

Supporting Southern-led Research: Implications for North–South Research Partnerships

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ABSTRACT

Background: Global health research partnerships are commonly led by Northern investigators who come from resource-rich research environments, while Southern partners participate with a paucity of research skills and resources. This power asymmetry within North–South research partnerships may further exacerbate the unequal distribution of benefits from the research process.

Methods: This study is designed to present the benefits and challenges of engaging in the research process from the perspective of The AIDS Support Organization (TASO), an HIV/AIDS care and treatment organization that has been involved in global health research partnerships. It uses a validated research tool entitled “Is Research Working for You?” to facilitate qualitative interviews surrounding the experienced benefits and challenges in engaging in the research partnerships as described by TASO staff.

Results: Three key themes emerged from the content and thematic analysis: 1) the reported benefits of research (e.g., evidence-based management, advocacy, etc.), 2) the challenges the research committee members face in becoming more involved in the research process (e.g., lack of data analysis skill, lack of inclusion in the research process, etc.), and 3) the institutional ambition at TASO to develop a Southern-led research agenda.

Conclusions: This is one of the few studies to document the development of a Southern-led research agenda in addition to the challenges of engaging in the research process. Mechanisms for moderating power dynamics within North–South partnerships can provide opportunities for improved research capacity and quality.

Key words: Capacity building; research partnerships; neo-colonialism; sustainability; Uganda

La traduction du résumé se trouve à la fin de l'article.

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Global health research typically takes place within the North–South divide,¹⁻³ where the Northern partner is highly trained in research methods and comes from a resource-rich environment, while the Southern partner has a paucity of these skills and resources.⁴ As a result, Southern partners often have little input into the research process (e.g., research design, development of instruments, etc.) and remain dependent on Northern partners to conduct research.⁴⁻¹⁰ Accordingly, many North–South partnerships are criticized for remaining semi-colonial in nature, as the control and benefits of research (e.g., publications, results, research skills, etc.) continue to accrue in the North.^{6,7}

Unfortunately, there are very few successful models of how to develop a mutually beneficial research relationship. One of the few comes from community-based participatory research (CBPR), which is designed to mitigate the challenges inherent in asymmetric research relationships.^{11,12} Although beginning to gain traction,^{13,14} CBPR projects remain uncommon in the context of global health. Another collaborative model that may have relevance to the North–South divide was the development of the Canadian First Nations Information Governance Committee and the principles of Ownership, Control, Access and Possession (OCAP). OCAP principles help Aboriginal people in Canada regain control over research to mitigate neo-colonial aspects of research.¹⁵

Globally, Southern partners continue to ‘host’ research led by Northern researchers, while struggling to build the necessary capacity for Southern-led research.¹⁶ The objective of this study was to

document North–South research collaborations and provide insight into the ongoing benefits and challenges of engaging in the research process from the Southern perspective. These examples demonstrate that opportunities to build research capacity in the South are often present within global research partnerships, but not always optimized.

METHODS

The AIDS Support Organization (TASO) in Uganda was founded in 1987 and since that time has been involved in research with organ-

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izations from Northern countries, including the US Centers for Disease Control,¹⁷ the UK Medical Research Council¹⁸ and many universities. TASO's central mandate is to support people living with HIV/AIDS and their families. Since 2008, however, TASO has been formalizing an internal research structure. It has developed an institutional review board (IRB) at their headquarters, and research committees at each of its 11 countrywide branches. TASO staff interested in supporting research initiatives volunteer for the committees and to date have supported several successful research projects.¹⁹⁻²²

Four TASO branches were selected for this study because of their experience working in North-South research collaborations. A convenience sample of available and interested research committee members was invited to explore how research is conceptualized and utilized in this setting. Written informed consent was obtained. The scientifically validated survey instrument entitled 'Is Research Working for You? A self-assessment tool and discussion guide for health services management and policy organizations,' developed by the Canadian Health Services Research Foundation,²³ and subsequently used by the WHO,²⁴ was administered to all participants. Each section contains 5-15 likert-scale questions measuring organizational research capacity. Nineteen research committee members completed the survey. In addition to providing quantitative measures, the survey is useful for stimulating discussion.²⁵ Therefore, all available survey respondents (n=12) were subsequently interviewed in-depth about research at TASO. Interviewees came from 2 TASO branches and included nurses, doctors, counsellors, information technology personnel, laboratory technicians, and human resource managers. A free attitude interview technique, alternatively called a non-directive controlled depth interview,²⁶ was employed and participants were asked to freely reflect on the survey and how it applied to TASO. All interviews were conducted by a single interviewer (KM) in English, were digitally recorded, and lasted 40 to 60 minutes. The interviews were transcribed verbatim and double-checked against audio recordings, personal identifiers were deleted and QSR NVivo 8 software (Cambridge, MA, 2000) was used to organize data. The preliminary code-book was formed *a priori* based on survey themes and areas of interest identified by TASO. Analysis followed grounded theory to incorporate emergent themes. Narrative accuracy checks with TASO staff and collaborators were used to improve validity. The Research Ethics Boards of Simon Fraser University, the University of British Columbia, the Ugandan Virus Research Institute, and TASO approved this research.

