The PELICAN Study

Patient Experience of Living with CANcer associated thrombosis

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Background

• Cancer associated thrombosis (CAT) is now recognised as a separate disease that should be managed differently to venous thromboembolism (VTE) in patients without cancer.

• Whilst the management of CAT is clearly well known, the effect of CAT on the patient’s quality of life (QoL) is yet to be properly measured.
How CAT differs to VTE

• Most precipitants of VTE (e.g. surgery, immobility, acute illness) are transient and have passed by the time VTE has been treated.

• The presence of VTE in patients confers a poor prognosis when compared to similar stage cancer patients without VTE (Sorensen et al 2000).

• The symptoms attributable to VTE are similar to other cancer related conditions and as such, CAT may be under-diagnosed or diagnosed later than VTE in non-cancer patients (Noble 2007).

• Anticoagulation of CAT is associated with an increased risk of bleeding and a greater rate of thrombosis recurrence when compared to VTE in non-cancer patients (Prandoni et al 2002).

• The gold standard treatment for most patients with VTE remains warfarin after initial anticoagulation with low molecular weight heparin (LMWH) (Keeling et al 2011). However, it is recommended that patients with CAT should receive three to six months LMWH (Noble et al 2008).

• Although the evidence only supports LMWH for six months in the treatment of CAT, some cancer patients may require indefinite anticoagulation since the cancer, and thus the pro-thrombotic risk, remains.
Aim

• To evaluate the experiences of patients with CAT in the UK in order to have an understanding of the impact of CAT and to find ways to improve their QoL.
Objectives

- Are the current validated VTE QoL tools understandable and usable for patients?

- What do patients view as important about their condition?

- The impact of the treatment for CAT.

- How does CAT affect them emotionally?

- Additional support needed for patients.
Sample

• Royal Gwent Hospital, Newport (n=10)
• Velindre Cancer Centre, Cardiff (n=10)

Inclusion Criteria:
• Patients with histologically confirmed cancer;
• Patients with radiologically confirmed VTE both DVT and PE;
• Patients receiving anticoagulation for at least eight weeks at the time of interview;
• Patients able to give informed consent;
• Patients able to communicate in English and take part in an interview;
• Patients age 16 and over.
Methods

• Interview consisting of two components:
  – Semi-structured interview;
  – Cognitive interview.
The semi-structured interview

- To explore the patient’s understanding of their diagnosis and the impact this has on their quality of life.

- To consider the physical, psychological and social aspects of their lives.
The Cognitive Interview

- To test existing QoL questionnaires pertaining to pulmonary embolism (PE) and deep vein thrombosis (DVT) and to ascertain how relevant these documents are for use with patients with CAT.
Cognitive Interviewing

• Cognitive interviewing is based on cognitive psychology and can be used as a method for pre-testing questionnaires prior to their distribution (Drennan 2003).

• Using verbal probing, observation of participants’ behaviour and encouragement of respondents to think aloud, it can be used to understand human information processing (Drennan 2003).
The Cognitive Interview

• Participants will be asked to complete one or two QoL questionnaires relating to CVD measures depending on whether they have a DVT, a PE or both.

• Either:

  – The PEmb-QoL questionnaire - measures QoL for patients with pulmonary embolism (PE) (Cohn et al 2009);

  – The VEINES_QOL/SYM questionnaire - measures QoL for patients with a deep vein thrombosis (DVT) – (Kahn et al 2006).
Analysis
Semi-structured interview
“Framework Analysis”

• ‘involves a systematic process of sifting, charting and sorting material according to key issues and themes’
  (Richie and Spencer 1994 p. 177)
• Familiarization with data;
• Identifying a thematic framework;
• Indexing the data;
• Charting;
• Mapping and interpretation.
Analysis
Cognitive Interviews

• Deductive analysis (Crabtree 1999): limited to fixed categories determined prior to data analysis such as the items on the questionnaires used for the Pelican Study.

• Inductive analysis (Boyatzis 1998): where themes emerge from the analysis. This will capture any comments that participants make spontaneously as well as those comments relating to general probes (use of thematic analysis).
References


