Insights on conducting research in low-resource settings: examples from Vietnam and Uganda

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Cite this as: *TBM* 2011;1:299–302
doi: 10.1007/s13142-011-0040-4

ABSTRACT

This commentary describes key observations and strategies, based on the author's experiences in Vietnam and Uganda, for tailoring evidence-based behavioral medicine research in low-resource settings.

KEYWORDS

Low-resource settings, Type 2 diabetes

INTRODUCTION

Conducting research in Asian and African settings provides an array of contextual factors related to culture, language, and globalization that present challenges for researchers, communities, and the populations being studied. My work in Vietnam and Uganda is used to describe insights that I have gained in researching diabetes self-care and in educating health care providers who care for persons with diabetes. Although the studies and activities are tailored to each setting, I will share five key insights common to both settings and suggest strategies to further behavioral research that supports positive health outcomes.

KEY INSIGHTS

Ensure that the research meets local needs and priorities
Ensuring that research meets local needs and priorities requires an assessment step to explore with local partners the specific focus of a project, such as the physical location, the readiness of community participants, and the project's alignment with ongoing research. Individuals in low-resource settings are often over-researched because of (a) the prevalence of a problem, such as high rates of HIV/AIDS in some regions, or (b) linkages to international organizations conducting surveillance studies to document changing patterns of health and disease. One example of a changing pattern of health is the transition from infectious to non-communicable diseases (NCDs) associated with an aging world population.

Although the burden from NCDs is greater than that of infectious diseases in low-income countries [6], competing health priorities from diseases such as HIV/AIDS, SARS, influenza, and malaria remain major causes of death. These competing demands create inequities in care. For example, disproportional resources are used in Uganda for a

Implications

Practice: Communities and researchers need to engage early in mutually respectful partnerships as a means of sustaining the positive health impact of an intervention. Publications should reflect how local partners were involved in identifying research questions, selecting methods, managing resources, and interpreting and disseminating findings.

Policy: Funders of research need to invest in the early development of partnerships in settings that reflect a range of economic development so that innovations can be integrated into health care delivery systems and health policies.

Research: Early recognition of setting-specific health priorities, beliefs, and health system characteristics will help to avoid missteps that can squander precious time and resources when conducting research in a low-resource setting.

few diseases at the cost of other health areas such as maternal child health, NCD, mental health, and unintentional injury and violence. Accordingly, patients may wish they were diagnosed with HIV/AIDS instead of diabetes because of the resources available for HIV/AIDS, but not for diabetes.

Furthermore, in these settings, diabetes is associated with a high burden of disease because of late diagnosis. The diagnosis of diabetes in Uganda is most often done in the emergency department when a person is in a ketoacidotic coma. The majority of study participants in both Vietnam and Uganda reported symptoms such as numbness of fingers and toes and blurred vision, which are indications of neuropathy and retinopathy. The high rates of these symptoms reflect the consequences of late diagnosis and poor metabolic control and the challenge of including participants who already have major complications of disease in community-based intervention studies.

Know the environment

Research participants in low-resource settings are likely to live in conditions of inadequate resources and extreme poverty where access to adequate and

safe food and water is a daily challenge. Travel is time consuming and costly, causing an individual to lose productive work hours. We paid rural Ugandan participants for transportation to our educational meetings, which typically entailed a 30–60 min one-way trip by public minibus. However, some participants lived in remote areas of the district; one participant traveled 4 h each way to attend the meetings.

Residents in low-resource settings are often challenged by disruptive environments with unpredictable circumstances—roads in poor condition, frequent family health crises such as the recurrence of malaria in Uganda, extreme climate conditions such as droughts and flooding, political unrest, and electricity outages occurring daily. During our debriefing meeting with Ugandan study participants, several commented on changing their eating patterns to one meal per day largely because the 7-year drought was leading to scarcity of food. In Vietnam, motorbike travel can be treacherous even in urban areas that experience seasonal flooding, tropical storms, and vehicle-congested roads.

Environmental characteristics have a major impact on research processes and potential risks for researchers. Risks include poorly maintained and unsafe roads, exposure to vector-borne diseases such as malaria, and exposure to unsafe water and sanitation systems. Risk-related environmental exposures are more likely to occur in overcrowded and understaffed clinical settings. While attending rounds at a large referral hospital in Uganda, the attending physician posed differential diagnoses of either advanced HIV/AIDS or Ebola virus. The case proved to be HIV/AIDS, but if it had been Ebola, we all would have been exposed.

