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Referral recommendations for osteoarthritis of the knee incorporating patients' preferences

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Background. GPs have to respond to conflicting policy developments. As gatekeeper they are supposed to manage the growing demand for specialist services and as patient advocate they should be responsive to patients' preferences. We used an innovative approach to develop a referral guideline for patients with chronic knee pain that explicitly incorporates patients' preferences.

Methods. A guideline development group of 12 members including patients, GPs, orthopaedic surgeons and other health care professionals used formal consensus development informed by systematic evidence reviews. They rated the appropriateness of referral for 108 case scenarios describing patients according to symptom severity, age, body mass, co-morbidity and referral preference. Appropriateness was expressed on scale from 1 ('strongly disagree') to 9 ('strongly agree').

Results. Ratings of referral appropriateness were strongly influenced by symptom severity and patients' referral preferences. The influence of other patient characteristics was small. There was consensus that patients with severe knee symptoms who want to be referred should be referred and that patient with moderate or mild symptoms and strong preference against referral should not be referred. Referral preference had a greater impact on the ratings of referral appropriateness when symptoms were moderate or severe than when symptoms were mild.

Conclusions. Referral decisions for patients with osteoarthritis of the knee should only be guided by symptom severity and patients' referral preferences. The guideline development group seemed to have given priority to avoiding inefficient resource use in patients with mild symptoms and to respecting patient autonomy in patients with severe symptoms.

Keywords. Clinical practice guideline, gatekeeping, knee, osteoarthritis, patient preference, referral and consultation.

Introduction

About 10% of adults >60 years of age experience chronic knee pain and disability that is caused by osteoarthritis. One option for a GP is referral to a specialist service. In 2001, the National Institute for Health and Clinical Excellence (NICE) recommended that patients with rapidly increasing symptoms and those whose quality of life is impaired should be referred¹ advice that was reiterated in 2008 with the addition

that referral should be made 'before there is prolonged and established function limitation and severe pain'.²

There is increasing pressure on primary care staff within the National Health Service to manage demand for health care. One of the most visible initiatives in this context is the establishment of referral management by primary care trusts (PCTs), which aim to avoid or reduce referrals not deemed cost-effective.³ There is also a commitment to strengthen patients'

involvement in decision making about the management of their condition.⁴ However, there is a potential conflict between these initiatives. For example, what are GPs supposed to do when they see a patient with osteoarthritis of the knee who has only mild symptoms but a strong preference to be referred? Currently, there are no guidelines as regards when a referral is appropriate or how to incorporate patients' preferences.

Our aim was to develop a referral guideline for patients with osteoarthritis of the knee that explicitly incorporates patients' preferences for referral. This guideline addresses the decision to refer a patient to a specialist rather than the decision to recommend surgical treatment. We used a streamlined approach to develop this guideline, largely based on a recently published method that aims to make guideline development more succinct and transparent.⁵

Methods

The guideline development group included 12 representatives of relevant people in the management of osteoarthritis [three patient representatives (two were recruited from organizations representing the interest of patients based in the London area; none of the patient representatives had undergone treatment for osteoarthritis of the knee themselves), three GPs, three orthopaedic surgeons, one nurse specialist, one physiotherapist and one public health consultant].

In the preparatory phase, two clinicians (a GP and an orthopaedic surgeon) supported the research team to identify areas of uncertainty that required reviews of the literature. The team also carried out a review of existing clinical guidelines for the management of osteoarthritis of the knee.

At its first meeting, the guideline development group defined key concepts: osteoarthritis of the knee, the referral decision and the concept of an appropriate referral (see Table 1). The research team presented the results of evidence reviews on three topics:

TABLE 1 *Definition of key concepts of the referral process for patients with osteoarthritis of the knee*

| | |
|----------------------------|---|
| Osteoarthritis of the knee | Patients are considered to have osteoarthritis of the knee if they are aged ≥ 50 years and have chronic knee pain that worsens with use and is not caused by rheumatoid arthritis. |
| Referral decision | Referrals from a GP to a health care professional who is in a position to put patients on the waiting list for knee replacement. This professional can be an orthopaedic surgeon, an orthopaedic nurse specialist or a physiotherapist. |
| Appropriate referral | A referral is appropriate if it is likely to be beneficial to a patient, given the best available research evidence as well as the patient's preferences. |

predictors of outcome after knee replacement that can readily be evaluated in primary care, existing guidelines on non-surgical and non-pharmacological interventions for patients with osteoarthritis of the knee (the NICE osteoarthritis guideline had not been published at that time) and mortality and its risk factors after knee replacement surgery. Four additional topics were identified: role of an X-ray of the knee, patient satisfaction after knee replacement, revision rates after primary knee replacement and age and sex-specific mortality according to the National Joint Registry.⁶ Subsequent rapid reviews were carried out on these topics.

After the first meeting, we drafted 12 recommendations for good primary care practice based on the group's informal views. We also designed case scenarios based on five patient characteristics presented: age, symptom severity, body mass, co-morbidity and patients' preference for referral (see Table 2 and Box 1). The number of possible combinations amounted to 108.

A questionnaire was mailed to the members of the guideline development group asking them to rate their agreement with the 12 recommendations for primary care as well as with the appropriateness of referral of patients described in the 108 case scenarios (see Supplementary appendix in the supplementary material online). Agreement was scored on a scale of 1 (strongly disagree) to 9 (strongly agree).

At the second meeting of the guideline development group, graphical representations of the distribution of the members' ratings were presented. Following discussions of each rating, the group members had the opportunity to rescore their personal views. During this process, a number of practice recommendations were modified to clarify any perceived ambiguities and subsequently rescored.

We based our definition of consensus on the 'strict' definition in the RAND approach.⁷ Ratings of 1–3 were considered as indicating 'disagreement', rating of 4–6 as 'equivocal' and ratings of 7–9 as indicating 'agreement'. Four levels of consensus were established: 'unanimous' consensus (12 out of 12 group members have ratings in one of the three ranges), 'strong' consensus (11 out of 12), 'moderate' consensus (10 out of 12) and 'weak' consensus (9 out of 12). When ratings were considered for a series of case scenarios at the same time, we used the corresponding percentages to determine the level of consensus. In other words, we considered that consensus was unanimous if 100% (corresponding to 12 out of 12) of the ratings were in one of the three ranges, strong if $>92\%$ (corresponding to 11 out of 12) but $<100\%$ were in one of the ranges and so on.

To investigate the effects of patient characteristics on the appropriateness of referral, we compared means of ratings for each level of the characteristics.

TABLE 3 *Recommendations for good primary care practice*

| Recommendations for good primary care practice | Level of consensus | Distribution of ratings (%) ^a | | |
|---|---------------------|--|-----|-----------------|
| | | ≤3 | 4-6 | ≥7 ^b |
| In patients with suspected osteoarthritis of the knee, a clinical assessment that includes both a medical history and a physical examination should be used by GPs to ascertain that the experienced knee pain is not originating from elsewhere in the body (such as the back or hip). | Unanimous in favour | 0 | 0 | 100 |
| Non-specialist GPs should have the results of an X-ray (weight-bearing, AP view) of the knee for patients with osteoarthritis of the knee when making the referral decision. | Weak against | 75 | 8 | 17 |
| A patient with osteoarthritis of the knee should only be referred if non-surgical and non-pharmacological interventions, in addition to conservative management, have not sufficiently improved the limited daily activities. | No consensus | 8 | 33 | 58 |
| Co-morbidities that increase the risk of perioperative and post-operative complications should be reversed or stabilized as soon as the decision is made to refer a patient with osteoarthritis of the knee. | Strong in favour | 0 | 8 | 92 |
| Patients with osteoarthritis of the knee who are smokers and are considered for referral should be advised to stop smoking. | Strong in favour | 0 | 8 | 92 |
| Patients with osteoarthritis of the knee who are smokers and are considered for referral should be advised to participate in a smoking cessation programme. | Weak in favour | 0 | 25 | 75 |
| Patients with osteoarthritis of the knee who are obese and are considered for referral should be advised to lose weight. | Strong in favour | 0 | 8 | 92 |
| Patients with osteoarthritis of the knee who are obese and are considered for referral should be advised to participate in a weight loss programme. | Moderate in favour | 0 | 17 | 83 |
| Patients with osteoarthritis of the knee considering referral should be informed about the likely outcomes after the surgical procedure as much as possible, while taking their individual condition and circumstances into account. | Moderate in favour | 0 | 17 | 83 |
| Patients with osteoarthritis of the knee considering referral should be informed about the risk of mortality following the surgical procedure. | Moderate in favour | 8 | 8 | 83 |
| Patients with osteoarthritis of the knee considering referral should be informed about health-related quality of life following the surgical procedure. | Weak in favour | 0 | 25 | 75 |
| Patients with osteoarthritis of the knee considering referral should be informed about satisfaction of patients who have undergone the surgical procedure. | Moderate in favour | 8 | 8 | 83 |

