

COVID-19 and the ‘ethics of disruption’: Current dilemmas facing longitudinal research in low- and middle-income countries

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Abstract

In this piece, we draw on recent experiences from the Young Lives study to discuss some of the ethical and practical challenges facing longitudinal cohort studies in low- and middle-income countries in the time of coronavirus. We argue that COVID-19 has instigated an ‘ethics of disruption’ for social researchers across the world, and for longitudinal cohort studies like Young Lives, this requires navigating three core considerations: first, managing research relationships and reciprocity within an observational study design; second, maintaining methodological continuity and consistency across time; and third, balancing an immediate short-term response to COVID-19 against the long-term perspective. We refer to the study’s plan to implement a new COVID-19 phone survey to illustrate how the team are navigating this altered ethical terrain.

Keywords

Ethics, longitudinal research, low- and middle-income countries, COVID-19, phone survey

Introduction

The coronavirus pandemic raises several complicated ethical and practical issues for conducting longitudinal cohort studies, particularly in low- and middle-income countries where health systems and research infrastructure are generally weak, and the scale and impact of the virus continues to evolve. The threat of COVID-19 has disrupted social research across the world and required researchers to evaluate whether and how to continue their active studies. Maintaining scientific rigour and high ethical standards while also generating timely and useful evidence directly related to COVID-19 are combined challenges. It feels as though we have entered a new ethical landscape, one that is compelling social researchers to re-examine previously held assumptions about what is appropriate, possible, valuable and relevant for their research, and the nature of ethical responsibilities to all those enmeshed in the research relationship during this time (Dawson et al., 2020: 1).

In this piece, we draw on recent experiences from the Young Lives study to discuss these challenges within an emerging ‘ethics of disruption’ caused by the current COVID-19 crises, that is, destabilising ‘business as usual’ for ongoing longitudinal cohort studies. Young Lives’

decision to undertake a new rapid phone survey during the pandemic precipitated the need to think through several of these ethical concerns, requiring inputs from across our international team so that local expertise and contextual knowledge inform mitigating strategies.

Young Lives

It is 19 years since the Young Lives study of childhood poverty began following the life trajectories of 12,000 girls and boys in two birth cohorts growing up in over 100 communities across Ethiopia, India (Andhra Pradesh and Telangana states), Peru and Vietnam, core funded by the UK’s Foreign, Commonwealth & Development Office (FCDO). This multi-disciplinary, mixed-method study is coordinated by a small team based in the University of Oxford and is implemented collaboratively

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with long-standing research partners located in the four study countries.

The two cohorts of young participants at the core of this study are now aged 19 and 26 years. They are part of the largest demographic cohort of youth ever and their generation stands to be especially affected by the global economic fallout caused by the pandemic, which means that competition for jobs, particularly decent jobs, is likely to be fierce. We do not yet know what the impacts will be from prolonged school and work closures; reduced access to modern contraception; vulnerability to gender-based violence; increased care burdens; and the forced return of young migrants and of family members to their homes and associated job and remittance loss. There is growing evidence that the pandemic is exacerbating existing social and economic inequalities, including among the world's youth.

Young Lives is familiar with the many challenges that come with conducting long-term research with vulnerable populations among whom hunger, economic struggle, illness and premature death were common threats well before the coronavirus pandemic. Indeed, the study has documented a plethora of 'disruptions' at differing scales affecting Young Lives families and communities (for instance, interrupted school trajectories, unintended adolescent pregnancies, droughts and economic shocks). However, the threat of COVID-19 has greatly altered our usual ways of conducting research and has affected the family and working lives of everyone involved in the study.

Coronavirus reached our four study countries at different times and the numbers of reported COVID-19 cases currently differ markedly; for example, as of 4 February 2021, Ethiopia¹ recorded 139,408 confirmed cases in the country, in contrast to the 1,158,337 confirmed cases in Peru (480,438 in Lima² alone). Like social researchers everywhere, we have had to quickly reassess the viability of our research, addressing the realities of remote working, probable delays to fieldwork, pauses, cancellations and protracted uncertainties. By late March 2020, the University of Oxford required staff and students to 'pause or postpone ongoing or planned non-essential University research involving face-to-face interactions with human participants (unless arrangements can be made for the research to be conducted remotely or online)', with the exception of research related to COVID-19 and clinical research.

