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Leadership, empowerment, and social capital in a civil society mental health program population in El Salvador

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Leadership, empowerment, and social capital in a

civil society mental health program population in El Salvador

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DEDICATIONS

To my parents Janet and George, who gave me the example of what it means to be loving and persistent and who lived a life of advocacy and support for people living with mental conditions and their caregivers. To my brother Steve, who helped me understand and appreciate those living with such conditions. To my wife Cindy Hunter, for patience and all your support over the years. And to my children Heather, Alex and Ana, for your encouragement, willingness to put up with my extended absences, questions and curiosity about the study, your belief in me, and your joy of life.

To those with mental health conditions and those family caregivers who cheerfully gave themselves to long interviews, to the staff and volunteers of the FESEP program, and to the inspirational leaders of ACISAM, AFAPDIM and ASFAE. May our joint efforts find fruit in alleviating the suffering of families and in finding lives of meaning and joy in our shared journey towards mental health.

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ABSTRACT

Leadership, empowerment and social capital have been associated with successful outcomes for grassroots and nonprofit organizations, but little experimental research exists to demonstrate this connection. The purpose of this study is to determine whether participants in a civil society program in El Salvador have achieved attributes of leadership, empowerment, and social capital above that observed in a group of non-participants.

This study is a single-measure comparison of all available participants in an intervention program with a matched control group. The target population is persons with mental illness and their family caregivers (n=140). The intervention is a community-based mental health program in El Salvador. The control group was drawn from outpatient visitors to the national psychiatric hospital. Outcome measures were transformational leadership, volunteer leadership, empowerment, and social capital measures of trust and civic engagement.

ANCOVA analyses comparing intervention and control groups on 14 primary outcomes showed only a few outcomes were significant for people with mental illness or family carers. Post hoc analyses demonstrated that longer and more intense program participation slightly increased the number of significant outcomes.

This study provided limited evidence that a marginalized population in a low resource country that participates in a grassroots, shared leadership program run by civil society organizations can develop leadership attributes, a sense of empowerment, and increased social capital. It may take long-term organizational and funding support to develop these capacities because of the challenges inherent in low and middle income

countries. Organizations need to identify and implement structured programs to help increase the chances of developing these individual and organizational capacities. The study demonstrated the multiple challenges inherent in carrying out such a study in a low resource country with high levels of violence.

CHAPTER 1: INTRODUCTION

This chapter covers the study's purpose, the context and significance of the study,

defines the terminology used, and presents the research question and hypotheses.

Purpose

Leadership, empowerment and social capital are important to achieving

community change (Narayan, 2005; Speer, Peterson, Zippay, and Christens, 2011;

Taylor, Taylor, and Taylor, 2012; Theory of Change, 2016). This study sought to

determine empirically whether a civil society program in a low resource country was

associated with leadership development, empowerment, and social capital for member

participants. This study was carried out on a program intervention run by civil society

groups since 2002 in El Salvador. We[1] sought to determine if program participants had

increased levels of leadership, social capital, and empowerment compared to persons who

had not participated in the community program.

Significance of the study

The study is significant for several reasons. As will be demonstrated, there is a

gap in the literature concerning whether individual participants in community programs

in low and middle income countries (LMICs)[2] have developed leadership, empowerment,

social capital and other attributes that benefit them and help their organizations to better

achieve their service and social change goals. There is little in the literature on the

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[1] I use the terms "I" and "We" throughout this dissertation study. When it is work that I did alone I use "I", but when the work involved other persons I use "We" because it better represents the fact that this study would not have been possible without the hard work of other interviewers, advisors, and my research assistant, Mariely Campos.

[2] We use this generally accepted term and acronym in accordance with the definitions established by the World Bank, the categories of which are low income, lower middle income, upper middle income, and high income. El Salvador is listed as a lower middle income country. Retrieved from: http://econ.worldbank.org/WBSITE/EXTERNAL/DATASTATISTICS/0,,contentMDK:20421402~menuPK:6413 3156~pagePK:64133150~piPK:64133175~theSitePK:239419,00.html#Lower_middle_income

diversity of benefits that these programs and organizations develop in their participants and that in turn help the organizations succeed (Nickels, 2011). Fleenor (2006) notes "there has been little systematic research on the processes by which individuals acquire the capacity for leadership" (831). This is especially noticeable in relation to the development of leadership at the grassroots level, in both the U.S. (Kellog, 2003) and in LMICs. In particular, in my review for this study I found very little literature and even fewer quantitative studies addressing how leadership, empowerment, and social capital are related and interact in grassroots associations, especially in LMIC countries. This study hopes to contribute to filling in the gaps in these areas of knowledge. In general, grassroots organizations have been neglected in research, in all countries, and there are few experimental studies on grassroots organizations, including on specific factors that relate to their success (Smith, 2000).

My own search for appropriate measurement instruments for grassroots volunteer instruments revealed that quantitative tools were almost non-existent. This is surprising considering the plethora of leadership scales used in leadership studies (Bass, 1990). Some instruments are sold stating they have been used across the organizational spectrum (including volunteer organizations), while in fact either that is not case, or their results are questionable because they have not identified the appropriateness of their scale with volunteer-run organizations. Instruments appropriate to low-literacy low-education populations, and validated in other languages, are also hard to find, yet important. Several of our tools were translated and adapted to the cultural context in El Salvador, so I trust our work in this area will help a bit to ameliorate this gap, since our tools may now be usable in a number of Latin American countries with low-education populations and for a

variety of areas of study where researchers are interested in the development of leadership, empowerment, and social capital in their voluntary organizations.

Context of the study

People across the world participate in civil society efforts, whether informal groups, grassroots associations, nonprofit organizations or community development programs in order to improve their lives. It may be helping others, or advocating for political change, or collaborating to start a new program. As I worked with Central American grassroots and nonprofit groups, I wanted to understand the drivers that underlie success for such groups. How are they the same and different in low and middle income countries than in my country, the United States? Through my studies at James Madison University's School of Strategic Leadership Studies, my interchanges with grassroots leaders and nonprofit and academic colleagues in Central America, with researchers in Washington DC and Boston, and reading widely, I decided to explore three drivers: leadership, empowerment, and social capital. From my perspective, success would be defined as meeting organizational goals, improved quality of life for member participants, and achieving systemic changes that demonstrably benefit the mission population.

My interest grew out of working with grassroots mental health associations and a nonprofit mental health agency in El Salvador for the last 14 years. Globally, when researchers evaluate impacts of mental health programs, the focus is generally on individual psychometric outcomes. But I was interested in the whole of what we were doing for people and how we were doing it through grassroots and nonprofit organizations. It seemed to me our program was doing a lot more than reducing relapse

rates, encouraging compliance with taking medications, or reducing family caregiver burden. Our organizations were developing leaders and providing spaces for disabled persons to advocate for their rights and laws. We were creating collaborative networks and extending our reach into the countryside. Many questions were swirling in my head. What are community-based social change organizations and how are they important in low and middle income countries (LMICs)? What effect do these organizations have on their participants in terms of leadership development, empowerment, and social capital and how in turn do these characteristics benefit the organizations? Because of my familiarity with participative and shared leadership theories and grassroots associations in the U.S. and in Central America, I suspected that participation in such grassroots groups would develop leadership skills as well as a sense of empowerment and increased social capital for their members.

In reviewing the literature and talking with practitioners in LMICs, it was clear to me that there are several gaps in research on: 1) grassroots associations and nonprofits in general in LMICs, 2) the broad and interconnected benefits those programs achieve through their efforts, such as leadership development, empowerment, and social capital, which in turn are necessary for these organizations to achieve social change, and 3) research using experimental or quantitative techniques. I decided to carry out my dissertation on our program intervention in El Salvador, and to use the highest level of experimental design that I could. I selected a number of outcome measures based on the literature that I felt were most appropriate for the work of community-based nonprofit mental health organizations in El Salvador. The design is a single comparison of intervention and control groups, using a matching process to mimic randomization. My

outcomes span the spectrum from psychometric measures on the individual to family

measures such as income and knowledge acquisition, and quality of life, empowerment,

leadership, and social capital measures. Only the measures related to leadership,

empowerment, and social capital are reported in this paper. Working in a LMIC presents

many challenges. The study's limitations are at the end of this paper.

A word about organizational terminology. David Horton Smith (2000) in his book

"Grassroots Associations" defines grassroots associations as "local based, significantly

autonomous, volunteer-run, formal nonprofit (i.e., voluntary) groups that manifest

substantial voluntary altruism as groups and use the associational form of organization

and … memberships of volunteers who perform [most if not all of the work]" (7). He

calls paid-staff voluntary groups "VGs" and arbitrarily states that if more than 50% of an

organization's work is carried out by paid staff, then it is a voluntary group (VA) rather

than a grassroots association (GA).

Terminology for civil society groups can be confusing since it is defined

differently by theorists. To clarify my own terminology in this study: I use civil society as

a broad category that includes non-state and non-market actors, also known as the

voluntary, nonprofit, or third sector (Van Til, 2011); global civil society is this sector

expanded across national borders;[3] the nonprofit sector here refers to legally recognized

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[3] The World Health Organization has a wonderful description of the overlapping meanings and layers of civil society: "Civil society is seen as a social sphere separate from both the state and the market. The increasingly accepted understanding of the term civil society organizations (CSOs) is that of non-state, not-for-profit, voluntary organizations formed by people in that social sphere. This term is used to describe a wide range of organizations, networks, associations, groups and movements that are independent from government and that sometimes come together to advance their common interests through collective action. Traditionally, civil society includes all organizations that occupy the 'social space' between the family and the state, excluding political parties and firms. Some definitions of civil society also include certain businesses, such as the media, private schools, and for-profit associations, while others exclude them. By definition, all such civic groups are nongovernmental organizations (NGOs), in that they are organizations not affiliated with government. However, in practice, the term "NGOs" is

non-governmental organizations (NGOs) with paid staff that function on both local and

national levels; grassroots associations are local, autonomous, voluntary groups that may

be legally recognized or more informal, and may provide very limited services, or may be

involved in running programs and carrying out advocacy (Smith, 2000); I use

"community-based organizations" synonymously with "grassroots associations"; "self-

help groups" (SHGs) and "participatory groups" are terms to describe grassroots groups

using particular methodological approaches (peer assistance and participatory

leadership). Figure 1 outlines a simple visual structure reflecting how I use these terms in

this study. The intervention program studied in this dissertation is run by two grassroots

associations and a nonprofit organization. Their methodology includes developing

participatory leadership and using self-help groups for various components of the

program.

     Michael Edwards is well-known for his work on civil society (Edwards, 2014).

He outlines a three-part definition of civil society. The first sense of civil society is

associational life represented by non-governmental associations. In LMICs, one benefit

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used to describe non-profit making, non-violent organizations, which seek to influence the policy of governments and international organizations and/or to complement government services (such as health and education). They usually have a formal structure, offer services to people other than their members, and are, in most cases, registered with national authorities. NGOs vary hugely in their size, scope of activity and goals. They may operate nationally, or internationally, e.g. Oxfam, Save the Children and Médecins Sans Frontières (all of which are sometimes called international NGOs), or they may be small community-based organizations (CBOs) that aim to mobilize, organize or empower their members, usually in a local area. There are issues of transparency, accountability, and rights of representation around NGOs, particularly international ones. In practice, state involvement in the funding and establishment of CSOs/NGOs may blur the borders between state and non-state bodies. The line between market and non-market may also be blurred by organizations that are non-profit but closely related to commercial enterprises, such as the Shell Foundation. Global civil society refers to civil society groups or movements that enjoy support, or operate, in many countries, e.g. global campaigns against landmines or for debt relief. This term also refers to a key phenomenon of the globalization process: citizens in one country acting in support of citizens in another. Global citizen action can take the form of consumer boycotts in wealthier nations in support of people in poorer nations. This reflects the globalization of communications and information, and the increasingly global market." (WHO website, retrieved from http://www.who.int/trade/glossary/story006/en/)

of working with local organizations is that they are closer to local constituencies. Our

program in El Salvador involves two grassroots organizations that are directly

"representative" of people in society. They include people living with mental illness and

family caregivers and friends, including volunteer mental health professionals and

students.

Secondly, civil society represents the norms of society as it strives to be "the good

society." This is a vision of a society ruled by love and forgiveness, truth and beauty,

courage and compassion. Although people differ regarding values, there are still many

common commitments through social justice movements to face the challenges of

economic distribution, resource restriction, and cultural traditions. Examples include

disability rights, feeding the hungry and sheltering the homeless, agencies addressing

sexual or child abuse, international
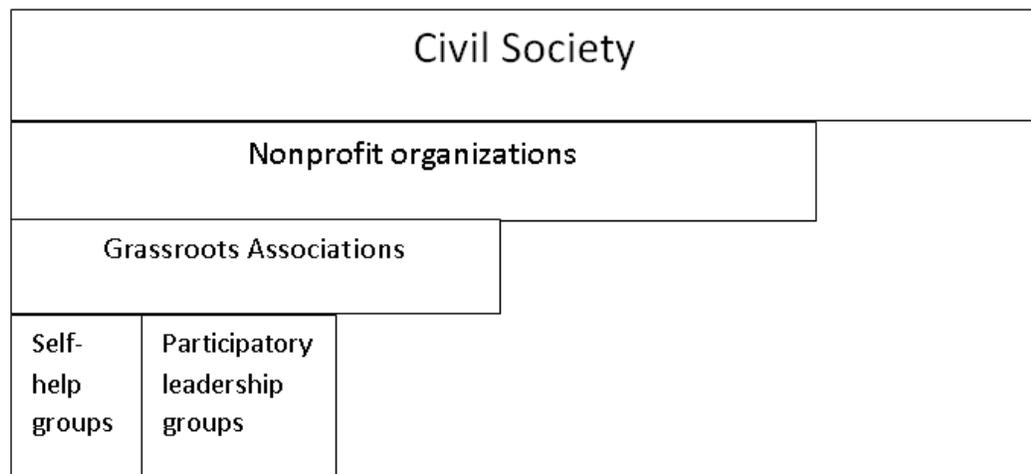
Figure 1. Schemata of organizational types. This figure outlines the relationships
between civil society terms used in this study. For example, nonprofits are a subgroup of
civil society, and grassroots associations are a subtype of nonprofit organizations.

festivals celebrating diversity of cultures, free health clinics, daycare centers run by

churches, and so on. Here the "good society" is striving for social justice, meeting human

need, greater equity, and tolerance. The grassroots associations in El Salvador are

struggling with the same – recognition of their rights and dignity as persons with mental

disabilities (anti-stigma), increased access to psychiatric treatment, funding to cover the

cost of needed medications, better humane treatment in the psychiatric hospital, access to

employment, and the challenge of how to expand community services to people in need

across the country.

Finally, for Edwards civil society is the public sphere, the place where people

carry out their democracy. It is the place where citizens are engaged and enter into public

debate. Although some decry the control of society by elites and corporations,[4] it is still

true there is a long history of success for civil society efforts. To name a few in the

United States: the Civil Rights Movement and more recently the rights for the lesbian gay

community, overcoming child labor, the success of unions 80 years ago, the

establishment of child and adult protective services, passage of tenants rights laws, the

disability rights movement, and the grassroots efforts to improve the mental health care

system (1980-2008) ending in passage of parity laws for those with mental conditions

(equal access to insurance despite having pre-existing mental condition). El Salvador also

has a long tradition of grassroots efforts, from organizing unions, to community service

through churches, to efforts for democracy, many of which were suppressed in the 1960's

and 1970's resulting in the 1980-1992 civil war. The grassroots associations in the

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[4] For an alternative perspective on civil society, see Chandhoke (2005). She criticizes Edward's definition of civil society by noting that nonprofits don't often consult with their constituencies, that in fact norms vary widely across a society, especially for women and minorities, and that public discourse is more controlled by special interests with money than by the common citizen.

intervention program in El Salvador advocate for change and empower and engage ordinary people to participate in the public discourse. For example, these groups participated in a three-year campaign (2010-2012) and achieved the passage of a law to reduce the cost and improve the quality of medications in the country (Villarán, 2014). The broader disability rights movement (of which these groups were a part) was key to that successful grassroots campaign.

The program intervention we study in El Salvador is composed of nonprofit and grassroots associations of the civil society whose members are persons living with mental illnesses (PLMI) and family caregivers (carers). The World Health Organization (WHO, 2013) discusses the importance of civil society organizations in its latest strategic plan, the "Mental Health Action Plan: 2013-2020." WHO notes that civil society movements for mental health in LMICs are not well developed. PLMI groups are present in only 49% of low income countries compared to 83% in high income countries, while family associations are only 39% and 80% respectively. In terms of human resources, psychiatrists are in short supply in LMICs, where half the world's population has only one psychiatrist to serve 200,000 people on average. WHO goes further to state that other mental health providers, such as those working and volunteering with the intervention program in El Salvador, who are "trained in psychosocial interventions are even scarcer" (8). Only 36% of people living in low income countries have mental health rights legislation. Governments in LMICs cannot solve these complex problems alone. A strong civil society sector is a potentially valuable partner for governments. The above problems are equally important advocacy targets for civil society organizations to work on. Grassroots organizations cannot achieve such difficult advocacy goals without strong

leadership and empowered memberships that are able to access expanding social networks to bring about change.

The theoretical bases for this study and its constructs are detailed in Chapter 2. Theories I discuss include Theory of Change, complexity theory applied to social change, empowerment theory, participative leadership theory, social capital theory, grassroots associational theory, sustainable development theory, participatory leadership theory, Freire's theory of empowerment through popular education, critical disability theory, and political economy theory. This seems an unusually large number of theories for a single paper, but the constructs discussed, their interrelationships, the organizational setting of the study, and the international scope, seem to warrant exploring a variety of foundations. Together these theories provide a diverse yet coherent and cogent basis for exploring factors related to social change from the grassroots up.

Research question

Empowerment of marginalized and poor populations in LMICs is critical to achieving social and economic development. Leadership is critical to organizing people into organizations that can effectively advocate for social and systemic change. Social capital networks are important factors in helping individuals and groups to access resources and achieve success. Leadership, empowerment and social capital, then, potentially mediate the achievement of goals for grassroots organizations. I theorize the evolution of a successful program in this way: people participate in a process that gives them a sense of empowerment; as activities flow from this empowerment, leadership is developed; over time social networks at both the individual and group levels are expanded, knowing and trust is increased, and the organization is better able to obtain

needed resources. As leaders continue their development, program improvements are implemented as programs are evaluated, leading to more success for the organization. In turn this leads to further resources to expand programs and achieve further successes, including developing partnerships at the macro levels to achieve systemic change. One assumption in this theory of successful grassroots organizational development is that participation in such programs helps to create empowerment, leadership and social capital, that is, the successes provide feedback to the individual leaders who experience increases in their sense of empowerment, leadership abilities, and social networks.

Thus, this study seeks to answer the following question: Do marginalized populations in low and middle income countries who participate in grassroots, participatory leadership programs run by civil society organizations develop leadership attributes, a sense of empowerment, and increased social capital?

CHAPTER 2: LITERATURE REVIEW

Because this study looks at multiple outcomes, this literature review covers areas related to those outcomes—leadership, empowerment, and social capital—and their connections to grassroots and nonprofit organizations and their goals for social change. First I discuss general theoretical frameworks underlying this work. Then I discuss the constructs of leadership, empowerment and social capital, how they intersect with one another, and how they influence grassroots and nonprofit organizations. I then discuss literature related to the intersection between mental health and these constructs. I also cover issues related to measuring leadership development, empowerment, and social capital in the context of civil society organizations in low and middle income countries (LMICs) and describe and justify what instruments I used in this study to measure these constructs.

Theoretical frameworks

Looking at grassroots participatory associations and their development of leadership, empowerment and social capital within the context of working with marginalized populations in LMIC countries is a complicated task. As a result, I pull on a number of diverse theories to help frame the discussion. These relate to social change as a major goal of many grassroots organizations, the constructs of empowerment and social capital and participative (or shared) leadership as means and ends for both individuals and organizations, grassroots associational theory to understand the specific context in which these organizations function, sustainable development theory to frame the international context in which the intervention program functions, critical theory related to human rights (particularly of marginalized populations) along with political economy

theory to frame the discussion of advocacy and the motivations of grassroots groups of marginalized persons to overcome stigma and discrimination in order to meet their needs, and complexity theory to frame the larger context of multiple variables and adaptive organizations and social interactions in which the program exists and seeks to find innovative solutions to meeting human needs.

   Sustainable development theory. Sustainable development was a term introduced by the World Commission on Environment and Development in its report *Our Common Future.* It was defined as "development that meets the needs of the present without compromising the ability of future generations to meet their own needs" (WCED, 1987, 41). Although originating in the study of the environment, it eventually came to be applied to a wide range of social and economic concerns, from poverty to healthcare. If resources are not carefully managed, few viable options will be left for the quality of life in a community. These resources include social, political, economic, and cultural relationships fundamental to the organization of society. People and their social institutions must be included in the community planning process to increase the probability of achieving a successful outcome. De Vita, Fleming, and Twombly (2001) write,

Empirical evidence indicates that lasting change generally comes from local involvement. Communities from San Francisco, California, to Curitiba, Brazil, have engaged their citizenry in the process of planning for sustainable development and achieved remarkable results….The longterm goals of the sustainable development movement are to empower people, increase community participation, foster social cohesion, enhance cultural identity, and strengthen institutional development. (7)

Freire and "concientización" through popular education. Paolo Freire is an inspiration for community organizers, along with Saul Alinsky. Freire's work during repressive dictatorships in Brazil in the middle of the last century, typically referred to as "popular education," was a means of liberation for oppressed illiterate people. He is often cited by change agents and social change theorists. Freire helped people understand their reality and act on it through a dialectical process of doing and reflecting/learning as his process of helping people become conscious ("concientizacion") to their reality, a part of the empowerment process (Freire, 1969; Golensky, 2011). He used tools appropriate to the educational level and cultural context of poor marginalized people. He believed in the ability of grassroots people, even the most uneducated, to understand power dynamics and to organize to demand change. In many poor countries, and with the intervention program in El Salvador in particular, Freire's process is the means by which marginalized people obtain awareness that results in their sense of empowerment, their development as leaders, and their growing social capital.

Community organizing. Community organizing carries on this tradition of awakening people to their reality in at least two strains. One refers to professional outsider organizers coming in and is associated with Saul Alinsky's Industrial Areas Foundation. The other refers to insiders working among their own people/group, with Jane Addams cited as an example of organizing women (Stall & Stoecker, 2008). This approach can be referred to as grassroots or women-centered, because women sought the development of power of everyone in the group. Community organizing has a long tradition of value on empowering grassroots organizations and developing their leadership and social networks because those activities are seen as mediators of success. I

discuss this in greater detail below under the sections on empowerment, leadership and social capital.

Human development theory in the realm of international development. Rapley (2007) discusses the history of international development theory, starting in the 1950's with modernization theory and neoliberal development theory, which both emphasized globalization and free markets. These were followed by dependency theory and post-colonial theory critiques that saw wealthy countries in the North as using racism and dependency to sustain their wealth. These in turn informed alternative development (human development) theory that widened the definition of what is development and put humans front and center. It emphasized reducing barriers to freedom so people could make their own decisions and achieve what they valued as development. Finally, post-development theory saw development itself as an evil carried out by wealthy countries towards the poor. Others argue the contrary position, that in fact much progress has been made via the Millennium Development Goals, for example, in reducing poverty and infant mortality and increasing access to clean water (United Nations, 2015).

Rapley (2007) concludes there has been a "coalescence of scholarly opinion around the needs of both people and poor countries," away from arguing about whether more or less government is the answer and toward a more pragmatic approach to, simply, better government (7). Theorists are taking the best of different traditions and highlighting what works – human development theory places people front and center and focuses on individual freedom (Sen, 1999); neoclassical development theory focuses on decentralizing administration to make government leaner, more flexible, and better

adaptive; and post-development theorists contributed the importance of participatory development.

While governments, international organizations, and multilateral agencies have included social capital among their measures of development (De Silva, 2005; Iisakka, 2006)(see Appendix E for an outline of the frameworks and dimensions used by these institutions to measure social capital), other institutions from the World Bank to international non-governmental organizations (INGOs) have increasingly understood the importance of empowering people at the grassroots. In turn, this has grown out of the human development tradition noted above. The approach is based on experience gained over many years of how *not* to do development work. When organizations come in to a country with a program and pay people to carry it out and then leave, the program typically falls apart, a process I've witnessed in my work many times. This is because people did not have buy-in, that is, their ideas and cultural norms and practices were not involved in planning and implementing. They were disempowered. When I arrived in El Salvador, I observed large dry latrine structures scattered all over the community, but they were being used for chickens and storing firewood. The latrines stand even today as a monument to the failure of bringing in outside ideas rather than starting with the people themselves. The work of Taylor, Taylor, and Taylor (2012) exemplifies this approach as their methodology focuses on empowerment and the use and development of local leaders and their social capital (discussed in detail below). The foundation of human development theory increasingly underlies the work of grassroots organizations and nonprofits in LMICs, for example, as they try to develop leadership (African Leadership

Academy, n.d.). This is also the case with the approach we take in the intervention program studied in this paper.

Theory of Change. The theory of change (TOC) recognizes as a central tenant that to achieve social change one has to address the complex social, economic, political and institutional processes that are part of the complex web of society (Weiss, 1995). This approach has become a best practice within the nonprofit and global development/poverty sectors as they incorporate complexity theory into their planning models (Weaver, 1948; White, 2001; Selsky and Parker, 2005). Successful nonprofits, for example, combine services with advocacy, increase their social capital and networks, collaborate effectively across sectors, develop leadership internally and across time, and empower marginalized populations (Kellogg Foundation, 2003; Narayan, 2005; Grant and Crutchfield, 2007). The development of a theory of change is also a participatory process that empowers stakeholders and produces a better product, it ensures a transparent distribution of power dynamics and the process is necessarily inclusive of many perspectives (Theory of Change, 2016; Brest, 2010; Weiss, 1995). It is thus closely allied with the idea of empowerment of marginalized persons and groups.

Complexity theory in the social context. In "The social labs revolution: A new approach to solving our most complex challenges," Zaid Hasan (2014) discusses how social problems are fraught with complexity, how they are continuously emergent as social context continually change and evolve, and how the traditional paradigm of strategic planning and evaluation restricts the ability of groups to address complex social problems in creative, dynamic, adaptive ways. He encourages groups to fail early and regularly and to learn from each failure. Diversity in forming collaboratives can cause

friction, but it is also the driver of better initiatives, including ones that come from the grassroots. He encourages multiple trials so that groups can winnow down to the most effective initiatives over time. High trust relationships among leaders and organizations enable groups to work through problems together and sustain initiatives. Learning and capacity building is also important to success for deeply innovative solutions. Getting the right leaders and staff and groups on board is key, but this is less a process of finding the rights skills and experience than it is finding the right passions. Using personal networks can allow people who are passionate about the topic, and who will have perseverance, to self-select into the group. "Habitus" is ingrained behaviors that prevent change. Breaking down these barriers requires multiple stocks of capital—financial, human, natural, physical, and social. Enhancing these capitals increases our chances of being able to change things. Participants commit to social change not because they are told to or paid to, but because they believe deeply in the need to shift a system from its current state to a desired state. And it is this will-power that ultimately makes the change sustainable. Volition and volunteer come from the same Latin and French roots (Oxford Dictionary, 2016). In grassroots associations it is people with strong will who are willing to volunteer and who persevere in their cause. Essentially, Hasan's message is that emergent, adaptive, collaborative efforts, built on strong social capital and creative leadership, can empower people to achieve even complex change.

Political economy. I will touch briefly on two other theories that provide insight into the functioning of grassroots and nonprofit organizations and their relationship to leadership development, empowerment, and social capital. Political economy recognizes economic needs as an individual and organizational driver which must be resolved in the

larger political context. Economic and political structures, pressures and constraints are

significant motivators of change (Golensky, 2011; Wamsley & Zald, 1973; Wernet,

1994). For example, in our Salvadoran program lack of access to medications is a huge

issues, and this is due to both cost and government policy. To address policy changes our

groups must have empowered leaders with sufficient social capital to influence

government officials.

   Critical theory. Critical theory, and more specifically critical disability theory,

sees disabled people's problems as a result of an unequal society. It ties solutions to

social action and change. For example, the problem with public transport is not the

inability of some people to walk but that buses are not designed to take wheelchairs

(Oliver, 1998). This theory, along with theoretical work that undergirds the Convention

on the Rights of Persons with Disabilities (United Nations, 2016), are the guiding

principals for the idea of inclusion, that people with disabilities (including psychosocial

disabilities) are equal members of society and have rights to equal access to employment,

transportation, social inclusion, and so on. Critical theory helps explain what people

"wake up to" when they pass through a process of empowerment. It explains why people

are highly motivated, act as volunteers in joining grassroots organizations, and are willing

to take on leadership roles even though they may have little education or experience

leading organizations.

Constructs

   The constructs measured in this study include leadership, empowerment and

social capital. The discussion of these constructs below are divided into sub-topics that

relate more specifically to the target population. I note their relationships to participants

in grassroots and nonprofit organizations and to our program in El Salvador. I also cover

measurement issues and tools. We measured subjects' levels of transformational

leadership, volunteer leadership, psychological empowerment, family caregiver

Figure 2. Disability accommodations. Sidewalks are one clear example in El
Salvador of how infrastructure is not adapted to and inclusive of persons with
disabilities. Photo by the author, San Salvador, 2015.

Figure 3. Protest. In the photo below, grassroots associations combined
their strength to call for new laws in favor of their members. Photo provided
by ACISAM, San Salvador, 2012.

empowerment (for carers), empowerment of patients (persons living with mental illness), and social capital (trust, civic engagement, etc.).

The construct of leadership

Traditional leadership theory and grassroots associations (GAs). As noted in the discussion of political economy, leadership tends to be carried out via either power-politics or empowerment. The debate has been carried out over the years in different theories and approach to leadership—vertical versus horizontal modes of organizational leadership, trait versus learning, coercive versus referent/reward, transactional versus transformational leadership, male and female leadership styles, and so on. In the nonprofit sector, and the grassroots organizational sector in particular, a great deal of emphasis is put on an empowerment approach to leadership. This is due to the voluntary nature of these organizations, beliefs from community organizing and human development sectors, and what has worked or not worked in practice. To delve a bit further, French and Raven (1959) identified five bases of power across a spectrum from coercive (punishment) to reward, legitimate (authority), expert, and referent (identification with the leader to gain approval). But grassroots organizations and shared leadership nonprofits are different from most of the subjects of traditional leadership research (business, military, and government sectors). Because their organizations are composed of all volunteers, GAs have only access to non-financial reward and referent forms of power. A motivational leader may be able to exert the best referent influence on followers in GAs, which is why transformational leadership skills are of such importance at the grassroots level. Indeed, one of our measures in this study is "Global Transformational Leadership."

Trait theory posits that leadership is inherited and due to one's personality traits. For years a debate waged over whether leadership could be taught or was essentially genetic. Today the debate is more complex, and often focuses on personality versus learning and environment (Van Til, 2011). Avolio and Bass (2004) discuss how transformational leadership develops in people. They cite studies to show that from 25 percent to as much as 50 percent of the variance in the scores on their Mutlifactor Leadership Questionnaire can be attributed to heredity. They state that child development plays a role too, for example, in one study favorable experiences in elementary and high school predicted transformational leadership as an adult, as did positive experiences in the a leaders' first full-time job. However, parental interest in their children's education and the parental high moral standards were less impactful to the development of transformational leadership. Finally, characteristics of people as adult workers rounds out the influences. Their transformational leadership level is predicted by their internalization of their organization's moral values, their own collectivistic orientation, ability to actively engagement in tasks, and their level of self-efficacy (Avolio & Bass, 2004, 35).

Trait theory has resurfaced in studies related to the Big Five Personality Traits model, a now highly validated psychological framework for describing personality (Fleenor, 2006; Liu, Wong, & Fu, 2012). Fleenor (2006) states that recent research has sought to correct the methodological shortcomings of earlier research on leadership traits. For example, "researchers have developed conceptual models linking leadership attributes to organizational performance…[and have shown] consistent relationships between traits and performance measures….linking clusters of personality traits to success in different situations" (Fleenor, 2006, 831). Some research suggests that the Big

Five should not be conceived of as dichotomies (such as extraversion vs. introversion) but as continua (Fleeson, 2001). Each individual has the capacity to move along each dimension as circumstances change.

Another study examined the connections between emotional intelligence (EI), openness (one of the big give personality traits), and empowerment on an outcome of team climate (Liu, Wong, & Fu, 2012). The authors showed that EI and openness helped to facilitate positive team outcome via leaders' empowerment behaviors. These behaviors were defined as coaching, informing, leading by example, showing concern, and participative decision-making (Arnold et al., 2000, cited in Liu, Wong, & Fu, 2012). The authors note that personality has been recognized as playing an important role in leadership effectiveness, and the Big Five model provides a comprehensive framework for examining the relationship between a leader's personality and leadership style (De Hoogh, Den Hartog, & Koopman, 2005, cited in Liu, Wong, & Fu, 2012), yet only 16% of the variance of leadership effectiveness can be explained by personality (Judge, Bono, Ilies and Gerhardt, 2002, cited in Liu, Wong, & Fu, 2012). While some grassroots association authors like Smith (2000) decry the lack of research on leaders, it is clear that some of the research applies equally well to grassroots leaders. This appears true for personality trait research.

Day (2012) cites more recent meta-analyses and twins studies to conclude that inherited capabilities account for 30% of leadership success while a far larger proportion of variance is associated with environmental influences, including over 11% with work experience via leadership role occupancy. Enriched social environments (individuals reared in higher family SES, higher parental support, and lower conflict w parents) are

moderating variables on leadership outcomes. From the emerging literature of longitudinal studies, Day argues that leaders can and do develop over time, but that individual difference variables (personality, psychosocial developmental level, motivation to lead, self-esteem, leader identity construction, goal orientation, and adult development processes) can be used to predict leadership development and its forms.

Judge and Long (2012) demonstrate the complexity of trait theory and its up and down history by using evolutionary theory and recent meta-analysis. They argue that individual differences matter, but not only do positive traits equal positive leadership action, but bad traits equal positive action too. The benefits of a trait at one time in one context may be reversed in other times and situations. For example, extroversion predicts leader emergence and extroverts may be assertive, energetic and charismatic, but these same characteristics may result in conflictual relations with others, short and shallow communications, and risky decision making. Likewise, intelligence is highly related to both leadership and job performance, but its down side can include being considered an outsider and potentially indecisive, and creating conflicts over mismatches among team intelligence levels. Traits are also affected by styles and dispositions, as well as individual difference among followers. Further, because leaders work in diverse and complex organizations, context matters and affects leadership outcomes.

If it is so complex, can leaders be developed? Is there a learning component? Day (2012) argues that historically, there is a wide gap between leadership theory and practice: "The field of leadership development is mainly a collection of disparate best practices…rather than a coherent, theoretically guided, and evidence-based process" (pp 108-9). Yet he is hopeful that science is moving in the direction of providing an evidence

base for developing leadership. Day outlines various frameworks and structures that are covered in the theoretical literature, but the empirical literature is also contributing more and more to our knowledge. For example, Day argues there are two types of leadership development traditions—structured programs and experiential learning. In a meta-analysis, 40% of leadership development interventions had negative effects and 15% had no effect (Kluger & DeNisi, 1996), yet positive outcomes are possible if conditions are met, such as individuals having a positive feedback orientation and actions are taken like setting appropriate goals and taking actions (Day, Harrison, & Halpin, 2009). Day concludes that what is critical is time: it is not primarily what happens during a program that matters as much as the motivation and perseverance to engage in practicing desired skills during an extensive period of time.

Day (2012) also notes that leadership development is promoted through experiences. Organizations can develop their own frameworks to support a contextual process for developing their leaders. Attention should be given to helping learners gain the desired lessons as part of the development process. Leadership development, he argues, is an inherently dynamic, multilevel, and multidisciplinary process that requires theoretical frameworks reflecting this diversity. While complex, leadership development can be seen as presenting a wealth of opportunities for researchers. But they are more likely to provide scientific insight if their designs incorporate multiple measurement perspectives, mixed methods, and longitudinal components. Thus Day argues that, to some extent, anyone can develop leadership skills. This is important in grassroots organizations that depend on recruiting new volunteers and developing them to take on leadership roles and fill volunteer jobs with significant responsibility.

While leadership theory evolved into the era of transformational leadership (Bass, 1985; Burns, 1978) which, with charismatic leadership, were the major topics of discussion at the turn of the century (Pierce & Newstrom, 2008), other leadership theories became prominent as alternative ways of viewing leadership, such as shared (participatory) and servant leadership (Crutchfield & Grant, 2010; Greenleaf, 2002). Some of these are particularly useful for nonprofit and grassroots leadership development. For example, within the nonprofit sector if one does not share power, the domination of one person or faction can become problematic for the organization. It can create dependence, bad feelings, inability to develop the organization's other human resources, and can result in poor decisions and cronyism (Golensky, 2011).

Like Day (2012), Van Wart (2010) notes that, according to most research, leaders are made through two avenues—formal training and experience. Of the two, experience appears to be the better teacher, meaning leadership can be learned better than it can be taught. Formal training is beneficial for technical skills, credibility, management knowledge, external awareness, and coaching. But emphasis should also be put on rotational and other means of providing experiential learning for leaders. This may reflect why participative organizations who provide multiple opportunities for experiential leader development are effective at building leaders (Keddy, 2010).

For a somewhat contrasting view, Blunt (2010) states that it is now understood that leaders are not born, they are "grown," their capabilities can be learned, even character qualities can be shaped within an organization. His conclusions are based on years of data gathered on leaders by the Center for Creative Leadership in Greensboro, North Carolina, and are highly consistent across private, nonprofit, and public sectors,

although the focus here is not grassroots organizations but the most successful corporate,

military, government/public, and large nonprofit organizations. Leader learning is found

in four broad categories: challenging job assignments (42%), learning from others'

examples (22%), hardships and setbacks (20%), and other such as training and education

(16%). To some degree these can certainly be applied in the context of grassroots

associations. Can they be applied in the context of organizations of persons with mental

disabilities? Can challenging assignments that stretch and grow the person, learning from

others, learning from setbacks, and leader training be obtained in a group setting of

persons with mental illness and family caregivers? I would say yes, although perhaps

such groups need to move slowly and patiently to balance the needs of their members for

emotional stability and self-confidence.

Blunt (2010) states, "We see clearly that the task of growing leaders may be as

important a task as can be found today in public service" (39). Replicating best practices

in leadership training is not enough: "Leaders develop over time primarily through

challenging and diverse experiences" (39).

Participatory leadership. The study of participative leadership research dates

back to studies in the 1930's comparing authoritarian, laissez-faire, and democratic styles

of leadership (Lewin, K. & Lippitt, R., 1938; Lewin, K., Lippitt., R. & White, R. K.,

1939). The authors concluded that democratic leadership had multiple advantages over

authoritarian because it created less hostility and discontent, more friendliness, less

dependency and more creativity, more group-mindedness, and groups were more

productive even when the leaders was not present. Miller and Monge (1988) conducted a

meta analysis on participation research (n=48). They concluded that participation has a

significant impact on both satisfaction and productivity. They theorize that participation fulfills higher order needs, which leads to higher levels of satisfaction, which increases motivation, which leads to increased productivity. In a broad review of the literature, Bass (1990) notes there are longterm benefits to democratic leadership versus autocratic styles and that these differences are enhanced when looking at distinctive components of democratic leadership such as participation and relation orientation (435).

Bass (1990) highlights three models of participation—cognitive, affective and contingent. Cognitive models propose that participation contributes to subordinates' satisfaction and productivity because it improves the interchange of important information, with satisfaction being a side effect of employee participation. The affective model from the human relations school of thought suggests participation generates satisfaction of higher-order needs which in turn increase the subordinates' motivation, satisfaction, and quality and quantity of performance. The contingencies model highlights the importance to subordinates of their perception of participation and the felt opportunity to participate (457-458). Like democratic leadership, participative leadership yields greater payoffs when considering longer term relations and outcomes.

In the traditional leadership literature, "empowering" is viewed from the perspective of the leader/supervisor who seeks to enable and motivate subordinates to meet their goals (Bass, 1990). Leaders can help convert threats into opportunities, provide subordinates with greater autonomy, or inspire with a vision. But this sense of empowerment is not about awakening a new sense of meaning in life, or a new way of seeing one's problems or reality. It is empowerment as a means. But empowerment for grassroots associations is a means and an end. It is about creating leaders from people

who are not leaders by position. It is also about inspiring a new understanding of reality and being empowered to act for social change.

Unfortunately, the focus of leadership study has not been on the nonprofit and grassroots sectors. For example, in his highly respected leadership tome, Bass (1990) references thousands of articles on leadership. Apart from educational studies and hospitals, he cites a total of only 13 references when he discusses the nonprofit sector. Of 914 pages he dedicates only three to this sector. However, the studies he does cite tend to coincide with findings in the other sectors (business, military, government, higher education) in areas on consideration and initiation behaviors of leaders, and democratic versus autocratic styles.

In his chapter on leadership in different countries, Bass (1990) notes how leadership varies across cultures. For example, in some countries having a high degree of trust in an organization influences the organizational climate, including the degree to which participative leadership is observed. However, participative leadership may have negative impacts. Bass states that in England, subordinates react negatively to the number of meetings called by participative leaders; studies in West Africa, the Middle East and Nigeria showed that cultures with high levels of power distance resulted in less use of participative leadership; and a study in Turkey showed there was a general societal preference for directive leadership. Other more recent studies like the GLOBE study in 62 societies have expanded international work on leadership and begun global comparative research (House, Hanges, Javidan, Dorfman, & Gupta, 2004).

The cross-national differences in participative leadership are consistent with findings in the area of social capital, where trust is a principal measure that differs highly

across culture. The World Values Survey (2016) provides insight into a number of issues

for studies are carried out in different cultures. For example, across waves of

international surveys, El Salvador consistently rates at the top of the scale for countries

with traditional values (which includes deference to authority); while on the scale

between survival values (which includes low levels of trust and tolerance) and self-

expression values (which includes participative decision-making), El Salvador finds itself

near the middle of the scale (World Values Survey, 2016).

What is clear from observing these leadership and values studies on a global

basis, is that findings in one country may not apply in another, although values tend to

cluster in groups of nearby countries with similar cultures. As Bass (1990) notes:

"Considerable evidence points to the greater effectiveness of autocratic leadership

behavior in authoritarian cultures and of democratic leadership behaviors in democratic

cultures. The same is seen for direction versus participation" (803). One implication is

that a program developed in one country may need to be greatly adapted to function well

in another country.

In a study of hospital trauma resuscitation teams, leader ability and flexibility to

choose between an empowering or directive approach was critical to success (Yun, Faraj,

and Sims, 2004). This is consistent with Golensky's (2011) conclusion that nonprofit

leaders and boards are best served by taking a situational approach to leadership. The

point is that a participatory approach or style can be useful in certain contexts. In El

Salvador the program is working with participants who have self-selected into the

program. Leaders and instructors are primarily volunteers, and the lack of resources for

such a grassroots effort demands that people be empowered to advocate for themselves

and others. Hence, the approach taken over the years has been primarily a participatory leadership development process where participants move from taking classes, to leading classes, to organizing events, to joining the leadership team, which in turns functions on a consensus basis. Horizontal leadership ("liderazgo horizontal") is the phrase used by program staff and associational leaders.

