

Palliative care in your hospital

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ABSTRACT This thought-provoking symposium explored some of the issues related to the provision of palliative care within hospital settings. Session one focused on difficult symptoms – neuropathic pain, dyspnoea and malignant bone pain – and the new techniques and science that inform their management. The theme of delivering targeted, individual care was developed through the sessions, and the challenges of providing equitable, effective care were repeatedly highlighted. Importantly, there is a need to combine current, developing research and clinical knowledge to provide high-quality, individual symptom management.

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INTRODUCTION

Hospital palliative medicine is a young, developing area of palliative care that operates within an increasingly complex environment. The first UK hospital palliative care team was established at St Thomas' Hospital, London, in 1976.¹ The model of service established at that time has remained the basis of most hospital palliative care teams. This includes providing supportive care and symptom control expertise alongside the current hospital treatment, assessment for transfer to hospice, advising on prognosis and discharge support. Since 1976 hospital teams have become involved at earlier stages in disease trajectories and have broadened referral acceptance to include patients with non-malignant disease. More recently, hospital-based outpatient services and acute palliative care units have been developed.^{2,3} By 2006 there were 307 hospital support teams in the UK (39 of which were in Scotland).⁴ This symposium focused on the developing role that palliative care plays within hospitals. In keeping with the recent Scottish Government national action plan (Living and Dying Well), there is a challenge to provide supportive care to all patients, independent of disease, stage or prognosis.⁵ The symposium heard a view of holistic care encompassing improved scientific understanding of symptom management and response to individual subtleties, which operates with deliberate commitment, compassion and humanity.

SESSION I DIFFICULT SYMPTOMS

Neuropathic pain – new concepts

Neuropathic pain has been recently defined as 'pain arising as a direct consequence of a lesion or disease affecting the somatosensory system'.⁶ It can occur both in malignant and non-malignant conditions and be disease- or treatment-related. One third of cancer pains have a neuropathic component.⁷ Fifty per cent of difficult-to-manage cancer pains are neuropathic.^{8,9} Professor Marie

Fallon (St Columba's Hospice Chair of Palliative Medicine, University of Edinburgh) outlined the characteristics, mechanisms, assessment and management of neuropathic pain. Neuropathic pain is described as 'burning', 'pricking' or 'shooting'. It is generally 'constant' and may have additional touch or temperature-evoked components. It is located within areas of disturbance of sensation to touch and temperature. Various neuropathic pain syndromes are thought to share common mechanisms. Central and peripheral neuronal plastic changes result in heightened sensitivity to sensory stimuli, disturbed balances between excitation and inhibition and both central and peripheral sensitisation. Such changes occur through excitation at the glutamate receptors, altered facilitation-inhibition balance, altered sodium channel expression¹⁰ and through cytokine-releasing activation of glial cells within the spinal cord.¹¹ This complex system feeds into, and is modified by, both midbrain and cortical pathways. Through these connections, the existent psycho-emotional environment can be altered by the presence of pain, but it can also modify the experience of that pain. The presence of anxiety, depression or fear can heighten the intensity and impact of pain.⁷

It is often difficult to determine which neuropathic pain mechanisms are active in any single patient. Despite this, there is a need to develop individualised, rapid and effective treatments in patients with limited prognosis. Professor Fallon emphasised the importance of full assessment of neuropathic pain. Quantitative sensory testing (QST) bedside evaluation of somatosensory dysfunction could allow a standardised approach to assessment that identifies subtle differences in neuropathic pain within clinical and research settings.¹²

General pharmacological management should be tailored to individuals, bearing in mind harmful or helpful secondary effects and interactions. Current guidelines use 'numbers needed to treat' to aid selection of first and second drugs,

but this remains limited by the heterogeneity of the trials available. The mainstay of treatment remains tricyclic antidepressants, calcium channel alpha-2-delta agonists (gabapentin or pregabalin), selective noradrenaline re-uptake inhibitors (duloxetine or venlafaxine) and topical lidocaine patches (when pain is focal and associated with allodynia). These may be given in combination with an opioid. Second-line strategies include lamotrigine, cannabinoids, opioid switching or combination therapies.⁷ The session was completed by outlining a case of successfully using topical menthol 0.5% to treat refractory, bortezomib-induced peripheral neuropathic pain. The rationale was based on preclinical data targeting topical transient receptor potential melastatin (TRPM) receptors with activators such as menthol.¹³

