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## WHO CARES FOR THE CAREGIVERS?

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Caregiving is a major preoccupation that needs to be shared not only by caregivers and care-recipients, but by everyone concerned with the health, social, and economic consequences associated with caregiving. This includes practically all of us, because *When*, rather than *if* one is likely to become a caregiver, may well become the appropriate question in coming years.

In more than twenty years I have encountered many hundreds of caregivers. Their binding commonality is the challenges they have face, often under very trying circumstances. My experience with caregivers is mainly in the context of mental illness, and I will refer to it later in my remarks. However, caregiving is caregiving, and while there may be some unique characteristics associated with different contexts, the commonalities are many.

I was asked to talk about family caregiving, women, and mental health. We can approach it from different perspectives. For example:

**Women as caregivers** (paid or unpaid);  
**Mental health of women** (caregivers or not);  
**Mental health of women who are caregivers**;  
**Women caregivers** to someone with **mental health** challenges...

This is a vast field. It can be viewed as a triangle in which each side is important and intriguing in its own right. Putting it together is a challenge that cannot be under-estimated. The inter-relations between **women, caregiving, and mental health** can create a potent construct. To understand it we should start by exploring one parameter at a time.

I. Let's start with **caregiving**, or more precisely with **family caregiving**. Unlike paid caregivers, family caregivers are members of the family who provide care and assistance for spouses, children, parents and other extended family members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long term illness or disability.

- Statistics Canada reports that in 2002, more than 1.7 million adults aged 45 to 64 provided informal care to almost 2.3 million **seniors** with long-term disabilities or physical limitations. 7 out of every 10 caregivers in this age range were employed, and many were women.
- A 2006 survey of health care in Canada found that 26% of **all** Canadians reported having cared for a family member or close friend with a serious problem in the last 12 months. 22% of these people missed one or more months of work and 41% used personal savings.
- A Health Canada report from 2002 suggests that the **intensity and length** of unpaid caregiving can be significant. Over 700,000 caregivers provide more than 10 hours of care per week and 60% of caregivers provide care for more than three years.
- More than one third of caregivers report extra expenses due to their caregiving responsibilities. Two-thirds of these caregivers spend more than \$100 per month on caregiving. This conservatively translates to an annual cost to Canadians of \$80 million.
- The same Health Canada report suggests that unpaid caregivers provide more than 80% of care needed by individuals with 'long-term condition.'
- The economic value of caregivers' unpaid eldercare to the Canadian economy is estimated to be over \$5 billion and between \$6-9 billion for all caregivers (chronic and palliative care) unpaid work.

The concept of family caregiving is not new. However it is taking on a more urgent role with the changing infrastructure of families and communities. Families are smaller and more dispersed; more women are involved in the formal workforce; families often start later in life; retirement is delayed; the population is aging; and the increased life expectancy is likely to be coupled with an increased rate of disability.

II. Now let's add to this equation **women as caregivers**. Women provide most informal care. They play many roles, such as hands-on health providers, care manager, friend, companion, surrogate decision maker and advocate.

- A US study from 2002 found that between 59% and 75% of unpaid caregivers are women
- A 1997 study of the National Alliance for Caregiving found that the average caregiver in the US is 46 years old, female, married and working outside the home, earning an annual salary of \$35,000.
- Although men also provide assistance, female caregivers may spend as much as 50% more time than male caregivers providing care.
- Additionally women live longer than men, tend to outlive their spouses, and have less access to retirement savings such as pensions.
- Women who were 65 in the year 2000, can expect to live another 19 years to age 84;
- In 2000, almost 40% of women age 65+ were living alone; 51% of women age 80 were living alone

