Volunteer Handbook

My Student Information

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Home Phone: _________________________________________
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Family Centered Experience Program

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TABLE OF CONTENTS

Welcome.......................................................... p.1
Expectations of Volunteers and Program Objectives........ p.2
Teaching Suggestions........................................... p.4
M1 FAMILY CENTERED EXPERIENCE – YEAR 1....... p.5
M1 Volunteer Schedule ........................................... p.6
M1 Home Visit #1 .................................................. p.7
M1 Home Visit #2 .................................................. p.13
M1 Home Visit #3 .................................................. p.17
M1 Clinic Visit ..................................................... p.24
M1 Interpretive Project............................................. p.25
M2 FAMILY CENTERED EXPERIENCE – YEAR 2....... p.26
M2 Volunteer Schedule ........................................... p.27
M2 Home Visit #4 .................................................. p.28
M2 Home Visit #5 .................................................. p.32
Frequently Asked Questions................................... p.34
Appendix................................................................... p.39

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Dear Family Centered Experience Volunteer:

Welcome to the Family Centered Experience! Over the next two years you will have the opportunity to provide invaluable training to a pair of University of Michigan medical students; an experience that cannot be duplicated in any classroom or clinic. In your role as mentor, you will teach the students how to see a patient as a whole person and help them better understand how illness affects many aspects of your daily life.

The purpose of this handbook is to provide you with general information about the program as well as the home visit schedule and topics. In addition, we have included tips that might assist you in making the visits more enjoyable and productive.

Thank you for playing such an important and essential role in the training of University of Michigan medical students - our future physicians!

Warmest regards,

Arno K. Kumagai, M.D.
Director

Eric P. Skye, M.D.
Associate Director

EXPECTATIONS OF PROGRAM VOLUNTEERS

FCE Volunteers are expected to:

• Use the stories of their experiences with chronic or serious medical conditions to teach beginning medical students the human side of medicine.

• Help medical students reflect on their own ideas, assumptions and biases about illness, doctors, patients, and social factors such as gender, age, race/ethnicity, financial status, sexual orientation and religious faith, in the context of medicine.

• Help medical students develop communication and listening skills that may eventually be used in practicing medicine with compassion and understanding.

• Help medical students develop a sense of professional responsibility to all those under their medical care.
EDUCATIONAL OBJECTIVES OF THE PROGRAM

The overall goals of the Family Centered Experience Program are for medical students to understand the human dimensions of chronic or serious illness, including:

• The impact of illness on one’s sense of self, one’s relationship with one’s family, friends, environment, activities, and future goals and aspirations.

• The influence of doctors on the way in which patients view themselves and their conditions.

• The beliefs and assumptions held by physicians, other people, and society regarding illness or different characteristics of an individual with a medical condition (gender, age, race/ethnicity, national origin, language spoken, appearance, etc.) may have on the patient and his/her family.

• How life-changing news has been broken to individuals with illness: how it can be done well or done badly.

• What “lessons” physicians-in-training may learn from patients that may be incorporated into a practice of medicine that is characterized by compassion, respect, and concern and advocacy for the patient and his or her needs.

FACILITATE LEARNING

1. Make each visit a discussion and not a lecture. The purpose of these visits is to help the students think about what it is like to live with a chronic or serious medical condition and how this condition might affect one’s views of oneself, others, the future and the world. Since you are among the most important teachers the students will have during their first two years in medical school (or in their medical careers, for that matter), do not be afraid to ask them about their own backgrounds, thoughts, feelings, and reactions to the topics you’re discussing—do no hesitate to fully engage them in a conversation by asking them questions, such as, “If you were in my/my family’s/my doctor’s shoes, what would you do?”

2. Think about the theme of the visit before the visit. What is it that you would want to let the students know about your experience: that would make them better doctors? What stories can you tell to illustrate these points? Spend time thinking about the experience—how you felt, what you were concerned about at the time, how the experience changed the way you see yourself and your world—and consider talking with your friends and family about their views, feelings, thoughts, and impressions to prepare you for the conversation you’ll have with the students.

3. Involve your family and friends in the discussion. Often there is more than one person who has had experiences with illness in one family. Although there is a “primary volunteer,” this is done only for bookkeeping purposes. If other members of your family or support group are willing to share stories that pertain to the theme of the visit, we encourage them to do so because it will allow all of you to look at the theme from a variety of different points of view.
M1 Family Centered Experience

Year 1

<table>
<thead>
<tr>
<th>M1 VOLUNTEER SCHEDULE</th>
<th>Visit Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome Reception</td>
<td>Mid August</td>
</tr>
<tr>
<td>6:00 p.m. – 8:00 p.m. at Kensington Court</td>
<td></td>
</tr>
<tr>
<td>M1 Home Visit #1:</td>
<td>Mid August – Late September</td>
</tr>
<tr>
<td>Self, Family &amp; Illness</td>
<td></td>
</tr>
<tr>
<td>M1 Home Visit #2:</td>
<td>Early October – Late November</td>
</tr>
<tr>
<td>Doctors &amp; Patients</td>
<td></td>
</tr>
<tr>
<td>M1 Home Visit #3:</td>
<td>Early January – Mid February</td>
</tr>
<tr>
<td>Stigma &amp; Illness</td>
<td></td>
</tr>
<tr>
<td>Clinic Visit</td>
<td>Mid August – Mid April</td>
</tr>
<tr>
<td>Interpretive Project Reception</td>
<td>Mid to late April</td>
</tr>
<tr>
<td>6:00 p.m. – 8:00 p.m. at BSRB Atrium</td>
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</table>
M1 HOME VISIT #1
SELF, FAMILY & ILLNESS

Contributed by A.K. Kumagai, M.D.

Visit Period:  Mid August – Late September

Objective: Please use this visit to explore the impact of illness on you and your family: its impact on your sense of who you are, your daily life, the relationships within your family and with other people outside of your family, your thoughts about the past, the present, and the future.

Before the visit, consider taking a few moments to think about these themes and discussing them with your family members or friends.

Introduction:

Self-Identity and Illness

Who am I? This is a question that we rarely ask ourselves. We nonetheless provide an answer to this question by our actions, thoughts and perspectives. People often define themselves by the things they do—“I am a school teacher, a parent, business executive, a construction worker, a sales person, an advocate, a medical student.” This identity helps put our lives and priorities in perspective and helps provide us with a comfortable place in the world. This interplay between self-identity and social identity become the way in which we know ourselves and are known by those around us.

Life-altering illness or conditions may profoundly affect this sense of identity. The social labels that we give to ourselves (or are given to us by others) are stripped away, and one is left with a new self: the patient, of a sick person. The successful business entrepreneur, the award-winning athlete, the popular teacher or the dedicated student becomes “the asthmatic,” “the diabetic,” “the heart attack in hospital room 5,” “the guy with AIDS” or “the woman with breast cancer.” Much of the stress that comes with being told of a diagnosis, and much of the challenge of learning to readapt to one’s life afterward is the struggle to learn to integrate the demands of physiological, psychosocial, logistical, and financial - of the condition and its treatment into a new way of being oneself.

