LEARNING A FOUNDATION FOR COMMUNICATION IN MEDICAL SITUATIONS: AN ATTITUDINAL AND RELATIONAL APPROACH

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ABSTRACT

Learning a Foundation for Communication in Medical Situations: An Attitudinal And Relational Approach

Doctor of Medical Humanities Dissertation by

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A native of Canada with American citizenship, I am a lifelong student and a retired United Methodist Minister with an intense interest in Medical Humanities.

This paper attempts to lay a foundation for communication in medical situations by focusing on attitudes and relationships. The medical situations are those which I have experienced as a patient, those which I have witnessed as a visiting minister, or those about which I have learned as a student. The medical situations are experiences of illness, including uncertainty and hope, changes in the lived body and the lived world, pain and suffering, death and dying.

The model of inquiry is observation, questions to clarify what is observed or inferred, and an attempt to make judgments. The scholarship is drawn from the Humanities.

The paper resists studies suggesting that communication is merely a matter of learning skills. It contends that without a stress on attitudes, skills learning tends to produce artificial, scripted communication; attention to attitudes tends to produce authentic, relational communication.

The audience is healthcare professionals and patients. Anyone interested in healthcare, however, may benefit from the material.

At the heart of medical practice lie questions that ask about the way professionals actually interact with their patients and the attitudes displayed in these interactions. The professional, then, works to understand the patient by inviting him or her to participate in the healing process.

The conclusion is that competence at communication is an indication of the health of personality and the health of personality is a foundation for effective communication. As a result of this correlation, the person who is a healthy personality and an effective communicator is always in process of learning, growing, and maturing.

Future research is needed on the hypothesis that communication is more effective if it is spontaneous rather than formulaic.

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CHAPTER

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INTRODUCTION

Topic Overview

At six years of age, my mother entered me in an elocution contest. Through that inchoate experience, I uncovered a natural predisposition for communication, both verbal and written. In the years of my formative education, my communication capability was honed through numerous public speaking competitions. As a clergy with a penchant for homiletics, I had untold opportunities over thirty-five years to become fluent and effective not only in speaking and writing, but also in listening.

Now imagine my dismay in discovering, through my clinical practicum, that a surprising number of aspiring healthcare professionals appeared inarticulate and inattentive in their work. This finding was verified by some of their patients. Hence, my topic will address the need for learning a foundation for communication in medical situations.

The medical situations will include some in which I have participated as a patient, some that I have observed as a visiting minister, and some about which I have learned through reading medical books. The medical situations may be comprised of healthcare professionals, patients, and visitors; these persons will also be my potential audience.

My method of uncovering a foundation for communication in medical situations will be humanistic and phenomenological. Conceptual theories will be drawn from the area of Communications Studies; the theories chosen will be those I regard as most tenable.

It is true that an increasing volume of materials and continuing education programs in health communication have appeared in recent years. In my research, however, all the present efforts to improve communication facility use a *skills* approach. The uniqueness of my study is an *attitudinal* approach. I will contend that without a focus on attitudes, learning communication skills tends to produce artificial, scripted communication. Attention to attitudes tends to produce authentic, relational communication.

Communication Theory: Processes of Inquiry

Communication is intrinsic to human life.[1] Any study of human life must impinge upon communication. It is central to human experience.

Any attempt to explain an experience is a theory.[2] Theories guide understandings and actions. They identify patterns that yield knowledge of what to expect. They separate the important and the trivial.

My particular interest is *communication* theory.

A Model of Inquiry

Inquiry is the study of experience that leads to understanding.[3] It is an attempt to find out about something in a systematic way.[4]

All inquiry involves three stages.[5] One stage is questions: Questions of *definition* call for concepts as answers, seeking to clarify what is observed or inferred.[6] Questions of

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[1] Stephen W. Littlejohn, *Theories of Human Communication*. (Belmont, CA: Wadsworth/Thomson Learning, 2002), 2.

[2] Littlejohn, 2.

[3] Gerald R. Miller and Henry Nicholson, *Communication Inquiry*. (Reading, MA: Addison-Wesley, 1976), ix.

[4] Miller and Nicholson, ix.

[5] Michael B. Salwen and Don W. Stacks, "Integrating Theory and Research: Starting with Questions," in *An Integrated Approach to Communication Theory and Research*. Eds. M. B. Salwen and D. W. Stacks. (Mahwah, NJ: Erlbaum, 1996), 3.

[6] Salwen and Stacks, 6.

fact ask about relations in what is observed.[7] Questions of value probe ethical qualities of the observed.[8] Another stage is observations. Here the inquiry is for answers.[9] My method of observation is personal involvement (as patient or visiting minister) and scrutiny of narratives (as student). Constructing answers is yet another stage; it depends on my judgment.[10] As a result, this stage of inquiry is usually referred to as theory.[11]

These stages are not linear; each stage affects and is affected by the others[12] (e.g., observations are determined in part by theories and often stimulate new questions; theories are challenged by both observations and new questions).

A Method of Inquiry

My method of inquiry is humanistic. While I will occasionally include elements of the scientific method in my quest, I will assume that the central philosophical issue is humanistic.

Science is associated with objectivity; the Humanities are associated with subjectivity. Science attempts to standardize observation; the Humanities seek creative individuality.[13] I am more interested in individual cases than generalized theory.

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[7] Salwen and Stacks, 9.

[8] Salwen and Stacks, 12.

[9] Salwen and Stacks, 15.

[10] Salwen and Stacks, 15.

[11] Littlejohn, 9.

[12] Littlejohn, 9-10.

[13] James A. Diefenbach, *A Celebration of Subjective Though*t. (Carbondale, IL: Southern Illinois University Press, 1984), 1.

Science focuses on the discovered world; the Humanities stress the discovering person.[14] Indeed, humanists tend not to separate the knower from the known.[15] The humanist position is that who one is determines what one sees.[16] Because of its emphasis on subjective response, humanism is especially well-suited to issues and problems of art, experience, and values.[17]

Communication Theory: An Epistemological Foundation

A Basic Premise

Communication is the primary process by which human life is experienced; as such, communication constitutes reality.[18] How we communicate about our experience forms our experience. The many forms of our experience are made in many forms of communication.[19] Our meanings change from one person or group to another, from one situation to another, from one time to another, because communication is dynamic.[20] R. T. Craig describes the importance of this thought to communication: "Communication…is not a secondary phenomenon that can be explained by antecedent

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[14] Littlejohn, 10.

[15] Littlejohn, 10.

[16] Littlejohn, 11.

[17] Littlejohn, 11.

[18] Robert T. Craig. "Communication Theory as a Field," *Communication Theory 9*, (1999), 119-161.

[19] Craig, 123.

[20] Craig, 124.

psychological, sociological, cultural, or economic factors; rather communication itself is the primary, constitutive social process that explains all these factors."[21]

Craig suggests that we move this basic principle to another level.[22] Theories are forms of communication, so theories constitute or make an experience of communication.[23] In other words, theories communicate about communication!

A Practical Approach

Craig further writes that all communication theories are ultimately practical because every theory is a response to some aspect of a communication encountered in everyday life.[24] We need to point, therefore, to *what* and *how* theories address the social world in which we live.[25] Craig describes seven standpoints.[26] Although my emphasis will be on the phenomenological, I will allude to all of the traditions.

The Rhetorical Tradition

In this tradition, the communicator develops a strategy to move another or an audience. Logical and emotional appeals are typically featured in this theory which sees the communicator as governed by art.

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[21] Craig, 126.

[22] Craig, 128.

[23] Craig, 130.

[24] Craig, 148.

[25] Craig, 148.

[26] Craig, 149.

The Semiotic Tradition

This tradition treats communication as a bridge between the worlds of individuals and those in which signs elicit meanings. It speaks in a language that includes terms such as sign, symbol, meaning, and understanding. The power of the semiotic lies in its identification of subjectivity as a barrier to understanding and its engagement with the multiple meanings of signs.

The Phenomenological Tradition

This tradition concentrates on personal experience, including how individuals experience one another. Communication is seen as a sharing of personal experience through dialogue. Authentic human relationships are honored in this tradition, and it is particularly well-adapted theoretically to respond to issues and problems related to the erosion of relationships. In this tradition, discourse includes such notions as experience, self, others, dialogue, authenticity, supportiveness, helpfulness, and openness. It is appealing as a theoretical approach by pointing out the need for human contact, respect, acknowledgement of difference, and common ground. It resists discourses suggesting that communication is a mere skill, that words and things are separate, or that values are separate from facts.

The Cybernetic Tradition

Communication in this tradition is viewed primarily as information processing. It seems most plausible when issues or problems related to complex systems arise.

The Socio-Psychological Tradition

This tradition concentrates chiefly on those aspects of communication that include expression, interaction, and influence. This tradition accents behavior, effects, personalities, perception, cognition, attitudes, and interaction. It has been powerful in situations in which personality seems important, in which judgments are biased by beliefs and feelings, in which persons have an obvious influence over one another.

The Socio-Cultural Tradition

This genre sees communication as the glue of society. The issues and problems it addresses are conflict, alienation, and a failure to coordinate. Its language features struggles, rituals, guidelines, and culture.

The Critical Tradition

This convention sees communication as a social arrangement of power and oppression. It responds to issues and problems of ideology, power, and domination. Its discourse includes such terms as ideology, dialectic, oppression, consciousness raising, resistance, and freedom.

Communication Theory: An Attitudinal Foundation

Communication is not simply a skill. I argue that issues and problems of communication lie at the deeper level of attitude.

The Concept of Attitude

Today attitude is usually viewed as an element of the cognitive system that is held in memory and accessed when responding to various situations.[27] More specifically, attitude is a mental and emotional evaluation that characterizes a person and predisposes the person to react or respond in a positive or negative manner to a given person, object, or situation.[28] Tersely, attitude is a quality of mind.[29]

An attitude is a concept that cannot be observed directly but can be inferred from a person's actions.[30] This does not mean, however, that attitude is not real. This is the fallacy of behaviorism; behaviorism is the theory that all human activity can be reduced to behavior.[31] Thoughts and emotions lose their essential qualities when viewed simply as behaviors.[32] An attitude, I would contend, is no less real than physical behavior.[33]

The Characteristics of an Attitude

a) An attitude is learned; it is not innate.[34] In fact, even if it is discovered at some future time that an attitude has a genetic antecedent, the inherited predisposition is not equivalent to an attitude. This is because an attitude cannot develop without information

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[27] David R. Roskos-Ewoldsen, "Attitude Accessibility and Persuasion: Review and a Transactive Model," in *Communication Yearbook 20*, Ed. Brent Burleson. (Thousand Oaks, CA: Sage, 1997), 185-225.

[28] Roskos-Ewoldsen, 185-225.

[29] Roskos-Ewoldsen, 185-225.

[30] Richard M. Perloff, *The Dynamics of Persuasion: Communication and Attitudes in the 21st Century, 2nd ed*. (Mahwah, NJ: Lawrence Erlbaum, 2003), 38.

[31] Perloff, 38.

[32] Perloff, 38.

[33] Perloff, 38.

[34] Perloff, 39.

and evaluation. b) An attitude is an emotional evaluation.[35] Having an attitude means making a judgment about the value of someone or something. As such, emotion usually is an important part of an attitude. c) An attitude influences thought and action.[36] An attitude shapes perception and effects judgment. An attitude guides actions. d) An attitude may be strong in the sense that there is a consistency between thought and behavior.[37] On the other hand, an attitude may be weak and susceptible to influence and result in a person behaving against his or her thinking.

The conclusion of persuasion scholar Muzafer Sherif is very good: "When we talk about attitudes, we are talking about what a person has *learned* in the process of becoming a member of a family, a member of a group, and of a society that makes him (*sic*) react to his social world in a *consistent* and *characteristic* way, instead of a transitory and haphazard way. We are talking about the fact that he is no longer neutral in sizing up the world around him; he is *attracted* or *repelled, for* or *against*, *favorable* or *unfavorable*."[38]

The Components of an Attitude

I have found three different perspectives: a) an attitude has two components – beliefs (i.e., expectations) and evaluations (i.e., feelings about expectations).[39] Attitude, therefore, is a combination of what is believed or expected and how one feels about these

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[35] Perloff, 40.

[36] Perloff, 41.

[37] Perloff, 41.

[38] M. Sherif, Introduction, in C. W. Sherif and M. Sherif, Eds., *Attitude, Ego-Involvement, and Change*. (New York, NY: Wiley, 1967), 2.

[39] Perloff, 46-47.

expectations (i.e., evaluation). b) An attitude has two components – emotion and symbols.[40] In this case, "an attitude has emotional reactions, sweeping sentiments, and powerful prejudices"[41] which, rather than beliefs, lie at the core of evaluations. These evaluations, moreover, are packed with symbols. c) An attitude has one component -- ideology[42] (i.e., world view). Unlike those who respond primarily on the basis of symbols, ideologues respond from a set of principles or predispositions that have been acquired.[43]

I can see that expectations, emotions, symbols, and ideology are all part of the nature of an attitude.

The Consistency of an Attitude

a) A weak attitude is an ambivalent one.[44] Ambivalence occurs when a person feels both positively and negatively about a person, object, or situation.[45] Ambivalence is uncertainty or conflict between attitude components.[46] For example, ambivalence occurs when a person holds seemingly incompatible beliefs or when there is a dichotomy between beliefs and feelings. As a result, a person can have strong beliefs about two or more outcomes but evaluate the outcomes very differently.

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[40] Perloff, 47-48.

[41] Perloff, 47.

[42] Perloff, 48-50.

[43] Perloff, 50.

[44] Perloff, 51.

[45] Perloff, 51.

[46] Perloff, 51.

Attempts to restore harmony do not always succeed.[47] Cognitive inconsistency is inevitably a fact of life. It would seem to involve either a change of attitude or a change of value.

b) From Maurben Wang Erber and her associates, I learn about strong attitudes:

> First, strong attitudes are probably anchored by other beliefs and values, making them more resistant to change. If people were to change their basic religious beliefs, for example, many other attitudes and values linked to these beliefs would have to be changed as well. Second, people are likely to know more about issues they feel strongly about, making them resistant to counter arguments. Third, people are likely to associate with others who feel similarly on important issues, and these people help to maintain and support these attitudes. Fourth, strong attitudes are often more elaborated and accessible, making it more likely that they will be on the tip of the tongue when people are asked how they feel on different occasions. Fifth, people with strong attitudes are likely to attend to and seek out information relevant to the topic, arming them with still more arguments with which to resist attempts to change their minds.[48]

The Connection between Attitude and Behavior

Theoretically, an attitude is assumed to predispose a person to behave in a certain way.[49] I know, however, that an attitude does not always predict behavior.

There is research available whereby I can identify the factors that affect the attitude – behavior relationship. The key variables are: a) aspects of the situation (e.g., norms of appropriate behavior);[50] b) characteristics of the person (e.g., some look to the situation to

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[47] Perloff, 53-54.

[48] M. Wang Erber, S. D. Hodges, T. D. Wilson. "Attitude Strength, Attitude Stability, and the Effects of Analyzing Reasons," in R. E. Petty and J. A. Krosnick, Eds., *Attitude Strength: Antecedents and Consequences*. (Hillsdale, NJ: Lawrence Erlbaum Associates, 1995). 437-438.

[49] Perloff, 82.

[50] Perloff, 83.

know how to behave, others consult their inner beliefs and feelings);[51] c) qualities of the attitude (e.g., a strong attitude is more likely to forecast behavior).[52]

The Conditions of Attitude – Behavior Relations

It seems that there are conditions under which an attitude is more or less likely to influence behavior: a) deliberation and b) accessibility.[53]

There are four segments of the theory of deliberation.[54] There is a person's judgment that performing the behavior is either good or bad, a person's perception of the social pressure to perform or not perform the behavior, a person's intention to perform a particular behavior, and a person's estimate of how easy or difficult it will be to perform the behavior.

The central notion of accessibility is this: An attitude must come to mind spontaneously in a situation; otherwise, a person is susceptible to being swayed by other factors in the situation.[55]

The Consistency of Attitude – Behavior Relations

When some observe inconsistencies between attitude and behavior, they think the person is a "hypocrite." Others, however, view the situation differently. For example, critic Michael Dyson argues that "it is hypocritical to fail to achieve the moral standards

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[51] Perloff, 83.

[52] Perloff, 83.

[53] Perloff, 90-98.

[54] I. Ajzen and M. Fishbern. *Understanding Attitudes and Predicting Social Behavior.* (Englewood Cliffs, NJ: Prentice-Hall, 1980), 6.

[55] R. H. Fazio and D. R. Roskos-Ewoldsen, "Acting As We Feel: When and How Attitudes Guide Behavior," in S. Shavitt and T. C. Block, eds. *Persuasion: Psychological Insights and Perspectives*. (Boston, MA: Allyn and Bacon, 1994), 85.

that one believes are correct. Hypocrisy comes when leaders conjure moral standards that they refuse to apply to themselves and when they do not accept the same consequences they imagine for others who offend moral standards."[56]

In trying to decide if someone is a hypocrite, what criterion do I use? Is it enough for a person to display an inconsistency between attitude and behavior? Is this perhaps too harsh a criterion? Is anyone faultless in this regard? How many inconsistencies must be committed before the hypocrite label fits? Are some inconsistencies worse than others? Is it possible that the hypocrite term tells me more about the observer than the observed?

It is important, I believe, to understand that the use of the tag "hypocrite" reflects assumptions about what counts as an inconsistency, the weight given to the inconsistency, and the observer's own value judgments.[57]

The Change of Attitude

The most comprehensive theory of attitude change is the consistency theory.[58] In the end, a person is guided by the need for consistency and, therefore, inconsistency creates pressure to change.[59] The most significant inconsistencies are those involving cognitions about the self. Consequently, only when inconsistencies involve the self-concept is there

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[56] Dyson, M. E. "Moral Leaders Need Not Be Flawless." New York Times, January 22, 2001, A23, quoted in Perloff, *The Dynamics of Persuasion,* 99.

[57] Perloff, 100.

[58] Milton Rokeach. *Beliefs, Attitudes and Values*. (San Francisco, CA: Jossey-Bass, 1969), 164.

[59] Rokeach, 135.

lasting change.[60] The reason for this is that these contradictions increase self-dissatisfaction.[61]

Another theory of attitude change is the information-integration theory.[62] Here two variables are involved in attitude change. a) *Valence* refers to whether information supports a person's beliefs (i.e., positive valence) or refutes them (i.e., negative valence).[63] b) *Weight* is a function of credibility.[64] The information has more or less weight depending on whether a person thinks the information is true.[65] Attitude change occurs because new information changes a person's judgment about the weight or valence of other information.[66]

The Communication of Communication

How then do I communicate communication? The answer, I believe, depends on the concept of outcome. a) What is it that overcomes issues and problems of communication? b) What is it that can produce an outcome of genuinely caring communication? c) How can such communication be thought and learned?

Every book I have read on health communication takes a skills approach to the issues and problems of communication. The way to teach and learn communication, then, is focused on skills acquisition. The rationale of a skills approach is: a) Communication is a

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[60] Rokeach, 181.

[61] Rokeach, 181.

[62] Norman H. Anderson. "Integration Theory and Attitude Change," in *Psychological Review 78* (1971), 171-206.

[63] Littlejohn, 123.

[64] Littlejohn, 123-124.

[65] Littlejohn, 124.

[66] Littlejohn, 124.

skill; b) skills can be delineated and learned; c) practice is required to achieve acquisition of skills; and d) communication training requires formal instruction (e.g., videotaping, simulated patients, role playing).

I hold that the issues and problems of communication do not lie primarily with skills but at the deeper level of attitudes. Healthcare professionals may have all the necessary skills but not be using these skills because of blocks in their relationships with others. Many of these attitudinal problems relate to the institution of medicine itself, to previous experiences, and to the behavior of role models that are observed within the system. I believe that only when these blocks of attitude are confronted, understood, and changed, will the healthcare professionals be able to communicate effectively with others.

Communication Theory: A Relational Foundation

As defined by Littlejohn, "A relationship is a set of expectations that two persons have for their behavior based on the pattern of interaction between them."[67] This idea lies at the heart of interpersonal communication theory.

Although research on relationships has been done from a diversity of perspectives, relational communication theory is based on five assumptions.[68] a) Relationships are always connected to communication and cannot be separated from it. b) The relationship is defined by the communication between persons. c) Relationships are usually defined implicitly rather than explicitly. d) Relationships develop through a negotiation process between those involved. e) Relationships are dynamic.

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[67] Littlejohn, 234.

[68] Carol M. Werner and Leslie A. Baxter. "Temporal Qualities of Relationships: Organismic, Transactional, and Dialectical Views," in *Handbook of Interpersonal Communication*, eds. Mark L. Knapp and Gerald R. Miller. (Thousand Oaks, CA: Sage, 1994), 323-379.

The Nature of Relationships

Relationships are an important part of any system. Two persons communicating with each other, in addition to whatever else they may be doing, are also defining their relationship.[69] Persons in relationships are always creating, reinforcing, or changing a pattern of interaction.[70]

Relationships are generated through interaction[71] (e.g., if one person exerts control over the other, a dominant-submissive relationship will result. Communication between workers in an organization might result in a status relationship in which one person is more highly esteemed than the other). Implicit rules are numerous in any relationship.[72]

Paul Watzlawick, Janet Beavin, and Donald Jackson present five basic axioms of relational communication.[73]

a) *One cannot not communicate*. It emphasizes that I am always affecting others' perceptions whether I want to or not. This axiom also stresses that any perceivable behavior is potentially communicative. It does not mean that every behavior always communicates, but it does mean that when in the presence of another person, I am always communicating something about my relationship with the other person. Even if I do not want a relationship, I will find some way to signal this to the other person, which itself is information about the "non-communicating" relationship.[74]

b) Every conversation, no matter how brief, involves two messages – a *content message* and a *relationship message*. When two persons are interacting, each is relating information to the other and simultaneously each is commenting on the information. This synchronous relationship talk is often nonverbal.

Judee Burgoon and her colleagues have conducted a survey to find possible elements of relation communication and have isolated twelve aspects of relationships that seem to

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[69] Littlejohn, 235.

[70] Littlejohn, 235.

[71] Littlejohn, 235.

[72] Littlejohn, 235.

[73] Paul Watzlawick, Janet Beavin, and Don Jackson. *Pragmatics of Human Communication.* (New York, NY: Norton, 1967), 120-121.

[74] Janet Beavin Bavelis. "Behaving and Communicating a Reply to Motley," in *Western Journal of Speech Communication 54* (1990), 593-602.

be communicated: dominance, intimacy, affection, involvement, inclusion, trust, superficiality, emotional arousal, composure, similarity, formality, and task-social orientation.[75]

Burgoon and her associates further studied how non-verbal behaviors specifically affect these perceptions.[76] Four behaviors seem especially important. *Proximity* can be significant in communicating intimacy, attraction, trust, caring, dominance, persuasiveness, and aggressiveness. *Smiling* seems especially important in emotional arousal, composure, and formality, as well as intimacy and liking. *Touching* also communicates intimacy. *Eye contact* is like an exclamation mark in intensifying the effect of other non-verbal behaviors.

c) Interaction is always organized by communicators into meaningful patterns, called punctuation. Interaction sequences cannot be understood as a string of isolated elements. To make sense, they must be punctuated.

Certain behaviors are perceived to be a response to other behaviors. Behaviors, therefore, are grouped or punctuated into larger units which help define their meaning of the whole interaction. Of course, this grouping is mostly a matter of personal perception, and there is no guarantee that the communicators will punctuate their interaction in the same way.

d) Persons use both *digital codes* and *analogic codes*. Digital coding is arbitrary, for the sign and the referent, though related, have no intrinsic relation to each other. The most common digital code in communication is language. Sounds, words, phrases are digital signs to communicate meanings.

Analogical signs are not arbitrary but are part of the condition being signified (e.g., a facial expression of surprise is not only a sign of a feeling or condition but is actually part of the surprise itself. The meaning is intrinsic).

Although the digital and analogic codes are different from each other, they are used together in communication (e.g., a word, which is digital, can be spoken in various analogic ways such as loudly or softly).

While the codes blend within interaction, they serve different functions. So, as persons are communicating *content* digitally, they are commenting about their *relationships* analogically (e.g., suppose I am at the playground with my granddaughter. She falls and skins her knee. She screams. I say, “Granddad is here.” The content message is clear, but the relationship message depends on how the message is spoken. I might communicate my own fear, worry, anger, boredom, or dominance. I might also communicate some perceptions, such as “you are careless,” “you just want attention,” or “yes, I was paying attention”).

e) This axiom states that communicators may respond similarly to, or different from, each other. In the former case, the relationship is said to be *symmetrical*; in the latter case, the relationship is called *complementary* (e.g., co-workers are communicating

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[75] Judee K. Burgoon, David B. Buller, Jerold L. Hale, and Mark A. Deturck, “Relational Messages Associated with Nonverbal Behaviors,” in *Human Communication Research 10* (1984), 351-378.

[76] Judee K. Burgoon, et al., 351-378.

symmetrically when each wants the other to tell him or her what to do. A complementary relationship exists when the boss gives orders, and the employee is happy to comply).

The variable most often examined in regard to this axiom is *control*.[77] A complementary exchange occurs when one person asserts a *one-up* message (i.e., a rejection or counter-assertion) and the other person responds *one-down* (i.e., accepts the assertion). The person whose one-up message predominates is said to be *dominant*. A one-up message is domineering, but it is not dominant unless the other person accepts it. A symmetrical exchange involves both persons responding in the same way.

The Dialectics of Relationships

A dialectic is a tension between two or more contradictory elements of a system.[78] Looked at dialectically, relationships are defined and shaped by the ways in which persons manage contradictions.[79]

Leslie Baxter and Barbara Montgomery edit a work that explores dialectics in the area of relationships.[80] The study is organized around the four dimensions of dialectics outlined in their theory.[81]

a) Contradiction is tension among opposites that arise in the give and take of interaction in a relationship. At any moment, certain dominant or *centripetal* forces work in opposition to countervailing or *centrifugal* forces. Baxter and Montgomery see these forces as a "knot of contradiction."[82]

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[77] Frank E. Millar and L. Edna Rogers. "A Relational Approach to Interpersonal Communication," in *Explorations in Interpersonal Communication*, ed. G. R. Miller. (Beverly Hills. CA: Sage, 1976), 87-105.

[78] Littlejohn, 238.

[79] Littlejohn, 238.

[80] Barbara M. Montgomery and Leslie Baxter, eds., *Dialectical Approaches to Studying Personal Relationships.* (Mahwah, NJ: 1998), 257-273.

[81] Montgomery and Baxter, 1-15.

[82] Montgomery and Baxter, 160.

Each knot consists of a variety of related contradictions that can occur in relationships.[83] One knot is *integration-separation* (e.g., this can be a tension between meeting the demands of one person versus interacting with others. It could also include a struggle between individuality and mutuality). A second knot is *expression-non-expression.* This is the tension between whether to disclose information or keep it hidden. A third knot is *stability-change*, the tension between being predictable and being spontaneous.

b) The dynamic interplay among opposing forces leads to *change*. The struggle with contradictions within a relationship almost always involves attempts to manage the tension between stability and change.

Generally, the management of contradiction is the primary force leading to relationship development. Development naturally implies change and, over time, relationships do change in many ways.

c) *Praxis*, in relationship theory, means that some sort of relational pattern and definition arises in the give and take of interaction. This means that relationships are not worked out cognitively but are made through communication.

d) *Totality* means that contradictions cannot be separated from each other. Totality is the "knot" of contradictions.

e) Arthur Van Lear delineates four patterns that are used in dialectic management.[84] In the first pattern, a person *re-defines* one of the opposing elements so that it does not appear to contradict others (e.g., in the struggle over what to do, one person decides that what he or she really wants is for the other person to be happy). A second approach is *balancing* (i.e., behaving in a moderate way on both options). A third strategy is *contingent selection* (i.e., doing one thing in one situation and something else in another situation based on how passionately the person feels about it). *Cyclical alternation* is a fourth pattern; it involves a periodic trade-off between one action or another.

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[83] Leslie Baxter, "The Social Side of Personal Relationships: A Dialectical Perspective," in *Social Context and Relationships: Understanding Relationship Processes, Vol. 3,* ed. Steve Duck. (Newbury Park, CA: Sage, 1993), 139-169.

[84] C. Arthur Van Lear. "Dialectical Empiricism: Science and Relationship Metaphors," in *Dialectical Approaches to Studying Personal Relationships,* eds. Barbara Montgomery and Leslie Baxter. (Mahwah, NJ: Erlbaum, 1998), 109-136.

Research Methodology: The Situation

The Unique Situation

I am not interested in studying a medical situation primarily to understand other situations. I want to understand this particular situation. Having observed or read about a situation, I have a question, a puzzlement, concerning communication in the situation; I have a need for clarity; I have a feeling that I may get insight into the question by surveying this specific situation (i.e., instrumental study).[85]

Selection of Situations

1. I will select situations in which I have participated as a patient, observed as a visiting minister, or read about in my research as a student.

2. I will select situations that maximize what I and others can learn, situations that lead to greater understanding.
3. I will select situations that suit my purpose (e.g., I may want to learn about communication in a situation of suffering or dying).

4. I will select situations that are hospitable to further inquiry (e.g., situations for which there are others who are interested enough that they would be willing to comment).

5. I will make some early assessments to see whether a situation should be dropped if I remember another situation that I think provides a greater opportunity for learning or is more relevant to my area of interest.

6. While I may not be conscious or fully conscious of it, I will be predisposed to select situations that tend to address my own issues and problems in communication.

Interpretation of Situations

The most distinctive characteristic of my inquiry will be an emphasis on interpretation; this interpretation will focus on understanding others in the situation,

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[85] Robert Stake. *The Art of Case Study Research*. (Thousand Oaks, CA: Sage Publications, 1995), 3.

available data, and my own evaluative conclusions. My goal is to understand the situation as fully as possible.

The logical route to conclusions often is apparent neither to the reader nor the researcher. What I describe happening in the situation and what I conclude do not have to be closely tied together. For my conclusions, I will draw from understandings deep within me, understandings the deprivation of which is a hidden mix of personal experience, scholarship, and the conclusions of other researchers. The reader should understand that my conclusions are my theory.

I want to be cognizant of different views of the situation. In the words of researcher Robert Stake, “An ethic of caution is not contradictory to an ethic of interpretation.”[86]

My interpretation will be non-interventive and empathic. I will try to get all the information I want by discreet observation or examination of other accounts. I will try to understand how others see things. In the final analysis, I will likely emphasize my interpretation more than others but I will certainly try to present the different views of what is happening in the situation.

The Conceptual Structure

I am seeking a greater understanding of the medical situation. I want to appreciate the uniqueness and complexity, the embeddedness and interaction. I choose to focus on issues and problems as a conceptual structure. I choose issues *and* problems because issues are more abstract and problems are more concrete. I become familiar with the medical situation by observing how the participants struggle against constraints and cope

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[86] Stake, 12.

with problems. I have found that the nature of the people and the system become more transparent in their struggles and problems.

What is an issue? It is a problematic situation. Issues are intricately part of social and personal contexts. Issues draw me to observe the problems in the situation, the conflicts, the complexity of human concern. Issues help me expand on the moment, help me to see the situation in perspective, help me to recognize the problems in human communication and interaction. I believe that issue statements or issue questions provide a powerful conceptual structure for studying a medical situation.

Research Methodology: The Nature of Qualitative Research

Philosopher Wilhelm Dilthey argued that science was not moving in the direction of helping humans understand themselves: “Only from his (sic) action, his fixed utterances, his effects upon others, can man learn about himself; thus he learns to know himself only by the round-about way of understanding…We understand ourselves and others only when we transfer our own lived experience into every kind of expression of our own and other people’s lives.”[87]

Experiential Understanding

Whereas quantitative researchers press for explanation and control; qualitative researchers press for understanding complex inter-relationships.[88] The distinction is between inquiry for making explanations versus inquiry for promoting understanding. Philosopher Georg Henrik Von Wright emphasizes the epistemological difference as

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[87] H. Richman, ed. W. Dilthey, *Selected Writings*. (Cambridge, UK: Cambridge University Press, 1976), 163.

[88] Stake, 37.

between seeking to identify cause and effect relationships and those seeking understanding of human experience.[89]

Von Wright also speaks of empathy, the knowledge of the plight of another by experiencing it yourself.[90] The qualitative researcher tends to establish an empathetic understanding.[91]

Quantitative researchers treat uniqueness of contexts as "error," outside the system of explained science.[92] Qualitative researchers treat the uniqueness of contexts as important to understanding.[93]

To sharpen the search for explanation, quantitative researchers perceive what is happening in terms of descriptive variables, represent happenings with scales and measurements (i.e., numbers).[94] To sharpen the search for understanding, qualitative researchers perceive what is happening in episodes, represent happenings with their own direct interpretation and stories (i.e., narratives).[95]

Data Gathering

There is not a particular time when data gathering begins. It takes place during the course of my life and work. Consequently, a considerable portion of my data is impressionistic, picked up informally by my interest in a particular situation. Later some

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[89] Stake, 38.

[90] Von Wright, *G. Explanation and Understanding*. (London: Routledge and Kegan Paul, 1971), 6.

[91] Stake, 39.

[92] Stake, 39.

[93] Stake, 39.

[94] Stake, 40.

[95] Stake, 40.

of my impressions are refined or even replaced, but the pool of data will include my initial observations.

Qualitative research capitalizes on natural ways of getting acquainted with things.[96] The acquaintance is largely cerebral, only a few things get recorded. These notes, nevertheless, are often used in my sermons. As a researcher, I have the privilege to pay attention to what I consider worthy of attention and the obligation to make conclusions meaningful to those interested in health communication. In addition to the experience of ordinary looking and thinking, my experience is one of having learned to know what leads to significant understanding, to recognize good information, and consciously or unconsciously to test the veracity of communication by the look in people's eyes and the expression on their faces.[97] In short, my data gathering comes largely through reflective practice.

Quantitative data requires sorting in order for meanings to become clear. Qualitative data have meanings directly recognized by the observer[98] (e.g., physician and patient interviews need not be coded but can be captured in narrative accounts).

Analysis

There is no particular moment when analysis begins. Analysis is a matter of giving meaning to my impressions as well as to my compilations.[99] Analysis essentially means taking something apart. I take my observations apart (i.e., the parts that are important to me).

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[96] Stake, 49.

[97] Stake, 49.

[98] Stake, 50.

[99] Stake, 71.

Qualitative study capitalizes on ordinary ways of making sense.[100] I have considerable experience encountering medical situations. Sometimes, a situation does not fit anything with which I am familiar. Later, some of it is familiar (e.g., I encounter someone I have not seen for years. He is a stranger. Then I remember).

Occasionally, I encounter something new, something that has little relation to my previous experience. Mentally, I see the parts separately and relatedly. I attempt to see how this phenomena relates to other situations. I do this automatically, without conscious protocol. Yet, I do have certain protocols, apart from which I could not recognize the situation at all, that help me to draw systematically from previous knowledge and cut down on misperception. Still, there is much art and intuitive processing to the search for meaning.[101]

Research Methodology: The Researcher

Facilitator

In some situations, I am the teacher. The intention of the research is to inform, to increase competence and maturity.[102] As teacher, I offer opportunities for others to follow a human inclination to educate themselves. My selection of information and/or my experiences is intended to facilitate learning.

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[100] Stake, 72.

[101] Stake, 72.

[102] L. Crowbach, and Associates. *Toward Reform of Program Evaluation*. (San Francisco, CA: Jossey-Bass, 1980), 1.

As teacher, I am also an exemplar of a way to understand, a persuader of a way to follow.[103] I realize that my presentation of information will attract and repel. Few interpretations will have exactly the same meaning to different readers.

There is very little that I know about my prospective readers. I do not know how familiar my words, are, how similar my experiences are, how attractive my vignettes are. I have talked to some potential readers, but I recognize that even they may be only partially representative of my audience. There remains so much I do not know about my readers, whether healthcare professional, patient, or visitor.

Interpreter

As researcher, I recognize new meanings.[104] I recognize a problem of perplexity and study it hoping to connect it better with the known.[105] Finding new connections is a way to make the new interpretations comprehensible to others. Research is not just the domain of scientists; it is the domain of artists as well. Indeed, it belongs to all who study and interpret.

As researcher, I struggle to liberate the reader from simplistic and illusionary views.[106] I am an artist, the agent of new interpretation, new knowledge, but presumably also new illusion.

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[103] Stake, 92.

[104] Stake, 92.

[105] Stake, 97.

[106] Stake, 97.

Learner

Qualitative researchers tend to nourish the belief that knowledge is constructed rather than discovered.[107] The world we know is a particularly human construction. All of us construct our understanding from experience and from being told what the world is, not by discovering it untouched by experience. What we know of reality is only what we have experienced or have come to believe, not what we have verified outside our experience.

Relativist

Because they emphasize experiential and personal determination of knowledge, qualitative researchers are relativists.[108] This does not mean that they consider all views of equal value.[109] Equality is an absolutist view. Relativists believe that the value of interpretations vary, some are better than others.

The principle of relativity is strong in qualitative study.[110] The researcher contributes uniquely to the study; the reader derives unique meanings.[111]

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[107] Stake, 97.

[108] Stake, 99.

[109] Stake, 99.

[110] Stake, 102.

[111] Stake, 103

CHAPTER 1

AN EXPERIENCE OF MEDICINE: THE UNCERTAINTY

An Attitude of Faith

The human being lives in faith. Given this basic assumption, it seems that any attempt to describe faith necessitates an understanding of the human being. If faith is to be realized as a phenomenon that inheres in me, I must ask who I am.

Self-knowledge, however, seems to be so hard to acquire. On the one hand, it cannot be a matter of indifference or merely abstract knowledge. On the other hand, the very theories that I embrace about the human being itself are themselves powerful factors in shaping the reality that I am.

My theory of the human being is phenomenological and existential. As such, the human being lives in the polarity of finitude and freedom. I am finite. My body is limited, liable to injury, disease, and death. My mind, too, is limited. I have been put into existence and cannot escape my existence to get a detached, objective view of it. I can, therefore, never know my human existence with certainty. My why and wherefore are ultimately enigmas to me. Yet, I am also free and responsible to shape my self and my world in accordance with my ideals. Every day I just take the risk of deciding to understand my human existence in one way or another.

To some writers this polarity is a contradiction so that the human being is essentially an absurdity (e.g., Sarte). To other authors it is precisely the tension of the human being that gives it hope, for this seems to indicate that the human being is not finished but a dynamic reality struggling to be born.

That the viability of the human being can be so radically put in question brings me to a second polarity. A human life lived in tension can never be free from despair, that is, from a sense of the threat of absurdity. Yet such a life can be lived only on the basis of hope that it does or can make sense; in short, hope is a quest for wholeness and meaning.

Both despair and hope, moreover, seem to be embedded in the human being. Indeed, they may be understood as two ways of experiencing the same relation. Despair is the sense of alienation between my human being and the mysterious totality in which I have an insignificant place. Hope emerges from the sense of belonging to that inscrutable wholeness and having some affinity with it.

What I have portrayed is, I believe, an attitude of faith. I call this phenomenon an attitude of faith because it encompasses the entire human being—will, emotion, and belief. Much modern theory, in my view, stresses behavior and feeling. When the belief element is undervalued, however, faith is thoughtlessly turned into uncritical acceptance.

There is also a need to distinguish belief from knowledge in the sense that there is conclusive evidence for what I know. Many of my beliefs relate only to trivial matters and so a lack of certainty is no concern to me. Other beliefs, however, relate to significant issues (e.g., medical problems) and so I care deeply about them. Besides, I am painfully aware of the limitations of my human knowledge, for medical questions can neither be ignored nor answered with certainty. If only implicitly, I cannot help giving answers. My only option, therefore, is to take a risk. It cannot be denied, I think, that many of us, whether physicians or patients, have tried to avoid the risk by putting the answers to medical questions in the category of certitude. Some of us, since we cannot know assuredly the answers to medical questions, try to remain noncommittal. Others of us, convinced that medical issues are too important to be answered tentatively, attempt to turn belief into definite knowledge. Neither the too-cautious nor the too-sure can live with uncertainty.

With such an intense craving in the human being for indisputable answers, it is not surprising that medical questions have not escaped the seductive illusion that it is possible to know indubitably my diagnosis, treatment, and prognosis. Such unquestionable certainty about my medical concerns eliminates the anxiety and seriousness of faith; it removes all real decision; it demands, even coerces, acquiescence.

Uncertainty in Diagnosis

I was only in my mid-twenties when I noticed bulges on both legs. Given my history, my self-diagnosis was that the lumps were varicose veins.

My mother had huge distended veins. Since they did not hurt, my mother never considered surgery an option. Certainly, there was no evidence that her medical problem caused her a personal or social problem.

An aberration occurred, however, when I was thirty-two years old. I noticed a bulb, the size of a golf ball, in my crotch. This was not something I could wish away. Although denial was my way to cope with adverse circumstances in life, I knew that denial would be useless in this instance. A doctor was needed.

I contacted my family physician’s office and made an appointment. That the appointment was only days later was fortuitous. Psychologically, the rub in my groin really irritated me.

Following the customary wait of thirty minutes in the waiting room and twenty minutes in the practicing room, the doctor arrived. Having met him on prior visits, I already knew that I liked him. He was young and chipper. Best of all, he was someone I could trust.

"Rev. Lynn, you have a problem?"

"Yes, I do. I have a lump on my groin."

"Well, drop your pants and I will take a look at it."

He glanced at the anomaly. Without any indication of uncertainty, he intrepidly announced, "You have a hernia."

How can any healthcare professional make a diagnosis by peeking at the problem? Given my history, why not consider a varicose vein? In doubt, why not check a medical textbook or a medical journal? Would it be a frivolous suggestion to run some tests? Should I not have expected some questions? Do not other doctors use both closed and open questions to make a diagnosis? How can anyone solve a serious problem so superficially? Is life that simple?

Was there no fear of a mistake? Did he not consider what could happen to me if his dauntless diagnosis was wrong? Did he not consider what could happen to him if his fearless diagnosis was in err? Or, was there so much fear of making a mistake that he had to act sure of himself? Was apparent dogmatism born out of dubiousness? If there was no question about his diagnosis, there should have been. In any case, I wanted to know how he arrived at his decision.

My primary doctor's decision was to send me to a surgeon for medical attention to my "hernia." He selected one of the better known surgeons in the area. The surgeon's credentials were well-established; he was bright, competent, successful, and mature.

The day for the scheduled meeting with the surgeon arrived. My wait to see the surgeon was barely five minutes. Could this be a good or bad omen? Did the brief wait indicate that the surgeon was disciplined, efficient, and all-business? Would I have time to get to know something about him? Would I be given time for questions? Or, did it mean that he was cursory, treating people like an assembly line? Did everyone automatically get the knife? Was he money-driven?

When the surgeon arrived, he was pleasant but grave. Whatever the motivation, he appeared focused and committed. His observation, like that of my primary physician, elicited an immediate diagnosis. My bulge was a varicose vein! Did he not consider that the lump might be a hernia? After all, a varicose vein and a hernia have a resemblance.

I interrupted to tell him about the visit with my primary physician. The surgeon retorted that "no reputable doctor would call that bulge a hernia." My reaction was to think, "But that is what he said."

Surely the surgeon realized that he was on the horns of dilemma. On the one hand, if he believed me, he would impugn his colleague. Did he imply that his fellow physician was inept? Does that not violate professional medical ethics? On the other hand, if he did not believe me, how could I trust him as my surgeon? Maybe there was good reason that my primary physician knew instantly the surgeon to whom I should be sent. Maybe his quick decision had nothing to do with the skill of the surgeon. Or, maybe the surgeon judged me to be naïve. In that case, he could afford to take the risk of disbelieving me.

In the surgeon's office that day there was an uneasy silence. Could the surgeon have been thinking about his embarrassment over an egregious mistake by his colleague? Did it really annoy him enough to implicitly suggest that his fellow doctor was incompetent?

On the other hand, maybe the surgeon was trying to cover up for his colleague. If so, how did this smart surgeon really feel about defending an indefensible diagnosis? Did he reckon with the cost of vindicating his colleague, while insulting a prospective patient? I knew what I was thinking: How could this astute surgeon, on my initial visit, so facilely call my integrity into question? Was the loss of friendship with the primary physician of greater value to him than the loss of a patient?

Should I leave? Why let a surgeon, who did not trust me, cut me? Still, his qualifications were impeccable. His reputation as a surgeon was outstanding. I hated being in this position, especially since I believed I may have been the victim of a ruse to circumvent a ticklish situation. Yet, it was a situation into which the surgeon had thrust himself. Of course, I am not saying that the surgeon was culpable for the situation, and yet the decision he made in the situation was disingenuous. Should any healthcare professional place collegial satisfaction above patient satisfaction, position above altruism, pretense above principle, collusion above cordiality? If the surgeon could not corroborate his colleague's diagnosis, why risk the alienation of a patient by disclosing one's feelings about the hasty diagnosis?

I had to make a decision; I felt the pressure. The surgeon was capable and therefore I would opt to have him do the surgery on my varicose vein. Yet, the choice was not without reluctance. I would have preferred someone who was capable *and* considerate, exceptional *and* empathetic.

The varicose vein, the surgeon told me, was dangerously enlarged. It could easily burst. So surgery was scheduled immediately.

It was deeply disturbing, nevertheless, that the surgeon repeated the error of my primary physician by not second-guessing his diagnostic decision. If a medical record had been forwarded from my primary physician's office to the surgeon's, there was no reference to it. Indeed, no questions about my medical, social, or family history were asked except those relevant to the upcoming surgery. No tests were ordered. Overconfidence prevailed.

I believe diagnosis is not a crisis but a process; it is a process that depends on the clarity of communication between physician and patient. Do I place too much emphasis on kindness and compassion? Some physicians think that these attitudes really don't matter. For me, these attitudes are a critical aspect of communication. They matter. Communication involves not only *what* is communicated but *how* it is communicated. A physician is responsible for receiving and giving communication. Indeed, it is the failure to communicate effectively that intensifies uncertainty in the patient. I can only speculate what might have happened to me—an otherwise healthy thirty-two year-old man—if the surgeon would have determined the need for surgery based on my primary physician's diagnosis. From my viewpoint, both the primary care physician and the surgeon passed judgment too quickly. It was the impetuous judgment above all that increased the uncertainty in me. Both more and better communication were needed.

The analysis of my diagnosis by my primary physician is this: I knew that he did not know the diagnosis; I needed him to tell me that he did not know. He did not! My suspicion is that he feared telling me that he did not know because he thought that I expected him to know. What he did not know, however, was that I knew that a diagnosis requires guesswork; it is an uncertainty. The real problem, therefore, was not uncertainty but rather presuppositions about uncertainty that engendered a lack of communication. In turn, a lack of communication exacerbated uncertainty.

The analysis of my diagnosis by my surgeon is this: The surgeon, for whatever reason, believed he had a greater responsibility to my primary physician than to me, the patient. Consequently, he was determined to protect his colleague. Mistrust grew in this situation because I believed the surgeon was more interested in playing a game with me than in getting me better.

To the extent that my analysis is correct, I felt coerced into making a decision *between* the surgeon's functional skills and his indifferent attitude to creating mistrust in me. I will never know how much better the encounter with the surgeon might have been if he had admitted to a degree of skepticism about the situation. Mistrust developed when I thought the surgeon did not have my best interests uppermost in his mind.

Of course, both doctors might soon be out of business if they practiced medicine with the honesty and openness I want. Yet, do they really not want patients like me? By "patients like me," I mean patients that know mistrust poisons communication and dishonest communication strengthens uncertainty.

Physicians must live and work with uncertainty. They cannot tell me *what* they do not know. They can tell me, however, *that* they do not know with certainty. It is a chance, a risk. I believe, therefore, that only physicians with attitudes of humility and honesty, care and compassion, empathy and excellence, will tell me about diagnostic uncertainty. Uncertainty is precisely what makes it imperative that physician and patient work together to find healing.

Uncertainty in Treatment

It irked me that my surgeon was so hasty in determining that my varicose vein required surgery. Were there other options? Did he consider them? Am I too cynical in thinking that a surgeon would give priority to surgery?

There were three ways for my surgeon to take care of my medical problem – identify it, eliminate it, and predict its possible outcome. All three are interconnected. After making a diagnosis, treatment and prognosis follow necessarily. Yet my surgeon made a distinction among the three, giving explicit attention only to diagnosis and treatment. Once he made a diagnosis and determined a form of treatment, the clinical course was fixed. A favorable outcome was presumed, so an explicit prediction was superfluous.

This reductionism implies an evasion of the individual, the atypical, and the idiosyncratic. Medical illness is “natural” and “typical.” Clinical practice is based on the diagnostic and therapeutic rather than the individual and specific. Consequently, medical conditions have a life discrete from the life of the patient. Treatment shifts clinical care away from the patient.

In this section of my paper I want to focus particularly on the uncertainty in treatment. In my case, the medical problem was that of a bulging varicose vein. The issue of conflicting interests was paramount when I became aware of how much preference impacts treatment decisions. The treatment decision in my medical condition exposes two of these preferences.