MANAGEMENT OF BREATHLESSNESS: SCIENCE AND CLINICAL PRACTICE

Dr Sara Booth (Macmillan Consultant in Palliative Medicine, Addenbrooke's Hospital, Cambridge) challenged an often nihilistic approach to managing breathlessness. By integrating non-pharmacological measures, drug therapy and deliberate support of carers, she emphasised that we can help patients with dyspnoea. 'Dyspnoea' can be considered as subjective, involving multiple different sensations and reflective of varying pathophysiological processes.¹⁴ Functional magnetic resonance imaging (MRI) scans can now demonstrate that the perception of dyspnoea is located within the central nervous system, activating the insular cortex within wider neural pathways connecting with frontoparietal attentional networks.^{15,16} The mechanisms of dyspnoea can be used to educate patients that breathlessness is 'perception', open to modification. This approach can alter the common but unhelpful advice of 'don't panic', to an acceptable, structured cognitive-behavioural response to dyspnoea. Further measures including pacing (using energy and respiratory reserves to achieve goals within realistic timeframes), mindfulness techniques and family support are vital to the success of management. Promoting well-being through supporting patients' ability to engage, experience pleasure and have meaning added definition to a supportive approach.¹⁷ Dr Booth outlined the lack of evidence for using oxygen to decrease the sensation of breathlessness in the absence of significant hypoxaemia.^{18,19} She detailed the increasing evidence for reduction of dyspnoea by hand-held, fan-generated airflow.²⁰

The pharmacological management of dyspnoea centres around appropriate opioid titration. Differing strategies for cancer-related dyspnoea and chronic non-malignant conditions were recommended. Benzodiazepines should be targeted for end-of-life and not routinely used in those with longer prognoses, to avoid tolerance and dependence. The potential role of other agents, such as levomepromazine, cannabinoids, nebulised furosemide and heliox, was described.²¹ The issue of proactive, end-

of-life care planning in chronic disease was addressed, noting that most patients expect a trusted professional to open the subject.²² This integrated management strategy can be used to improve the lives of those with intractable dyspnoea.²³

NEW INTERVENTIONS FOR BONE METASTASES

Cancer-related bone pain is a major clinical problem which adversely affects quality of life. Current management includes surgery, radiotherapy, chemotherapy and analgesics.²⁴ However, treatment must also take into account the individual's prognosis and performance status. Surgery is often inappropriate and radiotherapy may not achieve a response within an acceptable time frame.²⁵ Dr Richard Edwards (Consultant Interventional Radiologist, Gartnavel Hospital, Glasgow) discussed the developing use of interventional percutaneous techniques to treat malignant and osteoporotic bone disease. The first vertebroplasty was reported in 1987²⁶ and has been developed since with increasing application. Indications include moderate to severe refractory pain, progressive vertebral collapse, analgesic intolerance and impending cord compression.²⁷ Dr Edwards described a low major complication rate (<1%) and the positive evidence base of case series and prospective studies in the literature. He called for further studies to assess these techniques to provide randomised controlled trial evidence.

Kyphoplasty²⁸ (the use of a high-pressure balloon to make space for cement injection), cementoplasty²⁹ (cement injection of non-vertebral bones), radiofrequency ablation³⁰ (thermal ablation of focal lesions) and embolisation³¹ (adjunctive treatment for hypervascular lesions) can also be used to target bone-related pain. An assessment of the underlying painful bone by computed tomography (CT) and MRI imaging allows the appropriate technique(s) to be chosen. Cementoplasty is contraindicated in weight-bearing long bones but has been used to treat acetabular, sacral, pubic and sternal malignant bone pain. In closing, Dr Edwards described the challenges in providing an interventional radiological service and the requirements for increased resources and trainees to make these procedures more widely available.

