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# *Caregiver Perspective Across the Lifespan: Developing Understanding and Exploring Clinical Implications*

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## Disclosures

- Disclosure
  - Financial: Employee of CCHMC
- Non-Financial: None

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## Course Description

This course will guide attendees through an in-depth exploration of the role of the caregiver in the therapy process. Specifically, we will explore the importance of understanding caregiver's unique perspective on the patient and treatment process and explore factors that impact level of engagement in treatment.

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## Learner Outcomes

- Participants will be able to explain the importance of understanding caregivers' perspective in the treatment process
- Participants will be able to identify factors that impact caregivers' ability to engage in the treatment process
- Participants will be able to discuss how the presented information is relevant to their daily practice with patients and families

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## Rationale

### WHY???

- Personal Journey ***My role as a caregiver***
- Clinical Experience→
  - Importance of Engaging Caregivers in the therapy process
  - Reflecting on personal experience
  - Importance of understanding unique perspective of caregivers
  - Perspective helped in perceived “challenging” clinical relationships
- Strive to improve how I work and relate with patients and families
- Share what has been helpful and learn from the stories of others

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## My Story

- My role as a caregiver
  - History
    - Began in childhood
    - Role-reversal
    - Stress in the home
    - Long-term/progressive
    - Impact on health of other family members

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## My Story cont.

- Factors that impeded my ability to engage with parent
  - Greif
    - Expected parent
    - Loss of parent
  - Exhaustion
    - Long-term
    - Variability
    - Life balance (work/caregiver/parent)
  - Acceptance
    - Parent
    - Role-reversal
    - Fluctuation in feelings
- Solutions that helped me engage (end of session)

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## My Story cont.

- Clinical Impact of life situation
  - Perspective
  - Empathy
  - Understanding of grief process
    - Impact on engagement
    - Fluctuation
  - Relatedness to family
- Reason for today's session: Learning from other's stories
  - Enhancing caregiver perspective
  - Enhance engagement with caregivers in treatment process

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## Rationale

- **WHY** is *understanding the caregivers* relevant to the therapy process???
- **WHAT** are some considerations for *acute* conditions as compared to *long-term* conditions???
- *Longterm*→**WHAT** possible factors impact caregiver involvement??
- **WHAT** role does grief have in treatment??

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## Rationale

- In contrast: **WHAT** is the disadvantage of not establishing an understanding between ourselves and the families of those we treat???
- Barriers: **What** are some common barriers you encounter when working with families??
- **What** holds families back from fully participating??

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## Literature Review

- Reviewing the Literature
  - PubMed
    - Caregiver AND Perspective AND Allied Health
    - Caregiver AND Allied Health
    - Caregiver AND Speech Therapy
    - Caregiver AND Audiology

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## Lit Review

- Barbic S. P., Mayo, N. E., White, C. L. & Bartlett S. J. ( 2014). *Emotional vitality in family caregivers: content validation of a theoretical framework*. *Quality Life Research*, (23) 2865-2872.
- Caregiver = “Invisible backbone”
  - Roughly 80-90% of the necessary daily care
  - Family, Friends, Neighbors
  - Possible Impacts
    - Physical and emotional energy
    - Reorganize roles
    - Manage complex medical needs
    - Greater risk for stress, anxiety, depression, social isolation additional health problems
  - Most interventions address the needs of the person receiving care with little effort towards supporting needs of the caregiver

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## Lit Review

- Barbic et. Al. (cont.)
- Emotional Vitality DEFINED-positive energy and effective emotional regulation (though difficult to define)
  - Importance of assessing caregivers level of emotional vitality
  - Examined 4 domains: physical health, emotional health, mastery of new skills and participation in meaningful activities
- 30 caregivers interviewed, caring for stroke survivors

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## Lit Review

- Barbic et al. (cont.)
- Impact on Caregivers
  - Physical Health
    - Negative changes in own health
    - Higher levels of fatigue
  - Emotional Health
    - Anxiousness
    - Low Mood
    - Irritability
    - Increased loneliness and isolation
  - Mastering New Skills
    - Related to caregiving and skills previously used by individual receiving care
    - Managing medical appointments
    - Finances
    - Support from healthcare system

