Community Engagement in Public Health Research

Presented by Claire LeBovidge

in partial fulfillment of the requirements for completion of the
Evidence and Inquiry certificate and the
Polymathic Scholars honors program in the College of Natural Sciences at
The University of Texas at Austin

Spring 2020

Nina Palmo, Ph.D.
Thesis Supervisor
Department of Sociology
The University of Texas at Austin

Date

Rebecca A. Wilcox, Ph.D.
Second Reader
CNS Honors
The University of Texas at Austin

Date

Table of Contents

Acknowledgements

I would like to first thank my thesis advisor, Dr. Nina Palmo, for her guidance and expertise throughout my thesis writing process. Dr. Palmo continually pushed me to get my ideas on paper and to look at varying perspectives within the sociology and anthropology disciplines. Thank you for introducing me to *The Spirit Catches You and You Fall Down*, as well! That book, while sad to read, was incredibly insightful and important to recognize. I would also like to thank Dr. Rebecca Wilcox who dedicates so much of herself to the honors programs and her students. There were many times she was still on campus at 8pm working, while we studied down the hall in Painter. This program would truly not be the same without her. Dr. Wilcox broke down a monumental task into something that was truly a growing experience. Recognition also goes to Madison Searle, Director of CNS Honors, who has been there every step of the way since my very first time on campus during summer orientation. Thank you, Madison, for always being a sounding board when I was unsure of my future path. Lastly, I want to thank my sister Elise. She was a Polymath two years my senior, and I could not have written this thesis without her. She has had confidence in me when I have doubted myself, and this has spanned probably my entire life. Thank you, Elise, for seeing in me what I sometimes struggle to see myself and pushing me to break every barrier.

Abstract

Community engagement (CE) is a collaborative practice between communities and researchers to improve the health outcomes and well-being of the community afflicted, while also potentially mitigating the negative consequences that result from the sometimes haphazard research conducted by outsiders. Presently, there is confusion regarding community engagement techniques due to discrepancies between prescribed models. To address the confusion surrounding community engagement, I created a consistent model that compounds current effective methods with ethical considerations for application across varying cultural and research contexts. I use a literature review to assess the different existing frameworks of community engagement for their advantages and disadvantages in public health research. Using this information, I constructed the new model with 5 major tenets including: prior understanding of community, encompassing application, involvement and representation, genuine consent, and self-reflection. This CE model is applied to a well-known case study involving a young Hmong girl, Lia Lee, who is caught in the crossfire of two conflicting cultures and their understanding of medicine. This analysis suggests that if the new CE model was properly employed, the frustration and pain in both the Hmong community, as well as the doctors treating Lia, may have been mitigated. While past health interventions cannot be changed, the way researchers conduct public health measures in the future can be adapted to implement community engagement as the default approach, instead.

Introduction

In public health, outsider research is considered research that is conducted by members who do not belong to the community under study (Bridges, 2001). The field of public health arose within the context of imperialization and colonization, and outsider research is inextricably linked with this background (Reynolds & Sariola, 2018). Research is an elitist field because it requires immense funding and resources that are only accessible to countries of higher income and status. These implications of public health research skew the results of the research because of the lack of diversity and representation in the demography. Since outsider research sits in this tension, there are potential negative consequences for the communities implicated in the studies including, but not limited to, exploitation, discrimination, and disempowerment. Some opponents to outsider research state that investigators can never fully understand the community under study, and therefore should not conduct research in these populations. However, holding such an individualistic outlook can be dangerous, because this mindset creates a lack of empathy and shared humanity (Bridges, 2001).

The negative connotations surrounding outsider research are largely formed due to unethical research practices that disempower the local communities, however, this can be acknowledged and addressed through community engagement approaches to research. Community engagement is the collaboration and shared leadership between researchers and the community members to design and implement public health measures. While this is the intention, poorly outlined community engagement approaches can skew power dynamics, tokenize and further marginalize minorities, and be used to solely increase the buy-in for participants in research studies. If executed thoughtfully, however, community engagement can serve to empower populations, provide representation to vulnerable perspectives, and improve the understanding and participation in research studies (Reynolds & Sariola, 2018). Community engagement shifts outsider research by minimizing the distinction between the research team and the community and the power that comes along with this distinction – instead the community is a part of the research team. Although this shift in outsider research would be productive, the ethical implications and fundamental principles that make up community engagement guidelines remain ambivalent in their acceptance and use in public health.

Public health professionals acknowledge the importance of community engagement in research through increased regulations regarding research ethics, but there is no cohesive framework – everything seems to be superficially discussed (Lavery *et al.*, 2010). Part of this ambiguity in guidelines arises from the diversity of cultures and the complexity that comes with these differences. This diversity makes it harder to create a single model for community engagement, as the model needs to be adaptable to a variety of cultural environments and contexts. Regardless of the complexity of research, ethics and integrity are demanded in public health measures, so it is crucial to establish a widely accepted approach to carryout global health and outsider research.

In current models of public health research, whether community-engaged or not, protection against exploitation is loosely defined and understood. This calls for an approach that is medically ethical, where all parties involved have their costs and benefits weighted to ensure that the vulnerable population receives a larger share of the benefits, preventing the possibility of exploitation (Gbadegesin & Wendler, 2006). Arguably, outsider research should never fully be "outsider" research. Rather, there should be deliberate and comprehensive involvement from the communities to ensure the research study is ethical; an example of this engagement can be observed in a Canadian research effort with the Aboriginal community that is discussed later in this thesis (Boffa *et al*., 2011).

To understand the ethics involved in community engagement, King *et al.* (2014) describes the human infrastructure and the three core responsibilities that consolidate the ethical goals behind community engagement, which are 1) identifying and addressing nuanced risks, 2) extending respect to communities, and 3) strengthening the legitimacy of the research. The human infrastructure is the "web of relationships between researchers and the stakeholder community" (King *et al.*, 2014, p.1), and this infrastructure mitigates the injustices that outsider research creates, including exploitation and disempowerment of communities, by promoting researchers to employ the three core ethical responsibilities (King *et al.,* 2014).

The first core responsibility of researchers is to identify and address risks that may not be blatantly apparent to themselves, or even the participants of the study. Researchers typically outline risks when seeking approval for any study, but there are risks that may not be accessible to the researchers, and these non-obvious risks should be acknowledged and addressed in the study. The second core responsibility of researchers is to extend "respect beyond the individual to the stakeholder community" (King *et al.*, 2014, p.2). Community engagement in public health research shifts researchers' mindsets from the individual participant to the entire affected community. By understanding what is important to the community and listening to their concerns and hopes, the outsider researchers create a sense of trust and respect that is pervasive throughout the community. The final core responsibility focuses on strengthening the legitimacy of the public health measure. King *et al.* defines legitimacy as "the political concern about the justification of authority over groups of people" (King *et al.,* 2014, p. 3).

Ensuring that the research project is legitimate in its claims and processes is important, especially in public health research, because these interventions can impact the lives of others and the communities' well-being in general. The human infrastructure builds legitimacy in research projects because the connection between researchers and stakeholders stems from this network – the lack of a solid human infrastructure in the context of the project prevents researchers and stakeholders from discussing the study in a productive manner. Legitimacy can be reinforced both formally and informally between researchers and invested stakeholders, including participants. Researchers and participants can openly discuss and deliberate aspects of the given study to air grievances or highlight interests that may arise throughout a public health measure, which advances the project's legitimacy for both parties. When executed effectively, community engagement upholds these three core responsibilities and fortifies the human infrastructure to create a more ethical approach to outsider research than compared to other methods.

Ethical considerations are important to discuss because outsider research and public health measures can be ineffective, exploitative, and disempowering to the communities under study (Bridges, 2001). Implementing community engagement practices as an approach to conducting outsider research can serve to alleviate these consequences. The lack of consensus regarding community engagement models, however, reduces the use of these approaches and increases the distrust surrounding outsider research. Therefore, this thesis aims to provide a consistent model that compounds current effective community engagement methods with appropriate ethical considerations for use across varying cultural and research contexts. I then applied this novel community engagement model to a popular case study that demonstrates the struggles a Hmong girl and her American doctors face when there is no determined framework to conduct outsider health measures.

Community Engagement Research: A solution to outsider research

Community engagement reduces the ethical repercussions that are associated with outsider research including diminishing exploitation and ensuring a community's rights are upheld (Wrigley & Dawson, 2016). Public health measures conducted using a community engagement approach improve the community's knowledge and awareness surrounding the study and the intervention while also informing the researchers about the communities' needs and priorities, and how to address these communal values in a culturally proficient way (Ahmed & Palermo, 2010). A successful case study of community engagement in the Aboriginal community in Canada emphasizes outsider public health research's harm, but more importantly, how these negative consequences are mitigated through the use of community engagement (Boffa *et al.*, 2011).

