THE ROLE OF THE RHEUMATOLOGY NURSE PRACTITIONER IN PRIMARY CARE: AN EXPERIMENT IN THE FURTHER EDUCATION OF THE PRACTICE NURSE

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SUMMARY

The aim of the project was to explore the possibility of conferring, on the practice nurse (PN), the skills and knowledge of the rheumatology nurse practitioner (RNP), hitherto, exclusively, a member of the hospital team. A trained and experienced RNP paid a series of regular visits to participating general practices in SE London. The subjects were 11 PNs and 30 patients with chronic rheumatic diseases. Interactive sessions involving the RNP, PN and patients were set up with a view to (1) instructing the PNs in the role of the RNP in the education and care of patients, and (2) educating patients about their disease and its treatment. Practice nurse and patient questionnaires were used to assess PN and patient knowledge before and after the instructional sessions. Only eight out of the 392 (2%) practices approached participated in the project and, even with these, difficulties were encountered, arising from the PNs' workload and pattern of work, and the reluctance of the general practitioners to enter a new project in the present climate of change in the NHS, unless clear and immediate financial advantages were in prospect. Statistically significant results were obtained in before/after comparisons of patient and nurse knowledge scores ($P < 0.00001$ and $P = 0.001$, respectively) following the RPN visits. The basic instructional format is sound and workable. A PN, if allocated protected time and appropriate patients, can acquire the knowledge and skills needed to manage patients with chronic rheumatic diseases in primary care. Both the instruments of measurement used can register changes over time, leading in a small number of patients (30) and PNs (11) to a statistically highly significant result.

KEY WORDS: Rheumatology, Primary care, Practice nurse, Further education, Rheumatology nurse practitioner.

RHEUMATIC disease constitutes the major cause of physical disability today. Some 20 million people per year in Great Britain experience some sort of rheumatic problem, and in a single year 8 million of them will seek advice from their general practitioner (GP) for a rheumatic condition. It has been estimated that about one in four of patients consulting a GP do so with a rheumatic complaint [1]. Attempts have been made over the past decade to enable GPs to acquire the necessary additional skills and knowledge to equip them to meet the challenges posed by the high prevalence of rheumatic disorders in the community [2]. The current programme of courses in local injection techniques for GPs (conducted personally by ourselves) have been particularly popular, some 160 doctors having completed courses since their reinitiation in March 1991. Another example of the burgeoning collaboration between GPs and rheumatologists is the 'shared care' of patients in the monitoring of so-called second-line drugs used in the treatment of diseases like rheumatoid arthritis, a process which is facilitated by the protocols for shared care now in widespread use.

The supportive educational approach of nurse practitioners has been shown to bring about an improvement in outcome [3, 4]. This is especially so in chronic diseases, where the provision of care, education and support are the most important elements of treatment [5]. In arthritis clinics, educating patients enhances compliance with treatment [6] and increases their knowledge of the disease [7]. The pioneering work of the Leeds group has succeeded in developing the concept of the rheumatology nurse practitioner (RNP), which evolved from that of a clinical metrologist (whose job it was to undertake measurements and assessments in research, notably drug trials) into what is now an active provider of health care [5]. In a recent study by the Leeds group, patients attending an RNP-led outpatient clinic did significantly better (in terms of levels of pain, knowledge and satisfaction) than a similar group treated by a consultant [8].

The RNP is now a key member of the rheumatology clinic and ward therapeutic team in many units. The significantly innovative feature of the present project was the attempt to extend the role of the RNP into primary care, with the aim of improving further the management of rheumatic disorders in the community.

METHODS

In the initial plan, all GP practices within the area of the former Lewisham & N Southwark District were approached and invited to take part in the project. Twenty GPs signified immediate interest in participating. The plan provided for an initial series of 12 weekly half-day visits to be made to each practice. At these sessions (to be reserved for the practice's chronic rheumatic disease patients), the RNP would sit with the practice nurse (PN) and, together with each patient and his or her principal carer, go through the history and current problems in detail.

At Visit 1, after discussion of the project, a questionnaire was given to the PN and completed, in
order to assess practice standards, her current role in the care of rheumatic patients, her job satisfaction, her working knowledge of rheumatic disease, the drugs used, the methods of monitoring them (blood/urine/skin checks, etc.), the methods of functional assessment, e.g. the Health Assessment Questionnaire, and the concept of shared care.

