PSYCHOSOCIAL SUPPORT GROUPS FOR NORTH INDIAN WOMEN

"HOW CAN WE SHARE WHEN WE DON'T GO OUT?"
PSYCHOSOCIAL SUPPORT GROUPS FOR NORTH INDIAN WOMEN

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment
of the Requirements for the Degree Master of Science (Global Health)

McMaster University MASTER OF SCIENCE (2015) Hamilton, Ontario (Global Health)

TITLE: "How Can We Share When We Don't Go Out?" Psychosocial Support Groups For North Indian Women

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NUMBER OF PAGES: 112

ABSTRACT

Background: Although major depression is one of the leading causes of premature death and disability in India, there is little infrastructure to provide mental health services in the rural North Indian state of Uttarakhand. The worldwide burden of depression is 50% higher in women than men, however Indian women experience the double burden of gender disadvantage and poverty which restricts their autonomy and access to social support, and increases their risk for common mental disorders (CMDs). In this low resource setting, community mental health (CMH) models of care may offer the best approach to supporting women with CMDs.

Objective: This study partnered with a local NGO in Uttarakhand to examine the factors influencing women's participation in psychosocial support groups (PSSGs), and the groups' impact on the women and their communities. PSSGs had been set up in the communities for a minimum of 6 months

Methodology: Focused ethnographic research was conducted over three months in 2016, involving ten focus group discussions (FGDs) with seven unique PSSGs, representing a total of 43 women. FGDs were conducted with PSSGs that had been active a minimum of 6 months. They included both persons with psychosocial disability and their caregivers, primarily divided into separate PSSGs. FGDs were conducted across three different sites, with predominantly Muslim and Hindu populations. Additionally, eight key informant interviews were conducted with community health workers and mental health professionals. Data was translated and transcribed from Hindi to English.

Results: The principal barrier to PSSG participation was gender inequality, more specifically, women not being granted permission to leave the home to participate. In terms of impact, the women explained how learning and talking about their own depression and anxiety increased their knowledge and improved their mental health. PSSGs created safe social spaces for women to talk, which increased women's confidence to speak freely in their community. As a result of the PSSGs, women felt that they had reimagined their roles as community members, shifting from the role of receiver of help to provider. Communities were impacted by the PSSGs as women shared their mental health (MH) knowledge widely, and referred and accompanied community members to MH services.

Discussion: These findings are significant because women in PSSGs were able to work together to improve their MH in the context of high gender inequality and mental health stigma. Greater ability to speak out and act collectively may empower women to contribute to household and community decisions, and participate economically, advancing their health and social interests. This research demonstrates how PSSGs can benefit not only the women involved but their community and its mental health. It highlights the importance of understanding models for CMH services that build on local resources and can serve as a model for other underserved communities.

ACKNOWLEDGEMENTS

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LIST OF ABBREVIATIONS AND SYMBOLS

CHW Community Health Worker: Those who organize and run the PSSGs

GM Group member: a woman in a PSSG, interviewed as part of an FGD

KII Key Informant Interview

PI Principal investigator: Nicola Gailits

PPSD Person with psychosocial disability: someone with a mental disorder.

Project Burans Name of the mental health program running in the community

PSSG Psychosocial Support Group

RA Research assistant

DECLARATION OF ACADEMIC ACHIEVEMENT

       The following is a declaration that the content of the research in this document has been completed by Nicola Gailits and recognizes the contributions of Dr. Lisa Schwartz and Dr. Elysée Nouvet in both the research process and the completion of the thesis.

CHAPTER 1: INTRODUCTION AND BACKGROUND

This chapter will begin with a quick summary of the study's rationale, goals, and definitions used. It will then proceed to provide a background on the specific case of common mental disorders in Indian women and how the current global response to mental health care provision has left behind the importance of engaging local communities. A background on India's currently mental health policies will follow, as well as a section on community mental health approaches. Lastly, a review of psychosocial support groups in the Global South literature will be presented, along with a short summary on how this research study contributes to the literature.

Summary: Study Rationale

Major depression is one of the leading causes of premature death and disability in India (Khandelwal *et al.*, 2004) and mental disorders are responsible for 11.8% of the national disease burden (Patel *et al.*, 2011). In the North Indian state of Uttarakhand, there is little to no primary care infrastructure or psychiatrist resources to provide mental health services (Project Burans, 2014), representing "a huge mismatch between disease burden and health service provision" (Mathias *et al.*, 2015b). For women worldwide, the WHO reports that the burden of depression is 50% higher than in men (Chowdhury, 2013). In India, there are culturally specific and socio-economic causes for depression in women: for example, the rigid traditional roles women have in Indian culture restrict their agency and lower their social status (Kermode *et al.*, 2007). Furthermore, exposure to domestic and sexual violence makes Indian women more susceptible to depression (Kermode *et al.*, 2007).

Health beliefs, idioms of distress, and ways of dealing with mental health problems vary greatly across cultures (Tribe, 2014). The current need is to work alongside communities to develop "definitions of illness for healing that resonate with local worldviews and realities" (Campbell and Burgess, 2012). Campbell and Burgess (2012) argue for communities as experts and active agents in promoting community

mental health (CMH) competence, and highlight the role communities can have to promote mental health.

Study Purpose

The overarching aim of this research was to investigate the impact of psychosocial support groups (PSSGs) for North Indian women with common mental disorders. This study addressed the following three questions:

1) What factors influence North Indian women's participation in PSSGs?
2) What is the impact of PSSGs on the women?
3) What is the impact of PSSGs on the community?

The principal investigator (PI) for this project, Nicola Gailits, conducted this research in Mussoorie, Uttarakhand, alongside the NGO Project Burans and its director Dr. Kaaren Mathias, from early May to late July, 2016. Pooja Pillai, the study's local research assistant, also aided greatly throughout the data collection and analysis process.

Definitions

It is important to note that the term "persons with psychosocial disability" will be used throughout this thesis. According to the North Indian NGO Project Burans, this is the more appropriate and appreciated term to describe individuals suffering from mental health problems or disorders. The term "psychosocial" as opposed to "mental health" emphasizes the significant social factors that frame and influence our psychological condition. In the same way, psychosocial support groups are therefore groups with the goal of improving an individual's mental health. The meaning of PSSGs can be roughly defined along the same lines that Pistrang, Barker, and Humphreys (2008) defined mutual support groups: "a group of people sharing a similar problem, who meet regularly to exchange information and to give and receive psychological support." The exact meaning of PSSGs in this context is detailed in the section entitled Intervention (Chapter 2).

As this study is examining women with common mental disorders specifically, it

is important to clarify this term. Common mental disorders (CMDs) include anxiety disorders, depression, and related neurotic disorders. Although these disorders are classified into separate categories, CMDs is an appropriate way to group the terms, as "they often occur as comorbid conditions, and their treatment also tends to be along similar principles" (Chadda, 2015).

