HEALTH CARE TECHNOLOGIES AT HOME

ISSUES IN ORGANIZATION AND DELIVERY IN QUÉBEC

SUMMARY

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

Québec

Health Care Technology at Home

Issues in Organization and Delivery in Québec

Report prepared for AETMIS
by Pascale Lehoux and Susan Law
with the collaboration of Lucy Boothroyd

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FOREWORD

Complex forms of clinical treatments administered at home have begun to emerge, such as intravenous therapy, artificial life support, assisted ventilation, cancer chemotherapy, and palliative care. This homeward shift of specialized care previously provided only in hospitals is leading to the creation of a new model of care, of which advanced technologies are a ubiquitous component. However, these changes are raising many organizational issues that one should better define before devising measures fostering the development of such services in Québec.

Such is the chief objective of this *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS) report. The report does not stem from a formal assessment request from policymakers in the health-care and social services system but was, instead, initiated in the wake of numerous discussions on the shift toward ambulatory care and the role that technology might play in such care.

Since the assessment of this new intervention modality is necessarily context-based, it first describes the main problems attendant upon the evolution of home-based care in Canada. We first note the weak interface between community-based home care and hospital-based home care programs. In addition to leading to increased responsibility being delegated to patients and caregivers, the introduction of specialized equipment into the home setting poses a number of risks. Lastly, despite the lack of cost-effectiveness data on home care services, they continue to be implemented.

The report then examines the prevalence and patterns of home use of certain advanced technologies by Québec's local community health centres (CLSCs) before the new local health and social services networks were established, and highlights the potential obstacles to and the opportunities for expanding the range of specialized home care. To broaden the discussion, this is followed by a synopsis, based on a review of the international scientific literature, of the organizational, social, ethical and legal aspects of specialized home care. Lastly, we examine how these aspects could be taken into account when providing and evaluating home care services in the specific context of Québec health-care reform.

The assessment thus brings out four main messages, around which are formulated recommendations aimed at better coordination of specialized home services, increased patient and caregiver support, a more critical look at the medicalization of the home, and the need to perform cost-effectiveness studies of these services.

In submitting this report, AETMIS hopes to promote delivery of home care that is satisfactory to patients and their families and effective from a clinical and organizational standpoint.

Dr. Luc Deschênes
Chairman and Chief Executive Officer

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CONFLICT OF INTEREST

None declared.

EXECUTIVE SUMMARY

INTRODUCTION

Most industrialized countries have initiated health care system reforms that are aiming to increase the number and scope of health services delivered on an ambulatory basis and at the patient's home. In Québec, this shift is called the *"virage ambulatoire"*. Traditional home healthcare services include case management, nursing, personal care, home support (or homemaking), occupational and physical therapies, social work counseling, nutrition counseling, and respiratory therapy [MacAdam, 2000]. More complex forms of clinical treatments at home are emerging, such as IV therapy, life support/ventilator assistance systems, cancer therapy, palliative care, and services for persons with AIDS or Alzheimer's disease [CIHI, 2003a]. This report is mainly concerned with these latter forms of interventions, i.e. high-tech home care. Technology, we argue, cannot simply be seen as one of several factors driving change in home care, but should be viewed as a pervasive component of a new model of care. The aim of this report is to identify the organizational issues associated with an increased use of health care technology at home and provide recommendations regarding the development of such services in Québec.

This report is organized in six parts. First, we present the rationale for this investigation and describe the methods and data sources. Second, we summarize the features of home health care service developments in Canada and present four problems raised by the increased use of technology at home. Third, we describe in greater detail the prevalence and patterns of the use of technology in home care services as provided by Québec local community health centres (CLSCs), and highlight potential barriers and opportunities in the expansion of such services. Fourth, we synthesize the organizational, social, ethical, and legal dimensions of technology-enhanced home care from a review of the international literature. Fifth, we analyze how such dimensions could be addressed in the delivery and evaluation of home care services, referring specifically to the Québec health care reform. Finally, in conclusion, we formulate recommendations and identify the actors whose decisions and actions might be influenced by this report.

