

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

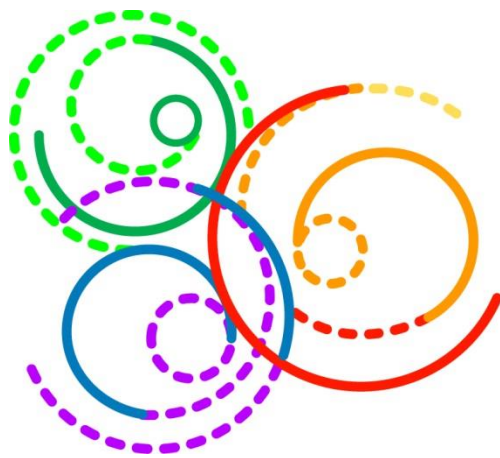
Clarissa Kripke, MD, FAAFP

Clinical Professor

UCSF Family and Community Medicine

<http://odpc.ucsf.edu>

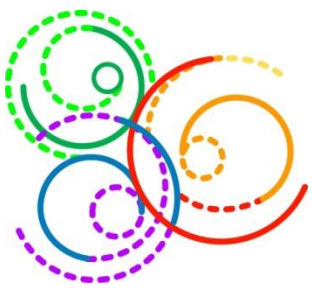
April 11, 2018



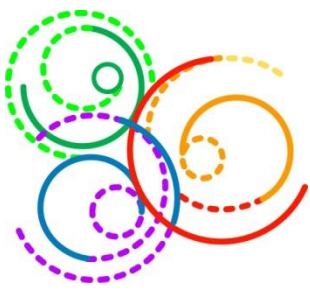
Disclosures

I have no relationships with commercial interests.

Thanks to the WITH, Shaw Family and Stupski Foundations, and Alta California, Golden Gate, Far Northern, and Redwood Coast Regional Centers.

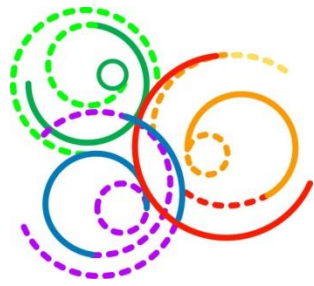


Brainstorming Activity



Core Concepts

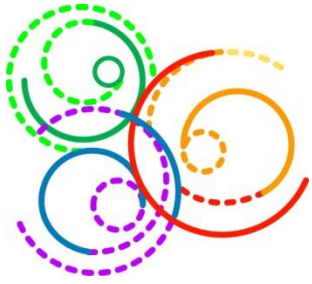
- Life is meaningful and valuable at all stages regardless of disability or functional status
- The impact of a loss of functional status can be reduced by improving the social and physical environment
- Accommodations, adaptive equipment, access, inclusion and participation improve quality of life
- 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.



Scenarios

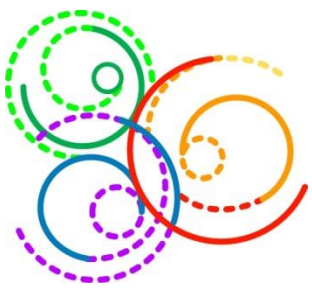
Scenario 2:

- 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.

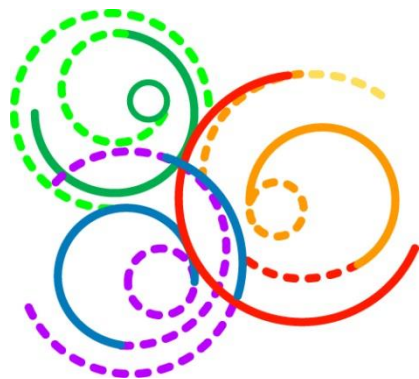


Summary: Goals of Care Best Practices

- 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



Office of Developmental Primary Care

<http://ODPC.ucsf.edu>

(415) 476-4641 (office)

odpc@fcm.ucsf.edu

