Develop a greater understanding of the importance of gathering a comprehensive emotional, psychological and spiritual history.

Recognize how prior life experiences and traumas can influence health care decisions.

Gain knowledge of one’s ability to reset self-destructive beliefs and patterns.
The Challenge

- **Question:** Do we sometimes treat psychological pain with physical medicine?

- **Saying:** If the only tool in the tool box is a hammer, everything begins to look like a nail.

The Questions

- **Question:** Do prior life events, both good and bad play a role in a person’s response to a chronic illness?

- **Question:** Can psychological factors play a role in a person’s belief about hope and pain and their response to it?
Life Stuff Model
Whole Person Care

Birth

Stuff

Chronic Illness

Death

Medical Care

Stuff

Mental Health/Spiritual Care

What if

About 1 in 7 children experienced child abuse and neglect in the last year.
What if

Early Adversity has Lasting Impacts

Adverse Childhood Experiences

Physical
- Functional ability
- Strength/Tendons
- Sleep & Rest
- Vision
- Appetite
- Pain

Psychological
- Depression
- Anxiety
- Enjoyment/Leisure
- Happiness
- Fear

Social
- Emotional Burden
- Caregiver Burden
- Roles & Relationships
- Appearance
- Physical/ Sexual Function

Quality Of Life

Spiritual
- Hope
- Suffering
- Meaning of Pain
- Resilience
- Transcendence

Adverse Childhood Experiences have a tremendous impact on future violence victimization and perpetration and lifelong health and opportunity.
Neuroplasticity involves molecular, cellular and synaptic processes that modify connectivity between neurons and neuronal circuits.

Circuits are modulated by behavioral, sensory, cognitive and emotional experience, and are also influenced by pathological states and chronic pain or depression.

An automatic way of thinking, feeling or behaving based upon a belief system constructed through past experience.
References:
https://www.nursingworld.org/~495e9b/globalassets/docs/ana/ethics/theethicalresponsibilitytomanagepainandthesufferingitcauses2018.pdf


Curtis, M. Life Stuff Handbook of Palliative Care. 2018


Objectives

• Appreciate the important role caregivers provide in healthcare
• Recognize positive components of caregiving
• Understand the Family Resilience Theory and role of the professional caregiver in promoting resilience for caregivers

Ohio has roughly 1.5 million family caregivers who provide nearly 1.4 billion hours of unpaid care a year, according to AARP Ohio, and that number will likely grow as the state's over-65 population increases

Caregiving

• Unpaid family caregivers provide 90% of care
• Provide an estimate $375 billion in cost savings nationwide
• In the next decades the demand for family caregivers is expected to rise by 85%
• Factors for this continuous increase
  1. Shorter hospital stays
  2. Changes in insurance reimbursement
  3. Limited hospital discharge planning
  4. Increase in home care technology
  5. Aging population
• 2030 one in 5 adults will be 65 and older

Collins, Lauren, MD, and Kristine Swartz, MD. (2011). Caregiving
The average duration of a caregiver’s role is 4 years. Only 30% of caregivers provide care for less than a year. 24% of caregivers provide care for more than 5 years. 15% of caregivers provide care for 10 or more years. Higher-hour caregivers are twice as likely to have been in their caregiving role for 10 years or more.

National Alliance for Caregiving and AARP. (2015).

Who is providing the caregiving?

- Elderly spouse
- 45% male
- Retired children attempting to cope with their own health issues in addition to their parents
- Children juggling their children’s needs and needs of parents
- Younger adults raised by their grandparents, now taking on the role of the caregiver

Genders impact on perceived stress and burden

- Female caregivers perceive more stress and burden than male
  - emotional connection
  - sacrifice social life
  - reluctance to ask for help

Friedemann, Marie-Luise, PhD; Kral and kaduszkie, K, PhD, MS, FAAN. (2014). pp. 313-336.
Male caregivers

- Males may not feel comfortable with title of "caregiver"
- Initially may at first be more comfortable with concrete tasks
- Not as comfortable with ADL assistance

*Getz, Lindsey (2012) p. 38*

Caregiver identity theory

- Caregiving as a systematic process of identity change in which familial relationship gives away to a relationship characterized by caregiving role
- Caregiving is a dynamic change process
- Changes in caregiving needs along with changes in relationship and caregiver's identity

*Montgomery, Rhonda, J.V (2007)*

Burdens of Caregiving vs. Benefits
People bring themselves

- People bring a past and a present to anything they do
  - Their schemas and beliefs
  - Their stigma beliefs
  - Their social support systems
    - Positive support
    - Negative support
  - Their history of trauma and illness
  - Their families and close others
  - Their economic situation

Positive aspects of caregiving

- 2014 Survey by National Opinion Research results
  - 83% of caregivers found it to be a positive experience

Positives of spousal caregiving

- When the caregiving spouse feels that help provided has made a positive difference, and that the difference is noticed and appreciated can lead to improved sense of well-being according to new study at Yale School of Public health
  - Christiansen, Sherry. (2017)
Resilience Theory for caregiving

How a family confronts and manages a disruptive experience, buffers stress, effectively reorganizes, and moves forward with life will influence immediate and long-term adaptation for every family member and for the very survival and well-being of the family unit (Walsh, 2016, p. 15).

