Engaging Communities in Obesity Prevention: A Case Study of Partnership Dynamics and Participant Experience in Community Based Participatory Research

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Abstract

Community Based Participatory Research (CBPR) has been proposed as a potentially effective research approach for addressing complex public health issues such as obesity, particularly in traditionally marginalized populations such as new immigrants. However, much remains to be understood about creating and maintaining successful CBPR partnerships. Additionally, the potential pathways for CBPR efficacy have been understudied. This dissertation conducted a case study of Live Well, a CBPR trial to prevent obesity in new immigrant women, in order to contribute to our understanding of the operationalization and mechanisms of CBPR, exploring portions of the pathway from CBPR process to outcomes by analyzing both the CBPR partnership and the study participants.

For the first study, interviews were conducted with community-academic partners in fall 2010 and winter-spring 2012 (n = 16 at each point). Interviews were coded for themes related to organizational dimensions. Ten interrelated themes arose: goals, roles, sociometric structure, power structure, decision making, perception of conflict, communication, capacity, contextual influences, and complexity. Analysis showed that over time informal interpersonal structures superseded formalized structures and helped the group to work from a foundation of a sense of shared purpose and mutual respect and commitment to one another.

The second study explored associations of the Live Well participants' perceptions of intervention relevance and responsiveness with their attendance and self-reported adherence to the intervention. Participants (n =124) reported overall high perceived relevance and responsiveness. Relevance of information ($p < .01$), relevance of activities ($p < .00$), and sense of voice being considered ($p = .02$) were each significantly positively associated with self-reported adherence but not with group or individual session attendance, after adjusting for covariates.

In the third study, 13 Live Well participants were interviewed about their experience of Live Well. Interviews were analyzed for themes related to the project's integration into their lives. Seven dominant themes arose including: summary statements, activities or information experienced as useful, the social experience, family effect, empowering/empowered experiences, experiences with the staff, and changes in lives. Overall participants reported having very positive, even life changing, experiences in the Live Well program and that it integrated well into their lives. The elements that the women described as most important in their experiences were also components of the intervention that had specifically been co-created by the academic-community partnership.

We conclude that using CBPR is complex, but has the potential to increase the efficacy of public health research and interventions at least insofar as it may contribute to more appropriate and relevant research design and this may enhance study acceptance and adherence. The findings of this thesis particularly underscore the critical human element that makes participation work.

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Section I

Introduction

Researchers, clinicians, and public health practitioners are recognizing that addressing a complex health issue such as obesity requires addressing social as well as biological determinants of disease [1]. Community Based Participatory Research (CBPR) has been proposed as a promising approach to do this [2], yet there has been little study of the process of operationalizing the principles of CBPR in research or of the mechanisms for how following these principles might impact study outcomes. The purpose of this thesis was to conduct a case study of a CBPR randomized controlled trial to assess and prevent obesity in new immigrants, collecting the data during the time period while the CBPR study was ongoing in order to contribute to our understanding of the operationalization and mechanisms of CBPR and to explore portions of the pathway from CBPR process to outcomes by analyzing both the partnership and the study participants. We were particularly interested in this case where the CBPR approach was being used for understanding and addressing a complex public health problem – obesity – in a traditionally under-researched population – new immigrants.

Aims and Hypotheses

The specific aims and hypotheses of this dissertation were:

Within a CBPR randomized-controlled intervention to prevent obesity in new immigrant women and children

Specific Aim 1: To apply an organizational theory lens to a community-academic partnership to explore the dynamics that are mechanisms of the partnership function while following the basic principles of CBPR over the "life course" of the intervention.

Hypothesis 1: *There will be discernable dynamics of the partnership that are complex and non-linear, and established through the ongoing negotiation of roles, goals, and project meanings.*

Specific Aim 2: To assess the associations between the perceived program relevance, responsiveness, program attendance and adherence for program participants.

Hypothesis 2: *Participants with higher levels of perceived relevance and responsiveness will have higher attendance and self-reported adherence.*

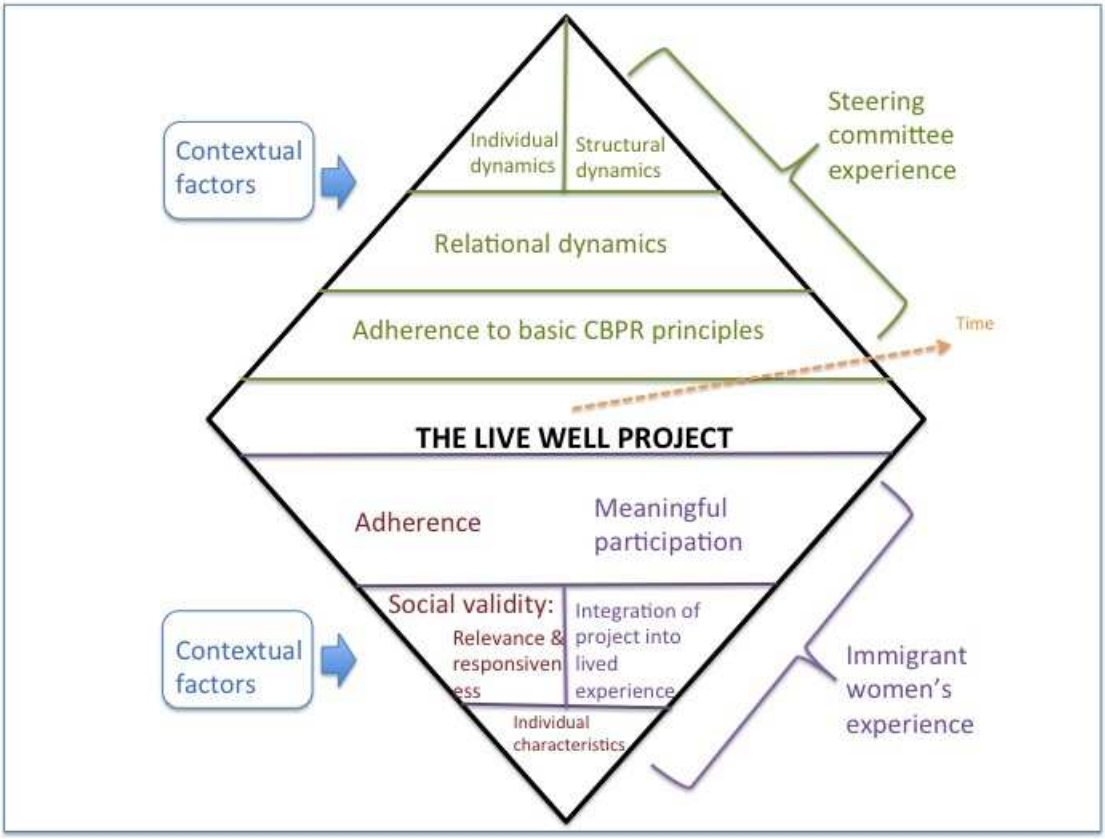
Specific Aim 3: To explore the experiences of new immigrant women participating in the intervention, particularly the conditions and meanings that underlie intervention relevance and nutrition or physical activity behavior change.

Hypothesis 3a: *There will be identifiable commonalities among the experiences of the women that relate to the design and organization of the intervention, the meaning they generate from it, and how they incorporate this into their lives and behavior.*

Hypothesis 3b: *There will be different commonalities among women who were successful (weight loss or maintenance) and unsuccessful in the program.*

The conceptual framework for this work is as follows:

Figure 1: Conceptual Framework



This framework provides a visualization of the different components of this research project and how they fit within the larger case of the Live Well project. The "Live Well project", which includes every element of the Live Well randomized controlled trial (RCT) from conceptualization to recruitment to measurement to retention to dissemination, lies at the center of the research. On one side of it (above it, in the model) is the steering committee (SC), an academic and community partnership, that conducted the research, and that created, implemented, and reported on the project. The elements of interest were the dynamics of the SC as well as the contextual factors that came into play in adhering to the principles of CBPR throughout the course of creating and implementing the project. (Time is in a 3rd dimension, moving from conceptualization to implementation to dissemination of

findings and sustainability.) The variables explored in the data were those suggested by organizational theory as important in the functioning of an organization, which was the lens that was applied in analysis of the SC. The experiences of the SC were analyzed to explore and reveal in what ways the SC members experienced Live Well as an organizational system.

On the other side of the Live Well project were the immigrant women who were in the intervention created by the SC. Their experience of the intervention and the impact it had on their health behaviors was likely to have been influenced by the way the project was designed. It is likely that an intervention designed with community input could increase adherence because it is perceived as being more relevant to the participants and more responsive to their needs and lived experiences. Additionally, through examining the experience of program participants, it may be possible to better understand the meaning that participants took from their participation and the ways they integrated it into their lives and behavior, including whether the design of the intervention (particularly the "CBPR-ness" of it) emerged as having played an important role. This would be indicated by the emergence of variables such as empowerment, a sense of their voices being heard and of being important to the project, and being motivated to participate because of elements of the program design.

Review of the Relevant Literature

The Obesity Epidemic

Public health is currently facing a number of intractable problems, and among the most serious is the prevalence of obesity, particularly because of the association between obesity and increased risk of a number of chronic diseases including cardiovascular disease and type II diabetes [3]. Obesity has reached epidemic proportions in the United States and is widely acknowledged to be a major public health concern [4, 5]. In low-income, poorly-resourced communities and among ethnic minorities the prevalence of overweight and obesity tends to be particularly high [6-10]. While apparently a simple problem caused by an imbalance between calories consumed and calories expended, obesity is in fact a complicated problem to address because it has biological, psychological, and societal underpinnings [11-13]. Obesity has remained an urgent public health problem in spite of millions of research and programmatic dollars spent in trying to prevent and reduce it [14]. In order to address the high prevalence of obesity, focused, evidence-based changes must be made, including at the policy and community levels [1, 6].

Obesity in Immigrants

Obesity is a particular problem for immigrants to the United States. While the majority of immigrants come to the U.S. with lower rates of obesity and other chronic diseases than the general US population, the longer they stay the higher their obesity and disease rates climb, converging on the population-wide rates [15-19]. Immigrants

tend to face socio-economic and racial/ethnic health disparities as well [8]. As with obesity in general, the underlying causes of increases in obesity among immigrants are complex, related to a variety of issues ranging from low socio-economic status, lack of time, language barriers, poor access to healthy foods or facilities for physical activity, poor access to healthcare, discrimination, identity threats, acculturation, and stress [20-23]. Given the high medical costs associated with obesity, estimated at $147 billion per year in 2008 [24], along with the high rates of immigration to the United States (some estimates project that by 2050, 1 in 5 Americans will be foreign born [25]) both the obesity epidemic in general and obesity in immigrants are critical issues to address [26-28]. Yet, very little research has been done on interventions to prevent excess weight gain among new immigrants to the United States.

The recognition that the roots of these individual level diseases are related not only to individual behavior but also to multiple levels of influence, including the social and built environments, has stimulated an interest in engaging the communities impacted by the health problems in research and treatment/intervention [29]. The turn toward community engagement is reflected in the growth of a variety of approaches to research on and treatment of public health problems like obesity including patient-centered trials, translational research, action research, and participatory research. In fact, Healthy People 2020 emphasizes collaboration among different groups and diverse stakeholders as a strategy to improve health [4], and funding for public health projects is increasingly contingent on including community engagement [30, 31].

Community Engagement in Research

There are two central reasons for engaging communities in research and intervention. The first is moral. There is an ethical imperative to engage the community impacted by the problem and empower them in creating its solution. This stands especially in contrast to the way past research has often been conducted and has contributed unwittingly to increased marginalization and disempowerment or misunderstanding of communities experiencing health problems. Community engagement, on the other hand, is grounded in principles of fairness, justice, empowerment, and self-determination [32-35]. The second reason for engaging communities is related to efficacy. Decades of research have started to make a case that community engagement/participatory research can be efficacious in creating change, including both individual level health changes and policy/community-level systems changes [36]. The rationale in the literature for the ways in which community engagement can improve research efficacy include:

- Bringing together diverse skill sets
- Enhancing the relevance of the findings
- Improving the external validity of the research
- Creating theory that is grounded in social experience
- Generating intervention designs that are more appropriate for the study population
- Increasing capacity to recruit, retain, or involve communities that have traditionally been marginalized or hard to reach
- Providing additional sources of funding

- Increasing participants' commitment to the research process
- Increasing likelihood that published findings accurately represent communities

[37, 38].

Community engagement can take many forms and engage many different types of partners from individuals to organizations. Research can also vary greatly in the level of engagement they seek from community members, ranging from reviewing plans to community members being engaged as full partners/collaborators in research and intervention [39]. All types of community engagement share some of the same foundations and can benefit from improved understanding of engagement practices and processes.

Community Based Participatory Research

Community Based Participatory Research (CBPR) is currently one of the most widely recognized forms of engagement in public health research [30]. The goal of CBPR is to engage members of affected communities as collaborators in research on the issues that affect them thereby, ideally, both generating useful and applicable new knowledge and democratizing the knowledge generating process to increase communities' capacity to address their own needs [36]. Israel and colleagues have proposed 9 principles to define CBPR research:

1) Acknowledges community as a unit of identity

2) Builds on the strengths and resources within the community

3) Facilitates a collaborative, equitable partnership in all phases of the research, involving an empowering and power sharing process that attends to social inequalities

4) Fosters co-learning and capacity building among all partners

5) Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners

6) Focuses on local relevance of public health problems and ecological perspectives that attend to the multiple determinants of health

7) Involves systems development, and is a cyclical and iterative process

8) Disseminates results to all partners and involves them in wider dissemination

9) Includes a long-term process and commitment to sustainability

[40, 41].

The Challenge of Implementing CBPR

Community participation is increasingly an essential aspect of successful research and of translating research into practice, yet the challenges of it means that many researchers and their partners struggle with how to operationalize participatory research principles across the lifespan of their efforts. How CBPR principals actually translate into research practices has been little studied [42-44]. CBPR grows out of complex situations - there are usually large power and resource differentials between the academic researchers and the community partners. While models for conducting CBPR exist, they provide only general guidance, and few academics receive training in the implementation of participatory research. Indeed,

this has been called a "serious gap in academe [45]." Training opportunities in how to put CBPR principles into practice are just now starting to be available, and such opportunities are still limited and would greatly benefit from more of an evidence base on the process of CBPR implementation [44, 45]. Partnering is undertaken with the a goal of deriving a collaborative advantage, combining and leveraging complementary capabilities, but just as often partnerships result in more frustration than function [46]. For the most part, our understanding of CBPR partnership functioning grows out of process evaluations that look at partners' assessments of how well the partnership is functioning – for example, level of trust, satisfaction with level of input, satisfaction with communication and power sharing, perceptions of cohesiveness and perceived effectiveness at achieving goals – combined with retrospective reports on lessons learned [47-50].

These types of assessments of CBPR partnerships and projects have revealed a variety of barriers to partnership functioning and facilitators of partnership functioning. Barriers have included: lack of trust, inequitable distribution of power, conflicts from differing perspectives on roles, differing opinions on funding, and a sense of the community just "rubber stamping" projects rather than having the opportunity to give substantive input. Facilitators/lessons learned have included: jointly identified operating norms, common objectives, democratic leadership, having support staff, and academics who are skilled at community engagement [2, 38, 39, 41, 51-56]. In spite of the usefulness of these assessments of barriers and facilitators, we still have a limited understanding of the dynamics of how a partnership works through barriers and implements facilitators. Our understanding

of and ability to implement CBPR would benefit from more research carried out longitudinally while CBPR projects are ongoing to analyze how CBPR actually works in practice, with the goal of understanding mechanisms that contribute to efficacy of community engagement [53].

Organizational Theory as a Lens for CBPR

Because a CBPR partnership calls for individuals with widely different backgrounds and areas of expertise to work together, our understanding of how CBPR partnerships can work most effectively could benefit from drawing on the research from other fields that explore the interface between individual psychology, relationships, social dynamics, and culture. One such field providing a particularly useful, as well as novel, lens for analyzing the group dynamics of a CBPR partnership, is organizational theory. There are numerous definitions for what an organization is and wide variation of characteristics amongst organizations; however, most analysts agree that organizations are "social structures created by individuals to support the collaborative pursuit of specific goals. [57]. As such, a CBPR research project and all those involved can certainly be seen as an organization. In the context of CBPR, organizational theory underscores the importance of considering goals, the formalization of power structures, leadership, participants and their motivations, negotiation, and contextual elements [57, 58]. This is important when considering process in participatory research because these are closely related to some of the challenges frequently arising when working to initiate and sustain participation from partners over the course of a CBPR project [38, 51, 55].

Organizations as Systems

There are three major perspectives generally used in analyzing organizations. They are: organizations as rational systems, as natural systems, and as open systems [57]. The rational system perspective focuses on the centrality of goals for driving organizational behavior. This perspective assumes relatively high specificity of goals and a relatively formalized structure [57, 59, 60]. The natural system perspective contends that, although organizations may appear to have specific goals, often the behavior of participants in the organization are not driven by them, nor do the goals necessarily predict an organization's behavior. Rather, this perspective argues that organizations are collections of individuals pursuing multiple interests only some of which are shared, but that the organization provides an important resource for them in their pursuit of their goals [57, 61, 62]. This perspective also emphasizes the importance of the informal social structure that develops between the people involved in an organization over the importance of the formal structure [63]. Finally, the open system perspective recognizes organizations not as entities but as systems of interdependent activities. It is not the organization that is important but the organizing. This perspective emphasizes even more than the other two that individuals have multiple loyalties and identities and that both the resource and institutional environments within which the organization exists are critical. In this definition, the persistence of an organization is dependent on the ongoing production and reproduction of activities through interactions between individuals [57, 64, 65]. No one of these perspectives on organizations is necessarily *the* correct perspective.

Any one can be applied to a particular organizational event to help elucidate what happened and why, however one may be more useful than another in a given instance.

Gaps in Understanding The Mechanisms of CBPR

That there are dynamics that contribute to successful CBPR partnering is not the only hypothesis implicit in the models of CBPR or the rationales given for using CBPR. It is also largely an untested assumption that successful partnering increases the likelihood that an intervention will be relevant to the community in question or the likelihood that the community will feel represented; nor is there much research looking at whether research and interventions that integrate into the lived experience of the community will increase the likelihood of intervention success. A few studies have assessed community partners' perceptions of the research process [66, 67]. However, there is a dearth of research that explores the experiences of the community members who comprise the study population in a CBPR project, and how they experience the research. Yet, exploring and analyzing the experience of participants in a CBPR intervention could further our understanding both of meanings that underlie health behaviors for those individuals and of how the tailoring of the intervention through community participation impacted the participants' experiences and behavior.

Current models of CBPR propose that potential elements of intervention success that could grow out of community engagement and more appropriate research design include increased adherence, behavior change, more sustained change, diffusion of innovations and eventual systems/policy change [68, 69]. But,

potential mechanisms for CBPR efficacy are rarely tested - including the assumption that research and intervention carried out through CBPR is more likely to be relevant to and responsive to the study population and that this will improve the likelihood of positive outcomes. We know of one study that assessed community members' perceptions of trust, benefit, and burden in a CBPR study. This study found the community members had overall high levels of trust and perceived benefit [37]. Another community-based nutrition intervention for diabetes prevention in African American women analyzed the relationship between program satisfaction, cultural relevance, attendance, and dietary pattern, and found that cultural relevancy predicted greater satisfaction and changed dietary pattern, and this was mediated by attendance [70].

In conclusion, researchers and community members interested in undertaking community engaged or participatory research could benefit from research that enhances our understanding of the dynamics involved in operationalizing participatory principles as well as research that contributes to the understanding of what pathways can lead to greater efficacy when using participatory research.

References

1. Huang T, Drewnowski A, Kumanyika S, Glass T: **A systems-oriented multi-level framework for addressing obesity in the 21st century**. *Preventing Chronic Disease* 2009, **6**(3).
2. Shalowitz M, Isacco A, Barquin N, Clark-Kauffman E, Delger P, Nelson D, . . . Wagenaar K: **Community-based participatory research: A review of the literature with strategies for community engagement**. *Journal of Developmental and Behavioral Pediatrics* 2009, **30**(4):350-361.

3. Must A, Spadano J, Coakley E, Field A, Colditz G, Dietz W: **The Disease Burden Associated With Overweight and Obesity**. *The Journal of The American Medical Association* 1999, **282**(16):1523-1529.
4. **Healthy People 2020 Objectives**. In. Edited by Services USDoHaH; 2010.
5. **White House Task Force on Childhood Obesity report to the President**. In.: White House Task Force on Childhood Obesity; 2010.
6. Ogden C, Carroll M, Curtin L, Lamb M, Flegal K: **Prevalence of High Body Mass Index in US Children and Adolescents, 2007-2008**. *Journal of the American Medical Association* 2010, **303**(3):242-249.
7. Sobal J, Stunkard A: **Socioeconomic status and obesity: A review of the literature**. *Psychological Bulletin* 1989, **105**(2):260-275.
8. Williams D, Mohammed S, Leavell J, Collins C: **Race, socioeconomic status, and health: complexities, ongoing challenges, and research opportunities**. *Annals of the New York Academy of Sciences* 2010, **1186**:69-101.
9. **CDC Health Disparities and Inequality Report – United States, 2011**. In: *Morbidity and Mortality Weekly Report.* vol. 60(suppl.): Centers for Disease Control and Prevention; 2011: 73-77.
10. Ogden C, Carroll M, Kit B, Flegal K: **Prevalence of Childhood and Adult Obesity in the United States, 2011-2012**. *Journal of the American Medical Association* 2014, **311**(8):806-814.
11. Swinburn B, Caterson I, Seidell J, James W: **Diet, nutrition and the prevention of excess weight gain and obesity**. *Public Health Nutrition* 2004, **7**(1A):123-146.
12. Nestle M, Jacobson M: **Halting the obesity epidemic: a public health policy approach**. *Public Health Reports* 2000, **115**(1):12-24.
13. Finkelstein E, Ruhm C, Kosa K: **Economic causes and consequences of obesity**. *Annual Review of Public Health* 2005, **26**:239-257.
14. Flegal K, Carroll M, Ogden C, Curtin L: **Prevalence and Trends in Obesity Among US Adults, 1999-2008**. *Journal of the American Medical Association* 2010, **303**(3):235-241.
15. Goel M, McCarthy E, Phillips R, Wee C: **Obesity among US immigrant subgroups by duration of residence**. *Journal of the American Medical Association* 2004, **292**(23):2860-2867.
16. Kaplan M, Huguet N, Newsom J, McFarland B: **The association between length of residence and obesity among Hispanic immigrants**. *American Journal of Preventive Medicine* 2004, **27**(4):323-326.
17. Oza-Frank R, Cunningham S: **The weight of US residence among immigrants: a systematic review**. *Obesity Reviews* 2010, **11**(4):271-280.
18. McDonald J, Kennedy S: **Is migration to Canada associated with unhealthy weight gain? Overweight and obesity among Canada's immigrants**. *Social Science and Medicine* 2005, **61**(12):2469-2481.
19. Lauderdale D, Rathouz P: **Body mass index in a US national sample of Asian Americans: effects of nativity, years since immigration and socioeconomic status**. *International Journal of Obesity* 2000, **24**(9):1188-1194.

20. Neuhouser M, Thompson B, Coronado G, Solomon C: **Higher fat intake and lower fruit and vegetables intakes are associated with greater acculturation among Mexicans living in Washington State**. *Journal of the American Dietetic Association* 2004, **104**(1):51-57.
21. Lara M, Gamboa C, Kahramanian M, Morales L, Bautista D: **Acculturation and Latino health in the United States: a review of the literature and its sociopolitical context**. *Annual Review of Public Health* 2005, **26**:367-397.
22. Gordon-Larsen P, Harris K, Ward D, Popkin B: **Acculturation and overweight-related behaviors among Hispanic immigrants to the US: the National Longitudinal Study of Adolescent Health**. *Social Science and Medicine* 2003, **57**(11):2023-2034.
23. Devine C, Sobal J, Bisogni C, Connors M: **Food Choices in Three Ethnic Groups: Interactions of Ideals, Identities, and Roles**. *Journal of Nutrition Education* 1999, **31**(2):86-93.
24. Finkelstein E, Trogdon J, Cohen J, Dietz W: **Annual medical spending attributable to obesity: Payer- and service-specific estimates**. *Health Affairs* 2009, **28**(5):w822-w831.
25. Passle J, Cohn D: **U.S. Population Projections: 2005-2050**. In: *Pew Research Center Social and Demographic Trends.* Pew Research Center; 2008.
26. Colditz G: **Economic costs of obesity and inactivity**. *Med Sci Sports Exerc* 1999, **31**(11 Suppl):S663-667.
27. **Population Projections -U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin**. In. Washington DC: United States Census Bureau; 2009.
28. **Statistical Portrait of the Foreign-Born Population in the United States, 2008**. In. Washington DC: Pew Hispanic Center; 2010.
29. Economos C, Irish-Hauser S: **Community Interventions: A Brief Overview and Their Application to the Obesity Epidemic**. *The Journal of Law, Medicine & Ethics* 2007, **35**(1):131-137.
30. Horowitz C, Robinson M, Seifer S: **Community-based participatory research from the margin to the mainstream: Are researchers prepared?** *Circulation* 2009, **119**(19):2633-2642.
31. Minkler M, Wallerstein N: **Appendix B, Tracing federal support for participatory research in public health**. In: *Communitybased participatory research for health.* edn. San Francisco: Jossey-Bass; 2003: 410–417.
32. Freire P: **Pedagogy of the Oppressed**. New York: Continuum; 1970.
33. Wallerstein N, Duran B: **Using community-based participatory research to address health disparities**. *Health Promotion Practice* 2006, **7**(3):312-323.
34. Alinsky S: **Rules for Radicals: A Pragmatic Primer for Realistic Radicals** New York: Random House; 1971.
35. Minkler M, Wallerstein N: **Community-Based Participatory Research for Health: From Process to Outcomes**, 2 edn. San Francisco: Jossey-Bass; 2008.
36. Viswanathan M, Ammerman A, Eng E, Gartlehner G, Lohr K, Griffith D, . . . Whitener L: **Community-based participatory research: Assessing the**

evidence. In: *Evidence Report/Technology Assessment No 99.* Rockville, MD: Agency for Healthcare Research and Quality; 2004.

