Mental Fatigue in Family Caregivers of Cancer Patients

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Overview

• What is attention
• Mental Fatigue
• Family caregivers
• Mental fatigue and family caregiver research
• Directions for future research
Define Attention

- Focus
- Concentrate
Attention

• Taking possession by the mind in a clear and vivid form of one out of what seems several simultaneously possible objects or trains of thought.

William James 1863
The immediate effects of attention make us a) think, b) perceive, c) distinguish, d) remember, better than we otherwise could, and e) shortens reaction time.

Two Kinds of Selective Attention

• Involuntary
  o Spontaneous, effortless inhibitory response based on interest
  o Sources: survival, natural, novel, valuable

• Voluntary - directed attention
  o The capacity to actively block distraction by sustained application of mental effort
  o Sources: intentions and purposes
Directed Attention

- Problem solving
- Effective social/interpersonal functioning
- Establishing goals
- Formulating and carrying out plans
Common Daily Demands On Directed Attention

- **Informational:** Distractions e.g., noise, multi-tasking, attending meetings and conferences
- **Affective:** Worries, concerns, loss
- **Behavioral:** Constraints, unreasonable expectations
- **Physical:** Bad weather, poor vision/hearing, pain

(Cimprich, 1990; Jansen, 2000; Kaplan, 1995).
Mental Fatigue

Attentional Fatigue

Cognitive Fatigue
Mental Fatigue

Attentional Fatigue
Cognitive Fatigue

- The waning ability to inhibit distractions
  - Irritability
  - Making mistakes
  - Socially inappropriate behavior
Attention Restoration Theory

• Feeling of being away
• Sense of fascination
• Extended feelings
• Compatibility between person and environment; permits a person to function based on his/her purposes
Nature Intervention Research

• Children with attention deficit disorder
• College students
• Heart failure patients
• Women with breast cancer
Mental Fatigue in Women With and Without Breast Cancer

- 95 female volunteers; 47 newly diagnosed breast cancer and 48 without breast cancer
- Inclusion criteria: Mini Mental State Examination score of $\geq 20$, no history of cognitive fatigue or mental disorders, not taking medications known to impair or enhance attention, command of the English language

- Cimprich and Ronis, 2001
Digit Span: repeat a string of digits read aloud at a rate of one per second.

- Digit Span Forward measures the number of digits a person can attend to at one time.
- Digit Span Backward requires sustained attention to mentally track, manipulate, and recite the string of digits in reverse order.
- The score is the number of correct responses within a 90 second period.
The Necker Cube Pattern Control Test

- Measures the ability to inhibit competing stimuli or to direct attention.
- Three dimensional wire cube, can be viewed from two different perspectives with reversals of the foreground and background.
- Maintaining focus on one of the patterns requires inhibition of the active alternative.
• Symptom Distress Scale
  o Measures degree of distress experienced in relation to 10 common symptoms: fatigue, insomnia, mood disturbance, loss of appetite, nausea, pain, loss of concentration, bowel disturbance, changes in mobility and appearance.
Cancer and the Family
Cancer and the Family

• Diagnosis of cancer affects family and friends
  o Family Systems Theory
    • The family as a whole is greater than its parts
    • A change in one family member affects all family members
    • The family is able to create a balance between change and stability (Wright & Leahey, 1994).

• Family and friends are primary source of support to people with cancer
• Assist patients with symptom management and other demands associated with cancer.
• First to recognize changes in patients’ health status in the community setting.
Schulz and Sherwood (2008) describe caregiving as a chronic physical and psychological stress experience.

Exposure to chronic stress provokes secretion of catecholamines and glucocorticoids. Prolonged exposure to these cytokines negatively affect synaptic plasticity and loss of neurons.