Lastly, this study will define collective action for mental health as action taken together between individuals (women, in this case) in the community to alleviate mental health problems, including the support groups organized by NGOs, but primarily focusing on action from women themselves in the community.

BACKGROUND

Indian Women's Mental Health: A Special Case

Approximately 6.6% of Indian women have a common mental disorder, as determined by a cross sectional survey of 3000 women in the Southern state of Goa (V. Patel et al., 2006). Worldwide, the World Health Organization (WHO) reports that the burden of depression is 50% higher in women than men (Chowdhury, 2013). Given India's population is currently just over 1 billion inhabitants, the number of Indian women struggling with CMDs is currently equal to the entire population of Canada.

As defined by the WHO, mental health is a "state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community" (Kermode et al., 2007). However, in a qualitative study in Maharashtra, Indian women's definitions of mental health differed significantly (Kermode et al., 2007). While the WHO defines mental health as a *presence* of abilities and contributions, women in the Kermode et al. (2007) study defined their mental health as an *absence* of certain stressors. Stressors women experienced were related to their husbands, mothers in law, domestic violence, and poverty (Kermode et al., 2007). As Kermode writes, "essentially, if a woman is lucky enough to be married to a man who does not drink or gamble,

remains faithful and earns some money, and the mother-in-law does not harass her, and she has sons, then she will have good mental health" (Kermode et al., 2007).

V. Patel et al. (2006) cites "the double burden of gender disadvantage and poverty" as a factor that increases the risk of CMDs in Indian women, restricting their autonomy and access to social support. Other factors that increase women's gender vulnerability include "social class, marital and childbearing roles, lack of education, and social oppression" (Rao, Vanguri, & Premchander, 2011). Lastly, the patriarchal dominance in Indian culture exposes women to partner alcohol use, and domestic and sexual violence, rendering her even more susceptible to CMDs (Nayak, Patel, Bond, & Greenfield, 2010). Overall, Kermode et al. (2007) suggest Indian women's psychosocial disabilities are caused by cultural and socio-economic factors, which are felt to be largely out of a woman's control.

Consequently, interventions that focus on the provision of social and economic interventions have been shown to improve women's mental health (Kermode et al., 2007). Access to social and economic skills increases women's competence and self-reliance, which empowers and improves their mental health (Kermode et al., 2007). Dasgupta et al. (2013) emphasize the importance of social interventions, as their research found that women with high levels of social support were less likely to experience depression. The above findings also align with the social and economic determinants of mental health outlined by Devine, Kermode, Chandra, and Herrman (2007), which include social inclusion, access to economic resources, and freedom from discrimination and violence. These results point towards to the possible effectiveness of psychosocial support groups, where social support is central to the process.

The Solution: Global Scale Up of Western Medicine?

Anti-depressants and other psychotropic medications are often the first approach to treating mental disorders. The provision of psychotropic medication has been shown to have both short and long term benefits for North Indians with mental disorders (Mathias, 2015). Mathias (2015) emphasizes that "even sub-optimal bio-medical care can make a difference to individual people and families." However, across India there are many other

ways to treat mental disorders that are different from Western psychiatry's biomedical approach. Halliburton (2004) reports on psychiatric pluralism, emphasizing that there is no "best" approach. He examines patients' use of several types of treatments in India including ayurvedic (indigenous) psychiatry, allopathic (western) psychiatry, and religious healing (Halliburton, 2004). He discovered that "each therapy was found by some to be helpful and by others to be ineffective" (Halliburton, 2004).

While each treatment may be effective for subsets of the population, they are not all equally accessible. For example, a study in the state of Uttarakhand showed that there is a complete lack of access to talk therapy, and only 3% of the population is able to access anti-depressants (Mathias et al., 2015). The case of Uttarakhand can be expanded across the country: access to mental health treatment in India is very poor and varies tremendously from urban to rural areas (Reddy & Chandrashekar, 1998). As a way to improve access to mental health care in the Global South, the WHO's Mental Health Global Action Programme (mhGAP) was established, with an aim to "scale up services for mental, neurological and substance use disorders, especially for countries with low and lower incomes" (Ng et al., 2013). MhGAP is also working to bring together governments, policymakers, international organizations, and other stakeholders to form partnerships to improve mental health care in low and middle-income countries.

However, there has been significant critique of this scale-up approach and Western psychiatry's "foundational assumption" that a "mental disorder can be viewed outside of the contexts of society and culture…ignoring difference, diversity and cultural specificity" (Campbell & Burgess, 2012). Although some Indian women seek anti-depressants, Tribe (2014) suggests that treating depression pharmacologically is not effective at addressing the surrounding poverty, gender inequalities, and other structural inequalities, which are the source of the mood disorder. She suggests that perhaps a focus on poverty reduction would be more constructive (Tribe, 2014).

Furthermore, Summerfield (2008) asserts that training individuals in western biomedical models and silencing community voices may be potentially damaging. His research highlights the need to discuss the role of culture and community in treating

mental health problems and suggests that it may be more appropriate to view mental disorders "as complex socio-cultural responses to adversity" (Summerfield, 2012). Similarly, mental health models of care in the Global South that integrate components of a community's culture into a western biomedical model have been critiqued as approaches that only minimally incorporate non-western knowledge as opposed to creating "an equal partnership, with each cultural health tradition having things to learn from the others" (Tribe, 2014).

Further critiques of the dominant western model suggest that it assumes "a unidirectional flow of power and influence from active global agents to passive local communities, or from powerful psychiatrists to powerless patients" (Campbell & Burgess, 2012). This is cited to be problematic for two reasons: it ignores the ability of communities to use their own knowledge and resources to help themselves, and furthermore, it also "draws attention away from the potential for dialogue and partnership between global and local actors, in which communities would be able to advance their health and social interests" (Campbell & Burgess, 2012).

The burden of common mental disorders in women across India is immense, and a rapid response is needed. Communities must be able to self-direct how best treatment should proceed within their own social, economic, and cultural context. Particular attention to culture is needed in the case of Indian women's mental health, not only because dominant global actors can remove local stakeholder's agency in their own health but also due to the patriarchal dominance within Indian society itself, and women's current gender disadvantage. Instead of Global South models of care that only minimally incorporate non-western knowledge, it is clear that equal partnerships are needed, "with each cultural health tradition having things to learn from the others" (Tribe, 2014).

