Into the Unknown: Aging with Autism and Caregiver Challenges
Elizabeth A. Perkins, PhD, RNMH
Research Assistant Professor
University of South Florida
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Overview:
- General overview of aging and its diversity
- Modifiable and unmodifiable factors
- Universally experienced aging processes
- Aging outcomes specific to individuals with autism
- Optimizing the aging process
- General overview of caregiving
- Compound caregiving
- How to assist older caregivers

What is Aging?
- Changes that are caused by processes within the individual which significantly decrease the probability of survival.
- The changes cannot be avoided or reversed; no one can escape the process of aging.
- Differs from disease, which may be avoided, managed, or cured, in some cases.

The Diversity of the Aging Process
- Susceptibility to disease
- Individual organ systems age differently
- Social and cultural factors
- Genetic makeup
- Compensatory behaviors + access to resources
- Gender
- Lifestyle

Lifespan
Jeanne Calment
b. 21st Feb 1875
d. 4th August 1997
Age: 122 years, 164 days

Christian Mortensen (oldest man ever - 115 years). "Friends, a good cigar, drinking lots of good water, no alcohol, staying positive and lots of singing will keep you alive for a long time"

Worldwide there are currently 80 verified Super-Centarians (aged 110 years plus).

Life Expectancy
Refers to the age that 50% of a cohort will still be alive.
Overall life expectancy of United States is 78 years.
Gender and ethnicity impacts that figure.

<table>
<thead>
<tr>
<th>Age</th>
<th>White Population</th>
<th>Black Population</th>
<th>Difference (White-Black)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>F</td>
<td>M</td>
</tr>
<tr>
<td>0</td>
<td>78.0</td>
<td>75.4</td>
<td>80.5</td>
</tr>
</tbody>
</table>
Life Expectancy: Persons with Intellectual Disabilities

1930's = 18.5 years
1970 = 59.1 years
1993 = 66.2 years (Braddock, 1999)
2000 = 68.6 years (Bittles et al., 2002)

It is predicted that people with intellectual disabilities (in particular, those without severe disabilities) will eventually have same life span as the general population (Janicki, 1996).

Reasons for the Dramatic Increase

- Improved access and treatment of associated secondary conditions (e.g. surgical repair of congenital heart defects, long term management of epilepsy and status epilepticus).
- Use of antibiotics (recurrent infections).
- Development of proactive, holistic and individualized care philosophies within community settings, and decline in large scale institutionalized generic care.
- Increase in family caregiving.

Types of Aging

- Primary Aging
  - Normal, disease free movement across adulthood
  - Changes are inevitable
- Secondary Aging
  - Changes related to disease and poor health practices
- Tertiary Aging
  - Rapid losses in function shortly before death

(Birren & Cunningham, 1985)

Disease and Old Age

Aging is not a disease, does not mean disease, and does not automatically include disease.

Many abnormal changes associated with aging can be prevented or slowed enough to never appear during normal life span.

Medical advancements ➞ longer life expectancy
New research findings, health promotion/education ➞ disease prevention ➞ longer healthy life expectancy

Modifiable versus Unmodifiable Factors for Successful Aging

Unmodifiable

- Age
- Gender
- Genetics
- Ethnicity
Modifiable versus Unmodifiable Factors for Successful Aging

**Modifiable**
- Eat a balanced and healthy diet (and supplements)
- Maintain a healthy weight
- Exercise on a regular basis (include weight bearing exercises)
- Manage stress / allow time for relaxation
- Smoking (and secondary smoking!)
- Education (promote lifelong learning)
- Occupation (esp. promotes curiosity, or working with people)
- Leisure activities (mental, social, physical)
- Enriching relationships (evolving)
- Living in a nurturing/clean physical environment

**Universal Physical Changes**

**Sarcopenia** – progressive loss of mass during adulthood.

Caused by:
- Slowing metabolism
- Reduction in testosterone/growth hormone
- Reduced protein intake/inadequate calorie intake
- Increasingly sedentary lifestyle

Results in:
- Loss of elasticity/flexibility
- Loss of muscle strength
- Efficiency of the heart is reduced
- Increase in slowness of movement/frailty

**Osteopenia** - normal aging-related bone loss (a precursor to osteoporosis)
Osteoporosis “porous bones” – weak and brittle, greatly increases risk of fractures.

