Needs and Support Service Use among Distressed Family Caregivers of Lung Cancer Patients

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August 18, 2016
Background

- Up to 50% of family caregivers of lung cancer patients experience high levels of distress (Carmack-Taylor et al., 2008; Mosher et al., 2013).

- Caregiving stress has been associated with poor health behaviors (e.g., inadequate exercise and rest and smoking) (Braun et al., 2007; Gallant et al., 1997; Schulz et al., 1997).

- Caregivers are more likely to disregard their own health care and develop health problems than noncaregivers (Stein et al., 2000; Vitaliano et al., 2003).
Goals of my research:

- Assess the psychosocial and practical needs of distressed family caregivers of lung cancer patients
- Assess caregivers’ interest in support services and use of these services
- Assess caregivers’ greatest challenges in dealing with the illness

Mosher et al., 2013, *Psycho-Oncology*; Mosher et al., 2013, *Supportive Care in Cancer*; Mosher et al., 2015, *European Journal of Cancer Care*
Eligibility Criteria

- Primary family caregiver identified by a lung cancer patient who was within 4-10 weeks of a new visit to the thoracic clinic at Memorial Sloan-Kettering Cancer Center, Indiana University Cancer Center, or Roudebush VA Medical Center

- Caregiver reported high distress on the Hospital Anxiety and Depression Scale
Study Time Points

- First assessment of distressed caregivers within 4-10 weeks of the patient’s new visit to the thoracic clinic
- Three-month follow-up assessment of caregivers
- In-depth interviews with subgroup of caregivers within 3 weeks of follow-up
Caregiver Demographics (N = 83)

- 77% female
- Relationship to the patient: 65% spouse, 25% child, 10% sibling or other relative
- Average age = 55 years (range = 29-80)
- 86% Caucasian, 10% African American
- 34% Catholic, 37% Protestant, 11% Jewish
Caregiver Demographics ($N = 83$)

- Mean years of education = 15 (range = 8-27)
- 70% had incomes over $50,000$
- 61% employed full or part-time
- 83% married or marriage equivalent
Patient Medical Characteristics ($N = 83$)

- Average time since lung cancer diagnosis = 8 weeks ($SD = 8$)
- 60% had stage III or IV non-small cell lung cancer
- Treatments received for lung cancer:
  - 33% surgery
  - 51% chemotherapy
  - 36% radiation
Support Service Needs and Use among Family Caregivers of Lung Cancer Patients

- Individual Emotional Support (ns = 81 & 83)
  - Need: 67%
  - Use: 13%

- Support for their Family (ns = 83 & 82)
  - Need: 48%
  - Use: 0%
Support Service Use among Family Caregivers of Lung Cancer Patients (N = 83)
Interest in Support Services among Family Caregivers Who Did Not Use Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking to staff member about feelings</td>
<td>29</td>
</tr>
<tr>
<td>Support group</td>
<td>29</td>
</tr>
<tr>
<td>Family Counseling</td>
<td>14</td>
</tr>
<tr>
<td>Integrative Medicine Services</td>
<td>40</td>
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(n = 72)
Informational Needs and Receipt of Education among Family Caregivers of Lung Cancer Patients ($N = 83$)

- **Need**
- **Receipt of Written Information**
- **Caregiver Education Class Attendance**

![Bar chart showing the percentage of caregivers' needs and receipt of information on managing the patient's illness. The chart indicates that 61% of caregivers have a need for information, 74% have received written information, and 2% have attended a caregiver education class.](chart.png)
Practical Needs and Service Use among Family Caregivers of Lung Cancer Patients

- Help with Work-related Concerns (ns = 57 & 56): Need 36, Receipt 3
- Help with Insurance Concerns (n = 83): Need 29, Receipt 9
- Help with Other Practical Needs (n = 83): Need 25, Receipt 3
Spiritual Needs and Receipt of Spiritual Support among Family Caregivers of Lung Cancer Patients ($N = 83$)

![Graph showing the percentage of need and receipt of support from a spiritual leader.]

- Need
- Receipt of Support from Spiritual Leader
Interest in Support Services among Family Caregivers Who Did Not Use Services

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Caregiver education class</td>
<td>47%</td>
</tr>
<tr>
<td>Help with work-related concerns</td>
<td>17%</td>
</tr>
<tr>
<td>Help with insurance concerns</td>
<td>36%</td>
</tr>
<tr>
<td>Help with practical needs</td>
<td>28%</td>
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</tbody>
</table>

Number of caregivers for each service:
- Caregiver education class: 80
- Help with work-related concerns: 53
- Help with insurance concerns: 75
- Help with practical needs: 79
Interest in Spiritual Support among Family Caregivers Who Did Not Obtain this Support ($N = 55$)
Service Use during 3-month Study Period

- 26% used mental health services (medication or counseling)
- 39% used integrative medicine services (e.g., yoga, meditation, massage)
Who uses services?

- Predictors of caregivers’ mental health service use:
  - Patients’ receipt of chemotherapy

- Predictors of caregivers’ use of integrative medicine services:
  - Greater education
  - Greater assistance from paid or unpaid helpers with caregiving tasks
Why do distressed caregivers underuse mental health services?

- Negative views of mental health professionals
- Desire to independently manage emotional concerns
- Conflict between mental health service use and caregiving role
- Stigma
Why do distressed caregivers underuse mental health services? (cont.)

- Inadequate financial resources
- Lack of information about services
- Availability of alternative support
Greatest Challenges \((n = 21)\)

- 38%--coping with uncertainty about the future
- 33%--managing the patient’s emotional reactions to the illness
- 14%--practical tasks such as coordinating the patient’s medical care
Discussion

- Many distressed caregivers reported a range of concerns, including the need for information on managing the patient’s illness and emotional concerns.

- Consistent with prior research (Vanderwerker et al., 2005), there was a low rate of mental health service use (26%) among caregivers who endorsed distress.
Discussion (cont.)

- Interview data suggest that use of mental health services is still stigmatized and caregivers want to handle emotional concerns independently.

- Use of services is viewed as “indulgent” or taking time away from the patient.
Distressed caregivers who did not access support services expressed more interest in receiving information about the patient’s disease, practical support, and integrative medicine services than some psychosocial support services (e.g., family counseling).
Discussion (cont.)

- In this primarily middle to upper class sample, emotional concerns were more likely to be the greatest challenge than practical concerns.
- Dealing with future-oriented fears was the most prevalent challenge.
Take Home Points

- Caregivers have increased physical and mental health risks due to the stress of caregiving and their own self-neglect.
- Caregivers: assess whether you are focusing on the patient’s needs to the neglect of your own needs.
- Do not hesitate to access necessary support and health care.
Acknowledgments

Memorial Sloan-Kettering Cancer Center Research Team:

Jamie Ostroff, Ph.D., Christopher Azzoli, M.D., Marina Lenderman, M.S.W., Elyse Shuk, M.A., Scarlett Ho, B.A.

IU Cancer Center and Roudebush VA Research Team:

Victoria Champion, Ph.D., Nasser Hanna, M.D., Shadia Jalal, M.D., Thomas Birdas, M.D., Ikenna Okereke, M.D., Kenneth Kesler, M.D., Lawrence Einhorn, M.D., Patrick Monahan, Ph.D., Aigul Amankeldi, M.P.H., Shannon Christy, Ph.D.

Study Consultant: Barbara Given, Ph.D., Michigan State University

Supported by National Cancer Institute grant
No. R03CA139862, PI: Catherine Mosher, Ph.D.