Indian Mental Health: Policy Context

India's mental health system is currently facing weaknesses that need to be addressed. At the national level, less than 1% of the health budget is attributed towards mental health service provision (WHO, 2011). This contributes to the current state of the

mental health system where only around 10% of the Indian population with psychosocial disabilities access evidence-based mental health services (Murthy, 2004). In terms of human resources, "India currently has almost four psychiatrists per million people" (Khandelwal, Jhingan, Ramesh, Gupta, & Srivastava, 2004). Furthermore, the majority of health providers are based in urban areas, and rural community health centres in some states face vacancies in specialist positions of up to 80% (Vikram Patel et al., 2015).

The public sector is unable to reach the demand for care, and therefore the private health sector provides the majority of care, which accounted for 70% of outpatient care in 2014 (Vikram Patel et al., 2015). However, the private sector is largely unregulated: one study in Madhya Pradesh uncovered that among sampled private-care providers, only 11% had a medical degree and only half had completed high school (Das et al., 2012a, 2012b). In terms of mental health training, physicians receive very minimal training and exposure in the field of psychiatry during medical school. This lack of knowledge leaves India in the position where "primary care physicians have an inadequate knowledge of the CMDs and are often unable to reach a correct diagnosis in such patients, since they are not familiar with the appropriate questions to be asked" (Chadda, 2015). As the majority of health care is financed privately (Khandelwal et al., 2004), treating CMDs causes tremendous out of pocket expenses for consumers. Depression, anemia and reproductive tract infections are the three most common health problems affecting women, however, only depression causes "catastrophic health expenditure" for women seeking pharmacological treatment (V. Patel, Chisholm, Kirkwood, & Mabey, 2007).

In terms of policies, the first national mental health policy was brought forward in 1982, with an explicit focus on integration and treatment of mental illness in primary health care, and community participation in the development of services (Jain & Jadhav, 2009). However, this policy was not systematically implemented. In 1996, the District Mental Health Plan (DMHP) was created, with an aim to provide mental health services to community at community health centre and primary health centre level, detect mental illness early, reduce stigma, and take pressure off mental hospitals (Alok, 2013). However, from 2002 to 2007, the DMHP was re-strategized into the National Mental

Health Plan, or NMHP (Jain & Jadhav, 2009). Even though depression has become one of the top five causes of death and disability in India (Khandelwal et al., 2004), the NMHP shifted priorities away from CMDs. Its aim was amended to focus on treating severe mental disorders and providing psychotropic medication (Jain & Jadhav, 2009).

These policies have left India with huge gaps in their mental health system. For example, the DMHP was implemented incompletely, leaving 529 out of 652 districts in India out of the policy's implementation (Ng et al., 2013). This leaves large populations without care. Currently, policies have largely ignored approaches to mental health that involve community participation or attention to local context. As Jain and Jadhav (2009) emphasize, "community participation and psychosocial approaches remain unrealized policy principles." Furthermore, current policies overemphasize the use of medication as the sole treatment plan, which leaves community psychiatry in a state where it has become "focused on the effective distribution of psychotropic medication" (Jain & Jadhav, 2009). In their ethnographic study *Pills That Swallow Policy*, these two prominent Indian mental health researchers address the symbolism of the psychotropic pill, stating that while "it initially embodies ideas of accessibility and participation, the 'pill' eventually achieves the opposite: silencing community voices, reinforcing existing barriers to care, and relying on pharmacological solutions to address psychosocial concerns" (Jain & Jadhav, 2009)

Community Mental Health

Over time, institution-based care has been proven potentially inappropriate and harmful, and a global shift towards community mental health (CMH) has begun (Wiley-Exley, 2007). This is particularly important in the face of recent programs in India that have reduced mental health treatment to "nothing more than the transport of psychiatrists to remote areas to prescribe psycho-tropic drugs to queues of patients" (Campbell & Burgess, 2012). New approaches are needed, and Jain and Jadhav (2009) suggest that mental health care provision in Northern India could be improved "through the promotion of a better understanding of local communities by health professionals." Current CMH

research, including the community readiness model and the CMH competence framework, described below, emphasize the pressing need for community engagement.

<u>Community Readiness Model</u>

A CMH program in West Bengal found that although their program had good results, not enough individuals were aware or interested in the program (Sahu, 2014). To improve this, respondents suggested that community members have more responsibility and overall involvement with the program (Sahu, 2014). As a way to involve communities further in health interventions, the Tri-Ethnic Center For Prevention Research created the community readiness model in 1995 (Plested, Edwards, Jumper-Thurman, 2006). Readiness, defined as "the degree to which a community is prepared to take action on an issue" is part of a model that aims to more effectively address a specific issue in a community by measurably examining the community's local resources, culture, and level of readiness. The model's focus is to build "cooperation among systems and individuals," while increasing "community capacity for prevention and intervention," which ensures community involvement in the issue (Plested, Edwards, Jumper-Thurman, 2006). Their argument is that the only way to create an effective intervention is to match it with the community's level of readiness for the intervention.

The community readiness model has many similar components to this research and its overarching framework (detailed below) in terms of addressing knowledge and collective action around the health issue. Dimensions of readiness include community efforts to address the issue, community knowledge of the issue, community attitudes around the issue, and community resources and efforts (Pested, Edwards, Jumper-Thurman, 2006). This model is able to "create a community vision for healthy change," and in doing so better understand local principles and values to amplify the success of an intervention (Plested, Edwards, Jumper-Thurman, 2006).

<u>CMH Competence Framework</u>

Campbell and Jovchelovitch, discussing the area of empowerment, believe it is a community level construct that begins with an assumption that "powerlessness or a 'lack

of control over destiny' severely undermines the health of people in chronically marginalised or demanding situations" (Campbell & Jovchelovitch, 2000). Under their definition, being able to cope in difficult conditions requires access to political, economic, or psychological resources (Campbell & Jovchelovitch, 2000). In low resource settings, these resources may not be available and therefore coping with life stresses becomes increasingly difficult, and eventually impacts health status. In response, concepts surrounding "community competence," "collective efficacy," and "sense of community," have emerged in the literature, highlighting the ability of communities to increase health-promoting behaviours and decrease stress (Campbell & Jovchelovitch, 2000). One of these concepts, Community Mental Health Competence, provided a framework for this research (see Figure 1 below).

Campbell and Burgess (2012) advocate for the importance of building community mental health (CMH) competence, defined as, "the ability of community members to work collectively to facilitate more effective prevention, care, treatment and advocacy." This framework includes three core dimensions: knowledge, safe social spaces, and partnerships for action (see Figure 1). Knowledge includes recognizing symptoms and accessing services, while safe social spaces focus on discussion and social inclusion in the community. Partnerships and collective action, the focus for this research, involves relationship formation, health-promoting behaviours, and collective action for mental health, all within the context of social and economic participation (Mathias, 2015). This framework inspired this study's focus on the impact of PSSGs on the *community*, and the possibility for PSSG discussion of collective action for mental health.

