

Home-Based Chemotherapy for Cancer

Issues for Patients, Caregivers and the Health Care System

SUMMARY

AGENCE D'ÉVALUATION DES TECHNOLOGIES
ET DES MODES D'INTERVENTION EN SANTÉ

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Issues for Patients, Caregivers and the Health Care System

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Report prepared for AETMIS
by Lucy Boothroyd and Pascale Lehoux

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FOREWORD

HOME-BASED CHEMOTHERAPY FOR CANCER: ISSUES FOR PATIENTS, CAREGIVERS, AND THE HEALTH CARE SYSTEM

Home care is the fastest growing service delivery model in industrialized nations, and raises a number of significant issues and implications for health care decision-makers in Québec. Advances in cancer treatment modalities and technological improvements have made it possible to offer some forms of chemotherapy safely in the home under strict conditions.

The current assessment is part of a series of reports initiated by AETMIS on the use of health technologies in the home setting. The report is particularly timely given current cancer care initiatives by the *Programme québécois de lutte contre le cancer*.

In this report, the term ‘home chemotherapy’ denotes any modality of administration of chemotherapeutic agents for cancer cure or control at home (intravenous, subcutaneous, oral, etc.), with or without on-site supervision by a nurse. This assessment reviews the evidence concerning effectiveness, safety, patient preference and satisfaction, patient quality of life, and costs of home chemotherapy. Organizational, access, and patient choice issues were also examined. Published information was enriched with interviews with home chemotherapy providers at selected institutions in Québec and, for comparison, in Ontario, a province with similar demographics but a markedly different organizational structure for cancer care.

Establishing safe chemotherapy practices at home is resource intensive and requires a well-integrated, collaborative team of health care professionals. The home delivery model cannot wholly replace outpatient nor inpatient treatment, but can be a safe and acceptable option for some cancer patients who choose it, particularly those receiving continuous infusion therapies. The report recommends standardization of home treatment programs, enhanced collaboration between health care providers, and a comprehensive model of provincial cancer services that ensures the patient’s continuity of care. However, due to insufficient evidence on effectiveness, the perspective of cancer patients in Québec and particularly cost implications in comparison with outpatient settings, there is a need for well-designed evaluations of home chemotherapy before its use is greatly expanded in Québec.

In submitting this report, AETMIS wishes to provide the best possible information on this mode of treatment delivery to decision-makers in Québec’s health care system.

Renaldo N. Battista
President

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SUMMARY

A recent AETMIS report on high-tech home care—of which home-based chemotherapy for cancer is an example—found home care to be the fastest growing service delivery model in industrialized nations, and raised a number of significant issues and implications for health care decision-makers in Québec [Lehoux and Law, in press]. Recent advances in cancer treatment modalities and technological improvements have made it possible to offer some forms of chemotherapy in the home under strict conditions, related to the specific protocol prescribed, caregiver availability, motivation, and training, the home environment and location, and patient characteristics.

In this report we use the term ‘home chemotherapy’ to denote any modality of administration of chemotherapeutic agents at home (intravenous, subcutaneous, oral, etc.), with or without on-site supervision by a nurse. Examples thus include short-term infusions by a nurse (staying in the home throughout delivery), multi-day continuous infusions started by a nurse at a hospital and continued (without on-site supervision) at home, and injections delivered by parents in the home to a child. It should be noted that oral therapies in particular are not always considered by the medical community as home chemotherapy *per se*; in some places, ‘home chemotherapy’ is used more strictly to refer to treatment which is entirely carried out by a nurse in the home. We use the broad definition in order to capture the reality of current home-based cancer treatment in Québec and to be more inclusive in the scientific literature.

Cancer is responsible for almost 30% of the total annual deaths in Québec. It was estimated that there would be 35,500 cases diagnosed in Québec in 2003, the most frequent being breast cancer for women (expected incidence=110/100,000) and lung cancer for men (101/100,000) [NCIC, 2003]. The probability of ever having cancer has increased to 43% among men and 37% among women in Québec [MSSS, 1997b]. Hospitalization costs alone related to cancer amounted to

\$317 million in 1994-95 [MSSS, 1997a, 1998], and social and health costs (direct and indirect) in 1993 totalled about \$3 billion in the province [MSSS, 1997b, 1998]. Total direct and indirect costs related to cancer in Canada in 1998 were estimated at \$14.2 billion [Health Canada, 2002].

