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FINANCIAL
ADVOCACY
NETWORK

Financial Toxicity and Cancer: Proactive Screening, Assessment, and Treatment

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Association of Community Cancer Centers

Disclosures

- I have nothing to disclose.

Learning Objectives

- I. Recognize the rising impact of cancer-related financial hardship.
- II. Discuss the assessment of financial toxicity as a part of supportive care in the provision of comprehensive cancer care.
- III. Compare different screening methods that assess for financial distress among oncology patients.
- IV. Explore opportunities for social workers to proactively improve screening and referral processes to adequately support financial well-being among oncology patients.

Self Assessed Well-Being and Income

Figure A. Income-related word pairs among those
“doing okay” or “living comfortably”

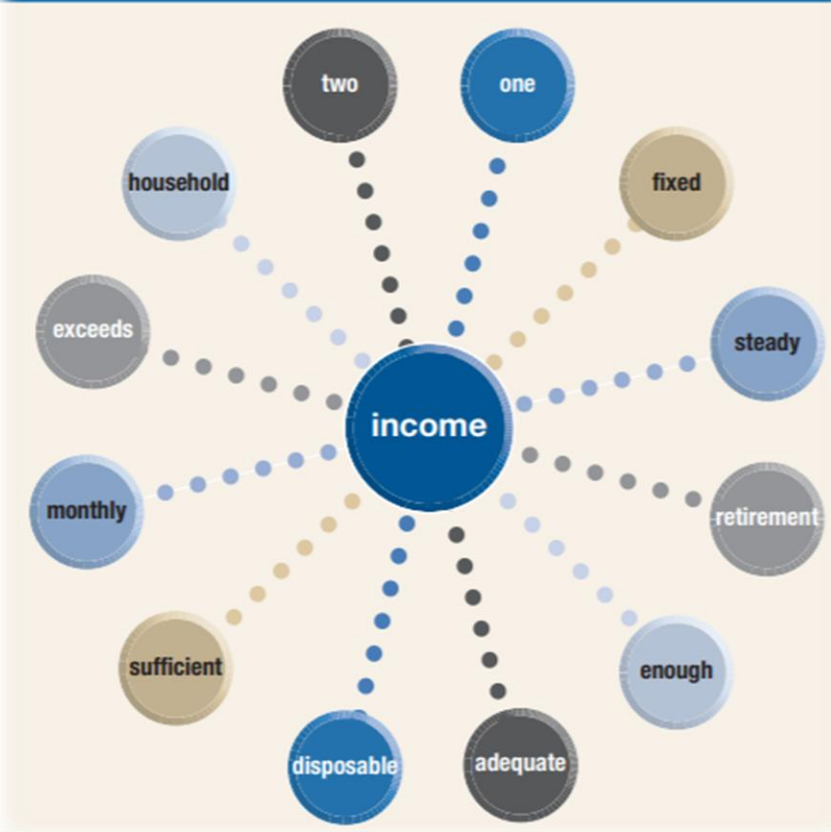
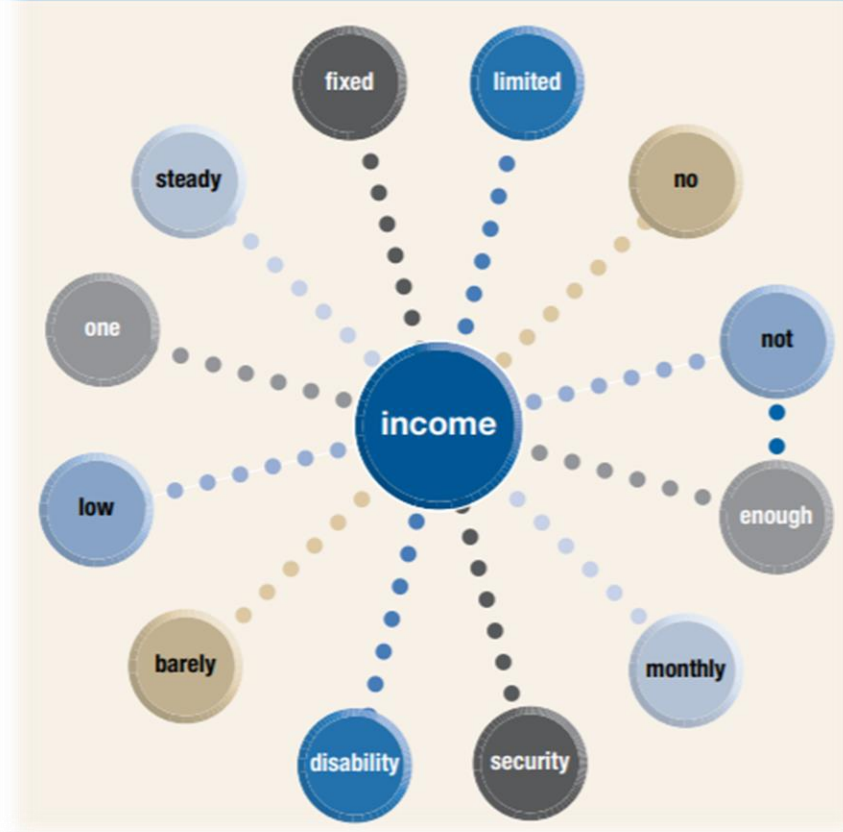


