Relation between agendas of the research community and the research consumer

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Summary

Background Previous studies have suggested that research agendas can be biased. To determine whether there is a mismatch between available research evidence and the research preferences of consumers we examined research on interventions for the treatment of osteoarthritis of the knee joint.

Methods We searched published and unpublished studies on interventions in this condition to assess the structure of the evidence base. Focus groups and a postal survey of research consumers were then undertaken to examine their views and research priorities.

Findings Review of published and unpublished reports showed that the evidence base was dominated by studies of pharmaceutical (550, 59%) and surgical (238, 26%) interventions. 24 (36%) of 67 survey respondents ranked knee replacement as the highest priority for research, whereas 14 (21%) chose education and advice as their first choice.

Interpretation There is a mismatch between the amount of published work on different interventions, and the degree of interest of consumers. We suggest that broadening of the research agenda would be more in line with current treatment patterns and consumer views. If this mismatch is not addressed, then evidence-based medicine will not be representative of consumer needs.

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Introduction

The move towards evidence-based medicine has been a valid response to the variations in practice and behaviour in healthcare. The amount of evidence published has risen steadily over the past 50 years in response to calls for reliable information on efficacy and effectiveness of treatments. As a result, there is too much information for any individual clinician to assimilate. The response to this difficulty has been the publication of systematic reviews, meta-analyses, and guidelines, which have been used to summarise the evidence base for health professionals.

With establishment of the Cochrane Collaboration and publication of their guidelines,[1] the methodology used for collating evidence has become more standardised. However, there could be biases that affect research—eg, Gross and colleagues[2] have shown how US National Institutes of Health research funding does not reflect the burden of disease on the population. Factors such as funding sources,[3] vested researcher interests, publication bias,[4] and consumer pressure could all be influencing the research agenda away from the needs of the population it is meant to serve. A biased research agenda could have several consequences. First, treatments that are ineffective might continue to be widely used because of lack of evidence. Second, treatments that are effective might not be used because of lack of evidence. Third, treatments could be restricted only to those interventions for which (potentially biased) evidence does exist. Fourth, treatments that patients find unacceptable may be promoted, resulting in problems with adherence.

As evidence-based medicine has developed there has been a concurrent move towards increasing the role of patients in health-care decision making and policy. More consumer involvement could be creating friction with existing research interests (commercial interest, research groups, government policymakers); the areas and interventions that consumers feel warrant more research attention may not match priorities of those who currently control the research agenda. As a result, there will be an increasing need to find better ways of matching research to consumer needs to provide high quality evidence in areas of importance to consumers. The potential impact of this problem has already been noted.[5,6]

We aimed to examine the possible mismatch between the current research base and the agenda of current consumers of that research, using interventions for osteoarthritis of the knee as an example. By mismatch we mean a discrepancy between the treatments investigated by researchers, and those preferred and prioritised by consumers. Osteoarthritis was selected since we have experience of this disease, and it is a good example of a chronic disease with a spectrum of available treatment options. This was a pilot study to explore the views and priorities of groups of research consumers.

Methods

Review of published and unpublished studies

Any study of an intervention for treatment of osteoarthritis of the knee in humans published in the English language was included in our analysis. The inclusion criteria were deliberately open to capture the entire research base on interventions, and not specific areas. The selection was undertaken by JAC. A second investigator (PAD) independently checked a random 10% sample of selected studies. Three methods were used to identify articles for review. First, searches were done on electronic databases to identify any articles related to the treatment of the disease in human beings. Ovid Medline (1965–98), Ovid Embase (1980–98), BIDS Institute for Scientific Information (1981–98), and the Cochrane Library were searched (panel). All searches were done during March, 1998. Second, a postal survey of 261 members (87%) of the Osteoarthritis Research Society International (OARSI) was undertaken. People were selected if they were a current member of OARSI and based within a rheumatology research unit. Third, we manually searched bibliographies of review articles for useful studies. Reviews identified by electronic searches or those already known to us were gathered and references lists searched. All relevant articles were collated on an Excel datasheet.