Caused by:
- Reduction in estrogen (especially in post-menopausal women)
- Reduced calcium intake/absorption/reduced vitamin D
- Lack of exercise, heavy drinking, smoking, prolonged use of certain medications, (e.g. steroids, anti-epileptic, anti-psychotic, anti-anxiety, anti-depressants).

Caution for persons with developmental disabilities!
1) Nutrition issues (eg. food sensitivities or intolerances, may result in inadequate levels of dietary calcium/vitamin D)
2) High usage of medications to treat secondary conditions (e.g. epilepsy) and behavioral issues/psychiatric illness

**Reducing the Severity of Sarcopenia and Osteopenia**

- Most “aging” is caused by inactivity, and poor nutrition
- Healthy diet, adequate protein and calorie intake is essential
- Exposure to sunlight, calcium, and Vitamin D supplements
- Response to exercise is maintained until extreme old age
- Exercises can be adaptable to any age and physical ability
- Age is no barrier to developing and maintaining muscle with regular exercise!

**Age-Related Changes in Vision**

- **Presbyopia**: The lens of the eye loses becomes stiffer and less flexible – affecting the ability to focus on close objects

- **Decline in sharpness of vision**.
- Longer time required to focus on objects at different distances (e.g. looking at something in the distance, then reading a book).
- Decreased color discrimination due to yellowing of eye lens.
- Decrease in ability to adapt to changing levels of light (e.g. coming out of a movie theatre into the daylight).
- Decrease in ability to judge distances (depth perception).

Eye problems/impairments are notably more common in persons with IDD throughout the lifespan compared with general population!
Detecting the Onset of New Visual Impairment

Rubbing the eye, squinting, or covering one eye.
Tilting or thrusting the head.
Complaints of headaches.
Self-Injurious Behaviors / Challenging Behaviors.
Stumbling, and hesitancy on steps or curbs.
Sitting closer to the television than in the past.
Refusing to engage in activities that were previously enjoyed.
Becoming confused or anxious in new environments/around new people.

*Imperative that eyes are regularly checked throughout the lifespan but becomes more critical in adulthood to ensure vision issues are properly assessed and corrected.*

Hearing Loss/Impairment

**Presbycusis** – aging related change in the ability to detect higher pitches – more noticeable in those age 50+.
When more severe – can interfere with understanding speech. Difficulty with sounds that are often found at the start or end of words e.g. the “st” in street, “ch” in church.
Illness, accidents, and cumulative exposure to environmental noise (loud music/headphones) are all possible factors that can lead to late onset hearing loss.

Hearing impairment/loss/and hyperacusis is notably more common in persons with I/DD throughout the lifespan compared with general population!

Detecting the Onset of New Hearing Impairment

Turning up TV or radio volume.
Speaking/vocalizing more loudly.
Inappropriate responses to questions.
Repetition of conversation.

Inattention to other conversations.
Not following tasks as directed.
Confusion, and agitation in noisier environments, (e.g. parties).
Sudden social withdrawal.
Self-injurious behavior/challenging behavior.

For people who have vision & hearing loss...

- If a person has lifelong hearing loss, a vision loss can make the functional effects of any hearing loss much more severe, and vice versa (Saxon, Etten, & Perkins, 2010).
- Those who develop both hearing and vision losses may have much more difficulty communicating and interacting with their environment.
- Imperative that we continue to monitor vision and hearing throughout the lifespan.
- In all populations – very important to check vision and hearing with increasing age (can often be mistaken for onset of dementia-like symptoms!)

Taste and Smell

**Gustation** (i.e. the sense of taste) decrements become more noticeable beyond 60+.
Decrease in taste receptors and increase in the stimulus threshold can result in food tasting blander with increasing age.
Often older adults may add more salt and sugar than used previously to compensate.

