Perceptions of control in patients with rheumatoid arthritis

RHEUMATOID arthritis (RA) is a relatively common and chronic condition but it is not usually life-threatening. It is characterised by unpredictability - in the occurrence of symptoms, the outcome of the treatment programme and the overall prognosis.

Because of this inherent unpredictability, patients with RA tend to perceive that they have less personal control over their health than other patients with more predictable chronic illnesses (Felton and Revenson, 1984). Consequently, one of the treatment objectives is to enable RA patients to cope with this unpredictability and to feel they have an element of control over their condition. Affleck et al (1987) demonstrated that perceived control over daily symptoms was associated with more positive mood and adjustment.

Control can be objective (actual) and concerned with a person's capacity to exert a significant degree of influence over others or events. Control can also be subjective (perceived) when individuals hold the belief that they can determine their own behaviour, influence their environment and/or bring about desired outcomes (Tones, 1991).

From a psychological viewpoint the distinction between objective and subjective control is often immaterial (Wallston, 1995). If the nurse is trying to understand a patient’s behaviour, it is the patient’s perceptions that are paramount, not the objective situation. Most of the research on perceived control in RA has adopted this psychological viewpoint (Tennan et al, 1992; Affleck et al, 1987). These studies have demonstrated that an individual’s perception of control over the disease, the symptoms, and the treatment can have a positive effect on well-being.

In cases of RA, patients have a key role in managing their care. For example, they control the amount of analgesia they take, decide on their level of exercise and implement pacing strategies in response to a variable presentation of symptoms (Hill, 1995). It is in this area that nurses can inform and involve patients in the decision-making process.

The primary objective of our research was to identify the factors that patients perceive as prerequisites in obtaining a sense of control over living with the daily symptoms of their RA. It was hoped that once these factors were established they could be used to inform care management.

Method
A sample of 40 participants was randomly selected from patients attending an RA review clinic in an outpatient department over a three-month period. The clinic is for patients with the full range of RA symptoms. Only patients with a diagnosis of RA, as determined by the rheumatologist in accordance with the criteria outlined by the American Rheumatology Association (Arnett et al, 1998), were recruited.

A convenience sampling technique was used. A research assistant, who distributed the information sheet and obtained consent, approached every second patient who registered for the clinic. Of all the potential participants approached, only two declined to take part. Any potential participants who had been diagnosed with the disease for less than four months were excluded on the grounds that they would have a limited experience of the disease to reflect on. Ethical approval was obtained from the local research ethics committee.

A pragmatic decision was taken to recruit 40 patients. Arcury and Quandt (1998) state that although the sample size is usually estimated in advance, a final sample size determination is made during the course of the research. It was only after the researcher had transcribed and analysed all the data, that it was possible to suggest saturation had occurred after 30 interviews. Morse (1995) defines saturation as a repetition of discovered information and confirmation of previously collected data.

Hermeneutics
A hermeneutical approach was adopted. Hermeneutics is one particular branch of qualitative methodology. Its major objective is to gain an understanding of the situation or experience under investigation (Gadamer, 1975) using a ‘fusion’ of all relevant sources of data. Sources may include a literature review, the personal experience of the interviewer and the results from the interviews. These sources of information affect both the design and the analysis of the research.
The interview
All 40 participants were interviewed in depth by one researcher to identify factors that influenced their perceptions of control over their daily symptoms of RA. A panel of rheumatology health professionals and members of the local arthritis support group assessed the validity of the semi-structured interview schedule (see Fig. 1).

Data analysis
In hermeneutics it is the enquirer’s responsibility to determine the framework for analysis (Koch, 1996). The first level of analysis commences during the interview itself and involves attentive, reflective listening and the generation of new questions from the content and nature of the responses.

After completion, the interviews were audiorecorded and transcribed in their entirety using Colaizzi’s procedural steps (see Fig. 2). From the transcribed data, significant statements relating to control perception were identified. This enabled clear themes to emerge, which were then classified into categories (Colaizzi, 1978).

Validity was addressed in two ways. First, the interview transcripts were returned to all 40 participants to confirm their accuracy (a process referred to as ‘member-checking’). Second, two researchers reviewed eight of the interview transcripts to verify that the categories identified reflected the original data.

Results
The demographic details of the 40 participants are shown in Table 1. About two-thirds of the participants were female and the average age was 56 years. On average, participants had been diagnosed with RA for 11 years although the longest duration was 38 years.

