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Waiting Lists: Management, Legalities and Ethics

A recent report by the Fraser Institute suggests that wait times have increased slightly in 2004. The survey of almost 2,900 physicians in 12 specialties found the average elapsed time was 17.9 weeks between patients getting a referral from a GP to see a specialist and receiving treatment. This broke down into 8.4 weeks for the referral portion and 9.5 weeks for the treatment portion. The overall wait time was calculated to be 17.7 weeks in 2003.

The problem of waiting lists presents a challenge for all Canadian surgeons, and the predicted demographic factors of the Canadian population indicate that the problem will increase. A symposium was held at the Canadian Surgery Forum in London, Ontario, on September 20, 2002, to present state-of-the-art thinking about waiting lists and to stimulate discussion among Canadian surgeons. The three invited speakers are prominent in their respective fields of expertise. In this issue of Law & Governance we present a commentary of their oral presentations.

Dr. Dennis Pitt

Waiting lists are a problem and a challenge for all of us nationwide, and with time this difficulty is going to increase. In this article Dr. Tom Noseworthy, Professor and Head of Community Health Sciences at the University of Calgary and Chair of the Western Canada Waiting List (WCWL) Project, discusses management of waiting lists. Dr. Jacques Guilbert from the Canadian Medical Protective Association (CMPA) addresses legal issues. Thirdly, Dr. John

Williams, Director of Ethics at the Canadian Medical Association, speaks about the ethics of waiting lists.

Dr. Tom Noseworthy

To take the first of the three aspects dealing with waiting lists in this symposium, namely the management of waiting lists, let us start with what we think we know and what we are trying to manage, and then add a few comments about the mission and strategies of the WCWL Project.

What do we know about long waiting times? First, they are common to all publicly funded services, worldwide. Virtually every country that has a publicly funded healthcare system has some issue with access to services and waiting. The issues vary with place, sometimes even within a single geographical confine such as a city. It is simplistic to believe that long waiting times are easy to fix and are simple problems with simple solutions. There are a host of factors that drive long waiting times. We all believe there is a resource issue here, whether it is operating room time or whether it is people or money. Yet, simply adding more resources does not appear to offer consistent or sustained improvements.

We do not manage very well when it comes to waiting lists and waiting times, for a lot of different reasons. It is not because managers are necessarily uninformed or of poor quality, but because we do not have the necessary tools. What is it we are trying to manage, anyway? How about starting with who should come next – in

short, how do we order the queue? A second and frequent question encountered every day in many clinical situations at which scheduled services are being considered is “How long ought I to wait for that, doctor?” How many times a day are you asked that when you are doing clinical work? Think sometimes of the answers you may give and imagine if you were the recipient of them... “Oh, 18 months maybe, if we are really lucky.” We do not do a good job of answering that question, and it is not necessarily the clinician’s fault. Generally, we don’t know what the right answer is. Even if we did, there remains the question of when the intervention can actually be done.

With respect to the issue of fairness to the patients whom we serve, there are all sorts of ways of attempting to achieve fairness: first come, first served; a lottery; special criteria or merit; or, urgency criteria. If the first come, first served method were used, you might not like it but it is intrinsically fair at one level. So might be a lottery that gives everybody equal opportunity. As for merit, might we consider putting children first, for instance, at the start of each operating room list? If we were to use urgency, we would perhaps have some difficulty in agreeing exactly what that means. But it certainly seems, at least from a clinical and management perspective, that something related to urgency would be much more reasonable than first come, first served, a lottery, or special criteria or merit.

Let us focus for a moment on something that we might be able to agree on, whether we represent a provincial medical association, a government, a research organization or a regional health authority. Let’s think of urgency, excluding the emergent case. Urgency is a multidimensional construct and includes the range of disease acuity, social and role impact factors and the potential to benefit from the intervention – a concept that surgeons know well: “What will happen if I do this, and in reverse, what if I don’t?” – the delta benefit.

We set out in the WCWL Project to establish a goal to improve the fairness of the system such that access to appropriate and effective healthcare is both timely and prioritized on the basis of need and potential benefit. We have not worked on appropriateness. Our work starts from the proposition that a patient who is on a list for elective or scheduled services needs to be there. As we all know, this is not necessarily the case for some on lists. Similarly, we are not doing work on effectiveness, showing the value of specific interventions for specific patients. What we are working on is, “Can we make waiting fairer, where fair is considered on the basis of urgency? Can we make it timelier? And, can we align this to the need and potential for benefit?” We are definitely not trying to develop tools for rationing care, although WCWL Project is regularly

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assessed as doing so, by developing these scoring systems. In short, we want tools that get the order of the line correct, based on urgency. It is possible, I believe, to make this a more patient-centric system. The order of the way patients are now served in the operating room and elsewhere is often determined more by provider-centric or systemic organization, such as the way operating room block time works. I think it is both possible and necessary to harmonize the approaches, making the system more patient-centric.

