

# **Lecture Outline: Informal/Non-Waged Health Care**

## **Introduction:**

- **Defining caregiving**
- **Romanow Report & home care**

## **1. Home Care & the Canadian Health Care System**

- **Mental Health, Post-acute Home Care, Palliative Home Care**
- **Provincial Programs**

## **2. Who Cares?**

- **Canadian Statistics**
- **Caregiving Profiles**

## **3. The burden of care?**

- **Family dynamics**
- **The work of caring**
- **The finances of caring**
- **The health of caregivers**
- **The emotional aspects of caring**

## **Conclusion**

**“People take care of each other; it’s one of the things that makes us human. We have all been taken care of, at least when we were young, and most of us will, at some time in our lives, care for a child, spouse, parent, friend, or neighbour. For many adults, taking care of others is a fact of life for decades. Then, when we become old, it may be our turn again to be the one who depends on others.”**

**Vanier Institute 2007**

# Caregiving – generational patterns

**“Everyone seems to know intuitively what home care is: yet there is no single definition of what home care means. At a minimum, it is a term used for an array of services that allow individuals who suffer some mental or physical incapacity to live at home and receive the care they need. Quite often, the effect of this is to prevent, delay or substitute home care for hospital or long-term residential care.”**

**Romanow Report, 2001**

# Deconstructing Romanow

- 1. “everyone seems to know intuitively what it is” – home care is invisible & unacknowledged**
- 2. “the effect of this is to prevent, delay or substitute home care for hospital or long-term residential care” - home care takes up the slack from institutions**
- 3. “an array of services” - diverse, not linked to specific type of care**
- 4. tied up with ideology of home**

# **Home Care: Areas of Expansion**

**1. Mental Health Care**

**2. Post-acute Home Care**

**3. Palliative Home Care**

# Canada's Ageing Population

- **between 1991-2001  
Canadians 80+  
increased by 40+%**
- **2004 - 13%  
Canadians 65+**
- **2026 – 21%  
Canadians 65+**

# Home Care Programs

- **Provincial home care programs since 1970s**
- **1996: Ontario established Community Care Access Centres (CCACs) or Local Health Integration Networks (LHINS)**
- **2007: Ontario launched 3-yr \$700 million Aging at Home Strategy**



# Home Care: Policy vs Practice

- Home care & the Canada Health Act (1984) – Comprehensive, Accessible & Universal?
- Jurisdiction vs Practice/Systems in Place
- Home care - Best value to whom?

# Who are the Caregivers?

- **2002 – total 2.4 million eldercare providers in Canada**
- **1997 Health Charities Council of Canada estimated 93 million hours of formal volunteering yearly + 2 billion hours of informal care giving - combined value of these services = 20-30 billion dollars**
- **93 million hours formal caregiving yearly plus 2 billion hours of informal caregiving**
- **85-90% home care provided by family & friends**
- **80% of elder care provided by family members**

# Caregivers in Focus

- **62% caregivers active for 5 years; 20% for 10+ years**
- **average size of care network: 3 caregivers**
- **20% Cdns over 45 providing care to family or friends 65+**
- **3/10 Cdns aged 45-64 with unmarried children <25 (712,000 indivs) also caring for a senior**
- **54% caregivers women; 46% caregivers men**
- **women spend 17 yrs caring for children; 18 yrs caring for aged parents**
- **women do 29 hrs/mth in senior care – men do 13 hrs/mth**