Should my surgeon choose traditional surgery or laser surgery? Should my surgeon choose the option that is medically the better or the one that is more expensive, assuming there is that difference? Of course I do not know that reimbursement is a primary factor in making my treatment decision. I am suspicious, however, that the surgeon chooses the treatment with the higher surgical fee. I can only trust that option is also better for me as patient. Where there is uncertainty – where neither option has been determined to be clearly better than the other, I think my surgeon allows money to help him decide.

This treatment decision process may therefore have more to do with trust than any other attitude. Surgeons have various capabilities in inviting patients into the space of uncertainty in treatment. It is the space of an empathetic mind, a compassionate face, an amiable demeanor. It is the space that communicates trust. In turn, a patient will only enter that space through trust. Once inside the space with patients, surgeons may know more or less that what is offered can truly help their patients. Can surgeons with uncertain knowledge about treatment options be trusted to inform their patients? Can patients be trusted to learn what surgeons know and do not know?

Convoluting the issue, the data will change. Surgeons need to adjust their practice as it changes. If surgeons acknowledge the uncertainty and limits of the present data, there will be no need for a strong reaction to the new data. On the other hand, if medicine continues to hide uncertainty behind a façade of confidence, surgeons will continue to lose face when current practice is proven to be of lesser value than future data.

An orthopedic surgeon in Iowa, Dr. Richard C. Johnson, is quoted by Jones as telling his medical trainees: “You will err. Just make sure you err in the right direction.”[112] Jones explains that Dr. Johnson strives for precision in his clinical practice, but he considers it presumptuous to think that he can achieve perfect execution in surgery.[113] Surgeons

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[112] Dr. Richard C. Johnson quoted in Kevin B. Jones, *What Doctors Cannot Tell You: Clarity, Confidence, and Uncertainty in Medicine* (Salt Lake City, UT: Tallow Book Publishers, 2013), 131.

[113] Johnson quoted in Kevin B. Jones, *What Doctors Cannot Tell You,* 132.

manage some uncertainties in treatment by erring on the side of caution or by erring on the side of doing more…. They don't erase the uncertainty but choose which type of uncertainty they prefer to…experience."[114]

Dr. Johnson also complains about having "no good measure of co-morbidities"[115] (i.e., other medical problems that patients bring with them to surgery, such as low socioeconomic status, substance abuse, and a pessimistic attitude toward life, etc.). These elements affect patients' change in function that results from surgery. Surgeons know that these factors will lead them to err, but they know neither in which direction nor how far astray.[116]

Other uncertainties in treatment are due to questions surgeons have not yet studied or have studied superficially. This is not a time to be pretentious; this is a time to recognize limitations. Admitting ignorance, the surgeons need to consider a referral.

Guidelines are a means of managing uncertainty in treatment. I worry that criteria imposed from a hierarchical administrated medical system only discourages surgeons from realizing how uncertain the actual evidence is for many of their treatment decisions. "Guidelines made an accepted standard treatment the apparently cut-and-dried answer for a given clinical situation."[117]

I favor, instead, a caring honesty as the means of handling uncertainty in treatment decision making. Surgery subjects patients to invasive, uncomfortable treatment that is uncertain both in benefits and harms. Can surgeons and patients tolerate such honesty?

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[114] Johnson quoted in Kevin B. Jones, 132.

[115] Johnson quoted in Kevin B. Jones, 132.

[116] Johnson quoted in Kevin B. Jones, 132.

[117] Kevin B. Jones, *What Doctors Cannot Tell You: Clarity, Confidence, and Uncertainty in Medicine. (*Salt Lake City, UT: Tallow Book Publishers, 2013), 146.

Can they still master the gumption to undertake it, knowing the uncertainties involved? Renee Fox, currently the Professor of the Social Sciences at the University of Pennsylvania, speaks to this issue of uncertainty in her book, *Experiment Perilous*.[118] Physicians, she claims, have “a characteristic way of coming to terms: the guessing and wagering behavior in which they engage…The gambling lingo that some physicians use…is descriptive of the high degree of uncertainty, unpredictability, and risk taking that characterizes a considerable portion of their work.”[119] Guesswork it may be, but my guess is that it is their best guess.

I want my surgeon to guide me through the surgical decision. I do not need certainty even though I may want and expect certainty; what I do need is the truth. If only my surgeon can suppress his own insecurities and confidence more in honesty than bravado, he will provide me with a critical medical service.

Jones relates a short vignette about a colleague, Dr. Nathan Rich, who has a medical oncology practice in a small town in Utah.[120] Rich does not consider himself a great clinician. No medical publications list his name. He has no financial relationship with any drug company. If he discovers that the desired cancer treatment is not available through his practice, he refers the patient to a larger center. What is significant about this young oncologist, out of training only five years? First, medical uncertainty does not bother him. He employs a very simple method of honesty. Jones tells us that Rich’s demeanor or “bedside manner” disarms with quiet confidence. He knows that he does not know everything. He cannot control everything. These facts do not fluster him one bit. It almost

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[118] Renée C. Fox, *Experiment Perilous: Physicians and Patients Facing the Unknown* (New Brunswick, NJ: Transaction Publishers, 1998).

[119] Fox, *Experiment Perilous*, 82.

[120] Kevin B. Jones, 165-166.

seems that he lets his patients borrow his own courage, especially if they are choosing hospice care rather than aggressive treatments with little foreseeable benefit. He is a gifted communicator. He communicates not as a politician or salesman, slick at the job of cajoling patients into his way of thinking. Rich inspires patients to make decisions valiantly and sincerely, rather than from fear of the unknown.

Jones believes this ability to communicate may be every surgeon's primary job.[121] It is a job for which no surgeon receives training; more accurately, every surgeon receives training on how to communicate only with other surgeons.[122] This involves immersion in learning the lingo of medicine. After graduation, however, most surgeons spend their time communicating with patients who do not have a medical education.

What I am arguing is not an exclusive use of the vernacular simply because it is intelligible. Even though it requires translation, precision and accuracy have an important place in effective medical communication.

If surgeons use esoteric language without regard for communication, they are ostentatious. If surgeons use jargon but feel pity for the patients who lack the surgeon's knowledge, they are patronizing. If surgeons act concerned about communication but then ask their patients if they can comprehend, surgeons are insolent. If surgeons pride themselves on their ability to speak unequivocally and then ask patients to reiterate what they have said, they are belittling. Effectual communication only begins when it is more important to learn to know patients than to teach patients to understand what has been said.

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[121] Kevin B. Jones, 166.

[122] Kevin B. Jones, 167.

The need for surgeons is not to be consumed with their educational achievements, professional status, or social prestige, their condescension in instructing obtuse patients, their patronization in deciding what patients need to know, their haughtiness in inveigling the patients to see the wisdom of their choice, and their technical success so as to limit treatment interventions.

Are surgeons genuinely concerned about their patients? Do surgeons really care about their patients as human beings? Will surgeons, who understand their own biases, inform their patients about possibilities and uncertainties of treatment options?

Complicating the communication of uncertainties in treatment as well as compromising real and shared decision making is the concept of informed consent. Even if patients do not choose the surgeons' treatment plan after being taught the options, the patients must consent to it after being informed what it entails.

The history of informed consent dates from a court case, *Canterbury v. Spence*, in 1972.[123] The court ruled on the patients' right to decide on a given medical intervention after learning about its risks. Previous cases dealt only with the right to information, but this ruling specifically created the necessity for risk disclosure.

What fascinates me about this case is its absurdity in a medical context. The adolescent patient Canterbury, with the signature of his impoverished mother, sues surgeon Spence when, the day after back surgery, the teen accidentally falls out of bed, resulting in partial paralysis. What is the relation between the paralysis and the surgery? This is a freak anomaly that follows successful surgery. It is not the surgery but tumbling out of bed that causes the paralysis. If the court decides that Spence has an *ethical* duty to

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[123] Details of the California 1972 court case Canterbury v. Spence are recorded, along with extracts from the judicial beliefs, in the following book about the history of informed consent: R. Faden, T. Beauchamp, and N. King, *A History and Theory of Informed Consent* (New York, NY: Oxford University Press, 1986).

inform his patients so that they can choose surgery interventions wisely, I understand. Informed consent, however, arises from the *legal* duty to warn all patients of every outlandish event that may happen not just during but also after surgery. Consequently, surgical interventions require documentation that surgeons and patients have had an exhaustive discussion about treatment plans and the risks involved.

Informed consent notwithstanding, the best surgeons can only make educated guesses in communicating treatment plans and risks involved, hoping to err on the side of safety. The need is for surgeons who are more honest and less wheedling in conversations with patients about treatment. Will surgeons be courageous enough to admit that they do not know the "right" answer? Will surgeons fail to inform their patients about the treatment uncertainties that they unavoidably will face? Will surgeons reduce the entire human experience to surgeons' subtlety and patients' pain?

Uncertainty in Prognosis

With the imminent danger of my varicose vein exploding, the need for immediate medical attention was clear. It was only after the surgery, therefore, that I realized my surgeon had not given me a prognosis. Even though I had not specifically asked for a prediction, I did wonder why it would not be as routine for my surgeon to talk about prognosis as diagnosis and treatment. Since both diagnosis and treatment options in my situation were relatively easy, perhaps he regarded prognosis as less important. In any case, my surgeon omitted the prognosis.

Why do I regard my prognosis with a significance that even my surgeon did not attach to it? It is not that I think of my prognosis as *the* outcome. My actual prognosis can never be known definitively because as a specific patient my experience is unique and because my experience, in turn, modifies the course of recovery. Rather, prognosis is what my surgeon thinks the actual outcome will be; it is the anticipated outcome, including what the surgeon thinks my experience of the operation will be.

Prognosis may also be a paradox for my surgeon.[124] He may both fear and recoil from it but also may desire and wish to discuss it. Consequently, not to take the risk of uncertainty in prognosis leads to evasion; to take the risk leads to a feeling of control.[125]

As a seasoned surgeon, facing an operation on a varicose vein in an otherwise healthy thirty-two year old male, he must have had some sense of the likely outcome. He had a latent and implicit prognosis in mind that was informing his action; this inexplicit prognosis was a vital part of his diagnostic and therapeutic decision making, and would also be a critical part of his clinical care. Why, then, did he not communicate this information to me?

I decided on my postoperative visit to ask him that very question. Let me enumerate several reasons he gave me for his reluctance to prognosticate an outcome for my surgery. I discovered that my surgeon thought prognostic information would eclipse my interest in the diagnosis and treatment. He thought that a prognosis would become the principal determinant of my decision making. Could I not assume that both of us had already made a prognosis implicitly? I wondered whether this was the reason that so many parishioner-patients complained to me, as their minister, about the lack of prognostic information they and their families received from their own physicians.

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[124] Nicholas A. Christakas, *Death Foretold: Prophecy and Prognosis in Medical Care* (Chicago, IL: The University of Chicago Press, 1999), xvii.

[125] Christakis, *Death Foretold*, xvii.

Nicholas Christakas, an Associate Professor of Medicine and Sociology at the University of Chicago, expresses so well the physicians' dilemma regarding prognosis:

> Despite its usefulness, physicians regard prognosis with anxiety and disdain, and they avoid it if at all possible. If patients do insist on being told, physicians generally will forswear making a prediction or will be as vague as the situation permits. Several professional norms restrict whether and how prognoses are offered to patients. These norms insulate physicians from both the need for and the consequences of prognostication—decreasing the strain associated with offering prognoses and mitigating physicians' concern that prognostication is arrogant, hubristic, or harmful.[126]

Retrospectively, this is my scenario of what happened in that initial visit with my surgeon. He seemed to overcompensate for his prognostic reticence by acting sure about my diagnosis and treatment. In other words, he had more uncertainty associated with the outcome than with determining my medical need.[127] He knew that treatment could not change the diagnosis; treatment could change the prognosis.[128] He felt safe, therefore, in adopting an attitude of certainty in diagnosis and treatment that he did not in prognosis. This attitude of ambiguity in prognosis may have been compounded by the fact that my surgeon thought that I expected certainty in his prognosis.

The closeness and length of the relationship would also have affected my surgeon's need to give me prognostic information. Although a personal relationship may not have made the task of giving me a prognosis any easier, it would have meant thinking more in terms of empathy and individuality rather than knowledge and accuracy.

In my mind's eye, I now moved to the scene immediately before surgery. The surgeon offered me details of the treatment procedure but he did not give me a prognosis.

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[126] N. A. Christakas, *Death Foretold,* 84.

[127] N. A. Christakas and T. J. Iwashyna, "Attitude and Self-Reported Practice Regarding Prognostication in a National Sample of Internists," in *Archives of Internal Medicine 158* (1998): 2389-2395.

[128] Renée C. Fox, "Training for Uncertainty," in *Essays in Medical Sociology: Journeys into the Field, 2nd Ed.* (New Brunswick, NJ: Transaction Books, 1988), 19-50.

I thought of the many times I had been with parishioners just prior to surgery. When the surgeon arrived, in place of a prognosis that involved an educated guess, he or she would cite five minutes' worth of statistics (the so-called science of probabilistic reasoning). It appears that there is a general attitude in the medical profession that disdains probabilistic reasoning. For example, Christakas quotes one physician's thoughts about giving statistics to patients:

> Prognostication is inherently difficult at best, since it is based on statistics. It is great for large populations but very unreliable in individual patients (whose outcomes are always 0 or 100—a situation extraordinarily rare in statistics). When asked to make a prognosis, this uncertainty has to be related to the inquirer, and the prognosis made reluctantly.[129]

As a patient and as a minister, I theorized that another reason my surgeon may have found prognostication so difficult was because he feared it would reveal his professional limitations. In the words of Christakas himself, "Ironically, prognostication shows physicians the imperfect fit between what they do for the patient and what the outcome might be."[130]

On the other hand, let's hypothesize what might have happened if my surgeon had given me a prognosis. Prognosis is an exercise in uncertainty, but it is also a way of coping with uncertainty. Prognosis is an exercise in uncertainty because any knowledge of the future must be provisional.[131] It is also a way for surgeons to cope with uncertainty. Adumbrating an outcome can make the surgeons feel as if they have some understanding, and therefore, control, over the outcome of their patients' medical problems.[132]

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[129] Christakas and Iwashyna, 88.

[130] Christakas and Iwashyna, 88-89.

[131] Christakas and Iwashyna, 58.

[132] Christakas and Iwashyna, 59.

While a prognosis of the outcome of a clinical situation is desirable, Kevin Jones, who sees patients and does research at the Huntsman Cancer Institute and the University of Utah, succinctly informs us that:

> It remains a correlation, not a fact. As uncertain as a prognosis is, it provides our best identification of diagnosis. Prognosis may be no more than diagnosis in the same way that diagnosis may be no more than prognosis…the meaning of a diagnosis is primarily couched in the predicted natural course of (a medical problem) that some treatment would hope to alter."[133]

For example, an implicit prognosis regarding the progression of my varicose vein must have guided my surgeon's decision when to intervene. The prognosis, accordingly, became a diagnosis, needing certain therapy. In short, the prognosis *was* the diagnosis.

Uncertainty in prognosis is also connected to uncertainty in treatment. Every treatment decision depends on a prognosis. The best information my surgeon could have given me was to offer a possible outcome. This is one area of medical practice where surgeons, revealing their uncertainty, fallibility, and vulnerability to patients might help them, as surgeons, bond with their patients and humanize them in their patients' eyes. If most surgeons are like mine, however, they rarely explicitly voice uncertainty at all. In my case, I believe this was because prognosis was construed as being connected to the treatment that it was standardized and uncontested. In short, the prognosis was construed as being connected to the treatment and the treatment was known to have certain effects. On the basis of my limited experience, surgeons seldom attribute any uncertainty to inadequate training, experience, or knowledge. Uncertainty in prognosis, whether the prognosis is explicit or implicit, is perceived as being caused by the medical predicament rather than by the surgeons.

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[133] Kevin B. Jones, 190-191.

On the other hand, I suspect that some ends relatively well-known from the beginning will always be difficult to communicate at the beginning to some patients who will experience them in the end.[134] "Even certainties become uncertainties when we communicate them to another person."[135] It takes a long time, if ever, for some patients to become comfortable with uncertainty. No conversation can prepare some patients for what they may face. Even honesty cannot efface the experience of uncertainty.

How then does a surgeon help a patient get through the experience of uncertainty? The answer I would venture would be that honest communication is the best way to deal with uncertainty. Still, I must acknowledge that even empathetic honesty cannot erase the experience of uncertainty.

My best scenario is this: My surgeon and I make judgments of each other and make judgments together of the decisions that needed to be made.[136] My actual case was this: the surgeon judged, uncertain of how I would judge him in return but apparently unaware that facing uncertainty bravely with me would have been much easier than trying to disregard it. When uncertainty remained veiled in unspoken secrets, my surgeon suffered alone in awareness of it; I suffered alone in experiencing it.[137]

My surgeon had no power to change the uncertainty of my medical situation but I wanted him to tell me about it. I wanted him to do his best to help me understand what might lie ahead and that he would be with me in the unfolding of the future. I wanted him to trust me because I know something of the strength that is born in trusting another

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[134] Kevin B. Jones, 225.

[135] Kevin B. Jones, 225.

[136] Kevin B. Jones, 248.

[137] Kevin B. Jones, 248.

person. He clearly prepared himself to face the uncertainty of my medical situation, but why not do the same for me? Why not face the vagaries of the medical situation as I must do? How much more I could have trusted my surgeon if he had shared with me the uncertainty of his prognosis.

Uncertainty in Hope

I have focused in this paper on uncertainty as fundamental to a physician and patient communication about diagnosis, treatment, and prognosis. Now I want to show how uncertainty leads to the attitude of hope.

The reason for uncertainty in hope is that patients want to know the future. Will I get better? If I will get better, when will it happen? The future, however, cannot be empirically known in the present.

Imagine the problems in a physician claiming certainty of knowledge about the future. For example, a physician may claim certain knowledge of a patient's outcome, but the outcome is the reverse of what the physician "knows." More explicitly, the physician expresses certainty of recovery to a patient whom the physician feels certain will not recover.

It is for these reasons that uncertainty in hope is a source of relief. Particularly in medical situations where the future looks grim, it is comforting that uncertainty permits both physicians and patients to entertain the possibility of a favorable outcome.[138] Uncertainty is a prerequisite for hope; hope is a way of coping with uncertainty.

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[138] Christakas and Iwashyna, 60.

Earlier I spoke about the need for physicians to be honest with patients. Is it possible to maintain uncertainty in hope while meeting the demands of honesty? One physician, quoted by Christakas, expresses the problem as follows:

> Being definite or exact about survival time destroys hope. Without destroying hope, it is important to be realistic also. If hope is denied, there is no possibility for improvement; if realism is not faced, physicians do not help patients to prepare for the possibility of death or life with disability. If physicians are not honest, they are misleading.[139]

Physicians use several approaches to cope with these ambivalent demands. To speak about the future at all is viewed by some physicians as hubristic; physicians should not play God.[140] Some physicians do formulate a future outcome but do not communicate it to patients.[141] Many physicians do not *volunteer* information about the course of the illness. If there is communication at all, it is in response to patients' questions.[142] According to Christakas, most physicians, when asked by patients for a trajectory, avoid the extremes of optimism or pessimism. In coping with uncertainty in diagnosis, physicians have a pessimistic bias of preferring to judge a patient sick. The attitude is one of suspicion. The complementary bias in the uncertainty of prognosis is optimism. The attitude is one of hope.[143]

Despite the benefits of optimism, however, it may have adverse consequences. Physicians facing uncertainty may assume that patients are likely to live longer than they actually do and, acting on this assumption, may overuse or misuse certain treatments.

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[139] Christakas and Iwashyna, 91.

[140] Christakas and Iwashyna, 92-93.

[141] Christakas and Iwashyna, 94-95.

[142] Christakas and Iwashyna, 95.

[143] Christakas and Iwashyna, 176. I disagree with Christakas that optimism is hope. I will explain below.

Optimism may reinforce an already strong imperative in the medical field to treat patients at all costs, leading physicians to exaggerate the success of their treatments, to neglect side effects, and to favor aggressive treatments.[144]

Having looked at how uncertainty may lead to hope, I now want to focus on the attitude of hope itself. Physicians do not regard the denial of information, much less the ways they communicate information, as deceitful or self-interested; rather they justify them as humane ways of fostering hope in their patients.[145]

Physicians realize that there are different kinds of hope. Of course, there is the hope for a cure. Sensitive physicians, however, will sometimes deliberately refocus patients' hope toward other objectives, such as relief of symptoms, improvement in the quality of life, or resolution of interpersonal problems, or attention to personal/spiritual growth.[146]

Medical interactions, therefore, are predicted on hope, the belief that physicians will be able to help patients to relieve their suffering and to improve their condition. I believe that both physicians and patients hope, but they speak about this common desire in circumlocution, if at all; this relative absence of articulate discussion about the future suggests that both physicians and patients are apprehensive that their wishes for a cure may not be met.[147]

The belief that transparent communication is vulgar and offensive is also prevalent in physicians. Hope is indiscreetly used to permit a confusion between duplicity and tact.

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[144] Howard M. Spiro, Mary G. McCrea Curnen, Lee Palmer Wandel, eds., *Facing Death* (New Haven, CT: Yale University Press, 1996), 48. An example of how optimism may lead to detrimental consequences is the problem of timing the referral of terminally ill patients for hospice care.

[145] Christakas and Iwashyna, 130.

[146] Christakas and Iwashyna, 131.

[147] Christakas and Iwashyna, 133.

Physicians use hope in prognosis, not to be affable, but to enunciate realities which are too obscure, in their thinking, for straightforward talk.[148] So hope is not only an active way to disclose reality, but a passive way to disguise it.[149]

For the most part, I believe that for physicians to claim that they give hope or at least do not take away hope, they mean that they have an attitude of optimism; indeed, hope is optimism. For me, hope is not optimism, the attitude that things *will* turn out for the best; hope is not positive thinking; it is not hearing a rosy forecast from a physician.

Hope means that there is no dead end in life; there is always a way into the future. Within that cosmic context, hope is a *possibility* that things will turn out for the best; it is a possibility that both physicians and patients envision, expect, and want.

Hope is vulnerable; it acknowledges that there may be obstructions in the future. Hope is not deluded. Hope is rooted in reality. Hope offers the chance for a good outcome. Hope gives patients courage to overcome the hurdles and move them forward to a place where healing may occur.

In the context of restrictions, I find true hope and false hope. False hope does not recognize the possibility of loss and disappointment. False hope can lead to fanciful choices and zealous decision making. True hope takes into account the menace to well-being. True hope tempers fear so that patients can deliberate and choose without panic. Unbridled fear overwhelms hope, blocking the reception of information that may be given. Hope recognizes the dangers and faces them. Jerome Groopman, who holds the Chair of Medicine at Harvard Medical School, speaks compellingly about the issue:

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[148] Jerome Groopman, *The Anatomy of Hope: How People Prevail in the Face of Illness* (New York, NY: Random House Publishers, 2004), 49.

[149] Christakas and Iwashyna, 133.

"This is the great paradox of true hope: because nothing is absolutely determined, there is not only reason to fear but also reason to hope."[150]

Hope does not cling to the illusion that there *will* be a "miracle," a favorable outcome that is unexpected and unaccountable; hope does not frantically believe that there will be a cure from the laboratory in the nick of time.[151] This is not to deny that the uncertainty of science brings hope. It brings the hope of someday understanding the workings of nature that produce so-called miracles; it also brings the hope that new therapies can make the incurable curable.[152] Hope is not, however, the desire that death *will* be escaped.[153]

On the other hand, hope prevails in spite of a pessimistic prognosis, the attitude that things *will* turn out for the worst. Hope is a calm acceptance of the *possibility* that things will be better, but that they may be worse.

Why then would physicians act like judges over desperate patients and hand down a fixed sentence of death or a fixed forecast of full recovery? To close off options *a priori* is premature and mistaken.

Hope is present only if I have real options. Hope can flourish only when I can do something to produce a future different from the present. To have hope is for me to have some control over my medical situation. Without hope, my vision is blurred because I think I am unable to exert any power over my medical situation.

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[150] Groopman, 210.

[151] Groopman, 144.

[152] Groopman, 211.

[153] Groopman, 143.

It seems likely to me that in certain medical situations of recovery, the attitude of the physicians and patients make a contribution. Groopman is convinced: “Patients who are hopeful, trusting in God, nature, and/or their physician, have a more rapid return to health and a higher rate of survival.”[154] I feel confident there is a correlation, but not causation, between hope and recovery.

Clinical medicine is a puzzle.[155] My physician searches for pieces; they may be found in my past medical history and present social history. My family background is also important, since there is a growing awareness of genetic predispositions to disease.[156] Then the physical examinations can point to *an* answer. Nothing in the diagnostic method, however, exhibits evidence for this enigma: Why do I, as a patient, have or not have hope?

As a patient, I seek models of hope and despair, and my sense of hope or despair is generated by direct contact with a physician or patient who has either prevailed through hope or floundered through despair. More importantly, to help me, as a patient, find hope, it is not only necessary for my physician to know my vulnerabilities, it is equally important for my physician to disclose his vulnerabilities to me.

Hope is faith in the future; more specifically, it is a faith in doubt that fosters hope in the future. Doubt presupposes faith; it is incipient faith. Doubt has a moral quality about it; it is good because to doubt is to care about the truth. Not to doubt is to be faithless. The untrustworthy physicians and patients do not doubt; the trustworthy ones care enough about the truth to doubt. Pace Rousseau: I care, therefore I doubt.

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[154] Groopman, 185.

[155] Spiro, Curnen, and Wandel, eds. *Facing Death*, 39-40.

[156] Groopman, 119.

In the Christian tradition, the gospel lection for the Sunday after Easter is the story of Thomas.[157] Thomas is a disciple who, through faith in doubt, comes to experience healing of relationship by seeing and touching the scars of the Great Physician. Today, through faith in doubt, both physicians and patients can still experience healing of relationship when they see and touch each other's wounds.

In a medical situation of diagnostic, prognostic, and treatment decisions, both my surgeon and I may become aware of the need for attitudes of uncertainty in hope. Uncertainty in hope embraces trust for the present and faith in the future. These attitudes shape our relationship as we see and touch each other's wounds. Truthful, compassionate, and fitting communication issues from that kind of relationship.

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[157] John 20:19-31.

CHAPTER 2

AN EXPERIENCE OF ILLNESS: THE LIVED BODY

Body Talk

The Body Concept

Do I have a body or am I a body? I know that there is a very tiny part of the world that is my territory, my space; this part of the world is my body. In fact, it is only through existing in a body that I can be in the world. Through my body I perceive others that constitute the world. Through my body I am able to communicate and interact with them and they are able to communicate and interact with me.

I can see my body, or at least part of it, but my body is not just a thing in the world; my body is part of *me*. As a result, I do not say "my body feels sick," but "I feel sick." Maurice Merleau-Ponty, a phenomenologist, remarks: "When my right hand touches my left, I am aware of it as a 'physical thing.' But at the same moment…my left hand is starting to perceive my right."[158] This reciprocity illustrates that my body is not just a thing which "I" animate or control. On the other hand, "I" am not just a body understood as a physical organism.

It is because my body is at once part of me and yet I am more than my body that I asked the question: Do I *have* a body or *am* I a body? I believe I have a double relation to my body – I both *have* a body and *am* a body. I can say, "I *have* a body," because I can transcend my body; I can within limits objectify it; I can make it my instrument. It is possible to become alienated from my body; but this alienated body may in turn react

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[158] Maurice Merleau-Ponty, *Signs*, trans. Richard C. McLeary. (Evanston, IL: Northwestern University Press, 1964), 166.

against me to destroy me (e.g., gluttony, drug addiction, alcoholism). Yet I must also say, "I *am* my body," because I am nothing apart from it; when my body experiences pain or illness, it is I who experience them.

As a body in the world, I live in constant communication and interaction with other bodies. To put the matter another way, to be a human being is impossible apart from a world. I am not, however, *a* human being in the world, but a human being *with others*. I believe that human existence is fundamentally communal; without others, I cannot exist.

Is this claim tenable? After all, it seems to contradict so much of what our society believes about the individual. For us, the basic characteristic of the human being is the uniqueness of the individual. "Mine" is a term we use to express the awareness that my being is unique and distinct from the being of everyone else.

In addition, there are contentions that may be made that seem to confirm the stress on the solitary character of the human being. Above I averred that it is only through existing in a body that I can be in the world. Does this not mean, however, that I look on that world from a unique point of view and that my body is also the center on which the world reflects back, so that I am a unique microcosm, a world in miniature? I also asserted that to *have* a body is to *be* a body. Does this not mean that one has an intimate and immediate relation to the body that I *am*, perceiving it from "inside" whereas I am "outside" of every other body and can perceive other bodies only by external observation? Is there not then an evitable privacy from which no human being can escape? Is it not reasonable, therefore, to allege that privacy of being – the character of "mine" – is more representative of the human being than a communal character? Is not relating to others something that is subsequent to the individual?

Perhaps it is impossible to say much about the character of the human being without noticing a polarity between the individual and the community. If I reject individualism, I must equally refuse a collectivism that gathers human beings into a monolithic uniformity. Collectivism misses the meaning of community; the meaning of community is discovered in the concreteness of being with others. With others is not attached to an individual; both the individual and the others find themselves in a whole wherein they are already related.

That community is the fundamental constitution of the human being may be shown in various ways. My chief defense uses the thought of Martin Buber. "There is no (human) existent taken in itself, but only the 'I' of the primary word 'I-thou.'"[159] Buber's sentence could be expressed: There is no (human) existent taken in itself, but only the existent who constitutes being with others. In fact, is not the idea of a solitary human being a delusion? My understanding of Buber is this: The "I" and the "thou" are both part of the primary "I-thou." To speak, therefore, of "I" is already implicitly to recognize the "thou" from which the "I" distinguishes itself. Prior to either "I" or "thou," taken separately, is "I-thou." "I-thou" is the communal reality which makes the individual reality possible.

Could I not use the same justification for the claim that others are *a priori* – conditions of human existence rather than extras that get added to the individual – by considering language? An essential function of language is communication, a meaningful exchange between persons. There is no such thing as a private language, but there could be no human existence apart from language. I do not believe that thinking is possible apart from language; but language is also what externalizes thought and makes it accessible to the other human being.

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[159] Martin Buber, *I and Thou*, trans. R. G. Smith, 2nd Ed. (New York, NY: Scribner's Sons, 1958), 4.

The individual is not the reality from which community is established. Try to isolate the individual and we find he or she escapes us. The individual is intelligible only within the social.

The relation between human beings I shall call, following Martin Heidegger, *solicitude*.[160] Solicitude is an attitude that means showing care and consideration for another person's well-being (the German word is *fűsorge).*[161]

Although I have taken the term "solicitude" from Heidegger, I prefer the analysis of this attitude from Buber. There are two primary ways in which I can relate to others: "I-thou" can only be spoken with my whole being. "I-it" can never be spoken with the whole being.[162]

What is the language that is spoken or not spoken with the whole being? I relate totally to others by an attitude of becoming open to them.[163] Others are not just eternally "there" for me; nor are others an end to some satisfaction beyond themselves.[164] "I-it" language expresses an attitude that turns others into things, instruments;[165] those with whom I am concerned remain external to me. An instance of this is whenever patients are treated as less than personal.

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[160] Martin Heidegger, *Being and Time,* trans. John Macquarie and E. S. Robinson. (New York, NY: Harper and Row, 1962) 158-159.

[161] Heidegger, 159.

[162] Buber, 4.

[163] Buber, 4.

[164] Buber, 4.

[165] Buber, 4.

In developing the nature of interpersonal relationship, I will use interpretations from Buber, Heidegger, and Gabriel Marcel[166]. Buber's word is "dialogue."[167] To say that the interpersonal relationship is dialogical is to insist on its *mutual* character.[168] A genuine relation cannot be one-sided, dominating, or possessive; it must consist in openness, a willingness to listen and receive, as well as to speak and give.[169] Another germane aspect of Buber's thought on the nature of interpersonal relationship is *relation* and *distance.*[170] True relationship preserves others in their uniqueness; I respect others and do not try to change them in accordance with my idea of what they ought to be; I leave them space to be themselves.[171] The dialogical relation does not permit one side to be merged into the other; it is a dialectic of relation and distance. Within an authentic interpersonal relationship, I am confirmed by the other[172] (i.e., I really become myself through my relation to the other).

Heidegger recognizes two possibilities in which solicitude reveals itself, both of which address my relation to others. In one possibility, I "leap in" for the other.[173] This kind of solicitude takes over for the other; it is to take away that with which the other is

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[166] Gabriel Marcel, *Homo Viator: An Introduction to a Metaphysic of Hope*, trans. E. Craufurd. (New York, NY: Harper and Brothers, 1951), 15.

[167] Buber, 5.

[168] Buber, 5.

[169] Buber, 5.

[170] Buber, 6.

[171] Buber, 6.

[172] Buber, 6.

[173] Heidegger, 212.

to care for him or herself; it is the dominating mode of solicitude.[174] The contrasting possibility of solicitude is to "leap ahead" of the other, "not to take away the other's care but to give it back to him or her authentically as such for the first time.[175] In this approach to solicitude, I help to open up for others their own possibilities. In Heidegger's words, "It helps the other to become transparent to himself (sic) in his care, and to become free for it."[176]

An expression that is characteristic of Marcel's understanding of the relation to the other is "availability."[177] It means to be willing to put myself at the disposal of others.[178] When I am unavailable, I am preoccupied with myself and so I am closed against the other.[179] My being is something I *have*, and my unavailability arises from my anxiety to maintain myself.[180] The way of availability lies through being open and able to expend myself, and to do this generously and even extravagantly.[181] The way of availability is the way to genuine human being.[182]

In virtue of this kind of availability I am *present* to others.[183] "Presence," writes Marcel, "denotes something rather different and more comprehensive than the fact of just

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[174] Heidegger, 212.

[175] Heidegger, 212.

[176] Heidegger, 212.

[177] Marcel, 15.

[178] Marcel, 15.

[179] Marcel, 15.

[180] Marcel, 15.

[181] Marcel, 15

[182] Marcel, 16.

[183] Marcel, 16.

being there; presence depends on a person's coming out of himself or transcending himself toward the other."[184]

Body Blues

What Is Happening to Me?

"Mom's front door on her house wouldn't shut," explained my friend Dick. "I was planing for about half an hour when I experienced pains in my right shoulder and arm." Eventually the pains subsided.

One week later Dick was working in the garage. He reached for a board and felt stabbing chest pains. Dick went to the house and told his wife Jane, who took Dick to his in-laws. When Bayer aspirins brought no relief, Jane suggested to Dick that he was having a heart attack. Although he initially denied it, he agreed to go to the local hospital when the pains became even more intense.

When the body broke down, eventually Dick was forced to ask, in fear and frustration, "What is happening to *me*?" That is the beginning of the experience of illness.

Once at the hospital, the attending physician suggested an intravenous load of blood thinner. The order, however, could not be filled until Dick came up with $5,000. Since Dick and Jane did not have the funds, Jane called a relative for the money. After being stabilized, Dick was transferred to the VA hospital in Indianapolis.

The medical profession answers my question, "What is happening to me?" by naming a diagnosis and treatment. The answer is limited inasmuch as the illness or disease is assumed as having to do only with the *body* but not with *me*. What is happening to me when my body breaks down, however, is not just happening to my body but also to my

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[184] Marcel, 16.

life lived in and through my body. To the extent that this is the case, the expression of illness transcends the limits of the medical profession's understanding.

My point is not that the medical professionals are incompetent; the medical professionals do exactly what they are trained to do. The problem is that the healthcare professionals do not express to the patient that they recognize expressions of fear and frustration. They talk only about the *body* that has broken down, not about the *life* that has broken down.

Moreover, healthcare staff limitations dictate the reciprocal role the patients are expected to play in responding to the physicians and nurses. The problem of patients is naiveté about healthcare and illness. Consequently, patients accept the limitations and may, therefore, not recognize the experience of illness in terms of what it does to their thinking about themselves and to changing their lives. In doing so, ill persons lose their lives.

Fortunately, Dick was able to surmount the failing of the healthcare workers. At the VA hospital, Dick ruminated on how the heart attack had and would change his life. In Dick's pre-illness days he wanted a good life. He thought of his expectations as modest: to be healthy, happy, and safe. After his heart disease, Dick's expectations seemed unrealistic; they had to change. Now all Dick really wanted was to live.

How then should I think about illness? In Merleau-Ponty's view of the body, it is both object and subject. He speaks of the biological body and the lived body.[185] Normally in

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[185] Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. S. Smith. (New York, NY: Routledge and Kegan Paul Company, 1962), 77-83.

the everyday experience of a healthy body, the two bodies are aligned.[186] The healthy body is transparent, taken for granted.[187]

It is only when something goes wrong with the body that I begin to notice it.[188] My attention is drawn to the malfunctioning body part and it becomes the focus of my attention. The harmony between the biological body and the lived body is disrupted and the difference between the two becomes evident.[189]

"Illness," I think, is the expression of living with sickness, disease, injury, disability, dying. Illness is an attitude of fear and frustration that is triggered by living in a body that is breaking down. Illness is the recognition that what is happening to my body is happening to my life.

Medicine did well with Dick's biological body; it did not do well for his lived body. Medicine can diagnose, treat, and prognosticate an outcome for the defective body part, but this does not mend the apprehension and anger that have been aroused in the ill person. There is an experience of illness that goes beyond medicine.

Dick is a car mechanic and so he noticed how the doctor spoke about his heart; "it" had a problem. "It" needed surgery. So what is wrong with this language? It is aloof, cold; it is professional in the pejorative sense. More than that, Dick heard his doctor use management language: "A serious problem we may have here, but we can handle it."

What is Dick's part in the conversation? Dick did not know what to say. All Dick needed was some recognition of what was happening to *him*. Dick was thinking about

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[186] Merleau-Ponty, *Phenomenology of Perception*, 171-177.

[187] Merleau-Ponty, *Phenomenology of Perception*, 171.

[188] Merleau-Ponty, *Phenomenology of Perception*, 173.

[189] Merleau-Ponty, *Phenomenology of Perception*, 175.

dying and how, if he survived this heart attack, it would transform his way of life. Even though Dick wanted his doctor to recognize that, his doctor never did.

Is medical talk designed to make patients realize that only sickness, disease, injury, and disability can be discussed? Are the questions I have about my life allowed? Ironically, what talking to doctors and nurses often does to me as an ill person is to make me conscious of what I am not to say. My questions, therefore, end up being phrased in medical terms, but what I really want and need to know is how to live with illness. The help for which I most yearn is not to have my medical questions answered, but my illness experiences shared!

Body Care

Hardening of the Categories

Differences are part of the individual experience of illness. In Frank's thinking, "Care begins when difference is recognized."[190] This means that there are no "right" words to say to a patient; there is no formula because a patient as a generic being does not exist.[191] The common diagnostic categories into which medicine places patients are only for medical treatment; they are irrelevant for personal care.

Following Frank, healthcare professionals do not, as a rule, recognize differences in patients and in their patients' experiences of illness.[192] To learn differences requires

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[190] Arthur Frank, *At the Will of the Body*. (Boston, MA: Houghton Mifflin, 1991), 42.

[191] Frank, *At the Will of the Body*, 45.

[192] Frank, *At the Will of the Body*, 45.

communication and interaction; to talk and to become involved takes time.[193] As a result, the patient goes unheard, the experience is evaded, and the person is ignored.[194]

The reality appears to be that diagnostic labels impose treatment on groups of patients, mandate the conventional "care" those patients should receive, and predict the patterns of their recovery. To quote Frank: "Treatment is not care. Treatment gets away with making a compromise between efficiency and care by creating an illusion of involvement. This illusion begins with a recipe…that tells treatment providers what behavior to expect."[195]

The most famous recipe, in my knowledge, is Elisabeth Küebler-Ross's stage theory of the illness experience.[196] Her five stages are: denial, anger, bargaining, grief, and acceptance. Even though I do not think it was Küebler-Ross's intent, her theory has been used by healthcare professionals to categorize rather than to get patients to open up about their illness experiences. For example, anger is not understood as an aspect of the illness experience, the particulars of which need to be explored with each patient. Instead, anger is just a stage to be expected and, therefore, may be dismissed as something that every patient goes through in the course of the illness experience.

What makes an experience of illness real is that it is *my* experience. My experience of anger may be so different from the others that calling it by a common name obscures what is really happening. Consequently, simply using the words denial, anger, bargaining, grief, and acceptance, I may conceal more than I reveal. How, then, do I

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[193] Frank, *At the Will of the Body,* 45.

[194] Frank, *At the Will of the Body,* 45.

[195] Frank, *At the Will of the Body,* 47.

[196] Elisabeth Küebler-Ross, *On Death and Dying*. (New York, NY: Simon and Schuster, 1997 [1969]), 34.

account for the popularity of such a theory? By using common words I think I can understand without having to become involved in the experience of illness with all its variations. In effect, though, I have only an illusion of understanding.

A theory of possible stages has been valuable to me, however, as a patient learning to know that others share something of my experience. It has been satisfying to know that depression is a “normal” reaction to living with an intractable migraine. I am not going crazy; others, with a similar medical condition, are also depressed. It is important for me to know that my state of mind is not *totally* specific. Still, I need to remember that *my* despondency is mine alone, and not just some “stage.” My depression may be mitigated because it is shared; it cannot be dismissed because it is common.

Given the need for a recognition of difference, I think of caring as welcoming and listening to individual experiences of illness and responding appropriately. Caring does not have to do with categories; it does have to do with recognizing how differently patients may experience the same illness. Caring shows the patient that his or her life has value because of its particularity. Caring communicates to the patient that I care about that particularity; through that communication I make the patient’s life meaningful. Caring is understanding; caring is symmetrical. Listening to the other, I hear myself. Caring for the other, I care for myself. Otherwise I would burn out.

Perhaps many healthcare professionals do not feel that they have the time to care about differences; perhaps many do not want to care in this way. They are content to provide treatment. Treatment is equally important to caring about individual experiences, but it is different. Indeed, even family and friends who are involved with the patient may only be service providers rather than also caregivers.

Caring is listening to the uniqueness of a patient's story; to listen to the particularity of a patient's experience is to make the patient's life meaningful. To make the patient's life story part of the caregiver's story is to make the caregiver's life meaningful as well.

Softening of the Contacts

Nurses must learn to rely on their senses to detect the medical condition of the patient.[197] Quite literally, the healthcare professional scrutinizes the body of the patient by pressing, stroking, tapping, blowing, striking, feeling, sensing, vibrating, watching, listening, and smelling.[198] All of these practices are, at least potentially, charged with the intimacy of touch.[199]The technique of physical examination that is used for touch is "palpation."[200] It may be defined as "the receptivity to different types of sensation through touch."[201] It seems, moreover, that there are at least two kinds of touch that may be distinguished in reflecting on the medical situation: the "gnostic" touch and the "pathic" touch.[202]

First, I may speak of the gnostic touch of palpation, the objective of which is (dia)gnostic."[203] Literally, "(dia)gnostic" means "to know thoroughly" in the sense of

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[197] Max Van Manen, "The Pathic Nature of Inquiry and Nursing," in Irena Madjar and Jo Ann Walton, eds. *Nursing and the Experience of Illness*. (New York, NY: Routledge, 1999), 22.

[198] Van Manen, 22.

[199] Van Manen, 22.

[200] Van Manen, 22.

[201] Van Manen, 22.

[202] Van Manen, 24.

[203] Van Manen, 24.

"seeing through the body."[204] It is, however, the palpating hand that brings about the gnostic "view."[205] Perhaps I could say that an assessment of the anatomy is facilitated by touching and visualizing during the physical examination.[206]

The gnostic (i.e., knowing) attitude in healthcare proceeds on the principle that curing is to be defined in rationalistic terms. It is not surprising, therefore, that we find the designation "gnostic" so often in medical terminology (e.g., "(dia)gnostic" and "(pro)gnostic").[207]

I know from experience that to touch the other and to be touched by the other are two different experiences, even though the pressure on my skin may be exactly the same. When the other touches me, I not only feel the skin of the other's hand, I also feel myself through my own skin. Merleau-Ponty terms this phenomenon "physical reflection."[208] He indicates how, for example, in a handshake I feel the hand of the other as if it were my own other hand.[209]

What does this mean for palpation? It means that the patient is in the position of feeling the palpating hand of the doctor or nurse and at the same time also feeling his or

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[204] Van Manen, 24.

[205] Van Manen, 24.

[206] Van Manen, 25.

[207] Van Manen, 26.

[208] Merleau-Ponty, *Phenomenology of Perception*, 166.

[209] Merleau-Ponty, *Phenomenology of Perception*, 166-172.

her own body.[210] The probing hand of the healthcare professional is anatomical, and it is possible that the patient participates in the probing attitude.[211]

"Pathic" is a word that derives from "pathos" meaning "a quality that arouses pity or sorrow and passion interpreted as very strong emotion."[212] The pathic hand may be seen to lie at the heart of nursing since its effect is to reunite or reintegrate the lived body of the patient with the biological body.[213] Significantly, the gnostic and pathic aspects of healthcare work in opposite directions.[214] The gnostic attitude analyzes, anatomizes, and makes diagnoses that tend to separate the patient from his or her body.[215] The pathic attitude consoles, comforts, and assists healing that tends to make the patient feel whole.[216]

Ironically, the notion of touch presupposes distance.[217] Without touch it would not be possible to go away from, let go of, or lose contact with, nor would it be possible to come back from, retake hold of, or regain contact with. This means that touch is the primordial medium by which to overcome separation.[218] Indeed, it is possible that the most direct experience of human contact is touch.[219]

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[210] Van Manen, 27.

[211] Van Manen, 27.

[212] Van Manen, 26.

[213] Van Manen, 27.

[214] Van Manen, 30.

[215] Van Manen, 29.

[216] Van Manen, 31.

[217] Van Manen, 31.

[218] Van Manen, 31-32.

[219] Van Manen, 29.

The pathic relation demands a very personal involvement with the other.[220] In one act, the healthcare professional's hand has a double function: gnostic and pathic, instrumental and caring.[221] This gnostic and pathic ambiguity brings together the medical hand and the medical relation.[222]

What then makes the pathic practice distinct? The pathic thought turns directly to the patient.[223] The pathic relation is always specific. The pathic orientation meets the patient without trying to reduce him or her to a diagnostic image, case, category, type, or classification.[224] What is pathically compelling is the way in which any particular patient fails to match diagnostic judgments and prognostic projections.[225] The individual patient always falls, to a certain extent, outside of the diagnosis and prognosis.

Searching for the Words

To be sensitive to the pathic nature of medical practice the healthcare professional needs to pursue pathic language.[226] Pathic questions cannot be answered by words that primarily communicate cognitive meaning.[227] The therapist E. T. Glendlin suggests that pathic experience is not cognitive in the usual sense: "It is sensed or felt, rather than

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[220] Van Manen, 30.

[221] Van Manen, 30.

[222] Van Manen, 33.

[223] Van Manen, 33.

[224] Van Manen, 32.

[225] Van Manen, 33.

[226] Van Manen, 34.

[227] Van Manen, 34.

thought."[228] Yet my sense of the pathic can become a topic for reflection.[229] The important point appears to be that cognitive insights alone cannot address non-cognitive meaning; the pathic is an implicit, felt understanding that is difficult to put into words.[230] Perhaps a place to begin the use of pathic language is to get beyond the objectifying effects of naming things in medical practice with labels that distance.[231]

In order to explore living relations I maintain with the world, I first need to unname things, according to author Ursula Leguin.[232] In a short story, based on the Jewish creation myth, she hints at what happens in unnaming.

The fiction is about a woman who asks Adam to take back her name, a name he had given her, as well as the names he had given to all the creatures. The effect of unnaming is dramatic. After the unnaming, to which Adam agrees, she discovers with surprise how close she feels to all the creatures around her: "They seemed far closer than when their names had stood between myself and them like a clear barrier: So close that my fear of them and their fear of me became one and the same fear."[233] Is it possible that when things are unnamed I can no longer ignore the hidden aspects of the phenomena that words tend to hide?

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[228] E. T. Gendlin, "Befindlichkeit: Heidegger and the Philosophy of Psychology," *Review of Existential Psychology and Psychiatry*, 1988, 45.

[229] Van Manen, 30.

[230] Van Manen, 30.

[231] Van Manen, 34.

[232] U. K. Leguin, "She Unnames Them," in *Buffalo Gals and other Animal Presences*. (Markham, Ontario: Penguin, 1987), 194-196.

[233] Leguin, 195.

Clearly, reflecting on names helps me to realize how closely related language is to thinking and to my way of being in the world.[234] Still, what exactly happens in unnaming things?

The question of unnaming arises because I naturally assume it means that I discard words.[235] Suppose, however, that to unnamed means to make words *transparent*.[236] Then I could become oriented to my environment as if I were removing “a clear barrier” that stands between me and my experiences.[237] Furthermore, I could not take things for granted.[238]

How then could I unname illness? I could no longer assume that this or that illness is known by its diagnostic label, or that the clinical trajectory of illness is what matters most.[239] I would have to unname the illness and scrutinize the complexity, subjectivity, and variability of different patients’ lives.[240] Of course, the purpose of my unnaming would not be a repudiation of medical science; it would be an attempt to understand patients’ experiences of illness.[241] The outcome of my unnaming would be to get close to my patients so that their hopes become my hopes, their fears become my fears; it would be to listen and speak, to read and to write in a manner that is attentive to the experiences

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[234] Van Manen, 19.