Figure B. Income-related word pairs among those
“just getting by” or “struggling to get by”



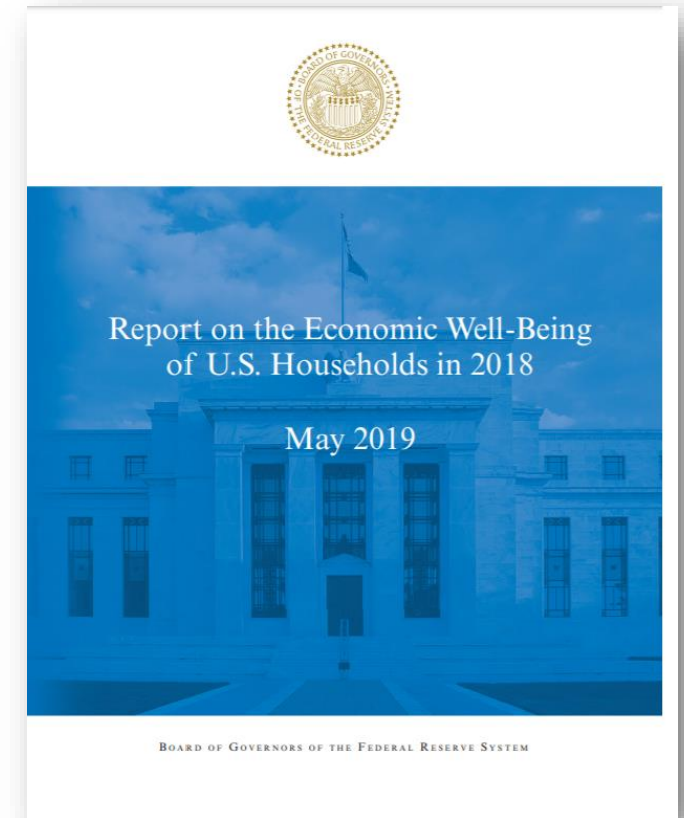
Report on the Economic Well-being of US Households in 2018. Federal Reserve. May 2019

Economic Well-Being of US Households

Dealing with unexpected expenses –

If faced with an unexpected expense of \$400,

- **61%** of adults say they would cover it with **cash, savings, or a credit card paid off at the next statement**
- **27%** would **borrow or sell** something to pay for the expense
- **12%** would **not be able to cover the expense at all**

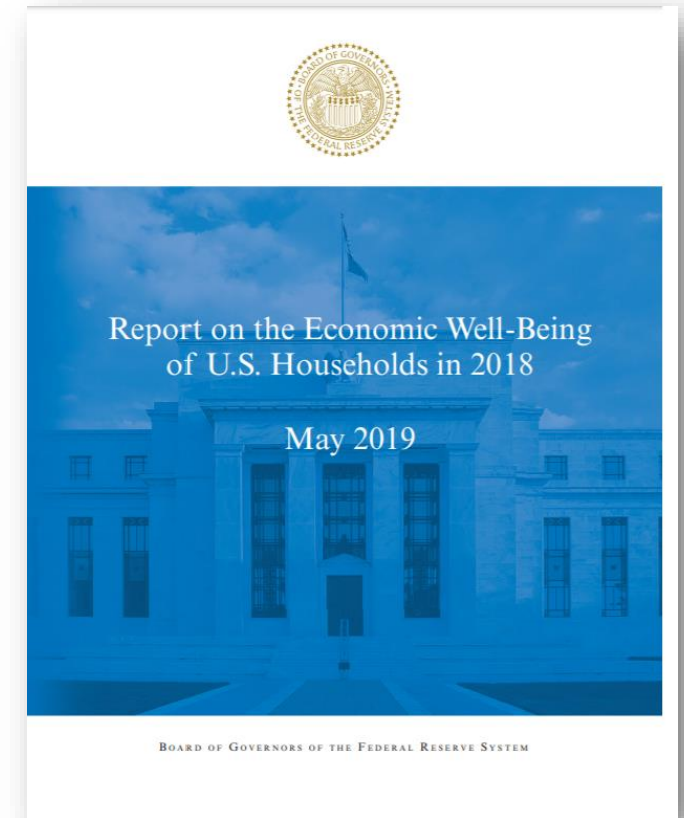


Report on the Economic Well-being of US Households in 2018. May 2019

Economic Well-Being of US Households

Dealing with unexpected expenses –

- **1/5th** of adults had **major, unexpected medical bills** to pay in the prior year.
 - Median expense between \$1,000 and \$4,999
 - 4 in 10 have unpaid debt from these bills
- **1/4th** of adults **skipped necessary medical care** in 2018 because they were unable to afford the cost.

