Illness, Disease & Health

PHRM 831

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Objectives

• Be familiar with
  – Passive nature of US HC system
  – Lay and professional referral systems
  – Pharmacist’s role across referral systems
  – Health, Illness, and Disease
  – The role of norms in defining each
  – Idea of social roles
  – Illness behavior
  – Sick Role Behavior
  – Rights and Obligations of the patient in the sick role
  – Right and obligations of the provider in the sick role
Health????? Care?

- Remember, in our quest for understanding WHY the US government is so much a part of HC in the United States and WHY the HC “system” is so dysfunctional, we had attempted to define “Health”?

- Health is not something like the Higg’s Boson, theoretically inferred, mathematically described, and eventually (after 50+ years) empirically “discovered”.

- Please show me a “healthomemeter”

- I do research in the development of quality of life instruments—maybe as close as we come to a measurement of health, and no one agrees what these things mean and what changes in score are worth.
Jazz

- “What is Jazz? Dude, if you have to ask, you'll never know.” - Louis Armstrong
Health

- Health, like Jazz, is something that is very much defined socially and culturally.
- Each society, each culture has an internal conceptualization of what constitutes health.
- Consider that in 1901, the US male life expectancy was, what, 50 or so? Move the clock back 100 years, and I’d be Superman!
- Or move me to the south of Sudan today.
- We like to think the world revolves around the US—But, again, other countries, other ways.
Health Care Across The World

• We will spend considerable time contrasting and comparing how different countries approach the problem of how to organize, pay for, and provide health care.

• But as Health is very much defined socially and culturally, so the answers found differ as well. We will discuss the U.S. perspective, but cultural sensitivity requires understanding that our patients may come from a different tradition, whether they were born here or not. The root of cultural competence
U.S. system is passive

- The “system” is passive, from the provider's point of view
- Patient initiates contact with the provider
- if not, may be considered quackery
- MD who goes door to door would be looked at suspiciously, to say the least.
The Lay referral system

- lay person = not a health care professional
- Ask for opinion and advice of others, or listen to their suggestions
- Sunburn- seek out advice
- if suggestions don’t lead to improvement, may then seek professional help
- Usually seek advice from those perceived to be knowledgeable - new mothers ask their mothers
- Also use system to verify personal judgment- knee injury leads to talking with friends with prior knee injuries
- A series of steps that either lead to satisfaction or gradually escalate to the use of professional services
Professional referral system

• Professionals use this system
• Advice from other professionals- MD asks R.Ph., G.P. asks specialist, etc.
• Not as clear cut a process as the public thinks
• up to 50% of all MD office visits have no firm diagnosis and autopsies show diagnostic errors in 20%+ range
Pharmacist role

• consumer often thinks of R.Ph. as part of lay referral system, or perhaps a bridge between the two.
• Depends on the quality and nature of the therapeutic relationship you have developed
• a “sounding board”
• “if doc says it is serious, I’m going to the Doctor”
• Easy accessibility
• Crucial role for R.Ph. as link between the two systems
• What I call “Community Triage”
• If only we could get paid for it……..
Bridging The Gap

NEED?

Patient Behaviors (Lay Referral System)

Professional Behaviors (Professional Referral System)

RPh Linkage Role

USE OF SERVICES

OUTCOMES

MEDICAL CARE PROCESS

Bridging The Gap
Health, Illness and Disease
Health

• as an open-ended concept: "Health is a state of complete physical mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization)

• as an elastic concept: "Health is the perfect continuing adjustment by an individual to his environment. “(H. Spencer)

• As we’ve already said- difficult, if not impossible to fully define
The Dark Side of “Health”

- I’m thinking of the commercials right now with the guy sitting with the little kids in the classroom.
- Is it better to be sick, or healthy?
- So what happens when someone decides YOU’RE sick?
- Health is as much a social and political concept as a medical or scientific one
- Some argue society uses “health” and “disease” as a mechanism for social control
- Consider: your doctor can have you confined against your will. (and, in some cases, probably should….)-before you’ve committed ANY crime. What was that movie?
- As much a range of possibilities as any kind of absolute
Disease

• a process which creates a state of dysfunction or departure from normality in the individual.
• Disease is defined by medicine- MD determines just what constitutes a departure from normality
• Diagnosis as problem solving- MD asks questions, gathers physical evidence, and narrows down possible explanations
• You will develop a similar skill set with respect to drug related matters
Disease Designation

