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DIFFUSION OF STANDARDS OF CARE FOR CANCER PAIN

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Abstract • Résumé

The authors report the results of a symposium on improving the standards of care for patients with cancer pain. The symposium was sponsored by the Advisory Committee on Cancer Control of the National Cancer Institute of Canada and was held Apr. 8 to 10, 1994, in Toronto. Participants included experts on control of cancer pain and on diffusion techniques, patients with cancer and representatives of regulatory agencies. They suggested the following strategies to improve outcomes in patients with cancer pain. Processes for accreditation of health care institutions should require documentation of cancer pain, its treatment and its outcome. Tertiary care facilities that provide cancer treatment should have expert, subspecialty, multidisciplinary programs for pain control and should provide adequate psychosocial support to patients suffering cancer pain. The Canadian Cancer Society should conduct a public-education campaign to encourage patients to report pain to health care providers. The National Cancer Institute of Canada should foster research on cancer pain by restructuring its process for review of pain-research protocols. Examinations for professionals who care for patients with cancer should include a defined number of questions concerning pain and symptom control. Provincial programs to monitor prescribing through the use of triplicate prescription pads should have an educational as well as a regulatory purpose.

Les auteurs présentent les résultats d'un symposium sur l'amélioration des normes de soins pour les patients qui souffrent de douleur cancéreuse. Parrainé par le Comité consultatif sur le contrôle du cancer de l'Institut national du cancer du Canada, le symposium a eu lieu du 8 au 10 avr. 1994, à Toronto. Il a réuni notamment des experts du contrôle de la douleur cancéreuse et des techniques de diffusion, des patients atteints du cancer et des représentants d'organismes de réglementation. Ils ont suggéré les stratégies suivantes pour améliorer les résultats chez les patients souffrant de douleur cancéreuse. Dans le cadre des processus d'agrément des établissements d'oncologie, il faudrait exiger des documents sur la douleur cancéreuse, son traitement et les résultats du traitement. Les établissements de soins tertiaires qui traitent le cancer devraient disposer de programmes spécialisés, sous-spécialisés et multidisciplinaires de contrôle de la douleur et fournir un appui psychosocial suffisant aux patients qui souffrent de douleur cancéreuse. La Société canadienne du cancer devrait lancer une campagne d'information du public afin d'encourager les patients à signaler leur douleur aux fournisseurs de soins de santé. L'Institut national du cancer du Canada devrait favoriser la recherche sur la douleur cancéreuse en restructurant son mécanisme d'examen des protocoles de recherche sur la douleur. Les examens imposés aux professionnels qui traitent des patients atteints du cancer devraient comprendre des questions sur le contrôle de la douleur et des symptômes. Les programmes provinciaux de surveillance des ordonnances par l'utilisation de tablettes d'ordonnances en trois exemplaires devraient viser à informer tout autant qu'à réglementer.

Cancer pain is prevalent in Canada and elsewhere and is frequently undertreated, despite the availability of validated pain-assessment techniques, potent drugs and other analgesic interventions and algorithms for applying these interventions.[1–3] The primary cause of the current burden of cancer pain is the underuse of techniques to manage cancer pain, not a lack of available, effective tools.[2,3]

In 1994 the Advisory Committee on Cancer Control of the National Cancer Institute of Canada (NCIC) assembled a panel of experts to consider methods for dissemination of techniques for the assessment and management of cancer pain in clinical practice.

The symposium, held Apr. 8 to 10, 1994, in Toronto, involved experts on control of cancer pain and on techniques for the diffusion of innovations, patients with cancer and representatives of regulatory agencies and the NCIC.

The symposium began with six sessions; five dealt with the evaluation of particular aspects of cancer-pain assessment or treatment in Canada and one concerned

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the principles of diffusion of medical innovations. In two final sessions participants identified major barriers to improving outcomes and developed strategies to surmount these barriers.