The interview with the first patient commenced with a questionnaire to establish a baseline estimate of the patient's knowledge of the disease and its treatment, how to recognize side-effects and what to do about them. It then covered the following areas: the history of the patient's disease; family and previous drug history; joint examination (teaching the PN how to perform the Ritchie Articular Index, how to recognize joint inflammation and deformity); discussion with the patient about current treatment and any problems relating to it; social, family (interpersonal), work/home, financial, mobility and dietary problems; education of the patient about the disease, its treatment and how to protect their joints. This took an average 45 min per patient. In accordance with good clinical practice, a PN file was opened for each patient for recording the above information.

In the interview with the second and subsequent patients, the same procedures applied, this time the PN playing a more active role, and the process thereby initially requiring ~45–60 min per patient. The remainder of the first session concentrated on enabling the PN to achieve a better understanding of state benefits, the range of aids to daily living (and how to obtain them), and how to establish links with the RNP, the community occupational therapist, physiotherapist, chiropodist, social worker, GP, hospital doctor and local Arthritis Care Visitor.

At Visit 2, semi-structured interviews with questionnaires were conducted with further patients with the PN playing the major role, aimed at ensuring that the PN acquired the key skills of listening and of asking the relevant questions. The main areas of emphasis were: (1) answering patients' questions and educating them and their relatives/carers on strategies for coping with the disease, thereby restoring a standard of independence and self-esteem, which allowed them to obtain the optimal results of treatment; (2) detecting fluctuations in the disease activity so that they could alert the GP accordingly; (3) ensuring that monitoring of second-line and other drug therapy is being carried out to adequate standards in order to ensure maximum benefit at minimum risk (taking blood, checking blood and urine tests and skin, interpreting laboratory results and taking appropriate action); (4) encouraging awareness of and support for local self-help groups, e.g. Arthritis Care.

At Visit 3 (and subsequent ones), a mix of new and follow-up patients was seen and discussed. Other previously discussed patients were also discussed in absence from the records. Every opportunity was taken to establish whether (or not) the quality of patient management had changed. Patient questionnaires were re-administered to each patient wherever possible during the period of the visits. At Visit 12, the PN questionnaire, which assessed her knowledge, role in patient care and job satisfaction, was repeated.

<table>
<thead>
<tr>
<th>TABLE I</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs' response to the initial invitation to take part in the project</td>
</tr>
<tr>
<td>----------------------------------</td>
</tr>
<tr>
<td>Total number of letters sent</td>
</tr>
<tr>
<td>Total number of replies</td>
</tr>
<tr>
<td>No reply</td>
</tr>
<tr>
<td>Total number of negative replies</td>
</tr>
<tr>
<td>Total number of positive replies</td>
</tr>
<tr>
<td>Number of GPs moved/deceased</td>
</tr>
<tr>
<td>Number agreeing to pre-visit</td>
</tr>
<tr>
<td>Number declining pre-visit</td>
</tr>
<tr>
<td>Declined after pre-visit</td>
</tr>
<tr>
<td>Practices recruited</td>
</tr>
<tr>
<td>Total declined</td>
</tr>
</tbody>
</table>

**TABLE Ia**

Reasons given for declining pre-visit after expressing interest

| 1. Projects need to generate income, as is the case with diabetes, hypertension, well-women and asthma clinics |
| 2. The monitoring of second-line drugs (including blood tests) and patient education is 'unproductive' and is best performed by hospital staff |
| 3. Second-line agents are 'toxic' and should not be handled by PNs |
| 4. There are too few patients (identified) in the practice needing such care |
| 5. A consultant would be more useful than a nurse |
| 6. What is needed is someone who can inject joints and teach the PNs to do so |
| 7. It is a political move to offload patient care on to the practice |
| 8. It was not within the job description of the PN to worry about the problems of second-line drugs. The GP should handle such problems |
| 9. GPs were better equipped to train their PN in rheumatology as they need to know more |
| 10. The premises are being refurbished |
| 11. The practice is outside the Guy's area; our patients do not attend Guy's; so that it would be inappropriate for a Guy's RNP to attend them |
| 12. Our PN is part-time |
| 13. The PN was interested in participating, but the GP was not |

