1) Introduction to Chronic Illness
   a) John Gazewood, MD, MSPH
   b) Practice of Medicine
I. Chronic Illness – definitions and demographics

2) What is Chronic Illness?
   a) An illness that lasts more than three months, is persistent or recurring, and has meaningful impact on a person’s health status
   b) Chronic illnesses are often not curable. People may live with these illnesses for years. Symptoms may be constant (someone with chronic lung disease), or intermittent (someone with exercise induced asthma). The disease process may be progressive, with increasing severity, (congestive heart failure), or stable over long periods of time (chronic sinusitis). Chronic illnesses can range from mild severity (mild hayfever) to fatal (DM, CHF). Many can be asymptomatic for long periods of time (hypertension, diabetes mellitus, hyperlipidemia)

    Rank and prevalence (%) of chronic conditions in US

<table>
<thead>
<tr>
<th>Rank</th>
<th>Condition</th>
<th>% of pop.</th>
<th>Rank</th>
<th>Condition</th>
<th>% of pop</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Men 18-44</strong></td>
<td>Women 18-44</td>
<td></td>
<td><strong>Men 18-44</strong></td>
<td>Women 18-44</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Chronic sinusitis</td>
<td>14</td>
<td>1</td>
<td>Chronic sinusitis</td>
<td>18</td>
</tr>
<tr>
<td>2</td>
<td>Hay fever</td>
<td>10</td>
<td>2</td>
<td>Hay fever</td>
<td>12</td>
</tr>
<tr>
<td>3</td>
<td>Hypertension</td>
<td>7</td>
<td>3</td>
<td>Asthma and others</td>
<td>9</td>
</tr>
<tr>
<td>4</td>
<td>Hearing problems</td>
<td>6</td>
<td>4</td>
<td>Back problems</td>
<td>8</td>
</tr>
<tr>
<td>5</td>
<td>Back problem</td>
<td>6</td>
<td>5</td>
<td>Migraine headache</td>
<td>7</td>
</tr>
<tr>
<td><strong>Men 45-64</strong></td>
<td>Women 45-64</td>
<td></td>
<td><strong>Men 45-64</strong></td>
<td>Women 45-64</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Hypertension</td>
<td>25</td>
<td>1</td>
<td>Arthritis</td>
<td>34</td>
</tr>
<tr>
<td>2</td>
<td>Arthritis</td>
<td>21</td>
<td>2</td>
<td>Hypertension</td>
<td>27</td>
</tr>
<tr>
<td>3</td>
<td>Hearing problems</td>
<td>20</td>
<td>3</td>
<td>Chronic sinusitis</td>
<td>20</td>
</tr>
<tr>
<td>4</td>
<td>Chronic sinusitis</td>
<td>16</td>
<td>4</td>
<td>COPD (lung disease)</td>
<td>11</td>
</tr>
<tr>
<td>5</td>
<td>COPD (lung disease)</td>
<td>9</td>
<td>5</td>
<td>Hearing impairment</td>
<td>11</td>
</tr>
<tr>
<td>6</td>
<td>Coronary Art. Dz</td>
<td>8</td>
<td>6</td>
<td>Hay fever</td>
<td>10</td>
</tr>
<tr>
<td><strong>Men &gt;64</strong></td>
<td>Women &gt;64</td>
<td></td>
<td><strong>Men &gt;64</strong></td>
<td>Women &gt;64</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Arthritis</td>
<td>38</td>
<td>1</td>
<td>Arthritis</td>
<td>54</td>
</tr>
<tr>
<td>2</td>
<td>Hearing impairment</td>
<td>36</td>
<td>2</td>
<td>Hypertension</td>
<td>46</td>
</tr>
<tr>
<td>3</td>
<td>Hypertension</td>
<td>33</td>
<td>3</td>
<td>Hearing impairment</td>
<td>27</td>
</tr>
<tr>
<td>4</td>
<td>Coronary Art. Dz</td>
<td>18</td>
<td>4</td>
<td>Cataracts</td>
<td>19</td>
</tr>
<tr>
<td>5</td>
<td>COPD</td>
<td>17</td>
<td>5</td>
<td>Chronic sinusitis</td>
<td>17</td>
</tr>
<tr>
<td>9</td>
<td>Diabetes</td>
<td>9</td>
<td>10</td>
<td>Diabetes</td>
<td>10</td>
</tr>
</tbody>
</table>

c) Take home message: note that the percentage of persons with chronic illnesses increases with age, and that the type of common chronic illnesses changes with age and gender.

