

HealthSystems to AssistCaregivers: CancerSurvivors asan Example

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Trends in Family Care of Older Adults

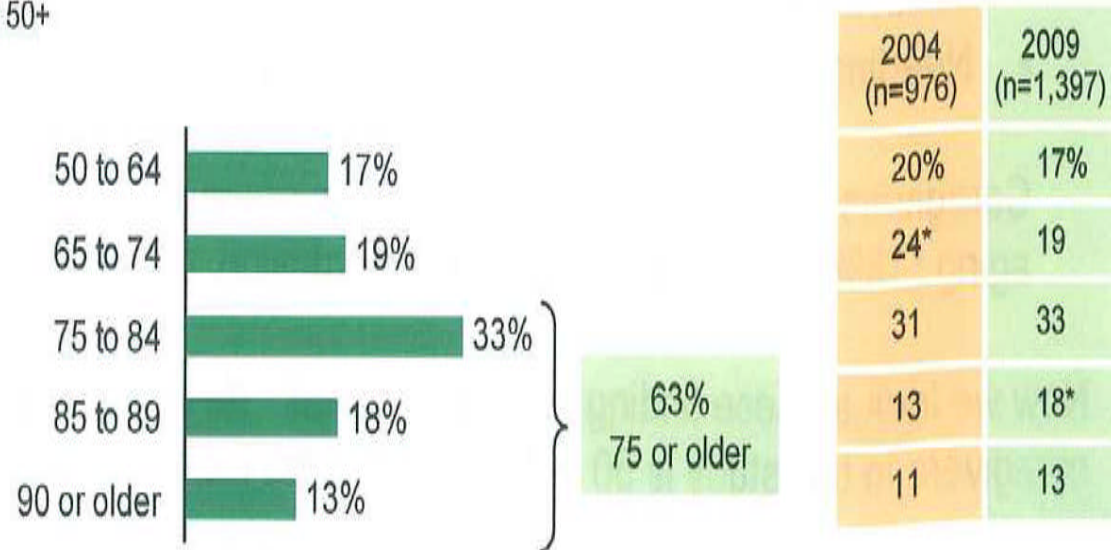
- **Aging issue becomes family issue with public health consequences**
- **Older carers and older, more complex recipients**
- **Culture matters**
- **More long-distance family care**
- **Less paid help and less secondary family support**
- **Employee caregiver issues: absentee, lost wages**
- **Negative health effects on older family caregivers**

L. Gwyther, 2010

Figure 5: Age of Care Recipient

Q5. *[IF 1 RECIPIENT] Now, I'd like to ask you some questions about the person for whom you provide/provided care.
[IF 2+ RECIPIENTS] Let's focus on the person for whom you provide/provided the most assistance. How old is/was that person?*

Base: 2009 All caregivers of people 50+

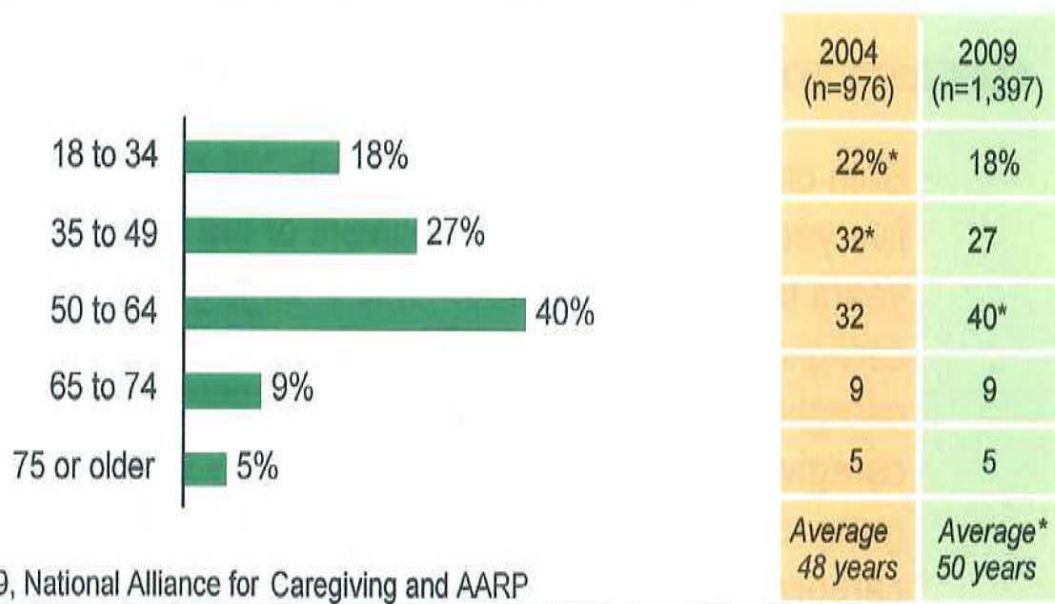


Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

Figure 3: Age of Caregiver

S2, S15. How old were you on your last birthday?

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

Figure 6: Main Problem or Illness Identified by Caregiver

Q18. What would you say is/was the main problem or illness your [relation] has/had for which he/she needs/needed your care?

