

BUILDING A RESEARCH CAREER

Focused on Alcohol Use in a Stigmatized and Marginalized Population Group

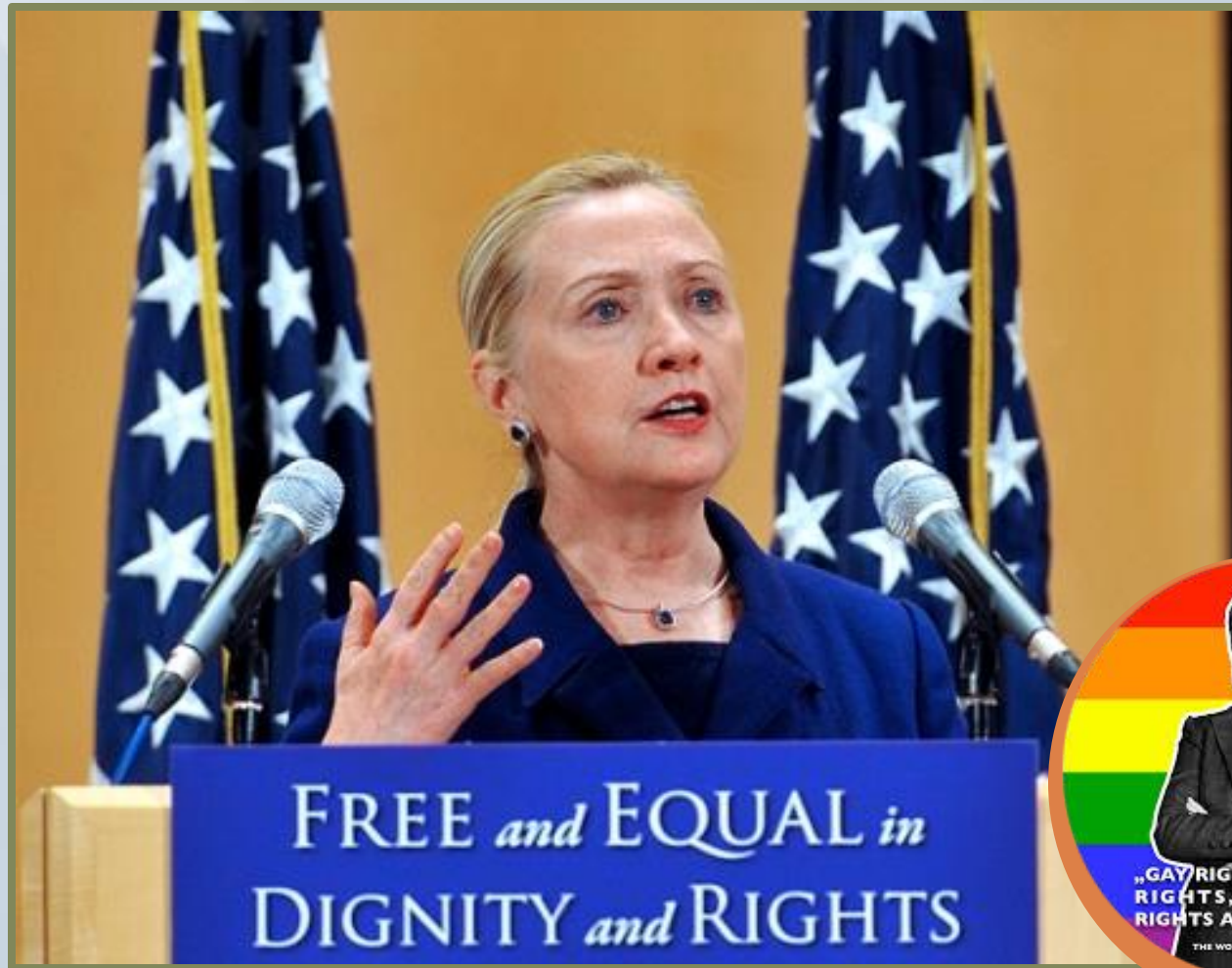
Tonda L. Hughes, PhD, RN, FAAN

Professor & Associate Dean for Global Health



STTI, 26th Annual International Research Congress
July 26-27, 2015

United Nations Address, 2011

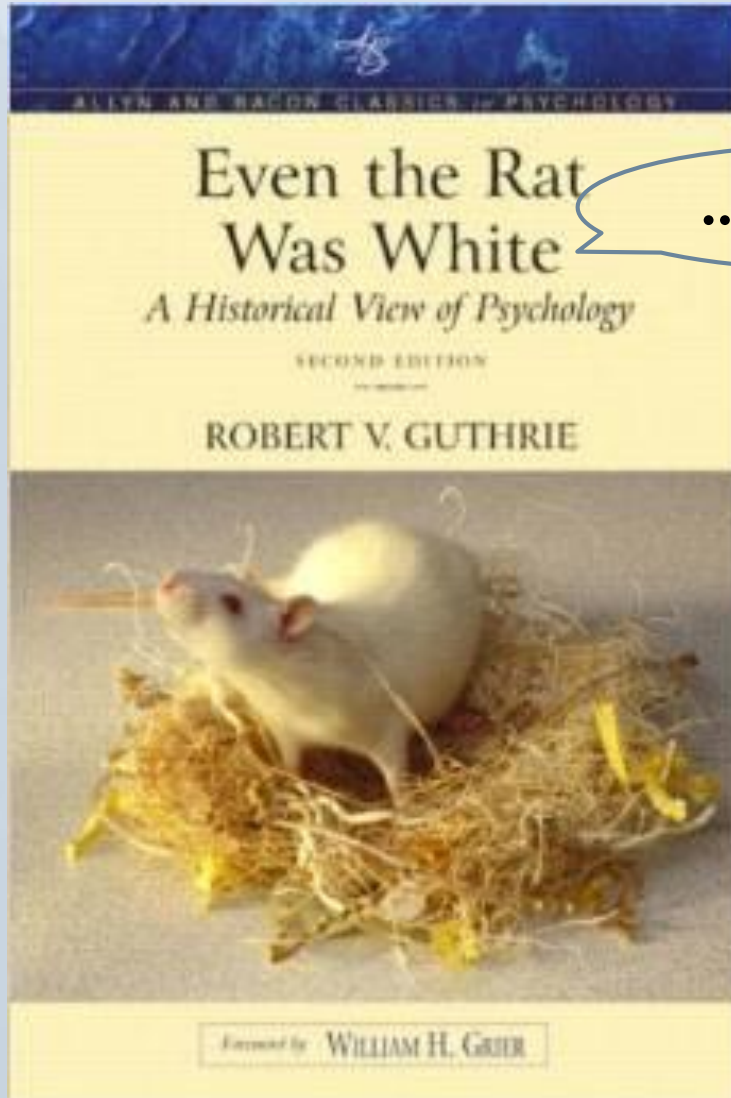


<https://www.youtube.com/watch?v=MudnsExyV78>

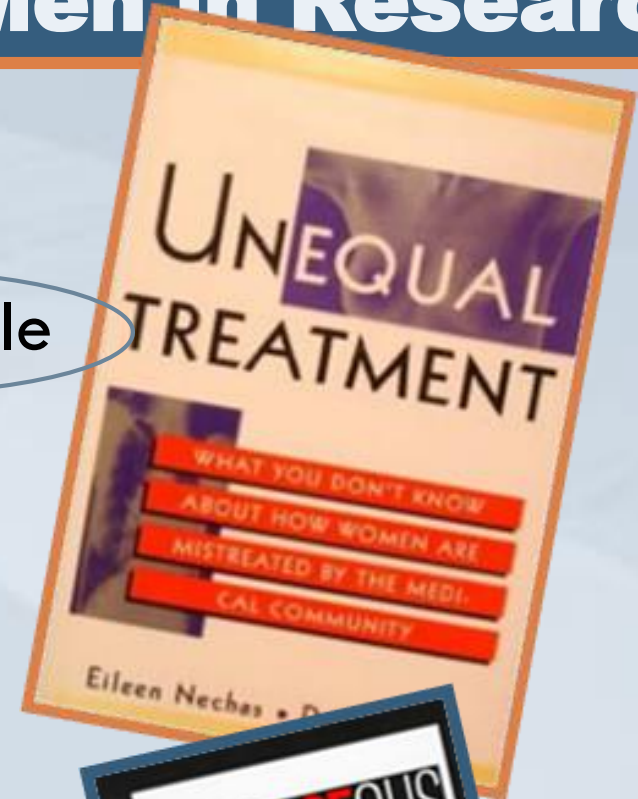
Objectives

- ❖ **Provide an overview of my research career development including how and why I chose to focus on the health of sexual minority women (SMW: lesbian, bisexual, mostly heterosexual);**
- ❖ **Highlight some of the most interesting findings from my research with SMW;**
- ❖ **Describe some of the barriers that I encountered in doing work focused on SMW's drinking; and**
- ❖ **Describe future directions for research related to SMW's drinking and health.**

Predominant Focus on Men in Research



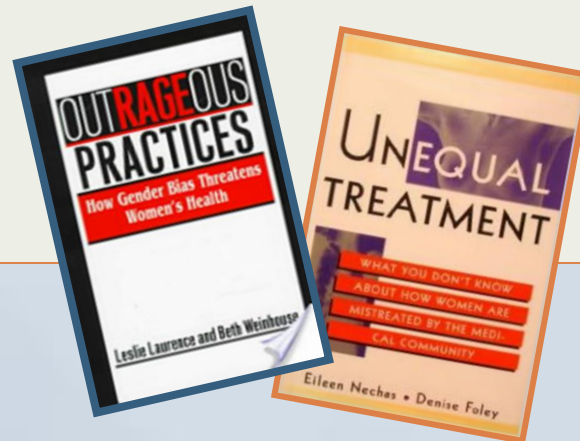
...and Male




Government Accounting Office, 1990

In 1990 the GAO criticized NIH for “...excluding women from most studies involving diseases, treatments, and drug effects and for devoting **only 13% of its research funds to women**”

