Pain Practices: A Cross-Canada Survey of Pediatric Oncology Centers

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Before implementing a pain education program, the Canadian Association of Nurses in Oncology conducted a national survey on cancer pain management. The survey focused primarily on adult cancer pain and a second survey was undertaken to describe the supports in place across Canada for best practice pediatric cancer pain management. Twenty-eight pediatric cancer centers responded to a survey that was composed of 48 questions about the types of supports that are in place related to pain assessment, management, and pain-related staff and family education. Results of the survey indicated that, for the most part, children have access to the components of best practice pain management. In addition, areas of strength and areas that need to be further developed were identified and the implications for the findings discussed.
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All children with cancer experience pain at some point during the diagnosis or treatment of their disease. Pain is primarily from the growth of the cancer as it impinges on organs, bones, and nerves or from the treatment that may involve surgery, radiation, and chemotherapy. Procedural pain that is typically associated with considerable distress is also a significant part of cancer treatment. In anticipation of painful procedures such as bone marrow aspirations, venipunctures, and lumbar punctures, some children develop anxiety-related symptoms such as nausea, vomiting, anorexia, skin rashes, insomnia, and nightmares (Katz, Kellerman, & Siegel, 1980). Other children are combative and uncooperative, which lengthens the time to perform procedures and may compromise the safety of the child and the accuracy of the procedure (Adams & McKenna, 1991; Perin & Frase, 1985). The prevention and relief of pain and distress should be part of an institutional commitment to comfort for children with cancer. Pediatric health care providers must have the education, values, attitudes, and motivations to put this commitment into operation. In addition, the protocols and supports must be in place within the organization to use the available pharmacologic and nonpharmacologic methods for managing pain and distress.

The World Health Organization (1998) suggests that up to 90% of cancer pain can be controlled easily and effectively with the proper assessment and treatment protocols in place. The Canadian Association of Nurses in Oncology (CANO) has developed a pain initiative to improve cancer pain management by establishing national nursing practice standards and providing pain education to nurses at basic and advanced levels (Balneaves, Hershon, & Allen, 1999). CANO is also committed to developing strategies to overcome barriers to cancer pain management and raise public awareness about what constitutes proper pain management. As

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part of the assessment phase of the CANO pain initiative, a national survey on cancer pain management was conducted in June 1998. The results of the survey, which focused primarily on adult cancer pain, indicated that more detailed information about pediatric cancer pain management was needed. The purpose of this study was to examine current pain assessment and management practices in pediatric oncology centers across Canada.

Many studies have examined the problem of uncontrolled pain in pediatric oncology patients. Miser, Dothage, Wesley, and Miser (1987) analyzed 356 patient visits to the pediatric branch of the National Cancer Institute and reported that 54% of outpatients and 26% of inpatients reported pain. The predominant cause of pain for both inpatients and outpatients was treatment related, rather than from the cancer itself. Oral mucositis was most problematic, followed by postoperative pain, neuropathic pain from vincristine and phantom limb pain from amputation. Approximately 50% of the inpatients and 33% of the outpatients were receiving opioid analgesia for pain. McGrath, Hsu, Cappelli, Luke, Goodman, and Dunn-Geier (1990) surveyed children who were outpatients at a cancer clinic and reported that 75% of the children experienced severe pain from bone marrow aspirations, 50% experienced moderate to severe pain from treatment, and 25% had recent pain from the disease. In addition, they reported that analgesics were not widely prescribed. Broome, Richtsmeier, Maikler, and Alexander (1996) surveyed physicians and nurses about pain assessment and management practices in U.S. teaching hospitals. Sixty percent of respondents identified pain-specific standards of care or treatment protocols in place in their institutions, but only 25% of respondents acknowledged that these protocols were being used greater than 80% of the time. In addition, the respondents reported that pain assessment and management was less effective for infants and younger children as compared to other age groups.