Data were extracted from each study by use of a predefined protocol and included: researcher affiliation; study methodology (randomised controlled trial, observational); study treatment being tested (knee replacement, physiotherapy &c); justification for study; study inclusion and exclusion criteria (age, sex, allergic reactions); study outcome measures (pain, function); study statistics (sample size, dropout rate); study conclusion (recommend use or not); and study funding source. The article was classified as commercially funded if the researcher stated receipt of commercial funding, or if the research was undertaken by a company testing one of its own products. Articles were judged to have a positive outcome if the researchers supported or recommended use of the intervention in their abstract or discussion.

Research consumers focus groups

We asked four focus groups of research consumers (rheumatologists [six approached, five attended], general practitioners [15 approached, three attended], physiotherapists [nine approached, five attended], and patients [37 approached, seven attended]) their opinions about research into osteoarthritis of the knee. These groups were selected since they were likely to be research consumers, even though some professional groups could themselves be involved in research. The physiotherapists, rheumatologists, and general practitioners (GPs) were recruited with the help of colleagues in each of these groups. Patients were recruited with the help of local GPs, who supplied lists of patients with the disorder who had consented to be approached by the research team. Each group was kept exclusive to avoid one group potentially dominating conversation, or disagreement between groups limiting the information we gained. The discussion focused on exploring which aspects of the disease were perceived as most problematic, which interventions were viewed as most effective for osteoarthritis of the knee, and which treatments were under-researched and over-researched. Towards the end of the discussion we presented consumers with summary results from our review (table 1) and asked for their views on the current research effort.

Outline of search strategy of published reports

Osteoarthritis as keyword and/or MeSH heading search

and

Survey and synonyms as keyword and/or MeSH heading search
Experiment as keyword and/or MeSH heading search
Clinical trials and synonyms as keyword and/or MeSH heading search
Observational/cohort studies and synonyms as keyword and/or MeSH heading search
Review as keyword and/or MeSH heading search
Systematic reviews as keyword and/or MeSH heading search
Meta-analysis as keyword and/or MeSH heading search
Management guidelines and synonyms as keyword and/or MeSH heading search

Each discussion was transcribed word for word and analysed with the QSR NUD*IST software package (version 3.0) by DT. This package facilitates the coding and organisation of qualitative data such as interview or focus group transcripts. Each focus group revealed a series of themes, representing general areas or topics that emerged through discussion. Two reviewers (DT and JAC) independently identified the common themes of each focus group and there were no important discrepancies. The themes from the focus groups were compared with each other and with the results of the review.

Patient questionnaire

The themes that emerged from the focus groups were used to develop a postal questionnaire. The survey sample was drawn from a separate longitudinal study of osteoarthritis of the knee. Inclusion criteria for the longitudinal study were knee pain and radiographic evidence of mild to moderate osteoarthritis of the knee. Exclusion criteria included; other knee disorders (eg, severe joint destruction, previous fracture, inflammatory arthritis), ipsilateral hip osteoarthritis, and other diseases preventing participation (eg, severe cardiorespiratory condition, severe back pain). For the longitudinal study, participants were recruited between May, 1996, and May, 1997, from four sources; the Somerset and Avon Survey of Health (n=48);[7] collaborating local GPs (39); previous studies (27); and rheumatology outpatient clinics (27). This original sample consisted of 63 men and 72 women, mean age 64 (range 38–81 years). 118 patients remained within the inclusion criteria when our survey was undertaken in May, 1999. We invited 105 of these patients to participate in the survey (13 patients who were known to have severe family or health problems, or questionnaire fatigue were not recruited). We also invited the original seven focus group participants to take part. Thus, a total of 112 patients were sent an information sheet and questionnaire. The 93-item questionnaire used both open and closed questions about problems relating to the condition, which interventions (including those not prescribed by a doctor) were perceived as most effective, and which treatments should be prioritised for further research.

