Developing primary palliative care

Continuity of care is paramount but needs to be tailored individually

Editor—Riley suggests that completion of a form detailing palliative care management should be mandatory for general practitioners. I have spent a great deal of time promoting palliative medicine in primary care, with variable success. Much depends on the individual practitioner’s experience and interest, which probably accounts for the variable success of handover forms to communicate with out of hours services.

Making this a compulsory part of general practice might bring all practice to the same level. But the initial answer to the question, “Would I be surprised if my patient died in the next 12 months?” would then make the difference. Cynical practitioners would probably answer no for nearly all of their patients, for the longer you practise the less often you are surprised.

But, in truth, for many patients in general practice the answer to this question would be no: many elderly patients who live in nursing or residential homes, nearly all patients with chronic disease, including heart disease, chronic obstructive pulmonary disease, neurological disease, and so on. The workload in handing these patients over to the out of hours service would be huge, more so for the out of hours service than the individual practice.

Continuity of care for patients who most need it is paramount, including all those with chronic disease. However, more sophisticated systems are needed to meet patient needs: perhaps different systems for different diseases, possibly different systems for each stage of a disease. Whatever the system, it must meet the needs of the individual patient. This entails dialogue between primary care (including out of hours), secondary care, and tertiary care to thrash out the detail.

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Competing interests: None declared.

Primary palliative care services must be better funded by both day and night

Editor—Guthrie’s response to our editorial of 6 November on developing primary palliative care is helpful in pointing out that the new out of hours organisations are now responsible for three quarters of the week’s on call hours, while primary care teams working during the day are responsible for only a quarter. This of course means that general practitioners and district nurses working out of hours will often attend people dying at home.

Unfortunately such busy organisations are often extremely stretched to deal with the diverse out of hours workload, and hand over forms for identifying patients receiving palliative care who could deteriorate in the short term are in our experience rarely in place. Progress is being made by some practices which routinely notify NHS24 in Scotland or NHS Direct in England of such patients, as recommended, for instance, in the gold standards framework.

We do not yet know what effect the new call centre triaging and accompanying out of hours arrangements will have on helping patients to die at home if they so wish. Care by call centres can be problematic and perceived as impersonal. This underscores the urgent need to develop plans for providing 24 hour care for dying people.

As out of hours services continue to evolve, the attempt to meet the last wishes of patients, many of whom would like to die at home if they could, must not be lost sight of. This means, as Guthrie highlights, that more community nurses and social support need to be available out of hours. Ways of targeting additional support at home for those with particularly complex needs should be explored, with community providers being encouraged to make greater use of the out of hours advice available from specialist palliative care services. Otherwise, as Levack et al suggest, only those with the fewest symptoms and greatest personal resources will be able to die at home.1

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Specialist palliative care in dementia

Patients with dementia are unable to access appropriate palliative care

Editor—Hughes et al suggest that specialised units with outreach and liaison are needed for palliative care of patients with dementia.1 The United States has taken a much more holistic approach than the United Kingdom in this area. Although several papers have been published over the past few years that highlight the need for palliative care for such patients,1 little more than lip service is paid to this group of patients. In our experience, even if patients with dementia develop advanced cancer they are seldom admitted to specialist palliative care units, and palliative care teams are only too ready to declare such patients as having no specialist needs or not being appropriate for their service.

Evidence shows that where psychiatry and palliative care teams collaborate well, appropriate palliative care can be delivered to patients with advanced dementia wherever they may be located.2 The need for bereavement care for relatives where social death occurs many months or years before the physical death must also be included.

We advocate Hughes et al’s suggestion that through outreach and liaison, palliative care for people with dementia can be delivered in the community, including in nursing and residential homes. Palliative care services need to look beyond cancer. Patients with dementia and their families have a high symptom burden and all too often are not offered or provided with the care they require.

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Home based palliative care is important in developing countries . . .

Editor—The issues raised by Hughes et al are particularly relevant to dementia care in settings with limited resources.1 Home based interventions based on principles of palliative care can provide help to people with dementia in low income countries. But control of symptoms can prove to be difficult when behavioural and psychological symptoms of dementia are present. Unless these symptoms are identified, caregivers could misinterpret them as deliberate misbehaviour.2 Incontinence of bowel and bladder and impairment in other activities of daily living also need special attention.

