

Does Culture Matter in Health Services Research?

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General Overview

1. The Time Come to Rethink Our Models of Healthcare Service Delivery and the Training Needs of the Next Cadre of Health Providers and Researchers
2. Why does it matter to understand the culture of the patient? *Culture-not only the experience of race, ethnicity, or country of origin but also norms, values, and beliefs, and the historical, contextual and social circumstances in the social structure*
3. What will it take to conquer the next frontier in health service delivery?

Sources of Information

- ***National Institute of Mental Health
National Latino and Asian American
Study***

(Alegria and Takeuchi, PIs)-A national psychiatric epidemiologic survey conducted to measure psychiatric disorders and service usage in a nationally representative sample of Asians and Latinos (NLAAS).

Sources of Information

- ***National Institute of Minority Health and Health Disparities - The University of Puerto Rico (UPR) and the Cambridge Health Alliance (CHA) EXPORT Exploratory Center***

(Canino, PI) -Projects to increase access to health services, improve the timeliness and engagement in needed services, address adherence to evidence-based treatments, and improve the quality of these treatments by increasing professional awareness of culturally and contextually appropriate care.

Sources of Information

- ***National Institute of Mental Health
Advanced Latino Center for Mental
Health Service Disparities***

(Alegria PI)- Focuses on understanding the mechanisms of mental health service disparities and generating research and knowledge that can eliminate them.

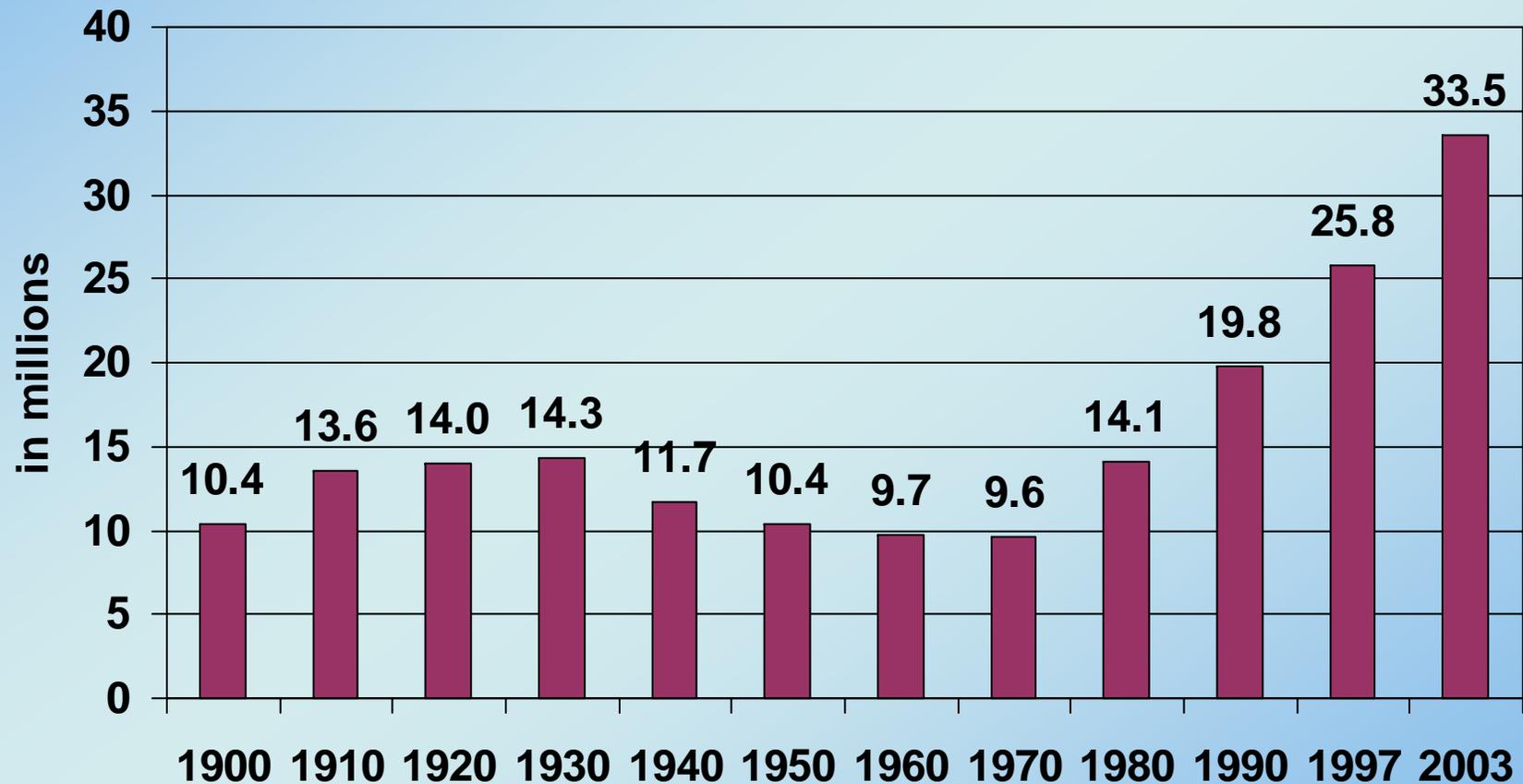
The Time Come to Rethink Our
Models of Healthcare Service
Delivery and the Training Needs
of the Next Cadre of Health
Providers and Researchers