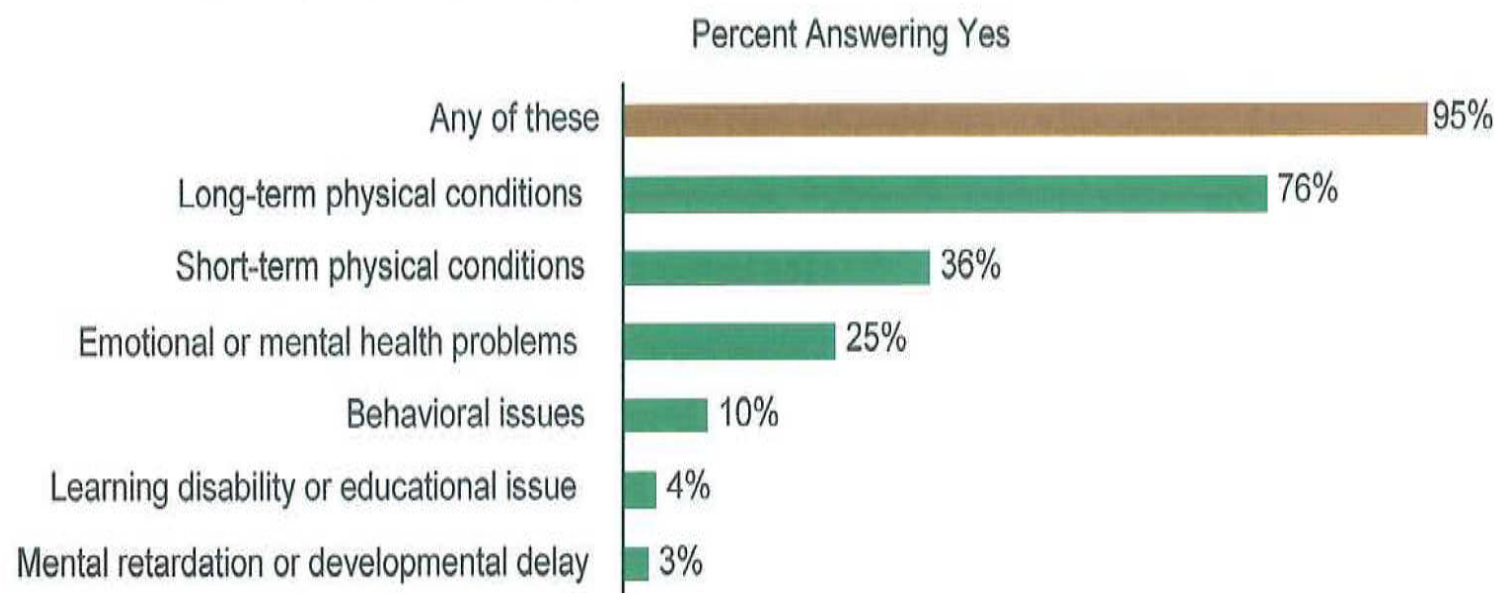
Base: 2009 All caregivers of people 50+

		2004 (n=976)	2009 (n=1,397)
Top Mentions			
Old age	15%	15%	15%
Alzheimer's/confusion	15%	8	15*
Heart disease	8%	9	8
Cancer	8%	9	8
Stroke	6%	6	6
Mobility	5%	6	5
Diabetes	5%	9*	5
Arthritis	4%	5	4
Mental/emotional illness	4%	3	4

Figure 7: Types of Care Recipient Conditions

Q17. *Would you say that your [relation] needs/needed care because of any...?*
[MULTIPLE RESPONSES ALLOWED]

Base: 2009 All caregivers of people 50+ (n=1,397)

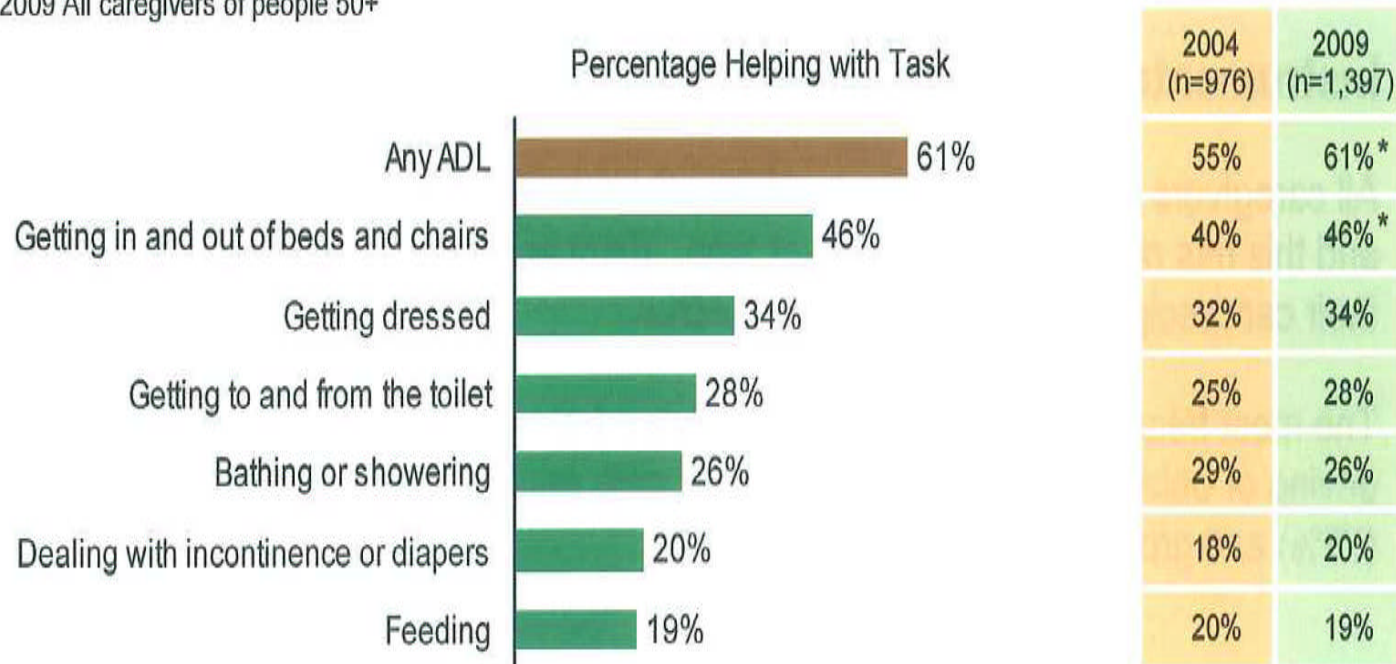


Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

Figure 9: Help with Activities of Daily Living (ADLs)

