

Résumé - Virage ambulatoire : le prix caché pour les femmes

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SUMMARY

AMBULATORY CARE: THE HIDDEN PRICE FOR WOMEN

Not a day goes by in Québec without the media talking about problems in our health and social services system, pointing to troubles that changes to the system in the last few years have caused, or taking special aim at shortcomings in ambulatory care, one of the system's central tenets. In one of the first documents published on the question in Québec, *Virage ambulatoire : notes exploratoires*, the Council warned of the negative consequences of the move to ambulatory care, which posed a particular threat to women as system users, as caregivers, and as workers.

Four years after the much-ballyhooed introduction of ambulatory care, what are the consequences today for women? What have the effects been on their physical health and on perinatal care?

1. What exactly is ambulatory care?

Ambulatory care means providing care and services to people within their community environment by eliminating or shortening hospital stays for surgery or illness. People are inclined to think that ambulatory services are provided solely at home, but in actual fact the word "ambulatory" is used in two ways: to designate services provided in the home and to designate services the patient must go outside the home to receive.

The effects of ambulatory care are sometimes difficult to distinguish from those of other reforms of the health and social services system, such as hospital closings and mergers. The fact is that structural change and the shift to ambulatory care go hand in hand and obey the same economic logic: hospitalization is costly

and many essential services can be provided elsewhere for less.

The current focus on ambulatory care is part of a trend begun a number of years ago with deinstitutionalization, which claimed to offer psychiatric patients and elderly clients with special needs the opportunity to remain in their natural environment. Likewise, ambulatory care seeks to keep the sick in their communities by "dehospitalizing" them. In comparing the two movements, we become aware of the potentially negative effects of this trend.

2. A critical look at the underlying ideology

Defenders of ambulatory care base their rationale on two main arguments: that a new approach was inevitable and that the public will benefit. The inevitability of ambulatory care has been economic in nature—health spending must be slashed to reduce the public debt, or so we've been told. Our aging population has also been cited as reason for swift action—it costs 3.8 times more to provide health care to someone 65 or over than to the average person. The defenders of ambulatory care also point out that science has developed new ways of treating illness that have shortened convalescence periods.

The second main justification for ambulatory care is that it is good for the public—it puts an end to hospital-centred health care while promoting patient autonomy. Although this argument is in some ways consistent with feminism in its line of reasoning, it conceals a number of traps. The people we are asking to be autonomous are the ones in need of help. What's more, it would simply appear that we are trading one source of assistance—in this case the state—

for another, namely the family. And in the context of care-giving, "family" means women.

The Ministère de la Santé et des Services sociaux has often repeated that the public supports ambulatory care. Although the idea of developing patient services at the home and community level is generally well-received by the public, surveys reveal an awareness that the primary motivation is economic and that the impact on health care services is negative. The validity of surveys indicating high levels of satisfaction among health care users must be questioned, as the whole notion of satisfaction is notoriously fuzzy and difficult to evaluate, and varies considerably depending on expectations.

3. The impact on woman patients

In many ways, the impact of ambulatory care on woman patients is similar to that on men. However, aggravating factors include the fact that women tend to live longer, be in poorer health, live alone or in poverty more often, and be bigger consumers of health care services. Shorter hospital stays may also mean that women have to combine convalescence with the challenge of keeping house, providing childcare, or arranging alternative daycare.

- The difficult return home

Deficiencies have been noted in the resources available to patients released from hospital. Patients feel they're being sent home too soon, with insufficient information and preparation. They are unsure about what they can do to speed their recovery, and they worry about complications. Surveys of ambulatory care patients have shown that problems occurring after shortened stays have required them to go back to the hospital for further consultation.

Many patients mention the need to bridge the gap between hospital and home. There is a shortage of convalescence centers for those patients who no longer require hospital care, but who aren't yet sufficiently stable or autonomous to return home. There are also not enough places

for patients to go on a short term basis to give their home caregivers a rest.

