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Momentum and Longevity for Tribally-Driven Health Equity Science: Evidence from the Gathering for Health Project

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Short Title: Momentum and Longevity for Tribally-Driven Health Equity Science

KEY WORDS: INDIGENOUS KNOWLEDGE, INDIGENOUS METHODOLOGIES, VALUES, CULTURE, INDIGENOUS PEOPLES, DIABETES MELLITUS, TRANSLATIONAL SCIENCE, COMMUNITY-BASED PARTICIPATORY RESEARCH, COMMUNITY-ENGAGED RESEARCH, STRESS PROCESS, HISTORICAL TRAUMA

Abstract

American Indian (AI) health disparities have reached crisis levels, and there is a need to develop culturally congruent interventions through meaningful tribal involvement and ethical community-oriented approaches. Hence, it is imperative that researchers and university administrators better understand how research translation occurs for tribally-driven, health equity research projects. Utilizing thematic analysis methods, we examined documents from a 12-year community-based participatory research partnership called the Gathering for Health Project to elucidate factors that ignite momentum and support partnership longevity. The overarching finding was that trust and respect provide a foundation for momentum and longevity and are closely intertwined with other themes identified in analyses. Seven themes were extrapolated and classified into two domains: 1) investments, which are catalyzing factors that advance research, and 2) intermediate processes, which link investments to success. Investment themes include Indigenous scholar involvement, time and effort, establishing rapport, and clear and appropriate communication. Generative co-learning, active participation, and recognition and celebration were themes classified into the domain of intermediate processes. Community-based participatory research principles were reflected in our findings. This study also upholds prior published work on Indigenous research methodologies, promotes the lived experiences of Indigenous people, and contributes to Indigenous theory building and science.

The widening gap of health disparities between American Indians (AIs) and U.S. races (Best et al. 2018) marks the urgent need to develop culturally congruent interventions (Whitesell et al. 2018; Stanley et al. 2017). Yet, little is known about how to support AI health equity research agendas and community partnerships in improving population health status through successful intervention development (Beans et al. 2019). Moreover, few studies have investigated indicators of longevity among community-engaged research partnerships (Brush et al. 2019). Partnership longevity is important because it may increase the likelihood that prior research findings will be applied to culturally-specific intervention development. Another important consideration within the translational research process is momentum, or acceleration through the translational science pathway, which is necessary for efficiency. This study uses the example of an ongoing 12-year academic-tribal collaboration [the Gathering for Health Project (G4HP)], qualitative methods, and primary documents to identify factors that support partnership longevity and ignite and propel research momentum, thus facilitating research translation. Findings from this study could potentially inform future research strategies and approaches, advance the science of community-based participatory research (CBPR), and contribute to guidance for institutions seeking to support successful academic-tribal research partnerships.

Gathering for Health Project

The G4HP is an ongoing innovative research endeavor with the overall goal of addressing the type 2 diabetes (T2D) epidemic, a problem affecting many tribal communities (Centers for Disease Control and Prevention, 2020). The G4HP partnership began in 2008 when two local Indigenous health and human services providers approached Dr. Melissa Walls, Principal Investigator (PI) from the University of Minnesota, Duluth Campus (UMD). The providers

expressed concern that patients with T2D within their communities exhibited malaise or apathy toward lifestyle changes (e.g., diet, exercise, and self-care), all critical attitudes and behaviors that influence glycemic control (Carlson et al. 2017). These conversations led to a formal academic-tribal research collaboration between reservation-based tribal communities in the Great Lakes region and UMD. Together, this community-engaged research project is referred to as the G4HP and includes three research studies funded by the National Institutes of Health (NIH). The first two of these studies are represented in this manuscript. A common goal across both of these studies was to examine the stress process. The stress process model explains that differential exposure to social stressors (e.g., discrimination and violence) is the underlying mechanism that drives health inequities (Pearlin 1989; Turner 2013). Therefore, understanding and addressing stressor exposures and their interactions with health has implications for multiple health challenges that disproportionately impact Indian Country, including T2D.

