From Diagnosis to Acceptance: The Emotional Impact of Chronic Illness
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Three Parts
- Discuss the emotional challenges of people diagnosed with chronic illness
- Discuss three models of coping that might apply to people diagnosed with chronic illness
- Discuss actions to help patients approach acceptance and thus maximize treatment outcomes

Emotions & Nutrition Consulting
- Have you ever had a consultation when you were barely there?
- Have you ever been filled with negative thoughts and found it hard to engage when faced with a patient who has a grave diagnosis?
- Are you occasionally judgmental about a patient’s health condition?
- Have you ever been frustrated by a patient who continually cancels or comes late to appointments?

JAND, April 2014: Practice Applications
“Bedside Manner Heals Patient—Practitioner Communication” by Tony Peregrin
- Calling for better (practiced) “bedside” manner
- Active listening & body language
- Effective communication

Starfish Parable
- The Star Thrower (1969 by Loren Eiseley) Why is it important?
  - With a little help they can live (individual)
  - Important to family
  - Important to ecosystem (society)
- Cloak your nutrition message in compassion, empathy, and hope for everyone you help – because the bottom line is that each appointment has far reaching consequences

Emotional Challenges of Chronically Ill
- Emotional state of patients is often last to be addressed
- Chicken and egg scenario?
  - Some conditions can physically change the brain causing anxiety or depression
  - Mood disorders can contribute to physical problems
- Prevalence of mood disorders in chronically ill is 2x general population
- Dilemma of drug treatments
- Exhaustion and/or mood changes become barriers to seeking help or implementing self-care, or lead to misunderstanding of treatments

1 http://www.eiseley.org/Star_Thrower_Cook.pdf
Isolation and Relationship Challenges

- 75 to 80% divorce among chronically ill – More women than men “abandoned”
- “Role reversal” challenging/isn’t always successful if woman is ill
- Pain & time spent on illness reduce “fun” times, accentuate “bad”
- Up to 70% of suicides may be connected to disability or pain

Miscellaneous Challenges

- Absenteeism and presenteeism at work
- Income Loss
  - Medical Costs and Earning Potential
  - Current and Future Earnings Affected
- Lost children
- Miscellaneous:
  - Lack of nutritious/family meals
  - Abortions
  - Accidents
  - Crime

Little Things CAN Make a Difference

- Treatment of emotional state key to success of medical and nutrition therapies
- Developing coping/problem solving skills essential to general wellbeing and condition management
- Acceptance/empowerment/coping skills may reduce anxiety and depression
- Success breeds success

Models to Consider

- Stages of Change (Transtheoretical Model)
- Common Sense Model/ Illness Representation
- Stages of Grief (Acceptance)

Stages of Change

- Pre-contemplation: Avoidance. Not seeing a problem behavior or not considering change.
- Preparation (Determination): Testing the waters, getting ready to change.
- Action: Actively making the change and engaging in new behaviors, often becomes fanatical.
- Maintenance: Maintaining and integrating changes into daily life…behaviors become habitual.

Additional construct of value: Self-efficacy

Identifying Readiness to Change

- Various research trying to develop tools to identify readiness to change (osteoarthritis, chronic pain organizations)
- Pros: Tools may allow for some categorizing of patients, the act of taking survey can nudge patients to identify need to change
- Cons: Leading questions, not necessarily identifying emotional, energy resources needed to implement change

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Common Sense Model
- Based on “Illness Representations”
- Part of Leventhal’s Self-Regulation Theory (1970)
- Six constructs, beliefs and expectations about an illness
  - Identity: Naming or labeling a threat
  - Cause: Understanding threat’s causal mechanism
  - Timeline: Patient perception of time trajectory
  - Consequences: Believed consequence of threat
  - Control/cure: Belief of whether something can be done to control the threat & efficacy of such


Stages of Grief/Acceptance
- Elizabeth Kübler-Ross “On Death and Dying”
- More than dying/surviving. Many use model for adapting to chronic illness.
- Not step-by-step, but emotional waves...
- May return to different emotions at any time
- So what are the stages?

Stages of Grief/Acceptance
- Interesting note: Stages of Grief has not been validated despite years of research
- Yet, one of the most widely recognized and used models by both practitioners and people grieving
- People who are grieving intuitively accept it — Listen to patients, research will come
- Maybe grief/acceptance is just too complicated

Applications for RDNs
- Denial
- Bargaining
- Anger
- Depression (pre-acceptance)
- Acceptance

*Elizabeth Kübler-Ross Foundation: http://www.ekrfoundation.org/
Assessing Patient

- Assess without judgment
- Don’t let lack of research stop you from using your intuition
- Use language of models to guide consultations:
  - Readiness
  - Motivation
  - Progress
  - Acceptance
- Keep in mind that family/spouses may be going through changes/stages also

Encourage Goal Setting

- Have patients visualize the end result
- Help patients break big picture into smaller pieces...encourage baby steps
- Encourage self-reflection and intuitive experimentation (Atkins? Gluten-free? No problem. You are there to help patients learn, not judge unless dangerous.)
- Guide/moderate expectations
- Schedule time for recuperation/rest/healing

Tame the Negative

- Negatives necessary to process, but may hinder assimilation of information
- Use reflective/active listening to acknowledge the transient nature of most negative episodes. (Depression, anger, exhaustion)
- Try to bring patient back to an active state by encouraging them to talk about overcoming past
- Encourage journaling
- Provide a template to record questions for their appointment

Emphasize “Coping,” not “Positive Thinking”

- Coping implies ability to navigate & problem solve.
- Coping doesn’t mean every day is great
- “Positive thinking” could be covering up emotional pain
- Providers or family/social group who push “positive thinking” may reinforce patient hiding reasonable concern/illness/appropriate negative emotions.

Develop Problem Solving Skills

- You are not always going to be there...chronic disease changes all the time
- Problem solving empowers patients to become independent & handle situations as they arise
- Guide toward high quality research sites/materials
- Practice/role play during sessions (recipe modification, create meal plans, ordering from menus)

Minimize “Sick” Labels/Tasks

- Suggest patients combine doctor appointments (primary doctor as coordinator of care)
- Encourage patients to simplify tasks & ask for help (meds/supplements in cases/zipper bags)
- Ask about social media activity (Is Facebook a positive or negative experience?)
- Accommodate missed appointments without judgment within reason (try phone or video consultations)
“Being There” for Your Patients

- Remember the scenarios in the beginning?
- You may be first medical professional who spends more than 15 minutes with patient.
- If you are not qualified to help with an issue, be ready with resources/referrals.
- Key words? “self-management,” “hope,” and “encouragement”

For More Information

Theory at a Glance:

Elizabeth Kübler-Ross Foundation: www.ekrfoundation.org/

Molly Kellogg’s counseling tips website: www.mollykellogg.com

Academy of Nutrition and Dietetics Nutrition Care Process:
www.eatright.org/HealthProfessionals/content.aspx?id=7077

Families, Illness & Disability: An Integrative Treatment Model
by John S. Rolland, M.D.

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Finally: If you are going to FNCE this fall check out my presentation with Melissa Dobbins:

“Claim the Spotlight! Videos, Podcasts and Self-Publishing Alternatives to Traditional Media”