SHARED DECISION MAKING:
ANOTHER LEGACY OF
JOHN E. WENNBERG

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
THE INSIGHT

• [Jack has had quite a few]
[Jack has had quite a few]

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

- [Jack has had quite a few]
- This particular one came out of the work related to BPH
• [Jack has had quite a few]
• This particular one came out of the work related to BPH (with his colleagues on the BPH PORT team in 1986-7 and then walking on the beach in Santa Monica in 1988)
[Jack has had quite a few]

This particular one came out of the work related to BPH
- The urologists had got some of the science wrong
THE INSIGHT

- [Jack has had quite a few]
- This particular one came out of the work related to BPH
  - The urologists had got some of the science wrong
  - The real issue for most was a trade-off of benefits and risks
THE INSIGHT

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  - The urologists had got some of the science wrong
  - The real issue for most was a trade-off of benefits and risks
    - Not having to get up 2-3 times a night to pee
• [Jack has had quite a few]
• This particular one came out of the work related to BPH
  – The urologists had got some of the science wrong
  – The real issue for most was a trade-off of benefits and risks
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THE INSIGHT

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    • Not having to get up 2-3 times a night to pee or being able to pee your initials in the snow (at least at Dartmouth)
    vs
  • Risk of things like incontinence, impotence, retrograde ejaculation, etc.
THE INSIGHT

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  – The urologists had got some of the science wrong
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  – But most urologists:
    ∙ Likely don’t know the numbers
    ∙ Aren’t trained for this sort of communication
    ∙ May feel they don’t have the time
    ∙ May have other incentives
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    • Which can lead to variation rates of surgery
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  - Yada, yada, yada
  - Dartmouth Atlas 101
THE INSIGHT

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  - Then what’s needed is a way to get patient’s more informed and involved in these decisions
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  – The urologists had got some of the science wrong
  – The real issue for most was a trade-off of benefits and risks
  – And towards benefits and risks
    Typical scholarly approach at this point:
    • Publish a trifecta of articles in JAMA
    • Go on to the next topic
  – But attitudes towards benefits and risks
  – So attitudes towards benefits and risks
  – Then what’s needed is a way to get patient’s more informed and involved in these decisions ➔ ➔ ➔ decisions aids
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Then what’s needed is a way to get patients more informed and involved in these decisions ➔ ➔ ➔ decisions aids.

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
[Jack has had quite a few]

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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
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- But most urologists...
- So often the treatment decision reflects the urologist’s attitudes towards benefits and risks
- Then what’s needed is a way to get patients more informed and involved in these decisions
  - 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
- Somebody’s got to make them
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- But most urologists...
- So often the treatment decision reflects the urologist’s attitudes towards benefits and risks
- 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
• The not-for-profit “Foundation for Informed Medical Decision Making” was founded by Jack, Al, Bob Derzon, and me in 1989
THE FOUNDATION

• The not-for-profit “Foundation for Informed Medical Decision Making” was founded by Jack, Al, Bob Derzon, and me in 1989

• Later, under auspices of current president, Michael Barry, changed it’s name to “Informed Medical Decisions 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]
• Jack and Corky on the floor of their living room in the house in Vermont editing the first program on BPH
THE EARLY YEARS [SPIELBERG ERA]

• 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

• Jack and Corky on the floor of their living room in the house in Vermont editing the first program on BPH
• Created an amazing (award winning) interactive laser disc program
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• Ross Jaffe and I crafted a “business plan” for the Foundation
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

• Created an amazing (award winning) interactive laser disc program

• Ross Jaffe and I crafted a “business plan” for the Foundation
  – Started with the premise we needed $20/yr million in revenue
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  – Started with the premise we needed $20/yr million in revenue
  – And then dreamed up revenue streams that had no basis in reality to get to $20 million
THE FOUNDATION
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• Ross Jaffe and I crafted a “business plan” for the Foundation
  – Started with the premise we needed $20/yr million in revenue
  – And then dreamed up revenue streams that had no basis in reality to get to $20 million
  – Probably best characterized as faith-based business planning (as opposed to evidence-based business planning)
• Jack and Corky on the floor of their living room in the house in Vermont editing the first program on BPH

• Created an amazing (award winning) interactive laser disc program

• Ross Jaffe and I crafted a “business plan” for the Foundation

• Hartford Foundation consultant described the work as “over-produced” and “over-engineered”
• We could clearly create beautiful decision aids
We could clearly create beautiful decision aids
But getting them into the hands of patients was a real challenge
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• Found a partner in Sony Medical
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   - Dartmouth connection with Sony U.S. CEO
• We could clearly create beautiful decision aids

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• Found a partner in Sony Medical
  – Dartmouth connection with Sony U.S. CEO
  – Among other things wanted to sell Sony laser disc players
• We could clearly create beautiful decision aids
• But getting them into the hands of patients was a real challenge
• Found a partner in Sony Medical
• Lasted a couple of years
We could clearly create beautiful decision aids
But getting them into the hands of patients was a real challenge
Found a partner in Sony Medical
Lasted a couple of years
  – Few sales
• We could clearly create beautiful decision aids
• But getting them into the hands of patients was a real challenge
• Found a partner in Sony Medical
• Lasted a couple of years
  – Few sales
  – Flawed business model
• We could clearly create beautiful decision aids
• But getting them into the hands of patients was a real challenge
• Found a partner in Sony Medical
• Lasted a couple of years
• Several years of looking for new partners
THE FOUNDATION
THE WANDERING IN THE WILDERNESS YEARS