Illness has meaning

With a life-altering condition, an individual is frequently shocked into the recognition that his or her view of a world in which everything is in its rightful place is fundamentally, and often permanently, altered. Among his or her first responses to this change are attempts to place this new development within a framework of understanding that “makes sense” to the patient, in essence, to develop what the medical anthropologist, Arthur Kleinman, refers to as an explanatory model of their illness (Illness Narratives, p. 121).

These explanatory models are created in response to questions such as “What is this illness?” “Why me?” “Why now?” “How did this happen?” “What does it mean for me, for my family, and for my future?” “What can I (or we) do?” As we have discussed previously, the answers to these questions are highly personal and are influenced by previous experiences, family interactions, and cultural, socioeconomic and religious backgrounds.

Physicians and other health care providers develop their own subjective, often unspoken, descriptive models of their patients and their illness that act as a foundation upon which they build diagnostic and therapeutic approaches. To believe that physicians are guided only by “pure, objective science” in their work is to be mistaken. (I one doubts that the clinician’s approach is anything but objective, i helps to think of the images that come to mind when you hear the terms “alcoholic,” “AIDS,” “psychotic,” “poor,” “homeless,” etc. Although these are mere descriptions, they are loaded with social
cultural and even political meaning.) There are often conflicts between the explanatory models that physicians and patients develop, especially since these belief systems are usually not verbalized, and these conflicts may create misunderstandings, mutual suspicion, and obstacles to care.

Illness & the Family
In suffering and in attempting to come to terms with major life-altering events, an individual often turns to his or her family for comfort, guidance and support. This “family” may be broadly defined to include, not only blood relations, but also anyone with whom the individual has significant emotional ties, such as partners, friends, coworkers, teammates, religious mentor/leaders, or caregivers. The individual’s illness and its treatment may have a major impact on this critical support system (albeit, not as directly as that experienced by the patient) and may fundamentally change the relationships within this network of human contacts: the previously hard-driving executive may be incapacitated by a stroke and become a more vulnerable, dependent member of his or her family; the happy, energetic 2-year-old may develop insulin-dependent diabetes that requires constant parental monitoring of blood sugars and multiple daily injections of insulin; the active mother of two may be afflicted with profound depression and an inability to rise from bed in the morning. These events may have profound effects on the interactions of the most important people inhabiting an individual’s world and, conversely, the dynamics of these relationships may affect his or her ability and resources to cope with major illness.

In addition, family dynamics may have a profound impact on the way in which an individual learns to cope with illness. The stress of a diagnosis of a serious or life-threatening illness may pull the members of the support system together; however, it may also worsen underlying conflicts and tensions, which may add to the stress of coping with illness.

Despite the best of support systems, the experience of illness is, by its very nature, a solitary endeavor. The discomfort, pain, and sense of loss belong to the individual who is ill and may become emotional barriers between the patient and those who are well. Fears of dependence—of being a burden to one’s friends and family—may intensify this isolation and may create stress and conflict within the family.

Objectives
M1 Home Visit #1 has three (3) related objectives:

1. The Meaning of Illness. During this visit, students will be introduced to the volunteer’s “illness narrative,” i.e., the history of the illness, its diagnosis, and the beginning of its treatment from the patient’s perspective. It is through these stories that students will learn of the meaning that the illness or condition has for the volunteer and his or her family. This sense of understanding helps the individual and family to cope with the major changes in their perspectives and lives that coping with the condition requires, and the act of telling their stories allows them to give their experiences meaning and validation.

2. Illness and Self-Identity. This visit represents a valuable opportunity to explore the ways in which the illness or condition may affect an individual’s view of him/herself, the world, and the future, and to understand the means by which an individual adapts to this new situation. For example, illness oftentimes represents a loss, not only of health, but of abilities: for someone with diabetes, the ability to eat without worry; for someone with heart disease, the ability to exercise without chest pain; for someone with asthma, the ability to run without wheezing. These losses may greatly affect the individual’s sense of well being and autonomy. On the other hand, the individual may gain something from his or her condition, such as greater understanding and insight, patience and adaptability, and forbearance and courage in the face of discomfort, fears and suffering. Through your conversations with the patients and their families you may be introduced to these perspectives and
begin to understand the many dimensions that exist when working with individuals with chronic or significant medical conditions.

3. **Illness and the Family.** A mother of a child with autism once said to me, “When my son was diagnosed with autism, we all shared the diagnosis.” This visit may be used to explore how the illness/condition has affected the family, friends, and coworkers - the members of the individual’s support system and how the relationships with others has affected the perspective of the individual living with illness.

**Reminders for FCE Volunteers:**

- **Questions used in discussion**
  In order to give students, volunteers and their families some help in structuring their exploration of the issues above from a variety of points of view, we provide students with some recommended questions for the visits. Please feel free to go off the list, however, and not feel restricted by it. We also encourage you to ask questions to your students about their thoughts, feelings and beliefs. The direction the conversation takes depends entirely on your personal, and your family’s, experiences with illness.

- **These are students, not doctors (yet)**
  What’s important in this discussion are your feelings, insights, and reactions to what has happened to you. The students whom you’re working with are at the beginning of their careers and know much less than you do about the science of the condition that affects you and your family. In other words, we’d like you to teach the students the human dimensions of what has happened to you and your family in order to help them to see what patients often go through when coping with a serious or chronic medical condition.

- **Keep a focus**
  Since there are future visits devoted to a variety of subjects, please try to stay with the theme of the visit (Ex-Visit #1 is impact of illness on self and family) as the basis for the conversation. We are aware that these are somewhat artificial separations, but this will avoid repetition in the discussions.

**Some Tips**

1. Tell the students about who you are when you’re not a “patient.” How do you like to spend your time? Also, please feel free to ask them about themselves.

2. What medical conditions have affected you and your family?

3. When discussing your condition, try to recall how you felt when you learned of your condition? How have you come to accept it (or not)?

4. What about your illness affected you the most? What impact did your illness have on your daily activities and schedule, job/school and plans for the future?

5. What impact did your illness have on the way in which you see yourself?

6. Describe or demonstrate any changes made to your home or living conditions.

7. What have you lost (if anything) as a result of your condition? What have you gained?

8. What fears (if any) do you have of the condition? Of its treatment?

9. What made you (or your family) happiest before finding out about the condition? What has made you or your family happiest afterward? Have your general priorities changed since you learned of your condition?

10. What, if anything, in your past experiences prepared you to cope with your condition?
M1 HOME VISIT # 2
DOCTORS & PATIENTS

Contributed by A.K. Kumagai, M.D.

Visit Period  Early October – Late November

Educational Objectives:
To understand:
1. The characteristics, qualities, and behaviors that make a “good” and a “bad” doctor, from the patient’s perspective.
2. The importance of communication in the interactions between doctors and patients.
3. The ways in which individual physician’s and patient’s identities—in terms of culture/race/ethnicity, religion, gender, sexual orientation, and socioeconomic background—may affect the interactions that take place between doctors and patients and may lead to miscommunication, distrust, and conflicts.
4. The differences in authority and power between doctors and patients: when and how patients and doctors express and deal with disagreement regarding medical care.