SESSION 2 A QUARTER CENTURY OF HOSPITAL PALLIATIVE MEDICINE: CONFLICTS, CONFUSION AND CO-OPERATION

The Sydney Watson Smith lecture was given by Professor Sam Ahmedzai (Professor of Palliative Medicine, Academic Unit of Supportive Care, University of Sheffield). He reviewed the historical background of palliative medicine and supportive care,³² challenged the 'cure versus care myth' and outlined possible future directions for palliative care within hospitals. Three key drivers were identified: listening to patients' voices, being innovative about service delivery and the relief of pain and suffering.

The language of palliative care has developed over time. Hospice and hospital share the latin root *hospes*, meaning guest or host. The term 'palliation' (to cloak) was coined by Balfour Mount in Montreal when he established a hospital-based palliative care service. In the last decade, 'supportive care' has developed in response to societal and medical changes, where cure and care are not mutually exclusive. The premise of the 'medicalisation' of palliative care debate was challenged by identifying a rebound phenomenon of 'nurs-isation'. Professor Ahmedzai reaffirmed a patient-centred, focused multidisciplinary approach to care, identifying need and using the most appropriate person within the team to meet that need. The objectives of palliative care services³³ should include:

- The optimisation of quality of life and dignity in illness and dying;
- Recognising the patient's choice and autonomy;
- Recognising the patient's needs in any care setting;
- Recognising the needs of family members during the illness and, if required, for bereavement support.

Within the acute setting, oncology has developed to widen its goals from cure to survival improvement, symptom control and improved quality of life. The European School of Oncology's new framework states: 'When a patient has difficult symptoms which cannot be controlled by his/her current healthcare team, he/she has a right to be referred, and the current healthcare provider has an obligation to refer, to the local specialised palliative care team.'³³

Commitment to an entitlement to effective symptom control should be recognised as an expression of common humanity. Recent national surveys have found that pain and other symptoms remain poorly controlled in hospitals,³⁴ indicating there is a need for improved symptom control. Borrowing the language of the human genome project, the concept of 'symptomics' was described. This science of symptoms involves mapping a human 'symptome' (collating and characterising symptoms), understanding pharmacosymptomics (how drugs target symptoms), explaining symptoms and side effects, explaining individual variation in response (symptom-genomics) and embedding this knowledge at the core of modern medicine.

New challenges in providing palliative and supportive care within the increasingly complex hospital environment require developing strategies and models of care appropriate to that setting. Hospital teams are involved earlier in disease trajectories, in treating patients' chronic non-malignant disease and in supporting those who survive life-threatening illness.² Within the acute environment there is need for rapid and focused symptom control.³⁵ Acute palliative care units are a developing strategy for providing intense, supportive care to those who continue to require other components of the acute setting.^{36,37}

The challenge is not to target the disease or the stage of disease but the needs of the person.

SESSIONS 3 AND 4 WHAT I WANT AND DON'T WANT FROM HOSPITAL PALLIATIVE MEDICINE

These sessions were designed to provoke thought and discussion and to hear perspectives of professionals in other areas of practice. Each speaker was asked to describe what they expect from hospital palliative care.

An oncologist's perspective

Professor Alastair Munro (Professor of Radiation Oncology, University of Dundee) started the discussion with a thought-provoking analysis of hospital care and the need for culture change in the care of patients with incurable disease. He described care of those near the end of life as entwined with the 'buttresses' and 'foundations' of society. In the UK, there are 154,000 cancer-related deaths per annum. Two thirds are anticipated and can be planned for. Playing on a quote from Elizabeth Barrett Browning, he summed up our standard of care for the dying: 'How do I fail thee – let me count the ways.' He argued that resources are not the only issue and that we need to restore continuity and consistency of care permeated with humanity.

Dissecting out issues of importance, he highlighted the treatment of physical and emotional stress, respecting autonomy, communication (listening and hearing), supporting completion ('taking care of unfinished business'), contribution (supporting those at the end of life in continuing meaningful, engaged lives), continuity, leadership (tempering multidisciplinary approaches with clear direction and messages) and prognostication. He described the loss of humanity, grace and effectiveness through systemic approaches that do not recognise transitions from curable to incurable to end-of-life. He called for improvement in palliative care education, efficient and rapid delivery of physical support into homes and individualised care to be located at each bedside. He challenged hospital palliative care to be equitable, accessible, consistent and available at the time of need. While recognising the usefulness of symptom control, he warned of the danger of pharmacological solutions to human problems. He completed his talk by reciting John Donne's tenth Holy Sonnet, 'Death, be not proud.'