^a*n* = 12.^bScale ranging from 1 ('strongly disagree') to 9 ('strongly agree').

During the group's discussions, it became clear that an important factor underlying the lack of consensus on the appropriateness of referral for patients with mild symptoms and a strong preference in favour of referral was that some group members felt that these patients may benefit from receiving information about knee replacement surgery from a specialist, whereas others took the view that GPs should be equally competent to provide this information. Moreover, a lack of consensus for patients with severe symptoms and a strong preference against referral was due to some group members proposing that these patients might benefit from referral as they believed a surgeon could persuade them of the benefits of surgery.

Discussion

The guideline development group reached consensus as to the appropriateness of referral for patients with severe knee symptoms who want to be referred and the inappropriateness of referral for patients with mild symptoms and either no or a strong preference against referral (see Box 2). The scope of this guideline is the decision to refer a patient to a specialist service for assessment rather than the decision about appropriateness of surgical treatment. Decisions about surgical treatment require specialist knowledge and should acknowledge a gradual shift towards less invasive procedures.

These results demonstrate for the first time the relative weight given to the referral preference of patients in conjunction to the severity of their symptoms. In

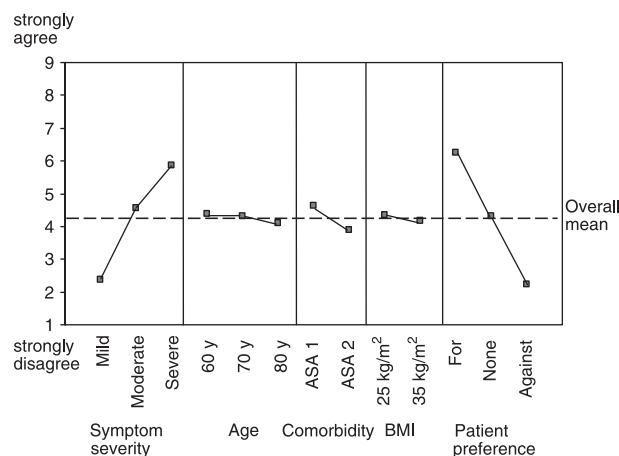


FIGURE 1 Mean rating of referral appropriateness for each level of the patient characteristics

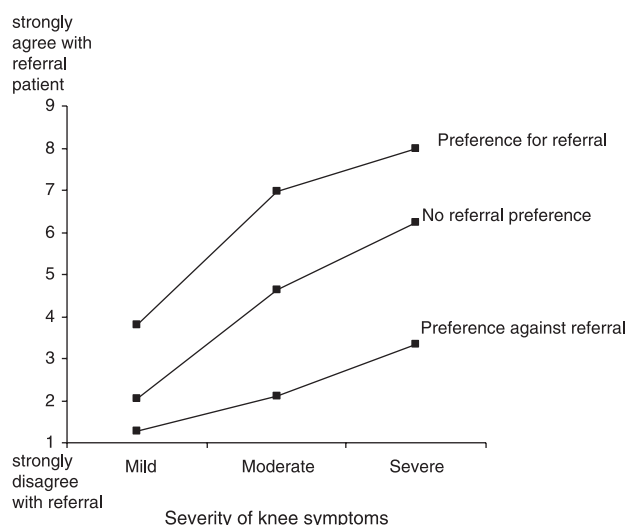


FIGURE 2 Mean rating of referral appropriateness according to symptom severity and referral preference