[235] Van Manen, 19.

[236] Van Manen, 19.

[237] Van Manen, 19.

[238] Van Manen, 19.

[239] Van Manen, 19.

[240] Van Manen, 19.

[241] Van Manen, 19.

of illness that are ultimately unnameable.[242] My words would be "as slow, as new, as single, as tentative"[243] as if I were exploring an unfamiliar territory.

Body Bonds

Health within Illness

A problem with the view of recovery as the end of illness is that some patients do not recover. If recovery is taken to be the last word, how is it possible to find value in the experience of illness that lingers? What happens to the well-being of patients who are chronically ill?

Do not most of us assume that health and illness are mutually exclusive concepts? Susan Sontag offers a different view of this presumed dichotomy: "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship in the kingdom of the well and in the kingdom of the sick.[244]

I believe that in the same way that illness occurs within health, so an experience of health within illness is possible. What is required is a shift in how I think and talk about health and illness. Instead of interpreting them as polarities, I need to understand them as a continuum. This change of viewpoint allows for talking about health within illness. Another shift is required, from an objective dysfunctional health assessment to a more subjective disruption of lived experience. Laconically, the alteration is from cure to care; a switch from a model of illness that promotes cure to a model of care that promotes

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[242] Van Manen, 19.

[243] Van Manen, 34.

[244] Susan Sontag, *Illness as Metaphor*. (New York, NY: Doubleday, 1988 [1978]), 3.

health. The intention is to transform medical practices by re-conceptualizing my ideas of health and illness and offering an enlarged perspective on the experience of health.

A telling series of studies is recorded by Senior Lecturer in Philosophy at Bristol University, Havi Carel.[245] When the chronically ill are asked about the experience of illness, the responses focus on illness, dysfunctionality, and negative attitudes. There seems to be a hidden experience of health within illness that only emerges when the incurable patients are asked explicitly whether they experience a sense of well-being, of health within illness.

What then might be an example of a positive attitude that enables a patient to perceive health within illness? I propose, on the basis of my experience, perspective, a way of seeing, facing the reality of, and living with the experience of illness; perspective enables adaptability and creativity.

Shel Silverstein has written a book called *The Missing Piece*.[246] This is a précis: Once there was a circle that was missing a piece. The circle wanted to be whole, so it looked for its missing piece. Because it was incomplete, it could only roll very slowly through the world. As it rolled slowly, it admired the flowers along the way. It chatted with butterflies. It enjoyed the sunshine.

Then one day it found a piece that fit perfectly. Now that it was a perfect circle, it could roll very fast, too fast to notice the flowers, too fast to talk to the butterflies. When it realized how different the world seemed when it rolled through it so quickly, it stopped, left its missing piece by the side of the road, and rolled slowly away.

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[245] Havi Carel, *Illness*. (Durham, UK: Acumen Publishing, 2013 [2008]), 93-94.

[246] Shel Silverstein, *The Missing Piece*. (New York, NY: Harper and Row, 2006), the entire book.

It does seem that I am more whole when I am incomplete, when I am missing something. There is a wholeness about coming to terms with my limitations, knowing that I am vulnerable, letting go of my unrealistic dreams, and yet not feeling like a failure. There is a wholeness about enjoying whatever measure of health I may have without making it a condition of my life. I am whole only when I no longer require health to live a whole life.

There is a wholeness about being able to accept my illness, knowing there is also health in me. I do not feel guilty or culpable for being ill; nor do I crow and gloat if my health improves. I can take what happens to me and continue to look for possibilities of how to live or, if necessary, of how to die. To be whole means not needing to pretend that I am better or worse than I really am.

There is a wholeness about being able to deal with stigmatization. Even family and friends may be so obsessed with health that they reject and isolate the ill for being scarred. Wholeness is found in my being cut off and yet not feeling like I am part of a broken relationship. When I have lost part of myself through illness and can continue to roll through life and appreciate it, I will have a wholeness to which others can only aspire.

At the beginning of this chapter I wrote of Merleau-Ponty's view of bodily experience exposed in illness, a prospect he calls the "ambiguity"[247] of the body. Encountering illness, my attention is drawn to the breakdown in my body and suddenly it becomes the focus of my concern rather than the invisible instrument for my activities. The unity between the biological and lived body is disrupted and the difference becomes discernible.

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[247] Merleau-Ponty *Phenomenology of Perception*, xix.

I am made “whole” when the biological body that is transformed by illness is reunited with the lived body.[248] The synthesizing takes place through a changed perspective and acceptance of the altered, ill, biological body. “The two bodies are reconciled by appropriating the transformed body and integrating it into the experience of illness.”[249] This means wholeness is possible with or without resolution of my illness.

Wholeness beyond Health

In the Christian Scripture there is a healing story that surpasses even the notion of health (i.e., healing wholeness) *within* illness; it is wholeness *beyond* health.[250] The attitude that enables this experience is “gratitude.” It is the story of ten ill persons who were one in their disease. They were all healed. Their solidarity was broken, however, by one of them giving thanks. It is likely that he grasped his good fortune in terms of luck, and he was appreciative. Receiving health with gratitude led the one into an experience of wholeness beyond the recovery of health.

The others simply took their healing for granted. They may have understood their good fortune in terms of sheer chance, waving any sense of obligation to be grateful. They may have viewed their good fortune in terms of fate, in which case the appropriate response would be gratitude. Unfortunately, the acceptance of one’s fate does not lead naturally from enjoying good fortune to gratitude. It is possible to adopt a rigid concept of fate, a predetermined fate, which makes gratitude seem unnecessary. Why be thankful for that which is going to happen anyway?

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[248] Carel, 15-16.

[249] Carel, 102-103.

[250] Luke 17:11-19.

I need only be grateful for that which might not have happened but did. Gratitude recognizes the fact that I am not, in fact, the author of my own destiny, that I owe my good fortune to others.

It is frighteningly possible to take the restoration of health for granted. Ingratitude does not deny me health; it denies me wholeness beyond health. The nine took all they could get from their benefactor and went on their way. To take health for granted is to experience life as something to be exploited. To receive health with gratitude is to experience life as generous.

In a medical situation, I want healthcare professionals who speak and act with generosity. In turn I want to express my gratitude to those who care for me with such hospitality. More than giving thanks, I want to pass on to others the generosity that I have been given. In short, I not only want to give thanks for "getting," but I want to be grateful in "giving."[251] I can only imagine living in a society where both professionals and patients practice a cycle of generosity, gratitude, and generosity.[252]

I feel that generosity is what I ought to want as a human being. To practice generosity, I feel grateful. I have a human impulse to be generous, to be in dialogue with and respond magnanimously to the experience of illness in the other, and I will do it with gratitude.

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[251] Taylor, James, *An Everyday God*. (Vancouver, B.C.: Wood Lake Publishers, 1982), 54.

[252] Arthur Frank. *The Renewal of Generosity*. (Chicago, IL: University of Chicago Press, 2004), 1.

CHAPTER 3

AN EXPERIENCE OF ILLNESS: THE LIVED WORLD

The Façade of the Ill

Keeping Up Appearances

In my world, ill persons are praised for appearing happy and optimistic. Hospital staff and visitors appreciate patients who have a good sense of humor, who are witty, and in good spirits. Ill persons who make professionals and visitors feel good are regarded as "good" patients. Everyone around the ill person is committed to recovery. An attitude of "you will be fine" prevails.

I have often wondered how much energy the ill must expend to make others feel chipper, how much work the ill person does to keep up an appearance, an appearance which is the expectation of healthy workers and friends.

The appearance most approved and admired is one of not speaking or acting as if I am ill: "I couldn't even tell you were sick." The appearance least approved but still applauded is one of convincing others that being ill is not a "bad" experience; it is a stoical smile.

Usually the ill person feels ill and, therefore, does not feel like being good-humored. For this reason it takes work to keep up an appearance of feeling upbeat.

Significantly, I have never heard an ill person praised for expressing gloominess, distress, or sorrow. In part, ill persons usually feel a need to apologize for showing any "negative" emotions. If sick and not able to laugh, the ill person must be treated for depression. Why are the healthy so unwilling to accept the possibility that depression may be the ill person's most appropriate response to the situation?

What makes me depressed is seeing the energy and effort spent by those with a fatal illness to sustain a "good patient" image. In one town where I worked, a colleague, age forty-five, was stricken with inoperable brain cancer. The community of faith met weekly for prayer. The immediate family of my fellow clergy was optimistic. As for my minister friend himself, he had a positive attitude and an indomitable spirit. His nurses called him a "wonderful patient, so brave and cheerful." His condition, nevertheless, worsened. In the end stage, there were no more prayer meetings. His wife, son, and I were the only visitors. As for my dying friend, he dropped his act and began to grieve openly. His nurses could not understand what happened to the "trooper." I can only imagine what it cost my colleague to sustain a happy face for so long, what it cost in terms of energy, understanding life, diminished relationships with others, and medical support.

For the medical staff, a "good" patient is in denial, is buoyant, makes few, if any, demands, and asks no tough questions. I suggest that what is being denied above all is that the medical situation is created by healthcare professionals and visitors. Arthur Frank, Sociology Professor at the University of Calgary, expresses the idea persuasively: "To be ill is to be dependent on medical staff, family, and friends. Since all these people value cheerfulness, the ill must summon up their energies to be cheerful. Denial may not be what they want or need, but it is what they perceive those around them wanting and needing. This is not the ill person's own denial, but rather his or her accommodation to the denial of others."[253]

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[253] Arthur Frank, *At the Will of the Body*. (Boston, MA: Houghton Mifflin, 1991, 67-68.

Fear and depression are a part of the experience of life; fear and depression in illness are not negative emotions but experiences of life. What is needed, therefore, is not denial but affirmation. The patient needs someone to acknowledge his or her pain and fear. The patient and caregiver need to acknowledge that they have pain and fear in common.[254]

As medical staff, family, and friends we need to see ourselves as participants in the process of illness. We need to see how our speech and behavior shape the speech and behavior of the ill person. Consequently, those who make cheerfulness and courage the price of support deny their own humanity.[255]

Hiding Disabilities

I am sitting in the lobby of the hospital when I see her. Her disability is grotesque and awesome. For a fleeting moment I am both fascinated and repelled. I am transfixed. I do not know what to say or what to do.

For many years, disability in others challenged me because I assumed that only some of us are disabled. So I would inaudibly give thanks for being spared from such a hardship. In this view I was able to set the disabled apart from me as not disabled. This thought collapsed when disability struck me and I discovered that I was not as able-bodied as I had imagined.

I have come to believe that we are all disabled in some way. Our disabilities vary in kind and degree, and may differ according to the age and stage of life. All of us, nevertheless, know the anger and frustration of disabling limitations. To see some as disabled and some as not disabled is an illusion.

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[254] Frank, *At the Will of the Body*, 71.

[255] Frank, *At the Will of the Body*, 71.

The difference is not between those who are impaired and those who are not, but between those whose defects are obvious and those whose defects are hidden. An even greater difference is between those who accept their afflictions, talk about them, and live them with passion and purpose and those who reject their afflictions with rancor and despair.

When I separate myself from those whose disabilities are obvious, I flee from my own. I condemn myself to living in fear of a day when my disability can no longer be hidden. I lack solidarity with the disabled because I do not see myself as “one of them.”

There is a price for having such an outlook about myself and others. It means that when the outward impression is the criterion I not only ignore the disabled, but I ignore my own disability. I am separated, as a result, not only from those I see as disabled, but I am separated from my own disabled body.

Such a stance about disability creates an apprehension of being regarded as disabled. I learn how to lie in order to conceal or isolate others who are disabled. This frame of mind that sees me as able and others as disabled makes virtues of “suffering in silence” or “bearing the burden so that no one will ever know.” The model for those of us who hide afflictions is the tearless stoic. It is no wonder that isolation, rejection, and solitude are the greatest worry of the disabled.

In contrast, my perspective calls for the affirmation or acceptance of disability in myself and others as part of the affirmation or acceptance of the whole of life with its disabilities. It means rejecting the egocentric hope of being free from disease, deformity, disability, debility, and dying in order to have “the good life.” It is accepting my disability and living in spite of it.

I stand together with others when I am able to affirm the whole of life, when I am able to assert, “I am dying; nevertheless, I live!” To do so is to reject the notion of simply enduring my disability as an encumbrance. Rather, I take my disability on myself and live it with passion. Only then is life accepted and appreciated in a way that enables me to live with others both as givers and receivers.

When I can accept first my own disability, there can be an acceptance of the disability of others. Such an acceptance and affirmation of disability is a response of trust in life. That trust frees me from stoical resignation. I am freed to use my strength for the struggles of living.

To affirm my disability is quite the opposite of doing nothing. It is to share, reach out, live with passion, and reject silence and concealment. From the vantage point of disability, I am compelled to think and talk in new ways about the value of my life. Disability takes away part of my life but in so doing gives me the possibility to choose a new way of living.

The risk is that of becoming attached to my disability, using it to withdraw from myself and others. To seize the possibilities offered by disability, I must think and talk about it. Only then can I learn that being disabled is just another way of living.

I am, as a disabled person, deprived of conversation. I believe I cannot talk about my disability. By talking about disability, I do not mean medical explanations; I mean talk about my hopes and fears, about what it is like to be in pain. I mean talk about being stigmatized and secluded; I mean talk about the loneliness of wanting to hide my disability and to hide myself. Such talk, however, embarrasses others. So they are tight-lipped. I then believe that disability is not something about which I can talk. I miss the possibility of experiencing disability with another. I can only imagine the difference if all the energy wasted on fleeing and rejecting my disability and the disability of others were released for living.

The Perception of the Ill

By Nurses

After being diagnosed with a chronic migraine, I was hospitalized for two weeks the purpose of which was to find a drug treatment. The worst part of that experience was a lack of understanding (i.e., empathy) by the healthcare professionals.

On several occasions I wondered: “What sort of training made my nurse able to stand at my bedside, giving me pills, saying nothing? Why did she never even offer a word of consolation? Did she “care” for all of her patients the same way? Why did she seem to be annoyed with me? Why did I feel like the patient in room ten, bed one?

While it was true that none of my nurses was rude or refused to answer my medical questions, it is also true that none seemed to care enough to make my experience less apprehensive. None asked me how I felt about my experience of suffering. I was asked, “How are you?” By the reaction to my response, I correctly assumed that what was meant was, “How is your head?”

Once several nurses and doctors stood inside my room and discussed my “case.” I was excluded despite being several feet away from them. I assumed that they did not want to know about how my life was changed because of the oppressive affliction. I further assumed that they did not consider how learning about my experience of illness could benefit the relationship between them and me.

It seemed to me that there was a consensus among the medical staff to speak *to* each other and *about* me and my illness. The consultation, moreover, was addressed impassively. On the other hand, when the healthcare workers did speak to me, their words were chary, sanitized, and invariably medical. I wondered why this was considered the "right way" to speak about me and my illness. Why not, for example, ask me: "How has illness changed your life? What have you lost through your illness? How can we (i.e., nurses) help you compensate for those losses?"

My criticism of the attitude toward the patient and illness that I found in the medical field is not sentimental; I am not suggesting that the medical staff's precious time be wasted on euphoric chit-chat. Must, however, the encounter between professional and patient be so impersonal, so guarded? Could not some genuine care be introduced to the exchange? What difference might it make if healthcare practitioners devoted some time to understanding the experience of illness and the impact of that illness on a particular patient's life?

By Strangers

Social exchanges normally occur between persons who wish to be perceived in a particular way, to be liked. The presence of illness radically curtails the ability to control what others think about me and places the communication and interaction in the shadow of illness.

Jean-Paul Sartre's idea of the transparency of health is illuminating here.[256] According to Sartre, the healthy body is transparent;[257] it simply does as I bid it and it

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[256] Jean-Paul Sarte, *Being and Nothingness*. (New York, NY: ET Methuen, 1943), 460-470.

[257] Sarte, *Being and Nothingness*, 461.

requires no special consideration or reflection.[258] In illness, the transparency is lost.[259] The transparent and natural way in which I engage in social interactions suddenly becomes cumbersome, weighed down by unspoken doubts and discomfort, and the effort required for genuine communication becomes greater.[260] The social impact of illness is the loss of this transparency and immediacy of social interaction.[261] University of Bristol Philosophy lecturer Havi Carel holds that when persons who are ill in a way that can be perceived at once by others, they may feel exposed, as if others can see through them.[262] Instead of choosing what they disclose about themselves, they become passive bodies of information.[263] It is not that their illness is a secret, something they choose whether to disclose; it is rather that their bodies embody their situation as ill persons.[264] A stranger takes a cursory glance at them and already knows much about them that is sensitive, intimate, and painful.[265] Yet they know nothing about the stranger. For the stranger, ill persons are reduced to their illness (e.g., “you are the woman with the oxygen tank”), memorable because of their deficiency.[266]

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[258] Sarte, *Being and Nothingness*, 462.

[259] Sarte, *Being and Nothingness*, 465.

[260] Sarte, *Being and Nothingness*, 467.

[261] Sarte, *Being and Nothingness*, 469-470.

[262] Havi Carel, *Illness*. (Durham, UK: Acumen Publishing, 2013 [2008]), 70.

[263] Carel, 70.

[264] Carel, 70.

[265] Carel, 70

[266] Carel, 70.

By Friends

Illness marks a new day in the relationship of ill persons and their friends. In my experience, some do not communicate at all; illness is seen as something about which they do not comment or mention.[267] There may be any number of reasons for silence; some of which are: 1) Talk about illness is impolite, insensitive, and inappropriate.[268] 2) Talk about illness is emotionally draining, more than they (the friends) can handle.[269] 3) Talk about illness is meddling or prying.[270]

For other friends, illness makes not talking difficult, but they are not sure what to say, how to say it, or when to say it.[271] If they do talk, they think that they should censor their expressions beforehand lest they offend the ill person.[272] The result is awkwardness, discomfort, and edginess.

Fortunate indeed are the ill persons who have a friend with whom they can have an intimate conversation about their illness and its effects on their lives. By an "intimate conversation" I mean an exchange that is so thoughtful and emotional; so honest and compassionate; that it has the potential to move the participants to tears, whether of pain or pleasure.

The threat that illness poses to intimate conversation with my friends leaves me bitter. Because most of my friends do not know what to say or if they want or should talk at all,

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[267] Carel, 65.

[268] Carel, 61.

[269] Carel, 65.

[270] Carel, 60.

[271] Carel, 61.

[272] Carel, 61.

they place strict limitations on what I may or may not say.[273] An attempt to overcome the uneasiness of the situation is to maneuver me (the ill person) into a more socially acceptable position.[274] The ruse is to tell me that I am so courageous, so uncomplaining, so cheerful. First, I am set up in a social context that forbids me from talking about my illness.[275] Then, when I talk about anything other than my illness, I am perceived as strong, gracious, and chirpy.[276] That is how I am regarded when I acquiesce to the implicit demands and expectations of others.

Incidentally, this social gauche has a flip side.[277] It is also true that some of my friends may be damned if they do talk and damned if they do not. If they ask questions, I (the ill person) may feel as if they are intruding.[278] If they are reticent, I may think they do not care about my plight.[279]

What then is a way of communication with ill persons? 1) Give the ill persons the opportunity to share their thoughts and feelings about their illness, and 2) give them a listening presence.

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[273] Carel, 66.

[274] Carel, 66.

[275] Carel, 66.

[276] Carel, 66.

[277] Carel, 69.

[278] Carel, 69.

[279] Carel, 69.

The Communication with the Ill

The Need for Opportunities to Share

As a visiting minister I have had many opportunities to observe what hospital personnel have tagged "the bedside manner."[280] It appears to be a rigid routine in the administering of duties.[281] Of more relevance to me, however, is *how* the various functions are performed. Many times I have heard platitudes and have seen exuberance. Questions are given programmed answers. Smiles seem artificial. The demeanor is patronizing. It strikes me as so orchestrated, so perfunctory. If the purpose of "the bedside manner" is to permit nurses to carry out their responsibilities uninhibited by their patients, it is effective. In fact, I can imagine the nurse-in-training asked this question, "How should you as a nurse talk to patients and behave in their presence?" Conceivably, through some learning exercise like role-playing, the student nurse arrives at a procedure that "works" for her or him.

I have placed "works" in quotation marks because I believe this technique may be impugned. Since "the bedside manner" is contrived, nurses must repress their own reactions to their exchanges.[282] With sanitized interaction that conforms to a fixed role, nurses stifle and replace their own spontaneous interaction.[283] Nurses educated in "the bedside manner" are able to speak and act as they "*should,*" not as they "*are*." As a result, patients find it difficult to interact in any way that threatens nurses.[284]

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[280] Sidney M. Jourard, *The Transparent Self*. (Princeton, NJ: D. Van Nostrand Company, 1964), 111-120.

[281] Jourard, *The Transparent Self*, 112.

[282] Jourard, *The Transparent Self*, 112.

[283] Jourard, *The Transparent Self*, 113.

[284] Jourard, *The Transparent Self*, 113.

Another pertinent consequence of “the bedside manner” is that it interferes with the avowed purpose of healthcare professionals.[285] Is not the medical vocation dedicated to the promotion of patient well-being? Yet, “the bedside manner” is designed to preclude a source of information that is apposite to the patient’s healing; it is information that can be known only through the patients’ disclosure.[286] This is because “the bedside manner” attempts to impose uniformity in patients, the kind of uniformity with which nurses feel most competent to cope (e.g., diagnostic labels and conventional treatment).[287]

Patricia Munhall, a well-known writer on nursing research, speaks incisively to the matter: “To be authentically present to a patient we need to take an open stance and recognize that we do not know the other person and his or her subjective world. Assuming that we know something, or someone, gives us confidence to act. Yet our actions may be inappropriate if they are based on what we presume to know about the patients in our care rather than on what we have allowed them to teach us about their experience and their need.”[288]

In contrast, to be inauthentically present to a patient (e.g., “the bedside manner”) is to recognize that medical language “simplifies, unifies, and homogenizes”[289] patients’ experience of illness. Clinical jargon also clouds the untidy reality of the experience of illness (i.e., the confusion, futility, helplessness, and incoherence of the experience of

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[285] Jourard, *The Transparent Self*, 114.

[286] Jourard, *The Transparent Self*, 114-115.

[287] Frank, *At the Will of the Body*, 45.

[288] Patricia L. Munhall, “Unknowing: Toward Another Pattern of Knowing in Nursing,” in *Nursing Outlook*, Volume 41 No. 3, 1993, 125.

[289] Audre Lorde, *The Cancer Journal*, (San Francisco, CA: Spinsters Inc., 1980), 22.

illness).[290] My questions are: Would nurses be willing to learn to share illness talk with patients instead of merely imposing medical talk on them? Would nurses be willing to invite patients to communicate the turbulence and uncertainty of their experience? In my opinion, to deny patients the opportunity to communicate their bewilderment and lostness is to deny them the respect and dignity of being humans.

On the other hand, Arthur Frank writes about the problems created by not giving the opportunity to patients who need to talk about their experience: "When I face someone who does not seem willing or able to help me work toward what I might eventually say, I become mute. A person who finds no one willing to take time and offer the help necessary to bring forth speech will protect himself by saying nothing. But the time when I cannot immediately put something into words is usually the time I most need to express myself. Having no questions hardly means having nothing to say. You cannot be told that you have had a heart attack without having a great deal to express and needing to express it. The problem is finding someone who will help you work out the terms of that expression."[291]

Sociologist Simon Williams describes illness as a "biographical disruption".[292] The disruption is of taken for granted assumptions and behaviors and of the explanatory framework (e.g., "Why me?").[293] Becoming ill creates a need to find meaning for a new narrative: the narrative of health that has now been disrupted by illness.[294] Ill persons

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[290] Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics*. (Chicago, IL: The University of Chicago, Press, 1995), 109.

[291] Frank, *At the Will of the Body*, 14.

[292] Sidney J. Williams, *Medicine and the Body.* (London, England: Sage Publishers, 2003), 96.

[293] Williams, 96.

[294] Williams, 97.

seek an explanation for the limitations; they must renegotiate habits and relationships; they may need to give up an identity and create a new approach to both the present and future.[295] In adapting, ill persons often need to retell their life story (e.g., "This is the way I was living until…").[296] The old narrative is no longer suitable and a new narrative must be created and endowed with meaning.

It seems to me that, in doing their work, nurses often assume that they "know" what patients are experiencing. The assumptions do not have to be wrong, but they are assumptions nevertheless. To actually know what patients are experiencing it is necessary, as Munhall says, "to stand in one's own socially constructed world and unearth the other's world by admitting, 'I don't know your subjective world.' Such 'unknowing,' and the openness needed to make it possible, offers fresh possibilities for knowledge that is true to individual experience…and that can inform nursing practice."[297]

The Need for a Listening Presence

In *Phenomenology and Nursing*, Jo Ann Walton and Irena Madjar state that "to truly listen is to create a space within which patients can begin to make sense of their experience."[298] Listening in an engaged, empathetic manner to whatever individual patients feel they need to tell nurses about their illness experience is a way in which care

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[295] Williams, 97.

[296] Williams, 97.

[297] Munhall, 125.

[298] Irena Madjar and Jo Ann Walton, eds., *Nursing and the Experience of Illness. (*New York, NY: Routledge, 1999), 7.

is given and outcomes changed.[299] Sincere attempts to know and understand patients increase their sense of identity and seems to be a factor in healing.[300]

On the other hand, impersonal relationships with patients undermine their sense of identity and make them feel like nobodies. Nursing is caring. Can I, however, really care about patients I do not know?[301] Knowing patients calls for listening.[302]

Nurse turned writer, Elizabeth Jolley, speaks about the heart of nursing as requiring "a gaze which is searching and undisturbedly compassionate and yet detached."[303] I think that Jolley's thought is noteworthy, but I do not think that "gaze" expresses the idea she intends. "Gaze" means "to look steadily,"[304] the connotation of which is "to stare." For me, therefore, "gaze" communicates an affected look, a posturing. Metaphors of vision are, nonetheless, an effective access to "listening" (e.g., "I see" means "I understand"). Perhaps a better word is "regard," encompassing the concepts of contemplation, consideration, and respect. I look with regard.

Listening begins in a patient getting my attention; I am alerted to notice a patient.[305] My perception is of a patient who is brooding because there is none who has heard the experience of her or his illness. A patient must be heard into speech and discover a safe place to name the feelings and thoughts of her or his heart. Why do I pay heed to the patient and take to heart the tacit process at the core of her or his being? I do not know. It

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[299] Madjar and Walton, eds., 7.

[300] Madjar and Walton, eds., 7.

[301] Madjar and Walton, eds., 6.

[302] Madjar and Walton, eds., 6.

[303] Elizabeth Jolley, *Central Mischief*. (Ringwood, Victoria: Viking Books, 1992), 51.

[304] Webster's New World Dictionary

[305] Madjar and Walton, eds., 5.

is too complex. I suspect my consideration is initiated by my past experiences and my determination to learn through them; in short, my “seeing” has been influenced and developed through my personal maturation process.

By entering feelingly into what I intuit, I know myself as deeply and passionately involved in a patient’s painful longing to be heard. I compassionately confront the patient in her or his situation. My heart and mind reach out in amiability, empathy, and understanding. Responsibly and respectfully I respond to the patient who lies in front of me and whose life makes a claim on me.

Listening is not just “looking,” however. It is an outlook, a perspective – an attitude of openness to patients.[306] It is a frame of mind that is attuned to the concerns of patients in order to understand their experience of illness and to respond with care.[307] The openness attitude of the “listening look” is learned through a circle of practice and reflection.[308]

Hearing What Illness Is

Expressing Our Illnesses

In his book, *At the Will of the Body,* Arthur Frank recounts a newspaper story that suggests how little we understand about the expression of the illness experience.[309] The article’s motif is the need for cancer patients to talk openly about their illness. The report contrasts two teenagers with leukemia. One is open about her illness (e.g., when a

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[306] Madjar and Walton, eds., 11.

[307] Madjar and Walton, eds., 11-12.

[308] Madjar and Walton, eds., 12.

[309] Frank, *At the Will of the Body*, 124.

stranger in a supermarket asks her if she is ill, she takes off her wig). The other is closed about her plight (e.g., she withdraws from family and friends and refuses further treatment). The account implies that the "open" teen is a "good" patient and will survive; the "closed" teen is a "bad" patient and will not.

Significantly, the story never mentions social context, despite the fact that responses are learned. Each teen has a social history and it is likely to be that influence that has affected the different reactions. In all probability the teens' responses have been shaped by the responses of their family, friends, and healthcare professionals.

The adolescent who is "open" demonstrates that she is valued regardless of being ill. She takes a risk, therefore, in anticipating that a stranger will respond in the same supportive way. In any case, whatever the stranger may say or do, she has a sense of worth.

The ill teen who is closed and withdrawn exhibits that she is devalued, stigmatized as a failure for being ill. To her parents she embodies their failure to have a healthy teenager. To her siblings and friends her presence brings a fear of what could happen to them. To her healthcare team she represents their failure to cure her illness. The teen is inhibited and uncommunicative because she thinks others would be happier if they did not see her. None may reject her overtly; it is enough that she senses from their expressions that she has been stigmatized and is regarded as the reason for their misery.

The social world of each teen impacts her responses to others. Many people, nonetheless, accept the myth that the experience of illness is merely an inward reality (i.e., personal), cut off from any outward influence (i.e., social). The teen who is "open" is the good patient who stays in treatment and *wants* to get well. She, therefore, *deserves* to get well. The teen who is “closed” is playing the sick role badly. She rejects treatment and *does not want* to get well. She, therefore, does *not deserve* to get well. The first teen is “well-adjusted; the second is “maladjusted.” I am arguing that it is primarily the social world that is disturbed.

Where then is responsibility in this story? I think the sick adolescents are equally responsible. The teen who lifts her wig and announces that she is a leukemia patient performs a significant act of communication and education. When she perpetuates the openness she has experienced from others, she extends recognition. By expressing her experience of illness she fulfills her responsibility. On the other hand, the teen who seeks isolation and rejects treatment is no less a witness to her experience of illness. Like the teen who shows her bald head, the teen who is withdrawn no less reflects the attitudes of those around her. By expressing her experience of illness, she too fulfills her obligation.

Of course, I need to mention the strong individuals who are able to non-conform to the social script for illness, but I also believe that such courageous persons are rare. In any case, even the ill persons who refuse to let their attitude, speech, and actions be fashioned by the way they are treated, base their response on resources developed earlier in their lives.

If the ill have already fulfilled their responsibility by expressing the illness experience, what is the responsibility of the rest of us? Arthur Frank’s answer is insightful: “Can we be responsible enough to see and hear what illness is, which ultimately means seeing and hearing what life is? Being alive is a dual responsibility: to our shared frailty, on the one hand, and to all we can create, on the other. The mutual responsibilities of the ill to express and the healthy to hear meet in the recognition that our creativity depends on our frailty.”[310]

Grieving Our Losses

Losses accompany illness. Losses may include quixotic dreams, impossible expectations, illusions of freedom, energy, and safety, as well as the loss of a younger self, a self that has been thought to be unwrinkled, unassailable, and undying.

It is in the experience of illness that I gain the wisdom of recognizing that I can only do what I want within the limitations imposed by reality -- a reality of diminished strength, restricted freedom, and affected relationships. Perhaps it is in the experience of illness that I also come to know that losses are a necessary part of life. I live by losing. Indeed, it is only through losing that I become more fully human.

Some rail against the losses of illness. There is, however, another point of view that claims if I truly grieve my losses of infirmity, grieving can liberate and empower me to further development, joy, and capability to embrace life. It is my attitude toward my losses of sickness as much as the nature of my losses which will determine the quality of my life.

In the Christian Scripture there is a “be-attitude” that speaks to the need to mourn the losses of illness: “Blessed are those who mourn, for they shall be comforted.”[311] To treat the losses of illness as simply an incident from which to bounce back devalues what has been lost. Only through mourning losses can I find the value of life, true happiness.

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[310] Frank, *At the Will of the Body*, 128.

[311] Matthew 5:4.

Significantly, the gospel beatitude is a paradox. Whatever is meant by the joy of sorrow, the gladness of grief, the bliss of the brokenhearted?

The losses that are concomitant with illness establish an emptiness through renunciation. It leaves me with a void. The beatitude to be sorrowful warns me of a purely negative detachment (i.e., distancing), one which would say, “I don’t care.” Those who do not care do not sorrow. This rules out emotional apathy.

This beatitude is a defense for authentic emotional response, including negative emotion: “Blessed are those who feel miserable, who weep.”[312] At the very least this beatitude supports me when I am blue and blesses me when I am too distressed to accommodate myself to unsympathetic healthcare workers, family members, and friends.

No doubt I mean well when I try to raise the spirits of the sick, but am I myself not relieved when the sick cheer up? After all, they bore me with their misery, embarrass me with their emotion, and perplex me with their pain. To the extent this is the case, my attempts to humor are a flight and a protection from my own authentic emotions.

Is there not, however, an argument for always being happy?[313] Because life is complicated, emotions must be complex. It appears to me that a capacity for happiness is inseparable from a capacity for sadness. Happiness is not found in the avoidance of sadness. If I am perpetually on the defensive against unhappiness I am not likely to be very happy, because there can be no real happiness until I have stopped running from unhappiness.

Nor is this an argument for always being miserable. The misery that is bona fide is not the misery of selfishness, frustrated ambitions, or the bitter emptiness of renunciation.

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[312] Luke 6:21.

[313] Philippians 4:4.

There is no comfort about whining self-pity, the petulance of "this should not be happening to me." There is also a theatrical sorrow that is worked out to achieve an effect. It is satisfying to dramatize my sorrows to myself and others. In addition, real or imagined heartbreaks can be exploited to secure attention and sympathy to myself. There is yet another falsification of sorrow. It is to persist in sorrowing until I distort my honest experience of grief into a pathological grief that refuses to be comforted.

Those who truly grieve their losses find strength and courage. The spirit of sorrowing is to live in the joy of caring.

Hearing What Life Is

The Expression of Serving

In *How Can I Help?* Ram Dass and Paul Gorman share this story:

> In the early stages of my father's cancer, I found it very difficult to know how best to help. I lived a thousand miles away and would come for visits. It was hard seeing him going downhill, harder still feeling so clumsy, not sure what to do, not sure what to say.
>
> Toward the end, I was called to come suddenly. He'd been slipping. I went straight from the airport to the hospital, then directly to the room he was listed in.
>
> When I entered, I saw that I'd made a mistake. There was a very, very old man there, pale and hairless,…breathing with great gasps, fast asleep, seemingly near death. So I turned to find my dad's room. Then I froze. I suddenly realized, "My God, that's him!" I hadn't recognized my own father. It was the single most shocking moment in my life.
>
> Thank God he was asleep. All I could do was sit next to him and try to get past this image before he woke up and saw my shock. I had to look through him and fine something beside this astonishing appearance of a father I could barely recognize.
>
> By the time he awoke, I'd gotten part of the way. But we were still quite uncomfortable with one another. There was still this sense of distance. We both could feel it. It was very painful. We both were self-conscious…infrequent eye contact.
>
> Several days later, I came into his room and found him asleep again. Again such a hard sight. So I sat and looked some more. Suddenly this thought came to

> me, words of Mother Teresa, describing lepers she cared for as "Christ in all his distressing disguises."
>
> …What came through to me was a feeling for my father's identity…that was who he really was, behind the "distressing disguise." And it was my real identity too, I felt. I felt a great bond with him which wasn't anything like I'd felt as father and daughter.
>
> In a way, this was my father's final gift to me: the chance to see him as something more than my father; the chance to see the common identity of spirit we both shared; the chance to see just how much that makes possible in the way of love and comfort. And I feel I can call on it now with anyone else. [314]

It seems that the most familiar models of who we are – father/daughter, physician/patient, care-giver/care-receiver – often turn out to be obstacles to the expression of serving; they limit the fuller measure of what I have to offer the other.[315] When I break through the barriers, therefore, and meet the other in a unity that transcends the separateness, I experience profound moments of compassion.[316] These moments give me access to increasingly deeper levels of generosity.

The painful moments are those times in which I feel cut off from the other, when I reach out to help but do not connect. Despite the yearning of the heart, I try to help the other, but I still feel alienated. It is to myself, then, that I must look in an effort to see what limits the expression of my serving instinct.[317]

However much I may wish to reach out to the other, I am held back by fear and caution – self-protectiveness.[318]I feel nervous, even defensive, about responding to the needs of others, particularly those in pain, and those who may make demands on me, those whose reactions are volatile, and those who may remind me of my own

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[314] Ram Dass and Paul Gorman, *How Can I Help?* (New York, NY: Alfred A. Knopf, 2001), 18-20.

[315] Dass and Gorman, 20.

[316] Dass and Gorman, 20.

[317] Dass and Gorman, 21.

[318] Dass and Gorman, 23.

vulnerability.[319] Consequently, my response to the impulse to serve may simply be a reluctance to get involved.

I may have to contend with feelings of inadequacy.[320] Because I identify myself with my shortcomings, I may feel that I do not have enough, that I am not enough, to help meet the needs of others.[321] I give little because I feel small.

The sense of inadequacy may also lead me to cling to a private agenda.[322] Insofar as I feel lonely, angry, or powerless, I will serve, motivated by a need to secure friendship, vent rage, or gain control.[323] Catering to my own needs, I am less likely to hear what others really need.

Implicit in any understanding of who I think I am is a message to others about who they are.[324] The more I think of myself as a "nurse," the more pressure on the other to be a "patient." The more I see myself as the "helper," the more need for the other to be the "helped." Caught in an image of an isolated self, I end up diminishing the other.[325]

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[319] Dass and Gorman, 24.

[320] Dass and Gorman, 24.

[321] Dass and Gorman, 24.

[322] Dass and Gorman, 25.

[323] Dass and Gorman, 25.

[324] Dass and Gorman, 28.

[325] Dass and Gorman, 28.

With increasing perspective, I see that all of my ego identities, models, and images can be useful, but need not entrap me.[326] I need another vantage point from which to observe who I am.[327] I need to be someone who is together with others.[328]

Now I am a helpful being.[329] What I have to offer others comes from a sense of connection. Beyond all that separates me from others, we are together. I comfort a “sick” child, I console a frightened sufferer, or I offer to push a wheelchair for a disabled senior. I feel I am a vehicle of kindness, an instrument of love. There is more to the expression of serving, however, than the deed or the doer; I feel myself transformed and related.[330]

The expression of my serving changes.[331] I am less fearful, more trusting. I am less cautious, more venturesome. I am less self-conscious, more other-regarding. This awareness gives me a greater capacity to listen to others and to hear what is really needed. In short, the expression of my serving is less a function of personal motive and more an expression of spontaneous and appropriate caring.[332] Now it is not so much “me” helping “you” but “we” helping “us.”[333]

Now when I hold a scared child or hear the grief of a stranger or bandage the wound of an angry teen or sit with a dying friend, I make it possible for them to feel in who I am

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[326] Dass and Gorman, 34.

[327] Dass and Gorman, 34.

[328] Dass and Gorman, 38.

[329] Dass and Gorman, 38.

[330] Dass and Gorman, 39.

[331] Dass and Gorman, 46.

[332] Dass and Gorman, 48.

[333] Dass and Gorman, 49.

the reassurance that they are not isolated, lonely, cut-off beings. They can feel the solace that we are in this together.

The Gravy of Life

In the course of my ministry I have often wondered why the ministerial Book of Services does not have a ritual or ceremony of recovery. The ritual could celebrate rebirth. For example, my friend Dick, after heart surgery, had an angiogram that showed all of his arteries working normally. The event could have been given a ritual value. Healthcare professionals, however, reduced the significance of the angiogram to the end of an incident, a disruption, a breakdown; it was not an occasion for change, rebirth, or renewal.

A problem with the view of recovery as the end of illness is that some do not recover at all (i.e., they die) or do not fully recover (i.e., they are in remission).[334] The better response seems to be to focus less on recovery as regaining a past state of health and more on renewal as moving forward to the best state of health possible.[335] I need to live illness, think about it and talk about it, in order to accept it but not to become attached to it.[336] Accepting illness is never easy because illness leads me to live differently. The answer to illness is to enter into the experience of illness, discover it possibilities, let it go, and move on.[337]

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[334] Frank, *At the Will of the Body*, 2.

[335] Frank, *At the Will of the Body*, 2.

[336] Frank, *At the Will of the Body*, 2.

[337] Frank, *At the Will of the Body*, 2.

Now let me recount the renewal experience in the writings of the late Raymond Carver. It is a poem entitled *Gravy*.[338]

> No other word will do. For that’s what it was. Gravy. Gravy, these past ten years.
>
> Alive, sober, working, loving and being loved by a good woman. Eleven years ago he was told he had six months to live at the rate he was going. And he was going nowhere but down. So he changed his ways somehow. He quit drinking! And the rest? After that it was all gravy, every minute of it, up to and including when he was told about, well, some things that were breaking down and building up inside his head. “Don’t weep for me,” he said to his friends. “I’m a lucky man. I’ve had ten years longer than I or anyone expected…Pure gravy. And don’t forget it.”

It is hard for me to experience health without making it a condition of my life.[339] It is hard for me to experience illness without being discontented at not having my health.[340] In recovery, however, I do not seek health but rather the renewal of life. In recovery, I do not fear illness or death, yet I know either might happen any day. What then is the meaning of recovery? With Carver, I call it “gravy.”

Gravy is beyond health and illness.[341] Indeed, it is even beyond the desire for health.[342] Gravy is the wonder of just being alive. It is the strangeness of living with contingency. It is the knowledge of living with vulnerability. Secure in the understanding that I am dust, I enjoy life to the full.

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[338] Raymond Carver, *A New Path to the Waterfall*. (New York, NY: The Atlantic Monthly Press, 1989), 118.

[339] Frank, *At the Will of the Body*, 21.

[340] Frank, *At the Will of the Body*, 135.

[341] Frank, *At the Will of the Body*, 140.

[342] Frank, *At the Will of the Body*, 140.

Gravy is the realization that life is a gift with the capacity to choose how I live each day, however limited my choices.[343] It is the solitary experience of watching the sunrise and sunset, communing with and meditating on the spirit of life. It is the social experience of being with my family and friends, talking and listening, laughing and crying, touching and being touched.

When I can imagine the sunrise and sunset without me, however, then my life rests in a world beyond me and I know I can die.[344] When I can imagine my family and friends finding pleasure in life and each other without me, then I know I can die.[345]

Recovery needs a ceremony, a ritual that shows how life can be born anew.[346] For example, the CAT scan with shrunken tumors, the intravenous line being pulled out, the last chemo treatment, could be passages through real and symbolic interventions in preparation for a life enhanced by that passage.[347] The rite could mark the patient as having moved through the experience of illness into the experience of life as renewal. Call it gravy!

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[343] Frank, *At the Will of the Body*, 138.

[344] Frank, *At the Will of the Body*, 141.

[345] Frank, *At the Will of the Body*, 141.

[346] Frank, *At the Will of the Body*, 129.

[347] Frank, *At the Will of the Body*, 131.

CHAPTER 4

AN EXPERIENCE OF ILLNESS: PAIN AND SUFFERING

The Experience and Expression of Pain

Pain: A Phenomenological Perspective

In the month of August, 1999, I was seized by a chronic migraine. In the first five years after being struck with the intractable condition, a large part of my life was consumed by pain. Those who knew me well knew that I was in pain. How did they know? How did I communicate my pain? They told me that my face was drawn, my eyes were dim, and my words were occasionally slurred. Those who did not know me well seemed to detect nothing.

A superficial interpretation of the description of my demeanor implies that the way to *know* someone is in pain is to read clues from the nuances of behavior. Of course, I experienced pain even if no one noticed it. It is also true that I became adept at assuaging the expression of my pain. In any case, my pain illustrates the problem of an epistemological inquiry into pain: How do I *know* that someone is in pain? In both the past and present, the response appears to hinge on a distinction between pain experience (i.e., sensation) and pain behavior.[348]

In noting how sensation and behavior are discrete, Calvin Schrag, Professor of Philosophy at Purdue University, draws attention to the vocabulary of pain. Alluding to the pains of sensation, Schrag lists "dull, leaden, gnawing, sharp, shooting, jabbing, and

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[348] Calvin O. Schrag, "Being in Pain" in *The Humanity of the Ill*, Victor Kestenbaum, ed. (Knoxville, TN: The University of Tennessee Press, 1982), 103.

throbbing."[349] Terms which are used to describe pain behavior are "wincing, grimacing, sighing, moaning, groaning, lamenting, crying, screaming, and writhing."[350] The vocabulary does seem to recognize some difference between internal sensations and external behavior. Does the study of words, however, really help to answer my question: How can I *know* that someone is in pain?

Historically, both René Descartes and David Hume addressed the subject of an epistemology of pain.[351] For Descartes, the perception of pain is "a clear but not distinct idea"; it is not distinct because of "the obscure judgments about its nature."[352] For example, the pain sufferer blends and confuses the perception of pain with other perceptions, such as the perception of something existing in the part affected. So the perception of pain does not stand alone; it involves having other perceptions. In sum, the perception of pain is a conception, involving claims, however obscure, about its nature and location. For Hume, the perception of pain is an "original impression" or an "impression of sensation," which happens in the immediacy of sensing.[353] Knowing that one is in pain, therefore, is to be construed as a direct, non-mediated acquaintance with a condition.

In our day, this thinking has led to behaviorism (knowledge based on the observation of *external behavior*) and introspectionism (knowledge based on the immediate sensation

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[349] Schrag, 103.

[350] Schrag, 103.

[351] Schrag, 107.

[352] R. M. Eaton, ed. *Descartes Selections*. (London: Scribner's, 1927), 272.

[353] David Hume, *A Treatise of Human Nature*, ed. L. A. Selby-Bridge. (Oxford: Clarendon Press, 1955), 215.

of an *internal condition*).[354] Ostensibly, behaviorism provides a more straightforward account of the matter of knowing that someone is in pain. One *knows* someone else is in pain by observing his or her external behavior – wincing, moaning, groaning, and so on. It was in this manner that those who knew me knew when my migraine pain was severe. Introspectionism encounters difficulty in offering a viable account of how anyone would have *known* that I was in pain.

In introspectionism, is there not an implied distinction between the act of perceiving and that which is perceived (i.e., the pain)? Furthermore, if pain has reality only by being perceived, then is there not a reduction of the external to the internal? Even though I think behaviorism has the stronger position, it is not without criticism. Opting for knowing pain in terms of external reactions, does behaviorism not need some way of distinguishing feigned pain from genuine pain? How is it possible to even attempt this distinction apart from an appeal to inward mental activity?

In any case, a more fundamental problem for me in both behaviorism and introspectionism is the metaphor of external and internal;[355] it is too narrow, too ambiguous, too abstract. What I need is a metaphor that will put pain in the framework of human life.[356] What I propose, therefore, is a new metaphor, "the *sphere* of pain." I will attempt to show how the notion of the *sphere* of pain can bring about a fresh perspective to *knowing* that someone is in pain. This view changes the features which characterize pain to: 1) consciousness, 2) embodiment, and 3) attitude.[357]

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[354] Schrag, 109.

[355] Schrag, 112.

[356] Schrag, 112.

[357] Schrag, 114.

Included in *consciousness* as a sphere of pain are *sensations* (seeing, hearing, tasting, smelling, touching) and *affects* (e.g., sadness, disquietude, depression, misery, irritation).[358] Pain also has a component in which previous experiences of pain are *remembered* and compared with the present pain[359] (e.g., in my case, the standard of judgment is migraine pain). Through *imagination*,[360] I regard my pain as getting better or getting worse. I *conceive* a throbbing in my head and I know it is the pain of a migraine.[361] The *sphere* metaphor is crucial here, for without it the phenomenon of being in pain suffers the abstraction of a sensation or a feeling. The sphere metaphor provides access to an understanding of pain in its lived concreteness as a configuration of sensation, emotion, memory, imagination, and conception.

The phases of consciousness, moreover, do not comprise a sphere of interiority apart from exteriority. To avoid the internal versus external metaphor, it is necessary, therefore, not only to speak of sensation, feeling, memory, imagination, and conception as interacting modes of consciousness but also to speak of the interacting modes of consciousness as embodied.[362] Embodiment is co-present with consciousness; I speak of embodied consciousness.

Embodiment, then, is a sphere of pain that gives tangible expression to my pain. Usually when I speak of my pain I mention a body part. For example, when someone asks me, “Lynn, *where* is your pain?” I answer, “The pain is *in* my head.” Now I have a

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[358] Schrag, 114.

[359] Schrag, 116.

[360] Schrag, 116.

[361] Schrag, 116. I am confused. I speak of a head*ache*. Why do I not speak of a head *pain*? The precise difference eludes me.

