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## RESEARCH ARTICLE

# Better arthritis care: Patients' expectations and priorities, the competencies that community-based health professionals need to improve their care of people with arthritis?

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## Abstract

**Objective:** The aim of the present study was to identify the competencies that patients think non-specialist community-based nurses and allied health professionals (AHPs) need to enable them to assess, care for and manage arthritis appropriately.

**Methods:** Four face-to-face focus groups were held with a total of 16 women and nine men with arthritis, to discuss the care they received from community-based health professionals, the skills and knowledge they expected from community-based health professionals and what they prioritized.

**Results:** People with arthritis wanted health providers to have an understanding of the difference between inflammatory arthritis (IA) and osteoarthritis (OA), of how serious OA can be, and of the unpredictability of IA and flares. They emphasized the need for nurses and AHPs to understand the psychosocial impact of arthritis on individuals, family and friends, and the psychological adjustment needed when diagnosed with IA. They wanted community-based health professionals to have some knowledge of the types of drug treatments that people with IA receive and the implications of taking immunosuppressive drugs. They also wanted them to understand the pain associated with arthritis, particularly OA, which participants felt was not taken seriously enough. They wanted nurses and AHPs in the community to be able to give basic advice on pacing and pain management, to make multidisciplinary referrals, to communicate effectively between referral points and to be able to signpost people to sources of help and good, reliable sources of education and information (especially for OA). They also wanted them to understand that patients who have had a diagnosis for a long time are the experts in their own disease. Other areas which were emphasized as being important were good communication skills and taking a holistic approach to caring for people with arthritis.

**Conclusions:** OA and IA differ significantly, both in their nature and their management. However, patients with arthritis want health professionals working in the community to be able to take a holistic approach to arthritis, with an understanding not just of the physical effects, but also their impact on the lives of patients, their family and their wider social circle, and on their ability to participate. People with OA want their condition to be taken seriously and to be offered appropriate management options, while people with IA want professionals to understand the unpredictability of their condition and to have a basic understanding of the drugs used for its treatment.

## KEYWORDS

allied health professionals, arthritis, community-based, competencies, nurses, patients

## 1 | INTRODUCTION

The term “arthritis” encompasses osteoarthritis (OA) and inflammatory arthritis (IA). OA is the most common form of arthritis, with approximately one-third of people aged 45 years and over in the UK having sought treatment for it (Arthritis Research UK, 2014; Cross et al., 2014). IA, of which there are many types, including rheumatoid arthritis (RA), affects approximately 2% of the female UK population (Arthritis Research UK, 2014). Community-based nurses, occupational therapists (OTs), physiotherapists, podiatrists and pharmacists routinely encounter patients with arthritis in their clinical practice either as a presenting problem or, particularly with OA, as a co-morbidity. Despite this, the management of arthritis in primary care does not always meet guidelines (Goodwin et al., 2010). Insufficient knowledge of RA and OA means that opportunities to educate and inform patients may be lost (Scott et al., 2008). This situation led the National Audit Office (2009) to recommend that awareness of RA be improved in primary care. A report by the King's Fund (Goodwin et al., 2010), an influential health policy think tank, called for a more proactive approach to the management of arthritis, with high-quality care for people with arthritis shared across care settings and multi-professional teams.

There is little evidence on the competencies needed by these professionals in order fulfil these goals (Almeida et al. 2006, Fletcher et al. 2012, Hewlett et al. 2008; Lillie et al. 2013; Mann, 2012). The current study therefore sought to explore the competencies needed by non-specialist community-based nurses and AHPs to enable them to assess, care for and manage arthritis appropriately. This was carried out using a Delphi approach to consult with rheumatology experts, together with focus groups and interviews with community-based health professional and patients. The results of the Delphi and the professional focus groups are reported elsewhere (see Erwin et al., elsewhere in this Issue).