37. Ammerman A, Washington C, Jackson B, Weathers B, Campbell M, Davis G, Garson-Angert D, Paige Rev J, Parks-Bani C, Joyner M *et al*: **The PRAISE! Project: a church-based nutrition intervention designed for cultural appropriateness, sustainability, and diffusion**. *Journal of Health Promotion and Practice* 2002, **3**(2):286-301.
38. Israel B, Schulz A, Parker E, Becker A: **Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health**. *Annual Review of Public Health* 1998, **19**:173-202.
39. Chunga K, Lounsbury D: **The role of power, process, and relationships in participatory research for statewide HIV/AIDS programming**. *Social Science and Medicine* 2006, **63**:2129–2140.
40. Israel BA, Parker EA, Rowe Z, Salvatore A, Minkler M, Lopez J, Halstead S: **Community-based participatory research: Lessons learned from the centers for children's environmental health and disease prevention research**. *Environmental Health Perspectives* 2005, **113**(10):1463-1471.
41. Schulz A, Israel B, Selig S, Bayer I: **Development and Implementation of Principles for Community-Based Research in Public Health**. In: *Research Strategies for Community Practice.* edn. Edited by MacNair RH. New York: The Haworth Press, Inc; 1998.
42. **Principles of Community Engagement, 2nd Edition**. In.: Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement; 2011.
43. Cargo M, Mercer S: **The value and challenges of participatory research: strengthening its practice**. *Annual Review of Public Health* 2008, **29**:325-350.
44. Burke J, Hess S, Hoffman K, Guizzetti L, Loy E, Gielen A, Bailey M, Walnoha A, Barbee G, Yonas M: **Translating Community-Based Participatory Research Principles Into Practice**. *Progress in Community Health and Partnerships* 2013, **7**(2):115-122.
45. Griffith D, Citrin T, Jerome N, Bayer I, Mebane E: **The Origins and Overview of the W. K. Kellogg Community Health Scholars Program**. *Progress in Community Health and Partnerships* 2009, **3**(4):33-348.
46. Lasker R, Weiss E, Miller R: **Partnership synergy: A practical framework for studying and strengthening the collaborative advantage**. *Milbank Quarterly* 2001, **79**:179-205.
47. Schulz A, Israel B, Lantz P: **Instrument for evaluating dimensions of group dynamics within community-based participatory research partnerships**. *Evaluation and Program Planning* 2003, **26**:249–262.
48. Roussel A, Fan N, Fulmer E: **Identifying Characteristics of Successful Researcher/Community- Based Organization Collaboration in the Development of Behavioral Interventions to Prevent HIV Infection**. In. Edited by CDC, vol. Task Order No. 0621-26.; 2002.

49. Christopher S, Watts V, McCormick A, Young S: **Building and Maintaining Trust in a Community-Based Participatory Research Partnership**. *American Journal of Public Health* 2008, **98**(8):1398-1406.
50. Sánchez V, Carrillo C, Wallerstein N: **From the Ground Up: Building a Participatory Evaluation Model**. *Progress in Community Health and Partnerships* 2011, **5**(1):45-52.
51. Shoultz J, Oneha M, Magnussen L, Hla M, Brees-Saunders Z, Dela Cruz M, Douglas M: **Finding solutions to challenges faced in community based participatory research between academic and community organizations**. *Journal of Interprofessional Care* 2006, **20**(2):133-144.
52. Friedman Ross L, Loup A, Nelson R, Botkin J, Kost R, Smith G, Gelher S: **The Challenges of Collaboration for Academic and Community Partners in a Research Partnership: Points to Consider**. *Journal of Empirical Research on Human Research Ethics* 2010, **5**(1):19-31.
53. Pinto R, Spector A, Rahman R, Gastolomendo J: **Research advisory board members' contributions and expectations in the USA**. *Health Promotion International* 2013.
54. Roussos S, Fawcett S: **A review of collaborative partnerships as a strategy for improving community health**. *Annual Review of Public Health* 2000, **21**:369–402.
55. Benoit C, Jansson M, Millar A, Phillips R: **Community-Academic Research on Hard-to-Reach Populations: Benefits and Challenges**. *Qualitative Health Research* 2005, **15**(2):263-282.
56. Kelly K, Van Vlaenderen H: **Dynamics of Participation in a Community Health Project**. *Social Science and Medicine* 1996, **42**(9):1235-1124.
57. Scott W: **Organizations: rational, natural, and open systems**, 4 edn. Upper Saddle River, NJ: Pearson Education, Inc.; 2003.
58. Dubrin A: **Leadership: Research Findings, Practice, and Skills**, 5 edn. Boston: Houghton Mifflin Company; 2007.
59. Simon H, Smithberg D, Thompson V: **Public Administration**. New York: Knopf; 1950.
60. Simon H: **Administrative Behavior: A Study of Decision Making Processes in Administrative Organizations**, 4 edn. New York: Free Press; 1997.
61. Michels R: **Political Parties**. Glencoe, IL: Free Press; 1949(trans).
62. Gouldner A: **Organizational Analysis**. In: *Sociology Today.* edn. Edited by Merton R, Broom L, Cottrell L. New York: Basic Books; 1959: 400-428.
63. Gross E: **Some Functional Consequences of Primary Controls in Formal Work Organizations**. *American Sociological Review* 1953, **18**:368-373.
64. Weick K: **The Social Psychology of Organizing**. Reading, MA: Addison-Wesley; 1969.
65. Weick K: **Middle Range Theories of Social Systems**. *Behavioral Science* 1974, **19**:357-367.
66. Sullivan M, Kone A, Senturia K, Chrisman N, Ciske S, Krieger J: **Researcher and researched community perspectives: toward bridging the gap**. *Health Education and Behavior* 2001, **28**:130-149.

67. Lantz P, Viruell-Fuentes E, Israel B, Softley D, Guzman R: **Can communities and academia work together on public health research? Evaluation results from a community-based participa- tory research partnership in Detroit**. *Journal of Urban Health* 2001, **78**:495-507.
68. Minkler M: **Linking science and policy through community-based participatory research to study and address health disparities**. *American Journal of Public Health* 2010, **100**(Suppl 1):S81-87.
69. Francisco V, Butterfoss F: **Social Validation of Goals, Procedures, and Effects in Public Health**. *Health Promotion Practice* 2007, **8**(2):128-133.
70. Williams J, Auslander W, de Groot M, Robinson A, Houston C, Haire-Joshu D: **Cultural Relevancy of a Diabetes Prevention Nutrition Program for African American Women**. *Health Promotion Practice* 2006, **7**(1):56-67.

Section II

Research Design and Methods

Research context

Live Well was a randomized controlled lifestyle intervention (NIH grant 5R01HD057841) designed to encourage obesity prevention behaviors in new immigrant women. It was developed and implemented using CBPR strategies. The central premise of the study was that an appropriately timed intervention, co-created by community and academic partners, can prevent excess weight gain in new immigrant mothers (less than 10 years in the US and aged 22-55y) and children (3-12y) from Haiti, Brazil, and Latin America living in the greater Somerville, MA area. These three populations constitute major immigrant groups in the northeast [1].

A steering committee (SC) was formed at the beginning of the study and worked on the study through all of its stages, including proposal writing, study conceptualization, implementation, data collection, analysis, interpretation, and dissemination. The SC met on a monthly basis to discuss and make decisions about all aspects pertinent to the project. There was also frequent communication through emails and phone calls. The committee consisted of professionally and culturally diverse members including three project coordinators who could communicate fluently in Spanish, Portuguese, or Haitian-Creole; a project manager; Tufts researchers and students representing different specializations such as nutrition, sociology, public health, and engineering; and representatives from five local

community organizations that work closely with the immigrants in Somerville, MA. These community organizations include: 1) The Immigrant Services Providers Group/Health (ISPG); 2) The Welcome Project; 3) Brazilian Women's Group; 4) The Haitian Coalition; and 5) The Community Action Agency of Somerville.

Although the funding for the Live Well project started in 2007, relationships between the community and Tufts researchers had been built prior to this through two other CBPR projects in the Somerville area, Shape up Somerville[2] and the New Immigrant Occupational Safety and Health (NIOSH) grant [3], as well as through work on formative research [4].

A total of 383 mother-child dyads were recruited and had baseline assessments taken. Recruitment was undertaken in two cohorts: the first cohort completed baseline measurements in Spring 2010, and the second was enrolled and completed measurements in Spring and early Summer 2011. Participants were recruited from three groups, designed to represent the largest new immigrant populations in the greater Somerville, MA area: a "Haitian" group, a "Brazilian" group, and a pan-ethnic "Latina" group that included women from Central and South America and the Caribbean (e.g. El Salvador, Dominican Republic, Peru, Honduras, Colombia).

After baseline assessments, the women were randomized to a control or intervention group. The intervention group (N = 215) participated in small group sessions conducted every other month by a project coordinator. The groups were divided by language and were conducted in the native language of the women in the small group. The sessions used a learner-centered nutrition and physical activity curriculum, co-created by the partners on the SC, which drew on popular education

and used problem posing and dialogue to facilitate the women in speaking about their health behaviors and making healthy changes [5]. In the months that the intervention group women did not have a small group session, they had an individual motivational interviewing session with a project coordinator to discuss progress on individual nutrition or physical activity goals. The first cohort of women received a two-year intervention, the first year curriculum focused on nutrition, physical activity, and stress reduction and the second year focused on active citizenship and organizing around health issues the women identified as important. The second cohort of women received the first year of the intervention with only the nutrition, physical activity, and stress reduction curriculum.

Methods: Specific aim 1

Data for this aim were collected through individual interviews with the members of the Live Well SC. The main researcher was a doctoral student with a research interest in CBPR who participated throughout the intervention as a participant-observer on the SC. Interviews were conducted in two rounds - first in the fall of 2010, second in the winter-spring of 2012 - in order to capture the experiences of SC members at multiple time points. All participating members of the SC at each time point (N=20; N=18) were invited to be interviewed. The final number of interviews was 16 individuals at each time point and included the spectrum of members. Those who were not interviewed had either left the project due to leaving an organization or were unable to find a time they could be interviewed after 5 scheduling attempts.

Interview times lasted 45 minutes - 2 hours and averaged 70 minutes. Interviews were conducted using a semi-structured interview guide as described below. Interviews were recorded, transcribed, and analyzed using QSR NVivo10 [6]. To develop the interview guide, first we conducted an extensive review of tools used for evaluating CBPR partnership process, including asking for resources from the Community-Campus Partnerships for Health List Serve. Based on this review we created a matrix of elements of CBPR process to be aware of in our interviews. Then we evaluated where these elements from CBPR process overlapped with domains/concepts from Organizational Theory to guide our development of questions and probes for the interviews (appendix A) [7-9]. Questions were designed to elicit conversation about motivations, goals, committee structure, group dynamics, the roles played by self and others, project meaning, and perceptions of group effectiveness. However, rather than asking about these concepts directly, questions asked interviewees to recount direct experiences in narrative form because our goal was to understand committee dynamics through the experiences of committee members [10, 11]. Questions asked for accounts of how and why the individual became and stayed involved in the project, how they and others had contributed to the project, and events they saw as critical or memorable during the course of the project (appendix B).

Interviews were coded line-by-line and analyzed for themes. Themes were refined over multiple readings. The dimensions of organizations were used to guide the theming. These dimensions are: the social structure, goals, technologies, participants, and the environment. Participants are the individuals who make contributions to the organization for a variety of inducements. The social structure is

the patterned elements of relationships between the participants. Goals are the ends that participants desire and are trying to achieve through their participation in the organization. Technologies are the means by which materials the organization deals with are transformed; this is a broad term in this context and could be anything from the machinery that processes metal into cars to the means by which an orchestra organizes and creates music. Finally, the environment is specifically the environment from which an organization draws inputs and which the organization influences through outputs. All of these dimensions influence and are influenced by one another [12]. Themes unrelated to organizational dimensions were also allowed to inductively emerge as appropriate. Themes were grouped into organizational dimensions and examined to determine their underlying concepts. The way concepts were spoken about at different time points were compared. We also frequently referred back to full interviews to ensure quotes were contextualized within the narratives of the individual from whom they came. Themes and a subset of de-identified key-quotes were shared with SC members for discussion before finalization. Finally, themes and concepts were analyzed in the context of organizational theory, exploring the ways in which Live Well, as experienced by SC members, fit or did not fit with rational, natural, and open system views of an organization.

Methods: Specific aim 2

Measurements

Perceived relevance and responsiveness:

Short questionnaires were administered to the Live Well participants at the end of the study as part of a longer survey. The questionnaires for the participants

who had been in the intervention group consisted of survey items asking the participants to rank their perceptions of program relevance, program responsiveness, and self-reported adherence, on Likert-type scales. To assess relevance, participants were asked to rank how relevant the information from Live Well had been in their lives on a 5-point scale and how relevant the activities from Live Well had been in their lives on a 5-point scale. To assess responsiveness participants were asked to rank whether Live Well felt like it was designed more for someone like them or for somebody else on a 3-point scale and how much they felt like their voice (thoughts and opinions) were taken into consideration by the people implementing the project on a 5-point scale (appendix C).

Community partners were consulted in the development of the questions and checked the final questions and amended them to ensure accessibility of wording and cultural validity. The questionnaires were translated into the native languages of the participants and back translated to ensure accuracy. The participants were told before receiving the questionnaire that it would not influence their ability to participate in future programs and that their honest answers would be the most helpful because they could contribute to improving future programs.

Attendance/adherence:

Attendance was recorded at group sessions and individual sessions by the study coordinator facilitating that session. In the questionnaires administered at the end of the study, participants were also asked to self-report their adherence with a single questionnaire item: “On a scale from 1-5 where 1 means not at all and 5 means

all of the time, how well would you say you stuck with the health changes you started because of Live Well?"

Covariates:

Demographic information and other descriptive data were collected through self-administered surveys that were completed at the baseline measurement. Variables collected included ethnic group, time in country, marital status, level of education, number of children, employment status, and self-perceived acculturation. Self-perceived level of acculturation was rated using the following statement: "When you think about your daily life now, where would you place yourself?" Participants answered using a 10-point scale with 1 indicating "More American" and 10 indicating "More Brazilian/Latino/Haitian."

Statistical analysis

Of the 215 intervention group women who had data collected at baseline, 15 dropped out, 49 were lost to follow up, and 17 became pregnant during the intervention. 135 intervention group women had final assessments taken, and of these 124 completed the additional questionnaire at the end of the study. We used SPSS version 18 [13] for all data analysis. We used chi-square tests to compare the intervention-questionnaire respondents to the overall group on descriptive characteristics such as education level and employment status. We examined frequency distributions of relevance, responsiveness, attendance, and adherence measures in the intervention-questionnaire response group. We used one-way analysis of variance or t-tests to compare distributions of continuous variables and we used chi-square or Fisher's exact tests to compare categorical variables between

ethnic groups (Haitian, Latina, Brazilian) and between intervention cohorts. Because of high inter-correlation between the variables, associations between perceptions of relevance or responsiveness with attendance or adherence were estimated using separate regression models. Group session attendance and individual session attendance were each converted to binomial variables (ie. high or low attendance) because of their non-normal distributions. Attendance in 50% or higher of each type of session was classified as high attendance in that type of session. Associations of the perceptions of relevance or responsiveness with attendance were estimated using logit models. Associations of the relevance or responsiveness variables with self-reported adherence were estimated using ordinal logistic regression. Models were adjusted for covariates we hypothesized may be related to perceptions of relevance or responsiveness and attendance or adherence, including ethnic group, recruitment cohort, duration of residence in the US, self-perceived acculturation, number of children under 18, and employment status. Finally, we used forward and backward stepwise regression in order to generate a model that considered all of the responsiveness and relevance measures plus our pre-specified covariates to address multicolinearity and to determine the most parsimonious models for predicting individual session attendance, group session attendance, and adherence in these data. Stepwise logistic regression was used for attendance and linear regression was used for adherence.

Methods: Specific aim 3

Participants were recruited from the intervention group of the larger Live Well study to participate in this aim. Purposive sampling was used to choose

and recruit participants who would be likely to have had a range of different experiences with Live Well. We sought to recruit women from each of the three language groups in the study, from both cohorts of the intervention group, women who had had high levels of attendance and participation as well as women with low levels of participation, and finally women who would or would not have likely noticed a perceptible change in their own weight. Participants meeting each of these criteria were identified and contacted through the study coordinators and asked if they would be willing to participate in a phone interview to talk about how they experienced Live Well. If they agreed, a time for a phone call was set up. Participants were recruited and interviews conducted until saturation was reached, with a goal of conducting no fewer than 9 and no more than 21 interviews. Interviews were conducted over the course of two weeks.

Phone calls were conducted with the aid of an interpreter fluent in the interviewee's native language hired from the Optimal Phone Interpreters company[14]. Interviews were conducted using a semi-structured interview guide that was developed based on a set of preliminary focus groups that had been conducted in the summer of 2011 with women from the first cohort of Live Well. The questions were well received by the women and elicited considerable discussion on subjects including meaningful participation, their roles in the project, and how the project has changed their lives. Thus, for the individual phone interviews we followed an interview guide that drew on the questions from the focus groups, however to minimize burden, the interview guide was considerably shortened and designed for interviews to last less than one hour (appendix E). After obtaining verbal consent to

be interviewed and recorded, the interviews began by asking how and why the interviewee had joined Live Well and about how the interviewee had experienced the Live Well project, leaving what to talk about completely open to the individual. This was followed with questions about how the interviewee had experienced the project specifically with regards to nutrition and physical activity. The interviewees were asked to describe any particularly positive experiences and negative experiences; and finally to tell stories of any instances when it felt like the people who had designed the project really understood the participant and what she needed in her life to improve her health and instances when it felt like she was not understood or the project did not fit what she needed in. Interviews ranged from 15-45 minutes and averaged half an hour.

Thirteen women were interviewed before reaching saturation. Interviews were recorded and transcribed verbatim. Transcripts were managed and analyzed using QSR NVivo 10[6]. Transcripts were read through in multiple passes, using line-by-line coding with 5 transcripts to inductively generate themes related to project relevance and the ways it did or did not integrate into the women's lives as well as behavioral implications of the integration of the project. These were used as a coding framework that was applied to all the transcripts. Themes were then analyzed for their underlying concepts and concepts were analyzed for their relationship to community involvement. Data were also sorted by the recruitment attributes in order to analyze whether women with different characteristics spoke about their experiences in noticeably different ways.

All aspects of this study were approved by the Tufts University Social, Behavioral, and Educational Research IRB.

References

1. Adventure FRBoBsNEE: **Largest Immigrant groups in each county**. In. Boston; 2000.
2. Economos CD, Hyatt RR, Goldberg JP, Must A, Naumova EN, Collins JJ, Nelson ME: **A community intervention reduces BMI z-score in children: Shape Up Somerville first year results**. *Obesity (Silver Spring)* 2007, **15**(5):1325-1336.
3. Hyatt R, Gute D, Pirie A, Page H, Vasquez I, Dalembert F: **Initiating the transfer of research capability in environmental justice within a community-based participatory research project – Bringing in the IRB**. *American Journal of Public Health* 2009, **99**:S526-S531.
4. Tovar A, Must A, Metayer N, Gute D, Pirie A, Hyatt R, Economos C: **Immigrating to the US: What Brazilian, Latin American and Haitian Women Have to Say About Changes to Their Lifestyle That May be Associated with Obesity**. *Journal of Immigrant and Minority Health* 2012, **15**(2):357-364.
5. Tovar A, Vikre E, Gute D, Kamins C, Pirie A, Boulos R, Metayer N, Economos C: **Development of the Live Well Curriculum for Recent Immigrants: A Community Based Participatory Approach** *Progress in Community Health and Partnerships* 2012, **6**(2):195-204.
6. **NVivo qualitative data analysis software; Version 10**. In.: QSR International Pty Ltd.; 2012.
7. Butterfoss FD: **Process evaluation for community participation**. *Annual Review of Public Health* 2006, **27**:323-340.
8. Schulz A, Israel B, Lantz P: **Instrument for evaluating dimensions of group dynamics within community-based participatory research partnerships**. *Evaluation and Program Planning* 2003, **26**:249–262.
9. Schulz A, Israel B, Selig S, Bayer I: **Development and Implementation of Principles for Community-Based Research in Public Health**. In: *Research Strategies for Community Practice.* edn. Edited by MacNair RH. New York: The Haworth Press, Inc; 1998.
10. Blumer H: **Symbolic Interactionism: Perspective and Method**. Berkeley: University of California Press; 1969.
11. Ospina S, Dodge J: **Narrative Inquiry and the Search for Connectedness: Practitioners and Academics Developing Public Administration Scholarship**. *Public Administration Review* 2005, **65**(4):409-423.
12. Scott W: **Organizations: rational, natural, and open systems**, 4 edn. Upper Saddle River, NJ: Pearson Education, Inc.; 2003.

13. SPSS Inc. Released 2009. PASW Statistics for Windows VCSI. In.
14. http://www.callopi.com

Section III

Results

An Organizational Perspective on the Dynamics of a CBPR Partnership – A Case Study of the Live Well Steering Committee

(Social Science and Medicine)

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Abstract

This study used a case study of a CBPR randomized controlled trial to explore the dynamics of an existing community-academic partnership. We sought to bring a new perspective to research on CBPR by analyzing the extent to which the experiences of the partners fit each of three organizational system perspectives – rational, natural, and open systems – in order to better understand the CBPR process and how a real world partnership worked. The members of the community-academic partnership were interviewed at two time points during the course of the intervention; these interviews were analyzed and coded for themes related to organizational functioning. A variety of interrelated themes arose, and the reflections of the partners around these themes revealed that while elements of the social and power structures of the partnership were formalized, much of the dynamics that helped the group function were informal and facilitated by opportunities for group bonding and building of strong interpersonal connections. Dynamics were complex and variable, and many were established through ongoing interaction. Over time the informal personal structures superseded formalized structures and helped the group to work from a foundation of a sense of shared purpose and mutual respect and commitment to one another. We conclude that understanding the complex, variable nature of the dynamics of a CBPR process through organizational theory can provide insight for researchers and practitioners, helping them have realistic expectations of the process, for example the degree to which the relationships and activities of a CBPR partnership can or should be formalized and the time it takes to build trusting, personal relationships.

Introduction

Researchers, clinicians, and public health practitioners increasingly recognize that addressing complex health issues requires addressing social as well as biological determinants of disease(Huang, Drewnowski, Kumanyika, & Glass, 2009). This has stimulated a shift to working at the community and policy levels to promote health, with the understanding that such work can result in sustained individual-level health behavior change(CD Economos & Irish-Hauser, 2007). Participatory Research (PR) in particular, has been proposed as an effective research and intervention method for working in a community-based manner to address complex public health problems

that have resisted traditional methods of intervention(Horowitz, Robinson, & Seifer, 2009; Shalowitz et al., 2009; Viswanathan et al., 2004). A growing body of evidence indicates that PR has the potential to improve health promotion and practice efforts (Staley, 2009; Viswanathan, et al., 2004). Currently Community Based Participatory Research (CBPR) is one of the most widely recognized forms of PR in health fields (Viswanathan, et al., 2004).

The goal of CBPR is to engage members of communities as collaborators on self-defined research questions. Ideally, this both generates applicable new knowledge and democratizes the knowledge generating process to increase communities' capacity to address their own needs (Viswanathan, et al., 2004). Israel and colleagues have proposed a set of principles for CBPR research that emphasize equitable participation and mutual benefit (Israel et al., 2005; Schulz, Israel, Selig, & Bayer, 1998). The ideal of equitable participation and mutual benefit is difficult to achieve in practice; according to an extensive review of PR literature, "Many academic researchers and their partners struggle with how to operationalize PR principles, steps, and guidelines across the lifespan of their PR efforts"(Cargo & Mercer, 2008). How CBPR principles are applied and experienced by parties who have widely different capacities for engaging in research and disparate access to resources remains relatively understudied (Principles of Community Engagement, 2nd Edition, 2011). There is a particular lack of research conducted during the time period while the research is ongoing and that includes the perspectives of both academics and community members.

A CBPR research partnership can be seen as an organization, for organizations are fundamentally "social structures created by individuals to support the collaborative pursuit of specific goals (Scott, 2003)." Therefore, organizational theory may provide an elucidating lens from which to analyze the process of working toward successful partnership in CBPR. Three major views of organizations predominate: organizations as rational, natural, or open systems (Table 1) (Gouldner, 1959; Gross, 1953; Michels, 1949(trans); Scott, 2003; Weick, 1969, 1974). No one of these perspectives on organizations is *the* correct perspective; each can be applied to events to elucidate what happened and why. The purpose of this study was to use a case study of a CBPR randomized controlled trial (RCT) to explore the dynamics of a community-academic partnership by analyzing the extent to which the experiences of the partners fit or did not fit each of these three organizational perspectives, to better understand the dynamics of a CBPR process and how a real world partnership worked toward equitable participation and mutual benefit. We have found no other studies using an organizational theory lens to examine important characteristics and processes of CBPR partnership functioning.

Methods

Context

Live Well was a randomized controlled lifestyle intervention (NIH grant 5R01HD057841) from September 2008-June 2012, designed to promote obesity preventive behaviors in new immigrant women, and developed and implemented using CBPR strategies. The central premise was that an appropriately timed

intervention, co-created by community and academic partners, could prevent excess weight gain in new immigrant mothers (less than 10 years in the US; aged 22-55y) and children (3-12y) from Haiti, Brazil, and Latin America, living in the greater Somerville, MA area. Study methods and baseline results have been described elsewhere (Tovar et al., 2013; Tovar, Hennesy, et al., 2012; Tovar, Vikre, et al., 2012).

A steering committee (SC) was formed at the beginning of the study, and worked through all of its stages, including proposal writing, study conceptualization, and implementation, meeting on a monthly basis to discuss and make decisions about each project stage. The committee consisted of professionally and culturally diverse members including three project coordinators fluent in Spanish, Portuguese, or Haitian-Creole; a project manager; Tufts researchers and doctoral students from departments of nutrition, public health, and engineering; and 1-2 representatives from each of 5 local community organizations that work closely with immigrants in Somerville. Although the funding for Live Well started in 2008, relationships between the community and Tufts researchers had been built earlier through 2 CBPR projects in the Somerville area (CD Economos et al., 2013; Hyatt et al., 2009), plus 2 years of formative research in preparation for grant submission.

Data Collection and Analysis

Data for this study were collected through individual interviews with Live Well SC members. The main researcher was a doctoral student with a research interest in CBPR who participated throughout the intervention as a participant-observer on the SC. Interviews were conducted in two rounds, first in the fall of 2010, second in the

winter-spring of 2012, in order to capture the experiences of SC members at multiple time points. All participating members of the SC at each time point (N=20; N=18) were invited to be interviewed. The final number of interviews was 16 individuals at each time point and included the spectrum of members. Those who were not interviewed had either left the project due to leaving an organization or were unable to find a time they could be interviewed after 5 attempts.

Interview times lasted 45 minutes - 2 hours and averaged 70 minutes. Interviews were conducted by the main researcher using a semi-structured interview guide. The guide was developed by conducting a literature review of tools and concepts from CBPR process evaluation and overlaying these with concepts from organizational theory literature. Rather than asking about concepts directly, questions asked interviewees to recount direct experiences in narrative form because our goal was to understand committee dynamics through the experiences of committee members (Blumer, 1969; Ospina & Dodge, 2005). Questions asked for accounts of how and why the individual became and stayed involved in the project, how they and others had contributed to the project, and events they saw as critical or memorable during the project. Questions were designed to elicit conversation about motivations, goals, committee structure, group dynamics, the roles played by self and others, and perceptions of group effectiveness. Interviews were recorded, transcribed, and analyzed using QSR NVivo10 (NVivo qualitative data analysis software; Version 10, 2012). All aspects of the study were approved by the Tufts University Institutional Review Board.

