Words Matter
Patient Perspectives on Language used in Research and Care Settings

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What is stigmatizing language?

Stereotypes are defined as widely held and often untrue generalized ideas or beliefs about a particular category of people.

Negative stereotypes lead to stigmatizing language through implicit bias. Implicit bias is the automatic activation of stereotypes, which may override deliberate thought and influence one’s judgment in unintentional and unrecognized ways.

Stigmatizing language in healthcare can perpetuate negative discriminatory attitudes and influence clinicians' decision making when treating a patient. This impacts the quality of care and contributes to health disparities.
Patients’ Experience in Bias

Assumptions are often based on:

- Socioeconomic status
- Age
- Race
- Gender
- Medical Condition
- Limited-resourced

Commonly-Used Negative Terms:

- Underserved
- Vulnerable
- Marginalized
- Socially disadvantaged
- Under-resourced
- Limited-resourced
Methods

Data and insights were collected via survey to our Patient Insight Network and follow-up listening sessions.

This group has a chronic or complex illness and a history of access and/or affordability challenges.
A little over 20% of participants were unfamiliar with the term “financial toxicity”.
Comfort with word/phrase use

- Health-Related Social Needs
- Limited-resourced
- Social Needs
- Under-resourced
- Patient compliant/Non-compliant
- Low income
- At-risk
- Underserved
- Financially insecure
- Federal Poverty Level (FPL)
- Vulnerable
- Social distress
- Disadvantaged
- Marginalized
- Social risk
- Socially disadvantaged
- Financial Toxicity
When you think about the financial challenges you or others have experienced, do you feel the phrase “Financial Toxicity” is a patient-friendly way to describe this experience?

Yes, I like the term

No, I dislike the term

I dislike it because it “Sounds like the patient is 'at fault' somehow.”
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Reasons for Disliking Term “Financial Toxicity”

“Toxicity = poison.”
“Don’t like combining money with poison to describe a person or situation.”

“feels like a judgement about me, rather than a description of what I'm experiencing.”
Alternative Phrases with >20% Support

- Financial hardship
- Economic challenges
- Financial pressure
- Financial worry
- Excess financial strain
- Unaffordable care burden
- Financial distress
There are many frequently used terms that patients feel are negative and are uncomfortable when being used to describe them.

Financial Toxicity is a term with the least patient support for use. This is not related to just being unfamiliar or not knowing meaning.
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Solutions for Future Research

- Utilize person-centered communication during conversations and ask patients how they would like to be addressed.
- Create generic surveys that ask patients to provide a self-description. Upon acquiring this information, researchers may reach out to those who fit the criteria needed for their study.
- Refrain from labeling patients based on their job, income, or health condition.
- Avoid generalizing patients. Each person has a unique situation and should not be categorized when spoken to individually.
thank you