this way, they reflect how the guideline development group juggled with a number of key principles of 'evidence-based patient choice'.¹⁷ Firstly, the guideline development group demonstrated a strong commitment to the principle of 'patient autonomy'. This commitment became especially apparent during discussions of case scenarios describing patients with mild symptoms but with strong preference for referral or patients with severe symptoms with strong preference against referral. Secondly, arguments related to 'patient benefit' were often mentioned. For example, a number of guideline group members felt that the risk of surgery (including post-operative mortality, thromboembolic events, infections of the prosthesis, poor functional results and need for revision surgery) outweighs the benefit of knee replacement in patients with mild symptoms. Thirdly, referrals of patients with mild symptoms were by some members considered to

Box 2 Referral guideline for patients with osteoarthritis of the knee

Patients should be referred if they have severe knee symptoms and have a strong preference in favour of referral. Patients should not be referred if they have mild knee symptoms and have a strong preference against referral or no referral preference either way. For all other patient groups, defined according to symptom severity and referral preference, there was no consensus with regard referral. Age, co-morbidity and body mass do not affect the appropriateness of referral.

The referral guideline should be interpreted in the light of following recommendations for good clinical practice: GPs should take a detailed medical history and carry out a physical examination to verify the origins of the knee pain. Results of a knee X-ray need not to be considered. GPs should attempt to reverse surgical risk factors, such as smoking and obesity. GPs should provide information about the expected outcome of knee replacement surgery.

TABLE 4 Recommendations for appropriateness of referral

| Severity of symptoms | Patients' preference | Level of consensus on appropriateness of referral | Distribution of appropriateness ratings (%) ^a | | |
|----------------------|----------------------|---|--|-----|-----------------|
| | | | ≤3 | 4-6 | ≥7 ^b |
| Mild | For referral | No consensus | 51 | 36 | 13 |
| | No preference | Moderate against | 88 | 8 | 4 |
| | Against referral | Strong against | 99 | 1 | 0 |
| Moderate | For referral | No consensus | 2 | 33 | 65 |
| | No preference | No consensus | 32 | 49 | 19 |
| | Against referral | Moderate against | 90 | 7 | 3 |
| Severe | For referral | Moderate in favour | 1 | 9 | 90 |
| | No preference | No consensus | 11 | 43 | 46 |
| | Against referral | No consensus | 61 | 26 | 13 |

^an = 144 (12 guideline development group members × 12 scenarios).

^bScale ranging from 1 ('strongly disagree') to 9 ('strongly agree').

be an 'inefficient use of limited resources' given that it is unlikely that the referral will lead to a surgical intervention or other forms of specialist treatment. Others, however, argued when discussing this issue that a referral to an orthopaedic surgeon might help patients with mild symptoms but with strong preference for referral because these patients might need a consultation with a specialist before they accept that surgical treatment might not be beneficial.

The outcome of this juggling act was that the impact of patients' preferences on the ratings of referral appropriateness was on average smaller in patients with mild symptoms than in those with severe symptoms. In other words, the guideline development group assigned a greater value to avoiding inefficient resource use in patients who were least likely to benefit from referral and a greater value to respecting patient autonomy in patients who are most likely to benefit from surgery.

Methodological limitations

The group consisted of 12 members, a group size which is often recommended.^{18–19} Inevitably, the number representing each stakeholder group was small, limiting our ability to compare stakeholders' views.

Also, the results may have been unduly influenced by the opinions of individual members. To investigate the extent to which judgements were representative, we mailed a questionnaire containing nine simplified case scenarios to wider groups of patients (who had responded to an advert), GPs (who were randomly selected within 10 PCTs) and orthopaedic surgeons (who were randomly selected from the membership list of the British Orthopaedic Association). The results were similar to the results observed within the guideline development group, confirming the referral guideline's overall representativeness (results not shown).