RESULTS

Three key themes emerged concerning research at TASO: the reported benefits of research, the challenges the research committee members face in becoming more involved in research, and the institutional ambition at TASO to develop a Southern-led research agenda.

Benefits of research

The participants described how research increased the credibility of the organization. Respondents valued the process of collecting data to inform their decision-making because, as one respondent explains, "... previously we've had no facts and it's very hard to base decisions on rumours or just estimations." Research supported "an informed point of view," especially in the context of advo-

ating for best practices for HIV/AIDS care. Several respondents said that the Ministry of Health was now interested in the success of TASO's HIV/AIDS prevention programming "...because we told them so out of the research that happened at TASO." This comment referred to outcomes from one of TASO's research partnerships with a Northern organization that evaluated the cost-effectiveness of a home-based program to administer antiretroviral treatment in rural areas. A study was published in a peer-reviewed journal, and TASO protocols were adapted to reflect the findings.

Interviewees also valued presenting research at conferences, as it allowed them to showcase TASO as a top-quality African care provider. Participants voiced the importance for "the world to know what we are doing" in terms of innovative HIV programming and research. Additionally, conferences provided the opportunity to network with researchers and broaden one's own knowledge about HIV/AIDS. In sum, conferences provided a reason to do research.

An important practical benefit of research involved the tangible resources provided by Northern partners. Employment was an important benefit, as one respondent described it, "The trickle down was that of course, that study gave people jobs." Additionally, TASO has developed a policy where research projects contribute to the budget to supply antiretroviral treatment to clients. This tangible benefit was widely appreciated by all respondents because extra treatment slots can be quickly incorporated into the clinical care program and these immediately benefit clients.

Challenges to engaging in the research process

Despite keen interest, there were still significant challenges to fully engaging in research. While data entry is routinely carried out at TASO, staff lacked analytical skills needed for research. Analyzing data remains predominantly under the control of Northern partners. As one respondent describes:

"...sometimes our data gets sent to [Northern researchers]. They do the analysis and then they send us the reports... But we should be able to have the capacity to do that... We need data analysis training as an organization, badly. Because we have so much data that we cannot even analyze."

Having more control over data analysis was perceived as an important mechanism for improving research capacity and ultimately organizational policies.

Every member of the research committee had a full-time job at TASO and volunteered for the committee out of interest. Researchable questions commonly emerge from staff and research committee members (as described below), but lack of resources such as money or allotted time was a common barrier to pursuing research.

Participants also highlighted neo-colonial dynamics within North-South research partnerships that minimized Southern engagement. Interviewees described quasi-exploitative research partnerships where Northerners would establish a project at TASO but employ separate staff on higher salary scales, who operated independently from other branch members. One participant described such a research project: "If you go past certain points you will be questioned. You're not allowed. So somehow we are all in TASO but we are two different people." The participants acknowledged that although the research relationship was designed so the primary role of the branch was to host the study, they wanted the opportunity to be involved in and learn from the ongoing project.

"If they would involve staff in their work then that would enhance staff capacity. Because if you act with them you learn the skills they are doing, but it is not very common. They are very independent. There are certain points where staff have been banned, so somehow the staff are not familiar."

Despite TASO's hosting very complex projects, the research capacity that was transferred to TASO branch or members in these cases was minimal.

Aspiration for Southern-initiated research

"But if we are able, because we have the resources, we have the educated people, we know what it takes... surely, certainly, I want to believe we have the capacity to do it without too much involvement from the Western people."

Interviewees were motivated to go beyond 'hosting' global research projects to designing their own research projects. Many had gained experience working under Northern partnerships and now wanted to apply their research skills to their own initiatives. As described above, participants commonly mentioned the magnitude of data accumulating at TASO and the research committees wanted to use these data. As one committee member stated:

"Some people are interested and they come up and say yes, I would like to find out how many mothers are on ART and have given birth to children, and how their children are progressing. Things like that at the local level."

An important example of research capacity development was the abstract committee. A Northern research partner conducted a workshop for selected TASO staff on how to write scientific abstracts. The attendees quickly understood the utility of this skill and developed an abstract committee to train other TASO staff. Every TASO member (including clients living with HIV) was encouraged to analyze TASO data and submit abstracts to the committee, who would review and provide feedback. Finally, abstracts were approved at headquarters before being submitted to conferences. In this important example, the Northern partner built capacity around abstract writing, while the Southern partner institutionalized mechanisms to diffuse and strengthen this skill throughout the organization.

DISCUSSION

Supporting research capacity building

Despite a keen interest, TASO faces several challenges in developing a Southern-initiated research agenda. One is the neo-colonial dynamics that remain in North-South partnerships where the majority of control and resources still belong to Northern partners.²⁷ TASO has commonly amassed participants for studies, only to have limited subsequent involvement. In some circumstances, TASO staff have even been banned from entering the "partner's" research facilities. This parallels a common neo-colonial pattern of resources being extracted from the South and flowing towards the North to sustain the growth of the Northern economy. In this case, however, the data are collected in the South and analyzed in the North, sustaining the growth of a Northern research infrastructure. This is a challenging dynamic to navigate because many Northern researchers might not independently notice or be bothered by the inherent power imbalance. The limited resources and time extant within TASO to develop research infrastructure exacerbate this imbalance.

