Canadian Home Care Association: 2017 Home Care Summits

Priority Action Tables: Empowering Patients and Caregivers

Dr. Jasneet Parmar, Associate Professor, Department of Family Medicine, University of Alberta
Medical Director, Network of Excellence in Seniors' Health and Wellness, Covenant Health
Medical Lead, AHS EZ Home Living and Transitions

“It’s not if, it’s when you will be a family caregiver.”

- Nadine Henningsen, President, Carers Canada

Objectives

By the end of this session you will learn about:

- The interface between case managers and family caregivers and
- How it can be improved to promote caregiver wellbeing and resilience.

Family Caregivers

Definition: The World Health Organization (WHO) defines family caregivers as those who provide informal care without pay*.

*World Health Organization and Alzheimer's Disease International. Dementia: A public health priority. Geneva, Switzerland: World Health Organization; 2012.

Number of Caregivers (Stats Canada 2016)

- 28% of population
  - **10.1 million** caregivers in Canada
  - **1.2 million** caregivers in Alberta
    (http://www.statcan.gc.ca/pub/91-520-x/2010001/tablesectlist-listetableauxsect-eng.htm)

Significance of Family Caregiving

- **Family caregivers are the backbone and increasingly overburdened part of the health care system** (1,2,3).
  - Our healthcare system will be faced with an increasingly aging population and resultant growths in health care services.
  - The importance of the growing size of the senior population, particularly the rapidly increasing number of those in their eighties and nineties raises the question of families' ability to provide the care needed to maintain a senior population in their own homes.

Significance of Family Caregiving

- **There is increasing evidence that caregiving is being provided at significant physical, emotional and financial costs to the caregiver** (1,2,3,4).
  - Multiple Canadian national reports outline the need to support caregivers and recognize their indispensable contribution to the sustainability of the health system.
  - Given the essential role of caregivers within the health care system, supporting them has become a national public health priority and needs attention in Canada.

Case Management Practice

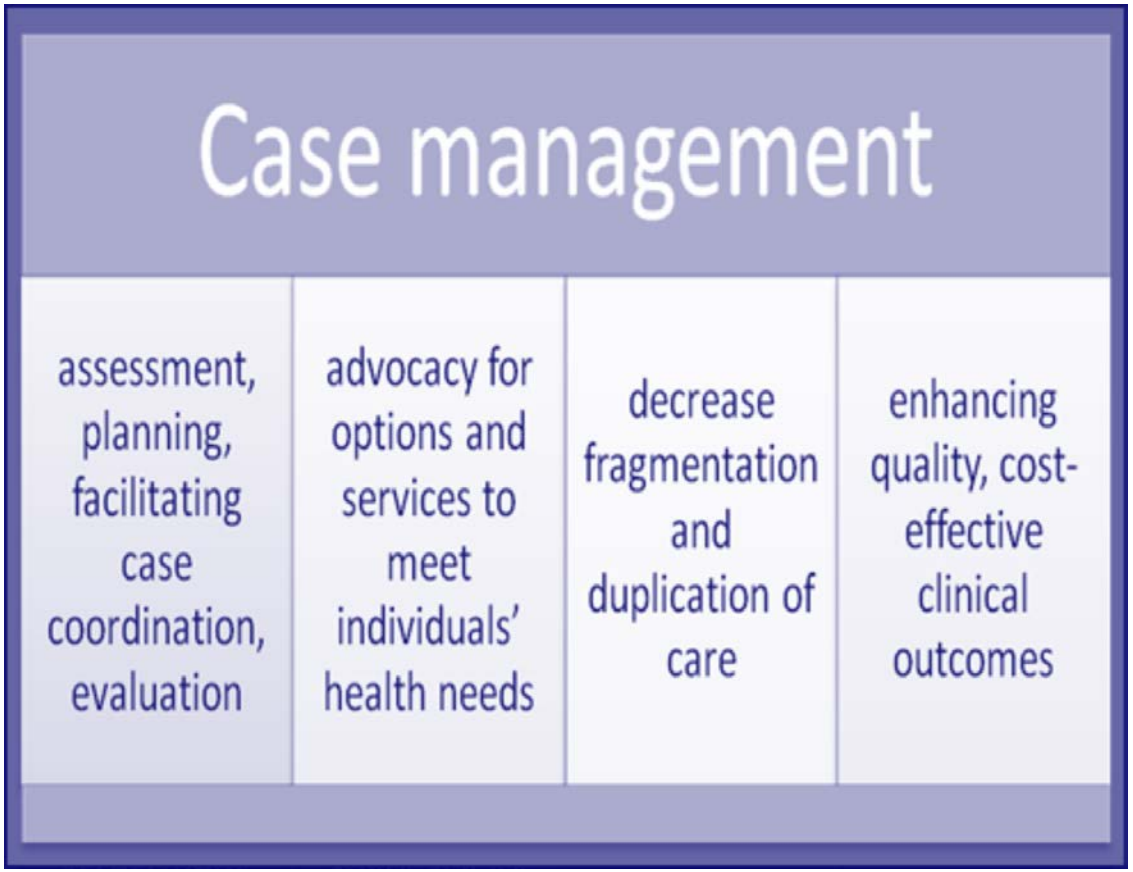

Illustration of Case Management based on the definition by Case Management Society of America

‘Case management’ practice

- In recent years, services that provide for integrated care, have been implemented to support old adults in their homes e.g. the ‘case management’ practice (5).
- Family caregivers are crucial to care as this practice is intended to be a complement to their support.
- There is a growing importance of assessing and addressing how the issues emerging with family caregiving will impact provincial homecare strategies, including case management(5).

