

# Correspondence

## INSTRUCTIONS FOR LETTERS TO THE EDITOR

Editorial comment in the form of a Letter to the Editor is invited; however, it should not exceed 800 words, with a maximum of 10 references and no more than 2 figures (submitted as camera ready hard copy per Journal Guidelines) or tables and no subdivision for an Abstract, Methods, or Results. Letters should have no more than 3 authors. Full name(s) and address of the author(s) should accompany the letter as well as the telephone number, fax number, or E-mail address.

Contact: The Managing Editor, The Journal of Rheumatology, 920 Yonge Street, Suite 115, Toronto, Ontario M4W 3C7, CANADA. Tel: 416-967-5155; Fax: 416-967-7556; E-mail: jrheum@jrheum.com Financial associations or other possible conflicts of interest should always be disclosed.

## Patient Expectations and Total Joint Arthroplasty

To the Editor:

We read with interest the article on patient expectations and total joint arthroplasty outcomes by Mahomed, *et al*<sup>1</sup>. However, we have major reservations about this work that we would like to raise.

We believe that the methodology used is inappropriate and that the concept of “expectations” of surgical outcomes is a flawed one. It has commonly been stated that expectations play a central and dominant role in influencing satisfaction (as Mahomed has shown)<sup>2,4</sup>, although the nature of this relationship remains unclear. The majority of the quantitative studies that examine this relationship report that patients are able to describe their expectations of an outcome, via the use of questionnaires, rating scales, or open-ended questions<sup>5,6</sup>. However, qualitative studies (using semistructured interviews) find the opposite: individuals actually find it difficult to identify or articulate their expectations<sup>7,8</sup>. We conducted a qualitative study to further explore the relationship between expectations and satisfaction. Twenty-five patients were interviewed 3 months before primary total knee replacement (TKR) and 10 were followed up and interviewed again 6 months after their TKR. We found (like the previous qualitative studies) that most patients were unable or unwilling to express expectations and were generally evasive and noncommittal in their replies. They often began with a disclaimer such as “I don’t know until the time comes,” or “I’m not expecting anything.” Instead, they framed their responses in terms of hopes and fears. The majority of the informants generally held 2 types of hopes: “ideal” hopes and “pragmatic” hopes, reflecting both the optimistic view of the outcome and the probability of achieving this. Expectations and hopes are very different concepts. Hopes tend to be based more upon emotions or wishes, things that individuals want reality to be, whereas expectations tend to rely more heavily upon rational thought and logical reasoning. Thus, the informants in this study were not able to “forecast” what they thought would happen, but were only able to theorize their hopes and fears.

An important finding from our research was that it was only at the post-operation interview that the informants were able to describe their expectations (what they really thought would happen) in the light of what actually occurred in the hospital and operation process. Thus, it was only in retro-

spect and evaluation after the event that the informants were able to formulate ideas of what they were really expecting. This has important implications for research that suggests satisfaction is influenced by expectations. The fact that many realities are unanticipated means that individuals may not know what to expect. Therefore, expectations cannot be used as a starting place on which to base an assessment of the level of satisfaction.

An important question remains: Why do quantitative studies demonstrate that patients have clear expectations about the outcomes of surgery, but qualitative studies tend to report them as tentative, vague, and even nonexistent? One reason may be due to the limitations of questionnaire design. Simple and direct questions about expectations may result in simplistic answers. In addition, the limited fixed choices provided in questionnaires or the few open-ended questions about their expectations may have led some patients to “pigeon-hole” responses or express a view that did not represent or capture the complexity of this concept. Qualitative studies, however, retain the complexity and contradictions in the analysis and therefore explore in more detail the context in which statements are made. Mahomed, *et al* used a self-report questionnaire to ascertain the expectations for pain relief, activities of daily living, overall success of surgery, and likelihood of complications, with a 4-point Likert scale of responses. A better construct may be to record the main hopes and fears of the patients, rather than forcing views into a narrow range of responses.