Mino Giizhigad

The first of the three G4HP studies, launched in 2009, was a pilot study called *Mino Giizhigad* (meaning “Good day” in the Ojibwe language; MG). This study sought to characterize the impact of mental health on diabetes-related outcomes among AI adults with T2D. The first aim of MG was to create and evaluate sustainable, synergistic partnerships between UMD researchers and two Great Lakes region tribes. The second aim was to utilize a simultaneous mixed-methods design to identify the impact of mental health, substance use, and protective effects on self-care behaviors and well-being among AI patients diagnosed with T2D.

Maawaji’idi-oog Mino ayaawin

The pilot study paved the way for the *Maawaji'idi-oog Mino ayaawin* (or Gathering for Health; G4H) study. Funded in 2012, G4H extended the capacity of MG to include a total of five tribal communities in the Great Lakes region. The broad goal of G4H was to advance the measurement of stress processes for AIs. The first aim of G4H was to adapt conventional social stressor exposure measures and measures related to health promotion and protective effects that are typically used in general population studies (e.g., Diabetes-specific support, adapted from Fitzgerald 1996). This was completed through focus groups and community member feedback. The second and third aims of G4H included use of multiple measures of stress process dimensions (e.g., salivary cortisol, self-reported psychosocial stressors, and symptoms of distress) to investigate the influence of stressor exposures on mental health, disease complication risk factors, and T2D treatment compliance. G4H was innovative because of the extensive community capacity-building that resulted, including the training of community members to collect salivary cortisol samples. The G4H study led to the third study of the G4HP, Together on Diabetes (TOD), a recently launched clinical trial (not included in our analyses).

Methods

Coding and Analyses

To assess for indicators of momentum and longevity, the authors conducted a thematic analysis (Attride-Stirling 2001) using four types of primary documents (1) a detailed written narrative of the G4HP, provided by the PI; (2) the G4H institutional review board application; (3) reflexive written accounts from both authors of this manuscript (Nicholls 2009); and (4) methods sections of previously published literature on the G4HP (Aronson et al. 2016; Aronson, Palombi, and Walls 2016; Aronson et al. 2019; Brockie, Elm, and Walls 2018; Carlson et al. 2017; Coser et al.

2018; Elm 2020; Elm, Walls, and Aronson 2019; Gonzalez et al. 2018; Kading et al. 2015; Ratner et al. 2017; Schultz, Walls, and Grana 2019; Sittner, Greenfield, and Walls 2018; Walls et al. 2017; Walls et al. 2016; Walls et al. 2015; Walls et al. 2014; Walls et al. 2019). The narrative provided by the PI began by describing the relationship-building phase, including discussion of community member concerns (described above) and the conceptual phase of the pilot study. It continued through the application and award for the third study, TOD.

The first step in the analytic process involved each author independently reviewing documents to identify broad patterns in the data, then coming together for discussion. During this stage, the authors discussed the overarching phenomena of trust and respect as foundational to G4HP and agreed that two domains provided structure for organizing themes. In the second phase of analysis, the first author carefully read and re-read the documents (Rice and Ezzy, 1999) for recognition, encoding, and interpretation of the data (Boyatzis, 1998) and engaged in frequent member-checking (Cho and Trent 2006; Lincoln and Guba, 1985) with other research team members (see also the Positionality and Methodology sub-section). Lastly, the authors reflexively and iteratively discussed the expansion and contraction of themes (Charmaz, 2014) until they concluded that two domains and seven themes best reflected the data.

Methodology and Positionality

Aligned with Indigenous methodologies and values which suggest that researchers follow an ethic of transparency (Claw et al. 2018) we as the manuscript authors, introduce ourselves as G4HP research partners and team members. The first author, Elm, is from neighboring tribes in the Great Lakes region (Oneida Nation and Stockbridge-Munsee Band of the Mohicans) with recognizable cultural differences from the tribes that participated in the G4HP; thus, bringing an

insider/outsider approach to the analyses. The second author, Handeland, is from one of the tribal communities participating in the G4HP (Lac du Flambeau Band of Lake Superior Chippewa Indians) and is thus a cultural insider. The authors, bringing with them their relative positions, drew from separate yet complementary knowledge bases (e.g., community-based and academic training), cultural understandings, and experiences to interpret the data and offer unique insight while adding depth and richness to findings (Merriam et al. 2001; Smith 2012). To reduce bias that may have resulted from their positionality, the authors systematically and carefully included perspectives of other research team members through structured member checks (Cho and Trent, 2006; Lincoln and Guba, 1985). For example, a non-Native, pharmacist, and former student researcher on G4HP provided insight and clarification regarding the theme of generative co-learning.

