

Background

Rheumatoid arthritis (RA) is a chronic inflammatory disease affecting approximately 1% of the population.(1) To limit long term joint damage and disability, disease modifying treatment should be started within the first three months following the onset of symptoms.(2-5) However, a recent multicentre European study highlighted that less than 20% of patients are seen by a rheumatologist within this time window.(6) Delays can occur at multiple points between symptom onset and the initiation of treatment, including delays on the part of the patients in seeking medical advice at symptom onset, delays by general practitioners (GPs) in recognising symptoms and referring the patient to a rheumatologist, and delays in secondary care.(7-9) In countries such as the UK, patients have been shown to wait for considerable lengths of time before seeking help.(10-15)

At the onset of symptoms, patients engage in a process of symptom appraisal and interpretation, which can help them make sense of their experiences.(16-18) However, at the onset of RA, symptoms such as joint pain, stiffness and swelling can be mild and only slowly progressive and are often non-specific.(19) The nature of early RA symptoms can make it difficult for patients to interpret their significance and decide whether help is needed.(16) A recent meta-synthesis identified several factors related to patient delay at RA onset including their initial interpretation of early symptoms, how they went about searching for information about their symptoms and their interactions with friends and family, with whom symptoms and help-seeking were discussed.(18)

The way that a person interprets the early symptoms of an illness is informed by pre-existing perceptions about what it might be like to experience that illness (the illness'

prototype). Prototypes are often informed by cultural understandings and stereotypes of illness, and can thus contain inaccurate representations that do not necessarily conform to medical knowledge.(20) However, prototypes are used as a reference point for the appraisal and interpretation of new symptoms and for deciding whether help is required. Studies in the field of cardiology have shown that when pre-existing ideas about cardiac events do not match the symptoms experienced at the onset of a heart attack that there are often greater delays in help-seeking as opposed to when there is a close match.(20) Therefore, the nature of pre-existing beliefs about illness, or prototypes, can affect the way that symptoms are interpreted and the individual's decision about help-seeking.

However, symptom interpretation does not occur in isolation. People experiencing the early symptoms of disease have the opportunity to gather information and engage with other people in the interpretation of their symptoms and determining the necessity of help-seeking. A review of help-seeking in patients with lung cancer revealed the influences of social networks and interactions, which affected the interpretation process at the onset of disease.(21;22) Furthermore help-seeking at the onset of mental illnesses, such as depression and schizophrenia, has been shown to be strongly influenced and facilitated by the family members and friends of the affected individual.(23-25) Family and friends may play a role in helping patients formulate the initial interpretation of symptoms and may directly influence help-seeking decisions by offering advice. Furthermore, family members may indirectly influence help-seeking behaviour by showing low levels of concern and dismissing early symptoms as trivial. The relationship between the patient and their partner is one of the most obvious and important sources for social support and help-seeking advice. Spousal social support has been shown to be an important determinant of the

patient's well-being.(26) However, the input from partners, relatives and significant others is not always helpful or supportive, and negative social interactions can have negative implications for well-being and health, and may also have an impact on help-seeking behaviour. Despite this, little is known about how social networks operate surrounding help-seeking decisions and encouraging help-seeking behaviour at the onset of RA.

The aim of this study was to explore the influence of family and friends in help-seeking decisions at the onset of RA, and how help-seeking behaviour was influenced by significant others. These issues were explored from the perspectives of both newly diagnosed patients with RA and their significant others.

Patient involvement

This study was formulated and conducted in collaboration with Patient Research Partners. Active patient and public involvement (PPI) ensures that patients' priorities, perspectives and interpretations are represented fully, and that the research remains grounded in patient experiences.(27) Patient Research Partners formulated research priorities and explored future research questions during PPI meetings convened to discuss reasons for delay in help-seeking in the context of RA. During these discussions, Patient Research Partners highlighted the importance of social relationships and social interactions at RA onset and how these influenced decisions to seek help. The researchers identified that primary data in this area was lacking, leading to the present qualitative study.

Methods

Ethical approval was obtained from Preston Research Ethics Committee. All participants provided informed written consent.

