Caring for the Caregiver

Keli DeVries, LMSW
Who is included in patient care planning at your practice?
Caregiver Polls – Regional Meetings

What resources are you currently providing to caregivers?

- Treatment Plan: 80%
- Side Effects: 80%
- FAQ: 50%
- Financial/Social: 50%
- Caregiver support groups: 50%
- Health/Well-being: 30%
- ACP/Palliative/EOL: 50%
- Don't provide: 10%
What resources, information and/or training does your practice have and/or need in order to best support caregivers?
Caring for the Caregiver Panel

Addressing the Needs of Family Caregivers of Cancer Patients

Laurel Northouse, PhD, RN, FAAN
Addressing the Needs of Family Caregivers of Cancer Patients

Laurel Northouse PhD, RN, FAAN
Professor Emerita
University of Michigan

Michigan Oncology Quality Consortium, June 17, 2022
Cancer Has a Ripple Effect on the Family

...like a stone dropping in a pond...

Cancer creates fear and uncertainty, disrupts life plans, and can alter family roles and communication.
• Describe current experience of family caregivers
• Compare cancer caregivers with other caregivers
• Examine the role of interdependence between patient and caregiver
• Discuss how professionals can help family caregivers
CURRENT EXPERIENCE OF FAMILY CAREGIVERS
• Provide complex care in home with NO training

• Lack information, support, and confidence

• Experience mental fatigue

• Have distress higher than normal population

• Balance multiple competing demands
In a national survey of caregivers...

• Only 29% reported that a doctor, nurse or social worker asked them what they needed to care for patient

• Only 13% reported that a doctor, nurse, or social worker asked them what they needed to care for self

Caregiving in the U.S. 2020 Report by AARP & the National Alliance for Caregiving (NAC)
Comparison of Cancer Caregivers with Other Caregivers
## Cancer Caregiving in U.S.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cancer Caregivers</th>
<th>Other Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration of caregiving</td>
<td>1.9 yrs</td>
<td>4.1 yrs</td>
</tr>
<tr>
<td>Hours per week</td>
<td>32.9 hrs</td>
<td>23.9 hrs</td>
</tr>
<tr>
<td>Do Medical/Nursing tasks</td>
<td>72%</td>
<td>56%</td>
</tr>
<tr>
<td>Communicate w/health professional</td>
<td>82%</td>
<td>62%</td>
</tr>
<tr>
<td>High caregiver burden</td>
<td>62%</td>
<td>38%</td>
</tr>
<tr>
<td>High emotional distress</td>
<td>50%</td>
<td>37%</td>
</tr>
</tbody>
</table>

Cancer Caregiving in U.S. (2016), NAC
Caregiving in the U.S. (2020), AARP, NAC
Role of Interdependence between Patient & Caregiver
Interdependence: Key Concept in Family Research

They react to cancer as an emotional system: Each person affects the other.

Patient \( r = 0.29 \) to \( 0.35 \) Caregiver
Patients and Caregivers
Face the Illness Together

They are the unit of care
Caregiver’s Well-being Affects Patient’s Perceived Quality of Care

**Caregiver Health**  →  **Quality of Home Care**

Odds Ratio Analysis

- Major depression: Quality of Care 4.8 times lower
- Fair/Poor health: Quality of Care 3.8 times lower

Possible reasons:
- Less ability to coordinate care
- Less likely to attend clinic visits
- Less likely to understand information or make decisions

Data from CanCOR survey, Litzelman et al., 2016
Established Programs for Caregivers
### Psychosocial Interventions with Cancer Caregivers

<table>
<thead>
<tr>
<th>Types</th>
<th>Primary Focus</th>
<th>Delivery Format:</th>
<th>Length: 5-7 sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psycho-educational</td>
<td>Provide information, Symptom management, Physical / emotional needs</td>
<td>• Face to face, • Telephone, • Combined, • Small Group, • Web-based</td>
<td></td>
</tr>
<tr>
<td>Skills training</td>
<td>Coping skills, Communication skills, Problem-solving skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counseling</td>
<td>Therapeutic relationship, Marital / family relations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Existential</td>
<td>Mindfulness and meaning</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
FOCUS Program
1996 to Present

Nurse Delivers Program to
Patients and Caregivers Together
FOCUS Program Content
Total Participants in Studies = 994 Patients and a Caregiver

- **Family**: Communication, support, strengths
- **Optimism**: Positive outlook, realistic goals
- **Coping**: Active coping, healthy lifestyle
- **Uncertainty**: Information, living with uncertainty
- **Symptoms**: Management of symptoms
FOCUS Outcomes from RCTs

Decreased:
- Negative appraisal of illness/caregiving (pt, cg)
- Uncertainty (pt, cg)
- Hopelessness (pt, cg)
- Emotional distress (pt, cg)
- Symptom distress (cg)

Increased:
- Quality of life (pt, cg)
- Communication (pt, cg)
- Coping (cg)
- Self-efficacy (pt, cg)

pt = patient       cg = caregiver
Most caregiver interventions are not implemented in practice

Why Not?

• Practice settings are patient-oriented
• Lack of awareness of caregiver needs
• Shortage of time and staff
• Reimbursement issues
WAYS PROFESSIONALS CAN HELP FAMILY CAREGIVERS
Meet with Patient and Caregiver Together

- Ask about each person’s concerns
- What information or help do they need?
- Encourage teamwork
Identify Patient and Caregiver Strengths to Increase Self-efficacy

**Examples:**

“You do a good job of supporting one another. You make a good team……”

“It sounds like humor is one of your family strengths.”

“It is helpful you are here for your wife’s appointment. Your input is important……”
Promote Open Family Communication

- Plan time to talk, include children
- Share your concerns; it makes them less overwhelming
- Try not to interrupt, argue or criticize
- Find “common ground” if your communication styles differ
Encourage Caregivers to Take Care of Themselves

- Use exercise to relieve stress
- Try to eat nutritious food
- Get adequate sleep
- Keep your regular health check ups
Refer Caregivers to Supportive Resources

CANCERcare.org – telephone and online programs

Cancer Support Community / Gilda’s Club
   – 12 sites in Michigan –

NCI and ACS educational materials for caregivers

Family Caregiver Alliance – locates state resources
Conclusion

- Patients and caregivers are interdependent
- Helping caregivers helps patients
- Interventions can improve both caregiver and patient outcomes
- Promote caregiver interventions in practice settings
Caring for the Caregiver Panel Discussion

Keli DeVries, LMSW
Beth Fisher-Polasky, BS
Cynthia Koch, PhD
Jenny Moeller, MS
David Smith, MD
Panel Discussion