## 2 | METHODS

Four face-to-face focus groups were held, with a total of 16 women and nine men with arthritis. These were held in Bristol, Exeter and Cornwall. Participants were recruited to the focus groups through posting on the National Rheumatology Arthritis Society and Arthritis Research UK websites and Facebook pages, posters in GP surgeries, advertisements in local newspapers and through local support groups. Two groups were attended by people with IA (RA and psoriatic arthritis); one group had patients with RA and OA. A fourth group had people with OA only. The age of participants ranged from 28 to 84 years, and they were of varying socioeconomic backgrounds. The focus groups varied in size, the largest having eight participants and the smallest having four. Each focus group lasted approximately 1 hour. The focus groups participants were asked about their experiences of receiving care for their arthritis from community-based nurses and AHPs; how this care might be improved and what they would want nurse and AHPs working in the community to know about arthritis. The study used a phenomenological approach to the focus groups which facilitated the gaining of insights into people's perceptions, perspectives and understanding of receiving arthritis-related healthcare.

## 2.1 | Data analysis

The data from the focus groups were transcribed verbatim, and analysed by a researcher (J.E.) using deductive thematic analysis. Initial codes were generated, and themes identified, reviewed and defined. Five of the transcripts were also coded by another researcher (K.E.). Final themes were refined through discussions between J.E. and K.E. The final codes and themes were reviewed by A.W.

## 3 | RESULTS

### 3.1 | Patient focus groups

People with IA reported having little contact with community-based health providers for their condition, other than blood monitoring. Podiatry services were reported to be used by participants in Bristol, but in Exeter and Truro very few participants had used a podiatrist. Community-based physiotherapy and occupational health services were also not widely used. Despite the fact that people with OA receive their care in primary care, they too reported having little interaction with community-based nurses and AHPs, other than pharmacists. Below are short descriptions with illustrative quotes, highlighting the key issues raised by patients in the focus groups.

#### 3.1.1 | To understand and be able to distinguish between IA and OA

Participants did not expect community-based nurses and AHPs to know everything about all the various types of arthritis and treatments but they did expect them to have some basic rheumatology training and to know who can be affected. It was felt that some professionals still thought of arthritis as “an old persons' disease” and were not sufficiently aware that inflammatory arthritis can present differently and can affect all ages:

*There are so many different types of arthritis - I don't think they can learn all about it. They need basic training in rheumatology, then asking and listening to what the patients say. They've got to get it from the horse's mouth and that's what they don't do. (Woman, PA).*

*It was a physio that picked up my psoriatic arthritis - she had a suspicion ... completely ignored how old I was - so I was 27, 28 at that point - so she ignored my age and just looked at the condition, then passed on the information. (Male, PA).*

They also expected them to be able to give a simple explanation of the common types of arthritis:

*In terms of the knowledge and skills needed by the community, I think first of all being able to understand that people perhaps don't understand the condition they've got, and need some explanations about the condition; so, you know, the person you are talking to should be knowledgeable about the various conditions and the basic treatment options. (Male, OA).*

### 3.1.2 | To be able to take a holistic approach

The need for a holistic approach was strongly emphasized by all participants. Those with osteoarthritis felt that often health professionals dealing with their condition were reductionist and did not look at the impact on the whole person:

*We're just dismissed. They deal with one thing and then that's it. You've had a new knee. You're seen a year later ... that's OK, you're walking OK. They deal with one joint at a time and that's it. (Woman, OA).*

### 3.1.3 | To take OA seriously and understand its impact

It was strongly felt by participants with OA that their condition was not taken sufficiently seriously by health professionals, including nurses and AHPs working in the community, and that they did not understand its impact:

*The thing I would say about arthritis which I think we all agree on is that it's taken very casually. You've got osteoarthritis; well, it's just one of those things you've got to put up with, like having a headache – one of those things you've got to learn to live with. Nobody takes it seriously. Like, if you've got it then hard luck! (Man, OA).*