(Fletcher, 1996)



Research on Sexual Minority Health



1980-2000

Boehmer (2002). AJPH

LGBT-Related Studies Funded by NIH

NIH Funded Research 1989-2011

628 studies related to LGBT health

- Only **0.1%** focused on aspects of LGBT health **other than HIV/AIDS**
- Of these:
 - **13.5%** included **lesbian/bisexual** women

Coulter et al. (2014) AJPH

Early Studies of Sexual Minorities' Drinking



Maud's—Lesbian Bar in San Francisco (Circa 1966)

Academic Mentors



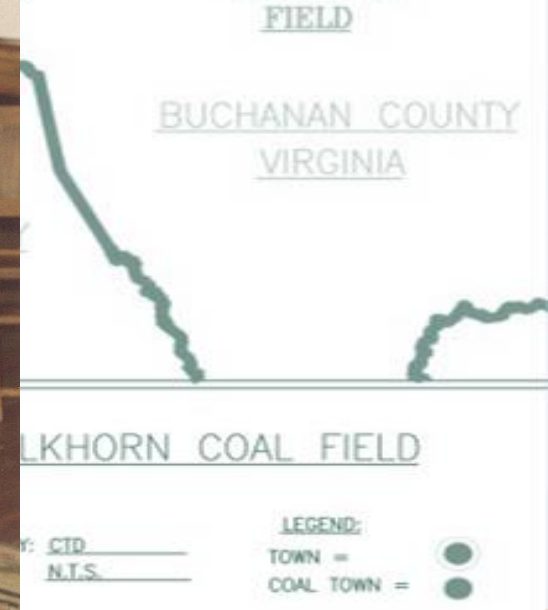
Early Beginnings: Eastern Kentucky



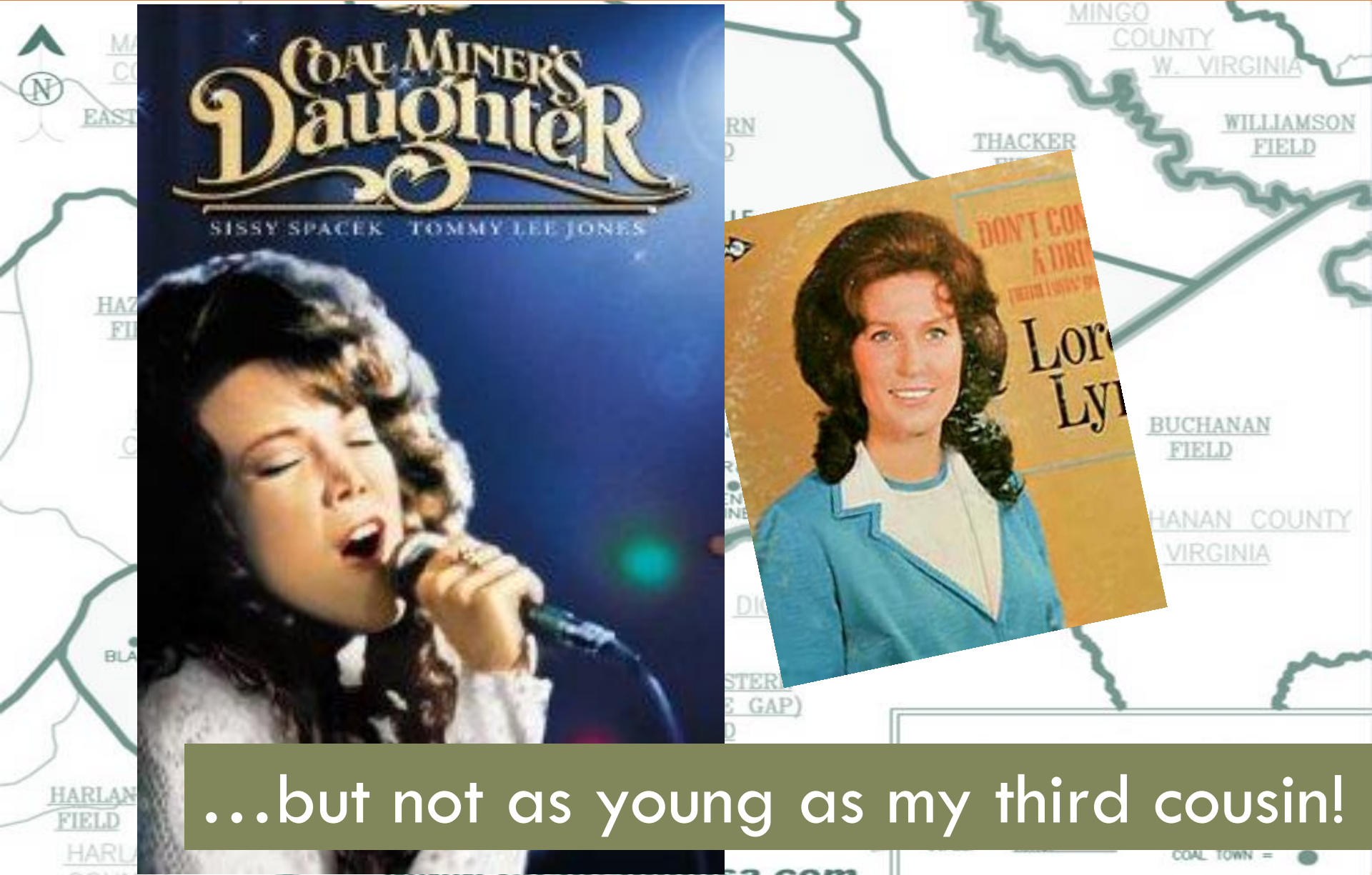
Early Beginnings: Eastern Kentucky



Married Young



Early Beginnings: Eastern Kentucky



...but not as young as my third cousin!

ASN & BSN: Eastern Kentucky University



Master's Degree: University of Kentucky

UK
UNIVERSITY OF
KENTUCKY
College of Nursing



University of Kentucky

Nurses Assisting Nurses Program



*NURSES
ASSISTING
NURSES*

Doctoral Education: University of Illinois



Beverly McElmurry,
EdD, RN, FAAN



Denny Webster,
PhD, RN, CS



Alice J. Dan, PhD

LETTERS

Nursing Research

Re Nursing Practice in Women's Health—Concept Paper

To the Editor:
The Women's Health faculty and graduate students at the University of Illinois College of Nursing have developed a concept paper about nursing practice with women. We would like to share this document with as many nurses as possible. Our hope is that Nursing Research readers in turn will share their reactions to the paper with you and/or us.

We anticipate presenting this concept paper at the National Conference on Women's Health to be held at the National Institutes of Health in June 1998. This conference is jointly sponsored by the Food and Drug Administration and Public Health Service. We believe it will provide an important forum for discussion of women's health concerns—MORNING STAR CATEGORY SOURCE OF TRUST OR WOMEN'S HEALTH. DENNY WEBSTER, PhD, RN, LINDA LAMIC, MS, RN, BEVERLY J. McELMURRY, EdD, FAAN, ALICE DAN, PhD, RN, DORIS BISHOP, PhD, RN, DORIS ROYER, PhD, RN, CINA SPOSS-SIMPSON, MS, RN, MARCO LUTTI, PhD, and JANE NEWCOMB, MS, RN, Women's Health Exchange (WHEX), College of Nursing, The University of Illinois at Chicago, 645 S. Damen, Chicago, IL 60612.

CONCEPT PAPER

The literature in women's health and accompanying experience in the provision of women's health care have resulted in the identification of some essential criteria for defining women's health practice. These can be organized according to the assumptions, content issues, process issues, structural issues, and outcomes issues involved in the provision of health care for women. They are consistent with various research within nursing theory.

Assumptions: (1) The human body, mind, and spirit form an integrated whole. (2) People have capacity for self-care and self-healing. (3) Events and interactions in the family, community, and world affect and shape the health of people. (4) Health care is the shared responsibility of all.

Content issues: graduate students in nursing who read and shared this concept paper, especially Linda Bishop, Doris Royer, Linda Lamic, and Jane Newcomb, are acknowledged.

The work of the faculty and students has been partially funded by Division of Nursing Grant Number NS 00058, US Department of Health and Human Services.

References

Oster, D. E. (1985). *Nursing: Concepts of practice* (2nd ed.). New York: McGraw-Hill.

ability of society, the health care system, and the individual. (5) Health refers integrally, festively, the capacity to develop, and the capability to creatively transcend difficult situations. (6) Control over one's body is a basic right. (7) A woman's lived experience are the starting point for future action. (8) Women's health care practice can occur in a variety of settings, including ambulatory care clinics, communities, hospitals, and university settings. (9) By focusing on women, health care for all will be improved, men are not excluded as either providers or recipients.

Structural issues: Historically, nursing practice in women's health care has been primarily linked to reproductive health. The emerging practice in women's health care provide comprehensive attention to women from birth through old age, with an emphasis on illness prevention and health promotion. Thus, contributions are needed from a variety of perspectives working collaboratively.

