Optimizing the Contribution of Family Caregivers in the Oncology Careforce

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Disclaimers: Views my own; No financial conflicts to disclose

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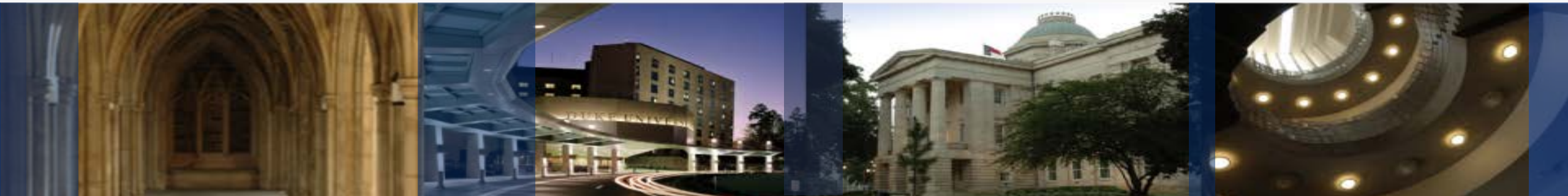

Agenda

1. Prevalence of cancer caregivers
2. Caregiving tasks performed
3. Caregiver capacity
4. Negative spillover effects
5. Practice and policy solutions

Informal Cancer Caregivers

Family members or friends, typically uncompensated and providing care at home, devoting significant time, energy, and costs caring for an individual with cancer.[1]

Prevalence of Cancer Caregivers in the United States

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National Alliance for Caregiving June 2016

- Estimated 2.8 million caregivers who reported cancer was the "main problem or illness" [2]

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Caregiver Profile [2]

- 58% female
- Average age ~ 53
- 40% College degree or higher
- 64% household income <$75,000

Prevalence of Cancer Caregivers in the United States

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Caregiver Profile [2]

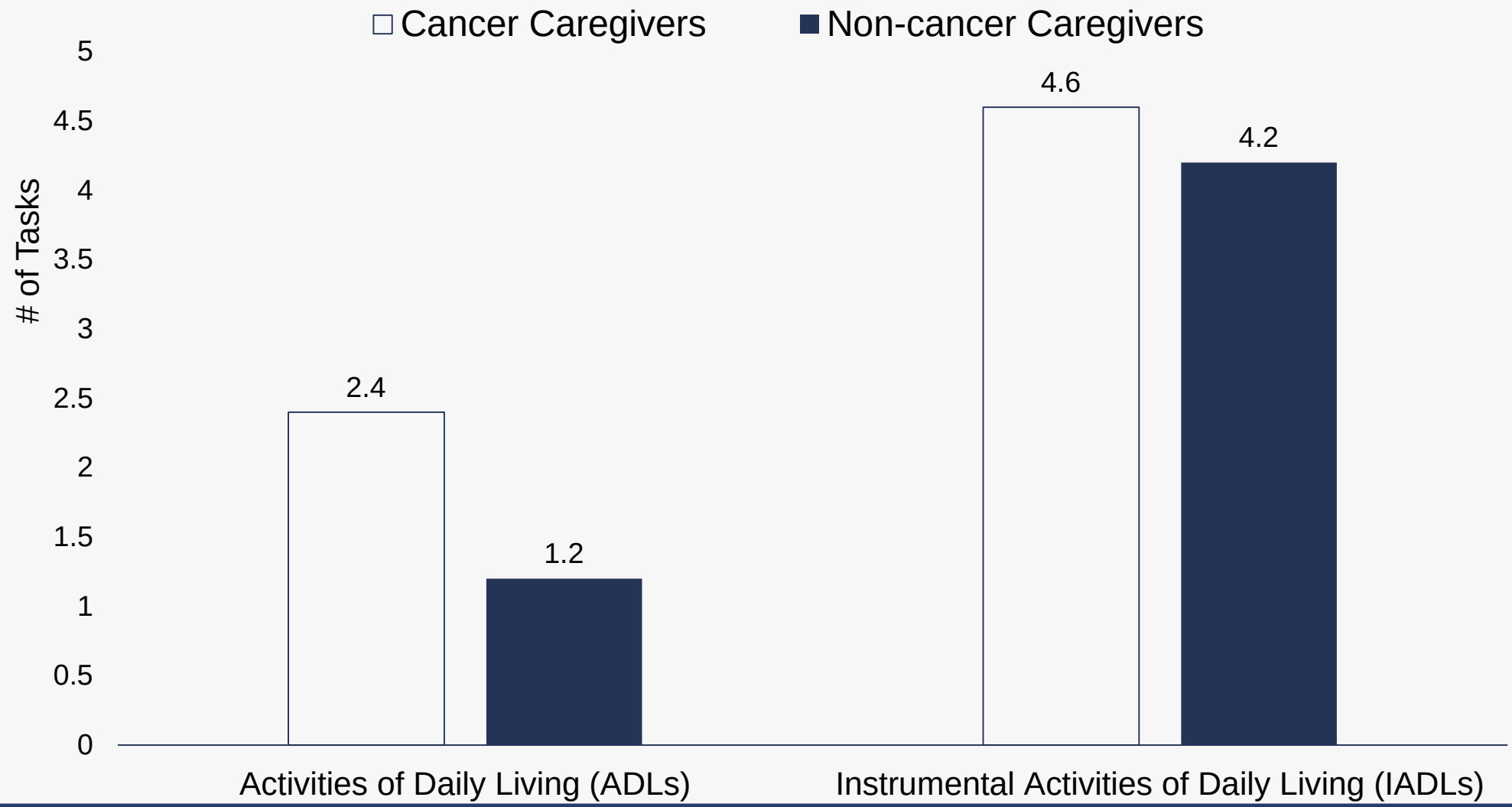
- 58% female
- Average age ~ 53
- 40% College degree or higher
- 64% household income <$75,000

