ASSOCIATION OF COMMUNITY CANCER CENTERS

FINANCIAL ADVOCACY NETWORK

Shared Decision Making for Financial Advocates

ACCC Financial Advocacy Network Summit August 16, 2018 <u>Downtown Washing</u>ton DC

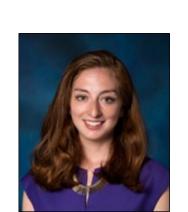




Understanding and Navigating Financial Distress

Panel Discussion





Teresa Hagan Thomas, PhD, RN Assistant Professor University of Pittsburgh School of Nursing



Virginia Vaitones MSW, OSW-CE, FAOSW Oncology Social Worker - Retired

Panelists



Abra Kelson, MSW, LSWA-IC Medical Social Work Supervisor Northwest Medical Specialties, PLLC



Nicole Taglione Oncology Financial Navigator Saint Agnes Cancer Institute

Financial Toxicity: State of the Science and a Call to Action Teresa Hagan Thomas, PhD, RN Assistant Professor

University of Pittsburgh School of Nursing



ASSOCIATION OF COMMUNITY CANCER CENTER



Disclosures

• I have no disclosures.



Case Study

- Patient X, 43 yo is on Cycle 4 for Stage III breast cancer receiving adjuvant treatment.
 - Lives 1 hour away from hospital
 - 3 children
 - Married and carries family health insurance
 - Working; missed 20 days related to cancer
 - 20% co-insurance; Copayments
- Disease progression
- Deciding on new trial



Case Study

- Patient X, 43 yo is on Cycle 4 for Stage III breast cancer receiving adjuvant treatment
 - Lives 1 hour away from hospital
 - 3 children
 - Married and carries family health insurance
 - Working; missed 20 days related to cancer
 - 20% co-insurance; Copayments
- Disease progression
- Deciding on new trial

Travel (gas, tolls, food, parking) + Childcare costs + Missed work + Co-insurance + Co-payments + STRESS



Background

What is financial toxicity and why is it an issue?

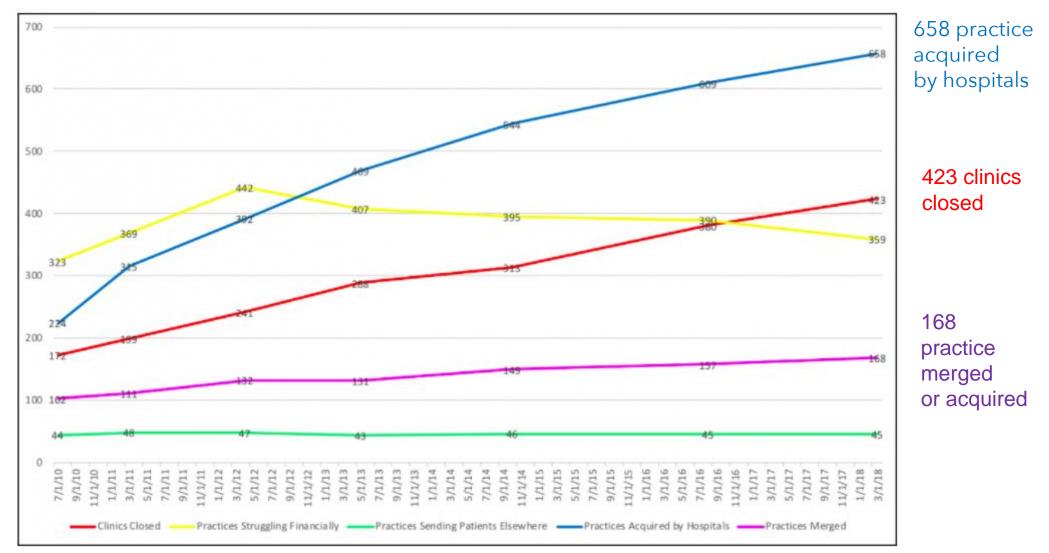
© 2018 Association of Community Cancer Centers



Historical Context

- 1. Higher national health care expenditures
- 2. Shift from community- to hospital-based care
- 3. Higher costs of novel drugs

