KentuckyOne Health™

Care of the ALS Patient:

Psychological Services for Patients and Families

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Psychological Services - ALS

- I have the **following relevant financial relationship(s)** in the products or services described, reviewed, evaluated or compared in this presentation.
  - University of Louisville Office of Continuing Medical Education and Professional Development
    - Financial compensation for speaking
  - Frazier Rehab Institute
    - Employee
- I have **no relevant nonfinancial relationship(s)** to disclose.

Quality of Life

Psychological Services - ALS

Quality of Life – defined:

A broad ranging concept affected in a complex way by a person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features in their environment.

-World Health Organization, 1998

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In patients with ALS, quality of life has been reported to be negatively correlated to suffering, a sense of burden, and hopelessness, and positively correlated to social support.

(Epton, Harris, and Jenkins, 2009)

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It has been found that quality of life in ALS patients was more likely to be related to the psychosocial aspects of life than the physical aspects.

(Clarke, et al, 2001)

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Research has concluded that patients with ALS and their caregivers would benefit from some kind of psychological or psychosocial intervention, however, there is no literature on the efficacy of such interventions.

-Wijesekera & Leigh, 2009

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At our clinic, the focus of psychology services for patients with ALS:

Assessing and addressing the biopsychosocial adjustment of individuals with ALS and their families/caregivers.

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- ►Initial psychology clinic visit with a patient and family:
  - – Traditional/brief clinical interview
  - – Assessment of caregiver coping and available social/family support
- ►Follow up re-assess/therapy session approximately every three months

Mood

- Psychiatric history
- Depression
- Anxiety
- Grief
- Bulbar-onset ALS/mood lability

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Common psychological symptoms that ALS patients experience and that impact quality of life:

- Emotional lability/excessive and inappropriate laughter or crying, most frequently experienced by those patients with bulbar-onset ALS (approximately 30-50% of patients)
- Depression (11-75% of patients)
- Anxiety (up to 33% of patients)
- Fatigue (75-83% of patients)

Grief:

A normal reaction to change or loss.

Understanding Grief

- Educating regarding the stages of adjustment
  - Denial
  - Anger
  - Bargaining
  - Depression
  - Acceptance

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Interventions for mood:

- Medication management
  - Selective Serotonin Reuptake Inhibitors (SSRIs – Celexa, Lexapro, Prozac, Paxil, Zoloft, etc)
  - Selective Serotonin and Norepinephrine Reuptake Inhibitor (Cymbalta)
  - Nuedexta (bulbar-onset ALS)
  - Anxiolytics

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Interventions for mood:

- Behavioral Interventions
  - Identification of feelings and supportive counseling
  - Education about disease and disease process
  - Cognitive-Behavioral therapy
    - Thought restructuring
    - Relaxation training
    - Identification of additional coping skills

Caregiver and family functioning

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- Research has shown that the burden experienced by ALS caregivers is severe.
- Caregivers who believe that they cannot leave the patient are most distressed.
- Caregivers are often found to have increased anxiety and depressive symptoms.
- It is important to identify factors relevant to quality of life for both the patient and the caregiver.
- Perceived social support is an important predictor of caregiver distress and marital relationship satisfaction.

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Self-care for caregivers:

- Routine/planned breaks
- Attending to their own medical needs/care
- Willingness to accept help that is offered or ask for help when needed
- Awareness that patient's perception of caregiver burden is negatively correlated with patient coping/QOL
- Support group

Resources

Local Support Group

Patricia Peak

Care Services Manager

The ALS Association Kentucky Chapter

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The ALS Association

www.alsa.org

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Questions and Comments