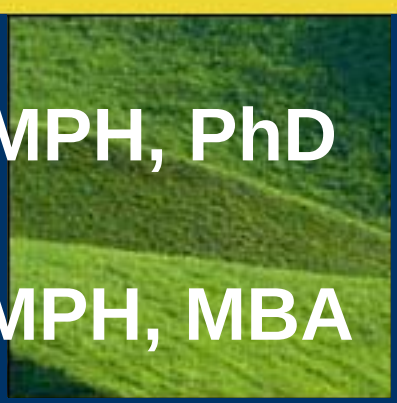
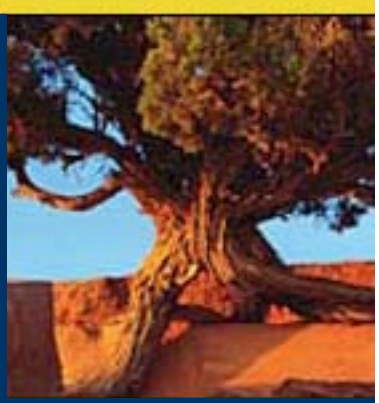
Including Patient Perspectives
in Policy-Relevant Health Service Research





Mathilda Ruwe, MD, MPH, PhD
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American Public Health Association 135th Meeting and Expo., November 3-7, 2007

Learning Institute, Course 1001

CENTRAL VALLEY HEALTH POLICY INSTITUTE
Central California Center for Health and Human Services
California State University, Fresno

Course Introduction

The early health care system set the pace for a structure where patient views are valued less than the clinician's. Although well-intended efforts to empower patients to take part in their own care and in research has increased, patient perspectives are rarely well represented in policy, partly because of the difficulty in measuring concepts and demonstrating impact. A large body of literature focuses on understanding how patient knowledge, beliefs, attitude and practices influence health behavior. Researchers, however, have not been very successful at demonstrating a consistent strong effect.

Policy-relevant research often requires demonstrating evidence. In this course you will learn a systematic approach to integrating patient perspectives into health access research with a high probability of demonstrating evidence.

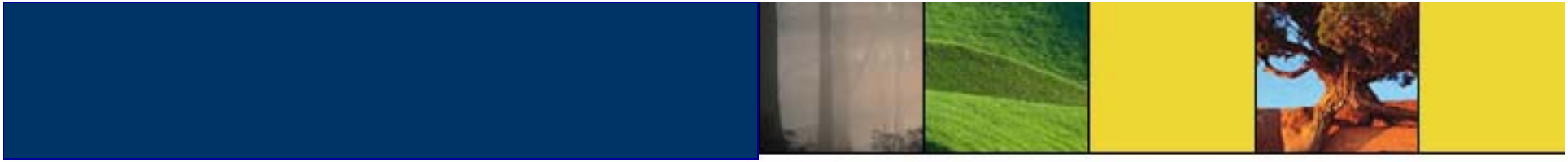
The course uses the Haitian Breast Cancer Study of mammography access and adherence which evaluated the utility of Kleinman's cultural explanatory theory as a case study. This study uses patient-derived qualitative data to predict appropriate mammography initiation (uptake) and interval adherence by a multi-ethnic sample of women. Innovative, validated approaches are used to convert patient-based qualitative data to quantitative data. Self-reported knowledge and major themes of what causes cancer are the qualitative data-derived independent variables.

What is policy relevant research anyway? The course includes an overview of what policy-relevant research is. It also includes an overview of patient care challenges in multi-cultural society and an example of how clinicians at Boston Medical Center have adapted Kleinman's cultural explanatory model to their practice.

This is a three-hour seminar with three sessions. You may choose to attend part or all of the sessions. However, to fully benefit, participants are encouraged to attend all three sessions.

Course Schedule

Time	Activity/Faculty	CE Credits
9:00 - 9:15	Welcome remarks and course introduction Dr. Ruwe	15 minutes
9:15 - 9:35	Participants self introduction and goals for attending course Dr. Capitman	20 minutes
9:35- 9:55	Challenges of Clinical Practice In a Multi-Cultural Setting and Introduction to The Boston Medical Centers' RESPECT MODEL Dr. David	20 minutes
9:55 – 10:15	What is policy-relevant research? Dr. Capitman	20 minutes
10:15 – 10:30	Break	15 minutes
10:30-10:45	Context Haitian Breast Cancer Study and Sampling Dr. David	15 minutes
10:45-11:50	The Case for Including Patient Perspectives In Policy-Relevant Health Access Research: Lessons From the Haitian Breast Cancer Study of Mammography Access and Adherence Dr. Ruwe	65 minutes
10:50-12:30	Panel: Discussion, Application to Participant Research Interests, Question/Answers, and Conclusion John Capitman, PhD Mathilda Ruwe, MD,MPH, PhD Michelle David, MD, MPH	40 minutes



Challenges of Clinical Practice in a Multi-Cultural Setting and Introduction to The Boston Medical Centers' RESPECT MODEL

Michelle David, MD, MPH, MBA

Objectives

- Why cultural diversity in medicine?
- RESPECT: A useful framework
- Skills building: homework assignment

Seminar developed by the Boston University Internal Medicine Diversity Curriculum Taskforce

Why develop a diversity curriculum?

- Changing Demographics
- Health Outcomes Disparities
- Patient Distrust/Dissatisfaction
- Professional Development/Career Satisfaction

Cultural/Racial Diversity Seminar --> Segment 2

Health Outcomes Disparities – Why?

- Poverty
- Education
- Access/Insurance
- Race
- Provider Bias?

Intercultural Development: The “Bennett Model"

Denial-->

Defense-->

Minimization-->

Acceptance-->

Adaptation-->

Integration

How to teach/learn about Cultural Diversity?

- Knowledge – to know, describe, define about….
- Skills – to effectively: communicate, facilitate, elicit….
- Attitudes – demonstrable verbal and non-verbal cues that reflect empathy and respect

Skills Development

ESFT

- EXPLANATORY MODEL
- SOCIO/CULTURAL CONTEXT
- FEARS/CONCERNS
- THERAPEUTIC PLAN

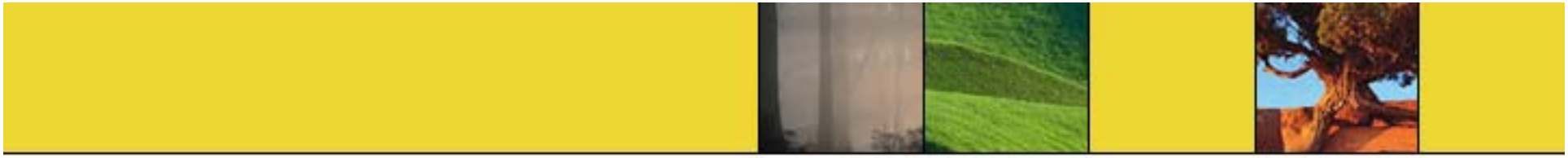
RESPECT

- Explanatory Model
- Socio/Cultural Context
- Power
- Empathy
- Concerns/Fears
- Therapeutic Alliance/Trust

RESPECT

- **R** espect - A demonstrable attitude involving both verbal and nonverbal communications
- **E** xplanatory Model - What is the patient's point of view about his or her illness? How does it relate to the physician's point of view? All points of view must be elicited and reconciled.
- **S** ociocultural context - How class, race, ethnicity, gender, education, sexual orientation, immigrant status, and family and gender roles, for example, affect care
- **P** ower - Acknowledging the power differential between patients and physicians
- **E** mpathy - Putting into words the significance of the patient's concerns so that he or she feels understood by the physician
- **C** oncerns and fears - Eliciting the patient's emotions and concerns
- **T** herapeutic alliance/Trust - A measurable outcome that enhances adherence to, and engagement in, health care

