

The Challenges of Cancer Pain Assessment and Management

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Pain, being one of the most common symptoms of cancer¹, is a heavy weight that a patient often has to carry with them along their journey from pre diagnosis, through treatment and even when in remission¹⁻³. It is a debilitating symptom, interfering with not only their physical state, but also their psychological and social wellbeing¹. It has been shown that 67% of patients find their cancer pain distressing⁴ and it is now well noted that uncontrolled pain is a key promoter of the legalisation of physician assisted suicide^{1,5-7}. The World Health Organisation analgesic ladder has now been used for over 2 decades^{6,8} and is still considered to be the basis for cancer pain management². Revalidation of this ladder, along with many other studies, have repeatedly documented that effective treatment is accessible for 70 – 90% of patients^{1,6,8-10}. Despite this reassuring statistic, 66-74% of patients with advanced disease experience pain² and nearly one in two patients are being undertreated¹¹. This essay therefore aims to explain the discrepancy between publication and practice.

Dame Cicely Saunders coined the term ‘total pain’ >30 years ago¹² recognizing that a patient’s pain experience has physical, emotional, social and spiritual dimensions. This idea, along with the subjective nature of pain and increasing complexity in treatment modalities for cancer², highlight that pain as a basic concept is complex and open to ambiguity in its assessment and management.

Studies looking into challenges of managing this complex symptom are no longer few and far between. These were initially captured by the Agency for Healthcare Policy and Research in 1994¹³. Since then, organisations including the American Pain society, the Joint Commission¹⁴ and the Expert working group of the European Association for Palliative care¹¹ have published guidelines.

Inadequate pain assessment is believed to be the leading barrier to adequate pain management¹⁵. Recognition of pain should begin at pre-diagnosis¹⁶ and its assessment should include a detailed history, psychosocial evaluation and physical examination². Current guidelines recommend the use of one of 3 validated assessment tools: the visual analogue scale, verbal rating scale or the most commonly used numerical rating scale (NRS)³.

Furthermore, guidelines state baseline pain assessment, reassessment and analgesia efficacy must be documented within the patient’s record¹⁷. However, the recent EPIC study

revealed that 27% of patients said their doctor doesn’t always ask them about their pain⁴ and one study by Chih-Yi Sun et al. found that only 7.9% had documentation of their pain and evidence of reassessment¹³. This may reflect the fact that there is still the need for a common language when classifying and assessing pain¹⁸. In fact, over recent years, attempts to include pain as the ‘5th vital sign’ have not been as promising as hoped¹⁹ due to ambiguity over what exact assessment method should be used, causing healthcare workers (HCWs) to adopt a more informal approach¹⁸. There has been extensive research into the refinement of cancer pain assessment resulting in the continuous influx of new tools with different nomenclature¹⁸. This may further burden HCWs and in turn cause the gravitation towards informal assessment. It may be time to recognise that perfection is occurring at the expense of efficacy and that an international collaboration is needed to review assessment techniques.

It has now been over 4 decades since McCaffery’s definition stating that “Pain is what the experiencing person says it is, existing whenever he says it does”²⁰. It highlights that the patient’s self report is the most reliable indicator of the presence and severity of pain. However, some patients, often termed as ‘non verbal’, may be unable to report their pain²¹. These include infants, the cognitively impaired, critically ill, anaesthetised or comatose and some patients reaching the end of their life. In these cases the traditional pain measurement tools are often difficult to employ. Therefore alternative approaches need to be considered and those based on the ‘Hierarchy of Importance of Pain Measures’ have proved successful²⁰. The fact that ‘non verbal’ patients can often be found within oncology, highlights the importance of increasing awareness of this hierarchy to overcome communication barriers.

In addition to inadequate assessment, further management issues have been recognised in relation to both patients and HCWs as well as within healthcare and regulatory systems^{1,11,13,14}.