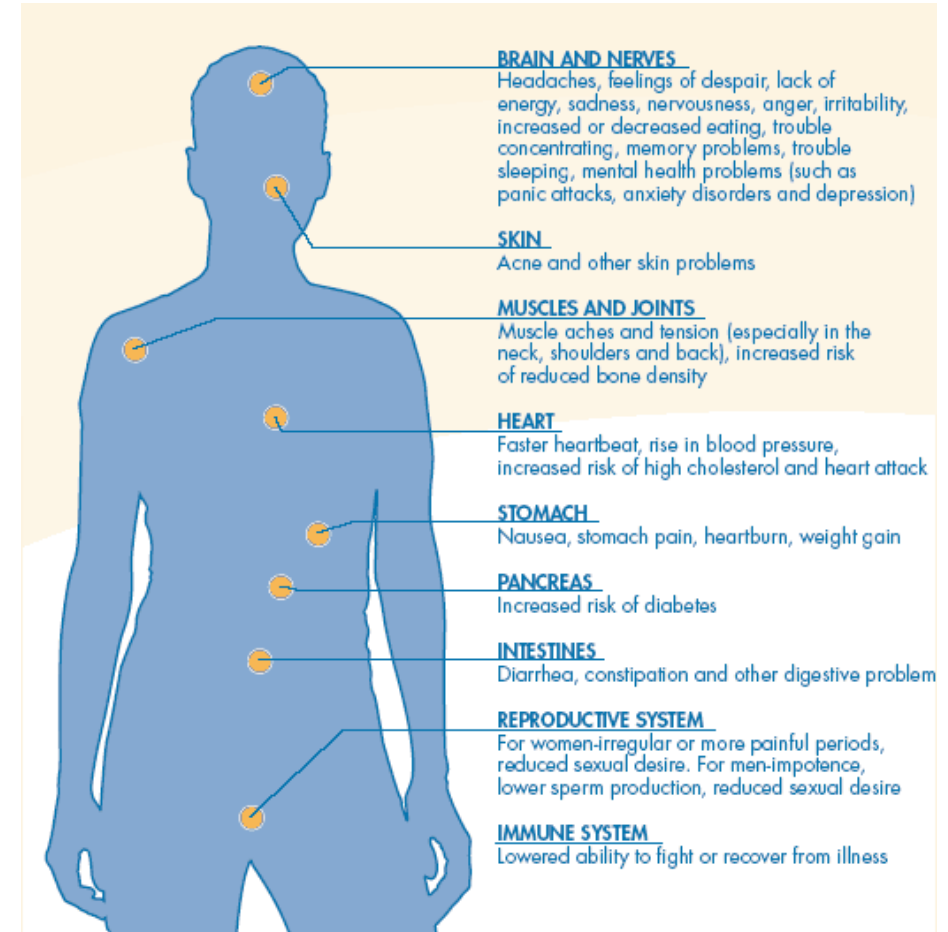


Report on the Economic Well-being of US Households in 2018. May 2019

Allostatic Load

Cumulative damage done to health and well-being under the burden of an unrelenting stressor in a critically important life domain.

Prolonged stress leads to wear and tear on the body.



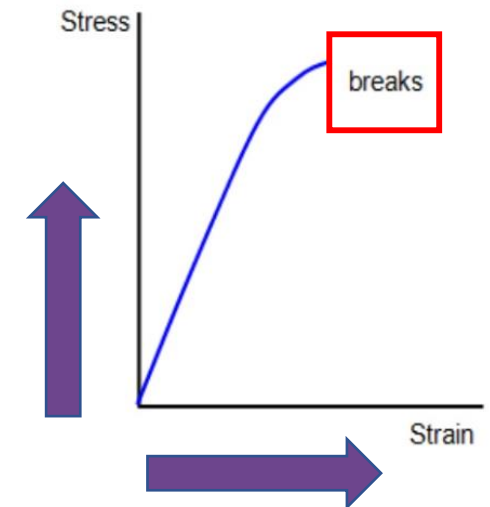
Kahn, Joan R., and Leonard I. Pearlin. "Financial strain over the life course and health among older adults." *Journal of health and social behavior* 47.1 (2006): 17-31.

Stress and Strain

<u>Stress</u>	<u>Strain</u>
Illness related financial burden	Perception of financial hardship

Physics lesson –

- Strain is relative change due to externally applied force
- Stress is external force associated with a strain
- Stress is proportional to strain (Hooke's law)



Financial Hardship

- I. Material
- II. Psychological

Yabroff KR, Dowling EC, Guy GP Jr, et al. *J Clin Oncol* 2016;34:259-267.

Material Financial Hardship

- I. Borrowing money or going in debt,
- II. Filing for bankruptcy,
- III. Being unable to cover one's own share of medical care costs,
- IV. Making other financial sacrifices because of cancer, its treatment, and lasting effects of treatment

Yabroff KR, Dowling EC, Guy GP Jr, et al. *J Clin Oncol* 2016;34:259-267.

Psychological Financial Hardship

I. Worrying about paying large medical bills

Yabroff KR, Dowling EC, Guy GP Jr, et al. *J Clin Oncol* 2016;34:259-267.