One of the most persistent problems with ambulatory care is the lack of communication and cooperation between institutions and service providers. There are often coordination problems between hospitals, CLSCs (which generally provide homecare services), private clinics, and community organizations, particularly when patients are released from hospital. Hospitals and CLSCs don't always exchange information, which causes an interruption in services—and insecurity for patients. Follow-up visits are sometimes not made until long after patients have returned home. What's more, patients are ill-informed about the services available and don't know where to inquire.

- Problems with homecare and home services

Despite increased patient loads since the introduction of ambulatory care, there has been no proportional increase in either personnel or funding. According to health care professionals, homecare workers are overwhelmed and services have suffered as a result. Routine visits are spaced further apart, living conditions are not always assessed, and workers spend less time with each patient. Care and services are not always available when needed, are often insufficient, and may require payment. Patients are sometimes obliged to go outside the home for care, and may even have to carry out professional tasks themselves or get help from family or friends.

CLSCs are ill-equipped to meet the need for ambulatory care and have been forced to set priorities. Increasingly, their focus is on personal assistance (getting up, going to bed, bathing, etc.) to the detriment of domestic assistance (house cleaning, laundry, meals, etc.).

Rehabilitation is another area that has suffered under ambulatory care. Patients are assessed for physiotherapy needs, but treatment and follow-up are insufficient. Psychosocial and preventive services have also been neglected.

Nor are ambulatory services necessarily synonymous with homecare. Patients who are mobile are urged—or required—to go to a CLSC or hospital, which can cause major transportation and childcare headaches for some people. Women are particularly affected; not only are they less likely than men to have cars, but they are also more likely to have children in their care.

Furthermore, with ambulatory care, patients are often unable to consult with their referring physicians or other doctors in the event of an emergency, as doctors very rarely make home visits. The shortage of doctors at CLSCs has also been identified as a problem. As long as there are too few or no doctors working at CLSCs, home medical services will never develop properly.

4. The impact on women as caregivers

Ambulatory care has an impact on women as patients, but the women most affected by it are those who are caregivers. Women are seen as natural helpers for a number of reasons: the different social roles of men and women; the distinct link of women to parenting, to the workplace, and to their bodies and health; and more globally, the persistent inequality between the sexes.

- Women are already caregivers

A vast study in Quebec reported that 67% of those who care for the semi-autonomous elderly were women. A Santé Québec survey also revealed that 80% of woman caregivers are the primary care providers, compared with 46% of men in the same situation. Women already make up the large majority of "natural" helpers. By forcing women to care for early-release hospital patients too, we are adding to the unpaid care they have been traditionally forced to provide while, elsewhere, women are struggling to break out of this mold. What's more, we're imposing additional responsibilities on women, ones that are not necessarily compatible with the phenomena of an aging population, smaller families, family breakups, step-parenting, or the

simple reality of being a woman who works for a living.

- What being caregivers means to women

Studies on the negative impact that being caregivers has on women do not deal specifically with ambulatory care, but they do allow us to draw certain conclusions. For example, being caregivers can adversely affect their careers. One study showed that 9% of caregivers had reduced their working hours, 5% had turned down professional responsibilities, and 6% had quit their jobs altogether. Another study revealed that 9% of Canadian women between 55 and 64 quit their jobs to look after a relative.

Caregivers also experience considerable stress. According to Santé Québec, woman caregivers who live with their care recipients have a less favorable perception of their own health, are more likely to use tranquilizers, and suffer more constraints on their social lives than those who are not caregivers.

- Ambulatory care or how the state walks off with savings

For years, the state has defined families and women as resources rather than partners. It has come to depend on families and to view state-run services as complementary. This trend has accelerated with ambulatory care. In fact, certain ambulatory services explicitly require the participation of a family member. In some cases, reference is made to the "user/family," an indication of how indispensable the involvement of family is.

From the informal caregivers that they were, women have become official caregivers against their wishes. They are expected to perform professional acts such as change bandages, give injections, or administer medication. Although this care by "natural" helpers represents a considerable savings for the government, health care that is normally provided by specially trained hospital workers should be left to the professionals—the quality of care is at stake. As for providing more general care, some caregivers may find it easier than others. Some of those

surveyed expressed feelings of insecurity and stress at having to provide certain services for which they lacked training.

