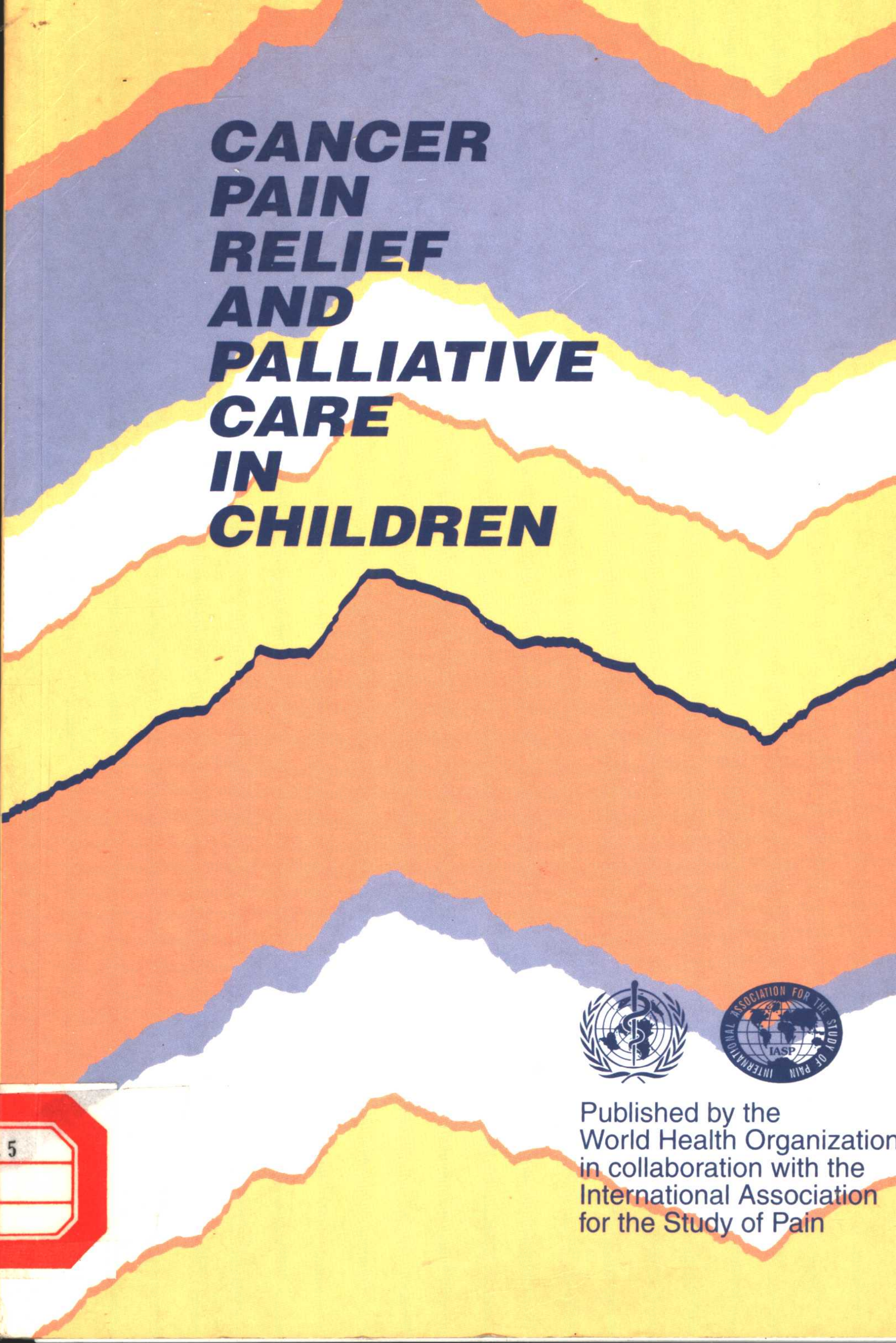

CANCER PAIN RELIEF AND PALLIATIVE CARE IN CHILDREN

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Preface

In 1993, WHO and the International Association for the Study of Pain (IASP) invited experts in the fields of oncology, anaesthesiology, neurology, paediatrics, nursing, palliative care, psychiatry, psychology, and pastoral care to attend a conference on the management of paediatric cancer pain and palliative care. At this meeting, in Gargonza, Italy, it was agreed that pain relief should be regarded as an essential component of cancer care and that, with commitment and the appropriate use of available technology, most children with cancer throughout the world can receive both pain relief and palliative care – even if cure is impossible.

