Patient-Centred Care

The idea that patients should be at the centre of the health-care system has become a topical issue. In many systems today, including Ontario’s, health care is not patient-centred. Rather, the patient is required to adapt to the system and to navigate through its many intersections. Patient-centred care has been identified as an important problem by organizations around the world, including the World Health Organization (WHO), the Organization for Economic Co-operation and Development (OECD), the National Health Service in Britain, the National Health and Hospitals Reform Commission in Australia, and the Commonwealth Fund Commission, and American Agency for Healthcare Research and Quality (AHRQ) in the United States.

In this paper, patient-centred care research is reviewed from both the system standpoint and the practitioner standpoint, including research and experience in other jurisdictions, and challenges to providing patient-centred care. OMA “Policy Recommendations for System Change” are presented, along with “Principles of Patient-Centred Care for Physicians,” on pages 43 and 44 respectively.

What Constitutes Patient-Centred Care?

Patient-centred care is a somewhat tenuous concept. In some systems, it seems to encompass all that is synonymous with good care and good communication. With such broad definitions, any care element considered desirable could be called patient-centred. The OMA definition of patient-centred care is as follows:

“A patient-centred care system is one where patients can move freely along a care pathway without regard to which physician, other health-care provider, institution or community resource they need at that moment in time. The system is one that considers the individual needs of patients and treats them with respect and dignity.”

Regardless of the specific definition, patients will vary in the extent to which they desire and are able to participate in decision-making. Moreover, the same patient may want to participate fully in some situations, but in others prefer to rely upon the physician’s advice entirely.

From the physician’s perspective, the propensity to be patient-centred will vary with knowledge of the patient. Both the attitudes and the behaviours of physicians and other health-care providers will determine whether care is centred on patients.

Although the two concepts are not entirely separate, patient-centred care can be addressed from both a systemic level and from the perspective of physicians and other health-care professionals.

Patient-Centred Care: System Level

Challenges to patient-centred care at the system level include integration and access. Funding is also a factor that will be addressed later in the paper.
Integration

For a system to be truly patient-centred, care must be integrated across the system. This problem of lack of integration has been recognized as one of the most difficult challenges facing the Ontario health-care system. When a patient moves from one part of the system to another—from hospital to home or to another facility, from home to long-term care, from long-term care to hospital, or from general practitioner to specialist—our system often fails the patient. It is built with individual system components, rather than with the patient as the centre of a pathway that moves easily through intersections from one part of the system to another. Patients with comorbidities, those with high-risk conditions, and the frail elderly are most vulnerable. We are not alone in facing this challenge. The OECD has recently undertaken a survey to gather information on care co-ordination concerns, problems, and practices among OECD and European Union (EU) countries. Twenty-six countries responded. The OECD report suggests that care co-ordination problems are worst at the interfaces between health-care sectors and between providers.

The OECD report indicates that most policies directed toward system change share the intent of reducing the need for high-cost hospitalization for the chronically ill by shifting the locus of policy attention and program toward ensuring high-quality, patient-centred care outside of acute hospital settings. They suggest that disease and case management programs seem to improve quality, but that their cost-effectiveness is inconclusive and that better information transfer between parts of the system could be achieved by electronic medical records. Multidisciplinary teams are proposed as a better method of ensuring care co-ordination than the solo family practitioner. This is in concert with the OMA’s Policy on Interprofessional Care, which states that the collaboration that occurs in interprofessional team care could improve patient care in Ontario. The policy is available on the OMA website at: https://www.oma.org/Resources/Documents/2007IPCPaper.pdf.

Access

Another key problem is that for the health-care system to function effectively, the system needs to match demand to capacity, and do so with minimal delay. When demand exceeds capacity at any point in the system, there will be delay and a bog in the system. This is a tremendous impediment to access in Ontario, and one of the main reasons that the system fails patients.

Some populations have more difficulty accessing the system than do others. Those who are educated and health literate are more able to negotiate and navigate the system. The less educated, the frail elderly, those for whom English is not a first language, and those with mental illness or substance use problems have more difficulty.

At the practitioner level, problems with patient accessibility to physicians include such matters as quick access to appointments for sick patients, telephone or e-mail access, and office hours that extend beyond the 9:00 to 5:00 weekday. Many physicians are already overworked, and there are continuing demands to increase availability and take on more patients. Both patients and physicians see access as problematic. In a survey of Canadian households commissioned by the Canadian Medical Association, respondents gave an overall score of 5.63 of a possible 10 to the extent to which health care in their community is patient-centred, with the lowest scores for waiting after arrival for health-care appointments and for wait times for appointments to see specialists. In a survey of 11 countries, only 43% of Canadian primary care physicians reported after-hours arrangements to see a physician or nurse without going to the ER. This rating was 10th among 11 countries. With regard to perceptions of access to specialists, 75% of Canadian primary care physicians surveyed reported that patients often faced long waiting times. Canada tied for last place.

Compared to other countries, Canada also rates poorly in comparisons of time for sicker adults to see a physician. In same-day service or next-day service for these patients, Canada rated 6th of 6 countries, including the U.S., with just 36% able to access care the same day or the next day, compared to 81% of New Zealanders. Thirty-six per cent waited six days or more. Canada also fared poorly comparatively with access to care on nights, weekends, and holidays without going to the emergency room. Over half of Canadian adults surveyed reported getting care “very” or “somewhat” difficult at such times.

The concept of advanced access to primary care has come to the fore as systems have examined ways to make primary care more accessible, some on a 24/7 basis, and some by reducing the delays for patient appointments and permitting same-day service.