Crucially, at the time the pandemic was declared, the Young Lives household survey team were finalising plans to undertake our Round 6 survey with the full sample of participants, having secured new funding from FCDO to support two survey rounds over the next 5 years as part of the 'Young Lives at Work' research programme. Our most pressing decision was therefore what to do about the upcoming household survey for which much of the tracking had been completed but face-to-face survey administration would no longer be possible. The team considered delaying the survey by 6 months, but this raised concerns about seasonality effects, and whether lockdown orders would be lifted by that time.

Delaying any later would affect the potential for inter-cohort comparison, since the survey is timed to ask the younger cohort (age 19) the same questions that the older cohort were asked (7 years earlier) at the same age.

Following an intense consultation, the survey team agreed a two-pronged plan: (1) to delay the Round 6 survey by 1 year (thus retaining consistency in seasonality and continuity in the research instrument); and (2) to conduct a new phone survey, beginning in June 2020, using an adapted scaled-down version of the Round 6 survey with additional questions to directly assess the impact of COVID-19, thus retaining the potential for inter-cohort comparison of key outcomes (e.g. work, education, marriage and fertility). The threat of COVID-19 has required that all the survey development is conducted remotely, including the drafting of instruments, field guides and ethical and safeguarding protocols, programming for Computer-Assisted Personal Interviewing (CAPI), training of enumerators, pre-piloting and piloting,³ survey administration, research reciprocity,⁴ data management and stakeholder engagement.

Weighing practical and ethical risks

The huge potential added value of data collection during a pandemic must be weighed against related practical and ethical risks, including safeguarding the health and well-being of Young Lives respondents and staff. Maintaining data quality and high ethical standards is still paramount when conducting social research in a climate of emergency, and just because new data collection is possible does not make it justified.⁵ Indeed, whether we should request people in low- and middle-income countries to engage in research at all during this kind of crisis is an important ethical dilemma.

We reasoned that Young Lives is in a unique position to inform policy makers in both our study countries and globally about the effects of the pandemic on young people's lives and well-being, and to do so relatively quickly. The fact that significant progress had already been made in designing and preparing for the Round 6 survey meant the team were poised to rapidly respond to the current situation; this included up-to-date contact information for the majority of over 11,000 families, with tracking of current locations already completed in three out of four of our study countries.

Weighing up and mitigating the risks of continuing longitudinal research at this time is central to what we mean by the ethics of disruption, and in Young Lives, this has required addressing several core considerations underpinning its study design and principles:

- Managing research relationships and reciprocity within an observational study design;
- Maintaining methodological continuity and consistency across time;
- Balancing immediate response against the long-term perspective.

Reciprocating within the constraints of an observational study

Longitudinal cohort studies rely heavily on the quality of the relationships between researchers and respondents to underpin research vitality and longevity. Preserving the cohort for future data rounds and taking steps to minimise respondent attrition and respondent fatigue over long periods of time is a methodological priority. Research reciprocity is a core value within Young Lives and a key strategy to reduce attrition, but it is complicated by unequal power relations, the realities of poverty and human suffering and the study's observational research design. The decision to move to a phone-based survey sought to minimise, if not eliminate, physical and health risks for both research participants and survey enumerators. But the projects' ethical commitments are multi-layered and even in a global health crisis are not limited to health concerns.

Trust, for example, is crucial for long-term research relationships yet can be difficult to manage in emergency situations (Dawson et al., 2020: 5). And although mobile phones are now widely used in the four study countries, the phone is not the most user-friendly mechanism for eliciting potentially sensitive information and it is impossible to read body language. For this reason, certain topics of policy interest, such as individual experiences of domestic violence during lockdown, have purposefully been excluded from the phone survey. One advantage of a longitudinal study is that a level of trust already exists, and some enumerators have been recruited because they have interviewed the families before. However, there is a risk of the phone survey inadvertently taking advantage of this long-term engagement with the families, rendering informed consent ever more important.