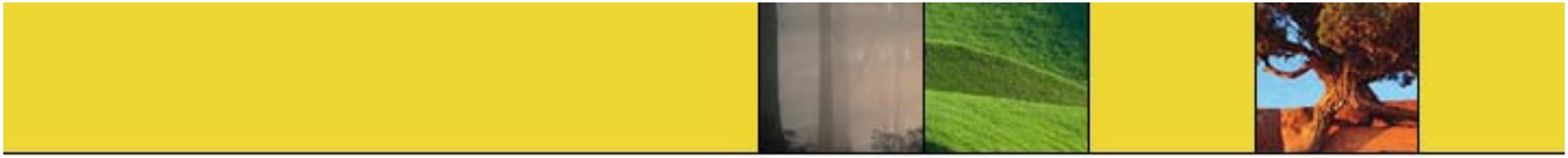
RESPECT model developed by the Boston University Internal Medicine Diversity Curriculum Taskforce



Explanatory Model

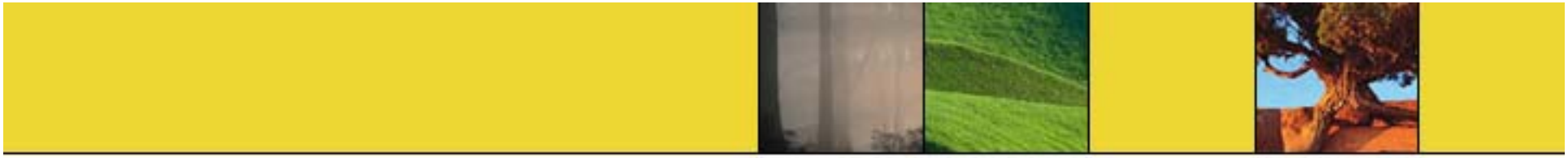
- A patient's point of view.
- The healer's point of view.

- What do you think caused your problem?
- Why did this problem occur?
- How has it affected your life?



Socio-Cultural Context

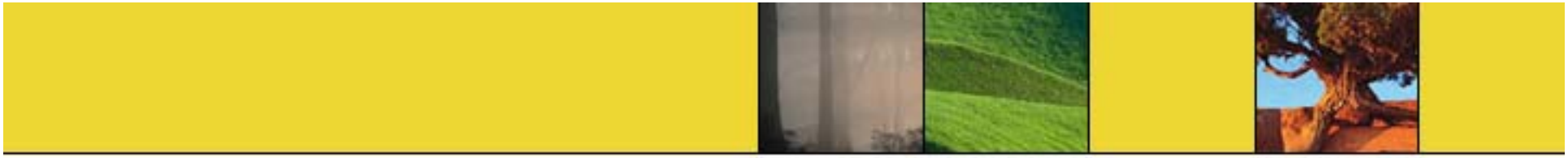
- Who is this patient with this illness?
- Cultural influences on health, illness, and medicine
- Social structure and coping strategies in illness
- Culturally normative communication and behavior



Socio-Cultural Context

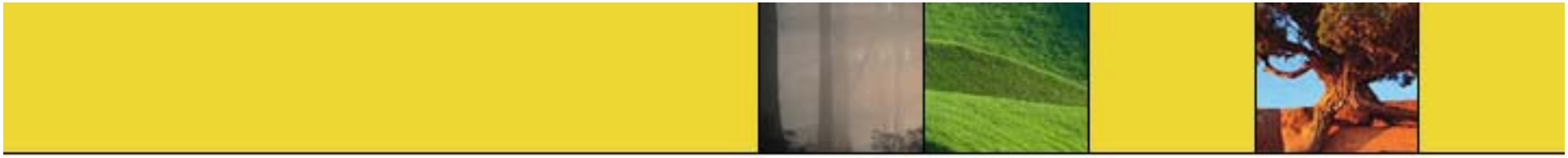
- Questions you might ask?

- How does your problem affect your life?
- Is there anything in your life that makes your problem worse, better?
- How is your family affected by your problem?
- Who can help you make decisions about your health?



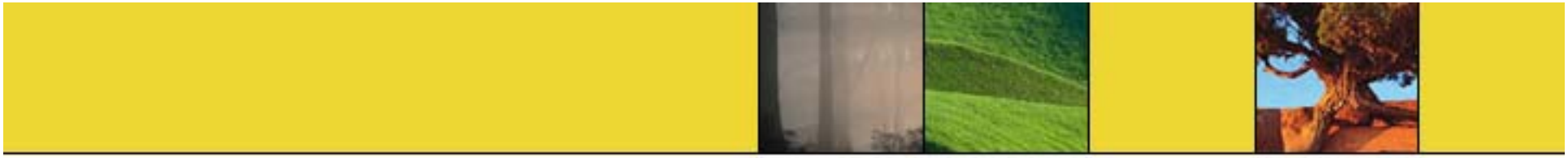
Power

- Awareness of difference
- Awareness of power of culturally formed beliefs
- Willingness to accept a balance of power



Empathy

- Learning to listen actively
- Allowing the other to tell his/her story
- Attempting to understand the significance of this patient’s problem
- Verbal and non-verbal empathy



Concerns and Fears

- Re-eliciting the patient's perspective and his/her hope for healing
- Ensuring both patient and provider understanding
- Allowing patient to share difficult feelings

Therapeutic Alliance/Trust

- Negotiating across differences in culture, beliefs, explanatory models
- Negotiating with a better knowledge of who the patient is
- Developing a successful plan by establishing trust

Cultural/Racial Diversity Seminar

Goals:

- To increase awareness of cultural diversity
- To have residents describe their cultural self-identity
- To have residents recognize personal bias

Cultural/Racial Diversity Seminar

- To have residents identify and discuss factors in health outcomes disparities

- To develop and practice resident skills in providing health-care across cultural and racial barriers: ESFT*--> RESPECT

ESFT*- Betancourt et al. Hypertension in multicultural populations. Curr Hypertens Rep. 1999;1:482-488

Cultural/Racial Diversity Seminar --> Segment 1

Cultural Awareness Exercise

- What culture do you identify as your own?
- What values do like….or dislike?
- Describe an experience where you felt different

Cultural/Racial Diversity Seminar

- How have you experienced power, or a lack of power, in relation to other groups?

Pinderhughes EB. Teaching Empathy: Ethnicity, Race and Power at the Cross-Cultural Treatment Interface. American Journal of Social Psychiatry 1984;4:5-12

What is Policy Relevant Research?

John Capitman, PhD

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US Health Policy 101

- Private and public financing of health care
- Private and public delivery of health care
- Public oversight of financing, provider organizations, and professionals
- Publicly subsidized professional training
- Public health education in multiple contexts
- Public health oversight of indoor and outdoor environments and products
- Public and private policies and practices that create and sustain opportunity, power, exposure, and resistance at individual and macro-individual levels (taxes, monetary, military, immigration, industrial, environmental, etc.)

What is Health Policy Relevant Research?

- Research that advances public understanding of local, state and federal public health and healthcare challenges and the policies and programs addressing these challenges.

- Policy relevant research is intended to assist decision-makers (individuals, advocacy organizations, providers, payers, regulators and elected officials) by documenting the effects of current policies and programs and explicating potential ameliorative efforts.

How can research influence policy and practice?

- Raise awareness of a problem
- Develop a useful conceptual framework
- Assess how big/important a problem is
- Analyze underlying causes of environmental/economic behavior
- Contradict conventional wisdom
- Anticipate/model policy impact
- Assess impact of an actual policy
- Take advantage of the latest policy or research buzzword (i.e., evidence-based research, consumer-driven healthcare)
- Researchers have an opportunity to play an important part in the "sea change" toward evidence-based policymaking

How data is used to influence policy?

The data you collect depends on:

1. The research questions (the debate)
   - Solving a problem? Research → Knowledge → Policy/Practice
   - Informing? Interactive/ First Framing and getting attention
   - Supporting a political point? Tactical (shotgun research)
   - Newly developed area? Uncertainty driven

2. Data availability

3. Data Relevance
   - Will quantitative data be more helpful in answering the questions?
   - Would qualitative data be more helpful in answering the questions?