Broadening the scope of palliative care services to meet the needs of people with dementia would be a welcome step, particularly in developing regions of the world. India’s 10/66 dementia research group has developed a community based intervention programme that uses trained community health workers to identify people with dementia and deliver simple community based interventions in the community.3 This training programme takes into consideration the specific needs of dementia care while adhering to the general principles of palliative care.4

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Competing interests: None declared.


. . . and hope for terminal care at home is needed in developed countries

Editor—Good quality care for advanced dementia is right and laudable and should be supported. However, we echo the view of Sivaraman (above) that home based palliative care of dementia is important and badly needed in the developed world as well as the developing world. We think that the methods required will also be quite different for cancer care.

We have been developing and pioneering skills around managing people with advanced dementia at home for several years. This is a welcome initiative for carers and has produced some excellent feedback from carers and also good observational data for patients. The skills required are diverse and certainly bear little resemblance to any one discipline. Antipsychotic and antidepressant drugs remain important, but physical care, aids, mobility, bowel care, pressure care, and other symptom control are essential components.

The assumption in the editorial by Hughes et al that pain relief is central is worrying.1 This seems to be simple transference of the issue of pain in cancer care. We have seen severely ill and behaviourally disturbed patients with dementia nearly die from low doses of opiates, and pain relief may not necessarily be required in such cases very often. Palliative care teams have helped in the work we have been doing, but not often in a central way.

We would therefore caution against translating too many of the lessons of cancer care into dementia care. A strong similarity with cancer care should be the opportunity to think about terminal care occurring at home when possible. However, the situations are not the same, and the expertise required for the care of advanced dementia has several aspects making it substantially different from cancer care.

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Managing osteoarthritis of the knee

Conclusions about use of NSAIDs are misleading

Editor—The meta-analysis by Bjordal et al of randomised controlled trials assessing the efficacy of non-steroidal anti-inflammatory drugs (NSAIDs) in osteoarthritic knee pain is technically well done, but the authors’ conclusions are misleading.1 They assert that the mean change in pain, as measured on a visual analogue scale, over placebo was 10.1 mm (95% confidence interval 7.4 to 12.8) and claim a non-relevant difference, since the minimal clinically perceptible difference was 9.7 mm.

They mixed up the interpretations at group and individual levels. Indeed, 9.7 is the perceptible difference at the individual level (a change lower than 9.7 mm would not be perceived by the patient). However, the 10.1 mm estimate assessed by Bjordal et al makes sense only at the group level. To understand this multilevel interpretation better, we performed some calculations, classifying patients as improved or not if they achieved a change greater than 10.1 mm. Thus, hypothesising that in the placebo group, the change equals 5±20 mm, 40.1% of the placebo group patients would show improvement (under the reasonable assumption of a normal distribution of change in pain on a visual analogue scale). A treatment effect of 10.1 mm leads to a mean change of 15.1 mm in the experimental group, and 60.1% of patients would therefore show improvement. The number of patients needed to treat is then estimated at 5.0, the same way, if the placebo group was 20±20 mm, 69.2% of patients would show improvement in this group and 84.3% in the experimental group, and the number needed to treat would then be 6.6. These examples show that using the minimal clinically perceptible difference to interpret changes at the group level is inadequate: a small variation at the group level does not mean no clinically relevant change in the individuals of the group.

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Competing interests: None declared.


Authors’ reply

Editor—Tubach et al say that we misinterpret data by confusing group responses and individual responses. They present hypothetical calculations that supposedly show a number needed to treat of 5-6.6 for non-steroidal anti-inflammatory drugs (NSAIDs) in osteoarthritic knee pain.

Their calculations are based on a weighted mean difference of 10.1 mm on a visual analogue scale from our analysis. However, we showed that this group response value was inflated by patient selection bias in a subgroup of trials. When this subgroup of bias was excluded, the meta-analysis in our paper, the unbiased weighted mean difference fell to 5.9 mm (3.8 to 7.9).

