

# **Adherence is a system problem:**

**Is there a “common-sense” approach to implementation?**

**Creating & disseminating two faces of expertise in institutional,  
community and cultural settings.**

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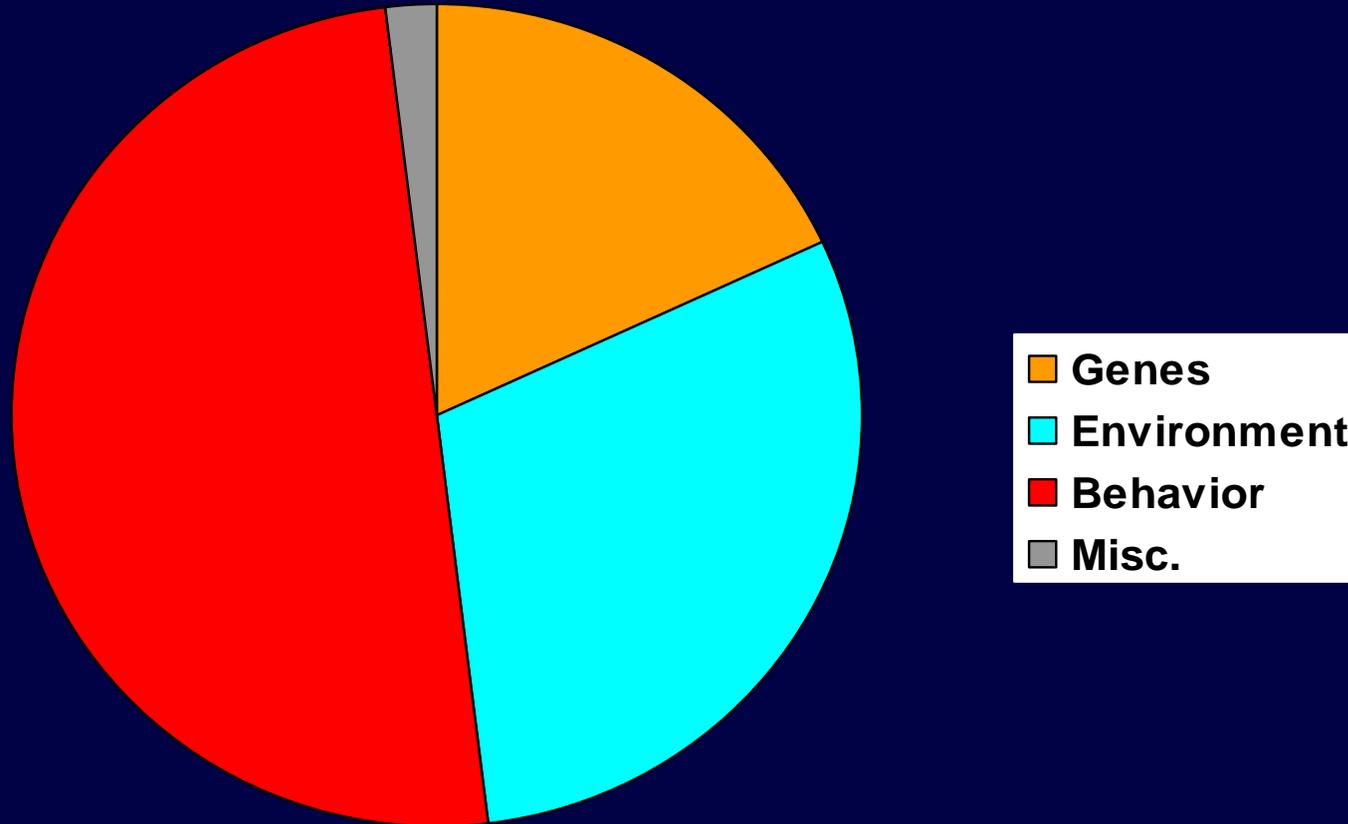
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**Behavioral (environmental; social; psychological) Factors play a key role in health outcomes: Morbidity & mortality**



# Can changes in behavior improve health outcomes?

Epidemiological studies suggest it can

**BUT**

**Correlation is NOT causation!**

**Randomized, clinical trial is the “Gold Standard”**

# Lifestyle change is Very Effective for diabetes prevention!

Knowler, W. C., Barrett-Connor, E., Fowler, S. E., Hamman, R. F., Lachin, J. M., Walker, E. A., Nathan, D. M., & Diabetes Prevention Program Research, G. (2002). Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. *New England Journal of Medicine*, 346(6), 393-403.

Condition	N	Adhere	-Kg Lost	Exercise	<sup>a</sup> cases per 100 person years	
					Cases	-% Diabetic
Lifestyle	1079	-----	5.6	6 MET-hr/wk	4.8 <sup>a</sup>	58%
Metformin	1073	72%	2.1	1 MET-hr/wk	7.8	31%
Placebo	1082	77%	.1	1 MET-hr/wk	11.0	-----

Female – 67%; White – 55%; Age – 51; Family Hist. Diabetes – 69%; Wt. – 94.Kg.; BMI – 34;  
 Plasma glucose: Fasting = 106; 2 Hours post load = 164; HBA1c = 5.9; Leisure Activity – 16.3 MET-hr/wk

# **The world outside the trial looks very different!**

## **Adherence is poor for management of ALL chronic illnesses**

### **The example of Hypertension**

**In 1976: Sacket & Haynes proposed The 1/2 Rule**

**1/2 of those with hypertension have been diagnosed**

**1/2 of diagnosed in treatment**

**1/2 of those in treatment are in control**

**Approximately 12.5% of individuals with hypertension are adequately controlled.**

# The situation has changed relatively little

1. Burt, VL. Et al, (1995). Prevalence of hypertension in the US adult population, *Hypertension*, 25, 305 – 313.
  2. Dunbar-Jacob, J., & Schlenk, E. (2001). Patient adherence to treatment regimens. In *Handbook of health psychology* (pp. 571-580). Mahwah, NJ: Erlbaum.
- Phillips, L. S., Branch, W. T., Cook, C. B., et. Al.. (2001). Clinical Inertia. *Annals of Internal Medicine*, 135, 825-834.

## Why?

**Intense Effort to promote change in the clinical trial**

**System failures outside the trial?**

**Physician Response to Trial Data**

**Evidence based medicine for drugs, but not behavior**

**Don't attribute the problems in adherence the  
public or patient!**

**Don't BLAME THE PATIENT!**

**It is a system failure!**

**Can the system be improved?**

**How?**

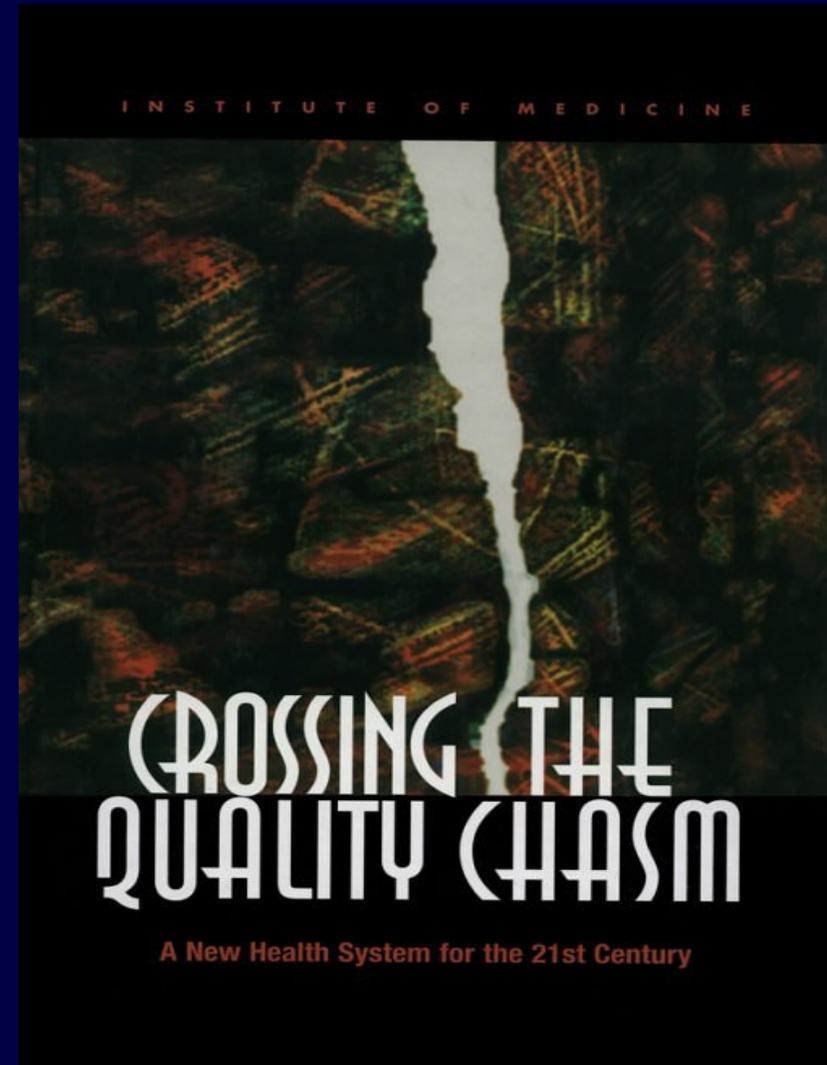
# The SYSTEM!

- **What is it?**  
What are its components?
- **Where does implementation begin?**

# Institute of Medicine Report: 2001

Berwick, 2002, Health Affairs

## IOM Report: The 4 Levels



# Four Levels Involved in the Quality Chasm

Berwick, 2002, Health Affairs, 21, (Pp 80 – 90)

**Level A:** Experience of PATIENTS and communities

**Level B:** Microsystems of care: Small units of work that actually give care

**Level C: Health care organizations:** Systems for finding best practices;  
Better use of information technology; development of teamwork;  
Coordination of care; etc.

**Level D: Health care environment.** Policies re payment,  
information sharing, Culture

# Where do we start?

1. Policy, i.e. from the Top Down? Improves access but may not improve health outcomes.

Bickman, 1999 American Psychologist

2. Ground Level, i.e., from the Bottom Up?

3. Do we do everything at once?

What do we learn if it doesn't work?

