‘It’s hard to grasp the enormity of it all’:
Perceived needs of people upon diagnosis of rheumatoid arthritis

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Abstract

Objectives: The diagnosis of rheumatoid arthritis (RA) brings rapid pharmacological and multi-disciplinary team interventions to address inflammatory processes and symptom management. However, people may also need support on the journey to self-management. The aim of this study was to explore what support patients feel they receive upon diagnosis, and what support they feel would be most helpful.

Methods: Two focus groups comprised patients with at least 5 years disease duration (n=7), and patients more recently diagnosed (n=5). The latter had attended at least 2 appointments in a Rheumatology Nurse Specialist clinic during the previous year, aimed at providing support upon diagnosis. Transcripts were subjected to thematic analysis to identify common issues regarding support needs, which were then grouped into themes. Interviewing and analysis was performed by researchers not involved in clinical care.

Results: Four overarching themes emerged. ‘Information’ was needed about the symptoms of RA, its management and personal outcome. ‘Support’ related to emotional needs (“Grasping the enormity of it all”). Information and Support overlapped in that patients wanted someone to talk to, and to be listened to. These two themes were underpinned by issues of service delivery: ‘Choice’ (patient or professional to talk to, groups, one-to-one) and ‘Involvement’ (holistic care, partnership). Choice and Involvement overlapped in terms of the opportunity to decide when and which interventions to access.

Conclusions: People with RA report not only informational but also emotional support needs at diagnosis. The potential for delivering emotional support to patients around the time of diagnosis warrants further exploration.
Introduction

Rheumatoid arthritis (RA) is an auto-immune, systemic, inflammatory condition causing pain and synovitis in multiple joints, with a lifelong, unpredictable and fluctuating course.\textsuperscript{1} A combination of early pharmacological and multidisciplinary team interventions aim to alter the inflammatory process, reduce symptoms, and enhance self-management.\textsuperscript{2}

At diagnosis, people with RA may experience not only a range of physical problems such as pain, disability and fatigue but also associated emotional consequences, including depressive symptoms and anxiety.\textsuperscript{3-6} Unpredictability disrupts life plans, increasing psychological distress and helplessness, and roles and relationships come under stress.\textsuperscript{7,8} In clinical practice, many patients who attended a pilot ‘New Patient Support’ clinic with a Rheumatology Nurse Specialist (RNS) within a few weeks of a diagnosis of RA, were anxious, expressed disbelief, and were tearful, with many fears for the future. They described struggling to cope with a life devastated by the onset of RA, which was outside anything they had experienced before.

Such anecdotal data may reflect coping and adaptation theories relating to the onset of a long-term condition. These suggest that people have pre-existing beliefs (illness perceptions) about the cause, identity, timeline, consequence and cure or control of the illness, and that these beliefs may influence the adoption of behaviours to manage that illness.\textsuperscript{9} For example, most people only have experience of acute or self-limiting illnesses, and may struggle to understand that RA is a chronic condition, thus they may see no need to take disease-modifying medication. Initially, people often attribute RA symptoms to ‘normal’ causes such as a sprain, leading to disbelief and denial of the diagnosis.\textsuperscript{10} Mismatch (or dissonance) between inaccurate illness perceptions and fact can lead to only limited adoption of helpful coping strategies, self-management behaviours and concordance with therapy, which may result in poorer physical and psychological outcome.\textsuperscript{11-14} Patients with a belief that RA can be easily cured, but who continue to experience significant symptoms months later, are at increased risk of depression,\textsuperscript{12} while excessive wishful thinking that RA will resolve, or limited acceptance of RA, predict anxiety and depression.\textsuperscript{5,15}

At the time of diagnosis therefore, people with RA may have particular support needs relating to emotions, beliefs or coping strategies. However, these needs may not be met by the healthcare team as there may be a 3-6 month gap from diagnosis and initiation of medication, to subsequent follow-up appointments, which may concentrate largely on medication or physical symptoms. The single study exploring the development of support services at diagnosis is an action research study where qualitative interviews with 6 recently-
diagnosed RA patients’ suggested that patients want information and support very early, especially between the time of GP referral and the first hospital appointment.\textsuperscript{16} Emotional adaptation to RA takes many years,\textsuperscript{10} therefore patients with a longer disease duration might, on reflection, offer additional insights into the support required at diagnosis. The aim of this study was therefore to explore what support patients feel they received upon diagnosis, and what support system they feel would be most helpful.

