Ethics of caregiving for elderly cancer patients

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Ethics of informal caregiving

Understanding/studying caregivers needs & meeting them adequately is
- an integral part of patient-centred care
- a professional/ethical duty of health care workers & policy makers

Physicians should engage in extended patient-doctor-family relationships while
keeping focused on their patient and preserving their privacy & dignity

Relating/partnering with caregivers carries many ethical & social ramifications

Mitnick S, Leffler C, Hudt V-L, for the ACP Ethics, Professionalism and Human Rights Committee.
J Gen Intern Med 2010

Caregiving to older patients

Health care workforce in geriatrics includes:
- Health care professionals
- Direct-care workers
- Informal care givers
- Patients themselves

Caregiving to older patients

- Caregivers of older people tend to be themselves elderly
  - average age of caregivers for patients 65+ is 63 in the US
  - 1/3 in fair to poor health
- Caregiving hours increase with the age of the caregiver
- Mortality rates among older caregivers are 63% > among non-caregivers
- Nearly 65% of older caregivers report physical or mental-health problems
- Nearly 50% have a chronic health condition requiring ongoing medical care


Ethics of caregiving to older cancer patients:
shift in the patient-doctor relationship

Family caregivers are an integral part of global cancer care
Caregivers add a layer of complexity to the patient-doctor relationship
Clinicians may experience a loss of intimacy with patients
Patient-caregiver concordance may be suboptimal
Caregivers help gather medical information, especially through the Internet

Lowenstein J, Johns Hopkins Univ Press 2004; Bylund et al, Psychosoc Oncol 2010; Kinnane & Milne, Supp Care Cancer 2010 ; Silveira et al, Chronic Illn 2010

Ethics of caregiving to older cancer patients:
shift in professional responsibility

Traditionally, western health professionals carry responsibility only toward their patients
In other cultures, health professionals consider patients & their families as the “basic unit of care”

The practice of global oncology involves broader responsibility toward patients’ families during the illness and grieving processes

Surbone & Baider, ASCO Educational Book 2012
Ethics of caregiving to older cancer patients: information & communication

New communication guidelines include family members.

Older patients may have various degrees of physical, mental and functional impairment affecting the communication process.

Caregivers do not always correctly interpret patients’ needs and wishes or tend to substitute themselves as physicians’ sole interlocutors.


Ethics of caregiving to older cancer patients: respecting patient autonomy

- Not all patients are in a state of physical, emotional or functional dependency.
- Patients with mild cognitive impairment should encourage clarification of goals among family members and, or refer for counseling.
- In the absence of reduced mental capacity, physicians should:
  - avoid any form of paternalism and focus on patients’ privacy;
  - address confidential matters with patients alone;
  - elicit possible concerns about the quality of caregiving;
  - evaluate for neglect in view of state reporting statutes.


Ethics of caregiving to older cancer patients: respecting cultural differences

- Not all cultures have the same concepts of age.
- Some may have different beliefs about the family, caregiving and illness.
- Multi-lingual patients may face discrimination.

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Ethics of caregiving: providing psychosocial support for caregivers

- Recognize and intervene on caregivers’
  - feeling the burden of care (anxiety, depression);
  - fear of not being qualified to provide medical care;
  - financial preoccupations;
  - fear of losing their jobs or their reliability at the work place;
  - loss of social contacts sometimes leading to isolation.


Ethics of caregiving: providing guidance to online resources for caregivers

- www.lotsahelpinghands.com (on cancer patients’ practical needs)
- www.talkingaboutancer.com (on the emotional impact of cancer)
- www.carepages.com (for families wishing to share information)
- www.cancer.org (American Cancer Society)
- www.cancer.net (American Society of Clinical Oncology)
- www.cancer.gov (National Cancer Institute)