Participants considered information from a wide range of sources. The results of clinical studies were supplemented by unpublished Canadian data, including demographic data on patients with cancer pain and an inventory of programs for the treatment of cancer pain through the 28 tertiary care facilities that provide cancer treatment in Canada. Published studies of diffusion techniques were reviewed, and the views of participants were obtained.

THE PROBLEM

The introduction of simple methods for assessment and treatment of cancer pain is the result of major advances in clinical research. Although most patients with cancer will experience pain at some time during their illness, with effective application of these techniques up to 90% of them will have pain relief.[3] A national policy for management of cancer pain was established in Canada in 1984; similar national policies have been instituted in many other countries.[4] Simple, validated algorithms for the management of this type of pain have been distributed around the world by the World Health Organization and have been translated into many languages. Clinical assessment of these techniques in several countries has confirmed their efficacy in many practice settings.[5-7]

The availability of effective pain-management techniques stands in contrast to the fact that, for many patients, cancer pain is common, severe and undertreated. In a large survey of Canadian patients listed in a cancer registry, 50% of randomly selected registrants had pain at some time during the course of their illness.[1] In 25% of patients who had had pain in the previous week, the pain was characterized as "severe" or worse. The sample included patients newly diagnosed with cancer, those undergoing treatment, those terminally ill and long-term survivors with no sign of disease.

In a recent survey of 1397 patients undergoing chemotherapy in 54 treatment locations affiliated with the Eastern Co-operative Oncology Group, two-thirds of patients had pain or had taken medications to relieve pain in the previous week.[2] Reviews of patient charts showed that 42% of patients with pain were given inadequate analgesic therapy.

The disparity between the effectiveness of pain-management techniques and the current poor outcome in regard to cancer pain is due to complex interactions among the many stakeholders in the delivery of cancer care: health care providers, patients, cancer-care facilities, regulatory agencies and organizations that fund cancer research. Knowledge and application of standard pain-management techniques by physicians, nurses and other health care providers is poor.[2,3] Many patients believe that "good" patients do not complain about pain, and fear of addiction to opioids is common.[8] Most, but not all, tertiary care facilities providing cancer treatment in Canada have established a comprehensive program to manage cancer pain or are associated with a multipurpose "pain clinic." However, use of these programs has been less than optimal. Some pain clinics function primarily to administer nerve block, to assess and refer patients for palliative care services within the community or to treat chronic pain due to causes other than cancer; patients with cancer pain are welcome in such clinics but are seldom referred to them.[9] Assessment techniques,[10,11] which encourage patients to communicate pain problems to their health care providers, are not uniformly applied within tertiary care facilities for cancer treatment. As a result, patients use their allotted time with their physician to talk about the underlying disease and its treatment, but not about pain.

Controlled trials have shown that routine assessment of pain with the use of simple, validated tools results in improved pain control.[10,11] However, agencies that accredit health care facilities do not require the use of such nursing tools or any other routine documentation of pain or its management.

Five provincial colleges of physicians and surgeons have established programs involving triplicate prescription pads to monitor the use of scheduled medications such as opioids. In Alberta, such a program has resulted in reduced prescribing of opioids.[12] One authority on pain has contended that such a reduction may indicate underprescribing for pain relief because of the perceived risk of sanctions by licensing bodies.[13]

Research funding in Canada and elsewhere is spent on basic science and clinical research on disease treatment, with much less emphasis on pain research; studies of the control of pain and symptoms other than nausea represent a tiny fraction of the major studies funded by Canadian granting agencies during the past decade.[14] There have been several advances in clinical cancer care in the last 10 years, and the results of research trials on cancer pain are among the leading developments, despite the fact that these trials have not received a proportionate share of support.[15] For example, studies have defined the safe and effective use of opioids and coanalgesics. Oral analgesics are effective in relieving most cancer pain. However, when oral administration fails to relieve pain, the preferred parenteral method of delivering opioids is subcutaneous administration, direct or through the use of portable infusion systems. Oral or parenteral administration of analgesics has enabled hospital-bound patients to return home, improving their dignity and quality of life and reducing hospital costs.[16,17]