We start at a specific place so we can tell what works & what does not work

# How & where can we intervene?

**One target will be Level B: Microsystems of care:**

**Small units of work that actually give care**

**What do practitioners need to KNOW and DO to change the practitioner-patient relationship to:**

**Enhance quality of experience?**

**Insure effective self care at home?**

**Improve the quality of care?**

**Second Target: How can we influence the other levels of the system to support change at the Micro-system?**

**Medical Care System**  
**Social context**  
**Cultural level**

**To improve the quality of care for chronic illness  
practitioners need to KNOW:**

- 1. What chronically ill patients do both when in and out  
of the health care system**
- 2. How patient SELF REGULATE at HOME**

**We have studied how the elderly manage chronic illness & use health care because they:**

- **Have lots of chronic illnesses**  
high costs, high morbidity & mortality
- **Have much experience in processing illness information**
- **Are good at telling us about their health & what they do**

**A Qualification**

**We do not assume that what they think, feel & do gives an accurate picture as to how to treat chronic illness!**

# Common-Sense & Self-Regulation

## Proposition

People are Active Problem Solvers

**They are Common-sense  
biologists-physicians / psychologists  
*connecting somatic experience with words,*  
i.e., labels with generalized meaning**

# They construct:

Representations or “models” of illnesses

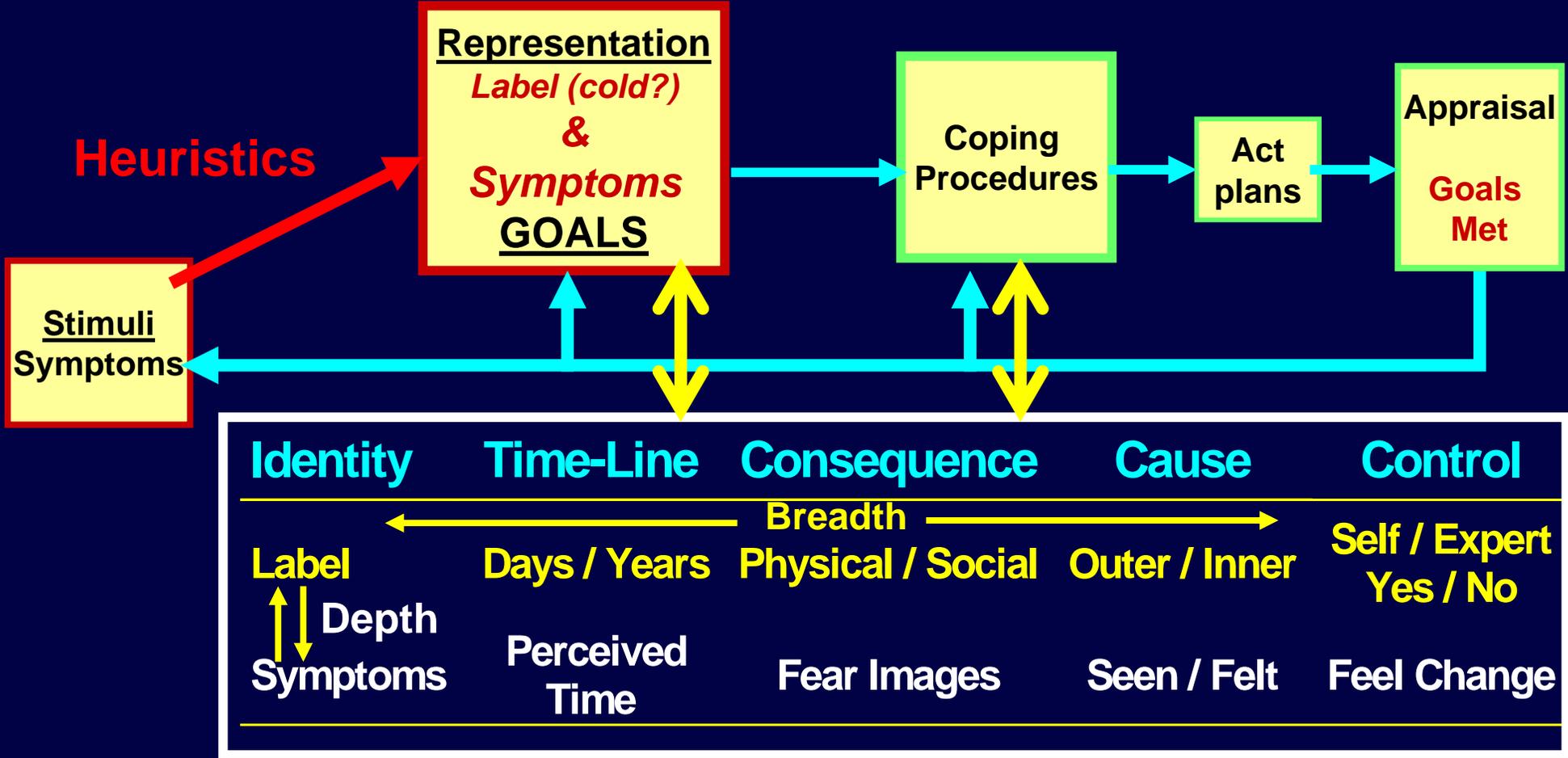
Representations of Procedures

Create Action Plans & ACT

Appraise outcomes of action

An integrated & temporally extended  
Common-Sense, Self-Regulation Process!

Somatic change initiates the construction of a common-sense model in the “problem space”