**TABLE Ib**

Reasons given for declining after receiving pre-visit

| 1. PN is shared with another practice; there are financial problems; we must utilize nurse time on income-generating activities |
| 2. Our PN is leaving and we are trying to recruit a successor. Time would be a problem |
| 3. We have a large practice with three full-time PNs two of whom are going on maternity leave. It would be difficult for the remaining PN and the locum PNs to cope with the project |
| 4. We are a new practice and as yet cannot afford a PN |
| 5. Our part-time PN works only 12 h a week. Income generation is required if the hours are to be increased |
| 6. There is inadequate accommodation as the premises are about to be upgraded |
| 7. We are not convinced that PN involvement is necessary at the present time |
| 8. The PNs are not interested enough to undertake training. They feel that problems arising from therapy fall within the doctors' domain |
It was anticipated that once the pilot scheme had been completed and evaluated (see below), any necessary modification to the pattern of visiting for a wider definitive scheme would be made. Depending on take-up from GPs within the local district, it might be thought desirable to extend the study to the larger South East London Commissioning Authority area and beyond into other SE Thames Regional Health Authority districts. It was considered that at an optimistic estimate eight practices can be covered in each 12 week period. This would allow the RNP to spend 1 day each week in the department, working on administration, consulting with colleagues, and liaising with PNs and GPs. Allowing for at least one ‘booster’ visit after 3 months and 6 monthly thereafter, it was optimistically thought that over the course of 3 yr, a substantial proportion of nearby practices wishing to collaborate could be included in the scheme.

METHODS OF EVALUATION

The following methods of evaluation were adopted.

1. A practice nurse questionnaire was developed (Appendix 1) testing knowledge of attitudes to rheumatic disease and their impact on patients, their role in patient care and job satisfaction, and changes thereof. This includes multiple choice question elements and questions on case histories (Visits 1 and 12), and was administered to participating PNs at the first and last visits to the practice.

2. A patient knowledge questionnaire (Appendix 2), modified from that of Hill et al. [9], testing knowledge of and attitudes to rheumatic disease, the impact on their lives and their satisfaction with the care, was administered to patients prior to the start of the scheme and prior to the final practice visit, and the results compared.

TABLE III

<table>
<thead>
<tr>
<th>Practice</th>
<th>No. nurses</th>
<th>No. visits</th>
<th>No. patients</th>
<th>Follow-ups</th>
<th>Nurse questionnaire (%)</th>
<th>Patient (%)</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>L</td>
<td>2</td>
<td>10</td>
<td>6</td>
<td>2</td>
<td>52-66</td>
<td>9-12</td>
<td>pts not referred</td>
</tr>
<tr>
<td>M</td>
<td>1</td>
<td>8</td>
<td>6</td>
<td>3</td>
<td>44-60</td>
<td>0-12</td>
<td>Enthusiastic PNs</td>
</tr>
<tr>
<td>G</td>
<td>1</td>
<td>8</td>
<td>8</td>
<td>3</td>
<td>80-88</td>
<td>17-20</td>
<td>Mastered material</td>
</tr>
<tr>
<td>C</td>
<td>1</td>
<td>12</td>
<td>14</td>
<td>4</td>
<td>24-86</td>
<td>16-17</td>
<td>PN enthusiastic, set up database to identify pts/treatments/outcomes</td>
</tr>
<tr>
<td>E</td>
<td>1</td>
<td>9</td>
<td>7</td>
<td>6</td>
<td>72-80</td>
<td>6-8</td>
<td>Nurse away × 1</td>
</tr>
<tr>
<td>R</td>
<td>3</td>
<td>9</td>
<td>3</td>
<td>2</td>
<td>68-74</td>
<td>3-9</td>
<td>Nurse refused to identify pts if doctor away/busy/forgot</td>
</tr>
<tr>
<td>J</td>
<td>2</td>
<td>12</td>
<td>9</td>
<td>5</td>
<td>70-84</td>
<td>6-12</td>
<td>Pt refused</td>
</tr>
<tr>
<td>H</td>
<td>1</td>
<td>10</td>
<td>8</td>
<td>5</td>
<td>74-86</td>
<td>7-12</td>
<td>Nurse unable to identify pts. Doctor</td>
</tr>
</tbody>
</table>

pt, patient.
administered to each participating patient before and after the sessions in which they took part.