Historical Trend in the Changing Landscape of Cancer Care

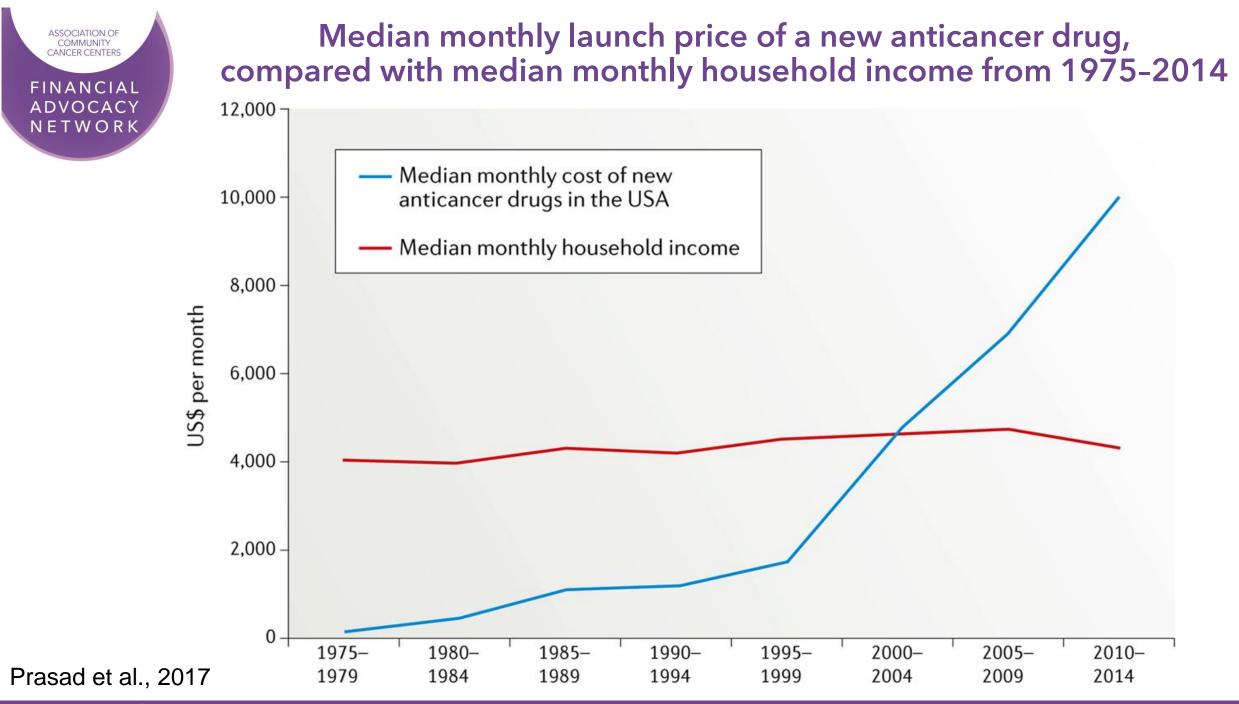


Community Oncology Alliance, 2018

ASSOCIATION OF

COMMUNITY CANCER CENTERS

FINANCIAL ADVOCACY NETWORK





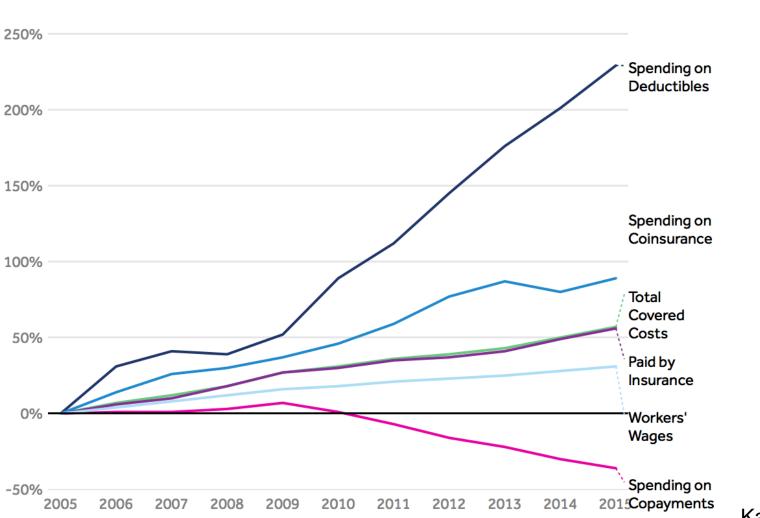
Health Insurance

Higher premiums, deductibles, and co-insurance and co-payment rates

ASSOCIATION OF COMMUNITY CANCER CENTERS FINANCIAL ADVOCACY NETWORK

300%

Cumulative Increases in Health Costs, Amounts Paid by Insurance, Amounts Paid for Cost Sharing, and Workers Wages (2005-2015)



Kaiser Family Foundation, 2017



Health Insurance

- Cancer treatment drug prices
 - Immunotherapies
 - Targeted therapies
 - IV vs. oral chemotherapy prices



Terminology

- Financial burden / distress / hardship / stress / strain
- Economic burden / hardship
- Costs of care
- Financial toxicity