Medical Financial Hardship

- More than 100 million people in the U.S. experience medical financial hardship

Yabroff KR, et al. Prevalence and Correlates of Medical Financial Hardship in the USA. Journal of General Internal Medicine : 1 May 2019.

Medical Financial Hardship Domains

- 1. Material conditions - increased OOP expense**
 - 2. Psychological responses – distress**
 - 3. Coping behaviors – forgoing care**
- Maladaptive coping leads to poor health and non- health outcomes



Material Conditions

Example concepts within this domain:

- Out-of-pocket expenses
- Missed work
- Reduced/lost income
- Medical debt/bankruptcy

Psychological Response

Example concepts within this domain:

- Feeling of distress due to costs of cancer care
- Concern about wages/income meeting expenses related to costs of cancer care

Coping Behaviors

Example concepts within this domain:

- Took less or skipped medication
- Delayed or missed physician visit

Altice, Cheryl K., et al. "Financial hardships experienced by cancer survivors: a systematic review." *JNCI: Journal of the National Cancer Institute* 109.2 (2017).

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

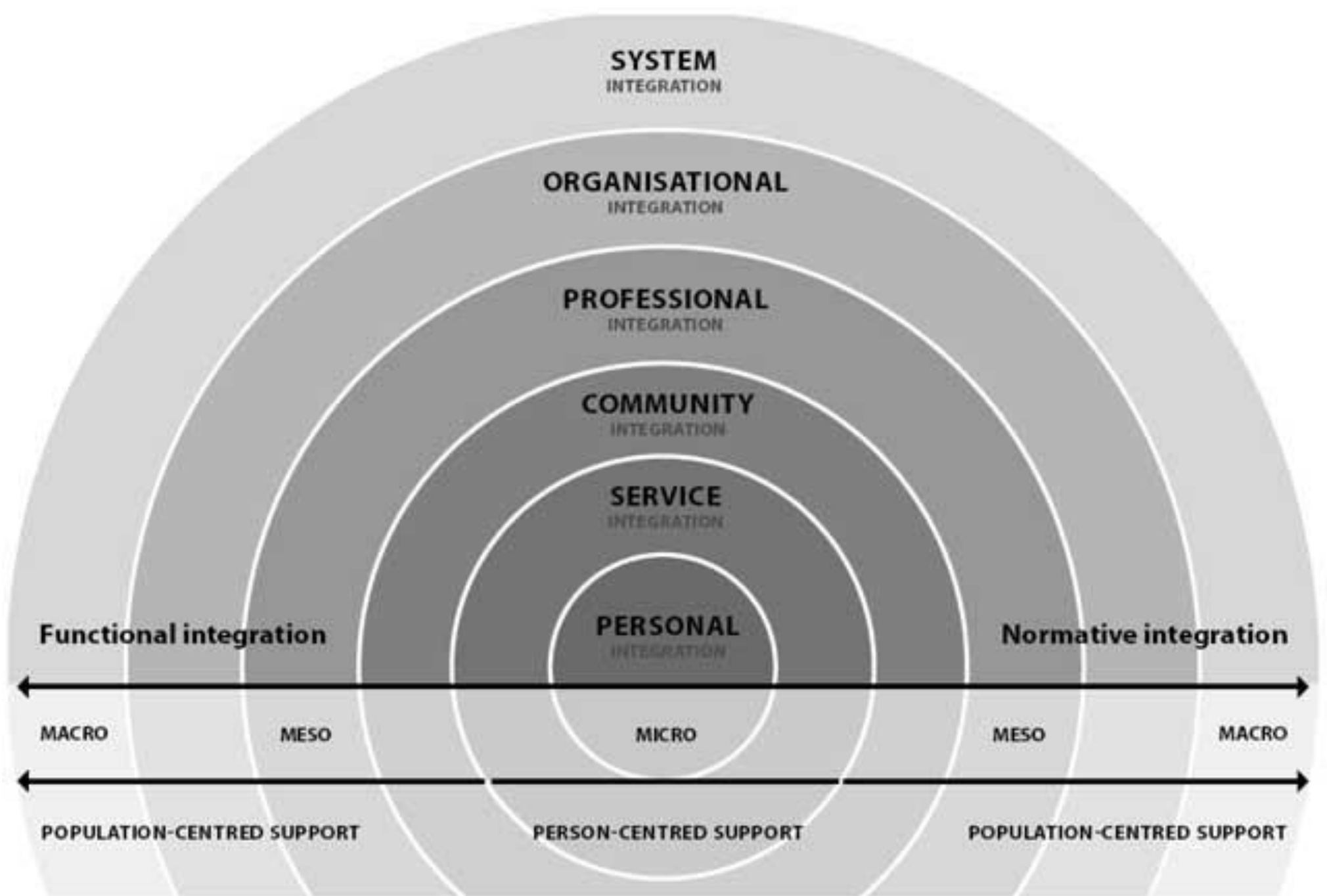
Financial Toxicity in the Care Continuum

Direct Medical Costs –
medication,
appointments, imaging

**Direct Nonmedical or
Ancillary Costs –**
childcare,
transportation, caregiving

Indirect Costs –
less time at work





Integrated care
model, Van Dijk
HM, Cramm JM,
Nieboer AP

Financial Burden of Cancer Treatment

Financial impact of patient's care overwhelms their available resources, and impacts their quality of life.

