5 Coping with Uncertainty

When I was still a medical student, several of my teachers, in agreement rare among psychiatrists, pointed out that a well-trained mental health clinician can make a valid diagnosis after a single interview about four times out of five; on the fifth, however, the clinician could interview for hours and still be uncertain. Over the intervening decades, that figure hasn't changed much, if at all. The result is that if you evaluate several new patients a week, you'll have to learn to cope with diagnostic uncertainty. This chapter presents some ideas on dealing with uncertainty when it arises, and explains why the concept itself is so valuable to the pursuit of accurate diagnoses.

Why Aren't We Certain?

You might suppose that someday all the uncertainty will be gone from the diagnostic process, but I think that this happy state will be a very long time in coming. The main reason is as obvious as it is inescapable: We can hardly avoid patients for whom we lack adequate information. Although patients with cognitive deficits such as Alzheimer's dementia may want very much to cooperate, they will have difficulty remembering important facts. Relatives may have been out of contact with such patients too long to have essential information to contribute. Someone who is paranoid or who has previously had unhappy experiences with health care may be afraid to reveal facts pertinent to diagnosis.

> When Nigel first consulted his new caregiver, a young woman still in training at the university clinic, he felt suddenly embarrassed about the cause of his anxiety and depression. It required most of the first session before he finally disclosed that he had been repeatedly impotent with his fiancée, who had suggested the evaluation.

Other patients may try to shield themselves or others from possible prosecution.

> Accused of destroying his neighbor's home in a futile search for money and drugs, Trevor was interviewed in jail. He alleged that he had a bipolar disorder, and he said that he was "blacked out" for the events in question. He refused to allow clinicians to contact family members for additional information that could validate—or, of course, refute—his claim of a potentially exculpatory mental disorder.

Still other patients who seek to restrict information about their histories include those who have factitious and paranoid disorders. And some, for a great variety of reasons, just plain don't tell the truth.

It happens more often than we sometimes realize that a patient's database simply will never be complete until we've obtained collateral information—usually from a relative, but sometimes from old charts or previous clinicians.

> Jeff gave a history of bipolar illness, with manic and depressive mood swings. Although he denied that he had ever used alcohol heavily, Louise, his ex-wife, left me a voice mail message that she had often seen him in a stupor. It wasn't until I went to his house one evening, after a neighbor had called Louise to express concern about a raucous disturbance, that I saw him acutely intoxicated on both alcohol and cocaine. I persuaded him to be admitted to a hospital; the following day, he finally confessed that his mood swings had all occurred while he was under the influence.

Sometimes the clinician must bear the responsibility for insufficient information. If I omit questions about anxiety symptoms in the rush to complete an evaluation, I risk overlooking an important diagnosis. In the middle of the night, a sleepy clinician who doesn't dig through a thick chart may fail to note that a psychotic patient had an abnormal EEG the year before and was successfully treated with anticonvulsants. I believe that many missed and incorrect diagnoses stem from failure to collect and use all the relevant data, although I have no data other than my years of observing interviewer performance to support this belief.

On the other hand (wouldn't you know?), sometimes extra information confuses the diagnosis. The situation can be something rather simple, as when a patient with a long history of psychosis has symptoms that are not typical for schizophrenia—terrific insight and well-modulated affect, per-

haps. Or consider a patient with somatization disorder who gives positive answers to such a broad array of questions that you can't rule out anything. Then it's a matter of sifting through the facts and deciding which are most relevant to your diagnosis. I've already described in Chapter 4 how contradictory information sources can lead to diagnostic confusion.

An issue we don't often mention is the clinician who fails to keep up to date with the explosive growth of knowledge. I've encountered any number of mental health professionals who base diagnoses of schizophrenia on their clinical intuition, rather than on the best practices informed by scientific studies. Such irresponsible behavior represents the sort of nightmare that drives most of us—almost from the moment we complete training and embark on independent careers as health care providers—to read journals, attend conferences, and accumulate continuing education credits, all in the effort to stay current with the latest developments in diagnosis and therapy. Keeping current has become institutionalized for medical professionals, whose board certifications are now good only for a limited time (usually 10 years), after which they must sit for a recertification exam.

