

The education of patients with rheumatoid arthritis – the knowledge and expectation of patients – the opinions of rheumatology nurses

Sierakowska M¹, Krajewska-Kułak E¹, Lewko J¹,
Przeorska-Najgebauer T², Jankowiak B¹, Rolka H¹, Szyszko-Perłowska A¹

¹ Department of General Nursing, Faculty of Nursing and Healthcare, Medical University of Białystok, Poland.

² Department of Internal Nursing, Faculty of The Healthcare and Education, Medical Academy of Silesia in Katowice, Poland

Abstract

Rheumatoid arthritis (RA) is a chronic, progressive, immunologically dependent, systemic diseases of connective tissue, leading to disability, cripplehood or even premature death. Helping to improve the quality of life of RA patients involves teaching them how to cope with disease-related problems of everyday life, with stress and with suffering.

The aim of the presented work is to determine the following: the patients' level of knowledge about rheumatoid arthritis; their educational needs; the impact of the level of knowledge on the patients' pro-health behaviours; the knowledge of nurses and their ability to recognize patients' problems; the nurse's tasks in preparing an RA patient for self-care.

The subject group consisted of patients with RA diagnosed according to The American Rheumatism Association criteria and nurses from rheumatology clinics and wards. The research method used was a survey questionnaire, which had been constructed for the purpose of the research.

The research results indicate a great need of patients, especially those with early rheumatoid arthritis, for education, support and help in adaptation. At the same time, the nurses, even though they do not fully fulfil their educational role, declare a willingness to participate in organized forms of health education.

Key words: knowledge about the disease, self-care, nurse's educational tasks.

Introduction

Education means the activities connected with the process of teaching, the aim of which is to raise the competence of individuals/families in dealing with diseases and health hazards [1].

The role of patient educators should be fulfilled by different kinds of specialists, including nurses, according to their competence in respect of achieving educational goals and realizing planned tasks. By taking care of a patient, his/her family and environment, a nurse influences, through her educational behaviours, the attitudes, health beliefs, motivations and systems of values of the patient/family, and educates them by giving knowledge and developing skills [2].

It is believed that patient education is one of the ways to limit disablement in rheumatological diseases and to improve the patients' quality of life. It follows The Therapeutic-Diagnostic Standards of the Polish Rheumatology Association, which state that in rheumatic diseases patient education is recommended as the most important part of the therapeutic procedure [3].

Chronic rheumatoid arthritis (RA) is a systemic disease of connective tissue, characterised by the inflammation of joints, extra-articular changes and systemic complications. The long and progressive course of the disease leads to disablement, cripplehood or even premature death [3]. Numerous studies have shown that in case of 60-90% of patients irreversible joint changes develop during the first years of RA [4,5].

The objective of the presented work is to determine the following: the patient's knowledge about rheumatoid arthritis, their educational needs; the impact of the level of knowledge on pro-health behaviours; the level and scope of the nurses' knowledge about RA and their ability to recognize patients' problems; the nurse's tasks in preparing an RA patient for self-care and self-nursing.

ADDRESS FOR CORRESPONDENCE:

Matylda Sierakowska, Ph.D.
Department of General Nursing, Medical University of Białystok,
7a M. Skłodowska-Curie Str., 15-096 Białystok, Poland
Tel: +48 85 7485528
e-mail: matyldasierakowska@gazeta.pl

Table 1. Health problems reported by patients and disease duration

| Health problems | Disease duration | | | | | |
|--------------------------|-------------------|-------|--------------------|-------|-------------------|-------|
| | Group I | | Group II | | Group III | |
| | 0-5 years n=28 | | 6-10 years n=29 | | ≥11 years n=43 | |
| pain | 28 | 100% | 29 | 100% | 41 | 95.4% |
| joint stiffness | 22 | 78.6% | 27 | 93.1% | 33 | 76.7% |
| lack of physical fitness | 18 | 64.3% | 23 | 79.3% | 36 | 83.7% |
| weakness, discomfort | 15 | 53.6% | 13 | 44.8% | 25 | 58.1% |
| low spirits | 11 | 39.3% | 12 | 41.4% | 28 | 65.1% |
| poor drug tolerance | 8 | 28.6% | 6 | 20.7% | 17 | 39.5% |

* Variable of multiple answers – the values do not add up to 100%

Materials and methods

The subject group consisted of 100 inpatients and outpatients with RA diagnosed according to the ARA criteria. The material was collected individually by means of personal meetings with patients. The research also covered 175 nurses from 10 rheumatology clinics and wards in Poland.