Keddy (2010) outlines an alternative to the Saul Alinsky process that is grassroots-focused. Keddy describes a model of grassroots leadership in which the human development of leaders and followers is central. Grassroots leadership prepares local leaders, regular people in their communities, to become powerful actors who are part of the long-term human infrastructure in the places where they live: "the interplay between human dignity and the leadership development process is what enables this kind of organizing to have a deep and long-lasting impact" (49). Keddy describes how the organization PICO (Pacific Institute of Community Organizing) develops community leaders: 1) organizers awaken people to a sense of their own worth through one on one conversations about the conditions in which they live and envisioning a new reality; 2) people are then moved from being spectators and sidelined in society to being actors and participants in change efforts; 3) people emerge as leaders through relationships with others, visiting and building long-lasting relationships; 4) as leaders become engaged, they become active learners, conversant in public policy issues, able to analyze complex issues and learn new public speaking and group facilitation skills. Tasks like chairing meetings are rotated so everyone has a chance to learn and grow and lead. Leadership development at PICO is not simply learning a set of skills, it is a process of becoming. As people become leaders they are transformed, their lives become a truer reflection of

dignity. In our focus group study of the Salvador program in 2013 there was much discussion of how the program transforms people, both as individuals (internal or "transformarse") to discover their worth and their abilities, and as social movement changers (external or "transformer") (Nickels, Flamenco, & Rojas, 2016).

Leadership in the nonprofit sector, while sometimes having much in common with other sectors, is its own niche. In "Share Leadership" Crutchfield and Grant (2010) acknowledge a recent radical turn in thinking about leadership, from the individual to the collective. They describe organizations in which leadership is integrated or shared, collective and distributed. "Changing the unit of leadership analysis from individuals to social collectives…would radically change leadership theory and research…[but is] eminently well matched to the institutional nexus within which nonprofit and public organizations operate" (71).

Leadership in the nonprofit sector. Leadership is seen as a key resource and even the centerpiece or lynchpin in nonprofits with organizational structures that lead to success (Brothers & Sherman, 2012). Keefe (2009) notes that in one study of grassroots efforts to obtain clean water in West Virginia coal mining towns, successful mobilization of public support depended greatly upon the leadership of individuals who put the community's interest above self-interest. Lewis (2009) observed community development processes in devastated communities in Appalachia and learned that while charismatic leaders may be important to get a process started, broader diverse leadership is needed for longterm sustainability of the organization. Leadership development and staff training is important, and outside expertise can often help. These observations also fit well with the idea of participative leadership and its relation to empowerment for

group members. It builds on the "strengths perspective" where one begins with the strengths of the individual's or community's resources rather than their problems. It is a concept has influenced practice in many fields now, from social work to community development (e.g., asset building community development) to the patient-centered medical home model. In El Salvador, the program of study keeps the needs and priorities of participants in the center of its focus. We also seek to develop leadership from the membership, provide opportunities for leadership roles, encourage the development of a shared leadership philosophy, and recognize the accomplishments of those leaders (reward power). Keefe (2009) says this is counter to the corporate model of development that focuses on gross domestic product rather than happiness, and one-size-fits-all fast food restaurants rather than mom and pop culturally diverse and healthier restaurants, that tends to exclude voices beyond the mainstream. Beneficiaries tend to assume the role of passive recipients, while specialized knowledge remains in the hands of a few, and the concentration of wealth results in a slow deterioration of democracy. "What is needed, critics argue, is a development process done *by* the people, not one done *to* them" (8). For Keefe, participatory development means strengthening stakeholders and empowering them to contest power holder's control, valuing production of social capital and not just economic capital, and focusing on people-development by fostering *their* research skills and development of *their* local leadership. As an example, she describes a process in which powerful elites manipulate and control other stakeholders at the community level, resulting in acquiescence to authority and power relations even though it is obviously detrimental to their own self-interest. Low self-worth and apathy are the outcomes that then serve to reinforce the low status of the powerless. "The purpose of…participatory

development is to strengthen stakeholders in contesting power holders' authoritative control…[resulting in] higher levels of trust within the community; and a sense of 'creation and control'" (9). Although using different words, Keefe is referring to higher levels of social capital and a sense of empowerment. In support of this, she later notes, the "goal of participatory development is to empower participants" (11). She states this approach results in self-confidence, self-reliance, and self-development, which sound very similar to characteristics of psychological empowerment I discuss later under empowerment.

    Grassroots leadership. Smith (2000) in his book "Grassroots Associations" focuses extensively on leadership, although almost exclusively within the U.S. context. He differentiates grassroots associations of volunteers (GAs) from paid-staff nonprofits, which he calls "voluntary groups" (VGs). He says organizational staff size, membership and resources help to determine leadership structure and style. Leaders are more critical to GAs than to VGs because there are no resources and structures to replace leadership in GAs. Although highly dependent on these leaders, GAs still should have a goal of creating a strong enough organization that they can be sustained when leaders leave. Table 1 highlights the typical differences between GAs and VGs.

    Smith (2000) cites a number of authors to make the point that there is no compelling evidence that leadership research will apply meaningfully to grassroots associations, that the usual organizational management theory does not fit small associations, and that the attempt to apply such techniques might even harm GAs because GAs may not be able to manage implementing complex strategic plans. This is because they operate as volunteers, have fewer officers, no departmental paid-staff structures, and

Table 1

Comparison of Grassroots Associations and Paid-Staff Voluntary Groups

Grassroots Associations	Paid-Staff Voluntary Groups
Association form with members	Association form with or without members
Formal (legal/registered) or informal	Formal
Local (small in territory or scope)	Local or regional or national or international
Voluntarily staffed (majority work by volunteers)	Paid-staff (majority work done by paid staff)
Mostly member benefit	Mostly non-member benefit
Mostly informal group style	Mostly formal group style
Mostly high autonomy	Mostly high autonomy
High internal democracy	Low internal democracy
Some sociodemographic membership criteria	Some paid-staff performance criteria
More diffuse goals	Fewer and more specific goals

This table is drawn from two tables by Smith (2000, 9 and 89).

less formalization and training of leadership.[5] Interestingly, Smith carried out a study of

GA leaders using traditional measures of personality traits for leadership. It showed GA

leaders were higher than their members in consideration, intelligence, extraversion,

assertiveness, emotional closeness, self-confidence, efficacy (internal control). In other

words, very similar to leaders in other sectors such as government and business. He notes

a dearth of research on GA leadership, especially with control groups.

Smith (2000) notes that consideration and initiating structure are the two primary

findings of good leaders in the general leadership literature. He believes that

consideration is an even more important skill or ability for GA leaders because their

"staff" is all or mostly volunteer. Likewise, to be able to initiate structure (provide

direction and supervision) is equally hard and takes someone who can master the art of

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[5] Authors he cites include Klausen, 1995; Knoke and Prensky, 1984; Leat, 1993; Walker, 1983; Smith, 1992b; and Chapin and Tsouderos, 1956. See Smith, 2000 for full references.

guiding volunteers to quality work, especially since there is no leverage such as withholding rewards or sanctions.

Smith (2000) discusses a particularly difficult area for GAs—leadership change. Sometimes leaders need to be changed because they are ineffective, hurtful, or do not permit new persons to grow and assume leadership. This is a challenge for GAs because of the non-professional informal structures, the lack of applicants for voluntary positions, and the need to deal with internal conflicts in a way that preserves the participation of volunteers.

Smith (2000) discusses GAs in developing countries only briefly. He focuses on the negatives but not on the positives, highlighting corruption, ignorance and poor quality leadership in a study on India. He notes leaders are often unfamiliar with leadership roles and have no role models. This could equally be said of many small GAs in the U.S. But my greater concern is a lack of appreciation for the strengths inherent in grassroots communities throughout the world, all of whom have leadership structures and traditions. The key is to understand these and build upon them.

Smith does emphasize that Western research/literature may not be appropriate for development world GAs. I would concur with this, although I'd say that learning from the literature should be adapted and tested to see if it works well enough in a low income country. Important differences that can affect implementation of outside leadership development models include culture, beliefs, traditional practices and authority structures, language translations of words and concepts, and sociodemographic differences, especially education and financial resources.

Kellogg Foundation (2003) produced a report entitled "Grassroots leadership development: A guide for grassroots leaders, support organizations, and funders." The report is based on a Kellogg-funded case study by Campbell & Associates of 23 grantees and describes several key findings. 1) Grassroots leaders have different motivations and needs than those of traditional positional leaders. 2) Investing in grassroots leadership development leads to increased community well-being and encourages longterm problem solving. 3) The best results for developing leaders are achieved by using a triple focus— individual leaders, involved organizations, and the community or issue of concern. This report highlights not only the differences between GA leadership and other sectors, but how leadership development differs for GAs.

Leadership development. A participative and empowerment approach emphasizes the need to develop leaders in organizations where there are none, or where the members are oppressed and marginalized from the typical opportunities for leadership development, and yet leadership development is necessary if grassroots organizations are to achieve positive social change (Kellogg Foundation, 2003).

The Kellogg Foundation (2003) report notes similar interests for leadership training programs across foundation, grassroots, and business/nonprofit sectors. Similarities include building sustaining- learning networks; the need for new information and skills; and enhancing personal leadership visions (12-13). The report also notes that grassroots leader training is different from traditional organizational leaders training, including that grassroots leadership programs need to exercise patience and a willingness to invest in longer time frames (working with volunteers takes longer to train and to develop and carry out plans); meet community leaders where they are (customize support

to meet the immediate needs of community leaders); and treat community leaders like the special people they are (nurture and celebrate) (13).

Finally, the Kellogg Foundation (2003) report highlights five components of successful leadership development programs for grassroots organizations: 1) develop leaders—leadership identification (finding a leader, which is more typical in larger nonprofit and business/ government sectors) is different from leadership development (identifying early leaders and providing them support during their development over an extended time period, which is typical in grassroots organizations); 2) use formal and informal pedagogy techniques, ones that are participatory and engaging for adult learners (who often have little formal education); 3) use as much hands-on learning as possible to develop skills and networks in the real world of their community; 4) use appropriate language capacity and cultural connections; and 5) provide one-on-one evaluation and attention to growth (skills, confidence, resiliency in the face of conflict, accuracy, and self-awareness, gained through a consistent cycle of assessing strengths, challenges and goals) (Kellogg Foundation, 2003, 17-18). These are techniques that are regularly employed in the intervention program in El Salvador, although there has not been a formal evaluation of the extent to which these have been applied, and therefore some uncertainly in my opinion, particularly regarding hands-on learning and one-on-one attention and evaluation.

De Vita and Fleming (2001) edited an extensive Urban Institute report on the importance of capacity building for nonprofit organizations. They were inclusive, focusing equally on grassroots associations, thinking clearly throughout the report about impacts on both paid and unpaid staffed organizations. For both groups they put

leadership front and center, calling leadership the linchpin of effective organizations. But they note leadership is difficult to define and capture. Yet they note leader characteristics, saying leaders motivate, initiate, envision, articulate goals, establish systems to meet those goals, and have a deep commitment to fulfilling the mission (18). This appears a good list to me that captures leadership (or at least the characteristics of what leaders do) in an inclusive way that applies equally well to grassroots volunteer-run organizations.

As in the community organizing model of participative leadership, De Vita, Fleming, and Twombly (2001) note that an organization requires leadership at every level, which encourages problem solving and decision making throughout the organization, and frees the organization from top-down management. Leaders with longer term experience seek to empower others. Spillover effects include the acquisition of new resources and enhanced outreach activities.

De Vita, Fleming, and Twombly (2001) state that to build capacity in the leadership of nonprofits, one should consider both enhancing existing leadership and developing new leadership. Working with existing leadership can take a variety of forms. Administrative and procedural policies can be reviewed and updated to streamline operations and better reflect environmental conditions. Training can be provided to staff and volunteers to upgrade skills or promote team-building efforts. The organization can also formulate a board development strategy to review the functions of the board and help individuals understand and fulfill their roles and responsibilities as board members. Identifying and developing new leadership is akin to the sustainable development process. Without an eye toward the future, the present leadership runs the risk of becoming outdated, obsolete, and depleted. Not only must new leaders with new ideas

and energy be brought into an organization from time to time to stimulate and invigorate

the work, but also current leaders should be aware of the need to mentor the next

generation of leaders.[6] This process is likely to lead to greater racial and ethnic diversity

within the leadership ranks of the nonprofit sector as organizations reflect the people and

communities that they serve. (18-19)

Smith (2000) also addresses the issue of leadership development. He cites studies

on a two-year leadership training program (Cook, Howell, & Weir, 1985; Cook, Howell,

& Weir, 1987) that showed subjects developed more problem-solving skills, learned new

roles, understood public issues better, and became more cooperative with other leaders.

Bolton (1991), in a later study of the same data, noted that although trainees learned

information, they did not actually increase their capacity for leadership by being better

able to use new skills and information in the community. Smith suggests, then, that some

practice elements of training need to be included in addition to information. Indeed, this

is a technique applied successfully by the Pacific Institute for Community Organizing

(discussed above).

Baldwin and Ford (1988; 2008) and Blume, Ford, Baldwin, and Huang (2010)

review best practices for transferring knowledge through training. They state that

leadership development has been linked to three variables: individual learning

characteristics, the quality and nature of the leadership development program, and the

support for behavioral change from the leader's supervisor. For GAs, the latter point does

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[6] A particular type of mentoring is leadership coaching. I think it is an approach important for grassroots associations. It has "great potential" by helping a leader look in the mirror and be honest about the reflection, requires trust between the coach and the leader, and good communication (Brothers & Sherman, 2012).

not really hold, but a proxy could be longterm support from the organization/foundation providing the leadership development program or a mentor.

The African Leadership Academy provides scholarships to African youth that combines a high school graduation with leadership development to create the next generation of African leaders (African Leadership Academy, n.d.). Begun in 2004, the Academy has recently recognized the need to demonstrate they are developing leadership. It has developed a mixed methods research study that is in progress by an American university, but it will be a while before there are results to share.

In this brief review of leadership development in grassroots associations, it is clear there is little in the way of studies, particularly experimental studies that can demonstrate evidence for or against the effectiveness of leadership development programs in nonprofit and grassroots associations.

The construct of empowerment

Definitions and types of empowerment. A review of the literature reveals that there are several types or angles to empowerment, all of which I see embedded in our Salvador program. One type is emphasized in much of the literature on women's empowerment and centers on the concepts of voice and agency. Voice to being able to speak and be heard, while agency is having the power to make choices (Klugman et al., 2014; Narayan, 2005; Shankar, Onyura, & Alderman, 2015). Another view of empowerment is through the lens of personal enlightenment, or consciousness (Freire, 1970; Keddy, 2010; Nickels et al., 2016). This refers to both personal understanding and awareness of social structures and realities such as human rights and inclusion. A third perspective is that of experience and becoming. Through practice one gains through

experience a psychological sense that one is empowered; it is a process and results in self-confidence and a sense of efficacy as well as concrete knowledge (Diener & Biswas-Diener, 2005; Keddy, 2010). There is also the empowerment of groups and organizations, but I think that personal empowerment is a precursor to organizational empowerment. Thus I focus on personal empowerment in this study.

In the LMIC women's empowerment workshops studied by Shankar et al. (2015), participants examine aspects of their emotions, relationships, their health/body, money, and work. These topics are similar to the topics covered in our mental health programs in El Salvador related to self-care and recovery. However, other parts are more focused on advocacy related to systemic change in national mental health programs, and appear similar to some of the work discussed by Keddy (2010) related to the Pacific Institute for Community Organizing, which focuses on participation in organizing groups and campaigns, learning to become empowered through an experiential process that results in knowledge, leadership skills, increased ability to communicate and increased social capital via trust and networks.

Shankar et al. (n.d.) note that the recent seminal World Bank report (Klugman et al., 2014) on the need to enhance women's voice and agency stated that fostering agency can lead to positive development outcomes for women, their families and society as a whole. For example, in a health study in Indonesia, empowered women was a protective factor for their infants, reducing diarrhea and acute respiratory tract infections (Agustina, Shankar, Ayuningtyas, Achadi, & Shankar, 2014). In the El Salvador program in 2014, 83% of caregiver participants were female, and the vast majority of those were mothers. In the context of the mental health program in El Salvador, one could consider whether

mothers in and of themselves are protective factors for the health and wellbeing of the persons for whom they care, whether empowered women better able to advocate for their loved ones with nurses and psychiatrists to improve care and outcomes, and whether they are engaged to advocate on a systemic level to improve mental health services for other families in their country. That is, women as leaders may be empowered to achieve outcomes on individual, family, and societal levels. As Shankar et al. (n.d.) wrote, "women's individual agency is crucial for development as it enhances one's capacity to navigate the psychological, sociocultural, and structural challenges that are faced on a daily basis" (74).

Empowerment and development. The World Bank study "Voices of the Poor" showed that voicelessness and powerlessness are pervasive among the poor because they feel trapped in poverty and barred from opportunity (Narayan, 1999). Narayan cites a growing body of evidence to show the linkages between empowerment and development effectiveness at both the society-wide and grassroots levels. When citizens are engaged, exercise voice, and demand accountability, government performance improves. Citizen participation can also build consensus in support of difficult reforms. As a result of the massive study, the World Bank decided on a two-prong strategy: improve the investment climate in developing countries and empower poor people.

In "Measuring Empowerment: Cross-Disciplinary Perspective" published by the World Bank Group (Narayan, 2005), Bank president James Wolfensohn is quoted: Poor people "do not want charity. They want opportunity....They have managed construction of rural roads and water systems and have monitored government employees, including health providers and school teachers, to improve their

performance….When poor women com together in credit groups to build their

confidence…they can outperform all other customers in profitability….Poor people are

the most important resource in the fight against poverty….Yet most decision makers still

resist trusting poor people to take care of public or private investments. We hope that this

book, with its focus on measuring empowerment, will help spread approaches to poverty

reduction that empower poor people. Unless poor people are at the center of poverty

reduction, policy making and program design will not benefit them." (vii)

    While there has been considerable study of empowerment related to poverty and

development,

> "there are few, if any, rigorous evaluations that allow the contribution of
>
> empowerment to be measured and compared with other influences on developmental
>
> outcomes, whether at the local or society-wide level. There is also a paucity of
>
> empirical analysis of the causal influences on empowerment itself. Yet this type of
>
> information is crucial…for according it priority relative to other pressing concerns of
>
> policy makers and other development actors." (Petesch, Smulovitz, & Walton, 2005,
>
> 39)

    Our current study contributes to this arena, as it experimentally explores the

relationships of empowerment, leadership and social capital for grassroots associations.

    Narayan (2005) defines empowerment in the context of global poverty as "the

expansion of assets and capabilities of poor people to participate in, negotiate with,

influence, control, and hold accountable institutions that affect their lives" (5). Narayan

presents a conceptual framework of empowerment with four important aspects:

- empowerment is fundamentally a relational concept, it emerges out of the interaction of poor people with their environment;

- poor people's assets and capabilities are usually conceptualized as individual attributes, but their collective organizations are often critical in helping to break through constraints of powerlessness and voicelessness;

- empowerment of poor people requires both top-down changes in institutions and bottom-up changes in poor people's organizations and networks along with access to individual assets; and

- intervention points vary depending on the nature of constraints and barriers and on what is feasible.

She outlines the important outcomes that come out of an empowered development process: improved incomes; improved governance and access to justice; functioning services; equitable access to markets; and strengthened civil society and poor people's organizations. For example, the World Bank, involved at the global level in addressing poverty, focuses on strengthening the civic society sector and grassroots organizations in particular. But it is a reflection that the issues of justice and access are complex, responses need to be multi-faceted, and people affected by issues need to be included as key stakeholders. Without personal and organizational empowerment, people themselves are not able to achieve their role.

Narayan outlines a list of assets that people must have to achieve empowerment. Some that relate to this dissertation include human, social and psychological assets, including good health, social belonging, leadership, relations of trust, the capacity to organize and form associations, political capabilities, participation in political life, and

access to information. For Narayan it appears that empowerment, leadership and social

capital are closely intertwined.

Most empowerment measures are economic, but also include subjective measures

of control of finances and authority over decision making. Narayan (2005) notes that

psychological assets are often overlooked as a dimension of empowerment, so she

devotes a whole chapter to the topic—"Psychological empowerment and subjective well-

being," written by Diener and Biswas-Diener (2005). Psychological assets include self-

confidence, self-efficacy, capacity to aspire (envision alternatives), competence, energy,

and desire to act, often measured with subjective wellbeing scales. For example, Diener

and Fujita (1995) found that self-confidence was the resource that most strongly

predicted life satisfaction more than material resources or social resources. Psychological

assets or capabilities are closely related to the conceptual framework of this dissertation

(for example, the Ryff scale, a psychological wellbeing scale, used in this study).[7]

Empowerment and international non-governmental organizations (INGOs). :

Taylor et al. (2012), in their book on empowerment in grassroots development programs

in LMICs, note there is no argument among researchers and practitioners about the

importance of empowerment, only how to achieve it. They argue for an approach to

empowerment that is multi-directional—top-down, bottom-up, and lateral. Still, they

believe people at the grassroots must be at the center of the process, that empowerment

must start with them and be based on what resources they already have. People should be

---

[7] Another scale of wellbeing was used as well, the Mental Health Wellbeing scale. I and two Salvadoran colleagues carried out a focus group study in which we listened to PLMI and family carers regarding how they define mental health wellbeing (Nickels et al., 2016). Many of the findings were similar to the psychological assets listed above. From that study we developed an instrument (Mental Health Wellbeing scale) and collected the data with our current subjects, but results are not reported in this dissertation study.

intimately engaged in participative planning, implementation and evaluation for programs

to be effective and sustainable. Such an approach is based on obtaining the benefits of

partnerships – the energy and resources and ideas of local leaders and people,

government resources and structures, and outside NGOs and advisors for expert

information, what is referred to as "support organizations" in Kellogg Foundation's

(2003) report on grassroots organization capacity building in the U.S. Like Narayan

(2005), Taylor et al. (2012) agree that empowerment is context-specific, and that for each

site, appropriate indicators must be developed. "What is clear is that empowerment

connects to almost every aspect of human well-being. And those linkages, reaching into

the complexity of human experience, are exactly why [empowerment] is so powerful"

(41).

The Center for International Stabilization and Recovery (CISR) is an INGO that

carries out work with landmine survivors. In a two-year CISR study of a peer outreach

program for people with disabilities due to landmine accidents (Macauley, Townsend,

Freeman, & Maxwell, 2011), participants reported improved physical and mental health.

They also exhibited characteristics related to empowerment, which the authors call

"social empowerment"; namely, decision making, ability to self-advocate for their rights,

understanding of disability as a rights issue, and capacity to describe laws and policies

related to people with disabilities (see Figure 4 below). This program is similar to our

program in El Salvador in that it depends on peer support and education and takes a

human rights based approach to helping empower people to deal with disability. Indeed,

Macauley et al. (2011) state, "empowerment is seen as crucial to reaching greater social

capital and reduced violence" (19). Upon entering the program only 21% could discuss

disability from a rights-perspective or describe local laws or policies affecting them,

while after one year of peer support 67% were able to do so.
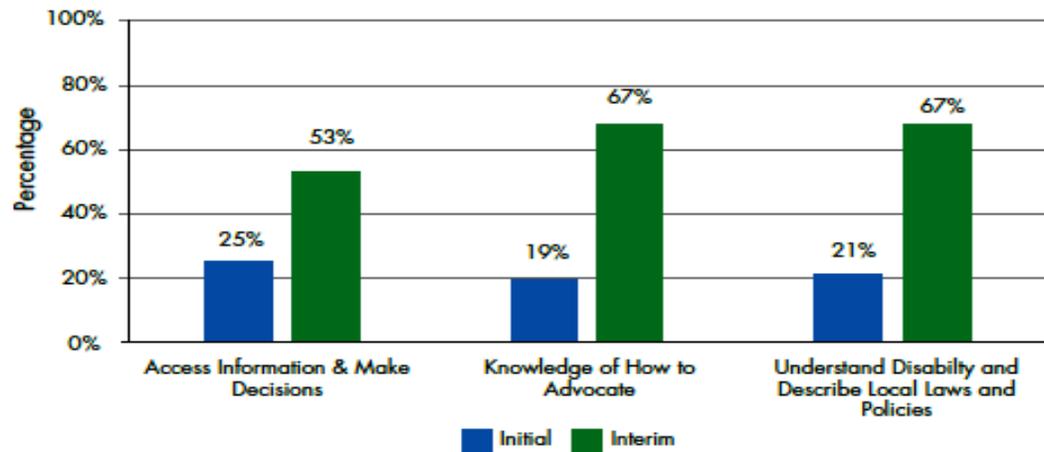
Figure 10. Social empowerment (interim). This data sample represents all the survivors who had both an Initial Interview and an Interim Interview completed. N=433.

Figure 4. Social empowerment. Source: Figure 10 in Macauley, Townsend, Freeman, & Maxwell, 2011 ("Peer support and recovery from limb loss in post-conflict settings").

Empowerment, community organizing and grassroots associations. Speer, Peterson, Zippay, and Christens (2011) carried out a study of a five-year community organizing program in the U.S. They defined empowerment in this context as "a social action process through which individuals, organizations, and communities gain greater control over issues of concern to them" (200). Their review of the literature indicates that community participation in activities such as community organizing has been identified as a critical route to empowerment.

Their mixed method study combined a two-measure randomized controlled study with a case study and outcomes were civic engagement and psychological empowerment. Findings were significant for these outcomes. They note that few studies have evaluated

organizing outcomes using experimental methods. The key aim was to "measure the

degree to which the PICO National Network organizing effort engaged and empowered

citizens toward changing policies and practices of community institutions that shape the

context for the development and maintenance of quality of life in one community" (201).

Although the case study demonstrated changed policies and practices, they were not able

to achieve any measure (despite trying with housing) that could show that quality of life

actually improved as a result of the engagement and empowerment. The authors

concluded that the organizing project gave political voice to a wider range of community

members (the "voice" part of "agency and voice," which defined empowerment earlier).

Regarding direction of causality, the study showed at the individual level that

participation increased civic engagement and empowerment but could not demonstrate

which caused the other. Speer et al. (2011) state that most theorists posit civic

engagement precedes the development of empowerment while others have suggested the

link is more reciprocal in nature.

Speer et al. (2011) conclude with several recommendations pertinent to this paper:

that grassroots participants be provided formal roles or opportunity structures to build

relationships, leadership skills, and organizational competencies (for example, rotating

through roles/ responsibilities) and organizations pursue inter-organizational connections

to build relational and material resources. The groups they studied and the approach to

shared leadership, leadership development, and an empowering process used by the

organizing agency are similar to our approach in El Salvador. For example, the

intervention program seeks to develop leaders through sharing leadership roles and

providing opportunities to serve internally and externally. There are also a variety of

opportunities that provide education and insight into human rights and other issues that can motivate and inspire participants to assume leadership roles. I would expect our findings in this study to be similar to theirs in terms of positive outcomes for civic engagement and empowerment.

Empowerment, social capital, and leadership development are intertwined and interdependent in the PICO model of community organizing studied by Speer et al. (2011). These many components are necessary to achieve social change:

At the individual level, participation in a community organization provides experience that challenges individual cognitions of social power…a feature of an empowerment setting would be "opportunity role structure" (Maton & Salem, 1995) or the roles available in organizational settings that encourage individual participation (Speer & Hughey, 1995)…[resulting in] opportunities for members to cooperate and build relationships and to strengthen their leadership skills and competencies….At the organizational level, empowerment…involves the development of collective or organizational power that can change policies or practices of communities (Peterson & Zimmerman, 2004)." (202)

Findings suggest community based organizations can implement strategies to help them achieve their social change goals. These include developing opportunities internally for learning leadership roles that will strengthen organizational capacity and empower individuals, accessing the social networks of other organizations to increase social capital and access to resources resulting in alliances to leverage policy change, and implementing a learning process for leadership development, personal transformation, and increased networks to other advocates, the media, and public officials.

Participation in community organizations are important. They provide an experience that challenges individual cognitions of social power and provide a collective context through which emotional reaction to that power can be processed or reflected upon. "Freire (1970) and Keiffer (1984) described this action-reflection process as 'dynamic praxis'" (206). Empowerment theory is reflected at both the individual level and is a process cultivated by specific settings, that is, empowering organizations. Individual empowerment is learned and expressed through membership in an association, relationship building with community members, and participating in the advocacy and organizing processes.

Empowerment outcomes at the individual level are products of cognitive, emotional, and behavioral changes. Empowerment at the organizational level serves to develop individual empowerment, providing participatory niches for individuals, developing inter-organizational relationships, and sustaining a pattern of action. Empowerment outcomes are the ability to reward and punish through the number of members it can mobilize, the ability to shape topics for debate, and its ability to reshape societal thinking on issues, often accomplished by powerful entities coming to interpret issues from the perspective of the organization (Speer & Hughey, 2008).

Exploring a latent phenomenon. In Narayan's (2005) edited book she explores a variety of measurement challenges related to empowerment. There are challenges because measurement of empowerment is a relatively new field, and because empowerment is a complex latent phenomenon. At the individual level observed behaviors and self-reports must act as proxies. At the organizational and societal level, indicators that can be used cross-nationally need to be developed. Specifically, she lists

the following measurement challenges: whether to focus on the universal concept of

empowerment, or to use a context/culture-specific conceptualization; what unit of

analysis should we use—the individual or collective impact of empowerment; what level

should we measure—household, community, local government, or national level; who

will measure (outsider researchers or a participative approach that has a greater potential

for empowerment); and whether quantitative or qualitative is better (Narayan argues that

generally a mixed methods approach is more complete and reliable)(25).

   One challenge in particular is important to this paper: to decide if empowerment

should be conceptualized as a means, an end, or both? Participation in meetings of

decision making can be viewed as a measure of empowerment. If participation is seen as

having intrinsic value, then meeting attendance can be the measure. But if participation is

seen as leading to decision making that benefits the poor, then meeting outcomes would

be the appropriate measure, which is important since research has shown that poor

people's attendance at meetings often does not result in benefits to them. Others are clear

about outcomes for empowerment: "The litmus test for empowerment is whether poor

and subordinate groups have *effectively* advanced their particular interests through their

own choice and action" (Petesch, Smulovitz, & Walton, 2005, p. 40). One limitation of

this dissertation is that we focused on self-reported empowerment as an end in itself to

the exclusion of measures that would show the benefits or impacts of that empowerment.

However, we did collect data on quality of life, self-reported relapse rates, family

income, wellbeing, family burden, self-stigma and other measures that we will assess

later to help determine the potential influence of empowerment on these individual level

psychological outcomes, which are important in the context of community-based mental health programs.

Regarding causality, measuring empowerment is most useful if the role of empowerment is defined as well as the causal pathway. Narayan (2005) displays a variety of techniques that can contribute to this, including participative research, across the chapters of her book. Are the measures linked to clear concepts and a theoretical causal framework? This is important with empowerment since most measures are either proxies or factors that enable empowerment.

On an organizational level, Petesch, Smulovitz, and Walton (2005) layout a two-part framework for understanding organizational empowerment and outcomes. First they agency of groups (their ability to wield power) and the opportunity structure (the socio-political context within which those groups function, such as power of elites and cooperation from government) interact on one another. These in turn are influenced by other factors (Figure 5). Next they place this within a causal framework in which group empowerment and opportunity structures impact policy and then service, which finally result in outcomes such as health, incomes, dignity, and self-confidence. These outcomes in turn feedback in loops to the groups and structures within society that start the process over again (Figure 6).

This study does not deal directly at all with the opportunity structure side of the equation, but does explore economic and human capital, the capacity to aspire, and at least indirectly organizational capacity.
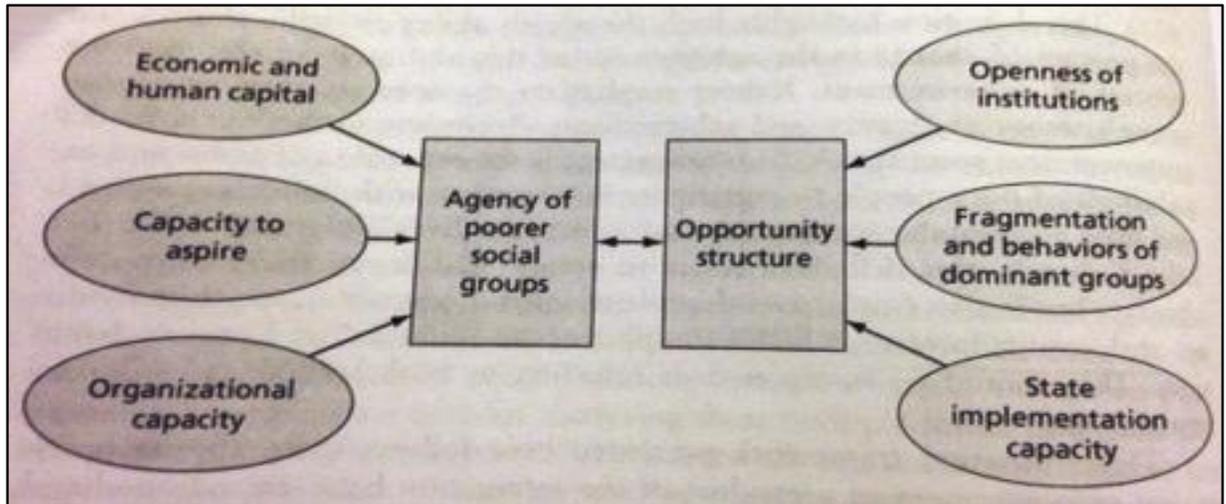
Figure 5. Causal framework for empowerment in state-society contexts. *Source: Petesch, Smulovitz, & Walton, 2005, 42.*
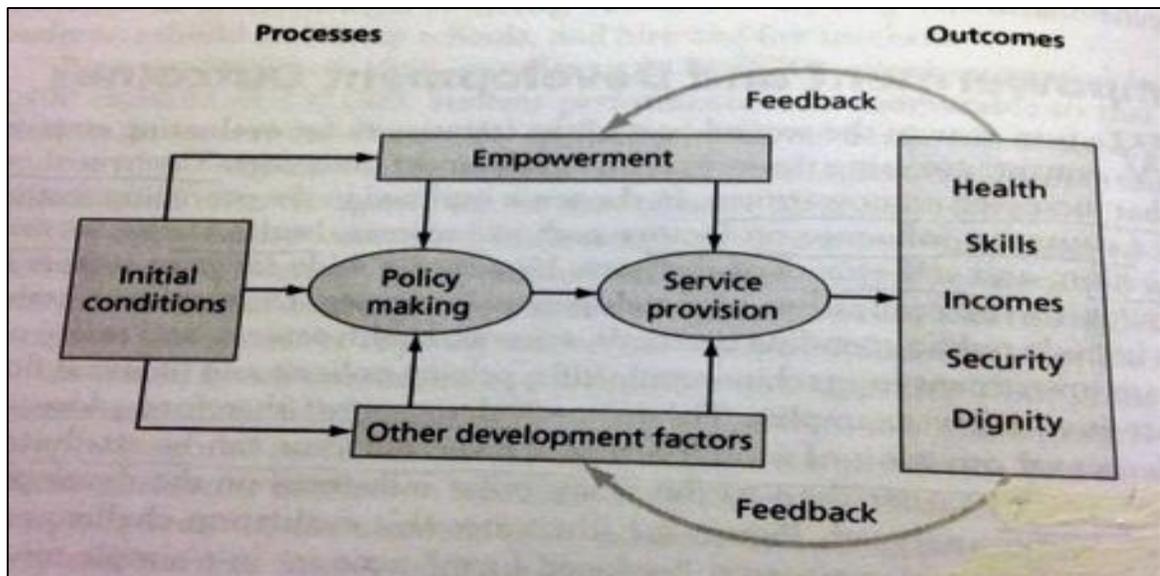
Figure 6. Causal framework for empowerment in state-society contexts with conditions and feedback loops added. *Source: Petesch, Smulovitz, & Walton, 2005, 54.*

Malhotra and Schuler (2005) in "Women's empowerment as a variable in international development" also develop a framework for empowerment indicators. Their

list of indicators is given below. The dimensions and indicators work equally well as a

description of the goals of the intervention program in El Salvador. However, that

program struggles to measure most of these indicators. The present study collected data

on 2.1, 4.1, 5.1 and 5.3, far from giving a complete picture of empowerment.

1. Economic dimension
    1.1. Community level: employment
    1.2. Macro level: federal budgets
2. Social and cultural dimension
    2.1. Community level: access to social groups/networks, increased value and autonomy of women within cultural systems
    2.2. Macro level: positive media images, educational access, and health system access
3. Legal dimension
    3.1. Household level: knowledge of legal rights and familial support for exercising those rights
    3.2. Community level: includes community mobilization for rights, participation in campaigns for rights awareness, and effective local enforcement of legal rights
    3.3. Macro level: laws supporting rights and access to resources
4. Political dimension
    4.1. Household level: knowledge of political system and means to access it, familial support for political engagement, ability to and access to voting
    4.2. Macro level: representation in government at all levels
5. Psychological dimension
    5.1. Household level: self-esteem, self-efficacy, and wellbeing
    5.2. Community level: collective awareness of injustice and potential of mobilization
    5.3. Macro level: systemic acceptance of entitlement and inclusion (Malhotra and Schuler, 2005, 83)

Variability of empowerment studies: this review of empowerment studies

demonstrates that many different fields have incorporated the concept into their analysis

(community organizing, community development, women's rights, poverty reduction,

disability rights, and so on). I identified few studies in the area of community mental

health empowerment in LMICs, although there are a number of studies in the area of

consumer/patient inclusion and employment, and peer support, primarily in the United

States.[8]

Diener and Biswas-Diener (2005) discuss how measures of psychological

empowerment are nested within the concept of subjective wellbeing, which itself is

nested within the larger concept of quality of life. Psychological empowerment is a micro

level or individual measure that reflects whether I believe I have the resources, energy,

and competence to accomplish important goals in my life. Subjective wellbeing (SWB) is

a more inclusive concept that reflects my positive feelings about my life – happiness,

satisfaction, fulfillment. Quality of life includes SWB as one of its measures and gives

insight into defining and measuring empowerment.

But what are the causes of subjective wellbeing? Like leadership, the debate

centers on the extent to which wellbeing is genetic or environmental. Twins studies show

that half the variance in SWB is due to genetics. Two personality traits in particular can

influence happiness/SWB. The positive one is extraversion (energy and upbeat emotions)

and the negative one is neuroticism (worry, sadness, anger). Correlations of strong SWB

include social relationships, self-confidence leading to goal attainment; and sufficient

income leading to meeting one's basic needs and desires. But income is relative. For

example, Diener and Biswas-Diener (2005) studied people with materially simple lives –

the Amish in the U.S., slum dwellers in Calcutta India, and homeless individuals in

Calcutta and California. The Maasai in East Africa have no electricity, plumbing or

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[8] Why is there not a unified theory and evaluation process for empowerment. Probably because empowerment interests and outcomes, political processes, cultural-community dynamics, and so on are so different across areas of study. It appears that the area of mental health is arriving late to the arena of evaluating empowerment within its programs. After learning from the work and experiences of researchers in other fields, I hope this study will contribute to bringing awareness to the important role that empowerment can and should play in improving mental health for people in LMICs and that this study will contribute to reducing the knowledge gap in the area of mental health empowerment.

quality health care, yet are happier than California's homeless, who have more income. This is likely because the Maasai have a high quality of social relationships, important in SWB, which the homeless do not (they suffer deficiency also in basic needs including security and respect). Mental inpatients are near the bottom of the wellbeing scale.[9]

Diener and Biswas-Diener (2005) state that research suggests that psychological empowerment follows from other facets of SWB such positive affect. Positive emotions, when induced in experimental studies, have been found to have predictable consequences such as sociability, self-confidence, leadership and dominance (and to fill leadership roles), flexible thinking, altruism, active engagement with the environment, self-regulatory ability, energy, creativity, and perhaps better immune functioning and cardiovascular fitness. Longitudinal studies show positive emotions are the cause of these attributes and not a result of them. "Several of the characteristics associated with positive emotions sound similar to empowerment in that the happy individual is self-confident and likely to pursue goals in an active way" (126-127). Self-report survey questionnaires have been the mainstay of the field of SWB research for the last two decades, questions like "How happy are you?" and "How satisfied are you with your life?" SWB is composed of "facets" including life satisfaction, satisfaction in specific domains (marriage, work, health), low levels of negative feelings (depression, anger), high levels of pleasant affect (affection, joy), meaning and purpose, engagement (interest in one's activities), and

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[9] Diener and Biswas-Diener (2005) show a table of their results, on a scale of 7 to 1 (7=extremely satisfied; 4=neutral; 1= extremely dissatisfied). The highest life satisfaction was the "Forbes richest Americans" at 5.8. Interestingly, this is followed closely by Maasai (5.4) and Amish (5.1). Some of the other groups include Illinois nurses are 4.8, Calcutta slum dwellers are 4.4, who, interestingly, are happier than the neutral rating of 4.0. These are followed by people on the negative side of the satisfaction scale: Calcutta sex workers (3.6), Uganda college students (3.2), California homeless (2.8), mental inpatients (2.4), and Detroit sex workers (2.1). This dissertation study focuses on persons living with mental illness who generally are former mental inpatients. The low ratings for life satisfaction of persons who are patients in mental hospitals, relative to others, reflects the tremendous distance that these persons must travel to obtain a positive life satisfaction.

empowerment. Aspects of the empowerment facet include: self-efficacy,[10] self-confidence, mastery, and communal efficacy (a belief I can accomplish group goals with others). Apart from the data this dissertation study collects using empowerment, leadership and social capital scales, our data collection included a quality of life measure, a general health questionnaire that included a question on happiness, and several other scales that measure these facets. Some of this information will be detailed in the results chapter to supplement the primary empowerment instruments we used. Diener and Biswas-Diener (2005) also note that events can work to empowerment or disempower: "Empowered feelings and successful action can form a self-reinforcing loop, but repeated failures and the resulting negative emotions can stop the cycle of psychological empowerment and result in depression, resignation, or learned helplessness" (135). People working for empowerment should keep this in mind as a means to protect those they are working with in the empowerment process, and to understand that it is important for people to experience success, so they can enter the positive feedback loop where success leads to positive emotions, which yields empowerment, which feeds back to more success, and so on.

However, Diener and Biswas-Diener (2005) caution us that "we do not know the degree to which happy people are more successful in other cultures" (127), including

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[10] Diener and Biswas-Diener (2005) give self-efficacy (the belief that one can accomplish one's goals, what I might call perseverance) a central role: "Bandura (1995) points out that when beliefs about self-efficacy are experimentally manipulated independently of performance and external conditions...this leads to changes in performance. This finding indicates that internal self-efficacy does play a causal role" (137-138). However, other facets are also causal: "Social factors...such as falling in love (Aron, Paris, and Aron 1995) and emotional social support (McAvay, Seeman, and Rodin 1996), can boost people's feelings of empowerment, leading in turn to motivation and performance enhancements (Bandura and Locke 2003). Thus, the case that psychological empowerment plays a causal role in action...is strong. In the words of Bandura, 'People's beliefs that they can produce desired effects by their actions influence the choices they make, their aspirations, level of effort and perseverance, resilience to adversity, and vulnerability to stress and depression' (1998, 51)" (138).

LMIC countries. It should also be noted that these authors discuss the possible benefits of dysthymia (restlessness/ anxiety) in certain jobs such as those requiring constant vigilance. Nassir Ghaemi (2011) goes further in his book "A first-rate madness: Uncovering the links between leadership and mental illness" discussing how manic, depressed and bipolar leaders such as Abraham Lincoln, General Sherman, Mahatma Gandhi, Winston Churchill, Franklin D. Roosevelt, John F. Kennedy, Martin Luther King, and media mogul Ted Turner each benefitted in various ways from their illnesses that drove their successes (high energy from manic conditions and realism and empathy from the experience of depression). On the other hand, Adolf Hitler is an example of the consequences of tragic leadership born of a medically mismanaged bipolar disorder.

Human rights. In our work in El Salvador there is often discussion of the human rights of persons with disabilities. We have been successful in bringing to the consciousness of the disability rights community that mental conditions should be included among disabilities and persons living with mental illness (PLMI) included on disability rights commissions in the country. Because of the closeness of the conceptualizations and language of the human rights based approach (HRBA) and empowerment (both use "inclusion" and encourage people to speak for themselves), I discuss this relationship here and its implications for this paper.

