The Stress of Caregiving for Ill Family Members: Impact on Health Outcomes

Presentation by:
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Chronic Illness in the US

- Chronic illness and disability among adults and children affect more than 20.3 million families in the United States representing about 30% of all households.

Increase in People Living with Chronic Conditions

Why should we be concerned?

- **Demographic trends**
  - baby boomers age and the U.S. population becomes increasingly older

- **Increases in the prevalence and incidence of chronic illness**
  - Along with shrinking pool of family caregivers

- **Sandwich generation**
  - New caregiving responsibilities for the first time in history
Growth in Caregiver Households

Millions

Source: Family Caregiving in the U.S. 1997
Proportion Of Caregivers Who Say Their Own Health Is Fair Or Poor

- All caregivers: 17%
- Level 5 caregivers: 35%
- Lower income (<$30k): 38%
- Living with care recipient: 26%
- Caregivers 50 or older: 24%
- Lower educated (HS or less): 24%

Base: 1,247 caregivers in the U.S.
Caregiving Creates More Emotional Stress than Physical Strain

- 35% of caregivers say taking care of the person they help is stressful (NAC, AARP, April 2004)
- Caregivers who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than noncaregiving controls (Schulz et al, 1999)
Demands, Coping, and Subjective Health Complaints

Family Socio-demographics, Health, and Mental Health

- Research on Childhood Disability and the Family
- Qualitative Research on the Experience of Informal Caregiving
Background

- Childhood chronic illness and disability are potential stressors
- Children with disabilities are at increased risk for psychological morbidity, as are their family members
  - Research indicates that
    - family factors may be more predictive of mental health than disease parameters
    - May have an elevated need for mental health services
- Clinical data exists
  - Paucity of national data
Trends In Prevalence Of Disability Due To Asthma And Other Conditions Among US Children Younger Than 17 Years, NHIS
National Study

- Family factors affecting psychosocial adjustment of children with disabilities
- 1994-5 National Health Interview Survey, Disability Supplement
Family Factors Significantly Associated to Poor Psychosocial Adjustment Among Children With Disabilities

<table>
<thead>
<tr>
<th>Odds Ratio (95% Confidence Interval)</th>
<th>Full Model</th>
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<tbody>
<tr>
<td>Child fair or poor health status</td>
<td>0.9 (0.6-1.4)</td>
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<tr>
<td>Child's functional status</td>
<td></td>
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<tr>
<td>Limited functioning in self-care or mobility§</td>
<td>1.1 (0.7-1.7)</td>
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<tr>
<td>Limited functioning in communication§</td>
<td>1.6 (1.2-2.1)†</td>
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<tr>
<td>Limited functioning in learning§</td>
<td>4.4 (3.1-6.3)†</td>
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<tr>
<td>Maternal distress or depression§</td>
<td>1.9 (1.3-2.7)†</td>
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<tr>
<td>Maternal fair or poor health status</td>
<td>1.7 (1.2-2.5)†</td>
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<tr>
<td>Maternal activity limitation</td>
<td>1.1 (0.7-1.6)</td>
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<tr>
<td>Burden of child's chronic condition on family</td>
<td></td>
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<tr>
<td>Work-related family burden</td>
<td>2.3 (1.7-3.2)†</td>
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<tr>
<td>Sleep-related family burden</td>
<td>2.2 (1.3-3.6)†</td>
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<tr>
<td>Financially related family burden</td>
<td>2.5 (1.4-4.4)†</td>
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<tr>
<td>Below the poverty threshold§</td>
<td>1.8 (1.3-2.6)†</td>
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<tr>
<td>Single-parent status§</td>
<td>0.9 (0.6-1.3)</td>
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</table>

| Sex|| | 0.9 (0.7-1.3) |
| Child's age, y|| |            |
| 11-14 | 0.8 (0.6-1.1) |
| 15-17 | 0.5 (0.4-0.8)† |
| Child's race/ethnicity# |            |
| Black (non-Hispanic) | 0.9 (0.6-1.4) |
| Other (non-Hispanic)  | 0.6 (0.2-2.0) |
| Hispanic              | 1.0 (0.6-1.7) |

One parent describes the financial impact on the family:

- “if one…partner who was used to working full time…—needs to be the caretaker, and the manager—making sure all the appointments—taking hurdles—has to not work full time anymore, that’s income that’s missing, plus you’re adding bills on top of that.”

Feelings of depression were also commonly reported by family members:

- “we [parents] each went through periods of having—of being depressed. I mean, my husband went through a real period of depression—which was really hard on me, because he really wasn’t able to help me.”
Psychobiology of Caregiving
Family Burden

- Chronic illness can place a substantial burden on the family.
- Little is known about how this distress affects physiology and health of the caregiver.
- Few studies have examined stress biomarkers in a sample of caregivers of children and adults with chronic conditions.
  - How well these measures correlate with subsequent patient health outcomes.
Framework for Understanding the Impact of Caregiving on the Aging Process

**Stress Stimuli**
- Illness-related family burden
  - Acute illness
  - Chronic illness
  - Palliative care
- Life stress
- Discrimination/Racism

**Genetic Inheritability**

**Biological Expressions of Stress**

**Perceived Stress**

**Physiological Manifestation of Symptoms**

**Aging**

Hypothetical Physiologic Responses of Chronically Stressed Caregivers

Source: (Grant, 1999)
Psychobiology of Caregiving (1)

- Increased cortisol production during caregiving episodes (Davis et al, 2004)
Caregivers exhibited a slightly greater risk for health problems than did noncaregivers. Stronger relationships occurred with stress hormones, antibodies, and global reported health.

Caregivers had a 23% higher level of stress hormones and a 15% lower level of antibody responses than did noncaregivers.

(Source: Vitaliano et al, 2003)
Antibody Responses to Pneumococcal Pneumonia Vaccine, by Caregiver Status

(Source: Glaser et al, 2000)
Scatter Plot of Chronicity of Stress by Telomere Length in Caregivers

Source: Epel et al., PNAS (December 2004)
Scatter Plot of Perceived Stress Scores
Stress by Telomere Length in Caregivers

Source: Epel et al., PNAS (December 2004)
Ongoing and Future Studies Focused on the Psychobiology of Informal Caregiving

- Parents of children with chronic illness
- Informal caregivers of prostate cancer patients
- Impact of war memories on terminally-ill veterans and their informal caregivers
Analytic Approach

- Feasibility of obtaining stress biomarkers
- Concordance of immunological biomarkers and self-reported chronic psychological stress
- Examine if and to what extent caregiver psychological stress, both biologically-measured and self-reported, mediate the racial, ethnic, and socioeconomic disparities for the patients and their families
Hypothesized Conclusions

- Biomarkers make a unique contribution to explaining poor outcomes among patients with chronic illness
- Both measures need to be included in future studies
- Interventions targeted at supported families might reduce burden and reduce disparities
Next Steps

- Longitudinal studies
- Intervention research
- Life course perspective
  - What impact does stress have on the aging process?
- Multilevel approach
  - Biological and self-reported data
  - Family and community information
- Factor in changes in population dynamics
Room for Improvement

People were always telling Franz he had room for improvement...so he decided to build on a sun porch.