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## Lit Review

- Barbic et al. cont.
- Participation in meaningful activities
  - Major change in activities they engage in
  - Less time for meaningful leisure
  - Impact on employment
  - Changes in volunteering
- New Theme
  - ***Recognition and Support for caregiver role***
    - Financial
    - Social/coping
  - Lack of support from family

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## Lit Review

- Barbic et al. (cont)
- Clinical Implications
  - Perhaps maintaining Emotional Vitality is important for maintaining the Caregiver Role
  - Important to assess when prior to patient going home
    - Getting supports in place
  - Consider assessing ongoing
  - Assess caregivers values, goals and needs: They are a major part of the equation

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## Lit Review: Caregiver of adults

Llanque, S. Savage, L, Rosenberg, N. & Caserta, M. (2014). *Concept Analysis: Alzheimer's Caregiver Stress*, Nursing Forum 2014.

- Varying Definitions of caregiver stress
  - "A person who provides direct care, who experiences bodily or mental tension resulting from factors that tend to alter an existing equilibrium" (authors)
  - "The emotional strain of caregiving (National Women's Health Information Center, 2006)
  - Unequal exchange of assistance among people in close relationship (Pearlin et al. 1990)
    - Perceived by the caregiver
    - Tension and fatigue

## Lit Review

- Llanque et al., cont.
  - Most common caregivers are spouses and parents (US Dept of Health and Human Services, Office of Women's Health, 2006)
  - Impacts of caregiver role
    - Elderly family caregivers of physically disabled-not able to leave house alone (Baines, 1984); need for recreational activities
    - Grandparents raising grandchildren: social isolation/restriction of role corresponded with increased psychological distress (Kelley, 1993)
    - Caregivers of adults receiving chemo: social support and coping serves to reduce stress ( Schumacher, Dodd, and Paul 1993)

## Lit Review

- Llanque et al., cont.
  - Caregivers of patients with AD
    - Increased depression and loneliness (Beeson, 2003)
    - Mental health issues (anxiety, depression, delusional thinking) (Bedard, Pedlar, Martin, Malott, & Stones, 2000; Connell, Janevic, & Gallant, 2001)
    - Higher risk of hospitalization (Alzheimer's Association, 2013)
    - Risk for burnout and chronic health problems, poor emotional and physical health (Kiecolt-Glaser, McGuire, Robles & Glaser, 2002)

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## Lit Review

- **Llanque et al., 2014** continued
- Antecedents of caregiver stress
  - Care receiver with a chronic illness
  - Lack of informal and formal support
  - Constriction of the caregiver's social life
  - Problematic behaviors expressed by the care receiver (attitude of the care receiver)
  - Cognitive status of the care receiver
  - Functional status of the care receiver
- Consequences of caregiver stress
  - Depression
  - Anxiety
  - Irrascibility
  - Cognitive disturbance
  - Poor health status
  - Yielding role
  - Role entrapment

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## Lit Review

- **Llanque et al., 2014** continued
- Clinical Implications
  - Caregiver stress is impacted by the perception of the individual
    - Similar situations with different impact
    - Unique perspective
  - Look to develop interventions tailored to the unique needs of the caregiver (manageable)
  - Communicate with Caregivers to understand their perspective
  - Develop caregiver stress assessment tools
  - Support systems for caregivers

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## Lit Review

- Srivastava, Grima et. al. ( 2016). *Caregiver Burden and Quality of Life of Key Caregivers of Patients with Dementia*. Indian Journal of Psychological Medicine, 38, 133-136.
- Examine the impact of caregiving for patients with dementia on caregiver's quality of life

