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.1 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 practitioner.

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
PAFox@aad.com

Competing interests: None declared.

1 Riley J. Developing primary palliative care. BMJ 2005; 330:42. (1 January.)

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.2 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 NHSS24 in Scotland or NHS Direct in England of such patients, as recommended, for instance, in the gold standards framework.3

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.4 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,5 only those with the fewest symptoms and greatest personal resources will be able to die at home.6

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.

1 Guthrie CI. Developing primary palliative care. BMJ 2005; 330:42. (1 January.)

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.2 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,3 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.4 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
mbl@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, Leicester General Hospital, Leicester LE5 4PG

Competing interests: None declared.

1 Hughes JC, Robinson L, Volier L. Specialist palliative care in dementia. BMJ 2005;330:263. (1 January.)


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. 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-680506, India shajiks@vcl.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.3 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 change in 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.

**Florence Tubach assistant professor of epidemiology florence.tubach@bch.ap-hop-paris.fr**

P Ravault professor of epidemiology INSERM U758; Groupe Hospitalier Bichat-Claude Bernard (Assistance Publique—Hôpitaux de Paris); Faculté Xavier Bichat (Université Paris 7), 46 rue Henri Fruchard, 75018 Paris, France

B Girardeau assistant professor of biostatistics INSERM CIC 292, Faculté de Médecine, 2 bis Bd Tonnelle, 37032 Tours, France

Competing interests: None declared.


Authors’ reply

**Editor**—Tubach et al say that we misinterpreted 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 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 biased trials was removed from our analysis, 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 resulting 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

References


The article discusses the management of osteoarthritis of the knee in primary care. It highlights the chronic underinvestment in other evidence-based medicine and the dependence of health professionals on anti-inflammatory drugs in primary care. The article also addresses the role of holistic approaches in managing osteoarthritis, emphasizing patient-centered care and the importance of avoiding unnecessary procedures such as surgery. The article concludes with recommendations for the appropriate use of opioids in persistent non-cancer pain and the need for further research into the effects of different treatments on pain and function.
adverse effects occur in about 50% of patients after spinal manipulation. Such adverse effects might then also influence general practitioners’ referrals.

Edvard Ernst  director
Complementary Medicine, Peninsula Medical School, Exeter EX2 4NT
Edvard.Ernst@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. 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 20% 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 quite impressive piece of research.

Richard Tillett  senior primary care physiotherapist,
Maidenhead Primary Care Trial
Blackdown Practice, Henley, Devon EX15 3SF
Tillett@breathe.com

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. 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
tchurch@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.)

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, with only published European guidelines for treatment of chronic low back pain (www.worldbackpain.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 prefer 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.

Terri H Tveito  research fellow
Terri.Tveito@psychu.h.no
Hege R Eriksen  professor
Department of Biological and Medical Psychology, University of Bergen, Jonas Lieveit 91, N-5009 Bergen, Norway

Competing interests: None declared.

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

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Terri H Tveito  research fellow
Terri.Tveito@psychu.h.no
Hege R Eriksen  professor
Department of Biological and Medical Psychology, University of Bergen, Jonas Lieveit 91, N-5009 Bergen, Norway

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