Participants

Adult patients (aged > 18) diagnosed with RA within the past 12 months were identified from a secondary care early arthritis clinic database and were invited to participate in an interview. Patients with RA were asked to select a relative, spouse or close friend (this individual is from here on referred to as a 'significant other') who had been involved in their decision to seek help at RA onset to also be interviewed. A total of nineteen people were interviewed; eleven people newly diagnosed RA were recruited, of whom, eight chose a significant other to be interviewed. Three participants with RA requested to be interviewed alone because of self-reported social problems including recent divorce and isolation. The participants' ages ranged from 18- 90 years (mean 54 years). Participants' details are shown in table 1.

Interview procedure

Interviews were semi-structured and were guided by an interview schedule, developed from a literature review and in collaboration with Patient Research Partners. The interview schedule primarily consisted of open ended questions to elicit social interactions and the role of significant others from the time of symptom onset to seeking medical attention. The initial interview schedule was changed inductively to reflect and incorporate the topics discussed by early interview participants. Table 2 shows the final interview schedule.

The interviews were conducted in a hospital out-patient department, University setting or in the participant's home. Patients with new onset RA and significant others were interviewed separately, unless the participants requested to be interviewed together (this occurred in 3 cases). All interviews were audio recorded and transcribed verbatim.

Analysis procedure

Data were analysed using thematic analysis. Data were collected until saturation had been reached with no new themes emerging. Data collection, transcribing and analysis of interviews were undertaken in parallel to ensure that the themes derived from earlier interviews could be incorporated into later interviews. Initial coding was used to generate analytical summaries of accounts provided by interviewees. Independent blind coding was undertaken on four transcripts by RT, RJS and Patient Research Partners. In general the coding of the selected transcripts was similar between the researchers and patients partners. However, patient partners did highlight that greater consideration should be given to the negative feelings and actions made by significant others. In response, the transcripts were re-reviewed with patient partners to identify negative codes, which were then discussed and absorbed into the developing themes. This processes added most greatly to the content of theme three, where negative actions were described most often. Following validation, the initial codes were grouped together into the most noteworthy and frequently occurring categories and core themes were developed. Patient Research Partners participated in formulating and revising the emerging themes.

Results

Theme 1. The impact of early symptoms on significant others

The early experience of RA was characterised by intense pain. Participants, and their significant others, recalled the way that the early symptoms limited their ability to carry out daily activities which formed an important part of their social role. Activities such as shopping, housework and parenting were particularly affected. Parents spoke of how the early symptoms affected their family and their ability to care for their children. Some parents described how they were no longer able to participate in social activities with their children, and in some cases children were asked to take on some of the activities that their parent would normally carry out.

"I feel guilty in my heart, you know that they had to do everything themselves, now when they are making their own food and it hurts being a mum." (Female with RA).

"I couldn't feed my children. I couldn't do no housework. It was like twenty four seven in bed I just wanted to be left alone because I had pain in my hands, thumbs & my wrists. I couldn't walk and my husband used to carry me to go to the toilet and stuff like that I was unable to cook in the house." (Female with RA)

"Swimming, shoulder, can't swim. I got my bike out with the kids, can't go out. It can come on that sudden." (Male with RA).

"I'd call on my son to carry out things around the house instead of [husband's name]. I'd say "[son's name] can you come and give me a hand?" (Wife of person with RA).

The early symptoms of RA were often so severe that significant others would assist at meal times by cutting up food. People with RA also spoke about significant others' help with personal care such as dressing and going to the toilet.

"The stiffness, so I can't hardly move them...my friend bless her she was as good as gold she said to me "do you need me to cut your meal up for you?" and I said "yes please". And she would cut it up and soon as she did I was able to pick it up. When I try to cut the meat they go stiff and rigid and painful, so I can't use the hand." (Female with RA).

"She asked me 'can you help me?' so I had to tie back her pyjama string. How can she clean herself after going to the toilet? It's so painful." (Husband of person with RA).

Significant others described the dramatic impact the early symptoms of RA had on their friend or family member; high levels of pain, discomfort and changes in mood were described. Perceived mood changes, including depression, frustration and aggression, had a large emotional impact on significant others. Significant others described their distress witnessing pain and mood changes in their friend or family member.

"I then could think back yes mom did talk about a lot of discomfort at night and not being able to sleep a lot of aching and just generally feeling pretty rubbish quite low and low in sort of mood as well." (Daughter of person with RA).

"My dad became snappy and aggressive. Think it was due to the pain." (Son of person with RA).

