The Dimock Center
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Tufts UNIVERSITY

Assessing Community Engagement (ACE) @ The Dimock Center

A Community-Based Participatory Research (CBPR) Project

April 30, 2015

Community-Academic Research Team

Team Members (from left to right):
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Not pictured:
Alice Chan
Dr. Nandini Sengupta, The Dimock Center

Introduction/Overview

- ACE @ Dimock was a joint research project carried out by undergraduate students in a course at Tufts University in the Community Health Program and The Dimock Center.
- Undergraduate students participated in a community-based project over the course of the year to learn about the value and conduct of CBPR as a tool to improve community health.
- Our research team was led by Dr. Shalini Tendulkar, Tufts faculty and our community partner at Dimock, Dr. Nandini Sengupta, Director of Medical Services.

Team Planning

Initial Planning and Assignment of Tasks in Class

→

Student Work and Efforts
Outside of Class
Communication

→

Implementation
Analysis
Feedback

Week by Week

Keeping the Community in Mind
Keeping Research Team in Mind

Positive outcomes for all involved

Research Design

- **Provider Interviews**
  - 7 Participants selected by Dr. Sengupta
  - Included doctors, nurses, nutritionists, psychiatrists
  - Followed standard interview protocol developed by the research team.

- **Patient and Parent Surveys**
  - Survey was developed by the research team
  - Eligibility requirements
    - Patients 18 years old and older
    - Parents of patients of all ages
  - IRB approval obtained from The Dimock Center and Tufts University

Provider Interview and Patient/Parent Survey Tools

Provider *sample* interview questions (13 total questions):

Focused on defining patient engagement and perceived factors that facilitate and hinder patient engagement.

- Who is a typical patient at Dimock?
- What are the usual problems that are faced by you as a provider?
- Is there anything you wish Dimock could do differently? etc.

Parent/Patient *sample* survey questions (22 total questions):

Focused on patient engagement with their providers, feedback on care etc.

- Demographic information
- How comfortable do you feel with your healthcare provider?
- Overall how satisfied are you with the health care service you/your child received at Dimock?

Interview Tool/Survey Development Process

- The research team crafted interview and survey questions to align with project goals.
- Questions were developed through group brainstorming sessions with input from our community partner.
- Each interview and survey question was debated over and revised by the team several times before finalizing the tools.

Community Involvement: Dr. Sengupta was sent copies of the interview and survey tool and helped us refine questions. For example, she provided input on the appropriate reading level for the survey tool.

Provider Interviews Data Collection and Analysis

- Interviews conducted in pairs by student researchers
- Interviews were recorded and transcribed
- Research team reviewed transcripts and created a code book
- Code book were applied to transcripts
- Themes were extracted

Community Involvement: Dr. Sengupta chose the providers for the research team to interview. She also provided feedback on the interview tool.

Sample Standard Script for Provider Interviews

Hello, My name is _____ and I'm a Student Researcher

"We are conducting this survey through Dr. Sengupta and the Tufts University Community Health program"

"All of your responses are voluntary"

"Though we are using recording devices to transcribe the interview, you can ask to take anything off the record at any time"

"THANK YOU for the opportunity to interview you."

Patient/Parent Surveys Data Collection and Preliminary Analysis

- Collected from seven visits to the Dimock Center
- Consent form was obtained before participation
- Basic summary statistics were generated using Stata IC13

Community Involvement: Dr. Sengupta notified the research team of times when the highest volume of surveys could be collected based off of volume of appointment times.

