PATIENT-CENTERED Research

119.12

3

Jon Tilburt MD MPH

Whole-Person Care

ARTHUR FRANK Q —

MAKING BIOMED RESEARCH & EVIDENCE MORE PATIENT-FOCUSED

~~OBJECTIVES~~ — B

Care "DISCRETE RESEARCHED INTERVENTIONS"

BIOMED SCIENCE: LACK OF IMPACT

BIOMED WORLDVIEW

JAMA → CHANGES BIOMEDICAL Care

Social value DRIVING Research

FEEL BETTER!

Patient Conclusion

MAKING Research MORE PATIENT-CENTERED

ADJUST RIGOROUS METHOD

IMPORTANT OUTCOMES – PATIENT-IMPORTANT OUTCOMES

MEANINGFUL BENEFIT – WARM RELATIONSHIPS

SOLID EVIDENCE – PLACEBO DISCLOSURE

TRUTH BENE VALUES — BORROWED FROM WAYNE

EXPAND Cadre – DIFFERENT VOICES

USER-CENTERED Design POOR

BioMed RESEARCH

SCIENTIST & REGULATOR-CENTERED

YADA, YADA, YADA...

FACTS: OBJECTIVE REALITIES

REALITY: MIND/BODY DUALITY

KNOWLEDGE COMES FROM SCIENCE

- THERE'S A PROBLEM
- PAY ATTN TO ASSUMPTIONS

Josephine Briggs MD

OUR HEALTH CARE SYSTEM — TOO MUCH TOO LITTLE — MAJOR PROBLEMS — IT SUCKS

NO! — LIFE-SAVING

HIGH MORTALITY

TOO MUCH STUFF — PLENTY OF FINANCIAL INCENTIVES FOR IT

TOO LITTLE TIME & ATTENTION

A SIMPLE, MORE NATURAL WAY? AVOIDING DRUGS? DIY?

Überdosis

WILL BRING RIGOROUS SCIENCE TO PATIENT

PATIENTS PREDICAMENTS

STAGE 4 COLORECTAL — PATIENTS EXPECTED TO BE CURED BY CHEMO — LIVING WITH INCORRECT ASSUMPTIONS

INEFFECTIVE

(CHALLENGE OF MISINFORMATION) — BEING HONEST, STRAIGHTFORWARD IS NOT EASY

CHRONIC HEADACHE & OSTEOPOROSIS — TRUE — SHAM!

(Meh.)

BESIEGED WITH DATA

POM — WEIGHT LOSS — SEXUAL DISFUNC. — Acai — MUSCLE-BUILDING

ADVERTISING CLAIMS

PATIENTS AT THE TABLE IN A ☑ WAY (SYMBOLICALLY)

DAVID SACKETT: EVIDENCE-BASED MEDICINE

THOUGHTFULNESS OF PATIENTS' PREDICAMENTS

RIGHTS

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4 Research Priorities

11-9-12 (4)

END POINT

James Brown

FEEL GOOD
QUALITY OF LIFE
MOBILITY
MORBIDITY
MORTALITY

- Lorenzo LAMAS EFFECT

Affluence

EXERCISE IN A BOTTLE

FAT TRAPPER

I NEEDED TO ANETHETIZE AN OBESE TEEN

...SHE LEFT IN TEARS

TELLING THE TRUTH: DOCTOR

HEARING THE TRUTH: PATIENT

RESPONSIBILITY

NO MORE RITALIN

WASHINGTONIAN

ACCUPUNCTION AS WRINKLE-REMOVER.

0 EVIDENCE

FLEXIBLE APPROACH

DANGEROUS

MIGHT WORK

MOST LIKELY WILL WORK

TOO MUCH POLYPHARMACY

What works?

OFTEN TIMES

Truth

....WE DON'T KNOW. — AND THAT'S OKAY.

Hel-lo!

Alzheimers SOLUTIONS

NON-EVIDENCE BASED AIDS

ALTERNATIVE MEDICINE

MAGIC BULLET Rx

BIG Pharma

HEALTH CARE

ENHANCING RESEARCH EDUCATION

FEAR

REGULATORY

HIPPA ISSUES

IGNORANCE RE EVIDENCE

BRITISH COOKBOOK MEDICINE

ENORMOUS DEPLOYMENT OF ELECTRONIC HEALTH RECORDS.

SOCIAL NETWORKING TAPPED FOR HEALTH TRIALS

What keeps you up at night?

WHAT PATIENTS WANT

RIGEROUS SCIENCE

RISKS & BENEFITS

CURRENT HIERARCHY MODEL

GOAL: MEANINGFUL INFO FOR BROAD AUDIENCE

NEED NEW PORTFOLIO

REGULATORY APPARATUS

FDA

THE SCIENCE OF ESSENCE INNER LIFE

ANCIENT CHINESE MEDICINE

CONCIOUS CONSIDERATION OF MANIFOLD TECHNIQUES — EVEN PLACEBOS

CLINICIANS: DIRECT-CONTACT WITH PATIENTS

DIALOG

I STRESSED OUT SOME RATS

GAINED INSIGHT INTO PATIENT ISSUES.

REAL

PLACEBO

CULTURAL REVOLUTION

MEDICAL RESEARCH INDUSTRIAL COMPLEX

EX JOURNAL EDITORS CRUSADE AGAINST JOURNALS & PEER REVIEW

The Natural Way

ENVIRONMENTAL · CULTURAL.

WHO DECIDES?

IT'S A POWER ISSUE.

DOCS ON TOP

A COUNTER INTUITIVE CULTURE

ALL PARTICIPANTS EQUAL

not.

COST PER QUALITY

WE SPEND 2x GDP AS SCANDANAVIAN

TIERED FORMULAS = Pharma LAY-OFFS

the Patients VOICE

1ST ROUND OF PCORI: ALL RESEARCHERS

NURSING RESEARCH

BRINGING WITH

BIOMEDICAL RESEARCH

MULTI DISCIPLINARY CONDUITS

PATIENT PERSPECTIVE

— HARD TO FIND ARTICULATE REPRESENATIVE ADVOCATES

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