With the strong encouragement of the NCIC, Canadian researchers have recently conducted trials to assess quality-of-life issues in addition to the traditional measures of response to cancer treatment. However, the transfer of assessments of pain and quality of life from clinical trials to practice is constrained by several factors. Instruments used in clinical trials may not lend themselves to day-to-day practice because they are time-consuming and complex to use. Furthermore, validated instruments that are more easily applied in clinical practice, such as the Edmonton Symptom Assessment Scale,[18] are not widely known among oncologists. Other practical constraints include the depth and breadth of care needed for patients with cancer (assessment, treatment, treatment of side effects and help for the patient and family in coping with a life-threatening illness) and the reluctance of many patients to discuss pain.

DIFFUSION TECHNIQUES: A SOLUTION

At the symposium, published knowledge about diffusion techniques was summarized and applied to the problem of undertreatment of cancer pain in Canada. Constraining factors that have contributed to poor pain-relief outcomes were identified; oncologists, other health care professionals, patients, regulatory institutions, and hospitals and other health care delivery organizations were identified as groups that could change these constraining factors.

Diffusion is "the process by which an innovation is communicated through certain channels over time among the members of a social system."[19] An innovation is an idea, technique or technology that is new to the potential adopters. Adoption of an innovation by a small group can result in initial uncertainty among peers of the group, and they will seek new information to clarify the potential benefit of the innovation. Ultimately, peer pressure causes others to copy the innovation.[20,21]

Diffusion research was first widely applied in the 1930s to the agricultural extension program in the United States, and it has subsequently been applied to a wide variety of programs and disciplines. Diffusion strategies have been successful in introducing many powerful innovations such as programs for agriculture,[19] family planning,[22] seatbelt use[23] and cervical cancer prevention through periodic screening of populations at risk.[24] The application of diffusion principles to vaccination programs resulted in the worldwide eradication of smallpox.

Acceptance of an innovation is not equivalent to its implementation. Practice guidelines for treatment of cancer pain are of no benefit to patients unless physicians, patients, facilities caring for cancer patients and regulatory agencies concur that the guidelines are important, implement them readily and raise concern about substandard practice if they are not followed.

Support from peer groups and regulatory bodies and pressure from the community and patients can have a significant effect on diffusion.

For successful diffusion, innovations must be advanced by professionals trusted by their peers.[19] Physicians respond positively to local "opinion leaders," who are viewed as familiar, similar to the responding physicians, trustworthy and expert.

Administrative interventions are also useful tools for diffusion. The importance of an innovation may be highlighted by including questions about it in professional examinations and in internal and external assessments in institutions. Such assessments may include internal audits and, once the innovation is established as part of a national standard, institutional accreditation. Efforts will be less effective if health care providers perceive the innovation as simply increasing the "hassle factor" in medical practice. Multiple channels of diffusion must be used for a lengthy period to inform and persuade; one-shot attempts at diffusion by regulatory agencies typically fail or are short-lived. The characteristics of an innovation advocated by a regulatory agency may also affect its adoption. Innovations that are simple to apply, result in substantial improvement in care and are congruent with the perceived role of the health care provider are more likely to be adopted.[19]

New research findings do not usually change medical practice unless the environment supports the implementation of the innovation.[19] Feedback to health care providers by regulatory agencies is helpful in showing that the implementation of the innovation results in improved patient outcome.