Of course, the myriad combinations of symptoms individual patients present can confuse even the best-trained, most up-to-date practitioners. Some examples are well recognized and are even written into established criteria. A commonplace example is atypical depression, in which appetite and sleep may be increased, not decreased as you'd expect in the usual case of depression. However, other instances get less attention and can cause a practitioner who sticks too closely to established criteria to miss a diagnosis.

> A rare example would be the case of Corrine, whose magnum of red wine every day never caused her problems. Single all her life, she lived on inherited wealth. A companion managed her affairs and saw to it that she got proper nutrition and health care. If you insisted upon the exact criteria for alcohol use disorder, Corrine might not qualify.

The point is that established criteria don't cover every possible manifestation of mental disease, and plenty of patients have symptoms that don't conform to conventional notions of a given disorder.

> Arvin recently moved west from Indiana, where he had attended college. At 35, he had a long history of mood disorder, beginning at the age of 10 when he attempted suicide by drinking Lysol. Fortunately, before he could get much of the liquid down, he gagged and suffered

no lasting ill effects. At about that time he also took his first drink of alcohol, and thus began a long downward spiral of substance use (marijuana and amphetamines when he was 12) and depression. Because he was bright and could take tests easily, he finished high school with his class, but when he was 19 he suffered his first episode of mania.

Arvin's depressions had always been brief, lasting 10 days at most, and about half the time they were interwoven with bursts of mania. Both his lows and his highs met symptomatic criteria for major depression and either manic episode or mixed episode (a mixture of depressive and manic symptoms). However, because his depressive episodes were so brief, a doctor had recently refused to diagnose him with bipolar I disorder. "He told me that I had 'mood disorder not otherwise specified,'" Arvin reported in some consternation when a medical student presented his case. "What does that mean?"

Despite his diagnosis, Arvin's moods leveled out when he started taking a mood-stabilizing medication. Every experienced clinician has seen countless patients like Arvin who in some way or other don't quite fit official diagnostic criteria. Mostly therapy proceeds just as though the criteria had been fully met, and mostly it works out just fine. I echo the view of many expert clinicians, enshrined in the easily overlooked statement in the fine print of official criteria sets: Criteria should be viewed as guidelines, not straitjackets, and clinicians should use them with judgment that takes all the individual circumstances into account.

We must also acknowledge that some behaviors can resemble mental illness at first glance, but are actually more or less "normal" (see the sidebar "What's Normal?" on page 48). Sometimes these are termed *mental illness confounds*. For example, many people will respond to a variety of situations with emotion that is more intense than average. What I'm trying to warn against is overinterpreting behavior that may differ from what our own might be in a similar circumstance. Here are a few examples:

- Francine is a senior in college. Her anxiety could signal GAD, but it might reflect a normal response to the divorce of her parents and the impending Graduate Record Examination. Often anxiety is perfectly normal, even expected.
- Do Oscar's feelings of intense sadness indicate mood disorder or a response to breaking up with his fiancée? Personal unhappiness isn't necessarily abnormal.
- At 16, Winnie repeatedly shoplifts from several stores in the mall. She could have kleptomania, but might she be responding to a

schoolmate's threats to tell her religiously strict parents that she has had an abortion? Isolated bits of behavior can suggest a diagnosis, but they often don't constitute one.

- Gordon wore the colors of his school's arch-rival team on the day of the big game. He courted social disapproval and undoubtedly craved attention, but his behavior didn't qualify him for a diagnosis. A need for individuality and recognition is part of growing up, and of the human condition in general.
- Sandy drinks and uses drugs excessively, to the point of having declining grades and an arrest for drunk driving. Does this extremely common behavior foreshadow substance use disorder, or is it simply going along with the gang?

Resolving Diagnostic Uncertainty

As I have noted earlier, only about 80% of new patients can be diagnosed on first interview. This section provides some techniques that may help you improve on that percentage.

It is natural that whenever we come to a stumbling block in the diagnostic process, our first impulse is usually to look for more information. Sometimes an additional patient interview, focused on the specifics of what we need to resolve our doubts, will succeed. At other times, information from another resource (such as a relative, friend, or former physician of the patient) or a review of previous health care records can make the difference. However, some histories are just plain confusing and will remain so well past the appropriate time to start treatment. Then we must look for clues that will help us arrange the possible diagnoses into a workable differential list.