The American Institute for Healthcare Improvement (IHI) has a model for improvement that has been specifically adapted to improving primary care access. It suggests that three strategies for improving patient access are: increasing the ability of the system to predict and absorb demand; matching supply and demand; and, redesigning the system by making it more efficient. In terms of process, IHI suggests a “plan, do, study, act” cycle for testing a change in the work setting by planning it, trying it, observing results, and acting on what is learned. Although it seems that these strategies may also be useful for specialty care, IHI has a specific website for specialty care that provides examples of systems where access to various types of specialties has been improved.
Dutch use the concept of responsiveness, and Health First Europe asserts that care for patients should include access to health-care services warranted by their condition.

Ontario
Ontario has implemented a variety of funding models in the last decade that vary somewhat in terms of services to patients and incentives to physicians. But all of these new models require comprehensive care and provide extended access to patients. There has not yet been a published evaluation.

Telehealth Ontario is a service designed to provide health advice or information on a 24/7 basis. It is staffed by nurses who will assess the situation and recommend a visit to a clinic, physician, hospital, or other community resource, as the situation warrants.

A variety of other initiatives have been undertaken over the past five years or so with a goal of improving patient transitions from one part of the system to another, and addressing the disparity between supply and demand. These include Ontario Ministry of Health and Long-Term Care (MOHLTC) initiatives such as the Wait Times Strategy, the Aging at Home Strategy, and the Critical Care Strategy. These initiatives are laudable; whether they will change the system has yet to be determined.

The MOHLTC has strategies in place to reduce wait times for surgical procedures and in hospital emergency rooms. This is one way of addressing demand exceeding the capacity of the system. Wait time information is transparent and available online for ERs and for current surgical and diagnostic imaging procedures. Results are generally positive. Surgical and diagnostic imaging wait time information is collected and posted for general, heart, ophthalmic, orthopedic, and pediatric surgery, and for MRIs and CT scans. Except for bypass surgery, they show significant reductions in all major categories. Although there has been no overall change since 2008 in emergency room wait times, results for patients with more complex conditions in ERs have been reduced significantly.

More recently, the MOHLTC, in collaboration with the Collaborative for Health Sector Strategy of the Rotman School of Management, and the Ontario Association of Community Care Access Centres, has embarked on an integrated client care project. It is intended to be a multi-year, multi-project initiative, with the first project to deliver patient-centred wound care for people receiving home-care services.

Canada
Patient-centred care is a focus in other provinces, including British Columbia, Alberta, Saskatchewan, and New Brunswick. The Calgary Health Region is evaluating several strategies to improve system integration, including creation of a central access and triage system, prioritization tools for specialty access, and redesign of clinic process flow to reduce wait times.

International
In the past decade or so, the U.S. Veterans Administration (VA) has transformed itself. Patient-centred care co-ordination is organized so that the patient is the locus of control and the provision of care is seamless across environments. The VA uses technology to support patients’ ability to successfully age and manage disease in their own home. It has identified care co-ordination and supportive technologies as its preferred mechanisms to preserve independence and postpone or alleviate the need for institutional care for those who are frail from chronic illness or advanced age. Since 1996, improved outcomes have been achieved in all dimensions, while reducing the cost per patient by more than 25%. The VA achieved this by the use of evidence-based practices, proactive approaches to patient safety, and use of advanced technologies, such as electronic health records and bar-coded medication administration. Structurally, it has been transformed from a hospital system to a health-care system, with co-ordination among facilities and resources. Financial incentives were provided for co-ordination of care and resources among previously competing facilities. The VA measures both performance and value on multiple dimensions.

Patient care in Denmark is considered to be highly accessible, while enjoying low total health-care expenditures. A system has been developed so that, in every county, clinics see patients at nights and weekends. Weekend physicians take telephone calls from patients and can readily access their electronic records; they can prescribe medications electronically, or ask patients to come in to see them. They are paid a higher fee for telephone consultation than visits. The patient’s own primary care physician receives an e-mail the next day with a record of the consultation. All (98%) of primary care physicians are required to have an electronic medical record. The easy accessibility of physician advice by telephone or e-mail, and electronic systems for prescriptions and refills, reduces both physician time and patient time.

Health First Europe is comprised of 24 member organizations that represent patients, health-care workers, academics, policy-makers and medical industry experts, and is supported by 19 members of the European parliament. Its recent report exploring approaches to health care in the coming decades contains an essay defining principles on patient-centred care. These principles have some appeal in that they incorporate the notion of the partnership between patient, family, and physician; patient responsibility for health care and involvement in decision-making; and information provided to enable informed choices. Most importantly, the principles assert that patients should be involved at their level of choice. This will vary from patient to patient and situation to situation.

Both Australia and Holland have also focused on patient-centred care, with the Dutch equating patient-centred care with responsiveness.
The Concept of the Medical Home
The “medical home” is much in vogue, particularly in the United States. Here in Canada, the College of Family Physicians of Canada recently issued a discussion paper on the concept of the medical home. In the U.S., several associations — the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association, have jointly developed principles of the patient-centred medical home. They are summarized as follows:

- Personal physician: each patient has an ongoing relationship with a personal physician who provides first contact, continuous and comprehensive care.
- Physician-directed medical practice: the physician leads a team who care for patients collectively.
- Whole person orientation: the personal physician is responsible for providing or arranging for care at all stages of life — acute care, chronic care, preventive services, and end of life care.
- Care is co-ordinated and/or integrated across all elements of the health-care system, such as specialty care, hospitals, home health agencies, nursing homes, and the community. Care is facilitated by registries, information technology, and other information exchange.
- Quality and safety, including patient-centred outcomes, evidence-based medicine with clinical decision support tools, physician accountability, patient participation in decision-making, information technology, government recognition process, and patient participation in quality improvement.
- Enhanced access through open scheduling, expanded hours, and other communication options.
- A payment structure that recognizes the added value provided to patients with a patient-centred medical home.

