What investigations and procedures do patients in hospices want? Interview based survey of patients and their nurses

Chantal J N Meystre, Neil M J Burley, Sam Ahmedzai

Leicestershire Hospice, Leicester LE3 9QE
Chantal J N Meystre, *senior registrar*
Neil M J Burley, *medical student*
Section of Palliative Medicine, Department of Surgical and Anaesthetic Sciences, University of Sheffield, Floor K, Royal Hallamshire Hospital, Sheffield S10 2JF
Sam Ahmedzai, *professor of palliative medicine*
Correspondence to: Dr Meystre.

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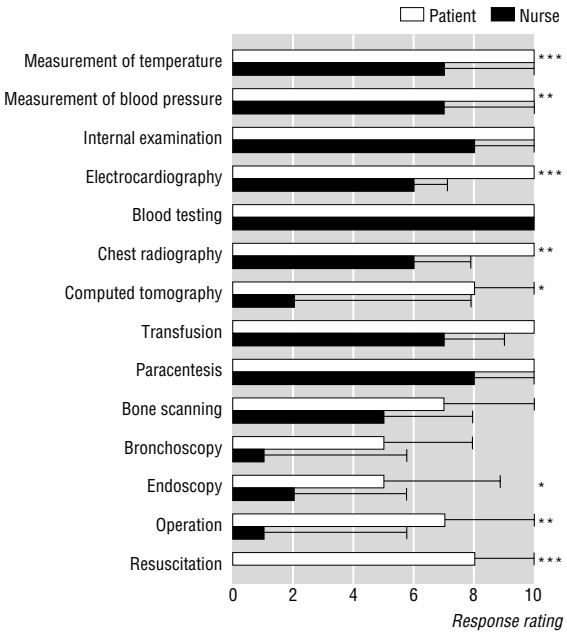
Slevin et al reported that patients with cancer were much more likely to opt for chemotherapy with minimal chance of benefit than were their professional carers and people without cancer.[1] They also said that attitudes changed dramatically once cancer had been diagnosed. We investigated the attitudes of terminally ill patients in our hospice towards investigations and invasive procedures and compared these with the attitudes of their nurses.

Subjects, methods, and results

Randomly selected inpatients with advanced cancer at our hospice and their key nurses took part in an interview based survey. Patients were asked about 14 procedures of increasing invasiveness. Travelling was mentioned when necessary. The questions were prefaced by: "If we thought it would help us improve your care would you want...?" Procedures ranged from having temperatures taken to having an operation, and the survey culminated in the question, "If your heart stopped unexpectedly would you want to be resuscitated?" Standard descriptions of all the tests and procedures were available.

Responses were rated 0-10 (0 = no, definitely not; 5 = don't mind; 10 = yes, definitely). The European Organisation for Research and Treatment of Cancer's questionnaire was administered to obtain concurrent quality of life data,[2] and patients were asked to assess their status on the World Health Organisation performance scale.[3] The nurses were asked how appropriate it would be to carry out these 14 investigations or procedures if they were thought necessary for the medical management of their patient. Responses were graded 0-10 (0 = inappropriate, 5 = no strong feeling either way, and 10 = appropriate). They were also asked to assess the patient's status on the WHO performance scale. Non-parametric statistics were used.

Twenty three patients (15 women; median age 67 (range 47-81) years) and 18 nurses completed the questionnaire. No nurse was interviewed more than twice. One patient became distressed during the interview. Patients were consistently more likely to accept investigations and invasive procedures than were nurses (figure). The greatest divergence of opinion was in relation to resuscitation: 12 patients but no nurses were in favour of the procedure. Patients' responses about intervention were unrelated to age, quality of life, disease stage, or self rated status on the WHO performance scale. Patients with a worse status on the performance scale were more reluctant to accept blood transfusions ($r_s = -0.44$, $P < 0.05$). The responses about resuscitation were independent of subscale scores for pain and for emotional, cognitive, and physical functioning on the European organisation's questionnaire.[2] Patients self assessed status on the performance scale and their score for global quality of life were significantly correlated ($r_s = -0.55$, $P < 0.01$), indicating decreasing quality of life with increasing disability. Patients' and nurses' scores on the performance scale agreed strongly (κ (unweighted) = 0.81, 95% confidence interval 0.61 to 1.01).



Acceptability of investigations and procedures to inpatients with advanced cancer (0=no, definitely not; 10=yes, definitely) compared with their nurses' opinion (0=inappropriate, 10=appropriate). Values are medians with upper quartile ranges. *P<0.05, **P<0.01, ***P<0.001 in Mann-Whitney U test

Comment

Even patients who are terminally ill are prepared to accept invasive procedures and treatments more readily than are their nurses. That this is not because nurses misinterpret the clinical state of patients is shown by the agreement in nurses' and patients' scores on the performance scale.

Hill et al found that patients' requests for resuscitation declined with increasing age,[4] but in our study acceptance of resuscitation was not related to age, quality of life, or score on the performance scale. Legal advice suggests that if patients request resuscitation it should be provided,[5] but whether patients in hospices would benefit from this is doubtful.

Our most important findings are those relating to patients' acceptance of procedures less dramatic than resuscitation. Care must be taken to ensure that the judgments and attitudes of staff are not denying patients the opportunity of simple tests or therapeutic interventions from which they may obtain clinical benefit.

The National Council for Hospice and Specialist Palliative Care Services with the Association for Palliative Medicine of Great

Britain and Ireland has recently published guidelines on artificial hydration and cardiopulmonary resuscitation for people who are terminally ill (*European Journal of Palliative Care* 1997;4(4):124, 125, 126-8 (discussion of guidelines)).