As a benchmark for response, Tubach et al have selected what the inventors termed the “minimally perceptible difference” at 9.7 mm on the visual analogue scale.1 A more clinically relevant benchmark in knee osteoarthritis would be the “minimal clinically important difference,” which corresponds to 19.9 mm on the scale.2 Using the unbiased weighted mean difference and the latter benchmark for treatment success, the required number needed to treat is in the 9-20 range.

Tubach et al make a point of the fact that the occasional patient may experience benefit from NSAID treatment. In our view, it seems more relevant to question if patients should be put at jeopardy for adverse effects from oral NSAIDs when only a few of them are likely to notice if their NSAID is replaced by a placebo.

We stand by our conclusion that there is a lack of evidence for clinically relevant
Opioids help manage pain in osteoarthritis

Editor—MacAuley raises an important point about the poor long term management of pain in osteoarthritis of the knee.1 A recent survey carried out by Arthritis Care to assess the impact of osteoarthritis on patients showed that 81% of the sample said they experience constant pain and that when their osteoarthritis is bad, 69% have difficulty carrying out even the simplest of daily household tasks. Exercise is undoubtedly of benefit to patients with mild to moderate osteoarthritis, so the priority of healthcare professionals should be the symptomatic relief of chronic pain. Along with paracetamol and non-steroidal anti-inflammatory drugs there is further ammunition for pain relief. Opioids can and should be considered in these patients. As stated by the Pain Society,2 the primary effect of the appropriate use of opioids in chronic pain is analgesia that leads to improved function, sleep, and reduced distress. Their use may also result in reduced use of other analgesics.

With improved education of healthcare professionals and the patient, opioid treatment can be initiated and managed in primary care through developing an individualised treatment plan in discussion with the patient. Doctors in general practice should therefore recognise that appropriate prescribing of opioids can offer a substantial improvement in a patient’s quality of life.

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Competing interests: MJ has carried out consultancy work with Napp Pharmaceuticals, Pfizer, Janssen-Cilag.


United Kingdom back pain exercise and manipulation (UK BEAM) trial

Touch may have had non-specific effect, among other things

Editor—I have three brief comments on the United Kingdom back pain exercise and manipulation (UK BEAM) trial.3

Firstly, the data are compatible with a non-specific effect caused by the presence of the investigators. This has a significantly positive effect on back pain which can be enhanced by touch. If this “devil’s advocate” view is correct, the effects have little to do with spinal manipulation itself.

Secondly, which of the three professional groups (chiropractors, osteopaths, physiotherapists) generated the largest effect size is relevant. This might significantly influence the referral pattern. A post-hoc analysis might answer this question.

Lastly, the study monitored only serious adverse effects. Data show that minor
adverse effects occur in about 50% of patients after spinal manipulation. Such adverse effects might then also influence general practitioners’ referrals.

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Competing interests: None declared.

1 UK BEAM Trial Team. United Kingdom back pain exercise and manipulation (UK BEAM) randomised trial: effectiveness of physical treatments for back pain in primary care. BMJ 2004;329:1577-81. (11 December.)


What happened to participants who were not included in analysis?

Editor—The UK BEAM Trial Team has produced a broad piece of research that has attempted to answer many questions about managing chronic back pain all at the same time. However, I find it difficult to understand how any conclusions can be drawn from the published results if 25% of the study population were not included in the analysis (25% at three months and 26% at 12 months). Knowing what happened to these participants would be helpful because any conclusions drawn from the remaining data without an intention to treat analysis severely weaken what is a brave piece of research.

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1 UK BEAM Trial Team. United Kingdom back pain exercise and manipulation (UK BEAM) randomised trial: effectiveness of physical treatments for back pain in primary care. BMJ 2004;329:1577-81. (11 December.)

Is manipulation the most cost effective addition to “best care”?

Editor—We are surprised by the conclusions of the two papers by the UK BEAM Trial Team. The authors compared three interventions: manipulation, exercise, and the combination of manipulation and exercise, with a recently published European guideline for treatment of chronic low back pain (www.backpain-europe.org) the trial is rated as of high quality. However, the treatment effects are small, and they are not clinically significant.

