Caring for the Care Giver

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Outline

- Definitions
- Caregiver Experience-Burnout
  - Magnitude of the problem
  - Effect on outcome
    - Client
    - Caregiver
- Coping strategies
- Support services

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Definitions & terminology

- **Caregiver # Caretaker**
  - A family member or paid helper who regularly takes care of a child or a sick, elderly, or disabled person.
  - An individual, such as a physician, nurse, or social worker, who assists in the identification, prevention, or treatment of an illness or disability....
Definitions

- **Caregiver burden**: an all-encompassing term describing the physical, emotional, and financial toll of providing care to dependent persons.

- **Caregiver burnout**: a debilitating physical or emotional condition that develops when the caregiver needs exceed available resources and coping skills.
Aging-at-home approach

- Over the past two decades significant resources have been allocated in Europe and North America for managing chronic debilitating diseases at home.
  - Rapid increase in the number of elderly requiring specialized services
  - Limited number of long-term care facilities qualified to provide these services
  - Steep cost of institutionalizing patients
Aging-at-home approach

In Lebanon:
- Living in a paternalistic society, they have very close family ties; extended family with children not leaving their home until they are married or even married children live with their parents.

Illness affects the Entire Family
- Family members accompany the patient to hospital
- Family members make frequent visits to hospital
- Family members stay with patient in the hospital
- Family members over protect the patient
Long-term care institutions in Lebanon

- Number of institutions: 49
- Number of long-term care beds: 4000
- Percent of institutions managed by geriatricians: 18%
- Percent of elderly that live in long-term care facilities: 1.2% (98.8% reside at home)
- Number of respite programs: 0
Aging-at-home approach

- US: 5% of all elderly (>65 y) live in nursing homes.

- Lebanon: less than 1.5% of elderly live in nursing homes. (60% in nursing homes residents have dementia)


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Abu-Saad Huijer, 2007 highlighted the importance of assessing the needs of caregivers in addition to patients to obtain a complete picture of the needed care for both. She also emphasized the necessity of mapping caregivers' needs during the different stages of the disease as an essential step toward meeting the needs of caregivers. The reviewed studies from different cultures revealed the magnitude of the experience of being a family caregiver of a cancer patient. This experience permeated the caregiver's life and tended to be overwhelming, stressful, and demanding. It also engendered feelings of anxiety, depression, and vulnerability.
Doumit, Myrna & et al, 2008 studied, through in-depth semi-structured interviews, the lived experience of Lebanese family caregivers of cancer patients and acquired a better knowledge of the meaning and interpretation of their experience.

Eight core themes describing the participants' lived experience emerged from the interviews: living with fears and uncertainty, loss of happiness, feeling of added responsibility (financial, psychological, and the physical burden), living in a state of emergency, sharing the pain, living the dilemma of truth telling, disturbed by being pitied (the sickness of their loved one and their perceived added responsibilities for their loved one), and reliance on God.

The results of this study challenge healthcare professionals to be conscious of the nature and difficulties that family caregivers are encountering.

Responses of Caregivers

- **Emotional response:** anxiety, depression and financial stresses. Worry about the patient’s future more than the patient, terror, frustration & powerlessness.

- **Physical responses:** fatigue, difficulty in concentrating & performing usual activities, altered sleep pattern and appetite disturbances.

- **Experiential responses:** role changes, financial concerns, denial that their schedule has been changed leading to repeated struggles with time management.

- **Hence the need to educate & support caregivers**
Grunfeld et al in Canada revealed that caregivers' depression and perceived burden increased as patients' functional status declined.

**stressors intensifying the caregivers' vulnerability:**
- Care burden; restricted activities; fear; insecurity;
- Loneliness; facing death; and lack of emotional, practical, and information-related support.

These reactions are consistent with caregiver burnout as described in the literature.

Caregivers Burnout - Contributing Factors

- Intrinsic factors
  - Coping skills
  - Psychosocial makeup of provider
  - Expectations

- Extrinsic factors
  - Support services
  - Smaller and/or fragmented families
Causes of caregiver burnout (CB)

- Patient characteristics
- Caregiver characteristics

Surprisingly, studies have shown that the perceived burden does not correlate with the duration of time spent in the caregiving role, or the degree of cognitive and functional impairment.
Patient characteristics

- When depression is present, caregivers report **higher level of burden**.
Caregiver characteristics

- Caregiver coping strategies are affected by:
  - Gender
  - Kinship
  - Psychosocial conditions
  - Culture
Caregiver characteristics - gender

- Some studies indicate that female caregivers experience more depression, anxiety, and health problems than males.

- Coping strategies:
  - Problem-focused: seeking information, modifying the problem, learning new skills to manage stress. More common in men.
  - Appraisal-focused. how we think about a problem. denial, using humor, altering values and goals.