What are we trying to fix? Fairness, timeliness and certainty: Who is next? When should the intervention be done? When is it done? The way we are tackling this with the WCWL Project is first implementing priority criteria scores for urgency. We feel that reliable prioritization tools should be used to get patients in the correct order.¹

Another phase of our work now underway is to develop benchmark waiting times. It's not good enough to be without a standard answer when a patient asks, "How long ought I to wait for that, doctor?" We do not have standardized responses for virtually anything. The only areas in this country right now where the patient can ask such a question and get a relatively consistent response, based on some level of evidence, are in cancer therapy and, specifically, with cardiovascular surgery in Ontario.

When the outcome of the problem is not death but a potentially slow clinical deterioration with, for instance, pain a little worse in the hip today than it was maybe a month ago, it is hard to know exactly when you should or must intervene. For cataract and hip and knee surgery, and indeed our other examples, general surgery, magnetic resonance imaging (MRI) and children's mental health, we do not clearly understand when we should intervene.

Beyond the potential development of benchmark waiting times and the question "How long ought I to wait?" is the issue of certainty, and "When will I be booked?" The United Kingdom is working on schedule guarantees now, because Prime Minister Tony Blair has made the decision that no one will wait longer than 15 months for joint replacement, with the target eventually dropping to 12 months. They are trying to work towards that and put a schedule guarantee in place, ultimately without a waiting list. You are booked at the time, for instance, that you meet and decide with your surgeon. The UK is early in this, but I think it would be

an excellent addition, once we had prioritizing tools working to have people in the correct order and benchmark waiting times to determine a reasonable wait, if we would attempt to put in a schedule guarantee to match. To see that is my five-year dream. The strategy only fully works when it gets towards its end. We are just at the beginning.

What are our limitations? We have lots of them. We are trying solve the problem of waiting lists in a systematic and orderly way, but we have not as yet addressed waiting times. And that's what doctors seem to care about. Others criticize us because what we have done is model the judgment of clinicians and the view is that clinical judgment is not very good. There may be many people who can say "your clinical judgment is not tight around the seams." I do not believe we can apologize for the fact that eventually we must get down to making a decision about who is going next. So I do not think it is wrong that we have at least started from a proposition that we will model clinical judgment for the purposes of the tools.

We are in the process of beginning the outcomes validation of following patients through until the end. We have partners and a community of interest. The public has been consulted. The regions are prepared, and the deputy ministers in Western Canada and Health Canada are highly supportive, and we have started to disseminate the findings broadly. We have international contacts or collaboration in five countries and a project infrastructure that works.

When medical associations, government health departments, research organizations and regional health authorities are gathered in the same room, there is a guaranteed spectrum of views about what the problems are and what the solutions are. The strength of the WCWL partnership is the richness and diversity of the group that is at the table. This is fundamental to keep for action research that matters.

There is no point in having the tools on the shelf. We should implement them and study them and understand what works and does not work and how clinicians respond. We should get on with the business of formulating the waiting times and work towards schedule guarantees.

Finally, we need to remind ourselves that, like it or not, waiting for scheduled services is a phenomenon that is characteristic of all publicly funded systems. I think we really can improve the management, and we must. We

have not solved all the problems with the WCWL Project, but have started a systematic way to unbundle this nightmare called waiting times and waiting lists and begin to work it through. Sound management tools can be used to ensure that the process is right. If this is properly done, I can imagine a time when there may be no waiting lists, and we would give people a guarantee that, once they have been assessed, we schedule them and follow through. That's accountability!

Dr. Jacques Guilbert

In my presentation I will put forward four questions for discussion.

- What are the risks to doctors when they are faced with waiting lists?
- What are doctors' obligations?
- Can doctors share these risks and obligations with other "players"?
- What can the CMPA do to assist?

What are the risks?

The greatest medico-legal risk that doctors face when they deal with patients is being accused of negligence. Negligence is a legal concept that is made up of four parts: duty of care, standard of care (or breach of duty), harm and injury, and causation. Here, I shall focus on duty of care and standard of care, because these are the two areas that relate to waiting lists.