Five ways to think about change

1. Focus on Inclusion: *How do we work together?*

2. Focus on Power and Fairness: *What are our interests? What outcomes do we want? How does this differ from other actors?*

3. Focus on Resources: *How does the money flow? How does this impact outcomes?*

4. Focus on Delivery Systems: *How are provider organizations working? How does this impact outcomes?*

5. Focus on Opportunities for Change: *Can we address root cause of poor outcomes? How can outcomes be improved in the short run?*

Health Policy Is About Power

Power Concepts	Target—Excluded and discounted by policies and culture	Non Target—Empowered and advantaged by policies
Racism	African American, Latino, NHOPI, Native American, Asian American	Whites
Sexism Heterosexism	Women GLBT	Men Heterosexual
Classism	Working class	Middle/owning class
Agism	Ages <25 and >55	Ages 25-55
Ethnocentrism	Immigrants and their children	US born
Abilism	Chronically ill/disabled	Temporarily able-bodied

Ecological/Related Models

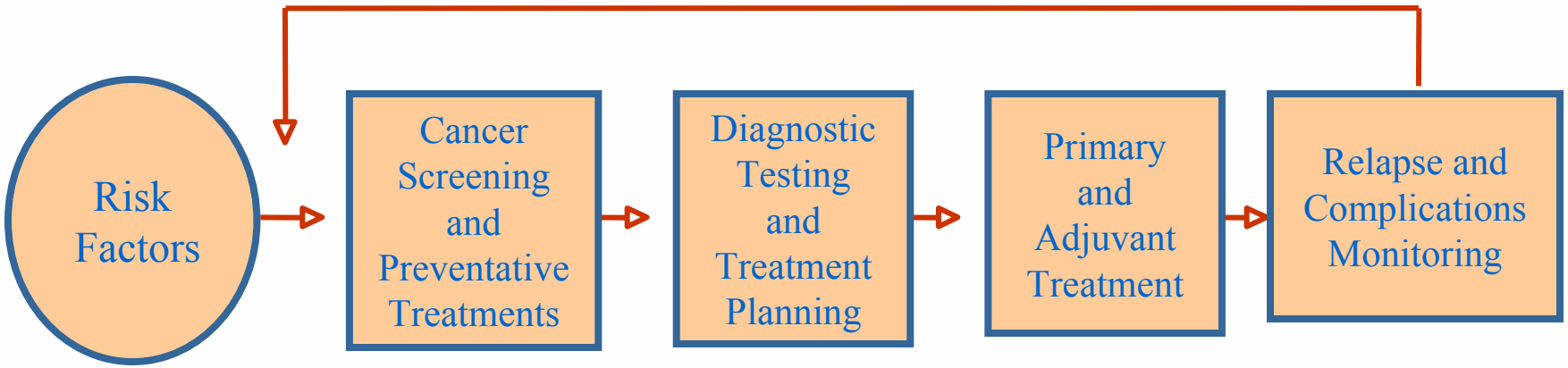
1) Focus on multiple levels of causation
   - **Individual**
   - **Time**
   - **Setting/Organization/Clinic**
   - **Context/Community**

How do individual and macro-individual factors determine individual outcomes?

2) Focus on setting/context variables
   - **Sequential and cyclical effects of technology and operations**
   - **Organizational culture**
   - **Social capital frameworks**
   - **Practitioner/street-level bureaucrat effects**
   - **Resource mobilization effects**

How do organizations create and sustain macro-individual influences on individual outcomes?

Basic Sequential Model



Questions for Exploring System Design and Unmet Needs

- Are there organizational barriers to access for primary or specialty care?
- Are there clinic barriers to access?
- Does provider maximize payment sources? How does provider address medical debt?
- Do quality assurance systems work?
- Does provider assist with behavior change?
- Does provider attend to linguistic and cultural factors?
- Does provider partner with others to address community-level determinants of health?

LOOK for individual stories and available data. Consider how to use data to gain power.

FOCUS on the un-served, under-served, and dissatisfied – how does this happen?

Value of Patient Perspective

- Identifying at what points in implemented policies care failures occur
- Improving health/healthcare communications
- Engaging patients as political allies in seeking changes in healthcare financing or organization
- Developing more accurate theories of individual health-relevant behaviors as bases for intervention

Context Haitian Breast Cancer Study and Sampling

Haitian Breast Cancer Control Study

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Collaborators

- Nicole Prudent, M.D., M.P.H
- Rachelle Jean-Baptiste, M.P.H.
- Bart Laws, M.D
- Jo Anne Fordham, M.A.

Background

- Primary care is largely unavailable in Haiti
- Per capita income is $440; and literacy rate estimates range from 52.9%
- 90% of Haitians live in rural areas
  - About 80 percent of the rural population live below the poverty line
  - 1 physician per 44,000 people

Background

- Migration from Haiti occurred in three major waves spanning 40 years.
- It was usually occasioned by political and economic turmoil.
- U.S. Haitians are concentrated in New York, Miami, New Jersey, and Boston.

Background

- **Case series at Boston Medical Center revealed Haitian women represent 10% of the breast cancer cases.**
- **Haitian women reportedly present late to BMC breast clinic for evaluation.**

Objectives

- **The Haitian Breast Cancer Control Study first sought to generate estimated rates of screening mammography for Haitian women over 40 in Boston.**
- **To develop a culturally competent and sensitive methodology with which to measure adherence to allopathic and nonallopathic models of health and illness including the impact of this adherence upon the likelihood that respondents will comply with, seek, or avoid breast cancer screening, follow-up, and treatment services**

Methods

- Population-based, cross-sectional survey of 753 women over 40 years old.
- Neighborhoods with high concentrations of Haitians were identified and included in sample blocks.
- In-person interviews were conducted by trained, bilingual interviewers.

Methods

Sampling method

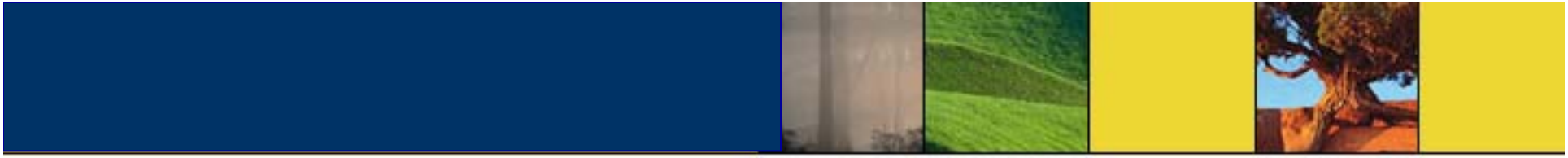
- **Initial survey canvas street maps were compiled by combining information obtained through interviews with Haitian Consul and representatives from community-based organizations, businesses, and churches.**
- **We used City of Boston Assessing Department's Property Parcel Data for fiscal year 2000 to obtain listing of housing units from the provided street names.**
- **Units identified as Haitian residence were visited to ask their residents for further street names where other Haitian families are likely to reside. Informants were asked to indicate if they knew of any other blocks that should be added to the prospect list ("snowball sampling").**
- **Blocks that were estimated by two or more credible informants to contain at least 20% Haitian households, or at least 10 Haitian households, were included in the survey universe.**
- **We defined 50 units as a block and it excluded businesses and other no housing units. In each block, all housing units were enumerated and 12 of the 50 units were randomly selected.**

Enrollment

- **Total N= 753**
- **Haitian N=286**
- White N=144
- African American N=160
- Caribbean N=64
- Latina N=72

Summary

- This study shows that an immigrant population will participate in a research study.
- Our study had a response rate of 74%.



Including Patient Perspectives in Policy-Relevant Research:

The case of *"The Cultural Concepts of Cancer and Mammography Uptake and Adherence Study"*

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Presentation Outline

- Goals
- Learning objectives
- **Introduction**
  - Why patient perspectives?
  - What approaches are used to include patient perspectives?
  - Why mixed methods?
  - What approaches are used to combine qualitative and quantitative data?
- Case study
- Conceptual framework
- **Research design**
- Qualitative analysis
- From qualitative to quantitative
- Quantitative analysis
- Summary of findings
- **Discussion**
- ➢ Study limitations
- ➢ Policy, practice and research implications

Learning Objectives

- Understand importance of using qualitative data as an approach for including patient perspectives in policy-relevant (PR) health services research
- Articulate various approaches to combining qualitative and quantitative data in PR
- Describe the framework approach to analyzing policy-relevant qualitative data
- Appreciate value added to the study by including patient perspectives

Why Patient Perspectives

- **Patients are co-constructors of health**
  - Patients bring to clinical encounter not only personal characteristics but also their knowledge, concerns and social experience
  - How the provider understands a health problem may differ from how the patient understands it.
- **Unreliable researcher-derived measures**
  - Systematic reviews show failure to demonstrate a strong or consistent effect of patient knowledge, beliefs, attitude and practices influencing health behavior (Capitman, Bhalotra and Ruwe, 2005)
- **Potentially more effective applications due to:**
  - Satisfaction with care
  - Acceptability
  - Accuracy or validity of measures—face and construct validity

What are the approaches to including patient perspectives in research?