Figure 1: Framework of Community Mental Health Competence (Campbell & Burgess, 2012, expanded by Kaaren Mathias, redesigned by Vanessa Low).
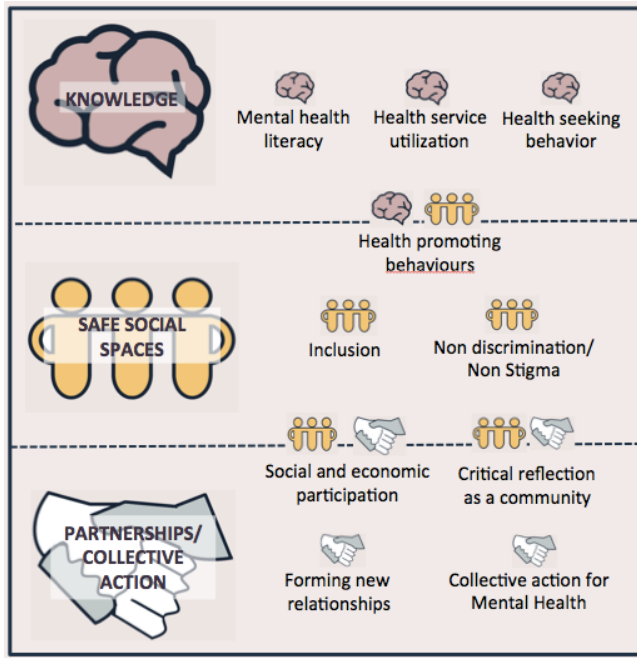
Psychosocial Support Groups in the Literature

Effectiveness of PSSG models

One review has been conducted on the effectiveness of mutual support groups, and whether they improve psychological and social functioning for those with mental health disorders (Pistrang et al., 2008). Of the 12 studies in the review, seven studies "reported positive changes for those attending support groups," two randomized trials found the groups equivalent to costly professional interventions, and five found no differences in mental health outcomes (Pistrang et al., 2008). There are two reasons why this review's results are less applicable to this PSSG research in India. First, this review only covered studies in the Global North where the resources and culture around care differ significantly. Second, the mutual support groups were run primarily by the members themselves and not a professional or external support, which differentiates them

from the PSSGs in this study. A deeper literature review below details PSSG studies in the Global South, as well as in the Indian context, to provide a background on PSSG effectiveness and previous research.

<u>Global South PSSG Studies</u>

The majority of studies providing PSSG or PSSG-like interventions primarily studied populations living with HIV (Kermode et al., 2008; Nakimuli-Mpungu et al., 2014; Smith Fawzi et al., 2012; Walstrom et al., 2013), mostly in African countries (Petersen, Baillie, Bhana, Mental, & Poverty Research Programme, 2012). Other ways PSSG studies differed was in the inclusion of a microfinance component using self-help groups (Cohen et al., 2012; Rao et al., 2011).

Several PSSG studies with populations living with HIV have demonstrated the effectiveness of PSSGs in their local context. Burgess and Campbell (2014) examined South African HIV-infected women's accounts of coping outside of medical support services, and the impact of social context. The women emphasized the importance of informal support groups they found in their community. These groups helped the women cope, and "offered emotional and practical assistance" (Burgess & Campbell, 2014). Another study developed a "culturally sensitive group support psychotherapeutic intervention for depressed HIV affected Ugandan adults" (Nakimuli-Mpungu et al., 2014). The study assessed the intervention's feasibility, acceptability and impact on depression, functioning, social support and self-esteem (Nakimuli-Mpungu et al., 2014). Over eight weeks, participants were given psychoeducation, learned to share and solve their problems, as well as acquired coping and livelihood skills. Within four weeks, they observed reduced depression symptoms and increased functionality. However one of the study's limitations was a lack of long-term follow up with the participants.

A third study explored the narratives of Rwandan women living with HIV. It examined how attending psychosocial support groups affected their mental health and HIV treatment (Walstrom et al., 2013). Results indicated "positive psychological and physical changes as well as behaviour changes in relationships with men, which

participants attributed to support group attendance" (Walstrom et al., 2013). This study had similar results to the PI's research in India, which will be unpacked in the discussion section. Lastly, one study in central Haiti examined the feasibility and effectiveness of a PSSG intervention for HIV-affected youth and their caregivers (Smith Fawzi et al., 2012). The groups, which were based on social cognitive theory, mostly focused on increasing coping skills and social support, using family-based components. Findings revealed both HIV-affected youth and their caregivers decreased psychological symptoms, and improved social support (Smith Fawzi et al., 2012).

Other Global South studies on group psychosocial interventions did not primarily focus on mental health aspects or populations with CMDs specifically. One Ghanaian study, run through the Basic Needs Programme, set up mental health self-help groups (SHGs), which were for both mental health and loan purposes (Cohen et al., 2012). They were similar to this research in that half of the groups were for caregivers, however only 4% of participants had CMDs, as the majority were individuals with epilepsy or severe mental disorders (Cohen et al., 2012). The program was successful at providing a space for mutual support both emotionally as well as physically, for example, helping fellow members to hospital. The caregivers involved learned from each other and increased patience towards those they care for. Although the above studies are different from the PI's research, learnings from other populations and world regions can be useful for understanding the potential impact of PSSGs, and what research still needs to be done.

Indian PSSG Research (and other Mental Health Interventions)

Within India, many studies have focused on individualized care interventions, as opposed to group interventions. These individualized studies include V. Patel et al. (2010)'s collaborative stepped care cluster randomized trial in Goa and Chatterjee's studies on community based mental health rehabilitation (Sudipto Chatterjee et al., 2014; S. Chatterjee, Pillai, Jain, Cohen, & Patel, 2009). Although Chatterjee's studies involved a primarily one-on-one treatment component, they also provided access to self-help

groups. Self-help groups improved social inclusion for people with psychosis through access to microcredit activities (Sudipto Chatterjee et al., 2014; S. Chatterjee et al., 2009). Another Indian study used ASHA (Accredit Social Health Activist) workers to provide individual counseling and support to women living with HIV. This randomized pilot study compared the outcomes of women receiving informational sessions on coping and stigma, nutritional information, and life skills classes, to a control group who received information solely about HIV/AIDS and how to be positive parents (Usual Care group) (Nyamathi et al., 2012). Those in the intervention arm were visited more frequently, and also received basic counseling and promotion of healthy lifestyle choices (Nyamathi et al., 2012). The study found that for the women in the intervention arm, it "significantly reduced their depressive symptom scores compared to the Usual Care participants" (Nyamathi et al., 2012).

