

SHARED DECISION MAKING: ANOTHER LEGACY OF JOHN E. WENNBURG

October 15, 2013



New York University
Robert F. Wagner Graduate School of Public Service

WHAT WE ARE GOING TO TALK ABOUT

- **John Billings:** A bit of history about the Foundation for Informed Medical Decision Making
 - The shared decision making insight
 - Making it happen/affecting policy
- **Al Mulley:** Ethical and economic imperatives of shared decision making
- **George Bennett:** The fiery furnace

THE INSIGHT

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- [Jack has had quite a few]

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 - If there were a Nobel Prize for health services research, Jack would have won _____

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- VS
- Risk of things like incontinence, impotence, retrograde ejaculation, etc.

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 - May have other incentives

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 - Dartmouth Atlas 101

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 - An **Typical scholarly approach at this point:** attitudes
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 - **Publish a trifecta of articles in JAMA**
 - **Go on to the next topic**
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Jack Wennberg

Typical scholarly approach at this point:

- Publish a trifecta of articles in JAMA
- Go on to the next topics
- Affect policy/find a way to make it happen

attitudes

attitudes

formed

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And if you are going to make decision aids, you...

- Need to know what patients care about
- Need to get the science right about benefits and risks
- Need to present the information in a fair and balanced way
- Need to evaluate how they affect patient knowledge and choices

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- **Need to find a way to get them in the hands of patients**

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 - Then what's needed is a way to get patient's more informed and involved in these decisions →→→ decisions aids
 - Somebody's got to make them and get them in the hands of patients →→→ [The Foundation](#)

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- Later, under auspices of current president, Michael Barry, changed it’s name to “Informed Medical Decisions Foundation”
- I’m going to be talking about three phases:
 - The early years
 - The wandering in the wilderness years
 - The fiery furnace era

THE FOUNDATION

THE EARLY YEARS

- *[Memories are a little foggy here]*

THE FOUNDATION

THE EARLY YEARS

- Jack and Corky on the floor of their living room in the house in Vermont editing the first program on BPH

THE FOUNDATION

THE EARLY YEARS [SPIELBERG ERA]

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 - Started with the premise we needed \$20/yr million in revenue

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 - Probably best characterized as faith-based business planning (as opposed to evidence-based business planning)

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- Hartford Foundation consultant described the work as “over-produced” and “over-engineered”

THE FOUNDATION
THE WANDERING IN THE WILDERNESS
YEARS

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 - Dartmouth connection with Sony U.S. CEO
 - Among other things wanted to sell Sony laser disc players

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- Lasted a couple of years

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 - Flawed business model

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 - Continued to run up some debt at Dartmouth and MGH

THE FOUNDATION

THE HEALTH DIALOG/FIERY FURNACE ERA

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 - Editors typically drawn for general internal medicine
 - Free of any financial relationship with a group or organization with interest in treatment choices or approaches involve

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 - The Foundation receives:
 - Contracts to support cost of content development
 - Royalties based on related HD revenue + bit of equity

THE FOUNDATION

THE HEALTH DIALOG/FIERY FURNACE ERA

- So what kind of revenue from HD to the Foundation are we talking about?

THE FOUNDATION

THE HEALTH DIALOG/FIERY FURNACE ERA

- *So what kind of revenue did Jack's relentless, dogged pursuit to promote the insight about the importance of shared decision making produce?*

THE FOUNDATION

THE HEALTH DIALOG/FIERY FURNACE ERA

- So what kind of revenue from HD to the Foundation are we talking about: **\$110+ million**

THE FOUNDATION

THE HEALTH DIALOG/FIERY FURNACE ERA

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THE FOUNDATION

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| Activity | Amount |
|--|----------|
| Decision Aid Content Development, Production, and Updating | \$27.7 M |
| Shared Decision Making Related Research | \$19.7 M |
| Demonstration Sites for Implementing SDM | \$25.2 M |
| Hearts and Minds Initiatives to Promote SDM | \$16.5 M |
| International Activities | \$1.8 M |
| Dartmouth/MGH Debt Repayment | \$4.1 M |
| Reserves for Future Development | \$18.0 M |

THE FOUNDATION

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- So what kind of revenue from HD to the Foundation are we talking about: **\$110+ million**
- What has the Foundation done with all this revenue?
- *Keep in mind all of the activity I am about to describe was the work of Jack Fowler and Michael Barry*
 - *Foundation presidents during the Fiery Furnace Era*
 - *Often accomplished despite officious intermeddling by board members like Jack Wennberg and me*

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Current Decision Aids

Back Care Programs (4)
Breast Cancer Programs (5)
Cardiovascular Disease Programs (6)
Chronic Condition Programs (3)
End of Life Programs (2)
General Health Programs (2)
Mental Health Programs (2)
Ophthalmology Program (1)
Orthopedic Programs (4)
Prostate Programs (4)
Colon Cancer Screening Program (1)
Weight Loss Program (1)
Women's Health Programs (3)

