

**A PARTICIPATORY APPROACH TO PHYSICAL ACTIVITY AMONG
PEOPLE WITH SEVERE AND PERSISTENT MENTAL ILLNESS**

by

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ABSTRACT

People with severe and persistent mental illness (SPMI) in the U.S. have rates of co-occurring chronic medical illnesses two to three times higher than the general population and a corresponding reduction in life expectancy of 25 years. People with SPMI in the community setting are a vulnerable population, subject to self- and perceived stigma that prevent them from seeking adequate medical care. A majority of early mortality among people with SPMI is related to preventable causes such as cardiovascular diseases and diabetes. Involvement in physical activity has shown to improve the mental and physical health of people with SPMI.

The goal of this dissertation is to explore challenges and prospects in the development of a tailored physical activity intervention for people with SPMI and in a community setting. The data is organized into three manuscripts predicated on an established community-academic partnership that led to the development, design, implementation and evaluation of the intervention through a Community Based Participatory Research (CBPR) approach. Manuscript one is a literature review that examines what is known regarding community-based physical activity interventions and outcomes and mental and physical health outcomes among people with SPMI, identifying critical gaps in the literature. Manuscript two studies the perceived benefits and barriers to physical activity among people with SPMI in the community setting where the

intervention took place to provide qualitative evidence for the intervention design. Manuscript three focuses on the community-academic partnership and the development and implementation of a feasibility study focused on the effect of physical activity on the physical and mental health outcomes among people with SPMI in this community setting.

This dissertation brings an innovative approach to recovery in adjunct to pharmaceutical treatments or cognitive approaches. It provides a platform to understand what is required to carry out a community-based intervention with rigor and collaboration. The public health significance of this dissertation is presented in the findings of this research, which suggest that it is paramount to understand the needs of the population, while recognizing that tailoring a physical activity intervention based on these needs to improve the physical and mental health among this vulnerable population has challenges and opportunities for collaboration. Future research, programs, and policy should consider these findings to improve the well-being of people living with SPMI in the U.S. and globally.

TABLE OF CONTENTS

PREFACE.....	XIII
1.0 INTRODUCTION.....	1
1.1 STATEMENT OF PROBLEM	2
1.2 DEFINITION AND IMPORTANCE OF PHYSICAL ACTIVITY IN THE GENERAL POPULATION AND AMONG PEOPLE WITH SPMI.....	5
2.0 COMMUNITY EXERCISE AND MENTAL HEALTH	6
2.1 ABSTRACT.....	7
2.2 BACKGROUND	8
2.3 AIM.....	9
2.4 METHODS.....	10
2.5 RESULTS	11
2.5.1 Sample sizes, participants, and design.....	11
2.5.2 Type of intervention	11
2.5.3 Mental health outcomes	15
2.5.4 Physical health outcomes	16
2.5.5 Mental and physical health outcomes.....	16
2.5.6 Other measures	17
2.6 LIMITATIONS.....	18

2.7	CONCLUSIONS	18
2.8	FIGURES.....	21
2.9	TABLES.....	22
2.10	REFERENCES FOR ARTICLE.....	26
3.0	METHODS	30
3.1	CONCEPTUAL FRAMEWORKS	30
3.1.1	Social Cognitive Theory and the Transtheoretical Model.....	30
3.1.2	Motivational Interviewing	33
3.2	WORKING HYPOTHESES AND SPECIFIC AIMS.....	35
3.2.1	Specific Aims	35
3.2.2	Hypotheses.....	35
3.3	APPROACH.....	36
3.4	COMPONENT I: DEVELOPMENT.....	41
3.4.1	Population and Sampling.....	41
3.4.2	Recruitment of Participants	42
3.4.3	Data Collection.....	42
3.4.4	Data Analysis.....	43
3.5	COMPONENT II: IMPLEMENTATION & EVALUATION.....	44
3.5.1	Study Population and Recruitment.....	44
3.5.2	Research Design.....	44
3.5.3	Data Collection.....	45
3.5.4	Data Analysis.....	46
3.5.5	Data Management.....	47

3.5.6	Confidentiality of Data Sources.....	47
4.0	PERCEIVED BENEFITS AND BARRIERS TO PHYSICAL ACTIVITY AMONG PEOPLE WITH SEVERE AND PERSISTENT MENTAL ILLNESS: A QUALITATIVE STUDY.....	49
4.1	ABSTRACT.....	50
4.2	INTRODUCTION	50
4.3	METHODS.....	52
4.3.1	Design.....	52
4.3.2	Ethical Procedures.....	53
4.3.3	Sample and Setting	53
4.3.4	Recruitment of Participants	54
4.3.5	Data Collection.....	54
4.3.6	Data Analysis.....	55
4.4	CONFLICT OF INTEREST	55
4.5	RESULTS	56
4.6	DISCUSSION.....	60
4.7	FIGURES.....	64
4.8	REFERENCES FOR ARTICLE.....	65
5.0	ON THE MOVE: THE INTERVENTION.....	70
5.1	BACKGROUND	70
5.2	INTERVENTION AND PILOT TEST APPROACH.....	73
5.2.1	Hiring and training of Physical Activity Leaders (PALS).....	73
5.2.2	Motivational Interviewing (MI) training.....	74

5.2.3	Design of intervention	74
5.2.4	Recruitment, informed consent and physician’s clearance	74
5.2.5	Baseline glucose, weight and blood pressure.....	75
5.2.6	Pre-survey administration	75
5.2.7	Physical activity intervention	75
5.2.8	Weekly meetings with PALS	76
5.2.9	Bi-monthly meetings with research team	77
5.2.10	Presence of PI at CHS locations	77
5.2.11	Additional components	77
5.2.12	Post-survey administration.....	78
5.2.13	Materials developed	78
5.2.14	Post program team meeting and next steps	78
6.0	A PARTICIPATORY APPROACH TO PHYSICAL ACTIVITY AMONG PEOPLE WITH SEVERE AND PERSISTENT MENTAL ILLNESS	80
6.1	ABSTRACT.....	81
6.2	KEYWORDS.....	82
6.3	INTRODUCTION	82
6.4	METHODS.....	84
6.5	RESULTS	88
6.6	DISCUSSION.....	93
6.7	IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE	96
6.8	CONCLUSION	99
6.9	ACKNOWLEDGEMENTS	99

6.10	FIGURES.....	101
6.11	TABLES.....	102
6.12	REFERENCES FOR ARTICLE.....	110
7.0	DISCUSSION	115
7.1	STRENGTHS.....	115
7.2	LIMITATIONS.....	117
7.3	AIM 1 DISCUSSION.....	118
7.4	AIM 2 DISCUSSION.....	120
7.5	AIM 3 DISCUSSION.....	124
7.6	PROGRAM AND POLICY IMPLICATIONS.....	130
7.7	FUTURE RESEARCH.....	132
8.0	CONCLUSION.....	135
APPENDIX A : COMPONENT ONE INSTRUMENT: FOCUS GROUP QUESTIONNAIRE.....		137
APPENDIX B : COMPONENT TWO: CODE BOOK.....		143
APPENDIX C : COMPONENT TWO: SURVEY INSTRUMENT.....		145
APPENDIX D : GANNT CHART FOR ON THE MOVE ACTIVITIES.....		155
APPENDIX E : OPEN ENDED QUESTIONNAIRE POST INTERVENTION.....		157
BIBLIOGRAPHY		159

LIST OF TABLES

Table 2-1: Literature Review: Data Extraction Table.....	22
Table 5-1: Key Individuals and Their Roles in the Project	71
Table 6-1: Demographic Characteristics of the Participants	102
Table 6-2: Reasons for Non-Participation in Exercise Program among Participants.....	103
Table 6-3: Post-Survey qualitative responses, On the Move.....	104
Table 6-6: Impact of Research on Participants, Agency, and Community.....	107
Table 6-7: Possible Positive and Negative Impacts of Program on Agency	108
Table 6-8: Lessons Learned from On the Move Exercise Sessions.....	109

LIST OF FIGURES

Figure 2-1: Process of Literature Review (current to 11/11/12).....	21
Figure 3-1: Conceptual Model of SCT and TTM Combined	32
Figure 3-2: Early Tasks in Negotiating Behavior Change.....	34
Figure 3-3: Overview of Dissertation Process	40
Figure 4-1: Example Questions from Focus Group Discussion Guide.....	64
Figure 5-1: On the Move Logo	72
Figure 6-1: Overview of the Partnership and Process	101

PREFACE

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1.0 INTRODUCTION

People with a severe and persistent mental illness (SPMI), such as schizophrenia, schizoaffective disorder, bipolar disorder, obsessive compulsive disorder, multiple personality disorder, and major depression have poorer health and die much earlier than the rest of the general population [1]. To date, behavioral and pharmacological treatments are the main interventions used with this population to reduce morbidity and mortality. Physical activity appears to be an underutilized intervention in mental health care; while very little is published on physical activity and its effect on mental health, some behavioral and mental health professionals have advocated for exercise as a therapeutic tool to treat a variety of mental health issues [2]. The National Institute of Mental Health (NIMH) has prioritized innovative and effective interventions to prevent and cure mental illness and to reduce its associated medical comorbidities together with new partnerships to accelerate the achievement of these goals [3]. With regard to innovation and personalized treatment, in the last few decades, physical activity and wellness strategies to improve morbidity and mortality rates among this population have been implemented on a small scale. Most of this research was in more institutional or controlled settings, but increasingly this research is moving towards community settings. This is particularly important for people with SPMI as this population is shifting from institutionalized to community settings [4].

This study has three aims. Aim 1 is to complete a literature review regarding physical activity interventions undertaken in community settings among people with SPMI and to identify

research gaps. Aim 2 is to explore the perceived benefits and barriers to involvement in physical activity among individuals with SPMI in a community within a specific geographic area in Pittsburgh, Pennsylvania. Aim 3 is to describe the feasibility of developing and implementing a tailored physical activity program based on the outputs of Aim 2 regarding physical and mental health outcomes among participants with SPMI, through a CBPR approach among the same population as referenced in Aim 2.

1.1 STATEMENT OF PROBLEM

It is estimated that 26.2 percent of adults in the U.S. over the age of 18 suffer from a diagnosable mental disorder in a given year. Mental health disorders are the leading cause of disability in the U.S. and are responsible for 25 percent of all years of life lost to disability and premature mortality [3]. Findings from a nationally representative face-to-face household survey to determine levels of health care use among those with mental illness and SPMI suggest that as a result of greater perceived stigma of their mental disorder, individuals with mental illness and SPMI have higher risks of under-treatment [5]. While mental disorders are widespread in the general population, the burden of severe illness focuses on a much smaller proportion of the population; about 6 percent, or 1 in 17, people suffer from a severe and persistent mental illness [3].

The National Institute of Mental Health reached consensus on the following definition for SPMI, one that is widely used for community based interventions.

The definition is based on three [co-occurring] conditions:

1. *The diagnostic criterion, described as a nonorganic psychosis and personality disorder;*

2. *The duration criterion, which described the seriously mentally ill as having a long history of previous hospitalizations or outpatient treatment; and*
3. *The disability criterion, which included dangerous or disturbing social behavior, moderate impairment in work and non-work activities and mild impairment in basic needs.[6]*

While the definition of severe and persistent mental illness (SPMI) can vary slightly by state, it is a term that is regularly used to identify a group of mental disorders that often affect people during early adulthood; disorders typically encompassed under SPMI include schizophrenia, schizoaffective disorder, bipolar disorder, major depression, autism, and obsessive-compulsive disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) [7].

In Pennsylvania, according to the Allegheny County Health Choices program, between 1999 and 2009 over 100,000 people used behavioral services in Allegheny County (62,000 adults) and 93,000 people used mental health services [8]. Prevalence of SPMI in the past decade within Allegheny County are comparable to nationwide statistics; men with SPMI range from 8% (White) to 13% (African American) and women with SPMI range from 8% (White) to 10% (African American) [9].

People with SPMI have rates of co-occurring chronic medical illnesses two to three times higher than the general population [10]. Lifestyle issues including cigarette smoking, poor physical fitness, and poor nutrition that lead to a greater risk of medical issues among people with SPMI are more prevalent as related to the general population [1, 11]. People with SPMI may experience low satisfaction with life based on poor living conditions, lack of and discontent with social relationships, lack of health services, and unemployment [12]. Several studies have

examined relative risk among this population by state. Felker et al. conducted a literature review of standardized mortality ratios (SMRs), or statistical derivatives measuring the degree to which the risk of mortality is higher or lower in a cohort compared with a reference population. Numerous studies found SMRs among people with SPMI ranging between 1.7 to 4.2, showing a relative risk two to four times higher than the general population [13]. Colton et al. undertook a review among eight states in the U.S. and found that the relative risk of death for public mental health clients was higher in all eight states from 1997 to 2000 than for general populations in each state; actual numbers of deaths among public mental health clients ranged from 4.9 to 1.2 times higher than the expected number of deaths [14]. Dembling et al. found that in Massachusetts, on average between 1989 and 1994, people with SPMI that were served by the department of mental health lost 8.8 more years of potential life than people in the general population, with a mean of 14.1 years for men and 5.7 for women [15].

Mental disorders are one of the five most costly conditions among the civilian non-institutionalized population [16]. For example, the inactive lifestyle common among those with SPMI can double their risk of morbidity and mortality from heart disease [17]. Cardiovascular disease (CVD) is the leading cause of death in the United States [18]. A majority of disability adjusted life years (DALYs) among people with SPMI is attributable to preventable causes such as CVD. In addition, people with SPMI experience perceived and social stigmas that are barriers to receiving adequate primary medical care [19, 20].

1.2 DEFINITION AND IMPORTANCE OF PHYSICAL ACTIVITY IN THE GENERAL POPULATION AND AMONG PEOPLE WITH SPMI

According to the World Health Organization (WHO) physical activity is defined as any bodily movement produced by skeletal muscles that requires energy expenditure [21]. Physical activity is a broad category that includes exercise, which is defined as a “physical activity that is planned, structured, repetitive, and purposeful in the sense that the improvement or maintenance of one or more components of physical fitness is the objective” [21]. Physical inactivity is the fourth leading risk factor of mortality worldwide [22]. It is well known and accepted that regular physical activity is linked with various health benefits and a reduced risk of some chronic diseases [23]. In the late 1980s NIMH brought together a group of experts to reach a consensus statement on the mental health effects of exercise to bring together research and clinical practice. This resulted in the following statement: “Exercise is (1) positively linked with mental health and well-being, (2) reduces stress and state anxiety, and (3) has emotional benefits for all ages and in both genders [24]”.

Physical activity has shown to reduce the risk of cardiovascular disease and other risk factors leading to premature morbidity and mortality among adults, particularly among adults that are obese [25]. The lifestyle of people with SPMI strongly underscores the need for health promotion activities, including physical activity [20]. The movement from institutionalized to community settings among people with SPMI has shown that social and environmental influences are important determinants of health among this population [26-28]. It is important to use other interventions such as physical activity in addition to behavioral and pharmacological methods to lower the mortality rates and risk of early death for people with mental illness, especially those with SPMI [14].

2.0 COMMUNITY EXERCISE AND MENTAL HEALTH

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2.1 ABSTRACT

Background: People with severe and persistent mental illness have rates of co-occurring chronic medical illnesses 2-3 times higher than the general population. The relationship between mental illness and poor physical health is well known. Physical activity has shown a positive effect on mental and physical outcomes among this population. Aims: To review the literature regarding the effect of physical activity on mental and physical health outcomes among people with SPMI in community settings. Methods: A database search including Pubmed, PsycINFO, and CINAHL was conducted to identify physical activity interventions among people with SPMI. The studies were assessed, extracted, and synthesized. Results: Eleven studies met the criteria: one study focused on mental health outcomes, nine studies focused on mental and physical health outcomes, and one study was exploratory. Research designs and instruments to measure mental and physical health varied. Eight studies had significant health outcomes. Conclusions: Physical activity in community settings requires attention to participants' needs, perceived benefits, and barriers, and a structured group setting may lead to increased motivation and attendance. Further studies are necessary to determine the effect of a tailored approach to physical activity interventions among people with SPMI in community settings. Declaration of Interest: None.

Key Words: Severe and Persistent Mental Illness, Physical Activity, Mental Health Outcomes, Physical Health Outcomes

2.2 BACKGROUND

Mental health disorders are the leading cause of disability in the U.S. and are responsible for 25 percent of all years of life lost to disability and premature mortality (NIMH, 2010). It is estimated that one quarter (26%) of adults in the U.S. over the age of 18 suffer from a diagnosable mental disorder each year. The burden of severe illness focuses on a smaller proportion of the population; about six percent of people suffer from a severe and persistent mental illness (SPMI) (NIMH, 2010), which is defined by three co-occurring criteria: diagnosis, duration, and disability. These criteria translate to a long history of severe mental illness and hospitalizations, dangerous or disturbing social behaviors, and inability to carry out basic work and non-work related functions without assistance (Parabiaghi, et al., 2006).

In the 1960s sociologists and other behavioral specialists became concerned with rapid institutionalization of people with mental illness. They felt it was against efforts to reintegrate clients into society to help lessen the stigma and destructive social effects of institutionalization (Wright et al., 2000). The subsequent deinstitutionalization movement intended to normalize the lives and relationships of people with mental illness and bring them into their own communities for treatment and recovery. This was based on the supposition that networks kept within a mental health system stigmatize people with mental illness and therefore diminish their quality of life (Rosenfield & Wenzel, 1997). More recent work examining the movement from institutionalized to community settings among people with SPMI shows social and environmental factors are also important determinants of health among this population (Meisler et al., 1988).

The relationship between mental illness and poor physical health has been acknowledged for almost eighty years (Philips, 1934). People with multiple lifetime psychiatric diagnoses have much higher rates of smoking than people without mental illness (Lasser K, 2000). Cigarette

smoking, poor physical fitness, and poor nutritional status are factors that lead to higher risk of medical problems among people with SPMI (Banham & Gilbody, 2010; Byrne et al., 1999). People with SPMI have about 1.5 to 2 times the general population prevalence of diabetes, dyslipidemia, hypertension, and obesity (Newcomer & Hennekens, 2007; Parks et al., 2010). Additional research in numerous countries has further established that psychiatric patients have high rates of physical illness (Phelan et al., 2001), which is underscored as a serious issue that requires attention (Colton & Manderscheid, 2006; Holmberg & Kane, 1995). People with SPMI experience perceived and actual stigmas that are obstacles to receiving adequate primary medical care (Rosenfield & Wenzel, 1997). For example, symptoms related to schizophrenia including cognitive impairment, social isolation, and suspicion could affect care seeking or adherence to treatment (Phelan et al., 2001). Physical activity has shown to decrease the risk of cardiovascular disease and other risk factors leading to early morbidity and mortality among adults, particularly among adults that are overweight (Jakicic & Davis, 2011). Given the higher prevalence of contributing factors to cardiovascular disease and other diseases leading to early morbidity and mortality among people with SPMI, physical activity in addition to behavioral and pharmacological methods ought to be considered (Colton & Manderscheid, 2006).

2.3 AIM

The aim of this review is to synthesize the current peer-reviewed published literature regarding physical activity interventions and their effect on mental and physical health outcomes among people with SPMI in community or deinstitutionalized settings.

2.4 METHODS

A comprehensive literature review was conducted using PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature) and PsycINFO databases to examine published literature using keyword searches of terms relevant to physical activity, exercise, intervention, evaluation and mental health. Articles found in searches were reviewed against the following inclusion criteria: published in peer-reviewed journals, English language, adult population age 18 or older; diagnosis of a disorder typically encompassed under SPMI including schizophrenia, schizoaffective disorder, bipolar disorder, major depression, and obsessive-compulsive disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (Carey & Carey, 1999); implementation of physical activity or exercise intervention; included at least one mental health outcome; and took place in a community and/or deinstitutionalized setting. Five thousand eight hundred and eighty four articles were identified searching the scientific databases and reference lists of literature reviews from relevant articles. After screening based on inclusion and exclusion criteria and removing duplicate articles, 58 articles were reviewed from CINAHL, 42 articles were reviewed from PsycINFO, 68 articles were reviewed from PubMed, and 31 articles were identified through hand-picked articles or from references in literature reviews. Two researchers reviewed articles against the criteria and developed a short-list of eligible articles; researchers compared short-lists and reached consensus on eligible articles. **Figure 2-1** presents the search process.

The papers were read by the primary researcher who extracted relevant data from each study. The second researcher read articles separately and reviewed the table for accuracy. Both researchers reviewed revisions and reached consensus on table contents. **Table 2-1** displays the data extraction table.

2.5 RESULTS

Eleven articles addressing physical activity and mental health outcomes met the criteria. The following sections provide a summary of participants, study designs, intervention types, significant mental and physical health outcomes, and instruments used to measure physical and mental health outcomes of the intervention.

2.5.1 Sample sizes, participants, and design

Study settings included community health centers and care units, community mental health programs, partial hospitalization programs, and psychiatric rehabilitation programs. Participant ages ranged from 18 to over 70 years of age. A majority of studies took place in the U.S. with the exception of Portugal, Australia and Canada. The studies ranged in design and included: pilot studies; randomized control trials; experimental randomized control trials; a prospective, randomized, investigator blinded two-arm parallel assignment; pre-post feasibility studies, and exploratory studies.

2.5.2 Type of intervention

The type of exercise is important depending on fitness and comfort level of participants. A tailored approach taking into account the individual's personal health goals, needs, and readiness to change could help participants develop approaches to foster self-efficacy to participate in exercise (Van Citters et al., 2010). A graduated program, increasing from low impact activities, could also prevent onset of pain from new activities (Marzolini et al., 2009). According to Beebe

et al., it is important to determine feasible delivery mechanisms (Beebe et al., 2005). Motivational interviewing (MI) was used in several studies as a tool in several interventions to identify barriers to participation and evoke change among participants (Usher et al., 2012; Van Citters et al., 2010).

Physical activities addressed in the eleven studies included walking, exercises combined with nutritional or other counseling, dance classes, and other unique activities such as Tai Chi, Salsa dancing, and resistance training. Some interventions merely encouraged exercise on a group or individual basis, while others organized and supervised group sessions. The interventions ranged in length and follow up from ten weeks to 13 months. The individual exercise activity, whether once a week or several times a week, ranged from 30 minutes to one hour.

Among the eleven, three studies focused on a walking program. In one study, thirty three participants diagnosed with major depressive disorder (MDD) were randomized to assess the impact of aerobic walking on depression and functioning parameters (Mota-Pereira et al., 2011). Along with their usual pharmacological therapy, 22 individuals participated in moderate intensity exercise using treadmills, 30-45 minutes, five days a week, for 12 weeks. In another walking intervention, fifteen inactive adult outpatients undertook a quasi-experimental pilot study to examine adherence, health status, and motivation in a 12-week structured group-based walking program. The first four weeks focused on conditioning, warm up and cool down; subsequent weeks gradually increased in intensity and duration (McDevitt et al., 2005). Lastly, ten people with schizophrenia were enrolled in a pilot study to examine the effect of a 16-week walking program. Participants were randomized to a control or experimental group. Participants in the experimental group met three times a week for 16 weeks for treadmill walking. Control

participants did not participate in exercise but were offered the same exercise program at the study's conclusion (Beebe et al., 2005).