Luttrell and Quiroz (2007) note that HRBA and empowerment have many similarities. For example, the United Nation's HRBA "Common Understanding" approach is based on a number of principles, one of which is empowerment. However, there are differences as well, the most obvious one being the obligations of the duty-bearer (the state) to comply with and enforce the legal rights of persons, for example as

found in the Convention on the Rights of Persons with Disabilities. This convention was signed by 160 countries including El Salvador, but rejected by the U.S. senate in 2012, as my colleagues in Latin America frequently remind me.

A human rights approach has helped to shift public discourse on development away from a needs approach based on "charity," to a recognition of the rights of poor people. Some development agencies have also moved away from a generic empowerment approach to a human rights approach as the social and political constraints on the poor are increasingly recognized. The thinking is that civil and political rights empower poor people not only to claim their economic and social rights but also to demand accountability for good public services, pro-poor public policies and a transparent participatory process open to hearing their views.

Power imbalances and strong cultural norms influence the use of HRBA vs. empowerment strategies. For example,

> Save the Children has faced concerns associated with the empowerment of children in contexts where there is no acceptance of children expressing their views. Projects aimed at taking children out of employment to go to school were halted following consultations with children themselves. Instead, Save the Children decided to stop advocating for the full eradication of child labour, and has tried instead to find ways of combining education opportunities with children's responsibilities towards their families, including through appropriate labour practices that do not undermine their development….Save the Children's initial focus on "power to" and the structural aspects of discrimination (which a HRBA encourages) was therefore less effective in this example. A subsequent

focus on building "power within" attempts to change individuals' own perceptions about their rights, capacities and potential in order to tackle [internalized] power" (2).

For many large NGOs, it can be a challenge to avoid disempowering partners while introducing a HRBA to previously service-delivery orientated organizations. A HRBA forces engagement in politics and power relations and can increase tensions when partners are not themselves committed to a HRBA. A HRBA helps transform passive beneficiaries into active citizens, and implies greater attention to advocacy and capacity building (Luttrell & Quiroz, 2007).

Empowerment and mental health populations. Interestingly, the above discussion of building internal power and changing individual's perceptions of themselves and their rights is closely reflected in the psychological concept of "internalized stigma." Also known as "self-stigma," this is a situation in which a person with mental illness internalizes society's negative attitudes towards PLMI (e.g., "People with mental illness are dangerous." Or, "I can't work."). Internalized stigma impedes recovery; it is associated with depression, reduced self-esteem, reduced recovery orientation, reduced empowerment, and increased perceived devaluation and discrimination (Boyd, Otilingam, & DeForge, 2014). People are dissuaded from pursuing opportunities and life goals because of diminished self-esteem and self-efficacy, and people may avoid accessing evidence-based practices that help them achieve life goals (Corrigan, Larson, & Rüsch, 2009). Internalized stigma negatively correlates with measures of empowerment and recovery orientation (Ritshera, Otilingama, & Grajalesa, 2003). A large European study showed that self-stigma appears to be common and

sometimes severe in people with schizophrenia, with 41.7% of persons participating in nonprofit programs reporting moderate to high levels of self-stigma. Interestingly, 42% of variance in self-stigma scores was predicted by levels of empowerment, perceived discrimination and social contact (Brohan, Elgie, Sartorius, Thornicroft, & the GAMIAN-Europe Study Group, 2010). In other words, self-stigma is a problem for almost half of people with mental conditions, even in community-based nonprofit programs, and it is correlated with two interests of this study—lower empowerment scores and less social contact.

Many mental health researchers view empowerment through the advocacy lens, at a mezzo and macro level only. For example, empowerment has come to be defined by mental health researchers as "gaining control over one's life in influencing the organizational and societal structures in which one lives" (Segal et al., 1995, 1). On a systems level, the consumer movement has substantially influenced mental health policy to tailor services to consumer needs. Consumers are now involved in all aspects of the planning, delivery, and evaluation of mental health services, and in the protection of individual rights. One prominent example is the passage of Public Law 102-321, which established mental health planning councils in every state…[with] membership from consumers and families" (95).

In this same vein, empowerment is an important focus in the World Health Organization's "Mental Health Action Plan: 2013-2020 (World Health Organization, 2013). The plan has four strategies and six cross-cutting principles. The first strategy is about including mental health civil society groups in planning and evaluating mental healthy policies, laws, budgets, and strategic plans. That in itself can be an empowering

process for grassroots associations in LMICs. Cross-cutting strategy #6 is "*Empowerment of persons with mental disorders and psychosocial disabilities:* Persons with mental disorders and psychosocial disabilities should be empowered and involved in mental health advocacy, policy, planning, legislation, service provision, monitoring, research and evaluation" (10). The "Actions" called for correspond to the strategies and principles. For example, "*Strengthening and empowerment of people with mental disorders and psychosocial disabilities and their organizations:* Engage organizations of people with mental disorders and psychosocial disabilities in policy making at international, regional and national levels…and provide support to organizations to design technical tools for capacity building, based on international and regional human rights instruments" (13).

In the same report, the World Health Organization (WHO) discusses empowerment and a human rights approach in relation to PLMI and families. For example, "Recovery" is defined as "gaining and retaining hope, understanding of ones abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life and a positive sense of self" (39). Recovery does not mean cure, but rather "refers to both internal conditions experienced by persons who describe themselves as being in recovery - hope, healing, empowerment and connection - and external conditions that facilitate recovery - implementation of human rights, a positive culture of healing, and recovery-oriented services" (39). The WHO Mental Health Plan brings together the issues of interest in this paper – development of civil society leaders through experiential learning and inclusiveness, empowerment of PLMI and family carers through a call for them to advocate for changes/improvements in national mental

health care systems, and calling governments to create social links with mental health

civil society groups and to meet social inclusiveness/support/service needs of PLMI.[11]

Empowerment and leadership. In "The Tasks of Leadership" Gardner (2010)

argues that a central task of leadership is to empower others. The actions required are

sharing information, helping people get the training they need, allowing others to take

initiative and assume responsibility, building the confidence of followers to achieve their

own goals, removing barriers for followers' energy and use of talents, seeking the

resources that followers need, resolving conflicts that paralyze a group, and structuring an

organization that facilitates group effort. Likewise, Kouzes and Posner (2010) list

enabling or empowering others as one of their five practices of exemplary leadership. In

turn, this act fosters trust and collaboration, two key reflections of social capital.

In a different historical twist, ignored by the male leadership researchers of early

participative leadership theory, Stall and Stoecker (2008) meld leadership and

empowerment. In "Community organizing or organizing community: Gender and the

crafts of empowerment," they argue for the benefits of a women-centered model of

leadership. This "private" model carried out in women's homes contrasts with a "public"

model best represented by Saul Alinsky's IAF community organizing organization,

where professional organizers from outside a community come in to identify and develop

leaders. Stall and Stoecker write the women-centered model grew out of African

American and Anglo women organizing through their private home and neighbor

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[11] Empowerment is sometimes related to external factors such as housing. These factors are known as social determinants of health and are related to both prevention and recovery for people with mental conditions. For example, "one study found that personal empowerment and functioning were enhanced, and hospitalization reduced, after 5 months in a supported housing program (McCarthy & Nelson, 1991)." And in other studies, "resident control over decisions was directly related to satisfaction and empowerment (Seilheimer & Doyal, 1996) [and]… having greater choice in housing was associated with greater happiness and life satisfaction (Srebnik et al., 1995)" (U.S. DHHS, 1999, 293).

networks, a prime example being the settlement house movement in Chicago led by Jane

Addams. Women sought the development of the power of everyone in the group.

The goal of a women-centered organizing process is "empowerment"—a development

process that includes building skills through repetitive cycles of action and reflection that

evoke new skills and understanding, and in turn provoke new and more effective

actions…Empowerment includes developing a more positive self-concept and self-

confidence." (244)

Women organizers find they need to deal with women's sense of powerlessness

and low self-esteem before involving them in sustained organizing efforts. The emphasis

then is on developing "group centered" leadership that embraces participation rather than

individual leader development. Their private networks blossom into community

networks, raising consciousness and transforming networks into a political force.

Essentially, leadership is about empowering others to participate.

The construct of social capital

Definitions and types of social capital. Social capital is a measure of the quality

and extensiveness of relationships that facilitate what we need (Keefe, 2009). We have

come to think of social capital as one of many kinds of capital that are useful to us—

human, political, cultural, financial, psychological, and so on.[12] Social capital is a way of

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[12] Keefe (2009) has an amazing review of different types of capital and their benefits. For those with interest, I quote her at length here because her explanation is so comprehensive: "Human capital is a form of nonphysical capital that was identified by economists early in the twentieth century as more skilled workers became necessary in the industrial economy. It includes individual skills, qualifications, and educational training. Political capital is used by political scientists to refer to the political influence and power gained through the electoral process. "Cultural capital" is a term developed by Pierre Bourdieu to refer to the information and knowledge about how to behave appropriately assumed by growing up in an upper-class family (Bourdieu 1984, 1987). While Bourdieu was interested in the way elites use cultural capital to set themselves apart from subordinates, other writers have applied the concept to illuminate way in which knowledge of ethnic minority (or alternative) cultural capital operates among such disparate groups as Nuyorican crack dealers (Bourgois 1996) and Zapotecan peasant migrant associations in Mexico

conceptualizing the intersection of social norms or values within reciprocal dependent

relationships that exist across social networks observed in individuals, families,

communities, organizations and at national and global levels. It is a concept that has

evolved over time and is grounded in the ideas of Pierre Bourdieu (1986), James

Coleman (1988) and Robert D. Putnam (1993, 2000). The authors differ somewhat on

their focus (individual vs. community level analysis).

The concept of social capital is important because it helps to explain why people

interact in social networks, how relational capital (developed over time) allows people

with strong networks to accomplish their goals, explains why some

people/organizations/governments are successful and efficient while others are not, and

provides a great deal of fodder for aspiring researchers and nonprofit professors. It adds

to game theory, organizational development theory, and community organizing theory. It

has been used to help explain human behavior across multiple disciplines from

economics to engineering (B. Rosser, personal communication, September 9, 2012;

Brown, Flick & Williamson, 2005).

Halpern (2005) defines and contextualizes social capital by putting it in a matrix

of Definition, Types and Levels. He stresses the enforcement of values, in addition to

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City (Hirabayashi 1993). Social capital refers to relationships of trust embedded in social networks and the resources available to individuals and groups that they do not have as isolates. It refers to the advantages of social connections and the investment in social relationships….Symbolic capital, also identified by Bourdieu (1987), refers to the prestige attached to a family and a surname. For example, family name may get your foot in the door for a job interview. Psychological capital has been identified by Sherry Ortner (2002) as significant in determining social class outcomes for graduates in her study of a New Jersey high school class of 1958. This refers to certain positive personality traits, such as being an extrovert or a risk-taker or having charisma, which can improve one's chances for leadership, opportunities, and mobility. Finally, spiritual capital is used by Raquel Rombert (2003) to refer to access to supernatural power and the influence it gives to witches (brujos) in urban Puerto Rico. In her analysis, brujos are spiritual entrepreneurs who use their access to knowledge and power gained from the supernatural to advise clients on compliance with state laws and new economic opportunities, help lawyers win custody suits, and help sick employees to resolve labor disability claims." (34-35) For a broader application of the last concept, substitute "TV evanagelists" for "witches."

norms and connections. Bridging (external), bonding (internal), and linking (linking capital builds relationships between layers of inequality, power differentials, etc.) concepts help us understand the horizontal and vertical nature of relationships that link people across communities and inequalities, allowing access to power. Halpern and others call trust the best tool for measuring social capital (Halpern, 2005; Schneider, 2009).

Referring to the seminal works on social capital by Putnam (1993, 2000), Van Til (2011) writes, "Putnam's work illustrates that social capital is a public good, one that markets and their private agents alone cannot provide. Third-sector [nonprofit] organizations, on the other hand, can play a crucial role in its amassing" (91).

Social capital and the nonprofit sector. Writing about capacity building in the nonprofit sector, De Vita, Fleming, and Twombly (2001) write that civil society and social capital theories emphasize the relational aspects of community life, that participation in formal and informal organizations builds trust in individuals and institutions, and forms habits of interaction. One role of nonprofit organizations is that they facilitate interaction and trust building among those seeking community development.

De Vita, Fleming, and Twombly (2001) suggest that civil society and social capital literature provide insight into the dynamics of building trust among individuals and institutions, which leads to citizen action. Sustainable development theory suggests that human and social capital should be treated much like natural resources—that is, "carefully nurtured and effectively used to provide long-term, sustainable benefit to local communities" (8).

Nonprofit organizations build and maintain important social relationships, provide a means by which people can interact and work toward common goals, and create social capital through multiple channels—"volunteers working alongside each other, staff interacting with clients, or board members promoting the organization's activities in the community" (De Vita, Fleming, and Twombly, 2001, 9). On a community level, nonprofits create community relationship infrastructure by working jointly on common concerns and sharing ideas and resources, including with the governmental and business sectors. These strengthen a community and contribute to overall quality of life and perceptions of satisfaction and effectiveness.

Galaskiewicz and Bielefeld (1998) note that nonprofits who have strong social ties have tremendous advantages. This is not unlike the social advantages that persons with the personality trait of extroversion have. Social networks can help facilitate strategy change by:

- increasing organizational capacity to leverage favors through trust that has been built;

- providing access to others, especially friends in high places, "good contacts," e.g., getting corporate managers on a board or involved as volunteers can help an organization gain access to corporate sponsorships and foundation funds;

- networks can lend credibility, resulting in greater status and reputation; and

- networks facilitate learning, within and across organizational boundaries, and innovation because good networks provide timely access to information.

The downside is that innovations and secrets can leak, just as in the business world, so it is important to base relationships on trust, or within "communities."

Galaskiewicz and Bielefeld (1998) conclude that social networks are different from other assets because one does not know when they'll be needed, they have to be replenished and maintained, and there is not a "social networking" item in the budget usually.

But how do you create social capital through deliberate intervention? Hyman (2008) notes that civic engagement, i.e., participation in community activities, is the necessary precursor to individuals and organizations developing social capital. The creation of social capital, then, is dependent on getting people involved and engaged. Hyman developed a community-building framework to increase and sustain people's engagement in a community change process. In this model, people are engaged by facilitating a process in which the individual interests of people can be joined with those of others into a group (community) discussion "so they can resonate with other community members in a way that can gain their support and provoke them to action" (227). In turn, this leads to people coming together to respond and act collectively. "Starting and maintaining these conversations and organizing [the group are] major community-building challenges" (227). This describes well the process that happens in the PICO community organizing model discussed earlier, and in the programs for PLMI and carers in El Salvador.

Social capital in the international realm. Social capital moved quickly into the international sphere with the World Bank and the Organization of Economic Cooperation and Development (OECD) incorporating the concept into their work on poverty alleviation, and national governments incorporating it into measures for health and wellbeing (Schneider, 2009; Lisakka, 2006). Several global surveys now incorporate

social capital into their questionnaires, for example, the World Values Survey, the Gallop

International Poll, the Global Civil Society Index, and the European Social Survey.

A study by Delhey and Welzel (2012) uses data from 50 countries in the World

Values Survey to analyze under which conditions outgroup-trust emerges independent of

ingroup-trust. Ingroup-trust, related to bonding social capital, is a measure of bonds in

groups of similar persons. Outgroup-trust, related to bridging social capital, is a measure

of bonds to others who are different. In their review of the data, Delhey and Welzel draw

several conclusions: that it is necessary for individuals to develop high ingroup-trust as a

condition for high outgroup-trust, that empowerment is the necessary condition for

outgroup-trust because it fosters exposure and cooperation in the group's individuals,

and, once outgroup-trust is achieved, the combination of empowerment and outgroup-

trust is able to overcome challenges of cultural legacies (e.g., of collectivist traditions

such as communism, Islam, and Confucianism) and social divisions (e.g., of income,

ethnicity, and religion) experienced by each individual. This is important in the context of

Latin America, where cultures lean toward the collectivist tradition. People with mental

illness struggle with trying to work, so they and their families often find themselves with

high unemployment and low incomes (WHO and ILO, 2000). This finding holds out

hope that people in empowerment programs are able to develop attributes of bridging

capital, and that once established, neither cultural traditions nor socioeconomic divisions

can erase those gains for them. Delhey and Welzel conclude that, "to a large extent, trust

generalizes to outgroups as a result of modernity's emancipative impulses" (46).

Social capital and leadership. Trust and leadership are closely tied together.

Brothers and Sherman (2012) encourage nonprofits to return to values as a key to

facilitating successful organizational change. When values and trust intersect in the right way, an organization creates strong social capital and organizational change can be successful, because people are able to focus on the shared values when there are conflicts. They believe that shared values is the way to create trust. On that basis an organization can be experiencing rapid change without upsetting people. "Any constructive conversation about significant change is going to depend, to a greater or lesser extent, on the degree of trust that exists within the organization" (31). External trust may also mediate an organization's ability to facilitate community and policy change. As change makers, leaders have a key role to play in creating and maintaining internal and external trust.

Green and Haines (2008) note that community-based organizations "can promote social capital by ensuring they have a diverse leadership" (117). Leadership opportunities are important too. Internally this allows more chances for leadership development for individuals and for expanding their personal social networks. Externally, more leaders means the organization is expanding its network of external connections.

Social capital and empowerment. In "Assessing empowerment at the national level in Eastern Europe and Central Asia," Christiaan Grootaert (2005) develops a macro level single measure of national level empowerment that depends heavily on the concept of social capital. He does so because the incorporation of empowerment into poverty analysis has been hampered by the lack of measures.[13] His 50 indicators (aggregated into a single empowerment score) cover both "micro and macro levels, since empowerment

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[13] Narayan includes in her book other authors who focus on macro level measures of empowerment (e.g., "The CIVICUS Civil Society Index," by Malena and Heinrich, 2005), but our focus here is micro measures. Thus I limit coverage of macro measures, even though they are important for understanding the context within which community based organizations have to function.

requires action at the levels of the household, the community, and the state" (309). His

theoretical foundation comes from the World Development Report 2000/2001 (World

Bank, 2000), whose "third pillar" for empowerment is "Building social institutions and

social capital." He states: "Social capital plays an important role in enhancing the

productivity of other assets available to the poor….The formation of local organizations

will often play a key role, and strengthening the capacity of such local organizations

helps empower their members" (327). For some countries, "local networks are now often

critical for survival and access to essential services in situations where the state fails to

provide an effective social safety net" (327), as is the case in El Salvador. His "priority

indicator" for social capital as "density of networks and associations" (Table 2).

Table 2
National level empowerment indicators

Empowerment action	Indicator
Strengthening local organizations and networks	
	o Density of networks and associations
	o Extent of diversity of membership
	o Measures of trust and adherence to norms
	o Extent of local collective action
Creating linking social capital	
	o Linkages between associations
Promoting community-based development	
	o Incidence of community-driven development programs

This study uses similar measures but only at the micro (individual) analysis level.

They include participation in associations and trust, among other measures (discussed

further below). We aggregate certain measures together, taken primarily from World

Values Survey questions that are related to one another.

Social capital and mental health. Increasingly in recent years, research is being carried out that looks at mental health with social capital theory. Cullen and Whiteford (2001) provide an in-depth review of how social capital might be measured and incorporated into improving mental health programs. Interestingly, because they believe this is a two way street, they discuss how social capital mechanisms could improve mental health and how mental health improvements on both the individual and social levels could build community social capital. Brusilovskiy and Salzer (2012) find that community social capital indicators may not have a major impact on individuals who have already developed a significant psychiatric condition, and that personal factors play a more significant role.

In a systematic review, De Silva (2005) looked at quantitative studies focused on the relationship between social capital and mental health. She did this because, while the World Bank and World Health Organization had begun to incorporate the idea of social capital into health, there did not appear to be a strong experimental basis for doing so. In her review only 21 studies met inclusion criteria, 14 measured social capital at the individual level (social relations/group membership) and 7 at the ecological level (aggregated measure). She also notes social capital is described as having a behavioral/activity component (measured by participation) and a cognitive/perceptual component (measured, eg, by trust). She concluded the ecological studies were too diverse to summarize, while the 14 individual level studies demonstrated some findings: an inverse relationship between cognitive social capital (trust) and common mental disorders, and an inverse relationship between a combined measure of cognitive (trust) and behavioral (civic participation) social capital and common mental disorders. While

her final conclusion states that current evidence was inadequate to inform the development of specific social capital interventions to combat mental illness, it is still clear that mental illness is destructive of trust in relationships and civic participation. Hence, community programs that help PLMI to regain social connections, re-create relationships of trust, and increase their capacity to participate more in civic society (voting, joining groups, reading the newspaper) would seem to be important in achieving a good quality of life for these persons.

Anderson, Laxhman, and Priebe (2015) carried out a systematic review of studies of social networks of patients with psychosis titled "Can mental health interventions change social networks? A systematic review." Most program interventions target symptoms and developing social skills but are largely unsuccessful at improving social networks indirectly. As an alternative, interventions may directly focus on expanding networks. Their review assessed what interventions had previously been tested for this and to what extent they were effective.

Five studies from Ireland, Israel, Spain, Holland and Italy (n = 631 patients) met the complete inclusion criteria. Four trials had significant positive results for an increase in patients' social network size at the end of the intervention. The successful interventions were guided peer support, supported engagement in social activity, dog-assisted integrative psychological therapy, and psychosocial skills training; the positive but non-significant intervention was a volunteer partner scheme). Almost all programs included professionals as at least facilitators, and involved group work, except the non-significant study. This would seem to indicate that "supported" programs with professionals is important, as is the social interactions of participating in group therapy,

including self-help groups. They concluded that interventions directly targeting social isolation can be effective and achieve a meaningful increase in patients' networks. The researchers stated that although limited, the existing evidence is encouraging, and future research is needed to test the findings in different settings, identify which components are particularly effective, and determine to what extent the increased networks, over time, impact on patients' symptoms and quality of life.

In noting the importance of community social capital to the success of addressing health and mental health needs, Halpern (2005) parallels the interests of this paper when he notes a useful purpose of measuring the development of social capital in marginalized groups is to empower them to advocate for and effectively provide needed community mental health services. The creation of "enclave communities," an attempt to construct deepening communities of social capital for persons, families and professionals working with the mentally ill, follows in the same vein (Mandiberg, 2010; J. Mandiberg, personal communication, November 11, 2012). Mandiberg's work is based in part on racial and ethnic minority communities that construct their own bonding communities in order to provide social capital for their members who cannot obtain much of it in the larger society because of discrimination. This is reminiscent of Dilulio's (2000) work on Black churches in urban settings in the U.S. that are effective community organizations that struggle with little access to society's wealth controlled by the majority population. In summary, marginalized groups can and do make a difference in building community social capital, but they face special challenges to obtaining social capital. Measuring the levels of individual social capital is an important step in understanding the empowerment of marginalized groups.

The intersection of leadership, empowerment, and social capital with health

      Grassroots associations and health. Smith (2000) discusses a variety of positive impacts that grassroots associations (GAs) can have on families and communities in the area of health. He cites studies that show that benefits associated with participation in voluntary organizations include less illness, less mortality, quicker recovery from illness among members, less depression, more satisfaction, happiness and general health. He also cites studies on GAs in Nicaragua on malaria, Brazil on health care, and unions in Australia for health and safety.[14]

      One type of GA in the area of health that he discusses is self-help groups (SHGs). These groups exhibit internal and external impacts. The most researched SHG is Alcoholics Anonymous, which shows positive findings for mental health, physical health, and health-related behaviors. Likewise, the findings in a previous focus group study in El Salvador on the intervention program indicate multiple potential benefits of our self-help group components (Nickels et al., 2016). Smith notes SHGs can improve members' knowledge, coping, and self-care behavior and SHG participation has been found to reduce use of health care resources and reduce the use of sick days for employees in stressful work. These benefits are mediated by level of involvement and by the member both receiving and giving in the group.[15]

      Cohen et al. (2012) also discuss the importance of SHGs for PLMI and carers. They note how such groups not only are places for peer support and organizing for policy change, but also provide an opportunity for self-empowerment. Their study of 18 mental

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[14] Authors he cites include Bradburn, 1969; Bradburn and Caplovitz, 1965; Cutler, 1981, 1982; Lin, Dean, and Ensel, 1986; Palisi, 1985; Adler and Matthews, 1994; Moen, Dempster-McClain, and Williams, 1992; Rodin and Salovey, 1989; and Vauz, 1988. See Smith, 2000, for full references.

[15] Authors he cites include Humphreys, 1997; Cullinan, 1992; and Kurtz, 1990. See Smith, 2000, for full references.

health SHGs in Ghana West Africa showed evidence that SHGs provide a range of support, e.g., social, financial, and practical. The SHGs also fostered greater acceptance of PLMI by their families and communities. Finally, members in SHGs appeared to be associated with more consistent treatment and better outcomes for those who are ill.

Governmental agencies and the intersection of constructs. The World Health Organization's "Mental Health Action Plan: 2013-2020" (2013) is its most recent and major strategic plan. The Action Plan lists four objectives, the first of which is "to strengthen effective leadership and governance for mental health" (10). WHO recognizes that an empowered civil society has a leading role to play in social change: "A strong civil society, particularly organizations of people with mental disorders and psychosocial disabilities and families and carers, can help to create more effective and accountable policies, laws and services for mental health in a manner consistent with international and regional human rights instruments" (11).

In the U.S. Surgeon General's major report on mental health (U.S. DHHS, 1999), social networks, social support, and structures like self-help groups are emphasized as important means for creating social capital for PLMI. "Support groups, which are an adjunct to formal treatment, are designed to provide mutual support, information, and a broader social network. They can be professionally led by counselors or psychologists, but when they are run by consumers or family members, they are known as self-help groups" (378).[16]

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[16] The Report (U.S. DHHS, 1999) notes there are multiple other benefits to support groups, some of which are related to measures we collected with the additional instruments: participation by PLMI and carers in support groups has been found to reduce feeling of isolation, increase knowledge, and promote coping. Support groups may also reduce stigma, help with illness comorbidity, and improve compliance with formal interventions. Two studies of persons in self-help bereavement groups showed reduced

People with mental illness and their families actually suffer a loss of social

support, networks and capital due to the challenges of their situation. "Too often…natural

support systems are often diminished for families of [persons] with serious emotional,

behavioral, or physical disorders or handicaps because of the stigma" (U.S. DHHS, 1999,

332). Caregivers report a loss of quality of life, they feel less competent, more depressed,

worried, and tired and have more problems with spouses and other family relationships

than other parents (U.S. DHHS, 1999). This may indicate a special need in this

population for empowerment and social capital, which provide increased self-esteem,

self-confidence, and self-efficacy.

Social support, found through social networks, acts as a factor in resilience

(prevention). For example, Single mothers face twice the risk of depression as do married

mothers. "Vulnerability to depression and anxiety is greater among those with a personal

history of mental disorders earlier in life and is lessened by strong social support" (U.S.

DHHS, 1999, 230). Likewise, the causes of depression include intensity the duration of

stressful life events, genetic endowment, coping skills, and social support network. "That

is why depression and many other mental disorders are broadly described as the product

of a complex interaction between biological and psychosocial factors" (251). For people

across various mental illnesses, participation in self-help groups is "thought to contribute

greatly to increased coping, empowerment, and realistic hope for the future" (289).

Summary findings from this review of literature

Characteristics of psychological wellbeing such as happiness not only reflect

psychological empowerment but also drive leadership, which in turn is a benefit to

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depression, anxiety, somatic symptoms, self-esteem, less depression, quicker recovery, and quicker
establishment of new relationships.

organizations that are seeking to empower people to social change. Chronically happy

people are more successful in a number of domains, including that they are more likely to

have more friends and be involved in community and volunteer activities (Narayan,

2005). In turn, these characteristics reflect high levels of social capital. Disentangling

causal directions of the influences of these concepts has spawned many methodological

and theoretical ideas and much debate. The reality may be so complex that it is not worth

the effort and cost to resolve these debates when it may be more useful to simply

acknowledge that empowerment, leadership and social capital are interdependent. They

are all necessary but none sufficient.

In all the areas in this literature review (women's empowerment, psychological

empowerment, community organizing, grassroots leadership development, global mental

health calls for civil society involvement, nonprofit and grassroots organizational

capacity building, international development and poverty), authors and researchers

describe each construct in terms of the others. Leadership means empowering others,

empowerment means increased social capital, social capital grows in tandem with

leadership development, and so on. Few authors try to tease out causal direction. What

seems more important is that programs can be more impactful if they focus on developing

characteristics that these constructs represent.

Developing leadership, developing empowerment, and developing social capital,

like any advanced ability, must pass through a process of change. For example, to start

the process of empowerment one becomes conscious of one's personal and social reality

(injustice, disability, need), then passes through a process of learning by observing and

participating in change processes, and finally arrives at a sense of confidence that one has

power. Working in tandem with others, developing organizational capacity skills, sharing leadership, and bringing in new people with new networks and resources leads to organizational empowerment. In turn, this allows grassroots leaders to use their organizations effectively to accomplish their ends.

On the individual level in this review, self-confidence and self-efficacy seem to pop up repeatedly. On an organizational level, opportunities for experiential learning and respect for the dignity of the powerless or poor or excluded also seem to come up repeatedly. In other words, there are specific techniques and processes we can use as individuals, organizational leaders, outside experts, or government officials that can help develop the full potential of persons at the grassroots to develop their leadership, empowerment, and social capital, as well as the capacities or strengths of their organizations.

We come full circle to the research question for this study. Do people of a marginalized population in a low and middle income country who participate in a grassroots, shared leadership program run by civil society organizations develop leadership attributes, a sense of empowerment, and increased social capital?

CHAPTER 3: METHOD[17]

Design and Overview

The study is a quasi-experimental retrospective comparison of an intervention group with a matched control group on outcomes of leadership development, empowerment, and social capital. The focus is on grassroots associations and nonprofit organizations that carry out programs, leadership development, and advocacy to achieve social change goals in low and middle income countries. The specific target population is persons living with mental illness (PLMI) and family caregivers (carers) in El Salvador. The intervention group is a subset of the target population that has participated in a community mental health program (described below). The control group was drawn from PLMI and carers who attend the outpatient clinic at the national psychiatric hospital but who have not participated in any type of community based mental health association or program. Goals of the program include improving member quality of life, developing grassroots leaders, and creating strong civil society organizations in order to advocate effectively for improvements in the national mental health system.

Research question

Do marginalized populations in low and middle income countries who participate in grassroots, shared leadership programs run by civil society organizations develop leadership attributes, a sense of empowerment, and increased social capital?

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[17] "The American Psychological Association's Publications and Communications Board formed the Working Group on Journal Article Reporting Standards (JARS) and charged it to provide the board with background and recommendations on information that should be included in manuscripts submitted to APA journals." (APA, 2008, 839) The new standards are based on reports in the areas of social, behavioral, and medical sciences…demanding improved evidence based practices and clear explanations of methodology. My dissertation will use the APA JARS recommendations for reporting to supplement the dissertation guidelines provided by the JMU Graduate School.

Hypotheses

My hypotheses relate to the intervention program participants, both persons living with mental illness (PLMI) and their family caregivers (carers).

1. Marginalized persons with mental illness participating in a grassroots participatory intervention program demonstrate higher gains in leadership, empowerment, and social capital than a control group of non-participants.

   To answer hypothesis one, I use a series of ANCOVAs to compare PLMI in the control and intervention groups on leadership, empowerment, and social capital respectively, while controlling for confounding variables.

2. Marginalized family members (carers) participating in a grassroots participatory intervention program demonstrate higher gains in leadership, empowerment, and social capital than a control group of non-participants.

   To answer hypothesis two, I use a series of ANCOVAs to compare carers in the control and intervention groups on leadership, empowerment, and social capital, while controlling for confounding variables.

3. PLMI and carers in the intervention group demonstrate different levels of leadership, empowerment and social capital.

   To answer hypothesis three, I use a series of ANCOVAs to compare PLMI and carers in the intervention group on leadership, empowerment, and social capital, while controlling for confounding variables.

4. Moderating variables influence the outcome variables.

To answer hypothesis four, I perform an initial examination of possible moderating variables through a correlation matrix of moderating variables with outcome variables.

Intervention setting

The study took place in San Salvador, the capital city of El Salvador, a lower middle income country. Partners in the study included 1) the Association for Training and Research in Mental Health (ACISAM), a government-registered nonprofit organization that has been working for 29 years in a variety of community mental health and youth-risk programs, and has run the intervention program since 2002 (Raul Duran, executive director; Nelson Flamenco, mental health program coordinator); 2) the National Psychiatric Hospital (Hospital), which is the single public hospital that provides psychiatric services for approximately 70% of persons with mental health conditions throughout the country (Dr. Moises Gomez, director; Dr. Dina Callejas, ethics committee chair); 3) AFAPDIM and ASFAE,[18] two grassroots associations that partner with ACISAM to provide services and advocacy; and 4) two Salvadoran advisors (Dr. Ricardo Gutierrez, researcher with the "Universidad Tecnológica," and Rafael Paz Narvaez, professor of Sociology with the "Universidad de El Salvador"). Most subjects were interviewed in private spaces in the office of ACISAM and a consulting room at the Hospital. A few interviews were held in a small hotel meeting room and in participant homes to accommodate the needs of these participants.

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[18] AFAPDIM is the Spanish acronym for the Association of Families and Persons with Mental Disabilities (Asociación de Familias y Personas con Discapacidad Mental); ASFAE is the Spanish acronym for the Salvadoran Association of Families and Friends of Persons with Schizophrenia and Other Mental Disorders (Asociación Salvadoreña de Familiares y amigos de personas que padecen Esquizofrenia y otros Desordenes Mentales).

Intervention description

The Family Education, Support and Empowerment Program (FESEP) is a nonprofit-run, community based, mental health program in El Salvador. Volunteer professionals and paid staff partner with volunteer PLMI and carers to facilitate the program. The FESEP program is run by ACISAM in partnership with family and user leaders in two grassroots associations (AFAPDIM and ASFAE). These leaders provide support and educational programs (described in detail below) and serve on national disability rights and health care commissions on behalf of their associations. Program components, adapted from evidence-based practices in the U.S., may be for carers (family class) or users (psychosocial group) or both (monthly assembly/celebrations and recreational trips).[19] Association members are family caregivers and people with mental

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[19] Recent studies for the family education component include randomized controlled trials by Dixon et al. (2011) and Lucksted et al. (2013). Older studies are reported in the U.S. Surgeon General's report on mental health (U.S. DHHS, 1999): Randomized trials have been conducted for interventions that educate families about schizophrenia, provide support and crisis intervention, and offer training in effective problem solving and communication. These interventions have strongly and consistently demonstrated their value in preventing or delaying symptom relapse and appear to improve the patient's overall functioning and family well-being (Goldstein et al., 1978; Falloon et al., 1985; Strachan, 1986; Lam, 1991; Tarrier et al., 1994; Goldstein 1995a; Penn & Mueser, 1996). Research has suggested that groups of multiple families are more effective and less expensive than individual family interventions (McFarlane et al., 1995). Incorporating family religious and ethnic background may prove useful in family interventions (Guamaccia et al., 1992). "Many mental disorders are best treated by a constellation of medical and psychosocial services (Goldman, 1998b). Access to a delivery system is critical for individuals with severe mental illness not only for treatment of symptoms but also to achieve a measure of community participation. Among the fundamental elements of effective service delivery are integrated community-based services, continuity of providers and treatments, and culturally sensitive and high-quality, empowering services (Mowbray et al., 1997; Lehman & Steinwachs, 1998a). Effective service delivery also requires support from the social welfare system in the form of housing, job opportunities, welfare, and transportation (Goldman, 1998a). What models of service delivery are most effective for people with severe mental disorders? Despite the body of research on mental health services delivery for this population being extensive, existing service systems [in the U.S.] are seriously deficient. The majority of people with schizophrenia do not receive the treatment and support they need, according to a groundbreaking finding of PORT (Lehman & Steinwachs, 1998a). PORT developed a series of basic treatment recommendations after reviewing hundreds of outcome studies. Effective services are case management, assertive community treatment, psychosocial rehabilitation services, inpatient hospitalization and community alternatives for crisis care, and combined treatment for people with the dual diagnosis of substance abuse and severe mental illness. SHGs are helpful to family members as well. Families attend support groups to receive emotional support and accurate information about mental

illnesses (primarily schizophrenia, but also bipolar, and to a lesser extent major

depression and anxiety, autism, trauma, personality disorders, and uncertain diagnoses).

Caregivers are generally family members such as parents or adult children caring for an

ill parent, but are sometimes extended family members, neighbors, or friends who

provide support. A few members are professionals or others with interest in volunteering

with the associations.

The FESEP program provides education by trained volunteer family instructors, a

monthly support group, crisis home intervention, attention via phone, a psychosocial

group for persons with mental illness, a small income generation support for users and

their family members, national forums on mental health and disability rights,

opportunities for legislative advocacy and service on national health and disability rights

commissions, recreational and social activities, and training of community workers and

professionals in institutions that have a direct impact on the quality of life of users and

family caregivers, such as public health clinic personnel, police officers, and psychiatric

hospital personnel. The program does not provide structured individualized therapy,

medications, or psychiatric treatment. It is meant to be a community-based complement

to private and public psychiatric treatment.[20]

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illness and mental health services (Heller et al., 1997a, 1997b). Participation often leads to better quality of life for the attending family members and also indirectly benefits the member diagnosed as mentally ill (Wahl & Harman, 1989; Monking, 1994). Family self-help groups can result in better communication and interaction among family members (Heller et al., 1997b)." (U.S. DHHS, 1999, 292)

[20] In reality, nothing is as clear as it seems in LMICs. Sometimes volunteer professionals or family carers bring unused prescriptions or meds samples to ACISAM where they are distributed on an as-needs basis. In Nicaragua, where the shortage of medications is more extreme than in El Salvador, one family association hands out meds similarly. The "administrator" who does so is a family carer who hands out only enough for a few days when someone is in crisis. Families obviously often make similar trade-off decisions in their homes for their loved ones with illness. These limited/targeted medication services are not advertised by the associations because the supply is very limited. This is because the supply is a tiny fraction of what is needed. People often come to these associations thinking they will receive medications or money to buy meds, and leave in great disappointment.

FESEP receives collaborative support from Mental Health International, a project of the Center for Health and Human Development (CHHD). CHHD is a small U.S.-based nonprofit run by myself which acts as liaison to the funding foundation and provides support in the form of organizational capacity building, best practices and research. Program leaders also have formed collaborative work projects with government and other NGO actors to accomplish goals. The goals of the program are to improve the quality of life of people with mental conditions and their family caregivers, to strengthen the organizations and their leadership, to reform the mental health system toward improved access and quality of care, and to reduce stigma and improve mental health disability rights across society.

Population and study sample

The intervention group included persons living with a psychiatric condition that we labeled under broad ICD-10 categories, including the schizophrenia spectrum, mood disorders (divided by depression, bipolar), and neurotic disorders (anxiety, obsessive compulsive disorder). Persons screened for the control group exhibiting symptoms of psychosis or other mental conditions similar to illnesses noted above, but whose primary diagnoses were behavioral disorders, personality disorders, or substance abuse, were excluded.[21]

Carers were generally but not always family members, yet had primary or shared responsibility for the wellbeing of someone with a mental condition. Carers included in

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[21] Persons living with these classifications of illnesses were not excluded from the control group for any reason other than that they were not present in the intervention group. One might ask why? I suspect that these illnesses are very different from the others in etiology, symptoms, course of treatment, or client needs. For example, behavioral and personality illnesses by definition include persons who have trouble getting along with others, so may not be conducive to a program that focuses on socialization, group sharing, and group activities.

the study sometimes cared for persons with conditions other than those mentioned above, such as dementia, mental retardation, and autism. While their carers could be interviewed, PLMI with these conditions could not be interviewed directly because of their level of competency.

The original intention was to select intervention group participants randomly from a list of FESEP program participants from the records of the facilitating nonprofit ACISAM that dates back to the beginning of the program (2002). However, it turned out to be very difficult to contact program participants as records were lost, were not updated, and phones numbers no longer worked. Many people had no address or phone listed. We had to contact as many participants as possible to obtain a sufficient number for the study. Following is the process we used to identify and interview participants in the intervention group.

The number of unduplicated participants in ACISAM's program over the full period of program existence from 2002-2015 is estimated at 1035. When we began the search for intervention group subjects from the ACISAM program in mid-2015, the number of participants that were actually on computer records at ACISAM was only 295. These computer records were lost, shortly before we began using them for the study, when the computer with the records failed and no backup had been made. Records were then reconstructed from files in order to identify all possible PLMI and carers who had contact information. ACISAM was able to identify 121 persons (87 carers and 34 PLMI) with contact information. Because this number would not be enough, we then contacted ACISAM's sister organization ASFAE and obtained approximately 20 additional PLMI and 30 carer names to attempt to contact, and we obtained another 12 from ACISAM's

program participant list from the city of Cojutepeque. This brought our potential pool of persons with contact information to 183.

We were unable to contact about half of this group due to phone numbers that did not work, wrong numbers, or unanswered rings. Multiple attempts were made, including at different times of the day and on weekends by at least two investigators. We talked with some persons when they came in to program events. Over the course of several months, the number of persons we were finally able to contact successfully was 94 persons (44 PLMI and 50 carers).

Of 94 successfully contacted, we were able to successfully complete full interviews with 79 subjects (36 PLMI and 43 carers). Of the 15 we were unable to interview, 2 PLMI refused to be interviewed, 2 PLMI were unable to complete interviews, 4 PLMI were unable to be interviewed because they were in crisis or hospitalized or had logistical problems to get to the interview, 1 carer refused to be interviewed and 6 carers were unable to be interviewed because they were too busy with work or unable to get away from caregiving duties.

We were able to match 70 intervention group participants (38 carers and 32 PLMI) with control group subjects. Of the 9 intervention subjects we were unable to match, 2 were PLMI removed for inability to complete an interview (incompetency), 2 were PLMI we were unable to find control subjects to match them with, 4 were carers we were unable to find control matches for, and 1 person we withdrew after discovering that she was not a current caregiver (her sibling PLMI had died 5 years earlier).[22]

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[22] We attempted to match all intervention subjects as closely as possible with control subjects. Of the 70 pairs, 54 were matched within the criteria established in the matching protocol. However, an additional 16 were what we called "close matches." Five were PLMI who were matched on gender and illness type but were only closely matched on the age range criteria (off by 1 year, 2 years, 2 years, 4 years, and 5

The control group was drawn from outpatient PLMI and family carers at the national psychiatric hospital in San Salvador, the capital of El Salvador. The population of patients associated with the hospital, according to the director of medical records, is about 70,000 during the last two years. This includes inpatients and outpatients at both the general and psychiatric sections of the hospital. About half of this population (35,000) is seen at the psychiatric section of the hospital.

After failing at obtaining control subjects through a process of reviewing medical records, we began to screen people directly in the outpatient clinic. Over a period of several months we talked to approximately 3000 outpatients and carers. We did a brief screening with about 80 people per day, a more extensive screening with about 10 people who appeared to be potential matches. Of these 10, about 4 turned out to be potential matches we wanted to interview. Of the 4, about 3 were willing to be interviewed, but only 1 or 2 were able to stay and be interviewed after their treatment appointment. Hence, the control group had a 1 in 4 refusal rate, which was high compared to the refusal rate for the intervention group at about 1 in 30.