Dramatic Shift in Populations to be Served in Health Care

The massive influx of immigrants (54% primarily from Latin America and 26% from Asia) in the last three decades has transformed the demographics of this country, with 40% of the U.S. population expected to be ethnic or racial minorities by the year 2050.



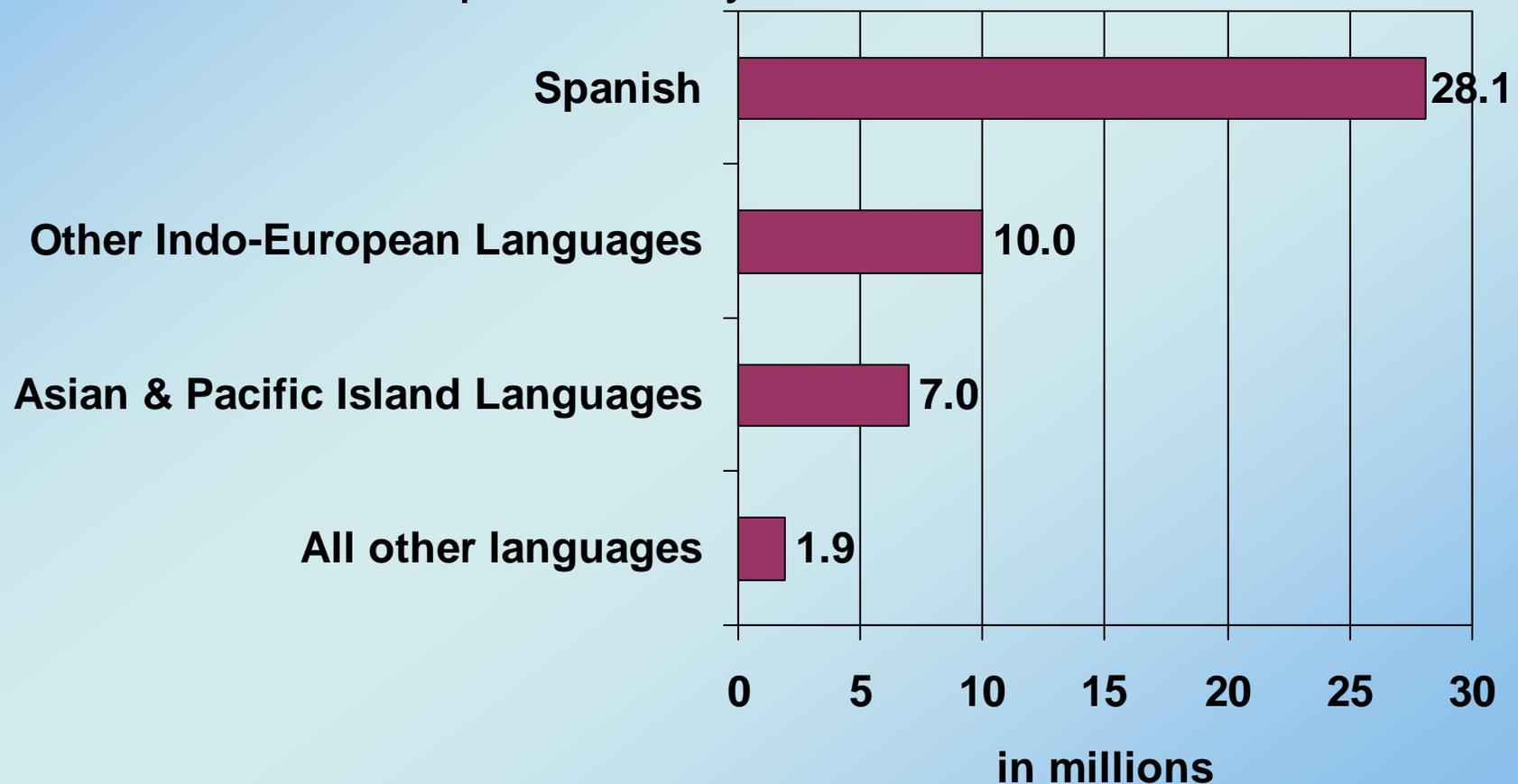
Foreign-born population: 1900 to 2003



Source: U.S. Census Bureau, WE-7, P20-551, P23-195.

Primary Language Other Than English Spoken at Home by Language Group: 2000

Population 5 years and older



Source: U.S. Census Bureau, Census 2000 Summary File 3.

Challenges Like Never Before

- Communicating information for effective healthcare
- Working effectively with patients who have limited exposure to the US health system
- Adapting or developing appropriate services for these diverse populations
- Connecting patients and families with appropriate services
- Helping healthcare personnel who may not be accustomed to working with diverse populations with different customs, values and experiences

Why does it matter to understand
the culture of the patient?

For Matching Services to Needs

Cultural Factors that Impact Patient-Provider Interaction

- Patient and Provider may not share the same linguistic skills
- Patient and Provider may not share same ideas about illness
- Patient and Provider may not share similar role expectations
- Patient and Provider have their own biases and stereotypes

Hard for both to share information for decision-making

Difficult to arrive at same problem definition

Behavior and actions in the clinical encounter may not match expectations

Bias or stereotyping may influence the exchange of information and may result in provider ignoring some information

