

The Challenge of Cancer Pain Assessment

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INTRODUCTION:

Pain is a debilitating consequence of a cancer diagnosis, affecting approximately 50.7% of patients¹. Often going beyond the physical threshold, cancer pain is a multidimensional experience affecting the psychological, social and spiritual domains of patients' lives. Nonetheless cancer pain is not inevitable; it is estimated that pain can be controlled in up to 90% of cases². In the United Kingdom (UK), this under-treatment of cancer pain is widely recognised to be due to human factors, rather than a lack of available treatment options. Inadequate assessment is a major barrier to pain control, and this evaluation can be limited by patient, provider and system challenges; optimising these factors is likely to bring the greatest improvements to pain management.

CANCER PAIN ASSESSMENT: CURRENT GUIDANCE

Pain is a complex phenomenon and varies widely both across the cancer continuum and the patient population. During cancer treatment 55% of patients experience pain³. The aetiology of this is multifaceted, involving interactions between tumour, treatment and psychological factors, as well as pre-existing comorbidities patients may have. After remission, 40% of cancer survivors continue to have pain and treatment-related factors (e.g. post-radiotherapy fibrosis) play an important role⁴. The experience of pain also differs between cancer patients: pain may be acute, chronic or intermittent; neuropathic or nociceptive, and can affect patients' sleep, mood and even cancer prognosis to varying degrees^{5,6}.

The assessment provides a basis for inferring the individual pathophysiology and consequences of pain, helping to guide diagnostic and treatment decisions. Current guidance recommends that cancer pain should be evaluated at every clinical visit, incorporating a pain history, physical examination, psychosocial assessment and appropriate diagnostic investigations⁷⁻⁹. Throughout assessment, 'total pain' should be assessed, looking beyond the tumour to address the psychological, cultural, spiritual and social influences of pain¹⁰. As pain is inherently subjective, self-report is the gold standard of assessment, however validated assessment tools can be used to aid systematic evaluation and communication. While the National Institute of Health and Care Excellence (NICE) recommends unidimensional tools (e.g. visual analogue score), The British Pain Society (BPS) advocates for the use of multidimensional tools (e.g. McGill Pain Questionnaire)^{8,9}.

PATIENT CHALLENGES: Misconceptions and misinformation:

The assessment of pain relies on patients' self-reports, however in practice patients may be reluctant to accurately report their pain. This may be due to concerns about side effects or addiction to pain medications; not wanting to 'complain' about pain; trying to ensure that doctors prioritise cancer treatment over symptom control; or misconceptions about the inevitability of pain^{7,11}. Older patients, those with a lower education level, and Asian patients have been reported to have higher prevalence of common cancer misbeliefs. Chen et al. found that Asian patients were particularly worried about opioid tolerance and had fatalistic views about cancer pain^{12,13}. Lee et al. found in systematic review that patient education programmes can help to correct misconceptions and in turn reduce cancer pain, albeit slightly. In one study, Koh et al. found that the use of an educational booklet had the greatest effect on changing misconceptions around opioids, whereas views on pain 'distracting doctors from cancer treatment' changed the least. This reduced pain however did not improve satisfaction with pain management, suggesting changes in pain are not substantial and resonating that 'total pain' is multidimensional^{14,15}.

RECALL BIAS:

The retrospective nature of pain histories may also lead to inaccurate reporting, with retrospective recall generally overestimating pain^{16,17}. Lindberg et al. found that negative emotion at the time of recall also lead to an overestimation of pain in a group of breast cancer survivors¹⁸. Electronic diaries collecting real-time, patient-reported pain measures (PROMs) can help to minimise recall bias. Electronic diaries are easy to use and improve symptom recording, including the level of detail of pain reports and analgesia use¹⁹⁻²¹. PROMs have shown to increase the frequency of pain discussions, improve patient satisfaction and reduce pain intensity²².

CANCER SURVIVORSHIP:

Advancements in cancer screening and treatment have improved cancer survival. In the UK there are currently over two million people living with or beyond cancer, with 62%

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living beyond five years after diagnosis²³. There is a lack of guidance and research however into pain assessment in this population. Nijs et al. suggests that pain in cancer survivors should first be assessed for a neuropathic component, followed by classification as either nociceptive or central sensitisation pain²⁴. However, this model fails to acknowledge the holistic nature of pain (e.g. spiritual and psychological distress) and is based on non-systematic evidence (i.e. expert opinion).

Moreover, with the chronic nature of pain in survivors, concerns around opioid tolerance and addiction need to be addressed. Vizthum et al. found that 8.3% of veteran cancer survivors in the United States had persistent opioid use, with 2.9% being classified as being opioid-dependent²⁵. The 'pain medication questionnaire' (PMQ) and 'screeener and opioid assessment for patients with pain' (SOAPP) tools can be used to predict opioid misuse in those with chronic pain, however further research needs to assess the validity of these tools in those with cancer pain. Pain management needs to balance optimising pain control with harm reduction principles, and should consider how changes in the processing of pain stimuli and the stigma of addiction can affect assessment^{7,25}.

HEALTHCARE PROVIDER CHALLENGES:

Improving undergraduate education:

Several studies have outlined that the frequency and quality of cancer pain assessment by healthcare professionals (HCPs) is inadequate: the 'EPIC' report showed that 22% of patients were not asked about pain; Berry et al. found that doctors omitted addressing emotional issues; and El Rahi et al. demonstrated that nurses failed to examine pain intensity and characteristics in cancer patients^{26,27}. Poor knowledge, insufficient experience and common misbeliefs around cancer pain, particularly opioid addiction, are the most pervasive challenges to assessment for both nurses and doctors^{7,11,13,28}.

