Research with Homeless Populations

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Objectives

• Discuss challenges of conducting research with the homeless population, as a model of the exciting possibilities of working with “difficult to study populations”
"I see one-third of the nation ill-housed, ill-clad and ill-nourished. The test of our progress is not whether we add more to the abundance of those who have much, it is whether we provide enough for those who have too little."

Franklin D. Roosevelt
# HOMELESSNESS IS A CRISIS

**Homeless currently**

<table>
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<tr>
<th></th>
<th>%</th>
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<tr>
<td>currently</td>
<td>2</td>
<td>3.5 Million</td>
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**Homeless past 5 Years**

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>On the street or in shelters</td>
<td>3</td>
<td>6 Million</td>
</tr>
<tr>
<td>Inc temporarily doubled-up</td>
<td>5</td>
<td>9 Million</td>
</tr>
<tr>
<td>Los Angeles County</td>
<td>6</td>
<td>254,000</td>
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**Homeless during lifetime**

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<tbody>
<tr>
<td>On the street or in shelters</td>
<td>7</td>
<td>14 Million</td>
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<tr>
<td>Inc temporarily doubled-up</td>
<td>14</td>
<td>26 Million</td>
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**Homeless doubling up**

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Non poverty household</td>
<td>19</td>
</tr>
<tr>
<td>Poverty household</td>
<td>25</td>
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</tbody>
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3. Institute for the Study of Homelessness and Poverty at the Weingart Center, 2008
US Homeless Prevalence

• **Point-in-Time Prevalence**
  – 643,067
  – Single night, January 2009
  – Sheltered and unsheltered

• **Annual Prevalence**
  – 1.56 M were homeless
  – Sheltered only

2009 Annual Homeless Assessment Report to Congress (AHAR)
Who Are The Homeless?

• Past
  – Middle-aged, white, alcoholic men

• Today
  – A typical homeless person is a middle-aged, adult male who is a member of a minority group and is by himself
  – Fastest growing segments are women, families, and ethnic minorities

2009 Annual Homeless Assessment Report to Congress (AHAR), Sheltered Pop Annual Rates
Who Are the Homeless?

• Most are members of Minority Ethnic Groups
  – Af American 39%
  – White 38%
  – Latino 12%
  – Multiple Races 7%
• Most are men (adults)
  – Male 64%
  – Female 36%
• Somewhat more Veterans (adults) 11%
  (vs 8%)
• High rates of Disability 38%
• Mostly live in Urban areas 68%

2009 Annual Homeless Assessment Report to Congress (AHAR), Sheltered Pop Annual Rates
Social Research: Background

• 1960s-70s: Large-scale experiments
  – Costly
  – Took several years to complete
  – Results--inconclusive

• 1980s-current: Short-term demonstrations
  – Less costly
  – Required well-trained researchers
  – Homeless research began here

• Today: Interest in social indicators
  – Inexpensive and timely measures
  – Rely on administrative databases
    • Not well developed for homeless

** Hotz et al. Joint Center for Poverty Research, 1999
Sampling Issues

• Definition of Homelessness
  – Users of services for the homeless
  – Persons who live in emergency shelters or in the outdoors, or in buildings not meant for shelter
  – Persons who have unstable housing
    • Live in hotel or motel
    • Double up with family or friends
DEFINITION OF HOMELESSNESS

Individual who lacks a fixed, regular and adequate nighttime residence, or who has a primary nighttime residence, that is:
(a) a supervised publicly or privately operated shelter designed to provide temporary living accommodations
(b) a public or private place that provides a temporary residence for individuals intended to be institutionalized
(c) a public or private place not designed for, or ordinarily used as, regular sleeping accommodations for human beings.

1 Stewart B. McKinney Homeless Assistance Act of 1987
Sampling Issues

• Geographic variation
  – Local
  – National

• Comparison Group
  – General population
    • Homeless look their worst
  – Impoverished Population
    • Can assess impact of lack of housing in addition to income
Sampling Issues

• Sampling method
  – Convenience sample
    • Chronically homeless and high service utilizers will be over-represented
    • May not generalize to source population
  – Probability sample
    • Very difficult and costly
Sampling Issues

• Location
  – Medical setting
  – Emergency shelter
  – Meal programs
  – Hotels, motels
  – Outdoor areas

• Interviewers
  – Non threatening, simple clothing
  – Pairs of two for safety
Time Period

