

“Whenever your cholesterol gets too high, a sensor will send out a signal that automatically locks the kitchen door and turns on your treadmill.”

Advancing from activated patient to autonomous patient in chronic illness care

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Previous Outline (11/2014)

- **Overall question:**
 - How do we personalize care in a health care system organized around an impersonal and objective medical diagnosis?
- Personalization of care
 - Patient-centered care vs activated patient
- Personalization of treatment choice
 - Respecting vs. promoting autonomy
- Personalizing outcome assessment
 - HRQL vs PCH as capacity for action

Today's outline

- **Overall question:**
 - How are we to understand and promote the patient's participation in the production of health?
- Concept of health behavior retards innovation in chronic illness care
 - We seek not just an activated patient, but an autonomous patient who sets and pursues her own vital goals.

Today's outline

- To fully enlist patients, we must bridge the gap between impersonal disease processes and personal life processes.
 - We must understand how the roots of patient autonomy lie in the biological autonomy that allows organisms to carve their biological niche.
- Patient agency is both the primary means and primary end of health care.

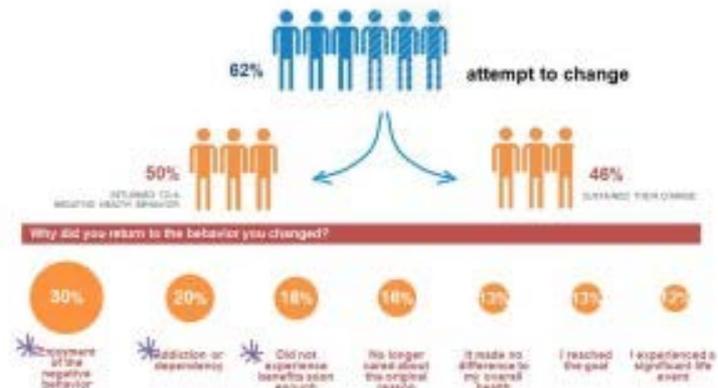
Health behavior or action?



Maintaining a Healthy Lifestyle



Half Fail to Sustain Their Positive Behavior



Source: 2011 Coulter Health Barometer



How are action and health related? extrinsic and intrinsic

- Extrinsic: healthy action produces health-
diet, exercise, medication adherence
 - Unavoidable in chronic illness care
- Intrinsic: meaningful action is a component of
health- acting is being healthy,
 - Can mitigate and retard progress of pathology
 - Organ impairments, activity restrictions,
participation limitations– circular relationship

Progress in conception of health behavior

- Past: Compliance, adherence
 - Provide information to obedient patient
- Present: self-management of chronic illness
 - Provides skills in responsive system (CCM)
 - Patient goals=clinician goals (A_{1c}, LDL, SBP)
- Future: patient empowerment
 - patient's vital goals → clinical goals
 - Focus on maintenance of healthy action
 - Emphasize intrinsic rather than extrinsic motivation

Modern health psychology: patients become more active

- From behavior to intentional action
 - Bandura: patients “are agents of experience rather than simply undergoers of experience.”
 - Shift from reinforcers to confidence allowed advance from predicting to changing behavior
- From confidence to personal importance motivational interviewing (MI)
 - elicit rather than instill motivation for change
 - move conflict between aspirations and actions *inside* the patient

Approaches to health action: self-mgmt. vs self-transformation

Theory	Social Cognitive Theory (SCT)	Motivational Interviewing (MI)	Health Action Process Approach (TTM or HAPA)	Self-Determination Theory (SDT)	Shared Decision Making (SDM)	Patient Empowerment
Process	Self-management (clinician goals, self vs. disease)			Self-transformation (internalized and intrinsic motivation)		
Goals for behavior change [MEANS]	Goals are product of capabilities (self-efficacy, outcome expectancies) [CONFIDENCE]	Goals arise from clinician agenda, who seeks grounds in patient aspirations [IMPORTANCE]	Operationalizes intention formation (goal setting) [IMPORTANCE] separately from action execution (goal pursuit) [CONFIDENCE]	Specifies ultimate goals: autonomy, relatedness, and competence, but not proximate change goals [INTERNALIZATION]	Unlike classical informed consent, both means and ends are negotiable [HEALING DIALOGUE]	Abjures pursuit of adherence in favor of facilitating patient goal pursuit [AUTONOMY]
Self who takes action	Self is self-reflexive and socially shaped	Self as site of potential ambivalence to be drawn upon	Health behavior seen as part of Health self-regulation	Altered by internalization of new goals; as goals become intrinsic, self is transformed	Self of patient is in dialogue with clinician, and may be altered in the process (rather than a stable self, giving permission: informed consent)	Empowerment explicitly aims for transformation of the patient rather than just self-management of illness

Focus: what is to be changed, how to change → why change, who is changing

Self-determination theory: the quality of motivation

- maintenance of new health behaviors requires patients to internalize both skills and values for change
- Internalization promoted by support of:
 - Autonomy: act intentionally c/w values
 - Competence: confidence plus agency
 - Relatedness: inclination to seek close relat.
- *Effective for tobacco cessation, physical activity, weight loss, diabetes management, dental health, medication adherence*

Shared decision-making (SDM)

“pinnacle of patient-centered care”

- SDM vs informed consent
 - Aim: promoting vs. respecting autonomy
 - Refusals: negotiated not simply honored
 - Role: part of care not prior to care
 - Application: “preference sensitive decisions”
 - Setting: chronic rather than acute care
 - Process: collaboration rather than permission
 - Focus: goals rather than means

Self-management or self-transformation? relationship between person and disease

- Self-mgmt. of disease separate from self
 - Mgmt. dictated by nature of disease
 - Manage diabetes as professional would
 - Little attention to threats to identity
- Consider self-management of depression
 - Focused on *both* disease and person
 - Disease goals and personal goals relevant
 - Not just adherence, but agency and autonomy

Patient empowerment: broadening or subverting the self-management agenda?