ASSOCIATION OF COMMUNITY CANCER CENTERS FINANCIAL ADVOCACY NETWORK

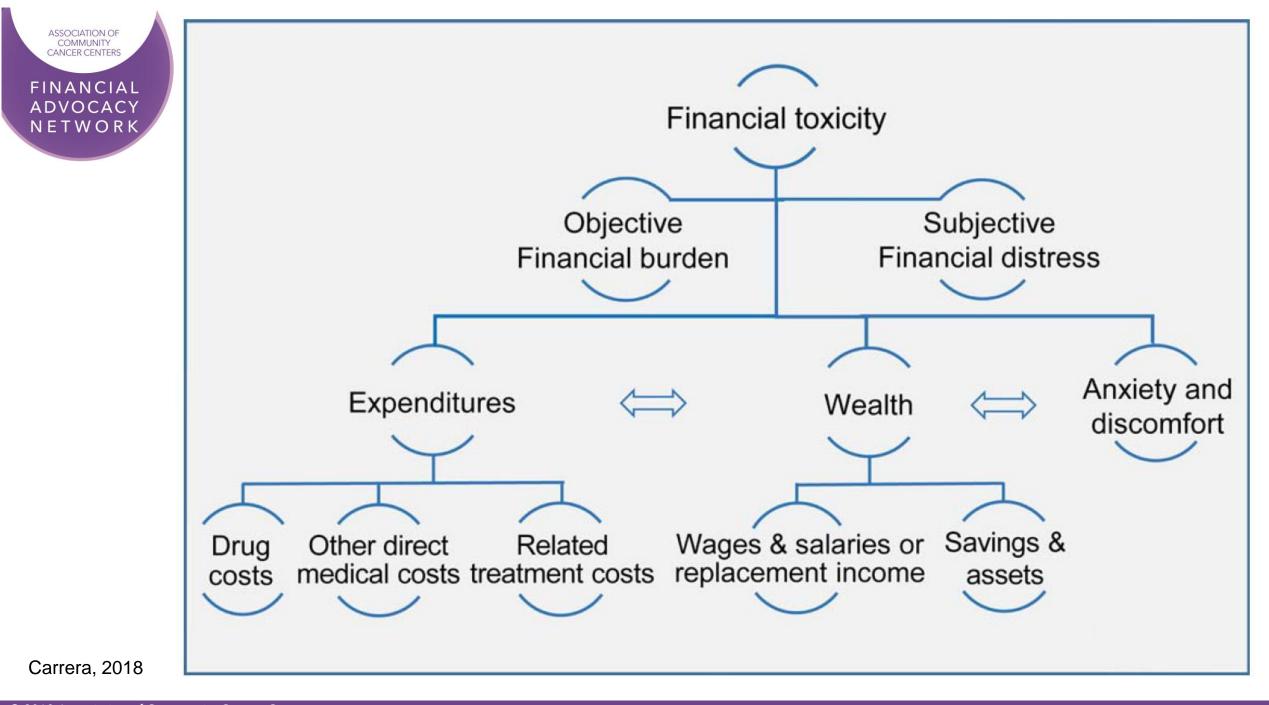
Definition

Objective **Burden**:

- borrowing money
- being unable to cover costs of care
- declaring bankruptcy

Subjective **Distress**:

• distress about the ability to pay for care





Prevalence

- Adults in treatment
 - Monetary measures: 28 48%
 - Objective or subjective measures: 16 73%
- Adults post-treatment
 - 15% reported financial difficulty
 - 20% reported worry



Theoretical Model

• Who is at risk? What are the consequences?



Patient Risk Factors

- Health
 - Advanced/recurrent/multiple cancer(s)
 - Co-morbidities
 - Treatment with chemotherapy and/or radiation
- Socio-demographic variables
 - Female gender
 - Younger age
 - Lower income
 - Race
- Health access
 - Change in employment
 - Health insurance





Patient Experiences

- Higher out-of-pocket costs
- Asset depletion/debt/bankruptcy
- Productivity loss
- Reduced employment-based health insurance options
- Reduced funds for leisure, food, clothing

