

Shared Decision Making for People with Mental Illnesses

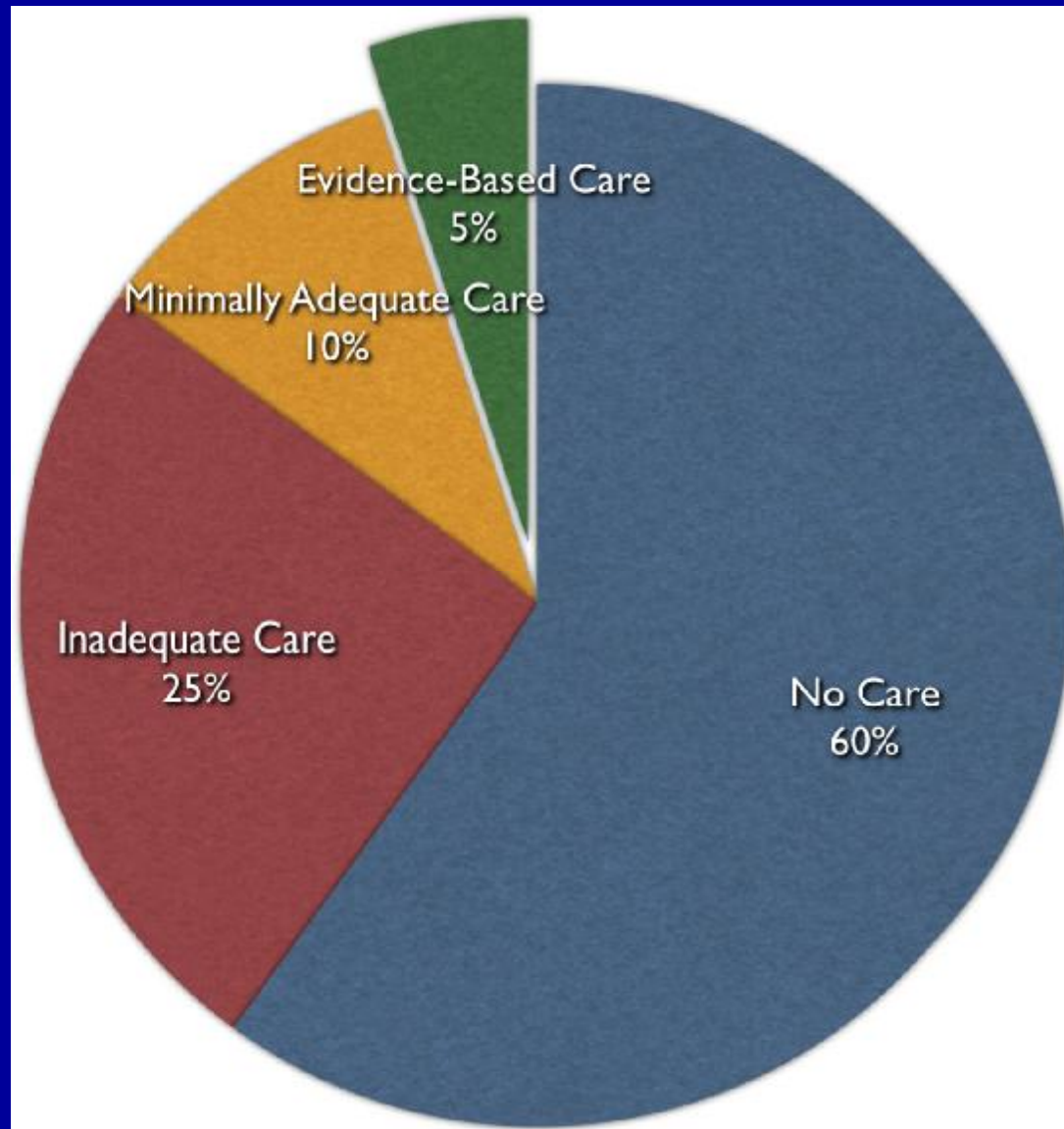
Robert E. Drake

June, 2009

Dartmouth Medical School

Person-Centered Care

- Engagement
- Information
- Values, preferences, and choices
- Concordance
- Retention
- Shared decision-making



What About the 95%?

- Access, acceptability, concordance, quality, continuity, etc.
- 60% without care: dropouts
 - (New Freedom Commission, 2003)
- 35% with inadequate care: science-to-service gap (Institute of Medicine, 2006)

Does Treatment Make a Difference?

- Early morbidity and mortality
- New institutions: jails, prisons, nursing homes, and homeless shelters
- Housing, symptoms, functional outcomes, psychological outcomes
- Recovery

Could Shared Decision Making Help?

- What is shared decision making?
- Ethical imperative
- Practical considerations
- Implementation
- Health policy

Shared Decision-Making

- Two experts
- Balint and Engel
- Women's movement (Our Bodies, Ourselves)
- Ethical, legal, practical, economic (O'Connor)
- Preference-sensitive care (Wennberg)
- Activation, decision aids, preferences, self-management (Deegan)

Examples

- **Critical Time Intervention** (Susser)
- **Housing First** (Tsemberis)
- **Supported Employment** (Becker and Bond)
- **Illness Management and Recovery** (Mueser)
- **Common Ground** (Deegan)

