Part I

Goals of medical care

1

Goals and objectives

Introduction

Mrs. M., 54, has been your patient for 15 years, and in that time she's been largely healthy. You've seen her through a broken wrist and one hospitalization for dehydration as a result of severe gastroenteritis, as well as her annual physical examinations and routine preventative health screenings. When she presented to you with a history of coughing up blood and facial swelling, you immediately ordered a chest x-ray. The radiograph showed a mass and computed tomography of the chest the next day was strongly suggestive of small cell lung cancer with some metastasis to the mediastinal lymph nodes.

You referred Mrs. M. to a highly regarded cancer center in your area that uses a team approach. Mrs. M.'s team includes a thoracic surgeon, an oncologist, a pulmonologist, and a social worker. They discuss her condition and formulate several alternate treatment plans. They all agree, given the complexity of the situation, that Mrs. M. could reasonably decide to proceed with one of several treatments. Having come to consensus, the oncologist and social worker met with Mrs. M. to discuss the options. They carefully described four different interventions and asked her which would be her choice. They also patiently answered questions about side effects and chances of success. Mrs. M., in the end, told the team she wanted some time to think about the options. They endorsed this need and scheduled a follow-up in 10 days.

Mrs. M. went home distressed, anxious, and confused. The next day she called your office and made an appointment to see you. She wanted your guidance on the different chemotherapy protocols and on surgical resection of the primary tumor and lymph nodes involved. She has realized that she may face a considerably shorter life than she once expected.

The case of Mrs. M. presages nearly all of the facets of decision making that face primary care physicians and their patients. In most cases, Mrs. M.'s treatment team will recommend a workup for staging her disease and then recommend a treatment plan that will, in their best judgment and in light of the best available

evidence, afford her the greatest length of life or the highest chance of survival 3 or 5 years later. In many cases, Mrs. M. will follow these recommendations without question, because they have been developed by highly educated and experienced physicians and may be presented as the only sensible choices. And, indeed, for someone whose aim in life is to live as long as possible, they may well be the only sensible choices.

As Mrs. M.'s physician, you want her to make good medical decisions. But what makes a good decision? When physicians are asked about the characteristics of a good decision by their patients, four are often cited:

- A good decision is one that leads to a good outcome.
- A good decision takes into account all of the relevant information known at the time and does not depend on irrelevant information.
- A good decision can be justified or defended to others.
- A good decision is arrived at through a deliberative process.

Less obvious, but just as important, is a fifth principle:

- A good decision is consistent with the way the decision maker wants to live his or her life.

Let's consider each of these characteristics in turn.

Decisions and outcomes

Most people have a sense that a good decision is one that leads to a good outcome. However, they are also quick to recognize that someone may make the best available decision and yet have a bad outcome through no fault of their own or that someone may make a decision for nonsensical reasons and yet, through a stroke of luck, obtain good results.

In a world without uncertainty, making a good decision would be, if not simple, at least less challenging. A good decision would be a decision that was known to lead to a good outcome. For example, a mechanic who examines a car and finds that its brake pads are worn should replace them. There is no question that improperly functioning brakes are dangerous, that worn pads reduce brake function, and that replacing the pads is the proper procedure to restore the car to full functioning. When outcomes are uncertain, however, the best we can do is say that a good decision is a decision that is likely to lead to a good outcome.

Decisions and information

An informed decision ought to be a better decision. In principle, having additional relevant information should always lead to a decision that is at least as good as the decision that would be made without the information. Similarly, avoiding irrelevant information minimizes the chance that it will inappropriately bias a decision. This requires both distinguishing relevant from irrelevant information and then selectively ignoring irrelevant information. Both have proven to be difficult in practice.

Consider a couple looking for a house to buy. Each house they visit has the current owner's furniture and decorations in it, but the furnishings are not being sold with the house. Although the buyers may recognize that they should pay closer attention to the relevant (to them) structural features of the house and ignore the irrelevant furnishings, there is an almost irresistible impact of the decorative appearance that could play a significant and unwanted role in the decision.

Managing information is a key component of improving decision making. In practice, however, determining which information is available and assessing its relevance is not always a simple matter. We return to this topic in much greater detail in Part IV.