Further, the interviews carried out after surgery in our qualitative study indicated that individuals struggled to understand their outcome and often described their outcome in contradictory terms: they viewed the outcome of the TKR as positive despite the continued experience of pain and immobility. They presented both a “public” expression of the outcome, reflecting their socially desired view as a success, and a “private” expression of the TKR outcome, reflecting the remaining pain and disability. The public statement of the outcome from TKR may correspond to the favorable published results of TKR. However, the private expression of any remaining pain and restriction of movement may not be captured with quantitative methods. Examination of the case studies demonstrated that these apparently contradictory accounts were consistent in the context of the informants’ lives, and represented adaptation, rationalization, or accommodation to their changed health state. As a result of these explanations, they continued to consider the TKR with high regard, even if they had considerable pain and disability.

We recommend that the concept of expectations needs reconceptualizing, and more sensitive assessments of outcome are needed to capture patients’ experiences, which incorporate the process of reconceptualizing outcome and take into account the context of the individual.

GILLIAN WOOLHEAD, PhD; JENNY DONOVAN, PhD; PAUL DIEPPE, MD, Department of Social Medicine, the University of Bristol, MRC Health Services Research Collaboration, University of Bristol, Bristol, UK.

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### Drs. Mohamed, et al reply

*To the Editor:*

We are pleased to have the opportunity to respond to the letter by Drs. Woolhead, Donovan, and Dieppe concerning our article<sup>1</sup>. They raise interesting concerns about the methodology we used and the concept of expectations.

Our study was a prospective cohort design that evaluated the determinants of functional outcomes following primary total hip and knee arthroplasty in 2 centers. Subjects were evaluated using standardized outcome instruments that have been validated in the literature<sup>2,3</sup>. As Dr. Woolhead acknowledges, the use of quantitative methods to measure expectations is commonly used. It is not surprising that qualitative methods often lead to different insights, as the responses are often influenced by the context of the interview. Both approaches provide valuable information and are useful in understanding the complex relationship between expectations and outcomes.

A growing body of literature examines the association of patient expectations on outcomes following medical or surgical interventions<sup>4,8</sup>. In fact, Dr. Woolhead cites a number of these in her letter. We agree that the relationship between patient expectations and satisfaction is poorly understood, although it is likely that initial expectations shape the perceptions of later experiences, and that gaps between expected and achieved outcomes strongly influence satisfaction<sup>9</sup>. In part, this may reflect lack of conceptual clarity about what expectations truly mean and lack of uniformity in how expectations are measured. It seems Dr. Woolhead and colleagues are addressing these very issues in their current research; we look forward to learning from their findings. In our study, however, we looked at the relationship between expectations and functional outcomes following surgery. Functional outcomes as defined in our study measure self-reported pain and disability rather than satisfaction with the result of the surgery. The field of measurement technology is quite mature in the area of functional outcomes. Indeed the Western Ontario McMaster Osteoarthritis Index (WOMAC, the primary dependent outcome in our study) has been validated and used extensively<sup>2,3,10-12</sup>. When Woolhead, *et al* refer to functional outcomes and satisfaction as interchangeable constructs, this in our opinion is incorrect.

Finally, we disagree with the suggestion that expectations regarding a procedure should be measured after the intervention. Recalled expectations are subject to strong recall bias and can be confounded by outcomes of the surgery. Patients' recall of their expectations may be dramatically altered from prior to surgery if they had a complication or adverse event after surgery. Conversely, if they achieve an excellent result they may raise their recalled level of expectations. The only way to accurately assess patient expectations of surgery is to measure them before the intervention. This is the strength of our study, as most previous reports have relied on recall expectations<sup>4,5</sup>. Ideally, researchers could combine quantitative assessments of expectation with qualitative assessments of hopes and fear in prospective research to illuminate their contributions to both outcomes and satisfaction.