- Interestingly, most elderly care-recipients are also women. A 1997 survey reports that 70% of older persons ages 75+ who needed assistance with daily activities were women.
- As workforce participation increases, caregiving could pose even greater financial challenges to many women workers, due mostly to lost wages from reduced work hours, time out of the workforce, family leave or early retirement.
- Caregiving has a significant **economic impact** on a family. A 1998 study found that 49% of Baby Boomer women caregivers suffered 'financial hardship' as a result of caregiving.
- Apart from the economic cost, the demands on caregivers' **time** are also substantial. Working women don't abandon their caregiving responsibilities because of employment. Instead, they cope with the combined pressures of caring for a loved one, their need for income, reliance on often-inadequate public programs, and fewer employment related benefits.
- Women caregivers are significantly less likely to receive a pension and when they do, it is about half as much as those that men receive.
- Women are likely to spend an average of 12 years out of the workforce raising children and caring for an older relative or friend.
- To complicate the picture even further, it was found that once the caregiving stops, women who reduced their working hours because of it do not return to full time employment.
- Caregiving also has a substantial impact on the work place. Absenteeism and replacing employees who quit in order to provide care can have serious financial consequences to employers.

III. This brings us to the third part of the triangle, which is **mental health**. The toll that caregiving exacts is not just financial. **Depression, anxiety** and other **mental health** challenges are common among women caregivers.

- A 2002 US-based study found that middle-aged and older women who provided care for an ill or disabled **spouse** were almost **6 times** as likely to suffer depression or anxiety symptoms as those who had no caregiving responsibilities.
- Women who cared for ill **parents** were **twice** as likely to suffer depressive or anxious symptoms.
- Additionally, women caregivers were found to have a higher level of **hostility** and a greater decline in **happiness** as a result of caregiving. They demonstrated less 'personal mastery' and less self-acceptance, as well as higher caregiving-related **stress**.
- **Physical health problems** are also evident: more than **one-third** of caregivers providing intense and continuing care to others suffered from **poor health themselves**. A US study found that as many as two out of three older women caregivers do not take advantage of preventive health services due to lack of **information** and high out-of-pocket **costs**.

- A 2003 study found that **health problems** such as coronary heart disease, elevated blood pressure, increased risk for hypertension, poor immune function and increased risk of mortality were evident in 25% of women caregivers as a result of their caregiving activities.
- Despite the physical and emotional tolls of caregiving and risk factors for disease, **women caregivers are less likely to have their own health needs met.**
- A 1999 study that compared women caregivers to non-caregivers found that:
  - 25% (vs. 17%) rated their own health as fair or poor
  - 54% (vs. 41%) had one or more chronic health conditions
  - 51% (vs. 38%) exhibited depressive symptoms
  - 16% (vs. 8%) were twice as likely in the past year not to get needed medical care
  - 25% (vs. 16%) had difficulty getting medical care.

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### **THE SPECIAL CASE OF CAREGIVING TO A LOVED ONE WITH MENTAL ILLNESS.**

You may have noticed that my remarks have so far referred primarily to caregiving to older adults. It's not a coincidence: With an increasing life span the proportion of older adults requiring help is growing, and the ramifications are substantial. No wonder then that much of caregiving **research** is related to this segment of the population.

I would like to make some comments, however, about **caregiving in the context of mental illness**, because despite the evidence that such caregiving can exact a heavy toll on the caregiver's well-being, this group is often under-estimated and not explicitly included in policy recommendations. Here I refer to caregivers in general, both men and women; but since we have already seen that the majority of caregivers are women, you can infer from the comments I made earlier to this special case.

The **burden** associated with the role of family members as caregivers to a loved one with mental illness has been widely documented in scientific literature and reflects the overall level of distress associated with this role. Mona Wasow (1995) observed: "**As with a large stone skipping across water, the ripple effect of mental illness on the entire family is enormous**". A typical trajectory of mental illness includes cycles of crises and remissions, often over many years, and subjects family members to ongoing burdens and stress that can become chronic.

The notion that families cause, precipitate, or exacerbate mental illness in a loved one was common a few decades ago. This perception is gradually

changing, and there is a growing recognition that families are co-victims of what is widely viewed today as a biologically-based illness that affects their relatives. However, while the blame is gradually lifting, families continue to be entrusted with the role of caring for their ill loved one. This role often lasts a lifetime and carries a significant level of burden.

