



Moral Stress Among Frontline Workers Conducting Research Involving Drug Use And HIV Risk

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Ethical Challenges for Research Extenders Responsible for the Integrity of Community-Based Drug Use Research

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Broad Goals of the Research

To assess the moral stressors and protective factors associated with front-line researchers (CRWs) working on community-based drug use research



Drug Use Research: “Hidden Populations”

- Health and economic vulnerabilities: HIV and hepatitis, inadequate health care services, poverty, homelessness
- Cognitive vulnerabilities: Education, intoxication, cravings and withdrawal
- Social vulnerabilities: Stigma, ethnic minority status, illegal behaviors to obtain drugs



Frontline Researchers (CRWs): Direct Contact

- Recruitment
- Screening, Enrollment, Intake
- Informed Consent
- Conduct interviews
- Lead or assist with harm reduction or focus groups
- Debrief



Preliminary Study

6 Focus groups (N = 38) with CRW's working on diverse drug use projects in NYC, Hartford, Philadelphia

(True, Alexander & Fisher, 2012)



Moral Practice Dilemmas

Focus Groups

- Shouldn't tell them about placebo at end of study that will scare them away and they won't be in future studies
- Telling them about the risks takes away the participant's hope; telling them it's a coin toss is discouraging.
- Do [informec consent] and people are nodding off until I mention incentives and they listen more attentively.



Distress

Focus Group Comments

- Blurred boundaries – community pressure to provide counseling, money or other services outside the research protocol
- Talking about money is the best way to get drug users' attention, **But** drug users ignore research risks/benefits if money is offered
- Confidentiality is difficult: "I'm known as the HIV lady"
- The protocol makes it hard for me to exclude individuals I know are lying.
- I felt very bad that the comparison group could not get treatment for 6 months



Burnout

Focus Group Comments

- **Sometimes I have to close out my emotions.**
- **Even in off hours some participants invade my privacy**
- **I feel burned out**
- **This job is very stressful**
- **I feel pressured by my organization and participants**



Definition of Moral Distress

Drawn from Nursing

- Feelings of anger, frustration, powerlessness, anxiety and regret that arise when morally appropriate actions cannot be implemented due to institutional or other obstacles (Corely et al., 2001; Jameton, 1984; Jameton, 1993).
- Moral Stress = Moral Distress + Burnout



Research Ethics Climate

Focus Groups

- Provided research ethics training... but did not encourage CRWs to discuss their ethical concerns
- Stressed the importance of informed consent...but procedures were sometimes misleading for drug users desperate for treatment



[Lack of] Organizational Support Focus Groups

- PIs are often unfamiliar with community and participants
- Constant pressure to “get the numbers”
- Often asked to play dual roles, e.g. recruitment and service delivery



Research Responsibility & Mistrust

Focus Groups

- I believe the results of studies I work on will improve the lives of people in the community; *However the results will first be used to help middle class communities*
- It is my responsibility to increase the community's trust in research; *But I sometimes feel the people I work for exploit research participants*



Ethical Framework for Survey Study

For CRWs with direct contact with participants

- Research is a moral endeavor involving the dual obligations of scientific integrity and research participant protections.
- Obstacles to meeting these obligations are increased in community-based research involving persons who use illegal drugs.
- Encountering such obstacles presents moral practice dilemmas that can lead to moral distress
- Organizational climate and attitudes toward research and the CRW role are associated with levels of moral distress and moral practice dilemmas



Specific Goals of Survey Research

Obtain quantitative data from a national sample of CRWs working on community-based drug use studies to explore:

- Work-related Moral Distress
- Moral Practice Dilemmas
- Research Ethics Climate
- Organizational Support
- Research Commitment
- Research Mistrust



Who are the Frontline Researchers?

