



End of Life Caregiving

Literature Review & Framework for Action

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Basic Concept!

“[Caregivers] felt positive when they experienced that the professionals’ goal was the same as their own: a good death.”

(Andershed, 2006, p. 1165)

What?

- ▣ Synthesize & gather information
- ▣ Examine gaps in policies & research
- ▣ Identify available resources in NS
- ▣ Create framework to support caregivers at end of life

Definitions

End of Life

- Last 6 months
- Predicted by health professionals
- Determination is still a challenge

End of Life Care

- Live as well as possible until death within weeks/months/years of life threatening illness

Caregivers

- Persons assist in (mobility, transportation, communication, housework and self care)
- Becoming more complex

Supportive Care

- Help patients + caregivers cope better
- Not specific to disease/time

Palliative Care

- Improve quality of life at latest stages
- Focus on physical, psychological, social and spiritual factors
- Delivered by specialized personnel
- Can overlap curative treatment.

Terminal Care

- Services provided at last days or hours of life

Proposed Conceptualization of End of Life Caregiving

Unit of Care

Relative Importance of Forms of Care

Family & Friends
Caregivers

Other Health
and Life
Concerns

Person with End
Stage Chronic
Disease

Supportive
Care

Palliative
Care

Terminal
Care

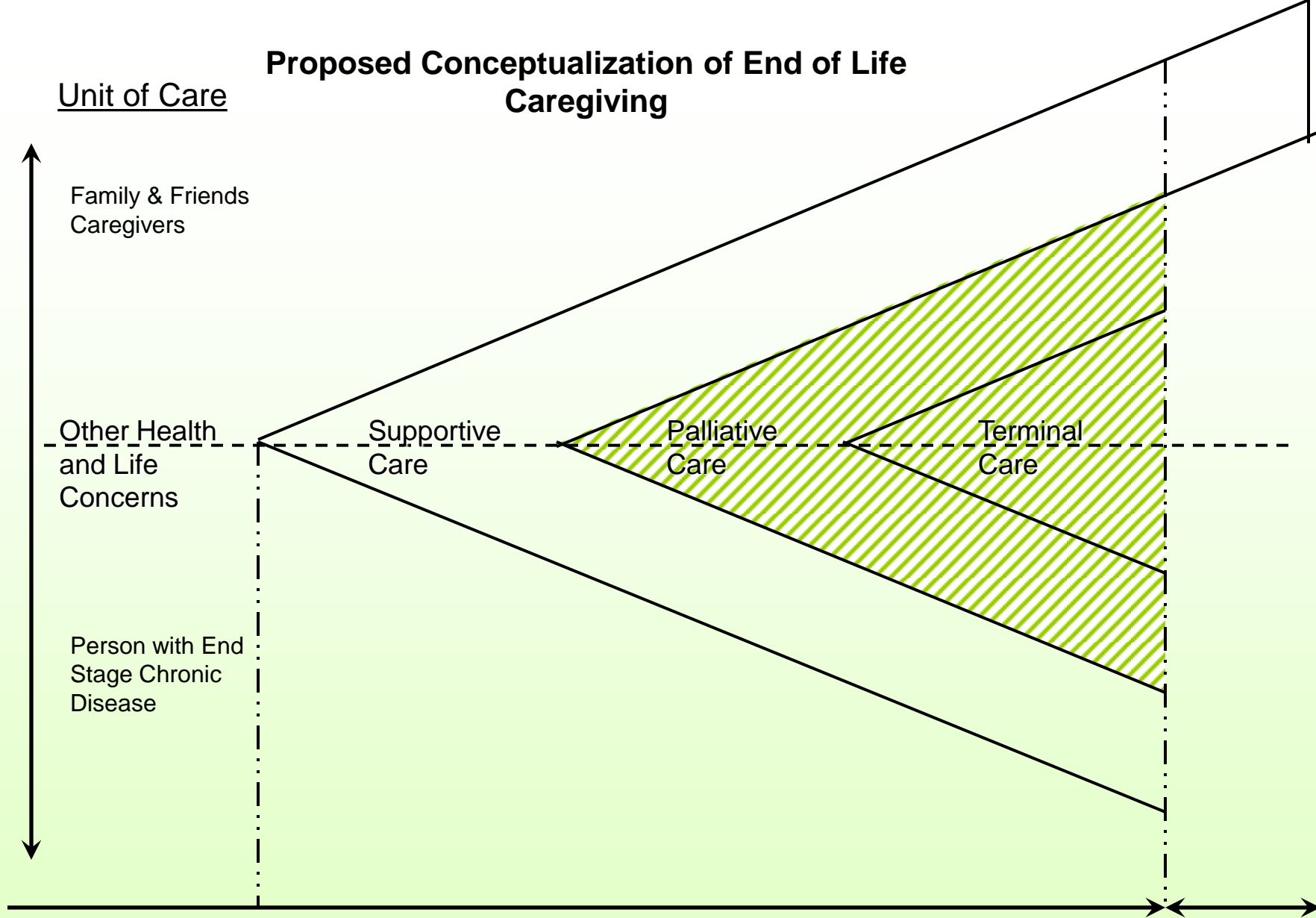
Time

Diagnosis of
Terminal Disease

End of Life Stage

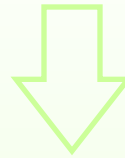
Death

Bereavement



Why?

Benefits to



Person Dying

Emotional support:
Familiarity of home
Presence of loved ones
Possibility of enjoying a
“normal” life

Caregivers

Pay back
