Evaluating and improving the quality of information for patients

HP0032 PROBLEMS REPORTED BY PERSONS WITH RHEUMATIC DISEASES

MA Larsson, AM Andersson, M Aronsson, R Holtin, L Olausson, M Thyberg. *Department of Pharmacy, Apoteket AB, Stockholm, Sweden*

10.1136/annrheumdis-2001.1264

Background Since 1991, Apoteket AB (the national corporation of Swedish pharmacies) has conducted so called "theme years", focusing on one widespread disease each year, in order to improve drug use. In 2002, Swedish pharmacies will pay special attention to persons with Rheumatic disorders. To prepare for this, we wanted to learn more about the problems associated with these diseases.

Objectives In order to identify disease-related difficulties in this group of patients, a Problem Detection Study (PDS) was performed. A PDS study not only identifies problems, it also ranks the problems according to how troublesome the patients find them.

Methods Initially, interviews with individuals and groups of patients were performed in order to identify all problems. This qualitative step identified 116 different problems. A questionnaire based on the problems was distributed to 950 patients in Sweden. The patients were to give each problem a grade, from 0 (no problem at all) to 3 (large problem). The average grade for each problem was calculated and a list of all problems, ranked by their average grade, was generated. The problem with the highest average was the worst one.

Results 75% of the 950 patients included answered the questionnaire. This large response rate may be due to an eager among these patients to improve their situation. Problems regarding everyday life were found most troublesome. The largest problem was "It is frustrating that I'm unable to do everything I wish to, due to my RD". The average grade for this problem was 2,5, which is very high compared to results from similar studies on other groups. The top 50 problems were further analysed, and divided into six categories. Many large problems were connected to everyday life. Problems regarding understanding, from others and from the community, were also important, as well as problems concerning the use of drugs and lack of information. The five subgroups, RA, Arthritis, SLE, Mb Bechterew, Fibromyalgia had very similar experiences, although the latter group differed to some extent.

Conclusions These results are important in several ways. First, they indicate what measures pharmacists can take to solve some of these problems. For instance by counselling in the pharmacies or by information to relatives and others close to the patients. Second, the results will help pharmacists understand these patients better and thereby improve their ability to meet the patients professionally. The study is also of great value in the production of material for continuing education of the Swedish pharmacists.

SP0177 PARTNERSHIP IN ACTION – HOW PATIENT AND PROFESSIONAL ORGANISATIONS ARE WORKING TOGETHER IN THE UK

S Edwards. *British League Against Rheumatism, (An Umbrella Group for 23 Support and Professional Organisations in the Field of Musculoskeletal Conditions), London, UK*

10.1136/annrheumdis-2001.1265

Background With the advent of patient empowerment and self-management, it is more important than ever that people with arthritis/rheumatism and those who treat them understand each others' needs and are able to work together. National organisations of patients and professionals have an important role to play in promoting partnership and mutual understanding.

BLAR is an umbrella group which brings patient and professional organisations together to work for better services for people with arthritis/rheumatism in the UK. We have 23 Member organisations. We promote partnership and communication at a local and national level through a number of ways, for example: A multi-disciplinary project to agree and audit patient-centred standards of care.

Establishing local networks of service users, health professionals and patient groups.

Joint parliamentary lobbying for higher priority for arthritis/rheumatism.

Joint policy development on issues of mutual concern.

Workshops and meetings for service users and professionals to exchange information and best practice.

Results These projects have been very successful, and have demonstrated that partnership can be beneficial to both patient and professional organisations. We have also learned that by working together, we strengthen our voice. Partnership is not possible on every issue, and there will always be differences of opinion. However, we have succeeded in building lasting partnerships on key issues.

Health professional and education

HP0033 DEVELOPMENT OF A SYSTEM OF NETWORKS AND CONTINUING EDUCATION FOR PHYSICAL THERAPISTS REGARDING THE TREATMENT OF PATIENTS WITH RHEUMATIC DISEASES: THE FYRANET PROJECT

¹J Verhoef, ²R Hoekman, ³M Bakker, ⁴HM de Vries-van der Zwan, ^{2,5}FGJ Oosterveld, ^{1,6}TPM Vliet Vlieland. ¹Department of Physical Therapy; ²Department of Physical Therapy, Medisch Spektrum Twente, Enschede; ³School of Physiotherapy, Leiden; ⁴Comprehensive Cancer Center, Leiden; ⁵Saxion School of Physiotherapy, Enschede, The Netherlands; ⁶Department of Rheumatology, Leiden University Medical Center

10.1136/annrheumdis-2001.1266

Objectives It has been observed by physical therapists and patients that treatment of patients with rheumatic diseases by physical therapists is hampered by a lack of specific knowledge and technical and communicative skills. Moreover, co-ordination between different health professionals involved in the treatment has been perceived as not optimal. Aim of the study was to set up a system of continuous improvement of specific knowledge and skills regarding the physiotherapeutic treatment of patients with rheumatic diseases and to start networks of physical therapists working in primary care, hospitals and rehabilitation centres.