Statistical evaluation was performed comparing the before and after scores in both cases using the Wilcoxon sign rank test for non-parametric data.

RESULTS

The first task was to invite practices to participate in the study. This was initially done by letter. A total of 392 were invited between September 1992 and August 1993. Ninety-two (23.5%) replies were received, of which 46 (48%) expressed positive interest. Details of the responses are given in Table I. All 46 were offered a preliminary visit to discuss the project in more detail, but only 16 (35%) accepted. The reasons given by the remainder for not so doing are given in Table IIa. Eight declined entry to the study for reasons given in Table IIb. Even with the eight practices (L, M, G, C, E, R, J and H) which were recruited into the study, a number of difficulties were encountered. Their progress is detailed in Table III. Paired (before and after) data were available on 30 patients and on 11 PNs. There were statistically highly significant increases in the scores in both cases ($P < 0.00001$ and $P = 0.001$, respectively). Details of the statistical analyses are given in Table IV.

DISCUSSION

We were wildly overoptimistic in a number of areas, in particular the difficulties in 'selling' the project to GPs and their PNs. The numerous and varied difficulties currently being experienced by GPs in the present climate of NHS changes mitigated against their willingness to enter a new project (no matter how exciting), unless it proffered clear advantages to them or their practices. Of these, financial advantages loomed largest and outweighed potential improvements in clinical care and heightened professional self-esteem. Several of the 'interested' practices said that they wanted to defer their involvement until a later date; some were put off by accommodation problems. Those practices that did enter rarely allocated protected nurse time for the sessions, which tended to be interrupted or curtailed by double-booking. GPs did not identify their patients with chronic rheumatic diseases in adequate numbers. Lack of communication between partners and nurse often impeded progress. In some cases, enthusiasm of the GP and the PN varied inversely! On more than one occasion, the investigators were on the point of abandoning the project through lack of recruitment, but were urged to persevere by their advisors, and agreed to do so until completion.

In the event, only eight GP practices out of a total of 392 approached eventually participated in the project, despite the fact that it offered a good prospect of improving standards of nursing care to their patients with chronic rheumatic diseases, thereby making a significant contribution to improving the overall care of these patients. What it did not offer (and this was pointed out to us by large numbers of GPs approached) was 'income generation', which in the current climate of the internal market would appear to be an overriding consideration. Many lessons have been learnt from the attempt, which we are eager to pass on so that valuable time, effort and resources need not be wasted in repeating the exercise.

However, in the small number of practices that were prepared to take part, it was possible to establish that: (1) the basic instructional format proposed, with the RPN attending GP premises on a series of occasions to sit with the PN to discuss the practice's own patients and their problems, is a sound and workable one; (2) a well-motivated PN, if allocated protected time and referred appropriate patients, can successfully complete a syllabus leading to the acquisition of the necessary knowledge and skills needed to manage chronic rheumatic diseases in primary care, playing a similar role to the one played by the RNP in the hospital setting; (3) the instruments of measurements of knowledge used, i.e. the nurse and patient questionnaires, respectively, can both register changes over time. Furthermore, these changes can be quantitated and in a form that lends itself, in a relatively small number of patients (30) and PNs (11), to a statistical evaluation with a gratifyingly positive result.

We concede that the experiment as originally conceived was overambitious and, as it transpired, needlessly so. Much time and effort was consumed in vain attempts to recruit practices into the study at a time of great change, which we were to learn was clearly inopportune. We encountered numbers of PNs who were most eager to learn and GPs who were keen to improve standards in their practices. Involvement in any study does require the allocation of additional time and a degree of reorganization that is not always easy to achieve. It does seem that the acceptance of such additional demands without financial reimbursement

| TABLE IV |
|-------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Statistical comparison of patient and nurse knowledge questionnaire scores before and after training |
|                             | Mean  | Median | s.d.  | S.E.M. | 95% confidence intervals | $P^*$ |
| Patient knowledge questionnaire scores                        |
| Before training         | 8.93  | 7.5    | 5.1   | 0.93  | 8.93 ± 1.9                | < 0.00001 |
| After training          | 14.9  | 15.5   | 4.02  | 0.73  | 14.9 ± 1.5                |
| Nurse knowledge questionnaire scores                          |
| Before training         | 62.36 | 70     | 16.36 | 4.92  | 62.4 ± 11                 | 0.001 |
| After training          | 75.5  | 74     | 8.72  | 2.63  | 75.5 ± 5.9                |

*Wilcoxon sign rank test.*
was an imposition that few GPs felt able to bear in the present climate. This has important implications for community-based research in the reformed Health Service. Despite these difficulties, it was possible to extract sufficient usable data in order to achieve a statistical result, and thereby establish the hypothesis we set out to prove. An alternative approach to exploring the role of the RNP in the community using the medium of the community nurse is currently under investigation.

One of the main shortcomings of the study is that it concentrated on measuring increases in patient and nurse knowledge, but did not address the question of changes in practice or behaviour that may have resulted from that increase in knowledge. We acknowledge this deficiency, but would submit that the study was not designed with this latter goal in view. It will be for others to take up that challenge.

EPILLOGUE

When it became clear that both the numbers of patients referred, as well as the time available for PN training, was falling far below that required to implement the original protocol, a decision was made to recruit practices by initially approaching the practice manager. Ten practices that had originally declined to enter the study were reapproached, this time through the practice manager (PM), by posing the following question: 'If you were offered the opportunity to use the experience of a RNP (without charge) in what area(s) would you find her services most useful?' Advice was available on pain control (including optimal use of analgesics), diet, exercise, footwear, aids to daily living, joint protection and coping skills.

Of the 10 practices approached via the PM, seven agreed to the RNP paying a preliminary visit for discussion with staff at which PNs and PMs were present. Although closer cooperation between hospital clinic and primary care (including shared care) was seen as desirable, patient education (a pivotal role of the RNP) was seen as being exclusively within the province of the hospital clinic. Furthermore, there was wide variation in the perceived needs for the skills of the RNP among GPs, and little enthusiasm for participating in an evaluation process. PMs were keen to undertake any project that would enhance the practice profile. However, at the same time, they were aware of the need to attract a financial reward. A single practice (H2) took up the offer and received a total of five visits from the RNP at monthly intervals. The numbers of patients referred to the RNP were eight, two, one, one and none, respectively. The apparent declining interest and the ultimate demise of the arrangement may have been due to the fact that suitable patients had been diverted to a physiotherapist, whose services had been simultaneously purchased!

ACKNOWLEDGEMENTS

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REFERENCES


APPENDIX 1: UNITED MEDICAL AND DENTAL SCHOOLS, GUY'S HOSPITAL, RHEUMATOLOGY NURSE PRACTITIONER PROJECT PRACTITIONER NURSE QUESTIONNAIRE

This questionnaire has been devised to help us determine how much Rheumatology experience you have had and how you would deal with certain problems when they arise.

Please note:

This is just a questionnaire and not an exam paper. No marks will be awarded for correct answers or deducted for incorrect answers.

Could you please circle the letter opposite your answer. An example is illustrated below.

1. RHEUMATOID ARTHRITIS
   a is an inflammatory disease
   b is a degenerative joint disease
   c will affect only the large joints
   d can be cured
   e is caused by damp conditions
   f causes erosions
   g may affect the small joints
   h not sure
MANY OF THE QUESTIONS WILL REQUIRE MORE THAN ONE ANSWER. PLEASE CIRCLE AS MANY AS YOU THINK ARE CORRECT.

