Patients with Disabilities: Avoiding Unconscious Bias When Discussing Goals of Care

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Brainstorming Activity
Core Concepts

• Life is meaningful and valuable at all stages regardless of disability or functional status
• The impact of a loss of functional status can be reduced by improving the social and physical environment
• Accommodations, adaptive equipment, access, inclusion and participation improve quality of life
• Caregivers also require resources and support
• With appropriate supports, people with disabilities are usually much happier and capable than they are judged to be by others
• We all internalize messages about disability/loss of function: burden, suffering from, unfortunate, wheelchair bound, vegetable, heroic, childlike
• Awareness of internalized messages is key so that we don’t pass these judgments on to our patients
Common Pitfalls Discussing Goals of Care

- Pity
- Abandonment
- Misleading prognosis
- Threat of institutionalization
- Offering interventions without context
- Dehumanization
- Devaluing the life of a person with a disability
- Hopelessness
- Disrespecting autonomy

* Well meaning and *intent* is to convey empathy
Scenarios

Scenario 1:

An 80-year-old woman with mild dementia goes to her doctor’s office with her daughter and is told she has metastatic lung cancer.
Scenario 2:

• A 25-year-old man with cerebral palsy and quadriplegia, who is non-verbal, was admitted to the hospital with pneumonia. He was improving slowly on antibiotics and did not have any other pre-existing lung diseases.
Summary: Goals of Care
Best Practices

• Distinguish illness from disability
• Address both
• Meaningful lives are possible with disability or loss of function
• When there isn’t a cure, focus on improving the environment, access, and participation
• Words matter – the stories and narratives we tell our patients impact their experiences and symptoms
Brainstorming Activity
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