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"I suddenly felt I'd aged": A Qualitative Study of Patient Experiences of Polymyalgia Rheumatica (PMR)

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Key words

Polymyalgia rheumatica, patient perspective, qualitative research

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 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 1) was developed, informed by discussion with members of a PMR patient support group, 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 0-7 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 2 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 3).

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 – Pain, stiffness and weakness

"And I really screamed in pain. You know, to get dressed. Or even to lift my arms up. The pain was terrible." *UPN 18*

"Well it's not pain, it were more of a bad ache and I couldn't do much, you know." *UPN 13*

"..the shoulders and the biceps... they felt very weak… they weren't painful, just wouldn't work" *UPN 5*

"When you first have PMR, it used to take me til about tea-time to actually come round. And even when I started on the prednisolone, I didn't sort of come round straight away as I've told you. But that's when I noticed the prednisolone was working, that the pain was -, I was freer much earlier in the day." *UPN 2*

"I would say my best time is 10 o'clock while 3 and then I seem to get really tired. I think it's when you've done most of what you want to do and then you sit down and then I kind of seize up." *UPN 3*

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 previously been

active and suddenly suffered a life-changing reduction in their ability to carry out many activities of daily living. It was notable that participants often described their experience of PMR in terms of what the condition stopped them doing, rather than detailing specific symptoms.

One repeated observation by patients was that they became so stiff that they couldn't turn over in bed. A range of other activities were affected including getting dressed, toileting, managing stairs and getting in and out of a bath or the car.

Box 2: Disability

"I went on holiday in the September and on the holiday, I thought it was the travelling that had done it, I couldn't turn over from front to back in bed. And I couldn't get my hips down onto the loo. I was fine then for a few more days and then still on that holiday, I had that same thing again. I woke up and I was on my front, I couldn't get over in bed. And I developed strange pains across the top of my shoulders. I came back from that holiday….and I just went down within about a week of not being able to get out of bed, not being able to turn over in bed. And my husband was actually swinging my legs out, getting my arms and pulling me up out of bed." *UPN 2*

"I didn't know how to get in the car because my legs wouldn't bend, my arms wouldn't bend, she had to put one of her little one's booster seats on the front seat so I didn't have to lower myself quite so low and it had got to the stage where I couldn't lift my arms to comb my hair… really struggling with everything, walking upstairs and everything." *UPN 14*

"…it got to such a stage where I were laying in bed and quite frankly I could hardly move in bed and at the top of my arms – certainly from the elbow up to the top of the shoulder here and here I was sort of getting these cramp type pains." *UPN 21*

Theme 3: Experience of care

"I mean if they'd have given me steroids for like 24, 48 hours and it had the effect it did, they would have known long before." UPN 6

The path to diagnosis was very variable. Whilst some patients were diagnosed early on in the course of their illness, many felt that, with hindsight, a diagnosis could have been made earlier. Some expressed significant frustration about this. Several patients saw doctors multiple times and were tried on a range of treatments including analgesia, stopping statins, physiotherapy and in one case even antidepressants, prior to a diagnosis being made.

Participants tended to feel that their condition was poorly understood by the medical profession. Many had been given patient information leaflets (PILS) and some found these useful in that they validated their experiences and gave them confidence. Others however, were frustrated that the PILs portrayed the condition as mild and resolving within 2 years when this wasn't their experience. Patients and their relatives frequently sought information from the internet but despite this, were often left with a sense of uncertainty about PMR and its management.

Box 3: Experience of care

"And I went to the doctors, well they were telling me to take paracetamols like and then they were no good, he increased it to some stronger stuff and I went back again, I said 'they weren't doing us any good' and then I suggested to him could it be this Simvastatin that I were on. And he said he'd thought of that and stopped it for about a month I think. And that didn't have any effect and so I went, I had a blood test and went for results of the blood test and he more or less knew what it were then straightaway." *UPN 11*

"I think I'd been up to see her when it first started, 'cause I could hardly walk... She kept sending me for these blood tests and the last time they wanted another blood test off me, my husband went up; he says, 'Look, my wife can't get out of bed this morning.' And they sent a doctor down to take it. And then he says to her, 'I think you ought to send her in hospital. She needs treating. She's not getting anywhere.' And that's what she did then, you see – she sent me to hospital." *UPN 18*

