The Diagnosis of Cancer and Financial Toxicity

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Today's discussion

- What is financial toxicity?
- Research
- Case studies
- What can/should you do?

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Financial Toxicity: What is it?

- Concept first hinted at in 2011
  - Researchers from Fred Hutchinson Cancer Research Center in Washington state presented a study that noted "strong evidence of a link between cancer diagnosis and increased risk for personal bankruptcy" which they believed "represents an extreme manifestation of what is probably a larger picture of economic hardship for cancer patients"

    (Ramsey et al. Health Affairs, June 2013)

- Two years later, researchers from Duke proposed a term to describe a new adverse event in cancer treatment
  - "Out-of-pocket expenses might have such an impact on the cancer experience as to warrant a new term: 'financial toxicity.' Out-of-pocket expenses related to treatment are akin to physical toxicity, in that costs can diminish quality of life."

    (Zafar SY, Abernethy AP. Financial Toxicity, Part 1: a new name for a growing problem. Oncology. 2013 Feb;27(2):80-1, 149.)

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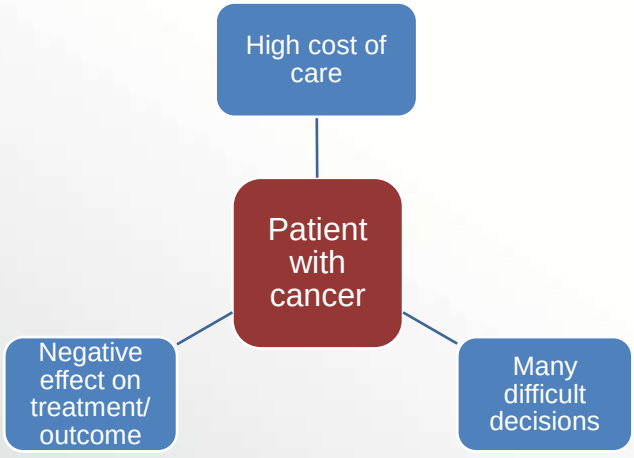
What does it mean?



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Financial toxicity facts

- The CDC, in a survey of more than 10,000 patients, found that roughly one in three families reported significant financial burdens as a consequence of medical care.
- The degree to which cancer caused financial problems was the strongest independent predictor of quality of life when compared to various other factors including age, race, education, insurance status, and family income.
- 81% of academic oncologists agreed that out-of-pocket costs had the potential to influence treatment recommendations, but only 30% reported changing treatment recommendations because of financial considerations.
- Patients reporting “a lot” of financial distress were more likely to be non-white, female, and younger than 61 years old. These patients were also more likely to have less than a four-year college education and a total household income lower than $35,000 per year.

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https://costofcancercare.uchicago.edu/page/financial-toxicity-facts

Financial stresses on three fronts

1. Out-of-pocket expenditures for medical care – co-pays, coinsurance, deductibles, premiums – and related non-medical expenses (e.g. costs of transportation and parking).
    - One estimate is that ~5% of total medical expense per patient is paid directly out-of-pocket by patients
    - Another estimate: out-of-pockets expenses for insured patients are at least $5,000/year
2. Loss of earnings for the affected individual - and sometimes loss of access to insurance.
    - Individual earnings for cancer survivors tend to fall during the 5-year period after diagnosis.
3. Potential loss of household income of other family members due to caregiving needs.

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Not just an economic concern

- Health care-related financial distress is not just an economic concern but has also been associated with worse quality of life, lower adherence and excess mortality.

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Multi-factorial issue

- Complex (and sometimes dysfunctional) health care system
- Rapidly rising drug costs
- High hospital costs
- Frequently weak insurance coverage
- Uneven and inadequate sick leave policies with many (most?) employers
- Generally poor financial state of many families in the US

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Insured patients and financial distress

Zafar, Peppercorn et al, 2013 pilot study assessing out-of-pocket expenses and the insured cancer patient's experience.