Supported Employment

Person-first decisions

Rapid job search

Client preferences

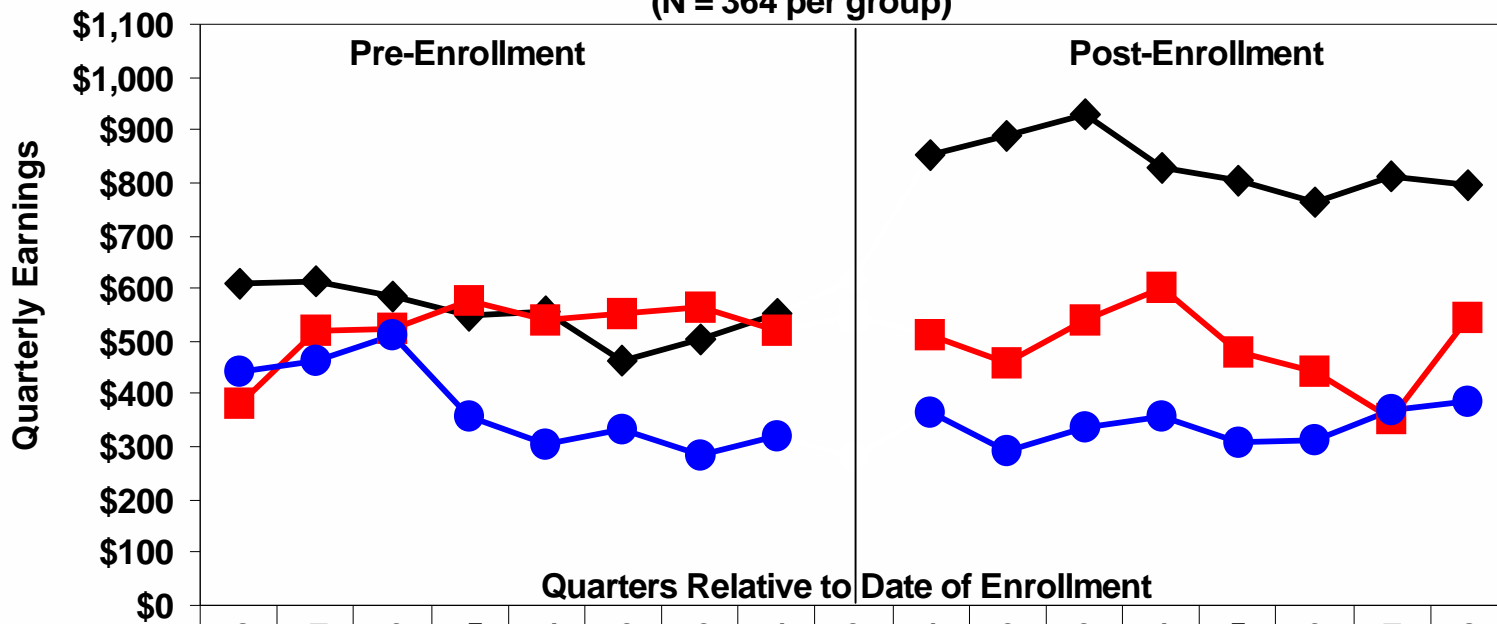
Team approach

Follow-along supports

Supported Employment

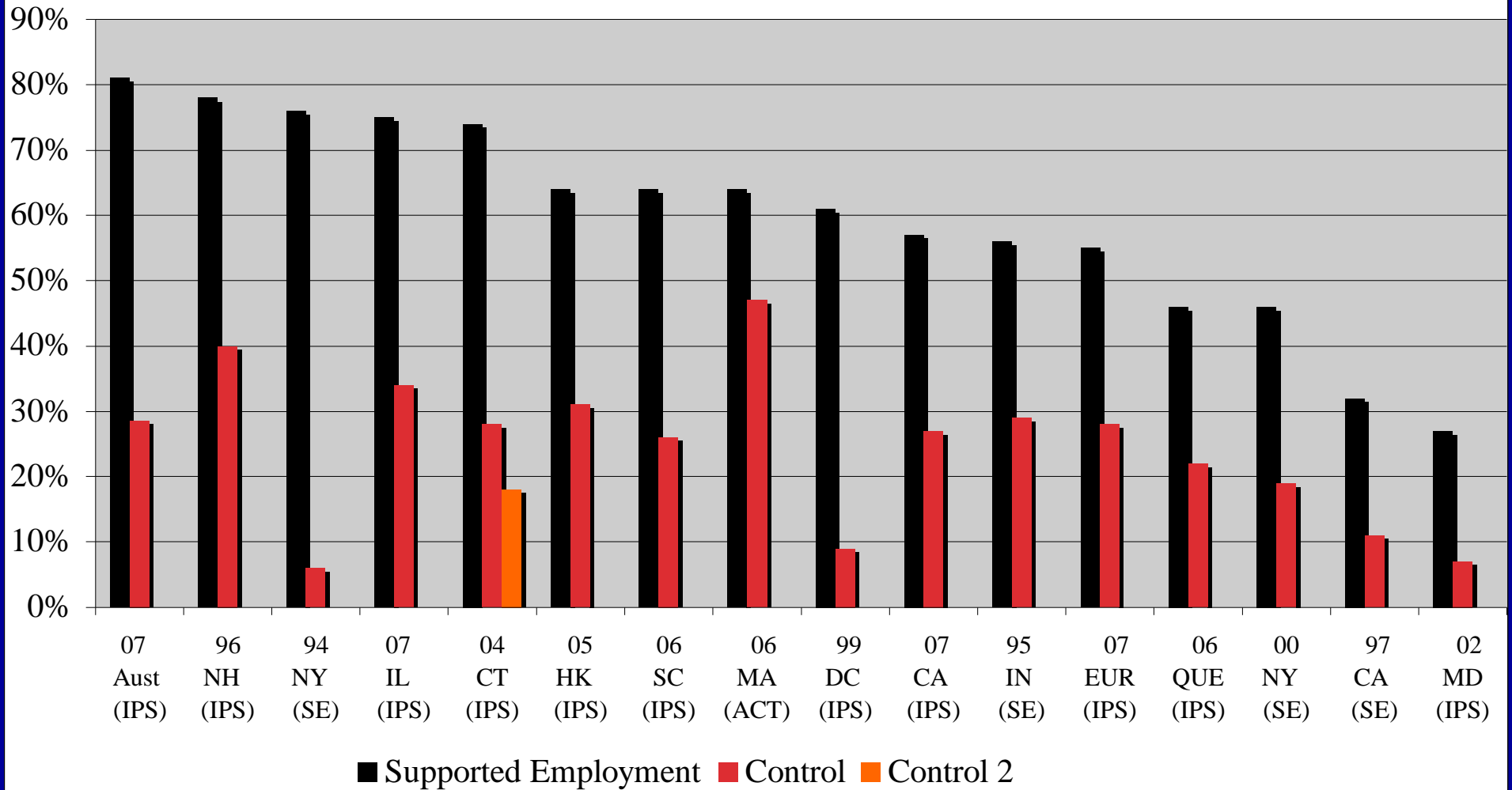
- Engagement: 10% vs. 43% dropouts
 - (Bond et al., 2008)
- Job Preferences: job tenure twice as long
 - (Becker et al., 1999)
- Employment and Education: increased retention in treatment for first-episode patients
 - (Nuechterlein et al., 2008)

