The Challenges of Conducting International Public Health Research: Data Collection Lessons from the Field

Caroline Kuo
Brown University

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The challenges of conducting international public health research: Data collection lessons from the field

Caroline Kuo, DPhil, MPhil
Department of Behavioral and Social Sciences, Brown University
Department of Psychiatry and Mental Health, University of Cape Town
Behavioral Interventions

Human subjects

- vulnerable populations
- special ethical considerations

Sensitive topics

- sexual behavior
- HIV
- mental health
- familial illness and death

Participatory & community-engaged research agenda

Teen Advisory Group Annual Retreat – Team building exercise

Photo credit: Andrew Naysmith; participatory documentary film to dissemination research findings

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Collaborative research: Science to inform policy and practice

**South African Policymakers**

**Medical Experts**
- KidzPositive
- Red Cross War Memorial
- Children’s Hospital

**Our studies:**
Building Resilient Youth and Families

**Community Organizations**
- Tholulwazi Uzivikele
- Grassroot Soccer

**Advisory Group & Community Consultations**
- Youth advisory group team building exercise
Public health campaign on building at research site, KwaZulu Natal
Research studies

Family Challenges (2005-2007)
- Qualitative, exploratory approach
- K=3 focus groups with caregivers of children orphaned by AIDS
- N=15 key informant interviews

Caregiver Wellbeing Study (2007-2009)
- Cross-sectional survey
- N=2477 caregivers aged 18+

Young Carers Study: Kwa-Zulu Natal (2010-2012)
- Mixed methods: cross-sectional survey and embedded qualitative research
- N=4954 children aged 10-17, caregivers aged 18+

- Two group randomized design
- Assessments at baseline, 1- and 3-month post-intervention
- Acceptability and feasibility data

Data collection, KwaZulu Natal research site
Health disparities: HIV affected children at risk for poor mental health

South Africa
- Anxiety
- Depression
- Trauma

Uganda
- Depression
- Anxiety
- Hopelessness

Zimbabwe
- Depression
- Anxiety

China
- Depression
- Trauma
- Loneliness

USA
- Depression
- Anxiety
- Internalizing disorders

Statistically significant associations in bold

Young Carers KZN Study
Health disparities: HIV affected parents at risk for poor mental health

- **Depression:** 30-36%

- **Anxiety:** 49-73%

- **PTSD:** 19%
**Syndemic of poor mental health and HIV**

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver not HIV-ill, no child orphaned by AIDS</td>
<td>43%</td>
</tr>
<tr>
<td>Child orphaned by AIDS, but caregiver not HIV-ill</td>
<td>48%</td>
</tr>
<tr>
<td>Caregiver HIV-ill, but no child orphaned by AIDS</td>
<td>65%</td>
</tr>
<tr>
<td>Dually affected HIV households</td>
<td>76%</td>
</tr>
</tbody>
</table>

***p<0.001**

Cumulative Effects of HIV Illness and Caring for Children Orphaned by AIDS on Anxiety Symptoms Among Adults Caring for Children in HIV-Endemic South Africa

Caroline Kuo, MD, Lucie Cluver, MD, Marisa Casale, and Tyler Lane
Adolescents a key group for HIV prevention

- 63% used condoms inconsistently
- >30% engaged in sex with casual or age disparate partners, or while using alcohol or substances
- 14% engaged in transactional sex

Low Perception of HIV Risk among Sexually Active Adolescents

- No chance of getting HIV
- A little chance
- 50/50 chance
- A big chance
- Been tested in past 3 months and know status
- I don't know what HIV is
Family interventions: Integrating HIV and mental health prevention

Depression and sexual risk
Lehrer et al. 2006
Brown et al. 2006

Negative affect
Shrier et al. 2008

Lower self-efficacy
DiClemente 2001

Parental monitoring
DiClemente et al. 2007

Parent-child communication about sex
Sutton et al. 2014

Rates of HIV risk behavior among children with depression or anxiety

<table>
<thead>
<tr>
<th></th>
<th>Not depressed or anxious</th>
<th>Depressed or anxious</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexually active</td>
<td>7%</td>
<td>18%</td>
</tr>
<tr>
<td>Engaged in risky sex</td>
<td>5%</td>
<td>15%</td>
</tr>
</tbody>
</table>

AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/caic20

Positive parenting for positive parents: HIV/AIDS, poverty, caregiver depression, child behavior, and parenting in South Africa
Jamie M. Lachman, Lucio D. Cluver, Mark E. Boyes, Caroline Ku, & Marisa Casale
Risk to resilience paradigm shift

% children with disorder

<table>
<thead>
<tr>
<th>Category</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver no disorder, Child not AIDS-affected</td>
<td>13%</td>
</tr>
<tr>
<td>Caregiver no disorder, Child AIDS-affected</td>
<td>79%</td>
</tr>
<tr>
<td>Caregiver disorder, Child not AIDS-affected</td>
<td>69%</td>
</tr>
<tr>
<td>Caregiver disorder, Child AIDS-affected</td>
<td>[VALUE]</td>
</tr>
</tbody>
</table>

***p<0.001

Young Carers KZN Study
Family solutions for resilience

**RECIPROCITY:** Families has to go back in helping each other in terms of a strong family connection. Before, families used to—if my brother is struggling, and he doesn't have something, and I am having, or if a neighbor child is struggling, she doesn't have something, and I can be able to actually help that particular kid, I do. You see? Those ways, strong family ties. That means you don't need to be a biological or parent to actually support another child. Like my children—I've got two grown up children, you see, and now it's that time where I can take another child, one that is not my biological child, but just to give back to the community. You see? To give back to the community and help another person. Could be even—either way that she’s not in my family member, or whatever, but just to give back—to give.

**MUTUAL CARE:** Adults taking care of the children. Children taking care of the adults. When you see the person with bags you go for help. Not expecting anything in return.

**FAMILY SUPPORT:** Well, I think the most important one is for them to work together to be one, not to allow things like stressors and conditions and their circumstances to divide them. You find that a lot of times when families have problems, they allow the problem to break the family to pieces. If families could learn or could be taught how to take the problem and make it something to step onto, make the problem a building block so that from the problem you grow and not let the problem break you, but to let the problem build you.

**GENEROSITY:** There is this word Ubuntu that is being generous. We are getting, people that—people that helping each other in the community. Like if you are part of a church and then you speak about your child that is in the church, people volunteer to help you. Some people access that. Also, if there is an income, I think that’s—I cannot leave that behind. If there is an income and the family’s able to survive, that is a strong factor that keeps the family really going.
DATA SYSTEMS: FILE STORAGE, SECURITY, AND ACCESS
Multiple sites, multiple time zones, large international teams
Large data, but slow upload and download speed

Watch our documentary film on YouTube!

https://www.youtube.com/watch?v=KnOAVf9iAY4
Cloud based data systems with encryption and compression

- Cloud based data systems via Dropbox + Security “fence” through nCrypted Cloud
  - Compression of files
  - Encryption of files
  - Secured sharing
    - Turning on/off access for individuals sharing folders
    - Different levels access for folders and files
      - Pin-enabled files
      - Download and upload privileges
      - Watermarking of documents
    - Statistics on user activity
Investing in local staff and capacity building
User manuals and remote access

Our Family
Our Future
Family Prevention of HIV Risk and Depression in South Africa
Dr. Caroline C. Kuo
Standard Operating Procedures Manual

www.teamviewer.com
DATA SYSTEMS: DATA COLLECTION
Data collection needs: Visual data collection for low-literate populations

<table>
<thead>
<tr>
<th>7.1(SADH): Does your household have ..... / Kungabe kulomzi ikhona .....</th>
<th>No / Cha</th>
<th>Yes / Yebo</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.1a: electricity? / ugesi?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>7.1b: radio? / umsakazo?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>7.1c: television? / umabonakude?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>7.1d: telephone? / ucingo?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>7.1e: refrigerator? / isibandisi?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>7.1f: personal computer or pc? / i-computer?</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
Data collection needs: Visual data for engaging child populations

My Journey

Program Enrollment & Session 1
Session 2
Family Meeting Session 3
Home Visit #1
Home Visit #2
Home Visit #3

TEEN TALK SOUTH AFRICA

Whatever you say is confidential. This means we will not report your real name.

Please write your name here:

...........................................

Now, please think of a different name which we can use when we are writing about this research. You can pick any name you want!

...........................................

Questionnaire number: .............. Boy/Girl
Place of interview: ..................................
School/org: ..................................... Grade: ......
ID number: ......................................
Interviewer: ................................. Date: ....
Enumeration Area Number: ......................
GPS latitude (S): S 0 0 0
GPS longitude (E): E 0 0 0

Would you mind if we contacted you again? Please write your address and telephone number so we can get back in touch:

Address: ........................................
........................................
Telephone: .................................

