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Fostering Effective Intersectoral Collaborations: Lessons from a Researcher-NGO Partnership to Improve Quality of Life in Children with Epilepsy and Their Parents

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Abstract

Background

Intersectoral collaboration between researchers and community-based organizations (CBOs) is essential for addressing complex social and health issues in pediatric populations. However, practical guidance on building and sustaining these partnerships remains scarce. This study presents an example of a successful partnership between a non-governmental organization (NGO) and academic researchers through the *Making Mindfulness Matter© in Children with Epilepsy (M3-E) Study*, offering practical recommendations for intersectoral researcher-community collaborations.

Methods

A community epilepsy agency approached academic researchers seeking an intervention to support children with epilepsy and their parents in managing stress and emotions. Together, we implemented and evaluated M3©, a mindfulness-based parent and child program designed to improve mental health. The M3-E pilot randomized trial examined the feasibility of interactive online delivery by agency staff to support widespread delivery. After completion of the M3-E trial, 19 stakeholders – including university and community investigators, study coordinators, intervention facilitators, and research assistants – participated in a focus group and online survey to reflect on the collaboration. Using a semi-structured topic guide, participants discussed the benefits and challenges of our community-researcher collaboration and experiences with M3© implementation. Data were analyzed using inductive content analysis.

Results

Four key categories emerged: (1) mutual goals and shared decision-making, emphasizing the need for early and intentional collaboration, and meaningful NGO involvement in research; (2) relationship building, highlighting trust, open communication, and role clarity as essential for partnership success; (3) resource optimization, underscoring the value of leveraging institutional support and diverse expertise; and (4) sustainability, requiring long-term funding, capacity building, and knowledge translation beyond the research phase. While strong partnership enhanced program implementation, systemic barriers, including funding constraints and academic structures that undervalue community-engaged research, posed challenges to equitable collaboration.

Conclusions

Effective researcher-CBO partnerships depend on mutual goals, equitable power dynamics, intentional relationship building, meaningful knowledge exchange, and structural support for long-term

sustainability. We recommend that funding agencies prioritize community engagement in grant applications, institutions adopt inclusive evaluation metrics for collaborative research, and mechanisms be established to sustain evidence-based programs. Strengthening intersectoral collaborations enables researchers and CBOs to co-develop impactful interventions that improve health outcomes in pediatric populations.

Trial Registration:

The M3-E trial was prospectively registered with ClinicalTrials.gov (identifier: NCT04020484) on July 16, 2019. Please note that the results reported in this manuscript are separate from the M3-E trial. They reflect findings from a focus group and survey conducted with stakeholders involved in the collaboration, as part of a quality improvement initiative that took place after the M3-E trial's data collection was completed.

Background

Intersectoral collaboration between researchers and community-based organizations (CBOs) is increasingly recognized as essential for addressing complex social and health issues in pediatric populations. These multifaceted problems require solutions beyond the scope of single sectors, making partnerships that combine diverse expertise critical. The World Health Organization (WHO) defines intersectoral collaboration as "a recognized relationship between many sectors to take action on an issue to achieve health outcomes in a more effective, efficient, or sustainable way than can be achieved singularly".[1] This approach leverages practical, 'on-the-ground' knowledge of CBOs with methodologically multidisciplinary research.[2]

A recent example is the WHO's Intersectoral Global Action Plan on epilepsy and other neurological disorders (IGAP), a ten-year initiative ratified in 2022 by 194 member states. IGAP aims to reduce mortality, morbidity, and stigma associated with neurological conditions through person-centered, intersectoral research and interventions. It emphasizes collaboration across sectors to address social determinants of health to address the needs of individuals living with brain conditions.[3]

The IGAP framework underscores the critical role of CBOs and civil society, including non-profit organizations (NGOs), who operate at the grassroots level engaging in care planning and service delivery. Despite their importance, NGOs are often overlooked or under-compensated in research collaborations. The IGAP advocates for increased engagement and support for these organizations to ensure they can fully participate as equal partners.

While the benefits of intersectoral collaboration are evident, guidance on initiating, developing, and sustaining these partnerships is limited.[4] Most research focuses on clinical-community linkages,[5] reinforcing the biomedical discourse of eradicating disease while rarely addressing the social aspects or

quality of life of people with lived experience.[5–7] Overcoming these challenges requires building capacity, engaging community partners, and developing frameworks that align clinical and community resources with shared health goals.[5,8,9]

The challenges specific to community-researcher partnerships, particularly with NGOs, remain unexplored. Without clear guidelines, the process can be daunting, reducing the likelihood of achieving meaningful and lasting outcomes. This paper presents an example of a successful partnership between a CBO, hereinafter referred to as an NGO, and academic researchers through the *Making Mindfulness Matter in Children with Epilepsy (M3-E)* study.[10] We aim to provide practical recommendations for initiating and developing collaborations between NGOs and researchers, ensuring active involvement of community partners in both the development and implementation of research. These recommendations are intended to accelerate the uptake of evidence-based strategies that improve health and well-being in pediatric populations.

Methods

Formation of Partnership

Our research partnership was formed through intersectoral collaboration between university-based researchers and Epilepsy Southwestern Ontario (ESWO), an NGO dedicated to epilepsy support, education, and community awareness.[11] The team included epidemiologists and a clinical psychologist from Western University, and ESWO staff. The collaboration arose from a grassroots need identified by ESWO: parents of children with epilepsy feel burdened and overwhelmed in their care-giving role. Seeking to address this need, the NGO approached university researchers for assistance.