"I did actually have a month on a, what do they call it, you know the antidepressants, because I was going with all these pains and I wasn't getting anywhere at all. But I knew as soon as I started on the antidep-, it wasn't for me and that was it, after the month I came off them and I thought well, you know, I'm just going to see this through and I'm just going to have to see what's going to happen. And I'm going to have to create eventually and ask to see a specialist or something, because when you get to my age and you've been fit, you do know your own body, you know if there's something right or wrong." *UPN 2*

"When they fetched me back in and told me what I'd got and she printed so many sheets out and she said, the doctor, 'this is exactly you' and it was, that you can't get out of bed and you can't do this and you can't do the other….I mean it was all about it and it was me, definitely me." *UPN 17*

"When they said what I'd got, I was very pleased when they gave me the medication and it started to work so well. I was very happy about that but when they said that there's no cure for it because we don't know what it is, that was a bit upsetting." *UPN 5*

"I then looked online. There's quite a bit online actually but it all says the same thing – they don't know." *UPN 6*

Theme 4: Treatment and course of the condition

"I was smiling again because I'd got the power and I'd got the strength back. I got the walking back, I could go out." UPN 5

Prednisolone treatment brought about rapid resolution of symptoms in the majority of patients and many reported being amazed and relieved at how quickly they were able to resume normal activities. However, the burden of side effects from steroid treatment was also a strong theme. Weight gain, hyperactivity and irritability were the most frequently mentioned but there was a wide range of symptoms which patients attributed to the prednisolone. For some patients it reached a point where they felt the side effects were worse than the symptoms of PMR itself, though others viewed the side effects as 'a small price to pay'. Several patients also commented on the additional tablet burden associated with being on long term prednisolone treatment as most were also prescribed calcium and vitamin D supplements, a bisphosphonate and a proton pump inhibitor.

The rate and pattern of reduction of prednisolone dose varied considerably between participants, as did the degree to which patients took charge of this themselves versus being guided by their doctor. Many described being aware of a slight worsening in symptoms with each dose reduction but that this would settle after a few days. Several patients had had more significant relapses at points during the disease course necessitating increasing their prednisolone dose. In most cases this was experienced as a resurgence of their original symptoms though at a less severe intensity.

Some of the participants were interviewed at a stage in their condition where they had reached very low doses of prednisolone or had even had a trial of stopping treatment altogether. In some cases participants described balancing the negative effects of being on low dose prednisolone with the, by then mild, PMR symptoms to achieve their desired quality of life. In general however there was a sense of not quite being back to the level of health that they had enjoyed prior to developing PMR. Some commented on the fact that they had aged during the disease course and become less fit due to reduced activity and the weight gain associated with treatment. This combination of factors resulted in them not feeling that they were able to recover fully to their pre-morbid state.

Box 4: Treatment and course of the condition

"He put me on these Prednisolone and it was like magic, it was just so good, you know, that I had no pain and I went back again to let him know how I was going on and I says 'thank you, you know, I can't say to you what a difference that's made to me'" *UPN 12*

"I just didn't feel like me, you know, it was almost like somebody else was living inside. I became tense, sometimes, or a bit ratty. And I really didn't like the weight gain and I think I put on over a stone in the first few months, you know, I went up a whole size of clothing and everything, which was not nice really." *UPN 19*

"Well I can put up with it, I can live with it, it's affected me all these aches and pains, aching and that, it's not as much of a sharp pain, it's just, you know, like, nagging ache. I can put up with that, but it's just, I think it's these side effects what I'm getting with the tablets what's worse. I feel as though this is worse now than the actual bad aching." *UPN 13*

"Yeah, I have put a bit of weight on with it and I've noticed that my stomach gets -, I never had a stomach but it gets really swollen, more so when I've had something to eat kind of thing and my face looks really bloated some days, you know, yeah, but I just think back to when I first started with it, you know, and I think to me it's a small price to pay, you know." *UPN 14*

"Every time he dropped the dose for a week, I could tell that it had dropped dose and I weren't very well, but I carried on and it like worked itself off, I worked through it sort of thing" *UPN 11*

Theme 5: Psychological impact

"But, well, I thought worst, you know, I thought I were like, what these illnesses where you just finish paralysed, I don't know what they call them but I felt it were going to be something like that, because I were getting worse." UPN 11

This was a striking and recurrent theme which linked closely with all of the other themes but particularly with that of disability. The pain and disability itself clearly impacted on patients' mood but many also described feeling fearful about the possible diagnosis and prognosis. Several patients

specifically mentioned fearing that they had developed motor neurone disease, multiple sclerosis or some form of terminal muscle wasting illness. Previously fit people suddenly felt vulnerable and lost confidence and independence.