• We could clearly create beautiful decision aids
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• Found a partner in Sony Medical
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  – Some near misses (Aetna/TCI in 1996)
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• Found a partner in Sony Medical
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• Several years of looking for new partners
  – Some near misses (Aetna/TCI in 1996)
  – Continued to run up some debt at Dartmouth and MGH
THE FOUNDATION
THE HEALTH DIALOG/FIERY FURNACE ERA
• Forged a partnership with creative entrepreneurs who were forming a new company in 1997: Health Dialog
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Through trial/innovation, HD evolved into a dynamic company that provided nurse coaching/disease management/etc services to health plans
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  – Where preference sensitive decisions on care were involved, provided video decision aids to patients
THE FOUNDATION

THE HEALTH DIALOG/FIERY FURNACE ERA

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  – Programs produced by HD, but a cadre of Foundation medical editors marshal the medical evidence and maintain editorial control of the content
THE FOUNDATION

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  – Where preference sensitive decisions on care were involved, provided video decision aids to patients
  – Programs produced by HD, but a cadre of Foundation medical editors marshal the medical evidence and maintain editorial control of the content
    • 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
Forged a partnership with creative entrepreneurs who were forming a new company in 1997: Health Dialog

Through trial/innovation, HD evolved into a dynamic company that provided nurse coaching/disease management/etc services to health plans

The business model:
- Health Dialog maintains/stokes the fiery furnace
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- The relationship with Foundation helps differentiate HD in a very competitive market place
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• The business model:
  – Health Dialog maintains/stokes the fiery furnace
  – The relationship with Foundation helps differentiate HD in a very competitive market place
  – The Foundation receives:
    • Contracts to support cost of content development
    • Royalties based on related HD revenue + bit of equity
• 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?
So what kind of revenue from HD to the Foundation are we talking about: **$110+ million**
THE FOUNDATION
THE HEALTH DIALOG/FIERY FURNACE ERA

• 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?
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?

<table>
<thead>
<tr>
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<td>Shared Decision Making Related Research</td>
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<td>Demonstration Sites for Implementing SDM</td>
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THE FOUNDATION
THE HEALTH DIALOG/FIERY FURNACE ERA

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

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Current Foundation decision aids (38):
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<td>Breast Cancer Programs (5)</td>
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<tr>
<td>Cardiovascular Disease Programs (6)</td>
</tr>
<tr>
<td>Chronic Condition Programs (3)</td>
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<tr>
<td>End of Life Programs (2)</td>
</tr>
<tr>
<td>General Health Programs (2)</td>
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<tr>
<td>Mental Health Programs (2)</td>
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<tr>
<td>Ophthalmology Program (1)</td>
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<tr>
<td>Orthopedic Programs (4)</td>
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<td>Prostate Programs (4)</td>
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<tr>
<td>Colon Cancer Screening Program (1)</td>
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<tr>
<td>Weight Loss Program (1)</td>
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<td>Women’s Health Programs (3)</td>
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• 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
• Current Foundation decision aids: 38

• On the way:
  – Maternity suite (4-6)
  – Conversion of existing portfolio to “next generation” (web-based) decision aids
    • Interactive
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• Decision aids distributed: 800,000
• So what kind of revenue from HD to the Foundation are we talking about: $110+ million

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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)
• 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.
• Decision aid design and content
• 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
SHARED DECISION MAKING
RELATED RESEARCH

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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)
• 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?

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DEMONSTRATION SITES FOR SHARED DECISION MAKING

• 15+ primary care and specialty care sites
DEMONSTRATION SITES FOR SHARED DECISION MAKING

• 15+ primary care and specialty care sites:

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<td>Massachusetts General Hospital - MA</td>
</tr>
<tr>
<td>Allegheny Gen’l Hosp Breast Care Center - PA</td>
</tr>
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<td>Carol Milgard Breast Center - WA</td>
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<tr>
<td>Everett Clinic - WA</td>
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<tr>
<td>Group Health Cooperative - WA</td>
</tr>
<tr>
<td>MaineHealth - ME</td>
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<tr>
<td>Mercy Clinics - IA</td>
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<tr>
<td>MulCare Health System - WA</td>
</tr>
<tr>
<td>National Nursing Centers Consortium</td>
</tr>
<tr>
<td>Oregon Rural Practice-based Research Network - OR</td>
</tr>
<tr>
<td>Palo Alto Medical Foundation - CA</td>
</tr>
<tr>
<td>Stillwater Medical Group - MN</td>
</tr>
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<td>UCSF Breast Care Center - CA</td>
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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
THE FOUNDATION
THE HEALTH DIALOG/FIERY FURNACE ERA

• 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?

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

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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
• So that’s a quick history of the Foundation and it’s role in shared decision making
• Pretty classic Jack Wennberg story
So that’s a quick history of the Foundation and it’s role in shared decision making.

Pretty classic Jack Wennberg story:
- From an insight of Jack and BPH PORT team
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  – Still a ways to go…
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Pretty classic Jack Wennberg story:
- From an insight of Jack and BPH PORT team
- Reaching beyond scholarship, with a relentless assault on the status quo
- Pushing for change and taking the concept of shared decision making beyond the policy tipping point
- 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