

Exploring the Priorities of Patients with Osteoarthritis of the Knee

Deborah Tallon, Jiri Chard, and Paul Dieppe

Objective. To explore the perceived importance of symptoms, treatment preferences, and research priorities of people with osteoarthritis (OA) of the knee.

Methods. Results of a focus group were used to facilitate the design of a questionnaire, distributed to 112 people with knee OA.

Results. Pain, disability, and instability in the joint were the most important symptoms, and anxiety about knee OA caused distress to many people. Oral drugs (90%), physical therapy (62%), and aids and adaptations (56%) were the most commonly used treatments. Surgery, oral drugs, and intra-articular injections were perceived as the most efficacious interventions. Patients' highest priorities for research were surgery and educational interventions, despite the fact that few had had surgery and education was not perceived as very effective.

Conclusions. The lack of a patient-centered approach to care leads professionals to ignore key symptoms and issues for individuals, and to a pre-occupation with pharmaceutical interventions, rather than the treatment options that their patients prefer.

Key words. Priorities; Osteoarthritis; Survey; Qualitative.

INTRODUCTION

Osteoarthritis (OA) of the knee is a common cause of pain and disability in older people (1). There is no cure for the condition, but a variety of different interventions are available to reduce pain, improve function, and (possibly) limit the risk of disease progression (2). Primary care physicians, as well as rheumatologists, orthopedic surgeons, and physiotherapists, all see large numbers of patients with knee OA, and have to develop management strategies for and with them.

Research on interventions for knee OA has been prolific. A recent assessment of the published research evidence located 930 English-language intervention studies on human subjects, published between 1950 and 1997 (3). Research on pharmaceutical and surgical interventions dominate this literature, accounting for 59% and 26% of the studies, respectively. In contrast, research on physiotherapy and exercise (6%), complementary and alternative therapies (5%), and educational interventions (3%) appears under-represented. The research agenda may be skewed and influenced by factors such as commercial interests (4) and publication biases (5).

The management strategies advocated by health professionals may also be influenced by commercial and other interests. A recent observational study of the management practices of physicians in the United States indicated that nonsteroidal anti-inflammatory drugs (NSAIDs) were the most popular pharmaceutical treatment for OA (6,7), despite the majority of evidence suggesting that these drugs are

Supported by Medical Research Council Health Services Research Collaboration. Bristol is the lead center of the MRC Health Services Research Collaboration.

Deborah Tallon, BSc, MSc, Jiri Chard, BSc, MSc, and Paul Dieppe, MD, FRCP, FFPHM, Medical Research Council Health Services Research Collaboration, Department of Social Medicine, University of Bristol, Bristol, UK.

Address correspondence to Deborah Tallon, BSc, MSc, Medical Research Council Health Services Research Collaboration, Department of Social Medicine, University of Bristol, Canynge Hall, Whiteladies Road, Bristol, BS8 2PR, UK.

Submitted for publication March 12, 2000; accepted in revised form May 24, 2000.

© 2000 by the American College of Rheumatology.

not superior to simple analgesics in the relief of joint pain (8–11). These studies and others also suggest that nonpharmaceutical treatments tend to be relatively underutilized in the management of knee OA.

The mismatch between the agendas and interests of the research community, health care professionals, and the consumer has been a matter of recent debate (12–14). However, there has been relatively little empirical research into the issue. In the specific context of knee OA, published research on the priorities of patients has been scarce. Similarly, patient involvement in the development of outcome measures has been uncommon. A number of recommendations have been published on the most appropriate outcome measures, particularly in the context of intervention research (15–19). Panels of physicians in the field typically develop such guidelines. This raises concern about the extent to which such outcome measures reflect the symptoms and experiences of patients.

The purpose of this study was to explore the symptoms, treatments, and research agenda from the perspective of the individual with OA of the knee. We specifically aimed to elucidate the most patient-relevant outcomes by evaluating the perceived importance of different symptoms and to explore the treatment preferences and research priorities of patients using both qualitative and quantitative methodology.