**Outcomes for Psychiatric Benefit Counseling Intervention Group
Versus Two Nonparticipant Psychiatric Voc Rehab Comparison Groups
(N = 364 per group)**



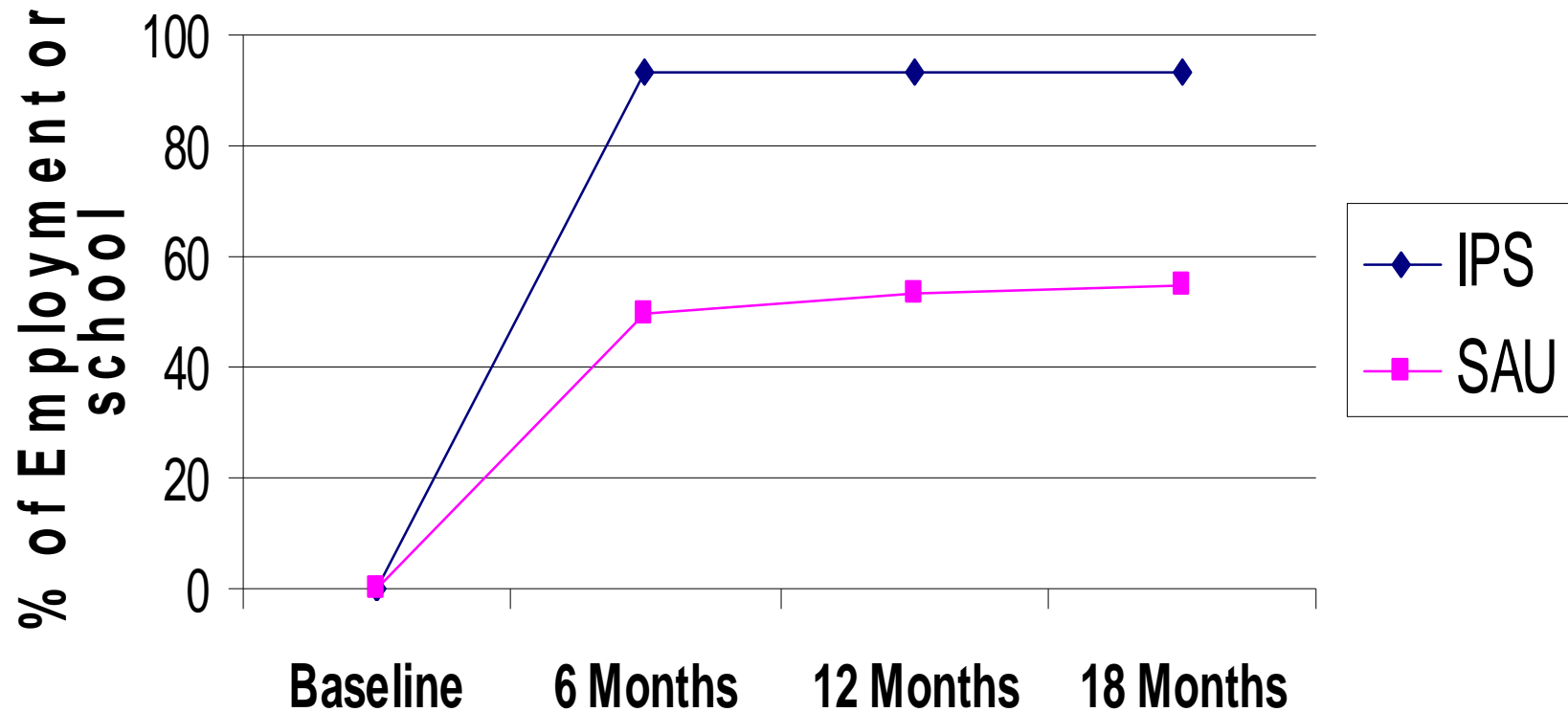
	-8	-7	-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6	7	8
◆ Intervention	608	612	585	549	557	464	504	552	615	852	887	928	830	804	765	812	796
■ Contemporaneous	382	521	525	575	540	553	566	519	546	511	459	538	602	478	441	353	542
● Historical	441	464	511	359	305	333	284	320	279	365	290	335	357	309	315	369	384

Figure 1. Competitive Employment Rates in 16 Randomized Controlled Trials of Supported Employment



