Celebrating the Positive Aspect of Caregiving

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Outline

- What is Alzheimer’s Disease (AD)?
- Prevalence of AD in Canadians
- Health care utilization by AD clients
- Family caregiving
- Positive aspects of caregiving
  - Conceptual framework
  - Effects on caregivers
  - Assessment tool
- Resources for caregivers
- Sample caregivers’ experiences
What is Alzheimer’s Disease?

- Alzheimer’s Disease (AD) is the most common form of dementia
- AD is a progressive neurodegenerative disease characterized by neurofibrillary tangles and amyloid plaques
- It later affects individuals’ abilities to speak, make decisions, think, and remember
Canadian Alzheimer Facts

- **Incidence:** Number of new cases of Dementia per year in Canada
  - **2008:** 103,700 new dementia cases per year or one case every 5 minutes
  - **2038:** 257,800 new dementia cases per year or one new case every 2 minutes

- Women represent 72% of all cases of Alzheimer’s Disease

(Rising Tide: 2010)
Dementia Prevalence in Canada

Current and Future Dementia Prevalence in Canada, All Age Groups: 2008-2038

Prevalence of Dementia by Sex 2008 to 2038

Number of Canadians Living With Dementia

Year

2008 2018 2028 2038

0 100,000 250,000 500,000 750,000 1,000,000 1,250,000

Total  Females  Males
Health Utilization of AD Clients

With an increase in prevalence of AD, there will be a substantial increase in burden on:

- Community-based services
- Caregivers
What is Family Caregiving?

- **Caregiving**: provision of assistance to sick or disabled persons in need of help with activities of daily living

- Caregiving may be either formal or informal
  - Formal caregivers are usually paid health care workers
  - Informal caregivers are usually unpaid family members or friends
Family Caregiving - Cont’d

- Family members are the primary and preferred caregivers and make up a high percentage of informal caregivers

- Family caregivers include spouses followed by adult children and friends

  (Novak & Campbell, 2006)
Positive Aspects of Caregiving (PAC)

- **PAC**: defined as the rewards and satisfaction derived from the caregiving relationship (Tarlow et al., 2004)

- A common source of satisfaction for family is knowing that their loved one has the best quality care
Conceptual Framework of Positive Aspects of Caregiving

Main thrust of framework: positive aspects emerge due to enrichment events in caregivers’ daily lives, which, in turn, are dependent on the sense of self-efficacy of individuals (Carbonneau et al., 2010)
Conceptual Framework of the Positive Aspect of Caregiving (Carbonneau, 2010)
Evidence of Positive Effects of Caregiving

- In a study of 289 Canadian caregivers, 73% could identify at least one PAC, i.e. feeling fulfilled (Cohen et al., 2002)
- Lower levels of caregiver depression & behavioral bother were associated with positive appraisals of caregiving experience (Pinquart & Soerensen, 2003)
- Satisfaction with caregiving and rewarding appraisals reduced caregivers’ stress and improved emotional outcomes (Roff et al., 2004)
- Caregivers who reported lower burdens associated with the provision of ADL care to their care recipient over time also reported higher PAC over time (Hilgeman et al., 2007)
### Assessment Tool for Identification of Positive Aspects of Caregiving

#### Quantitative Aspect of Likert Scale Item

<table>
<thead>
<tr>
<th>Statements</th>
<th>Response Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a sense of achievement in your caregiving role?</td>
<td>Never, Sometimes, Often, Always</td>
</tr>
<tr>
<td>Do you feel satisfied in your role as a caregiver?</td>
<td>Never, Sometimes, Often, Always</td>
</tr>
<tr>
<td>Do you feel your self-esteem has improved?</td>
<td>Never, Sometimes, Often, Always</td>
</tr>
<tr>
<td>Do you feel your relationship has grown stronger with your love one?</td>
<td>Never, Sometimes, Often, Always</td>
</tr>
<tr>
<td>Do you feel you are being appreciated with your role in caregiving?</td>
<td>Never, Sometimes, Often, Always</td>
</tr>
</tbody>
</table>
Qualitative Aspect: Responses to Open-ended Questions