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## Lit Review

- **Srivastava, Grima et. al. (cont.)**
  - 24 caregivers interviewed (50% male 50% female)
    - Average age 42 (+/- 8.44)
    - Duration of caregiving 2.7 (+/- 1.43)
  - Zarit Burden Interview & WHOQOL-BREF
    - Mild-moderate range of burden overall
    - “burden” increased with progression of symptoms and duration of care
    - Males greater burden in social relationships, incompetence and dependence
    - Females greater burden in expectation, management, dependence and overall burden was higher
    - Females had greater risk of depression overall
    - Males at higher risk for depression if caregiver for spouse

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## Lit Review: Caregivers of children

- **Shu, Bih-Ching (2009). The Quality of life of family caregiver of children with autism, *Sage Publications and The National Autistic Society* 13: 81-91.**
  - Explored the quality of life (QOL) of mothers of children with autism
    - Examined the physical, psychological, social and environmental domains
    - Contributing variables examined included demographic characteristics, history or chronic disease, mother's feelings regarding caring for children with autism
  - Major findings
    - Mothers feelings had biggest impact on quality of life overall. In particular, in the physical, psychological and social domains (similar results found in prior studies)
    - Mothers with history of chronic diseases has overall lower QOL ratings
    - Religion negatively correlated with the psychological and environmental domains (perhaps a more stressful situation)

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## Lit Review

- Shu, Bih-Ching
- Clinical Implications
  - Caregivers views/feelings regarding their child impacting their engagement in treatment process
  - Feelings impacting their ability to follow through outside the therapy setting
  - Seek to understand social supports for caregiver (social domain)
  - Involve more than one caregiver in treatment
  - Foster a positive experience in Treatment
  - Build off what child is doing, vrs focusing on deficits (Child may never be "normal")
- Limitations: does not define "better feelings"

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## Lit Review

- Sosanadhan. S. and Larkin P. J. (2016). *Parents' experiences of living with, and caring for children, adolescents and young adults with Mucopolysaccharidosis (MPS)*. Orphanet Journal of Rare Diseases, 11, 138.
- Mucopolysaccharidosis
  - Metabolic disorder
  - Bodies inability to produce specific lysosomal enzymes
  - Progressive cellular damage
  - Life-limiting

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## Lit Review

- Somanadhan et al. (cont.)
- Research has historically examined patient's journey, not considered caregiver journey in detail
- Aim of the study:
  - Understand and interpret parents' experience of living and carrying for a child with MPS
  - Examine the knowledge and understanding of MPS from the perspective of the parents
  - Explore the impact of regular hospitalization of children living with MPS on family

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## Lit Review

- Somanadhan et al. (cont.)
- 8 parents interviewed
  - 17 month period
  - 3 interviews
  - Interviewer reflected on themes that arose at previous interviews
- Themes Developed
  - Child-Parent factors
    - Challenges of getting diagnosis and chronic/progressive nature of the disease
    - Impact on child's quality of life/wellbeing
    - Stigma and isolation
    - Challenges of meeting child's progressing needs
    - Women more likely to take on role of caregivers (consistent with literature)
    - Strain on marital relations
  - Additional Healthcare factors
    - Financial strain
    - Frustration for accessing services
    - Mental Health needs of caregivers Unmet

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## Lit Review

- Halle, M.C., Le Dorze, G. & Mingant A. (2014). *Speech-language therapists' process of including significant others in aphasia rehabilitation*, International Journal of Language & Communication Disorders, 49, 748-760.
  - Aim: to explore how SLPs work with caregivers to engage them in rehab for patients with aphasia
  - Subjects: 8 SLPs, interviewed

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## Lit Review

- Halle, et al. cont.
  - Results
    - Including significant others in treatment was challenging yet a bonus
    - Challenges include
      - Limited access
      - The grieving process-sharing hard news
      - Preserve sense of "competence" as caregiver
      - Organization of team meetings
    - **Clinical perception impacted caregiver involvement in treatment**
      - Influenced by workplace environment
    - Greater Job Satisfaction
  - Further Clinical Implications
    - Examine concept of "patient"
    - Examine "Best-Practice" for working with patients and families
    - Positive impact on health of caregiver