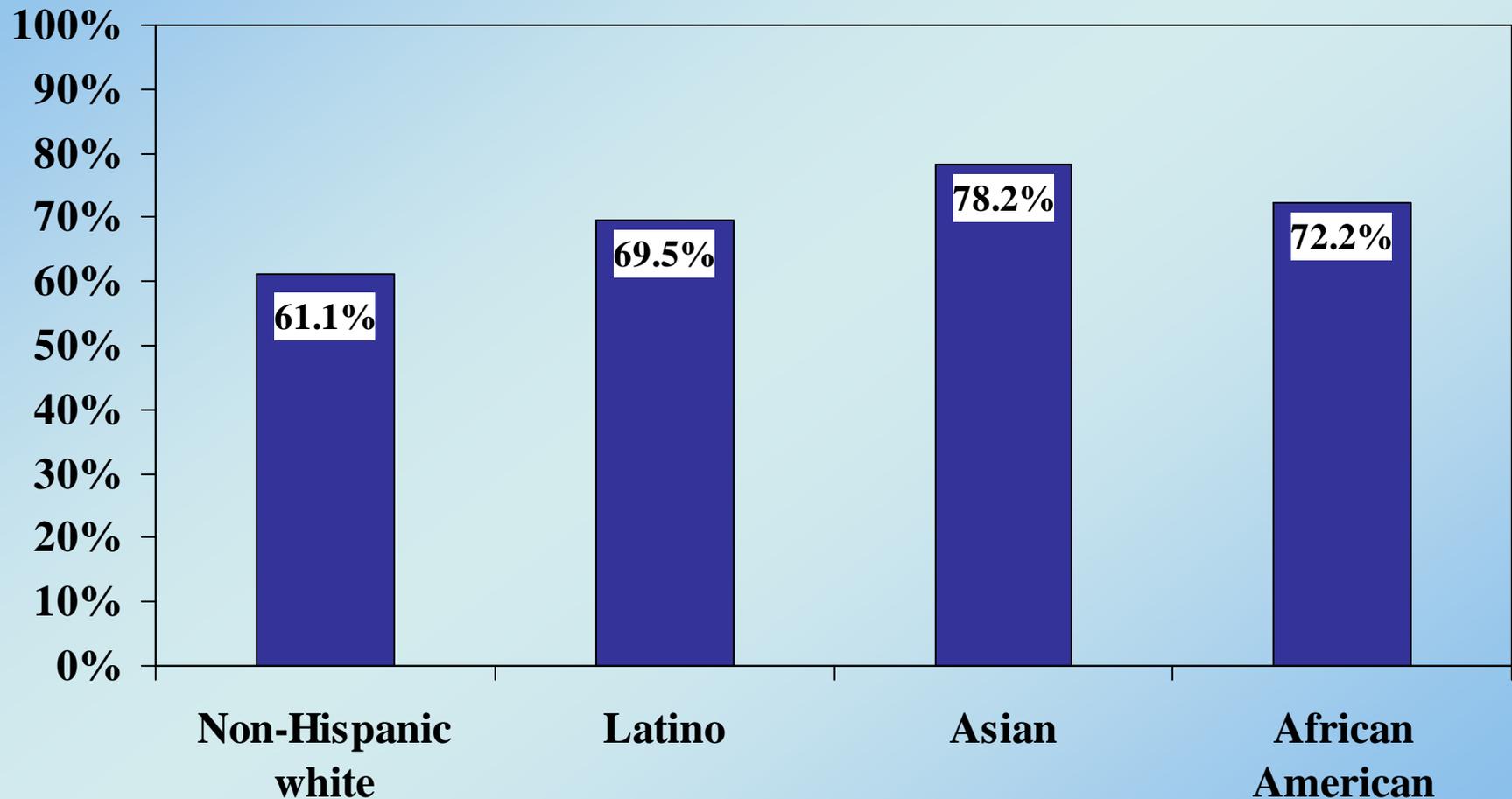
Suurmond and Seeleman, 2006

Patients' Lack of Engagement in Behavioral Healthcare

NLAAS Findings

- **Experience that Tx helps little: only 54% rated psychiatric Tx as helping them a lot.**
- **Dropping out of Tx: only 57% of respondents say they completed the treatment.**
- **Mode number of visits is 1 and median is 3 to both psychiatrists and psychologists.**

Levels of Unmet Psychiatric Need by Racial/Ethnic Group (NLAAS/NCS-R combined national sample)



■ Not receiving Speciality or generalist care in the past 12 months for those with any last year psychiatric disorder

REVIEW

Theresa Miskimen · Humberto Marin · Javier Escobar

Psychopharmacological research ethics: special issues affecting US ethnic minorities