Surprisingly, there are no comparisons between the treatments. So far as we can tell from the information given in the papers, simple Student’s t-tests do not show any significant differences between exercise and manipulation on Roland Morris or the physical component scale of the SF-36. The only significant difference is on the mental component scale of the SF-36: manipulation being significantly better than exercise at three months.

It is, therefore, difficult to follow why the authors claim that chronic manipulation is a cost effective addition to “best care” for back pain in general practice, and that manipulation alone may give better value for money than manipulation followed by exercise.

As we understand the papers, manipulation and best care were of equal benefit regarding clinical significance (Roland Morris), and there was no significant difference between exercise and manipulation (Roland Morris and SF-36 physical component).

Given that there is no clinical effect, we would expect that the least expensive treatment would be recommended. If any treatment should be added on to best care, we think that exercise would be the better choice because of all the other health benefits.

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1 UK BEAM Trial Team. United Kingdom back pain exercise and manipulation (UK BEAM) randomised trial: effectiveness of physical treatments for back pain in primary care. BMJ 2004;329:1577-81. (11 December.)

2 UK BEAM Trial Team. United Kingdom back pain exercise and manipulation (UK BEAM) randomised trial: cost effectiveness of physical treatments for back pain in primary care. BMJ 2004;329:1581-5. (11 December.)


Manipulation alone costs more than other options so why is it recommended?

Editor—It is not clear why the UK Beam Trial Team recommends manipulation alone for back pain because it costs more per quality adjusted life year (QALY) than exercise and manipulation combined and even slightly more than exercise alone. The average effect of exercise and manipulation combined is also larger than the other two in absolute terms.

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Competing interests: None declared.

1 UK BEAM Trial Team. United Kingdom back pain exercise and manipulation (UK BEAM) randomised trial: cost effectiveness of physical treatments for back pain in primary care. BMJ 2004;329:1581-5. (11 December.)

Authors’ reply

Editor—Ernst is correct that the beneficial effects UK BEAM found for manipulation could be a non-specific effect. This was a pragmatic study testing a package of manipulative treatment, not an explanatory study seeking to assess the effect of manipulation itself.

All the manipulation practitioners used a common treatment package agreed by the three professional groups. Any comparisons between the professions would be underpowered and, because participants were allocated to therapists nearest their home, non-randomised. Such a comparison was specifically predefined when the professions agreed to the treatment package.

Ernst’s data do not support the assertion that adverse effects occur after 50% of spinal manipulations. Any such effects are usually minor and short lived. Set against the positive effect of being able to do one more daily activity one year later we would not expect this to influence general practitioners’ referral decisions.

Tillett is concerned about our follow up rate. For a large nationwide trial of this nature it was, if anything, better than might be expected. Since the characteristics of those lost to follow up were consistent across all randomised groups, and the largest difference in follow up rates between treatment and control groups was only 4.1%, little risk of bias exists. Our sensitivity analysis, using the last observation carried forward, does not change our findings.

Tveito and Eriksen argue that we should recommend adding exercise to “best care” even though exercise did not produce a statistically significant benefit at one year and its overall cost is greater than either manipulation or best care. Our data do not support the premise that manipulation and exercise are equally effective. The average benefits of the BEAM interventions for individual patients are small. However, at a population level, our manipulation or combined packages produce an overall benefit at modest cost, as other healthcare users fell during the following year.

Church is unclear on our health economic conclusions. We are not recommending manipulation as the only treatment option. Instead we are saying that the UK BEAM manipulation package is the best strategy should the decision maker be willing to pay £8700 or more for each additional quality adjusted life year (QALY). If a decision maker is willing to pay > £3800 and < £8700 per additional QALY, combined treatment is the best strategy. When the decision maker is willing to pay < £3800 per QALY general practitioner care is the best strategy.

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Competing interests: MU has received a salary from the MRC and fees for speaking from Menarini Pharmaceuticals, the manufacturers of desloratadine and ketoprofen, and Pfizer, the manufacturers of celecoxib and valdecoxib.


2 Ernst E. Prospective Investigation into the safety of spinal manipulation. Journal of Pain and Symptom Management 2002;24:417-29.