Managing expectations within the long-term research relationship during these difficult times is indeed a challenge. We recognise that many respondents who agree to the phone survey are likely to be living in very stressful and precarious circumstances. The phone survey is purposefully short (any one call should be no more than 30 minutes) to reduce respondent burden, and only experienced enumerators who have worked previously on data collection for Young Lives will be hired.

Young Lives families are already feeling the economic repercussions of the pandemic. We know of two families that emailed one of the country teams to ask for financial help, compelling the team to agree to develop a country protocol. One researcher queried what a 'compassionate response' to these pleas might look like in the current circumstances, 'remembering that we are human and so are our cohort members'. In these very initial cases, a few members of the team who were familiar with the families collated a modest donation out of their own pockets and agreed a carefully worded script to explain (over the phone) to the families that these were personal one-off donations, not from the project, aware that they might be setting a precedent.

The need to develop well-defined protocols for responding to respondents' requests in the time of COVID-19 have quickly become apparent. Such protocols need to: promote equity by equipping survey enumerators with guidance to treat respondents equitably; help avoid creating false expectations, particularly in relation to the next data collection round; protect the psychological well-being of enumerators by reducing the burden of responsibility to make difficult decisions themselves; and provide research teams with a systematic way of recording cases of concern.

In the past, country teams intervened in individual cases of emergency health crisis, for example, facilitating transportation to a hospital, but avoided other types of intervention (e.g. paying school fees). They determine how best to thank participating families and to compensate them for potential lost wages for the time taken up by the interviews, usually a small amount of cash or a gift (e.g. child's backpack, mini radio) and photos, such approaches agreed and consistently applied at country level. Other than this, researchers remind participants that they will not personally benefit by participating in the study.

It is not possible for researchers to physically hand over thank-you gifts to respondents of the upcoming phone survey. Instead, the project will offer phone credit or an equivalent bank transfer as a token of thanks to those who respond to the survey. The amount of phone credit is considerably higher than what would normally have been provided owing to the exceptional circumstances. In addition, a resource leaflet containing information about COVID-19 and the details for country-specific services, including for emotional support, will be sent via messenger or email to all participants and posted on the international and country Young Lives websites. Many communities are poorly resourced when it comes to services for youth in difficulty.

We acknowledge that introducing changes presents risks to the research but are nonetheless appropriate responses within an ethics of disruption. For example, increasing the amount of compensation has potential to bias answers and might raise families' expectations in future survey rounds post-COVID-19. Also, this monetary compensation, however modest, and the information provided in the leaflet might impact on behaviours, and thus, be an intervention, potentially affecting outcomes and research findings. Navigating an ethics of disruption has meant weighing up these risks against new demands on research reciprocity in the current crisis.

Maintaining continuity and consistency

Responding to the pandemic obviously requires research flexibility and adaptation, but some changes may threaten to dilute the strength of the longitudinal study design particularly in relation to data consistency and cohort continuity across many years. Administering both the new phone survey and the delayed Round 6 survey requires careful planning, for

example, around seasonality (returning to communities at the same time of year) and age (same timing for older and younger cohorts); the order in which survey questions are asked; using the same wording for questions; and handling of the data (use of consistent identifiers and security protocols).

Our new phone survey introduces some new targeted questions that will elicit sensitive information about illness and death to understand how many young people have been affected directly or indirectly by COVID-19. The new data will be linked to individual, household, community and school-level data collected in previous rounds, so that the new data are integrated in a consistent manner within the wider corpus of data.

Recent successes using phone-based tracking (pre-pandemic) in preparation for the Round 6 survey suggest this is a suitable communication method for contacting Young Lives families; however, it is unclear what impact this new data collection method (phone survey) or a new line of questioning (about coronavirus) might have on future survey rounds and funders' and participants' expectations. It might be that certain changes will stick over the long term and be adopted for future survey rounds, such as a greater reliance on remote data collection techniques. Such decisions will need to be revisited in the course of future research planning.