Cell phone penetration is nearly universal, and phones have become cheaper. Paying for the calls, however, is another challenge. We could not maintain a pre-paid phone network between peers and health care providers in Uganda, despite the relatively low cost of \$10.00 USD a person per month (and even less when more people join the network). We provided a computer and printer for the clinic, but Internet services were limited and unreliable. A stark contrast between Vietnam and Uganda is Internet connectivity. In Vietnam, a high proportion of the population use the Internet and Wi-Fi, and Internet cafes are widely available at a low cost. One reason for this is the proliferation of pirated software. In contrast, Uganda has relatively low Internet penetration, and connectivity is much less reliable.

Acknowledge that language and literacy issues vary by setting

My Ugandan physician colleague noted that in our first descriptive study of adults with type 2 diabetes, 47% indicated that they had a primary school level of education [2]. He thought that this percentage was inflated because, often, patients are not truthful

about being illiterate for they fear discrimination and exploitation. For example, patients with low literacy may hesitate to acknowledge that they cannot read an informed consent form, even when they are asked to affix their thumb print to indicate understanding [5].

Ugandan primary education is free, but extreme poverty often necessitates that children—girls especially—work instead of attending school. Many families struggle to pay the school fees for uniforms and housing for their own children or relatives. Although the official language is English, most Ugandans are familiar with their tribal spoken language, and in a country with over 50 tribal languages, oral or pictorial messages are more widely used than the written word. However, in an intervention study we conducted in which participants completed a questionnaire, the majority of participants could not read because of poor eyesight and the inability to afford corrective glasses, not because of language barriers.

Vietnamese culture has a strong tradition of valuing education and high literacy rates. Despite north and south differences, Vietnam has a common language, both written and spoken. In research studies, few participants read or speak English, but they are generally literate in Vietnamese. Our Vietnamese physician colleagues reviewed study materials with translators at every phase of the work. Despite this collaboration and high literacy rates, we sometimes had difficulty interpreting the meaning of participants' responses. For example, interpreting the answer “Diabetes is boring” to the question “What is a problem in managing your diabetes?” raises ambiguity. We interpreted this to mean that diabetes involved drudgery of performing daily self-care tasks for the rest of one's life. Paying attention to the words being used and the cultural understanding of what that language means to those being studied can affect the results of the research.

Know features of the health care system

Paternalism is the prevailing global model of doctor–patient and doctor–nurse interactions. Patients generally assume a passive role in their care and can be confused when asked for their informed consent to participate in a study. This approach challenges the role of the physician, who typically tells the patient what to do. It can erode a patient's trust when a physician demonstrates uncertainty in the best treatment and, therefore, wants to experiment with them. Gender inequity is prevalent in these settings, and traditional expectations of a woman's role remains strong, even among women who are highly educated. This can affect the conduct of research because women oftentimes need permission from spouses to engage in interactions with men outside of marriage.

There are well-established institutional and national ethical guidelines for the review and

approval of research on human subjects, yet there is a lack of ethical mandates to provide a minimum level of care, such as ensuring that essential medications for managing diabetes are available and affordable [7]. In low-resource settings, health care systems are not designed to provide ongoing management of NCDs. They are also systems that are underfunded and have severe shortages of appropriately qualified health care workers.

Recognize prevalent health beliefs

In many low-resource settings, disease is a stigma. Having a chronic condition can be construed as something that will cause one to be less productive in work and incur health care costs for the family; therefore, such information should not be shared with others, especially anyone outside of the family. In Vietnam and Uganda, patients with diabetes do not wear medical alert bracelets or identification because they fear being labeled as a person with a serious health problem. Sharing health problems with others could reduce one's chances of marriage by raising anxieties about infertility in a culture where reproduction is expected of a married couple. Also, chronic conditions such as hypertension or diabetes are associated with complications from medications or disease processes that lead to impotence. In many parts of Africa, infertility is a ground for divorce. These beliefs will influence who participates in studies and how honest they may be about sharing their condition with researchers.

STRATEGIES

Develop strong local partnerships

Partnering with ongoing research, training, and evaluation projects in low-resource settings has proven to be a key strategy in successfully seeing projects through from conceptualization to measurement of outcomes. A strong local partnership needs to be built on community trust and mutual respect so that participation is safe and the community is able to actively engage with researchers to discuss their concerns. Partnering requires ongoing work to identify shared interests, build trust, establish rigorous methodology, and yet provide useful research outcomes. A trusting partnership allows for flexibility in ongoing learning while working within systems that may seem messy and within cultures that we know somewhat superficially. We designed our diabetes intervention to complement our Ugandan partners' ongoing research funded by the World Diabetes Federation, to provide training in diabetes management and basic equipment to 20 hospitals throughout the country. In Vietnam, we were invited by the national referral center for endocrine disorders to help address the need to improve diabetes care that was part of the Ministry of Health's plan to address the growing burden of NCD [1].

