

Opening the Door: A Much-Needed Dialogue on Current Health Care Delivery

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Health care is becoming a critical concern for people in New Brunswick as increases in chronic illnesses, rates of obesity, and a larger senior population increase demands on a system that is already overburdened. This inevitably results in many people feeling that their needs are not being met. As a health care specialist, I have heard these concerns many times over the past four years, as friends, neighbours, and even strangers reached out to me for advice.

“Penny, your name was given to me as someone who might help me talk to my doctor about my concerns for my mother.”

“Penny, you won’t believe what happened to my husband in the ambulance on the way home from Saint John!”

“Penny, do you know a doctor who will give me pills to lose weight?”

The above quotations are from telephone calls I received around the time I submitted a paper to Horizon Health (August 2013) that focused on recommendations for improvements to health services. The document was based upon what I had observed and heard during seven months of daily visits with my husband, Carl. His first two months at the Dr. Chalmers Hospital were spent in the emergency room, the stroke unit, and the rehabilitation unit. In his final five months, he stayed on the alternate level of care unit. The unit is designed for individuals who are waiting for nursing home placement. Carl died before a nursing home bed became available.

The paper, entitled “Carl’s Last Class,” was publicized by the local CBC radio and television stations and *The Daily Gleaner* in September 2013. I delivered copies to the Department of Health, Horizon Health, the medical society, the New Brunswick Nurses Association, the New Brunswick Nurses Union, the faculty of nursing at the University of New Brunswick, and to my family physician. As a result, politicians and health care workers stated their interest in discussing my concerns.

“Carl’s Last Class” was also used by Horizon Health as part of its justification for inviting patients and family members to serve as advisors on committees. As a result, the Patient/Family Advisory Council was founded in February 2014. I became co-chair along with Margaret Melanson, whose job is vice-president, quality and patient-centred care for Horizon Health. As a council, our mandate was to address issues of concern about access to and the quality of health care within Horizon Health. We proposed solutions, and worked to expand the patient/family volunteer participation on Horizon Health working committees. This initiative has opened the door to members of the public who can now have a positive influence on the delivery of care. Patients and family members are also welcomed to volunteer for committee work within Horizon Health. Volunteers are selected to work with committees that focus on the issues that are familiar and important to them. Examples of positive changes based upon the support of volunteers are expanded visiting hours, a non-smoking policy, and improved standards of cleanliness throughout the hospitals.

Furthermore, while the patient/family advisors contribute to the successes of committee goals, they are also leaders in the process of holding politicians and professionals accountable for their decisions regarding our health. Because responsibility for our health is a triangle—personal, professional, and political—such accountability is key.

In fact, health can be seen as a kaleidoscope. It has a number of coloured pieces inside, but turning them from the outside can change the picture. We are like kaleidoscopes in that we have many pieces internally that create a personal health picture, and the outside world presents us with challenges and benefits than can alter that personal health picture.

This essay will explore health and health care as it is shared between personal responsibility, health care professionals' roles, and the government's responsibilities in terms of maintaining a healthy population. This paper is based on my sixty-five years of working within health care settings, and sixty years of working in a variety of environments from the perspective of a nurse, and on my observations as a user of the health care system. This is not a research paper. It is a reflection.

Personal Health Responsibilities

Managing personal health is a challenge despite the fact that information about the importance of exercise, food choices, rest, and disease prevention is widely available. It is important to acknowledge that the gap between knowing how to create a healthy lifestyle and applying this knowledge varies greatly from person to person, but it can be positively affected by access to appropriate health care professionals. There are still too many individuals and families in New Brunswick that are without access to a family physician or a clinic within Horizon Health. We need to open more doors for learning how to care for ourselves. Health education in schools is as important as it is at home. Public health nurses' contributions to health learning at school and at home have decreased over the past fifty years due to government cutbacks. Many employers have improved health standards and health education in the workplace over the past fifty years, but there is still room for growth. "We the people" can ask for and lobby for more doors to be opened in these areas. The most important area for growth is for each of us to understand that we are responsible for our health in tandem with the professionals who guide our knowledge. The expression that is used by health professionals to denote knowledge about health is "health literacy." Paradoxically, one of the challenges to our health literacy is the vast amount of information that is provided by advertisements, the Internet, and personal opinions. The misinformation that results from these sometimes-unreliable sources is another reason for all of us to open the doors to health professionals and government health agencies to dispense research-based information that will be helpful to the general population. There are no shortcuts to good and lasting health, but New Brunswickers have a better chance of making enlightened decisions if they have quick and reliable access to appropriate health professionals.