d) Older people, minorities, and persons of lower socioeconomic status are more likely to suffer from chronic diseases
3) Chronic illness is the major challenge facing our health care system
   a) This is due in part to the success of our health care system. Diseases that many
   people used to die from, such as infections, are now curable, allowing people to
   live to an older age. We are now able to treat other diseases, such as coronary
   artery disease, much more effectively. People now survive large heart attacks, and
   live for years with congestive heart failure. Life expectancy has increased
dramatically, and the population over age 65 is growing rapidly. The fastest
growing segment of our population is over age 85.
b) These successes though, mean many people in our country now have a chronic
   illness.
   i) About 100 million Americans (45% of population) have a chronic illness
   ii) 1 in 6 Americans (41 million) suffers some form of impairment from a
       chronic illness
   iii) 10 million Americans require help with basic activities of daily living.
   iv) 44% of patients with chronic illness have more than one chronic illness

c) Patients with chronic illnesses use a disproportionate share of medical services
   i) 80% of hospital days
   ii) 69% of hospital admissions
   iii) 83% of prescription drug use
   iv) 66% of physician visits
d) Chronic health care is expensive
   i) 1996, 75% ($659 billion) of US health care expenditures were for patients
      with chronic illness.
   ii) By 2050, we will spend $906 billion caring for 167 million Americans with
      chronic illness

e) Contrary to popular perceptions, many people with chronic illness are not old.
   i) 6.5% of children are disabled, resulting in 66 million restricted activity days,
      and 24 million days lost from school
   ii) 31% of patients with chronic illness are between ages 18 and 44

4) Take home message:
   a) Chronic illness is common (45% of population!)
   b) Most of our health care resources (and most of physician’s time) is directed
      towards caring for patients with chronic illness
   c) Chronic illness is very expensive
   d) Chronic illness affects people of all ages

5) Chronic conditions can lead to disability, through a sequence that has been
    characterized through a series of steps defined by levels of decreasing function. A
    chronic illness can lead to an impairment, that in turn leads to an activity limitation,
    that can then lead to a disability. This progression is really more of a continuous
    nature, but the steps provide a useful framework to think about these individuals.
    a) Impairment
       i) A physiological, psychological, or anatomical abnormality of bodily structure
          or function. For example, a child with asthma has impaired lung function

b) Limitation
   i) A restriction or lack of ability to perform an action or activity in a normal manner. For example, a child with asthma has trouble keeping up in gym class because his asthma is not adequately treated.

c) Disability
   i) A limitation or inability to perform socially defined activities and roles. For example, a child with severe, poorly treated asthma misses school frequently.

d) Some diseases are much more likely to result in disability than are others. For example, back problems are the most common cause of disability among young adults, even though they are only the 4th (women) or 5th (men) ranked chronic illness in this group. The most common diseases that cause disability include Arthritis, Heart Disease (includes heart failure and coronary artery disease), COPD, visual impairment, hypertension, diabetes and back problems.

II. Preventing Disability

1) Preventing Disability
   Disability can be prevented. Disability rates are actually falling. For example, there were 7.1 million disabled older adults in 1994, when earlier projections had suggested there would be 8.3 million. This is probably the result of better treatment for chronic conditions. The model of chronic disease care discussed here can be applied to most chronic conditions, although it requires a good understanding of the pathophysiology and optimal treatment for different diseases. There are different types of interventions that can be applied at various stages of disease progression:

   a) Primary prevention – modifying risk factors before disease occurs. Examples include smoking cessation, diet, exercise, treatment of hypertension or hyperlipidemia to prevent a first heart attack, and immunizations.
   b) Secondary prevention – identifying disease before it becomes symptomatic and treating. Examples include Pap smears to help prevent cervical cancer, treating high cholesterol in a patient with known heart disease to prevent further heart damage.
   c) Tertiary prevention – includes treatment of active disease, including helping people cope with impairments caused by the disease. For example, treating a patient with a stroke with a “clot-buster” to limit the damage caused by the stroke, performing surgery to remove a blockage to prevent an additional stroke, and rehabilitation of the stroke patient to return home to independent function.

2) Chronic Care Goals differ somewhat from acute care. Most individuals who have acute illnesses will recover fully. They are willing to tolerate intensive and sometimes uncomfortable treatment to achieve a cure, and are often able to dramatically change their lifestyle for a short period of time to achieve this goal. Patients with chronic illness, especially if it is asymptomatic or minimally symptomatic, may value their immediate quality of life more than other goals. They may define a high quality of
life differently than would their physician. They may value some of the goals listed below and not others, and their decisions about health care will reflect this.

a) Prevent premature morbidity, mortality
b) Maintain function
c) Maximize quality of life

