

BPS response to Macmillan announcement on inadequate pain relief for cancer patients

On 13 February 2016 Macmillan Cancer Support published a media statement¹ on what it called the 'pain and heartbreak' of terminally ill patients with cancer who are faced with the dilemma of either dying at home with inadequate pain relief, or being admitted to hospitals 'against their wishes', in order to access better pain control.

As a multiprofessional society which is concerned about all kinds of pain affecting people in the UK, the British Pain Society is concerned by these comments. But what is the evidence behind the Macmillan report? They based their analyses on two main sources: first, the 2015 publication from the Office of National Statistics (ONS) on its National Survey of Bereaved People (VOICES)², conducted in 2014. This sought the views of 49,000 people, of whom 6703 (14%) responded on behalf of person who had died of cancer. (A further 8194 (17%) did not respond, which introduces the possibility of a significant bias in the answers.)

Second, Macmillan cited its own February 2010 online survey³ of 1,019 UK adults living with cancer, in which 73% of people with cancer said they would prefer to die at home if all their concerns about dying at home (such as access to pain relief, round the clock care, and support for their family and carers) were addressed.

Put together, the following key findings emerged that led to Macmillan's media release. Combining the cancer patients who had been 'treated at home' and in whom pain had been relieved *completely, all of the time or some of the time*, the figure was 63.2%. Combining those in whom pain was only relieved *partially or not at all*, the figure was 36.8%. Furthermore, the VOICES data showed that of those who had pain treated *completely, all of the time*, 82.3% eventually died in their 'preferred place of care'. Conversely, of the cancer patients whose pain was treated *not at all*, 63.7% had not died in their preferred place of care.

Thus Macmillan's assertion is that cancer patients at home, whose pain control was inadequate, were being forced 'against their wishes' to be transferred to hospital in order to get pain relief before they died. The British Pain Society feels that this finding is sadly predictable, given the current state of cancer pain management in the UK. In 2010 it published a report on Cancer Pain Management⁴, which was compiled by a multidisciplinary team of experts from the BPS itself as well as the Association for Palliative Medicine and the Royal College of General Practitioners. In the report's executive summary it stated:

"The management of cancer pain can and should be improved by better collaboration between the disciplines of oncology, pain medicine and palliative medicine. This must start in the training programmes of doctors, but is also needed in established teams in terms of funding, time for joint working and the education of all healthcare professionals involved in the treatment of cancer pain.

Cancer pain is often very complex, but the most intractable pain is often neuropathic in origin, arising from tumour invasion of the meninges, spinal cord and dura, nerve roots, plexuses and peripheral nerves. Multimodal therapies are necessary."

The report and the two journal articles^{5,6} that were published from it, addressed the complexity of cancer-related pain, from acute pain arising from the disease or after surgery, to chronic pains caused by progressive disease and also damage to nerves from surgery, drugs or radiotherapy used in cancer treatment. The BPS report highlighted the outmoded concept of cancer pain that was prevailing in 2010 – and sadly still in 2016 – based on the 1986 WHO three-step analgesic ladder. This may have been appropriate as a tool to influence both clinicians and governments about the

legitimate use of opioids like morphine in the developing world 30 years ago. But there are now many alternatives to morphine and many other classes of drugs which do not carry the side-effects and risks that opioids bring⁷. Indeed, recent research has shown that when opioids are used for chronic pain, they lead to many unwanted and potentially serious adverse effects such as tolerance, hyperalgesia and even the risk of overdose⁸. Since the 1980s, there has been much progress with cancer control itself and for many patients, cancer is now a chronic disease. When patients eventually do succumb to the effects of advancing malignant disease, often the doses of opioids, when used according to the 30 year old WHO concept, may be sufficiently high to produce problems such as excessive sedation or agitation, which may necessitate admission to hospital or hospice to manage effectively.

The BPS strongly echoes Macmillan's concerns about the poor state of multidisciplinary pain management for cancer patients, especially in their own homes or in care homes. Admission to hospital may not have been the patient's (or family's) preferred choice, but at least in most UK hospitals there are professional teams available who can address the pain or drug-related side-effects. Hospital supportive and palliative care teams (sometimes staffed by professionals coming in from nearby hospices) are often the first point of call. These should be backed up by pain medicine specialists, which are usually based in multidisciplinary pain clinics. For a small but significant number of patients with intolerable cancer-related pain or drug side-effects, these pain specialists can offer dramatic improvements by means of nerve blocks, spinal drug delivery directly to the central nervous system, topical patches or other advanced techniques: the multimodal therapy that the BPS declared in 2010.

Indeed, the BPS believes that introducing cancer patients to pain specialists at an earlier stage – well before the end of life in terms of the last days or weeks – can bring significant benefits as these specialist interventions will have a longer time to work and may thus be more cost-effective.

BPS endorses the view expressed by Lynda Thomas, Chief Executive of Macmillan Cancer Support, who said: "Quite simply, in the 21st century people should not be spending their final hours in pain in this country because the support is not there." We are willing to work with Macmillan, other non-governmental agencies and the Department of Health to ensure that its specialist knowledge and skills are brought fully to bear on correcting this major weakness of British end of life care.

NICE published its new guidelines on 'Care of the Dying Adult'⁹ in December 2015. That guidance specifically covered management of pain and other symptoms in the last 2-3 days of life. Two of BPS council members (Professor Sam H Ahmedzai and Dr Arun Bhaskar) had direct input into the production of this guidance. The Society regrets, however, that the corresponding guidelines that are still being produced for care of dying children, has so far not sought the same degree of specialist pain management input. We hope that Macmillan's latest initiative will ensure that all who are involved in making dying in Britain as comfortable as possible, are receptive to the broad range expertise of pain specialists. As cancer is only one of many diseases which can lead to a painful death, the potential benefits go far beyond the scope of Macmillan's cancer pain announcement.

References

1. Macmillan media statement, online 13 February 2016. (web link)
2. ONS report on VOICES survey, 2015. (web address)
3. Macmillan 2010, cited in (1).
4. BPS 2010. Cancer Pain Management. (web address)

5. Raphael J, Ahmedzai S, Hester J, Urch C, et al. Cancer pain: part 1: Pathophysiology; oncological, pharmacological, and psychological treatments: a perspective from the British Pain Society endorsed by the UK Association of Palliative Medicine and the Royal College of General Practitioners. *Pain Med.* 2010 May;11(5):742-64Raphael et al, *Pain Medicine* 2011 (b)
6. Raphael J, Hester J, Ahmedzai S, Barrie J, et al. Cancer pain: part 2: physical, interventional and complimentary therapies; management in the community; acute, treatment-related and complex cancer pain: a perspective from the British Pain Society endorsed by the UK Association of Palliative Medicine and the Royal College of General Practitioners. *Pain Med.* 2010 Jun;11(6):872-96.
7. Ahmedzai SH. Cancer pain for the 21st century: stepping off the ladder, stepping up to new challenges. *Br J Pain.* 2014 Nov;8(4):131-2.
8. Ballantyne JC, Kalso E, Stannard C. WHO analgesic ladder: a good concept gone astray. *Brit Med J* 2016;352:i20. doi: 10.1136/bmj.i20.
9. NICE 2015. NG31: Care of the dying adult. (web address)