Five studies combined exercise and nutrition/wellness counseling. Over a nine-month period in one study, 76 adults were enrolled in a pilot program developed by a consumer advisory panel at a community mental health center. Participants were paired with a health mentor experienced in fitness training, goal setting, MI, and healthy eating behaviors. Fitness and diet plans were tailored to each participant's fitness status, goals, and preference for exercise type. Participants received a free YMCA membership, and exercise included attending classes at the YMCA, walking, swimming, Tai-Chi, yoga, strength training, or cardiovascular fitness training. Health mentors encouraged participation in group-based exercise and nutritional education activities that were provided by health mentors and professionals at local fitness facilities and other community locations. Every six weeks a motivational celebration took place and prizes were awarded for reaching goals (Van Citters et al., 2010). A single-arm pilot study was developed in two psychiatric rehabilitation day programs to look at the effect of exercise on weight loss among 63 people who were overweight or obese over six months. The study included counseling sessions on weight management, 45 minute group aerobic/dance sessions and provision of healthier meals (Daumit et al., 2011). Thirty nine participants took part in a pre-post feasibility study comprised of nine one-hour sessions regarding diet and exercise and overcoming barriers to diet and changes over 18 weeks; the last 20 minutes of the hour consisted of a warm up and group walk. An unanticipated result of the study included several participants organizing a walking group at a local mall (Richardson et al., 2005). A nurse-led intervention among 101 participants focused on preventing weight gain among those taking second-generation antipsychotics over 12 weeks including nutrition and exercise counseling, exercise,

and MI. The intervention group was given a copy of an educational booklet and met weekly to discuss different healthy lifestyles, followed by 30 minutes of exercise; the control group just received the educational booklet (Usher et al., 2012). Lastly, nine participants living in homes for residents, discharged from psychiatric programs and unable to live independently, participated in a wellness education and exercise over 12 weeks (Byrne et al., 1994).

Three studies comprised a unique type of physical activity. Thirteen participants were randomized in a pilot study to assess the feasibility and effects of aerobic and resistance training on people with schizophrenia and/or schizoaffective disorders. The 12 week exercise program took place at a community center located within walking distance or bus transport. The experimental group exercised 90 minutes twice a week including warm up and cool down under supervision. The control group received care as usual (Marzolini et al., 2009). A Tai Chi program was developed to treat MDD (Yeung et al., 2012) wherein one hour group classes were held weekly for 12 weeks. Outcomes were assessed at baseline, week six, and week 12. Although not significant, dose-effect was observed in the intervention regarding improved response and remission rates: those completing the Tai Chi improved the most; those not completing the Tai Chi improved the least. Twelve participants were enrolled in a pilot study to analyze the effects of a 1-hour Salsa dance lesson weekly for 10 weeks. Participants were members of the Independence Center in St. Louis, Missouri, following a Clubhouse model; participants were blinded to study hypotheses and asked not to change exercise habits during the study (Hackney & Earhart, 2010).

2.5.3 Mental health outcomes

The mental health outcomes addressed in the eleven studies included severity of depression and functioning, quality of life, social support, anxiety, confidence, decisional balance, and mental health status. Five out of eleven studies showed significant changes in mental health outcomes; the results are below.

Significant improvement was found in the Hamilton Rating Scale for Depression (HAM-D₁₇), Beck Depression Inventory (BDI), Clinical Global Impression Scale (CGI-S) and higher Global Assessment of Functioning (GAF) at last observation when compared to baseline in the walking program (Mota-Pereira et al., 2011). Depression scores on the Center for Epidemiologic Studies depression scale (CES-D) improved significantly from baseline to follow-up in the combined education and exercise program (Daumit et al., 2011). The group-based walking program showed significant improvements in psychosocial functioning measured through the Multnomah community Ability Scale and in mood (McDevitt et al., 2005). The intervention including fitness and healthy lifestyle assessment, mentor meetings, and an incentive program showed significant improvement in mental health functioning over time measured by the SF-12 (between baseline (31.8 +/- 12.9) and 9-month follow up (36.2 +/- 13.4); $t(53) = -2.411$, $P = .019$) and a decrease in the severity of negative symptoms (baseline (2.5 +/- .7 and 9-month follow up (2.3 +/- .6; $t(56) = 2.128$, $P = .038$) measured through the Scale for the Assessment of Negative Symptoms. There was a significant interaction between time and number of quarterly contacts with a health mentor; people involved more with their health mentor were more likely to have improvements in mental health functioning (Van Citters et al., 2010). There was significant improvement from baseline to 12 weeks in total scores on the Mental Health Inventory (MHI) in

the aerobic and resistance training program among the intervention group ($p = .03$) with no significant improvement in the control group ($p = .57$) (Marzolini et al., 2009).

2.5.4 Physical health outcomes

Physical health outcomes were measured through anthropometric measurements such as Body Mass Index (BMI) or weight/circumference measurements, cholesterol, blood pressure, cardiovascular fitness, and mobility/agility tests (6-minute walk test, Timed Get up and Go Test (TUG), Gait velocity, one-leg stance, step counts). Two out of the eleven studies showed significant changes in physical health outcomes. Richardson et al. showed significant changes pre and post intervention in weight (baseline to 18th week: -5.3 lbs., $p=.045$) among participants in the walking program coupled with one-hour group sessions (Richardson et al., 2005). Hackney and Earhart found significant improvements between pre and post measurements in the TUG test ($p = .012$) among participants in the Salsa dance class (Hackney & Earhart, 2010).

2.5.5 Mental and physical health outcomes

Three studies cited earlier showing significant improvements in mental health outcomes also had significant results in physical health outcomes. Daumit et al., in addition to the significant mental health outcomes, showed significant changes pre and post intervention regarding weight, BMI, waist circumference, and the 6-minute fitness walk test in the study focused on a combined education and exercise program (Daumit et al., 2011). Marzolini et al. found significant improvement in strength among the exercise group (28.3 +/- 8.8%; $p = .01$) and none for the

control group (12.5 +/- 8.5%; $p = .02$, effect size of .94) (Marzolini et al., 2009). Van Citters et al. showed significant reduction in waist circumferences (Van Citters et al., 2010).

2.5.6 Other measures

Several studies measured satisfaction (Marzolini et al., 2009; Richardson et al., 2005; Van Citters et al., 2010; Yeung et al., 2012) and changes in amount of exercise per day, week, or month (Van Citters et al., 2010; Vreeland et al., 2003). One study focused on exploratory measures; the overarching message from participants was that people who were previously not involved in healthy lifestyle activities found encouragement from a new focus on health (Byrne et al., 1994). Some studies included an open-ended questionnaire eliciting participants' feedback on what they liked and didn't like in the programs (Hackney & Earhart, 2010; Marzolini et al., 2009). Compliance and drop-out rates were measured in several studies and provided different explanations for lower compliance: deficits and stigma; lack of motivation (Hackney & Earhart, 2010); participating alone in exercise or low comfort level (Marzolini et al., 2009); and irregular attendance due to illness or transportation issues (Richardson et al., 2005). The study that focused on a disease specific program for MDD resulted in high compliance rates (91%). Although the enrollment of one diagnosis may support generalizability for specific diagnoses, in practice it can be difficult to separate out SPMI diagnoses (Richardson et al., 2005).

2.6 LIMITATIONS

The methodology undertaken in this review has some limitations worth noting. First, this methodical study covered three well known databases versus a complete systematic review including other mental and physical health databases such as PsycARTICLES or SportDiscus. Next, only studies in English were reviewed. Finally, only peer-reviewed journals were included and grey literature was not included, which may exclude less rigorous programmatic interventions as opposed to research interventions.

2.7 CONCLUSIONS

This review demonstrates important findings related to the effects of physical activity on mental and physical outcomes of people with SPMI. Several themes were generated that merit exploration in future research in order to improve the lives of people with SPMI in community settings. Attendance in a structured, supervised, group-based exercise program can address barriers specifically related to people with SPMI (Marzolini et al., 2009; McDevitt et al., 2005; Richardson et al., 2005). Group attendance also affects motivation, cited as a reason attributed to compliance rates in some studies (Hackney & Earhart, 2010; Marzolini et al., 2009; Van Citters et al., 2010).

Several of these studies demonstrated statistical significance; however qualitative responses revealed successes or lessons learned that could not have been discovered through statistical analyses alone (Hackney & Earhart, 2010; Marzolini et al., 2009). Intervention effectiveness relies on compliance, and motivation is an important aspect to success (Hackney &

Earhart, 2010). Motivational Interviewing (MI) can be beneficial for people who show less initial motivation to change, feedback can provide useful material for MI, and often reveals possible reasons for change not apparent before (Rollnick, et al., 2008). Offering MI to participants by someone known and trusted may facilitate change toward increased motivation and involvement in exercise.

Two studies continued the exercise programs after study completion (Marzolini et al., 2009; Richardson et al., 2005). Given the nature of community settings, community engagement and sustainability are factors that cannot be ignored. Physical activity interventions that are based in community settings, rather than institutionalized settings, may benefit from participatory approaches to allow for ownership and sustainability beyond the life of the intervention. While Community Based Participatory Research (CBPR) has been identified as an effective strategy for increasing buy-in of marginalized communities and increasing the likelihood of both successful research and subsequent uptake of intervention practices (Israel et al., 1998), to the authors' knowledge no existing physical activity intervention focusing on people with SPMI has adopted such an approach. There is potential to expand this research in community settings that lends itself to what CBPR is predicated upon: a partnership approach to research that equitably involves community members, academic researchers, and others such as healthcare providers in all phases of the research process. All partners contribute expertise and share decision making and ownership of the project (Burke, et al., 2010; Israel et al., 1998; Yonas et al., 2006). According to Wallerstein and Duran, CBPR is a “transformative research opportunity to unite the growing interest of health professionals, academics, and communities in giving underserved communities a genuine voice in research, and therefore to increase the likelihood of an intervention’s success” (Wallerstein & Duran, 2010).

Additionally, two studies reviewed included tailored activities based on each individual's fitness, link to health promotion, and goals; however no consistent structured group activity resulted from these assessments (Byrne et al., 1994; Van Citters et al., 2010). To encourage physical activity in this population, participants' interests must be considered beyond individual fitness, including type of activity, preferred place to participate, and social influences (Ussher et al., 2007).

Ussher et al. and McDevitt et al. have documented perceived barriers and preferences regarding physical activity among people with SPMI (McDevitt et al., 2006; Ussher et al., 2007). To the authors' knowledge, there are no published papers to date undertaking structured group-based exercise programs tailored and designed based on focus group discussions that identify perceived benefits and barriers to exercise, or studies that include gender specific exercise programs. Beginning with this type of approach to inform the intervention could lead to improved tailored programs for increased adherence and acceptability. It is essential to understand how to implement more effective interventions that foster acceptance of physical activity as an essential lifestyle component among people with SPMI in community or deinstitutionalized settings (Faulkner & Sparkes, 1999).

2.8 FIGURES

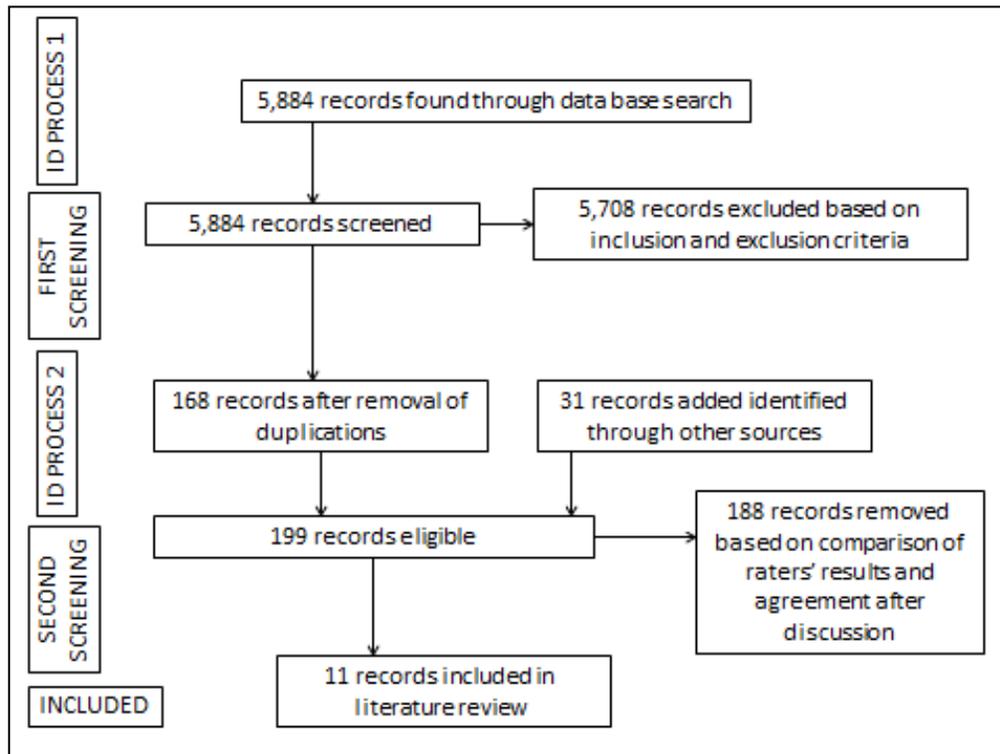


Figure 2-1: Process of Literature Review (current to 11/11/12)

2.9 TABLES

Table 2-1: Literature Review: Data Extraction Table

Mental Health Outcomes Focus					
Study/Author/Date	Participant Diagnosis, Inclusion criteria, Sample Size	Study Design	Physical activity intervention, groups, length of follow up	Outcome Measures	Results
Yeung, A. et al (2012)	Chinese Americans recruited from Boston's Chinese community. Self-identification of Chinese ethnicity and fluent in Mandarin and/or Cantonese, 18 to 70 years of age, DSM diagnosis of MDD, baseline score ≥ 12 on HAM-D17 (n = 39)	Randomized controlled trial	Tai Chi intervention of 1-hr group classes held twice weekly for 12 weeks. Participants in waitlisted group were assessed at weeks 6 and 12 but received no other interventions during waiting period.	HAM-D17, CGI-S and GGI-Improvement, Quality-of-Life Enjoyment and Satisfaction Questionnaire, (SF) Multidimensional Scale of Perceived Social Support.	No significant differences in outcome measures.
Mental and Physical Health Outcomes					
Mota-Pereira, J. et al. (2011)	Outpatient psychiatry clinic in Portugal, diagnosed with MDD for 9 to 15 months, aged 18-60 years, able/willing to provide written informed consent, taking	Prospective, randomized, investigator blinded, two-arm, parallel assignment	Exercise group: 30-45 min/day walks, 5 days/week, for 12 weeks.	HAMD17, CGI-S, BDI-II, GAF, BMI, Total cholesterol, LDL-cholesterol and HDL-cholesterol, compliance	Exercise group showed improvement in all depression/functioning parameters compared to baseline. Difference in pharmacological agents used between responders and non-

Table 2-2 Continued

	combined therapy in doses considered apt for between 9 and 15 months, no clinical remission, physical fitness to endure moderate intensity exercise confirmed by physician, normal ECG (n = 33)				responders concerning antidepressants with non-responders being more heavily medicated than responders.
Daumit, G. L., et al. (2011)	Individuals from two psychiatric rehabilitation day programs in Maryland. Ages >= 18 attending rehabilitation programs, overweight /obese, BMI > 25 kg m ⁻² , diagnosis of SMI, plans to remain at rehabilitation program at least 6 months (n=63)	Single-arm pilot study	6-month weight-loss Three components: weight management counseling sessions, group physical activity sessions	Weight, waist circumference, accelerometry, blood pressure, 6-min walk, fasting serum measurements, CES-D	Significant changes pre/post intervention for weight, BMI, waist circumference, 6-min fitness walk, min/day moderate physical activity in bouts of >= 10min, LDLs. Secondary outcomes: depression scores on the CES-D improved from baseline to follow up.
Hackney, M. E., & Earhart, G. M. (2010)	At least 18 years old; diagnosis of SPMI; otherwise normal central, peripheral neurological function; vision corrected to 20/40 or better (n=12)	Pilot study	1-hour Salsa dance lessons weekly, 10 weeks.	Gait velocity, one-leg stance, TUG, 6-minute walk tests, Beck Depression and Beck Anxiety Inventories, Activities-specific Balance Confidence Scale	Significant improvements in TUG (p < .01).
McDevitt, J., et al. (2005)	Psychiatrically stable, 20-65 years old, sedentary in leisure time. Affiliated with the outpatient part of a program site of a leading psychosocial rehabilitation agency in	Quasi-experimental pilot study	12-week walking program meeting three times/week for 1 hour, four health information workshops at beginning of	Cardiovascular risk, adherence, health status (SF-12, Multnomah community Ability Scale) exercise motivation	There was a significant change in mode and psychosocial functioning pre- and post- intervention.

Table 2-3 Continued

	Chicago. (n=15)		study.		
Beebe, L. H., et al. (2005)	People receiving care at outpatient clinic in a Southeast VA hospital. Diagnosis of schizophrenia, , medical clearance for moderate exercise. (n=12)	Pilot study, randomly assigned to experimental (n=4) or control groups (n=6)	Treadmill exercise program, meeting three times a week for 16 weeks. Approximately 13 month follow up	6-minute walking distance, BMI, % body fat, PANSS scale	Experimental participants reduced their % body fat more than controls. Non-significant but clinically meaningful changes in positive and negative symptoms on PANSS scale
Van Citters, A. D., et al. (2010)	Aged 18 or older with a primary DSM-IV Axis I or Axis II diagnosis enrolled in an ongoing health promotion program, physician approval, no potential medical problem based on the Physical Activity Readiness Questionnaire (n=76)	Pilot study	Individualized fitness and healthy lifestyle assessment, fitness plan, weekly meetings with health mentor, access to fitness facilities, incentive program, celebrations. 3, 6, 9 month follow up	Yale Physical Activity Scale; Weight Loss Behavior-Stage of Change Scale; height, weight, blood pressure, waist circumference; SF-12; Center for Epidemiologic Studies-Depression Scale; Revised Self-Efficacy Scale; Scale for the Assessment of Negative Symptoms	Participants significantly increased exercise participation over time. Significant reduction in waist circumference. Significant improvement in satisfaction with fitness and mental health functioning. Significant reduction in severity of negative symptoms.
Marzolini, S., et al. (2008)	Recruited from “Impact” program; physician’s signature, diagnosis of schizophrenia/ schizoaffective disorder based on DMV-IV, one or more cardiovascular risk factors (n=13)	Two-group randomized controlled study	Participants in exercise arm attended group exercise sessions twice a week for 12 weeks at local community recreation center	6 minute walk test; one repetition maximum test; pre-post anthropometric measurements, adherence, Mental Health Inventory (MHI); program satisfaction	Exercise group had significant improvement in strength for exercise group; significant improvements from baseline to 12 weeks in total MHI score. Mean attendance of group based exercise was 72% while home-based was 35%
Richardson, C. R.,	Recruited by case	Pre-post,	Nine 1-hour	Participation,	22 stayed in the

Table 2-4 Continued

et al. (2005)	workers or therapists from university-based depression center, community-based mental health clinic, community-based clubhouse program Age 18 or older, diagnosis of SMI, sedentary, passed Physical Activity Readiness Questionnaire or obtained medical clearance (n=39).	feasibility study	group sessions, educational discussions, topics related to diet and exercise, overcoming barriers; warm up and group walk. 18 week follow up	participant satisfaction; secondary outcome measures: weight loss, step counts, psychiatric diagnosis, blood pressure, mood and mental health symptoms, and qualitative data	program until the end of week 6; 12 completed final questionnaire at week 18. Significant change in weight loss pre-post intervention. At 6 and 18 weeks, most participants were satisfied with program.
Usher, K. et al. (2012)	Individuals with SMI taking second-generation antipsychotics (n = 101)	Experimental randomized controlled trial	12-week, nurse-led. Includes nutrition and exercise education, weekly exercise activity	Girth, weight, height, BMI, medication compliance, drug attitude, side effect rating, SF-36	No statistically significant results.
Exploratory Outcomes					
Byrne, et al. (1994)	From lodging home in community, 25-45 years of age, unemployed, majority had a diagnosis of schizophrenia (n=9)	Exploratory	Three pronged: wellness education and exercise/activity sessions, smoking reduction course. 12 weeks.	Participant evaluation and observation of group leaders for outcomes	Participation encouraged through resident involvement in planning/ design; few clients able or willing to engage in sustained moderate/ vigorous activity

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3.0 METHODS

This chapter introduces conceptual frameworks that are relevant and are used in this research, working hypotheses and specific aims, the overall approach to the research, and Component I and II, which comprise the development and implementation & evaluation components respectively.

3.1 CONCEPTUAL FRAMEWORKS

3.1.1 Social Cognitive Theory and the Transtheoretical Model

Two behavior change theories are relevant to understanding the determinants and prospect for behavior change to increase physical activity among people with SPMI: the Social Cognitive Theory (SCT) and the Transtheoretical Model (TTM). The SCT was used to inform the focus group guide used in the focus group discussions for Component I. The TTM was used in the pilot study specifically related to measurements used to gauge the impact of the intervention on the population in Component II.

The SCT focuses on key determinants including: knowledge of health risks and benefits among a diversity of health practices; perceived self-efficacy that one can have control over their own health habits; outcome expectations about the anticipated costs and benefits for different

health practices; health goals people set and how they plan to reach them; and perceived facilitators and social and structural impediments related to the behavior they desire to change [29]. Knowing health risks and benefits are important for behavior change to occur. The SCT expands the individual model to the collective group; behavior can be informed based on subsequent social reactions and effects in interpersonal relationships. Constructs that were explored in this research from the SCT include: self-efficacy among the participants to be able to participate in a physical activity program; socio-structural factors including facilitators, e.g. trusted staff, a safe environment, and impediments including self-stigma or fear of falling; and outcome expectations including having to change a known daily routine, the possibility of feeling better after exercise, and possible muscle pain.

The TTM aligns well with the principles of recovery oriented services and psychosocial rehabilitation [30]. TTM allows for assessment of readiness to change a particular behavior [31]. There are five stages: precontemplation (not considering changing behavior); contemplation (intending to change behavior in six months); preparation (intending to change behavior in 30 days); action (engaged in behavior for six months); and maintenance (engaged in behavior for more than six months). The TTM allows for cognitive and behavioral approaches related to each stage that can help an individual move through these stages. This includes bolstering self-efficacy or belief to engage in a particular behavior, increased recognition of advantages as opposed to disadvantages, and specific changes in behavior. Illustrative constructs that were explored in this research from the TTM include: Contemplation—does the person think about or are they ready to participate in physical activity? Preparation—will the person work with their Case Manager to get involved in the physical activity? Action—will the person participate in the physical activity intervention?

To stimulate the process of behavior change, SCT constructs such as self-efficacy and outcome expectancies have to be changed at the right time, or the right stage [32]. In physical activity, self-efficacy, change processes, and pros and cons have received empirical support in differentiating between stages of change [33]. The balance between pros and cons depends upon which stage the individual is in. For example, Prochaska et al. found among twelve groups of individuals with different problem behaviors, the cons of changing the problem behaviors outweighed the pros for subjects who were in the precontemplation stage while in the action stage the contrary was true [34]. The collaboration of these two models allows for a deeper understanding of the influence of specific constructs during the behavior change continuum. **Figure 3-1** provides an example of how the two theories can be integrated as a model for implementing behavior change in physical activity among the population in this research.