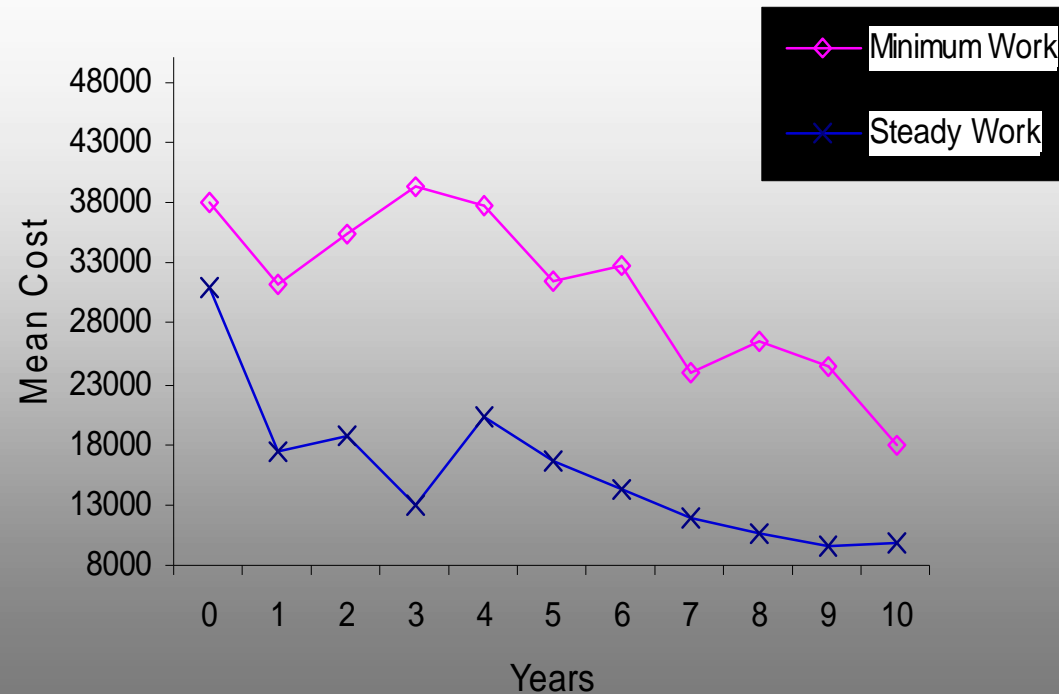
UCLA Study (Neuchterlein, 2005)

IPS Supported Employment for Clients with First-episode Schizophrenia



Cost Savings

Figure 1. Cost Outpatient Services and Institution Days



- Ø Each person with a SMI who becomes employed achieves an average savings in health costs of \$5,000 per year (Bush et al. in press 2009)

Benefit Cost Analysis

- $N = 3,464,000$
- SE enrollment = 1,513,000
- Net savings = \$168 million
- Sensitivity analyses

– Modeling by Jon Skinner (in Drake et al., Health Affairs, 2009)

Why Do We Provide Expensive
New Medications and Dangerous
Polypharmacy to Nearly
Everyone and Supported
Employment to Almost No One?

Vitamin C for Scurvy: An Early Randomized Trial

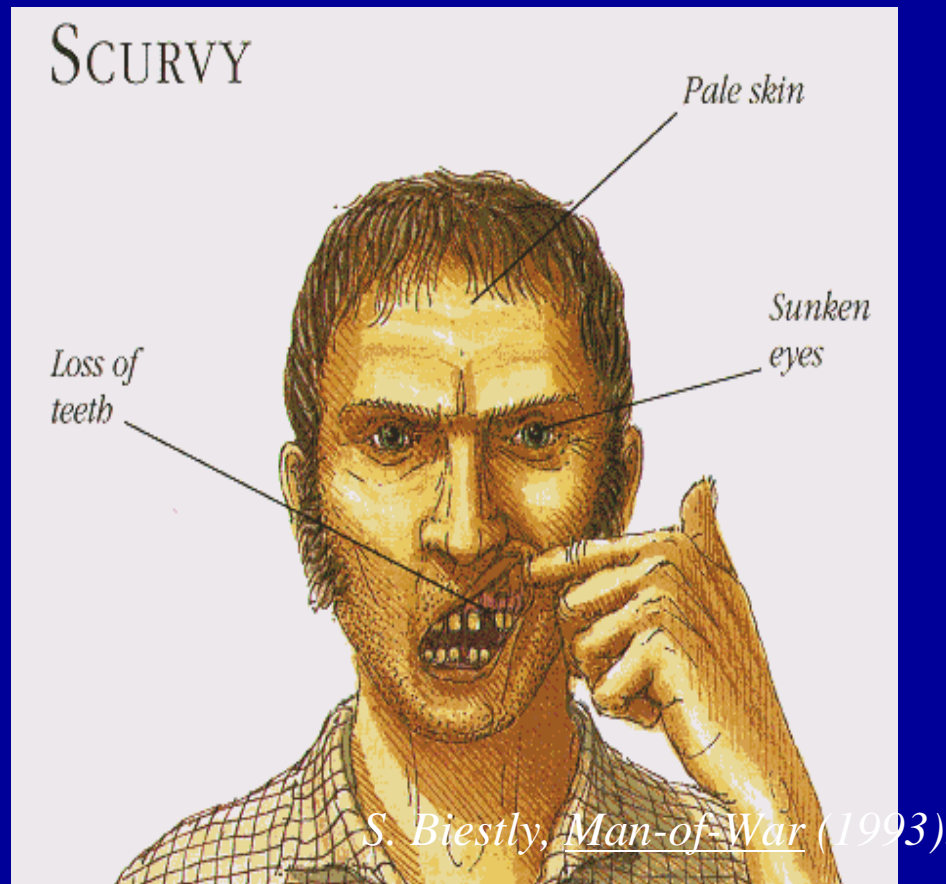
- Methods: Four-ship voyage to India in 1601. In one ship, sailors received 3 teaspoons of lemon juice per day
- Results: At halfway point, no sailors had died in the treatment group. In the control group 110 of 278 (40%) had died of scurvy