PATIENTS AND METHODS

We used two methods. First, we conducted a focus group in order to gain some qualitative understanding of the experiences of patients with knee OA and their priorities. Second, we developed a 93-item questionnaire in order to obtain quantitative information on the issues of interest to the patients and to us.

Focus group. Participants were recruited with the assistance of local general practitioners (GPs). Thirty-seven knee OA patients who were registered with these GPs were invited to participate. The GP explained the aims of the study to each potential participant, and requested permission to forward the patient's contact details to the research team. Interested individuals were then sent an information sheet and invited to attend the focus group meeting. Of the 37 patients who were approached, 7 agreed to take part. The discussion lasted approximately two hours and addressed two key themes: the patients' experience of the symptoms of OA of the knee, and

their experience of and preferences for treatment (and treatment research). Coping strategies were also discussed. The meeting was tape-recorded and transcribed verbatim. The qualitative software package QSR NUD*IST (20) was used to facilitate analysis, and the transcript was analyzed for emerging themes (recurring topics, ideas, opinions, or perceptions).

Questionnaire. A 93-item questionnaire was used to assess the symptoms, treatment experiences, preferences, and research priorities of patients with OA of the knee. We specifically aimed to probe patient-relevant outcomes that had emerged from the focus group discussion. Local ethics committee approval was obtained for the patient survey.

The survey sample comprised patients who were currently participating in a longitudinal study of knee OA. The inclusion criterion for the longitudinal study was activity-related knee pain with radiographic evidence of mild to moderate knee OA (Kellgren and Lawrence grade 2 or 3) (21). Exclusion criteria included severe radiographic knee OA (Kellgren and Lawrence grade 4), other causes of knee pain such as inflammatory arthritis, ipsilateral hip OA, and other conditions preventing participation such as severe cardiorespiratory disease. Subjects for this study had been recruited from previous studies ($n = 27$), a community-based study ($n = 48$), local primary care physicians ($n = 39$), and local rheumatology clinics ($n = 21$). This sample of 135 patients included 63 men and 72 women with a mean age of 64 years (range 38–81).

At the time of our investigation, 118 patients remained in this longitudinal study. We excluded 13 on the basis of current significant psychosocial problems or questionnaire fatigue. The remaining 105, as well as the 7 patients involved in the focus group, were sent the questionnaire (a total of 112).

The survey questions consisted of both closed (categorical) and open responses. The questions addressed the following issues: the onset and experience of symptoms of OA of the knee, treatments (used and preferred) for knee OA and perceptions of efficacy, and priorities for research into treatments for knee OA. Respondents were also asked about their ways of coping with the condition, using an adaptation of the Ways of Coping Questionnaire (22).

RESULTS

Focus group. The symptoms and impact of knee OA was the first area explored. The 7 subjects varied in their stage of illness, treatments used, and in what

they found most problematic about their illness. However, pain, disability, depression, and anxiety were the major problems for all participants. A striking feature of the symptoms reported was the psychological impact of the pain and disability. Examples are given below.

Mr. A: “[Pain] was destroying me, mentally. Well I mean it was *very* painful. And it seemed to, it seemed to *sap* me *mentally* as well. And I used to sit there and think ‘*My God!* I’m *sick* and *tired* of this thing.’ And the *pain* was the *main* thing that took my attention because it, it also affected me psychologically. I just felt *sapped* with it!”

Mr. B: “I don’t know how to describe it. It’s not *real pain*, if you understand what I mean. I think it was more psychological. I was *scared* what was happening. Of what was gonna happen.”

Treatment was the second topic of discussion. Drugs were seen as helpful, though several participants took drugs as little as possible. Examples of this follow.

Mr. A: “[The GP] offered me some tablets once. He said ‘the only thing about *these* is that you get a nasty after-effect.’ I said ‘I’m not in sufficient pain to take a chance on that.’ ”

Mrs. C: “There’s side effects to *every* tablet. I don’t like to take too many tablets, but if you’re in pain, you *need* them.”

Surgery was perceived as the only way to “cure” the disease, but some wanted to avoid this due to fear of risks or because they felt they were too old to benefit.

Mr. B: “And if the bone’s worn like mine was, the pain will be there. There’s only one thing to do, it’s like cancer, is to cut it away.”

