Understanding and Managing the Psychosocial Issues of Chronic Disease

Gary Gilles, MA, LCPC
info@garygilless.com
CHRONIC DISEASE!
Chronic Conditions – A Sampling

- Asthma
- Mental health disorders
- COPD/Respiratory
- Heart disease
- Kidney failure
- Hypertension
- Crohn’s disease
- Diabetes
- Epilepsy
- HIV/AIDS
- Multiple Sclerosis
- Alzheimer’s
- Parkinson’s
- Arthritis
- Colitis
- Cystic fibrosis
- Gout
- Osteoporosis
- ALS
- Lyme disease
- Lupus
- Chronic fatigue syndrome
Prevalence of Chronic Disease

• Today 6 out of every 10 Americans adults live with a chronic condition, such as paralysis, Alzheimer's disease, mental disorders, HIV/AIDS, allergies, asthma, diabetes and high blood pressure.

• Four out of every 10 American adults live with two or more chronic conditions
Most Common Chronic Diseases

7 MOST COMMON CHRONIC CONDITIONS

- Arthritis
- Heart disease
- Cancer
- Diabetes
- Hypertension
- Alzheimer’s/Mental conditions
- Pulmonary conditions

Cardiovascular disease and cancer account for almost two-thirds of all deaths among Americans.
Chronic Disease and Older Adults

As the population of older adults increases so does the percentage of people living with chronic disease

• More than 10,000 people turn 70 years old every single day.

• Those 65-80 years of age comprise 2/3 of all people who are living with multiple conditions.

• The fastest growing segment of our population are those 85 years of age and older.
Psychosocial Issues and Chronic Illness

• The psychosocial issues surrounding chronic illness are perhaps the most important component of management

• Research has repeatedly shown that the psychosocial factors consistently undermine management strategies and lead to poorer outcomes

• Yet, the emotional dimensions of chronic conditions are often overlooked when medical care is considered

• Doctors may be well equipped for the biomedical aspects of care but not for the challenges of understanding the psychological, social, and cultural dimensions of illness and health
Diagnosis of Chronic Illness

• Varying degrees of distress are common following a chronic illness diagnosis.

• It often prompts a crisis, especially if a life-threatening illness is discovered.

• It’s not uncommon for the patient and family members to be overwhelmed as they attempt to take in all of current and future information about the condition, what to expect and how to manage the symptoms.
Illness Trajectory

The term trajectory refers to the course of a chronic disease in different stages and phases.

Illness trajectory helps to predict the physical and psychosocial issues that will be incurred over time and helps inform the actions taken by patients, families and health professionals to manage or shape the course.
Short period of evident decline

- Mostly cancer
- Specialist palliative care input available
- Death

Onset of incurable cancer

Often a few years, but decline usually over a few months
Long term limitations with intermittent serious episodes

Function

High

Mostly heart and lung failure

Low

Sometimes emergency hospital admissions

2-5 years, but death usually seems “sudden”

Time
Prolonged dwindling

Function
High

Mostly frailty and dementia

Low
Onset could be deficits in functional capacity, speech, cognition

Death
Quite variable – up to 6-8 years

Time →
Loss: The Organizing Principle
Loss: The Organizing Principle

Loss issues are nearly universal in living with a chronic illness.

• Health
• Control
• Independence
• Certainty
• Connectedness
Loss of Health

• The one characteristic common to all chronic illnesses is that the person can never fully return to his or her pre-illness state of health.

• Not a point in time, but continual.

• Each loss requires mental, emotional and social adjustments.
Loss of Control

It is often perceived by the person, that the disease has now taken control of their life and they have little to no ability to resist it. This results in a sense of powerlessness, that if continued, can cycle into low self-esteem, depression and utter hopelessness.
The Primary Task of Childhood
Diminishing Control Imposed by Chronic Illness
Cycle of Control Loss

- Diminished control over their life
  - Less empowerment/fewer available choices
  - Lower self-efficacy
  - Less effort exerted to make changes
Paul Baltes’ Selection, Optimization and Compensation Theory

• **Selection** is based on the concept that older adults (and those with chronic conditions) have a reduced capacity and loss of functioning, which require a reduction in performance in most life domains.

• **Optimization** suggests that it is possible to maintain performance in some areas through continued practice and the use of new technologies.