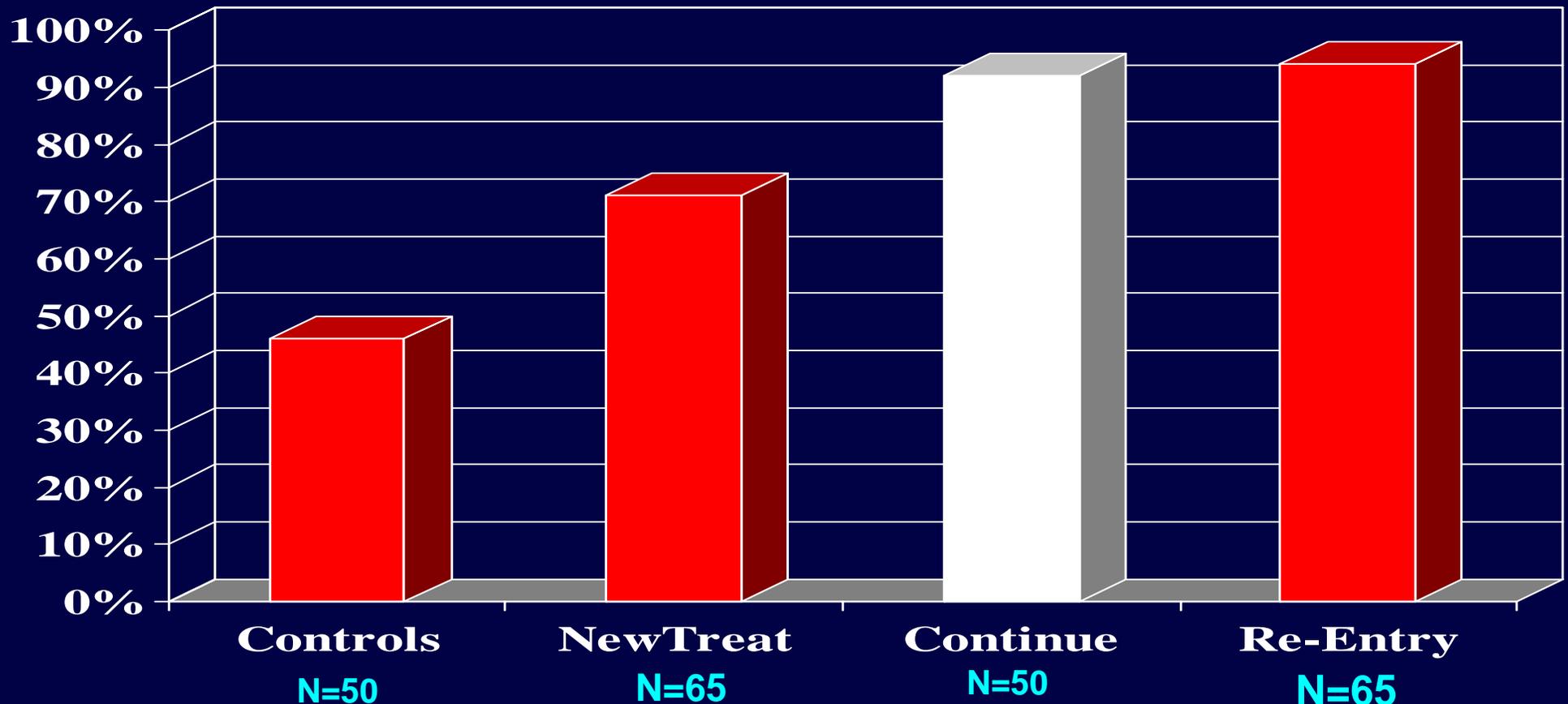
# EXAMPLE OF HYPERTENSION

**A SILENT “DISEASE” that can cause serious outcomes**  
**Heart attack; Strokes**

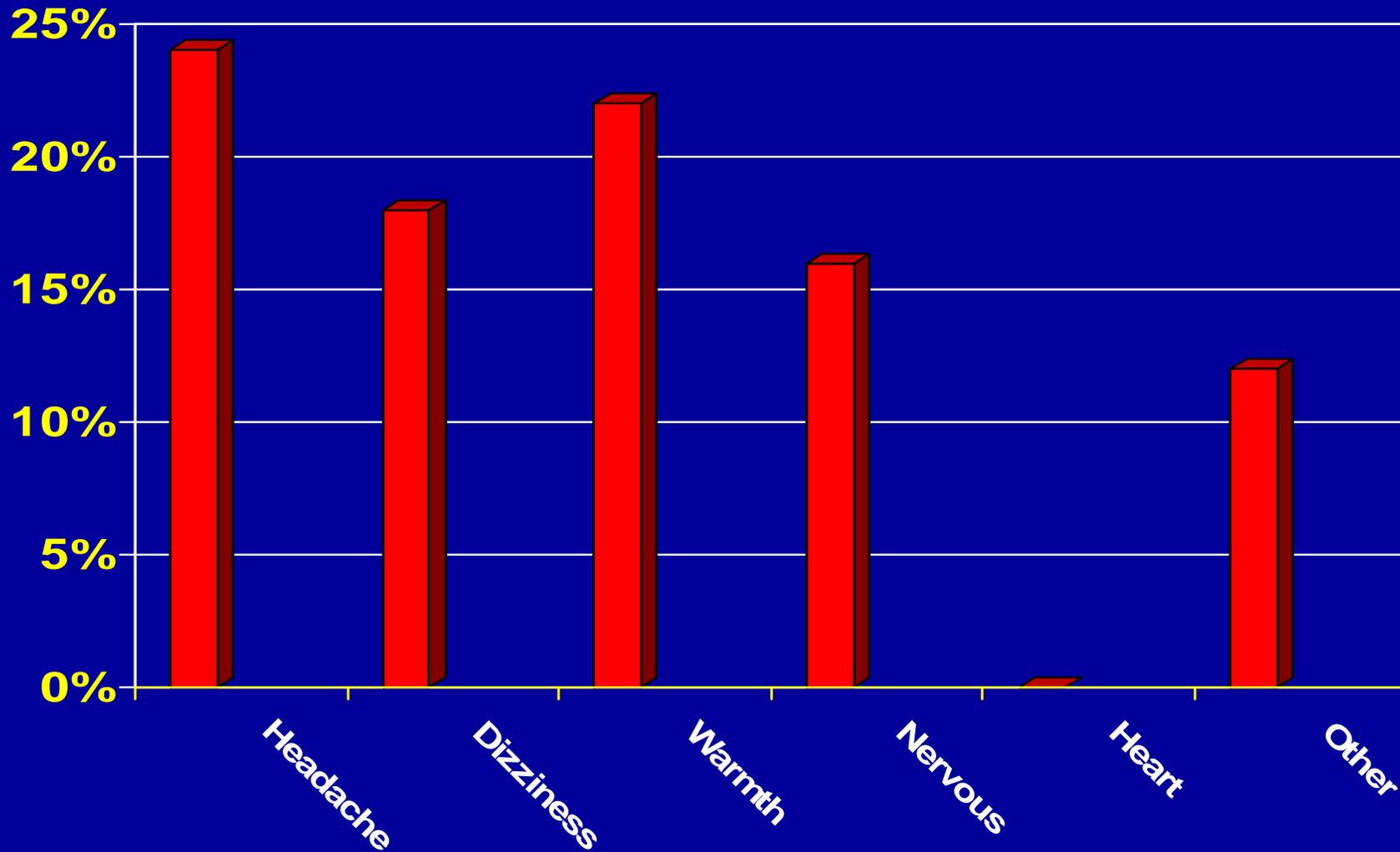
**Leading to Invasive, threatening, & expensive**  
**(to individual & system) interventions**

**80% of Continuing treatment patients agreed that**  
**“People can’t tell when their blood pressure is up.”**

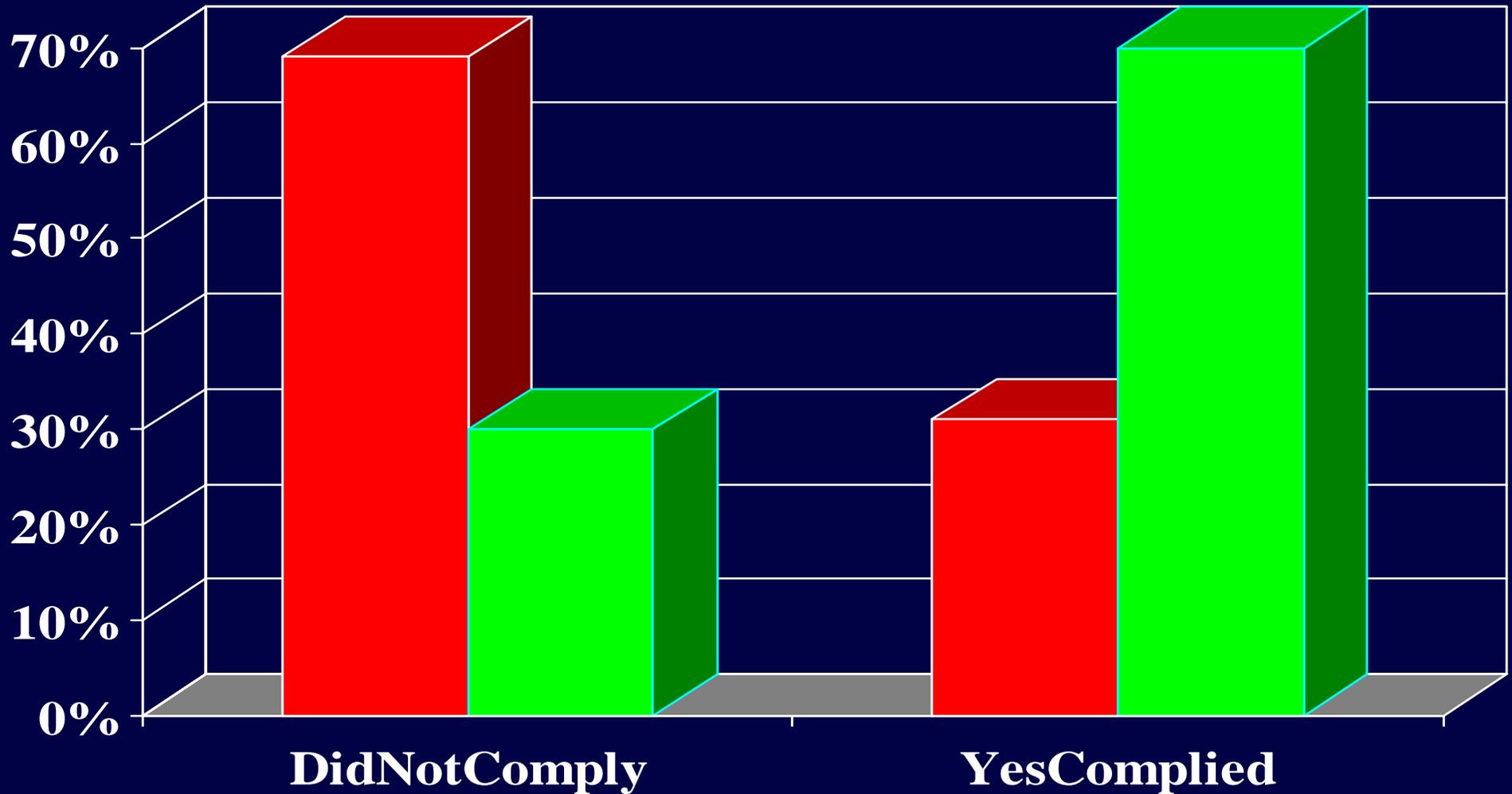
**92% indicated that they could tell**  
**“Do you think you can tell when your blood pressure is up?”**



# Symptoms Reported by the 50 Patients in the Continuing Treatment Group



# Medication Compliance - Continuing Treatment Patients



**■ No: DidNotAffectSymptoms** **■ Yes: DidAffectSymptoms**

# **Medication Compliance Affects Blood Pressure Control in Continuing Treatment Patients**

**53% of compliers have blood pressure Controlled**

**24% of non compliers have blood pressure Controlled**

**But control is not perfect!**

**Why did 64% of the continuing treatment patients  
say:**

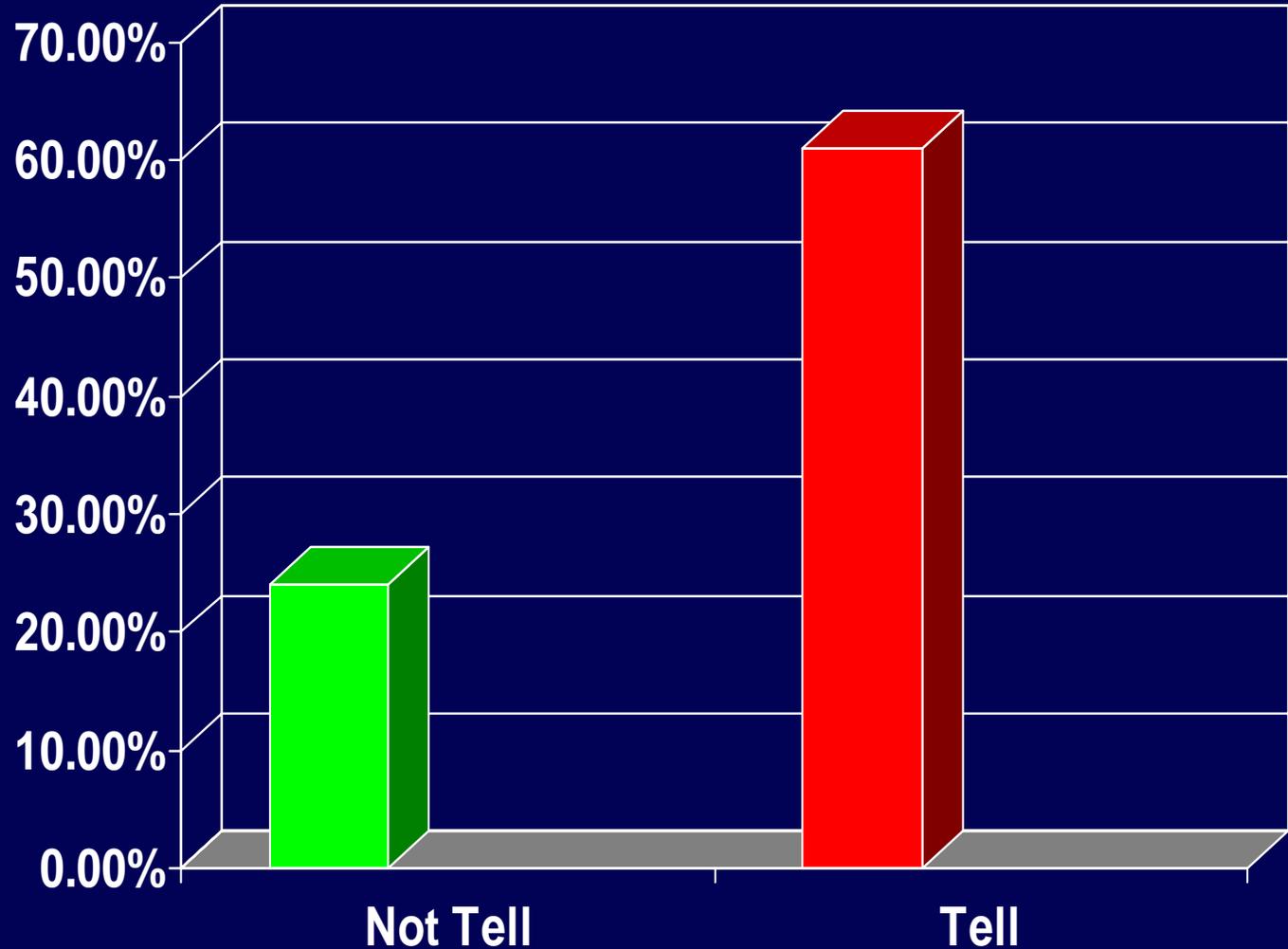
**“Don’t tell my doctor what I said!”**

**What happens if they tell their doctors?**

# Telling Doctor “I can monitor BP with my symptoms” increased DROPPING OUT of treatment 9 Months later

Patients new to treatment (n=65)