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© Springer-Verlag 2003

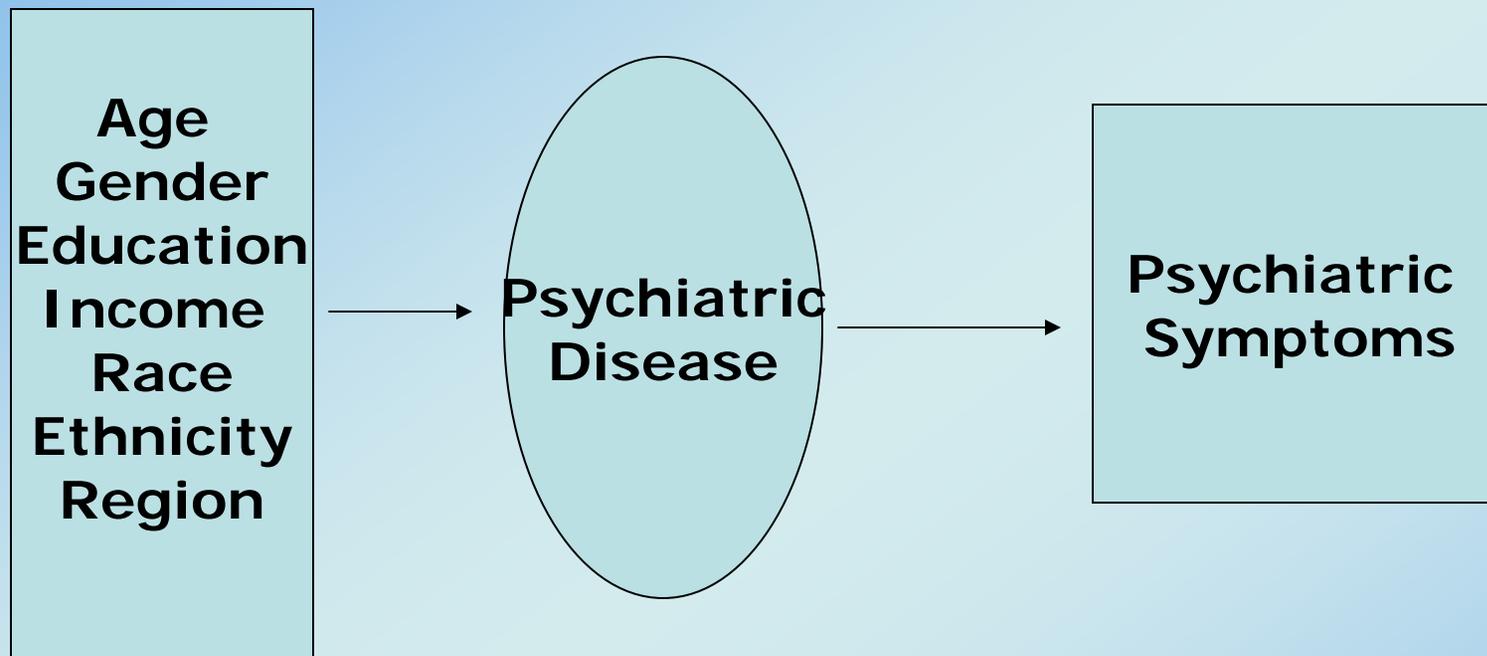
Abstract Rationale: This review examines how minority status and the participation of subjects in clinical research. **Objectives and methods:** The review was performed using key words “clinical trials”, “psychiatric ethics”. Major goals of this review were to update the knowledge base and identify existing gaps in a new area of psychiatric research. **Results:** Only extremely few papers addressing the ethical issues and references to minority groups were identified, and many of these were extrapolated from work done on non-minority patients. **Conclusions:** Systematic, controlled studies are needed to elucidate the ethnicity impact on such issues.

Evelyn and colleagues (2001) reviewed the representation of minorities participating in clinical trials that had been submitted to the Food and Drug Administration (FDA) between 1 January 1995, and 31 December 1999, for approval of new drugs. The review determined that, when race could be determined from the records (53% of all trials), 88% of the participants were reported to be white, 8% African-American, 3% Hispanic, and 1% or less ‘other minorities.’ Moreover, it was observed that there had been a steady decline in the participation of minority groups over time.”

Why does it matter to understand
the culture of the patient?

