Developing primary palliative care

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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.

Paul A Fox general practitioner
Stanley Health Centre, Wakefield WF3 4BH
Paulfox@aol.com
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.

Scott A Murray clinical reader
Scott.Murray@ed.ac.uk

Kirsty Boyd honorary senior lecturer
Aziz Sheikh professor of primary care research and development
Primary Palliative Care Research Group, Division of Community Health Sciences: General Practice Section, University of Edinburgh, Edinburgh EH8 9DX

Competing interests: None declared.

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. 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, 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. 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.

Mari Lloyd-Williams professor
Division of Primary Care, School of Population, Community and Behavioural Sciences, University of Liverpool, Liverpool L69 3GB
mhw@liverpool.ac.uk

Sheila Payne professor
School of Nursing, University of Sheffield, Sheffield S3 7ND

Mick Dennis senior lecturer
Academic Department of Psychiatry for the Elderly, Leicestere General Hospital, Leicester LE5 5PG

Competing interests: None declared.

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.3 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.1 This training programme takes into consideration the specific needs of dementia care while adhering to the general principles of palliative care.

Shaji K Sivaraman assistant professor of psychiatry Medical College, Thrissur-680596, India shajiks@vsnl.com

Competing interests: None declared.

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.

B Florence Tubach assistant professor of epidemiology Florence.tubach@bch.ap-hop-paris.fr
P Ravaud professor of epidemiology INSERM U758; Groupe Hospitalier Bichat-Claude Bernard (Assistance Publique—Hôpitaux de Paris), Faculté Xavier Bichat (Université Paris 7), 46 rue Henri Fuchard, 75018 Paris, France
B Giraudoux assistant professor of biostatistics INSERM CIC 202, Faculté de Médecine, 2 bis Bd Tonnelle, 37032 Tours, France

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 5.66 for non-steroidal anti-inflammatory drugs (NSAIDs) in osteoarthritis of the knee. 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 corrected, the difference in our analysis in the 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 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 responding 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
effects from oral NSAIDS in knee osteoarthritis pain.

Jan M Bjordal research fellow Janbjordal@hib.no
Anne Elisabeth Ljunggren professor Ate Klouning associate professor
Department of Public Health and Primary Health Care, University of Bergen, 5018 Bergen, Norway
Lars Sleråd professor Department of Laboratory Medicine, Children’s and Women’s Health, Norwegian University of Science and Technology, 7489 Trondheim, Norway

Competing interests: None declared.

2 Tubach F, Raouf P, Barou C, Falmign H, Logeart I, Lars Slørdal. Community Sports 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 walking aids, footwear and pain relief techniques including acupuncture and steroid injections.

The new cohort of NHS physiotherapy practitioners with extended scope can independently assess, treat, and improve appropriate referral of orthopaedic consultants. A physiotherapist may be a highly appropriate lead musculoskeletal specialist in primary care, providing a functional approach to treatment to minimise disability for people with osteoarthritis of the knee and overall offering far more in a consultation than the average general practitioner.

The large community disability burden and high knee pain referral rates to orthopaedic specialists, warrant intervention at a population level and an integrated care pathway for osteoarthritis of the knee. Primary care trusts are in an ideal position to develop expert initiatives for patients, encourage the use of community sports facilities, and promote the work of voluntary bodies such as the Arthritis Research Campaign, which provide excellent patient information and professional education resources.

Caroline A Mitchell general practitioner Woodhouse Medical Centre, Sheffield S13 7LY Camitchell@sheffield.ac.uk
Ade Adehajo consultant rheumatologist Barnsley District General Hospital, Barnsley S75 2ED

Competing interests: None declared.

3 Underwood MR. Community management of knee pain in older people: is knee pain the new back pain? Rheumato-


Glucosamine-chondroitin should be prescribed by doctors

Editor—In his editorial on the management of osteoarthritis of the knee MacAuley recommended glucosamine-chondroitin as an off prescription preparation. Can any-one explain why it is usually recommended so, despite evidence of efficacy that is as good or better than most non-steroidal anti-inflammatory drugs (NSAIDS), which cause a huge burden of morbidity and mortality? Yet NSAIDS, and cleverly marketed variations of the theme, continue to be licensed and adopted for NHS prescription for osteoarthritis, and I am sure will continue to do so despite the debacle surrounding the cyclo-oxygenase 2 inhibitors. Remember also benecaprofen 25 years ago.

Most patients with osteoarthritis will qualify for free prescriptions and are in the age group with least income flexibility. Most do not need surgery but are still suffering. I understand that glucosamine is prescribable, but rheumatologists and general practitioners seem to advise patients to buy their own—why? I fear that the background to this is the huge threat to NSAID sales that can be enhanced by touch. If this “dev-il’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

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.

Firstly, the data are compatible with a non-specific effect caused by a placebo effect which can be enhanced by touch. If this “dev-il’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.
adverse effects occur in about 50% of patients after spinal manipulation. Such adverse events might then also influence general practitioners' referrals.

Edward Ernst
director
Complementary Medicine, Peninsula Medical School, Exeter EX2 4NT
Edward.Ernest@prms.ac.uk

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.1 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.

Richard Tillett
senior primary care physiotherapist,
Musculoskeletal Physiotherapy, Blackdown Practice, Hemyock, Devon EX15 3SF

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.)

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.1,2 The authors compared three interventions: manipulation, exercise, and the combination of manipulation and exercise. They published European guidelines for treatment of chronic low back pain (www.backpaineurope.org) the trial is rated as of high quality.3 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 SF-36 physical component.4 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 have chosen to manipulate 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.

Toreil H Tveito
research fellow
Torill.Tveito@psych.uio.no

Hege R Eriksen
professor
Department of Biological and Medical Psychology, University of Bergen, Jonas Lievej 91, N-5009 Bergen, Norway

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.)
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.5 The average effect of exercise and manipulation combined is also larger than the other two in absolute terms.

Timothy R Church
associate professor
University of Minnesota, Minneapolis, MN 55455, USA
trc@cccs.umn.edu

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.)

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 precluded 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.6 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.

Titev 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.7 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 £8700 or more, combined treatment is the best strategy. When the decision maker is willing to pay £3800 and less, other healthcare use fell during the following year.

Martin Underwood
professor of general practice
Centre for General Practice and Primary Care, Institute of Community Health Sciences, Barts and the London, Queen Mary's School of Medicine and Dentistry, Queen Mary University of London, London E1 4NS
munderwood@qmul.ac.uk

On behalf of the UK BEAM Trial Team

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