Interviews were coded line-by-line and analyzed for themes by the main researcher. Themes were refined over multiple readings. The dimensions of organizations were used to guide the theming (see Figure 1), however other themes were allowed to inductively emerge as appropriate. Themes were grouped into organizational dimensions and examined for underlying concepts. The themes and a sub-set of de-identified key-quotes were shared with SC members for discussion before finalization. Finally, themes and concepts were analyzed in the context of organizational theory, exploring the ways in which Live Well, as experienced by SC members, fit or did not fit with rational, natural, and open system views of an organization.

Results

Themes fell into four dimensions of organizations – goals, social structure, technologies, and environment. While themes emerged as distinct from one another, they were also integrally connected, all influencing and overlapping one another. (For a list of themes, concepts, and sample quotes see Appendix E.)

Themes within the goals dimension:

Goals: What SC members hoped to get out of the Live Well project - the reasons why they became and stayed involved - was a prominent theme in discussions. Committee members held goals at multiple levels: individual goals (eg. learning about CBPR, helping others, career goals); individual organizational goals (eg. organizational capacity building, serving or increasing a constituency); and project goals (eg. the goals stated in the grant proposal, goals of improving the health and

wellbeing of study participants, project sustainability). Goals shifted at times during the project to reflect the influences of different individual, individual organization, and project goals. Throughout the project, goals were held in tension, particularly when someone had a strongly held goal for their individual organization that did not clearly align with others' perceptions of overall project goals. However, most of the committee members also expressed a sense that while people had different individual and organizational goals, there was alignment on many central goals. As one committee member described, "we all started out in the beginning with a shared ideology about preventing obesity in these populations, and I think the reasons why we cared about that were different, but we all really cared about it." Though motivations reflect individual goals, committee members spoke about what *kept* them motivated to keep working on the project separately from speaking about individual goals. Motivators included a personal interest in the research question or the study population, the relationships built during the project, a belief in the power of CBPR, and a sense of fulfillment in knowing the project was doing good work. These powerful motivational elements reflect underlying psychological goals, particularly a desire for connection and a desire for self-actualization, that drove much of individual behaviors in the context of the project.

Themes within the social structure dimension:

Roles: Committee members defined themselves and others as falling into specific categories of roles frequently used in CBPR literature, particularly "community" or "academic." But most individuals on the committee also saw themselves or were seen by others as falling between those two categories into roles such as "student,"

"intervention staff," "facilitator," or "connector." Some roles people filled were assigned by the granting and hiring processes, others were roles people took upon themselves or that emerged through the process. Partners struggled with roles, particularly early in the project, because many felt roles were not clearly defined; there was overlap between roles; and there was lack of accountability for fulfilling the duties of some roles stemming from undefined expectations, particularly among the community partners.

Sociometric Structure: The sociometric structure described by committee members was one of close personal bonds, even friendship, formed both through the strengthening of existing ties and a variety of team bonding experiences. As one committee member explained, "I like everyone on it, I like seeing them, I like talking to them. So we are working on this really great project but I just, I look forward to our meetings and it's not just… another annoying meeting I have to go to." The majority of SC members had worked with at least one, and usually more than one, of the other partners prior to the start of Live Well. Additionally, the group grew close through bonding experiences that were outside of and different from the standard meeting context. For example, they attended a planning retreat, skill-building workshops on subjects in which none of the partners was an expert (eg. popular education and motivational interviewing), and held celebrations to mark holidays and personal events like weddings and births.

Power Structure: Committee power structure was diffuse. The grant leadership made a conscious effort to have all voices at the table as much as possible. As one observed, "once a voice is not there to articulate, to brainstorm, and finally decide

with you, you might lose that voice for a long time;" another pointed out, "I think that's how we managed. We brought everybody into the process." Within the purposeful power sharing, some hierarchical elements were perceived to exist, predominantly in the administrative and implementation aspects where a manager - who reported directly to the Principal Investigator (PI) - oversaw staff. Everyone in the group saw the PI as being the top position. However, the leadership and management of the project were also pulled off onto other projects at intervals, opening space for others to step into leadership roles. Shifts in power were perceived to occur in response to the capacities required to fulfill the requirements of different phases of the project. For example, academic partners were perceived (by both academic and community partners) to have had more influence on data collection and processing, and as having largely set the original budget of the grant. On the other hand, the community partners were seen as having greater influence on the design of the intervention and materials as well as in data interpretation.

Decision-Making: Group decision-making was described as predominantly collaborative. Decisions were made and problems solved through hearing all sides, discussing, negotiating, and coming to consensus. Through the process of the project, committee members came to feel that the decision-making process itself was as important as the resulting decisions and that incorporating all sides created synergistic results with ideas that no individual would have come to on their own. In one committee member's words, "when there's been an idea that has come potentially from an individual, maybe it was in some form, but through conversations in the steering committee, I feel like that's been one of the amazing

things with the steering committee is that it's like, through conversation it like really moves to a different level."

Perception of Conflict: Conflict was viewed as an important and necessary part of the CBPR process. Committee members referred to conflicts and contention as a sign that all sides were being brought into the conversations, that people cared about the project, and as an opportunity to learn from others. Partners frequently pointed out the way everyone had remained respectful of one another throughout even the most heated discussions. As one academic committee member explained, "you can't do this work and not be a diplomat. You can't do this work and not be willing to sit down and have an honest conversation."

Communication: Committee members described several venues through which communication in the group occurred, including face-to-face monthly meetings, phone calls, emails, subcommittee meetings, and sidebar conversations between individuals. Communication at group meetings was seen as a critical factor in keeping everyone on the same page and allowing for group decision-making. It was in these meetings that everyone had an opportunity to voice their opinions; staff provided feedback from the field; and subcommittees reported back on their work. Meetings were cited as where the most successful communication occurred. However, there were also challenges with communication that were perceived to arise because of the reliance on meetings as the main form of communication. The time required to attend meetings was a challenge for partners because all were balancing Live Well with other work. Involvement tended to drop off between meetings, and some members struggled to stay on the same page because they

didn't see a structure to facilitate between-meeting communication. Meeting time was sometimes used up on getting people on the same page, and other discussions had to be postponed. Informal communication between individuals was an important way people were able to share and negotiate their positions on the groups' decisions and stay up-to-date between meetings.

Themes within the technologies dimension:

Capacity: Partners described capacities of the partners and partnership itself; capacity building during the project; and areas of insufficient capacity. The main capacities perceived to be coming from the partners included: language and cultural capacities from staff and community partners; financial resources and research skills from the academic partners; and social capital, particularly from the community partners. Capacity was built intentionally and as a side effect of participation. Through discussions with each other in the committee meetings and through trainings led by either committee members with expertise or outside experts, the community partners increased their ability to engage in academic research and understand the science of obesity while academic partners increased their ability to understand and connect with the lived experience of the community. All partners felt they increased in their understanding of empowerment education techniques and community organizing through trainings.

Conversely, there were descriptions of missed opportunity for capacity building and frequent discussions of struggles arising from inadequate capacity. Lack of capacity - especially money, staffing, and time - was cited by academics, community partners, and staff as the reason community partners did not contribute

as much to recruitment, implementation, and measurement efforts as originally intended. Similar capacity shortfalls were cited as the reason for difficulty the group ran into in devising a project sustainability plan.

Themes within the environment dimension:

Contextual influences: A variety of contextual elements influenced the dynamics of the project. A major one was the many confounding events that took place during the course of the project. These events, such as an earthquake in Haiti (the home country of many study participants) and the start of economic recession in the U.S., influenced where partners' attention was focused and how the committee could reach and retain the study's target population. Another critical aspect of the context was previous work members of the SC had done together. Through this previous work the community and academic partners had increased familiarity with CBPR and what it takes to do participatory research. As one community partner put it, "we were more sophisticated coming into (Live Well) than we had been." An academic partner explained, "(in prior CBPR projects) it was novel for universities. It's much less novel now than it used to be four or five years ago...it was *really* novel for us. And we were used to having our investigator's meetings being with our colleagues, with a small group of like-speaking people."

Complexity: A related element of the environment was complexity faced by the SC. There was great complexity in the issues that the study participants faced on a day-to-day basis, including the challenges of immigration and adaptation to a new country. This impacted the project and the SC's decisions as they tried to focus on obesity within this complexity. In response, the design of the project itself became

very complex. One committee member summarized, "it's just a very multilevel project and it's got a lot of moving parts." Finally, the partners faced complexity within their own jobs. Only one person was full-time on the Live Well project. All the rest had competing commitments from projects, deadlines, and expectations in their other work.

Live Well as an Organization

By analyzing how SC members spoke about these themes, we can now explore the ways in which their experiences did or did not correspond with the expected characteristics of organizational dynamics according to the different perspectives on organizations as rational, natural, or open systems.

Live Well as a Rational System

The Live Well SC, viewed as an organization, fits some predictions of the rational system perspective. As often seen in organizations whose overarching goals are broad and value related – in Live Well, one member explained "we were really all on the same page, that what we really wanted was for people to live well" – the day to day operations were driven by more specific goals that provided obvious criteria for choosing work behaviors. Live Well was funded by the NIH as a randomized controlled trial, therefore the SC had a set of specifically defined goals stated in the grant application for the project, including recruiting a certain number of study participants and randomizing them, and implementing an obesity prevention intervention. These goals drove central aspects of the decision-making and group activity, particularly when goals were clearly evaluable and had

accountability measures in place for reaching them. Such a situation should theoretically lead to more rational and efficient behavior (Meyer & Rowan, 1977); this seemed the case with such situations in this group, for example recruitment. A number was set via statistical procedures and had to be reached. Accountability resided outside the group with a powerful interest, the funder. When the group was failing to recruit adequate numbers of participants, that specific goal acted as a trump card, where the need to get the numbers was more important than a more ideological goal the group held of keeping recruitment within the geographic area where the community-based organizations were based. One committee member expressed the view of many when she explained, "It was just the bottom line. We have to. We can't get the people that we need, and we need this many people. We're powered for this many people and if we don't get it then we aren't going to find anything and we're going to have to change our aims."

Similarly, because of budget cuts the group was required to restrict its focus part of the way through the project. Again, those goals seen to receive the most focus were those that were being evaluated and for which there was accountability. Although these decisions on focus were group decisions, they were challenges. As one partner described, "what happens is the grant itself, the grant process suffers. The basic knowledge piece will still be accomplished, so that doesn't get diminished…in a sense the group that takes the hit is the group outside which is the community because they're getting less…in the sense that it jeopardizes the further development of the process that we all created together."

Elements of power sharing were formalized, but much was informal. Early in the project, academic and community partners were formally brought in equally in the hiring of project staff, which committee members cited as critical in setting the tone for power sharing later on. Over time the group developed policies requiring that there would always be both academic and community partners included on any subcommittees the group assembled for specific tasks, including paper writing. They also put a policy in place to alternate monthly meeting locations between a university location and a community location. These policies were adhered to, and provided a critical backbone structure for power sharing, but they weren't described as being what ultimately drove power sharing. Based on the expectations set early by the formal decisions, on a day-to-day level much of the power sharing was described as occurring informally through individual commitments to the spirit of CBPR. Committee members shared the sentiment that everyone had something to contribute. Being able to "*really* listen" was given as the critical quality for participating in a partnership such as this.

Rather than individuals on the SC leaving aside their individual characteristics to fulfill particular job roles, roles were defined by individual idiosyncratic contributions, goals, and relationships. In the words of one academic, "I think each person brings a different skill set, and I don't mean that just community and academic, I mean each *individual* brings a different skill set." These characteristics typify a natural system more than rational system.

Live Well as a Natural System

Most elements of the social structure, including roles, the sociometric structure, and power structure, were perceived to have low levels of formalization. SC members saw themselves as having pre-defined roles as "community," "academic," "staff," or "student," but most also felt these roles were "not really that clear." Additionally, committee members expressed that with interaction over time, "the separations died away a bit. It was never hierarchical, but now people don't have the tags on them."

A number of SC members described being unsure where they or others fit within a formal power structure, and the post-doctoral researcher, doctoral students, and community partners all occasionally stepped in and played manager, staff, or even PI-like roles at times based on the project's needs. One committee member recounted, "I asked [another committee member] to draw me a chart of like, who's in charge, and who reports to who, and who am I responsible to, and she couldn't!"

Many aspects of the goals and motivations of the Live Well SC fit a natural system view. An implicit cost-benefit analysis of continuing participation was visible in individuals' recounting of the things that kept them motivated. Committee members were motivated by personal interests in addressing social problems; the opportunity to learn; a sense of the work being fulfilling; a sense of personal connection to others on the committee; and a strong belief in the potential of using CBPR to do good in the world. These personal goals and motivations, while separate from the stated goals of the committee as an organization, allowed coordination between individuals through establishing a collective purpose directed toward

"making a difference in people's lives," and the sense of "creating something together." In the words of one committee member, "it's a group of people who surprisingly uniformly have good social level or community level intentions. That want the project that can be successful not just for the Welcome Project or for the Immigrant Service Providers Group or for Tufts University but...within these three immigrant communities." A few committee members mentioned career advancement as a motivator, but it was always as a secondary factor, below other social and psychological goals.

The natural system lens argues the unifying purpose of an organization may change over time to ensure its survival (Gouldner, 1959). This is visible in the SC's reflections on sustainability. Sustainability was held as a value by all, but was proving to be a challenge at the end of the intervention's funded period. With the explicit goals of the grant achieved, sustainability took center stage as a goal with each member having their own motivation. Committee members spoke of sustainability in terms of: different potential operational goals that would require the continuation of the organization, including sustaining the relationships between the people on the committee to continue working together on any type of project; embedding the activities of the Live Well project into the community in some way to broaden the audience of people benefiting from activities; or turning the attention of the SC to some of the tangential findings and activities of the project in order to secure more funding and the organization's continuance. By the end of the funded project period, a new unifying concept had not been reached, and the SC continued to struggle with sustainability. As one person put it, "it has been difficult

to…produce some sort of closure, you know. Or key direction. You know, what's going to be the next step, you know? How are you going to concentrate your activities?" Everyone had individual goals that made them want to sustain the organization though the grant had no remaining stated goals to fulfill, but there was insufficient time or funds to complete the process of negotiating and arriving at a new common direction.

A natural system view of organizations emphasizes the existence of informal social structures and the coordination of cooperative behaviors that influence overall structure and function of organizations. The SC members' comments about the social structure and relationships in the committee centered on previously existing relationships that continued into the project and on the strong informal structure that developed among the members based on individual relationships and personalities. These were underpinned by experiences that "emphasized the human element" and allowed the committee members to get to know each other as "human beings." Each member brought their personality, not just their cultural or work role, into their participation.

During times members described as being particularly successful, the group allowed individuals to play to their strengths and contribute from their areas of capacity. This meant that the level of contribution did not always seem equal between all partners, and expectations and contributions had to be renegotiated. Early in the project, many partners expected all the work to be divided evenly; frustration and tension arose when adequate capacity wasn't there. In early interviews, many of the academic partners and staff complained, "the expectation of

the community members is almost like they tell us what they think needs to be done, but not to be a part of the doing." Over the course of working together, expectations shifted to focus more on giving people the opportunity to use the skills and capacity they *could* contribute, rather than asking them to do work they were not yet able to. One of the people who expressed the most frustration in the early interview, in the second interview reflected, "you can't necessarily expect it to be 50/50, and nobody can have that expectation. Everyone has what they can bring to the table."

As partners got to know where the others were coming from, they came to respect others' motivations and contributions more. Committee members often mentioned being inspired to work harder by seeing other members' commitment, being motivated to attend meetings because they enjoyed seeing the other members, and being willing to work through conflicts and solve problems because they believed everyone there was a good person and wanted what they wanted for good reasons. In the words of one member, "everyone is just really good hearted, and passionate, and kind. And it's great, everyone has kind of different agendas in what they're good hearted and passionate and kind about, but it's really awesome to see that." The personal relationships formed within the committee built a foundation of trust and understanding that contributed to the development of collective purpose and facilitated communication, power sharing, problem solving, and conflict resolution.

Within this informal relational structure there was an important role for committee members who acted as relationship brokers. These people - described

by others as having "a foot in both worlds" (the academic and community worlds) - participated in "side bar conversations" with other committee members and acted as sounding boards for ideas and complaints that people may have felt uncomfortable sharing in a group context. Brokers then communicated these ideas or complaints to those that needed to hear them to make sure the work continued to run smoothly. This was summarized by one committee member as he described the role he took on himself, "(I do) sort of like, coordinating… activities in such a way that this stuff could come in. And then sort of protecting it in a way...So I do a lot of listening to people over on the side… You know, 'oh so and so isn't blablahblah.' Brokering relationships." Another committee member described a broker, saying "he was in on *all* the information whether it was the scientific stuff that's harder to understand or whether it was having coffee with community members who at times weren't happy with the way things were going… I think he understood maybe where I was coming from, where they were coming from."

Formal power sharing was emphasized early in the work of the group, creating an atmosphere supportive of informal power sharing as well. Over time, power in the group was established through leadership abilities and enthusiasm of individuals. Individuals who were described as having shaped the vision of the group's work and influenced decisions did so not by exerting formally held power, but through inspiration, facilitation, responsiveness in discussions, and sometimes by being the proverbial squeaky wheel. When committee members spoke of other committee members whom they saw as having played leadership roles, they saw this as having happened through individuals' abilities such as: "taking the long view,

and trying not to personally get brought down by some of the challenges, and to help others problem solve and work through those;" being "skilled at directed facilitation;" and "handl[ing] herself admirably [in response to conflict and criticism]."

In addition to having relatively low levels of formalization, many of the elements of the power and sociometric structure were developed through interaction. Goals were held in tension and renegotiated in an ongoing manner through the project. These are characteristics predicted by an open system perspectives.

Live Well as an Open System

The influence of the environment on the structure and function of Live Well is visible in the data in a variety of ways. As expected from an open system, the environment required ongoing adjustments of the project and influenced many decisions. Feedback particularly came from the project coordinators who had the most interaction with the community and women in the intervention. Of particular note is how the dynamics of the SC strongly correspond with Weick's models of organizing (Weick, 1969, 1995). Almost nothing about the work of the committee was static. As described above, roles, relationships, systems of behavior, expectations, and the intervention itself were largely created through interaction. Beyond basic contracts set up in the grant, much of the work was carried out by establishing social and psychological contracts among the group members that were built through transparency, earning and maintaining trust, sharing power, consensus decision making, and being willing to participate and make contributions

beyond a narrowly defined work role. These types of behaviors were repeated over time until they became established behavioral systems. The dynamics shifted on an ongoing basis. One committee member explained, "the steering committee's focus and interests has evolved over time. From figuring out how we're doing what we're doing [to] how to work together."

An important example of how the project and group's way of working was established was visible in the decision to use popular education to engage the study participants around physical activity and nutrition. This process was described by most of the partners as "one of the best things we did together." The decision to use popular education took place at a retreat at which the partners shared meals and even bunkrooms. This intimate and unusual setting seems to have helped the partners step outside their set concepts of work roles and think more broadly in terms of what would be best for the project. One partner explained, "As soon as you go outside of a work environment and you are sitting on a lake in your jeans, and sharing meals, and talking about your life, and reflecting on your life, and sharing personal things with each other, you know, walls come down pretty quickly." Partners described how the interactions at the retreat set the stage for future work. One expressed, "I think for me that was kind of where it all happened!…where we got to know each other and understand… what people's roles were." They described how, "everybody was willing and able to listen to everybody else. So the community and the academic sides were having dialogues with, they weren't just meaningful dialogues, they were dialogues with consequences, and agreements, and working plans." The decision to use popular education was reached through extensive

discussion during which different points of view were synthesized into something new (Tovar, Vikre, et al., 2012). One partner explained, "it was kind of like the community members were more focused on the approach… whereas the academics were more focused on the content and not thinking about, well 'how are we going to deliver this?' but 'what we're delivering has to have research'...And I think that's why there ended up being kind of a perfect compromise."

Though there was no rule established about it, major early decisions were made by consensus, and this "set the stage" so all large decisions were made by consensus. From engaging in a consensus decision-making process, committee members felt they learned to trust that this process would result in more creative solutions to problems than any individual had to offer. One person summarized, "I realize that it's through the actual discussion that you get somewhere. It's not about someone being right or wrong, it's kind of the process."

As committee members grew closer to each other during the project they ceased to blame individuals when they didn't come through on something they were supposed to deliver. Instead, they were willing to look at the situation and assume that apparent negligence was actually the fault of bigger structures or capacity issues that weren't under the control of an individual (Fig. 2). Whereas people expressed frustration with one another in early interviews, this statement typifies the sentiments of later interviews: "I don't think he's maniacal or anything like that. I think it might be part of working with very small organizations that live grant by grant… I *get* that. I don't know if I got that earlier on." Similarly, the approach to dealing with conflict and the expanded understanding of others' roles and

motivations already described in the natural systems section was described as growing from interaction and reproduction of behaviors, rather than from organizational structures that had been put in place when the group formed.

Implications

Elements of rational, natural, and open systems all contribute to understanding the complexities of a CBPR partnership process in this case study. Many of the goals and social structural dynamics related to carrying out the research were formalized and created the foundation from which the group worked. Meanwhile, the dynamics that allowed the partnership to work successfully together over time - including communication, handling conflict, power-sharing, and collaborative decision-making - grew out of the development of close personal relationships, leading to greater trust and synergistic problem solving. This informal structure, and the interactions that created it by establishing shared systems of behavior and belief, became the most powerful drivers of how the group functioned.

As the use of PR grows, and its principles are applied in different contexts, there is increasing pressure to focus on best practices, replicability, and scaleability, focusing on formalized methods of achieving these goals. In the face of this push, it is important to remember that the "human" elements of PR, established through relationship building and ongoing interactions to create a common sense of purpose and a nuanced, generous understanding of others' roles and motivations, may be critical for effective group dynamics. This may be true of any work that brings together people and organizations with different backgrounds and strengths to address a common question or problem. Understanding the importance of this

complex and dynamic element may help researchers and community members enter PR better prepared.

This is similar to the findings of research on collaboration, which has shown that when personal relationships supplement formal relationships, the psychological contracts that arise from a sense of common purpose and mutual obligation may supplant formal contracts, and collaboration may be more successful over time (Ring & Van de Ven, 1994; Thomson & Perry, 2006). There may be no real substitute for time in creating the necessary relationships, thus extending the time, energy, and budget needed for a study. Funding bodies as well as practitioners must keep in mind this requirement.

Communication and capacity were ongoing challenges for the SC. While the group successfully built capacity in a number of ways and achieved many of its goals, inadequate capacity still presented a challenge and was seen as the reason individuals couldn't always contribute as intended. This may be common among CBPR projects. While the partnership and research process directly builds some capacity, it may not be adequate for achieving all research or policy goals. In this case, extra attention must be given to intentionally building capacity in addition to drawing on the pre-existing strengths of those involved.

This is a case study, which limits generalizeability. However, elements of how this partnership functioned may help us understand other CBPR projects and partnerships and improve our ability to conduct participatory health research. It is also impossible to determine causality outside of perceptions of causality in those interviewed. Our purpose, rather, was to better understand the partnership's

dominant dynamics by viewing it through organizational systems lenses. Future research could examine organizational dynamics across multiple CPBR partnerships or within specific problems or environments, and how dynamics may influence research outcomes. This study was made possible by, but is also limited by, its recursive nature. Several of the authors were members of the Live Well SC, and the study required the researchers to research themselves. This is a fundamental element of participant-observation, and the need for self-reflection and inclusion of the self in co-constructing knowledge must be acknowledged. Through discussion, the authors of this study made continual efforts to examine and address the ways their understanding of the data was influenced by their personal involvement in the SC.

Conclusions

The dynamics of a CBPR partnership over time are complex and variable. Viewing the group as an organizational system showed that rational, natural, and open systems perspectives all contribute to understanding the dynamics of the CBPR process in this case study, however the partnership seemed to have more natural and open system characteristics. Elements of the group's goals, roles, and power structure were formalized, however, the majority of the dynamics of the group arose as a result of individual goals and motivations, personal connections, and the idiosyncratic contributions of individuals apart from what would be expected from their formal roles. Many of these elements of the dynamics arose over time through interactions between the SC members.

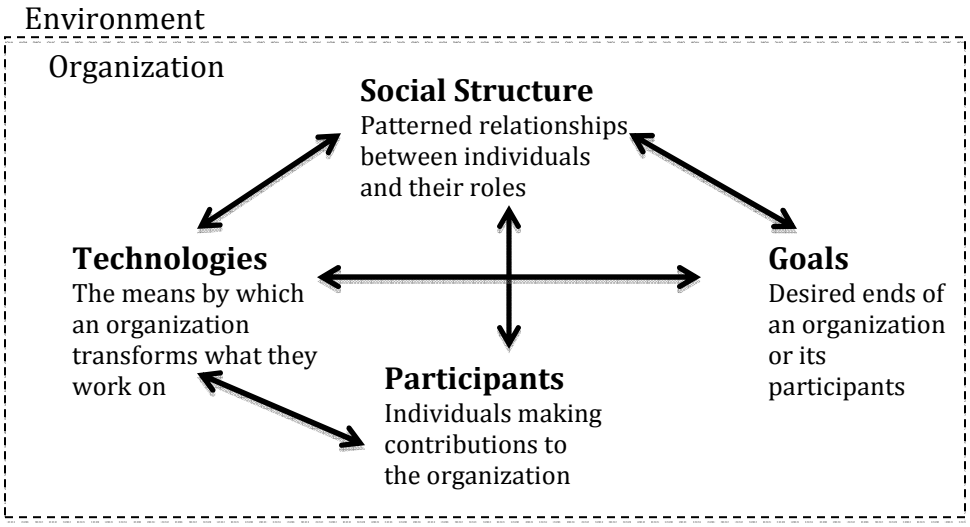
Understanding the dynamics of a CBPR process through organizational theory can provide insight for PR researchers and practitioners, helping them have realistic expectations of the complexity of the process, for example the degree to which the relationships and activities of a partnership can or should be formalized. The very purpose of CBPR is that it should be context specific and tailored to a population, therefore the processes and structures that arise will be different for every project. Still, working to systematically understand these processes can further PR application and improve our ability to achieve equitable participation and mutual benefit in health research.

