

Pain and symptom management: preserving quality of life

Henry Ddungu explains the broad range of resources that need to be developed if real patient needs are to be met

Symptom and pain burden

Life-threatening illnesses such as cancer and HIV infection, and neuromuscular disorders such as multiple sclerosis and end-stage heart disease, among others, are often associated with a multitude of symptoms that make a patient's quality of life unbearable.

Cancer patients might also suffer from a plethora of symptoms at all stages of their disease.¹ The prevalence of individual symptoms varies along the disease trajectory, but cancer is almost always associated with pain.² Distressing symptoms are a result of many factors, including the various treatment options: surgery, chemotherapy, and radiotherapy, among others. The symptoms caused by treatment may delay treatment or lead to premature treatment termination; when treatment is no longer possible symptom control becomes the focus of cancer care.

Pain may be the dominating symptom at the time of diagnosis of cancer, a sign of disease relapse, a symptom of late toxicity, and indeed, a key symptom in patients with advanced incurable disease. Cancer patients are often suffering from more than one symptom at a time, with fatigue, severe pain, lack of energy, weakness, and loss of appetite being the five most prevalent symptoms reported.³ The prevalence of cancer pain ranges from 30–50% in patients under chronic treatment and it increases to more than 70% in patients with advanced cancer.⁴ In a review of the existing epidemiological evidence on the occurrence and epidemiological characteristics of cancer-related pain, Goudas and colleagues concluded that cancer pain is a substantial burden for the cancer patient but it is frequently underestimated and under-treated.³

The HIV epidemic has affected sub-Saharan Africa more than the rest of the world, with over 67% of the global prevalence for HIV infection and 75% of AIDS global deaths.⁶ There is a high prevalence of symptoms in HIV infection, irrespective of the disease stage.

HIV care, therefore, needs to go beyond an antiretroviral-focused approach to a focus on the heterogeneous and complex elements of long-term infection, chronic disease management that recognises primary care.⁷ Primary care, defined as the provision of integrated, accessible health services by clinicians accountable for addressing a large majority of personal health needs, has been found to be associated with improved survival.⁸

Pain is also a common symptom in HIV infection

although it is usually under-rated and under-treated by clinicians. In a study in Nigeria to determine the frequency of pain and its various forms and correlates, in a cohort of HIV-positive patients attending an antiretroviral therapy clinic, pain was present in 27.8% of the respondents.⁹

In another study aimed at: i) measuring symptom burden prior to antiretroviral therapy initiation, in a population of adults with low CD4 counts presenting for HIV care and treatment in Uganda; and ii) exploring the relationship between World Health Organization (WHO) stage, CD4 count, and symptomatology, the study showed that the burden of HIV-related symptoms in such individuals is significant and debilitating.¹⁰

The burden of symptoms among HIV/AIDS patients, irrespective of CD4 counts, remains enormous even in high-income countries. In a report of an ongoing prospective longitudinal study describing symptoms experienced by 317 men and women living with HIV/AIDS in San Francisco, the median number of symptoms was 9 with symptoms experienced including lack of energy (65%), drowsiness (57%), difficulty sleeping (56%), and pain (55%). The report also noted that those with an AIDS diagnosis had significantly higher symptom burden scores, as did those currently receiving antiretroviral therapy.¹¹

Depression is a common serious HIV co-morbidity in sub-Saharan Africa. A cross-sectional population-based study of adults in Botswana examined for depressive symptoms, found that 25.3% of women and 31.4% of men had depression.¹² Such findings highlight the need to integrate mental health counselling and treatment into primary healthcare to decrease morbidity and improve HIV management efforts.