As a consequence there was frequently a significant sense of relief when a diagnosis of PMR was made. The importance of having a label to validate their experience and symptoms was apparent and the relief was even greater because a diagnosis of PMR meant that they could immediately receive an effective treatment.

After diagnosis, the focus of the psychological impact was different but it was still present. Many then reported anxiety about disease trajectory and adverse effects of medication, as well as experiencing a sense of loss for the life they had prior to the condition developing.

Box 5: Psychological impact

"At one time he was in the bathroom and he'd been trying to perform with a towel and couldn't and he started crying and he broke down and I went to him and I've never known him cry like that before and he says 'I'm bloody useless'."
"Well, I thought me life, I wouldn't say me life had come to an end but I was so – "
"You thought your life, as it had been, had finished." *UPN 1 and his wife*

"Not being able, as I say, those 3 days I didn't take any Ibuprofen before I saw the doctor, I really had to depend on my daughter, you know, yeah. and frightened, really, being in the house on my own, like going upstairs, you know, because although there's a rail, as I say, my legs just wouldn't bend to go up and once I got to the top of the stairs when the rail finished, I didn't know how I were going to go any further, it were a real ordeal, you know, yeah. And there were certain things that I daren't to when I were on my own, I wouldn't have dared got in the bath, you know, unless somebody was in the house and I just kept the phone on me all the time, because I really thought I were going to fall at some point." *UPN 14*

"But as I say, it were just – it got to a stage as I say when I went to the doctors – it got to a stage when I were literally struggling to turn over in bed – that were quite frightening because you'd lay on your back and all of a sudden you're thinking 'well, it's almost like being locked in your body in a way'. Yeah – you hear about – and I forget what the name of these – some of these things – but these wasting away diseases – I forget – I can't remember what the name is – it's on the tip of my tongue now – but you think 'well, if it's something to do with the muscles or if it's something like that have I got something like multiple sclerosis coming on or something like that' and not being a doctor I wouldn't know what the symptoms are. It frightened me quite frankly and it knocked me off balance in a way because – so it's made me feel more vulnerable." *UPN 21*

"I was just glad to get a diagnosis, you know, and I was euphoric, you won't believe this! But the day they told me I'd got PMR, I was euphoric, I was picking the phone up to my sister and said 'I've got an answer now, I've got this' because to me I were then going to get the cure and get better." *UPN 2*

"Because I hadn't heard of it at all. I really did think oh thank God somebody's listening to me. I thought I was imagining it." *UPN 3*

4. DISCUSSION AND CONCLUSION

4.1 Discussion

This is the first qualitative study to explore the effect of PMR on patients' lives. Studies of other chronic rheumatological conditions have contributed to a wealth of models describing the effects of long term conditions on patients and their families e.g. Bury's 'Chronic illness as biographical disruption' [16] and Weiner's 'Strategies for tolerating uncertainty' [17], and many of the themes identified in this study correlate well with these existing models. Eisenberg's concept of the distinction between 'diseases' (which doctors diagnose and treat) and 'illnesses' (which patients' experience) [18] is also highly relevant to PMR. Given that PMR is a heterogenous condition, affects older age groups (who will have a huge range of comorbidities, life experiences and coping strategies), causes pain and disability and is treated with medication capable of causing significant harm, the importance of assessing 'illness' rather than focussing on 'disease' is particularly pronounced. The risk otherwise is of significant under- or over-treatment with associated harms. A patient reported outcome measure for PMR could significantly contribute to a holistic assessment, acting as a bridge between 'disease' and 'illness' and thus between doctor and patient.