In the health care of women, the provider and the client enter into an egalitarian and collaborative relationship. Each brings different strengths to the relationship. In particular, the provider brings scientific knowledge, and the client brings knowledge of her own body/mind/spirit and experience. Women make health-related decisions and identify health goals in collaboration with the behavior.

Process issues: Self-care is defined as the practice of caring for one's own health personally or with the help of others. It is an own belief in one's ability to care for oneself and to seek the assistance of others when needed accordingly.

Content issues: Women's health encompasses throughout the life-cycle and recognizes the unique needs of women. The emphasis is on self-care and self-healing. It includes developmental, social, and occupational activities while recognizing the individual's right to privacy.

Structural issues: Health promotion and illness prevention are essential nursing encounters in women's health care. The focus is on the client's process-oriented. Health care is a continuing

process as well as an outcome. The woman is the ultimate responsibility for and control over self-care. The provider encourages people to trust themselves as sources of knowledge, and to learn about alternate sources of knowledge as well. Thus, outcomes include increased knowledge, increased self-confidence, choice of illness, expanded competence in self-care, and an increased sense of choice and control. The overall goal of health care is to enable women to make choices that expand their ability to care for their health and effectively use sources of illness care when necessary.

Chicago School of Thought in Women's Health

PhD Program: Dissertation

**Pre-doctoral Fellowship
National Center for
Nursing Research
F31 NR006001**


B. McElmurry, Sponsor

**Chief Nurse Executives' Responses To
Chemically Dependent Nurses (1989)**

CHIEF NURSE EXECUTIVES' RESPONSES
TO CHEMICALLY DEPENDENT NURSES

BY
TONDA L. HUGHES

PhD Program: UIC



ADDICTION in the Nursing Profession

Mary R. Haack, R.N., Ph.D., C.A.C.
Tonda L. Hughes, R.N., M.S.N.
Editors

NURSING SCAN: WOMEN'S HEALTH

Published by the Graduate Nursing Concentration in
Women's Health Program,
an Advanced Nurse Training Grant
Supported by DHHS, PHS, Division of Nursing (1D23 NU 004 55-01).

University of Illinois at Chicago
College of Nursing

THE NURSING CLINICS OF NORTH AMERICA

VOLUME 21 / NUMBER 1
MARCH 1986

MEN'S HEALTH

Felissa L. Cohen, Ph.D., R.N., and Jerry D. Durham, Ph.D., R.N.,
Guest Editors

WOMEN'S HEALTH

Denise Webster, R.N., Ph.D., C.S., and Tonda Hughes, R.N., Ph.D.,
Guest Editors

W. B. SAUNDERS COMPANY
Philadelphia London Toronto Mexico City
Rio de Janeiro Sydney Tokyo Hong Kong

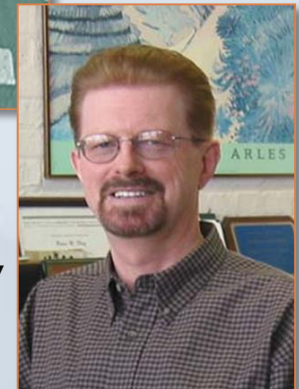
Patterns of AOD Use among Women (1992-94)

Individual NRSA, National Institute on Drug Abuse (NIDA), T32 DA 05466

Mentors



A. Dan



B. Flay

AWHONNS Clin Issues Perinat Womens Health Nurs. 1993;4(2):203-12.

Patterns of alcohol and drug use among women: focus on special populations.

Hughes TL, Fox ML.

Abstract

Despite the growing national concern about the effect of the use of alcohol and other drugs on the health and productivity of men and women, relatively little is known about alcohol and other drug (AOD) problems in women. Because of this lack of research and the stigma associated with women who are alcoholic or drug addicted, AOD problems among women are less likely to be recognized and addressed. This article reviews patterns and consequences of AOD use among a number of special populations of women. Information about risk factors and assessment and screening are included to assist the nurse in the identification, counseling, and referral of women with AOD-related problems.

PMID: 8242041 [PubMed - indexed for MEDLINE]