Professional Responsibilities

Professional associations set standards for the education and practice of their members. Rapid changes in technology and in health care issues present challenges to those associations to keep their programs and practice standards current. They are the experts, but we need to open the doors to their offices to tell them how important it is for us to have health care professionals who deal appropriately with health promotion as well as disease prevention and curative treatments.

The New Brunswick Medical Society, for example, has developed a program for using family physicians more effectively through a professional team approach. The goal is to have access to care for longer hours and on weekends. This is aimed at diminishing the inappropriate use of the emergency room while also allowing patients and families to access health care more quickly.

The New Brunswick Medical Society has also participated in developing documents for the Department of Health to use in addressing the serious issues of obesity as well as the increasing number of seniors in need of health assistance. They are also encouraging the government to hire the appropriate number of specialists and to manage the hospitals effectively so that specialists can practice to their capacity. One of the challenges to accomplishing this is to deal with the problem of using hospital beds for individuals waiting for long-term care. Our voices need to be raised to insist that more nursing home beds are opened for those who need them.

Similarly, the Nursing Association of New Brunswick has supported the education of and need for both nurse midwives and nurse practitioners. The benefits that these professionals bring to us need to be shared with the public. Our population is not dissimilar from others in Canada. We ask for change and improved services, but when change occurs we sometimes push back, resisting centralization or closing small-town facilities. We would benefit from opening the door to change! Nurse midwives and nurse practitioners are used across Canada successfully. We would benefit from accepting their professional services more readily.

One of the challenges for all health organizations is to provide their members with continuing education in the area of palliative care. The New Brunswick Association of Licensed Practical Nurses has created a curriculum that has advanced the practice of their graduates to important roles in acute-care settings as well as responsible positions in long-term care environments. The benefit of using a Canadian curriculum is that it meets our accreditation standards. It is also designed to help professionals have important and appropriate conversations with ill patients of all ages and their families. As a society, we and health care professionals are guilty of not being realistic about the fact that our lifespan is limited. We believe these conversations can wait, despite the fact that a health crisis can occur at any moment. End-of-life and treatment questions, preferences, and concerns should be discussed *before* they become immediate decisions.

Personal support workers (PSWs) do not have an association in New Brunswick, nor do they follow a standard curriculum. The number of PSWs need to be increased to meet the growing need. Their education also needs to be standardized and supervised, and they need better compensation for the critical support they offer in nursing homes, special care homes, and private homes. PSWs fulfill an important role in the health kaleidoscope, filling in gaps such as sitting with patients in acute-care settings when individuals can't be left alone for safety or comfort reasons.

Those of us who have cared for a family member at home realize how difficult and tiring it can be for the caregiver. Statistics reveal that the health of an elderly caregiver is frequently compromised to the point that the caregiver dies before the patient. Family members who work and provide care for a needy family member are trying to help as best they can, but it is often a juggling act of working and caring competently. Spouses or family members may be competent at knowing the needs of their loved one, but sometimes they don't know the appropriate care strategies. They need help beyond being told to install a wheelchair ramp. They need greater assistance from health care teams (including PSWs). We need to open the door for this conversation with the politicians who control the budgets

and make decisions affecting health care within both the Department of Health and the Department of Social Development.

