Chronic Illness: Empowering Families in the Journey - Part 1

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Today’s Presenter

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Learning Objectives

In this session we will:

1. Discuss the stressors associated with chronic illness and its impact on health and wellness of individuals and families

2. Explore the ways families influence the health and well-being of each other

3. Learn effective strategies for interdisciplinary collaboration among service providers when working with families struggling with chronic illness
Research has long shown a powerful and reciprocal link between the health of couples’ relationships and the physical health of those who inhabit the couple(s).
Let’s Discuss...

What are some examples of the link between the health of a couple’s relationship and their individual physical health?
Relationship Health ↔ Physical Health

- Relationship quality affects partners’ health
  - Immune functioning
  - Endocrine stress hormones
  - Development and course of chronic illnesses

- Physical health affects relationship quality
  - Partner match vs. mismatch in health status
  - Illness “in the way” of the couple
  - Caregiver stress and burden

For example…
Chronic Pain in Relational Context(s)

- Chronic pain is significantly associated with:
  - Poor relationship satisfaction
  - Poor dyadic adjustment
  - Both partners’ development of:
    - Depressive symptoms
    - Anxiety symptoms
Chronic Pain, cont.

- Spousal involvement through facilitative communication, responsiveness, and support is strongly associated with
  - Decreased intensity of pain
  - Less depressive symptoms
  - Increased relationship satisfaction
Connecting the Dots

• Biopsychosocial lens(es)
• Biopsychosocial/spiritual lens(es)
• Medicine Wheel lens(es)
• Collaborative Family Health Care
• Integrated Family Health Care
• Patient-centered Medical Home model(s)
• Family-centered Medical Home model(s)
• Community-oriented Primary Care
• Community-based Participatory Research
Connecting the Dots, cont.

- Individual Health (1)
- Couple / Dyadic Health (1+1=2)
- Family Health (1+1+1\ldots)
- Community / Public Health (1+1+1+10000s)
Connecting the Dots, cont.

• Collaborative / Integrated Health Care
  – Primary Care
  – Mental Health Care
  – Co-located Care
  – Coordinated Care
  – Shared Care
  – Integrated Behavioral Health
  – Patient/Family-centered…
Health (and Healthcare) is a **Systemic Phenomenon**

**Biological**- e.g., muscular, neurological, cardiovascular

**Psychological**- e.g., emotions, mood, personality

**Behavioral**- e.g., personal conduct, reactivity

**Dyadic/Family**- e.g., interactional, comm patterns, boundaries

**Social**- e.g., friends, faith communities, school, work

**Ethnic/Cultural**- e.g., heritage, socioeconomic status

**Ecological**- e.g., government, healthcare system, environmental
Health and Resiliency in Individuals

• Perceptions
  – Stress Theory / Perceptions > Stressors or Resources
• Cognitions
  – Attribution Styles / Automatic personal “tapes”
  – Narrative Styles / Use of History ↔ Present/Future
• Mood
  – Depression / Anxiety / Anger
• Behaviors
  – Physical, Medication, Do’s and Don’ts
Individuals, cont.

- Mastery vs. Fatalism
  - Mastery can be empowering or destabilizing
  - Fatalism can facilitate appropriate acceptance or circumvent personal efficacy
Individuals, cont.

- The person we are with 24 hours per day is the person primarily responsible for our health
- The way(s) that we perceive something defines how it affects us
- Personal (cognitive) “tapes” and attribution styles define our context(s)
- Moods and Emotions can empower or immobilize us
- High mastery-orientation can be a blessing or a curse, depending on its focus and relative flexibility
But most of us reside in couple- or family-relationships...
Dyadic / Family
Communication Patterns
Interaction Patterns
Power Structure
Subsystems
Interpersonal Boundaries
The Couple/Family System is in the middle of the Biopsychosocial Continuum

(It connects Individuals to larger Social Systems)
Health and Resiliency in Couple/Family Systems

- Communication Patterns
- Interaction Patterns
- Power Structure
- Subsystems
- Interpersonal Boundaries
Communication

• Communicating all the time vs. only when there is a problem
• Communicating regarding what is GOOD vs. what is bad
• Healthy communication makes us vulnerable, but all growth involves risk
• “This is what I need” vs. “This is what you should do”
• “This is how I feel” vs. “This is how you feel” or “This is what you are doing wrong”
Communication, cont.

- Listening vs. waiting for the other to stop talking
- Reflecting vs. “Yeah, but…” or minimizing
- Focusing on behavior vs. character
- Win/Win vs. Compromise vs. Win/Lose
- Being Assertive vs. Being Aggressive
- Honesty vs. Niceties (e.g., “nothing,” “fine”)
- Dyadic communication vs. triangulation
- Time outs and cool-offs vs. marathon finishes
Couple/Families

• Interaction Patterns
  – Relationship “dances”
  – Balancing Unconditional vs. Conditional Love

• Power Structure
  – Rigid vs. Chaotic

• Interpersonal Boundaries
  – Disengaged vs. Enmeshed
  – Changes over time as developmentally appropriate
Couples/Families, cont.

• Most people reside in families, and members’ lives are interwoven
• The family’s main function is to protect the safety of its members
• Health-related behaviors are learned in the family
• Families carry on cultural rituals
• Much of life’s stress is family-related
• Better outcomes occur when family members co-own issues of illness and health
Let’s Discuss...

