Control perceptions in patients with rheumatoid arthritis: the impact of the medical consultation

S. Ryan, A. Hassell, P. Dawes and S. Kendall

Objective. To identify factors that patients perceive as influencing control in living with the symptoms of rheumatoid arthritis (RA).

Method. A sample of 40 patients with RA were recruited randomly from an out-patient population. The participants of the sample were interviewed in depth by one researcher to identify perceptions of control. They also completed two self-administered questionnaires, the Health Assessment Questionnaire and the Rheumatology Attitude Index.

Results. Four major categories were identified that positively influenced perceptions of control in patients living with the consequences of RA. These included: (i) the reduction of physical symptoms; (ii) social support matching perceived need; (iii) the provision of information; and (iv) the medical consultation. Components of the consultation included patient involvement, provision of information, feedback and reassurance, empathy and access to an expert.

Conclusion. The categories identified can be influenced by health-care professionals in the management of the patient, and if the medical consultation is utilized to its full potential it can play a major role in enabling patients with RA to manage the daily symptoms of their condition.

KEY WORDS: Rheumatoid arthritis, Qualitative interview, Control perceptions, Medical consultation.

Rheumatoid arthritis (RA) is a relatively common chronic heterogeneous condition. It is characterized by unpredictability regarding the occurrence of symptoms, the efficacy of the treatment programme and the overall prognosis. Patients with RA perceive less personal control over their health than do other patients with more predictable chronic illness [1]. Consequently, one of the objectives of treatment is to enable patients to cope with this unpredictability and to gain perceived control over the daily consequences of their condition. Affleck et al. [2] demonstrated that perceived control over daily symptoms was associated with more positive mood and adjustment.

Patients with RA are not able to alter the physiological progression of their condition through their own action but they can influence the effect on everyday life. For example, a patient with erosive damage to a hip joint will not be able to alter the presence of the damage but may choose to make alterations to their environment or learn relaxation techniques to limit the consequences of pain and reduced function. Langer [3] refers to control as the active belief that one has a choice amongst responses that are differentially effective in achieving the desired result. It is in this area that health-care professionals can inform and involve patients in the decision-making process regarding the management of their arthritis. Researchers have demonstrated that an individual’s perception of control over the management of their RA can have a positive effect on well-being [2, 4, 5]. There are many psychologically based models of health behaviour [6–8] which endorse the viewpoint that the individual makes a major contribution to health behaviour. In RA, the individual has a key role in implementing and manipulating the management of care (e.g., alteration of analgesia intake, exercise and pacing strategies) in response to coping with the physical consequences of RA [9]. The individual also has to find a way of coping with the psychological and social consequences of the condition. This may involve engaging in new social roles such as becoming actively involved in a local support group.

Staffordshire Rheumatology Centre, The Haywood Hospital, High Lane, Burslem, Stoke-on-Trent ST6 7AG and 1Faculty of Health and Human Sciences, University of Hertfordshire, Hatfield, Hertfordshire, UK.

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Correspondence to: S. Ryan, Staffordshire Rheumatology Centre, Haywood Hospital, High Lane, Burslem, Stoke-on-Trent ST6 7AG, UK. E-mail: sarah@stoke1.junglelink.co.uk

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Control is a multifaceted concept. It can be objective (or actual), concerned with the capacity to exert a significant degree of influence over others or events [10], or subjective (perceived), when the individual holds the belief that they can determine their own behaviour and influence their environment [11].

If a patient has been unsuccessful in the past in obtaining perceived control over the daily consequences of arthritis due to emotional, cognitive or motivational factors, this experience will adversely affect future attempts to obtain perceived control over the daily consequences of the arthritis [11] and unfavourably influence the development of effective coping strategies. Perceived control can be regarded as a prerequisite for the adoption of strategies to manage the daily internal and external demands of the condition [12].

In this study, control encompasses those factors which patients feel enable them to cope with the consequences, physical and psychological, of the arthritis. This could potentially include physical measures to reduce symptoms as well as strategies for addressing the inevitable consequences of their arthritis, e.g. the need for increased functional support as the condition progresses.

Thus the primary objective of this research was to identify those factors that patients perceive as prerequisites in obtaining a sense of control over living with the consequences of their arthritis.

Methods

Sample

Patients were recruited at the Staffordshire Rheumatology Centre, which serves a population of 475 000 people. The total number of patients with RA in the department is approximately 3000, in accordance with epidemiological predictions. The sample consisted of 40 patients attending an RA review clinic in an out-patient department over a 3-month period. The patients were reviewed by one of a team of rheumatology doctors including one consultant rheumatologist and three specialist registrars. This clinic caters for patients with the whole spectrum of RA severity. Only patients with a diagnosis of RA, as determined by the rheumatologist in accordance with American Rheumatology Association criteria [13], were recruited. A convenience sampling technique was employed, a research assistant approaching every second patient as they registered for clinic. The research assistant gave out the information sheet and obtained written informed consent. Of all the potential participants who were approached, only two declined to take part; both were men and they stated that they would not be comfortable exploring their feelings in an interview situation. All participants completed the Rheumatology Attitude Index (RAI) [14], the Health Assessment Questionnaire (HAQ) [15] and a demographic information sheet. The RAI is a disease-specific, self-administered scale which measures a patient’s perception of their ability to control their arthritis. The score ranges from 15 to 60, a lower score indicating a greater perception of control. The HAQ is a well-used measure of disability, with a range of 0–3, 3 indicating severe disability.

Hermeneutics

A hermeneutical approach was adopted. Hermeneutics is one particular limb of qualitative methodology. Its major objective is to obtain understanding of the situation or experience under investigation [16] through the fusion of all relevant sources of data, including literature review, the personal experience of the interviewer and the results from the interview. These sources of information inform both the design and the analysis of the research.

The interview

The 40 participants were interviewed once in depth by one researcher (SR) to identify factors that influenced perceived control over the daily consequences of RA. The semistructured interview schedule (Table 1) generated from the researcher’s reading of the literature was reviewed by a panel of rheumatology health professionals and members of the local arthritis support group to assess content validity. The interviews were audiotaped and transcribed in their entirety using Colaizzi’s procedural steps (Table 2) [17]. The researcher was not involved in the direct clinical care management of any of the participants interviewed. Potential participants with a disease duration less than 4 months were excluded as they would have limited disease experience to reflect on. Ethical approval was obtained from the North Staffordshire Local Research Ethics Committee.

Data analysis

In hermeneutics it is the inquirer’s responsibility to determine the framework for analysis [18]. The first level of analysis commences during the interview itself and involves attentive reflective listening, thereby generating new questions from the content and nature of the responses. Following completion of the interviews, Colaizzi’s procedural steps were used. From the transcribed data, significant statements relating to perceived control were identified. This enabled clear themes to emerge, which were classified into categories. To illustrate this process, one recurrent theme that emerged from all the transcripts was the significance of the medical consultation. Eighty-three

