Coping EB review


Use of strategies for coping that are congruent with one’s own core values & beliefs can be most effective. Even nuns with physical impairments expressed willingness to help others. Altruism is a value in their community. Close knit community...with physical impairment they can still be present for others, listen and console. They still have gifts to offer to help others.


Caregivers (CGs) of person's with dementia experience stress and burden due to the caregiving role, which negatively affects their physical and psychological health. Caregivers utilize various coping strategies, including relying on social support and using religious and/or spiritual practice to deal with the daily stress and burden of providing care. The main goal of this study was to examine two specific means of coping, namely, social support and religious and spiritual coping, and the relation of these coping mechanisms to physical health outcome. 435 people were studied. 61-84 years of age. CGs who relied on social support networks had better physical health. Implications of understanding coping mechanisms that CGs use which may inform the development of interventions to improve physical and psychological outcomes for CGs will be discussed.


Sense of self is challenged. Support groups: in person versus virtual. Could be run by a professional. Many today are run by volunteers. Seeing people with the same disease who are better or worse than oneself can be disturbing. Virtual groups-advantages: flexibility. Can get benefits of group without being physically present. A sense of anonymity encourages fuller communication. One can discuss any aspect of the disease: diagnosis, treatments, coping, equipment and resources...only thing not allowed is to criticize another group member for their perspective. Courage is required for participation. Roles vary and can change wot time and circumstances. People may need assistive technology to participate.


When diseases are long-term (such as surviving cancer)...the early phase is “accommodation and mitigation”. The individual strives to find ways to live life with the ongoing presence of the disease. In the chronic phase: “existence and extension”. The chronic phase may be deeply affected by the nature and symptoms of the disease. In diseases with slow, continuous patterns of decline, the family and individual have to cope with the psychological distress of constant and continued deterioration. “Every night I wake up weaker.” Relapses and remissions versus periods of stability, may be followed by sharp
declines in function. The particular symptoms of the underlying disease. Hard to anticipate contingencies. Varied crisis points occur. Disposition can have a major impact, such as when a person goes to a nursing home versus to their own home. When one loses mobility-such as needing a wheelchair. Chronic phase may allow a return to work or school. It can be a new opportunity to renew or resume relationships. Tasks may include: managing symptoms ad side effects; Carrying out medical regimens; preventing and managing medical crises; managing stress ad examining coping; normalizing life in the face of disease; dealing with financial concerns; preserving self-concept; redefining relationships with others throughout the course of the disease; ventilating feeling and fears; & finding meaning in suffering, chronicity, uncertainty or decline.

Pain control is critical in the chronic phase-and it can be difficult. Pain is influenced by physical factors, but is also influenced by psychological states, spiritual concerns, or social factors. Some measurements used to measure general adaptation to disability are: Quality of Life Scale (QOL), Psychological Adjustment to Illness Scale (PAIS), the Million Behavioral Health Inventory (MBHI), the Reactions to Impairment and Disability Inventory (RIDI), and the Handicap Problems Inventory (HIP).

Clients may also need to explore the full meaning of the impact of the chronic illness disability on their own quality of life and sense of identity.

New behaviors also come with survival: adhering to a medical regimen-such as ongoing chemo treatments or massive changes in diet or lifestyle. Adherence versus compliance.

Situational barriers-crises, for example can be social barriers (lack of flexibility re when to eat/what to eat, for example. Chaotic lifestyles characterized by constant crises. It may be too difficult to balance the demands of simultaneous regimens. A therapeutic alliance amongst caregivers, treatment team members and the individual may be necessary. Intervention usually works best when the individual actively seeks input. Alliance involves respecting people’s choices. Contingency plan need to be developed for how to respond in a medical crisis. If people travel, they need contingency plans. If they lie alone, for example, they may require periodic reassurance calls.

Living with disease is stressful in and of itself: varying degrees of diminished capacity, energy, and resources, as well as pain, psychological distress and increased demands of treatment.

Assuring social support and minimizing social isolation re needed over time. There can be social saboteurs-beware. Factors that can contribute to isolation are: physical capacitation, stigma, immobility, shrinking social roles, other’s discomfort and fears or anxieties, or other psychological factors that inhibit interaction. Each of these can be readdressed and strategies can be developed to overcome social isolation. Try to normalize life in face of the disease. Sexual relationships may suffer. PLISSET Model: permission, LI: limited information, SS-specific suggestions and IT-intensive therapy.