In Canada, there is a longstanding distrust for Canadian researchers in the Aboriginal population – even the word research has negative connotations for the community. A Canadian federally funded project, the Determinants of TB Transmission (DTT), studied the factors contributing to the higher disparate spread of TB in Aboriginal populations compared to non-Aboriginal populations using a community engagement approach. The first step of the DTT project sought to include Aboriginal researchers on the research team and establish Provincial Network Committees (PNCs) to promote widespread collaboration. The PNC model allowed Elders, Aboriginal and non-Aboriginal researchers, the federal government, and community members to collaborate beyond the traditional researcher-participant paradigm. PNCs were not merely consultants, instead, these committees served on the frontline of the project to develop questions and solutions pertinent to the research. The dissemination of the research protocols and findings were translated and discussed over the Aboriginal radio stations, as well as being presented to all major Aboriginal organizations. Ultimately, the intense and thorough effort to ensure the First Nation communities were equal partners throughout DTT, resulted in a more effective and positive experience for both researchers and community participants.

Boffa *et al.* noted that the communication protocol developed in the DTT project was a powerful strength to the overall initiative. The protocol was created by a member of the Aboriginal community and specifically focused on "Aboriginal forms of conflict resolution" and further "integrated the Aboriginal participants' and researchers' reality within the research process" (Boffa *et al.*, 2011, p. 735). This protocol was supplemented with trainings for non-Aboriginal researchers to better understand the Aboriginal community and culture, including their ethics and "ways of knowing" (Boffa *et al.*, 2011, p. 735). Throughout the study, the PNCs held forums and sweat lodge ceremonies (an Aboriginal practice intended to purify the mind, body, and soul) for the community members and non-community members to bond and learn more about each other's cultures and rebuild trust. By integrating the Aboriginal way of life into every stage of the process, including interviews that took place in either a clinical setting or homes within the community, researchers created a sense of familiarity and comfortability for the DTT study. The steps taken to promote equal and ethical collaboration between Aboriginal and non-Aboriginal members in the DTT study proved successful because the Aboriginal support for the project was strong and lasting. Moreover, every single First Nation community agreed to take part in the study which was unprecedented, given the history of distrust and animosity toward research (Boffa *et al.*, 2011).

Despite the successes of the Canadian DTT example that reflect the positive outcomes of applied community engagement, inconsistencies and barriers still remain that prevent the widespread use of community engagement. In Western society, specifically ones that uphold a capitalistic mindset, such as the US, cost and time are quite possibly the largest consideration when designing and executing experiments and public health initiatives. The breadth of community engagement research demands a larger amount of funding and time to be performed successfully and to the fullest extent (Boffa *et al.*, 2011). While the costs of community engagement research are higher, the outcomes and long-term sustainability of these research projects are stronger and more reliable. Utilizing social and technological knowledge to better understand the context of a public health issue can, as Mosavel *et al.* argues, increase the likelihood that any intervention is successful. (Mosavel et al., 2005). Community engagement models improve the relationships between community members and investigators, which is necessary to create competent intervention and treatment options, increasing the likelihood that the interventions work as proposed (Reynolds & Sariola, 2018).

Inconsistent Terminology

The inconsistent terminology regarding community engagement is the first issue that should be addressed. The National Institute of Health proposed the *Principles of Community Engagement*, which breaks down the term “community” into four different perspectives, including the systems, social, virtual, and individual perspectives (Clinical and Translational Science Awards Consortium, 2011). The systems perspective of a community refers to the varying institutions in a society that all work together to improve the welfare of the population. The social perspective of a community looks more at the personal connections and networks within a community. This perspective becomes particularly important when discussing community engagement practices that deal with disseminating information and support. Communities can also be defined through a virtual perspective. With the advancement of technology, people can connect with one another past geographic barriers. There are communities that exist over the internet who influence and connect with one another, which must be taken into account when trying to define what a community is. The final perspective presented was the individual one. Communities are, of course, a group dynamic, but each individual person has their own perspective of what their community is and with which community they identify. This perspective becomes intertwined with community engagement because outsider researchers may identify the community differently than the individuals that make up this community, which could result in harmful or ineffective solutions (Clinical and Translational Science Awards Consortium, 2011). Each perspective must be taken into consideration within the context of any research study. Furthermore, these perspectives should be used to reach a collective agreement regarding terminology and parameters, so that those involved with the study can be on the same page.

The second term that needs to be explored is community engagement. There are different types of community engagement practices, and this term serves as an umbrella for other community-based research practices. *Principles of Community Engagement* defines community engagement as, "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people" (Centers for Disease Control and Prevention [CDC], 1997, p. 9). When considering community engagement, community involvement is a core principle. There is a spectrum of involvement in every community that ranges between: outreach, consultation, involvement, collaboration, and shared leadership. As you move along this spectrum, the amount of community involvement increases at each level. Each portion of the spectrum has advantages and disadvantages, but oftentimes research projects will only enact superficial levels of involvement that meet the minimum requirements of the regulations to “involve” participants. Community engagement that is done properly, will include all aspects of community involvement to a significant degree.

Other sources, including the Bill and Melinda Gates Foundation, define community engagement differently. Tindana *et al.,* supported by the Gates Foundation, outlines community engagement as research that “goes beyond community participation; it is the process of working collaboratively with relevant partners who share common goals and interests” (Tindana et al., 2007, p.1452). Both sources have similarities in their definitions, but there are nuanced differences that create barriers when establishing a public health project. The latter definition of community engagement stresses the idea that participation is not the sole factor of community engagement, but the definition does not specify how the common goals and interests of participants presents itself. A more comprehensive definition for an effective community engagement protocol will include involvement techniques that are present at every place on the spectrum, as outlined by the NIH, including shared leadership, which is often the most difficult level to reach in public health applications.

The lack of consistent terminology creates confusion when designing a study, but it also increases the difficulty of reviewing and approving public health initiatives. There is no standardized approval process for research projects that employ community engagement practices, which creates a negative feedback loop that maintains the status quo of using research techniques that do not meet community engagement standards. Institutional review boards (IRBs) are fundamental to research ethics. Members of IRBs, however, are not usually trained or even aware of community engagement as a practice (Brown *et al.* 2008). Researchers and reviewers being unaware of community engagement approaches creates a negative feedback loop for studies that do, in fact, try to employ a community engagement approach. Lack of education over this type of methodology for peer-reviewers usually results in the rejection of the study, and this leads researchers to use other methods that will more likely be approved. Therefore, investigators often avoid community engagement approaches to prevent their studies from being rejected. Unfortunately, this leads to a lapse in knowledge and familiarity of CE for peer reviewers, which results in the reduction of accepted proposals. Now having come full circle, researchers fear that their project will not get approved in the first place, and the cycle continues (Ahmed & Palermo, 2010).

Various Types of Community Engagement

Of the many forms and approaches that fall under the umbrella of community engagement, two stand out in particular: community-based participatory research (CBPR) and participatory action research (PAR). CBPR is an action-based approach to epidemiological research that goes beyond external applications of research, but moreso to improve the health of the community currently being impacted (Burke *et al.,* 2013). A main tenet of CBPR is to ensure that the community – however it may be defined – is at the core of the research (Brown *et al*., 2008). Community-based participatory research has political implications, however, which can be beneficial or detrimental to the community at hand depending on the political context. From a Western standpoint, it may seem helpful to have community organizations and leaders fighting for policy change which is crucial for long-term implementation of any public health measure (Freduenberg & Tsui, 2014). Conversely, Molyneux *et al.* highlights the idea of stigmatization and ostracization with certain health afflictions that makes it harder or dangerous for governmental and political changes (Molyneux *et al.,* 2016).

For example, in Sub-Saharan African studies involving men who have sex with men (MSM) communities, investigators must be weary of the social climate to avoid dangerous situations. MSM communities are ostracized in the general population, so if researchers take a rights-based approach to community engagement this could result in political conflicts and difficulties for the MSM community and the researchers, as well (Molyneux *et al.,* 2016). A rights-based approach to community engagement aims to change the policies and the societal perspective on the target health issue. In the prior example, HIV/AIDS presents as a large health disparity between MSM and other populations in Sub-Saharan Africa. However, because homosexuality is typically condemned, conversations and political changes at a governmental level could be beyond the reach of outsider investigators and possibly lead to civil strife. For this reason, any community engagement model applied must clearly state and communicate the goals of the public health measure to avoid overstepping and losing sight of the original purpose, and thus ensuring the trust of the community.

