Assessing Financial Toxicity for Patient Benefit

A Patient Perspective

Mary (Dicey) Jackson Scroggins Pinkie Hugs, LLC In My Sister's Care



To Focus our Efforts...

A Tribute to Patients and Survivors

In remission, in recurrence, in active treatment, and in every conceivable state of personal discomfort and challenge, Cancer Survivors

- Advocate for themselves, their families, their friends, their neighbors, and strangers unable to advocate for themselves
- Educate health professionals and the general public about cancer prevention, access to care, and treatment and about the everyday personal side of life with and after cancer
- Participate in scientific review panels and clinical trials
- Walk, run, and wheel in chairs in support of research funding and legislative action
- Put human faces and real lives on the disease
- Advocate and fight for Equal Access, Quality Care, and the Best Possible Quality of Life for Everyone
- Choose Hope even when despair seems so tempting and requires so little
- Understand that Every Second, Every New Dawn is a Gift, a Blessing undisguised

I stand with you, yet in awe of you, and I stand in your debt.

Just My Perspective on

Why we must and How we can learn more about
Financial Toxicity—
to benefit patients, families, the health care system

Clearly,

Patients, Families, Communities shouldn't

- Suffer in silence or in shame
- Have to choose between medication/care and family health/well-being
- Compromise their survival or survivorship
- Fear the results of being "exposed"

Financial Toxicity

- Is inadequately defined/explained
- Has shallow coverage
- Is avoided, in part, because of embarrassment/discomfort factor (two way)
- Can exacerbate health disparities
- Is not fully understood or supported as a legitimate avenue of research or inquiry
- Lacks a sufficient research evidence base

And the development of interventions will continue to lag behind need absent greater understanding of/attention to its impact.

Assumptions—Some True

- Patients and families are **reluctant to discuss** financial matters.
- Health professionals are reluctant and unprepared to discuss financial matters.
- Low-income individuals and "vulnerable" populations are most unlikely to want to discuss financial matters.
- Financial Toxicity within vulnerable populations is **not health- or cancer-linked** (i.e., a pre-existing condition or even their fault).
- Patients, families, and the general public understand what "financial toxicity" is or encompasses.

Establishing an Assumption-Free Zone*

- Survey everyone and ask everyone the same questions.
- As with other surveys, explain the option of not answering particular questions (tread carefully).
- **Do not assume** who will be open to questions/ discussion.
- Allow individuals to meander to the responses or conversely to be excessively expansive.

^{*...}that is also stigma free

Establishing an Assumption-Free Zone (continued)

- Prejudgment (no matter the reason) results in uneven participation and less-generalizable information.
- Assumptions about particular populations relative to various demographics contribute to unequal information gathering and potentially disparities in application, care, and outcomes.

Understand that...

- Patients and families may have certain concerns related to post-survey care. Anticipate and be prepared to discuss/address.
- This is an opportunity to enhance transparency and to increase health literacy, which benefits everyone in the health care system.
- Cultural competence, including but not limited to language issues, is essential.

A Few Basic Considerations

- How we approach the questions—first things first
- Who asks the questions/gathers the information
- Mutual levels of discomfort/embarrassment
- The need for training
- Timing, time, and administration
- Rationale for every question
- Assurance on who, what, when, where, why, how

A Few Basic Considerations (continued)

- An approved script delivered naturally (and a checklist)
- Language and administration
- Location and privacy (on contact and afterward)

The value of the outcomes

And Also Consider

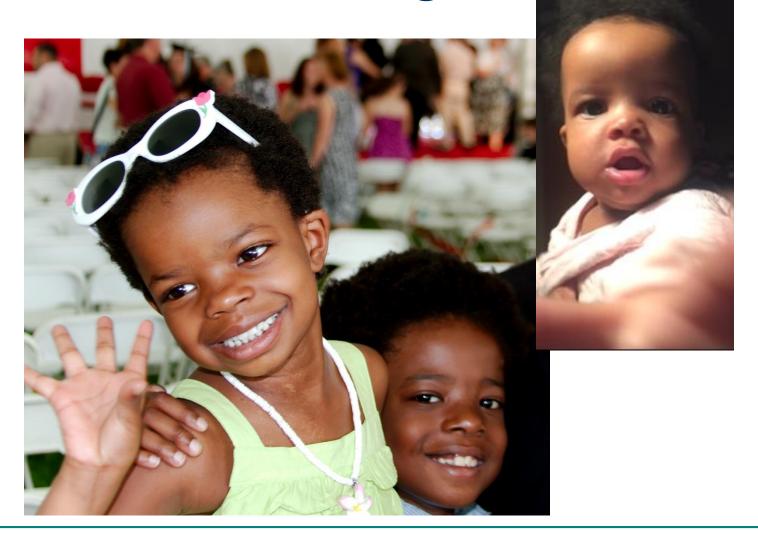
- Clarifying what financial toxicity covers—not just, for example, co-pays—repeatedly as needed
- Surveying at a number of points both to establish baseline and to improve likelihood of responses
- Engaging patient/advocacy communities in all phases, including but not limited to questionnaire development—wording and content

An Opportunity and an Obligation to

- Establish guidelines for researching financial toxicity
- Add to the research and evidence base
- Assess patient needs and educate and learn from patients and the community
- Engage the patient/survivor and advocacy communities in developing and validating research tools/questions and interpretation
- Reduce/eliminate suffering in silence or in shame
- Enhance patient care and outcomes

Greetings from Three Little

Advocates-in-Training



Thank you!