Q22. I'm going to read a list of kinds of help which might be provided to a person if the person cannot do this by him or herself. Do/Did you help your [relation] with [ADL]?

Base: 2009 All caregivers of people 50+

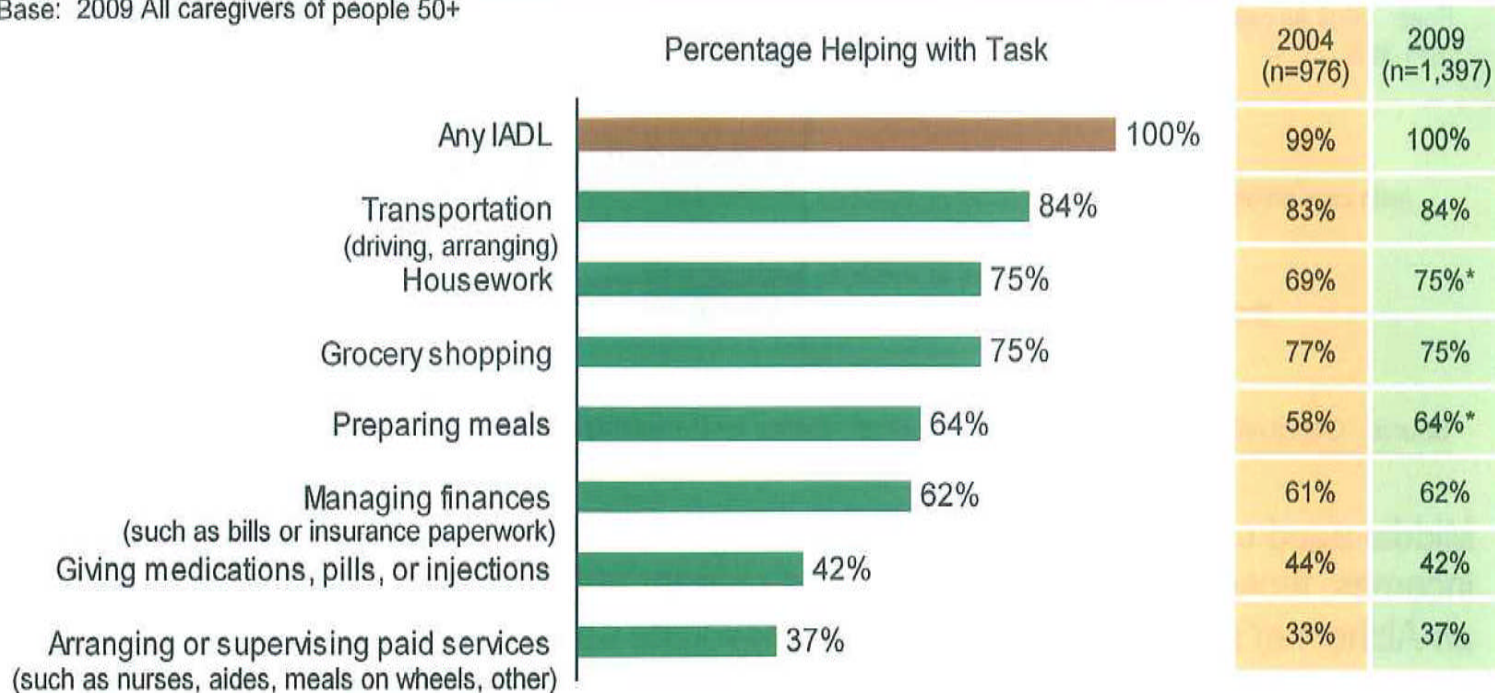


Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

Figure 10: Help with Instrumental Activities of Daily Living (IADLs)

Q23. Do/Did you provide help to your [relation]...?

Base: 2009 All caregivers of people 50+

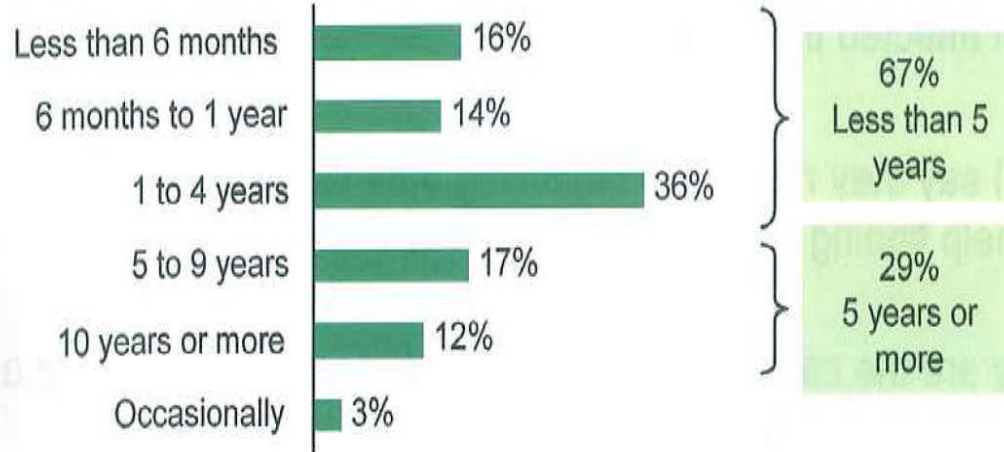


Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

Figure 4: Duration of Care for Recipient

Q21. For how long have you been providing/did you provide care to your [relation]?