- **Qualitative approaches are increasingly being used in studies, including clinical trials, to give a voice to those being studied.**
  - Qualitative studies seek deeper understanding of lived experience of the social actor within a specific context not to generalize.
  - Quantitative studies aim at understanding relationships between variables, predict health behavior from a set of variables and generalize findings to source population.
  - If research goal is to understand the lived experience from the social actor's perspective within a specific context as well as to understand strength of relationships, make prediction and generalize to larger populations, then combining qualitative and quantitative approaches becomes ideal.

There are four approaches to combining qualitative and quantitative research?

- **Sequential**: qualitative then quantitative
- **Parallel:** Simultaneous studies
- **Coordinated sub-studies**
- **Integrative** :Combined data

- Most researchers use sequential, parallel or coordinated sub- studies, partly because of philosophical divide between quantitative and qualitative; but integrative studies, offers the most direct means for demonstrating impact of patient perspectives on a policy-relevant outcome
- Integration is done at three levels – sampling, data collection, and data analysis (Sandelowski, 2000)

Integration of methods is done in the design at four levels

- **Theory**—interpretive and predictive
- **Sampling**
  - Probability and purposeful sampling are used
- **Data collection**
  - Open-ended instruments generate qualitative data, closed-ended generate quantitative
  - Theoretical frameworks and research instruments generate variables
- **Data analysis**
  - Qualitative data is expressed as descriptive narratives, connotative expressions, major themes, or latent variables
  - Integrating qualitative data into quantitative involves converting major themes, connotative expressions and latent variables on a numeric scale
  - Challenge, lies in preserving original accounts
  - The framework approach (Pope, Ziebland, and Mays, 2000) provides guidelines for analyzing qualitative data that preserves original patient account

Methods are combined to:

- Achieve convergence of results
- Identify overlapping facets that emerge on closer inspection using multiple methods
- Augment information gained from an initial approach
- Identify and examine contradictions obtained from multiple sources
- Add scope and breadth to a study
- Guide the use of additional sampling, data collection and analysis techniques.

(Sandelowski, 2000)

Case Study

You have read the literature that shows mammography saves lives through early detection up to 30-40%. Lifetime and recent screening have increased across race/ethnicity, because there have been policies aimed at eliminating financial barriers by providing low-income women and elders with health insurance and free mammograms. You notice that mortality due to breast cancer has remained higher for some groups, especially women of color and elders. You also notice that disparities in age at uptake and adherence to recommended intervals have persisted even among insured. You are surprised and are greatly troubled by these findings.

You become interested in the role of culture, as an alternative explanation. You do a literature review and find that existing theories such as acculturation, Health Belief Model, and cultural norms do not consistently predict mammography use. You are interested in testing a culturally sensitive theoretical framework to see if it can help to explain this situation. You have also come across literature that shows culturally tailored interventions can increase adherence. Based on this, you are convinced that there must be a cultural explanation.

You have come across a theory that says that differences in understanding concepts of illness and health between the clinician and the provider can lead to miscommunication and patient inability to follow recommended care. You want to use this theory to do a study in your setting. You have a diverse population and women who go to your local heath care facilities are mostly low educated and low-income, from diverse cultural backgrounds, including Caucasians, African Americans, Latinas, English speaking Caribbeans and Haitians.

Coincidentally, one bright morning, as you were going through a flood of e-mails, you come across an federal program announcement requesting for studies of socio-cultural determinants of health and health access for a number of priority areas including cancer screening. This is a one time solicitation and studies must be completed within 18 months. You say to yourself Voila! This really fits what I have been thinking of doing research on; and you decide that you will apply for this grant.

You want answers to the following questions:

1. Can lay understanding of cancer help explain racial/ethnic disparities in mammography use?
2. Is there a unique role for lay understandings of illness/health in predicting mammography?
3. If so, is the impact of lay understanding of cancer independent of insurance and other structural variables?

Study Questions:

1. How would you go about designing a study that is both culturally sensitive and would convince federal grant reviewers that lay understandings of cancer are indeed important predictors of mammography screening and are partly responsible for disparities in mammography screening of elders and racial ethnic minorities?
2. How would you ensure that patient perspectives are included?

Conceptual Challenge-1

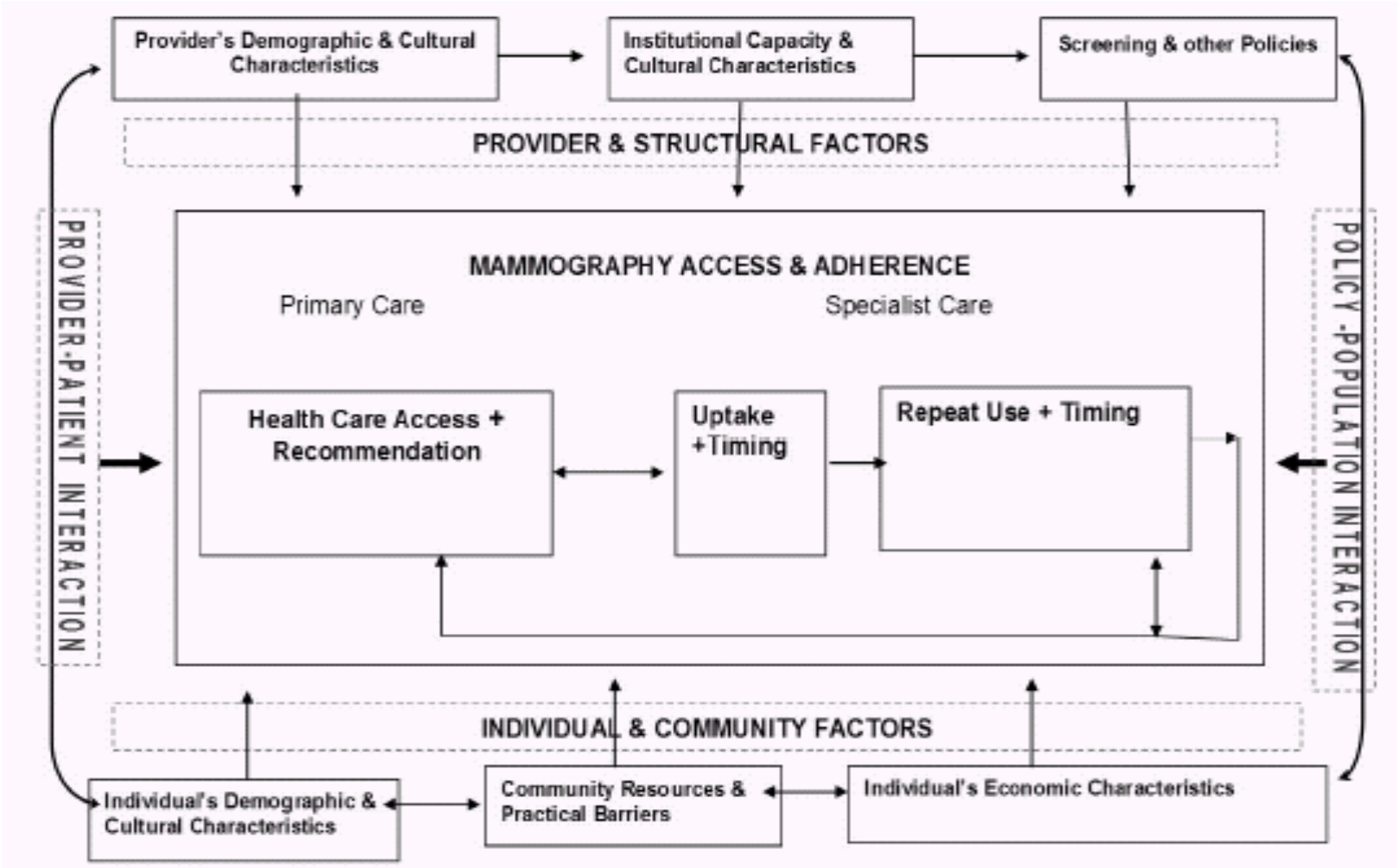
- Defining mammography access
  - **Mammography access is a dynamic process**
  - **Involves entry to the health care system and recommendations by the primary care providers to initiate and repeat use, guided by existing screening policies**
  - **Mammography adherence involves both repeat use and timing of the screening according to recommended intervals.**
  - **Most studies focus on prevalence of screening and not uptake or adherence**