% Dropping Out



**Patients treat symptoms**

**Doctors treat hypertension**

**Their models of hypertension are different  
Discrepant!**

**How does self regulation proceed when patients do not construct a model of their disease?**

**Example of Congestive Heart Failure**

**Wait for an emergency & Call 911**

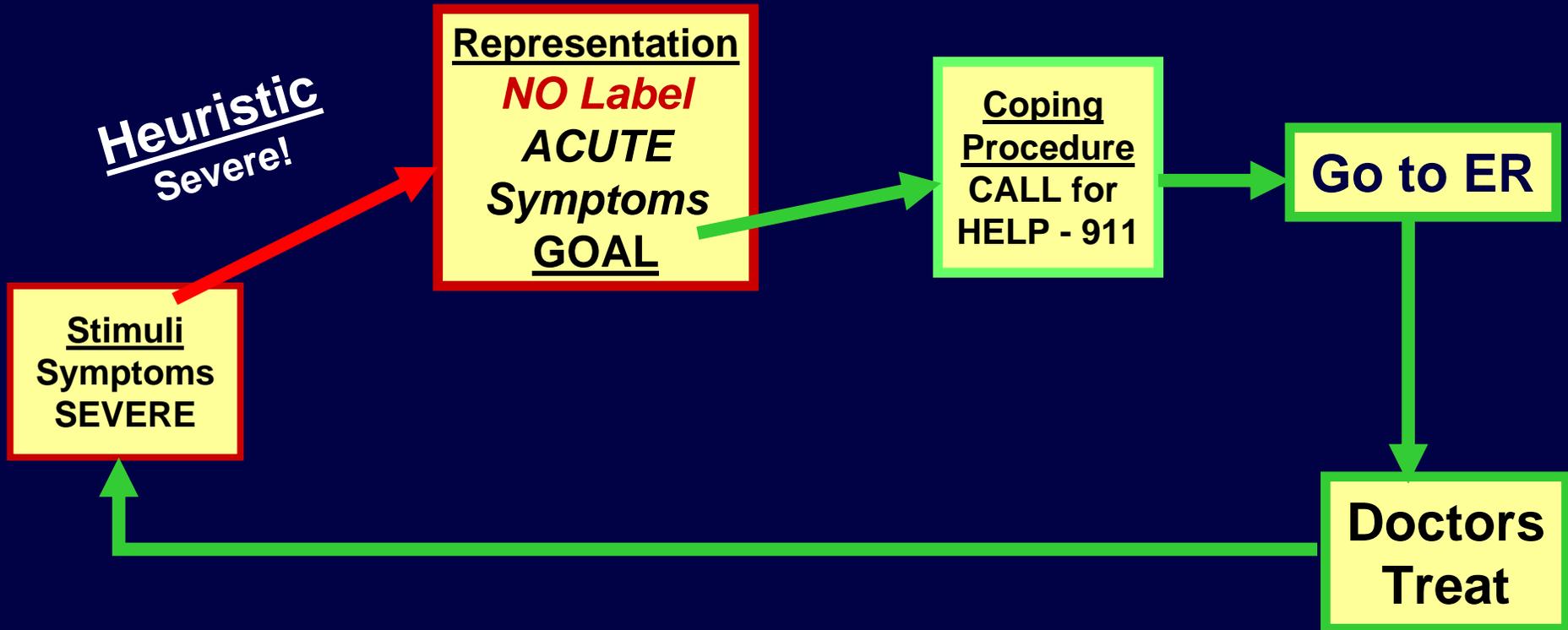
**Or**

**Monitor Symptoms, use diuretics, call practitioner**

# Problem Space with No Connection of Symptoms & Label



# SEVERE Symptoms not connected to Label (Problem space)



## **Absence of Depth**

**No connection of symptoms to label**

**“When you hear about having heart problems, ...you’re supposed to feel maybe a pain in your left arm, maybe a pain in your chest, or pressure. I couldn’t describe what I felt as pressure but I guess it must have been that, uh because I had to struggle in order to talk... I guess it would have been more clear to me if I had chest pain and then I would have said okay, I’ll call and say I’m having chest pain but it didn’t just seem to me like anything came together where I could call.”**

**No depth → No monitoring of change**  
**And lack of breadth**

**Interviewer Q: “And how do you make that decision that it’s time to go to the emergency room?”**

***Patient* “...well, all these things seem to happen in the middle of the night so I don’t call doctors.”**

**Interviewer Q: “During the week, you said you weren’t feeling that great,…”**

***Patient* : “May be I was kind of tired but it just didn’t seem to be anything out of the ordinary.”**

**Interviewer Q: “Were there any warning signs earlier?”**

***Patient:* “Not that I could detect. Like I said I didn’t feel that great. Oh, I guess that I could have gone to the doctor after I had that collapse on the hallway floor. It might have been a good idea.”**

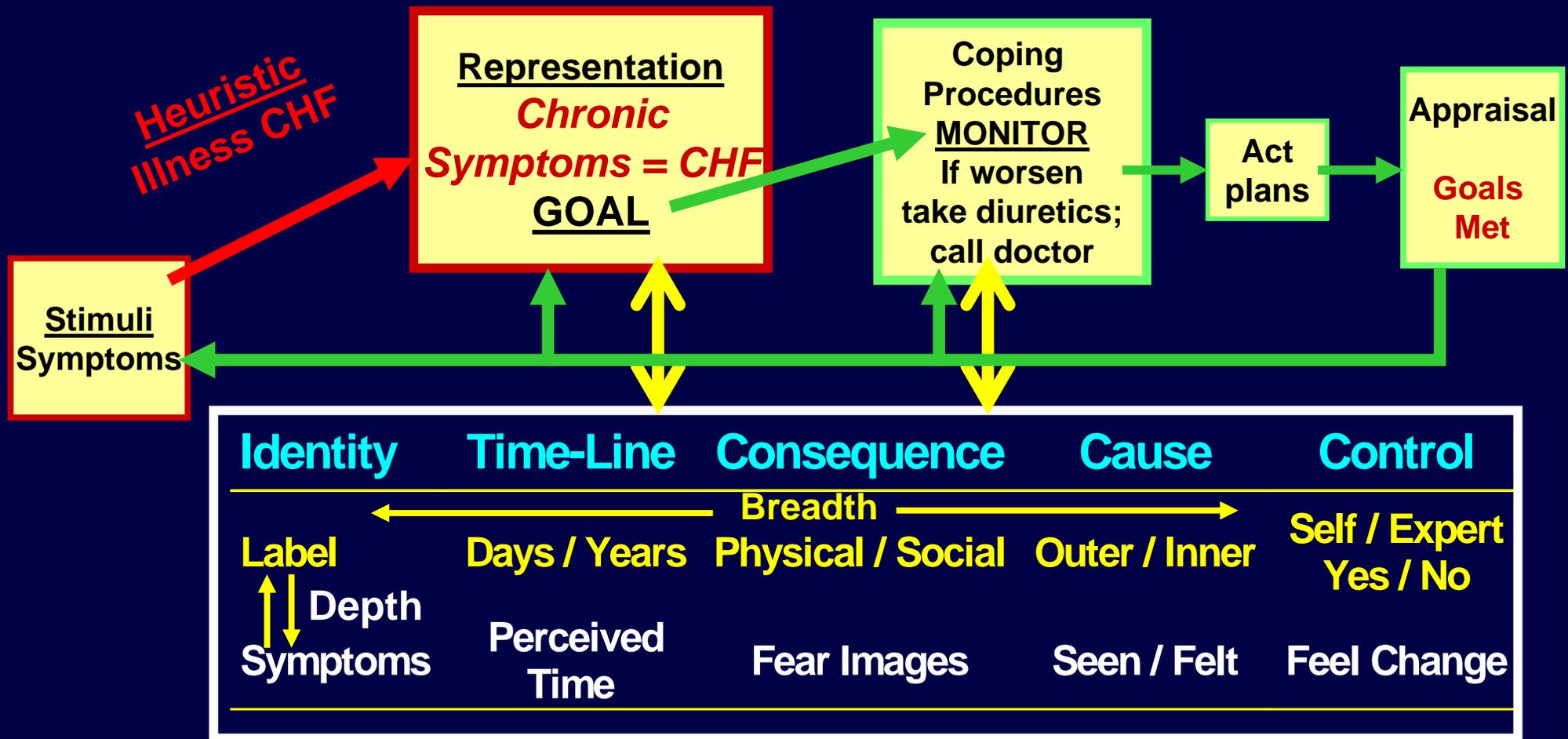
# Failure to link symptoms with procedures Absence of a Coherent Chronic Model

Interviewer Q: “So insulin needs to be adjusted to control the diabetes... Which medicine needs to be adjusted to control the heart failure?”