Ljungman, Kreuger, Gordh, Berg, Soresen, and Rawal (1996) surveyed all 47 pediatric hospitals in Sweden about their pain management practices with pediatric oncology patients. Physicians and nurses from 35 oncology centers responded to the survey. Forty percent of respondents indicated that moderate to severe pain was observed frequently in children with cancer and 72% believed that pain could be controlled and treated more effectively. Forty-one percent of respondents indicated that treatment-related pain was the greatest contributing factor to pain in these patients, and 34% identified procedural pain as more difficult to cope with then pain from the disease itself. Tyc, Bieberach, Hinds, and Sifford (1998) surveyed 35 U.S. hospitals that provided cancer treatment to children. They reported that the delivery of pain management services varied considerably and there was a lack of standard pain assessment and management guidelines, protocols, and algorithms.

To date, no cross-Canada studies have focused on the types of supports that are in place for best practice pain management for children with cancer. The purpose of this survey was to describe current practice, to identify the best methods to obtain continuing education, and to describe nurses' perceptions of their practice with respect to pain management.

Methods

Survey Development

A survey that examined pain assessment and management practices specific to pediatric oncology was developed with input from oncology nurse experts, palliative care experts, and an oncology pharmacist. The survey has 48 questions and is divided into sections that examine the following components: pain assessment and documentation; procedural pain; treatment-related pain; patient education and home care; staff education; institutional support for best practice pain management; complementary therapies; palliative/end-of-life care; and demographics. A panel of eight pediatric oncology nurse experts reviewed the survey for clarity, relevance, and completeness. Revisions to the survey were made based on their feedback and the survey was then piloted with members of the CANO pain initiative committee that developed the adult cancer pain survey. The survey was in English and the introductory letter was in French and English.

Sampling Frame/Procedures

We were interested in sampling all Canadian hospitals and satellite clinics that provide pediatric cancer treatment. A list of all pediatric oncology centers was generated using lists obtained from the National Childhood Cancer Foundation, Candlelighters, and the Canadian Pediatric Society. This was cross-referenced with the CANO members' directory to find a CANO contact at each of these organizations. A cover letter and survey was sent via e-mail or fax to one contact person at each organization with the instructions to complete the survey alone or in consultation with colleagues. Respondents had the option of returning the survey by e-mail, fax, or mail. Follow-up e-mails and phone calls were made every 7 to 10 days until information was obtained from all oncology centers or respondents indicated they did not want to participate in the survey. Schaefer and Dillman (1998) suggest that giving individuals more than one format to respond to the survey will improve response rates.

Results

There were 28 organizations identified across Canada that provide pediatric cancer care; of those, 26 completed the survey for a response rate of 93%. Ten of the 11 pediatric hospitals in Canada are represented in the sample. Survey data were coded and analyzed using SPSS software and presented according to the categories that appeared in the survey.

Pain Assessment and Documentation

Respondents were asked to indicate if their nursing history or intake interview examined: current level of pain; history of pain; pain management regimen at home; child's behavior when in pain; and child's developmental level. Nine respondents (35%) indicated that their oncology center included all of these elements; five respondents (19%) indicated that no questions about pain were included in the intake interview. Most centers did include information about current level of pain (20/26; 77%), pain regimen at home (17/26; 65%), and, less frequently, the child's behavior when in pain (11/26; 42%).

All oncology centers used at least one type of pain assessment scale on the inpatient units. A numerical scale (0-10) was most frequently used (16/26; 62%), followed by a visual analog scale (10/26; 39%), and, infrequently, a behavioral observation scale (4/26; 15%). The 0 to 5 scale (7/26; 27%) and the cartoon faces scale (8/26; 31%) may be confounded because at least one of the cartoon faces scale, the Wong-Baker FACES scale, has an associated numerical scale of 0 to 5. All of the outpatient cancer clinics with the exception of two use a pain scale. Similar to the inpatient units, the most frequently used scale was a 0 to 10 numerical rating scale (15/26; 54%), followed by a 0 to 5 scale (6/26; 23%), a cartoon faces scale (7/26; 27%), a visual analog scale (5/26; 19), and, infrequently, a behavioral observation scale (3/26; 11%).