Sharon Wilsnack: Research Mentor



Chester Fritz Distinguished Professor

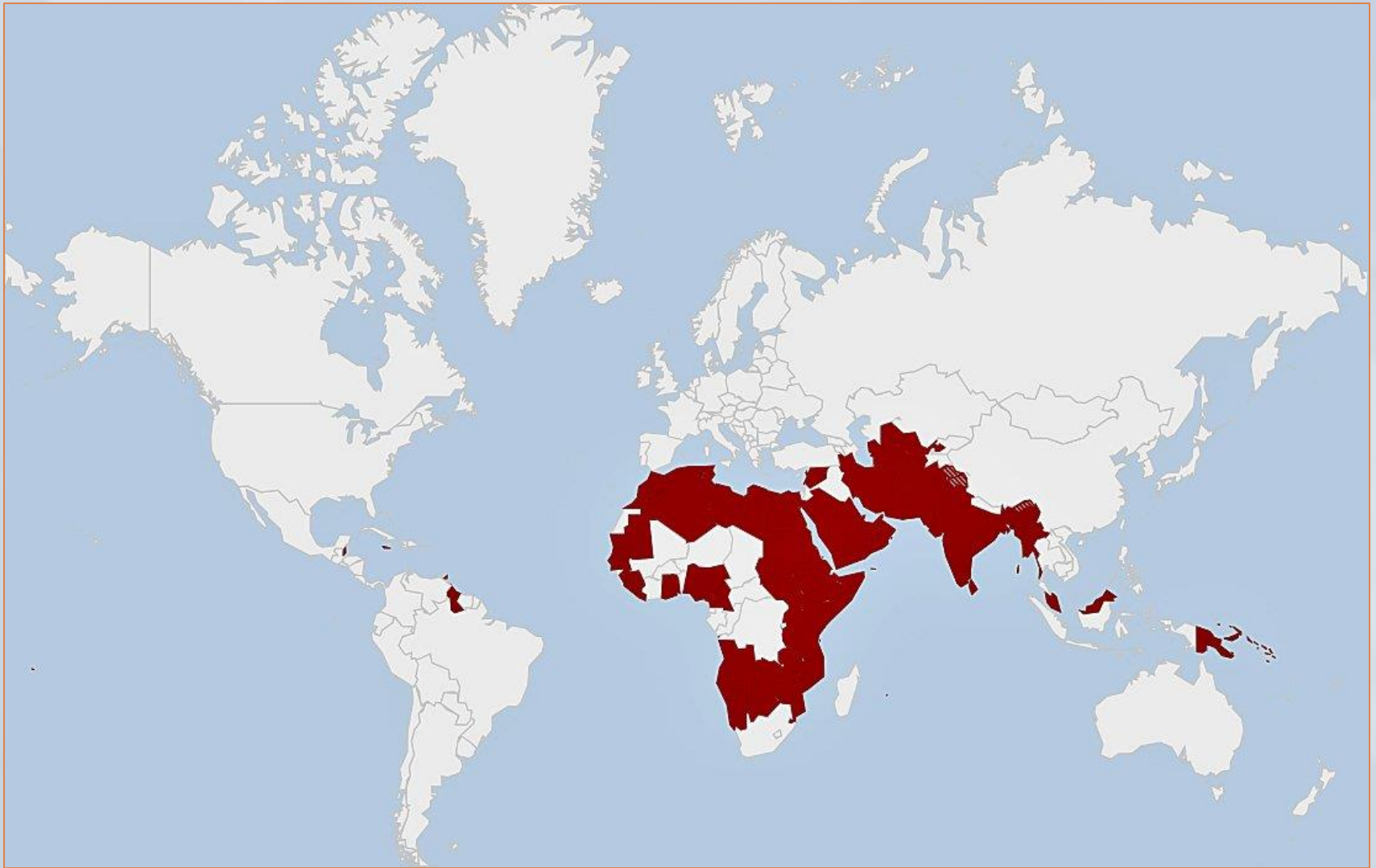
Department of Clinical
Neuroscience

University of North Dakota
School of Medicine &
Health Sciences

Health Equity and Social Justice



Countries where Homosexuality is Illegal



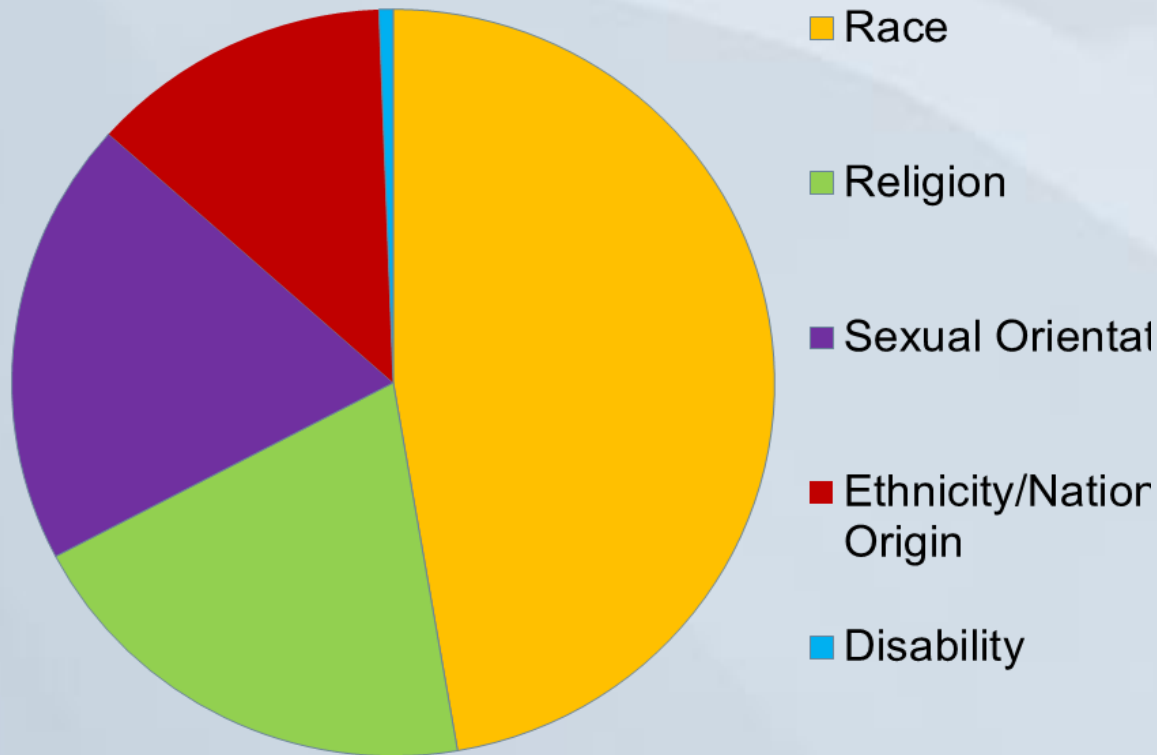
Employment Discrimination in the U.S.

- **In 29 states**, it is legal to fire someone for being “out” as gay, lesbian or bisexual in the workplace.
- **In 34 states**, employers have the legal right to fire people who are transgender.



Hate Crimes in the U.S.

19% of Hate Crimes Target Sexual Minorities



Victims of “Corrective Rape”



Building a Research Career: Early Work

- **Chicago Women's Health Study**
(1992-1994) In collaboration with the Chicago Department of Public Health & Lesbian Community Cancer Project
- **Multi-site Women's Health Study**
(1994-1996). Chicago, NYC, St. Paul/Minneapolis, Columbus

Comparing Lesbians' and Heterosexual Women's Mental Health: A Multi-Site Survey

Tonda L. Hughes
Ann Pollinger Haas
Lisa Razzano
Roberta Cassidy
Alicia Matthews

ABSTRACT. Despite increased awareness of, and interest in, the health status of lesbians over the past two decades, many gaps remain in our knowledge of lesbians' mental health. Much of the existing research on lesbian health has been conducted with small, homogenous samples and few studies have included comparison groups of heterosexual women. This paper presents descriptive data from a study of lesbian health conducted in Chicago.

Tonda Hughes, PhD, RN, is Assistant Professor at the University of Illinois at Chicago. Ann Haas, PhD, is Professor in the Department of Health Services, Lehman College of The City University of New York, Bronx, New York. Lisa Razzano, PhD, is Assistant Professor of Psychiatry and Director of Research at the Mental Health Services Research Program, University of Illinois. Roberta Cassidy, MS, RN, is a doctoral student in PMA at the University of Illinois at Chicago and Alicia Matthews, PhD, is Assistant Professor in the Department of Psychiatry at the University of Chicago.

Correspondence should be addressed to: Tonda Hughes, Department of Public Health, Mental Health, and Administrative (PMA) Nursing, Room 956-M/C 802, 845 S. Damen Avenue, Chicago, IL 60612 (E-mail: THughes@uic.edu).

Merging of the three data sets, data analysis, and preparation of this manuscript were supported by the Lesbian Health Fund, the Mental Health Services Research Grant on Women and Gender from the National Institute on Mental Health #1R2, MH54212, University of Illinois (UIC) Department of Psychiatry, and an Internal Research Support Grant (IRSP) from the UIC College of Nursing. The Chicago survey was supported by the Chicago Board of Health and the Chicago Foundation for Women.

Journal of Gay & Lesbian Social Services, Vol. 11(1) 2000
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National Study of Health & Life Experiences of Women



- 20-year longitudinal study of women's drinking
- National probability sample of adult women

*Funded by NIAAA,
5R01AA 004610
S. Wilsnack, PI*



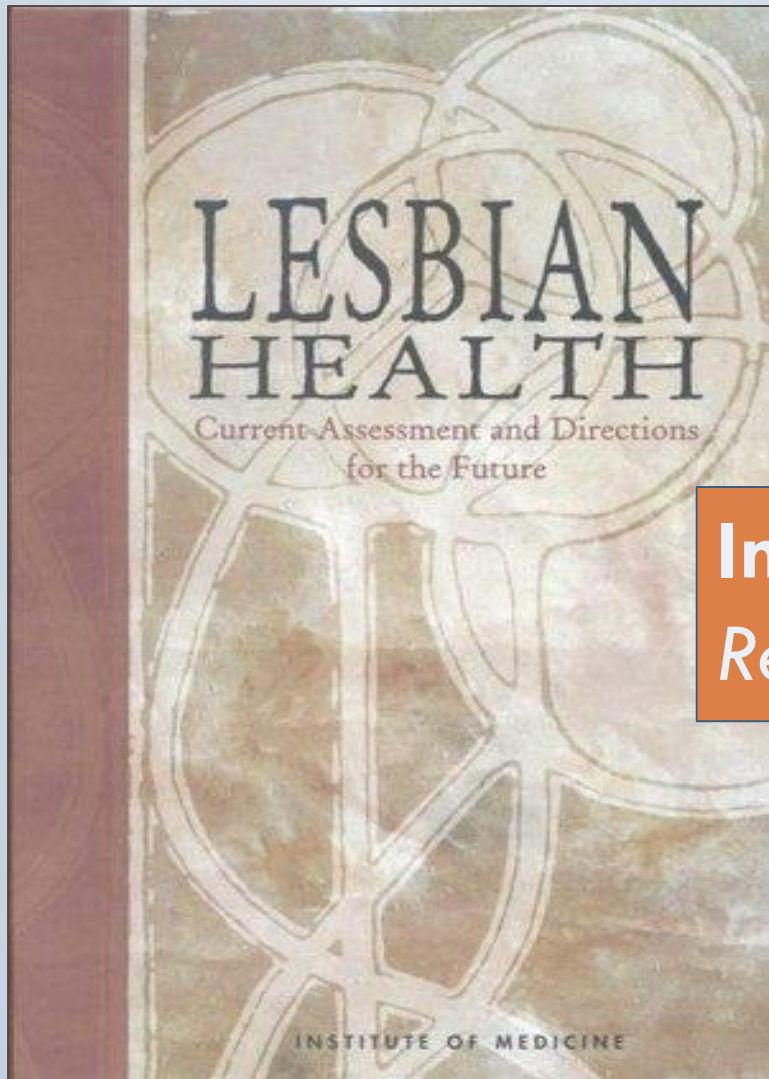
Building a Research Career

Stigmatized and Marginalized Population Groups



The Chicago Health and Life Experiences of Women Study (CHLEW)

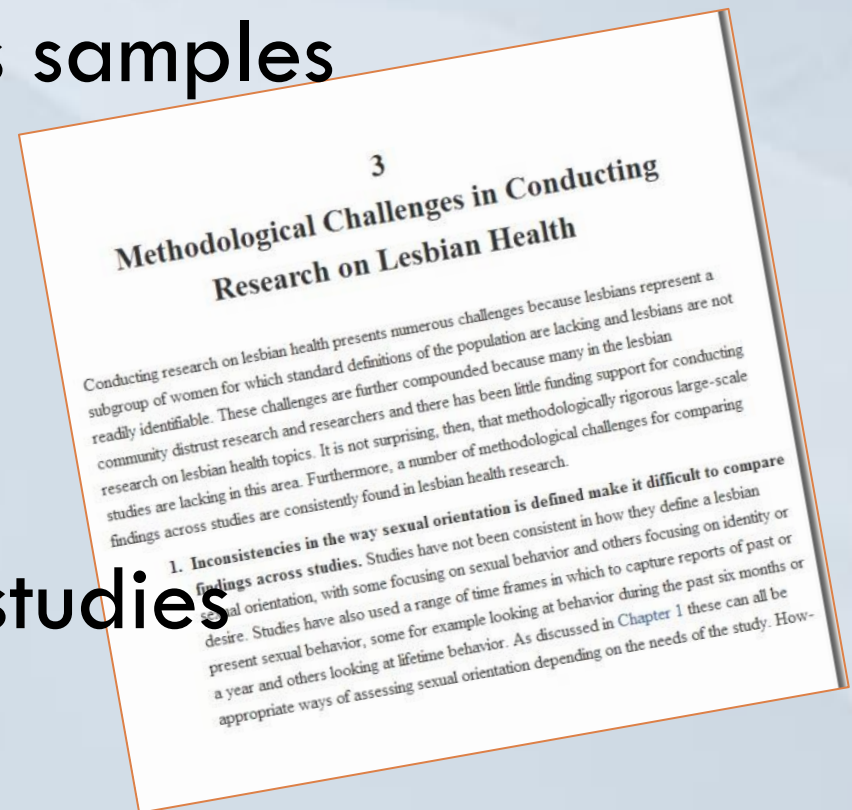
Funded by NIH (NIAAA & ORWH)
K01 AA00266, 1999-2002



Institute of Medicine (IOM)
Report on Lesbian Health 1999

Methodological Limitations (IOM Report)

