Approaching tensions in administrative health data research: Creating space for co-production in citizen science HIV research

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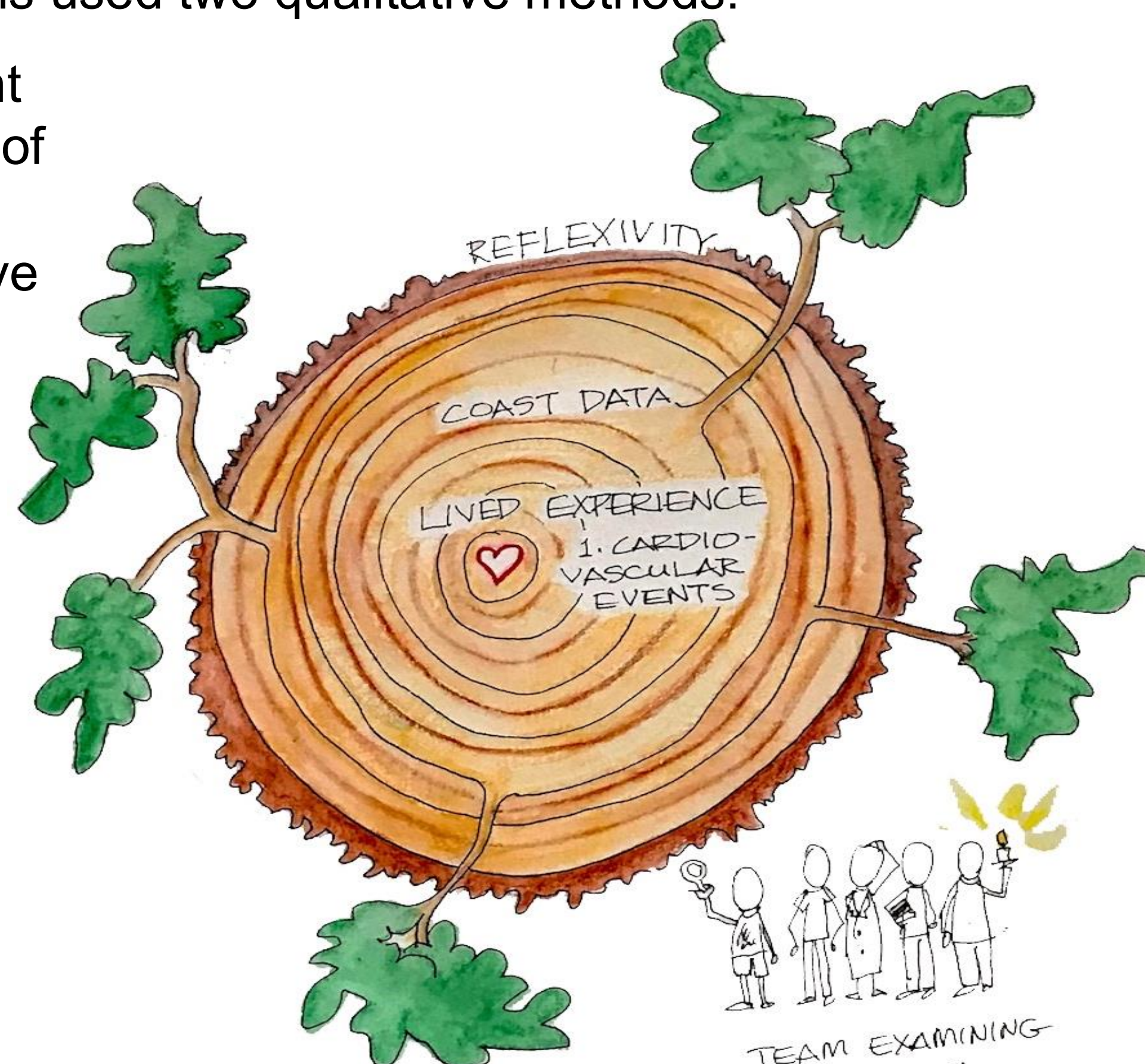
Rationale

- Community-based participatory research (CBPR) is widely applied in the HIV field. However, CBPR—and its embrace of differing knowledge systems, methods, and disciplines—has not yet reached into HIV research that uses administrative health data, a major tool of health research in general.