- 42% of individuals applying for co-pay assistance reported a significant or catastrophic subjective financial burden
- 68% cut back on leisure activities
- 46% reduced spending on food and clothing
- 46% used savings to defray out-of-pocket expenses
- 20% took less than the prescribed amount of medication
- 19% partially filled prescriptions
- 24% avoided filling prescriptions altogether

Conclusion: **having health insurance does NOT eliminate financial distress among cancer patients.**

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Case study: Janet

- 67 year old insured woman with metastatic breast cancer

"We don't travel, we don't do anything now because it's a $100,000 illness. And it sucks… What are you going to do? Caught between a rock and a hard spot."

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Case study: D.T.

- 71 year old married male, stage IV colon cancer
- Monthly household gross income is $1,590; he has $10,000 in assets
- Medicare Parts A, B and D; no secondary insurance
- Total treatment costs for one year (surgery, radiation, chemotherapy) estimated to be $350,000; patient responsibility estimated to be approximately $40,000

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Mike and his mom

- 5 year old Mike diagnosed with rare form of cancer
- Mom worried about his chances of survival and side effects of treatment…. didn't anticipate the financial toll his illness would take on the family
- Mom had to quit her job; family income fell to half, faced with mounting medical bills
- Months into treatment….
  - family's savings were obliterated
  - fell behind on mortgage and utility payment
  - Neighbors held a fundraising drive but it was only a temporary fix.

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Tools

- ASCO's *Journal of Oncology Practice*
  - www.asco.pubs.org/journal/jop
- Almost 100 articles in search for "financial toxicity"
  - Assessing financial toxicity
  - Financial toxicity and counseling
  - Financial toxicity…. Potential areas of intervention
  - Development of a financial toxicity patient-reported outcomes instrument
  - Financial toxicity and health-related quality of life
  - Addressing risk of financial toxicity in an ambulatory oncology practice

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Tools

- Association of Community Cancer Centers Financial Advocacy Boot Camp
  - Free eLearning Program from the ACCC Financial Advocacy Network (FAN)
- Comprehensive online program – 5 domain areas, 14 learning modules
  - Financial advocacy fundamentals
  - Enhancing communication
  - Improving insurance coverage
  - Maximizing external assistance
  - Developing and improving financial advocacy programs and services
- Great resources available
  - www.accc-cancer.org/resources/financialadvocacy-bootcamp.asp

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Tools

- Pharmaceutical company programs
- Other patient assistance programs & resources
- Patient assistance and reimbursement assistance programs by drug or product

https://www.accc-cancer.org/publications/PatientAssistanceGuide.asp

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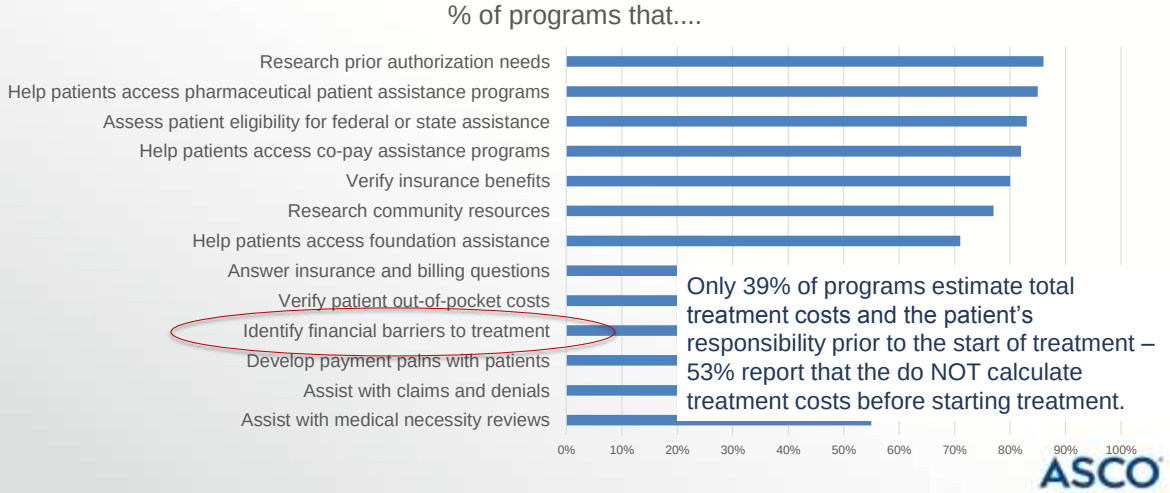
The role of the financial counselor/advocate