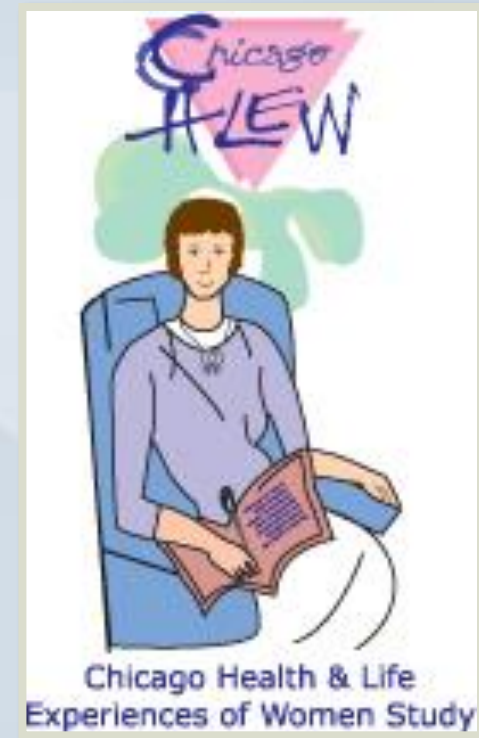
- Lack of appropriate heterosexual comparison groups
- Small or homogenous samples
 - White
 - Well-educated
 - Young
- Lack of longitudinal studies





Sample Characteristics (N=447)

- 18-83 years (average = 39 yrs)
- 25% household income <\$20,000
- 52% SMW of color
- 56% bachelor's degree or higher
- 68% in committed relationship
- 31% at least one child



NSHLEW Survey Instrument

INTERVIEWER: BEFORE STARTING INTERVIEW, COPY CASE ID NUMBER ON LABEL ABOVE ONTO SELF-ADMINISTERED QUESTIONNAIRE, AND ONTO "PRIVACY ENVELOPE."

IF MORE THAN ONE INTERVIEW IN SAME HOUSEHOLD, WRITE CASE ID NUMBER OF SECOND INTERVIEW HERE:

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INTRODUCTION:

Hello, I'm (NAME) from the University of Chicago's National Opinion Research Center (SHOW ID CARD). You may remember that a few years ago one of our representatives interviewed you. Now we're contacting exactly the same people and asking them to participate in a follow-up survey. (SHOW LETTER) We recently sent you this letter to explain the reasons for the survey.

The interview takes about an hour, but the time can be shorter depending on how many questions apply to you. We will be asking you about your work and family experiences; about stresses and satisfactions in your life; your health; your use of alcohol and other substances; and aspects of your important personal relationships.

Main Questionnaire

National Study of Health and Life Experiences of Women and Their Partners

University of Chicago

National Opinion Research Center

any time. If there is a question you
name is never associated with the
can ever be identified. We
experience.