‘Case management’ practice

- There is a sense that we are spending more on home-based and community services than ever before, yet there is the recognition that older Albertans and their caregivers still find it challenging at times to access the right services, in the right place, at the right time (5).
- It is these types of programs where linkages need to occur in order to provide the best services to meet the unique needs of caregivers.
- A better understanding is needed of family caregiver-care manger interface so that case management reaches its’ intended potential of fostering caregiver wellbeing and resilience.

Analysis: Current Themes

- **CM is an integral component of community–based care of older adults** (5,6,8,9) :
  - It is seen as addressing the complexity of the older adults and fragmentation within the health care system.
  - It assumes the responsibility of coordinating a comprehensive scope of health related service needs.
  - It is expected to enhance quality of care and quality of life while reducing costs to the system.

Analysis: Current Themes

- **CM is applied in a variety of ways** (5,6,8,9):
  - CM is a heterogeneous and broad concept that includes preventive home visits, follow-ups, health promotion and hands-on care at home.
  - It takes on many forms based on context i.e. urban versus rural. It exists in a variety of models e.g. integrated, clinical, team, self-directed etc.
  - The choice of CM range from being a matter of cost control to a comprehensive approach, guided by policy.

Analysis: Current Themes

- **CM has shown mixed results** (6,8,9) :
  - The impact of CM in the literature is variable and lack of specificity is challenging to study comparisons.
  - Preventive home visits targeting older people have shown reductions in emergency room visits and hospitalizations and reduce health care utilization.
  - Results suggest that high-intensity CM is necessary to produce positive clinical outcomes and to optimize service use.

Analysis: Current Themes

Case managers lack role clarity and expectations; suffer from role ambiguity and conflict (7):

- CM may demand that the case manager match the available resources to the needs of the older person as efficiently as possible.
- Significant role conflict is experienced by bedside nurses as they transition from direct nursing roles into the case manager role.
- A major factor of role conflict is the dichotomy observed between cost containment and patient advocacy.

Analysis: Current Themes

- **Family caregivers are not the primary focus of CM (6, 8, 9) :**
  - Most of the CM interventions do not focus on caregiver; and attention of care managers' support to the caregivers is not evident.
  - Few studies on CM include a family-oriented approach, support or education for the informal caregivers.
  - The studies point to a lack of knowledge about the effects of integrated and coordinated care on the caregiver.

Analysis: Current Themes

- **Expanding the role of case managers to be more holistic and inclusive of the caregiver (5, 6, 8, 9) :**
  - Caregivers' physical and mental quality of life measures are related to the caregivers' sense of coherence and satisfaction with their care manager.
  - Caregivers viewed case managers as important sources of advice, practical and emotional support and to help them cope with the stress of caregiving.
  - The need for psychosocial support was viewed as equally important as clinical care.

Implications

- There is an awareness that the aging population means that older adults will need care for longer periods of time. The recognition that family caregivers have taken on significant and uncharted responsibilities necessitates their inclusion in the scope of CM.
- The capacity of family caregivers could be significantly improved through coaching and mentoring, education and training. Their input needs to be taken into account when designing CM. Evaluative studies of CM must include the family caregivers' perspective.

Implications

- Understanding of the psychosocial and environmental context, which builds on the resilience of the older adult-family caregiver unit, is needed to address the needs of community-based older adults.
- The need for psychosocial support is viewed as equally important as clinical care. Psychosocial support needs to be added as an additional domain to the competencies of case managers.

Implications

A clarification of standards of practice for CM would be most useful. Preparing and supporting case managers in this role should be an essential component of all CM models.

Conclusion

Family caregivers are recognized as the shadow workforce in the geriatric health care system. The provision of adequate evidence-based family caregiver supports needs to be an important part of any CM strategy.

References

- 1 Kitts J. Health council of Canada Report on homecare priorities(2012), 'Seniors in need, Caregivers in distress'.
- 2 Maire Sinha. Results from General Social Survey (2012), 'Portrait of Caregivers', Statistics Canada.
- 3 Butler-Jones D. Report on State of Public Health in Canada (2010), 'Growing older– adding life to years'.
- 4 Hollander M, Guiping L, Chappell N. (2009), Who Cares and How Much? Healthcare Quarterly. 12 (2):42.
- 5 Brandt K. (2010) , AHS Integrated Case Management Seniors Health, Case Management Literature Review.
- 6) Khassonov V, Vedel I, Pluye P. (2014), Barriers to implementation of a Case Management model for patients with dementia: A systematic mixed studies review. *Annals Family Medicine, 12,* 456-465.
- 7) Smith A. (2011), Role ambiguity and role conflict in nurse case managers. *Professional CM, 16(4,)* 182-196.
- 8) Eklund K, Wilhelmson K. (2009), Outcomes of coordinated and integrated interventions targeting frail elderly people: A systematic review of randomized controlled trials. *Heath and Social care in the community, 17(5),* 447-458.
- 9) Sargent P, Pickard S, Sheaff R, Boaden R. (2007) Patient and carer perceptions of case management for long term conditions. *Health and Social care in the Community 15(6)*, 511-519.