Share your experiences and insights
Social
Friends
Community Groups
Healthcare Teams
Faith Communities
School / Work
Social Systems

• Friends
  – Peer support is invaluable and cannot be replaced by family support

• Support Groups
  – Esoteric empathy and empowerment

• Community Groups
  – Support groups + outward mission

• Faith Communities / School / Work
  – Can offer sense of purpose and meaning
Healthcare Teams

Coordinated treatment by medical and behavioral health providers in the care of individual patients/clients and their families

Effective multidisciplinary collaboration encompasses non-hierarchical working relationships between providers
Healthcare Teams, cont.

- A practice team tailored to the needs of each patient/family
  - with a shared population and mission
  - using a systemic clinical approach(es)
  - supported by a community that expects behavioral and primary care integration as “standard” care
  - supported by office practices, leadership, and business models
  - with continuous quality improvement efforts (and responsive practice refinements)

Source: CJ Peek (2013)
Healthcare Teams, cont.

- Team Membership (or accessible collaborators)
  - Primary care physicians (and physician extenders)
  - Nurses, Nurse Practitioners
  - Educator (diabetes, dietitian, etc.)
  - Pharmacist
  - Behavioral Health (LMFT, LP, LICSW, LADC, etc.)
  - Psychiatrist
  - Patient Advocate
  - Care Coordinator
  - Others (by clinic, population, specialty)
Healthcare Teams, cont.

• Work to understand patients’/families’ worlds
• Find out about personhoods first, “issues” later
• Listen (vs only talking, problem-solving, or directing); maintain an empathic presence
• Endeavor to see the world through your patients’/families’ eyes
• Embrace your patients’/families’ lived-experience and wisdom…
Embracing Patients’ & Families’ Wisdom

• Where’s “the line” between being supportive and being a nag?
• How can partners not burn-out from supporting a spouse whose pain is chronic and whose complaints are never-ending?
• How can someone with a terminal illness share his/her feelings about dying without alarming or upsetting his/her partner?
Embracing Wisdom, cont.

- How can someone share their feelings about his/her partners’ dying without alarming or upsetting the partner?
- How do we help couples handle the sometimes intrusive role of health professionals in their lives?
- How can a couple get support for their relationship when family and friends do not know what to say or do to be helpful?
Healthcare Teams, cont.

• Don’t be afraid to be emotionally honest and vivid
• Include patients/families as members of your team
Let’s Discuss...

What are other strategies for working with families struggling with chronic illness?
Case Study

Family Structure:

Eve is a 40 year old mother of two (Thomas-5 y/o; Jenna-7 y/o) who has served 3 tours of duty overseas. She has a husband who is retired Air Force and served in combat.
Chronic Illness Struggles:

Eve has been diagnosed with Systemic Lupus Erythematosus, an auto-immune disease causing severe inflammation due to the body’s immune system attacking healthy tissues instead of only bacteria and viruses. Symptoms that she experiences include: severe fatigue, gastrointestinal (GI) issues, skin rash, hair loss, joint pain, swelling and inflammation. Eve is on a medication regimen that assists in alleviating some of the pain and discomfort but struggles with not knowing how bad she will feel each day. Eve has started a gluten free diet as her doctor relayed she has a gluten intolerance and also that gluten can worsen inflammation experienced.
Impact on Family:

Eve loves her family and wants to be very involved in her children’s lives. She often feels guilty for not feeling well and being able to keep up with 2 small children. She feels as though she is not participating as fully in her marriage and family’s day to day routines.
Questions to Consider

- What are the strengths of this family?

- What seems to be the common stressors experienced by this family?

- How can we as service professionals empower this family? In what ways?

- What tools/resources would be beneficial to share with this family?
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We invite MFLN Service Provider Partners to our private LinkedIn Group!

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https://www.linkedin.com/groups/8409844
CEU Credit & Certificate of Completion

• One survey, three different ways to receive a certificate
  – MFLN Military Caregiving and Family Development concentration areas are offering 1.5 CEU credits from the UT School of Social Work and the Georgia Marriage and Family Therapy (GMFT) to credentialed participants.
  – MFLN Nutrition and Wellness is offering a CPEU Certificate for the Commission of Dietetics Registration (CDR)/Certificate of Completion.
  – MFLN Certificate of Completion for providers interested in receiving general training.

• To receive a CEU credit OR certificate of completion, please complete the evaluation survey found at:

https://vte.co1.qualtrics.com/SE/?SID=SV_2lfvK2p2CXh0vwp
Upcoming Events

Chronic Illness: Empowering Families in the Journey- Part II
• Date: Thursday, January 26
• Time: 11:00 am – 12:00 pm Eastern
• Location: https://learn.extension.org/events/2900

Medicare 2017 & What it Means for You
• Date: Wednesday, February 22
• Time: 11:00 am – 12:00 pm Eastern
• Location: https://learn.extension.org/events/2921

The Scoop on Gluten Free: Research and Practice Tips
• Date: Tuesday, February 14
• Time: 11:00 am – 12:00 pm Eastern
• Location: https://learn.extension.org/events/2832
Upcoming Events, cont.

Engaging Across Generations Part I: Unique Mindsets
- Date: Tuesday, May 2
- Time: 11:00 am – 12:30 pm Eastern
- Location: https://learn.extension.org/events/2911

Engaging Across Generations Part II: Tools & Techniques
- Date: Tuesday, May 9
- Time: 11:00 am – 12:30 pm Eastern
- Location: https://learn.extension.org/events/2912
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