Base: 2009 All caregivers of people 65+



	2004 (n=976)	2009 (n=1,397)
Less than 5 years	15%	16%
5 years or more	17	14
	35	36
	14	17
	13	12
	5	3
Average	Average	
4 years	4 years	

Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

Critical Issues for Healthcare in Assisting Family Caregivers

- **Communication**
- **Coordination**
- **Transitions**
- **Caregiver Health**

Helping the Family Caregiver

The Players

Primary Care Physicians/Geriatricians

Nurses

Social Workers

Pharmacists

Nurse Practitioners

Physicians Assistants

Rehabilitation Therapist (OT, PT)

Family & Informal Caregivers

Home Care Workers

Patient

Helping the Family Caregiver

ThePlaces

Home

Clinic

Hospital

Emergency Rooms

Senior Centers

Nursing Homes

Hospice

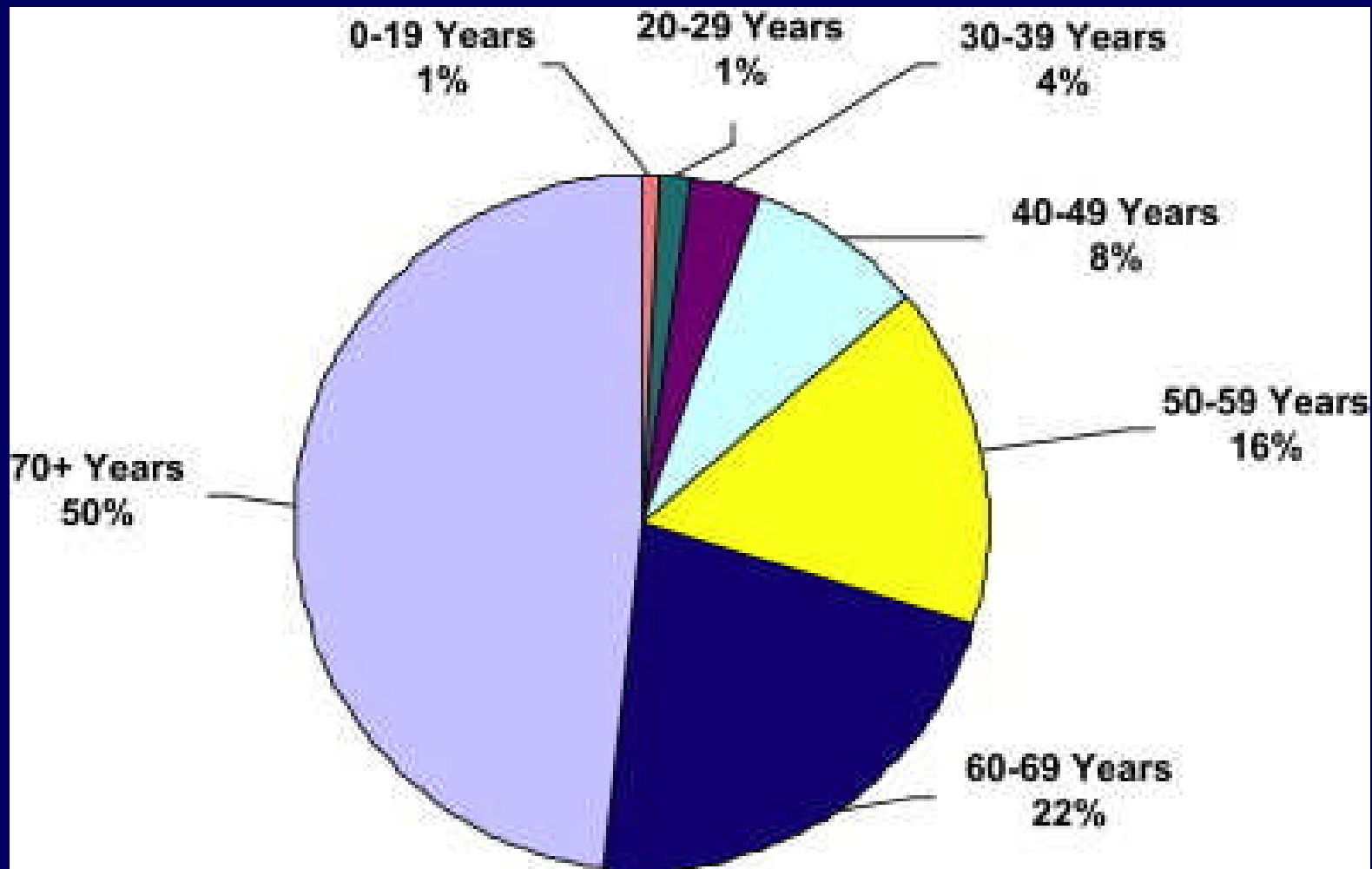
Comprehensive Care for Older Adults with Chronic Conditions

**Interdisciplinary Primary Care
Care or Case Management
Disease Management
Preventive Home Visits
Outpatient CGA & GEM
Pharmaceutical Care
Chronic Disease Self Mgmt
Prevention/mgmt**

**Proactive Rehabilitation
Caregiver Support
Transitional Care
Hospital-at-Home
Nursing Home
Delirium Management
Comprehensive
Hospital Care**

Caringfor theCancer Survivor

NUMBER OF PEOPLE ALIVE IN THE U.S. DIAGNOSED WITH CANCER BY CURRENT AGE



WHAT'S DIFFERENT ABOUT OLDER PATIENTS?