By the time we finished interviewing (due to time and cost constraints), we were able to match 70 control group subjects to the 79 potential intervention matches available. This included 32 intervention PLMI matched with 32 control PLMI, as well as 38 intervention carers matched with 38 control carers. Total time committed to locating and

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years, respectively). These decisions were made based on how important such age differences might be based on the current age of the two persons in each pair. For example, the older the pair, the less the age difference mattered, and so we permitted a bit more flexibility. Regarding carers, of the 38 matches, 12 were "closely matched." There were more of these close matches in the carer group because there were 6 criteria instead of 3 to match, so matching was more difficult. Most of the close matching was, again, due to greater differences in age of the carer, but there were differences in criteria related to their ill relative as well. For the 12 carers closely matched (that is, slightly mismatched), 7 were (closely) mismatched on only 1 criteria, 3 on 2 criteria, and only 2 on 3 of the 6 criteria.

interviewing participants was 6 months with a team of several people. See Figure 7 for a flow chart description of participant numbers. An additional month was spent doing follow-up to obtain missing data from the first round of interviews.[23] Then a sample of SPSS entries were checked against the paper questionnaires for quality control.[24]

Challenges in obtaining control group participants

After obtaining human subjects protocol approval by the hospital ethics committee and hospital director, we screened control group participants from visitors to the outpatient clinic. The first choice had been to review digital records to randomly select a sample of matched participants. The digital records system, however, was only two years old, included no information related to doctor's notes, included minimal information, and included only half of the Hospital's population who had attended the hospital during the previous two years, approximately 35,000 records. We then spent a month reviewing medical records directly. This turned out to be difficult for several reasons. Half of the records belonged to non-psychiatric patients who attended the part of the hospital that was a general hospital (separate but contiguous to the psychiatric hospital). Many records contained no phone numbers for us to call, and those that did have phone numbers were often outdated, because the hospital updated its demographic information only when a patient was hospitalized. That is, for the many patients who had

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[23] Missing data was, initially, a significant problem, as several interviewers missed collecting small data pieces and one interviewer had to be retrained and had to re-do parts of interviews. However, through re-contacting subjects, we were able to obtain nearly all the missing data. All 149 questionnaires were reviewed in detail by the principal author, and all entries into SPSS were also reviewed for completeness.

[24] I selected a random sample of questionnaires across the timespan of data entries to check for errors in data entry into SPSS. I reviewed 16 questionnaires (11%) and found that 1 entry was a duplicate of another entry, so the questionnaire had to be completely re-entered. As a result, I reviewed all SPSS database entries to ensure there were no more duplicates. Of the remaining 15 questionnaires reviewed, 5 contained no errors and 10 contained from 1 to 6 error items. The average number of item errors in this sample was 1.9 of 428 potential errors per case, or .0045. That is, less than ½ of 1% of potential entries had data entry errors.
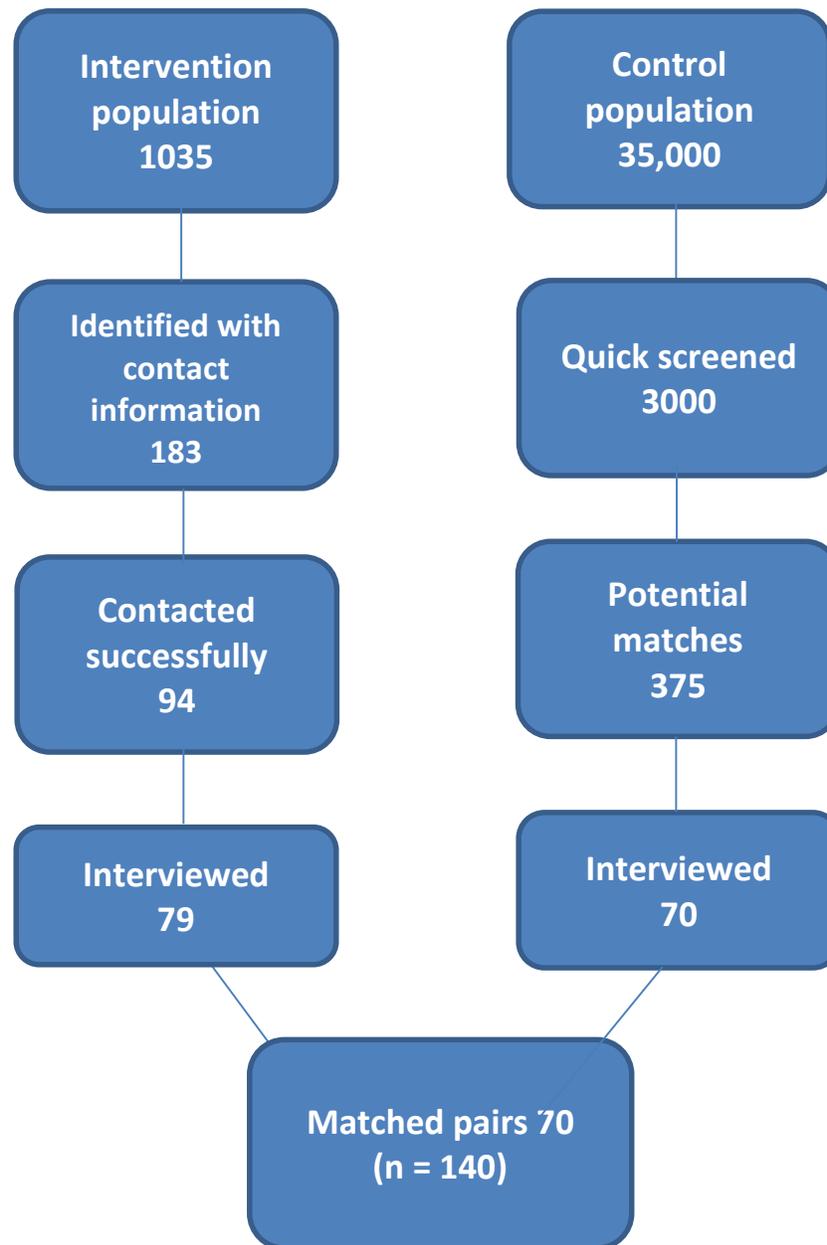
Figure 7. Flow chart of populations, interviews and final matched subjects.

returned for 5 or 10 or 20 years to the outpatient clinic for their meds, their demographic

information had never been updated.

A further difficulty was determining the diagnosis from the hospital's medical records. As might be suspected, the handwriting was often illegible. Diagnoses in psychiatric care begin as tentative, are often revised over time as symptoms become more clear, and are subject to the interpretations of the different psychiatrists. Thus to determine a diagnosis we had to review several sections of each medical record, and usually accepted the most recent diagnosis. Sometimes the diagnosis was not specific, or was listed as Organic Mental Illness (Trastorno Mental Orgánico) but the subdiagnosis (psychosis, depression, etc.) would not be specified. Sometimes we confirmed diagnoses by talking with the attending psychiatrist. Other times the doctors were unavailable and we determined diagnosis by talking with patients and asking detailed questions regarding their knowledge of the diagnosis and history of symptoms. If their interpretation seemed strong and the symptoms clearly coincided with their perceived diagnosis, then we tried to match the person based on their self-reported diagnosis. While not optimal, this is the technique we used with the intervention group as well. Their diagnoses were determined either by self-report or by the professional staff and volunteers who worked with the PLMI and families in the FESEP program.

The process we ended up using for selecting control group participants did not require randomization as it was based simply on matching by criteria (see description below). We would arrive early at the Hospital's outpatient clinic, publicly announce who we were and what we were doing, then ask each person or family criteria questions while they were waiting. This quick screening tool allowed us to talk with 60 to 80 persons per morning in 3 waves of group appointments (7am, 10:30am, and 12:30pm). Anyone who was a potential match was given an explanation of the study, asked further questions to

clarify their eligibility and willingness to participate, and, assuming willingness to participate, asked to do the interview with us. We attempted, and usually achieved, doing the interview right after their medical consultation so we would not lose them. However, after waiting in line for the psychiatric appointment they had to get their prescriptions stamped by the nurses office and then wait in line for up to an hour at the pharmacy, so it typically took 1 to 3 hours before the person was able to come back to us for the interview. If they could not interview the same day, we'd try to set up another time at the hospital. Sometimes I would offer to go to their homes, for example if they wanted to be interviewed but had to return home to care for another person. My assistant, a 25-year old female, did not offer to do interviews in homes. Four of the seven interviewers were young females. Additionally, among some interviewers there was great hesitancy to go to neighborhoods that were considered dangerous. I often went to these neighborhoods, but only after asking the person who lived there if it would be dangerous for me. Typically they said they would meet me at the bus and accompany me to their residence, which worked well as I did about 10 of these home interviews.

Each interview then began with reading the informed consent to more fully explain and answer questions about the study. Upon completion of the interview, $10 were paid to each participant in both the intervention and control groups. Breaks were provided as needed. Carers were encouraged to attend interviews with their PLMI, if the PLMI signed off on giving permission, but were asked to leave during parts of the interview in which the PLMI was asked questions about their relationships with family members. Dominating carers were also asked to leave when they were disruptive to the ability of their PLMI to answer on their own. Generally, for people with higher

educational levels the interviews passed in about an hour, while people without education

and persons with slow cognitive processing abilities could take up to 2.5 hours.

Interviewers were trained to give people the time they needed to answer questions

without prompting.

Matching protocol

For the matching protocol we had hoped to use a propensity score matching

method. However, the program and hospital populations were not large enough. Nor did

the hospital's new system of digital records contain enough information to match all the

needed criteria.[25] We decided to match by hand by looking directly at medical records.

After two months of searching for matches through almost 900 thick files and locating

only 50 files with usable contact information and obtaining only 2 interviews, we

abandoned this method. Problems included the time it took to have staff obtain records

for us, our inability to read the handwriting of doctors for diagnoses, differing diagnoses

over time in different parts of the files, and inability to locate various criteria we needed.

Importantly, files rarely had updated contact information. For example, phone numbers

were often 10 or 20 years old, or simply did not exist in the file.

The matching criteria were selected based on a combination of typical

sociodemographic variables that are known to influence differences in a population

(gender, age, urban vs. rural) and other variables that I selected based on the global

mental health literature, such as type of illness. This information was supplemented

through conversations with two psychiatrists who are familiar with the program (one is a

volunteer in the program, the other is the head of the government's mental health policy

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[25] The hospital system had illness type, name, and gender, but not address, age, or family and contact information.
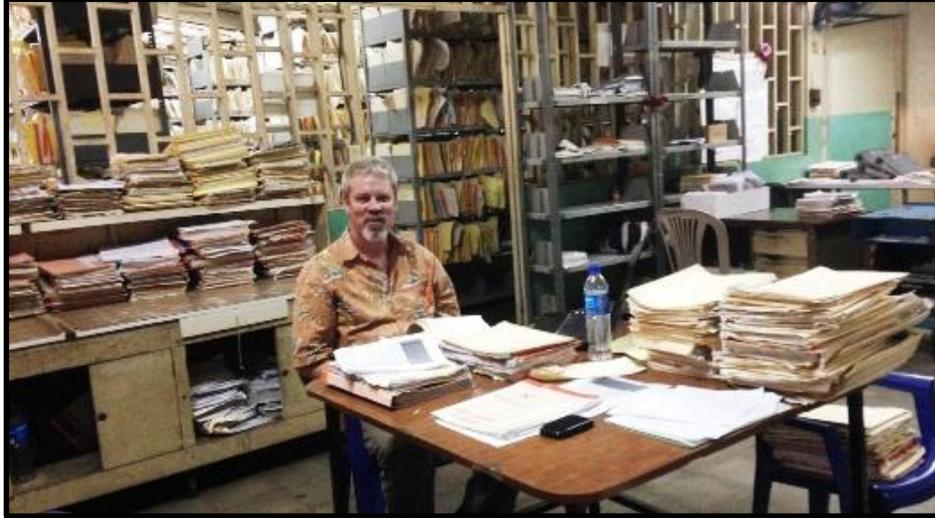
Figure 8. Author in medical files. The author reviewing medical files in the archives storage area of the psychiatric hospital, San Salvador, July 2015. Matching control and intervention subjects with this method was not successful, despite nearly two months of effort.

department). As a result, we determined to try to match on these additional variables: period of time with illness, period of time under treatment (to determine length of time during which the person was not treated) and, for carers, their relation with their PLMI (parent, sibling, adult child, other). However, obtaining information on amount of time with the illness and amount of time under treatment through self-reports proved to be highly unreliable, so these were discarded as matching criteria.

Selection criteria also included exclusion criteria, including issues of competency such as the PLMI not being in crisis or having the capacity to respond logically to questions, and having sufficient memory to answer the full range of sociodemographic questions (see Appendix B for sociodemographic and medical information questions). On the latter we permitted assistance from a caregiver who could be present with the permission of the PLMI.

The above matching process was used for the PLMI matching process. The matching criteria were similar for caregivers: living in urban setting, gender, age range, and relationship to their PLMI (e.g., mother or brother or daughter). There were criteria related to their PLMI as well, such as illness type, gender and age of the PLMI. For details of the matching criteria such as age ranges, see Appendix D.

Variables

Outcomes of interest. Outcome variables included social capital as measured by several subdomains, transformational leadership and leadership development, and empowerment measured by psychological wellbeing and mental health empowerment scales (Table 3). Descriptions follow under the Instruments section of this chapter.

Table 3
Outcomes and Tools

Hypothesis	Outcome of interest	Tool
1,2,3	Leadership	Global Transformational Leadership (GTL)
		Volunteer Leadership Development Instr. (VLDI)
1,2,3	Social capital	World Values Survey
1,2,3	Empowerment	Ryff subscales
		Empowerment Scale for PLMI (BUES)
		Family Empowerment Scale, and certain questions from other scales[26]
4	Relationships between variables and confounders	Statistical analysis using correlation matrix

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[26] The dissertation and the human subjects protocol were different for this study. The dissertation focused on scales related to leadership, empowerment, and social capital, while the protocol included a number of other instruments. We collected data using these other instruments as well, but do not report their findings in this study, unless certain of the questions pertain to a construct of interest in the dissertation.

Moderating/mediating variables. These include level of family support, type of illness, and participation variables. We collected data on the participation variables, which include duration (years/months), intensity (number of program components in which the person has participated), and frequency (number of meetings/events attended during the year of highest intensity of participation), which are explored in a correlation matrix with the outcome variables.

Confounding variables. These are either controlled as covariates or through the matching process to reduce bias. Confounding variables controlled through the matching process included:

- gender (exact match)
- age (match within pre-determined range)
- type of illness (exact match by illness categories of ICD-10)
- relationship with loved one (PLMI) of carer
- geography (exact match: living in urban areas, defined as cities of greater than 30,000 in population)
- location of treatment (exact match: all having received inpatient treatment in a psychiatric hospital or psychiatric unit in El Salvador)

Additional confounders, which I explored through a simple process to determine such variables,[27] included: level of education, family income, occupation, whether there was more than 1 adult caregiver, marital status, whether the person lived with others, family size, and whether the caregiver also had a mental condition. As covariates were

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[27] Field (2009) recommends first identifying potential confounding variables, and once known to have an influence on the outcome variable, then to include them as a covariate. One simple way is to compare the estimated measure of association before and after adjusting for confounding. If the difference is less than 10%, then there is little to no confounding. Magnitude can be determined thus: (RR_{crude} - $RR_{adjusted}$) / $RR_{crude.}$ (Boston University School of Public Health, n.d.).

identified for PLMI, carers, and the full groups, I selected the strongest 2 or 3 to use in

the ANCOVA for each outcome measure.[28]

I also explored other areas to understand the impact of other potential influences

and whether we should include them as matching criteria, especially to eliminate them as

bias factors. With university advisors, psychiatrists, and the research team, discussions

focused on: hospital policies for making referrals to the intervention program (Are only

the healthiest or most needy families referred?); ACISAM acceptance policies/practices

(Does ACISAM only accept certain functioning levels that might exclude many people

from the Hospital?); participants' self-selection thinking/processes (Why did they enter

the program and does that make them different than the Hospital population?); number of

adult caregivers in the household (Does it make a difference to the outcomes whether

there is only one or multiple caregivers to share the caregiver burden and generate family

income?); and treatment characteristics such as length of time with illness and number of

years without treatment before treatment was begun. Most of these were determined not

to be influential, or difficult to obtain as accurate information, with the possible exception

of the last one—number of caregivers, which has an influence on sharing caregiving

burden and providing financially for the family.

The map below (Figure 9) indicates that the intervention leads to positive

outcomes in empowerment, social capital and leadership, that these are moderated by

influences such as level of participation (and family support for the PLMI), and that

empowerment, social capital and leadership are correlated (build upon one another in a

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[28] Eleven potential covariates were run at the group, PLMI/carer levels (2) for 17 outcomes totaled 374 ANCOVAs to tease out the right confounders for each outcome. Then the top confounders were chosen up to 2 or 3 so as not to overcome the rule of thumb on ratio of variables to sample size (1 to 10). I was then able to run the final 17 ANCOVAs.

positive loop). Leadership and social capital strengthen one another and take longer to develop so are shown last. Empowerment is a necessary antecedent for most people with strong leadership and social capital.
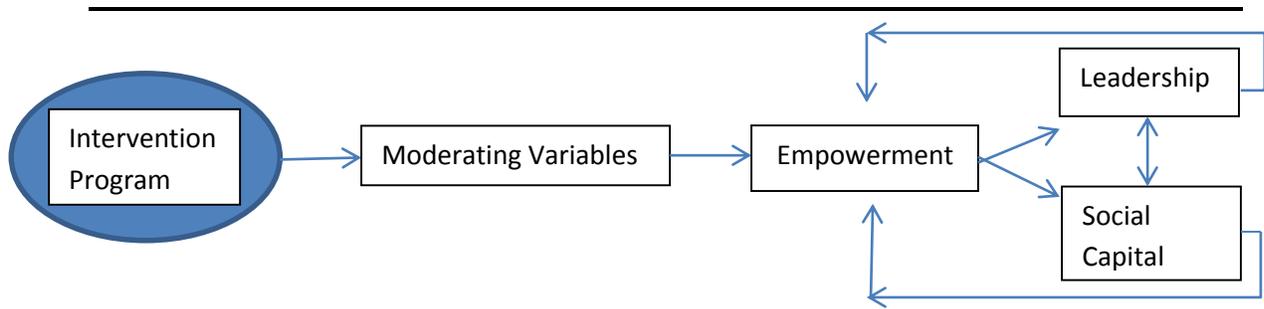
Figure 9. Variables and directional/causal influences.

Instruments

　　Measuring leadership: GTL. While the most broadly used leadership instrument is the Multifactor Leadership Questionnaire (MLQ), I did not feel it was useful in our situation for its length, uncertain application to grassroots association leaders, lack of focus on participatory leadership development, and educational level required (minimum 9th grade reading level). However, characteristics of transformational leadership such as ability to vision, motivate, and care for followers are key benefits to grassroots associations and nonprofit leaders in general, so I opted for a 7-item tool called the Global Transformation Leadership (GTL) scale. It has been used in a small number of studies and shown strong reliability and validity (see below for details). We translated it through a back-translation process to ensure quality and used cognitive interviews to

improve comprehension and clarity.[29] While the scale only focuses on transformational leadership, to the exclusion of the other parts of Bass's scale (transactional and laissez-faire styles), I reasoned that as a continuous scale with transformational style "on top," and with our interest being only in the transformational end, then just measuring that construct would accomplish the study's goal. The original scale was rater-focused, so was adjusted for self-assessment, which seemed justified since other important instruments such as the Multifactor Leadership Questionnaire also come in self-assessment versions.

The GTL was developed by Carless, Wearing, and Mann (2000) as a parsimonious way to measure transformational leadership. They base their 7 items on a review of the literature, identifying 7 behaviors that encompass transformational leadership style, and used the Leadership Practices Inventory (LPI) and MLQ scales for validity analysis. The study was of managers in an Australian international banking firm, with 695 managers rated by 1440 subordinates and 66 supervisors (n=1506). Principal components factor analysis demonstrated a single underlying factor, the eigenvalue of 5.0 explained 71% of variance, and factor loadings were between .78 and .88. As an alternative, they ran chi-square goodness-of-fit RMSEA, RMSR, and RNI tests, all of which demonstrated good fit between the observed variance-covariance matrix and the tested model. They also ran an Amount of Variance Extracted (AVE) test, which came back at .93. All together these tests demonstrated strong evidence that the 7-item GTL is highly reliable. Additionally, the Cronbach alpha was .93.

The authors demonstrated convergent validity by comparing the GTL with the MLQ and PLI, arriving at correlations between .76 and .88. Discriminant validity was

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[29] A cognitive interview is a set of techniques for questionnaire development, such as "think aloud" and "verbal probing," to ascertain whether the test taker is comprehending correctly the intent of the questions (Willis, 1999; Crocker & Algina, 1986).

demonstrated by comparing groups of managers who would be expected to have different GTL score on high and low subordinate extra effort, high and weak performing managers, and more effective versus less effective managers. T-tests showed the GTL discriminates significantly between all contrasting groups. Appendix C contains the questions and additional information on the instrument.

The scale was back-translated for use in Spanish. I also expanded the introduction to focus not just on leaders, but on each person as a "leader or member of a community group."

Measuring leadership: VLDI. After an extensive search for a scale directly used with voluntary leaders, I found only one scale usable in our context – the Volunteer Leader Development Instrument (VLDI), an 20-item scale used in just one study to determine if leaders had developed knowledge and skills that community-based voluntary leaders should find beneficial. No other studies have validated the instrument, but it functioned reasonably well in the seminal study. We adapted and translated it and ran it through a cognitive interview.

The VLDI was developed by Meier, Singletary, and Hill (2012) as a both way to determine what the volunteer leaders learned in the program and as a means to developing useful items for measuring volunteer leadership development. Questions are based on literature related to leadership skills, especially for volunteers, and focus on learned leadership skills.[30] Each question begins with "As a result of volunteering with this community development program, I learned..." We adapted this to read "When I

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[30] Skills covered include communication, social interaction, how to work with others, conflict management, goal setting, personal time management, how to run effective meetings, market and evaluate a program, acquire program support, and how volunteerism helped strengthen leadership skills that were helpful at home, school or at work.

participate in an organization or community group, I…" in order to allow non-participant

subjects to respond equally to leadership skills/behavior questions. We also consolidated

two questions and dropped one that was not appropriate to a general questionnaire,

ending up with 18 items. We translated it with a back-translation process in the

Salvadoran context. Appendix C contains the questions and additional information on the

instrument.

The questionnaire was reviewed by a panel of experts for content validity,

question clarity, and comprehension. The Cronbach internal consistency alpha was high

(r=.943). The authors note that volunteers achieved knowledge gains with respect to "the

majority" of leadership items. In fact, all 20 items show above-neutral means. This

coupled with such a high Cronbach alpha may indicate that items are too highly

correlated, or that negative and contrasting items are needed.

Measuring empowerment: PLMI empowerment scale (BUES). My search for

instruments to measure empowerment in members of grassroots organizations turned up

only one instrument but it carried very little reliability or validity testing data. I located

two sources listing empowerment scales for PLMI (U.S. DHHS, 1999) and family

caregivers (Dixon et al., 2011). The instruments were in English and developed and used

in a high income country (the U.S.) but seemed to be appropriate if adapted to the

Salvadoran context.

The PLMI instrument is known as the Boston University Empowerment Scale

(BUES). It was developed by Rogers, Chamberlin, Ellison, and Crean (1997)[31] with

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[31] Their study, entitled "A consumer-constructed scale to measure empowerment among users of mental health services," was developed by a group of consumers with consultant-researchers. After testing a 28-item scale on members of six self-help programs in six states, factor analysis revealed the underlying dimensions of empowerment to be (1) self-efficacy-self-esteem; (2) power-powerless-ness ; (3)

strong input from users of mental health services, has strong reliability and validity, and

has been used in a number of studies. It is very appropriate for our PLMI population in

this study and required minimal adaptation. It required translation and thus cognitive

review, which we completed. We reduced the length from 28 to 14 items by choosing up

to 4 items from each factor that loaded at greater than .60 and that did not load on other

factors (see Appendix C for the factor analysis). The final item turned out to be

ambiguous with our subjects, so we calculated scores and statistics using only the first 13

items, which align with the following factors: self-esteem and self-efficacy (4 items),

power and powerlessness (4 items), community activism and autonomy (3 items), and

optimism and control over the future (2 items).

The 28-item scale has a Cronbach alpha of .86 (n=261). Principal component

factor analysis revealed 5 factors accounting for 54% of variance: self esteem—self

efficacy, power—powerlessness, community activism and autonomy, optimism and

control over the future, and righteous anger.

Rogers, Chamberlin, Ellison, and Crean (1997) performed several tests for

construct validity. Correlations came back with mixed results for their hypotheses. No

significant relationship was found between empowerment and self-help participation

(number of hours/week or total number of years of involvement in SHGs) as they had

hypothesized. T-tests revealed no significant difference between empowerment score and

demographics such as gender, race, marital status, educational level, or number of

previous psychiatric hospitalizations. Small but significant differences were found

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community activism; (4) righteous anger; and (5) optimism-control over the future. The effort for
developing outcome measures from the perspective of PLMI continues in recent years (Rose, Evans,
Sweeney, & Wiles, 2011; Nickels et al., 2016).

between empowerment and number of community activities engaged in (writing a letter to a government official, voting) (r=.15) and use of traditional mental health services (r= -.14), although the authors were uncertain why this relationship was negative. Occupation and productivity (regular work, sheltered work, volunteer work, no work at all, and other categories) showed no significant relationship to empowerment. There were significant relationships found with quality of life (r=.36), social support (r=.17), self-esteem (r=.51), and satisfaction with their self-help program (r=.28).

Two step-wise multiple regressions were done to determine the best predictors for empowerment. Of age, gender, education, ethnicity, age at first psychiatric contact, work status, housing status, marital status, total monthly income, and total number of lifetime psychiatric hospitalizations, only income was significant (r^2 = .048, or 5% of variance). The other regression looked at quality of life, number of community activities engaged in, satisfaction with self-help program, number of traditional mental health services received, and social support. They found the most useful predictors showing 22% of variance were quality of life, use of traditional services, number of community activities engaged in, and life satisfaction. Interestingly, income (only significant item from the first regression) lost its predictive power when combined with quality of life and satisfaction, which would indicate that income plays a mediating role for empowerment by increasing quality of life/life satisfaction.

They ran two more studies to discriminate the instrument with self-help program participants from two other groups – inpatients at a psychiatric hospital and college students. The former mean was about 2 standard deviations below the study mean, while

the latter group was about 2 standard deviations above the study mean, showing adequate

discrimination for those in mental health self-help programs.

Rogers et al. (1997) conclude that empowerment is difficult to understand. They

adopt a tripod metaphor as a framework. One leg is self-esteem, self-efficacy, optimism,

and control over the future, which can be thought of as sense of self worth and ability to

have some control over one's future. This component of empowerment was one of

strongest and most consistent factors in the factor analyses and partly equivalent to the

concept of internal locus of control and other concepts of self-efficacy and mastery.

The second leg of their tripod framework is actual power, which was also

consistent among factors. Righteous anger and community activism constitute the third

leg of the tripod and represent the sociopolitical component of empowerment.

I see this tripod framework and the authors' conclusions reflected in the women's

empowerment concepts of voice (self-confidence) and agency (ability to exercise power).

I also see it consistent with the Petesch, Smulovitz, and Walton (2005) framework for

understanding organizational empowerment, discussed in the literature review above,

with its focus on the agency of groups and the opportunity structure (the socio-political

context within which those groups function), which in turn provide opportunities for

impacting policy and services (behaviors of community activism).

Finally, Rogers et al. (1997) note their study could be strengthened by further

studies demonstrating test-retest reliability/stability and by administering the scale with

other instruments to show convergent/divergent validity. Appendix C contains the

questions and additional information on the instrument.

Measuring empowerment: Family Empowerment Scale (FES). The FES is a very good instrument for our family population that covers empowerment from the knowledge, attitude and behavior angles while simultaneously looking at the individual, family, and community social levels. The 34-item scale was developed by Koren, DeChillo, and Friesen (1992) as a questionnaire for assessing empowerment in families whose children have emotional disabilities. The questionnaire is based on a two-dimensional conceptual framework of empowerment derived from the literature—a dimension reflecting empowerment with respect to the family, service system, and larger community and political environment, and a dimension of expression of empowerment as attitudes, knowledge, and behaviors.

The authors developed items with standard techniques, then piloted the questionnaire on a sample of 96 family caregivers. Because the literature emphasizes distinctions among personal, interpersonal, and political levels of empowerment, the scoring strategy reflects the categories of the Level Dimension, i.e., Family, Service System, and Community/Political. Scoring is accomplished by summing responses from items within the Family (12 items), Service System (12 items), and Community/Political (10 items) categories to yield three subscores N=441 parents from many states across the U.S.

Tests were run on two groups (test and retest). Cronbach alphas on subscores ranged from .87 to .88 on the test group and .77 to .85 on the retest group. A kappa was calculated for inter-rater reliability at .77, which is above the .75 standard for substantial agreement among raters. Factor analysis showed 4 factors that fit well within the 3-dimension framework the authors had proposed, with loadings ranging from .40 to .70.

The authors used a MANOVA to run subscores against a checklist of activities, all of which came back significantly discriminating parents in each activity by subgroup score.

The authors conclude with several observations. While some authors theorize parents first focus on immediate family concerns of their child's development and behavior, then turn their attention to securing information and services they need, then finally engage in individual or collective action to assist other families and address the needs of all children, the authors note "anecdotal evidence suggests that for some family members, difficulty in obtaining appropriate services for their children is a galvanizing experience leading to involvement in the community/ political arena" (Koren, DeChillo, & Friesen, 1992, 318). They also recommend future research may focus on the degree to which each of the three levels (Family, Service System, and Community/Political) is differentially responsive to targeted interventions, and further exploration of the means by which parents gain empowerment, and the various paths through which their empowerment may be pursued and developed.

We had to adapt the instrument to our specific population because it was written for a population of parents of minor children, while almost all of our subjects were caregivers of adult PLMI (issue of parental rights for adult children versus minor children). There were a few questions that did not make sense in the Salvadoran cultural context. For example, the question "When necessary, I take the initiative in looking for services for my loved one and family." But in El Salvador there are no community services, there is only the national public psychiatric hospital and the social security hospital psychiatric unit. That is, there are no choices, so even if a person was motivated or empowered to look for services, it is not an option. We cut the question. Eventually we

reduced the scale slightly from 34 to 30 questions and then took it through the three-step back-translation process.[32] Appendix C contains the questions and additional information on the instrument.

Measuring empowerment: Ryff Psychological Wellbeing Inventory (Ryff). In addition to the specific instruments for sub-populations noted above (one for PLMI and one for carers), we used the Ryff Psychological Wellbeing Inventory as a general empowerment measure for everyone. The Ryff scale is a more generic measure on wellbeing but has been used numerous studies, including for empowerment (Shankar et al., n.d.). The subdomains cover areas related to psychological empowerment as well. We were able to find a shortened version in Spanish that was validated several times (Díaz et al., 2006; Dierendonck et al., 2008; Rodríguez-Carvajal et al., 2010). These studies confirm an underlying 6-domain structure to the Ryff scale, with good internal reliabilities for the 29-item version with Cronbach's ranging from .70 to .84. I selected subscales for use in this study, based on 1) their use in the Shankar et al. (n.d.) empowerment study in Kenya that demonstrated significance on these subscales in a randomized controlled study, and 2) based on the context of our program in El Salvador. I ended up with 14 items in the following three subscales: positive relations, life meaning, and personal growth. Appendix C contains the questions and additional information on the instrument.

Measuring social capital: the World Values Survey. Social capital is a construct that can be measured in different ways at the micro, mezzo and macro levels. National level organizational level measures are not included in this study. I used

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[32] I plan on doing a follow-up paper that will focus on the scales we translated, adapted, or created for the grassroots and nonprofit LMIC target population of our study. I hope they may be helpful to others needing such instruments.

questions from a well established instrument, the World Values Survey (see Appendix C for the questions we selected). The World Values Survey (WVS) was developed in 1981 and has been used in almost 100 countries covering 90% of the world's population (World Values Survey, 2016). The indicators are consistent so that cross-national comparisons can be made. As in this study, internal (within-country) comparisons can also be made between groups on the principal domains. I chose questions that related to civic participation (number of civil society groups in which the person has participated, and frequency of religious participation), trust (of people in general, of family and neighbors and other groups) and effectiveness (of different mental health service providers), having a sense of meaning in life, level of connectedness to others (on a community, national and global scale), participation in voting (frequency as a measure of civic duty), and quantity and frequency of consumption of news sources, which is another measure of civic engagement.

The WVS contains over 250 questions, far too many to be added to other instruments and asked to a vulnerable population. I selected 35 questions that took less than 10 minutes to ask. Three questions were later discarded as not being closely related to the concepts of interest. The remaining questions I grouped into the following areas of interest related to social capital: trust (8 questions), civic engagement (11), identity (3), political participation (2), and information/news (8).

Kocer (n.d.) reviewed four waves of WVS data and determined that the various questions related to social capital concepts of trust, confidence in institutions, political engagement, participation in networks, and civil morality could not be combined into a single index to use across all countries. Kocer's alternative suggestion was to use

generalized trust because it is correlated with all other trust measures, used most

commonly across all waves of surveys, and is the most crucial element of social capital

literature. The social capital items measure internal and external social trust, network

memberships, identity, political participation via voting and consumption of news

sources, and generalized trust. Social capital measures have been shown to run up against

barriers in LMIC countries due to the inability of people to obtain social capital when

they are dealing with obstacles such as ethnic or caste differences, or high levels of

poverty in their society (Bird, Hulme, Moore, & Shepherd, n.d.; Delany-Brumsey, 2012;

Mays & Cochran, 2014; World Bank, 2000). For example, Godquin and Quisumbing

(2006) in a study on Philippine villages find that asset-rich and better-educated

households are more likely to participate in groups and to have larger social and

economic assistance networks, which may reflect higher returns to social capital for the

wealthy, or greater barriers to participation for the poor. Internal conflict, a large issue in

El Salvador due to its history of civil was in the 1980's and gang violence in recent years,

is also a barrier to social capital (Moser & Holland, 1997). As Colletta and Cullen (2000)

note: "Unlike interstate conflict, which often mobilizes national unity [against the outside

enemy…], violent conflict within a state weakens its social fabric. It divides the

population by undermining interpersonal and communal trust" (3). As a result of the

cultural contexts so different in LMICs, I added a second generalized trust question on a

larger scale (four responses instead of two) to try to tease out a more nuanced response

from my Salvadoran study participants, which the results showed to be a useful

addition.[33]

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[33] Nor is social capital always a positive factor. Dinesen et al. (2013) find in a multivariate analysis
(n=1300) that 1) structural social capital (participation in social networks and civil society) was a risk factor

The World Bank discusses social capital in depth and notes that social capital's

multiple dimensions are quite different concepts (groups and networks, trust, collective

action, social inclusion, and information and communication) and it is unlikely to be

productive to create a single index (World Bank, 2011). However, at the single-country

level, the World Bank also cites studies that created single indices (for example, Temple

and Johnson, 1998). As a result, I decided to experiment by creating a single index of

social capital constructed from the dimensions measured to test it as a more

comprehensive measurement tool.

Statistical procedures

I ran descriptive statistics on our sample (n=142) followed by analyses of

covariance on the first three hypotheses. For these analyses the independent variable was

group (intervention versus control). The ANCOVAs were run individually on outcome

variables that represented one of the constructs. I ran two for leadership, three for

empowerment, and several on subdomains of social capital. Covariates are detailed in the

results section. I also ran various analyses to compare our adapted instruments to the

originals, such as a rank order of the means of items on the VLDI instrument and a

Spearman rank order correlation to determine the strength of the relationships among the

items. Finally, for hypothesis four I ran a correlation matrix of the construct (outcome)

measures with moderating variables to determine strength of relationships.

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for violence, and 2) cognitive social capital (measured as trust, norms, and sense of belonging) was a
protective factor for violence. They conclude that the opposite direction of the association between
violence and structural and violence and cognitive social capital challenges the use of social capital as a
unified concept. Hansen-Nord et al. (2014) arrive at the same findings in Honduras (n=1000) and conclude
that cooperative action rather than social organization reduces violence.

Issues related to the use of instruments

  Translations. Where possible we obtained instruments already translated into and validated in Spanish. When necessary, we translated the instruments.[34] This process included cultural, age, and population adaptations, followed by a first draft translation by a team that included at least one Salvadoran and one American. Then we used a back-translation process by a native English speaker who had 15 years of experience living and working in El Salvador but no connection to our work or the instruments. The back-translation was then compared with the original English for alignment. Final adjustments were then made.

  Cognitive interviews, piloting and fatigue. Cognitive interviews were done on new instruments and new translations with three persons, and then piloted as part of a complete interview process with two program participants (one PLMI and one Carer). A significant concern was potential interviewee fatigue due to length of the interviews. However, because we provided breaks as needed and because almost all subjects had a high level of interest in the interview purpose and questions, fatigue turned out not to be a problem. The majority of interviews were completed under two hours, including most PLMI, although it ranged from 1 to 3 hours (this included the time for the informed consent process).

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[34] Of the full battery of instruments we translated the Global Transformational Leadership, Volunteer Leader Development Instrument, Expressed Emotion, Boston University Empowerment Scale, Internalized Stigma of Mental Illness, and Social Contacts, and Knowledge instruments. We were able to find validated translations into Spanish of the Ryff, World Values Survey, General Health Questionnaire, WHOQOL-BREF quality of life, Family Coping, Zarit Family Burden, and WHODAS disability functioning instruments. The Mental Health Well-Being instrument was developed in Spanish but not validated.

Reporting procedures

The audiences potentially interested in the findings include: the JMU School of Strategic Leadership Studies (SSLS) doctoral faculty and dissertation committee, the directors and staff of the partner agencies (ACISAM and Hospital), the Mental Health Unit of the Salvadoran Ministry of Health, program participants in El Salvador (the two grassroots associations), leaders in the Pan American Health Organization, program funders, and leaders and researchers in the global mental health movement, as well as conference attendees, and peer journal readers. The results will be presented as a dissertation study, in papers for publication in peer review journals and at conferences, and in summary form for people in El Salvador. For any quotes that may appear from subjects, pseudonyms will be used.

Institutional review board (IRB) protocol

For information related to data safety, exposure assessment, risks and benefits for subjects, and other safety and ethics procedures, the Institutional Review Board protocol is available upon request: James Madison University IRB protocol # 15-0463, and/or the Spanish version submitted to and approved by the Hospital's director and research committee chair. The consent form appears in Appendix A.

Parties involved in the study

Sam Nickels was principal investigator and doctoral candidate. He was responsible for all facets of the study. He designed the study; managed IRB protocols in both countries; selected and obtained instruments; oversaw the adaptation, translation, cognitive review, and piloting processes; hired, trained and monitored interviewers; performed many of the interviews of subjects (42%); reviewed questionnaires and SPSS

data entry to ensure quality control; performed the data analysis; wrote all chapters of the dissertation; and obtained funding and oversaw management of finances.

Dr. Margaret Sloan, Associate Professor of Strategic Leadership Studies and Advisor to the Nonprofit and Community Leadership Concentration, acted as dissertation advisor and committee chair. Dr. Robin Anderson, Department Head and Professor, Department of Graduate Psychology, James Madison University, and Dr. Karen Ford, Director and Professor of Strategic Leadership Studies, James Madison University, were members of the committee.

Lic. Nelson Flamenco, ACISAM Director of Mental Health Programs, and Dr. Myrna, volunteer psychiatrist with ACISAM Mental Health Programs, helped with identifying personnel, oversaw hired staff from ACISAM's institutional base, evaluated or provided information on PLMI evaluation, reviewed instruments as experts, served as general advisors, and helped with important logistics related to the study's success.

Licda. Mariely Campos Tomasino acted as research assistant and completed 26% of the interviews, managed funds, found instruments validated in Spanish, served on the team that translated instruments, entered data, maintained tracking documents, tracked down missing data, and helped perform data analysis.

Dr. Melvin Gómez, Director, Hospital Nacional General y de Psiquiatría "Dr. Jose Molina Martinez," (also known as the National Psychiatric Hospital) approved the IRB and helped with facilitating our work in the hospital. Dr. Karina Juarez Cañas, Subdirector Médico, Hospital Nacional General y de Psiquiatría "Dr. Jose Molina Martinez," introduced us to staff at the hospital and approved all logistics to make it possible for us to carry out the screening and interviews for the study on hospital

grounds. Dr. Dina Ileana Callejas, Jefa del Comité de Ética, Hospital Nacional General y de Psiquiatría "Dr. Jose Molina Martinez," reviewed and approved the IRB and addendums on behalf of the hospital.

Lic. Rafael Paz Narvaez at the University of El Salvador and Dr. Ricardo Gutierrez at the University of Technology acted as advisors on design, cultural, and research issues.

Four University of El Salvador social work and psychology students and one ACISAM intern completed their practicums in part by joining our team as interviewers, together completing the remaining interviews (32%). All persons who had contact with human subjects or their personal data in this study obtained human subjects research certification via online certification processes either at James Madison University or the Spanish version online at the U.S. National Institutes of Health.

CHAPTER 4: RESULTS

This chapter presents the results of statistical analyses and post hoc analyses to determine if a civil society grassroots association program (intervention) was linked to increased leadership, empowerment, and social capital outcomes compared to a control group. At the end of the chapter I discuss whether the findings confirm or refute my hypotheses.

Descriptive data and findings

There were 93 women (66.4%) and 47 men (33.6) in the total sample. Breakdown by family and PLMI shows that this is due to women being the prevalent carers in families: family carers consisted of 65 women (85.5%) and only 11 men (14.5%). Men outnumbered women PLMI but only by a small amount: 36 men (56%) and 28 women (44%) (Table 4).

Like gender, age was a matching criterion between the intervention and control groups. As a result, little difference was observed in the means, standard deviations (SDs) and ranges (Table 4).

Marital status found the largest overall number to be un-married (54, 38.6%) while married and living together ("acompañado/a") combined accounted for another 35.7% (50). The largest difference between groups was in the never married category, where intervention subjects outnumbered control subjects for both carers and PLMI: 21.1% vs. 10.5% for carers, and 75% vs. 56.3% for PLMI (Table 4).

Illness type was a matching criteria, but differed significantly among diagnoses: schizophrenia 104 (74.3%), depression and anxiety 17 (12.1%), bipolar 14 (10.0%), epilepsy 3 (2.1%), and other/undiagnosed 2 (1.4%). A few differences existed between

groups because of flexibility I provided due to diagnosis uncertainties (discussed under

Methods). For example, among the PLMI, control had more schizophrenia (23 vs. 20, or

71.9% vs. 62.5%) while intervention had more bipolar (7 vs. 5, or 21.9% vs. 15.6%)

(Table 3).

Education level demonstrated some large differences, particularly between

intervention and control groups. The control group had 4 persons with no education or

just a literacy class (5.7%) while the intervention group had none in these categories.

Intervention had 20 college graduates (28.6%) while control had only 5 (7.1). Differences

were more prevalent between family carers than between PLMI (Table 4).

Occupation also showed some differences. Almost 50% of intervention group was

employed in some way while only 40% of the control group was working. However, the

control group was much higher on household work (26 vs. 8, or 37.1% vs. 11.4%).

However, upon breakdown we see that employment is the same among PLMI (12, or

37.5 among both groups), while "unemployed due to mental health" is higher in the

intervention group (10 vs. 4, or 31.3% vs. 12.5), which is balanced among PLMI in the

control group being much higher on household work (Table 4). While occupation was

sometimes used as a covariate in this study's analyses, I wonder if it really captured the

qualitative differences that these descriptives reflect: that among PLMI in the

intervention group many were so constrained by their illness that they could not work.

Income differences were very significant (Table 4). Here I analyze two income

descriptives. First is income of the PLMI in the family. Overall mean PLMI income was

$78.25 during the last 30 days, with SD 547.388 and range $0-$1000. Broken down by

group, intervention PLMI income is three times greater than control PLMI income:

$119.49 (SD=225.913, range $0-$1000) vs. $37.60 (SD=104.179, range $0-$550).

Despite a higher unemployment rate due to illness, those who were working in the PLMI

intervention group still had far higher average income than the control group PLMI.