[362] Schrag, 117.

problem with the use of the preposition *in* when I talk about the *location* of my pain. Specifically, my dilemma is in thinking of my body as simply an external object, composed of parts.[363] Attending to the sphere metaphor, however, my body is a totality, exhibiting a structure of meaning.[364] As a result, I think of the throbbing in my head not as taking place in some isolated body part but as constitutive of meaning. For example, some people tell me, "Lynn, you are always smiling"; but my smile separated from the concrete embodiment of my face ceases to have the meaning of a smile. Similarly, when I am in pain, I am probably grimacing which, without the concrete embodiment of my face, ceases to have the meaning of a grimace. Grimacing is *not* an external sign of an inward condition; my pain is *in* my grimacing face as affection is *in* my smile. My grimacing face comports the meaning of my *being in pain*.[365] *Being in pain* is a *sign* of pain, *not* its *location*, and it is manifested within the spheres of consciousness and embodiment.[366] It is not that my face, eyes, and speech indicate my migraine pain; rather, my being in pain is felt in certain concrete bodily signs.

Consciousness and embodiment are still abstractions from a wider experience of mundane preoccupations. Embodied consciousness emerges only against a broader background of a natural and social world of human action and communication.[367] My lived body is the base of operation from which the world is experienced, from which I

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[363] Schrag, 118.

[364] Schrag, 118.

[365] Schrag, 118.

[366] Schrag, 119.

[367] Schrag, 119.

project my actions, and from which I communicate with the other. Now I need to speak of another sphere; it is *attitude*.

Being in pain, therefore, also requires for its understanding a wider context of world perception.[368] My being in pain assumes a certain stance in the world. Pain is a way of living in the world against a background of attitudes and values to be assumed and projects and goals to be realized. My point is made by British Philosopher Patrick L. Gardiner, "It seems important to recognize the degree to which the notion of pain…is embedded in our conception of what it is to be a human being."[369] Being in pain is living through pain within a situation, involving attitudes, values, projects, and goals.

I think of a professional hockey player who continues to play the game despite the pain of an injury. His attitude is that the game must be won whatever the personal cost. His attitude transfigures the pain in such a way that the pain becomes peripheral to winning the game. Indeed, I have heard such hockey players speak after the game about being so filled with a sense of "goal" (i.e., purpose) that they did not even notice the pain. The point of my illustration is to show that attitudes, values, projects, and goals are intrinsic rather than extrinsic features of being in pain. Attitude, therefore, needs to be understood not as being added to pain; rather, attitude shapes the meaning and expression of pain.

Pain and Suffering: A Phenomenological Distinction

In his discussion of the nature of suffering, Eric Cassell, Clinical Professor of Public Health at Cornell University Medical College, asseverates: "Although pain and suffering

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[368] Schrag, 120.

[369] Patrick L. Gardiner and R. M. Hare, "Pain and Evil," in *The Aristotelian Society, Vol. 38,* 1964, 108-109.

are closely identified in the minds of most people and in medical literature, they are phenomenologically distinct."[370] On the one hand, Cassell explains that it is possible for patients to be in *much pain* and yet *not suffering* when they *know* the source of their pain.[371] On the other hand, Cassell believes that patients may have *much suffering* and *little pain* when they *do not know* the source of their pain.[372] In such situations, perhaps, healthcare staff has a responsibility to listen to patients, no matter how much time is required.

Cassell summarizes the phenomenological distinction between pain and suffering this way: "People in pain frequently report suffering when they feel out of control, when the pain is overwhelming, when the source of pain is unknown, when the meaning of pain is dire, or when the pain is apparently without end."[373] The relation of pain to suffering is suggested by the fact that suffering can usually be relieved in continual pain by making known the source of pain, by changing the meaning of pain, by demonstrating that pain can be controlled, or that pain is not endless.[374]

The World and Language of Pain and Suffering

A World Unsharable and Un-made

Elaine Scarry, Professor of English at the University of Pennsylvania, in a brilliant exploration of pain, avers that pain is ultimately unsharable: "Pain comes unsharably into

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[370] Eric J. Cassell, *The Nature of Suffering*. (New York, NY: Oxford University Press, 1991), 35.

[371] Cassell, 35.

[372] Cassell, 35.

[373] Cassell, 36.

[374] Cassell, 36.

our midst as at once that which cannot be denied and that which cannot be confirmed."[375] Intense pain, according to the substance of Scarry's thought, "un-makes a world."[376]

What, however, does Scarry mean by using the term "world" in the context of pain? In what way is the world of pain an "unsharable" world? How can pain be said to "un-make" the world of the pain sufferer?

I am helped to understand Scarry's concept of "world" by Edmund Husserl, Father of Phenomenology. He speaks of "the life world" (*lebenswelt*) as the world of my common and immediate lived experiences.[377]

One of the basic assumptions of "the life world" is that my experiences are shared by others.[378] When I am racked with pain, however, this assumption seems to be impugned. My world of pain is experienced as a world that others cannot fathom. Indeed, others may believe my world of pain is illusory. For me, as a pain sufferer, nevertheless, pain is a vital reality, dominating my experience and expression. As Scarry phrases it: "Pain monopolizes language, becomes its only subject: complaint becomes the exclusive mode of speech."[379] The usual suspension of skepticism which allows me to accept the other's account of the life world is withheld from the account of the pain sufferer.[380] Consequently, my world as a pain sufferer is threatened with being "un-made."

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[375] Elaine Scarry, *The Body in Pain*. (New York, NY: Oxford University Press, 1985), 4.

[376] Scarry, 29.

[377] Gero Brand, "Intentionality, Reduction, and Intentional Analysis" in Husserl's later manuscripts, in *The Philosophy of Edmund Husserl and Its Interpretation*. J. J. Cockelmans, ed. (Garden City, NY: Doubleday, 1967), 197-217.

[378] Alfred Schutz, "On Multiple Realities" in *Collected Papers I: The Problem of Social Reality*, Maurice Nathanson, ed. (The Hague: Martinus Nijhoff, 1971), 216.

[379] Scarry, 54.

[380] Schutz, 229.

Even the structures of the life world – time and space – begin to dissolve, according to Alfred Schutz. He declares that in the life world the *experience* of time is synchronized with *chronological* time.[381] Pain slows experienced time and accelerates chronological time.[382] Space is overwhelmed by pain and the private world of the pain sufferers loses its relation to the world of others.[383]

In sum, pain floods my consciousness, dominates my time, and severs the relationships between myself and the experienced life world, producing profound isolations. In this way, the world of the pain sufferer is a world "un-made."

Even though my experience of pain is generated by my body, it is also constituted by my body's relationships. First, I believe that the dichotomies I have found present in medical ideology (e.g., nature/spirit, mind/body, objective/subjective) and the response of medical professionals to pain springing from these conceptual separations, manipulates the pain experience of many pain sufferers.[384] That which is objective and observable is juxtaposed with that which is subjective and spoken. As a result, pain tends to be marginalized in the practice of biomedicine.[385]

Second, according to a journal article on depression and somatization, W. Katon and others indicate that "in the United States, pain has become a common idiom for

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[381] Schutz, 218-222.

[382] Schutz, 218-222.

[383] Schutz, 218-222.

[384] Mary Jo Good, Paul E. Brodwin, Byron J. Good, and Arthur Kleinman, eds., *Pain as Human Experience*. (Berkeley, CA: University of California Press, 1992), 11.

[385] Good, et al., 3.

communicating personal and interpersonal problems."[386] Depression, anxiety, tensions, and conflicts, are all conducive to the onset or exacerbation of pain.[387] Pain complaints, therefore, include painful relationships and painful experiences.[388] Consequently, "a range of meanings expressed in pain are anger, loss, failure, and fear."[389]

Clearly, the condition of pain creates a double bind for the pain sufferer. Pain is a personal experience, and even those closest to the pain sufferer cannot observe or share the suffering; it is "unsharable." Pain sufferers have no means to establish the validity of their pain for healthcare professionals, family members, or friends. What is privately indubitable to the pain sufferer is publicly incredulous to the observer. The outcome is a pervasive distrust that tends to undermine the communication and relationships of the pain sufferer.

A World Incoherent and Coherent

Arthur Frank, Professor of Sociology at the University of Calgary, places the world of pain in the darkness: "In the darkness, the world of those in pain becomes incoherent…language goes wrong."[390] Frank attempts to use the metaphor "face to face,"[391] only to find that the symbol "distorts the experience."[392] Although at first he thinks that in the darkness of night he comes to know pain "face to face" and thereby is

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[386] W. Katon, A. Kleinman, and G. Rosen, "Depression and Somatization: A Review" in the *American Journal of Medicine*, 1982, 72:127-134.

[387] Good, et al., 5.

[388] Good, et al., 5.

[389] Good, et al., 5.

[390] Arthur Frank, *At the Will of the Body*. (Boston, MA: Houghton Mifflin Company, 1991), 30.

[391] Frank, *At the Will of the Body*, 30.

[392] Frank, *At the Will of the Body*, 30.

able to give it coherence, it slowly dawns on him that pain "is not a presence."[393] The reality with which Frank needs to come face to face is that giving pain a face "only muddles things."[394] He cannot hoodwink himself. In the darkness of night he faces only himself.[395]

In ministry, I have encountered a number of patients who have spoken to me about a feeling, in pain, of being taken over by "someone" or "something" that is spooky. It appears that the human response to an experience of threat is to create a mythology of what frightens us. Is not pain turned into an "adversary," an "ogre," a "malevolent ghost," a "monster"?

It is noteworthy that Frank does make the turn from the fanciful to the real: "Pain has no face because it is not alien. It is from myself. Pain is my body signaling that something is wrong. It is my body talking to itself."[396]

How then can a patient regain "coherence?" I suggest that, if "incoherence" begins in darkness and isolation, to recover "coherence" is to find a way out of the shadows and loneliness.[397] Frank illuminates his pivot in this manner: "Although I never discovered a formula for dealing with pain, I did break through its incoherence…I found a way back to those from whom I was separated…I saw beauty where there only seemed to be darkness."[398]

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[393] Frank, *At the Will of the Body*, 30.

[394] Frank, *At the Will of the Body*, 30.

[395] Frank, *At the Will of the Body*, 30.

[396] Frank, *At the Will of the Body*, 31.

[397] Frank, *At the Will of the Body*, 31.

[398] Frank, *At the Will of the Body*, 31.

Both encounters with others and with beauty have also been effective for me in dealing with the pain of migraine. Whenever, in pain, I have attempted to reunite myself to others and communicate with them, life is coherent. Whenever, in pain, I have been surprised by beauty, life is coherent. The sense and expression of being with others and of seeing beauty all around me has been to profoundly care. Others, beauty, and caring – those are feelings that have made the pain of a migraine, despite analgesics, an experience with which I can live coherently.

A World Metaphorical and Rhetorical

Although Scarry speaks of the world of pain as "unsharable" and Frank as "incoherent," other writers employ metaphorical language in an attempt to understand pain. Indeed, I myself have described the feeling of migraine pain as being like that of a jackhammer. What I mean by that figurative use of language is that my head*ache* feels like the *pounding* of a jackhammer. In any other context, headache and jackhammer have nothing in common. When I as a migraine sufferer invoke this imagery, however, I am able to make my pain intelligible.

I use rhetoric when I want to reveal my emotions of having a migraine to others in order to convince them to act toward me in a certain way.[399] I have discovered that by drawing attention to my symptoms, I can avoid unpleasant activities or gain sympathy.[400] For example, I realize that my migraine has suddenly worsened on the day of a planned visit to some disliked in-law.[401] On a more positive note, rhetoric also allows a broader

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[399] Good, et. al., 78.

[400] Good, et. al., 78.

[401] Good, et. al., 78.

interpretation of my pain and helps me to communicate my needs and wants in social relationships.[402] Germane to my present emphasis is the notion of "performance." Erving Goffman thinks of "performance" as the presentation of the self in everyday life.[403] Because much of my personal identity arises from the reactions of people around me, I attempt to influence the impact I make on others through what Goffman calls, "impression management."[404] By controlling the information that others have about me, I try to project a certain "performance."[405]

This concept of "impression control" is especially important for me in migraine pain. After all, as I indicated above, even for those who know me well there are few visible signs of pain. Indeed, the only *certain* indication of pain is through the words I use to refer to my pain. Consequently, as one in pain I must constantly decide what to say and to whom to say it.

As a pain sufferer, I am very aware of "self-presentation."[406] This *does not* imply, however, that my pain is a performance (i.e., a pretense). It does mean that I have a growing awareness of when to hide and when to reveal my pain in conversation and interaction with others.[407]

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[402] Good, et. al., 78.

[403] E. Goffman. *The Presentation of Self in Everyday Life*. (Garden City, NY: Doubleday, 1959), 17.

[404] Goffman, 208.

[405] Goffman, 209.

[406] Goffman, 252.

[407] Goffman, 70-74.

The Meaning of Suffering?

Contextual and Incarnational

I think that pain and suffering have meaning when they can be seen as part of a larger whole (i.e., a fuller humanity), and in such a way that they constitute, in some measure, the unity of the whole.[408] The whole also has meaning as a unity and not just as a collection of parts.[409] In the process of thinking, for example, "ideas" incarnate themselves in "words." Already in this stage, ideas are not just images; they are concepts that participate in meaning.[410] Similarly, words are not just sounds; they are also conveyors of meaning.[411] To continue my contextual and incarnational understanding of meaning, a word has meaning in a sentence, a sentence in a paragraph, a paragraph in a story, and a story in a human life.

Pain and suffering are a problem only if I believe that the world is shaped by meaning.[412] If I attribute everything to chance and necessity, pain and suffering are neither alarming nor cause for concern.[413] Since the problem of pain and suffering cannot logically exist for the one who does not believe in meaning, ubiquitous concern over the problem of pain and suffering (e.g., Why me? Why pain and suffering?) is an impressive

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[408] John Macquarrie. *The Problem of God*. (London: SCM Press, 1975), 77.

[409] Macquarrie, *The Problem of God*, 77.

[410] Macquarrie, *The Problem of God*, 78.

[411] Macquarrie, *The Problem of God*, 78.

[412] David Elton Trueblood. *Philosophy of Religion*. (New York, NY: Harper and Row, 1957), 232.

[413] Trueblood, 232.

piece of evidence.[414] The fact that the demand for meaning is so widespread is an indication of how universal belief in meaning may be.[415]

The meaning of pain and suffering may be seen in various forms – physical, mental, moral, and vicarious.[416] All of the information is useful in communication about pain and suffering.

Physical pain is an alarm that something is amiss with my body.[417] The pain is an integral aspect of my experience and I am grateful for pain alerting me to this bodily malfunction. Furthermore, the fact that I have known *some* pain makes it possible for me to feel compassion for others who know pain; including those who know *more* pain than me.[418] In this way, pain and compassion contribute to human solidarity.[419] Then, too, I have known some who, through suffering horrific, constant, and debilitating pain, have learned to become patient, gentle, and understanding, to an extraordinary degree.[420] Of course, I have also known some who have not been able, through suffering, to transform their lives but have been broken and even defeated by pain.[421]

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[414] Trueblood, 232.

[415] Trueblood, 232.

[416] John Macquarrie. *In Search of Humanity*. (New York, NY: Cross Road Publishing Company 1983), 225.

[417] Macquarrie, *In Search of Humanity*, 226.

[418] Macquarrie, *In Search of Humanity*, 226.

[419] Macquarrie, *In Search of Humanity*, 226.

[420] Macquarrie, *In Search of Humanity*, 226.

[421] Macquarrie, *In Search of Humanity*, 226.

A second form of suffering is mental pain.[422] In mental pain my pattern of life is thrown into confusion. Hopes are cheated. I feel frustration and deprivation, failure and loss.[423] There are also benefits from this pain. If I never experienced a setback, would I facilely form an exaggerated estimate of my capabilities?[424] Is not a significant step to personhood the knowing and accepting of my limitations? Is it possible that, through the suffering of mental pain, I am being brought to a proper self-understanding? Still, I believe that there are some cases of frustration, deprivation, failure, and loss that are so disastrous that I cannot justify them.[425]

Moral pain is a third form of suffering.[426] Moral pain may be understood as a kind of uneasiness, either as a deterrent from contemplated wrongdoing or as a result of actual wrongdoing.[427] In short, it is an uncomfortable, unpleasant feeling against speech and actions that diminish my humanity.[428] Often, however, guilt feelings are infantile and excessive, resulting in torment, paralysis, and a feeling of culpability out of proportion to the anticipated or actual peccadillo.[429] Indeed, sometimes guilt feelings may be totally unnecessary[430] (e.g., churchgoers who have tried to make me feel guilty for not being healed from my intractable migraine condition). As a result, whenever anything comes up

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[422] Macquarrie, *In Search of Humanity*, 226.

[423] Macquarrie, *In Search of Humanity*, 226.

[424] Macquarrie, *In Search of Humanity*, 226.

[425] Macquarrie, *In Search of Humanity*, 227.

[426] Macquarrie, *In Search of Humanity*, 227.

[427] Macquarrie, *In Search of Humanity*, 228.

[428] Macquarrie, *In Search of Humanity*, 228.

[429] Macquarrie, *In Search of Humanity*, 227.

[430] Macquarrie, *In Search of Humanity*, 227.

in communication that arouses a sense of guilt, I am apt to retreat, or come back with a counter-accusation.

I believe that if I learn to deal with guilt I can communicate more successfully. This means learning to accept guilt when it belongs to me and refusing it if it does not.[431] Consequently, I need to discuss the difference between *true* guilt and *false* guilt.

False guilt stems from an accusing voice.[432] When I hear it, it is like listening to thoughts that criticize and judge me, that put me down.[433] It can be likened to a judge who hears my speech, observes my actions and, at the slightest opportunity, jumps in with a negative comment.[434]

So, how can I overcome the negative effects of the accusing voice? First, it helps to identify the accusing voice.[435] Second, I need to pay close attention to the accusations so that I can identify exactly what the accusations against me are; no more do I deal with vague feelings of guilt![436] Third, I can share the accusations with another trusted person, a fellow human being with whom I can speak frankly without fear of being judged.[437] This also relieves my sense of isolation and helps me feel accepted.[438]

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[431] John A. Sanford. *Between People*. (New York, NY: Paulist Press, 1982), 61.

[432] Sanford, 61.

[433] Sanford, 61.

[434] Sanford, 61.

[435] Sanford, 62.

[436] Sanford, 61.

[437] Sanford, 63.

[438] Sanford, 63.

Real guilt stems from a correcting voice.[439] Whereas the accusing voice is destructive, the correcting voice is constructive.[440] Painful though such corrections may be, they lead to a true humanity.[441] For these corrections come from a violation or deviation from my true being.[442] I really am guilty when I go against my own nature. The redeeming fact is this: While false guilt disintegrates my personality, true guilt integrates me.[443]

Suffering may also be vicarious.[444] The many links that bind me in the solidarity of society require that, even though I may remain relatively untouched by suffering, I cannot stay unscathed by the suffering of others.[445] To the extent that I am unaffected by human suffering, I am callous.[446] On the other hand, the suffering of others can awaken in me feelings of compassion and solidarity.[447]

The crux of the matter is that suffering is not a *total* evil, for it can be integrated into the character of the sufferer in such a way as to make a contribution to a fuller humanity.[448] Is this realistic however? Why should we not make every effort to eliminate suffering? Given the powers of science and technology, why not sweep away this mass of human misery? Is there not something morbid and masochistic in the claim that suffering

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[439] Sanford, 64.

[440] Sanford, 64.

[441] Sanford, 64.

[442] Sanford, 64.

[443] Sanford, *Between People*, 64.

[444] Macquarrie, *In Search of Humanity*, 228.

[445] Macquarrie, *In Search of Humanity*, 228.

[446] Macquarrie, *In Search of Humanity*, 228.

[447] Macquarrie, *In Search of Humanity*, 229.

[448] Macquarrie, *In Search of Humanity*, 229.

is not *all* bad? On the other hand, what would it be like if we succeeded in getting rid of suffering? Would this not be like living in a cocoon? Is *that* realistic? Sentience (i.e., the ability to perceive or feel) opens to us the possibilities of suffering and meaning in suffering. Suffering cannot be abolished short of a lapse into pre-sentience, but suffering can become, according to Philosopher Jean-Paul Sarte, an "adversary co-efficient"[449] (i.e., suffering is an additional agency in the drive for the meaning of life).

Contrariwise, suffering can become so vehement, so relentless, and so disabling that it dehumanizes and disintegrates the life of the sufferer in such a way as to decrease the meaning of life. What do I say? I am speechless. Yet my loss for words is not the taciturnity of despair; it is, rather, the silence of realizing the mystery of life.[450]

Significantly, I have noticed a correlation between the maturity of the sufferer and the capability for suffering. Those who close themselves in heartless indifference become incapable of suffering with others. Those who open themselves in self-sacrificing love are especially vulnerable to the suffering of others. If those who have fallen into apathy and even cruelty become numb, losing a capacity for suffering, it is conceivable that the more mature the human being, the greater the capacity for suffering (e.g., as I have grown as a human being, I have discovered in my encounters with the suffering that I increasingly *know* when to be silent and when to speak).

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[449] Jean-Paul Sarte. *Being and Nothingness*. (New York, NY: ET Methuen, 1957), 495.

[450] Macquarrie, *In Search of Humanity*, 231.

Denial and Blame

The denial of suffering is rife in my pastoral ministry. It begins with the premise that "whatever happens, happens for a reason." Then there is a search for someone or something to blame.

I have found that the most common attitude that refuses to accept that suffering happens and insists on rationalization is that of *entitlement*.[451] The notion is: If I suffer, the suffering is not my fault. I, therefore, deserve compensation. Although it may appear that I am to blame for my suffering, I will produce mitigating circumstances. Someone or something else is *really* responsible for my suffering.

The assumption is that I am entitled to the good life:[452] "Someone or something else must be shown to have deprived me of the good life I deserve. Therefore, he, she, or it *owes* me."[453] In my ministry, I have suggested the idea of being *unlucky*. It is rarely acceptable. The sufferer's thinking is this: Although I would rather be down on my luck than culpable for my suffering, I would still rather blame someone or something else.

The comments of Robert Solomon, Professor of Philosophy at the University of Texas (Austin), are enlightening:

> We live with other people in a society such that they can be held responsible for what they do. Within that social context, we are right to be offended, angered, resentful, and even punitive when they cheat us. But we also live in and are sometimes confronted by an indifferent universe. This is a very different context. We say that nature cheats us, but we realize that we have moved to the land of metaphor. Nature doesn't cheat. There is no one to blame.[454]

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[451] Robert C. Solomon and Fernando Flores. *Spirituality and the Skeptic*. (New York, NY: Oxford University Press, 2002), 80.

[452] Solomon and Flores, *Spirituality and the Skeptic*, 80.

[453] Solomon and Flores, *Spirituality and the Skeptic*, 80.

[454] Solomon and Flores, *Spirituality and the Skeptic*, 80.

Suffering, by its very nature, cannot be fully explained. Suffering, therefore, involves giving meaning to that which cannot be completely described.[455] In suffering, even my best interpretations are denial, a refusal to accept the hard facts of human life.[456]

Another popular strategy of accounting for suffering is "the problem of evil."[457] The enigma is a "why me?" reaction to my undeserved misfortune.[458] When I react to the unmerited adversity of others, the quandary is simply "Why? Whether I am a theist or atheist, I have a predisposition to personify the world and expect justice.[459]

Actually, the problem of evil turns out to be yet another attempt to blame or to claim entitlement.[460] It is apparent that bad things happen to good people and good things happen to bad people. In response to this conundrum, I find many who have subscribed to the theory that there will be justice in a life beyond death.

Solomon's conclusion, I think, is both intellectually and morally tenable: "To challenge the problem of evil, we need not call into question either the nature and existence of God or the belief in an afterlife. To challenge the problem of evil we must rather remind ourselves of the contingency of our good fortune and how unreasonable we are to deny the inevitability of misfortune."[461]

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[455] Solomon and Flores, *Spirituality and the Skeptic*, 80.

[456] Solomon and Flores, *Spirituality and the Skeptic*, 80.

[457] Solomon and Flores, *Spirituality and the Skeptic*, 81.

[458] Solomon and Flores, *Spirituality and the Skeptic*, 81.

[459] Solomon and Flores, *Spirituality and the Skeptic*, 81.

[460] Solomon and Flores, *Spirituality and the Skeptic*, 82.

[461] Solomon and Flores, *Spirituality and the Skeptic*, 83-84.

Finitude and Perspective

In much of my Judeo-Christian faith, misfortunes are my own fault. Consequently, the meaning of suffering is punishment. A notable exception, however, is the unwarranted suffering of Job.

According to the orthodox viewpoint of the time, if one suffered, it must be the result of one's own sins, known or unknown, admitted or hidden. The remedy was to repent and implore God for mercy. It is this facile solution to the issue of suffering which the poet of the drama of Job rejects. Job is shown to be a virtuous man and yet is the victim of appalling disaster. The elaborately constructed attack by Job's three friends represents the conventional belief. Job demands justice, boldly questioning why the bad prosper and why misfortune has happened to him.

In the end, Job humbly acknowledges his finitude. His friends have been so concerned to defend the traditional dogma that they have bludgeoned Job into refuting a God whom his conscience has rejected as a caricature. Far more than a recognition of innocence, Job's problem has been transfigured by the reality that he is graciously accepted by the creative love of the world whether he is in prosperity or adversity; he is intimately cared for even though he is suffering, lonely, and confused. Overcome by deep sorrow, Job finds peace of mind by unpretentiously accepting his proper place in the scheme of things as a creature living by faith in a world the ways of which are ultimately beyond human understanding.

How then can I find meaning in suffering? I believe there is an answer that does justice to suffering and life. It does not deny suffering. It does not deny that life is unfair.

It does deny that suffering and life are meaningless. The answer lies in my perspective.[462] I often acknowledge my experiences of suffering; I rarely speak about my experiences of pleasure. Why do I so often look for blame, entitlement, victimization? Is there not a better way of looking at suffering and life? I believe it is important not to deny suffering but to affirm it as part of the life I love and for which I ought to be grateful. I am not a Pollyanna person. I do realize the suffering of many people whose lives are so impoverished, oppressed, and filled with suffering that I could not expect them to be grateful. Yet, in my experience, some are! What I need to embrace is a perspective of life as an admixture of fortune and misfortune, gain and loss, blessing and bane. From this point of view, suffering has meaning because life has meaning.[463]

The Overcoming of Suffering

Through Making Meaning

I use the word “overcoming” to indicate process. “Overcoming” does not mean the end of suffering, for there is no way to overcome except through suffering. How, then, can I overcome suffering even as I am living through it?

My answer points to an experience of overcoming through *making* meaning of suffering.[464] I believe that suffering *has* meaning, but meaning is not given with suffering.[465] I *make* meaning through inner talk and talk with others. It is in the context of

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[462] Solomon and Flores, *Spirituality and the Skeptic*, 87.

[463] Solomon and Flores, *Spirituality and the Skeptic*, 88.

[464] Solomon and Flores, *Spirituality and the Skeptic*, 76.

[465] Solomon and Flores, *Spirituality and the Skeptic*, 76.

making meaning that suffering can be shifted away from the center of my life. It is by making meaning that I free myself from the meaninglessness of suffering.

If suffering has meaning because life has meaning, how do I *make* meaning of life? I *make* meaning of life by passionate commitments[466] -- vocational, romantic, religious, social, educational, health. Moreover, if the meaning of life is the meaning I make, I recognize a contingency to my commitments.[467] My commitments are ultimately limited. There is no final answer to the questions, "Why?" or "Why me?"

There is no passionate commitment without rationality.[468] Nor is there any escape from the confrontation between my rational, demanding mind and an indifferent universe.[469] The confrontation, however, can be turned into acceptance.[470] There is no denying suffering, but suffering can have meaning; suffering can have meaning because life has meaning, and suffering is a part of life.

In life, both justice and rationality have limits. In life, I know that bad things happen to anyone. The attitude that is called for, therefore, is not "cosmic chutzpah" (Miguel De Unamuno) or "facing the absurd" (Albert Camus), but adoption of the tragic sense of life.[471] To adopt the tragic sense of life is nothing less than accepting reality.

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[466] Soren Kierkegaard, *Either/Or: A fragment of Life*, trans. Walter Lowrie. (Princeton, NJ: 1944), 55.

[467] Kierkegaard, 55.

[468] Harold Kushner, *When Bad Things Happen to Good People*. (New York, NY: Avon, 1993), 6.

[469] Solomon and Flores, *Spirituality and the Skeptic*, 78.

[470] Solomon and Flores, *Spirituality and the Skeptic*, 78.

[471] Miguel De Unamuno, *The Tragic View of Life*. (New York, NY: Dover, 1954), 29.

Through Suffering Love

Sometimes I meet people who suffer vicariously; that is, they accept others, suffer with them, and give them the possibility of experiencing worth. To understand suffering love, then, is to know it as the care in the world which is manifest in human life.

To believe in suffering love is to be able to say, “I am disabled, deformed, diseased, debilitated, dying; nevertheless, I am accepted and live!” To believe in suffering love is to be able to say, “I am a failure, frustrated, bitter, angry, depressed; nevertheless, I am accepted and live!” To believe in suffering love is to be able to say, “I am guilty, stupid, humiliated, ashamed, misunderstood; nevertheless, I am accepted and live!”

In accepting myself, I face realistically and courageously the threat of relinquishing cherished and superficial images of who I am and also of taking the risk of who I can become. Accepting acceptance, knowing that nothing in my suffering destroys the possibility of being understood by someone who cares, releases power to transform my broken life. First, I accept myself. Second, I accept others. Third, I have an experience of suffering love that I cannot otherwise know.

If only I could believe that the creative dynamic that sustains the world is a love that suffers with me through others no matter what happens to me; if only I could believe that my attitudes, speech, and actions, have an indispensable place in shaping the world; then surely my world of suffering – fears, frustrations, guilt – could give place to a world of faith, love, and hope.

In the Christian tradition, the suffering of Jesus is, above all, vicarious suffering. When Jesus, on the cross, sees his mother and the beloved disciple standing beside her, he says to his mother, “Woman, here is your son.” Then Jesus addresses the disciple, “Here is your mother.”[472] This is a parable of participation with Jesus in his suffering; it is a parable of “dying” with Jesus. Mary and the disciple find in their participation with Jesus in his suffering the basis of a new relationship to each other; they find a new humanity. Under the cross, a new relationship is born, a relationship not based on natural kinship or mutual grief, but a relationship based on sharing in suffering love. By their common exchange of suffering love, Mary and the disciple are saved from the slow burn of self-pity.

That relationship continues in the world today as we share in suffering love for suffering humanity. As such, suffering may be seen as an important part of what makes us truly human.

Through Natural Compassion

Sometimes I am naturally compassionate. It just happens. It seems to be an instinctive, innate reflex. A friend relates his concern to me about the suffering of a family member. I respond immediately. I remind him of the depth of our friendship and of my suffering care. I offer my availability to do whatever I can whenever I may be needed. Nothing in my daily planner will keep me from fulfilling that promise. Because the commitment of care is made naturally, it is easy, effortless, and makes me feel good. I believe I have done the right thing. Above all, it gives me an awareness of relating to a concerned human being in such a way that I can feel the unity. If this is true, however, why am I not naturally compassionate all the time instead of just some of the time?

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[472] John 19:25-27.

Sometimes there is an inner conflict, an ambivalence between an attitude of begrudging coolness and welcoming warmth, between protectiveness and generosity.[473] As a result, on some occasions, I am naturally compassionate and demonstrate my care. Other times, despite knowing the feeling of solidarity that comes from being compassionate, I remain apathetic and uninvolved.

Two men work together for twenty-two years. Then one of them is hospitalized with a debilitating illness, but the healthy one will not visit his suffering co-worker. "He is suffering. He is unsightly I am told. I cannot see him that way." The potential visitor claims that he dreads the experience of seeing his comrade in such a repulsive condition. What really alarms him is his own suffering. The buddy is apprehensive of a day when he might be lying on a hospital bed and racked with suffering. He cannot brook the thought of it. He must stay away from the hospital as long as that decision is in his power.

Another factor in my checkered history of being naturally compassionate is cultural conditioning.[474] I have been taught that when it comes to suffering, *family* is first. After my kin, I may offer my help to the suffering *neighbor* or *friend*. Under no circumstances, however, do I give to the suffering *stranger*.

I live in a community that, at Christmastime, has school children make crafts for the local nursing home residents. The handmade items are then delivered to the nursing home office by a school teacher. Would it not be better if the children were to go to the nursing home and give their gifts in person? Would it not be better if the children themselves could hear and feel the gratitude of the suffering? Would it not, then, be an unforgettable experience for the children as well as the residents?

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[473] Dass and Gorman. 12.

[474] Dass and Gorman, 12.

In a South Indiana town, I served on the Board of Directors for a thrift shop. One day I walked into the thrift store and overheard a young mother poignantly explain to her two small children, “I don’t have the money to get you what you want. Mommy has too many hospital bills from the time she was sick.” I walked to the woman. With sensitivity and compassion, I addressed the issue by offering to pay for what her children wanted. The mother demurred, “You can’t do that. You don’t know me.” I responded empathetically, “I may not know you, but I do know that you are suffering. I would like to help you.” She nodded. I went to the cashier to make arrangements. The cashier quizzed me: “But Lynn, you don’t know her.” I reflected, “Wouldn’t life be so much better if we could overcome our fear of the suffering stranger?” I visualized a world in which we acted without partiality and naturally experienced an impassioned oneness with suffering humanity.

Is not the question finally this: “Who am I to myself and who am I to others?” If I can honestly deal with that question, I may yet discover what it means to express creative and suffering love, to be naturally compassionate, to grow as a human being, to expand my vision, to increase my service; in short, to think, say and do what I really want to think, say and do. The paradox is that the people who are the most resolute in seeking to overcome the world’s suffering are the very ones who have been the most deepened by their struggle with it (e.g., Albert Schweitzer, Mother Teresa).

CHAPTER 5

AN EXPERIENCE OF ILLNESS: DEATH AND DYING

Death Awareness

The Personal Awareness

Louis Wittgenstein once declared, “Death is not an event of life. Death is not lived through.”[475] The word translated “lived through” (in German, *erlebt*) could equally well be rendered “experienced.” It seems clear that my experiences of life are lived through but death is not lived through, for it is the end of life. Even so, Wittgenstein’s understanding of death is too atomistic, as if I were strictly confined to my own private experience. I think John Donne had a more adequate concept of the human when he wrote, “No man (*sic*) is an island, entire of itself; every man is a piece of the continent, a part of the mainland…any man’s death diminishes me, because I am involved in mankind.”[476] Regarding myself as involved in humanity, I share an experience of death in which whatever diminishes the whole is experienced by me as a diminution too.

Furthermore, even if death is experienced vicariously in the death of the other, my own death may already have entered into my experience by anticipation.[477] In my understanding, death is not just that moment when life actually ends, but it is also the

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[475] L. Wittgenstein, *Tractatus Logico-Philosophicus.* (New York, NY: Cosimo Classics, 2007 [1921]), 185.

[476] John Donne, *Complete Poetry and Selected Prose,* ed. John Haywood. (New York, NY: Nonesuch Press, 1927), 536-538.

[477] John Macquarrie, *In Search of Humanity*. (New York, NY: The Crossroad Publishing Company, 1982), 235.

process of dying, and this process has already begun in any human being.[478] Clinical death may well be declared, in agreement with Wittgenstein, to be not an event of life but its end, yet as a human phenomenon death cannot be reduced to the medically certifiable moment. [479] In awareness and expectation as well as in my shared experiences with others, death and dying cannot be excluded from my experience of life and may profoundly affect my understanding and communication of it.

The Social Significance

Many of us, I think, approach death with the self-indulgent thought that my death is bad because it deprives the world of me.[480] Implicit in the reflection on my death is the impression, "Without me, what will happen to them? What will my family and friends do without me? Will someone else replace me?" Already I see myself as a social being. So my death will be a disruption of a network of relationships. It is unnatural to die alone.[481]

When I think of my death, therefore, I cannot help but think how others will see me, think about me, talk about me, remember me.[482] In short, I worry about my reputation. My thinking about death is irreducibly social and interpersonal.

In my advanced society, however, such a notion is all but ignored, perhaps even explicitly denied. For most in my community, I believe, death is something I go through alone. What creates anxiety is my impending nothingness.

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[478] Macquarrie, *In Search of Humanity*, 235.

[479] Macquarrie, *In Search of Humanity*, 235.

[480] Robert C. Solomon and Fernando Flores, *Spirituality for the Skeptic*. (New York, NY: Oxford University Press, 2002), 120.

[481] Solomon and Flores, *Spirituality for the Skeptic*, 120.

[482] Solomon and Flores, *Spirituality for the Skeptic*, 120.

I believe it is so important that I think, no matter how gruesome or undignified my death, that the moment of death is nothing less than the whole story of my life.[483] In place of the "death is nothing"[484] argument, I maintain that it is the passion of life that provokes the pathos of death. I want to live because I love life; I love my family, friends, and my projects, all of which involve others.

In thinking about death, therefore, what I really care about is the people I will leave behind. My concern is not only altruistic, however, it is also self-interest. Death is what individuates me only insofar as it targets the vulnerability of my intimate and significant relationships. In itself, death and dying are not worth celebrating. It is ultimately significant only because my life is significant and my life is significant because I am wrapped up in others.

I may fear death because it will bring the end of my life, but I can appreciate death because I live with others. Indeed, to the extent that I live with others, death is not the end at all.

Death Awareness: The Medical Perspective

Predicting Death

I still have vivid memories of my mother's aborted surgery for a cancerous mass on her pelvis; the cancer had so metastasized that to continue the operation was deemed futile. Concluding her cancer was terminal, my mother's question was whether she would live until Christmas (The surgery was in June). In effect, "How long do I have?"

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[483] Solomon and Flores, *Spirituality for the Skeptic*, 121.

[484] Solomon and Flores, *Spirituality for the Skeptic*, 117-119.

The situation was ineffably sad. My mother, although in her eighty-first year, was so full of life. The surgeon, so competent and committed, was rattled by the question. I regarded his answer as obviously truthful but evasive: "You will die, but I cannot say when." No one better echoes my thinking on this subject than Nicholas Christakis, Associate Professor of Medicine and Sociology at the University of Chicago. Christakis unequivocally states that doctors must frankly answer the question of time of death:

> "Over the course of my clinical training, I came to regard explicit, precise, and compassionate responses to patients' requests for prognosis to be a key part of my role as a physician. I came to see the deliberate assessment of prognosis as absolutely obligatory, even if patients did not happen to ask. I became convinced that establishing the patient's prognosis…should be as routine for me as diagnostic possibilities or considering therapeutic options."[485]

Both in my readings about, and encounters with, physicians, nevertheless, I have found that the prospect of predicting the death of a patient is something that most doctors want to avoid. Surely this is not the only aspect of medical work that is frightening or unpleasant. So why are so many physicians reticent to forecast a patient's death? Why is it so difficult to give a prognosis?

In virtually all of my reading and my conversations with doctors, the answer to these questions is placed within the patients' (e.g., patients do not want to know that they are dying or that truthful information harms patients). While there may well be some truth in both of these claims, the primary answer to the questions lies, in my view, within the physician. Specifically, the principal problem is the physician's thinking about death. The doctor does not want to talk about death and dying; he or she feels uncomfortable with the subject and therefore wants to avoid it. To think and talk about death may cause the doctor to think about the limits of his or her ability to change an outcome, to cure. The

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[485] Nicholas A. Christakis, *Death Foretold*. (Chicago, IL: The University of Chicago Press, 1999), xi.

doctor may wish to deceive himself or herself about the inevitability of death, especially perhaps, his or her own demise.

Christakis avers that he has seen, on various occasions, the avoidance of prognostication or a needlessly optimistic prognosis harm patients.[486] He cites an example.

> The Thursday before my husband died, I thought he was dying and he thought he was dying. But the doctor was talking about aggressive chemotherapy. I asked if this was palliative, and he said that he still hoped for a cure. I was with him at the time of his death (three days later). But the room was filled with eight other people hanging bags of blood and monitoring vital signs…If I had been told the truth, we could have spent days with the children, together, not filled with painful regiments in the hospital.[487]

The doctor did not want to tell the patient or his family that death was imminent. As a result, he encouraged inappropriately an optimistic expectation that was harmful in that it prevented preparation for death.

Given the need to predict death, how does a doctor do it? The best answer I have found is given by Christakis:

> Cogent and compassionate prognostication…is a sensitively delivered and well calibrated best guess about the patient's future. It requires physicians to be as versed in the art of prognosis as they are in diagnosis and therapy, to make strenuous efforts both to learn the state of the art with respect to the prognosis problem presented by the patient and to communicate that knowledge in a way that the patient can comprehend, to the extent that the patient wants this. Moreover, it requires physicians to adopt a broader view of the meaning of hope and to realize that there is much that patients can realistically hope for even if death is imminent and unavoidable. The kind of prognostication I have in mind includes physicians' willingness to spend time talking with patients, assuring them that they will not be abandoned. It entails, finally, the willingness of physicians to act on predictions, despite the risk of error. Such behavior by physicians would reflect the realization that temporizing or self-delusion in

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[486] Christakis, *Death Foretold*, xiii.

[487] Christakis, *Death Foretold*, xiii.

> prognosis can be as harmful to patients as an incorrect diagnosis or a mistaken treatment.[488]

Lying to the Dying

My particular concern here is the vexing dilemmas which confront those in the medical profession who lie to their patients, who do not think that their lies matter, or who think that lying can protect the patient.

According to Sissela Bok, Lecturer on the Core Curriculum at Howard University, some argue that truthfulness is impossible.[489] If this means "the truth, the whole truth, and nothing but the truth," then the fact that truthfulness is not possible is obvious. If the *absolute* truth is the criterion, then I would despair of any *human* communication.

I believe a critical distinction can be made between *truth* and *truthfulness*.[490] The moral question of lying is not determined by whether I speak truth or falsehood; the question is whether I *intend*[491] to mislead or deceive by what I say. The crucial distinction is between *truthfulness* and *deception*.

It is a bogus argument, therefore, to hold that since I can never know *the truth* anyway, it does not matter if I lie. I believe that whenever I attempt to deceive the other intentionally, I am communicating a message that is meant to mislead, to cause the other to believe what I myself do not believe.

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[488] Christakis, *Death Foretold*, xv.

[489] Sissela Bok, *Lying.* (New York, NY: Random House, 1989), 4.

[490] Bok, *Lying*, 6.

[491] Bok, *Lying*, 6-8.

To collapse “truth” and “truthfulness,” moreover, clears the way for lying by “strategically discouraging the question of truthfulness.”[492] Since telling the “truth” is unattainable, the choice of what to say is left to the judgment of the healthcare professional.[493]

This reasoning is also used by medical staff in the case of patients who are regarded as not lucid.[494] Such patients, it is maintained paternalistically, need help in making choices even if it means keeping them uninformed.[495] My conjecture is that very few are incompetent and even they have a right to have someone else receive the information.

The paternalistic assumption holds the danger of contempt for those who are incompetent.[496] In my experience, the patients are usually suspicious that the choices kept from them will be made by healthcare professionals whose motives of helpfulness are mixed with the less altruistic motives of self-protection, manipulation, and control. Indeed, insofar as the professional is not aware of his or her own motives, the judgment of acting benevolently is itself biased and unreliable.[497]

Doubtless, the most extreme form of defending paternalistic lying that I discovered in my reading on the subject is to regard deception as a part of the patient’s treatment.[498] The reasons for distortion or concealment are not to cause the patient unnecessary

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[492] Bok, *Lying*, 227.

[493] Bok, *Lying*, 227.

[494] Bok, *Lying*, 227.

[495] Bok, *Lying*, 227.

[496] Bok, *Lying*, 227.

[497] Bok, *Lying*, 212.

[498] Bok, *Lying*, 221.

suffering or to leave the patient without hope.[499] Besides, why assume the need for truthfulness to patients about their diagnosis, treatment, or prognosis?[500] Given such freedom, medical staff can tell as much or as little as they want the patient to know. Consequently, some healthcare workers feel justified in lying for the good of the patient.[501]

Interestingly, Christakis contends that many of the physicians who perceive deception as therapy would claim not only that a lie can avoid harm for the patient, but that it helps *them* come to terms with many of their fears.[502] Doctors fear that a pessimistic outlook was wrong in the first place.[503] They also fear that disclosing their own fears might reduce faith in the possibilities for recovery.[504] They fear, too, that to speak about risks might result in self-fulfilling prophecy.[505] In addition, there is the fear of an improper use of time.[506] Doctors know that it takes time to discuss a critical illness honestly and sensitively, and this may take time away from patients whose outcomes appear less uncertain.[507] These reasons help to explain further why some doctors of the seriously ill

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[499] Bok, *Lying*, 222.

[500] Bok, *Lying*, 223.

[501] Bok, *Lying*, 226.

[502] Christakis, *Death Foretold*, 116-124.

[503] Christakis, *Death Foretold*, 124-128.

[504] Christakis, *Death Foretold*, 128-134.

[505] Christakis, *Death Foretold*, xx-xxi, 135-162.

[506] Bok, *Lying*, 225.

[507] Bok, *Lying*, 225.

and dying prefer not to be bound by any scruples that might limit their freedom to conceal or misrepresent information.[508]

The problem of lying is still more complex. Doctors are not the only healthcare professionals who work with the dying. In fact, doctors are always in consultation with others, especially nurses. If the doctor chooses to lie, the choice may not have the approval of others who also care for the patient.[509] A nurse, quoted by Sissela Bok, expresses the predicament:

> From personal experience I would say that the patients who aren’t told about their terminal illness have so many verbal and mental questions unanswered that many will begin to realize that their illness is more serious than they’re being told…Nurses care for these patients twenty-four hours a day compared to a doctor’s daily brief visit, and it is the nurse many times that the patient will relate to, once his (*sic*) underlying fears become overwhelming…This is difficult for us nurses because being in constant contact with patients we can see the events leading up to this. The patient continually asks you, ‘Why isn’t my pain decreasing?’ or ‘Why isn’t the radiation treatment easing the pain?’…We cannot legally give these patients an honest answer as a nurse (and I am sure I wouldn’t want to), yet the problem is still not resolved and the circle grows larger and larger with the patient alone in the middle.[510]

Relating to the Dying

Medical interactions with the dying about dying are usually referred to as “the breaking of bad news.” To address this problem, researchers have investigated the experiences of healthcare professionals, patients, and patients’ families in multiple

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[508] Bok, *Lying*, 225.

[509] Bok, *Lying*, 225.

[510] Bok, *Lying*, 226.

medical settings.[511] On the basis of these results, others have developed guidelines for the effective communication of "bad news."[512]

These guidelines assume that medical interactions in which "bad news" is delivered are linear and composed of three phases: preparing to disclose bad news, disclosing bad news, and responding to reactions to the bad news.[513]

I would like to call into question three basic assumptions underlying the guidelines. Then I will offer my suggestions for changes that I believe will enhance their applicability.

The initial assumption is that healthcare professionals can plan a bad news interaction before it happens.[514] My question is based on the concept of "bad news." In my understanding, "bad news" is information that produces a negative alteration to a patient's expectations. "Bad news," moreover, is always a subjective evaluation by the patient receiving it. I might conjecture, therefore, that virtually any news has the potential to be bad news. This means that the evaluation may not be predicted by an objective source before the information has been disclosed. While I need to allow for the possibility of information that may be universally appraised as bad news (e.g., the sudden death of a child), most information is assessed as positive or negative within the context of a patient's expectations and values. This accounts for patients who express relief, dismay, and indifference on being given "bad news."

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[511] Susan Eggly, Louis Penner, Terrance L. Albrecht, R. J. W. Cline, Tanina Foster, Michael Naughton, Amy Peterson, and John C. Ruckdeschel, "Discussing Bad News in the Outpatient Oncology Clinic: Rethinking Current Communication Guidelines," in *Journal of Clinical Oncology*, Vol. 24 (4), February 1, 2006.

[512] Eggly et al., 716.

[513] Eggly et al., 717.

[514] Eggly et al., 718.

My recommendation is that healthcare professionals prepare for all interactions in which they will disclose information by building relationships that are rooted in attitudes of respect and trust. With such relationships, adequate time and privacy are assured. This is because the information delivery process will then focus on the patient and his or her needs.

The second assumption is that "bad news" interactions center on one main piece of information[515] (e.g., the diagnosis of pancreatic cancer). My challenge is based on the actual need of patients for at least several related pieces of information (e.g., diagnostic details, treatment options, and prognostic probabilities). As a result, I propose that healthcare staff offer several pieces of information rather than making one part of "bad news" the linchpin. Indeed, some of the information will probably be given as a result of questions or comments by patients or their families.

I would further maintain that such issues as the amount of information to be given, the transitions between various segments of information, the language used, the speaking pace, the listening attentiveness, are all governed by communication that flows from an attitude of empathy and a relationship of care for the patient and his or her family. In this way, patients and their families will be given, in a considerate and sensitive manner, the opportunity to absorb each aspect of the information and to elicit questions and comments, while realizing that the responses to any of the information is not predictable.

The third assumption is that "bad news" interactions consist of a professional-patient dyad.[516] Typically, however, "bad news" interactions, in my experience, are not limited to a professional-patient dyad, but include at least one family member and possibly others

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[515] Eggly et al., 718.