Mr. D: “I wouldn’t want an operation at *my* stage of life.”

Similarly, canes were perceived as useful, but some participants who felt their pride would be affected did not use them. Physiotherapy and regular exercise were seen as beneficial treatments.

Mr. D: “I’ll tell you what I would like—a program of exercises. I think the right type of exercise is about the *best* thing. The *right* type. Providing people *do* it. And I would do it. Because I’m more concerned about what’s gonna happen.”

Alternative therapies such as ginger, cod liver oil, acupuncture, magnets, and others were discussed and used frequently by many of the participants. Some felt such treatments were helpful, and others suggested they might benefit from placebo effects. Despite a lack of evidence for complementary therapies, and perceived dismissal by the medical pro-

fession, these patients said they were prepared to try anything that other patients had found helpful.

Most participants appeared satisfied with their treatment and felt there was little more their GP could do for them, as the problem was viewed as a part of the aging process. However, they wanted more information about the condition, self-help (e.g., exercises, ways to avoid aggravating the condition), and available treatment options.

There were a variety of coping strategies that included carrying on regardless, taking medication as required, the use of aids to daily living, restricting movement, and resting. Others felt that they wanted to remain active as long as possible and that exercise was a good coping strategy.

Questionnaire. Ninety-six (86%) completed questionnaires were returned. Of these respondents, 41 (43%) were men and 51 (53%) were women (4 did not report their sex). The mean age of respondents was 61 years. Most (90%) had experienced knee problems for over 5 years, and 48% first experienced problems over 10 years ago.

Participants were asked to rate their experience of various symptoms as “not a problem,” “mild,” “moderate,” or “extremely severe” (Table 1). When asked about the symptom that upset them most, limitations of activity and pain were the most distressing. Feelings of instability (weakness) in the knee joint and problems with mobility were also frequently experienced as the most upsetting symptom. Swelling in the knee joint, depressed mood or anxiety about the knee, and clicking or cracking sensations were perceived as less upsetting. When asked which symptom they would most like treated, 88% of respondents agreed or strongly agreed that pain management was their priority. Treatments for limitations in activity and feelings of instability in the knee joint were also seen as important (Table 2). Respondents did not view symptoms that were perceived as the least upsetting (swelling, clicking sensations, depressed mood) as a priority for treatment.

Oral drugs (simple analgesics and anti-inflammatories) were the most commonly used treatments. (We used the word “tablets” throughout the questionnaire, rather than “NSAIDs” or “analgesics,” since focus group discussion suggested some patients do not differentiate between these drug types.) Eighty-five respondents (90%) reported they had taken tablets for their condition, and 53% (n = 50) used tablets “often” or “very often” (Table 3). Aids and adaptations (e.g., canes, braces, bath/stair rails) and physical therapy (e.g., physiotherapy, exercise, chiropractice) were also frequently used. The sub-

Table 1. Patients' current experience of symptoms

	Not a problem, no. (%)	Mild, no. (%)	Moderately or extremely severe, no. (%)	Total responses to question
Pain in my knee	3 (3)	24 (26)	66 (71)	93
Unable to do activities I used to do	5 (5)	27 (28)	63 (66)	95
Feeling fed up about my knee	19 (21)	28 (30)	45 (49)	92
Difficulty getting about	20 (22)	30 (32)	43 (46)	93
Clicking or cracking in my knee	16 (17)	37 (39)	41 (44)	94
Feeling my knee "give out"	12 (13)	42 (46)	37 (41)	91
Swelling in my knee	26 (28)	34 (37)	33 (35)	93
Worry/anxiety about my knee	31 (34)	35 (39)	24 (27)	90
Other symptom	10 (30)	9 (27)	14 (42)	33

jects' perceptions of the effectiveness of these interventions for their pain or disability are shown in Table 4.

