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Patient-Centred Interviewing Part I: Understanding Patients' Experiences

SUMMARY

Effective patient care requires attending as much to patients' personal experiences of illnesses as to their diseases. Diseases are ferreted out by using the conventional medical model, but understanding illnesses requires a different approach. A patientcentred method focuses on four principal dimensions of patients' experiences: their ideas about what is wrong with them; their feelings about their illnesses, especially their fears; the impact of their problems on functioning; and their expectations about what should be done. The key to this approach is attention to patients' cues related to these dimensions; the goal is to follow patients' leads, to understand patients' experiences from their own point of view. This method improves patient satisfaction, compliance and outcome, and is applicable to the everyday work of family physicians with "ordinary" patients. (Can Fam Physician 1989; 35:147–151.)

RÉSUMÉ

L'efficacité des soins nécessite qu'on s'occupe autant des expériences personnelles du vécu entourant la maladie que de la maladie elle-même. Le modèle médical traditionnel sait comment rechercher les maladies, mais leur compréhension exige une approche différente. La méthode centrée sur le patient met l'emphase sur quatre aspects importants des expériences vécues par les patients: leur perception de ce qui ne va pas; les sentiments qu'ils éprouvent face à leur maladie, en particulier leurs craintes; l'impact de ce problème sur leur fonctionnement; et leurs attentes face à ce qui devrait être fait. La clé de cette approche est l'attention portée aux indices donnés par le patient dans chacune de ces quatre dimensions; l'objectif est de suivre les indices donnés par le patient, et de tenter de comprendre le vécu du patient à partir de son point de vue à lui. Cette méthode améliore la satisfation du patient, son niveau d'observance, et le résultat ultime peut s'appliquer à la pratique quotidienne pour la majorité des soins de première ligne.

Key words: interviewing, physician-patient relationships

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POR SEVERAL YEARS our group at The University of Western Ontario has been developing a model of family practice.¹⁻⁴ This paper outlines some of the theoretical

background of this approach and provides practical advice for implementation.

Disease and Illness

The basis of this conceptual model is a distinction between two modes of ill health: disease and illness. Disease is an abstraction: the "thing" that is wrong with the body-as-machine; illness, on the other hand, is the patient's personal experience of sickness: the thoughts, feelings, and altered behaviour of someone who feels sick (Figure 1).

In the biomedical model, sickness is explained in terms of pathophysiol-

ogy: abnormal structure and function of tissues and organs. This model is a conceptual framework for understanding the biological dimensions of sickness by reducing sickness to disease. The focus is on the body, not the person. A particular disease is what everyone with that disease has in common, but the illness experiences of each person are unique. Disease and illness do not always coexist. Patients with undiagnosed asymptomatic disease are not ill; people who are grieving or worried may feel ill but have no disease. Patients and doctors who recognize this distinction and who realize how common it is to feel ill and have no disease, are less likely to search needlessly and fruitlessly for pathology. However, even when disease is present, it may not adequately explain the patient's suffering, since the amount of distress a patient experiences refers not only to the amount of tissue damage but to the personal meaning of the illness.

Several authors have described this same distinction between disease and illness from different perspectives. In analysing medical interviews, Mishler⁵ identifies two contrasting voices: the voice of medicine and the voice of the "lifeworld". The voice of medicine reflects a scientific, detached attitude. Typical questions of interest to the doctor include: "Where does it hurt? When did it start? How long does it last? What makes it better or worse?" The voice of the lifeworld, on the other hand, reflects a "common sense" view of the world which centres on individuals in a particular social context, the primary meaning of illness events, and how they may affect the achievement of personal goals. Typical questions to explore the lifeworld include: "What are you most concerned about? How does it disrupt your life? What do you think it is? How do you think I can help you?"

Mishler⁵ argues that typical interactions between doctors and patients are doctor-centred: they are dominated by a technocratic perspective. The physician's task is to make a diagnosis; thus, in the interview, the doctor selectively attends to the voice of medicine, often not even hearing patients' own attempts to make sense of

their suffering. What is needed, he maintains, is a different approach, in which doctors give priority to "patients' lifeworld contexts of meaning as the basis for understanding, diagnosing and treating their problems."

Eric Cassell⁶ has a corresponding message:

The story of an illness — the patient's history — has two protagonists: the body and the person. By careful questioning, it is possible to separate out the facts that speak of disturbed bodily functioning the pathophysiology that gives you the diagnosis. To do this the facts about the body's dysfunction must be separated from the meanings that the patient has attached to them. Skillful physicians have been doing this for ages. All too often, however, the personal meanings are then discarded. With them goes the doctor's opportunity to know who the patient is.

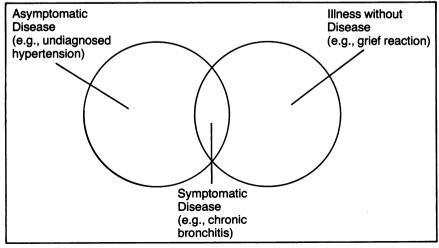
Kleinman and others have described an ethnomedical model based on their work in anthropology, 7-10 This model emphasizes the importance of eliciting patients' "explanatory models" of their illnesses and offers a series of questions to ask patients which they call a "cultural status exam". The physician might ask, for example: "How would you describe the problem that has brought you to me? Does anyone else that you know have these problems? What do you think is causing the problem? Why do you think this problem has happened to you and why now? What do you think will clear up this problem? Apart from me, who else do you think can help you get better?"8

Several studies in primary care demonstrate the inadequacy of the conventional medical model for explaining many of the problems pabring to their doctors. Blacklock¹¹ found that in 50% of 109 patients who presented to their family physicians with chest pain, the etiology was unproven after six months follow-up. In Jerritt's study¹² of 300 patients who complained of lethargy, fatigue or tiredness, no organic cause could be found in 62.3% of patients, who were evaluated in a general practice over a three-year period. Wasson and colleagues¹³ investigating 552 unselected male patients with abdominal pain who presented to an outpatient clinic, found no evidence for specific organic diagnosis in 79%.

Several authors^{14–16} have suggested that in only half of all patients presenting to a family doctor, can the physician find a disease to explain the patient's problem. Rarely is this because the disease is hidden; most often it is because the patient's feelings of ill health have their source in nonmedical factors: an unhappy marriage, job dissatisfaction, guilt or lack of purpose in life. In a study of housewives, who kept health diaries, Freer¹⁷ found that this group of women frequently described "symptoms" such as headaches, feeling tired and run down, or various aches and pains. Most of these complaints they handled on their own by resting or putting up with them. Many women reported that doing housework or going shopping made them feel better. For only one out of 40 complaints did they seek medical advice.

The number of times a person visits a doctor in a year varies tremendously, depending on the doctor, the social class and the country. It would be difficult to explain these differences on the basis of disease prevalence: social and cultural factors have a stronger influence on help-seeking behaviour than has symptom severity. This may be one of the reasons why hospital-trained physicians become frustrated by primary care. It does not take long for physicians in the front lines of general practice to realize that a strictly biomedical approach to illness is ineffective. This

Figure 1
Disease and Illness



highlights the importance of having additional approaches to understanding human sickness.

Diagnostic Issues: Understanding the Dimensions of Illness

The reasons patients present themselves to their family doctors when they do are often more important than the diagnosis. Frequently the diagnosis is obvious or is already known from previous contacts; often there is no biomedical label to explain the patient's problem. Thus, it is often more helpful to answer the question "Why now?" than the question "What's the diagnosis?" chronic illness, for example, a change in a social situation is a more common reason for presenting than a change in the disease or the symptoms.

Illness experience has many dimensions. Illness is often a painful crisis that will overwhelm the coping abilities of some patients and challenge others to increased personal growth. It is helpful to understand these reactions as part of a developmental process that has three stages: awareness, disorganization, and reorganization.¹⁸ The first stage, awareness, is characterized by ambivalence about knowing: on the one hand, wanting to know the truth and to understand the illness and on the other, not wanting to admit that anything could be wrong. At the same time patients are often struggling with conflicting wishes to remain independent and a longing to be taken care of. Eventually, if the symptoms do not go away, the fact of the illness hits home and their sense of being in control of their own lives is shattered.

This disrupts the universal defence—the magical belief that somehow we are immune from disease, injury and death...The patient who has struggled to forestall his awareness of serious illness and then has finally recognized the truth is one of the most fragile, defenseless, and exquisitely vulnerable people one can ever find. This is a time of terror and depression.¹⁸

At this stage patients typically regress to childhood defenses and react to their caretakers as parents rather than as equals. They often become

self-centred and demanding, and although they may be aware of this reaction and embarrassed by it, they cannot seem to stop it. They may withdraw from the external world and become preoccupied with each little change in their bodies. Their sense of time becomes constricted and the future seems uncertain; they may lose a sense of continuity of self. They can no longer trust their bodies, and they feel diminished and out of control. Their whole sense of their personal identities may be severely threatened. One reaction to this state of mind in some patients is rebellion: a desperate attempt to have at least some small measure of control over their lives even if it is self-destructive in the end.