Conceptual Challenge-2

- **Explaining Mammography Access**
  - **Most of the behavioral research focuses on explaining individual behavior and has not paid attention to interpersonal or contextual factors.**
  - **This study sought to understand how patient beliefs that deviate from providers beliefs may influence age at first mammogram and adherence to recommended intervals of screening.**
  - **According to Kleinman, differences in concepts of illness/health between the provider and the patient can result in miscommunication and failure by the patient to adhere to recommended care (Kleinman, 1978).**

Conceptual Framework

Integrated Culture-Sensitive Mammography Access and Repeat Theoretical (IC-SMART) Model



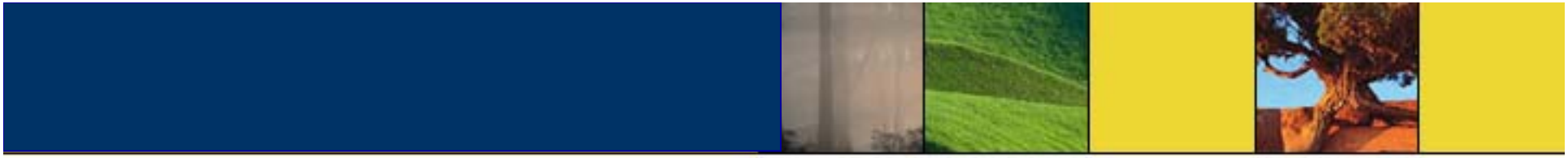
•Mammography use is a dynamic process with many factors influencing it; provider-patient interaction plays major role.

Research Design

- **Part of the larger Haitian breast cancer study, with focus on patient perspectives**
- **Population-based, cross-sectional study**
- **Probability and snowball sampling techniques**
- **Sample: Multi-ethnic N=750**
- **Haitians :284**
  - **White : 143**
  - **African American: 163**
  - **Latina/Caribbean/other: 160**
  - **Age: 40 and over**
- **Setting: Eastern Massachusetts—Greater Boston area**

Research Approaches

- Exploratory
  - **Were open to discovery**
- Theory driven
  - **Theories could be explanatory or predictive – good theory should do both**
- Qualitative and Quantitative
  - **Used the integrative approach to combine qualitative and quantitative data**
  - **Used framework approach to analyze qualitative data**



QUALITATIVE ANALYSIS

- Framework approach
- Lay explanatory accounts

The Framework Approach

- Developed for applied or policy-relevant qualitative research
- Objectives set in advance and shaped by information requirements
- Research timescales are short, often need to link analysis with quantitative findings
- Starts deductively from pre-set aims and objectives; but reflects the original accounts/observations of people studied (“grounded” and inductive)
- Has more structured data collection than norm in qualitative research
- Analytical process more explicit and more strongly informed by a priori reasoning
- Analysis designed to be viewed and assessed by people other than the primary analyst (Pope, Ziebland, and Mays, 2000)

Steps in Framework Approach

1. Frame Familiarization – studying response to identify response structure
2. Thematic Frames' Identification
3. Thematic Coding or Indexing
4. Charting
5. Mapping
6. Interpretation

(Pope, Ziebland, and Mays, 2000)

Summary of Qualitative Analyses

WHAT IS CANCER? **WHAT CAN CAUSE CANCER?** **WHAT CAN CURE CANCER?**

Raw Data **Raw Data** **Raw Data**

Step1 — **Frame Analysis: Explanatory Frame**

What, How, Why, Where, Why Not ***Why*** ***Why Not***

Step2 — **Thematic Coding: Unique Connotative Expressions: 100-125**

Step 3 — **Data reduction: Major Themes,6-25**

Step 4 — **Data reduction 2: Secondary Themes, Variable Development and Construct Validation**

Factor analysis, regroup themes, triangulate and validate with external constructs,

test preliminary associations with dependent variable

1.Self-reported knowledge 2.Molecular thru clinical to metaphysical/abstract concepts	1.Self-reported knowledge 2.Preclinical/molecular thru clinical/health status to super naturals	1.Self-reported knowledge 2.Faith(God, MD, Science, Research, No hope/cure) 3.Prevention levels(1^{o},2^{o}, 3^{o})

Exhibit 1a. Frame analysis: What is cancer

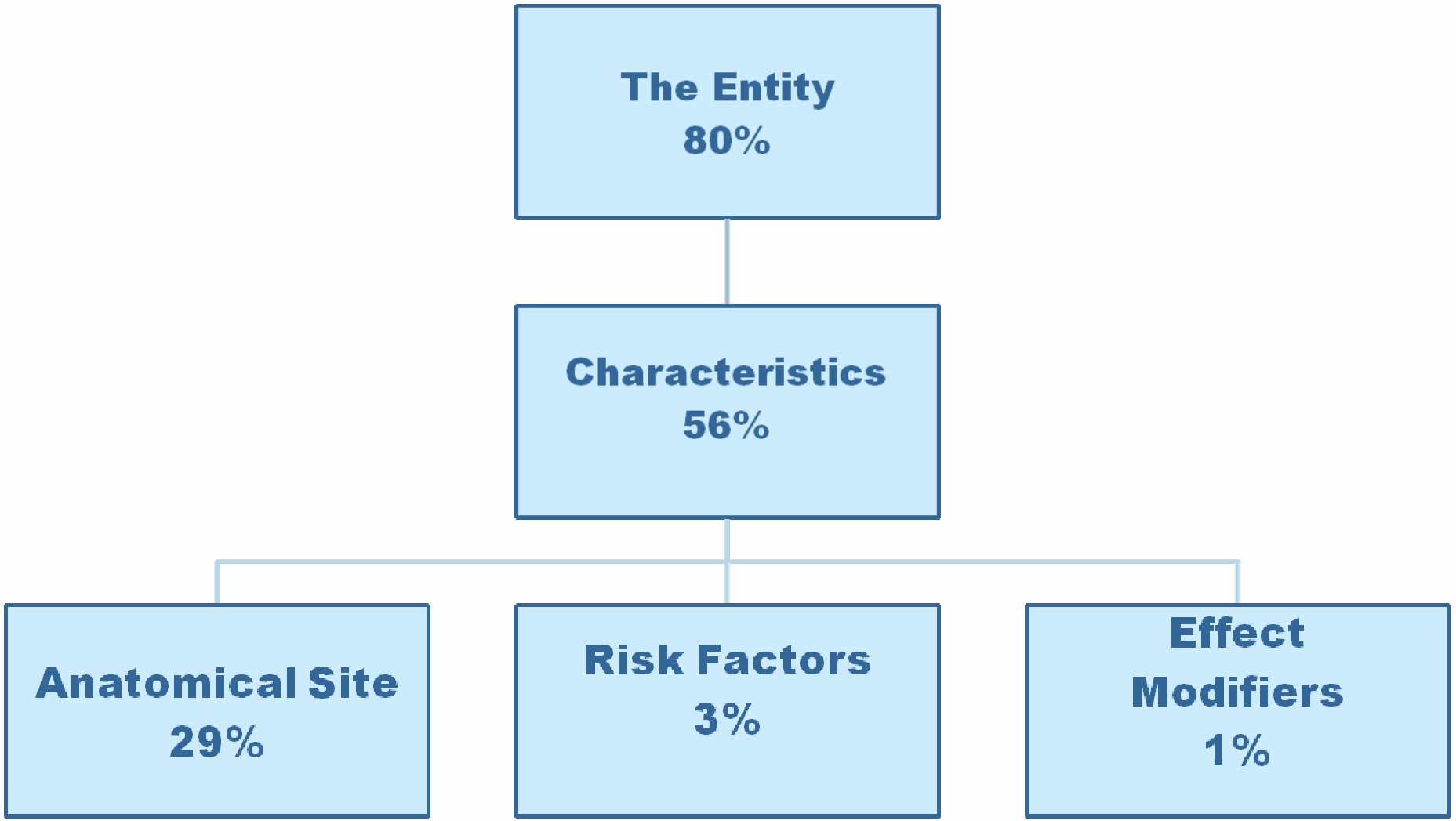


Exhibit 1b: Frame analysis for what is cancer?