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1 Slevin ML, Stubbs L, Plant HJ, Wilson P, Gregory WM, Armes PJ. Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors, nurses, and general public. *BMJ* 1990;300:1458-60.

2 Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ. The European Organisation for Research and Treatment of Cancer QLQ-C30: a quality of life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85:365-76.

3 World Health Organisation. *WHO handbook for reporting results of cancer treatment.* Geneva: WHO, 1979.

4 Hill ME, MacQuillan G, Forsyth M, Heath DA. Cardiopulmonary resuscitation: who makes the decision? *BMJ* 1994;308:1677.

5 Morgan R, King D, Prajapati C, Rowe J. Views of elderly patients and their relatives on cardiopulmonary resuscitation. *BMJ* 1994;308:1677-8.

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Aseptic meningitis associated with high dose immunoglobulin: case report

Paul Picton, Morag Chisholm

Aseptic meningitis is a recognised complication of high dose intravenous immunoglobulin. We report a case of aseptic meningitis diagnosed on the basis of eosinophilia in cerebrospinal fluid.

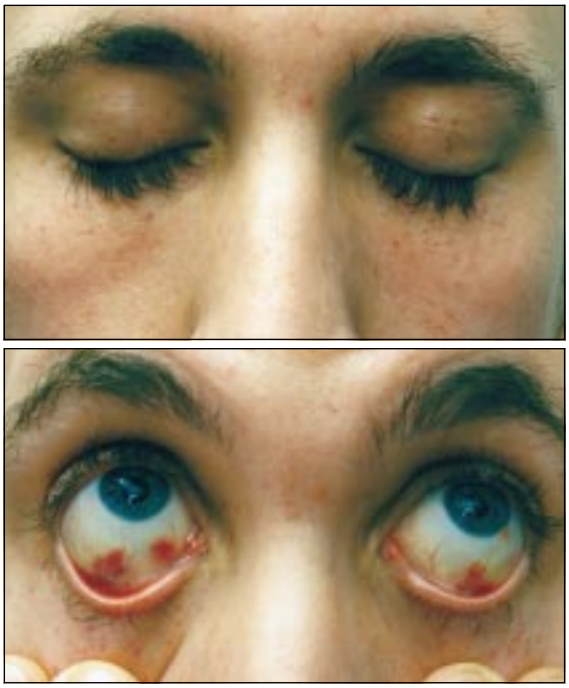
Case report

A 21 year old man with autoimmune thrombocytopenia was admitted with severe headache, photophobia, obvious neck stiffness, and vomiting. Symptoms began after taking high dose intravenous immunoglobulin for two days. This was his first exposure to intravenous immunoglobulin. On day 1 he received 24 g of immunoglobulin. On day 2 he received 60 g but complained of mild headache. He was given paracetamol and allowed home. He was admitted to hospital six hours later with worsening headache.

On examination he was drowsy and had a temperature of 37.4°C, a newly developed extensive purpuric rash, and bilateral subconjunctival haemorrhages (figure). The remainder of the examination gave normal results. The platelet count had not changed from pretreatment values (14×10^9/l), and a coagulation screen gave normal results. Lumbar puncture was delayed because he needed a platelet infusion to cover it, and intravenous cefotaxime was given in the meantime. His cerebrospinal fluid was clear and colourless and contained glucose 3.1 mmol/l (plasma glucose concentration 5.1 mmol/l), protein 0.54 g/l, and immunoglobulin 0.05 g/l. A chamber count showed 80 leucocytes/mm^3; no organisms were seen. Giemsa staining on a spun sample of cerebrospinal fluid revealed many disrupted and some intact eosinophils; a cell count (Cell-Dyn 3500 analyser, Abbott Diagnostics, CA) gave an absolute leucocyte count of 0.06×10^9/l and confirmed these were all eosinophils. The peripheral blood eosinophil count was normal (0.1×10^9/l). These findings excluded acute bacterial meningitis and supported the presence of aseptic meningitis secondary to immunoglobulin infusion. Antibiotic treatment was discontinued, and the patient recovered over the next 24 hours. Blood cultures, cerebrospinal fluid culture, throat swabs, and the polymerase chain reaction for meningococcal DNA all gave negative results.

Comment

High dose intravenous immunoglobulin is used for many conditions.[1] Common side effects include headache, fever, chills, and nausea; these usually resolve within an hour of stopping or slowing the infusion and respond to symptomatic treatment.[2] More serious effects are anaphylaxis, haemolysis, hepatitis, thrombosis, and aseptic meningitis.[3]



Purpuric rash and subconjunctival haemorrhages in patient with aseptic meningitis. Reproduced with patient's permission

Aseptic meningitis after high dose immunoglobulin has been reported in several conditions, including idiopathic thrombocytopenic purpura,[4] chronic inflammatory demyelinating polyneuropathy,[3] and other immune related neuromuscular diseases.[1] In two separate studies the incidence ranged from 11% to 17% of 137 patients. [1 4] At least six immunoglobulin preparations have been implicated.[2] Symptoms often develop after several courses, beginning six to 48 hours after infusion and clearing within three to five days. Corticosteroids are non-protective. Recurrent symptoms usually develop on rechallenge despite varying the rate of infusion, spreading the treatment over more days, or using different immunoglobulin products.[1]

Cerebrospinal fluid analysis commonly shows a leucocyte pleocytosis with raised protein and IgG con-

Department of Haematology, Southampton University Hospitals Trust, Southampton SO16 6YD

Paul Picton, *senior house officer in haematology*

Morag Chisholm, *senior lecturer in haematology*

Correspondence to: Dr Chisholm.

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