Total family income was also very different (Table 4 below). While the overall

mean was $566.83 (SD=547.388, range $0-$3000), breakdown showed that family carer

total income in the intervention group was $730.71 (SD=622.814, range $50-$3000)

compared to control group of $413.79 (SD=499.608, range $0-$2300), a 56.6%

difference. Not surprisingly, using either PLMI income or total family income was the

most commonly identified covariate in my analyses below. Why were these income

differences so large? While the control group was drawn from the national psychiatric

hospital, which is a public hospital and caters to people with less money or access to

insurance, the intervention group included a subgroup (ASFAE) that tends to have higher

incomes, have insurance, and receive treatment at the social security hospital, which has

more health personnel. Future studies need to better control for subjects from different

types of hospitals and those with insurance and higher incomes, since not all these

differences were captured in this study's matching process.

To confirm the above observations, I ran a MANCOVA with the

sociodemographic matching variables as outcomes and group as the independent variable

to see if there were any significant differences between the intervention and control

groups on these variables. Based on my matching process, I had hypothesized that there

would not be differences. Using income and education as covariates, the MANCOVA

demonstrated that all other covariates were highly non-significant (.442 to .953) except

age, which was also non-significant but at a lower level (.101), which is not surprising

since age was matched not on an exact criteria but on age ranges.

Table 4
Descriptive statistics

	Total		Intervention		Control		Intervention family caregiver		Control family caregiver		Intervention PLMI		Control PLMI	
Gender	93 (F)	47 (M)	47 (F)	23 (M)	46 (F)	24 (M)	33 (F)	5 (M)	32 (F)	6 (M)	14 (F)	18 (M)	14 (F)	18 (M)
Percentage	66.4%	33.6%	67.1%	32.9%	65.7%	34.3%	86.8%	13.2%	84.2%	15.8%	43.8%	56.3%	43.8%	56.3%
Age														
Mean	49		49.31		48.69		56.56		54.11		40.70		42.24	
SD	14.27		14.71		13.93		13.48		13.04		11.12		12.26	
Range	22-81		22-81		23-78		29-81		23-77		22-61		23-78	
Marital status														
Never mar.	54	38.6%					8	21.1%	4	10.5%	24	75.0%	18	56.3%
Married	37	26.4%					15	39.5%	16	42.1%	2	6.3%	4	12.5%
Accompanied	13	9.3%					4	10.5%	4	10.5%	1	3.1%	4	12.5%
Widow/er	14	10.0%					5	13.2%	8	21.1%	1	3.1%	0	0%
Divor/Separ.	22	15.7%					6	15.8%	6	15.8%	4	12.5%	6	18.8%
Type of illness														
Depression	15	10.7%	7	10.0%	8	11.4%	3	7.9%	4	10.5%	4	12.5%	4	12.5%
Schizophrenia	104	74.3%	51	72.9%	53	75.7%	31	81.6%	30	78.9%	20	62.5%	23	71.9%
Anxiety	2	1.4%	1	1.4%	1	1.4%	0	0%	1	2.6%	1	3.1%	0	0%
Bipolar	14	10.0%	9	12.9%	5	7.1%	2	5.3%	0	0%	7	21.9%	5	15.6%
Epilepsy	3	2.1%	1	1.4%	2	2.9%	1	2.6%	2	5.3%	0	0%	0	0%
Other	2	1.4%	1	1.4%	1	1.4%	1	2.6%	1	2.6%	0	0%	0	0%
Education														
Non school	3	2.1%	0	0%	3	4.3%	0	0%	2	5.3%	0	0%	1	3.1%
Literate	1	0.7%	0	0%	1	1.4%	0	0%	1	2.6%	0	0%	0	0%
Grades 1-3	8	5.7%	3	4.3%	5	7.1%	2	5.3%	3	7.9%	1	3.1%	2	6.3%
Grades 4-6	13	9.3%	6	8.6%	7	10.0%	6	15.8%	7	18.4%	0	0%	0	0%
Grades 7-9	30	21.4%	9	12.9%	21	30.0%	3	7.9%	10	26.3%	6	18.8%	11	34.4%
High school	34	24.3%	17	24.3%	17	24.3%	5	13.2%	8	21.1%	12	37.5%	9	28.1%
Technical	7	5.0%	4	5.7%	3	4.3%	3	7.9%	2	5.3%	1	3.1%	1	3.1%
Univ. incom.	18	12.9%	10	14.3%	8	11.4%	3	7.9%	2	5.3%	9	21.9%	6	18.8%
Univ. com.	25	17.9%	20	28.6%	5	7.1%	15	39.5%	3	7.9%	5	15.6%	2	6.3%
Postgraduate	1	0.7%	1	1.4%	0	0%	1	2.6%	0	0%	0	0%	0	0%
Occupation														
Work	63	45.0%	35	49.8%	28	40.0%	23	60.5%	16	42.1%	12	37.6%	12	37.5%
Volunteer	2	1.4%	1	1.4%	1	1.4%	1	2.6%	0	0%	0	0%	1	3.1%
Student	7	5.0%	5	7.1%	2	2.9%	1	2.6%	1	2.6%	4	12.5%	1	3.1%
Home	34	24.3%	8	11.4%	26	37.1%	6	15.8%	15	39.5%	2	6.3%	11	34.4%
Retired	8	5.7%	5	7.1%	3	4.3%	5	13.2%	3	7.9%	0	0%	0	0%
Unemployed mental ill.	14	10.0%	10	14.3%	4	5.7%	0	0%	0	0%	10	31.3%	4	12.5%
Unemployed other	12	8.6%	6	8.6%	6	8.6%	2	5.3%	3	7.9%	4	12.5%	3	9.4%
Income users														
Mean	$78.25										$119.49		$37.60	
SD	$179.622										225.913		104.179	
Range	$0-$1000										$0-$1000		$0-$550	
Income total														
Mean	$566.83		$716.18		$419.61		$730.71		$413.79		$698.39		$426.53	
SD	547.388		641.487		386.565		622.814		499.608		673.606		302.068	
Range	$0-$3000		$0-$3000		$0-$2300		$50-$3000		$0-$2300		$0-2600		$0-1100	

Data challenges: statistical assumptions, distributions, missing data, deviations from matching process, and deleted cases

Challenges in the matching process were addressed in detail in footnote 22 on page 89 of the Methods chapter.

We reviewed all hardcopy questionnaires and all SPSS data entries as well as frequency tables for missing data. Some missing data was not at random while some was missing at random (MAR). Two control PLMI refused to complete the leadership scales because they felt they were not leaders and had never been part of any group as a member or leader. Of the MAR data, very little was actually missing. Apart from the two cases mentioned above that did not complete any responses on two instruments (a total of 32 items), there were about 20 pieces of missing data out of a potential 6768 responses from the leadership, empowerment and social capital instruments (20/6768=.0029, or less than 1/3 of 1% of total potential item responses). Because there were so few missing data and because each subgroup of subjects was relatively small (30 to 38), I decided to replace missing data with the average score of the subject on the remaining items in the instrument that had the missing piece of data. Our best guess is that MAR data was due primarily to interviewer error, accidentally skipping a question here and there. Missing data caused no more than one case deletion for each outcome.

On the sociodemographic and medical information sections of the interview, we made the assumption that all subjects would be in contact with a psychiatrist or doctor regarding their illness. While this was true for the control group (since we obtained all control subjects from the outpatient clinic of the psychiatric hospital), not all intervention PLMI (or the loved ones of carers) were currently in treatment, and some had never been

in treatment. This caused missing data on a few questions in the sociodemographic and medication information sections of the interview.

Skew and kurtosis was often high in the frequencies I ran. Levene's test of homogeneity was often significant and so failed the test. Power was sometimes low for results in the ANCOVA tables. These are significant issues that I address in the conclusion chapter.

Instrument reliability

Table 5 below shows that instruments generally had strong inter-item correlations as measured by Cronbach's alpha, meaning items measured the same construct fairly well. The transformational leadership instrument (GTL) had 1 item that should have been dropped, but this did not affect its alpha. The PLMI user empowerment scale (BUES) did have major problems, with a low alpha and 5 of 14 items could have been dropped to improve measurement of the construct with this population.

Services usage and ratings

Services usage. Regarding how many subjects used different types of mental health services, the largest number used the national psychiatric hospital as a service (Table 5). Over 90% of the intervention group and 100% of the control group used this or similar hospital services. It should be noted here that most people in the country do not access treatment for mental health needs. Estimates range from 1 in 10 to 1 in 20 people on a global basis who do not have access to treatment. Applied to El Salvador this means that somewhere between 300,000 and 600,000 people in a country of 6.3 million do not have access to services. Some Central American studies put the figures much higher, at between 28% (Guatemala) and 50% (El Salvador) suffering some kind of detrimental

Table 5
Reliability results

Construct	Instrument	Alpha	Number of items needing removal
Leadership	GTL	.833	1 of 7
	VLDI	.850	1 of 18
Empowerment	Ryff1 Positive Rels.	.623	0 of 4
	Ryff2 Purpose in Life	.741	0 of 5
	Ryff3 Personal Grwth	.589	1 of 4
	Ryff total score	.785	0 of 14
	BUES	.569	5 of 14
	FES1 Family	.778	3 of 11
	FES2 System	.674	0 of 9
	FES3 Comm/Advoc.	.834	0 of 10
	FES total score	.885	0 of 30
Social Capital	N/A[a]		

[a] Social capital questions were taken from the World Values Survey. The survey's questions are mostly nominal or ordinal and groups of questions do not constitute domains of a larger construct. As such, one cannot run inter-item correlation tests.

mental condition (the accuracy of these studies is uncertain).

From our study, it is clear that very few people who pass through the psychiatric hospital know about or are made aware of the FESEP community-based program, and there are no other community-based mental health programs in El Salvador.

Private clinics are used at more than twice the rate of public clinics for mental health services (44.3% vs. 17.1%). This may be due to 1) the intervention group has a much higher mean income than the control group (about $700 vs. $400) and can thus better afford private clinic services; and 2) public clinics are not structured to offer mental health services. For example, few public clinics have psychologists or medications, none have psychiatrists, and only recently has the government launched a

program to train primary care physicians in diagnosis and treatment of mental health conditions (World Health Organization's mhGAP program).

Despite not having mental health professionals on staff, subjects perceived significant help coming from churches or other religious sources (22.1%). The intervention group was also higher than the control group (25.7% vs. 18.6%), which may indicate that the intervention group receives more social support and understanding of their condition from churches/religious groups.

Intervention group usage of public clinics is much higher than the control group (24.3% vs. 10%), which may indicate that intervention subjects have had negative experiences at the psychiatric hospital and prefer to be attended by a primary care physician, or that control group subjects are more attached to their psychiatrists at the hospital or less trusting of primary care physicians. Qualitative research is needed to tease out these kinds of questions.

Services rated. The highest rating was for types of mental health services was the CBMHP/NGO, that is, the FESEP program participants (Table 6). It was rated very high 8.93 out of 10. This was followed by "Other," which was also the smallest in number; of the 10 responses, 9 were from the intervention group. This category included a "friend psychologist," two naturalists (alternative medicine such as homeopathy), house nursing visits, "my mother," and five unspecified.

Next came Church/Rel. at 7.69, over 2 points below the FESEP program.

The national hospital ranked in the middle as mode with a mean of 7.50. Hospital outpatients (control group) not surprisingly rated the hospital better than the intervention group drawn from the community program (8.11 with a range of 4-10 vs. 6.83 with a

Table 6

Services usage by number of people accessing each type of service. Broken down by Intervention and Control group as well as PLMI and Family Carer.

Service	Total (of 140)	By I vs C (of 70)	PLMI, I vs C (of 32)	FC, I vs C (of 38)
NPH	134 (95.7%)	64 (91.4%) vs 70 (100%)	29 (90.6%) vs 32 (100%)	35 (92.1%) vs 38 (100%)
CBMHP/NGO[a]	70 (50%)[b]	70 (100%) vs 0 (0%)	32 (100%) vs 0 (0%)	38 (100%) vs 0 (0%)
Private Clinic	62 (44.3%)	45 (64.3%) vs 17 (24.3%)	20 (62.5%) vs 9 (28.1%)	25 (65.8%) vs 8 (21.1%)
Church/Rel.	31 (22.1%)	18 (25.7%) vs 13 (18.6%)	12 (37.5%) vs 10 (31.3%)	6 (15.8%) vs 3 (7.9%)
Public Clinic	24 (17.1%)	17 (24.3%) vs 7 (10%)	7 (21.9%) vs 4 (12.5)	10 (26.3%) vs 3 (7.9%)
Trad. Healer	16 (11.4%)	11 (15.7%) vs 5 (7.1%)	3 (9.4%) vs 1 (3.1%)	8 (21.1%) vs 4 (10.5%)
Other	11 (7.9%)	10 (14.3%) vs 1 (1.4%)	6 (18.8%) vs 0 (0%)	4 (10.5%) vs 1 (2.6%)

Note: NPH=National Psychiatric Hospital of El Salvador; CBMHP/NGO=community based mental health program/non-governmental organization (any program that is run in the community by any entity including nonprofit organizations; programs run in the hospital were specifically excluded). I=Intervention group; C=Control group; PLMI=people living with mental illness; FC=family carer; Church/Rel.=mental health services received in/from any church or religious organization; Trad. Healer=Traditional healer (*curandero/curandera*) may be anyone from a grandmother in the community who uses herbs to a witch (*brujo*) who uses magic spells to cast out demons/spirits or the evil eye; sometimes it is hard to tell the difference between the two, for example, when a grandmother diagnoses the evil eye by rubbing an egg over a sick child, then analyzes the resulting egg whites in a glass of water, and then prescribes various herbs for the mother to prepare for the child (the author observed this process in a very poor community that did not have the economic means to access appropriate diagnostics and medicines).

[a] We did not screen for PLMI or FC to exclude people as controls who had participated in the hospital's programs, whether the day program for PLMI (frequency uncertain) or education and support group for carers (monthly). While the structure, intensity, and activities differ between FESEP and hospital programs, it is a strong potential bias that was undetected until too late in the study and should be taken into account in future studies.

[b] Subjects were selected because they were either members/participants in the FESEP CBMH program or were not. Hence the result of 50%. However, of the 70 control subjects we fully interviewed, none had been in any CBMH program that was different from the FESEP program apart from the day program at the national psychiatric hospital. This confirmed our understanding that there are no other community based mental health programs apart from the ones we run and who composed the intervention group).

larger range of 1-10). Interestingly, the PLMI in both the intervention and control group rated the hospital similarly (7.33 vs 7.69) while the family carers expressed a full 2-point difference (6.41 vs. 8.46). From conversations with both intervention and control group subjects, my sense is that PLMI patients generally expressed satisfaction with the help they received at the hospital in times of crisis and maintenance medications, while control group families expressed appreciation for the same reasons, but intervention group families expressed frustration with hospital treatment they saw as not compassionate or dignified. In turn, this may be a result of the exposure of program participant family carers to human rights training related to disability rights for PLMI and families.

Surprisingly, private clinic treatment was rated below the national hospital, but was close (7.37 vs. 7.50). Public clinic rating was a full point below that of private clinic.

Traditional healers were rated the lowest at 4.31, which was the only rating below the mid-point of 5.5. However, there were large differences. For example, the intervention group rated healers much lower than control group (3.73 vs. 5.60). PLMI rated healers higher than families, and again the lowest rating came from intervention family carers at a mere 2.75, which may be due to the same reasons above related to awareness of their human rights.

Analytic process

Mediating variables. First, I determined what variables I should explore as potential mediating or moderating variables and how the measures we collected could be used. For example, which measure of illness severity should I use? Which combination of Expressed Emotion best reflected a measure with variance? I used frequencies and correlation matrices to explore these questions.

Table 7

Services ratings ranked on a scale of 1-10 with mean, standard deviation, and range provided, and broken down by Intervention and Control group as well as by PLMI and Family Carer.

Service	Total (of 140)	By I vs C (of 70)	PLMI, I vs C (of 32)	FC, I vs C (of 38)
CBMHP/NGO[a]	N/A	8.93, 1.31, 3-10[b] vs N/A	8.98, 1.33, 4-10 vs N/A	8.89, 1.31, 3-10 vs N/A
Other	7.82, 1.40, 5-10	7.90, 1.45, 5-10 vs 7.00, No SD, 7-7[c]	8.67, 1.03, 8-10 vs No responses[c]	6.75, 1.26, 5-8 vs 7.00, No SD, 7-7[c]
Church/Rel.	7.69, 2.08, 2-10	7.47, 2.43, 2-10 vs 8.00, 1.53, 5-10	8.13, 1.86, 4-10 vs 7.70, 1.57, 5-10	6.17, 3.06, 2-10 vs 9.00, 1.00, 8-10[c]
NPH	7.50, 2.03, 1-10	6.83, 2.20, 1-10 vs 8.11, 1.66, 4-10	7.33, 2.12, 1-10 vs 7.69, 1.69, 4-10	6.41, 2.21, 1-10 vs 8.46, 1.57, 5-10
Private Clinic	7.37, 2.44, 1-10	7.11, 2.69, 1-10 vs 8.06, 1.43, 6-10	7.58, 2.52, 1-10 vs 7.78, 1.30, 6-10	6.74, 2.81, 1-10 vs 8.38, 1.60, 6-10
Public Clinic	6.41, 2.54, 1-10	6.35, 2.64, 1-10 vs 6.57, 2.34, 2-10	6.86, 2.48, 3-10 vs 6.75, 3.40, 2-10	6.00, 2.83, 1-8, vs 6.33, 0.58, 6-7
Trad. Healer	4.31, 3.36, 1-10	3.73, 2.76, 1-8 vs 5.60, 4.50, 1-10	6.33, 1.53, 5-8 vs 10.00, no SD, 10-10[c]	2.75, 2.49, 1-7 vs 4.50, 4.36, 1-10

Note: NPH=National Psychiatric Hospital of El Salvador; CBMHP/NGO=community based mental health program/non-governmental organization (any program that is run in the community by any entity including nonprofit organizations; programs run in the hospital were specifically excluded). I=Intervention group; C=Control group; PLMI=people living with mental illness; FC=family carer; Church/Rel.=mental health services received in/from any church or religious organization; Trad. Healer=Traditional healer.

[a] We did not screen for PLMI or FC to exclude people as controls who had participated in the hospital's programs, whether the day program for PLMI (frequency uncertain) or education and support group for carers (monthly). While the structure, intensity, and activities differ between FESEP and hospital programs, it is a strong potential bias that was undetected until too late in the study and should be taken into account in future studies.

[b] Subjects were selected because they were either members/participants in the FESEP CBMH program or were not. Hence there is no control response to rating a CBMHP/NGO. However, of the 70 control subjects we fully interviewed, none had been in any CBMH program that was different from the FESEP program. This confirmed our understanding that there are no other community based mental health programs apart from the ones we run and who composed the intervention group).

[c] These results included few responses, between 0 and 2 responses.

Then I ran a correlation matrix to explore the relationships among six potential mediating variables and 17 outcome measures.[35] The significant correlations were not strong enough to include as mediating variables (Table 8; for the full SPSS correlation matrix see Appendix F).

Table 8
Correlation matrix to explore potential mediating variables with outcomes

Mediating variable	Type of Subject	Significant with outcome (correlation, alpha)
Social Contacts	PLMI	Empowerment-Ryff1 (.281, <.01) Empowerment-RyffTotal (.229, <.05) Empowerment-BUES (.194, <.05)
Years without Treatment	Carers	Empowerment-Ryff3 (-.197, <.05) Empowerment-FES1 (.144, <.10) SocialCapital-PublicNew (.189, <.05)
Diagnosis	Both PLMI & Carers	None
Severity of Illness (last 15 days)	Both PLMI & Carers	Empowerment-Ryff2 (-.136, <.05) Empowerment-FES2 (-.167, <.10) SocialCapital-Trust1 (-.192, <.01)
Family Support[a]	PLMI	Empowerment-Ryff1 (-.166, <.10) Empowerment-Ryff2 (-.154, <.10) Empowerment-RyffTotal (-.165, <.10) SocialCapital-Trust1 (-.234, <.05)
Years in Program	FESEP Participants	Leadership-VLDI (.177, <.05) Empowerment-Ryff1 (.201, <.05) Empowerment-Ryff2 (.223, <.05) Empowerment-RyffTotal (.241, <.01) Empowerment-FES1 (.348, <.01) Empowerment-FES3 (.263, <.05) Empowerment-FESTotal (.258, <.05)

Notes: Blue = $p < .01$; green = $p < .05$; white = $p < .10$. See Appendix F for full matrix.
[a] Measured using a combination of variables to represent family support (two measures of expressed emotion derived from the literature and two questions from a global mental health survey used in Africa. Based on correlations, I chose the combined 1+2+3+4 measure as the best measure of overall "family support." Kendall's tau (2-tailed).

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[35] I used a Kendall's tau correlation matrix since it is for sample sizes that are nonparametric and small.

Confounding variables. I then ran a series of statistics to determine whether each

potential covariate was significant.[36] Details of this process are found in Appendix G.

The covariates used appear below in the ANCOVA results table (Table 9).

ANCOVA results

The ANCOVA results follow in Table 9. There are 14 primary outcomes scores

that are of importance.[37] Only one of the 14 outcome measures was found to be

significant at the .001 level, the social capital outcome of civic participation (participation

in number of civil society groups). It was significant for intervention vs. control groups

$(F(1,133)=25.092$, $p < .000$, partial eta squared = .159, power = .999 at alpha .05) and for

carer subgroup comparison $(F(1,72)=8.070$, $p = .006$, partial eta squared = .101, power =

.80) and for PLMI subgroup comparison $(F(1,60)=17.779$, $p < .000$, partial eta squared =

.229, power = .986) subgroups. By commonly accepted estimates, these are medium to

large eta squared effect sizes.[38]

No outcomes were significant at the .05 level, but three outcome measures were

significant at the .10 level: Ryff Psychological Wellbeing Inventory for carers, Positive

Relations domain, as a general measure of empowerment related to the ability to have

positive relationships with others $(F(1,72)=3.014$, $p = .087)$; the Community/Political

domain of the Family Empowerment Scale for carers, as a measure of family

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[36] Frequencies demonstrated that the total and subgroup (carer and PLMI) samples across 17 outcomes were generally nonparametric. Although usually considered a parametric statistic, ANCOVA has been shown to be robust with nonparametric samples and it has advantages such as reporting effect size, so I used it with my sample in this study (Vickers, 2005). However, others suggest that skewed data can be transformed through log-transformations but are better dealt with through generalized estimating equations (Feng et al., 2014). I depended on the robustness of ANCOVA rather than using transformations, which may be a limitation in this study's approach.

[37] I tested 17 outcomes scores, but one is a duplicate trust measure that is weaker than generalized trust, and two others are total scores (FES total and Ryff total) that are not part of the original instruments. In the analysis I ended up eliminating these 3 and discussing only the remaining 14 scores.

[38] Cohen suggests the following eta squared effect sizes: .02 ~ small, .13 ~ medium, and .26 ~ large (Cohen, J., 1988; Miles, J. & Shevlin, M., 2001; as cited in Watson, 2014).

empowerment in the area of community involvement and political advocacy

$(F(1,72)=3.031, p = .086)$; and Political Participation (voting) as a social capital measure

of civic engagement for PLMI $(F(1,59)=3.016, p = .088)$.

Table 9
ANCOVA F statistics, covariates, and (for significant findings) effects and powers for leadership, empowerment, and social capital outcomes.

Leadership

Instrument and type of subject	F statistic	Covariates used
Global Transformational Leadership scale		
Combined FC and PLMI	$F(1,134)=1.093, p=.298$	Education, Family Size
FC	$F(1,70)=28.216, p=.802$	Education, Income
PLMI	$F(1,60)=0.003, p=.953$	Family Size, Marital Status
Volunteer Leadership Development Instrument		
Combined FC and PLMI	$F(1,133)=7.426, p=.800$	Education, Income
FC	$F(1,70)=0.064, p=.802$	Education, Income
PLMI	$F(1,59)=0.012, p=.914$	Education, Income

Empowerment

Ryff Psychological Wellbeing inventory, Positive Relations domain		
Combined FC and PLMI	$F(1,135)=2.303, p=.132$	Education, Income, Marital Status, Occupation
FC	$F(1,72)=3.014, p=.087$	Education, Age
PLMI	$F(1,59)=0.088, p=.767$	Income, Marital Status
Ryff Psychological Wellbeing inventory, Purpose in Live domain		
Combined FC and PLMI	$F(1,134)=0.027, p=.869$	Education, Age, Income
FC	$F(1,72)=0.055, p=.816$	Education
PLMI	$F(1,59)=0.149, p=. 701$	Income, Marital Status
Ryff Psychological Wellbeing inventory, Personal Growth domain		
Combined FC and PLMI	$F(1,136)=1.192, p=.277$	Education, Family Size
FC	$F(1,72)=1.759, p=.189$	Education, Income
PLMI	$F(1,59)=1.126, p=.293$	Income, Occupation

Instrument and type of subject	F statistic	Covariates used

Boston University Empowerment Scale (BUES)

Combined FC and PLMI	N/A (PLMI-only instrument)	
FC	N/A	
PLMI	$F_{(1,59)}=0.630$, $p=.431$	Income, Occupation

Family Empowerment Scale, Family domain

Combined FC and PLMI	N/A (FC-only instrument)	
FC	$F_{(1,72)}=0.087$, $p=.769$	Income, Education
PLMI	N/A	

Family Empowerment Scale, Service System domain

Combined FC and PLMI	N/A	
FC	$F_{(1,72)}=0.729$, $p=.396$	Income, Education
PLMI	N/A	

Family Empowerment Scale, Community/Political domain

Combined FC and PLMI	N/A	
FC	$F_{(1,72)}=3.031$, $p=.086$	Income, Education
PLMI	N/A	

Social Capital

Trust question

Combined FC and PLMI	$F_{(1,135)}=1.694$, $p=.195$	Education, Income, Gender
FC	$F_{(1,72)}=0.025$, $p=.874$	Education, Income
PLMI	$F_{(1,60)}=2.614$, $p=.111$	Education, Family Size

Civic Participation[a]

Combined FC and PLMI	$F_{(1,133)}=25.092$, $p<.000$[b]	Income, Live with Others, Marital Status, Education
FC	$F_{(1,72)}=8.070$, $p=.006$[c]	Education, PLMI income
PLMI	$F_{(1,60)}=17.779$, $p<.000$[d]	Occupation, Marital Status

Identity[a]

Combined FC and PLMI	$F_{(1,135)}=0.014$, $p=.906$	Education, Income
FC	$F_{(1,70)}=0.079$, $p=.780$	Income, Also Diagnosed
PLMI	$F_{(1,59)}=0.633$, $p=.429$	Occupation, Income

Instrument and type of subject	F statistic	Covariates used
Political Participation[a]		
Combined FC and PLMI	F(1,134)=1.409, p=.237	Marital Status, Education, Income
FC	F(1,70)=0.497, p=.483	Also Diagnosed, PLMI Income
PLMI	F(1,59)=3.016, p=.088	Income, Marital Status
Interest in Public News[a]		
Combined FC and PLMI	F(1,135)=0.372, p=.543	Education, Income
FC	F(1,72)=0.408, p=.525	Education, PLMI Income
PLMI	F(1,59)=0.493, p=.485	Education, PLMI Income

Note: FC=family carer, PLMI=person living with mental illness. Significant findings at the .05 p level are shown in green. Weaker findings at the .10 p level are shown in yellow. White is non-significant findings.
[a] Questions taken from the World Values Survey, Colombia version in Spanish.
[b] Levene's test not significant at .134, partial eta squared = .159 (r^2 = .306), power at alpha .05 = .999.
[c] Levene's test significant at .020, partial eta squared = .101 (r^2 = .348), power at alpha .05 = .80.
[d] Levene's test not significant at .813, partial eta squared = .229 (r^2 = .274), power at alpha .05 = .986.

Measures applied to intervention group only: Level of participation

In the design phase, I considered level of participation to be an important potential mediating variable. Indeed, using "Years in Program" as the primary measure of level of participation in the correlation matrix (see Table 7 above), this variable is more highly correlated than any of the other five potential mediating variables tested. Although the correlations were weak, it was much more frequently correlated with the outcomes variables (7 of 17) than were other potential mediators, including two at the .01 level. The correlations indicate that Years in Program has a somewhat broad impact.

Although this variable related only to the intervention group, and I could not include it as a covariate in the full analysis, I ran several other exploratory tests related to the potential influence of level of participation on the outcomes.

Different potential measures could be indicators of level of participation, including years in program (duration), number of program components in which the subject participated (breadth), and number of activities within each component (intensity). "Years in program" was a clearer measure, and likely a proxy for breadth and intensity, so I used Years in Program for the analyses I ran.

One idea for exploratory analysis was to break the intervention group down into sequential groups of years and test each subgroup against the control group on the outcomes to see if increasingly large groups of years at some point might become significant compared to the control group. Because I feared that the relationship might not be linear, I decided to test by each year. I thus divided the intervention group into subgroups by years of participation: 1 year, 2 years, 3 years…14 years, then ran ANCOVAs of each year of participation on each outcome with its appropriate covariates. I then reviewed the results to see if there were significance relationships between number of years of participation and each outcome. The results in Table 10 showed two things. First, there was a large percentage of the intervention subjects that had been part of the program for only a short time: 40% were between 1 month and 1 year, 24% had 2 to 4 years of participation, and 36% had more than four years. Second, some years were significant and other were not, and some were significant consistently (for example, 4 years of participation). This would indicate that the participants themselves within these particular year groups were more important than the number of years. However, the sample was very small for each year group (ranging from 1 to 28 people), which means that it would be difficult to detect significance. Having stated the limitations, the table shows that participating for only 1 or 2 years led to only one positive outcome.

Table 10

ANCOVAs for "Years in Program" on selected outcomes[a]

Data organized by construct and measure

Construct	Instrument	Years in Program with significance
Leadership		
	VLDI	3, 4, 6, and 10 years were significant at the .05 or .10 alpha level for either PLMI, carers, or combined.
Empowerment		
	Ryff1	4 and 10 years were significant at the .05 alpha level for either PLMI, carers, or combined.
	Ryff3	6 years was significant at the .10 alpha level for PLMI only.
	RyffT	4,8, and 10 years were significant at the .05 or .10 alpha level for either PLMI, carers, or combined.
	BUES	8,9, and 10 years were significant at the .05 or .10 alpha level for PLMI.
	FES3	5,9, and 12 years were significant at the .05 or .10 alpha level for carers.
Social capital		
	Trust	1, 3, 6, 12, and 14 years were significant at the .05 or .10 alpha level for either PLMI, carers, or combined.
	PublicNews	2 and 10 years were significant at the .05 or .10 alpha level for either PLMI, carers, or combined.

Data organized by year

Year	# of subjects by year	# of signif. outcomes	% of outcomes with signif.
1	28	1/9[a]	11%
2	7	1/9	11%
3	6	2/9	22%
4	4	3/9	33%
5	7	1/9	11%
6	3	3/9	33%
7	4	0	
8	2	2/9	22%
9	1	2/9	22%
10	6	5/9	55%
11	0	---	---
12	1	2/9	22%
13	0	---	---
14	1	1/9	11%

[a] Because this was an exploratory analysis, I selected only the nine most likely outcome variables to show significance (of the 17 outcomes).

Participating for 3 years led to two positive outcomes, participating for 4 or 6

years led to three outcomes, and participating for 10 years resulted in having five positive

outcomes.

The pattern indicated a general trend linking increasing years in program and

increasing number of significant outcomes, so I also ran a regression model to see if

Years in Program predicted scores on each outcome for the intervention group. Table 11

has data for significant and non-significant relationships for the regression model.

Looking at 16 of the outcome measures, more than half were significant—six at the .05

level and another three at the .10 level. These included one leadership measure, one

social capital, and seven empowerment outcomes.

Table 11
Regressions to see if "Years in Program" predicts outcomes

	Construct	Outcome name	P value, R^2 value, alpha		
Significant	Leadership	Volunteer Leadership Development	.016	.08	.05
	Empowerment	Ryff1-Positive Relations	.007	.10	.01
	Empowerment	Ryff2-Purpose in Live	.025	.07	.05
	Empowerment	Ryff3-Personal Growth	.088	.04	.10
	Empowerment	Ryff Total score	.003	.12	.01
	Empowerment	FES1-Family	.021	.14	.05
	Empowerment	FES2-Community/Political	.049	.10	.05
	Empowerment	FES-total score	.054	.10	.10
	Social Capital	Civic Participation	.095	.04	.10
Non-significant	Leadership	Global Transformational Leadership	.305		
	Empowerment	PLMI empowerment scale (BUES)	.456		
	Empowerment	FES2-Service System	.481		
	Social Capital	Trust	.882		
	Social Capital	Identity	.624		
	Social Capital	Political Participation	.314		
	Social Capital	Public News Interest	.448		

Note: For the regression model I eliminated year 7 as an outlier and eliminated any measure with 1 or less subjects (years 9, 11, 12, 13 and 14). Results through the first 10 years of participation (n=67), showed a significant linear relationship between years participating and number of significant outcomes at .031 (<.05), with $R^2 = .56$.

Table 12 shows the results of another analysis, a correlation matrix of years of participation with selected outcome measures. Similar to the regression model, empowerment comprises six of the seven outcomes that show significant correlation at the .05 and .01 levels. Most effect sizes are weak, with only two in the moderate effect size range.

The final analysis was a set of ANCOVAs using a different measure of level of participation—participation in what leaders consider the most intensive components of the program. For carers, this is the 12 to 17 week family education and support course.

Table 12
Correlations between "Years in Program" and outcome variables

Significance	Variable (p level, correlation)	Construct
Significant at < .01	Ryff total (.005, .241)	Empowerment
at < .01	FES1-Family (.003, .348)	Empowerment
Significant at < .05	VLDI (.037, .177)	Leadership
at < .05	Ryff1-Positive Relations (.018, .201)	Empowerment
at < .05	Ryff2-Purpose in Life (.010, .223)	Empowerment
at < .05	FES3-Community Political (.026, .263)	Empowerment
at < .05	FES Total (.026, .258)	Empowerment
Not significant	GTL (.493, .059)	Leadership
	Ryff3-Personal Growth (.180, .119)	Empowerment
	BUES (.948, .008)	Empowerment
	FES2-Service System (.259, .134)	Empowerment
	Trust (.902, .012)	Social capital
	Civic participation (.458, 065)	Social capital
	Identity (.765, -0.27)	Social capital
	Political participation (.672, -0.41)	Social capital
	Public news interest (.488, -0.59)	Social capital

Kendall's tau (2-tailed).

For PLMI this is the weekly art therapy group. For purposes of analysis, FESEP family participants were selected into this intervention group if they had a higher than 50% participation rate in the family education course, and PLMI were selected if they had participated for more than 1 year in the weekly art therapy group. This is essentially the same output as reported in Table 9, but with only higher level FESEP participants included in the intervention group. Instead of significant findings of one outcome at .001 (civic participation) and three at .10 (political participation, Ryff positive relations, and FES community/political) (Table 8), the new results in Table 13 show one outcome at .001 (civic participation), one significant finding at nearly .01 (.016)(Ryff positive relations), and two more almost significant at the .05 level (.056 and .057)(Ryff total score, and FES community/political). Most findings come from the empowerment scales.

Measures applied to intervention group only: Satisfaction, effectiveness, sense of belonging, and importance of program

There were additional questions after the scales that were for FESEP program participants only. These included level of participation questions such as what program components were participated in for how many years and months and how frequently (just discussed above). We also asked people how satisfied they were with the program, how effective they felt it was, how much of a sense of belonging it provided for them, and how important the program was compared to other programs. These were all on a 3 to 4 item Likert scale for ease of response. Finally, we asked people an open-ended question regarding what most satisfied or helped them during their experience in the program. These findings are presented below.

Table 13

ANCOVA F statistics, covariates, and (for significant findings) effects and powers for leadership, empowerment, and social capital outcomes on high-impact-component FESEP program participants as intervention group.

Leadership

None significant below .10

Empowerment

Instrument and type of subject	F statistic	Covariates used
Ryff Psychological Wellbeing inventory, Positive Relations domain		
Combined FC and PLMI	$F(1,112)=5.927$, p=.016[a]	Education, Income, Marital Status, Occupation
FC	$F(1,64)=5.953$, p=.017[b]	Education, Age
Ryff Total Score		
FC	$F(1,65)=3.778$, p=.056[c]	Education, Income
Family Empowerment Scale, Community/Political domain		
FC	$F(1,65)=3.750$, p=.057[d]	Income, Education

Social Capital

	F statistic	Covariates used
Civic Participation[e]		
Combined FC and PLMI	$F(1,114)=32.770$, p<.000[f]	Income, Live with Others, Marital Status, Education
FC	$F(1,65)=9.101$, p=.004[g]	Education, PLMI income
PLMI	$F(1,45)=14.748$, p<.000[h]	Occupation, Marital Status

Note: FC=family carer, PLMI=person living with mental illness. Significant findings at the .05 p level are shown in green. Weaker findings at the .10 p level are shown in yellow.

[a] Levene's test not significant at .295, partial eta squared = .050 (r^2 = .07), power at alpha .05 = .68

[b] Levene's test not significant at .089, partial eta squared = .101 (r^2 = .12), power at alpha .05 = .76

[c] Levene's test not significant at .944, partial eta squared = .055 (r^2 = .17), power at alpha .05 = .48

[d] Levene's test not significant at .916, partial eta squared = .055 (r^2 = .21), power at alpha .05 = .48

[e] Questions taken from the World Values Survey, Colombia version in Spanish.

[f] Levene's test significant at .024, partial eta squared = .186 (r^2 = .33), power at alpha .05 = .99

[g] Levene's test significant at .006, partial eta squared = .123 (r^2 = .40), power at alpha .05 = .84

[h] Levene's test significant at .002, partial eta squared = .270 (r^2 = .31), power at alpha .05 = .99

Table 14 presents qualitative themes on the question "What satisfied you the most about the program?" Perceived benefits spanned a broad range, from help with a personal crisis and education on mental illness to longer term types of needs and opportunities for service and advocacy.

Table 14
What satisfied you the most about the program?

Theme	Examples (number of similar comments)
Relational support: Companionship, a place to enjoy life, a place to unburden	Recreational outings (2 comments). I like art therapy and I like the monthly assemblies. (1) We all feel equal. (1) Support, empowerment, loyalty, cordiality in general, companionship, new knowledge, and support (20). The psychoeducation workshop helped me a lot. It is important the relationship between people with the same difficulty. I feel part of a family. It is great that my child has a sense of belonging with his peers.(9)
Help: Crisis support: Help: External service	We found help in the program. (1 comments) The program gave me the opportunity to help others going through the same thing. (1) My sister has improved. (1) We entered the struggle to improve living conditions for families through advocacy and direct support to groups. (1)
Informational support: Knowledge, education, sharing experiences	Acquired knowledge about mental illnesses and treatment. Learning and practicing relaxation techniques, recovery, crisis management. (21 comments) Having an art therapy weekly program to attend. (5) I like teaching the family education course. (1) This program helps break paradigms. (1)
Everything	I like just about everything, all the activities, everything that's done. (4)

Table 15 presents findings from the Likert questions on program satisfaction, effectiveness, sense of belonging, and importance of the program compared to other civil society groups in which the person has participated. On a 1 to 3 (low, moderate, high) response scale for the satisfaction, effectiveness and sense of belonging scales, all responses are quite high, with 53% to 64% responding with a 3 (very satisfied, very effective, very strong sense of belonging) with a mean of almost 2.6. Sense of belonging was on a 4-point scale. Over 77% responded that the FESEP program was either more important than most, or more important than all other groups (questions are listed at the bottom of Table 15).

Research question

I attempted to answer the research question of whether marginalized populations in low and middle income countries who participate in grassroots, shared leadership programs run by civil society organizations develop leadership attributes, a sense of empowerment, and increased social capital. To do so I ran a set of ANCOVAs comparing a group of grassroots organization program participants against a matched control group of non-participants. The strongest significant finding was that the intervention group subjects did participate significantly in civil society organizations compared to the control group. Beyond that finding, there was little evidence in the initial analysis that program participants developed leadership, empowerment, or social capital. However, post hoc analyses focusing on different aspects of "level of participation" did show increased differences between the groups when intervention group participants with more time in the program or who had participated in the most intensive program components were compared against the control group.

Table 15

FESEP program ratings by satisfaction, effectiveness, sense of community, and importance relative to other groups.

	Satisfaction	Effectiveness	Sense of Community	Importance
Sample size	n = 70	n = 70	n = 70	n = 70
Range	1-3	1-3	1-3	1-3
Mean	2.59	2.63	2.47	3.21
Items: Weak	2.9%	1.4%	5.7%	1.4%
Moderate	35.7%	34.3%	41.4%	21.4%
High	61.4%	64.3%	52.9%	31.4%
Very High	---			45.7%

Note: Questions for each measure were:

Satisfaction: Not very satisfied, Satisfied, Very satisfied

Effectiveness: Not very effective, Effective, Very effective

Sense of Community: Little sense of belonging, Strong sense of belonging, Very strong sense of belonging

Importance: Less important than other groups, More or less the same importance as other groups, More important than most other groups, More important than any other group

Hypotheses

I carried out initial analyses related to four hypotheses.

Hypothesis 1 stated "Marginalized persons with mental illness participating in a grassroots participatory intervention program demonstrate higher gains in leadership, empowerment, and social capital than a control group of non-participants." ANCOVA analyses showed only one outcome to be significant at $p < .001$ level—civic participation, which measured the number of civil society groups that they participated in $(F(1,60) = 17.779, p < .000, r^2 = .27,$ partial eta squared $= .229)$—and one outcome that was significant at the .10 level—political participation, which measured how frequently subjects voted in local and national elections $(F(1,59)=3.016, p=.088, r^2 = .13)$(Table 8). Thus this hypothesis was weakly supported in that PLMI appear to develop some social capital attributes, but not many, while leadership and empowerment were not significant.

Hypothesis two stated, "Marginalized family members (carers) participating in a grassroots participatory intervention program demonstrate higher gains in leadership, empowerment, and social capital than a control group of non-participants." Only the same civic participation outcome was significant at the .001 level $(F(1,72)=8.070, p = .006,$ partial eta squared $= .101)$ and two outcomes were significant at the .10 level—the positive relations domain of the Ryff psychological wellbeing inventory, which measures how well people get along with others $(F(1,72)=3.014, p=.087)$, and the community/political domain of the Family Empowerment Scale, which measures people's involvement in community activities and advocacy related to improving services $(F(1,72)=3.031, p=.086)$(Table 9). Therefore this hypothesis was also weakly supported,

with carers potentially benefiting from some empowerment domains and from the civic participation domain of social capital, but not from leadership.

Hypothesis three stated, "PLMI and carers in the intervention group demonstrate different levels of leadership, empowerment and social capital." From the results discussed above for hypotheses 1 and 2 it is evident that this hypothesis was partially confirmed. PLMI tended to have more benefits in the area of social capital, while carers had stronger benefits in the area of empowerment.

Hypothesis four stated, "Moderating variables influence the outcome variables." I ran a correlation matrix that showed primarily weak relationships on six potential moderating variables against 17 outcomes variables. Therefore, this hypothesis was not supported. However, level of participation as represented in the variable "Years in Program" was related to a much larger number of outcomes than other potential moderating variables. As a result, I performed a number of post hoc analyses related to level of participation, which confirmed the importance of time and intensity of participation as a moderating factor for all constructs (discussed below).

Post hoc analyses

Because skew was a concern, I ran a SPSS non-parametric test on covariates and outcome variables by group using the independent samples Mann-Whitney U test. The results showed no noticeable differences between parametric ANOVA and non-parametric Mann-Whitney tests, meaning that the final ANCOVA analyses I ran (and discussed above under hypotheses) essentially hold despite non-parametric issues.