Few studies have examined PSSGs (or similar interventions) in the Indian context specifically. One study in Eastern India of injecting drug use widows, many of whom were HIV-infected, created participatory action groups, which focused on mental health promotion and reduction in HIV risk behaviours (Kermode et al., 2008). The groups significantly improved physical and mental health: the proportion of those experiencing a common mental disorder decreased from 70% at the beginning of the intervention to 42% at the end of the 20 week (10 session) period (Kermode et al., 2008). Furthermore, the qualitative aspect of the study found that the "participants' quality of life, mental health, and experience of somatic symptoms improved significantly over the course of the intervention" (Kermode et al., 2008).

One study conducted in Karnataka, in Southern India is the most similar to this thesis research. Rao et al. (2011)'s study focused on women's mental health groups, however, the mental health intervention (group counseling and stress management) was combined with a microcredit economic activity. It found a reduction of psychological symptoms and an increase in social support, and argued for the addition of mental health components to livelihood activities to improve social and economic capital for poor rural Indian women (Rao et al., 2011). Although the study included mental health support

groups, the added microcredit activity differs from this thesis research, as well as the region (South India), and the population (no inclusion of caregivers). Both of the above studies demonstrate the success of reducing women's mental health symptoms through community-based mental health interventions in Indian women.

Depression: Cross Cultural Variations

When conducting mental health research across different cultures, it is extremely important to understand local meanings and understandings of mental health and illness. As Ethan Watters demonstrates in his book "Crazy Like Us: The Globalization of the American Psyche," an individual's symptoms of mental disorders depend on the context in which she or he lives. Men and women with depression in North Indian contexts experience symptoms significantly different to that of those in typical Canadian contexts. For example, many of the symptoms are somatic, such as headaches and backaches, and some women experience leukorhhea, a type of vaginal discharge. In an anthropological study, Dr. Karen Trollope-Kumar suggests that "leukorrhea may represent a discourse of distress…of resistance to social oppression…" (Trollope-Kumar, 2001). These distinctions in differences of symptoms across cultures are extremely important, considering Western psychology's use of the DSM-V. The DSM-V focuses on primarily mood symptoms of depression, and largely ignores somatic symptoms. This makes it in appropriate to be used to diagnose depression in contexts such as North India, however, many mental health studies fail to acknowledge and incorporate these differences.

It is equally important to note that the words used to describe depression or anxiety may not translate across languages and cultures. In this context, mental health was translated to "*mansik swastiya*" which is a literal translation in Hindi. Instead of using a translated word for depression, local community members referred to it as tension ("*tenao*" or "*tenav*" in Hindi), or used the English word "depression." Given the difference in ways depression and anxiety are expressed in North Indians, and spoken about, it becomes clear that treating mental health and researching mental health must also be fit within this local context. This is just one of the reasons why this study's

contribution to the literature is important, given the paucity of North Indian mental health research.

Contribution of Study to Existing Literature

There are other few ways this thesis research differs from previous studies. No previous studies have examined the impact of psychosocial support groups for Indian women with CMDs as well as their caregivers of those with CMDs. Furthermore, this research was conducted in Northern India, where the status of women is often lower than in Southern India, as kinship structures in the region further marginalize women (Bloom, Wypij, & Das Gupta, 2001). Overall, this study has several distinguishing factors: its investigation of participatory factors, its focus on caregivers, and its examination of PSSG's impact on the community.

CHAPTER 2: INTERVENTION AND COMMUNITY CONTEXT

Project Burans

Project Burans was a community partner in this research. Burans is a program of the Emmanuel Hospital Association NGO that seeks to identify people with psychosocial disability (PPSD), facilitate access to care, and deliver low-tech supportive community-based interventions. Project Burans began in 2014 and since then has been running several programs in communities, one of which is the psychosocial support groups. Other Project Burans programs include organization and facilitation of self-help groups that aid individuals in the community to begin micro credit saving and learn about banking. There are also community "corner meetings" that inform community members about mental health, as well as meetings with panchayat (local government) members and religious leaders. Burans also trains community health workers (CHWs) to deliver door-to-door information and counselling. CHWs counsel, refer, and accompany community members for care at hospitals. Burans has also developed excellent relationships with local hospitals and mental health professionals, which enables their own clients to receive prompt care. At the government level, Burans leaders Dr. Kaaren Mathias and Jeet Bahadu have been meeting with district and state government members including chief medical officers and the director general of health. They are lobbying the government for increased access to psychotropic medication in public hospitals, and training of health care workers in mental health.

Intervention: Psychosocial Support Groups

Objectives and Drivers for Development

The psychosocial support groups (PSSGs) run through Project Burans could be described using Pistrang et al. (2008)'s definition of mutual support groups: "a group of people sharing a similar problem, who meet regularly to exchange information and to give and receive psychological support." Project Burans created the support groups with

similar objectives: they aimed to develop a safe space for co-learning and sharing experiences, strengthen relationships and networks in the community, create opportunities for mutual and social support, as well as opportunities for collective action and livelihood.

There were several drivers for the development of Project Burans PSSGs. Burans staff felt that one to one counseling was counter cultural and that in this context, people would feel more comfortable sharing their learnings and experiences in a group. Furthermore, staff resources were limited, and therefore spending time providing psychoeducation and support would be best in groups. Lastly, the importance of sustainability was a driver: Burans wanted to establish community based structures that would remain in the community after Burans program funding finishes and they are no longer in the community.

Organization and Topics Covered

The women involved in Project Burans PSSGs are those with common mental disorders, or the caregivers of persons with psychosocial disability (PPSD). The groups were separated due to the difference in needs between caregivers and PPSDs. To clarify, female caregivers in the North Indian context are family members of those with psychosocial disability, primarily wives but also includes sisters and daughters-in-law. Female caregivers in this context suffer from psychological and social distress that is unique to their role as a *female* caregiver, and is not experienced by their male caregiving counterparts in these communities (Mathias, Kermode, San Sebastian, & Davar, n.d.). This makes female caregivers as a group, an important population to be included in PSSGs. Overall, caregiver PSSGs are more aligned to delivering broad training and support whereas PPSD groups were more aligned to help individuals cope with everyday tasks.

PSSGs involved groups of 5-10 women who meet for one hour every week to two weeks in their community. Normally, PSSGs meet in the houses of one group member, or on the grass outside houses when possible. CHWs organize the groups and gather the

women together every week. The CHW is trained in mental health knowledge, support group facilitation, and CMD counselling skills. The curricula of the support groups include 9 modules in the form of a flipchart. The aim is to work through the modules during the first two months. Each week a new topic is covered. As outlined by the flipchart Project Burans created called "Being Mentally Healthy in the Community," the guide covers the following topics:

1. Introduction: What is mental health, the story of Aruna and spheres of health (See Appendix for the Introductory session (charts 1-3), to see an example of the flipchart material. Text is in English here, however, the local version is in Hindi)
2. Spheres of control, and more of the story of Aruna
3. Tension, resilience and sleep
4. Kadam and positive thinking
5. Thinking in a new way about the past –forgiveness and benefit finding
6. Taking action for my own mental health
7. Taking action for mental health in my community
8. Depression - what is it and what contributes
9. Depression - how can someone recover from depression

After these modules are complete, PSSGs for caregivers specifically complete 9 extra caregiving modules. These modules include topics on: mental illness medication, how to treat someone with a mental illness, alcohol and health, stress, and self-care.

