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Addressing the hidden toxicities of cancer: a call to action for clinicians, researchers and clinical trialists

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The impact of adverse events on patient adherence to cancer treatments is well documented. Most relationships of interest to the clinician focus on biochemical interactions between the patient, treatment and tumour. Yet these events and outcomes are a subset of cancer and cancer treatment toxicity. Patients, caregivers, family and friends navigate treacherous waters behind the scenes to overcome hidden toxicities.

Failure to uncover and treat hidden toxicities—direct and indirect results of treatment—can result in delayed and aborted treatments with suboptimal results and propagation of inequities. Because they also tend to be understudied, substantial opportunities exist for clinicians and researchers to improve patient outcomes. By exposing hidden toxicities and subsequently intervening, patients, family and friends will see positive benefits and disparities will be reduced.

Awareness of hidden toxicities is a prerequisite to intervention to improve outcomes and reduce disparities. Hidden toxicities fall into three major categories: mental health, logistical and financial, and interpersonal.

Cancer diagnosis and treatment are tremendously stressful and negatively impact mental health. An estimated 25% of patients with cancer[1] suffer from depression and distress. Less crippling but noteworthy is 'scanxiety'—anxiety related to surveillance and waiting for and receiving results. In addition, cancer harms partners, caregivers and families emotionally. In some cases, cancer diagnosis and treatment can even create post-traumatic stress.[2]

Understanding and easing financial toxicities has recently received overdue attention. However, research has focused on medical costs. Less studied are non-medical costs such as transportation, lodging, parking, lost wages, child/elder/special needs/pet care, etc. Total costs absorbed by patients are generally unknown. A recent review of transportation and other health-related social risks found a paucity of evidence for intervening in all of them, though transportation fared best.[3 4] Beyond immediate financial challenges, patients with cancer also experience impacts on promotions and promotability, with long-term financial implications.

The intersection between logistical and financial challenges is significant. Patients who cannot afford transportation or do not have reliable transportation are more likely to delay or not take treatment. But there is also time toxicity inherent in diagnosis and treatment. Time spent getting to and from the clinic, waiting in the clinic, receiving treatments and dealing with side effects are clearly toxic to daily living. But so, too, is time spent coordinating, contemplating, discussing, and scheduling care and care providers.

Finally, cancer's burden on partners, caregivers, family, friends and business colleagues is substantial, with potentially detrimental impacts on interpersonal relationships. Efforts to guide and execute diagnosis and treatment or arrange and/or provide transportation, home care, time off, alternative child, elder, special needs and pet care are often considerable. Knowing when and how (and whether) to provide emotional support and input, particularly when the outcomes are undesirable and trending worse, strains relationships. In some cases, the patient may make choices not aligned with caregiver and family values, resulting in additional stress and mental health challenges.

Busy clinicians cannot and should not be expected to investigate and address each obstacle with every patient. Further, they may not have resources available. However, a basic understanding of risks and consistent, longitudinal screening/assessment coupled with intervention should deliver improved outcomes.

Addressing hidden toxicities starts with screening: asking what challenges patient, family and caregivers anticipate or experience during care delivery that might prevent compliance. Probing the three major challenge categories rather than interrogating subitems may be most productive.

Once obstacles are exposed, clinicians can refer to internal resources or pre-established external relationships. External resources such as professional societies (oncology social workers or American Cancer Society, eg) may be very appropriate referrals to assist or provide connections. Cancer advocacy groups and patient and caregiver communities can often provide recommendations within their networks. As appropriate, clinicians can leverage less costly treatment alternatives (drug A vs drug B) and generics, allow virtual appointments and local testing, and bundle appointments to reduce cost and logistical burdens.

Several practical considerations must be addressed as we move forward. One size will not fit all patients, clinicians and clinical settings. Also, assessment must be ongoing as challenges and needs often evolve. Thus, assessments must be made over time. Extreme demands on clinician time and limited access to effective local resources must be acknowledged. With an increasing understanding of hidden burdens, resources are maturing and more plentiful. However, resources will remain local to the geographic context.

Researchers, including clinical trialists, must continue to build a better understanding of the obstacles that patients face and the evidence to support best practices, guidelines and resources. The current paucity of information should be viewed as an opportunity with substantial potential and reward for the research community.

For treatment trials, clinical trialists must recognise that improved survival alone is insufficient. The use of a metric such as Q-Twist[5] which offsets incremental gains in survival with 'losses' in (quality) time is recommended as it creates a more nuanced and balanced understanding of the incremental improvement being proposed and achieved.

Like many chronic and potentially lethal conditions, cancer diagnosis and treatment are toxic to patients beyond the obvious consequences of side effects. Mental health, logistical and financial, and interpersonal challenges impede the delivery of guideline care and optimal outcomes. By consistently screening and intervening against these challenges, every patient will have the opportunity to have an optimal outcome for their circumstances.

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