Explanatory Frame	Response structure	Explanatory accounts
What	It is . . .	It is a virus, it is a gene, it a microbe, it is a sore, it is a lump
Why	Something due to . . . or caused by . . .	Something due to lack of self care, or caused by environmental pollution
Where	Something in . . ., something that affects . . .	It affects blood cells, breast, colon, skin or affects whole body or any part of the body
Why not	If or unless, if not	It can be treated if caught early, it can kill unless caught early, or if not malignant

Lay Explanatory Accounts

- Resemble the biomedical explanatory model
- Three main lay explanatory accounts identified by Stern & Kirmayer, 2004
  - a. **Causal factors.** Specify or imply a causal relationship between the factors described and the symptom (or disease entity), without reference to any specific process.
  - b. **Causal process.** Description of causal factors as well as causal process or mechanism.
  - c. **Nominal accounts.** Describe symptoms through the use of a specific diagnostic label which may imply the existence of an explanatory model.

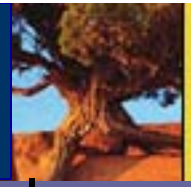
Thematic coding

- **Inductive analysis** (abstracting or regrouping)
  - Primary themes to secondary themes
  - Develop latent variables using appropriate numeric scales

Exhibit. 2. What is cancer? The entity, by race/ethnicity

	Distribution	Haitian	AA	White	Latina/Caribbe
Gene /Cells	12%			(++++)	
Virus, bacteria/microbes(5%,3%)	8%			(----)	
Growth	10%	(++++)			
Disease	38%	(++++)			
Sore/ulcer	6%				
Something ,that is ...	19%	(++++)			
Devil/Satan/curse	1%	(++++)			
bad blood/blood clot,tissue(1% each)	2%				
immune reaction,poison, hormonal	3%				
Combination	1%				

Exhibit 3. What is cancer? Characteristics by race/ethnicity



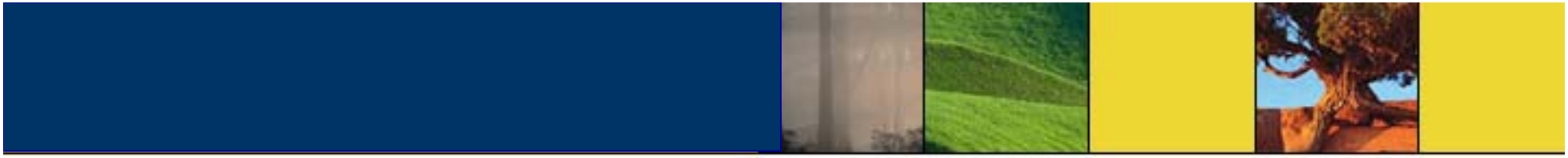
	Distribution	Haitian	AA	White	Latina/Caribbean
What is Cancer?					
Is inherited		(++++)			
It spreads to rest of body	6%	(++++)			
It is scary	2%	(++++)			
It eats/gnaws you inside	19%	(++++)	(++++)		
It is incurable	13%	(++++)	(++++)		
…If caught early		(++++)	(++++)		
Rapidly replicates/grows/crazy/wired	12%	(++++)	(----)		
abnormal deformity	9%				
painfull	3%				
severe/major	5%				
Creates growghth	5%				
Due to being hit being hit	3%				
something ,due to what develops inside	4%				
something , due to what gets in from outside	2%				

Exbt. 4. What can cause cancer? By race/ethnicity

	Distribution	Haitian	AA	White	Latina/Caribbean
What can cause cancer?					
Chronic health condition/sores	5%	(++++)			
Radiation from commercial appliance	1%	(++++)			
Trauma/injury	10%	(++++)			
Genes/Genetics		(----)		(++++)	(----)
Industrial radiation—nuclear plants, el	2%	(----)		(++++)	
Environmental pollution	25%	(----)			
Environmental radiation	3%	(----)	(----)		
Substance abuse	32%	(----)	(++++)		
Hight tech food/ canned food	3%				
Bad nutrition /unhealthy diet	5%	(----)			
Stress	5%	(----)			
Meds/birth control pills	1%				
Sexual behavior, not breastfeeding	1%				
Many factors	1%				
Virus, bacteria/microbes	2%				
Sun	2%				
All other	2%				

Exbt. 5. Major themes of what can cure cancer By race/ethnicity

	Distribution	Haitian	AA	White	Latina/Caribbean
What can cure cancer?					
Early detection	4%	(++++)			
Food without chemicals	1%	(++++)			
Medical care with doctors	31%	(++++)			
Traditional medicine	2%	(++++)			
More research/technology	18%	(++++)			
Prayers/faith in God/miracle	19%	(++++)			
Death/no cure	9%	(++++)			
Control gene or cell causing it or vaccine		(----)			
Self efficacy	1%				
Money/government	3%				
Clean environment	3%				
Change in lifestyle	7%	(++++)			(----)
All other	2%				



FROM QUALITATIVE TO QUANTITATIVE

- Developed latent variables using numeric scales
- **Validated latent variables**
  - Factor analysis
  - Discriminant analysis
  - **Triangulation**
  - Merged latent variables with quantitative data
  - **Quantitative Analysis**
  - Bivariate and multivariate analyses

Exbt. 6a. Data reduction: Factors analysis of what can cause cancer

	1	2	3	4	5
1.Molecular	-.292	.416	-.074	.014	-.199
2.Clinical	-.077	.219	-.125	**.894**	-.039
3.Social Behavior	-.054	.386	-.193	-.495	-.003
4.Environmental	**.687**	.246	.014	-.171	-.081
5.High Tech	**.763**	-.131	-.110	.068	-.037
6.Trauma	-.162	**-.860**	-.140	-.163	-.123
7.Stress	.084	.047	**.752**	.003	-.026
8.Spiritual	-.200	.061	**.718**	-.087	-.030
9.Others Including Superstition	-.084	.045	-.044	-.038	**.980**

Validation of qualitative variables

- Aimed at understanding discriminant validity of self-reported knowledge—does it distinguish between related and unrelated concepts, what are the possible underlying concepts?
- Correlated self-reported knowledge with other well established variables

Exbt.7a.
Discriminant validity of self-reported Knowledge

	What is cancer	What can cause cancer	What can cure cancer
Fatalism (1-5)	-.03	-.23**	.08*
Fatalism1	-.01	-.16**	.03
Fatalism2	-.06	-.19**	.09*
Efficacy (1-5)	.02	.14**	-.05
Efficacy1	.04	.13**	-.07
Efficacy 2	.02	.08*	-.01
Efficacy 3	.04	.15**	-.07
Modesty(1-5)	.04	.09*	-.00
Modesty 1	.04	.01	.05
Modesty 2	.03	.09*	-.02

Knowledge of cause was negatively correlated with fatalism, positively correlates with perceived efficacy of mammography and modesty

Exb.7b.
Discriminant Validity of Self-Reported Knowledge

	What is cancer	What can cause cancer	What can cure cancer
Education (≥high school)	.07	.28**	-.07
Evaluated Knowledge	.01	.09*	-.04
Evaluated Knowledge (1,0)	.00	.09*	-.03
Marital Status (married)	.05	-.04	-.05
Patient Language (Non-English)	-.04	-.28**	.10**
To US before age 16	.03	.02	-.03
Patient preference of MD's Language	-.05	-.03	.01
Patient preference of Staff Language	-.04	-.04	.11*
MD's Gender (female)	-.01	-.14**	.00
Income (≥20,000)	.12*	.10*	-.11*
Insurance Type (Medicaid/Medicare vs. private	-.01	.00	-.03
Poverty	-.09	-.02	.03
Alcohol use	-.03	.08*	.01
Keeps appointment	-.08	.11	.14
Medical Check Up	.05	.06	-.06

QUANTITATIVE ANALYSIS

- ❖ Goal is to understand relationships between variables

- Descriptive or bivariate statistics
- Multivariate associations
- Level-1 Logistic regression

- ➢ Aimed at understanding covariance structure of self-reported knowledge and health insurance

- Level- 2 (Full) Logistic regression

- ➢ Separate models for uptake and adherence
- ➢ Controlled for health insurance and covariates
- ➢ Hausman omitted variable test-- for impact of endogeneity bias
- ➢ Fully adjusted models

Variables

- **Dependent variables**
  - Appropriate Mammography uptake—At age 40 or less
  - Appropriate mammography adherence— annual/biennial rate
- **Independent variables**
  - **Quantitative**
    - Health insurance
    - Race/ethnicity
  - Qualitative
    - Self-reported knowledge of cancer cause
    - Major themes of cancer cause
- **Covariates:** age, provider factors, income, employment status, etc.