members of the directors of the project



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STICK ASSIGNMENT LABEL OR COPY
CASE ID FOR THIS CASE HERE

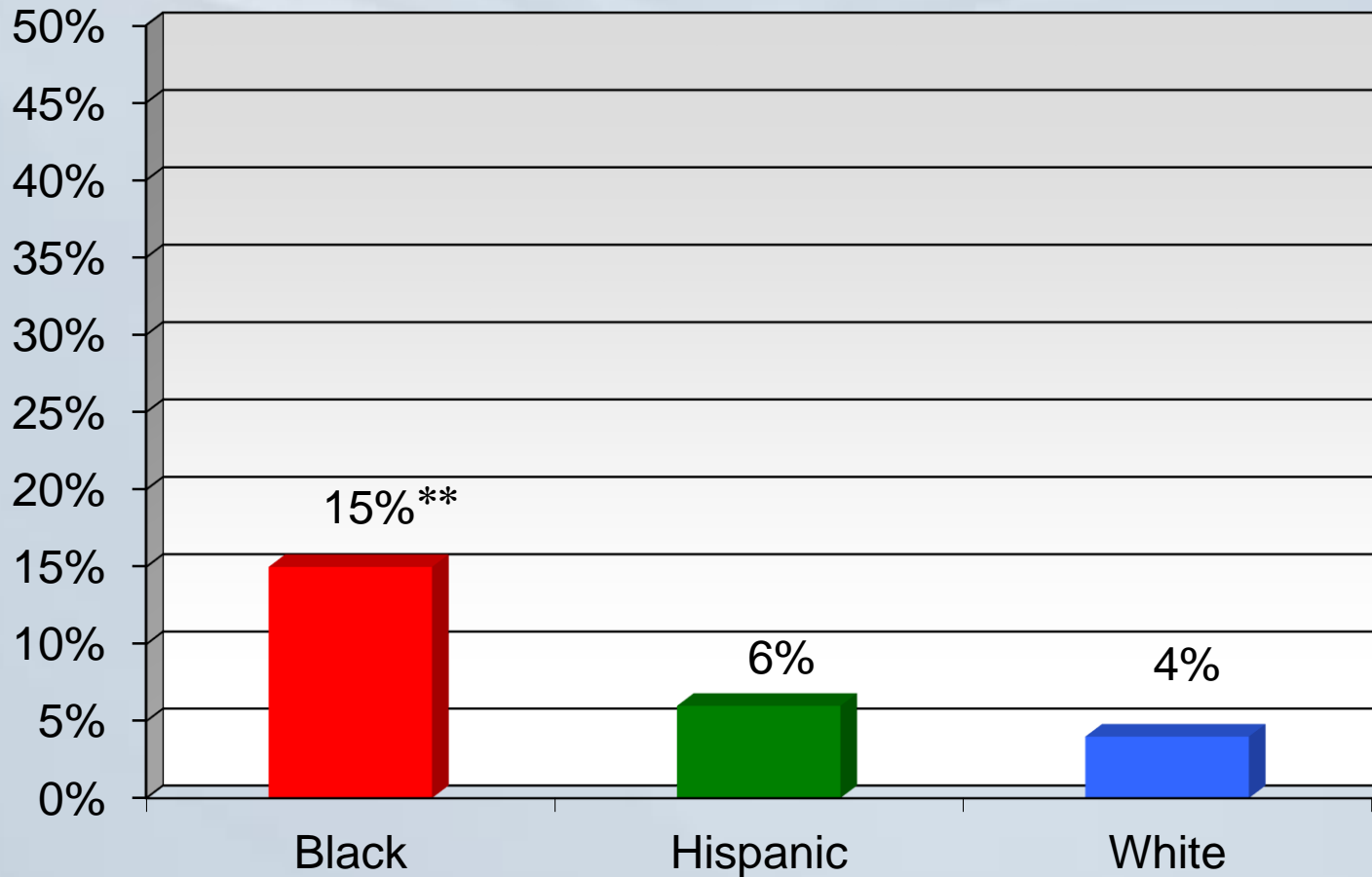
Data Collection



Heavy Drinking by Race/Ethnic Group



Two or More Drinks per Day on Average

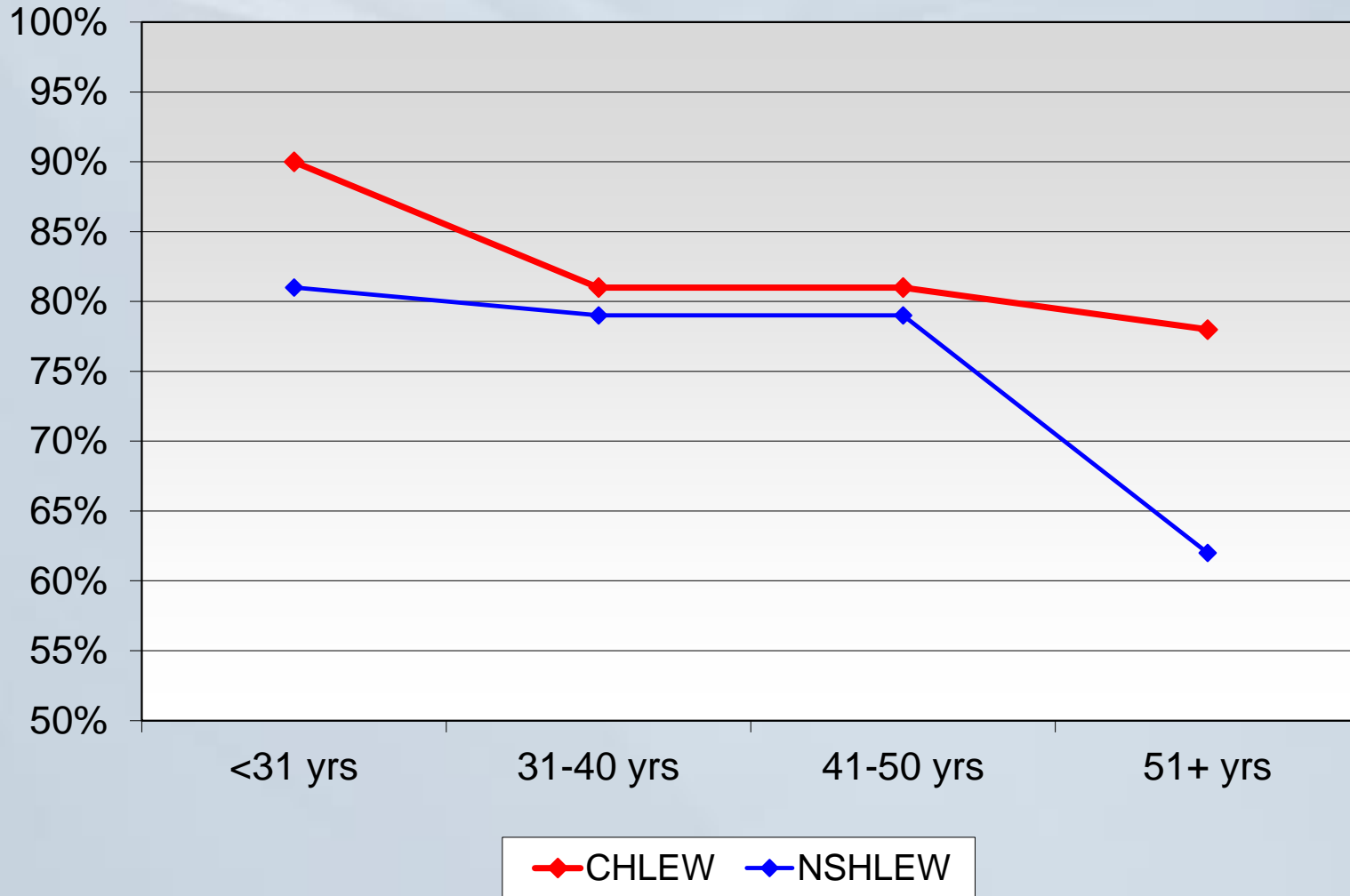


** $P < .001$

Hughes et al., 2006

12-Month Drinkers by Age Group

Comparison of **SMW** & **Heterosexual Women**



CHLEW Study Now in its 15th Year!!

- **Sexual Identity and Drinking:
A Longitudinal Follow-Up**
(2003-2008; R01 AA13328)
- **Cumulative Stress and
Hazardous Drinking in a
Community Sample of Adult
Sexual Minority Women**
(2009-2014; 2R01 AA13328-9)



Other Collaborative Research

Probability Samples

- **Health risks across sexual identity groups in a national sample of young Australian women (ALSWH)** T. Hughes, PI; Lesbian Health Fund
- **Sexual orientation, mental health and substance use: Secondary analyses of the NESARC data** S. McCabe, PI, UMich; NIMH & NIDA, R21 DA023055
- **Sexual Orientation and Correlates of Alcohol Problems (National Alcohol Survey)** L. Drabble, PI, Alcohol Research Group, Berkeley, CA; NIAAA R21 AA017947



Other Collaborative Research

Non-probability Samples

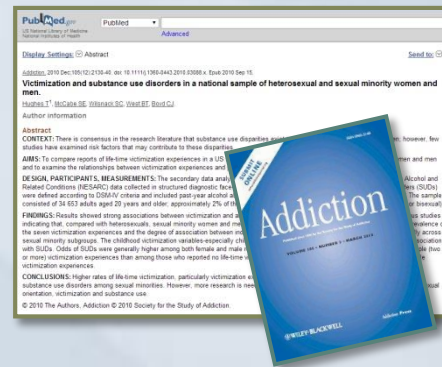
- **Women's Health Update Project (WHUP). National internet-based study of young SMW**

Kaysen, PI; University of Washington, NIH/NIAAA R01 AA018292



- **Relationships between alcohol use, depression and anxiety in SMW women**

McNair, PI; University of Melbourne, Australia. BeyondBlue



- **Sexual orientation differences in prevalence & correlates of substance use**
- **Drabble & Trocki PIs; NIH/NIDA R01 DA036606**



