European Journal of Oncology Nursing 17 (2013) 541–545

Contents lists available at SciVerse ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Patient experiences of having a neuroendocrine tumour: A qualitative study

Y. Feinberg [a,*], C. Law [b], S. Singh [a], F.C. Wright [b]

[a] *Medical Oncology, Odette Cancer Centre, Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Toronto, ON M4N 3M5, Canada*
[b] *Surgical Oncology, Odette Cancer Centre, Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Toronto, ON M4N 3M5, Canada*

Keywords:
Multidisciplinary clinic
Neuroendocrine tumours
Qualitative research
Rare diseases
Social support
Patient experience
Patient care pathway

ABSTRACT

Background and objectives: Limited qualitative studies exist regarding the patient experience of having a rare cancer. We sought to understand the patient experience of having a rare malignancy by interviewing patients diagnosed with neuroendocrine tumours (NET).

Methods: Semi-structured qualitative interviews were used to examine the cancer journey experience of NET patients. Purposive sampling was utilized and 18 telephone interviews were completed by a single interviewer. Eight interviewees were female, median age was 63 (age range 45–77). Median interview time was 31 min (range 9 min – 2 h 8 min). Patient interviews were transcribed verbatim and analysed using qualitative research methodology. Grounded theory guided the generation of the interview guide and analysis.

Results: The dominant theme identified was that of ‘no clear pathway’ of care for the patient with NETs. Four subthemes that influenced this theory included: (1) difficulty with obtaining a diagnosis; (2) difficulty finding appropriate information about NETs from physicians; (3) difficulty finding treatment centres with knowledge of NETs and (4) difficulty finding disease specific support. Two global modifiers were also identified; satisfaction with a specialized clinic and long term physical and psychological side effects of treatment. These modifiers did not affect the overall theme but do potentially offer a solution for some of the difficulties the patients experienced.

Conclusions: Patients with NETs had ‘no clear pathway’ of care in their cancer journey. A multidisciplinary specialized clinic for NETs is recommended as well as a strong role for nursing in providing support and building patient and family resilience.

Introduction

Cancer is a common term used for numerous separate and distinct diagnoses (Midtgaard et al., 2009). Understandably, patients will have very different experiences of cancer depending on the particular type of cancer with which they are diagnosed. In particular, patients with rare cancers often have different experiences during their cancer journeys compared to patients with common cancers. Few qualitative studies have described patient experiences with rare malignancies and none in North America (Bullen et al., 2010; Griffiths et al., 2007; Jefferies and Clifford, 2009; Midtgaard et al., 2009; Witham et al., 2008). European studies that have explored this phenomenon describe how patients have difficulty obtaining a diagnosis, how they ‘search’ for information and cancer treatment and how they need recognition and acknowledgement of their distinct cancer journey (Bullen et al., 2010; Griffiths et al., 2007; Jefferies and Clifford, 2009; Midtgaard et al., 2009; Witham et al., 2008).

Neuroendocrine tumours (NETs) are uncommon cancers with an incidence of 5.5 cases per 100 000 persons in 2004 (Yao et al., 2008). Since 1973, the incidence of NETs has increased five-fold although this may be partially attributed to improved classification, increased screening and better diagnosis (Yao et al., 2008). There have not been any published qualitative studies focussing entirely on the cancer journey experience of NET patients.

Patient with NETs often require multi-modal treatment with integration of complex treatment strategies. Multidisciplinary cancer clinics facilitate multiple specialist consultations in one visit for such patients. Such clinics also can foster improved communication between specialists and co-ordinated delivery of treatments for patients (Chang, 1998). Multidisciplinary cancer clinics dedicated to a particular cancer type are suited for providing care for

---

[*] Corresponding author. Sunnybrook Health Sciences Centre, 2075 Bayview Ave., Toronto, ON M4N 3M5, Canada. Tel.: +1 647 504 0871; fax: +1 416 480 6002.

E-mail addresses: yael.feinberg@mail.utoronto.ca (Y. Feinberg), calvin.law@sunnybrook.ca (C. Law), simron.singh@sunnybrook.ca (S. Singh), frances.wright@sunnybrook.ca (F.C. Wright).

1462-3889/$ – see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ejon.2013.02.003

patients with rare cancers where knowledge is limited to specialists that encounter higher volumes of patients with the uncommon condition. For example, the creation of a high volume sarcoma centre has been successfully described for soft-tissue sarcomas, another rare cancer. Gutierrez et al. (2007) demonstrated that a high volume centre produced better outcomes for 30 day mortality, lower limb amputation rate and higher receipt of radiation and chemotherapy. In addition, improved survival for high grade sarcomas and those over 10 cm in size was demonstrated for high volume centres. Gutierrez et al. (2007) suggested that low volume centres have less experience, and outdated or inadequate resources that precludes them from adequately treating rare and heterogeneous cancers.