• **Compensation** becomes relevant when life tasks require a level of capacity beyond the current level of the older adult’s (or person with a chronic condition) performance potential.
Loss of Independence

Can be real or perceived

The restrictions the disease imposes may limit activities and cause the loss or modification of:

• Mobility (physical and driving privileges)
• Bodily functions
• Roles (provider, spouse, father, etc.)

All of which promote greater dependence on others and risk stigma.
Loss of Certainty

• Most people live day-to-day with a sense of the future remaining stable.
• Chronic illness calls into question virtually everything about the future.
• Life that was previously viewed as a toggle between present and future is now more firmly focused on the present and a question mark looms over the future.
• Calls into question one’s mortality
Loss of Connectedness

• Some people can no longer relate to others as they had before the onset of the illness. They feel different and often isolate themselves.
• They are often perceived AS an illness and not as an individual WITH an illness. They feel like they live by a different set of rules than everyone else.
• Some are reluctant to talk with family members for fear of emotionally burdening them. So they isolate from the people who could be most supportive of them.
• They often have a perception of being invisible – people don’t look at them to avoid seeing their deformed hands or oxygen tubes, etc. It leaves the person feeling dismissed and contributes to low self-esteem/depression.
Unique stressors - Patients

- Management burnout
- Feeling different from others
- Anger/resentment
- Redefinition of self and health
Unique Stressors - Family

- Rigors of learning about condition and management routine
- Problems knowing how to manage the condition or emotionally support the chronically ill person
- Physical and mental burden
- Restricted time with other family members
- Difficulty integrating family needs and desires with the limitations imposed by the chronic illness
- Changing dynamics among the members of the family
family support
caregiver
caregiving
love
life
learned
group
time
also
people
plan
disease
wonderful
insight
knowledge
journey
last
things
tough
taking
volunteer
help
family
husband
opportunity
give
defined
live
thought
journey
have
done
needed
things
new
loved
journey
knowledge
become
sanity
had
performed
neither
thanked
feeling
doing
advice
times
best
important
friends
you
important
child
thought
insight
nothing
stuff
spreading
believe
enjoyed
put
spreading
hobby
begun
begun
helped
becomes
many
now
now
members
taken
through
given
let
thing
family
enough
humor
comes
caregivers
elderly
individuals
physical
place
inside
father
every
given
something
usual
hands
experience
worker
read
involved
involved
now
friend
involved
impact
something
idea
health
weight
light
child
appears
one
long
one
love
long
THANK
THANK
THANK
Caregivers – Who Are They?

A caregiver is anyone who provides physical, emotional or financial assistance to another person and can include:

- **Practical assistance** with basic activities of daily living (e.g. housekeeping, shopping, meal preparation)
- **Personal care** (e.g. help with monitoring medication, bathing)
- **Physical help** (e.g. assistance with movement, supervision, direct medical care)
- **Emotional and social support** (e.g. visiting, transportation, talking about emotions)
- **Finding and accessing services** (e.g. housing, medical supports)
- **Behavioral support** (e.g. communicating effectively, managing challenging behaviors)
- **Financial help** (e.g. financial support, managing finances)
Caregivers are the “glue”

- Caregivers serve as the glue that connects healthcare and social service providers to the individual in need of care.
- Caregivers interact with physicians, nurses, social workers, psychologists, pharmacists, physical and occupational therapists and others.
- Caregivers serve as the primary source of information about the patient’s health history, abilities and preferences.
- Despite their essential role in the patient-care process, they are largely marginalized in the delivery of healthcare for their loved one.
Caregivers

More than 65 million people, 29% of the U.S. population, nearly one in every three households, provides care for a chronically ill, disabled or aged family member or friend during any given year.

The typical family caregiver is:

- a 49-year-old woman caring for her widowed 69-year-old mother who does not live with her.
- married
- employed
How Caregiving Looks

- **20 hours per week** is the average number of hours family caregivers spend caring for their loved ones.
- 1 in 7 caregivers provide 40 hours of care a week or more.
- 51% of care recipients live in their own home.
- 29% live with their family caregiver.
- 4% live in nursing homes and assisted living.
- Three quarters of those living at home or with family depend *exclusively* on family and friends as their *only* source of help.
The Act of Caregiving

- Four of every five caregivers indicate that some aspect of helping was difficult, tiring, or emotionally upsetting.
- Six out of ten said they had no idea what to do in many situations and that the person they cared for made too many demands on them.
Unique Stressors Facing Caregivers

• **Life imbalance.** Caregivers often spend a disproportionate amount of their physical and emotional resources on the person requiring care. Resentment can easily build.