1. RHEUMATOID ARTHRITIS
   a. is an inflammatory disease
   b. is a degenerative joint disease
   c. will affect only the large joints
   d. can be cured
   e. is caused by damp conditions
   f. causes erosions
   g. may affect the small joints
   h. not sure

2. OSTEOARTHRITIS
   a. affects large joints only
   b. is a degenerative disease
   c. never affects the hands
   d. never occurs in patients under 50 yr of age
   e. does not cause inflammation of the synovial membrane
   f. causes erosions
   g. will be cured by surgery
   h. not sure

3. THE COMMON SYMPTOMS OF OA ARE:
   a. pyrexia
   b. stiffness
   c. loss of appetite
   d. nausea
   e. pain
   f. swelling
   g. tiredness
   h. obesity

4. THE COMMON SYMPTOMS OF RA ARE:
   a. loss of weight
   b. pain
   c. nausea
   d. loss of appetite
   e. swelling
   f. fatigue
   g. stiffness
   h. not sure

5. WHICH OF THE FOLLOWING STATEMENTS ABOUT RA ARE TRUE:
   a. it is found mostly in men
   b. it does not only affect women
   c. it is seen in women three times more commonly than in men
   d. it affects only the elderly
   e. it can affect any age group
   f. it is never seen in women
   g. it can be cured
   h. not sure

6. WHICH OF THE FOLLOWING STATEMENTS IS TRUE? RHEUMATOID ARTHRITIS:
   a. will only affect the joints
   b. occasionally affects the eyes, lungs and other tissues
   c. is infectious
   d. is a long-term disease
   e. RA patients will require a wheelchair sooner or later
   f. will not be affected by stress
   g. not sure

7. A PATIENT HAS BEEN DIAGNOSED AS RA AND COMMENCED TREATMENT ON A NSAID. HOW WOULD YOU EXPLAIN TO THE PATIENT WHAT THESE TABLETS DO?
   a. they stop the disease from progressing
   b. will take several weeks to work
   c. will reduce pain, swelling and stiffness
   d. can cause gastric problems
   e. can be taken at any time of the day
   f. only taken with food or after a meal
   g. should only be taken if pain is bad
   h. not sure

8. WHAT ARE THE COMMON SIDE-EFFECTS OF NSAIDS?
   a. itchy skin
   b. vomiting
   c. haematuria
   d. indigestion
   e. bruising
   f. mouth ulcers
   g. not sure

9. WHICH OF THE FOLLOWING ARE NSAIDS?
   a. Indomethacin
   b. Sulphasalazine
   c. Methotrexate
   d. Diclofenac
   e. Chloroquine
   f. Ketoprofen
   g. Naproxen

10. AS THE DISEASE PROGRESSES PATIENTS WILL REQUIRE A 2ND LINE AGENT. CAN YOU IDENTIFY THOSE FROM THE LIST BELOW?
    a. D-penicillamine
    b. Diclofenac
    c. Chloroquine
    d. Indomethacin
    e. Myocrisin
    f. Methotrexate
    g. Flurbiprofen
    h. Sulphasalazine

11. ALL YOUR PATIENTS RECEIVING 2ND LINE DRUGS WILL REQUIRE REGULAR BLOOD TESTS, WHICH OF THE FOLLOWING TESTS WOULD YOU DO?
    a. plasma proteins
    b. liver function tests
    c. cholesterol levels
    d. erythrocyte sedimentation rate
    e. white cell count
    f. haemoglobin levels
    g. platelet levels
    h. calcium levels
    i. rheumatoid factor
    j. not sure

12. YOUR PATIENT ON 2ND LINE DRUGS WOULD LIKE TO KNOW THE LIKELY SIDE-EFFECTS, HOW WOULD YOU ANSWER?
    a. itchy skin
    b. rash
    c. loss of appetite
    d. dyspepsia
13. TO-DATE MRS M. HAS RESPONDED WELL TO THE GOLD THERAPY BUT DURING HER VISIT FOR TREATMENT YOU DETECT A POSITIVE READING FOR HAEMATURIA ON DIP STICK (TOTAL MYOCRISIN DOSE TO DATE IS 760 mg) DO YOU:
   a stop the gold immediately and do an MSU
   b stop the gold and await the outcome
   c do an MSU but continue gold therapy
   d do an MSU, reduce the gold dose but continue weekly injections
   e suggest that the patient returns to hospital immediately
   f ring hospital for advice
   g suggest that as they have done so well opt for reducing the therapy to monthly but still do a MSU