Pain assessment information is most likely to be found in the nurses or progress notes (25/26; 96%). In addition, eight (31%) oncology centers indicated that they had a specific pain flow sheet. Only four centers (15%) charted pain information on the graphic sheet with vital signs and three (11%) respondents indicated that there is no designated place for charting pain assessment information.

Perceptions of Practice

Respondents were asked to indicate how adequately pain is assessed, documented, and treated at their oncology center. The response categories were from 0% to 100% of the time in increments of 10. Most respondents (15 of 26) believed that pain was adequately assessed 80% of the time and only three respondents believed that pain was adequately assessed 50% or less of the time. The modal response for adequately treating pain was 80% of the time (7 of 26); four respondents indicated that pain was adequately treated 90% of the time and three respondents believed that pain was adequately treated 50% of the time or less. The adequacy of pain documentation was somewhat less than assessment or treatment. The modal score was 70% (7 of 26), and 10 respondents believed that pain assessment information was documented adequately 50% of the time or less. Only five respondents (19%) felt that pain was documented

TABLE 1.
Intravenous Sedation by Age for Bone Marrow Aspirations and Lumbar Punctures

Age*	Never *n*/%	Rarely *n*/%	Sometimes *n*/%	Most of the Time *n*/%	Always *n*/%
Young children (< 6 y)	7/27	0/0	3/12	3/12	10/39
School-age children (6-12 y)	7/27	2/8	1/4	4/16	9/35
Adolescents (>12 y)	6/23	3/12	2/8	4/16	8/31

*n = 23 respondents for all age categories.

adequately 80% of the time and no one indicated 90% or 100% of the time.

Respondents were asked to indicate, on a scale of 0 (not at all committed) to 5 (strongly committed), how committed they believe their oncology center is to excellence in pain management. Sixteen (62%) respondents believed their center to be strongly committed and chose "5" as the response, six (23%) respondents chose "4," and two (7%) respondents chose "3."

Procedural Pain

Respondents were asked to indicate what percentage of patients had a venous access device at their center. Eight (31%) centers indicated that 100% of their patients had venous access devices and 12 (46%) centers indicated that 90% of their patients had venous access devices. Other responses included one center each for 20%, 30%, 50%, 60%, and 70% of patients with venous access devices.

Respondents were asked to indicate if intravenous (IV) sedation was used for bone marrow aspirations (BMAs) and lumbar punctures (LPs) for young children, school-age children, and adolescents. Table 1 indicates the numbers and percentages for each response by age group. In 18 centers (69%) the department of anesthesia was responsible for administering IV sedation; the oncologist in two centers (8%); and a clinical nurse specialist, nurse practitioner, and registered nurse in one center (4%) each. The intensive care unit physician and the clinical associate were also specified in one center each.

For BMAs and LPs, eutectic mixture of local anesthetics was always used at 13 of 26 (50%) oncology centers; and for needlesticks (e.g., venipunctures, injections, implanted devices), sometimes 7/26 (27%), most of the time (12/26; 46%), or always (2/26; 8%). Intravenous midazolam (20/26; 77%), propofol (14/26; 54%), ketamine (9/26; 35%), and lorazepam (6/26; 23%) were the drugs used for procedural sedation. Other sedatives included oral Lorazepam (14/26; 54%), oral midazolam (7/26; 30%), chloral hydrate (both oral [19%] and rectal [12%]), and oral ketamine (2/26; 8%). Sublingual lorazepam and intranasal midazolam were both used by only one center. For pain control, IV morphine (13/26; 50%) and IV fentanyl (10/26; 39%) were most commonly used, followed by oral morphine (6/26; 23%), intradermal fentanyl (4/26; 15%), subcutaneous morphine (3/26; 12%), and sublingual fentanyl (1/26; 4%). Respondents were asked about the pain management strategies used for granulocyte colony-stimulating factor injection pain; and rotation of sites was specified by 21/26; 81% centers and Insuflon (Maersk Medical, Lynge, Denmark) by (13/26; 50%) centers. Eutectic mixture of local anesthetics was used by 4 of 26 (16%) centers.

