

Setting priorities for waiting lists: defining our terms

David C. Hadorn and the Steering Committee of the Western Canada Waiting List Project*

Abstract

IN ORDER TO DEVELOP STANDARDIZED MEASURES TO ASSESS patients' relative priority for services for which there are waiting lists, it is essential that key terms be clearly defined. We propose that severity be defined as the degree or extent of suffering, limits to activities or risk of death; that urgency be defined as severity combined with considerations of the expected benefit and the natural history of the condition; that need be considered equivalent to urgency; and that priority be defined in terms of urgency (or need) with or without consideration of social factors.

Fair access to services is a primary concern of every publicly funded health care system. Waiting times vary substantially from doctor to doctor and hospital to hospital, and the length of time patients wait for services is not always commensurate with the severity of their conditions. In principle, patients with more urgent conditions should receive services ahead of those with less urgent conditions, and patients with approximately the same degree of urgency should wait about the same length of time regardless of where they live. Moreover, it should be possible to assess whether and to what extent these ideals are being met.

Standardized measures are needed to assess and compare patients' priority based on the urgency of their conditions and the extent of benefit expected from services for which there are waiting lists. The Western Canada Waiting List Project (www.wcwl.org) is developing such measures in 5 clinical areas: MRI scanning, hip and knee replacement, cataract surgery, general surgery procedures and children's mental health.

Arriving at shared understandings concerning the meaning of key terms will facilitate the development of an understandable and transparent process for developing priority criteria. It must be kept in mind that these criteria will have a real impact on patients, perhaps playing a substantial role in determining how long they must suffer, be limited in their activities or face an increased risk of premature death. Given what is at stake, there should be no confusion regarding the "ingredients" that make up the criteria used for assessing relative priority.

Waiting lists and waiting times

A waiting list is a queue of patients who are deemed to need a health service that is in short supply relative to demand. In effect, patients on waiting lists "reside" in a common, imaginary "waiting room," with certain patients being called for treatment sooner than others. Two waiting lists are often operating: one to see the specialist who controls access to the desired service and another to receive the service once medical need has been verified. This second list is generally what is referred to by the unqualified term "waiting list," and almost all the existing data concern waits for services, not for evaluation, even though these "preliminary waits" can sometimes be the longer of the 2.

Each waiting list is associated with an average waiting time, namely, the number of days, weeks or months expected to elapse from the time patients are placed on a list to the time they receive the service. Waiting time is determined by a complex interplay of factors, including system capacity, the number of patients on waiting lists and the number of emergencies arising while elective cases are waiting.

The remainder of this paper concerns several key concepts underlying the development of criteria for assessing patients' relative priority on waiting lists. These

Review

Synthèse

Dr. Hadorn is Research Director of the Western Canada Waiting List Project, Department of Public Health Sciences, University of Alberta, Edmonton, Alta.

**The list of committee members appears at the end of the article.*

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concepts are severity, urgency, relative priority, need and expected benefit. These terms must be assigned standard meanings in order to advance the debate. In particular, it is necessary to understand how severity, urgency, need and expected benefit relate to relative priority.

Severity

Of these terms, probably the most straightforward is severity, which refers to the degree, extent or intensity of suffering (e.g., pain, nausea, shortness of breath, depression, anxiety), limits to activities (e.g., ability to work, care for one's basic needs) and risk of premature death. The more a patient is suffering, for example, the more severe his or her condition, other things being equal. In essence, severity reflects the extent of departure from normal functioning, from either a physiological or psychological perspective.

Phrased this way, the notion of severity seems straightforward enough. However, difficulties arise when attempting to assess and compare the severity of patients' conditions. These difficulties stem in part from the absence of agreed upon, standardized measures of pain, disability and risk of death. An even more fundamental problem concerns the task of comparing degrees of suffering with degrees of disability, or of risk of death.

In addition, certain conditions that may not be associated with suffering or disability on initial presentation could, if left untreated, evolve into more serious situations with less benefit available from treatment. This potential divergence between "proximal" and "distal" severity is accommodated under the rubric of urgency.

Severity may be defined as the degree or extent of suffering, severe symptoms or risks of death that are less amenable to treatment. Certain early stage cancers are a good example of this situation. In such cases, urgency exceeds severity because the expected benefit from intervention is greater than would be inferred simply from a consideration of present clinical severity.

Urgency

Urgency refers to the extent to which immediate clinical action is required. A clinical situation might be urgent with respect to one particular form of action (e.g., providing pain medication) but not another (e.g., providing a surgical procedure). Cases in which patients are in severe pain are almost always considered urgent; however, some such patients urgently need an analgesic but have no need for surgery, whereas for others the opposite is true. Severity, in contrast to urgency, is not tied to any particular intervention.

Severity and urgency also diverge in the setting of many terminal conditions. Just before death, everyone has, almost by definition, an extremely severe condition. However, if such patients are pain free and no intervention is available to forestall death, the situation cannot be said to be urgent.