We presented a list of 11 factors relating to symptoms, treatment, and outcomes and asked participants to rate the importance of each factor in making them "feel better." Response options were "not important," "slightly important," "moderately important," or "extremely important." Cure emerged as the most important factor, with 87% of respondents rating this as extremely important. Improved quality of life was rated extremely important by 68% of respondents. Other factors that frequently provoked this response were: increased confidence in mobility (56%), increased mobility (55%), pain relief (54%), information about knee OA (49%), improved sleep (46%), and reduced swelling (39%). Advice on self-help, having someone to talk to, and adaptations to the home environment were perceived as less important to their well-being; these factors were rated as moderately or extremely important to 52%, 46%, and 33% of respondents, respectively.

Table 2. A comparison of symptom perception and treatment preferences*

Symptom	Most upsetting symptom	Want treated most†
Unable to do activities I used to do	73 (82)	65 (79)
Pain in my knee	71 (81)	76 (88)
Feeling my knee "give out"	54 (66)	56 (72)
Difficulty getting about	55 (64)	50 (64)
Swelling in my knee	41 (49)	35 (47)
Feeling fed up about my knee	33 (40)	26 (37)
Worry/anxiety about my knee	29 (36)	20 (28)
Clicking or cracking in my knee	26 (35)	29 (40)
Other symptom	14 (70)	12 (70)

* Number (percentage) of respondents who "agree" or "agree strongly."
 † Ideally, this symptom would be their priority for treatment.

Next, we asked respondents to state which treatments should be made a priority for researchers, and to rank their 5 choices in order of importance. This question raised fewer responses than others in the survey. Seventy participants (73%) stated their first priority, and only 41 (43%) gave all 5 choices. Knee replacement surgery was the most popular priority and was ranked as the first choice by 37% of respondents. Education, advice, and methods of self-help was the other popular option, with 21% ranking this as their first choice. A summary of responses is presented in Table 5.

Finally, participants were asked which 3 strategies they found most helpful in coping with their knee OA. Keeping active was perceived as the most helpful strategy; 45 (21%) gave this response. Other popular choices were lifestyle adaptations (10%) and maintaining a positive attitude (8%).

Table 3. Summary of the treatments used by participants

Treatment	Never, no. (%)	Often or very often, no. (%)	Ever, no. (%)	Total responses
Tablets*	9 (10)	50 (53)	85 (90)	94
Physical therapy	33 (38)	14 (16)	53 (62)	86
Aids and adaptations	39 (44)	24 (27)	49 (56)	88
Education and advice	38 (46)	9 (11)	44 (54)	82
Injections in the knee	44 (53)	9 (11)	39 (47)	83
Removal of fluid/debris	51 (61)	3 (4)	33 (39)	84
No treatment at all	36 (69)	5 (10)	16 (31)	52
Complementary therapy	62 (77)	7 (9)	19 (23)	81
Knee replacement	76 (94)	0 (0)	5 (6)	81
Other treatment	10 (48)	6 (24)	11 (52)	21

* The word "tablets" was used throughout the questionnaire, rather than "nonsteroidal anti-inflammatory drugs" or "analgesics," since focus group discussion suggested some patients do not differentiate between these drug types.

Table 4. Summary of responses to the question: how helpful do you find these treatments for reducing pain and disability?

Treatment	Haven't tried	Not helpful	Slightly helpful	Moderately helpful	Extremely helpful	Total response
Knee replacement	77	0	1	1	3	82
Tablets	9	6	17	38	22	92
Injections in the knee	45	7	10	14	9	85
Removal of fluid/debris	52	6	8	6	10	82
Aids and adaptations	39	1	22	15	11	88
Physical therapy	38	8	19	7	13	85
Complementary therapy	59	6	8	7	2	82
Education and advice	41	6	21	13	4	85
No treatment at all	37	6	5	1	0	49
Other treatment*	14	1	4	3	2	24

* Other treatments included support bandages (n = 4), hot/cold compress, etc. (n = 4), exercises (n = 3), cream/gel (n = 2), self-massage (n = 1), "keeping going" (n = 1), and hydrotherapy (n = 1).