This partnership built upon an existing relationship from prior collaborations evaluating programs aimed at improving epilepsy knowledge and attitudes of teachers[12], elementary school students[13,14], and adults with epilepsy[15]. Recognizing the value of rigorous program evaluation in gaining policy-maker respect and donor funding, ESWO was eager to continue the partnership. The M3-E study represents our most ambitious collaboration to date. Through this partnership, we conducted a pilot randomized controlled trial (RCT) assessing the feasibility of an 8-week mindfulness program, Making Mindfulness Matter© (M3©), aimed at enhancing quality of life and mental health for children with epilepsy and their families.[10] The study protocol, as well as preliminary results from the trial, have been published elsewhere.[10,16]

Partners in the M3-E trial brought diverse expertise and resources critical to its success. KS, an epidemiologist with longstanding collaboration with the NGO on previous projects, acted as co-principal investigator (Co-PI). She led the grant application and oversaw all aspects of study execution and administration, supervising project coordinators and graduate students who acted as research assistants (RAs). KB, a clinical psychologist and Co-PI, developed the M3© program used in the trial and oversaw its implementation to ensure fidelity and effectiveness. Leveraging her clinical expertise, she

monitored adverse events to prioritize participant safety. She also supervised graduate students who facilitated M3© sessions and acted as RAs and developed the RA data collection manual to ensure accurate and consistent data collection. KP, an epidemiologist and Co-PI, specializes in behavioral interventions in children with chronic conditions and their statistical analyses. He drafted the M3-E trial protocol and led the development of trial design and statistical analyses. The NGO was represented by MS and MF. They had gained the trust of parents and children with epilepsy and had extensive experience delivering community-based programs. They recommended modifications to program delivery (e.g., timing, location, length of sessions) and provided seizure training and safety protocols to ensure a supportive environment for parents and children. MF hired and supervised individuals with prior experience working with children with epilepsy to co-facilitate the intervention. MF facilitated communication with eligible families and partner agencies across the province to aid in recruitment of families. Neurology clinicians and hospital research staff were involved in clinical aspects of the M3-E trial, including patient recruitment, eligibility screening, and providing data on the clinical characteristics of the child's epilepsy. Hospital research staff also managed study coordination, including research ethics, program management, data collection, and administrative tasks.

Study Design

We conducted a focus group collecting feedback from members of the M3-E team on the collaboration. The focus group occurred after completing data collection for the M3-E trial. Those unable to attend were invited to complete an online survey to provide their feedback.

Participant Selection

We invited all stakeholders involved in the M3-E trial to participate in a focus group, using purposive sampling. Stakeholders included ESWO staff, neurology clinicians and research staff from Children's Hospital, London Health Sciences Centre (LHSC) and faculty and graduate students from Western University.

Ethical considerations

Stakeholders were invited via email to participate in the focus group, describing the session's purpose to solicit feedback on the community agency-academic researcher partnership supporting the M3-E trial and capture lessons learned. The email invitation served as an information letter, detailing the voluntary nature of participation, the expected duration, and the procedures to be followed. Implied consent was obtained through voluntary participation in the focus group and survey.

Prior to the focus group, verbal consent was explicitly requested for audio-recording and documenting information on sticky notes. To protect participant privacy while maintaining context, quotes were anonymized by omitting unique identifiers. Instead, speakers' roles within the M3-E study (i.e., university investigator, community investigator, coordinator, facilitator, research assistant) were noted.

Research Team and Reflexivity

Two Co-PIs, KB and KS, led the focus group. They both had prior experience in community-based research, and KB in focus group moderation.

Setting

The focus group was conducted on March 27, 2023, at the office of the community partner, ESWO, with only participants and moderators present.

Data Collection

A respondent-moderator format was employed, with the Co-PIs both facilitating and participating in the discussion. This approach aimed to foster a collaborative environment, reduce moderator bias, and encourage diverse perspectives.

A semi-structured topic guide was developed based on partnership evaluation literature and the Co-PIs' previous experience (Supplement 2). The guide was informed by previous research but not pilot tested.[17–20] The focus group lasted approximately three hours, including a 20-minute break. The moderators opened by introducing the purpose, setting ground rules, and creating a supportive environment for discussion. Participants were then asked to identify aspects of the partnership that they believed "glowed" (i.e., worked well) and those that "needed to grow" (i.e., required improvement) across eight pre-defined domains of the partnership (Table 1). Responses were documented on sticky notes, which were subsequently photographed. The content of these notes was then transcribed for analysis. The session was audio-recorded and transcribed *verbatim*. Select participants reviewed the transcripts for comment and correction.

Participants who did not attend the focus group completed an online questionnaire via Qualtrics software Version: March 2023[21], mirroring the focus group questions (Supplement 3).

Data Analysis

We employed inductive content analysis, aligning with principles of qualitative description suitable when existing research and theories are limited.[22–24] Analysis focused on manifest content, describing surface-level responses using informants' own words.[25]

Following Elo & Kyngäs' framework[26], the analysis involved preparation, organizing, and reporting. In the preparation phase, qualitative data were carefully read to gain a comprehensive understanding of responses. The organizing phase included open coding, creating categories, and abstraction. The abstraction process continued until a reasonable and feasible level of categorization was achieved. In the reporting phase, categories were interpreted to uncover meaningful patterns and insights, with interpretations grounded in participants' responses. Five independent reviewers (KS, KB, KT, MS, AP) analyzed focus group data (i.e., sticky notes, transcripts), while two reviewers (KT, AP) analyzed survey

responses. The coding list was developed during analysis. Coding disagreements were resolved through discussion and consensus.

Focus group and survey results were merged to increase the sample size and gain a more comprehensive understanding of the data, identifying recurring patterns and relationships. Select participants provided feedback on findings to ensure accuracy and alignment with their perspectives. Data were managed using Microsoft Excel software.[27] Findings are reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.[28]

Results

All thirty-seven stakeholders involved in the M3-E trial were invited to participate. The study sample comprised of 19 participants – 12 in the focus group and 7 in the survey. Non-participation was primarily due to scheduling conflicts. Participant characteristics are described in Table 2. Participants included university investigators (UI), community investigators (CI), coordinators (C), group facilitators (FA), research assistants (RA), and those with dual roles as research assistants and facilitators (RF). Facilitators were the most represented role (32% overall). The sample was balanced between research (58%) and community (42%) perspectives.