In the setting of elective surgery, however, severity and urgency often coincide. This is because many elective procedures are able to reverse or eliminate the pathophysiological basis for the severity of the condition. For example, cataracts can be removed and replaced with a clear artificial lens. In this case the urgency of surgery is directly related

to the severity of visual dysfunction, namely, the worse the visual disability, the more urgent the situation. Hip replacement for arthritis is another setting in which severity and urgency generally coincide. In each case an *effective* treatment exists. This is in contrast to the near-death situation postulated earlier.

A middle ground of urgency exists when patients' conditions cannot be fully alleviated. If, for example, patients with a visual dysfunction due to cataracts also have significant coexisting retinal damage, the urgency of cataract surgery is mitigated because surgery cannot fully restore visual function. Similarly, many treatments for which there are waiting lists offer less than full symptom relief or return to normal life expectancy (e.g., certain surgeries for back pain or cancer). Here again, severity and urgency diverge, with the extent of divergence resting largely on the *expected benefit* of treatments. The greater the expected benefit (i.e., the more effective the treatment), the closer the congruence between severity and urgency.

An important factor in estimating the urgency of a patient's condition is the natural history of the untreated condition. Thus, for example, certain patients might experience severe pain or limits to activities, but their situation would not necessarily be considered urgent if the condition were benign and relatively short-lived. In such cases the (net) expected benefit of curative interventions would be relatively small, and severity would exceed urgency.

On the other hand, patients may have conditions that have a low level of severity (i.e., are not associated with significant suffering, limits to activities or the risk of premature death) but that might, if left untreated, produce more severe symptoms or risks of death that are less amenable to treatment. Certain early stage cancers are a good example of this situation. In such cases, urgency exceeds severity because the expected benefit from intervention is greater than would be inferred simply from a consideration of present clinical severity.

Urgency may be defined as severity in addition to considerations of the expected benefit and the natural history of the condition.

Urgency and priority

How does urgency relate to priority? In common parlance, the 2 terms seem virtually identical. The more urgent a situation, the higher priority it should be given. However, Kee and colleagues¹ have suggested that a distinction can be drawn between these 2 terms on the basis of nonclinical factors, including age, social factors and considerations of personal responsibility.

Doctors might agree that a patient who smokes needs urgent intervention but disagree over the priority this patient should be accorded on a waiting list for surgery. Judgments about urgency and priority can produce different weighting for demographic and lifestyle factors such as age and smoking habit. Lifestyle characteristics often influence doctors' judgments on priority independently of their beliefs about the probable effectiveness of surgery.

Kee and coworkers found that physicians rated a series of "paper cases" of equivalent clinical urgency differently in terms of priority, based on nonclinical factors.

These findings are consistent with the New Zealand experience, in which clinicians insisted that certain nonclinical factors be included among the priority criteria, specifically the extent to which medical conditions threatened patients' ability to work, provide care to dependents or live independently.² Because clinicians take these factors into account when determining relative priority on waiting lists, they were incorporated in the form of a "social factor" into all initial sets of criteria. In addition, the patient's age was taken into account in the criteria developed for coronary artery bypass graft surgery, again to reflect clinicians' current practices.

The relevance of nonclinical factors to priority is an important and controversial topic. Is it right, for example, that a person who is working or caring for an elderly parent should receive higher priority than another (clinically comparable) patient who is unemployed or not caring for a parent? In New Zealand this issue was addressed by the National Advisory Committee on Core Health and Disability Support Services, which convened 2 formal public hearings focused on this subject. The committee found cautious support for the social factor, provided that the number of points assigned to it was not large compared with the clinical factors.

The experience of the Western Canada Waiting List Project is that, at least in the setting of elective surgery, doctors were generally comfortable with the inclusion of such a social factor. Preliminary experience in the United Kingdom appears to be similar.³

Relative priority may be defined as urgency with or without consideration of social factors.

Need

The concept of "need" (or health need or health care need) is frequently invoked in discussions of priority setting in health care. Unfortunately the term is sometimes taken to be roughly equivalent to severity; at other times, it means urgency. The main issue is whether or not to incorporate the notion of expected benefit, as in urgency, or to equate need with the presence of a severe illness or condition, regardless of likely benefit.

A substantial philosophical literature exists on the question of what constitutes a legitimate "need-claim." Philosophers who have examined this notion are in general agreement that need denotes urgency. For example, in his seminal 1975 paper "Preference and urgency," Scanlon⁴ argued that whether a particular person's desire for something constitutes a need depends on the degree of objective urgency inherent in that person's situation.

The fact that somebody would be willing to forego a decent diet in order to build a monument to his god does not mean that his

claim on others for aid in his project has the same strength as a claim for aid in obtaining enough to eat.

