Family Caregivers in dementia

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Caregivers

- The strongest determinant of the outcome of patients with dementia is the quality of their caregivers.

What will we cover

- Brief review of Dementia
- Caregivers- who are they and what do they do?
- Caregiver burden
- What can we do as Healthcare professionals to support them?
- Role of Alzheimer's society
- Super caregivers – what are the characteristics

Declaration of conflict

- No competing interests.

Prevalence of Dementia in Canada

- Canadian Study on Health and Aging
- In people 65 years of age or older in Canada **8.0%** have dementia. 6.5% have AD
- People over the age of 85 years have a prevalence of 34.5% . A further 15.7% have Cognitive impairment but are not demented
- 49 % of AD pt's live in the community and 51% live in institutional settings

Rising tide: The impact of dementia on Canadian Society

- 545,000 Canadians have dementia today (2010)
- In 2038 - 1,125,200 will have dementia(2.8% of Canadians)
- Currently Canadians spend 231 million hours per year in informal care for dementia
- This is expected to become 756 million hour per year in 2038

Dementia numbers in Alberta

- In 2008 - 40,000 people in Alberta had a diagnosis of dementia.
- In 2038 this is expected to grow to over 100,000 or 2.8% of our population.
- In 2008 it is estimated that the direct economic burden for dementia care was $640 million

Rising tide – economic burden of dementia

- Total direct cost for the treatment of dementia in Canada is $8 Billion /year (2008)
- Total economic burden is estimated to be $15 Billion (2008)
- Total direct cost is expected to increase to $93 billion /year by 2038

New information on Alzheimer’s dementia

- Prevalence of dementia (total number of people with this diagnosis) increased by 18.2% from 2004 – 2012 in Ontario (Institute for Clinical Evaluative Sciences). 100,00 to 150,000.
- The Incidence (The number of new cases diagnosed per year) is falling 18.2 per 1000 to 17 per 1000. (between 2004-2012)

Caregivers

- Who are they? If patients live in the community
  - Spouses – 37% of primary caregivers
  - Daughters 29% or DIL – 12%
  - For Caregivers under 60 years – 60% hold jobs outside of their home and over 50% have had a major interruption in their work schedule and have had to take time off outside of their scheduled holidays.

What do caregivers do?

- Depends on the stage of dementia
  - Early – mostly take over Instrumental ADL’s
    - Banking, shopping, driving, taking medications, going to appointments, cooking, laundry, house cleaning, outside house work, etc.
  - Middle stages –
    - Cueing for bathing and hygiene, changing clothing,
    - Deal with lack of insight and behavioral problems

What do care givers do?

- Late stages-
    - Everything – feeding, bathing, changing clothes, making sure they are safe, (wandering)
    - Arrange for placement into care facilities.
    - Even patients who are placed the caregivers provide 40% of the support with ongoing visits.

Behavioral disturbances in dementia

- Caregivers deal with –
    - Hallucinations, delusions, aggression, agitation, wandering, day-night reversal, inappropriate sexual behaviors.

Caregiver burden

- Measured by various measures.
- It depends on the relationship between the patient and the caregiver.

- Caregiver Burden Scale – rate all questions from 0-5.
  - 0 = never
  - 1 = Rarely
  - 2 = sometimes
  - 3 = frequently
  - 4 = Nearly Always

Caregiver Burden Scale

1. Do you feel your relative asks for more help than he or she needs?
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
4. Do you feel embarrassed over your relative’s behaviors?

Caregiver Burden Scale

5. Do you feel angry when you are around your relative?
6. Do you feel your relative currently affects your relationship with others in a negative way?
7. Are you afraid about what the future holds for your relative?
8. Do you feel your relative is dependent on you?

Caregiver Burden Scale

9. Do you feel strained when around your relative?
10. Do you feel your health has suffered because of your involvement?
11. Do you feel you do not have as much privacy as you would like?
12. Do you feel your social life has suffered because you are caring for your relative?

Caregiver Burden Scale

13. Do you feel uncomfortable about having friends over, because of your relative?
14. Do you feel that your relative seems to expect you take care of him or her, as if you are the only one he or she could depend on?
15. Do you feel you do not have enough money to care for your relative?
16. Do you feel that you will not be able take care of your relative much longer?

Caregiver Burden Scale

17. Do you feel you have lost control of your life since your relative's illness?
18. Do you wish you could just leave the care of your relative to someone else?
19. Do you feel uncertain about what to do about your relative?
20. Do you feel you should be doing more for your relative?
21. Do you feel you could be doing a better job in caring for your relative?
22. Overall, how burdened do you feel in caring for your relative?

Caregiver Burden Scale

- 0 – 20 = Little or no burden
- 21- 40 = Mild to moderate burden
- 41 – 60 = Moderate to severe burden
- 61 – 88 = Severe burden

Caregivers – what they do

- 70-90% of caregivers do not get support from formal caregivers in the community!
- 70% of family caregivers are aware of homecare and other resources in the community.

Caregiver burden

- Depends on many factors including:
  - Relationship between the CG and Pt.
  - Stage of dementia (behaviors)
  - Living situation
  - Caregiver factors
  - Patient factors
  - Other factors

Relationship Between CG and Pt

What was the relationship between the CG and Pt prior to the onset of dementia?

What was the role of the person with dementia?

There is often a change from a sharing partner to one of helper-dependent.

There is often a major change in social patterns. Less social interactions and loss of friendships.

If the CG is a child then they experience role reversals.

Caregiver burden

- The living situation can affect the degree of burden.
  - If living apart there is often increased worry.
  - If living together there is often perceived over dependence.

CG factors that affect burden

- The CG health – both physical and mental and spiritual
- There is a high rate of depression in CG of pts with dementia
- Coping style and personality
- Use of formal supports
- Knowledge of the disease process

Patient factors that affect burden

- Stage of the dementia and presence of behavioral issues
- Personality and prior role in the family
- Physical and mental health – eg diabetic needing insulin.

Other factors that mediate burden

- Economic factors
- Other family and informal support networks
- Living location – availability of formal support
- Driving

What can clinicians do to help CG under stress?

- Provide active treatment
- Be knowledgeable about dementia
- Validation of their caregiving
- Reassurance
- Information and education
- Control over the situation and have choices about care options

What can the AD society do?

- Information and education
- Caregiver support groups
- Public education
- Supports research

What can caregivers do?

- Learn about the disease and care strategies
- Attend support groups
- Be realistic about the disease and yourself
- Accept your feelings
- Share information and feelings with others
- Plan ahead with the support of your family
- Be positive and make everyday count

What can CG do?

- Structured and simple daily routines
- Look for humor
- Take time for your self
- Ask for help and start formal support early.
- Write down reminders

Super caregivers

- There are a few people (6) who I would call super caregivers.
- How do they do it??
- What are the common characteristics of super caregivers?

Super caregivers

- 68 yr old with Huntington's disease.
- She is now needing total care including lift transfers into her wheelchair, feeding, bathing and toileting
- She exhibits disinhibition, mild paranoid ideations and accusations of infidelity.
- Her spouse has continued to look after her for the past 5 years with only limited assistance from HC and family.
- Caregiver burden scale as only 9/88!

Characteristics of a Super CG

- + ve attitude, Patients and compassion
- Empathy, Dependable, Patient, Flexible and strength of conviction to help.
- They plan ahead
- Accept inevitable changes, including placement and death openly and with grace.
- Must have good health and the physical ability to provide the care.

Summary

- The role of the Caregiver in patients with dementia is very important
- Caregivers will experience stress due to their role.
- The degree of burden depends on many factors
- We need to support caregivers in what ever way is possible to help them succeed.