DECISION AID DEVELOPMENT, PRODUCTION, AND UPDATING

- Current Foundation decision aids: 38
- On the way:
 - Maternity suite (4-6)
 - Conversion of existing portfolio to “next generation” (web-based) decision aids
 - Interactive
 - Personalized

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 - Interactive
 - Personalized
- Decision aids distributed: 800,000

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SHARED DECISION MAKING RELATED RESEARCH

- Decision aid design and content
- Assessing decision aid impact
- Measuring decision quality
- Assessing shared decision make implementation
- George Bennett Dissertation Fellowships (33)
- Robert Derzon Post Doctoral Grants (6)
- DECISIONS Study (2007)

SHARED DECISION MAKING RELATED RESEARCH

- Decision aid design and content
 - DVD vs. Web
 - Testimonials vs. none
 - Video testimonials vs. narrative
 - Communicating risk
 - Presenting data
 - Use of pictographs
 - Animated graphics and Interactive risk calculators vs static text and graphs
 - Use of personalized risk calculators
 - Health literacy
 - Numeracy
 - Responding to the needs of special populations

SHARED DECISION MAKING RELATED RESEARCH

- Decision aid design and content
- Assessing decision aid impact
 - Knowledge
 - Preferences/choices
 - Costs
 - Satisfaction
 - Etc.

SHARED DECISION MAKING RELATED RESEARCH

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- Assessing decision aid impact
- Measuring decision quality
 - Knowledge
 - Values exploration, clarification, concordance
 - Patient involvement/activation

SHARED DECISION MAKING RELATED RESEARCH

- Decision aid design and content
- Assessing decision aid impact
- Measuring decision quality
- **Assessing shared decision making implementation**
 - What it takes
 - Who does what to whom
 - Barriers and facilitators

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- **DECISIONS Study (2007)**
 - Level of knowledge among patients making decisions (low)
 - Provider discussions were intervention focused (duh)
 - Patient input uneven, especially for medications/screening (duh)
 - TRENDS study - follow-up (2011)

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DEMONSTRATION SITES FOR SHARED DECISION MAKING

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Shared Decision Making Demonstration Sites

Dartmouth Hitchcock Medical Center - NH

Massachusetts General Hospital - MA

Allegheny Gen'l Hosp Breast Care Center - PA

Carol Milgard Breast Center - WA

Everett Clinic - WA

Group Health Cooperative - WA

MaineHealth - ME

Mercy Clinics - IA

MultiCare Health System - WA

National Nursing Centers Consortium

Oregon Rural Practice-based Research Network - OR

Palo Alto Medical Foundation - CA

Stillwater Medical Group - MN

UCSF Breast Care Center - CA

University of North Carolina at Chapel Hill - NC

DEMONSTRATION SITES FOR SHARED DECISION MAKING

- 15+ primary care and specialty care sites
- Clearly this was a critical investment as the health care delivery system is careening towards major change
 - Providers more directly involved in financing and management
 - ACOs, shared savings, bundled payments
 - Why/how to implement shared decision making is creeping up the pile of things to do in this new paradigm

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| Dartmouth/MGH Debt Repayment | \$4.1 M |
| Reserves for Future Development | \$18.0 M |

“HEARTS AND MINDS” INITIATIVES FOR SHARED DECISION MAKING

- Promoting the concept of shared decision making [SDM]
 - Federal level
 - State level
 - Professional groups
 - Provider groups
 - Health News Review
- Partly as result of these activities, SDM...
 - Buzz word de jour
 - In ACA - §3506
 - In ACO and some PCMH regulations
 - 4 states have enacted laws to mandate/encourage SDM
 - Professional societies have increasingly embraced SDM
 - Try Googling “Shared Decision Making” – 94M hits

THE FOUNDATION

THE HEALTH DIALOG/FIERY FURNACE ERA

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- What has the Foundation done with all this revenue?

| Activity | Amount |
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INTERNATIONAL ACTIVITIES

- Support for Angela Coulter
- More hearts and minds activities
- Salzburg Conference 2010 on shared decision making
- Assisting Bupa in its 2020 vision to implement shared decision making across its world-wide reach

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RESERVES FOR FUTURE DEVELOPMENT

- “Next generation” (web-based) decision aids
- Responding to new market circumstances
- Responding to new market opportunities

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 - Still a ways to go, *but the guy's still in his 70s and is just starting to hit his stride*

WHAT WE ARE GOING TO TALK ABOUT

- **John Billings:** A bit of history about the Foundation for Informed Medical Decision Making
 - The shared decision making insight
 - Making it happen/affecting policy
- **Al Mulley:** Ethical and economic imperatives of shared decision making
- **George Bennett:** The fiery furnace