• **Anxiety.** Additional anxiety can occur in trying to coordinate the caregiver’s personal life with caregiving responsibilities.

• **Poor personal care.** The lack of time and energy to attend to even the most basic tasks often leaves personal care as a last priority.

• **Financial.** The personal financial resources of the caregiver may be seriously drained or wiped out by prolonged medical care.
Caregiver Burnout

The overwhelming stressors can lead to caregiving burnout. This is defined as the point where the care being given is no longer a viable or healthy option for either the caregiver or the person receiving care.
99% of disease management is in the hands of individuals and their families.
Barriers to Compliance

- Insufficient understanding of condition and/or health care professional’s instructions
- Lack of motivation to follow the treatment plan
- Behavioral habit patterns that run counter to the treatment plan
- Lack of social accountability and support

An additional barrier to compliance may be the concept of compliance itself.
Facilitating Self-management

1. **Help patients maintain as much control as possible.** The greatest way to facilitate self-management is to empower them with a sense of control.

Focus on Balte’s principles of adaptation: Physically, emotionally and socially adapt to what they are capable of doing.

- **Realistically assess** what the person can and cannot effectively do across various life domains given their age and chronic condition.
- **Optimize** their engagement in those areas where they can perform through continued practice and the use of new technologies. Create an ongoing optimal challenge.
- Build in resilience by helping the person to emotionally **compensate** when chronic condition limits their ongoing ability to accomplish certain life tasks. Reassess and re-optimize.
Perform a Psychosocial Assessment

A psychosocial assessment would account for:

• The mental capacity of the person
• Degree of relational support and any relational problems that occupy them to a significant degree
• Habitual patterns (dietary-related, smoking, substance abuse, other compulsive behaviors, etc.)
• Current or recent stressors
• Patient’s perceived ability to cope with chronic condition and other life stressors
• Prior mental health treatment
• Current or past psychotropic medication
• Person’s mental understanding of their condition
Facilitating Self-management

3. Empower the patient:
   • Encourage them to tell their story and put them in touch with people/families in similar situations
   • Allow them to be part of setting the treatment plan
   • Create as much choice as possible into the patient’s treatment plan
   • Avoid a one-up/one-down professional relationship
   • Avoid ultimatums, scare tactics, deadlines, rewards
   • Offer well-placed affirmation and recognition
   • Encourage self-management by inviting experimentation with treatment plan
Facilitating Self-management

4. Teach self-maintenance skills

• Help the patient deal with the emotional and social consequences of the disease and not just the physiological aspects.
• Teach the patient practical problem-solving and decision-making skills instead of simply asking for compliance to directives.
• Encourage patients to be their own managers by detailing what the partnership between the health care professional and themselves entails.
Combating Caregiver Burnout

• Encourage caregivers to **seek support** for themselves through caregiver groups.

• **Express their emotions** by talking regularly with someone they trust and cares for them.

• Encourage caregivers to **involve multiple people** in the caregiving process so that no one person is doing all of the work.

• Help caregiver balance personal life by pursuing **self-care**, recreation, social activities, etc.

• Provide information and **community resources** that specifically address the needs of the caregiver.

• Suggest supportive **counseling** as a way to help them vent their emotions and concerns in a safe, supportive environment.

• Help caregivers **strategize potential problems** and solutions to those problems in advance.
Optimistic Prognosis

Moving ahead, if we focus more on implementing effective strategies to help patients and families better self-manage their chronic conditions and the psychosocial issues that accompany them, we could see the following:

• Improved quality of life for patients and families
• Less burden on an already stretched healthcare system
• Fewer chronic conditions
• Reduction in treatment costs

Source: Milken Institute
Conclusion

“The kind of society we are will be measured in the years ahead by how well (or how poorly) we care for those who are sick, disabled and the elderly persons who cannot care for themselves...”