The third stage is reorganization. In this stage patients call upon all of their inner strengths to find new meaning in the face of illness and, if possible, to transcend their plight. Their degree of mastery will be affected, of course, by the nature and severity of the illness. But in addition, the outcome is profoundly influenced by the patients' social supports, especially loving relationships within their families, and by the type of support their physician can provide.

These stages of illness are part of a normal human response to disaster and not another set of disease categories or psychopathology. But this description emphasizes how the humanity of the ill person is compromised and points to an added obligation of physicians to their wounded patients.

So great is the assault of illness upon our being that "it is almost as if our natures themselves were ill, as if the strands or parts of us were being forced apart and we verged on the loss of our own humanness. A phenomenon so great in its effects that it can threaten us with the loss of our fundamental humanness clearly requires more than technical competence from those who would "treat" illness. 19

Interviewing Methods

Patients often provide physicians with cues and prompts about the reason they are presenting. These may be verbal or non-verbal signals. The patient may look tearful, sigh deeply, or be short of breath. They may say directly, "I feel awful, Doctor. I

think this flu is going to kill me." Or, indirectly, they may present a variety of vague symptoms that are masking a more serious illness such as depression. As physicians sit down with patients and ask them, "What brings you in today?" they must ask themselves, "Why did the patient come now? What has precipitated this visit?"

We propose four dimensions of illness experience that physicians should explore: patients' ideas about what is wrong; their feelings, especially their fears, about their problems; their expectations of the doctor; and the effect of the illness on functioning. When physicians address these aspects of illness, patients are more likely to be satisfied with their doctors, more likely to comply with the treatment recommendations, and also more likely to recover.²⁰

What are the patient's *ideas* about their illness? What meaning do they attach to the illness experience? Many persons endure illness as an irreparable loss; others may view it as an opportunity to gain valuable insight into their life experience. Is the illness seen as a form of punishment or as an opportunity for dependency? Whatever the illness, knowing its meaning is paramount for understanding the patient.

What are the patients' feelings? Do they fear that the symptoms they present may be the precursor of a more serious problem such as cancer? Some patients may feel a sense of relief and view the illness as an opportunity for respite from demands or responsibilities. Patients often feel angry or guilty about being ill.

What are their *expectations* of the doctor? Does the presentation of a sore throat carry with it an expectation of penicillin? Do they want the doctor to do something or just listen?

What are the effects of the illness on function? Does it limit patients' daily activities? Does it impair their family relationships? Does it require a change in lifestyle?

The following examples of physician-patient dialogue contain specific questions that physicians might ask to elicit this information.

To the doctor's question, "What brings you in today?", a patient responds, "I've had these severe headaches for the last few weeks. I'm wondering if there is something that I

can do about them." To examine the patient's ideas about the headaches, the physician might ask (waiting after each question for the patient's reply): "What do you think is causing the headaches? Have you any ideas or theories about why you might be having them? Do you think there is any relationship between the headaches and current events in your life?"

The patient's feelings about the headaches can be elicited by questions such as: "What are your concerns about the headache? Do you think that something sinister is causing them? Is there something particularly worrisome for you about the headaches?"

To determine how the headaches may be impeding the patient's function, the physician might ask: "How are your headaches affecting your day-to-day living? Are they stopping you from participating in any activities? Is there any connection between the headaches and the way your life is going?"

Finally, to identify the patient's expectations of the physician at this visit, the doctor might enquire: "What do you think would help you to deal with these headaches? Is there some specific management that you want for your headaches? In what way may I help you? Have you a particular test in mind? What do you think would reassure you about these headaches?"

Certain illnesses or events in the lives of individuals may cause them embarrassment or emotional discomfort. As a result, patients may not always feel at ease with themselves or their physician and may cloak their primary concerns by presenting multiple symptoms. The doctor must, on occasion, respond to each of these symptoms to create an environment in which patients may feel more trusting and comfortable about exposing their concerns. Often, the physician will provide them with an avenue to express their feelings by commenting: "I sense that there is something troubling you or something more going on. Can I help you with that?"

The following case illustrates patient-centred interviewing in more detail:

Case History: Mr. R.

Mr. R. is a 58-year-old man who has been a patient in the practice for

10 years. Until eight months ago, when he had a massive myocardial infarction and required triple coronary artery bypass surgery, he had been a healthy man with few problems. He is married, with grown children and has returned to work as a plumber. He has come to the office for diet counselling about his elevated cholesterol.