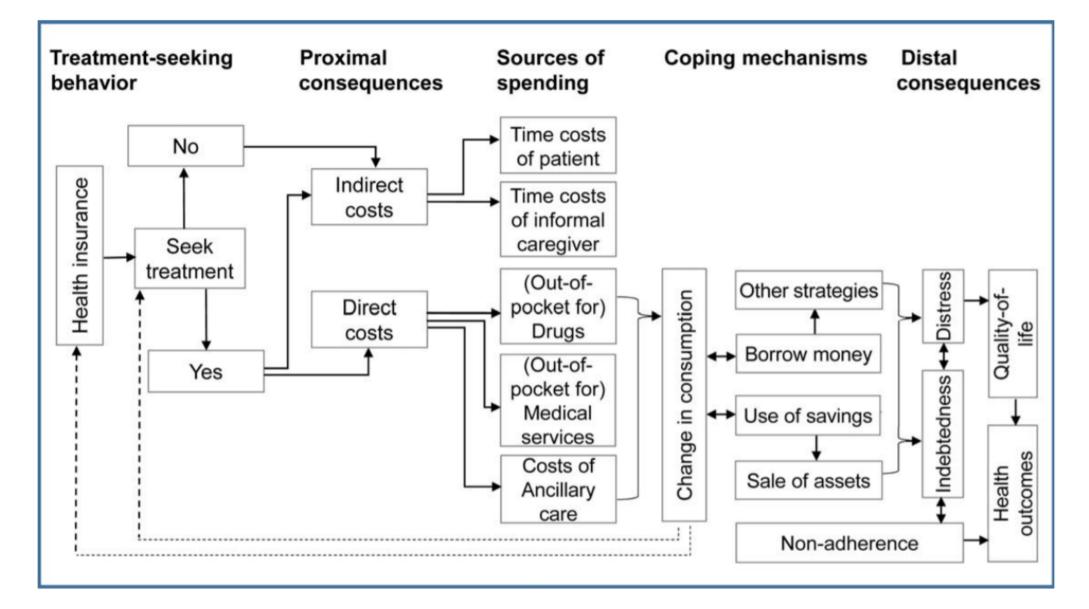


Patient Consequences

- Distress
- Non-adherence
 - 20% skipping doses
 - 18% take less medication
 - 24% do not fill prescriptions
- Lower health-related quality of life
- Lower quality health care
- Survival



Model of Financial Toxicity



Carrera, 2018

ASSOCIATION OF COMMUNITY CANCER CENTERS FINANCIAL ADVOCACY NETWORK

Clinical care

•What does financial toxicity look like in the clinic?



Clinical Presentation

- Assessment and/or discussion of:
 - Costs of treatment
 - Delaying/skipping treatment, medications, appointments
 - Missed work; over-worked
 - Insurance concerns
 - Distress related to costs



Current Interventions

- Referral to:
 - Social work
 - Patient navigator
- Financial counseling:
 - Patient assistance programs
 - Local resources



Current Interventions

- Referral to:
 - Social work
 - Patient navigator
- Financial counseling:
 - Patient assistance programs
 - Local resources

Are we doing enough?



Low Rates of Cost Communication

- 52% of patients want to discuss treatment-related out-of-pocket costs
 - 22% of visits discuss costs
 - Median duration = 33 seconds
 - 38% of conversations mentioned costreducing strategies



Patient Preferences

- •71% do NOT want personal or societal costs to influence treatment
 - *independent of degree of financial toxicity*
- Low-income patients more likely to prioritize avoidance of expensive treatments compared to high-income patients
- 31% feel informed about costs of cancer care before treatment

Meisenburg et al., 2015; Mileshkin et al., 2009; Wong et al., 2013



Clinical Barriers

- Perceptions of clinicians' time
- Embarrassment
- Efficacy expectations
- Financial information relative to treatment decisions



Methods in Financial Toxicity Research

•What are the issues in financial toxicity research?



Methodological Concerns

- Measurements
- Study design
- Nursing care



Measures of Financial Toxicity

Name	What it measures	Pros	Cons
Out of pocket spending reports	Objective costs of care	Accurate	Access to billing/insurance; no subjective
C ollection of I ndirect and N onmedical D irect Costs (COIN) [17-items]	Missed work, visiting nurses, home care, etc.	Comprehensive	Length; recall bias
Economic Impact Assessment [13-items]	Socio-demographic information related to income, salary, insurance	Economic profile	Non-cost specific
CO mprehensive S core for Financial T oxicity (COST) [11-items]	Patient perceptions of costs, resources, concerns	Subjective	Not comprehensive
Personal Financial Wellness Scale (PFWS) [8-items]		Subjective	Not cancer specific
Single-item screen	Income: household needs	Short	Not comprehensive

ASSOCIATION OF COMMUNITY CANCER CENTERS FINANCIAL ADVOCACY NETWORK

Financial Toxicity Grading Scale

Grade	Description
1	Lifestyle modification (deferral of large purchases or reduced spending on vacation and leisure activities) because of medical expenditure
	Use of charity grants/fundraising/copayment program mechanisms to meet costs of care
2	Temporary loss of employment resulting from medical treatment
	Need to sell stocks/investments for medical expenditure
	Use of savings accounts, disability income, or retirement funds for medical expenditure
3	Need to mortgage/refinance home to pay medical bills
	Permanent loss of job as a result of medical treatment
	Current debts > household income
	Inability to pay for necessities such as food or utilities
4	Need to sell home to pay for medical bills
	Declaration of bankruptcy because of medical treatment
	Need to stop treatment because of financial burden
	Consideration of suicide because of financial burden of care

Khera, et al., 2014



Study Designs

- Retrospective analyses
- Descriptive, cross-sectional
 - Recall bias
 - Nonresponse bias
- Few intervention trials



Interventions

- Published
 - One prospective pilot intervention study
- Current
 - National Cancer Institute Community Oncology Research Program (NCT02728804)
 - Observational, 12-month
 - Metastatic colorectal cancer



Research and PRACTICE Priorities

What should our focus be?