NO national data base

Best Guess

- Academically trained researchers *[76% of online job database for RAs required a 4 year degree or higher]*
- “Indigenous research workers” drawn from the participant community for their “insider knowledge”

Personal history of drug use

Community residence

Shared ethnicity, culture or language



Recruitment

- 188 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 CDRWs.
- Inclusion/Exclusion Criteria:
 - CRW position within the past 12 months
 - Job responsibilities included direct participant contact
- Web-based anonymous survey; participants received a \$40 Amazon.com certificate



Participant Characteristics (N=275)

- 33% Male
- M = 35.7 yrs (20-63)
- 81% College or graduate degree
- 23% History of drug use
- 67% Lived in research community
- Mean Income \$30,000- \$40,000

Ethnicity

- 12% Black non-Hispanic
- 15% Hispanic
- 62% Non-Hispanic White
- 11% Other

Geographic Location 20 states

HIV Related Research 225 (82%)

- HIV/HEP Trials 177 (64%)
- HIV + (69%)
- HIV + partner (48%)



Work Experience

Experience as CRW

- 77% \geq 2 years
- 71% Full-time /CRW work
- 58% Met with PI > monthly
- 80% Worked on federally-funded study

CRW Study Participants

- 80% PWID
- 80% with or at risk for HIV
- 78% Homeless
- 63% MSM
- 53% Sex worker
- 46% Victim Domestic Violence

CRW Study Types

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

CRW Duties: Participant Contact

- 84% Interviews
- 83% Informed consent
- 79% Survey administration
- 58% Recruitment
- 36% Harm Reduction Training
- 33% Debriefing
- 28% Focus Group



Exploratory Scale Development

- Items drawn from focus group statements; adapted from scales created for nurses, healthcare workers and graduate students.
- Items and scale format refined by CAB
- All items scored on a 4-point Likert-type scale ranging from “Strongly Disagree” to “ Strongly Agree.”
- SPSS “Corrected-item total” and “Alpha-if-item-deleted” were used to increase scale reliability.



Scale Characteristics and Correlations with Moral Distress

Scale	# Items	Alpha	M (SD)	Soc Des
Moral Distress	25	.89	1.89 (.44)	-.21***
Moral Practice Dilemmas	12	.66	1.98 (.41)	-.14*
Research Ethics Climate	13	.91	3.42 (.50)	.12*
Organizational Support	16	.91	3.08 (.57)	.12*
Research Commitment	6	.77	3.24 (.52)	.12*
Research Mistrust	8	.82	1.92 (.58)	-.24***



Moral Distress: Most Frequent Moral Stress Items

I was emotionally drained at the end of the day.	56%
This job was very stressful.	52%
I worried the job was hardening me emotionally	41%
I was over-burdened by the demands of my job.	36%
I questioned the meaningfulness of my job.	29%



Moral Distress:

Most Frequent Items Reflecting Moral Obstacles

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 participate in.	55%
I believed that offering money made some participants ignore the risks of the research.	45%
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%



Multiple Regression on Predictors of Moral Distress (MD)

($R^2 = .71, p < .001$)

Variable <i>Transformed Scores</i>	Correlation with MD (SD Partialed)	Independent Contribution to MD
Social Desirability (SD)	-.20***	$\beta = -.04$
Age	-.24***	$\beta = -.05$
Freq Meetings w/ PI	-.17**	$\beta = -.17$
Financial Security	+.47	$\beta = -.04$
Moral Practice	+.47*	$\beta = +.12^{**}$
Research Ethics Climate	-.71*** -.36***	$\beta = -.17^{**}$
Organizational Support	-.71*** -.37***	$\beta = -.32^{***}$
Research Commitment	-.12	$\beta = -.03$
Research Mistrust	+.73***	$\beta = +.36^{***}$



Research Ethics Climate

Had adequate policies to protect participant privacy and confidentiality.	97%
Provided participants with fair and non-coercive payment/compensation.	95%
Stressed the importance of making sure participants understand the informed consent information.	94%
Provided training in research ethics for CRWs.	81%
Had ethics policies relevant to the real ethical challenges faced by CRWs (R)	77%
Provided a summary of research results to communities in which research was conducted	68%



Organizational Support

Gave CRWs enough information to do their job well.	88%
Had policies to protect CRW safety in doing their job.	84%
Included CRWs in recruitment and data collection planning.	80%
Provided counseling for CRWs who experienced trauma on the job.	62%
Had realistic expectations about the number of drug users that CRWs can recruit (R)	58%
Did not require CRWs to take on too many different roles for the same study.	57%



Moral Practice Dilemmas

RECRUITMENT

	Total	HIV/HEP
I won't go out to 'sell' a study to drug users if I don't trust the investigator.	67%	64%
I find it hard to 'sell' a study to drug users when I do not believe the study will produce useful results.	43%	42%
I exclude drug users from participating if I believe they are lying about which drugs they use.	30%	33%
I discourage drug users from participating in a study if I believe it will not be good for them.	37%	36%



