

Slide 1: Making Decisions When You Disagree With the Doctor: The Social/Family Context

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Slide 2: Factors Affecting Patient Requests for Medical Services

- Patient's Personal Factors
 - Age
 - Sex
 - Education
 - Family
 - Information Sources
 - Socioeconomic Context
- Contextual Factors
 - Type of Visit
 - Physician's Specialty
 - System of Care
- Needs
 - Medical Conditions
 - Health-related Distress

Slide3: Social and Cultural Influences (1 of 2)

What is culture?

- A set of norms and beliefs (“guidelines”) that individuals learn as members of a particular society. These norms and beliefs shape how individuals perceive and experience the world and tell them how they should behave in relation to other people and forces (animal, religious, natural) in their environment.
- Culture is not race or ethnicity itself but the product of belonging to a group that can be derivative of having a racial identity but can also result from geographic proximity, being a member of an occupational group, or having a shared language.
 - Individuals can belong to more than one cultural group
 - Cultural identities can be acquired as the result of new activities or taking on new roles (e.g., breast cancer survivor).

Slide 4: Social and Cultural Influences (2 of 2)

- What are social influences?
 - Factors that affect an individual's relationships with others and with the environment
 - Socioeconomic status
 - Gender
 - Family structure/relationships
 - Neighborhood
 - Stressful life events
 - Job loss
 - Death in family
 - Discrimination

Slide 5: Emic and Etic Perspectives

- Emic
 - Cultural distinctions meaningful to members of a given group
 - "Tumors exposed to air will spread."
 - "Flu vaccination causes the flu (you can tell because the area gets red and people run fevers)."
 - "Blood in the stool is the result of eating too many tomatoes."
 - The most common concern of patients with diabetes is "loss of a limb."
- Etic
 - Objective analysis of social and material phenomena
 - "Tumors need to be removed to prevent the spread of cancer."
 - "Flu vaccination helps prevent or attenuate the flu."
 - "Blood in the stool is an indication of several serious diseases."
 - The most common concern of physicians treating diabetes is "renal failure."

Slide 6: Family Involvement in Health Care Decisions

- Surrogates
 - Pediatrics
 - End of life
- Families as auxiliary decision makers
 - Acute diseases
 - Chronic diseases
 - Life-threatening illness

Slide 7: Family and Sociocultural Influences of Care Seeking

- Two examples:
 - Seeking a diagnosis
 - Making treatment decisions

Slide 8: Diagnosis

- Physician's approach
 - Application of accrued medical knowledge to a specific set of facts, namely the patient's reported signs and symptoms and accrued objective tests
 - Medical history
 - Physical exam
 - Laboratory tests
- Patient's approach
 - Application of assessment of their personal normal to the bodily sensations and observations that signal there is a problem
 - Work or social life disrupted
 - Others notice a problem
 - Worry or distress becomes predominant
 - Period of self-treatment
 - Self or others take action to obtain medical assessment

Slide 9: Seeking a Diagnosis: Colorectal Cancer (1 of 4)

- Sample: 242 patients diagnosed with stage I, II, III, or IV colon cancer within the past 6 months
- Exclusion: Diagnosed on routine screening
- Sites: Five clinical sites in two states, Virginia and Ohio
- Conducted interviews with patients and performed chart reviews
 - Semi-structured, qualitative, cognitive interview
 - Chart review
 - Verification of physician encounters and recommendations

Slide 10: Seeking a Diagnosis: Colorectal Cancer (2 of 4)

- Interview data
 - Symptom recognition and appraisal
 - Influence of family and friends
 - Social support
 - Ease of access to care
 - Communication with health care provider
 - Sociodemographic and psychological factors

- Qualitative data themed and coded by trained coders

Slide 11: Seeking a Diagnosis: Colorectal Cancer (3 of 4)

Patient Characteristics

- Male 52.1%
- African American 43%
- Age 58.1 years (SD = 12.2)
- Martial status 53.3% married
- Household size 2.4 people
- Education 20.2% <high school
60.1% high school + some college

Slide 12: Seeking a Diagnosis: Colorectal Cancer (4 of 4)

Patient Characteristics (Continued)

- Income 40.1% <\$30,00
- Health insurance 26% uninsured or Medicaid
- Chronic disease 51.7%
- Prior colonoscopy 18.3%
- Stage 36.4% (stage III)
- Appraisal delay 4.6 months
- Diagnostic delay 4.8 months

Slide 13: Role of the Family in Symptom Appraisal and Health Seeking

- Many (92.1%) patients told someone about their symptoms.
 - Over half (52%) confided in someone within 28 days of recognizing their symptoms.
 - Over half (51.4%) consulted with two or more people.
 - Spouse: 51.6%
 - Neighbors/friends: 22.2%
 - Children: 21.8%
 - Coworkers: 14.3%

Slide 14: Influence of Family on Health-Seeking Behaviors

Role	Percentage
Confidant confirmed symptom appraisal	56.0%
Confidants advocated getting more information/tests	42.5%
After confiding in others thought something worse was wrong	48.4%
After confiding in others, took action	66.7%
Patient influenced by personal health experiences of others	26.9%

Slide 15: Seeking Colorectal Cancer Information Through the Internet

- Internet use: 25.2%
- Age: 53 years versus 60 years (odds ratio [OR] = 0.97)
- Insurance status (OR = 2.72)
 - Private insurance: 37.6%
 - Medicaid/Medicare: 8.8%
- Patients with elimination symptoms and embarrassment are more likely to use the Internet (OR = 1.36).