In the UK, the topic of pain, including cancer pain, is under-represented in both medical and nursing school, with students only receiving 13 and 10.2 hours of teaching respectively; only 4.8% of time was devoted to pain assessment for medical students²⁹. The International Association for the Study of Pain recommends that pain education should be integrated across different modules and use a diverse range of teaching methods, including online-learning, interprofessional learning and patient stories. This has shown to improve student knowledge and beliefs around pain, setting the foundation for effective pain management^{30,31}.

PAIN ASSESSMENT TOOLS:

However, education alone is unlikely to lead to substantial improvements and should be combined with changes to working practice. The use of pain assessment tools, particularly multidimensional tools, are limited. In one nationwide Swedish study, 97% of cancer departments reported using history alone to assess pain³². Reported barriers to use of assessment tools include time constraints, lack of policies and guidelines and insufficient training in using pain assessment

scales³³. It has been proposed that pain assessment should be incorporated as the 'fifth vital sign' in patient records as a means to promote HCPs in assessing pain regularly and systematically^{10,34}. However, unlike heart rate or temperature, pain is not an objective measure and over-relying on these tools takes away the individual voices from patients expressing their pain.

INFORMAL CAREGIVERS:

Family members, and other informal caregivers, play a key and often overlooked role in cancer pain management. This responsibility is only expected to increase with an ageing population, increasing prevalence of chronic illness and care being moved towards the community. However caregiver reports of pain are not always congruent with those of the patient; over-reporting being associated with patient concealment of pain and poor patient-caregiver communication, whilst under-reporting can result from caregiver fears about opioid addiction and 'distracting' doctors from curative treatment³⁵⁻³⁸. Caregiver misconceptions have also shown to influence patient beliefs around cancer pain³⁵. Moreover, caregivers may not have the knowledge or skills to assess pain and educational programmes should address this³⁹. Mehta et al. found that caregivers particularly struggled with identifying pain that they did not have direct experience of and distinguishing between pain types^{38,40}. Furthermore communication may be poor between caregivers and HCPs, with one study finding that only 24.3% of hospice interdisciplinary meetings about pain included caregivers⁴¹. Shared-decision making can be facilitated by actively involving caregivers in care plans and team meetings^{42,43}. Nonetheless, greater involvement in decision-making should not add undue stress to caregivers. Watching their loved ones experiencing pain is deeply distressing, and holistic support needs to be offered to all those involved in patient care.

SYSTEMIC CHALLENGES:

Inter-disciplinary collaboration:

In the UK, cancer services are divided across community and hospital-based care, involving multidisciplinary input from primary care, oncology, surgical, palliative care and allied health services. The role of pain medicine specialists however is surprisingly limited⁶. For example, despite 92% of palliative care units in England having access to specialist pain services, only 16% regularly use them⁹. While specialist-input is not efficient in every case, partnership between cancer and pain services may help in the assessment of more complex cases (e.g. chronic pain and substance use disorders). Partnership between oncology and pain specialists can be facilitated through greater crossover in training and funding for joint-services, including research projects and out-of-hours pain services.

In contrast, general practitioners (GPs) are already known to be heavily involved in cancer care. More recently, their role in survivorship care, particularly pain management, is being increasingly recognised^{23,44}. However, a key area of



concern for GPs is providing surveillance testing for cancer survivors, where new-onset and increasing pain may indicate recurrence^{10,44}. Likewise, improving partnership between oncologists and primary care can help improve this aspect of pain assessment for cancer survivors. This can be facilitated through shared data management systems, treatment summaries and survivorship care plans⁴⁴⁻⁴⁶. However, cancer survivors are a heterogeneous group and collaboration is unlikely to suit all patients. For example, Hudson et al. found that while prostate cancer survivors preferred primary care follow-up, breast cancer survivors preferred care from oncologists⁴⁷. Moreover, Cheung et al. found that the majority of oncologists were resistant to a shared-care model⁴⁸.

RESEARCH CHALLENGES:

Cancer services are underpinned by the values of evidence-based medicine. However the quality of research on cancer pain assessment is often poor, particularly in the development of pain assessment tools where few are validated and tested⁴⁹. Multiple studies do not adequately describe their methodologies, with the risk of bias often being unclear. Furthermore, recruitment into research studies is as low as 5.5%, limiting the generalisability of results^{14,50}. Ransom et al. found that barriers to participation included patients having non-cancer related pain syndromes and participant perception of study burden⁵⁰. It is imperative that researchers improve the transparency of their work, recruit from a broader patient base and collaborate with each other to improve the quality of their research.

There are also key research gaps that need to be addressed, including the assessment of cancer survivors and culturally diverse groups, as well as developing a unanimous classification system for cancer pain⁵¹. In more recent times, the COVID-19 pandemic has undoubtedly disrupted services and increasing time constraints, staff burnout and psychological stress among patients may contribute to inadequate pain assessment in the future. Further research needs to assess the impact of COVID-19 on cancer services and the effectiveness of pain assessment with changes to working practice (e.g. telemedicine).

CONCLUSION:

Pain is a distressing and often feared consequence of a cancer diagnosis, disrupting all aspects of patients' and their families' lives. The assessment of pain forms the foundation of successful management, however the multidimensional nature of cancer pain makes this a complex task. Effective pain assessment needs to address common misconceptions and knowledge deficits; improve clinical recording; and facilitate HCP, caregiver and researcher collaboration around cancer pain. As HCPs, we all have an ethical duty to strive towards an improved standard of care and only by working together, can we provide hope to numerous patients suffering with cancer pain.

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