**Olfaction** (i.e. the sense of smell), decrements become more noticeable after age 70+.
Anosmia loss has also been associated with Alzheimer’s & Parkinson’s disease.
Touch

- Somatosensory System - detects external touch, but also responsible for experience of pain, temperature, pressure, and one's awareness of one's own body position.
- Reduction in sensitivity to pain, touch, temperature, and possible contributing factor to increased risk of falls.

Aging Persons with Autism

Scant research on health aspects and lifespan physical health issues.

Common causes of death:
- Seizures (SUD)
- Heart Disease
- Cancer
- Nervous System Disorders
- Respiratory Disorders (mostly pneumonia)
- Accidental Death (Drowning, Suffocation)

(Shavelle et al., 2001)

Aging Persons with Autism

With regard to behavioral aspects there are 3 possible outcomes:
- Some improve (abatement of symptoms)
- Some plateau
- Some lose skills (esp. associated with psychiatric disorders)

Psychiatric disorders are common:
Anxiety Disorders, Obsessive Compulsive Disorder, Depression, Substance Abuse, Attention Deficit Hyperactive Disorder, Tourette Syndrome.

Aging Persons with Autism

Recent study (Esbensen et al., 2009) noted that restrictive repetitive behaviors, i.e.
- restricted interests
- stereotypical movements
- need for rituals/sameness
- compulsive behaviors
- self-injurious behaviors
were less severe and more infrequent with increasing age.

Aging Persons with Autism

- Those with language skills and no ID often fare better across lifespan in terms of education, employment, and social relationships, although much lower rates of participation when compared to the general population.
- Emphasizes importance of lifelong learning, enriched environments, and community inclusion to optimize well-being over the lifespan.

Are Reduction in Behavioral Symptoms Related to Aging of the Sensory Systems?

- Sensory seeking and sensory defensiveness (i.e. high and low thresholds for response to sensory stimuli, oral, tactile, auditory, and visual)
- With increasing age – there are changes in threshold levels in both directions to levels usual in the general population (i.e. hypersensitivity decreases and hyposensitivity increases) (Kern et al., 2008).
- Therefore previous triggers to sensory defensiveness and sensory seeking behaviors are no longer as salient.
Remember – there are many modifiable factors that can change the way we experience aging!

- Eat a balanced and healthy diet
- Maintain a healthy weight
- Exercise on a regular basis
- Manage stress / allow time for relaxation
- Smoking
- Education
- Occupation
- Leisure activities
- Enriching relationships
- Living in a nurturing/clean physical environment

Optimizing Successful Aging for Older Adults with IDD

- Health promotion/health prevention
- Wellness screenings/checkups in adulthood/older adulthood (e.g. cancer screenings, dental checkups, mammograms)
- Advocate to ensure availability of optimal treatments/medications for those with chronic illness/diseases
- Polypharmacy (careful monitoring with increasing age)

STOPS CHAOS!

If you pay attention to the factors that cause heart disease – they can also help lower the risk of developing many other diseases that are more likely to be experienced with increasing age - including diabetes, stroke, and cancer.

Advocate for better geriatric care for older adults with autism and other developmental disabilities!

- increase training, preparation, and sensitivity of health care professionals towards persons with intellectual disabilities
- create less dependency on pediatricians who provide care to patients with IDD long after the transition to adult medical services should have occurred, and
- require that curricula (currently there are no requirements) for US medical schools incorporate teaching competency in the provision of lifespan care to persons with intellectual disabilities.


“There are four kinds of people in the world: Those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers.”

Former First Lady Rosalynn Carter

~ 1 in 5 Americans are currently engaged in an informal caregiving role.

General Caregiving Research – An Overview

- Originally developed from concern of the challenges faced by caregivers of persons with Alzheimer’s disease.
- Highly stressed caregivers are at risk for poorer physical and psychological health outcomes.
- Time devoted to caregiving can also affect financial stability, employment opportunities, availability for other relationships.
General Caregiving Research – An Overview

- Does have benefits, reconnect or strengthen a relationship.
- Can be personally rewarding and boost self-esteem.
- Allows the care recipient to enjoy individualized attention in their home environment.