Respondents were asked to indicate the types of cognitive-behavioral and imagery-based techniques that were used for procedural pain and distress on a scale that included never, rarely, sometimes, most of the time, and always. Deep breathing and distraction were used at 24 of 26 (92%) of the oncology centers sometimes or more often. Guided imagery was used sometimes or more often at 16 of 26 (62%) centers, touch by 15 of 26 (58%) centers, music by 12 of 26 (46%) centers, and progressive relaxation by 10 of 26 (38%) centers. Hypnosis was rarely or never used by any of the centers. Health care professionals most likely to help the child use the nonpharmacologic techniques included nurses (22/26; 85%), child life workers (17/26; 65%), social workers (9/26; 35%), and psychologists (8/26; 31%).

Treatment-related Pain

Treatment-related pain included mucositis pain and chemotherapy-related pain from vincristine and prednisone. Standard protocols for treating mucositis were available in 16 of 26 (62%) centers and unavailable in 9 of 26 (35%) centers. There were eight modalities listed for managing mucositis pain, and 18 of 26 (47%) centers used at least four of the eight modalities. Opioids were used by 19 of 26 (73%) centers and supportive modalities such as total parental nutrition and ice chips were used by 15 of 26 (58%) centers. Other treatments for mucositis pain included antifungals (22/26; 84%), clotrimazole plus lidocaine (15/26; 58%), chlorhexidine 0.12% (13/26; 50%), sulcrate (8/26; 31%), and, less frequently, biotene (2/26; 8%).

The jaw and abdominal pain that is associated with vincristine was most frequently treated with acetaminophen (21/26; 81%), followed by opioids (12/26; 46%), and, less frequently, metoclopramide (3/26; 12%). A similar treatment pattern was found for prednisone-related bone pain, body aches, and malaise; acetaminophen (20/26; 77%) was most frequently used, followed by opioids (9/26; 35%), and, less frequently, metoclopramide (2/26; 8%). Amitriptyline, nonsteroidal anti-inflammatory agents, and ranitidine were added under "other" by one center each.

Complementary Therapies

Respondents were asked what types of complementary therapies were offered at their oncology center. Transcutaneous electrical nerve stimulation was offered at 14 centers (54%), acupuncture and hypnosis were offered at 4 centers (15%), massage therapy at 8 centers (31%), therapeutic touch at 7 centers (27%), and biofeedback at 1 center (4%). Comments from the respondents suggested that if parents were interested in pursuing complementary therapies they were provided with information about consultants and were responsible for the cost themselves.

Patient Education/Home Care

Two questions inquired about the types of supports that are in place for parents managing their child's pain at home and who families consult when they are having difficulty managing pain. Respondents were given a list of six supports and asked to indicate which are available to families in their catchment area. Most oncology centers (19/26; 73%) provided 24-hour phone access to health care professionals (e.g., nurse, physician, pharmacist), and for seven centers (27%) phone access was the only pain management support available to parents. Pain and symptom documentation records for home use were available at three centers (12%), and a pain-specific care plan or care map that travels between hospital and home was available at five centers (19%). Written information about the use and side effects of analgesia was available at seven centers (27%) and sliding scales for analgesia dosages were available at four centers (15%). A community-based pain service was available in the catchment areas of seven oncology centers (27%). Of the 26 respondents that answered the survey five (19%) did not know what home supports were available to parents caring for a child with cancer pain. Two centers had four of the six supports available to their families and seven centers had at least three of the supports available.

Parents most often consulted nursing staff (21/26; 81%) when they were having difficulty managing their child's pain at home, followed by the oncologist (19/26; 73%) and the family physician (11/26; 42%). In addition, the home care nurse collaborates with the hospital liaison nurse (10/26; 39%) and with the clinic nurse (12/26; 46%) to assist families with pain management. Only one oncology center used e-mail as a way to maintain contact with families.

