

Focusing on the advantages of a multi-dimensional approach



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While professional assistance is usually directed to the care recipient, as health care professionals we need to be cognizant of the needs of the caregiver as well. The purpose of this article is to explore the complex connection between caregivers and care recipients. It is an attempt to clarify the concept of the caregiving relationship, and identify the advantages and emerging practices that should be considered in the development of programs and services that recognize caregivers and care recipients as partners in care. The article is based on personal experience as well as a scan of the literature.

Impact on the caregiver

More than three million Canadians provide care to a family member or friend who has a chronic health condition or disability. The vast majority of caregivers—more than 2.3 million—are employed, and one in five Canadians 45 years and older provided care to a senior in 2007.¹ These figures are expected to increase dramatically over the next 25 years, with the growing prevalence of chronic disease and the changing nature of health care.

Early literature focused on caregiver experiences in terms of negative consequences, such as stress and burden. Current thinking challenges this notion and suggests caregivers also experience a level of satisfaction and well-being.² Yet, while many caregivers acknowledge positive aspects to caring (e.g., giving back, strengthening relationships, finding meaning), their caregiving responsibilities can take a toll on their health and general well-being.³ (See “Impact on caregiving.”) How do we as professionals support a caring relationship that supports the health and well-being of both parties?

Define the client

As program planners and professionals, we need to understand the implications and consequences of when care is provided

by family members. The following is a summary of the different approaches to the caregiving relationship.

Care-recipient as client: In the majority of cases, the care-recipient is viewed as the primary client. A program that focuses exclusively on the care-recipient, such as a self-managed education program, is an example of this type of approach.

Caregiver as provider: Various family members often step up to provide care required by another family member. However, as the demand for care increases, it is often the primary caregiver who takes on more responsibility in the actual hands-on provision of care. When this occurs, the relationship can be marked by high levels of tension⁴ and may leave care-recipients feeling like a burden.⁵ A caregiver education program that focuses on practical ways of providing hands-on care, such as transferring, bathing, feeding, injections or wound care, is an example of this approach.

Caregiver as co-client: Oftentimes the caregiver becomes the client due to overload and competing and increasing demands. When we see caregivers as clients, the focus needs to be on reducing the stress and assessing their support needs.⁶ An example would be a support program that offers respite and counselling to provide caregivers with ways to help balance their dual role.

Caregiver and care-recipients as partners in care: This orientation puts the onus on providers to integrate the knowledge and experience of the caregiver and care-recipient into the care plan⁶: to emphasize changing roles and responsibilities in the context of their relationship⁴ and to build on the strengths of the

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family.⁷ A family meeting is an excellent way to identify needs of both the caregiver and care-recipient, and to determine who can contribute to meet the identified needs. Other examples of this approach are a family council in a hospital or an adult day program that offers activities for the care-recipient as well as support and respite for the caregiver.

Community partnerships: There is recognition that no single program can meet all the needs of the caregiver and care-recipient. An emerging trend in the community care sector is the formation of partnerships to identify gaps and find solutions for these unmet needs, such as the development of a dementia network or regional caregiver support network.

Benefits of “partners in care”

There are several advantages to recognizing caregivers and care recipients as partners in care, including:

Sustained and strengthened caring relationship: In our experience, most caring relationships are about give and take. A problem-solving approach is required to build trust, to address issues that are not working and to focus on the health and well-being of both the caregiver and care-recipient.

Integrated caregiver assessment: Being able to focus and ask questions of the caregiver and care-recipient is critical to develop future plans and to help tailor the services, whether it is additional respite care or other program activities. Through a structured assessment that includes the caregiver, one can better understand the diagnosis and anticipated journey ahead. This helps so that expectations, as well as each other’s needs and goals, are better understood. This allows providers to help clarify roles, to

understand the impact on family and to work toward balancing the demands.

Increased flexibility and choice: When helping professionals are aware of the whole picture, they can provide some flexibility and choice to the caring dyad. New program offerings can be identified and developed in response to any emerging need.

Support for transitions in care: A strong caregiver/care-recipient relationship is a bonus during times of transition, especially when a community program can no longer meet both their needs. Helping both caregivers and care-recipients to anticipate the next stage of care and what possible decisions lie ahead is crucial to ensuring smooth transitions across the continuum of care. This is especially relevant for professionals working in hospital settings and who are providing discharge support services to frail seniors, as well as for those who work in the community and assist with the transition from home to long-term care.

Conclusions

We anticipate seeing much greater demands being placed on the family caregiver as the health system is constantly being stretched to keep up with the increasing care needs of an aging population who are living longer and with chronic health conditions. A multi-dimensional approach is required to maximize support and to help mitigate the potentially negative impacts for the caregiver, care-recipient and health care system. It will require programs and services that:

- help caregivers and care-recipients manage their own health, as well as access supports and services to build and strengthen their circle of support;
- recognize caregivers and care-recipients as ‘partners in care’;

Impact on caregiving

Health

- 50 per cent of caregivers report health problems related to their caregiving.⁸

Financial

- Families can expect, on average, \$50,000 in added expenses in the six-month period following a family member’s stroke.⁹
- Having a family member die at home comes with an average bill of \$5,000.¹⁰

Social

- The caregiving role may come into conflict or compete with the individual’s other roles within the family, social and work life. When caregivers experience role overload, they also experience decreased quality of relationships.¹¹

Emotional

- 16 per cent of caregivers for seniors receiving home care report feelings of distress.¹²
- That number is 23 per cent for caregivers caring for someone at the end of life and 40 per cent for caregivers caring for someone with Alzheimer’s and other forms of dementia.¹³
- 63 per cent of employed caregivers report feeling emotional consequences (including stress, anxiety and frustration) from juggling work and family.¹⁴



- encourage the development of effective practices, programs and policies based on rigorous and systematic research programs;
 - use standardized and validated caregiver assessment tools to provide the necessary data on demographics, caregiver needs and program effectiveness;
 - provide education and professional development; and
 - incorporate government support for families, such as tax credits and/or allowances for caregivers, and workplace supports such as compassionate care benefits and family leave
- Although we cannot predict how the trends will unfold, the recommendations presented in this article suggest ways to improve programs and services that support both the caregiver/ care-recipient, now and into the future. ❖

References available on request.

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Resources:

Alzheimer Knowledge Exchange (Ontario)
www.akeresourcecentre.org

Canadian Best Practice Recommendations for Stroke, Section 6.1: Supporting Patients, Families and Caregivers, 2010
www.strokebestpractices.ca

Canadian Coalition for Seniors' Mental Health
www.ccsmh.ca

Canadian Guidelines on Parkinson's Disease, Section 1: Communications, 2012
www.parkinsonclinicalguidelines.ca

The Geriatrics Interprofessional Practice and Interorganizational Collaboration (GiiC) Initiative
<http://giiic.rgps.on.ca>

Registered Nurses Association of Ontario (RNAO), Best Practice Guidelines
<http://rnao.ca/bpg>

Saint Elizabeth, Caring for Caregivers Resource Centre
www.saintelizabeth.com/Caregiver-Database/Home.aspx

Supporting the Caregivers of Seniors through Policy: The Caregiver Policy Lens and Resource Guide, 2011
www.caregivertoolkit.ca

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