

When is Life Not Worth Living? A Thought Experiment on Imagining Intolerable States

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Suppose You are Sitting Down to Write Your Advance Directive...

- What are five elements, qualities or conditions you believe you need to have a “good life?”
- What are conditions or states that would make you question whether your life was “worth living?”
- **HOW CERTAIN ARE YOU?**

Responses from Others....

Elements, qualities or conditions needed to have a “good life”

- Independence
- Free of pain
- Ability to communicate
- Friends and families
- Ability to contribute
- Cognitive abilities
- *What else is on your list?*

If You Are Like Others....

Conditions or states that would make you question whether life was “worth living”

- Dementia
- Severe brain injury
- Quadriplegia
- Vegetative state
- Lock-in syndrome
- *What else would be on your list?*

How do we you think physicians should handle these feelings & perceptions when working with patients/ families/ surrogates who are facing these conditions?

“Doc— what would you do if your family member had this condition? What would you want for yourself?”

The Golden Rule

“Do onto to others as you would have them do onto you.”

Luke 6:31

**How Accurate are Physicians at
Understanding Life with Disability?**

**How Good are They at Predicting
Quality of Life in Various
Circumstances?**

Quality of Life (QOL) Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers

Gerhart KA, et al. Annals of Emergency Medicine 23:4 April 1994

- “Glad to be alive”
 - Emergency medical providers
 - Persons with chronic quadriplegia

- “QOL average to above average”
 - Emergency medical providers
 - Persons with chronic quadriplegia

Quality of Life (QOL) Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers

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- “Glad to be alive”
 - Emergency medical providers 18%
 - Persons with chronic quadriplegia

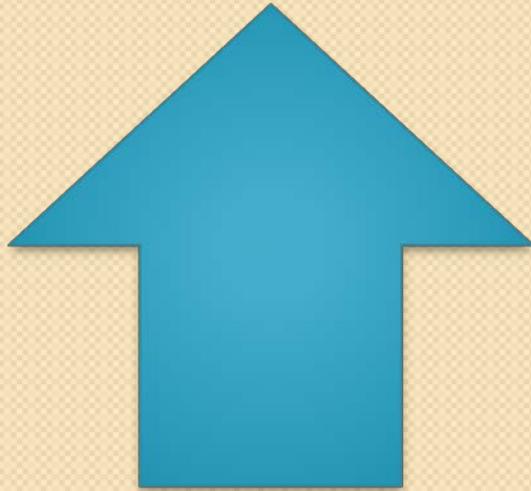
- “QOL average to above average”
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Quality of Life (QOL) Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers

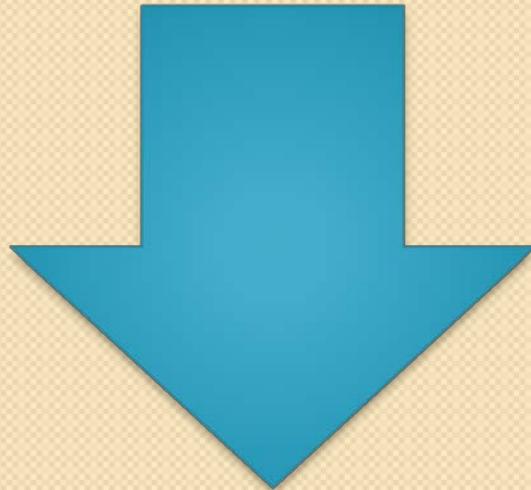
Gerhart KA, et al. Annals of Emergency Medicine 23:4 April 1994

- “Glad to be alive”
 - Emergency medical providers 18%
 - Persons with chronic quadriplegia 92%
- “QOL average to above average”
 - Emergency medical providers 17%
 - Persons with chronic quadriplegia 86%

Think About Your Life Over the Last Month...



If you had to pick a number between 1 and 7 to represent your average QOL during that time, what would your number be?