Note to FCE Volunteers:  This visit is devoted to a conversation about your experiences with doctors and other health care providers. Please use this visit as an opportunity to engage your students in a discussion about your—and their—views about what makes a good doctor. What actions, approaches, and qualities might they incorporate into their emerging identities as physicians that expresses an understanding and appreciation for the dignity, autonomy and perspectives of their patients?

The text below is part of a handout that the students receive to orient them to the theme of the visit. Please feel free to use it as a springboard for your conversations with the students. We would also like to suggest that you to start your conversation by participating in an Exercise on Loss, which is described at the end of the handout. This exercise is intended to help frame the discussion on doctoring in terms of what is helpful—or harmful—in addressing someone’s emotional, psychological, and spiritual needs during very difficult times.

What makes a “good” doctor? (Handout Provided to Students—optional reading)

So often these days, medicine is practiced in a pressure cooker atmosphere. From the physician’s perspective, the optimism which inspires one to become a doctor is gradually weakened through repeated exposure to the more unpleasant aspects of the profession. Examples are the endless paperwork, lack of time, the pressure to keep abreast of changes, the stress, as well as litigious patients demanding administrators, and unresponsive insurance companies and governmental agencies.

From the perspective of the patient, the idea of the old-fashioned doctor who was willing to make house calls in the middle of the night is but a quaint vestige of one’s grandparents’ past; modern medicine instead involves continuous hassles with insurance companies and clinic schedules, impersonal, harried doctors who appear to pay more attention to test results than to what the patient says, intimidating technology and complicated medical regimens, and sub-specialization to the point of viewing the patient as a sum of poorly functioning “parts” rather than a whole person. In the press medical horror stories abound: the young woman who died within 24 hours after being admitted to the hospital with a minor infection; the man with a gangrenous diabetic foot who had the wrong leg amputated; the cytology lab that misread hundreds of Pap smears as “normal” when in fact they showed evidence of cancer. News reports of the conflict of interest between clinical researchers and the pharmaceutical industry, and reports that estrogen, a medication used by millions of women for prevention of postmenopausal osteoporosis and cardiac protection, actually increases the risk of heart attack.
stroke and certain cancers. These problems make treatment of illness and maintenance of health a complicated affair. In the setting of an occasional illness, such as a sprained wrist or a case of “strep throat,” they may be the cause of annoyance or concern. In the setting, of chronic or serious illness, these problems may represent insurmountable obstacles in seeking and maintaining medical care.

At the center of this world of technology and regulation lies the relationship between the physician and the patient. As you have gathered by now through visits with FCE volunteers and their families, this may have a major impact on how that individual deals with chronic or serious illness. The purpose of Visit 2 is to explore the experiences FCE volunteers have had with their physicians, and ultimately, the nature of healing and the role of the physician in this process.

1. **Exercise on Loss.** Please start the visit by performing the exercise with your FCE volunteer and any member of his/her family that wishes to do so. Use the discussion arising from this exercise as a starting point for your discussion of physicians and patients. As with Visit #1, please review the material above, as well as your notes from the last visit, and develop open-ended questions to guide the discussion prior to the visit itself. The better you are prepared for the discussion, the more effective you will be in eliciting insightful comments from your volunteers.

2. **Suggested Topics for Discussion**

1. Please talk about the best experience that you’ve had dealing with doctors. What specific things did the doctor do or say that you appreciated most? How did he/she put you at ease?

2. Please talk about the worst experience that you’ve had dealing with doctors. What were the specific aspects about the experience that distressed you the most? Can you recall how you felt during the experience? Did you discuss your feelings with anyone? A relative or friend? Other patients? Your doctor?

3. Do you feel that your doctor listens to you? How can you tell? Does he/she do something (body language, responses) that gives you that impression? Does your doctor do anything else while you are talking, such as writing in a chart, looking things up on a computer, reviewing lab results or filling prescriptions? Do you ever feel that you need to fight for his/her attention?

4. Has any doctor helped you deal with a significant loss (e.g. of an ability to do something or of a loved one)? How effective was he/she in helping you?

5. Have you ever challenged or questioned your doctor’s recommendations? Was this difficult for you to do? How did your doctor react? Have you ever had an argument with your doctor?

6. Do you ever discuss your use of alternative approaches and therapies for your condition(s) with your doctor? Who raises the issue? How does your doctor respond? How does your doctor’s response make you feel?

7. How important is the reputation of your doctor to you? For example, where he/she trained, the reputation of the clinic or medical center where he/she works, how well he/she is known in the medical community?

8. If you were to list the five top qualities that you think are most important in a doctor, what would they be?
M1 Home Visit #3
STIGMA & ILLNESS

Contributed by A.K. Kumagai, M.D.

Visit Period: Early January – Mid February

Educational Objectives:
To understand:
1. The ways in which specific diseases, medical conditions, physical attributes or identities may be stigmatized and expose the individual to bias, unequal treatment, social ostracism, and personal embarrassment or shame.
2. The ways in which individuals with medical conditions decide what—if anything—to reveal to others about their conditions, and what the consequences are of telling people about them.
3. The social and cultural forces that give rise to negative images of specific medical conditions and the individuals suffering from them.
4. The manner in which physicians may assume society’s biases and unconsciously incorporate them in the care of patients with certain medical conditions.

To:
1. Identify and explore society’s, as well as the students’ own, biases and attitudes regarding various physical or medical conditions, attributes or personal or social identities.

Stigma: a condition, characteristic, trait or identity that may be viewed in a negative light by others.

Note to FCE Volunteers: This visit is devoted to a conversation with you about your experiences with stigma and illness. This is the difficulties you may have had dealing with how other people see you because of your medical condition. The text below is a more detailed description of stigma and is part of a handout that the students receive to orient them to the theme of the visit. Please feel free to use it as a springboard for your conversations. We encourage you to define stigma very broadly and explore how other people—and society—may often treat individuals badly, not only targeted at one’s medical condition, but also at one’s gender, age, religion, race, ethnicity, sexual orientation or financial status. The purpose of this conversation is to help students explore their own and society’s biases so they may treat all individuals who seek their medical attention with justice and compassion.

Stigma and Illness

Hell: it’s other people.
J.P. Sartre, No Exit

Stigma may be defined as negative views that society or others may hold about an individual’s personal quality, identity or characteristics. People who are stigmatized are “labeled” by others (think of the Scarlet Letter), and these labels often ignore personal qualities that contradict the labels themselves. Broadly defined stigma may involve negative opinions or views directed at individuals because of their financial status, gender, race, religion, sexual orientation, language or country of origin. In the setting of health care, many conditions may be stigmatized (for example, lung disease from smoking, obesity, mental illness) and may heavily influence the treatment of affected individuals. In fact, illness itself may be viewed negatively in this health-conscious society.

Another important aspect of stigma is whether the condition is clearly visible to others or is something that is not apparent to the casual observer. In my own practice as a diabetes specialist, diabetes is not readily apparent to others, and very often, individuals with diabetes have to constantly decide whether to tell friends, acquaintances, coworkers, or employers that they have the condition.
During this visit, we would like to encourage you to explore the theme of stigma in the broadest sense with your students and to consider the ideas of “visible” and “invisible” stigma with regards to your own experiences.