Table 3 summarizes results from the content analysis, revealing four key categories: mutual goals and shared decision-making, relationship building, resource optimization, and sustainability.

Category 1: Mutual goals and shared decision-making

This category highlights the importance of shared decision-making guided by mutual goals between community agencies and academic researchers. Four sub-categories emerged: shared goals guiding the process, meaningful stakeholder engagement, addressing power dynamics, and guidelines for decision-making.

Shared goals guiding the process

Participants stressed the need to establish a mutual goal at the start of the research process and prioritize this goal throughout. Community agency staff highlighted the importance of aligning the need for the program and clearly communicating project goals to the community. Participants recognized that the partnership's shared goal centered on the well-being of children and families and expressed the belief that the project emanated this goal.

Meaningful Stakeholder Engagement

Meaningful stakeholder engagement was viewed as critical for successful collaborations, including meeting community needs and balancing the interests of academic researchers and community agencies.

Engaging the Community of Interest

Participants stressed the need to ensure that research processes were relevant to families in the study. Researchers noted that attaining the shared goal from the research perspective involved two components: evaluating the feasibility of the intervention by examining the process and evaluating health outcomes for families. Participants acknowledged the challenges families might face due to the complexity of the study:

C: *"I feel like [as a participant] I might have been a quitter… I would have come for the intervention, and I would have been really fatigued by the amount of things that I was being asked to do as a participant."*

Participants suggested involving families earlier in the process, such as through focus groups, to understand their needs before designing and implementing the program.

Engaging the Community Organization

Community representatives noted that shared decision-making, such as curriculum delivery, was most evident in program-related decisions. However, they expressed a desire for greater involvement in research decisions, suggesting that earlier engagement could lead to more tailored interventions:

FA: *"I didn't feel like there were many decisions that I was necessarily involved in apart from some smaller ones related to curriculum..... As a community partner, perhaps there was more that I could have been involved with but wasn't and I think this could potentially be an area for growth... as the organization often knows the client population and their needs very well."*

Community agency staff highlighted the importance of consulting community partners in areas researchers might overlook, such as protocols for managing seizures during sessions, to leverage the organization's expertise. Participants suggested involving community representatives in earlier phases of the research process to enhance stakeholder engagement (e.g., by recruiting families through the community agency rather than only through physicians), noting that involving community partners in decision-making from the outset can lead to more comprehensive and inclusive research processes.

Addressing power dynamics

Balancing power dynamics between researchers and community agencies was identified as crucial. Consistent communication through regular meetings and emails supported sharing of ideas for decision making and balancing power:

RA: *"I felt like I had a voice because we had a lot of meetings to discuss any issues. [The] research coordinator often checked in on me to see if there were any issues too which was really nice*."

Community representatives felt they had equitable representation and inclusivity in meetings. They appreciated it when there were collaborative discussions about roles and updates during weekly meetings, which helped foster a sense of shared power. However, community agency staff noted

frustration when decisions impacting their organization were made unilaterally by researchers, demonstrating a power imbalance (FA: *"Some decisions* [e.g., scheduling M3© intervention sessions] *that directly impacted community agency capacity were made because it worked better for research"*).

Guidelines for decision-making

Participants highlighted the importance of clarifying decision-making processes within the team, specifically when to use consensus or defer to specific expertise. While the research protocol was often deferred to for decision-making, participants from both the research and community perspectives expressed frustration when decisions were not communicated effectively across all team members. UIs acknowledged challenges in balancing consensus and compromise:

UI: *"The goal was a consensus but sometimes that isn't possible, so then there seemed to be more compromise on one side or the other, so [it's] really hard to think about how we're going to manage that process."*

Researchers also noted instances where decisions had to be made without a clear process or manual to refer to, leading to challenges in making informed and consistent decisions. Participants recommended establishing a framework or set of principles at the outset of the partnership to guide decisions and prevent potential conflicts.

Category 2: Communication and Relationship Building

This category emphasizes the importance of communication and relationship building within collaborations, with four sub-categories emerging: consistent and open communication, clear roles and responsibilities, ongoing relationship building, and team building.

Consistent and Open Communication

Regular meetings were identified as a crucial communication tool for maintaining dialogue and cohesiveness. Participants noted that effective communication involved attentiveness to team members' needs. However, some community agency staff felt excluded from broader discussions:

FA: *"In terms of cohesiveness, I felt a bit siloed in the sense that I would have enjoyed hearing a bit more about the broad picture aspects of the program and how the curriculum came to be and why choices were made, etc., from a community partner standpoint."*

Clear Roles and Responsibilities

Clear roles and responsibilities were important to a successful partnership. Facilitators and researchers noted the value of clear communication of one's roles and responsibilities, such as through clear protocols, especially at the program's start. However, as the program progressed, some roles became less defined due to changing circumstances, leading to confusion (CI: "*Lines became blurred sometimes.*

I felt [ESWO] staff didn't know who to take direction from."). When participants were involved in multiple roles throughout the process, their role was less defined:

FA: *I felt that as a community partner, my role was less well defined for me because I wasn't really sure how much I could offer families outside of the program or what I could share with them beyond M3.*"

Participants suggested that outlining roles and responsibilities should be continuously considered throughout the entire process, particularly when unexpected situations occur, to prevent miscommunication.

Ongoing Relationship Building

Participants highlighted the importance of initiating and nurturing partnerships early on (i.e., before the study begins) and continuously evaluating the relationship throughout the process. Community representatives shared that trust was earned through open communication, and principal investigators played an important role in facilitating this open communication, which fostered a safe space for sharing concerns and ideas (RF: "*I felt that I could voice my concerns/opinions to others on the project. I felt that there was trust among other project members and felt that we were acting as a team*"). Having champions on both sides to advocate for their respective perspectives was also noted as critical for building strong relationships.

Team Building

Team-building activities were instrumental in fostering collaboration. Participants appreciated being asked for feedback, which made them feel valued. Support extended beyond the study, with researchers attending community events and celebrations, further strengthening relationships (CI: "*Support of community agency fundraising events shows commitment… it feels like family*"). Social gatherings, such as lunches and celebrations, also helped build camaraderie and improve team dynamics.