A number of fears and misunderstandings have led to inadequate pain control in children with cancer. These include:

- fear of drug "addiction", in the lay sense of the term, which has led to the limited administration of opioid analgesics, generally as a last resort, with the result that children have been deprived of the potent drugs that can effectively relieve severe cancer pain;
- misunderstanding of the pharmacodynamics and pharmacokinetics of opioid analgesics in children and consequent use of inadequate doses, at inappropriate intervals, by unnecessarily painful or less effective routes;
- lack of knowledge about the nature of children's perception of pain and illness, so that some individuals responsible for treating children with cancer fail to evaluate all the factors that cause or contribute to pain and thus fail to treat it adequately;
- lack of information about the simple behavioural, cognitive, and supportive techniques that can reduce pain, so that health professionals cannot teach these valuable techniques to children or their families.

It is for reasons such as these that it was considered necessary to produce a book dealing exclusively with cancer pain relief and palliative care in children. The intention is to clear up the misunderstandings and provide the missing information, and thus offer a comprehensive guide to pain management in childhood cancer.

The guidelines contained in this book have been approved by both WHO and IASP. Although intended largely for health-care workers with primary responsibility for treating children with cancer, the book should find wider readership among policy-makers and those concerned with the legislation that governs availability of opioid analgesics. It is a companion volume to WHO's *Cancer pain relief*, published in its second edition in 1996 and containing a guide to opioid availability. As noted in that publication, management of cancer pain should not be undertaken in isolation, but as part of comprehensive palliative care. Relief of other cancer symptoms, and of psychological, social, and spiritual problems, is paramount. Attempting to relieve pain without addressing the patient's non-physical concerns is likely to lead to frustration and failure.

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Contents

Introduction

Children with cancer do not need to suffer unrelieved pain. Existing knowledge provides a basic approach for relieving cancer pain that can be implemented in developed and developing countries alike. Effective pain management and palliative care are major priorities of the WHO cancer programme, together with primary prevention, early detection, and treatment of curable cancers.

Pain management must begin when a child is first diagnosed with cancer and must continue throughout the course of the illness. Analgesic and anaesthetic drug therapies are essential in controlling pain and should be combined with appropriate psychosocial, physical, and supportive approaches to this problem.

Extent of the problem

Cancer is a major world health problem with wide geographical variations in its incidence. Out of every one million children aged 0–14 years, approximately 130 develop cancer every year (*1*). In developed countries cancer is the leading cause of death from disease in 1–14-year-olds (*1*). Approximately 67% of children can be cured if the disease is diagnosed early and appropriately treated (*2*), although the cure rate depends upon the specific type of cancer. Unfortunately, however, most children with cancer do not receive curative therapies because they live in developing countries (*3*): the disease is usually advanced by the time of diagnosis and curative therapies are frequently unavailable. Palliation of pain and other symptoms is a component of care for all children with cancer. For some children, the emphasis of care may be primarily one of palliation.

During the course of their illness, almost all children with cancer experience some pain, caused either directly by the disease or by invasive procedures, treatments, or psychological distress. At present, there are no accurate figures on the worldwide magnitude of different types of cancer pain in children because countries differ widely in their diagnostic capabilities and reporting systems. However, recent documentation of childhood cancer pain within specific treatment centres in developed countries indicates that all children with cancer do experience pain related to their disease and/or treatment, with more than 70% of them suffering from severe pain at some point (*4*). Although the means exist for its effective relief, children's pain is often not recognized or, if recognized, may be inadequately treated, even when sufficient resources are available.