Responding quickly with an eye to the future

Longitudinal cohort researchers responding to COVID-19 are managing multiple, sometimes competing short-term and long-term research demands. There is understandably a sense of urgency; donors want to fund research that can provide rapid answers to how to best address COVID-19 and inform related policy responses, including adapting existing funded projects.⁶ Yet longitudinal researchers must maintain an eye on the long term even as they attempt to respond quickly to the immediate emergency and humanitarian crisis. For example, they must balance the imperative to archive new data as soon as possible for wider public use with the need to maintain the high quality of the panel data set and ethical commitments, and to not jeopardise the potential for future post-pandemic data collection.⁷

An incredible amount of work goes into preparing Young Lives survey data sets for public archiving; normally, survey researchers within the project have priority access to use the data for up to 1 year after the end of data collection before it is placed in the public domain. The period of data embargo is made in agreement with the funder to acknowledge the time and intellectual input of the Young Lives staff and to support capacity building. In the case of the new COVID-19 phone survey, both the funder and international team of researchers agreed to prioritise rapid sharing of the data over academic exclusivity, on the understanding that early release of new data must in no way jeopardise our legal and moral obligation to protect the anonymity of research participants and the places where they live.

Concluding thoughts

There is a distinct sense among many social researchers that COVID-19 has transformed our familiar ethical and practical landscapes for conducting research. In this short piece, we described some of the ways in which the Young Lives longitudinal cohort study has navigated this altered terrain, or 'ethics of disruption'. However, many of the ethical and practical issues we highlight are not unique to either longitudinal cohort studies or to research conducted in low- and middle-income countries. On one hand, concerns around research integrity, reciprocity and safeguarding are necessarily shared across distant geographies and different study designs. On the other hand, each study has its unique history and constellation of relationships, resources and constraints. Perhaps it is the way considerations of temporality, vulnerability and relationship combine in longitudinal cohort studies in low- and middle-income countries that creates their challenges and opportunities in the time of COVID. In our experience, what feels different this time is that the global pandemic affects and connects us all, albeit differently, and foments a renewed sense of solidarity with and ethical responsibility to the study's young people and families for whom the effects of the crisis will be long-lasting.

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Notes

1. <https://coronavirus.jhu.edu/map.html> (accessed 4 February 2021).
2. https://covid19.minsa.gob.pe/sala_situacional.asp (accessed 4 February 2021).
3. The phone survey is pre-piloted and piloted remotely in the four study countries with youth from outside the Young Lives sample who are of the same age and from similar communities as

- their Young Lives counterparts. The pre-pilot gauges the time required to administer the survey; tests the feasibility, sensitivity and strength of specific questions; and informs development of the Computer-Assisted Personal Interviewing (CAPI) programme. Enumerators then pilot the survey to familiarise themselves with the instrument and protocols, re-test questions and conduct a final check of the CAPI programme.
4. Research reciprocity requires researchers to consider what they take from research participants as well as what they offer them in return. Young Lives country teams lead on the reciprocity strategies in their contexts, focusing on fairness and consistency. Reciprocity within research relationships is nevertheless frequently imbalanced and expectations change over time; it is therefore an aspect of research ethics practice that warrants frequent review by longitudinal researchers working with vulnerable populations.
 5. See Mormina et al. (2020). <https://researchsupport.admin.ox.ac.uk/files/guidanceforresearchinresponsetopublichealthorhumanitarianemergenciespdf> (accessed 4 February 2021).
 6. Reflecting this sense of urgency, some journals are using their pre-print servers to publish papers on COVID-19 prior to peer review so that findings are immediately available.
 7. See Rob Davies' 'COVID-19: a defining moment for longitudinal research?' <https://www.closer.ac.uk/news-opinion/blog/covid-19-defining-moment-longitudinal-research/> (accessed 4 February 2021).

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