Duty of care, or the obligation to the patient and the engagement of responsibility, generally begins when the doctor first sees a patient. It also exists when a doctor discusses a patient either verbally or in writing with a referring physician or with others. It can also exist even though the doctor has not yet seen the patient. The courts may decide that a duty of care exists when you become aware of a patient's problem or when a patient is put on your waiting list and you know about it. A duty of care may also be considered to have been created when, knowing that there is no reasonable time for you to see this patient, you fail to notify the patient or the referring physician that you cannot attend to the patient in reasonable time. A duty of care will not be created if you have not been made aware of the nature of a patient's problem or if no one has informed you that a patient has been put on your waiting list. A duty of care will not exist when, knowing that the patient cannot be assessed or treated or taken care of in any reasonable time, you then take the required steps to inform either the patient or the referring physician that you simply cannot be available.

What are doctors' obligations?

The obligations of the physician to the standard of care is to inform patients and other physicians, because what you will be accused of is nonavailability of a standard of care or the fact that you did not use what was available. The obligation extends to being an advocate for the patient. Doctors are their patients' fiduciary advocates and have an obligation to try to obtain a fair share of resources available for them. No court in Canada has yet accepted reduced or restricted resources or cost constraints as a justifiable defence for a negligent act.

Can doctors share these risks and obligations?

Obviously, physicians share risks with hospitals. Hospitals have a duty to provide adequate staff and adequate medical supplies, and to maintain equipment. They also have a legal responsibility for the work of their employees. Most doctors are not hospital employees, but staff usually are. Doctors will share risk and responsibility with physician managers. Physician managers often have clinical responsibilities, and they also have administrative responsibilities on behalf of hospitals, clinics and health authorities. About 75% of all legal actions in Canada take place after an event that has happened in a hospital setting, and the plaintiff and the plaintiff's lawyer decide who is going to be sued. Very often hospitals are named, and administrators can be named individually. In addition, health facilities have the opportunity of cross-claiming against physicians.

Even though doctors may believe they have no responsibility, the hospital may not share that opinion.

What can the Canadian Medical Protective Association do to assist?

How can the CMPA assist its members when they are faced with these difficulties? The CMPA does not defend the policies of other groups and associations, or procedures and directives that have been established by other groups. It can recommend to its members some actions when they are faced with resources that seem to be diminishing. I remind you that the best interest of your patient is a doctor's first duty, and, as was pointed out by Dr. Noseworthy, sound medical judgment remains the guide. Doctors are fiduciaries of their patients and have a duty to act for them and to be their advocates. There are times when doctors may be wise to share with patients the problems related to restricted resources. Doctors should not presume that they can rely on poor resources or a lack of resources to provide substandard care. If a doctor takes no steps to obtaining

resources, the courts may interpret that (and have done so) as tacit acceptance on the part of the doctor of an unacceptable situation. Document, document, document. When you have concerns about resources, manifest those concerns, preferably in writing, and don't be shy to share this opinion with all the medical administrative levels that you face in a hospital, in your community, in your health region and in your province. Having put in the effort, having noted your objections, having written your objections, it's likely that you will not be liable if resources simply cannot be obtained. The final reminder is that when you are faced with a decision or with a choice of treatment, sound medical judgment is what the courts will expect you to use as a standard.

Dr. John Williams

My job here is to make explicit certain ideas that were implicit in what Drs. Noseworthy and Guilbert said and perhaps expand beyond what they said. I want to start by asking the question, "Whose problem is this?" The problem occurs at three different levels – the micro, meso and macro levels. I will present three scenarios to illustrate the different dimensions of the waiting list issue.

The first scenario deals with the micro level, where it is an issue for individual doctors.

Dr. Jones, a general surgeon, receives a request from his long-time colleague and friend, Dr. Smith, to replace an artificial hip in Dr. Smith's 80-year-old father-in-law. Dr. Smith feels that a new hip will encourage his father-in-law to resume physical activity and thereby arrest the decline in his health. Dr. Jones is sympathetic but wonders whether this patient needs surgery more than the others on the waiting list.

The next scenario deals with the issue at the meso, or institutional, level. Stung by criticism that their waiting list management is woefully inadequate, especially when compared with cardiac care in Ontario, the general surgeons of "Metropolitan Regional Hospital" meet to establish a waiting list policy that could serve not just their hospital but the entire province. They decide to begin by establishing maximum waiting times for the 10 most common surgical procedures in the hospital. Disagreements soon surface regarding the reliability of available data, interpretation of the data and the responsibility of the surgeons to abide by the group's conclusions. As one of them puts it: "What do we mean by a 'reasonable' waiting time, and what right do we have to decide this?"