- *"The empowerment approach requires changing from feeling responsible for patients to feeling responsible to patients."--- Robert Anderson and Martha Funnell*
- Empowerment is more about self-determination than self-management. "It is more a question of what you are than what you do." (Aujoulat)
- Empowerment is a combination of competence and autonomous self-regulation (Geoffrey Williams, SDT)

Empowerment as clinical outcome

- Empowerment as clinical process or outcome?
 - Process: as a means toward other health outcomes: A1c, LDL...
 - Outcome: as a component of health or marker of health
- Empowerment as fostering autonomy
 - Fostering the development of the patient as a subject in psychoanalysis and in diabetes care
 - Physicians are classically responsible for their patients, analysts are responsible to their patients.
 - Raises the basic ethical question: how should you live your life?

Efficacy vs. Effectiveness vs Empowerment Trials

Trial types	Efficacy	Effectiveness	Empowerment
What is tested	Treatment	Treatment-clinical context	Engagement-inspiration
Scientific strength	Internal validity	External validity	Ecological validity
Treatment target	Disease	Disease in context	Health
Treatment goal	Cure, remission, surrogate	Remission, improvement	Autonomy Biological / personal
Therapy-patient relationship	Patient removed as much as possible	Patient included in selection and use of means of care	Patient fully included in selection of means and goals of care
Role of adherence	Adherence minimized	Adherence incorporated	Adherence surpassed
Source of therapeutic action	Clinician-treatment	Clinician and patient	Patient + supports

Empowering the patient-subject

- We aim to treat disease through the patient (effectiveness) rather than around the patient (efficacy).
- With empowerment, we not only treat through the patient, but on the patient's terms and toward the patient's goals. *Knowing the patient becomes as important as knowing the disease.*
- The clinician has a much more ambitious task than respecting patient preferences, a common definition of patient-centeredness. If the clinician is to not only respect but promote patient autonomy, he needs to know how to "*promote the development of the patient as a subject.*"

Patient action as a means to health and as a component of health itself

- We have been interested in how patient action *causes* patient health. We have examined patient action as a *means to* patient health: mortality, morbidity, A1c...
- We will now examine how the capacity for patient action is patient health.
- Healthy organisms are active organisms, not simply surviving or defusing environmental perturbations, but shaping their environment to their own ends.



From patient autonomy to biological autonomy

- Patient autonomy on a personal level is ultimately rooted in biological autonomy on a sub-personal level.
- All healthy organisms have the capacity, not only to maintain themselves in the face of environmental stresses (homeostasis), but to actively carve an environmental niche.
- Beneath the power of humans to make autonomous choices, lies the basic power of organisms to initiate movement or action.



Explaining movement

- Modern biological science explains events mechanically in terms of causes that precede events, not goals that follow these events.
- Mechanical explanations are claimed to be exhaustive and complete.
- But compare kicking a ball vs kicking a dog
 - Both move after being kicked
 - The ball moves according to the force of the kick
 - The dog moves according to the meaning of the kick

Patient authorship of health itself

- The capacity for action is common to basic organisms that have only biological autonomy and to humans that also have personal (decisional) autonomy. It is this capacity for action that I am defining as the essence of patient-centered health.
- This primacy of action means that the most fundamental form of self-awareness is not the “I think” of Descartes, but “I can.”
- The healthy body is perceived as “I can,” for it is fundamentally a vehicle for action. The unhealthy body is a barrier to action. The healthy body is a transparent window onto the world, the unhealthy body is a wall between us and the world.

FOUR FACETS OF PATIENT ACTION

Patient as Health Care Chooser (Ch 3-4)
patient autonomy
informed consent to treatments

Patient as Health Actor (Ch 7-8)
health behavior
treatment adherence
preventive medicine
shared decision-making

Patient choosing health care
vs.

Patient participation in health care

Does shared decision-making
have health benefits itself?

How does HRQL motivate
health behavior?

Patient supplying values
vs.

Patient supplying facts
Nature of clinical problem
Criteria for effective treatment

How does agency in non-
health behavior domains
produce health benefits?

How does the link to patient
action affect the valuation of
health outcomes?

What is the biology of patient
empowerment?

What is the link between vitality and longevity?

Patient as Health Perceiver (Ch 5-6)
patient-reported outcomes
SRH: self-rated health
Health-Related Quality of
Life (HRQL)
health-state utilities

Patient as Health Creator (Ch 9-10)
infection resistance
vitality and vitalism
Biological autonomy
Niche construction

Is self-rated health a state (of biological order)
or a capacity (for ordering the environment)?

My new book

- In order to meet the challenge of chronic illness, we must promote patient participation in the production of health.
- Patients are the primary producers and perceivers of health.
- Available from Oxford or Amazon
- markdsullivan.org

The Patient as Agent of Health and Health Care

MARK D. SULLIVAN