DISCUSSION

We undertook this study in order to investigate the health experiences and priorities of individuals with OA of the knee. As outlined in the introduction, one of the reasons for wanting to do this was the concern that there may be a mismatch between the treatment and research agendas of professionals and those of people with the condition (12–14). We explored 3 main areas of patient experience and views: the symptom experience, use of and responses to interventions, and research priorities. We included personal coping strategies within the focus group and

Table 5. Summary of responses to the question: which treatments should be made a priority for researchers?

Treatment priority	1st choice, no. (%)	1st or 2nd choice, no. (%)	1st–5th choice, no. (%)
Knee replacement	26 (37)	29 (22)	44 (16)
Education and advice	15 (21)	22 (17)	41 (15)
Physical therapy	2 (3)	14 (11)	38 (14)
Tablets	3 (4)	13 (10)	30 (11)
Injections in the knee	3 (4)	10 (8)	24 (9)
Complementary therapy	4 (6)	8 (6)	21 (8)
Removal of fluid/debris	0 (0)	6 (5)	22 (8)
Aids and adaptations	0 (0)	4 (3)	17 (6)
No treatment at all	1 (1)	2 (2)	2 (1)
Other priority*	16 (23)	22 (17)	30 (11)
Total responses	70 (100)	130 (100)	269 (100)

* Other research priorities listed include: pain relief (n = 9), a cure (n = 4), reduced swelling (n = 2), other surgical procedures (n = 2), improved mobility (n = 2), diagnostics (n = 2), prevention (n = 1), counseling (n = 1), holistic approaches (n = 1), diet (n = 1), other (illegible/not specified) (n = 5).

questionnaire, as this is clearly a major issue for the participants, but this project was not focused on coping strategies, which have been explored extensively by others (23,24).

We used a combination of qualitative and quantitative methods. We only undertook one focus group, and note that of the 37 patients approached, only 7 agreed to take part. This low response and self-selection of participants could have introduced bias, which is inherent in any voluntary research method. However, we do not claim that their views are representative of all people with knee OA. Our intention was not to elicit the entire range of possible experiences, ideas, or priorities of patients with knee OA, but rather to obtain some idea of their perceptions in order to help us design a questionnaire for the main, quantitative part of the study. In spite of the paucity of our qualitative data, our one focus group provided rich material on the experiences of people with knee OA. The questions used in our postal survey were based on the themes and topics that emerged from this focus group, as well as our own knowledge (based in part on a comprehensive literature review reported elsewhere [3]) and concerns.

The subjects chosen for both the focus group and the questionnaire present a major issue in terms of the interpretation of our findings. Most of our study group was from the community, rather than a hospital-based practice, suggesting that the data should be more generalizable than much of the published work on knee OA. Our subjects' demography, in terms of sex ratio and age, is similar to that described in community studies of OA (25–28). Since the epidemiologic data on knee OA show consistency here, we feel our study group does reflect community knee

OA patients. We chose to select people with mild to moderate OA of long standing. This strategy has the advantage that the participants will be accustomed to having the condition, having had time to become familiar with it and to understand what interventions and help is available, as well as time to develop effective coping strategies. A disadvantage is that some of these subjects may have become prejudiced for or against specific interventions through personal experience or because of individual relationships with health care professionals.

Comorbidities such as depression clearly affect pain and the responses of patients to the survey. However, in this study it was not possible to gather data on all such parameters, so the prevalence of these factors, and their impact on pain reporting and other responses, is impossible to ascertain. The involvement of the chosen subjects in both the focus group and postal survey was excellent; all those in the focus group spoke extensively about their problems. In addition, the response rate to all parts of the questionnaire was very high, with the exception of questions about research priorities; this may suggest some reticence or uncertainty among participants on this issue. Given that there has been very little research of this sort published elsewhere, it is impossible for us to say how representative our findings are.

The data obtained on the symptom experiences of those with knee OA illustrate the diversity of problems encountered. Pain and problems with daily activities came out as the most important problems. Additional issues of importance to the patients were feelings of instability (or weakness) in the knee joint, lack of mobility and confidence in mobility, and anxiety or depression ("being fed up about my knee"). The focus group transcripts, as well as the questionnaire results, indicate that these psychological impacts were a major issue to many individuals.