Other factors: decisions about leaving work. Financial concerns. Four step process: 1. Become aware of the cost of illness-budget; 2. Identify resources from family and community; 3. Explore one’s own resistance and reluctance; 4. Financial planner may be of help-decisions about liquidating assets.

Preserve self-concept (‘look good/feel better’). Work to avoid the ‘Gregor effect’ (Metamorphosis). Life threatening illness can change relationships.
Help people through feelings that intensify such as fear of increasing disability, dependency, and dying. Challenge assumptions, rationalizations, and other defenses. Prayer, meditation or change behaviors may help. However, crises can overwhelm defenses and result in strong affect and anxieties. Discussing individual meaning to the functional change is important. Emotions can ‘bounce’...sometimes people may feel positive and upbeat/ at other times, they may feel depressed, angry or lonely. Venting emotions may allow clients a sense of resolution and comfort.

Finding meaning in suffering, chronicity, uncertainty or decline. Frankl (2004): while one may have no choice about suffering, one has choices within suffering.


In this study, authors analyzed the dyads’ responses on the SF–12 to discover how each member viewed their own and each other’s QOL in two domains: physical and mental health. The results revealed perspective differences and similarities within the dyads. In terms of the more readily observed physical condition, patients with ALS and their caregivers gave similar ratings of each other’s status. However, regarding mental, social, and emotional well-being, patients with ALS and their caregivers did not have accurate views of the other’s mental state. This highlights the importance of clinicians emphasizing communication between patients and their caregivers in relation to each other’s emotional well-being, including spirituality, social wellness, and overall mental wellness. Patients with ALS most frequently scored themselves as more burdensome than their caregivers rated them on the questionnaire. Although the caregivers may have felt that caregiving for their loved one added value and meaning to their life, the care recipients may have viewed caregiving only as adding burden and stress to the life of the caregiver.


Stigma is a common problems regarding people who have borderline personality disorder. Caregivers often do not give the same level of care to people who have a diagnosis of borderline personality, because they have been classified as being ‘untreatable’. Personality disorder is defined as ‘any disorder in which an individual’s personal characteristics cause regular and long-term problems in the way they cope with life and interact with people, and in their ability to respond emotionally.’

Team approach to care, listen to the person, validate and display an understanding of their emotions, display hope and optimism, increase self-awareness/ be aware of the effect that interpersonal and physical interventions can have on a person with BPD. Treat self-injury with the same level of empathy as if it had occurred accidentally.

Engage with people who have BPD-break the cycle of sub-standard care.

Debrief after interval of care with team.

Use collaborative team approaches (mental health team with primary care team)

Recognize counter-transference (can decrease CGs negative thoughts).
33 subjects were recruited and evaluation of coping was made at 3 and 6 months following diagnosis with ALS. Tools used: the Motor Neuron Coping Scale, the Hospital Anxiety & Depression Scale, & the ALS Functional Rating Scale. No differences were found between the sexes. Changes were found between the first and second interval (as symptoms progressed). Support and independence were the most used coping strategies. The use of strategies changed over time.


Lazarus and Folkman’s stress and coping theory. 3 broad coping strategies-cognitive appraisal, coping strategies, and coping resources. The result of the appraisal indicates to what degree the person views the process as stressful. People adjust their appraisals with experience. Coping is a dynamic, transactional process responsive to internal and external feedback loops.

According to stress and coping theory models: appraisals, coping strategies, and coping resources have the potential to mitigate or exacerbate the negative physiological and psychological effects of stressful events.

Difficulty doing self-care, having distressing emotions, relationship difficulties are frequently experienced. The number of physical distressors were related to poor adjustment in the areas of global distress and social role functioning. There are stressors from physical illness, practical, social, interpersonal psychological and existential issues/concerns. Dwindling support network, abandonment, perceived stigma, uncertainty and feelings of loss of control, unpredictability, presence of exacerbations makes uncertainty worse. Increasing disability with loss of employment, career, income, mobility, engagement in valued activities, energy and physical strength with fatigue limit participation.

