

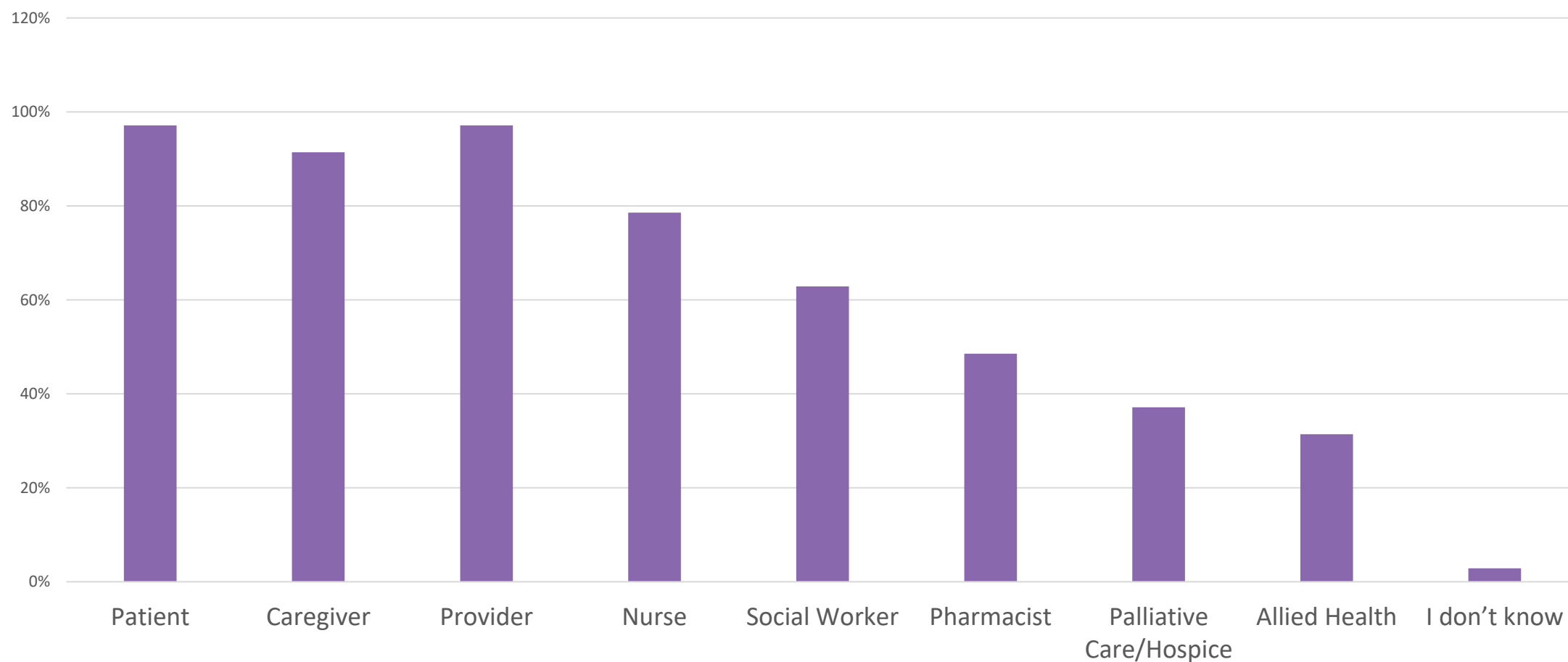
Caring for the Caregiver

Keli DeVries, LMSW



Caregiver Polls – Regional Meetings

Who is included in patient care planning at your practice?



Caregiver Polls – Regional Meetings

What resources are you currently providing to caregivers?