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<th>Table 1. The interview schedule</th>
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<td>How would you explain what rheumatoid arthritis is?</td>
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<td>How are you involved in the management of your arthritis?</td>
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<tr>
<td>Do you feel you can control the daily symptoms of your arthritis?</td>
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<td>What methods do you use to control the symptoms, e.g. pain?</td>
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<td>What factors influence whether you can control your arthritis?</td>
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<td>At what stage have you experienced control of the daily symptoms?</td>
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<td>Can you describe the situation?</td>
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<td>How do you know if your condition is improving?</td>
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<th>Table 2. Colaizzi’s procedural steps [17]</th>
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<td>Each participant’s verbatim transcript was read to acquire a sense of the whole.</td>
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<td>Significant statements and phrases pertaining to the experience of control were extracted from each manuscript.</td>
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<td>Meanings were formulated from the significant statements. Creative insight was employed at this stage to move from what the participant said to what they meant and to gain understanding from the encounter.</td>
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<td>Formulated meanings were then organized into themes. The themes in turn evolved into theme clusters and eventually categories were formed.</td>
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<td>Results were integrated into an exhaustive description from which understanding and meaning of those factors that influence control perception in living with the daily symptoms of RA were extracted.</td>
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<td>The essential structure of the phenomena was formulated. Validation was sought from the study participants.</td>
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significant statements were identified that related directly to the influence of the medical consultation on perceived control. Through exploration of the significance of these statements, themes arose relating to the components of the consultation that impacted on patients’ control perceptions and enabled a defined category of the nature of the medical consultation to be identified. This method of analysing the data enabled the contextual meaning of the medical consultation to emerge and its association with perceived control to be understood more clearly.

The validity of this process was analysed in two ways. First, the interview transcripts were returned to all 40 participants to confirm accuracy (a process referred to as ‘member checking’) and participants were invited to identify any error in the documenting of the interviews. Secondly, two fellow researchers reviewed eight of the interview transcripts to verify that the categories identified could be traced back to the significant statements made by the patients.

Results

Forty patients were interviewed; their demographic details are shown in Table 3. Four main categories relating to patients’ perceived control in living with the consequences of their arthritis were identified from the interview data. These were (i) the impact of the medical consultation; (ii) reduction in physical symptoms, e.g. pain and stiffness; (iii) social support to equate with perceived need; and (iv) the provision of information.

Impact of the medical consultation

Thirty-seven participants viewed their relationship with the rheumatologist as a major contributing factor in their perceived control over their RA. There appeared three principal aspects to the perceived impact of the medical consultation: (i) involvement in the consultation; (ii) expressive dimension of care; and (iii) expert knowledge.

Involvement in the consultation. Participants perceived that they were included in the consultation process and were able to share their concerns.

‘I always get feedback when I see the doctor, it is like a partnership, it is important for me to know how I am doing.’ (P:35).

‘If the doctor didn’t include me in the consultation I don’t think I would be able to cope so well.’ (P: 3).

‘I always take a list in with me, so I can tell them about any changes I have noticed or any problems I have had. They can’t help you unless you share with them how you have been.’ (P:8).

Expressive dimension of care. The consultation did not concentrate solely on physical aspects of the condition but also provided an arena to explore feelings and share emotions.

‘They get to know you so well and you know them. I don’t think I could have coped any other way with my arthritis if I didn’t have their help and support.’ (P:17).

‘They always want to know how you are feeling and listen carefully to what you have to say. I feel I can master my arthritis with their support.’ (P:21).

‘The doctor eases the pain by talking with you.’ (P:6).

Expert knowledge. The consultation was viewed as the opportunity to spend time with an expert and to utilize their knowledge in this area.

‘It is important to see the doctors with the specialist knowledge as they know how to help me.’ (P:1).

‘The relationship with the doctors is paramount, I rely on them to say what the different treatments are and to prescribe the drugs on their say so and expertise.’ (P:22).

‘I have real confidence in the doctors up here, if the drugs aren’t working they always change them for me and sort out any problems I have.’ (P:32).

By contrast, the nurse–patient relationship was important primarily for its expressive nature, and the participants felt that this was the medium through which to address psychosocial concerns.

‘The nurse was great. She listened to me and helped me see that I could do something, that I wasn’t as helpless as I thought I was. It plays a big part if people understand what you are going through.’ (P:18).

‘It was important to see the nurse to talk about how I was feeling, at that time I could see no way out. I felt ugly and unloved. I had given up on myself.... It was only after many sessions with the nurse that I began to see a way forward and it was at this stage that I began to take control again.’ (P:20).