Leads to:

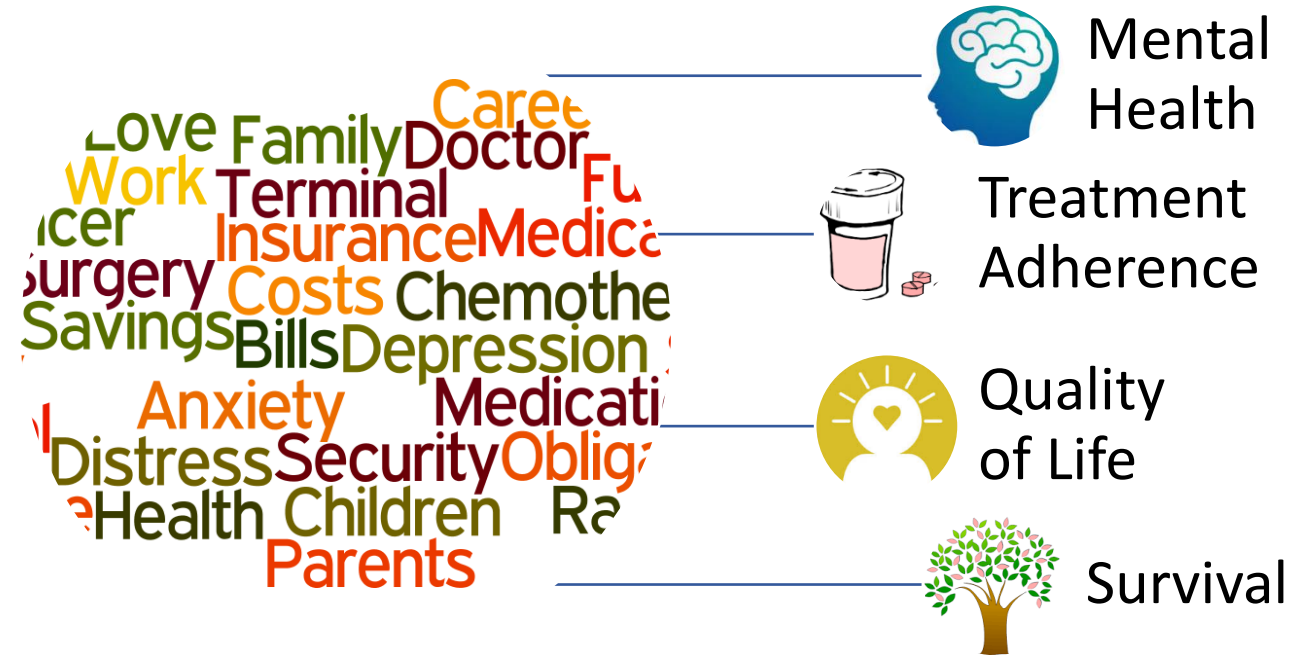
- Debt
- Bankruptcy
- Delayed/interrupted care
- Lifestyle/behavioral changes
- Shifting care location
- Chronic stress
 - individual, family, and community
- Diminished health related quality of life
- Higher mortality

Financial Distress: Psychosocial Impact

Financial
Distress



Emotional
Distress



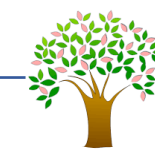
Mental
Health



Treatment
Adherence



Quality
of Life



Survival

Financial Toxicity

Out-of-pocket expenses related to treatment are akin to physical toxicity, in that costs can diminish quality of life and impede delivery of the highest quality care.

Existing data have identified both objective financial burden and subjective financial distress as key components of financial toxicity.

