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Qualitative research on community experiences in large HIV research trials: what have we learned?

Camlin CS, Seeley J. *J Int AIDS Soc.* 2018 Oct;21 Suppl 7:e25173. doi: 10.1002/jia2.25173.

Abstract

INTRODUCTION:

Very few pragmatic and community-level effectiveness trials integrate the use of qualitative research over all stages of the trial, to inform trial design, implementation optimization, results interpretation and post-trial policy recommendations. This is despite the growing demand for mixed methods research from funding agencies and awareness of the vital importance of qualitative and mixed methods research for understanding trial successes and challenges.

DISCUSSION:

We offer examples from work we have been involved in to illustrate how qualitative research conducted within trials can reveal vital contextual factors that influence implementation and outcomes, can enable an informed adaptation of trials as they are being conducted and can lead to the formulation of theory regarding the social and behavioural pathways of intervention, while also enabling community engagement in trial design and implementation. These examples are based on published findings from qualitative studies embedded within two ongoing large-scale studies demonstrating the population-level impacts of universal HIV testing and treatment strategies in southern and eastern Africa, and a qualitative study conducted alongside a clinical trial testing the adaptation, acceptability and experience of short-cycle therapy in children and adolescents living with HIV.

CONCLUSIONS:

We advocate for the integration of qualitative with clinical and survey research methods in pragmatic clinical and community-level trials and implementation studies, and for increasing visibility of qualitative and mixed methods research in medical journals. Qualitative research from trials ideally should be published along with clinical outcome data, either integrated into the "main" trial papers or published concurrently in the same journal issue. Integration of qualitative research within trials can help not only to understand the why behind success or failure of interventions in different contexts, but also inform the adaptation of interventions that

can facilitate their success, and lead to new alternative strategies and to policy changes that may be vital for achieving public health goals, including the end of AIDS.

Characterising antibody avidity in individuals of varied Mycobacterium tuberculosis infection status using surface plasmon resonance.

Kimuda SG, Biraro IA, Bagaya BS, Raynes JG, Cose S

PLoS One. 2018 Oct 12;13(10):e0205102. doi: 10.1371/journal.pone.0205102. eCollection 2018.

Abstract

There is increasing evidence supporting a role for antibodies in protection against tuberculosis (TB), with functional antibodies being described in the latent state of TB infection. Antibody avidity is an important determinant of antibody-mediated protection. This study characterised the avidity of antibodies against Ag85A, an immunodominant Mycobacterium tuberculosis (M.tb) antigen and constituent of several anti-TB vaccine candidates, in individuals of varied M.tb infection status. Avidity of Ag85A specific antibodies was measured in 30 uninfected controls, 34 individuals with latent TB infection (LTBI) and 75 active pulmonary TB (APT) cases, employing the more commonly used chaotrope-based dissociation assays, and surface plasmon resonance (SPR). Chaotrope-based assays indicated that APTB was associated with a higher antibody avidity index compared to uninfected controls [adjusted geometric mean ratio (GMR): 1.641, 95% confidence interval (CI): 1.153, 2.337, $p = 0.006$, $q = 0.018$] and to individuals with LTBI [adjusted GMR: 1.604, 95% CI: 1.282, 2.006, $p < 0.001$, $q < 0.001$]. SPR assays showed that APTB was associated with slower dissociation rates, an indication of higher avidity, compared to uninfected controls (adjusted GMR: 0.796, 95% CI: 0.681, 0.932, $p = 0.004$, $q = 0.012$) and there was also weak evidence of more avid antibodies in the LTBI compared to the uninfected controls (adjusted GMR: 0.871, 95% CI: 0.763, 0.994, $p = 0.041$, $q = 0.123$). We found no statistically significant differences in anti-Ag85A antibody avidity between the APTB and LTBI groups. This study shows that antibodies of increased avidity are generated against a principle vaccine antigen in M.tb infected individuals. It would be important to determine whether TB vaccines are able to elicit a similar response. Additionally, more research is needed to determine whether antibody avidity is important in protection against infection and disease.

A mixed-method pilot study to improve patient satisfaction in rural Uganda

Emily Warren, Ethel Nankya, Janet Seeley, Sarah Nakamanya, Gershim Asiki, Victoria Simms, Alex Karabarinde, Heidi Larson.