The Québec *ministère de la Santé et des Services sociaux* (MSSS) established a *Programme de lutte contre le cancer*, a *Conseil québécois de lutte contre le cancer* (CQLC)*, and a *Centre de coordination de la lutte contre le cancer au Québec* (CCLCQ)* in order to improve the quality and organization of services in cancer care in the province [MSSS, 1997b, 2001]. Our report is particularly timely given these current cancer care initiatives, which address organizational frameworks at the local, regional and provincial level, continuity of care, access to high quality oncology services, and patient quality of life, among other issues. We searched the scientific literature and reviewed the evidence concerning effectiveness, safety, patient preference and satisfaction, patient quality of life, and costs of home chemotherapy for cancer. We also examined organizational, access, and patient choice issues. This comprehensive review was supplemented with semi-structured interviews with service providers at selected institutions in Québec (n=10) and, for comparison, in Ontario (n=6), a province with similar demographics but a markedly different organizational structure for cancer care. The goal of the interviews was not to carry out a complete survey of programs but rather to collect perspectives on the benefits, barriers, facilitating factors, and challenges in providing home chemotherapy.

We utilized a broad approach to address the issues surrounding home chemotherapy for patients, their caregivers—both professional care providers and informal helpers such as family members—and the Québec health care system in general. In response to the needs of rural patients, for whom home chemotherapy is unlikely

* On July 1, 2004, the CQLC and the CCLCQ will be merged into the *Direction de lutte contre le cancer* (DLCC), which was created on April 1, 2004, as part of the administrative framework of Québec's *ministère de la Santé et des Services sociaux* (MSSS).

to be available or possible, we also examined a second treatment delivery model: ‘closer to home’ chemotherapy delivered at local clinics or hospitals and managed by general practitioners.

OVERVIEW OF HOME CHEMOTHERAPY FOR CANCER

In this report, we focus on chemotherapy in adults for cancer control and cure, rather than end-of-life cancer care. Chemotherapy involves the administration of cytotoxic drugs that prevent the growth and proliferation of cells, and is especially used in cancer treatment in order to destroy neoplastic cells that show uncontrolled growth. For some cancers chemotherapy may be the only treatment offering cure (e.g. Hodgkin’s disease, acute myelogenous leukemia), while for breast and colon cancer, chemotherapy can often cure if combined with surgery/radiation. In other cases, chemotherapy has controlling effects and can extend life without signs of disease for many years (e.g. chronic lymphocytic leukemia). In advanced or metastasized cancers, chemotherapy has been shown to alleviate symptoms and can extend survival. The specific treatment plan (e.g. drugs prescribed, delivery regimen, length of therapy) depends on the kind of cancer, its location, the degree of cancer spread, the effect of the disease on body functioning, the patient’s general health status, the body’s response to the chemotherapy, and the therapeutic goals. Cancer chemotherapy can be administered in many different ways, including orally, intramuscularly, and subcutaneously; the most common method is intravenously. Chemotherapy is usually delivered in treatment cycles, with non-treatment “rest” periods (of several days or weeks) in between; prolonged treatments are also increasingly used (e.g. 24 hours to 6 weeks of continuous drug infusion), which may increase efficacy and/or decrease drug toxicity, depending on the specific treatment protocol. For intravenous push, intravenous short infusion, or injection regimens, home chemotherapy (if permissible) usually replaces outpatient treatment; for intravenous continuous infusions of 24 hours in duration or longer, home treatment replaces inpatient hospitalization.

Due to the toxicity of the drugs, chemotherapy delivered in any setting is usually associated with a number of distressing side effects for the patient (e.g. nausea, vomiting, hair loss, fatigue). For intravenous treatment at home, there is the additional risk of complications related to the need for technical skills and the nature of the devices and agents used. The premise behind home therapy is that cancer patients may prefer to receive their treatments at home, if it is possible to do so, rather than at a hospital (as inpatients or in an outpatient department). The approach can be appealing to the patient for a number of reasons including receiving therapy in the comfort and security of the home, decreased travel to medical facilities, reduced risk of nosocomial infection, an increased sense of control over treatment and illness, and less disruption of family life.