Results

Review of published and unpublished studies

A search of published and unpublished reports identified 5134 studies. After selection criteria had been applied, English language constraints imposed, and multiple publication addressed, 930 articles remained for review (there was 87% agreement between PAD and JAC on study inclusion, based on a 10% sample of studies). Table 1 summarises the overview results by intervention type. Alternative and complementary treatment included homoeopathy, folk medicine, transcutaneous electrical nerve stimulation (TENS), acupuncture, and

Treatment	Total studies	Randomised controlled trials	Commercially funded	Positive outcome
Alternative and complementary	49 (5%)	29 (59%)	5 (4%)	43 (88%)
Drug (injected)	89 (10%)	50 (56%)	5 (4%)	87 (98%)
Drug (oral)	461 (50%)	330 (72%)	109 (85%)	447 (97%)
Education	33 (3%)	14 (42%)	1 (0·8%)	29 (88%)
Physiotherapy and exercise	60 (6%)	24 (40%)	3 (2%)	55 (92%)
Surgery	238 (26%)	13 (5%)	5 (4%)	215 (90%)
Total	930 (100%)	460 (49%)	128 (100%)	876 (94%)

Table 1: **Summary of results from review of studies on osteoarthritis of the knee**

Treatment	Have not tried	Not helpful	Slightly helpful	Moderately/ extremely helpful	Total responses
Knee replacement	73 (92%)	0	1 (1%)	5 (6%)	79
Tablets*	8 (9%)	6 (7%)	16 (18%)	59 (66%)	89
Injections in the knee	42 (51%)	7 (9%)	10 (12%)	23 (28%)	82
Aids and adaptions	37 (44%)	1 (1%)	22 (26%)	25 (29%)	85
Removal of fluid/debris	50 (63%)	6 (8%)	8 (10%)	15 (19%)	79
Other treatment	14 (58%)	1 (4%)	4 (17%)	5 (21%)	24
Physical therapy	36 (44%)	7 (9%)	19 (23%)	20 (24%)	82
Complementary therapy	57 (72%)	5 (6%)	8 (10%)	9 (11%)	79
Education and advice	40 (49%)	5 (6%)	20 (24%)	17 (21%)	82
No treatment at all	35 (76%)	6 (13%)	4 (9%)	1 (2%)	46

*We used the word tablets in the questionnaire, rather than NSAIDs or analgesics, since focus group discussion suggested some patients do not differentiate between these drug types.

Table 2: **Summary of patients' responses to the question: how helpful do you find these treatments for reducing pain and disability?**

supplements. Oral drugs included non-steroidal anti-inflammatory drugs (NSAIDs) and simple analgesics (paracetamol). Injected drugs included corticosteroids and hyaluronan. Education and behavioural change included support, coping strategies, behavioural changes, lifestyle adaptions, dietary changes, and psychological interventions. Exercise and physiotherapy included muscle strengthening, exercise regimens, and knee braces and aids. Surgery included total knee replacement, osteotomy, and debridement. Pharmaceutical (oral and injected) and surgical interventions accounted for the largest proportions of articles—59% and 26%, respectively. 128 (14%) of 930 studies included in the review were commercially funded, with 109 (85%) of this commercial funding associated with oral drug treatment. All studies had high rates of positive outcomes (94% of all interventions).

Focus groups

Rheumatologists felt that NSAIDs had been over-researched, especially through commercially sponsored drug trials. They suggested that indications for knee replacement surgery (optimum waits) warranted further research and that better outcome measures should be developed. Physiotherapists were concerned about the absence of research on physiotherapy and exercise, and the dominance of drug trials. They felt that physiotherapy research should be of higher quality and clinically relevant questions should be addressed. GPs wanted research on both surgical success rates and on conservative treatments such as education—they viewed oral drugs as over-researched. Patients favoured conservative treatment, such as physiotherapy and complementary medicine, and wanted more research on education and self-help.

Treatment priority	First choice	First or second	First-fifth choice
Knee replacement	24 (36%)	27 (22%)	42 (16%)
Education and advice	14 (21%)	21 (17%)	39 (15%)
Physical therapy	2 (3%)	14 (11%)	36 (14%)
Tablets	3 (4%)	13 (10%)	29 (11%)
Injections in the knee	3 (4%)	10 (8%)	24 (9%)
Complementary therapy	4 (6%)	8 (6%)	20 (8%)
Removal of fluids/debris	0 (0)	4 (3%)	20 (8%)
Aids and adaptations	0 (0)	4 (3%)	16 (6%)
No treatment at all	1 (1%)	2(2%)	2 (1%)
Other priority*	16 (24%)	22 (18%)	30 (12%)
Total responses	67	125	258

*Nine listed pain relief, four a cure, two reduced swelling, two other surgical procedures, two improved mobility, two diagnostics, one prevention, one counselling, one holistic approaches, one diet, and five other (illegible/not specified).