3) Chronic Care System

a) A team approach is needed, to a much greater degree than in caring for most acute illnesses. Our health system is largely set up to deal with acute illnesses. A patient comes to the office or hospital, the doctor evaluates the patient, and orders therapy that is then delivered by nurses or obtained by the patient. There is no need for ongoing care.
b) Patients with chronic illnesses require ongoing care, and their care may require the involvement of many health care workers for optimal outcomes. Patients will have a need for education about their disease, for strategies to help them change their behavior, for motivation to help them change their behavior, for medications, for social, psychological and emotional support, for regular surveillance, for financing of their health care, for equipment to help them manage their disease, and for ongoing surveillance and care. The most impaired patients may require home health care or even nursing home placement.

i) primary care and sub-specialist physicians, nurses, pharmacists, social worker, health educators, therapists, personal care aides
ii) Hospital, outpatient clinic, home health care, long term care, community service agencies (board of aging, social services)
iii) Integration and coordination necessary
   (1) physician, nurse, social worker

III. The Physician-Patient Relationship in Chronic Illness

A therapeutic relationship that is patient centered is fundamental to optimal chronic illness care. The best relationships are characterized by continuity over time, empathy, and interactions that empower the patient to play an active role in medical decision-making and in their care. Such relationships are associated with better outcomes, such as improved quality of life, less disability, and fewer patient days in the hospital.

1) Physician’s Agenda
   a) Assess effectiveness of therapy
   b) Check for progression of disease
   c) Assess for adverse effects of therapy
   d) Assess for impact of disease/therapy on patient’s life; coping mechanisms
   e) Assess if patient adhering to therapy
   f) Respond to patient concerns

   Framing questions from a functional reference point can be very helpful

2) Patient’s Agenda
   a) Live as “normal” a life as possible
   b) Avoid sickness and death
   c) Quality of life
d) Minimize impact of illness on lifestyle, family, finances

4) The Interview Should be Patient-Centered
Move from open-ended to close ended questions
The patient should be involved in agenda setting
Some sample questions:
“How are you doing?”
“What can I do for you today?”
“What concerns or issues do you need to discuss today?”
“I really want to talk with you about your (diabetes, hypertension, etc), but first I want to find out if you have anything we need to talk about.”

5) Negotiating and Maintaining a Treatment Plan
a) Check baseline information – what is the patient’s knowledge and belief about their illness and treatment?
b) Describe treatment goals and plans – discuss options with the patient
c) Check understanding – does the patient understand pros and cons of various options?
d) Elicit patient preferences and commitments – what would the patient prefer to do? What is the patient willing to do?
e) Negotiate a plan – empower patient to be partner in developing plan. Discuss potential problems, and problem solve them.
f) Affirmation of intent – have patient describe what they are going to do to manage their illness

6) What if Treatment not Effective?
a) Assess for “compliance”
b) Compliance - the extent to which a person’s behavior coincides with medical care or advice. This is a construct that may have little meaning for patients.
c) Non-compliance - the patient’s failure to comply with regimen specified by the physician.
i) The “Bad Patient,” or the physician’s cop-out? “Non-compliance” is a powerful label that we apply to patients who don’t/won’t/can’t follow our advice. It may keep us from appropriately addressing the barriers to adherence the patient faces.

7) Strategies to Promote Adherence
a) Check adherence - give permission to be non-adherent.
For example, instead of asking “Do you take all of your medicine?”, give permission for the patient to be non-adherent (it may improve accuracy of response): “Many patients have trouble taking medications – do you every have trouble remembering to take your medicine?”
The following four questions have been shown to accurately identify the majority of patients who have trouble taking their medicine.
i) Do you ever forget to take your medicines?
ii) Are you careless at times about taking your medicine?
iii) When you feel better, do you sometimes stop taking your medicine?
iv) Sometimes, if you feel worse when you take your medicine, do you stop taking it?
8) Strategies to Promote Adherence
   a) Diagnose adherence problems
      i) patient’s understanding of illness
      ii) patient’s understanding of treatment
      iii) barriers to adherence
         (1) obtaining medication; forgetting to take medicines; side effects; lack of motivation
   b) Respond to emotions
      i) be empathic, supportive, and offer praise where appropriate
   c) Elicit commitment
      i) recognize patient’s strengths;
         help the patient develop his own commitment – associated with better adherence
   d) Negotiate solutions
      i) elicit patient’s ideas
      ii) reality check – can the patient really accomplish that?
      iii) be specific – how will the patient accomplish goal?
      iv) anticipate problems
   e) Affirm patient’s intent
      i) what will the patient do?
   f) Make a follow-up plan

Selected References:

Cohen, AJ. Caring for the Chronically Ill: A Vital Subject for Medical Education. Acad Med. 1998; 73; 1261-1266