Match research designs with the setting

When choosing the most appropriate research design, it is critical to match the design with the needs of the setting. Although the randomized clinical trial (RCT) is held as the gold standard of evidence, it may not be the most appropriate study design to use in low-resource settings. Many successful interventions to improve physical activity are so resource intensive for relatively short periods of time that they are not sustainable [3]. In areas of limited resources and great need, the RCT is problematic because it does not address the need for a greater understanding of, and research on, setting-specific contextual factors. More research is needed on applying feasible, effective approaches to NCD self-care and examining metabolic, behavioral, and psychosocial outcomes across communities. Greater attention needs to be paid to documenting the intervention, reach, adoption, implementation, and maintenance [4].

Identify realistic and concrete deliverables

Most funders do not pay for buildings and physical infrastructure. However, this stance is based on assumptions that the most basic of resources, such as shelter, are available. Ugandan community leaders urged our team to “please, leave something concrete behind.”

Case in point—When we first visited the study site, the diabetes clinic consisted of one room, with a wooden bench and an old hospital bed frame to serve as a table, and a roof that leaked profusely. With donated space from the hospital, we used \$2,000 USD to create a diabetes clinic that included an exam room, an office, and lab space. The renovation included a large covered porch where patients could wait and hold group meetings under shelter from sun and rain. Providing space for the diabetes association's monthly educational meetings has encouraged patients with diabetes that efforts are being made to improve their care. Furthermore, we left behind written educational materials that could be taken home, referred to, and even shared with the patient's family and friends. Participants responding to a 30–45-min interview, in both Uganda and Vietnam, expressed gratitude for the opportunity to review what diabetes self-care involved; it made them want more information.

Address sustainability

Most grantors require that investigators address the sustainability of their project after funding has ended. However, research interventions require administrative structures and resources to continue—something that is often not present in health care systems with scarce resources. For example, community health and peer support approaches are criticized when the workers who help carry out these approaches are not compensated in order to sustain the intervention. Peers, like anyone, need

some reward. It need not be monetary. Involvement in research that is viewed as valuable to the community may provide an opportunity to fulfill one's sense of community, especially in sociocentric cultures that are more focused on achieving the collective well-being of its members. Furthermore, if the research has contributed positively to the health of the community, local leaders can influence how evidence can be integrated into health care delivery systems and health policies.

CONCLUSION

As more behavioral research is conducted in low-resource settings worldwide, the need grows for the research process to reflect setting-specific conditions that affect how evidence is gathered and how research outcomes are translated to meet needs of participants. Early recognition of health priorities, beliefs, and health system characteristics unique to communities of interest will help to avoid missteps that can squander precious time and resources.

Developing partnerships is a key strategy. We must question the relevance and sustainability of research conducted by investigators from another country in low-resource settings without evidence of a collaborative partnership in the development of research questions, methods chosen, management of resources, and strategies for the dissemination and implementation of outcomes. Funders need to invest in the early development of partnerships by ensuring that funded studies are conducted in settings that

reflect a range of economic development. Publishers and reviewers can communicate their expectations that authors specifically identify how local partners were involved in identifying research questions, selecting methods, managing resources, and interpreting and disseminating findings. There are no shortcuts, no quick-and-easy ways to develop productive and respectful partnerships. However, the work of partnership development is essential in generating evidence that will translate to improved health outcomes in low-resource settings.

1. Baumann, L. C., Blobner, D., Binh, T. V., & Lan, P. T. (2006). A training program for diabetes care in Vietnam. *The Diabetes Educator*, 32, 189–194.
2. Baumann, L. C., Opio, C. K., Otim, M., Olson, L., & Ellison, S. (2010). Self-care beliefs and behaviors in Ugandan adults with type 2 diabetes. *The Diabetes Educator*, 36, 293–300.
3. Glasgow, R. E., & Emmons, K. M. (2007). How can we increase translation of research into practice? Types of evidence needed. *Annual Review of Public Health*, 28, 413–433.
4. Glasgow, R. E., Lichtenstein, E., & Marcus, A. C. (2003). Why don't we see more translation of health promotion research to practice? Rethinking the efficacy-to-effectiveness transition. *American Journal of Public Health*, 93, 1261–1267.
5. List, J., & Sempeera, H. (2009). Do you trust me? Challenges and methods of trust-building among research participants in Kampala, Uganda. *Global Pulse*, 5(1), 1–4. http://www.globalpulsejournal.com/index_2009.full.html.
6. Narayan, K. M. V., Ali, M. K., & Koplan, J. P. (2010). Global noncommunicable diseases—Where worlds meet. *The New England Journal of Medicine*, 363, 1196–1198.
7. Wendland, C. L. (2008). Research, therapy, and bioethical hegemony: the controversy over perinatal AZT trials in Africa. *African Studies Review*, 51, 1–23.