Care Recipient Profile [2]

- 70% female
- 62% aged 65 or older
- 39% living with caregiver

- Recipient is…
  - 44% Parent/Parent-in-law
  - 16% Spouse/Partner
  - 14% Sibling/Sibling-in-law

Caregiving Tasks [2]



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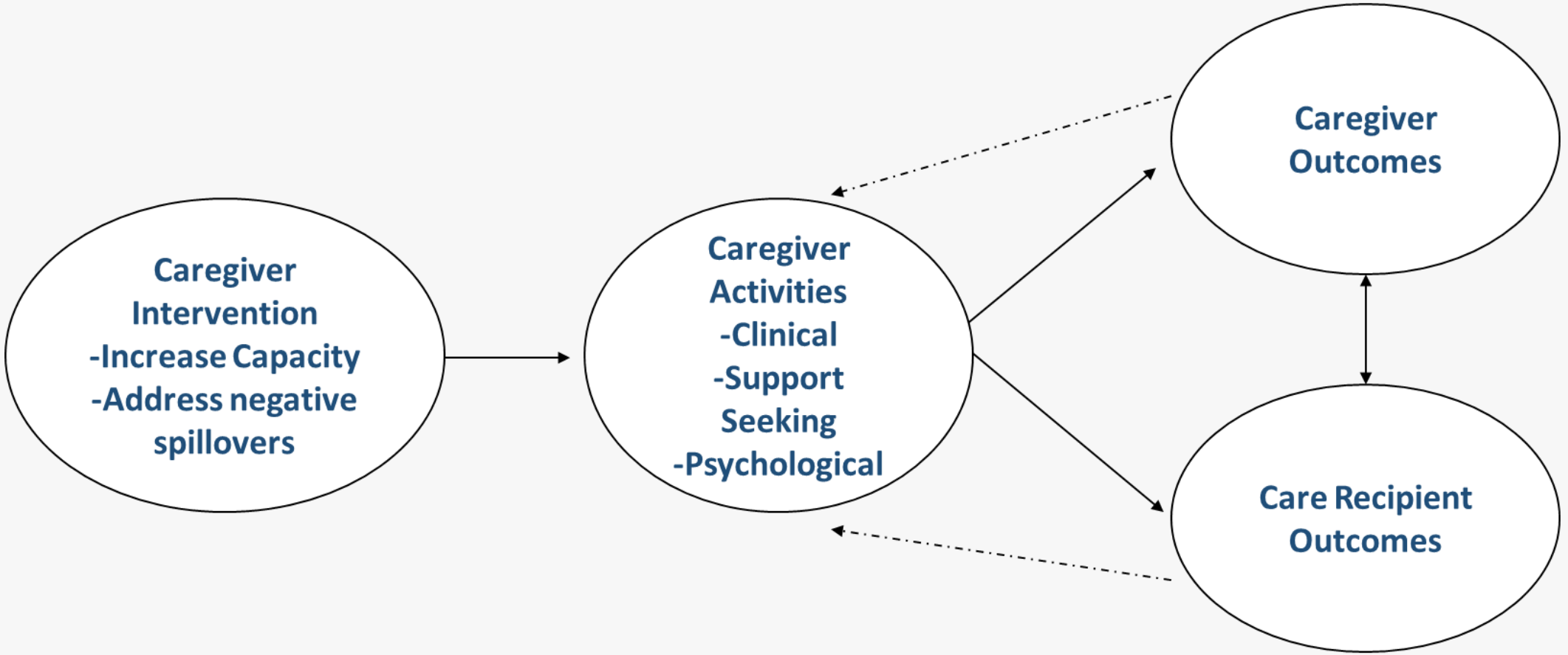