• If the MD determines a departure from normality exists, will diagnose a disease - the ‘Stamp of Approval’
• Medicine will occasionally invent NEW diseases (Tennis elbow, Repetitive Movement Syndrome, relational disorder, etc)
• YOU can’t self-diagnose (insurance won’t pay)
• Although there’s always a few gullible types out there…
• We’ve got data that says a third of the population has self-diagnosed a major disease
• Medicine, through the individual MD, defines the objective standards of normality that constitute DISEASE
Illness

- a subjective phenomenon in which individuals perceive themselves as not feeling well and thus they tend to modify their normal behavior. Defined by the individual and influenced by culture/society.
- Both disease and illness are defined by standards of normality
- disease by standards of MD
- illness by the standards of the individual
Illness – as clear as Health

• You may have a disease and not define yourself as ill
• Choose to ignore or exist in denial - obesity, skin rash, arthritis, cancer, addiction or other mental illnesses
• May not or don’t recognize - HBP, Cancer, HIV
• You may be decide you are ill, yet not have a disease
• vague complaints, feeling of malaise
The “worried well”

- a part of practice
- 20-30% of population
- Need someone to talk to, find reassurance
- a way to get attention
- Problem for health care students of all stripes
- read articles on disease states, start seeing symptoms in yourself
Social/cultural vs. medical perspective in defining disease and illness

• Standards vary within and across cultures
• Some cultures simply do not recognize mental illness - no words in the language
• some conditions are so common they are not seen as being a departure from normality
• TB, Malaria, certain genetic conditions
• South American Tribe (Peru) has dyschromatic spirochetosis (colored spots -yellow,brown,black,red)
• those without it cannot marry or inherit property - considered abnormal
Others Examples of….Normal

• Moon Children - San Blas Island, off Columbia
• intense intermarrying leads to albinism (no pigment)
• sun blisters skin, so they only come out at night.
• those with pigment considered lower class, forced to work during day, interact with outside world
• The Twilight Saga- with a vengeance
• The “Blue Fugates” of Tennessee.
• And in some regions, everyone likes Justin Berber……. 
Standards of normality often relative

- Society shapes the health care process- it also shapes the individual’s behavior as well
- Within a society, the standards may vary according to your place in that society or culture
- Occupation, economic status, education, religion, and those you come in contact with influence your decision to declare illness
- Some know more, some can’t afford to be sick, some will have every problem they can come up with
Cultural/ethnic factors determine response to illness

• Studies have found strong differences in willingness to acknowledge disease/illness.
• People of Irish or a Jewish/Hebrew background are far more likely to complain about problems they are having.
• WASPS tend to be very stoic (“John Wayne Syndrome”)
• Doesn’t mean one is “tougher” than the other, just a cultural/ethnic difference in whether it is OK to acknowledge limitations or express discomfort.
• You need to understand your patient’s background when exploring their health state.
Illness Behavior and the Sick Role
Illness Behavior

- Any activity undertaken by a person who feels ill, to define the state of his health and to discover a suitable remedy.
- Point - person only has to feel ill, not to have a disease.
- Seeks to define, that is, reduce uncertainty
- A continuum of possible events, driven in part by HBM
- May use lay referral system
- May purchase OTC remedy
- May see R.Ph., MD
- Because of accessibility, R.Ph. plays a large role
Contact with the health care system ("funnel of selection")

- start with 1000 people feeling “ill”
- Only a small number of the original 1000 visit a professional-
  - “Well Visits”
- Refills
- Out of the 750 with symptoms, many will self-treat or seek lay advice
- Actually seeing a physician is the point were there is an actual “approval” of a disease
- gradual reduction in numbers as intensity of care increases
- Lots of R.Ph. opportunities between the steps
Funnel of selection – the mirror of the physical structure of the HC system

1000 people in Community have illness symptoms, 750 see a physician, 250 go to see a hospital specialist, 9 go to a teaching hospital, 5 see a specialist, 1 goes to a hospital.
Sick-Role Behavior

• The activity undertaken by those who consider themselves to be ill, for the purposes of getting well.

• remember disease seen as deviation from norms

• when an individual has an illness, it effects society because adjustment must be made for the individual.

• So, the sick (illness) person has to do certain things for it to be “OK” to be sick (disease)
Involves the ideas of ROLES

• Roles
• we all play several roles- student, son/daughter, worker, significant other, wife or husband, father-mothers. Moms seem exempt- they can’t stop.
• role consists of a set of behaviors expected of you
• student role- show up, study, take tests.
• In return, expect to learn, have a fair shot, access to library, professor, activities
• failure to conform results in punishment- for the student- failure, loss of student status
Sickness impairs our ability to fulfill our regular roles

- what if failure to conform is caused by sickness?
- Role Failure
- Can’t rescind role status due to sickness, need a “temporary” role for the sick person to enter
- allows them a special status (sick) to relieve them from other role responsibilities
- Can expect some relaxing of societal expectations as long as they conform with:
The Sick Role (Talcott Parsons)