**Notes on Stigma (Handout Provided to Students—Optional Reading)**

An individual’s identity rests on the constant and complex interplay between the image that one creates for him- or herself, and the image of him or her that others may hold. As you have learned from your conversations with your FCE families, serious or chronic medical illnesses often have profound effects on the sense of self that the sick person may have. In addition, the experience of illness itself may serve to separate the individuals from others: isolation and *aloneness* are central themes in the experience of severe illness. Specific medical conditions—especially those that result in noticeable physical or psychological changes—may increase the isolation a sick person feels because of the negative manner in which others view the condition. Examples are legion: congenital or genetic abnormalities, such as cleft palate, cerebral palsy, or Down’s syndrome; absence or deficiency of some important body part or ability, such as amputation or paralysis, blindness, deafness or mutism, infertility or conditions requiring use of urinary or colostomy bags; failure to develop or a loss of an important component of self and its relation to others, such as delayed intellectual development, autism or dementia. If one understands *stigma* to mean a personal attribute, condition or identity which is regarded negatively by society, these medical conditions—and many others—are often the object of fear, suspicion, prejudice, and hostility—by society, by others, and often, by oneself.

At times stigmatization is based on a fear of contagion, which may or may not be supported by evidence of a clear danger to others. During its various epidemics, the bubonic plague—which, at its height in the 14th through 16th centuries, was said to have killed one quarter of Europe’s population—often required quarantine of the sick from the well; however, in contrast, individuals afflicted with leprosy—a disease of relatively low infectivity caused by *Mycobacterium leprae*—were until recently the objects of tremendous fear and were often shunned by society. In more contemporary times, the hysteria and hostility that arose when HIV/AIDS became well known often was—and is—out of proportion to the actual threat of the disease and has subjected those afflicted with HIV or AIDS to a degree of “medical prejudice” rarely seen with other disorders.

With many conditions, a sense of morality permeates the reactions of others. These conditions are often interpreted by others as signs—stigmata—of moral lapses on the part of the affected individuals conditions are thought to be acquired through excessive “abnormal” or “deviant” behaviors, and the individuals with these conditions are frequently blamed for the illness itself. Examples include obesity, alcoholism, drug abuse, HIV/AIDS, or pulmonary conditions, such as emphysema, COPD, or lung cancer, that are associated with tobacco use. “Serves ‘em right,” (or an equivalent expression) is often heard during conversations about someone suffering from such illnesses. In this regard, the stigmatization of mental illness is in a class all by itself. Perhaps because in mental illness it is the personality or sense of reality that is affected, individuals afflicted by mental illness are frequently looked upon with tremendous suspicion, fear, or contempt. These attitudes are frequently reinforced by treatment by the media through movies, television, and sensationalistic news stories.

A critical point in considering the stigmatization of illness is that stigmatization is a social act, and the characteristics attributed to the individual afflicted by the disease are often defined by cultura values and perspectives rather than medical ones. Therefore, the manner in which certain diseases or conditions are viewed depends in large part on the cultural and historical context in which they occur. In *Illness as Metaphor*, the American essayist Susan Sontag traces the historical meanings given to two major diseases—tuberculosis and cancer. Up through the beginning of the 20th century, individuals afflicted by tuberculosis (or “consumption”) were viewed—in literature and by Western society—as personalitie who were “artistic” in temperament and of “delicate” composition
In contrast, Sontag—herself a breast cancer survivor—makes the somewhat controversial argument that cancer is often regarded by society as the ultimate manifestation of “tension,” “stress,” or even neurosis in individuals afflicted with this type of disease (e.g., the “cancer “personality”).

Stigmatization of certain illnesses and those that suffer from them is in its essence a denial of individuality and autonomy. The disorders themselves are neither “good” nor “bad,” “moral” or “immoral”; however, through the lens of culture, derogatory images and beliefs merge with medical diagnoses and frequently have a major impact on the way in which individuals with these conditions see themselves and their lives. Internalization of this societal perspective often results in shame on the part of the individual with the condition—a feeling that what has befallen him or her is somehow deserved due to some past transgression. Out of this shame often arises a desire to hide the evidence of his or her condition from others in an attempt to “fit in” or to “pass” as “normal.”

Stigmatizing attitudes related to illness may also combine with other biases, such as prejudice based on race, religion, language, socioeconomic status, gender or sexual orientation to further marginalize the individual. Physicians and other medical personnel are not immune to such attitudes, and it is the context of medical practice that such biases, when expressed, may have terrible consequences. An example of this situation is of a young African American man in painful sickle cell crisis. Negative attitudes and assumptions based on race or dependence on narcotics for pain may lead to suspicion and hostility between medical staff and the patient and result in neglect of medical needs (rehydration, adequate pain control, evaluation for infections, bone infarcts or necrosis, pulmonary crises, and other acute complications of sickle cell disease).

In other situations, individuals with chronic illness often learn to control the amount of personal information that they disclose to others. Health, fitness, and physical vitality are valued in modern American society, and to declare that one has a chronic illness is to open oneself to being treated “differently.” Examples: the 17-year-old high school senior who is afraid to attend gym class because of her weight; the parents with a 7-year-old with asthma who worry that he will be ridiculed for his wheezing when he tries to play with others; the mother of a child with cerebral palsy who becomes angry when others act as though the child is retarded; the physician with severe depression who is reluctant to let colleagues know of her suffering. In my own practice as a diabetologist, I have patients whose close friends and coworkers are unaware that they have type 1 diabetes; other patients who feel awkward going to restaurants, where they are forced to test their blood sugars and inject insulin in restrooms (“feel like a drug addict and am often mistaken for one,” said a patient); still others who are reluctant to inform people of their diabetes because they are “sick and tired of being lectured to by total strangers” about what they should or should not eat.

The theme of Home Visit #3 is “stigma and illness.” It is an opportunity to explore with your FCE families the ways in which they have been treated differently by others because of their conditions. To whom have they disclosed their condition? To whom have they made such choices about who should and who should not know? What types of reactions have they received from others including doctors? Have they ever felt as though they have been treated differently by others because of their condition or for other reasons (race, ethnicity, religion, gender, sexual orientation, physical disability, etc.)? What steps, if any, have they taken to prevent disclosure of their medical conditions? If they have a readily apparent physical difference, how comfortable are they in public? What, if any, negative attitudes toward their condition have they encountered? Please take the time to explore this subject in detail with your volunteers.

Suggestions and Notes for Visit #3: Stigma & Illness

Start the visit out by discussing what stigma means (most people may be aware of the term, but some may not).

Stigma may be defined as a personal characteristic, quality or group identity that is viewed negatively by others.
Suggestions for Discussion:

• Discuss what types of stigma occur in society generally, as well as what types of stigma occur in the setting of medical conditions. Use some examples to illustrate different types of stigma—both in society and in health care.
• Consider the idea of “visible” and “invisible” stigma—conditions that are obvious to a casual observer and conditions that are “hidden” from view.
• Turn the conversation to the volunteers and their general life experiences: have they been in situations where they felt that they were pre-judged or judged for something that was not due to their personal behavior or attitudes? What occurred and how did they feel? Were there any consequences from this type of judging?
• Discuss their experiences with illness: were they ever treated differently—either positively or negatively—because of something other than their immediate condition? What occurred and how did they feel? What were the consequences of this treatment, if any?