Compared to CBPR, Participatory Action Research (PAR) is a rights-based approach to community engagement, which can be tricky to implement as stated by Molyneux *et al.* (2016). PAR's are implemented specifically in studies that aim to alleviate health inequities in vulnerable and oppressed populations. The ethical understanding of PAR is necessary to address because this form of research can have political repercussions that undermine the initial goal of improving the overall health of the community (Khanlou & Peter, 2005). This potential to overstep reinforces the conflict surrounding ostracized communities in public health that was mentioned by Molyneux *et al.* (2016) regarding the MSM community study. Underserved and underrepresented communities often appear to be “involved” in outsider studies because a researcher checks a box stating they were appropriately informed, and thus consented to the study and its consequences. Whereas, PAR goes beyond this surface level of consent to ensure that communities have proper autonomy and inclusivity in the process, implementation, and results of any study conducted.

Delving into the concept of informed consent is critical in PAR because the distinction between researcher and participant becomes blurry (Khanlou & Peter, 2005). In PAR, local populations are intended to have as much power and autonomy as the investigators – they essentially become a portion of the research team. Informed consent is meant to provide participants with outlined roles and expectations for themselves, the researchers, and the project as a whole. However, if both the community and the research team are partners in the project with equivalent power and autonomy, authority to determine the parameters of “informed consent” become blurred. While this specific dilemma regarding consent lies outside the scope of this thesis, it is still important to consider since informed consent is a critical component of community engagement and research.

In addition to understanding the voices and cultural backgrounds of the communities under study, community engagement also seeks to incorporate cultural competency. Cultural competency is a commonly cited term in healthcare, but there is controversy whether “competency” and cultural sensitivity is sufficient for effective and ethical approaches. Instead, healthcare professionals should be striving for “cultural proficiency” (Wells, 2000). Culture plays a significant role in health outcomes, which makes it an important factor to consider when designing and treating public health issues. Wells, a nursing professional, states that cultural proficiency is an extension of cultural competency where culturally competent methods become the standard and are integrated on an organizational level.

The idea of cultural proficiency relates back to the idea of making community engagement a standardized protocol in the world of public health research. Cultural proficiency is a systematic shift in how to conduct medicine; this same shift can be integrated in public health research to encourage proficiency in community engagement, rather than using it as a technique on an occasional or convenient basis. Community engagement has the potential to be the rule, not the exception, to conduct outsider research if this ideology follows suit with Wells' cultural proficiency concept. To shift from cultural competency to proficiency requires institutional and individual change, mirroring the need for a larger scale shift towards community engagement becoming the default method to conduct public health research, when applicable.

Currently Existing Models of Community Engagement

Community engagement is a type of research that aims to establish collaborative relationships and shared leadership between the community and research team involved in the study. Public health initiatives are often conducted by outsider researchers, which begs the need for a method of research that is culturally proficient – community engagement has the potential to fill this need. As mentioned in the previous section, there are different types of community engagement approaches, such as CBPR and PAR, where the former possesses lower motivations for political action than the latter. Models for community engagement, whether they include a portion about policy and governmental change, are varied in their terminology and principles. The lack of consensus in a community engagement model muddles the implementation of community engagement in outsider public health research; consequently, the absence of a consistent model prohibits the use of community engagement as a standard research approach.

There are different currently existing frameworks such as the PEN-3 model, the NIH Director's Council of Public Representatives' Model, and the Principles of Community Engagement framework that all attempt to outline the best process and values for community engagement research.

1. PEN-3 Model

The PEN-3 model was developed to provide a starting framework to address how health is affected by the cultural components of a society. Culture serves as the primary focus of the PEN-3 model, and is defined as the "shared values, norms, and codes that collectively shape a group's beliefs, attitudes, and behavior through their interaction in and with their environments" (Iwelunmor, Newsome, Airhihenbuwa, 2014, p.21). "PEN" is a complex acronym for three different categories and their associated subcategories (Iwelunmor, Newsome, Airhihenbuwa, 2014). The three categories in this model for community engagement include: cultural identity, relationships and expectations, and cultural empowerment. Within each category there are three themes from which the "PEN" acronym is derived. For cultural identity, the focus is on **P**erson, **E**xtended family, and **N**eighborhood. The relationships and expectations category look at **P**erceptions, **E**nablers, and **N**urturers. Finally, **P**ositive, **E**xistential, and **N**egative factors make up the cultural empowerment domain. The PEN-3 model stresses culture and its importance to public health research, making it a prime example of community engagement research for this thesis.

To assess the model's implementation and effectiveness, Iwelunmor *et al.* analyzed 45 different case studies that employed either portions or the entirety of the PEN-3 model (2014). The majority of PEN-3 applications only applied specific aspects of the model, which suggests the difficulty of use for PEN-3 models in public health. The actual model is segmented into numerous sections, making it cumbersome to apply in complex cultural situations. This model does, however, allow researchers to analyze cultural factors in their study which is foundational to community engagement research. For example, Krass and Barbara conducted a set of interviews with participants from a Maltese Community Social Centre in Sydney, Australia to understand more about the relationship between Maltese immigrants in Australia and their higher rate of Type 2 Diabetes compared to the rest of the population (Krass & Barbara, 2013). The PEN-3 model was not used to create their study, but rather to guide the analysis of the cultural predictors present in the interviews; this is an example of a partial application of the PEN-3 model. Although only a portion of the PEN-3 model was used, this theoretical framework provided Krass and Barbara techniques to assess how the health of Maltese immigrants is impacted by culture (Krass & Barbara, 2013).

After compiling the 45 different case studies, Iwelunmor *et al*. identified central themes in the PEN-3 model including: “the importance of context, the role of family as an intervention point of entry, and the need to explore positive aspects of culture on health behaviors” (Iwelunmor, Newsome, Airhihenbuwa, 2014, p.37). These three motifs arose in a majority of the case studies and emphasize culture’s role in health. The first theme of the PEN-3 model is the importance of cultural context which provides researchers a perspective to understand health behaviors in communities they may not belong to. This knowledge and perspective, in turn, allows researchers to design interventions and trials that address health behaviors from a viewpoint that may not have been considered. The second theme involves family. Oftentimes, health behaviors and experiences are only seen as an individual experience, but Iwelunmor *et al*. argues “that illness is the responsibility of the collective” (Iwelunmor, Newsome, Airhihenbuwa, 2014, p. 38). The emphasis on community through the PEN-3 model highlights its importance in promoting health interventions and impacting health outcomes for communities, and therefore demonstrates that CE should be the default approach to outsider public health research. By understanding family dynamics, researchers can inform their intervention and treatment plans to maximize potential success. The final theme discussed revolved around positive health behaviors associated with each respective culture “to strengthen and harness personal strengths that can act as buffers against illness” (Iwelunmor, Newsome, Airhihenbuwa, 2014, p. 39). The study of “positive” aspects of fields has become an increasingly popular approach, one discipline where this is present is in “Positive Psychology.” Approaching the health issue by studying the positive behaviors present in the cultural setting allows better prevention methods to form and promotes healthier actions that alleviate the burden of illness.

While this model does an excellent job of centering culture at the forefront of health interventions, it fails to adequately address transferability, the ability of a given model to be applied across varying contexts and situations, and measurement, how a model’s success is determined. As with most community engagement frameworks, transferring one prescribed protocol across diverse cultural contexts is challenging and the narrow guidelines provided by the PEN-3 model faces these same difficulties. Furthermore, the PEN-3 model is currently limited to only qualitative analysis, but the acquisition of both qualitative and quantitative data expounds and enhances one’s ability to understand the results stemming from the model (Iwelunmor, Newsome, Airhihenbuwa, 2014).

2. NIH Director’s Council of Public Representatives’ Model

The National Institute of Health supports the inclusion and participation of community in their researchers’ work, but there is no policy that requires these investigators to do so. Because there is no central rule to engage with communities, the need for training in community engagement techniques did not seem necessary to the NIH. This mindset, however, has since changed when the Director's Council of Public Representatives (COPR) stressed the impact community involvement has on the NIH's research and intervention practices. According to the council, participation should be added to the NIH's mission that medicine should be "more Predictive, Personalized, Preemptive, and Participatory" (Ahmed & Palermo, 2010, p. 1381). The NIH defines community engagement as "a process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community of focus" (Ahmed & Palermo, 2010, p. 1383).

