Informal Caregiving and Diversity

Diversity takes on many dimensions. A broad and comprehensive understanding includes religious beliefs, cultural traditions, mental and physical ability, sexual orientation and class, as well as differences in race, language and ethnicity (Elliot, 1999; Fried & Mehrotra, 1998). Other differences (e.g., intergenerational, income, religiosity, or degree of acculturation) complicate the picture. This *In Focus*, the second in our **Informal Caregiving** series, takes a closer look at diversity issues and informal caregiving.

Here we use the terms "informal" and "unpaid" "carer" and "caregiver" interchangeably, while recognizing the debates and lack of consensus around terminology. Caregivers provide ongoing assistance, without pay, for family members and friends needing support due to physical, cognitive, or mental conditions (Canadian Caregiver Coalition, 2001).

Why focus on diversity in informal caregiving?

Canada's changing population
Our earlier **Informal Caregiving *In Focus*** outlined how informal carers are important in maintaining the social, mental and physical well-being of individuals. In so doing, they also contribute substantially to the sustainability of the broader health system. Given Canada's changing ethnic, cultural and racial mix, it is important to consider the context of diversity in recognizing and supporting informal caregivers for diverse populations.

- Canada has over 200 ethnic groups. Visible minorities make up of 16% of the total population and over 7% of the senior population (Statistics Canada, 2010).

- In 2006, approximately 19% of the Canadian population was born outside Canada with a majority of the new immigrant population (1.1 million) choosing to live in larger metropolitan centres such as Toronto, Vancouver and Montreal (Statistics Canada, 2009).

Aside from the issues which all carers face (see **Informal Caregiver *In Focus***), informal carers from diverse populations encounter distinctive challenges.

Strategies to address the challenges of diversity and informal caregiving

Address linguistic barriers without compromising privacy
- Provide informal caregivers ready access to information, education, culturally-specific workshops, counselling, support and skills-training in multiple languages

- Similarly, provide caregivers access to system navigators who speak their language and understand their cultural obligations to help them find their way through our complex and siloed health and social care systems. As a result, informal carers can help care recipients get the appropriate level of care by the appropriate providers quickly and smoothly.

- While providing linguistically appropriate services sounds like a straight-forward solution, many community agencies as well as health and social care providers that support informal carers from new immigrant communities are overstretched and would need additional resources.

- Caregivers may rely on relatives (e.g., children) and volunteer translators. However,

some cultural and/or religious traditions more than others may deem care issues "personal" and private. Thus, one must be aware that using the translation services of relatives or volunteers who may come from the same community may compromise privacy and potentially, the helpfulness of caregiving. On sensitive care issues, using the translation services of someone who is not a relative or acquaintance may be prudent.

Disseminate caregiving information through pre-established social, cultural, religious networks
Caregivers in some communities may turn to religious/spiritual or ethnoculturally specific community centres to seek information and recommendations for support, educational services and respite.

- Tailoring promotional programs and information sharing, as well as disseminating caregiving information and resources through such pre-established networks within different cultures may help inform larger numbers of caregivers particularly from new and emergent immigrant communities rather than relying solely on mainstream avenues.

- Using multi pronged outreach approaches (e.g., internet, DVDs, brochure hand-outs in multiple languages and public service announcements on radio and television stations oriented to diverse populations) may help broaden where caregivers can access information.

Understand caregiving within the larger cultural context
Illness and diseases are socially constructed experiences. The meanings and experiences of illness and disease may vary from group to group. As such, informal caregivers and their recipients may approach caring in a variety of ways.

- For example, caregivers may need information and education to distinguish what some cultures consider as "normal aging" as opposed to symptoms requiring medical intervention.

- Some cultures have faith in alternative, holistic or naturopathic health. Culturally appropriate "best fit" models of care and support for older populations and their caregivers sho uld encompass the atmosphere, environment, culture, language, and food that is appropriate and familiar, such as Healing Lodges for First Nations and Inuit peoples, and traditional medicine and holistic methods for Eastern cultures.

Respite and culture
Respite services that respect the culture, religion, language, and the food preferences of care recipients would provide much needed breaks for caregivers. Caregivers may be more inclined to use adult day programs which are culturally welcoming by their appropriate décor, dress, activities and dietary options.

- Nonetheless, some carers may not identify and vocalize their need for support because of the expectations and responsibilities around caregiving in their community. The extent to which caregiving is perceived as a burden or the caregiver entitled to respite may depend on divergent ideas of appropriate gender roles and family obligations. Caregiver outreach programs must raise awareness around caregiving issues in diverse populations and encourage caregivers to identify themselves and seek respite support to avoid burnout, isolation, and other health and social costs.

Support intergenerational and intercontinental caregiving
Resource materials for caregivers should also consider how to support immigrant populations who provide care for family members across generations and continents, all of which add stress, conflict and isolation.

- For example, some employers may have the capacity to offer flexible work schedules to enable carers to take time off work to travel home to monitor care arrangements.

Diversity and informal caregiving in rural areas
In rural and remote areas, older people and their carers experience further barriers to accessing

supportive services. In addition to inadequate transportation systems and long distances to adult day centres, the challenges of finding culturally relevant education and support for caregivers are doubly difficult in smaller rural communities where recent immigrant communities do not form a critical mass.

- One suggestion is to use business associations with branches across regions to disseminate caregiver resources.