Unrelieved pain places an enormous burden on children and families. Children become afraid of future pain, and develop mistrust and fear of hospitals, medical staff, and treatment procedures. They become irritable, anxious, and restless in response to pain and may also experience night terrors, flashbacks, sleep disturbance, and eating problems. Children with uncontrolled pain may feel victimized, depressed, isolated, and lonely, and their capacity to cope with cancer treatment may be impaired.

Parents and other close relatives of a child in pain often feel angry and distrustful towards the medical system, and experience depression and guilt about being unable to prevent the pain. They may even come into conflict with the child and will have disturbing memories of his or her pain and suffering.

Poorly managed pain affects health care workers: it numbs their compassion, creates guilt, and encourages denial that children are suffering. Its effects on children and their families are enduring, and children can suffer from post-traumatic stress symptoms, phobic reactions, depression, and pain years after the end of treatment.

The nature of children's pain

Children understand the basic concept of pain at a very young age and can describe both its emotional and physical aspects. Nonetheless, pain is a difficult sensation to define simply and precisely; the definition provided by IASP is *"an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage"* (*5*).

Pain is always subjective; each individual learns the application of the word through experiences related to injury in early life. Physical pain is unquestionably a sensation in a part, or parts, of the body, but it is always unpleasant and is therefore also an emotional experience. New information about the nature of pain has led to an improved understanding of how children experience it and how their suffering can be alleviated. The pain system is now known to be much more variable and complex than was previously believed.

Simply expressed, tissue damage causes activity in specialized receptors and nerves that can lead to pain, but this nerve activity can be modified before the information is relayed to the brain. Activity in peripheral non-pain nerves (e.g. those stimulated by touch) can inhibit the effects of pain nerve activity at a spinal level. Also, activity in central nerves descending from the brain (i.e. nerve systems that are activated by thoughts, behaviours, and emotions) can inhibit the activity caused by tissue damage at spinal levels. Thus, the spinal cord provides a complex "gating" system for enhancing or blocking pain signals (*6*).

Pain in children with cancer is usually related to the disease or to its treatment. It depends not only upon the specific source of physical damage, but also upon the complex interactions among peripheral pain and non-pain nerves, and upon activity in central descending pain-inhibitory systems. Thus, the same type of tissue damage can cause pain of different nature or severity in different children or in the same child at different times.

In addition, environmental, developmental, behavioural, psychological, familial, and cultural factors profoundly affect pain and suffering (*7–11*). The physical environment and the attitudes and behaviour of caregivers, as well as children's own behaviour, thoughts, and emotional states, can profoundly increase or decrease children's cancer pain.

PART I

Comprehensive care for children with cancer

Introduction

Comprehensive care of children with cancer includes curative therapies, pain management, and symptom control, plus compassionate support both for the children and for their families. The diagnosis of cancer abruptly changes the lives of all family members. The initial reactions of parents are disbelief, anguish, and despair, and the sudden feeling that they have little control over their lives or the life of their child. They become anxious, frightened, and uncertain about the future; normal life temporarily stops. Parents and children therefore require special psychosocial and spiritual support to help them learn to live with cancer. In some specialized cancer centres, this type of support is provided from the time of diagnosis throughout the child's medical care. Other centres, however, continue to focus exclusively on the medical management of the disease and show little understanding of the importance of adequate analgesia and psychosocial and spiritual support. As a result, many children with cancer may not receive comprehensive care even though this should be possible in almost all countries.

It is essential for health providers to recognize that children, their parents, and their siblings will all react to a potentially fatal illness differently, according to their own personalities, past experiences, and perception of the disease. To support and assist children effectively, it is important to know them and their families, their beliefs about life and death, and their current sources of emotional support. Such an approach is central to the concept of palliative care.