The guideline development group members were asked to take the resources currently available in the English National Health Service into account. However, they were not presented with explicit evidence on the cost effectiveness of the different management options for two reasons. Firstly, the group felt that explicit economic evidence was only relevant if it contained an analysis of the cost effectiveness of referral from a societal perspective, in other words, including indirect costs including time off work as well as the costs of extra care needed for patients with severe symptoms. Such an analysis, which would need to include all treatment options available with and without referral as well as all their expected outcomes, was considered to be outside the scope of the current project. Secondly, a recent experimental study suggested that context factors related to the availability of resources have only a limited effect on the outcomes of consensus development.²⁰

Comparison with other studies

Our referral guideline for patients with osteoarthritis differs fundamentally from the referral advice published by NICE; in that, it explicitly considers the referral preferences of patients alongside a number of clinical characteristics.² Another difference is that we produced consensus about the appropriateness of referral for a number of individual patient profiles, whereas the NICE guideline only includes a number of general recommendations. Despite these differences in approach, the recommendations are similar. Both highlight the severity of the patient's symptoms and warn against the use of age, co-morbidity and body mass.

A study carried out in the UK that sought to explore the views of patients on a waiting list for joint replacement also found that pain and disability were mentioned as the factors that should determine priority for knee replacement.²¹ However, in this study, patients felt that other factors such as how long patients had their symptoms and whether there was a chance that they would return to work should contribute. Such factors were briefly discussed during the first meeting of the guideline development group but none were included in the case scenarios.

Previous consensus development concluded that the appropriateness of referral and knee replacement depends strongly on the severity of symptoms.^{22,23} Similarly, a Spanish study found that severity of symptoms was a dominant factor, but in this case, the appropriateness ratings were also influenced by the age of the patient and the presence of severe radiological abnormalities.²⁴ However, none of these previous studies explicitly considered patients' preferences.

In a related project to be reported elsewhere, we developed referral recommendations for patients with uncomplicated lower urinary tract symptoms. Its results correspond closely to those reported in this paper for osteoarthritis of the knee: the ratings of referral appropriateness depended only on symptom severity and patients' referral preferences. Furthermore, we found a significant interaction between these two factors, demonstrating again the complexity of the underlying decision-making processes.

Implications

These results confirm that within primary care, there is a 'gap between abstract ethical principles and practice'.²⁵ There are clear tensions between the GPs' role of patient advocate, which makes them responsive to patients' preferences and that of gatekeeper, which makes them accountable to the wider population for the efficient use of resources and demand management. Although there are no simple solutions if explicit referral procedures are to be implemented, they can only be sensibly developed if the potentially contradictory interests of individual patients and that of society in general are addressed. The musculoskeletal services framework

published by the Department of Health in 2006 seeks to improve the quality of referral and to control the number of patients referred to hospital by developing integrated care pathways and setting up intermediary multidisciplinary clinical assessment and treatment services.²⁶ The detailed advice in this framework about how to set up a clinical assessment, however, does not acknowledge that patients may have different preferences about where and by whom they will be treated.

A recent study has shown that the willingness of patients with osteoarthritis to undergo surgery is changing as a result of their accommodation to pain and disability, a phenomenon sometimes called 'the moving target'.²⁷ A further conclusion of that study was that a quantitative approach is unlikely to be able to capture the range of factors that many patients take into account. As a result, GPs and others who are responsible for referral decisions in primary care need to be prepared to explore, understand and respond to the specific individual circumstances and views of individual patients.

Supplementary material

Supplementary appendix is available at *Family Practice* online (<http://fampra.oupjournals.org/>).

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Author's contribution: AC, JHvdM, NB and NM designed the study. MU and AWMcC provided clinical expertise on osteoarthritis of the knee, supported the literature reviews and participated in the guideline development. NM and JHvdM carried out the literature review, organized the consensus meetings and analysed the data. NM and JHvdM wrote the paper with input from all authors. JHvdM is the guarantor.

Declaration

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Conflict of interest: MU was a member of the group that developed the NICE guideline for osteoarthritis.

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