*I suppose I do feel I've been written off ... there's not much we can do for you, just got on with it. (Man, OA).*

### 3.1.4 | To understand the unpredictability of IA

Participants felt that community-based health professionals did not sufficiently understand flares, the unpredictability of the condition and the impact of this. It was felt that this understanding was needed to enable them to give appropriate advice:

*They are used to people being bad and staying bad. They're not used to this sort of relapsing, remitting thing. Therefore, it's worth them having particular training on this, on the different types of arthritis and how they affect people. (Woman, RA).*

### 3.1.5 | To understand and be able to give basic advice on pacing

Pacing was recognized by participants as an important tool to manage their arthritis but many felt that nurses and AHPs did not have a good understanding of this and did not give sufficient advice. This was particularly true for patients with OA:

*Pacing ... if I have a long day one day, I take it a bit easy the next but no one's spoken to me about it. It's all down to me really. (Woman, OA).*

*Pacing is a difficult technique to accept. People in the community need to keep you in the loop, to keep you motivated. Pacing can feel like you're giving in. (Woman, OA).*

### 3.1.6 | To be able to adjust normal practice

Participants expressed the need for health professionals to be able to adjust normal practice for people with arthritis – for example, how to hold and manoeuvre limbs comfortably. This was raised particularly in relation to how health professionals in the community handle patients with sore joints and mobility problems which may not be evident:

*I see the nurses and the podiatrist. You suffer from RA and sometimes you can't move in the direction that they want you to move [in]. You look perfectly well and they grab your arm [and twist it round] and it's: "Oh flipping...!" Yes, sometimes because you look OK, they are a bit heavy handed... (Man, RA).*

### 3.1.7 | To understand the psychological adjustment needed

Participants agreed that health professionals needed an understanding of the psychological impact of being diagnosed with IA and the adjustment that patients needed to make:

*What would be really important, is for the staff in the GP practices to understand the psychological impact of the diagnosis as well as the physical... If people in the GP practices could take a bit more time to say to you: "Oh yeah, well, you'll find sometimes when you come in for your bloods you'll be feeling really low and perhaps a bit feverish and [in] a lot of pain, blah blah blah, and other times you'll be feeling a lot better. I think if they could help sometimes with that sort of psychological adjustment, and the ups and downs of flares and periods in between. So, perhaps some support about how it's going to affect you psychologically. (Man, RA).*

Others mentioned adjusting to feelings of isolation and felt that health professionals need to be aware of how isolated patients can feel:

*People who help[ed] the most, I think, were the OT, the physio, the hydrotherapy [receptionist]. I'd be talking to the OT and physio about how I was adjusting because I'd pretty much lost my... I gave up my job in the September ... I wasn't capable of walking. The receptionist at hydrotherapy probably got me through because, besides my wife, who is lovely, that was my only engagement because you suddenly go from seeing tons of people every day to a very little world, where you're suffering side effects, a lot of pain and a slowing down. (Man, RA).*

Participants felt that if health professional understood the psychological impact of their condition, it would help them to understand why patients responded in certain ways:

*Yes, psychologically, if they [community health professionals] could understand more about that because if you're used to being very very active and*

suddenly your spine is not responding the way you want it to, and you sit down and you cannot get up, or you have to haul yourself up on the bus, which you've never had to do before, yes, that's horrible. It's a horrible feeling, it's frustrating and probably it makes us more irritable with the community people; and, you know, we know that if we're irritable with people, they may respond, with all the best will in the world, slightly, you know: "She's a grumpy cow". The reality is that they're going to be on the receiving end of us in, maybe not in our best state, and it would help if they could understand why we're like this. (Woman, OA).