The interaction begins with the doctor stating, "So, Mr. R., you're in about your diet. Looks like your cholesterol levels are dropping nicely." "Yes," responds Mr. R. "That's good news and I'm feeling pretty good about my weight. I'm down five more pounds and almost at my goal." The doctor proceeds to explore Mr. R.'s diet in some detail.

The interview then shifts to Mr. R.'s weight-loss program, and he states that he has been dutifully following his exercise regimen throughout the summer months and is walking up to four miles a day. The doctor asks, "Will you be able to continue your walking during the winter?"

"Oh yes," says Mr. R., "I don't mind walking in the winter. I quite enjoy it. I just have to be careful on those very cold days."

"Yes, you do need to be cautious during the severe weather," replies the doctor. Mr. R. looks away and appears sad. The doctor pauses and asks, "Is there something concerning you, Mr. R.?"

"Oh well...no," says Mr. R. quickly. "No, not really."

"Not really?" says the doctor.

"Well," replies Mr. R., "I was just thinking about the winter and...well...no, I guess I'll be able to skidoo if I just keep warm."

"Why are you concerned that you won't be able to do that, Mr. R.?", says the doctor.

"Well, I don't know. I'd just miss it if I couldn't participate."

"It sounds as if that activity is important to you," responds the doctor.

"Well, yes, it has been a very important family activity. We have some land and a little cabin up north of here, and it's really how we spend our winter weekends — the whole family together."

"It sounds as if not being able to participate in something that's been an important family activity would be very difficult for you," reflects the doctor.

"Oh, yes it would be. I just feel

that so many things have been taken away from me that I really would miss not being able to do that."

The doctor responds, "Mr. R., it seems that in the last several months, you have experienced a lot of changes and a lot of losses. I sense it has been very difficult for you."

"Yes, Doc, it has. It's been tough. I've gone from being a man who is really healthy and has no problems to having a bad heart attack and a big operation and being a real weight watcher. It has been a big change, and it has had its tough moments, but I'm alive and I guess that is what matters," answers Mr. R.

"It seems that you still have a lot of feelings surrounding your heart attack and the surgery and the changes that have occurred," comments the doctor. "Yes, I have," says Mr. R., "...I have."

"Would it be helpful at some time for us to talk about that more, to set aside some time just to look at that?" asks the doctor.

Mr. R. replies, "Yes it would. It's hard to talk about, but it would be helpful."

"Just briefly, are you encountering any problems with sleep or appetite Mr. R.?", inquires the doctor.

"No, none at all," replies Mr. R.

The doctor asks a few more questions exploring possible symptoms of depression. Finding none, he again offers to talk further with Mr. R. at their next visit. Mr. R. answers affirmatively.

In this example the patient's situation can be summarized by using the patient-centred model as a framework:

A) Disease

- 1. Coronary artery disease with previous MI
- 2. Status post CABG
- 3. Obesity
- 4. Hypercholesterolemia

B) Illness

1. Ideas:

"No longer a healthy man." Seems to see himself as disabled.

2. Feelings:

Sad about his losses.

Fears that he will not be able to participate in family activities. Perhaps

fears another MI or even death.

3. Expectations:

Co-operates with doctor re diet.

Agrees that "talking it out" might help.

4. Function:

Walks four miles a day.

Sexual function should be explored on the next visit.

The doctor already knew the patient's disorders before the interview began. He picked up on the patient's sadness and his hesitancy in exploring how he was experiencing his illness. At the same time, the doctor ruled out serious depression by asking a few diagnostic questions and offered the patient an opportunity to explore further his feelings about his illness.

By considering the patient's illness experience as a legitimate focus of enquiry and management, the physician has avoided two potential errors. First, if the conventional biomedical model had been overused, by seeking a disease to explain the patient's distress, the doctor might have labelled the patient depressed and given him unnecessary and potentially hazardous medication. On the other hand, he might have decided the patient was not depressed, that his distress was normal and therefore not an issue to be discussed further.

This case also illustrates that doctors are often very limited in what they can do about a patient's disease. Lowering this man's cholesterol is unlikely to have a great effect on his health after his disease has progressed so far. However, dealing with this patient's experience of illness may be helpful by alleviating fears, correcting misconceptions, encouraging him to discuss his discouragement, or simply by "being there" and caring what happens to him. At the very least this compassionate concern is a testimony to the fundamental worth and dignity of the patient: it might help prevent him from becoming truly depressed; it might even help him to live more fully.

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