Methods

Focus Group discussion methodology was selected to provide a collaborative research environment in which participants could freely raise and discuss issues important to them, ensuring the data were grounded in participant experiences. Focus groups are designed to elicit information from individuals, and from the interactions between participants, who are encouraged to talk to one another and comment upon each other’s opinions in the same way as every day communication occurs between people.\textsuperscript{17,18} This allows participants to both validate and challenge each other’s accounts, and facilitates clarification of contentious or non-common issues.

Participants: One focus group comprised people with RA\textsuperscript{19} who had attended an RNS clinic within a few weeks of diagnosis. This pilot clinical service aims to offer RA patients an opportunity to discuss practical issues and explore associated emotions, coping difficulties and illness beliefs.\textsuperscript{9} After the initial 60 minute appointment patients decide if they would like any further appointments (30 minutes). Patients were eligible to join the new patient focus group (NP) if they had accessed at least 2 RNS appointments (suggesting they had engaged in the support offered) but were no longer attending. 24 patients fulfilled these criteria. The second focus group comprised experienced patients (EP) who had been diagnosed with RA at least 5 years previously, and would generally have been seen 3-6 months after receiving their diagnosis, with no interim support. Twenty potential EP participants were identified from the rheumatology outpatient department during a week of study recruitment.

Identification and subsequent selection of participants was by a researcher not involved in clinical care. Patients were purposefully selected to reflect a mix of age, gender, work and family status, in order to provide variation and contrasting opinions. Twelve patients agreed to participate (NP group 3 female, 2 male; EP group 7 female) (Table 1). Ethics approval and written consent were obtained.

Procedure: Participants were provided with a set of questions in advance, as a way of generating discussion. The questions were neutral and non-directive and were composed by a steering committee which
included a patient research partner (BD). The questions were: 1) What kind of support did you receive from the team when you were first diagnosed? 2) What was most helpful? 3) What was least helpful? 4) What else could be provided to support you? 5) When would be the right timing for support? Discussion was facilitated in a non-directive way by a clinical psychologist (SR), observed by a moderator (consultant nurse, MC), neither of whom were part of the local rheumatology team. Sessions lasted between 90-120 minutes and were audio-recorded. At the end of the sessions, the key points were summarised and reflected back to the group and the facilitator checked that no participant was distressed.

Analysis: The tapes were transcribed verbatim, anonymised and subjected to thematic analysis. The transcripts were read and re-read (SR, MC), with line by line analysis to identify issues arising from the data, giving each issue an appropriate descriptive code. Although working independently, comparison of analyses showed the two researchers had generated codes with essentially the same content. Final codes were agreed between them, clearly defined and quotations used to exemplify them. To help focus and bring clarity to the findings, the codes were then grouped into sub-ordinate themes and finally overarching themes. The data were independently analysed by a third researcher (ZC) whose analysis agreed with the findings and verified that the data supported the themes. All authors then reviewed, discussed and clarified the themes and supporting evidence.

Results

From the 17 themes, four overarching themes relating to needs at diagnosis were identified: Information, Support, Involvement and Choice (Figure 1). ‘Information’ encompassed the symptoms, management and personal outcome of RA, while ‘Support’ related to emotional needs. Information and Support overlapped in that people with RA wanted someone to talk to, and to be listened to. These two themes were underpinned by service delivery issues of ‘Choice’ (talking to patients or professionals, in groups or one-to-one) and ‘Involvement’ (holistic care, partnership). Choice and Involvement overlapped in terms of opportunities to decide when and which support to access.

