Pitfalls (and Opportunities) Using Routine Health Systems Information for Engagement Research:

*Using What’s in the Fridge*

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Routine Data for Implementation Science to End the HIV Epidemic

• Analyses from real world, clinic-based, or administrative sources are often very relevant and representative
  • Good for understanding engagement and retention
  • But there are shortcoming to this data

• Recipes to enhance rigor?
  • Novel counterfactual approaches
  • Targeted supplementation

• Value of research using data from program sources
  • From “garbage in garbage out” to “wabi sabi”
Hungry? Case Presentation

5:30 PM
Rush out of work mid-email

5:59 PM
Get to school one minute before it closes to pick up child

6:25 PM
Arrive at home with hungry child. Hungry partner is on the way home and sends you a text message

“What’s for dinner?”
Option A: Vs. Option B:
Data for engagement research: lots in the fridge

- Can do randomized trials (e.g., motivational interviewing, case management, peer navigation)

- International Epidemiological Databases to Evaluate AIDS
- CFAR Integrated Network of Clinical Systems
- Administrative EMR data
- Surveillance?

- Appointment and visits often captured well even when other elements are not
Research on Service Delivery and Engagement is like Dinner

• There are advantages to using what you have...
• *There is some urgency*
  • Get new data or use the data you got?
• *You want to be efficient*
  • If you don’t use what you have it’s going to get old

...But, what you have might not be exactly what the recipe calls for
Randomized Trials - Not the Only Recipe for Understanding Interventions

• “Only randomized trials give you causality”

• Not true... but need some assumptions*

• RCT’s (traditionally) control the context... but we want effects in context**

*Also some things you can’t randomize (e.g., air pollution)
**Some things get distorted in a trial setting
Alternative Recipes for Rigor in Engagement Research using Routine Data...

- Causal inference techniques in epidemiology
- Propensity scores
- Inverse probably weights
- Instrumental variables
- *Natural experiments*
Recipe for Using what’s in the Fridge: Natural experiments

• A condition or exposure not under the control of researchers but which is plausibly randomly assigned

• Can be used to learn about causal effects (in the real world)

• Examples
  • 1854 Cholera outbreak – water supply by two companies essentially randomly distributed in London (John Snow ~ 1854)
  • Effect of the draft into the Vietnam war on health outcomes

(Hearst, Newman and Hully NEJM 1986)
Case Presentation Continued: Pitfalls and (More) Opportunities

5:30 PM

Rush out of work mid-email

5:59 PM

Get to school one minute before it closes to pick up child

6:25 PM

Arrive at home with hungry child. Hungry spouse is on the way home and sends you a text message:

In fridge: chicken, broth, noodles, scallions, and anise – perfect for noodle soup. Now just missing one thing... Cilantro

6:27 PM

“Don’t forget, your mom is coming.”
Recipe 2: Using (mostly) what’s in the fridge and going to corner bodega
Just one problem: loss to follow-up (unknown outcomes)
Consequences...?

• Is the experience after dropping out the same as the it is for those who continue to be observed?

• If the answer is no then...
  • Descriptive estimates could be wrong (retention, mortality)
  • Analytic estimates wrong (spurious associations and miss effects)
  • Looking at heterogeneity (geographical, over time) a problem
  • Left with cross sectional analysis of patient characteristics at entry?

• Pitfalls with routine data? Like noodle soup with no noodles
A Sampling-based Solution?

All Patients in a Health Unit

Patients who Continue to be Observed

Patients lost to follow-up (B)

Patients sought by tracking (C)

Patients with outcome ascertained by tracking (D)

$P_w = \text{Patients Lost to Follow-up (B)}$

$\text{Patients Successfully Tracked (D)}$
Tracing a Sample: Targeted Supplementation

Active Patients in 71 CIDRZ Supported Facilities (185,343)

- Presumed Alive 183,585 (99%)
- Lost to Follow-up 40,485 (22%)
  - Random Sample 4,362 (11%)
  - Updated status found 3,257 (75%)
    - Found Alive 2,698 (83%)
    - Found dead 559 (17%)
  - Not found 1,105 (25%)
- Known Dead 1,758; (1%)
Retention in Four Provinces in Zambia (N=165,454)

From EMR

After targeted supplemental data from sampling

Izukani Sikazwe 2019 PLOS Medicine
(1) Consistently High Adherence/Retention (28.5%)

(2) Early Nonadherence/Consistent Retention (22.2%)

(3) Gradually Decreasing Adherence/Retention (21.6%)

(4) Early LTFU with Reengagement (8.6%)

(5) Early LTFU (8.7%)

(6) Late LTFU (10.4%)

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MPR over last 3 months  In Care (%)  Deaths
Cumulative Incidence of Mortality by Trajectory Group

log-rank p<0.0001

Days since ART Initiation

- Consistently High MPR/Retention
- Early nonadherence/Consistent retention
- Gradual Decreasing MPR/Retention
- Early LTFU with Recovery
- Early LTFU
- Late LTFU
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