Political Responsibilities

Health care is a shared federal and provincial responsibility, so we need to open the doors of elected MPs and MLAs to have meaningful conversations about improving the systems that are in place. However, one overarching challenge is the cycle of elections. Governments in power tend to choose short-term successes rather than planning for and initiating longer-term goals that would serve citizens more effectively. An example of this short-sightedness is the current lack of facilities for seniors with significant health problems who require substantial in-home care or institutional care appropriate for their needs. Demographic statistics have been abundantly clear for over fifty years that the post-World War II baby boomers were going to stress the facilities and services of the departments of Health and Social Development. Yet programs and finances have not been allocated appropriately to meet this need.

With all of the Canadian information available to us that supports successful strategies for delivering health care, why has our health care system struggled to adequately serve the health care needs of our province?

The simplistic answer is that our government's responsibilities are divided into sectors for management. The Department of Health and the Department of Social Development are the two primary health delivery systems. Each department has a budget, yet our health needs are not covered adequately by these two departments. We need to open the door to the discussion of the "overlaps" with other provincial and city departments. Transportation is one example. New Brunswick is a rural province. Access to health care is problematic if one doesn't have a car or a friend who is willing to provide a ride. The patient suffers if the driver can't come as planned. The health care professional is frustrated by the inability to help that person. Frequently, the appointment is cancelled at the last minute, which means it is too late to bring another person in for care. We need to initiate conversations with Horizon Health and the Departments of Health and Transportation at both the provincial and local levels to come up with successful strategies. Would the Department of Health, for example, consider sending teams of health care professionals to small towns for consolidated health assessments and care? Would the Departments of Health and Social Development schedule appointments with clients on income assistance between 10 a.m. and 3 p.m. if local bus or transportation services provided free service for them during these periods of low use?

Given that the literacy rate in New Brunswick hovers at around 65%, would it be beneficial to have a partnership between the Department of Health and the Department of Education that would use health information as part of reading and writing? Perhaps this is an area where the government departments could benefit from the model of patient/family advisors. Members of the legislative assembly have offices around the province and can meet with their constituents to discuss the challenges and bring suggestions forward to the various departments. We can learn a lot from the individuals who make things happen when it isn't easy! Some MLAs have committees of constituents who discuss challenges and solutions in the areas of health, justice, and transportation. We need to open more doors for citizens to participate in improving the systems that are established to keep us healthy.

Opening the Door for Better Communication

One of the challenges faced by professionals, politicians, and the people who depend upon them for quality health care is time for communication.

Consistent improvements in diagnostic technologies as well as surgical techniques and medical treatments have enabled patients to be diagnosed, treated, and discharged within hours or days rather than weeks, as was the case fifteen to fifty years ago. Technological progress, however, has resulted in lost time for the patient and family to learn about ongoing care once they return home. Specialized services, such as orthopedics, have provided pre-operative teaching sessions that explain the necessity for equipment that might be required as well as important exercises developed by physical therapists to enable proper recovery. In spite of this, and related to delays caused by long waiting lists, many patients forget valuable information. Post-operative telephone calls to patients at home have assisted many families, but not everyone who receives a call understands the questions or wants to admit that they don't. Home visits would be far more effective at uncovering problems or misunderstandings.

These and other examples provide another opportunity for health care professionals and department employees to meet with patients and families to discuss problems and solutions. Non-government organizations such as the Alzheimer Society or the Heart and Stroke Foundation also need to be included in the dialogue because of the programs they offer.

The Department of Finance, working with the Department of Health, could assist by integrating provincial and federal health data so that clinics and specialists are located according to the geographical needs for particular health challenges, as well as establishing the centres that deal with these challenges. Within Horizon Health, for instance, Saint John currently functions as a centre for cardiac and neurosurgical treatments as well as radiology. Horizon Health has also partnered with the nursing program at the University of New Brunswick in Fredericton to provide appropriate services for those whose care is overseen by Social Development as well as the Department of Health. Funding is not available to develop acute-care centres for all types of illness in every part of our province, but we do know that there are geographical differences in the numbers of individuals living with chronic illnesses that need monitoring to prevent acute episodes. Diabetes, heart disease, pulmonary disease, and dementia are examples of chronic illnesses that can be cared for by clinical services closer to patients' homes than the regional hospitals.