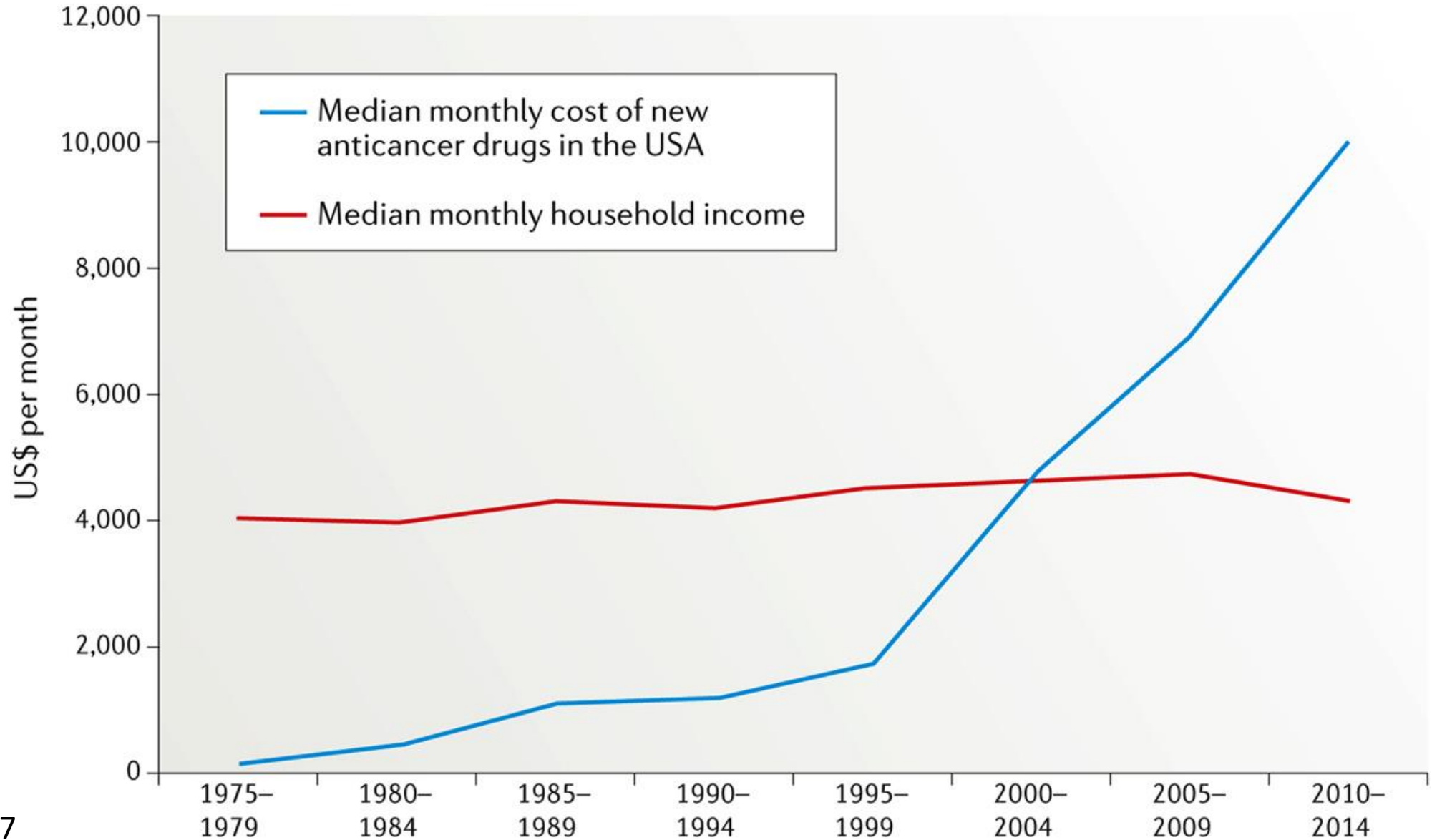
Zafar and Abernathy **Financial Toxicity, Part I: A New Name for a Growing Problem** *Oncology*
2013 Feb; 27(2): 80–149.

Why Financial Toxicity is More Prevalent

- Increase in costly treatments
- Lack of parity coverage
- Inadequate health insurance coverage
 - Underinsurance
- High deductible/copay plans
- Rising out of pocket costs
- Barriers to accessing patient assistance and financial support (eligibility criteria)



Median monthly launch price of a new anticancer drug, compared with median monthly household income from 1975–2014



Prasad et al., 2017

Health Insurance

Cancer treatment drug prices

- Immunotherapies
- Targeted therapies
- IV vs. oral chemotherapy prices

Health Insurance

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

Patient Risk Factors

- **Health/Clinical Characteristics**
 - Advanced/recurrent/multiple cancer(s)
 - Co-morbidities – diabetes, hypertension, lung disease, poor self reported health
 - Treatment with chemotherapy and/or radiation
- **Socio-demographic Variables**
 - Female gender
 - Younger age
 - Lower income
 - Race
- **Access to Health Care Services**
 - 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

High Financial Burden:



Quality of life
among patients with
active cancer and
survivors

adjusted beta 0.06 EQ-5D unit per financial burden category; $p < .001$

Zafar et al, JOP 2014

Prevalence

- **62%** reported being in debt due to cancer treatment
- **64%** worried about bills
- **33%** have gone into debt
 - 30% incurred 10-25K, 12% 25-50K, and 13% of over 50K Banegas et al. 2016
- Of households that recently experienced a cancer death, **1/3** of the households had exhausted their savings **and 22%** reported that cancer treatment was a major financial burden

- Effects don't end when treatment does
- Not including loss of income due to treatment

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**

Clinical Care

What does financial toxicity look like in the clinic?

- How ***aware*** are oncology social workers of the patient's financial situation?
- How ***comfortable*** are oncology social workers in discussing financial issues?
- How ***equipped*** are oncology social workers in assessing financial burden?

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**

Buying less clothing

Financial distress

Buying less food

Working longer hours

Spread out chemotherapy appointments

Cutting out vacations

Missed appointments

Bankruptcy

Using credit

Declining tests

Spending savings

Taking fewer medications

Using other people's medications

Borrowing from friends or family

Selling property

Replaced prescriptions with over the counter medications

Non-adherence

Delaying care

Current Interventions

Referral to:

- Social work
- Patient navigator, advocate, or counselor

Financial navigation, advocacy, and counseling:

- Patient assistance programs
- Local resources

Are we doing
enough to
screen?