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## Lit Review

- **Implications of Research in our *Clinical Practice***
  - Importance of including the caregiver in clinical decision making
    - Our clinical perspective impacts caregivers involvement in the treatment process
    - What supports do they need
  - Impact on engagement in the therapy process/follow through
    - Important to prioritize from the onset of treatment
    - To maintain role as care provider
    - Making things manageable
  - Caregivers attitude had impact on quality of life
    - Accessing caregivers “emotional” vitality
    - Ongoing assessment and adjusting supports
  - Greater risk of mental health issues
    - Need for further support/referrals for caregivers
    - Understand the caregiver’s support system
    - Increased “burden” with disease progression
  - Unbalanced care burden on females
  - Female/male caregiver role may have different impact on quality of life

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## Diagnosis with long-term Caregiver Needs

- Patients with the following dx as examples
  - Autism
  - Down Syndrome
  - Apraxia
  - Stuttering
  - Language Disorder
  - Alzheimer’s
  - Stroke
  - TBI
  - Hearing Loss

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## Grief

- *“You will not ‘get over’ the loss of a loved one; you will learn to live with it. You will heal and you will rebuilt yourself around the loss you have suffered. You will be whole again but you will never be the same. Nor should you be the same, nor should you want to.”* Elizabeth Kubler Ross & David Kessler

## Grief

- Moses, Ken. *The Impact of Childhood Disability: The Parents Struggle*. Ways Magazine, 1987.
  - Based on clinical experience working with families that have experiences “devastating and continuing loss”
    - Devastation of handicap in their child
    - Shattered dreams
  - Parents naturally have...
    - Dreams
    - Fantasies
    - Illusions
    - Projections
  - Observed 2 patterns in caregivers/families
    - Got Better
    - Got Worse

## Grief

- Realization that those that “got better” went through same *states of grief* involved in death *Surprised*
- Grief=way to separate from loss of dream
  - States vrs Stages
  - Each individual experiences in a unique manner/order
  - Not linear
  - Can move in and out of a state many times
    - “As often as the parent needs to experience it”
    - Continual learning from the “problem”
  - Impact of family, support system, culture
  - Each state assists in separation from lost dream

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## Grief

- Restricting experiencing/sharing feelings of grief=Stuck
  - Hold feelings in
  - Blame others/self
  - Disengage
  - Workaholic
  - Ect.
- Were “stuck” prior to having child
- “Experiencing and sharing the pain is the solution, not the problem”
  - Why is this relevant for us?
  - Do we have an opportunity?
  - Will this lead us to adjust our conversations with families?
  - How will this knowledge impact our ability to empathize?

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## Grief



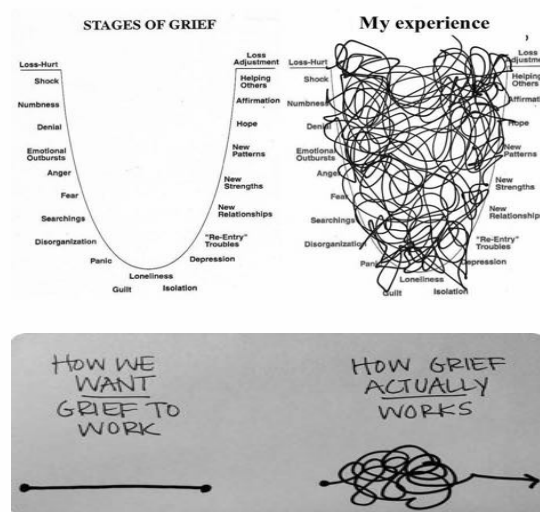
- What are some possible impact if you are “stuck” in a particular stage?
  - Caregiver?
  - Patient?