Staff Education/Institutional Support

Several questions were asked about the types of supports that were in place within the institution for best-practice pain management and about the barriers to providing optimal pain management. In the orientation for new nursing staff, information on pain assessment and management was included in writing at 10 oncology centers (39%), verbally at nine centers (35%), and was not included at six centers (23%). Pain-related inservices were offered at least once per year at 19 centers (73%), and 14 respondents

(50%) had attended at least one pain related inservice. Most respondents (19/26; 73%) felt that they had adequate knowledge to care for children with simple pain problems, and 11 respondents (42%) felt comfortable with complicated pain problems. Nine (35%) respondents did not feel that they had adequate knowledge to care for children with complicated pain problems. The low volume of patients with complicated pain problems was mentioned as a barrier to maintaining skills because the opportunities for this level of practice were limited.

The most significant barriers to obtaining education about best practice pain management included: lack of inservice opportunities (18/26; 69%); lack of time (14/26; 50%); lack of money (5/26; 19%); and lack of university or college courses on pain management (5/26; 19%). When education was available, most respondents preferred lecture (10/26; 39%) or case studies (8/26; 31%) as the best way to learn.

Eight (31%) oncology centers had a pain clinical specialist on staff, and pain resource nurses (which are unit-based and provide staff with information and support around pain management problems) were available at (11/26; 42%) centers. Most oncology centers did not capture pain assessment or management activities on their workload measurement tool (16/ 26; 61%).

End of Life/Palliative Care

Seventeen (65%) centers had a palliative care service, nine centers (35%) had a designated palliative care unit within the center, and only three centers (11%) were associated with a hospice. Eleven (42%) centers had a designated palliative care nurse and 17 of the centers (65%) had nurses with palliative care expertise that made home visits. The overall number of palliative care patients on service at the time of the survey was relatively low, and 18 centers (69%) had five or fewer patients; only four centers (16%) had more than six patients receiving palliative care. Respondents were asked to indicate if they had protocols in place to treat the most common problems associated with end-of-life care including seizures, excessive sedation, respiratory distress, anxiety, constipation, and nausea and vomiting. Eight (21%) of the centers did not have any protocols in place to deal with these problems, and seven centers (18%) had protocols for all of the problems. Constipation (13/26; 50%) and nausea and vomiting (15/26; 58%) were the most frequently addressed problems.

In addition, respondents were asked to describe the biggest issue that they face with respect to end-of-life care. Many of the comments addressed the difficulty of providing adequate pain control and comfort measures to children at home. Effective and timely links between the cancer center, the community, and the family were essential if the child was to die peacefully at home; however, the infrastructure for these links was often not in place. Education about the importance of good pain assessment and management for parents, physicians, and home care nurses was stressed. Four respondents commented on the attitudinal shift that needs to happen when a child is palliative and opioids are used differently than when the child is in the active phase of treatment. Addiction was mentioned as a barrier to optimal end-of-live pain management as well as the difficulty in establishing an appropriate balance between comfort and sedation. The ultimate goal was described by three respondents as providing the best pain relief so that the child was able to play and enjoy life as much as possible.

Discussion

A cross-Canada review of pediatric oncology pain management practices indicates that, for the most part, children have access to the components of best practice pain management. The results of the survey suggest areas of strength and areas that need to be further developed.

Pain History, Assessment, and Documentation

Pain history information that included all the essential elements was present in less than half (35%) of the centers and five centers did not collect any information about past pain experience. Most centers, however, did include some information such as current level of pain (77%), pain regimen at home (65%), and the child's behavior when in pain (42%). The need to establish baseline information about past pain experience is important for a number of reasons. The potential for pain from both the disease

itself and the associated treatment is significant and cancer treatment is typically months to years in length. For example, a child newly diagnosed with leukemia is facing 2.5 years of active treatment, which includes pain-producing medications such as vincristine and prednisone, and numerous procedures including bone marrow aspirations, lumbar punctures, and venipunctures. Families and children benefit from knowing at the outset that pain is a part of cancer treatment and that they have the right to talk about it and expect that it will be managed appropriately. In addition, identifying children at the time of diagnosis that are not perceived as "robust copers" by their families may allow health care providers to anticipate the need for a vigilant approach to pain prevention and management. If a child enters a cancer treatment regimen having had previous negative painful experiences or the child copes with chronic pain from a coexisting condition, this information would form the basis for the cancer-treatment care plan.