Category 3: Optimizing Resources

The third category consisted of statements reflecting the importance of optimizing resources to ensure sustainability of the collaboration. Three key sub-categories emerged: optimizing interdisciplinary expertise, time management, and budget.

Optimizing Interdisciplinary Expertise

Participants noted that interdisciplinary expertise formed the foundation of the collaboration, aiding both funding acquisition and partnership dynamics. A co-principal investigator highlighted how the breadth of experience among team members played a crucial role in securing funding for the trial:

UI: *"We have a wide range of experience on our team, which [the funding agency] really liked 'cause [the M3-E trial] was funded on the first try. They thought we had what we needed to be successful.*"

Optimizing this interdisciplinary expertise throughout the collaboration was crucial and relied on reciprocal knowledge transfer. Researchers gained insights into needs of the target population from the community organization while providing the organization with a contextual understanding of the research process. Education and role-specific training were recognized as critical for building team capacity. One participant in the role of both researcher and facilitator shared a positive perspective on the process of knowledge transfer:

RF: "*I think my training was very thorough. The M3-E staff and researchers were very patient and detailed throughout training sessions. Other researchers and the research coordinator were very helpful when I had questions. Also, the [RA protocol] was extremely helpful.*"

However, some community agency staff expressed that while they valued learning about research, certain aspects felt less relevant to their roles. Despite these challenges, participants across disciplines acknowledged the importance of interdisciplinary expertise in facilitating effective knowledge exchange and collaboration.

Optimizing Time Management

Participants appreciated that meetings were adaptable to the needs of the study (C: "The *team was flexible in having more or less meetings based on study needs and was very respectful of time*"). However, some participants highlighted the challenge of ensuring meetings were relevant to all attendees. To address this, suggestions were made to tailor meetings around specific roles or responsibilities. Others proposed structuring meeting agendas to prioritize topics more relevant to attendees' roles. This approach would help respect participants' time and ensure that discussions remain focused and efficient.

Optimizing Budget

Budget management was another prominent topic, with participants recognizing the importance of making the best use of financial resources. Participants noted their appreciation for the budget's flexibility and alignment with the project's evolving needs. Community investigators shared that while the budget was respected and costs covered by research funding, some administrative tasks were not compensated (CI: *"the budget of ESWO was respected, and any costs were covered with the exception of administrative time"*). As part of the M3© intervention, families were mailed supplies to keep (e.g., books, resource cards, chime for breathing breaks); focus group participants suggested lending materials to families rather than purchasing them for financial efficiency. Participants appreciated that facilitators were compensated fairly and essential resources were provided for families.

Category 4: Sustainability

Sustainability emerged as a critical consideration for collaboration, with two key sub-categories identified: maintaining the partnership beyond research and securing future funding.

Maintaining Partnerships Beyond Research

Participants drew attention to the importance of extending the collaboration beyond the research phase to disseminate the research findings and to implement the program long-term. Participants brainstormed various knowledge translation methods tailored to different audiences, including media and plain language summaries for the public, and information packages for community agencies and stakeholders. The dissemination of findings was identified as necessary to secure future funding to support further collaboration.

Participants stressed the broader implications of sustainability (CI: *"Sustainability is the ability of a community organization to continue providing a useful program without compromising other areas of their services"*). One approach discussed for ensuring the program's sustainability was the *"train the trainer"* (CI) method, in which facilitators are taught not only the program content but also how to effectively teach others the content, enabling them to become trainers themselves and facilitating the widespread dissemination and sustainability of the program beyond the initial research phase. Participants shared that this strategy would enable community organizations to build internal capacity, allowing them to implement and expand the program independently. Ongoing program evaluation was also viewed as essential for maintaining the program's relevance and impact once adopted into the community, with one participant sharing "*consistency in community involvement and quality assurance*" (CI) is crucial for ensuring the program remains sustainable over time.

Securing Future Funding

The need for funding emerged as a primary driver of sustainability. Stakeholders emphasized that the community organization needs financial resources to support program delivery, materials, and staff involvement when the program is implemented in the community. Participants highlighted the importance of identifying suitable funding opportunities and suggested one a community-based grant that is available to spread evidence-based interventions.

Advocacy for funding support for community agencies was deemed critical. Finally, participants highlighted that it would be useful for the research team to help secure funding to encourage the continued success of the program, noting that experience gained from the collaboration through the M3-E study would better equip partners for future grant applications to secure community-agency funding.

Discussion

Our study demonstrates successful collaboration between a NGO and academic researchers, emphasizing the importance of intersectoral collaboration in addressing complex social and health issues in pediatric populations.[6,29] This approach aligns with IGAP objectives to promote equity, diversity, and inclusion by actively engaging NGOs in care planning, service delivery, and research.[3] Based on our findings, we provide the following recommendations for successful researcher-NGO

partnerships: establish mutual goals, address power dynamics, build the relationship, transfer and translate knowledge, and plan for sustainability.

1. **Establish Mutual Goals**

Effective collaboration begins with defining shared goals that prioritize community needs.[2] Researchers and NGOs must align on mutual goals and communicate them clearly to all stakeholders. Regularly revisiting and celebrating this shared purpose fosters commitment and ensures that the research remains community centered. This approach helps leverage each partner's strengths while maintaining a focus on addressing community-defined problems.[30]

2. **Address Power Dynamics**

Structural barriers often limit NGOs' ability to fully participate as equal partners in research collaborations. For example, NGOs often cannot initiate research themselves as they are typically ineligible to apply for peer-reviewed research funding and approval from institutional ethics review boards available to academic and hospital-based researchers. Such structural barriers create power imbalances, with NGOs often participating in research on terms set by the researchers, typically without adequate compensation. Such dynamics hinder truly collaborative partnerships and marginalize the very organizations essential to conducting meaningful community-based research. The IGAP has called for increased support and capacity building for NGOs to address these inequities.[3]