CURRENT ISSUES IN BRINGING HOSPITAL TECHNOLOGY TO THE PATIENT'S HOME

Home care is included in the Canada Health Act as an Extended Health Care Service, but home care services are not regulated by the five principles of the Act. As a result, Canadians face varying eligibility, cost, quality, and access issues concerning home care services [MacAdam, 2000]. This explains, in part, why the Romanow Commission devoted a full chapter to home care, calling it the "next essential service" [Romanow, 2002, p. 171-188]. Globally, funding for home care has increased markedly over the past ten years. Home health care budgets nonetheless represent a small part of the total health budget in each province and territory. In 1999-2000, per capita public spending on home care in Québec was $69 (for a total of $508M) while the mean in Canada was $83 (www.hcerc.org). Each province/territory is responsible for making specific arrangements for the funding and delivery of home care, while the regional authorities have been increasingly important in the organization of services. Consumer involvement appears limited and inconsistent across provinces/ territories and regions. Finally, even though several provincial/territorial programs have stressed that high-tech home care is an issue in their jurisdiction, no formal national policy to ensure safe, cost-effective, and patient-centered use of technology at home has been developed.

Four aspects of the developments and increased use of health care technology at home require immediate attention. The first of these is the **weak interface between community-based and**

specialized, hospital-based home care. Ninety percent of home health care services in Canada are provided by coordinated home care programs that are largely community-based, and administered by provincial health departments or local community/regional health boards [Larsen, 1996]. Most Canadian home care programs were established in the late 1970s or early 1980s. Yet during this same time period, drastic changes in diagnostic methods and in the delivery of treatments and rehabilitation services took place. In Québec, CLSCs have historically focused on illness prevention and health maintenance objectives for elderly clients living within their territory, aiming to preserve their clients' autonomy for as long as possible, delaying admission to a nursing home. In the mean time, hospitals have been actively developing ambulatory and home care services for patients with both acute and chronic diseases, where patient education and health promotion are of prime interest. Such hospital-based home care programs (e.g. parenteral nutrition) require ready access to medical expertise, well-trained nursing staff, multidisciplinary teams, and specialized equipment. Both CLSCs and hospitals are extending their traditional frontiers in terms of the types of patients receiving home care and the increasing sophistication of technology used at home. It is uncertain to what extent health care managers and care providers from both hospitals and community health centres are adapting to their new roles and to what extent they are coordinating their efforts to provide home care where patient care crosses institutional boundaries.

The second issue is the **increased responsibility delegated to patients and caregivers**. Despite the fact that home-based patients and their caregivers must learn and master more technical knowledge and skills in comparison to hospitalized patients, very few studies have investigated the knowledge and skills required to manipulate home care technologies appropriately and independently, and/or the user-friendliness of the technologies themselves. Furthermore, it is not clear who is ultimately accountable (clinically and legally) for the quality of care when specialized technology is being manipulated by patients and caregivers rather than professional care providers. Some technologies impose considerable burden on patients and their families. There may be significant variations amongst patients and caregivers in terms of their ability and/or willingness to learn and carry out clinical/technical tasks on a routine basis.

Thirdly, the **risks associated with home environments** are important. There are both practical and philosophical implications of the increased use of technology in a patient's home. It is often taken for granted that most "typical houses" would be suitable for the delivery of home care. Nonetheless, critical observers have pointed out that the homes of chronic care patients become "small hospitals", due to the use of specialized equipment and drugs and the need for a sterile environment and storage room. This change in the context of use may not be simply a matter of increased hygiene, adaptation of physical design, or appropriate supervision. It may involve more complex dynamics or implications for patients/families, such as risk-taking, and impact on psychological well-being, family relationships, or social networks.