[516] Eggly et al., 719.

as well (e.g., other doctors, a chaplain). The need, therefore, is to facilitate effective communication among any number of participants. This sharing of information and ideas in a meaningful manner will happen only as it is realized that all participants in the interaction have varying needs to be addressed.[517]

Present theoretical perspectives are linear, causal, scripted, and simple.[518] I propound a theoretical perspective which assumes that actual interactions are nonlinear, unscripted, and highly complex, that actual interactions come out of relationships, and that the interpretation of the interaction (e.g., as bad news) emerges from the interaction itself.[519] From this viewpoint, I cannot plan for a “bad news” meeting before it happens because its interpretation as “bad” and as “news” results from the encounter.

With this view, healthcare professionals would not be trained through role playing or scripted interviews to anticipate and engage in “bad news” consultations. Instead, communication training would point to the need for the development of attitudes and relationships that would foster in healthcare staff the capacity and desire to adapt their speech and behavior appropriately in response to the fluctuating informational and emotional needs of all participants during all stages of an interaction.[520]

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[517] Susan L. Regan, Elaine M. Wittenberg-Lyles, Joy Goldsmith, and Sandra Sanchez-Reilly, *Communication as Comfort: Multiple Voices in Palliative Care*. (New York, NY: Routledge, 2008), 74.

[518] Regan et al., *Communication as Comfort: Multiple Voices in Palliative Care*, 74.

[519] Regan et al., *Communication as Comfort: Multiple Voices in Palliative Care*, 74.

[520] Sissela Bok, *Secrets*. (New York, NY: Random House, 1982), 60.

Death Awareness: The Patient Perspective

Dying and Knowing It?

I have observed a patient-parishioner listen to a doctor's explanation of his or her fatal illness, respond as if the doctor's message is understood, and yet know nothing about it only hours later. Self-deception has seemed to be the only way for me to explain a patient's failure to comprehend and recall the evident.[521]

It appears, moreover, to be secrecy that lies at the heart of self-deception.[522] "In deceiving myself," Bok makes clear, "I keep secret from myself the truth I cannot face."[523] If it was harmless, I would not even consider interfering. What troubles me, however, is that sometimes people are dangerously wrong about themselves (e.g., the alcoholic who drinks himself to death, the anorexic who starves herself to extinction). My help must somehow cause a recognition of the patient's need and the part he or she has in distorting it. This attempted service, however, is itself risky because of the difficulty in determining that there is self-deception.

Of all the responses that appear self-deceptive, perhaps the most evident is denial.[524] My example of patient-parishioners "forgetting" the doctor's declaration of their terminal illness is quite common. I have read that among seriously ill patients who are told repeatedly that death is imminent, at least twenty percent have no memory after a few days of having learned about their demise.[525] Faced with intolerable anxiety, they have

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[521] Bok, *Secrets*, 60.

[522] Bok, *Secrets*, 60.

[523] Bok, *Secrets*, 60.

[524] Elisabeth Küebler-Ross, *On Death and Dying*. (New York, NY: Simon and Schuster, 1997 [1969]), 51.

[525] Küebler-Ross, 51-52.

blocked out the information. Bok explains, "In such responses, there is separation, the setting aside and shifting apart that is present in all secrecy."[526]

Of course, sometimes this "separation, setting aside, and shifting apart" is quite conscious.[527] A psychiatrist, Arnold Beisser, has written of the way physicians may misinterpret as denial of serious illness what he regards as affirming attitudes that contribute to health.[528] He has used his own experience of a severe physical handicap to show how the focus can shift between degrees of awareness of one's condition:

> I am frequently asked, 'How do you bear to spend your life in a wheelchair?' On such occasions I am aware that my attention is redirected from what I am doing in an affirmative way to what I am unable to do in accordance with the standards implied by the question. Thus, when what I cannot do becomes foreground, I am aware that I am disabled; while I am working or carrying out my social or family activities, my disability becomes background and my competence and health are foreground.[529]

There are, nevertheless, times when patients seem to block information completely [530] (e.g., the diagnosis of terminal cancer). For some, such blockage is temporary, a reflex, a buffer to cope with shocking news; it allows time to process information, permitting time for patients to collect themselves. For others, the obstruction is permanent.[531]

It is when the form of avoidance no longer merely filters but blocks information, when it is not temporary but permanent, and when it prevents the patient from doing

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[526] Bok, *Secrets*, 70.

[527] Bok, *Secrets*, 70.

[528] Arnold R. Beisser, "Denial and Affirmation in Illness and Health." *American Journal of Psychiatry*, 136 (1979): 1029.

[529] Beisser, 1029.

[530] Bok, *Secrets*, 70.

[531] Bok, *Secrets*, 70.

something about a danger which could be averted or alleviated, that a form of avoidance does the greatest disservice.[532]

Because of the presence of denial, it is easy for healthcare professionals to argue that patients resist frightening or distressing information.[533] Concisely, does any patient really want to face up to death? While studies with which I am familiar generally reveal that most patients do want to know that they are dying,[534] medical workers contrapuntal is that the more the patients ask to know about their impending demise, the more the patients suffer from apprehensiveness which will lead to the denial of information even if it is given.[535]

While I think that it may be alleged that most patients experience denial at some point in the course of approaching death, to assert that denial is universal, as some healthcare professionals do, flies in the face of evidence and leaves no room for reasoned discourse.[536] In fact, it seems more tenable to me to take the view that patients differ in the degree to which they can welcome such knowledge, take it into account, and make peace with it.[537] It is true that there are some patients who request to be deceived rather than to perceive their lives as finite; there are others who reject the information about death; but most patients want to know that they are dying.[538]

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[532] Bok, *Secrets*, 71.

[533] Bok, *Lying*, 228.

[534] Bok, *Lying*, 229.

[535] Bok, *Lying*, 229.

[536] Küebler-Ross, 31.

[537] Küebler-Ross, 31.

[538] Bok, *Lying*, 228.

Of course, some disquiet about knowing the end of life is mere curiosity. For the most part, however, it is to be able to take a stance toward my life as a whole, to give it unity, meaning, and completion.

Dying and Choosing It?

Today I sense that increasing emphasis is being put on the notion of *choice* in dying.[539] I further sense that the significance of choice is being inspired, in part, by the dehumanizing medical and hospital practices of the past few decades[540] (e.g., patient helplessness in the face of control by healthcare professionals). It is relatively easy to keep knowledge from terminally ill patients. They are the most vulnerable, least able to learn about their condition or to protect their autonomy.[541] Consequently, the very fact of being deathly ill increases exponentially the probability of control by others.

Technology has created a further loss of control, an expanded dependency, and a distancing for the patient and others.[542] Machines, wires, paraphernalia, all intensify the sense of detachment and can become substitutes for compassionate communication and interactions. Hoodwinking patients about dying can cause them to slip unwittingly into subjection to procedures where death is delayed through respirators and resuscitation far beyond what most patients want.[543] The greater fear of the dying, therefore, is not the

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[539] Solomon and Flores, *Spirituality for the Skeptic*, 115.

[540] Bok, *Lying*, 232.

[541] Bok, *Lying*, 232.

[542] Bok, *Lying*, 233.

[543] Bok, *Lying*, 233.

moment of death but all that precedes it for many, the fear of prolonged deterioration and debility, uncertainty and meaninglessness.[544]

As a result, today there is growing demand for choice, for dying on my own terms, even by my own hands.[545] In *After Virtue*, Alasdair MacIntyre, however, bemoans the choice of some of the dying, those who prefer to die instantly rather than to suffer the slow, lingering death that allows them to reflect on and talk about their life, to assemble the story and meaning of their existence.[546]

I recall a conversation I had with a few parishioners in the wake of the explosion of TWA Flight 800 out of New York City in July, 1996. What would it mean to be a victim in such devastating circumstances? Most felt, given the suddenness of the explosion, the worst experience for the victims was that there was no time to anticipate the experience, no time for anything but terror and shock, no time to make death one's own.

Is there not something incongruous about this petty conjecturing in the aftermath of such a horrible tragedy? Why are we now so preoccupied with the amount of time for preparation of death? Furthermore, is it even possible to make death one's own?

Dying and Living It?

While writing this chapter I spoke to several people of different ages about their death. Generally, the responses were that death is not a big deal. An elderly woman said dismissively, "When I'm gone, I'm *gone*." Is that true? My mother died in 1990, but I still talk about her; her life goes on even though she is "gone." A young man brushed

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[544] Solomon and Flores, *Spirituality for the Skeptic*, 115.

[545] Alasdair MacIntyre, *After Virtue: A Study in Moral Theory*. (Notre Dame, IN: University of Notre Dame, 1981).120.

[546] MacIntyre, *After Virtue: A Study in Moral Theory*, 120.

aside the question of death, “Death is *nothing*.” Is that true? In my experience, the view that death is nothing feeds on or leads to the idea that life is nothing. A middle-aged congregant told me that “death is *just* the door to the afterlife.” Is that true? If life is suffering and death, and if death is the transcending of suffering and death, is this not a way of depreciating life before death?

What disturbs me about all these views is the way they evade the importance of death. It seems that either we make too much of death (see the above section) or we make too little of death (this section). The way to avoid the extremes, it seems to me, is to see death in the larger context of life. Death is all about the life that is being brought to an end. The meaning of death is the meaning of life![547]

Ever since I took my first Philosophy course I have been attracted to existentialism with its emphases on individual choice, personal responsibility, and the human passions. At the same time, paradoxically, I feel comfortable with Georg Hegel’s grand vision of the human cosmos. Hegel challenges me to stress the primacy of the social.[548] In contrast to my existential accent on taking control of my life, Hegel’s *Phenomenology of Spirit* speaks to me about “destiny,” “fate,” “lot,” and points to the futility of individual decision making in the face of the “spirit of the times” (zeitgeist).[549] He embraces the passions, but they are the passions of being “caught up”[550] in life rather than the “take charge” resolutions of my existentialism.

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[547] Solomon and Flores, *Spirituality for the Skeptic*, 119.

[548] Georg Hegel, *The Phenomenology of Spirit*. (New York, NY: Oxford University Press, 1976 [1807]), 58.

[549] Hegel, 294-327.

[550] Hegel, 284-285.

Particularly when thinking about death and dying I need a dialectic of existentialism and Hegelianism. I need both to understand my place in the world, that I matter, that my life counts. How then am I to live? How am I to cope with the tragedies in my life? How should I think and talk about death and dying?

The world, in Hegel's thought, is to be unified and fulfilled first and foremost in human consciousness, in the way I think and talk about myself and my place in the world.[551] In my individual life, this Hegelian concern remains existential. It also demands, however, that I have an understanding of "the big picture." I need the respect and humility that comes from seeing my place in the world. In this relationship to the world, I think and talk about myself in terms of my relations to others. These relations are characterized by compassion and understanding, by what I call "sharing the spirit of humanity." This shared spirit is the opposite of a narrow individualism. Now the crucial question is, "How can I maintain a sense of the big picture when I am so caught up in "the spirit of the times"?

I have discovered an ominous warning in Tolstoy's book, *The Death of Ivan Ilyich*. Here is the story of an ordinary man who has "done everything right"[552] by identifying fully with the assumptions of his society. By himself, however, as he is dying of cancer, he comes face to face with the big questions. Surely such an exit evokes profound regret. In the words of Ilyich himself, "Why was I not asking these questions all along?"[553]

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[551] Hegel, 79-103.

[552] Leo Tolstoy, *The Death of Ivan Ilyich*. (New York, NY: Barnes and Noble Books, 2004 [1915]), 95-103.

[553] Tolstoy, 137.

Death Awareness: The Mutual Perspective

Deceit

The 138th Sonnet by William Shakespeare describes a relatively common, poignant human agreement where two people deceive each other, each knowing of the posturing, each preferring to have it continue rather than to face what it masks. Each feigns belief in the blandishments which the other conveys.

An example of mutual deceit takes place when a healthcare professional rationalizes his or her mendacity in dealing with patients who are dying.[554] With the thought that "he (she) knows that I know that he (she) is dying," the caregiver escapes the necessity of speaking honestly. In a similar fashion, the dying patient muses, "The doctor (nurse) knows that I know I am dying." This creates a kind of imprisonment for both staff and patient. No information is transmitted.[555]

If, however, the dying patient *asks* not to know his or her prospects, surely an agreement can be made. The more convoluted situation is where the healthcare professional *thinks* that the dying patient does not want the truth about his or her condition but is afraid to ask. Author Leo Tolstoy pictures this maelstrom in *The Death of Ivan Ilyich*:

> This deception tortured him – their not wishing to admit what they all knew and what he knew, but wanting to lie to him concerning his terrible condition, and wishing and forcing him to participate in that lie. These lies – lies enacted over him on the eve of his death and destined to degrade this awful, solemn act to the level of their visitings, their curtains, their sturgeon for dinner – were a terrible agony for Ivan Ilyich.[556]

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[554] Barney G. Glaser and Anselm L. Strauss, *Awareness of Dying*. (New Brunswick, NJ: Aldine Transaction, 2009), 67.

[555] Glaser and Strauss, 67-70.

[556] Tolstoy, 127.

Respect

For dying patients, I believe the goal must be disclosure and the mood openness. This does not mean that patients can be told abruptly about a dismal prognosis. Truthfulness further requires humane sensitivity[557] (e.g., in the Christian Scriptures I am admonished to "speak the truth in love").[558] This means I always have to make a judgment about the patient to whom I am speaking. I have to decide how much of the truth I will disclose and how much I will mask. How, then, can I know when to conceal, evade, or withhold information? I believe the only way I can know to whom to speak the truth, when to speak the truth, and how much of the truth to speak, is to be wholly committed to being truthful and understanding. If I am not devoted to being truthful and considerate, I become sly.

Dr. Cicely Saunders, Founder of St. Christopher's Hospice in England, articulates the consideration that is needed:

> Every patient needs an explanation of his (*sic*) illness that will be understandable and convincing to him if he is to cooperate in his treatment or be relieved of the burden of unknown fears. This is true whether it is a question of giving a diagnosis in a hopeful situation or of confirming a poor prognosis.
>
> The fact that a patient does not ask does not mean that he has no questions. One visit or talk is rarely enough. It is only by waiting and listening that we can gain an idea of what we should be saying. Silences and gaps are often more revealing than words as we try to learn what a patient is facing as he travels along the constantly changing journey of his illness and his thoughts about it.
>
> So, much of the communication will be without words or given indirectly. This is true of all real meeting with people but especially true with those who are facing knowingly or not, difficult or threatening situations. It is particularly true of the very ill.
>
> The main argument against a policy of deliberate, invariable denial of unpleasant facts is that it makes such communication extremely difficult, if not impossible. Once the possibility of talking frankly with a patient has been admitted, it does not mean that this will always take place, but the whole

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[557] Bok, *Lying*, 239.

[558] Ephesians 4:15.

> atmosphere is changed. We are then free to wait quietly for clues from each patient, seeing them as individuals from whom we can expect intelligence, courage, and individual decisions. They will feel secure enough to give us these clues when they wish.[559]

Those who take care of the dying have to learn how to speak with them.[560] They will be helped to do so, I believe, if they consider the individuality of the dying patient.[561]

Whether from the perspective of needing care or providing it, the fundamental question is one of respect (i.e., consideration for the feelings of the other). To respect requires an attitude of, and an adherence to, honesty.

Honesty

Few of us, perhaps, whether caregivers or care receivers, talk about honesty. Even the few of us talk about it only if we feel duped by some act of blatant dishonesty. For the most part, we want to assume that others are honest, but having been deceived, we learn to be distrustful. It is precisely because so many of us seem to be crafty that we cannot take honesty for granted, that we need to ask what it takes to be honest.

The assumption that appears to me to lie behind an approach to honesty is that I need only to *intend* to be honest and I am. This being the case, it is further assumed that all of us already know how to be honest. The intention to be honest is a necessary beginning. Yet, the intention to be honest, though indispensable, is partial.

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[559] Cicely M. S. Saunders, “Telling Patients” in Reiser, Dyck, and Curran, *Ethics in Medicine*, 238-240. Quoted in Bok, *Lying*, 239-240.

[560] Bok. *Lying*, 240.

[561] Bok. *Lying*, 240.

Margaret Furse, Lecturer in American Studies at the University of Texas, maintains that "honesty must be an art, a way of life, a discipline that is practiced."[562] I understand the need for honesty to be a discipline because so often I am in the confusing position of intending to be honest but not knowing how to proceed. I have discovered that the best response to a bewildering situation is honesty as a discipline.

Disciplined honesty involves *inquiry*.[563] I want to be truthful but recognize that I am perplexed. It is hard to be honest in situations that are complicated. I do recognize, though, that it is myself that is confused. Consequently, disciplined honesty also requires self-reflection.[564] This is why disciplined honesty must take an interest in the humanities (e.g., Psychology inquires into the nature of the self; Philosophy inquires into the nature of truth).[565]

Another element in my experience of disciplined honesty is *perspective*.[566] I cannot be truthful without some implied reference to the nature of the world, its meaning, and its value. Of course, I do not *know* the meaning of the world in which I find myself. I must, however, make certain assumptions about it, and I cannot be honest in any disciplined way unless I take account of it. Even when I seem to speak only of myself, I inevitably speak also of and to others, and I also imply something about the world in which all of us are together.[567]

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[562] Margaret Lewis Furse, *Nothing but the truth?: What it takes to be honest*. (Nashville, TN: Abingdon, 1981), 15.

[563] Furse, 21.

[564] Furse, 19.

[565] Furse, 84-90, 95-101.

[566] Furse, 21.

[567] Furse, 21.

The term I use for my intention to be honest is *sincerity*.[568] By sincerity I mean both my intention to be honest and also the subject about which I intend to be honest, namely myself. If I intend to present myself as sincere, however, I cannot do so by intention alone; I need discipline to help me avoid self-deception (disciplined sincerity means disciplined honesty with respect to myself).

Through *self-reflection* I sense an inner conflict between sincerity and self-deception. Only through self-reflection, therefore, is *sincerity* of intention awakened and undertaken.

Still further, disciplined sincerity needs *self-acceptance*.[569] I tend to think of the insincere as appearing certain about themselves, whereas I have a tendency to see the sincere as having doubts about themselves. Significantly, there is a parable in the Christian Scriptures about the kind of self-acceptance that sincerity requires.[570] The story is about an arrogant man and a humble one. The first brashly trumpets his self-satisfaction and boasts that he is grateful to be better than others. The second man is unsure about himself and downcast.

The first man has a self-acceptance that is justified by its own virtue. By the need to make self-justifying claims, however, it betrays a fear of failure. Outwardly, he appears bold; inwardly, he fears failure. Consequently, this man cannot be truthful about himself.

The second man has a self-acceptance that is based on *perspective*. He sees his life in the whole scheme of things and this attitude warrants trust. Now he does not need to pretend to be other than who he is, even when he fails. Consequently, he can be truthful about himself.

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[568] Furse, 18.

[569] Furse, 19-20.

[570] Luke 18:9-14.

Now I see that the critical element of disciplined sincerity is *self-abasement*[571] (i.e., humility). Self-abasement is not a lack of self-respect; in fact, it is another word for self-respect. It is the prerequisite of all honest self-reflection. It is awareness of myself as I really am.

In communication with others the person disciplined in honesty always asks self-critically, “What is my motive?” Of course a benevolent motive for concealing, evading, or withholding the truth does not justify it; it may be harmful. In the moral judgment of what to say and what not to say, one must pay attention to the motive, the effect, the means, and the other involved. In medical decision-making with the dying, caregivers and care receivers alike must know themselves, must know the situation as well as possible, and must be committed to being respectful and truthful.

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[571] Furse, 20.

CHAPTER 6

A COMMUNITY OF HEALING

The Moral Nature of Medical Situations

A Trend in Medicine: Paternalism and Passivity

It is important to realize, according to Micah Hester, Bioethics Professor at Mercer University School of Medicine, that bioethics, perhaps the core of medical humanities, has developed in response to several trends in medicine, including coercive paternalism (the attitude that the doctor knows what is best for the patient) and technological solutions (based on the belief that patients are biophysical mechanisms).[572] Consequently, patients are not regarded as *active*, communicative partners in the healing process.[573]

Possibly the most influential treatise produced in bioethics is a landmark work by Tom Beauchamp and James Childress, Philosophers at Georgetown University, published in 1979. Their book places a priority on four principles. The principle of autonomy is championed as the most valuable standard and is conveyed both in a negative form as the need to provide an absence of coercive influences on a patient's decision-making and in a positive but passive form as "express and informed consent."[574]

Even to this day, as I was told in my clinical work, doctors and nurses alike attempt to justify their speech and actions toward patients either by way of "consent" or by acting in patients' "best interests." The principle of autonomy allegedly defends the right of every

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[572] Abraham Flexner, *Medical Education: A Comprehensive Study*. (New York, NY: Macmillan, 1925), 3.

[573] D. Micah Hester, *Community as Healing*. (Lanham, MD: Rowman and Littlefield Publishers, 2001), 1.

[574] Tom Beauchamp and James Childress, *Principles of Biomedical Ethics*, 4th Ed. (New York, NY: Oxford University Press, 1994), 128.

patient and procedures, such as “informed consent” forms and “patients’ rights” documents,[575] have been developed. In fact, however, the principle of autonomy as stated by these authors has no active response to coercion (i.e., there is no promotion of active patient communication and interaction in medical decisions).

A Problematic Dichotomy: Self and Community

Individualism (i.e., an account of the self as both prior to, and isolated from, community) is the theoretical foundation of the principle of autonomy. This postulate supports the individual over and against, rather than in connection with, the beliefs, interests, and desires of others. Adhering to the insularity of the individual is dangerous, I claim, because of the risk of a disintegrated life, detached from others, and paradoxically, from myself. Opposed to the character of community, individualism is unable to deal with change. John Dewey, Philosopher and Psychologist, elucidates: “Such thinking treats individualism as if it were something static, having a uniform content. It ignores the fact that the mental and moral structure of individuals…change with every change in social constitution.”[576] The crucial question is” How shall I re-find myself in a new situation?[577]

As a reaction against the notion of the insular individual is my account of the self as a product of communication and interaction. The self is a process that changes as individuals learn to adapt to and influence the community around them. This means that individual ends cannot be pursued in a vacuum; they are tied into the ends of others. To

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[575] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th Ed., 128.

[576] John Dewey, *John Dewey: The Later Works: 1925 – 1953*. 17 vols. ed. by Jo Ann Boydston. (Carbondale, IL: Southern Illinois University Press, 1981-1990, vol. 5), 80.

[577] Dewey, *Later Works*, Vol. 5, 81.

pursue my ends, then, means taking into account not only my own purposes, but those of others as well, engaging them in my communication while necessarily engaging in theirs.

Imagine the implications for medical situations. The engaged patient, not the passively consenting patient, becomes the model for medical staff and patient alike. Together, healthcare professionals and patients strive for ends that are the “right” (see below) healing actions for particular patients.

In working toward ends, moreover, it is important to realize that the value of any end is a “value of something which in being an end, an outcome, stands in relation to the means of which it is the consequence.”[578] This continuum of means and ends is typified by medical situations that involve the patients in their own healing process, making them communicative and interactive in the healthcare community.

A Moral Solution: Imagination and Narrative

In the thought of Beauchamp and Childress, ethical problem solving is the routine application of principles. I contend that moral deliberation cannot be a rigid or rote application of principles; it must be creatively adaptive.

Steven Fesmire, Professor of Philosophy at Green Mountain College, maintains that moral deliberation is best understood by Dewey’s concept of imagination: “Imagination, like drama, is story-structured and is spurred by conflicts and contrasts among characters and contingent events…Imagination is constrained and guided by the exigencies and pressures of a situation along with our vast array of internalized social habits.”[579] In the

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[578] Dewey, *Later Works*, vol. 13, 227.

[579] Steven A. Fesmire, “Dramatic Rehearsal and the Moral Artist,” in *Transactions of the Charles S. Pierce Society 31,* No. 3, 1995, 569-570.

words of Dewey himself, “Deliberation is a dramatic rehearsal in imagination of various compelling possible lines of action.”[580]

The imagination, then, has a moral function since in language and imagination I rehearse the response of others.[581] This “story-structured” capacity, “guided by” the pressures of the situation and the social habits, helps to deliberate among a variety of possible ends to choose a particular “line of action.” Moral deliberation, therefore, works through imagination to develop a coherent story that adequately expresses the conflicts that characterize the particular problem to be solved.

I say “a coherent story” because, through moral deliberation, I am attempting to bring about a situation in which I recognize the connection of my desires with those of others to fashion a common viewpoint. This is to reject the notion that moral activity is based on principles that demand accommodation to a universal “right.”

“Right” is the end, not the beginning, of moral deliberation, and as such arises only after consideration of all the persons affected by the situation and the consequences of the proposed actions. In short, deliberation must attempt to create a coherent story that includes as many interests as possible.

Fesmire informs me that moral deliberation is best done by putting myself in the place of the other.[582] I do not merely attempt to apply abstract principles but rather to view problems through creatively rehearsing possible solutions to the situation, adjusting my desires and the situation in order to develop a story that takes the other seriously.

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[580] John Dewey, *John Dewey: The Middle Works: 1899-1924*. 15 vols. Ed. Jo Ann Boydston. (Carbondale, IL: Southern Illinois University Press, 1976-1983, vol. 14), 132.

[581] Dewey, *Middle Works*, vol. 14, 216.

[582] Fesmire, 571.

These insights illustrate that the life of a patient is a communal process. They demand that in medical situations, healthcare professionals engage their patients in imaginative ways. I have shown that the "informed consent" upheld by Beauchamp and Childress is inadequate for active communication and interaction. What is required is recognition that I am a socially situated self who finds healing through my common participation in, with, and by community. Living in community, communicating and interactive, therefore, ought to be both the means and end of medical situations.

A Theory of Principalism

Common Morality

I remember being told that I could not write my bioethics term paper using any other approach than the "principalism"[583] of Beauchamp and Childress. The reason was that the principles of Beauchamp and Childress are the basis of conversations with and among healthcare professionals in virtually every hospital in the United States, concerning the ethical issues that they face in their clinical practices.[584]

Biomedical ethics are based on four principles according to Beauchamp and Childress. 1) The principle of autonomy obligates physicians to allow patients to give consent before any procedures are performed; 2) the principle of non-maleficence urges that physicians avoid harmful treatment of their patients; 3) the principle of beneficence states that physicians should attempt to "do good" (i.e., benefit their patients by acting in the patients' best interests); 4) the principle of justice expresses that physicians are bound

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[583] K. Danner Clouser and Bernard Gert, "A Critique of Principalism" in *Journal of Medicine and Philosophy, vol. 15*, 1990, 219-236.

[584] In personal conversation with my Professor.

to give patients what they deserve. Beauchamp and Childress regard these principles as "both indispensable and central to the enterprise"[585] (i.e., to biomedical ethics).

Superficially, these principles appear in agreement with common sense.[586] Patients should be allowed to make their own choices, avoid being harmed, and be benefited by medical treatment. I can envision situations, however, for which these principles are too non-specific or they may conflict with each other. How can I apply the principle of autonomy when patients' decision-making capacity is suspect or compromised (e.g., Alzheimer's). Situations of physician-assisted suicide bring into conflict beneficence and non-maleficence. How can physicians both follow their Hippocratic obligations and yet turn a deaf ear to the pleadings of terminally ill patients to die with dignity?

Employing John Rawl's notion of "reflective equilibrium" (i.e., the adjustment of considered judgments),[587] Beauchamp and Childress develop "a theory of common morality."[588] Let me cite their explanation: "The goal of reflective equilibrium is to match, prune, and adjust considered judgments so that they coincide and are rendered coherent with the premises of theory. That is, we start with paradigm judgments of moral rightness and wrongness, and then construct a more general theory that is consistent with these paradigm judgments."[589]Tersely, the use of reflective equilibrium helps determine a theory of "common morality that takes its basic premises directly from the morality

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[585] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th Ed., 40.

[586] Hester, 22.

[587] John A. Rawls, *A Theory of Justice*. (Cambridge, MA: Harvard University Press, 1971, quoted by Beauchamp, *Principles of Biomedical Ethics,* 4th Ed.), 21.

[588] Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th Ed., 100.

[589] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th Ed., 21.

shared in common by the members of a society."[590] Beauchamp and Childress believe that their principles arise from this shared morality and, therefore, are rooted in common sense.

While I concur with the notion of "reflective equilibrium," I disagree with where it starts in Beauchamp and Childress. Their reflection does not start with patients' experiences and judgments but with "paradigm judgments" (i.e., judgments abstracted from patients' experiences). Then, "considered judgments" are "matched and pruned" in order to "render them coherent with the premises of theory" (i.e., considered judgments are adjusted to principles but not principles to judgments).

Deductive Process

In the first and seminal edition of Beauchamp and Childress, the use of principles is a deductive process. As such, in my ethical practice, I justify my actions by beginning at a position of abstraction from patients' particular situations and work my way through various rules derived from the principles in order to apply any principle to a patient's particular situation. In the authors' own words, "Judgments about what ought to be done in particular situations are justified by moral rules, which in turn are grounded in principles and ultimately in ethical theories."[591]

In the fourth edition, Beauchamp and Childress modify but do not jettison the deductive approach. It now only "functions smoothly whenever a judgment can be

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[590] Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th Ed., 100-104.

[591] Tom Beauchamp and James Childress, *Principles of Biomedical Ethics, 1st Ed.* (New York, NY: Oxford University Press, 1979), 5.

brought directly under a rule or principle without intervening complexities such as appeals to several principles."[592]

Since principles themselves are not capable of guiding specific action, the authors introduce the practice of "specification" where principles are made useful by "specifying the content in a way that surpasses ethereal abstractness, while also indicating the cases that properly fall under the principles."[593] An example is provided by the writers. In order for physicians to follow rules against "deception," they must recognize that following these rules might clash with other rules. Using the situation of falsifying insurance forms in order to pay for diagnostic and therapeutic means, Beauchamp and Childress attempt to show that physicians "specify" rules against deception by such means as writing that a mammography examination is intended to "rule out cancer" as opposed to being merely "routine." In this way, physicians show that they operate under a "specific" definition of the rule against deception and their actions are rendered "coherent" with other rules (e.g., that "doctors should put their patients' interests first").[594]

I perceive two significant and related problems. 1) There is the problem of beginning from the place of abstraction since at that level no situation exists. In fact, every problem arises already and always as a particular problem, happening to a particular patient, in a particular situation. 2) Since Beauchamp and Childress recognize the inability of principles to directly dictate specific action, why do they insist on justifying all ethical activity from the position of abstract principles and not through reflection on specific

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[592] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th Ed., 16.

[593] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th Ed., 28.

[594] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th Ed., 29-30.

problems?[595] Dewey zeroes in on the pitfall: "Beginning with rules…general principles…and the like is a common form of the…error of isolation of deduction at the beginning of inquiry...The mistake is, logically, due to the attempt to introduce deductive considerations without first making acquaintance with the particular facts that create a need for the generalizing rational devices."[596]

Ethical discussion actually stems from a problematic situation. There are, moreover, specific details that constitute the subject matter of the discussion. By isolating these two aspects of ethical discussion, Beauchamp and Childress must approach any problematic situation from a deductive standpoint.

Beauchamp and Childress succumb to the error of deduction when they profess to develop principles and rules that "may appear to be distant from both history and contemporary problems in the biological sciences, medicine, nursing, and other modes of healthcare."[597] So what exactly will principles do for specific situations? The answer, according to Beauchamp and Childress, is that "in difficult cases, direct application of principles rarely works…Specification, then is an attractive strategy for the hard cases as long at the specification can be justified."[598] If the authors recognize that principles are, in difficult cases, impractical without specification, why begin with principles? In addition, what cases concern bioethics if not "difficult cases"?[599] I hold that ethical

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[595] Hester, 26.

[596] Dewey, *Middle Works, vol. 6,* 98-99.

[597] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th Ed., 3.

[598] Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th Ed., 29.

[599] Hester, 27.

practice needs to be rooted in, not “distant from,” medical situations and the practices of healthcare professionals.

From an ethical and clinical viewpoint, the consequence of a principle approach is that the uniqueness of situations and patients is disregarded, only later to find that specifications need to be made. Whatever minimal content the principle might contain (e.g., do no harm, do good) gets supplanted by some clarification based on the specific issues of a particular case. Does this not beg the question of the need for the principles at all? On the other hand, by placing a priority on the principles, Beauchamp and Childress delimit ethical discussion and cripple communication.

A Concept of Self

As Autonomous

The inadequacies of principalism become even clearer when I focus on the principle of autonomy. Beauchamp and Childress define “autonomy” as a “personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice, such as adequate understanding.”[600] In this interpretation, I discern the Enlightenment emphasis on liberation and individuality. In my understanding, Enlightenment philosophers (e.g., John Locke, Jean-Jacques Rousseau, and Immanuel Kant) view their position as entailing a radical liberation of the self from the social bonds that inhibited free expression and movement.

Later in their volume, Beauchamp and Childress analyze “autonomous action” as acting “1) intentionally, 2) with understanding, and 3) without controlling influences that

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[600] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th Ed., 120-121.

determine the action."[601] Significantly, they claim that intentionality is not a matter of degrees.[602] Understanding, however, is a matter of degrees.[603] Actually, I think a situation will allow understanding and be controlled by others to some extent, depending on the case (e.g., stroke victim). For Beauchamp and Childress, this leads to the requirement that an action be "substantially autonomous."[604] I search in vain, however, for an account of substantial autonomy since, according to Beauchamp and Childress, appropriate criteria of substantial autonomy are best addressed in particular contexts, rather than pinpointed through a general theory."[605] My question is this: Why not begin with a discussion of context rather than with the general notion of autonomy?

It is noteworthy that Beauchamp and Childress change "The Principle of Autonomy" (1st Edition) to "The Principle of Respect for Autonomy" (4th Edition). The reason for the alteration is that "being autonomous is not the same as being respected as an autonomous agent" and that this principle "should not be used for persons who cannot act in a sufficiently autonomous manner."[606] The principle is, however, still negatively interpreted: "Autonomous actions should not be subjected to controlling constraints by others."[607]

Beauchamp and Childress also construe the principle of respect for autonomy in a practical, positive way: "The basic paradigm of autonomy in healthcare is express and

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[601] Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th Ed., 123.

[602] Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th Ed., 208.

[603] Hester, 40.

[604] Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th Ed., 123.

[605] Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th Ed., 124.

[606] Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th Ed., 125.

[607] Beauchamp and Childress, *Principles of Biomedical Ethics*, 4th Ed., 126.

informed consent."[608] For my understanding, a consenting agent is the practical expression of autonomy, and making a space for that expression is the practice of respecting autonomy.

Despite the change in the principle, I am left with several concerns. What exactly constitutes a "controlling influence"? Who or what determines "substantial autonomy"? How does "informed consent" empower patients in medical situations?

In further musing on the principle of autonomy, I want to examine its basic assumption, the self as autonomous. The thought of Alasdair MacIntyre, Professor of Philosophy at Notre Dame University, is helpful in grasping this concept of the self. He begins with the idea that there is a fundamental contrast between myself as I happen to be and myself as I could be if I moved toward my potential character.[609] Ethics is to enable me to understand how to make the transition from the former condition to the latter.[610] However, I have "rejected" the latter condition, leaving me the self that I am.[611] What has been lost is the "teleological" concept of the self, according to which my purpose is to be a loving member of a family, a loyal citizen of my country, and a faithful employee of my corporation.[612] In my cultural context, I view myself as an individual prior to and apart from social contexts;[613] I do not see myself as constitutively relational in character.

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[608] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th Ed., 128.

[609] Alasdair MacIntyre, *After Virtue: A Study in Moral Theory*, 2nd Ed. (Notre Dame, IN: University of Notre Dame, 1984), 52.

[610] MacIntyre, *After Virtue: A Study in Moral Theory, 2nd Ed.*, 52.

[611] MacIntyre, *After Virtue: A Study in Moral Theory, 2nd Ed.*, 55.

[612] MacIntyre, *After Virtue: A Study in Moral Theory, 2nd Ed.*, 59.

[613] MacIntyre, *After Virtue: A Study in Moral Theory, 2nd Ed.*, 59.

MacIntyre's account of the contemporary consequences of the concept of the self as autonomous is incisive:

> Contemporary moral experience…has a paradoxical character. For each of us is taught to see himself or herself as an autonomous agent; but each of us also becomes engaged by modes of practice…which involve us in manipulative relationships with others. Seeking to project our autonomy, we aspire *not* to be manipulated by others; seeking to incarnate our own principles and standpoint in the world of practice, we find no way open to us to do so except by directing towards others those very manipulative modes of relationship which each of us aspires to resist in our own case. The incoherence of our attitudes and our experience arises from the incoherent conceptual scheme which we have inherited.[614]

The concept of the self as autonomous not only leaves me divided from others but gives me no recourse for moral deliberation.[615] The autonomous self, in MacIntyre's penetrating analysis, "can do no better than yield arbitrary choice because there is no positive account for constructive activity."[616] Without empirical content, choice and motive are divided from action; action ensues (i.e., follows and is caused by) choice and motive, which are movements of reason. The flaw lies precisely in the loss of a self that is defined in its relation to others, for the relational self shows that choice and motive are not pure reason and nor can they arise prior to acting within existential situations. Choice and motive are "not then a drive to action, or something which moves to do something. They are the movement of the self as a whole."[617]

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[614] MacIntyre, *After Virtue: A Study in Moral Theory, 2nd Ed.*, 68.

[615] Hester, 44.

[616] MacIntyre, *After Virtue: A Study in Moral Theory, 2nd Ed.*, 68.

[617] Dewey, *Later Works, vol. 7,* 291.

As Relational

I will attempt to reconstruct the idea of self, not as an isolated entity, but as a process of communication and interaction. I will leave behind the notion of an insular individual without losing individuality. Although I integrate with the communal structures in which I develop, I am not consumed by them. As Dewey puts it, "There is not merely difference or distinction between individuals, but something unique or irreplaceable in value, a unique difference in value."[618] I do not think this value is intrinsic (as Kant), but is developed, contingent, and changing through my communal interactions. My alternative to autonomy theory offers hope for future discussions in medical ethics by replacing the atomic self with a relational self.

My concept of the self is not a substance but a distinction that arises from specific experiences. It is impossible to set my individual self over and against community; I am developed by and develop community.

My thought is bolstered by the work of George Mead, American Philosopher and Sociologist at The University of Chicago. Mead determined, like William James before him, that the self comes to be in and because of communal processes.[619] Rather than being an entity in which traits are found, the self is an organized complex of attitudes that reflexively (i.e., myself) implicates both the individual and community.

At birth, I am no self; I am cells and biochemical activities. I become a self as a conscious, interacting being, a responsible, reflective character. Importantly, these qualities do not and cannot emerge until interactions with others occur. As an inchoate

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[618] Dewey, *Middle Works, vol. 15*, 170.

[619] George Herbert Mead, *Mind, Self, and Society*, ed. Charles W. Morris. (Chicago, IL: University of Chicago, Press, 1962 [1934]), 1.

self, I mirror (i.e., imitate) the actions of others, looking for responses from others. Indeed, these actions (Mead calls them "gestures") gain their meaning by the response others have to them[620] (e.g., as a baby, my cry means it is time for a diaper change because of the caregiver's response).

Soon I become aware of the attitudes of others to the extent that I begin anticipating those attitudes in choosing speech and action appropriate to the situation. This activity develops through the use of "significant symbols."[621] Mead asserts that "gestures become significant symbols when they implicitly arouse in the individual making them the same responses which they explicitly arouse, or are supposed to arouse in the individuals to whom they are addressed."[622] Most times these "significant symbols" are "vocal gestures" (i.e., language).[623] Language, Mead points out, objectifies within the conversation the self who is speaking (i.e., through language I am an object to myself).[624] Initially, therefore, the self comes into being reflexively.[625] The small child says "sippy cup" in anticipation of the response by the caregiver to hand over the container. The toddler, however, reacts to the cup in the same way as the youngster expects the caregiver to react. The child, in saying "sippy cup," is also listening to himself or herself, and so the child leans over and reaches for the desired cup.

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[620] Mead, 47.

[621] Mead, 47.

[622] Mead, 47.

[623] Mead, 47.

[624] Mead, 47.

[625] Mead, 47.

Briefly, the self comes about and comes to light in behavior that objectifies the self to itself. This objectifying activity incorporates an awareness of the attitudes of the other. More specifically, the self internalizes the attitudes of the community.[626]

In turn, I find the meaning of my actions through how they are taken by others. Mead expresses the thought succinctly:

> If we look towards the end of the action rather than toward the impulse itself, we find that those ends are good which lead to the realization of the self as a social being. Our morality gathers about our social conduct. It is as social beings that we are moral beings. On the one side stands the society which makes the self possible, and on the other side stands the self that makes a highly organized society possible…The two answer each other in moral conduct.[627]

Consequently, "one can never judge simply from his (*sic*) own point of view. We have to look at it from the point of view of a social situation…The only rule that an ethics can present is that an individual should rationally and imaginatively deal with all the values that are found in a specific problem."[628] In other words, my judgments are never exclusively my own; they arise, in part, from the situation in which I find myself and will, as a result, affect others in the social situation. So if I want to make my judgments "for the good," I must account for the other and often competing interests in the situation.

A Concept of Community

In Integrating Interests

I endorse the concept of community that is given by Dewey: "The parts of a machine work with a maximum of cooperativeness for a common result, but they do not form a

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[626] Mead, 154.

[627] Mead, 386.

[628] Mead, *3*87-388.

community. If, however, they were all cognizant of the common end and all interested in it so that they regulate their specific activity in view of it, then they would form a community."[629]

My understanding of Dewey's contrast is between a gathering of individuals (i.e., an aggregate or a collection of individuals who work toward their own ends) and a community (i.e., a group of individuals unified by a common purpose that transcends their individual interests and gives direction to their particular activities. The nurses in a hospital, for example, can easily find themselves members of a gathering in their daily activities to the extent that their activities are limited to individual tasks. Bonds are strengthened to form a community, however, when nurses become aware of the ends of others, take others' ends as common, and realize that sharing in the interests of others is of value to themselves. Nurses in a community, while attempting to fulfill their own interests, notice others' interests and adjust their own interests for the mutual fulfillment of common ends.

An integration of interests and an awareness of this integration (i.e., through an active process of adjusting activity) *is* the experience of community.[630] Individual and community interests are satisfied simultaneously. My observation is that this is exactly what happens in an emergency room, staffed by healthcare professionals who are familiar with and trust each other. As activity becomes hectic, all caregivers of a patient, through their particular roles, view their work not merely from a narrow individual stance but from the shared perspective of affecting a good end (e.g., the best possible care for this particular patient).

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[629] Dewey, *Middle Works, vol. 9*, 8.

[630] Hester, 52.

Beth Singer, American pragmatist and feminist, addresses the need to balance individual and community perspectives: “The condition of community is one of sameness-in-difference, of partial commonality of perspective among persons whose perspectives as individuals also include other perspectives, some unique to themselves and some shared with members of multiple communities to which they belong.”[631] The ideal is a community of individual interests that are integrated so that individual and social ends are inclusive.[632]

In Telling Stories

Another way to understand my human interactions is through narrative accounts. I construct stories to make sense of my experiences. My stories start where I am now, using both past and present situations. I weave stories that take account of certain “facts” in my life (i.e., my interpretation of events, people, places, and things). Because I choose these experiences, my stories are purposive (i.e., told for some reason). My stories also imaginatively project me into the future, placing history in the context of my evolving self and changing community. My stories are generated not simply in my tellings but also in my doings (e.g., when asked who I am, I speak. When showing who I am, I act). I enact the stories that are my life in the process of living. My stories are a means by which I create my life and give meaning to myself and others.[633]

I begin my analysis of this manner of conceiving community by considering the “I” of storytelling. As Stanley Hauerwas and David Burrell reveal: “The fact is that the first

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[631] Beth Singer, *Difference, Otherness, and Creation of Community,* 1995. Quoted by Hester, 51.

[632] Hester, 52.

[633] Hester, 54-55.

person singular is seldom the assertion of the solitary 'I,' but rather the narrative of the I."[634] The narrative of the I is the "I" that is expressed through words and actions and is always a result of community attitudes uniquely taken and developed by the individual. In other words, language is never simply mine alone; I use the language given to me by the community. Hauerwas and Burrell explain: "The language the agent uses to describe his (*sic*) behavior, to himself and others, is not uniquely his; it is *ours*. An agent cannot make his behavior mean anything he wants, since at the very least it must make sense within his own story, as well as be compatible with the narrative embodied in the language he uses."[635] Through the process of communication with others, using the language given to me by the community, I create a meaningful self.

I also need to consider *who* the "I" is that is telling the story. What is the individual's position, power, motive? In a medical situation, is it the healthcare professional or the patient who is telling the story? Arthur Frank, Sociology Professor at The University of Calgary, illustrates the problem of "authorship" through his own illness experience: "I began to realize that…any sense that was to be made of my experience was going to have to come from me. They (the physicians) were telling the story of my illness, but this story was not my experience, and if I was not to lose the experience that was mine, and lose part of myself with it, I needed to tell my own story."[636] Of course Frank is not suggesting that physicians not tell patients' stories, but rather that the physicians' account

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[634] David Burrell and Stanley Hauerwas, "From System to Story," in Stanley Hauerwas and L. George Jones eds., *Why Narrative? Readings in Narrative Theology*. (Grand Rapids, MI: Eerdmans, 1979), 168.

[635] Burrell and Hauerwas, 168.

[636] Arthur Frank, "Enacting Illness Stories: When, What, and Why," in *Stories and Their Limits: Narrative Approaches to Bioethics*, ed. Hilde L. Nelson. (New York, NY: Routledge, 1997), 32.

of the patient comes from a different community.[637] My unique story is a byproduct of the community in which I participate. Telling my story places me in community with others. The hearer (interpreter) of the story is also part of the creative process. Communication takes both meticulous crafting, on the one hand, and generous interpretation, on the other. To be a conscientious interpreter is hard work, in large part, because the hearer is responsible for the re-telling of the story. Both healthcare providers and patients need to become diligent translators who filter stories through the narrative of the hearer in order to make the stories fit together without doing harm to the teller's account.

Tristrom Engelhardt, Professor of Philosophy at Rice University, notes that there is an asymmetry in the healing relationship that, if unrecognized, may stifle narrative exchange:

> Patients, when they come to see a healthcare professional, are in unfamiliar territory. They enter a terrain of issues that has been carefully defined through the long history of the health professions. A patient is unlikely to present for care with as well-analyzed and considered judgments as those possessed by healthcare professionals. Professionals have a community of colleagues to reinforce their views and to sustain them in their recommendations. In addition, the interexchange of healthcare professional and patient is defined by the language of healthcare. Pains, disabilities, and even fears are translated into the special jargon of the healthcare professions.[638]

Given the danger of losing their patients' stories, I believe the health caregiver needs to provide a space for patients' stories in the patients' own language. The professional also needs to develop medical stories in which patients can find themselves. Then the

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[637] Frank, "Enacting Illness Stories: When, What, and Why," 45.

[638] Tristrom Engelhardt, Jr. *The Foundations of Bioethics.* (New York, NY: Oxford University Press, 1986), 256.

patients ought to strive to develop the medical story as their story, making it the account of their experience. Dewey elaborates:

> What is relied upon is personal contact and communication; while personal attitudes, going deeper than the mere asking of questions, are needed in order to establish the confidence which is a condition for the patient's telling the story of his (sic) past…Organic modification is there – it is indispensable…But that is not enough. The physical fact has to be taken up into the context of personal relations between human being and human being before it becomes a fact of the living present.[639]

This discussion of narrative speaks, I believe, to issues at the heart of a moral solution to medical situations. I do recognize the need for science to furnish the healthcare professional with the knowledge of inquiry into the individual case. In the degree, however, to which he or she subordinates the individual case to some classification of disease and some customary treatment, his or her knowledge becomes rigid and imperious instead of flexible and modest.[640]

The alternative is for both caregiver and patient to attend to the details of human living as expressed through the stories they tell. Moral imagination is required for this process of not merely biomedical erudition but medical creativity. The medical staff learns not to apply principles and rules, but to creatively rehearse possible solutions to problematic situations, adjusting desires and the situation in order to develop a story that takes the patient seriously. Fesmire speaks laconically about the crux of moral deliberation: "Deliberation is not a mathematical utilitarian calculation, nor is it a Kantian

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[639] Dewey, *Later Works, vol. 13*, 384.

[640] Dewey, *Middle Works, vol. 12*, 176.

determinate judgment; it has a dramatic story to tell."[641] Hauerwas and Burrell expand the thought further:

> There can be no normative theory of the moral life that is sufficient to capture the rich texture of the moral notions we inherit. What we actually possess are various and sometimes conflicting stories…What we need to develop is the reflective capacity to analyze those stories, so that we better understand how they function. It is not theory-building that develops such a capacity so much as close attention to the ways our distinctive communities tell their stories.[642]

A Concept of Healing

Through Re-inventing Myself

I believe that patient participation within a community of healing is essential to recuperation. This means treating patients as members of the healthcare community. This community of healing is best accomplished through encouraging patients to speak and act meaningfully within a medical situation.

Important for my purpose is seeing injury, disease, or debility as social disruptions. Richard Zaner, Professor of Medical Ethics and Phenomenologist at Vanderbilt University, explains: "Any sort of affliction, trivial or grievous, effectively breaks into the usual textures of daily life with its taken-for-granted network of concerns, interests, preoccupations, activities, and involvements."[643]

Whereas Zaner shows illness as a "break" into the everyday quality of my experiences, John McDermott, Professor of Philosophy at Texas A & M University, refers to situations that are experienced as a disconnection of vigor and vitality as

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[641] Fesmire, 574.