Four main categories relating to the patients’ perceptions of control were identified from the interview data:

1. Reduction in physical symptoms, such as pain and stiffness;
2. Whether their social support network equated with perceived need;
3. The nature of the clinical consultation;
4. The provision of information.

Reduction in physical symptoms
The consensus from all those interviewed was that the physical symptoms of the arthritis, namely pain and stiffness, needed to be minimised before patients perceive they have any control.

‘I cannot do anything when the pain is bad. I feel trapped by it, it robs you of any control.’
(Female, 58. Disease duration: 15 years.)

‘If I had been able to get better control of the pain, I think I would have felt more in control.’
(Male, 35. Disease duration: 3 years.)

‘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.’
(Female, 62. Disease duration: 12 years.)

Social support
Both male and female participants wanted to continue to function in both everyday practical activities, such as cooking and gardening, as well as more social roles, including involvement with the family. Support was required on a regular basis and not solely at times of increased disease activity. The support offered needs to equate with the patient’s requirements because too much input can feel 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.’
(Female, 61. Disease duration: 13 years.)

‘I need to be in control. I have always looked after the children and with a change in routine and my husband’s support I can still do it.’
(Female, 44. Disease duration: 10 years.)

References


References


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.’

(Male, 62. Disease duration: 16 years.)

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.’

(Female, 58. Disease duration: 18 years.)

The clinical consultation

The medical consultation was viewed by many participants as an opportunity to spend time with an expert and to utilise their knowledge.

‘It is important to see doctors with the specialist knowledge as they know how to help me.’

(Male, 59. Disease duration: 11 years.)

‘The relationship with the doctors is paramount, I rely on them to say what the different treatments are and to prescribe the drugs.’

(Female, 44. Disease duration: 10 years.)

‘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.’

(Female, 57. Disease duration: 14 years.)

In contrast, the nurse-patient relationship was important for its expressive nature and the participants felt that this was the medium through which they could 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.’

(Female, 58. Disease duration: 15 years.)

‘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 began to take control again.’

(Male, 45. Disease duration: 10 years.)

Provision of information

Information was regarded as enabling understanding and participation in care.

‘I have all the leaflets. I keep them in a folder. I like information at hand, it eases you, it settles you.’

(Female, 66. Disease duration: 15 years.)

‘The first thing was to learn about it, to accumulate all the knowledge and then implement it.’

(Female, 49. Disease duration: 11 years.)

Discussion

This research has demonstrated that perceptions of control are not static but are influenced by both internal and external factors. Participants often perceived that they were in control of their RA until they experienced an alteration in their symptoms, such as pain, or in the level of social support they were receiving. Either of these could un favourably alter the perception of control.

Pain and stiffness are the main features of RA and for most patients they shape the experience of living with the condition (Newman et al, 1996), and create concerns about resulting disability (Parker et al, 1998; Deyo, 1988). The nurse must be proactive in this area and not accept that pain is inevitable.

An assessment will determine whether the pain results from a physical, psychological or social stressor. The nurse can then begin the process of working with the patient to develop coping strategies. This may include reviewing drug therapy, addressing mood, and suggesting behavioural interventions such as exercise and relaxation techniques. After any new intervention, such as exercise to help reduce pain, the patient should be reviewed by the nurse to assess the impact of the strategy and to modify or change it if progress is not being made.

The need for balance between the participants’ perceptions of their support needs and the support being offered also influenced perceptions of control. In previous studies, patients with arthritis who received support from family and friends exhibited greater self-esteem (Fitzpatrick et al, 1988) and psychological adjustment (Affleck et al, 1987).

The nurse can act as a mediator, involving the family in care planning and enabling family members to negotiate what support they will provide. This lets the patient have a meaningful role in the family unit while knowing that in times of crisis increased support will be forthcoming.

According to Rotter’s (1966) locus of control theory, reliance on other people is regarded as a negative aspect of control in that the individual is deferring to an external source. But in our research, patients valued the contact with the doctor as a means of obtaining information, motivation and support, which enabled them to come to terms with their situation.

The nurse was identified as the member of the health care team who could address psychological and social issues. Hill et al (1994) demonstrated that attendance at a rheumatology nurse clinic improved knowledge and psychological adjustment.

Conclusion

This research has identified positive influences on perceptions of control. Additional work is required to determine the strength of each category identified. It is not possible to state whether the reduction of physical symptoms has a greater, lesser or equal importance compared with the other categories, or whether all factors have to be present for a patient to achieve a perception of control. However, the results do provide guidance for nurses and doctors involved in the care management of patients with RA.