Indigenous values and perspectives freely guided the analytic decision-making processes and contributed to construct development. Whereas, an "outsider" researcher would have applied an alternative worldview and likely constructed different themes, not emerging from Indigenous values (Merriam et al. 2001; Smith 2012). Interpretations of community-specific narratives include nuances and latent underpinnings that are not apparent to outsider researchers. Furthermore, insider positions as researchers provided a form of community protection.

Results

Seven themes were extrapolated and classified these into two broad domains: *investments* and *intermediate processes* (see Figure 1.). The domains were not mutually exclusive and some themes could be reasonably cross-classified into either domain (e.g., establishing rapport). The meta-theme of *trust and respect* cut across both domains and provided a foundation for G4HP,

operating as salient components of investments and necessary precursors for intermediate outcomes. Described throughout the results section are examples of trust and respect (See Figure 1).

Study Approval

Tribal governments approved the G4HP studies through resolutions and letters of support, consultations involving discussion of data ownership, research concepts, and applications for grant submissions to the NIH. Each study site engaged Community Research Councils (CRCs), which proved to be important protective bodies throughout the study. Councils were composed of six to eight local service providers, elders, or adults living with T2D. For the G4H study, the term CRC deliberately replaced the prior classification of “Advisory Boards” to reflect equal partnership (rather than passive advisors) in a mutually beneficial process. Academic researchers and CRCs collaboratively developed all research concepts and methods, project policies and procedures, study materials, and protocols. The CRCs also reviewed and approved empirical manuscripts prior to publication. Additionally, CRC members contributed to knowledge development by co-authoring articles, including this manuscript, and presenting at conferences. Evaluating CRC involvement and shared power involved regular partnership check-ins and biannual, anonymous surveys, to evaluate partnership equity.

Investments

The first of the two domains that we present is investments. We conceptualize investments as inputs, or actions and activities, that operate as catalysts for momentum and interact with the establishment of trust and respect. Investments can also be thought of as the conditions and

dynamics of research partnership formation (Jagosh et al. 2015). Investments advance the progress of the research project toward research translation; in the case of G4HP, from epidemiological and biological data collection to the development and testing of a culturally specific T2D intervention to improve health outcomes. Categorized as investments, were themes of Indigenous scholar involvement, establishing rapport, time and effort, and clear and appropriate communication.

Here we point out that *Indigenous scholar involvement* is a unique type of investment. It is the only type among those presented, which begins long before the conceptualization of any research project. As a member of one of the tribal communities, leading a team of primarily non-Native researchers, Dr. Walls (PI: G4HP) utilized her pre-existing cultural knowledge to honor cultural protocols and navigate political nuances throughout the research process. Particularly in the beginning phases, community members noted the PI's meaningful and equitable openness to collaboration, caring attitude, and good intentions. Dr. Walls' early behaviors and authenticity helped build a strong foundation of respect and trust. This foundational trust and respect led to "proxy trust," whereby the introduction of outside researchers, both Native and non-Native, to CRCs by Dr. Walls conferred trust in those individuals (Jagosh et al. 2015). Here we see how critical elements are linked to move the research process forward; i.e., Indigenous scholar, Dr. Walls' cultural knowledge, connects to her early behaviors, which leads to earned respect, which garners proxy trust, indicating the CRCs' confidence in and respect for Dr. Walls. In the following example, proxy trust allowed for new academic research team members to more seamlessly participate and be more readily accepted by CRCs.