- **Heterogeneity of health status**
- **Physiologic changes**
- **Increased prevalence of disease**
- **Tendency to have multiple, often interacting, diseases**
- **Under-reporting of symptoms**
- **Atypical presentation of common illnesses**
- **Increased importance of social support**
- **Increased rates of adverse effects to medications and therapies**
- **Different goals of therapy**

LATE EFFECTS OF CANCER AND ITS TREATMENT: “Premature Aging Syndrome”?

CARDIO- VASCULAR

Cardiomyopathy
Atherosclerotic CVD
LV dysfunction – CHF
Arrhythmias
Pericarditis
Valve dysfunction

PULMONARY

Interstitial pneumonitis
Pulmonary fibrosis
Restrictive lung disease
Obstructive lung disease

RENAL/GU

Glomerular toxicity
Tubular dysfunction
Erectile dysfunction
Dyspnea

SENSORY

Hearing loss
Tinnitus
Decreased vision
Cataracts

ENDOCRINE

Osteoporosis
Obesity, Metabolic syndrome
Hypothyroidism
Premature menopause

IMMUNE SYSTEM

Increased Infections
Asplenia

HEMATOLOGIC

Myelodysplasia

NEUROLOGIC

Peripheral neuropathy
Leukoencephalopathy
Stroke
Cerebellar dysfunction
Cognitive dysfunction

HEPATIC

Decreased hepatic function
Intestinal obstruction

GENERAL

Fatigue

**KEYNOTE COMMENT –
CANCER SURVIVORSHIP AND AGING –
A DOUBLE WHAMMY**

Cohen HJ, *Lancet Oncology* 7, 882, 2006

AGING AND CANCER SURVIVORSHIP

- **Physiologic changes of aging – decreased homeostasis**
- **Older cancer survivors have more physical function decline than younger** *Avis, Cancer 113: 3519, 2008*
- **Older cancer survivors have more comorbidity than younger** *Hewitt, JGMS 58: 82, 2003*
- **Older cancer survivors have more comorbidity than age matched non-cancer survivors** *Barker, Cancer 97: 674, 2003*
- **Older cancer survivors have functional decline, but comorbidity increases it geometrically** *Hewitt, JGMS 58: 82, 2003*
- **Comorbidities dominate QOL, functional status, survival costs** *Garman, JGMS 58: 1119-24, 2003*
Seo, Cancer 101: 2276-84, 2004

SURVIVORSHIP MANAGEMENT

Problem:

- **Oncologists do a good job of cancer related management – not so good at comorbidities and functional status**
- **Primary care providers do good job of comorbidity and functional status – not so good at cancer related**

Earle, *Cancer*, 101: 1712, 2004

Mao, *JCO* 27: 933, 2009

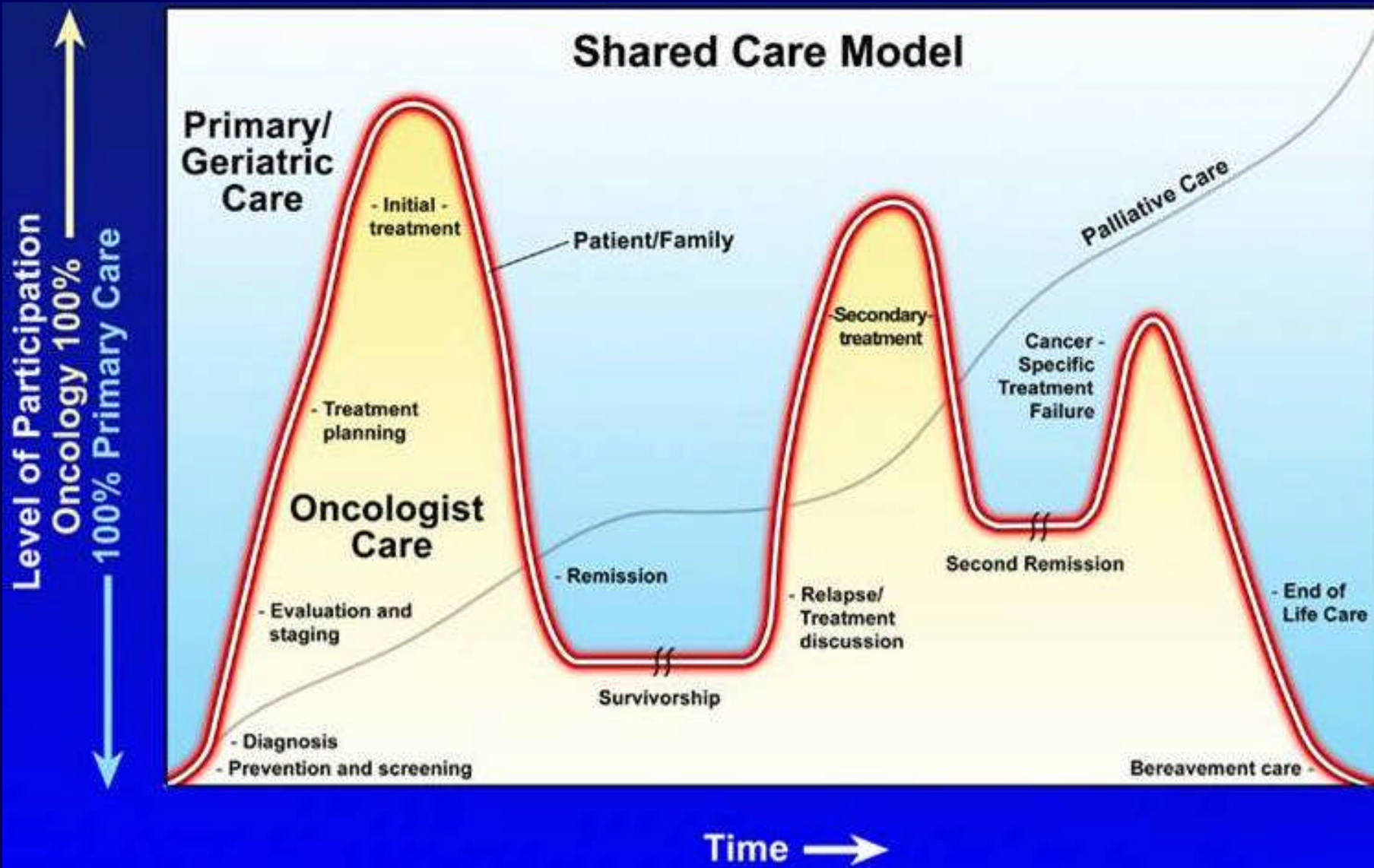
- **Current care plans concentrate on cancer related issues for the primary care provider**