Feeling of satisfaction
New ways of learning
about oneself
Inner strength

Health System


Substitute of professional
care
Relieve a system burdened
with:
Aging population
Increase in chronic disease
Save \$\$\$\$

Failure to support caregivers is counterproductive

(Andershed, 2006; Kwak et al., 2007; Waldrop et al., 2005)

When?

Determining End of Life

 20% accurate & 63% overoptimistic

(Christakis & Lamont, 2000)

 Accuracy of prediction influenced by

- Illness, healthcare input & social support
- Individual factors (physical factors, co-morbidities and mental health)
- Environmental factors (financial)

(Gomes & Higginson, 2006; Munday, Dale & Murray, 2007)

Models for Determining End of Life

Professional Prognostication

Based on professional experience
and evidence based

Statistical Model

Effective at population in assigning
patients to risk groups
Failed at individual level
(Henderson & Keiding, 2005)

Palliative Prognostic Score (PaP)

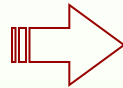
Uses Karnofsky Performance Score
(KPS) +5 other criteria
Generate numerical score (0 to 17.5)
Higher scores predict shorter survival
(Wilner & Arnold, 2006)

Trajectories

Long period of chronic illness and short
period of terminal decline
Gradual functional deterioration
punctuated by episodes of serious acute
illness
Prolonged dwindling of the very elderly
(Murray, Kendall, Boyd & Sheikh, 2005)

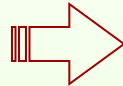
Caregivers' Burdens

Time & Logistic



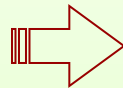
Full Time Job
Time conflict
Complex care

Physical Tasks



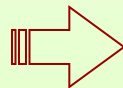
Physical injuries

Financial Burdens



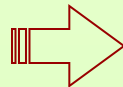
Career
Cannot afford to not work
Spending