Data revealed that relationship development between new researcher team members and CRCs began with *establishing rapport* as facilitated through proxy trust. The PI highly

encouraged new research partners to attend and participate in a CRC meeting as part of officially joining the team. During introductions which sometimes included formal presentations, new research team members offered personal and professional background information, demonstrated a willingness to work on CRC terms, presented their ideas and goals in a non-aggressive manner, and remained open to questions from CRC members. We found that the introductory process of new researchers led to establishing rapport. Other scholars have similarly noted rapport-building through introduction experiences, stating that acceptance of the new research team member led to beginnings of conversations about research goals (Oakley 2003). Through transactional in-person processes involving inquiry, clarification, and explanation, CRC members began to understand and appreciate the ideas, goals, and proposed research questions of the new researchers. These same personal engagements allowed new research team members to feel heard. Although rapport could have been reasonably classified into either domain, we chose to classify establishing rapport under investments because this process occurred more often as an early action of new researchers, brought on board at various stages across the studies.

To ignite momentum, PI Walls invested substantial amounts of *time and effort*, particularly early in the relationship development phase and at other critical junctures during the G4HP. Dr. Walls demonstrated supportive behaviors and attitudes through early investment of time and effort, which paved the way for her to respectfully facilitate researcher training and group decision-making processes with community members, activities viewed as honorable and community-serving, and all of which contributed to momentum and longevity. Continuing, outside of official research duties, PI, Walls invested significant time and effort by initiating cultural practices and activities (e.g., hosting of feasts, community-level sharing back of research findings). Dr. Walls' investments led to a shift from the "building trust and respect" phase into

the “maintaining trust and respect” phase (See Figure 1.) with deeper community connectedness.

Clear and appropriate communication is another theme we classified as an investment. One CRC team member described *appropriate communication* as the PI delivering “modest or unpretentious communication” that was relatable and reliable, thus significant in building, and later maintaining, trust and respect. Our example of ongoing, clear communication brings us back to the above example of bringing new researchers onto the team. If CRC members were not present at the meeting in which new academic research team members established rapport, an introductory article about each new research partner was included in quarterly newsletters so all CRC members could remain informed. Clarity and regularity of information sharing not only indicated an investment in the process, but it also contributed to building and maintaining momentum.

Intermediate Processes

The second domain we present is intermediate processes, which are built through investments, provide a linkage to distal successful outcomes, and are dependent on a foundational level of trust and respect. Intermediate processes also enhance trust and respect and in turn, increase motivation and stimulate momentum. We classified themes of *generative co-learning*, *active participation*, and *recognition and celebration*, under the domain of intermediate processes.

We illustrate contemporary Indigenous knowledge sharing at a CRC meeting to highlight themes of *generative co-learning* and *active participation*. The authors developed the concept of generative co-learning to refer to an intermediate process that combines shared learning experiences with the Indigenous value and quality of generativity, or the desire and ability to give back to the community through leadership and teaching (Lewis and Allen 2017). While

generative acts were identified throughout the data and among all research partners, they occurred most often and explicitly in the context of co-learning.

Active participation includes meaningful engaged actions and activities which feed momentum. All research team members, including CRC research partners, meaningfully engaged in active participation as a reflection of trust and respect for the partnership and the research itself. Below we present actions and activities that are found less in the literature, those which junior researchers engaged in with community-based research advisors.

During a discussion about a forthcoming publication, a CRC member brought up the issue of the new G4HP student researcher using the term “medication adherence”. The CRC member interjected to bring attention to the harm to AIs that resulted from a history of unethical medical practices and the belief that current health problems among AIs result from historically traumatic events which remain in the memory and bodies of many AIs, including those with T2D. Discussion of current clinical implications of this history followed. For example, lack of trust can negatively impact the patient-provider relationship, leading to low patient motivation to collaboratively develop a T2D care plan, and increased likelihood of forgoing provider advice regarding medication adherence. For the non-Native researchers in the room, this conversation illuminated the effects of historical injustices in tribal communities and brought about new reflections on individual-level pathological blame and reconceptualization of medication adherence for AIs. This informed the interpretation of data, shaped the discussion section of a peer-reviewed manuscript, and will likely help shift attitudes toward AI T2D patients among health care providers. Ultimately, Ratner and colleagues (2017) advised providers to use a patient-centered approach to promote T2D related empowerment, rather than use an authoritarian style approach, particularly when working with patients from communities who have been

harmed by institutions and government systems.