EVIDENCE FROM THE LITERATURE ON BENEFIT, COSTS, AND SAFETY

There is insufficient evidence on the clinical effectiveness of home chemotherapy compared to non-home settings (for outcomes such as survival, remission rates, or tumour control). There is more evidence to show that home treatment can be delivered safely, with few serious complications or accidents, although patients must be carefully selected and trained. Where home chemotherapy replaces inpatient treatment, convincing evidence of cost savings for hospitals and families arises from only one pediatric study. In studies where home chemotherapy replaces outpatient treatment, the mixed findings and variable study quality prevent a conclusion on the cost implications. Home chemotherapy causes cost shifting within the health care system from hospitals to home care organizations. Effects on costs to Québec hospitals and home care services, and to cancer patients and their families/informal caregivers, require more study. Improvements in patient quality of life at home have not been well documented in the literature, but are consistently reported anecdotally by care providers. Patient preference for and satisfaction with home therapy is supported, although the published evidence in this regard mostly arises

from studies where acceptance of the approach is required to participate.

INFORMATION FROM PROVIDERS ON CURRENT HOME CHEMOTHERAPY SERVICES

In our interviews with service providers in Québec (n=10; two in rural regions) we looked at the availability of home chemotherapy, patient eligibility criteria, role of hospital staff, cost issues, role of CLSCs, patient satisfaction, rural Québec treatment settings, organizational barriers and challenges, and facilitating factors. The components of different home treatment programs varied with respect to a number of factors, including structure, use of specific program guidelines, emergency procedures, and staff. Home visits by an oncology nurse were not provided by any of the programs. Use of CLSC services was highly variable. Oncology nurses and pharmacists had a pivotal role in managing the home therapy. Only one urban site had a specific budget for home chemotherapy. Interviews with rural providers pointed to a greater need for alternative outpatient delivery of chemotherapy ‘closer to home’ in remote areas (at local hospitals), rather than home treatment. Barriers to providing home chemotherapy services included limited resources, a requirement for high levels of nurse commitment, training, and autonomy, lack of organized collaboration with CLSCs, and a lack of program and protocol standardization.

Based on our interviews with service providers in Ontario (n=7 at six sites; one rural) it appears that the structure and financing of cancer and home care services in Ontario contributes to a capacity for greater patient load, greater uniformity of services, and inter-organizational collaboration that is more fully supported and developed. Access to chemotherapy both at home and ‘closer to home’ is facilitated in Ontario by centralized funding, a regionalized approach, support of alternative outpatient delivery (fostering liaisons between cancer centres and community hospitals), involvement of general practitioners in a network of rural chemotherapy clinics, access to oncology expertise through communication links, and certification of community

chemotherapy clinics. Home nursing visits during treatment (with on-site supervision throughout drug delivery for subcutaneous injections only) were an integral part of the home chemotherapy program at three of the four urban Ontario hospitals we studied. Organizational issues highlighted by contacts from both provinces related to the need for collaboration with community-based services, the importance of initiative and support by a multidisciplinary team, the role of nurses and pharmacists in program management, patient education, and home support, the need for sufficient outpatient resources, and the importance of communication and training links between different team members involved in home and ‘closer to home’ treatment.

ORGANIZATIONAL, ETHICAL, AND LEGAL ISSUES

The delivery of home chemotherapy requires high quality, integrated services by a specially trained multidisciplinary team in partnership with motivated, trained patients and their caregivers. This is particularly important for intravenous treatment, but is also relevant for oral treatment and other delivery modalities at home. Intra-organizational issues include the need for specialized nursing training and responsibilities, adherence to care and safety policies, education and transfer of skills from nurses and pharmacists to patients and informal caregivers, and coordination of services. A key aspect of home chemotherapy services is the requirement for a team of health professionals from various disciplines to work together. If communication networks are not strong, there is a real likelihood of fragmentation of care. Without team collaboration, the quality standards achieved for chemotherapy in the hospital setting will not be present in a home treatment service. A need for formalization of team functions and responsibilities emerged as another theme in our interviews. Coordination of chemotherapy services, particularly as treatment moves from the hospital to the community and home setting, is crucial. This coordination, in turn, is related to the overall organizational model for provincial cancer care. Of utmost importance is the ability of the service team to respond to the cancer patient’s needs. A

truly comprehensive cancer care system is one that provides supportive services (e.g. access to counselling and home help) and commits the necessary human and financial resources to ensure a continuum of care from the hospital to the community setting.