Emotional & Mental



Stress
Sorrow
Guilt and resentment

Health Risks



Neglect own health
Lack of leisure time

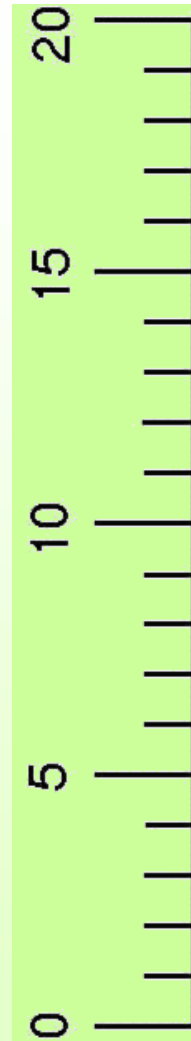


Vulnerability scale



Vulnerability Increasing Factors

Restricted activities
Fear
Insecurity
Loneliness
Facing death
Lack of support



Vulnerability Decreasing Factors = Capacity

Continuing previous activities
Hope
Keeping control
Satisfaction
Good support

'being an outsider'

'being in the dark'

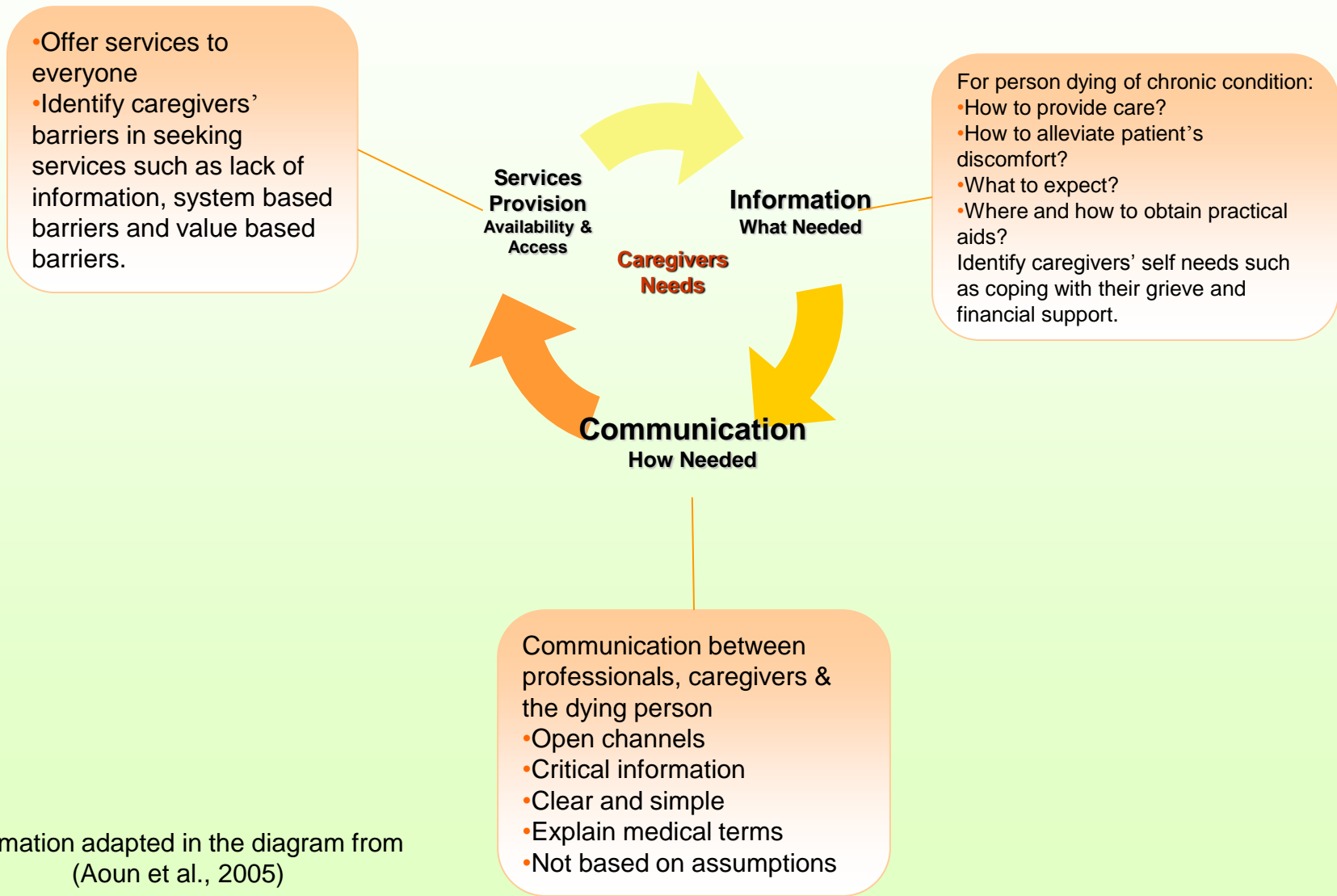


'not knowing'

'being unsure'

'having difficulty understanding'

Proposed Conceptualization of Caregivers' Needs



Professionals' Roles


- Unit of Care
- Realistic Determination of Death
- Align Palliative Care with Curative Care
- Periodic assessment of caregivers' needs
- Rabow, Hauser, & Adams (2004) identified professional roles in 5 areas:
 - Communication
 - Advance planning
 - Attention to grief and bereavement
 - Empathy for emotions and relationships
 - Support for homecare


Nova Scotia


End of Life Caregiver Support Network


 NS Department of Community Services

 The Continuing Care Branch of the Nova Scotia Department of Health

 The Nova Scotia's Seniors' Secretariat

 The Veterans Independence Program (VIP)


 Respite Care


 Home care


 Department of Veteran's Health affairs Canada


 Victoria Order of Nurses (VON)

 Caregivers NS

 Canadian Caregiver Coalition

 Diagnosis-specific Organizations

 Family Resource Centers

 Women's Centers CONNECT

Gaps in Policy & Research

- 📊 No clear recommendations

- 📊 Difficulties in conducting research

 - Recruiting participants

 - Rapid change in clinical situations

 - Ethical dilemmas

 - Gate keepers' behaviours

- 📊 Home Care - myths and realities

- 📊 Policies ignored:

 - Taxation, social security income benefit structure & employment labour market policies

- 📊 Lack of Flexibility in employment arrangement

- 📊 Lack of educational programs



Values to Consider!

- Family/community oriented care
- Key stakeholders early engagement