Information issues included experiencing lack of information, poor explanations, having negative expectations or illness beliefs, and concerns about delay in diagnosis. Both new and experienced participants discussed lack of information at diagnosis, although this was more often raised in the EP group:

“I was diagnosed about 30 years ago and I didn’t even know what was wrong with me. I was admitted to hospital, they did loads of tests, started me on treatment and nobody said what’s
wrong with me. I was so frightened at the time, I remember, because I didn’t know what was happening to me but nobody explained anything” (EP3)

“I think that’s the main thing that people don’t understand, you’re not told that rheumatoid arthritis makes you that tired, and you’re just told well, that’s why you get pain in your hands or, you know? You’re not told exactly how its going to affect you” (NP1)

Both groups commented on the perceived potential for poor outcome:

“You go on the ward and you see the worst cases who might even have had it for years but when I was 23 everyone else on the ward was 50, 60. They couldn’t walk, some of them couldn’t sit up themselves. I was absolutely terrified” (EP1)

Newly-diagnosed patients commented on the need to get a diagnosis and on the time taken to get this:

“And that’s what, 10 months without being told why I was feeling like this? It’s really important when you are first diagnosed to be told exactly what is going to happen to you” (NP1)

“I think what’s important is to know at the beginning why you’re feeling this way is because you’ve got rheumatoid arthritis and it’s not you going mad or just getting lazy” (NP2)

Participants indicated that they had valued being given information on practical issues such as exercise, driving, pacing, joint protection and medication, or would have valued it if it had been given:

“I don’t think I was given any advice at all, except to learn to drive ……so I still continued to do everything that I was doing before, as much as possible. I think that the advice which might have been helpful would have been to be told to rest when things got too difficult or too painful, and because I hadn’t realised that, by carrying on doing everything I was damaging my joints during a flare…” (EP6)

“I would have liked more exercise, someone whether physio or someone to help me with exercise which would benefit me, i.e. swimming, or maybe gym exercises, something I could do on a daily basis which wouldn’t do me any harm” (NP3)

Participants reported being unfamiliar with the hospital system and how to get information and help:

“You don’t know the system, and for me it was the first time I had had to see a consultant about anything so it was all, the whole thing was new. So you’re trying to cope with getting to know the system, lots of blood tests and going for x-rays, as well as coping with a condition that you know very little about, so you’ve got two things going on, and It’s quite hard to grasp the enormity of it, the sense that this is it for life, and I think if you knew, if you were familiar with the system, it would be easier then to tap into whatever resources are there, you know? But if you don’t know the system, you can’t do it” (EP6)

This confusion over the health system is reflected by one newly-diagnosed patient who praised the support she had received from a nurse, when in fact she had been undergoing a course of physiotherapy:

Support issues encompassed early emotional needs in particular, exemplified by the preceding quote (“it’s quite hard to grasp the enormity of it, the sense that this is it for life”) and other examples:
“I think your confidence goes low and because one of the causes is that you can’t do things you used to be able to. And the other thing that happens to me is that if I have a good day and I maybe do more than I should, then I suffer and go right down again.” (NP3)

“When you have physical symptoms and everybody stares at you and you can’t get clothes on like you used to be able to do and you can’t wear shoes that you really want to wear that go with the outfit that you’d like to wear, and suddenly you feel absolutely rubbish because you look awful and you need the kind of outlet to be able to talk those things through and to recognise what it is you’re feeling rather than just thinking it…….. you need to be acknowledged for it to be ok, to be given the permission to feel lousy. If you don’t have that process to go through you recognise that you’re very low and you feel bad about it”. (EP6)

Participants identified a number of ways in which emotional support could be provided, including being listened to, or talking to other people with RA during group education:

“I find between my diagnosis of 5 years ago and now, things are improving all the time as far as listening to patients is concerned” (EP 5)

“I went to 6 meetings and they were very informative and useful. I met people with the same symptoms and everybody was allowed to talk and when you heard people talking about the same symptoms as yourself, you realise you are not the only one and that there are other people out there with the same problems. That’s a great help when you know there are other people in the same boat”. (NP3)

Participants thought that some support for their carers or family would be helpful:

“I think most families don’t understand it, what you’re going through and before my husband knew the symptoms, he used to get really frustrated. Every day was a different pain and I was always tired and I think that somehow they can get rooms with families and even the children, to let families know what is going on, then that would be a help”. (NP1)

