Caregiving: a source of spiritual inspiration
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The caregiver
- 5.8 - 7 M Americans care for somebody 65+ with ADL impairment
- 52 M American care for a person 20+ with some form of disability

www.caregiver.org, 2003

Caregiver of Alzheimer patients
- Mean age: 64
- Women: 72%
- Spouses: 49%
- Average burden: 15

Sink et al Jam Ger Soc, 2006

Changes in caregiving
<table>
<thead>
<tr>
<th></th>
<th>1989</th>
<th>1999</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single caregiver</td>
<td>34.5%</td>
<td>52.8%</td>
</tr>
<tr>
<td>Chronically disabled receiving help</td>
<td>79%</td>
<td>72%</td>
</tr>
<tr>
<td>Unpaid caregiver</td>
<td>70%</td>
<td>51%</td>
</tr>
</tbody>
</table>
Woolf and Kasper, The gerontologist, 2006;46, 344

Social consequences of cancer
- Reduced commitments
- Reduced working hours
- Absence from work
- Unemployment
- Disability
- Absence from work without pay

The caregiver: the occult patient

<table>
<thead>
<tr>
<th>Primary stressors</th>
<th>Secondary stressors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care</td>
<td>Role strain</td>
</tr>
<tr>
<td>Symptom management</td>
<td>Financial strain</td>
</tr>
<tr>
<td>Patient suffering</td>
<td>Family conflicts</td>
</tr>
<tr>
<td>Metastatic development</td>
<td>Intra-psychic strain</td>
</tr>
<tr>
<td>Terminal care</td>
<td>Lack of family support</td>
</tr>
</tbody>
</table>

Haley WE: Cr Rev Oncol Hematol, 2003, 48, 151-158

Reduction of health care cost

The Lies:
- Preventive medicine
- Healthy life-style
- Evidence-based medicine
- Outcome-based compensation

The truth:
- Rationing
- Cost shifting to the family caregiver
- Reduction of oversight

Economic value of caregiving, 1997

Arnold et al, Datawatch, 2001

Personal vs societal perspective

Obstacles to the improvement of the caregiver’s health
- Personal vs societal perspective
- Ethical vs Moral imperatives
- Inadequate social support
- Loss of the sense of sacredness: I am disposable; I am perishable

Personal vs societal perspective
Personal vs societal perspective

Patient's rights
- Recognition
- Compensation and support
- Respite
- Limits

Caregiver's rights

Obstacles to the improvement of the caregiver’s health

- Personal vs societal perspective
- Ethical vs Moral imperatives
- Inadequate social support
- Loss of the sense of sacredness: I am disposable; I am perishable

The choice of the caregiver

Paper or Plastic?

Obstacles to the improvement of
the caregiver’s health

- Personal vs societal perspective
- Ethical vs Moral imperatives
- Inadequate social support
- Loss of the sense of sacredness: I am disposable; I am perishable

McCullough et al, 2009
Benefits of religion and spirituality

• Social network
• Coping resources
• Positive emotions

Hebert et al: Aging and Mental Health, 2006

The most ancient caregiver

Christian view of caregiving: caring for the wounded God

Christian interpretation of caregiving

• Sacrifice = sacrum facere = to make hallow, sacred. To reserve oneself to a special and unique function

Redemption as an universal need

History has the atrocious connotations of a nightmare. The greatness of humanity consists in making beautiful and durable works of art with the material of this nightmare.

Octavio Paz: the labyrinth of loneliness

Innovative research methods

• Narrative
• Group discussion
• Religious intervention
• Definition of spiritual and existential suffering