The method used in the research was a survey questionnaire, which had been constructed for patients and nurses for the purpose of the research.

Results

Patients group

Demographic data The patients studied (n=100) were divided into 3 groups according to the disease duration: Group I (0-5 years), Group II (6-10 years), Group III (≥11 years). The patients aged 41-50 were in majority in the group with up to 10 years of disease duration whereas the patients aged over 50 have usually suffered from RA ≥11 years (70%). 41% of the studied patients had secondary education. The majority of the respondents (66%) lived in a city/town. Patients living in a village are mainly those with disease duration ≥11 years.

As far as the professional activity criterion is concerned, the pensioners constituted the biggest group (42%), especially in the group with disease duration ≥11 years (53.5%) (p=0.036). 27% of patients from this group were also retired.

The health problems reported by patients most often concerned: pain, morning joint stiffness, a progressive lack of physical fitness and weakness. Patients from Group III more often mentioned bouts of low spirits and depression. The longer the disease duration the more intensive were the reported ailments (Tab. 1).

Altogether 71% of patients in early and later stages of disease duration complained about pain in the majority of joints. The patients with disease duration of 6-10 years reported pain in single joints statistically more often than the patients with disease duration of 0-5 years (p=0.038) and ≥11 years (Tab. 2).

Table 2. The location of the pain experienced by patients and disease duration

| Experienced pain | Disease duration | | | | | |
|--------------------------|-------------------------------|-------|--------------------|-------|-------------------|-------|
| | Group I | | Group II | | Group III | |
| | 0-5 years n=28 | | 6-10 years n=29 | | ≥11 years n=43 | |
| single joints | 5 | 17.9% | 16 | 55.2% | 8 | 18.6% |
| statistical significance | p=0.038 Group I vs Group II | | | | | |
| | p=0.022 Group II vs Group III | | | | | |
| the majority of joints | 23 | 82.1% | 13 | 44.8% | 35 | 81.4% |

Table 3. Nurses' evaluation of patient education usefulness in therapy and the overall practice

| Significance of education | Disease duration | | | | | | | |
|------------------------------|-----------------------|-------|------------------------|-------|------------------------|-------|-------------------|-------|
| | Group I | | Group II | | Group III | | Group IV | |
| | up to 5 years n=12 | | up to 10 years n=20 | | up to 20 years n=77 | | ≥21 years n=66 | |
| important element of therapy | 9 | 75.0% | 15 | 75.0% | 53 | 68.8% | 42 | 63.6% |
| one of many elements | 3 | 25.0% | 5 | 25.0% | 24 | 31.2% | 24 | 36.4% |

Half of the studied patients evaluated their health as bad. It particularly refers to the patients with early RA and with ≥11 years of disease duration.

Patients' health behaviours A considerable percentage of the studied patients (45%) took exercise every day, regardless of RA duration. The Group III patients exercised more often than the remaining surveyed. The majority of the surveyed (77%) went for a walk every day.

The surveyed believed that a light diet with low animal fat is recommended in arthropathy. More than 70% of the studied patients, particularly those from Group I, did not follow the dietetic recommendations for arthropathy.