Table 1. Characteristics of organizations when viewed as different types of systems

System Type	Characteristics
Rational System	• Organizational structures develop to pursue goals most effectively and efficiently • Power and sociometric (interpersonal relationship) structures are formalized and activities formally coordinated • Roles are formalized to allow interchangeability of individuals
Natural System	• Organizations are collaborations of individuals and influenced by individual goals • Organizational survival often becomes a tacit goal • Individuals must be induced to contribute and social or psychological inducements (eg. sense of belonging) are strongest • Formal structures are less important than informal for coordinating behavior
Open System	• The environment – including institutionalized belief systems - strongly influences organizational structure • Organizations are not entities but sets of "interlocked behaviors;" structures and systems are developed and perpetuated through the interactions of participants

(Scott, 2003)

Figure 1: A Model of an Organization and its Dimensions.



Adapted from Scott (2003)

Fig. 2 Interpersonal relationships and their effects over time on the Live Well Steering Committee

	Early	Middle	Late
Characteristics	• Mixed strengths of personal connections • Skepticism of others combined with a desire to work together and belief in the CBPR process	• Bonding • Expanding conceptions of roles and motivations • Increasing trust and ability to work together	• Close personal connections • Understanding of roles and motivations – giving the benefit of the doubt • Increased trust and ability to work together
Sample quotes	"Some of us had worked together a lot and some of us didn't know each other at all, so it wasn't like coming into a group that had history already. We had been meeting but we hadn't dealt with difficult issues particularly." "It seemed like there were some more personal interests being pushed." "I think we're all in it, most of us are in it for the long haul for the project and knowing that we want to make the process better."	"It gave us time to get to know each other a little bit personally and not just a two hour meeting, who are they and what they like to do, what they don't like to do. And I think having more of a personal relationship definitely helps build some of that trust." "The more you expand off of your narrow role, the more benefit, I think, there is to the whole group…And I know I feel better about my own participation when I haven't been kind of…narrow " "it's this feeling that you can, you don't have to hold back and we can work together well and we don't have to be cautious in a certain way that slows the process down…there's an efficiency that has developed, which is a function partly of the mutual trust that has begun to develop over time. "	"I don't think he's maniacal or anything like that. I think it might be part of working with very small organizations that live grant by grant… I *get* that. I don't know if I got that earlier on." "I think sometimes there is that, there is agendas. And they overshadow the actual goal of what we're doing…But on this flip side, sometimes those agendas are what, when you bring it all together, what makes this work." "In the steering committee there's a lot of people. All of them, I can see the strength of every one of them. There's also weaknesses, of course…I've come to learn or gain a lot from this interaction with all these people, just by their participation."

Time period

References

Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*. Berkeley: University of California Press.

Cargo, M., & Mercer, S. (2008). The value and challenges of participatory research: strengthening its practice. *Annual Review of Public Health, 29*, 325-350.

Economos, C., Hyatt, R., Must, A., Goldberg, J., Kuder, J., Naumova, E., . . . Nelson, M. (2013). Shape Up Somerville two-year results: A community-based environmental change intervention sustains weight reduction in children. *Preventive Medicine*. doi: http://dx.doi.org/10.1016/j.ypmed.2013.06.001

Economos, C., & Irish-Hauser, S. (2007). Community Interventions: A Brief Overview and Their Application to the Obesity Epidemic. *The Journal of Law, Medicine & Ethics, 35*(1), 131-137.

Gouldner, A. (1959). Organizational Analysis. In R. Merton, L. Broom & L. Cottrell (Eds.), *Sociology Today* (pp. 400-428). New York: Basic Books.

Gross, E. (1953). Some Functional Consequences of Primary Controls in Formal Work Organizations. *American Sociological Review, 18*, 368-373.

Horowitz, C., Robinson, M., & Seifer, S. (2009). Community-based participatory research from the margin to the mainstream: Are researchers prepared? *Circulation, 119*(19), 2633-2642.

Huang, T., Drewnowski, A., Kumanyika, S., & Glass, T. (2009). A systems-oriented multi-level framework for addressing obesity in the 21st century. *Preventing Chronic Disease, 6*(3).

Hyatt, R., Gute, D., Pirie, A., Page, H., Vasquez, I., & Dalembert, F. (2009). Initiating the transfer of research capability in environmental justice within a community-based participatory research project – Bringing in the IRB. *American Journal of Public Health, 99*, S526-S531.

Israel, B. A., Parker, E. A., Rowe, Z., Salvatore, A., Minkler, M., Lopez, J., & Halstead, S. (2005). Community-based participatory research: Lessons learned from the centers for children's environmental health and disease prevention research. *Environmental Health Perspectives, 113*(10), 1463-1471.

Meyer, J., & Rowan, B. (1977). Institutionalized Organizations: Formal Structure as Myth and Ceremony. *American Journal of Sociology, 83*(2), 340-363.

Michels, R. (1949(trans)). *Political Parties* (E. a. C. Paul, Trans.). Glencoe, IL: Free Press.

NVivo qualitative data analysis software; Version 10. (2012): QSR International Pty Ltd.

Ospina, S., & Dodge, J. (2005). Narrative Inquiry and the Search for Connectedness: Practitioners and Academics Developing Public Administration Scholarship. *Public Administration Review, 65*(4), 409-423.

Principles of Community Engagement, 2nd Edition. (2011): Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement.

Ring, P., & Van de Ven, A. (1994). Development Processes of Cooperative Interorganizational Relationships. *Academy of Management Review, 19*(1), 90–118.

Schulz, A., Israel, B., Selig, S., & Bayer, I. (1998). Development and Implementation of Principles for Community-Based Research in Public Health. In R. H. MacNair (Ed.), *Research Strategies for Community Practice*. New York: The Haworth Press, Inc.

Scott, W. (2003). *Organizations: rational, natural, and open systems* (4 ed.). Upper Saddle River, NJ: Pearson Education, Inc.

Shalowitz, M., Isacco, A., Barquin, N., Clark-Kauffman, E., Delger, P., Nelson, D., & . . . Wagenaar, K. (2009). Community-based participatory research: A review of the literature with strategies for community engagement. *Journal of Developmental and Behavioral Pediatrics, 30*(4), 350-361.

Staley, K. (2009). Exploring Impact: Public involvement in NHS, public health and social care research. Eastleigh: INVOLVE.

Thomson, A., & Perry, J. (2006). Collaboration Processes: Inside the Black Box. *Public Administration Review, 66*(s1), 20-32.

Tovar, A., Boulos, R., Sliwa, S., Must, A., Gute, D., Metayer, N., . . . Economos, C. (2013). Baseline Socio-Demographic Characteristics and Self-Reported Diet and Physical Activity Shifts Among Recent Immigrants Participating in the Randomized Controlled Lifestyle Intervention: "Live Well". *Journal of Immigrant and Minority Health*, 1-9.

Tovar, A., Hennesy, E., Pirie, A., Must, A., Gute, D., Hyatt, R., . . . Economos, C. (2012). Feeding Styles and Child Weight Status Among Recent Immigrant Mother-Child Dyads. *International Journal of Behavioral Nutrition and Physical Activity, 9*(61).

Tovar, A., Vikre, E., Gute, D., Kamins, C., Pirie, A., Boulos, R., . . . Economos, C. (2012). Development of the Live Well Curriculum for Recent Immigrants: A Community Based Participatory Approach *Progress in Community Health and Partnerships, 6*(2), 195-204.

Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K., Griffith, D., & . . . Whitener, L. (2004). Community-based participatory research: Assessing the evidence *Evidence Report/Technology Assessment No. 99*. Rockville, MD: Agency for Healthcare Research and Quality.

Weick, K. (1969). *The Social Psychology of Organizing*. Reading, MA: Addison-Wesley.

Weick, K. (1974). Middle Range Theories of Social Systems. *Behavioral Science, 19*, 357-367.

Weick, K. (1995). *Sensemaking in Organizations*. Thousand Oaks, CA: Sage.

Relevance, Responsiveness, Attendance, and Adherence in a Community Based Participatory Research Intervention to Prevent Weight Gain in New Immigrant Women

(Journal of Immigrant and Minority Health)

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Abstract

Background: Community Based Participatory Research (CBPR) approaches are assumed to generate more relevant and responsive research thereby enhancing intervention effectiveness.

Objective: To utilize a CBPR intervention to explore associations of perceived intervention relevance and responsiveness with attendance and self-reported adherence to the intervention.

Measurements: Data were generated from a CBPR intervention targeting immigrant (<10 years in the US) women from Haiti, Latin America and Brazil. Data were collected using self-administered surveys at the end of the intervention. Attendance at group and individual intervention sessions were recorded during the intervention.

Main Results: We found high levels of perceived intervention relevance and responsiveness. Perceptions varied significantly between the three ethnic groups in the study ($p < .05$). Perceived relevance of information ($p< .01$), relevance of activities ($p < .00$), and sense of voice being considered ($p= .02$) were each significantly positively associated with self-reported adherence but not with group or individual session attendance, after adjusting for covariates. Stepwise regression showed that the perceived relevance of activities, the perception that one's voice had been taken into consideration, ethnic group, and recruitment cohort had particularly strong predictive power.

Conclusions: An intervention designed and implemented using a CBPR approach was perceived as relevant and responsive. These perceptions were associated with increased adherence. The variations in perceptions between ethnic groups in this study highlight the challenges of representing a diverse community in research.

Background

Community engaged and participatory research approaches are gaining traction in many different realms of research, particularly research with traditionally underrepresented populations such as new immigrants [1-3]. Community Based Participatory Research (CBPR) is one of the most widely recognized participatory approaches in public health research [2]. The goal of CBPR is to engage members of affected communities as collaborators in research on the issues that affect them thereby,

ideally generating both useful and applicable new knowledge as well as democratizing the knowledge generating process to increase communities' capacity to address their own needs [3].

A growing body of evidence indicates that CBPR has been successful in health promotion interventions with outcomes as diverse as reduction in BMI-z, increase in serum HDL levels, or improvement in lung function [3-7]. However, the pathways of CBPR impact remains largely unexamined. One of the proposed benefits of CBPR is that participation of community members can increase the social validity of the research and result in an intervention that fits with local cultural beliefs, norms, and practices, which, it is assumed, will in turn result in a more effective and sustainable intervention. Increases in efficacy and sustainability could happen through increased acceptability, retention and adherence, and thereby eventual changes in health outcomes as well as increased dissemination and systems level changes [8-10].

The actual effect of program relevance and program responsiveness on adherence to an intervention that reflects community input have rarely been studied explicitly. The goal of this study was to use a CBPR intervention to assess the associations between perceptions of program relevance and responsiveness with program attendance and adherence for program participants. We hypothesized that perceptions of relevance and responsiveness would each be positively associated with higher attendance of the intervention sessions and of higher self-reported adherence to behavioral changes started in response to the intervention.

Methods

Study Overview:

The demographic data analyzed for this study were collected at baseline (2009-2011) from participants in Live Well, a community-based, participatory research project that used a randomized controlled lifestyle intervention to try to prevent weight gain in new immigrant mothers and their children [11]. The central premise of Live Well was that an intervention, co-created by community partners and academic researchers, can prevent excess weight gain in recently arrived immigrant women and children [12, 13]. 383 mother/child dyads had data collected at baseline and were then randomized into either the control or intervention group. Dyads were eligible if the mother met the following criteria: resided for <10 years in the U.S., of Haitian, Latino or Brazilian descent, 20-55 years of age, not pregnant (must be >6 months postpartum), has a child between 3 and 12 years of age, lives in the Greater Boston area, and willingness to be randomized. Informed consent was obtained on all participants. Study design and baseline characteristics of the study population have been described elsewhere [11]. All aspects of the study were approved by the Institutional Review Board of Tufts University.

Study participants were recruited in two cohorts, the first in early 2009 and the second in early 2010. After baseline assessments, each cohort was separately randomized into intervention and control groups. Intervention group participants received a lifestyle intervention that consisted of a combination of group and individual sessions focused on nutrition, physical activity, and stress management. Individual and group sessions were divided by ethnic/language group (Haitian, Latina, Brazilian) and were conducted in the native languages of the women by study coordinators fluent in the language. Group sessions met every other month at community-based locations in Greater Boston, MA while individual sessions were conducted through phone calls on alternate months from the group sessions. The curriculum used for the group sessions has been described in detail elsewhere [12].

Measurements:

Perceived relevance and responsiveness:

Short questionnaires were administered to the participants at the end of the study as part of a longer survey. To assess relevance, the questionnaires for the participants in the intervention group asked participants to rank how relevant the information from Live Well had been in their lives on a 5-point scale and how relevant the activities from Live Well had been in their lives on a 5-point scale. To assess responsiveness, participants were asked to rank whether Live Well felt like it was designed for someone like them or for somebody else on a 3-point scale and how much they felt like their voice (their thoughts and opinions) was taken into consideration by the people implementing the project, on a 5-point scale.

Community partners were consulted in the development of the questions, and they checked the final questions to ensure comprehension and cultural validity. The questionnaires were translated into the native languages of the participants and back translated to ensure accuracy. The participants were told before receiving the questionnaire that it would not influence their ability to participate in future programs and that their honest answers would be the most helpful because they could contribute to improving future programs.

Attendance/adherence:

Attendance was recorded at all group sessions and individual sessions by the study coordinator facilitating that session. In the end of study questionnaires participants were also asked to rate their adherence with a single questionnaire item that asked “On a scale from 1-5 where 1 means not at all and 5 means all of the time, how well would you say you stuck with the healthy changes you started because of Live Well?”

Covariates:

Demographic information and other descriptive data were collected through the self-administered surveys completed at the baseline measurement. Variables collected included ethnic group (Brazilian, Haitian, or Latina), time in country, marital status (never married; married; divorced, separated, or widowed), education level (less than high school; high school, trade school/technical school; some college; college graduate; graduate school), number of children under 18, employment status (full time; part time; seasonal; unemployed/looking for work; student; homemaker), and self-perceived acculturation. Self-perceived level of acculturation was rated using the following statement: "When you think about your daily life now, where would you place yourself?" Participants answered using a 10-point scale with 1 indicating "More American" and 10 indicating "More Brazilian/Latino/Haitian."
Statistical analysis:

124 intervention group participants completed the additional questionnaire at the end of the study. SPSS version 18 [14] was used for all data analysis. Chi-square tests to compare the intervention-questionnaire respondents to the overall group on descriptive characteristics such as education level and employment status were applied. Frequency distributions of relevance, responsiveness, attendance, and adherence measures were examined in the intervention-questionnaire respondent group. One-way analysis of variance or t-tests were used to compare distributions of continuous variables, and chi-square or Fisher's exact tests were used to compare categorical variables between ethnic groups (Haitian, Latina, Brazilian) and between intervention cohorts. Because of high intercorrelation between the variables, associations between perceptions of relevance or responsiveness with attendance or adherence were estimated using separate regression models. Group session attendance and individual session attendance were each converted to

binomial variables (i.e. high or low attendance) because of their non-normal distributions. Attendance in 50% or higher of each type of session was classified as high attendance. Associations of the perceptions of relevance or responsiveness with attendance were estimated using logit models. Associations of the relevance or responsiveness variables with self-reported adherence were estimated using ordinal logistic regression. Models were adjusted for covariates we hypothesized may be related to perceptions of relevance or responsiveness and attendance or adherence, including ethnic group, recruitment cohort, duration of residence in the US, self-perceived acculturation, number of children under 18, and employment status Finally, we used forward and backward stepwise regression in order to generate a model that considered all of the responsiveness and responsiveness measures plus our pre-specified covariates to address multicolinearity and to determine the most parsimonious models for predicting individual session attendance, group session attendance, and adherence in these data. Stepwise logistic regression was used for group session attendance and individual session attendance because they were binomial variables while stepwise linear regression was used for adherence.

Results

15 intervention group women dropped out, 49 were lost to follow up, and 17 became pregnant during the intervention. 135 intervention group women had final assessments taken. Of these, 124 - 50 Brazilians, 41 Haitians, and 32 Latinas – completed the additional end of study questionnaire. Table 1 contains descriptive data on the demographics of the questionnaire respondents. A comparison of these demographic variables with the overall Live Well study population revealed that the subgroup that completed the additional end of

study questionnaire differed significantly from the overall sample enrolled in Live Well in marital status and income. A significantly greater percentage of the questionnaire respondents made less than $200/week and a significantly lower percentage were married while a significantly higher percentage had never been married than in the overall sample enrolled in Live Well.

Overall, survey respondents reported positive perceptions of program relevance and responsiveness. For relevance, mean perceived relevance of information was 4.50±0.64 out of 5 and perceived relevance of activities was 4.37±0.97 out of 5. For responsiveness, the mean score for feeling their voice had been taken into consideration in the program design was 4.52±0.90 out of 5 while the sense the program had been designed for someone like them was 2.53±0.64 out of 3.

In bivariate analysis, perceived relevance of the program information, perceived relevance of the program activities, and a sense that their voice had been taken into consideration in program design differed by ethnic group. The Latina participants had significantly higher average perceptions of information relevance, activity relevance, and sense their voices had been taken into consideration compared to the Haitian and Brazilian participants (Table 2). Though the difference in mean self-perceived acculturation did not vary significantly by ethnic group, after adjusting for self-perceived acculturation and time in country (data not shown), the differences in perceived relevance and voice taken into consideration remained statistically significant only for the Brazilian participants ($p = .027$ for relevant info; $p = .039$ for relevant activities; $p = .000$ for voice). On the other hand, after adjusting for self-perceived acculturation and time in country, Haitian participants had significantly lower perception that the program was designed for someone like them ($p =$

.000). There were no differences in relevance or responsiveness by cohort. However, participants recruited in the first cohort had significantly higher attendance in both group and individual sessions (3.43±2.63 group sessions vs. 2.36±2.40 and 3.07±2.06 individual sessions vs. 2.00±1.84). (Table 3).

In separate, unadjusted models, higher perceived relevance of program information, perceived relevance of program activities, and higher perceptions of one's voice having been considered in program design were each significantly associated with increased odds of having high attendance in the individual sessions. In adjusted models the associations remained in the expected direction, however the effects became statistically insignificant (Table 4). In multivariate models, ethnic group (Haitian, Brazilian, or Latina) was the sole statistically significant predictor of differences in attendance in individual sessions. Ethnicity-separated regression models of individual session attendance were not significant. After adjusting for covariates, higher perceived relevance of activities had a close to statistically significant positive association with increased log-odds of high group session attendance (ß = .60, p = .06) as did sense of voice taken into consideration (ß = .63, p = .06). In multivariate models, being in cohort 1 was the sole significant predictor of high attendance in the group sessions.

In separate ordinal logistic regression models, higher perception of relevant information (ß = .640, p =.003), higher perception of relevant activities (ß = 1.01, p = .000), and a higher sense of voice being heard (ß = .539, p = .021) each significantly predicted a higher log-odds of reporting higher adherence, even after adjusting for covariates. The effect size of perceived relevance of activities was particularly large, with a one-point increase in

perceived relevance predicting 2.75 times the odds of reporting a higher level of adherence (Table 5).

We calculated forward stepwise regression models to assess the most parsimonious sets of variables for predicting each of the attendance and adherence variables in these data. In analyzing individual session attendance, being Brazilian or Haitian entered significantly in step 1 and cohort entered significantly in step 2 (final $R^2 = .231$, p=.000). For group session attendance, cohort 1 entered significantly in step 1 and perception of voice being taken into consideration entered significantly in step 2 (final $R^2 = .217$, p = .000). Finally, for adherence, perceived relevance of activities entered the model significantly in step 1 and being Haitian entered significantly in step 2 (final $R^2 = .244$, p = .000) (Table 6). Backwards stepwise regression confirmed these models as the most parsimonious predictive models for this set of independent variables in these data.

Discussion

The goal of this paper was to explore a potential pathway for CBPR impact, first by analyzing participants' perceptions of relevance and responsiveness of a CBPR program; and second, by analyzing the association of these perceptions with participants' attendance in the program and their self-reported adherence to health behavior changes made in response to the program. Overall we found that the study designed by using CBPR was perceived by participants as relevant and responsive according to our measures. We found that higher perceived relevance of information, relevance of activities, and higher perception of voice being taken into consideration were each positively associated with higher self-reported adherence after controlling for covariates. Perceived relevance of activities had a particularly

large effect size. Interestingly, the community-academic partnership that designed the study specifically chose to create a nutrition and physical activity curriculum that was hands-on and emphasized creative problem solving and personalized behavior change strategies that could be practiced immediately. The strong positive association of perceived relevance of activities with self-reported adherence provides some validation of that community-driven decision and of the utility of the curriculum.

Because adherence was self-reported, these significant associations may be due to reporting bias, where individuals who were motivated to positively report their perceptions of relevance and responsiveness were also more likely to be motivated to report that they had strongly adhered to changes. However, the associations between relevance and responsiveness with adherence could be stronger than with attendance because the women had fewer barriers to making small health behavior changes at home than they had to attending group sessions or scheduling individual session phone calls. The participants enrolled in the Live Well study had very busy lives. Many were working multiple jobs, caring for children, and facing other stressors that may have prevented them from attending group or individual sessions, even if they found them relevant [11, 13].

There were differences in attendance between the two recruitment cohorts, and being in cohort 1 was a particularly strong predictor of higher attendance in the group sessions. Recruitment was undertaken in two phases because the partnership faced many challenges recruiting adequate numbers of study participants in the first round of recruitment (eg. an Earthquake in Haiti and limited geography of the recruitment area). They redoubled efforts for the second round of recruitment, putting more effort into connecting with a wider variety of community-based organizations and churches in an expanded geography and trying even

harder to recruit hard to reach individuals. Anecdotally, because cohort 1 had already been participating in the intervention for several months, the intervention had gained additional recognition and traction in the community with the participants in the intervention even recommending it to friends, which enabled recruitment of more women into the second cohort. So, while the two cohorts had relatively similar demographic composition, they may have had different levels of internal motivation for participating, something none of our variables were able to capture.

The differences in perceptions of relevance and responsiveness between the three ethnic groups in the study were surprising, as was the strong association between ethnic group and individual session attendance. There were differences in the responses of the groups to the Live Well program, even after controlling for other characteristics related to cultural preference or adaptation to the US, including acculturation and time in country. All three groups were represented in the community-academic partnership, and the three study-coordinators (one for each group) who led the group and individual sessions received the same training in leading popular education classes and in motivational interviewing. The coordinators also did all their planning together to minimize differences in how the intervention was administered to the different groups. Although the steering committee did its best to represent each of these immigrant communities and consider their needs in the intervention design, it is possible that there were factors influencing the women's perceptions and participation, for example attitudes towards practitioners or autonomy support preferences, that the committee missed in the complexity of designing a single program to meet the needs of a diverse group of individuals. The differences between the groups in this study, underscores the need for more research with immigrants from these

communities. It also highlights one of the greatest challenges in CBPR, which is deciding how and by whom a community will be represented [17, 18].

The findings of this study must be interpreted in the context of its limitations. Generalizeability is limited due to the relatively small sample size of the study and its focus on three particular groups of immigrants to a particular part of the US (Greater Boston). Though demographically similar to the overall study population, the women who completed the end of study questionnaire were women who had stayed in the study, so their perceptions may have been different from the women who dropped out or were lost to follow up. Additionally, we were unable to find validated tools for assessing the relevance or responsiveness of an intervention in these groups, so while the questions used were designed with community input and based on social validity concepts, they were not validated. Future research should be undertaken to create validated tools for assessing perceptions of relevance and responsiveness as well as assessing the relationship between relevance and responsiveness for use with CBPR studies and interventions.

Caution should be exercised in interpreting the results of our stepwise regression analysis as stepwise regression generates models that are useful for prediction in a given set of data, but may not be as useful in other sets of data. Nevertheless, the results of the stepwise regression do give additional support to the associations that cohort, ethnic group, perceived relevance of activities, and sense of voice being taken into consideration had with attendance and adherence in these data. At the same time, most of the covariates we adjusted for, which we expected would be highly associated with attendance and adherence, were not predictive. There has been a great deal of research on promoting adherence/compliance in the context of clinical trials and patient treatment regimens, however we know less about barriers and

facilitators of adherence and participation in community-based research, and more research is needed, particularly in populations such as new immigrants. Finally, connecting perceived relevance, responsiveness, attendance, and adherence to actual reported changes in physical activity, diet, or BMI was beyond the scope of this study. However, to fully explore potential pathways for CBPR efficacy, further research should be conducted that examines an entire pathway from the proposed benefits of CBPR - like increasing relevance, responsiveness, and adherence - to improved health outcomes.

In conclusion, we found support for the hypothesis that CBPR can generate research studies that are perceived as relevant and responsive by the study participants, and study relevance and responsiveness may play a role in promoting adherence. Researchers developing interventions for hard to reach populations may therefore wish to seek community participation in intervention design to enhance relevance and responsiveness. Because relevance and representativeness don't necessarily promote higher attendance, researchers and practitioners working with study populations like new immigrants may also wish to focus specific efforts on addressing barriers to attendance. They may also wish to focus programming on behavior changes that can be practiced immediately and adhered to at home. Further study is needed with other CBPR projects and in other groups of study participants to more fully understand pathways for maximizing the potential positive impact of community engagement in research and interventions.

