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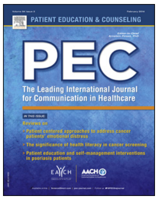

Patient perception, preference and participation

"I suddenly felt I'd aged": A qualitative study of patient experiences of polymyalgia rheumatica (PMR)

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ABSTRACT

Objectives: To explore patient experiences of living with, and receiving treatment for, PMR.
Methods: Semi-structured qualitative interviews, with 22 patients with PMR recruited from general practices in South Yorkshire. Thematic analysis using a constant comparative method, ran concurrently with the interviews and was used to derive a conceptual framework.
Results: 5 Key themes emerged highlighting the importance of: (1) pain, stiffness and weakness, (2) disability, (3) treatment and disease course, (4) experience of care, (5) psychological impact of PMR. Patients emphasised the profound disability experienced that was often associated with fear and vulnerability, highlighting how this was often not recognised by health care professionals. Patients' experiences also challenge medical convention, particularly around the concept of 'weakness' as a symptom, the use of morning stiffness as a measure of disease activity and the myth of full resolution of symptoms with steroid treatment. Treatment decisions were complex, with patients balancing glucocorticoid side effects against persistent symptoms.
Conclusions: Patients often described their experience of PMR in terms of disability rather than focussing on localised symptoms. The associated psychological impact was significant.
Practice implications: Recognising this is key to achieving shared understanding, reaching the correct diagnosis promptly, and formulating a patient-centred management plan.

1. Introduction

Polymyalgia rheumatica (PMR) is the most common inflammatory rheumatic condition in people aged over 50 with an incidence of 1 in 1000 in this age group and a lifetime risk of 2.4% for women and 1.7% for men [1,2]. It is characterised by pain and stiffness in the hips and shoulders, raised inflammatory markers and response to glucocorticosteroids, although atypical presentations can occur in up to 20% of those affected [3,4]. PMR has a major impact on quality of life [5] and treatment with corticosteroids is associated with a high rate of adverse effects [6]. Despite this, it remains an under-researched and poorly understood condition with the lack of primary care research particularly notable considering that the majority of PMR is diagnosed and managed in primary care [7].

Patients with PMR require frequent, comprehensive clinical assessments. At each consultation assessment of disease activity and response to treatment is needed, as well as evaluation of treatment side effects and assessment for complications [8]. Exploring and understanding the patient experience of PMR as an 'illness' is crucial in order to facilitate shared decisions about treatment, balancing symptom control and functional enablement against adverse effects of steroid therapy. Much of the research into PMR to date however focuses on a biomedical model of 'the disease' and current clinical assessment therefore tends to be set in this paradigm.

There is increasing emphasis in many areas of health care on patient reported outcome measures (PROMS) as one tool to help in the drive to achieve the goal of person-centred care. Only by

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exploring patient experiences can the outcomes which are meaningful to patients be identified. For example, in rheumatoid arthritis, an appreciation of the significance of fatigue was first identified through qualitative exploration [9,10] and it is now recommended that fatigue is measured in addition to the core outcome set in all clinical trials of the condition [11].

There is work being done towards agreeing a core set of outcome measures for use in clinical trials of PMR [12]. However, there are no measures available which assess outcomes directly from the perspective of a patient with the condition. A PROM developed specifically for PMR would contribute greatly to a comprehensive assessment of the condition. The first step in developing a PROM is to determine the conceptual framework through qualitative studies of the target population [13].

We therefore set out to explore patient experiences of living with, and receiving treatment for, PMR with the dual aims of enhancing understanding of the condition from the patient perspective and allowing derivation of a conceptual framework for future development of a PROM.

2. Methods

Ethical approval for this study was obtained from the Dyfed Powys Research Ethics Committee (REC 12/WA/0344, 15/11/12).

Participants were recruited from 10 general practices from South Yorkshire. A purposive sampling strategy was used to recruit practices which were diverse according to their Index of Multiple Deprivation score, list size and training status.

Patients aged 50 years and over with a Read coded PMR diagnosis and classical PMR symptoms (documented in the electronic medical record as having bilateral shoulder and/or pelvic girdle pain and stiffness for at least 2 weeks, and evidence of an acute phase response (raised ESR/CRP)) were included.