- Administrative heath data remains obscure to the public and non-expert academics.

- **Little scholarship considers how academic researchers and people with lived/living experience (citizen scientists) encounter and collaboratively navigate the unique characteristics of administrative health data research**, including underlying structures (e.g., classification and coding systems, billing structures), routine data collection procedures, and research methods and norms.

- Given the HIV community's longstanding research leadership, a deeper understanding of administrative health data nuances through community-led or citizen science HIV research can provide lessons for health research generally.

Methods

- Ethnography of citizen science. Analytical focus on the on-the-ground realities that shape scientific research and the synergies and tensions of collaborative scientific research.[1,2]

- Core team: Seven citizen scientists (People Living with HIV (PLHIV)), four epidemiologists, four social scientists, and two HIV clinicians used two qualitative methods:

1. Participant observation of our administrative health data research process

2. Critical reflexive analysis through "Gathering Wisdom" dialogue

Artwork by Peggy Frank

Thematic Findings

Tensions emerged under two major themes:

1. Epistemological/ontological differences. Working with administrative health data meant situating ourselves within a **positivist paradigm—reality exists outside you, it can be measured, known objectively through quantitative data**—which at times did not match team members' worldviews or ways of knowing.

2. The **social and institutional context of routinely collected health data** and dealing with the limitations of secondary use of data in our BC-based study: Data (including diagnostic codes) may not fully reflect what occurred, important data are not captured.

> "We were not there when that [cardiovascular event] happened, we only have the codes."
> --Epidemiologist

> "The [invisible/missing data about some People Living with HIV interacting with primary care providers] are *real*. And I think what it points out to me is that we need to do some qualitative data." --HIV citizen scientist

> The worry is that we're not 100% sure if they had a [cardiovascular event], it's hard to know without going through their whole chart. Clearly to me you'd want to count that event. If those are things that happened, you would want to count them…But how do you know?!" --HIV specialist

What gets recorded? How?

Coding and biling practices vary across sites

Coding and billing vary depending on the way clinicians are paid: Alternative Payment Plan vs. Fee-for-Service

On-the-ground, real-world circumstances

Financial restrictions can shape coding practices

Bill as individual clinicians; clinical team and clinic unknown

Data reflect dominant notions, e.g. sex as binary

Secondary experiences/ conditions may not get captured

Physicians and/or coders decide on main code/purpose for visit

Tensions were not endpoints but opportunities to innovate.

For instance, based on experiential knowledge of our diverse team, we are exploring several customized research definitions of "primary care engagement."

- ❖ HIV specialists are *primary* care providers in BC
- ❖ "Partnership" vs. "Attachment." Language matters.
- ❖ Number of visits in 20 months = spectrum of partnership. Based on:
  - Engagement norms of PLHIV and people living without HIV
  - Historical shifts
- ❖ Number of visits in 20 months with "Most Responsible Provider"
- ❖ Uncovering PLHIV visits concealed by billing structures:
  - Frequency and results of viral load tests
- ❖ Deep awareness of analytical consequences:
  - Certain regions and people not captured
  - Invisible exchanges (e.g., emails not billing for)
  - Historical changes in primary healthcare (current shift to team of providers)

Discussion

- While administrative data research nuances were at times troubling to citizen scientists and challenging for all, our collaborative work reveals how experiential knowledge can enrich administrative health data research.

- Departing from the philosophical debate between reality and representation in research on health records, standardization and coding in healthcare, we illustrate that administrative health data is fully neither reality or representation. **Our work reveals the legitimacy of empirical data collection, and processes of experimentation and evaluation of evidence, while also revealing that administrative data creation, from the onset, is social.**

- **Creative administrative data exploration, putting (bits of) data together, and understanding the strengths and limitations are best done through a team of people with diverse lived/living experience and knowledge.**

"…producing insight is more like making lures than pulling up fish—a matter of intentions….not the retrieving of objective relations from an obliging sea of data" [3]

Conclusion

Approaching tensions in collaborative research as productive sites for exploration can create innovations and new insights through synthesis helping to ensure co-production and collaborative equity.

Learn more about the HIV and Eng/aging Project