Table 1: Demographic Characteristics of the Live Well Intervention Subsample (n=124)			
		N	**%**
Age (mean, SD)		36.25	6.71
Education	Less than high school	41	33.33
	High school, trade/technical school	54	43.90
	Some college/college graduate/graduate	28	22.76
Income	<$200/wk	44	41.90
	$200-$600/wk	34	32.38
	>$600/wk	27	25.71
Employment Status	Full time (>35/wk)	27	21.95
	Part time (<35/wk	32	26.01
	Employed seasonally	15	12.20
	Unemployed/looking for work	27	21.95
	Student	2	1.62
	Homemaker	20	16.26
Marital status	Never married	69	57.50
	Married	26	21.67
	Widowed/divorced/separated	25	20.83
Children in household <18	1	28	23.73
	2	52	44.07
	≥3	38	32.20
Self-perceived acculturation (1-10) [a] (mean, SD)		7.97	2.22
Years in US (mean, SD)		6.50	3.25

Sample sizes vary slightly due to missing data

[a]1 indicates "more American;" 10 indicates "more Brazilian/Latino/Hatian"

Table 2: Perceived relevance, representativeness, attendance, and adherence by ethnicity			
	Brazilian	**Haitian**	**Latina**
	Mean (SD)	**Mean (SD)**	**Mean (SD)**
Perceived relevance of information *	4.33 (.99)	4.41 (1.12)	4.91 (.38)
Perceived relevance of activities**	4.13 (1.04)	4.35 (1.01)	4.74 (.68)
Voice taken into consideration**	4.15 (1.10)	4.61 (.77)	4.97 (.18)
[a]Designed for someone like me	2.54 (.65)	2.23 (.65)	2.85 (.44)
[b]Group session attendance	3.43 (2.63)	2 (2.46)	3.91 (2.21)
Individual session attendance**	2.07 (1.95)	1.57 (1.82)	3.79 (1.50)
Self-reported adherence*	3.69 (.90)	4.43 (.81)	4.25 (.62)

* $p < .05$, ** $p < .01$

[a] Relevance of information and activities, and voice scored out of 5; designed for someone like me scored out of 3

[b] Group attendance out of 7 total sessions; individual attendance out of 5 sessions; adherence scored out of 5

Table 3: Perceived relevance, representativeness, attendance, and adherence by recruitment cohort		
	Cohort 1	**Cohort 2**
	Mean (SD)	**Mean (SD)**
Perceived relevance of information	4.43 (.89)	4.56 (.97)
Perceived relevance of activities	4.25 (.99)	4.44 (.95)
Voice taken into consideration	4.41 (1.02)	4.59 (.81)
[a]Designed for someone like me	2.49 (.66)	2.56(.63)
[b]Group session attendance***	3.43 (2.63)	2 .36 (2.40)
Individual session attendance**	3.07 (2.06)	2.00 (1.84)
Self-reported adherence	3.96 (.85)	4.16 (.87)

** $p < .01$, *** $p<.001$

[a] Relevance of information and activities, and voice scored out of 5; designed for someone like me scored out of 3

[b] Group attendance out of 7 total sessions; individual attendance out of 5 sessions; adherence scored out of 5

Table 4: Regression analysis of recorded attendance in group or individual sessions												
	High individual session attendance						**High group session attendance**					
	Unadjusted			**Adjusted[a]**			**Unadjusted**			**Adjusted[a]**		
Predictor variable	**ß (SE)**	**e ß**	**Sig.**	**ß (SE)**	**e ß**	**Sig.**	**ß (SE)**	**e ß**	**Sig.**	**ß (SE)**	**e ß**	**Sig.**
Relevance of info	.58(.27)	1.78	.03	.40(.34)	1.50	.23	.28 (.23)	1.33	.22	.23(.30)	1.26	.44
Relevance of activities	.53(.24)	1.70	.03	.60(.33)	1.82	.07	.42 (.23)	1.52	.07	.60(.31)	1.82	.06
Voice taken into consideration	.60(.29)	1.82	.04	.41(.34)	1.50	.23	.42 (.26)	1.52	.11	.63(.34)	1.89	.06
Designed for someone like me	.59(.32)	1.81	.07	.19(.41)	1.21	.64	.67 (.33)	1.95	.82	.72(.44)	2.05	.10

[a]Adjusted for ethnic group, recruitment cohort, time in country, self-perceived acculturation, employment status, number of children under 18

Table 5: Regression analysis of high self-reported adherence						
	Unadjusted			**Adjusted[a]**		
Predictor variable	**ß (SE)**	**e ß**	**Sig.**	**ß (SE)**	**e ß**	**Sig.**
Relevance of info	.74(.20)	2.09	.000	.64 (.21)	1.90	.003
Relevance of activities	1.00 (.21)	2.71	.000	1.01 (.23)	2.75	.000
Voice taken into consideration	.70(.21)	2.01	.001	.54(.23)	1.71	.02
Designed for someone like me	.25 (.28)	1.28	.38	.37(.34)	1.44	.28

[a]Adjusted for ethnic group, recruitment cohort, time in country, self-perceived acculturation, employment status, number of children under 18

Table 6: Forward stepwise regression results for models predicting attendance or adherence

	Individual Session Attendance				
	Variable	**ß (SE)**	**Sig.**	**R^2**	**Model Sig.**
Step 1	Brazilian Haitian	-2.46(.65) -2.17(.64)	.000 .001	.11	.000
Step 2	Cohort 1	1.29(.54)	.02	.23	.000

Variables excluded from the final model: relevance of information, relevance of activities, voice taken into account, designed for someone like me, time in country, self-perceived acculturation, employment status, number of children under 18

	Group Session Attendance				
	Variable	**ß (SE)**	**Sig.**	**R^2**	**Model Sig.**
Step 1	Cohort 1	2.08(.51)	.000	.16	.000
Step 2	Voice	.69(.31)	.03	.22	.000

Variables excluded from the final model: relevance of information, relevance of activities, designed for someone like me, time in country, self-perceived acculturation, employment status, number of children under 18, ethnic group

	Adherence				
	Variable	**ß (SE)**	**Sig.**	**R^2**	**Model Sig.**
Step 1	Relevance of activities	.38(.08)	.000	.19	.000
Step 2	Haitian	.48(.16)	.004	.24	.000

Variables excluded from the final model: relevance of information, voice taken into account, designed for someone like me, time in country, self-perceived acculturation, employment status, number of children under 18, recruitment cohort

References

1. Shalowitz M, Isacco A, Barquin N, Clark-Kauffman E, Delger P, Nelson D, . . . Wagenaar K: **Community-based participatory research: A review of the literature with strategies for community engagement**. *Journal of Developmental and Behavioral Pediatrics* 2009, **30**(4):350-361.
2. Horowitz C, Robinson M, Seifer S: **Community-based participatory research from the margin to the mainstream: Are researchers prepared?** *Circulation* 2009, **119**(19):2633-2642.
3. Viswanathan M, Ammerman A, Eng E, Gartlehner G, Lohr K, Griffith D, . . . Whitener L: **Community-based participatory research: Assessing the evidence**. In: *Evidence Report/Technology Assessment No 99.* Rockville, MD: Agency for Healthcare Research and Quality; 2004.
4. Staley K: **Exploring Impact: Public involvement in NHS, public health and social care research**. In. Eastleigh: INVOLVE; 2009.
5. Economos C, Hyatt R, Must A, Goldberg J, Kuder J, Naumova E, Collins J, Nelson M: **Shape Up Somerville two-year results: A community-based environmental change intervention sustains weight reduction in children.** *Preventive Medicine* 2013.
6. Burnet D, Plaut A, Wolf S, Huo D, Solomon M, Dekayie G, Quinn M, Lipton R, Chin M: **Reach-Out: A family-based diabetes prevention program for African American youth**. *Journal of the National Medical Association* 2011, **103**(3):269-277.
7. Parker E, Israel B, Robins T, Mentz G, Xihong L, Brakefield-Caldwell W, Ramirez E, Edgren K, Salinas M, Lewis T: **Evaluation of Community Action Against Asthma: a community health worker intervention to improve children's asthma-related health by reducing household environmental triggers for asthma**. *Health Education & Behavior* 2008, **35**(3):376-395.
8. Francisco V, Butterfoss F: **Social Validation of Goals, Procedures, and Effects in Public Health**. *Health Promotion Practice* 2007, **8**(2):128-133.
9. Minkler M, Wallerstein N: **Community-Based Participatory Research for Health: From Process to Outcomes**, 2 edn. San Francisco: Jossey-Bass; 2008.
10. Corbie-Smith G, Ammerman A, Katz M, St. George D, Blumenthal C, Washington C, Weathers B, Keyserling T, Switzer B: **Trust, benefit, satisfaction and burden: a randomized controlled trial to reduce cancer risk through African-American churches**. *Journal of General Internal Medicine* 2003, **18**(7):531-541.
11. Tovar A, Boulos R, Sliwa S, Must A, Gute D, Metayer N, Hyatt R, Chui K, Pirie A, Kamins C *et al*: **Baseline Socio-Demographic Characteristics and Self-Reported Diet and Physical Activity Shifts Among Recent Immigrants Participating in the Randomized Controlled Lifestyle Intervention: "Live Well"**. *Journal of Immigrant and Minority Health* 2013:1-9.
12. Tovar A, Vikre E, Gute D, Kamins C, Pirie A, Boulos R, Metayer N, Economos C: **Development of the Live Well Curriculum for Recent Immigrants: A**

Community Based Participatory Approach *Progress in Community Health and Partnerships* 2012, **6**(2):195-204.

13. Tovar A, Must A, Metayer N, Gute D, Pirie A, Hyatt R, Economos C: **Immigrating to the US: What Brazilian, Latin American and Haitian Women Have to Say About Changes to Their Lifestyle That May be Associated with Obesity**. *Journal of Immigrant and Minority Health* 2012, **15**(2):357-364.
14. SPSS Inc. Released 2009. PASW Statistics for Windows VCSI. In.
15. Israel B, Schulz A, Parker E, Becker A: **Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health**. *Annual Review of Public Health* 1998, **19**:173-202.
16. Horowitz CR, Brenner BL, Lachapelle S, Amara DA, Arniella G: **Effective Recruitment of Minority Populations Through Community-Led Strategies**. *American Journal of Preventive Medicine* 2009, **37**(6 S1):S195-S200.
17. Israel BA, Parker EA, Rowe Z, Salvatore A, Minkler M, Lopez J, Halstead S: **Community-based participatory research: Lessons learned from the centers for children's environmental health and disease prevention research**. *Environmental Health Perspectives* 2005, **113**(10):1463-1471.
18. Ross LF, Loup A, Nelson RM, Botkin JR, Kost R, Smith GR, Gehlert S: **The Challenges of Collaboration for Academic and Community Partners in a Research Partnership: Points to Consider**. *J Empir Res Hum Res Ethics* 2010 **5**(1):19–31.

"Everything has changed" – A Qualitative Study of Immigrant Women's Experiences of a CBPR Weight Gain Prevention Intervention

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Abstract

Background: Community Based Participatory Research (CBPR) has been proposed as a potentially successful research approach for complex challenges like obesity, particularly in traditionally marginalized groups, because CBPR may generate interventions that are more relevant and applicable to the lived experience of the participants. Yet, there is still little known about how participants actually experience their involvement in these types of community-engaged research projects, or how this may impact the response to the research.

Methods: Live Well was a CBPR intervention aiming to prevent excess weight gain in new immigrant mothers and children in the Greater Boston Area. This study used interview data to explore how women involved in the Live Well project experienced the intervention, particularly how the intervention did or did not integrate into their lives and the impact this had on their health behaviors. Purposive sampling was used to select a sample of women in the intervention who were likely to have had a variety of experiences.

Results: Thirteen women were interviewed. Overall the women reported having very positive, even life changing, experiences in the Live Well program. The program integrated well with their lives because it offered them the opportunity to set goals and personalize behavior change strategies through offering simple tips and by using discussion, problem solving, and opportunities to immediately apply new information. The women experienced the intervention as empowering, particularly because they felt their voices were heard and taken into consideration in the running of the intervention. Women also reported making changes in their own and their families' health behaviors. The elements that the women described as most important in their experiences – the feeling that their voices were truly heard, personalized behavior change, and the social experience of the small groups – were also the components of the intervention that had specifically been designed through the CBPR process, having been co-created by academic and community partners.

Conclusions: These data provide evidence that using CBPR to design an intervention such as weight gain prevention in new immigrants can create an intervention that is appropriately tailored and that both fits into the lived experiences of the participants in the intervention and is empowering, which could facilitate increased health impact.

Background

Obesity and the socio-economic and racial/ethnic disparities in obesity comprise a serious and complex public health problem that has defied traditional

methods of prevention and treatment [1, 2]. The development of obesity in new immigrants is of particular concern as it is estimated that by 2050, 1 in 5 Americans may be foreign born [3, 4]. A variety of studies have shown that overweight and obesity increase with duration of residence in the U.S., which may be related to adaptation to an "obesogenic" environment in addition to financial, linguistic, and social stresses [5-8]. Yet, on the whole, little research has been done on interventions to prevent obesity in new immigrants.

Community Based Participatory Research (CBPR) has been proposed as a potentially more appropriate approach than traditional research interventions for addressing complex public health issues such as obesity, particularly in marginalized populations such as immigrants[9]. CBPR is an attitude toward research that asks those participating to create research or intervention designs that reflect reciprocal learning between researchers and the community. This is done in the hope that such research or interventions will be responsive to the reality of communities and fit with the lived experience of those involved and thus will empower communities and create more sustainable health change. In arguments for the efficacy of CBPR it is postulated that participation of community members will result in a study/intervention that fits with local cultural beliefs, norms, and practices, which, it is assumed, will in turn result in a more effective and sustainable intervention [10, 11]. Based on these models, a potential pathway for the efficacy of CBPR is that it will generate a more relevant intervention that integrates into the lived experiences of the participants and that this integration will increase intervention success. However, the

actual experiences of participants in an intervention that reflects community or participant involvement have rarely been studied explicitly [11].

The purpose of this study was to use interview data to explore the experiences of new immigrant women participating in a CBPR obesity prevention intervention and analyze these experiences to explore two elements of a potential pathway for CBPR impact: first, how an intervention including community and participant involvement did or did not integrate into the lives of the women; second, whether or how that relevance/integration of the intervention impacts the success of the intervention, particularly nutrition or physical activity behavior change in this sample of new immigrants. Figure 1 shows a conceptual model of how a CBPR process may impact participant experience.

Study Context

This study was part of a larger randomized controlled trial (RCT), called Live Well, whose aim was to prevent unhealthy weight gain in new immigrant mothers (<10 yrs in the US) and children (ages 3-12) in the greater Boston area. The women enrolled in the trial were from Haiti, Brazil, and Latin America (predominantly Central)[12], and between 20-55 years in age. Women were recruited into the intervention in two cohorts and randomized. The intervention groups participated in a one-year behavior change intervention focused on nutrition and physical activity [13], the first cohort's in 2010-2011 and the second's in 2011-2012. 383 mother-child dyads were enrolled and assessed at baseline. 215 dyads were

randomized into the intervention group. Baseline characteristics of the study participants have been described elsewhere [14].

Live Well was designed using a CBPR approach. A steering committee comprised of academic researchers and community partners from community based organizations that work directly with immigrants in the greater Boston area was formed even before the study was funded in order to write the grant and conduct formative research. The steering committee collaborated on study design, creation of the intervention and materials, and data collection and interpretation. Before the intervention the committee conducted focus groups with immigrant women as formative research. To design and implement the intervention, the committee engaged in a complex and time-consuming process of engaging in dialog, building relationships and trust, sharing power, and negotiating roles and expectations on an ongoing basis. Through this process the committee developed an intervention design that none of the parties involved would have come up with individually (Vikre, paper 1). The cornerstones of the intervention that was developed were: recognizing that none of the partners could fully understand the experience of the immigrant women, so the intervention should empower the women to be the experts on their own lives and ask them to bring their experiences as an asset; giving the women the opportunity to solve problems and come up with the changes and behaviors they felt would work in their lives; bringing the women together in groups to create the opportunity for building social support and engaging in group problem solving; having individually focused sessions as well to allow for discussing and setting individual goals.

The steering committee decided the best way to create an intervention that contained all these elements was to use a combination of Popular Education [15] for small group sessions and Motivational Interviewing [16] for individual sessions. Group sessions and individual sessions were held in alternating months. The groups were divided by language, and there were 6-12 women per small group. Both group and individual sessions were conducted in the native language of the women and led by a study coordinator fluent in the language. For a complete description of the curriculum and its development see Tovar et al., 2012 [13]. Individual counseling sessions were conducted by phone using Motivational Interviewing techniques [16].

Methods

Women were recruited from the intervention group of the larger Live Well study to participate in phone interviews for this study. Purposive sampling was used to recruit women who would be likely to have had a range of different experiences with Live Well. We sought to recruit women from each of the three language groups in the study, from both cohorts of the intervention group, women who had had high levels of attendance and participation as well as women with low levels of participation, and finally women who would or would not have likely noticed a perceptible change in their own weight. Women meeting each of these criteria were identified and contacted through the study coordinators and asked if they would be willing to participate in a phone interview to talk about how they experienced Live Well. If they agreed, a time for a phone call was set up. Women

were recruited and interviews conducted until saturation was reached with a goal of conducting no fewer than 9 and no more than 21 interviews. Interviews were conducted over the course of two weeks.

Phone calls were conducted by a researcher with the aid of an interpreter fluent in the interviewee's native language hired from the Optimal Phone Interpreters company [17]. Interviews were conducted using a semi-structured interview guide that began by asking broadly how the interviewee had experienced the Live Well project, leaving it completely open to the individual what to talk about. This was followed with questions about how the interviewee had experienced the project specifically with regards to nutrition and physical activity. The interviewees were asked to describe any particularly positive experiences and negative experiences; and finally to tell stories of any instances when it felt like the people who had designed the project really understood the interviewee and what she needed in her life to improve her health and instances when it felt like she was not understood or the project did not fit what she needed in. To minimize burden, the interview guide was designed for interviews to last less than one hour. Interviews ranged from 15-45 minutes and averaged half an hour.

Interviews were recorded and transcribed verbatim. Transcripts were managed and analyzed using QSR NVivo 10 [18]. Transcripts were read through in multiple passes by one researcher, using line-by-line coding with 5 transcripts to inductively generate themes related to project relevance and the ways it did or did not integrate into the women's lives as well as behavioral implications of the integration of the project. These were used as a coding framework that was applied to all the

transcripts. Themes were then analyzed for their underlying concepts and concepts were analyzed for their relationship to community involvement. Data were also sorted by the recruitment attributes in order to analyze whether women with different characteristics spoke about their experiences in noticeably different ways. The study was approved by the Tufts University Social, Behavioral, and Educational Research IRB.

Results

A total of 13 women consented and were interviewed. The women fit the criteria of the overall study, aged 20-55 (avg. 36 years) and less than 10 years in the country (avg. 6 years). Of the interviewees, 4 were Haitian, 4 Latina, and 5 Brazilian; 6 were from the first intervention cohort, 7 from the second; 9 had high participation in the intervention sessions, 4 low; 3 had easily observable weight gain while 4 had had noticeable weight loss and the others had no easily observable change. We found that the interviewees spoke about their experiences similarly in spite of these different characteristics.

The women participating in the interviews described a variety of experiences related to how the project did or did not integrate with their lives. They focused in particular on describing which experiences had been most useful to them and those that had been empowering. Additionally, they described how they had changed their behavior by applying their experiences in the program to their lives. (For a summary of themes and sample quotes, see Table 1.)

Summary Statements

In response to the question of how they experienced the Live Well program, the women both began and ended their descriptions with summary statements, or their personal synthesis of how they had experienced the program. They generally spoke of a strong positive emotional response to the program, explaining perceptions such as "everything was good," "everything worked for me," or "all our meetings were special to me." The women described their experience with Live Well as being something bigger than just involvement in a research study. One Latina woman explained, "it seemed like a different program that truly cared about the health of women and children." Another summarized at the end of her interview, "All I want to say is thank you, because this is something that I am going to remember for the rest of my life, something that is going to help me in my life and I just thought the program was excellent."

Changes in Lives

When asked how they had experienced the intervention with regards to nutrition or physical activity, the women's descriptions of their experiences with Live Well focused on the changes in their lives that they saw as the result of their involvement with the study. This included both behavioral changes and perceived physiological changes in themselves or their families. The behavioral changes women made were largely individualized. Some had started exercising while others said they had increased their physical activity through small changes like walking more or using an exercise band (given to them by the study) to do strength work while watching television. Some women chose both tactics, such as a Latina woman who explained, "They teach me how walking actually gives me more energy, helps me breathe

better, and on the weekends when it is not cold, I just bought a bicycle, so now I bicycle on the weekends when it is not cold." Many women described how they had increased their fruit and vegetable intake or cut down on processed food through substitutions. For example, one woman described how she had started adding vegetables to the family's rice at supper; another said she now snacks on fruit. Other women described how they had increased their water intake and cut out soda consumption.

The women also described noticing physical changes in their lives that they saw as the result of their behavioral changes. Several women pointed out that their tastes had changed and they now preferred foods with less salt and sugar. Some said they had lost weight, while others spoke of how they had not lost weight but their shape had changed. As one described, "my body looks different and I changed my lifestyle, [but] I still wear the same size clothing so I haven't really lost much weight." Others said they had not lost weight but they felt they had more energy. Many of the women felt their lives had changed in ways beyond nutrition and physical activity. As one Brazilian woman described, she saw this change as being connected to the possibility of making other changes in her life. "I think when you learn to eat healthy, you learn to change other things in your life too. You learn when you eat right, your body gets right, and you have more energy to do activity…So when you change eating, everything changes too." The woman who had started bicycling summed it up saying, "everything has changed."

Activities or Information Experienced as Useful

In elaborating how they experienced the program, the women tended to detail the specific activities or information in the program that they had personally experienced as useful in their lives. Useful activities/information fell into several categories:

Simple Tips – First were activities or behavior-focused "tips" or "hints" that were seen as being able to fit easily into a busy, high stress life. A Brazilian woman described, "When you come to a different country you think, you only focus about working and you forget to do anything else, and you end up thinking you don't have time for exercising or to do anything extra. In that program, I learned in the program that is not so... I am doing things out of working, where before I didn't think I had the time." Activities and tips were experienced as useful if they could be practiced immediately. In the words of a Latina participant, "Everything I learned by practicing. I tried to do all the activities, all the exercises, I like the Pilates and I ended up going to the gym."

Exchanging ideas – The women described the importance of participating in activities and discussions where everyone was able to bring their own experience to it and to share their experiences and ideas. A Latina woman summed this up when she explained, "For example, we would exchange ideas on how to prepare food differently, and we would exchange ideas on how to exercise, and so we learned with each other and even using things that were around us, we didn't see it before, that it could be for that purpose. By exchanging ideas we were able to understand those things, and we exchanged ideas and the end result was always positive."

Similarly, a Haitian woman described, " I think this was a gathering and exchange of ideas that each one of us had, that we learned with each other."

Navigating a new environment – Finally, women experienced information and activities as useful when it helped them navigate elements of the U.S. environment, especially activities like a tour of the supermarket that showed where to find healthy foods or activities on understanding food and nutrition labels. Four of the women said the supermarket tour that was part of the curriculum was their favorite activity. One described, "I would have to say that the thing that I remember the most, that was my favorite thing was actually going to the grocery store because when you walked in you were taught where the produce is nutritious, where the good products and the bad products were. I love the fact that they taught us where the fresh products were, how to walk around, what were the bad products…"

The Social Experience

The social experience of the group sessions in Live Well was also clearly a central part of the participants' experiences. The women described the importance of coming together with other women, discussing things that mattered to them all and learning from one another. One Latina woman explained, "What I really like there is that they really didn't care where you came from. It was just women that were worried about their over-weight children." The environment of these group sessions was experienced as friendly and relaxing. In particular, it was an opportunity to step outside of daily life and have some time to reflect. According to a Brazilian woman, "This program took a lot of working women out of their routine. They will always ask how your day was. They wanted you to get disconnected from

everything and just talk about yourself, and they will always listen." Adding to this experience of the space being a friendly space outside of normal life was the experience of how there was no favoritism shown toward particular participants and time was made to hear from everyone. In the words of a Latina participant, "Everything was nice, everything was relaxing. We all had time to give our opinions, give comments. There was never an interruption, like your opinion is not good or not valid. Everyone had an opportunity to speak, and everyone had an opportunity to be heard."

Experience with Live Well Staff

The participants described their experiences with the Live Well staff, in particular the coordinators who led the group sessions and conducted motivational interviews, but also with other intervention staff. Staff members were described as professional but friendly, warm, understanding, engaged, and accommodating. For example, one Latina woman described her experience saying, "Everyone in the program was very nice, the people that measure, everybody there was very nice. They never made me feel bad because I was chubby. I just felt I was in a place with professional people that really wanted to help." A Haitian woman spoke about how, "They were always there, always paying attention – helping with my diet…helping me with activities."

Empowering and Empowered Experiences

The participants also shared descriptions of empowering and empowered experiences they had as a result of participating in the intervention. These were closely related to the elements of the program they experienced as useful as well as

the social experience and experiences with the staff. A resonating theme among all the interviews was the sense of being truly heard and respected in the program. A Brazilian woman spoke of her experience saying, "The program gave us to share, all the things. That was very important because [when] people share, you feel better, you know? Its not just somebody telling you what to do, but the person that is there is looking for you and wants to know your experience, and this is important, because everyone feels like "I am important for the program and the program is important for me."" Another woman explained, "Everyone listened to everyone, everyone understood, and respected everyone's opinion and time to speak. And I think the people that were running the program actually allowed sufficient time for everyone to speak their mind and give their opinions and be heard."

The women also seemed to feel personally empowered by the experience of learning to set achievable goals, immediately implementing changes, achieving the goals, and having this celebrated. As one woman put it, "It was not just somebody listening, but we had the authority to practice it." Women spoke about the importance of goal setting and achieving their goals both in the abstract and also in speaking about specific changes they had made related to their goals. As an example, a Latina woman described how, "It helped me motivate myself so that I began exercising. I feel like I can accomplish a lot, and they help me make goals; they help me reach some of those goals already."

The participants showed their experience of empowerment not only through achieving personal goals and behavior change but also by experiencing both the desire and the feeling of being competent to pass on what they had learned to

others. Many women expressed how their participation in Live Well had led to them wanting to share the experience with others in the hope of helping others change their own health behaviors. One Latina woman described how, "everything that I have learned I have used. I keep using it with my family here, but also in my country. I am from El Salvador. I have six brothers and sisters, and I have taught them what I have learned and why it is important. I have also taught my husband's family, and I even mentioned it at work. Everyone I see I try to teach them everything that I have learned." And another woman spoke of how, "I know that wasn't the end. I still have the knowledge and I can pass that knowledge on to my neighbors, to my friends at work. I just have that feeling of sadness (that the program is over), but every time I see someone that is eating the wrong way, and they want it to change, I pass on the message. I believe that is something that stayed, and that is something that I can do better for others."

Family Effects

The participants reported that the intervention was experienced not only as impacting the individuals in the study, but as also influencing their families in a variety of ways. Related to their sense of empowerment, the women spoke in their interviews about purposefully teaching what they had learned, the tips and activities, to their families. One Haitian woman summarized it simply, saying, "I shared my experience with my kids. I taught them everything I learned, and we had family meals." A Brazilian woman described in detail one of her interactions with her daughter. "My daughter, she reads labels on the packages. You know when you go buy food, she always pays attention to how much sodium is in that food, that

sodium is not good for the body, especially not for kids. And she knows about the cholesterol, how much fat is in this or that food, and it is funny because she pays attention, and she helps me, and she asks me questions, like "mommy is this ok?," and I tell her "oh no that is not healthy," so we advise her to eat careful - things that are less processed."

The women spoke of making changes in their lives that influenced their families' health behaviors in addition to their own, such as changing the way they shopped and cooked, eliminating sugary beverages, and engaging their families in physical activity. One Latina woman described the process of eliminating soda from her and her family's diet. She concluded, "We used to think that whatever liquid we had, the sweeter the better. So it began with eliminating a lot of those products, and now we feel that our taste buds have changed. It is now used to not having sugar, and sweet liquids, and I think it is the same for my entire family." Finally, several women spoke of how their family members, particularly children, picked up elements of the intervention either because they occasionally came with their mothers to the group sessions, or because they read hand-outs from the sessions that their mothers had brought home.

Discussion

These data provide evidence that in this intervention, using the CBPR process generated an intervention that integrated well into the intervention participants' lives and impacted them not only in their health behaviors, but also on a deeper level of meaning. Interviewees' experiences with the intervention suggest that it was relevant, meaningful, and empowering to the research participants, and that these

attributes of the intervention promoted actual health behavior changes in the participants. These findings support models of CBPR that predict that its use will generate a more relevant intervention that integrates into participants' lived experience and that this will promote intervention success.