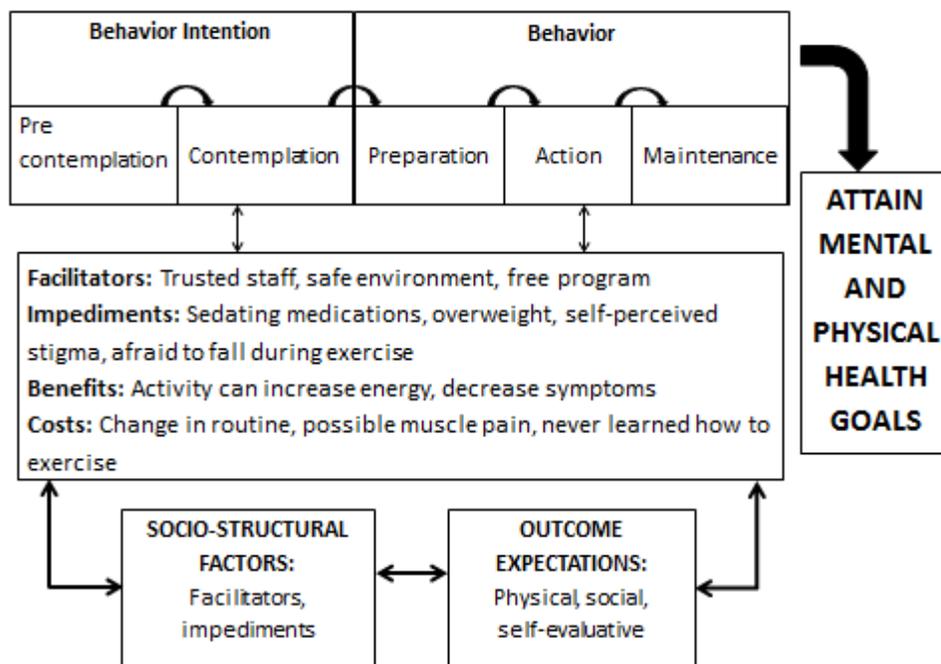


Figure 3-1: Conceptual Model of SCT and TTM Combined

3.1.2 Motivational Interviewing

For people who show less initial motivation to change (pre-contemplation to contemplation), rather than fault individuals for wanting to change, Motivational Interviewing (MI) can serve as a process to enhance motivation for change [35]. While MI is not a specific theory, its use with lay workers has been effective in demonstrating how to negotiate for effective behavior change in the early stages of the change process [36-38]. Constructs from MI that were explored include: confidence building among participants to participate in physical activity, undertaking a specific approach to information sharing between Case Managers and participants regarding benefits of physical activity, participants' reduction in resistance to discussing participation in physical activity, and relative importance of physical activity in the participant's lifestyle.

Figure 3-2 is adapted from well-known MI strategies [39] to illustrate how to negotiate for effective behavior change in physical activity in the early stages of the TTM, including pre contemplation and contemplation.

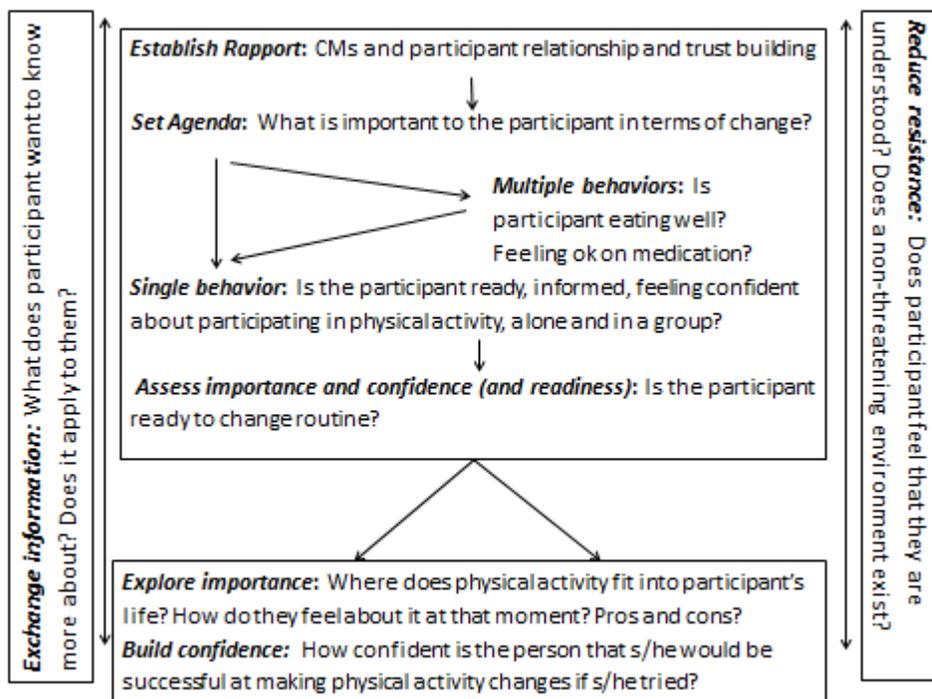


Figure 3-2: Early Tasks in Negotiating Behavior Change

3.2 WORKING HYPOTHESES AND SPECIFIC AIMS

3.2.1 Specific Aims

This study has three aims. Aim 1 is to identify research gaps through completing a literature review regarding physical activity interventions undertaken in community settings among people with SPMI. Aim 2 is to explore the perceived benefits and barriers to involvement in physical activity among individuals with SPMI in a community within a specific geographic area in Pittsburgh, Pennsylvania. Aim 3 is to describe the feasibility of developing and implementing a tailored physical activity program based on the outputs of Aim 2 regarding physical and mental health outcomes among participants with SPMI, through a CBPR approach among the same population as referenced in Aim 2.

3.2.2 Hypotheses

Aim 1 focuses on the hypothesis that gaps exist in the research literature regarding the effectiveness of physical activity interventions for people with SPMI in community settings that warrants additional research in this area.

Aim 2 uses qualitative research methods; therefore no hypothesis is proposed. This aim is intended to identify pilot interventions likely to be acceptable and feasible, given the perceived needs of the intended group.

Aim 3 has two hypotheses. Hypothesis one states that participants with SPMI will increase regular physical activity based on a tailored intervention. Hypothesis two states that people with SPMI will report improvements in physical and mental health after participating in the physical activity intervention.

3.3 APPROACH

After completing the literature review and defining important gaps in the literature, this study used a mixed methods design to understand the perceptions among the population regarding physical activity and used this data to tailor the intervention. The development phase of the research will be referred to as Component I (Study ID PRO12050514) and the implementation & evaluation phase of the research will be referred to as Component II (Study ID PRO12050697). Component I and Component II were approved by the University of Pittsburgh Institutional Review Board.

The research was carried out in two phases. Component I included focus group discussions (FGDs). Component II included a pre-post survey, physical activity logs, systematic observation and note taking, and a post-intervention open ended questionnaire. Funding for Component I and Component II was provided by the Staunton Farm Foundation and the University of Pittsburgh. The Principal Investigator (PI – Hoffmann) took the lead on preparing the IRB applications.

The study is grounded in Community Based Participatory Research (CBPR). This research is a partnership between the University of Pittsburgh Graduate School of Public Health and a local non-profit service organization named Community Human Services (CHS), located

in the neighborhood of Oakland in Pittsburgh. Oakland is a diverse neighborhood in the center of Pittsburgh made up of five distinct smaller geographically diverse subsets. Residents in this neighborhood range from short term students and young families to long term residents. Each group is made up of renters and homeowners. There are pockets of extreme poverty, high birth rates with low levels of prenatal care, dilapidated buildings and many single parent households. These factors have attracted and generated many organizations and partnerships that provide opportunities for social services and community development such as CHS.

CHS was developed through the strengths of citizens residing in South Oakland who were tired of the dilapidated homes and the social structure in the community. The concerned South Oakland neighborhood residents, including the founder and former Executive Director Phil Pappas, united to initiate a revitalization process. The door to door effort was based on the concept of doing—a philosophical underpinning to empower people through recognition of their strengths and capacities. Formed to serve the community of South Oakland, CHS expanded to serve the greater Pittsburgh area based on its original foundations. CHS programs include homeless assistance, mental health, and health and wellness and family assistance for those who suffer socio-economically. CHS has provided Residential Programming for individuals living with mental illness for over 30 years. In discussions with Adrienne Walnoha, the Chief Executive Officer (CEO), it was clear that persistent physical health issues profoundly impact the mental health residents who are at higher risk for early morbidity and mortality. The psychiatric medications taken by residents have a wide range of side effects that impact their physical health, and many of these residents are smokers. Due to all of these factors, CHS has been exploring ways to encourage and facilitate better nutrition and more regular physical activity in its residential programs.

Since fall 2010, a solid relationship was built between the PI and CHS that led to this community-engaged research. The PI's Graduate Student Research position initially brought this partnership together. Trust was built through the working partnership over time. Weekly visits to CHS, whether related to the research or just to have lunch at the daily Smile and Dine program, allowed this partnership to grow. New opportunities for this research emerged as the CEO expressed the need to develop a physical activity program that would benefit people with SPMI at CHS. The PI attended mental and behavioral health conferences during this time to increase knowledge in this area and learned of mental and behavioral health organizations that funded these types of programs. The community-academic partnership developed a proposal that focused on physical activity for people with SPMI, and a grant was awarded by the Staunton Farm Foundation, a local mental and behavioral health organization in Western Pennsylvania, to carry out the research.

The only physical activity options that existed in the community prior to this research for CHS clients included a fitness center that requires a wait-listed membership at a community gym a mile away, a mental health league for group sports, and access to several parks within walking distance. However, CHS staff note that clients have varying levels of motivation to participate; some are inactive, others moderately active.

Prior to grant funding, two focus groups were carried out with CHS research team members (approved by the Institutional Review Board, University of Pittsburgh, PRO11020054) to determine the feasibility of this research study in the community. Results from preliminary focus group discussions (FGDs) (n=3 in female group, n=4 in male group) illustrated that CHS clients understand the benefits of physical activity, and wanted to be involved in activities if made available. Weather, age, perceptions that changes in lifestyle, especially exercise, would be

overwhelming, and pain were expressed as some obstacles. Some clients said they found ways to overcome obstacles; one client indicated: "...for a long time I walked and my legs hurt...my doctor told me I had periphery artery disease...I kept walking and it just subsided and now I no longer have [the disease]...so I don't have that...you can get rid of diseases when you walk because I could have had a disease but I walk...".

Another client expressed pain, "...I sweep and mop my bedroom floor, but it's carpet...it's a bummer because I can't barely make one push-up, but I have been doing pushups but it's so painful I can only do one or two, I'd like to get back into motion but I can only count the steps up and down, doing my laundry is my physical activity...". This preliminary research indicated that while obstacles exist, these clients may be willing and interested to participate in physical activity. It was clear that further research was needed among a larger representative group to discover additional perceived benefits, barriers and preferences in physical activity.

Figure 3-3 provides an illustrative overview of the process from preparation of the dissertation topic through implementation and proposed next steps after the research is completed. Ensuring that research findings are disseminated back to the community to inform and translate findings for change at the individual, organizational, community and policy levels is one of the basic principles of CBPR [40]. The team discussed this early in the design: the CEO of CHS engaged mental and behavioral health stakeholders early in the program; and the PI secured a grant to support a community and stakeholder dissemination strategy and development of satellite exercise centers at CHS informed by intervention results.

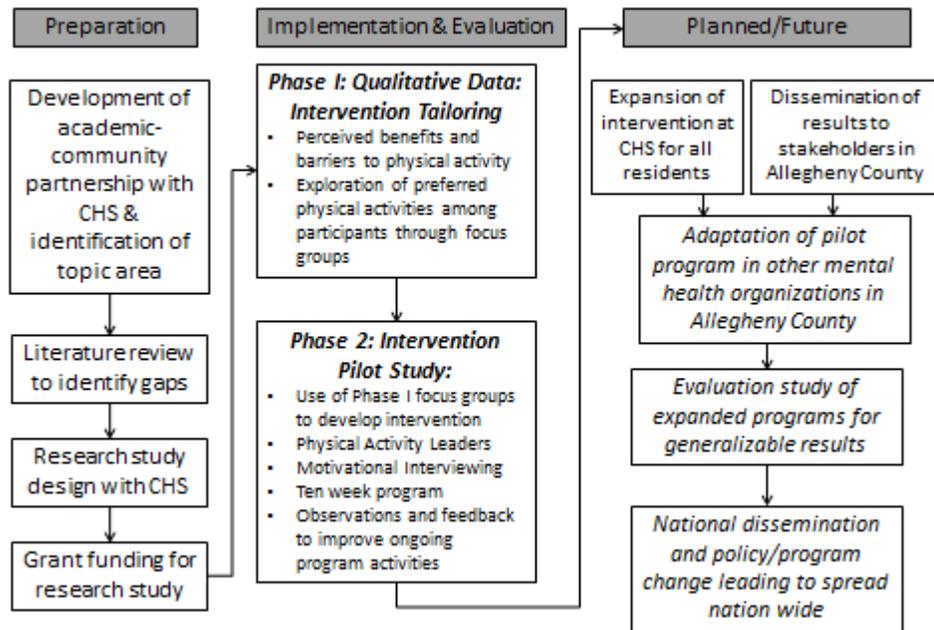


Figure 3-3: Overview of Dissertation Process

3.4 COMPONENT I: DEVELOPMENT

Based on the need to determine perceived benefits, barriers, and preferences related to physical activity among this population, a qualitative study was conducted at CHS. The study used FGDs to collect data related to perceptions, knowledge and attitudes towards physical activity. As opposed to individual interviews, focus groups allowed this population to experience a situation they are familiar with as in therapeutic interactions where they discuss their concerns in return for expert views or advice [41]. FGDs can also help identify group norms and encourage discussion around sensitive topic areas [42].

3.4.1 Population and Sampling

Three focus groups took place at CHS over a two week period in November 2012 including two female (n=5; n=3) and one male focus group (n=6). The focus groups were separated by gender to explore differences that may exist. Inclusion criteria required a diagnosis of schizophrenia or schizoaffective disorder as defined in the DSM-IV, age 18 or older, and current enrollment in a CHS program. Exclusion criteria specified no current or past episodes of violence or self-reported active substance abuse based on Case Manager referral and no diagnosis of cognitive impairment (Mental Retardation Developmental Disability).

3.4.2 Recruitment of Participants

Potential participants at CHS learned about the study through flyers posted at CHS and one on one communication between Case Managers and Interns. Potential participants were screened for eligibility by the Case Managers and referred for the study. While the flyers brought awareness of the FGDs to the clients, a research team member from CHS went door to door to remind clients of the opportunity; as the Director of Residential programming, the team member knew the clients well and the clients trusted him. Participants provided verbal consent. Participants received a \$20 gift card at the end of the session. The team was unable to recruit enough men for a fourth gender specific focus group.

3.4.3 Data Collection

The Principal Investigator moderated the discussions with one of the CHS research team members. The focus groups were audiotaped and transcribed verbatim. The discussions were semi-structured with a FGD guide adapted from other studies to identify perceived benefits and barriers to exercise [43-47]. The interview guide also included questions to understand what exercise activities participants currently engage in and what others types of exercise would be acceptable and feasible among the population at CHS. Sample questions included: Think about the neighborhood where you live. What is it about your neighborhood that makes it easy or hard for you to be physically active?; When you think of a physically active resident at CHS, what comes to your mind?; When you think of a physically inactive resident at CHS, what comes to your mind?; What do you think could be done to help people with a mental illness to be more physically active?

Before starting the discussion, the moderator explained that there were no right or wrong answers and that participation was completely voluntary. The CHS research team member helped guide the flow of conversation when the participants went off topic. Each discussion lasted approximately one hour.

3.4.4 Data Analysis

Members of the research team individually coded the transcripts and compared emergent themes to develop the draft code book based on consensus of themes. The transcripts were analyzed for a second time using the same code book among all researchers, and any new codes or sub-codes that emerged were discussed and included based on consensus of the team [48, 49]. The team used the second round of coding to ensure a systematic process to discuss results and reach consensus on major themes and outcomes from the results [50]. The transcripts and codes were entered into NVivo10 qualitative software [51, 52]. Two members of the research team re-analyzed each coded transcript, sub-codes and blocks of text to further explore recurrent themes within the code book using techniques that increase validity, including axial coding and saturation [53]. The primary research team members' transcripts, codes, and code segments were affirmed by two other members of the research team [54, 55].

3.5 COMPONENT II: IMPLEMENTATION & EVALUATION

3.5.1 Study Population and Recruitment

Participants in Component II included men and women who met the following inclusion criteria: having one or more disorders typically included under SPMI include schizophrenia, schizoaffective disorder, bipolar disorder, major depression, or obsessive-compulsive disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition DSM-IV; age 18 or older; physician's clearance; and current enrollment in a CHS program. Exclusion criteria were: current or past episodes of violence or self-reported active substance abuse as reported by Case Managers; diagnosis of cognitive impairment (Mental Retardation Developmental Disability). Case Managers (CMs) introduced the intervention to potential participants using a structured script to make residents aware of the project without having specific diagnoses on recruitment flyers. Based on review of CHS records, approximately 40 clients met the specified criteria. CHS CMs and staff consulted individually with clients to gauge interest in participation. Research staff read the consent form to potential participants and explained risks and benefits of participating in the research. After participants had an opportunity to ask questions about the study, participants gave written consent. The study was approved by the University of Pittsburgh Institutional Review Board (PRO12050697).

3.5.2 Research Design

Using a pre-post descriptive design, a pilot project was conducted to explore the feasibility of implementing a physical activity program in the CHS setting among clients with SPMI and to

gather data about the impact on the physical and mental health of participants. CBPR methods used in this study included participant feedback, which allows for adjustment of the intervention to fit participants' perceived and expressed needs. The study also examined the impact of the program on the Agency and on the larger Community CHS served and is surrounded by.

3.5.3 Data Collection

Component II of the study focused on the implementation of the intervention. To explore the impact of the physical activity intervention on participants, agency and the community, the team systematically collected daily notes to document the process during implementation, and PALS recorded notes and attendance after each exercise session. The PI met weekly with PALS and bi-monthly with community and academic team. The team used an investigator-designed survey combining instruments to measure: demographic characteristics; mental and physical health [56]; mood [57]; perceived social support [58-60]; and motivation [35]. PALS and the PI administered the survey at baseline and at the end of the 10-week program. The PALS recorded changes in mobility weekly using the Timed Get up and Go Test (TUG) [61]. The TUG test is a simple test wherein participants sit in a chair with their back to the chair; the participant stands up and walks ten feet forward, turns around, and walks back to the chair to sit down. The timing begins when the participant starts to rise from the chair and ends when they return and sit down in the chair. A practice trial and three actual trials are recorded. The average of the three actual trials is the score. Scores range as follows: less than ten seconds, freely mobile; less than 20 seconds, mostly independent; 20 – 29 seconds, variable mobility; and greater than 20 seconds, impaired mobility. Demographic variables collected included age, gender, ethnicity, period of time receiving psychiatric services, and length of time residing at a CHS location. Laminated cards were

developed for the pre-post survey for ease in use and comprehension. Water bottles at the pre-survey and \$20 gift cards at the post-survey were provided for the participants' time and efforts for completing the surveys.

Program satisfaction and feedback: To gain a better understanding of satisfaction, acceptance, and lessons learned for future exercise programs, an open ended questionnaire adapted from other studies accompanied the post-survey [62-64]. It included questions such as: What did you like about the exercise program?; What made you feel comfortable during the exercise sessions?; Do you feel that you are more physically fit as a result of the exercise sessions?; How beneficial was the exercise program to you; Do you plan to continue exercise on a weekly basis? Why or why not? What would help you continue; and what suggestions do you have to improve future exercise programs?

Systematically collected notes: Notes were systematically collected weekly by the PI to document the process and address any problems or challenges. The PALS and the PI recorded notes after each exercise session and discussed the notes weekly to make improvements in exercise classes based on feedback and observations. The observation form included date of exercise session, type, positive feedback, negative feedback, suggestions for improvement, and general observations.

3.5.4 Data Analysis

Statistical analyses consisted of descriptive statistics, including means, standard deviations, paired t-tests, and logistic regression modeling. Stata software version 12.0 was used to perform TUG test regression analysis; SPSS version 20.0 was used for pre-post analysis. Descriptive case

studies were developed through analysis of the systematically collected notes, observations, and post-survey questionnaires.

3.5.5 Data Management

Quantitative data collected was stored in password protected files only made available to key members of the research team. Backups of all files were made and kept in a separate location with a different password protected file name. Paper copies of surveys and transcripts were kept in a locked drawer in a locked office at CHS. All surveys had a de-identified number to ensure confidentiality. Long-term retention was secured through a transfer of all data files to a password protected disc that is stored under lock and key.

3.5.6 Confidentiality of Data Sources

The materials obtained during this study were audio recordings of the focus groups and a data record of participant's responses to the quantitative survey instrument. Each quantitative survey had a confidential identifier known only by the main researcher for purposes of pre- post comparisons. All transcriptions from audio recordings used non-identifying categories such as "group one, female one" among respondents. Attendance during exercise session and reasons for non-attendance were recorded using a password protected excel spreadsheet by participant ID. Because of the nature of the community setting, and the variety of residents that come to CHS, extra steps were taken to ensure participant confidentiality. For instance, data did not include identifying information. Study recruitment materials such as flyers and posters were not used in Component II to prevent any potential stigma; this information was communicated to potential

participants verbally through the Case Managers. Even though flyers were used in Component I to inform the population of the study, CHS research staff screened participants individually for eligibility. PALs met weekly with the PI to review data from each participant in order to ensure safety as well as protocol adherence and data confidentiality.

**4.0 PERCEIVED BENEFITS AND BARRIERS TO PHYSICAL ACTIVITY AMONG
PEOPLE WITH SEVERE AND PERSISTENT MENTAL ILLNESS: A QUALITATIVE
STUDY**

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4.1 ABSTRACT

Mental disorders are the leading cause of disability in the U.S. and responsible for 25 percent of all years of life lost to disability and premature mortality. An inactive lifestyle is common among people with Severe and Persistent Mental Illness (SPMI). This study used a Community-Based Participatory Research (CBPR) approach and focus group discussions among people with SPMI at a local community center to understand perceived benefits and barriers to exercise. Most participants saw the value of physical activity as part of a healthy lifestyle and felt that it is beneficial to physical and mental well-being. Some facilitators to physical activity that participants identified included an interest in weight-loss and having qualified physical activity instructors. Some barriers included existing medical conditions, self-esteem and feelings of isolation. Most participants felt more comfortable with gender-specific physical activity classes. Understanding preferences, perceived benefits and barriers to exercise among people with SPMI is essential for more effective physical activity program interventions.

Keywords: Community Based Participatory Research, Severe and Persistent Mental Illness, Focus Group Discussions, Physical Activity

4.2 INTRODUCTION

It is estimated that each year in the U.S. 26.2 percent of adults over the age of 18 suffer from a diagnosable mental disorder. While mental disorders are widespread in the general population, the burden of severe illness focuses on a much smaller proportion of the population; about 6

percent, or 1 in 17, people suffer from a severe and persistent mental illness (NIMH, 2010). A nationally representative face-to-face household survey meant to determine levels of health care use among those with mental illness and SPMI found that as a result of greater perceived stigma of their mental disorder, individuals with mental illness and SPMI have higher risks of under treatment (Wang et al., 2005).