In the above example, by explaining how historically traumatic events led to mistrust, the CRC member demonstrated generative co-learning. The CRC member gave back to his tribal community through leadership and protection. In what exemplifies active participation on behalf of a non-Native researcher, the above description demonstrates active listening, respect for the CRC member's knowledge, and the transfer of the learning experience into writing (see Ratner et al. 2017). The publishing of the article not only reflects the co-learning process but also contributes to generativity, as the CRC member's knowledge is "passed down" to the researcher and practitioner communities. This then reinforces the CRCs member's sense of meaning and purpose regarding participation as a CRC member (Lewis and Allen 2017), all of which contributes to momentum and longevity.

Recognition and celebration of accomplishments is the final theme that was extracted from the data. Recognition and celebration propelled the project forward via motivation. In GFHP, recognition, and celebration occurs for a range of successes from relatively minor individual level successes to highly significant intermediate outcomes that affect the entire research team and all communities involved. The third grant award of G4HP (TOD) was reason to celebrate because it ranked in the second percentile of research study grant proposals reviewed in the Psychosocial Risk and Disease Prevention Study Section in the Fall of 2018.

Our findings indicated that promoters of momentum and longevity include Indigenous scholar involvement, establishing rapport, time and effort, clear and appropriate communication, generative co-learning, active participation, and recognition and celebration. These promoters are classified into domains of (1) investments and (2) intermediate processes which generally contain time-ordered contributions to momentum and longevity, and thus are also precursors to

distal success. While all themes across both domains intersect in some way, this is particularly accurate for the themes that make up the investment domain. For example, in our presentation of findings, the Indigenous PI invested time and effort, engaged in clear and appropriate communication, and facilitated establishing rapport for new researchers.

Discussion

Through the examination of primary documents from an ongoing 12-year, tribally driven health equity research partnership, we report on factors that contribute to momentum and longevity – both useful indicators of success. Findings from our analyses are unique because few studies have directly assessed factors that contribute to the longevity of academic-community partnerships. This is particularly true for tribal collaborations. Indeed, in a recent scoping review, only three tribal CBPR collaborations reported on indicators of longstanding success, with the longest being a nine-year partnership, compared to twelve years in the G4HP (Brush et al., 2019).

The overarching finding that emerged from our research is that trust and respect act as a matrix from which investments and intermediate processes, momentum, and longevity can thrive. As seen in Figure 1., we conceptualized trust and respect as both processes that build over time and are in need of maintenance. Further, trust and respect lay the foundation for a tautology of deepening trust and respect throughout the translational research process. The concept of trust and respect as salient to G4HP, recapitulates Indigenous values and bolsters previous claims from Indigenous researchers that trust and respect as are central components of tribally engaged research (Brockie et al. 2017). Similarly, others have found trust as the leading mechanism that supports partnership sustainability for studies rooted in CBPR methodologies (Jagosh et al.

2015).

For AIs, establishing trust and respect for academic health researchers is complicated by legacies of unethical research practices (Sterling 2011) and historically traumatic events involving U.S. institutions, including abusive medical practices (Hodge 2012). In many tribal communities, mistrust of those who represent institutions remains a complicating factor. Given the historically disruptive and negative interactions of science and medicine with AIs and the situated power with which researchers enter into collaborations with tribal communities, researchers, particularly non-Natives, needed to establish trust and respect through investments. Without this basis, collaborative efforts are unlikely to move forward with much deliberation or at all. Given the unethical medical and scientific context levied against AIs, this layered process is critical to positive interdisciplinary and intercultural collaboration.

Trust and respect undergird the following three examples of critical community protection measures from G4HP that facilitate affirming, empowering, interdisciplinary work with tribal communities (Beans et al. 2019) in advancing health equity research. First, engaging in tribal consultations and acquiring proper approvals before research grant proposals are submitted is essential to working with tribes. The PI of G4HP demonstrated respect for the sovereign status of tribal nations by consulting with tribal governments, presenting research ideas, asking for input, and ensuring that tribal resolutions and letters of support were garnered prior to grant submission. Second, community protection from harm was ensured through the establishment of the CRCs. The CRCs function not merely as advisors but are active research supports who engage in activities such as democratic decision making, research design (e.g., survey instrument adaptations), and provide oversight (e.g., review academic manuscripts prior to publication). CRC's collaboration ensures ongoing shared power over the project. Lastly, the

employment of community members as data collectors contributes to community capacity development through training and other opportunities, which enhances respect and trust (Beans et al. 2019).