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## Grief



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**continued**™

## Interviews

- SLPs with family members that participated in therapy
- Questions to explore their role as a care provider and it's impact on their clinical perspective
- Not given questions prior to the recorded interviews

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## Questionnaire

- Please describe your relation to the individual in your family that received care
- Describe your role as a caregiver
- Describe your role as a supporter of the therapy process
- How did care providers that worked with your family seek to understand your perspective as a caregiver?
- How did your professional status impact your role and understanding of the therapy process?
- (when applicable) How did your clinical experience impact your ability to engage in the therapy process?
- What are some barriers that you found impacted your ability to support your family member in the therapy process?
- Please explain how your experience as a caregiver influenced your clinical practice
- What advice would you give to clinicians regarding working with the families?

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## Case 1

- Clip 1: Role as caregiver
- Clip 2: Supporter of tx process
- Clip 3: Hearing diagnosis
- Clip 4: Care providers
- Clip 5: Making it through
- Clip 6: Impact of professional status
- Clip 7: Realistic Expectations
- Clip 8: Grief
- Clip 9: Sharing your story
- Clip 10: Advice

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## Case 2

- Clip 1: Role as caregiver
- Clip 2: Management/impact on schedule
- Clip 3: Diagnosis
- Clip 4: Grief
- Clip 5: Grief, cont
- Clip 6: Searching for a reason
- Clip 7: Impact of work experience
- Clip 8: Prioritizing
- Clip 9: Financial burden/Time
- Clip 10: Medical bills
- Clip 11: Impact on clinical work
- Clip 12: Advice

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## Cases cont.

- Clinical Themes from Cases
  - Impact of hearing the diagnosis
  - Prioritizing in therapy: what is realistic for each family
  - Experience of grief process
  - Stressors: time, financial, schedule
  - Need for a support system: family, friends, counseling
  - Importance of **Listening** to the caregivers
- Common Barriers to Involvement
  - Time
  - Changes needs and priorities of the family
  - Finances
  - Possible grief

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## Cases cont.

- Parallels between Case Studies and Research
  - Need for supports for caregivers
    - Mental Health
    - Direct care providers
  - Stressors: time, medical management, finances
  - Impact on employment status (2<sup>nd</sup> case)
  - Challenge in receiving diagnosis
  - Impact on family activities

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## Take-Away recommendations from Case Studies

- Create a therapeutic environment that allows for **Listen** to the families story
  - Impact on therapeutic relationship
  - Impact on engagement in treatment
- Grief processing is a natural part of the process
- Be mindful of the impact of caregiver role on the individual
  - Need for further support
  - Realist expectations: negotiate with families what is reasonable for them
- When giving a diagnosis
  - Is this the first time for families??
  - Be present and available
- **WHAT** is **YOUR** take away message from the day ...

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## Helpful Clinical Tools

- Active Listening
  - Reflective Listening
  - Facilitate objective Problem Solving
  - Using affirmations
- Solution Focused Brief Therapy (SFBT) Overview (Steve de Shazer & Insoo Kim Berg)
  - Helps client discover strengths in management
  - Fosters autonomy
    - The Miracle Question
    - Scaling Questions
    - Exception-Seeking Questions: find what works
    - Coping-questions

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## Helpful tools, cont.

- Motivational Interviewing Questions (Miller & Rollnick)
  - Evoking Change Talk
    - Scaling Questions
  - Resolving Ambivalence
- ACT (Steve C. Hayes, later Robert Zettle)
  - Therapy rooted in the values of the patient and family
  - Moving forward even when things are challenging
  - Exploring discrepancies between behavior and values
  - Rather than avoid or react- ACT
- Remember to include the Caregiver In Therapy Planning/Discharge

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## Clinical Practice Take-Away: Practice

- Please explain how your experience as a caregiver influenced your clinical practice (Parent/Child)
- How have care providers worked to understand your perspective as a caregiver?
- What are some barriers that you found impacted your ability to support your family member in the therapy process?
- A particular client and their family that significantly impacted your clinical perspective

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## Take-Away, cont.

- Questions for Reflection
  - How has your perspective deepened/shifted?
  - How will you apply new knowledge from today to your daily clinical practice?

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## Thank You

- My Personal Journey: How I re-engaged
- Thank you for attending!!!

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