Patient: “The real key seems to be my diabetes... if you don’t take your medications you get sick. As far as the heart goes, I don’t really have enough knowledge about it and uh, I also do not have a sense of uneasiness.”

Patient: “I never do [use salt], since... my pressure went up on me years ago ... I don’t use salt like when I cook ... I use like a bouillon cube...”

# Connection of Symptoms to Label



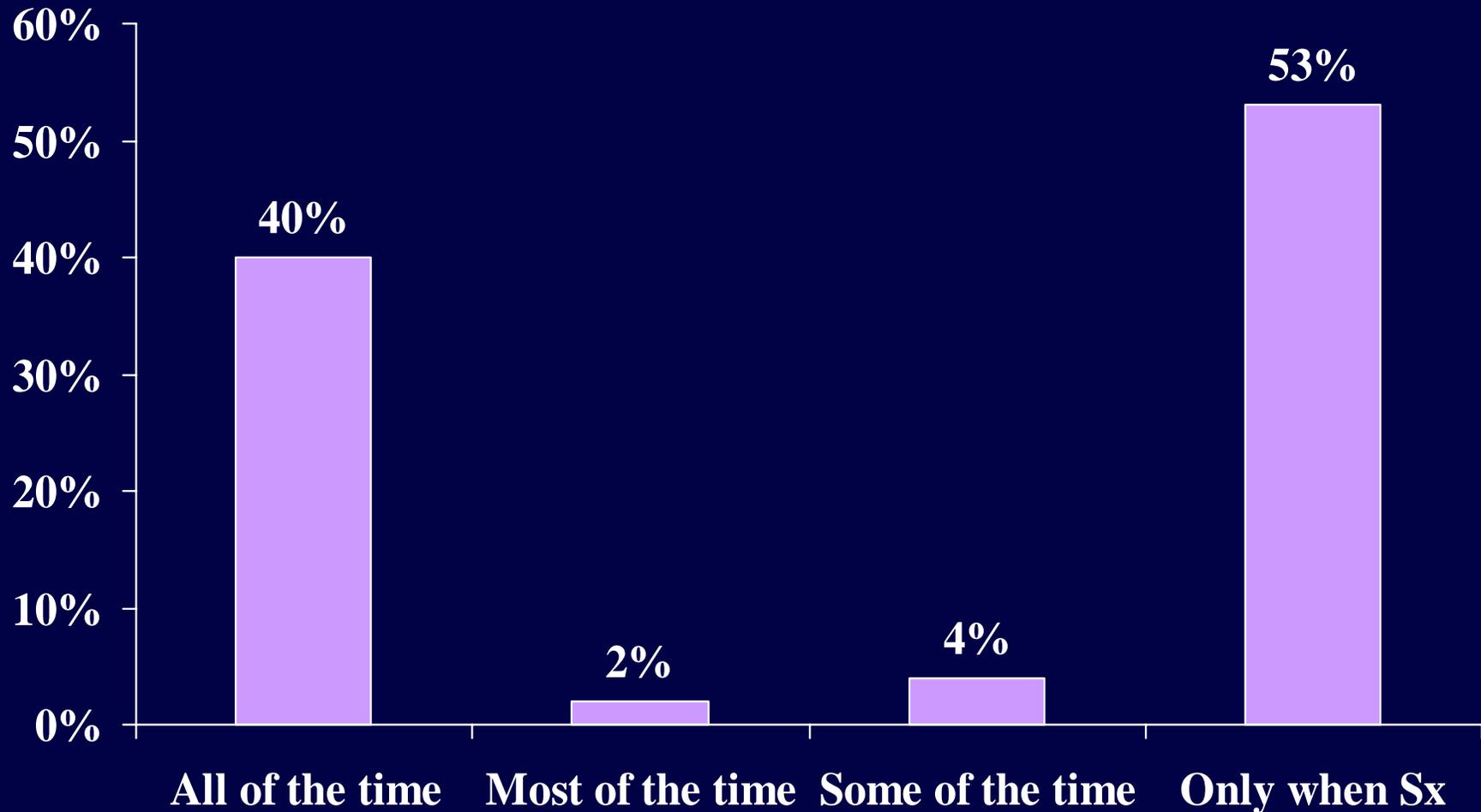
**Asthma: A second example of a chronic illness experienced as episodic**

# Representation of Asthma in hospitalized patients (n=198)

(28% Spanish speaking only)

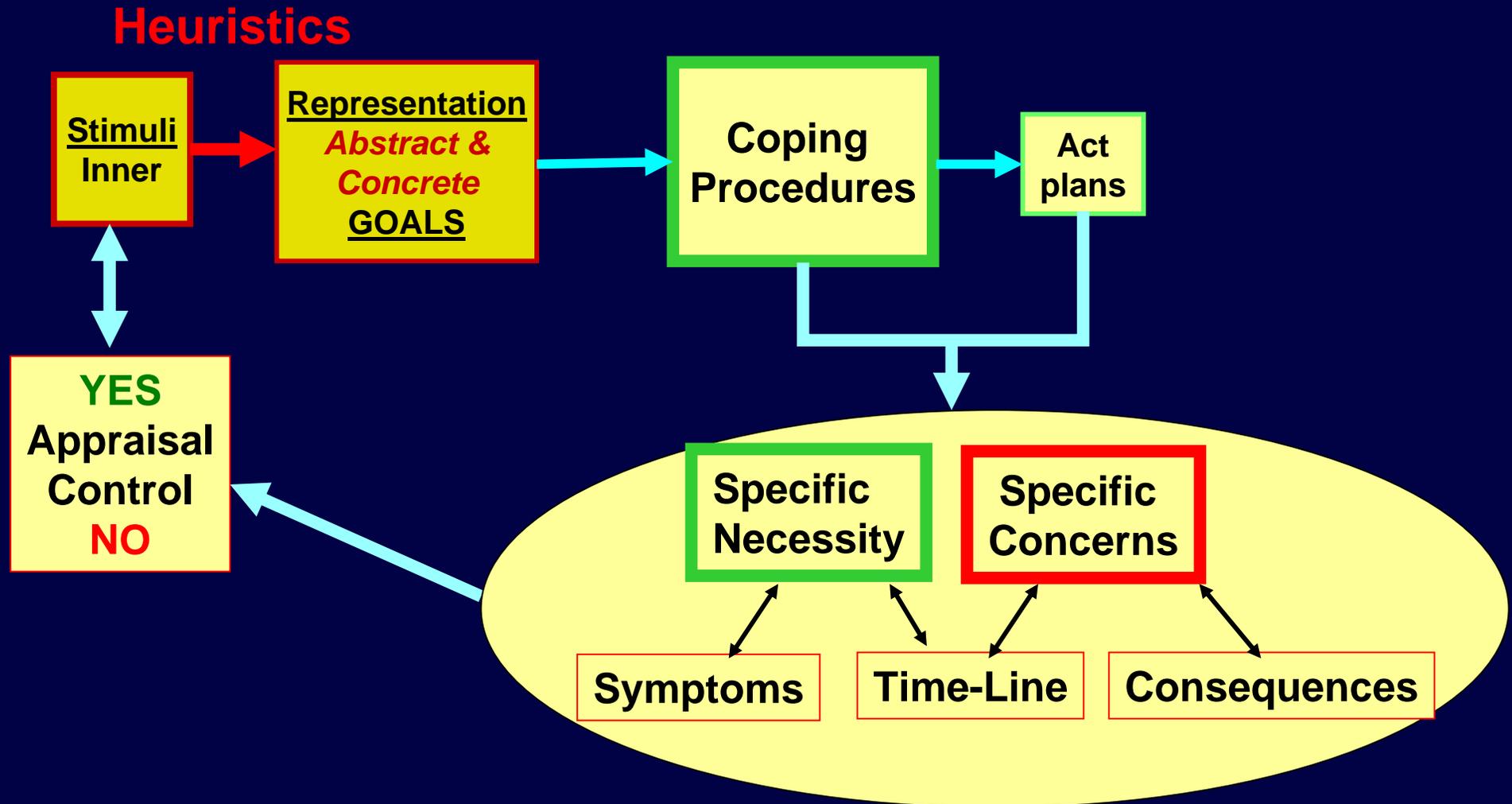
<b>Mean age, yrs</b>	<b>50 (18-101)</b>
<b>Female</b>	<b>78%</b>
<b>Hispanic</b>	<b>62%</b>
<b>Black</b>	<b>28%</b>
<b>Medicaid</b>	<b>65%</b>
<b>Uninsured</b>	<b>8%</b>
<b>Usual source of care</b>	<b>82%</b>
<b>Prior intubation</b>	<b>23%</b>
<b>Prior oral steroid use</b>	<b>88%</b>
<b>Oral steroids all/most of time</b>	<b>31%</b>

# Timeline: Do you think you have asthma all of the time or only when you're having symptoms?



**The biomedical properties of disease and treatment  
shape the mental representation, goals for self  
management and the appraisal of outcomes**