In 2006, the American Academy of Family Physicians launched the National Demonstration Project to test a model of the patient-centred medical home (PCMH) in 36 family practices. After three years, the evaluators have raised concerns about the demonstration project. In particular, they indicate that transformation to a PCMH requires epic whole-practice reimagining and redesign. It is not an incremental process. Because the components are interdependent, they represent a gestalt that cannot be broken into easily reconfigured pieces or put together in a temporal fashion. The evaluators assert that transformation requires new scheduling and access arrangements, new co-ordination arrangements with other parts of the health-care system, group visits, new ways of using evidence, quality improvement activities, more point-of-care services, development of team-based care, changes in practice management, new strategies for patient engagement, and multiple new uses of information systems and technology.

Their analysis indicated that the current designs seriously underestimate the magnitude and timeframe for the required changes, overestimate the readiness and expectations of information technology, and are seriously undercapitalized.

The PCMH requires different skills for most family practitioners. Physicians needed facilitative leadership skills, the ability to work in practice teams, manage chronic care using the chronic care model, use evidence-based medicine, integrate change management, and partner with patients. Change fatigue was a serious problem, even in highly motivated practices.

Another evaluation was done in Seattle, where a patient-centred medical home concept was evaluated over a one-year period. The results were more positive than the National Demonstration Project, but to achieve these results, physician panels were reduced to 1,800 patients, visit time was expanded from 20 to 30 minutes, “desktop medicine” time was allocated daily, staffing was increased for physicians (15%), physician assistants (44%), registered nurses (17%), medical assistants (18%), and clinical pharmacists (72%).

Apart from whether one adopts the medical home model, much of patient-centred care research and policy is directed toward the relationship between the patient and the general practitioner. However, the patient has other relationships with other types of physicians — specialists of one sort or another — and in other parts of the system, such as hospitals and long-term care facilities. Changing just one part of the system would not be a panacea.

INDIVIDUAL PRACTITIONER CARE
Although Ontario physicians are patient-centred in as much as they focus their care on the needs of the patient before them, the literature on patient-centred care abounds with information about the critical elements of this concept. Such information may be useful to physicians in refining their own interactions with patients and improving their patients’ interactions with the system. Two elements of patient-centred care at the practitioner level are common in the literature: effective communication between physician and patient, and a shared decision-making process. For the physician, effective communication includes an understanding of the patient’s life and how that contributes to their health, and clear explanation to the patient of the issues. Effective communication also entails showing respect for the patient. The shared decision-making process between patient and physician relates to decisions about treatment, given options, and about ongoing management of health problems. It assumes that both the physician and the patient bring valuable information. The physician brings information about the illness, treatment options, risks, benefits and evidence. The patient brings information about values, treatment preferences, and treatment goals. The decision-making process occurs in physicians’ offices and in other parts of the healthcare system, such as hospitals and long-term care facilities.

Communication with Patients
Communication with patients is perhaps most critical for the physician. However, communication problems occur...
between patients and other health-care providers, and they occur across the system, not just in the physician’s office. Showing respect for the patient is a key component of patient-centred care. Some information, such as communicating risk, is particularly difficult, and is exacerbated by poor health literacy. Patients with mental health or substance abuse illnesses, patients who are very ill, and pediatric patients present particular challenges to the physician and the health-care team in physician offices, in hospitals, and in other care facilities. Depersonalizing patients is a risk across the system, perhaps worse in acute care situations.

Respect for the Patient
In an American study examining whether patients feel respected in their physician’s office,26 about 3,500 adults responded to a survey about their feelings as to whether they were shown respect by their physicians. Questions were on a four-point semantic differential scale. Results showed that minorities and those for whom English was a not a first language were more likely to report that their doctor did not treat them respectfully, or looked down on the way they lived their lives. They believed they would have gotten better medical care if they belonged to a different race or ethnic group. Overall, 29% of Asians, 22% of Hispanics, and 19% of African Americans reported being treated with disrespect, compared to 13% of white Americans. Patients who had these feelings were more likely to report not following the physician’s advice and delaying needed care. Both the patients’ feelings of being treated disrespectfully, and their subsequent health behaviours, are of concern. Undoubtedly, the American experience of health care is different from the Ontario experience, however, there are indications that Canadian health-care providers could improve somewhat in ensuring that their patients feel respected.

In a survey of Canadian households commissioned by the Canadian Medical Association,27 respondents gave an average score of 7.45 on a scale of 0 to 10 to the validity of a statement that they are treated with respect and dignity by health-care providers. It is not a bad score, but there is room for improvement. Respect for patients is a key dimension of patient-centred care.