Provider Interview Results

Provider Interview Results: Definitions of Engagement

How providers define patient engagement	Sample quotes
Its about building rapport	“Um, and a lot of our patients are families that have been living in Roxbury and coming to this clinic for 30 years, so, myself and some of the newer staff have a harder time maybe making a connection with the families right away. They don’t trust us right away, which is understandable.”
Engage with patients around issues beyond their health care	"I don’t jump right into the content, I try to find something to make the patient comfortable… You read; you read faces, you read actions, you read how someone is in the moment. And even if you have a rapport with someone, if you've seen them several times, there might be something going on their day that makes them present very differently…

Provider Interview Results: Factors that influence engagement in health and nutrition services

Factors	Sample quotes
Social Determinants of Health	"... so our patients generally come from a lower socioeconomic status, which you guys probably already know, so, um, there is a lot of, a ton of issues outside of their health that are kind of, um, just, [pauses] I don't know, like on top of their life. Just every part of their lives, so they may not have the of um, the strategies, and the, um, abilities to manage their health like other people may be able to, if that makes sense
Stigma (specifically around engagement in nutrition services)	""And I think we see a lot of kids that are bullied and that may not come out until future visits. They may not want to talk about it because they are super embarrassed by it"

Provider Interview Results: Barriers to Engagement in Health and Nutrition Services

Factors	Sample quotes
Difficulty patients have following up/coming in to multiple visits	"... so our patients generally come from a lower socioeconomic status, which you guys probably already know, so, um, there is a lot of, a ton of issues outside of their health that are kind of, um, just, [pauses] I don't know, like on top of their life. Just every part of their lives, so they may not have the of um, the strategies, and the, um, abilities to manage their health like other people may be able to, if that makes sense
Stigma (specifically around engagement in nutrition services)	""And I think we see a lot of kids that are bullied and that may not come out until future visits. They may not want to talk about it because they are super embarrassed by it"

Provider Interview Results: Facilitators to Engagement in Health and Nutrition Services

Factors	Sample quotes
Provider Strategies -Focusing on Face time -Goal setting/Small steps -Providers coordinating with each other during patient visit	"If I'm here and I'm available I'll go in, I'll meet with them and try to schedule them an appointment at that time or at the very least if they're not interested in scheduling today, I'll at least give them my card and say give us a call…if I'm not available ideally they would make an appointment at the front desk before they leave and if that doesn't happen I'd have to follow up for them…call and reach out to them." "I recommend kind of small steps that they can take and realistic changes because especially when you're working with a family let's say you have a kid who's very overweight and you wanna really come at get them making changes if you try to say things like 'hey let's change everything' it's overwhelming and it's not gonna happen also especially with children focusing less on weight and more on just no their lifestyle habits is definitely helpful just because it can you know weight is a touchy subject especially with kids and a lot of times if parents get defensive they kind of shut down" "We do umm try to overlap services for example if a patient is coming for an asthma check or a flu shot or you know a behavioral health visit or something that's unrelated to that comprehensive exam we do try to kind of overlap services so we save them extra trips"

Patient/Parent Survey Results

(Please note, due to time constraints only limited findings are available. We hope to fully analyze the survey in the near future)

Parent Survey Results: Demographics

Total Number of Parent participants (n=16)

Race

Black	37.5% (n=6)
White	0% (n=0)
Two or more races	18.75% (n=3)
Prefer not to say	6.25% (n=1)
Other	37.5% (n=6)

Hispanic

Yes	37.5% (n=6)
No	62.5% (n=10)

Gender

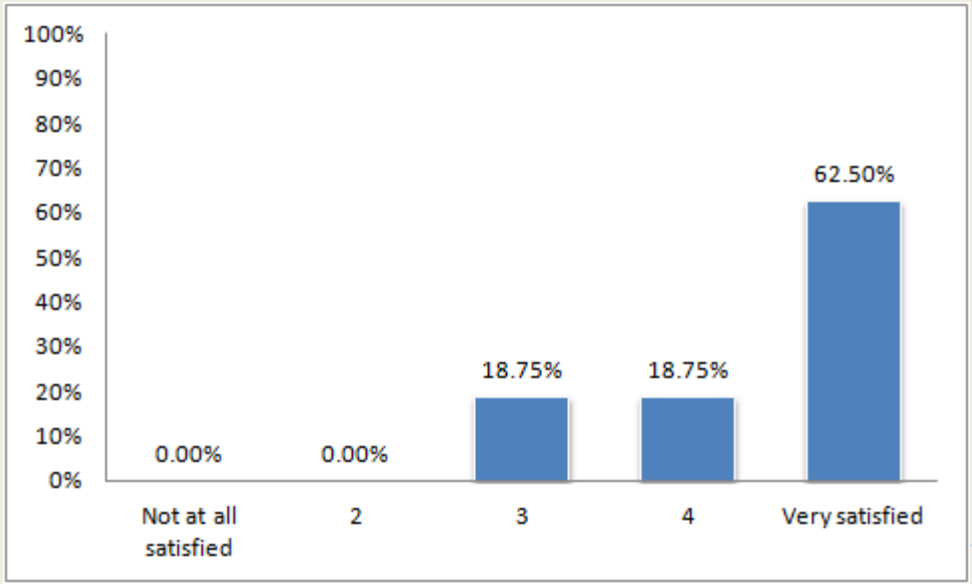
Female	81.25% (n=13)
Male	18.75% (n=3)