SURVIVORSHIP MANAGEMENT (cont.)

Potential Answers:

- **Share care, clear communications**
- **Geriatric specific “Survivorship Care Plan” for both oncologists and primary care providers**
- **Oncology providers can use Geriatric Assessment screening to indicate need for further evaluation, e.g. brief CGA**

Shared Care Model



OLDER CANCER SURVIVORS ROLE

- Few Cancer survivors adhere to current lifestyle guidelines for diet and exercise – do better with smoking

Blanchard, *JCO* 26: 2198, 2008

Alizzi, *JCO* 27: 960, 2009

- The Teachable Moment

Demark-Wahnefried, *JCO* 23: 5418, 2005

Ganz, *JCO* 23: 5458, 2005

- Older Cancer survivors can modify their lifestyle with help
 - Leading the way in Exercise and Diet (LEAD)
 - Reach out to Enhance Wellness (RENEW)

Reach out to ENhance Wellness among older cancer survivors (RENEW)

- **Randomized controlled trial of telephone counseling and mailed materials on Diet and Exercise**
- **641 Breast, Prostate and Colon Cancer survivors
> Age 65, Mean age 73
Years from diagnosis: Mean = 8.6**
- **1° Outcome – Physical Function (SF 36) at 1 year**
- **2° Outcomes – Other QOL (SF 36)
Dietary outcomes**

Reach out to ENhance Wellness among older cancer survivors (RENEW)

	I Δ	CΔ	Between Group Diff	p
Physical function SF 36	- 2.15	- 4.84	2.69	0.03
Lower ext function (score)	0.34	- 1.89	2.24	0.005
Duration endurance (min)	36.30	23.40	12.90	0.004
F and V (servings)	1.24	0.13	1.11	0.003
Sat fat (g/d)	- 3.06	- 1.07	1.99	0.004
Gen Health SF 36	0.77	- 1.94	2.71	0.007
Soc Function SF 36	- 1.29	- 5.05	3.75	0.008
Role Physical SF 36	- 2.43	- 4.68	2.25	0.025

CancerCaregiving

- **Shorter duration than dementia, diabetes, frailty**
- **Less physical strain than dementia; more than diabetes, frailty**
- **More emotional strain than other three**



Supporting the Hospital-to-Home Transition of Patients and their Informal Caregivers

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Hospital to Home Transition

- ▶ Hospital care is only for the sickest patients and then, discharged as soon as possible
- ▶ Success of care plan – from hospital to home – relies on patients and caregivers
- ▶ Caregivers are expected to assume health management roles in the home and carry out medical tasks