### 3.1.8 | To understand the social impact

Arthritis affects all aspects of your life, including your relationships with others:

*I think health professionals need to understand that it is very wearing and tiring, and that it changes your life. If my grown-up children and grandchildren ... I don't want to be the one who says no, I can't walk to the shops or no, I can't do the cliff walk. I want to scrabble around [in] the sand with my grandchildren. You think: "Oh God, I'm in pain". It's not... it isn't nice. I had a physio who just sat and said: you're getting older, it's going to get worse... you don't need that, you don't need the negative. (Woman, OA).*

### 3.1.9 | To understand the impact on mental health

Participants felt that the mental health impacts of having a long-term condition such as arthritis was not understood or fully addressed either in the community or in secondary care:

*Yeah, and they didn't really warn me about that [fatigue] much, they didn't tell me about how the fatigue was going to take essentially my life away. Yeah, and the isolation is quite typical; I wouldn't be surprised if everyone with this diagnosis goes through a period of depression – it's not addressed. (Woman, RA).*

### 3.1.10 | To have a broad understanding of drug treatments

Participants did not expect community staff to be experts in drug treatments but to have a basic understanding of the treatments used for IA, an awareness of major changes in effective treatment options and an understanding of the implications of using immunosuppressive drugs. They felt that there was also an important role for patients in sharing their knowledge:

*I have come across nurses who've never heard of anti-TNF [tumour necrosis factor], and I've become a bit sort of evangelical about it, and you know: "Oh, it's fantastic! It really works, it's amazing!" And you are actually almost educating them about what is really a big change in the*

*therapies available to us. I'd like them to know a little bit more about available therapies because I think they almost cannot understand how you can feel so much better in a year... so, perhaps training them in available therapies. (Man, RA).*

*Before I started my anti-TNF, I had to take some pneumonia injections and some other injections, and the nurse kept questioning me: "Why are you taking this? Because we don't usually give it just randomly, why are you taking these injections?" I explained, for the anti-TNF, and she said: "Oh, what is it?," and so I had to explain to her why, you know, how it worked and this and that. And every time I go for a blood test, I have to tell the nurse because they don't know – I have to have monthly blood [tests] – as they don't know why I am there... and what kind of bloods they need to collect. (Woman, RA).*

### 3.1.11 | To understand the pain associated with arthritis

People with OA talked about the need for nurses and AHPs to understand the severity of OA pain:

*I don't think they realize, although they would if they actually had it, how painful it is. I mean, severely painful. You can be screaming, you don't know where to put yourself. They really need to understand the pain and how severe it is. (Woman, OA).*

### 3.1.12 | To be able to advise on pain management

The participants felt that community-based nurses and AHPs should be able to give some basic advice on pain management. This was particularly true for participants with OA:

*I think in terms of self-management and pain, I am all for self-management but what I didn't know was at what point should I be saying: "Hang on a minute, I need some help here". You know, whether you're doing this right, or it's got to a stage where it's beyond your own control and you need to get help, and I think, again, in the community there doesn't seem to be that level of knowledge; it's very much, here's the paracetamol and off you go... There should be some way of accessing some information, will pain like that stop, or is it fine, it's a different movement and you've got to work through it. It's a simple question, isn't it, and if there was someone in the surgery like one particular nurse or ... who knew more about joints. (Man, OA).*

### 3.1.13 | To be able to advise on different management options for OA

Several of the participants with OA felt that they had not been made fully aware of the different management options for their condition

and had not been given adequate information to make an informed decision about how to manage their condition. They felt that this should be an important aspect of training for community-based health professionals:

*...Looking back, I would like to have known a lot more about what the options were, whether there were options within the community to manage the OA rather than just operate straight away. So, from that point of view, I'd be expecting community nurses to understand what the symptoms were, what the sort of management options were, what different things you could try, what you could do but having not encountered it, I don't know if they know that or not. (Woman, OA).*

*I printed off some care from the internet and, basically, 1 to 10, the steps are ... and step 1 was, was my OA diagnosed by a health professional? Well, yes it was, and then there's nine steps and the 10th one is, have I been informed about when surgery should be considered? So, I went from 1 to 10 - I didn't get 2 to 9 - and some of the things in there, I think, could have been referred, if you like; I could have been referred back into the community, as it were. (Man, OA).*