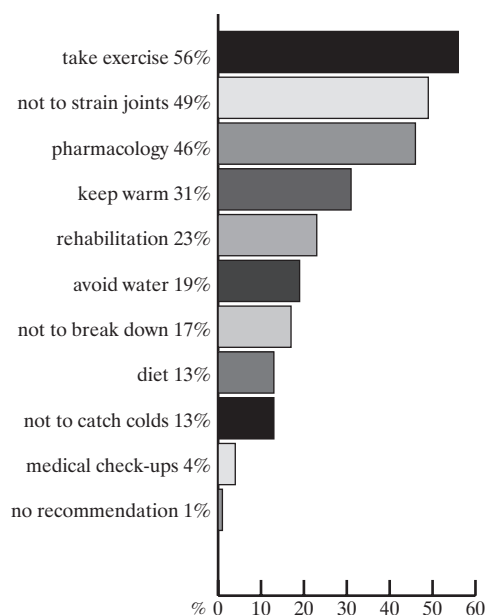
The majority of patients (85%) were regularly in touch with their therapist and took anti-inflammatory drugs. More than half of them (52%) did not have any therapeutic rehabilitation, or used to do it occasionally years ago.

The knowledge about the disease The patients believed that in RA the most important recommendations to limit the disease progress are: to take regular exercise, to protect the joints by not straining them and avoiding exposure to cold, to take regular medication (Fig. 1).

It appeared that the Group I patients to a greater extent declared a lack of knowledge about the disease in comparison with other patients (p=0.005). On the other hand, as many as 77% declared a willingness to broaden their knowledge about RA. The Group III patients were the least interested in education (18.6%) (Tab. 3).

Participation in RA educational activities The vast majority of patients (87%) did not take part in any organized forms of health education concerning RA. The participation in educa-

Figure 1. The recommended ways of limiting the disease progress quoted by patients



tion was several times bigger in case of patients who had been ill for a long time (23.3%) than those from Group I (3.6%) and Group II (6.9%) ($p=0.035$). The patients were particularly interested in the following subjects: the clinical course of RA, rehabilitation rules, psychological problems of chronic patients. They suggested different forms of active education, in particular a discussion and a chat.

The surveyed declared satisfaction from their interpersonal contacts with the nurse. They believed that she can support a patient in difficult situations.

Nurse group

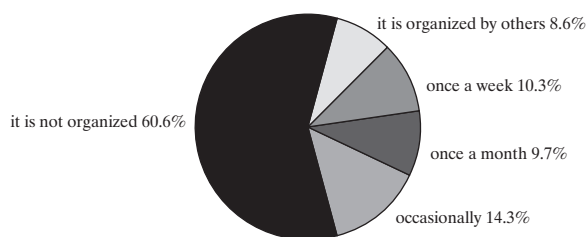
Education The studied nurses ($n=175$) were divided into 4 groups according to how long they had worked in the profession: 0-5 years (6.9%), 6-10 (11.0%), 11-20 (44.0%), ≥ 21 years (37.7%). The nurses with up to 20 years' experience in a rheumatology clinic/ward were the biggest group. The majority of the surveyed had secondary education (84%) ($p=0.004$) and the nurses with higher education and specialization were in minority. The vast majority (90%) felt a need for professional training.

Recognizing patients' health problems The problems the nurses recognized in RA patients included most of all a progressive physical disability, pain and swelling of joints. They also recognized bouts of low spirits, depression, giving up, difficulty to accept the disease, fear of pain and deformity. As far as self-care is concerned, they noticed patients' problems with doing everyday activities.

Patient education The vast majority of the surveyed believed that patient education is an important element of RA treatment (Tab. 3) and declared willingness to take an active part in it.

The nurses with longer experience (>10 years) used didactic aids in their educational work more often than the remaining

Figure 2. The frequency of organized patient education in the workplace of the surveyed nurses



group of nurses ($p=0.04$). It appeared that 56% of nurses did not use any didactic aids in their educational work with the patient. The surveyed believed that the best methods of working with the patient are, most of all, an individual conversation, a discussion and a chat.

The nurses were of the opinion that the most important ways of limiting disease effects and a progressive physical disability are physical activity and rehabilitation (74.9%) as well as taking medication (36.6%) and keeping a correct body weight (22.3%).

Over 60% of the surveyed reported that in their clinic/ward there is no organized education for RA patients (Fig. 2). The nurses who declared participation in education realized it by means of individual conversations and chats, using such didactic aids as prepared leaflets, medical magazines and newsletters. The conversations concerned mainly the rules of RA nursing and the methods of improving physical fitness.