Depersonalizing Patients
At all stages of the system, the capacity of physicians and other health-care professionals to respond to patients as individuals is at risk. There is an inherent conflict between the ability to cope daily with strangers who are partly dressed, sick, suffering, in pain, or dying, and the ability to remain sensitive to these individuals as people. The natural human defence in such situations is to depersonalize people in distress so that the health-care professionals can continue to cope. This creates practices that protect health-care professionals, but are insensitive to patients. From the patient’s perspective, events that are unique, profoundly important, and personal are transformed into matters of routine, and patients become one of “this group of patients,” “this type of problem,” or “this procedure.” Depersonalization is probably more prevalent at acute care settings where patients are sicker, but all care settings have the potential to depersonalize patients.28

Health Literacy
Patient health literacy impacts patients at all points in the health-care system—in accessing services, in the physician’s office, in hospitals, and in other care facilities. Health literacy is one of the challenges to patient-centred care. Patients who are not health literate will experience difficulty accessing preventive care, have poorer understanding of their conditions and care, higher use of health services, lower adherence to medication, and less participation in decision-making.29 In addition to poor document comprehension and deficient problem-solving skills, many patients have inadequate numeracy skills; thus, communicating risk in quantitative terms may be problematic.

The OMA recently released a background paper entitled, “Patient Health Literacy: Implications for Physician Practice and Health System Planning,” which contains information about how to assess patients’ comprehension and ensure that patients understand disease concepts and participate in decisions about treatment. Ensuring that patients comprehend information can also increase the likelihood that they are compliant with medication instructions. The paper is available on the OMA website at: https://www.oma.org/Resources/Documents/2009OMAHealthLiteracyImplications.pdf.

Communicating Risk
Many illnesses require the participation of the patient in making decisions about treatment options. Decisions about treatment for life-threatening illnesses are perhaps most difficult. A Canadian study done with relatively well-educated participants from southern Ontario was designed to test the ability of older Canadians (age 50 to 90) to understand Internet-based information about cancer risk and prevention, presented in paper form.30 The best predictors of scores were age and tests of numeracy skill, including ability to discern differences in the magnitude of health risks, and use percentages and proportions.

Patients with Mental Health Illnesses
Involving patients with mental health illnesses in decision-making is challenging for both the general practitioner and the psychiatrist. There is a paucity of research on this dimension of shared decision-making. Research from the U.S.,31 the United Kingdom,32 Germany,33 and Italy34 indicates that neither general practitioners (U.S., U.K., and Germany) nor psychiatrists (Italy) tend to involve patients with depression or other mental health illnesses in shared decision-making. There is some indication that when depressed patients are involved in decision-making in the primary care setting, their depression outcome is better.35 Results indicated that, with every 1-point increase in decision-making ratings, the prob-
Patients with Substance Abuse Illnesses
Like those with mental health illnesses, patients with substance abuse illnesses face discrimination and bias. They are often marginalized and disenfranchised from society. Such patients are also often treated with disrespect, as if the diagnosis of addiction is some sort of moral flaw. American evidence suggests that the public view of those with substance abuse problems is that they are incompetent in decision-making ability among patients with substance-abuse illnesses, with some patients performing as well as normal comparison subjects.

Pediatric Patients
Pediatric patients are dependent upon their families, so for these patients, patient-centred care is better conceptualized as family-centred care. As with patients with mental health illnesses, there is little research available. In 2009, a Cochrane review from 1966 to 2004 found no studies that met inclusion criteria to permit a review of the effects of family-centred models of care for hospitalized children when compared to standard or professionally-centred models on child, family, and health service outcomes. They conclude that research, using factors that can be measured, is needed to assess whether family-centred care improves a child’s experience of hospitalization.

Several hospitals have reported that parental involvement in rounds has been a positive experience. In a large academic children’s hospital in Seattle, participation in rounds was important to parents because it increased their ability to communicate, understand the plan, and participate with the team in decision-making about their child. Similarly, the Cincinnati Children’s Hospital found that family involvement in rounds seemed to improve communication, and that it shared decision-making. It also offered new learning for residents and students.

The Decision Process
One of the basic tenets of patient-centred care is that patients participate in the decision-making process about their treatment options, to the extent that they are able and willing to do so. The process may be shared; the decision resides with the patient. Informed consent is a basic premise in law.

To engage patients in the decision-making process, physicians need information about how people make decisions and the sorts of influences that will affect their decision-making processes. In the section below, some of these influences are discussed. As well, the type of decision being made will have an impact on decision-making for both physicians and patients.

Informed Consent
Under the Health Care Consent Act, 1996, physicians are required to obtain consent for treatment that is informed, given voluntarily, related to the treatment, and not obtained through misrepresentation or fraud. Such treatment is informed if the person receives information about the nature of the treatment, the expected benefits, the material risks, the material side-effects, alternative courses of action, and the likely consequences of not having the treatment. Moreover, the person must receive responses to his or her requests for additional information about those matters.

The courts have long recognized a capable patient’s right to make autonomous decisions. The right to make what physicians may consider “bad decisions” flows directly from the court-recognized right to patient autonomy. This concept of patient autonomy is a fundamental element of not only our common law on consent, but also our legislative framework under the Health Care Consent Act, Substitute Decisions Act, and the Mental Health Act.

By law, except in emergency situations where an override is possible, the physician proposes a treatment, explains the risks, benefits and alternatives, and the patient consents or refuses. In practice, patients rely heavily on the expertise of physicians, but at law it is always the patient’s decision.

Patient Health Literacy and Risk Level of Decision
The desire of patients to participate in the decision-making process will vary depending on the risk implications of the decision and the level of health literacy of the patient. If the patient’s level of health literacy is low, it is likely that reliance on physician expert input will always be high, regardless of the level of the risk of the decision. In contrast, if the patient’s health literacy is high, it is more likely that the patient’s desire for physician expertise will vary depending on the importance of the decision. When faced with an acute illness requiring immediate treatment, patients will usually rely on the expertise of their physician, regardless of their health literacy.
Patient Personality, Education, and Experience
Personality, education, and experience also influence the degree of participation that patients want in the decision-making process. Generally, baby boomers are more likely to want to be engaged in the decision-making process than their parents’ generation. Moreover, generation Y, the children of the baby boomers, not only want involvement; indeed they will demand it. This is, of course, a broad generalization—there will be variability among the generations depending on the individual patient’s intelligence, education, experience, and personality.