20+ Years of Research

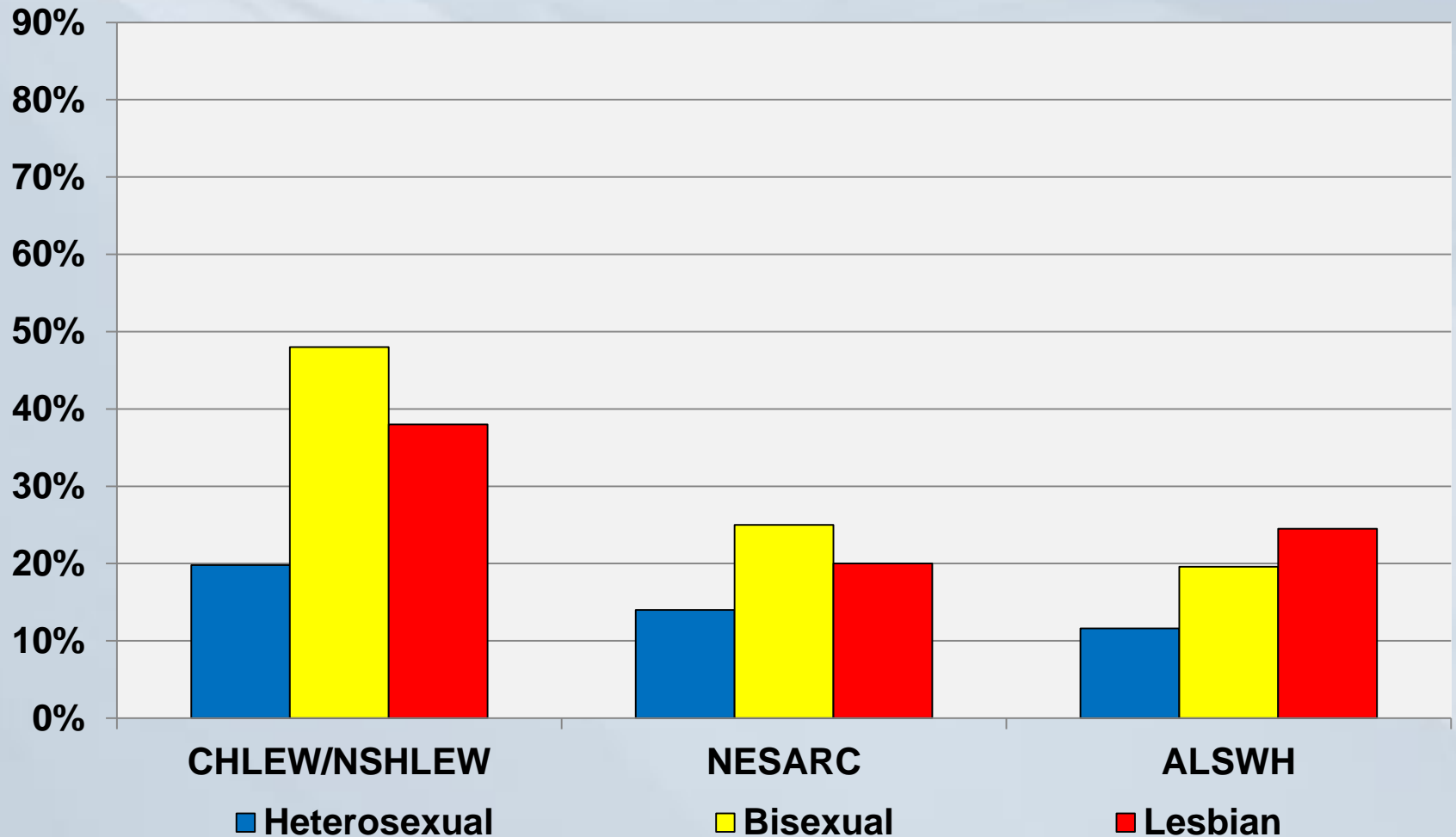


Important and Interesting Findings

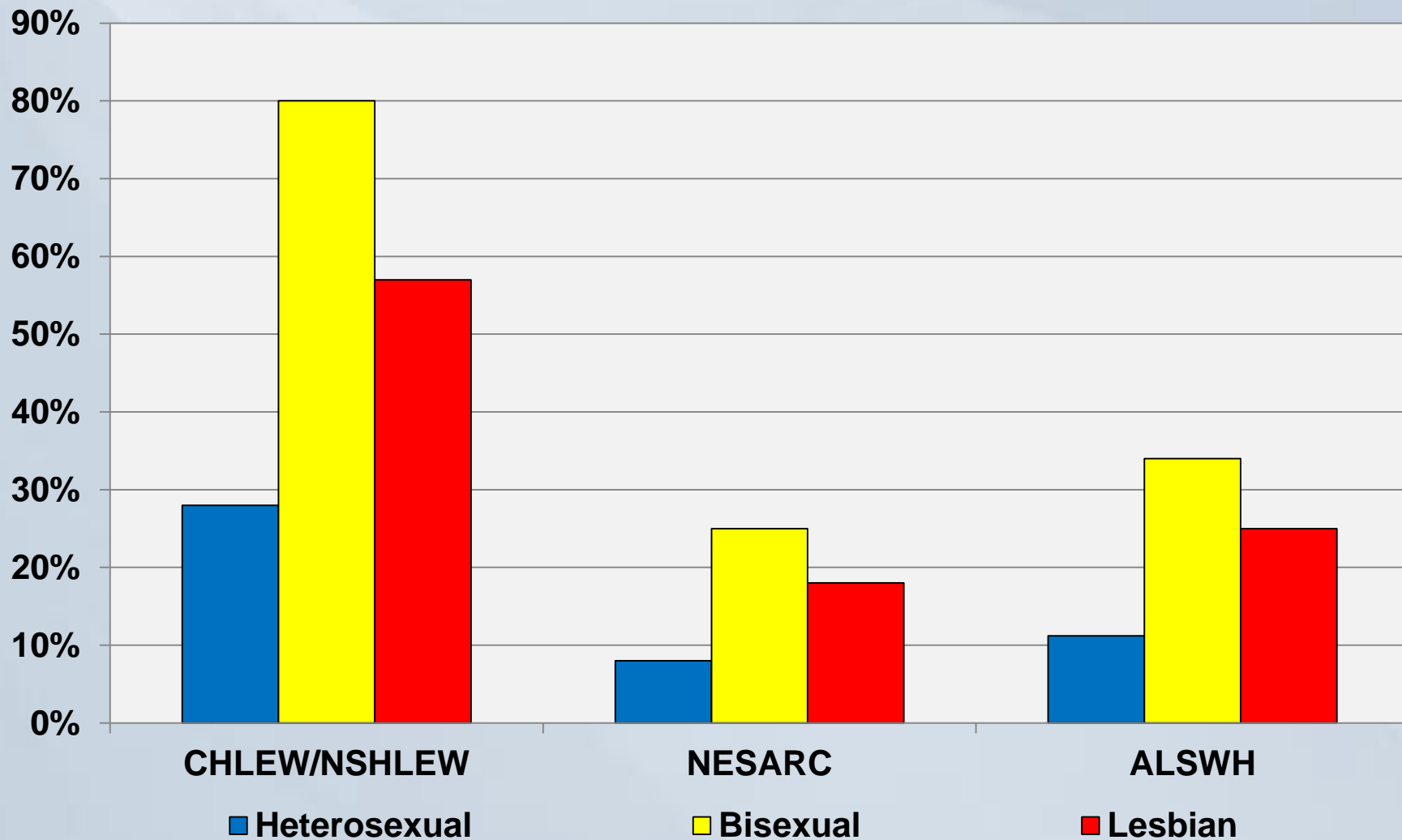
Everett et al., in review

Everett et al., in review

Past Year Hazardous Drinking



Past Year Depression



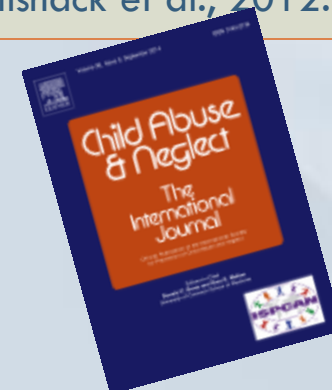
Research Findings

- **SMW's rates of lifetime victimization are 2-3 times higher than those of heterosexual women**
- **CSA and CPA appear to be much more severe among sexual minority than among heterosexual women**

Drabble et al., 2013; Hughes et al., 2010a, 2010b; 2014; Kaysen et al., 2012; Wilsnack et al., 2008



Alvy et al., 2013; Wilsnack et al., 2012.



Research Findings

- Risk behaviors and negative health outcomes vary substantially across sexual minority subgroups; **bisexual women** tend to show the highest risks & poorest health outcomes
- Women who **identify as lesbian and report only female partners** look very similar to heterosexual women in terms of health risks and outcomes

Bostwick et al., 2010;
Drabble et al., 2013;
Alvy et al., 2013; Hughes
et al., 2010; McCabe et
al., 2009; Wilsnack et
al., 2008

Bostwick et al., 2010

Sexual Identity Response Options

- **Exclusively lesbian/gay**
- **Mostly/mainly lesbian/gay**
- **Bisexual**
- **Mostly/mainly heterosexual**
- **Exclusively heterosexual**

Hughes et al., 2010; McCabe et al., 2011; McNair et al., 2011; Wilsnack et al., 2008

Research Findings

- Women who identify as **“mostly” heterosexual** differ in interesting ways from women who identify as **exclusively heterosexual**



Hughes et al., in review;
2010; McNair et al.,
2011; Wilsnack et al.,
2008)

Research Findings (NSLHEW)

Substance Use	Only Heterosexual	Mostly Heterosexual
Marijuana (ever)	18%	46%***
Marijuana (12 months)	6%	26%**
Cocaine (ever)	3%	11%**
Cocaine (12 mos)	1%	6%*
Heavy drinking (12 mos)	4%	15%***
Intoxication (12 mos)	28%	57%*
Binge drinking (12 mo)	13%	33%*
Adverse drinking consequences (12 mos)	13%	33%*
Alcohol dependence symptoms (12 mos)	10%	33%**
Ever concerned about having a drinking problem?	19%	37%*
Since last interview, concerned about having a drinking problem?	7%	22%*
Ever treated for a drinking problem?	4%	11%*

* $p < .05$; ** $p < .01$; *** $p < .001$

Hughes et al., 2014

Influence of Gender Presentation



Higher femininity scores

associated with lower levels of discrimination but higher levels of internalized stigma and depression

In Contrast

women who rate themselves as more masculine report lower levels of internalized stigma and depression, but higher levels of discrimination, victimization and hazardous drinking

Everett et al., in progress

CHLEW Research Findings (N=691)

- **20%** report high rates of **unintended pregnancy**;
- **Highest risk: SMW who are bisexual, black or have high school education;**
- **50%** identify as mostly or **exclusively lesbian.**

Everett et al., in review

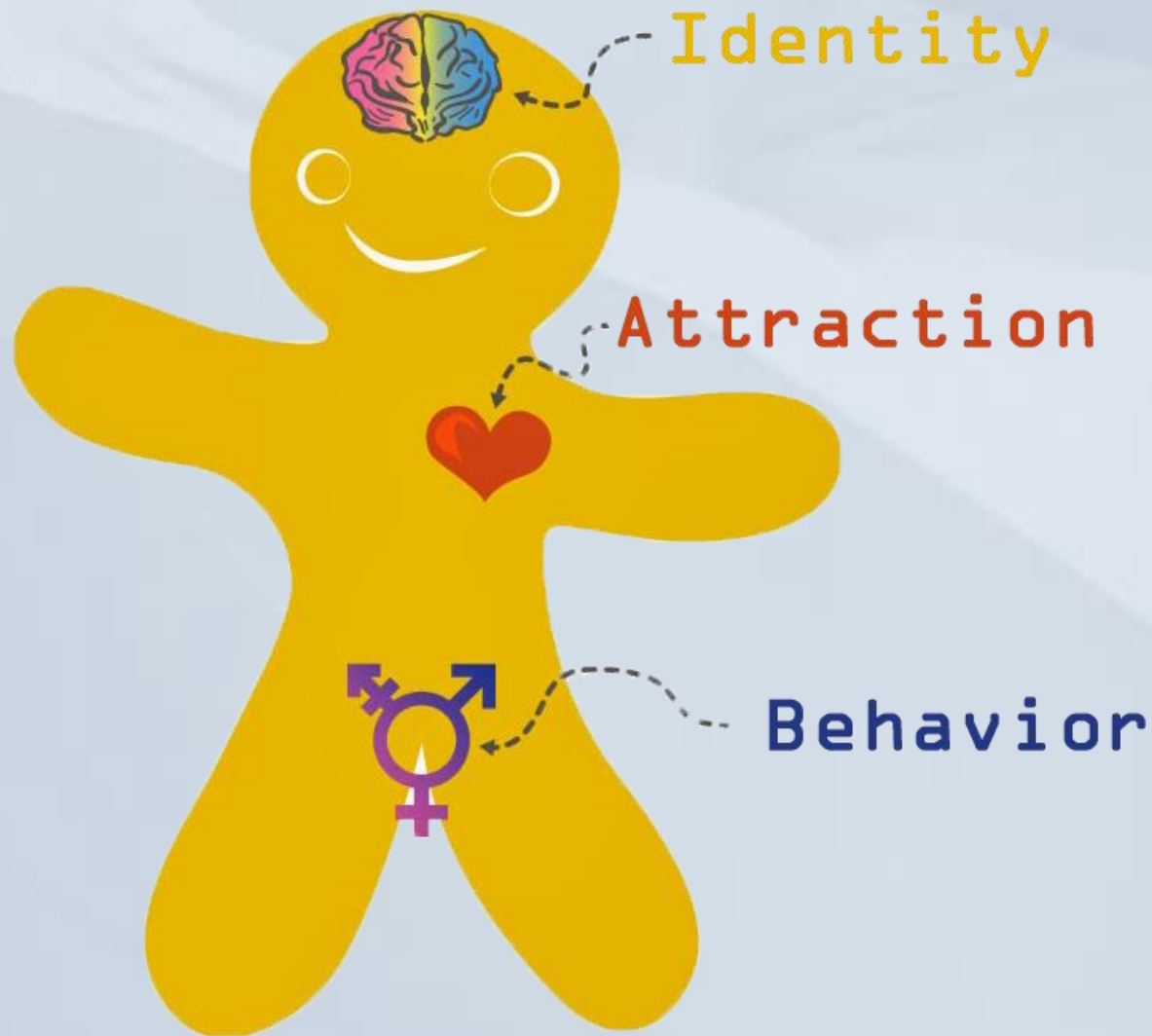


CHLEW Research Findings

- Unintended pregnancy **positively associated with depression and hazardous drinking.**
- **43%** of SMW who reported unintended pregnancy also reported **CSA** (30% reported **CPA**)
- **CSA and CPA mediated the relationship between unintended pregnancy and depression (but not unintended pregnancy and hazardous drinking).**



Major Dimensions of Sexual Orientation



Research Findings



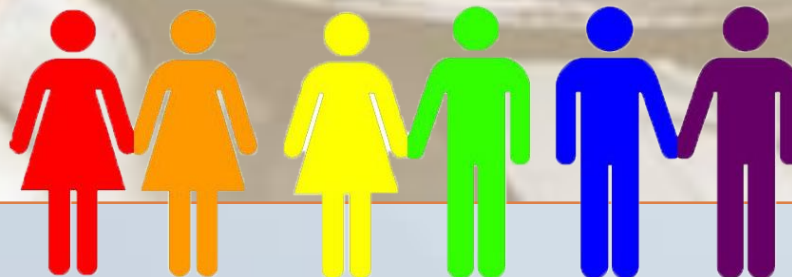
- Women whose sexual **identity matches their sexual behavior and attraction** (e.g., lesbian identity, female sexual partner[s]) are at **lower risk** than those whose identity does not match the other two major sexual orientation dimensions
- Women whose sexual **identity remains stable** have **lower risk** profiles than do those whose identity changes over time, *regardless of the direction of the change*

Everett et al., in review

Talley et al. (2015)



There is still much more to learn about the underlying causes of sexual-orientation related health disparities



Illinois Civil Union Act, 2011

Women interviewed **after bill** enacted show **better outcomes**, including lower levels of perceived stigma and discrimination, depressive symptoms and hazardous drinking.