Family resilience core

- The potential of families to strengthen their resilience in overcoming their challenges
- Ability for transformation and positive growth from adversity

(Walsh, 2016, p. 3)

Practices to increase individual resiliency

- Keep a positive attitude
- Reframe stressful thoughts
- Develop a moral compass
- Find a resilient role model
- Face your fears
- Develop active coping skills
- Establish and nurture a supportive network
- Prioritize your physical well being
- Train your brain
- Play to your strengths

(Wall, Thompson, 2015)
Dual roles: professional caregivers while being a family caregiver

• In any workplace nearly 20% of employees are family caregivers during their “off-work” hours.
  Partners On the Path website (2017)

Self care for professional/family caregivers

• Claim your Caregiver Role and confirm the importance of self-care
• Consider the facts about caregiver stress
• Care for yourself as you care for others
• Center yourself
• Channel your thoughts
• Choose wisely
• Cultivate Community
  Partners on the Path website (2017)

Resources

• Caregiver Action Network- https://caregiveractionnetwork.org
• Family caregiver alliance-https://caregiver.org
• Help for Alzheimer’s Families- www.helpforalzheimerfamilies.com
• Get Palliative Care-https://getpalliativecare.org
• Partners on the Path-http://partnersonthepath.org
• National Alliance for Caregiving-https://www.caregiving.org
Caregivers

There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver.

— Rosalyn Carter

Reference


National Hospice and Palliative Care Organization retrieved from https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures


Partners On the Path website (2018) found on https://www.partnersonthepath.org


Learning Objectives

• Participant will identify challenges of overlapping roles of caregiving
• Participant will identify signs and symptoms of compassion fatigue and burnout
• Participant will understand the application of Mindfulness practice in clinical and personal domains.

What is Mindfulness?

Mindfulness harnesses our capacity to be aware of what is going on in our bodies, minds, and hearts in the world -- and in the workplace. As we learn to pay closer attention to what is occurring within and around us, one thing we begin to discover is that we are swimming in an unavoidable sea of constantly changing events.

*Saki S. Santorelli
Mindfulness and Mastery in the Workplace
THE NATURE OF CAREGIVING

Compassion
• The urgent desire to help or aid someone
• Sympathy

...to suffer with another

The Nature of Caregiving:

Qualities of a caregiver
• Compassion
• Empathy
• Prioritize the needs of others over self
• Dedication

What is Missing?

Personal vs. Professional Caregiving

• Personal caregiving is longitudinal.
• Professional caregiving is episodic.
• Most professional caregivers are also caregivers in other roles.
• Different relationships call for different kinds of caregiving.
• You are still only one person.
Help Seeking in Professional Caregivers

We can be our own worst enemy

- Personal
- Professional
- Socialization
- Expectations of others

Work problems
Burnout
DEPRESSION and DYSFUNCTION

Seibert, 2007

We can be our own worst enemy

The Consequences of Caregiving

- Burnout
- Emotional Exhaustion
- Depersonalization
- Decreased sense of personal accomplishment

- Depression
- Anxiety
- Fatigue
- Denial
- Anger
- Social Withdrawal
- Irritability
- Lack of Concentration
- Health Problems

Yerkes Dodson Law

The Performance and Pressure Relationship: Optimal Performance

- Decreased Memory & Learning
- Anxiety
- Fall in Mood

- Increased Memory & Learning
- Low Anxiety & Improved Performance

High

Low

Strong

Weak

Depression

• Low mood
• Lack of pleasure
• Poor energy
• Appetite changes
• Lack of energy
• Hopeless/helplessness
• Excessive guilt

Anxiety

• Excessive worry
• Can't sleep
• Nausea, headache
• Poor concentration
• Can't relax

Clinical Syndromes

- Emotional Exhaustion
- Depersonalization
- Decreased sense of personal accomplishment

- Depression
- Anxiety
- Fatigue
- Denial
- Anger
- Social Withdrawal
- Irritability
- Lack of Concentration
- Health Problems

Caregiver Stress

- Caregiver Stress
- Emotional Fatigue
- Burnout
- Clinical Syndromes

- Personality
- Social Withdrawal
- Anxiety
- Depression
- Emotional
- Exhaustion
- Depersonalization
- Decreased sense of personal accomplishment
- Depression
- Anxiety
- Fatigue
- Denial
- Anger
- Social Withdrawal
- Irritability
- Lack of Concentration
- Health Problems
Impact on Healthcare

- Compassion Fatigue
  - Lower patient satisfaction
  - Increased incidence of sharps injuries
  - Increased hospital acquired infections

- Burnout
  - Reduced job performance
  - Increased rate of turnover
  - Increased medical errors
  - Increased risk of Substance Use Disorders

