

*Through the Community
Looking Glass:*

*Teenagers' and Parents' Attitudes
toward Ethical Issues in
Suicide Research*

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Importance of Community Perspectives

Scientific Validity:

Recruitment & Population

Sampling

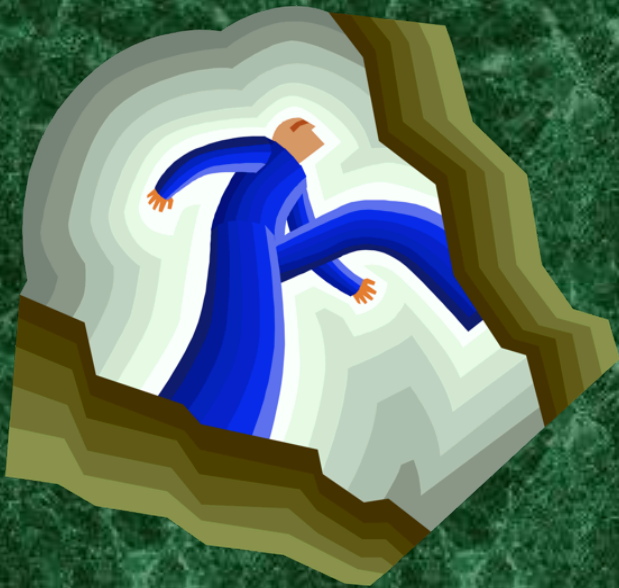
Internal Validity

External Validity

Ethical Validity

Over or under-estimation of research risks

Diversity in ethics relevant attitudes toward *Informed Consent and Confidentiality policies*



Suicide Research: Risks & Benefits

Benefits

- ***Self Knowledge***
- ***Informed parents, teachers, & practitioners***
- ***Suicide Prevention & Treatment***
 - Investigator Competence***
 - Past Failures***

Risks

- ***Attitudinal & Behavioral Changes***
- ***Personal or Family Distress***
- ***Personal Stigma***
- ***Risk of Family Involvements with Child Services***

Randomized Clinical Trials

Control Groups

Importance for Majority
Investigator Expectations
Guinea Pigs

Appropriateness for Community

Fair Assignment

Post-Experimental Treatment

Iatrogenic Effects

Community Friction
Reaction to Control Group Assignment

Scientific Validity

- Accuracy of self and informant reports
- Sampling bias
- Laboratory error
- Trickle down interventions
- Failure to study effect of racism
- Investigator bias & misuse of data

Studies on the Biological Basis of Suicide

- ❑ Biological factors underlying individual versus racial disparities
- ❑ Racial Distrust & Eugenics Based Policies
- ❑ Self-fulfilling Prophecies & Inflicted Insight
- ❑ Detract from Personal Responsibility
- ❑ Risk of Preventive Treatments



Community Suggestions

- **Allow parents to be with teen during blood sampling**
- **Base school intervention studies upon the needs of the community and not upon national trends.**
- **Provide treatment to control groups as soon as it is evident that the treatment is effective & consider time limits**
- **Assignment to experimental groups should be perceived as fair by participants & not create inter-group conflict**

Community Suggestions

- **Include teenagers from different ethnic groups, settings (urban/suburban) and economic strata.**
- **Move beyond the individual to study institutional, economic, and neighborhood risk factors.**
- **When disseminating results guard against media distortion and community stigmatization**
- **Actively demonstrate to communities that researchers can be trusted**

Parental Permission

Reasons to Require Parental Permission

Respect for Parents

Protection Against Coercion & Deception

Power Differentials

Post-Experimental Stress

Reasons to Waive Parental Permission

Cognitive Maturity

Teen Autonomy & Privacy

Parents Might Think Teen is in Trouble

Honesty of Disclosures/Enhance Recruitment

Appropriate if Parents are Cause of Problem or
data is anonymous

The Myth of Passive Consent

- OPRR
- Justice
- Community perspectives

Deceptive

Coercive & teaches children to deceive

Teens do not give parents the forms

*Parents are afraid to sign the form or
do not receive it*

Community Suggestions: Consent

- Verify that parents have received and understand the consent forms. [students forge forms]
- When evaluating existing intervention programs, do not assume that parents gave permission for their child to participate
- Insure that permission policies do not lead parents or participants to assume they have waived their rights to withdraw, complain about a study, or hold an investigator liable for misconduct.

Community Suggestions: Waiver

- When waiving parental permission, explain the rationale to teens and parents
- When waiving parental permission, insure protections through a participant advocate or enhancement of teen consent capacity

Research Participant's Bill of Rights

- ✓ To be fully informed
- ✓ To have all questions answered
- ✓ To freely choose to participate or to refuse participation
- ✓ To withdraw or not answer questions

- ✓ To privacy and confidentiality
- ✓ To be protected from harm
- ✓ To know the results of the study
- ✓ To understand these rights

Reasons for Maintaining Confidentiality

- **Avoids feelings of betrayal**
- **Allows teen to vent feelings**
- **Encourages teenagers to take responsibilities for their actions**
- **Avoids granting undue authority to investigators to make reporting decisions**
- **Prevents giving credibility to false or inaccurate responses**
- **Avoids involvement with child protection agencies**

Reasons to Disclose

- Teens revealing suicidal thoughts are asking for help
- Teens who are depressed may not know they need help
- Scientists have an obligation to help & would be responsible if problem worsens

Teen & Parent Preferences

Policy Preferred?

- **Not tell anyone**
Teens 10% Parents 6%
- **Discuss w/ Teen**
Teens 65% Parents 61%
- **Tell another adult who can help**
Teens 25% Parents 33%

Who Should be Told?

- **Parent**
Teens 32% Parents 56%
- **School Counselor**
Teens 31% Parents 27%
- **Doctor Outside School**
Teens 37% Parents 17%

Community Recommendations

- Evaluate the validity of teen reports, assessment instruments and team competence
- Determine clinical criteria for disclosure:
Distinguish between symptoms that need immediate attention and those that are minor
- Know relevant reporting laws & legal implications for family and for investigator

Community Recommendations

- **Determine if other adults/professionals are aware of the problem**
- **Have a disclosure plan that is explained during informed consent**
- **Monitor the impact of the policy & modify if necessary**

The Challenge and Potential of Community Advisory Boards

- ✓ Co-learning model
- ✓ Opinions-in-progress analysis
- ✓ Moral agency & the “is to ought” fallacy
- ✓ Doing good well