The Role of Social Workers in Financial Advocacy/Navigation

- The financial burden of cancer tx must be addressed in the larger context of a patient's personal circumstances and experiences.
- Many sources of financial burden that accompany cancer care and treatment must proactively be addressed to eliminate risk of cancer-related financial toxicity (CRFT).
- Adequate intervention can mitigate impact of financial burden.
- *How do we assess for financial distress?*

Toxicity as a “Scale”

- May change over time
- Can accumulate

“Toxicity Grading Criteria”

- **Grade 1** - lifestyle modification, defined as deferral of large purchases or reduced spending on vacation or leisure activities because of medical expenditures and/or use of assistance programs to meet the cost of care.
- **Grade 2** - temporary employment loss, selling stocks or using investments to pay for care, and/or use of savings or retirement funds for medical treatment and its costs.
- **Grade 3** - mortgaging or refinancing the home, permanent job loss, and/or inability to pay for necessities such as food and utilities.
- **Grade 4** - the need to sell the home, bankruptcy declaration, stopping treatment, and/or consideration of suicide because of the financial burden of care.

Khera, Nandita, Jimmie C. Holland, and Joan M. Griffin. "Setting the stage for universal financial distress screening in routine cancer care." *Cancer* 123.21 (2017): 4092-4096.

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
Collection of Indirect and Nonmedical Direct 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 Toxicity (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

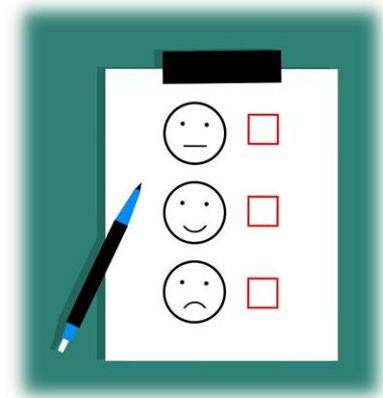
Exploring Methods to Assess Financial Distress Screening Methods

Survey Methods

- 7 question survey distributed electronically via ACCC newsletters, social media, forum, and Financial Advocacy Network

Findings: Respondents (N=118)

- ✓ No standardized method of Financial Distress Screening or intervention
- ✓ Social workers play an important part in recognizing financial hardship and providing support to decrease the burden
 - There are a variety of ways to do this in the oncology setting



Financial Distress Screening Methods Among Social Workers

- Screening tool given at initial consult/admission
- Screening tool given at initial and pivotal appointments (continued screening)
- Screening given by nurse/other staff
- Electronic – self reported
- SW meets with pt to discuss financial assistance programs & makes appropriate referrals
- FA meets with pt to discuss financial assistance programs
- Physician referral
- Insurance



Financial Distress Screening Methods

- Customize “task sets” EMR to trigger referrals
- Distress screening that assesses “Fears of Cost of Care”
- Customized screening tool used by social workers given at different points of care
- Treatment related triggers to prompt referral
- Oncology support services screening

Ongoing Assessment

Level of distress can change as treatment progresses -

- How oncology social workers maintain ongoing assessment of distress?
- How do we manage financial distress across the care continuum?
- What is the best practice?

Social Worker

Best practice?

- Collaborating with the care team
- Proactive assessment and intervention
- Ongoing assessment
- Resource knowledge

So you screened a patient, now what do you do?

Upon learning about the patient's circumstance, you recognize they are at risk of financial hardship – what do you do next?

- Refer to financial counselor, navigator, or advocate
- Have a conversation with the provider
- Flag their chart
- Give them a call to set up time to discuss
- Triage

We know enough upfront about the patient, their diagnosis, and circumstance to recognize risk of financial hardship. The intervention must take place at the start of care.

Financial Resources Available to Oncology Patients

Table 1. Financial Resources Available to Oncology Patients

Expense	Resources
Prescription drug co-pays	Income-based. Social work is the gatekeeper. Pharmaceutical companies provide support (mostly to uninsured patients); additional programs available: Leukemia/Lymphoma (LL), Patient Advocacy (PAF).
Visit co-pays	Very limited: LL, PAF, Cancer Care (CC), Co-Pay Relief Foundation (< \$1,000). Physicians may also choose to override charges.
Insurance premium payments	LL, Healthwell, Patient Assistance Organization.
Travel expenses (including parking, lodging, fuel, and meal costs)	American Cancer Society (\$50 gas card, Road to Recovery), CC (multiple myeloma only). Medicaid reimburses lodging and mileage (not covered by Medicare).
Time off work compensation	Short- or long-term disability insurance received prior to cancer.
Special dietary expenses	Hospital dietitians are free. BOOST indigent programs, food stamps, National Marrow Program, Caring Community Foundation.
Alternative therapy expenses	Hospital social work and patient support services are free of charge. Blue Cross discount on acupuncture.
Medical equipment costs	Private insurance and Medicaid covers well (eg, Medicaid pays 100%; Medicare, 80%).
Nonprescription drug costs	One-time, limited resource in social work department (up to \$50) if it helps to avoid hospitalization.
Private duty nursing care	Only covered under private pay long-term insurance.