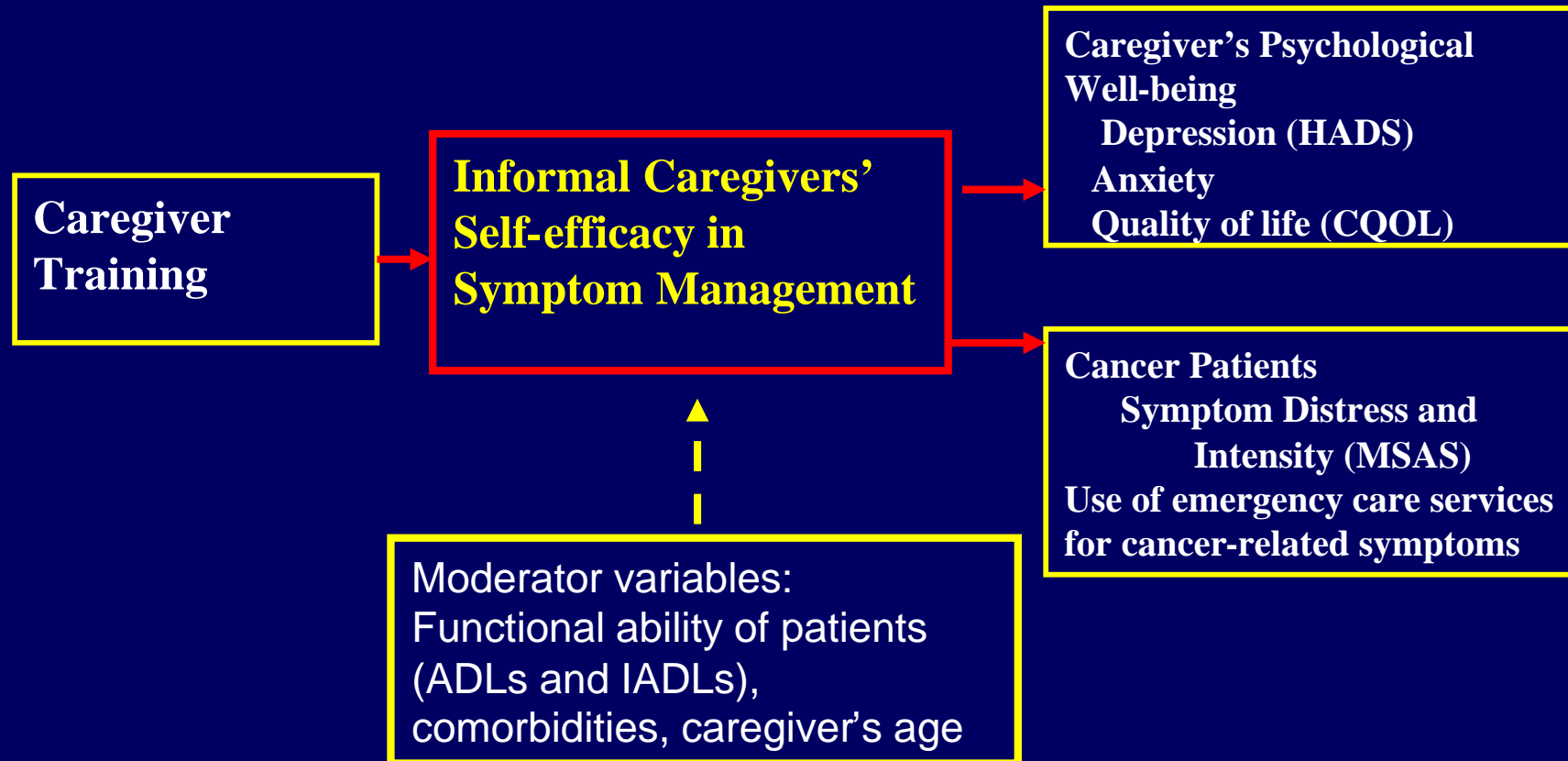


**How can we promote
preparedness and confidence
(self-efficacy) in home care
among informal caregivers of
older cancer patients?**

CancerCaregiver Study

- **Describe the effects of training on caregivers' self-efficacy (and preparedness)**
- **Describe the effects of training on caregivers' psychological well-being**
- **Describe the impact of the training on patients' symptom distress and their emergency care visits**