Decisions and reasons

Few patients are completely disconnected from the influences of others. There can be great pressure to make medical decisions, particularly those involving significant trade-offs, in a way that can be justified to family and friends by means of principles, narratives, or other reasons. Using familiar and well-accepted processes for coming to a decision may serve as a justification in itself, but patients are more often called upon to justify not only how the decision was made, but also why they believe the decision will serve their goals.

For example, the word *diet* on a box of cookies may provide a person trying to lose weight with a persuasive justification for purchasing those cookies, despite the lack of a standard meaning for the term as a food label. Having bought the cookies, the perceived rationale may be strong enough that the person may go to consume them in such quantities that any benefit from fewer calories per cookie is obviated.

It is not patients alone for whom the knowledge that they can provide a justification for a decision can be an important driver of the decision. The ability of physicians to defend medical decisions to peers has obvious importance in the context of malpractice suits.

Decisions and deliberation

It is often assumed that a good decision emerges from a well-considered reasoning process that analyzes the available information and weighs the available choices carefully. Decisions should not be made under time pressure or stress. On the other hand, a burgeoning literature suggest that intuitive judgments – made without conscious deliberation – are often the basis for choice and can even be highly successful.

Even when a decision is already made, however, there can be value in examining it deliberatively. Deliberative consideration may point out that the decision depends on important background assumptions and lead the decision maker to

take further action to ensure that those assumptions are met. Reconsideration may also lead to further comfort with the decision because it may highlight additional ways in which the decision serves the needs of the patient. Even when further consideration results in feelings of regret (such as the familiar phenomenon of "buyer's remorse" in real estate sales), it may serve to lessen the surprise of possible negative outcomes in the future, and thus lessen their emotional impact.

Decisions and life goals

Striving to attain goals gives purpose to life. Psychologically, goals serve as important reference points for the outcomes of decisions. Outcomes that achieve goals are often considered to be successes or gains by the decision maker, whereas outcomes that do not achieve goals are often considered failures or losses. Although decision researchers always emphasize the importance of goals in decision making, goals are rarely considered explicitly because they are unique to each decision maker, and it is often assumed that only the decision maker has good insight into his own goals. The incorporation of goals into medical decisions, although amenable to systematization, thus remains in large part an art practiced by physicians who excel in communication with patients in the clinical encounter.

Each patient may have unique goals. However, the desire to fulfill goals is common to all patients. For example:

- an author wants to complete a book
- an athlete wants to play on a championship team
- an artist struggles to complete a major work
- an engineer or architect endeavors to see a project to completion
- a politician strives to achieve higher office
- a celebrity wishes to complete memoirs
- a political activist seeks campaign reform legislation
- a patient wants to have children and raise a family
- a patient seeks the financial and social welfare of her family

Decisions that impact life expectancy clearly have important consequences for goal achievement. Some goals simply require a long time to accomplish, and early death obstructs goal achievement. Others are ongoing goals that emphasize a persistent state: to live as long as possible, to run a marathon each year, or to defend a championship chess title.

Similarly, decisions that impact quality of health can also be recast in terms of either requiring a minimal level of health to accomplish goals or the maintenance of a level of health itself as a persistent goal. The list above provides examples of the former; without adequate mental and physical functioning, it may not be possible to achieve a goal, no matter how long one's life. For examples of the latter, mobility, chronic pain, and emotional stress all affect quality of health,

and the corresponding goals – to increase mobility, to eliminate pain, and to reduce emotional stress – are common to many patients.

Goals may include both discrete and ongoing achievements. Individuals seeking the financial and social welfare of their families may want to provide quality child rearing – an ongoing goal – and also to live long enough to see their child graduate from high school – a goal achieved at a discrete point in time.

Another interesting feature of goals is that, although the ability to achieve them may depend on the duration of remaining life or quality of health, the value of achieving them may not. As a result, some patients may be willing to make decisions that result in somewhat shorter life expectancy, if they will be more likely to achieve a goal, but unwilling to make decisions that result in a much shorter life expectancy if they would run out of time to achieve the goal.

