Designing and Evaluating Action Research: analysis through an ethical lens

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Action research in public health

- Comparative research on the conditions and effects of various forms of social action
- Dual commitment
  - to study a system to generate knowledge
  - to collaborate with members of the system in changing it in what is together regarded as a desirable direction

Are the commitments conflicting?
The dual commitments: what they entail?

• **to study a system to generate knowledge**
  • Effectiveness, efficacy, processes of community based interventions
  • Using experimental methods to compare outcomes in intervention v/s control groups

• **to collaborate with members of the system in changing it in what is together regarded as a desirable direction**
  • Social, behavioural, biomedical interventions identified to address needs
  • ‘Action’ from knowledge – programmes & policies for the ‘public’
Case Study
The Reduction of Low Birth Weight Project
The Context of Jharkhand

Formed in 2000, predominantly tribal, rich in natural resources, hilly terrain with scattered settlements

- **Maternal and Child Health Indicators: a dismal scenario**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Undernutrition among children (0-5 years) (underweight)</td>
<td>54.6%</td>
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<tr>
<td>Low birth weight</td>
<td>41.7%</td>
</tr>
<tr>
<td>Undernutrition among women (15-49 years) (BMI &lt;18.5)</td>
<td>42.6% *</td>
</tr>
<tr>
<td>Anaemia among women (15-49 years)</td>
<td>70.6%</td>
</tr>
<tr>
<td>Anaemia among pregnant women</td>
<td>68.4% *</td>
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- **Health Infrastructure: significant shortfalls**

<table>
<thead>
<tr>
<th>Facility</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Health sub-centre (HSC)</td>
<td>38%</td>
</tr>
<tr>
<td>Primary health centres (PHC)</td>
<td>64%</td>
</tr>
<tr>
<td>Community health centres (CHC)</td>
<td>82%</td>
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The Project – an introduction

• **Aim**
  To study the effectiveness of lifecycle-based community level interventions in reducing the incidence of low birth weight and improving maternal, child and adolescent health in an area where mandated public health & related services are ensured.

• **Project Period - 2003 – 2008**

• **Project Intervention Area**
  Angara & Sili blocks, Ranchi district, Jharkhand (200,000 population approx)

• **Project Partners**
  • Krishi Gram Vikas Kendra
  • Child in Need in Institute
  • ICICI Centre for Child Health & Nutrition
  • Government of Jharkhand
Key interventions

1. Community level interventions
   - Hamlet level CHW (Sahiyya)
   - Village Health Committees

2. Mandated public health & related services (focus on sub-centres & PHC)
   - Demarcation & Renovation of health facilities
   - Training public health system & ICDS personnel
   - Regularising supplies of essential equipments
   - Placement of Mobile Medical Vans
   - Supporting potential FRU
The study design

4 blocks in Ranchi district

Intervention blocks

Angara & Sili

Comparison blocks

Sonahatu & Mandar

T1 Area
T1 intervention in 50%
SubCentre areas randomly selected

T2 Area
T2 intervention in 50%
SubCentre areas randomly selected

T0 Area
50% SubCentre areas selected randomly
How the study design evolved...

**IMPLEMENTATION REALITIES**
Presence of other groups with similar interventions

**STUDY DESIGN**

**POLITICAL FACTORS**
Sahiyya Programme (GoJ, 2004)
NRHM in 2005 & integration of the Sahiyyas into the ASHA Programme (2006)

**CHANGES IN COMMUNITY DYNAMICS**
Creation of a cadre of health workers & other forums

Sahiyyas & VHCs ("T2 – collective action") intervention across all blocks in Jharkhand, including T1 and T0 areas
**Ethical enquiry**

- Principles of biomedical ethics proposed by Beauchamp and Childress (1979)
  - **Beneficence** - which denotes the obligation to provide benefits and balance benefits against risks
  - **Non-maleficence** - which signifies the obligation to avoid the causation of harm
  - **Autonomy** - the obligation to respect the decision-making capacities of autonomous persons. Associated with several ideas, such as, privacy, voluntariness, choosing freely, participating, and accepting responsibility for one’s choices
  - **Justice** - indicates the obligations of fairness in the distribution of benefits and burdens. Justice, as an ethical principle, attends to the wider inequalities in health and health care provision
Ethical dilemmas faced...

- Do we support the government scale-up, or dissuade GoJ in order to maintain the study design & answer the research questions?
- Given the extremely poor health context of Jharkhand, do we maintain a comparison area?
- Cultural respect for local beliefs & practices vs. behaviour change based on scientific/medical knowledge
- Did we scale-up an intervention that we did not conclusively know to be beneficial?
- Can we attribute the positive outcomes of the research project to the interventions, since the rigour of the design was not preserved?
- Do we not owe conclusive rigorous research findings to the communities – as research participants?
Ethical dilemmas in action research for public health

**AUTONOMY**
- Research design: allocating ‘intervention’ & ‘control’ to communities randomly
- Intervention design: based on theories assuming community needs

**BENEFICENCE**
- How do we establish what is ‘most beneficial’ without research?
- In the context of poverty, vulnerability & information asymmetry, can the community make an informed choice?

**NON-MALEFICENCE**
- In asking research questions, some people will be denied the (seemingly beneficial) intervention
- Could it be harmful to have scaled-up/universalised public health interventions without ‘evidence’?

**JUSTICE**
- Do we compromise beneficence (through pursuit of knowledge) for justice (through universalisation of the intervention)?
- If the evidence of a beneficial intervention is not translated to practice and made available & accessible to all

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Re-thinking ethics, public health and research

• Positivist approach to research, action and health
• Ethical reductionism?
• Principlism versus communitarianism – moving beyond individualistic biases
• Ethical relativism v/s ethical universalism
Rethinking the 4 ethical principles

• **Autonomy** – Not simply to make one’s own choices, but to distinguish between a good and a bad choice

• **Non-Maleficence** – Not simply the prevention of physical harm or interference with liberty, but also threats posed to values. Social relationships and political welfare

• **Beneficence** – To include community reflection and support to determine what is beneficial

• **Justice** – Not only a judgment about what constitutes a fair distribution of health resources, but, especially in the context of scarce resources, determine what constitutes appropriate resources to distribute or should be created through research
Thank You