• developed by Talcott Parsons to explain people’s behavior when ill
Rights and Obligations

- Rights of sick role
1. Freedom from blame for condition

- not person’s fault they are sick
- not blamed for not fulfilling other role obligations
- not punished (won’t be kicked out of school)
2. Exemption from normal duties and tasks

- temporarily excluded from home, work and school responsibilities
- don’t have to go, don’t have to perform
- will be given chance to make it up
3. Claim on others for assistance and care

- derived form the idea of health care as a right
- can go to someone for help
- can pull others from their roles
C. Obligations (conditions) of sick role
1. Try to get well

- patient must recognize condition is undesirable
- patient must want to get well, get back to normal
- Can’t enjoy being sick (stay home watch Springer, Play MineCraft, Call of Duty, etc)
2. Seek help and cooperate with advice

- patient must seek out competent help and follow/cooperate with advice
- not enough to say you are sick, must go to MD or other HC pro and get an “official” designation
- work at getting better
- whole idea is to get out of the sick role and back to normal
• If you just accept the rights and don’t meet the obligations, society comes down hard and illness not viewed as legitimate

• you can get help from others when health is an issue, but if the problem continues and you don’t do something about it then help will become hard to find

• It is my opinion (backed by nothing) that the RPh plays a role in validating sick role in chronic condition-getting RX filled a ritual of ongoing sick role
The Future of Sick-role Behavior

• The long-term treatment of chronic diseases places greater stress and cost on the health care system.

• A time will come (has?) when failure to be a “compliant” patient, or to “adhere” to therapeutic orders for diet or exercise will result in some sort of penalty or social disapproval.

• Most likely higher co-pays or “high-risk” insurance.

• We are seeing a shift from “health care as a right” to “individual responsibility”.
Professional -- Patient Relationships

• A Quick Point

• If you will recall, I’ve explained that the professional’s role is subject to change in the new, corporate model of health care

• This area- the relationship between the professional and the patient, as already noted, is changing.

• I’m not sure how much longer what I am about to tell you will hold true.
I. The Physician (Professional) and the Sick Role

• MD is primary model, but applies to other HC professionals as well

• Just as the patient has rights and responsibilities, so does the caregiver
A. Rights
1. Physical and personal intimacy

- access to confidential information
- right to touch and probe the body
- can ask questions no one else can
- R.Ph. has this for drug related issues, history
- questions that aren’t obviously related to drug therapy may meet with resistance, need to clarify beforehand
2. Initiation and direction of treatment

• what to do and when

• the patient is certainly an individual and has a right to input, but MD orchestrates
3. Autonomy in conduct of role

- no outside interference
- this is one of the primary concerns with Managed Care, evidenced-based medicine, other forms of population-based health care decision making
B. Obligations (conditions)
1. Self-regulation (through ethics)

- Keep in line (individual practitioner as well as the profession as a whole)
- Do NOT, in any way, take advantage of the special relationship
2. Demonstrate constellation of attitudes

- attitudes in a general way
- approach to the job
- approach to the patient
- Ideals- not always followed completely
- Constitute the essence of professionalism in many people’s minds
a. collective orientation

• not just “how will this affect me?”
• Subjugate desires to the good of the patient
• professionals have profound levels of patient trust, would be easy to abuse
• may consider your own interests, but not at expense of the patient (health expense, money expense, emotional expense)
• The patient’s well-being comes first
b. universalism (vs. particularism)

• universalism - skills applied equally to everyone, no matter their money, race, sex, age or condition

• particularism - respond to particular people or groups of people differently

• professionals are people - we like to work with people who are like us - but -

• must work to overcome bias

• Universalism is the ideal
c. functional specificity

- don’t go beyond what you can do
- stay with the specific functions for which you have been trained
- don’t go beyond your abilities on your own, because the patient will have no way of knowing if you are “winging it”
- astronomers and UFO’s
- must recognize when help is needed- by YOU
- Don’t let your ego kill your patient
d. affective neutrality

- keep emotions out of care
- maintain objectivity
- doesn’t rule out being concerned, but maintain “clinical distance’, to keep from clouding decisions
- hardest to attain- failure to do so leads to “burnout”
- the lawyer who defends himself has a fool for a client
- Don’t treat self or family
The Future

• In many ways, your greatest challenge as pharmacists will be finding a workable definition of what it means to be a professional for Pharmacy.

• New roles and responsibilities shall be challenging.

• But failure to evolve these roles— to accept the default “insurance clerk” function—

• That is to accept the none too distant dissolution of the profession
QUESTIONS?