The design of the Live Well intervention would have been very different had it been designed by academic researchers without the input of community partners. The co-creation and co-learning processes led the committee to develop an intervention that focused on giving a voice to immigrant women who don't typically have the chance to assert their voices or authority. The steering committee intentionally chose to focus on giving the women the opportunity to co-construct knowledge - bringing them into the CBPR process - through supporting self-determination [19, 20] and Praxis (a cycle of learning, reflection, and action)[15] through the use of Motivational Interviewing and Popular Education. Interestingly, the committee chose to use these techniques for the intervention in spite of the fact that none of the partners involved had expertise in them. The committee sought training in Popular Education and Motivational Interviewing in order to apply them to the intervention because they felt it would be the best fit for the women.

These elements of the intervention that the community and academic partners co-created were experienced as quite powerful. With comments like, "it seemed like a different program that truly cared about the health of women and children," the women interviewed spoke of Live Well not as though it were a research study, but as something they felt like they were a part of, an important part of. Whether or not the information and activities of Live Well actually prevented

weight gain in the participants overall, a number of the women interviewed spoke of the intervention as life-changing because of the way they were given the authority to share their experiences and choose their own activities, and they felt this authority ramified out into their lives. In the words of one woman, "when you change eating, everything changes too."

As intended by the steering committee, the Live Well intervention was built around the best scientific evidence on nutrition and physical activity, but the participants weren't given the information in a didactic manner, instead they were asked to share how their own experiences related to this information. The women in these interviews described how important participating in a cycle of discussion, reflection, and action, had been in their experience of Live Well, as well as how this had felt unique and empowering to them, stimulating them to change their own nutrition and physical activity behaviors and enabling them to promote behavior change in their families and even in friends or acquaintances. Empowering the women to make healthy changes for both themselves and in their families was also one of the intentions of the design of Live Well. The descriptions of how they had experienced the cycle of Praxis as supporting them in changing their behaviors and those of others gives support to the assumption that an intervention that integrates into the lived experience of participants will increase the chances of intervention success.

Not only do the findings from these interviews provide some support for the hypothesis that community involvement creates research that integrates better into the lives of the research participants they also highlight the potential role of

empowerment as a mediator for program relevance and behavior change in a population like new immigrants. There is strong evidence that increasing self-efficacy, as a version of individual-level empowerment, can be instrumental in promoting behavior change [21]. However, self-efficacy is behavior specific, and the women in these interviews described the intervention giving them a more generalized sense of empowerment, beyond self-efficacy, that also motivated their behavior change. Powerlessness has been shown to be a risk factor for disease. On the other hand, empowerment, because it is difficult to evaluate, has rarely been looked at on its own as a mechanism for health promotion [22, 23]. The response of these women to the Live Well intervention suggests further study of the effects of empowerment on health behaviors and health may be worthwhile, especially with populations like new immigrants.

Haitian, Brazilian, and Latina women all received the same popular education curriculum, and they spoke about it similarly, in spite of the potential for cultural differences in perceptions and experiences. The women did not talk about the activities or information they worked with as feeling culturally tailored, but rather they described how it was applicable because they were given the opportunity to personalize it. This individual tailoring was reflected in the diversity of health behaviors the participants chose to work on. While the delivery of the intervention was standardized through using a curriculum, the use of Popular Education and Motivational Interviewing allowed individuals to choose and make the nutrition and physical activity related behaviors that most suited their lives. By using Popular Education, the Live Well intervention asked women to reflect on health behaviors in

the context of their cultures while giving them the opportunity to discuss similarities and differences between their individual experiences. This approach may have helped to dodge a potential problem raised in attempts at cultural tailoring, which is that just because people are from the same country does not mean they are culturally homogenous. Overall, using an approach that allowed individuals to choose which behavior changes best fit their own lives appears to have supported them in actually implementing those healthy changes.

The decision to use small group sessions was another part of the intention of the Live Well steering committee that had come out of the CBPR process. This decision, particularly, had been made through preliminary research and talking with immigrant women, who had expressed a desire to be involved in a program where they would be given the opportunity to connect with other women. The women interviewed for this study strongly focused on the importance of the social aspect of Live Well, their sense of being welcomed into a safe space and into a group that was a coming together of women with shared concerns. They described the group sessions as giving them the opportunity to step away from the stresses of their daily lives and instead to connect with the program coordinators and the other program participants, receiving support as everyone was given the opportunity to bring their voice to the table. Recent immigrants often experience high levels of stress from the acculturation process and may experience a sense of isolation that can lead to depression and negative health effects [23, 24]. Including social support in interventions with immigrants may be particularly important and effective because of social support's potential to alleviate some of the negative side effects of

acculturative stress [25]. But, the small group setting appears to have not only created the opportunity to receive some social support, it also created a venue for learning from the successes of others in the group and for group problem solving.

A particular concern with this study is the lack of virtually any negative comments from the interviewees, in spite of probing for negative feedback. This is especially concerning because the Live Well intervention experienced struggles with getting women to attend the sessions. It is hard to understand why this was a problem if the program was viewed so positively by participants, and suggests that there may have been bias in the interviewing or that the interviewees were not completely honest. The researchers on this study recognized the potential for bias and tried to minimize it. We genuinely wanted to hear any negative feedback participants had in order to help understand problems that arose in the intervention and to inform any future research or interventions. The women participating in the interviews were verbally assured of this and that their feedback would not influence the ability to participate in future programs. We hoped this would reduce the women's urge to give socially desirable answers. We also recognized there were power issues that could increase the likelihood that the interviewees would give socially desirable answers to questions. We hoped to minimize the drive to give socially desirable answers by having the interviews conducted by a researcher who hadn't been present for the intervention's implementation and by conducting the interviews in the women's native languages over the phone. However, it is also possible that the questions and probes simply were not the appropriate ones for eliciting negative feedback from these participants.

Purposive sampling was used to create a sample of women that would theoretically be likely to have had a variety of experiences with the program, including negative experiences. Women who had had low participation and who had gained weight during the program were included in the sample. However, even the women who had low participation were still women who had come to at least one session and had baseline and endpoint measurements taken. They may have been fundamentally different, and therefore experienced the program differently, from women who dropped out altogether.

Yet another possibility is that the women really did experience the program as positively as they described and that the low attendance rates for the program overall had other causes than it not being a good fit for the participants' lives. The immigrant experience can be an intensely stressful one with strong feelings of disempowerment and alienation [23, 24]. Language and cultural barriers as well as the experience of being treated as 'other' may negatively impact immigrants' health and their abilities to seek healthcare and information or to engage in health promoting activities[26-30]. Encounters with US health organizations and the medical system could lead to feeling misunderstood, unfamiliar, or even inept.

In Live Well, by contrast, the women participating felt empowered, and it is possible that this explains the lack of negative feedback the women gave. The women interviewed gave the sense that feeling heard and respected by the program was such a powerfully positive experience, that it created an overall positive lens from which they viewed their participation in the program and caused them not to focus on potential negatives. One woman, after being pressed to share any negative

experiences or ways in which the program didn't fit with her life explained outright, "It's not just somebody telling you what to do, but the person that is there is looking for you and wants to know your experience, and this is important, because everyone feels like "I am important for the program and the program is important for me." That is why I have nothing bad to say about the program." Another asserted, "I am saying this from my heart, not just, you know, to make you happy. I am just saying what I really felt. I never missed the meetings. I loved the meetings. I felt like I wanna learn, and from that I think I change my life in different ways."

Immigrants are likely to face stressors beyond cultural and linguistic ones. Immigrant women like those participating in Live Well may be working multiple jobs, facing domestic violence, afraid of immigration enforcement, and may have altogether so many other pressing concerns and stresses that participating in a health intervention may be pushed low on their priority list, even if they like the intervention and believe it is valuable. Further research is needed to understand and tease apart the various effects of these many influences on participation in and experience of research for new immigrants.

A further potential limitation of this study is that the interviews were conducted by phone rather than face-to-face. Phone interviews are not considered an optimal interview method because important facial cues or contextual information may be missed in the interviewing process. However, there is a lack of evidence showing that phone interviews actually produce lower quality data [31], and research comparing phone interviews to in person interviews showed no significant difference in results between the two [32]. In fact, research participants may be less likely to

give socially desirable answers over the phone than in a face-to-face interview [33]. Phone interviews were chosen to minimize participant burden given that these women had already been in an intensive research intervention for over a year. Both the study coordinators and the participants told the researchers that they would be much more willing and able to participate in an interview via phone than in person. It also allowed women who might have moved after the conclusion of the study still to participate in an interview.

The interviews were kept short to encourage women to agree to participate and were also occasionally cut short because an interviewee was called away to address an issue with her children or work. Longer interviews are preferable for gaining insight into an individual's experience, and the interviews in this study were too short to allow for real phenomenological analysis of the participants' experiences. But, the women still provided rich narratives of their experience of Live Well, and we were able to speak with women who might otherwise have declined to be interviewed because of the time commitment.

Conclusions

This study provides evidence that a behavioral obesity prevention intervention developed using CBPR integrated successfully into the lives of new immigrant women. Involvement in the intervention was experienced as a positive, and the information and activities of the intervention were described as meaningful, applicable, and empowering by the immigrant women who participated in the intervention. The program appears to have had this effect for several reasons. The main mechanism for the positive impact was the way in which engaging the participants to bring their own

experience to the table and to problem solve together about what types of changes they could make in their lives supported a cycle of Praxis, wherein the women discussed, reflected, and then took action. Another important element of what worked in the program was the positive social environment fostered in the small group sessions. The participants described being able to step away from the stress of their daily lives and be supported by the other women and the program staff. The women's positive experience of the intervention and the multifaceted ways in which the women had the opportunity to integrate it into their lives appears to have not only made for a relevant intervention, it also appears to have promoted actual health behavior changes in the women interviewed and motivated the women to disseminate health information and behavior change strategies to their families and friends.

The Live Well intervention is an interesting case because the community was engaged at two different levels. Community groups that work directly with new immigrant women were critical players on the steering committee that designed and implemented the intervention. Their involvement led to the use of Popular Education and Motivational Interviewing. Both the academic and community partners acknowledged the intervention would likely not have used these techniques if the study had not been co-created. The use of Popular Education and Motivational Interviewing brought the immigrant women themselves directly into the creation of the intervention by engaging the women in problem solving and choosing the behavior changes they felt would work in their own lives.

The women's descriptions of how positively they experienced the elements of the intervention that were purposefully designed by the steering committee as well as

the powerful impact of feeling truly heard and supported gives us some insight into whether and how a CBPR process may generate more effective research and interventions, as well as potentially successful mechanisms for engaging marginalized populations like new immigrants in the process of obesity prevention. However, this study was a case study of a single intervention and therefore may not be reflective of the mechanisms of all studies using CBPR. Further research is needed to continue to explore how promoting community involvement in interventions and research influences the experience of those involved. And, while this study gives some support to the idea that relevance and integration of the intervention into the lives of the participants did promote actual health behavior change, more research is needed to understand how the fit of research with the research participants' lives influences study outcomes.

Figure 1: Conceptual Model of Elements of Participant Experience Potentially Influenced by Using CBPR

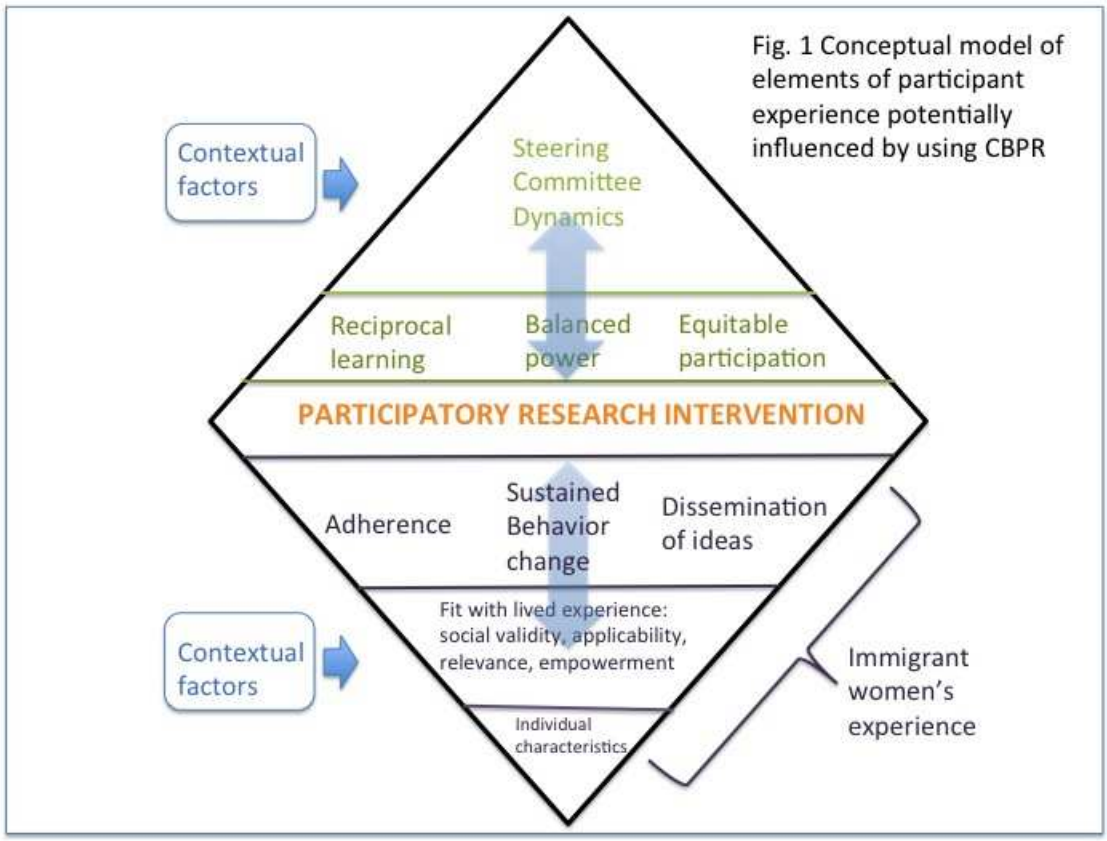

Table 1: Summary of Themes and Illustrative Quotes

Theme	Concepts	Sample Quotes
Activities or information experienced as useful	1. The changes fit into busy lives 2. Small changes – "tips" or "hints" - that could be practiced immediately 3. Activities where everyone brought their own experience and shared experiences and ideas 4. Activities that helped with navigating the U.S. environment (grocery store tour, reading labels, etc.)	1. "When you come to a different country you think, you only focus about working and you forget to do anything else, and you end up thinking you don't have time for exercising or to do anything extra. In that program, I learned in the program that is not so. I am walking more. I am riding my bicycle more. I am doing things out of working, where before I didn't think I had the time" 2. "She gave us some hints. [In] the hustle and bustle of everyday life, we don't think about, we don't pay attention to them (cooking and physical activity). But those things are easy to do, and you get better results, and I learned from those classes." 3. "For example, we would exchange ideas on how to prepare food differently, and we would exchange ideas on how to exercise, and so we learned with each other and even using things that were around us, we didn't see it before, that it could be for that purpose. By exchanging ideas we were able to understand those things, and we exchanged ideas and the end result was always positive." 4. "I would have to say that the thing that I remember the most, that was my favorite thing was actually going to the grocery store because when you walked in you were taught where the produce is nutritious where the good products and the bad products were. I love the fact that they taught us where the fresh products were, how to walk around, what were the bad products, we even had the manager at one of the super markets teach us which were bad products, this was poison, like MSG"

Theme	**Concepts**	**Sample Quotes**
The social experience of Live Well	1. Group sessions experienced as a group of women coming together to talk about things they shared 2. A relaxing, safe space, time to step out of daily life 3. There was time to hear from everyone, no favoritism	1. “what I really like there is that they really didn’t care where you came from. It was just women that were worried about their over-weight children. It didn’t matter which country you came from.” 2. “This program took a lot of working women out of their routine. They will always ask how your day was. They wanted you to get disconnected from everything and just talk about yourself, and they will always listen.” 3. “Everything was nice, everything was relaxing. We all had time to give our opinions, give comments. There was never an interruption, like your opinion is not good or not valid. Everyone had an opportunity to speak, and everyone had an opportunity to be heard.”

Theme	Concepts	Sample Quotes
Family effects of Live Well	1. Changes made by participants to their families' diets and physical activity (eg. change food served or portion sizes, reduce children's screen time, walk to the store) 2. Info picked up by family members (mostly kids) through attendance or handouts 3. Participants purposefully teaching other family members	1. “We used to think that whatever liquid we had, the sweeter the better. So it began with eliminating a lot of those products, and now we feel that our taste buds have changed. It is now used to not having sugar, and sweet liquids, and I think it is the same for my entire family” 2. “she (a daughter) can read, so the handouts sometimes we used to share at home. I still have the folder with all the papers and she is really good at listening, so I think that helps a lot. Before she was there she went with another kid with another woman seeing a patient, and she always asks me, and she loves to come with me.” 3. “My daughter, she reads labels on the packages. You know when you go buy food, she always pays attention to how much sodium? Is in that food, that sodium is not good for the body, especially not for kids. And she knows about the cholesterol, how much fat is in this or that food, and it is funny because she pays attention, and she helps me, and she asks me questions, like “mommy is this ok?,” and I tell her oh no that is no healthy, so we advise her to eat careful things that are less processed.”

Theme	**Concepts**	**Sample Quotes**
Personally empowering and empowered experiences	1. Feeling heard and respected 2. Teaching others, passing on the knowledge and ideas 3. Experiencing success with practicing changes and reaching goals	1. "Yeah the program gave us to share, all the things. That was very important because people share, you feel better, you know? Its not just somebody telling you what to do, but the person that is there is looking for you and wants to know your experience, and this is important, because everyone feels like "I am important for the program and the program is important for me." That is why I have nothing bad to say about the program." 2. "And even though I know that wasn't the end, I still have the knowledge and I can pass that knowledge on to my neighbors, to my friends at work. I just have that feeling of sadness (that the program is over), but every time I see someone that is eating the wrong way, and they want it to change, I pass on the message. I believe that is something that stayed, and that is something that I can do better for others." 3. "It helped me motivate myself so that I began exercising. I feel like I can accomplish a lot and they help me make goals they help me reach some of those goals already."

Theme	Concepts	Sample Quotes
The experience with coordinators and staff	1. Friendly but professional 2. Warm and understanding 3. Engaged	1. "Everyone in the program was very nice, the people that measure, everybody there was very nice. They never made me feel bad because I was chubby. I just felt I was in a place with professional people that really wanted to help." 2. "I found that they were very educated. They really weren't cold in their responses at all, especially when it came to talking about my two children. So they helped a great deal." 3. "They were always there, always paying attention – helping with my diet, helping me with low-fat decisions/low-fat meal choices, and helping me with activities."
Changes in participants' lives	1. Changes in behavior 2. Physical changes	1. "They teach me how walking actually gives me more energy, helps me breathe better, and on the weekends when it is not cold, I just bought a bicycle, so now I bicycle on the weekends when it is not cold. Everything has changed." 2. "I think when you learn to eat healthy, you learn to change other things in your life too. You learn when you eat right, your body gets right, and you have more energy to do activity. When you are going upstairs, walking around the house, being busy, because when you eat food that is heavy, it is not health for your body, your body is going to shut down, you gonna have less energy, you gonna wanna sleep. So when you change eating, everything changes too. Your body gets more right. I think your body recognizes the need to modify the need, you know."

Theme	**Concepts**	**Sample Quotes**
Negative experiences	1. None/That the program ended, and they wished it could continue 2. Individual minor suggestions	1. “It was a very nice experience, you know. I am saying this from my heart, not just, you know, to make you happy. I am just saying what I really felt. I never missed the meetings. I loved the meetings. I felt like I wanna learn, and from that I think I change my life in different ways.” 2. “Maybe if once a week if the group could have a workout together, like zumba or a bike ride, maybe that would be one suggestion.”
Summary statements	Positive emotional response; a different kind of program	“ Everything was very creative and good. It is easy for you to learn.”; “all I want to say is thank you, because this is something that I am going to remember for the rest of my life, something that is going to help me in my life and I just thought the program was excellent”; “ it seemed like a different program that truly cared about the health of women and children.”

References

1. **Healthy People 2020 Objectives.** US Department of Health and Human Services; 2010.
2. **CDC Health Disparities and Inequality Report – United States, 2011.** vol. 60(suppl.). Centers for Disease Control and Prevention; 2011:73-77.
3. **Population Projections -U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin.** United States Census Bureau; 2009.
4. **Statistical Portrait of the Foreign-Born Population in the United States, 2008.** Pew Hispanic Center; 2010.
5. Akresh I: **Dietary Assimilation and Health among Hispanic Immigrants to the United States.** *Journal of Health and Social Behavior* 2007, **48:**404-417.
6. Aldrich L, Variyam J: **Acculturation erodes the diet quality of U.S. Hispanic.** *Food Reviews* 2000, **23:**51-55.
7. Roshania R, Narayan K, Oza-Frank R: **Age at arrival and risk of obesity among US immigrants.** *Obesity (Silver Spring)* 2008, **16:**2669-2675.
8. Barcenas C, Wilkinson A, Strom S, Cao Y, Saunders K, Mahabir S: **Birthplace, years of residence in the United States, and obesity among Mexican-American adults.** *Obesity (Silver Spring)* 2007, **15:**1043-1052.
9. Shalowitz M, Isacco A, Barquin N, Clark-Kauffman E, Delger P, Nelson D, . . . Wagenaar K: **Community-based participatory research: A review of the literature with strategies for community engagement.** *Journal of Developmental and Behavioral Pediatrics* 2009, **30:**350-361.
10. Minkler M: **Linking science and policy through community-based participatory research to study and address health disparities.** *American Journal of Public Health* 2010, **100:**S81-87.
11. Francisco V, Butterfoss F: **Social Validation of Goals, Procedures, and Effects in Public Health.** *Health Promotion Practice* 2007, **8:**128-133.
12. Tovar A, Must A, Metayer N, Gute D, Pirie A, Hyatt R, Economos C: **Immigrating to the US: What Brazilian, Latin American and Haitian Women Have to Say About Changes to Their Lifestyle That May be Associated with Obesity.** *Journal of Immigrant and Minority Health* 2012, **15:**357-364.
13. Tovar A, Vikre E, Gute D, Kamins C, Pirie A, Boulos R, Metayer N, Economos C: **Development of the Live Well Curriculum for Recent Immigrants: A Community Based Participatory Approach** *Progress in Community Health and Partnerships* 2012, **6:**195-204.
14. Tovar A, Boulos R, Sliwa S, Must A, Gute D, Metayer N, Hyatt R, Chui K, Pirie A, Kamins C, Economos C: **Baseline Socio-Demographic Characteristics and Self-Reported Diet and Physical Activity Shifts Among Recent Immigrants Participating in the Randomized Controlled Lifestyle Intervention: "Live Well".** *Journal of Immigrant and Minority Health* 2013**:**1-9.
15. Freire P: *Pedagogy of the Oppressed.* New York: Continuum; 1970.

16. Hettema J, Steele J, Miller W: **Motivational Interviewing.** *Annual Review of Clinical Psychology* 2005, **1:**91-111.
17. http://www.callopi.com/
18. **NVivo qualitative data analysis software; Version 10.** QSR International Pty Ltd.; 2012.
19. Ryan R, Deci E: **Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being.** *American Psychologist* 2000, **55**.
20. Deci E, Ryan R: *Intrinsic motivation and self-determination in human behavior.* New York: Plenum; 1985.
21. Bandura A: **Self-efficacy: Toward a unifying theory of behavioral change.** *Psychological Review* 1977, **84:**191-215.
22. Wallerstein N: **Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs.** *American Journal of Health Promotion* 1992, **6:**197-205.
23. Dalgard OS, Thapa SB, Hauff E, McCubbin M, Syed HR: **Immigration, lack of control and psychological distress: Findings from the Oslo Health Study.** *Scandinavian Journal of Psychology* 2006, **47:**551-558.
24. Thomas T: **Acculturative stress in the adjustment of immigrant families.** *Journal of Social Distress and the Homeless* 1995, **4:**131-142.
25. Xu L, Chi I: **Acculturative stress and depressive symptoms among Asian immigrants in the United States: The roles of social support and negative interaction.** *Asian American Journal of Psychology* 2013, **4:**217-226.
26. Suurmond J, Seeleman C: **Shared decision-making in an intercultural context: Barriers in the interaction between physicians and immigrant patients.** *Patient Education and Counseling* 2006, **60:**253-259.
27. Finch BK, Hummer RA, Kol B, Vega WA: **The Role of Discrimination and Acculturative Stress in the Physical Health of Mexican-Origin Adults.** *Hispanic Journal of Behavioral Sciences* 2001, **23:**399-429.
28. Johnson JL, Bottorff JL, Browne AJ, Grewal S, Hilton BA, Clarke H: **Othering and Being Othered in the Context of Health Care Services.** *Health Communication* 2004, **16:**255-271.
29. Viruell-Fuentes EA: **Beyond acculturation: Immigration, discrimination, and health research among Mexicans in the United States.** *Social Science & Medicine* 2007, **65:**1524-1535.
30. Grove NJ, Zwi AB: **Our health and theirs: Forced migration, othering, and public health.** *Social Science & Medicine* 2006, **62:**1931-1942.
31. Novick G: **Is there a bias against telephone interviews in qualitative research?** *Research in Nursing and Health* 2008, **31:**391-398.
32. Sturges J, Hanrahan K: **Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note.** *Qualitative Research* 2004, **4:**107-118.
33. Hill C, Knox S, Thompson B, Williams E, Hess S, Ladany N: **Consensual qualitative research: An update.** *Journal of Counseling Psychology* 2005, **52:**196-205.

Section IV

Summary and Discussion

What follows is a summary of the findings of each of the three papers comprising this dissertation. These findings will be discussed, integrated and related to the broader field of CBPR. Finally, we will present public health implications and recommendations based on the findings of this research.

Paper 1 summary

The first study in this thesis showed that the dynamics of a CBPR partnership over time are complex and variable. Viewing the group as an organizational system showed that rational, natural, and open systems perspectives [1] all contributed to understanding the dynamics of the CBPR process in this case study.

Rational System: The Live Well Steering Committee (SC), viewed as an organization, fit some predictions of the rational system perspective, which emphasizes the centrality of formalized goals and formal roles for organizational functioning. For Live Well it was predominantly the goals and social structural dynamics that were related to carrying out the research trial that were formalized. Live Well was funded by the NIH as a randomized controlled trial (RCT), therefore the SC had a set of specifically defined goals stated in the grant application for the project, including recruiting a certain number of study participants, randomizing them, and implementing an obesity prevention intervention. These goals drove central aspects of the decision-making and group activity, particularly because these

goals were clearly evaluable and had accountability measures in place for reaching them. There were also formal structures set up at the beginning of the project to facilitate power sharing. These formalized structures helped to set a precedent that created the foundation of power sharing from which the group worked over time in the project.

