Who Cares for the Caregiver?
26th Annual Geriatric Medicine Refresher Day
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Learning Objectives
• To develop an awareness of the issues for Caregivers of Palliative Patients
• To recognize Caregiver burden/stress, and how to support Caregivers
• To enhance knowledge of resources available to Caregivers

Definitions
A Caregiver is an individual who provides ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental health conditions.

Speaker Disclosure Form
Andrew Feron
“I have not in the past 2 years, had a financial interest, arrangement or affiliation with one or more organizations that could be perceived as a direct/indirect conflict of interest in the content of the subject of this or any other program.”

Definitions
Family are all those in loving relationships with the person who is dying, the people who can be counted on for caring, and support, regardless of blood or legal ties.

Definitions
The term is sometimes qualified with; Family Caregiver, Informal Caregiver, or Unpaid Caregiver to differentiate them from Healthcare Professionals, or Formal Caregivers.
Definitions

The CHPCA defines **Informal Caregivers** as Caregivers who are not members of an organization. They have no formal training, and are not accountable to standards of conduct or practice.

**Hospice Palliative Care** is a broad term used to identify a standard of care that encompasses both Patient’s and their Caregivers. It refers to a holistic, multi-disciplinary approach that aims to improve the Patient’s quality of life. In HPC, the Patient & Family (Caregiver) are considered the Unit of Care.

Definitions

**Caregiver Burnout/Stress** are terms used to describe the physical and emotional exhaustion that Caregivers can experience after spending large amounts of time and energy on caring.

**Compassion Fatigue** is another condition marked by profound emotional and physical erosion that takes place when Caregivers are unable to refuel and regenerate.

The Facts

- Canada’s population is aging
  - By 2031, a quarter of Canadians will be 65 years or older, double the proportion of seniors today
  - The proportion of Canada’s oldest seniors, those over 80 years of age is expected to triple in the next four decades, meaning one in 10 Canadians will be over 80 years of age

- Canadians are living longer with multiple chronic health conditions placing increasing pressure on the health and social care systems, and on Canada’s 1.5 to 2 million family caregivers.
The Facts

- Increasing rates of divorce, remarriage, and blended families means more people will depend on fewer individuals for the care they will need in years to come
  - Traditional support networks are disappearing
  - Canadian adults are not marrying

Caregiving Trends

1. The belief that life can be prolonged in healthcare institutions through scientific based care
2. There tends to be a greater discomfort in discussing and acknowledging death

Caregiving Trends continued

3. Contributing to the prominence of institutional caregiving is the increasing mobility of the Canadian population
4. Due to the trend toward smaller family size, fewer adult children are available to share the caregiving responsibilities for older adults

Who Are Informal Caregivers?

- A majority of caregivers are women (77%), usually the partners, mothers, daughters, sisters, daughter-in-laws and friends of the dying person

Who Are Informal Caregivers?

- In 2007, the number of family caregivers, aged 45 years and older was 2.7 million. Between 2002 and 2007 the number of family caregivers aged 45 years and older increased 30% (over 670,000)
Who Are Informal Caregivers?

• 23% of Canadians have cared for a family member or close friend with a serious health problem in the last 12 months
• Up to 85% of all palliative care in Canada is provided by family members

Who Are Informal Caregivers?

• There are at least 2.85 million family caregivers in Canada
• More informal caregiving is falling on older, frailer, spouses, partners, and siblings, and on older children who may themselves have age-related problems

Work and Financial Issues

• 13% of Caregivers work situations were impacted.
  – 50% needed to reduce or modify their work hours
  – 1/3 used sick days & vacation
• A Family Caregiver loses approx. 23% of their workable hours
• 23% are missing 1 or more months of work

Work and Financial Issues

• 41% of Family Caregivers used personal savings
• More than 1/3 of Family Caregivers report extra expenses
• 65% of households with a Caregiver report a combined income of < $45,000
  23% report < $20,000

Work and Financial Issues

• Economic contribution of Family Caregivers has been estimated to be $25 – 26 Billion (2009)
• Caregiver out of pocket expenses are over $1,000 a month