Van Houtven, Voils, Weinberger, 2011

Caregiver Capacity

Stressors and Challenges

- **Lack of training**
  - Most caregivers report they did not receive formal training. [3, 4]
    - 72% of caregivers assist w/ medical/nursing tasks, e.g. administering injections, tube feedings, catheter and colostomy care, etc. [2]

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Caregivers have unique information about patient preferences, symptoms, and goals of care

Caregiving: Negative Spillover Effects

1. High direct and indirect economic costs over time

2. Direct: High out of pocket costs

3. Indirect: Missed Work

Caregiving: Negative Spillover Effects

1. **High direct and indirect economic costs over time**

Total Economic Burden for Lung/CRC Caregivers[13, 14, 15]		
Initial Phase	Continuing Phase	Terminal Phase
$7,028	$19,701	$14,234

2. Direct: High out of pocket costs

3. Indirect: Missed Work

Economic burden of cancer caregivers of persons with advanced solid tumor cancers

N	163
Highest reported personal economic strain	
I am in good shape, financially	52 (32.1%)
I am okay, financially	17 (10.5%)
I am barely getting by	16 (9.9%)
I am falling behind	35 (21.6%)
I am in serious financial trouble	41 (25.3%)
Not reported	1 (0.6%)
Ways caregiver helped pay for the cost of care for patient	
Used own savings	84 (51.5%)
Money gifts from friends, family, organizations	53 (32.5%)
Exhausted all assets	33 (20.2%)
Used retirement money prior to plan	14 (8.6%)
Sold home, car, other property or assets	13 (8.0%)
Total	*105 (64.4%)*

≥57% struggling

1R01CA196576; NCI
co-PIs: Siminoff, Thomson.

Economic burden of cancer caregivers of persons with advanced solid tumor cancers

N	163
Caregiver use of loans to help pay for the cost of care of patient	
Credit card	41 (25.2%)
Loans from family or friends	20 (12.3%)
Other loans/debts	19 (11.7%)
Bank loan, payday loan, loan from employer, home equity, mortgage	14 (8.6%)
Total	*61 (37.4%)*

≥32% loan

Note: Caregivers followed for median period of 10 weeks (range 2-24 weeks). Completed study will have followed caregivers for one year or until one month following patient death.

Project: 1R01CA196576; Funded by NCI; ; co-PIs: Laura A. Siminoff, Maria Thomson,

Caregiving: Negative Spillover Effects

1. High direct and indirect economic costs over time

2. **Direct: High out of pocket costs**
   - $1,243 over time for caregivers of Lung and CRC patients[13]
   - For advanced cancer, costs also high and varied.

3. Indirect: Missed Work

Top 10 (by median amount paid) types of out of pocket costs of 146 caregivers of persons with advanced solid tumor cancers

Type of Service	% of caregivers with out of pocket expenses	Median amount paid per caregiver (U.S. dollars)	Average amount paid per caregiver (U.S. dollars)	Max amount paid per caregiver (U.S. dollars)
Loans	**7%**	**350**	**2,361**	20,000
Nursing	**2%**	270	923	2,500
Babysitting	**1%**	260	260	430
Transportation	90%	224	377	4,592
Insurance	5%	197	195	420
House	32%	100	326	1,739
Appointments	42%	91	332	3,200
Prescriptions	64%	84	185	1,859
Groceries	65%	78	307	2,662
Clothes	19%	62	79	413
Overall	*96%*	***581***	***1,491***	*26,563*

Note: This is an interim report where caregivers were followed for median period of 10 weeks (range 2-24 weeks). Completed study will have followed caregivers for one year or until one month following patient death.

Project: 1R01CA196576; Funded by NCI; co-PIs: Laura A. Siminoff, Temple University, Maria Thomson, Virginia Commonwealth University; Title: Informal caregiver burden in advanced cancer: Economic and health outcomes.

Caregiving: Negative Spillover Effects

1. High direct and indirect economic costs over time

2. Direct: High out of pocket costs

3. **Indirect: Missed Work**
   - Lost productivity at work, changing hours, quitting work, retiring early [11, 12]
   - Heterogeneous work responses

Changes in work status for cancer caregivers of persons with advanced solid tumor cancers

	Baseline (T=1)
N	163
Working usual hours for pay	30 (18.4%)
Working reduced hours for pay	44 (27.0%)
Stopped working for pay	38 (23.3%)
Started working for pay or working more hours for pay	11 (6.7%)
Not applicable or missing	40 (24.6%)

Project: 1R01CA196576; Funded by NCI; ; co-PIs: Laura A. Siminoff, Temple University, Maria Thomson, Virginia Commonwealth University; Title: Informal caregiver burden in advanced cancer: Economic and health outcomes. Preliminary results, study still enrolling

Potential Solutions to Increase Caregiver Capacity

Longitudinal team-based care that places cancer patient and family at center

- Systematic skills **training**
- Traverse oncology silo to **include other specialties**, primary care, social services providers
- Dual role of the health care team:
  - (1) leverage caregiver expertise
  - (2) assess caregiver

Incentives to support systems solutions

– Performance measures to reward team based care with patient and caregiver at center

– Alternative Payment Models

Potential Solutions to Address Negative Spillovers for Caregivers

Direct Costs

- Insurance redesign
  - Lifetime cost caps

Indirect Costs

- Work place policy/benefits
  - Paid family leave or unpaid leave with job guarantees [16]
  - Home- and community-based care a standard health insurance benefit for short-term disability
  - Social security contribution program for caregivers who exit labor force (retire too early, etc.)