Importance of Family Caregivers

- Estimated 4.7 million people with IDD in 2008.
- 2.8 million live with their family caregivers.

Aging Family Caregivers

Breakdown by age group of the 2.82 million family caregivers.

- 25% Age < 41
- 40% Age 41-59
- 35% Age 60+

Background

Concerns
1. Extensive duration of caregiving role
2. Health care concerns due to aging in care recipient and caregiver
3. Fears about the long-term future of the care recipient

Benefits
1. Normative nature of parental caregiving
2. Expertise and feelings of mastery from long term caregiving

Caregiving: A Balancing Act

Stress

- Primary caregiving stressors
- Secondary stressors
- Ultra chronic stressors and life events

Coping

- Internal coping resources
- External coping resources

Case Study – Compound Caregiver

- Parent caregivers of adults with ID may actually undertake this role for the entirety of their own lifetime.
- Likelihood of becoming a sandwich caregiver (i.e. caregiving for an older parent) is also increasing (Rogerson & Kim, 2005).
- There is also the possibility that these primary caregivers may also undertake additional caregiving duties to other family members (e.g. in-laws, spouse, and siblings).
- Case study that described a mother of an adult son with Down syndrome, who became a caregiver to other family members on 4 occasions.

Case Study – Compound Caregiver

“Kay”, age 60, mother and primary caregiver to son Derek. “Derek”, age 28, has Down syndrome, severe intellectual disabilities, and requires considerable support with all activities of daily living. He has resided with his family since birth.

Kay became a caregiver to her mother-in-law, father, sister, and lastly, her mother, over the course of the last 15 years. Although each additional caregiving episode was brief, she described these periods as some of the most stressful times in her life.

Research Study

1) How common is compound caregiving?
2) Does compound caregiving status impact physical and mental well-being of compound caregivers compared with non-compound caregivers?


Caregiver Study

Cross-sectional, primary data collection
Sample N = 91 parental caregivers
Aged 50+ with co-residing son/daughter with ID aged 18+
Convenience sample drawn from various agencies, website recruitment, and parent-to-parent referral
Caregivers from various states participated: Florida (78), New Jersey (5), Georgia (4), Nevada (1), Maryland (1), Oklahoma (1), South Dakota (1).

Compound Caregiver Variables

Compound Caregiver Status.

Do you currently have any other caregiving responsibilities to another family member other than your son/daughter with ID?

Relationship to the compound care recipient.

Major health issue that prompted caregiving duties.

Caregiver and CareRecipient Characteristics (N = 91)

<table>
<thead>
<tr>
<th>Mean or %</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
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<tr>
<td>Age (years)</td>
<td>60.8</td>
<td>8.5</td>
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<tr>
<td>Education (years)</td>
<td>15.1</td>
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<tr>
<td>Gender (Female)</td>
<td>91%</td>
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<tr>
<td>Race/Ethnicity (White)</td>
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<tr>
<td>Household Income (&lt;$50,000)</td>
<td>78%</td>
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<tr>
<td>Health</td>
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<td>Total Comorbidities</td>
<td>5.1</td>
<td>2.9</td>
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<td>Comorbidity Interference</td>
<td>9.2</td>
<td>7.9</td>
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<tr>
<td>Caregiving</td>
<td></td>
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<tr>
<td>Total caregiving hours per week</td>
<td>39.4</td>
<td>21.3</td>
</tr>
<tr>
<td>Compound Caregiver Now (Yes)</td>
<td>37%</td>
<td></td>
</tr>
<tr>
<td>Compound Caregiver Ever (Yes)</td>
<td>68%</td>
<td></td>
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<tr>
<td>Anticipated Future Caregiving (Yes)</td>
<td>34%</td>
<td></td>
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<tr>
<td>Duration of compound caregiving (months)</td>
<td>36 *</td>
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</table>