Using this basis for community engagement, the Director's Council of Public Representatives created guidelines that are categorized into 5 different groupings: definitions and scope of community engagement, strong community-academic partnership, equitable power and responsibility, capacity building, and values for an effective dissemination plan. The first category, definition and scope of community engagement, provides context to investigators and medical practitioners who may not be well affiliated with community engagement approaches. The second category, strong community-academic partnership, highlights the importance of healthy partnerships in community engagement and delves into certain practices to promote these relationships. Outsider research in communities that have differing cultural values has the potential to create power disparities that can affect how a public health measure is designed and executed. The third principle, equitable power and responsibility, discusses how power should be shared between researchers and community members, and that "community engagement projects encourage, instead of merely tolerating, diverse populations and perspectives" (Ahmed & Palermo, 2010, p. 1385). With power and resource equity, comes shared knowledge and information which falls under the fourth principle, capacity building. “Capacity” appears in several forms whether that be the community’s capacity to make informed and deliberate decisions regarding their conflicts, or the researcher’s capacity to understand the community’s assets and strengths to functionally work within the society. Each principle builds upon itself, and the final principle covers the values to design an effective dissemination plan. Trust is frequently mentioned in this category as a result of transparency and joint decision making in implementation of any interventions. Readily carrying out the agreed upon expectations for the project is an important factor in this section of the framework, because mistrust, exploitation, and coercion can result if one party goes against the originally decided goals for the project.

3. Principles of Community Engagement

The Center for Disease Control (CDC) created an expansive document to address community engagement research. The CDC provided an important disclaimer that community engagement in public health stems from the concept that illness and health is more than a biological science. There are sociological, environmental, physical, and cultural factors that all play a hand in public health (Clinical and Translational Science Awards Consortium, 2011). This multidimensional outlook entails that public health research should be designed to include these varying facets of illness – which is one factor helping community engagement’s outlook in the research community. Inconsistent terminology is a recurring incident in community engagement research and understanding, and to address this, the authors define community engagement as “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people” (Centers for Disease Control and Prevention [CDC], 1997, p. 9).

While conducting community engagement, taking into account the culture, organization, and participation of the community is vital. Culture plays an important role in the way people identify with themselves and others, and it impacts how power and vulnerability are defined in the context of different populations, as well. Power dynamics and trust are contributing factors to community engagement, and therefore to conduct successful community engagement public health research, the culture of any community must be considered. Community organization deals with the social structure of a community and how people are united through this organization. The manner in which a community is organized provides understanding for engagement and mobilization of community members. Participation is another aspect of community engagement that can present issues to both researchers and community members, but its connection to community engagement is nevertheless strong.

The authors argue that participation “extends beyond physical involvement to include generation of ideas, contributions to decision making, and sharing of responsibility” (Clinical and Translational Science Awards Consortium, 2011, p. 13). Including the community in the intervention phase of public health measures is not enough to actively effect systemic change. Often, this superficial intervention will fall flat, and the public health measure will result in a short term and less effective outcome. Extensive participation enhances relationships between invested parties, promotes shared learning and access to resources, and improves problem solving capabilities (Clinical and Translational Science Awards Consortium, 2011). Cultivating community participation, however, requires a large amount of time, effort, and resources. This cost is a major drawback for research studies and public health measures who are either working during a crisis or with limited resources and funds.

The aspects of the community including the culture, organization, and member participation were used to inform the Principles of Community Engagement guide’s nine principles for researchers to consider when designing a community engagement protocol. These nine principles are divided into three categories to target the different stages of implementing a project: before, during, and after. The first principle included in the “before” stage is defining the community population under study, as well as defining clear goals and expectations of the effort. Secondly, the researchers should have an understanding of the community’s culture and perceptions of the situation, including their perceptions of the researchers. Next, the authors advocate for two principles that are essential for community engagement to occur. The first statement encourages investigators to go into the target community to begin establishing trust within the community, both formally and informally. The second statement prompts investigators to “remember and accept that collective self-determination is the responsibility and right of all people in the community” (Clinical and Translational Science Awards Consortium, 2011, p. 49). Essentially, this summarizes the idea that outsider research cannot deem what is best for the community and what is worst – only the community can.

After the community engagement process has begun, in order for the project to succeed the remaining five principles are offered. The first principle underlines the importance of partnership between communities and the researchers. Without this relationship, tangible change in health outcomes may be reduced and limited. The second principle in this category relates back to the second principle in the “before” category of the framework revolving around understanding the community’s culture. This principle, however, specifically addresses the ideal that cultures are different, and this diversity should be accounted for and respected in all aspects of the public health measure. The next concept in the framework notions that community engagement can only truly be implemented if the community's strengths are assessed and further used in the engagement effort. The mobilization of the community's current resources is the first step, but building up the capabilities to further strengthen and extend these assets can be accomplished as well.

The eighth principle, and fourth one in this specific category, states that any entity that is hoping to engage with the community must be adaptable and willing to relinquish aspects of control to said community. This principle emphasizes that community engagement is "community-driven" (Clinical and Translational Science Awards Consortium, 2011). The final and most crucial principle in this framework promotes a sustainable and long-lasting public health effort through dedication and commitment. While timing can differ for every public health measure, community engagement normally requires care and devotion on a longer scale of time. Developed, long-term community partnerships are more successful at addressing health concerns, and therefore creating successful public health initiatives (Clinical and Translational Science Awards Consortium, 2011).

Rather than presenting a step-by-step process, the Principles of Community Engagement provides guidelines and values that should be considered when designing and implementing a community engagement project. Step-by-step frameworks are hard to create and maintain because the nature of community engagement is so diverse across different communities, therefore it is difficult to ascertain a singular guide that can be applied across all situations. For this reason, most community engagement models balance ambiguity and specificness to allow for transferability while still being expansive.

A Condensed and Consistent Model for Community Engagement

The lack of consensus regarding an appropriate framework for practicing community engagement in the public health sphere creates uncertainty and confusion for how to create and deploy research practices that are often more beneficial to the researchers and communities involved. I aim to construct a framework for community engagement that takes the advantageous portions of prior models, combined with ethical guidelines and considerations, to form a consistent and easier to use model for researchers and practitioners to implement in their research. Having a model with agreement regarding terminology and values increases the likelihood of community engagement becoming a routinely used approach in public health measures.

Tenet #1: Prior Understanding of Community

When designing a research question or public health intervention, studying and understanding the cultures each community ascribes to is important to be able to ask relevant questions and propose feasible ideas. Without having an understanding of the cultures and communities involved, the research question or intervention is superficial and includes only one perspective. Defining the community within the context of the public health measure is an imperative action to take here. Characterizing the community is an important initial guideline in *Lavery et al.'s* framework for community engagement (Lavery *et al*., 2010). Lack of consensus regarding the parameters of the target community can lead to confusion and misguided studies and intervention methods. Furthermore, a public health measure can be harmful or rendered ineffective if the identified community does not support the research from the get-go, creating damaging long-term effects in the form of distrust and disbelief from the community and the researchers alike. Characterizing the community also helps define the health issues and expectations of the population from their perspective, which is necessary when creating a public health measure (Lavery *et al.*, 2010).

In addition to an understanding of community culture, the goals of a public health should also be fully understood before any intervention takes place. A clear understanding of the goals and expectations helps both parties – the researchers and the community members – execute their expected actions and increases the likelihood of positive relations and successful outcomes, whatever that may look like as agreed upon by both the community and the investigators. A caveat to establishing common goals for any initiative is whether those goals involve changing the societal structure of a community or improving the health outcomes for the community. The former is a slippery slope, especially in cases where a health issue is highly polarized, and plagues marginalized groups. Stigmatization in the political atmosphere of certain groups can make it harder to affect change outside of health outcomes. Thus, if the goal of the project is to change policies in a given community, this must be clarified from the beginning and structured to be attainable given the political context (Molyneux *et al.*, 2016). Depending on the public health measure and the communities' context, clarification whether the study is rights-based or not should be clarified to all involved parties. The goal of public health measures should first be on improving the health conditions of the community. While certain rights-based initiatives may be able to enact change regarding policies, the community involved must agree with this goal and extra caution should be exercised.

Tenet #2: Encompassing application

Researchers tend to interact with communities during specific and infrequent portions of a given study, which is passed off as "engagement" (Reynolds & Sariola, 2018). The most common place to involve participants is when they are carrying out the intervention and treatment methods. The idea of community engagement must be pervasive throughout the entire research process. Community engagement cannot merely be applied during data collection or treatment implementation, but rather, it is encouraged that community engagement is a part of the original research question as soon as a public health issue arises. If the target community is not involved when formulating the question and method, then any intervention and/or treatment is less likely to gain traction and could be designed completely incongruous with the community's values.

Dr. Peter Newman references a public health case studying HIV in Cambodia sex worker populations, where local populations "reported feelings of lack of power and the perceived absence of a forum for dialogue with the investigators" (Newman, 2006, p. 302). This indicates a breakdown in community engagement in the public health study. One of the main issues Newman cited was that this study focused mainly on drug development but did not take into account community engagement techniques including, building relationships with the participants and communities (Newman, 2006). While drug development is important in public health interventions, it does not diminish the importance of building trust and relationships within the target communities. A drug could be well developed, but without a developed network of community engagement, the dissemination and use of the drug may be severely affected. Community engagement and drug development go hand-in-hand and are both necessary for successful public health interventions.