Reduction in physical symptoms

The consensus from all those interviewed was that the physical symptoms of the arthritis, the pain and the

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<th>Table 3. Demographic description of the sample</th>
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<td><strong>Sex</strong></td>
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<td><strong>Age (yr)</strong></td>
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<td><strong>Disease duration (yr)</strong></td>
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<td><strong>Education (yr)</strong></td>
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<td><strong>RAI</strong></td>
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<td><strong>HAQ</strong></td>
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stiffness, required to be minimized before a perception of control could be obtained.

‘I cannot do anything when the pain is bad. I feel trapped by it, it robs you of any control.’ (P:18).

‘If I had been able to get better control of the pain, I think I would have felt more in control.’ (P:35).

‘The pain made me feel so low and helpless, it traps you. It demands your attention and you just can’t do anything, you try and do something and you just find that you have to stop because of the pain. It does make you feel a failure.’ (P:23).

Social support
Participants wanted to continue to function both in instrumental activities, such as cooking, and in nurturing roles, including making family arrangements. Support was required on a regular basis and not solely at times of increased disease activity. Support needs to equate with the patient’s requirements; too much input felt like a form of social control.

‘I may be slow but it is important for how I feel about myself to do all the things around the house still. I know he can do the windows but it is not the same; I want to do them.’ (P:29).

‘I need to be in control. I have always looked after the children and with a change in routine and with my husband’s support I can still do it.’ (P:22).

‘My wife is great; she listens, she understands, she is always there to support me, so is my daughter. It is important because it helps me try and do more things.’ (P:35).

‘You just don’t know what is around the corner with this condition and having a supportive family removes a lot of the worry because I know they will step in and help if needed.’ (P:39).

‘You would have thought that the arthritis had affected my brain not my joints, they all began making decisions for me, even deciding what I would wear, it was horrible.’ (P:3).

Provision of information. Information was regarded as enabling understanding and participation in care.

‘It makes it easier to live with, it is important to know what is happening.’ (P:13).

‘I have all the leaflets.... I keep them in a folder and if I think what is going on I look it up.... I like information at hand, it eases you, it settles you.’ (P:8).

‘The first thing was to learn about it, to accumulate all the knowledge and then implement it.’ (P:14).

Twelve of the participants had attended the structured education group and had found it a valuable experience.

‘The group gave me the means by which I could live with my arthritis, knowing about exercise and when to use it, it was great. For the first time I was able to take control of my arthritis.’ (P:25).

Discussion
This research has demonstrated that a patient’s perception of control is not a static entity but will be influenced by both internal and external factors. Participants often perceived that they were in control of the daily consequences of their RA until they experienced an alteration to their situation which was manifested either in their symptoms, e.g. pain, or in the level of social support they were receiving. Either of these occurrences could alter perceived control unfavourably.

The nature of medical consultation was viewed as an important component in obtaining perceived control over living with the daily consequences of the condition. Participants perceived the interaction as a partnership in which their view was sought and influenced the management plan. This finding is in discordance with the locus of control model [8], whereby an external locus (behaviour determined by the action of external sources) is associated with less perceived control. This research has demonstrated that when living with a chronic condition, external sources are necessary to influence internal perceptions of control positively. Daltroy [19] describes the provision of information as the primary means by which health-care professionals equip patients with the skills and knowledge to manage their symptoms in cooperation with care-providers. The findings from this research confirm this and demonstrate the wider influence of the medical consultation. The main objective of the consultation from the clinician’s perspective will focus on limiting the progression of the condition and minimizing the effects of the symptoms on everyday function. Whilst the patient would agree with these objectives, it is clear that the consultation has a host of other functions that include:

- sharing information about symptoms and care management;
- receiving feedback on progress;
- having access to an expert;
- providing information, support and reassurance;
- incorporating an expressive dimension of care, e.g. empathy.

Although these findings replicate some of the previous recommendations regarding the format of the consultation.
[19], they also identify the importance of accessing an expert, ensuring patient involvement and providing reassurance. Reassurance is an essential component which does not occur in all consultations [20].