- Depression and Anxiety
  - #1 cause of lost workplace productivity
  - Reduced job performance
  - Lower patient satisfaction
  - Increased incidence of sharps injuries
  - Increased hospital acquired infections
  - Increased risk of Substance Use Disorders

Financial Impact of Burnout on the Healthcare System

<table>
<thead>
<tr>
<th>Provider</th>
<th>Prevalence</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>25-35%, varies by specialty</td>
<td>30% turnover in hospital nursing nationwide</td>
</tr>
<tr>
<td>Physician</td>
<td>2x gen pop, up to 50%</td>
<td>Burned out physician more than 2x more likely to leave</td>
</tr>
<tr>
<td>Social Work</td>
<td>Higher than in general population, particularly for CSB/CPS</td>
<td></td>
</tr>
</tbody>
</table>

Caring for patients with chronic illness takes both courage and sacrifice.

✓ Emotional attachment is part of the work
✓ Repeated grieving is the fall out
✓ Always a shortage of time and resources
✓ Always more people to care for

Caring for patients with chronic illness takes RESILIENCE.
Mindfulness

What is Meditation?
An ancient practice, developed by various traditions to broaden consciousness and seek health

Concentration Meditation
- Mindfulness focused on an object
- Aims to quiet the mind of thoughts

Mindfulness Meditation
- The opening of perception of contents that emerge in the mind, without the individual judging or reacting to his/her own thoughts and emotions

Contemplative
- A blend of concentration meditation and mindfulness meditation

Benefits of Meditation

Physical
- Blood Pressure
- Rate of Pressor work and stroke
- Oxygen Consumption
- Heart Rate
- Respiratory Rate
- Parasympathetic activity (tension)

Psychological
- Attention and Concentration in daily activities
- Attentional skills and ability to learn
- Attention
- Emotional Regulation
- Empathy and Self-Compassion
- QOL in Chronic Disease
- Coping and adaptation to stress
What is Mindfulness?

The practice of being fully aware in the present moment without judgment

Mindlessness:
denial, self-deception and delusion

... "the tendency of the mind to seek premature closure...
That quality of the mind that imposes a definition on things and then mistakes the definition for the actual experience"

Epstein M, 1995

What can one be mindful of?

- Mindfulness of the body
  - Breath, contact, movements, technical skills
  - Bodily sensations as a clue to state of mind

- Mindfulness of feelings and emotions
  - Unpleasant and pleasant sensations (the "sinking feeling")
  - Suffering, arising, freshness, acceptance

- Mindfulness of thoughts, attitudes, beliefs
  - State of awareness/intent/concentration/distractfulness
  - "Holding on"/"letting go"
  - Cognitive processes (decision-making, "reflection")
Mindfulness in Clinical Practice

- Attentive observation
- Critical curiosity
- Beginners mind
- Presence

Quality of care
- Noticing
- Clinical reasoning
- Technical skills

Quality of caring
- Compassion
- Empathy
- Ethics

Well-being
- Adaptability
- Self-care
- Self-monitoring

The ideal and the threats

The ideal
- To self-monitor during everyday life
- To notice with greater mindfulness and being aware in everyday experience of life

The threats
- Feeling overwhelmed in the face of suffering
- Predilection to focus on what is wrong (judgment)
- Chronically feeling fatigued and burned out

Mindfulness
- Trust
- Acceptance
- Non-striving
- Beginner's Mind
- Non-attachment
- Non-judgment
- Patience

The ideal
- Trust in self-monitoring during everyday life
- Acceptance of what is real, not changing
- Non-striving to focus on what is suffering
- Beginner's mind, with being aware in everyday experience of life

The threats
- Feeling overwhelmed in the face of suffering
- Predilection to focus on what is wrong (judgment)
- Chronically feeling fatigued and burned out
Elements of Mindfulness

- Non-Judging
- Patience
- Trust
- Beginner's Mind
- Non-striving
- Acceptance
- Letting Go (Non-Attachment)

Non-judging
Taking the role of an impartial observer to whatever your current experience is. This means not making a positive or negative evaluation of what is happening, just simply observing it.

Patience
Cultivating the understanding that things must develop in their own time.

Trust
Having trust in yourself, your intuition, and your abilities.
Elements of Mindfulness

Beginner’s Mind
having the willingness to observe the world as if it was your first time doing so.

Acceptance
completely accepting the thoughts, feelings, sensations, and beliefs that you have, and understanding that they are simply those things only.

Non-Striving
the state of not doing anything, just simply accepting that things are happening in the moment just as they are supposed to.

Non-Attachment
avoidance of attaching meaning to thoughts and feelings, or connecting a given thought to a feeling.

Mindfulness
• Being responsive rather than reactive
• Noticing things about oneself and situations even though they might be unpleasant
• Acting with awareness and intention (not being on “automatic pilot”)
• Focusing on experience, not the labels and judgments we apply to them
A mindful response to suffering

• Being attentive both to the patient’s experience and to your own reactions
• Maintaining curiosity and interest
• Seeing the situation from more than one perspective
• Being present, without being overwhelmed, and without disengaging