Past Behavior

I've co-opted as a diagnostic principle the truism that the best predictor of future behavior is past behavior. It applies to many areas of life in general, but it is especially valuable in making diagnoses. It suggests that any patient who has had a syndrome or set of symptoms for months or years is likely to remain the same far into the future. Here's an example:

> Ned appeared to be in his mid-40s when the police brought him to the emergency room. That afternoon they had found him barricading the

What's Normal?

From my internet correspondents, I repeatedly hear this complaint: "The textbooks and diagnostic manuals don't tell me what's normal."

It's a fair cop. We're so used to spelling out the abnormal that we sometimes end up defining what's normal by what we believe. That puts it into the dubious category of "I know it when I see it," as Potter Stewart, associate justice of the U.S. Supreme Court, famously defined *pornography*. Derived from the Latin *norma* meaning "carpenter's square," the meanings of *normal* include "average," "healthy," "usual," and "the ideal." There are problems with each of these—you might even say that definitional problems are the norm. If we define *normal* as "average," then it would mean some (if minor) degree of impairment, because so many adults are impaired by mental disorder. If it means "healthy," as in the absence of disease, then nearly half of all Americans are mentally abnormal. If it's what's "usual," then we'd consider abnormal those who drink no alcohol at all. And if it's "the ideal," then normality is a state to which we can aspire, but never attain.

We are left bobbing in a sea of ad hoc decisions concerning each illness or group of illnesses we encounter. For example, we must differentiate the misuse of substances from social drinking, recreational drug use (however normal that may be), and the appropriate use of prescription drugs. We've even coined special terms for some conditions that we regard as normal and must differentiate from illness: *adult antisocial behavior*, for common criminals who lack the cachet of antisocial personality disorder; *age-related decline*, for the not-quite-dementia experienced by each of us lucky enough to survive middle age; *bereavement*, which we all (mostly) hope never to experience ourselves, yet assume others will one day experience on our behalf.

Below I've listed some mental states and symptoms, along with the normal situations from which we must differentiate them. Note that we sometimes use the words *common*, *ordinary*, or *everyday* as code for *normal*. This raises the interesting point that for some behaviors, the definition of what's normal is a little skewed. Consider, for example, ordinary shoplifting (as distinct from kleptomania), common criminality (vs. antisocial personality disorder), and everyday fire starting for profit (vs. pyromania).

Pathology	*Normal*
Psychosis	Dreams, imaginary playmates, *déjà vu*, and the hallucinations that occur when we are going to sleep or awakening
Depression, mania	Common sadness and joy experienced in daily life
Panic attacks	Adaptive fright that helps us avoid speeding trucks, raging torrents, and crashing bores

Phobias	Realistic concerns about being embarrassed (such as someone who stutters might feel) or unable to help oneself (as perhaps a paralyzed person might feel)
Social anxiety	Stage or microphone fright and ordinary shyness that doesn't result in clinically important distress or impairment
Obsessions, compulsions	Superstitions and one-time checking to see that the stove is turned off before we depart for the airport
Pathological worry	Legitimate concerns such as paying the rent and putting the kids through college when we've just been laid off
Somatization, hypochondriasis	Concerns about demonstrable physical disorders
Dissociation	Daydreams, reveries, and fantasies
Compulsive gambling	Professional and recreational betting
Rejection of one's own gender identity	Tomboyishness, theatrical role playing, and any other cross-gender behavior that doesn't cozily fit our cultural stereotypes
Paraphilias	Use of fantasy to enhance sexual excitement
Personality disorder	Personality and character traits that are merely annoying (yours) or even endearing (mine)

entry into a major shopping venue in the mall. Wearing a helmet made of aluminum foil, Ned was advising customers that a giant meteor was approaching the Pacific Northwest. When it struck, all life would be annihilated. He spoke rapidly, and his grandiose ideas (his ex-wife was a member of the Rockefeller family; he could control the outcome of the coming election) seemed to tumble after one another without logical connection. A telephone call to the number listed on a piece of paper in his pocket elicited the information that he had been chronically ill with psychosis for years. For the evaluating clinician, schizophrenia became the best working diagnosis.

