Caring for Caregivers: Challenging the Assumptions

A. Paul Williams, PhD.
Full Professor, Health Policy

Caring for Caregivers Symposium
Ryerson University
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Thinking About Caregivers: 
*Key Themes*
Caregivers: Who They Are, What They Do

Analytical paper
Spotlight on Canadians: Results from the General Social Survey

Portrait of caregivers, 2012

by Maire Sinha
Social and Aboriginal Statistics Division

September 2013
Caregivers: A Crucial and Growing Role

Living Longer, Living Well

Report Submitted to the Minister of Health and Long-Term Care and the Minister Responsible for Seniors on recommendations to Inform a Seniors Strategy for Ontario.

Dr. Samir K. Sinha, MD, DPNI, FRCPc
Provincial Lead, Ontario’s Seniors Strategy

December 20, 2012
Unit of Care: *Clients and Caregivers*
Costs and Consequences

IRPP Study

Caregiving for Older Adults with Disabilities

Present Costs, Future Challenges

Janet Fast

Canada needs a comprehensive strategy to support family caregivers, who bear a disproportionate share of the cost of assisting those with long-term disabilities.

Le Canada doit se doter d'une stratégie globale de soutien aux proches aidants, qui assument une part démesurée du coût des soins fournis aux personnes souffrant d'incapacité persistante.
What To Do: Caring About Caregivers

Supporting Caregivers and Caregiving in an Aging Canada
Janice Keefe

To ensure adequate home care services to seniors in coming years, Canadian governments will have to better support informal caregivers and adopt a comprehensive human resources strategy.
Caregivers: Base of the Health Care Iceberg

- The “backbone” of the home and community care sector (Lilly, 2011)
- The submerged iceberg (Columbo et al, 2011)
- Formal and informal care inextricably linked

Caring for Caregivers:
Challenging Assumptions
Healthcare Papers
New Models for the New Healthcare

Caring for Caregivers:
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A. Paul Williams, Allie Peckham, Kerry Kuluksi, Janet Lum, Natalie Warrick, Karen Spalding, Tommy Tam, Cindy Bruce-Barrett, Marta Grasic and Jennifer Im

Commentary from Shari Brotman, Neema L. Chappell, Eyal Cohen, Ilyan Ferret, Marcus J. Hollander, Janice Keefe, Krista Kelly, Candace L. Kemp, Tamara Krawchenko and Samit K. Sinha

https://www.longwoods.com/publications/healthcarepapers/24321
Assumption 1: Caregivers Ready, Willing and Able

- Traditionally, most people were born and died at home; hospitals a last resort
- With the rise of scientific medicine, people now born and died in hospitals
- In the 21st century, care again being shifted “closer to home”
  - In hospitals, paid professionals predominate
  - In home and community, caregivers take the lead role
Meanwhile, Society Changed

- Traditional caregiver pool shrinking
  - Smaller families, fewer children
  - Women more likely to participate in paid work
  - Older spouses may themselves require care
  - In rural & remote areas, younger persons first to leave
  - “Families of choice” (e.g., LGBT) may encompass fewer traditional caregivers
Demographics Reversed: Now More Older Than Younger Canadians

Care Gap Widened

“A growing family care gap means that the number of older people in need of care is predicted to outstrip the number of family members able to provide it for the first time in 2017. … creating a shortfall in our collective capacity to care for older generations.”

Source: Institute for Public Policy Research, UK, 2014
Assumption 2: 
*This is About Older Persons*

- More persons of all ages now living longer with multiple, chronic *health and social* needs
  - “Successes in medical survivorship”
  - Infants born prematurely, those born with various congenital anomalies and/or those with chronic conditions
  - Persons with mental and physical disabilities
  - Those at end-of-life
It’s Also About Formal Care Systems

- Caregiver stress and burnout assumed to result from needs of cared-for persons
- Formal care systems also play a key role
  - Multiple providers, programs and services that don’t talk to each other
  - Widely varying access points, assessments, eligibility criteria, service offerings, client records and user fees
  - Changing cast of unfamiliar faces in the home
Assumption 3: Money Alone Will do the Job

- The lure of cash
  - Politically popular, administratively easy
  - Empower individual choice?