A surgeon's view

Professor Peter Stonebridge (Professor of Vascular Surgery, Ninewells Hospital, Dundee) challenged hospital care through a revised utilitarian standard, 'the greatest happiness for the greatest number of people' (Jeremy Bentham). He advocated aiming for 'the best care for the greatest number of patients'. He described the life-altering impact of critical limb ischaemia in patients with vascular failure: pain and debility resulting in reduced quality of life, reduced mobility and pressured family life.

He made a compelling argument for palliative medicine extending care beyond patients with cancer or those at the end of life. He challenged the use of the term 'palliative care' and suggested provision of equitable 'supportive care'. Developing this theme, Professor Stonebridge told the story of a patient at the end of life, unable to access resources closer to home, and admitted to an acute surgical ward for end-of-life care because he did not meet criteria for palliative or community hospital care. He emphasised that each person has a right to die as close to home as possible. To resource this for cancer patients but not others is a failure of care. He finished by reiterating the challenge: to provide the greatest care for the greatest number of people possible; to move away from 'disease' to 'need'.

A physician's perspective

Dr Robert Milroy (Consultant Respiratory Physician, Stobhill Hospital, Glasgow) outlined the supportive care needs of patients with lung cancer. He noted the high symptom burden, poor prognosis and rapid mortality of this condition. He made a case for focused input from palliative care from the point of diagnosis.³⁸ He emphasised that fatigue, cachexia and systemic inflammation need to be addressed clinically and by future research.³⁹ Individualised treatment was proposed to help patients make the best decisions within this acute illness trajectory. In 1948, Karnofsky et al. first published evidence of symptom improvement in lung cancer using nitrogen mustards.⁴⁰ Symptom response rates in palliative chemotherapy are double objective response rates.⁴¹ In selected, good performance status patients, chemotherapy and radiotherapy should be offered for symptom benefit and potential survival benefit.⁴²

Palliative care must also tackle other cancers and non-malignant conditions and tailor care to meet each of these conditions. Collaborative, cohesive, educative, multidisciplinary working was suggested as a method of providing optimal clinical care. Dr Milroy proposed joint clinics and ward rounds, medical and nursing trainees rotating between specialties, and access to advice and communication. This cross-specialty approach to clinical care was widened to call for collaborative, patient-centred research. Recognising the leading position of the UK in palliative care, he challenged us to build on these strong foundations and continue to lead.

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A general practitioner's view

Framing his discussion with a quote from William Dunbar, *Timor mortis conturbat me* (the fear of death overwhelms me), Dr Euan Paterson (General Practitioner and Macmillan GP Facilitator, Govan Health Centre, Glasgow) outlined a proactive approach to palliative care in the community. William Osler said: 'Ask not what disease the person has but rather what person the disease has.' The therapeutic relationship between professional and patient can provide understanding, coupled with knowledge and skills, to meet patients' needs. This relationship is based on our shared humanity and mortality. The strength and consistency of pre-formed relationships between general practitioners and their patients can be harnessed to channel individual care. This should be underpinned by accessible advice and support from specialist palliative care. Dr Paterson also called for an educative approach to permeate the interface between secondary and primary care – empowering generalists to provide confident and competent care in the community, not taking over care. In challenging routinised, fragmented, multiprofessional care he called for each professional to provide a human touch. Palliative care should be about transmitting competence, commitment and compassion into difficult, fragmented situations.

The discussion following these talks developed the theme of providing care to those with needs. Embedded generalist palliative care across care sectors and specialties was proposed to meet this challenge. Joint education and training were seen as mechanisms for deployment. Professor Ahmedzai drew a distinction between general care and specialist palliative care. He emphasised that palliative care needs to address the changing needs of society and develop as an equitable, knowledge-based specialty.

CONCLUSION

This symposium highlighted the role of palliative medicine within hospitals and provoked a lively debate on the foundations of care. Drawing on the experiences of a wide spectrum of healthcare professionals, the presentations and discussions tackled many issues and highlighted the provision of equitable, consistent, accessible, knowledge-based, compassionate care.

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