

## Introduction

Neuroendocrine tumours (NETs) and carcinomas (NECs) are a heterogeneous group of malignancies, with no common clinical pathway, but previous study has highlighted a common need for effective, well-timed support (O'Toole et al 2016). The prevalence of NET is predicted to rise due to an increase in incidence, better 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 (Oberg 2013). They arise from neuroendocrine cells that are diffusely distributed throughout the body meaning that neuroendocrine tumours can occur almost anywhere.

The diagnosis and treatment of neuroendocrine tumours are uniquely challenging. They are a relatively uncommon cancer, diverse in origin, usually slow growing and frequently associated with clinical syndromes caused by hyper secreted 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 patients NET is an incurable, 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 timings, 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 groups during July, August and September 2017. The decision to hold three focus groups was pragmatic, influenced by timescales and the desire to cover a different parts of the UK.

The focus groups were facilitated by experienced NET specialist nurses, they lasted approximately one hour, were digitally recorded and discussion aided by a loose interview guide derived from the literature and expert advice (Table 1).

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## 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? Were you signposted towards or offered formal support from professional groups?*

**We would like to ask you about experiences that are unique to you and your patient journey.**

*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 where 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 (Elo and Kyngas 2008). Interviews were transcribed and anonymised. The transcripts were manually coded and abstracted into sub-categories, categories and themes (Table 2).

## 'I find the NET hard work'

### Living with Neuroendocrine cancer

Patients across the focus groups discussed how the physical symptoms of NET; an associated syndrome or treatment impacted on their lives. Individuals suffering from carcinoid syndromes agreed symptoms such as unpredictable diarrhoea placed limitations on living a normal life.

The psychosocial effects of living with a NET were considerable. Some participants had lived with NET for many years (Fig.1). All the groups discussed how they felt about being diagnosed with something so rare, frequently describing feelings of isolation and emotional distress, that they were the only with this, being different from other cancer sufferers and even other NET patients (Fig.2).

*'Mines in my lung, it makes me feel different to everybody else'*

*'I really learnt a lot since I came here (to the support group) but I don't seem to be able to relate it to my particular case because I don't seem to have any side effects'*

*'I found it really difficult being the only one with NET not knowing anyone that's had NETs before so not being able to relate to anyone else's cancer or deal with mine.'*

This feeling of being the only one resonated as the discussions turned to how individuals manage the physical and psychological consequences of having a neuroendocrine tumour.

Figure 1 Focus group participants: Year of diagnosis

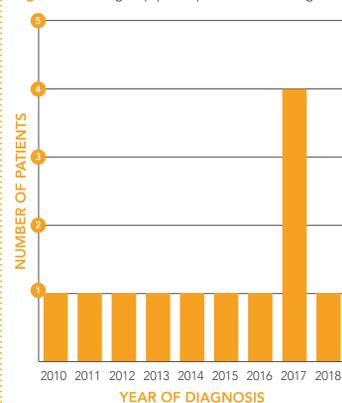
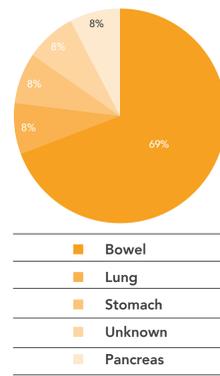


Figure 1 Focus group participants: NET primary site



## 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 (Frojd et al 2007; Ramage and Davies 2003). This study adds to that body of knowledge by giving further insight into the constant work living with a NET entails. The complex interaction of physical and emotional suffering and effects on a patients daily life identifies the importance of holistic and tailored supportive interventions. However, for the first time the participants in our study have revealed what type of support makes a meaningful difference, how it helps self

management and when they are most likely to be receptive.

Our data reveals extensive shortcomings in NET support from the community setting. This is partly due to a scarcity of services. But, services do exist and there is some excellent information available, the data showed that quality NET specific information was highly regarded and sought after. Most patients had performed internet searches for NET information, what they found most challenging was verifying whether the source was reliable. There are studies are being performed on the feasibility of specialist web based NET information and support systems (Bouma 2017). However, a consequence of the lack of awareness and signposting to these services from health care professionals and other

cancer services will mean they are under used and the patient that need them will be unaware of their existence.

## Limitations

The sample is small but is in accordance with the study's aims. Yet the findings reflect the experiences of a heterogeneous sample of participants in England and Wales. It is likely individuals volunteered to participate because they were in a familiar supportive environment and wanted to share their stories about how access to support and a specialist NET Network has changed their lives.

## Conclusions

Life with a NET can seem confusing and overwhelming, particularly in

## 'Who am I going to ask?'

### Barriers to support

From the participants perspective many health care professionals lack knowledge and awareness of NET. Many participants described encounters with health care professionals with insufficient awareness of NET or mistaken understanding, resulting in misinformation.

*'I was told I didn't have any symptoms. I didn't know what the symptoms were, no one ever asked, its only because I googled, I have 95% of the symptoms that I've put down to other things.'*

Another patient described an encounter where their healthcare professional appeared completely disinterested, unfortunately this wasn't a unique experience.

*'the surgical team said you've got a NET cancer, and there was a bit on my stomach and a bit on my liver, but it was a new one to them, they didn't know anything about it at all and suggested I had a look on the internet to find out about it.'*

This lack of awareness extended to support services for cancer sufferers. Participants described their attempts to look for support failing when asked what their diagnosis is.

*'you felt like you were on a different planet having NETs. You went to the cancer charities, any of them and they knew nothing about it'*

Internal influences were also highlighted. Timeliness of support was especially important.

*'I went into the I'm not ill, there's nothing the matter I've got a bit of diarrhoea but there's nothing the matter with me.'*

Even those who were signposted to support at the beginning of their journey admitted that if they weren't ready they ignored it. Then sought it out when they were ready.

*'I think I was told about support but I wasn't in that place at the time, it was just after my operation. I did not want to go to a group. It's taken me a year to get to a point where I could come here.'*

## 'Family support is not the same as talking to someone that's got it or got knowledge'

### Knowledge and skills to manage life with a Neuroendocrine cancer

The participants spoke of seeking information and peer support through the internet and social media.

This could come from NET specialists or other patients; both knowledge and experience of the disease were highly regarded. This desire to be signposted to information and support, yet to take it up at their own pace, was echoed throughout the groups.

There was agreement that peer support and referral to any kind of specialist NET services was positive.

Ultimately participants felt their quality of life had improved either as a direct result of the support received through the NET support group or afterwards feeling empowered to make changes in their care.

*'I only know about certain things from this group. About asking to go and see a dietitian and the tablet creon which helps you with your movements. And its only because of this group, which suggested I should see a dietitian, that I've asked to because it wasn't automatically given to me. So they're on that now sorting that out I'm much better than I was, I've been living with it for 9 years.'*

## Table 2

### Summary of themes, categories and sub-categories

Themes	Categories	Sub-categories
'I find the NET hard work' Living with Neuroendocrine cancer	Being understood Change in sense of self-identity Coping	Isolation Peer Support Being different Emotional Distress Self management Practical issues
'Who am I going to ask?' Barriers to support	Timeliness for individual Delay in receiving appropriate support	Readiness for support Readiness for NET information Misdiagnosis Disinterest from HCP Insufficient awareness Lack of NET pathway Findings from personal or family research
'Family support is not the same as talking to someone that's got it or got knowledge' Knowledge and skills to manage life with a Neuroendocrine cancer	Self directed learning Disease education	Signposting Tumour specific support Information approval