Priorities

- 1. Validate a screening tool
- 2. Describe the trajectory of financial toxicity
 - 1. Describe impact on:
 - 1. Adherence
 - 2. Symptom management
 - 3. Treatment decision-making
- 3. Identify and test intervention targets/timing

ASSOCIATION OF COMMUNITY CANCER CENTERS FINANCIAL ADVOCACY NETWORK

Policy Priorities

- Increased transparency in drug costs
- Value-based cancer care
- Training in financial stewardship
- Oncology Medical Home Demonstration Project
 - Cancer Care Payment Reform Act of 2017
- Oral drug parity laws
- Allow Centers for Medicare & Medicaid Services to negotiate drug prices
- Expand Medicaid Drug Rebate Program



Clinical nursing priorities

•What can I do?



Key Clinical Questions

- How *aware* are oncology nurses of their patients' financial situations?
- How *comfortable* are oncology nurses in discussing financial issues?
- How *equipped* are oncology nurses in assessing financial toxicity?

References

- Bestvina, C. M., Zullig, L. L., Rushing, C., Chino, F., Samsa, G. P., Altomare, I., ... & Abernethy, A. P. (2014). Patient-oncologist cost communication, financial distress, and medication adherence. Journal of Oncology Practice, 10(3), 162-167.
- Carrera, P. M., Kantarjian, H. M., & Blinder, V. S. (2018). The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. CA: a cancer journal for clinicians.
- Community Oncology Alliance (2018). Practice Impact Report. Accessed from: http://www.communityoncology.org/downloads/pir/COA-Practice-Impact-Report-2018-FINAL.pdf
- Dusetzina, S. B., Winn, A. N., Abel, G. A., Huskamp, H. A., & Keating, N. L. (2013). Cost sharing and adherence to tyrosine kinase inhibitors for patients with chronic myeloid leukemia. Journal of Clinical Oncology, 32(4), 306-311.
- Hunter, W. G., Zafar, S. Y., Hesson, A., Davis, J. K., Kirby, C., Barnett, J. A., & Ubel, P. A. (2017). Discussing Health Care Expenses in the Oncology Clinic: Analysis of Cost Conversations in Outpatient Encounters. Journal of oncology practice, 13(11), e944-e956.
- Jones, S. M., Walker, R., Fujii, M., Nekhlyudov, L., Rabin, B. A., & Chubak, J. (2018). Financial difficulty, worry about affording care, and benefit finding in long-term survivors of cancer. Psycho-Oncology, 27(4), 1320-1326.
- Kaisaeng, N., Harpe, S. E., & Carroll, N. V. (2014). Out-of-pocket costs and oral cancer medication discontinuation in the elderly. Journal of Managed Care Pharmacy, 20(7), 669-675.
- Kaiser Family Foundation analysis of Truven Health Analytics MarketScan Commercial Claims and Encounters Database, 2005-2015; Bureau of Labor Statistics, Seasonally Adjusted Data from the Current Employment Statistics Survey, 2005-2015 (April to April).
- Meisenberg, B. R., Varner, A., Ellis, E., Ebner, S., Moxley, J., Siegrist, E., & Weng, D. (2015). Patient attitudes regarding the cost of illness in cancer care. The Oncologist, 20(10), 1199-1204.
- Meropol, N. J., Schrag, D., Smith, T. J., Mulvey, T. M., Langdon Jr, R. M., Blum, D., ... & Schnipper, L. E. (2009). American Society of Clinical Oncology guidance statement: the cost of cancer care. Journal of Clinical Oncology, 27(23), 3868-3874.
- Mileshkin, L., Schofield, P. E., Jefford, M., Agalianos, E., Levine, M., Herschtal, A., ... & Zalcberg, J. R. (2009). To tell or not to tell: the community wants to know about expensive anticancer drugs as a potential treatment option. Journal of Clinical Oncology, 27(34), 5830-5837.
- Nipp, R. D., Zullig, L. L., Samsa, G., Peppercorn, J. M., Schrag, D., Taylor, D. H., ... & Zafar, Y. (2014). Coping with cancer treatment-related financial burden. 32 (31_Suppl), 161.