<https://doi.org/10.1080/09614524.2018.1465026>

Abstract

This article reports on a mixed-method longitudinal field study that was conducted using a tablet-based app capturing data on patients' satisfaction with an outpatient clinic in Kalungu District, Uganda. The app was developed, piloted, and refined using clinician and patient feedback.

Findings were reported and discussed in staff meetings, with change in reported levels of satisfaction assessed using descriptive statistical analysis and Chi² tests. Qualitative data were collected. Satisfaction was relatively high at baseline and increased by 4.4%, and staff found the feedback actionable. Patients reported fewer delays and better treatment after introducing the app, with the proportion of “very dissatisfied” patients decreasing from 2.3% to zero after six weeks.

Spinning plates: livelihood mobility, household responsibility and anti-retroviral treatment in an urban Zambian community during the HPTN 071 (PopART) study.

Bond V, Ngwenya F, Thomas A, Simuyaba M, Hoddinott G, Fidler S, Hayes R, Ayles H, Seeley J; HPTN 071 (PopART) study team. *J Int AIDS Soc.* 2018 Jul;21 Suppl 4:e25117. doi: 10.1002/jia2.25117.

Abstract

INTRODUCTION:

Qualitative data are lacking on the impact of mobility among people living with HIV (PLHIV) and their decision-making around anti-retroviral treatment (ART). We describe challenges of juggling household responsibility, livelihood mobility and HIV management for six PLHIV in urban Zambia.

METHODS:

Six PLHIV (three men and three women, aged 21 to 44) were recruited from different geographic zones in one urban community drawn from a qualitative cohort in a social science component of a cluster-randomized trial (HPTN071 PopART). Participants were on ART (n = 2), not on ART (n = 2) and had started and stopped ART (n = 2). At least two in-depth interviews and participant observations, and three drop-in household visits with each were carried out between February and August 2017. Themed and comparative analysis was conducted.

RESULTS:

The six participants relied on the informal economy to meet basic household needs. Routine livelihood mobility, either within the community and to a nearby town centre, or further afield for longer periods of time, was essential to get by. Although aware of ART benefits, only one of the six participants managed to successfully access and sustain treatment. The other five struggled to find time to access ART alongside other priorities, routine mobility and when daily routines were more chaotic. Difficulty in accessing ART was exacerbated by local health facility factors (congestion, a culture of reprimanding PLHIV who miss appointments, sporadic rationed drug supply), stigma and more limited social capital.

CONCLUSIONS:

Using a time-space framework illustrated how household responsibility, livelihood mobility and HIV management every day were like spinning plates, each liable to topple and demanding constant attention. If universal lifelong ART is to be delivered, the current service model needs to adjust the limited time that some PLHIV have to access ART because of household responsibilities and the need to earn a living moving around, often away from home. Practical strategies that could facilitate ART access in the context of livelihood mobility include challenging the practice of reprimand, improving drug supply, having ART services more widely distributed, mapped and available at night and weekends, and an effective centralized client health information system.

Bringing population mobility into focus to achieve HIV prevention goals

Carol S Camlin, Susan Cassels, and Janet Seeley

J Int AIDS Soc. 2018 Jul; 21(Suppl Suppl 4): e25136. Published online 2018 Jul 19.
doi: [10.1002/jia2.25136]

Abstract

The ambitious UNAIDS '90-90-90' targets, aiming to end the AIDS epidemic by the year 2030 [1](#), are a response to the profound therapeutic and preventive benefits of HIV treatment. Universal voluntary HIV counselling and testing followed by prompt initiation of antiretroviral therapy (ART) for all those diagnosed HIV-infected, an approach known as Universal Test and Treat (UTT), is now seen as the primary means through which the 90-90-90 targets can be achieved. Beyond the targets, the recently emergent concept of a prevention cascade [2](#) also recognizes the imperative of "coverage" for achieving population-level effects of HIV prevention interventions, which are needed together with the expansion of treatment to end the epidemic [3](#).