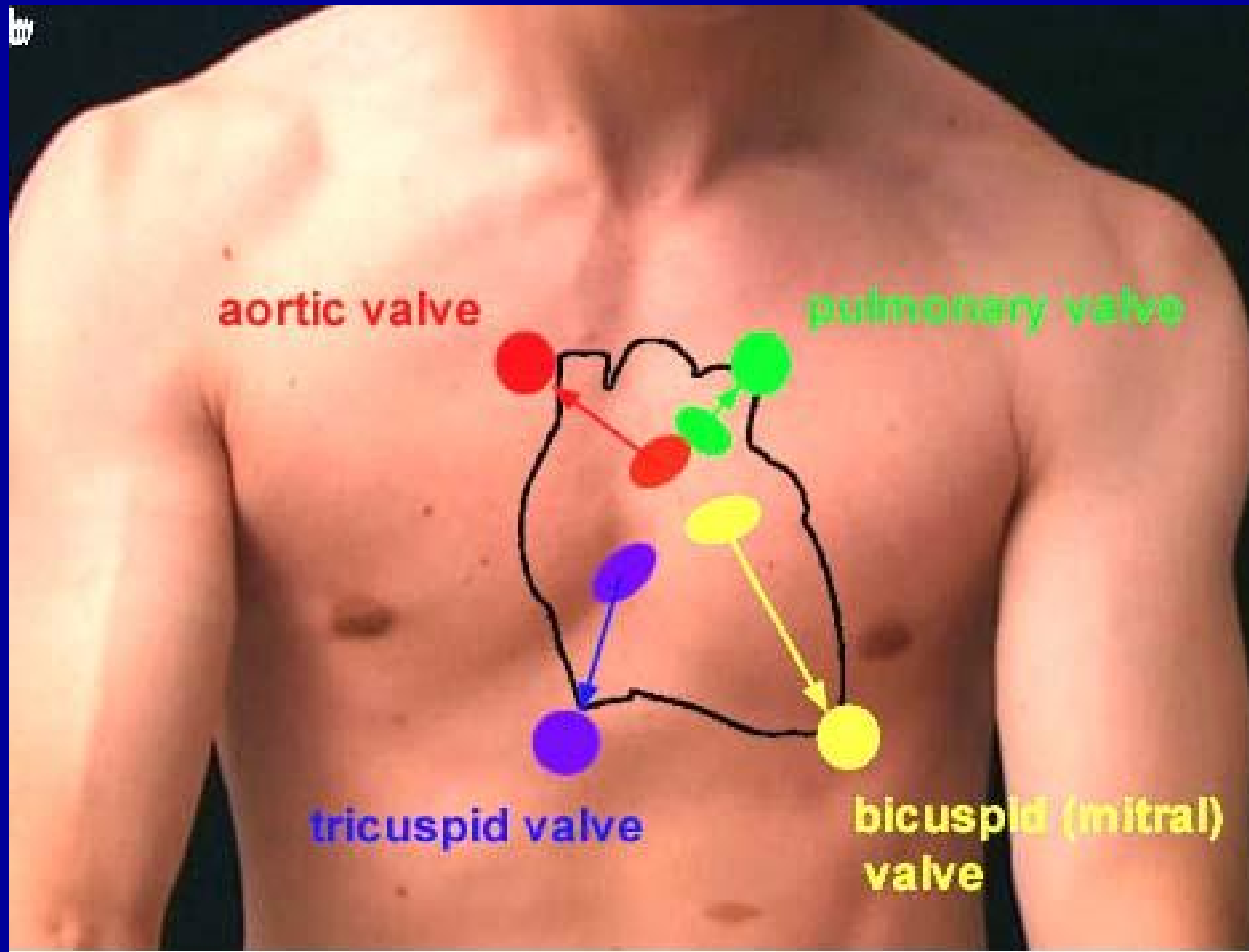
Source: Berwick, JAMA, 2003

The British Navy Adopted Dietary Standards for Scurvy:

- (a) 1602
- (b) 1625
- (c) 1697
- (d) 1795



Diffusion in the Treatment of

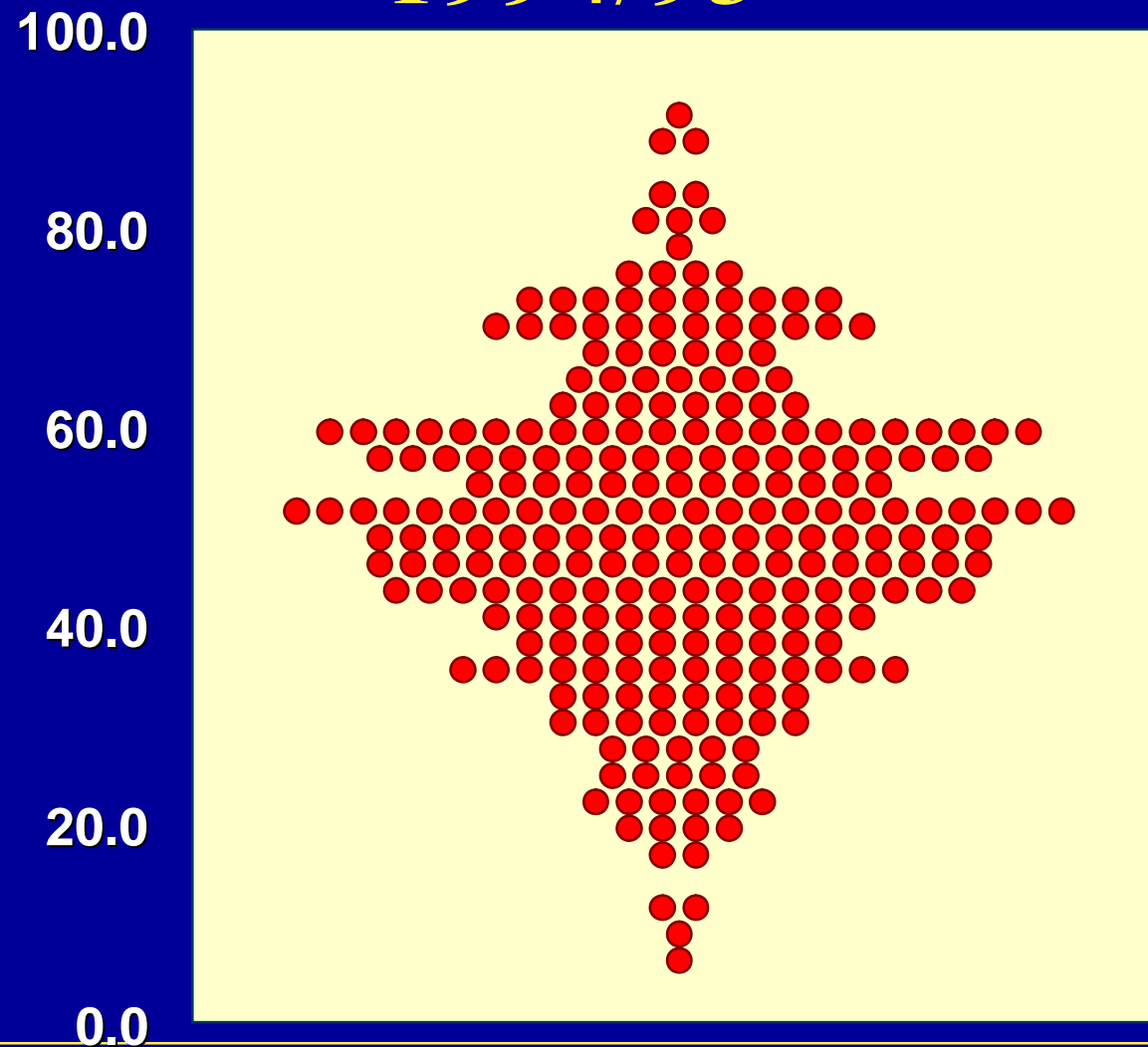


By 1985 the Benefits of Beta Blockers Were Well Established

“Long term beta blockade for perhaps a year or so following discharge after an MI is now of proven value, and for many such patients mortality reductions of about 25% can be achieved.”

Yusuf, S., et al, 1985. Progress in Cardiovascular Disease 27 (March/April): 335-71.

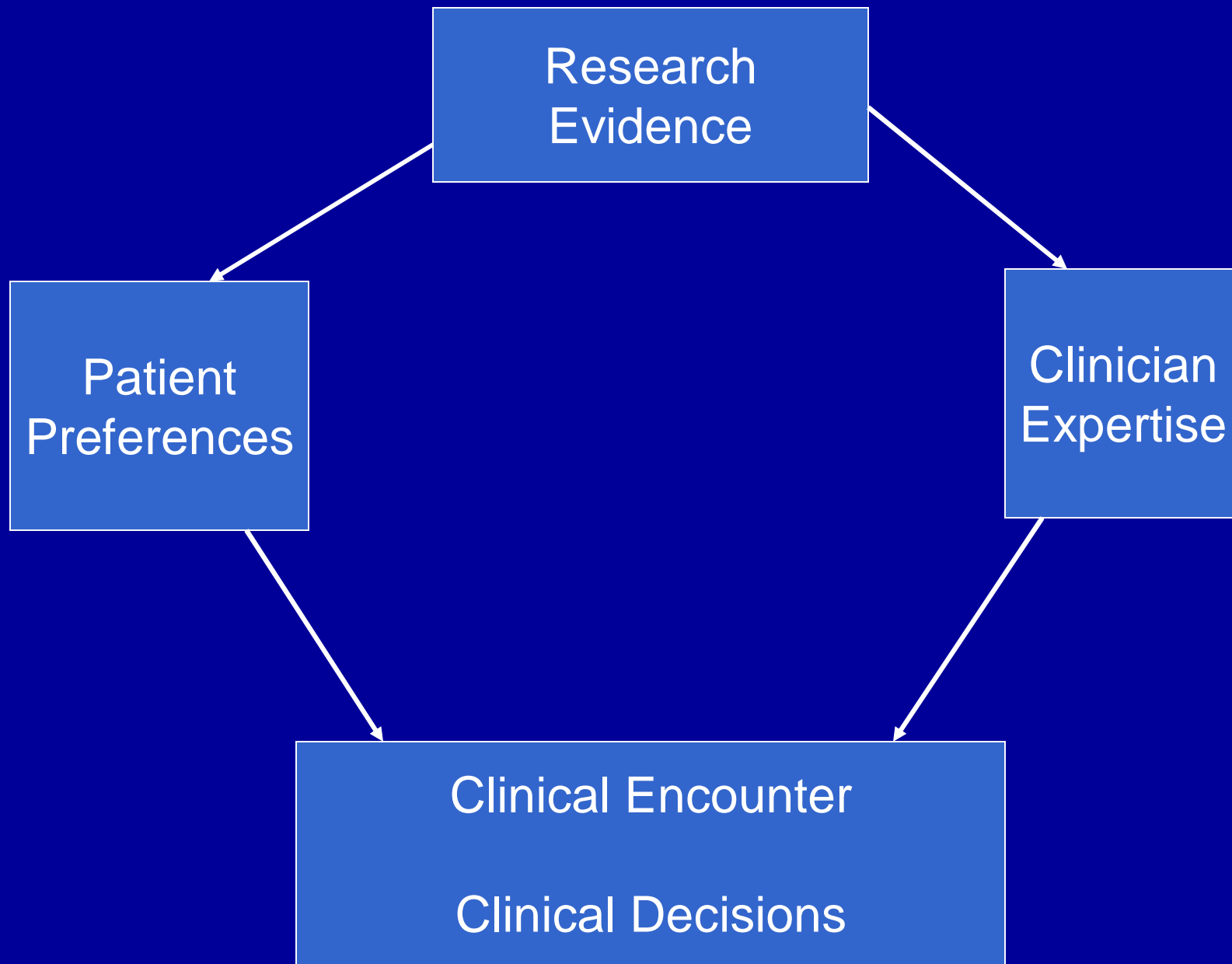
Adoption of Beta Blockers 1994/95



**Percent of "Ideal" Patients in each HRR Receiving
Beta Blockers at Discharge Following AMI (1994-95)**

Decision Support Systems

- Dorr (2007): 109 articles on chronic disease management, 23% in mental health
- Experiments: 67% positive results
- Helpful components: connection to EMR, computerized prompts, population management, specialized decision supports, electronic scheduling, personal health records
- Unhelpful: electronic access to guidelines
- Implementation key: cost-benefit to clinicians



