

**Setting Priorities on Waiting Lists:
Defining Our Terms¹**

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Introduction

Fair access to wait-listed services is a prime concern of every publicly funded health system. Waiting times vary substantially from doctor to doctor and hospital to hospital, and the length of patients' waits 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 nearly 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.

Toward this end, standardized measures are needed to permit the assessment and comparison of patients' priority based on (1) the urgency of their conditions and (2) the extent of benefit expected from wait-listed services. This paper discusses certain key concepts underlying these assessments and comparisons.

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, wait-listed patients "reside" in a common, imaginary "waiting room," with certain patients called out for treatment sooner than others. Often, two waiting lists are 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 data concern waits for services, not for evaluation—even though these "preliminary waits" can sometimes be the longer of the two.

Each waiting list is associated with an average waiting time, i.e., the number of days, weeks, or months expected to elapse from the time patients are placed on waiting lists 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 discusses several key concepts underlying the development of criteria for assessing patients' relative priority on waiting lists. These concepts are:

- severity
- urgency
- need
- expected benefit
- relative priority

It is essential that these terms be assigned standard meanings for purposes of advancing the debate. In particular, it is necessary to understand how the first four terms relate to the last.

Severity

Of the above terms, probably the most straightforward is severity, which refers to the degree, extent, or intensity of (1) suffering (e.g. pain, nausea, shortness of breath, depression, anxiety), (2) limits on activities (e.g. ability to work, care for one's basic needs), and (3) threats of premature mortality. The more a patient is suffering, for example, the more severe his or her condition, other things equal. In essence, severity reflects the extent of departure from normal species-typical 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, standardized measures of pain, disability, and mortality risk. But an even more fundamental problem concerns the task of comparing degrees of suffering with degrees of disability, or of mortality risk.

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 = Degree or extent of suffering, limits on activities, or threat to survival

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). Patients in severe pain are almost always considered urgent, but some such patients urgently need an analgesic, but have no need for surgery, while 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 prior to 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 so because many elective procedures are able to reverse or eliminate the pathophysiological basis for the severity of the condition. For example, cataracts can be physically removed and replaced with a clear artificial lens. In this case, the urgency of surgery is directly related to the severity of visual dysfunction, i.e. the worse the visual disability, the more urgent the situation. Hip replacement for arthritis is another example of severity and urgency (generally) coinciding. In each case, an *effective* treatment exists—in contrast to the near-death situation postulated above.

A middle ground of urgency exists when patients' conditions cannot be fully alleviated. If, for example, patients with visual dysfunction due to cataracts also have significant co-existing retinal damage, the urgency of cataract surgery is mitigated because surgery cannot fully restore visual function. Similarly, many wait-listed treatments 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 (see below). 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 on 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 which, while not associated with near-term suffering, limits on activities, or threats of premature mortality (i.e. low level of severity), might, if left untreated, produce more severe symptoms or mortality risks 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 = Severity + Considerations of expected benefit and natural history of condition

Urgency and Priority

How does urgency relate to priority? In common parlance, the two terms seem virtually identical. The more urgent a situation, the higher priority it should be given.

However, Kee et al. have suggested that a distinction can be drawn between these two terms on the basis of non-clinical 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 awaiting 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.¹

Kee et al. found that physicians rated a series of "paper cases" of equivalent clinical urgency differently in terms of priority, based on non-clinical factors.

These findings are consistent with the New Zealand experience, where clinicians insisted that certain non-clinical factors be included amongst the priority criteria, specifically the extent to

which medical conditions threatened patients' ability to (1) work, (2) provide care to dependents, or (3) 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, patients' age was taken into account in the criteria developed for coronary artery bypass graft surgery—again, to reflect clinicians' current practices.

The relevance of non-clinical factors to priority is an important and controversial topic. Is it right, for example, that a person who is (or who "happens to be") 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, the issue was addressed by the National Advisory Committee on Core Health and Disability Support Services, which convened two 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 to the clinical factors.

Whether and to what extent clinicians, politicians, and public in other countries will be comfortable with such formal incorporation of non-clinical factors into priority criteria remains to be seen.

Urgency = Severity + Considerations of expected benefit and natural history of condition

Relative priority = Urgency +/- social factors

Need

The concept of "need" (or health need or health care need) is frequently invoked in discussion of priority setting in health. Unfortunately, the term is sometimes taken as roughly equivalent to severity; at other time, it means urgency. The major 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, irrespective 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," William Scanlon 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."³

Implicit in this account is that distinctions must be made between needs and (mere) desires, and that 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. This account further entails that patients cannot *need* ineffective services. Thus, for example, patients with terminal conditions might understandably desire treatments that could return them to good

health, but such wishes do not constitute needs unless such treatments actually exist. Nonetheless, such patients do have needs—for comfort care and palliation. But these patients cannot claim, on this account, to *need* non-existent (if fervently wished for) curative remedies. This is true even if some day patients with precisely the same conditions do, in fact, have actual “health care needs,” by virtue of an effective treatment having been developed in the interim.

In most settings, ability to benefit is a clear and non-controversial component of deemed (or claimed) health care needs. As such, and in view of the above discussion, “need” can reasonably be equated with urgency:

Need = 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. For one thing, the concept has two distinct components: (1) the extent (or magnitude) of benefit and (2) the likelihood of that benefit occurring. In practice, these two 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.

The definition of “appropriateness” used by RAND investigators in the context of the Health Services Utilization Study (and related work) is relevant here. A service was considered appropriate to the extent

“the expected health benefit (e.g. increased life expectancy, relief of pain, reduction in anxiety, improved functional capacity, etc.) exceeds the expected negative consequences (i.e. mortality, morbidity, anxiety of anticipating the procedure, pain produced by the procedure, time lost from work, etc.).”⁴

Notice that no distinction is made in this definition between the degree of expected benefit and the likelihood of that benefit. RAND investigators have attempted to determine the extent to which one or the other of these components has played a paramount role in physicians’ judgment of appropriateness, but no clear pattern has emerged.

To complicate matters further, expected benefit incorporates two kinds of benefit: prolongation of life and improvement in quality of life. Often quality of life is regarded as more important by patients, particularly in the context of chronic painful or disabling conditions. A decades-long effort to develop a workable measure for integrating these two components of benefit, generally using a quality-adjusted life year (QALYs or similar) approach, has met with at best marginal success. Using this approach, quantitative estimates are made of the relative desirability of health outcomes.⁵

Expected benefit = Extent to which desired outcomes are likely to exceed undesired outcomes

Summary

In seeking to develop measures for assessing patients' relative priority for wait-listed services, 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 to avoid the confusion that has often plagued previous efforts.

Arriving at shared understandings of the meaning of key terms will also facilitate the sort of understandable and transparent process needed to develop priority criteria. It must always 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 mortality. Given what is at stake, there should be no confusion regarding the "ingredients" that make up the criteria designed to reflect clinical priority judgments.

In a nutshell, priority should be assigned based on urgency, plus or minus non-clinical factors such as the extent to which patients' ability to work is threatened. Whether such non-clinical factors should be incorporated into the criteria will depend on the social-medical culture within which those criteria are developed.

In summary, the following definitions are proposed:

Severity = Degree or extent of suffering, limits on activities, or threat to survival

Urgency = Need = Severity + Consideration of expected benefit and natural history

Priority = Urgency +/- consideration of non-clinical factors

Expected benefit = Extent to which desired outcomes are likely to exceed undesired outcomes

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