# People construct representations of treatment procedures

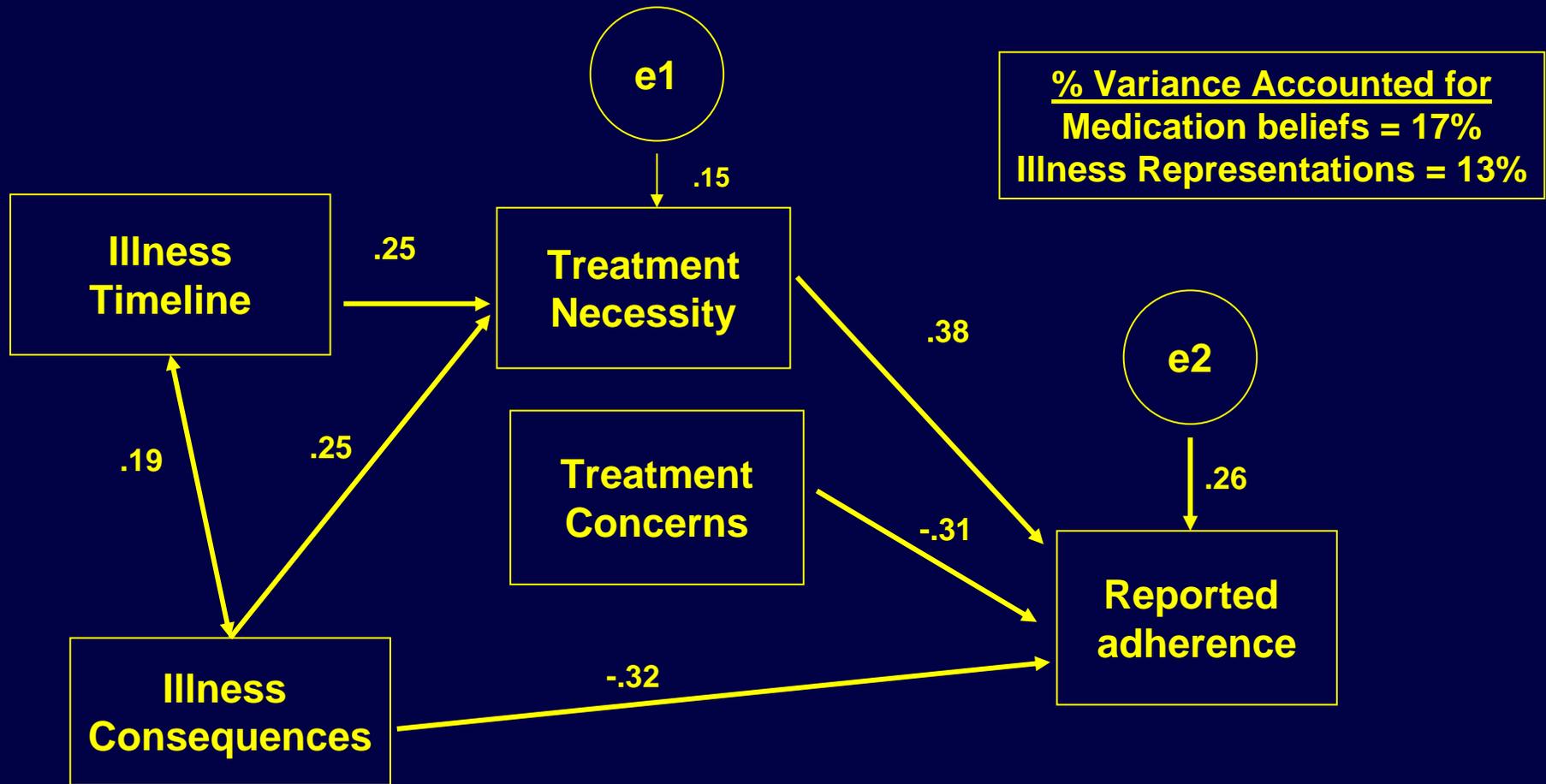


Horne (1997) Representation of medication and treatment. In K. Petrie & J. Weinman (Eds.) *Perceptions of health and illness*. London: Harwood

Horne, R. (2003). Treatment perceptions and self-regulation. In L. D. Cameron, & H. Leventhal (Ed.), *The Self-Regulation of Health and Illness Behaviour* (pp. 138-154). London: Routledge Taylor & Francis Group.

Horne, R., & Weinman, J. (1999). Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *J. Psychosomatic Res.* 47, 555-567.

# Structural equation model of reported adherence to inhaled preventive medication (inhaled cortico-steroid)



# **Multiple Heuristics are involved in the construction of meaning: i.e., representations**

**Symmetry: Labels → Experience symptoms / Symptoms → Labels**

**Duration: Felt time & clock time : Exceed expectations**

**Age / Illness: Chronic, Low level, Unchanging Vs Acute, Severe, Changing**

**Gender Stereotypes: Cardiac symptoms = stress in women, CHD in men**

**Stress / Illness: New symptoms & new stress = Stress if symptoms vague**

**Prevalence test: More have it = less serious; Only self = more serious**

**Location: Caused by organ at specific location**

**Similarity tests: Similarity of exposure; temperament & vulnerabilities**

**The Problem Space in which the processes of interpretation, action & appraisal of outcomes takes place, is nested in the context of the**

**Self System  
&**

**Environment - Social / Institutional / Ecological**

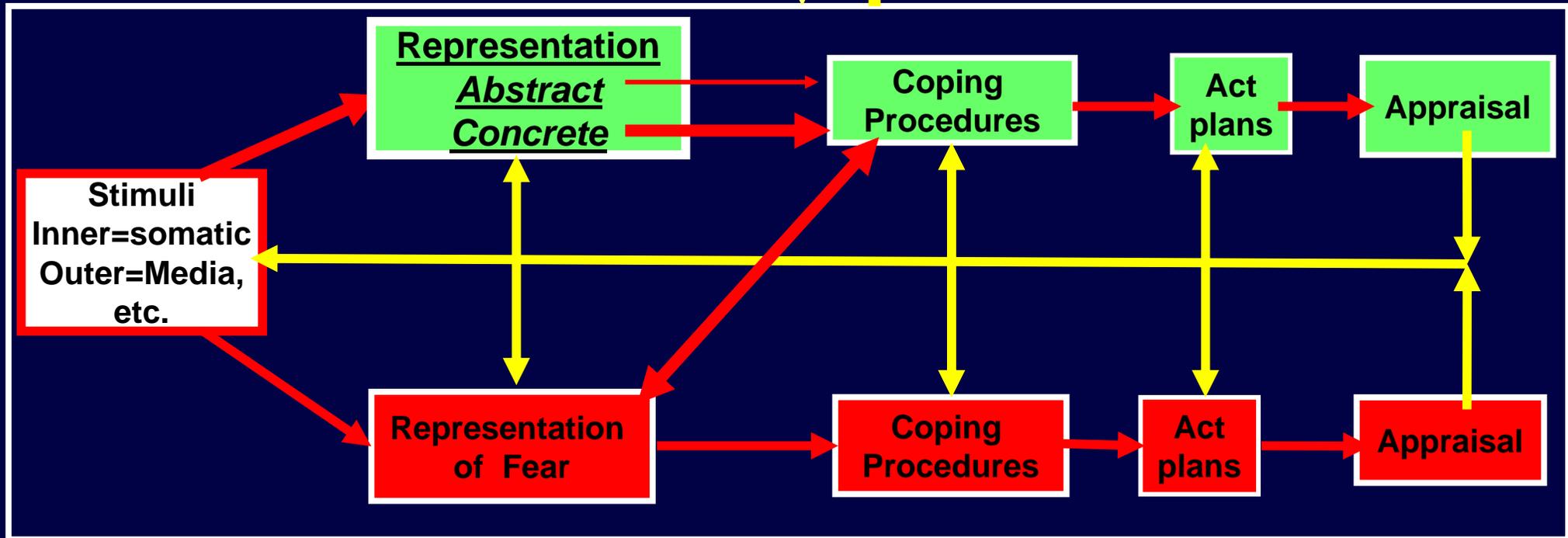
# Bi-directional relationships of Self, Social Factors & Problem Space

“Social” Health care institutions; Cultural Beliefs; Life stress

Self System: Physical & Cognitive Capacities  
Identities; Self regulation strategies