People with SPMI have rates of co-occurring chronic medical illnesses two to three times higher than the general population (Parks et al., 2010). Issues such as cigarette smoking, poor physical fitness, and poor nutritional status have a greater association with risk for medical problems among people with SPMI as compared to the general population (Banham et al., 2010; Byrne et al., 1999). Mental disorders are one of the five most costly conditions among the civilian non-institutionalized population (Soni, 2009). The inactive lifestyle common among those with SPMI can double their risk of morbidity and mortality from heart disease (Fox, 1999).

It is well known that physical activity decreases symptoms of depression and can positively affect psychosocial functioning in individuals experiencing psychoses (Craft & Landers, 1998; Craft & Perna, 2004; Ellis et al., 2007; Faulkner & Sparkes, 1999; Fox, 1999; Ussher et al., 2007). Stigma that arises from factors such as weight gain from medication or physical ailments, for example, affect symptoms, self-esteem, and life satisfaction among this population (Markowitz, 2001). Exercise can raise self-esteem and improve mood states as well as improve physical self-perceptions (Callaghan, 2004; Fox, 1999). Physical activity has also been shown to improve physical health, quality of life and social inclusion (Ellis et al., 2007). The prospect of a comfortable social setting, supporting relationships, and opportunities for leisure time is important among people with SPMI who feel social isolation and boredom throughout their days in community settings (Goering et al., 1984).

It is important to note that to encourage physical activity in this population, the interests of the participants must be considered, including type of activity, preferred place to participate, and social influences (Ussher et al., 2007). It is also crucial to learn more effective ways of improving acceptance of physical activity as an essential lifestyle component among people with mental illness in non-institutionalized settings (Faulkner & Sparkes, 1999). Very few studies to date explore the perceived benefits and barriers of physical activity programs for people with SPMI in the community (Hoffmann et al., 2013, manuscript in review). More research is needed to determine the perceived benefits and barriers, exercise preferences and other factors that influence desire and motivation among people with SPMI to participate in physical activity to improve their quality of life and longevity.

4.3 METHODS

4.3.1 Design

Community Based Participatory Research (CBPR) has been identified as an effective approach for increasing buy-in of marginalized communities and increasing the likelihood of both successful research and subsequent uptake of intervention practices (Israel et al., 1998). It promotes a partnership approach to research that equitably involves community members, academic researchers, and others such as healthcare providers in all phases of the research process; all partners contribute knowledge and share decisions and ownership of the project (Burke et al., 2010; Israel et al., 1998; Yonas et al., 2006). The research presented here involves a partnership between the University of Pittsburgh and Community Human Services (CHS).

CHS is a community-based center located near the University of Pittsburgh that has provided Residential Programming for individuals living with mental illness for over 30 years. Case Managers are assigned to each individual to assist them in accomplishing their daily needs including shopping and medication management. Based on the need for more research to determine perceived benefits, barriers, and preferences in physical activity among this population, a qualitative study was conducted using focus group discussions (FGDs) to understand perceptions, knowledge and attitudes towards physical activity. Focus groups can also help identify group norms and encourage discussion around sensitive topic areas (Kitzinger, 1994).

4.3.2 Ethical Procedures

The University of Pittsburgh Institutional Review Board approved this study on May 25, 2012 [PRO12050514].

4.3.3 Sample and Setting

Three focus groups took place at CHS over a two week period in November 2012 including two female (n=5; n=3) and one male focus group (n=6). The focus groups were separated by gender to explore differences that may exist. Inclusion criteria required a diagnosis of schizophrenia or schizoaffective disorder as defined in the DSM-IV, age 18 or older, and current enrollment in a CHS program. Exclusion criteria specified no current or past episodes of violence or self-reported active substance abuse based on Case Manager referral and no diagnosis of cognitive impairment (Mental Retardation Developmental Disability, MDDR).

4.3.4 Recruitment of Participants

Potential participants at CHS learned about the study through flyers posted at CHS and one on one communication between Case Managers and interns. Potential participants were screened for eligibility by the Case Managers and referred for the study. CHS staff helped organize the three focus groups and attendance. Participants provided verbal consent. Participants received a \$20 gift card at the end of the session.

4.3.5 Data Collection

The Principal Investigator moderated the discussions along with one of the CHS research team members. The focus groups were audiotaped and transcribed verbatim. The discussions were semi-structured with a FGD guide adapted from other studies to identify perceived benefits and barriers to exercise (Faulkner & Biddle, 1999; Faulkner & Biddle, 2004; McDevitt et al., 2006; Soundy et al., 2007; Ussher et al., 2007). The interview guide also included questions to understand what exercise activities participants currently engage in and what others types of exercise would be acceptable and feasible among the population at CHS. A sample of the questions is provided in **Figure 4-1**. Before starting the discussion, the moderator explained that there were no right or wrong answers and that participation was completely voluntary. The CHS research team member helped guide the flow of conversation when the participants went off topic. Each discussion lasted approximately one hour.

4.3.6 Data Analysis

Members of the research team individually coded the transcripts and compared emergent themes to develop the draft code book based on consensus of themes. The transcripts were analyzed again using the same code book among all researchers and any new codes or sub-codes that emerged were discussed and included based on consensus of the team (Kegler et al., 2009; Minkler et al., 2006). The team used the second round of coding to ensure a systematic process to discuss results and reach consensus on major themes and outcomes from the results (Welsh, 2002). The transcripts and codes were entered into NVivo10 qualitative software (Richards, 1999; Smyth, 2006). Two members of the research team re-analyzed each coded transcript, sub-codes and blocks of text to further explore recurrent themes within the code book using techniques that increase validity, including axial coding and saturation (Siccama & Penna, 2008). The primary research team members' transcripts, codes, and code segments were affirmed by two other members of the research team (Rütten et al., 2009; Yuksel & Corbett, 2005).

4.4 CONFLICT OF INTEREST

This paper is part of activities under academic research through the University of Pittsburgh. No conflicts of interest are reported by the authors. The authors alone are responsible for the content and writing of the paper.

4.5 RESULTS

Participants ranged in fitness levels from inactive a majority of the time to walking almost every day for exercise. More women expressed that they were inactive than men among the groups. Four major themes are presented in this paper and are separated by individual (personal) versus structural (physical environment) issues. The data is disaggregated by gender because the analysis shows notable differences between men and women regarding perceived benefits, barriers, and preferences to physical activity among this population.

Perceived Benefits: Most participants saw the value of exercise as part of a healthy lifestyle and felt that it is beneficial for physical and mental well-being. A majority of participants recognized an increased social benefit to participating in group exercise. Women saw improved body image and weight loss as a benefit; men did not seem as concerned about their weight as a result of exercise, although one male participant mentioned his desire to be as muscular as when he was younger. The women valued being able to do more functional daily activities as a result of increasing exercise:

“I had an exercise class at [a local mental health organization with an exercise gym] and we did stretches and I didn’t realize what that was doin’ to my body. ‘Cause when I went to walk up to the second floor, I walked up there like I was a teenager after those stretchin exercises. I couldn’t believe it, how the effect it had on me just that one time.” (Group one, female participant two)

Another female participant expressed her desire for functional strength exercises:

“I’m lookin for, um, more strength to do simple chores, simple chores like washin out the bath tub bendin over the bath tub, not havin the energy to scrub...” (Group one, female participant one)

Perceived Facilitators to Participating in Exercise: Several themes emerged regarding facilitators to participation in physical activity among participants at the individual level and the

structural level. At the individual level, participating in exercise in a group on a regular, consistent basis was important to most participants. They recognized that lack of exercise can lead to weight gain and obesity; many women want to lose weight or maintain weight loss. One woman was particularly concerned with her weight:

“...It’s sad; if I ever lose weight I’m never gonna get this big. I’m, I’m havin problems right now. I will never try to get this big. If I ever find myself getting too big I gotta run, I gotta do everything that I think is possible for me to do to lose to come down more, if I find myself getting this big. I’m havin’ very serious problems. I won’t never get this big.” (Group two, female participant three)

Eating healthy, drinking more water, developing better sleeping habits, and cutting back on alcohol and cigarettes were identified as important by men to make exercising easier. One male participant suggested a prescription to exercise:

“Get a physical – it’s a good thing to get a physical. Have your doctor uh, uh, uh, prescribe some kind of an outpatient treatment for you, uh, if he thinks that you should exercise.” (Male participant three)

It is clear that gender-based exercise sessions would facilitate greater participation in exercise among this population. Female participants expressed concern about particular issues that may come up during exercise that would be uncomfortable with men present:

“I feel that since I’ve been here, I’ve got to know some of the men here but I think I would like to have a women’s group because, I mean, there is some things that happen to women and they would be embarrassed if men and women were to be together.” (Group one, female participant four)

A majority of male participants felt women would slow them down during exercise sessions, and that men in general are stronger than women:

“...Oh...that’s why I don’t want to go with the ladies. They get a little toothache, they can’t walk, most of the ladies are overweight. And you know, it’s hard to work out with somebody overweight, because they can only do like, two pushups.” (Male participant five)

“Cause women are harder at – they’re hard to exercise.” (Location one, male participant three)

At the structural level, participants expressed a need for a dedicated indoor area for exercise, especially in the hot summer and cold winter weather. Participants also stated a desire for the interns hired at CHS to lead the physical activities and to have a safety plan to deal with any complications that might arise due to exhaustion or other physical related factors.

Other possible facilitators explored by the research team included preferred length of exercise time, locations, days, and how to remind participants of exercise sessions. A half hour to one hour of exercise was the consensus, with two days a week to start. Participants indicated that reminders such as telephone calls, knocks on participants’ doors, and general announcements prior to exercise sessions near places people congregate would be helpful:

“Well they [residents at CHS] usually sit now, they sit now in front of the Dom Care, you know, come around the Dom Care. That’s where most everybody sits down, and they can uh, have us remind, or whatever.” (Male participant four)

Perceived barriers: On an individual level, participants were concerned with the possibility of aches and pains or loss of breath as a result of participating in exercise. Participants that felt they were already overweight, had a medical condition (such as a pacemaker), or were simply “getting old” expressed concern with just being *able* to physically participate. The side effects of medication are another major perceived barrier among this population.

Self-esteem and feelings of isolation affecting one’s ability to participate in group exercise was a factor among some women:

“Self-esteem is a major major major major major major issue in here” (Group two, female participant three)

One participant expressed her concern about impatience as a barrier:

“You can do a lot more when your patient with yourself you know, and don’t expect too much outta your exercise, immediate results, when you don’t expect cause I do sit ups on my couch, I mean leg lifts on the couch when I’m layin on my couch. I keep lookin at my belly and it’s not goin down, and I just get impatient and I don’t follow through everyday a procedure like exercise routine. I don’t follow through exercise routine. Um impatience makes it difficult when you’re not patient with yourself.” (Group one, female participant one)

On a structural level, female participants are very concerned about weather conditions, especially the summer months when they expressed the possibility of heat stroke or other medical conditions resulting from exercise outdoors:

“...it does get hot in the weather and some if I do strenuous things outside I will be panting for water. Be the dogs...” (Group one, female participant three)

Male participants expressed concerns about overlapping appointments; many of the male participants have weekly appointments scheduled that are a priority for them.

Exercise preferences: Male participants preferred walking, biking, basketball, running up steps, push-ups, sit-ups, working at a job, lifting weights, dancing or listening to music, arm movements, calisthenics, and jumping jacks. A majority of male participants indicated the need for a tough workout:

“I don’t like [tapes] too much. I don’t like aerobics. I like more of like, a hard, more of a workout.” (Male participant five)

Female participants wanted low impact types of exercise, such as walking, chair exercises, stretching muscles, using exercise bands and balls, and exercising to music. Several participants mentioned exercise tapes, specifically Richard Simmons.

4.6 DISCUSSION

These results provide valuable insight into the design of future exercise programs to improve the mental and physical health among people with SPMI living in a community setting. Participants understand and appreciate the benefits of improved mood and increased physical health from physical activity; when participants engaged in exercise on a fairly regular basis, they indicated increases in functional movement to successfully carry out daily activities from involvement in the exercise.

Based on perceived individual and structural facilitators identified by the groups, there are elements in the design of an exercise program to consider. A group-based indoor program may be suitable especially in climates where temperatures can range significantly. Starting with low-impact activities led consistently by trained exercise individuals that can ensure safety during exercise is important. Having the ability to modify the sessions based on weekly feedback would continue to be responsive to the participants' needs thereby encouraging continued motivation and participation. As many participants are concerned about weight gain, a complementary healthy lunch could follow the group exercise sessions, exposing participants to healthier food options.

It is evident that a major facilitator to participation among this population in this community is the opportunity for gender-based group activities. In this study, women preferred lower impact activities while men favored a more challenging workout. As preferences may vary by location or setting, it is important to determine if the development of gender specific classes would be a facilitator to participation. This recommendation has been made for the general population as well (Cohen-Mansfield et al., 2004). In addition, some studies show different recovery patterns between men and women with severe mental illness that may support gender-

based exercise groups to determine the gender-specific effect of exercise on physical and mental health outcomes in the community (Grossman et al., 2008; Mendrek & Stip, 2011).

While benefits and individual and structural facilitators have been identified, it is critical to also address the perceived barriers to participation in exercise. Low self-esteem and self-efficacy to participate in physical activity were key barriers that resonated throughout discussions with this population. This is supported by the literature that people with SPMI tend to experience low levels of self-esteem (Wright et al., 2000). One approach to increase motivation among this population could be Motivational Interviewing (MI). MI seeks to explore and build on people's own motivation for change. MI is an approach used among people with SPMI regarding targeted behavior change (Carey et al., 2002; Carey et al., 2001; Cluss et al., 2011; Rubak et al., 2005; Swanson et al., 1999). It helps individuals work through their ambivalence about behavior change and allows the coach, case worker, or other member to adapt the content and format of the interaction to match the participant's readiness to change, subjective pros and cons for change, and level of efficacy (Miller & Rollnick, 2009; Resnicow et al., 2001). MI is relatively new in research among people with SPMI, but seems well suited to address the goal of increasing physical activity to improve mental and physical health outcomes in this population.

Along with low self-esteem and self-efficacy, medical conditions (as a result of one's diagnosis) are perceived as an obstacle to participation among this population. Fear of pain associated with increased activity is a reality and occurs in the general population as well, especially among older adults (Hill et al., 2011) or those with other medical conditions that affect daily living (Law et al., 2010). One way to address this is through a graduated exercise program, wherein the participant's level of fitness and needs are addressed, and exercises are modified for

individuals with special needs. These types of programs have been shown to help prevent onset of pain from new activities (Fogarty & Happell, 2005; Marzolini et al., 2009).

Lastly, some women wanted immediate results from exercise and expressed impatience as a barrier when not seeing these results instantly. Celebrating consistent participation through health-related rewards such as towels or inexpensive exercise equipment rather than the actual weight loss may be effective. This approach has been used in other community-based exercise programs among this population (Daumit et al., 2011; Van Citters et al., 2010).

Regarding preferences, participants want opportunities for a reliable, continuous exercise setting that will improve their quality of life. Given the nature of the community setting, community engagement and sustainability are factors that cannot be ignored. Physical activity interventions that are based in community settings, rather than institutionalized settings, may benefit from participatory approaches to allow for ownership and sustainability beyond the life of the intervention. As mentioned earlier, CBPR is effective in increasing the buy-in of marginalized communities and increasing the chance of successful research and following uptake of intervention practices (Israel et al., 1998). To the authors' knowledge, no existing physical activity and SPMI study has adopted such an approach.

Given the severity in diagnoses, patterns of co-morbidities, social isolation and other barriers identified within this population, it is very important to engage the participants early on regarding their preferences and needs to ensure acceptance and uptake of new physical activity interventions. Based on this feedback, engaging the community partners and community participants with whom the intervention will take place can lead to new possibilities for long-term programming beyond the life of the research intervention.

As with any qualitative study, there are limitations to note. Having more participants would have helped further explore and validate main themes. Due to the nature of the symptoms present among people with SPMI, it can be difficult to recruit large samples based on perceived stigma or paranoia of participating in a group setting. From an intervention perspective, the effects of medications pose barriers to participation in exercise. However, working closely with Case Managers to ensure adherence to medication and providing them with approaches such as Motivational Interviewing could be a way to mitigate this barrier.

The recommendations provided in this paper for physical activity interventions among people with SPMI in a community setting build on the current literature regarding potential effective physical activity programs for this population (Hoffmann et al., 2013, manuscript in review). The novel approaches suggested can supplement current pharmacological and cognitive approaches towards recovery-oriented strategies, resulting in an improved quality of life and longevity among people with SPMI.

4.7 FIGURES

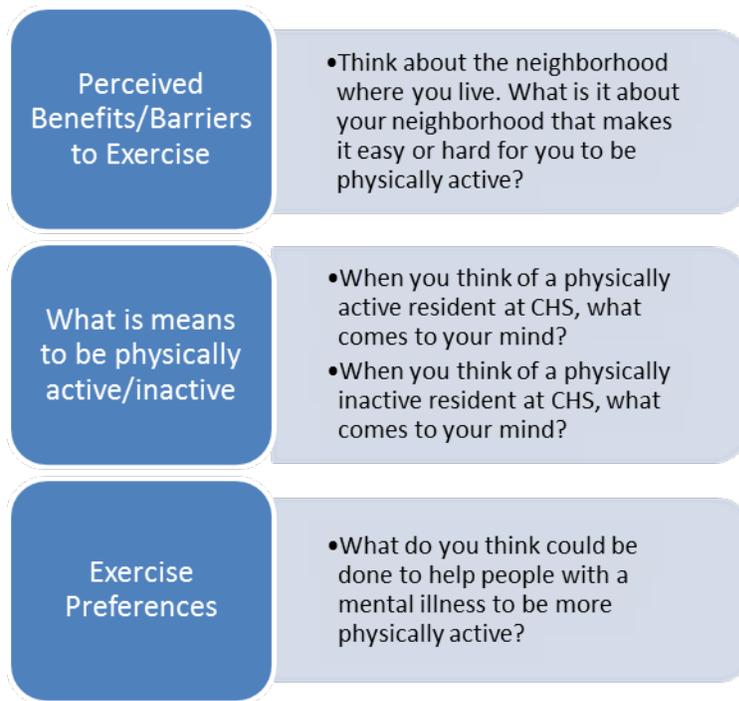


Figure 4-1: Example Questions from Focus Group Discussion Guide

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5.0 ON THE MOVE: THE INTERVENTION

5.1 BACKGROUND

The intervention team included a multidisciplinary group of professionals from the community organization, academics, and students, some of which lived in the surrounding community where the intervention took place. **Table 5-1** displays the key individuals involved in the intervention and their respective roles.

Table 5-1: Key Individuals and Their Roles in the Project

Name	Title	Roles
Adrienne Walnoha, MA	CEO, Community Human Services	Co-Investigator Liaison with funding agency and PhD student in research and program supervision
Kamden D. Hoffmann, MPH, MA	PhD Student, Department of Behavioral & Community Health Sciences University of Pittsburgh Graduate School of Public Health	Co-Investigator On the Move Program Coordinator Supervised all research and program activities
Jessica G. Burke, PhD, MHS	Associate Professor; Associate Chair for Administration Department of Behavioral & Community Health Sciences University of Pittsburgh Graduate School of Public Health	Member of research team Advisor to PhD student Assisted in data analysis and writing of manuscripts
Don McMillan	Director of Residential Services, CHS	Member of research team Facilitator of focus group discussions Led recruitment for focus group discussions and intervention
Jennifer Sloan	Master's student, Department of Behavioral & Community Health Sciences University of Pittsburgh Graduate School of Public Health	Physical Activity Leader Assisted in data collection, data analysis, and writing of manuscripts Co-developed PAL manual Co-developed PAL take home exercise guide
Jeff Dinztis	Case Manager, CHS	Physical Activity Leader Assisted in data collection and analysis
Haley Adams	Student, CCAC	Physical Activity Leader Assisted in data collection and analysis Developed community exercise resource guide Co-developed PAL manual Co-developed PAL take home exercise guide
Jesabel Rivera	Student Intern, School of Social Work, University of Pittsburgh	Co-developed PAL manual Transcribed and coded focus group tapes
Daphne Beers	Student Intern, School of Social Work, University of Pittsburgh	Co-developed PAL manual Transcribed and coded focus group tapes
Katie Macioce	Student Intern, School of Social Work, University of Pittsburgh	Co-developed PAL manual Transcribed and coded focus group tapes

The CEO of CHS thought of the name for the project entitled, “On the Move” (OTM); this name came about because the residents said the CEO was so skinny because she was always

"on the move." the team agreed this was a suitable name. The team wanted to brand the program and developed a logo to brand materials, see **Figure 5-1**.

Three interns from the School of Social Work from the University of Pittsburgh were brought on to assist in the beginning phases of the project. They spent time with the clients of CHS services, fostering trust and establish relationships. Originally the interns were to be trained



Figure 5-1: On the Move Logo

as Physical Activity Leaders (PALS). Additional part-time staff from the University of Pittsburgh Graduate School of Public Health and the Community College of Allegheny County was brought on as the three interns were ending their period with CHS and to provide an overlap and a sense of continuity between the interns and new staff. One additional CHS staff member from the Wood Street location was brought on pro-bono to assist in the physical activity intervention.

5.2 INTERVENTION AND PILOT TEST APPROACH

The intervention encompassed the following steps that are outlined in greater detail in this chapter: (1) in partnership with CHS, physical activity leaders (PALS) were identified and trained in key components of physical activity and group exercise instruction; (2) Case Managers were trained in modified Motivational Interviewing (MI); (3) the intervention was designed by the PI and the PALS based on the FGDs from Component I; (4) CHS Case Managers referred potential participants to the PI; (5) physician's clearances were obtained; (6) baseline weight, blood glucose and blood pressure was collected (not part of IRB approved research-for CHS program staff only) and informed consent was obtained; (7) the pre-survey was administered by the PI and PALS; (8) Case Managers worked one-on-one with the participants to explore internal motivation and evoke change talk; (9) PALS facilitated the physical activity intervention twice weekly for 10 weeks; the PALS met weekly with the PI to ensure adherence to manuals and intervention guidelines; (10) post-surveys with open ended questionnaires were administered by the PALS; (11) take-home exercise manuals and community resource guides were developed to assist in institutionalization of the program; and (12) dissemination of results and outcomes were planned at the participant/community level and County level.

5.2.1 Hiring and training of Physical Activity Leaders (PALS)

The PALS were trained by the PI in group exercise instruction; most PALS had experience with physical education or group exercise. The PALS were also trained in administration of the pre- and post- survey and the Timed Get up and Go (TUG) test.

5.2.2 Motivational Interviewing (MI) training

The PI and Dr. Patricia Cluss, a certified trainer of trainers and an expert in MI, conducted a two-day modified MI training for all CHS Case Managers. The two-day sessions were video-recorded, and the PI created a library with copies of the videotaped training sessions, copies of all relevant training materials and exercises, and refresher DVDs for Case Manager use.