Natural System: Meanwhile, the dynamics that allowed the partnership to continue to work successfully together over time - including effective communication, handling conflict, power-sharing, and collaborative decision-making - grew out of the development of close personal relationships, leading to greater trust and synergistic problem solving. The natural system perspective emphasizes the importance of the informal social structure in organizations. In Live Well the informal social structure was clearly critical. It was built from relationships that continued into the project and through group bonding experiences that were underpinned by experiences that "emphasized the human element" and allowed the committee members to get to know each other as "human beings." Consistent with a natural system view, each member brought their personality, not just their cultural or work role, into their participation. During times members described as being particularly successful, the group allowed individuals to play to their strengths and contribute from their areas of capacity.

Open System: Consistent with psycho-social open system views of organizations, in the SC roles, relationships, systems of behavior, expectations, and the intervention itself were largely created through interaction. Beyond basic contracts set up in the grant, much of the work was carried out by establishing

social and psychological contracts among the group members that were built through transparency, earning and maintaining trust, sharing power, consensus decision making, and being willing to participate and make contributions beyond a narrowly defined work role. These types of behaviors were repeated over time until they became established behavioral systems. As partners got to know where the others were coming from, they came to respect others' motivations and contributions more and more. The interactions that established shared systems of behavior and belief, became the most powerful drivers of how the group functioned. This "human" element of participatory research, established through relationship building and ongoing interactions to create a common sense of purpose and a nuanced, generous understanding of others' roles and motivations, may be critical for effective group dynamics and achieving synergy. This may be true of any work that brings together people and organizations with different backgrounds and strengths to address a common question or problem.

Paper 2 summary

The second study in this thesis found that the Live Well intervention, designed by using CBPR, was perceived as relevant and responsive by the immigrant women recruited to participate in the study. We found that relevance of information, relevance of activities, and a sense of voice being taken into consideration were each significantly positively associated with self-reported adherence, even after controlling for important covariates. Relevance of activities had a particularly large effect size, with a one-point increase in perceived relevance predicting 2.75 times the odds of reporting a higher level of adherence. This provides some validation of the

community-driven decision to use a hands-on curriculum that emphasized personalized behavior change strategies that could be practiced immediately and continued at home. There may have been bias in the measure of adherence because it was self-report. Conversely, adherence, rather than attendance, could also be a more important measure in an intervention with a group of individuals like new immigrant women, who may experience many barriers to attending a program even if they find it relevant, and who may be adopting change on their own at home even if unable to attend program sessions.

Being in the first recruitment cohort was a particularly strong predictor of higher attendance in the group sessions. Recruitment was undertaken in two phases because the partnership faced many challenges recruiting adequate numbers of study participants in the first round of recruitment (eg. an Earthquake in Haiti, limited geography of the specified recruitment area…). Anecdotally, because cohort 1 had already been participating in the intervention for several months, the intervention had gained additional recognition in the community with the participants in the intervention even recommending it to friends, which enabled recruitment of more women into the second cohort. So, while the two cohorts had relatively similar demographic composition, they may have had different levels of internal motivation for participating. There were also differences in perceptions of relevance and responsiveness between the three ethnic groups in the study, and a strong association between ethnic group and individual session attendance. Differences remained, even after controlling for characteristics related to cultural preference or adaptation to the US - including acculturation and time in country. These differences are challenging to

explain. All three groups were represented on the Live Well SC and played critical roles in the design of the intervention. The three study-coordinators (one for each group) who led the group and individual sessions received the same training in leading popular education classes and in motivational interviewing, and they did their planning together to minimize differences in how the intervention was administered to the different groups. However, due to other time commitments that sometimes prevented partners from attending meetings or joining sub-committees, there may have been more heavy involvement of some community representatives than others in the process of creating the intervention curriculum. There may also have been differences between the ethnic groups in unmeasured attributes – for example, attitudes towards health practitioners or preferences for autonomy-supportive styles of communication – that the SC missed in designing a single program to meet the needs of a diverse group of individuals. The differences between the groups in this study, underscores the need for more research with immigrants from these three communities as well as other new immigrants. It also highlights one of the greatest challenges in CBPR, which is deciding how and by whom a community will be represented.

Forward and backward stepwise regression showed that for this set of data, cohort, ethnic group, perceived activity relevance, and a sense of voice having been taken into consideration had the strongest associations with attendance and adherence.

Paper 3 summary

The third study in this thesis examined the experiences of a subset of the immigrant women who were study participants in Live Well. Findings suggested that in this intervention, using the CBPR process generated an intervention that integrated well into the participants' lives and impacted them not only in their health behaviors, but also on a deeper level of meaning. The women's experiences with the intervention suggested that it was relevant, meaningful, and empowering for them, and that these attributes of the intervention promoted actual health behavior changes. Themes from the interviews included: summary statements about their experience with the intervention, particularly about positive emotional responses; changes in their lives from the intervention; activities or information they experienced as useful, in particular simple changes they could practice immediately, the opportunity to bring their experiences and exchange ideas, and activities that helped them navigate their environment; the social experience with other women and the staff in Live Well; empowering and empowered experiences; and the effects of the intervention in their families.

In their interviews many of the women spoke of the intervention as life-changing because of the way they were given the authority to share their experiences and choose their own activities, and they felt this authority ramified out into their lives. In the words of one woman, "when you change eating, everything changes too." The co-creation and co-learning processes led the Live Well SC to develop an intervention that strove for giving a voice to immigrant women who don't typically have the chance to assert their voices or authority. The SC intentionally

chose to focus on giving the women in the intervention the opportunity to co-construct knowledge through the use of Motivational Interviewing and Popular Education.

As intended by the steering committee, the Live Well intervention was built around the best scientific evidence on nutrition and physical activity, but the women weren't given the information in a didactic manner, instead they were asked to share how their own experiences related to this information. The women interviewed described how important participating in a cycle of discussion, reflection, and action – a cycle termed Praxis in Popular Education – had been in their experience of Live Well. They described how this had felt unique and empowering to them, stimulating them to change their own nutrition and physical activity behaviors and enabling them to promote behavior change in their families and even in friends or acquaintances. Empowering the women to make healthy changes for both themselves and in their families was one of the intentions of the design of Live Well. The descriptions the women gave of how they had experienced a cycle of learning, reflection, and action as supporting them in changing their behaviors and those of their families gives support to the assumption that an intervention that integrates into the lived experience of participants will increase the chances of intervention success.

Another important element of what worked in the program was the positive social environment fostered in the small group sessions. The women in the interviews described the group sessions as giving them the opportunity to step away from the stresses of their daily lives and instead to connect with the program

coordinators and the other program participants, receiving support as everyone was given the opportunity to bring their voice to the table. Recent immigrants often experience high levels of stress from the acculturation process and may experience a sense of isolation that can lead to depression and negative health effects [2, 3]. Including social support in interventions with immigrants may be particularly important and effective because of social support's potential to alleviate some of the negative side effects of acculturative stress [4]. Additionally, the small group setting appears to have not only created the opportunity to receive social support, it also created a venue for learning from the successes of others in the group and for group problem solving.

Discussion

The goal of this thesis was to conduct a study of a CBPR study during the time period while the CBPR study was ongoing in order to contribute to our understanding of the operationalization and mechanisms of CBPR. We explored portions of the pathway from CBPR process to outcomes by analyzing in depth the partnership process over time as well as the study participants' perceptions and experiences. We were particularly interested in this case where the CBPR approach was being used for understanding and addressing a complex public health problem - obesity. Much of what was found provides validation of the principles of CBPR as having the potential to increase the efficacy of public health research and interventions at least insofar as it may contribute to more appropriate and relevant research design and this may enhance study acceptance and adherence. The findings of this thesis particularly

underscore the critical role of a human-engine, of sorts, that makes participation work.

Within the context of Live Well being an NIH-funded RCT, the dynamics of the SC that created and implemented the Live Well intervention were very complex and variable, more so even than a researcher or community member might expect from reading CBPR process evaluations and lessons learned. Amidst this complexity, an ongoing theme was the important role of the close personal relationships SC members developed with one another, their sense of doing something really worthwhile together, and the importance of truly listening and truly being heard. These core "human" (as they were often referred to in interviews) elements helped the SC work through a myriad of conflicts and challenges as well as achieve synergistic results. The moments when the committee members were most open, personal, caring, and willing to give one another the benefit of the doubt were also described as the moments when they worked most cooperatively, creatively and synergistically with one another.

Synergy has been proposed as the mechanism by which partnerships or collaborations can achieve better results than single entities, in particular by engendering comprehensive, creative, and transformative thinking [5]. Our data suggest that the emotional, personable interactions that built trust, and that facilitated power sharing, consensus decision-making and expanded understandings of one another's roles were also the elements that helped produce synergy in the SC. This has important implications for our understanding of how following CBPR principles can also lead to more effective work. It also has implications for how members of a

CBPR research partnership are chosen and trained, suggesting that partners that will be most effective are those that are willing not only to contribute from their areas of capacity, but will also truly listen to others, be prepared to learn from others and to demonstrate they are trustworthy and flexible, and will work with the other partners to create a shared vision for the research.

A number of papers on CBPR focus on the creation of formal, written documents – particularly Memoranda of Understanding (MOU) – to guide how the group will work [6-9]. However, the findings of this thesis suggest that while an MOU may be an important place to start, it is likely not enough on its own to promote partnership functioning and adherence to CBPR principles. On the other hand, our findings suggest that time spent in group and relationship building within partnerships is time well spent, even though partners may sometimes feel that this time and energy should instead be devoted to moving forward with project implementation [10-12]. Our findings similarly suggest that the time it takes to team-build and to co-create a study that is truly the product of co-learning can be time well spent as it can lead to synergistic ideas and decisions that may make a more appropriately designed intervention that is more relevant in the community, which may help with sustainability and dissemination.

Additionally, as group structure and dynamics are variable over time and can be established through interaction, it may be essential to continue group building and fostering positive interaction on an ongoing basis in a research project to continue to promote synergy and effectiveness. As an example, the SC built significant trust and group synergy during a retreat at which they developed the ideas for the curriculum

used in the intervention. This dynamic continued to be supported by co-learning in Popular Education and Motivational Interviewing trainings. However, these positive dynamics faced challenges as the project continued. For example, challenges with recruitment led to the expanding of the geography from which participants were recruited; this decision took many discussions and tense meetings as differing agendas surfaced, but the time and attention taken to fully discuss the options and implications resulted in a unanimous decision to expand the criteria in the end. As another example, one of the academic members of the SC wrote a paper for publication in which accepted research terminology was used, but some of the other SC members – particularly community partners – objected strongly to the terminology. Again, the SC took the time to fully discuss everyone's point of view, and as one committee member summarized, "we persevered, and sort of did some further looking around and found this different way… (that is) actually much more useful from my standpoint." Our findings in this regard support the descriptions given of processes and lessons learned from other CBPR projects that experienced the need for ongoing maintenance of relationships without which trust and sense of mutual purpose could be lost [13-16].

Taking an organizational theory perspective on the work of the SC provided a useful lens for understanding the multiple complex and interconnected elements that underpinned the group's dynamics and functioning. Future research could continue to consider CBPR partnerships as organizations, and researchers interested in engaging in participatory research or studying participatory research processes could benefit from training in organizational theory, organizational functioning, and group

dynamics. Future research could also include both CBPR partnerships and research participants together as an organization for analysis. Additionally, research not only on partnerships and collaborations, but also research on effectiveness in organizations – particularly research that considers the balance between rational, natural, and open system aspects of organizations – could crossover and provide insights into achieving effectiveness in CBPR partnerships.

At what members described as its most synergistic moment, the Live Well SC came up with an intervention strategy that actually replicated the participatory nature of their own work and adhered to the empowering and emancipatory attitude in which CBPR is fundamentally rooted. The SC chose to develop an evidence-based behavioral intervention that would also meet the immigrant women who were study participants "where they were," giving them a voice in the implementation of the intervention by using Popular Education and Motivational Interviewing. In this way, the principles of CBPR were applied not only at the level of study design, measurement, and analysis, but also in the implementation of the intervention on the ground. This is a fairly novel and unusual approach for a RCT. Additionally, Popular Education and Motivational Interviewing were novel techniques for the committee members. The committee chose to use these techniques for the intervention in spite of the fact that none of the partners involved had expertise in them because they felt it would be the best fit for the women. The committee sought training from outside experts in Popular Education and Motivational Interviewing in order to apply them to the intervention.

When asked about their experiences in the intervention, the women who were interviewed described the way they were engaged and given the opportunity to assert their voices and experiences while choosing their own behavior change strategies as having a more profound impact than one might expect from an obesity prevention RCT. For these women, the participatory process they experienced in the intervention helped them change their health behaviors and empowered them to work to make changes in their families and in some cases even in friends and acquaintances' lives as well. Participation, having their voices heard and respected, and coming together with other immigrant women to share experiences were described emotionally and powerfully as changing "everything." The interviews with the women suggest the possibility that the participatory nature of the intervention and its following of the principles of CBPR may have helped these women to make healthy changes in their lives, and it may also have given them a sense of empowerment and self-determination in the face of busy, stressful lives and experiences of isolation and "othering" (being treated as other - a process of being stereotyped and marginalized) that have been described as characteristic of the experiences of new immigrants to the US [17, 18]. Research has shown that stress and a lack of a sense of control over one's circumstances, both potential outcomes of "othering," can have negative health impacts including inhibiting individuals' self-control and decreasing overall well-being [19-21]. Given this and the findings of our research (and as suggested by the spirit of CBPR), researchers and public health practitioners working with marginalized populations may wish to incorporate methods that focus on giving a voice to the individuals they are working with and supporting their self-determination

as a first step towards then increasing those individuals' efficacy for making and sustaining health behavior changes.

In models of CBPR and the hypothesized pathways from CBPR principles to health impact, empowerment and improved health are tandem ultimate goals [22]. Empowerment and support of self-determination can be considered a successful CBPR outcome all on its own. The findings from the interviews with Live Well participants supports research that suggests that empowerment may also be a more directly important factor in effectively changing and sustaining health behaviors to improve health outcomes with respect to chronic diseases [23-26], and contributes to our understanding of empowerment as both process and outcome. Although we saw this relationship within the context of an RCT, it was captured through qualitative exploration of the participant experiences. Quantitatively measuring empowerment and capturing the multiple ways in which it may influence health is likely to continue to be a challenge, but one that merits further research.

The Live Well SC didn't always manage to embody the principles of CBPR. At times there were struggles with capacity and getting all the partners to contribute. Elements of the study, for example, choosing study measurements, were largely left to the researchers. Some of the community partners' voices – often those of non-immigrant men – were a bit louder than others' on the SC. The community partners were also a select group of people who held leadership positions in organizations, and many had previous experience with research, and were thus not necessarily representative of the community that was the study population. Yet through the synergy of the partnership, the community and academic partners chose an approach

to intervention that would more directly engage and give voice to the study population.

Of course, the intervention also did not fully, and perfectly engage the immigrant women in it. Some women dropped out or never even came to a session; the intervention was more relevant and responsive to some than to others. Recruitment and retention are one of the major challenges in health research or interventions with hard-to-reach populations, including new immigrants, and one of the proposed benefits of using CBPR is improved recruitment and retention [11]. Our experience with the Live Well study shows that with the involvement of the community, a sufficient sample was recruited from this hard-to-reach population of new immigrants. But in spite of the community-academic partnership's best efforts – including providing childcare and an adaptation midway through the intervention to include raffles to incentivize coming to sessions – it was still a struggle to get full participation of the study participants in the intervention when it required their attendance at an individual or group session every month. It seems likely that for some women, even if they wished to fully participate, there were some powerful structural or other barriers to participation that the committee was unaware of or unable to address. Future research should be undertaken with new immigrant populations to better understand barriers they face to participation. For those who did participate however, the moments when the work was the most human, the most humble, the most engaged, and participatory also seem to have been the moments when it was the most powerful and effective.

We also quantitatively evaluated a potential pathway for how following CBPR principles may lead to more effective research by assessing the association of relevance and responsiveness with intervention attendance and adherence. We found that increased relevance and responsiveness of an intervention generated through community participation may explain part of the mechanism that can make CBPR an effective approach. The women in the Live Well study reported overall high perceptions of relevance and responsiveness; and relevance and responsiveness were positively associated with attendance and adherence, particularly adherence. These findings support one of the rationales for CBPR in the literature, namely that community participation will generate more socially valid research and therefore research findings and program activities will be more likely to be implemented by the community [27]. However, the findings of this study also highlight that increased relevance and responsiveness only explained some of the variation in attendance and adherence and is likely only one of the mechanisms that can enhance the effectiveness of research through community participation. Though it would be a large task, future studies should evaluate all the multiple proposed mechanisms of CBPR effectiveness within studies and across multiple CBPR studies. Additionally, there were statistically significant differences between the groups – Haitian, Latina, and Brazilian – in perceptions of relevance and responsiveness, with the Brazilian women in particular reporting lower perceived relevance of activities and information and of feeling their voices were taken into consideration. The Live Well study was not designed to assess differences between the three groups in the study, particularly because of the way comparing groups can easily lead to findings that may be interpreted as judgmental.

However, both baseline assessments and working with the women quickly revealed that there were some definite differences between the groups. The Brazilian women, for example, tended to have been in the US for longer, were more likely to be employed, and to have lower BMI [28]. There may also have been differences in employment expectations, gender role expectations, or other characteristics for the Brazilian women that may have made them feel more empowered or more aware of healthy behaviors at the start of the Live Well program, thereby making the program seem less relevant. On the other hand, anecdotally, we heard that the Brazilian women who were participating in the sessions were so engaged they almost had to be pushed out of the room at the end of the session time. Without more direct inquiry with the women, we cannot fully understand the reported differences in perceptions.

In a related vein, the findings of this thesis highlight the complexity of participatory research, both in its implementation and in how it achieves outcomes. As CBPR strives to generate "socially relevant research" [29] and address complex socially-determined health problems like obesity, proponents of CBPR argue that it should attend to the multiple determinants of disease and health disparities as well as privilege multiple ways of knowing [22]. These principles, based both on theories of community organizing and on the reflections of CBPR practitioners on lessons learned, receive confirmation from this study of the CBPR process. Obesity is a complex public health problem, particularly in a traditionally marginalized community like new immigrants. The Live Well project was at its core an RCT, but through the interactions and input of the SC partners as well as that of the immigrant women in the study, Live Well as a whole entity grew to be much more complex than a

traditional RCT. As one SC member described it, it was, "just a very multilevel project and it's got a lot of moving parts" while another explained, "it all seems really simple when you start out, and then it keeps getting more complicated and changing. But I think we all adapted and have probably grown."

The complexity of the environment and the study participants' lives required ongoing adjustments of the project and influenced many decisions of the SC. Committee members contrasted the adaptability of working on Live Well versus more traditional research. For example one highlighted the committee's ability "to fine tune and adjust and compensate for information that was coming in, which to me is a characteristic of community based participatory research." Another reflected on the importance of adaptability, saying, "sometimes we get a little bit mired in everything else we have going on and don't take the time to reflect on how best to adapt and yet I think that is one of our strengths as a committee, is that ability to do that." Feedback particularly came from the project coordinators who had the most interaction with the community and women in the intervention. The coordinators developed a real rapport with the women and their families, and in their interviews the coordinators explained that they saw it as their duty to bring the women's perspective to the SC. In the words of one committee member, "if it weren't for (the coordinators) being with the women and hearing from those experiences I think we could have gone many different directions." In the words of another committee member, "we can come into things with an invisible screen that doesn't allow us to see certain things that are there because we don't know that they are there. And I think to some extent, particularly what the immigrant members of the Steering Committee have to offer

are glimpses into a reality, more than glimpses, a reflection of a reality that some of us have no insight into because we have no experience of it...So yeah, that the space was made available for that was not insignificant."

The SC incorporated the feedback from the women as well as the community partners to the best of their ability within the context of the project being an obesity-prevention RCT, for example getting training about domestic violence and resources they could point women to, adopting new language for talking about parenting styles so scientific findings wouldn't be misconstrued as judgmental, and creating a curriculum with the flexibility and openness to allow the women in the study to discuss what mattered to them. The project at times brought up the potential relationship of obesity in new immigrant women to occupational health and injury, domestic violence, immigration enforcement, stress and depression, active citizenship, time stress from sources such as children, multiple jobs and attending ESOL classes, and cultural and personal food or physical activity beliefs and preferences, amongst others. While the main study outcome of differences in BMI-change between intervention and control groups is an important outcome, Live Well would have been a less rich and less socially relevant study if these other factors had not been allowed to arise. In addition, in the interviews undertaken with a subsample of the Live Well participants, weight loss or obesity prevention was rarely brought up by the women. Instead they spoke of more general health changes, like eating more healthfully or getting physical activity, and especially of increased well-being like having more energy and feeling supported and heard. Change in BMI is unlikely to capture these healthy changes when the measurement period was limited to only one

year as it was in Live Well because of the study funding. However, these healthy changes could have led to other meaningful health outcomes that were measured but weren't the main study outcome, for example changes in diet patterns or stress, or to health outcomes that were not measured in Live Well, for example changes in blood pressure or markers of inflammation. On the whole, the women's rich descriptions of meaningful changes in their lives provides affirmation of the Live Well SC's decision to name the project "Live Well" – a decision that, like many of the others, took a great deal of time and negotiation – and to focus on general well being for immigrant women and children as a pathway to obesity prevention, rather than presenting the women with an intervention that was clearly weight-loss oriented.

Even for researchers committed to participatory research and attending to the multiple eco-social influences on public health, participating in CBPR can be a challenge because of institutional constraints, including universities', research journals', and funders' expectations. In interviews, SC members brought up struggles with funding cuts; with how to present findings for journals that don't typically publish participatory research; with getting approval from university financial administrators and Institutional Review Boards that weren't familiar with CBPR; and with continuing on a trajectory of advancement within the university while doing interdisciplinary and community-engaged research. As one academic researcher summed it up, "you are a creature of a department, and you're judged by narrow expertise in a field, not broad. The way academia is set up, you do have to be good in a narrow field, and by virtue of this, it is hard to make community based

work run easily, and hard to look broadly at the determinants of disease. It's still hard to take a broad, multidisciplinary approach."

CBPR literature has pointed out that though it is considered a gold-standard in research, the RCT is not necessarily feasible or appropriate for participatory research, particularly because community members may object to there being a control group who does not receive the benefit of an intervention. In the Live Well study, the community partners accepted the idea of having a control group to gain the potential research benefits an RCT has to offer, however implementing an RCT in the community context was challenging given that the reality is that a community is interconnected and neither really random nor controllable. Anecdotally we heard that women in the control group had connections to women in the intervention group. And, though not included in the analysis in this thesis, data collected from the end of study supplementary questionnaires (through which we collected relevance, responsiveness, and adherence data from the intervention group) also showed that the control group women felt involved in the study – perhaps because of the multiple times they had measurements taken (height and weight were measured at baseline, 6 months, and 12 months) or the coordinators' phone calls to check in and make sure the women didn't drop out of the study – and reported that they changed their physical activity and eating in response to being part of Live Well, even though they did not receive any intervention (see appendix F).

One of the greatest limitations of the research in this thesis is the lack of comparison to other studies. Using a case study of a single CBPR study allowed for detailed inquiry into the CBPR process, however because of this we did not have direct

measures with which to compare or contrast it with other CBPR studies or with non participatory obesity-prevention interventions. We believe that the CBPR process we observed in Live Well resulted in a different and more effective study than it would have been had it not used CBPR, but we cannot know for certain. This thesis is a unique contribution because of the way it studied CBPR on multiple levels while the CBPR project was ongoing, but it is only a first step. Further research is needed to explore the application of CBPR in public health research and interventions, including studies of how variations in CBPR process influence health outcomes and studies to further clarify mechanisms of CBPR impact, including the role of empowerment and self-determination in health. Additional research could also compare the outcomes and efficacy of research and interventions using different levels of, or approaches to, community engagement for addressing different health issues in different contexts. CBPR may be particularly suited to addressing complex problems like obesity or working with traditionally marginalized populations, but it is by no means the only approach nor is it likely to be the best approach in all contexts. At the same time, a variety of research approaches could potentially benefit from recognizing and embracing more of the "human element" in research, particularly when conducting research into health problems that are related to human behavior.

Research such as that undertaken in this thesis cannot be understood without acknowledging the role and perspective of the researcher. As a graduate student and participant-observer on the Live Well SC, I was in the lucky position of being in-between worlds. I was not an academic, and I was able to develop relationships with the community partners that had a very different power dynamic than would have

existed if they had perceived me as an academic. This built trust, and I have the sense that they were willing – especially because they were assured of confidentiality – to speak really frankly with me in our interviews. At the same time, I was in training to be an academic, and received support, advice, and insight from the academics on the committee as such. As a participant-observer I also benefitted from the overall development of trust and honesty that the SC interactions produced. I approached researching the CBPR process in Live Well with an interest in CBPR and a belief in its potential, but also a great deal of skepticism about the possibility of really adhering to CBPR principles and achieving the promise of CBPR in the real world.

With regards to researching the experiences of the immigrant women in the intervention, my research interest in immigrants and diet arose from being the child of an immigrant myself. However, during the planning phases of the intervention with the SC, I immediately realized that the immigrant experience of a white European moving to the Midwest was extremely different from the experiences of the women in Live Well, so I tried to continually acknowledge that I knew almost nothing about the women's lived experiences and earnestly listen to them and the immigrants on the SC to give me perspective. The interviews with the women were organized to have extremely open questions in order to allow the women to speak of their experiences entirely from their own perspectives, however my having little familiarity with the women may have hindered my ability to pick up on cues or ways of speaking during the interviews and to ask the best possible follow up questions. On the other hand, I had the benefit of being someone the women did not associate with the project, which may have decreased the potential impetus to paint their experiences as more positive

than they were. The composition of the thesis committee also necessarily influenced the research process and analytical perspectives. Having scholars who are CBPR practitioners – some of whom were also Live Well SC members – on the thesis committee both helped situate the research within the broader context of community engaged research and created the potential for bias in seeking a positive interpretation of CBPR and the Live Well study, and this was something we tried to be continually cognizant of. Having a committee member who is an immigrant and has significant experience working with immigrants also helped guide the analytical perspective, but the committee was lacking any community members to contribute to the research conceptualization or analysis. We deliberately chose not to have SC community partners give direct feedback on the thesis data interpretation so as not to bias the results and because this thesis was an exploration of CBPR not a CBPR project itself. However, it is also possible that a community perspective on data interpretation could have enhanced interpretation of the findings, and some of the findings of this thesis have now been shared with community partners.