Participants also felt that they could be given more advice on the day-to-day management of their OA:

*There're things I do, like stress balls for my hands. But I was in the caring profession, so I know a bit about it. No one tells you. You see the OT when you're coming out of hospital for what you've got - things are at the right height, and stuff like that - but you're not given information on how to deal with your arthritis, you know, things like the stress ball. I'm struggling with the kettle and stuff like ironing at the moment. (Woman, OA).*

### 3.1.14 | To be able to signpost to sources of help

Being able to signpost people to sources of help - for example, self-management programmes, expert patient programmes, support groups, advice lines - was an important aspect of care that participants strongly felt that all community-based nurses and AHPs should be able to do:

*If you're struggling with whatever condition you've got, you might find that CBT [cognitive behavioural therapy] or something helps, or you might find that attending a mindfulness meditation class helps, but you just don't know it's out there, you don't know it's available, you don't know if you have to pay, you don't know it exists. People like that [nurses and AHPs] when they are talking to you could discuss those options because, for a lot of people, it can help whatever you've got, just dealing with it. (Man, RA).*

*It would help if they could tell people about things like the NRAS [National Rheumatoid Arthritis Society] because they have a helpline that you can call up and speak to people with RA. They can be really really helpful if you're having trouble getting access to medication or something like that. It would be great if the community people could point you in the direction of things like that. People need that, someone they can phone up like the support group or volunteer helpline. (Woman, RA).*

*There is not enough of nurses going out into the community and finding out about support groups. It's not just about education, its information on where you can get help. Need to emphasize that it's a steep learning curve but you can come out the other end. The professionals need to give hope and answers, need to put this across in their attitude. (Woman, PA).*

### 3.1.15 | To be able to signpost to sources of education and information

Participants with RA shared learning through communicating with other patients:

*We kind of need to educate ourselves because, OK, physios and OTs have an important role but they [community-based health professionals] don't have the time to do it, and if we kind of, if we just teach each other... (Man, PA).*

However, they found that often information online was contradictory, particularly that relating to complementary therapies. It was strongly felt that nurses and AHPs should know where to signpost people for education and information:

*When you are diagnosed, it is a quite a big thing - well, it was for me to be diagnosed - and I was given a little booklet and I sort of trotted off home, and I did get most of my information about my condition online, and that's not always helpful because you can read two completely conflicting things... Going online for health is the worst thing you can do because it will drive you up the pole ... but maybe to go back and speak to someone like a nurse, at my surgery ... I think that would be useful; it's almost like a little bit of support, post-diagnosis, so you know you have a bit of a sounding board with somebody, who understands your condition. (Woman, RA).*

A number of people with OA felt that they hadn't received suitable information about their condition. The following comment is typical:

*I haven't had any information, really. I went to the doctors and he said, you've got osteoarthritis. And that's all the information I had, no other help other than that, really. I kept on falling over with my leg giving way, so I didn't have much option, I had to have a new knee. But it was*

*just off to the hospital to have a new knee – there wasn't much by way of information or anything. (Man, OA).*

It was recognized that information is constantly changing and that it is a time-consuming task for the person in the community to keep up with emerging information and new evidence. It was suggested that they should be able to signpost to good sources rather than try to provide all the information themselves:

*It would be good if a nurse etc. could have on their computers access to a pool of information, like there's an OT here, there's a number of pain management things, you can ask the doctor about it. If there was a general base of knowledge so they could download the piece of information for the patient... It's not about knowing everything but knowing a man or a woman who can. You can't expect everyone to know everything. We are all in different stages and at different times, so what we want in terms of knowledge is not necessarily what somebody else wants but if they had this sort of resource, they could have it at their fingertips. (Woman, RA).*