Several authors [21, 22] have called for specific training to enable the incorporation of patients’ preferences and beliefs into the consultation and in deciding the treatment plan. The development of consultation skills needs to be embedded within the training curriculum of all clinicians involved in the management of patients with RA. There is clear evidence to support this notion that consultation skills can be taught [23] in an undergraduate setting. Consultation skills teaching has been well received within a postgraduate context in training rheumatology specialist registrars [24]. We contend that the results of studies such as ours and that of Donovan and Blake [20] should influence the content of such teaching.

In many units the follow-up care of patients with RA will involve the nurse specialist. In the unit in which this study was performed, rheumatology nurses have a key role in patient management and nurse consultations are common. One might expect the nurse consultation to provide the same elements as those identified in the medical consultation. It is interesting that, in this study, patients perceived the nurse specialist consultation as the medium through which to address psychological concerns and had different expectations from the medical consultations. Work by Hill et al. [25] demonstrated the effectiveness of the rheumatology nurse in increasing patient knowledge and reducing both physical and psychological symptoms, but it was not the remit of Hill’s research to explore the effectiveness of the consultation on control beliefs. Further research is required in this area.

Other aspects that need to be addressed within the consultation include symptom management and support mechanisms. All 40 participants described the negative influence of pain on control perceptions and stated how an increase in symptoms could alter an internal perception of control to feelings of helplessness. Pain disrupts the lives of individuals in terms of their relationships with others, self-esteem, ability to complete tasks, and daily living [26]. If patients are experiencing heightened symptomology they will require an urgent review of their care management before feelings of helplessness occur and a negotiated care plan to be implemented. This may be achieved with a ‘drop-in’ clinic or through a telephone helpline system. Thirty-seven participants stated that the nature of social support provided influenced control perceptions. In previous studies, patients with arthritis who received support from family and friends exhibited greater self-esteem [27], psychological adjustment [2] and life satisfaction [28]. The perception that support is present on a daily basis and can increase at times of heightened disease activity was cited by all participants as positively enhancing their perceptions of control. Family members are often excluded from the assessment and planning of care management and may need to engage in this process to provide support from an informed basis. The influence of social support on control perceptions has been demonstrated in studies of other chronic diseases, including coronary artery disease [29] and muscular dystrophy [30].

We took a pragmatic decision to engage in 40 interviews. Arcury and Quandt [31] state that, although the sample size is usually estimated in advance, a final sample size determination is made during the course of the research. In the present work, it was only after the researcher had transcribed and analysed all the data that it was possible to suggest that saturation had occurred after 30 interviews. Morse [32] defines saturation as the repetition of discovered information and confirmation of previously collected data. Our use of a semistructured interview allowed considerable flexibility in scope and depth, enabling the participants in this study to identify the factors that influenced their perceived control. A series of three pilot interviews were carried out and revealed that the use of an unstructured interview was inappropriate as participants found the topic area difficult to focus on and required some structure to initiate the exploration.

It is not possible to state how generalizable these findings would be to other populations of RA patients. The participants were able to access a wide range of services within a secondary care specialist centre, which in itself will influence control perceptions. Additional information is required to ascertain the strength and magnitude of the components of the medical consultation identified, e.g. are all the components identified required or does the expressive dimension have a greater influence than accessing an expert, in terms of influencing control perceptions. Although this research has identified the factors that positively influence control perceptions, we are not able to state whether the medical consultation alone has greater, less or equal importance when compared with other identified categories in the context of influencing control perceptions.

Conclusion
The medical consultation is one of the factors that positively influenced the perception of control in patients with RA. If utilized to its full potential, this mechanism can play a major role in enabling patients to manage the daily symptoms of their condition. The multifaceted role of the consultation needs to be appreciated when service provision is being considered as the reduction in regular out-patient reviews may negatively influence control perceptions and ultimately patient management.

References