The results from this study support previous findings of the heterogeneity of PMR which contributes to the complexity of diagnosis and assessment of disease activity [3,19]. The terminology used when discussing symptoms is important in achieving a shared understanding between doctor and patient and enabling a correct diagnosis. Recognising therefore that patients may describe weakness as a feature of PMR is important, whether or not it is truly a separate construct from pain or stiffness.

Morning stiffness is a characteristic feature of inflammatory musculoskeletal conditions and is part of the diagnostic criteria for PMR. However, there have been questions raised over the usefulness of this concept in this condition [12,20] and the findings from this patient group echo the suggestion that stiffness often persists through the day and is worse after any period of rest. It may be more appropriate to discuss stiffness rather than 'morning stiffness' in PMR and the use of concepts such as duration of morning stiffness as outcome measures may be unhelpful.

Participants in this study tended to describe the impact of PMR in terms of 'disability' rather than detailing localised symptoms. Difficulty with carrying out a wide range of daily activities was described and this significantly affected quality of life. Key limitations mentioned on many occasions were the inability to turn over in bed and the inability to get up after bending down. These particular difficulties contributed to a sense of helplessness and vulnerability and exemplify the overlap between the themes of disability and the psychological impact of the condition. The relatively rapid change in people's ability to carry out every day activities was associated with disruption of normal roles, 'loss of self' and a sense of uncertainty as has been described in studies of other long term conditions [16,17,21].

Another striking emergent theme from these interviews was the profound psychological impact of the symptoms of PMR prior to diagnosis. Many patients had significant anxiety about a wide range of potentially serious neurological and malignant conditions. In cases where there was a perceived delay in diagnosis, this anxiety was exacerbated. The symptoms of PMR have a wide differential diagnosis and controversy still exists as to the defining characteristics of the condition [19]. The diagnosis is often made over a series of consultations forming a process which may include an initial trial of treatment [8]. Understanding and acknowledging patient anxiety and addressing their specific fears during this process could improve patient experience.

4.2 Strengths and limitations

This study is unusual in that it recruited patients from primary care, the setting where the majority of patients with PMR are managed [7]. This is a true strength of this study and allows a wider transferability of the findings. Whilst patients may not have received a 'gold standard' diagnosis from a rheumatology specialist, we only included those with a PMR diagnosis and evidence of meeting the classification criteria [3] for PMR – namely bilateral pain and stiffness in the hips and shoulders and elevated inflammatory markers. It was surprising that more men than women were recruited given that the quoted incidence ratio is 2:1 female to male [1] but, whilst we acknowledge that there are gender differences in the way patients experience chronic illnesses eg. in stress and relationships, we don't believe that this pattern of recruitment detracts from the transferability of the main findings.

Both of the researchers carrying out the interviews and analysis in this study were GPs. Their prior understanding of the condition therefore arose from this background and will no doubt have shaped the research process to some degree. However, as researchers they also had training in qualitative interviewing and reflexive analytical skills and were systematic and self-conscious in their approach. The participants were aware of the researchers' profession and this may have affected the way they discussed their experiences. However the setting of the interviews and naturalistic style (as opposed to general practice consultation in a surgery) will hopefully have mitigated this to some degree.

4.3 Conclusions

This qualitative primary care study has broadened our understanding of PMR and its effects on patients' lives. The discussions around pain and stiffness and the course of the condition were anticipated, but the severity and impact of the disability, the associated fear and vulnerability and the often less than ideal experience of care were all surprisingly strong themes. The systematic analytical approach used in this study allowed these themes to emerge and be tested through constant comparison, ensuring that the resulting concepts are truly grounded in the patient experience.

4.4 Practice implications

This study highlights several important aspects of patients' experiences of PMR which may not necessarily be recognised or considered by health care professionals in our traditional understanding of the condition. Through greater professional understanding of the ways in which the condition affects patients, patient care may be improved.

In addition to the 5 main themes identified from the interview data we have derived an itemised list of functional activities that participants reported being limited by their PMR. We plan to use this, set in the context of the conceptual framework developed from the rich interview data, to design a patient reported outcome measure specific to PMR. It is hoped that this will have both research and clinical utility by contributing to a standardised assessment of the condition

Word count

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Declarations

None of the authors have any competing interests.

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