[642] Burrell and Hauerwas, 170.

[643] Richard M. Zaner, *Ethics and the Clinical Encounter.* (Upper Saddle River, NJ: Prentice Hall, 1988), 53.

“pathological”: “Any situation which cripples or enervates the human organism, however unusual or vague its roots, is a pathological condition. The task of medicine conceived as a social science (which is not exclusive of medicine as a natural science) is to build into its diagnostic procedures a sensitivity to this dimension of contemporary human experience.”[644]

For McDermott, a patient in a medical situation that demoralizes and interrupts the usual flow of life is in a “pathological” condition. Consequently, medical situations undergone as stifling to human living need to be taken seriously by medicine in its practice of human interactions. The purview of medicine, then, is extended from medical science to include Medical Humanities.

Dewey further describes this pathological situation: “What are the resulting pathological phenomena but evidences that the self loses its integrity *within itself* when it loses integration with the medium (both somatic and social) in which it lives?”[645] Self and community are attached in healthy living. However, a pathological situation, created by a disconnection between the self and community, issues in a disintegration of the self as a product of social interactions. As a patient whose self-integration is thrust into question by my ailment, “I realize that I am not healthy. I need medical intervention. People treat me differently. My ability to carry out my obligations to family, friends, and work are (*sic*) compromised. I will either lose my life or re-invent myself.”[646]

Not only is my life changed when I become afflicted but others are changed too. Dewey captures the thought: “The person who is ill is rendered unfit to meet his (*sic*)

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[644] John McDermott, “Feeling As Insight: The Affective Dimension” in *Social Diagnosis,”* in *The Culture of Experience*. (Prospect Heights, IL: Waveland Publishers, 1976), 170.

[645] Dewey, *Later Works, vol. 13*, 328-329.

[646] Hester, 71.

ordinary social responsibilities…Moreover, his removal from the sphere of social relations does not merely leave a blank where he was; it involves a wrench upon the sympathies and affections of others."[647] My life is not insular. I affect and am affected by others. Ailment causes me to be incapacitated for service to those within my sphere of influence and removes me from the orbit of my relationships with others. For medicine to help me, healthcare professionals must forge relationships that make room for and promote my story and my participation in the healthcare community.

Through Living Healthily

Healing involves not only communal participation but also vital functioning. More accurately, healing is concerned with renewing the patient to some state of vital functioning which entails communal participation. In this light, Dewey reminds me that the end of any medical situation, though intimately related to community, must be taken individually. "How to live healthily is a matter which differs with every person. It varies with his (*sic*) past experience, his opportunities, his temperamental and acquired weaknesses and abilities."[648] Healthy living is to find new experiences and explore new activities in the face of new circumstances. Dewey also addresses this need to integrate my desires and my present situation.

> Healthy living is not something to be attained by itself apart from other ways of living. A man (*sic*) needs to be healthy *in* his life, not apart from it, and what does life mean except the aggregate of his pursuits and activities?...Surely, once more what a man needs is to live healthily, and this result so affects all the activities of his life that it cannot be set up as a separate and independent good.[649]

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[647] Dewey, *Later Works, vol. 2,* 99.

[648] Dewey, *Middle Works, vol. 12*, 175.

[649] Dewey, *Middle Works, vol. 12*, 175.

Notice that Dewey does not speak of "health" (a noun) but of "healthily" (an adverb). Health is living healthily.[650] Health as living healthily means the adjustment of my pursuits and activities constantly present in a healthy life. Living healthily is not a static but dynamic condition; it means actively pursuing goals and developing my *self* by considering the current demands of my situation.

The healing process, then, means reinventing my *self* by reorienting my life (i.e., reconstructing my life habits, rewriting my life story, reconsidering my life goals, and reconnecting with others). In short, healing is creating a "whole" new life.

Of course medicine must also be concerned with "living healthily." While the healing process I have enunciated is individualized, this should not be confused with thinking that individuals are atomic. Though I uniquely participate in the situation, my *self* is shaped by the community in which I find myself. Living healthily, therefore, is the healing process realized through communicating and interacting with others in community.

Indeed, in my experience patients do seek community. It is looked for so much that if a community is not provided for them during their encounters with healthcare professionals, patients will search for it elsewhere. James Buchanan, a Phenomenologist at Baylor University, writes about such a patient.

> Stanley Derek Ackroyd, Ph.D. (in Philosophy), was an extraordinary and exceptional person now reduced to an ordinary and predictable disease…In the face of ALS (amyotrophic lateral sclerosis), Stanley sought out the company of people who were ordinary, uninformed, and even quite unsophisticated. Formerly the thought of exchanging pleasantries with a cabdriver or a bellhop would have seemed preposterous, but now it had its charm…Stanley liked these people, and they offered him both the community and the non-judgmental acceptance he needed.[651]

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[650] Dewey, *Middle Works, vol. 12*, 175.

[651] James H. Buchanan, *Patient Encounters*. (New York, NY: Henry Holt, 1989), 24-25.

The extent to which healthcare professionals speak and interact with patients so as to include them within the community of healing is the extent through which the end of living healthily is already satisfied within the treatment itself. Patients who are extended the opportunity and encouragement to engage as members of the healthcare community (i.e., who are persuaded to find themselves within the story of medicine and to create a story about their experiences that makes medicine an integral part of it) have already begun to live healthily because they have started to experience integrated living with a community.

Through Overcoming Blindness

In my research I learned that the community of healthcare has often not regarded or treated patients as members of the community but has considered them as "tourists."[652] As a result, medical situations are merely means and not ends in themselves.

The problem is that there are obstacles to developing a community in medical situations. Physicians have held for a long time a position of authority in society and also in medical situations. This fact leads to an imbalance of power in physician and patient relationships which, I believe, acts as a primary barrier in communication.

Hester reveals that "it is not uncommon for physicians to tell just half the story, to explain the information only in the best possible light; or skew the information in a particular way to get a desired result."[653] Medical situations with these kinds of physicians are particular instances of William James' insight into human experience and practice.

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[652] Hester, 75.

[653] Hester, 76.

> We are practical beings, each of us with limited functions and duties to perform. Each is bound to feel intensely the importance of his (*sic*) own duties and the significance of the situations that call these forth. But this feeling is in each of us a vital secret, for sympathy with which we vainly look to others. The others are too much absorbed in their own vital secrets to take an interest in ours. Hence the stupidity and injustice of our opinions, so far as they deal with the significance of alien lives. Hence the falsity of our judgments so far as they presume to decide in an absolute way on the value of other persons' conditions or ideals.[654]

James, American Philosopher and Psychologist trained as a physician, speaks of my blindness to others' interests and values as an opacity caused by an immersion in my own interests and values. Given this un-mindfulness in me, James warns of the problems in making "absolute" judgments concerning others. My self-preoccupation leads to the easy judgment that what is best for others is merely what I judge to be best for me. This blindness is sure to interfere with the process of communication.

Fulfilling the desire to revitalize a patient to health takes competent medical judgment. This assessment is typically made by a healthcare professional about a patient. This evaluation is bound to be inappropriate to the extent that the medical staff does not engage the patient in the healing process. While the patient certainly must take responsibility of membership in the healthcare community, the opportunity to participate must be provided by the healthcare professionals. The medical staff must inquire about, communicate concerning, and include patient interests and values in the judgment process. Weaving medical interests and values with patient interests and values is the way to reach a viewpoint that will satisfy the convictions of the patient and the healthcare professionals. This requires professionals who listen to the patient, who get in touch with the patient's situation, and who invite the patient into the community of medicine.

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[654] William James, "On A Certain Blindness in Human Beings," in *The Writings of William James*, ed. John J. McDermott. (Chicago, IL: University of Chicago Press, 1977 [1899]), 629-630.

Medicine, however, is equated with technical, medical, and scientific knowledge. I believe this "objective" knowledge is necessary but not sufficient for good medicine. My point is made cogently by Dewey:

> We need to recover from the impression, now widespread, that the essential problem is solved when chemical, immunological, physiological, and anatomical knowledge is sufficiently obtained. We cannot understand and employ this knowledge until it is placed integrally in the context of what human beings do to one another in the vast variety of their contacts and associations.[655]

Medicine must not only account for physiological conditions but must inquire into how these conditions are worked out in the patient's experience. To welcome the patient to participate in the process of healing *is* itself a moment of regeneration to living healthily *by* and *for* the patient.

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[655] Dewey, *Later Works, vol. 13,* 336.

CHAPTER 7

A COMMUNITY OF TRUST

Talking about Trust

The Problem of Trust

In my view, creating trust begins with understanding, but it requires the discipline of practice. Consequently, I believe that teaching medical students about the importance of trust for communication in an institutional culture is inadequate. This form of education may cause aspiring healthcare professionals to *want* to trust, but such courses will not in themselves produce the embodiment of trust in everyday conversations. The key to getting trust as a prerequisite for effective communication into the work world is *commitment*.

Based on my institutional experience (the church), the problem of trust may be *the* problem in organizational life. I attended numerous workshops that were designed to deal with institutional problems. Usually the stress was on skills and motivational gimmicks. From my perspective, however, what causes the institution to falter is a lack of trust. Congregants and clergy do not trust District Superintendents (micromanagers) or the Bishop (CEO). The hierarchy consciously practices sanctified hypocrisy, and even if they genuinely *like* others in the system, they do not trust them.

Through gossip, I have learned that the situation may be much the same in medical institutions. When asked, healthcare staff are eager to confirm the trust they think extends throughout their system. If questioned, nevertheless, about providing evidence of that trust, I am treated to circumventions. What is described as trust I would call “hospitable hypocrisy." This is a strong tendency, because of loyalty or fear, to pretend that there is trust when there is not, to be polite in the name of unity. In actuality, cynicism (i.e., the refusal to trust) and distrust (i.e., paranoia) act like venom, killing possibilities, repressing healthy criticism, stifling hope, and making honest communication impossible. The status quo is resentfully accepted, bad ideas are insincerely praised, and objections are never voiced. Like a worm in an apple, suspicion and wariness eat away at the core of the organization.

Meetings, instead of being forums for addressing problems and facing criticism, are painful, strained, and frustrating ordeals because they fail to provide opportunities to solve complications by way of open discussion that releases creativity and forges solidarity. Chary medical employees sit on their ideas, abstain from disapproval, and courteously agree overtly to proposals with which they disagree covertly. After the meeting, sneers, sarcasm, and acrimony prevail.

The executives, with "fire" power, are given obeisance, but they do not earn the trust of their staff. The result is a community of disgruntled wage earners. The medical lackeys will do their jobs, but they will not give their minds (i.e., their ideas) or their hearts (i.e., their passion).

The Vision of Trust

Trust is not a thing. Trust does not have preexistence and nor can it be assumed.

What then is trust? Trust is an active and dynamic aspect of my life that I create with promises, commitments, moods, and integrity.[656] Trust is based in a relationship which it (trust) generates. Trust is an invisible force and therefore I take it for granted. In

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[656] Robert C. Solomon and Fernando Flores, *Building Trust*. (New York, NY: Oxford University Press, 2001), 13-15.

reflection, however, trust is actually the result of my constant attention and activity. Parenthetically, when trust becomes firmly established in my life, it increasingly becomes a subconscious attitude. I have discovered that trust always embraces the possibility of distrust, which is the reason that trust is often evident to me only in the breach. In my personal experience, I frequently regard trust as a revolutionary power, especially when I contemplate the dramatic changes that have taken place in my thinking and acting through trust.

Many times I have mused on how closely related trust and love are in my thought and behavior. Superficially, both trust and love are natural and are taken for granted. The outcome is seen in disappointments and breaches. In actuality, however, while both trust and love may seem to fail me, through inattention I fail at trust and love. Furthermore, in a lifelong process I have learned that both trust and love are moods. Consequently they require judgment and action. Still further, trust and love involve all the reciprocities of my human relationships. I decide to trust and love others. I make promises to them. I have expectations of them. I react to the fulfillment or frustration of my expectations of them. Trust and love are not things I have; they are ways in which I speak and act with others. My choices of trust and love determine, finally, the kind of being I am and the kind of life I live. It is in this manner that choices of trust and love direct what and how I speak.[657]

Trust may also be understood as a kind of freedom; it is freedom *from* distrust and freedom *for* the realization of possibilities.[658] For example, a freedom of healthcare

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[657] Annette C. Baier, *Moral Prejudices*. (Cambridge, MA: Harvard University Press, 1995), 120-124.

[658] Francis Fukuyama, *Trust: The Social Virtues and the Creation of Prosperity*. (New York, NY: Free Press, 1996), 155-156.

professionals that trust would provide is the freedom to think for themselves and voice their own ideas. This freedom, of course, would include a freedom to be questioned and criticized as well as a freedom to be recognized and appreciated.

In my society it is commonly believed that, given the increased complexity of life, it is easier to distrust than to trust. Significantly, the German Sociologist, Niklas Luhmann, maintains that trust is a way of dealing with increased complexity; trust lets me expand the complexity of my life as it simultaneously simplifies my life.[659] Trust promotes growth and change in all the ways that distrust distorts and prohibits.[660]

Society is composed of relationships – family, friends, social organizations, all of which require trust. Without trust, life falls into self-righteousness, alienation, and loneliness. With trust, I depend on a network of others to bring my ideas to fulfillment, to avail themselves of my services, and to maintain my reputation.

Can I Trust the Healthcare System?

Can I trust the leaders of my healthcare institution to act in the public interest? Can I trust my healthcare professionals to serve my interests? Can healthcare workers themselves trust the people with whom and for whom they work?

Listening to friends, I am often left with the impression that distrust of the medical system is growing. Yet, I think my friends demonstrate a high level of trust in their healthcare providers. What they *say* about their trust of the medical system is betrayed by their *behavior*. For example, how many of my companions have ever checked out their physician's professional training? How many of them have ever verified the pills

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[659] Niklas Luhmann, *Trust and Power*. (New York, NY: Wiley Press, 1980), 38.

[660] Luhmann, 38.

dispensed by their pharmacy? Do not my allies, for the most part, trust the people who work in healthcare? Egregious errors and unnecessary procedures notwithstanding, my comrades' attitude toward healthcare staff appears to be one of trust.

At the same time, I tend to agree with my friends that trust is waning in healthcare. After all, *how much* can I really trust my doctor? Indeed, does not the fact of liability suits brought against my doctor at least suggest that the bonds of trust have already cracked?

When I am told about the cordiality among healthcare workers, might it not be the same hospitable hypocrisy found in my church organization where feigned politeness and team spirit mask resentment that erodes the moral fabric of the system? Admittedly, sometimes I also pretend to trust those in the institution because suspicion and confrontation are too painful to contemplate constantly.

It may be that I am calling into question the degree of trust in the medical system because there is in fact a problem of distrust. Obversely, it may be that trust has come to be impugned precisely because I realize that trust is so imperative to healthcare in general and healthy communication in particular.

The Risk of Trust or the Security of Control?

Although I abhor Machiavellianism (i.e., using the fear of control to get what I want),[661] I have healthcare professionals tell me that this philosophy may still be found in the healthcare system. The cynical assumption is that people cannot be trusted. They must be controlled, therefore, through fear and threat (e.g., paternalism). I hold that it is

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[661] Niccolo Machiavelli, *The Prince*, trans. by Christian E. Detmold. (New York, NY: Armount Press, 1965), 79-82.

not by increasing control but by decreasing repression that I improve effectiveness, cooperation, team spirit, and communication.

Imagine the difference in the healthcare community if it looked to the European Renaissance for a philosophy of generating trust; the Renaissance depended on trust in humanity and the humanities.[662]

Trust and control, moreover, are incompatible because essential to trust is freedom (see above). For the most part, to trust others is to believe that they are trustworthy while recognizing the possibility that they may not be. Because of its critical link with freedom, trust always involves risk. That is exactly the reason that those who are in positions of power prefer to exercise control (coercion through fear, i.e., authoritarianism) rather than to trust through respect (i.e., authority). It is in the latter sense that I trust my doctor. I do not trust my doctor because he or she has control over my health; I trust my doctor because I respect his or her knowledge of and care for my well-being.

I have worked all of my adult life in an institution that relies on authoritarianism. For that reason alone, it tends to be a demoralizing place to serve. Dominated by authoritarianism, workers often become disgruntled and may become conspiratorial. When the central concern of the workforce is dodging reprimand or counting the cost of non-compliance, the motivating force of the organization is suspicion, not cooperation.

Speaking personally, I believe the most detrimental loss of an imperious structure is creativity. The forces of oppression tend to perceive creativity as threatening. Consequently, in a draconian establishment, employees are more nervous about satisfying the demands of overbearing bosses than about introducing new possibilities. Because the

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[662] Solomon and Flores, *Building Trust*, 23.

goal of the bureaucracy is succeeding or at least not failing, there is a drastic attempt to escape the risks of creativity that might increase the chances of failure.

The great advantage, I think, of a trusting culture over a controlling culture is the good that can come from others expressing their perspectives. The results are productive discussion, constructive criticism, and innovative ideas.

It has come to my attention, through healthcare educators, that the medical system today is recognizing the need for training in communication. If this education is understood merely as the exchange of medical information or even the exchange of material about personal feelings of affection or grievance, it misses the primary objective of communication. The foremost purpose, in my judgment, is to open oneself to the other, not so much in the ventilation of feelings as in the mutual appreciation of experiences. Coming to share each other's outlook on life is much more important than airing likes and dislikes.

When I attempt to control and manipulate instead of trust and respect, the results will always be sullied. Attempting to maximize efficiency with threats invites minimal performance and even sabotage. At best, authoritarianism provides "a pseudo-solidarity, a false intimacy, with an appearance of cooperation."[663] Ironically, it is through trust that I acquire the greatest power; it is not the power to control others but "the possibility for each and all of us to realize our full potential *together*."[664]

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[663] Quentin Quesnell, *The Authority for Authority*. (Milwaukee, WI: Marquette University Press, 1973), 18-41.

[664] Solomon and Flores, *Building Trust*, 29.

Basic Trust

The foundational nature of trust is called “basic trust” by Psychiatrist Erik Erikson.[665] It is an orientation toward the world, an attitude that is established early in life.[666] It is enhanced or compromised by my experiences with others.[667]

In my point of view, basic trust develops by *talking* about it. I am not thinking of some bland conversation but talk that has substance, interest, and emotion.

For some, in my experience, talking about trust is just too uncomfortable. For others, talking about trust is accepted as long as I steer clear of those areas of life where trust is in question. For still others, talking about trust means engaging in a conversation that is limited to blame, lament, and hypocrisy. Listen to the jeremiads: “How can I trust the healthcare system when it is so greedy?” “How can I trust my doctor when I know he is cheating Medicare?” Listen to the pretense: “I think it is better to simply trust than to talk about it. After all, even to raise the question of trust indicates distrust. That is why I feel all we need is to say ‘just trust me’ or ‘just trust it.’”

I think that talking about trust, like talking about love, is paradoxical. Whether talking about trust or love, it is an action that does not merely evince feelings, but to some extent also creates and shapes them. For example, “I trust you” and “I love you” are not so much expressions of a feeling as they are creative acts intended either to manipulate or reassure the other.

The conversation about trust begins with the question, “How will I trust?” I do not start talking about trust by asking, “Do I trust or distrust?” I am not denying that I find it

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[665] Erik Erikson, *Childhood and Society*. (New York, NY: Norton Press, 1993), 80.

[666] Erikson, 247.

[667] Erikson, 248.

difficult to trust some people, that I am suspicious of some people. Yet, even in the face of vehement distrust, talking about *trust* is the first step in the emergence of basic trust. For example, talking about how to trust may begin in a milieu of mutual accusations, but accusations may lead to negotiations, and negotiations may lead to mutual commitments, and mutual commitments develop trust.[668] Talking about trust is to recognize that we are in this (relationship, work, life) together.[669]

Distortions of Trust

Philosopher and author Friedrich Nietzsche points out that what is closest to us is often furthest from our awareness.[670] This certainly appears to be the case with trust. Except for situations of betrayal, I know some people who trust unthinkingly.

Such un-reflectiveness, however, can be deleterious.[671] It can lead to distortions of trust which occlude my view of authentic trust.[672]

Naïve Trust

Naïve trust is an assumed attitude regarding others. Perhaps naïve trust does not become conscious until I am in an unusual, unfamiliar, or unsafe situation. Naïve trust is basic trust that remains unreflective. It is trust without the possibility of distrust; it is to be unsuspicious.

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[668] Solomon and Flores, *Building Trust*, 46.

[669] Solomon and Flores, *Building Trust*, 46.

[670] Friedrich Nietzsche, *Thus Spoke Zarathustra*, trans. by W. Kaufmann. (New York, NY: Viking Press, 1954), 83.

[671] Solomon and Flores, *Building Trust*, 54.

[672] Solomon and Flores, *Building Trust*, 54.

Some people think of trust as naiveté, as taken for granted[673] (e.g., trust of a patient for his or her caregiver). I suggest that naïve trust is to authentic trust what infatuation is to true love.

I know people who claim that naïve trust is “human nature.” This, however, is to cut off the possibility of serious inquiry. Furthermore, I do not “naturally” trust others, even if some kind of infantile trust remains a possibility throughout my life.[674]

If, moreover, naïve trust is “human nature,” then its loss is a misfortune. On the contrary, I contend that the loss of naïve trust is an invitation to reflection and understanding. In fact, only in the loss of naïve trust can I perceive that it is not authentic trust.

Naïve trust remains unquestioned not because there is nothing to question, but rather because it is unbetrayed. As a result, it is not until my naïve trust is violated that I become aware of the threat of unthinking trust. Once I have faced life’s uncertainties and relinquished the illusions of naïve trust, I begin to ask about how I can practice authentic trust.

Blind Trust

Blind trust is denial.[675] It is to see but to refuse to see. Blind trust does not ask, or asking, does not listen. It excludes criticism, scrutiny, and looking at the evidence.

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[673] Baier, 95-129.

[674] Baier, 120-122.

[675] Karen Jones, “Trust as an Affective Attitude” in *Ethics 107,* No. 1, 1996, 4-25.

Indeed, blind trust is self-deceptive.[676] It not only refuses the evidence but is in complicity with untrustworthiness and even betrayal.[677]

The disregard of alternative evidence that characterizes blind trust is also true of anger.[678] Anger also has an obstinate blindness ("blind rage")[679] and an inconsideration of evidence ("anger is irrational").[680] I would argue, nonetheless, that both blind trust and anger are *rational* because both are directed. I concur with Jean-Paul Sartre who calls the "intentions"[681] of emotions such as blind trust and anger "strategies."[682] Passions involve strategies, even if they are inarticulate.

Another version of blind trust is unconditional trust.[683] I often generalize. So when I say that I trust someone, I seem to imply that I trust him or her in every way. I ought to distinguish, nevertheless, between what I say ("I trust you") and what is conversationally implied (to say or do something).[684] It appears that I always trust in certain aspects. For example, I trust a nurse to remember to make entries in my medical record, but not to remember my birthday. I trust the hospital emergency room supervisor to accurately report the working conditions of the ER, but not to tell me about her personal foibles.

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[676] Amelie Oksenberg Rorty, "User-Friendly Self-Deception" in *Self and Deception*, ed. by Roger Ames and W. Dissanayake. (Albany, NY: State University of New York Press, 1996), 73-87.

[677] Rorty, 73-87.

[678] Solomon and Flores, *Building Trust*, 67.

[679] Solomon and Flores, *Building Trust*, 67.

[680] Solomon and Flores, *Building Trust*, 67.

[681] Jean-Paul Sartre, *The Emotions,* trans. by B. Frechman. (New York, NY: Citadel Press, 1948), 50-94.

[682] Lawrence C. Becker, "Trust as Non-Cognitive Security about Motives" in *Ethics 107*, No. 1, 1996), 43-61.

[683] Solomon and Flores, *Building Trust*, 80.

[684] Solomon and Flores, *Building Trust*, 81.

Limits notwithstanding, generalization prevails. Accordingly, I say to my doctor, “I trust you” instead of saying, “I trust you to perform my hip replacement surgery.” My point is that there are always limits to trust and to recognize those limits is an important part of authentic trust.

Trust and Reliance

Although I often use trust and reliance (i.e., predictability)[685] interchangeably (e.g., “I trust my colleagues” or “I rely upon my colleagues”), I need to distinguish them. To equate trust with reliance is mistaken unless I am speaking about “things governed by regularities”[686] (e.g., “I trust that the respirator will start when I flip the switch”). My respirator does not know or care that I rely on it. I trust my colleagues because I believe that they know and care. Admittedly, I do talk about trusting the pharmacy to give me the correct medicine, but what I mean, of course, is that I trust the pharmacist or tech who fills my prescription.

What shall I say, however, about my doctor making a prognosis (i.e., prediction)[687] about the outcome of a certain treatment for my sickness? Trust cannot simply be equated with predictability; without an element of unpredictability, there is no place for trust.[688] I may regard my doctor as predictable, but that is because I trust him or her; I do not trust my doctor because he or she is predictable.

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[685] Baier, 98.

[686] Baier, 98.

[687] Baier, 99.

[688] Solomon and Flores, *Building Trust*, 71.

Predictability requires a high degree of probability, a kind of certainty.[689] Trust necessitates a reciprocal relationship with my doctor in which questions of expectation are more significant than questions of probability.[690] In reliance, predictability is definitive; in trust, there is invariably some risk. The probability of a favorable outcome, therefore, is always less than certain.

Trust and Competence

A condition of trust is the competence of the person trusted.[691] It makes no sense to trust someone to do something he or she cannot do. For example, take my trust in medical practitioners. Medicine has become too complicated and sophisticated for the family physician. Consequently a primary concern for trust is competence.

Still, there is a critical difference between trust and competence.[692] Karen Jones targets the difference as having a good will.[693] In regard to medicine, I see the distinction as between caring and expertise.

The primary concern of some patients, in my experience, is capability. They are apathetic about whether the doctor is caring. It is important only to have the best medical mechanic who can get the body fixed. The main concern of other patients is relationship. Is the doctor solicitous? For me, I want a healthcare professional who not only *knows* what he or she is saying and doing but is *attentive* to what he or she is saying and doing. I

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[689] Solomon and Flores, *Building Trust*, 71.

[690] Solomon and Flores, *Building Trust*, 83.

[691] Baier, 104-106.

[692] Baier, 99.

[693] Karen Jones, 4-25.

want someone who takes into account my thoughts and feelings as a patient. I want a healthcare professional who is not only competent but conscientious.

With Solomon and Flores, I believe competence may be defined as “the ability to perform as expected, according to standards appropriate to the role of the task in question.”[694] As a result, to trust involves assessing the level of competence.[695] For example, if I trust a medical student to do what he or she cannot yet do, it does not constitute a breach of trust. If, however, the neophyte pretends to know how to do what he or she cannot do, it is a breach of trust. Yet even here what violates trust is not the incompetence but the dishonesty.

Additionally, competence may be a matter of reliance (i.e., predictability), but trusting medical personnel to inform me truthfully about their competence or lack of skill is certainly a matter of trust.[696] Involved as well is the extent to which I trust healthcare professionals to be forthright with themselves about their proficiency[697] (e.g., a doctor who refuses to attend continuing education events or a nurse who cannot admit to a problem with alcohol). If healthcare workers want for the adeptness I have a right to expect from them, they have contravened my trust.

Trust and Responsibility

My particular subject matter in this section is trust in institutions. When it comes to trusting institutions (e.g., hospitals, hospices, nursing homes), notions of trust become especially problematic. Although the hospital is not the same as an aggregate of

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[694] Solomon and Flores, *Building Trust*, 85.

[695] Solomon and Flores, *Building Trust*, 85.

[696] Solomon and Flores, *Building Trust*, 85.

[697] Solomon and Flores, *Building Trust*, 85.

healthcare professionals (see above), the hospital is a human entity that is structured and operated by human decisions and actions. The problems seem to arise, in large part, because of an evasion of responsibility by one or more of the hospital's agencies.

In my world, hospitals are often thought to be run by financial interests and strategies. Whether this cynical view is correct or not, it implies nevertheless that hospitals do have interests and strategies. If so, they can be appealed to, and negotiated with, to fulfill their commitments. Indeed, what needs to define the hospital institution in my thinking is not profit margins but its sense of commitment and responsibility.

Every hospital institution is also an organization, which means that it has some method for making decisions (e.g., a Board of Directors). This means that even the hospital's chief executive officer may distinguish his or her personal opinions from his or her pronouncements as CEO. It seems, therefore, that the responsibilities of the hospital institution are derived from the responsibilities of selected persons to make decisions in the name of the hospital institution. Whatever the decision-making procedure and whatever the complications of identifying the responsible agency, however, what is essential in consideration of trust is that the hospital corporation be viewed in terms of human commitment and responsibility.

Authentic Trust

Trust as Choice

The term "authentic trust" is taken from existentialists Soren Kierkegaard and Martin Heidegger.[698] "Authenticity" involves an awareness of my identity and how my identity

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[698] John Macquarrie, *Existentialism*. (Philadelphia, PA: The Westminster Press, 1972), 33, 107.

changes with my circumstances and my commitments to others.[699] As a result, I believe that those who work in an environment where colleagues authentically trust each other work in a more vibrant atmosphere than those who do not.

Authentic trust is reflective, honest, and counts on others.[700] It entails vulnerability and risk;[701] it is aware of the possibilities for disappointment and betrayal.[702] Indeed, I cannot authentically trust unless I have experienced, in fact or in imagination, disappointment or betrayal.[703]

For me, however, the most important feature of authentic trust is communication.[704] Even in the most arduous cases of creating authentic trust (e.g., between people at loggerheads),[705] a key component is in making mutual commitments [706] (see above). In turn, through the process of forming commitments, there is the vital ingredient of talk (see above). As long as there is conversation, there is the possibility of authentic trust.

In most of my research into trust, the evidence justifying trust has been the evidence for the trusted person's trustworthiness.[707] By making a distinction between the act of

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[699] Macquarrie, *Existentialism*, 170.

[700] Solomon and Flores, *Building Trust*, 92.

[701] Solomon and Flores, *Building Trust*, 92.

[702] Solomon and Flores, *Building Trust*, 92.

[703] Solomon and Flores, *Building Trust*, 94.

[704] Solomon and Flores, *Building Trust*, 94.

[705] Solomon and Flores, *Building Trust*, 94.

[706] Solomon and Flores, *Building Trust*, 94.

[707] Solomon and Flores, *Building Trust*, 95.

trusting and being trusted, however, it becomes clear that I am talking about a complex relationship that is asymmetrical.[708]

To make trustworthiness depend on the person being trusted is to reduce trust to reliability. Trust, in my experience, is more dependent on the attitude of the one who trusts than on any facts about the one trusted. Indeed, I have trusted persons who are known to be untrustworthy. On the other hand, I have always been known to be trustworthy but I have not always been trusted.

I have found that to trust the other changes both the one who trusts and the one trusted. To trust is a decision that takes into consideration the possibilities for change as a result of that decision. Contrary to my naysayers, trust is not formed by beliefs and feelings *about* the other but by conversation and interaction *with* the other.

I do understand the argument for the need to consider the evidence to trust. Still, trust for me is more than evidentiary. By saying that, I do not mean that to trust is partly irrational. I do mean that rationality is not found only in the weight of evidence; it is also found in that about which I really *care*.[709] What makes trust rational is not the accumulation of evidence but the caring about the conversation and interaction with the other.[710]

At the heart of authentic trust, as I indicated above, is commitment. Now I want to say that what is significant about commitment is that it necessarily involves reciprocity

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[708] Solomon and Flores, *Building Trust*, 95.

[709] Harry Frankfurt, *The Importance of What We Care About*. (New York, NY: Cambridge University Press, 1988), 80-94.

[710] Frankfurt, 188-190.

and communication.[711] A commitment is not merely my expectation.[712] For example, if my doctor makes a commitment to have me discharged Friday, I can expect to be discharged Friday. I may, however, expect to be discharged without any commitment on the part of my doctor or my doctor may simply fulfill my expectation.

I trust authentically without regard for my advantage.[713] This means that I speak and act kindly because I am moved by the suffering of others or because I feel the need to help. If, however, I think of self-aggrandizement or of making a patient indebted to me, I am not being kind. I trust others because it is right to trust and I am concerned with the integrity of my conversation and interaction with the other, not because I am pursuing my own advantage.

The weighing of trust and distrust is so essential to trust that it makes no sense to perceive them as mutually exclusive. “Does not every conversation and interaction involve an awareness of risk and vulnerability; an assessment of the person and the situation; and a realization of the unknown future that will be opened up by trust?”[714] Indeed, it is the unknown that makes authentic trust always a matter of commitment and never just a matter of calculation.[715] Consider a hospital vice-president who suspects that the hospital treasurer may be misappropriating funds for his own interests. Rather than accusing him or resolving never again to trust him, the vice-president may simply speak of having a “concern” about the treasurer. The VP acts as if she trusts the treasurer,

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[711] John Macquarrie, *In Search of Humanity*. (New York, NY: Cross Road Publishing Company 1983), 151.

[712] Macquarrie, *In Search of Humanity*, 245.

[713] Philip Pettit, “The Cunning of Trust” in *Philosophy and Public Affairs 24*, no. 3, 1995, 202-225.

[714] Solomon and Flores, *Building Trust*, 95.

[715] Macquarrie, *In Search of Humanity*, 147-148.

although she does not, in order to see if she can actually trust the financial officer. Authentic trust does not simply trust or distrust; it is rather a progressive dialectic between trust and distrust.[716]

This existential understanding of authentic trust puts the act of trusting fully in my power.[717] Yet, I do not and, indeed, cannot only choose to trust or distrust because I cannot always choose my circumstances or the persons with whom I become engaged[718] (e.g., a nurse assigned to a certain patient). That is why it is also necessary to be aware of trust as mood.[719]

Trust as Mood

In this section, I lump emotion and mood because I think that, for the most part, what applies to one applies to the other. The sole apparent difference I see is in the extent. Whereas an emotion is directed at a person, a mood encompasses the world.[720]

I allege, therefore, that trust is more like a mood than an emotion. For example, I speak of a “fit” of anger or a “pang” of jealousy but a “steadfast” trust.

I have a mood because I care.[721] So Martin Heidegger describes mood as being “tuned” to the world in caring ways.[722] Caring, however, can take many forms (e.g.,

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[716] Solomon and Flores, *Building Trust,* 101.

[717] Solomon and Flores, *Building Trust,* 102.

[718] Solomon and Flores, *Building Trust,* 102.

[719] Fukuyama, 355-362.

[720] Solomon and Flores, 108.

[721] Martin Heidegger, *Being and Time,* trans. John Macquarie and E. S. Robinson. (New York, NY: Harper and Row, 1962), 131.

[722] Heidegger, 134-139.

anxiety, despair, hope, trust, love). The particular form of my mood determines to a large extent the scope of my speech and actions.[723]

For many years I thought of my mood as a result of what happened to me. This meant that my thinking about my mood was regressive; I was focused on getting out of my mood.

What a difference it has made to think of my mood not as a "happening" but as a "doing" for which I am responsible.[724] My focus now is not with what has happened but with what is to be done; now I attempt not to *get out* of my mood but to *get into* it (i.e., to understand it).

In a medical situation, mood may be a primary factor of dedication and efficiency.[725] If so, how can healthcare professionals cultivate a mood of trust and caring and get rid of "bad" moods that destroy medical institutions? Moods can be transformed not by identifying the cause of the mood but by identifying the assessments that constitute the mood.[726] This involves understanding, through conversation, how others perceive the situation, how others perceive me, and my place in the situation.[727] Conversation leads to understanding; understanding leads to speech and actions that bring about a new situation and new possibilities.[728] "Bad" moods cannot be sustained in an environment of trust and caring.[729]

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[723] Solomon and Flores, *Building Trust*, 109.

[724] Solomon and Flores, *Building Trust*, 109.

[725] Solomon and Flores, *Building Trust*, 110.

[726] Solomon and Flores, *Building Trust*, 111.

[727] Solomon and Flores, *Building Trust*, 113.

[728] Solomon and Flores, *Building Trust*, 113.

[729] Solomon and Flores, *Building Trust*, 113.

The exception is hospitable hypocrisy, the veneer of courtesy that is presented as a "good" mood.[730] Why is it that so many times workers in an ostensibly euphoric institution hate and complain about their jobs? Why does a probing of this pervasive "good" mood of politeness, jauntiness, and ebullience, often disclose a rife mood of despair, resignation, and resentment? Hospitable hypocrisy is the most dangerous threat to authentic trust because it poses *as* authentic trust![731]

Self-trust

Trust is a capacity to be matured over time so that eventually, without much reflection, I know increasingly when to speak or to listen, when to make or not make promises. It is a feeling of adequacy for dealing with any situation or person. Self-trust, therefore, is a feeling of confidence in my competence.[732]

Self-trust is enriched by trusting behavior.[733] If trust is to be learned, it will not be through complying with certain rules or adhering to some formula but by speaking and doing.[734] There are no steps through which to make myself more trusting or others more trustworthy. The way to trust is to practice trusting, and trusting involves a heightened sensibility to others precisely because I am confident in what I am saying and doing.

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[730] Solomon and Flores, *Building Trust,* 113.

[731] Solomon and Flores, *Building Trust,* 113.

[732] Keith Lehrer, *Self-Trust: A Study of Reason, Knowledge, and Autonomy*. (New York, NY: Oxford University Press, 1997), 3.

[733] Lehrer, 119.

[734] Lehrer, 59.

If trusting is a cultivated capacity on the one hand, it is “reflective scrutiny”[735] on the other hand. The point is that I never get beyond the possibility of making a mistake. It is by means of such perusal that relationships are matured as others become the focus of care.[736] What is matured, however, is not only the confidence I have in the relationship but the confidence I have in myself in the relationship.[737]

More specifically, trusting others requires self-confidence in making “assessments.”[738] By “assessments” I mean “statements of opinion, value judgments, evaluative assertions.”[739] Critical to making such appraisals is an awareness of my subjectivity;[740] I am aware of trusting in my ability to make valuations and use those valuations in forging a more intense, trusting relationship.[741] If, for example, I judge my co-worker as irresponsible for failing to talk with someone or to do something assigned, that judgment ought to be the beginning of a conversation about it.[742] Of course, to talk about it will not be easy or comfortable.[743] Despite the apprehension, my confidence in my ability to carry on such a conversation is at the heart of authentic trust.[744] On the other hand, authentic trust is also realized when I have the capacity to confront the judgments

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[735] Lehrer, 4.

[736] Lehrer, 4.

[737] Lehrer, 57.

[738] Solomon and Flores, *Building Trust*, 120.

[739] Solomon and Flores, *Building Trust*, 120.

[740] Solomon and Flores, *Building Trust*, 120.

[741] Solomon and Flores, *Building Trust*, 120.

[742] Jeffrey A. Kotter, *Beyond Blame*. (San Francisco, CA: Jossey-Bass, 1994), 56-76.

[743] Kotter, 59.

[744] Kotter, 151.

that are made about me and to me by others whom I respect and whom I believe care about me.[745]

Still, many people I know have a tendency to become defensive when their communication or activity is censured. This reaction, I think, is not only a matter of feeling upset and hurt; it is a matter of lacking self-trust. Being able to accept the possibility that my communication or activity could be improved is a source of authentic self-trust.

Failures of Trust

In every instance of trust lies the specter of failure. Indeed, without the possibility of collapse, there can be no trust. Not all breakdowns are equal, however. In fact, a reason that I mistakenly tend to think of trust as fragile is that I conflate disappointments with betrayals.[746] Trust involves risk, the consequences of which are often dismay but not necessarily treachery.

I need to know that authentic trust does not emphasize result (i.e., a satisfactory or favorable outcome) as much as relationship.[747] What I am suggesting is that a relationship built on authentic trust can endure letdowns. Indeed, basic to the notion of trusting myself and others is to tolerate omissions and learn from them.[748]

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[745] Kotter, 201-203.

[746] Milan Kundera, *The Unbearable Lightness of Being*, trans. Michael Hien. (New York, NY: Harper and Row, 1984), 90-92.

[747] Baier, 142-143.

[748] Baier, 143.

Let me identify two categories of disillusionment. The first is failure (e.g., “it didn’t work out”).[749] In medical treatment or biological experimentation, there is always the possibility that it will not develop in the desired way. My proposal may be thwarted or my efforts at negotiation may be derailed. There is no reason to attach blame[750] or lose confidence in the process.[751] Indeed, it is precisely at the point of defeat, where trust in the people and the process with which I am engaged, becomes crucial.[752]

The second category of disenchantment is oversight (e.g., “he slipped up”).[753] There is always the possibility of error; I may say or do the wrong thing. To trust people enough to make them part of the healthcare team means trusting them enough to make mistakes. To trust others is to open myself to the vulnerabilities of human behavior. To trust others is to be able to see beyond the miscalculations to the possibilities in spite of the defects.

Breaches of Trust

Blameworthy acts are not mere disappointments but breaches of trust.[754] Take, for example, a medical novice who, by using argot, poses as an expert on medicine. This is not an error; this is wrong; this is misrepresentation and fraud.[755] Even so, the culpability lies not in the fledgling’s speech but in his arrogance and pretense.[756]

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[749] Baier, 143-144.

[750] Baier, 150.

[751] Baier, 150.

[752] Baier, 150-151.

[753] Solomon and Flores, *Building Trust*, 131.

[754] Solomon and Flores, *Building Trust*, 132.

[755] Solomon and Flores, *Building Trust*, 132.

[756] Solomon and Flores, *Building Trust*, 132.

Let me identify two types of breach. The first is indifference[757] (i.e., a lack of caring), whether manifested as uncaringness or disregard.[758] Surely, it is obvious that a surgeon who does slipshod work is blameworthy. It is also clear to me, however, that a surgeon who performs magnificently but is inattentive to the emotional needs of the patient also breaches trust.

A second type of breach is insincerity.[759] I may be disingenuous in making a commitment or promise to the other, and the relationship as a result may be tarnished or terminated. On the other hand, I may be candid in making a commitment or promise to the other but be dishonest in my intention of fulfilling it.

I believe that one way to deal with breaches of trust is by apology. By "apology" I am thinking of an example of what Oxford University Philosopher J. L. Austin calls, "a way of doing things with words."[760] Consequently, an apology can be sincere or insincere; too early, on time, too late; appropriate or inappropriate.[761] Because it is a desire for conciliation that ought to prompt an apology, excuses (e.g., upbringing, circumstances) are an irresponsible and ineffective use of words. Similarly, an apology is not a blunt, heartless dismissal (e.g., "forget it!").

As a speech act, an apology is even more than a feeling of heartfelt remorse; it is a way of initiating a conversation.[762] In other words, I should not assume that saying the

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[757] Solomon and Flores, *Building Trust*, 133-134.

[758] Solomon and Flores, *Building Trust*, 134.

[759] Margaret Lewis Furse, *Nothing but the Truth?* (Nashville, TN: Abingdon Press, 1981), 18-28.

[760] J. L. Austin, *How to Do Things with Words*. (Cambridge, MA: Harvard University Press, 1997), 6.

[761] Austin, 39-52.

[762] Solomon and Flores, *Building Trust*, 133.

magic words (i.e., “I’m sorry”) erases the breach of trust and the damage it has done to the relationship. An apology is the beginning of a conversation about the seriousness of the breach of trust and about my sincere intention to redeem myself by honestly attempting to make amends for my hurtful words and/or actions.

Trust and Forgiveness

Forgiveness is another way of responding to a breach of trust. Forgiveness makes the renewal of trust possible. It is an action, not simply a state of mind.[763] As such, forgiveness is a making contact with and a speaking to the betrayer.

Does forgiveness, however, need to be expressed? For example, can I indicate forgiveness by simply talking and acting as if nothing is wrong? While it may be possible, I do not believe it is practical. First, I may be using a ruse to render the betrayer defenseless before attempting to get even.[764] Second, I may just be trying to return to a pre-betrayal state. In fact, any form of *implicit* forgiveness may indicate a failure to take betrayal seriously.[765] For these reasons, I believe *explicit* forgiveness is preferable (e.g., “I forgive you”).

Because forgiveness is possible without articulation, it is often, in my experience, interpreted as a merely mental act, putting myself in a frame of mind in which the betrayal is no longer taken seriously. In this way, I attempt to restore the pre-betrayal

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[763] Baier, 44-45, 103.

[764] Baier, 140.

[765] Baier, 140.

relationship. The error is in making forgiveness totally a subjective act, not realizing that it is also an indispensable part of the relationship.[766]

The problem of making forgiveness purely an act of mind is further indicated by the catch phrase, "forgive and forget." Are both necessary? If I forget (i.e., stop thinking about the betrayal), what is there to forgive? If I forgive (i.e., stop feeling resentful about the betrayal), why is it necessary to forget? Could "forgetting" simply be denial or self-deception? After all, has not betrayal now become an essential part of the relationship? Forgetting, therefore, is not likely to happen and even if it does, the failure to remember the betrayal is not to be considered a good thing. What is good, in terms of the relationship, is forgiveness.

What, then, is forgiveness? Plainly, I do not believe forgiveness means putting the betrayal out of mind. I do believe that forgiveness is the desire and the decision to progress, change, and grow through the experience of betrayal. I want to focus attention on moving ahead because I do not believe forgiveness can restore the relationship to a former state.

Still, from this point forward, trust will always be guarded.[767] Accordingly, the betrayal of trust, though forgiven, leads to a profound alteration of the trusting relationship.[768] Forgiveness is a way to renew trust, but it will not, in the nature of things, return the relationship to its prior state.

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[766] Baier, 141.

[767] Jeffrie G. Murphy, *Getting Even*. (New York, NY: Oxford University Press, 2003), 117.

[768] Murphy, 38.

I say, "in the nature of things," because forgiveness recognizes the appropriateness of revenge (i.e., the *actual* desire of getting even for the betrayal)[769] and resentment (the *fantasized* desire of getting even for the betrayal).[770] Yet, in spite of the feelings of fairness,[771] forgiveness decides for moving on. If I am able to advance in the sense of overcoming but not erasing the betrayal,[772] trust may be regenerated and mutual attention paid to the relationship in a way that will improve the communication and interaction.

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[769] Trudy Govier. *Forgiveness and Revenge*. (New York, NY: Routledge Press, 2002), 1-41.

[770] Govier, 50-54.

[771] Murphy, 31.

[772] Murphy, 12, 65, and 117.

CHAPTER 8

A COMMUNITY OF INHOSPITALITY

Inhospitality as Turning a Blind Eye

When Healthcare Is a Tunnel

A story, “The Tunnel,” appears in a small book written by a radiologist, Richard Peschel. It is co-authored by the Director of the Medical Humanities Program at Yale University, Enid Peschel. Richard tells about the medical situation and Enid juxtaposes the medical case with some passage in literature. Together the medical incident and the reflection serve as a link between medical experience and universal human experience.

The hospital in which Richard interns is divided into two buildings: one, older, is the location of the emergency room and the morgue. The other, newer, is the site of the intensive and coronary care units. An underground tunnel, approximately one and one-half city blocks from end to end and two stretchers wide, connects the two buildings.

While on-call, Richard receives a call to tend to a patient in emergency. Richard arranges to have the patient transported through the tunnel to the coronary care unit. Despite Richard’s reassurance, the patient is sure he is dying.

About half-way through the tunnel, Richard sees a stretcher completely covered in white coming toward them; it is a stretcher bearing a corpse draped in a sheet. Both conveyances slow down to pass. Richard’s patient turns his head and sees the stretcher with the white-cloaked corpse. No one speaks. From the expression on the patient’s face, however, Richard believes his patient has just seen an image of himself.

Two days later, the patient, while being visited by Richard, asks Richard if what he saw in the tunnel was a dead body. Richard responds: "I cannot escape answering. 'Yes, it was.' That was all that was said, then or ever."[773] After a few weeks, the patient is discharged. The memory of the cortege and his patient's face, however, continue to haunt Richard every time he walks through the tunnel. Significantly, he does not wonder what might haunt his patient or what he might have said to his patient in the tunnel and/or later.

The tunnel is an evocative metaphor for institutional medicine, the organizational structure through which healthcare is offered. Medicine can seem to be a constricting place that makes it difficult to see things in perspective and to talk about what these things mean. In the words of Barbara Rosenblum, "Hospitals are experienced as distorted corridors."[774]

The tunnel may also be a metaphor for medical relationships. In the course of serious illness, professionals and patients go through the tunnel together. Richard Peschel's case story poses the problem of who each will be for the other as they take this shared journey. It is also this problem that is addressed by Enid Peschel's literary parallels.

While Enid's reflections are drawn from many sources, most interesting for me is *The Death of Ivan Ilyich*. What I experience in Tolstoy's story is the anguish of the dying patient who has not been able to verbalize and, therefore, to cast out his fear of death. Because he has not been able to express his distress, Ivan's dying is a torture not only for him but for everyone around him.

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[773] Richard E. Peschel and Enid Rhodes Peschel, *When a Doctor Hates a Patient and Other Chapters in a Young Physician's Life*. (Berkeley and Los Angeles, CA: The University of California Press, 1986), 13-14.

[774] Sandra Butler and Barbara Rosenblum, *Cancer in Two Voices*. (San Francisco, CA: Spinsters Book Company, 1991), 10.