Exbt.8.
Racial ethnic comparison of self- reported knowledge

	Haitian	White	African American	Latina/ Caribbean/ Other	Total	P
What is Cancer?						
N	277	142	155	145	719	
Percent	79.4%	84.5%	77.4%	80.7%	80.3%	.460
What Can Cause Cancer?						
N	267	130	159	155	711	
Percent	40.8%	74.6%	71.1%	63.9%	58.8%	0.000
What Can Cure Cancer?						
N	267	131	159	155	712	
Percent	71.9%	66.4%	59.7%	60.6%	65.7%	0.031

There are racial/ethnic differences in self-reported knowledge of cause and cure

Exbt.9. Bivariate association of self-reported knowledge with mammography uptake

	Self-Reported Knowledge		
Appropriate Uptake (Yes)	Yes	No	P
What is Cancer?			
Percent	53.4%	49.3%	.383
N	577	142	
What Can Cause Cancer?			
Percent	61.3%	41.8%	.0000
N	421	294	
What Can Cure Cancer?			
Percent	53.9%	51.6%	.558
N	471	246	

Only self-reported knowledge cause of cancer was associated with mammography up-take

Exbt.9b. Bivariate association of self-reported knowledge with mammography adherence

	Self-Reported Knowledge		
Appropriate Adherence (Yes)	Yes	No	**P**
What is Cancer?			
Percent	49.6%	43.0%	.158
N	577	142	
What Can Cause Cancer?			
Percent	53.0%	42.9%	.008
N	421	294	
What Can Cure Cancer?			
Percent	50.3%	45.9%	.265
N	471	246	

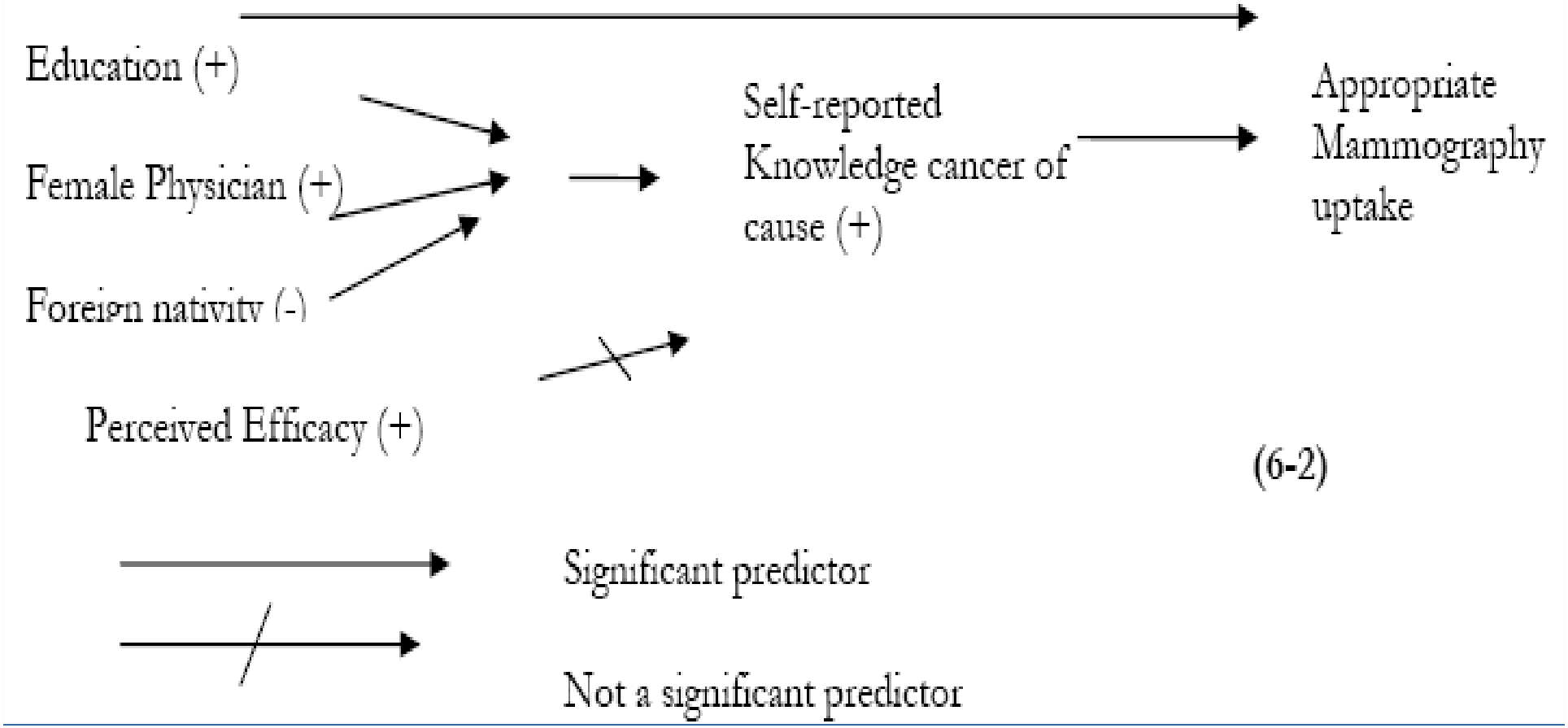
Only self-reported knowledge cause of cancer was associated with mammography adherence

Exbt.10. Racial ethnic differences in appropriate mammography. uptake and adherence

	Haitian	White	African American	Latina/ Caribbean/ Other	Total	P-
N	284	143	163	160	750	
Annual rate	12.7%	11.2%	13.5%	7.5%	11.5%	.313
Biennial/ Annual	41.9%	51.7%	60.7%	43.8%	43.8%	0.001
Age first mammogram= <40 years)	39.4%	53.1%	66.3%	62.5%	52.8%	0.000