Slide 16: Forms of Family Advice for Colorectal Cancer Symptoms (1 of 3)

- Casual
- Urgent
- Advice based on family members' experiences

Slide 17: Forms of Family Advice for Colorectal Cancer Symptoms (2 of 3)

- Casual advice
 - Interviewer: Did your husband advocate seeking more information or further testing?
Patient: "Well, he just figured I should go to the doctor more often."
- Urgent advice
 - Patient: "They all thought maybe it could've been a change of life, and I told them about my ulcers and they thought maybe that could be it... [W]hen the symptoms were getting worse and I wasn't feeling any better they said, 'You need to go to the doctor's, and you need to go as soon as possible.'"

Slide 18: Forms of Family Advice for Colorectal Cancer Symptoms (3 of 3)

- Advice based on family members' experiences
 - Advice from an aunt
Patient: "I told her, 'I know something's going on.' I said, 'I'm glad you stopped by because you and I have the same symptoms going on.' I said, 'Let me know what [the] doctor that you went to says.'"

Slide 19: Explanatory Models for Colorectal Cancer Symptoms

- Acute illness
- Chronic illness
- Female problems
- Lifestyle and diet
- Problems that "run in the family"

Slide 20: Explanatory Models (1 of 2)

- Acute illness
 - Patient: "So I'm thinking, 'It's probably a bug. It's probably going to work itself out on its own, and if it doesn't, I'm going to go to the doctor....'"
- Chronic illness
 - Patient: "[S]everal of my neighbors, when I mentioned it, said that...someone in their family had IBS [irritable bowel syndrome]. I thought that's what it was."
- "Female" problems
 - Patient: "They just knew I wasn't feeling good, and I told them I was having cramps. You know, sometimes those cramps just felt almost like labor pains. That's why I thought it could be that cyst [that] was on my ovary."

Slide 21: Explanatory Models (2 of 2)

- Lifestyle and diet
 - Interviewer: So [your boyfriend] said, "Maybe it's because you hadn't been [eating] enough greens?"
Patient: "Yeah, he'd [say], 'You hadn't been eating a whole lot of greens. Because usually [I] do, [and] he just noticed that I hadn't.'"
- Problems that run in the family
 - Patient: "Well, my aunt was hypoglycemic, and she has mentioned that she thought I might be a little bit, too. Like, it's in the family."

Slide 22: Choosing Treatment and Care: Advanced Lung Cancer

- Patients with advanced stage (stages III and IV) non-small-cell lung cancer
- Matched case series of patients and their primary family caregivers
- 190 patient-caregiver pairs

Slide 23: Characteristics of Patients With Lung Cancer and Their Primary Caregivers

	Patient	Caregiver
Variable	N (%)	N (%)
Age (mean ± SD)	65 ± 10	55 ± 14
Gender		
Male	102 (54)	47 (25)
Race		
Caucasian	164 (86)	160 (85)
African American	26 (14)	28 (15)
Relation to patient		
Spouse	---	108 (54)
Adult child	---	50 (26)
Other	---	32 (17)

Slide 24: Demographic Characteristics of Patients With Lung Cancer and Their Primary Caregivers (n = 190 pairs)

Variable	Patient N (%)	Caregiver N (%)
Education		
< High School	29 (15)	15 (8)
High School	70 (37)	64 (35)
> High School	90 (48)	106 (57)
Income		
<\$25,000	69 (41)	40 (24)
\$25-50,000	49 (29)	59 (35)
>\$50,000	50 (30)	70 (41)
Marital Status		
Married	127 (67)	158 (84)
Single/Widowed	38 (20)	

Slide 25: Role of the Family in Lung Cancer Care Decisions (1 of 5)

- Areas of disagreement
 - Smoking
 - Lifestyle
 - Alternative treatments
 - Treatment decisions
 - Surgery
 - Radiation
 - Chemotherapy
 - Pain Medication
 - Treating physician
 - Need for a second opinion
 - Family dislikes/distrusts or questions physician credibility
- Role of faith in decision making
- The patient withholds information from the physician or family members

Slide 26: Role of the Family in Lung Cancer Care Decisions (2 of 5)

- Most common conflict issues
 - Lifestyle 34.4%
 - Treatment 26.2%
 - Withholding information 17.5%

- Patient relationship with physicians
 - Frequency of leaving a physician's care 16.9%
 - Reasons for leaving care
 - Communication style of physician 7.7%
 - Limited treatment options 7.7%
 - Physician negativity 8.7%
 - Physician gave patient the diagnosis 81.8%

Slide 27: Role of the Family in Lung Cancer Care Decisions (3 of 5)

- Areas of disagreement
 - Smoking
 - A wife regarding her husband:
“Well [my husband] says, ‘[I]t doesn't do any good [to quit smoking]. My brother-in-law died of lung cancer; he quit two years before he died.’ [He then] said, ‘I think if you quit smoking, you're going to get cancer for sure.’ So [my husband] would never quit.”