The fourth aspect concerns the **implementation of home care services despite the lack of evidence about cost-effectiveness.** Hospital care services are generally very costly; it is thus often assumed intuitively that home care services are of equal or greater effectiveness at less cost. Some home care interventions have indeed been shown to be more cost-effective than hospital care, but the opposite has also been observed. Private and public costs—as well as indirect costs—have often not been assessed consistently. Overall, there is a lack of convincing evidence in the literature, and clinicians, as well as policy-makers, need to consider carefully the implications of proposals to substitute or complement traditional hospital care with home care services.

TECHNOLOGY AT HOME IN QUÉBEC

A study was conducted in 1999-2001 by the first author of this report (PL) and her colleagues at *Université de Montréal*. The aim of the research was to identify the organizational, technical, and human factors influencing the use of certain technologies at home by CLSCs. A mail-back

survey was sent to CLSCs; the response rate was close to 70%. Almost all responding CLSCs had been involved in the provision of home IV therapy. The two most common modes of IV delivery were gravity (81.3% of CLSCs) and programmable pumps (97.9%), whereas the mechanical delivery system was used less frequently (58.9%). Oxygen therapy was the second most frequent home care service provided by CLSCs (with fixed concentrators: 83.5% of CLSCs). The provision of services related to parenteral nutrition was limited but still significant (26.6%). A large proportion of CLSCs (78.1%) indicated that they had been involved in the delivery of peritoneal dialysis care. A majority of CLSCs had been involved in the provision of anticoagulant therapy services (87.9%), while a third (35.6%) had been involved in the delivery of IV chemotherapy. Despite the abundant literature underscoring the rapid growth of home telecare, the use of various information technology-based home monitoring services was infrequent.

Historically, CLSCs have been responsible for home care and other primary care services. The execution of their mandate has always been tightly linked to community approaches, emphasizing preventive services and educational interventions that aim to respond to local needs. With the *"virage ambulatoire"*, their mandate appears to shift towards post-acute, more specialized care. The provision of home IV therapy is an archetype of such a shift: the explicit goal is to shorten hospital length of stay, using CLSC staff to provide and monitor therapy at the patient's home. However, one may question whether the CLSC organizational design and professional expertise could be better supported to accommodate the *"virage ambulatoire"*. The advent of the *centres de santé et de services sociaux* and the *réseaux locaux de services*, resulting from CLSCs merging between them or with hospitals, might contribute to answer to this need.

ISSUES IN ORGANIZATION AND DELIVERY

Introducing sophisticated technologies into the home setting has created new types of patients, new treatment possibilities, new roles and responsibilities for providers and caregivers, new ethical dilemmas, and new areas of accountability. Part 4 of the report is an attempt to clarify and summarize issues that are often entangled both in the literature and in practice. Organizational dimensions of technology-enhanced home care are intimately linked to the characteristics of the home care delivery model, and to the particular needs of patients in terms of care, technology, and support. Social dimensions of the use of technology at home refer to the capacity of the patients and their relatives to maintain satisfying relationships, to engage in leisure activities, to raise a family, to carry out social roles, to be employed and earn an income, and to live without discrimination. Several factors suggest that issues of legal liability in home care will increase [Kapp, 1995a]: home care is becoming increasingly high-tech; patients are being discharged "quicker and sicker"; and the coordination of care provided by various professionals is becoming more complex (making it increasingly difficult to control legal risks).

Thus, a complete home care policy should include organizational incentives that promote collaboration and trusting relationships between organizations, between service providers, and between public health organizations and the informal/voluntary sector. A home care policy should also recognize the major role women play in informal care giving and sustain real choice by allowing them, for example, either to provide care without paying the indirect opportunity costs (in terms of career opportunities, health, etc.) or to choose not to play such a role. Finally, home care policy should be attuned to the ethical and legal considerations associated with high-tech (and possibly high-risk) interventions.

DISCUSSION

Part 5 of the report aims to bring together the issues raised in the previous parts. Recommendations are formulated around four central messages.