References

- Pollack, A. (2012, November 8). Sanofi halves price of cancer drug Zaltrap after Sloan-Kettering rejection. New York Times. Retrieved from http://nyti.ms/2yzr69G
- Prasad, V., De Jesús, K., & Mailankody, S. (2017). The high price of anticancer drugs: origins, implications, barriers, solutions. Nature Reviews Clinical Oncology, 14(6), 381.
- Ramsey, S. D., Bansal, A., Fedorenko, C. R., Blough, D. K., Overstreet, K. A., Shankaran, V., & Newcomb, P. (2016). Financial insolvency as a risk factor for early mortality among patients with cancer. Journal of Clinical Oncology, 34(9), 980.
- Shankaran, V., Leahy, T., Steelquist, J., Watabayashi, K., Linden, H., Ramsey, S., ... & Singleton, E. (2017). Pilot Feasibility Study of an Oncology Financial Navigation Program. Journal of Oncology Practice, JOP-2017.
- Sherman, Eric J., et al. "The collection of indirect and nonmedical direct costs (COIN) form." Cancer 91.4 (2001): 841-853.
- Soni, A. Top Five Most Costly Conditions among Adults Age 18 and Older, 2012: Estimates for the U.S. Civilian Noninstitutionalized Adult Population. Statistical Brief #471. April 2015. Agency for Healthcare Research and Quality, Rockville, MD. http://www.meps.ahrq.gov/mepsweb/data_files/publications/st471/stat471.pdf
- Souza, J. A., Yap, B. J., Hlubocky, F. J., Wroblewski, K., Ratain, M. J., Cella, D., & Daugherty, C. K. (2014). The development of a financial toxicity patient-reported outcome in cancer: The COST measure. Cancer, 120(20), 3245-3253.
- Souza, J. A., Yap, B. J., Wroblewski, K., Blinder, V., Araújo, F. S., Hlubocky, F. J., ... & Daugherty, C. K. (2017). Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). Cancer, 123(3), 476-484.Wong, Y. N., Egleston, B. L., Sachdeva, K., Eghan, N., Pirollo, M., Stump, T. K., ... & Meropol, N. J. (2013). Cancer patients' trade-offs among efficacy, toxicity and out-of-pocket cost in the curative and non-curative setting. Medical care, 51(9).
- Zafar, S. Y., Chino, F., Ubel, P. A., Rushing, C., Samsa, G., Altomare, I., ... & Peppercorn, J. M. (2015). The utility of cost discussions between patients with cancer and oncologists. The American journal of Managed Care, 21(9), 607-615.
- Zafar, S. Y., Peppercorn, J. M., Schrag, D., Taylor, D. H., Goetzinger, A. M., Zhong, X., & Abernethy, A. P. (2013). The financial toxicity of cancer treatment: A pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. The oncologist, 18(4), 381-390.



Thank you!

Teresa Hagan Thomas, PhD, RN

Assistant Professor

University of Pittsburgh School of Nursing



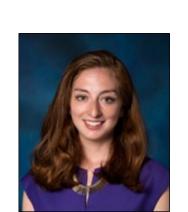
t.thomas@pitt.edu



Understanding and Navigating Financial Distress

Panel Discussion





Teresa Hagan Thomas, PhD, RN Assistant Professor University of Pittsburgh School of Nursing



Virginia Vaitones MSW, OSW-CE, FAOSW Oncology Social Worker - Retired

Panelists



Abra Kelson, MSW, LSWA-IC Medical Social Work Supervisor Northwest Medical Specialties, PLLC



Nicole Taglione Oncology Financial Navigator Saint Agnes Cancer Institute



ACCC Shared Decision Making for Financial Advocates Summit August 2018, Washington DC

Exploring Methods to Improve Financial Distress Screening ACCC Survey 2018

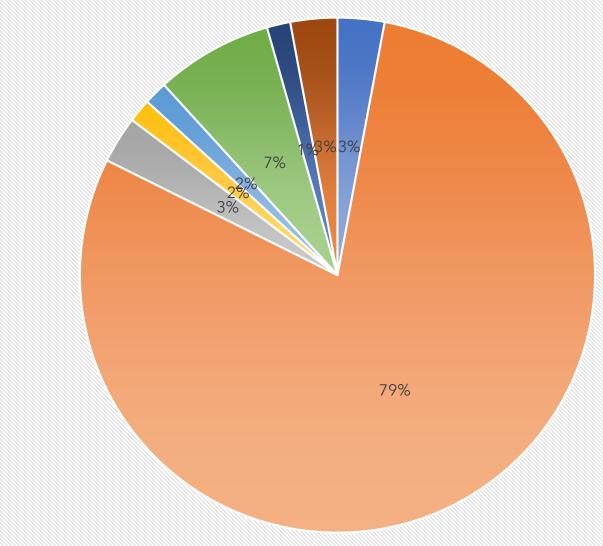
Abra Kelson, MSW, LSWA-IC Social Work Supervisor Rainier Hematology Oncology