Home chemotherapy presents legal and ethical challenges related to the home setting (where a nurse may visit alone, and/or the patient under treatment may be unsupervised), the potential for side effects and even life-threatening events due to the toxicity of the drugs, and the specific context of being diagnosed with cancer. The most important aspect of home chemotherapy delivery, when applicable and available, is acceptance of the treatment by the patient. Assisting with the administration of chemotherapy and management of the equipment requires both patients and their informal caregivers to gain highly technical skills. The patient with cancer must be fully informed about the implications of chemotherapy protocols in general and receiving therapy at home in particular. The professionals in the multidisciplinary home chemotherapy team must follow policies that reflect best practices. The person(s) ultimately responsible for the patient's care at home must be clearly identified. There are highly restrictive patient eligibility criteria for home chemotherapy, in order to minimize risks to safety. For some cancer patients, there will be no choice but to receive treatment in an institutional setting: patients in rural settings have less access to chemotherapy at home. For patients in rural areas, the 'closer to home' chemotherapy model (treatment delivery at rural hospitals managed by general practitioners) provides them with more choices and helps lessen their travel burden.

CONCLUSIONS AND RECOMMENDATIONS

Establishing safe chemotherapy practices at home is resource intensive and requires a well-integrated, collaborative team of health care professionals. Chemotherapy in any setting requires specially trained personnel. Evidence is insufficient on effectiveness, cost implications, and the patient's perspective, particularly in comparison

with outpatient settings. The home delivery model cannot wholly replace outpatient treatment, especially in the rural setting, but can be a safe and acceptable option for some cancer patients who choose it, particularly those receiving simple continuous infusion therapies. Certain conditions must be in place in order to ensure high quality chemotherapy in the home setting; these aspects should be taken into account when such initiatives are implemented. We make several recommendations about these conditions below. This assessment has led us to an additional recommendation related to access to chemotherapy: for rural cancer patients in Québec, priority needs to be given to the establishment of 'closer to home' chemotherapy. We have grouped our recommendations for Québec policy-makers, health care administrators, and care providers according to a number of issues:

(1) Support for program evaluation

In light of the insufficient evidence, there is a need for well-designed evaluations of home chemotherapy before its use is greatly expanded in Québec. In our interviews, we noted a lack of funds and time availability to carry out program evaluation, although one Québec site we visited had received a clinical innovation prize for their program initiative, for which an evaluation report had been completed. Comprehensive and ongoing evaluation of home chemotherapy programs is a crucial aspect of quality control. Program developers should be rewarded for their initiative and achievement of certain standards of care. Eligibility for specific home treatment funding from regional authorities could be linked to program evaluations which show appropriate positive outcomes. Program assessments must include the patient's perspectives on quality of life and satisfaction; patients and informal caregivers take on many care responsibilities during home chemotherapy. Economic evaluations of programs should apply a societal perspective, including costs of drugs, medical supplies and equipment, personnel (including time spent on patient teaching and follow-up, telephone contact with patients, and home visits), hospital service use (at outpatient clinics, emergency rooms, and inpatient departments), community health service use (at CLSC clinics), drug storage and delivery, teaching manual and

program development, other supportive care use (e.g. domestic help, counselling), and expenses saved/lost by the patient and his/her family and caregivers (e.g. travel, child care, employment income).

We view the evaluation of existing home chemotherapy programs in Québec as a priority in the light of insufficient data on effectiveness, costs, and the patient's perspective. In the meantime, the following issues should be considered by both program evaluators and current providers.