Considering the culture of the community before a drug or intervention is created can aid in the actual process of development. If there is a particular tradition or belief that could negate an intervention's deployment, this should be known before the intervention is ever made. By doing thorough and deliberate work to understand and respect the community beforehand, public health measures can be designed appropriately for different contexts, which can mitigate the larger issues that require more time and energy after a failed measure is applied. Community engagement is often an after-thought in public health research, but the status quo of public health research can be altered to consider community engagement during every step of the study design (Reynolds & Sariola, 2018).

Tenet #3: Involvement and Representation

While this theme seems implied, involvement in research is ill-defined and ambiguous. If a study is practicing community engagement, a clear understanding of involvement becomes a keystone portion of the initiative. Involvement, however, is understood on a spectrum. The base level of involvement, according to the CDC and NIH's Community Engagement Key Function Committee (2011), is outreach, followed by consulting, involvement, collaboration, and shared leadership. Each level has an increased amount of community involvement associated with it (Clinical and Translational Science Awards Consortium, 2011). In an ideal case, public health initiatives should strive for shared leadership to promote the highest level of community engagement and collaborative practices because at this level the broadest health outcomes are impacted in the community.

Collaboration and shared leadership allow for better communication between the community and the outsider researchers, which strengthens the public health intervention and increases the likelihood of its success. Community leaders, well-known members, advocates, and respected people help disseminate information, and can even design strategies and treatment plans that are most likely to succeed since they know their community best. With that being said, it is necessary that the most vulnerable in the population are equally as involved in creating treatment plans as the most revered in the community. In certain contexts, involving people holding power, such as government officials and leaders, as seen in the MSM example, could be detrimental to the members of the population facing health disparities in marginalized communities (Molyneux et al., 2016).

Keeping the political context in consideration, respected members and leaders of the community are still some of the most resourceful people for public health investigators to collaborate with. Working with community members informs the researchers on which practices mesh most effectively in the context of the culture. "The involvement of authentic leaders and institutional collaborations provides the community with a sense of familiarity, ownership, and security, and establishes the basis for mutual trust" (Lavery *et al*., 2010, p. 281). These traits create the most successful public health interventions, and trust is important for both the community and researchers alike. Researchers who have a shared trust with the community are more likely to listen and follow the guidance of the community to improve health outcomes. Trust is essential in building strong relationships, which promotes collaboration from both parties. Although, community leaders are not the only people researchers should collaborate with; instead, the entire community should be given the option and accessibility to participate and share leadership in the public health effort.

Ensuring the public health research is accessible to the entire community helps facilitate collaboration and conversations regarding the study. To improve the accessibility of the study, there should be established meetings and forums where the community and the outsider researchers can engage in discourse pertinent to the study. Fortunately, this also improves the legitimacy of the project, which was addressed earlier in this thesis as a way of conducting ethical research (King *et al.*, 2014). In the United States, town halls are a popular forum to allow people to come together and discuss issues in their community. Town halls, however, are not universal and every culture has a different way of uniting to discuss their experiences and preferences. Depending on the community, different gatherings can be formed to allow community members the access to work with the researchers, and vice versa.

Community gatherings promote trust between investigators and participants, improve communication and dissemination of information (on both sides), provide a safe space to educate researchers and participants, and establish common goals and expectations for the research study. CAPRISA, an AIDS research institute in Durban, South Africa, suggests creating "community research support groups" that convene every month to discuss concerns from both the researcher and participant perspective. This provides a setting for community members and participants to raise concerns or suggestions in a more intimate environment (Tindana *et al.,* 2007). Another example of a community gathering within cultural contexts are durbars, which are carried out by the Navrongo Health Research Centre while conducting a community-based research project in Ghana to study rural health care practices. Durbars are community gatherings where the researchers and community can meet to discuss and collaborate on research together. The use of a cultural establishment, such as durbars, encourages the exchange of knowledge and mobilizing the community in a familiar and comfortable manner (Tindana *et al*, 2007). A similar use of community-researcher gatherings was found in the previously mentioned DTT study in Aboriginal communities with the use of PNC meetings and sweat lodge gatherings. These gatherings also proved to be successful at improving relations between outsiders and community members (Boffa *et al.*, 2011).

Community engagement has the word "engagement" within its name; therefore, it can be garnered that collaboration between the researchers and the community is vital. This involvement can look different depending on the context, but it should always represent the community under study, however that may be defined, for the respective public health measure. Shared leadership in a public health initiative balances the power dynamics present to ensure communities are not being exploited or disempowered. An empowered community obtains influence and power over the circumstances affecting them (Fawcett *et al*., 1995). Therefore, through collaboration, the community retains their autonomy and decision making when it comes to the research project, which should be a goal of the study considering the community is the population afflicted in the first place.

Tenet #4: Genuine Consent

"Informed consent" is a popular phrase in bioethics, for good reason, but the actual guidelines to informed consent are muddled. Currently, informed consent can mean a participant signing a waiver that is informing them of the process and expectations – this, however, does not mean that they are genuinely informed and understand what they are signing. Disseminating information and receiving agreements in public health research cannot merely take on the appearance of consent, it must be voluntary and properly informed (Mcadam, 2004). Genuine consent goes hand-in-hand with making sure the community understands the goals and reach of the study, and that the researchers and community members have coinciding expectations.

In research and medical practice, consent almost always appears as a signed piece of paperwork because many federal and international guidelines demand this accountability. Unfortunately, paperwork is not the most accessible and rational choice for informing populations, especially ones that have no written form of language or where jargoned translations are confusing. Verbal consent with witnesses would be a possible alternative to signing forms in illiterate communities, but this would present its own ethical concerns, including coercion, that need to be accounted for. Notaries are used in the US when signing important and legally binding documents, therefore a similar witness position can be created to provide an official guarantee to unconventional consent processes and guarantee legitimacy. This, however, would require changes in policy and how research in most disciplines is conducted, which is a larger systematic change that would be difficult, albeit effective, to make. While this form of consent may not be viable yet, researchers should still strive to ensure genuine consent in their projects, which will be more attainable given the first three principles in this model are executed well.

Tenet #5: Self-Reflection

One major goal of this newly created model is transferability, to be applicable across varying cultural contexts and public health situations. Not only is transferability important, within every study or public health measure there must be adaptation and reflection. No model or system of community engagement is perfect, so including a tenet dedicated to self-reflection and critical thinking of methods promotes creative solutions to unexpected problems and consequences of application. Within self-reflection, the idea of "cultural proficiency" is significant to keep in mind. Research that is checking a box to be culturally aware is not conducting effective community engagement. Rather, cultural proficiency changes the default of research to integrate culture into the very framework in which investigators conduct public health efforts (Wells, 2000). Self-reflection ensures that cultural proficiency is strong and truly occurring in public health research and prevents research from becoming a monotonous routine. At every stage of the research process, investigators should be constantly discussing what works and what does not in order to construct sustainable and effective interventions.

An Application of My Model: *The Spirit Catches You and You Fall Down*

Anne Fadiman wrote *The Spirit Catches You and You Fall Down* in 1997 to highlight a case of cultural division from the 1980s in Merced, California. At the time, Merced had a large population of Hmong refugees, and Fadiman's book discusses a particular case involving a young Hmong girl, named Lia Lee, who was showing symptoms of *quag dab peg*, which translates to "the spirit catches you and you fall down." This is more commonly known in Western medicine as epilepsy. When dealing with this illness (it is important to note the distinct use of "illness" rather than "disease" here as the latter tends to leave out contributing social factors as well as the individual's perception of their condition), Lia and her family have wildly different expectations and understandings of the situation compared to Lia's doctors, and vice versa.

I include the well-known example Lia Lee faces to stress the harm and frustration that results from cultural views and beliefs clashing in a public health setting. Applying my new model to an actual example that is discussed in many cultural anthropological courses provides grounding for the reader to better understand the structure of my model, as well as the pitfalls that are associated with non-community engagement approaches. Not only does Fadiman's book illuminate the pervasive issue of cultural dissonance in Western medicine, but it also serves as an example to employ and understand my proposed model for community engagement, which better outlines its application and execution in a medical setting.

To adequately understand the importance and relevance of *The Spirit Catches You and You Fall Down,* I provide a summary of the book in its entirety, including Fadiman's explanations for both the Hmong and American backgrounds. Fadiman mainly focuses on Lia

Lee and her medical history and experiences, but to accurately represent the situation from different perspectives, Fadiman also expounds a great deal on Hmong history and traditions (which follows suit with the proposed CE model's tenet of "Prior Understanding of Community"). The Hmong are Southeastern Asian mountain people who fled from Laos during the Vietnam war. As refugees, many of them were in Thailand before being relocated around the world. The United States is one such place refugees were able to seek asylum. In the US, the Hmong were displaced to certain cities including Merced, CA, Detroit, MI, Minneapolis, MN, Philadelphia, PA, to name a few. The majority of *The Spirit Catches You and You Fall Down* takes place in Merced, CA where the Lees were living.