Years a Patient at Dimock

0-2	43.75% (n=7)
3-5	18.75% (n=3)
6-9	6.25% (n=1)
>9	12.5% (n=2)

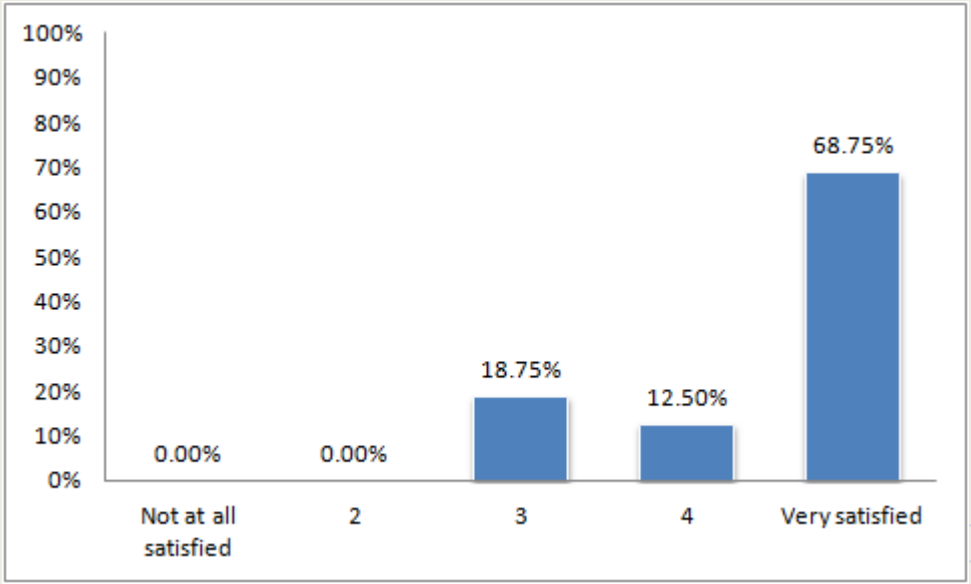
Parent Survey: Satisfaction with child's health care services (n=16)

Figure 1: Overall, how satisfied are you with the health care services your child has received at Dimock?
(Scale of 1-5 with 1 being "not at all satisfied" and 5 being "very satisfied")



Parent Survey: Comfort discussing child's health with provider (n=16)

Figure 4:Overall, how comfortable do you feel discussing your child's health with their healthcare provider at Dimock? *(Scale of 1-5 with 1 being "not at all satisfied" and 5 being "very satisfied")*



Patient Survey Results: Demographics

Total Number of patient participants (n=5)

Race

Black	60% (n=3)
White	0% (n=0)
Two or more races	20% (n=1)
Prefer not to say	20% (n=1)
Other	0% (n=0)

Hispanic

Yes	20% (n=1)
No	80% (n=4)