Similarly, patient requests can change the behaviour of health care providers. Examples include patient requests for regular checks of blood pressure, serum cholesterol levels and serum prostate-specific antigen levels.[25,26]

DIFFUSION IN ACTION

The Canadian Cancer Society has used the principles of diffusion research for many years in its programs to influence the behaviour of patients, health care providers and provider organizations such as cancer-treatment facilities. One of the best known programs of this type is the society's "Seven Steps to Health." Cancer-control agencies have recently considered explicit use of diffusion techniques to change behaviour and improve outcome. For example, the National Cancer Institute (NCI) in the United States has been asked to consider a policy under which cancer centres must implement certain pain-control techniques to be designated by the NCI.[27] These techniques include documentation of the amount of pain experienced in every patient medical record and on-site presence of a multidisciplinary cancer-pain assessment and management program.

PLAN OF ACTION

To foster diffusion of pain-control innovations, workshop participants recommended the following plan of action.

1. Tertiary care facilities and hospitals that care for patients with cancer should adopt simple techniques that involve questionnaires to be completed by the patient to assess pain and symptoms. These measures should be given the same priority as the assessment and monitoring of tumour mass and must form part of the standard medical record for each patient. The frequency of assessment should be guided by each patient's circumstances. For example, the prevalence of pain in patients receiving chemotherapy for metastatic cancer is extremely high; the pain level in such patients should be assessed at each visit.
2. Expert, subspecialty, multidisciplinary care should be available for patients whose symptoms are poorly controlled in tertiary care facilities and hospitals. Pain-management teams should provide leadership in pain and symptom control in the areas of patient care, education, research and quality assurance.
3. The formal process to accredit tertiary care facilities and hospitals should be changed to require documentation of regular assessment of pain in cancer patients, of the availability and widespread use of a multidisciplinary, subspecialty team for pain and symptom control and of the availability of psychosocial resources to help patients and their families cope with their suffering.
4. Posters and other educational devices to encourage patients to talk to their health care professionals about pain or other aspects of suffering should be placed in the waiting rooms of cancer-treatment clinics.
5. The Canadian Cancer Society should conduct a public-education campaign to alert patients and their families to the importance of reporting pain to their health care providers.
6. Faculties of medicine should regard expert pain and symptom control as part of the core curriculum for all medical practice. This tenet should be reflected in undergraduate, residency and continuing medical education programs.
7. Professional examinations, including the Medical Council of Canada's Qualifying Examination, specialty examinations of the Royal College of Physicians and Surgeons of Canada and professional examinations for other providers who care for patients with cancer, should include a defined number of questions on pain and symptom control.
8. Triplicate prescription-pad programs established by provincial colleges of physicians and surgeons should be used to identify communities or physicians with inappropriate prescribing practices. However, the aim of such identification should be to offer feedback to physicians; the program should be an educational tool rather than primarily a policing or punitive initiative.
9. NCIC review panels should expect clinical-research protocols to include evaluation of pain and symptom management in addition to other quality-of-life indicators, so that all aspects of the outcome of new treatments are documented.
10. The NCIC should restructure its process for review of pain-research protocols to ensure that a panel of experts is available to conduct these reviews.
11. The NCIC should sponsor a workshop in 1995 or 1996 to assess how methods for pain research can be diffused to researchers in Canada.
12. A network of Canadian experts on pain control should be established to encourage continual improvement in the quantity and quality of research on cancer pain in Canada.

CONCLUSION

As Daniel Callahan[28] states,

> No moral impulse seems more deeply embedded than the need to relieve suffering. . . . It has become a foundation stone for the practice of medicine, and it is at the core of the social and welfare programs of all civilized nations.

The effective management of pain is an ethical imperative for health care providers. Yet pain remains prevalent among Canadians with cancer, despite the availability of effective techniques for cancer-pain management. Reduction of the prevalence of cancer pain through diffusion of pain-management techniques will require a significant change in the behaviour of accreditation and regulatory agencies, medical schools, health care providers, agencies that fund cancer research, patients, their families and others within their communities. Practising physicians must play a pivotal role in effecting change by establishing standards for symptom control in their practices, offering education for health care providers and patients and, most important, acting as patient advocates.

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