Participants suggested they felt isolated upon diagnosis and valued having professionals to talk to:

“I just felt very, I don’t know, kind of isolated and I didn’t know what was going on” (EP7)

“It was very helpful to talk to other people in the rheumatology department. The education was very good and I wish I had it a long time before” (EP6)

The group discussed how such emotional support needed to be offered within a safe environment:

“…it’s just somebody who can answer your questions or get you over that time or can understand what you’re going through, and give you just that bit of emotional support you know?” (EP5)

“RA Samaritans!” (EP1)

“Well, no, I was thinking about, you know, to me if it was attached to the [rheumatology] unit, if it was almost like you ringing up and you get an appointment or something? So you go in this room for an hour instead of being treated for medication and physio, but you’re actually going to be able to talk about issues …” (EP6)

The ability to obtain input and advice from a telephone support help line was valued as a means of support:
“One other point which is very good is we have an open line. If I call the help line they phone me and it’s wonderful to know that they’re always at the end of the phone line.” (NP1)

**Involvement** encompassed views about patients as active partners in managing their own health needs.

Experienced patients felt that when they had been diagnosed many years ago, they had been expected to be a patient with no active partnership in their own care but they also felt the situation was now different:

“I mean that’s one of the things that you don’t start off being a patient. You start being a person who develops an illness who’s got a brain - but you’re not allowed (or certainly for quite a long time I think). The culture is changing now, that you weren’t allowed to be a person with a brain, you had to be a patient who did what they said and you weren’t given a choice and you weren’t asked about your options which you would prefer. You just had to do what you were told, but often you weren’t told anything other than take medication. You were almost pushed into being a patient and eventually you become a patient”. (EP6)

“I found now you’re given a choice like do you want this done or not? Like I refused the cortisone injection and I wasn’t made to feel I was being stupid but that my views of why I didn’t want it was respected and accepted and that was it.” (EP5)

The experienced patients also highlighted the need to be treated as a whole person:

“Sometimes if you go in to see a consultant with a problem, say in an elbow, well they just look at that one” (EP2)

“The prescriptions I get from him [homeopath] are not only to help with physical things but emotional things as well. His way of approaching how he treats patients is a really refreshing way of dealing with things. I don’t see it as alternative but complementary because you can use these treatments with the other ones you’re using at the hospital. For me it’s a really good combination somebody that actually cares about what they’re doing and cares about you as a patient.” (EP7)

Choice was raised in both focus groups, in terms of being able to choose the support they needed, and to access it when they needed it:

“When you’re ready, just when you’re ready. Just the emotional support of someone who might recognise or think that this person’s not ready to be told everything yet, or this person is asking for everything and they know themselves best, that they can get the information”. (EP1)

“Also, you need a person to talk to when you need to talk to them not sort of say I’ll see you in 6 weeks or something like that. It’s the time when you need it and by 6 weeks time you will have sorted it out probably” (EP3)

Such choice might include access not only to a single health professional, but also to group education:

“I came up to [local education group] it was five weeks I think, you had four weeks of an hour and then we went away for a few weeks, and then we came back and had a final meeting and that was extremely helpful, you know? We were actually being you know, instructed, no not instructed, not the right word, but discussing about the type of drugs available, what they did, about diet, about exercise, you know, topical to each time, and that was extraordinarily helpful
In addition the experienced patient group raised the idea of an accessible rheumatology ‘buddy’, which could be either a professional or patient:

“\textit{You might not need anything medical or professional at the time you might just need to talk with somebody to get things off your chest, but you need somebody who knows about RA, and I guess that’s what [EP1] was saying earlier about having a kind of RA Samaritan where you can just think ‘I really need to talk to someone, I’m having a flare, and I’m stressed because of this and this which is going on in my life at the time’ and just to know that there’s someone there that you can talk to. It can be, you know, a professional or it could just be someone like us on the end of a phone}” (EP7)

\textbf{Discussion}

These qualitative data on perceived support needs at the time of diagnosis, from both experienced and recently-diagnosed patients, suggest a need for information and emotional support, underpinned by involvement and choice. Most clinicians probably feel they give good face-to-face information supported by well-written leaflets, and the experienced patients reflected that information needs are now better met. However, it may be very precise information about personal outcomes that newly-diagnosed patients require, predictions that are as yet beyond our expertise.