Gender

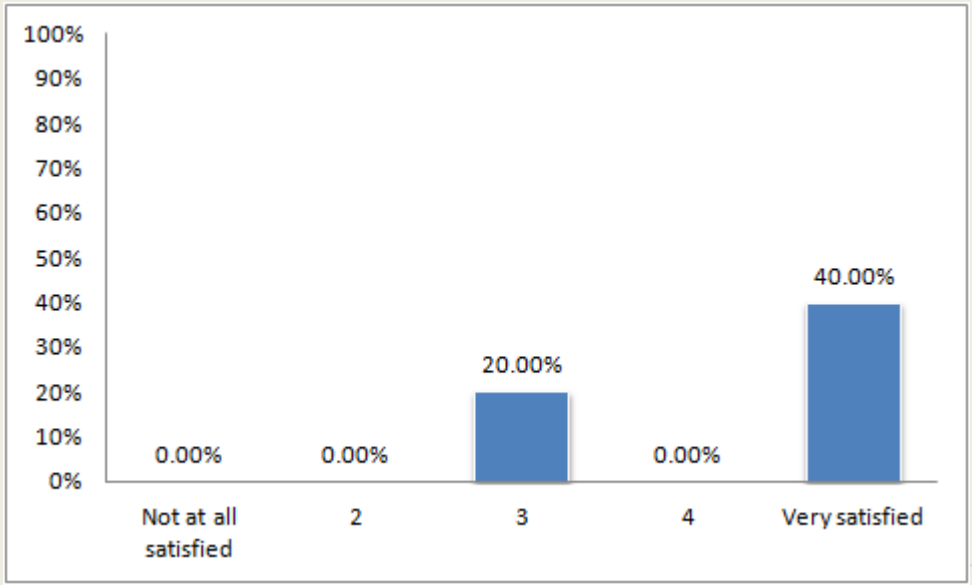
Female	100% (n=5)
Male	0% (n=0)

Years a Patient at Dimock

0-2	0% (n=0)
3-5	0% (n=0)
6-9	0% (n=0)
>9	60% (n=3)
No response	40% (n=2)

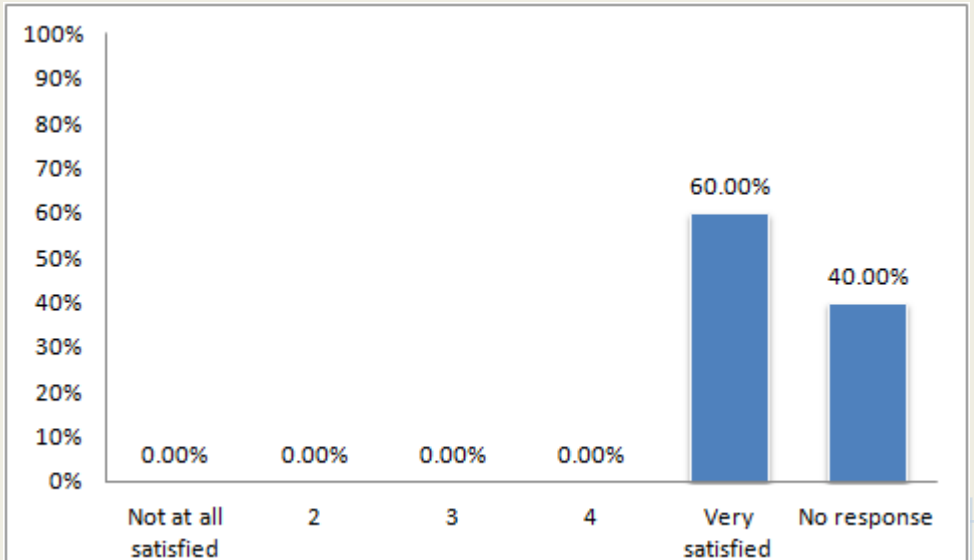
Patient Survey Results: Satisfaction with health care services received (n=5)

Figure 3: Overall, how satisfied are you with the health care services you receive at Dimock? *(Scale of 1-5 with 1 being "not at all satisfied" and 5 being "very satisfied")*



Patient Survey Results: Comfort with discussing health with provider (n=5)

Overall, how comfortable do you feel discussing your health with your healthcare provider at Dimock? *(Scale of 1-5 with 1 being "not at all satisfied" and 5 being "very satisfied")*



Overall Recommendations

From Provider Interviews:

- Continue to emphasize provider-provider coordination
- Continue to address social determinants of health for patients
- Continue to emphasize face to face interactions and focus on trust and rapport building
- The role of stigma in preventing engagement particularly in nutrition services is important
- Providers have great strategies that they are using that should be shared (if they aren't already!)