Study Framework

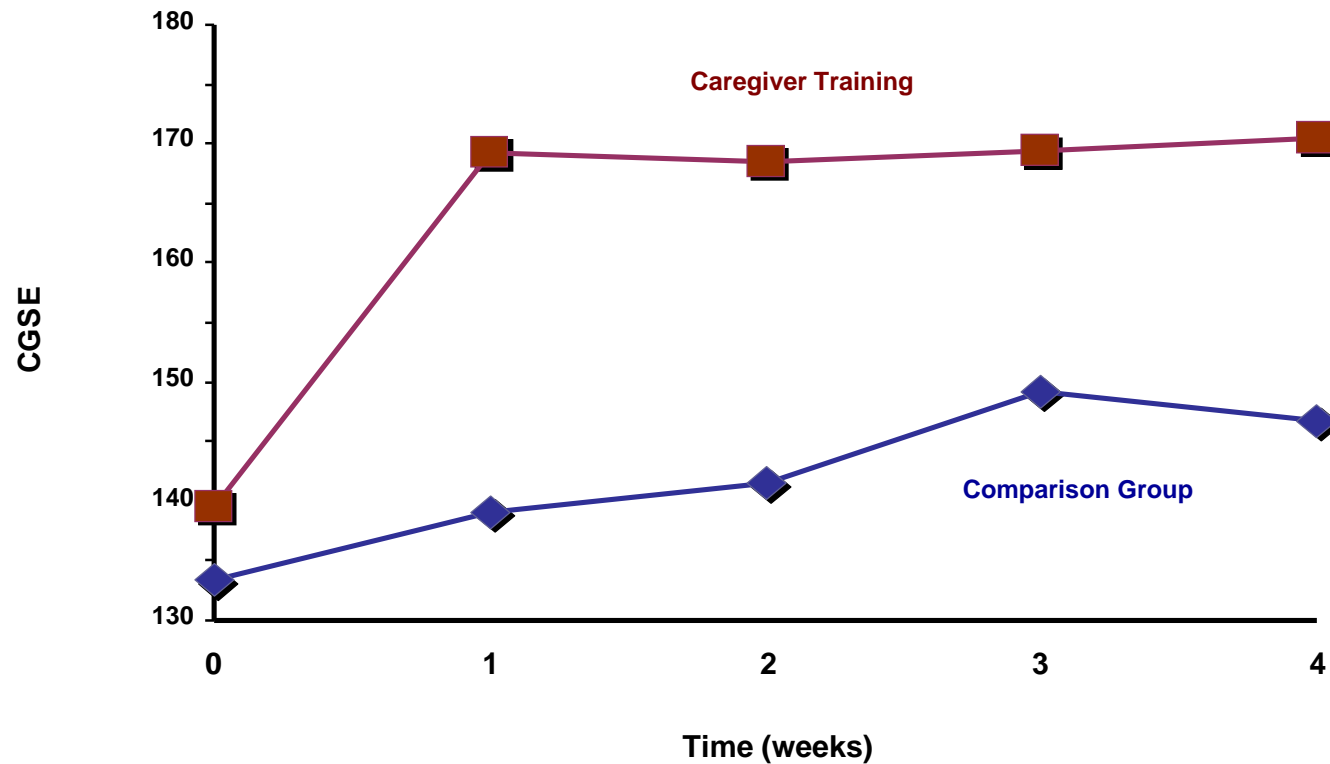


Caregiver Training

- ▶ About 2-3 hours long (can be divided into several sessions)
- ▶ Bedside, patient's participation is encouraged
- ▶ Experiential learning
- ▶ Our approach of a tailored intervention grounded in pre-defined areas of teaching provides requisite balance between reproducibility and patient/caregiver-centeredness.



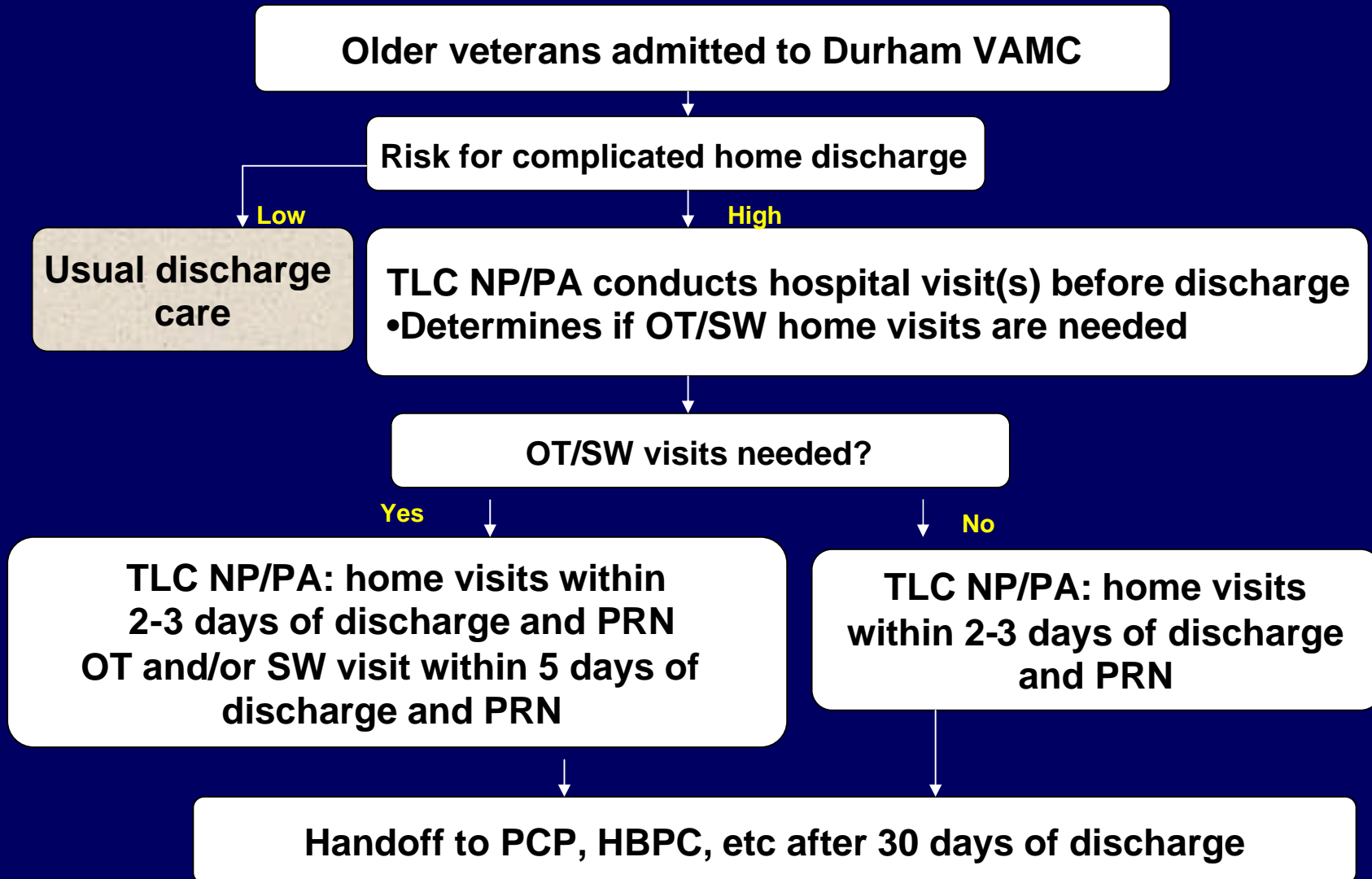
Predicted Caregiver Self-Efficacy by Intervention and Time (N=120)



Conclusion

- ❖ **An individualized, tailored caregiver training can promote self-efficacy in home and symptom management, and preparedness among caregivers.**
- ❖ **The training did not have a significant effect on caregivers' psychological well-being (depression, anxiety, and quality of life).**
- ❖ **There was no intervention effect on patients' symptom distress and emergency care visit**

TLC Partner Program*



*Based on Naylor's Transitional Care Model (LDI Issue Brief, 9(6): 1-4, 2004 Apr-May)

Conclusion

Better organized systems of care for older adults with chronic diseases can empower families and patients to optimize the informal care provided.