- Problem-focused coping skills allow better adjustment to ongoing challenges.
Caregiver characteristics - kinship

- When caregiver is a spouse, it is generally the wife taking care of her husband.
- No consensus on spouse or adult children.
- Closer kinship is associated with increased stress.
- Gender, kinship, and coping strategies are steeped in cultural norms.
  - Caucasian > Asian > Hispanic
- Religious belief = better coping skills
Assessment of caregiver burden (CB)

- Best way to assess caregiver burden …

- **Ask!**
  - How are you handling your role as caregiver?
  - Do you feel you are under a lot of stress?
  - How much time do you have for yourself?
  - Have you dropped many of your social activities and hobbies?
  - Do you feel you need more help?
Effect of caregiver burden

- Caregiver burden effects health of caregiver and care-recipient.
- Compared to non-caregivers, persons in caregiving role consistently score lower on Quality of Life questionnaires.
- Over half of caregivers (53%) report that their decline in health compromises their ability to provide proper care.

Caregivers report increased prevalence and severity of:

- Fatigue
- Insomnia
- Anxiety
- Depression
- Pain
More than just perception...

- Increased use of psychotropic drugs.
- Diminished cellular immunity:
  - More prolonged viral illnesses
  - Increased circulating inflammatory mediators
- Increased risk for weight loss, malnutrition, injuries, and medication use.

Lee S. American Journal of Preventive Medicine 2003; 24:113
Caregivers are more likely to neglect own health:

- Less likely to engage in preventive measures
- Abandon healthy habits: e.g. stop exercising, start smoking, use excessive alcohol.
Caregiving: a risk factor for mortality

- Caregivers are at increased risk for:
  - Heart disease
  - Strokes
  - Total mortality

- Increased mortality in older caregivers
  - A study of 800 subjects age 66-96 showed spousal caregivers with mental or emotional stress had a 63% increased mortality.

  - Haley WE, *Stroke* 2010; 41:331
  - Schulz R. *JAMA* 1999;282:2215
Menu of Misconceptions

1. I will “fix” the problem… make everything O.K… save the world…
2. I am responsible for outcomes.
3. If I care enough, everything will be O.K.
4. The sufferer/victim will appreciate everything I do for them.
5. I will have enough resources (time, money, material, skills and training) to fix things.
6. Significant people in my life will make things better
7. I know what I’m getting into
8. I can do it alone/I don’t need any help
9. If I’m spiritual enough, I can deal with the stress of working with suffering people.
10. My definition of success is………..
Symptoms
what might they look like for the caregiver

- Nervousness and anxiety
- Anger and irritability
- Mood swings
- Flashbacks
- Difficulty concentrating
- Lowered self-esteem
- Feeling less trusting of others and the world
- Withdrawing from others
- Changes in appetite, sleep or other habits
- Physical changes
- Depression
- Self-Medication
- Self-Entitlement
The Need for HELP !!!!!!!!!!

Would they ask for it???
Nature of caregiver support

- **Support program should be:**
  - Individualized
  - Multifaceted
  - Dynamic

- **Purpose:**
  - Identify modifiable risk factors
  - Improve well-being of caregiver
  - Prevent burnout
Sources of caregiver support

- Family & Friends
- Professional organizations
- NGOs
- Respite programs
- You and me

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Strategies to Help Caregivers

- **Education** of caregivers and family members about the disease, its effects on the patient, how best to manage care and respond to symptoms, and how to improve social support for caregivers.

- **Improving communication**, so that family members can better convey and understand each other's needs.

- **Counseling and ongoing support** for the caregiver and family members, including both individual and family counseling, encouragement for caregivers to join support groups, and telephone counseling for the caregiver and other family members when needed.
Strategies to Help Caregivers

- **Use of Problem solving techniques** whereby the problem can be broken into smaller more manageable tasks.
- **Make caregivers aware of available options and formal services.**
- **Improving social support and reducing family conflict** to help the caregiver withstand the hardships of caregivers and to help family member understand the primary caregiver's needs, and how best to be helpful.
- **Feeling supported by family and friends** can improve psychological responses to stress and boost the caregiver's sense of well-being.

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Connecting Caregivers with the Help They Need

- Focus on the **needs** of the **caregiver** and not the care recipient.

- **Eliminate prior personal biases** what caregivers should be able to do and for how long.

- **Move away from trying to fit people into pre-existing "slots"** in pre-designed models of care.

- **Move towards flexible wrap-around supports; individualized and customized help.**
Support the expert caregiver role:

- **Focus on caregiver goals** and whether needs are being addressed.
- **Allow adequate time for talking with caregiver;** contact by phone as needed.
- **Stay connected, provide follow-up** or find those who can.
- **Refer to specific organizations,** if needed.
- **Help them identify a network of support.**
Support the expert caregiver role:

- **Utilize enhanced support** which consists of:
  - Home visits by trained personnel
  - Remote contact with staff
  - Self-care educational information and training skills

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Respite care

- Most commonly requested service by caregivers
- **Temporary break for caregivers of the ill or disabled.**
- Programs vary in settings and services, but share the common **goal of providing short-term relief for caregiver to manage own affairs.**
- Delay nursing home placement
- Surprisingly, have little or variable impact on caregiver burden.
- Most respite programs are unaffordable or inaccessible.

Parks SM. Am Fam. Physician 2000; 62:2613
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“EVERYONE OF US NEEDS TO SHOW HOW MUCH WE CARE FOR EACH OTHER AND IN THE PROCESS CARE FOR OURSELVES.”

- Princess Diana
You and Me
What can we offer caregivers in this region?
Questions & Answers