5.2.3 Design of intervention

The physical activity intervention was designed to reflect the perceived benefits, barriers, and preferences among the participants from the results of the FGDs. Not all types of exercise were appropriate for the target population, given potential risk factors. As such low impact strength and aerobic sessions were designed according to stated preferences.

5.2.4 Recruitment, informed consent and physician's clearance

The PI utilized Case Manager referral to recruit for the intervention to protect confidentiality of the potential participants' diagnoses. While originally planned to recruit approximately 40 individuals based on the inclusion and exclusion criteria, only 16 participants were enrolled, nine female and seven male participants. Recruitment took longer than planned due to the nature of the diagnoses, hesitancy to start something new, and conflicting schedules among potential participants. Others lost interest due to the delay of the IRB approval for Component II after initial enthusiasm had been raised among potential participants. The PI obtained informed consent through an orientation session held with the PALS and the Director of Residential

programs and through individual meetings with participants. A branded water bottle was given to each participant during informed consent as a kick start to the program. Physician's clearances were obtained for each participant facilitated by Case Managers.

5.2.5 Baseline glucose, weight and blood pressure

CHS nursing staff met with each enrolled participant prior to the beginning of the physical activity intervention to gather baseline non-fasting glucose levels, weight and blood pressure. Although this was not part of the IRB approved protocol, the CEO wanted to track this information for program purposes.

5.2.6 Pre-survey administration

The PI pre-tested the surveys with the PALS to ensure questions were understood correctly and to determine the approximate time for survey administration; the orally administered surveys took about 15 minutes to administer. A set of three colored stretch bands were offered as a token of appreciation for their time, to be used during the strength sessions and on their own. Laminated cards with survey questions were designed to facilitate exchange and understanding between the PI/PALS and the participants.

5.2.7 Physical activity intervention

The exercise sessions were approximately 40 minutes long and were held twice weekly for ten weeks in a vacant room at CHS. The amount of time per session was determined based on focus

group feedback. The main trainer for the PALS was the PI, certified as a Triathlon Coach, Personal Trainer and Group Exercise Instructor. The three PALS co-led the sessions.

Tuesday sessions were devoted to low-impact aerobics with video tapes and PAL instruction. Thursday sessions were devoted to low-impact strength training with neoprene dumbbells, exercise bands, soft medicine balls, and chairs for modified exercise. Music changed rhythm according to the intensity. Healthy lunches were provided to all participants on physical activity days. PALS recorded each participant's TUG data at the beginning of each week and attendance prior to physical activity. Based on feedback from the participants and PAL/PI observations, the exercise sessions were modified to reflect the needs of the participants. The PALS and PI regular attendance at the sessions provided consistency from week to week for the participants. Reminders before class included phone calls and announcements in group areas prior to sessions.

The Thanksgiving holiday occurred during week nine of the physical activity intervention. The Tuesday session was still held and TUG data collected. PALS gave the participants a take-home exercise manual for Thursday. Due to the fact the team could not verify if participants did an exercise session individually at home, the team considered nineteen sessions as the total number of sessions held versus twenty.

5.2.8 Weekly meetings with PALS

The PI met weekly with the PALS to discuss observation notes and issues that arose the prior week regarding the physical activity sessions, participants, or other programmatic or administrative issues.

5.2.9 Bi-monthly meetings with research team

The PI met with CEO, the Director of residential programs, and her advisor to discuss ongoing program components, including technical and administrative aspects. Bi-monthly financial and technical reports were sent to the funding organization for updates on process outcomes.

5.2.10 Presence of PI at CHS locations

The PI worked off-site from April through August. It became clear that in order to ensure smooth processes during the research intervention, it was important for the PI to establish a permanent location at CHS; this ensured that the PI could attend all of the exercise sessions, lunches, adequately prepare and de-brief from the exercise classes, and maintain a presence among CHS staff and the community regularly.

5.2.11 Additional components

A contest for participation was developed to create a healthy atmosphere and reward participants for the process of participation than results of participation, since exceedingly noticeable differences in physical and mental health outcomes are difficult to measure on a weekly basis. If participants were present for one-quarter of the exercise sessions, they received a long-sleeve t-shirt; participants who were present for one-half of the sessions received sweatpants, and participants who were present for three-quarters of the sessions received gym bags. At the end of the exercise program, the PALS and PI led a closing ceremony and distributed certificates of accomplishment to participants who completed approximately half of the exercise sessions. One

of the female participants at the closing ceremony said “the exercise was really good and I am looking forward to more”.

5.2.12 Post-survey administration

The PALS or Case Manager administered the post-surveys to avoid survey bias. The survey bias was expressed by the CEO; the participants, knowing the PI was the physical activity session coordinator, may have presented answers to “please” the PI rather than answering the questions genuinely. The post-intervention non-fasting glucose, weight and blood pressure were difficult to obtain due to the interference of the holidays and were not measured.

5.2.13 Materials developed

The PALs led the development of several key documents: 1) a Physical Activity Leader Manual to train future PALS; 2) a take home exercise guide with pictorial demonstrations of exercises; and 3) a community exercise resource guide. All of the equipment used for the exercise sessions is available at CHS. Motivational Training DVDs, training packets, and resource materials, and video recordings of the two-day workshop are also available for CHS staff.

5.2.14 Post program team meeting and next steps

The research team and PALS met at the conclusion of the intervention to discuss next steps. The team agreed to develop and submit a “lessons learned” paper including materials to the funding agency. As a result, the funding organization asked CHS to submit a follow-on proposal. Site

visits took place in February 2013 and the funding agency awarded the follow on grant in April 2013.

CHS intends to continue On the Move. The PI conducted a physical activity demonstration during a Valentine's Social entitled "Love Yourself", to engage the clients and community in basic physical activity, and announce preparation for a follow-on program. The PI spends three to four hours per week in the nursing station of CHS to gauge interest in the program and answer questions community members, staff, or residents have. The PI also maintains presence at Smile and Dine lunch to engage with clients and the community. The research team began planning for the On the Move follow on program in April 2013.

**6.0 A PARTICIPATORY APPROACH TO PHYSICAL ACTIVITY AMONG
PEOPLE WITH SEVERE AND PERSISTENT MENTAL ILLNESS**

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6.1 ABSTRACT

Background: People with Severe and Persistent Mental Illness (SPMI) are at a greater risk of medical issues compared to the general population due to lifestyle issues including cigarette smoking, poor physical fitness, and poor nutrition. Physical activity has shown to have a positive effect on physical and mental health outcomes among this population in community settings.

Objectives: To describe Community Based Participatory Research (CBPR) methods used to tailor a physical activity program among people with SPMI, demonstrate its impact on participants, the agency and the community, and suggest future research based on lessons learned.

Methods: The community-academic partnership developed a pre-post descriptive pilot project to explore the feasibility of implementing a physical activity program at a community agency among clients with SPMI, and the impact of the intervention on their physical and mental health.

Results: Although quantitative results from the pre- and post-surveys did not show significance, the survey and post-intervention feedback showed improved trends in mood, social support, and physical and mental health outcomes.

Conclusions: A gender specific, group based tailored physical activity intervention developed through intensive collaboration with staff and clients of a community agency serving people with SPMI using CBPR methods is feasible, and the research suggests that people with SPMI can benefit from such a tailored exercise program.

Several challenges and lessons learned were identified as a result of this project. Using CBPR in this setting is important to the successful design and implementation of effective community-based programs.

6.2 KEYWORDS

Community-based participatory research, severe and persistent mental illness, physical activity, exercise, community partnership, sustainability, institutionalization

6.3 INTRODUCTION

Approximately one-fourth of U.S. adults experience a diagnosable mental disorder each year, contributing to 25 years of life lost to disability and premature mortality (NIMH, 2010). While the definition of severe and persistent mental illness (SPMI) varies by state, it is a term that is regularly used to identify a group of mental disorders that often affect people during early adulthood; disorders typically encompassed under SPMI include schizophrenia, schizoaffective disorder, bipolar disorder, major depression, autism, and obsessive-compulsive disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (Carey & Carey, 1999). In addition to the diagnosis, SPMI relates to a long history of hospitalizations, dangerous or disturbing social behaviors, and/or an inability to carry out basic work and non-work related functions without assistance (Parabiaghi et al., 2006). SPMI affects 1 in 17 people (NIMH, 2010); lifestyle issues including cigarette smoking, poor physical fitness, and poor nutrition lead to a greater risk of medical issues among people with SPMI compared to the general population (Banham & Gilbody, 2010; Byrne et al., 1999). People with SPMI may experience low satisfaction with life based on poor living conditions, lack of and discontent with social relationships, lack of health services, and unemployment (Lehman et al., 1982). Unfortunately, stigma, weight gain from medication, and physical ailments can negatively affect

symptoms, self-esteem, and the pursuit of life fulfillment among this population (Markowitz, 2001). The opportunity to have normality in their lives, reassuring relationships, and gratifying leisure time is important among people with SPMI in community settings (Goering et al., 1984). However, many people living with SPMI experience cognitive limitations, poor self-motivation, and decreased social communication, which are barriers to participation in lifestyle interventions (Roberts & Bailey, 2011).

Physical activity has shown to have an effect on physical and mental health outcomes among people with SPMI in community settings (Hoffmann et al., 2013, manuscript submitted). The mental and physical health benefits of physical activity and exercise among those living with SPMI include: improvements in psychosocial and mental health functioning; improved mood; reduction in body mass index, weight, and other anthropometric measures; and increased mobility and strength (Hoffmann et al., manuscript submitted, 2013). To date, only a few studies have shown significant improvements from physical activity interventions in the community setting among people with SPMI. Several factors have been found to negatively impact this populations' participation in physical activity interventions including: lack of self-motivation; scheduling conflicts; medical issues; cognitive deficits; self-stigma; and levels of diminished endurance compared to the general population (Beebe et al., 2005; Daumit et al., 2011; McDevitt, et al., 2005; Richardson et al., 2005; Van Citters et al., 2010). More work is required to design and tailor physical activity programs to address these barriers and identify other perceived barriers and benefits to participation.

Community Based Participatory Research (CBPR) may be a useful approach in gathering more information to achieve this goal. CBPR is an approach to research which contributes to increased buy-in of marginalized communities and increased likelihood of both successful

research and uptake of intervention practices (Israel et al., 1998). CBPR is an equitable partnership in research, involving community members, academic researchers, and others such as healthcare providers in all phases of the research process equally. All partners contribute expertise and share decision-making and ownership of the project (Burke et al., 2010; Israel et al., 1998; Yonas et al., 2006). CBPR has been used in physical activity interventions among different populations (Jackson et al., 2010; Krieger et al., 2009; Sharpe et al., 2010; Suminski et al., 2009; Zoellner et al., 2011); however, no study implementing a physical activity intervention focused on people with SPMI in the community has adopted such an approach. One of the values of the CBPR approach in the design and implementation of a physical activity intervention is the ability to tailor the intervention to the needs of the community. Ensuring the community's needs are addressed is critical in a CBPR approach (Kahn et al., 2012). CBPR methods used in this study are presented in the methods and intervention section.

The aims of this paper are to: (1) Describe CBPR methods used to develop a project to address physical activity promotion among people with SPMI; (2) Explore the impact of the physical activity program on participants, the agency and the community; and (3) Present implications for future research based on lessons learned.

6.4 METHODS

Development of the research/community collaboration was through a partnership between the University of Pittsburgh Graduate School of Public Health and Community Human Services (CHS), a local service organization located in a neighborhood in Pittsburgh. CHS serves the

greater Pittsburgh area through programs including homeless assistance, mental health, health and wellness and family assistance for those with low levels of socio-economic resources.

The CBPR project presented in this article was developed as a product of an existing relationship between the CEO of CHS and a doctoral student from the University of Pittsburgh Graduate School of Public Health. Weekly visits to CHS related to or outside of the research allowed this partnership to grow. An opportunity for research naturally emerged when the CEO expressed the need to design a physical activity program that would benefit people with SPMI. Given the doctoral student's background, training, and interest in exercise fitness and CBPR, the community-academic partnership jointly developed the proposal and secured support from a local foundation for implementation. The two phase CPBR project included 1) formative research used to design the tailored intervention and 2) a pilot of the tailored intervention.

Design: Using a pre-post descriptive design, a pilot project was conducted to explore the feasibility of implementing a physical activity program in the CHS setting among clients with SPMI and to gather data about the impact on the physical and mental health of participants. CBPR methods used in this study included participant feedback, which allows for adjustment of the intervention to fit participants' perceived and expressed needs.

Study Population and Recruitment: Project participants included men and women who met the following inclusion criteria: satisfying conditions for SPMI as defined in the DSM-IV; age 18 or older; physician's clearance; and current enrollment in a CHS program. Exclusion criteria were: current or past episodes of violence or self-reported active substance abuse as reported by Case Managers; diagnosis of cognitive impairment (Mental Retardation Developmental Disability). Case Managers (CMs) introduced the intervention to potential participants using a structured script to make residents aware of the project without having

specific diagnoses on recruitment flyers. Based on review of CHS records, approximately 40 clients met the specified criteria. CHS CMs and staff consulted individually with clients to gauge interest in participation. Research staff read the consent form to potential participants and explained risks and benefits of participating in the research. After participants had an opportunity to ask questions about the study, participants gave written consent. The study was approved by the University of Pittsburgh Institutional Review Board (PRO12050697).

Intervention Development: Based on the need for more research to determine perceived benefits, barriers, and preferences in physical activity among this population, another CBPR method was used: male and female focus group discussions (FGDs) were used among people with SPMI at CHS to understand perceptions, knowledge and attitudes towards physical activity. FGD results indicated people with SPMI at CHS understood the benefits of physical activity and would be involved in exercise activities if they were made available (Hoffmann et. al, 2013, manuscript submitted). This research confirmed that a physical activity program was a logical next step to addressing this population's needs at CHS. **Figure 1** gives an overview of the partnership and process.

Intervention: The "On the Move" intervention was designed using feedback from the FGDs. It consisted of two 40-minute exercise sessions per week (two for men, two for women) held on site at CHS. The sessions were co-led by the university researcher with credentials as a Sports Coach, Personal Trainer and Group Exercise Instructor, two students with exercise training, and a CHS CM, all of whom received On the Move training by the university researcher. Instructors were called "Physical Activity Leaders" or PALS. The sessions comprised: low-impact aerobics using video tapes and instruction; and low-impact strength training with neoprene dumbbells, exercise bands, medicine balls, and chairs for modified

exercise. Healthy lunches were provided to participants on exercise days. A contest was developed to encourage participation. Based on the percentage of sessions attended, participants received project-branded exercise merchandise (i.e. t-shirts, sweatpants, gym bags).

Data Collection: To explore the impact of the physical activity program on participants, agency and the community, the team systematically collected daily notes to document the process during implementation and PALS recorded notes and attendance after each exercise session. The university researcher met weekly with PALS and bi-monthly with the community and academic team members. The team used an investigator-designed survey combining instruments available in the research literature to measure: demographic characteristics; mental and physical health (Hays et al., 1995); mood (Watson et al., 1988); perceived social support (Cohen & Hoberman, 1983; Cohen et al., 1985; Crane & Constantino, 2003); and motivation (Rollnick et al., 2008). PALS and the university researcher administered the survey at baseline and at the end of the 10-week program. The PALS recorded changes in mobility weekly using the Timed Get up and Go Test (TUG) (Podsiadlo & Richardson, 1991). The TUG test is a simple test wherein participants are timed as they sit in a chair; stand up and walk ten feet forward, turn around, and walk back to the chair to sit down. Timed scores range as follows: less than ten seconds, freely mobile; less than 20 seconds, mostly independent; 20 – 29 seconds, variable mobility; and greater than 20 seconds, impaired mobility. Water bottles and \$20 gift cards were provided for the participants' time and efforts for completing the surveys.

In order to develop lessons learned and areas for improvement of research, an open ended questionnaire adapted from other studies (Hackney & Earhart, 2010; Marzolini et al., 2009; Richardson et al., 2005) was administered at the end of the intervention. It focused on participant

satisfaction with the classes, perceived impact of the program on health, and suggestions for improvement.

Data Analysis: Statistical analyses consisted of descriptive statistics, including means, standard deviations, paired t-tests, and logistic regression modeling. Stata software version 12.0 was used to perform TUG test regression analysis; SPSS version 20.0 was used for pre-post analysis. Descriptive case studies were developed through analysis of the systematically collected notes, observations, and post-survey questionnaires.

6.5 RESULTS

Participant Sample: Sixteen of forty potentially eligible participants signed consent forms to enter the program. The majority of participants were female (56%) and Non-Hispanic white (46.7%) or Non-Hispanic black (40%). **Table 6-1** shows the demographic characteristics of participants. Per HIPPA regulations, the diagnosis of participants was kept confidential by the CHS staff and not made available to the researchers.

Intervention Retention: Of the sixteen enrolled participants, five (31%) participated regularly (i.e. approximately half or more of the exercise sessions) and eleven (69%) did not (mean: 5.6; median: 3; range: 17). Reasons for infrequent participation included: increased mental health symptom severity; conflict in participation due to official disability status; complex service schedules; and exacerbation of medical issues related to obesity. More men than women terminated participation after enrolling (85% vs. 56%, respectively), citing reasons such as: conflicts with other scheduled activities; expressed lethargy; and sleeping late. **Table 6-**

2 provides total hours of exercise participation per participant, and reasons for non-participation based on participant feedback and staff observation and knowledge.

Impact of the Physical Activity Intervention on Participants: Pre- and post-survey results and case studies provided valuable feedback about the impact of the intervention. Although quantitative results from the pre- and post-surveys did not show significance based on the intervention, the survey did show improved trends in mood, social support, and physical and mental health outcomes. Though not statistically significant, the TUG test results showed improved mobility among those that participated regularly; these participants' TUG scores decreased approximately two seconds when compared pre- and post-intervention.

The post-intervention questionnaire provided details about participants' perceived experience with On the Move. While some participants experienced barriers to participation, feedback shows that the intervention was well received and lead to perceived improvements in their health. Many of the participants expressed an improvement in fitness or perceived social support regardless of the number of sessions attended. **Table 6-3** provides additional details on the post-intervention questionnaire.

To further describe participants' experiences with the intervention, the following case studies were prepared by compiling PAL and PI observations and post-survey feedback forms. Case studies were selected to give a representation of gender and high vs. low participation status.

Female Participant A: Participant A was between 45 – 64 years of age and had received psychiatric services for 26 – 30 years. Over 200 pounds, she was morbidly obese, and explained that she couldn't tie her shoes and had to visit the doctor to have her toenails cut. She progressed through the sessions from needing seated exercise modifications to not needing modified

exercises at all. In week four, she brought healthy snacks to class, demonstrating her commitment to the class and a healthier lifestyle. In week nine, she proudly told the PALS that she had purchased two pound weights and was now able to tie her shoes. When asked what she liked about the program, she said, “The fact that a highly-trained individual would spend time with mentally ill people... [I] liked the strength exercises.” When asked if she felt more physically fit as a result of the exercise, she said, “...Very. [It] boosted my self-confidence and discipline to exercise...It felt special, I was cared for by [the instructor and the PALS].”

Female Participant B: Participant B was between 45 – 64 years of age and had received psychiatric services for between one and five years. She shared with PALS that she had severe depression, affecting her ability to wake up at a regular time to do household chores. At first, she was hesitant to be involved in group exercise and exercised in a space away from others. Halfway through the program, she increased her interaction with other female participants during lunch. She was noticeably stronger as observed by the university researcher and PALS; in week eight the PALS modified her exercises to be more challenging, yet still low impact. At the end of ten weeks, she expressed fear that the program would end and her previous levels of depression might return. She stated that she plans to exercise on a weekly basis at home using the exercise guides developed by the program because, “it is important for my physical and mental health.” When asked if the program was beneficial to her, she answered, “...very beneficial, working out greatly improved my mood and feelings.”

Male Participant C: Participant C was between 18 – 30 years of age, and had received psychiatric services between one and five years. Before the program started he expressed his desire to lose weight and was concerned about his personal fitness. He only missed class due to holidays or job interviews. When asked what made him feel comfortable during the exercise

sessions, he said, “When I was feeling depressed, people [involved with the program] gave me energy.” When asked if the program was beneficial, he responded “...very beneficial. I found different techniques and motivation with music much easier to exercise to than on my own.”

Female Participant D: Participant D was 45 to 64 years of age and had received psychiatric services for over 30 years. During her pre-intervention survey, she inquired about one-on-one personal training, stating she may not be as active as other members in the class. She was enthusiastic at the first session; exercises were modified to match her fitness level. Due to unexpected circumstances and deterioration in her physical health, she was unable to continue the sessions. She was given a copy of the take home exercise guide developed by the program. Although she ceased participation in the sessions, she joined the PALS and other women for lunch. In reference to the session she attended, she said, “[We] felt treated as equals... [I liked] the encouragement from the instructors.”

Male Participant E: Participant E was 18 to 30 years of age, and had received psychiatric services for 16 to 20 years. When approached to enroll in the exercise program, he declined. When he discovered a close peer was enrolled, he also enrolled. Attending only two sessions, it seemed that his participation depended on whether or not his peers participated, which was confirmed by the CMs. Referring to the sessions he did attend, he said, “[The exercise] stretched me out, made me feel better about myself, [I] didn’t get any cramps in the middle of the night.” He plans to continue exercising on a weekly basis using a friend’s equipment. Similar to Female Participant D, Participant E regularly sought out the university researcher and PALs to have lunch together.

Impact of the Physical Activity Program on the Agency and Community: Details of the impact on these levels are provided in **Table 6-4**. At the agency level, CHS staff involved in

the research gained a deeper understanding of the intervention; consistent team meetings strengthened the effectiveness of the partnership. The program had possible positive and negative effects on other CHS staff, as shown in **Table 6-5**. Regarding program development, CHS staff members and CMs were enthusiastic about the program, but were also overburdened with the extra work needed to carry out the program. Some CHS staff were eager to participate in the exercise sessions while others felt disconnected to the program. The community showed interest in participating in the sessions and contacted the university researcher about participation, availability of take-home guides, and community resources. When the possibility of a follow on program to On the Move At the agency level, CHS staff involved in the research gained a deeper understanding of the intervention; consistent team meetings strengthened the effectiveness of the partnership. The program had possible positive and negative effects on other CHS staff, as shown in **Table 6-5**. Regarding program development, CHS staff members and CMs were enthusiastic about the program, but were also overburdened with the extra work needed to carry out the program. Some CHS staff were eager to participate in the exercise sessions while others felt disconnected to the program was announced, community members contacted CHS staff to sign up.

Lessons Learned from Physical Activity Sessions: The lessons learned that were gathered from PAL observations are presented in **Table 6-6**. The PALS tailored the exercise sessions based on the expressed needs of the participants; however during the 10-week program modifications were necessary based on participants' preferences, limitations, or improvement. Despite rescheduling sessions to fit participants' needs, conflicts arose weekly for some participants. Several PALS are necessary to lead sessions to ensure one on one support is available when needed, and modifications are available based on participants' progression.

Interaction among the PALS and participants outside of sessions built a sense of connection and improved participants' comfort levels with PALS.