Diagnostic Principle: **The best predictor of future behavior is past behavior.**

More Symptoms of a Diagnosis

You'd think that a patient who has a lot of symptoms would fit a given syndrome better than someone with just a few symptoms, and you'd be right—to a certain extent. I would certainly vote for depression in someone who has seven or eight of the usual symptoms. But in using this diagnostic principle, remember that some symptoms carry far greater weight than others. For example, hallucinations and delusions strongly suggest schizophrenia, whereas pacing and muttering don't. Someone who stays up half the night pacing the room and muttering could be an aspiring author trying to punch through a writer's block (trust me!).

Diagnostic Principle: **More symptoms of a disorder increase its likelihood as your diagnosis.**

And as a corollary, note that the mere fact of having *serious* symptoms doesn't necessarily mean that a given disorder is present. We'll see in Part II of this book that, for example, many people who have suicidal ideas don't necessarily have clinical depression as their primary diagnosis.

Presence of Typical Features

If your patient has symptoms or other features you usually expect to encounter in a given disorder, you'll want to consider it strongly for your working diagnosis. Loss of interest in work and leisure activities (including sex), poor concentration, and loss of appetite and insomnia point strongly to major depression. On the other hand, your diagnosis will be more secure if there aren't any symptoms that suggest other conditions. For example, if Serena complains of hallucinations, but you encounter a long history of multiple physical complaints or symptoms suggestive of mania, schizophrenia would seem a less attractive diagnosis.

Diagnostic Principle: **Typical features of a disorder increase its likelihood as your diagnosis; in the presence of nontypical features, look for alternatives.**

Previous Typical Response to Treatment

Response to treatment can be tricky (a substantial number of patients with nearly any condition will improve, even on sugar pills—even if they *know* they are sugar pills!). However, sometimes the response to treatment can provide a clue to diagnosis. If you learn that Morton's earlier episode of

Diagnostic Principle: **Previous typical response to treatment for a disorder increases its likelihood as your diagnosis.**

so-called schizophrenia resolved completely with a mood-stabilizing drug, you would strongly suspect that the actual diagnosis is a mood disorder.

The Value of the Term *Undiagnosed*

After you have recorded all the history you can find, pursued every clue from the MSE, interviewed relatives and friends, and consulted the available records, you still may not be able to come up with a definitive diagnosis. That's just fine. It is important to recognize that for some patients, no diagnosis will be possible immediately; for a few, you may not be sure for months or years. For all of these, you have at your disposal one of the most powerful descriptions in the book: *undiagnosed*.

Diagnostic Principle: **Use the word *undiagnosed* whenever you cannot be sure of your diagnosis.**

I'm not kidding about this. *Undiagnosed* is my favorite diagnostic term of all time. I think of it as a safety valve. It allows us to acknowledge that something is probably wrong without rushing into closure—the point at which we usually stop thinking. It allows us to avoid making a diagnosis such as schizophrenia, Alzheimer's dementia, or antisocial personality disorder that could harm someone if it turns out not to be true. This is doubly important, now that insurance companies, employers, law enforcement bodies, and patients themselves increasingly exercise the right to review medical records.

Undiagnosed can keep you alert to data that don't quite fit. When you write it, you mean "This patient probably has a mental disorder, though I'm not sure which one." By using this diagnostic principle, you keep yourself honest, and you demonstrate that honesty to others. Every time you see the *undiagnosed* label on a patient's chart or record, it forces you to think anew: "What additional information have I obtained since the last time? What have I learned about disease that might now be relevant to this patient?" If the answers continue to be "Not enough yet," *undiagnosed* stimulates further inquiry.

Some clinicians don't like to confess uncertainty: Could it reduce a patient's confidence in them? I think it far more likely that it will facilitate trust in a clinician candid enough to acknowledge that knowledge has its

limits. Furthermore, by reducing unrealistic expectations, it could mitigate the likelihood of litigation if unforeseen difficulties should arise in the course of therapy. *Undiagnosed* can restrain you from rushing into unwarranted treatment that could be high-risk. (For example, if you admit you don't know what's wrong, you're unlikely to recommend electroconvulsive therapy.) It should certainly bar a patient from participation in any experimental treatment trial.