Perhaps nowhere else in the world is more momentum required to bring HIV treatment *and* prevention to all who need it than in Africa. The HIV epidemic on the continent has been concentrated in eastern and southern Africa, where an estimated 19.4 million adults are living with HIV [4](#). Despite substantial progress in recent years, only approximately 60% of people living with HIV (PLHIV) in the region were receiving ART in 2016 [4](#); an estimated 45% had a suppressed viral load as a result of their successful engagement in care in 2015 [5](#)

One step ahead: timing and sexual networks in population mobility and HIV prevention and care

Susan Cassels, Carol S Camlin, and Janet Seeley

J Int AIDS Soc. 2018 Jul; 21(Suppl Suppl 4): e25140. Published online 2018 Jul 19.
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Introduction

Population mobility comes in heterogeneous forms and is triggered by many drivers. The diverse contexts of mobility can significantly influence the effectiveness of HIV prevention and care, as the contributions to this volume highlight. Nevertheless, some fundamental concepts are common across various forms of mobility. Two such concepts are time and sexual networks: mobility occurs in a space-time continuum, and migrants are situated within social and sexual networks. In this viewpoint, we argue that a closer examination of how (1) time scales of mobility and (2) sexual network characteristics of migrants present challenges to effective HIV prevention can help to optimize interventions.

Households, fluidity, and HIV service delivery in Zambia and South Africa - an exploratory analysis of longitudinal qualitative data from the HPTN 071 (PopART) trial.

Hoddinott G, Myburgh H, de Villiers L, Ndubani R, Mantantana J, Thomas A, Mbewe M, Ayles H, Bock P, Seeley J, Shanaube K, Hargreaves J, Bond V, Reynolds L; HPTN 071 (PopART) Study Team J Int AIDS Soc. 2018 Jul;21 Suppl 4:e25135. doi: 10.1002/jia2.25135.

Abstract

INTRODUCTION:

Population distributions, family and household compositions, and people's sense of belonging and social stability in southern Africa have been shaped by tumultuous, continuing large-scale historical disruptions. As a result, many people experience high levels of geographic and social fluidity, which intersect with individual and population-level migration patterns. We describe the complexities of household fluidity and HIV service access in South Africa and Zambia to explore implications for health systems and service delivery in contexts of high household fluidity.

METHODS:

HPTN 071 (PopART) is a three-arm cluster randomized controlled trial implemented in 21 peri-urban study communities in Zambia and South Africa between 2013 and 2018. A qualitative cohort nested in the trial included 148 purposively sampled households. Data collection was informed by ethnographic and participatory research principles. The analysis process was reflexive and findings are descriptive narrative summaries of emergent ideas.

RESULTS:

Households in southern Africa are extremely fluid, with people having a tenuous sense of security in their social networks. This fluidity intersects with high individual and population mobility. To characterize fluidity, we describe thematic patterns of household membership and residence. We also identify reasons people give for moving around and shifting social ties, including economic survival, fostering interpersonal relationships, participating in cultural, traditional, religious, or familial gatherings, being institutionalized, and maintaining patterns of substance use. High fluidity disrupted HIV service access for some participants. Despite these challenges, many participants were able to regularly access HIV testing services and participants living with HIV were especially resourceful in maintaining continuity of antiretroviral therapy (ART). We identify three key features of health service interactions that facilitated care continuity: disclosure to family members, understanding attitudes among health services staff including flexibility to accommodate clients' transient pressures, and participants' agency in ART-related decisions.

CONCLUSIONS:

Choices made to manage one's experiential sense of household fluidity are intentional responses to livelihood and social support constraints. To enhance retention in care for people living with HIV, policy makers and service providers should focus on creating responsive, flexible health service delivery systems designed to accommodate many shifts in client circumstances.

A blind spot? Confronting the stigma of hepatitis B virus (HBV) infection - A systematic review

Jolynne Mokaya, Anna L McNaughton, Lela Burbridge, Tongai Maponga, Geraldine O'Hara, Monique Andersson, Janet Seeley, Philippa C Matthews

<https://wellcomeopenresearch.org/articles/3-29/v1>

Abstract

Background: The Global Hepatitis Health Sector Strategy is aiming for the elimination of viral hepatitis as a public health threat by 2030. Successful diagnostic, treatment and preventive strategies can reduce incidence and morbidity; it is important to ensure that these interventions and services are not only available, but also accessible. Stigma, poverty, and lack of knowledge

may present a substantial barrier, especially in resource limited settings. We therefore set out to assimilate evidence for the nature and impact of stigma on the lives of people with HBV infection and on the community, and to suggest ways to tackle stigma and discrimination.