Patients with atypical features (e.g. normal ESR/CRP), were eligible if their diagnosis had been made by a rheumatologist. Patients were excluded if they had significant dementia or memory impairment, a primary diagnosis of giant cell arteritis, a concomitant inflammatory arthropathy, active cancer or if the GP decided that participation wasn't appropriate (e.g. other terminal illness).

An invitation letter and study information sheet were sent to suitable patients and if they wished to participate they replied directly to the research team. Reminder letters were sent 2 weeks later to those that had not replied to the initial invitation.

A topic guide (see Appendix A) was developed, informed by discussion with members of a PMR patient support group (PMR-GCA UK North East Support), a literature review and consultation with the study multidisciplinary advisory group. Topics included in the initial guide were onset of the condition, symptoms and functional effects, diagnosis, flares and relapses, starting and stopping treatment, resolution of the condition and information provision. An open questioning style was used with minimal prompts to allow themes to emerge naturally [14]. Interviews were conducted by either HT or CaM, in participants' homes or in the Academic Unit of Primary Medical Care (University of Sheffield) according to participant preference. After the interviews, patients' notes were reviewed by HT to gather data on comorbidities, ESR/CRP results and steroid dose regimes.

Interviews were taped, independently transcribed and then systematically analysed using a constant comparative method to establish themes grounded in the data [15]. NVivo10 software was used to manage the data. Analytic codes and categories were developed through an iterative, thematic and self-conscious process, beginning in parallel with the data collection and informing subsequent interviews as concepts and themes emerged. The process of constant comparison continued until theoretical saturation was reached and no new themes were emerging.

Two researchers (HT and CaM) analysed the data independently and any differences were considered and discussed until agreement was reached. A third researcher (NM) moderated a selection of interviews to ensure comprehensiveness and consistency of identified themes.

10 Practices took part in recruitment, with 7 of these identifying patients suitable for inclusion. Recruitment ranged from 0 to 7 patients per practice.

43 Patients were invited to participate. There were 18 non-responders and 3 patients (all male) who agreed to take part but weren't required for interview as data saturation had been reached.

12 Men and 10 women were interviewed. 2 Patients were excluded post-interview (one had his diagnosis revised to inflammatory arthritis during the course of his illness and one had extensive co-morbidities and could not distinguish the effects of PMR from other conditions). The age range of participants was 53–81 years and the range of time from diagnosis to interview was 5 months to 2 years 3 months. 3 had been referred to secondary care at some stage in the course of their condition and the rest had been managed entirely in primary care. (see Appendix A for table of participant details).

3. Results

5 Key themes were identified which were all interlinked and related. A conceptual framework was developed which reflected the relationship between the themes and subthemes (see Appendix A).

3.1. Theme 1: Pain, stiffness and weakness

> I could hardly move in bed, it was aching all down my back and I just felt, I suddenly felt I'd aged, like I were about 80 year old, that's what it felt like. And very stiff, very achy like when you turned over in bed it was painful. UPN 16.

There was significant heterogeneity in symptoms described by participants. Some described severe pain whilst others described muscle ache, likened to that caused by flu or vigorous exercise. In others, stiffness predominated and pain was mentioned secondarily to this.

Although weakness is not a widely accepted symptom of PMR, and is not part of the recent classification criteria [1], several patients used the term. In most cases, with greater elaboration, it became clear that the term 'weakness' was being used to describe limited function due to pain or stiffness. However, a few participants were certain that they were experiencing true weakness.

The majority of participants experienced variation in their symptoms through the day though there were a few who said that their pain and stiffness was constant. Some did describe a classical morning stiffness pattern but most painted a more nuanced picture of diurnal variation with worsening of symptoms after periods of rest or after any significant activity (Box 1).

3.2. Theme 2: Disability

> I couldn't put my coat on, couldn't get up the stairs, couldn't get in and out of the car and I noticed—I've got an allotment and I were in the greenhouse and on my knees and I couldn't get up, I'd got to crawl on my knees to get something to pull me up with. UPN 11.

Many participants described profound disability which came on over a relatively short time period of time (typically days to weeks). Often these were people who, despite their age, had