This is not a test. There are no right or wrong answers! This research aims to help young people in South Africa. Thank you for taking the time to help.
Large data images

Image Credit: Dr. Lucie Cluver's Studies
Low cost data collection software: visual deployment of questionnaire and visual image data capture

- Cost of software
- Cost for data collection quantity (by survey)
- Image collection capable

www.dooblo.net/stgi/surveytogo.aspx
SECURITY OF HUMAN SUBJECTS DATA AND STAFF SAFETY
High crime field sites including theft

Cartels Battle for Supremacy in South Africa’s Taxi Wars

The shattered windshield of a taxi owned by Khonzani Mono, who was killed last month in a shooting near Cape Town, a taxi cartel feud. More Photos >

Angry crowd stones armed thug to death

By MISHA ZUMRORPE
A 22-YEAR-OLD thug was stoned to death by angry residents in Khayelitsha.
The unidentified man had killed residents of their car in Khayelitsha, in Khayelitsha, on Tuesday.
Cops said residents of Khayelitsha informal settlement chased the suspect, who had a gun.
Police Captain Ephraim Nellorn said one of the residents, Ziyakhe Ndzimana, was shot dead when he attempted to catch the thug.

Nellorn said Ndzimana was returning home from a robbing after buying bread, when he saw the man chasing after the thug. He tried to stop the suspect, who pulled out a gun and shot Ndzimana.

Nellorn said that the man had spilled blood in the streets, but that did not stop them from continuing with the chase.

They cornered him at the Nkoloda informal settlement and stoned him to death.

At the time, we are investigating two counts of murder,” said Nellorn.

He appealed to the community not to take the law into their own hands.
Protection of data: Secure access

- Password controlled phone
- Password controlled data collection access
- Encryption of data
Protection of data: Remote lock, wipe, ring of phone with location capabilities
Theft possible: Limit data and minutes on phone with pay-as-you-go accounts with township phone stores
DATA SYSTEMS: OVERCOMING DATA COLLECTION CHALLENGES
Sensitive behavioral data: Audio computer assisted self-interviewing (A-CASI)

A-CASI capability

How many times have you had vaginal sex? By "vaginal sex" we mean when a man puts his penis in a woman's vagina.

Have you and your child ever talked about condoms?
Remote field sites: Mobile data systems

✓ Multiple device capability (phone, tablet, computer)
✓ Platform: Windows, Android vs. IOS device
Tracking and tracing participants for repeat measures: Location data

✓ GPS capable
✓ GPS capture automated

Take GIS coordinates:
Capture GPS

Captured on: N.A.
Latitude: N.A.
Longitude: N.A.
Altitude: N.A.
Bearing: N.A.
Speed: N.A.
Continued GPS Challenges

Metal sheeting for roofs and walls

Heavy African bush obscuring satellite access
Limited electricity and internet: Offline data capability, quick sync, long life battery systems

- Online data collection
- **Offline data** collection with fast loading speed
- Choice of device with long battery life

Lack of electricity or undependable electricity (and internet)
Things go wrong: Remote troubleshooting

- Linked to computer based software
- Web accessible from any location

www.mobizen.com
THANK YOU!

With special thanks to our Data Team, led by Ms. Suzanne Sales, Mr. Timothy Souza, and Mr. Rick Smith at Brown University School of Public Health.

Mentors and Research Collaborators

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Cathy Mathews, PhD
University of Cape Town
Dan Stein, MD
Jackie Hoare, MD
Brown University
Don Operario, PhD
Christopher Kahler, PhD
Larry Brown, MD
Oxford University
Lucie Cluver, DPhil
Harvard University
William Beardslee, MD

Community Collaborators

Kidz Positive, Paul Roux, MD
Grass Roots Soccer
Red Cross War Memorial Children’s Hospital, Kirsty Donald, MD
Tholuwazi
Ikamva LaBantu

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R21 NIAID 116309, PIs: Operario, Hoare; Co-I: Kuo
R24 NICHD 077976, PIs: Lurie, Colvin, Co-I: Kuo

Health Economics and HIV/AIDS Research Division

QUESTIONS
Caroline_Kuo@Brown.edu
THANK YOU!
Research driven by families in South Africa for families in South Africa.

Photo credit: Andrew Naysmith

QUESTIONS
Caroline_Kuo@Brown.edu