Power imbalances are further exacerbated by differing reward structures.[2,31] Expectations for researchers include success in peer-reviewed activities of securing research grants and publishing findings, whereas the mission of NGO staff is to prioritize immediate community support without incentive to participate in resource-intensive, long-term research projects. With limited budgets and missions focused on front-line work, NGOs often lack staff to manage data or engage in scholarly writing, leading staff to take on any additional research activities with little to no compensation. Meanwhile, career incentives may lead researchers to inadvertently prioritize academic outcomes over advancing the practical insights NGOs bring, further reinforcing imbalances.[2]

The IGAP framework provides guidance to address these challenges, fostering collaborations in which NGOs are key decision-makers rather than peripheral participants.[32] To mitigate power imbalances, researchers must value NGOs' unique contributions to community-based research, provide adequate compensation, ensure inclusive representation in decision-making, and engage champions from both research and community teams to advocate for their own perspectives. Establishing a decision-making framework at the outset—clarifying when consensus is needed and when to defer to domain experts—can prevent conflicts and guide collaboration. Sharing knowledge with NGOs on research processes, including ethical considerations, further empowers them to engage meaningfully. These principles ensure that interventions cocreated by researchers and NGOs are both scientifically rigorous and grounded in the realities of the community.[32]

3. **Build the Relationship**

Trust and intentional relationship building are fundamental to successful collaboration.[33] Initiating collaborations early – before seeking funding or launching projects – allows time for meaningful connections to develop.[34] Sustaining these relationships requires ongoing evaluation, communication, and team-building activities to reinforce trust and morale.[33]

Effective partnerships prioritize open communication, supported by a detailed communication plan with designated contact points, regular meetings, and a receptive environment where team members feel heard. Clearly defined roles prevent misunderstandings, enhance efficiency, and foster cohesion. Providing thorough training and ongoing support ensures that team members understand their roles and responsibilities, while periodically adjusting roles as needed allows teams to adapt to evolving dynamics as the project progresses.[33]

These elements must be integrated seamlessly, with trust forming the foundation for open communication, which in turn supports clarity in roles and enables effective problem solving. Maintaining adaptability and mutual respect ensures that collaborations respond effectively to changing needs. Finally, relationship building is an iterative, evolving process. Even small, consistent actions, such as supporting one another in meetings, events, presentations, and writing, strengthen relationships over time, making sustainability a natural byproduct of successful collaboration.[35]

4. **Knowledge Transfer and Translation**

Knowledge transfer involves two components: exchanging knowledge within the collaboration and translating it to the broader community. Effective partnerships optimize interdisciplinary expertise and prioritize reciprocal co-learning, where researchers and community organizations contribute their knowledge and benefit equally.[33] Researchers provide academic knowledge, whereas community organizations provide practical insights grounded in lived experience. This bidirectional exchange ensures that research is both enriched and relevant to the community's needs.

Sharing knowledge should extend beyond the study's conclusion, empowering NGOs to apply findings in ways that align with their goals. Community partners should play an active role in deciding how data are used, ensuring that use supports their values and those of the community.[2] Researchers, in turn, should present findings to both the NGO and the broader population in accessible, meaningful formats, fostering continued collaboration and maximizing the impact of shared knowledge.

5. **Plan for Sustainability**

Achieving long-term collaborative success requires proactive planning to address challenges to sustainability, such as time commitment, budget cuts, or the end of funding.[36] This includes strengthening community organizations' capacity to sustain initiatives independently by identifying resource needs and securing internal and external support.[37]

Structural barriers, including insufficient funding for long-term program implementation and evaluation, hinder NGOs' ability to sustain or expand evidence-based initiatives. Limited resources for NGOs to conduct and publish research further exacerbate these challenges, making it difficult to build the evidence base needed for future funding. Researchers should actively support NGOs in securing funding and co-developing strategies to ensure the partnership and its initiatives remain sustainable. Regularly evaluating the collaboration's impact and making necessary adjustments are also key to its long-term success.

Strengths and Limitations

This study provides insights into community-researcher partnerships, particularly collaborations between NGOs and academic researchers – an underexplored area in the literature. A major strength was the use of both in-depth focus group discussions and open-ended surveys, capturing diverse stakeholder perspectives. Purposive sampling ensured representation across various roles, and the respondent-moderator format fostered a collaborative environment. Credibility was enhanced through rigorous data analysis by multiple independent reviewers.

However, several limitations should be considered. Focus groups allowed for more in-depth probing and discussion than the survey, potentially leading to richer data from focus group attendees. Selection bias may have arisen due to unaccounted differences between focus group and survey participants. Additionally, findings are specific to one collaboration and may not generalize broadly. Pre-existing relationships between the NGO and researchers, while fostering trust and cohesiveness, may have introduced bias and further limited generalizability.

Considerations for Interpretation and Future Research

Building effective partnerships takes time, and systemic barriers may limit the feasibility of our recommendations. Traditional academic metrics often fail to capture the value of community-engaged work, and research collaborations are sometimes labeled "collaborative" with minimal community involvement. To address these challenges, we recommend:

1. Funding agencies prioritize evidence of genuine collaboration in grant applications, such as by allowing non-academic co-principal investigators, to promote equitable partnerships and enhance the relevance and impact of research.
2. Funding agencies allocate resources for knowledge translation to ensure programming extends beyond the research phase and can inform practice.
3. Academic institutions adopt inclusive, non-traditional methods of evaluating individual and organizational contributions to community-based research.
4. Academic institutions offer a community-based research ethics course for CBOs, funded through the project grant, to equip them with the knowledge necessary to engage in equitable partnerships.

5. Funding agencies establish structured support and targeted long-term funding to empower CBOs in adopting and sustaining evidence-based programs.

While we have made efforts to promote equity, such as including an NGO representative as a co-first author, broader reforms in academia are needed. Progress is ongoing but remains slow within academic structures. Despite its limits, this study provides a foundational exploration of researcher-NGO collaborations, highlighting the need for continued efforts to address systemic barriers and foster impactful partnerships.