Methods: We carried out a literature search in PubMed using the search terms ‘hepatitis B’, ‘stigma’ to identify relevant papers published between 2007 and 2017 (inclusive), with a particular focus on Africa.

Results: We identified a total of 34 articles, of which only one study was conducted in Africa. Lack of knowledge on HBV was consistently identified: there were misconceptions about HBV transmission among the public, healthcare workers (HCWs) provided inaccurate information to individuals diagnosed with HBV, and poor understanding resulted in lack of preventive precautions. Stigma negatively impacted on health behaviour such as help-seeking, screening, disclosure, prevention of transmission, and adherence to treatment.

Conclusion: Stigma is a potentially major barrier to the successful implementation of preventive, diagnostic and treatment strategies for HBV infection, and yet there is very limited recognition of the magnitude of this challenge, especially in Africa. There is a need for more research in this area, to identify and evaluate interventions that can be used effectively to tackle stigma in HBV, and to inform collaborative efforts between policy makers, HCWs, traditional healers, religious leaders, charity organisations and support groups, to improve awareness and tackle stigma in HBV in Africa.

Comparison of Antiretroviral Therapy Adherence Among HIV-Infected Older Adults with Younger Adults in Africa: Systematic Review and Meta-analysis.

Soomro N, Fitzgerald G, Seeley J, Schatz E, Nachege JB, Negin J.

AIDS Behav. 2018 Jul 3. doi: 10.1007/s10461-018-2196-0. [Epub ahead of print]

Abstract

As access to antiretroviral treatment in low- and middle-income countries improves, the number of older adults (aged ≥ 50 years) living with HIV is increasing. This study compares the adherence to antiretroviral treatment among older adults to that of younger adults living in Africa. We searched PubMed, Medline, Cochrane CENTRAL, CINAHL, Google Scholar and EMBASE for keywords (HIV, ART, compliance, adherence, age, Africa) on publications from 1st Jan 2000 to 1st March 2016. Eligible studies were pooled for meta-analysis using a random-effects model, with the odds ratio as the primary outcome. Twenty studies were included, among them were five randomised trials and five cohort studies. Overall, we pooled data for 148,819

individuals in two groups (older and younger adults) and found no significant difference in adherence between them [odds ratio (OR) 1.01; 95% CI 0.94-1.09]. Subgroup analyses of studies using medication possession ratio and clinician counts to measure adherence revealed higher proportions of older adults were adherent to medication regimens compared with younger adults (OR 1.06; 95% CI 1.02-1.11). Antiretroviral treatment adherence levels among older and younger adults in Africa are comparable. Further research is required to identify specific barriers to adherence in the aging HIV affected population in Africa which will help in development of interventions to improve their clinical outcomes and quality of life.

Ethical considerations in global HIV phylogenetic research

Coltart CEM, Hoppe A, Parker M, Dawson L, Amon JJ, Simwinga M, Geller G, Henderson G, Laeyendecker O, Tucker JD, Eba P, Novitsky V, Vandamme AM, Seeley J, Dallabetta G, Harling G, Grabowski MK, Godfrey-Faussett P, Fraser C, Cohen MS, Pillay D; Ethics in HIV Phylogenetics Working Group.

[Lancet HIV](#). 2018 Aug 30. pii: S2352-3018(18)30134-6. doi: 10.1016/S2352-3018(18)30134-6.

Abstract

Phylogenetic analysis of pathogens is an increasingly powerful way to reduce the spread of epidemics, including HIV. As a result, phylogenetic approaches are becoming embedded in public health and research programmes, as well as outbreak responses, presenting unique ethical, legal, and social issues that are not adequately addressed by existing bioethics literature. We formed a multidisciplinary working group to explore the ethical issues arising from the design of, conduct in, and use of results from HIV phylogenetic studies, and to propose recommendations to minimise the associated risks to both individuals and groups. We identified eight key ethical domains, within which we highlighted factors that make HIV phylogenetic research unique. In this Review, we endeavoured to provide a framework to assist researchers, public health practitioners, and funding institutions to ensure that HIV phylogenetic studies are designed, done, and disseminated in an ethical manner. Our conclusions also have broader relevance for pathogen phylogenetics.