Families and women don't wish to stop providing services and care for their loved ones. They simply want to do it on a voluntary basis and feel perfectly safe doing it. That's why it is essential for woman patients and caregivers alike that the health system offer a range of accessible, quality services to meet various needs as well as the special requirements of certain groups like ethnic minorities, for example.

5. The impact on female health care workers

It is very difficult to separate the effects of ambulatory care from those of other, more general reforms of the health care system, and especially the accompanying budget cuts. Work loads in hospitals are increasing, and, despite promises to the contrary by the defenders of ambulatory care, nurses in CLSCs no longer have time for prevention and promotion campaigns. Whether this is a consequence of ambulatory care itself or of the inadequate resources committed to its implementation is not apparent. Whatever the answer, certain negative impacts are particularly noticeable among female workers in the public health and social services network.

- Female health care workers

A certain number of woman hospital workers were transferred to CLSCs with the advent of ambulatory care. Others were offered early retirement packages. For those who remained behind, one of the main consequences has been an increase in workload. There is less personnel to provide care at a time when hospital patients have ever greater needs. Before ambulatory care, nurses cared for patients undergoing preoperative exams and others recovering from surgery or illness. As ambulatory care aims to maintain these particular patients in their home environment, those patients who *are* hospitalized are now generally in an acute care phase that demands considerable attention. Transfers to CLSCs, which disrupted work teams and

reduced levels of expertise, have also contributed to an overload of work for remaining hospital staff.

In the CLSCs, the transfers also led to upheaval and the need for transferred workers to adapt to new practices. Not only that, CLSC nurses work with a variety of hospitals, each with their own protocols and equipment for ambulatory services. These differences are a source of insecurity for workers. Training is insufficient and prevention and promotion programs have been neglected. In native communities, people are worried that health centers explicitly set up for prevention and promotion work now find themselves with curative responsibilities. Although unable to ascertain a cause and effect relation between health care reforms and the deteriorating state of mental health of nurses, researchers have nevertheless observed higher rates of psychological distress and more consultations with health professionals than among the general public.

Ambulatory care also forces a return to the privacy of the home of certain health care acts and services formerly provided in public institutions. This can adversely affect the health and safety of workers. Helping ill or semi-autonomous patients bathe, dress, or get in or out of bed exposes workers to injury. Following safety procedures in the home is sometimes difficult—workers work alone and are often dealing with people who don't understand the importance of safety measures for preventing injury and may pressure workers to dispense with them. The relative isolation of homecare workers can also lead to feelings of insecurity and the risk of violent acts. Some women even have to fend off exhibitionism or sexual harassment.

In spite of the problems experienced by a large number of woman health care workers, some positive effects of ambulatory care are worth mentioning. For some workers, ambulatory care has enabled them to take on new challenges and achieve greater autonomy. They have also had the opportunity to develop new partnership links, both within the health care system and outside. Some nurses enjoy the fact that an important part

of their job involves teaching patients, and others feel their skills are better respected in an increasingly multidisciplinary context.

- Woman workers outside the health care system

Since public homecare services promised under ambulatory care have not kept pace with needs, and ambulatory care has in fact created new needs itself, other health and social services organizations run mainly by women have sprung up and flourished. These groups include profit-seeking private organizations (about which we know little) as well as SEEs (Social Economy Enterprises) and community groups.

In 1995, on the occasion of the *Marche des femmes contre la pauvreté*, women demanded public funds for creating goods and services that were nongovernmental, but socially beneficial. SEEs are the outcome, and the number offering homecare services in the health and social services sector has literally exploded. For the workers involved, there are certain appealing aspects to the social economy, such as quick access to jobs. The fear has often been raised, however, that the social economy may turn into a job ghetto for women where public sector jobs are replaced with unstable, temporary positions that are lower-paying. Data available on SEEs in the home care industry shows that their workforce is primarily made up of women earning between minimum wage and \$8.30/hour and, in 4 cases out of 10, employed on a part-time basis.