Conclusion

Equitable partnerships between NGOs and academic researchers are critical for improving health outcomes, as demonstrated by our collaboration to enhance quality of life for children with epilepsy. Key recommendations include establishing mutual goals, addressing power dynamics, building strong relationships, ensuring knowledge transfer, and planning for sustainability. These principles should be co-developed from the outset – such as through a memorandum of agreement – and adapted throughout, recognizing that collaborations are dynamic and cyclical rather than linear.

Systemic barriers, including funding inequities and power imbalances, must be addressed to foster truly equitable partnerships. WHO's IGAP emphasizes the need for such partnerships, which can be strengthened by providing NGOs with resources, training, and support. By addressing these challenges, researchers and NGOs can co-create evidence-based strategies rooted in the lived experiences of the communities they aim to serve.

Our collaboration addressed a pressing community need and offers insights into building effective research partnerships to help others maximize the impact of similar collaborations. Future research should evaluate models of equitable collaborations, emphasizing long-term sustainability and measurable community impact.

Abbreviations

C: Coordinator

CBO: Community-based organization

CI: Community Investigator

COREQ: Consolidated Criteria for Reporting Qualitative Research

ESWO: Epilepsy Southwestern Ontario

FA: Group Facilitator

IGAP: Intersectoral Global Action Plan on epilepsy and other neurological disorders

M3©: Making Mindfulness Matter©

M3-E: Making Mindfulness Matter© in Children with Epilepsy

NGO: Nongovernmental organization

RA: Research Assistant

RF: Research assistant and Facilitator

RCT: Randomized Controlled Trial

UI: University Investigator

WHO: World Health Organization

Declarations

Ethics approval and consent to participate

This study adhered to the ethical principles outlined in the Declaration of Helsinki. The M3-E study was approved by the Western University Health Sciences Ethics Board (# 113896), registered prospectively with ClinicalTrials.gov (identifier: NCT04020484) on July 16, 2019, and its protocol previously published.[10] In the M3-E trial, informed consent was obtained from parents or legal guardians, and assent was obtained from participating children, in accordance with ethical requirements for research involving minors.

The current project is a separate quality improvement initiative that does not involve patient data or participation of individuals enrolled in the M3-E trial. Given its minimal risk and focus on quality improvement among stakeholders, implied consent was deemed appropriate for both the focus group and survey components. Stakeholders were invited via email to participate in the focus group and survey. The email invitation served as an information letter outlining the voluntary nature of participation, the expected duration, and the procedures to be followed (Supplement 1). The invitation email explicitly indicated that participation Participants were explicitly informed in the invitation email that participation, either by attending the focus group or completing the survey, would be considered as providing consent. Additionally, verbal consent was obtained prior to the focus group discussions for audio-recording and documentation of responses on sticky notes. This consent process was implemented to ensure respect for participants' autonomy while remaining proportionate to the low-risk nature of quality improvement activities aimed at enhancing the collaboration and improving the M3© program.

Consent for publication

No information presented here relates to patient information of participants in the M3-E trial. This study involved stakeholders who conducted the M3-E research whose comments were anonymized, therefore

written consent to publish was not applicable.

Availability of data and material

Since participants from the focus group and survey did not provide written consent for publication, individual-level data supporting findings cannot be made available. However, aggregated results from content analyses that do not compromise participant confidentiality may be available upon reasonable request, subject to ethical considerations.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Funding for the M3-E collaboration was obtained by KS, KB, and KP. All authors contributed to the concept and design of the manuscript. KS and KB moderated the focus group, and KB and AP administered the survey to acquire data. MF provided the setting for the focus group at the ESWO office. KT, AP, KS, KB, and MS analyzed data from the focus group, and KT and AP analyzed data from the survey. All authors contributed to the interpretation of data. KT and MS drafted the manuscript, and all authors contributed to critical revision of the manuscript.

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Tables

Table 1. Domains of Focus Group Questions

Domain	Content
1. Shared Goals	Did the project emanate shared goals?
2. Clarity of roles	Were roles well-defined and carried out effectively?
3. Sharing of power	Did you feel you had a "voice" in the project?
4. Building the relationship	Was there enough communication and cohesion within the team?
5. Sharing of resources	How could the partnership improve on sharing resources?
6. Respect for time	Was time well-used and meetings productive?
7. Building capacity	Did you gain knowledge and expertise in their roles?
8. Sustainability	How do you view the sustainability of the intervention in the community?

Table 2. Characteristics of participants

Characteristics	All (N = 19)	Focus Group (N = 12)	Survey (N = 7)
Role in M3-E	**No. (%)**	**No. (%)**	**No. (%)**
University investigator	2 (10)	2 (17)	0 (0)
Community investigator	2 (10)	2 (17)	0 (0)
Coordinator	3 (16)	3 (25)	0 (0)
Facilitator	6 (32)	3 (25)	3 (43)
Research assistant	3 (16)	1 (8)	2 (29)
Research assistant and facilitator	3 (16)	1 (8)	2 (29)
Profession*			
Researcher	2 (10)	2 (17)	0 (0)
Epidemiologist	1 (5)	1 (8)	0 (0)
Clinical psychologist	1 (5)	1 (8)	0 (0)
ESWO staff	8 (42)	5 (42)	3 (43)
University staff	2 (10)	2 (17)	0 (0)
Hospital staff	1 (5)	1 (8)	0 (0)
Graduate student	6 (32)	2 (17)	4 (57)
Affiliated Institution*			
Western University	10 (53)	6 (50)	4 (57)
Epilepsy Southwestern Ontario	8 (42)	5 (42)	3 (43)
Children’s Hospital, London Health Sciences Center	1 (5)	1 (8)	0 (0)
Children’s Health Research Institute	2 (11)	2 (17)	0 (0)
International Bureau for Epilepsy	1 (5)	1 (8)	0 (0)
Perspective			
Research	11 (58)	7 (58)	4 (57)
Community	8 (42)	5 (42)	3 (43)

*Participants can belong to more than one category.