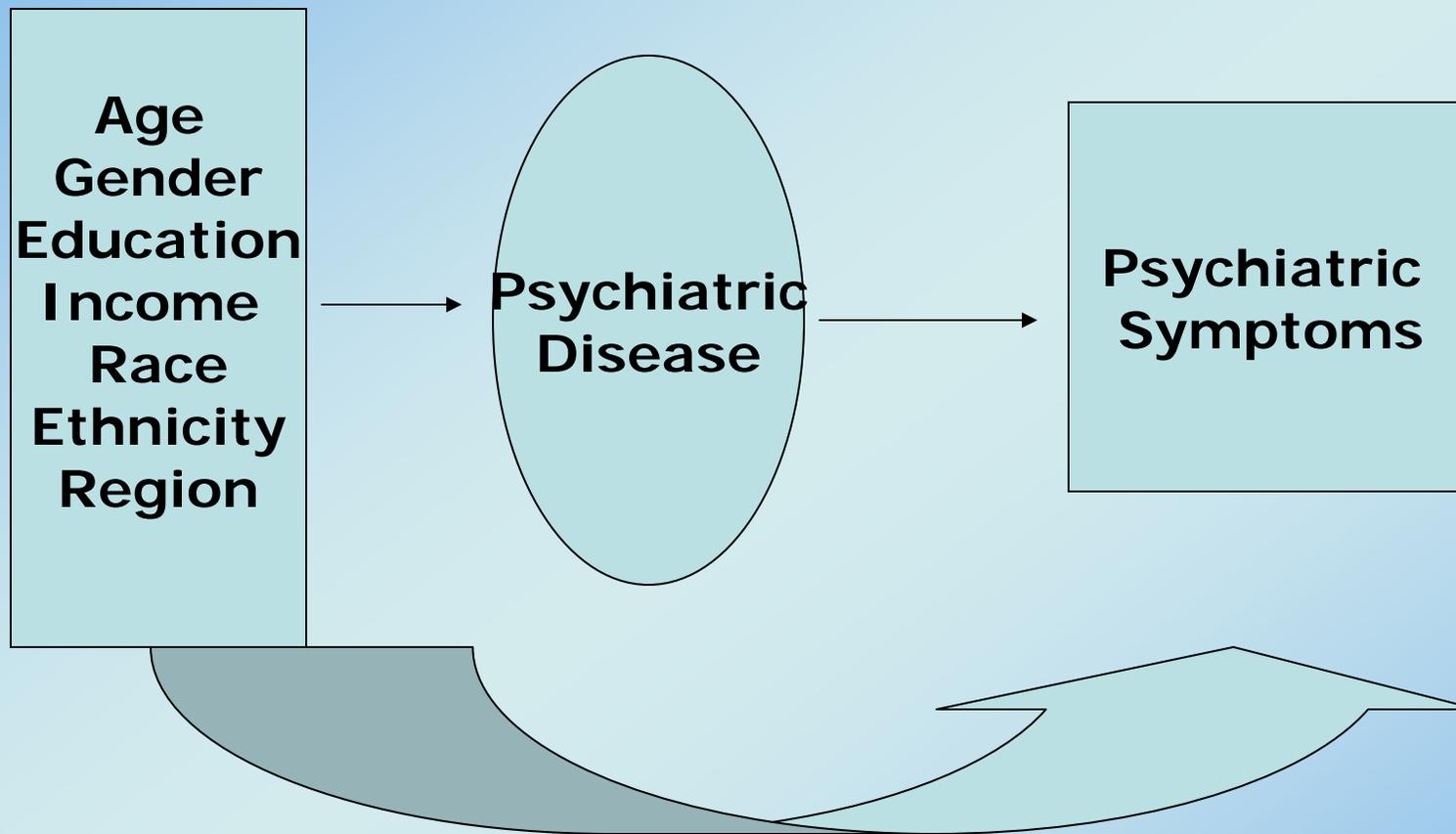
For Accurate Diagnosis

Universal relationship between Disease and symptoms



**Central assumption: normality and psychopathology are internal to the self
Rather than the product of experience in social relationships in local contexts
(Lewis-Fernandez and Kleinman, 1994)**

Relativistic relationship between Disease and symptoms



An inadequate understanding of how factors such as race, gender, culture or social class influence the relationship between symptoms and disorders can interfere with clinical inferences.

(Alegria and McGuire, Journal of Health and Social Behavior, 2003)



An Interpretation of an Interpretation

Most treatment is dependent on:

- patients' capacity to *describe* their experience of the presenting problem (e.g. symptoms) and to exhibit non-verbal cues that corroborate symptom descriptions - this is what we call the patient's culturally constructed experience of the illness
- clinicians' ability to accurately *comprehend* patients' language and the embodiment of that experience, correctly translate it and attribute meaning to it. This process is driven by clinician's own culturally constructed interpretation of symptom and affect

Racial Disparities in Clinical Trials

Physicians need to recognize and accept the fact that “Why are minority groups underrepresented in clinical trials of treatments for HIV infection?... Beliefs, behavior, attitudes, perceptions, and expectations influence both patients and physicians. Moreover, these factors may affect the patient-physician relationship in ways that neither party consciously perceives.”