Most of the outcome measures used to assess the severity of this condition and the responses to treatment, such as the Lequesne algofunctional index (29) and the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) (15), use pain and disability as their major domains, which is clearly appropriate. The OMERACT (Outcome Measures in Rheumatoid Arthritis Clinical Trials) III panel recommended 3 key outcome measurements for phase III clinical trials: pain, physical function, and patient global assessment (16); the authors claim that these factors are the most "highly patient relevant measures." However, patients were not involved in the consensus process. In light of our results, it is surprising that none of these standard outcome instruments mentions feelings of instability

or tackles the psychological impact of this condition, whereas other symptoms that were not stressed by our patients, such as stiffness, are included in some instruments, such as the WOMAC (15). (While emotional function was considered, this dimension was not retained in the final WOMAC.) We did not inquire about stiffness in our questionnaire, since this did not emerge as an important issue for the focus group participants. Given the diversity of individual experiences, it may be more appropriate to use patient-centered measures or individualized measures for knee OA, rather than a single standard instrument for all patients. Examples are the Disease Repercussion Profile (30) and the patient-specific index of Wright and Young (31).

The perceptions and priorities of health care professionals can only be inferred from what patients said about their treatment, as well as the available literature. In this regard, the data on symptom priorities suggested a degree of mismatch between the treatment priorities of the health care professionals treating these patients and those of the patients themselves. A significant proportion of patients (72%) wanted treatment for feelings of instability in the knee joint. This symptom was a cause of considerable distress to 66% of respondents. Despite evidence that this symptom can be alleviated with the relatively simple intervention of putting a support bandage around the knee (32), it appears to be currently undertreated in clinical practice. We suspect that clinicians are relatively unaware of the importance of this symptom and do not generally ask about it or think of treating it. Other symptoms that patients wanted help with, but generally were not addressed by the health care professionals, were feelings of lack of confidence in mobility and loss of sleep. The apparently differing concerns of health care professionals and their patients may reflect communication problems, rather than gaps in the knowledge of professionals.

Data on interventions used showed that the subjects surveyed had experience with a wide range of available treatments, not a surprising finding in view of their long disease duration. As expected (6,7), oral drugs were the most commonly prescribed and used treatment. However, it is interesting to note that 10% of patients never used tablets, and only 53% reported that they used them often. Some of the focus group quotations suggest that many patients are very suspicious of tablets, and limit their use as much as they can. Doctors prescribing these medications should probably think more about the patients' perceptions of them, and likely compliance. Aids, adaptations, and physical therapy were also widely

used and thought to be helpful. Our data on the use of complementary therapy show a rather lower rate of usage than in some other surveys (33,34). Educational interventions appear to be used less than the patients would like. It is interesting to note that a significant minority used no intervention and favored no treatment. Perhaps these people have the most effective coping strategies.

We were particularly interested in patients' views on research priorities, in light of our related work on the mismatch between the research agenda and priorities of the public (13,14). The question on priorities for intervention research generated fewer responses and, therefore, appeared more challenging than others in the survey. However, knee replacement surgery and educational interventions emerged as clear research priorities. The emphasis on surgery was of interest to us, as we had deliberately excluded patients with the most severe disease, and only a small minority (5) of those in the survey had experienced knee replacement surgery. We believe that this finding from the survey supports the quotations of people in the focus group, who said that it was clear to them that the only way to cure a damaged joint was to cut it out.

The priority of education cannot be explained by perceived efficacy, as only one respondent described education as the best treatment used. However, this finding is again reinforced by the qualitative data suggesting that when patients say they want more education they are asking for more help in taking control of the condition themselves and to be empowered to handle it more effectively. Lack of side effects seems to be another issue of importance in patient research priorities. Despite being perceived as the most effective and commonly used treatment, research on oral drugs was prioritized by only 3 (4%) respondents. These priorities clearly contrast with those of researchers (and perhaps funding bodies and editors) in the field, as indicated by the available literature. The research evidence published between 1950 and 1997 is dominated by literature on oral drugs (3). Further interesting mismatches emerged between patients' ratings of the efficacy of treatments and their research importance, and between the reported severity of symptoms and the importance of treating these symptoms. The reasons for these discrepancies remain unclear, and these issues clearly warrant further qualitative research.