I've always considered diagnosis to be a team sport, not a vehicle for individual showboating. *Undiagnosed* alerts other clinicians on the team to think deeply about this patient. This is especially important in an institutional setting, where patients typically encounter many clinicians. Even in private offices, clinicians refer patients for specialized problems and take night and weekend calls for one another—more opportunities for a hasty, incorrect diagnosis to cause harm. Perhaps a fresh set of eyes will react to the *undiagnosed* label by uncovering information or making a connection that you have missed; additional symptoms may develop later that will allow a definitive diagnosis. *Undiagnosed* forces us as clinicians to shine a light on uncertainty; without it, we could remain unaware that we are still in the dark.

Quite frankly, as I have gained experience with age, I have worried more about becoming too sanguine about my diagnostic ability. This is part of the reason I emphasize *undiagnosed* in my teaching and writing. One last note: *Undiagnosed* is somewhat safer than *unspecified X disorder*, which is the DSM-5 expression for a disorder that doesn't meet official criteria. My concern is that *unspecified X disorder* lends an aura of finality that tends to choke off further investigation. I try to avoid it.

Why Can't We Make a Diagnosis?

Managing uncertainty can be far more complicated than simply gathering additional information, though that's an excellent start. Here are several factors that can contribute to confusion about a given patient's diagnosis:

- Some people simply don't show enough traditional symptoms to justify a diagnosis. Perhaps it is so early in the course of a patient's illness that the typical symptoms have not yet developed. Although time will sort out this one, it can still leave clinicians struggling to create a sensible treatment plan. It raises this question: How close to the ideal patient should we require a person's symptoms to be before making a diagnosis? Any illness

close to the bottom of the hierarchy of safe diagnoses (Table 3.1) should require more symptoms and more typical symptoms before that diagnosis is made.

- Some patients have too many symptoms, promoting confusion. Although this should be simply a matter of further inquiry, sorting it out takes time and diligence. Resist the temptation to reach for the nearest likely approximation.

- Some features are unusual. Atypical features of depression have already been enshrined in their own special criteria, but a diagnostician who insists on the "letter of the law" could be perplexed by a patient who presents with unusual symptoms.

- Perhaps this patient has an illness that hasn't yet been identified. I admit that this is a long shot, but it's hardly beyond the realm of possibility. After all, textbooks of the early 1900s discussed only a few disorders, compared to the dozens of major ones (and hundreds of variants) we now recognize. Each of these relative newcomers came from somewhere, and there could still be other conditions out there waiting to be unmasked. Each edition of the DSM lists in an appendix research criteria for half a dozen or more new disorders for further study.

- Some emotional or behavioral characteristics may not lend themselves to being counted and lumped into categories. Perhaps dimensional criteria are needed instead. An example would be personality, for which various inventories have been devised that measure each individual (patient or otherwise) against a number of scales. Patterns of deviation on these scales constitute what we call *personality disorders*. The DSM-5 Task Force flirted with dimensional personality diagnoses—before finally adopting the same old system the DSM has used for years. So the debate rages on, with no clear end in sight. Brace yourself for further revisions. But you should be aware that other diagnostic systems may better describe some aspects of psychopathology.

- Finally, some patients simply don't require a diagnosis. These are the folks who seek help not because they are sick, but because they fear they might be. When it's because they have a problem of living, it can be as vital to diagnose *no* mental disorder as it is for others to receive the correct diagnosis of a mental disorder. In short, the ability to rule a diagnosis in or out is one of the most powerful tools the clinician can employ. Even diagnosis of a condition that is fairly far down on the safety hierarchy can provide the comfort of no longer having to fear the unknown. Of course, for the clinician, nothing beats the shared joy of informing a patient, "I don't find any indication of an actual mental illness. You're only experiencing the sort

Diagnostic Principle: **Consider the possibility that this patient should be given no mental diagnosis at all.**

of thing normal people encounter from time to time, and we can work on that together."

In the history that follows, look for evidence supporting the several reasons why I would choose to defer diagnosis.

Vickie

Though only 20 years old, Vickie complained of "lifelong depression." She had had two prior admissions to a psychiatric hospital for suicide attempts—the first one at age 10, when she overdosed on her mother's antidepressants. Now her husband's parents had just told her that they were moving to a retirement community, where they could no longer provide day care for her daughter.