Cognitive processes: perceived threat, challenge & controllability. ... ‘current worst adjustment’ as being the mediator.

Rebuilding meaning

Coping is enhanced by 1) finding reasons or an explanation for what has happened and 2) looking for the positive aspects of the event (sense making and benefit finding). Depends on person’s sense of self-worth, controllability, and predictability.

Making sense inventory-16 sense making themes/multi item scale.

Coping strategies “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person”. Problem-focused, emotion-focused, or meaning focused strategies. Emotion focused( those that are directly dealing with distress-regulation of avoidance or approach); Meaning-focused (creating, reinstating, or reinforcing meaning and include positive reframing, prayer, rearranging life priorities, finding the positives, and making sense of the event. Such as ‘who am I to complain when there are others who are worse off). Flexibility when dealing with change seems to be most valuable.
Coping resources: optimism, social support, disposition (hope & hardiness), external (financial & community assets). Optimism is generalized expectation of favorable outcomes. The higher the optimism, the better the psychological functioning/ability to mitigate negative stressors. Social support includes practical, emotional and material support. Feeling as though someone is hearing what you are saying/that people listen to you, especially with symptomology. Primary caregiver support is one of the most important supports. The problem w social support may be when communication is impaired. It is too difficult to interpret non-verbal communication cues. Stigma can be a barrier to social support. Higher perceived social support aides coping adjustment to disease and disease progression. Professionals must address/manage social support deficits, especially those associated with interpersonal conflicts, refusal to accept help, and mismatches in support. Coping strategies that hinder include: avoidance of internal feelings and thoughts and external unwanted symptoms and disability, with a focus on threat of stressors. There is no good, absolute good or bad coping skill or process. The production of the desired outcome is what counts. Manifestation of adjustment difficulties (ongoing distress, interpersonal conflict, and withdrawal) may indicate a problem with adjustment and coping that requires further intervention.

Assessment is individualized. Interview person and their caregiver. Reframe a perspective on what is currently happening in their disease process and factors that may be currently affecting their ability to cope (crises). Appraisal measures: 7 point scale 1-npo harm to 7-extemely harmful. 18 –item measure of self-efficacy (the MS self-efficacy scale (2 subscales w 9 items each). Focuses on self-efficacy expectation and function and control. 30-item uncertainty of illness scale-items are rated on a 5 point Likert scale.

Benefit-finding measures:

Generic measures of benefit finding include:

The Stress-related growth scale-revised (SRGS-R)

The Post Traumatic Growth Inventory (PTGI)

Benefit Finding in Multiple Sclerosis Scale (BiFMSS)-43 potential benefits, 7 psychometrically sound benefits: compassion/Empathy, Spiritual Growth, Mindfulness, Family Relations, Growth, Life Style Gains, Personal Growth, and New Opportunities.

Sense-making measures:

Sense Making Scale (SMS) Pakenham-38 items, specific to MS, 5 point rating scale (strongly agree-strongly disagree). Factor analysis revealed 6 factors: Redefined life purpose, Acceptance, Spiritual Perspective, Luck, Changed values and priorities, and Casual attribution. Psychometrically sound except for ‘luck’. Weak social desirability scale re Acceptance. SMS is not greatly influenced by social desirability. All constructs are correlated with one or more of the generic meaning constructs (it has convergent validity), SMS factors were able to predict positive and negative outcomes in care-giver – rated assessment of the person in their care.
Coping strategy measures:
COPE-brief COPE
Revised Ways of coping questionnaire (WOCQ) Pakenham-7 point rating scale (1-not at all stressful to 7-extremely stressful); 4 point scale: 0-does not apply to 4-very often re how often they used each of the 29 coping strategies in dealing with their main problem. Factor analysis revealed 7 factors: Problem solving, physical assistance, Acceptance, Avoidance, Personal health control, Energy conservation, and Emotional release.

