



Original article

Identification of adult knee primary bone tumour symptom presentation: A qualitative study



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ABSTRACT

Objectives: The aim of this study was to identify the symptom presentation of adult knee primary bone tumours from onset to Consultant diagnosis, from combined patient and healthcare professional perspectives.

Materials and methods: A qualitative study using in-depth semi-structured interviews recruited a purposive sample of adult patients with a knee primary bone tumour ($n = 8$) and healthcare professionals with expertise in orthopaedic oncology ($n = 6$). Following informed consent, recorded interviews explored participants' experiences of symptom presentation. A grounded theory approach was utilised to analyse transcribed data, producing themes. Methods to increase rigour and trustworthiness were employed. Recruitment continued until data saturation was achieved.

Results: Four key themes were established: 1] Symptoms started with intermittent pain which became more severe and more constant, 2] Pain was mechanical in nature but became more difficult to ease; 3] The pain story was unusual with a protracted symptom duration and failure to improve with conservative treatment; 4] Non-painful symptoms included swelling, and systemic signs were uncommon. More similarities between healthcare professionals' and patients' perceptions were found at Consultant diagnosis compared to onset.

Conclusion: New insights of symptom presentation, particularly in the early stages have been provided which are not reflected in current guidelines. Although starting similarly to routine musculoskeletal presentations, a number of distinctive features may enable earlier diagnosis.

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1. Introduction

Primary bone tumours (PBTs) (benign and malignant) are rare, with a UK estimated incidence of 600 per annum (Cancer Research UK, 2012). Delays in diagnosis are common, often contributing to the lesion increasing in size and poorer outcomes (Grimer, 2006), psychological distress (Goyal et al., 2004), and in some cases poorer survival rates (NHS, 2007). Professional delay (time between first consultation and initial treatment) is a key contributing factor (Schnurr et al., 2008), due to a low level of clinical suspicion combined with a lack of awareness of symptom presentation

(Wurtz et al., 1999; Schnurr et al., 2008; Grimer and Briggs, 2010). Pathological fractures normally lead to diagnosis but are frequently a late feature. Improving early sign and symptom recognition is recommended as a key way to reduce diagnostic delay (Ott et al., 2009; Department of Health, 2011).

Pain and swelling are cited as common symptoms for malignant primary bone tumours (Grimer and Sneath, 1990; Frink et al., 1998; Wihde and Wihde, 2000; National Institute for Clinical Excellence, 2005; Pan et al., 2010; Sumathi et al., 2012); along with tenderness and a limp (National Institute for Clinical Excellence, 2005). Other symptoms include a palpable mass (Frink et al., 1998), reduced function (National Institute for Clinical Excellence, 2005; George and Grimer, 2012) and systemic signs for spinal tumours (CSAG, 1994). Clinical guidelines (National Institute for Clinical Excellence, 2005) further describe pain as increasing, unexplained and persistent but this often does not correlate with clinical

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presentation or later research (Pan et al., 2010); probably due to variety of bone tumour typology, skeletal locations, study methodologies and time points of analysis.

Recently, George and Grimer (2012) retrospectively investigated symptom progression of various malignant PBTs, from initial healthcare professional (HCP) contact to definitive diagnosis. Key features at first HCP contact were deep pain, a worsening presentation, night pain, difficulty using the limb, and a palpable lump/swelling, with the incidence of all of these features increasing by the time of definitive diagnosis, suggesting symptoms change as the tumour grows.

The knee joint has a high incidence of both benign and malignant PBTs (Healy and Kennedy, 2003). Pan et al. (2010) have investigated the initial symptoms of one type of malignant PBT (osteosarcoma) around the knee. Symptoms often started as an intermittent ache after minor trauma that was worse on weight-bearing, followed by swelling and the development of a limp. However, participants were interviewed up to 5 years after symptom onset which may have affected recall. Regarding benign PBTs, pain with a swelling or mass are described as presenting features (Wurtz and Kollias, 1998), but there is little evidence to support this.

No studies to date have investigated the symptom presentation of both benign and malignant knee PBTs. Investigating this group, from onset of symptoms through to Consultant diagnosis may importantly provide greater understanding of pain patterns and consistency of information which could lead to improved and earlier diagnoses.

The aim of the study was to identify the common symptom presentation, from onset to Consultant diagnosis of knee PBTs in adult patients, from combined patient and HCP perspectives.