Problem Space

Problem Space



Problem space is bi-level: abstract & concrete/experiential

# **Person factors moderate the representation of symptoms & treatment preferences**

## **Self regulation strategies:**

**Conservation / Use it or Lose it**

## **Self appraisals of Vulnerability & Health Status**

**Disease specific vulnerabilities**

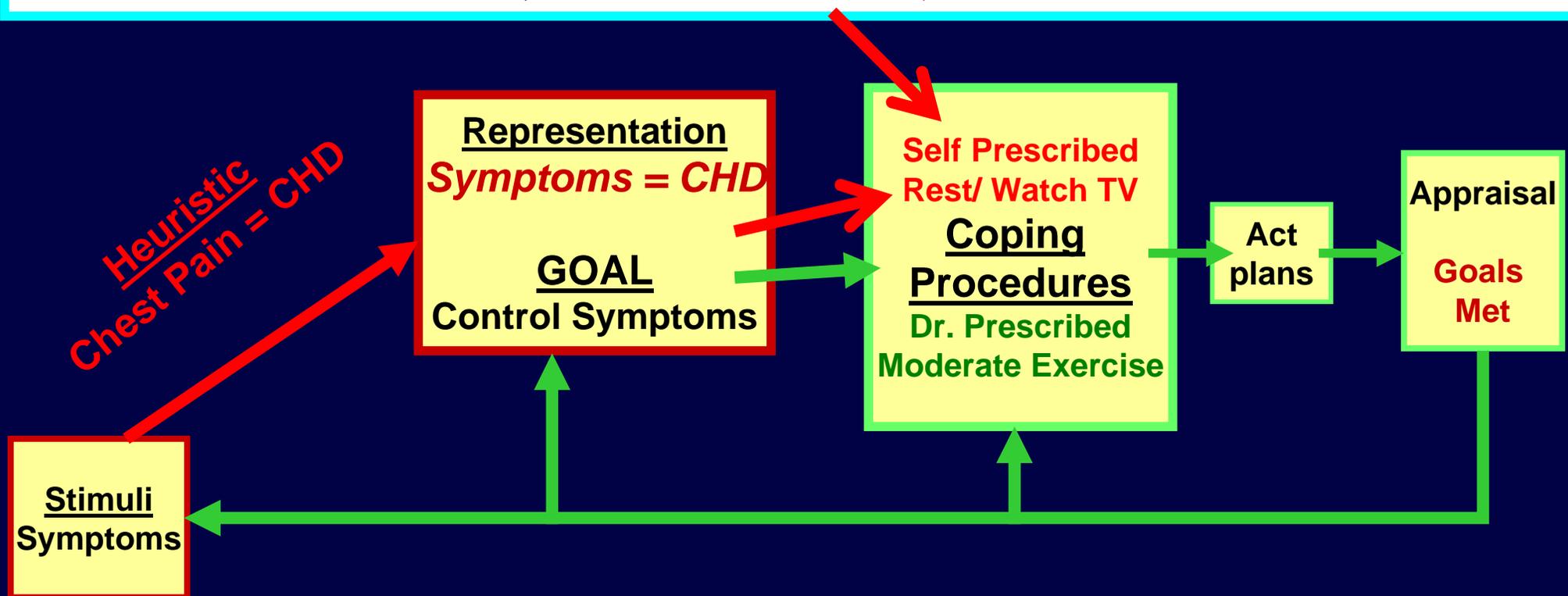
**Self Assessments of Health (SAH)**

**Emotional traits – E.g.: Trait Negative Affect; Extraversion; Etc.**

# Self regulation strategies & choice of coping procedures

Age related, SELF REGULATION strategies moderate coping

SAH; Sensitive soma; **Conservation**; Use it or lose it; Competence



**Strategies that reduce stress (optimize feelings) optimize health.**

## **A Strategy of Risk Aversion- Energy conservation**

**adopted by elderly persons to reduce risk in light of ambiguities in health status:**

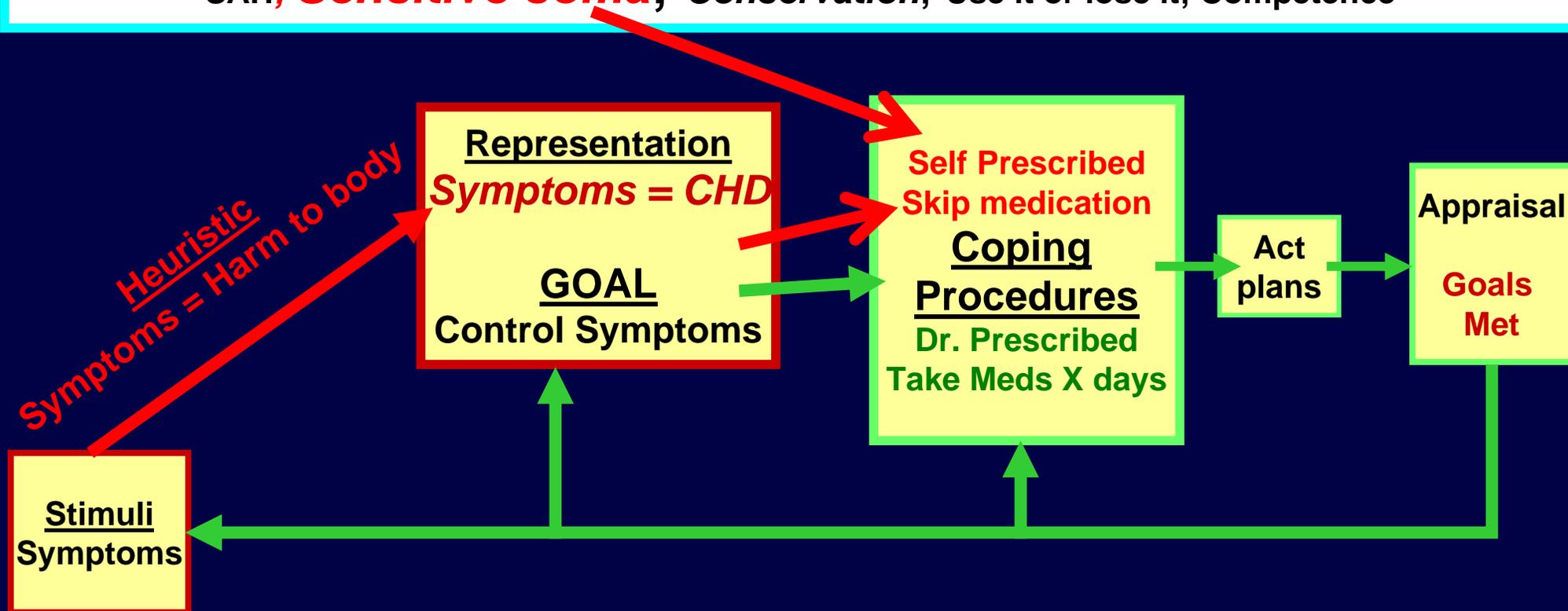
### **Underlies motivated actions**

- Swift seeking health care**
- Not replacing activities given up due to illness**
- Willingness to expend energy: exercise**

# Appraisal of somatic system affects coping procedures

## Age related, SELF REGULATION strategies moderate coping

SAH; **Sensitive soma**; Conservation; Use it or lose it; Competence



# Sensitive Soma is Associated With

My body is very sensitive to medicine

My body over-reacts to medicines

I usually have stronger reactions to medicines than most people

I have had a bad reaction to medicines in the past

Even very small amounts of medicine can upset my body

1 = Disagree 5 = Agree

<u>General Beliefs Re Medicine:</u>	<u>Overuse</u>	<u>Harm</u>	<u>Benefit</u>
HIV (n = 139)	+0.38	+0.32	-0.34

<u>Specific Beliefs Re Medicine:</u>	<u>Necessary</u>	<u>Concerns</u>
HIV Patients (n = 139; HAART)	-0.30	+0.39
Hypertension (n=230 ASCOT trial)	-0.13	+0.39

<u>Adherence (HAART):</u>	<u>Lo (n=11)</u>	<u>Hi (n=42)</u>
Sensitive Soma Means =	15.64	12.71

<u>Symptom Reports Post Vaccination (n= 121)</u>		
	<u># Symptoms</u>	<u># Attributed to Vaccination</u>
Correlation with Sensitive Soma	= +0.26	+0.27

# What factors are most strongly related to behavior!

## Factors in the problem space:

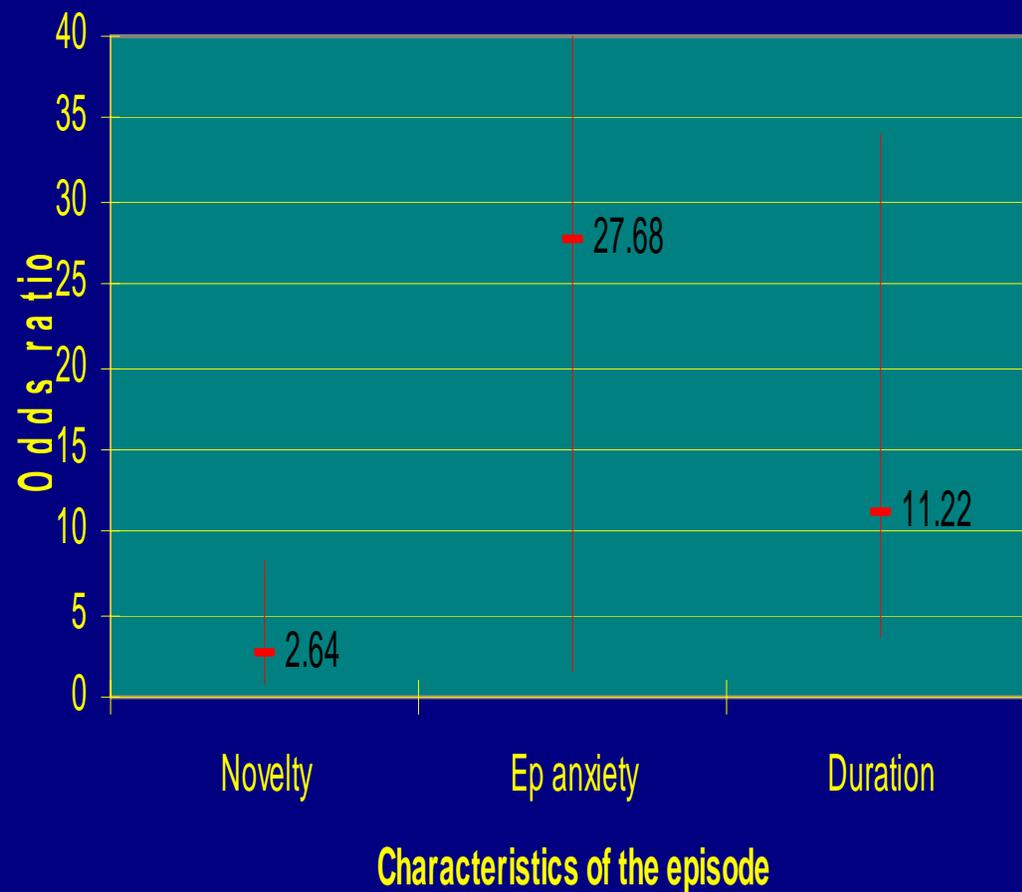
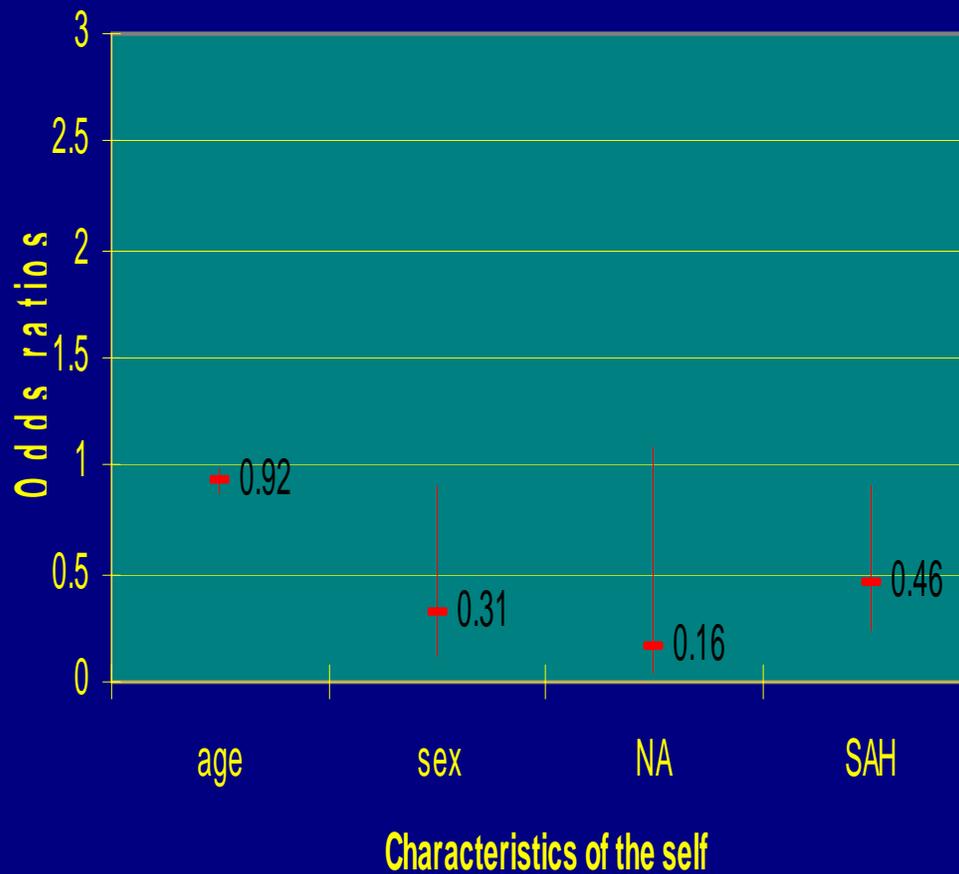
Heuristics & Interpretation of symptoms: Eg. Novelty