- Timely implementation
- Constant evaluation of program effectiveness
- Avoid “reinventing the wheel”
- Continuous education & training to:
Program administrators, health care providers,
community, faith centers, and families

(Feinberg, Wolkwitz, & Goldstein, 2006)

End of Life Caregiver Registration

Framework to Support End of Life Caregivers

1 Assessment

Create assessment tools for characteristics, issues & concerns)

2 Information Sharing

Open channels of communication (understanding, expectations, perceptions, cultural and religious values & needs)

3 Decision Making

Early in the process explain capacity and decisions expected to be made

4 Care Planning

The medical and palliative care plan agreed on by the patient and health team

5 Care Delivery

Training for the complicated needs delivery
Clarify expectations and emergencies that can occur and the proper management for emergencies.

6 Confirmation

Satisfaction
Understanding of pattern of decline

Periodic Assessment

Recommendations

- **Tool to Determine End of Life**

 - Create better tools

 - Evaluate existing Models

- **Caregivers Registry**

 - Prospective online registry

 - Accessible by professionals & Caregivers

- **End of Life Web Portal**

 - 24-hour access

 - Up-to-date information in relation to illness, expected pattern of decline and time of death

- **Unit of Care**

 - Mandate professionals to widen the doctor-patient dyad to include caregivers

Recommendations Cont...

- Universal **Assessment Tool** to identify Caregivers Needs
- Improve **Collaboration & Integration** of Different Parts of the System
- Improve **Communication** between all parties: professionals, the dying person & Caregivers
- Create **Workplace Policies** to Support Caregivers at End of Life
- **Respite Care** to provide breaks

Reality

- Health care system is barely able to fulfill basic health needs of the population
- Human needs are endless



??????

- Which services should be publicly funded and which should be private?
- How to prioritize?

Thank You!