Implications and Recommendations

The studies in this thesis interrogated the complexities of CBPR as an approach to research, looking at how CBPR principles and processes played out at the level of the research partnership and the level of the study participants. The findings of this thesis have a variety of implications for public health interventions, obesity prevention, and our understanding of CBPR, which have been brought up throughout this discussion. Chief among these is the complex, time consuming nature of promoting participation, as well as the importance of cultivating and maintaining

personal, "human" relationships, and the potential life-changing impact of giving people the opportunity to assert their voices and be truly heard. Embracing complexity, including flexibility in intervention design, maintaining relationships, and striving to make all levels of research participatory can be done even within a rigorous research design; and in the end, the "human" elements may be able to contribute to more relevant, enduring research contributions. Obesity is currently one of the most urgent public health issues we face. The need for interventions that are both based in scientific evidence and that inquire into and address the complex eco-social and dynamic human influences on obesity is critical. Research and interventions that succeed in being participatory may be able to help address this gap. At the same time, the challenge and complexity of putting CBPR principles into practice indicates that both academics and communities would benefit from access to training in the operationalization of CBPR principles. And the field of CBPR and the design of such trainings would benefit from even more research on participatory approaches and multiple in-depth case studies and comparisons of CBPR processes in a variety of contexts.

In summary, those interested in using community engaged research approaches should be aware that CBPR is a challenging but worthy research approach to take. It requires a commitment to forming and maintaining real relationships on top of filling work roles and implementing research. It requires flexibility and a high level of comfort with complexity and uncertainty. To quote a member of the Live Well SC, "we are moving at a fast pace where you cannot control everything all the time, the best you could do is to manage the uncertainty of the

work, and manage it well." In other words, researchers and community members using a CBPR approach must be prepared for an ongoing push-and-pull between the need to be flexible and adapt to feedback as the reality and complexity of a health issue reveals itself, along with the need to maintain enough structure and formal direction to ensure that research aims can be agreed upon and carried out. A CBPR project could benefit from having a formal frame that is maintained even while there is flexibility and adaptation within the confines of that frame. Funders and bodies such as Institutional Review Boards may also need to adapt to accomadate the need for flexibility.

How the formal frame is built and enforced may vary by project, particularly based on how the research was instigated. In Live Well, the academic partners proposed the focus on obesity-prevention in new immigrants to community partners, the community partners agreed it was an important issue, and partnership was undertaken. Thus, the PI of Live Well was an academic researcher, and she took on the task of making sure the group continued to focus on the central aims of the research even as complex issues and tangential interests arose. In other cases, CBPR may come from the community proposing research to a university or even hiring academic investigators to conduct research on an issue of the community's choosing. In these cases, the enforcement of the frame may come from community partners. In any situation however, a partnership will likely be more successful if the formal frame can be something that is mutually agreed upon by all members of the partnership. This may be achieved if enough time is allotted for conversation, hearing all sides, and knitting together diverse viewpoints into something that

reflects a collective vision and gives a sense of collective purpose. Additionally, as issues or conflicts arise, partnerships should continually make space and time for the dialogue and listening needed for integrating different points of view. Stated goals may need to be maintained while the way they are achieved is creatively adjusted, or goals themselves may need to be adjusted in response to new understanding of an issue. In order to strive for the balance of flexibility and incorporating everyone's voices while maintaining and working towards specific goals, anyone in a leadership position in a CBPR project may benefit from training in skills like directed facilitation, team building, and visionary or participative leadership styles.

All partners in a CBPR project may, in fact, benefit from trainings that teach skills related to facilitation, active listening, and working in groups. Although it was solely the program coordinators who actually used Popular Education and Motivational Interviewing in implementing the Live Well intervention, training in both approaches were provided to the entire SC as capacity building. Beyond simply building member organizations' capacities for using Popular Education and Motivational Interviewing, these trainings facilitated relationship building and learning how to work together as the partners all learned together about things none of them were experts in. Additionally, gaining an understanding of the principles underlying these methodologies and some of the skills required to implement them provided the partners with better skills for listening and communicating with each other, giving them specific techniques for eliciting and listening to multiple perspectives as well as for sharing power. Opportunities that

facilitate co-learning and team-building and that increase partners' capacities for engaging in real dialogue may be particularly important in cases where community engagement is instigated by an outside force, rather than an internal drive to use a community engaged approach. This can happen, for example, when a funding opportunity requires convening stakeholders or forming a partnership in order to receive the funding, or when an individual becomes part of a partnership because their supervisor assigns them to it.

In a related vein, the way a group comes together might impact the group's structure and function. It seems particularly likely to impact elements such as the sociometric structure (eg. through the strength of pre-existing relationships between people), the capacity of partners to engage in research dialogue, the level of buy-in to the CBPR process amongst the partners, and the degree to which a sense of collective purpose already exists. In Live Well, the SC was a somewhat self-selected group who had a pre-existing interest in immigrants, obesity, and CBPR. Most of the SC members – including the community partners – had already been involved in CBPR efforts and believed in the potential of CBPR as a research approach. Many had even worked together before. This meant the partners came in with a higher capacity for engaging in research and dialogue with academics/community members than might be the case with other groups. However it also meant that the set of partners may not have been as representative of the community as if, for example, a range of immigrant women, community leaders, public health practitioners, and city government members had been selected and convened to work on the same issue. This, again, is reflective of an ongoing push-and-pull that

anyone engaging in CBPR should remain cognizant of. It also reflects how engaging in CBPR may itself build capacity and teamwork, but research capacity and group identity may also need to be built up as a partnership first begins to form, prior to starting actual research.

Adequate capacity is also an issue for ensuring the sustainability of a project. This was a serious challenge in Live Well because at the end of the funded period of the project, none of the community partners involved had the capacity to take the helm and integrate the project into the community in a sustainable way, and the funding for project staff salaries ended, which means they moved on to other work. Meanwhile, the academic partners were also pulled away from continuing to give as much time as they would have liked to the project when there was no longer funding for it, and all their funding was coming from other projects that required their attention.

The problems with sustainability might have been averted in a number of ways. If there had been the opportunity for extended funding, the group might have continued their conversations on a sustainability plan as well as worked on capacity building and arrived at a collective vision and implementation plan. Or, if another entity such as a larger organization or city government had been engaged as a member of the SC, this entity might have had the capacity to help ensure sustainability. However, when a large organization or government department is engaged, the reasonable concern can arise that this entity may wind up taking over the project as their own and other voices will be lost. Therefore, in taking a CBPR approach, it may make sense to engage stakeholders with a higher capacity for

providing staff and infrastructure, but care must be taken to create equal space for all voices – ie. not just creating space for community voices vs. academic, but also a variety of community voices, including individuals and small organizations.

All of this speaks to the very great need for longer periods of funding for CBPR projects. As was visible in the SC, the reality is that even when people are committed to a project and its goals, their time will generally get pulled to where their funding is coming from or what their work performance is being evaluated on. Additionally, for decisions to be arrived at that actually reflect a collective vision and synergistic work, a partnership needs to have the time and space for long conversations and adjustment to feedback. Many of the conflicts in the SC arose if decisions were made under time pressure, but when the group could step back and work on a contentious issue without a sense of time pressure, solutions were found that suited everyone. Funding bodies should consider offering more extensive funding for CBPR projects to include funding partnership formation and maintenance, long periods of developing research and sustainability plans, and data analysis, interpretation, and dissemination.

With regards to working on health issues in marginalized populations, as previously discussed, the experiences of the immigrant women in Live Well suggest that researchers and practitioners working with people who's voices often go unheard should work to give them a voice and support their self-determination. At the same time, it became clear that creating a space for these women to voice their experiences and having an intervention that was perceived as relevant was not necessarily enough on its own to ensure participation. More attention should have

been given to addressing barriers to participation and to getting the women involved after they had been recruited. One potential approach to increasing involvement could have been to have a kick-off celebration with all the women recruited into Live Well invited. An event such as this might help participants see how they are part of something, how important they are to the research, and enable them to connect with other participants right from the start, creating momentum as the research and intervention begins. Future research should evaluate strategies such as this and other strategies for reducing barriers and promoting participation of traditionally marginalized populations in participatory research, to work towards ensuring that the research really is participatory.

Conclusions

Given the spirit of CBPR and the findings in this thesis emphasizing bringing out the voice of those studied, it seems most fitting to conclude with words from some of the people studied in this research. From a member of the Live Well SC, "I think you can't do this type of work and not partially be a community activist. And you can't do this type of work and not partially be a traditional academic. You know, you can't do this work and not be a diplomat. You can't do this work and not be willing to sit down and have an honest conversation...And you know, relationships are hard enough, who wants them in their research? (laughs) But I think it, I've learned that if you want to do CBPR that you have to be prepared to do that." And from a participant in the Live Well study, "it seemed like a different program, that truly cared about the health of women and children."

References

1. Scott, W., *Organizations: rational, natural, and open systems*. 4 ed2003, Upper Saddle River, NJ: Pearson Education, Inc.
2. Dalgard, O.S., et al., *Immigration, lack of control and psychological distress: Findings from the Oslo Health Study.* Scandinavian Journal of Psychology, 2006. **47**(6): p. 551-558.
3. Thomas, T., *Acculturative stress in the adjustment of immigrant families.* Journal of Social Distress and the Homeless, 1995. **4**: p. 131-142.
4. Xu, L. and I. Chi, *Acculturative stress and depressive symptoms among Asian immigrants in the United States: The roles of social support and negative interaction.* Asian American Journal of Psychology, 2013. **4**(3): p. 217-226.
5. Lasker, R., E. Weiss, and R. Miller, *Partnership synergy: A practical framework for studying and strengthening the collaborative advantage.* Milbank Quarterly, 2001. **79**: p. 179-205.
6. Pinto, R., et al., *Research advisory board members' contributions and expectations in the USA.* Health Promotion International, 2013.
7. Kegler, M., et al., *Factors That Contribute to Effective Community Health Promotion Coalitions: A Study of 10 Project ASSIST Coalitions in North Carolina.* Health Education & Behavior, 1998. **25** (3): p. 338-353.
8. Ross, L.F., et al., *The Challenges of Collaboration for Academic and Community Partners in a Research Partnership: Points to Consider.* J Empir Res Hum Res Ethics, 2010 **5**(1): p. 19–31.
9. Cargo, M. and S. Mercer, *The value and challenges of participatory research: strengthening its practice.* Annual Review of Public Health, 2008. **29**: p. 325-50.
10. Henderson, S., et al., *Partnership Functioning: A Case in Point Between Government, Nongovernment, and a University in Australia.* Progress in Community Health and Partnerships, 2013. **7**(4): p. 385-393.
11. Lantz, P., et al., *Can communities and academia work together on public health research? Evaluation results from a community-based participa- tory research partnership in Detroit.* Journal of Urban Health, 2001. **78**: p. 495-507.
12. Israel, B., et al., *The Detroit Community-Academic Urban Research Center: development, implementation, and evaluation.* Journal of Health Management and Practice, 2001. **7**: p. 1-19.
13. Strickland, C., *Challenges in Community-Based Participatory Research Implementation: Experiences in Cancer Prevention With Pacific Northwest American Indian Tribes.* Cancer Control, 2006. **13**(3): p. 230-236.
14. Christopher, S., et al., *Building and Maintaining Trust in a Community-Based Participatory Research Partnership.* American Journal of Public Health, 2008. **98**(8): p. 1398-1406.
15. Brush, B.L., J.M. Baiardi, and S. Lapides, *Moving Toward Synergy: Lessons Learned in Developing and Sustaining Community–Academic Partnerships.* Progress in Community Health and Partnerships, 2011. **5**(1): p. 27-34.

16. Metzler, M., et al., *Addressing urban health in Detroit, New York City, and Seattle through community-based participatory research partnerships.* American Journal of Public Health, 2003. **93**(5): p. 803-811.
17. Johnson, J.L., et al., *Othering and Being Othered in the Context of Health Care Services.* Health Communication, 2004. **16**(2): p. 255-271.
18. Viruell-Fuentes, E.A., *Beyond acculturation: Immigration, discrimination, and health research among Mexicans in the United States.* Social Science & Medicine, 2007. **65**(7): p. 1524-1535.
19. Muraven, M. and R.F. Baumeister, *Self-regulation and depletion of limited resources: Does self-control resemble a muscle?* Psychological Bulletin, 2000. **126**(2).
20. Lachman, M.E. and S.L. Weaver, *The sense of control as a moderator of social class differences in health and well-being.* Journal of Personality and Social Psychology, 1998. **74**(3).
21. Bosma, H., C. Schrijvers, and J.P. Mackenbach, *Socioeconomic inequalities in mortality and importance of perceived control: cohort study.* BMJ, 1999. **319**(7223): p. 1469-1470.
22. Minkler, M. and N. Wallerstein, *Community-Based Participatory Research for Health: From Process to Outcomes*. 2 ed2008, San Francisco: Jossey-Bass.
23. Angelmar, R. and P.C. Berman, *Patient Empowerment and Efficient Health Outcomes*, in *Financing Sustainable Healthcare in Europe*2007.
24. Wallerstein, N., *Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs.* American Journal of Health Promotion, 1992. **6**(3): p. 197-205.
25. Wallerstein, N., *What is the evidence on effectiveness of empowerment to improve health?*, 2006.
26. Laverack, G., *Improving Health Outcomes through Community Empowerment: A Review of the Literature.* Journal of Health and Population Nutrition, 2006. **24**(1): p. 113-120.
27. Israel, B., et al., *Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health.* Annual Review of Public Health, 1998. **19**: p. 173-202.
28. Tovar, A., et al., *Baseline Socio-Demographic Characteristics and Self-Reported Diet and Physical Activity Shifts Among Recent Immigrants Participating in the Randomized Controlled Lifestyle Intervention: "Live Well".* Journal of Immigrant and Minority Health, 2013: p. 1-9.
29. Chen, Y.-W., et al., *Challenges and benefits of community-based participatory research: A case of collaboratively examining ecocultural struggles.* Environmental Communication: A Journal of Nature and Culture, 2012. **6**(3): p. 403-421.

Section V

Appendices

APPENDIX A

CBPR Process and Organizational Theory Matrix

CBPR Process Component	Variable	Justification
Experience of SC Individual Dynamics	Goals	Core element of an organization[1] and organizational process/organizing[2]
	Motivation	Critical element for understanding organizational type[3, 4]
	Role Definition	Element of social construction in organizations[5]
Experience of SC Structural Dynamics	Leadership	Critical element in organizational function[6]
	Heterogeneity	Characteristic of organization structure that influences function [7]
	Formality of Structure (power and social)	Element of goal setting in organizations[8]
Experience of SC Relational Dynamics	Role negotiation	Element of goal setting and social construction in organizations [8]
	Goal negotiation	Element of goal setting and social construction in organizations [8]
	Conflict	Element of goal setting and social construction in organizations [8]
	Personal relationships	Element of social construction in organizations [8]; emerged from preliminary analysis of Y1 interviews
	Flows of interactions	Element of goal setting and social construction in organizations [8]
	Decision making	Element of CBPR process evaluation [9]
	Development of trust	Element of CBPR process evaluation [9]
	Management of meetings	Element of CBPR process evaluation [9]
	Perceived effectiveness of group in achieving goals	Element of CBPR process evaluation [9]
	Generation of project meaning	Underlying construct influencing behavior[10]
SC Context	Resources	Influential driver of action in organizations[8]
	History of collaboration	Likely to influence preexisting role and goal perceptions as well as project meaning [11]
	Institutional support for CBPR	Likely to influence a partnership by creating barriers or facilitation [12]

APPENDIX B

Steering Committee Interview Guide

1. How did you become involved in the Live Well project?
    a) When you first became involved, what did you hope to get out of the project as an individual? What did your organization hope to get out of the project?
    b) What do you, as an individual hope to get out the project now? What does your organization hope to get out of the project now?

2. How have you been involved in Live Well? (Follow up clarification, in what ways have you been involved? What have you contributed?)
    a) How were you involved in creating the project?
    b) How have you been involved in implementing the project?
    c) How have you been involved in interpreting the results of the project?
    d) How have you been involved in ensuring project sustainability?

3. What are some of the ways other members of the SC have affected the:
    a) creation of the project?
    b) implementation of the project?
    c) interpreting of the results of the project?
    d) ensuring project sustainability?

Can you tell me about what happened?

4. *Recounting the experience of critical incidents. For each incident ask:*
Think back to _____? Can you describe to me what happened during that time? How did you feel?

5. What are some of the other events that have been really important for the Live Well project - either for the steering committee or the project itself?
For each event: Can you describe what happened?

6. *Project outcomes.*
What do you see as the outcomes of the project so far?
For each outcome ask:
How have you experienced _____?

APPENDIX C

Additional Questionnaire Items

Questions for Women in the Intervention Group

Thinking about the year you spent in Live Well that was focused on nutrition and physical activity for you and your family, please answer the following questions:

1. Did Live Well feel like it was designed for somebody like you or for somebody else?

1	2	3
for somebody else	sort of for someone like me	definitely for someone like me

2. On a scale from 1-5 where 1 means not at all and 5 means completely, **how relevant has the *information* from Live Well been to your life**?

1	2	3	4	5
not at all		sort of		completely

3. On a scale from 1-5 where 1 means not at all and 5 means completely, **how relevant have the *activities* of Live Well been to your life**?

1	2	3	4	5
not at all		sort of		completely

4. On a scale from 1-5 where 1 means not at all and 5 means completely, **how much do you feel like your voice (your thoughts and opinions) was taken into consideration by the people implementing the Live Well project**?

1	2	3	4	5
not at all		sort of		completely

5. On a scale from 1-5 where 1 means not at all and 5 means all of the time, **how well would you say you stuck with the healthy changes you started because of Live Well**?

1	2	3	4	5
not at all	some, but very little	sometimes	most of the time	all of the time

APPENDIX D

Participant Interview Guide

Good (morning/afternoon/evening). Thank you for taking the time to join our discussion about Live Well. I'm _____, and I am from (organization) . Assisting me is _____, who is from (organization) . Today we would like to hear your thoughts about your experiences so far with Live Well. You have been invited to participate because you are almost through the full Live Well program. We really value your opinions, whether they are positive or negative. Telling us the truth about what you think is what is most important for us; we want to know how we can make this into the best possible program and improve community programming for women like you. What you say here won't affect your ability to participate in Live Well, but they may help us make it into a better program. So, it is important to say what you think and be as open and honest as possible. There are no right or wrong answers.
We're recording our session because we want to make sure we don't miss any of your comments. Your name or other information that would reveal who you are will not be included in anything we do with the information from this interview. Your comments are confidential with us. Before we begin, do you have any questions?

1. A. How did you become involved in Live Well?
B. What did you hope to get out of participating in the Live Well project when you began?
C. How has Live Well met/not met your expectations?

2. Overall, how have you experienced the Live Well project so far?
   (prompt: Can you tell me a little about what it has been like to be involved in the Live Well project? How has it influenced you? Influenced your family?)
   A. Can you describe a few of the most important experiences you've had with Live Well, either in the sessions or things that have happened in other parts of your life because of Live Well?
   Potential prompts (use each prompt if there has been little discussion about experiences in that area. If there was already plenty of discussion about the area from the original question, then skip that prompt):
      a. Thinking about eating healthy, could you tell me about an experience you had with Live Well that really influenced the way you cook or eat? What was important to you about that experience?
      b. Thinking about being physically active could you tell me about an experience you had with Live Well that really

influenced your physical activity? What was important to you about that experience?

c. Could you tell me about an experience with the Live Well project that was negative?

3. Do you have any stories (good or bad) on how the Live Well Project may have affected other areas of your life outside of nutrition and physical activity? Can you describe to me what happened?

4. Can you tell us about how Live Well has affected your family's eating and physical activity (as opposed to your own)?

5. *If it hasn't come up in the answers to any of the other questions ask:*
A. Can you tell me about a time in the Live Well project that made you feel like your voice (your opinions or what you needed) was really heard and made a difference to the people running the project?
B. Can you tell me about a time in the Live Well project that made you feel like your voice (your opinions or what you needed) was not at all heard by the people running the project, or like the people running Live Well just didn't understand what you needed from the project?

APPENDIX E

Select Themes, Concepts, and Quotations from the Live Well Steering Committee Interviews

ORGANIZATIONAL DIMENSION	THEMES	CONCEPTS	SELECT ILLUSTRATIVE QUOTES
Goals	Goals and Motivations	• Personal • Partner organization oriented • Collaborative • Sustainability • Alignment/Tension • Specificity and stability • Accountability • Motivation	"I think it's a group of people who surprisingly uniformly have good social level or community level intentions. That want the project that can be successful not just for the Welcome Project or for the Immigrant Service Providers Group or for Tufts University but... within these three immigrant communities." "The steering committee's focus and interests has evolved over time. From figuring out how we're doing what we're doing and how to work together."
Social Structure	Roles	• How determined • Categories • Flexibility • Struggles	"I think each person brings a different skill set, and I don't mean that just community and academic, I mean each individual brings a different skill set" "I think the separations died away a bit. It was never hierarchical, but now people don't have the tags on them." "I don't think we really had a clear description… and that has been challenging personally"
	Sociometric Structure	• Personal connections • Pre-existing ties	"I don't know if I learned a lot about research. I think I learned a lot about the relationships."

		• Team building • Relationship brokering • Perceptions of others	"I like everyone on it, I like seeing them, I like talking to them. So we are working on this really great project but I just I look forward to our meetings and it's not just… another annoying meeting I have to go to." "It gave us time to get to know each other a little bit personally and not just a two hour meeting, who are they and what they like to do, what they don't like to do. And I think having more of a personal relationship definitely helps build some of that trust."
	Power Structure	• Voices brought to the table • Power sharing • Shifting power • Hierarchies • Leadership	"But I think that's something that happens when you do this kind of partnership. Not as equal as we wished, because of all these implications." "I feel like sometimes there is a hesitation on the researchers' side because, so historically CBPR doesn't work because you have the university telling the community what to do and there is no community telling the university what they want, but I don't think that's our problem… I think sometimes though the university hesitates to push the community on things because they are afraid of that dynamic."
	Decision Making	• Collaborative decision making • Consensus-synergy • Adaptability • Problem solving • Feedback from participants • Constraints	"I realize that it's through the actual discussion that you get somewhere. It's not about someone being right or wrong, it's kind of the process." "So the community and the academic sides were having dialogues with, they weren't just meaningful dialogues, they were dialogues with consequences, and agreements, and working

			plans." "It was just the bottom line. We have to. We can't get the people that we need, and we need this many people. We're powered for this many people and if we don't get it then we aren't going to find anything and we're going to have to change our aims."
	Conflict	• Approach to • Perceptions of • Sources of • Conflict resolution	"I think disagreements are important. And generally for me when I disagree with someone and it goes back and forth a couple of times, I benefit from that tremendously." "We've maintained a culture of active listening and being able to disagree without being disagreeable" "You can't do this work and not be a diplomat. You can't do this work and not be willing to sit down and have an honest conversation"
	Communication	• Venues • Challenges • Facilitation • Being heard	"I think maintaining face to face contact. Making sure that that is done on a pretty regular basis. I feel like those have been the times when we've been most successful" "I think that's how we managed, we brought everybody into the process and into the conversation." "People are very involved when we are there and it feels like when we are not, it kind of drops off."
Technologies	Capacity	• Capacities used • Capacity shortfalls • Capacity building	"You can't necessarily expect it to be 50/50 and nobody can have that expectation. Everyone has what they can bring to the table." "I feel like when you have researchers that look to

			the literature for a lot of stuff, they forget there is not always literature on things like where your target population is, so we rely on community partners for that." "None of the community groups has the capacity to take it up and move it to the next level, so absent (the University) and any inclination to do this, we're not sure what's going to happen."
Environment	Context	• Confounding events • Previous work • Institutional constraints	"the earthquake so directly impacted the Haitian community…People going down to do rescue work, people sending stuff, and people's whole attention focused there, not here. And that happens." "I did talk to the person who was in charge, and… I am happy that the person was very good and very respectful and listened to it, but then said well, we just can't do it because according to the whatever whatever you can't do this and that. So there is a lot of restraints in it and I think that's one of the hardest parts to work as partners with the nonprofits and the academics." "I'm either going to push as hard as I can and find that there's a dead end. Or I'm going to make a breakthrough in the scientific community. It's really hard for me to predict. But I can see why people don't do this work."
	Complexity	• Complexity of issues faced by participants • Complexity of outside issues and competing	"it's very hard to work with these immigrant communities in these last years, and I think Live Well was caught in that…They're very suspicious, no matter who you are, and they don't have time

		commitments for partners • Complexity of project goals and structure	for you because they have to survive." "it's just a very multilevel project and it's got a lot of moving parts"

APPENDIX F

Control Group Responses to end of study questionnaire

(n = 116)			
Question	**Response**	**N**	**%**
How much did you feel like you were part of the Live Well project?	1-not at all	0	0
	2	0	0
	3- sort of	21	18.10
	4	14	12.07
	5 - completely	80	69.00
How much did you change your eating because of Live Well?	1 - not at all	2	1.72
	2 - some but very little	4	3.45
	3 – sometimes	33	28.45
	4 - most of the time	47	40.52
	5 - all the time	29	25.00
How much did you change your physical activity because of Live Well?	1 - not at all	5	4.31
	2 - some but very little	9	7.76
	3 – sometimes	32	27.59
	4 - most of the time	40	34.48
	5 - all the time	29	25.00

References

1. Leavitt H: **Applied Organizational Change in Industry: Structural, Technological, and Humanistic Approaches.** In *Handbook of Organizations.* Edited by March JG. Chicago: Rand McNally; 1965: 1144-1170
2. Weick K: *The Social Psychology of Organizing.* Reading, MA: Addison-Wesley; 1969.
3. Clark P, Wilson J: **Incentive Systems: A Theory of Organizations.** *Administrative Science Quarterly* 1961, **6:**129-166.
4. Etzioni A: *A Comparative Analysis of Complex Organizations.* New York: Free Press of Glencoe; 1961.
5. Giddens A: *Central Problems in Social Theory.* Berkeley: University of California Press; 1979.
6. Dubrin A: *Leadership: Research Findings, Practice, and Skills.* 5 edn. Boston: Houghton Mifflin Company; 2007.
7. Driskill G, Brenton A: *Organizational Culture in Action: A Cultural Analysis Workbook.* 2 edn. Thousand Oaks, CA: Sage Publications, Inc.; 2011.
8. Scott W: *Organizations: rational, natural, and open systems.* 4 edn. Upper Saddle River, NJ: Pearson Education, Inc.; 2003.
9. Schulz A, Israel B, Lantz P: **Instrument for evaluating dimensions of group dynamics within community-based participatory research partnerships.** *Evaluation and Program Planning* 2003, **26:**249–262.
10. Blumer H: *Symbolic Interactionism: Perspective and Method.* Berkeley: University of California Press; 1969.
11. Minkler M, Wallerstein N: *Community-Based Participatory Research for Health: From Process to Outcomes.* 2 edn. San Francisco: Jossey-Bass; 2008.
12. Israel B, Schulz A, Parker E, Becker A: **Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health.** *Annual Review of Public Health* 1998, **19:**173-202.