Implicit in this example is the distinction that must be made between needs and (mere) desires. Desires constitute needs only if and when the desired things *objectively* have (or can reasonably be expected to have) a substantial effect on a person's well-being. Thus, patients cannot *need* ineffective services. For example, patients with terminal conditions might have an understandable desire for treatments that could return them to good health, but such wishes do not constitute needs unless such treatments actually exist. Such patients do have needs, for comfort, care and palliation, but they cannot claim to *need* nonexistent (even if fervently wished for) curative remedies. This is true regardless of whether future patients with precisely the same conditions will, in fact, have actual "health care needs," by virtue of an effective treatment having been developed in the interim.

In most settings, the ability to benefit is a clear and noncontroversial component of deemed (or claimed) health care needs. As such, and in view of the preceding discussion, *need can reasonably be equated with urgency.*

Expected benefit

Up to this point we have referred to the notion of expected benefit without defining the term explicitly. This was possible because the concept is relatively straightforward in most settings. However, expected benefit can be a surprisingly difficult notion to pin down when examined closely. The concept has 2 distinct components: the extent (or magnitude) of benefit and the likelihood of that benefit occurring. In practice these 2 components are difficult to disentangle. For example, a particular service might offer some patients (or kinds of patient) a low probability of a large improvement, others a high probability of a small improvement, and still others a medium probability of medium improvement. In such situations it is necessary to estimate the overall expected benefit.

To complicate matters further, expected benefit incorporates 2 kinds of benefit: prolongation of life and improvement in quality of life. Quality of life is often regarded as more important by patients, particularly in the context of chronic pain or disabling conditions. Efforts to develop a workable measure for integrating these 2 components of benefit, generally using a quality-adjusted life-year or similar approach, have met with at best marginal success but have been used to produce quantitative estimates of the relative desirability of health outcomes.⁵

Expected benefit may be defined as the extent to which desired outcomes are likely to exceed undesired outcomes.

Conclusion

In order to develop measures for assessing patients' relative priority for services for which there are waiting lists, it

is important that key terms be used in a standardized manner. By adhering to common definitions, it will be possible to maintain conceptual clarity and avoid confusion.

Priority should be assigned based on urgency, with or without consideration of nonclinical factors such as the extent to which a patient's ability to work is threatened. Whether such nonclinical factors should be incorporated into the criteria will depend on the social-medical culture within which those criteria are developed. Although physicians appear generally willing to accept such factors, it is as yet unclear whether the general public feels the same way.

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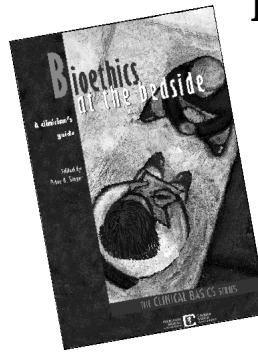
Reprint requests to: Dr. Tom Noseworthy, Department of Public Health Sciences, 13-103 Clinical Sciences Building, University of Alberta, Edmonton AB T6G 2G3; tom.noseworthy@ualberta.ca

Members of the Steering Committee of the Western Canada Waiting List Project: **Chair:** Dr. Tom Noseworthy, Professor and Chair, Department of Public Health Sciences, University of Alberta, Edmonton, Alta. **Members:** Dr. Morris L. Barer, Director, Centre for Health Services and Policy Research, and Professor, Department of Health Care and Epidemiology, University of British Columbia, Vancouver, BC; Dr. Charlyn Black, Codirector, Manitoba Centre for Health Policy and Evaluation, and Associate Head and Associate Professor, Department of Community Health Sciences, University of Manitoba, Winnipeg, Man.; Ms. Lauren Donnelly, Acting Executive Director, Acute and Emergency Services Branch, Saskatchewan Health, Regina, Sask.; Dr. Isra Levy, Director, Health Programs, Canadian Medical Association, Ottawa, Ont.; Mr. Steven Lewis, Partner, Access Consulting Ltd., Saskatoon, Sask.; Mr. John McGurran, Director, Western Canada Waiting List Project, and Research Associate, Department of Public Health Sciences, University of Alberta, Edmonton, Alta.; Dr. Mark C. Taylor, Assistant Professor, Department of Surgery, University of Manitoba, Winnipeg, Man.; Mr. Darrell Thomson, Director, Economics and Policy Analysis, British Columbia Medical Association, Vancouver, BC; Mrs. Barbara Young, Regional Utilization Consultant, Clinical Evaluation Services, Calgary Regional Health Authority, Calgary, Alta.

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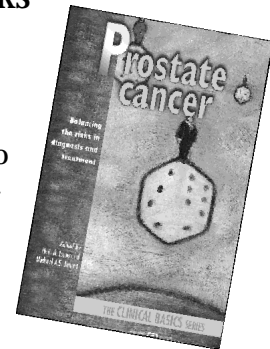
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