The provision of emotional support was seen as crucial, with suggestions of time and a safe environment, being listened to by professionals, help with low mood and meeting others with RA. Emotional support was less frequently raised by those more recently diagnosed, perhaps because they had been given the opportunity to discuss emotions in clinic, and may have considered this to be routine. The frequent comments from the experienced patients relating to emotional support, may suggest emotional needs at diagnosis that had not been met, although their perceptions may have been tempered with hindsight. The only way to clarify emotional needs upon diagnosis, would be by prospective qualitative interviews at the onset of RA. The 5 such qualitative studies that explore the patient experience of RA are either are retrospective (coloured by experience and hindsight), studied only women, or are 10-30 years old (current treatments are vastly different)\textsuperscript{10,21-24}

Involvement through collaboration and partnership were raised by experienced patients, with stories of past exclusion but examples of current involvement, reflecting the cultural shift toward shared-decision making in health care and recognition of patients as experts in particular areas.
Choice was seen as the option of accessing support rapidly, however and whenever it is required. Many units offer telephone access to specialist nurse advice and rapid access to medical reviews, but these participants recommended rapid access to emotional support. Emotional support to enhance coping strategies might potentially be provided by members of the multi-disciplinary team with appropriate training, and could also address illness beliefs.

The previous study found a need for information, and developed a multi-disciplinary 3-hour information and support session, but felt this resulted in information overload. This study found additional needs for emotional support, involvement and choice of how support is provided, for which other routes could be considered. Talking to other patients was raised as a source of support, and educational groups were valued by those who had attended them. The literature suggests that in early disease, group education does not stimulate the adoption of new self-management behaviours, nor have a lasting effect on symptoms. However, group education could be a way of meeting informational and emotional needs at the time of diagnosis. Indeed, from the laughter (and tears) that emerged during the focus groups, even joining the research group seemed valuable through the sharing of experiences. Developing a new patient education group might be an area for exploration, but an activity analysis of the GP letters sent out from this new patient support clinic indicated strong emotions were expressed, therefore skills in managing emotions in a group setting would be vital.

The study limitations are that no men participated in the experienced focus group (1 delayed by traffic on the day, no suitable date for 2 others) and men’s needs may be different to women’s needs. The new patient group was older than the experienced group, and the support needs at diagnosis of younger patients may be different due to lifestyle pressures or health expectations at different ages. There may be difficulties of recall about care provided at the time of diagnosis. Qualitative research does not aim to generalize but to shed light on the range of experiences, therefore the data need to be considered within the context of the individual participants. For example the negative perceptions of poor support in newly-diagnosed patients related largely to a single patient, perhaps reflecting that the team had neither identified nor addressed their particular support needs. The strengths of the study are the involvement of a patient research partner, and also that participant identification and selection, focus group leadership and data analysis were all conducted by researchers who were not part of the local clinical team.
This study suggests potential dimensions of support that are specific to people at the time of diagnosis, including informational and emotional needs, provided in a way that is responsive to individual patient timing, and can foster a sense of partnership in health care. Such support could be provided in many different ways, but, in order to design and test appropriate support interventions at the time of diagnosis, further data on the emotional reactions to RA, illness beliefs and the journey to adaptation, need to be collected through prospective qualitative and quantitative studies.

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References

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Table 1: Demographic data

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Fig 1: Schematic view of perceived needs of people at the time of diagnosis with RA

- **Information**
  - Disease
  - Treatment
  - Outcome

- **Support**
  - Emotions
  - Safe environment
  - Family

- **Choice**
  - Meet professionals
  - Meet other patients
  - One-to-one
  - Groups

- **Involvement**
  - Holistic care
  - Partnership
  - Joint decisions

- **Talking and Being listened to**
- **Timing and Options**
- **How provided?**