In pain, Ivan consults a doctor and asks if his case is serious. The doctor does not answer his question. As Ivan pays the doctor, he repeats his question. Again the doctor does not answer; he just looks askance at Ivan.

As Ivan's condition worsens, other doctors are consulted. No one, however, neither doctors nor others, will tell him or admit to him that he is dying.

When Richard Peschel is in the tunnel with his patient, what happens calls for a response. When Ivan asks his doctor a question regarding the gravity of his illness, the question requires an answer.

Physician and Philosopher Paul Komesaroff describes medical practice as "a series of practical tasks that include the most appropriate way to approach the patient, to talk with him (*sic*), to allay his fears, and to establish the common ground on which mutual decisions can be taken."[775] These tasks have their complementary responsibilities on the patient's side of the relationship. For both professional and patient, therefore, the clinical encounter involves a "continuous flow of ethical decisions,"[776] especially over "the degree of openness"[777] that each will adopt toward the other.

A patient's question is, according to Komesaroff, a "microethical moment."[778] It is an occasion when the healthcare staff must respond to the patient.[779] A micro-ethical moment is a time that professionals would often like to escape; it is the desire to escape

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[775] Paul A. Komesaroff, "From Bioethics to Microethics: Ethical Debates and Clinical Medicine," in *Troubled Bodies: Clinical Perspectives on Postmodernism, Medical Ethics, and the Body,* ed. Paul A. Komesaroff, (Durham, NC: Duke University Press, 1995), 65.

[776] Komesaroff, 69.

[777] Komesaroff, 69.

[778] Komesaroff, 68.

[779] Komesaroff, 68.

seeing oneself mirrored in one's action or inaction. The mirror shows the healthcare professional that there is no escape from the micro-ethical moment.[780]

Neither Richard's nor Ivan's doctors, though they want to elude a reply, is able to avoid a reply, if only to circumvent the question or retreat into silence. The more the doctors use circumlocution or taciturnity, the more the relationship between doctor and patient becomes a tunnel.

Let me now consider the substance about which Richard does not want to talk. When Richard's patient asks what happened in the tunnel, it is not a request for medical information; it is a question addressed to another human being about an incident that each of them experienced. Since each one's perspective is necessarily partial, each stands to gain a more complete sense of the experience by sharing perspectives.

In the tunnel, I perceive a micro-ethical moment. Both doctor and patient knows the fear of death within himself and the other. It is a moment to share feelings. Richard is inhospitable, however, just when hospitality is required.

What makes the medical situation a micro-ethical moment? Richard cuts off the invitation for communication with his patient; he renders both unheard. Seeing the corpse in the tunnel raises the question of death; the silence in the tunnel enacts the reality of death. The only means of life in the tunnel is in communication with the other, for to live is to communicate with the other.

Richard's evasion from communication is also an evasion from himself. What he is doing – heart monitoring – will not help. His medical expertise is irrelevant. What he cannot even imagine is that communication could help, because in that medical situation

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[780] Komesaroff, 67-71.

the heart patient on the stretcher is not so much his patient as his fellow human traveler. What Richard will not acknowledge is the human experience they share.

Similarly, Ivan's doctor not only skirts the question about the severity of Ivan's illness but will not admit to him that he is dying. Philosopher Hilde Nelson argues that being fully human requires "the ability to reveal through one's actions who one is as a person."[781] Nelson calls this revealing "normative self-disclosure."[782] What I do communicates who I am, the values I uphold and how well I uphold them. As I see others react to my self-disclosure, I know myself. Significantly, Tolstoy does not tell me Ivan's reaction to his doctor's truncated response to Ivan's question regarding the seriousness of his (Ivan's) illness.

Logically, Nelson then explores the requirement of dialogue for normative self-disclosure: "The person I see myself to be is seen most fully in the reaction of the other to me."[783] Consequently, the other can block the realization of myself.[784] In other words, self-disclosure that dialogue makes possible can be impeded when I refuse to accept the other as a partner in dialogue.

Not only does Ivan's doctor refuse to *answer* him, he refuses to *recognize* him. Charles Taylor, Philosophy Professor at McGill University, offers a statement about the damage we suffer from others' non-recognition:

> Our identity is partly shaped by recognition or its absence, often by misrecognition of others, so that a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them

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[781] Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair*. (Ithaca, NY: Cornell University Press, 2001), 25.

[782] Nelson, 25.

[783] Nelson, 25.

[784] Nelson, 27.

> a confining or demeaning or contemptible picture of themselves. Non-recognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being.[785]

Taylor continues to speak of the dialogical perspective: “If some of the things I value most are accessible to me only through the other, then the other becomes integral to my identity.”[786] Taylor acknowledges that I might find such dependence a limitation, but I have no choice.[787] “My own identity crucially depends on my dialogical relations with others.”[788]

In the story of Ivan’s dying, it is only after Ivan overhears his wife talking to a friend that he begins to realize that he is dying. From then on, Ivan is in continual despair.

There is light at the end of the tunnel, however. Two hours before Ivan dies he opens his eyes to find his young son kissing his hand. In that moment, Ivan suddenly feels compassion for others. Instantly, he is set free from his fear of death. Love for others frees him from his fear of dying, enabling him to face his death with equanimity.

What does Tolstoy mean by saying that Ivan is “freed from his fear of death”? Ivan is freed *from* being preoccupied with his own interests. He is freed *for* the interests of others. For Tolstoy, death loses its terror when the dying are able to care for others instead of just for themselves; in that connection with others, which is the completion of love, fear is driven out.[789]

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[785] Charles Taylor, *Multiculturalism*, ed. Amy Gutmann. (Princeton, NJ: Princeton University Press, 1994), 25.

[786] Taylor, 34.

[787] Taylor, 34.

[788] Taylor, 34.

[789] The notion that fear is cast out through a connection with others as the completion of love is found in the Christian Scriptures, I John 4:18.

When the Healthcare Professional Is Bigoted

The following story, taken from the Christian sacred writings, poses the problem of who the physician and patient will be for each other as they go through their own tunnel and share a micro-ethical moment.[790] In this vignette, the physician is inhospitable; the patient, a sick little girl represented by her mother, is congenial. The narrative pivots on the change that occurs in the physician's understanding of the other.

In this story, the physician is part of a culture that disavows those who are different socially, ethnically, and religiously. Aliens are referred to with slurs and treated with disdain.

On the other hand, the mother's faith is great because it overcomes prejudice within and without. She has a faith that overpowers feeling different, afraid, withdrawn; threatened, ignored, and insulted. It is a faith that is expressed with wit and grace. Outsider she may be, but in her heart she so loves her child and so feels the child's suffering that she is inwardly strengthened to approach a stranger, tolerate his silence, and suffer his exclusion.

On the other hand, the physician's attitude changes from rejection to affirmation when it is challenged by the foreigner's faith. Embedded in social and cultural circumstances, the physician finds he is reluctant to cross social, ethnic, and religious boundaries. Prejudiced he may be, nevertheless the woman touches him at the point of human need. It is a moment of illumination. It is as if the physician says to himself, "Do I really care whether this mother is socially, ethnically, and religiously different? Does it really matter that she is so dissimilar? What I see in front of me in this moment is a mother whose heart is broken because her daughter is deathly ill!" Turning his back on

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[790] Mark 7: 24-30.

all he has been taught culturally, the physician tends to the mother's child because she is a hurting human being.

In this context, the stranger and her faith in overcoming prejudice frees the physician to be more fully himself. The physician may or may not have needed this encounter to cross the ethnic hurdle, but certainly it is the mother who creates the opportunity for him to transcend it. She empowers the physician to see the situation in a different way and frees him to speak and act in a way apparently blocked to him before this meeting.

Part of what it means to be authentically human is to acknowledge and accept the diverse other. Such an understanding may well serve as an example, even in American society with its prejudices, that all people share human life and commune through speech.

When the Healthcare Patient Is Bigoted

Relevant as well to my subject of prejudice and inhospitality is the Parable of the Good Samaritan (Luke 10:30-36). John Crossan, Professor of Theology at DePaul University in Chicago, calls this extended metaphor a "Parable of Reversal"[791] (i.e., a parable that overturns my world, assumptions, and securities).[792]

I fail to *hear* the parable unless I recognize the emotional overtones of the word "Samaritan" for the first hearers.[793] A Jewish teacher is telling the story to a Jewish audience, presumably in a Jewish setting. Jews did not associate with Samaritans; they hated them.[794] To appreciate the context, think about how Americans felt about the Germans in the 1940's, the Russians in the 1950's-1980s, the Iraqis in the 1990's. To

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[791] John Dominic Crossan, *In Parables*. (New York, NY: Harper and Row Publishers, 1973), 53.

[792] Crossan, 65.

[793] Crossan, 63-64.

[794] Crossan, 64.

understand the situation is to hear the parable as a stinging indictment of social, ethnic, and religious superiority.

The climax of the narrative is the rhetorical question: “Which of these three (two Jewish religious leaders and a Samaritan enemy), do you think, was a neighbor?” When the hospitable one is neither religious leader, the audience begins to *feel* the outcome.

To ensure that no one misses the point, the teller exaggerates the goodness of the one who is despised.[795] With consummate hospitality, the adversary not only takes care of the immediate needs of the wounded man in the situation, but he is so good and feels so much compassion that he takes the injured man to the hospital where he can be treated as long as necessary at his benefactor’s expense.[796] The storyteller is trying to get his audience to *see*, *hear*, and *feel* the goodness of the enemy.

Both the setting and structure of the story combine to challenge the hearer to link two contradictory words, “Samaritan” and “neighbor.”[797] When good (the Jewish religious leaders) and bad (the Samaritan foe) are reversed [798]to become respectively bad and good, a world is being called into question. As such, the story confronts bigoted hearers with the necessity of questioning their presuppositions, prior values, closed options, set judgments, and established conclusions.[799]

Of course I ought to love my neighbor. Of course it is good to imitate what the Samaritan did. For me, however, the emphasis in this parable is not on the *action* of

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[795] Crossan, 63.

[796] Crossan, 63.

[797] Crossan, 64.

[798] Crossan, 64.

[799] Crossan, 65.

doing the good, but on the *person* who *does* the good. Nothing of what the person does is directed back at his own ego. Helping is not an end in itself, but rather it is the direct expression of his vital mode of being.

An antagonist helps me when I am sick, injured, disabled, dying. I struggle with the contradiction that a person against whom I am prejudiced does good to me. Yet, in and through that cognitive dissonance, I may experience healing. A dramatic reversal may be caused by the challenge to think the unthinkable, to speak the unspeakable, and admit thereby that my world – my way of seeing myself and others – has been placed under radical judgment.[800]

The implication is that I may expect, and should welcome, care from a doctor or nurse against whom I am biased. I struggle with it. Good equals gay, Muslim, Japanese, African American; good equals a healthcare worker who supports the right of abortion, euthanasia, DNR (Do Not Resuscitate). Nursing comes to me in this way in order that the nurse's world of hospitality may call into doubt my world of inhospitality.

Inhospitality as Holding at Arm's Length

When Healthcare Is Impersonal

"Artificial person" is a term resurrected by Elizabeth Wolgast to describe how organizations generate dilemmas of personal responsibility.[801] Thomas Hobbes, a seventeenth-century political Philosopher, coined the term "artificial person" to depict

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[800] Crossan, 66.

[801] Elizabeth Wolgast, *Ethics of an Artificial Person*. (Stanford, CA: Stanford University Press, 1992), 5-7.

those who “speak and act in the name of others” (e.g., as governments speak for the people or as parents speak for their children).[802]

The artificial person may also be empowered to “commit and obligate”[803] others (e.g., a hospital department head is an artificial person speaking on behalf of organizational rules and procedures). The department head (i.e., the bureaucrat) is personally responsible for maintaining hospital rules and procedures, but not for their effects on others’ lives.[804]

Artificial persons have administrative utility because they speak and act not on their own authority but to implement an authority that is superior to them.[805] This utility creates the problem that artificial persons no longer feel *personal* responsibility for what they say or do to others.[806]

Artificial persons, furthermore, can dissociate what they say and do from their character.[807] Indeed, in my world I hear about the functional person (i.e., a person is considered in terms of what he or she does). For example, a woman may be a doctor, but she is not a doctor all the time (the doctor may also be a wife and mother). She speaks, therefore, of being a doctor as a “role,” a word that also carries connotations of the external and superficial.

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[802] Wolgast, 1.

[803] Wolgast, 1.

[804] Wolgast, 2.

[805] Wolgast, 2.

[806] Wolgast, 40.

[807] Wolgast, 57.

My question is this: When, if ever, do I speak of the person herself, the person who remains in some sense identical through her various functions and roles, the person who not only *speaks* and *acts* but who *is* someone? Could it be that she has come to doubt whether she is a personal being at all, that she is nothing but the sum or aggregate of her changing functions and roles? Has she become so absorbed in what function or role she is fulfilling that she no longer has any sense of who she is?

I do not wish to deny that there is considerable truth in the idea of the functional person. Being and doing are closely related. Through her speaking and acting, she becomes a person. Is, however, her human reality exhausted by the functions she performs? Does it not make sense to ask *who* speaks or acts or *who* appears in these roles? What kind of *person* is my doctor? Is not vocation more than a role? If so, what scope for speaking and acting does the *person* have?

The word used by philosophers to designate a person, that which underlies and unites the various roles and functions and that which finds expression in them, is *character*.[808] Apart from character, the functional *person* is a *depersonalized* being, and her functions may eventually be taken over by machines without any difference in efficiency, or even with increased efficiency.[809] I believe that it is in the matter of *care* that the inadequacy of a merely functional view is exposed. The notion of character is meant to supply that which is lacking, namely *care*, in a functional account of the doctor or nurse.

How then shall the health*care* professional think of character? Clearly, character is not a thing, but it is more like a pattern – a pattern that can be traced in a person's attitude

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[808] John A. Macquarrie, *Theology, Church, and Ministry*. (New York, NY: Crossroad Publishing Company, 1986), 170.

[809] Macquarrie, *Theology, Church, and Ministry*, 170.

and behavior, a pattern that shows direction and consistency.[810] Character provides for a diversity of purposes and interests to be ordered in such a way that they are brought into a unity.[811] Unity is effected by having an overarching purpose or interest – an ultimate care.[812] Proximate cares are subordinated to the ultimate care which gives a definite set to the person's policies.[813] Character, however, is not just an adjective of some policy.[814] On the contrary, character produces some ways of speaking and acting rather than other ways because it is constituted by the priorities and value judgments of the person.[815]

The problem of artificial persons, from my viewpoint, is separating their speaking and acting from their character. Their responsibility is to carry out policies; this means uncritically speaking and acting as they are told to do, regardless of harm to their own person. Artificial persons consider what they say and do as beyond their control. Moreover, since their communications and actions are not on their own behalf, they can believe these activities disclose little about themselves. How, then, do artificial persons express responsibility? For artificial persons, responsibility consists in "following orders."[816]

The speech and conduct of artificial persons is a matter of doing their duty; it is also their moral liability.[817] As Elizabeth Wolgast says, "The important question is whether

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[810] Macquarrie, *Theology, Church, and Ministry*, 172.

[811] Macquarrie, *Theology, Church, and Ministry*, 172.

[812] Macquarrie, *Theology, Church, and Ministry*, 172.

[813] Macquarrie, *Theology, Church, and Ministry*, 172.

[814] Macquarrie, *Theology, Church, and Ministry*, 172.

[815] Macquarrie, *Theology, Church, and Ministry*, 172.

[816] Wolgast, 31.

[817] Wolgast, 3.

institutional practice can have priority over moral claims."[818] This dilemma is evident in medicine. "Care comes to denote a quantity of services expended, not a response of one person to another person. Care is an allocation, increasingly determined by forms of management."[819] Consequently, for medical workers, "moral ambiguity…stems in part from the fact that those receiving the orders are in the circumstances of action while those issuing them stay at a distance."[820] The nurse is face to face with patients, while those deciding forms of treatment remain at a distance.[821] The nurse is required to be an artificial person, speaking in the name of management.[822] Yet professional and personal ethics require responding to the face of the one before him or her.

There are several resulting problems: 1) there is a breakdown of human autonomy inasmuch as persons' speech and actions fail to be their own; speaking and acting are severed from the persons' decisions.[823] 2) Unable to locate responsibility, persons' cannot be represented morally. For representation to be possible, persons would need to speak and act non-autonomously, vitiating responsibility.[824] 3) A system of medical institutions and practices can alter the way persons view themselves.[825] "The context in which we speak and act determines whether our capacity for moral action is more or less central to our selves. When we accept and live among the ambiguities of artificial persons, when in

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[818] Wolgast, 3.

[819] Arthur W. Frank, *The Renewal of Generosity*. (Chicago, IL: University of Chicago Press, 2004), 128.

[820] Wolgast, 32.

[821] Frank, *The Renewal of Generosity*, 128.

[822] Frank, *The Renewal of Generosity*, 128.

[823] Frank, *The Renewal of Generosity*, 128.

[824] Wolgast, 144.

[825] Wolgast, 144.

that ambiguity we despair of locating responsibility, we stand at the edge of a context where these selves are diminished."[826]

How, then, can we move toward a solution to the problem of personal responsibility for speech and action? I do not believe a solution can be handled through an addition to or a revision of medical ethics.[827] These ethical requirements already assume a discreteness of roles and a detachment of roles that foster dependent speech and action.[828]

Nor do I believe that the solution is a change in moral vocabulary. "Moral terms have our perceptions linked to them, and words and perceptions both are part of our moral understanding."[829] To change the terms of moral discussion would simply beg the question.

What change(s), then, if any, can we make? I believe it is possible to retain a large measure of moral autonomy and responsibility in medical situations if we are willing to make dramatic changes in our own thinking and in the thinking of our medical institutions: 1) we need to reject the language of role moralities and dissolve the boundaries between the person and the role.[830] 2) We need to be aware of how our language of instrumentality encourages a dehumanizing view of persons, and how it can lead to an obstruction of a moral view of the human being as a person who deserves respect and is held responsible for speech and action.[831] In evaluating medical

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[826] Wolgast, 144.

[827] Wolgast, 145.

[828] Wolgast, 145.

[829] Wolgast, 145.

[830] Wolgast, 145.

[831] Wolgast, 146.

institutions, we need to consider not only their usefulness in producing medical benefit but also their moral effects on medical staff and patients, particularly the attitudes and communications that are fostered.[832] “This dimension is neglected when medical institutions are justified simply on broad, impersonal considerations of public benefit.”[833]

To move toward such changes we need an overarching principle: namely, we need a moral understanding of personhood.[834] The conditions are ones that would allow healthcare professionals to make their own decisions regarding speaking and acting from within the context of their many relations and obligations to patients. Within this context, medical workers would be fully responsible for what they say and do. Non-professional obligations would exist in juxtaposition with other obligations in all of life.

Imagine the medical situation that I envision. Healthcare professionals would work out their own decisions; they would speak and act in their own name; they would be able to reject morally doubtful projects; they would have full responsibility for their decisions, communication, and actions. In this view, there clearly cannot be artificial persons in the Hobbesian sense. There cannot be persons who do not speak and act as themselves.

The goal of this proposal for change is: 1) to endorse and adopt the conception of personhood that is endemic to moral theory,[835] 2) to have persons whose speech and actions are both critical and creative with respect to obligations;[836] and 3) to have persons whose convictions take actual, individualized forms.[837]

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[832] Wolgast, 114-130.

[833] Wolgast, 146.

[834] Wolgast, 146.

[835] Wolgast, 157.

[836] Wolgast, 158.

Inhospitality as Giving the Cold Shoulder

No Place for Recognition

The conditions of illness and disability make persons liable to be treated without personal recognition by healthcare personnel. A distinguished physician and author, Anatole Broyard, realizes that once he becomes a patient part of him is rendered absent to his physicians. Speaking to his colleagues about his own experiences, Broyard reminds them that their patients are evaluating how they, as physicians, imagine them as patients: "While he invariably feels superior to me because he is my doctor and I am his patient, I'd like him to know that I feel superior to him, too, that he is my patient also and I have my diagnosis of him."[838] Broyard realizes that until physicians see their patients as persons who are diagnosing them, illness will remain a sign of absence: "Without some such recognition, I am nothing but illness."[839]

The lifelong stigma of persons with Down syndrome, like Jamie Bérubé, is to be recognized only as an illness (i.e., "He is the kid with Down syndrome"). Jamie's father, Michael, has written a book to describe the problem of converting absence into presence and restoring persons who are ill or disabled to moral recognition. In short, Bérubé, an English Professor at the University of Illinois at Urbana-Champaign, refers to the difficulty of recognition as a lack of *representation*.[840] Bérubé writes, "Jamie has no idea what a busy intersection he's landed in: statutes, allocations, genetics, reproduction,

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[837] Wolgast, 158.

[838] Anatole Broyard, *Intoxicated by My Illness and Other Writings on Life and Death*. (New York, NY: Clarkson Potter, 1992), 45.

[839] Broyard, 45.

[840] Michael Bérubé, *Life as We Know It*. (New York, NY: Pantheon Books, 1996), 258.

representation…Individual humans like Jamie are compelling us daily to determine what *kind* of ‘individuality’ we will value, on what terms, and why.”[841] Institutions, testings, and medical technologies each has its own interest in how Jamie is represented.

Bérubé contends that representations matter: “Our world, as William Wordsworth once put it, is that which our eyes and ears half create and half perceive; and it is because Wordsworth is right that we need to deliberate the question of how we will represent the range of human variation to ourselves.”[842] How we understand persons with Down syndrome will become part of what it means to have Down syndrome.

Bérubé’s job is to represent his son hospitably, fearing that there are others who may represent him inhospitably. Bérubé uses the language of obligation to explain his purpose in writing about Jamie’s vulnerability to others’ representations of him: “Perhaps those of us who can understand the intersection…of individual idiosyncrasy and sociopolitical construction…have an obligation to ‘represent’ the children who can’t…As these children grow, perhaps we need to foster their abilities to represent themselves – and to listen to them as they do.”[843] Bérubé requires Jamie’s presence in his life in order to imagine his obligation to others like Jamie. For the rest of us to imagine our obligation to Jamie and others like him, we require the capacity to imagine them. To imagine our obligation to persons like Jamie, we need stories. In reading Bérubé’s story of Jamie, I can imagine my obligation to the ill and disabled.

“Storytelling,” explains Arthur Frank, “continually redraws the boundaries of a community’s recognitions; it renders present what would otherwise be absent. As

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[841] Bérubé, xix.

[842] Bérubé, 260.

[843] Bérubé, xix.

recognitions change, so do obligations. An obligation presupposes a face, and a face presupposes a story."[844]

Later in the book about Jamie, Bérubé expands on his reason for writing about his son: "My task ethically and aesthetically is to represent Jamie to you with all the fidelity that mere language can afford, the better to enable you to imagine him and to imagine what he might think of your ability to imagine him."[845]

Representation has both an ethical and stylistic consideration. Representation is for the purpose of enabling others to imagine the ill and disabled. Consequently, Bérubé feels a need to represent Jamie to the best of his communicative ability. Finally, then, Bérubé's concern has to do with how he expresses his representation of his son.

Bérubé's conclusion is this: "My job, for now, is to represent my son, to set his place at our collective table. But I know I am merely trying my best to prepare for the day he sets his own place. For I have no sweeter dream than to imagine that Jamie will someday be his own advocate, his own author, his own best representative."[846]

Significantly, common to our humanity, whether ill or well, disabled or able, is one crucial characteristic: "The desire to communicate, to understand, to place ourselves in some mutually reciprocal form of relation with another or others."[847] In our day, unfortunately, the desire to communicate has been no more effective in bringing about the mutual understanding and strong relations than any other human attribute, but I would argue, it stands a better chance.

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[844] Frank, *The Renewal of Generosity*, 62.

[845] Bérubé, 264.

[846] Bérubé, 264.
[847] Bérubé, 248.

Bérubé speaks of the origins of the universal desire to communicate:

> Among the most amazing and hopeful things about the species is that its offspring show up, from their day of birth, programmed to receive and transmit even in the most difficult circumstances; the ability to conduct mutual communicative relations is embedded in our material bodies, woven through our double-stranded fibers. Granted, the sociohistorical variables of human communication, like the variables in everything else about us, are more significant and numerous than any genetic determinism can admit. All the same, the ability to communicate lies in our software somewhere, and better still, it's a program that teaches itself how to operate each time we use it.[848]

Interpersonal communication is dialogical; it is a conversation or discussion. It is reciprocal; communication is a human capacity that requires another human being.[849] It is natural; it is a countering and potent impulse to mutual cueing.[850] It means satisfaction for actors and audience.[851] Representing Jamie in relation to communication, Bérubé speaks of Jamie's feelings of pleasure and fulfillment: "Nothing, nothing will delight Jamie so much as the realization that you have understood him – except the realization that he has understood *you*, and recursively understood his own understanding and yours."[852]

No Place for Participation

Essayist Nancy Mairs, who has advanced multiple sclerosis, expresses the problem that persons who are ill or disabled have of participating in the world on terms that are meaningful to themselves and are recognized as meaningful by others. Mairs' fears surpass the risk of becoming an institutionalized "disability." Knowing her body as the

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[848] Bérubé, 249.

[849] Bérubé, 249.

[850] Bérubé, 249.

[851] Bérubé, 249.

[852] Bérubé, 249.

vehicle for dialogue, her greater fear is “moral paralysis…If I don’t want to be reduced to a constellation of problems, I must imagine my body as something other than problematic: a vehicle for enmeshing the life I have been given into the lives of others. Easy enough to say. But to do? Who will have me? And on what terms?”[853]

Mairs is clear that the “non-disabled world”[854] cares little about her moral participation. It takes a “dismissive attitude”[855] toward those in wheelchairs, those who “live at the height of your waist…beyond cheerfulness and patience, people don’t generally expect much of a cripple’s character. And certainly they presume that care, which I have placed at the heart of moral experience, flows in one direction, ‘downward.’”[856] In Mairs’ thinking, “downward” care is the failure to recognize the person for whom care is being given as a moral presence.[857]

The asymmetrical relation that is inherent in some medical care means that care cannot be mutual in a physical sense, but each person in a relation of care can imagine the other as having something to contribute to the needs of the world. The problem is that most persons seem to assume that the moral core of being in the world lies in the physical care of others (i.e., in *doing* good rather than in *being* good).[858] Mairs asks: “Is there a place in the world for a woman who cannot even make soup for hungry people? Physical inability appears to rob such a woman of moral efficacy.”[859] To excuse her is to dismiss

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[853] Nancy Mairs, *Waist-High in the World*. (Boston, MA: Beacon Press, 1966), 60, 56.

[854] Mairs, 14.

[855] Mairs, 62.

[856] Mairs, 62.

[857] Mairs, 62.

[858] Mairs, 61.

[859] Mairs, 62.

her. Either to enable her or require her to withdraw from moral life altogether is morally offensive, however benevolent the intent.[860] She needs moral participation in order to exist as a fully human being, however incapacitated her body is.

Mairs' solution lies in a Catholic community where there is recognition of the different capabilities arising from each person's singularity. She cannot make soup, but she can write. "What I can still do – so far – is books. Catholic workers being extraordinarily tolerant of multiplicity, on the theory that it takes all kinds of parts to form a body, this activity will probably be counted good enough."[861]

Yet, how satisfactory is this solution? First, what fear still lies behind Mairs' qualifying words, "*so far*"? Does not Mairs already imagine an end of her ability to write? Second, what doubt lies behind the words, "this activity (i.e., writing) will *probably* be counted *good enough*"? Despite Catholic workers tolerance of multiplicity, does not Mairs sound somewhat dubious whether "writing" meets the standard of being "good enough"? Third, does Mairs intend to imply in the phrase, "counted good enough," that serving soup is *better,* but writing is probably *good enough*? Does this not sound, in any case, like a vitiated form of the principle of reciprocity (i.e., that we should repay, in kind, what another person has provided for us)?

What, in fact, will happen to Mairs' moral participation if, for reasons both physical and intellectual, she loses her ability to write as her distinct form of participation? Then, presumably she will need to find a way to participate that is still less good and less reciprocal. In the end, will she not need a world that defines moral participation in terms

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[860] Mairs, 63.

[861] Mairs, 63.

of *being* and *without any reciprocity*? I speak of a world where downward care retains a vision of the human face, and a face is more than enough to create an obligation of care.

When I envision Mairs in the final stage of multiple sclerosis, I feel the need for an obligation of care that is nonreciprocal. As enunciated by the Philosopher Emmanuel Levinas, the concept is this: "I am generous toward the other without this generosity being claimed as reciprocal…I therefore insist upon the signification of gratuitousness of being *for-the-other*."[862]

According to Levinas, my obligation is to help the other who is weaker than I, in part because I have already usurped, in many ways, what the other needs.[863] I must offer this help without compounding the original inequality by usurping what is other about the person.[864] By emphasizing the asymmetrical relation of obligation, Levinas also distinguishes himself from Martin Buber. Instead of Buber's equality (i.e., "We are from the outset in a society in which we are equals…I am to the other what the other is to me),[865] Levinas' notion of dialogical relations sees "the asymmetry of the I-thou relation and the radical inequality between the I and the thou, for every relation is a relation with a being toward whom I have obligations."[866]

Finally, therefore, I suggest that moral participation for Mairs will depend on hospitality. Mairs concludes: "My infinitely harder task (i.e., harder than finding an activity) is to conceptualize not merely a habitable body but a habitable world: a world

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[862] Emmanuel Levinas, *Is it Righteous to Be?* ed. Jill Robbins. Stanford, CA: Stanford University Press, 2001), 213.

[863] Levinas, 191.

[864] Levinas, 191.

[865] Levinas, 213.

[866] Levinas, 213.

that wants me in it."[867] My observation is that, in the medical world today, patients are still too often treated as if they are not wanted. Hospitable doctors and nurses may not say or do anything differently than their colleagues, but the difference is palpable. They talk to the patient as one who understands that the patient cannot "talk" to them. They listen to the patient as one who understands that the patient cannot listen to them.

No Place for Death

"When I was a small child, I lived with my parents in my grandmother's house in England. Of the six women in the house at that time, four of us have developed cancer over the years. Now only one of the four survives."[868] This family history of cancer, specifically breast cancer, is part of an essay written by Vanessa Kramer. The essay, "Case Story: Cancer Treatment and Ecology – the Long View," has been published in a journal on health, faith, and ethics.

In the first section of her essay, Kramer relates a story about her aunt's treatment for ovarian cancer. In the second division, she makes an ecological argument against toxic therapy for cancer, particularly radiation. The two parts of the paper are joined by the silence of death that can be heard in cancer clinics, the "loud silence that makes most cancer wards so bizarre, if you are paying attention."[869]

Kramer herself is suffering from breast cancer as she writes her journal article. Her hypothesis is that "medicine has no place for death and dying. Medicine prescribes how patients are to think about themselves, and how they are to tolerate being treated.

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[867] Mairs, 63.

[868] Vanessa Kramer, "Case Story: Cancer Treatment and Ecology – The Long View," in *Making the Rounds in Health, Faith, and Ethics 1*, No. 5, (November 6, 1995), 1.

[869] Kramer, 1.

Consequently, as her journal editor points out: “Medicine does not have patients who are in denial about dying; they are rather considerate enough to collude in medicine’s denying them a place.”[870]

Kramer makes this point in a narrative she recites about her aunt, who has just had exploratory abdominal surgery. The medical assessment is that nothing can be done. Kramer recounts the story as she relives it:

> It was late in the evening, and the staff was efficiently bustling around her bed setting up an automatic dispenser for pain control drugs…Everything was in place, the staff went away, and my aunt was left to ride the rollercoaster of her own thoughts, but the first time she pushed the button, the machine, to use her words, blew up.
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> This unfortunate happening created a frenzy: ’Do you know,’ she said, ‘I had six of them in there – all trying to fix the machine. They seemed to take an eternity.’ In the end, the machine was deemed impossible to repair, and the crowd of people left, wheeling it with them, leaving my aunt alone. They were all totally avoiding me, she said. ‘It made a person feel so alone, so utterly alone. I felt as though I must be the only person this ever happened to.
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> After a while a nurse came in, all efficient and professional, with a questionnaire. This was presumably a standard questionnaire to establish a course of pain control. My aunt said, ’you’ll never guess what the first question was: What do you perceive to be the source of your pain?’ How could the nurse not see? There’s always physical pain after this kind of surgery. There’s always emotional and psychological pain when treatments fail.
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> But here the thread of mortality that is within all of us, all our lives, was emerging and becoming clearly apparent in her. Everyone in the room knew it was so. But once the technology broke down, from my aunt’s point of view, that particular group of healthcare professionals was left resourceless. As my aunt said, ‘No one made eye contact with me. No one reached out to touch me.’[871]

Kramer responds to her aunt’s experience with a question: What do I perceive to be the source of my pain about all of this?”[872] Although Kramer acknowledges that palliative care has affected some medical practices, she questions how much it has

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[870] Kramer, 1.
[871] Kramer, 1.

[872] Kramer, 1.

changed.[873] In corroboration of her thinking, Kramer mentions a memo she received from the cancer clinic in which she was treated. The communiqué that medical treatments could no longer arrest the spread of cancer in a particular person was recorded as "patient failed to respond to treatments."[874] Does this report not give a misleading account of who or what failed? The patient is blamed for the treatment's breakdown. The worse misrepresentation is to call dying a failure. Could it be that the behavior of the six healthcare professionals in Kramer's aunt's room are a microcosm of the entire cancer clinic? When they cannot fix the machine, they all walk away, sidestepping the issue and blaming the dying patient. To avoid the dying patient is to avoid the inevitability of death.

"How can the medical staff appear so resourceless in the face of something that happens again and again?"[875] Kramer wants to know. She does realize, of course, that the staff cannot respond because her aunt's dying is not to be told or recorded by the healthcare professionals.[876] Her aunt's suffering becomes invisible.[877] Her aunt becomes another one of those patients who have failed to respond. Once the patient fails the chemotherapy and radiation treatments, the cancer clinic has no other resources. This is the end of the dying patient's story as far as the cancer clinic is concerned. Incidentally,

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[873] Kramer, 4.

[874] Kramer, 4.

[875] Kramer, 4.

[876] Kramer, 4.

[877] Kramer, 4.

Kramer herself has an answer to her own question about why the medical staff appears so resourceless: it is that “we lack an ability to think of death in ecological terms.”[878]

> The word ‘ecology’ comes from the Greek root meaning ‘house.’ Most of us have probably lived in houses and know well that they constantly need repair. If you wade out into a swamp, step by step you stir up and move through one of the foundations of our ecological house. You enter an earthy, fluid confluence of decay. Because the oxygen level in the water is low, the process of decay is slow and very evident. That’s what makes a swamp a good place to think about death. But amid this decay, the swamp is a nurturing habitat for hundreds of life forms. For whether we like it or not, death is the process that helps keep the ecosystem renovated. It’s the universal composter. In this sense, death is very much part of an endless recovery model. An endless process of renewal.[879]

The healthcare professionals who cannot look Kramer’s aunt in the eye do not think of death as a part of the ecology of life. They are, therefore, resourceless. There is nothing more to say or do. They do not even have any consolation to offer. They are confounded.

Because she is dying, Kramer’s aunt becomes an absence to be managed at a distance by machines and questionnaires.[880] Kramer portrays how the professionals’ treatment of her aunt was typical of their treatment of other patients:

> I am still haunted by the voices of cancer patients: ‘They are afraid to touch me.’ Or, ‘they touch me as if I am already dead.’ Or, ‘Most of the time they look right through me.’ Or, ‘I can’t tell one from another; they never introduce themselves.’ Sometimes I think there is a regulation that we are not allowed to be real people. Sometimes I think professionalism is a handicap we all labor under. On really bad days, I have had the urge to tap on the shoulder of a particular nurse or doctor or technician and shout, ‘Hey, is anybody in there?’[881]

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[878] Kramer, 4.

[879] Kramer, 4.

[880] Kramer, 4.

[881] Kramer, 4.

Kramer is also censorious about chemotherapy and radiation as treatments for cancer: "In the battle to prolong our lives as individuals, medical research has been given the green light to do whatever it takes to keep death at bay. Consequently, as a woman with breast cancer, I have been offered treatments that are incompatible with the function and spirit of the ecosystem."[882] In her refusal of such treatments, Kramer affirms the insight that "when one person falls ill or stays healthy, the entire universe is involved."[883] She adds that life needs each of us to die; it is our last hospitable service.[884]

Her main concern is not with living or dying; it is with the future of the human home. This solicitude rests on her dialogical insight that she exists only as part of this home. "Look at the big picture," Kramer says. "What's the use of being a survivor if you've got nowhere to go home to?"[885] I ask: What is the point of the medical injunction, "First, do no harm," if it does not extend beyond healthcare professionals to patients and to the ecology of life that sustains all of us?

How long will it be before medicine takes ecological recognition into the conversation? How long will it be before I hear and read stories on the ecology of illness? How long will it be before healthcare administrators will accept questions about the environmental ethics of medicine?

The first attempt to bring ecological concerns into medicine was Tim Brookes in a work entitled, *Catching My Breath: An Asthmatic Explores His Illness*. Brookes created the term *health ecology* in conceiving a new form of medicine that would reflect a *global*

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[882] Kramer, 5.

[883] Kramer, 5.

[884] Kramer, 4.

[885] Kramer, 4.

understanding of illness and health.[886] As an asthmatic patient Brookes is put off when his physicians define him in terms of compliance with conventional protocol.[887]

Medical writers sometimes distinguish curing from healing, the distinction being that healing involves the ill or disabled person's participation. In the story about Nancy Mairs (above), I addressed the *who* of healing and participation. Hence, whenever Mairs spoke of her part in healing, she talked about *moral* participation. Health ecology expands the question of healing from *who* needs healing to *what* needs healing. *Ecology*, as it applies to health, refers to the moral necessity of dialogue.[888] Health ecology, therefore, begins with both professionals and patients speaking and acting with the awareness that their lives are lived wholly on the boundary with others. Health ecology expands the notion of others to include the earth itself.[889] Consequently, Vanessa Kramer understands that pathology of the body reflects and results from relationships not only between body and body but between body and the earth.[890]

Illness, for Brookes, "presents an opportunity to learn about ourselves and the world we inhabit and create."[891] Brookes' statement is dialogical, first by linking the patient to the world and then by proposing that as patients we recreate our world. Health ecology is awareness of the moral risk and possibility inherent in how we recreate not only our own

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[886] Tim Brookes, *Catching My Breath: An Asthmatic Explores His Illness*. (New York, NY: Times Books, 1994), 283.

[887] Brookes, 277.

[888] Brookes, 283.

[889] Brookes, 283.

[890] Kramer, 5.

[891] Brookes, 277.

lives but the life of the world. For example, Vanessa Kramer understands health ecology as truth about how the world is recreated.[892]

As a corollary to comprehending life with illness as an opportunity to learn about ourselves and our world is the recognition of health ecology as a "continuous flow of ethical decisions that make up medical practice."[893] Health ecology "would study the way patients listen to doctors, and vice versa, and the way patients speak to doctors, and vice versa,"[894] claims Brookes. It is not that Brookes is unaware that enough literature exists on doctor-patient communication, but in health ecology, the study of communication would be moral.[895]

Brookes' morality is fully dialogical. As such,

> Health ecology assumes that neither the asthmatic (Brookes' own medical problem) nor his (*sic*) environment can ever suffer alone. If, as individuals or as a society, or as a species we don't understand ourselves, some of us will always be unhealthy, and all of us will suffer, even (though less obviously), those who prosper and profit from others' disease. Healing is a collective activity, not a commodity – a verb, not a noun. When one person falls ill or stays healthy, the entire universe is involved.[896]

Health ecology shifts the responsibility for healing from the ill to everyone. Just as the suffering of the ill is ultimately everyone's suffering, so no one can be healthy until each fears for the other and feels obligated to the other. In that sense of obligation is communication and relationship, healing and health.

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[892] Kramer, 5.

[893] Komesaroff, 69.

[894] Brookes, 284.

[895] Brookes, 284.

[896] Brookes, 284.

CHAPTER 9

A COMMUNITY OF HOSPITALITY

Hospitality as Communication

Communication and Relationship

Hospitality, the friendly and generous treatment of guests and strangers, begins in welcoming and receiving.[897] It signifies an opening of the self to the other.[898] It is an expression of courtesy and kindness.[899] Hospitality is initiated by effective communication.

When my oldest grandchild, Ashlynn, was a little girl, she liked to toss a ball back and forth with Granddad as we both sat on the floor. Although an oversimplification, communication is like that. Just as in throwing and catching the ball both Ashlynn and I were energized and related to each other, so in effective communication the other and I are linked by the energy that flows between us.

Ashlynn could not play catch by herself; she needed someone else. Similarly, communication requires someone else. When two persons effectively communicate, they are being brought into relationship.

Communication is both an aspect of, and a necessity for, relationship.[900] Relationship is greater than, but involved in, communication.[901] Indeed, without communication,

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[897] Cynthia A. Klingel, *Friendliness*. (Mankato, MN: *The Child's World*, 2008), 4.

[898] Cynthia A. Klingel, *Generosity*. (Mankato, MN: The Child's World, 2008), 4.

[899] Klingel, *Friendliness*, 4.

[900] John A. Sanford, *Between People*. (New York, NY: Paulist Press, 1982), 2.

[901] Sanford, 2.

relationship would be impossible.[902] Like a bridge, communication connects the other and me; communication is the span that makes relationship possible. Without communication, I would be an island.

The opposite of communication, therefore, is “isolation.”[903] Some writers (e.g., Carl Jung and his followers) make isolation the matrix in which evil takes root.[904] While some persons react to isolation by becoming ill, others, cloistered from the social world, turn against other human beings.[905]

Critical to playing catch is the way it starts. I must throw the ball to Ashlynn so that she can catch it and throw it back to me. It is important that my first toss is a good one, within Ashlynn’s reach, and gentle enough so she can handle it. I can imagine Ashlynn’s reaction if I started by throwing the ball as hard as I could at her head. She would justifiably become annoyed and refuse to play ball with me.

Crucial to communication as well as to playing ball is the way it begins. All too often the opening toss is bound to have negative effects. For example, in a medical situation, the healthcare professional may open the conversation with a pronouncement.[906] A pronouncement may be legitimate for certain purposes (e.g., the transmission of information), but it is not the way to start communicating interpersonally. The assumption that lies behind a pronouncement is that the matter is not open for

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[902] Sanford, 2.

[903] Sanford, 2.

[904] Sanford, 6.

[905] Sanford, 6.

[906] Sanford, 4.

discussion.[907] As a result, the words are spoken and heard, but the message is resisted. The ball is being thrown, but it is not being caught. Whatever wisdom the words that are spoken contain is lost because it is blocked out by the hearer. Often, I believe, the problem is not in the actual words spoken but in the tone of voice in which the words are spoken.

Those in positions of authority (e.g., healthcare professionals), from my perspective, are especially fond of making pronouncements in their interpersonal communication, thereby assuming an attitude of superiority in which there is no obligation to listen to the other (e.g., the patient).[908] Feeling shut out, the hearer is relegated to an inferior role. Consequently, the hearer's attitude is usually one of acquiescence or rebellion.[909]

Interpersonal communication starts a flow of energy between two people that can result, I have discovered, not necessarily in agreement or disagreement, but in mutual understanding. Therefore, I need to be considerate (i.e., attentive, kind, thoughtful, caring) of the other. I will only throw the ball in a way that the other can manage. An attitude of consideration of the other is essential to effective communication, for it is in taking the other into account that I speak so that the other will be able to receive what I say and also that I listen so that I will be able to receive what the other says.

Hospitality is the consideration of the other. It is the realization of what the healthcare professional and the patient can be in communication and relationship with each other.

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[907] Sanford, 4.

[908] Sanford, 5.

[909] Sanford, 5.

Communication and Listening

In hospitality, I believe, listening may be even more important than speaking. Listening takes place when I devote my attention wholeheartedly to what the other is saying. Listening is receptive but not passive. It is receptive because I am considering what the other is saying, feeling, and experiencing. It is active because I am trying to understand what the other is expressing.

There is creative power in listening because it develops a relationship between the other and me in which understanding can grow.[910] There is also a healing power in listening because it relieves isolation and, therefore, may prevent evil from erupting (see above).[911] Because listening is creative and healing, I believe healthcare professionals need to develop the capacity to hear what the other is saying.

In my reading of psychotherapy, I have found many stories in which the capacity of the therapist to listen creatively has released self-healing in a client. An example is found in Robert Lindner's book, *The Fifty Minute Hour*.[912] Doctor Lindner discusses a brilliant physicist who became psychotic. Lindner decided to listen attentively to his patient's fantasies. As the weeks went by Lindner gradually realized the physicist no longer believed in what he (the physicist) was saying. When confronted with Lindner's observation, the patient admitted that he gradually realized that what he was telling was delusion.

Here is an example of the creative and healing power of listening. Lindner never interpreted the meaning of the fantasies or delved into the patient's past. Solely by

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[910] Sanford, 17.

[911] Sanford, 17.

[912] Robert Lindner, *The Fifty Minute Hour*. (New York, NY: Bantam Books, 1954), 156-207.

listening he got inside his patient's fanciful world and this healed the physicist, for there is room for only one person in a psychosis. Once the isolation of the physicist was broken by Lindner's creative listening, the man was freed from his psychotic condition.

It must not be supposed, however, that such listening is another technique or that it is reserved for psychotherapists. Creative listening is a fundamental and important part of developing human relationships. To that end, it is essential for all of us to learn to listen creatively to others, including those who are difficult, argumentative and aggressive. Through listening, I have found that I may turn a hostile relationship around or, at least, provide understanding.

When I listen to the other, I am communicating. What I am communicating is that I am interested in the other. Hospitality is letting the other know that I am interested in him or her by listening. In other words, the way the other can know that he or she wants to speak to me is by my interest in him or her through listening.

The degree of my interest is demonstrated in my body language. For me, there may be no more important body language than the expression on my face, particularly in my eyes. If I am looking at the other while I am listening, I communicate that in that moment I have shut out everybody else. In that moment I am focusing on the other and what the other has to tell me. I am hanging on every word. I am listening with my eyes.

There appear to me to be many people in my culture who lack the art of creative and healing listening. In many cases, people seem to believe that listening comes naturally for some but not for others. I think that listening is an art that is learned in the life process through discipline and practice just as other capacities must be learned.

It takes discipline for me to hear what the other is saying. It takes discipline to restrain my own list of grievances or whatever else is on my mind. For example, to listen I must discipline that part of me that wants to interrupt, admonish, advise, or judge the other. If I really want to listen, it also means suppressing my own agenda and hearing what the other is saying and feeling. Moreover, it is only if the other feels heard that he or she is open to hearing me or anyone else.

I think of this devotion to listening as a sacrifice, for in listening I suspend my agenda and dedicate my energy in a sacrificial way to the other. This suspension both requires and develops maturity, for it takes maturity to be able to sacrifice in this way for the sake of communication.

I have long believed that I become what I do. Listening is a maturing activity. When I listen creatively, I not only help the other to healing, but I help myself to maturing.

While I have mentioned personal agenda, I have not spoken about the business meeting agenda. Anyone who has attended a meeting or conference knows that it takes time to work through an agenda. This is, at least in part, because anything that stifles the flow of energy in discussion is disruptive to communication. One of the most frequent curbs of the flow of energy is interruption. When the other interrupts me, I feel as though I have not been heard. It is as if the other does not throw the ball back to me but runs away with it.

Why does the other interrupt me? 1) The other has his or her own agenda and cannot wait for me to finish talking.[913] 2) The other is only interested in controlling the

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[913] Sanford, 15.

conversation.[914] In response to the first reason for interrupting, the other needs patience and maturity to listen to what I am saying before he or she interjects my speaking.[915] In regard to the second reason, I need the maturity to be able to indicate to the other who is controlling the conversation that I have already heard him or her.[916]

Even if there is no agreement, everyone needs to feel heard. For me, not to be heard produces frustration, isolation, and anger. Not only is it important to hear the other, it also helps to let the other know that I have heard him or her by making an appropriate response. To the extent that the other feels heard, the other can hear me. To listen creatively and hear what the other is saying, in my experience, takes discipline.

Communication and Caring

It is critical, I believe, for a healthcare professional to have a strong interest in caring for the whole person. This means 1) caring about other problems than just the illness; 2) learning to cope with one's own emotions in order to cope with the emotions of patients; and 3) letting the patients' questions and comments guide the conversation instead of delivering a message.

In my opinion, there is no way to plan what to say to patients. There is no formula for talking with patients. To talk with patients means talking about patients' lives. Because patients are all different, they cannot fit comfortably into some preconceived mold. Rather than force conformity, caregivers better serve patients when they learn to welcome diversity. This means being constantly aware of the need for the caregiver to

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[914] Sanford, 15.

[915] Sanford, 15.

[916] Sanford, 15.

change with changing circumstances, to adapt to patients' needs, and to keep on learning and growing.

In reading a book by a healthcare professional in practice, I have discovered that some patients are labeled "difficult,"[917] and they are excluded from moral participation in the healthcare community. To do so means that the needs of the caregiver take precedence over the needs of the patient. Hospitality invites *all* patients to feel accepted without stigma or isolation.