Action plans: Eg. Do X at Time 1 and place 1

## Personal appraisals & characteristics

Eg. SAH & TNA

# Odds Ratios From Logistic Regression Predicting Care Seeking for Ongoing Chronic Conditions (n=121)



# **Intervention: What can be changed?**

**Q: Factors in the problem space? Ans.: YES**

- **Specific meaning of symptoms &/or procedures**
- **Action plans: Finding a time & place to do X**

**Q: Features of the SELF? Ans.: NO**

- **Self regulation strategies: Beliefs about self; Personality?**

## The Expert System

**Defining the second face of the practitioner's role!**

- 1. Expertise in diagnosis and treatment**
- 2. Expertise in diagnosis and treatment of patient representations of illness & treatments**

# Facets of the expert system

- Action planning
- Symptom Interpretation
- Shaping the problem space

Identifying schemata for illness and treatments and linking both to experience

# **Two well documented interventions implemented by practitioners in everyday practice**

## **Implementation of action planning**

**Providing examples to encourage self-generated plans?**

**Who does it? Ans. The Patient**

## **Implementation of symptom interpretations**

**Preparation for experiencing sensations & providing benign interpretations**

**In what setting?**

**Who does it? Ans. The practitioner**

# Identifying, making public & revising patients' schemata that differ from those of practitioner

- 1) Life threat / No life threat with common symptoms
- 2) Silent, life threatening
- 3) Chronic, but experienced as episodic
- 4) Dysfunctional but not life threatening
- 5) Life threatening and vigilance inducing

## Underlying Schemata

Label

Timeline

Consequences

Cause

Control/coping

Appraisal

# 1) Life threat / No life threat with common symptoms

**CHEST PAIN** For MD --- 3 possible origins  
For patient --- only 1 origin

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<u>Source</u>	<u>Prognosis</u>	
	<u>MD</u>	<u>Patient</u>
Cardiac / angina →	Morbidity, mortality	Morbidity, Sudden death
Esophageal / GERD →	Morbidity	Morbidity, Sudden death
Chest wall →	Insignificant	Morbidity, Sudden death

# SOURCES of CHEST PAIN

**HEART: ANGINAL PAIN**

CHRONIC, with Morbidity, Mortality

**ESOPHAGOUS: SPASM, GERD**

CHRONIC, ? Morbidity, Mortality

**CHEST WALL: Musculoskeletal**

ACUTE, Minimal Morbidity

No Mortality

No Loss of Function

### 3) THE INTERMITTENT “FLARES”

*Medical Model = CHRONIC*

*Patient Model = ACUTE / CYCLIC*

*Examples: CHF, ASTHMA*

# Patient's Affective & Cognitive Model

**Fear - Distress -- Problem based**

**Identity**

**Time-Line**

**Consequence**

**Cause**

**Control**

**Label**

**Days / Years**

**Physical / Social**

**Outer / Inner**

**Self / Expert  
Yes / No**

**Symptoms**

**Perceived  
Time**

**Fear Images**

**Seen / Felt**

**Feel Change**

**Agreement on Identity  
time-line for disease  
& treatment**

**Agreed upon  
ACTION PLAN  
treatment plan**

**Agreed upon procedures &  
appraisals of outcomes**

# Practitioner's Cognitive Model

**Diagnosis  
Label &  
Symptoms**

**Projected  
Time Frames  
symptoms/treatment**

**Prognosis  
re Outcome**

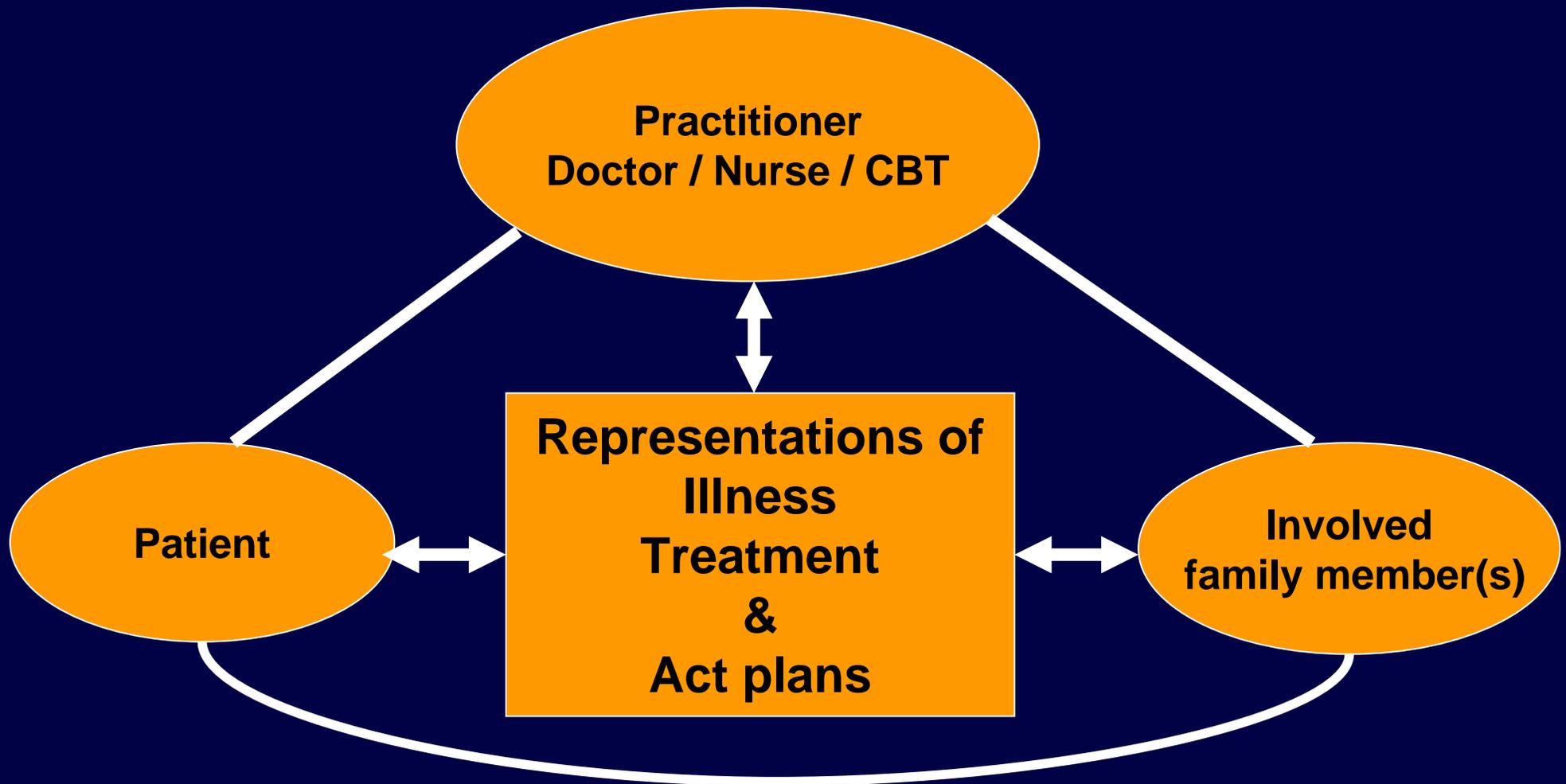
**Cause & Control  
Treatment**

**Practitioner's behavioral strategy simultaneously diagnoses the symptom and reshapes its meaning**

**The practitioner's behavior conveys meaning:**

**It is interpreted by heuristics consistent with patients underlying schemata that affect the salience & meaningfulness of the specific complaint**

The practitioner creates & shares representations  
with patients & family members



# **Is The Expert system an antidote to clinical inertia?**

Phillips, Branch, Cook, Doyle, El-Kebbi, et.al., Annals of Internal Medicine, 2001, 135, 825 – 834

**How do we embed it in the system?**

**What is needed to complement it in the practice setting?**

**How do we extend its influence outside the practice setting?**

**E.g., To family & involved others**

**What aspects of the management process do we target at the social cultural level?**

# **Motivating system change**

**Create Nodes of Excellence!**

**Transparency**

**Public Data Within Institution  
Across Institutions**

**Chassin, M. Department of Health Policy: Mt. Sinai School of Medicine**

# Disseminating across the Levels of the Quality Chasm

Berwick, 2002, Health Affairs, 21, (Pp 80 – 90)

**Level A: Experience of PATIENTS**

**Level B: Microsystems of care:** Developing shared definitions of presenting complaints chronic: That which is permanent & that which can be controlled. Interpreting, anticipating & assisting in regulation of Pt. experience.

**Publication of Quality of Care Indicators**

**Level C: Health care organizations:** Systems for finding best practices; **Better use of information technology;** development of teamwork; Coordination of care; etc.

**Level D: Health care environment.** Policies re payment, information sharing, **Culture**

# **Motivating change in the cultural context**

## **Create Nodes of Excellence!**

**Disseminate throughout the institution  
And across institutions in the payment system**

Chassin, M. Department of Health Policy: Mt. Sinai School of Medicine

## **Transparency Moved to the Public Domain**

**Publication of findings in local media  
Innovative Media Approaches regarding medication &  
alternative/complementary approaches**

**There is nothing so practical as a good theory!**

**K. Lewin**

**Q: Reverend Bayes' Question: Are your posterior probabilities  
higher than your prior?**

**The END Is But the Beginning**