Patients often respond to such attitudes with mistrust of the physician and reluctance to comply with treatment.”

King, T. (2002). Racial Disparities in Clinical Trials. *New England Journal of Medicine*, 346(18), 1401-1402.

Signal Endorsed at Different Illness Threshold

When independent clinical assessments are done with semi-structured interviews, Latinos are over diagnosed with depression and African Americans are over diagnosed with schizophrenia even though Latinos present more psychotic symptoms than African Americans (Minsky et al., 2004).

Sources of Clinical Uncertainty from the Transcripts of Providers

- **Language or cultural barriers (sx of mental illness are not exportable)**

(118 CN) He used the word “malestar” which means sort of... is not a malady it’s sort of an unease or not feeling well that has been with me and it involves that I have memory gaps, that I have difficulty assimilating certain things, that I have dreams, that... and the word he used in Spanish is “decaimiento” which is that he just felt very down and with energy that, that it involves a lack of energy and worry about his children, worry about the loss of memory and a lack of illusion and that ... and that he’s tired physically so that’s what he described.

Why does it matter to understand
the culture of the patient?

For Research-Study and Sample
Design, Data Collection and
Hypotheses

Pharmacological and Cultural Considerations in Alcohol Treatment Clinical Trials: Issues in Clinical Research Related to Race and Ethnicity

Robert E. Taylor

AS A RESULT of widely accepted social constructs of ethnicity and race, blacks and other minorities are perceived within narrow definitions of identity, which assume homogeneity. This assumption permeates social, cultural, environmental, and genetic areas of scientific inquiry and imposes potentially false generalizations in biologically based clinical research. Definitional improvements are needed to infuse quantifiable, biological meaning into these concepts. Total reliance on self-identification as the primary determinant of race is often misleading and introduces undefined bias into a research study. For ensuring a successful trial outcome, knowledge of critical social and cultural factors is essential in designing alcohol treatment trials in black and other minority populations. Operational issues related to recruitment, screening, exclusion criteria, and retention all are critical considerations that have an impact on participation and research outcomes, especially in minority populations. Important cultural factors, including peer or group dynamics, "stigmatization," trust, and ethnic/cultural identity, must also be incorporated into research design. Pharmacological issues related to gene polymorphism and group stratification are also examined for their relevance to research designs that incorporate minority populations. The overall aim is to examine how socio-cultural factors and pharmacological approaches may contribute to the successful execution of an alcohol treatment clinical trial.

RACE AND ETHNICITY IN CLINICAL TRIAL RESEARCH

The generalizations related to the homogeneity of racial populations are widespread and broadly accepted. Variations in skin color, culture, language, and self-declared

designations are routinely used in research (Jackson, 1993). These designations have no scientific meaning (Kau, 1993). From a scientific perspective, it is important to understand differences that

exist between populations for research purposes. For example, a population that is not homogeneous cannot be ignored. In New York might be different from Louisiana or California (Cannon, 1993). Diseases is not homogenous factors, when added to no determinants for disease treatment strategies. Definitions needed to define biological concepts so that research is not problematic (Foster and St

Although genotyping, the study of human variation, may be infeasible for reasons of cost, it should be recognized and investigated as an important issue. Researcher's understanding variations, defining characteristics leading to differences in research results (Guttman, 1993).

SOCIAL AND CULTURAL

There are many social and cultural factors that will influence the utilization of minority populations in the research design. From a historical standpoint, minority populations have been largely excluded from research protocols until recently as occasioned by federal mandates

"As a result of widely-accepted social constructs of ethnicity and race, blacks and other minorities are perceived within narrow definitions of identity, which assume homogeneity. This assumption permeates social, cultural, environmental, and genetic areas of scientific inquiry and imposes potentially false generalizations in biologically based clinical research.... Total reliance on self-identification as the primary determinant of race is often misleading and introduces undefined bias into a research study."

From the Collaborative Alcohol Research Center, Howard University, Washington, DC.