• Time of Day
  – Day
    • Many housed persons
  – Night
    • Need to awaken individuals
    • Need “bodyguard”

• Weekly and monthly cycles

• Seasonal variation
  – Less bothered by homelessness in good weather
  – Rates of health problems vary
Study Design

- Cross-sectional design
- Longitudinal (Cohort) design
- Experimental
- Randomized controlled trial
Cross-Sectional Studies

• Most studies of homeless are cross-sectional

• Cannot determine whether exposure preceded the outcome
  Mental illness $\rightarrow$ Homelessness
  or
  Homelessness $\rightarrow$ Mental Illness
Longitudinal Studies

• Difficult to conduct in the homeless population because of mobility and lack of an address and telephone for re-contact
• Expensive and time consuming
• Loss to follow-up (attrition) reduces effective sample size and can bias results
Successful Tracking Methods of Homeless Persons

• General tips
  – Patience, persistence, time, and travel\(^1\)
  – Persistence and creative team work\(^2\)

• Phone Tracking Tips\(^3\)
  – Make calls at various times of the day and night

- Desmond, Journal of Substance Abuse Treatment, 1995
- Cottler, Drug and Alcohol Dependence, 1996
- Wright, unpublished (In Pollio, 2000)
Tracking Tips: In Person Tracking

• **In person tracking tips**¹
  – Can reach 97% of drug abusers after 18 months
  – Complete locator information
  – Adequate incentive
  – Safe and convenient location of the re-interview
  – Reduce length of follow-up interview

• **In person tracking tips**²
  – 80% 12-month follow-up rates
  – Locator Guide
  – Interviewers have frequent contact with respondents
  – Frequent presence at homeless congregating sites
  – Search prisons, mental hospitals, coroner records

¹ Cottler, Drug and Alcohol Dependence, 1996
² Gelberg, Health Services Research, 2000
Sources of Secondary Data

• Clinic encounter forms
• Medical records
  – Limited information recorded in charts
  – Risk factor data often incomplete (hunger, housing status, mental illness, substance abuse)
• Jail records
• Birth/death certificates
  – Does not list housing status
• National Census
  – Does not list housing status
Sources of Secondary Data

- Linked records (Metraux et al. 2003)
  - Linked up computerized service records on housing, shelter use, and health care services
  - Created integrated data set for 3,167 persons who received NY/NY housing placements, which provided mental health services, and for a matched control group of persons with mental illness who used shelters but did not receive housing placements
  - Assessed the relationships between shelter use and receipt of a housing placement
  - NY/NY housing placement used 128.2 fewer shelter days than control group in subsequent 2 years
Sources of Primary Data

• Questionnaire
  – Illiteracy, items can be skipped

• Interview
  – Under-reporting of sensitive topics
    • Especially if sampled from settings that exclude clients from treatment because of certain characteristics (e.g., ongoing substance abuse) - severe sanctions influence the accuracy of self-report information.
  – Recall bias
  – Respondents often choose first response category
Sources of Primary Data

• Physical examination
  – Limited privacy in public settings

• Lab tests
  – Centrifuge, immediate freezing for specific lab tests; Needles, syringes dangerous commodity on streets
Sources of Primary Data

• Underreporting: Cocaine Abuse
  – Only 26% of those persons whose hair tested positive for cocaine admitted to having used cocaine in the past 30 days\(^1\)
  – Homeless women in Los Angeles – 75% admitted to, but 25% underreported cocaine use in past 6 months based on positive hair assays\(^2\)
  • Less underreporting if higher hair cocaine levels, Latino, younger, and living primarily in shelters

• Appel PW, J of Psychactive drugs, 2001
• Nyamathi, Nursing Research, 2001
Sources of Primary Data

- **Underreporting: Number of Clinic Visits**
  - Accurate: Reporting *presence or absence* of ambulatory medical care visits in past 3 months or 12 months, homeless respondents are accurate
  - Underreporting: Reporting *number* of visits in past 3 months or past 12 months are underreported\(^1\)

- **Short Form 12-Item Survey Test (SF-12)**
  - Accurate in homeless populations\(^4\)

- Gelberg, Health Services Research, 1997
- Larson, Health Services Research, 2002
Sources of Primary Data

• Time-Line Follow-Back Interview (TLFB)\(^1\)
  – Calendar instrument used to assess days and quantities of a variable
  – Measures days and quantities of alcohol use, drug use, homelessness
  – Reliable for use in past month and past 6 months
  – Accurate even for severely mentally ill, substance abusers, homeless