The health care system in New Brunswick is not dissimilar from other provinces in that it is trying to curtail costs and still retain standards that meet accreditation requirements. From the perspective of patients and their families, however, I believe that they are failing. Horizon Health, the designated English health authority, is struggling to support acute-care services that are increasingly required as the result of poorly managed chronic illnesses at the community level and the burgeoning number of seniors. Staffing is one of the most expensive features of the budgets of both the Departments of Health and Social Development. Consequently, there has been a reduction in staffing models in acute-care hospitals as well as nursing homes. The public needs and has a right to know "who is in charge" of these units and nursing homes.

Recognizing Change to Optimize Patient Care

Because of the administrative tasks that have been delegated to nurse managers, they have less time on the units within the hospitals or wings of the nursing homes. It is important in both settings that nurse managers promote working as a team that values and supports all levels of caregivers. Because of the additional administrative duties, nurse managers in acute-care settings are unable to work consistently with nurses to provide meaningful assessments and to ensure professional standards. Nurses who are new to a unit may not be familiar with the routines, and picking up the information from other team members may not be sufficient. The nurse managers who are not on the unit for the whole day miss opportunities to know the patients and families sufficiently to ensure that their concerns regarding the transition to home are met. They are not there to have important conversations with the physicians, physical therapists, occupational therapists, dietitians, and other specialists. The nurse manager's role likewise evolves as patients and families from countries where English is not a first language come into units. The nurse manager needs to make sure that adequate translations are provided for the family as well as the care providers. The work changes again when "sitters" are involved—non-professional staff paid by the family to stay with patients who require bedside monitoring for safety reasons. Sometimes these sitters are hired to walk dementia patients who need supervised walks. Sitters call for assistance when required, but they, too, need the expertise of nurse managers to use their time with patients effectively.

Nursing homes are supervised by the Department of Social Development rather than the Department of Health, but the requirements for competent leadership are equally important. The budget cuts to nursing homes have created new challenges. Registered nurses have administrative duties that take time away from supervising the actual care of the residents. Licensed practical nurses provide residents with medicines and treatments that are required, while PCWs are assigned to the daily physical care of residents. Because PCW education is not standardized within the province, and because the acuity level of patients in nursing homes is more complex than it was even fifteen years ago, this staffing group doesn't receive the team support that they frequently require to provide care that meets best-practice standards. PCWs are providing important, meaningful care to residents, but the time allotted for completing assignments leaves out in-service education. Patients in nursing homes generally remain there until end of life, yet physicians who serve nursing home residents as well as the registered nurses and licensed practical nurses are rarely comfortable with end-of-life conversations that should be held with the patients and families when they enter nursing homes. These skills are not currently taught in health care curricula, but there are guides for learning these skills that are available from many health authorities across Canada, and they should be utilized. Politicians need to consider and evaluate these issues when establishing budgets.

Palliative care is another body of knowledge that needs to be taught and utilized in hospitals and nursing homes. There are residential hospices in Saint John and Fredericton, and those cities also offer in-home hospice care. Moncton and Miramichi are moving to create similar centres for care, but four hospices are not sufficient to meet the end-of-life care required in New Brunswick.

The creation of hospices has been hampered by the fact that they are not included within the Canadian health care system's scope of support. In New Brunswick, the Department of Health will pay the clinical salaries of the doctors and nurses who provide care to the ten patients and their family members at a hospice. This means that all other costs need to be covered by the volunteer boards that support these facilities or the families themselves. This is an onerous responsibility for communities to absorb.