(2) Standardization of general policies and program components

Considering the current provision of home chemotherapy in Québec, we observed a need for basic provincial policies that set safety and program standards and provide structure for chemotherapy services both at home and in the rural hospital clinic environment. Several of our contacts stressed the importance of current initiatives to standardize treatment protocols. This could be extended to centralized policies specifying the basic components of both home chemotherapy programs and 'closer to home' services (with respect to organizational structure, staffing requirements, professional training, communication links, emergency patient support, and patient follow-up, for example). Initiatives such as the extensive chemotherapy guide developed by the *Regroupement des pharmaciens en oncologie* should be supported and widely diffused, and are an important step towards standardization of policies. In Ontario, greater uniformity of services and capacity to respond to both urban and rural patients' treatment needs appeared to be assisted by a regionalized approach with centralized funding, inter-organizational collaboration, and a certification system for rural clinics using standardized protocols.

(3) Enhanced collaboration and communication

The formation of multidisciplinary teams working together to provide the best care to the patient undergoing home or 'closer to home' chemotherapy is essential. This can be facilitated through standardized patient information sheets, the designation of a key health professional to coordinate care for the cancer patient, and training programs (e.g. oncology nurse—CLSC nurse

teaching; teleconferencing and other remote communications for rural health professionals, site visits, annual conferences). At some sites, it could be useful to form a coordination team to liaise between the different organizations involved (e.g. hospitals and CLSCs).

(4) Central standard setting but a regionalized approach

At the same time as detecting a need for standardized policies to ensure quality of care in home chemotherapy programs, we recognized the diversity of initiatives at different institutions and in different regions (e.g. rural versus urban). Central surveillance of programs, as a component of cancer treatment services, could be managed by a body such as the MSSS or DLCC. Roles for such an organization could include setting basic standards and general objectives. However, the specific planning and budgeting for programs should likely fall under the domain of the *Agences de développement de réseaux locaux de services de santé et de services sociaux* (formerly the *régies régionales*), who are better able to respond to the needs of their specific areas. A strategy could be developed whereby multidisciplinary hospital teams are encouraged to submit proposals to the *agences* regarding a home chemotherapy or 'closer to home' treatment service, in order to receive funding for program delivery and evaluation. In this way, regional bodies would be able to ensure high quality services while allowing for flexibility since different institutions (e.g. hospitals, CLSCs) may differ in their enthusiasm to be involved in these program initiatives. For example, depending on the site, oncology nurses could be involved in making home visits, or CLSC nurses could have more involvement in cancer care and be able to obtain specialized training. A regionalized approach is, in fact, favoured by the *Programme de lutte contre le cancer* and the DLCC initiatives.

(5) Increase in resources and use of specific budgets

The home chemotherapy programs we examined in Québec were restricted by a lack of financial and human resources (nurses, pharmacists), despite there being a general consensus that demand for services at home would increase. De-

pending on the results of proposed program evaluation, increased resources will likely be needed by existing home chemotherapy initiatives in Québec, and particularly if services are expanded, in order to guarantee high quality of care. The financial support of the transfer of skills from oncology to community nursing appears to be lacking. Sharing of expertise is crucial for continuity of care. The use of specific budgets for home chemotherapy relieves the burden of having to ‘borrow’ nursing time from inpatient and outpatient departments. Although only a minority of chemotherapy patients are able to have treatment at home at present, the technological and safety aspects are such that an integrated approach involving a number of different health care professionals must be sufficiently resourced. The value of supportive care services in the community—for cancer patients receiving chemotherapy both at outpatient clinics and at home—cannot be under-estimated.

(6) A comprehensive model of provincial cancer care

Finally, in carrying out this assessment it became apparent that issues regarding chemotherapy access and giving cancer patients the choice of quality treatment in the home environment are fundamentally related to the overall vision of and policies for cancer care in the province. A home chemotherapy program, in fact, presents a ‘microcosm’ of the general issues in cancer care: the need for comprehensive services that address different patient needs at different stages of their illness/treatment process and the integration of many disciplines and services to promote wellness. The objectives delineated by the *Programme de lutte contre le cancer* and the CCLCQ’s (now integrated to the new *Direction de lutte contre le cancer*) initiatives in cancer care organization represent an important starting point for the development of a comprehensive framework that addresses the varied and changing needs of cancer patients in Québec.

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