• Sachs, Journal of Nervous and Mental Disease, 2003
SOURCE OF MEASURES

• Measures tested in other populations
  – **Pro:** Already developed
    Already tested (validity, reliability)
    Comparison data
  – **Con:** May be inappropriate for homeless
    • Bed days
    • Source of medical care
      – Homeless may not accurately categorize the type of facility they go to; they perceive their clinic doctor is a private doctor

• Develop new measures
  – **Pro:** Consider issues of homelessness
  – **Con:** Expensive and time consuming to develop and test
Collaborators are Important

• Clinicians do not have to do the research alone, and don’t have to have all the skills. We all have our natural talents that need to be identified and fostered

• Clinicians bring a unique perspective to the research team
  – Access to a patient population
  – Experience providing care for the population leads to real life research questions

• Clinicians have a lot to offer university researchers as incentive to collaborate
  – School of Public Health, anthropology, sociology, psychology, economics, statistics, survey experts
Partners: Clinics, Social Services

- We need to entrust their support
- Staff may resent research
  - Resent publishing their hard earned data
  - Fear research will interfere with work
  - Overcrowded, lack space
  - Staff overworked, burned out
  - Fast pace of clinical activities
Partners: Clinics, Social Services

• Create liaison with service providers
  – Community based participatory research
    • Invite them to join in, better outcome for all
  – Research question development
    • Q must matter long term to improve their services, access, or outcomes
    • Intervention -- feasible, sustainable, acceptable
  – Study design development to minimize disruption to their ongoing activities and increase recruitment and retention of subjects
  – Interpretation of data
  – Dissemination of findings
Ethical Considerations

• Confidentiality
  – Sensitive topics often covered
  – Substance use, criminal behavior, victimization, communicable disease, runaways, immigrants
  – Certificate of Confidentiality

• Finding cases with abnormal lab results

• Use formerly homeless, but stable, persons to collect data, serve as patient advocates, find participants with abnormal lab results or who are lost to follow-up (Homeless Promotoras)

• IRB review often time consuming
  – Allow enough time
Ethics: Pharmaceutical Research on Homeless Persons

• Homeless often left out of drug studies
• Disadvantage of drug studies
  – Potential to be upsetting, inconvenient, or unpleasant
  – Potential for injury, health emergencies, and chronic health problems
• No ethical justification to exclude homeless persons from research
  – Homeless can get access to medications they cannot afford
• Multistage informed consent framework for homeless persons
  – Disclosure, dialogue, and permission-giving

Beauchamp TL et al., Journal of medicine and philosophy, 2002
Ethics: Pharmaceutical Research on Homeless Persons

- Ethical issues if offer inducements to the homeless in exchange for participation in drug studies.
  - Inducements can influence desperate persons who are seriously lacking in resources (coercive?)
  - The key is to strike a balance between a rate of payment high enough that it does not exploit subjects by underpayment and low enough that it does not create an irresistible inducement

- Ethical study designs so control group will eventually get treatment

- Ethical issues of stopping medications at end of trial

Beauchamp TL et al., Journal of Medicine and Philosophy, 2002
Ethics: Youth Consent

• In general population, parents must consent for their minor’s participation in studies or for treatment under most conditions

• Allowable treatment of minors without parental consent include the:
  – Emergency situation
  – Mature minor exemption
  – Emancipated minor

• Mature Minor Exemption
  – Court determines that the minor has the maturity to make independent decisions, that is to act in her own best interest and make an independent judgment to consent to treatment

Youth Consent: Emancipated Minors

• State statutes define an emancipated minor
  – Minimum age, usually 16 years old
  – Self-supporting and not living at home
    • Live apart from her parents
    • Economically self-sufficient
  – Married
  – Pregnant or a parent
  – In the military

• State statutes do vary
  – California - to be emancipated, a minor must be at least 14 years old
  – Montana - to be emancipated, the youth has graduated or is actively pursuing high school graduation
Youth Consent: Emancipated Minors

• Emancipated minors are considered adults for several purposes including ability to make complex decisions:
  – Enter into a contract
  – Rent an apartment
  – Consent to medical care
  – Consent to research

• Not immune from all state age requirements (e.g., they must be 18 years of age to vote)
RESEARCH ON HOMELESS: FUNDING SOURCES

• Federal government - NIH (major funder)
  – Long application
  – Long review
  – Big dollars

• Federal government - non NIH
  – Faster turnaround

• Local government
RESEARCH ON HOMELESS: FUNDING SOURCES

• **Private foundations**
  – Foundations in your state or city
  – Often need CBO as applicant, rather than the university
  – Often willing to fund program, but only small evaluation

• **Yourself/your friends**
  – Small/pilot studies
  – Can get published especially if new research questions, new findings
  – Provide basis for larger funded studies
“The Behavioral Model for Vulnerable Populations” and Health Care Disparities

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Ronald M. Andersen, PhD
UCLA Schools of Medicine & Public Health
Why a Theoretical Model?