### 3.1.16 | To be able to make multidisciplinary referrals

Patients felt it important that community-based nurses and AHPs knew about the services available and were able to make multidisciplinary referrals and to communicate effectively between referral points:

*Knowing about who and what to ask for requires initiative and intelligence – you don't just get told everything that's out there for you. (Woman, RA).*

*Probably, the kind of thing that would be simple information that would be useful to know, is which things can we just simply go to your GP [for] and which do you need to go back to your consultant for. So, for example, steroid injections, when I have needed them, when I have a really inflamed knee, and draining the knee and putting a steroid injection in it will fix it temporarily, you know... It was a little while before I discovered I could get that done in my GP's practice; I didn't need to make an appointment to go back to rheumatology to have it done at the hospital. I just discovered that by accident (Man, RA).*

*I think that they [AHPs] don't feel that they're, that they're valid enough, you know: "Oh, I am the physio and I'll just do this" – but actually they're the physio and they do so much more. It would be lovely if physios and OTs could feed that back and could be part of that referral thing because when you've had a joint score done by one person, you don't then want to have to go*

*10 minutes later and have it done by another person because it's painful, you know – why cannot you feed it back, and, again, it does come down to communication. (Woman, RA).*

### 3.1.17 | To understand that patients know their own disease

Participants also wanted community-based nurses and AHPs to understand that patients who have had a diagnosis for a long time know best about their own disease:

*The truth is, we've all got similar conditions but it affects us all differently and the only experts in what we've got are us ourselves. My GP openly admits, I'm never going to know as much about RA as you do, and that's because we feel it, we read up about it, we've probably taken everything. We know what works and what doesn't work... (Man, RA).*

*I think that probably because it's our condition, whatever condition we have, we're expecting, unrealistically, that the community nurse would know all the in-depth knowledge of that particular thing, when in fact he or she is dealing with all sorts of conditions. So, you know, let's pull back off that a little bit because I think that's probably ... we become experts of our own bodies ... and that there's nothing wrong with us being able to advise and say what we feel is best for us. (Woman, OA).*

### 3.1.18 | To have good communication skills

Participants highlighted the importance of good communication skills for community-based nurses and AHPs. They drew attention to the quality of communication available with AHPs, such as physiotherapists and OTs, who have longer appointments over a period of time. They also highlighted the need for better communication between health professionals:

*They have longer appointments. I have opened up to them, probably just because I am sat there talking to them. I have been – I was at the physio gym or physio appointments, and you are doing your stretches and you are just nattering away and then it's like: "Yeah, it's kind of getting me down a little bit". It's much more natural... coming from that field; that's how you have those conversations... The allied health professionals seem to have the more holistic approach; they're looking at other things – you can talk to them about pretty much anything... (Woman, RA).*

## 4 | DISCUSSION

OA and IA differ significantly, both in the nature of the disease and how they are managed. However, for all patients with arthritis, the

key competency that they wanted from health professionals working in the community was to be able to take a holistic approach to arthritis, with an understanding not just of the physical effects, but also of its wider psychosocial impact and its impact on patients' ability to participate in the widest sense.

For those with IA, a key priority was for community-based health professionals to have a greater understanding of the nature of the disease, who is affected, how it manifests and the unpredictability of its effects. They wanted professionals to have a basic knowledge of how IA is treated and why blood tests are performed in primary care.

As has been found in another UK study (Ryan et al., 2013), patients with OA often felt that their condition was not taken seriously by health professionals, including nurses and AHPs, working in the community. They felt that they were unsupported and left to find their own solutions. Patients wanted nurses and AHPs to have a basic understanding of management options and to support them in obtaining information on sources of support and information. They were realistic in their expectations – they did not expect community-based health professionals to be experts but to have enough basic knowledge to be able to discuss options, signpost and refer. Overall, participants felt that there was a need for a greater understanding of arthritis and its impact in the wider community, and felt that improved training for community staff could be a first step towards achieving this.

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