Neuroendocrine Tumour (NET) patients experiences of support in the community setting across the cancer treatment trajectory

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Introduction
Neuroendocrine tumours (NETs) and carcinomas (NECs) are a heterogeneous group of malignancies with no common clinical pathway, but previous studies have highlighted a common need for effective, well-timed support (O’Toole et al. 2016). The prevalence of NET is predicted to rise due to early detection and improved diagnosis, in parallel with increasing life expectancy (Caplin 2015; Lewis et al. 2017; ONS 2016; Guzman-Castillo et al. 2017). Placing additional pressure on sparse and busy specialist NET nursing services.

Background
The majority of NET tumours are sporadic, but there are several inherited syndromes (Obeng 2018). They arise from neuroendocrine cells that are diffusely distributed throughout the body meaning that a neuroendocrine tumour can occur almost anywhere.

The diagnosis and treatment of neuroendocrine tumours are specialist-based and ageing. They are relatively uncommon cancer, diverse in origin, usually slow-growing and frequently associated with clinical syndromes caused by hypersecreted hormones (Gilbert 2017).

A recent international survey documented the average time between onset of symptoms and diagnosis at 4.3 years (Singh et al. 2017). For most NET patients is an inexcusable, lifelong condition. This study is performed with the aim of generating knowledge of the patients experiences of support in the community as a foundation to generating knowledge in this specific area.

Aim
The aim of the study is to explore the changing nature of support requirements throughout the patient journey and identify sources, with optimal timing, of effective patient support.

Design
A qualitative exploratory study consisting of focus group interviews in NET Natter support groups in England and Wales.

Data Collection
Focus group interviews (n = 3) were conducted using attendees of NET Natter Neuroendocrine cancer support meetings in July, August and September 2017. The decision to hold three focus groups was pragmatic, influenced by timescales and the limited resources of the UK.

The focus groups were facilitated by experienced NET nurses. They took place within one hour, digitally recorded and discussion aided by a loose interview guide derived from the literature and expert advice.

Table 1
Focus group interview guide

We would like to ask you about your experiences of support in the community when you were first diagnosed with NET.

What kind of support was most important to you at this time?

Who and where did your main source of support come from at this time?

What support did you wish you had been offered at your NET diagnosis?

Do you have a memorable, stand out experience when you experienced the right support just when you needed it?

Can you tell us about a memorable experience when support didn’t meet your expectations?

We would like to ask you about future support

If you could go back and improve support what would you like to see that could benefit future patients?

What support would you like to be available to you in the future?

Data analysis
Data were analysed using an inductive qualitative content analysis process guided by the research aim (Skiöld and Kyrkja 2008). Interviews were transcribed, checked by the transcriber and the transcripts were manually coded and abstracted into sub-categories, categories and themes (Table 2).

Discussion
In this unique study, participants voiced their experiences of support in the community. Previous studies have examined the experiences of NET patients in terms of Health Related Quality of Life and psychosocial function (Frog 2007; Ramage and Davie 2003). This study adds to that body of knowledge by giving focus to the support received throughout the journey of living with a NET entails. The complex interplay of physical and psychological suffering and effects on a patient’s daily life identifies the importance of holistic and tailored supportive care.

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Table 2
Summary of themes, categories and sub-categories

References