From Patient/Parent Surveys:

- Patients/parents are quite satisfied with the care they are receiving at Dimock however it would be helpful to continue to some of the comments raised in the qualitative portion of the patient/parent survey
  - Address logistical concerns such as wait times and scheduling (raised in the qualitative portion of survey)
  - Work to provide more clarity around communication of health terminology

Limitations

We recognize the following limitations of our research process:

- Small sample size for Provider interviews and Parent/Patient surveys
- Mostly female Parent/Patient respondents (n=18)
- Each sample was convenient
- Patient and Parent data was self reported
- Missing data (came in the form of lack of completion of all questions in each survey)

CBPR Lessons Learned

- Set a timeline and keep to deadlines
- Keep each other (members of the research team) accountable
- Maintain communication with community partner
- Be flexible
- Be patient; there will be disagreements but this happens everywhere
- Listen to all who have something to say
- Be professional but approachable
- Keep community needs in mind at all times

Thank You!

Thank you so much for support of our work this entire academic year.

Dr. Nandini Sengupta
Dimock Staff and Providers
Patients and Parents Surveyed

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Assessing Community Engagement at Dimock: Reflections on Community Partnerships in Health Research

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Delivering high-quality, low-cost health care to countless Bostonians, the Dimock Center provides support, treatment, and preventive services to mitigate the health inequities experienced by many individuals in Boston's communities. The Dimock Center, established in the mid-19th century as the New England Hospital for Women and Children, has experienced drastic changes in its patient population since it first opened its doors, but the health center's mission, "to heal and uplift individuals, families, and our community," has remained constant (The Dimock Center). It is a community institution that has been recognized nationally as a model for providing low-cost, comprehensive healthcare services to the urban communities of Roxbury, Dorchester, Mattapan, Jamaica Plain, and Hyde Park. In addition to primary care, the Dimock Center delivers programs in women's health, OB/GYN, HIV/AIDs, eye care, and dentistry to thousands of individuals and families each year. Its vision is to treat and support individuals, families, and the wider Dimock Center patient community and to redefine the model of a healthy community by creating equitable access to comprehensive health care and education. Through direct health services, community-based interventions, and collaborations with many of Boston's community organizations, the Dimock Center seeks to reduce racial health disparities by addressing patients' individual and social health. It was through collaboration like this that a leader at the Dimock Center sought to better understand how patients engage with the health center, as described in this manuscript.

In the 2014-2015 academic year, a group of nine students enrolled in a Tufts University Community Health Program (CHP) seminar class collaborated with the Dimock Center in a yearlong community-based participatory research (CBPR) project called *ACE: Assessing Community Engagement at Dimock*. Informing and supporting us in our project with Dimock was Dr. Nandini Sengupta, the Dimock Center's Medical Director, who played a vital role in the structuring and implementation of our research. At the Dimock Center, Dr. Sengupta wears many hats, as she serves administrative, research, and clinical roles. She emphasizes the importance of communication and teamwork with her staff and prioritizes the cultural knowledge of the patient community to engage individuals and families. Regarding the patients as the managers of their own health, Dr. Sengupta empowers her patients by validating their health practices. Dr. Sengupta developed the impetus for our project, which focused on how Dimock patients engage with their healthcare providers, what strategies are currently in place to facilitate patient engagement, and how these methods can be improved. Along with our research team supervisor and professor, Dr. Shalini Tendulkar, Dr. Sengupta co-facilitated this project to emphasize the value and conduct of community-based and community-engaged research as a tool to improve community health. This manuscript reflects our experiences over the course of the academic year. The research team, referred to as such throughout this manuscript, was composed of Dr. Sengupta, Dr. Tendulkar, and the nine Tufts undergraduate students. The research aimed to learn more about how Dimock Center staff members define patient engagement, assess their

perceptions of patient-provider relationships, understand patient perspectives related to trust and confidence in the healthcare staff, and the barriers to accessing health services.