Legal, Ethical & Moral Issues

• The “idealization” of Dying at Home, and Pressures on Caregivers to provide Hospice Palliative Care at Home
• The expanded role of Caregivers
Legal, Ethical & Moral Issues

• Pain and Symptom Management
  – Reduce Pain/Symptom issues by:
    • Increase understanding & communication
    • Training in use/administration of drugs
    • Review plan & goals of care
    • Consider cultural views/use of complementary therapies
    • Understand limits of palliative care

Legal, Ethical & Moral Issues

• Support Available for Informal Caregivers

Legal, Ethical & Moral Issues

• Substitute Decision Making and Confidentiality
  – Encourage people to talk about their wishes
  – Encouraging people to prepare Advance Directives, Living Wills, and Powers of Attorney
  – Reassure people that they can change their mind
  – Involve Dying Person
  – Educated SDM about responsibilities
  – Provide counselling & education

Legal, Ethical & Moral Issues

• The Added Complexity Created by Culture, Disability, and Marginalization
• The Transition From Active to Palliative Care
Demands on Caregivers
- 71% helped with transportation
- 51% helped with house activities
- 39% helped with meals
- 35% helped with managing care
- 32% helped with personal care
- 27% helped with medical care

Role of Caregiver
- Residential Hospice

Role of Caregiver
- Long Term Care Facilities & Hospitals

Role of Caregiver
- Home

Caregiver Needs
Caregivers need training & information, delivered in an accessible manner

Caregiver Needs
Caregivers need help with the psychological distress & physical symptoms associated with caregiving
Caregiver Needs

Caregivers need recognition of the value of their caregiving role

Caregiver Needs

Caregivers need support dealing with the stresses that come with the caregiving role

Caregiver Needs

Caregivers need support dealing with financial pressures

Care For The Caregiver

Drummond Report

- Family Health Teams/Family Centred Care
  - Physical care & emotional support
  - Shared decision making
  - Focus on the Individual
  - Attends to needs of Family Members
  - Co-ordination of medical care

Caregiver Resources - Financial

- Caregiver Allowance
- Compassionate Care Benefit
- Canada Pension Plan

Caregiver Resources – Financial

Available to Patient/Care Receiver

- CPP Disability Benefits
- Provincial Social Assistance
- Employment Insurance
- Employers Insurance Plan
- Life Insurance/Living Benefits
- Tax Credits
- Provincial Drug Program
Caregiver Resources - Financial

Tax Measures
- Family Caregiver Tax Credit
- Medical Expenses Tax Credit

PCPCC Recommendations
Parliamentary Committee on Palliative and Compassionate Care

- Strengthen Homecare for First Nations, Metis, & Inuit communities
- Develop Rural Palliative Care Delivery
- Family not Disease Model, Interprofessional Team not Medical Model

PCPCC Recommendations
Parliamentary Committee on Palliative and Compassionate Care

- Introduce Palliative Care at point of diagnosis
- Utilize Social Networks
- Health Care System Navigators
- Build Capacity

Caregiver/Family Friendly Policies

- Family Friendly Workplace Policies (FFWP’s)
- Family Caregiving Agreements
  - Define Care Needs
  - It’s a job; Treat it like one
  - Make a financial plan
  - Put it in writing
  - Talk it over

Caregiver/Family Friendly Policies

- ?National Caregiver Strategy

Caregiver Resources

The ABC’s of Self Care
- Awareness
- Balance
- Connection
Caregiver Resources

Creating Your Own Support Team
• Trinity Home Hospice (Toronto)
• Share the Care
• Community of Care: A Parish Ministry of Care

Caregiver Resources

• Focus on one day at a time
• Learn what being a Caregiver means
• Join a Support Group
• Find the Positive
• Take care of Yourself
• Take on Smaller, Simpler Tasks
• Know your limits

Conclusion

References

Capossela, Cappy & Warnock, Sheila (2004). Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill. Fireside

Not to be Forgotten – Care of Vulnerable Canadians. Parliamentary Committee on Palliative and Compassionate Care


References

VOICE In Health Policy – The Role of Informal Caregivers in Hospice Palliative and End-of-Life Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges, prepared by the Canadian Hospice Palliative Care Association. April 2004