We created a dedicated, multidisciplinary NET clinic two years ago at the Odette Cancer Centre at Sunnybrook Health Sciences Centre in Toronto, Canada. This clinic has facilitated a single point of care for patient consultation with surgical and medical oncologists who have same site support from endocrinologists, dedicated NET pathologists, diagnostic radiologists, and interventional radiologists. Over two hundred patients have been seen at this clinic over the past two years. There has not yet been any research on patient perspectives from this multidisciplinary NET clinic.

The primary goal of the study was to better understand the experience of NET patients from the perspective of having a rare disease. A secondary research goal was to assess patient views on the new multidisciplinary NET clinic on the treatment of their disease.

Materials and methods

This was an exploratory study using qualitative methods to create a rich in-depth understanding of the patient experience of having a rare cancer, a neuroendocrine tumour. A qualitative approach was used to guide sampling, data collection, data analysis and data synthesis. Grounded theory was used in particular to identify themes or repeating ideas that led to the creation of a conceptual theory that described the experience of having a rare cancer and accessing care at a specialized NETs clinic at a tertiary care cancer centre (Pope et al., 2000).

Participants

Purposive sampling was used to contact NETs patients seen in the specialized NET clinic at the Odette Cancer Centre between June 2009 and June 2010. Packages were sent by mail to thirty nine of the most recently diagnosed patients with NETs who were English-speaking. These packages contained a cover letter explaining the study and a consent form with a stamped addressed return envelope. Two weeks after study packages were mailed, patients were phoned by YF to confirm they had received the package. Consent was obtained from twenty three participants. These participants were contacted by telephone to set up an interview. Eighteen of these participants were interviewed. The other five participants either could not be reached by telephone or were out of town when the interviews were performed in July 2010. Of the remaining sixteen participants that did not submit consent forms, ten could not be reached by telephone, one was later found not to have a diagnosis of NETs and one was deceased. Only four participants declined for reasons including being soon after surgery and feeling unwell due to their disease.

Data collection and analysis

Grounded theory guided the generation of the interview guide and analysis (Pope et al., 2000). Grounded theory is an iterative process of generating hypotheses while reviewing and interpreting raw data. Grounded theory starts by data collection; key findings from this textual data are then coded and organized into similar concepts which are then grouped into themes. These themes are utilized to generate hypotheses or overarching conceptual theory about the data (Pope et al., 2000). A semi-structured interview guide was developed by all the authors, one of whom is an expert in qualitative research methodology (FCW). The interview guide covered areas such as the participants' experience of being diagnosed with NETs, and their access to information, sources of support and treatment at a specialized NETs clinic. In addition, the interview guide contained probes for the participant to share specific aspects of their experiences with NETs, and provided opportunity for the participant to include topics not mentioned in the interview guide (see Table 1).

Interview questions were piloted with four patients and reviewed following the interviews (YF, CHLL, SS, FCW). The interview guide was then appropriately adjusted to ensure all areas of interest were addressed. Interviews were performed over the phone over a period of one month by one independent interviewer (YF) who was unknown to the participants, and under the supervision of an expert in qualitative research methodology (FCW). Interviews were audio-taped and saturation was reached after eighteen interviews. Interviews were transcribed verbatim and analysed using standard qualitative research methodology. Interviews were coded independently by two investigators (YF, FCW) to identify recurring ideas expressed by multiple participants (Auerbach and Silverstein, 2003). Common themes, "an implicit idea or topic that a group of repeating ideas have in common", were identified by each reader and from these themes an overarching theory was developed (Pope et al., 2000). There was minimal inter-reader variation in theme recognition and any differences were explored and resolved through consensus. These findings were then discussed with the entire research team (YF, FCW, SS, CHLL) and consensus of interpretation was achieved. Ethics approval was obtained from the Sunnybrook Health Sciences Research Ethics Board (REB).

Results

Participant demographics

A total of 18 telephone interviews were performed. Median interview times were 31 min (range 9 min to 2 h 8 min). Eight interviewees were female (46%) and ten were male. The median age was 63 (range 45–77). The diagnoses were 11 small bowel NET, 4 pancreas NET, 1 gastric NET, 1 bronchial NET and 1 NET of unknown origin. Date of diagnosis ranged between 1998 and 2009.

Thematic analysis

The conceptual theory derived from this study centres around the dominant theme of 'no clear pathway' of care for the patient.

Table 1
Areas of focus for interview.

Topic	Subtopic
Diagnosis	Symptoms, specialists seen, information provided
Experience with disease	Information access, quality of life, coping mechanisms, support groups
Treatment	Accessing and receiving treatments, confidence, decision making
Multidisciplinary clinic	Positive and negative aspects, comparison to other clinics (if applicable), travel