Ambulatory care has also had an impact on community organizations. Many have protested against the "dumping" of clients, who, insufficiently aided by the state, turn to them for last resort assistance, particularly social services. Groups complain about the increase in requests for assistance, notably for transportation between the home and the CLSC or hospital, and of their increasingly heavy caseload, the lack of consultation by public institutions, the insufficient information provided when hospital patients are referred to them, and funding levels that are inadequate for community needs. For volunteer workers, the consequences include

feelings of insecurity, powerlessness, and exhaustion.

Community groups also fear for their independence. They are feeling pressure from the health care system both directly and indirectly to adjust their activities and services to make up for deficiencies in government services. There is reason for concern about the consequences of such "dumping" on salaried work for women. Instead of creating public service jobs occupied principally by women, the government is offloading responsibilities onto community organizations that operate essentially on the strength of volunteer work by women. There is further cause for worry that volunteerism is being emptied of all notion of *voluntariness*.

6. The impact of ambulatory care on perinatal services

Some of the effects of ambulatory care on physical health—the lack of preparation for the return home, the occasionally deficient communication between hospitals and CLSCs, insufficient follow-up, etc.—also impact new mothers. The perinatal period, however, merits special attention. Pregnancy and childbirth are not illnesses, and women have long demanded a "demedicalization" of the childbirth process. Given that the perinatal clientele is healthy, one in need of primarily preventive and promotional services, and given the current context of budget cuts, there is a danger that perinatal care will get lost in the shuffle despite representing a crucial period of adaptation.

- Consequences of early release from hospital

For perinatal patients, the biggest effect of ambulatory care is the shortening of hospital stays after childbirth. Under current early release programs, stays are generally 2 days for vaginal delivery and 4 days for birth by Cesarean.

The Conseil d'évaluation des technologies de la santé has examined the possible risks and benefits of short perinatal hospital stays. According to available literature, there is no

conclusive link between early release and complications, hospital readmissions, or the use of health services for the child or mother. There is, however, very little data on the psychological or social consequences, and research generally looks at those women who *choose* early release. There is no data available for vulnerable categories such as poor women or cultural minorities.

Experts agree that systematic follow-up of mothers and newborns is key to the success of early release programs. Follow-up should be as soon after release from hospital as possible, should offer breastfeeding support, and should cover all mothers and their newborns. Focus should also be on the psychosocial aspect of the arrival of a new child. At the moment, postnatal follow-up is not systematic throughout Québec. Some hospitals have agreements with CLSCs and community organizations outlining their respective roles in follow-up care, but others don't. Sometimes follow-up is carried out by the hospital, in other cases by the CLSC. Some programs are designed for all women, whereas others are limited to target groups. In other instances mothers contact the institution as needed.

7. New costs for patients under ambulatory care

With the budget cuts that have accompanied ambulatory care, our free and universally available public services no longer meet the needs of the public. When patients don't receive all the ambulatory services they need following an early hospital release, they either have to do without, obtain them free of charge from family members or volunteers, or pay for them. Thus, patients and health care system users are now obliged to assume costs for services that were once funded by the government.

The privatization of health care and services is not a new phenomenon. It started well before ambulatory care. Private health spending in Québec now represents one third of total spending. This percentage is likely to increase under ambulatory care, especially given the

growing role of private insurers and private health care and service providers.

- Private insurance, public insurance, costs for individuals

With the advent of ambulatory care, insurance companies increasingly cover services like nursing homes, home nursing, and posthospitalization personal care and domestic help. They also continue to cover drug insurance for individuals (and their families) who have group insurance coverage through the workplace.

In 1996, the government created a public drug insurance plan for those without private coverage. It was forced to take action since patients were being released from hospital earlier and often needed drugs that used to be supplied by the hospital. Many patients had no private insurance and were obliged to pay the full cost of medication unless they qualified for free drugs as income security recipients or seniors (65 and over). The public plan covers every Quebecer, but it isn't free. Even the poorest have to pay part of the cost as well as a deductible. The consequences have been disastrous—the elderly and welfare recipients have cut their consumption of essential medication, resulting in more trips to the doctor's and the emergency ward, more hospital and nursing home admissions, and even death in some instances. The government is currently reviewing the plan.