Table 3. Qualitative coding table from content analysis of focus group and survey data

Category	Sub-categories	Key findings	Illustrative quotes
1. Mutual goals and shared decision-making	Shared goals guiding the process	• Establishing mutual goals early in research process. • Aligning program needs with clearly communicated project goals. • Prioritizing well-being of children and families as a central shared goal.	C: "*The shared goal was front and centre the entire time – improving the lives of families with epilepsy remained the focus. This shared goal was why the partnership with ESWO worked so well.*" RA: *"The RA team, coordinators, and facilitators during the program seemed to always have the wellbeing and health of children and their families as top priority."*
	Meaningful stakeholder engagement	• Balancing interests of researchers and community agencies. • Considering burden on participating families and adapting research processes accordingly. • Involving families and community organizations in research decisions. • Recognizing the need for more community partner involvement in broader research decisions, particularly in areas researchers might overlook.	RA: *"Priorities sometimes differed in terms of prioritizing family interests and the integrity of the research process."* C: *"I feel like [as a participant] I might have been a quitter… I would have come for the intervention, and I would have been really fatigued by the amount of things that I was being asked to do as a participant. I'm trying to imagine myself in that role as a mother of a child with epilepsy. I might have quit."* RA: *"I'm wondering if maybe for future programming…we started with a focus group with families of…what their perceived need would be when implementing a mindfulness program, and then we can consider that at the forefront when both designing and implementing the program as well.…so starting with the community first before implementing the remainder of the research."*

FA: *“I didn't feel like there were many decisions that I was necessarily involved in apart from some smaller ones related to curriculum but that may have been due to my role as an M3 facilitator. As a community partner, perhaps there was more that I could have been involved with but wasn't and I think this could potentially be an area for growth with other organizations as the organization often knows the client population and their needs very well.”*

RA: *“Somebody else suggested the seizure training for our facilitators and then we happened to have a child who had a seizure online and then we needed to come up with a protocol, and I’m thinking, why did we not anticipate that this was a thing, you know?”*

CI*: I think part of that ... was the whole process because I felt from a community side that we were sort of excluded ... The referrals were coming from the physicians, not us ... I understand why that happens but I think that's probably why that piece was missing ... in terms of relationships with our families ... [Could we have been] contacting families that we know struggle with their kids? ... I understand why the research protocols happen and why the recruitment was that way but ... maybe that's a piece that might have helped foster that ... [point] that people are making ..."*

Addressing power dynamics	• Balancing power dynamics through consistent communication and regular meetings. • Fostering a sense of shared power through collaborative discussions. • Acknowledging challenges when decisions impacting community agencies are made unilaterally by researchers.	RA: *"I felt like I had a voice because we had a lot of meetings to discuss any issues. [The] research coordinator often checked in on me to see if there were any issues too which was really nice*." RF: *"It was easy to share power; during the weekly meeting, we would work together to decide the roles of that week's session and provide updates on how families were doing."* FA: *"Some decisions that directly impacted community agency capacity were made because it worked better for research."*
Guidelines for decision making	• Establishing clear decision-making processes. • Balancing adherence to research protocols with inclusive decision-making. • Recognizing the need for a framework or set of principles to guide decisions and pre-empt potential conflicts. • Acknowledging the challenges in achieving consensus and managing compromises.	C: *"Many decisions were governed by the research protocol and came down to principal investigators, but I felt the team always had a voice and could share ideas."* UI: *"The goal was a consensus but sometimes that isn't possible, so then there seemed to be more compromise on one side or the other, so [it's] really hard to think about how we're going to manage that process."* UI: "*ESWO felt that… decisions were being made and had to fit into them…as opposed to co-creating those decisions…and that's something that we could have proactively dealt with at the start before we were*

			into individual situations… We had to keep making these adjustments like 'oh no, now we're going to have to step it up, now we're going to have to have more groups' and so we had all these collisions of decisions being made without really a process in the manual to look that up to see how we're going to make those decisions…Maybe that's something to look into about we have these principles and so we say – we agree at the beginning, we're going to follow these principles so when we get into one of these situations we're going to pull out that list of steps and we're going to work through that."
2. Communication and Relationship Building	Consistent and open communication	• Regular meetings crucial for maintaining dialogue and cohesiveness. • Effective communication involves attentiveness to all team members' needs. ◦ Involving community organizations in broader research discussions to avoid exclusion.	C: "*felt there was good communication plan and important to meet regularly*" FA*: "With the addition of added meetings (pre/middle and end of programs), we did have good communication and cohesiveness."* FA*: "In terms of cohesiveness, I felt a bit siloed in the sense that I would have enjoyed hearing a bit more about the broad picture aspects of the program and how the curriculum came to be and why choices were made, etc., from a community partner standpoint."*
	Clear roles and responsibilities	• Clear communication of roles and responsibilities,	FA: *"As an M3-facilitator, I do think that my role was well-defined and I knew what was expected of me. The training at the onset was very helpful*

		especially at start of collaboration, to prevent miscommunication. • Multiple roles or unclear boundaries can lead to confusion about responsibilities. • Roles and responsibilities should be updated throughout the process as circumstances change.	*and thorough, and the check in/beginning/end of group meetings were all good top ups for my role clarity. I was able to easily carry out this role."* CI: "*Lines became blurred sometimes. Felt [ESWO] staff didn't know who to take direction from.*" FA: *"I felt that as a community partner, my role was less well defined for me because I wasn't really sure how much I could offer families outside of the program or what I could share with them beyond M3."* C: "*Some roles morphed to accommodate circumstances. Would build in contingencies in the future"* C: "*I think because we were also learning while we were going. Some of the roles were undefined because we'd never crossed it before. We'd be in a group and something would happen and it's like, okay I guess that kind of lands on me, but someone's gotta answer right now anyway. I think that it wasn't just that we didn't have defined roles, but things come up. I mean we had no idea what we were going to expect. So I think… that protocol was great, it was always evolving and there would always be… something else with our roles that would have to change surrounding that from looking different*."

