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Avoiding Unconscious Bias About Disability when discussing Goals of Care

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Case Scenario

A 58 year old, non-speaking patient with an intellectual disability was admitted for cholecystitis. He also had a well-controlled seizure disorder, secondary Parkinsonism from medications he was no longer taking, and diabetes insipidus. His surgery was uncomplicated. Due to his underlying disability, and his need to drink a high volume of water to maintain sodium balance, his recovery proceeded at a slow rate. On post-operative day six, his ability to swallow had partially recovered, but he was still requiring fluids and food through a nasogastric tube. His attending physician took the initiative to invite hospice representatives to a team meeting to discuss goals of care. He recommended a transfer to hospice care due to what he called, "The patient's suffering and risk of aspiration." Hospice was willing to admit him based on the attending's referral, and initially his family followed their lead. However, when confronted with questions such as, "What is his terminal diagnosis?" and "What evidence of suffering have you observed?" it became clear that the recommendation for hospice was based on the physician's misperception of the patient's quality of life and pressures to advance discharge, rather than any specific medical indications . As it turned out, our patient was back home within a couple of months, eating his favorite foods, and recovered to his previous baseline function. He had returned to his day program and activities. What could his attending physician have done better to support and expedite this outcome?

Commentary

False assumptions about patients' quality of life can impact prognosis, the treatment options that we present, and the types of referrals that we offer. In this case, the physician

equated complex disability with terminal illness. This common confusion can result in premature withdrawal of life-preserving care. Disability is not a disease. People with physical, mental, and cognitive disabilities can and do live rich, full lives. They are often healthy, even if they need support for basic activities of daily living. If well-managed, secondary conditions such as aspiration, pressure sores, and osteoporosis can be prevented or minimized. With appropriate services and accommodations, people with disabilities can make decisions, have relationships, and contribute to their community. This outcome is more likely when people are welcomed, supported and valued. Despite a high prevalence of chronic medical conditions, the life-expectancy of people with developmental disabilities approaches that of the general population.¹

Physicians may mistakenly extrapolate high rates of significant functional decline seen in elderly patients after hospitalization to younger patients with complex disabilities. Younger patients with disabilities, however, are often healthier and more resilient than older patients, and their prognosis is often better after an acute illness.

This patient is recovering slowly from an acute, temporary illness. The physician's concern for aspiration, while understandable, hardly warranted transfer to hospice. Aspiration is a preventable secondary condition that can be effectively managed through diet texture, posture, careful supervision, and assistance with feeding. Falsely labeling a person with a disability as terminally ill risks becoming a self-fulfilling prophecy, especially for people who need long-term support to thrive.⁴

Physicians should be careful to avoid making assumptions about other people's quality of life, especially those who rely on external assistance. They should also avoid reinforcing

patient or caregiver fears and misconceptions about living with disability. . For example, in one study of hospitalized able patients with serious illnesses, over half of respondents felt that health states that were the same or worse than death included incontinence; requiring a breathing tube; relying on a feeding tube; or needing care from others all the time.¹⁰ But many people with developmental disabilities have required these supports since birth yet still have meaningful lives.¹¹ After a period of adjustment, people who live with acquired chronic illness and disability also typically rate their own quality of life significantly higher than their physicians and caregivers do. Self-reported quality of life for people with disabilities is not significantly different than that of the general population. 6, 7, 8

Instead of sharing decision-making and respecting autonomy, physicians may unconsciously project their own attitudes onto the people they serve through how they frame informed-consent discussions.⁵ Table 1 includes examples of how this commonly happens along with alternative scripts and resources. Being aware of unconscious biases will help physicians better support their patients during stressful times.

The attitudes and beliefs of clinicians can interfere with the care patients want or need.
⁹ We can improve access by reassuring patients that no matter what choices they face, we will care and advocate for them.

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Table 1: Common Pitfalls in Discussing Goals of Care

UNCONSCIOUS BIAS	SUPPORTIVE COMMUNICATION
Pity	Respect
This poor unfortunate man suffers from...	Mr. Smith is a 56 year-old, wheelchair user and volunteer patient advocate who presents with...
I understand that you don't want to be dependent and a burden to your family.	Adjusting to new functional limitations takes time. Maybe it would help if you hear directly from people living with disabilities.
Abandonment	Maintaining and deepening connection
There is nothing we can do.	While the risks of this treatment outweigh the benefit in your case, I look forward to seeing you regularly and providing you with care. What are your hopes, needs and fears?
Call me if your pain is out of control.	I'll call you to check on your pain. In the meantime, I'll get a consult from our Palliative Care team. There are support groups and mindful based stress reduction classes that might interest you.
Misleading prognosis	Share expertise and uncertainty
You have less than six months to live.	Nobody knows for sure how long you have to live. It is especially difficult to make accurate estimates in people with underlying disabilities. Most people with your condition live months rather than years.
Institutionalization	Home and Community Based Services
As your condition progresses, you may need to move to a nursing home.	I'm going to refer you to our social worker who can help you access extra help and

	home modifications so you can enjoy this time together.
Describing interventions without context	Information about person-specific goals, risks and benefits
Would you want to live on a machine if you could never get off? Would you want to be kept alive with a feeding tube?	You have weak muscles that are impacting your swallow and breathing. We can reduce aspiration pneumonia, improve your nutrition, and give you more energy with a tube for feeding and a home ventilator. It might help you to hear the stories of other people with neuromuscular disabilities who are living well on a home ventilator: http://dearjulianna.com/ ; https://www.youtube.com/watch?v=UfaGoTvWvMo&feature=youtu.be
Dehumanization	Inclusion
Alzheimer's will slowly rob your mother of her memory and dignity.	Here is some information on how to be a good friend or family member to a person with Alzheimer's: https://www.washingtonpost.com/video/national/health-science/heres-how-to-practice-good-alzheimers-etiquette/2016/05/30/5c13a6a6-25cc-11e6-8329-6104954928d2_video.html
Devaluing the life of a vulnerable person	Support to maximize potential
Are you sure you want the surgery and treatment even though it won't cure your disability?	We'll be sure to get physical therapy involved right after the surgery to prevent any loss of strength or mobility while you are recovering. Let's arrange extra help with managing your activities of daily living in the hospital and when you go home.
Stealing hope	Sharing hope and realistic planning
That's not realistic.	I hope that too! Wouldn't that be great! Let's keep that goal in mind and also make a plan to prepare for things that are most likely.
Disrespecting autonomy	Supported Decision Making
Who makes her medical decisions?	Do you want to name a trusted supporter to help you make medical decisions? http://odpc.ucsf.edu/supported-health-care-decision-making
Does she have pain?	How can we communicate best? Do any of these tips for non-traditional

	communicators work for you? http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/wiw%20non%20trad%20communicators%20final_0.pdf
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