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Source: ACCC's 2014 Trends in Cancer Programs survey

Oncology Care Model

- OCM putting in place 13 components of the Institute of Medicine's Care Management Plan requirements, many/most of which will influence the patient's sense of financial wellbeing.
  - Informing the patient of his/her diagnosis, prognosis, length of treatment, treatment benefits/harms – and providing an estimate of the total and out-of-pocket costs of treatment – all heavily impact the patients financial sense of security or wellbeing.
- BUT you must have well trained financial advocates to address these complex circumstances. Physicians and financial advocates need to be better prepared to deal with the many ramifications of financial toxicity.

Transforming Practices Through the Oncology Care Model: Financial Toxicity and Counseling. *Journal of Oncology Practice*, August 2017

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Financial Counselor

Financial Coordinator

Financial Advocate

Financial Navigator

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Lehigh Valley Health Network (3 hospital system)

- Protect Revenue
  - Authorizations and medical necessity
  - IV drug replacement
  - Advanced beneficiary notice
  - Denials and appeals
  - Benefit verification and out-of-pocket estimates
- Assist uninsured and underinsured patients
  - Drug assistance programs
  - Co-pay relief programs
  - Community programs/foundations
  - Access internal financial assistance program
  - Refer to insurance selection counselor, social worker, navigator
  - Negotiate with external programs to accept hospital financial assistance program and offer discount

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Lehigh Valley

- 2 roles:
  - Financial Coordinator in cancer program
  - Financial Counselor in hospital
- Patients are connected to Financial Coordinators
  - At new patient consultation visits (info packet)
  - Staff referrals – all staff are trained and empowered to make referrals
  - Hard-wired into multidisciplinary clinics – all MDC patients are reviewed
  - Distress screening tool throughout patients clinical journey
  - Continuous review of infusion schedule screening for high-risk patients and proactively reaching out
- Financial coordinators work closely with all hospital departments, cancer program staff, and referring physician offices
  - ***As much a member of the patient's care team as those who provide direct patient care***

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Measure results

METRIC	Dollar type	Other metrics
Infused drug replacements	LVNH cost in dollars	# of accounts
Oral, self-administered drug assistance	Patient cost in dollars	# of patients
Pre-authorization obtained	Total account charges	# of accounts
Appeal of denied claims	Total account charges	# of accounts (win/loss)
Financial assistance program applications		# of patients
Social work referrals		# of patients

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Lacks Cancer Center

- Pilot program in 2009 to provide financial navigation services to hospital's oncology population (0.5 FTE)
- Goals:
  - To improve access to care by reducing the financial barriers experienced by oncology patients
  - To reduce charity and bad debt by $70,000 within the pilot programs 6-month time period

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Lacks Cancer Center

- Pilot program targeted patients who were:
  - In health insurance plans with out-of-pocket responsibilities > $5,000/year
  - Medicare Part D patients in the coverage gap due to high cost oral oncology medications
  - Medicaid patients with spend down
  - Patients with Medicare A/B only
  - Patients without health insurance coverage
  - COBRA recipients who could not afford the COBRA premiums
  - Patients receiving off-label treatments
  - Any patients expressing financial distress due to cost of care
- Navigator identified patients – also educated social work, case management, nursing to refer patients to program

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Lacks Cancer Center

- Achieved $70,000 goal of savings to hospital in first two months
- By end of month five, reached $265,000 in hospital savings and decreased out-of-pocket expenses for patients by $700,000
- 78 patients navigated during pilot
- Hospital hired 1 FTE for financial navigator position

	# patients	Reduced out-of-pocket	Hospital savings
Year 2	218	$2,600,000	> $1,000,000
Year 3 (added 2nd .8 FTE)	168	$4,000,000	$2,500,000
Year 4	211	$5,000,000	$3,700,000