14. A PATIENT WITH RA COMES TO SEE YOU FOR A FOLLOW-UP VISIT AND TO COLLECT A REPEAT PRESCRIPTION FOR VOLTAROL TABLETS. WHilst WITH YOU THE PATIENT COMPLAINS OF HAVING HAD AN 'UPSET STOMACH' RECENTLY AND HAS NOTICED THEY GET SHORT OF BREATH. DO YOU:
   a immediately send them to casualty for an ECG
   b suggest they have a chest X-ray today
   c enquire what they mean by 'upset stomach' and suggest if they mean diarrhoea then you would like a specimen for testing
   d suggest it could be something they have eaten or they have a 'bug' that is going around
   e enquire whether they have had this problem before, stop the voltarol as it might be causing the shortness of breath
   f ask them to contact their hospital doctor
   g ring the hospital or speak to their GP for advice

15. IT WOULD APPEAR THAT YOUR PATIENT IS GOING THROUGH A MINOR FLARE OF THEIR ARTHRITIS, WHAT WOULD YOU SUGGEST?
   a go to bed and rest as much as possible
   b try to exercise the joints to stop them from becoming stiff
   c try not to sit around, go for a walk
   d go to work or try tackling the housework, it will take your mind off it
   e increase your pain killers but not more than necessary
   f take regular hot baths, they will ease the pain
   g contact the hospital

16. A YOUNG MALE PATIENT DOING A SEMI MANUAL JOB, ASKS ABOUT THE POSSIBLE CAUSE OF HIS BACK PAIN: WHICH OF THE FOLLOWING WOULD YOU GIVE AS ADVICE:
   a wear and tear
   b muscular fatigue from lifting infrequently
   c postural stress
   d hereditary
   e sleeping on the wrong type of mattress

17. WHICH OF THE FOLLOWING INVESTIGATIONS WILL AID THE DOCTOR IN DIAGNOSING THE TYPE OF BACK PAIN OF THIS PATIENT:
   a full blood picture
   b X-ray
   c magnetic resonance imaging
   d tomography
   e whole body scan

18. A PATIENT WITH SEVERE JOINT DISEASE COMPLAINS TO YOU THAT THEIR PAIN AT NIGHT IS SEVERE ENOUGH TO INTERFERE WITH THEIR SLEEP. DO YOU:
   a suggest they see the GP and obtain a prescription for sleeping tablets
   b suggest they have a warm milky drink before bed
   c enquire about their NSAIDs, when and how many they take
   d suggest that as long as they rest during the day it does not matter about night sleep
   e enquire how much activity they do during the day and try to help them to moderate it
   f suggest they take two paracetamol before retiring for the night

19. MRS S. IS A 75 YR-OLD-LADY WITH OA OF THE HIP WHO IS KEEN ON BOWLS. SHE HAS NOW ELECTED TO GO FOR A TOTAL HIP REPLACEMENT. HER GENERAL HEALTH IS GOOD AND SURGERY WILL HELP GIVE HER INCREASED MOBILITY. HOWEVER, SHE HAS COME TO YOU FOR ADVICE ON POST-OP. ACTIVITIES. WHEN AND HOW CAN SHE RESUME NORMAL ACTIVITIES? WHAT WOULD YOU SAY TO HER?
   a speak to your orthopaedic surgeon
   b this is a major operation so you must not expect an early return to full daily activities
   c that each surgeon has a different approach to post-op. activities
   d tell her that all being well she should expect to be walking with assistance within 3 days
   e bending should be avoided for a little while
   f walking sticks will not be necessary
   g over use of the new joint may cause it to become loose
   h mobility will always be a problem but at least you will be without pain

20. DURING A ROUTINE VISIT TO THE CLINIC MRS Y. WHO IS 28 YR OLD TELLS YOU THAT HER HUSBAND HAS JUST LEFT HER AND 'WHAT WITH HER ARTHRITIS AND THE TWO CHILDREN SHE DOES NOT KNOW WHAT TO DO'. WHAT DO YOU TELL HER?
   a that marriages where there is one partner with a disability are more likely to fail
   b suggest that she find a job, quickly
c suggest she contact Arthritis Care immediately
d suggest that she contact the hospital
e suggest that she find a job and Arthritis Care will get her
f contact her local council as she will receive higher priority
g not sure

APPENDIX 2: DEPARTMENT OF RHEUMATOLOGY, GUY'S HOSPITAL, PATIENT QUESTIONNAIRE

We would be most grateful for a few minutes of your time to answer the following questionnaire.