Caregivers (57) and Compound Caregivers (34)

<table>
<thead>
<tr>
<th>Mean or %</th>
<th>SD</th>
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<tbody>
<tr>
<td>Caregiver Characteristics</td>
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<tr>
<td>Demographic</td>
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<td></td>
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<tr>
<td>Age (years)</td>
<td>58.8</td>
<td>7.9</td>
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<tr>
<td>Education</td>
<td>14.7</td>
<td>2.29</td>
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<tr>
<td>Health and Caregiving</td>
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<tr>
<td>Total Comorbidities</td>
<td>4.79</td>
<td>2.96</td>
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<tr>
<td>Comorbidity Interference</td>
<td>8.68</td>
<td>8.66</td>
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<tr>
<td>Total Caregiving Hours</td>
<td>38.66</td>
<td>20.82</td>
</tr>
<tr>
<td>Caregiving Hours + CCG hours</td>
<td>51.60</td>
<td>26.34</td>
</tr>
</tbody>
</table>

*CCG = Compound caregiving  * p< .05 (2-tailed)
Who Do Compound Caregivers Care For and Why?

<table>
<thead>
<tr>
<th>Relationship</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>13</td>
<td>(38.2%)</td>
</tr>
<tr>
<td>Father</td>
<td>4</td>
<td>(11.8%)</td>
</tr>
<tr>
<td>Spouse</td>
<td>4</td>
<td>(11.8%)</td>
</tr>
<tr>
<td>Sibling</td>
<td>3</td>
<td>(8.8%)</td>
</tr>
<tr>
<td>Aunt/Uncle</td>
<td>3</td>
<td>(8.8%)</td>
</tr>
<tr>
<td>2nd Child with Intellectual Disability</td>
<td>3</td>
<td>(8.8%)</td>
</tr>
<tr>
<td>Mother in Law</td>
<td>2</td>
<td>(5.85%)</td>
</tr>
<tr>
<td>Grandchild with Medical Needs</td>
<td>1</td>
<td>(2.9%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Major Health Issue</th>
<th>N</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Alzheimer's Disease</td>
<td>7</td>
<td>(20.6%)</td>
</tr>
<tr>
<td>Elderly Frail</td>
<td>4</td>
<td>(11.8%)</td>
</tr>
<tr>
<td>Advanced Macular Degeneration</td>
<td>4</td>
<td>(11.8%)</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td>4</td>
<td>(11.8%)</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>4</td>
<td>(11.8%)</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>2</td>
<td>(5.9%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>2</td>
<td>(5.9%)</td>
</tr>
<tr>
<td>Chronic Mental Disorder</td>
<td>2</td>
<td>(5.9%)</td>
</tr>
<tr>
<td>Hip Fracture/Replacement</td>
<td>2</td>
<td>(5.9%)</td>
</tr>
<tr>
<td>Stroke</td>
<td>1</td>
<td>(2.9%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>(2.9%)</td>
</tr>
<tr>
<td>Post-Operative Convalescence</td>
<td>1</td>
<td>(2.9%)</td>
</tr>
</tbody>
</table>

Caregivers (57) and Compound Caregivers (34)

<table>
<thead>
<tr>
<th></th>
<th>Compound Caregiver</th>
<th>Non-Compound Caregiver</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>t</th>
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</thead>
<tbody>
<tr>
<td>Life Satisfaction</td>
<td>17.05</td>
<td>5.81</td>
<td>17.58</td>
<td>7.03</td>
<td>.36</td>
<td></td>
<td></td>
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<tr>
<td>Depression</td>
<td>10.94</td>
<td>9.30</td>
<td>12.61</td>
<td>9.65</td>
<td>.85</td>
<td></td>
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<tr>
<td>Physical Health</td>
<td>44.51</td>
<td>11.28</td>
<td>43.09</td>
<td>10.07</td>
<td>-.62</td>
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<tr>
<td>Mental Health</td>
<td>47.66</td>
<td>11.22</td>
<td>48.67</td>
<td>11.53</td>
<td>.41</td>
<td></td>
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<tr>
<td>Desire to Place</td>
<td>3.61</td>
<td>1.72</td>
<td>2.49</td>
<td>1.63</td>
<td>-3.11*</td>
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</table>

* p< .01 (2-tailed).