Despite the fact that opioid use is integral to cancer pain

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management¹⁴, HCWs are still displaying incorrect beliefs that affect their prescription to those in need. HCWs are traditionally taught to treat the underlying disease^{5,14}. This statement is reinforced by patients as studies have found that 38% feel that their doctor would rather treat their cancer than their pain⁴. The lack of pain recognition by clinicians may follow on from its lack of recognition in medical training^{1,14,22}. A survey of oncologists in 1993 revealed that 88% rated their medical school training in pain management as fair or poor and most experts believe not much has changed¹⁴. Lack of education has led to misplaced concerns over addiction and tolerance to analgesics as well as problems with key concepts such as side effect management and the use of alternative administration routes or adjuvant treatments^{1,7,9,13,14,22}. Indeed, recent reports have found that despite constipation being the most commonly experienced side effect of opioids, only 27% of patients were prescribed laxatives in conjunction with their pain medication⁴.

A patient's reluctance to report their pain and hesitancy to comply with treatment is also a major driver for inadequate pain management¹⁴. This reluctance often comes down to erroneous beliefs shared by patients. The Barriers Questionnaire has played a major part in identifying patient related barriers^{23,24}. Patients often view pain as an inevitable part of having cancer and that admitting pain is a sign of weakness^{14,24}. Furthermore, patients often hesitate to report their pain as they want to appear as a 'good' patient, they may not want to distract their doctor from treating their cancer or may fear that pain is a sign of disease progression^{1,9,13,14,24}. Some studies reinforce the impact of these beliefs in finding that patients continue to paradoxically report high pain intensities while conveying satisfaction with their pain management^{14,25}. Concerns about side effects of commonly used opioids follow on from HCWs failure to prevent them and fears over addiction and tolerance are also shared by patients^{1,9,13,14,24}.

The patient's age and ethnicity create special patient populations in need of mentioning. Elderly patients may provide communication barriers due to cognitive decline as well as having altered responses to analgesics and more complex pain experiences^{7,14}. It has also been well documented that ethnic minorities experience undertreatment of their cancer pain, yet most studies of patient-related barriers to pain management have assessed primarily Caucasian patients^{26,27}. Undertreatment may originate from an inability to communicate their pain experience with their doctor, socioeconomic challenges and unintentional biases such as racial stereotypes held by HCWs. In the face of an ageing and more ethnically diverse population⁷, the healthcare system should be more forthcoming in addressing these issues.

Regulatory bodies have played a part in hindering the provision of optimal care. Traditionally, opioid use has occurred in a highly regulated environment leading to conservative prescribing by doctors who fear scrutiny by those enforcing the regulations^{1,7,13,14}. Regulations are put

in place with the aim of curtailing abuse, yet standards haven't been clearly set as to what constitutes 'legitimate medical practice' resulting in controversy and intimidation of doctors¹⁴.

Further challenges lie within the fact that cancer patients are fragmented throughout the healthcare system. Most research on cancer pain has been conducted in secondary care, despite the fact that oncology patients are being increasingly cared for in the community^{2,28}. The recent EPIC study invited community based patients, >90% of whom rated their pain >5/10 on the NRS and ¼ of whom weren't receiving analgesics^{2,4} - a clear indicator that primary care is an area in need of attention. At the other extreme, there is evidence of under-referral to specialist pain management services and incoherent relationships between pain medicine and palliative care specialists^{2,4,14}. Studies as early as 1991 have shown improved outcomes from using specialist and multidisciplinary pain management services²⁹. Yet a survey in 2007 showed that while 92% of palliative care units had access to specialist advice, only 16% had regular sessions². Furthermore, an American survey highlighted that there were only 6 pain specialists for every 100,000 patients with persistent pain¹⁴ and only 25% of anaesthetists' job plans had time allocated for palliative medicine referrals² - statistics that again highlight areas needing increased consideration.

Although challenges of effective pain management have been an area of interest for almost two decades¹³, unsatisfactory pain management in oncology is clearly still a prevalent problem. The reputation of pain management needs to move towards becoming fundamental to all aspects of cancer care. What is required is an environment where appropriate treatment is available when and where it is needed, where pain education is the norm and there is open communication between patients and HCWs and across all levels of care. Only through international collaboration among HCWs, policy makers and patients will this much needed standard be met.

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