- Online Survey consisting of 7 questions to determine financial distress screening process and satisfaction across oncology practices
 - 5 multiple choice
 - 2 free text
- Delivered through ACCC website, AOSW listserv, shared by ACCC Financial Advocacy Advisory Committee Members with other professionals in the oncology field
- Open to all professionals working with oncology patientsongoing (survey still open)
- 68 participants completed survey, as of July 2018

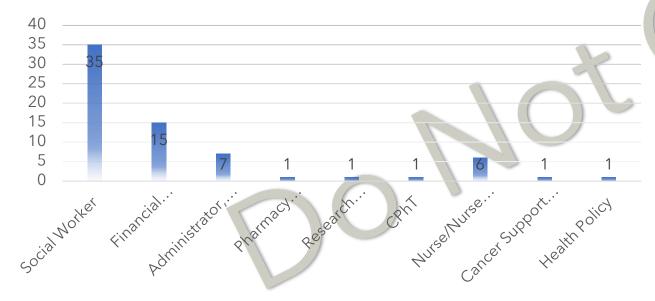
What is your practice setting?



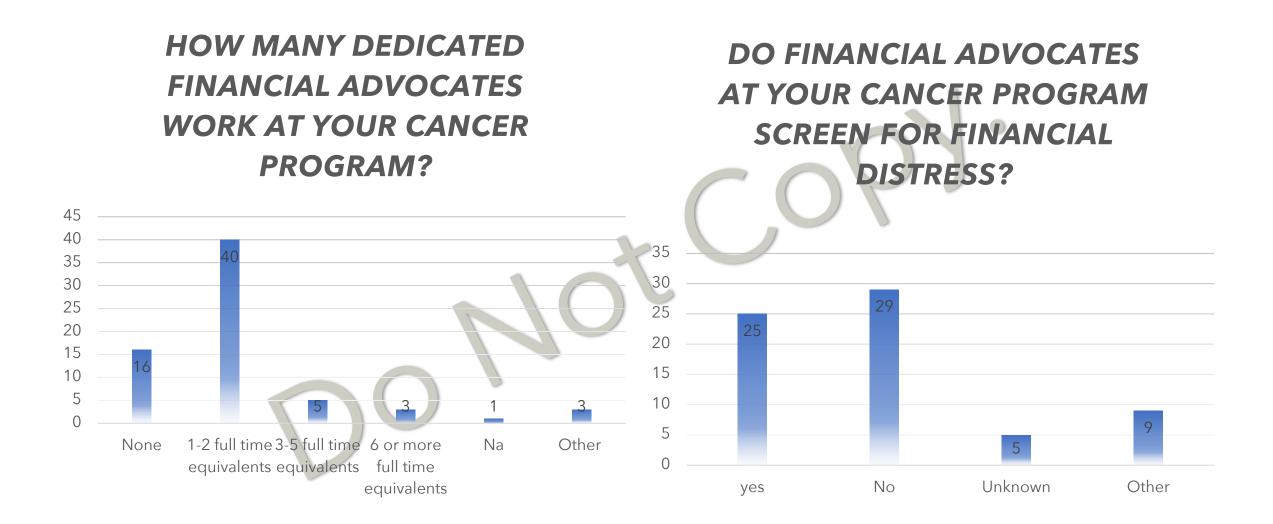
- Freestanding cancer center
- Hospital-based outpatient cancer center
- Physician-owned oncology practice
- OPPS and Physician's Office settings
- Industry
- Shared operation (an arrangement where resources are shared between two entitites, such as private practice and hosptial)
- 1/2 outpatient cancer center (bonemarrow transplant), 1/2 inpt