Problems with Managing Multiple Caregiving Roles (N = 34)

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to have the time to do things that I enjoy (e.g. hobbies, social</td>
<td>3.44</td>
</tr>
<tr>
<td>events, vacations etc.)</td>
<td></td>
</tr>
<tr>
<td>Lack of adequate help from others</td>
<td>2.94</td>
</tr>
<tr>
<td>Feeling stressed and emotionally drained</td>
<td>2.94</td>
</tr>
<tr>
<td>Being physically tired</td>
<td>2.85</td>
</tr>
<tr>
<td>Prioritizing caregiving demands (i.e. managing what tasks you need to</td>
<td>2.41</td>
</tr>
<tr>
<td>do, and when you can do it</td>
<td></td>
</tr>
<tr>
<td>Finding someone to care for my son/daughter when I’m caring for the</td>
<td>2.00</td>
</tr>
<tr>
<td>other care recipient</td>
<td></td>
</tr>
<tr>
<td>Unable to maintain my own job</td>
<td>2.00</td>
</tr>
<tr>
<td>Having to care for the very person who used to help me look after my</td>
<td>1.94</td>
</tr>
<tr>
<td>own son/daughter with intellectual disabilities</td>
<td></td>
</tr>
</tbody>
</table>

A Selection of Quotes from Compound Caregivers

My biggest problem is how do I integrate my son into all the demands of my roles. I feel bad that my time is taken up with my many caregiving duties – it stops me from being able to encourage my son to do more.

A difficult problem is having the responsibility of running all the maintenance of the home...it’s all new to me.

I feel guilty that I am not able to spend quality time with my other children, and guilty that I need their help.

I feel anxiety and resentment simultaneously dealing with my husband’s issues – it has affected the quality of my marital relationship.

Discussion

- Compound caregiving was often experienced.
- Older parental caregivers no less likely to undertake additional roles, even if they are primary caregivers to an adult child with ID.
- Compound caregivers – increased desire to place – caring for another relative might galvanize discussions of “What happens if I become sick?”.
- Compound caregivers not significantly different to non-compound caregivers in the other quality of life outcomes. Why little difference?
  - Knowledge and mastery of caregiving roles, easy adaptation, natural self-selection.
  - However, caregivers may also minimize impact of compound caregiving as a coping mechanism.

Multiple Compound Caregiving – A More Serious Concern?

- 5 “Triple” caregivers i.e. currently looking after 2 others care recipients plus their son/daughter with intellectual disabilities (e.g. one caregiver was caring for her daughter, a mother with Alzheimer’s disease, and a father with Parkinson’s disease).
- Depression - 18.2 (12.0 for the sample)
- Life Satisfaction 12.4 - (17.4 for the sample)
### Practice & Policy Implications

- Advocate for prioritizing resources to ensure that greater support is available for compound caregiving periods when needed (not just on increasing age).
- Special attention to compound caregivers who have multiple concurrent caregiving roles, or have highly dependent compound care recipients (e.g., persons with Alzheimer’s disease) - eligibility to receive additional support, or prioritized to receive services, if currently on wait list.

### How Can We Assist Caregivers?

- Encourage use of available services and options (e.g., meals on wheels, home help, companion services, respite).
- The caregiver should be encouraged to take mini-breaks or go on vacation when the opportunity arises.
- Use of support groups for caregivers should be encouraged where available, allowing caregivers the opportunity to vent frustrations to other caregivers who are familiar with such experiences, and peer problem solving.

### A Request to Caregivers.......

Start making those – “What if” – or “What happens when” – plans.

Recognize that adjustments to new living arrangements are better when planned and purposeful – not as a sudden change due to a crisis!

### References

References