• Reconsider the idea of “visible” and “invisible” stigma.
  If their medical condition is readily apparent:
  ✔ How do others react to their condition? Friends, family, neighbors, coworkers, supervisors or doctors?
  ✔ How do the reactions of others affect their own views?
  ✔ What have been the consequences of the views of others of them and their condition?

  If their medical condition(s) is not readily apparent:
  ✔ Whom do they tell? Friends, family, neighbors, coworkers, supervisors or doctors?
  ✔ How do they tell?
  ✔ What are the consequences of telling?
  ✔ To whom would they feel uncomfortable disclosing their diagnosis?
  ✔ Do they do anything—do they use any strategies—to prevent disclosure of this information?

M1 Clinic Visit

In addition to home visits, we are requesting the FCE volunteer families to allow their medical students to accompany them on a scheduled clinic visit. All students are required to accompany the family on at least one visit during the first (M1) year.

The goal of this clinic visit is for the students to witness interactions and discussions between doctors and the FCE volunteers from the patient’s point of view. This is a unique opportunity for the students to observe you and your doctor after having talked to you about doctoring and patient care, for it is virtually the only time during the students’ entire medical careers that they are asked to watch doctors and patients interact from the patient’s perspective.

Some additional points:

1. The clinic visits should be arranged according to you or your family’s clinical needs.
2. Students are expected to wait for the doctor appointments in the waiting room with you. Yes, medical students are busy but so are you!
3. It is helpful to take a few minutes before you see your doctor to discuss with your students your expectations of the visit that is, what you would like to have addressed in seeing you doctor.
4. Similarly, it is helpful to meet for a few minutes after the visit to talk about how the visit went: What did the students observe? What was eye-opening? How well did the doctor communicate? How well did he/she address your questions?

If you have any questions or wish to discuss this further, please do not hesitate to contact the FCE Office at (734) 615-4886.
M1 INTERPRETIVE PROJECT

Contributed by A.K. Kumagai, M.D.

Project Period:  Mid August – Late March

Objective: To work collaboratively using a variety of media to capture one aspect of the experience of illness learned in speaking with the FCE volunteers. Students are expected to work in groups of 2-3, which should represent 2-3 different FCE volunteers and their families. From the diverse experiences, each group is expected to find a few common themes regarding the lived experience of illness from the patient’s perspective and then to capture this experience in their project.

Last year, the forms these projects took were as varied as the families and their experiences: poetry and songs, interpretive dance, artwork (collage, painting, sculpture, an illustrated children’s book), slide presentations with music, among others. Themes ranged from the impact of illness on self-identity and on the family, to the role of faith in coping with illness, to the challenges and obstacles encountered in living with illness. The choice of medium is up to the collaborative group and the projects should reflect a thoughtful approach to the subject.
### M2 VOLUNTEER SCHEDULE

<table>
<thead>
<tr>
<th>Visit Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>M2 Home Visit #4: Breaking Bad News</td>
</tr>
<tr>
<td>Late August – Mid October</td>
</tr>
<tr>
<td>M2 Home Visit #5: Wrap-up and “Lessons Learned”</td>
</tr>
<tr>
<td>Mid January – Early March</td>
</tr>
<tr>
<td>Volunteer Appreciation Lunch</td>
</tr>
<tr>
<td>Late March</td>
</tr>
</tbody>
</table>

### M2 HOME VISIT #4

**BREAKING BAD NEWS**

Contributed by A.K. Kumagai, M.D.

**Visit Period:** Late August – Mid October

**Intended Learning Outcomes**

To understand:
1. Different settings in which bad news is delivered.
2. Varieties of experiences of, and reactions to, bad news.
3. The emotional (and physical) aftermath of bad news.
4. One’s own personal experiences and perspectives and how these may influence one’s ability to effectively break bad news.
5. The ways in which individuals may wish to hear bad news when it’s delivered.

To learn:
1. Personal approaches to delivering bad news.
2. The impact of one’s own perspectives, values, and experience on discussing difficult subjects (e.g., suffering, loss, injury or death).
3. Personal approaches to the care of people that incorporate the patient’s perspective.

Life changes fast.
Life changes in the instant.
You sit down at dinner and life as you know it ends.

Joan Didion
*The Year of Magical Thinking*
Overview for Volunteers: The purpose of this fourth FCE home visit is to explore the topic of breaking bad news. The goal of the conversations that you have with your students are meant to stimulate their reflections on the subject and ultimately to help them to develop ways in which they can deliver bad news to patients and to help patients and their families cope with the consequences. The conversations that you will have with your students, as well as the small group discussions that they will have in the medical school after the visit, play a vital role in training them to develop compassionate, humanistic, patient-centered care.

Introduction

More recently, most people can remember exactly where they were on the morning of September 11, 2001 when news broke of the hijacked airlines hitting the World Trade Center buildings, the Pentagon, and the isolated field in Pennsylvania. This type of news may affect an entire society, and life is often thought to be divided into The Time Before and The Time After. Within the context of an individual’s life and within the context of one’s family and close friends, bad news involving one’s health or life may have an even greater immediacy and impact.

“You have cancer…”
“You have cancer…”
“You child has autism…”
“The test results are not good…”
“I’m sorry to have to tell you that your child has died…”

Upon hearing the news, a certain paralysis of disbelief sets in: “This can’t be happening…” “This can’t be right. They have the wrong person…” “This must be a dream…” Subsequent details are filtered through this “fog” of unreality and numbness sets in; however, little by little, a painful awareness dawns that, in Didion’s words, “life as you know it ends.” Often, the impact of the diagnosis has only a minor relationship to its medical severity: the word “cancer”—regardless of the overall prognosis of the type—can be devastating for anyone to hear, and even a common diagnosis, such as diabetes or childhood asthma, may overwhelm someone who is used to thinking of themselves or their child as healthy or “normal.” The frequent mismatch between the doctor’s understanding of the diagnosis and the meaning that diagnosis may have for the patient represents the vast difference between the medical disease and the subjective experience of illness from which miscommunication may arise.

From the doctor’s perspective, the delivery of bad news is an integral part of medicine—as much as physical examinations, diagnosis, and treatment—and is undoubtedly one of the most difficult aspects of the profession. Bad news itself causes the recipient pain, confusion, distress, and even anger against its bearer, and witnessing—this suffering can be anguishing for the physician and may force him or her to directly confront emotionally difficult areas, such as profound loss, despair, and death. As a physician, one’s own life experiences, background, and attitudes toward pain, loss, and suffering may have a great impact on how one breaks bad news.