Discussion

The research results analysis indicates that the main health problems of RA patients were as follows: pain, morning joint stiffness, a progressive physical disability, general discomfort, weakness and bouts of low spirits and feeling down. The surveyed nurses noticed similar health problems in their patients. The disease symptoms of the surveyed patients intensified with disease duration, which influenced their emotional state and caused a worse frame of mind. In her research Kossakowska also states that rheumatoid arthritis often co-exists with depression symptoms, which can occur in every third patient, with, most often, low or moderate intensity [6]. It is confirmed by other researchers, who diagnose depression of low intensity in about 20-36% of RA patients [7,8].

Also the disease duration significantly influences the subjective evaluation of health. The majority of patients with disease duration up to 5 years evaluated their health as bad.

The adaptation to the situation of the disease must include the elements of coping with the disease itself, the treatment etc. as well as with the life changes that the disease brings about. Shaul describes the adaptation process of nurses, who subsequently go through the stages of uncertainty and learning about the disease, followed by discovering methods of coping and strategies. As a result of such a procedure, they have become experts in managing their own disease and developed an ability

of coping with its symptoms [9]. Other research by Newbold also shows that RA sufferers need support and advice in the early stage of the disease to help them adapt to the new changed circumstances [10].

In the light of own research, rheumatoid arthritis, in the vast majority of cases, affected pensioners and retirees (68%). The disease, by causing disablement, excludes patients from fulfilling their professional functions, which has also been shown in the research by Kossakowska, where 80% of the studied patients were professionally inactive and most of them received a pension [6].

A considerable percentage of respondents (45%) claim to exercise and walk every day, regardless of disease duration. Some patients knew that, apart from pharmacological treatment, they should also have dietetic treatment – eat light dishes with low animal fat, but 70% of them did not follow these recommendations. In subject literature there are reports proving that diet is an equally important element supporting the therapeutic process. A light diet, basing on unsaturated fatty acids, is recommended as it does not strain the joints [11].

It is very worrying that over 67% of respondents declared a lack of knowledge about their disease. The shorter was the RA duration, the lower was the patient's knowledge. In the research conducted by Neville et al., the factors influencing the patient's interest in his/her disease were analyzed. It has been ascertained that it is mostly conditioned by the level of pain and disablement [12].

The nurses differed in their evaluation of the importance of patient education in the process of complex therapy of patients. Those with up to 10 years of experience attached more importance to this kind of procedure. The role of patient education is emphasized by many authors. According to researchers, education is one of the ways to limit disablement in rheumatic diseases and to improve the patients' quality of life [13,14].

The fact that the role of the nurse as an educator is changing was indicated by the opinion of 88% of the studied, who declared a willingness to take an active part in RA patient education.

The studied patients declared a willingness to enlarge their knowledge about RA. Similarly to nurses, they preferred different active forms of educational work, in particular a discussion, a chat and individual conversations. Such forms of patient education are widespread and recommended in literature [2]. It is especially emphasized that the information should include practical advice, which should be comprehensible and clear for the patient [12,15].

It seems that education in rheumatic diseases can significantly influence the level of the patient's functioning in the physical, psychic and social sphere, their adaptation and, as a result, ensure a better comfort of life with a chronic, progressive disease. Thus, it should be included to the complex therapeutic procedure in RA.

Conclusions

1. Chronic rheumatoid arthritis is the cause of pain and progressive disability, which makes self-care very difficult and significantly influences the patients' frame of mind and self-evaluation of health.
2. The surveyed patients, especially those in early stages of rheumatoid arthritis, admitted to a lack of knowledge about the disease, the rules of behaving and self-care, and declared a need to improve it.
3. Patient education is realized to a small extent, in the form of individual conversations and chats with patients, with the use of leaflets, brochures and medical magazines.
4. Nurses believe that education plays a significant role in the process of complex patient therapy and declare a willingness to participate in patient education, to which, however, they must be methodically prepared.

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