Could lead to diminished attention, memory and learning.
Caregiver and Stress

- Caregivers experience as much emotional distress as patients (Northouse et al., 2002).
- Caregivers of terminally ill family members demonstrated significant impairment in attention, including reduced monitoring of self-performance and concentration (Mackenzie, Smith, Hasher, Leach & Behl, 2007).
Mental Fatigue in Family Caregivers of Cancer Patients
Study Aims

• Examine the experience of mental fatigue in family caregivers of patients participating in Phase I clinical trials
• Evaluate the extent to which caregivers’ perceive that mental fatigue interferes with their caregiving
• Identify the type of distractions that affect caregivers’ ability to direct attention
• Examine strategies that caregivers use to manage mental fatigue
Methods

• Descriptive cross-sectional study using qualitative methodology
• 79 family caregivers of patients who were participating in a Phase I clinical trial were interviewed for the study
• Caregivers were eligible to participate in the study if they met inclusion criteria:
  o 18 years or older
  o Identified by patients as their primary caregiver (i.e., provider of emotional and/or physical care)
  o Cognitively intact (score > 24 on the Mini Mental State Exam)
  o Had command of the English language
Data Collection

- Demographic questionnaire
- Researcher devised qualitative questionnaire made up of open-ended questions
  - Caregivers’ definition and experience of mental fatigue, self care and symptom management
Results

- Average age of family caregivers 54.8 years (range 18-80)
- 63% female
- 58% Caucasian
- 56% college educated
- 39% reported an annual household income greater than $75,000
- 58% spouses
- 48% worked outside the home
- 58% reported having at least one co-morbidity
Themes Obtained From Qualitative Data

- Caregivers characterization of mental fatigue
- Ways caregivers manage mental fatigue
- Benefits of caregiving
Caregivers Characterization of Mental Fatigue

- Definition of mental fatigue
  - Feeling tired
  - Difficulty concentrating
  - Being overwhelmed by the circumstance
    - A husband reported “Feeling tired, depressed, while trying hard to be optimistic.”
    - “My mind churning and thinking of stressful decision continuously.”
    - “Challenged beyond my capacity to cope, and not having enough recovery time.”
      - These quotes indicate the caregivers were able to clearly describe what mental fatigue meant to them.
Problems with memory and concentration

- A wife stated, “My short term memory has become basically non-existent.”
- A husband admitted to having difficulty “Remembering to remind the patient about timing of drugs, remembering conversations, and social activities.”
- A daughter that manages a veterinary clinic said “I have had trouble remembering to do basic things like feed my dogs. I had to make a calendar for me to check off because they were either getting fed too much or not at all.”
- A wife wrote, “If I am getting his medications together or doing his dressings and have to stop for something else, I sometimes forget what I was doing.”
- A husband shared, “I turn pages in a book but don’t know what the words meant.”

Each of these statements characterize caregivers’ problem with memory and concentration.
Caregivers Characterization of Mental Fatigue

- **Effect on caregiving role**
  - A female relative explained, “I feel like there’s so much to take care of that’s so important. Feel I may not be doing my best.”
  - A wife stated, “I’m sure I have been short with Joe at times.”
  - Another relative explained, “When I feel tired and overwhelmed it can make me short tempered.”
  - A son disclosed, “I tend to be shorter and more easily annoyed with her at times.”
  - A sister commented, “I may sometimes snap at him or not be fully attentive, then we both feel bad.”
Caregivers were asked to identify distractions to directed attention, most mentioned persistent intrusive thoughts.

- A wife stated, “Knowing my husband is not feeling well, or his tumors appear larger.”
- Another wife listed, “The cancer, making sure he is eating correctly, getting exercise, and keeping his mood positive.”
- A few husbands summarized, “Thinking about my wife’s condition,” “Worrying for my loved one, making sure she is following her regimen,” and “Making her always the first priority.”

