The use of outcome measures and pain scales in palliative care and clinical practice

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Abstract
The provision of palliative care in sub-Saharan Africa is a concern. A limited number of well resourced palliative care settings are available. Patient-level outcome measures are necessary to monitor and improve practice and patient care. This paper focuses on the use of the African Palliative Care Association (APCA) African Palliative Outcome Scale (POS) and pain scales used in clinical practice.

Introduction
Over the last two decades, the need for palliative care in sub-Saharan Africa has increased with the growing human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) pandemic and the high burden of disease. Palliative care is relevant for patients at any stage of an incurable illness, and not only for patients with a terminal illness approaching the end of their lives.1

The World Health Organization (WHO) defines palliative care as an “approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychosocial and spiritual”.3 This definition underscores the provision of holistic care to enhance patients’ quality of life. Furthermore, it clearly highlights the importance of an accurate assessment and monitoring of symptoms and their causes so that good palliative care can be provided.1

Assessment of pain and outcomes in practice
Pain is regarded as one of the most common and distressing symptoms encountered by patients requiring palliative care.3 Evidence has shown that inadequate pain management in HIV-positive patients is common.4 An appropriate assessment of pain remains the cornerstone to optimal pain management in clinical practice. Pain requires ongoing individualised assessment, conducted at regular intervals, and recorded so that everybody involved in the patient’s care is aware of the pain problem.5 A number of tools are available for the assessment of pain, each focusing on a different dimension of pain.3 Unidimensional pain rating scales are used when considering pain assessment limited to the dimension of intensity. Commonly used pain rating scales include the visual analogue scale, categorical numerical rating scale and the categorical verbal rating scale (Figure 1). Although these scales are used to measure pain intensity, they can also be used to measure whether or not the patient’s pain has been relieved, e.g. by asking the patient to compare his or her current pain with previous pain experienced.3

Multidimensional pain scales are used to assess different dimensions of pain, i.e. functional, emotional, social and spiritual. Examples of multidimensional pain scales include the Brief Pain Inventory (BPI), which provides information on the history, intensity, location and quality of the pain; and the McGill Pain Questionnaire, which provides global scores and subscale scores that reflect the sensory, affective and evaluative dimensions of pain.3

With a holistic approach to palliative care, the focus is not only on physical pain and its dimensions, but also on the psychological and spiritual care of the patient and his or her family. This necessitates assessment of other needs, in addition to pain measurement.6 The APCA African POS is a multidimensional scale which was developed for this purpose and measures pain, as well as other palliative care outcomes.7

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African Palliative Care Association African Palliative Outcome Scale

Although considerable progress has been made in terms of the provision of palliative care in sub-Saharan Africa, it is still in the early stages of development and faces many of the same challenges as the provision of all health care, namely poverty, weak economies and health systems, a lack of healthcare professionals and in many cases, patients living in isolated rural areas, far from healthcare facilities, with poor transport facilities.6,7

The APCA African POS was the first patient-level outcomes measure to be validated in Africa with evidence of good psychometric properties. It was reported to be well comprehended and easy to use, making it ideal for use by African patients and families affected by life-limiting diseases.8 The tool is suitable for measuring care outcomes in patients with life-threatening conditions, as well as outcomes in patients suffering from chronic conditions, such as hypertension, diabetes and epilepsy, but also receiving palliative care.

The APCA African POS addresses five key domains of palliative care (Figure 2), in line with the WHO definition of palliative care. It contains 10 questions. The first seven are directed at the patients and the last three at the family caregivers. Responses to all of the questions are scored using a Likert scale from 0-5, with numerical and descriptive labels (Figure 3).9

The questions in the APCA African POS are simple (brief), and repeated over a short period (ideally seven days). This enables the healthcare team to assess and subsequently adjust the care provided as required.6 Another advantage is that information on the services being provided is obtained from both the patient and the family which provides the healthcare professional with an indication of the care and services provided to the patient.8

A more detailed analysis of the results of all of the patients in the facility would provide an overview of service delivery and areas requiring improvement.6 The repetitive use of the APCA African POS can also demonstrate improved outcomes for patients and families receiving palliative care over time.6

Pain and symptom relief form an integral part of paediatric palliative care, which relates closely to adult palliative care, and has been identified as a global concern.10

Management of pain according to the World Health Organization analgesic ladder

Pain management is one of the main domains of palliative care. The WHO11 recommends the use of a three-step analgesic ladder, based on the severity of the pain, when managing pain in adult patients. Any of the rating scales or the pain scale included in the APCA African POS can be used to measure the patient’s pain
and guide treatment of the pain according to the WHO analgesic ladder.