6.6 DISCUSSION

On the Move was a gender specific, group based exercise intervention developed via intensive collaboration with staff and clients of a community agency serving people with SPMI. It was tailored to fit the perceived exercise benefits, barriers and preferences of people served by the agency. The case studies and post-program survey suggest that people with SPMI can benefit from such a tailored exercise program. Several challenges to conducting CBPR to address the intersection of physical activity and mental illness were identified as a result of this project.

Recruitment: Although similar methods of recruitment from other studies were used including word of mouth and CM referral (Richardson, et al., 2005; Usher et al., 2012), it was difficult to obtain the desired number of participants. The timeline for recruitment, given complications related to the population's diagnoses, needs to be carefully planned. Some complications among people with SPMI can include the nature of symptoms among different diagnoses. For example, people with schizophrenia often experience paranoia and a lack of emotional involvement with others (Beebe et al., 2005). In addition, people with SPMI can experience symptoms including lethargy, disorientation, appetite changes, weight gain, hot flashes, and sweating; these symptoms can also be a side effect of their medications. Furthermore, this population may experience disassociation, fatigue, hopelessness, and helplessness, which may affect their willingness and ability to participate in physical activity (McDevitt et al., 2006; Ussher et al., 2007). Symptom recognition and management must be

recognized as a part of recruitment and motivation. Using CMs to recruit may have been more effective if CMs had a specific role in the program. Future programming should consider selecting Champions among the staff as PALS and including it in their job descriptions, with related compensation either through discounted gym memberships or other incentives. Identification of Champions among the participants could be a peer-to-peer model to improve enrollment, especially among those who had a positive experience with the program. Perceived benefits and barriers to participation were discovered through initial FGDs; addressing benefits and barriers during recruitment and enrollment may have an effect on recruitment.

Retention: Despite concerted efforts of CHS and On the Move staff, development of consistent engagement was challenging. Women adhered more regularly to the exercise sessions than men; even with reminders and announcements, after the fifth week a majority of the men had dropped out. The high attrition rates could be linked partly to the severity of participants' diagnoses, adherence to pharmacological treatment, employment, and other conflicting schedules as noted in other studies (Daumit et al., 2011; Mota-Pereira et al., 2011; Velligan et al., 2010). In addition, there are gender differences in recovery patterns and severity of disorders (Grossman et al., 2008; Mendrek & Stip, 2011). Post intervention FGDs could be useful in future research to determine barriers among those who participated regularly and those who did not; the FGDs could also help to learn about factors influencing general community participation in structured group exercise.

Impact of the Program on Physical and Mental Health Indicators: Due to the pilot nature of the project, the study was not powered to find statistically significant changes in physical and mental health measures; low enrollment and high attrition further impacted these outcomes. Anecdotal reports from participants and the small TUG time changes provide some

descriptive outcomes suggesting that the On the Move project had a beneficial impact regarding participants' physical and mental well-being.

Impact on Participants, CHS Staff and the Community: The design and development of the intervention involved all partners in every step. CHS staff brought invaluable experience in their knowledge and understanding of the participant population, community setting, and complex social dynamics. The university researchers brought experience in research, implementation, data collection and analysis, and physical activity. This partnership led to participation from some CHS staff during initial recruitment, but motivation remained difficult among other CHS staff to encourage participation among their clients. Part of this could be related to the staffs' own perceived wellness concerns. Individuals who do not value physical activity or have limited physical capacity may not be able to advocate effectively for these types of activities. Developing a worksite wellness program alongside the exercise program for people with SPMI could create a normative atmosphere for wellness (Krieger et al., 2009; Sharpe et al., 2010; Siegel et al., 2010). Significant investment was put into relationship building among PALS and participants, which built trust. Through regular meetings with the research team, challenges and successes were recognized early and addressed. The presence of the university researcher at CHS on a weekly basis showed the commitment to the research project.

Lessons Learned from Physical Activity Sessions: Based on different fitness levels among participants, fitness assessments could be useful to cluster participants, provided the participant enrollment is adequate to form groups. This may help reduce self-consciousness among participants and allow them to exercise among peers of the same fitness level. Conflicts in scheduling are inevitable. There could be opportunities to have multiple weekly options for group fitness, especially with more than one PAL available, as is offered in private gym exercise

classes. The project-induced time spent outside the exercise sessions is just as important as the time spent during the exercise sessions; the social interaction and acceptance, especially given the self-perceived and society-induced stigmas associated with their diagnoses, is important to this population.

Strengths: Without the strong partnership developed and expressed community need combined with each partners' expertise, this research might not have been undertaken. The CBPR approach in this intervention pilot, based on mutual trust and respect for roles in the partnership, was critical to its development and implementation in this community setting among this vulnerable population. Despite the small sample and high attrition, the team was able to use other sources of data to elaborate on the impact of the program on the participants, agency, and community.

Limitations: This study has several limitations. The scope of the pilot project is relatively small, so caution should be taken when generalizing to other communities or CBPR partnerships. Future studies should aim for a bigger sample size based on lessons learned in this research regarding recruitment and retention challenges. Selection bias could be a factor among participants already engaged in physical activity. Funding and availability of staff for motivation and follow up were also limitations.

6.7 IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE

Although other programs may not adopt the exact model applied in this programmatic research (Green & Glasgow, 2006), there are important elements outlined in this paper that should be considered when adapting a program akin to the one implemented here.

Encourage open communication: All roles, responsibilities, and expectations of each member in the partnership should be clarified early through logical and transparent dialogue. When all team members were brought together to discuss discordance, the partnership became stronger and more effective. A debriefing plan was established to ensure staff had a confidential outlet to share information. These steps were critical in the CBPR process.

Maintain flexibility while upholding rigor: Participatory research methods are often considered to be reflexive, flexible and iterative, as opposed to more linear models in conventional science (Cornwall & Jewkes, 1995). In this study, an iterative process of documentation and ongoing team discussion allowed for modification of the exercise sessions and other components while ensuring the core structure was intact. In CBPR processes, it is accepted to “let go of the planning” and allow for this iterative process to occur (NIH, 2008).

Provide a range of tailored physical activity options: As participants may have a wide range of exercise capability, it is important to tailor to each participant’s needs to avoid injury or monotony. As noted by Weiland et al. and in our study, a range of options based on participants’ need as related to fitness level, perceived barriers, and preferences, may encourage participation (Weiland et al., 2012). Future research should consider weekly programs with varying activities, including: weight training; low-impact aerobics; walking clubs; stretching; yoga; dancing; and other activities based on participants’ needs.

Disseminate results back to the community: Ensuring that research findings are disseminated back to the community to inform and translate findings for change at the individual, organizational, community and policy levels is one of the basic principles of CBPR (Israel et al., 2005). The team discussed this need early in the design: mental and behavioral health stakeholders were engaged early in the program and a grant to support a community and

stakeholder dissemination strategy and development of satellite exercise centers at CHS was secured. Local insurance companies expressed interest in supporting activities that improve overall health outcomes of their members. An example of this is the Silver Sneakers program, created and funded by a local insurance company, providing physical activity options for seniors at no cost. On the Move could translate into a similar offering.

Understand that community-academic tensions may arise and need to be addressed:

While community-academic partnerships have their successes, challenges remain. During the initial months of the study during IRB approval, some CHS staff involved in the research understood the difficulty obtaining approval quickly based on prior experience; however, frustration arose among other CHS staff and potential program participants, and enthusiasm for the program waned due to the delays. True cooperation takes significant time throughout the research. As highlighted in **Table 5**, the university researcher could devote more time to the intervention while other CHS staff has multiple priorities to manage, and agendas did not always coincide. These types of “insider-outsider” tensions can arise from differences in the timetable and priority attributed to the research among partners (Minkler, 2004), and need to be understood and addressed accordingly.

Recognize different levels of dynamics within a community and their interaction:

Dynamics within and between levels can influence outcomes of community-engaged research. In this community, three levels interacted: CHS staff and participants; participants and other clients; and participants and members of the community. Each interaction throughout the intervention had an impact on the participants, and awareness of these interactions is important. For example, the relationships observed during class and the new sense of connection and civic responsibility were evident through participants bringing healthy snacks for their group partners. Green and

Glasgow emphasize the importance of program elements aligned with multiple levels including policy, regulatory, or among individuals representing organizations or whole communities (Green & Glasgow, 2006), a concept called *ecological alignment*, wherein there is an appreciation for the interdependence of levels in a collective system (Green & Glasgow, 2006). This concept is particularly critical when working in this type of multi-level community setting. In addition, social network size and social support are linked to better recovery for people with SPMI (Corrigan & Phelan, 2004; Hendryx et al., 2009), and is understudied among this population who want to be involved in regular exercise (Carless & Douglas, 2008).

6.8 CONCLUSION

This article described how the CBPR project to address physical activity promotion among people with SPMI was developed, illustrated the impact of the physical activity program on people with SPMI, the agency, and the community, and presented lessons learned for future CBPR research in this area. Using CBPR in this setting, while challenging given complex dynamics among people with SPMI and within the community, is critical to the successful design and implementation of effective community-based programs.

6.9 ACKNOWLEDGEMENTS

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6.10 FIGURES

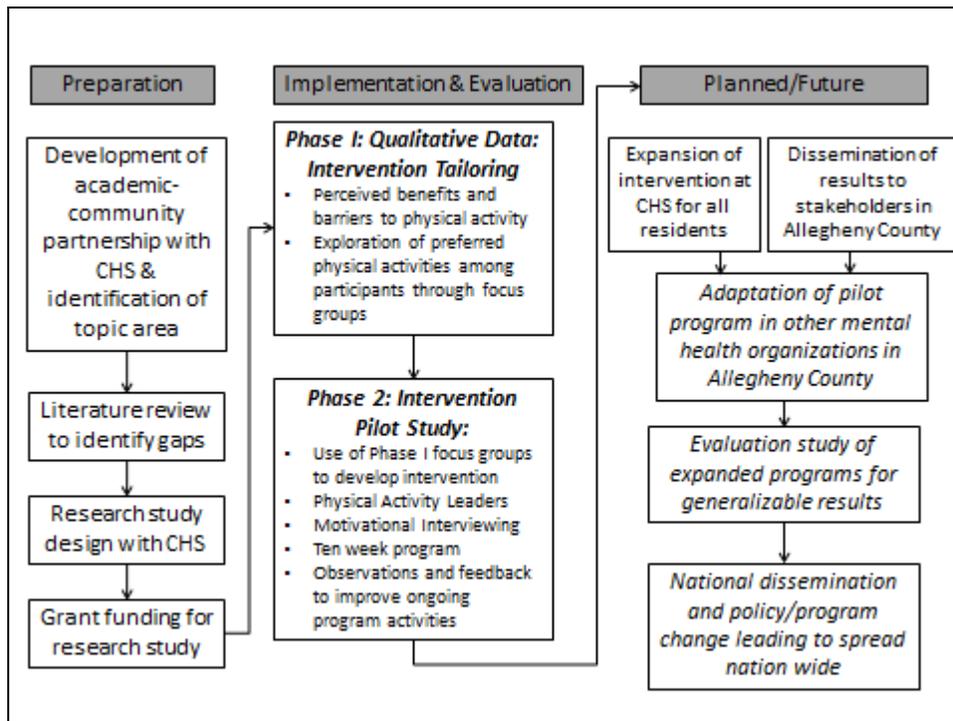


Figure 6-1: Overview of the Partnership and Process

6.11 TABLES

Table 6-1: Demographic Characteristics of the Participants

Characteristics	Total
<i>Age</i>	
18-30	3 (18.75)
31-44	4 (25)
45-64	7 (43.75)
65 or older	2 (12.5)
<i>Race/Ethnicity ^a</i>	
Non-Hispanic white	7 (46.67)
Non-Hispanic black	6 (40)
Hispanic	0
Other	2 (13.33)
<i>Gender</i>	
Female	9 (56.25)
Male	7 (43.75)
<i>Years Spent in CHS Supported Housing</i>	
Less than 1 year	4 (25)
1-3 years	5 (31.25)
4-6 years	4 (25)
7-9 years	2 (12.5)
10 or more years	1 (6.25)
<i>Years Receiving Psychiatric Services</i>	
Less than 1 year	2 (12.5)
1-5 years	3 (18.75)
6-10 years	1 (6.25)
11-15 years	1 (6.25)
16-20 years	2 (12.5)
21-25 years	1 (6.25)
26-30 years	2 (12.5)
Over 30 years	4 (25)

Data is presented as count (%) unless otherwise indicated

^a n=15

Table 6-2: Reasons for Non-Participation in Exercise Program among Participants

Participant #, Male/Female	Minutes of Exercise During Ten Weeks	Reasons for Non-Participation**
3 - Female	680	Family related travel
5 - Female	680	Weather
7 - Female	600	Knee pain, weather
2 - Female	560	Transportation, weather
8 - Female	160	Conflict with disability office
4 - Female	40	Sick roommate, pinched nerve, toothache, apt. Self-conscious of not being able to keep up with exercise group, needed one-on-one encouragement and support, taking care of sick roommate
6 - Female	0	Transportation
9 - Female	0	Unknown
1 - Female	0	Transportation, forgot Severity of disease disabled her from participation
14 - Male	360	Job interview, travel
10 - Male	160	Work Used own weights to exercise in room
11 - Male	160	Sick, didn't feel like it
13 - Male	80	Didn't feel like it, not in mood His peers weren't participating
12 - Male	40	Conflicting appointments Didn't like the first aerobic session attended
15 - Male	40	Exercises were too hard Exacerbated medical conditions related to obesity
16 - Male	40	Worked out prior to sessions
Average	225	

**Based on Participant Feedback, Staff Observation, and Knowledge

Table 6-3: Post-Survey qualitative responses, On the Move

Open ended questions – Female responses*

Questions	Regular Participants (attending approximately half or more sessions)	Non participants, irregular participants
What did you like?	<ul style="list-style-type: none"> • Strength exercises • Lunches, getting together with others to work out • Reminders • PALS wanted participants to enjoy exercise & not just work hard • PALS made their own “video” (live choreographed sessions) for participants, asked participants to contribute songs to work out to 	<ul style="list-style-type: none"> • Shown other ways to do exercises (modifications) • Teachers were interesting
What made you feel comfortable during sessions?	<ul style="list-style-type: none"> • Emotional support from PALS, PAL instructions, PAL attitudes (laughing/joking) • If tired, allowed to sit down or given water • Finally getting the chance to exercise, doing cardio/stretching • Urinary incontinence and issues associated; felt ashamed, that she was annoying other people 	<ul style="list-style-type: none"> • PAL encouragement • Felt treated as equals • It was optional
What made you feel uncomfortable during sessions?	<ul style="list-style-type: none"> • Fast exercises (“Denise Austin lost me a long time ago”) • One instructor didn’t seem to have her heart fully in the exercises and was distracting*** 	
Feel more physically fit as a result of the exercise sessions?	<ul style="list-style-type: none"> • More than before • Yes...”I feel improvement in the right direction” 	<ul style="list-style-type: none"> • “I only went to one session, but yes, felt very happy to be there”

(*Data not included here is written up in case studies as quotations or feedback among case studies) Responses in Bold indicate item appears three or more times

Table 6-4 Continued

How beneficial was the exercise program to you?	<ul style="list-style-type: none"> • Separation between strength/cardio helped understand exercises better 	<ul style="list-style-type: none"> • It was a healthy option
Do you plan to continue exercise on a weekly basis? Why or why not?	<ul style="list-style-type: none"> • Yes, continue exercising, lose weight, tone muscles • Yes, “I need to lose weight and it helps build muscles and reverses age-related deterioration” 	<ul style="list-style-type: none"> • Maybe walking up steps, waking up daily, helps to continue exercising
What would help you continue?	<ul style="list-style-type: none"> • Workout buddy 	<ul style="list-style-type: none"> • Positive motivation would help me continue • Need motivation-more one on one encouragement, support and training
What suggestions do you have for improve future exercise programs?	<ul style="list-style-type: none"> • More exercise to music instead of videos • More variety of videos • Mat/floor work to get a more full benefit • Have everyone make their own video (choreographed sessions) 	<ul style="list-style-type: none"> • More instruction on how to properly complete exercises and activities • Encouragement, little incentives, one on one training, “I really like the booklet, I have been using it a little bit” • Less smoking cigarettes, more water

***Discussion post intervention to screen further PALS to ensure maturity, knowledge and attitude are appropriate for this type of group exercise instruction

Open ended questions – Male responses

Questions	Regular Participants (attending approximately half or more sessions)	Non participants, irregular participants
What did you like?	<ul style="list-style-type: none"> • Constant moving 	<ul style="list-style-type: none"> • Lunch, PALS • Gave him energy, woke him up, good workout • Videos, instructors, music, exercising with other people
What made you feel comfortable during sessions?	<ul style="list-style-type: none"> • Collaboration with a group of people 	<ul style="list-style-type: none"> • Having other people around – made it very comfortable • People made him feel at home

Table 6-5 Continued

What made you feel uncomfortable during sessions?		<ul style="list-style-type: none"> • Had to sit down and could not keep up with people
Feel more physically fit as a result of the exercise sessions?	<ul style="list-style-type: none"> • Yes 	<ul style="list-style-type: none"> • Yes
How beneficial was the exercise program to you?		<ul style="list-style-type: none"> • “If I could have stuck it out it would have been very beneficial to me”^^
Do you plan to continue exercise on a weekly basis? Why or why not?		<ul style="list-style-type: none"> • Yes, walking mostly, lots of stairs • Yes, but not related to On the Move (was exercising before and only attended one class) • Yes, will use friend’s weights
What would help you continue?	<ul style="list-style-type: none"> • Music would help to continue and a healthy diet 	<ul style="list-style-type: none"> • If exercise group was at location of resident (WSC); group walks, Wii system games
What suggestions do you have for improve future exercise programs?		<ul style="list-style-type: none"> • Some type of exercise open in morning before work • Prefer evening sessions; too much standing • No sweating to the oldies (Richard Simmons); interested in open gym option • Lots of weights and resistance bands; before lunch, good music, “...something to loosen you up, get you going, ‘sounds of nature’” • Get the Wii hooked up

^^Participant who had to stop attending due to serious health issues

Table 6-6: Impact of Research on Participants, Agency, and Community

Activities	Impact
Participant Level	
Implementation of On the Move exercise sessions	Improved physical and mental health Improved self-confidence Increased social interaction Desire to continue
Dissemination of results to participants	Understanding of results of exercise Appreciation of involvement in evolving design of exercise program
Agency Level	
Involvement of staff in research	Ownership, trust built within partnership
Invitation for staff participation	Staff participation, deeper understanding of intervention
Development and availability of Physical Activity Leader (PAL) Manual	Opportunity to create training of trainers model to root program within the agency
Ongoing meetings with all members of research team	Ability to solve process issues and reach consensus on next steps
Dissemination of results to staff	Staff interest in program and continuation
Documentation of lessons learned	Additional funding availability for continuation
Community Level	
Development of On the Move resource guides	Expansion of opportunities for people in the community living near and users of CHS services in the community to exercise
Development of On the Move exercise manual	Opportunities for community to exercise independently
Dissemination of results to community	Community appreciation to the agency for creating an opportunity to exercise

Table 6-7: Possible Positive and Negative Impacts of Program on Agency

Positive Impact	Negative Impact
Program Development	
<p>Case Managers glad to be involved and receive training related to motivation for participants that could be used in other areas in addition to exercise</p> <p>Staff appreciated having PI on site and willing to travel to different CHS locations and being flexible to the needs of the organization and staff</p>	<p>Staff frustrated with length of time taken to start exercise sessions</p> <p>Staff overwhelmed with numerous emails from PI</p> <p>Staff felt extra burden to recruit participants, obtain medical clearances</p>
Exercise Sessions	
<p>Staff enthusiastic about participating</p> <p>Case Managers appreciative of PI notifying them when assistance needed;</p> <p>Good relationship developed by several Case Managers and the PI</p> <p>Staff appreciative of post-program dissemination and opportunity to provide feedback</p>	<p>Not all staff exposed to the sessions due to job constraints and ability to attend sessions</p> <p>Staff experienced a disconnect from the program as it was “the PI’s program”, not owned by staff</p> <p>Staff frustrated when program ended with no follow on already planned</p>
Data Collection	
<p>Staff invested in project through involvement and sharing of community knowledge and expertise</p>	<p>Staff weren’t as concerned with the nuances of the data; more focused on the participants’ responses</p>

Table 6-8: Lessons Learned from On the Move Exercise Sessions

Lesson	Rationale
Importance of Scheduling Sessions based on Participants' Needs – but Can't Always Capture All	Men's sessions moved from 10am to 11am to accommodate sleeping in Some men felt new 11am start interfered with their typical lunch hour Some men had weekly doctor's appointments at that time and can't attend
Recognize Importance of Warm-Up and Cool-Down	Changed music to match slower pace of movements PALS needed to explain the purpose of warm-up and cool-down so that participants know the importance
Alter Routines from Feedback	Men didn't favor cardio videos, therefore PALS designed cardio and strength routines which were received well Women did not enjoy certain videos, as a result they were removed from aerobic exercise rotation
Provide Exercise Modifications	Introduce regular exercise and two modifications, one more challenging and one less so to cater to all fitness needs of participants
Have Three PALS at Each Session	PAL was sick one session, proved difficult to led exercise session that was effective for all participants Participants need extra attention because of low experience level with exercise One-on-one attention important in helping participants feel included and cared for
Provide Water at Each Session	Participants often forgot water bottles; providing water to ensure participants are hydrated throughout the workout prevented dehydration
Maintain Positive Environment	Personality clashes occurred between participants; it is important to be conscious of participant spacing and encouraging all levels of participation equally
Maintain Interactions Outside of Sessions	Joining participants during their lunch hour seemed to build their trust and comfort level with PALS

6.12 REFERENCES FOR ARTICLE

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7.0 DISCUSSION

This chapter highlights the strengths and limitations of this dissertation, a discussion regarding outcomes from the three Aims, program and policy implications, and suggestions for future research.

7.1 STRENGTHS

This dissertation has notable strengths. A well-developed community-academic partnership led to the development and implementation of a community-engaged physical activity research intervention that involved participants, the agency, as well as the community. Without the strong partnership developed, and expressed community need combined with each partners' expertise, this research may not have been undertaken. The CBPR approach in this intervention, based on mutual trust and respect for roles in the partnership, was critical to its success. The use of CBPR allowed for ownership in the community of the intervention and subsequent buy-in for certain CHS staff and consumers to participate throughout the intervention. By involving trusted staff members in the recruitment, participants may have been more likely to participate as well as offer their perceptions more readily. There is an established relationship between the PI, CHS staff and participants, which built additional trust in the partnership.

The study is based on sound theoretical models appropriate for the intervention. These include the Transtheoretical model and the Social Cognitive Theory. Both of these theories have been validated as applicable models to use with this population, especially in physical activity interventions. The FGDs in Component I are based on previous studies that were used among similar populations. This research takes those studies to the next logical step by using the results to tailor a physical activity program based on the perceived benefits, barriers and preferences discovered from these FGDs. The evaluation instruments for Component II chosen were based on these theoretical models and previous literature that validate their psychometric properties.

The intervention was carried out on a very low budget from the Staunton Farm Foundation, including support from both CHS and the University of Pittsburgh. This demonstrates the commitment of the partners, and what can be accomplished with a shared vision and understanding of research or program elements and expected outcomes among all partners.