These **benefits most apparent for Black and Latina** women and women **without college level education**.



Here come the Brides!

After 72 years together, Vivian Boyack and Alice Dubes finally tie the knot!



'Hit List' Targeting NIH Research, 2003

POLITICS

Hit list on the Hill



Insiders say a Capitol Hill "hit list" of controversial AIDS and sexuality researchers was circulated by mistake, but scientists actually on the list say it's further evidence that Congress is taking political potshots at their work **BY MUBARAK DAHIR**

"We had nothing to do with that longer list," he says.

An aide to the House Energy and Commerce Committee, who spoke on condition of anonymity, acknowledges to *The Advocate* that there has been "an ongoing investigation of NIH-funded studies since last March," meaning the NIH's federal funded research. In October, he says, "a staffer on our commit-

Traditional Values COALITION

NIH Head Defends Grants To Questionable Research Projects

Summary: The director of the National Institutes of Health (NIH) is issuing a letter this week to defend hundreds of questionable research projects brought to light by the Traditional Values Coalition last year.

Updated May 20, 2009

NIH Spends \$178,000 to Study Why Prostitutes in Thailand Have High HIV Risk

By Joseph Abrams - FOXNews.com

Posted: Tuesday, 21 July 2009 2:57PM

\$3M NIH grant to UIC to study lesbian drinking

Posted on Tue, Nov. 18, 2008

Study: Sex scientists fear family-values scrutiny

By Tom Avril
Inquirer Staff Writer

Sex, drugs, and NIH

Email: Ted Agres - tedagres@lycos.com

News from *The Scientist* 2003, 4(1):20031103-06



Science Insider

Breaking news and analysis from the world of science policy

Lawmakers Attack Federal Research on Sex Workers, Ravers

by Jocelyn Kaiser on September 25, 2009 5:04 PM

Positive Press

Lesbians & Research

The National Institutes of Health has awarded University of Illinois-Chicago nursing professor Dr. Tonda Hughes a \$400,000 grant to study, "Sexual Identity and Drinking: Risks and Protective Factors." The issue is not just whether all lesbians drink, or whether lesbians drink more than straight women. What's important is that the NIH financial stamp of approval validated the long-overlooked field of American lesbian health per se.

See page 13 for an interview.



Honors roll in for UIC researcher

BY ROSS FORMAN

Dr. Tonda L. Hughes will receive the inaugural Distinguished Research Award, one of the most prestigious honors presented by the UIC (University of Illinois at Chicago) College of Nursing Sept. 26, marking the third career award she's received this year.

And those go alongside her 2003 induction into the Chicago Gay and Lesbian Hall of Fame—and countless other awards, honors and highlights to an illustrious, decades-long career.

Hughes, 60, who lives in Oak Park, is a professor in the Department of Health Systems Science (HSS). She has worked in Australia, Boston and elsewhere around the world—and is an international expert in the area of alcohol use among lesbians. Hughes has secured more than \$10 million in research funding throughout her career.

She is also the associate dean for global health at the UIC College of Nursing, and is co-director of BIRCWH: Building Interdisciplinary Research Careers in Women's Health.

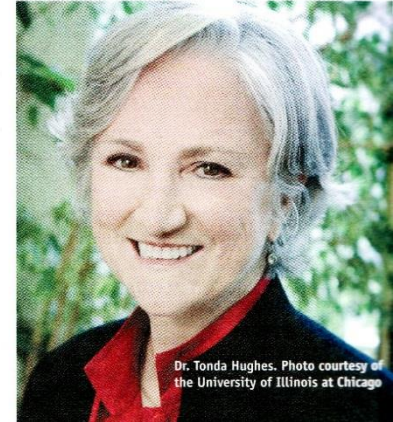
Hughes, without question, is considered one of the greatest contributors in the field of lesbian health.

She said being selected for three awards this year, "is some recognition of my work, but the work related to LGBT health in general."

"With all of the attention [given] to same-sex marriage, people are finally recognizing the impact of policies on health, including substance abuse and other things. I think people are just paying more attention," she said. "The [UIC] award is particularly important to me because it's recognition by my peers, which is always important to me."

Hughes' research dates back to the early 1990s. She said the UIC award "legitimizes my

Turn to page 9



Dr. Tonda Hughes. Photo courtesy of the University of Illinois at Chicago

March 3rd

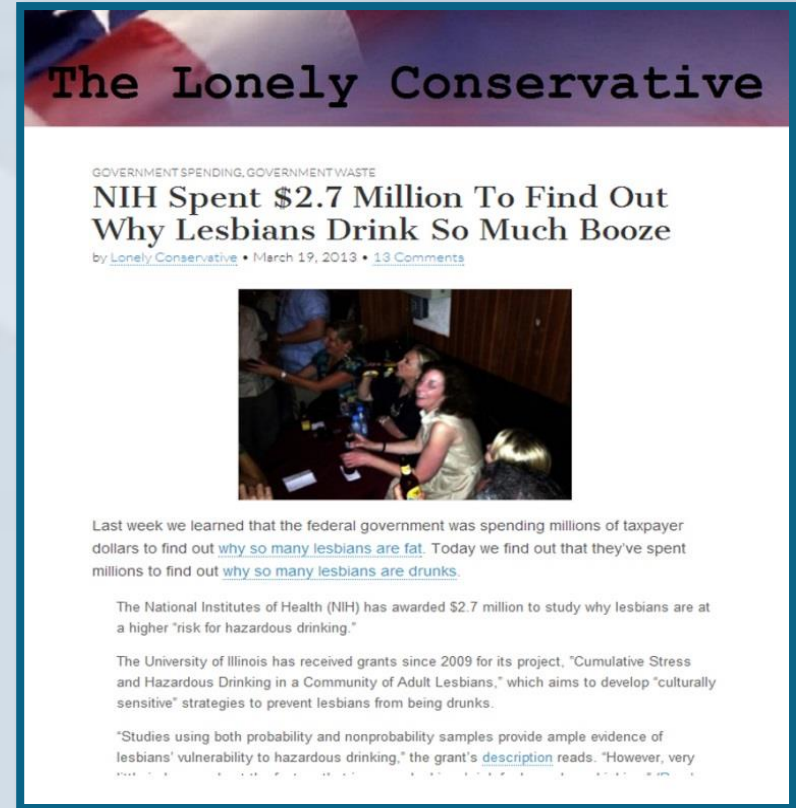
1999

August 20th

2014

Not So Positive Press...

- ❖ **Government Spends Nearly \$2.7 Million to Study Booze-Loving...**
www.theblaze.com/.../government-spends-nearly-2-7-million-to-study-b...
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Building a Research Career



I AM GAY
I AM STRAIGHT
I AM LESBIAN
I AM BISEXUAL
I AM TRANSGENDERED
I AM HUMAN





Acknowledgements: Research Collaborators

CHLEW Study

Lisa Alvy, PhD, VA Hospital, San Francisco

Frances Aranda, MPH, PhD, UIC

Perry Benson, PhD, U. North Dakota

Young Cho, PhD, UW-Milwaukee

Bethany Everett, PhD, UIC

Tim Johnson, PhD, UIC

Arlinda Kristjanson, PhD, U. North Dakota

Kelly Martin, MEd, MPH, UIC

Alicia Matthews, PhD, UIC

Robyn Nisi, MPH

Barth Riley, PhD, UIC

Alana Steffen, PhD, UIC

Laura Szalacha, PhD, OSU

Amelia Talley, PhD, Texas Tech

Sharon Wilsnack, PhD, U. North Dakota

Other Research Collaborators

Kimberly Balsam, PhD, Palo Alto Univ.

Wendy Bostwick, MPH, PhD

Carol Boyd, RN, PhD, FAAN, UMich

Rhonda Brown, RN, PhD, Deakin University

Laurie Drabble, San Jose State Univ.

Mickey Eliason, RN, PhD, San Fran State

Debra Kaysen, PhD, UWash-Seattle

Trish Livingston, RN, PhD, Deakin University

Mike Marshall, PhD, Univ. Pittsburgh

Sean McCabe, PhD, UMich

Ruth McNair, MD, PhD, University of Melbourne

Karen Trocki, PhD., Alcohol Research Group,
Berkeley, CA

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Special thanks to...

NIAAA
**National Institute on Alcohol
Abuse and Alcoholism**

Our major funder



*The 100s of women who
have participated in the
CHLEW and related studies*



Thank You!



BUILDING A RESEARCH CAREER
Focused on Stigmatized and Marginalized Population Groups

Tonda L. Hughes, PhD, RN, FAAN
University of Illinois At Chicago College of Nursing