The development and success of the abstract committee is an empowering example of Northern partners transferring writing skills and Southern partners capitalizing on one capacity-building workshop to develop their own research agenda. The staff's narratives reveal how the combination of hands-on experience working on Northern-led research projects; having a full, available database; and benefitting from a training session on how to write scientific abstracts sparked TASO's aspiration to create a space where the staff could explore their own research questions and potential. To demonstrate the success of this initiative, TASO submitted 60 abstracts to the International AIDS Society Conference 2010 (held in Vienna, Austria in July 2010); 39 abstracts were accepted as posters or oral presentations, and 15 presenters received scholarships. Many of these abstracts used data derived from partnerships with Northern researchers, but others were written from TASO-driven initiatives and research questions. Through this activity, TASO has developed research capacity to analyze and disseminate research findings, but has also ensured that writing abstracts remains an accessible skill to all interested TASO members, including clients. This has improved institutional control over the research agenda, and the production and dissemination of research at TASO. These results suggest that Southern partners feel that they are capable of initiating research capacity-building activities and do not have to wait for their capacity to be 'built' by the Northern partners.

An empowering demonstration of strengthened research capacity came from the Southern partners deciding to institutionalize research in their organization through the development of research committees, abstract committees and an institutional review board. Northern investigators can ensure that their partnerships capitalize on opportunities to build Southern research capacity by including Southern partners in all aspects of the research process and supporting them in exploring their research interests and developing a unique Southern-led research agenda.

Limitations

The paucity of extant resources to support a purely Southern-initiated research project is largely reflective of and responsible for the neo-colonial dynamics at play within this study. Despite efforts to maximize the participatory and collaborative nature of the work, the Northern lead researcher conducted most of the analysis. However, establishing and maintaining an equitable research partnership was a priority and included negotiating terms of reference for all stages of the research process and continual communication between partners. Finally, we cannot exclude the possibility that participants self-selected into the study and possibly answered questions in a socially desirable way.

CONCLUSION

North-South collaborative research partnerships present benefits and challenges to Southern researchers at TASO. Research projects improve organizational credibility, provide opportunities for research dissemination at conferences and create jobs for local staff. In addition to time constraints and minimal training in data analysis, ongoing neo-colonial dynamics between North and South partners limit opportunities for Southern scientific growth and development. Despite these challenges, this study documents an organization that values research and has institutionalized oppor-

tunities for Southern-initiated research through the key development of an abstract committee. This is a practical example of supporting South-led research that can easily be incorporated into North-South research projects. The meaningful involvement of Southern partners has been documented as an important strategy to inform the development of a research agenda that responds to local needs.²⁸⁻³⁰ Incorporating Southern research capacity building into research project design, from inception to exit, will maximize the integrity of global health research and strengthen the ability of Southern organizations to translate findings into action.

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RÉSUMÉ

Contexte : Les partenariats de recherche mondiaux en santé sont communément dirigés par des chercheurs du Nord issus de milieux de recherche riches en ressources, tandis que les ressources et les compétences en recherche de leurs partenaires du Sud sont beaucoup plus maigres. Cette asymétrie du pouvoir dans les partenariats de recherche Nord-Sud pourrait exacerber la répartition déjà inégale des avantages du processus de recherche.

Méthode : Nous avons voulu présenter les avantages et les difficultés de participer au processus de recherche du point de vue de TASO (The AIDS Support Organization), un organisme de soins et de traitement du VIH et du sida qui intervient dans des partenariats de recherche mondiaux en santé. L'étude utilise un outil de recherche éprouvé (Is Research Working for You?) pour faciliter les entretiens qualitatifs sur les avantages et les difficultés vécus au sein des partenariats de recherche selon le personnel de TASO.

Résultats : Trois grands thèmes émergent de l'analyse du contenu et des thèmes des entretiens : 1) les avantages déclarés de la recherche (gestion fondée sur les preuves, plaidoyer, etc.), 2) les difficultés éprouvées par les membres du comité de recherche pour s'impliquer davantage dans le processus (manque de compétences en analyse de données, inclusion insuffisante dans le processus de recherche, etc.) et 3) l'ambition institutionnelle de TASO d'élaborer une liste de priorités de recherche sous l'égide de ses partenaires du Sud.

Conclusion : Cette étude est l'une des rares à faire état de l'élaboration de priorités de recherche pilotées par le Sud en plus des difficultés de participer au processus de recherche. Des mécanismes pour atténuer la dynamique du pouvoir au sein des partenariats Nord-Sud peuvent être l'occasion d'améliorer à la fois les capacités et la qualité de la recherche.

Mots clés : renforcement des capacités; partenariats de recherche; néocolonialisme; durabilité; Ouganda