Physician's Predictions of QOL for People Who Are Ventilator-Dependent after SCI

- Physicians for Themselves
- Physicians for the Injured
- The Injured for Themselves

-Bach et al 1994

Physician's Predictions of QOL for People Who Are Ventilator-Dependent after SCI

- Physicians for Themselves
5.36
- Physicians for the Injured
- The Injured for Themselves

Physician's Predictions of QOL for People Who Are Ventilator-Dependent after SCI

- Physicians for Themselves 5.36
- Physicians for the Injured 2.50
- The Injured for Themselves

-Bach et al 1994

Physician's Predictions of QOL for People Who Are Ventilator-dependent after SCI

- Physicians for themselves 5.36
- Physicians for the Injured 2.50
- The Injured for Themselves 4.39

-Bach et al 1994

“The Disability Paradox: High Quality of Life Against All Odds”

Albrecht GL, Devlieger PJ. *Social Science and
Medicine* 48 (1999), 977-988.

What is Meant By The “Disability Paradox”?

“Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable existence?”

Albrecht GL, Devlieger PJ. (1999)

Medical Model vs. Social Model

(M. Oliver)

- Negative
- Resides within the person
- Medical goals- to cure, prevent, or ameliorate
- Rehabilitation goals- restoring the loss of normal function
- Remedies reside within the healthcare providers
- Neutral– not necessarily bad.
- Resides between the person & environment
- Goals -to change social structures and attitudes of people.
- Remedies reside within society-- peers, healthcare providers, social justice system, etc.

BIOPSYCHOSOCIAL MODEL (G.ENGLE)

**Does it Matter Whether Physicians
have Poor Accuracy in Predicting
QOL or Whether They Ascribe to
the Medical Model View of Disability?**

YES!

- Affects framing of information
- Affects willingness to offer choices
- Can foreclose options

Example: Differing Concepts of Autonomy

- **Physical Independence:** *“I can do everything by myself– I don’t need help from anyone.”*
- **Autonomy:** *“I’m in charge of my life”*
- **Self-determination:** *“I have the ability to control what happens to my body and to make choices for myself.” (interdependence)*

Example: Medical Treatment of Polio Patients

“The goal was to be a real person who could walk. Walking was the whole deal. He’ll never walk again was the ultimate killer Hollywood movie line.”

(Charles Mee, A Nearly Normal Life, p95)

“A Nearly Normal Life”

Charles Mee

“The isolation ward was well named: I have never been so alone in my life as in that bed, where I was confined for the next three weeks, feverish and contagious; where I would learn, thoroughly, the lesson of self-reliance. It was an education that would sustain me for the rest of my life—and cut me off from others so that, even today, I have to work to remember that what I learned so well was wrong, or incomplete. And somewhere deep inside I turned tough as old leather for ten or fifteen years.....” (p. 16)

Some Implications of the Polio Stories

- Focus on “normalization” as opposed to compensation (i.e., learning to navigate with a wheelchair) caused some unwitting harms
- Importance of social roles and relationships and meaningful activities
- Physicians not always the “experts”—need to understand and include PWD’s in all decision-making that will directly affect their lives, including policy, resource allocation, and goals for medical treatment.

Some Practical Implications....

- Physicians are not very good at predicting the QOL of PWD's and indeed are invariably more negative than those who live with certain conditions
- People frequently change their minds when their reference point changes
- Longterm adjustment is more tightly correlated with relationships, social roles and meaning-making

Returning to the Golden Rule in Medicine...

Caveat: Be cautious about using the “Golden Rule” in medical decision-making-particularly in situations of new-onset disability (or in any situation which is personally unfamiliar to you).

Rely on first-person data of the lived experience as much as possible!

Suggestions for Navigating Pertinent Issues

- Recognize the limits of information based upon the availability of treatments at the time a study was done!
- Try to frame with neutral, descriptive language; avoid words such as “severe”
- Avoid prescriptive answers: there are many person-centered variables --e.g., psychological factors, resiliency, social/financial supports, spirituality/world view