Level of participation showed itself to be a potential variable of influence. The problem was, only intervention group subjects could answer these questions. To get

around this issue, I subdivided the intervention group into years of participation and

tested each year against the control group. Although the resulting sample sizes of these

year groups was very small, and now no longer "matched" to the control group, I decided

to go ahead and run ANCOVAs, regressions, and a correlation matrix.[39] These reflected

an increased influence on several outcome variables above the initial analyses. For

example, different groups of years of participation were significant for Volunteer

Leadership Development (which measures attributes of volunteer leaders in grassroots

organizations), the positive relations domain of the Ryff psychological wellbeing

inventory, the combined score of the three domains measured of the Ryff inventory

(which measures positive relations, purpose in life, and personal growth), the Boston

University Empowerment Scale (which measures empowerment characteristics important

to users of community mental health services who are part of grassroots associations), the

community/political domain of the Family Empowerment Scale (which measures

people's involvement in community activities and advocacy related to improving

services), and two social capital measures of generalized trust and interest in public news

(all at the $p<.05$ level). See Table 13 for details.

To determine if there was a linear correlation between years in program and

various outcomes, I ran a simple regression model to for each year and each outcome.

The results showed significant results for nine outcomes (six at the .05 level and three at

the .10 level), and seven outcomes with no significance. Interestingly, seven of the nine

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[39] Resulting intervention group sizes by year were 28 for year 1; years 2 to 10 ranged from 1 to 7 subjects with a mean of 4.4 for each year; and years 11-14 had only 2 persons, one for year 12 and one for year 14. In running the regression between years in program and outcomes, I used only years 1 through 10. See Table 10 for details.

significant outcomes were empowerment measures. Only one was leadership (VLDI) and one was social capital (civic participation). See Table 11 for details.

Finally, I ran a correlation matrix on the groups of years and outcomes to explore the strength of relationships. Seven of the nine in the regression model were found to be significant in the correlation matrix. However, correlation relationships were generally week, ranging from .177 to .263. One correlation had moderate effect size at .348 (the family domain of the Family Empowerment Scale, which measures support and advocacy for one's loved one with a disability). Six of the seven significant correlations were empowerment measures. The seventh was the Volunteer Leadership Development scale.

Reflecting further with a Salvadoran program colleague on the potential influence of level of participation on the outcomes, it seemed worth it to analyze an additional potential influence on outcomes—the strongest program components.[40] The most intensive program component for family carers is the 12 to 17 week family education and support course. For PLMI, participation in the weekly art therapy and psychosocial group is the most intensive. I thus de-selected anyone in the intervention group who was not part of these two subgroups. The new analysis improved the number of significant findings. Compared to the original ANCOVA analysis with one significant finding (civic participation) at the .001 level, the new analysis increased the number of significant outcomes to one at the .001 level, one at .01 and two at nearly the .05 level. The findings all related to two empowerment scales (Ryff and FES related to families) and one social capital scale (civic empowerment for both family carers and PLMI). See Table 13 for details. Thus it appears that both years in the program and whether program members participated in the most intensive program components have an influence on improving

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[40] Personal communication, Cecilia Almendarez, March 9, 2016.

outcomes, especially related to empowerment, and to a lesser degree leadership and

social capital measures.

This seems consistent with the design of the FESEP program. For example, while

many people come to the program looking for a quick fix such as a supply of medications

to help their loved one in crisis, medications are not offered by the program. In contrast,

the main components of the program offer long-term assistance: a 12 to 17 week

education and support course for carers, a weekly art therapy program for PLMI (which

also helps them learn how to better manage their illnesses), and the opportunity to serve

in leadership positions to plan the activities and lead public awareness campaigns (which

are infrequent). The nature of the program, then, is on development of knowledge,

supportive relationships, healthy attitudes and skills, empowered activity such as

advocacy, and leadership experience that eventually result in improved quality of life for

oneself and for others.

Figure 10. Man in the middle of a busy intersection. San Salvador.
This is typical of those on the street with substance abuse or mental
illness conditions. Photo by the author.

CHAPTER 5: CONCLUSIONS

Comparison of findings to the literature

My review of the literature indicated that 1) constructs of leadership, empowerment and social capital are important to achieving community change; 2) there are few empirical studies measuring these constructs as they relate to grassroots organizations or efforts with marginalized groups such as poor women or persons with psychosocial disabilities, even in LMIC countries where 80% of the world's population lives; 3) when experimental studies are completed, they are sometimes unable to get to the impact variables that matter most, for example, they may show that changes occurred in a government structure but not that such a change improved the quality of life of the people seeking the change[41]; 4) studies do exist (Shankar et al., n.d.), that demonstrate psychological measures of empowerment can be achieved and that they contribute to improved outcomes for individuals and families; and 5) that the research community is still grappling with how to measure these broad complex concepts. This study supports the last point in that we encountered multiple difficulties in identifying appropriate measures and multiple challenges carrying out those measures, which are detailed in the limitations section at the end of this chapter.

Shankar et al. (n.d.), in one of the few RCT studies on an empowerment intervention in LMICs, found positive effects from increased entrepreneur sales to Ryff psychological wellbeing measures. Their sample size was larger than mine (n=257 vs. n=140) and likely impacted their ability to pick up variance. The RCT design also

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[41] Petesch, Smulovitz, and Walton (2005) write regarding empowerment, "We can conclude that empowerment has occurred when [disenfranchised] individuals and groups exercise agency with a reasonable prospect of having an influence on…processes and outcomes [related to their concerns]" (40).

eliminated multiple potential bias factors that may have overwhelmed my study's ability to obtain valid information.

Speer, Peterson, Zippay, and Christens (2011) carried out a study of a five-year community organizing program in the U.S., part of which included a RCT design. They found positive outcomes for civic engagement and psychological empowerment. Although the case study demonstrated changed policies and practices, they were not able to achieve any measure that could show that quality of life actually improved as a result of the engagement and empowerment. My study supported their finding that civic engagement and empowerment are related.

De Vita, Fleming, and Twombly (2001) note that empirical evidence on creating lasting social change comes from local involvement. They cite "remarkable results" from efforts in San Francisco, California and Curitiba, Brazil and note that the goals for empowering people to become involved, foster social cohesion, and strengthen institutions is a long-term effort. This brings up the question of whether we were measuring the wrong level of impact—individual empowerment rather than concrete durable changes at the institutional, service, national budget and policy levels. For example, better research questions might have been: Have the efforts of the FESEP program created spaces for their members to be involved in institutions of power related to changes they wish to see? Have community based services to PLMI and families increased in the country? How many more people are receiving treatment near their home instead of long distances to the capital city? Have new laws and policies been put in place that seek to support the human rights of persons with psychosocial disabilities? Has the national budget for services increased? Do people have access to more and better quality

treatments? The challenge of course is obtaining this information. Little of it is available. For example, ministry of health officials in El Salvador, Nicaragua and Costa Rica have told us that defining a mental health budget is virtually impossible. If it can't be defined, or the institutions in charge of such budgets are unwilling to define some imperfect measure that can at least be used consistently over years, then one can't measure it.

Families tended to have more and stronger outcome findings than PLMI in this study. This might be explained by the composition of the PLMI group, which consisted primarily of persons with schizophrenia (67.2%). Some community studies that included multiple diagnoses show significant benefits for people across many diagnoses except for persons with schizophrenia. For example, in a longitudinal cohort study in India by Chatterjee et al., 2009, n=236, researchers found participation in a self-help group to be an independent predictor of good outcomes, but schizophrenia was an independent predictor of poor outcomes. They found that, similar this study, lack of education was a predictor of poor outcomes. Finally, engagement in the program predicted good outcomes while dropping out of the program predicted poor outcomes. This supports our finding that people in the program longer (years in program) had better outcome measures. Despite global estimates showing that depression, anxiety, bipolar, and other disorders have higher prevalence rates than schizophrenia, community mental health programs in the U.S. and El Salvador tend to have a higher proportion of persons with schizophrenia or their caregivers. This is likely due to the seriousness and disabling qualities of the symptoms, resulting in increased need for employment help and family support. The end result is that persons with schizophrenia or their family carers tend to dominate community based programs. In turn, people with less disabling conditions tend to get

turned off and stop attending such programs because they don't want to, or need to be, in programs that are catering to persons who are worse off than they are.

Incongruence of study findings with other evidence

This study indicates that the impact of a grassroots civil society program was only weakly influential on developing leadership, empowerment, and social capital in participants. Further, the positive findings primarily apply to persons with longer and more intensive investment in the program. These findings contrast with other data collected in this same study on program participation, including participant perceptions of satisfaction with the program, program effectiveness, sense of belonging, and importance of the program compared to other groups they have participated in, all of which showed very high levels of positive response. Many participants also have a very high level of commitment to participating and leading the organization, evidenced by their long-term commitments. For example, in the study's intervention sample, 34% had been in the program for 2 to 5 years, and another 26% had been in the program for 6 to 14 years. Further, intervention participants rated the FESEP program 8.9 out of 10 for usefulness. This is very high compared to other ratings given by the entire study population—for the hospital (7.5), private clinics (7.4) and public clinics (6.4). This evidence combined with other studies in the U.S. that included empowerment (Dixon et al., 2011; Lucksted et al., 2013), quantitative studies in LMICs cited above, qualitative studies in Central American countries (Nickels et al., 2016; Rojas, 2011; van Rimke, 2009), and years of anecdotal evidence and program reports (see Appendix G) all indicate strong impact on development of leadership, empowerment, social capital, and a host of psychosocial measures that would indicate improvements in quality of life for program participants.

Why then did the study not find stronger indications of improvements in these areas across all participants and subgroups of participants as hypothesized? Two responses can be made—that the program is not as effective at developing these outcomes as I hypothesized; or that there was something wrong in the implementation of the program or the measurement of the outcomes. Below I address the many possibilities of implementation and measurement error that may have caused a type II statistical error conclusion (that I did not detect a difference between groups when in fact there really was one).

There are three typical responses to incongruent data from the area of measurement theory. Either we did not have the right measures, or the measures were not sensitive enough to pick up the differences, or we were not getting accurate or truthful responses (personal communication, Dr. Robin Anderson, March 3, 2016). From the arena of program evaluation I would add other possibilities: the program theory was not sound, the program was not implemented with fidelity, or the research design (for example, in the selection of subjects) was not sound. I will address these one at a time.

Measurement accuracy. Did we have the right measures? Aside from sample size, having the right measures may be the most important bias issue in this study. It is possible that I was defining the outcomes of interest differently than the subjects, that is, perhaps the social-cultural-economic context in which I operate caused me to look for outcomes that were different than what the subjects care about, find useful, or important for their lives. However, in an earlier focus group study in El Salvador (Nickels et al., 2016) it was apparent that leadership, empowerment, and social networks and capital are

important to program participants and that they saw the program as effective in accomplishing these goals.

Validity of instruments. All the instruments I used were developed in high income countries. Despite validated translations in Spanish (from Spain and Colombia), this is not enough to overcome strong contrasting modes of thinking or cultural norms. This was noticeable in a number of the instruments where respondents had trouble understanding a question or answering a question because it created conflictual feelings for them. For example, the GTL leadership questionnaire asked if leaders created respect and pride in their followers. In the Salvadoran culture humility is prized, not pride, so people wanted to respond yes to respect but no to pride. Greater adaptation and validity testing of instruments needs to occur. This is true even of the World Values Survey instrument we used for social capital questions, translated in Colombia, which had words that were unfamiliar in El Salvador, and a few responses that again were conflictual for people in the Latino subculture of El Salvador.

Defining leadership. Another problem related to measuring leadership is the issue of who is a leader. We targeted our instruments to everyone in the study. In fact, most organizations have only a few people who carry leadership responsibilities while the vast majority do not. We did not use any measure to determine who was a leader. Thus it's likely that, looking at the entire intervention pool, the small number of people who were leaders would not show as significantly different across the whole sample. This may be why leadership scales in particular in this study showed little differentiation between control and intervention groups.

Measurement sensitivity. Were the measures sensitive enough to pick up significant differences? To the extent that we used valid and reliable instruments, the instruments should have measured the constructs we were interested in. But sensitivity is another question that depends in large part on the sample size. Other studies that found positive results had sample sizes that were two to three times larger than what we were able to attain. Variances due to non-randomized bias errors may have reduced the ability of statistics to detect differences. Increasing sample size and reducing error will be critical to better assessing differences in future quantitative studies on leadership, empowerment, and social capital in the Salvadoran context.

Cultural time and process challenges. Does time move more slowly in El Salvador? Things take longer, much longer, to achieve in El Salvador than in the U.S. El Salvador has many challenges—the large percentage of the population with low educational levels, extreme income differences across society, high levels of fear and trauma that people carry from the past civil war and into the present with crime and gang warfare (El Salvador is among the most dangerous and violent countries in the world, tied for number one with Honduras for highest levels of murder). Does the fact that people have to deal with high levels of violence and fear reduce the benefits of programs like FESEP to such an extent that instruments won't pick up the differences because the effect sizes are smaller? It appears that the correlation of our variable "Years in Program" with a number of outcomes would indicate that the program does make a difference, but that difference can only be captured over longer periods of time.

The impact of social desirability. Did we get accurate or truthful responses from study subjects? Evidenced by the large number of frequencies run that showed high

levels of skewing, inaccurate responding is a possibility. This non-parametric data may

have been caused by several factors. The Salvadoran society has a high respect for

authority and an unwillingness to say no. Highly educated interviewers (including myself

as a foreigner) could have influenced people to "fake well." If people across groups

consistently rate themselves high, it reflects a social desirability effect, that is, they are

trying to make themselves look good for the respected person, or to respond in a way that

is socially accepted, according to social norms rather than as individuals. Because almost

all the data we collected was self-report, there is a possibility that social desirability

influenced findings. In speaking about my results with two Salvadoran professional

university researchers, this was the primary negative influence on my data that they

raised as a possibility (personal communication, Licda. Ana Aguilar de Mendoza and Dr.

Ricardo Gutierrez, March 7, 2016). Implications might include the need for more

objective types of assessments—less self-report data, and more outside input, for

example, 3rd party raters for leadership, assessing the number of empowerment activities

participated in, and counting the number of persons in someone's social networks.

       Program theory. Was the program theory sound? The theory behind the program

is based in the literature on psychosocial rehabilitation, global mental health, social

change, disability rights, and on other areas. The theory that undergirds the program, and

that has guided how the program is structured, is sound and international in scope.

       Program fidelity. Was the program implemented with fidelity? Over the last 14

years, great pains were taken to implement the program accurately. This included,

however, a great deal of adaptation from the original U.S. model to the Salvadoran

context. That process has been ongoing, which speaks to both the need to adapt materials

across cultures and the attention that the Salvadoran team leadership has given to this

process to obtain as fine and useful a product and program as possible in their own

context. This included revisions of program materials by PLMI and family carers as well

as professional psychology and psychiatric staff and volunteers. However, participation

rates have often been very low (one course in 2014 had a rate of 36%) due to multiple

logistical factors and lack of strong follow-up by volunteer leaders. Additionally, there is

little that is systematic among the program components, and thus little with which to

measure fidelity. The family education program is very structured, but none of the many

other components of the program has, to date, been systematized, although the program is

now in the process of systematizing the PLMI weekly art therapy program.

Design. Was the study design and selection of subjects flawed? The design was

selected after extensive discussion Dr. Anuraj Shankar, a senior scientist at Harvard and

specialist in international public health. Although we did our best in this study, the

matching protocol and actual matching process were full of potential biases, from the

overlap in symptomology of mental illnesses, to the uncertainty about what factors may

be influential on outcomes. The context in El Salvador proved difficult to obtain accurate

information for the matching process. We often relied on self-report instead of

consistently written and assessed medical records, and administrative/logistical issues

were difficult to resolve within the national psychiatric hospital.

Entrenched barriers. An interesting question raised by my committee chair was

whether barriers in the Salvadoran context are too strong for measures to overcome to

detect group differences (personal communication, Dr. Margaret Sloan, March 1, 2016).

This harks back to writings by various sociologists as well as Edwards (2014) on social

capital. He states, "the structural barriers that undermine the conditions in which […civil

society] can develop […include] poverty and inequality." These barriers, "remove the

support systems people need to be active citizens and deprive them of the security

required to reach out and make connections with other people" (117). Meeting people's

basic needs is the foundational theory behind the establishment of a mental health

development model by an English NGO called "BasicNeeds," which includes economic

development as a cornerstone of its model along with self-help groups, and psychiatric

treatment and access to medications in rural areas of Africa and Asia.[42] If basic needs

such as unemployment and food cannot be satisfied, how can people have the time and

energy to participate in organizing a civil society group to advocate for systemic change?

The ANOVA statistical tests I ran before taking into account income and other covariates

showed significant differences on many outcomes.[43] However, after taking confounding

variables into account there were few differences. The most frequent covariates were

income and education. In other words, are the outcomes just too difficult to achieve

without higher education and income levels? Do these factors help people attain more

outcomes because they are able to get work and live in neighborhoods where there is less

violence and fear, which in turn reduces barriers to consistent participation? For example,

a frequent concern among some FESEP program participants is that they do not have

$0.20 bus fares to attend workshops. Single parents tend to be poorer and have fewer

other adults to share the caregiving burden, meaning it is more difficult for them to get

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[42] See www.BasicNeeds.org for more information.

[43] Carers on transformational leadership at .060, carers on voluntary leadership at .057, carers on Ryff positive relationships at .055, combined carers and PLMI on Ryff personal growth at .047, Ryff total score for carers at .007, FES community/advocacy domain for carers at .005, social capital trust score for combined carers and PLMI at .014, civil participation for combined and separate scores for carers and PLMI at <.000, and public news interest for carers at .003 and combined carers and PLMI at .016.

away and attend classes or support groups. What is the implication of this idea? For studies, perhaps that randomization, or at least matching along economic and educational factors, is critical to research design. Cluster randomization is another option in which similar communities are matched based on socioeconomic criteria. For programs, perhaps extra support for very poor participants is necessary to facilitate their consistent participation in order to reap real benefits from the program.

Improving program impact for leadership. Meaney (2015), in a quantitative retrospective study of a college leadership development program, and Pyle (2013), in a similar quantitative prospective control and intervention comparison study, both note the importance of using a structured program to obtain positive outcomes. Meaney concluded that leadership experiences at the college and pre-college level without a leadership development program do not result in improved wellbeing. Pyle concluded that a structured semester-long course in leadership does increase leadership capacity and leadership self-efficacy. This study sought to measure development of leadership, yet the intervention does not have a structured leadership development program. Nor does it have structured activities or a defined process through which members can develop a sense of empowerment and increased social capital. These benefits are currently seen and experienced as by-products of participation in the program. This may be a key finding for the program—that to develop complex leadership capacities such as leadership attributes and skills, empowerment to advocate at the individual and societal levels, and social capital that facilitates individual and organizational goals, a structured program based on successful models needs to be developed and incorporated in the FESEP program.

In summary, it appears that the relatively weak findings of this study are due to three major factors: significant types of error (instrument problems, social desirability responses, insufficient sample size); the lack of structured programs that target the development of leadership, empowerment, and social capital; and the challenges of measuring long-term constructs such as leadership and empowerment in the context of a LMIC country.

Generalizability of findings and implications

This study contributes to the field of knowledge in leadership, empowerment, and social capital studies of grassroots programs in LMIC countries by showing that such programs can help develop individual capacities that are important for organizational success, including volunteer leadership attributes, empowerment characteristics, and increased social networks. Certain factors help to increase these capacities, including longer and more intensive participation. Ensuring that such grassroots associations have structured evidence-based programs will increase the likelihood of developing leadership, empowerment, and social capital. In turn, these attributes should results in improved wellbeing for individuals and organizational capacity and success.

Civic engagement was a consistently strong finding in the data analyses. This is reflective of social capital and increased social networks. It is consistent with the high marks given by program participants for "sense of belonging" and the qualitative comments that indicated social support, having friends, having a place to enjoy life, and a safe place to unburden. Some participants also expanded their social networks to the institutional level by participating in advocacy activities and national commissions on

health care reform and disability rights. No control group subjects were participants in civil society organizations involved in these kinds of activities.

This study also raised a number of questions about the appropriateness of some instruments that had not been used or validated before in international settings. In particular, we found no leadership instruments that were appropriate for, tested, or validated in low income countries with grassroots organizational leaders, especially volunteer leaders. The same holds for empowerment scales that can be used with grassroots programs in the area of psychosocial disabilities. This indicates that much more work needs to be done to develop instruments that can measure these kinds of difficult constructs in LMIC countries.

Within the limitations noted in this study, findings are generalizable to other LMIC grassroots organizations that are interested in the development of leadership, empowerment and social capital for their members and organizations. Attaining such benefits is likely to require long-term investments by organizations to achieve these capacities for their members and organizations. External barriers such as poverty, lack of education, and high levels of violence appear to extend the time required for attaining program benefits and reduce the level of benefits attained by members and organizations.

In "Evaluating empowerment: A framework with cases from Latin America," Petesch, Smulovitz, and Walton (2005) note that empowerment is a relatively new concept with many methodological issues to resolve. Being a latent variable that is both an ends and a means to other ends, and functioning within complex communities with cultural, economic and political dynamics, the challenges of measuring empowerment are enormous. Yet "many development practitioners and observers, activists, and poor people

believe that empowerment lies at the core of effective development" (61). In light of this,

and the competing array of demands on the resources, effort, and political capital of

different groups in a society, it is paramount that researchers learn how to assess

empowerment within systematic approaches to evaluation. In other words, implementing

and measuring programs of empowerment is worth the effort despite the cost. I believe

this applies equally well to the development of leadership skills and social capital for

grassroots organizations and nonprofits in LMIC countries where the challenges and

barriers are high and costly.

Recommendations

      Program and policy recommendations. I would urge the organizations that run

FESEP to implement structured programs that are based on successful models to develop

leadership, empowerment, and social capital. The family education and support program

does this to some extent for empowerment, which is probably why empowerment was the

most consistent positive finding, especially for family carers. But other program

components lack such structure. For example, aside from providing limited leadership

experience opportunities, no components focus on leadership development, which was

the weakest area of finding among the three constructs.

      I concur with Speer et al. (2011) in their recommendation that grassroots

participants be provided formal roles or opportunity structures to build relationships,

leadership skills, and organizational competencies (for example, rotating through roles/

responsibilities) and that organizations pursue inter-organizational connections to build

relational and material resources.

Most people in the country go through the government for mental health services, yet the FESEP program is unknown to almost everyone we talked to at the national psychiatric hospital. The associations and the coordinating nonprofit ACISAM need to take advantage of their growing institutional social networks to promote their program and get the hospital to make referrals. Because religious help was valued by a significant proportion of subjects, and because PLMI intervention participants found churches to be especially helpful in their recovery process, churches are another potentially beneficial partner for both referring people to the program and as a site for carrying out public awareness campaigns, helping the religious community to better understand and support their members with mental health conditions.

Because these programs develop important skills and attributes over long periods of time, governments and foundations need to provide long-term support, which is the same conclusion drawn by a Kellogg Foundation (2003) report on leadership and organizational capacity development among U.S. grassroots organizations. Government ministries of health in Central America, unlike in the U.S., are not accustomed to providing financial

Figure 11. FESEP program participants on a home visit to a
member who was ill. Photo by ACISAM.

support to facilitate the development and ongoing work of PLMI and family organizations. This is an important advocacy role that grassroots organizations can assume in these countries.

Recommendations for further research. What have I learned in this study that could improve future detection of real differences for grassroots organizations in LMICs on leadership, empowerment, and social capital outcomes? In order of importance, I list the following recommendations:

- Create structured development programs for leadership, empowerment, and social capital that are grounded in research and thus more likely to show positive outcomes.

- Increase the study sample size. Finding a way to determine appropriate sample size for constructs such as leadership and empowerment is critical. RCT and longitudinal studies referenced in the literature review all had over 200 subjects compared to 140 in this study.

- Randomization is the best means to eliminate bias in a situation in which so much potential bias occurs. Short of randomization, closer matching of groups on additional income and education variables, as well as location of treatment, might improve homogeneity of variance. This will be a huge challenge in LMIC countries where administrative records, logistics, safety, politics, and other issues present significant barriers.

- Further qualitative work needs to be done to better understand these constructs in the context of El Salvador. Too many instruments we used were developed outside the country, usually in countries with very different socioeconomic and cultural realities, and not piloted and tested sufficiently to obtain validity. For example, two

instruments that recorded low outcome results were the transformational leadership

GTL instrument and the PLMI user empowerment scale (BUES). A total item

reliability test showed that 1 of 7 items needed to be removed from the GTL

instrument, while the BUES Cronbach alpha was low at .569, meaning questions

were not measuring well the same underlying construct (PLMI empowerment). In

general this means that we need improved instruments that better capture PLMI-

identified and family carer-identified end-outcomes. I also recommend a continued

focus on measuring a broad range of benefits.

My literature review identified few empirical studies dealing with the

development of leadership, empowerment, or social capital. Likewise, Malhotra and

Schuler (2005) in "Women's empowerment as a variable in international development"

identified 45 empirical studies dealing with women's empowerment. Most were mixed

methods. Only three used repeat measures. This is a reflection of the need for further

studies that can better demonstrate causality through repeat measure studies, especially

randomized and controlled trials.

I also recommend longer studies that can capture changes that appear only over

long periods of time and additional measures that capture changes at institutional levels

and determine if those changes also result in end-impacts on PLMI and family carers,

such as improved access to services and medications and improved quality of life.

Although this study measured PLMI income, it was used only as a covariate. We

did not attempt to determine whether the PLMI intervention mean income (which was

larger than the control group mean income) was a result of participating in the program. It

is possible this is the case, since we know that several participants have learned skills in

the program that have resulted in their ability to make and sell crafts. Some have achieved the courage (thanks to the support of the group, they say) to start their own businesses. For example, one woman went to "Ciudad Mujer," a women's program, to ask for business start-up funds for a fruit-vender business, which she obtained.

We did not ask direct questions to subjects related to their self-perceptions for our study's constructs. For example: Are you a leader? Do you feel empowered? Do you have strong social network and support? This could have provided good information to support or contrast with the instrument measures of characteristics. Asking quantitative questions about their experiences could have provided more objective evidence as well. For example: In how many groups have you had leadership roles? How many times have you participated in advocacy activities? How many people are you connected to in what organizations?

Limitations and Strengths

Limitations. It is possible that the sheer number of statistical analyses run on the data had the potential to result in the relatively few significant findings simply being error. For example, there were 54 original ANCOVA tests run on 16 outcomes but only three findings were found significant at $p < .05$ and all were related to just one outcome (civic participation).

Threats to validity included multiple sources of potential bias, the most important being difficulties and inconsistencies in the matching process, lack of randomization to deal with unforeseen biases, insufficient sample size, uncertainty in some items on measurement instruments, self-report approach to data collection without sufficient triangulation from other data sources, and social desirability response patterns.

Self-report measures are not only problematic for social desirability response issues, but can involve other problems such as memory and other cognitive problems, presentational styles of respondents, and biases arising out of the context within which interviews are carried out or by whom (Diener & Biswas-Diener, 2005).

Perhaps the largest potential bias in this study, aside from our inability to carry out a longitudinal trial, was lack of any database from which we could randomly select the control subjects from the general population rather than from PLMI and carers who already obtain outpatient services from the national psychiatric hospital. It is likely that many carers are already advocates and certainly go to great pains to obtain services for their loved ones. Likewise, PLMI receiving services currently have access to psychiatrists, social workers, psychologists, and other services at the hospital.

Another potentially large bias was that we did not screen for PLMI or carers who had participated in the hospital's programs, whether the day program for PLMI (frequency uncertain) or education and support group for carers (monthly), in order to exclude them from the control group. While the structure, intensity, and activities differ between FESEP and hospital programs, there is still a potential for significant overlap. This is a strong potential bias that went undetected until too late in the study and should be taken into account in future studies.

We had a great deal of difficulty reading the handwriting in medical files to determine diagnoses. Patients usually did not know or understanding their diagnoses. The medical files reflected that diagnoses changed over time and to some extent were likely different due to skills and interpretations of different doctors. Sometimes medical students did initial diagnosis, which would later be corrected or altered by the attending

psychiatrist. Patients, especially within educated families, sometimes research and learn about different conditions and begin to think or realize they have a diagnosis different than what a psychiatrist has labeled them. Another difficulty was interpreting "TMO" (organic mental disorder), which means any symptoms that are the result of a lesion, car accident, or other organic event, yet the person still suffers symptoms similar to (and effectively is) psychosis, depression, or other diagnoses not specified as organic. We encountered two problems related to TMO – one in older files in which for many years doctors used TMO as a generic description of mental illness, a sort of catch-all or simple diagnosis. In more recent medical files TMO was used in reference to organic or potentially organic causes, yet the sub-category was not labeled, so we often had to wait for the doctor, or dig deep into the files, or ask many questions to the patient to determine on our own what the primary condition was. We also categorized some conditions such as deliria and psychosis under the schizophrenia spectrum even though these illnesses could be listed under personality or other disorders, but we did not have sufficient information to make that determination. Finally, confusion and disagreement about what is a mental illness, its label as an illness vs. symptomology, the complicated taxonomy of illnesses (nosology), the difficulty and time required for accurate diagnoses, and the impact of comorbid illnesses and organic causes on the brain, all make for psychiatry being perhaps the most inexact of medical sciences. Combining these challenges with illiteracy, low levels of education, and issues of stigma (doctors often acquiesce to patients' and families' desire not to use psychiatric labels, so diagnoses are not known by families or patients, other than "I can't sleep" and "I have nerve problems") implies significant limitations and potential bias in our study in El Salvador.

Finally, much of my literature review is based on what is available in English. As a result, I've done little to investigate studies in Spanish databases, which was simply a time limitation.

Strengths. The study took a quasi-experimental approach with a matched control group and selection of as many intervention program participants as could be found to help limit bias. The study is a first look at leadership development, social capital and empowerment in members of a civil society association and nonprofit context in LMICs. The study counted on the support of a wide variety of partners, including the government psychiatric hospital, so there was good buy-in from several important stakeholders, reflecting a high level of interest in the study from those partners in El Salvador. Funding allowed costs to be covered, which otherwise would have prevented our ability to carry out such a study in a LMIC country. Subjects in the study genuinely enjoyed the interview process. Some comments included: Thanks for the opportunity to participate. I learned a lot. This interview helped us. The interview was really interesting. It was long but it is important.

Significance of the study

This study adds evidence to the literature that marginalized populations in low and middle income countries who participate in grassroots, participatory programs run by civil society organizations can potentially develop leadership attributes, a sense of empowerment, and increased social capital. It takes long-term organizational and funding support to develop these capacities because of the challenges inherent in LMIC countries. Programs need to identify and implement structured programs to help increase the chances of developing these individual and organizational capacities.

This is the first quantitative study of leadership, empowerment, and social capital development in grassroots mental health organizations in LMIC countries. Much more remains to be done to improve quantitative measures that can help accumulate evidence, demonstrate causality, and help us better understand how these important constructs are developed and what outcomes they are able to accomplish for those who participate in community-based programs in low resource countries that have significant educational, poverty and violence challenges.

GALLERY

Art therapy participant. Photo by ACISAM.

Author with National Psychiatric Hospital director Dr. Gomez and subdirector Dra. Juarez, along with ACISAM staff Nelson Flamenco and Cecilia Almendarez.

Homeless man with mental illness walking near the entrance to the national psychiatric hospital. Photo by the author.

FESEP program PLMI planning activities for the year. Photo by ACISAM.

FESEP program family education and support group. Photo by ACISAM.

ACISAM training social workers at the national psychiatric hospital.
Photo by the author.

Appendix A

Consent Forms in English and Spanish

CONSENT FORM - ENGLISH

Consent to Participate in Research
Identification of Investigators & Purpose of Study

You are being asked to participate in a research study conducted by Samuel Nickels and Dr. Margaret Sloan from James Madison University. We will be assisted by Lic. Nelson Flamenco and Dr. Myrna Rojas from ACISAM, staff from the national psychiatric hospital in Soyapongo, and a research assistant. The purpose of this study is to obtain evidence regarding whether a community program in El Salvador is effective at improving mental health for users of mental health services and family caregivers. There are two groups participating in the study. One group has been part of the community program, while the other group has not been part of the program. At the end of the study we will tell you about the program and invite you to participate if you would like. This study is part of the requirements for Mr. Nickels' doctoral degree program at James Madison University in the United States.

Research Procedures

Should you decide to participate in this research study, you will be asked to sign this consent form once all your questions have been answered to your satisfaction. This study consists of several questionnaires and several research measurement tools that are all in form of questions for you to respond to. The interviews will be carried out in the offices of ACISAM, a hospital, or another place convenient to you as the subject of the study. Researchers will complete the questionnaires and take notes during the interview. We may also review your hospital records. Your information will remain confidential and private to the researchers. An incentive will be provided to each participant of $10/visit for completing an interview, primarily to help reimburse transportation costs. These payments are coming from sources in the United States that are funding the study (the Dorothy Ann Foundation and the Inter-American Foundation).

Time Required

The anticipated length of time to complete the interview is two hours. This does not include time for going to and from the location of the interview. If we cannot finish the interview during two hours, or you are unable to continue, we may decide to schedule a second interview to finish.

Risks

To help reduce the potential risks to you, we are informing you of your rights, including your right to stop participating at any time you wish. The investigators perceive the following are possible risks arising from your involvement with this study:

- You may fear losing access to services at ACISAM or the Hospital, especially if you criticize the programs or services of these organizations. But we assure you that regardless of what you say or how much you criticize, you will not lose access to any programs or services.
- Your comments and answers and personal information are all confidential. They will not be shared with anyone other than the researchers.
- Sometimes people feel stress during a long interview. While the intent of the research is not to induce emotional stress, it may arise. We will take at least one break during the interview. We also encourage you to ask for a break whenever you need it. If we are at ACISAM or the Hospital, there will be a psychologist or psychiatrist available to provide you assistance should you need it.
- We will provide you a copy of this informed consent, if you would like it.
- All of your information will be stored in secure locations where only the researchers will have access to the information.
- The results of this study will be published and presented to the public. However, none of your private information will be shared with anyone outside of the researchers. If we decide to use any of your comments in publications or presentations, we will not use your real name, so your privacy can be protected.
- There are often limits to the protection of confidential data. These can include required reporting of child abuse, specific communicable diseases, the intent to harm oneself or thers, and elder abuse or abuse of vulnerable populations. Finally, investigators may be compelled to release study data in response to legal action.

Benefits

Potential benefits from participation in this study include participants having the opportunity to express their views about mental health issues, programs, and needs. Through this study, participants will contribute to a greater understanding of mental health services in El Salvador, as well as the benefits that can be obtained through programs that seek to develop leadership, empowerment, social inclusion, and other benefits. This research will be shared with people around the world who are interested in improving mental health services for users and families.

Incentives

Finally, there is a small financial incentive of $10 per interview session for participating in the study and to help cover transportation costs to and from the location. Anyone coming to an interview, including a support person or family caregiver, will also receive a $10 payment in addition to the user. This funding would come from the Inter-American

Foundation, which is still pending approval, or from other sources including the Center for Health and Human Development.

Confidentiality

The results of this research may be presented at conferences, as an article in a journal, and shared with mental health leaders in the Salvadoran ministry of health, with global mental health researchers in different countries, and with you. A summary of the results will be made available through ACISAM to any individual wishing to learn about the results of the study, including any and all participants in the study. The results of this project will be written in such a way that participants' identities will not be recognizable. The researcher retains the right to use and publish non-identifiable data.

Participation & Withdrawal

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind. Participants will be paid only upon completion of interviews. Any data collected up to the point of withdrawal may still be used by the researchers as part of the study.

Questions about the Study

If you have questions or concerns during the time of your participation in this study, or after its completion, or you would like to receive a copy of the final aggregate results of this study, please contact:

Samuel Nickels, Researcher   Dr. Margaret Sloan, Advisor
School of Strategic Leadership Studies School of Strategic Leadership Studies
James Madison University   James Madison University
NickelSV@dukes.jmu.edu   Telephone: (540) 568-7020
                                        SloanMF@jmu.edu

Questions about Your Rights as a Research Subject

If you have questions about your rights and wish to communicate with the Chair of the Board that oversees the human subjects research, he may be contacted here:

Dr. David Cockley
Chair, Institutional Review Board
James Madison University
(540) 568-2834
cocklede@jmu.edu

Giving of Consent

I have read this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. I have been given satisfactory answers to my questions. The investigator offered to provide me with a copy of this form. I certify that I am at least 18 years of age.

☐ I give consent for the caregiver or friend listed below to participate in the study with me and to assist me as needed. _____ (initials)

_____

Printed Name of Participant

_____   _____

Signature of Participant   Date

_____

Printed name of assisting caregiver or friend

_____   _____

Signature of assisting caregiver or friend   Date

_____

Name of Researcher completing form

_____   _____

Signature of Researcher   Date

CONSENTIMIENTO INFORMADO – ESPANOL

Consentimiento para participar en la Investigación

Identificación de los investigadores y Propósito del Estudio

Se le pide participar en un estudio de investigación realizado por Samuel Nickels y la Dra. Margaret Sloan de la Universidad James Madison de EEUU. Vamos a contar con la asistencia del Lic. Nelson Flamenco y la Dra. Myrna Rojas de ACISAM, el personal del Hospital Policlinico Arce, y una asistente de investigación. El propósito de este estudio es obtener evidencia con respecto a si un programa comunitario en El Salvador es eficaz en

la mejora de la salud mental para los usuarios de los servicios de salud mental y los cuidadores familiares. Hay dos grupos que participan en el estudio. Un grupo ha sido parte del programa de la comunidad, mientras que el otro grupo no ha sido parte del programa. Al final del estudio, le informaremos sobre el programa y le invitaremos a participar si usted quisiera. Este estudio forma parte de los requisitos para el programa de doctorado del Sr. Nickels en la Universidad James Madison.

Procedimientos de Investigación

Si usted decide participar en este estudio de investigación, se le pedirá que firme este formulario de consentimiento una vez que todas sus preguntas han sido contestadas a su satisfacción. Este estudio consiste en varios cuestionarios y varias herramientas de medida de investigación que están todos en forma de preguntas para que responda. Las entrevistas se llevarán a cabo en las oficinas de ACISAM, un hospital, o en otro lugar conveniente para usted como sujeto de estudio. Los investigadores completarán los cuestionarios y tomarán notas durante la entrevista. También podemos revisar sus registros hospitalarios. Su información se mantendrá confidencial y privada con los investigadores. Un incentivo se proporcionará a cada participante de US $ 10/visita para completar una entrevista, principalmente para ayudar a reembolsar los gastos de transporte. Estos pagos provienen de fuentes en los Estados Unidos que están financiando el estudio (la Fundación Ann Dorothy y la Fundación Interamericana).

Tiempo requerido

La duración prevista de tiempo para completar la entrevista es de dos horas. Esto no incluye el tiempo para ir y venir de la ubicación de la entrevista. Si no podemos terminar la entrevista durante dos horas o si no podemos continuar, podemos decidir programar una segunda entrevista para terminar.

Riesgos

Para ayudar a reducir los riesgos potenciales para usted, le informamos de sus derechos, incluido su derecho a dejar de participar en cualquier momento que desee. Los investigadores perciben como posibles riesgos derivados de su participación en este estudio los siguientes:

• Usted puede temer perder el acceso a los servicios en ACISAM o el Hospital, especialmente si usted critica los programas o servicios de estas organizaciones. Pero le aseguramos que, independientemente de lo que diga o lo mucho que critique, no perderá el acceso a todos los programas o servicios.

• Sus comentarios y respuestas y la información personal son confidenciales. Ellos no serán compartidos con nadie más que con los investigadores.

• A veces la gente se siente estresada durante una larga entrevista. Aunque la intención de la investigación es no inducir el estrés emocional, puede surgir. Vamos a tomar por lo menos un descanso durante la entrevista. Le invitamos a pedir un descanso siempre que lo necesite. Si estamos en ACISAM o el Hospital, habrá un psicólogo o psiquiatra disponible para proporcionarle asistencia en caso de necesitarla.

• Nosotros le proporcionaremos una copia de este consentimiento informado, si lo quisiera.

• Toda su información se guardarán en lugares seguros donde sólo los investigadores tendrán acceso a la información.

• Los resultados de este estudio serán publicados y presentados al público. Sin embargo, ninguna de su información privada será compartida con nadie fuera de los investigadores. Si decidimos utilizar cualquiera de sus comentarios en publicaciones o presentaciones, no vamos a usar su nombre real, por lo que su privacidad será protegida.

• También, a menudo hay límites a la protección de los datos confidenciales. Estos pueden incluir informes requeridos de la intención de hacer daño a sí mismo o a los demás, y de maltrato a personas mayores o personas vulnerables. Por último, los investigadores pueden ser obligados a conocer los datos del estudio en respuesta a una acción legal.

Beneficios

Los beneficios potenciales de la participación en este estudio incluyen: para los participantes tienen la oportunidad de expresar sus puntos de vista sobre cuestiones de salud mental, programas y necesidades. A través de este estudio, los participantes contribuirán a una mayor comprensión de los servicios de salud mental en El Salvador, así como los beneficios que se puedan obtener a través de programas que buscan desarrollar el liderazgo, el empoderamiento, la inclusión social y otros beneficios. Al final de la entrevista recibirán una invitación para participar en el programa que estamos estudiando. Esta investigación será compartida con personas de todo el mundo que están interesados en mejorar los servicios de salud mental para los usuarios y las familias. Por último, hay un pequeño beneficio económico de $ 10 por entrevista por participar en el estudio y para ayudar a los costos de transporte cubriendo hacia y desde la ubicación. Cualquiera que venga a una entrevista, incluyendo una persona de apoyo o cuidador familiar, también recibirá un pago de $ 10 además del usuario. Estos fondos provienen de la Fundación Interamericana u otra fuente como Centro de Salud y Desarrollo Humano.

Confidencialidad

Los resultados de esta investigación pueden ser presentados en conferencias, como un artículo en una revista, y se comparten con los líderes de salud mental en el Ministerio de Salud de El Salvador, con los investigadores mundiales de salud mental en los diferentes

países, y con ustedes. Un resumen de los resultados se pondrá a disposición a través de ACISAM y el Hospital para cualquier persona que desee aprender sobre los resultados del estudio, incluyendo cualquier y todos los participantes en el estudio. Los resultados de este proyecto serán escritos de tal manera que las identidades de los participantes no serán reconocibles. El investigador se reserva el derecho a utilizar y publicar los datos no identificables.

Participación y Retiro

Su participación es completamente voluntaria. Usted es libre de optar por no participar. Si decide participar, puede retirarse en cualquier momento sin consecuencias de ningún tipo. Los participantes serán pagados sólo al final de las entrevistas. Los datos recogidos hasta el punto de retirada todavía pueden ser utilizados por los investigadores como parte del estudio.

Preguntas sobre el Estudio

Si usted tiene preguntas o preocupaciones durante el tiempo de su participación en este estudio, o después de su terminación, o le gustaría recibir una copia de los resultados agregados finales de este estudio, por favor póngase en contacto con:

Samuel Nickels, Investigador
Universidad James Madison
NickelSV@dukes.jmu.edu, Teléfono: (540) 568-7020
o
Dra. Margaret Sloan, Asesor
Facultad de la Escuela de Estudios de Liderazgo Estratégico de Estudios de
Liderazgo Estratégico
SloanMF@jmu.edu, Teléfono: (540) 568-7020

Preguntas sobre sus derechos como sujeto de investigación

Si usted tiene preguntas acerca de sus derechos y desea comunicarse con el Presidente de la Junta que supervisa la investigación con sujetos humanos, puede ser contactado en:

Dr. David Cockley
Presidente de la Junta de Revisión Institucional
James Madison University
(540) 568-2834
cocklede@jmu.edu

Consentimiento

He leído este formulario de consentimiento y entiendo lo que se solicitó de mí como participante en este estudio. Doy mi consentimiento a tomar parte libremente. Se me han dado respuestas satisfactorias a mis preguntas. El investigador se ofreció a darme una copia de este formulario. Certifico que soy mayor de 18 años de edad.