It was encouraging to note that all oncology centers used at least one type of self-report pain scale on inpatient units and all, with the exception of two centers, used a self-report scale on outpatient clinics. Less encouraging, however, was the infrequent use of behavioral observation scales that were used by only four centers on the inpatient units and three centers on outpatient units. The lack of alternative scales that do not rely on self-report indicates that pain in preverbal children is probably not adequately assessed and documented. Broome et al. (1996) reported that 73% of 113 oncology centers in the United States used a self-report pain scale and, similar to our findings, only 20% of the centers used a behavioral observation scale for pain assessment. Stevens (1990) reported that when a pain scale and documentation record were used by nurses, their patients were more likely to have less pain and receive more medication. The use of a pain scale does not guarantee that pain will be assessed and documented but it is a first step toward using a shared and institutionally sanctioned language to talk about pain.

The documentation of pain information was problematic in that most often there was either no designated place or pain information was recorded in the progress notes. Typically progress notes contain summary information that reflects one shift which may be 8 or 12 hours. This type of summary format is not adequate or user-friendly for recording pain assessment data that are collected before and after medication administration, and hourly in the case of unstable pain. It was encouraging to note that eight centers had a pain flow sheet and four centers charted pain on the graphic sheet. The lack of strong supports for documentation of pain information was reflected in respondents overall evaluation of the adequacy of pain documentation in their center. No respondents felt that pain was adequately documented greater than 80% of the time, and 10 respondents indicated that it was adequately documented 50% or less of the time. The missing link between collecting pain information and documenting it is clearly a designated place for pain data—even if it is simply a line on the graphic sheet that captures pain intensity along with information about vital signs.

Procedural and Treatment-related Pain

There were a number of supports available for preventing procedural pain. Most centers (77%) indicated that at least 90% of their patients had a venous access device and 70% of respondents indicated that EMLA is used sometimes or always before any type of puncture. This is important because cancer treatment typically involves weekly blood tests and chemotherapy treatments that require peripheral venous sticks if the child does not have an access device in place. As the child progresses through the treatment it often becomes more difficult to find an adequate peripheral blood vessel for cannulation and the pain and distress from repeated sticks is considerable. McGrath et al. (1990) reported children's' usual pain from venipuncture was in the moderate to severe range and pain from their last venipuncture was severe.

Another significant source of pain and distress is the repeated bone marrow aspirations and lumbar punctures that are an essential part of cancer diagnosis and treatment. It was encouraging to note that children had access to a range of pharmacologic and nonpharmacologic strategies to relieve pain and distress. IV sedation coupled with analgesia is one of the most pow-

erful interventions to treat procedural pain and distress and to prevent the anticipatory distress that may develop in children that have been traumatized by difficult procedures (Ellis, McCarthy, Splinter, & Gosselin, 2000). Thirteen of the 23 centers (57%) that responded to the question used IV sedation most of the time or always for young children and 13 and 12 centers, respectively, for school-age children and adolescents. There were seven centers that never used IV sedation for young and school-age children and six centers never used this strategy for adolescents. This is not optimal because children at these centers are being denied procedural pain management strategies that should be considered integral to cancer care. An anesthetist administered IV sedation at most centers, which is ideal in that it provides maximum safety for the patients and flexibility in terms of what drugs and dosages can be used. For example, ultra–short-acting drugs such as propofol or remifentanil are excellent for procedural sedation but are typically administered by an anesthetist because of the higher likelihood of inadvertent oversedation (Krauss & Green, 2000).

Simple cognitive behavioral techniques such as distraction, imagery, and touch were used by most centers for control of procedural pain and distress and it was either nurses or child life workers that helped children and families use these techniques. Two longitudinal studies examined the utility of distraction for young children receiving chemotherapy or treatment for chronic illness and in both studies distress reduction was maintained over the 16 weeks of the studies (Dahlquist et al., 2002; Pringle et al., 2001).