Dealing with "difficult" patients has more to do with the art of medicine than the science. "Difficult" patients, I have found, are often helpful in talking about the problems they are facing.[918] Listening to querulous patients enabled me, as a minister, to uncover the troubled world in which they lived. On the other hand, thanks to the insight the "difficult" patients had given me, I learned to look beyond the superficial smiles of my more compliant parishioner patients to catch a glimpse of their deeper needs. Caregivers or visitors who accept the "burden" of listening to hidden problems send a clear signal to patients that they are able to share their secret worries.[919] Hospitality does not pre-judge the needy on the basis of whether they are disruptive and demeaning or quiet and compliant.

In talking to family members or friends of the patient, the question I hear most often is, "What do I say?" Frankly, I think most patients want someone to listen. Listening, however, is more difficult than talking.[920] It takes bracketing one's own thoughts and

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[917] Daniel Rosenblum, *A Time to Hear, a Time to Help*. (New York, NY: The Free Press, 1993), 38.

[918] Rosenblum, 39.

[919] Rosenblum, 39.

[920] Rosenblum, 42.

feelings,[921] concentration,[922] and being comfortable with intimacy.[923] Listening is being a guest in the others' world.[924] Oncologist Daniel Rosenblum expresses the thought in beautiful prose: "I can be a companion in the darkness. I can stretch out my hand and wait for the other to grasp it. Listening is the kindest thing you can do for the other."[925]

I see at least two obstacles to listening: 1) my anxiety and the anxiety of the patient set my tongue in motion, as if a stream of words could protect me from the pain of hearing the patients' hurts;[926] 2) I like to identify problems and solve them on the spot. I forget that I am there to *help* the patients, not to *make* them feel better.[927] When I help patients, I take time to listen. Such help is almost always welcome.

In my experience, listening to patients causes me to feel less like a minister and more like a friend. Consequently, rather than trying to manage patients' feelings because they bother me, I will simply listen. In this way, I witness patients' pain rather than seeking ways to make them hide it.

Perhaps this is the reason that many patients have told me that friends may have given them more important help than the medical staff. I am thinking of a medical situation in which the caregiver gives only medical care and friends give a love that listens. In that case, love may be the better therapy. Hospitality is a promise of loving care without qualification.

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[921] Rosenblum, 42.

[922] Rosenblum, 42.

[923] Rosenblum, 42.

[924] Rosenblum, 42.

[925] Rosenblum, 43.

[926] Rosenblum, 44.

[927] Rosenblum, 44.

Consider the incongruity of medicine's ideals and outcomes. Medicine strives to eliminate suffering; despite its best efforts, it often fails.[928] Medicine believes it is best qualified to select treatment; the treatment may simply add to suffering.[929] Medicine's goal is to successfully treat; yet, I have found healthcare professionals who would rather "help" than merely "treat."[930]

My question is whether medical workers can "help" without being willing to listen? By "to listen," I mean to consider who the patients are, how they see themselves, and how they picture their needs. By "to listen," I mean to form a relationship. Relationships have healing power of their own, even when treatments fail. Significantly, Rosenblum says: "You can always tell when doctors care about their patients. The minute you walk into the office, you can tell. If the receptionists are warm and friendly, if the nurses seem ready to help, the doctors care."[931]

In my experience, even some family members and friends shun the seriously ill. They drop their voices, ostracize them, or, worse yet, become overly solicitous. Too easily those who wall off the ailing forget their own membership in the human community. When one is sick, to some degree, it affects all of us.

What is it about some family members and friends that makes words flow so glibly when they are unnecessary and not to have any words when they are critical? What is it about love that causes some to always have something to say about trivial matters and yet

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[928] Rosenblum, 56.

[929] Rosenblum, 56.

[930] Rosenblum, 56.

[931] Rosenblum, 248.

have nothing to say about grave concerns? What is it about some hearts that enables them to be open when things are going well but closed when adversity strikes?

Obviously, the patient is not the only needy person. Family members and friends are needy too. Frightened by illness, they feel threatened knowing that they too could contract a sickness. Furthermore, they are angry knowing that a family member or friend could die. They want to do something. They need someone to tell them that they may help most through listening and hearing.

I learn to hear by listening. I learn to listen by making myself available. Patients are my teachers as they, through incoherent thoughts and inarticulate groans and screams, tell me how it feels. Most often I learn in silence, by taking time, by lending attention, by self-giving commitment, and by a willingness to accept whatever may come.

Hospitality as Dialogue

Accommodating Autonomous Voices

Miriam Lambert's story is part of a work entitled, *Crossing Over: Narratives of Palliative Care*.[932] The chapter about Miriam is narrated by Anna Towers, a palliative care physician. Miriam is a sixty-eight year-old woman with melanoma that has spread from her foot to her pelvis and spine. She is admitted to the palliative care unit because of uncontrollable pain. Although all possible pain medications are tried, none works for Miriam.

Since increased pain medication does have side effects that include decreased lucidity, the preferred treatment is to alter the patient's experience of pain by facilitating

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[932] David Barnard, Anna Towers, Patricia Boston, and Yanna Lambrinidou, *Crossing Over*. (New York, NY: Oxford University Press, 2004), 177-195.

a deeper level of understanding so that less pain medication is necessary. Miriam, however, never experiences this transformation. After four months in the palliative care unit, she dies.

Within Miriam's story, I noticed the story of Linda, Miriam's primary nurse. Linda's narration reflects a tension between her commitment to dialogue as practiced by her particular palliative care unit and the monologue that, according to some medical writers, characterizes much healthcare narration. For example, Arthur Frank, Sociology Professor at the University of Calgary, avows: "Medical reports aspire to monological unity. The speaking or writing voice denies that the reality it expresses makes sense only at the level of a specific consciousness; other, lesser voices speak from their particular perspectives. The monological voice speaks from beyond such limitation, and thus claims authority. Monologue silences other voices. Dialogue, on the other hand, invites response, because each dialogical voice recognizes its own limitation."[933]

While Linda recognizes that the reality…makes sense only at the level of (her) specific consciousness,[934] her consciousness is a myriad of voices. Linda struggles to live with the disparate voices in her thoughts and feelings, each voice trying to describe what palliative care ought to be and what Linda ought to be in relation to her patients and colleagues. The voices are pieces of a whole in which they remain distinct but interdependent.

The issue is this: Hospitality requires harmony. The different voices need not be unified but must be arranged to create a harmony that holds them together. Chaos, many

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[933] Arthur Frank, *The Renewal of Generosity*. (Chicago, IL: University of Chicago Press, 2004), 109.

[934] Mikhail Bakhtin. *Problems of Dostoevsky's Poetics*, ed. and trans. Caryl Emerson. (Minneapolis, MN: University of Minnesota Press, 1984), 21.

voices with no harmony, is the constant danger in Linda's nursing work. Indeed, Linda's way of being a nurse, while not requiring her to renounce her own consciousness, does require her to broaden, deepen, and adjust her consciousness. As a result, when Linda approaches her patient Miriam, it is with an expectation that she (Linda) will expand and alter her own consciousness in order to accommodate the specific consciousness of her patient, Miriam.

Let me suggest that nursing care in general and palliative care in particular need to be committed to hospitality by aspiring to accommodate autonomous patient voices rather than attempting to assimilate them in a monological unity. Nursing care is not distinguished by expertise in caring for patients, important as this is; nursing care is distinguished by resisting the impulse to unify what can and is said about patients within the single monological voice of scientific knowledge and technological control. Healthcare is dialogical. It depends on the capacity of the nurse to encourage patients to talk about themselves and to hear what the patients say.

Working on the Boundary

Mikhail Bakhtin, a major thinker of the twentieth century in many fields, has interest for me because of his writings on the philosophy of the person. An example is found in these words: "A person has no internal sovereignty, he (*sic*) is wholly and always on the boundary; looking inside of himself, he looks into the eyes of another or with the eyes of another."[935] Dialogue is on this boundary. It is a precarious boundary because of the risk of falling off either side. For Bakhtin, dialogue on the boundary prevents "absolute

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[935] Bakhtin, *Problems of Dostoevsky's Poetics*, 21.

death,"[936] which he defines as "being unheard, unrecognized, unremembered."[937] Is it not a goal of palliative care to prevent the absolute death of being unheard, unrecognized, unremembered?

Palliative care nurse, Linda, places herself on the boundary in her work by trying to find the balance between unification in her own consciousness (Bakhtin calls it "nonself-sufficiency")[938] and merging into the consciousness of her patient. To this end, I want to suggest the possibility of three different relationships of a nurse to a patient. 1) In assimilation, the nurse-patient relationship is *all* about medical practice. 2) In identification, the relationship is *all* about empathy; it is all about the patient but not in a way that helps the patient.[939] Whether unification or fusion, both are monologues. 3) On the boundary, the relationship is where each of the two identities (i.e., nurse and patient) remains affirmed, where communication takes the form of a dialogue with a "thou" similar to the "I" and yet different from it.

I have been taught that empathy is necessary for dialogue. For Bakhtin, however, empathy, or identification, has merely a preparatory, transitory role.[940] Empathy is necessary but only as a way into dialogue. In both unification and fusion, "empathy" reaches over the boundary and forestalls dialogue; it does not help.[941] The value of empathy is in finding the boundary space between nurse and patient.

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[936] Bakhtin, *Problems of Dostoevsky's Poetics*, 287.

[937] Bakhtin, *Problems of Dostoevsky's Poetics*, 287.

[938] Bakhtin, *Problems of Dostoevsky's Poetics*, 287.

[939] Bakhtin, *Problems of Dostoevsky's Poetics*, 287-248.

[940] Bakhtin, *Problems of Dostoevsky's Poetics*, 287.

[941] Bakhtin, *Problems of Dostoevsky's Poetics*, 287.

The boundary space, moreover, can only exist if both nurse and patient enter it together.[942]As a nurse, Linda tries to get into the boundary space between herself and her patient, Miriam. For any number of reasons, Linda may be unprepared to enter into a dialogical relationship. She needs, therefore, to be encouraged to try to get into the boundary space between herself and Miriam. In doing so, however, she needs to be aware of the risk of sinking into Miriam and *crossing over* the boundary.

Sustaining the difference that dialogue requires means never speaking "finalizing words"[943] about another. No word can ever be final because anyone can choose to speak and act differently;[944] this is what requires the nurse to speak *with* the patient, not *about* the patient.[945] To speak with a patient is hospitality; to speak about a patient is to finalize him or her.

Linda, as nurse, also needs to recognize the danger of assuming that the communication problem lies in Miriam, her patient. This too would finalize Miriam and make dialogue impossible.[946] In fact, Miriam may be unprepared to enter into dialogue for many reasons. As nurse, Linda can keep open the possibility of dialogue by imagining herself in the boundary space. This posture helps her to avoid overstepping the boundary[947] and thereby foreclosing the possibility of communication.

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[942] Barnard, et al., 182.

[943] Bakhtin, *Problems of Dostoevsky's Poetics*, 296.

[944] Bakhtin, *Problems of Dostoevsky's Poetics*, 296.

[945] Barnard, et al., 191.

[946] Bakhtin, *Problems of Dostoevsky's Poetics*, 252.

[947] Barnard, et al, 190.

It is difficult for Linda to keep her balance on the boundary. If Miriam does not balance Linda's presence on Linda's side of the boundary with her (Miriam's) presence on the other side of the boundary, Linda tends to fall back into herself or forward into Miriam. To fall back is, for Linda, to project herself onto Miriam. To fall forward is, for Linda, to merge herself into Miriam. Hospitality is inviting and welcoming Miriam to balance Linda's presence on the boundary.

Living with Otherness (Intrinsic)

The basis of dialogue is a relationship of otherness (i.e., a difference and distance so that there can be a space between persons).[948] When I think of otherness, I invariably think either of differences in personal characteristics (e.g., age, gender) or differences in social conditions (e.g., ethnicity, economic status). Dialogue, however, requires another concept of otherness that precedes and transcends the otherness of attributes. Philosopher Emmanuel Levinas calls this otherness, "alterity," from the Latin "alter."[949] It is an intrinsic quality of being human.[950] "This otherness is not merely dialectical alienation on its way to a sublation that will endow it with a unifying identity in higher consciousness. On the contrary, in dialogism, consciousness is otherness."[951]

Indeed, Levinas believes that "to infringe on the intrinsic otherness of a person is to commit symbolic violence against the other. This violence claims to object to specific choices, but the objection shifts from the choice that a person makes to the person who

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[948] Bakhtin, *Problems of Dostoevsky's Poetics*, 176.

[949] Emmanuel Levinas, *Is it Righteous to Be?* ed. Jill Robbins. (Stanford, CA: Stanford University Press, 2001), 49.

[950] Levinas, 49.

[951] Levinas, 49.

makes the choice. It is, as a result, the violence of telling persons that they should not be who they are."[952]

Medical practice is especially at risk of committing symbolic violence because healthcare professionals claim to speak with authority and to act in the patients' best interests. Persons come to medical experts because they have a need. The healthcare professionals find it too easy to see the patients' needs but not to see the patients themselves and, therefore, not to respect them for whom they really are.

In the philosophy of Levinas, the core postulate is that "all men (*sic*) are responsible for one another."[953] How Levinas understands this responsibility is to see the other's *face*.[954] To see the other's face is to recognize the other as needing me and to feel chosen in the primacy of my obligation to meet that need.[955]

> The face…is like a being's exposure to death; the without – defense, the nudity and the misery of the other. It is also the commandment to take the other upon oneself, not to let him (*sic*) alone…If you conceive of the face as the object of a photographer, of course you are dealing with an object like any other object. But if you *encounter* the face, responsibility arises in the strangeness of the other and in his (*sic*) misery. The face offers itself to your compassion and to your obligation.[956]

To see the face of the other is to see the other's vulnerability.[957] To see the face, therefore, begins with empathy[958] (i.e., to imagine how the other feels). Empathy, however, risks "the symbolic violence of telling the other how to feel better. Alterity is

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[952] Quoted by Frank in *The Renewal of Generosity*, 115.

[953] Levinas, 169.

[954] Levinas, 48.

[955] Levinas, 48.

[956] Levinas, 48.

[957] Levinas, 161.

[958] Frank, *The Renewal of Generosity*, 116.

not opposed to empathic imagination but, when empathy becomes an end in itself, it tends toward unification either by projecting what would make me feel better onto you or by fusing me with your suffering.[959] Seeing the face requires respect for alterity.[960] I must recognize that there are aspects of your suffering that I cannot imagine.[961] For example, if Linda, even for the best of motives, exceeds the boundary and violates Miriam's alterity, dialogue is impossible. In caring for Miriam, I think that Linda can best recognize Miriam's face by empathic imagination, dialoguing with her, and staying with her (i.e., not abandoning her), without an over-empathizing that leads to unification or fusion.

Alterity makes dialogue possible. Alterity sustains dialogue. Alterity drives the communicative relationship, but alterity is also what makes dialogue difficult, "simply because the other *is* other."[962] Indeed, to ask, "What is alterity?", with its demand for meaning, risks symbolic violence.[963] To interpret Miriam's alterity is to assimilate her into a unifying voice that claims to explain her. In the unity of that explanation, alterity is explained away.[964] Defining a patient's alterity is the symbolic violence of finalizing the other by reducing the patient to certain inherent properties that explain why he or she is a problem, and why that problem cannot be solved.

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[959] Frank, *The Renewal of Generosity*, 116.

[960] Frank, *The Renewal of Generosity*, 116.

[961] Frank, *The Renewal of Generosity*, 116.

[962] Frank, *The Renewal of Generosity*, 117.

[963] Frank, *The Renewal of Generosity*, 117.

[964] Frank, *The Renewal of Generosity*, 117.

Dialogue through Doubt

Part of Linda's hospitality is her refusal to label Miriam as a "difficult" patient. That would be symbolic violence. When Linda thinks that Miriam may die soon, Linda tells a palliative care physician how she tries to empathize with Miriam and the repercussions of it:

> I entered her pain…On that day, my neck went into spasm from stress…I knew then that I had overstepped my boundary…She (Miriam) greeted me crying…She told me that her emotional pain is more than her physical pain…
>
> She has learned to express her needs, which she had difficulty doing before…She realized that some people (nurses) may come for their own comfort, not hers. Sometimes we (nurses) need to feel that we are doing something, but it doesn't help.[965]

Throughout most of Miriam's stay in the palliative care unit, Linda carries on an earnest dialogue with Miriam, who "had no intimate friends,"[966] "felt unloved,"[967] "found it difficult to communicate,"[968] and "felt alone."[969] In the above quote, however, I see an aberration in Linda's nursing care; Linda doubts herself. Linda's neck spasm is her way of feeling that she is doing something. Even if she cannot relieve Miriam's pain, she can identify so intimately with her patient's pain that she (Linda) goes into spasm. Doubting herself, Linda oversteps her boundary and limits her ability to help Miriam. Linda's neck spasm contravenes a boundary between empathy and egocentricity; it is all about a nurse feeling how much she is doing for Miriam. It ends dialogue.

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[965] Barnard, et al., 190-191.

[966] Barnard, et al., 178.

[967] Barnard, et al., 178.

[968] Barnard, et al., 178.

[969] Barnard, et al., 179.

“Emotional pain” marks the distance between patient and nurse. It also indicates Linda’s failure to use dialogue to allay the intensity of Miriam’s physical pain. At this point in her conversation with the doctor, Linda’s account changes tone. Faced with her own incapability to talk *with* Miriam, Linda now begins to talk *about* her. What follows is a clinical report card: “She (Miriam) has learned…” Miriam is no longer a dialogical partner whose consciousness is respected in its alterity. Rather, Miriam is a good patient because she has met institutional expectations. Linda’s assessment is professional monologue.

Regard for Miriam’s alterity reappears, however, when Linda perceives the palliative care nurses from Miriam’s point of view: “She realized that some people may come for their own comfort, not hers.” Dialogue returns as Linda’s talk shifts from an assessment of Miriam to Miriam’s assessment of the nurses: “Sometimes *we* need to feel that we are doing something, but it doesn’t help.” Doubt appears to be pervasive among the palliative care nurses. Doubts are endemic to hospitality. Cultural historian Jean Starobinski concludes that gift giving always elicits doubts: “Have people not always divined and denounced the countless simulacra that accompany the gift (i.e., counterfeit gifts or gifts given for counterfeit motives) like its own shadow, thus eliciting doubt about the generosity of intentions…? It is the serpent who sometimes whispers in our ear that the gifts we are witnessing are not true gifts, but only the guise of egoism.”[970]

Some of the nurses’ care may be “only the guise of egoism.” On the other hand, the patients may be affected by, what Bakhtin calls, “elements of infantilism in self-

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[970] Jean Starobinski, *Largese*, trans. Jane Marie Todd. (Chicago, IL: University of Chicago Press, 1997), 157.

awareness”[971] (e.g., “Who can care about a person like me?”). Such questions are also serpents who whisper in the patients’ ears. In the story of Miriam Lambert, Miriam “realized that some people (i.e., nurses) may come for their own comfort and not hers”[972] (i.e., the patient). However, Miriam’s doubts about her care could also have been some “element of infantilism” that prevented her from accepting the comfort the nurses offered. She may have projected her inability to feel loved onto the nurses. Consequently, in her thinking the nurses cannot love her, and they care for their own sake only, not hers. On the other hand, Miriam may have had the courage to recognize and express what other patients find it more comfortable to ignore; this realization and voicing of it calls for bravery because it denies Miriam some of the comfort that she might have received from the nurses.

In any case, the significant point is this: In speaking to Miriam, Linda becomes aware of who Miriam is and this awareness results in an assessment of who Linda is. Hospitality is discovered in the realization that who you are depends on who I am.

Hospitality as Understanding

The Secret of the Hospitable

In the Introduction of his book, *The Renewal of Generosity*, Arthur Frank, Professor of Sociology at the University of Calgary, zeroes in on the problem of hospitality: “A physician once asked me if I had ever expressed ‘unqualified gratitude’ to the doctors

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[971] Mikhail Bakhtin, *Speech Genres and Other Late Essays*, trans. Vern W. McGee. (Austin, TX: University of Texas Press, 1986), 138.

[972] Frank, *The Renewal of Generosity*, 119.

who treated me when I had cancer. I hadn't. The other side of the question is how often I felt that I was being cared for with unqualified generosity. Not often enough."[973]

How can I help to bring about an increase in hospitality? I realize that I am most hospitable when I feel grateful for what I have been given by others and, in some measure, desire to share what I have been given through others. When I live gratefully, my work becomes a labor of love. Medical care, I believe, can play a privileged role in this cycle of gratitude and hospitality.

In practice, medical hospitality is rooted in gratitude for the gifts I have been given. This means that beyond the capacity to relieve suffering, I speak and act graciously to those who suffer. Indeed, it is arguable that the greater need of medicine is not so much in new treatments but in the hospitality with which it offers its current treatments. Medicine rightly requires medical capabilities, but beyond all scientific and technological knowledge, medicine is human beings working together in varying degrees of hospitality.

Valuing the Patients' Otherness (Attributable)

Healthcare professionals encounter patients who are not only intrinsically different (see above) but also very different in the material, mental, and moral conditions of their lives. The problem is how to be hospitable to the other. It is difficult, if not impossible, to be any more hospitable to the external other than I am to the internal other (i.e., an internal relation of otherness).[974]

As healthcare providers encounter the otherness of their patients, I believe it is possible that the relationship to the external other mirrors an internal relation of

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[973] Frank, *The Renewal of Generosity*, 1.

[974] Frank, *The Renewal of Generosity*, 87.

otherness. For example, Abraham Verghese, born in Africa, trained in India, and practiced in America, traces his medical progress from taking a literary interest in his patients to seeing his own problems reflected in theirs. This switch, he believes, makes him better able to help and heal.

Verghese describes letting his patients be stories for him: “I was fascinated by the voyage that had brought them to my clinic door. The anecdotes they told me lingered in my mind and became the way I identified them.”[975] Significantly, in learning about his patients, Verghese indicates that he was learning about himself.[976]

Verghese realizes, of course, that his patients are other to him. Their otherness is realized, above all, in their disease. His patients have AIDS. They are on the other side of a divide that Verghese is able to cross only in a recurring dream of being infected himself:

> The dream recurred so often – always in a different form – I thought of it as the ‘infection’ dream. (Verghese describes the dream, to the moment when he is told his blood test for the presence of HIV positive.) ‘Noooo!’ I screamed. I wept and said it was a mistake, but she shook her head, a little amused by my histrionics, as if one should be able to take this sort of news in one’s stride – particularly a medical man…
>
> I woke in a cold sweat. Each time I had this dream, I immediately recalled the last time I had broken the news of a positive test to a young man. I remembered my concern, my empathy, my encouraging and supportive tone, as if to say, ‘Don’t worry, I know what you are going through, and it will be all right.’ But a dream like this made me feel I had no idea what I was saying. In my waking hours I never understood the absolute terror of finding out you have HIV; in my dreams I understood all too well.[977]

Verghese can suffer with his patients, but he has no idea what his patients are experiencing. He knows the distance of their otherness. He also realizes that his ability to

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[975] Abraham Verghese, *My Own Country*. (New York, NY: Simon and Schuster, 1994), 104.

[976] Verghese, 269.

[977] Verghese, 302-303.

care for them as their physician depends on how he balances the communicative closeness of their relationship (i.e., the existence of each on the boundary with the other) against that with which his consciousness can never merge. His patients' lives will always remain other to him, but as other they command his respect.

Verghese further explains the interdependence between his patients' otherness and his own sense of not belonging: "There was an obvious parallel: society considered his gay patients who had AIDS as alien and much of their life was spent faking conformity; in my case my green card labeled me as a 'resident alien.'"[978] One evening Verghese studies a map of the United States, asking himself if there was "some place in the country where I could walk around anonymously, where I could blend in completely with a community, be undistinguished by appearance, accent or speech?"[979] He fashions a story in which his encounters with his patients, the external others, are informed and enhanced by his sense of being alien in his foreignness, the internal other.

Another example of appreciating the patients' otherness is an encounter related by Lori Alvord. As a child, Alvord is raised on a Navajo Reservation in New Mexico. The daughter of a Navajo father and a Caucasian mother, Alvord recognizes the feeling of being doubly marginalized because she feels "peripheral to a culture that is itself peripheral to the larger culture that engulfs it."[980]

Marginalization continues at medical school in Stanford. Alvord is hospitalized for a critical infection: "Strangers were constantly coming into my room unannounced, without introducing themselves, and physically probing my body…Doctors and nurses gazed into

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[978] Verghese, 51.

[979] Verghese, 249.

[980] Lori Arviso Alvord and Elizabeth Cohen Van Pelt, *The Scalpel and the Silver Bear*. (New York, NY: Bantam Books, 1999), 12.

my eyes, and for the first time I was profoundly aware of the experience of a Navajo person in the medical system."[981]

Alvord's commitment to the Navajo emphasis on harmony and balance in her practice of medicine is tested when a little girl, Melanie, is brought to the hospital in New Mexico with symptoms of appendicitis. Her Navajo grandmother, Bernice, who brings Melanie, is asked to give her consent (on behalf of the family) for surgery. Alvord admits that the diagnosis for appendicitis, while not conclusive, is about 80% accurate.[982] These odds make the decision obvious if one believes in Western Medicine and ideas of the body. With different beliefs about medicine and the body, the decision is not obvious to a Navajo grandmother.[983]

Alvord, conscious of the risk that a perforated appendix will lead to infection and possibly death, talks to the grandmother and understands her fears. Says Alvord, "I could see both sides…The Western view sees a high-risk condition that can be treated by low-risk surgery. The Navajo vision sees that the beauty of the body would be disturbed. Hence, the inappropriateness of interfering with the sacredness and harmony of the body."[984]

"Two worlds were colliding."[985] Alvord chooses to give the grandmother "control of the situation,"[986] accepting the risks. Since the risks fall on medicine, Alvord accepts

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[981] Alvord and Van Pelt, 54.

[982] Alvord and Van Pelt, 139.

[983] Alvord and Van Pelt, 139.

[984] Alvord and Van Pelt, 144.

[985] Alvord and Van Pelt, 144.

[986] Alvord and Van Pelt, 145.

Melanie’s place in the moral experience of her (Melanie’s) world. In that world, the highest and most important good is not violating the harmony of the body. Alvord also understands the hospital social workers who, guided by a different value, seek a court injunction to operate on Melanie. Alvord’s decision to be guided by the Navajo value of harmony requires respecting both Bernice and Melanie as well as the values they represent. That respect champions Melanie’s life because her life exists only as part of that harmony.

This narrative is a reminder that nothing can be said or done without risk. Communication neither creates nor diminishes risk. It allows recognition, appreciation, and understanding of all values to be considered whenever one is responding to the risk that is inherent in being human.

Going through Illness Together

I have found the writings of Russian literary critic Mikhail Bakhtin on dialogue most helpful in my search to discover how I can communicate with the other in such a way as to *understand* the other. Bakhtin links understanding of the other with an understanding of the self: “There can be no firm image of the (other) answering to the question, ‘Who is he *(sic)*?’”[987] Significantly, “the standard medical question is ‘Who is he or she?’ and the answer is a presentation of the patient’s condition, including diagnosis, treatment, prognosis, and perhaps a social history.”[988] Bakhtin’s proposal is that “he” or “she” exists only in relation to “I.” As I communicate with the other, who he or she is depends crucially on who I am.

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[987] Bakhtin, *Problems of Dostoevsky’s Poetics*, 251.

[988] Frank, *The Renewal of Generosity*, 99.

Bakhtin describes the other as "the subject of an address," which means that "one cannot talk *about* him; one can only address oneself *to* him."[989] For example, after hearing the diagnosis, Melanie's grandmother, Bernice, asks Alvord if she will let the family decide whether to have surgery. In effect, Bernice is asking whether Alvord will talk *to* the family, or whether Alvord will communicate like a Western doctor and talk *about* the family. To speak as a human being *to* another human being, the medical voice needs to speak in the first or second person (i.e., "I-you"). When I talk *about* the other (i.e., monologue), not *with* him or her (i.e., dialogue), I close some avenues within me that ought to be open. When I talk *with* rather than *about*, how I as a healthcare professional conceive the patient is altered. A critical part of that alteration is how I conceive myself.

Since I exist on the boundary with others, who I am is always changing in response to who you are; neither identity can be fixed. Part of what it means to understand the other is to recognize that he or she is not exactly whom I believe him or her to be. This is to understand, as Bakhtin maintains, that "there is no final, finalizing discourse that defines anything once and forever."[990] I cannot say the final word about the other, who is always becoming. In Bakhtin's thought, "As long as a person is alive, he *(sic)* lives by the fact that he is not yet finalized, that he has not yet uttered his ultimate word."[991] Alvord's decision to respect the decision of Melanie's grandmother, who speaks for the family, is to respect the unfinalizability of Melanie's family. Alvord refuses to usurp the last word that is theirs to say.

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[989] Bakhtin, *Problems of Dostoevsky's Poetics*, 251.

[990] Bakhtin, *Problems of Dostoevsky's Poetics*, 251.

[991] Bakhtin, *Problems of Dostoevsky's Poetics*, 59.

Bakhtin understands the human reality as persons' "sense of their own inner unfinalizability, their capacity to outgrow, as it were, from within and to render untrue any externalization and finalizing definition of them."[992] While acknowledging my affirmation of Bakhtin's insight, I think that the "capacity to outgrow" is even more relational than Bakhtin states. I see the capacity for outgrowth, not only from within but from between myself and the other. The other, therefore, is unfinalized as long as I sustain a communicative relationship with him or her.

Even quarreling, as long as it takes place in dialogue, is, for Bakhtin, an example of each remaining unfinalized for the other.[993] Consequently, the quarrel is only a bad action when I finalize the other or the other finalizes me, not allowing for change. Then there is no more purpose in talking. For example, obtaining a court order for Melanie's surgery would have ended the dialogue between Alvord and Melanie's grandmother. It would have finalized both of them.

The dialogical goal in medical situations is that the healthcare professional "reconstitutes himself or herself in the voice of his or her patients."[994] Just so, Alvord allows Melanie's grandmother to become part of who she (Alvord) is as a surgeon. She allows herself to be remade in the voice of her patient (as represented by her patient's grandmother).

Bakhtin describes the process of change through the dialogical voice:

> He (*sic*) receives the word from another's voice and is filled with that other voice. The word enters his context from another context, permeated with the interpretations of others. His own thought finds the word already

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[992] Bakhtin, *Problems of Dostoevsky's Poetics*, 59.

[993] Bakhtin, *Problems of Dostoevsky's Poetics*, 30.

[994] Frank, *The Renewal of Generosity*, 101.

> inhabited…When there is no access to one's own personal 'ultimate' word, then every thought, feeling, experience must be refracted through the medium of someone else's discourse, someone else's style, someone else's manner, with which it cannot immediately be merged without reservation, without distance, without refraction.[995]

This passage may be refracted through the story of Alvord and Melanie's grandmother (as representing Melanie). As a healthcare professional, Alvord relinquishes the illusion of having some final word and she accepts that her thoughts and voice are refracted through her patient's discourse. Alvord's patient (as represented by her patient's grandmother), on the other hand, rejects the fanciful notion that the healthcare professional can pronounce the final word. Healing requires that both professional and patient be freed of any fantasies regarding the other. The professional's healing presence elicits a new response to the question, "Who am I?"; "I" comes to be the subject of the patient's words (i.e., the patient's face, the patient's vulnerability), creating a new self-understanding.

To identify with the other in the sense that the other is identical with what I believe him or her to be, is not to understand the other. With Bakhtin, I do not believe in "the exact, passive mirroring or duplication of another's experience within myself."[996] As a result, an *identical* suffering with the other is impossible; a *dialogical* suffering with the other is possible.

Bakhtin uses suffering as an example of how people understand each other. He begins with the distance of otherness: "The *other's* suffering as co-experienced by me is in

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[995] Bakhtin, *Problems of Dostoevsky's Poetics*, 202.

[996] Mikhail Bakhtin, *Art and Answerability: Early Philosophical Essays*, ***1st** Ed.*, ed. Michael Holquist, trans. Vadim Liapunov and Kenneth Brostrom. (Austin, TX: University of Texas Press; 1990, 102.

principle different…from the other's suffering as *he* (*sic*) experiences it."[997] Despite the distance there can develop between us, according to Bakhtin, "a completely new *ontic* formation that I alone actualize *inwardly* from my unique place *outside* another's inner life."[998] Now there can be "co-experienced suffering" that is not the same as either person experiences. This is a suffering, apart from what each experiences; it is a suffering that they go through together.[999]

The healthcare professional, whose voice creates this space of co-experienced suffering, does not pretend to understand that which the patient is experiencing. Hospitality is allowing the patient access to the space of what they are going through together, producing a new way of understanding each other.

The Parable of the Stranger

Medicine seeks, I believe, to resist the fate of my body's vulnerability. My body's vulnerability that medicine seeks to resist, however, is part of what it is to be human. Medicine, therefore, in its commitment to the goal of reducing suffering, always risks rejecting a vital aspect of my humanity. In its highest intentions, indeed, medicine can unwittingly increase my suffering. My greater need may be, not how to be free *from* suffering, but how to be free *with* suffering.

The medical profession, of course, needs to cure illness when it can. It is that very need, however, that can blind it to an equally important goal: How can the medical staff help patients to adjust their lives to what cannot be cured? The greater goal may be to

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[997] Bakhtin, *Art and Answerability: Early Philosophical Essays*, *1st Ed.,* 102.

[998] Bakhtin, *Art and Answerability: Early Philosophical Essays*, *1st Ed.,* 103.

[999] Bakhtin, *Art and Answerability: Early Philosophical Essays*, *1st Ed.,* 103.

help patients understand how to live with illness, injury, disease, disability, and dying, either as an attitude toward life or as an obstacle to living.

Literary scholar Northrup Frye speaks of the “resonance”[1000] of stories in guiding my thinking and acting. He defines “resonance” as “how a particular statement in a particular context acquires a universal significance.”[1001] This is not truth for all times in all places. It is the ability of stories to raise questions and offer examples that inform my life today in my situation. These examples do not tell me what to think or do; they are examples of striving to understand what to think or do and finding the resolve to do it. Medical storytellers battle with uncertainty to find what it means to be hospitable in the situation, facing what must be faced. The struggle is their resonance.

In the Christian Scriptures, there is an event that takes place at Emmaus.[1002] Archaeologists have never discovered Emmaus. Their conclusion is that Emmaus never existed. I, therefore, think the story is a parable.

Emmaus is where I go when my life is disrupted by sickness, injury, disability and death. Emmaus is where I go when life seems unbearable, futile, empty, hopeless. Emmaus is walking toward the sunset.

Only yesterday life seemed so filled with promise. Today, however, life is nothing but shattered dreams.

Suddenly, I realize that someone is walking with me. While trudging to Emmaus, I am met by a stranger who not only walks with me but listens to me. In my pain and

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[1000] Northrup Frye, *The Great Code*. (Toronto, ON: Academic Press Canada, 1982), 217.

[1001] Frye, 217.

[1002] Luke 24:1-13.

preoccupation, I know a stranger's presence. It does not matter to me *who* the stranger is. It is enough to know that I am not alone.

The stranger is so self-giving, walking alongside of me, talking with me. I only discover the identity of the stranger when I invite the visitor to stay with me. In the very moment of identity, however, the stranger suddenly disappears. It seems to be quite enough that I should see the stranger through eyes of faith and love.

In the autumn of 1999, I was given an MRI, the purpose of which was to better ascertain the cause of a chronic migraine. I was asked not to leave the building until the MRI was read. After thirty minutes, the radiologist told me that I had a cerebral aneurysm and was to go directly to the hospital.

Arriving at the healthcare institution, I was met by two doctors. One was Amy. Amy told me that I would die that night. For the following week I was treated in the hospital intensive care unit. Amy was faithful in visiting me, but I must confess that I was never impressed with her competence.

After a week, the seven doctors assigned to me determined that the immediate crisis was over. The threat of memory loss through surgery was greater than the possibility of the aneurysm rupturing without surgery. The aneurysm (circa four-five millimeters) would be monitored with an annual MRI. I was moved out of the intensive care unit and told that I could go home the following day.

I fell into a dark mood. I had come to the hospital with an intractable migraine. One week later I was going home with an intractable migraine. All of the doctors, except Amy, visited me that day. It was impossible to talk to any of them about my headache. They were all so proud of saving my life. I was angry, frustrated, and depressed.

About eleven o'clock that evening, Amy came into my room and quietly sat down on the edge of the bed beside me. Deliberately, she told me that she had gone home after finishing her day. Relaxing and watching television, she thought of me and felt my need. Coming to the hospital, Amy listened to me vent for over an hour. At twelve-thirty, she leaned against me, took her hand and placed it on mine. We sat in silence for about a minute. Amy told me that on her way out she would order a bedtime snack for me. With that, she vanished.

Now I had eyes to see Amy differently. I saw an Amy I had not seen before. Seeing her differently, I thought about her differently. Now I was aware of the stranger. I will never forget Amy, a stranger who came to talk with me and to listen to me in a deeply troubled time.

My encounter with Amy did not solve my problem; it did change the way I solved my problem. The encounter with Amy did not protect me from pain and loss; it did change the way I dealt with pain and loss.

Because of Amy and her hospitality, I now recognize the stranger as one who not only walks with me toward sunset – a life of anger, frustration, depression, but one who walks with me toward sunrise – a new way of living with my aneurysm and my headache. In the words of Stan McKay, a former moderator of the United Church of Canada: "Stay with (me) through the night, stay with (me) through the pain, stay with (me) blessed stranger, 'til the morning breaks again."[1003]

[1003] Stan McKay is a Christian Minister from Fisher River Creek Nation, Manitoba, Canada. He served as the 34th Moderator of the United Church of Canada (1992-1994) and was the first Aboriginal person to have led a mainline Protestant denomination in Canada. This quote is taken from a United Church Observer article while McKay served as Moderator.

CONCLUSION

Firstly, I conclude that competence at communication is an indication of the health of personality,[1004] and that the indication of the health of personality is a foundation for effective communication. In short, there is a correlation between successful communication and personal maturity.

By effective communication, I mean the ability to transmit “messages” (i.e., thoughts, feelings, and wishes) and the ability to perceive or decode messages (i.e., understand the meaning of them).

By healthy personality relative to effective communication, I mean a person who –

1) has a wholesome self-acceptance and self-respect, able to face reality in oneself, in others, and the world.

2) recognizes the limitations of life and seeks to distinguish between the alterable and unalterable conditions of existence, and so lives with an attitude of humility.

3) has an attitude of trust in self, others, and life as a whole.

4) is simple, sincere, open, honest, and non-sophisticated in attitude, speech, and behavior.

5) has emotional responses which consistently give evidence of appropriateness and proportion.

6) guards the integrity of the personality and unique individuality of every person.

7) cultivates wholesome adaptability.

8) cultivates the art of empathy.

9) seeks to grasp in practice the meaning of true love.
    a) Love involves the response of one whole person to another; it is total response.
    b) Love involves a profound respect for the other person.

[1004] J. Ruesch and G. Bateson, *Communication, the Social Matrix of Psychiatry*. (New York, NY: Norton, 1951), 87.

    - c) Love involves a seeking for the growth and enhancement of the other person.
    - d) Love involves an effort to know the other person more deeply and truly.
    - e) Love responds to the needs of the other person (i.e., love cares).
    - f) Love is the supreme good, consisting of patience, kindness, generosity, humility, courtesy, unselfishness, gentleness, gratitude and self-control.
    - g) Love involves growth in understanding, judgment, and sincerity.
    - h) Love involves strengthening the weak.
    - i) Love is inclusive.
    - j) Love is creative conflict. G. A. Studdert-Kennedy expressed it so well: “Love is the creative conflict between two or more free, self-conscious persons who have no desire to possess, dominate, or destroy one another but who, through the clash of mind on mind, and will on will, work out an ever-increasing but never finally completed unity.”[1005]

10) cultivates the art of giving and receiving appreciation.

11) seeks to grasp in practice the meaning of true peace (i.e., integrity, wholeness, unity).
    - a) Peace involves understanding.
    - b) Peace involves forgiveness.
    - c) Peace involves taking the initiative.
    - d) Peace is a process of talking (i.e., negotiation).

12) seeks to view all issues and problems in one’s own person, in one’s relationships, and in life situations, with a sense of perspective.

By correlating the learning of communication and the process of maturity, I mean that healthy personality entails mastery of issues and problems involved in communication and that honest and free communication makes possible a fuller human being.

Secondly, I conclude that learning and growing as a healthy personality is intimately connected to learning and growing as an effective communicator. The “real self”[1006] is a term which Karen Horney uses to refer to “that central inner force, common to all human beings, and yet unique in each, which is the deep source of growth.”[1007] Spurred by the

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[1005] G. A. Studdert-Kennedy, *The Unutterable Beauty*. (London: Hodder and Stoughton, 1927), Preface.

[1006] Karen Horney, *Neurosis and Human Growth*. (New York, NY: Norton, 1950). 17.

[1007] Horney, 17.

work of Carl Rogers, Humanistic Psychology teaches that the goal of communication is accurate understanding of self and others and that understanding can only happen with genuine self-disclosure.[1008]

How, then, is self-disclosure "the deep source of growth"? As small children, we *are* our real selves. We say what we think, ask for what we want, and tell what we did. These spontaneous disclosures meet variable consequences (e.g., we are ignored, rewarded, punished, or disciplined). So, we learn to withhold certain disclosures because of the possible painful repercussions to which they may lead. As growing children, we soon learn to display an expurgated self to others, the outcome of which is to divide the self into "the real self" and "the public self."[1009] We monitor (i.e., censor) our disclosures in order to construct in the mind of others a concept of ourselves which we *want* others to have. In fact, our public selves may become so estranged from our real selves that the result is "self-alienation"[1010] (i.e., we no longer know our real selves). Our disclosures do not reflect our spontaneous thoughts, feelings, and wishes, but rather pretended experiences which will avoid disapproval and win approval. We say that we believe and feel that which we do not believe or feel. In this way of self-alienation, we lose our real selves.

Self-disclosure entails courage, the courage to be known. How, then, do we obtain an accurate concept of the other's experiencing?

[1008] Kenneth J. Cissna and Rob Anderson, "The Contributions of Carl R. Rogers to Philosophical Praxis of Dialogue," in *Western Journal of Speech Communication* 54 (1990): 125-147.

[1009] Sidney M. Jourard, *Personal Adjustment: An Approach through the Study of Healthy Personality*. (London: The MacMillan Company, 1969 [1958]), 173-175.

[1010] Horney, 155-175.

The other is a mystery. Our concepts and beliefs about the other are usually based on insufficient or emotionally distorted evidence, and so they are often false. Consequently, we become afraid. The simple fact is that when someone discloses the self, the mystery decreases unless I have a vested interest to believe what is false.

Why do we disclose ourselves, and why do we not? Self-disclosure follows an attitude of love and trust. If I love, I strive to know the other so that I can devote myself more fully to his or her well-being; if I love, I also let the other know me, permitting the other to love me.

Disclosure – honest, uncontrived – is the necessary condition for reducing the mystery there is for the other. Disclosure appears to be the most direct means by which we can learn how we are similar and different. Such knowledge provides us with the basis for communication and interaction which can either destroy the other or meet the other's needs for fuller human life.

Self-disclosure, my communication of my private world to you, in language you understand, is vital for me to learn. You can know me truly only if I let you, only if I *want* you to know me. Your misunderstanding of me is only partly your fault. If I want you to know me, I shall find a means of communicating myself to you.

How much of the real self, then, am I willing to communicate to you? I am willing and able to communicate any of the real self to you. I am willing to translate my thoughts, feelings, and wishes into words and actions so that you can have an accurate idea of my real self.

It should not be construed from this discussion, however, that the sheer amount of communication that takes place between us is an index of our health as persons or of the health of our relationship. There are such factors as timing, interest in the other person, appropriateness, and effect of disclosure on either person which must be considered in any such judgment.[1011] If a relationship exists between effective communication and healthy personality, it is curvilinear and not linear; that is, too much or too little communication may be associated with unhealthy personality, while some intermediate amount, under appropriate conditions, is indicative of healthy personality.[1012]

In short, the invitation to self-disclosure is an invitation to be an authentic human being. It means being oneself honestly in one's relations with others. It means dropping pretenses, defenses, and duplicity. The invitation is filled with risk; indeed, it may evoke terror in some. Yet the theory is that, while honesty with others and oneself may produce scars, it is likely to be an effective safeguard of both physical and mental health.[1013]

Think of a medical situation where the healthcare professional encourages the patient to try the authentic way. The patient is most likely to accept the call to authenticity when the healthcare worker is a model of uncontrived honesty. Then the need for sneaky projective tests or for decoding hidden messages disappears. The patient wants to make his or her thoughts, feelings, and needs known. In this defenseless situation, the interpretations, suggestions, and advice of the expert have maximum impact on the patient.

Is it possible that medical educators have actually fostered concealment and inauthenticity in medical students and then reported that healthcare professionals are

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[1011] Sidney M. Jourard, *The Transparent Self*. (New York, NY: D. Van Nostrand Company, 1964), 15.

[1012] Jourard, *The Transparent Self*, 15.

[1013] Jourard, *The Transparent Self*, 153.

notoriously duplicitous? What would happen if we regarded the medical staff as collaborators rather than concealers?

Thirdly, I conclude that the person who is a healthy personality and an effective communicator is always in process of living and learning, growing and maturing.

If healthcare is to rise to its potential status in the healing arts, professionals, in my opinion, must grow in being able to establish communication with patients as different kinds of persons, because I believe that such contact is a *sine qua non* for helpful healthcare transactions. If medical staff can permit patients to be themselves in their (i.e., the professionals') presences and not be driven away by whatever the patients say when they are granted freedom of self-expression; if medical staff can communicate profoundly with patients so that they (i.e., the patients) overcome a deep sense of loneliness that seems to be part of illness; if medical staff can help patients feel that here is someone who cares, someone to whom their thoughts and feelings matter, they (i.e., the professionals) may restore identity and morale to patients so that they are enabled to get well in spite of the usually impersonal regimen of institutional life.

If honest, open communication with patients is consoling and encouraging, and I believe it is, then it follows that every transaction in which a caregiver establishes contact with patients so that patients know that the caregiver knows what is on their (i.e., the patients') minds will foster healing. Caregivers must learn to create their own roles guided by the particularities of each patient. Specifically, the way that caregivers can be more effective healing agents or catalysts is for them to establish personal communication with this very patient, who may feel sentenced to solitary confinement in the prison of his or herself and his or her role as patient.

In sum, healthcare professionals will better learn the art of role creation when there are at least two changes. First, I would propose a change in hospital structure such that healthcare roles are not rigidly defined by job descriptions of administrators and so that healthcare professionals are freed from many of the chores which keep the administration functioning smoothly (e.g., assign non-nursing functions such as clerical tasks to unit managers, so freeing nurses for more personal contact with patients). The second change I would put forward comes from within any particular healthcare worker. The professional needs to be able to benefit from increased freedom and to have the courage to be him or herself. If these changes were implemented, patients might be treated less with drugs and more with human communication that heals.

Fourthly, I conclude that the goal of living and learning, growing and maturing, is the ability of the healthcare worker to give personalized care to others.

Who, then, is a personally cared for patient? He or she knows the diagnosis, treatment, and prognosis. He or she feels that the healthcare professionals really care about what happens to him or her. The patient knows that the healthcare workers know him or her as a unique person because they take time to learn about him or her.

Who, then, is this healthcare professional who is able to give such personalized care? This is a person who is able to get into empathic, communicative contact with any patient; this is a person who tries to understand this very patient by trying to learn the patient’s worldview, values, and wishes; this is a person who cares about all human beings, not just some; this is a person who wants to know this particular human being, help him or her, and be an effective agent in his or her comfort and healing.

Who, then, becomes this kind of healthcare professional? This kind of medical expert is a growing paragon who learns with each patient. The becoming, maturing doctor or nurse is a person who is open to his or her own experience, who genuinely cares about his or herself and others. The evidence of effective caring about oneself is a self which is happy, growing, and open; it is a self which, in the past, has been cared for by others and which, in the present, is being cared about by others. This is the person who is free to care for and about others.

This paragon is a person who is always in process of living and learning, growing and maturing. He or she can look into his or her experience and find that somehow he or she has thought, felt, and wished something similar though not identical, to what other human beings are experiencing. This openness to his or her own experience makes it possible to establish empathic contact with patients. Yet, this healthcare professional also realizes that each patient is unique and there is no stereotyped, easy way to take care of individual patients. Consequently, the doctor or nurse never assumes that he or she knows a patient before becoming acquainted with the other's self and experience.

Knowing patients calls for communication. Respect for the other's individuality calls for maturity, for a growing acquaintance with one's own inner experience. This means that to know others, one begins by looking within oneself.

I believe that one factor, above all, which inspires faith and hope in a patient is the conviction that somebody cares about him or her. Direct communicative contact with a patient appears to increase a sense of worth, and this experience heartens the patient – it does something that appears to be a vital influence in the patient's wellbeing (i.e., sincere attempts to know and understand a patient increase the patient’s sense of identity and integrity, and this experience seems to be a crucial element in healing).

Future Research

More studies are needed on the hypothesis that communication is more effective if it is spontaneous rather than formulaic.

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