

Chapter 1

***How to Use This Guide***

***Overview***

Welcome to *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa*, hereafter referred to as ‘The Guide’. The Guide is adapted from *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS*, published in the United States in 2003. This new version has brought writers working in HIV/AIDS and palliative care in different parts of Sub-Saharan Africa, together with some of the original authors, to produce what we hope will be a comprehensive, yet simple and user-friendly manual for quality HIV/AIDS Palliative Care, relevant to our varying circumstances in sub-Saharan Africa (SSA).

The Guide is organized to address the many aspects of palliative care that are key in caring for the person living with HIV/AIDS. We have designed it to be a resource to health care workers (HCWs) of all cadres caring for patients with HIV/AIDS. It addresses the added social issues that are part of the HIV pandemic in Africa, such as poverty alleviation, food security, and planning care for orphans and vulnerable children. The Guide also covers models of care appropriate to Africa, training and health policy development for palliative care, and availability of drugs including opioid analgesics. A wealth of expertise and experience in the areas of HIV/AIDS and palliative care has provided a unique document that expands the realms of both disciplines.

It is our sincere hope that you and your colleagues will find this guide useful as you integrate the principles and framework of palliative care into the practice of high-quality HIV/AIDS care.

***Authors***

Lydia Mpanga Sebuyira

Liz Gwyther

Anne Merriman

***At a Glance***

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## What Do We Mean by Sub-Saharan Africa?

Sub-Saharan Africa (SSA) is a term commonly used to talk about countries south of the Sahara desert. These are shown in the map (see Figure 1.1). Sub-Saharan Africa has just over 10% of the world's population, but is home to more than 60% of all people living with HIV. (UNAIDS/WHO 2004). The HIV/AIDS epidemics coursing through this region are highly varied — both between and within sub-regions. It is therefore inaccurate to speak of a single, 'African' epidemic, and misleading to apply insights about the epidemic gleaned from specific parts or sub regions, to the entire sub-Saharan Africa region. In the same way, different countries within the region have different economic capacities, and health care systems, drugs, and other resources available vary widely. This Guide addresses the needs of people living with HIV/AIDS and meeting these needs in widely differing cultures, settings and economic circumstances.

Because of this, some of the medications and advice given in this Guide may not always suit your own circumstances. We have tried to address different situations by having many authors from all over SSA. You need to have experience and ability to discern what is acceptable and affordable to each particular patient and family in order for your care to be personalised and holistic.

Countries differ in what is right for them today according to their history and economic circumstances. Needs change, not just today but also over the years leading up to today, the day I am in need. In no other area of medicine are we closer to knowing the personal lives of our patients and families. Let us respect this privileged position and be there for them, treating them as guests and assuring them of our continued support through us or our networking friends.

Some more sophisticated and expensive medicines, not affordable to most, are discussed in this guide; we need to know about them. Many affluent African patients from more resource-limited countries are nowadays going to private hospitals in South Africa or even Europe for treatment and come back on these drugs. We need a reference to help us find out more about these drugs, and if these are not available, to change to one that is suitable and available in our own economic circumstances.



## Why Have This Palliative Care Guide?

### *Palliative Care Is Part of HIV/AIDS Care*

**Both/and, not either/or:** Palliative care is a vital part of the continuum of care necessary for people living with HIV/AIDS and their families. Contrary to previous thinking, this is not an ‘either/or’ situation, where patients receive *either* disease-modifying treatment (e.g., treatment of opportunistic infections and antiretroviral therapy) *or* palliative care. In this Guide describe the ‘both/and’ position, in which disease-modifying treatments are offered *together* with palliative care, appropriate to the needs of patients and their families, at any stage in the disease, and in the place best suited to them. This promotes the best quality of care for patients and their families.

**Palliative care is a new field:** Many HCWs in SSA will not have received palliative care training in their pre-registration training, making this Guide important for those currently providing care.

**ART does not replace palliative care:** And finally, with ART becoming available in greater areas of SSA, HCWs need to see palliative care as relevant to the care of all of their patients with HIV/AIDS, including those receiving ART.

See Chapter 2 for a detailed discussion of the role of palliative care in HIV/AIDS.

### *Other Interesting Definitions for Africa*

#### **Different Approaches to Healing**

In this Guide, we will use the following definitions of different approaches to medicine that are relevant in Africa:

**Western medicine:** The medical profession as practiced within formal health care systems by trained doctors, nurses, clinical officers, and other health care workers.

**Traditional medicine:** The profession of healing as practiced by traditional healers and practitioners who function within a long historical tradition in a specific cultural community. Traditional Medicine can ‘complement’ or work alongside Western medicine but is referred to in this Guide as traditional, not complementary. For clarity, we will avoid the term ‘alternative’. In an effort to regulate the profession and protect the community from harmful or exploitive practices, many countries have begun to regulate the practice of Traditional Medicine. Following the example of the health care system for Western medicine, practitioners join or are certified by national organisations. (See Chapter 15: Traditional Medicine for more detail.)

**Complementary care:** Practices such as acupuncture, massage, reflexology, and other usually ancillary treatments which are often practiced outside the formal health care system or in conjunction with Western medicine; again, we avoid the term ‘alternative’. (See Chapter 18: Complementary Care for more detail.)