The burden of symptoms is significant among paediatric patients with life-threatening illnesses – cancer, HIV infection, and sickle cell disease, among others. However, paediatric clinical trials have traditionally focused on survival and treatment toxicities with minimal interest in the measurement of outcomes that reflect the impact of treatment on patients and families. In a study to determine symptom prevalence, characteristics, and distress in children with cancer, using an adapted Memorial Symptom Assessment Scale (MSAS) that was administered to 160 children with cancer aged 10–18 years, researchers found a high prevalence of symptoms overall and the existence of subgroups with high distress associated with one or multiple symptoms.¹³

There is also limited knowledge about parents' perceptions about the symptom prevalence and symptom burden for their children. In a study to describe

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which symptoms that, according to parents, cause most problems for children receiving cancer treatment; and to explore whether there is a relationship between parents' ratings of their children's symptoms and their own post-traumatic stress at 1 week (T1), 2 months (T2), and 4 months (T3) after a child's cancer diagnosis, the following symptom areas were identified to cause the most problems for children undergoing cancer treatment: emotional distress, fatigue, nutrition, and pain (most problematic). The opinions of both the patient and the parent are important in paediatrics.¹⁴

Children with cancer experience repeated invasive and almost always painful medical procedures such as bone marrow biopsies, lumbar punctures, dressing of wounds, etc. The American Academy of Pediatrics recommendations on the management of pain and anxiety associated with procedures for children with cancer are as follows:

- maximise comfort and minimise pain using both non-pharmacologic and pharmacologic interventions;
- prepare the child and family, consider the developmental age of the child;
- support family and child involvement;
- assure provider competency in performing procedures and sedation;
- use appropriate monitoring to assure safety.¹⁵

However, management of painful procedures in children with cancer must be tailored to the individual patient by effective communication between the child, parents, and medical staff of successful multimodal interventions.¹⁶

Conclusion

Relief from pain and troubling symptoms is vital for preserving the quality of life for patients with life-limiting illnesses across Africa. It is important, therefore, that clinicians and providers continue to advocate for effective strategies that address the multiple challenges to opioid availability in the continent. More specifically, strategies are needed to facilitate the introduction of supportive policy environments, e.g. a task-shifting policy to enable suitably trained nurses to prescribe stronger medicines (such as morphine), educational initiatives to address the misperceptions of the general public and healthcare workers regarding opioids, and measures to address supply-chain obstacles that impede drug availability.

Case study

A 9-year-old HIV-negative girl was referred to the Cancer Institute with a histological diagnosis of Burkitt's lymphoma (BL). She presented with a 5-week history of a right mandibular swelling and associated B symptoms. Her parents are peasant farmers with a very limited income and they could not afford treatment. The swelling was painful and she described it as 'too much' so that she could not sleep. She was unable to eat because of loose teeth and the growing size of the tumour. The swelling produced an offensive odour that was distressing to the patient and family. She had nausea and vomiting, and was extremely worried.

Physical examination revealed a firm tender swelling involving the right mandible with a foul-smelling discharge. The patient had loose teeth with some missing. She also had a hepatosplenomegaly and two small pelvic masses. Investigations revealed hilar adenopathy, bilateral ovarian masses, lymphadenopathy, and moderate ascites.

She was started on first-line chemotherapy (cyclophosphamide 30 mg/kg; Vincristine 2 mg/m² and methotrexate 15 mg/m²) but received only four courses out of six because the parents lacked the funds to take her back for chemotherapy. This resulted in disease progression and a need for second-line therapy for which she received only two courses with no improvement. Her symptoms were getting worse even when she was started on third-line therapy, following support from a well-wisher.

Her pain was controlled using oral morphine and NSAIDs and distressing symptoms were controlled with support from the palliative care team. The disease progressed and eventually she passed on peacefully at home.

A doctor's comment

Over 95% of the patients on my cancer ward experience pain. By the time they are admitted most of them have been on NSAIDs (non-steroidal anti-inflammatory drugs) but without optimal pain control, and in need of strong opioids such as morphine. The second most common symptom is nausea and vomiting usually as a complication of chemotherapy. Most patients have more than one symptom and this is made worse by the absolute lack of funds to help meet the costs for investigations and medicines that might not be in the hospital. Sometimes we get frustrated seeing a patient suffering because they have no means of either buying the missing medicines and/or investigations. Some also come back late with advanced disease because they did not have transport to come back to the hospital.

We are lucky that there is a hospital palliative care team that helps our patients get their pain and other distressing symptoms controlled. Oral morphine is now readily available on the ward for patients with moderate-to-severe pain. *S Kibudde MD*

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