Despite the small sample size and inability to obtain statistically significant results, as this study was not powered to do so, the impact of the program on the participants, agency, and community was supported by other sources of data. These sources included systematic collected notes, weekly observations, and post-intervention qualitative surveys. When the PI approached CHS with the results from the qualitative data, it was not surprising to them that this intervention had an effect on the populations' physical and mental health.

7.2 LIMITATIONS

While this dissertation addresses knowledge gaps that currently exist and provides insight for future research, there are some limitations to note. Component I had limitations. The targeted group did not have full ethnicity representation based on the demographics of 20% of the targeted group identifying as Latino or African-American. Having more participants would help further explore and validate main themes. Due to the nature of the symptoms present among people with SPMI, it can be difficult to recruit large samples based on perceived stigma or paranoia among potential participants being involved in a group setting. From an intervention perspective, the effects of medications pose some barriers to participation in physical activity, included lethargy and weight gain. However, working closely with Case Managers to ensure adherence to medication and providing them with approaches such as Motivational Interviewing could be a way to mitigate this barrier.

Component II had limitations. The scope of the pilot project is relatively small, so caution should be taken when generalizing to other communities or CBPR partnerships. Future studies should aim for a bigger sample size based on lessons learned in this research regarding recruitment and retention, including difficulty in recruiting based on the nature of the diagnoses such as cognitive dysfunction of schizophrenia. Participants provided self-reported outcomes. Participants may self-select based on their own perceived ability to participate or current involvement in physical activity. Limited funding and availability of staff for motivation and follow up were limitations. While modified Motivational Interviewing training was provided to Case Managers, its accurate use was not measured due to practical and financial considerations. These analyses will hopefully be pursued in

future research. The research setting is a real world environment and there are factors that cannot be controlled, yet must be acknowledged.

7.3 AIM 1 DISCUSSION

This review demonstrates important findings related to the effects of physical activity on mental and physical outcomes of people with SPMI. Several themes were generated that merit exploration in future research in order to improve the lives of people with SPMI in community settings. Attendance in a structured, supervised, group-based exercise program can address barriers specifically related to people with SPMI [63-65]. Group attendance also affects motivation, cited as a reason attributed to compliance rates in some studies [63, 66, 67].

Several of these studies demonstrated statistical significance; however qualitative responses revealed successes or lessons learned that could not have been discovered through statistical analyses alone [63, 66]. Intervention effectiveness relies on compliance, and motivation is an important aspect to success [66]. Motivational Interviewing (MI) can be beneficial for people who show less initial motivation to change, feedback can provide useful material for MI, and often reveals possible reasons for change not apparent before [35]. Offering MI to participants by someone known and trusted may facilitate change toward increased motivation and involvement in exercise.

Two studies continued the exercise programs after study completion [63, 64]. Given the nature of community settings, community engagement and sustainability are factors that cannot be ignored. Physical activity interventions that are based in community settings,

rather than institutionalized settings, may benefit from participatory approaches to allow for ownership and sustainability beyond the life of the intervention. While Community Based Participatory Research (CBPR) has been identified as an effective strategy for increasing buy-in of marginalized communities and increasing the likelihood of both successful research and subsequent uptake of intervention practices [68], to the authors' knowledge no existing physical activity intervention focusing on people with SPMI has adopted such an approach. There is potential to expand this research in community settings that lends itself to what CBPR is predicated upon: a partnership approach to research that equitably involves community members, academic researchers, and others such as healthcare providers in all phases of the research process. All partners contribute expertise and share decision making and ownership of the project [68-70]. According to Wallerstein and Duran, CBPR is a "transformative research opportunity to unite the growing interest of health professionals, academics, and communities in giving underserved communities a genuine voice in research, and therefore to increase the likelihood of an intervention's success" [71].

Additionally, two studies reviewed included tailored activities based on each individual's fitness, link to health promotion, and goals; however no consistent structured group activity resulted from these assessments [4, 67]. To encourage physical activity in this population, participants' interests must be considered beyond individual fitness, including type of activity, preferred place to participate, and social influences[47].

Ussher et al. and McDevitt et al. have documented perceived barriers and preferences regarding physical activity among people with SPMI [45, 47]. To the authors' knowledge, there are no published papers to date undertaking structured group-based exercise programs tailored and designed based on focus group discussions that identify

perceived benefits and barriers to exercise, or studies that include gender specific exercise programs. Beginning with this type of approach to inform the intervention could lead to improved tailored programs for increased adherence and acceptability. It is essential to understand how to implement more effective interventions that foster acceptance of physical activity as an essential lifestyle component among people with SPMI in community or deinstitutionalized settings [72].

7.4 AIM 2 DISCUSSION

The focus group discussions provide valuable insight into the design of future exercise programs to improve the mental and physical health among people with SPMI living in a community setting. Participants understand and appreciate the benefits of improved mood and increased physical health from physical activity; when participants engaged in exercise on a fairly regular basis, they indicated increases in functional movement to successfully carry out daily activities from involvement in the exercise.

Based on perceived individual and structural facilitators identified by the groups, there are elements in the design of an exercise program to consider. A group-based indoor program may be suitable especially in climates where temperatures can range significantly. Starting with low-impact activities led consistently by trained exercise individuals that can ensure safety during exercise is important. Having the ability to modify the sessions based on weekly feedback would continue to be responsive to the participants' needs thereby encouraging continued motivation and participation. As many participants are concerned

about weight gain, a complementary healthy lunch could follow the group exercise sessions, exposing participants to healthier food options.

It is evident that a major facilitator to participation among this population in this community is the opportunity for gender-based group activities. In this study, women preferred lower impact activities while men favored a more challenging workout. As preferences may vary by location or setting, it is important to determine if the development of gender specific classes would be a facilitator to participation. This recommendation has been made for the general population as well [73]. In addition, some studies show different recovery patterns between men and women with severe mental illness that may support gender-based exercise groups to determine the gender-specific effect of exercise on physical and mental health outcomes in the community [74, 75].

While benefits and individual and structural facilitators have been identified, it is critical to also address the perceived barriers to participation in exercise. Low self-esteem and self-efficacy to participate in physical activity were key barriers that resonated throughout discussions with this population. This is supported by the literature that people with SPMI tend to experience low levels of self-esteem [76]. One approach to increase motivation among this population could be Motivational Interviewing (MI). MI seeks to explore and build on people's own motivation for change. MI is an approach used among people with SPMI regarding targeted behavior change [77-81]. It helps individuals work through their ambivalence about behavior change and allows the coach, case worker, or other member to adapt the content and format of the interaction to match the participant's readiness to change, subjective pros and cons for change, and level of efficacy [36, 82]. MI is relatively new in research among people with SPMI, but seems well suited to address the

goal of increasing physical activity to improve mental and physical health outcomes in this population.

Along with low self-esteem and self-efficacy, medical conditions (as a result of one's diagnosis) are perceived as an obstacle to participation among this population. Fear of pain associated with increased activity is a reality and occurs in the general population as well, especially among older adults [83] or those with other medical conditions that affect daily living [84]. One way to address this is through a graduated exercise program, wherein the participant's level of fitness and needs are addressed, and exercises are modified for individuals with special needs. These types of programs have been shown to help prevent onset of pain from new activities [63, 85].

Lastly, some women wanted immediate results from exercise and expressed impatience as a barrier when not seeing these results instantly. Celebrating consistent participation through health-related rewards such as towels or inexpensive exercise equipment rather than the actual weight loss may be effective. This approach has been used in other community-based exercise programs among this population [67, 86].

Regarding preferences, participants want opportunities for a reliable, continuous exercise setting that will improve their quality of life. Given the nature of the community setting, community engagement and sustainability are factors that cannot be ignored. Physical activity interventions that are based in community settings, rather than institutionalized settings, may benefit from participatory approaches to allow for ownership and sustainability beyond the life of the intervention. As mentioned earlier, CBPR is effective in increasing the buy-in of marginalized communities and increasing the chance of

successful research and following uptake of intervention practices [68]. To the authors' knowledge, no existing physical activity and SPMI study has adopted such an approach.

Given the severity in diagnoses, patterns of co-morbidities, social isolation and other barriers identified within this population, it is very important to engage the participants early on regarding their preferences and needs to ensure acceptance and uptake of new physical activity interventions. Based on this feedback, engaging the community partners and community participants with whom the intervention will take place can lead to new possibilities for long-term programming beyond the life of the research intervention.

As with any qualitative study, there are limitations to note. Having more participants would have helped further explore and validate main themes. Due to the nature of the symptoms present among people with SPMI, it can be difficult to recruit large samples based on perceived stigma or paranoia of participating in a group setting. From an intervention perspective, the effects of medications pose barriers to participation in exercise. However, working closely with Case Managers to ensure adherence to medication and providing them with approaches such as Motivational Interviewing could be a way to mitigate this barrier.

The recommendations provided in this paper for physical activity interventions among people with SPMI in a community setting build on the current literature regarding potential effective physical activity programs for this population [87]. The novel approaches suggested can supplement current pharmacological and cognitive approaches towards recovery-oriented strategies, resulting in an improved quality of life and longevity among people with SPMI.

7.5 AIM 3 DISCUSSION

On the Move was a gender specific, group based exercise intervention developed via intensive collaboration with staff and clients of a community agency serving people with SPMI. It was tailored to fit the perceived exercise benefits, barriers and preferences of people served by the agency. The case studies and post-program survey suggest that people with SPMI can benefit from such a tailored exercise program. Several challenges to conducting CBPR to address the intersection of physical activity and mental illness were identified as a result of this project.

Recruitment: Although similar methods of recruitment from other studies were used including word of mouth and CM referral [64, 88], it was difficult to obtain the desired number of participants. The timeline for recruitment, given complications related to the population's diagnoses, needs to be carefully planned. Some complications among people with SPMI can include the nature of symptoms among different diagnoses. For example, people with schizophrenia often experience paranoia and a lack of emotional involvement with others [89]. In addition, people with SPMI can experience symptoms including lethargy, disorientation, appetite changes, weight gain, hot flashes, and sweating; these symptoms can also be a side effect of their medications. Furthermore, this population may experience disassociation, fatigue, hopelessness, and helplessness, which may affect their willingness and ability to participate in physical activity [45, 47]. Symptom recognition and management must be recognized as a part of recruitment and motivation. Using CMs to recruit may have been more effective if CMs had a specific role in the program. Future programming should consider selecting Champions among the staff as PALS and including it in their job descriptions, with related compensation either through discounted gym

memberships or other incentives. Identification of Champions among the participants could be a peer-to-peer model to improve enrollment, especially among those who had a positive experience with the program. Perceived benefits and barriers to participation were discovered through initial FGDs; addressing benefits and barriers during recruitment and enrollment may have an effect on recruitment.

Retention: Despite concerted efforts of CHS and On the Move staff, development of consistent engagement was challenging. Women adhered more regularly to the exercise sessions than men; even with reminders and announcements, after the fifth week a majority of the men had dropped out. The high attrition rates could be linked partly to the severity of participants' diagnoses, adherence to pharmacological treatment, employment, and other conflicting schedules as noted in other studies [86, 90, 91]. In addition, there are gender differences in recovery patterns and severity of disorders [74, 75]. Post intervention FGDs could be useful in future research to determine barriers among those who participated regularly and those who did not; the FGDs could also help to learn about factors influencing general community participation in structured group exercise.

Impact of the Program on Physical and Mental Health Indicators: Due to the pilot nature of the project, the study was not powered to find statistically significant changes in physical and mental health measures; low enrollment and high attrition further impacted these outcomes. Anecdotal reports from participants and the small TUG time changes provide some descriptive outcomes suggesting that the On the Move project had a beneficial impact regarding participants' physical and mental well-being.

Impact on Participants, CHS Staff and the Community: The design and development of the intervention involved all partners in every step. CHS staff brought

invaluable experience in their knowledge and understanding of the participant population, community setting, and complex social dynamics. The university researchers brought experience in research, implementation, data collection and analysis, and physical activity. This partnership led to participation from some CHS staff during initial recruitment, but motivation remained difficult among other CHS staff to encourage participation among their clients. Part of this could be related to the staffs' own perceived wellness concerns. Individuals who do not value physical activity or have limited physical capacity may not be able to advocate effectively for these types of activities. Developing a worksite wellness program alongside the exercise program for people with SPMI could create a normative atmosphere for wellness [92-94]. Significant investment was put into relationship building among PALS and participants, which built trust. Through regular meetings with the research team, challenges and successes were recognized early and addressed. The presence of the university researcher at CHS on a weekly basis showed the commitment to the research project.

Lessons Learned from Physical Activity Sessions: Based on different fitness levels among participants, fitness assessments could be useful to cluster participants, provided the participant enrollment is adequate to form groups. This may help reduce self-consciousness among participants and allow them to exercise among peers of the same fitness level. Conflicts in scheduling are inevitable. There could be opportunities to have multiple weekly options for group fitness, especially with more than one PAL available, as is offered in private gym exercise classes. The project-induced time spent outside the exercise sessions is just as important as the time spent during the exercise sessions; the social interaction and

acceptance, especially given the self-perceived and society-induced stigmas associated with their diagnoses, is important to this population.

Strengths: Without the strong partnership developed and expressed community need combined with each partners' expertise, this research might not have been undertaken. The CBPR approach in this intervention pilot, based on mutual trust and respect for roles in the partnership, was critical to its development and implementation in this community setting among this vulnerable population. Despite the small sample and high attrition, the team was able to use other sources of data to elaborate on the impact of the program on the participants, agency, and community.

Limitations: This study has several limitations. The scope of the pilot project is relatively small, so caution should be taken when generalizing to other communities or CBPR partnerships. Future studies should aim for a bigger sample size based on lessons learned in this research regarding recruitment and retention challenges. Selection bias could be a factor among participants already engaged in physical activity. Funding and availability of staff for motivation and follow up were also limitations.

Implications for Future Research and Practice

Although other programs may not adopt the exact model applied in this programmatic research [95], there are important elements outlined in this paper that should be considered when adapting a program akin to the one implemented here.

Encourage open communication: All roles, responsibilities, and expectations of each member in the partnership should be clarified early through logical and transparent dialogue. When all team members were brought together to discuss discordance, the partnership became stronger and more effective. A debriefing plan was established to ensure

staff had a confidential outlet to share information. These steps were critical in the CBPR process.

Maintain flexibility while upholding rigor: Participatory research methods are often considered to be reflexive, flexible and iterative, as opposed to more linear models in conventional science [96]. In this study, an iterative process of documentation and ongoing team discussion allowed for modification of the exercise sessions and other components while ensuring the core structure was intact. In CBPR processes, it is accepted to “let go of the planning” and allow for this iterative process to occur [97].

Provide a range of tailored physical activity options: As participants may have a wide range of exercise capability, it is important to tailor to each participant’s needs to avoid injury or monotony. As noted by Weiland et al. and in our study, a range of options based on participants’ need as related to fitness level, perceived barriers, and preferences, may encourage participation [98]. Future research should consider weekly programs with varying activities, including: weight training; low-impact aerobics; walking clubs; stretching; yoga; dancing; and other activities based on participants’ needs.

Disseminate results back to the community: Ensuring that research findings are disseminated back to the community to inform and translate findings for change at the individual, organizational, community and policy levels is one of the basic principles of CBPR [40]. The team discussed this need early in the design: mental and behavioral health stakeholders were engaged early in the program; and a grant to support a community and stakeholder dissemination strategy and development of satellite exercise centers at CHS was secured. Local insurance companies expressed interest in supporting activities that improve overall health outcomes of their members. An example of this is the Silver Sneakers

program, created and funded by a local insurance company, providing physical activity options for seniors at no cost. On the Move could translate into a similar offering.

Understand that community-academic tensions may arise and need to be addressed: While community-academic partnerships have their successes, challenges remain. During the initial months of the study during IRB approval, some CHS staff involved in the research understood the difficulty obtaining approval quickly based on prior experience; however, frustration arose among other CHS staff and potential program participants, and enthusiasm for the program waned due to the delays. True cooperation takes significant time throughout the research. The university researcher could devote more time to the intervention while other CHS staff has multiple priorities to manage, and agendas did not always coincide. These types of “insider-outsider” tensions can arise from differences in the timetable and priority attributed to the research among partners [99], and need to be understood and addressed accordingly.

Recognize different levels of dynamics within a community and their interaction: Dynamics within and between levels can influence outcomes of community-engaged research. In this community, three levels interacted: CHS staff and participants; participants and other clients; and participants and members of the community. Each interaction throughout the intervention had an impact on the participants, and awareness of these interactions is important. For example, the relationships observed during class and the new sense of connection and civic responsibility were evident through participants bringing healthy snacks for their group partners. Green and Glasgow emphasize the importance of program elements aligned with multiple levels including policy, regulatory, or among individuals representing organizations or whole communities [95], a concept called

ecological alignment, wherein there is an appreciation for the interdependence of levels in a collective system [95]. This concept is particularly critical when working in this type of multi-level community setting. In addition, social network size and social support are linked to better recovery for people with SPMI [100, 101], and is understudied among this population who want to be involved in regular exercise [102].

This research described how the CBPR project to address physical activity promotion among people with SPMI was developed, illustrated the impact of the physical activity program on people with SPMI, the agency, and the community, and presented lessons learned for future CBPR research in this area. Using CBPR in this setting, while challenging given complex dynamics among people with SPMI and within the community, is critical to the successful design and implementation of effective community-based programs.

7.6 PROGRAM AND POLICY IMPLICATIONS

This dissertation presents realistic options for public health programming in community settings that focus on improving the well-being of a specific vulnerable and marginalized population. The implications of this research have enormous potential to improve the quality of life among people with SPMI. This area of research is relatively new; however, the need for additional research and programming is evident. Moreover, implementation science within the field of translational research in mental health is nascent [103]. The findings from this research can be adapted to other mental health organizations in the community

based on the lessons provided throughout the design, implementation and evaluation of this community-academic partnered research.

One important program implication for institutionalization is the buy-in from the staff. In discussions with the CEO, it was found that Case Managers may not feel adequately trained or physically prepared to encourage physical activity among their clients. In the next phase of the program, an anonymous survey via email could be circulated among all staff regarding preferences for physical activity options at CHS. While options will exist for people with SPMI and the general community to continue the physical activity program, staff could be invited to certain days to create a culture of worksite wellness. This would hopefully make a shift in the normative environment at CHS regarding staff opinions on physical activity as worksite wellness programs have an impact on not only the employee, but those they serve as well. Champions among CHS staff can be identified to lead the movement towards a healthier environment for CHS employees, clients, and community members they serve. The PI may not be able to provide assistance to the program at CHS infinitely; however through this type of institutionalization process, the program would have all the components necessary from manuals and equipment to trained staff to integrate the program into ongoing CHS activities.

As part of the process of community engaged research, outcomes are currently being shared with the participants to engage in a discussion about appropriate next steps. These lessons learned will be shared at the Community/Neighborhood level as well as the County level with Department of Human Services/Office of Behavioral Health (DHS/OBH), Staunton Farm Foundation (the funding agency), and other organizations supporting individuals with SPMI for possible program adaptation and piloting.

The DHS/OBH is focusing on this area of recovery and developed a System Transformation Unit creating “Communities of Wellness”. The opportunity to engage insurance stakeholders to discuss coverage of exercise options for people with SPMI is a possibility.

7.7 FUTURE RESEARCH

As noted, previous studies examining the effect of physical activity interventions on the physical and mental health outcomes of people with SPMI are limited in a community setting. Factors to consider in future research studies include recruitment methods, attrition rates, motivational factors to participate in exercise, gender differences, and tailored approaches based on participants’ perceived benefits, barriers and preferences to physical activity.

A number of studies lasted approximately twelve weeks or less [4, 63, 65, 88, 104, 105] and the length of the intervention was often noted as a limitation among several studies due to time and funding constraints. Based on previous studies [86, 104] future research should consider lengthening the intervention for follow up to a six or nine month period, provided time and financial resources are available. This would allow for measurement and assessment of the sustainability of change over time (maintenance stage within the TTM model) and whether participants could maintain the benefits gained [106].

Certain quasi-experimental designs could be considered given the multitude of community factors that can lead to “practice-based processes” that influence evidence-base methods, versus a more rigid and controlled randomized clinical trial [107]. One design to

consider is a wait-list control study among two community mental health organizations that are matched for specific demographic characteristics. The intervention group would receive similar gender-specific physical activity sessions as described in this study, taking into account lessons learned regarding recruitment and retention. The control group would receive the intervention six months later. Results would be analyzed to discover any statistically significant differences in the intervention versus control group over the first six month period. As mentioned earlier, qualitative instruments would enrich the outcome data and provide additional information regarding the success or failure of the intervention.

Several studies included components that complemented the exercise intervention, [4, 64, 86, 88, 106] including this study, such as Motivational Interviewing, nutritional advice, and other lifestyle elements. A wait-list control design could also be applicable allowing the control group to receive solely the physical activity intervention, while introducing educational or wellness components to the experimental group to determine the effect of these outcomes including motivation to change, participation, and maintenance in continued exercise. These designs require a significant amount of time; partners must be mindful of this and determine if this type of design is feasible within the practical and financial boundaries of the community setting [107].

Another design could include using the same sample at CHS, aiming for a higher recruitment level based on lessons learned from this research. Bias could occur among previous participants that re-enroll in the study due to the perceived effect or satisfaction of the exercise in the first study. However, this design could focus more on measuring the effect of Motivational Interviewing as a mediating factor influencing participants' degree of participation. The design could also take into account the effect of gender on participation in

exercise as a moderator, given the gender differences in recovery found among this population, and based on other researcher's suggestions to examine the role of gender-tailored physical activity programs [102].

Through systematic note taking and observations during the intervention, it was clear that social networks played a role in influencing women's and men's decisions to participate. Some men were motivated by their peers' participation, or consequently unmotivated by their peers' lack of participation. Some women became more involved as social relationships evolved through meeting over lunch and during physical activity. Limited research exists regarding the most effective means of social support offered to people with mental health illnesses who want to become involved in regular physical activity [102]. Further designs could explore the role that social support plays in motivation and adherence to physical activity based on previous studies emphasizing the importance of social support in recovery among people with SPMI [100, 101]. Some studies have shown observational or qualitative feedback but not quantitatively tested results of social support influencing motivation to participate in physical activity [62, 63, 86]. A non-randomized quasi-experimental study could be undertaken that clusters two groups based on pre-intervention social support instruments; one clustered group reporting little to no social support, and the other clustered group reporting moderate to high social support. Each group would receive the same physical activity intervention to determine the influence of social support on participation in physical activity. Cut off points and measurements would be derived from existing psychometrically sound social support instruments such as the Interpersonal Support Evaluation List, Short Form (ISEL-12).

8.0 CONCLUSION

Novel conceptual frameworks, new research tools, and practices are essential to further the development of effective intervention approaches to improve the well-being of people with SPMI. The National Institute of Mental Health has prioritized innovative and effective interventions to prevent and cure mental illness and to reduce associated medical comorbidities and disabilities along with new partnerships to accelerate the achievement of these goals. Efforts are focused on personalized treatment that is tailored to the individual and concentrate on prevention of illnesses related to diagnoses of people with SPMI before its onset [108]. Furthermore, the U.S. Government's Healthy People 2020 Initiative recognizes that mental health disorders are one of the leading causes of disability; the initiative provides the following definition of mental health:

“...a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with challenges. Mental health is essential to personal well-being, family and interpersonal relationships, and the ability to contribute to community or society [109].”

