"Beyond the ToRs": strengthening ethical research partnerships through reflection, recognition, and realism in humanitarian settings

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Brief description of context

This case study reflects on an implementation evaluation of the 'Care and Comfort for Children' (3C) nurturing care intervention in Rwanda (Dec 2020–Apr 2023), conducted under COVID travel bans with remote supervision using weekly calls, monthly reports, and the evaluation dataset.

Implemented by World Vision Rwanda (WVR) with technical support from WV International and academic collaborators, the program aimed to strengthen responsive caregiving and early learning in fragile settings. The intervention achieved positive results, including high caregiver engagement and improved parenting practices. **Caregivers** receiving the high dose & low dose (HD/LD) packages were far more likely to engage in 4+ early learning activities than controls—67.2% and 61.7% vs 36.9% ($p < 0.001$). They also showed higher responsive feeding behaviors—52.2% and 45.0% vs 34.6% in the control ($p = 0.001$). However, the research process revealed important lessons about equity, sustainability, and motivation within research partnerships. **Frontline staff** were trained to monitor fidelity (content, dose, sequence, methods, quality) using dedicated tools for adaptive management. However, uptake was inconsistent due to workload, low pay, and morale concerns linked to anticipated program closure and job insecurity. Many facilitators viewed additional monitoring tasks as outside their core duties. Local mentors demonstrated strong commitment and contextual knowledge, yet their contributions were rarely integrated into the broader research process. Key **duty-bearers** (social affairs staff, police, faith leaders) joined only a few sessions due to heavy workloads and couldn't monitor with project staff, limiting continuity and the sustainability of positive parenting practices in refugee and host communities. These findings highlight a broader challenge in fragile settings: the gap between program success and ethical research partnerships that fully recognize and sustain local knowledge.

Discussion of ethical issues

As a technical lead in early childhood development in FCV contexts, I was engaged in this process and worked closely with both field teams and academic partners. This experience brought into sharp focus the disconnect between institutional expectations and the lived realities of frontline staff. Our study faced ethics risks such as consent under pressure**,** safeguarding/referrals, and data use. Staff were reluctant to report problems for fear of blame; In a context where INGOs/UN are associated with tangible aid (cash, food), a 'soft' parenting intervention prompted disappointment and volunteer moral distress. Remote oversight and self-report increased under/mis-reporting; a design change (two intensity arms planned for mobile populations, then everyone became static) created perceived unfairness. The volunteer-workforce was expected to deliver quality programs, collect data, and engage in reflection, often without the enabling conditions or incentives to do so. At times, this meant encountering situations that created ethical tensions for example, visiting a household where a caregiver was visibly distressed or a child was unwell, yet being required to simply deliver a parenting message and leave. In other instances, staff observed domestic violence or severe stress, but had no clear referral pathways and felt powerless to respond. Staff were also under pressure to complete a set number of household visits per day, even when a caregiver wanted to share her struggles at length. These tensions were compounded by reductions in humanitarian assistance: many refugees expected tangible aid, and when the project could offer only parenting support, staff absorbed the disappointment, deepening moral distress. Such moments heightened awareness of problems that facilitators were powerless to solve, producing what the literature calls moral distress: knowing the right thing to do but being constrained by workload, lack of power, authority, or absence of referral pathways. Uncertainty surrounding project continuation further undermined motivation and long-term engagement, while participation in data collection or mentorship activities felt burdensome when not tied to immediate, tangible value such as compensation, recognition, skill-building, or improved working conditions.

These dilemmas echo what scholars of global health bioethics (e.g., Patricia Kingori, Dorcas Kamuya, and Sassy Molyneux), describe as the “everyday ethics” of frontline work. Frontline workers in global health routinely juggle multiple, competing obligations to institutions, supervisors, and communities often with unclear roles, low pay, and high data demands. Their labour extends beyond technical delivery into invisible and emotional work: comforting distressed caregivers, managing expectations, and translating institutional norms into local realities, all rarely recognized or resourced. They face accountability tensions between “upward” reporting requirements and “downward” responsibilities to families, with institutional metrics are frequently prioritized over ethical practice. When staff use practical workarounds like simplifying consent scripts or collecting only feasible data, it often reflects system constraints rather than individual shortcomings, and signals where processes could be improved. As the literature on moral distress reminds us, ethical partnerships must create enabling conditions: fair remuneration, realistic targets, supportive supervision, safe spaces for reflection, and tools co-designed with staff. Without these, trust in institutions remains fragile, and what appear to be operational challenges are, at their core, questions of fairness and respect for those with the least voice.

At the same time, this case illustrates that ethical research partnerships in humanitarian settings are inherently political. As the Nuffield Council on Bioethics has emphasized in its report on global health emergencies (1), ethics requires more than good protocols; it requires genuine power-sharing in contexts marked by poverty and constrained civic voice. Following the Council’s “ethical compass” of equal respect, fairness, and helping to reduce suffering, duty-bearers including funders, NGOs, and governments must redesign partnerships so that communities and frontline workers have real decision rights, fair compensation, and meaningful control over data use. This implies concrete changes: sharing power and voice through community and frontline co-governance structures with decision rights and grievance mechanisms; ensuring fair work conditions with living wages, protected time, supervision, and opt-out options for extra research tasks; advancing data justice by pre-agreeing on data return, authorship, and benefit-sharing; and strengthening preparedness by naming and resourcing those responsible for ethical practice before and during emergencies (1). Together, these shifts move ethical research beyond compliance to a model that foregrounds equity, accountability, and the lived realities of those most affected.

In this sense, strengthening ethical partnerships is also a decolonising project: it challenges extractive models of research that treat local staff and communities as data sources rather than decision-makers, and instead insists on shared ownership, mutual accountability, and recognition of local expertise.

Conclusions and recommendations

This case highlights the need to rethink how ethical research partnerships are structured in humanitarian settings, particularly how NGOs engage with local staff, authorities, and communities under conditions of uncertainty and scarcity.

Recommendation 1: Align expectations with lived realities

Research design should reflect frontline staff workloads, incentive structures, and employment insecurity. Co-developing tools that are practical, relevant, and easily integrated into daily routines can improve both ownership and implementation quality. In fragile settings, expecting unpaid participation may unintentionally reinforce inequity. Ethical partnerships require not only consent but also enabling conditions that foster sustained engagement. For funders, ensure budget lines for staff time, supervision/coaching, transport/airtime, childcare, and moral-distress supports, are available, including indicators to track the uptake.

Recommendation 2: Reframe community and workforce engagement as empowering

Local staff and volunteers—especially community mobilizers and mentors—play vital roles in program success. Recognizing them as knowledge holders, integrating their insights into learning systems, and ensuring their time is fairly valued can help foster greater equity, trust, and resilience. Implication for NGOs: Poverty shapes how people engage with institutions, time, and trust. Programs that overlook these dynamics risk becoming ineffective or perceived as extractive. By promoting inclusive governance, transparent timelines, and meaningful investment in local capacity, NGO leadership can strengthen both ethical practice and long-term impact. Ethical partnerships are built not only on protocols, but on relationships grounded in respect, shared ownership, and contextual understanding.

Recommendation 3: Anticipate ethics-in-practice and equip the workforce

Identify likely ethical challenges in advance such as consent under pressure, confidentiality, safeguarding, referrals, or data use, and build ethics preparedness: brief, practical training; supportive supervision; and access to moral-distress debriefs/supports, to successfully navigate these aspects of their job.

References

1. Nuffield Council on Bioethics in Research (2020) “Research in global health emergencies: ethical issues” www.nuffieldbioethics.org/publication/research-in-global-health-emergencies-ethical-issues/