In Canada, there are many resources available for patients receiving palliative care both in institutions and in their homes; however, within New Brunswick the national standards for palliative care have not yet been adopted. Until this gap is addressed, palliative care in this province will not meet national standards. Inappropriate end-of-life care is traumatic to both the individual and the family. Other health care services provided in its place can be inadequate and more expensive. Hospices and other health care facilities that provide palliative care can and should be accredited to ensure consistent standards.

Seniors in New Brunswick will be facing end of life in increasingly larger numbers over the next two decades. The Department of Health seems reluctant to spend money to build the nursing homes required to care for this rapidly rising population. Citizens and politicians support the benefits of staying at home because that option seems more comfortable, private, and cost-effective for the taxpayer. Politicians in the past have supported programs to improve residential homes to accommodate the needs of frail residents and ease the work of the caregiver. This model seems a wise one to implement as a way to unburden the units in hospitals currently filled with patients receiving alternate levels of care (ALC).

ALC seniors who are waiting for nursing home beds have generally had one or more chronic illnesses for an extended period of time, but it was a particular event that brought them to the emergency room and subsequent ALC admission. Research within Horizon Health has demonstrated that the majority of these seniors had not been in a hospital within the previous year. A fractured hip, a stroke, or a heart attack occurred and overwhelmed the ability of the caregiver to continue providing care. This is why more nursing home beds are needed.

Families with financial resources can often extend the period of staying at home by paying for PCWs or licensed practical nurses to assist with the twenty-four-hour care. Nonetheless, this becomes very difficult for families, because few care workers are willing to work evenings, night shifts, or weekends. Family members living out-of-province find it almost impossible to support home care in New Brunswick without giving up their jobs.

Without the benefits of palliative care at home, family caregivers may experience exhaustion and panic as the patients approach the last few days of life. Sometimes the pain experienced by the dying person or the lack of knowledge about the final stages of life can result in a family member placing a 911 call for help. It is not surprising that the family is distressed and disappointed by the frequently unpleasant end-of-life experiences in an acute-care setting. Have we opened the door to discuss end-of-life care with politicians and physicians? As a society, are we doing the best we can for those who need care and for the family members who are trying to provide that care?

The New Brunswick provincial government is reluctant to add more to the current plan for additional nursing home beds because it is concerned that beds will be redundant in another two to three decades. What they are not taking into consideration is the change in the health care dynamic within our province. The beds used now for seniors will be required for other patients with chronic care issues. We may have the most seniors in the country, but we have the second-highest number of obese citizens. We know that obesity and lack of exercise are detrimental to managing chronic illnesses. Consequently, the need for nursing home care will be needed for a younger cohort.

In Canada, we pride ourselves on having a health care system that is available to all, but that is not entirely true. Seniors with adequate pensions can afford medications that are not on the formulary. They

can afford to pay for physical therapy rather than wait in a long line for similar services in the hospital. They can go to the United States or other provinces for quicker access to joint replacements or cardiac assessments and treatments. They can afford to have services and service providers brought to their homes. This access to alternate health care distorts the numbers that represent what we actually need and receive. Have we opened the door to discuss these issues with our politicians? Will these services be available for the generations working without pension plans who are following the baby boomers?

Summary

As citizens, I believe that we recognize the financial challenges of living in New Brunswick. I also believe that we want to see changes in the health care system that will provide more timely access, more communication about our health that is meaningful, and more respect for what we know as individuals about our own health challenges. We need professional coaching to increase our abilities to deal with health setbacks. This desire for improvement will not occur if citizens of this province do not demand changes from their MLAs and MPs. These are the two major funders of health care, and without their support changes will not occur. We cannot expect health care to improve without making it an election mandate. We do not need studies. We do not need more research. There are successful programs all across this country—from childbirth and pediatric care to palliative end-of-life care—that can be borrowed and implemented. Successful health clinics, hospitals, nursing homes, and teaching facilities are only too happy to share. If we truly care, we *will* speak up and take our concerns to those who *can* and *should* make the health care system in New Brunswick better. Working together, we can find an effective way to move forward.

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