

**Who Cares for the Caregivers?
or
How do Caregivers Factor into the
Health Care Equation?**

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✿ All changes involve loss,
just as all losses require change

(Goldsworthy, 2005)

Definition: Caregivers

✿ The term “caregiver” identifies the person who undertakes unpaid care work for kin and is likely to be the person who shares most in the illness experience (Thomas & Morris, 2002)



❁ ‘lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management’ (Grande, Stajduhar, Aoun, Toyne, Funk et al, 2009)

Context affecting caregiving

❖ Caregiving takes place “in the context of relationships in which norms of obligation, responsibility, and feelings of affection and resentment intertwine” (Baines, Evans, & Neysmith, 1998)

Caregivers: Who are they and what do they do?

- ✿ Can be family, friends, community
- ✿ Participate in patient life experience
- ✿ Providers of practical day to day care
- ✿ Providers of emotional support
- ✿ “**co-workers**” (Grande, Stajduhar et al., 2009)

Who are the Caregivers?

- ✿ **Patient definition of main support**
- ✿ **Caregiver definition of the role**
- ✿ **Health providers' definition of who is in the role**
- ✿ **The distinctions are relevant to care**

The caregiver role includes:

✿ Care Work:

- ✿ Physical care
- ✿ Activities and tasks of daily living
- ✿ Advocacy
- ✿ Interpretation
- ✿ Supervision

The caregiver role includes:

✿ Emotion Work

- ✿ This work ensures the patient does not feel alone or abandoned
- ✿ It provides reassurance that the illness would be faced together
- ✿ It involves being positive and keeping things as normal as possible
- ✿ It requires that the caregiver deal with the patients' depression and negative emotions



❖ Emotion work is reported as being more
challenging than the physical care (Golant &
Haskins, 2008)

Why is this topic important?

✿ Growing numbers of caregivers in the community

Why is this topic important?

✿ Health care restructuring has driven the shift of care from institutions to the community

Why is this topic important?

✿ Family caregiving is an integral part of patient care

Why is this topic important?

✿ Interest in emotional and physical health of caregivers has increased

Issues to consider:

- ❖ Family availability
- ❖ Resource availability

Issues to consider:

❁ Caregivers are “the hidden patients”

(Kristjanson, 2004)

❁ The “other cancer survivors” (Golant & Haskins, 2008)

❁ “they have the unique position of both providing and needing support”

Identifying caregiver needs:

• Screening

- Questionnaires

• On-going assessment

- By health care providers

• Self-identification / self-referral

- Asking for help

Primary Need Identified is Information Pertaining to:

- Illness
- Available treatment
- Health care system
- Resources

Information venues...

• Written

• Verbal

• Internet

• Specific content at distinct times

Access to information promotes:

✿ AUTONOMY

✿ PARTICIPATION IN CARE

✿ INFORMED DECISIONS

✿ SENSE OF SECURITY

Information promotes:

- ✿ New skill development and enhanced coping strategies
- ✿ new skills are required to meet new demands



❖ Information needs are different at different points in the illness

AND

❖ Patients and caregivers have different information needs

Caregiver needs include:

- ✿ Skill development and teaching about:
 - ✿ Physical care
 - ✿ Emotional care
 - ✿ Symptom management

Caregiver needs are also interventions:

- Respite
 - Time off for caregiver
 - Childcare support
- Community resources
- Financial counseling /support
- Social support
 - Support groups

Mediating factors:

❁ Age

❁ Gender

❁ Multiple roles

❁ Health issues

Factors affecting meeting caregiver needs are complex:

1. Untrained health care providers
2. Communication skills are learned
3. Limited Information to minimize burden
4. Collusion to maintain silence
5. Cancer diagnosis = burden and stress
6. Caregiver stress

Consequences of unmet needs include:

- ❖ Ill health: physical, psychological and emotional
- ❖ Added burdens
- ❖ Complicated grief

Positive outcomes for caregivers
include:

- ✿ Improved self-esteem
- ✿ Enhanced competence
- ✿ Opportunity for growth

Recommendations for a better experience:

- ✿ Give yourself permission to ask
- ✿ Give yourself permission to receive
- ✿ **Incorporate self-care in your routine**
- ✿ **Expect open communication**

Concluding thoughts:

- ✿ Caregivers are entitled to care
- ✿ Interventions are varied
- ✿ Caregivers are not invisible
- ✿ Caregiver well-being is correlated with caregiver and patient quality of life

Resources

✿ <http://www.mskcc.org> (Sloan-Kettering)

✿ <http://bccancer.bc.ca> (BC Cancer Agency)

✿ <http://www.netofcare.org> (Beth Israel

University Hospital and Manhattan Campus
for the Albert Einstein College of Medicine

✿ <http://www.cancercare.org> (Fact sheets on
various topics in different languages)