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Lacks Cancer Center

- Program now targets:
  - Uninsured
  - Underinsured (as self-identified by patients)
  - Patients on high-dollar orals who need assistance with co-pays
  - COBRA recipients
  - Medicaid with spend-down
  - Medicare A/B only
  - Patients entering Medicare system
  - Every patient with advanced-stage disease

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Lessons learned

- Financial toxicity and patient satisfaction
  - Duke study: *Understanding the connection between financial burden and patient satisfaction may help identify the extent to which modification of burden can improve this important metric of quality patient-centered care and improve the downstream results of an enhanced patient experience.*
  - Lack Cancer Center:
    - Improved patient satisfaction scores
    - Reduced patient distress

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Lessons learned

- The right person for the job
  - Singular focus on the task
  - Comprehensive training
  - One-on-one education
  - Peer support – solutions and programs constantly change and evolve
  - Support from different departments – billing, pharmacy, social services
- Multiple skill sets
  - Clinical, financial, mental health skills
  - Must be able to quickly build trust with patients and families
  - Must be prepared to have treatment planning conversations with order physicians
  - Must have skills to have difficult conversations with patients

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Green Bay Oncology

- Program began 10 years ago with 1 financial counselor working with 7 physicians and 6 clincic locations
  - Before need to pre-auth every chemo drug
  - Program focused on working with pharma companies to obtain free drug
- Today, team of 6 counselors assisting 9 medical oncologists, 3 pediatric oncologists, 3 radiation oncologists, 1 gyn oncologist, 8 nurse practitioners, 3 physician assistants (16 physicians, 11 APPs) across 6 cancer center locations
  - Financial counselors follow patients from start to completion of treatment journey; an integral part of the patient experience
  - Liaison between the patient, the provider and other clinic departments, as well as the patients insurance carrier

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Green Bay Oncology

- KEY: providers who understand the important message concerning financial toxicity and its potential to impact patient outcomes
  - "…. But by neglecting financial factors in cancer treatment, we've exposed our patients to terrible harm."
- Financial counseling is not only a service to assist the patients; it also guarantees the clinic is going to get paid.

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Green Bay Oncology - Process

- Before patient's first appointment, verify insurance benefits and ensure patient is in-network
- When treatment is prescribed,
  - Verify that treatment is indicated for diagnosis (NCCN compendium)
  - Does insurance require prior authorization? Follow patient through course of treatment to ensure authorization does not lapse
- Meet with patients before they start treatment; discuss cost and options to help alleviate financial burdens of cancer treatment

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Green Bay Oncology - Process

- For oral therapy, financial counselors initiate first prescription fill with specialty pharmacy to verify insurance approval and make sure medication is affordable for patient; educate patient about specialty pharmacy process; obtain authorization if needed
- If treatment is off-label, obtain approval from insurance company.
  - If denied, go to pharma company and apply for patient assistance; all forms are completed and submitted by financial counselor
- Present foundation and co-pay assistance programs as needed
- Work closely with social workers and nurse navigators to ensure patients are cared for both inside and outside of clinic
- Direct point of contact for patient billing concerns

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Financial Impact

- Patients
  - 2015 – saved patients $573,000 on oral chemotherapy co-pays
  - 2015 – IV and oral chemotherapy assistance…saved patients over $1,000,000
- Practice
  - Paid to clinic from foundation assistance and pharma co-pay cards

2011	$167,807
2012	$168,863
2013	$281,512
2014	$340,604
2015	$436,483

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Four opportunities

1. Increase the practice/institution commitment to the role of financial advocacy.
   - Invest in the role.
   - Hire and train appropriately.
2. Improve processes to identify patients in need.
   - Financial advocacy services should be located in the oncology practice/department.
   - Provide financial navigation services before incurring medical debt for the patient.
3. Increase physician engagement in understanding the dynamics of financial toxicity.
   - Oncologists should be prepared to have discussions with the financial navigation team and patients as needed.
4. Establish certification and education requirements for the financial advocate role.
   - Our complex health system needs well trained, educated financial advocates to guide our patients.

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Transforming Practices Through the Oncology Care Model: Financial Toxicity and Counseling. *Journal of Oncology Practice*, August 2017

Thank you for caring for people with cancer

- What were your goals for today?
- Any questions or comments?

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