The Lee family consists of parents Foua Yang, Nao Kao Lee, and their fifteen total children, of which only eight survived to live in the US. Lia was the fourteenth child in their family, and the first to be born in the US. Lia was only three months old when her first episode occurred. Lia's diagnosis, in terms of Western medicine, was epilepsy, but this was not diagnosed on her first visit. Lia would have several seizures before she was properly diagnosed. From the time she was three months old until she was four and a half years old, Lia faced many health issues that would leave her with no neural activity outside of her brainstem – her final visit to the hospital resulted in brain death. These health issues were exacerbated by the cultural chasm between the Western doctors and the Hmong population.

Before I delve into the analysis and application of my model in the context of Lia's case, I have my own bias to disclose. Having grown up in the US, I am most familiar with Western medicine and noticed this bias while reading *The Spirit Catches You and You Fall Down*. This familiarity, however, was minimized by employing cultural anthropological techniques to avoid an ethnocentric perspective. One such saying I kept in my head while reading was "make the strange feel familiar, and the familiar feel strange." While I strive to acknowledge and avoid my own bias, it is important to recognize that it does exist regardless of my ability to examine this work from a removed perspective.

Application of Tenet #1: Prior Understanding of Community

The first tenet in my proposed CE model is Prior Understanding of the Community. Before beginning any public health measure, or medical practice, having comprehensive, rich knowledge over the culture under study is critical. Without this prior understanding, doctors and investigators could introduce more harm and stress for themselves, as well as the community with which they are collaborating. Fadiman extensively researches and participates in the Hmong culture by moving to Merced and fully immersing herself in the community. Fadiman sought different prevalent figures in the Hmong population in Merced. Arguably one of the most crucial relationships Fadiman made was with May Yang Xiong, a young Hmong woman living in Merced. Fadiman refers to May as her "cultural broker," which is essentially a person who is aware of the differing culture and can serve as an effective intermediary, and more importantly guide Fadiman in her interactions. May was not merely a language interpreter, which only implies aiding in the language barrier, but rather a direct link to the Hmong culture and community. May was closely related with many powerful clans in the Hmong population and was a member of Foua Yang's clan. By connecting with the right people, Fadiman was setting herself up to have a productive interaction, and subsequently, healthy relationship with the Lee's. These vital connections allowed Fadiman a better starting point to learn about the Hmong population in Merced, as well as the Hmong culture in general.

There are two major characteristics of the Hmong culture that are especially important in understanding the struggle between the Hmong people – including the Lee's – and the doctors in

America. The first is that the Hmong people resist assimilation (Fadiman, 1997). Throughout their long history, they have faced migrations and wars, but they have maintained a strong sense of identity for themselves and have not allowed outside forces to alter their belief system and way of life. The second characteristic is their group mentality, where the group is seen as the most important unit in their culture (Fadiman, 1997). This is a stark contrast to America's individualistic ideology. Furthermore, the Hmong hold an unshakable sense of identity, but to American's this was perceived as "stubborn" and "difficult" (Fadiman, 1997). Some Americans even believed that the Hmong were the most unsuccessful migrant population in the US at the time (Fadiman, 1997). This was true for doctors as well. Specifically, the health professionals working at Merced Community Medical Center (MCMC) with the Lee family had preconceived notions that this family was troubling to work with. Many of the professionals actively avoided or were wary of working with the Lee's, even if they had never met them before. These cultural characteristics illuminate potential clashes between Westerners and the Hmong, but had they been aware could have aided professional and personal relationships had this been acknowledged in a study that included "prior understanding" as a starting factor.

Application of Tenet #2: Encompassing Application

The newly devised model does not necessarily follow an order when applying each category – they all work in tandem with one another. However, the first two categories, prior understanding and encompassing application, are by nature both involved in the beginnings of any public health measure. Encompassing application refers to the universal manner of collaboration and shared leadership throughout the entire research process, from the development of a research question all the way through the intervention, results, and implications of the study. Through Fadiman's book, Lia's doctors do not conduct community engagement approaches to treat her epilepsy. The second category, encompassing application, was absent for most of Lia's experience because there wasn't true community engagement to begin with. In contrast, Fadiman addresses this by meeting May Xiong before ever meeting the Lee's. From the very beginning, Fadiman employs community engagement techniques to better comprehend the health barriers at hand. This same comprehensive application could have been used by the doctors by having improved trainings and awareness. It may seem costly to have doctors expend energy on learning about the Hmong population, but in Merced, the Hmong population make up 20% of the total population; one in five people are Hmong (Fadiman, 1997, pg. 24). Having an interest in or at minimum, a basic familiarity with such a significant portion of the Merced population would have improved how healthcare professionals were able to treat and care for the Hmong.

An encompassing application of community engagement techniques from the very beginning of the doctor's involvement could have clarified the Lee's perspective on Lia's health conflict. To the Lee's, this had nothing to do with the brain, but rather everything to do with Lia's soul. The Merced doctors were unaware that the Lee's thought the cause of their daughter's illness was because she had lost her soul because of a dab (a spirit). The Lee's belief that Lia caught a spirit, compounded with their fear of Western medicine, instilled in them as refuges in Thailand, lead them to believe that the hospital was making her sicker and that the medicine prescribed was doing more harm than good. This is perhaps the largest breakdown in communication throughout Lia's entire case – the doctors thought the parents were noncompliant with their medical orders, and the Lee's thought the doctors were causing Lia more harm. The doctors were completely unaware the Lee's – and the Hmong community – held this belief in the first place, however. Western doctors normally help patients who view their actions and personality as good and wanting to help, but this is not always how the Hmong community viewed them. A deeper understanding of the Hmong culture and community could have created a safe environment where this could have been discussed between the doctors and the Lees.

Application of Tenet #3: Involvement and Representation

The third category of the model is Involvement and Representation, which ensures accurate community representation on the research team, as well as productive communication standards between the community and the researchers. This specific principle proved difficult during Lia's medical treatment due to both language and cultural barriers. Lia's doctors were almost exclusively Westerners, there were, however, Hmong translators that would be present on very limited occasions. When Lia visited MCMC for the first time, there was no translator present which started a long chain of miscommunication and distrust for both the Lee's and the doctors. Another issue regarding translation services were that the doctors never asked what the translator would do. The translators were Hmong, yet the doctors rarely asked for their thoughts or to help bridge any barriers between the Lee's outside of a language barrier. The only instance an interpreter was asked how the doctor should act was when Nao Kao threatened to commit suicide if they did not treat Lia the way he believed they should (Fadiman, 1997, pg. 51). The idea of a cultural broker ties in here. May Xiong helped Fadiman navigate Merced and the Hmong culture, and without this, Fadiman would not have truly heard the Lee's perspective on the events that occurred or been able to sympathize with their perspective.

In medical settings, the language barrier is only one aspect that can reduce the quality of care. The cultural barrier that is present is an even larger barrier that prevents public health interventions from succeeding, and because of this barrier it is necessary to ensure outsider public health teams involve a representative portion of the community under study. Health and culture are inexplicably linked, and there needs to be a balance of biological sciences and cultural proficiency. In the case of MCMC, having more Hmong doctors, shamans, and community representatives can help nurture a safe and productive space for Hmong patients. Specifically, for the Lee's, having their *tvix neeb,* a Hmong shaman, involved in Lia's medical care alongside the doctors would have been more productive. The MCMC doctors were unaware altogether of the traditional remedies the Lee's were using to treat Lia, and collaboration between the two cultures could have yielded comfort and an open relationship to discuss treatment options. This collaboration would have not only promoted a safer treatment plan for Lia, but it would have also fostered a positive relationship between the Lee's, the doctors, and the rest of the Merced Hmong population.

Since the Hmong community is very close-knit, they hold the larger collective unit above anything else, and this could have been seen as an advantageous value to Lia's case rather than a detriment. Though Lia's experience became well-known throughout the community, it came with negative connotations. Other families feared the hospitals and the doctors in turn viewed many of them as "difficult" patients as well. Having cultural brokers working alongside healthcare professionals would increase the knowledge for both doctors and patients, while improving the interactions experienced in healthcare settings. With improved relationships and communication, health issues can be more sufficiently addressed and treated.

