



FORDHAM UNIVERSITY  
THE JESUIT UNIVERSITY OF NEW YORK

THE CENTER FOR ETHICS EDUCATION  
CELIA B. FISHER, PH.D., DIRECTOR

# Quantitative Approaches to ERRE

Celia B. Fisher  
Marie Ward Doty University Chair  
Director Center for Ethics Education  
Professor Psychology  
Fisher@Fordham.edu

Fisher, C. B. True, G., Alexander, L., & Fried, A. (2013). **Moral Stress, Moral Practice, and Ethical Climate in Community-Based Drug Use Research: Views from the Front Line.** *AJOB: Primary Research*

*National Center for Research Resources # 1R21RR026302-01*



# Preliminary Qualitative Study

Specific Aim: To understand ethical challenges faced by staff conducting community-based drug use research

6 focus groups (N = 38) front-line research staff working on community-based drug use research in NYC, Hartford, Philadelphia



# Theme: Institutional Stressors

- PIs are often unfamiliar with community and participants;
- PIs have unrealistic inclusion criteria
- Often exploit the community
- Constant pressure to “get the numbers”
- Opinions are not sought
- Often asked to play dual roles



# Theme: Community Stressors

- Neighborhoods are sometimes unsafe
- Community begins to see research worker as a source of expertise and other resources that can be burdensome
- Sometimes difficult to maintain personal and professional boundaries
- Must defend research to community members



## Theme: Ethical Dilemmas

- Providing counseling and referrals
- Discourage participation
- Confidentiality challenges (e.g. HIV lady)
- Unrealistic screening protocols
- Participant misreporting drug use
- Influence of monetary payment on consent
- Difficulty maintaining profession/personal boundaries



# Moral Stress

Perceived barriers to conducting research in a morally appropriate manner



Job burnout, job cynicism, emotional exhaustion and professional inefficacy

*(Adapted from Moral Distress studies in nursing: Corely et al., 2001, 2005; Jameton, 1993; Maslach, 2003)*



## Quantitative Study: Specific Aims

- To assess and identify factors contributing to moral stress among staff conducting community based addiction research



# Hypotheses

- Moral stress will be associated with higher rates of moral practice dilemmas and research mistrust and lower levels of institutional support and commitment to the research.





# Recruitment

- Investigators identified through the NIH Research Portfolio Online Reporting Tool and the Clinical Trial Network databases asked to forward a web-based survey announcement to current or recent CRWs.
- Exclusion Criteria:
  - Participated in a focus group in Phase 1 of the study
  - Last CRW experience was more than 1 year ago
- Web-based anonymous survey; participants received a \$40 Amazon.com certificate



# Participant Characteristics (N=175)

## Demographics

- 33% Male
- Age range: 20 – 63 (M = 35.7)
- 81% College graduate or higher
- 23% History of drug use
- 67% Lived in research community
- 50% Experience as substance abuse counselor
- \$30,000- \$40,000 annual income
- 60% Financial situation : just enough to get along

## Ethnicity

- 12% Black non-Hispanic
- 20% Hispanic
- 60% Non-Hispanic White
- 8% Other

## Geographic Location

Responses from 20 states across US

- 54% East coast
- 8% South
- 15% Midwest
- 23% West coast



# CDRW Current and Past Drug Study Work Experience

## Experience as CDRW

- 77% Two or more years experience
- 90% Currently working as CDRW
- 71% Full-time CRW worker
- 58% Met with PI more than once monthly
- 80% Worked on federally-funded study
- 18% CDRW worked as GA or Credit

## CDRW Study Participant Characteristics

- 77% Injection drug user
- 73% Homeless
- 79% Unemployed
- 54% Mentally ill
- 63% HIV +
- 53% Sex worker

## CDRW Study Types

- 65% HIV study
- 65% Survey
- 51% Harm reduction
- 37% Drug prevention

## CDRW Duties Performed

- 65% Street recruitment
- 81% Informed consent
- 73% Survey administration
- 81% Interviews
- 38% Qualitative data coding
- 31% Statistical analysis
- 43% Collaboration on writing



# Instructions

**“The statements below are based on opinions expressed in focus groups by community-based research workers (CRW) involved in drug use and related research studies.**

**For each statement, think about your experiences as a CRW working on studies involving drug use. Check the box that indicates how much you agree or disagree with each statement.**

**There are no right or wrong answers—we are just interested in your experiences and opinions**



# Moral Distress Scale

*25 Items ( $\alpha = .89$ )*

*M = 1.89 (SD. 45)*

*In my most recent or current job working on drug use research...*

**“I found my moral values conflicted with what I was asked to do”**

**“I could not provide participants with the service referrals they needed..”**

**“I believed the risks of participation were too high for some drug users.”**

**“I knew some participants had given false answers to get in the study”**



# Research Ethics Climate

*13 Items ( $\alpha = .90$ )*

*M = 3.39 (SD .46)*

*The organization at which I currently or most recently worked...*

*“Stressed the importance of making sure participants understand the informed consent information.”*