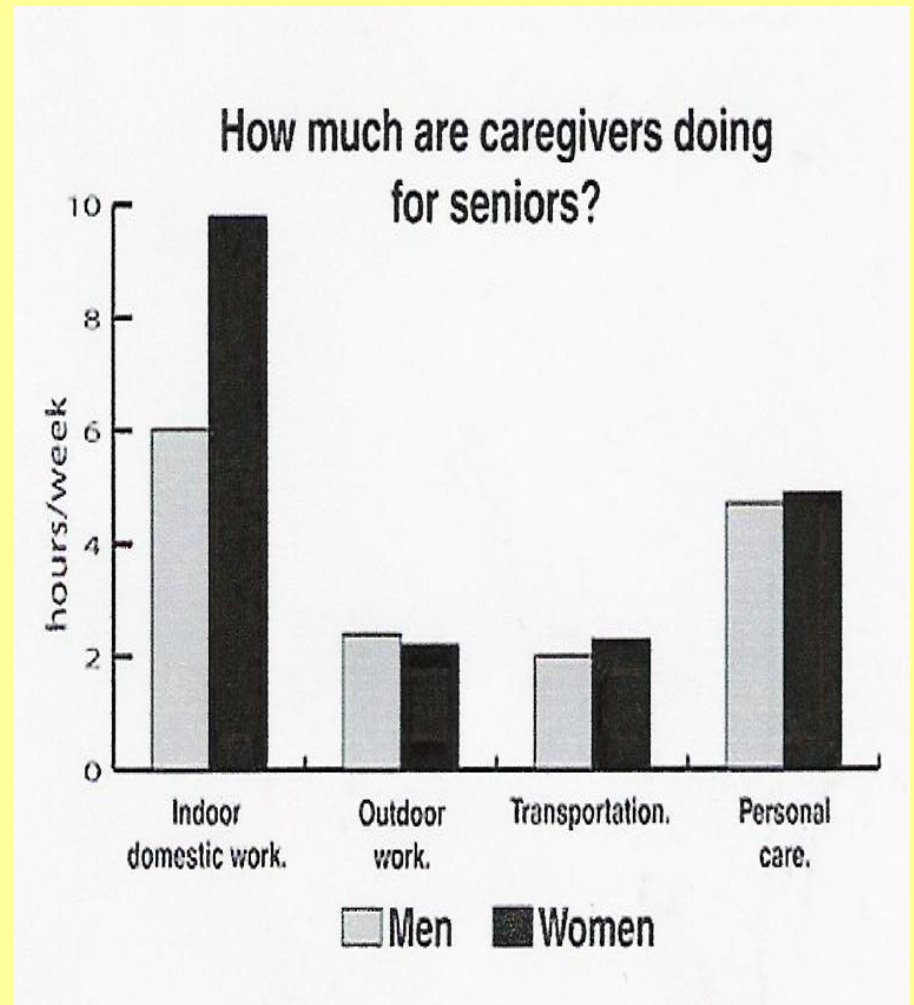
# Women as Caregivers

# **The work of caregiving?**

# The work of caregiving

- laundry
- household cleaning
- meal preparation
- grocery shopping
- bathing
- routine bathroom
- bladder function
- changing pads
- bowel function
- incontinence
- shaving
- brushing teeth
- supervision
- administering medication orally
- administering medication by needle
- administering medication by other means
- physiotherapy/exercise
- decision-making
- acting as a confidante
- ordering medication
- purchasing medication
- driving to doctor or physiotherapy

# Caregiving: Gendered Work



“Our children come & they cry. And I cry. We reminisce about old times. We try to recall what Anna was like before this happened. But I can see it wears them out just being here for a day or two... Me? It’s made a different person out of me. I expect you wouldn’t have recognized me if you had met me ten years ago. I feel at least ten years older than I am. I’m afraid what will happen if I go first. This illness didn’t just destroy Anna’s mind, it has killed something in me, in the family, too. If anyone asks about Alzheimer’s, tell them it is a disease of the whole family.”