There were racial/ethnic differences in mammography adherence

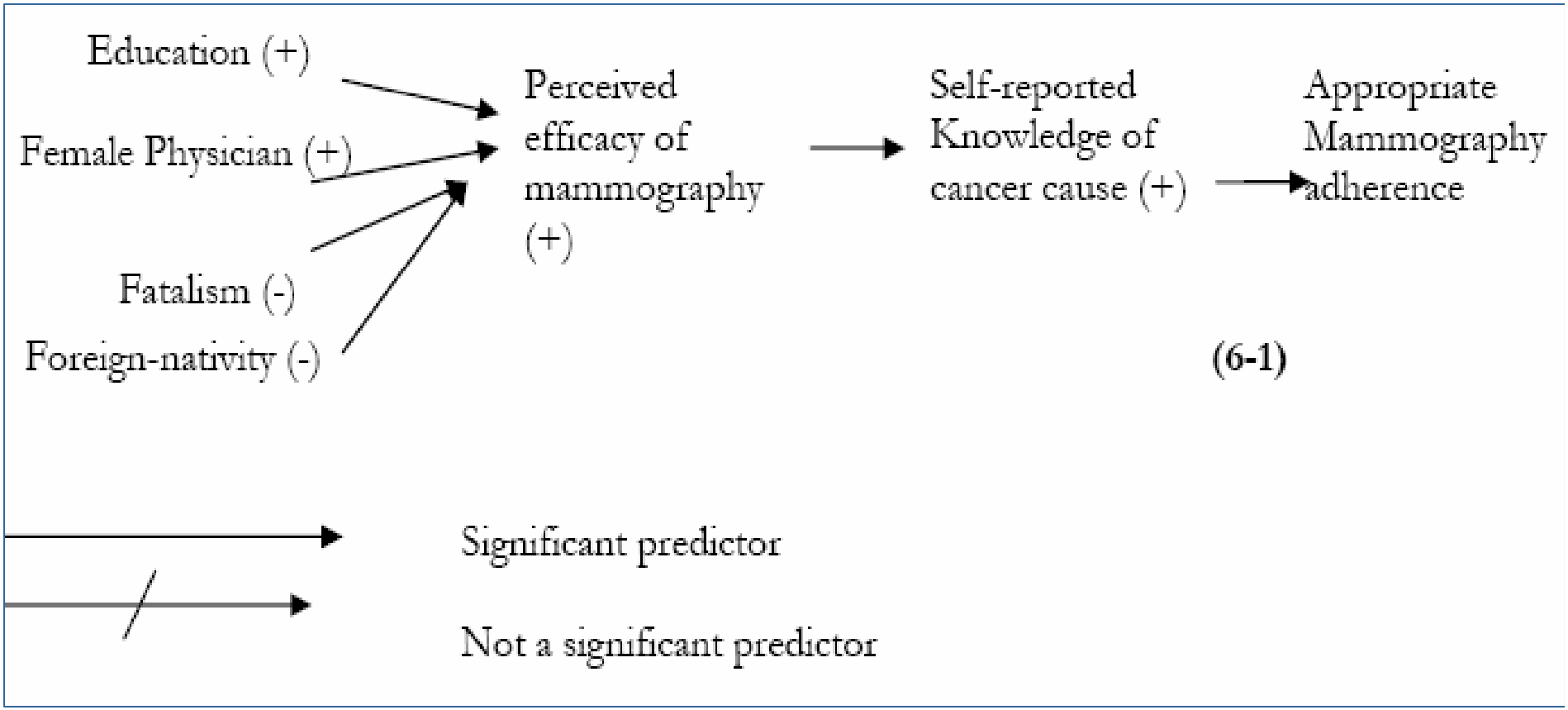
Exbt.11a: Covariance structure of self-reported knowledge of cancer cause in relation to mammography uptake



A hierarchical relationship was observed.

- **Self-reported knowledge was significantly predicted by education, having a female MD, foreign nativity and it in turn predicted mammography uptake.**

Exbt.11b.
Covariance structure of Self-Reported Knowledge of cancer Cause, in relation to mammography adherence



A similarly, hierarchical relationship was observed, like for uptake.

- **Self-reported knowledge was endogenous to perceived efficacy of screening.**
- **Impact of perceived efficacy of screening disappeared in the presence of self-reported knowledge**
- **Perceived efficacy of mammography was predicted by education, female gender of MD, fatalism and foreign nativity**

Exbt.12. Logistic regression of mammography adherence

	Step 3: Adjusted for Insurance Type			*Step 4: Adjusted for Endogeneity/Simultaneity*		
	OR	**S.E.**	**95% CI**	**OR**	**S.E.**	**95% CI**
Self-report knowledge of cause	1.70*	.22	1.11-2.6	2.13	0.71	0.53-8.60
Haitian	1.21	.27	.71-2.04	1.31	0.31	0.71-2.42
Haitian X self-report knows cause	.49*	.35	.25-.96	0.46*	0.35	0.23-0.91
US years>= 40	1.44‡	.21	.96-2.15	1.40	0.21	0.93-2.11
Age>=65 years	.58**	.22	.38-.89	0.58*	0.22	0.38-0.89
Trauma	1.24	.34	.64-2.43	1.26	0.34	0.64-2.48
Spiritual	.27	1.23	.02-2.99	0.26	1.24	0.02-2.93
Medicaid	.88	.17	.63-1.24	0.86	0.18	0.61-1.21
Medicare	.84	.28	.48-1.46	0.82	0.28	0.47-1.43
Res_1(fitted errors for self-reported knowledge)	---	---	---	0.80	0.72	0.19-3.28
Constant	.78	.23	---	0.71	0.52	

Dependent variable=Appropriate mammography adherence (adherence)
Step 3 Chi-square = 29.34, df =6, P. =. 001, -2 Log likelihood= 927.11; Cox & Snell R Square=. .04 Nagelkerke R-Square= .056;
Step 4 Chi-square=29.954; Df=10; Sig. = .001; -2 Log likelihood=916.708; Cox & Snell R Square=. 043; Nagelkerke R Square=057;

Self-reported knowledge of cancer cause was positively associated with mammography adherence, being Haitian and age 65 and over had negative association

Exb.13.: Logistic regression of mammography Uptake

	Step5a: Adjusted for endogeneity-unweighted			*Step5b: Adjusted for endogeneity and weighted with (IPW)*		
Variable	**OR**	**S.E.**	**95%CI**	**OR**	**S.E.**	**95%CI**
Self-reported knowledge of cause	19.81***	.797	4.16-94.41	2.50*	.43	1.08-5.79
Haitian	.62‡	.340	0.32-1.20	.35***	.30	.19-.62
Haitian X self-report knows cause	2.17*	.387	1.02-4.63	2.89*	.46	1.17-7.14
US years 40 and over	1.06	.24	0.66-1.71	1.18	.24	.74-1.87
Age >=65 years	.14***	.26	0.08-0.23	.14***	.26	.08-.23
Trauma	.34**	.38	0.16-0.72	.35**	.38	.17-.73
Spiritual	.10‡	1.25	0.01-1.14	.12‡	1.25	.01-1.33
Medicaid	.57**	.193	0.39-0.84	.54**	.19	.37-.78
Medicare	.70	.319	0.37-1.31	.69	.32	.37-1.29
Res-1(fitted errors for predicted self-reported knowledge)	.06**	.806	0.01-0.30			
Res-1xinverpred1(fitted errors weighted by inverse of predicted probability for self-reported knowledge)				.69¥	.24	.43-1.11
Constant	.48	.566		1.95	.35	

Step 5: Chi-square =162.146; df=10; Sig. =. 000; -2 Log likelihood=778.441 Cox & Snell R Square; =. 211; Nagelkerke R Square=. 283

¥P=.122

Self-reported knowledge of cancer cause was positively associated with uptake, age>=65, Trauma and Medicaid had negative association

Summary of Findings-1

- ❖Non-biomedical concepts of cancer cause were important predictors of mammography use.

- Women who thought physical trauma caused cancer were significantly less likely to have appropriate mammography uptake.

Summary of Findings-2

- Complementary relationship between self-reported knowledge of cancer cause and health insurance
  - Self-reported knowledge of cancer cause predicted both mammography adherence and uptake.
  - Health insurance type independently predicted mammography uptake but not adherence.

Summary of Findings-3

- Self-reported knowledge of cancer cause is the empirically active frame.
  - Consistently correlated with external constructs
  - Associated with mammography use
  - More stable in multivariate analysis than beliefs

Summary of Findings-3

- Significant age and racial ethnic differences in Self-reported knowledge and mammography use

  - **Haitians significantly less likely to self-report knowledge of cancer causes**

  - **Haitians and women 65 years and older significantly less likely to have appropriate mammography uptake or adherence**

Conclusion

- Including patient perspectives provided a better understanding of barriers to appropriate mammography use
  - Self-reported knowledge and non-biomedical concepts of cancer play a complementary role to health insurance.
  - Study also suggests that different factors influence age at first mammogram and interval adherence and that these measures should be included in routine surveillance
  - The association of self-reported knowledge and non-biomedical constructs to mammography has implication for providing culturally sensitive

End of Presentation

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- The California Endowment

Discussion-1

- Discuss
  - Strengths and limitations of the study
  - The policy implications
  - The practice implications
  - Implications for further research

Discussion-2

- What are the issues in applying this approach in terms of : data collection, coding, multi-stage analytic framework, and potential influence on policy and practice?
- What are the implications for culturally responsive clinical practice?
- What are the implications for screening policy?

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