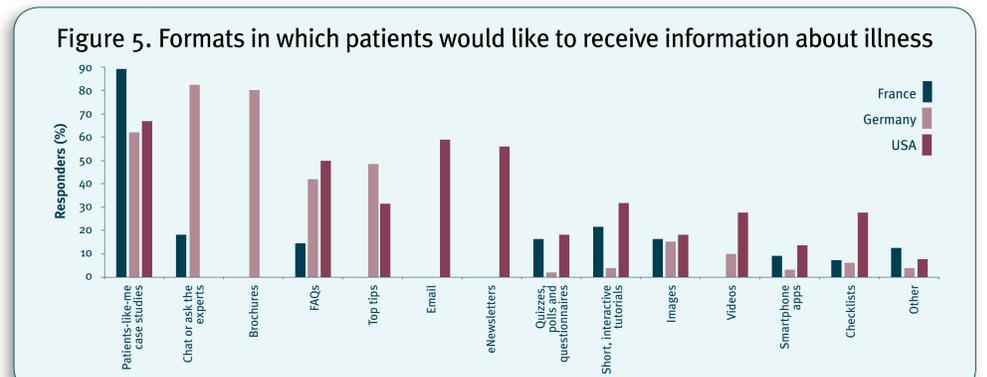
- Overall, after diagnosis, anxiety was the predominant emotion, with many patients feeling overwhelmed by the implications of their diagnosis; however, many patients reported being resigned (Fig. 2)
- Although a relatively small proportion felt empowered by their diagnosis as it allowed them to have a grasp of the condition and take back control, a distinctly larger proportion reported relief upon being diagnosed, possibly for similar reasons



- 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; journals specializing in NET information, and patient brochures, are edited and published by Netzwerk NeT e.V. in Germany
- Patients' perceptions may well have overlapped about 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:** Specialist NET journals, patient association websites, brochures



- Overall, "Patients-like-me" case studies were the most favored format, particularly in France (Fig. 5)
- Patients in Germany would prefer disease-specific booklets or brochures, and an opportunity to "Chat or ask the expert"
- Emails and eNewsletters were formats preferred by patients in the USA
- In general, free-text responses to questions about information sources and formats suggested an unmet need for simple, clear, precise and focused explanations that are readily accessible, not too technical, and relevant to circumstantial, physical and/or emotional difficulties

Conclusions

- A significant proportion of patients with NETs still experience physical and psychological symptoms, which are unaddressed
- Patients with NETs use a variety of different information sources, which may be country-dependent and reliant on availability
- Tailored access to information resources may help patients to face negative emotions, which may be exacerbated by untreated physical symptoms

Acknowledgements

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