"I think, maybe last year, you got really down with it, really depressed and I got really worried. He would stay in his bed and it became a slippery slope I think that's when we started to realise that it was a bigger problem." (Wife of person with RA).

A patient with RA, who requested to be interviewed alone because of the breakdown in her marriage following the onset of symptoms, described how her early symptoms and her inability to perform daily activities led to the breakdown of her marriage.

"My mom and dad were really supportive my especially mum but she's naturally like that. My husband on the other hand, he was a bit taken aback at the time. As well he was going through helping his mom and dad because they're again quite elderly. He was having to put himself out and helping out round their house and as well as ours and he looked at me and he kind of gave me an impression as if he was thinking 'another person to look after', that's the reaction I got him and I don't think how he knew how to deal with it. He wasn't really very supportive, and I don't think he knew how to help me..... It was just causing arguments and I think you knew who wanted to help and I knew he wanted to. But he's just so rubbish at it." (Female with RA)

Theme 2. Communicating to significant others that there was a problem

Participants with RA spoke of difficulties in communicating their early experience of symptoms to their significant others. Some patients would purposefully hold back information which they found difficult to communicate. In some cases, patients described lying about their symptoms, for example, one patient described lying about why she was unable to use her hands. Patients described how it was difficult to communicate the enormity of the impact of their symptoms, and their concern that others would not be able to understand their experience.

"[Interviewer: What did you tell your husband when your symptoms began?] Patient: I never told him actually." (Female with RA).

"I didn't tell them all but I told close relations who asked me how I was doing." (Male with RA).

"I've had to hide from work. I've had to go in on Monday and, hand bandaged saying I've fell off the ladder cleaning the windows and can't use my hand." (Male with RA).

In many cases the significant other's advice about whether further action was needed was strongly influenced by the patient's own perspectives on the cause of their symptoms. Where patients were themselves dismissive of their symptoms, significant others often were too.

"The first person I spoke to was my husband, he discounted it at first because I was thinking it was repetitive strain. I was just put an ice pack on it to call it down at the end of day. None of us thought it was rheumatoid arthritis, because I was so dismissive of my symptoms." (Female with RA).

However, in some cases when patients felt that they had properly communicated their symptom experiences, they still did not feel that their significant others legitimised their concerns. One patient spoke of how he had attempted to explain his experience of symptoms to his siblings. This led to his siblings trivialising the symptoms and resulted in the patient feeling frustrated and that he needed to simply put up with his symptoms.

"They haven't got a clue! They say 'Oh I understand, I had a sore ankle the other day. So I do understand'." (Male with RA)

"You get to a stage where you are sick of explaining yourself and you have to get on with it and put the symptoms which you are experiencing to just not being well." (Male with RA)

Significant others acknowledged their lack of initial compassion, and reflected on how they had changed their interpretation of symptoms when the disease had advanced and become more severe. They reflected that at later stages of disease, when symptoms were more apparent, they had more information on which to base their interpretation and decision.

"I think maybe last year he got really down with it really depressed, I got really worried. He had a couple of days off then because he couldn't move. He would stay in his bed, it become a slippery slope. I think that's when we started to realise that it a bigger problem that we thought this may sound horrible, but he walks really slow. I had to really.. I think I've changed, I think I'm more supportive now than I have been.....I think I've kind of changed my attitude about it. I think last year I was like 'come on get on with it, you can do it' and then I realised he can't do it." (Wife of person with RA)

However, other people were more sympathetic and understanding. One participant spoke of how she was sympathetic towards her friend's symptoms as she had experienced similar symptoms.

"Well I thought that she would have to go through all the things I went through but I think she's coped better with it than I did I wanted to help in every way I could I would give her advice....I felt more sympathetic to her because she had gone through what I had and the stress of it.....And yes I mean we would talk about it and I would understand what she was going through yes." (Friend of person with RA)

Theme 3: Significant others' beliefs about the possible causes of symptoms

Some significant others recognised the symptoms as being a problem, but did not always associate the symptoms with the emergence of a new "illness". Instead symptoms were attributed to problems which did not require urgent medical attention, such as a hormonal imbalance or overuse (e.g. excess manual labour).