Application of Tenet #4: Genuine Consent

The fourth tenet, Genuine Consent, establishes the precedent for consent and confirmation that is more deliberate and thorough than the industry standard of informed consent, which can be superficial, especially considering language barriers. The "non-compliance" issue between Lia's doctors and her family became a source of evidence showing the need for genuine consent, rather than simply informed consent. The Hmong population is illiterate – they have no written language. When the Lee’s moved to the US, they spoke no English and never had to write or read, even in their own native language because it did not exist. However, the Lee’s learned how to sign their name for documents pertaining to their migration to America from Thai refugee camps. What was unclear was whether they were aware that they were signing their name, or if the process became a mundane task they completed.

According to their documents, both Foua and Nao Kao would have different signatures for every document they signed. Sometimes it would say FOUA, other times FOUAYANG, it frequently changed. In the case of Lia’s healthcare, this pattern remained consistent. There were many medical documents and forms given to the Lee’s to sign in regard to Lia’s treatments, but they did not speak English, let alone read it. Even with the forms explained to them through translators, the Hmong culture was so different from the American healthcare system many things like “CT scan” or “pneumonia” did not make sense or were not easily translated into Hmong. Regardless, the Lee’s would sign their name on the form because this is what they thought the doctors wanted, most of the time it was unclear whether they actually knew what they were consenting to. So, while the doctors technically achieved “informed consent,” it was not genuine. This example is tricky to navigate and not something the doctors would have been able to easily solve given the larger context of the healthcare system. Consent right now has to be in the form of a signature, but this could be changed to allow more accessible formats for cases like the Lee’s. Although, given that the doctors needed a signature on a form, more time and resources could be dedicated to each individual case to create genuine consent. If Hmong professionals and leaders work as and with healthcare professionals, they can aid in bridging the gap in cultural knowledge to strengthen the Lee’s understanding of what they were consenting to.

Application of Tenet #5: Self-reflection

The last pillar in the community engagement model is Self-reflection, where researchers and community members consistently evaluate what is successful and what is damaging in their study and its implementation. This principle is on-going, similar to the other four. At every step of the process, the MCMC healthcare professionals should be re-evaluating their course of action, especially since Lia was declining in health as time went on. There were occasions this self-reflection occurred. When the doctor's realized the Lee's were not following the prescribed orders of medicine, they had an in-home nurse meet with the Lee's to clarify their routine. While this was a step in the right direction, it could have been furthered by addressing and understanding the exact cause to why the Lee's were not giving Lia the medication. This realization would have required deeper critical thinking, and unfortunately the doctors were already swamped with their case load – as many tend to be. Cases like Lia are not at the fault of the doctors or the Lee's, but rather the larger systems that create barriers – including low patient-doctor ratios, financial constraints, limited time allotted per patient, and ineffective communication of care – to conduct approaches such as community engagement. The retrospective application of community engagement is evident in examples like Lia's, but these techniques may not be as clear cut when applied to real-time research, which is why self-reflection is critical in any community engagement protocol.

Limitations, Future Applications and Implications

Fadiman's book, *The Spirit Catches You and You Fall Down*, documents an instance of cultural division, but there are varying critiques and perspectives on whether Fadiman did this appropriately. The arguments against Fadiman's representation of the Hmong and their experience are important to note as potential limitations for the book as a case study. One essay by Monica Chiu, a student at the University of New Hampshire, claims Fadiman places “the Hmong subjects into the very colonial parameters from which the book attempts to extract them” (Chiu, 2005, p.1). Paired with this criticism, Chiu also argues that Fadiman creates “sympathies” by which the audience views the Lee’s and the Hmong population, thus assuming the audience is from a Western background. According to Chiu’s analysis, Fadiman’s own bias prevents *The Spirit* from being a novel that accurately depicts the collision between two varying cultures without portraying the context through a Western lens (Chiu, 2005).

Acknowledging the criticisms of Fadiman’s work promotes a deeper and more well-rounded understanding of *The Spirit* and the nature of her writing. Although Chiu disapproves of Fadiman’s approach, Brian Richards defends *The Spirit* in his essay rebutting Chiu’s original work (Richards, 2010). Richards argues that Fadiman’s work is a “writer’s personal journey in reporting back to her culture” rather than one that attempts to pass itself off as an “Associate Press report” (Richards, 2010, p.1). Writing that focuses on cultural aspects, including Fadiman’s work, is prone to bias and ethical considerations – these should not be overlooked, but they should also not serve as an impenetrable barrier to writing of this kind. Fadiman does acknowledge her own biases, but she further declares in the preface of *The Spirit* that she is not well-informed about the American medical culture nor the Hmong traditional culture – which presumably suggests that she is a neutral source. The main defense of Fadiman’s work rests on the notion that the book was intended to interact with the writer’s and the reader’s own outlooks regarding the cultural collision, but it is not necessarily intended to influence their views. All-in-all, Fadiman writes *The Spirit* as “an educational and personal depiction of medicine and tradition” (Richards, 2010, p. 3).

I reference both Chiu's critique and Richard's defense to raise questions that remain difficult to answer in cross-cultural research. One statement Chiu made resonated with me: "Is it possible to have it both ways—to know as well as to resist an entitlement to knowing?" (Chiu, 2005, p. 27). This question may not have a clear-cut answer, but cultural anthropological techniques avoid placing cultures into delineated entities. Rather, cultural anthropologists strive to make the unfamiliar seem familiar, and the familiar seem unfamiliar. In doing so, these researchers can better understand other perspectives and a commonality can be achieved. An outsider researcher is not expected to become a member of a community, and vice versa, but researchers and community members should share leadership and power when collaborating on public health interventions — community engagement is a way to achieve this and address negative consequences traditionally associated with outsider research.

Currently, the default approach to outsider research does not include community engagement techniques, but even if it did, there are no standardized regulations or guidelines to conduct community engagement practices. Outsider research conducted without deliberate collaboration with the communities under study can result negatively for both parties (Bridges, 2001). The costly and timely manner of community engagement, however, makes it less than ideal for the American research atmosphere. For real change to occur, policies must be created to support community engagement research because presently there are little to no incentives in line with Western values and expectations to complete a more taxing and costly research process; this maintains the status quo of outsider research (Reynolds & Sariola, 2018).

This newly organized model provides a consistent and methodological approach to conducting community engagement. An important feature of this model is its transferability across public health scenarios. This model's purpose serves to act as a framework that can be plugged into different cultural contexts and research projects to ensure ethical and effective interventions that benefit all parties involved; in future public health initiatives, this community engagement model can be applied to promote these interventions.

Continued and widespread use of this model will provide data on the effectiveness and pitfalls of the framework. Community engagement models, including the PEN-3 model, tend to only be analyzed qualitatively, but qualitative and quantitative analyses can be executed on this proposed model to provide detail of impact on multiple scales (Iwelunmor, Newsome, Airhihenbuwa, 2014). The more widely used community engagement is in public health, the more evidence can be collected to better understand the advantages and disadvantages to this approach. Subsequently, community engagement models and applications can be adjusted accordingly, after self-reflection, to create more successful interventions in public health research.

Conclusion

Outsider research in public health is a widespread approach, therefore, addressing the possible negative consequences of this method of research is important to improve health outcomes for afflicted communities, as well as enhancing public health interventions and research as a whole. Outsider research that is not culturally proficient can lead to disempowerment of the community, ineffective interventions, increased distrust in researchers, and exploitation of communities, to name a few of the consequences. Community engagement is a specific approach to outsider research that is shown to help alleviate these repercussions. Despite its potential, community engagement is not routinely employed or understood due to its ambiguous terminology and nature to go against the normal grain of research. Community engagement techniques require more resources and energy, which are not factors that are valued highly in Western public health measures – ironically, Western cultures are normally the ones conducting outsider research. Existing models of community engagement outline foundational principles to abide by during research, but these models are cumbersome to understand and apply in the context of public health initiatives. Most of the existing frameworks present a list of principles that lack a cohesive force to tie them together to be readily employed. The barriers to apply community engagement make it necessary to develop a user-friendly, theoretical model, that incentivizes and encourages public health professionals to take a community engagement approach as opposed to status quo study designs. The absence of a consistent model uncovers the opportunity to create a novel approach to community engagement.

I analyzed different community engagement models that were used in recent public health research and designed a singular model that condenses varying themes into five categories for public health professionals to address in their own endeavors. The five categories are: prior understanding of community, encompassing application, involvement and representation, genuine consent, and self-reflection. These categories are not mutually exclusive entities, but rather they work in tandem to create a comprehensive public health effort for communities that work with outsider researchers. Prior understanding of the community and its cultural norms prepares researchers to better collaborate with the target population through knowledge and familiarity with the community's culture. This understanding is necessary to set the stage for outsider researchers to collaborate and share leadership with any community in a culturally proficient manner. Encompassing application enforces continuous application of community engagement techniques throughout the entire public health effort, rather than picking and choosing steps where it can be used. An encompassing application of community engagement creates a fair and deliberate study. Community engagement endeavors must involve the community members under study in a representative manner. The entire basis of community engagement is to form relationships and a shared leadership between the community and the outsider researchers, which increases the success of public health interventions. To foster an ethical study, genuine consent is required in community engagement protocols to protect both the community participants and the researchers. Finally, community engagement is not stagnant, therefore, public health investigators should reflect on their actions and procedures throughout the process. The community should be included in this reflection to create a dynamic intervention measure and practice community engagement to its fullest extent.