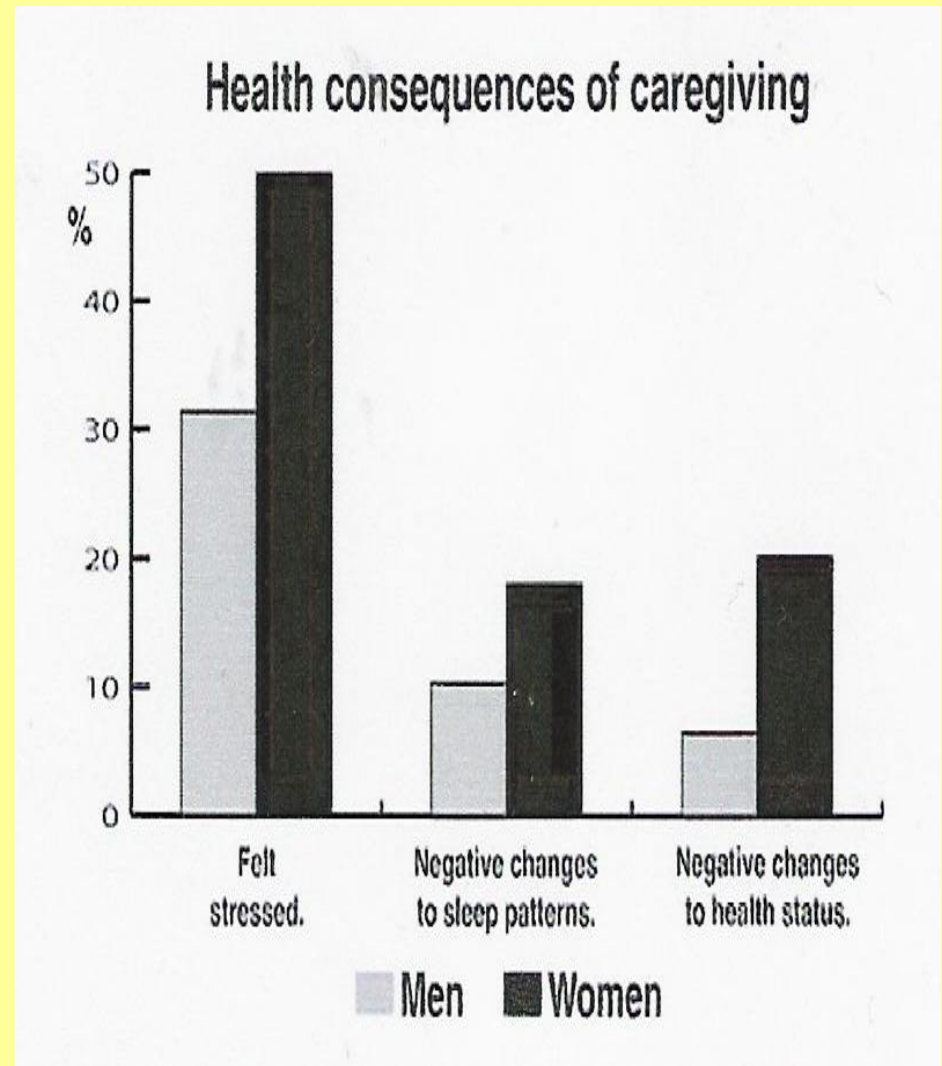
Quoted in Kleinman, 1988



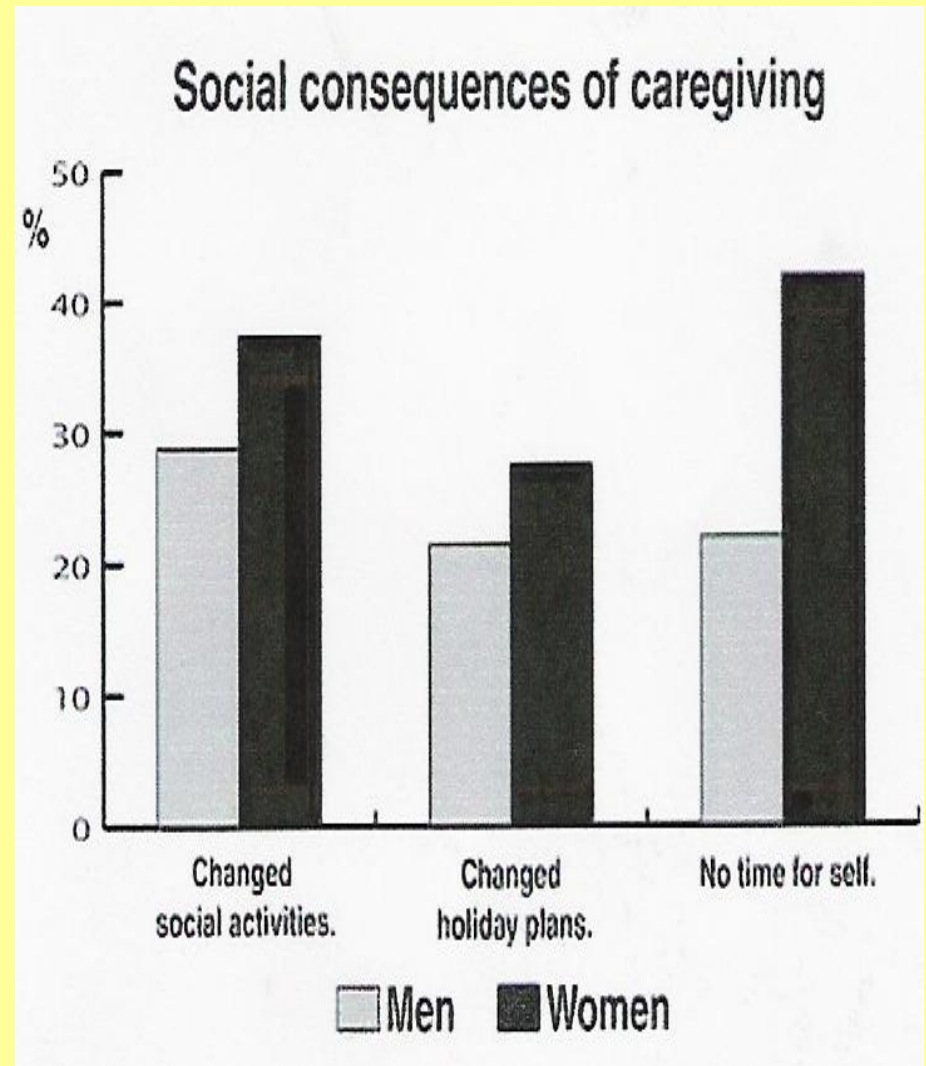
# **The Burden of Care? Financial**

- **outlay for goods & services**
- **loss of waged labour & retirement funds**
- **gendered patterns & attitudes**
- **indirect compensation (through federal tax credits)- Caregiver Credit, Infirm Dependent Age 18 or Older Credit, Eligible Dependent Tax Credit, Disability Tax Credit Transferred from a Dependent, Medical Expense Tax Credit**
- **labour policies - Compassionate Care Benefit (Employment Insurance Benefit)**

# The Burden of Care? Health



# The Burden of Care? Emotional



# **Future Directions?**

- 1. Recognition of monetary value of caregivers work**
- 2. Acknowledgement & support from Canadian health care system**
- 3. Input from caregivers into the policy process**
- 4. Provision of support services & information**

**Dr. Mark Nowaczynski: House Calls**