It is an unfortunate error for a patient to expend effort and invest emotion in making a decision that seeks to achieve some goal only to discover that the goal achieved is relatively unimportant to them. It is sensible to seek to avoid vomiting, but for a cancer patient to avoid chemotherapy to achieve that goal may be penny wise and pound foolish. One of the most important ways a physician can aid their patients' decisions is to help them clarify the goals they hope to achieve in the decision.

Goals, objectives, and constraints

In their seminal book, *Decisions with Multiple Objectives*, Keeney and Raiffa (1976) provide a useful distinction between goals and objectives. An objective, they write, "generally indicates the 'direction' in which we should strive to do better" (p. 34), whereas a goal is "either achieved or not" (p. 34). That is, in their framework, objectives are ongoing and goals are discrete. Others use these terms somewhat differently; educators, for example, traditionally define broad goals for their teaching and then associate more specific objectives with each goal. The key conceptual distinctions – between ongoing and discrete aims and between high-level pursuits and intermediate subpursuits that are meaningful as steps on the path to a higher level pursuit – recur throughout the literature on goals and are more important than the particular terminology chosen.

Each goal held by a patient implies a set of objectives that leads to an increased likelihood of achieving the goal. For example, a patient who wishes to dance at her child's wedding has the following objectives:

- to stay alive (at least until the day after the wedding)
- to stay or become healthy (enough to be present at the wedding)
- to remain or become ambulatory (enough to dance)
- to maintain or acquire wealth (enough to travel to the wedding)
- to maintain or improve their relationship with their child and their child's partner

Goals and objectives define what patients are striving for in their decisions. On the other hand, *constraints* define how a patient is limited in his or her decisions. Some constraints are social or economic; a patient may rule out a surgery with a long recovery because he cannot afford to be away from work or because he has caretaking responsibilities for a child. Other constraints are moral, and based on what Baron and Spranca (1997) have referred to as "protected values." For example, the patient who wants to dance at his child's wedding would probably not be willing to do so at the expense of the child's health, or an important religious conviction, or if it meant driving an endangered species to extinction. More recently, a large-scale telephone survey of California parents found a subgroup who were unwilling to allow their daughters to be vaccinated against human papilloma virus owing to moral concerns about the potential effect on their daughters' sexual behavior (Constantine and Jerman, 2007).

Just as patients should understand goals and objectives clearly to ensure that their decisions are going to further their objectives, it can be important for patients to clarify their constraints, to ensure that their decisions will not violate them. It is equally important that physicians understand their patients' goals and constraints; as Dr William Cayley put it, "If we test or treat just because the treatment or test is available, but we disregard our patients' needs and goals, we are not being good doctors" (2004, p. 11).

A typology of life goals

Tim Kasser and his colleagues have developed a useful typology of life goals and a questionnaire for asking about them that they call the Aspiration Index (Kasser, 1996; Kasser and Ryan, 1993, 1996, 2001; Grouzet *et al.*, 2005). A recent version of the Aspiration Index measures the relative importance of these goal domains:

- financial success
- image
- popularity
- self-acceptance
- affiliation
- community feeling
- physical health
- spirituality
- conformity
- hedonism
- safety

On the basis of interviews with patients and community members, one of the authors of this book developed a goal typology with a similar set of goals (Schwartz *et al.*, in press):

- wealth (property and financial security)
- professional achievement (career and retirement)
- family (growing one's own, or promoting achievements of family members)
- health and fitness
- education
- travel
- personal or spiritual fulfillment

Nearly all investigations of goals in medical decision making point to the particular importance of family goals. Patients who have significant family goals, such as attending their child's wedding or being present at a grandchild's birth, are likely to strongly avoid medical options that may limit their ability to achieve the goal and strongly favor options that preserve this ability. These decisions may come at the cost of their long-term health but can reflect a consistent, rational decision to sacrifice other opportunities to participate more fully in their family life.

Clarifying life goals

Goal typologies provide a useful mechanism for helping patients to clarify their goals. In a consultation to introduce significant medical decisions, a typology can be used as a checklist to catalog the patient's individual goals and to avoid overlooking any important goals. In the goal clarification exercise, it is best to keep the focus on goals, and not on the medical decisions themselves, which are only a means to the achievement of the goals.