Health Care System

Research
Evidence

Electronic Decision Support

Information
Problems, Goals, Values
Decision Aids
EMR
Risk Adjustment
Guidelines/Algorithms
Outcomes

Patient
Preferences

Clinician
Expertise

Clinical Encounter
[Shared Decision Making]
Clinical Decisions

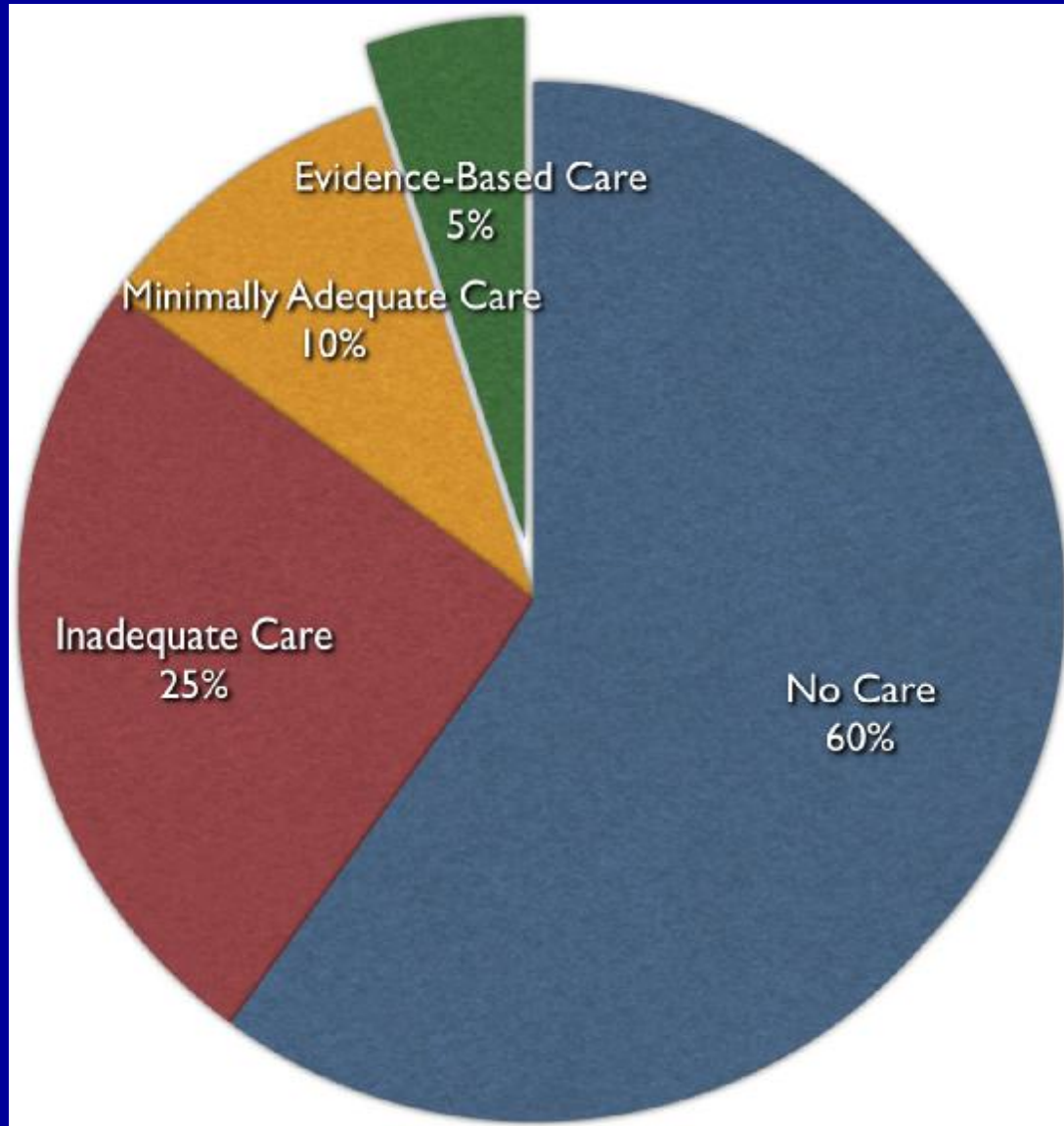
Health Care System

Critical Questions

- Do people want shared decision making?
- What information and help do they want and need?
- Decisional incapacity?
- Activation?
- Research?

Research Evidence

- 7 Randomized controlled trials
 - Depression: Van Korff (2003), Loh (2007)
 - Schizophrenia: (Malm (2003), Hamann (2006), Priebe (2007), Woltmann (2009)
 - Addiction: Joosten (2009)
- Results: SDM increases knowledge, satisfaction, decision quality, participation.
- Longitudinal health outcomes, recovery, and costs?



What Can We Do?

Where is the outrage?

Users

Families

Practitioners

Administrators

Researchers

Conclusions

- Failure of public mental health non-systems
- Need to use health information technology
- Role of shared decision-making

Financial Support to PRC

- Grants from NIDA, NIDRR, NIMH, RWJF, SAMHSA
- Contracts from Guilford Press, Hazelden Press, MacArthur Foundation, Oxford Press, New York Office of Mental Health, Research Foundation for Mental Health
- Gifts from Johnson & Johnson Corporate Contributions, Segal Foundation, Thomson Foundation, Vail Foundation, West Foundation

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Severe Mental Illness

- Diagnosis, disability, duration
- 5-7% of adults in any year (Kessler, 1997)
- 30% of SSI (Medicaid), SSDI (Medicare)
- Quality of treatment? Recovery?
- The 95% problem
 - (Lehman, 1998; Wang, 2002)

II. Practitioner Skills

- More and more critical
- Realities of the mental health system
- Training, supervision, and turnover in CMH
- Failure of continuing education system
- Lack of outcome data in CMH