- Some big “if’s”:
  - “If” there are services to choose from
  - “If” caregivers have the personal resources to navigate fragmented systems
  - “If” money fails, will caregivers shoulder the blame?
A Promising Alternative: Supported Self-Management

- **Caregiver Framework for Medically Complex Children**
  - ‘At risk’ caregivers of children living with complex medical conditions
  - Led by Hospital for Sick Children

- **Caregiver Support Project for Older Adults**
  - ‘At risk’ caregivers of high needs older adults at risk of hospitalization or residential long-term care.
  - Led by the Alzheimer Society of Toronto

- **SMILE (Seniors Managing Independent Living Easily)**
  - High needs older persons and caregivers living in urban and rural areas of south east Ontario
  - Led by VON
Supported Self-Management: Bolstering the Formal/Informal Interface

- Informal caregivers supported by professional care managers (or teams) equipped with modest budgets
  - Problem-identification and problem-solving
  - Identification of health and social supports available at the local level (including non-traditional providers)
  - Co-creation of care packages tailored to individual needs and circumstances (including religious and cultural communities)
  - Ongoing monitoring and updating of care packages
Assumption 4:
You Can Wait and See

- Delay will buy time and save resources
  - Wait until the point of crisis
  - Applies equally to individual caregivers and caregivers as a group (wait until “at risk”)

Informal Care Predominates

Average hours of care in a week provided by family caregivers and home care services
Family caregivers provide roughly three-quarters of the care to seniors.

Increasing Speed of Population Aging: 65+ Rise from 7% to 14%

Assumption 5: Leave it to the Front-Line Professionals

- Many dedicated and compassionate care managers who go above and beyond
- However, few guidelines, benchmarks, best practices
  - No universal access to home care
  - No home care service “floor”
  - Caregivers not typically considered home care “clients”
  - Little tracking, analysis of allocation decisions
Innovation? Inequity?

- Leaves room for flexibility and innovation
- Also permits highly subjective and possibly inequitable decisions with little transparency
  - Who “deserves” support?
  - Should working spouses or parents get more support? Or less?
  - Should “means” outdo “needs”?
  - What about “families of choice?”
Assumption 6: 
Address Caregivers Separately

- Separate assessments and care plans to validate and support the caregiver role
- Can also reinforce separation of caregiver and cared-for person and draw attention away from need to look beyond individuals to support networks
Go Big: Neighborhood Networks

- Since 2005, each local area in Leeds, UK, has had its own dedicated Neighborhood Network
  - Local older people and their families get help with the everyday tasks of care, such as free or cheap transport, social activities, shopping, practical help at home, cleaning, gardening and breaks for carers.
  - Families and carers get help to juggle the demands of family, work and caring, delay entry into formal care, and reduce reliance on the NHS.

Source: http://www.ageuk.org.uk/leeds/about-age-uk-leeds/neighbourhood-networks/
Japan’s Open Houses: Sakura-chan & Suzu-no-ya

- Run by volunteers who offer people with dementia and carers access to all-day support in private homes
  - Volunteer training
  - Caregiver peer support
  - 24/7 help line
  - “Light touch” regulation

Part 3: 
Take-Away
Rethink The Caregiver “Problem”

- Informal care not “apart from” formal care systems
  - Formal system sustainability increasingly relies on informal capacity – the “base of the iceberg”

- Essential to put caregivers back into the equation when doing “capacity planning”
  - How can you plan when 70-90% of capacity is off the table?
  - Avoid load shifting that erodes caregiver base
Recognize and Support Caregivers

- Scale-up and spread support initiatives that demonstrate “proof of concept”
  - Including supported self-management models which work at the interface of informal/formal care
Build Supportive Communities

“Overstretched services will struggle to provide extra care … Adult children and partners will take on even greater caring responsibilities and more people, particularly women who outnumber men as carers by nearly two to one, are likely to have to give up work to do so.

Our plan should be to 'build' and 'adapt': to build new community institutions capable of sustaining us through the changes ahead and to adapt the social structures already in place, such as family caring, public services, workplaces and neighbourhoods.”

Source: Institute for Public Policy Research, UK, 2014
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