The third scenario deals with the issue at the macro, or government, level. The provincial government is preparing next year's budget. The minister of health wants an extra \$100 million to reduce waiting times for thoracic and colon and rectal surgery. She is armed with reports that the average waiting times in the province are twice the recommended maximums, and faster treatment in these areas will reduce morbidity and thereby save the health system money in the medium to long term. She has polling data that show this expenditure would be popular with voters. She is met with considerable skepticism from other ministers who have different spending priorities.

Each of these scenarios depicts a problem to be solved, an issue to be resolved. Until recently, they would probably have been regarded simply as management, legal or political problems or issues, to be dealt with according to management, legal or political criteria, such as cost-effectiveness, relevant legislation and voter satisfaction. There is an emerging realization that they are also ethical issues.

An issue involves conflict and controversy. Ethical issues bear upon the rights and wrongs of human decision-making and behaviour. They involve conflicting beliefs about how human beings should live, about the values individuals and groups should uphold, and about the values that may be sacrificed when all values in a situation cannot be honoured and maintained. Issues in bioethics centre on right and wrong decisions, policies and actions in medicine and in the uses of biomedical science and technology.²

The ethical challenge in each of the three scenarios can be stated as follows: If it is not possible to offer healthcare services to everyone in need or those who might benefit, how do we decide which groups or individuals ought to receive priority? To deal with this question we need both ethical criteria and an ethical process. The criteria and the process will vary according to whether the issue is considered at the macro, meso or micro level.

We will begin at the macro level. What ethical criteria are operative here? Dr. Noseworthy mentioned fairness. Clearly, that should predominate at all levels, especially the macro. But fairness is not easy to determine or to define. Does it consist in giving people what they want? Politicians with their polling are constantly trying to determine what is politically popular, that is, what the majority (not necessarily the individual patient) want.

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They feel they must try to satisfy voters' desires if they are going to be re-elected. Or does fairness mean providing what people need? If so, how can we determine which groups of patients – for example, cardiac, cancer, psychiatric or AIDS patients – are most needy? Perhaps fairness requires attention to the needs of the entire population, the healthy as well as the sick, for example, by spending more on preventing rather than on curing illness. Does fairness require consistency (i.e., equal treatment within and between patient categories), or should disadvantaged groups be given preferential treatment? And certainly fairness must involve affordability, which governments have to be concerned about. All these criteria must be considered when determining fairness in the allocation of healthcare resources.

Another key value or criterion for establishing or doing away with waiting lists at the political level is efficiency. And here the government has to decide whether it is more efficient to devote funds to healthcare as opposed to other social expenditures that may provide better health benefits in the long run. Housing, employment stimulation and nutrition are examples. And within the health envelope, what is the most efficient use of funds? Is it for curative measures and emergency rooms, or is it better to bite the bullet and put the money into less popular, less urgent programs that might have better long-term results? Finally, are waiting lists the most efficient tool for allocating scarce resources, as opposed to rationing by price or in some other way? As Dr. Noseworthy mentioned, waiting lists are not an issue in the United States because there is overcapacity. There is undercapacity in Canada. Are waiting lists a good way to reduce demand or to save money?

Somewhat different ethical criteria for waiting lists are operative at the meso level, in institutional and professional policies such as that of the Ontario cardiac care network. Once again fairness predominates, but the relevant considerations for fairness are not the same as at the macro level. In addition to collective wants and needs, it is important to consider individual needs and wants. Should individual patients have the opportunity to seek immediate treatment and pay more for it? There are collective wants as well. Patient groups are advocating strongly for extra resources to go to their particular needs. Fairness requires deciding which patient or group of patients is more needy than others. There are also exclusion criteria to be considered. Should psychosocial and economic factors such as age or likelihood of compliance with treatment regimens be excluded, or should they be recognized and built into waiting list policies? All these issues come under the aegis of justice and fairness.

At the micro level of decision-making, the surgeon has to decide how to prioritize individual patients on waiting lists. Here there is often a conflict between one patient's wants or needs and those of other patients. Does fairness exclude preferential treatment for one's family and friends, or can this be accommodated within a general framework of fairness? Another criterion to consider at this level is

efficiency, including optimal waiting times and the best use of institutional resources.

A third criterion is professionalism, especially the relationship between collective self-governance and individual clinical autonomy. What should be the role of the profession in decision-making about waiting lists? What should be the role of clinicians as opposed to the public, as opposed to the government, as opposed to the patient groups, and so on? And where does clinical autonomy come in here? Should clinicians have to abide by waiting list rules that they don't necessarily agree with?