	Ongoing relationship building	• Initiating partnerships early and continuously evaluating relationships throughout the process. • Open communication fosters trust and creates a safe space for sharing concerns and ideas. • Having champions on both sides to advocate for their perspectives to build stronger relationships.	CI: *“Building the relationship between the community agency and the research principal investigators has been ongoing for years (prior to the study)”*. C: "*We earned trust through open communication and [principal investigators] fostered safe space*". RF: “*I felt that I could voice my concerns/opinions to others on the project. I felt that there was trust among other project members and felt that we were acting as a team*.” CI: *“A need for champions on both teams”*
	Team building	• Requesting feedback from team members helps them feel valued and engaged. • Team building activities (e.g., celebrations, lunches) strengthen relationships and improve team dynamics.	FA: “*Really appreciated meetings where we were directly asked for feedback.”* CI: “*Support of community agency fundraising events shows commitment… it feels like family*.” UI: “*Pre party, lunches out, post party - were important ways to grow the relationship*.”
3. Optimizing Resources	Optimizing interdisciplinary expertise	• Diverse expertise was crucial for securing funding and facilitating collaboration. • Reciprocal knowledge transfer between researchers and community organizations was valuable.	UI: *“We have a wide range of experience on our time, which [the funding agency] really liked ‘cause [the M3-E trial] was funded on the first try. They thought we had what we needed to be successful.”* C: “*M3 training was superb and gave me a better*

	• Role-specific training and education important for building team capacity. • Interdisciplinary learning may need to be tailored to specific roles.	*appreciation of ESWO's functioning during the study"* RF: *"I think my training was very thorough. The M3-E staff and researchers were very patient and detailed throughout training sessions. Other researchers and the research coordinator were very helpful when I had questions. Also, the* [RA protocol] *was extremely helpful."* CI: *"I learned a lot about the research side, but a lot was over my head and not related to my role."*
Time management	• Flexible meeting schedules were appreciated and adapted to study needs. • Challenges arose in ensuring meeting relevance for all attendees. • Suggestions included tailoring meetings to specific roles and structuring agendas to prioritize relevant topics.	C: "*The team was flexible in having more or less meetings based on study needs and was very respectful of time*." FA: "*Sometimes tricky to juggle what topics were relevant to which meetings"* UI: *"With our agenda, we could put the things that are most prominent for your role first*"
Optimizing Budget	• Budget flexibility and alignment with evolving project needs were valued. • Some administrative tasks for community organization went uncompensated. • Important to make best use of financial resources.	C: *"The budget from [the funding agency] was healthy; resources were reallocated as the protocol shifted."* CI: *"The budget of ESWO was respected, and any costs were covered with the exception of administrative time."*

		• Fair compensation for facilitators and providing resources for families emphasized as important.	FA: *“Maybe loan out parent/family kits rather than purchase.”* FA: *“Important to pay facilitators, great to get kits for parents and children*.”
4. Sustainability	Maintaining partnership beyond research	• Extending collaboration beyond initial research phase is crucial for long-term success. • Effective dissemination of research findings and program to support long-term sustainability. • Building capacity within the community is essential for enabling ongoing program delivery. • Consistency of researchers in community involvement and quality assurance are important factors for sustainability.	CI*: “Media to share results with the community. People in our work don’t go to publications to decide how to run a program. So we have to look at it a bit different for knowledge translation.”* RA*: “I think even a modification of that… investigator update that we did with just the most pertinent results – that might be the most relevant to families.”* CI: *“And when we did* [past collaboration] *we went to all our agencies to show them the whole program. So everyone knows these programs exist because we presented them to everybody.”* C*: We do that in other partnerships. Like a plain language summary.* UI: *And then also using… these information packages not just to the agencies but to the funders…Like peddling this around to politicians and who might actually see this as a win for them.”* C*: I think it depends on what is the goal of how you want to disseminate [the program]. If you want to go far like across country through all the pediatric*

		centres and work with the agencies in Ontario and beyond then you're looking at something that is...a licensed curriculum that's available in maybe even recorded sessions at the of diagnosis – how to cope with the extra stress. But if you want to just keep it more central and personable then you're looking at something that's got more depth and can be owned by a community partner. So yeah, it kind of depends on the goal. CI: *"Sustainability is the ability of a community organization to continue providing a useful program without compromising other areas of their services."* CI: *"'Train the trainer'* is *instrumental in program spread."* CI: "C*onsistency in community involvement and quality assurance*"
Securing future funding	• Securing future funding is critical for long-term success of the program. • Organizations need financial resources to cover costs of program delivery. • Targeted funding and advocacy for community agencies are key facilitators for sustainability. • Experience gained from current project better equips partners for future grant applications for	FA: "*Organizations need to be able to pay for the cost of the materials in the kit and for the delivery of it, as well as the cost of their staff to be involved. Giving curriculum and advertising materials to the agency and helping them to advertise the program could also be helpful in sustaining the program."* CI: *"There is going to be… grants and we could apply for those and have it broader than our agency…They're community-based grants to spread programs that are*

	community-agency funding.	*evidence-based, which is exactly what this is."* CI: *"A key facilitator for sustainability will be targeted funding to community agencies. We need to advocate."* *CI: "So we work on the first [project] grant together. We need a template with the research behind the need, the process, the benefits, the expected outcomes and then if you [researchers] could help us identify some funding partners?"* UI: *"Now better equipped for next grant application to build in community agency-specific support"*

Abbreviations: C, Coordinator; CI, Community Investigator; ESWO, Epilepsy Southwestern Ontario; FA, Group Facilitator; M3©, Making Mindfulness Matter©; M3-E, Making Mindfulness Matter© in Children with Epilepsy; RA, Research Assistant; RF, Research Assistant and Facilitator; UI, University Investigator

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Supplement2InterviewGuide.pdf
- Supplement3PartnershipQuestionnaire.docx