Most caregivers reported that they provided high quality of care but were irritable at times and distracted by worry and concern for their loved one.
Caregivers Characterization of Mental Fatigue

• **Effect on own self-care**
  
  o A granddaughter stated that “I spend more time doing things for her, leaving less time for my life.”
  o A wife stated, “I have less overall care for my appearance. I forget to take medications and exercise. I am diabetic and not following my diet as close as I was before.”
  o A husband wrote, “I don’t care for myself well at all. I need to and my doctor is trying to get me on a better track. But I will always put my wife and kids before myself.”
  o A sister reflected, “I spend less time on physical appearance.”
  o A husband noted, “I feel uninterested about my health.”
  o Another husband wrote, “I’ve been drinking alcohol more to cope.”

  • These examples indicate the majority of caregivers had difficulty with self-care
Theme 2: Management of Mental Fatigue

- **Self-care strategies**
  - 38% stated that they use rest as a means to manage mental fatigue.
  - 30% exercised
  - 14% talked the situation over with family and friends
  - 13% read
  - 8% self-medicated
  - 6% watched television
    - A wife wrote, “I take a nap, watch some up-beat TV to change the outlook of my mind that keeps running over and over the same things.”
    - A sister shared, “Reassign activities to something physical.”
    - A husband mentioned, “Play basketball and talk with good friends.”
    - A wife stated, “Take a Xanax as needed—it helps me breathe.”
Theme 2: Management of Mental Fatigue

• Caregivers were asked to identify ways the healthcare system could assist them in managing mental fatigue.
  o 19% wanted to have more social support available, i.e., social worker, group and individual resources,
  o 10% reported being satisfied with the support they received.
  o 16% wanted more information
  o 8% listed including the caregiver in discussions
    • A husband mentioned, “Keep things as simple as possible. Verbal pats on the back. Include caregiver in conversations. Understand caregiver has own pain.”
    • A wife cited, “Listen to the caregiver’s assessment of what is happening to the patient. Include us in the treatment plans.”
Theme 3: Benefits of Caregiving

• 29% of caregivers relayed that caregiving is hard work
• 25% described the role of caregiver as fulfilling.
  o A daughter wrote, “No matter how crappy or overwhelmed I’m feeling I wouldn’t have it any other way. I love the relationship I’ve formed with my mom’s health team. No matter what, I know I’m doing everything I can. It’s totally exhausting!”
  o A friend remarked, “I am honored to have the opportunity. I am a cancer survivor myself.”
  o A husband noted, “It’s a tough job but I would do anything for Susan.”
  o A daughter wrote, “Prior to becoming the primary caregiver I focused more on myself and my happiness. This illness was a tornado of events and has thrown my life out of whack. I have not been able to do things/enjoy as much. However I would not give up the opportunity to be with my mother and help her through this.”
Family Systems Theory

- The family as a whole is greater than its parts
- A change in one family member affects all family members
- The family is able to create a balance between change and stability (Wright & Leahey, 1994).
Clinical Implications

- Caregivers experienced mental fatigue while providing good care.
- Caregivers reported a compromise in their own health to provide high quality of care.
  - Healthcare professionals need to give attention to the health care needs of the family caregivers.
  - Healthcare providers need to assess the health practices of caregivers and encourage them to attend to their own health so that they can continue to provide care to the patient.
Clinical Implications

- Health professionals need to provide information to caregivers about the nature of the patient’s illness and treatment for it and also inform them about resources available to obtain support.
- http://www.rosalynncarter.org
- Many caregivers may not be able to attend support groups, providing them with reliable websites or community resources may be alternative ways for them to obtain support.
- Tailored information to address the unique needs of caregivers at the individual level may help caregivers cope.
Clinical Implications

- Encourage caregivers to spend time in nature, viewing pictures of nature
- Conserve directed attention by minimizing excess noise and distractions in the environment
- Decrease time constraints
- Streamline large tasks into smaller objectives and provide structure to daily routine
  - (Cimpirch, 1995)
Directions for Future Research
Directions for Future Research

• Apply attention restoration theory to family caregivers of cancer patients.
• Will spending time in nature benefit the family caregiver?
• Will looking at photographs of nature supply restorative benefit?
• Will listening to recorded waves or nature sound during periods of respite restore attention fatigue?
Thank You

Questions?