- Do you have a sense of achievement in your caregiving role?
- Do you feel satisfied in your role as a caregiver?
- Do you feel your self-esteem has improved?
- Do you feel your relationship has grown stronger with your loved one?
- Do you feel you are being appreciated in your role as a caregiver?
Conclusion

The issue of family caregiving is important, resulting in many studies examining:

- Negative impact on caregivers, such as burden or stress
- The positive aspects of caregiving identified by researchers in the past decade

Positive aspects should be considered when helping families, since support for caregivers should not only reduce the difficulties they face but also enhance the positive aspects of their caregiving (Carbonneau et al., 2010)
Resources for Caregivers

- Available resources can provide caregivers with:
  - Information about AD
  - Support services, including Help lines and local support groups
  - Referrals for financial assistance

- Examples of places where caregivers can seek help include:

  1) The Alzheimer Society of Manitoba
     Provincial Office
     10-120 Donald Street
     Winnipeg, MB
     R3C 4G2
     Phone: (204) 943-6622
     Fax: (204) 942-5408
     Email: alzmb@alzheimer.mb.ca
     Website: www.alzheimer.mb.ca/a.html
2) DementiaGuide.ca is a website to help people with Alzheimer's disease and their caregivers recognize, understand, record and monitor their symptoms through an interactive tool. For more information on this tool including subscriber cost, please visit the site.

3) Canadian Study of Health and Aging

http://www.csha.ca/

The website provide information on caregiver questionnaires, study methods, data collection and results summary.
Sample Caregivers’ Experiences

- Adapting

"I can already hear it: 'There's nothing to laugh about when you're a caregiver.' Well, that's what I thought 3 years ago. I cried for a year or more—gained 20 pounds from worrying and eating—you know how that is. Cried some more and it went on and on. Then—I don't know how or when—I began to see that life does go on! And I began to realize that you don't have to wash on the same day every week, groceries will still be in the store if you don't go the same day every week, the house doesn't have to be 'just so,' and you don't have to eat at the same time everyday…This new attitude helped with stress and I began to see things a lot differently—little things weren't BIG anymore. And life went on."

—Mary W.

Source: http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/default
Getting Help

"I was standing in the grocery store, totally exhausted, trying to decide what I had come for. I looked down at my cart and all I had were diapers for my incontinent mother and for my two-year-old grandson. Diapers were the only thing I could remember. I had asked a neighbor to stay with my mother and Tim because we were out of everything and there I was. I couldn't remember what I had come for. It was this simple incident that forced me to consider getting help. For almost a year I had been walking around in a semi-trance trying to do everything myself. I had to face the fact that this situation was no longer safe for my mother, for Tim, or for me."

—E. W.

Source: http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/default
Sample Caregivers’ Experiences

- **Loneliness**
  "There is nothing as lonely as fixing three meals a day for someone who can no longer talk to you."
  —A wife

- **Love**
  "Even I wonder why I can sit daily by his side as I play tapes, relate bits and pieces of news, hold his hand, tell him I love him. Yet I am content when I am with him, though I grieve for the loss of his smile, the sound of my name on his lips."
  —Mrs. C.

Source: http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/default
Rewards of Caregiving

"He has given me so much all my life, and now he can only take. Yet his presence now, as always, provides deep comfort to my soul. Now I give to him in every way I can. I realize that my giving to him is a result of his giving to me: emotional support, love, spiritual direction, wisdom, advice, and all that a daughter needs when she is maturing into a young woman."
—Phyllis I.

Source: http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/default
Sample Caregivers’ Experiences

- **Verbal Abuse**
  "My mom cusses at me every day, usually in public, and usually loudly. I suppose I am beyond the point of being mortified. There's nothing to do but accept it with good humor. That did not come easily or quickly. People in the support group tell me that this period probably will not last."
  — Lucille

Source: http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/default