2. Materials and methods

The COREQ reporting guidelines (Tong et al., 2007) were used in the presentation of methods and findings within this study. An exploratory qualitative design, using face to face interviews with HCP and patient participants was employed to allow a close rapport, and completeness of answers (Patel et al., 2003). Semi-structured interviews using open and closed questions were utilised to capture new data on this topic (Polgar and Thomas, 1995; Robson, 2002) as part of an inductive process using some of the tools of grounded theory (Glaser and Strauss, 1967; Denzin, 2008), whilst also exploring symptoms reported in the literature (Grimer and Sneath, 1990; CSAG, 1994; Wihde and Wihde, 2000; National Institute for Clinical Excellence, 2005; Pan et al., 2010; George and Grimer, 2012). The author (LG) adopted a post-positivist epistemological position (Guba and Lincoln, 1994), acknowledging the knowledge already available, whilst also searching for new signs and symptoms. Ontologically, the author's standpoint was one of a critical realist (Guba and Lincoln, 1994), understanding that their experience would influence the findings. The approach aimed to build categories and themes based on exploring and analysing emerging data.

The interviewer (LG) was a female Senior Chartered Physiotherapist with previous experience of treating patients with PBTs at a UK Specialist Bone Tumour Centre, their knowledge was used to enhance understanding of the topic and draw more out of the interview (Glaser and Strauss, 1967). The interviewer's reason for researching this topic was based on their experience of patients with PBTs suffering misdiagnoses due to symptom presentation which did not fit with clinical guidelines, ultimately delaying their treatment and causing psychological distress. Participants were informed that the reason for undertaking the research was to understand more about the symptom presentation of PBTs in order to improve diagnosis. The relationship between interviewer and

patients was purely researcher: participant. Data triangulation using a matrix of symptom presentation of participants from two different data sources: patient and HCPs, was employed to examine the topic from two different vantage points, to cross-check the consistency of specific data and allow confirmation of results, thus ensuring more comprehensive, meaningful and reliable findings (Pope and May, 1999) and minimising investigator bias.

2.1. Participants

Fourteen adult participants were drawn from 2 subgroups at a UK Specialist Bone Tumour Centre: i) patients with a knee PBT ($n = 8$), ii) HCPs ($n = 6$). Purposive sampling was utilised to capture a wide range of views and perspectives of participant experience (Bowen, 2008), based on age, gender and tumour type for patients, and Orthopaedic Oncology experience for HCPs. Patients were eligible if aged >18 years and had a confirmed PBT diagnosis in the distal femur or proximal tibia within the last 4 months (to enhance veracity of recall) (Bell, 2005). Children were not included as the questionnaire was only piloted on an adult population. HCPs with a minimum of 10 years of experience managing patients with PBTs were selected in order to ensure high levels of knowledge and expertise in this area (Ericsson, 2014). Participants who could not understand English were excluded due to the scope of the study.

2.2. Interview topic guide

An interview topic guide was developed for patient and HCP participants (Appendices A & B respectively), to explore symptom presentation from onset to Consultant diagnosis, following a recommended format (Robson, 2002) and guided by available literature (Grimer and Sneath, 1990; CSAG, 1994; Frink et al., 1998; Wurtz and Kollias, 1998; Wihde and Wihde, 2000; Healy and Kennedy, 2003; National Institute for Clinical Excellence, 2005; Ott et al., 2009; Pan et al., 2010; Department of Health (2011); Sumathi et al., 2012; George and Grimer, 2012). Where relevant, participants were only asked about symptoms up to the point of pathological fracture. Topic guide questions were previously piloted at a National Bone Tumour Conference where a nominal group of 11 adult delegates, who had previously had a PBT, were invited to review them. Feedback was used to modify question phrasing, depth and coverage.

2.3. Recruitment

Clinicians introduced the study to eligible patients face to face and provided an information pack. If patients were interested in the study, the lead researcher (LG) contacted them to answer questions, ascertain understanding (Patel et al., 2003) and interest in participation. LG approached HCPs in person, providing an explanation of the research, anticipated patient benefit (Patel et al., 2003) and information pack. All participants who were approached about the study agreed to participate. Following this, a meeting was arranged at the UK specialist centre where eligibility was evaluated and confirmed in all cases; any remaining questions were answered before obtaining written informed consent and commencing the audio recorded interview. During the interview, field notes were made and no non-participants were present. Repeat interviews were not conducted. Macmillan support was made available in the event of patient distress, but was not required by any participants. Interviews lasted on average 23 min. Audiotapes were professionally transcribed verbatim (Robson, 2002) and anonymised. Transcripts were stored electronically and securely in accordance with Good Clinical Practice Guidelines (2011) (NIHR, 2011). Recruitment continued until saturation (Bowen, 2008) of data was achieved whereby no new themes emerged.

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