Methods In November 1999 all physical therapists working within the catchment area of two rheumatological centres (Leiden, Enschede) were invited to participate. Education programmes were organised in parallel in both regions and consisted of a 5-day postgraduate training programme, followed by 2-monthly seminars. The programme focussed on examination and treatment of patients with rheumatic diseases and on communication with patients with a chronic disease. Communication among health professionals was enhanced by teaching practices within the rheumatological centres and by developing a draft guideline on communication among health professionals. Outcome measurements included questionnaires on the organisation, didactics and contents of the training programme (6-point scales, range 1; very bad to 6; very good), knowledge, interdisciplinary communication and patient satisfaction.

Results 63 of the 64 physical therapists (98.4%) finished the education programme and were formally registered. Evaluation of the training programme measured directly after each part of it showed positive scores with respect to contents, didactics and organisation (all medians 5, ranges 2–6). Knowledge scores increased significantly directly following the training programme ($p < 0.001$; Mann Whitney U). Measurements regarding the effectiveness on quality of care (interdisciplinary communication and patient satisfaction) will be completed in 2001.

Conclusions The preliminary results indicate that setting up a system of networks and continuing education for physical therapists with respect to the treatment of patients with rheumatic diseases is feasible. The complete set of results will be available by the end of 2001. Further research will focus on the implementation of the system on a larger scale. Funded by The Health Research and Development Council of The Netherlands; ZON.

SP0170 IMPLEMENTING EDUCATIONAL TRAINING PROGRAMS FOR HEALTH CARE PERSONNEL IN ARTHRITIS

LX Hansson. *Research and Development, The Swedish Rheumatism Association, Stockholm, Sweden*

10.1136/annrheumdis-2001.1267

Co-operation for education of health care personal in arthritis.

In Sweden we have 24 County Councils that are responsible for health care.

One of the most important tasks the Swedish Rheumatism Association, the SRA, is to give health care professionals more knowledge so they can discover early arthritis. If they do we today have a good arsenal of therapies to give people with arthritis a hopeful future. The communities themselves don't have resources to give their personnel further education in medical specialties. In Sweden as in other countries the medical companies offer the doctors a lot of specialised education. This is criticised by the public and there are forces in movement to change the situation.

For a long time the Swedish Arthritis/Rheumatism Association has given courses to health care personnel but this has only been the case in some parts of Sweden. Therefore our organisation, with support from 6 medical companies, now has started an educational project. This last autumn we negotiated with the medical companies to support us and in January we employed one person to contact all the County Councils to get a co-operation project with them to plan for educational days i.e. training for the medical profession.

We have a board, a steering group for this which includes representatives for the organisation of the GPs, for the organisation SRF (the rheumatologists), for Sverefo which represents the professionals from the arthritis team, for our own hospital Spenshult (owned by the SRA) representing the Patient Partner Project in Sweden which is employed by us and some other additional important partners.

The contents of the education is decided upon in cooperation between representatives from the SRA and the county councils mainly on the basis of some educational programs in arthrosis, rheumatoid arthritis, fibromyalgia och osteoporosis which the board picks out. Our patient owned hospital Spenshult in Halmstad on the west coast of Sweden has the main responsibility for the implementation of the educational days and the medical quality. We also try to stress patient influence and the point of view of the patients.

The companies can have exhibitions in the vicinity and treat the participants to food and an attractive free time program. The curriculum usually doesn't contain themes from rheumatology but instead fields like leadership, conflict management and personal development. The educational days vary from a group of 20 participating doctors working with dialogue pedagogy to lectures with 150 participants. We stress a qualitatively good documentation.

The year 2001 is a formative year for the project. Until now we have carried out three educational programs this spring and plan seven for the fall. In 2002, which together with the Swedish Pharmacies has been declared the year of Arthritis/Rheumatism, we plan to carry through approximately forty such educational programs in all county councils in Sweden.

Another project which I want to mention here also covers the education of health care professionals is to build up "e-learning" for the rheuma team.

At our next conference we hope to be able to present some more experiences from both these projects.

Health services, economics and outcome research

HP0034 RESPONSIVENESS OF SELECTED DISEASE-SPECIFIC PATIENT-ASSESSED INSTRUMENTS IN ANKYLOSING SPONDYLITIS (AS)

¹KL Haywood, ²AM Garratt, ³K Dziedzic, ⁴PT Dawes. ¹Department of Health Sciences and Clinical Evaluation, University of York, York; ²Unit of Health Care Epidemiology, Institute of Health Sciences, Oxford; ³Primary Care Sciences Research Centre, Keele University, Newcastle-Under-Lyme; ⁴Staffordshire Rheumatology Centre, North Staffordshire Acute Hospitals Trust, Stoke-on-Trent, UK

10.1136/annrheumdis-2001.1268

Introduction Five instruments, including an individualised measure of AS-related quality of life, the Patient-Generated Index (PGI-AS), have been assessed for measurement properties of reliability, validity and responsiveness in a large group of AS patients. Responsiveness refers to the ability to detect clinically important change and is an essential requirement for evaluative instruments.

Objective To establish comparative evidence in support of instrument longitudinal validity and responsiveness.

Methodology A questionnaire containing all instruments was mailed to over 450 patients randomly selected from six AS databases. Patients completed the questionnaire at baseline (response