Vickie had been under treatment for the past 3 years, during which she tried at least six antidepressant medications. Most recently, she took venlafaxine (300 mg per day); several weeks earlier, when she was instructed to double the dose of this medication, her moods began to "fly up and down" and she was rediagnosed as having bipolar disorder. She then discontinued the drug because of hives. At interview, she described her moods as being depressed for up to a week, followed by 2 or 3 days of "high," by which she appeared to mean "approximately normal"—she denied grandiosity, rapid thoughts, or hyperactivity that would be typical of mania. Even when she was depressed, she reported feeling better when events distracted her ("I can be goofy at work").

She complained that her sleep had been terrible for years: "I go all night without any sleep at all, even when I take a double dose of medicine." Because her sleep was so poor, she had trouble concentrating on her usual activities, and she worried that she would be unable to keep her two jobs, both of which she needed for the money. Her appetite was down, though she had not lost weight.

For a long time Vickie had heard voices in her head that she didn't recognize; sometimes they said mean things to her, though often it was "just conversation." At times, as if watching a TV program, she could view herself "talking to someone else." As a result of these experiences, she had been tried on several antipsychotic medications, most recently ziprasidone. However, she denied ever feeling that she was being harassed, spied upon, followed, or otherwise persecuted.

Vickie had felt worse in the past 6 months. This decline was precipitated by current problems, including many bills to pay, some of which were the results of her multiple medical problems. She was also

having disagreements with her husband, to whom she'd been married for 3 years. Some of this marital friction was due to her working two jobs; because their work schedules never seemed to match, they saw each other rarely. Moreover, Vickie despaired of finding another caregiver who would be as caring (and inexpensive) as her mother-in-law.

Besides her emotional difficulties, Vickie had been diagnosed as having fibromyalgia, hypothyroidism, and asthma. However, her physical symptoms weren't extensive enough for somatization disorder. When she was a child, her parents both drank heavily, and her father refused to seek help for an older sister who had mental retardation (as it was then called) and problems with acting-out behavior. There was no other history of mental illness in her immediate or extended family. When she was 8, however, her mother's favorite brother got into bed with her when intoxicated and fondled her under her nightdress—an episode she had been forever afraid to reveal to her parents.

Vickie looked somewhat older than her stated age. Slightly overweight, she sat quietly during the interview. She was clean and neat, dressed casually in slacks and a brightly colored blouse. Her forearms were covered with red marks that looked like healed-over scabs. She admitted that she picked at herself repeatedly "because I'm so nervous," and thin white scars on her wrists marked where she had often cut herself during her early teens. She spoke clearly and coherently, and her mood seemed to be about medium and appropriate to the content of her thought. She brightened when she talked about the city in California where she was brought up ("I'd love to move back there some day"). Although the thought of suicide had been "my constant companion," she denied that she was having those thoughts now.

Analysis

Vickie presented a history of depression that she described extravagantly—it had been "lifelong," she went "all night without any sleep at all"—and with too few criteria to make any solid diagnosis. Although she claimed to be depressed, neither her mood nor her affect was currently depressed (we must invoke the diagnostic principle about contradictory information). Her symptoms of mania seemed too weak and too brief for bipolar disorder (in other words, she didn't meet the "typical features" diagnostic principle). She claimed some psychotic symptoms (hallucinations), but displayed no other signs of schizophrenia, such as delusions or abnormalities of affect

or speech. The lesions on her forearms make us consult DSM-5 for the additional, new possibility of excoriation disorder. There was evidence that she and her husband had interpersonal problems; these, with a history of unpaid bills and of cutting and picking at herself, would make me wonder whether she might have a personality disorder. However, as we'll discuss in the next chapter, I much prefer not to invoke a personality diagnosis so soon and in the face of a possible major mental diagnosis. Vickie's multiple trials on antidepressants had been fruitless. Of course, this could simply mean that they weren't the right ones, but after several trials, you would begin to think how strongly Vickie's "depression" contravened the diagnostic principle about typical response to treatment. On top of all this, she came to the clinic in the midst of a personal crisis—a diagnostic principle that we've already noted should make us careful in evaluating her information. In short, I can't get close to a concrete diagnosis for Vickie; for now, I feel we would be far better off with the *undiagnosed* label.

Comment

The term *undiagnosed* is hardly a recent invention. The *Oxford English Dictionary* notes its first appearance in 1864, but it wasn't until 1917 that it was first used to mean "psychosis not diagnosed" by the American Medico-Psychological Association, the forerunner of today's American Psychiatric Association.