There is a potential conflict for surgeons between their responsibility to the individual patient in front of them and their responsibility to other patients on the waiting list or who are not yet on the waiting list. When the Canadian Medical Association's Code of Ethics was revised in 1996, a statement was added that doctors have a responsibility for just allocation of resources beyond their individual patients. This departs from the Hippocratic tradition that it's the patient in front of you that you have to do everything for, and you don't have to worry about others. Now there is a growing recognition that doctors have some responsibility for appropriate allocation of resources across the board. This is an ethical issue, and a legal one.

Finally, there is the decision-making process. This is important at all levels – macro, meso and micro – in the determination of a fair allocation of resources. Evidence is important.

The WCWL Project is trying to bring to the attention of the decision-makers what available evidence there is, so they will make evidence-based decisions. Consultation is important. It's becoming more of a shared responsibility to make these decisions and develop these policies. Ethical values are important. We have to address competing values and competing interests among patients and among different groups of patients. A tolerable compromise should be the ultimate goal, because even if waiting lists are eliminated there will still be the problem of who gets booked first. There is always going to be a shortage of resources. Not everybody is always going to be perfectly satisfied with the treatment they receive. A process that is evidence-based, transparent and accountable, and that includes communication and justification of decisions, will go a long way to making people feel that even if they haven't received

a high priority, at least they have been dealt with fairly. In conclusion, ethical values are important factors when establishing policies about waiting lists and making decisions about placing patients on them. Policy- and decision-makers at all levels should deal with these ethical considerations as systematically and rigorously as they do with management, political and legal considerations.

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Money Alone Won't Help Wait Lists, Poll Finds

A recent Leger public opinion poll for the Montreal Economic Institute has found Canadians skeptical about any new public funds curing the problem of waiting lists. In total, 45% of respondents said the money would only solve the problem temporarily, and another 32% said it would not solve the problem at all.

However, the question in the poll was somewhat leading. It read, "Knowing that the funds contributed to healthcare by different levels of government never cease to increase, do you believe that injecting new public funds will solve the problem of waiting lists in the healthcare sector?" (Source: *Health Edition Online*, Volume 8, Issue 34)

Canadians Concerned about Healthcare Inefficiencies

Canadians have a dimmer view of the quality of available healthcare services in 2004 than in previous years, according to the Canadian Medical Association's fourth annual report card on the healthcare system. The report card is based on a public opinion survey of 1,057 Canadians conducted in July by Ipsos-Reid.

While 18% of respondents awarded health service quality an "A," this was well down from 27% in last year's poll. Furthermore, the same proportion of people (41%) gave healthcare a "C" or a failing grade of "F" as gave it a "B." (Source: *Health Edition Online*, Volume 8, Issue 32)

Little Support for Pharmacare Program

There is little support for a national pharmacare program, a poll by Vector Research for the National Union of Public and General Employees has found. In terms of priorities, 57% favoured a focus on waiting lists, 17% said home care, and 11% said pharmacare. Fully 72% of respondents also rejected the argument of Alberta Premier Ralph Klein that there should be no conditions on how provinces spend

money they get from the federal government. (Source: *Health Edition Online*, Volume 8, Issue 34)

Physician Supply Getting Worse

Nova Scotia has the highest per capita supply of physicians in Canada, while the neighbouring province of PEI has the second lowest (next to Saskatchewan), according to a recent report from the Canadian Institute for Health Information.

On a national basis, there were 59,454 physicians working in Canada in 2003. This figure is up slightly from 59,412 in 2002. While the number of family physicians increased, it has not kept up with population growth. There were 187 family physicians per 100,000 population in 2003, compared to 194 in 2002. The number of specialists went down in 2003, and the per capita supply sagged to 97 per 100,000 population. This is down from 99 in 2002 but is the same level it was in 2001. (Source: *Health Edition Online*, Volume 8, Issue 33)

Canadians Do Not Expect Much from New Accord

Almost 8 out of 10 Canadians are satisfied with the health accord reached by First Ministers in September. In a recent public opinion survey conducted by Environics Research, the accord was described as giving the provinces \$18 billion "in new health care funding over the next six years, within a framework of accountability on how this new money is spent by the provinces."

However, Canadians do not believe the accord will achieve a lot of progress in fixing the problems facing healthcare. Only 9% of respondents said they expect significant progress; almost as many expect no progress at all. Forty-six percent of respondents anticipate some progress, and 34% expect only a little progress. Almost 7 of 10 respondents disapproved of Quebec's being exempted from some of the new requirements for reporting on the use of the new health funds. (Source: *Health Edition Online*, Volume 8, Issue 41)

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