Efforts to Improve Workforce Skills

- **Toolkits** (SAMHSA Evidence-based Practices)
- **Training centers** (Ohio; Johnson & Johnson-Dartmouth)
- **Training supervisors** (Kansas University)
- **Decision support systems** (Dorr, 2007)

Implementation Model

Other Factors

Consumers

MHAs

Families

Community Mental Health Center

Program Leaders & Practitioners

Implementation Packages
(materials, training, & supervision)

(materials, training, & supervision)

EBP Implementation

Consumer Outcomes

Intervention

Stakeholder System

Implementation Outcomes

Practical Outcomes

III. Research Evidence

Shojania & Grimshaw (2005):

1. Passive diffusion: articles
2. Guidelines, systematic reviews, CME
3. Implementation packages and quality control from industry
4. Systems engineering: EMR and electronic decision supports

Vitamin C for Scurvy: An Early Randomized Trial by Captain James Lancaster (1601)

- Methods: Four-ship voyage to India. In one ship, sailors received 3 teaspoons of lemon juice per day



Vitamin C for Scurvy: An Early Randomized Trial

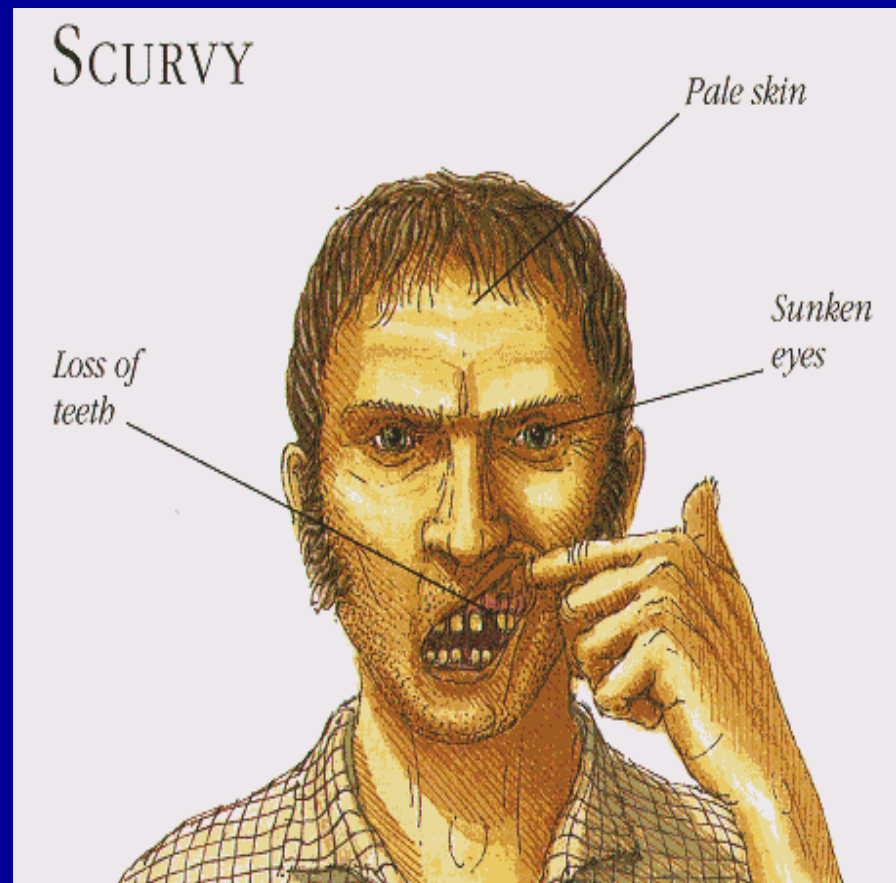
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S. Biestly, Man-of-War (1993).

Key Questions

- How to make research evidence understandable, convincing, relevant, available?
- Purity, hierarchy, updates, bias, cultural variation, credibility, relevance?
- Individualization?
- Point of contact?
- For patients also?

Suggestions

- Multi-stakeholder teams
- Neutral funding source
- Transparent methods
- Combine data across studies to determine effects and individualized risks
- Present the evidence to patients/families and practitioners in multiple, validated formats
- Update yearly

IV. Mental Health System

- Don Berwick: “Every system is perfectly designed to get exactly the outcomes it gets.”
- Costs and outcomes in the U.S.
- Bob Michaels: mental health is a cottage industry
- **Need for fundamental changes** (NAMI, 2006; New Freedom Commission, 2003; Institute of Medicine, 2006)

Health and Social Service Systems

IOM (2006) guidelines:

Collaborative systems

Unlink insurance and disability

Align funding with access and quality:

Integrated, evidence-based, patient-centered care

Standardized data systems and outcomes

Interactive, skills-based, continuous learning

Shared Decision-making and Decision Support Systems - I

- Easy access to best evidence on treatments, local resources, and research for patients and practitioners
- Cancer center model
- Multiple entry points
- Patient portals for data entry
- Support options

Shared Decision-making and Decision Support Systems - II

- Patient data entry is feasible and enhances meaningful interactions
- Course and outcome data plotted automatically
- Evidence-based information for patients and clinicians
- Prevent errors, guide decisions, educate patients and clinicians in process

Critical Issues for Research - I

- How to synthesize and update information?
- How to individualize risks?
- How to link EMRs, patient portals, electronic decision supports?
- How to provide flexibility and portability?
- How to provide supports?
- How to handle decisional incapacity?

Critical Issues for Research - II

- How to form collaborative partnerships?
- How to activate clinicians and patients for shared decision-making?
- How to study and improve the process?
- How to educate, train, and update the workforce continuously?
- How to collect and use outcomes?

Possible Models

- Comprehensive Cancer Centers
- Spine Center (Weinstein)
- Shared Decision-Making Center (Wennberg)
- Cystic Fibrosis Collaborative (O'Connor)
- Common Ground (Deegan)

Roles for SDM Center

- Clarify preferences and needs of patients, families, and clinicians
- Develop and test resource materials
- Study process of SDM
- Study outcomes of SDM
- Refine and disseminate flexible decision support systems