NIZAR N. MAHOMED, MD, ScD, Toronto Western Hospital, Toronto, Canada; MATTHEW H. LIANG, MD, MPH; LAWREN H. DALTRY, PhD; PAUL R. FORTIN, MD, MPH; JEFFREY N. KATZ, MD, MSc, Brigham and Women's Hospital, Boston, Massachusetts, USA.

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### Development of Tuberculosis in a Patient Treated with Infliximab Who Had Received Prophylactic Therapy with Isoniazid

*To the Editor:*

Rheumatoid arthritis (RA) is a common chronic inflammatory and destructive arthropathy that cannot be cured and that has substantial personal, social, and economic costs. Because of the imbalance existing in RA between the mediators that initiate and maintain inflammation and mediators that shut down the process leading to cellular damage<sup>1</sup>, therapy in RA demands agents that block inflammation, retard synovial proliferation, and prevent joint erosion. Since proliferation is linked to inflammation, agents that limit immune responses may affect the entire

process<sup>2</sup>. Weekly methotrexate (MTX) played a dominant role in the 1980s and 1990s because its efficacy and safety were proved in short term trials and longterm observational studies<sup>3</sup>, but because of evidence of progressive bone loss and the inability to eliminate synovial proliferation with MTX, it became apparent that therapy for RA needed further advancement.

Infliximab is a humanized antibody against tumor necrosis factor- $\alpha$  (TNF- $\alpha$ ) that is used in the treatment of RA. Infliximab neutralizes the TNF- $\alpha$  inflammatory effect by binding with its soluble subunit and membranous TNF- $\alpha$  so that it may not interact with its receptor<sup>4</sup>. The understanding of some of the biologic functions of TNF- $\alpha$  has led to concerns that agents inhibiting TNF- $\alpha$  may increase the risk of certain infections<sup>5,6</sup>. In the last few months there have been reports of tuberculosis (TB) in patients treated with one such anti-TNF agent, infliximab<sup>7</sup>.

We describe the case of a 65-year-old woman with RA for 3 years, who had previously received treatment with MTX, azathioprine, sulfasalazine, hydroxychloroquine, corticosteroids, and nonsteroidal antiinflammatory drugs (NSAID), alone or in combination. Initially she improved, but therapy failed to suppress symptoms and prevent progression of the RA. Because of the inadequate response to other disease modifying antirheumatic drugs, she started infliximab as a part of her RA therapy, which by that time included prednisone 10 mg/day, azathioprine 50 mg/day, and NSAID. She had been found to be Mantoux positive, so after active disease was ruled out by chest radiograph and sputum culture, which were normal and negative, respectively, she had completed a course of prophylactic therapy with isoniazid for 6 months prior to starting infliximab. After 11 doses of infliximab (19 mo of therapy), she presented persistent aseptic leukocyturia. On urinalysis *Mycobacterium tuberculosis* was observed in the urine culture. Treatment with infliximab was immediately discontinued and tuberculostatic treatment started. The isolate had no resistance to usual anti-tuberculous medication.

It has been proposed that all patients in whom infliximab therapy is considered should be screened for both active and latent TB. In the event of active TB, patients should not receive infliximab or other anti-TNF agents. If latent TB is diagnosed, prophylactic therapy should be initiated prior to starting infliximab<sup>7</sup>, but because of the profound alterations in the immune response caused by infliximab, it may be reasonable to complete a course of prophylactic therapy with isoniazid. A course of 9 months may be necessary, as recommended by the US Centers for Disease Control in patients with human immunodeficiency virus infection<sup>8</sup>, in contrast to our local Spanish recommendations<sup>9</sup>, because of the absence of evidence that the traditional 6-month prophylactic therapy is efficacious in all such patients. Even in the healthy host there is no evidence of efficacy greater than 70%<sup>10</sup>.