Strengths and Weaknesses of Each PSSG:

It is important to note that not all groups were able to stick to the above format and follow the curricula closely. For example, some groups only met once a month, and the group members varied (low rates of attendance). This was mostly the case at one site, whereas the other two sites had developed stronger groups. The same women met every meeting, often once a week, and sometimes even more often for enthusiastic groups. Some groups at these two sites had already independently selected leaders for their groups by the time they were interviewed. The women stated that if the CHW was not present, their leader would be able to call the group together. Other groups were not as independent, and relied almost entirely on the CHWs to gather and facilitate groups. The difference in the strength of each group may also relate to how long the group had been

running, as all the groups had been running for different amounts of time (see Table 2 in methods section). The strength of the CHW at facilitating the groups and enabling independent behaviour impacted the success of the groups, however, community context, gender norms, and religion also played a role. For example, Muslim communities had less successful support groups. Many of those interviewed confirmed that women in Muslim households had less freedom of movement, and therefore would have a more difficult time attending PSSGs, and developing independent groups. Following the publication of this thesis, a separate paper will examine the data gathered on the factors that affect PSSG independence, leadership, and long-term sustainability.

Study Population And Site Contextual Features

Study Population

This research was conducted in the Northern state of Uttarakhand. Uttarakhand's capital, Dehradun, is a large, bustling cite. The district surrounding the capital is characterised by vibrant towns, and productive green fields. The region is a major supplier of fruits, as well as the production of rice, wheat, barley, corn, mandua, and hangora. A profile of key socio-demographic features of Dehradun, Uttarakhand are summarised in Figure 1. Dehradun was one of three sites where this research was conducted, and represents the most highly educated, employed, and urban of the three populations.

Uttarakhand is one state particularly bereft of mental health resources, particularly due to its position in the North and rural population. There are a total of 7 psychiatrists in the state, for the entire population of 10 million people (WHO, 2006). There is currently no state-specific mental health policy in the state of Uttarakhand (WHO, 2006). In communication with Dr. Mathias, the PI learned that the National Mental Health Plan was approved in a limited form in all districts of Uttarakhand in September 2016.

Figure 3: Sociodemographic Features of Dehradun, Uttarakhand

Dehradun District, Uttarakhand State

Rural 56% 1.7 Million Urban 44%

Population

Male to Female Population Ratio

1000 902

78%

Female Literacy Rate
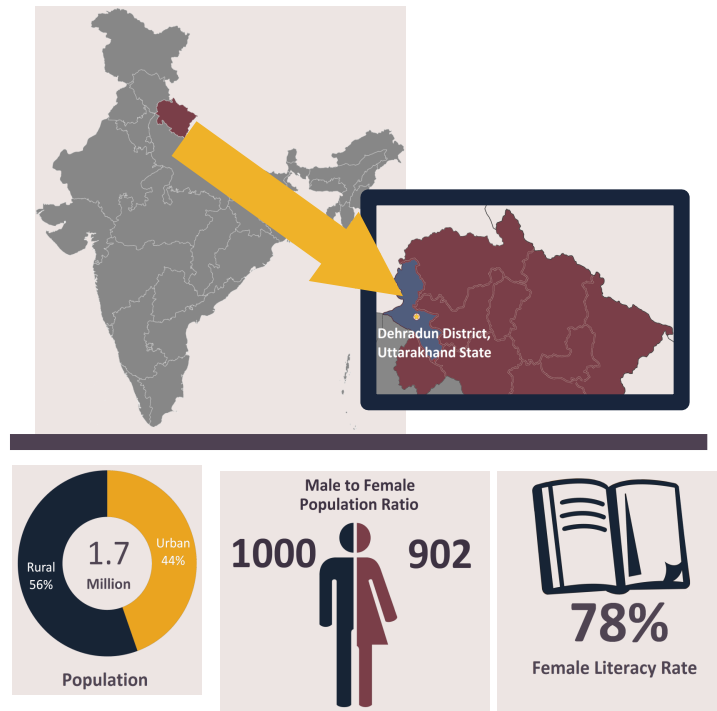
Site Contextual Features

This study aimed to examine a range of responses and therefore both PPSD and caregiver groups from three different sites were included. All sites are run with the support of a different NGO. Dr. Kaaren Mathias is the director of Project Burans and therefore supervises all sites, however, each site has its own project officer, and four CHWs. All of the staff members live in the community, and have grown up close by. The exceptions include Kaaren Mathias, who grew up between India and New Zealand, and Pooja Pillai, who grew up between Southern India and Uganda. Each site covers a population of 24 000 people, and therefore each CHW cover a population of 6000 individuals. The three sites were located in Mussoorie, Dehradun, and the plains of Sahaspur. Overall, all sites had a mix of groups where some women were employed and others were not. The older women (40-60 years old) in PSSGs were often uneducated, and the younger women (20-30 years old) had often completed primary or high school.

Across all three sites, there were more women with CMDs and more men with severe mental disorders. Additionally, all three sites have had the problem of NGOs continuously entering their communities, setting up unsustainable projects, and leaving, resulting in a community with little trust for NGOs. As a result, Project Burans has spent months building trust at these sites.

Mussoorie's site is located in a mountainous region, with the majority of groups within a one hour walk to the town of Mussoorie, a tourist destination with a population of over 30 000 inhabitants (Census, 2011). The PSSGs were run with the support (non-financial) of Emmanuel Hospital Association. The women in Mussoorie's PSSGs were predominantly Hindu. The second site was in Dehradun (capital of Uttarakhand), and is run by the NGO Organisation for Prosperity Education and Nurture (OPEN). This site was located in an urban area where women were often more educated than at the other two sites. More of the women at this site were employed, and some worked seasonally for six months of the year as brick makers linked with brick kilns. The women involved in PSSGs were a mix of Hindu and Muslim. The last site, Sahaspur, is a rural village area outside of Dehradun, located on the plains. The site is run by the NGO HOPE, part of the Agnes Kunze Society. The population in Sahaspur was predominantly Muslim, however PSSGs included Hindus as well. The women at this site's PSSGs were the least educated of the three sites. Their PSSGs met the least often, and were often the least successful. Three of the four CHWs at this site were male, as opposed to the other sites, where all the CHWs were female.