"Women are always prone to get back pain because of their hormonal balances in their body, this could be the reason for experiencing pain, did not think it may be arthritis." (Husband of person with RA)

"He had pains, but I thought that it was because of work. He has a hard and demanding job, making engines, all hand work." (Son of person with RA)

However, some significant others did attribute early symptoms to RA, but their advice to seek help was ignored because the person experiencing the symptoms did not share the same interpretation.

"My mother-in-law has got RA. She actually said 8 months before my doctor said that it is RA, and I would say I'm too young and because my mother-in-law is nearly 70 now, too young and too active so I just dismissed it." (Male with RA)

Gaining support and understanding from significant others was difficult when significant others, and people in their wider social circle, attributed the symptoms of early RA to processes such as "normal aging", or "laziness". Patients spoke of how significant others, in particular male friends, were unhelpful and negative, which they perceived may be due to lack of understanding and knowledge.

The "invisibility" of early RA symptoms to other people was a particular concern making it difficult for others to appreciate the pain and fatigue experienced. Participants felt that their lack of visible signs of illness prevented acceptance of their illness by others.

"All male friends think you are swinging the lead, because they see you and because you can't see it. Exactly, broken leg, they could understand, but then they see you, what you know, when they see you, more often going

to see you on a good day, not going to go out on a bad day. So, every time they see you, thinking hold on, nothing wrong with him, every time I see him, he's fine but they are not there when I'm curled up in a ball in pain. So all male friends." (Male with RA)

"When with your friends they think it's a laugh because no one really knows what you're going through but they know you in pain and things like that but probably one of them things it will clear up and go away." (Male with RA)

Theme 4. The influence of significant others in encouraging prompt help seeking

Many significant others played a key role in the decision to seek medical help. Patients with RA spoke about how their family members had encouraged them and had often physically taken them to see the doctor.

"Encouraged by my wife again: my back bone." (Male with RA).

"They were quite sympathetic and my brother and sister-in-law who are our nearest relations were very concerned, it was my brother who took me to the doctors, my sister-in-law came as well." (Female with RA).

Some significant others were very proactive in requesting that their significant other sought help quickly, and were described as the catalyst for seeking help.

"My sister said 'you had to go to the doctor otherwise there is no alternative', and she went with me to the doctor." (Female with RA).

"I was waiting but my sister encouraged me not to, she said "no, you must go to the doctor because it is getting too much out of hand, you know, your painkillers are not helping", so then I went to my GP." (Female with RA).

However, in other cases significant others were not listened to, and their concerns were only validated when a diagnosis of RA was finally made.

"I didn't pay attention to it, she (wife of person with RA) said it a couple of times, just put it to the back of my mind. I didn't pay much attention to what she was saying actually until I was finally told I did have RA." (Male with RA)

Significant others often felt in a difficult position, caught between having to respect the autonomy of the person experiencing the symptoms to make their own decisions, and the need to intervene and influence decisions to seek help where they felt it was necessary. One significant other spoke of how he would let his wife make her own decisions. However, when the participant noticed that his wife was unwell or unable to carry out daily activities, he advised her to go and see a doctor.

“I let her take her own actions; except for on this occasion, I tell her to go and see her GP, ask your GP to refer you to the hospital.” (Husband of person with RA)

“When I noticed something was not right with my wife I told her to go and see her GP.” (Husband of person with RA)

Significant others' influences were often positive and supportive. As shown in earlier themes they were willing to undertake tasks and encouraged prompt help-seeking when the symptoms were recognised. However, some may have hindered the initial help seek behaviour causing a delay by influencing the individual to try alternative treatments.

“My sister was saying ‘come on I will take you to India, we will try some medicines there’.” (Female with RA)

Discussion

This research highlights the importance of significant others in early symptom interpretation and the role they play in encouraging help seeking behaviour on the onset of RA. The help-seeking decision making process does not occur solely as an intrapersonal phenomenon, and is strongly influenced by an individual's friends and family members at the onset of RA. Significant others have a multi-dimensional influence on the help-seeking process, for example supporting activities, changing social roles, offering advice, and facilitating help-seeking. While some significant others promoted and encouraged help seeking behaviour, others hindered the initial process to seek help by offering or suggesting alternative treatments. In addition, this study also revealed the impact the early symptoms of RA had on significant others, and the emotional burden many significant others experienced before help was sought, highlighting the often neglected emotional need of friends and family in those newly diagnosed with RA.