- Guides choice of predictor and outcome variables
- Guides analysis plan
- Gives structure for interpretation of data
Why Concern about Vulnerable Populations?

- Vulnerable populations are a key concept for examining health care disparities
- Vulnerable populations
  - Are a focus at federal, state, and local levels
  - Experience disparities in health and health care
    - High risk for disease and injury
    - Barriers to accessing timely and appropriate medical care
- Research is limited regarding compelling issues of vulnerability on the use of health services and health status of vulnerable populations
Who are Vulnerable Populations?

• Social Groups with:
  – Increased relative risk (i.e. exposure to risk factors)
  – Increased susceptibility to health-related problems

• Evidence of Vulnerability
  – Higher mortality rates
  – Lower life expectancy
  – Reduced access to care
  – Diminished quality of life

• Why Vulnerable
  – Discriminated against
  – Marginalized and disenfranchised from mainstream society
  – Lower social status
  – Lack of power in personal, social, and political relationships

*Center for Vulnerable Populations Research, UCLA School of Nursing
Vulnerable Populations: Examples

- Ethnic/minority groups
- Poor
- Undocumented immigrants
- Children and adolescents
- Mentally ill
- Chronically ill
- Disabled
- Elderly
- Lesbian, gay, bisexual, transgender, transsexual, undecided (LGBT2U)
- Homeless
- Prisoners
- Geographically isolated
Why Model for Vulnerable Populations?

• To identify particular challenges vulnerable populations face in obtaining needed services
  – The factors that make homeless and other populations vulnerable might also affect their use of health services and health status

• To provide insights into maintaining or improving their health status
Behavioral Model for Vulnerable Populations: Origin

- Adaptation of the Behavioral Model
A Behavioral Model of Health Services Use Stressing Contextual as well as Individual Characteristics

Contextual Characteristics
- Demographic
- Health Policy
- Environmental
- Social
- Financing
- Population
- Health Indices
- Beliefs
- Organization

Individual Characteristics
- Personal Health Practices
- Perceived Health Practices
- Process of Medical Care
- Use of Personal Health Services
- Perceived Health
- Evaluated Health
- Consumer Satisfaction

Behaviors
- PREDISPOSING
- ENABLING
- NEED

Outcomes
Behavioral Model for Vulnerable Populations: Vulnerable Domains

• The Model is divided into traditional and vulnerable domains
• Vulnerable domains were added to the Behavioral Model as we expanded it for relevance in studying vulnerable populations
• Vulnerable domains focus on:
  – Social Structure
  – Enabling Resources
# Behavioral Model for Vulnerable Populations

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<th>Predisposing</th>
<th>Enabling</th>
<th>Need</th>
<th>Health Behaviors</th>
<th>Outcomes</th>
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One Model for All Vulnerable Populations?

- Model includes factors to consider when studying the use of services and health outcomes of vulnerable populations
- Some categories of the model will need to be tailored to specific vulnerable populations when the model is applied to them
Concluding Thoughts

• “The study of social and economic factors in public health may have unintended consequences that, paradoxically, serve to preserve disparities rather than eliminate them.

• This can occur because public health research transports social issues into the health domain, where they are examined through the narrow prism of health relevance instead of within their political, social, and economic contexts.

• We refer to this as the ‘public healthification’ of social problems, akin to the ‘medicalization’ and “healthism” that have occurred with the advance of biomedicine in the last century.”

Meyer, IH, AJPH, 2000
Concluding Thoughts

• “We continue paying to put homeless in hospital beds while not providing them with ordinary beds of their own.”

• Primary predictor of housing stability = Receipt of subsidized housing.

• Factors such as social and housing conditions not typically conceptualized as relevant to health, but which can have a tremendous impact on health outcomes, need to be included in the dialogue on health policy for the poor.

1 Starr P, New England J. Medicine, 1998
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