Patient Education and Home Care

The support systems that are in place for families caring for a child at home are minimal and need improvement. Around-the-clock phone access is important and was provided by most centers, but for seven centers this was the only support available. Support mechanisms such as pain documentation records and care plans or maps for home use were not widely available to families. Written information about analgesic dosages, side effects, and sliding scales for dosing was available in less than 30% of centers. Only seven centers had a community-based pain service available in their catchment area and, of the 26 respondents, 5 did not know what services were available for families. Families that travel long distances to receive cancer treatment must have the appropriate support in place after they return home. Telephone access should be considered adjuvant to other basic support such as written information and a systematic structure for collecting and documenting pain information. Family support through e-mail communication was only used by one center. As more families become connected to the Internet, e-mail and other electronic applications are a viable alternative to phone contact and should be explored.

The lack of an infrastructure that provides support to families, nurses, and in many cases communities, caring for a dying child, was a major barrier to providing adequate end-of-life care. The pain and symptom management needs of these children are complex and in some cases rapidly changing over a 24-hour period. Seamless care between hospital and home is facilitated when oncology interlink nurses, palliative care nurses, and family physicians have access to the specialized knowledge and skills required to provide end-of-life care. Pediatric deaths are uncommon in most community medical practices; consequently, many physicians and home care nurses do not feel comfortable providing this care. A communication network that connects oncology centers to the home communities is possible with the newest telehealth technologies that are being developed and piloted. These applications should be explored to provide support for pediatric oncology patients in their home communities.

Staff Education and Institutional Supports

Pain assessment and management is a critical component of pediatric cancer care and should be an integral part of new staff orientation and inservice. Six centers did not include any pain information in orientation materials and nine centers offered verbal but not written information regarding pain. Pain-related inservices were available at 73% of the centers and 50% of the respondents attended one in the past year. Most respondents felt comfortable caring for patients with simple pain problems but a lack of oppor-

tunity to practice the skills necessary for handling complicated pain problems was an issue. In addition, most centers did not have a pain clinical specialist on staff and unit-based pain resource nurses were only available in 40% of the centers. The biggest barriers to obtaining knowledge about best practice pain management were lack of inservice opportunities and lack of time. The sharing of resources across institutions that span the country is essential in times of budget cuts and fiscal restraint. A cancer center that cares for a small number of children with complicated pain problems is unlikely to hire a pain expert, and nurses may feel that they lack the opportunities to develop expert skills in this area. Yet each child and family struggling with pain needs adequate relief.

What may be a cost-effective and efficient strategy for sharing expertise is for staff to become involved in online discussions about pain, cancer care, and palliative care. For example, the PEDIATRIC-PAIN electronic mail list is an international Internet forum for pain. Questions posed to the list are answered by health professionals from around the world and discussions related to difficult pain problems often results in information, strategies, and interventions. Instructions about how to access the list serve are available at http://www.pediatric-pain.ca (under "resources," click on "professional & research").

Perceptions of Practice and Commitment to Excellence

Generally, respondents believed that pain was being adequately assessed and treated at least 80% of the time, and there were only a few centers that fell below this mark. In addition, most respondents felt that their oncology center was committed to excellence in pain management; however, 60% of the centers did not capture pain assessment or management activities on the workload measurement tool. Pain-related activities consume nursing time and as such should be captured as part of their workload. For cancer patients with difficult or complicated pain problems the amount of time devoted to pain assessment and management may be substantial. A commitment to excellence needs to be put into operation in such a way that the resources are allocated to ensure that nurses have the time to provide best practice pain management.

Limitation/Recommendations

This survey gives a brief view of pain management at oncology centers across Canada. The limitation to gathering information in a survey format is that one or two individuals were expected to provide very detailed information about all aspects of pain services at their center. Their views may or may not accurately reflect the entire picture of pain management activities. However, these data are a first step, and more detailed information should be gathered through site visits, interviews, and patient record audits.

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