Smith, Sophia K., Jonathan Nicolla, and S. Yousuf Zafar. "Bridging the gap between financial distress and available resources for patients with cancer: A qualitative study." *Journal of oncology practice* 10.5 (2014): e368-e372.

Resources Snapshot

- **Patient Support:**

- Triage Cancer
- Patient Advocate Foundation (PAF)
- Leukemia & Lymphoma Society (LLS)
- Susan G. Komen
- Pink Fund
- CancerCare
- HealthWell Foundation
- Patient Access Network (PAN) Foundation
- Family Reach
- Cancer Support Community (CSC)
- Needy Meds

- **Health Care Professional Training**

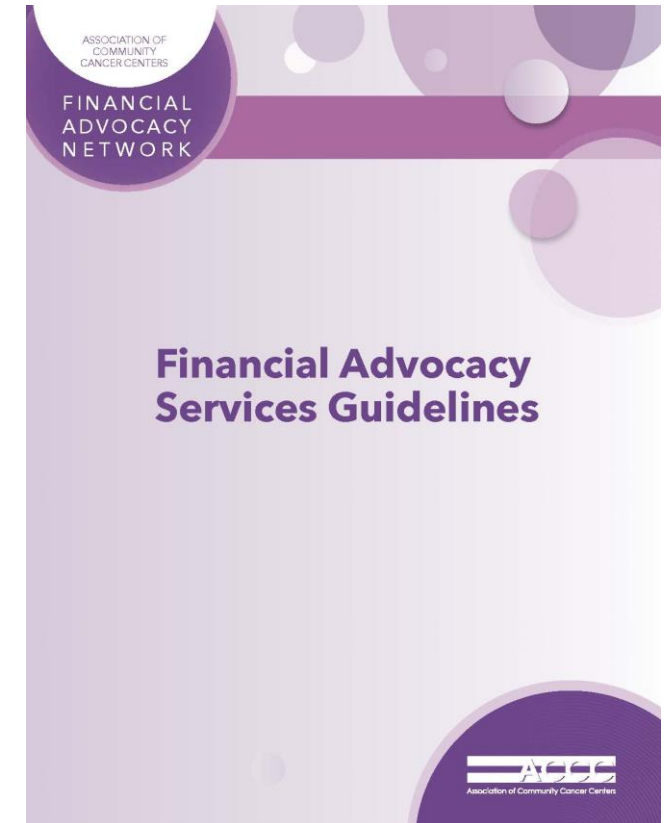
- Association of Community Cancer Centers
- GW Cancer Center's Institute for Patient-Centered Initiatives and Health Equity (formerly, GW Cancer Institute)

*List is not
comprehensive

Financial Advocacy Services

The goals of financial advocacy services are to:

- I. Proactively identify and evaluate how to maximize the patient's health insurance benefits
- II. Proactively reduce economic barriers to care by having working knowledge of available patient assistance programs, financial advocacy tools, and resources
- III. Accurately explain insurance coverage and assistance options and skillfully communicate with patients and their caregivers focusing on issues of cost of care, patient assistance support, and additional resources
- IV. Manage, track, and report on all financial advocacy and patient access services interactions
- V. Ensure that providers and cancer program staff are aware of ongoing policy requirements from payers for coverage of services
- VI. Help mitigate institutional financial toxicity



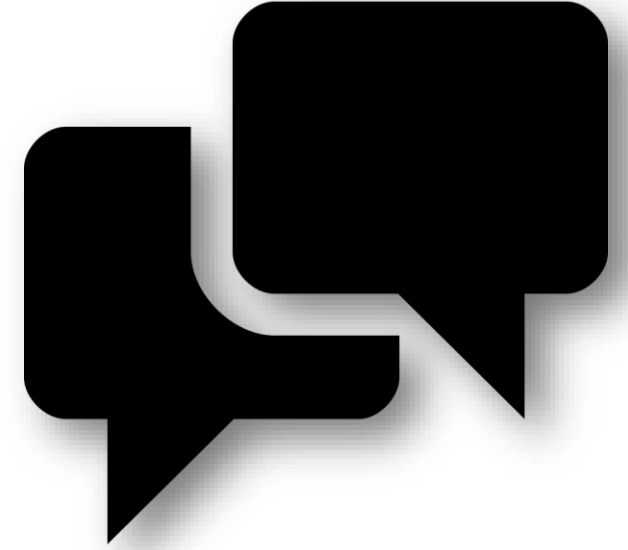
Ask for a copy!

ACCC Financial Advocacy Network

ACCC recommends that every cancer program or practice offer financial advocacy services and identify a central system and/or dedicated staff member to coordinate and liaise with the oncology treatment team to ensure streamlined communication and access to needed care for the patient.

acc-cancer.org/fan

Q&A



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Thank
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Thank you!

For more information about ACCC's Financial
Advocacy Network,

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