Different types of patients value different attributes of patient-centred care. Using statistical methodology that permits analysis of multiple combinations rather than just single preferences,1 Ontario researchers have found that patients and their families can be categorized into two broad groups: an informed group and a convenience group.42,43 The informed group values the opportunity to learn health improvement skills, teamwork and interprofessional communication, and brief waiting times. In contrast, the convenience group values convenient settings, a welcoming environment, and ease of both internal and external hospital access. Demographic differences showed that participants in the informed care segment were significantly more likely to have higher education.

Patient Self-Management of Chronic Conditions
Although there are no accepted defining criteria, most patient-centred care models include the idea that the patient and the physician share management of health problems, and that patients self-manage some aspects of their condition, particularly chronic conditions. Here, the goal is supporting a wide range of people in living well with chronic conditions.

The OMA’s Policy on Chronic Disease Management provides information about the prevalence of chronic conditions in Ontario, the effectiveness of Ontario’s current chronic disease management, and models of chronic disease management and their implementation in Canada and internationally. It also contains OMA policy recommendations regarding chronic disease management. The policy is available on the OMA website at: https://www.oma.org/Resources/Documents/2009ChronicDiseaseManagement.pdf.

Framing Effects
Contrary to popular opinion, people do not make logical decisions in situations involving risk. It turns out that their decisions have biases that can be determined experimentally. Prospect theory, the leading model of decision-making to explain these biases, was developed by psychologists Daniel Kahneman and Amos Tversky.43 One of those biases depends on how risks are framed.44 The idea is that people will make different decisions depending on whether the same choice is framed positively or negatively. This has implications for physicians when they are explaining to patients the risks and benefits of particular drugs or drug combinations,45 or the potential outcomes of treatment options. In hundreds of experiments over decades, Kahneman and Tversky and their colleagues have found that responses to a choice framed negatively (as 1 in 100 people will be affected by this drug) or positively (not affecting 99 of 100 people) will differ. People overwhelmingly prefer the latter choice, a positive frame, even though they are logically equivalent. Similarly, people will prefer a procedure in which 75% of people live to one in which 25% die, despite their equivalence.46 These experimental outcomes hold with a variety of participants, including those who are statistically sophisticated, the young and old. Effects are exacerbated by affect, such as will occur when patients are stressed.

What should physicians do? The best option is to provide the information in both positive and negative frames. Thus, when explaining side-effects of medication, the best strategy is to indicate that among 100 people, 99 will not be affected and 1 will. Similarly, when discussing treatment outcomes, indicate both the positive and negative outcomes for each choice.47

Decisions at the End of Life
Decisions about end-of-life care for adults and for the families of children and neonates are difficult for both patients and physicians. Physicians are trained to prolong life, but in some situations prolonging life may be the wrong choice. Not having conversations about patients’ desires and wishes is consequential for patients, for physicians, and for the health-care system. In the absence of informed shared decisions that are responsive to the needs and values of individual patients, interventions may be provided to patients who would not choose them, and withheld from those who would.48

These situations are often anguishing for families. It is during such times that they most need good communication and interaction with physicians and other members of the health-care team so that they can be informed and participate in the decisions that need to be made.

Communication with Patients and Families in the Intensive Care Unit (ICU) and Emergency Department (ED)
The American College of Critical Care Medicine Task Force has developed clinical practice guidelines for support of the patient and family for adult, neonatal, and pediatric patient-centred care in the ICU.49 The Task Force did an extensive review of the literature, much of which it found to be of a low level (Cochrane 4 or 5) or non-existent. The guidelines were developed and debated until consensus was achieved. The Task Force made 43 recommendations, all of which will not be reiterated here. They included:

- Endorsement of a shared decision-making model.
- Early and repeated care conferencing to reduce family stress and improve consistency in communication.
- Honouring culturally appropriate requests for truth-telling and informed refusal.
- Spiritual support.
- Family presence at both rounds and resuscitation.
- Open flexible visitation.
- Family support before, during, and after a death.
With regard to the latter point, interventions to support bereaved families, particularly families of pediatric patients, have been found to be ineffective, sometimes intrusive, and unwarranted. The consensus seems to be that any interventions undertaken should target only high-risk caregivers and mourners who are highly distressed or depressed.50

Similar guidelines56 have been developed for family member presence for pediatric patients in emergency rooms. The recommendations are that, if they wish, family members should be permitted to be present during procedures and resuscitation attempts.51,52

**EFFECT OF PATIENT-CENTRED CARE ON OUTCOMES**

Patient-centred care is a difficult concept to measure because it is multifaceted and, at its heart, it is a dialogue between two people with differing personalities, perspectives, and attributes. Thus, the process itself is hard to measure.53 Moreover, as will be seen from the studies below, not all physicians or patients are willing to have data collected, and those giving consent to participate in studies may differ from those who do not. For those who do participate in studies, both patient and physician will modify their behaviour when they are being observed. These problems are faced commonly in any measures of human interaction.