Three key concepts of pain management apply, namely “by mouth”, “by the clock” and “for the individual”. Firstly, analgesic medicine should be given by mouth, if possible. Secondly, it should be given at fixed time intervals and the dose titrated according to the patient’s pain. The next dose should be given before the previous dose has fully worn off. Lastly, the choice and dosages of the analgesic must be tailored to the patient.

Compared to adults, not as much published literature is available in terms of pain measurement and management in children. Similar to adults, children’s needs should also be addressed. This highlights the importance of having an outcome measure available for them as well. Work is currently in progress in sub-Saharan Africa on the development and validation of an APCA African POS for children.10

The WHO recently reviewed the three-step approach to pain treatment and subsequently advocated a two-step paediatric pain ladder. According to these new guidelines, the first step, as with adults, would be the treatment of mild pain with non-opioid analgesics, e.g. paracetamol and ibuprofen. The intermediate step (step 2 in the case of adults), which entails the use of a weak opioid (mainly codeine), is no longer advocated for pain management in children. Therefore, the second step for children (step 3 in the case of adults) is the use of strong opioid analgesics, e.g. morphine, for the relief of moderate to severe persisting pain.12,13

**Conclusion**

Palliative care in sub-Saharan Africa is a growing concern. There has been an increase in the patient numbers with respect to both communicable and non-communicable disease. Pain management is a central part of palliative care. The APCA African POS, together with the WHO analgesic ladder, can be used in the palliative care setting to monitor and improve practice and the quality of care provided to patients and their family members. Pharmacists who are involved in the direct care of patients can use these and other tools to measure patient outcomes and to guide treatment in palliative care.

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**Figure 3: African Palliative Care Association African Palliative Outcome Scale**

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<thead>
<tr>
<th>Ask the patient</th>
<th>Possible answers</th>
</tr>
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<tbody>
<tr>
<td>1. Please rate your pain [from 0 (no pain) to 5 (the worst or overwhelming pain)] during the last three days</td>
<td>0 (No pain) to 5 (worst or overwhelming pain)</td>
</tr>
<tr>
<td>2. Have any other symptoms, e.g. nausea, coughing or constipation, affected how you feel in the last three days?</td>
<td>0 (Not at all) to 5 (overwhelmingly)</td>
</tr>
<tr>
<td>3. Have you felt worried about your illness in the past three days?</td>
<td>0 (Not at all) to 5 (worst or overwhelming worry)</td>
</tr>
<tr>
<td>4. Over the past three days, have you been able to share how you feel with your family or friends?</td>
<td>0 (Not at all) to 5 (yes, I’ve talked freely about it)</td>
</tr>
<tr>
<td>5. Over the past three days, have you felt that life is worthwhile?</td>
<td>0 (No, not at all) to 5 (yes, all the time)</td>
</tr>
<tr>
<td>6. Over the past three days, have you felt at peace?</td>
<td>0 (No, not at all) to 5 (yes all the time)</td>
</tr>
<tr>
<td>7. Have you had enough help and advice for your family to plan for the future?</td>
<td>0 (Not at all) to 5 (as much as wanted)</td>
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<tr>
<th>Ask the family carer</th>
<th>Possible answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. How much information have you and your family been given?</td>
<td>0 (None) to 5 (as much as wanted)</td>
</tr>
<tr>
<td>9. How confident does the family feel for caring?</td>
<td>0 (Not at all) to 5 (very confident)</td>
</tr>
<tr>
<td>10. Has the family been worried about the patient over the last three days?</td>
<td>0 (Not at all) to 5 (severe worry)</td>
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Undergraduate and in-service training of healthcare professionals to equip them in the use of outcome scales, such as the APCA African POS, would benefit the integration of palliative care into the national health system in South Africa.

References


Erratum

The June issue of the SAPJ carried a report on the Fellows dinner held in Port Elizabeth during the Pharmaceutical Society of South Africa (PSSA) conference. In the article, the KwaZulu-Natal Coastal Branch of the PSSA was thanked for organising the dinner, which was in fact organised by the Cape Midlands Branch. The editor apologises to the Cape Midlands Branch for the embarrassment caused, especially since it was a superb evening.

Ronnie Hill and Mellis Moorcroft, both Fellows from the Cape Midlands Branch of the PSSA