Coping resource measures:
General support scales:
Zich & Temoshok- availability, use, and usefulness of emotional, problem-solving, physical and indirect personal support. 3 subscale scores: availability, utilization and usefulness of social support. Brief measure of satisfaction with social support -6 item Social Support Questionnaire. Rate level of satisfaction with several types of support.
Brief measure of satisfaction with social support- 6th item on the Social Support Questionnaire-rate satisfaction, 6 point scale: 4 filler items/ 6 optimism items, 5 point scale

Stressor measures
Holmes & Rehe Readjustment Rating Scale-43 life events
Hassles Scale-117 common stressful events

Identify and target coping processes –discuss outcomes of measure and focus on the areas the person wishes to address

Treatment:
Focus on cognitive appraisal, coping strategies, coping resources

Specific strategies/treatment approaches:
Cognitive behavioral therapy (CBT)-identify problems 1 by 1, then replace dysfunctional thinking with more adaptive strategies: identify problematic behaviors and dysfunctional thinking with more adaptive behaviors and thoughts using classical conditioning, operant conditioning, or modeling. CBT techniques include: systematic desensitization, exposure, contingency management, self-monitoring, behavioral rehearsal, and cognitive restructuring (replacing negative thoughts with more adaptive thinking).

ACT-3rd generation CBT: uses mindfulness, acceptance and behavior change through 6 core processes: acceptance, cognitive diffusion, and contact with present moment, self-as-content, values and developing willingness to behave in ways that are harmonious.

This study explored differences in perspectives on quality of life (QOL) between people affected by amyotrophic lateral sclerosis (ALS) and their caregivers. QOL is often thought of as related to physical limitations, without consideration of other factors (e.g., cognitive, emotional) that may be stronger predictors of QOL in people with long-term degenerative diseases. Because QOL is complex and influenced by multiple factors, people with ALS and their caregivers may have different perspectives on what constitutes QOL. This study investigated potential discrepancies in QOL perspectives between people with ALS and their caregivers. Thirty dyads from the Augusta University Health ALS Clinic completed a measure of QOL, and we compared the results and identified patterns. The most prominent finding was that members of the dyads misunderstood the mental experiences of one another.


Created from drake on 2017-04-18 12:32:36.

Overview:

-Sleep–wake disturbance is seen as a major component of virtually every neurodegenerative disease
- Symptoms arising from poor quality sleep and impaired daytime wakefulness may mimic those arising from the underlying neurodegenerative process
- Patients with Parkinson’s disease (PD) can develop virtually any type of sleep-related symptom, often in advance of physical or motor signs of the illness
- Fragmented overnight sleep and narcoleptic levels of daytime sleepiness are relatively common in PD and increase with age
- Motor symptoms responsive to dopaminergic therapy may account for many overnight symptoms in PD
- Advanced PD with cognitive impairment is associated with very severe sleep disturbance, often with hallucinations and nocturnal confusion
- Alzheimer’s disease (AD) commonly leads to disturbed circadian rhythms and sleep–wake disturbance, often with minimal insight from the patient
- Promoting daytime alertness by non-pharmacological means may improve quality of life in AD sufferers
- In motor neuron disease (MND), an early sign of diaphragmatic weakness is poor quality overnight sleep with daytime lethargy secondary to nocturnal hypoventilation
- Non-invasive ventilation is now an established and proven
treatment for many MND patients with hypoventilation


There has been a change in disease classification and management: advances in genetics (*C9orf72 gene*) have changed classification to viewing MND as a continuum of other primary neurodegenerative disorders, including frontotemporal dementia.


Chronic stress may “get under the skin” and alter human development and impact later health. The study found that negative circumstances during childhood, collected prospectively through a British cohort, could be associated with physiological wear and tear in midlife (allostatic load). There is a biological adverse reaction between childhood exposures and adult health.

Allostatic load is "the wear and tear on the body" that accumulates as an individual is exposed to repeated or chronic stress. It represents the physiological consequences of chronic exposure to fluctuating or heightened neural or neuroendocrine response that results from repeated or chronic stress.


OT educators and practitioners should collaborate with students to educate, learn, and practice using an array of clinical and self-care tools to provide compassionate patient-centered care. Mindful awareness and self-care protocols may guide occupational therapy practitioners, educators, and students to access adaptive coping skills. Combating stress, compassion fatigue, and burnout states becomes possible while making room for essential, attentive presence in student and therapeutic encounters—and greater patient and student outcomes and satisfaction is a potential outcome.