The particular measures used are factors to consider—some may be more valid indices of patient-centred care than others. Patient satisfaction is a common measure. However, the British system has chosen to measure patient experience, not patient satisfaction. The Picker Institute54 argues that patient experience surveys are more useful in describing encounters with service, and a more valid measure of progress. Like Canadians, many British patients report overall satisfaction with their health care, but experience surveys can reveal areas that would benefit from attention, as well as those that are working well. Typically, satisfaction results do not provide useful information for system improvement.

Physician behaviours that improve patient satisfaction may be distinct from those that improve health outcomes, thus when patient satisfaction is used as the measure, patient-centred care may be rated highly, but health outcomes poor.55 There is some preliminary research that supports this distinction. In an analysis of studies of health-care communication with patients with chronic illness, researchers found that they could distinguish two aspects of patient-centred care: the ability to elicit and discuss patients’ beliefs, and the ability to activate patients to take control in the consultation or in the management of their illness. Preliminary results indicate that the former leads to improved patient satisfaction, but that to improve health outcomes, the ability to activate the patient is needed.55

Is it important that patient-centred care affects health outcomes positively? The consequential view maintains that actions are morally right to the extent that they lead to desirable consequences. Thus, if it could be shown that patient-centredness improved patient outcomes, by this view it would be desirable. However, it may be that patient-centredness is intrinsically important, regardless of whether it impacts health outcomes positively.56 Results of the research relating the effects of patient-centred care on outcomes is conflicting and often methodologically weak, so there is not strong evidence that patient-centred care affects health outcomes positively, as indicated below.

In an excellent evaluation of the relationships between patient-centredness, outcomes, and cost in a hospital situation, researchers found that hospital units that were more patient-centred had statistically significantly better outcomes, but higher costs than those that were less patient-centred.57 An American review of 23 studies58 examined whether fulfillment of patients’ expectations about their primary care visit affected their satisfaction with the visit. Results indicated that, in about half of the studies, addressing patients’ expectations positively influenced their satisfaction. Similarly, fulfillment of patients’ expectations influenced other outcomes, such as symptom improvement or disease control, in three of five studies. Results regarding outcomes of prescription compliance or health status were also ambivalent. In the United Kingdom, a comprehensive review of published research between 1969 and 2000 yielded only nine papers that met inclusion criteria. The authors concluded that the evidence that patient-centred consulting leads to better outcomes in primary care is ambiguous.59

**BARRIERS TO A PATIENT-CENTRED CARE SYSTEM IN ONTARIO**

Ontario’s health-care system is a large, lumbering giant that needs fundamental reform. It was developed in the 1960s, and has served us well for decades. Now, service demand exceeds the capacity of the system, causing bottlenecks. Because of its size and complexity, intervening at any one part of the system tends to move the bottleneck from one part to another, without resolving the fundamental problems. To change the system, we will need to address institutional funding, integration and co-ordination of care, and service demand exceeding supply.

**Institutional Funding**

One of the advantages and disadvantages of the American system of institutions is that it is competitive. Ownership is not entirely by the state, and there is sufficient redundancy in the system that patients have choice. The competitive nature of the institutional system has led to some innovative and patient-centred programs. However, the American system is also much more inequitable than our system, such that those who are better educated and wealthier can access services more easily. The principle of universal health care, such as we have in Canada, is not a recognized right in the U.S.; the result is that for many Americans, the cost of services is the determining factor.
In Ontario, current funding models are one of the main deterrents to efficient and integrated services for hospitals and other health-care institutions.

Hospitals
Operational funding for Ontario hospitals occurs through the Local Health Integration Networks (LHINs) and is on a global basis; that is, hospitals receive a global budget for their operational costs. Hospitals have service accountability agreements with the LHINs. The result of this type of funding is that there are few incentives for hospitals to work together or with other health-care organizations to improve efficiencies or to provide more integrated services. This contrasts with the system developed by the U.S. Veterans Administration, which provides financial incentives for co-ordination of care and resources among facilities. There is also a lack of knowledge about cost breakdowns in our hospital system. The Kirby Commission reported that, within hospitals, costs of individual procedures, even those such as simple appendectomies, are often unknown with the present funding model.

Within hospitals, savings in one department do not translate to other departments. This is exemplified in the LHIN Hospital Service Accountability Agreements, which provide the formula for “total margin.” Total margin is the per cent by which total revenues exceed or fall short of total expenses, in a given year. The formula specifies that interdepartmental recoveries and expenses are excluded in both the numerator and denominator of the formula.

In 2002, the Kirby report recommended that the global method used for remunerating hospital funding should be replaced by service-based funding. More recently, the same recommendation has been made in a report published jointly by the Ontario Hospital Association (OHA), Ontario Association of Community Care Access Centres (OACCAC), Ontario Federation of Community Mental Health and Addiction Programs (OFCMhAP), Ontario Association of Non-Profit Homes and Services for Seniors, and Ontario Long-Term Care Association.

Funding for other Institutional Health Service Providers
Although funding for other institutional health service providers differs from hospital funding, they suffer from some of the same problems of lack of co-ordination and efficiencies. Long-term care funding is a mix of across-the-board funding increases and allocations based on an equity funding formula. The community mental health and addictions funding is based on transfer payment agreements between the Ministry of Health and Long-Term Care and service providers for specific programs. In the future, LHINs will determine each service provider’s funding allocations where otherwise not specified in the Ministry/LHIN Accountability Agreement. This could cause increased variability across the province. The recent report cited above of the OHA, OACCAC, OFCMhAP, and others suggests a service-based funding system for operational funding to all providers funded through LHINs.