*“Had a safe and confidential procedure for CRWs to report ethical violations by other staff.”*

*“Stressed concern for participant welfare in all aspects of the research.”*

*“Provided training in research ethics for CRWs”*



# Organizational Research Support

*16 Items; ( $\alpha = .91$ )*

*M = 3.08 (SD = .57)*

*The organization at which I currently or most recently worked...*

**“Had policies to protect CRW safety in doing their job”**

**“Gave CRWs enough information to do their job well”**

**“Respected CRWs’ assessment of participant inclusion”**



# Research Commitment Index

*6 Items ( $\alpha = .77$ )*

*$M = 3.24$  ( $SD = .52$ )*

- **“I see myself as a bridge between the community and the research organization.”**
- **“...I believe the results of the studies I work on will be used to improve the lives of people in the community.”**
- ***“It is my responsibility to increase the community’s trust in research”***





# Research Mistrust

*6 Items ( $\alpha = .82$ )*

*M = 1.80 (SD=.63)*

- “Research exploits drug users who are desperate for help”
- “Research is conducted in poor communities will mostly benefit middle class communities”
- “Participants accepted do not really meet eligibility criteria”



# Research Moral Dilemma Scale

*12 Items ( $\alpha = .66$ )*

*$M = 1.71$  ( $SD = .39$ )*

- “I find it hard to “sell” a study to drug users when I do not believe the study will produce useful results”
- “I discourage drug users from participating in a study if I believe it will not be good for them”
- *The questions I am told to ask unintentionally give away the drug use inclusion criteria to participants”*



# Significant Correlations with Moral Distress

Variable	Correlation with Moral Distress Controlling for Social Desirability ( $r = .22^{***}$ )
Research Mistrust	$+.70^{***}$
Research Moral Dilemmas	$+.47^{***}$
Research Ethics Climate	$-.71^{***}$
Organizational Research Support	$-.72^{***}$
Research Commitment	$-.16^{***}$



## Multiple Regression on Predictors of Moral Distress ( $R^2 = .69, p < .001$ )

Variable	$\beta$ and $P$ at Block 2
Social Desirability	$\beta = -.05$
Age	$\beta = -.06$
Freq Meeting with PI	$\beta = -.03$
Research Ethics Climate	$\beta = -.42^{***}$
Research Mistrust	$\beta = .36^{***}$
Research Moral Dilemmas	$\beta = -.13^{***}$
Research Commitment	$\beta = -.00$



# Discussion

*This study represents the first step in:*

- 1. Using psychometric scale construction techniques to draw empirical attention to attitudes and oral tensions experienced by a national sample of front-line staff conducting community based research*
- 2. Extending the use of quantitative measures of work-related moral stress to the experiences of research staff members.*
- 3. Identifying the characteristics of front-line drug use researchers*



# Moral Stress

*50% of CRWs reported moderate levels of moral stress*

*Protective factors include positive organization research climate and research support*

*Risk factors include research mistrust and encounters with research ethics dilemmas*



# Institutional Support

- The majority of CDRWs' work settings have a supportive organizational climate and procedures to ensure research integrity.
- The majority of CDRWs see themselves as an important bridge between the community and research

## *However 40% Reported Their Organizations*

- Do not provide counseling for job related stress
- Had unrealistic demands for recruitment numbers and multiple role assignments



## Moral Stress and Challenges to Research Integrity

Items	%
I knew some participants had given false answers to get into the study	56%
I did not believe some participants really understood the research they agreed to participant	56%
I believed that offering money made some participants ignore the risks of the research	54%
I could not provide participants with the service referrals they needed	36%
I could not correct a problem in how the research was conducted	34%
I believed the research screening criteria excluded people who should be in the study	31%





## *Moral Dilemmas and Challenges to Research Integrity*

<b>Moral Practice Dilemma Items Endorsed</b>	<b>%</b>
I won't go out to "sell" a study to drug users if I don't trust the investigator	76%
I find it hard "sell" a study to drug users when I do not believe the study will produce useful results	43%
Even when it is not part of my job I counsel participants about their drug problems	39%
I discourage drug users from participating in a study if I believe it will not be good for them	37%
The questions I am told to ask unintentionally give away the drug inclusion criteria	32%
I use my own money to buy coffee or small goods to keep drug users interested in participating	31%
I exclude drug users from participating if I believe they are lying about which drugs they use	30%



# Implications for Principal Investigators

- The unique experience of CRWs provides them with both valuable expertise in research challenges in the field and vulnerability to moral stress and moral research challenges
- Include CRWs in the design of recruitment, inclusion/exclusion, and other community relevant research procedures
- Create an organizational climate that is respectful of CDRWs' expertise, sensitive to the unique community challenges they face and that provides adequate guidance and support for ensuring ethical practices
- Set aside regular team sessions for debriefing and increase familiarity with the community