What has been done to support diversity and informal caring?

Here we showcase some useful local, regional and international policy and practice initiatives which support individuals, their carers and the formal health system.

- Bendale Acres Long-Term Care and Home Services offers long term care and respite services catering specifically to older persons with dementia from the Ismailia and French-speaking communities. The organization uses volunteers from both the Ismaili and French communities to facilitate sensitivity to culture, language, and religion. This is especially important as some dementia patients tend to lose their second language as the disease progresses (Toronto Long-Term Care Homes and Services, 2011). http://www.toronto.ca/ltc/bendaleacres.htm

- Meno Ya Win Health Centre provides a full range of culturally appropriate respite and relief services for family caregivers for Aboriginal communities within Ontario. These services include community-based personal care, counselling services, case management, and relief for caregivers in the community through traditional healing, music and food. http://www.slmhc.on.ca/traditional_support_program/the_meno_ya_win_elder_care

- With funding from the Central and Central East Local Health Integration Networks (LHIN), the Yee Hong Centre for Geriatric Care is expanding its caregiver education and support services beyond various Chinese populations to other linguistic and cultural communities (e.g., Tamil, Japanese). Services, offered in multiple languages, include mutual help, resource sharing workshops, supportive counselling, DVDs, etc (Yee Hong Centre for Geriatric Care, 2011). http://www.yeehong.com/centre/caregiver_support.php

- The Canadian Virtual Hospice offers a wide selection of resources for caregiving and collaboration. Its website is Canada's largest repository of information on palliative and end-of-life care, and addresses every aspect of caregiving, in community and clinical settings. It covers topics from spiritual challenges to the day-to-day practicalities. All content is compiled and reviewed by a respected team of palliative care professionals. www.virtualhospice.ca

- The Canadian Mental Health Association developed a "Diversity Lens Checklist" for healthcare professionals to address the diverse needs of staff, clients and their informal caregivers. The checklist covers areas including access to information, policy and procedures, recruitment and evaluation, and programs and services. It suggests courses of actions to identify systemic barriers to accessing services, recruiting volunteers to be more reflective of the community, and providing diversity development and training for staff members. http://www.marketingisland.com/mi/tmm/en/cataloguemanager/CMHA/CMHA_diversity_guide_EN.pdf

- Pauktuutit Inuit Women of Canada's Inuit Family Caregivers Strategy used creative strategies such as telephone interviews, community visits, promotional materials and radio call-ins to raise awareness for caregiving issues, and to encourage caregivers to identify themselves and seek respite support (Pauktuutit Inuit Women of Canada, ND). http://www.pauktuutit.ca/pdf/ART_PauktuutitAnnual0607_ENG.pdf

- The Victorian Order of Nurses, Canada (VON) has an online resource guide which highlights diversity issues in informal caregiving. For example, it includes resources for culturally specific understandings of aging, and ways to assist long-distance caregiving (e.g., how to navigate a foreign healthcare system). http://www.von.ca/english/Caregiving/CaregiverManual/ResourceGuide/Module%206%20-%20Diversity%20in%20Caregiving/Module6_DiversityCaregiving.pdf

- With funding from the Weinberg Foundation's Family and Informal Caregiver Support Program - Caring Together, Living Better, AgeOptions in Oak Park, Illinois worked directly with local churches and grassroots organizations to help diverse caregivers with respite care, transportation and access to benefits such as food stamps. http://www.ageoptions.org/networkOfCare/resourceConnections.cfm

- The Jewish Healthcare Foundation in Pittsburgh, PA, introduced *Caregiver Champions* to support and empower caregivers. The program looks to recruit experienced family and informal caregivers to become a resource for information and support within their own communities. www.caregiverchampions.org

- The Asian Community Center and Sacramento Asian Pacific Islander Dementia Care Network's joint project assist Sacramento's Asian caregivers, including Thai, Filipino, Hmong, Korean, Samoan, Tongan, and Native Hawaiian, with services such as caregiver education, drop-in respite, in-home nursing. It also provides education to service providers on how to work with linguistically and culturally diverse populations. http://www.accsv.org/

- Alzheimer's Disease and Related Disorders Association of Southern California partnered with linguistically and culturally fluent community care managers to provide services to caregivers directly through four Asian cultural and linguistic organizations. Services offered include respite care and legal and financial counselling related to caregiving. http://www.alz.org/national/documents/C_EDU-APIDementiaCare.pdf

Summary

1. Recognize that funding for caregiving is vital not only to care recipients but also to the formal health system and the broader economy.
2. Provide easy access to education, skills training, wellness programs in multiple languages through varying formats and avenues.
3. Ease system navigation for caregivers with case managers who share the same culture and speak the same language as caregivers.
4. When addressing the linguistic and cultural barriers which carers from diverse communities face, consider also the ways in which using relatives and family members as translators may compromise privacy.
5. Disseminate caregiving information through pre-established social, cultural or religious networks.
6. Use community outreach to raise awareness around caregiving issues among diverse populations and encourage caregivers to identify themselves, and to seek respite support to avoid burnout, isolation and other health and social costs.
7. Facilitate linguistically and culturally appropriate respite services.
8. Support intergenerational and intercontinental caregiving.
9. Find innovative ways to support informal caregiving for diverse populations in rural areas (such as using business associations that have branches across regions).

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