
Assessing Financial Toxicity for Patient Benefit

A Patient Perspective

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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”
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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.

*We have the Opportunity to add to research and literature
and to develop Best Practices.*

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.**

None can be excuses for not aggressively pursuing answers and interventions.

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.
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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.
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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
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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
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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**
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Greetings from Three Little
Advocates-in-Training



Thank you!