Ambulatory care has also resulted in a proliferation of privately run care and service providers. In some cases, waiting lists for specialized public services have forced newly released hospital patients to turn to the private sector. Patients receiving treatment in ambulatory care centers who need accommodation close to the centers must cover the costs themselves. Private nursing homes and agencies offering a range of homecare services have sprung up. By summer 1998, there were some 70 such agencies in Québec. There has also been an increase in the number of nurses working in the private sector. Although their numbers are still relatively low, they went up by 11% between 1996 and 1997. In January 1999, a

Québec university announced the first nursing program specializing in private practice. The number of social economy enterprises (SEEs) working in housekeeping has also taken off. Although they are not private, for-profit organizations, users must still pay for SEE services.

Another example of privatization is the new tax credit to help the semi-autonomous elderly pay for personal services (assistance with dressing, eating, bathing) and general housekeeping. The tax credit is not aimed specifically at former hospital patients, although there is concern it will eventually spread to this clientele. Carefully disguised as a "gift" equivalent to 23% of eligible expenses, the tax credit actually masks the fact that 77% of costs are covered by the individual, whereas personal services are normally provided free of charge by CLSCs.

- Rethinking free, universal public services

Expanding involvement by the private sector in the health field, whether through the increase in private insurance coverage or the proliferation of private health care service providers, forces us to rethink the fundamental question of the "basket" of services that should be universal and free of charge under ambulatory care. Private sector growth is possible where public services are too few, too late, or too imperfect. Currently, the guarantee of gratuity applies to services provided by doctors and in hospitals. Shouldn't the same gratuity for other services made increasingly necessary under ambulatory care also be written into law? What about nursing care, personal care, and in some instances, domestic help? The question of drug costs must also be reviewed. It is clearly time for public debate on these societal issues.

Putting the focus on health

In early 1999, the government announced an injection of new money into the health system. Part of this money will go towards homecare, which should help. Ambulatory care got off to a very shaky start because of the budget cutbacks at the time of its introduction. Will the new funding really resolve such problems as the lack

of resources for convalescing patients, the lack of coordination between hospitals and CLSCs with regard to patient follow-up, the lack of homecare services, and the increasingly important role of the private sector?

Given their social and economic conditions, woman patients are particularly affected by ambulatory care. The longer the problems persist, the more likely they are to have an impact on them. Moreover, in fields such as perinatal care, women are the main users—and thus the main victims—of deficiencies in prenatal and postnatal services.

The notions of empowerment and freedom as conveyed by ambulatory care are suspect for women patients. Of course women have every reason to question the idea of a hospital-centred health system, to rely less on so-called experts, and to take back control of their health. But the autonomy that feminists have been fighting for is far removed from the autonomy that ambulatory care claims to deliver.

The most pernicious effect of ambulatory care on women is that it has once again branded them as the "natural" helper/caregivers for family upon hospital release. Support measures for caregivers, whether in the form of services or financial assistance, are largely insufficient. Before demanding more, women should question whether they are willing to accept this role the government has tossed into their laps. Will the new funding for health care provide patients with the services they need so that caregivers are not "forced" to volunteer their help?

Lastly, woman health workers and community group volunteers are also feeling the effects of ambulatory care. For some, the situation has been an opportunity to take on new challenges, and feel useful and recognized for their work. For many workers and volunteers, however, it has created very difficult conditions. Women everywhere are complaining about overwork and stress. Will the new government funding make conditions acceptable once again? Will community groups gain the flexibility they need to fulfill their missions?

Putting an end to budget cuts should help alleviate the negative consequences of ambulatory care on woman patients, helpers, and workers. But money alone won't solve the problems. First of all, we must acknowledge the adverse effects on women and show the political will to attack the problem head-on. The government must take concrete action. Over the next few months, the Conseil du statut de la femme will issue its report and recommendations to the government to ensure that ambulatory care respects the needs of women.

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