One way to do this might be to actually ask the patient to complete Kasser's Aspiration Index or a similar questionnaire and then look at the scores. Another approach, which is both more time consuming and more rewarding, is to discuss goals directly with the patient. For example, here's how a goal clarification exercise with Mrs. M. might proceed:

Doctor: Before we get into details about different treatment options, I'd like to ask you about some of your goals, because when we're considering your treatment, we should do it with your goals in mind. So, let's think about what's important to you, what you want to achieve in life, ok?

Mrs. M.: OK. I know I don't want to die young.

Doctor: You want to live as long as possible?

Mrs. M.: Well, yes, but not if it's just surviving, if you know what I mean. I want to be able to do things that make life worth living.

Doctor: So if you could stay healthy, you'd live as long as possible, but you could imagine being so sick that you wouldn't want to prolong your life?

Mrs. M.: Yes. I'm not sure how sick I'd have to be though.

Doctor: That's OK, we don't have to determine everything now. I'll write down that you have a goal of living as long as possible, but with the constraint that you don't want to live if you can't do certain things, and we'll just leave what those things are blank for now, how about that?
Mrs. M.: That's fine.
Doctor: OK, let me ask you about some specific kinds of goals you might have. First, let's talk about family goals. I know you're married and you have two children. You don't plan to have any others, I take it?
Mrs. M.: [laughing] No, I'm through with that.
Doctor: Do you still need to take care of your children?
Mrs. M.: No, my son is 30 and my daughter is 27, and they're both doing fine on their own. I've got two grandchildren from my son. My daughter's not married yet; she's focusing on her job.
Doctor: So do you have any specific family goals or concerns that are important to you now?
Mrs. M.: Well, I don't want to do anything that would make me a hardship for my husband or my kids.
Doctor: So you want to be sure that your family remains financially secure and independent?
Mrs. M.: Yes, that's important to me.
Doctor: OK, I'll write that down.
Mrs. M.: And – this is related to that, I guess – I'd like to be able to keep working. I'm not ready to retire; I'd be bored.
Doctor: That's part of financial security, sure, but even if you could afford to retire today, you'd want to be able to keep working at something, to keep active?
Mrs. M.: Right . . .

When patients have supportive friends or family involved in their decision making, it can be helpful to suggest that patients discuss their goals with them. Supports can serve as advocates for patients' goals and can help patients check their decisions against their goals.

Using goals in decisions

One useful tool for incorporating goals into decisions is to provide the patient with details about her alternatives and ask her to build a table of goals and alternatives (Table 1.1). Constraints can also be included as goals; in this case, the patient is pointing out that she has important values that would prevent her from making some kinds of choices. The patient should then fill in the table, showing how each alternative would or would not lead to achieving each goal (Table 1.2).

Table 1.1 Goals and alternatives

Alternative	Goal 1: Live as long as possible	Goal 2: Be able to keep working	Goal 3: Keep my family financially secure
1. Chemotherapy, surgery, chemotherapy			
2. Chemotherapy alone			
3. No treatment			

Table 1.2 Goals and alternatives specified

Alternative	Goal 1: Live as long as possible	Goal 2: Be able to keep working	Goal 3: Keep my family financially secure
1. Chemotherapy, surgery, chemotherapy	Best chance for long-term survival, likely live ≥5 years	Will be unable to work for some months	Insurance coverage sufficient to pay for procedure, disability and life insurance coverage sufficient to provide for family
2. Chemotherapy alone	May shrink tumor, likely to live 3–5 years	Will be unable to work for some weeks	Insurance coverage sufficient to pay for procedure, disability and life insurance coverage sufficient to provide for family
3. No treatment	Worst chance, likely to live ≤2 years	Can immediately resume work until condition worsens	Insurance coverage sufficient to pay for procedure, disability and life insurance coverage sufficient to provide for family

The patient should discuss the table with her physician, who should point out any assumptions that are medically untenable (e.g., the patient may have misunderstood or overestimated her life expectancy without treatment).

At this point, the patient can use the table as a simple decision aid; it makes explicit the trade-offs that she must consider when choosing between alternatives. If, as in goal 3 in the example above, every alternative fulfills one of the goals equally well, the patient should be directed to focus attention on the other goals by crossing out that goal column. If the patient has strong constraints on