Address Equity Concerns

- Wealthier, working caregiver pay more OOP but they may feel it less, able to take unpaid or paid family leave; low income families struggling the most.[18]
- Identify policy levers to target scarce resources to least resilient in face of a cancer diagnosis.

Thank you

Caregiver resources: https://www.cancer.net/coping-with-cancer/caring-loved-one
(Thank you Jeannine Salamone)
https://www.caregiver.va.gov/
(Thank you Meg Kabat)

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References

1. Biegel D, E S, Schulz R. *Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke.* Thousand Oaks, CA: Sage Publications; 1991.
2. National Alliance for Caregiving. (June 2016) "Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience." In partnership with the National Cancer Institute and the Cancer Support Community.
3. van Ryn, M., S. Sanders , K. Kahn, C.H. Van Houtven, J. Griffin, M. Martin, A. Atienza, S. Phelan, S. Finstad, and J Rowland. 2011. "Objective Burden, Resources and Other Stressors among Informal Cancer Caregivers; A Hidden Quality Issue?" *Psycho-Oncology* 20, no. 1: 44-52,
4. Mollica MA, Litzelman K, Rowland JH, Kent EE. "The role of medical/nursing skills training in caregiver confidence and burden: A CanCORS study." *Cancer.* 2017;123(22):4481-4487.
5. Kent EE, Dionne-Odom N. "Population-based profile of mental health and support service need among family caregivers of adults with cancer." *Journal of Oncology Practice*. 2018 :Jop1800522.
6. Schneider E, Abrams M, Shah Arnav, Lewis C and Shah T. *Health Care in America: The Experience of People with Serious Illness*. (October 2018) The Commonwealth Fund. https://www.commonwealthfund.org/sites/default/files/2018-10/Schneider_HealthCareinAmerica.pdf
7. Rosland AM, Piette JD. "Emerging models for mobilizing family support for chronic disease management: a structured review." *Chronic illness.* 2010;6(1):7-21.
8. Silliman RA, Bhatti S, Khan A, Dukes KA, Sullivan LM. The care of older persons with diabetes mellitus: families and primary care physicians. *J Am Geriatr Soc.* 1996;44(11):1314-1321.
9. Spillman B, Wolff J, Freedman V, Kasper J. *Informal caregiving for older Americans: An analysis of the 2011 National Survey of Caregiving.* Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, Health and Human Services;2014.
10. Wolff JL, Spillman BC, Freedman VA, Kasper JD. *A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities*. (2168-6114 (Electronic)).
11. Kamal KM, Covvey JR, Dashputre A, et al. "A Systematic Review of the Effect of Cancer Treatment on Work Productivity of Patients and Caregivers." *J Manag Care Spec Pharm.* 2017;23(2):136-162
12. de Moor JS, Dowling EC, Ekwueme DU, et al. "Employment implications of informal cancer caregiving." *Journal of cancer survivorship : research and practice*. 2016.
13. Van Houtven CH, Ramsey SD, Hornbrook MC, Atienza AA, van Ryn M. "Economic burden for informal caregivers of lung and colorectal cancer patients." *The Oncologist*. 2010;15(8):883-893.
14. Yabroff KR, Kim Y. "Time costs associated with informal caregiving for cancer survivors." *Cancer.* 2009;115(18 Suppl):4362-4373.
15. Kent E, Longacre M, Chou W, Mollica M. Chapter 1: "Who are Informal Cancer Caregivers?". (2019) Chapter for Oxford University Press: *Informal Cancer Caregivers*.
16. A Mathur, IV Sawhill, et *al* ***T****he AEI-Brookings Working Group Report on Paid Family and Medical Leave: Charting a Path Forward*, September 2018AEI-Brookings Working Group
17. Zheng, Z, Jeman, A, Han, Q, Guy, GP, Li, C, Davidoff, AJ, Banegas, MP, Ekwueme, DU, KR Yabroff, "Medical financial hardship among cancer survivors in the US". *Cancer*, 2019
18. Deniz H, Inci F. "The burden of care and quality of life of caregivers of leukemia and lymphoma patients following peripheric stem cell transplantation." *Journal of psychosocial oncology.* 2015;33(3):250-262.