Here is an interesting observation: While caregiving to elderly adults with Alzheimer's or dementia, for example, is usually limited to the latter part of the person's life, caregiving to a mentally ill relative can last for a long time, often for life. Another difference is that caregivers to the elderly are perceived by the healthcare system as an **extension** of the system; there is an expectation that families would support their elderly relatives. In mental illness, despite the gradual lessening of the blaming attitude towards families as the cause of their relatives' illness, families are still commonly **excluded** from the treatment process. This does not free them from their caregiving responsibilities, just makes it that much more difficult.

Family members are often involved with providing care and support, regardless of the illness severity. However, families with relatives suffering from a severe mental illness (SMI) are most likely to assume long-term, often life-long, caregiving responsibilities. This accounts for an estimated 1.8 million families in Canada alone.

It is estimated that between **one third** and **one half** of adults diagnosed with mental illness live with their families. A study from the early 80s found that of those who were **not** living in their family home, 90% were in contact with their families if they lived nearby. Overall it is estimated that regardless of their living situation, 70% of adults with severe mental illness have family members who can or will be involved in their care.

The living situation of adults with mental illness is not necessarily indicative of the caregiver's burden. Many family members whose loved ones live on their own (or in supported settings outside of the family home) provide assistance that is associated with high levels of burden. Therefore separate living arrangements do not necessarily imply less caregiver burden.

In the context of caregiving to a mentally ill loved one, researchers have distinguished between **objective burden** and **subjective burden**. Objective burden refers to the actual hardship and disruptions associated with caregiver duties; subjective burden reflects the personal suffering endured by the caregiver. Grief, chronic sorrow, a roller coaster emotions and empathetic pain are central themes in describing the subjective burden of families. These experiences are difficult to quantify but their impact on the caregiver is often dramatic, traumatic and life changing.

For these reasons, the importance of adequate support for families caring for a mentally ill relative cannot be over-estimated. The cost of NOT responding to the needs of families, I believe, is likely to be much higher than the cost of promoting and offering proper services.

Caregivers – and here I refer to all caregivers, not only for mental illness – require support by virtue of their **caregiving role**, in order to mitigate the **consequences** of that role. The consequence of NOT supporting caregivers with adequate services is a double whammy, because it can translate not only into worse outcomes for their ill relatives, but also into negative outcomes for the caregiver's own health. Long-term caregiving is a high risk factor for the caregivers' health, both physically and mentally.

The last point I would like to make is about the **rewards** associated with caregiving. We talked about hardship and the negative outcomes, but it is important to note that although caregiving can exact physical, emotional, and financial tolls, it can also be rewarding.

- In a study on family resilience in the face of mental illness, 88% reported some positive consequences to the family, which included **stronger bonds and commitments, resourcefulness, pride and satisfaction**, as well as **growth and adaptation**.
- In addition to the rewards for the family as a unit, most individuals reported some benefits for themselves as well, such as a stronger sense of **purpose in life, increased tolerance, empathy, compassion and understanding**. They also talked about their **contribution to their ill relatives and to their family**, and felt they have gained a **clearer sense of priorities**. More **autonomy**, and more **self-acceptance** were also mentioned.

It is important to recognize that, because proper supports can do more than minimize the risks associated with caregiving; they can also enhance the benefits and rewards associated with this role.

In conclusion, we see that caregiving, especially long-term caregiving, is associated with significant burdens for the caregiver, and in many cases can be qualified as a chronic stressor. If not addressed, chronic stress can be harmful for the caregiver's health, can affect the recipient's quality of care, and could have wide spread economic and social ramifications. To reduce the risks and enhance the benefits caregiving can provide to the caregiver, adequate supports are vital. And if not for humanitarian reasons, than certainly for social and economic reasons.

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