Patient-Centered Medicine: The Patient, The Doctor, and The Experience of Illness

Disease in man is never exactly the same as disease in an experimental animal, for in man the disease at once affects and is affected by what we call the emotional life. Thus, the physician who attempts to take care of the patient while he neglects this factor is as unscientific as the investigator who neglects to control all of the conditions that may affect his experiment. The good physician knows his patients through and through, and his knowledge is bought dearly. Time, sympathy and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.

Francis Peabody, M.D.
The Care of the Patient, 1927

Introduction:

To be an effective physician, you need to understand why patients have come to you, including their expectations, hopes and fears. You need to understand how people react to and cope with illness. You also need to know something about yourself, because your own reactions, feelings and expectations strongly influence the way you relate to your patients and the way they respond to you.

Illness is not an isolated event in a patient’s life. It occurs at a particular time in an individual’s development and in the context of unique and personal circumstances. This determines, to a considerable extent, how patients experience and cope with illness, and how illness affects their lives. This, in turn will influence both the course and outcome of the illness.

The willingness and ability to listen carefully and openly to the patient’s story is an essential skill for physicians. Your interest and curiosity will become the foundation of your connection with the patient, allowing you to show genuine compassion, empathy and understanding, and it will promote trust and openness in the relationship. It also results in improved health outcomes.
Goals and Objectives:

Knowledge
1. Gain familiarity with common responses to illness
2. Know the common developmental tasks at various stages of the life cycle – childhood, adolescence and adulthood (including late-life)
3. Understand the ways illness can impact on functioning – physical, emotional, interpersonal, task-related
4. Recognize the impact that cultural, spiritual and health beliefs can have on the experience of illness as well as expectations regarding care

Skills
1. Elicit the patient’s story through respectful, open-ended inquiry
2. Ask about the patient’s ideas, feelings and reactions to illness as well as their expectations about care
3. Acknowledge and respond to the patient’s emotions
4. Inquire about the patient’s spiritual values, cultural background and health beliefs

Attitudes
1. Be willing to spend the time and energy to explore the patient’s experience of illness
2. Be interested in and curious about the patient’s life story
3. Recognize the therapeutic potential of the doctor-patient encounter
Core principles every physician should know about patients’ experience of illness:

1. Patients experience disease through the lenses of their personal emotions, stage of life, social relationships, responsibilities and stressors as well as cultural and spiritual beliefs. This experience of disease is called illness. Medical care requires attention to both the disease and the patients’ experience of illness. The Biopsychosocial Model (Engel) defines an approach to patient care that includes attention to the various biological, psychological and social factors that influence the patients’ experience of illness.

2. There is a universal component to the way people react to and cope with illness. This includes a socially defined sick role (Parsons), with specific rights and obligations. For example, patients are exempt from certain activities and responsibilities, and are not blamed for their condition. However, they are expected to cooperate with medical care and attempt to get well. There is also a relatively predictable set of emotional responses to illness, including sadness, denial, anxiety, anger and dependency. Knowledge about these components will help you as a physician understand the patients’ experience and behavior.

3. The human dimension of your work can be compromised by the continuous competition for your attention and demands on your time (learn more, master new technology, be more productive, etc.). Yet taking the time and making the effort to listen to your patient’s story will promote trust, compassion and understanding in the doctor-patient relationship, improve patient satisfaction and cooperation, lead to better health outcomes and help preserve meaning, connection and satisfaction in your own work as a physician.
The Biopsychosocial Model - Components of the Patient’s Story:

**Biological**
- Nature of the illness
- How it affects the body
  - Physiological
  - Functional

**Psychological**
- Responses to illness
  - Sadness and loss
  - Denial
  - Anxiety
  - Anger
  - Dependency
  - Humor
  - Altruism

- Stage in the life cycle
  - Childhood
  - Adolescence
  - Adulthood (including late-life)

**Social**
- Relationships and support systems
- Roles and responsibilities
- Work and finances
- Stress
- Culture
- Spirituality
- Explanatory model/beliefs about health and illness

These components of the patient’s story form the basis of the Biopsychosocial Model, and for the way the patient experiences illness. It is by asking about and listening to the patient’s story (the *patient-centered* part of the interview) that you:

- learn about your patient’s ideas and feelings about being ill
- hear about the impact of the illness on your patients life and functioning as well as the impact on others
- establish rapport and begin to make a meaningful connection
- develop a shared understanding of what your patient expects from the illness and from you
- utilize the therapeutic potential of the doctor-patient relationship.
Common Responses to Illness:

The emotions that patients experience when faced with illness and the behaviors they demonstrate reflect the psychological impact of the illness and their attempts to cope with it. Awareness about common reactions to illness can help you better understand patients and their behaviors towards you and others. This will allow you to connect more effectively and respond more empathically. With attention to how the patient is coping, you can acknowledge and support the patient’s strengths as well as identify and respond to areas of struggle. Here are some common responses:

Sadness and Loss
- Sadness over loss of health, and
- Diminished functional capacity
- Loss of self-esteem, sense of worthiness
- Can enable the patient to face their situation, express their emotions directly, elicit empathy and support from others and reorganize their life appropriately
- Can lead to depression, isolation, withdrawal, lack of motivation for treatment

Anxiety
- Fear about diagnosis and outcome
- Worry about toll on family, work responsibilities, relationships
- Can alert the patient to danger and signal them to get help
- Can lead to undue or excessive worry, demands for reassurance

Anger
- Frustration and resentment about becoming ill (“why me?”)
- Can help the patient face and express feelings and signal personal distress to others
- Can be misdirected at loved ones, lead to criticism of and struggles with caregivers, loss of religious faith

Denial
- Ignore or minimize the presence of illness
- Can keep the patient from feeling anxious, overwhelmed
- May promote recovery
- Can lead to delay in seeking medical care, poor cooperation and compliance

Dependency
- Giving control to others
- Exempting self from usual responsibilities can allow for a period of rest and adjustment
- Can help the patient allow others, family and caregivers, to take an appropriate caring role
- Can lead to excessive demands for time, attention from others
Humor
- Ability to find something funny or amusing about the illness and its’ impact
- Allows patients to place the illness in perspective, as well as maintain a positive, upbeat attitude
- Can limit distress and give relief from sadness and worry
- Can help put others at ease, engage caregivers
- Can reflect an avoidance of and inability to face sadness and anxiety

Altruism
- Activity related to the illness directed at helping others
- Helps the patient find meaning and purpose in the face of illness
- Leads to feelings of empowerment and usefulness
- Can distract the patient from facing own feelings and attending to own care
Developmental Stages in the Life Cycle:

As each person progresses through life, there are a series of tasks to be achieved and challenges to be met at each successive stage of development (Erikson). These include social, emotional and cognitive development as well as the formation of a stable identity. The experience and impact of illness will be influenced and in part determined by when it occurs in the patient’s life.

Childhood
Infancy (birth-1 yr.), toddler (1-3 yrs.), pre-school (3-6 yrs.) and latency (6-12 yrs.) define the stages of childhood. Learning to trust the world and view it as a safe, comforting place, is a critical task of early emotional development. Erikson referred to this feeling about the world, which begins to develop in infancy, as “basic trust”. Initial total dependence on caregivers for sustenance, guidance and emotional needs must later give way to increasing levels of autonomy and self-reliance in order for self-confidence, positive self-esteem and a separate identity to develop. This task of relinquishing dependency and developing a separate sense of self is often referred to as “separation-individuation”. Because one of the child’s challenges is to find a way to become more separate from and less dependent on caregivers without feeling ashamed of their distancing and doubtful of their ability to be more independent, Erikson referred to this part of the toddler phase as “autonomy versus shame and doubt”. Later in childhood, with increasing abilities and recognition from others, a more stable sense of competence and positive self-esteem develops, allowing more autonomy, self-direction and productivity. Because failure at this stage, during latency, is associated with feelings of incompetence and low self-esteem, Erikson referred to it as “industry versus inferiority”.

Adolescence
Adolescence (12-20 yrs.) is sometimes referred to as the second phase of separation-individuation. There is a need for further disengagement from parents in order to secure a greater sense of psychological autonomy and individuality. Strong identification with peers, rebellious and oppositional behavior and distancing from parents are often part of this process. Risk-taking behaviors and feelings of invincibility can be understood as attempts to “prove” competence and independence, and counteract feelings of dependence, vulnerability and insecurity. Lacking a stable sense of identity and self-esteem, adolescents frequently feel confused and unsettled, and there is a quest for a more clear sense of one’s values, self-worth, purpose and direction. Puberty, emerging sexual feelings and formation of intimate relationships are part of a developing sexual identity, and self-esteem is often highly influenced by physical characteristics, body-image and acceptance from others. Erikson called this struggle to achieve a more stable identity and clear sense of purpose rather than remain in turmoil, with uncertainty about one’s future, “identity versus role confusion”.

Adulthood (including late-life)
Young adulthood (20-40 yrs.), mid-life (40-65 yrs.) and late-life (over 65 yrs.) define the stages of adulthood. Much of adult life centers on work and love. Adults tend to define themselves by their career productivity and measure much of their self-esteem by work-related recognition. In addition, adults are concerned with achieving stable, lasting intimacy, often through marriage and parenthood, intense friendships and life-long attachments. With a more consolidated and secure identity, adults can begin to look beyond their own needs and focus on their place in the world and their responsibility to the next generation. Then, in late life, the task is to maintain a sense of identity, purpose and self-worth in the
face of retirement, declining health and isolation due to the loss of loved ones. This requires finding new sources of enjoyment and support, reflecting on one’s life and viewing it as productive and worthwhile, and facing the inevitability of death. Erikson referred to this struggle to achieve a sense of satisfaction, peace and acceptance in late life as “integrity versus despair”.

Bibliography:


