

Original Article

Pediatric Pain Prevalence and Parents' Attitudes at a Cancer Hospital in Jordan

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Abstract

There has been little research on implementation of pediatric pain programs. These studies are part of a project to develop such a program for the King Hussein Cancer Centre in Jordan. Study 1 captured information on pain prevalence in 35 children using chart reviews and parent/child interviews to establish baseline pain burden. Forty-seven percent of children had pain at the time of interview; 11% had "a lot" of pain and only 22% received analgesics. Twenty-two parents were interviewed in Study 2 to identify attitudes toward pain management. Thematic analysis revealed six themes: 1) pain can and should be managed; 2) God's will; 3) parent's worst pain was emotional pain due to child's diagnosis; 4) belief that their presence could ameliorate their child's pain; 5) desire for shared decision making; and 6) the child's responsibility to express pain. These study results were used to inform the action research approach in the overall project. J Pain Symptom Manage 2006;31:440-448. © 2006 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Pediatric pain, pain service, child health services, cancer pain, developing countries

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Introduction

Management of children's pain has become the focus of attention for clinicians, researchers, and policy-makers worldwide. Since work in the early 1980s showed that children received less treatment than adults with equivalent pain, and the publication of the first textbook on pain in children in 1987,¹ there have been significant improvements in awareness, assessment, and treatment of children's pain. Hundreds of research papers and textbooks have been published, and international research meetings are held on the subject every year. However, many children still suffer pain unnecessarily.

Cancer is recognized as a significant cause of children's pain due to the disease itself, diagnostic and treatment procedures, and the side effects of surgery, chemotherapy, and radiotherapy. Miser et al.^{2,3} reported that three-quarters of children had pain at diagnosis of cancer and that pain was an issue in 50% on a continuing basis. Advancements in pediatric cancer treatment programs in many countries, both developed and developing, have not been associated with parallel advancements in pain management services. Concern about children's pain management at the King Hussein Cancer Center (KHCC) in Amman, Jordan, provided an unprecedented opportunity to develop a comprehensive pediatric pain program and to study its implementation.

Despite the fact that many of the children who suffer from cancer live in the developing world, only a small number have access to cancer control resources.⁴ As a result, many children with cancer receive care only after the disease has reached an advanced stage.⁵ The World Health Organization⁶ asserts that simple pain management practices could be implemented worldwide, and these practices would bring about the greatest improvements in the lives of children with cancer and their families. Yet, there are barriers to the implementation of basic pain relief measures in the developing world, which include the countries' resources, access to opioids, and cultural influences.^{4,7}

As in many other low- and middle-income countries, one of the barriers to appropriate pain management in Jordan has been access to opioids. In Jordan, there exist restrictive laws with respect to the ordering and dispensing of opioids, leading to ineffective prescribing and a decrease in opioid access for the public. All pharmacies in Jordan can apply for an opioid license, but very few do. Presently, there is only one community pharmacy in Amman that stocks morphine, but in limited forms and at a relatively high cost (Dr. Imad Treish, personal communication). The reality is that patients must have their opioid prescriptions filled at the treating hospital to obtain the opioid in the form ordered by the physician, even if the patient lives in a rural community many miles away.

Culture is reported to be another potential barrier to pain relief strategies. Culture influences the meaning and expression of pain

and, therefore, may impact the treatment of pain in a particular society.⁸⁻¹⁰ A number of assumptions exist concerning pain management in Arab and/or Muslim cultures. Abu-Saad¹⁰ suggested that pain management would be complicated by cultural or religious beliefs. Pain might be viewed as a result of God's will and thus should be accepted. Arab Muslim families are said to have a patriarchal structure;¹¹ and decisions about treatment might not be made in the father's absence.¹² There is also a belief that children and family members may be reluctant to express pain in front of strangers,⁹ and, therefore, their suffering may go unnoticed. It might be expected that families would have a fear of opioids and would be reluctant to use medications, both from interpretations of the teachings of Islam and from government regulations constraining opioid use. However, many of these assumptions have not been validated. There is limited information and no research on Jordanian parents' attitudes and beliefs regarding their child's pain management.

It has been asserted that education of health professionals is the first step in changing practice in the management of pain. However, some studies indicate that education alone is inadequate in changing practice^{13,14} and suggest that other approaches to improving pain management are necessary, including implementation of assessment tools, policies, and documentation, and staff participation during the planning and implementation of change.¹⁵⁻¹⁸ Because of these identified barriers and challenges, we planned three studies: an audit of pain prevalence; assessment of parents' attitudes and beliefs about cancer pain and its treatment; and an action research project with the professional staff at KHCC to develop an effective pain service. The results of the first two studies helped to inform the process for the third study and are reported here.

Methods

Setting

The KHCC was built in Amman, Jordan, in the late 1990s to provide state-of-the-art cancer care for adults and children without discrimination on the basis of personal financial resources. In 2003, two of the authors (GAF

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