Findings from this study are useful for several reasons. First, G4HP will be able to utilize findings to guide a tailored partnership evaluation in future research. Second, our observations can inform other tribal research partnerships. We propose that our observations are likely relevant to other AI health equity research projects. Findings have the potential to inform research strategies and approaches, including the evaluation of community-based research efforts. Third, non-Native academic CBPR partnerships can benefit from our findings. Our proximal indicators of success are unique additions to the literature about how to sustain longevity. Our work contributes to the science of CBPR by augmenting prior findings, including additional considerations for measurement of partnership success (Brush et al. 2019; Duran et al. 2019). This is particularly salient because CBPR methodologies are increasingly being adopted in response to grant requirements (Mercer and Green 2008). Findings offer additional guidance for institutions seeking to support successful academic-tribal research partnerships.

Although our analytical approach did not seek to identify CBPR practices explicitly, we found that several themes identified in this manuscript reflect and reinforce CBPR principles. For example, threaded throughout the data, the theme trust is a recommended metric for evaluating community-engaged research (Eder et al. 2018). In another example, we concluded that co-learning, a common CBPR principle, matched the G4HP process in conjunction with generativity. Co-learning, a CBPR principle involving mutual transfer of expertise between researchers, has been connected to empowerment in the literature (Israel et al. 1998), and we agreed it was an empowering process that contributed to momentum in G4HP (Viswanathan et

al. 2004). Knowledge sharing, through generative co-learning allows for collective “ownership” of the research process and results which contributes to empowerment and activates further momentum.

Our work builds upon the theory of other Indigenous scholars, such as Smith (2012), by reporting specific examples of applied methods, rather than describing the methodology. Our insightful perspective and interpretations benefit Indigenous knowledge building our insider positions as researchers provided a form of community protection in that we have control over the narrative about Indigenous people (Beans et al. 2019).

This study included some limitations and opportunities for future research. We did not explicitly link investments and intermediate processes and outcomes to the ultimate goal of improving community health. However, we provide a basis for future research to include these distal outcomes. Our overall presentation of investments contributing to intermediate processes and outcomes is partially reflective of a logic model, a useful tool for evaluation of CBPR processes. Our model is not comprehensive or ready for use in evaluating CBPR partnership but adds unique dimensions for consideration in evaluation and for improving the science of CBPR. Future work could expand upon this study to complete a logic model framework for prospective evaluation. The authors recognize that some methodological perspectives are in contrast to our analytical approach (e.g., positivism), potentially viewing our work as too biased; yet, we privilege an Indigenous methodological approach and find that it brings a unique richness to the study. Lastly, we recognize the wide historical, cultural, and geographical variation among tribes and that findings from this study may not generalize to other communities.

Perspectives

In closing, we propose that this study reflects the development of *contemporary* Indigenous knowledge. Whereas a significant proportion of research that refers to Indigenous knowledge does so as *traditional* Indigenous knowledge, it is important to emphasize that Indigenous knowledge development is ongoing. Without this clear stance, we risk feeding the stereotype of "living in the past" or "the vanishing Indian." Yet, by asserting ourselves as Indigenous scientists with the capacity to rely on traditional values and knowledge, while developing contemporary Indigenous knowledge, we help to counteract these stereotypes – in both academic and non-academic settings.

Acknowledgments

We thank Dr. Melissa Walls for access to primary documents and assistance in the review process, the CRC members, and other stakeholders in the G4HP. Funding for the *Mino Giizhigad* (“Good day”) study and the *Maawaji’idi-oog Mino ayaawin* (“Gathering for Health”) study came from the National Institutes of Health (NIH), National Institute of Digestive Diabetes and Kidney Disease (NIDDK), grant numbers MH085852 (PI: Melissa Walls) and R01 DK091250 (PI: Melissa Walls), respectively.

Received 13 August 2019; accepted for publication 19 March 2020.

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Figure Captions

Figure 1. Factors contributing to intervention success, health equity, and improved population health.

Figure 1.