Recommendation 1: Establish innovative organizational mechanisms that support the delivery of coordinated home care. As shown throughout this report, technology-enhanced home care is not a straightforward solution to a health system shift such as the *"virage ambulatoire"*. The integration of technology into existing models of care gives a prominent role to community-based and primary care organizations. The survey on the use of technology in CLSCs revealed that their involvement in specialized home care was uneven across Québec, and was often unknown to specialized hospital home care teams [Law and Lehoux, 2001]. The number of patients they visit, as well as the ade quacy of the information and training available to CLSC staff, raises issues on the quality of service provided.. Although relationships between CLSCs and hospitals were perceived as generally positive, important organizational limitations inherent to the current model of home care delivery have been reached: good relationships alone are not sufficient, and the effective coordination of services requires inter-organizational communication.

Recommendation 2: Increase the level of support for patients and caregivers. The contribution of caregivers to home care "has been by default, and not by design" [Parent and Anderson, 2000, p. 50]. For several observers, the benefits of home care outweigh the risks and liabilities, which can in turn be minimized by addressing the family's needs [Schachter and Holland, 1995]. To do so, care providers need to be trained and rewarded in a way that recognizes the importance of training, supporting, and supervising the patients' and caregivers' learning. Standards for supervision and the periodic verification of provider competence must be established. Nurses need to supplement their knowledge of nursing interventions with further training in ethics, health law, and technology. This new generation of nurses should also be aware of the means by which patients' needs and preferences can be elicited, given that appropriate and acceptable services can best be developed by integrating users' views into decisions about health services.

Recommendation 3: Revisit the medicalization of home. It may be an opportune moment to pause and consider the rationale for the rapid development of technology-enhanced home care. Kaye [1995, p. 3] expresses concerns about this hastened development: "the fact that home care exists in so many shapes and forms leads to questions about the capacity of such providers to deliver home care services in a consistent manner reflecting high levels of effectiveness and efficiency. This kind of concern should remain at the root of home care development. Specialized equipment should be designed in order to fill existing gaps in our ability to respond to health needs. In addition, the effectiveness of home care is inherently linked to the social and clinical criteria by which patients are selected. This implies that some patients will be excluded from home care services, a situation that calls for particular attention.

Recommendation 4: Support high quality research into the cost-effectiveness of home care. More research should be conducted on home care services, especially to investigate the cost-effectiveness of specific technology-enhanced services. However, supporting the production of research is far from enough. The results of such studies should be widely disseminated and discussed with key decision-makers and clinicians. Home care is not a static, homogeneous category of interventions. Its impact on health and social service costs depends on the intervention, on the particular health condition, and on the way services are provided and organized [Soderstrom et al., 1999]. Given outstanding challenges in the methodology and controversy in the interpretation of the results of cost-effectiveness studies, it seems important to create specific forums in which the cost-effectiveness of particular home care programs would be clarified and debated amongst practitioners, researchers, and policy-makers. Clinicians, hospital-based home care program managers, CLSC home care program managers, researchers, and planners from the *Ministère de*

la Santé et des Services sociaux should attend such forums with the aim of reaching some form of consensus with respect to what type of home care interventions should be supported in Québec.

CONCLUSION

Current challenges in the organization and delivery of home care call for immediate policy actions. Sophisticated technology is changing the nature of health systems across industrialized countries, and one of its most significant developments is the use of complex equipment in the patient's home. The use of such equipment often requires the clinical and technical expertise of secondary and tertiary level care providers, as well as a keen understanding of home care patients' needs—an expertise that CLSC home care program staff have developed for particular clientele over the last two decades in Québec. One critical challenge, for the next decade, will be to bring these two types of expertise together in order to provide specialized home care that remains meaningful for the patients and their relatives, while being effective from clinical and organizational perspectives. In this endeavour, coordination among individual care providers and among health organizations is key, as is building the technical and clinical competence of providers, patients, and caregivers. Each of our four recommendations addresses a particular facet of the 'home care problem'. While a global vision of home care should help structure the future of this service in Québec, regional leadership is required to support and implement organizational incentives that will enable effective coordination between hospitals and CLSCs or the *réseaux locaux de services* in which they are now integrated.

Agence d'évaluation des technologies et des modes d'intervention en santé

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