Demand and Supply
A 2006 report of the Physician Hospital Care Committee informs that the number of acute care beds in Ontario declined by 22% during the mid to late-1990s, and that occupancy rates have remained consistently well above 90% since 2000. There is no redundancy in the system. The report suggests that the obstacles inhibiting patient flow through the health-care system occur at both ends of the hospital experience: a lack of inpatient beds, and a lack of integration between hospital and community. The result is overcrowding in the emergency room, and patients occupying acute care beds who are ready to be discharged. There are multiple causal factors: emergency room assessment and disposition is slow; moving patients from either the emergency room or from acute care beds to alternative levels of care settings is problematic because of inefficiencies in planning and lack of community resources. Waits to get from hospital to long-term care are an impediment to efficient use of hospital resources. In the last quarter of 2007/2008, the median number of days to long-term care from acute care was 50. Undoubtedly, some of these patients will be difficult to place. Canada-wide, 24% of alternative levels of care days are for patients who have dementia as a comorbidity; another 10% have dementia as their main diagnosis.

A comparison of the American Kaiser Permanente system with the British National Health System revealed starting differences in per capita acute bed days. The NHS had a rate of 1,000 per 1,000 population per year compared to the Kaiser Permanente rate of almost one-quarter that (270 per 1000 population per year). Key differences are that Kaiser Permanente focuses attention and resources on monitoring admissions, reducing lengths of stay, creating disease management programs for chronic conditions, and opening physicians’ offices in the evenings and weekends to reduce the use of hospital emergency rooms for non-emergency care. Because of reduced hospital costs, Kaiser has many more specialists per capita, particularly in those areas needed for those with chronic diseases. Kaiser also exists in a highly competitive market. Per capita costs of the two systems are similar.

Ontario physicians report that demand exceeds resources not just for primary and specialty physician care, but for community programs to help patients with chronic diseases manage, such as programs for patients who have pulmonary illnesses or are diabetic. Community programs to assist the elderly to remain at home, and to help those leaving institutional care, are also insufficient. Palliative care programs are not easily accessible to all who would benefit.

The Canadian Medical Association commissioned a survey of public views on the health-care system from about 1,000 Canadian households. More than half of respondents indicated that they have to have the same medical tests repeated simply because they are seeing different medical professionals; that they have to repeat their health history each time they encounter a different health-care provider; and that they have
Policy Recommendations for System Change

• The OMA believes that patient-centred care provides benefits to patients and the health-care system beyond its effect on health outcomes or system costs. To this end, it will strive to join together with other stakeholders in the health-care system to transform the system to one that is centred on the patient. It commends those organizations that have begun this process.

• The Ministry of Health and Long-Term Care should be accountable for ensuring that hospitals and other health-care institutions are patient-centred. Results of patient-centred policies and activities should be assessed on the basis of evidence and made public, including results of both patient outcomes and patient experience.

• The OMA encourages the Ministry of Health and Long-Term Care and other health-system stakeholders to continue to expand transparency in the system, such as is exemplified by online posting and publication of wait times information and hospital evaluations.

• The OMA encourages the Ministry of Health and Long-Term Care to review hospital funding in Ontario in light of the worldwide trend away from reliance on global budgets. The OMA will be issuing a policy in the coming months that recommends patient-focused funding.

• The OMA encourages the Ministry of Health and Long-Term Care and other health-care stakeholders to continue efforts to integrate the health-care system and to systematically evaluate those efforts to determine which succeed in improving patient care and quality, and to determine their costs.

• Access to experts and increased availability of supportive services in communities is needed to augment medical care and treatment. This is particularly relevant for patients with mental health and substance abuse disorders, and for patients who need community assistance to manage chronic disease. The OMA recommends that the Ministry of Health and Long-Term Care address these unmet needs.

• The OMA encourages the Ministry of Health and Long-Term Care to review the OHIP Schedule of Benefits with regard to providing adequate funding for physicians for electronic and telephone communications between them and their patients.

Transition Planning

In its 2009 report on Ontario’s health system, the Ontario Health Quality Council (OHQC) reports that 1 in 5 (20%) of patients leaving emergency rooms did not know who to contact if they had questions or problems, and 1 in 3 (38%) discharged from hospital did not have that information. These data are based on patient reports. Often, patients are stressed when leaving hospital, so information may have been conveyed, but forgotten if presented verbally, or there may have been language or other communication barriers. Nevertheless, these are indicators that better ways are needed to convey information so that patients are aware of what to do when problems arise.

The Change Foundation, in collaboration with the Ontario Association of Community Care Access Centres, has
Principles of Patient-Centred Care for Physicians

- The OMA believes that optimal patient care is achieved when accountability for health-care outcomes is shared between physicians and their patients. This is most readily accomplished when their relationship is characterized by mutual respect and trust. (from the OMA policy, Accountability in the Health Care Sector)

- Physicians should share decision-making with patients about all aspects of their health care, including treatment options, risks, benefits, and evidence. For patients with mental health or substance abuse illnesses, physicians may need to augment support in the decision-making process. By default, decisions about care reside with patients.

- Physicians should endeavour to communicate information about all relevant aspects of health care to their patients in a manner that is comprehensive and comprehensible.

- To help curtail waste in the system, physicians should endeavour to reduce unnecessary duplication of medical tests and discourage their patients from demanding unnecessary tests.

- Physicians are patient-centred regarding their patients. They should continue to act as advocates for their patients for the resources to meet their health-care needs.