The patients we surveyed used a wide variety of coping strategies to manage their knee problems. Keeping active, adapting, and resting were reported to be the most helpful strategies. A smaller proportion of respondents rated professional help and med-

ication as the best way of coping. This reinforces the suggestion that these patients prefer to actively manage their own condition, illustrating the potential for educational and self-help interventions for OA of the knee.

In spite of the relatively small size of our survey, we believe that it has uncovered a number of important issues for consideration by health care professionals who help take care of those with knee OA. The data suggest that the relative lack of a patient-centered approach to care leads to professionals' ignoring key symptoms and issues for individuals, and that the professional preoccupation with pharmaceutical interventions is misplaced.

We believe that more research needs to be undertaken on methods of consumer involvement in the research priority-setting process. We recommend that researchers and physicians consult patients about their needs and preferences and that these views be incorporated into decisions about treatment, outcome measurement, and priorities for research. In particular, practitioners and researchers should endeavor to individualize interventions and outcome measurements, rather than generalize them, if we are to accurately represent and effectively treat the patient's needs.

We thank all the study participants for giving their time and information. We also thank Andrea Litva and John Duddy for their invaluable help with the organization of this project.

REFERENCES

1. Dieppe PA, Chard JA. Osteoarthritis. In: Godlee F, editor. *Clinical evidence*. London: BMJ Publishing Group; 1999. p. 219-24.
2. Hochberg MC, Altman RD, Brandt KD, Clark BM, Dieppe PA, Griffin MR, et al. Guidelines for the medical management of osteoarthritis. Part II. Osteoarthritis of the knee. *Arthritis Rheum* 1995;38:1541-6.
3. Chard J, Tallon D, Dieppe PA. The epidemiology of research into interventions for the treatment of osteoarthritis of the knee joint. *Ann Rheum Dis* 2000;59:414-8.
4. Dickersin K, Min YI, Meinert CL. Factors influencing publication of research results: follow-up of applications submitted to two institutional review boards. *JAMA* 1992;267:374-8.
5. Easterbrook PJ, Berlin JA, Gopalan R, Matthews DR. Publication bias in clinical research. *Lancet* 1991;337:867-72.
6. Mazzuca SA, Brandt KD, Katz BP, Dittus RS, Freund DA, Lubitz R, et al. Comparison of general internists, family physicians, and rheumatologists managing pa-