Since 1975, CHP has provided students with a diverse, integrative experience in learning. The program's relatively small size encourages a sense of community among fellow students, faculty, and staff. As a multidisciplinary program, CHP touches on diverse aspects of health and society, and encourages the exploration of health issues from a variety of perspectives. CHP is an ideal major for students interested in pursuing careers in health-related fields, including but not limited to: public health, health policy, health economics, social work, health care, or medicine. Students gain an understanding of factors that shape health policy and the institutions that plan, regulate, and deliver healthcare services. Through classes and fieldwork, CHP exposes students to the major health issues of today and of the institutions that plan and deliver services, the variety of social, psychological, environmental, cultural, and political factors that influence decision-making about health and health care, as well as the ways people maintain health and cope with illness. The program is multidisciplinary in nature, drawing students from all academic majors, and includes courses in economics, public health, epidemiology, medical ethics, history, and sociology as they relate to health and health care. CHP students analyze the factors that determine health and illness, how communities define and try to resolve health-related problems, the formation of healthcare policy in the United States with a comparative look at other countries, and the institutions that plan, regulate, and deliver healthcare services **(**Tufts University 2015).

The ACE project was initially focused on understanding patient engagement specifically in the context of pediatric nutritional services; however, with the input of Dr. Sengupta, we expanded our objectives to encompass patient engagement in pediatric services in general. The research team identified the appropriate methodology to understand the questions of interest and developed two data collection instruments – a provider interview guide and a patient survey – after: numerous tool development conversations, a review of the literature, and a tool piloting process. The student researchers subsequently conducted key informant interviews with seven Dimock healthcare providers and administrators and collected surveys from 21 patients in English.

Through our engagement in a CBPR project with Dimock, we as a student research team experienced many of the benefits and challenges of implementing this type of project and this particular approach to research. We describe our key reflections below.

Reflection #1: The Value of CBPR

For the upperclassmen in our research group who had conducted research in the past, whether health-based or not, the CBPR method provided a new lens through which they viewed research. In looking back on her year in the research group, one student commented, "I was very excited about this course when we first met last fall and it has thus far exceeded my expectations because I have finally connected my in-class academic learning with hands-on community-based learning." Grounding our prior knowledge gained from other community health courses in our work with Dimock served as a transformative experience for us. Rather than basing our project goals on our own assumptions, involving our community partners at Dimock in every step of the project process provided us with a more informed approach to conducting our research. Unlike a traditional research approach, CBPR enabled us to incorporate our community partner's knowledge, opinions, and values into our work to inform our decisions. This sort of approach also provided Dr. Sengupta with the opportunity to be involved in the entire research process.

CBPR is about combining different perspectives to inform research and ultimately create social change in communities.

Reflection #2: The Importance of Building Rapport

Our student team, consisting of undergraduates ranging from college freshman to seniors, developed an efficient and collaborative dynamic in the year. Early on in the process, we divided group roles and assigned tasks to provide every team member with the opportunity to be a leader and gain new skills. The seniors in the course served unofficially as mentors to the underclassman. This mentorship manifested in the form of sharing skills and provision of support related not only to the project but also to general mentorship related to extracurricular activities and internships. One of the underclassmen student researchers reflected, "I think the team works really well together. We are really good at building off of others' ideas and creating a quality product. Everyone is very receptive to criticism and suggestions because we all know that our primary objective is to provide the best and most thorough research. Without the research team dynamic, I think that we wouldn't be as cognizant of factors that we didn't realize were important." For example, while our focus was on directing our efforts to the health center, this project also provided us with an opportunity to engage in difficult conversations around race and privilege. These conversations emerged in discussions, such as those we had around the development of tools, when we were considering issues related to language and literacy. Our instructor recognized that in order to effectively engage in these discussions, developing rapport and trust among each other would be necessary; there were efforts throughout the year to provide us with opportunities to have meals and classes together specifically to share our own personal and professional interests and life experiences. This allowed us to build connections with each other and provided a framework to discuss racial equity in community health research. Ultimately, for many of us, the research never actually felt like work because we saw how our involvement in this project reflected on our own lives and families and because we were able to build such great rapport with each other. CBPR grounded our personal experiences to our research project. Unlike what a traditional approach would offer, CBPR enabled us to personalize the research and put faces to the people that we were working with.