Although TB is usually reactivated within the first few doses of infliximab, we believe that reactivation of latent TB was the mechanism in our patient. Nevertheless we cannot exclude the possibility, albeit rare, of recent infection nor the contribution of prednisone to the development of active disease. Finally, we would like to stress the need to rule out active TB, and if necessary, to complete at least 9 months of prophylactic therapy with INH, before starting infliximab<sup>11</sup>.

JORGE PARRA RUIZ, MD; NORBERTO ORTEGO CENTENO, MD, ENRIQUE RAYA ALVAREZ, MD, Unidad de Enfermedades Autoinmunes Sistémicas, Servicio de Medicina Interna B, Servicio de Reumatología, Hospital Clínico San Cecilio, Granada, Spain.

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## Book reviews

### Living Well with Arthritis: A Sourcebook for Understanding and Managing Your Arthritis

Dianne Mosher, MD, Howard Stein, MD, and Gunnar Kraag, MD, Toronto, Canada: Penguin Books, Viking, 2002, 338 pages, price \$29.00.

There is no shortage of booklets on how to cope with arthritis and related conditions, but the appearance of this full-length book, written by Canadian experts, and directed to Canadian patients, will provide an important resource for all those suffering from, or treating, these disabling diseases. The 14 chapters are clearly written, and tables and illustrations, though few, are well designed. Some patients may be intimidated by the detailed scientific information provided, though this is, on the whole, clearly set out.

The chapter on childhood arthritis can be especially recommended for its well thought out and straightforward presentation of a complex subject, in language most parents will find easy to follow. The topic of "Complementary Therapies", of passionate interest to patients, is dealt with in a chapter of 40 pages, where sympathy and scepticism are finely balanced. Other chapters cover the diagnostic varieties of rheumatic diseases and their management, with a helpful emphasis on the value of a team-based approach to therapy. There are also useful outlines of the role of surgery, diet, and exercise in the management of arthritic conditions, and excellent sections on sexuality, pregnancy, and disability. An appendix deals with genetics and the environment.

A few comments might be considered in a second edition. The discussions of therapy in Chapters 1 and 7 show considerable reduplication. It would have been helpful to explain "DMARD" on its first text appearance; references to Raynaud's syndrome are only found under "Scleroderma", which might dismay patients with primary Raynaud's. Many of the conditions discussed in this book have no relation to joints. The extension of

rheumatology to include non-arthritic musculoskeletal disorders is clearly described in Chapter 2, but it might be useful to consider a title that directs the potential purchaser to a range of conditions beyond diseases of joints.

John Verrier Jones, BM, BCh, FRCP, FRCPC, former Head, Division of Rheumatology, Dalhousie University, Halifax, Nova Scotia, Canada.

### **Clinical Pain Management, 4 volume set.**

ASC Rice, C Warfield, D Justins, C Eccleston, editors. Toronto: Oxford University Press, 2003, Price \$499.50 (Can).

This is an impressive set of 4 volumes dealing with the management of pain. Three volumes address acute, chronic, and cancer pain and the fourth discusses practical aspects of clinical management and clinical research. There are over 200 authors from 16 different countries, representing a broad range of disciplines dealing with different aspects of pain.

The authors outline management strategies based on current standards of practice but also if available relying on evidence-based studies. They use a scoring system to indicate the quality of evidence available. As well, references of key primary papers and major review articles are highlighted in the indexes.

As the editors point out *Clinical Pain Management* is a work complementary to the *Textbook of Pain* and focusses on principles of clinical management rather than laboratory research into pain. Nonetheless each volume has introductory chapters dealing with basic principals of the respective topic. These are followed by chapters covering specific aspects of pain management.

Overall, *Clinical Pain Management* is a comprehensive coverage of the topic of pain management. Each chapter is well written. It will doubtless be a major reference text for any physician or health practitioner who deals with acute, chronic, or cancer pain.

W. John Reynolds, MD, FRCPC, Associate Professor of Medicine, University of Toronto, Toronto Western Hospital, Toronto, Canada.