Appearances can be deceiving. As varied as human beings are, so are their reactions to bad news. A doctor’s unease at delivery of bad news may be heightened by the fact that the patient’s response to the news may be unpredictable and may range from crying and visible anguish to stony silence or incomprehension. At times, an overwhelming reaction may come “out of the blue,” such as the tearful reaction and anxiety that results from an ophthalmologist after a routine exam, telling his diabetic patient she has new but very minor changes in her retina: for the ophthalmologist, the findings are insignificant; for the patient, the findings are the first sign of the devastating blindness that she fears. Reactions may vary based on one’s previous experience, one’s personality, one’s culture, language, and background. A visible display of pain may be accepted and even encouraged in some cultures but discouraged in others, and consequently the lack of apparent emotion upon hearing news does not necessarily imply the absence of turmoil within.

From the patient’s perspective, the manner in which bad news is delivered may have a profound effect on the way in which the illness is viewed from that point forward. Small gestures or words o
comfort—or their absence—may foster hope or despair; particularly insensitive or callous approaches may be as traumatic as the news itself and may be recalled with great clarity (as well as pain) years afterward. *How the news is delivered is often as critical as the actual content of the message.*

Some families and individuals may feel that this subject isn’t appropriate to them or the conditions with which they live. Should that be the case, consider other situations in which bad news (school, work, other people’s bad news, etc) has been broken and how it felt.

For this visit, we ask the students to consider:

- The setting in which they heard of the news: how and where was the news delivered? Who was present? How did people react?
- The emotions, “body language,” and gestures the physicians made when delivering news, as well as the doctor’s responses to their reactions to the news.
- How prepared they were to receive bad news and how prepared was the physician in delivering the news;
- How much information were they able to initially absorb and how did they acquire information over time;
- How the volunteer’s feelings regarding the news changed over time: how were they able to come to terms with this new knowledge? Did this process involve loss or grief? How was this addressed by the doctor(s)?
- What “lessons” may they impart to you that you can use in working with future patients about how bad news should be broken?

### M2 HOME VISIT #5

**“LESSONS LEARNED” AND WRAP-UP**

Visit Period: Late January – Early March

Volunteer Overview

Home Visit #5 is the final official visit that you will have with you medical students, so please use the visit as an opportunity to discuss:

- what “lessons” about doctoring you wish the medical students to have learned from your interactions
- explore issues that you have not discussed and which you feel are important for doctors to understand about the individuals they care for such as problems with insurance you have had; financial challenges and how they may affect your health and the medical care you receive; matters of faith and spirituality and the role this plays in helping patients and their families cope with illness; and ways in which doctors, nurses, and other health care professionals may keep patient and their families at the center of their approaches to medical care.

Among some specific topics to discuss are:

1. **Impact of Hearing Stories of Illness.** How has your students understanding of chronic illness and its treatment changed in hearing the stories that you and your families have told about your experiences with illness and its care? What specific insights have your students gained from the discussions that they would like to incorporate in their future work with patients?

2. **Impact of Telling Stories of Illness.** What did you and your family get out of these discussions? Have your views toward your medical condition or its care changed as a result? Have you
understanding and beliefs about medical training, medical students, and doctors changed? In what specific ways would you like to impact the training of future physicians?

3. “Lessons Learned.” What specific “lessons” would you hope that your students have taken away from your discussions and from their observations of you interacting with your own doctors that you would like to see incorporated in their practice of medicine? Given the pressures and time constraints involved in the practice of modern medicine, what suggestions do you have to your students to help keep the “human face of medicine” at the forefront of their approaches to patient care? What advice can you give your students in terms of balancing their work and family so that they can avoid the “burnout” that’s so common among physicians?

FREQUENTLY ASKED QUESTIONS

Home Visits:
Q: Whose responsibility is it to schedule the visits?
A: The responsibility is entirely on the students’ part. They should contact you to set up the visit; of course, please let them know if you will be gone during part of a visit period. This will help all of you to schedule a date in advance.

Q: How long in advance should I expect the students to give me when scheduling a home visit?
A: The students are expected to give you at least 2-3 weeks’ notice before the visit. It is generally a good idea to schedule the visit toward the beginning of the visit period in the event of unforeseen circumstances (snow storm, sick child, out of town trip or hospitalization, etc.). If the students are giving you an unreasonably short time to schedule a visit (for example, during the weekend before the end of the visit period), please let us know.

Q: Do the visits need to be conducted at my home?
A: The purpose of scheduling home visits is to allow the students to get to know who you are apart from your lives as patients. Therefore, it is important they see you on your own “turf” so that they may recognize the multiple dimensions and complexity of the lives of individuals and families with chronic medical conditions. Under special circumstances, some of the visits may be conducted outside of the home; however, if you plan to do this, please have the students contact the FCE Office in advance for guidance.

Q: May we conduct the visit over the phone?
A: We ask that you don’t. Much of the learning the students do in this program is based on the connections that they make and the rapport that they build as they interact with their FCE volunteers. These types of interactions are generally much more effective in person than over the phone.
Q: What if I wish to share a meal with my students?
A: You and your family are under absolutely no obligation to feed or entertain your students. Your time and willingness to share your stories are more than enough of a gift. If, however, you do wish to provide them with refreshments or to share a meal, that is completely your choice. We do ask, however, that there is no alcohol served during meals.

Q: What if I need to reschedule my home visit?
A: Please let the students know as soon as possible so that you and they can plan to meet later during the visit period. If the visit cannot be completed during the visit period, please ask the students to contact the FCE Office for guidance asap.

Q: May I ask my students for medical advice?
A: No. The students you will be working with are at the beginning of their medical careers, and know much less medicine than you and your families do. Therefore, they should not provide you with medical care or advice.

Q: May we arrange for additional meetings with my students outside of the usual home visits?
A: Any visits, outings, meetings or events in addition to the scheduled visits are up to you and your students. Please keep in mind that students do carry a full class load and may not be able to accept invitations beyond what is required.

Q: Is it appropriate for me to give the students feedback?
A: Absolutely. You are among the most important teachers the students will have during their first two years in medical school (or in their medical careers, for that matter), and one of the primary responsibilities of any teacher is to provide feedback to help the students do better. In giving feedback, please be as specific as possible and provide specific examples. If it affects only one of the students, consider taking him or her aside after the visit (or by a phone call, for example) and speaking with him/her individually. If you wish guidance on this, or if the problem is very serious (missed visits, lack of time scheduling a visit, grossly inappropriate or rude behavior, etc.), please let the Family Centered Experience Program Office know.

Q: What if I can’t think of anything to talk about for a given visit?
A: Please don’t hesitate to call us at the Family Centered Experience Program Office (734) 615-4886 to discuss the theme and get ideas. You may also wish to discuss something else during a particular visit that is not covered in the FCE visit themes or to revisit one subject in much more detail with your students. If this is the case, please discuss this with your students prior to the visit in order to give them time to think about the theme. Possible themes for discussion that are currently not covered in a specific visit include:

- **Finances and health care.** Currently 47 million people in the U.S. have no medical insurance coverage, and among those who are insured, most have to assume an increasing financial burden for the health care of their families.
  - Have you ever had to go without health insurance? Do you have difficulties with this? When seeking medical care, were you treated differently than when you were insured?
  - How much does your health insurance cost you and your family? What kind of deductible do you have to meet before the costs are covered? How is the insurance paid for? Employer contribution? Individual contribution? What factors led you to choose the insurance plan you currently have?
  - How much do your medicines cost? How much do you pay for them? What proportion does your insurance cover? (You can even consider “assigning” your medical students to find out the cost of the medications that you’re currently using before the visit in order to put you discussions into “dollars and cents (or sense—forgive the pun)."