Figure 2: Mussoorie, Uttarakhand. Photo by Nicola Gailits

COMMUNITY CONTEXT

This sections draws from information collected orally while present in the local context, and not from the literature, thereby providing informal contextual impressions through the eyes of the PI. The information in this section was drawn from the FGDs that were conducted with women in PSSGs. It is also draws on the key informant interviews (KIIs) conducted with mental health professionals and Project Burans staff members. Lastly, this section draws on the PI's field notes from the three months she spent living, working, and speaking to community members around Mussoorie and Dehradun.

Daily Wage Earners

The majority of community members are daily wage earners, and therefore they do not have a lot of money saved, and are often managing costs day to day. In a KII with a psychiatrist, the PI asked why prescriptions are only given out on a 2-week basis. The assumption from a Canadian perspective is that this would be a waste of time to have to

return to the hospital every two weeks. The psychiatrist stated that because the community members are daily wage earners, they cannot afford to pay one or two months worth of medication all at once, and therefore the 2-week model works for them. However, the travel costs and loss of daily wages every time they need to go to hospital are not negligible.

Community Attitudes

Some participants interviewed stated that if other community members heard about the groups, they would only participate if they were to get something out of it, particularly of monetary value. Talking about the local mentality around participating, one psychiatrist reinforced that community members often frame their participation in this way. She said that community members often think:

> *"KII: Are you going to get us free medicine? Are you going to give us something free?"*

Other participants expressed that they felt community members would sabotage them or hold them back if something positive happens to them. One of the women in a PSSG revealed that she feels even if she wants to step forward and do something, there are community people around her that want to hold her back. She said this stops her. Although several individuals commented on this self-interested aspect of some community members, it is clear that this does not represent everyone, considering that those who participate in PSSGs are keen to work to improve their communities.

Community Attitude on Women and Gender Roles:

The difference in treatment between females and males in the community was apparent. KII participants agreed that women's role was to cook and remain at home. Participants acknowledged that times are changing, however, there is still unequal treatment. Generally, men are allowed to go out and return home when they desire, but women are questioned heavily if they leave home. Some women are employed but many remain at home, taking care of the house, leaving them to be quite isolated. Gender roles

were particularly strong in Muslim communities. One KII participant, speaking of women in the community, stated:

> *"KII: They work for the families from morning till night and do not have any time for self. Due to this whole confused state and lot of thinking, they go into "depression." They feel they have no one to talk to, no entertainment, they don't even stay long if they go to visit someone due to burden of work at home."*

Those interviewed believed that women in the community have little control over decisions in their lives. According to the KII participants, the majority of women do not feel ownership over their own health. If she needs to go to the doctor for example, her husband would suggest it and he would accompany her. One CHW emphasized the difference between how boys and girls are treated in terms of their health:

> *"KII: If something happens to the girls they say that no problem she will get better. If the girl gets fine after rest of 2 or 3 days, it is ok, otherwise they will be forced to take her to the doctor. But if the boy sneezes even, they will tell him to go and get medicines immediately."*

Community Mental Health Context:

This section's information was gathered from the KIIs with mental health professionals working in private hospitals.

<u>Mental Health Awareness and Stigma in Community</u>:

Some groups shared that community members around them do not know what their groups are about. Some community members consider that the women are wasting their time sitting and talking. However, women stated that what the community thinks about them is very important.

> *"GM: I think if an outsider says anything to them, they will not come."*

Before Burans came to the communities, most people did not know that mental health or mental illness existed. As one woman in an FGD says:

"GM: There was 'tension' in the mind but no one knew what this thing is. We did not have knowledge about it."

By the time Burans reached many individuals, some had been mentally unwell for several years. Women told stories of them or their husbands being in depression for the last 6-7 years. With little information of mental health, one common occurrence in the community is individuals trying to commit suicide with toxic pesticides, and often times ending up in the hospitals. The mental health professionals interviewed stated that this problem is due to a lack of skills in coping.

Lastly, there is significant mental health stigma in the community. Community members uneducated in mental health or those outside of Project Burans often refer to PPSDs as "paagal," meaning mad or crazy. Women in the PSSGs told many stories of being mocked in their community, and some PPSDs are excluded from community events such as weddings. However, other respondents reported that there was no problem of stigma in their community.

Causes of Common Mental Disorders

There are various social causes of depression in this context. According to the local mental health professionals, the top causes of CMDs include financial issues, a death or illness in the family, lack of support from husband, and poor problem solving or coping skills. The psychiatrist interviewed also cited social causes including families with high levels of poverty. This, combined with a lack of mental health knowledge can create panic symptoms and catastrophic thinking, without the necessary tools for coping. The psychiatrist also cited unmet female needs as a cause for CMDs. She talked about the emotional gap between the partners, whereby the women need emotional support from husbands, but their husbands believe that their job is mainly to provide financial support.

"KII: A lot attention seeking is there involved in that…Yeah I mean, because you don't get the attention in the marital relationship so there's an emotional gap between the two partners and that what is leading to these huge burden of anxiety and depression."

Lack of Access to Mental Health Care

Problems with access to care start with the lack of community knowledge around mental health. Normally, community members will approach traditional healers when they suspect mental illness. Some will believe that there are demons or bad spirits within the person who has the illness, and they will look to the traditional healer for help. After that, they may also visit a quack. A quack is someone employed and trained by the government, but has received very little training (less than one year). They are not meant to prescribe medication, but they often do, frequently causing significant damage.

The psychiatrist interviewed described the process of "doctor shopping," when patients begin to approach medical doctors for care. This "shopping" occurs when patients visit several doctors and have several appointments and tests done before they reach a psychiatrist or mental health professional. Once they are told to come to the hospital, it is often difficult for a woman to get there. Sometimes this will mean taking a day off work and traveling 1-2 hours, possibly more. This is difficult on the household, as the children will need to be taken care of. It is also difficult financially, due to the high cost of medical fees and transport. Furthermore, a lack of ability to plan and understand appointment times decreases access to care as women often arrive at the clinic at the wrong time. Lastly, those admitted to the state mental hospital can only do so if a family member stays with them at the hospital, and this is not feasible for many families.

Treatment Challenges

In of terms of challenges in treating the community, at the primary care level, there are problems with diagnosis. Many women present with exclusively somatic symptoms, as opposed to complaints of depressive thoughts. These somatic symptoms

may include headache, backache, gastrointestinal symptoms, and multiple other aches. Somatic symptoms often remain unrecognizable to local health care professionals in this context, and as a result, patients often only receive vitamins and orders to rest. This applies to the public hospitals, as it was the mental health professionals working at private hospitals recounting the above treatment challenges. There is also widespread lack of education on mental health, and difficulty convincing patients that something psychological is causing a physical problem. Furthermore, the community has a lack of ability to understand cognitive behavioural therapy (CBT). The psychiatrist interviewed emphasized that CBT is very difficult to use on populations with lower education levels (for example, those with no schooling, or some primary or high school) due to the complexity of understanding how to analyze one's own thoughts.