RHEUMATOID ARTHRITIS PATIENT QUESTIONNAIRE

1. WHICH OF THE FOLLOWING STATEMENTS DO YOU CONSIDER TO BE TRUE?

Rheumatoid arthritis:
(a) is inherited
(b) starts following a joint injury
(c) caused by damp conditions
(d) cause is unknown
(e) may be triggered by a bacteria or virus
(f) affects only the bones
(g) may occasionally affect the lungs, eyes and heart
(h) is a long-term disease
(i) can be cured

2. WHICH OF THE FOLLOWING PROBLEMS DO YOU THINK MAY ALSO BE FOUND WITH RHEUMATOID ARTHRITIS?

(a) overweight
(b) hair loss
(c) nodules
(d) mouth ulcers
(e) anemia
(f) weight loss

3. DURING VISITS TO THE GP/HOSPITAL DOCTOR YOU WILL UNDERGO A BLOOD TEST. FROM THE FOLLOWING LIST CAN YOU TICK THOSE THAT YOU BELIEVE TO BE THE REASON FOR THIS?

(a) to check my ESR, for the disease activity
(b) to see if I'm anaemic
(c) to check if the tablets are working
(d) to check my cholesterol level
(e) to check for side-effects from my treatment
(f) don't know

4. ONE OF THE TABLETS YOU ARE TAKING WILL BE A 'NON-Steroidal ANTI-INFLAMMATORY DRUG'. CAN YOU FROM THE FOLLOWING TICK THE STATEMENT YOU THINK IS TRUE?

(a) they stop the disease from progressing
(b) they reduce the pain, swelling and stiffness
(c) they often take several weeks to start working
(d) they should always be taken with food
(e) they should only be taken when the pain is bad

5. CAN YOU CHOOSE FROM THE FOLLOWING LIST THOSE THAT YOU HAVE BEEN TOLD ARE COMMON SIDE EFFECTS OF NON-Steroidal ANTI-INFLAMMATORY DRUGS?

(a) itchy skin
(b) bruising
(c) indigestion
(d) dry mouth
(e) loss of taste
(f) hair loss

6. ANSWER ONLY IF APPLICABLE:

You may be on other treatment which we call 'long-term drugs' or 2nd line agents, such as:

Gold
Penicillamine
Azathioprine
Methotrexate
Sulphasalazine

Can you from the following list identify what these drugs do?
(a) relieve the pain
(b) assist in disease remission
(c) reduce swelling
(d) allow me to lead an active life
(e) helping to cure me of this disease
(f) not sure

7. CAN YOU FROM THE FOLLOWING STATEMENTS CHOOSE THOSE THAT YOU THINK ARE TRUE ABOUT PAIN KILLING TABLETS?

Pain killers:
(a) are not addictive
(b) should only be taken when the pain is severe
(c) should be taken before you carry out a painful activity
(d) should be taken when the pain starts to build up
(e) should be taken only with food

8. WHICH OF THE FOLLOWING ACTIVITIES SHOULD YOU CARRY OUT WHEN ALL YOUR JOINTS ARE PAINFUL AND STIFF?

(a) stop all forms of exercise
(b) rest in bed for most of the day
(c) put your joints through their usual range of movement exercises
(d) exercise quite vigorously
(e) exercise weakens damaged joints

9. CAN YOU CHOOSE FROM THE FOLLOWING THE MOST SUITABLE PLAN WHEN YOU HAVE A BUSY DAY AHEAD OF YOU, BUT YOU REALISE YOU ARE FEELING TIRED?

(a) take the day off and do more tomorrow
(b) do everything as planned
(c) rest in between and then do all the things planned
(d) do only the essentials and leave the rest
(e) spend the day in bed

10. FROM THE FOLLOWING HOW WOULD YOU HELP PROTECT YOUR JOINT FROM STRAIN?

(a) use them quickly
(b) slide objects rather than lift them
(c) do as little as possible
(d) use a dish cloth rather than a sponge
(e) grip objects tightly
(f) use both hands to carry fairly heavy objects