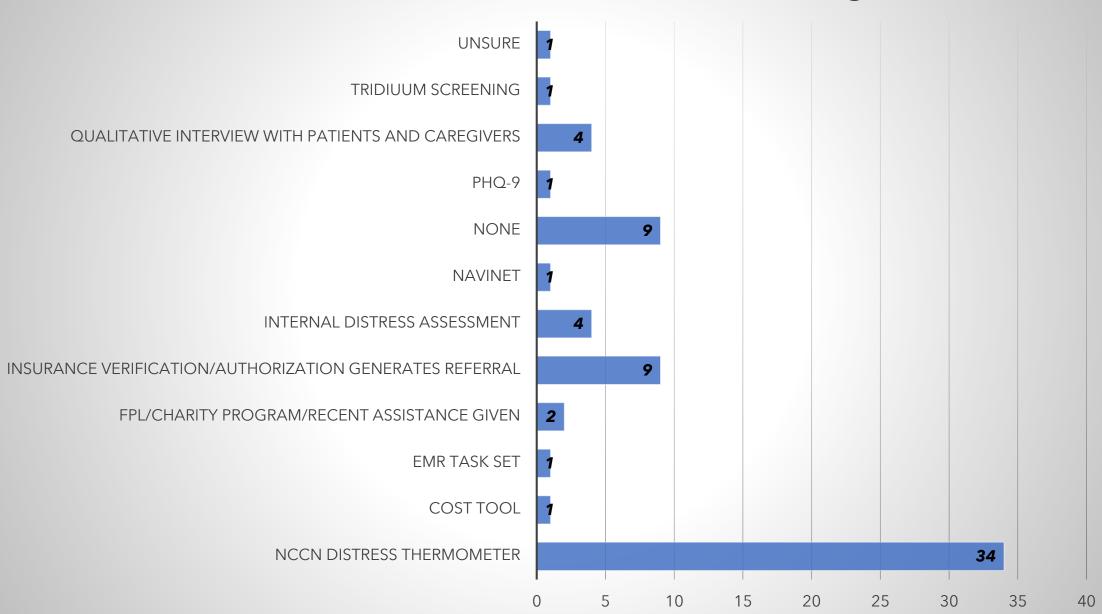
WHICH ROLE BEST DESCRIBES YOUR POSITION?



- Majority of respondents were Social Workers
- Majority of respondents work in an hospital-based outpatient cancer center



Tool Utilized for Financial Distress Screening





Advocates & Navigators

Do you screen for financial distress?		What tools do you use?	
Yes	53% (8)	NCCN DT	47% (7)
Νο	27% (4)	Internal Distress Assessment	7% (1)
Unknown	7% (1)	Distress Tool (not specified)	7% (1)
Other	13% (2)	Referral based on NP	13% (2)
		Insurance verification/authorization	13% (2)
		None	13% (2)



Advocates & Navigators

How is it implemented?	
Screening tool given at initial consult/admission	3
Screening given by nurse/other staff	1
Electronic	1
Estimate Cost of Care	1
Referral through EMR to FA	1
Financial Application sent/given to patient	2
FA meets with pt to discuss financial assistance programs	2
None or N/A	4

Satisfaction 1-5					
1	1				
2	1				
3	7				
4	2				
5	4				
Average Overall Satisfaction	3.46				



Advocates & Navigators

- Of the financial advocates that rated a 5
 - 2 used the NCCN distress thermometer
 - 2 were based off of reviewal of insurance to indicate financial need
- Majority of 3's use NCCN DT
- Financial advocate who rated 2 use insurance to identify patients
- Financial advocate who rated 1 indicated no standard process



Social Workers

Do you financial advocates at your cancer center screen for financial distress?		What tools do you use?	
Yes	26% (9)	NCCN DT	60% (21)
Νο	66% (23)	Internal Distress Assessment	6% (2)
Unknown	6% (2)	Distress Tool (PHQ-9, Triddiuum)	6% (2)
Other	2% (1)	Social Work assessment/psychosocial assessment then referred to FC	6% (2)
		Insurance verification/authorization or Financial Assistance application	6% (2)
		None	17% (6)

Social workers, Cont.

How is it implemented?	Satisfaction 1-5		
Screening tool given at initial	9	1	6
consult/admission		2	4
Screening tool given at initial and pivotal appointments (continued screening)	7	3	17
Screening given by nurse/other staff	3	4	8
	0	5	0
Electronic	1		0.77
SW meets with pt to discuss financial assistance programs. Makes appropriate referrals	3	Average Overall Satisfaction	2.77
FA meets with pt to discuss financial assistance programs	1		
Physician referral	1		
Insurance	1		
None or N/A	9		

ASSOCIATION OF COMMUNITY

CANCER CENTERS

FINANCIAL ADVOCACY NETWORK



Social Workers, Cont.

- Social Workers who rated 4
 - 5 identify SW, RN or FC assessment, or other tool
 - 3 identify NCCN DT
- Social Workers who rated 3
 - 11 identify NCCN DT
 - The remaining identify, SW assessment, other tool, or n/a (7)
- Social Workers who rated 2 all identify NCCN DT as the tool utilized (4)
- Social Workers who rated 1
 - 2 use NCCN DT
 - 4 have no specific tool or process



Take Away

- NCCN DT is the most widely used tool in screening for financial distress
- From the data received nearly half of the respondents indicated financial counselors do screen for distress
- Of the SW's who participated the majority (66%) reported FCs did not screen for distress
- No standard process for screening or implementing financial distress screening
- FC are more satisfied with FDS screening than their SW counterparts



Thank you!