- **Obstacles and Barriers to Health Care.** What kinds of obstacles or barriers have you and your family faced in attempting to get the health care you need? What have you done to try to overcome them?
• **Death and Dying.** Have you or your family had personal experiences with someone who is dying? What kinds of feelings did you have at the time? How did this impact the relationships in the family and among friends? What helped during this time? What didn’t help? Was hospice involved? Who helped the most? [Note: there will be a visit during the second year devoted to Breaking Bad News, so if you think that this will be repetitive, please consider another theme.]

• **Another Theme of Your Choosing.** You are the experts at living with chronic conditions, so if there is another important theme that we have overlooked, please feel free to discuss it with your students. Also, let us know as well—if it’s applicable to many conditions, we may consider using it as a theme for a specific visit.

**The Clinic Visit:**

**Q:** Do I have to arrange my clinic visit around the students’ schedules?

**A:** No. Schedule your clinic visits entirely according to your clinical needs—your clinical needs are most important and should take precedence over the students’ needs. What helps: Any pre-planned clinic visits can be shared with students as early as possible. See if you can find a date that works, but if not, please call the FCE Program Office.

**Q:** Should I tell my doctor ahead of time about my students’ accompanying me to my clinic visit?

**A:** That is completely up to you and your doctor. In our experience, doctors have a natural tendency to teach, so for some of them, they may step into “teaching mode” and talk to the students during the visit. The purpose of the visit, however, is to address your clinical concerns.

**Q:** What should I do if I’m uncomfortable with having the students present during a physical exam at a clinic visit or what if I wish to discuss something in private with my doctor?

**A:** Please do not hesitate to ask them to step out of the room for physical exams, etc. if you are not comfortable.

**Q:** Are the students expected to wait with me in the waiting room for my appointment?

**A:** Absolutely. Part of the value of the clinic visit is to give the students an idea of what patients must go through in seeking medical care. Yes, the students are busy, but so are you. As one FCE instructor put it, “Believe me, if a medical student is made to wait a couple of hours for a 15-minute conversation with a doctor, they will never forget about keeping people waiting for the rest of their careers.”

Please feel free to contact the Family Centered Experience Office a (734) 615-4886 or fce@umich.edu if you have additional questions or concerns.
APPENDIX

THE FAMILY CENTERED EXPERIENCE
EDUCATIONAL PHILOSOPHY

Contributed by A.K. Kumagai, M.D.

“Our ultimate salvation lies in that fragile
web of understanding that one human being
has for the suffering of another.”

--John Dos Passos

“Technological intervention may ameliorate or even cure the disease
but not the illness. To treat the illness, the healer must dare to meet
the patient in the messy, confusing, always special context of lived
experience.”

--Arthur Kleinman
The Illness Narratives, p. 206

INTRODUCTION:

Illness and Disease: The Nexus of the Clinical Interaction.

When dealing with a given medical condition, physicians and
patients regard the same entity—the problem for which the patient
seeks help—as two entirely different things. On the one hand, the
patient is confronted with an illness: a process that disrupts his or her
physical—and often, emotional and social—equilibrium, a voice that
at times whispers and at other times insists “there’s something
wrong.” The patient defines this process in subjective, experiential
terms: he or she describes how it makes him or her “feel not quite
like myself” and how it interferes with enjoyment of daily life,
relationships with friends, loved ones and coworkers, and plans for
the future. For the physician, on the other hand, the problem that the
patient describes paints an entirely different picture. It is a disease,
something that has its origins in disruption of a physical or metabolic
state and a condition that may be diagnosed and cured—or at least
ameliorated or controlled—by specific interventions. Although the
patient and physician are confronted by the same problem when they
meet in the clinic, they often speak in two different languages from
two entirely different perspectives about two different things
Furthermore, given the authority and power with which the physician
is vested in the clinical relationship, his or her inability to perceive
both images within the dichotomy of disease and illness often results
in a devaluation of the patient’s perspective and creates an
atmosphere from which mutual misunderstandings
miscommunication and mistrust arise.

The World of Medicine and the Universe of Illness.

The physician enters the clinical encounter with years of
training and an armamentarium of tests, drugs, and procedures, the
objective of all of which is to diagnose and correct some
abnormality. Although it is clear that there are many controversies
in the treatment of various diseases, e.g., whether a given procedure
is better in one situation or another, or whether drug X is more
effective in treating a certain condition than drug Y, an ostensible
belief in the strength of empirical reasoning and the scientific
method directs the physician’s approach. In contrast, the range of
attitudes, beliefs, and values that patients associate with their illness
is virtually limitless. The inherent subjectivity of one’s illness opens
up a universe of influences based on personal beliefs, life
experiences, and cultural, linguistic, and socioeconomic background.

In short, the exact same disease may manifest itself in illness as
different things to different people. The psychiatrist and Holocaust
survivor Viktor Frankel once identified one of man’s most basic
drives as a quest for meaning. Illness is no exception. When
confronted with a major, life-altering illness, individuals often ask
themselves, “why did this happen to me? What was its cause? What
will this mean to my life? My work? My family?” Out of these
questions arise a highly personal rationale that is profoundly
influenced by an individual worldview, and it is this worldview that
helps to place unexpected events within a comprehensible
framework. In the context of the clinical encounter, the patient
gradually acquires a new vocabulary filled with medical
terminology. Simultaneously, however, he or she learns a new and
different vocabulary—that of symptoms, of feelings, and of discomfort and pain—and although there are terms common to both new “languages,” they are by no means mutually intelligible. The first set of terms tends to be technical and assumes a certain homogeneity and predictable effect of the disease on “the body physic” on the one hand, while on the other, the second set of terms represents an individual expression of the inner world of illness and loss. [As first- and second-year medical students, you are in a unique position, for you have one foot in both worlds: while you are working towards learning the language of medicine, you are still close enough to the “lay world” to understand the language of illness. Among the greatest challenges in your training will be to acquire mastery of the one language without sacrificing “fluency” in the other.]

Acute versus Chronic Illness: A Shift from Immediate Intervention to “the Long Haul.”

The duration and prognosis of the medical problem also make a difference in the evolution of a subjective language of illness. With an acute condition, such as a heart attack or stroke or trauma from a car accident, the search for meaning recedes into the background during the crisis itself, and emphasis is placed on mobilizing resources to overcome the immediate challenge. In contrast, with major chronic illness, such as diabetes, multiple sclerosis, cancer, or AIDS, one often has time to ask “why?” and to sort out, among the various bits of information gleaned from conversations with medical personnel, the future trajectory of one’s life.

In the setting of chronic illness, the chronic condition may have an impact on a wide range of spheres within one’s life: one’s self, one’s family and support group, one’s financial, educational and social situation, and one’s relationship to the health care system (Figure 1). In turn, each of these spheres may influence one’s reaction to one’s illness and the course the illness takes in an individual’s life. While in many ways the actual diagnosis of a medical disorder may represent an end to the physician’s search for an answer to the question, “what’s wrong,” for the patient, the same diagnosis represents just the beginning of a search to “fit” this illness into a changed life.