Moral Practice Dilemmas

SCIENTIFIC INTEGRITY

	<u>Total</u>	<u>HIV/HEP</u>
Even when it is not part of my job I counsel participants about their drug problems	39%	42%
The questions I am told to ask unintentionally give away the drug inclusion criteria	33%	30%
I use my own money to buy coffee or other small goods to keep drug users interested in participating	31%	32%
I find it difficult to protect participant confidentiality when people in the community know what type of study I am working on.	20%	20%



Multiple Regression on Predictors of Moral Practice Dilemmas

($R^2 = .36, p < .001$)

Variable <i>Transformed Scores</i>	Correlation with MD (SD Partialed)	Independent Contribution to MD
Social Desirability (SD)	-.14*	$\beta = -.03$
Research Ethics Climate	-.32***	$\beta = -.10$
Organizational Support	-.35***	$\beta = -.02$
Research Commitment	+.14*	$\beta = +.25***$
Research Mistrust	+.54***	$\beta = +.54***$



Role Commitment

54% Endorsed all 6 items

I believe the results of studies I work on will be used to improve the lives of people in the community. 94%

It is my responsibility to increase the community's trust in research. 89%

I see myself as a bridge between the community and the research organization. 86%

I feel responsible for educating the community about the importance of participating in research. 85%



Research Mistrust

51% endorse 2 or more items (range 0 – 8)

Some people in the community distrust me because I am a research worker. 32%

Most investigators do not care about participants; they just want to get the study done. 30%

Drug users in poor communities are paid less for being in a study than middle class drug users. 26%

Drug use related research that is conducted in poor communities will mostly benefit middle class 23%

Research exploits drug users who are desperate for help. 22%



DISCUSSION: Major Findings

- The majority of CRWs work settings have a supportive organizational climate and procedures to ensure research integrity.
- The majority of CRWs are highly committed to their work and see themselves as an important bridge between the community and research.

However

- 75% endorse at least 1 item viewing research as exploitative
- Over half are faced with difficult personal and professional moral practice dilemmas



Moral Distress

- CRWs “see themselves as moral agents attempting to achieve an overarching moral good.” (Sunderland, 2011)
- They feel a moral responsibility to address social injustices experienced by vulnerable participants.
- Moral distress arises when [researchers] cannot actualize these values via their work.



Moral Distress

- Approximately half of CRWs experience some level of moral distress; Although levels are not high. 58% endorsed ≥ 6 items.
- Protective factors include: Higher levels of research ethics climate and organizational support
- Risk factors include: Perceptions of research as exploitative and moral practice dilemmas



Moral Practice Dilemmas

- Moral practice dilemmas arise in instances in which adhering to either scientific integrity or to social justice, requires abandoning the other ideal.
- Research Mistrust and Research Responsibility are risk factors independent of research ethics climate and organizational support



Risks to Generalizability

Poor ecological/external validity of
screening protocols



Exclusion of representative populations

Alerting drug users to inclusion criteria

Inclusion of Ss misrepresenting their drug use

Erratic application of screening criteria



Risks to Scientific Validity

Research designs with little perceived participant/community benefit



- Threats to internal validity if CRWs feel responsible to counsel or provide referrals participants
- Threats to generalizability” Lowered recruitment levels when CRWs do not believe in study benefits



Threats to Research Integrity

Inattention to *dual role burdens* perceived by
CRWs and CRWs *feedback*



CRW exploitation by community

Threats to participant confidentiality

CRW burnout

Uncorrected problems w/ research implementation



Implications for Principal Investigators

- CRWs have valuable expertise in research challenges in the field that can strengthen scientific validity and integrity
- Their jobs → vulnerability to moral practice dilemmas and moral distress
- CRW efforts to overcome obstacles to actualizing their perceived moral responsibilities threatens the scientific validity and integrity



Implications for Principal Investigators

- Include CRWs in the design of recruitment, inclusion/exclusion, and other community relevant research procedures
- Set aside regular team sessions for debriefing and feedback
- Obtain first hand knowledge of the research community to enhance scientific validity and research integrity



Questions/further discussion