- tients with symptoms of osteoarthritis of the knee. *Arthritis Care Res* 1997;10:289–99.
7. Mazzuca SA, Brandt KD, Katz BP, Li W, Stewart KD. Therapeutic strategies distinguish community based primary care physicians from rheumatologists in the management of osteoarthritis. *J Rheumatol* 1993;20:80–6.
 8. Bradley JD, Brandt KD, Katz BP, Kalinski LA, Ryan SI. Comparison of an anti-inflammatory dose of ibuprofen, an analgesic dose of ibuprofen, and acetaminophen in the treatment of patients with osteoarthritis of the knee. *N Engl J Med* 1991;325:87–91.
 9. Williams HJ, Ward JR, Egger MJ, Neuner R, Brooks RH, Clegg DO, et al. Comparison of naproxen and acetaminophen in a two-year study of treatment of osteoarthritis of the knee. *Arthritis Rheum* 1993;36:1196–206.
 10. Towheed TE, Hochberg MC. A systematic review of randomized controlled trials of pharmacological therapy in osteoarthritis of the knee, with emphasis on trial methodology. *Semin Arthritis Rheum* 1997;26:755–70.
 11. Gøtzsche PC. Non-steroidal anti-inflammatory drugs. *BMJ* 2000;320:1058–61.
 12. Grant-Pearce C, Miles I, Hills P. Mismatches in priorities for health research between professionals and consumers [online, cited Sep 1998]. Available from: URL: <http://les.man.ac.uk/PREST>.
 13. Tallon D, Chard J, Dieppe PA. The mismatch between the agendas of the research community and the research consumer—the example of osteoarthritis of the knee joint. *Lancet* 2000;355:2037–40.
 14. Tallon D, Chard J, Dieppe PA. Consumer involvement in research is essential [letter]. *BMJ* 2000;320:380.
 15. Bellamy N, Buchanan WW, Goldsmith CH, Campbell J, Stitt LW. Validation study of WOMAC: a health status instrument for measuring clinically important patient relevant outcomes to antirheumatic drug therapy in patients with osteoarthritis of the hip or knee. *J Rheumatol* 1988;15:1833–40.
 16. Bellamy N, Kirwan J, Boers M, Brooks P, Strand V, Tugwell P, et al. Recommendations for a core set of outcome measures for future phase III clinical trials in knee, hip, and hand osteoarthritis. Consensus development at OMERACT III. *J Rheumatol* 1997;24:799–802.
 17. Food and Drug Administration. Guidelines for the clinical evaluation of anti-inflammatory and anti-rheumatic drugs (adults and children). Rockville (MD): US Department of Health and Human Services, Public Health Services, Food and Drug Administration; 1988.
 18. World Health Organization, European League Against Rheumatism. Guidelines for the clinical investigations of drugs used in rheumatic diseases. European drug guidelines, series 5. Copenhagen: World Health Organization, Regional Office for Europe, European League Against Rheumatism; 1985.
 19. Lequesne M, Brandt K, Bellamy N, Moskowitz R, Menkes CJ, Pelletier J-P. Guidelines for testing slow acting drugs in osteoarthritis. *J Rheumatol* 1994;21 Suppl 41:65–73.
 20. Richards T, Richards L. QSR NUD*IST, version 3.0. London: Sage; 1994.
 21. Kellgren JH, Lawrence JS. Radiological assessment of osteoarthritis. *Ann Rheum Dis* 1957;16:494–501.
 22. Folkman S, Lazarus RS. The Ways of Coping Questionnaire. Palo Alto (CA): Consulting Psychologists Press; 1988.
 23. Felton BJ, Revenson TA, Hinrichsen GA. Stress and coping in the explanation of psychological adjustment among chronically ill adults. *Soc Sci Med* 1984;18:889–98.
 24. Hampson SE, Glasgow RE, Zeiss AM. Coping with osteoarthritis by older adults. *Arthritis Care Res* 1996;9:133–41.
 25. Van Saase JLC, van Romunde LKJ, Cats A, Vanderbrouke JP, Valkenburg HA. Epidemiology of osteoarthritis: Zoetermeer survey. *Ann Rheum Dis* 1989;48:271–80.
 26. Hochberg MC. Epidemiology of osteoarthritis: current concepts and new insights. *J Rheumatol* 1991;18 Suppl 27:4–6.
 27. Lethbridge-Cejku M, Tobin JD, Scott WW, Reichle R, Plato CC, Hochberg MC. The relationship of age and gender to prevalence and pattern of radiographic changes of osteoarthritis of the knee—data from Caucasian participants in the Baltimore Longitudinal Study of Aging. *Aging Clin Exp Res* 1994;6:353–7.
 28. McAlindon TE, Cooper C, Kirwan JR, Dieppe PA. Knee pain and disability in the community. *Br J Rheumatol* 1992;31:189–92.
 29. Lequesne M, Mery C, Samson M, Gerard P. Indices of severity for osteoarthritis of the hip and knee. *Scand J Rheumatol* 1987;65 Suppl:85–9.
 30. Carr AJ. A patient-centred approach to evaluation and treatment in rheumatoid arthritis: the development of a clinical tool to measure patient-perceived handicap. *Br J Rheumatol* 1996;35:921–32.
 31. Wright JG, Young NL. The patient-specific index: asking patients what they want. *J Bone Joint Surg Am* 1997;79:974–83.
 32. Perlau R, Frank C, Frick G. The effect of elastic bandages on human knee proprioception in the uninjured population. *Am J Sports Med* 1995;23:251–5.
 33. Research Council for Complementary Medicine. Public usage of complementary medicine: an overview. London: RCCM; 1998.
 34. Fisher P, Ward A. Complementary medicine in Europe. *BMJ* 1994;309:107–11.