Caregiver Polls – Regional Meetings

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

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

OVERVIEW

- 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

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

Clinician-Caregiver Communication is Limited

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

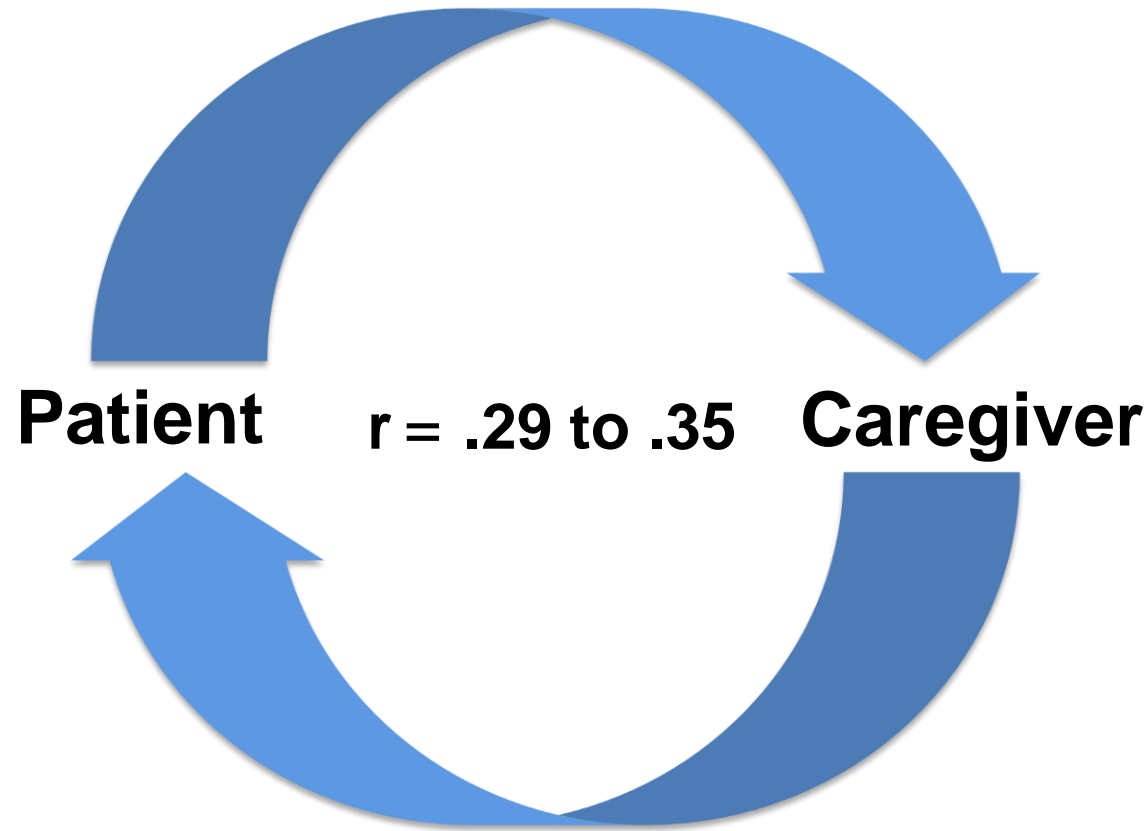
Cancer Caregiving in U.S.

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

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**

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

Established Programs for Caregivers

Psychosocial Interventions with Cancer Caregivers

Types	Primary Focus	
Psycho-educational	Provide information Symptom management Physical / emotional needs	Delivery Format: <ul style="list-style-type: none">• Face to face• Telephone• Combined• Small Group• Web-based Length: 5-7 sessions
Skills training	Coping skills Communication skills Problem-solving skills	
Counseling	Therapeutic relationship Marital / family relations	
Existential	Mindfulness and meaning	

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

F	Family	Communication, support, strengths
O	Optimism	Positive outlook, realistic goals
C	Coping	Active coping, healthy lifestyle
U	Uncertainty	Information, living with uncertainty
S	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)

Most caregiver interventions are not implemented in practice

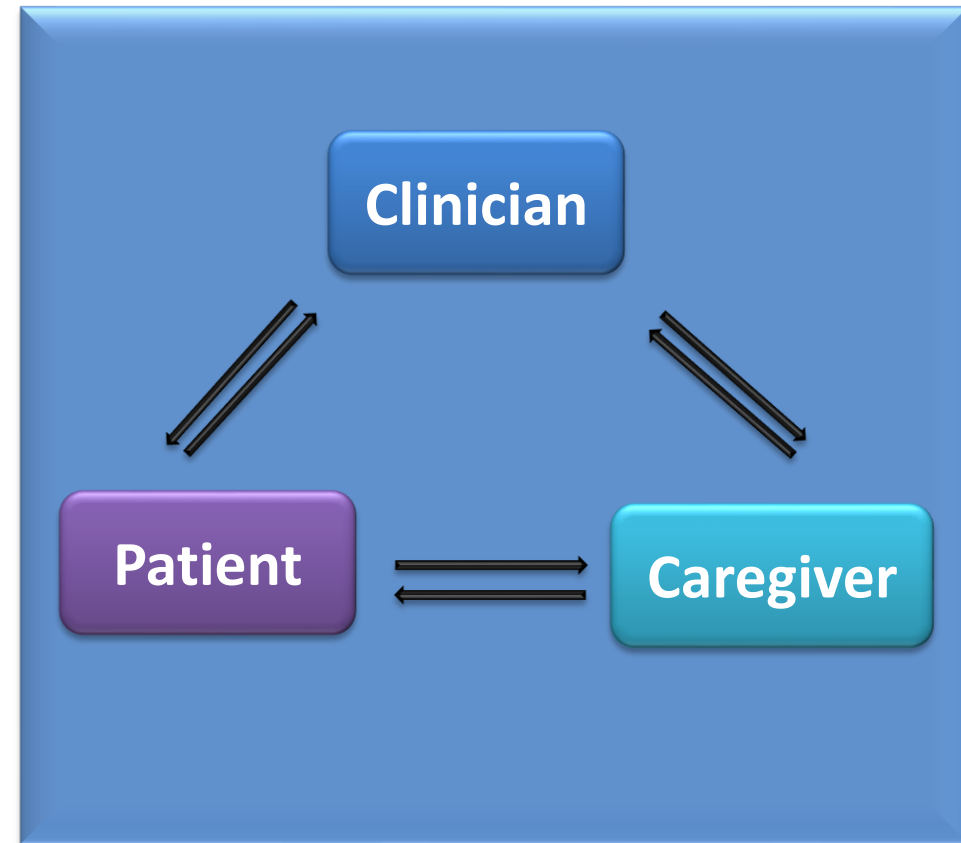
Why Not?

- 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