### Categories of Palliative Care Interventions

In this guide, in keeping with the philosophy of palliative care, **non-pharmacologic interventions** for care to the patient and family are highlighted as being equally as important as **pharmacologic interventions**. Non-pharmacologic methods must be passed on to the family as well as to informal caregivers who reach the majority of people. Community-based caregivers can help to identify patients needing referral on to formal health care workers. It must be stressed that non-pharmacologic management is not a substitute for care in settings where drugs are not available. It is a part of all palliative care,

whatever the level of resources. The two types of interventions should be used together whenever possible as part of best practice. The considered opinion and the experience of the palliative care experts writing this guide is that quality palliative care can be given in a resource-limited setting, using sound palliative care knowledge, skills, and an essential drugs list (see Appendix 2).

Please refer to the List of Abbreviations to see other terms we have chosen to use in this Guide.

### Who Is the Guide For?

This Guide is intended to be used by all HCWs in SSA. By reason of sheer numbers, the HCW who is most likely to be involved in caring for people living with HIV/AIDS, and thus would need palliative care knowledge and skills, would be a nurse. There may be doctors, clinical officers, nursing aides and in a few urban areas, allied professionals like social workers, occupational therapists and physiotherapists, and spiritual leaders, who would constitute the ideal multidisciplinary team of palliative care. However, the reality in most of SSA is that these latter cadres are scarce and the nurse may be the lone practitioner or the most accessible and available HCW. Therefore, this Guide is particularly intended to be easily understood by and useful to the nurse.

The Guide also contains a considerable amount of drug information, useful for doctors, who in most SSA countries are the legal prescribers, and for other HCWs looking after patients taking these drugs. Because drugs and standard treatments vary throughout SSA, readers are also encouraged to consult their national treatment guidelines as well as their local primary care and HIV/AIDS HCWs.

Another hard reality in SSA is that many people may never see a health care worker in their lives. It may either be by choice or due to distance to the nearest health centre. For example, 88% of the Ugandan population live more than 10 km away from the nearest health facility (Armstrong 2000). This majority would likely be seen by traditional healers and other informal caregivers such as community care workers, who can be trained and linked into the health care system by referral networks.

## What Can be Found in This Guide?

### *What Each Part Contains*

**Part 1: Introduction** provides our vision for the use of the guide and presents an overview of the key issues in HIV/AIDS and palliative care in Africa today.

**Part 2: Clinical Supportive Care** addresses pain and symptoms that cause much of the burden to patients in more advanced stages of HIV disease. It includes chapters on neuro-psychiatric problems, pharmacology, integration of palliative care with antiretroviral therapy, and a chapter on care at the end of life. Readers should also consult their own national guidelines for the most up-to-date, locally-appropriate treatments.

**Part 3: Psychosocial/Spiritual and Traditional Care** focuses on the many other dimensions included in the palliative care approach. Part 3 incorporates spirituality, care for the caregiver, communication issues, and nutrition in HIV/AIDS. Topics that hitherto have not been widely written about in palliative care, but are pertinent to HIV/AIDS and to the African context, are discussed in chapters on traditional (African) medicine and human sexuality.

**Part 4: Environmental Factors that Influence Care** includes chapters on issues that affect palliative care in Africa, such as ethics and human rights, financial and legal issues, and issues related to special populations. The role of the nurse in palliative care in resource-limited settings is examined.

**Part 5: Care of Children and Adolescents** deals with the whole range of issues relevant to the growing number of children and adolescents living with HIV/AIDS.

**Part 6: The Public Health Approach to Palliative Care** looks at the systems aspects of providing palliative care, including the effects of economics on provision of service and models of care. Chapters discuss each of the three foundation measures necessary for a sustainable palliative care service, namely, the role of the government, drug policy, and education. Other chapters provide information on setting up new palliative care services, management issues in palliative care, and palliative care associations in Africa.

**Appendices** includes a list of resources for palliative care relevant to Africa, a table of recommended essential drugs for HIV/AIDS palliative care, and a table of drug interactions.

### *Finding Your Way Round the Chapters*

Navigation through the chapters has been made easy by the following means:

- The list of **Abbreviations** at the front of the Guide provides easy reference.
- Each chapter begins with an Overview and list of the topics At a Glance.
- The **Table of Contents** on each chapter's second page includes page numbers, and sometimes major subheadings, for easy reference.
- The Clinical Chapters in Parts 2 (Clinical Supportive Care) and 5 (Care of Children and Adolescents) generally address symptoms and conditions in the following order:

#### **Assessment**

#### **Management:**

*Treating Reversible Causes*

*Non-pharmacologic Management*

*Pharmacologic Management*

- The order of management interventions is deliberate. As discussed above, all three aspects of management are important, including non-pharmacological and pharmacological care.

- The essential palliative care interventions are mentioned first. Additional interventions not often available in resource-limited settings are listed separately, preceded by the phrase **If available, consider....**
- Important points are highlighted with the use of Tables, Boxes, Figures, and Bulleted Lists.
- Most chapters include **References** and **Suggested Resources**.
- The **Appendices** provide reference information for the reader.
- The **Topics Index** and the **Drug and Therapies Index** at the end of the Guide can be used to find specific information.

## References

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