Doy mi consentimiento para que un/a cuidador/a o amigo/a participe en el estudio conmigo y que me ayude cuando sea necesario. _____ (iniciales)

_____

Nombre del participante

_____ _____

Firma del participante   Fecha

_____

Nombre ayudante cuidador o amigo

_____ _____

Firma de ayudante cuidador o amigo   Fecha

_____

Nombre del Investigador

_____ _____

Firma del Investigador   Fecha

Appendix B[44]

Sociodemographic and medical information questionnaire[45,46]

TOTAL ESTIMATED TIME FOR ADMINISTRATION OF CONSENT, QUESTIONNAIRES, AND TESTS = 1 HR 45 MINUTES + 15 MIN BREAK = 2 HRS. Process notes:

Users will not be present when caregivers answer their questionnaires.

Caregivers[47] will be present for the first section of questions for the user, pending consent from the user. Later questions will be asked without the presence of caregivers (for example expressed emotion questions where the user is asked to state how critical the caregiver is of the user). Caregivers may be asked to return when instruments are used, if the user prefers to have the caregiver present.

The interviewer will instruct any caregiver helping a user to permit the user to speak fully and completely to each answer without any assistance first before contributing further information. If the caregiver appears to be dominating the answers, the interviewer may ask the caregiver to remain silent unless asked by the user or by the interviewer for assistance.[48]

1. **Administrative information**

2. Unique ID number:
3. Subject is
a. CONTROL group
b. INTERVENTION group
4. Date of interview1:

---

[44] The English and Spanish versions here are slightly different due to adjustments we made to make questions more clear and readable, but content is essentially the same.

[45] Portions of this questionnaire are taken from a tool obtained through the Mental Health Innovation Network website (MHInnovation.net). A special thanks to Grace Ryan from MHIN for her assistance.

[46] The questionnaire will be divided into 4 questionnaire formats (control users, interventional users, control caregivers, intervention caregivers. For ease of presentation, this questionnaire is a combined format.

[47] Because some users are independent and/or offended by calling the family member a caregiver, the term "familiar" (family member) will be used rather than "cuidador" (caregiver) in the Spanish versions. This will also support the validity of the Expressed Emotion questions, which determine the level of criticism of family members towards the person with a mental condition.

[48] Disagreements or differing information may occur frequently between user and family caregiver. Another issue may be that either the caregiver or the user is dominant, having developed a pattern of relational behavior in which the other person will not correct or provide accurate information or even their own opinion in front of the other person. The interviewer will need to make decisions that balance the need for accurate information with right of the user to answer her own questions, reflecting the mental health disability rights moto "Nothing about us without us."

a. Interviewer(s):
5. Date of interview2:
a. Interviewer(s):
6. Has subject given consent to participate in study? Y N
7. First names:
8. Surnames:
9. Contact info (phone, email, address):
a. Self:
b. Backup: (name, relationship to subject):
c. Description of location of residence in case we have to follow-up visit:
10. Is this location: rural (outside of cities) or   urban (city)

2. Demographic information
1. Date of birth:
2. Subject is age 18 or above? (if no, then discontinue interview) Y N
3. Gender: male / female
4. Marital status: never married, married, co-habiting, separated, widowed, divorced
5. Number of children:
6. Educational level (completed):
a. no school, not literate
b. literacy classes/literate
c. primary 1-3
d. primary 4-6
e. secondary
f. trade school
g. some college
h. completed university
i. graduate degree completion
7. Occupation:
a. unable to work due to disability (mental or physical ?)
b. able to work but unemployed
c. in training
d. student
e. homemaker/childcare/adultcare
f. formal sector work (part time, fulltime)
g. informal sector work (part time, fulltime)
h. retired
i. uncertain response
j. disagreement between caregiver and

8. Who lives together with you? (list relationships: father, mother, sibling, your children, other children, grandparents, grandchildren, uncles, aunts, adult friends, etc.)
Family caregiver only:
9. Are there more than one user in the family with mental illness? How many?
10. Age of your loved one(s) (user):
11. Number of years user(s) had his/her illness:
NOTE: if a caregiver cares for more than one person with mental illness, then the interviewer should note the names of each one and write down responses of the caregiver for each person with mental illness. For example, if there are 2 children a mother cares for who both have mental illness, then the diagnosis for each one would be notated. Thus, below "user" is singular, but 1 or 2 or more individuals may be listed.]
12. Do you live with your family caregiver(s) (or for caregiver: Does your user live with you?). Y N
      a. If not, How often do you interact?
    b. What kind of support does the family provide to the user?
      c. Why do you not live together?
13. The person being interviewed is a user, caregiver or both?
NOTE: If person is both a user and caregiver, the person may choose whether to be interviewed as a user or as a caregiver. The interviewer should explore with the person which is the predominant role this person plays. For example, if the person does not suffer significantly from an illness, but plays a primary caretaker role for another person with a mental illness, then we would encourage the person to be interviewed as a caregiver; or if the person lives with a spouse and both have severe illnesses while helping to take care of each other, then we would encourage the person to be interviewed as a user.

3. Income/Productivity information
1. User information (user gives this information, or family members gives it for loved one[49])
Types of productivity that the user performs:
1. Can perform volunteer work (4 hrs/month, 1 hr/week or more)? Y N
      a. If yes, do you (he/she) perform volunteer work? Y N
      b. If yes, what kind of volunteer work?
2. Can perform regular paid work: Y N
      a. If yes, do you (he/she) perform paid work?
      b. If yes, is it part time or fulltime?
3. Can you perform unpaid work such as childcare or adult care? Y N
      a. If yes, do you (he/she) perform unpaid work?
      b. If yes, what kind of unpaid work?

---

[49] The phrase "loved one" refers to the person with a mental condition for whom this person is caring.

      c. If yes, is it part time or fulltime?

4. Can perform regular chores and responsibilities at home? Y N

5. Have a disability which totally incapacitates (cannot even do chores)? Y N

6. Receive disability payments?

7. Receive retirement income?

8. Income over the last 30 days from paid work (estimated amount):

9. Income over the last 30 days from retirement or disability payments:

10. Income over the last 30 days received from gifts:

      a. Who provided the gift (relationship):

11. Income from other sources (from where, and how much):

12. Total income for the last 30 days (sum the last 4 items):

      a. How accurate is this information?

      Not very accurate, Pretty accurate, Very accurate

    2. Family caregiver information

Types of productivity that the caregiver performs:

1. Can perform volunteer work (4 hrs/month, 1 hr/week or more)? Y N

      a. If yes, do you perform volunteer work? Y N

      b. If yes, what kind of volunteer work?

2. Can perform regular paid work: Y N

      a. If yes, do you perform paid work?

      b. If yes, is it part time or fulltime?

3. Can you perform unpaid work such as childcare or adult care? Y N

      a. If yes, do you perform unpaid work?

      b. If yes, what kind of unpaid work?

      c. If yes, is it part time or fulltime?

4. Can perform regular chores and responsibilities at home? Y N

5. Have a disability which totally incapacitates (cannot even do chores)? Y N

6. Receive disability payments?

7. Receive retirement income?

8. Income over the last 30 days from paid work (estimated amount):

9. Income over the last 30 days from retirement or disability payments:

10. Income over the last 30 days received from gifts:

      a. Who provided the gift (relationship):

11. Income from other sources (from where, and how much):

12. Total income for the last 30 days (sum the last 4 items):

      a. How accurate is this information?

      Not very accurate, Pretty accurate, Very accurate

3. Family income (everyone living together)

8. Income over the last 30 days from paid work (estimated amount):

9. Income over the last 30 days from retirement or disability payments:

10. Income over the last 30 days received from gifts:

    a. Who provided the gift (relationship):

11. Income from other sources (from where, and how much):

12. Total income for the last 30 days (sum the last 4 items):

    a. How accurate is this information?

    Not very accurate, Pretty accurate, Very accurate

4. Mental health program participation information

1. Are you familiar with ACISAM or have you participated in any of ACISAM's mental health programs? Y N

    a. If no, confirm person is in control group

    b. If yes, confirm person is in intervention group

2. Is the caregiver directly related to the user? Y N

    a. If not, what is the relationship?

3. Which of the following services or treatment programs have you as a user or caregiver participated in at any time in the past (for user, answer for self; for caregiver, answer for self and loved one):

a. Psychiatric hospital or hospital psychiatric unit?

b. Mental health assistance at a public health clinic?

c. Mental health assistance from a private family doctor?

d. Mental health assistance at a Ciudad Mujer women's center?

e. Mental health assistance from any other government program?

f. Mental health assistance from a non-governmental community mental health program?

g. Mental health assistance from a religious leader?

h. Mental health assistance from a curandero/a?

i. Mental health assistance from any other individual or

Institution?

j. If yes, specifically name the person/institution:

Program/service ratings

For each program/service above that the person participated in, ask them to rate it on the following scale: 1-10 from very helpful to very hurtful. If the person doesn't know or doesn't answer, circle the appropriate response:

a. SELF:

Very helpful ……………………………………………………… very hurtful

    1   2   3   4   5   6   7   8   9   10

Don't know, No answer

b. LOVED-ONE:

Very helpful ……………………………………………………… very hurtful

    1   2   3   4   5   6   7   8   9   10

Don't know, No answer

5. FESEP program participation information

[THIS SECTION IS LOCATED AT THE END OF ALL THE QUESTIONNAIRES AND IS ADDRESSED ONLY TO INTERVENTION PARTICIPANTS.]

FESEP intervention subjects only:

1. For participants in the FESEP program, ask them to rate it on the following scale: 1-10 from very helpful to very hurtful. If the person doesn't know or doesn't answer, circle the appropriate response:

      a. SELF:

Very helpful …………………………………………………………… very hurtful

      1   2   3   4   5   6   7   8   9   10

      Don't know, No answer

      b. LOVED-ONE:

Very helpful …………………………………………………………… very hurtful

      1   2   3   4   5   6   7   8   9   10

      Don't know, No answer

Level of participation in the FESEP program:

2. Which program components have you (and your loved one) participated in? (see list, Card A)

      a. How many months/years of participation in each component?

3. For caregivers only: Which program components if any your consumer family member participated in?

      a. How many months/years of participation in each component?

      Program components include:

Family to family classes for family caregivers

Psychosocial art therapy group for users

Assemblies

Telephone attention

Home visits attention

Received training as a family class instructor

Marches or other protests and advocacy for improving mental health laws

Awareness raising workshops for professionals

Recreational trips

Service on a national human rights, disability, health, or other commission

Special trainings

Service on the organizational board

Service on the planning committee

Other activity not included above (describe it)

6. Medical information

Diagnosis

    1. Diagnosis(es) (if not known, write "uncertain"). You may check more than one.

      SELF   LOVED-ONE

Depression

Schizophrenia

Anxiety

PTSD/Trauma

Bipolar

Epilepsy

Other (write it out):

Undiagnosed/uncertain

2. How long have you (and/or user) had problem? MONTHS _ _   YEARS _ _

Enter only months if less than one year, and 00 for years

Illness severity[50]

    3. Severity of illness over last 30 days (user self-report or report of caregiver about user):

1	2	3	4	5	6	7
Normal	borderline	mild	moderate	marked	severe	worst

Expressed emotion (questions only for user)[51] **[THIS SECTION WAS RE-WORKED ON A SCALE OF 1-10 TO BE CONSISTENT WITH THE PERCEIVED CRITICISM QUESTIONS BELOW, #6 AND #7.]**

4. Attitude of family towards problem:

    positive (try to change attitudes of others toward problem)

    accepting (open about problem)

    ashamed (try to hide problem)

5. Willingness of family to help:

    supportive and want to help

    reluctant to help

    refuse to help

Perceived Criticism questions:

6. How critical of you are your relatives (that is, those who live with you)?

7. When your relative criticizes you, how upset do you get?

---

[50] Caregiver-report and user self-report severity will be compared against GHQ-12 outcomes to determine the strength of correlation between non-professional family and self-reporting and the GHQ-12 validated test for severity.

[51] The expressed emotion questions are very important to not have present the family caregiver when the user is answering these questions due to the strong potential for bias.

Grade each on 10pt Likert scale:

Extremely critical …………………….…………………… Not critical at all

1	2	3	4	5	6	7	8	9	10

Extremely upset ………………………………………...…….. Not upset at all

1	2	3	4	5	6	7	8	9	10

Medications: access and compliance

8. How often do you have access to the medications you need for yourself (or your loved one)?

All the time   Often   Sometimes   Not often   Rarely   Never

9. How compliant are you (or your loved one) with taking medications prescribed by the doctor for your mental condition?

Very compliant, Sometimes compliant, Not usually compliant, Never compliant

10. Do you (or your loved one) think that you have a mental condition? Y N

Crises/relapses/hospitalizations

11. Number of crises that you (or your loved one) had during the last 12 months?

12. Number of crises in the last 12 months that resulted in hospitalizations?

13. Number of hospitalizations during your (or your loved one's) lifetime?

Cuestionario Sociodemográfico[52]

INSTRUCCIONES: en cursivo. Las instrucciones deben ser seguidas estrictamente ya que la validez del instrumento y sus resultados depende de que los/as entrevistadores/as sigan todas las directrices. Si hay preguntas, deben consultar a Sam para aclararlas, si Sam no está presente, entonces deben consultar con Mariely. El número de Sam es 7050-8053. El número de Mariely es 7831-9339.

[TODOS]

A. Información administrativa

1. Número de ID: _____ *[Dado por Sam/Mariely, no se llena]*
2. El sujeto es

---

[52] Una parte de este cuestionario fue tomada de una herramienta obtenida a través del sitio web de la Red de Innovación en Salud Mental (MHInnovation.net). Un agradecimiento especial a Grace Ryan de la MHIN por su colaboración.

a. Grupo CONTROL
b. Grupo de INTERVENCIÓN
3. Fecha de la entrevista 1:
a. Entrevistador(es):
4. Fecha de la entrevista 2:
a. Entrevistador(es):
5. El sujeto ¿ha dado su consentimiento para participar en el estudio? Sí   No

B. Información demográfica

1. Nombres:
2. Apellidos:
3. Información de contacto (teléfono, email, dirección):
a. Propia:
b. Respaldo (nombre, relación con el sujeto):
   4. Este lugar es: rural (en el campo)   urbano (ciudad)
   5. Fecha de nacimiento:
   6. El sujeto tiene 18 años o más (si no, entonces termine la entrevista)   Sí   No   *[Si NO, detenga la entrevista. No podemos entrevistar a personas menos de 18 años.]*
   7. Género: Femenino Masculino
   8. Estado civil: nunca casado/a   casado/a   acompañado/a   viudo/a

           divorciado/a o separado/a

[SÓLO SUJETOS DEL GRUPO DE CONTROL]

C. Verificación del Grupo de Control

1. ¿Está usted familiarizado con ACISAM, ASFAE o AFAPDIM y ha participado en alguno de los programas de salud mental de esos grupos? Sí   No
           [a. Si, no, está verificado que la persona está en el grupo control]
        [b. Si, si, parece que la persona posiblemente tiene que cambiar grupos: aclarar con Mariely o Sam si la entrevista debe continuar]

[SÓLO CUIDADORES/AS]

D. Verificación de Estatus de CUIDADOR/A
¿Es usted cuidador/a principal[53] de alguien que tiene una enfermedad mental?   Sí   No

---

[53] Un/a cuidador/a puede ser familiar o amigo/a o cuidador legal. El punto es que la persona tiene responsabilidad más que cualquier otra persona para el/la usuario/a. Puede vivir o no vivir con la persona. Para este estudio es también importante que la persona cuidadora conoce bien y conoce por tiempo al usuario/a.

[Si, NO, determinar si el cuidador/a cumple con los siguientes criterios como cuidador:

- *Es de hecho, un/a cuidador/a de una persona con una enfermedad mental o un desorden neurológico,*
- *Conoce bien al usuario/a, y*
- *Tiene conocimiento de la historia de vida del usuario/a.]*

[Si la persona no es un cuidador/a (primario o secundario) entonces aclarar con Mariely o Sam si la entrevista debe continuar.]

E. Relaciones familiares y condiciones de vida

[TODOS]

Contactos sociales

1. ¿Usted vive con otras personas? *[no vive solo, no es indigente]*   Sí   No
     [Si vive con otros, ¿Con Quién?]
a. Padres (número _____)
b. Esposo/a o compañero/a (número _____)
c. Hermanos/as (número _____)
d. Hijos (número _____)
e. Abuelos/as (número _____)
f. Nietos/as (número _____)
g. Otros familiares (número _____)
h. Amigos/as (número _____)
i. Otros (número _____)

[USUARIOS SOLAMENTE]

2. ¿Usted vive con un/a esposo/a o compañero/a (usted no está soltero/a, separado/a, divorciado/a, viudo/a)? Sí   No
3. ¿Cuál es su nivel de contacto con su familia (incluida la familia extendida):
    Nada   Poco   Bastante   Mucho
4. Fuera de su familia, ¿tiene amigos/as (personas con las que habla y se divierte, por ejemplo, personas de su vecindario, de una organización de la comunidad, o la iglesia) Sí No
5. ¿Asiste a eventos, convivios sociales, reuniones o celebraciones fuera de su casa por lo menos una vez al mes? Sí   No
6. ¿Tiene un/a mejor amigo/a, alguien en quien usted confíe? (esto puede ser alguien en su familia o fuera de su familia) Sí   No

[SÓLO CUIDADORES/AS]

Relaciones entre Usuarios y Familiares

1. ¿Cuales son los nombres de personas con problemas de salud mental, trastornos mentales o discapacidades mentales en la casa o quien lo/la cuida?
    i. Nombre:
        1. Vive contigo? Si   No
        2. Relación con el usuario:
    ii. Nombre:
        1. Vive contigo? Si   No
        2. Relación con el usuario:
    iii. Nombre:
        1. Vive contigo? Si   No
        2. Relación con el usuario:
2. ¿Hay otros adultos cuidadores que le ayudan?   Sí   No
3. ¿Tiene usted, también, un diagnóstico de enfermedad mental? Sí   No   *[si, SÍ, entonces, aclarar si la persona es cuidador/a principal, si él/ella no es cuidador/a principal, preguntar a Sam o Mariely porqué esta persona está siendo entrevistado como cuidador/a en vez de como usuario/a]*
4. *Características de ser/es querido/s a quienes ella cuida (sin importar si viven con ella o no):*
    i. Edad de su/s ser/es querido/s (usuario/s): ___
    ii. Número de años que el/los usuario/s ha/n tenido la enfermedad: ___
    iii. Número de años con tratamiento: ___
    iv. Género:

[NOTA: si el cuidador cuida a más de una persona con enfermedad mental, el entrevistador debe anotar los nombres de cada uno y escribir las respuestas del cuidador por cada persona con enfermedad mental. Por ejemplo, si hay una madre cuida a dos hijos con enfermedad mental, entonces debería ser anotado el diagnóstico de cada uno. Así, bajo "usuario" es singular, pero 1 o 2 o más personas pueden ser enlistadas.]

[TODOS]

F. Educación
1. Último grado que completó: _____ *[circular la letra abajo][**selecciona solamente uno**]*
a. Nunca fue a la escuela
b. Clases de alfabetización/ lee y escribe
c. Primer ciclo de educación básica (1° a 3°)

d. Segundo ciclo de educación básica (4° a 6°)
e. Tercer ciclo de educación básica (7° a 9°)
f. Bachillerato
g. Estudios técnicos
h. Universidad incompleto
i. Universidad
j. Postgrado

G. Ocupación

¿Cuál es su ocupación? *[**selecciona solamente uno**, lo mejor opción, lo ocupación principal]*

1. Trabajo remunerado (formal o informal)
2. Autoempleo, como su propio negocio o agricultor.
3. Trabajo no remunerado, como trabajo voluntario o caridad.
4. Estudiante
5. Oficios en casa (ama de casa)
6. Retirado/a
7. Desempleado (motivos de salud-psicológica/psiquiátrica o mental)
8. Desempleado (otros motivos)
9. Otra ocupación (especificar): _____

H. Ingreso Familiar (en los últimos 30 días)
Ingreso familiar (Usted y otras personas que viven con usted; cantidad estimada)

1. Ingreso por trabajo remunerado de usuario/a: _____
2. Ingreso por trabajo remunerado de los demás en la casa: _____
3. Ingreso por pensión de retiro o discapacidad de usuario/a: _____
4. Ingreso por pensión de retiro o discapacidad de los demás en la casa: _____
5. Ingreso por ayudas (regalos, remesas) en los últimos 30 días: _____
a. Quien da la ayuda (regalo) (relación/parentesco): _____
6. Ingreso de otras fuentes (de dónde y cuánto):   _____
7. Total de ingresos en los últimos 30 días (total de los montos arriba):   _____
a. *¿Qué tan precisa es esta información?*
1) *No muy precisa*
2) *Precisa*
3) *Muy precisa*
QUIÉN DA LA INFORMACIÓN:

_____

ENTREVISTADOR/A: persona es [seleccionar SÓLO una respuesta, 1 o 2]
1. *Desempleado*
2. *Tiene algún tipo de ingreso o es productivo/a (productivo es trabajar en casa, hacer quehaceres, estudiar, etc.)*

I. Participación en servicios de salud mental (sobre Usuario/a)

¿En cuáles de los siguientes servicios de salud mental o programas de tratamiento ha participado usted *[o ser querido]* en cualquier momento en el pasado? Por cada servicio en que usted *[o ser querido]* ha participado, como los califique con la siguiente escala: 1-10 desde de muy perjudicial a muy útil:

Muy perjudicial…..……………………………………………… Muy útil
1   2   3   4   5   6   7   8   9   10   *No sabe No responde*

		USUARIO/A	CALIFICACIÓN
	Hospital psiquiátrico o unidad psiquiátrica en un hospital general	Sí No	
	Unidad de salud	Sí No	
	Clínica privada	Sí No	
	Programas comunitarios de salud mental de una organización no-gubernamental (*)	Sí No	
	Iglesias o líderes religiosos	Sí No	
	Curandero/a tradicional	Sí No	
	Otra persona o institución. Especifique:	Sí No	

(*) referiere a ACISAM, AFAPDIM, ASFAE u otros programas de salud mental de los ONGs, iglesias, etc.

J. Información Médica

Diagnóstico
Puede marcar más de uno.

	USTED MISMO/A	SU SER QUERIDO/A
Depresión		
Esquizofrenia		
Ansiedad		

TSPT/Trauma		
Bipolar		
Epilepsia		
Otro (escríbalo):		
Sin diagnóstico/dudoso		

[ENSEÑA AL SUJETO LOS ESCALAS POR ABAJO]

Severidad de la enfermedad

¿Qué fue lo más severo de la enfermedad en los últimos 15 días?

1	2	3	4	5
Leve	Moderada	Notable	Severa	Crisis

Medicamentos: acceso y cumplimiento

1. ¿Qué tan a menudo tiene acceso a los medicamentos de salud mental que usted *(o su ser querido)* necesita?

Todo el tiempo   A menudo   No tan a menudo   Nunca   No toma medicamentos

2. ¿Qué tan cumplido es usted *(o su ser querido)* con la toma de los medicamentos? *[No importa   si lo toma por el o ella misma o alguien se lo da.]*

Todo el tiempo   A menudo   No tan a menudo   Nunca   No toma medicamentos

3. ¿Usted *(o su ser querido)* piensa/reconoce que tiene una enfermedad mental? Sí No

Cumplimiento del tratamiento

1. ¿Que tan cumplido es Ud (o su ser querido) con citas al psiquiatra?
Para nada   Algunas veces   Siempre

2. ¿Ud (o su ser querido) se apega a las instrucciones del médico?
Para nada   Algunas veces   Siempre

Recaídas e ingresos
1. Cuantas recaídas (crisis) durante los últimos 12 meses: ____
2. Cuantas recaídas que resultaron en ingresos en un hospital o unidad de psiquiatría durante los últimos 12 meses: ____

3. Cuantas recaídas en los últimos 12 meses que Uds. manejaron sin ingresar a un hospital: ____

4. Cuantas ingresos durante todo la vida: ____ *(número de ingresos)*

Definimos "recaída" en este estudio asi: comportamiento que incluye uno o más de estos comportamientos -- violencia, intento de suicidio, psicosis fuerte, sintomas que causa la persona para estar incapacitado, o ingreso en un hospital o unidad de psiquiatría. La familia puede definir un recaída en referencia al comportamiento típico de su ser querido.

Appendix C

Instruments

This appendix includes questions from the instruments used in this study. Copyrighted instruments show only sample questions. Open access instruments are provided complete. Some information on sources, reliability and validity, our adaptations, and other information is also included.

LEADERSHIP

GTL—Global transformational leadership scale

This instrument has been used in a few studies and has strong reliability and validity. It is a short 7 item tool that, unlike the better-known Multifactorial Leadership Questionnaire (MLQ), measures only transformational leadership. The MLQ measures leadership styles across a single spectrum, from transformational to passive. My thinking is that if the MLQ measures a spectrum, then the stronger someone is on transformational leadership, the weaker they are on passive leadership (with transactional style being in between). Thus, measuring just transformational leadership is sufficient if the goal is to measure the most important impact of interest to use (transformational leadership is the best style in terms of follower satisfaction and performance). In light of these issues, I chose the GTL over the MLQ for this study. The GTL required translation and cognitive interviews, which we completed. No cultural adaptations were needed, and translation was checked with back-translation technique.

Items and Time to administer: 7 items, 2-4 minutes to administer

Instrument development and history: The instrument was developed by Carless and colleagues (Carless, Wearing, & Mann, 2000) as an alternative to long instruments such as the Multifactor Leadership Questionnaire (MLQ; Avolio, Bass, & Jung, 1995), the Conger-Kanungo scale (Conger & Kanungo, 1994) and the Leadership Practices Inventory (LPI; Kouzes & Posner, 1990) that assess a range of leader behaviors but are time consuming to complete. Their goal was to develop a short, practical instrument of transformational leadership which is easily administered and scored yet is also reliable and valid. They developed the questions using a literature review of transformational leadership by Podsakoff, McKenzie, Moorman, and Fetter (1990), and concluded that transformational leadership can be summarized by six behaviors: identifying and articulating a vision, providing an appropriate model, fostering the acceptance of group goals, high performance expectations, providing individualized support to staff and intellectual stimulation. They then added charismatic behavior (Bass, 1985) and proposed the following behaviors encompass the concept of transformational leadership: (1) communicates a vision, (2) develops staff, (3) provides support, (4) empowers staff, (5) is innovative, (6) leads by example, and (7) is charismatic." The GTL was compared to the LPI and MLQ for convergent validity, and correlations ranged from .76 to .88 with a

mean of .83 (SD = .04), indicating strong convergent validity. T-tests were used to show that the GTL discriminates significantly between all of the contrasted groups: (a) highly motivated subordinates compared with less motivated subordinates; (b) high and poor performing managers (based on District Manager and subordinate ratings); and (c) highly effective leaders compared with less effective leaders. These findings provide substantial evidence of the discriminant validity of the GTL. I also found that several other studies had used this instrument with adequate indications of reliability and validity.

Reliability and Validity: The study had a sample of 1,440 subordinates who assessed the leader behaviour of 695 branch managers in a large Australian financial organisation. Exploratory and confirmatory factor analysis showed that the GTL measured a single construct of leadership
and had satisfactory reliability. The possible range in scores on the GTL is 7-35. The mean score was 25.00 and the standard deviation was 6.76. These statistics indicate that there is adequate dispersion of scores on the GTL. Cronbach's alpha was calculated as .93, which supports the conclusion that the GTL is a reliable measure of transformational leadership. The EFA eigenvalue was 5.0 which explained 71% of the variance. The exploratory factor loadings ranged from .78 to .88 with a mean of .84 (SD = .05).

Changes and Limitations: The GTL was designed and tested as an instrument to be filled out by either a subordinate or a direct superior. We adapted the instrument into a self-assessment instrument. While this is similar to what the World Health Organization does with its instruments (e.g., WHODAS and WHOQOL), which are offered in self-assessment, 3rd party or proxy assessment, or interviewer-administered versions, the original article reliability and validity work was done on a 3rd party assessment model.

Language: We could not find a Spanish version, so we translated and used a back-translation process with independent translators to test the accuracy of translation. The scale was then run through a cognitive interview with 3 subjects and revised for clarity and simplicity.

Scoring: Item scores are summed for a total score. "High scores suggest the manager makes extensive use of transformational leadership, low scores are associated with infrequent or rare use of transformational leadership."

Permission obtained, and from whom: The scale is available in the seminal article cited above. The scale does not appear on the web anywhere for sale or use. I tried to contact the lead author without success. She doesn't appear to be at the institutions where she was 10-15 years ago, indicating possible retirement or perhaps deceased. I will cite the seminal article when using the scale in this publication and report coefficients from use with our sample.

	SampleSize	Raters	Mean	Stand. Dev.	
Cronbach alpha					
Original findings:	n=1440	external raters	25.00	6.76	.93.
This study	n=138	self-raters	21.20	5.29	.83.

Conclusions: The alpha is strong but not as strong as the Australian study. Removing 1 of 7 items (#7) would not improve the alpha but nor would it significantly diminish the alpha (.831); this last question has the potential to improve the alpha if it is adjusted to be more culturally appropriate. Third party rating may also improve the alpha (our study used only self-rating).

Questions in English and Spanish:
How often do you do the following as part of a group or as a group leader?

(1) As a leader or group member I communicate a clear and positive vision of the future.

Rarely or never	infrequently	sometimes	frequently	very frequently or always
0	1	2	3	4

(2) As a leader or group member I support and encourage the development of other individuals.

Rarely or never	infrequently	sometimes	frequently	very frequently or always
0	1	2	3	4

(3) As a leader or group member I give encouragement and recognition to others.

Rarely or never	infrequently	sometimes	frequently	very frequently or always
0	1	2	3	4

(4) As a leader or group member I foster trust, involvement and co-operation among team members.

Rarely or never	infrequently	sometimes	frequently	very frequently or always
0	1	2	3	4

(5) As a leader or group member I encourage thinking about problems in new ways and I question assumptions.

Rarely or never	infrequently	sometimes	frequently	very frequently or always
0	1	2	3	4

(6) As a leader or group member I am clear about my values and I practice what I preach.

Rarely or never	infrequently	sometimes	frequently	very frequently or always
0	1	2	3	4

(7) As a leader or group member I instill pride and respect in others and I inspire others by being highly competent.

Rarely or never	infrequently	sometimes	frequently	very frequently or always
0	1	2	3	4

Como lider o miembro del grupo, que tan a menudo realiza seguimiento?

(1) Como líder o miembro del grupo, yo comunico una visión clara y positiva del futuro.

Nunca	Rara vez	A veces	Frequentemente	Casi siempre
0	1	2	3	4

(2) Como líder o miembro del grupo, yo apoyo y animo el desarrollo de los demás.

Nunca	Rara vez	A veces	Frequentemente	Casi siempre
0	1	2	3	4

(3) Como líder o miembro del grupo, yo doy ánimo y reconocimiento a los demás.

Nunca	Rara vez	A veces	Frequentemente	Casi siempre
0	1	2	3	4

(4) Como líder o miembro del grupo, yo fomento confianza, participación y cooperación entre los miembros del equipo.

Nunca	Rara vez	A veces	Frequentemente	Casi siempre
0	1	2	3	4

(5) Como líder o miembro del grupo, yo animo a los demás pensar sobre problemas y nuevas maneras de solucionarlos.

Nunca	Rara vez	A veces	Frequentemente	Casi siempre
0	1	2	3	4

(6) Como líder o miembro del grupo, yo soy claro sobre mis valores y pongo en práctica lo que digo.

Nunca	Rara vez	A veces	Frequentemente	Casi siempre
0	1	2	3	4

(7) Como líder o miembro muy competente del grupo, yo inspiro orgullo y respeto en los demás.

Nunca	Rara vez	A veces	Frequentemente	Casi siempre
0	1	2	3	4

VLDI (volunteer leadership development instrument)

I looked hard for a leadership measurement instrument that was specifically for small volunteer organizations and that focused on measuring leadership development. The VLDI was the only such instrument in any study I could find that met these criteria. This is an instrument used only one study previously, and little information was collected on its reliability and validity, but the authors were satisfied with how it functioned in their small, retrospective, cross-sectional study. Questions were well developed from the literature, then reviewed by a panel of experts for content validity (Meier et al., 2009). We adapted it to our population, translated it, back-translated to check quality, and ran it through a cognitive review with several subjects.

Comparison of the original VLDI and adapted VLDI instruments

Original: n=35, Cronbach alpha on 20 items was high (r = .943), Spearman's rank order correlation was chosen because the data were finite and the total N was small, collected using a Likert-type scale questionnaire. Personal time management was the variable that showed the highest congruence among the 20 leadership skill impact items. Authors then showed a table with the spearman correlations of the other 19 variables to this strongest variable. Eighteen of the 19 items were statistically significant, and 10 of these showed high correlation coefficients as well (above .600), indicating strong relationships. However, the authors did not show the whole table and discuss other correlations, including low ones. Nor did they compare them to any other leadership measure.

Adapted version (out study): n=138, Cronbach alpha on 18 items was moderately high (r = .850). Inter-item correlations indicated that 1 of 18 items could be removed to improve the alpha score.

In another paper we will discuss removal of items, correlations with items in the GTL instrument, and other comparisons and issues related to the future adaptation and use of this instrument, both in English and Spanish in their respective cultural settings.

Scoring: items are summed; there are no reverse items. The questions for this instrument are available online, and there does not appear to be any copyright. I wrote the authors for permission.

Questions in English and Spanish:

1. **When participating in a community organization or group, I…**
   Value the viewpoints of others. (openness)

   1=very little; 2=little; 3=neutral; 4=much; 5=very much
   6=don't know,7=don't understand the question,8=doesn't apply to me

2. **When participating in a community organization or group, I…**
Share the workload with other group participants. (ability to share responsibilities, delegate, empower others)

3. **When participating in a community organization or group, I…**
Listen to others. (ability to listen, provide support)

4. **When participating in a community organization or group, I…**
Apply my individual talents and knowledge to help the group. (insight into personal knowledge skills and abilities, self-learning, authentic leadership)

5. **When participating in a community organization or group, I…**
invite others to the group. (outreach)

6. **When participating in a community organization or group, I…**
interact well with other individuals or groups. (network building)

7. **When participating in a community organization or group, I…**
help establish group goals. (capacity related to planning and evaluation, vision)

8. **When participating in a community organization or group, I…**
understand why it's important to evaluate the impact of my group. (impact evaluation)

9. **When participating in a community organization or group, I…**
use skills I've learned to help solve problems. (problem-solving focus, problem- solving skills)

10. **When participating in a community organization or group, I…**express my personal viewpoint to others. (self-confidence, self-efficacy, empowerment)

11. **When participating in a community organization or group, I…**
manage my time well. (ability to prioritize, focus, manage time for self and for group)

12. When participating in a community organization or group, I…get support for my group from other organizations. (collaboration, networking, obtaining resources)

13. When participating in a community organization or group, I…look at an issue or decision critically. (objectivity, ability to listen to criticism about self or group)

14. When participating in a community organization or group, I…use good skills of social interaction. (communication, listening, support, respect)

15. When participating in a community organization or group, I…manage conflicts and mediate between persons in my group. (motivation and ability to resolve conflicts between individuals and groups)

16. When participating in a community organization or group, I…am able to carry out effective advocacy with my government. (advocacy as complement to services, ability to adapt to meet goals, focus on larger impact)

17. When participating in a community organization or group, I…apply what I learn to help me and others at home, or school, or work. (ability to apply learning to other contexts)

18. When participating in a community organization or group, I…can run an effective meeting. (management for efficiency and effectiveness)

SPANISH VERSION

Muy poco	**Poco**	**A veces**	**Bastante**	**Mucho**
1	2	3	4	5

6=no sabe, 7=no entiende la pregunta, 8=no aplica para mí

Cuando participo en una organización o grupo comunitario,

1. yo valoro los puntos de vista de otros.   1 2 3 4 5

2. yo comparto la carga de trabajo con otros participantes.   1 2 3 4 5

3. yo escucho a otros.   1 2 3 4 5

4. yo aplico mis talentos y conocimientos individuales para ayudar al grupo.   1 2 3 4 5

5. yo invito a otros al grupo.   1 2 3 4 5

6. yo interactúo bien con otros individuos o grupos.   1 2 3 4 5

7. yo ayudo a establecer las metas del grupo.   1 2 3 4 5

8. yo entiendo por qué es importante evaluar el impacto (o logros) de mi grupo.   1 2 3 4 5

9. yo uso las destrezas que he aprendido para ayudar a resolver problemas.   1 2 3 4 5

10. yo expreso a otros mi punto de vista personal.   1 2 3 4 5

11. yo manejo bien mí tiempo.   1 2 3 4 5

12. yo obtengo apoyo de otras organizaciones para mi grupo.   1 2 3 4 5

13. yo veo críticamente un problema o decisión.   1 2 3 4 5

14. yo uso bien las destrezas de interacción social (comunicación, escuchar, apoyar, respetar).

                    1 2 3 4 5

15. yo manejo conflictos entre personas en mi grupo y les ayudo a resolverlos.   1 2 3 4 5

16. yo soy capaz de llevar a cabo efectivamente abogacía (hablar para defender mis derechos)

    ante mi gobierno.   1 2 3 4 5

17. yo aplico lo que aprendo para ayudarme a mí y a otros en la casa, o la escuela, o el trabajo.

                    1 2 3 4 5

18. yo puedo realizar una reunión eficaz.   1 2 3 4 5

Ryff Psychological Wellbeing Inventory—6 separate scales, of which I used 3, as well as a summed score of the 3 used domain scales

Of the 6 Ryff subscales, 4 seem most appropriate to the concept of empowerment. One subscale Environmental Mastery is covered well in the other two empowerment instruments (BUES and FES). The other three subscales included:

- *Positive relationships:* assessing the belief that one has positive relationships in their life (Ryff et al, 1995)
- *Personal Growth:* assessing interest and belief that one continues to grow and learn (Ryff et al, 1995)
- *Purpose in life:* assessing the belief that there is a larger purpose in their life and they are moving towards that (Ryff et al, 1995)

Through a literature review and contacts with authors of Spanish version instruments, we obtained two versions (29 and 36 items) that were well validated (Díaz, et al., 2006; Dierendonck, et al., 2008; Rodríguez-Carvajal, et al., 2010). The shorter version has 4-5 items per subscale, with a total of just 14 items for the 3 domains I selected as of most interest. Both the original and adapted versions are available at no cost.

	1995 (14 items/subscale)	2006 Span. Ver. (4-5 items)[54]	My study[1]
Ryff1 Positive Rels.	.88	.78	.62
Ryff3 Personal Grwth	.85	.71	.59
Ryff2 Purpose in Life	.88	.70	.74
Total (the above combined)	----	----	.79

Questions

English Version: We used the following three subdomains of a validated shortened versión of Ryff. Thus, the following Personal Growth questions in parentheses were used in our study.

PERSONAL GROWTH (2,6,9,11)

Definition: High Scorer: Has a feeling of continued development; sees self as growing and expanding; is open to new experiences; has sense of realizing his or her potential; sees improvement in self and behavior over time; is changing in ways that reflect more self knowledge and effectiveness.

Low Scorer: Has a sense of personal stagnation; lacks sense of improvement or expansion over time; feels bored and uninterested with life; feels unable to develop new attitudes or behaviors.

(-)   [1.]   I am not interested in activities that will expand my horizons.

(+)   2.   In general, I feel that I continue to learn more about myself as time goes by.

(+)   3.   I am the kind of person who likes to give new things a try.

(-)   [4.]   I don't want to try new ways of doing things--my life is fine the way it is.

(+)   [5.]   *I think it is important to have new experiences that challenge how you think about yourself and the world.*

(-)   [6.]   When I think about it, I haven't really improved much as a person over the years.

(+)   7.   In my view, people of every age are able to continue growing and developing.

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[54] These two used the same Spanish version, yet had very different alphas.

(+)   8.   With time, I have gained a lot of insight about life that has made me a stronger, more capable person.

(+)   [9.]   I have the sense that I have developed a lot as a person over time.

(-)   [10.]   I do not enjoy being in new situations that require me to change my old familiar ways of doing things.

(+)   [11.]   *For me, life has been a continuous process of learning, changing, and growth.*

(+)   12.   I enjoy seeing how my views have changed and matured over the years.

(-)   [13.]   *I gave up trying to make big improvements or changes in my life a long time ago.*

(-)   [14.]   There is truth to the saying you can't teach an old dog new tricks.

Internal consistency (coefficient alpha) = .85

Correlation with 20-item parent scale = .97

POSITIVE RELATIONS WITH OTHERS (questions 3,6,10,12,14)

Definition: High Scorer: Has warm satisfying, trusting relationships with others; is concerned about the welfare of others; capable of strong empathy, affection, and intimacy; understands give and take of human relationships.

Low Scorer: Has few close, trusting relationships with others; finds it difficult to be warm, open, and concerned about others; is isolated and frustrated in interpersonal relationships; not willing to make compromises to sustain important ties with others.

(+)   [1.]   Most people see me as loving and affectionate.

(-)   [2.]   *Maintaining close relationships has been difficult and frustrating for me*

(-)   [3.]   I often feel lonely because I have few close friends with whom to share my concerns.

(+)   [4.]   I enjoy personal and mutual conversations with family members or friends.

(+)   5.   It is important to me to be a good listener when close friends talk to me about their problems.

(-)   [6.]   I don't have many people who want to listen when I need to talk.

(+)   7.   I feel like I get a lot out of my friendships.

(-)   [8.]   It seems to me that most other people have more friends than I do.

(+)   [9.]   *People would describe me as a giving person, willing to share my time with others.*

(-)   [10.]   **I h*ave not experienced many warm and trusting relationships with others.***

(-)   11.   I often feel like I'm on the outside looking in when it comes to friendships.

(+)   [12.]   I know that I can trust my friends, and they know they can trust me.

(-)   13.   I find it difficult to really open up when I talk with others.

(+)   14.   My friends and I sympathize with each other's problems.

Internal consistency (coefficient alpha) = .88

Correlation with 20-item parent scale = .98

PURPOSE IN LIFE (1,4,8,9,12)

Definition: High Scorer: Has goals in life and a sense of directedness; feels there is meaning to present and past life; holds beliefs that give life purpose; has aims and objectives for living.

Low Scorer: Lacks a sense of meaning in life; has few goals or aims, lacks sense of direction; does not see purpose of past life; has no outlook or beliefs that give life meaning.

(+)   1.   I feel good when I think of what I've done in the past and what I hope to do in the future.

(-)   [2.]   *I live life one day at a time and don't really think about the future.*

(-)   [3.]   I tend to focus on the present, because the future nearly always brings me problems.

(+)   4.   I have a sense of direction and purpose in life.

(-)   [5.]   My daily activities often seem trivial and unimportant to me.

(-)   [6.]   I don't have a good sense of what it is I'm trying to accomplish in life.

(-)   [7.]   I used to set goals for myself, but that now seems like a waste of time.

(+)   [8.]   I enjoy making plans for the future and working to make them a reality.

(+)   [9.]   I am an active person in carrying out the plans I set for myself.

(+)   [10.]   *Some people wander aimlessly through life, but I am not one of them.*

(-)   [11.]   *I sometimes feel as if I've done all there is to do in life.*

(+)   12.   My aims in life have been more a source of satisfaction than frustration to me.

(+)   13.   I find it satisfying to think about what I have accomplished in life.

(-)   14.   In the final analysis, I'm not so sure that my life adds up to much.
Internal consistency (coefficient alpha) = .88

Correlation with 20-item parent scale = .98

Spanish Version—La versión que usamos es en negrito, pero usamos solamente las preguntas de tres subdominios: Relaciones positivas: Ítems 2, 8, 14, 26, y 32. Crecimiento personal: Ítems 24, 36, 37, y 38. Propósito en la vida: Ítems 6, 12, 17, 18, y 23).