Table 3: **Summary of patients' responses to the question: which treatments should be made a priority for researchers?**

Patient survey

We received 93 (83%) replies from the 112 questionnaires sent out. Table 2 shows responses to questions about treatment preference. Patients used many treatments. Tablets (NSAIDs, painkillers) were the most commonly used (81, 91%) of 89 respondents, and knee replacement the least common (6, 8%) of 79. Five of six patients who had undergone knee replacement surgery rated it as moderately or extremely helpful. Education and advice was viewed as the least effective treatment; only 17 (40%) of 42 people who had received it rated it as moderately or extremely helpful. Most respondents ranked knee replacement as the highest priority for research, followed by education and advice (table 3).

Discussion

We have noted a clear mismatch between the interventions that are researched, and those regularly used and prioritised by consumers. The results of our focus groups and survey show that people use various treatment options and want information on all these, and that professional groups want high-quality evidence for all interventions. However, the review of published and unpublished studies shows a massive concentration of research in drug and surgical treatments. This finding suggests a need to broaden the research agenda to investigate whether other treatments are as effective as drug and surgical interventions.

Because we only reviewed English language publications we cannot infer that our findings would be replicated in non-English language publications. Egger and colleagues[8] showed that articles published in English language medical journals were more likely to report statistically significant results than non-English language journals matched for the same research.

We have not attempted to do a comprehensive qualitative assessment of consumer opinions, which would have necessitated large numbers of focus groups.[9] Rather, we were interested in the range of views held by different groups of research consumers. Research in consumers is often restricted to patients alone, but the consumers of research findings include the professionals who provide advice on the basis of research evidence. Thus, we organised focus groups of various types of people involved in treating patients with knee osteoarthritis, as well as the patients themselves. The views of our groups will not be representative of all the views that might come from people of different backgrounds—cultural factors affect health beliefs,[10] and socioeconomic status may affect views on research priorities.

Our results are in line with those of others investigating different types of agenda bias in research. In an investigation of professional and consumer mismatch in research priorities, funded by the NHS research and development standing group on consumer involvement in research, Grant-Pearce and colleagues[11] concluded that a mismatch exists between the research preferences of these two groups, although they did not compare published research with consumer views. They suggested that differences between consumers and researchers in: values and life experience; understanding of science and technology; and access to decision-making structures, cause the research agenda to be mismatched with consumer needs.[11] Although their study concentrated more on psychological and managerial aspects of research mismatch, Grant-Pearce and colleagues' findings echo our own. Gross and colleagues' study,[1] although based on a different premise (that funding should be based on disease burden rather consumer wishes) also shows that sources of bias exist and affect the research agenda. We think that mismatch between the research community and consumers is probably caused by a combination of factors: commercial funding bias; vested researcher interests; professional dominance of research (ie, medical and surgical professions directing research funding); publication bias (our results showed that 94% of all studies provided a positive conclusion); and a lack of consumer involvement in research (ie, consumers not consulted about priorities). All these factors may be acting to skew the research agenda.

The implications for evidence-based medicine are worrying. The mismatch we have identified is unlikely to be specific for osteoarthritis of the knee; similar difficulties could exist in other areas of medicine and at other stages of the research process. If reviews are based on biased sources, validity and applicability of their results has to be questioned.[12] As evidence-based medicine becomes increasingly important in healthcare, it is essential that the issues we have raised are dealt within review methodology. The identification and discussion of agenda biases and mismatch with consumer needs have to be made standard for reviews in which patient care may be affected. Perhaps the Cochrane Collaboration could undertake such a task, since they have become the standard setters for systematic reviews. Our recommendations are: a more democratic research funding process; encouraging all clinical trialists to report findings, even if results are negative; and the mandatory reporting of funding sources and degree of consumer involvement.

Contributors

All investigators contributed to the design of the project. Jiri Chard and Paul Dieppe undertook the review of published and unpublished studies. Deborah Tallon did the qualitative work and questionnaire survey. All investigators were involved in the data analysis and contributed to the preparation of the manuscript.

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