Previous research may have underestimated the role of social processes in help-seeking, and not fully considered the extent to which significant others influence the interpretation of symptoms, and the ongoing evaluation of symptoms as they change over time. Significant others also play a critical role in the decisions to eventually seek help, often attending the first medical appointment. These data have implications for theoretical models attempting to explain patient help-seeking at the onset of symptoms, which would benefit from taking full account of the influence of social processes that influence decision making. For example, theories surrounding the influence of prototypical beliefs on help-seeking have focused on how prior beliefs and stereotypes of illness influence personal decisions to seek-help. Our

research highlights that significant others' prototypical understandings can be highly influential, and that in some cases shared understanding about the nature of symptoms may be negotiated in order to determine whether further action is needed. This is particularly important as this study identified that friends and family were often confided in about symptoms. Significant others were used as "lay consultants", with the affected person describing symptoms and obtaining advice, and in return significant others offered their own interpretations of symptoms.

A lack of awareness and understanding about the early symptoms of RA was reported by significant others. Some significant others suggested that their initial reactions were negative because they did not fully understand the extent of the pain and the difficulty the individual with RA was experiencing. In these cases, the invisibility of early RA symptoms, poor communication and hiding or covering up symptoms led to the full extent of suffering not being appreciated. However, in other cases prototypical understandings of symptoms of joint pain, stiffness and other symptoms being experienced by the patient, caused significant others to conclude that symptoms were trivial or would soon resolve. Studies have shown that public knowledge of RA is poor, for example with widely held inaccurate beliefs that RA is a natural part of aging or that it is a condition which is self-resolving.(30;31) Inaccurate prototypes of RA among friends and family members may drive many of the negative reactions to early symptoms reported in this paper. This lack of understanding and inaccurate prototypes suggest that there is an opportunity to inform members of the public about the potential causes of joint pain, the importance of musculoskeletal health and when it is appropriate to seek help. A challenge for future

health promotion future campaigns is thus to identify ways of targeting friends and family and informing them about the early symptoms of RA through well-constructed messages.

This study has a number of limitations. Firstly, only three male participants with RA were included. A criticism of many qualitative studies in the field of RA is that the male views are underrepresented.(18) While the female: male ratio of RA is typically 2:1, it is essential that RA studies include more male participants to ensure that a wider understanding of how males cope with the early symptoms of illness, and make decisions about help-seeking are captured. The way that males are influenced by significant others in their decisions to seek help may differ from the way that females are influenced. Thus conclusions cannot be drawn about the nature of male help-seeking from this study and further research is recommended in this area. Secondly, some participants with RA experienced so much social negativity at the onset of symptoms that they chose to be interviewed alone. Not interviewing those significant others who were described by the person with RA as “negative”, may mean that this study been unable to capture the full extent of negative encounters that some people with RA faced. Thirdly, information on the health status of the significant other was not gathered. It is possible that significant others may have been diagnosed with a rheumatic disease or musculoskeletal disorder. If this was the case, the way that significant others responded to symptoms may have been a combination of prototypical and personal perceptions of illness (as opposed to being driven primarily by prototypical understandings). This is particularly important in RA, as the first degree relatives of people with RA are genetically predisposed to develop RA, and therefore may have experience of symptoms directly and developed their own personal perceptions of the

disease. Research investigating the perceptions of family members who are genetically susceptible to developing RA may uncover interesting family dynamics which are affected by illness perceptions and might in turn influence help-seeking behaviour.

More research is needed to promote early intervention at the onset of RA. To do this, researchers and healthcare professionals need to develop a better understanding of the nature of RA symptom onset and the dynamics of early symptom interpretation at the level of the individual experiencing the symptoms, their significant others and healthcare professionals who may not immediately recognise the severity of early symptoms.⁽³²⁾ A challenge for future health promotion campaigns is thus to identify ways of targeting friends and family and informing them about the early symptoms of RA through well-constructed messages, which do not unduly worry members of the public and cause the overuse of health services through inappropriate help-seeking. However, it is possible that multi-faceted campaigns encouraging multiple parties to interpret the nature of symptom onset and appropriateness of help-seeking may result in more collective decision making opportunities which may increase the appropriateness and speed of help-seeking decisions. More research on the validity of health promotion campaigns targeting multiple parties is needed.

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