Take for example, breast cancer. The significance of an incidentally discovered breast mass and the subsequent diagnosis of breast cancer may have a profound impact on a woman’s sense of self-identity, including her own sexuality and self-image, and her sense of security, meaning and comfort in the world. Her cancer may also affect her relationships with her spouse or partner, family and friends in that it may strengthen bonds on the one hand, or may serve to isolate and even stigmatize her on the other. How she comes to terms with this illness and what impact the illness has on her sense of self and her relationship with others are greatly influenced by personal experiences, family history, and cultural background. In addition, this individual must also learn to navigate through the health care system, to deal with financial constraints, as well as requirements, and frequently, obstacles, imposed by third parties (e.g., insurance companies) and to develop working relationships with health care professionals that she will encounter (primary care physicians, oncologists, surgeons, radiation oncologists, etc.) in an attempt to obtain effective therapy of her cancer. How successful she is in her adjustment—psychological, emotional, social, physical, and financial—depends on her ability to access and use resources on a variety of levels and the quality of the relationships that she establishes along the way. As is evident from the foregoing discussion, much of the way in which this patient—or any other—learns to live with the burden of a chronic medical condition generally falls outside of the medical treatment of the underlying disease. It is nonetheless critical that the physician understands and supports the patient’s struggles to live with his or her illness.

The Family Centered Experience: Stepping into the Patient’s Shoes.
In this course, you will be asked to visit a family that has or has had ongoing contact with the University of Michigan Medical Center. During these visits, you will be given an introduction to the subjective side of the medical disorders that you will study in other courses during the first two years of medical school: you will be allowed a glimpse at, in Kleinman’s words, that “messy, confusing, always special, context of lived experience” by experts—the patients themselves. It is the goal of this course to help you to incorporate these privileged introductions to the experience of illness into your emerging understanding of medicine, which is at its core, a humanistic activity.

Required Reading for Medical Students:

Suggested Reading:
Nonfiction:


Feudtner, a pediatrician, documents the history of the treatment of type 1 diabetes in the U.S. and describes how, with the advent of insulin, diabetes was transformed from a uniformly fatal illness into a life-long struggle to prevent long-term complications. The book describes in detail the struggles individuals with diabetes have faced during the history of the treatment of the disease.


Kleinman, a psychiatrist and medical anthropologist at Harvard, discusses the important role that illness narratives—the stories that patients tell of their illness and suffering—have in understanding the meaning of the experience of illness from the patient’s perspective.


Lorde, a prize-winning author, essayist, and intellectual, describes her fight with cancer, with an emphasis on the interplay between race, gender, and illness in this eloquent series of essays.


In a series of vignettes, Sacks, who is a professor of clinical neurology at Albert Einstein School of Medicine, eloquently describes the transformation of perceived reality among his patients with neurological disorders.

Sontag, Susan Illness as Metaphor; AIDS and Its Metaphors New York: Picador, 2001

Two essays on the stigmatization of illness, specifically cancer and AIDS, by the American writer Susan Sontag, who herself is a breast cancer survivor.


A very readable, extremely compelling collection of persona narratives, complemented by “facts & figures” that elucidate the personal impact of living (and dying) without health insurance.

Memoirs/Fiction
A memoir of a series of meetings between the author and Morrie Schwartz, his former college sociology professor, who was afflicted by amyotrophic lateral sclerosis (ALS), during the final year of Morrie’s life.


A classic of 20th century literature, the Plague describes the struggles of the inhabitants of a city ravaged by a modern epidemic of bubonic plague. While the descriptions are fairly accurate from a clinical point of view, the emotional, psychological and philosophical turmoil of the main character, the physician, Bernard Rieux, his colleagues and patients elevate this work from mere description to an important and lyrical discourse on illness, death, human dignity and courage.


A series of diary entries about living—and dying—with pain from a degenerative neurological disorder: neurosyphilis.


A memoir by one of the leaders of French Existentialism on the death of her mother from cancer.

Edson, Margaret  Wit  New York: Farrar, Straus, and Giroux, 1999

The Pulitzer Prize-winning play about Vivian Bearing, a professor of English, and her relentless struggle for meaning when diagnosed and treated for terminal ovarian cancer. (see also film adaptation by Nichols, below).


A memoir by the poet Lucy Grealy about her experiences growing up with a major visible stigma. Grealy was 9-years-old when she was diagnosed with Ewing’s sarcoma of the mandible, and the resultant surgeries, chemotherapy, and radiation therapy left her with severe facial deformities. I (see also Ann Patchett’s Truth and Beauty).


A lyrical account by one of Japan’s greatest modern writers of the struggles of his family in dealing with his mother’s advancing age and senility.


A highly personal, insightful account of her life with bipolar disorder by Jamison, a psychologist on the faculty of Yale Medical School. An extremely important book for anyone dealing with an individual with manic depression.


A thoughtful memoir in which Patchett discusses her friendship and the life of Lucy Grealy (Autobiography of a Face) and Grealy’s struggles with stigma and drug addiction.


Glimpses of lives affected by blindness by one of the giants of 20th century German literature. [Note: Going Blind is included in the volume, On Doctoring.]


Styron, the author of Sophie’s Choice and other novels, provides an extremely moving account of his gradual descent into severe, suicidal major depression.

Considered by many to be one of the greatest short stories of Western literature, The Death of Ivan Illych describes the struggles for meaning and identity of a comfortable, middle class businessman who is confronted with his own death.

Suggested Films

*The Doctor*, Randa Haines, Director, 1991

> In this movie, William Hurt plays the role of Dr. Jack McKee, a gifted but arrogant surgeon, who learns what it’s like on the other end of the stethoscope” when he is diagnosed with cancer.

*Ikiru (To Live)*, Akira Kurosawa, Director, 1952

> This eloquent little film, directed by Japan’s greatest 20th century director, deals with the reaction of a low-level bureaucrat upon learning that he has terminal cancer. The diagnosis prompts him to consider the meaning of his life and to launch a personal campaign to justify his life and death.

*Wings of Desire*, Wim Wenders, Director, 1987

> This off-beat German film follows two angels, Daniel (played by Bruno Ganz) and Cassiel (played by Otter Sander) who observe the world of humans from the omniscient, albeit, sterile, world of immortals. Daniel struggles with his desire to be human: to feel the breeze in his face, the bitterness of a cup of coffee, and the gentleness of a woman’s smile. Although the film does not directly deal with illness, it is a wonderful mediation on living and mortality. (Note: there is an American adaptation of this film, *Wit*, Mike Nichols, Director, 2001)

*Wit*, Mike Nichols, Director, 2001

> This is a film adaptation of Margaret Edson’s Pulitzer-Prize winning play of the same title and stars Emma Thompson. Thompson plays the role of Emma Bearing, a professor of English literature and specialist in the sonnets of John Donne, who struggles with the meaning of learning that she has advanced ovarian cancer.