Reflection #3: Comfort with Discomfort

In addition to building rapport with each other, CBPR is also about building rapport with our external partners. Many of us were apprehensive but excited and optimistic about embarking on a research project that involved a high level of engagement with a partner outside of Tufts. For most of us, this was our first time implementing a CBPR project. Initially, students expressed concerns about being viewed as outsiders by both the healthcare providers and the patients. Assuring us, Dr. Tendulkar emphasized that discomfort and uncertainty were natural parts of the CBPR process and encouraged us to work through the discomfort in order to develop our methods and goals and better support our community partner. We also implemented several strategies to acquaint ourselves with the community environment and minimize the discomfort of the experience. For example, we conducted observational site visits to the Dimock Center and practiced how we would approach staff and patients at Dimock. We also created scripts to help us have these conversations more systematically. Dr. Sengupta encouraged us to explore these hesitations throughout the process as she provided us with direction in our project and collaborated with the research team to create goals, which guided us in the already difficult task

of defining abstract concepts, such as patient engagement. She also took great care to ensure that every visit to Dimock was structured and that we felt supported while on the premises.

Reflection #4: Time and Distance Challenge Student Engagement in CBPR

As part of our work, we also reflected on the challenges that are inherent with CBPR and identified two specific things that challenged our ability to engage with our partner, namely time and distance constraints. As a student research group involved with the Dimock Center for the 2014-2015 academic year, we often struggled to balance our many school commitments with our desire to form a strong relationship with our community partner. Many of us would have liked to visit the Dimock Center more frequently; however, the distance and scheduling issues posed a great challenge. We found that meeting in-person with our partner was very difficult to schedule, especially because we are not only 45 minutes away from the Dimock Center via public transportation but are also full-time college students. We were also mindful of the fact that our partners at the Dimock Center could not drop everything that they were doing to help us with our research project.

Many members of the group were unable to spend large amounts of time physically at the Dimock Center. In regards to her experience with these difficulties, one student researcher stressed the value of setting realistic goals. She stated, "more often than not both parties were busy doing other things, so it was hard to meet. Although I know it was completely necessary to get Dr. Sengupta's input to make sure the surveys were the best that they could be, it still felt like a very slow process." Despite our best efforts, it was difficult to find the opportunity to engage as closely and frequently with our community partner as we would have liked. If we were to improve this process, more efficient scheduling practices would be necessary. Many of us felt that spending more time at the Dimock Center would have provided us with more opportunities to form stronger relationships with a greater range of Dimock Center staff and patients and develop a more holistic understanding about the organization and its impact on the surrounding neighborhoods. Likewise, more in-class discussion about our impact on the Dimock Center population and background on successful CBPR projects in the past would greatly facilitate the research process.

Despite these barriers, working closely with our community partner, Dr. Sengupta, reinforced the collaboration between our research group and the Dimock Center and it was an integral component to the success of the project. This collaboration is an inherent component of CBPR that makes this type of research unique and well-received with community members. This successful process is very much due to Dr. Sengupta's experience not only with her organization, but also with the neighborhood and patient community.

Conclusion

In summary, our research project, ACE: Assessing Community Engagement at Dimock, provided us insight to the values of CBPR and tied our classroom learning to hands-on learning. ACE offered us new perspectives to the benefits and challenges of this alternative method of research. Overall, our work with Dimock throughout the year was incredibly enjoyable and rewarding, and our partners at Dimock were essential in pushing this project forward.

~

We would like to thank our community partner, Dr. Nandini Sengupta, MD and our professor, Dr. Shalini Tendulkar, ScD, ScM for their continuous support, guidance, and dedication through this project. We would also like to extend our thanks to Shirley Mark, the Tisch College of Citizenship and Public Service, and the Tufts Spirit Fund for their encouragement and commitment to our efforts. Lastly, we would like to thank the patients and providers of the Dimock Community Health Center for their collaboration and hard work that made our research possible.

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