

Decision Making in SMA

Old Dilemmas/New Dilemmas

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*Old Dilemmas:
Spectrum of Go/No Go Decisions*

Titration Level of Care

(Respiratory, GI, Orthopedic, Function)

Who Decides

Macro Level Issues (Resources)

Old Dilemmas:

The Hegemony of Hope

Hope has salutary properties

But potential for leading to places unwanted

Dilemma

My Operational Definition

Search for a/the “correct” choice

Non-applicability of precedent

(Swift: “whatever hath been done before must be done again”)

(not defined by equality of paths,
but by justifiability of choices)

We all seek to feel justified in our actions
And justification of the choice is a source of solace

Dilemma

My Operational Definition

Emphasis on *process* rather than choice

Defines role for caring providers

Resolve what is right for this child, not for all children

(I solicit pledge of non-proselytization)

Additional Principles of the Dilemma

People exist simultaneously in different places

Impossibility of informed choice at outset

Evolution of understanding

Facebook/CureSMA Woes

Coercive choice is institutional preference

The pain of choosing well is essential to solace of the choice

Old Dilemmas:

Who has standing?

Balance of burden and benefit is unequally distributed:

SMA-burdened individual

Mother

Father

Grandparents

Siblings

Extended Family

Providers

Medical Institutions

Insurance

Pharma

Society

Old Dilemmas:

Cases

SMA 0

13 year old

Mother/Father divide

“Hospital or Heaven”

New Dilemma

Initiation of treatment seductively easier

Do families know the burden of repeated LPs?

New Dilemma

Is there a new Hegemony of Hope²?

Borderline cases will remain

(hope they are rarer, but rarity will make it more difficult for those affected)

Type 0

Advanced Weakness

New Dilemma

Macro-level

Will optimal therapy increase the population of severely affected?

Can we justify the costs in a zero-sum world?