- Physicians may wish to consider ways to organize their practices so that patients have more convenient access to them. This may occur by same-day appointments, e-mail or telephone communications and may require physicians to undertake an organized effort to reduce backlog and improve access. Use of the IHI “plan, do, study, act” cycle may be beneficial. Physicians should read the Canadian Medical Protective Association’s publication, “Using email communication with your patients: legal risks,” available from: www.cmpa-acpm.ca/cmpapd04/docs/resource_files/info_sheets/2005/com_is0586-e.cfm before commencing e-mail communications with patients.

- To facilitate sharing of patient information among physicians and among health sectors, the OMA encourages physicians to avail themselves of opportunities for assistance in obtaining electronic medical records.

- Physicians should take the lead in fostering and promoting compassion and empathy for patients and in promoting behaviours that are patient-centred and positive for patients. This should occur in their own practices including their front office staff, in their health-care teams, and at all stages of the health-care system where they and their patients interact.

embarked upon a quality improvement project to investigate and make recommendations about care for elderly patients who made the transition from hospital to home or long-term care facility. In one example of hospital to home, they found that there were 247 steps in the hospital to home process, using 9 databases, 35 forms/tracking sheets/brochures, and 11 handoffs/waits for patients. The project was undertaken with the Southeast CCAC and Quinte Health Care’s Trenton Memorial Hospital, and with the Toronto Central CCAC and Toronto Western Hospital. Both systems have undertaken strategies that have succeeded in improving patient transitions. Care co-ordinators work more closely with hospitals to plan discharges, they are in hospitals at certain times each day, allowing families to know when their service is available; they carry smaller caseloads of complex, high-risk patients, providing more intensive support and following the patients through the continuum of care, and they have been added to the emergency department in one hospital. Hospitals are examining the discharge processes, and the CCACs are meeting with hospital partners.

A similar process has been undertaken in New York to reduce the number of steps and the turnaround time for patients in laboratory settings. Laboratories can play a role in promoting patient-centred care by ensuring that the information patients receive about clinical testing and test results is understandable and thus facilitates shared decision-making.

**SUMMARY**

The Ontario health-care system needs fundamental reform. The OMA definition of patient-centred care is of a system where patients can move freely along a care pathway without regard to which physician, other health-care provider, institution or community resource they need at that moment in time. This system is one that would consider the individual needs of patients and treat them with respect and dignity.
The present system needs fundamental reform to achieve that vision. At the system level, integration, access, funding, and the manner of treating patients needs change. Denmark and the U.S. Veterans Administration present successful models of patient-centred systems.

One of the impediments to a patient-centred system is the manner by which hospitals and other health-care institutions are funded. The present funding models do not encourage co-ordination of care and efficient use of resources. Recent reports have recommended replacing the current systems with modified service-based funding models.

A variety of initiatives have been undertaken in Ontario to improve transition planning, but the problem is multifaceted, expensive, and not amenable to easy solutions. At the institutional level, the demand for beds exceeds the supply, there are inefficiencies in planning, and there is a lack of community resources. The result is that expensive acute care beds are being used for patients who are suitable for alternative levels of care.

Comparatively, Canada rates poorly in access to care. Processes have been developed that are known to help physicians improve access. A variety of capitated primary care models have been implemented in Ontario in the last 10 years to improve access to primary health care. At the system level, other strategies, such as the Wait Times Strategy and the Aging at Home Strategy, have been implemented with mixed results.

Although the medical home concept has been much touted, comprehensive evaluations indicate that the current designs seriously underestimate the time and effort for the changes, overestimate the readiness of information technology, and are undercapitalized. Transformation to a medical home requires a whole practice redesign that cannot be undertaken incrementally. It also requires staffing increases and reductions in patient rosters. Moreover, quality of care differences between the patient-centred medical home and other new models of care are minimal.

At the practitioner level, patient-centred care can improve communication between physician and patient, permit patient participation in decision-making to the extent desired by the patient, and improve access for patients. It may be desirable in and of itself, but its impact on patient outcomes has not been demonstrated. The research relating the effects of patient-centred care to patient outcomes is conflicting and methodologically weak.

Communication of some types of information, such as risk, is particularly difficult and is exacerbated by poor patient health literacy. Patients with mental health or substance abuse illnesses, patients who are very ill, and pediatric patients present particular challenges to the physician.

Patients must be involved in the decision-making process to the extent that they are willing and able to participate. Awareness of biases in decision processes may be useful for physicians in the joint decision-making process. Some types of decisions, such as end-of-life decisions, are particularly difficult for both patients and physicians.

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Footnotes
f. The base before increases was: for every 3 physicians, the teams included 4 medical assistants, 1 registered nurse, 0.5 physician assistants or NPs, and 0.3 clinical pharmacists. The clinics have on-site pharmacies, laboratories and radiology suites. The 20 clinics are supported by a system of 4 specialty clinics, 6 urgent care/emergency departments, and 7 hospitals. Each physician had a roster of 2,300 patients.
g. Patients were 1,706 patients who had visited their primary care physician within 2 weeks of the baseline interview. It was a multi-site, nationwide, American clinical trial. Patients rated their involvement in decision-making on a 5-point semantic differential scale 6 months after study entry and the receipt of guideline-concordant depression care at study entry and every 6 months for 2 years. The probabilities of patients receiving guideline-concordant depression care and depression remission were adjusted for overall satisfaction with health care.
Ontario Medical Review

Patient-Centred Care


11. Ontario Ministry of Health and Long-Term Care, Ontario Association of Community Care Access Centres, and Collaborative for Health Sector Strategy, University of Toronto Rotman School of Management;