1. Cuando repaso la historia de mi vida estoy contento con cómo han resultado las cosas
2. A menudo me siento solo porque tengo pocos amigos íntimos con quienes compartir mis preocupaciones
3. No tengo miedo de expresar mis opiniones, incluso cuando son opuestas a las opiniones de la mayoría de la gente
4. Me preocupa cómo otra gente evalúa las elecciones que he hecho en mi vida
5. Me resulta difícil dirigir mi vida hacia un camino que me satisfaga
6. Disfruto haciendo planes para el futuro y trabajar para hacerlos realidad
7. En general, me siento seguro y positivo conmigo mismo
8. No tengo muchas personas que quieran escucharme cuando necesito hablar
9. Tiendo a preocuparme sobre lo que otra gente piensa de mí
10. Me juzgo por lo que yo creo que es importante, no por los valores que otros piensan que son importantes
11. He sido capaz de construir un hogar y un modo de vida a mi gusto
12. Soy una persona activa al realizar los proyectos que propuse para mí mismo
13. Si tuviera la oportunidad, hay muchas cosas de mí mismo que cambiaría
14. Siento que mis amistades me aportan muchas cosas
15. Tiendo a estar influenciado por la gente con fuertes convicciones
16. En general, siento que soy responsable de la situación en la que vivo
17. Me siento bien cuando pienso en lo que he hecho en el pasado y lo que espero hacer en el futuro
18. Mis objetivos en la vida han sido más una fuente de satisfacción que de frustración para mí
19. Me gusta la mayor parte de los aspectos de mi personalidad
20. Me parece que la mayor parte de las personas tienen más amigos que yo
21. Tengo confianza en mis opiniones incluso si son contrarias al consenso general
22. Las demandas de la vida diaria a menudo me deprimen
23. Tengo clara la dirección y el objetivo de mi vida
24. En general, con el tiempo siento que sigo aprendiendo más sobre mí mismo
25. En muchos aspectos, me siento decepcionado de mis logros en la vida
26. No he experimentado muchas relaciones cercanas y de confianza
27. Es difícil para mí expresar mis propias opiniones en asuntos polémicos
28. Soy bastante bueno manejando muchas de mis responsabilidades en la vida diaria

29. No tengo claro qué es lo que intento conseguir en la vida
30. Hace mucho tiempo que dejé de intentar hacer grandes mejoras o cambios en mi vida
31. En su mayor parte, me siento orgulloso de quien soy y la vida que llevo
32. Sé que puedo confiar en mis amigos, y ellos saben que pueden confiar en mí
33. A menudo cambio mis decisiones si mis amigos o mi familia están en desacuerdo
34. No quiero intentar nuevas formas de hacer las cosas; mi vida está bien como está
35. Pienso que es importante tener nuevas experiencias que desafíen lo que uno piensa sobre sí mismo y sobre el mundo
36. Cuando pienso en ello, realmente con los años no he mejorado mucho como persona
37. Tengo la sensación de que con el tiempo me he desarrollado mucho como persona
38. Para mí, la vida ha sido un proceso continuo de estudio, cambio y crecimiento
39. Si me sintiera infeliz con mi situación de vida daría los pasos más eficaces para cambiarla

NOTES: Autoaceptación: Ítems 1, 7, 13, 19, 25, y 31. Relaciones positivas: Ítems 2, 8, 14, 20, 26, y 32. Autonomía: Ítems 3, 4, 9, 10, 15, 21, 27, y 33. Dominio del entorno: Ítems 5, 11, 16, 22, 28, y 39. Crecimiento personal: Ítems 24, 30, 34, 35, 36, 37, y 38. Propósito en la vida: Ítems 6, 12, 17, 18, 23 y 29.
Los ítems inversos se presentan en letra cursiva.
Los ítems seleccionados para la versión de 29 ítems se presentan resaltados en negrita.

Family Empowerment Scale

The Family Empowerment Scale (FES) appears to be a very good instrument for our family population that covers empowerment from the knowledge, attitude and behavior domains while simultaneously looking at the individual, family, and community social levels. The 34-item scale was developed by Koren, DeChillo, and Friesen (1992) as a questionnaire for assessing empowerment in families whose children have emotional disabilities. The questionnaire is based on a two-dimensional conceptual framework of empowerment derived from the literature—a dimension reflecting empowerment with respect to the family, service system, and larger community and political environment, and a dimension of expression of empowerment as attitudes, knowledge, and behaviors.

The authors developed items with standard techniques, then piloted the questionnaire on a sample of 96 family caregivers. Because the literature emphasizes distinctions among personal, interpersonal, and political levels of empowerment, the scoring strategy reflects the categories of the Level Dimension, i.e., Family, Service System, and Community/Political. Scoring is accomplished by summing responses from items within the Family (12 items), Service System (12 items), and Community/Political (10 items) categories to yield three subscores N=441 parents from many states across the U.S.

Tests were run on two groups (test and retest). Cronbach alphas on subscores ranged from .87 to .88 on the test group and .77 to .85 on the retest group. A kappa was calculated for inter-rater reliability at .77, which is above the .75 standard for substantial agreement among raters. Factor analysis showed 4 factors that fit well within the 3-dimension framework the authors had proposed, with loadings ranging from .40 to .70. The authors used a MANOVA to run subscores against a checklist of activities, all of which came back significantly discriminating parents in each activity by subgroup score.

The authors conclude with several observations. While some authors theorize parents first focus on immediate family concerns of their child's development and behavior, then turn their attention to securing information and services they need, then finally engage in individual or collective action to assist other families and address the needs of all children, the authors note "anecdotal evidence suggests that for some family members, difficulty in obtaining appropriate services for their children is a galvanizing experience leading to involvement in the community/ political arena" (Koren, DeChillo, & Friesen, 1992, 318). They also recommend future research may focus on the degree to which each of the three levels (Family, Service System, and Community/Political) is differentially responsive to targeted interventions, and further exploration of the means by which parents gain empowerment, and the various paths through which their empowerment may be pursued and developed.

Unfortunately, we had to adapt the instrument to our specific population (adults vs children). We had to adapt it because it was written for a population of parents of minor children, while almost all of our subjects were caregivers of adult PLMI, and these adults have rights that minors do not in terms of parental rights. There were a few questions that did not make sense in the Salvadoran cultural context. For example, the question "When necessary, I take the initiative in looking for services for my loved one and family." But in El Salvador there are no community services, there is only the national public psychiatric hospital and the social security hospital psychiatric unit. That is, there are no choices, so even if a person was motivated or empowered to look for services, it is not an option. We cut the question. Eventually we reduced the scale slightly from 34 to 30 questions and then took it through the three-step back-translation process.[55] Permission for use was obtained from the authors.

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[55] I plan on doing a follow-up paper that will focus on the scales we translated, adapted, or created for the grassroots and nonprofit LMIC target population of our study. I hope they may be helpful to others needing such instruments.

Level

		Family	Service System	Community/Political
E x p r e s s i o n	**Attitudes**	- I feel confident in my ability to help my child grow and develop. (4) - I feel my family life is under control. (9) - I believe I can solve problems with my child when they happen. (21) - I feel I am a good parent. (34)	- I feel that I have a right to approve all services my child receives. (1) - My opinion is just as important as professionals' opinions in deciding what services my child needs. (18) - Professionals should ask me what services I want for my child. (32)	- I feel I can have a part in improving services for children in my community. (3) - I believe that other parents and I can have an influence on services for children. (17) - I feel that my knowledge and experience as a parent can be used to improve services for children and families. (25)
	Knowledge	- I know what to do when problems arise with my child. (7) - I am able to get information to help me better understand my child. (16) - When I need help with problems in my family, I am able to ask for help from others. (26) - I have a good understanding of my child's disorder. (33)	- I know the steps to take when I am concerned my child is receiving poor services. (5) - I am able to make good decisions about what services my child needs. (11) - I am able to work with agencies and professionals to decide what services my child needs. (12) - I know what services my child needs. (23) - I have a good understanding of the service system that my child is involved in. (30)	- I understand how the service system for children is organized. (10) - I have ideas about the ideal service system for children. (14) - I know how to get agency administrators or legislators to listen to me. (22) - I know what the rights of parents and children are under the special education laws. (24)
	Behaviors	- When problems arise with my child, I handle them pretty well. (2) - I make efforts to learn new ways to help my child grow and develop. (27) - When dealing with my child, I focus on the good things as well as the problems. (29) - When faced with a problem involving my child, I decide what to do and then do it. (31)	- I make sure that professionals understand my opinions about what services my child needs. (6) - I make sure I stay in regular contact with professionals who are providing services to my child. (13) - I tell professionals what I think about services being provided to my child. (19) - When necessary, I take the initiative in looking for services for my child and family. (28)	- I get in touch with my legislators when important bills or issues concerning children are pending. (8) - I help other families get the services they need. (15) - I tell people in agencies and government how services for children can be improved. (20)

Figure 1. Conceptual framework and item stems for Family Empowerment Scale. (Numbers in parentheses indicate item numbers.)

Results of internal reliability testing from this study:

		Original	This study	
FES1	Family	.88	.78	Adequate; but 3 of 11 items could be removed to improve the alpha.
FES2	System	.87	.67	Not adequate ($< .70$); 0 of 9 need to be removed.
FES3	Comm/Advoc.	.88	.83	Good internal reliability; 0 of 10 need to be removed.
FES	Total score	----	.89	Strong internal reliability; 0 of 30 need to be removed.

QUESTIONS

English (see matrix above)

Spanish (see below)

		Para nada cierto	No muy cierto	Ni cierto, ni falso	Algo cierto	Muy cierto
1	Cuando surgen problemas con mi ser querido, yo los manejo bien.	1	2	3	4	5
2	Siento que puedo ser parte de la mejora de los servicios para familias y personas con discapacidades mentales en mi comunidad.					
3	Me siento confiado en mí habilidad para ayudar a mi ser querido a crecer y desarrollarse.					
4	Sé que hacer cuando surgen problemas con mi ser querido.					
5	Me aseguro de que los profesionales entiendan mi opinión sobre qué servicios necesita mi ser querido.					
6	Participo en actividades de abogacía para mejorar las leyes y servicios de salud mental en El Salvador.					
7	Siento que mi vida familiar está bajo control.					
8	Entiendo cómo está organizado el sistema de salud mental.					
9	Me aseguro de estar regularmente en contacto con los profesionales que le dan servicios a mi ser querido.					
10	Soy capaz de tomar buenas decisiones sobre qué servicios necesita mi ser querido.					
11	Soy capaz de trabajar con organizaciones y profesionales para decidir qué servicios necesita mi ser querido.					
12	Tengo ideas sobre cómo mejorar el sistema de salud mental.					
13	Ayudo a otras familias a conseguir los servicios que necesitan.					
14	Soy capaz de obtener información que me ayude a entender mejor a mi ser querido.					
15	Creo que otras familias y yo podemos mejorar los servicios para personas con discapacidades mentales.					
16	Mi opinión como familiar cuidador, decidiendo qué servicios necesita mi ser querido, es tan					

	importante como la de un profesional .					
17	Le digo a los profesionales lo que pienso sobre los servicios que le dan a mi ser querido.					
18	Le digo a la gente en organizaciones, hospitales, clínicas y el gobierno cómo pueden ser mejorados los servicios de salud mental .					
19	Puedo resolver problemas con mi ser querido cuando suceden.					
20	Sé cómo funciona el sistema político y qué hacer para mejorar políticas, leyes y servicios para la salud mental.					
21	Sé qué servicios necesita mi ser querido.					
22	Conozco los derechos para personas con discapacidades mentales y sus familias que están en las leyes salvadoreñas.					
23	Siento que mi conocimiento y experiencia como cuidador puede ser usada para mejorar los servicios para personas con discapacidades mentales y sus familias.					
24	Cuando necesito ayuda con problemas en mi familia, soy capaz de pedir ayuda de otros.					
25	Me esfuerzo por aprender nuevas maneras de ayudar a mi ser querido a crecer y desarrollarse.					
26	Cuando trato con mi ser querido, me concentro tanto en las cosas buenas como en los problemas.					
27	Tengo un buen entendimiento del Sistema de servicios en el que está involucrado mi ser querido.					
28	Los profesionales deberían incluirme en el proceso de decidir qué servicios necesita mi ser querido.					
29	Tengo un buen entendimiento del trastorno de mi ser querido.					
30	Siento que soy un buen/a cuidador/a.					

Boston University Empowerment Scale (BUES).

For PLMI only. This scale was developed with strong input from users of mental health services, has strong reliability and validity, and has been used in a number of other studies. It is very appropriate for our user population and required minimal adaptation. It required translation and thus cognitive review, which we completed. We attempted to contact the authors, and used the questions from the seminal article as the basis for our translation.

Principal components analysis identified 5 factors, which include self-esteem-self-efficacy (explains 24.5% of total variance); power/powerlessness (12.4%); community activism (7.6%); optimism/control (5.4%) over future; and anger (4%). Rogers et al., 1997. The original scale was 28 items. To reduce the length I selected the top factor loading items within each of the 5 factors. I did so by choosing up to 4 items from each factor that loaded at greater than .60 and that did not load on other factors. This left me with 14 high-loading items.

Reliability using Cronbach alphas:
Original   .88 (28 items)
This study   .57 (14 items) This alpha is below the adequate level of .70. Five of 14 items could be removed to improve the alpha, which signifies there are significant problems with the questions in the cultural context, or the sample size was too small, or reduction of the number of items reduced the alpha too much.

Factors derived from the Empowerment Scale

Factor and scale item[1]	Loading
Factor 1: Self-esteem–self-efficacy[2]	
I generally accomplish what I set out to do	.79
I have a positive attitude about myself	.74
When I make plans, I am almost certain to make them work	.72
I am usually confident about the decisions I make	.70
I am often able to overcome barriers	.56
I feel I am a person of worth, at least on an equal basis with others	.47
I see myself as a capable person	.46
I am able to do things as well as most other people	.41
I feel I have a number of good qualities	.41
Factor 2: Power–powerlessness[3]	
I feel powerless most of the time	.69
Making waves never gets you anywhere[4]	.66
You can't fight city hall	.66
When I am unsure about something, I usually go along with the group	.66
Experts are in the best position to decide what people should do or learn	.63
Most of the misfortunes in my life were due to bad luck	.62
Usually, I feel alone	.60
People have no right to get angry just because they don't like something[4]	.43
Factor 3: Community activism and autonomy[5]	
People have a right to make their own decisions, even if they are bad ones	.68
People should try to live their lives the way they want to	.64
People working together can have an effect on their community	.62
People have more power if they join together as a group	.53
Working with others in my community can help to change things for the better	.52
Very often a problem can be solved by taking action[4]	.41
Factor 4: Optimism and control over the future[6]	
People are limited only by what they think possible	.78
I can pretty much determine what will happen in my life	.62
I am generally optimistic about the future	.58
Very often a problem can be solved by taking action[3]	.42
Factor 5: Righteous anger[7]	
Getting angry about something is often the first step toward changing it	.73
People have no right to get angry just because they don't like something[4]	.52
Getting angry about something never helps	.48
Making waves never gets you anywhere[4]	.40

[1] Items that are negatively worded were recoded for consistency before the factor analysis.
[2] Eigenvalue=6.85, variance explained=24.5 percent
[3] Eigenvalue=3.48, variance explained=12.4 percent
[4] This item loaded on more than one factor.
[5] Eigenvalue=2.13, variance explained=7.6 percent
[6] Eigenvalue=1.5, variance explained=5.4 percent
[7] Eigenvalue=1.12, variance explained=4 percent

QUESTIONS

English (see table above)

Spanish (see below)

<u>BUES - Escala de Empoderamiento de Boston University para Usuarios</u>

Esta escala es sobre sus sentimientos de empoderamiento en su vida. Se puede responder 1 a 4:

1	2	3	4
Muy en desacuerdo	Algo en desacuerdo	Algo de acuerdo	Muy de acuerdo

1. Generalmente logro lo que me propongo hacer.   1 2 3 4

2. Tengo una actitud positiva acerca de mí mismo/a.   1 2 3 4

3. Cuando hago planes, estoy casi seguro/a de que funcionarán.   1 2 3 4

4. Por lo general confío en las decisiones que tomo.   1 2 3 4

5. La mayoría del tiempo me siento impotente.   1 2 3 4

6. No se puede luchar contra la administración (autoridad).   etc.…

7. Cuando no estoy seguro/a de algo, normalmente sigo el criterio de los demás.

8. Los expertos están en mejor posición para decidir lo que la gente debe hacer.

9. La gente tiene derecho a tomar sus propias decisiones, aunque sean malas.

10. La gente debe tratar de vivir sus vidas de la manera que quieran.

11. Las personas que trabajan juntas pueden tener un efecto en su comunidad.

12. La gente está limitada solamente por lo que creen que es posible.

13. Casi puedo determinar qué va a pasar en mi vida.

14. Enfadarse por algo es a menudo el primer paso para cambiarlo.

<u>SOCIAL CAPITAL</u>

Instrument: World Values Survey

The World Values Survey (WVS, www.worldvaluessurvey.org) is a global network of social scientists studying changing values and their impact on social and political life. Led by an international team of scholars, headquartered in Stockholm, Sweden, and started in 1981, the WVS is the largest non-commercial, cross-national, time series investigation of human beliefs and values ever executed. Currently over 400,000 respondents have been interviewed. WVS is the only academic study covering the full range of global variations, from very poor to very rich countries, in all of the world's major cultural zones. WVS helps scientists and policy makers understand changes in the beliefs, values and motivations of people throughout the world. Data has been analyzed on such topics as economic development, democratization, religion, gender equality, social capital, and subjective well-being.

The study is carried out in waves across the world, with surveys being carried out by researchers and organizations voluntarily. Minimum sample size is 1000 per country. For each wave, suggestions for questions are solicited by social scientists from all over the world and a final master questionnaire is developed in English. Since the start in 1981 each successive wave has covered a broader range of societies than the previous one. Analysis of the data from each wave has indicated that certain questions tapped interesting and important concepts while others were of little value. This has led to the more useful questions or themes being replicated in future waves while the less useful ones have been dropped making room for new questions. The questionnaire is translated into the various national languages and in many cases independently translated back to English to check the accuracy of the translation. In most countries, the translated questionnaire is pre-tested to help identify questions for which the translation is problematic. In some cases certain problematic questions are omitted from the national questionnaire. The members of the World Values Survey Association carry out representative national surveys of the values and beliefs of people in their own countries. The data collected is shared immediately among the members of the network, and two years after completion of fieldwork, the data is published for public use.

Language: We used the version translated and tested in Colombia, which is the only Spanish version we found, and is apparently the version used throughout Latin America.

Reliability is measured within each study as necessary. Indices are generally not used, so questions are simply compared among groups within a country or cross-nationally. The structure
of the questions for our study did not led themselves to measures of internal reliability.

I selected 35 questions that measure trust (8), identity (4), meaning in life (1), religious participation (1), civic participation (11), political participation (2), and interest in public news (8). The instrument is open source.

QUESTIONS

English

V24. Generally speaking, would you say that most people can be trusted or that you need to be very careful in dealing with people? (Code one answer):

> 1 Most people can be trusted.   2 Need to be very careful.

Now I am going to read off a list of voluntary organizations. For each organization, could you tell me whether you are an active member, an inactive member, or not a member of that type of organization?

V25. Church or religious organization   2 (active member)   1 (inactive member)   0 (don't belong)

V26 Sport of recreational organization   2 (active member)   1 (inactive member)   0 (don't belong)

V27. Art, music or educational organization   2 (active member) 1 (inactive member)   0 (don't belong)

V28. Labor union   2 (active member)   1 (inactive member)   0 (don't belong)

V29. Political party   2 (active member)   1 (inactive member)   0 (don't belong)

V30. Environmental organization   2 (active member)   1 (inactive member)   0 (don't belong)

V31. Professional association   2 (active member)   1 (inactive member)   0 (don't belong)

V32. Humanitarian or charitable organization   2 (active member) 1 (inactive member)   0 (don't belong)

V33. Consumer organization   2 (active member)   1 (inactive member)   0 (don't belong)

V34. Self-help group, mutual aid group   2 (active member)   1 (inactive member)   0 (don't belong)

V35. Other organization   2 (active member)   1 (inactive member)   0 (don't belong)

I'd like to ask you how much you trust people from various groups. Could you tell me for each whether you trust people from this group completely(1), somewhat(2), not very much(3), or not at all(4)?

V102.   Your family   1   2   3   4
V103.   Your neighborhood   1   2   3   4
V104.   People you know personally   1   2   3   4
V105.   People you meet for the first time 1   2   3   4
V106.   People of another religion   1   2   3   4
V107.   People of another nationality   1   2   3   4

V143. Now let"s turn to another topic. How often, if at all, do you think about the meaning and purpose of life? (Read out and code one answer!)

        1 Often   2 Sometimes   3 Rarely   4 Never

V145. Apart from weddings and funerals, about how often do you attend religious services these days?

1 More than once a week

2 Once a week

3 Once a month

4 Only on special holy days

5 Once a year

6 Less often

7 Never, practically never

People have different views about themselves and how they related to the world. Would you tell me how strongly you agree or disagree with each of the following statements about how you see yourself?

	StronglyAgree	Agree	Disagree	StronglyDisagree
V212. I see myself as a world citizen.	1	2	3	4
V213. I see myself as part of my local community.				
V214. I see myself as part of the Salvadoran nation.				
V215. I see myself as an autonomous person.				

People learn what is going on in this country and the world from various sources. For each of the following source, please indicate whether you use it to obtain information daily, weekly, monthly, less than monthly, or never.

	Daily	Weekly	Monthly	Less	Never
V217. Daily newspaper	1	2	3	4	5
V218. Printed magazines	1	2	3	4	5
V219. TV news	1	2	3	4	5
V220. Radio news	1	2	3	4	5
V221. Mobile phone	1	2	3	4	5
V222. Email	1	2	3	4	5
V223. Internet	1	2	3	4	5
V224. Talking with friends or colleagues	1	2	3	4	5

When elections take place, do you vote always(1), usually(2), or never(3)?

V227. National level	1	2	3
V228. Local level	1	2	3

Spanish

CS1. En general, ¿usted cree que se puede confiar en otras personas?

Nada en absoluto   No mucho   Bastante   Mucho

Ahora me gustaría preguntarle cuánto confía en varios grupos de gente. ¿Me podría decir, para cada uno, si usted confía completamente en la gente de ese grupo, confía algo, confía poco o no confía nada?
1. Confía completamente
2. Confía algo
3. Confía poco
4. No confía nada
   -1. No sabe (NO LEER)   -2. No contesta (NO LEER)
   V102 Su familia   1 2 3 4 -1 -2
   V103 Sus vecinos   1 2 3 4 -1 -2
   V104 La gente que usted conoce personalmente   1 2 3 4 -1 -2
   V105 La gente que conoce por primera vez   1 2 3 4 -1 -2
   V106 La gente de otra religión   1 2 3 4 -1 -2
   V107 La gente de otra nacionalidad   1 2 3 4 -1 -2

V143   ¿Qué tan frecuentemente piensa Ud. en el significado y propósito de la vida?
1. Frecuentemente
2. Algunas veces
3. Rara vez
4. Nunca
   -1. No sabe (NO LEER)   -2. No contesta (NO LEER)

V145 Excluyendo bodas y funerales, ¿Con qué frecuencia asiste usted a servicios religiosos actualmente
1. Más de una vez por semana
2. Una vez por semana
3. Una vez al mes
4. Otros días festivos
5. Una vez al año
6. Con menor frecuencia
7. Nunca, casi nunca
   -1. No sabe (NO LEER)   -2. No contesta (NO LEER)

V24 En términos generales,¿diría usted que se puede confiar en la mayoría de las personas o que es necesario ser muy cuidadoso al tratar a la gente?

1. Se puede confiar en la mayoría de las personas.
2. Es necesario ser muy cuidadoso al tratar a la gente.
-1. No sabe (NO LEER) -2. No contesta (NO LEER) ____

Ahora voy a leer una lista de organizaciones voluntarias. Para cada una, podría usted decirme si es miembro activo, miembro inactivo o no es usted miembro de esa organización. (*Lea en voz alta y codifique una respuesta para cada organización*):

Miembro activo	Miembro Inactivo	No pertenece	NS	NC
2	1	0	-1	-2

V25	Iglesia u Organizaciones religiosas	2 1 0 -1 -2
V26	Organizaciones de deportes o recreación	2 1 0 -1 -2
V27	Organizaciones educativas, artísticas o musicales	2 1 0 -1 -2
V28	Sindicatos	2 1 0 -1 -2
V29	Partidos políticos	2 1 0 -1 -2
V30	Organizaciones ambientales y ecológicas	2 1 0 -1 -2
V31	Asociaciones profesionales	2 1 0 -1 -2
V32	Organizaciones humanitarias o de derechos humanos	2 1 0 -1 -2
V33	Organizaciones de consumidores	2 1 0 -1 -2
V34	Grupo de autoayuda, grupo de ayuda mutua	2 1 0 -1 -2
V35	Alguna otra org. Voluntaria (ANOTAR):	2 1 0 -1 -2

_____

La gente tiene distintos puntos de vista acerca de si misma y de cómo se relaciona con el mundo (indentidad). Me podria decir si usted está de acuerdo con cada una de las siguientes afirmaciones acerca de cómo se ve Ud a si mismo.
1. Muy de acuerdo
2. De acuerdo
3. En desacuerdo
4. Muy en desacuerdo
   -1. No sabe (NO LEER)   -2. No contesta (NO LEER)

V212	Yo me veo como un ciudadano del mundo.	1 2 3 4 -1 -2
V213	Yo me veo como miembro de mi comunidad local.	1 2 3 4 -1 -2
V214	Yo me veo como ciudadano salvadoreño.	1 2 3 4 -1 -2
V215	Yo me veo como un individuo autónomo.	1 2 3 4 -1 -2

Cuando hay elecciones, ¿siempre vota, habitualmente vota, o no vota nunca? Por favor, le pedimos que indique de forma separada para cada uno de los siguientes niveles.
1. Siempre voto
2. Habitualmente voto
3. No voto nunca

-1. No sabe (NO LEER)   -2. No contesta (NO LEER)

| V226 | Nivel de la alcaldía. | 1 2 3 -1 -2 |
| V227 | Nivel nacional (presidenciales). | 1 2 3 -1 -2 |

La gente usa diversas fuentes para informarse de lo que sucede en el país y en el mundo. Para cada una de las siguientes fuentes, favor indique si la usa para obtener información.

1. Diariamente
2. Semanalmente
3. Una vez al mes
4. Menos de una vez al mes
5. Nunca

-1. No sabe (NO LEER)   -2. No contesta (NO LEER)

V217	Periódico o diario.	1 2 3 4 5 -1 -2
V218	Revistas impresas.	1 2 3 4 5 -1 -2
V219	Noticias por televisión.	1 2 3 4 5 -1 -2
V220	Noticias por radio.	1 2 3 4 5 -1 -2
V221	Noticias por teléfono celular.	1 2 3 4 5 -1 -2
V222	Noticias por correo electrónico.	1 2 3 4 5 -1 -2
V223	Noticias por internet.	1 2 3 4 5 -1 -2
V224	Noticias por hablar con amigos.	1 2 3 4 5 -1 -2

Appendix D

Matching Protocol

1) <u>**Protocol for Matching PLMI Intervention and Control Group Subjects**</u>

Population: people with serious mental health conditions, including schizophrenia, chronic depression, bipolar, anxiety, and other disabling conditions living in a low resource country (El Salvador)

Required criteria

A. Gender: exact match required (Male/Female)

B. Illness type: exact match (using categories common in El Salvador, and based on the ICD-10)

C. Geographic region lived in: exact match with urban areas of the country (see definition and list of eligible cities below)

D. Location of treatment: exact match (treatment history at a psychiatric hospital or psychiatric unit)[56]

E. Current age of adult subject:
- 18, 19, 20 – exact match
- 21-25 (match up to 1 year above or below 22-25 years of age)
- 26-30 (match up to 2 years above or below 27-30 years of age)
- 31-40 (match up to 3 years above or below 32-40 years of age)
- 41-50+ (match up to 5 years above or below 43+ years of age)

---

[56] All of our control subjects were patients at the public national psychiatric hospital, while 93% of intervention subjects were also treated at hospitals or psychiatric units. This means that the program intervention is capturing a portion of persons (7%) who would not otherwise receive some sort of mental health services. Approximately ¼ of the intervention group had received treatment exclusively or at some time from the psychiatric unit of the social security hospital. This hospital caters to higher income families with more stable income, is said to have better services and attention, and is a much more inviting and supportive atmosphere. While we had hoped to obtain some of our controls from the social security hospital, it proved to be too much for us to work with more than one hospital at a time. As a result, we treated this matching criteria as effectively met by all subjects.

Optional criteria[57]

F. Age when the illness first began (and to calculate how many years the person has lived with his/her illness, based on current age):

- <18 (match within a range of 1 year above or below the age)
- 18-25 (match up to 2 years above or below 19-25 years of age)
- 26-30 (match up to 3 years above or above or below 27-30 years of age)
- 31+ (match up to 5 years above below 33+ years of age)

G. Number of years before treatment began (treatment gap)

- <1 (exact match)
- 1 (exact match)
- 2 (exact match)
- 3 (exact match)
- 4-5 (match within a range of 1 year above or below the treatment gap of 5 years)
- 6-9 (match within a range of 2 years above or below the treatment gap of 7 years)
- 10-15 (match within a range of 3 years above or below the treatment gap of 11 years)
- 16+ (match within a range of 5 years above or below the treatment gap of 18 years)

2) Protocol for Matching Carer Intervention and Control Group Subjects

Required criteria

A. Step 1
a. Geographic regions—same as above
b. Treatment location—same as above

B. Step 2 (matching between carers)
a. Gender: exact match required (M / F)
b. Caregiver age range: within 15 years (to keep people within the same generation)
c. Relationship to the PLMI
 i. Parent/Grandparent
 ii. Spouse/Companion
iii. Adult child
 iv. Brother/Sister
 v. Other extended family/friend

C. Step 3 (matching between PLMI loved ones of two carers)
a. Age range of loved one PLMI: within 5 years if <30, and within 10 years if >30

---

[57] This data was collected but not used in the matching process.

b. Type of illness: exact match
c. Gender of PLMI: exact match

Notes on Geographic Criteria

We revised the protocol for matching characteristics (with IRB approval) by expanding the definition of "urban" to include not only the San Salvador metropolitan area, but additional large cities in the country > 30,000 and that have characteristics similar to the San Salvador area, such as dangerous street crossing, pollution, close living quarters, gang issues, etc. (see list below). This will allow us to more easily capture additional control subjects.

Urban characteristics from a psychosocial perspective: Analysis of differing size cities at 40,000 and 20,000 in comparison to San Salvador (500,000) led to a cut-off decision of 30,000 for "urban":

Characteristics of large urban area

San Salvador (capital) (500,000 people)	SanMartin(40,000)	Sensuntepeque(20,000)
• Crowded living conditions	yes	no
• Poor air quality, trash and pollution	yes medium	yes partially
• Distrust due to gangs	yes	no
• Not knowing neighbors	yes medium	no
• Danger crossing streets	no	no
• Lots of cars/vehicles	yes medium	no
• Few trees and fields/agricultural area	yes	yes
• Fast food, big box stores, malls	yes partially	no
• Universities	no	no
• Places to work (large selection)	no	no
• Access to specialty health care	no	no

DEFINE URBAN AS: larger cities (>30,000) where characteristics are similar to San Salvador and other large urban areas, where there are not health promoters, and we will ask people whether they live in an urban or rural area, and they will know this because of their community situation (eg, whether a water source is shared, whether there is electricity, whether there is a farm field next to their house, etc.)

CITIES TO INCLUDE:

• Current cities
  ▪ San Salvador (SS)
  ▪ Soyapongo
  ▪ Mejicanos
  ▪ Santa Tecla

- Apopa
- Delgado
- San Marcos
- Ilopango
- Antiguo Cuscatlan
- Cities to be added (outside of San Salvador urban metropolitan area, but > 30,000)
  - Santa Ana
  - San Miguel
  - Sonsonate
  - Usulutan
  - Cojutepeque
  - Cuscatancingo
  - San Vincente
  - Zacatecaluca
  - San Martin
  - Ahuachapan
  - Chalchuapa (Santa Ana)

APPENDIX E

INTERNATIONAL MEASURES OF SOCIAL CAPITAL

This summary is taken from "Social Capital in Finland – Statistical Review," Iisakka (2006), which reviewed international measures of social capital along with their justifications and dimensions. Refer to the original article for references.

The New Zealand Statistical Office began measuring social capital in 1997 to determine whether social capital had potential for policy development at both the local and central government levels. The four main components of its framework are behaviors (helping and supporting others, participation in formal and informal networks, compliance with rules and norms, and wider interest in society), attitudes and values (trust and reciprocity, attitudes to government and social institutions, attitudes towards self and others and confidence in the future), population groups (demographic factors, family, culture, employment and communication), and organizations (numbers, type, size, structure and cooperation between organizations) (Spellerberg, 2001).

The Organization for Economic Cooperation and Development developed an internationally harmonized measurement system for social capital based on four main dimensions of social participation, social networks and support, reciprocity and trust, and civic participation (OECD, 2003).

The UK Office of National Statistics (ONS) was the first to launch a systematic program aimed at developing a national model in this field. The ONS framework (Harper & Kelly 2003) comprises the most widely used dimensions of social capital in the UK as well as other factors that are crucial to understanding social capital.

The Australian statistical framework is one of the most comprehensive systems developed for the measurement of social capital. The Australian concept of social capital is built

around networks, which are divided according to their type, quality, structure and transactions taking place within the networks. The model identifies the composition of the network, describing the potential network participants: family, friends, neighbors, work colleagues, organizations and groups, people in general and acquaintances. It includes negative as well as positive indicators. The ABS framework includes the dimensions of network qualities (norms such as trust reciprocity and cooperation; common purpose such as participation, helping others and friends); network structure (size, number, intensity, density, openness, etc.); network transactions (sharing support, information, negotiation, sanctions); and network types (bonding, bridging, linking, isolation) (ABS, 2004).

The World Bank launched Social Capital Initiative (SCI) in 2006 with a focus on developing methods of measuring social capital as part of an action program aimed at preventing poverty and at boosting economic growth in developing countries. It's dimensions include cognitive measures (groups and networks, trust and solidarity), environment measures (collective action and collaboration, information and communication), and application/output measures (social cohesion and inclusion, and empowerment and political action).

Iisakka (2006) also covers frameworks developed in the U.K. and Canada, which are similar to other countries.

Appendix F
Correlation Matrix of Potential Moderating Variables against Outcomes

			SocialContactsScore	DIAGNOSIS	SEVERITY_LAST_FIFTEENDAYS	EE01_02_03_04	Si_No_YRS_Participate	YEARS_WITHOUT_TREATMENT_LO_A
Kendall's tau_b	SocialContactsScore	Correlation Coefficient	1.000	-.064	.008	.116	.074	.
		Sig. (2-tailed)	.	.562	.940	.228	.610	.
		N	64	64	64	64	32	0
	DIAGNOSIS	Correlation Coefficient	-.064	1.000	.023	.023	-.135	-.139
		Sig. (2-tailed)	.562	.	.750	.822	.166	.156
		N	64	140	140	64	70	75
	SEVERITY_LAST_FIFTEENDAYS	Correlation Coefficient	.008	.023	1.000	.145	.022	-.152
		Sig. (2-tailed)	.940	.750	.	.128	.814	.095
		N	64	140	140	64	70	75
	EE01_02_03_04	Correlation Coefficient	.116	.023	.145	1.000	.017	.
		Sig. (2-tailed)	.228	.822	.128	.	.896	.
		N	64	64	64	64	32	0
	Si_No_YRS_Participate	Correlation Coefficient	.074	-.135	.022	.017	1.000	.048
		Sig. (2-tailed)	.610	.166	.814	.896	.	.705
		N	32	70	70	32	70	37
	YEARS_WITHOUT_TREATMENT_LO_A	Correlation Coefficient	.	-.139	-.152	.	.048	1.000
		Sig. (2-tailed)	.	.156	.095	.	.705	.
		N	0	75	75	0	37	75
	GTLScore	Correlation Coefficient	.138	-.052	-.051	-.010	.059	.012
		Sig. (2-tailed)	.155	.452	.429	.907	.493	.890
		N	64	138	138	64	70	73
	VLDIScore	Correlation Coefficient	.125	.003	-.104	.014	.177*	-.032
		Sig. (2-tailed)	.191	.961	.105	.871	.037	.709
		N	64	138	138	64	70	73
	RyffPositiveRels1_3_5_10_11	Correlation Coefficient	.281**	-.008	-.045	-.166	.201*	.002
		Sig. (2-tailed)	.004	.906	.481	.062	.018	.977
		N	64	140	140	64	70	75
	RyffPurposeLife2_4_6_7_8	Correlation Coefficient	.140	-.079	-.136*	-.154	.223*	-.061
		Sig. (2-tailed)	.150	.255	.037	.086	.010	.485
		N	64	140	140	64	70	75
	RyffPersonalGrwth9_12_13_14	Correlation Coefficient	.160	-.062	-.019	-.077	.119	-.197*
		Sig. (2-tailed)	.110	.382	.775	.403	.180	.026
		N	64	140	140	64	70	75
	RyffScore	Correlation Coefficient	.229*	-.059	-.079	-.165	.241**	-.095
		Sig. (2-tailed)	.016	.386	.213	.061	.005	.264
		N	64	140	140	64	70	75
	BUESScore	Correlation Coefficient	.194*	.118	-.102	-.054	.008	.
		Sig. (2-tailed)	.045	.247	.289	.545	.948	.
		N	64	64	64	64	32	0
	Family1_3_4_7_14_19_24_25_26_29_30	Correlation Coefficient	.	.034	-.103	.	.348**	.144
		Sig. (2-tailed)	.	.716	.243	.	.003	.092
		N	0	76	76	0	38	75
	ServiceSys5_9_10_11_16_17_21_27_28	Correlation Coefficient	.	.063	-.167	.	.134	.092
		Sig. (2-tailed)	.	.503	.058	.	.259	.285
		N	0	76	76	0	38	75
	Comm_Political2_6_8_12_13_15_18_20_22_23	Correlation Coefficient	.	-.051	-.035	.	.263*	-.027
		Sig. (2-tailed)	.	.582	.688	.	.026	.748
		N	0	76	76	0	38	75
	FESScore	Correlation Coefficient	.	.002	-.099	.	.258*	.041
		Sig. (2-tailed)	.	.984	.248	.	.026	.624
		N	0	76	76	0	38	75
	CS01	Correlation Coefficient	-.022	.090	-.192**	-.234*	-.012	-.013
		Sig. (2-tailed)	.842	.236	.007	.018	.902	.894
		N	64	140	140	64	70	75
	CivicParticipation25to35	Correlation Coefficient	.158	.050	.030	.008	.065	-.132
		Sig. (2-tailed)	.114	.479	.647	.934	.458	.132
		N	64	140	140	64	70	75
	Identity212to214	Correlation Coefficient	-.142	-.035	.067	.023	-.027	.113
		Sig. (2-tailed)	.162	.630	.325	.803	.765	.217
		N	64	140	140	64	70	75
	PoliticalPartic226to227	Correlation Coefficient	-.178	.125	.033	.140	-.041	.085
		Sig. (2-tailed)	.101	.108	.654	.161	.672	.384
		N	64	140	140	64	70	75
	PublicNewsInterest217to224	Correlation Coefficient	-.059	-.102	.088	-.143	-.059	.189*
		Sig. (2-tailed)	.542	.136	.170	.107	.488	.026
		N	64	140	140	64	70	75

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

NOTE: EE01_02_03_04 represents Family Support. Si_No_YRS_Participate represents Years in Program.

Appendix G

Process for Identifying Covariates

To deal with confounding variables, I ran a series of statistics to determine whether each of several potential covariates was significant. I did this by running the statistic without the potential covariate (ANOVA) and then with the potential covariate (ANCOVA) and obtained the difference between the two measures. This process was carried out by intervention vs. control groups and then again by further dividing groups into carers and PLMI to observe the covariate differences on those subgroups. Completing this process with 11 potential covariates for 17 outcomes resulted in running over 500 statistics. For each potential covariate, if the difference was greater than 10%, the variable was rated as a covariate. Further, I rated the covariate as weak, strong, or very strong. Using the rule of thumb that the number of variables in an ANCOVA should not exceed the sample size by a ratio greater than 1 to 10, I selected the top 2 to 4 covariates for each outcome and ran a final ANCOVA with group as the independent variable and each outcome as a single dependent variable. Subgroups (carers and PLMI) were also compared by splitting the data file. Multivariate analysis was not used because I had too many dependent variables for my sample size. The covariates used in the final analyses appear in Table 9.

Appendix H

FESEP Program Achievements[58]

Evidence of achievements in the FESEP program that indicate empowerment, leadership and social capital include:

- For three years ACISAM and the two grassroots mental health associations were part of a disabilities coalition that advocated for passage of the "Medications Law" to control quality and reduce prices of medications in a country that had by far the highest costs of medications in the region. In 2012 the law was finally passed and many medications were reduced by up to 60% in cost (Villarán, 2014).

- ACISAM being invited to participate by the Pan American Health Organization in a strategic planning meeting with the Salvadoran ministry of health (March 2015), which resulted in four strategies to be carried out, one of which is a collaboration between ACISAM and MINSAL to carry out family education and support groups in a pilot in three regional clinics around the country.

- A family carer has served for the last year in a key advocacy position on the National Forum for Healthcare Reform on a subcommittee in charge of installing and monitoring suggestions/ complaints boxes in the national psychiatric hospital. A presentation was made by the subcommittee to hospital staff, government health officers, and civil society members on the results of the first 6 months of suggestion box data.

- For the last 5-8 years, ACISAM and the two grassroots mental health associations have had representatives serving on the disability roundtable of the national human

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[58] This data comes from program foundation reports, conversations with staff and PLMI and their families, and three qualitative studies of these programs over the last 7 years.

rights ombudsman office, on the lead committee and mental health subcommittee of the national forum for healthcare reform, and on the national intersectoral counsel for persons with disabilities. On all of these commissions, the participation of staff, PLMI and carers provided, for the first time, participation related to persons with mental disabilities and has firmly established mental conditions as a qualifying condition for disability on the national stage.

- In 2015, ACISAM received a four-year grant from the Inter-American Foundation to provide support, capacity training, and incentive programs to eight PLMI and family associations in four Central American countries (2 in El Salvador, 3 in Nicaragua, 2 in Costa Rica, and 1 in Panama).

- ACISAM and the family associations in four countries have now provided family education and support via the four-month family to family course to approximately 300 individual family carers and a few PLMI. Over the years I have listened to carers give personal testimonies, often in tears, regarding the ways this program has changed their lives and the lives of their loved ones—relief that they are not alone in this struggle, treating one another with respect instead of constantly criticizing, getting along and having fun together and feeling a sense of love in the family once again, understanding how to treat a loved someone in crisis and how to get along with the police, no longer suffering shame and fear when going into public with their loved one, or not having to keep watch on the loved one or keep the loved one locked indoors for their own safety, having their eyes opened to the issue of the human rights and dignity of persons with mental disabilities, and being empowered to advocate with professionals for the needs of their loved one or with institutions like the

national psychiatric hospital for needed changes in the mental health system. PLMI have also testified how much better their lives are now that their carers have taken the course and understand them and treat them with respect, and how their participation in various program components has improved their lives, for example, they are able to leave the home independently and not fear for safety, they have regained the ability to have friends and maintain a marriage, or experienced the joy of being among others like yourself who are struggling with the same illness conditions, they are able to go out on recreational excursions for the first time in one's adult life, and have the confidence that they can manage their own illness and have a good life despite the challenges the illness presents, and the pride experienced when being empowered to take on a leadership role within their association or on a governmental commission related to their rights.

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