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Inclusion Enrollment Report

This report format should NOT be used for data collection from study participants.

| PART A. TOTAL ENROLLMENT REPORT: Number of Subjects Enrolled to Date (Cumulative) by Ethnicity and Race | | | | |
|--|------------|-------|-------------------------|-------|
| Ethnic Category | Sex/Gender | | | |
| | Females | Males | Unknown or Not Reported | Total |
| Hispanic or Latino | | | | ** |
| Not Hispanic or Latino | | | | |
| Unknown (individuals not reporting ethnicity) | | | | |
| Ethnic Category: Total of All Subjects* | | | | * |
| Racial Categories | | | | |
| American Indian/Alaska Native | | | | |
| Asian | | | | |
| Native Hawaiian or Other Pacific Islander | | | | |
| Black or African American | | | | |
| White | | | | |
| More Than One Race | | | | |
| Unknown or Not Reported | | | | |
| Racial Categories: Total of All Subjects* | | | | * |
| PART B. HISPANIC ENROLLMENT REPORT: Number of Hispanics or Latinos Enrolled to Date (Cumulative) | | | | |
| Racial Categories | Females | Males | Unknown or Not Reported | Total |
| American Indian or Alaska Native | | | | |
| Asian | | | | |
| Native Hawaiian or Other Pacific Islander | | | | |
| Black or African American | | | | |
| White | | | | |
| More Than One Race | | | | |
| Unknown or Not Reported | | | | |
| Racial Categories: Total of Hispanics or | | | | ** |

* These totals must agree.

** These totals must agree.

Why ethnic minority groups are under-represented in clinical trials: a review of the literature

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Research is required in developing culturally sensitive research methods, materials and data

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Box 1 Barriers to ethnic minority participation in clinical trials

- Fear and mistrust
- Inappropriate exclusion criteria
- Poorly designed trials
- Access
- Costs associated with interpretation/translation
- Shortage of ethnic minority trial coordinators
- Consent issues
- Socio-cultural barriers
- Stereotypes and cultural myths

Great Variation in Latino Paradox Effect (NLAAS)

- There is great variation across Latino subgroups in the size of the Latino paradox effect. For lifetime prevalence rates, the immigrant paradox pattern is most apparent for Mexicans in major depressive disorders (males and females) and social phobia (females) as compared to the other groups.
- For substance use disorders, the paradox effect is observed for all Latino subgroups (except Puerto Rican males).

Our results indicate that during the time Latinos reside in their country of origin prior to immigration, they are protected against the onset of psychiatric disorders. Hence, the longer they remain in their country of origin, the less cumulative risk of onset of the disorder they experience, resulting in lower lifetime prevalence rates. This is especially true if they remain in their country of origin during ages at which one sees the greatest risk of onset for the disorder (teens and early twenties for depressive and substance-use disorders and childhood and early teens for anxiety disorders).

The Importance of Culture in explaining disease

- Culture: Latino immigrant women uniformly report lower rates of substance-use disorders as compared to US-born can be explained by strong cultural norms against alcohol and drug use and prescription of gender roles (i.e. early marriage and pregnancy).

What will it take to conquer the
next frontier in healthcare
services?

Changing Practitioner Behavior and Training

- Some studies suggest that retention and outcomes are superior when clients and clinicians are matched ethnically. Others contradict this assertion.
- The crux of the matter appears to be cognitive match:
 - Similarity of “explanatory models for clients’ problems in terms of etiology, symptom meaning, course, and appropriate treatment”

Work Collaboratively and Proactively to Reduce Mistrust and to Engage Minorities, including Immigrants in Health Care

- Minorities will not necessarily seek professional health care services. They will tend to rely on community sources (e.g. churches, WIC offices) . Viewing this as an asset, not a problem, reminds the interventionist to work collaboratively with natural helpers in the community.
- Programs must build trust and be highly proactive in trying to understand the culture of the patient.
- Programs should employ minority practitioners in the recruitment, retention, and recovery efforts.

Training Needs

- Understanding the culture of the patient will require training in:
 - the clinical basis of treatment and the barriers to care (factors that impact retention, enrollment, adherence)
 - approaches to service use that integrate cultural liaisons to help match services to needs
 - models of participatory decision-making that help align Tx to patients' expectations, health literacy and desired health outcomes