I created a theoretical community engagement model informed by previous guidelines and frameworks, and then I applied this theory to a well-known example to anchor its meaning and importance for readers. In Lia Lee's case, from *The Spirit Catches You and You Fall Down,* there was a lack of community engagement throughout most of her treatment, which resulted in various cultural clashes between the Lee family and the doctors. Instead, the doctors maintained a majority Western-perspective towards medicine, while the Lee's abided by traditional Hmong cultural and medicinal practices. However, this does not put the blame on the doctors or the Lee's – there is no "fault" in this situation. Community engagement is not the current standard of public health research and application, and therefore it is understandable that doctors – especially one's from the 1980s – would not have been trained or proficient in these techniques. Moving forward, there should be a greater emphasis and application of community engagement in public health initiatives to avoid or diminish negative health outcomes for communities involved in outsider research.

References

Ahmed, S. M., & Palermo, A. G. S. (2010). Community engagement in research: frameworks for education and peer review. American journal of public health, 100(8), 1380-1387. https://doi.org/10.2105/AJPH.2009.178137

Ahmed, S. M., Young, S. N., DeFino, M. C., Franco, Z., & Nelson, D. A. (2017). Towards a practical model for community engagement: Advancing the art and science in academic health centers. *Journal of clinical and translational science, 1*(5), 310-315. https://doi.org/10.1017/cts.2017.304

Boffa, J., King, M., McMullin, K., & Long, R. (2011). A process for the inclusion of Aboriginal people in health research: lessons from the *Determinants of TB Transmission Project*. *Social Science & Medicine*, *72*(5), 733-738. https://doi.org/10.1016/j.socscimed.2010.10.033

Bridges, D. (2001). The ethics of outsider research. *Journal of Philosophy of Education*, *35*(3), 371-386. https://doi.org/10.1111/1467-9752.00233

Brown, P., Morello-Frosch, R., Brody, J. G., Altman, R. G., Rudel, R. A., Senier, L., & Pérez, C. (2008). IRB challenges in multi-partner community-based participatory research. In the *American Sociological Association annual meeting*. doi: 10.1186/1476-069X-9-39

Burke, J. G., Hess, S., Hoffmann, K., Guizzetti, L., Loy, E., Gielen, A., ... & Yonas, M. (2013). Translating community-based participatory research (CBPR) principles into practice: Building a research agenda to reduce intimate partner violence. *Progress in community health partnerships: research, education, and action, 7*(2), 115. DOI: 10.1353/cpr.2013.0025

Centers for Disease Control and Prevention (1997). Principles of community engagement. *CDC/ATSDR Committee on Community Engagement*, 1st ed. 1997.

Chiu, M. E. (2005). Medical, Racist, and Colonial Constructions of Power in Anne Fadiman's The Spirit Catches You and You Fall Down. *Hmong Studies Journal.* https://scholars.unh.edu/cgi/viewcontent.cgi?article=1147&context=eng_facpub

Clinical and Translational Science Awards Consortium. Community Engagement Key Function Committee Task Force on the Principles of Community Engagement. (2011). Principles of community engagement. *NIH Publication*, 11-7782.

Fawcett, S. B., Paine-Andrews, A., Francisco, V. T., Schultz, J. A., Richter, K. P., Lewis, R. K., ... & Lopez, C. M. (1995). Using empowerment theory in collaborative partnerships for community health and development. *American journal of community psychology, 23*(5), 677-697. https://doi.org/10.1007/BF02506987

Freudenberg, N., & Tsui, E. (2014). Evidence, power, and policy change in community-based participatory research. *American Journal of Public Health, 104*(1), 11-14. https://doi.org/10.2105/AJPH.2013.301471

Gbadegesin, S., & Wendler, D. (2006). Protecting communities in health research from exploitation. *Bioethics, 20*(5), 248-253. https://doi.org/10.1111/j.1467-8519.2006.00501.x

Iwelunmor, J., Newsome, V., & Airhihenbuwa, C. O. (2014). Framing the impact of culture on health: a systematic review of the PEN-3 cultural model and its application in public health research and interventions. *Ethnicity & health, 19*(1), 20-46. https://doi.org/10.1080/13557858.2013.857768

Khanlou, N., & Peter, E. (2005). Participatory action research: considerations for ethical review. *Social science & medicine, 60*(10), 2333-2340. https://doi.org/10.1016/j.socscimed.2004.10.004

King, K. F., Kolopack, P., Merritt, M. W., & Lavery, J. V. (2014). Community engagement and the human infrastructure of global health research. *BMC medical ethics, 15*(1), 84. https://doi.org/10.1186/1472-6939-15-84

Barbara, S., & I. Krass. (2013). Self Management of Type 2 Diabetes by Maltese Immigrants in Australia: Can Community Pharmacies Play a Supporting Role? *International Journal of Pharmacy practice, 21*(5), 305-313.

Lavery, J. V., Tinadana, P. O., Scott, T. W., Harrington, L. C., Ramsey, J. M., Ytuarte-Nuñez, C., & James, A. A. (2010). Towards a framework for community engagement in global health research. *Trends in parasitology*, *26*(6), 279-283. https://doi.org/10.1016/j.pt.2010.02.009

Molyneux, S., Sariola, S., Allman, D., Dijkstra, M., Gichuru, E., Graham, S., ... & Maleche, A. (2016). Public/community engagement in health research with men who have sex with men in sub-Saharan Africa: challenges and opportunities. *Health research policy and systems, 14*(1), 40. https://doi.org/10.1186/s12961-016-0106-3

Newman, P. A. (2006). Towards a science of community engagement. *The Lancet, 367*(9507), 302. https://doi.org/10.1016/S0140-6736(06)68067-7

Reynolds, L., & Sariola, S. (2018). The ethics and politics of community engagement in global health research. *Critical public health, 28*(3), 257-268. https://doi.org/10.1080/09581596.2018.1449598

Richards, B. (2010). In Defense of The Spirit of An Author: On Anne Fadiman's 'The Spirit Catches You and You Fall Down'. Inquiries Journal/Student Pulse, *2*(2). http://www.inquiriesjournal.com/a?id=174

Shakya, H. B., Stafford, D., Hughes, D. A., Keegan, T., Negron, R., Broome, J., ... & Ordonez, M. (2017). Exploiting social influence to magnify population-level behaviour change in maternal and child health: study protocol for a randomised controlled trial of network targeting algorithms in rural Honduras. *BMJ open, 7*(3). doi: 10.1136/bmjopen-2016-012996

Tindana, P. O., Singh, J. A., Tracy, C. S., Upshur, R. E., Daar, A. S., Singer, P. A., ... & Lavery, J. V. (2007). Grand challenges in global health: community engagement in research in developing countries. *Plos medicine, 4*(9), e273. https://doi.org/10.1371/journal.pmed.0040273

Wells, M. I. (2000). Beyond cultural competence: A model for individual and institutional cultural development. *Journal of community health nursing, 17*(4), 189-199. https://doi.org/10.1207/S15327655JCHN1704_1

Wrigley, A., & Dawson, A. (2016). Vulnerability and marginalized populations. In *Public Health Ethics: Cases Spanning the Globe, 3*, 203-240.

Author Biography

My name is Claire LeBovidge and I am a fourth-year Polymathic Scholar graduating in May 2020 with a Bachelors in Science and Art in Biology and an Evidence and Inquiry Certificate. Following graduation from UT, I will be pursuing my Masters in Education at George Washington University in Washington, D.C. After receiving my M.Ed, I plan to teach and then intend to return to graduate school for my Ph.D in Education Policy and Research to study informal and formal STEM spaces and their impact on STEM reform in America.

During my four years at UT, I was involved with the Polymathic Scholars Student Leadership Panel and served as the Public Relations chair. Outside of the Polymath community, I was very interested in teaching, so I served as an Undergraduate Teaching Assistant for three different courses across three years. One of my UGTA positions was as an OAS mentor, and working with Dr. De Lozanne influenced my path of pursuing a career in education. I began working at The Thinkery, the children's museum here in Austin, as a STEAM Educator – this solidified my passion for STEM Education. The Thinkery, while not an on-campus activity, shaped much of how I hope to teach in the future as well as what I hope to study.