As revealed in this dissertation, significant disparities exist to achieve this state of well-being among people with SPMI. Few studies address the intersection of physical activity and mental health, especially at the community level. In order to tailor physical activity interventions to improve uptake and ongoing participation among people with SPMI in the community, more research is necessary regarding gender specific perceived benefits, barriers, and preferences at the community level. As each community differs, it is imperative

to consider the interactions among different members of each community in the design and implementation of physical activity interventions. The CBPR approaches used in this dissertation and the lessons learned have great public health significance. People with SPMI are a vulnerable population, often needlessly ostracized and neglected in the health care system. Innovative methods in addition to pharmacological and cognitive behavioral therapies are necessary for people with SPMI to lower the burden of disease from mental illness. Physical activity interventions in the community have proven to have a positive impact on the physical and mental health of people with SPMI. This dissertation provides valuable insight and implications for future research and health policy that can help address these disparities among this population. Further research in this area is necessary to expand what is currently feasible and effective in order to expand the data available for policy and programmatic decision making throughout the United States. These changes in programs and policy can help contribute to a higher level of health equity among vulnerable populations such as people with SPMI, and ultimately lead to a more healthy and productive population.

**APPENDIX A: COMPONENT ONE INSTRUMENT: FOCUS GROUP
QUESTIONNAIRE**

CHS Resident's Opinions Regarding Participation in Physical Activity

Focus Group Guide

June 2012

Introduction

I'd like to welcome everyone here today and make some introductions. My name is Kamden Hoffmann, and I will be facilitating today's focus group. [TBD, CHS staff member] will be facilitating also. I'd like to thank everyone for coming and agreeing to help by participating in this focus group; we know how important your time is. Our overall purpose for this this research study is to find ways to improve exercise activities available to residents at CHS. The focus group will help us understand what exercise activities you participate in now, why or why not you participate in these exercise activities, what additional activities you would like to have, and what your thoughts are regarding participation in exercise here at the center. We'll talk for about an hour, and you will have an opportunity to ask questions at the end if you have any. Are there any questions about the introduction?

Ground Rules (Kamden)

Before we get started with the focus group session, I would like to mention a few ground rules. First, there is no right or wrong comments, and please feel comfortable responding "I don't know" to questions you are unsure of. It is completely ok to say I don't know.

Second, we're interested in *all* of your opinions and input. We're not trying to get everyone to agree, but rather to get everyone's input.

This session is being audio recorded and observers are making notes so that we can capture what everyone said correctly and use that information later to help make decisions about new activities. Next, because this is audio recorded, please try not to use names so everyone can remain unidentified. Your name will not be used when any results are used or presented. Your responses will be anonymous. The audio files and observer notes will be securely stored, and I will ensure that all materials are kept in a confidential and anonymous place.

We also ask that you not discuss any of the information shared today with others outside this group because we want everyone to feel comfortable during the session to be upfront and honest about their opinions. We don't think anything today will make you feel uncomfortable but your participation is voluntary and you may stop at any time, just let us know during your participation today. There are no foreseeable risks associated with the focus group, nor are there any direct benefits to you.

We will compensate each of you with a \$20 WePay card as a thank you for your time today. You can use the card like a normal debit card at any store or ATM machine, and we will give the cards to Don with instructions on how to activate the card. If you have any questions please contact me by email at kdh30@pitt.edu or by phone at (202) 247-1227.

Are there any questions about the ground rules?

Procedures (CHS Facilitator)

It is our role as the facilitators to move the group along and to keep us on task. We may “call on” you to respond to some questions or ask you to hold comments so we can hear from everyone. Since there several topics we hope to cover today, we may try to move the discussion along at times. Please feel free stop us at any time if you want to add something.

We want this to be a group discussion, so you needn't wait for us to call on you. Please speak up and one at a time, so that the recorder can pick up everything. We may ask that you repeat or clarify your statements. Does anyone have any questions about the procedures?

We will start today by introducing ourselves and share one thing we like to do during the day. This is just so we get to know each other (Note: go around the room with introductions) (Kamden)

Turn on the recorder.

[NOTE: The groups to be interviewed are residents with diagnosed schizophrenia at CHS, referred to hereafter as “residents”. Focus group questions will be based on several themes continuously asked about in similar studies among people with severe and persistent mental illness. These themes will include: Resident’s thoughts of what physical activity may consist of; Availability of physical activity services at CHS; Resident’s current participation

in physical activity, both at CHS and outside CHS; Positive or negative experiences of residents with physical activity; Perceived benefits and barriers to participation in physical activity; Interaction of residents with other residents regarding physical activity]

Example questions and probes: (Kamden with CHS staff facilitation)

[Note: Physical activity is any activity that causes the body to work harder than normal. It describes activities that are beyond the daily routine—this is for internal purposes to gauge what the residents view as physical activity. We will use the term exercise to keep consistent with what residents perceive as physical activity.]

When you think of a physically active resident at CHS, what comes to your mind?

When you think of a physically inactive resident at CHS, what comes to your mind?

What opportunities to do exercise are near where you live?

Think about the neighborhood where you live. What is it about your neighborhood that makes it easy or hard for you to be physically active?

What things here at CHS make it easier or harder for you to be more physically active?

Now we would like your ideas about how to change things.

What do you think could be done to help people with a mental illness to be more physically active?

What do you think could be done here at CHS to help people be more physically active?

If you could choose a physical activity, what do you think you would like to do on a weekly basis?

Would you do it with others at CHS? Why or why not?

(Probe with activities mentioned earlier that already exist at CHS/in the neighborhood, others that are readily available at CHS but are not actively used)

Conclusion (Kamden/CHS staff)

Before we end our session today, we'd like to ask if there are any other issues you would like to discuss that weren't addressed during the focus group. Does anyone have any additional comments or questions about physical activity?

We would like to thank everyone again for your time and cooperation, you've given us a lot of important information, and we appreciate all of your help.

APPENDIX B: COMPONENT TWO: CODE BOOK

Code 1: Exercise Preferences

Code 2: Issues Related to Gender and Exercise

Code 3: Logistics/Scheduling

Code 4: Perceived Barriers to participating in Exercise

Sub-code 4: Mental Health

Sub-code 4: Physical Health

Sub-code 4: Social Barriers

Code 5: Perceived Benefits of doing exercise

Code 6: Perceived Consequences of Not Doing Exercise

Code 7: Perceived facilitators to participating in exercise

Sub-code 7: Motivators

Sub-sub-code 7: Program Motivators

Sub-sub-code 7: Self-motivators

Sub-sub-code 7: Social interaction

Code 8: Perceived Measurements of Progress

Sub-node: In general daily life

Sub-node: In on the move program

Code 9: Perception of Definition of a Physically Active Person

Code 10: Perceptions of a Physically non-active person

Code 11: Things Perceived as Associated with Exercise

APPENDIX C: COMPONENT TWO: SURVEY INSTRUMENT

Introduction: Hello and thank you for agreeing to participate in this survey now and at the end of the exercise program. This should not take more than 20 minutes to finish. I am going to ask some basic questions about you, then about your feelings about exercise, how you feel around your friends and in your neighborhood, and about your current mood. At any time please let me know if you would like clarification with what I'm asking. I'm going to use some scales that you can point to for the answer when I ask questions. I will explain them all. Ok, the first questions we will start with focus on some basic information about you.

Non identifiable Demographic Questions: On the Move Exercise Program

D1. Please specify your age range:

- 1 18-30
- 2 31-44
- 3 45-64
- 4 65 or older

D2. What race and/or ethnicity do you consider yourself to be? Check all that apply.

- 1 non-Hispanic white
- 2 non-Hispanic black
- 3 Hispanic
- 4 "other" (includes American Indian, Alaska Native, Native Hawaiian or Other Pacific Islander, Asian, and two or more races)

D3. What is your gender:

- 1 Female
- 2 Male

D4. How long have you lived in CHS supported housing?

- 1 Less than one year
- 2 1-3 years
- 3 4-6 years
- 4 7-9 years
- 5 10 or more years

D5. Approximately how long have you been a recipient of psychiatric services?

- 1 Less than one year
- 2 1-5 years
- 3 6-10 years
- 4 11-15 years
- 5 16-20 years
- 6 21-25 years
- 7 26-30 years
- 8 Over 30 years

Great, thank you. Now I am going to ask you some questions about your participation in exercise.

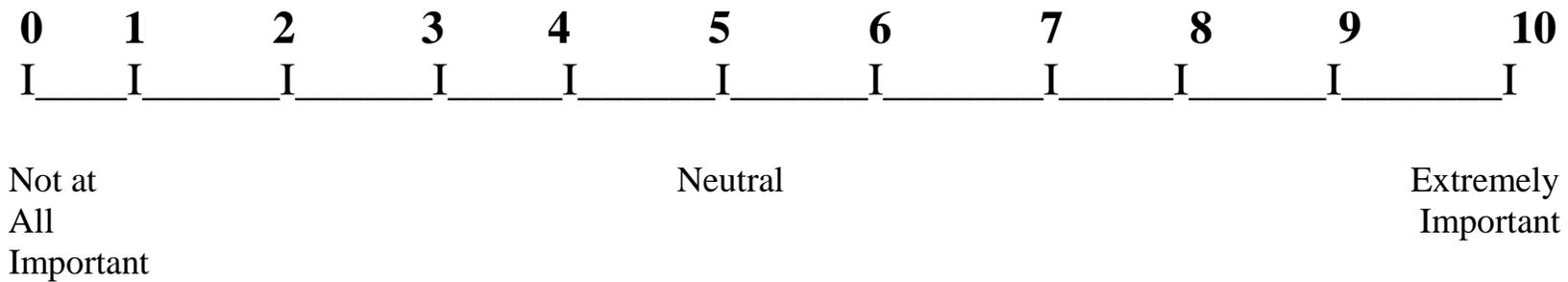
Stages of change assessment tool

Question	Stage of Change
<p>SOC 1: Do you currently participate in exercise weekly?</p> <p>(If yes, go to question 2, if no, go to question 3)</p>	<p>1a <input type="checkbox"/> Yes, I do participate in exercise weekly (ACTION)</p>
<p>SOC 2: How many months have you been participating in exercise?</p>	<p>1b <input type="checkbox"/> Less than one month (ACTION)</p> <p>2 <input type="checkbox"/> More than 6 months (MAINTENANCE)</p> <p>3a <input type="checkbox"/> No, I do not currently exercise (PRECONTEMPLATION)</p>
<p>SOC 3: Would you consider participating in exercise?</p>	<p>3b <input type="checkbox"/> No, I would not consider participating exercise (PRECONTEMPLATION)</p> <p>4 <input type="checkbox"/> Yes, I may consider participating in exercise (CONTEMPLATION)</p> <p>5 <input type="checkbox"/> Yes, I am planning soon to participating in exercise (PREPARATION)</p>

Great, thank you. Now I am going to show you two scales, ranging from 0 to 10. I am going to ask you to rate two things, and I'll explain each of the scales to you.

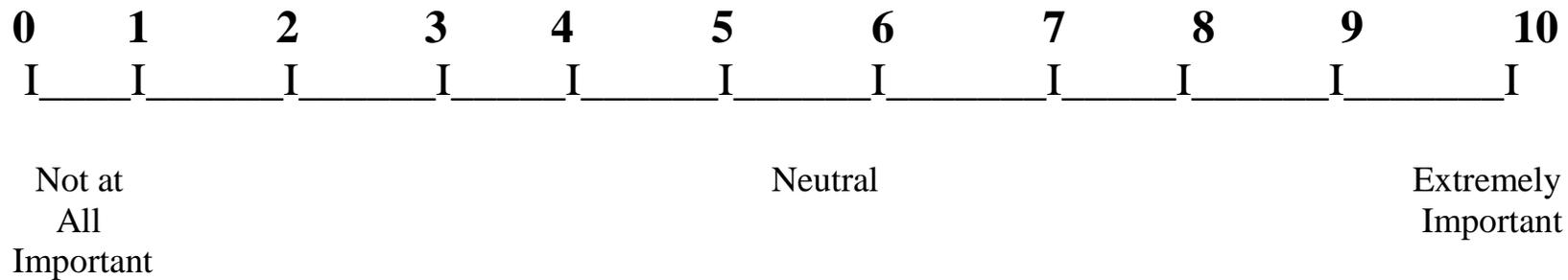
SOC 4: IMPORTANCE to YOU

Of making this Change to participate in exercise (or increase exercise if you currently do exercise)



On a scale of 0 being not at all important, and 10 being extremely important, how important is it to you to participate in exercise? And if you already participate in exercise, how important is it to you to increase your current exercise? (Note which question is being answered from the participant)

SOC 5: Your CONFIDENCE in being able to make this change to participate in exercise if you decide to do so (or increase exercise if you currently do exercise)



On a scale of 0 being not at all confident, and 10 being extremely confident, how confident are you that you are able to make this change to participate in exercise? And if you already participate in exercise, how confident are you that you can make this change to increase your current exercise? (Note which question is being answered from the participant)

Great, thank you. Now I would like to ask you some questions about your feelings and emotions today or over the past week.

Positive Affect Negative Affect Schedule (PANAS) Questionnaire

This scale consists of a number of words that describe different feelings and emotions. Read each item and then list the number from the scale below next to each word. **Indicate to what extent you feel this way right now, that is, at the present moment OR indicate the extent you have felt this way over the past week (circle the instructions you followed when taking this measure)**

1 Very Slightly or Not at All	2 A Little	3 Moderately	4 Quite a Bit	5 Extremely
-------------------------------------	---------------	-----------------	------------------	----------------

- | | |
|--|---|
| <p>_____ PANAS1. Interested</p> <p>_____ PANAS2. Distressed</p> <p>_____ PANAS3. Excited</p> <p>_____ PANAS4. Upset</p> <p>_____ PANAS5. Strong</p> <p>_____ PANAS6. Guilty</p> <p>_____ PANAS7. Scared</p> <p>_____ PANAS8. Hostile</p> <p>_____ PANAS9. Enthusiastic</p> <p>_____ PANAS10. Proud</p> | <p>_____ PANAS11. Irritable</p> <p>_____ PANAS12. Alert</p> <p>_____ PANAS13. Ashamed</p> <p>_____ PANAS14. Inspired</p> <p>_____ PANAS15. Nervous</p> <p>_____ PANAS16. Determined</p> <p>_____ PANAS17. Attentive</p> <p>_____ PANAS18. Jittery</p> <p>_____ PANAS19. Active</p> <p>_____ PANAS20. Afraid</p> |
|--|---|

Scoring Instructions:

Positive Affect Score: Add the scores on items 1, 3, 5, 9, 10, 12, 14, 16, 17, and 19. Scores can range from 10 – 50, with higher scores representing higher levels of positive affect.

Mean Scores: Momentary = 29.7 (*SD* = 7.9); Weekly = 33.3 (*SD* = 7.2)

Negative Affect Score: Add the scores on items 2, 4, 6, 7, 8, 11, 13, 15, 18, and 20. Scores can range from 10 – 50, with lower scores representing lower levels of negative affect.

Mean Score: Momentary =14.8 (*SD* = 5.4); Weekly = 17.4 (*SD* = 6.2)

Great, thank you. Now I would like to ask you a few questions about social support at CHS and in your neighborhood.

Interpersonal Support Evaluation List, Short Form (ISEL-12)

Instructions: This scale is made up of a list of statements each of which may or may not be true about you. For each statement circle "definitely true" if you are sure it is true about you and "probably true" if you think it is true but are not absolutely certain. Similarly, you should circle "definitely false" if you are sure the statement is false and "probably false" if you think it is false but are not absolutely certain.

INES1. I feel that there is no one I can share my most private worries and fears with.

1 . definitely false 2 . probably false 3 . probably true 4 . definitely true

INES2. If I were sick, I could easily find someone to help me with my daily chores.

1 . definitely false 2 . probably false 3 . probably true 4 . definitely true

INES3. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.

1 . definitely false 2 . probably false 3 . probably true 4 . definitely true

INES4. I don't often get invited to do things with others.

1 . definitely false 2 . probably false 3 . probably true 4 . definitely true

INES5. If I wanted to have lunch with someone, I could easily find someone to join me.

1 . definitely false 2 . probably false 3 . probably true 4 . definitely true

Great, thank you. Ok, we are now at the last set of questions. I am going to ask you some questions that relate to your current physical and mental health.

**ACISR for Late-Life Depression Prevention
RAND12**

ID#: _____ **Date:** _____ **Timepoint:** _____

ACISR 1. In general, would you say your health is:

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

ACISR 2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

- 1 Yes, limited a lot
- 2 Yes, limited a little
- 3 No, not limited at all

ACISR 3. Climbing **several** flights of stairs

- 1 Yes, limited a lot
- 2 Yes, limited a little
- 3 No, not limited at all

ACISR 4. During the **past 4 weeks**, have you accomplished less than you would like **as a result of your physical health**?

- 1 Yes
- 2 No

ACISR 5. During the **past 4 weeks**, were you limited in the **kind** of work or other activities you do **as a result of your physical health**?

- 1 Yes
- 2 No

ACISR 6. During the **past 4 weeks**, have you accomplished less than you would like **as a result of any emotional problems** (such as feeling depressed or anxious)?

- 1 Yes
- 2 No

ACISR 7. During the **past four weeks**, did you not do work or other regular daily activities as **carefully** as usual **as a result of any emotional problems** (such as feeling depressed or anxious)?

- 1 Yes
- 2 No

ACISR 8. During the **past four weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

- 1 Not at all
- 2 A little bit
- 3 Moderately
- 4 Quite a bit
- 5 Extremely

The following questions are about how you feel and how things have been with you during the past four weeks. For each question, please give me one answer that comes closest to the way you have been feeling.

ACISR 9. How much of the time during the **past 4 weeks** have you felt calm and peaceful?

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

ACISR 10. How much of the time during the **past 4 weeks** did you have a lot of energy?

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

**ACISR for Late-Life Depression Prevention
RAND12**

ID#: _____ **Date:** _____ **Timepoint:** _____

ACISR 11. How much of the time during the **past 4 weeks** have you felt downhearted or blue?

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

ACISR 12. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

- 1 All of the time
- 2 Most of the time
- 3 Some of the time
- 4 A little of the time
- 5 None of the time

Great, thank you. We have finished the survey. Thank you for your time and I hope you enjoy the exercise program. If you have any questions, please let us know.

APPENDIX D: GANTT CHART FOR ON THE MOVE ACTIVITIES

Timeline for On the Move	Persons Involved	May	June	July	August	Sept	October	Nov	Dec	
Activity		Recruitment and sensitization for staff and participants								
Develop overview materials for Case Managers (CM) meetings	KH, AW									
Develop overview materials for possible Physical Activity Leaders (PALS)	KH, TS									
Create master list of CMs and PALS to be trained	AW, DM									
Meet with CMs re: MI training and program details	KH, AW, DM									
Sensitize CMs on recruitment of participants	KH, AW, DM									
Outreach to PALS	AW									
Final list of CMs for MI training	AW, DM									
Final list of staff/students for PAL training	KH, AW, TS									
Recruit participants for intervention	AW, DM, CMS									
Informed consent among participants	KH, CMS									
Obtain medical clearance from all participants	KH, CMS									
Follow up with participants to ensure medical clearance is still valid, able to participate	KH, PALS, DM									
Activity		IRB approval								
Contact IRB and start process of approval	KH, JB									
Follow up for final IRB approval	KH, JB									
Schedule of reporting (if needed) for IRB	KH									
Activity		Trainings for research staff implementing program								
Personal training certification renewed	KH									
MI training May 23-25	KH									
Group exercise certification	KH									
Activity		Training for CHS staff, supervision and follow up								
Training on Schizophrenia for staff	DM									
Contact Dr. Cluss to organize MI training protocol	KH									
Solidify dates for MI training	KH, PC									
Pre-test to gauge PA/MI knowledge	KH, TS									
Develop MI training manual outline	KH, PC									
Development and pretesting of MI training manuals and agenda	KH, PC, AW									
MI training for CMs	KH, PC									
Posttest to gauge MI knowledge	KH									
Development of draft PAL manuals, the "basics"	KH, AW, TS									
Develop PAL training draft guidelines	KH, AW, TS									
PAL training	KH, TS									
Posttest to gauge PAL knowledge	KH, TS									
Activity		Tailoring of physical activity								
Literature review and discussion about physical activity among people with SPMI and previous focus group discussion (FGD) topics/questions	KH, AW									
Development of draft focus group discussion (FGD) questionnaires and pre-testing	KH, AW, DM									
FGDs at Lawn Street and Wood street	KH, TBD									
Development of physical activity program	KH, AW, DM, TS									
Finalization of PAL guidelines and final part PAL training based on FGD outcome	KH, AW, TS									
Incentives for participants distributed	CHS STAFF									
Participant enrollment in PA activity	KH, TS									
PA activity begins	KH, PALS, TS									
PA activity continuation	KH, PALS, TS									
PA activity continuation/ wrap up (10-12ish weeks)	KA, PALS, TS									
Post intervention FGDs with participants	KH, CHS STAFF									
Activity		Implementation of intervention								
Development of incentive structure for participation	KH, AW, DM									
Review of SF-12 form with staff to ensure feasibility in administration	KH, AW, DM, CMS									
SF-12 pre-intervention among participants and non-participants	KH, CMS									
Implementation begins--ongoing	KH, PALS, AW, DM									
Recording of compliance to PAL sessions	PALS									
SF-12 post-intervention among participants and non-participants	KH									
Activity		Analysis of results								
Initial analysis of SF-12 pre-intervention surveys	KH, AW									
Analysis of FGDs	KH, AW, DM									
Analysis of SF-12 post-intervention results	KH, AW									
Analysis of FGDs	KAH, AW, DM									
Activity		Dissemination and follow up								
Organize central location for all program materials	KH, TS									
Begin documentation of program activities	KH, TS									
Start write up of results from FGDs for dissemination	KH, AW									
Documentation of process outcomes	KH, AW, DM, TS									
Write up of program outcomes and dissemination plan	KH, AW									
Activity		Ongoing reporting								
Develop reporting plan: process, outcome reporting	KH, AW, TS									
Updates on number of trainees recruited, number of materials developed, number of outreach sessions	KH, TS									
Updates on number of staff trained, pre-post test results after training, number of participants enrolled in intervention	KH, TS									
Updates on participant compliance	KH, PALS, TS									

APPENDIX E: OPEN ENDED QUESTIONNAIRE POST INTERVENTION

Post-Survey, K.Hoffmann

1. What did you like about the exercise program? [Probe for class content, provision of lunch, contest, transport, reminders, gender specific sessions]
2. What made you feel comfortable during the exercise sessions? [Probe may also use the words, feel good/happy]
3. What made you feel uncomfortable during the exercise sessions? [Probe may be feel sad/frustrated]
4. Do you feel that you are more physically fit as a result of the exercise sessions? [Ask those who participated in one or more sessions]
5. How beneficial was the exercise program to you? What other feelings do you have about your participation in the exercise program?
6. Do you plan to continue exercise on a weekly basis? Why or why not? What would help you continue? [Probe for what kind of exercise, where, alone or with other people]
7. What suggestions do you have for improve future exercise programs?

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