Systems Level Problems

Lastly, there are drastic problems at the health systems level. To begin, the availability of medication is very poor. For those able to access medication at the state mental hospital or public hospitals, they are often receiving the wrong drugs or doses. Patients are given a "cocktail" of low dose psychotropic medications including an anti-depressant, an anti-anxiety medication, a mood stabilizer and an anti-psychotic medication. Therefore someone with depression will end up receiving anti-psychotic medication, which is inappropriate for his or her mental disorder. Additionally, many patients end up with a benzodiazepine addiction. This is true within the public system, whereas the mental health professionals working at the private hospitals have had more training in psychiatry. They stated the above dose and medication problems are due to poor psychiatric training of mental health and health care professionals within the public system. Currently, there have not been trainings of mental health care at the primary health centre or community health centre level. Project Burans is lobbying the government to provide trainings.

This chapter has provided a detailed description of the context within which this research was conducted. It is clear that gender norms within the community restrict women's agency over their own health, and oftentimes leave them isolated in their homes. The community's lack of mental health knowledge, lower education levels, and poor training of mental health professionals creates a challenging situation for enabling treatment for psychosocial disability. Despite the difficulties present in the local context, the organization of Project Burans' psychosocial support groups offers a pathway to recovery for women at the community level. The next chapter will detail the methodology behind the study's examination of PSSG impact on the women and their community, beginning with research approach, followed by recruitment, data collection, and analysis.

CHAPTER 3: METHODOLOGY

This chapter will begin by examining this study's research methodology and approach, including ethics approval as well as the supervision and experience of the researchers involved. The recruitment of participants will follow, including a description of the local entry point, and the sampling of FGDs and KIIs. The largest section by far will address in detail the collection of data, first describing the process and limitation of the FGDs before turning to the KIIs. A section on data analysis will follow the data collection section. The chapter will conclude with a rich description of rigour in the PI's research, as well as additional ethical considerations that the PI thought were of note.

Research Methodology

Focused Ethnography:

This research used focused ethnography as the methodology, which is a type of ethnography that seeks to "understand the shared systems and meaning of a culture," with the assumption that "culture is learned and shared among members of the group, and that culture can be described and understood" (Secor-Turner, Sieving, Garwick, Spratt, & Duke, 2010). Ethnographic research is essential to understand and investigate "on the ground" views of marginal people in their "actual social, political, and environmental context," which is often "misrepresented and misunderstood by health policy makers and health professionals" (Ecks & Sax, 2005). Focused ethnography as a specific methodology can be used to "provide focused and efficient ways to understand complex issues such as cultural perspectives, behaviour and social context" in a relatively short period of time (McElroy et al., 2011). Thus, focused ethnography begins with a research question already established and background research prepared (Wall, 2015), as opposed to the more inductive aspects of classical ethnography. The methodology is "characterized by selected, specified, ...focused aspects of a field" (Knoblauch, 2005). (Higginbottom, Pillay, & Boadu, 2013). This methodology was very fitting for this research as it allowed for a short but immersive study of the culture and social context of women's mental health in Northern India. The research needed to be completed within

several months and therefore focused ethnography, with its focus on collecting large quantities of data over a short period of time, while paying utmost attention to context, was appropriate.

Community-Engaged Research Approach

Integrated into the focused ethnography, this study used a community-engaged research (CEnR) approach. CEnR focuses on "partnership development, cooperation and negotiation, collaboration with community partners and a commitment to addressing local health issues" (McDonald, n.d.). This means that it focused on building on the community's strengths and resources, working with the community, and disseminating knowledge across the community to all involved (Israel, Schulz, Parker, & Becker, 1998). Hacker and Taylor (2011) assert that, "a fundamental premise of community-engaged research is that community-based organizations have credible, legitimate, and intimate understandings of the assets, concerns, values and activities of their constituents and communities." This was a reason for which this research was partnered with a local NGO, to ensure a greater understanding and contribution to the community and its values.

Those within the CEnR community are calling for more culturally appropriate research approaches (Stacciarini, Shattell, Coady, & Wiens, 2011). For example, Chung et al. (2006) asserts that although some communities are aware of the need to discuss depression, shifting to a "wellness" approach as opposed to an "illness" approach was deemed more culturally appropriate. This research had similar aims, and made sure that the PI understood local mental health terminology and that those terms were used when interviewing women.

Ethnography and CEnR have different ways to approach research and therefore adaptations were introduced to merge the two approaches and avoid confusion. Succinctly put, *focused ethnography was the methodology and CEnR was the approach*.This meant that a focus on community collaboration, partnership development, and understanding community values framed the ethnographic research. This ensured that the PI did not simply enter a community to obtain data for research and then leave. As Mary McDonald

from Duke University states, "what characterizes community engaged research is not the methods used, but the principles that guide the research and the relationships between researchers and the community" (McDonald, n.d.). This means that having a "commitment to addressing local health issues" was a primary focus for the research, and doing so in a culturally appropriate way that pulled the community into the research conversation was the goal (McDonald, n.d.). This emphasizes the importance of partnerships and creating a strong relationship between the researchers and the local community members and NGOs.

Ethics Approval

This study was part of a larger research project that Dr. Kaaren Mathias has been conducting in relation to Project Burans' outcomes. Dr. Mathias' research protocol was submitted to the Emmanuel Hospital Association's REB for approval in 2015. The REB application was for approval for a study on community mental health competence, as well as to evaluate the effectiveness of Project Burans, by measuring outcomes in individual clients who participated. Ethics approval for this sub-study was obtained from both the Hamilton Integrated Research Ethics Board of McMaster University in Canada as well as Emmanuel Hospital Association (EHA) in India. The PI's name for this study was added to the research protocol Dr. Mathias had already submitted to EHA.

Supervision, Support, and Experience

This research was given appropriate academic supervision in order to ensure a high level of ethical and methodological rigour. While in Canada, the research was supported by the two MSc. thesis committee members, Dr. Lisa Schwartz and Dr. Elysee Nouvet. They solidified the study's qualitative methodology, clarified key ethical concerns, and provided guidance through the process of analysis and discussion. While in Uttarakhand, the PI worked with Dr. Kaaren Mathias, the Mental Health Programme Manager for Emmanuel Hospital Association. She has lived in Mussoorie for the last 15

years, and has significant experience conducting research on persons with psychosocial disability (PPSD) in the region (Mathias, 2015; Mathias et al., 2015). Her experience in qualitative research and analysis enabled supervision of the study, helping work through appropriate interview guides, coding, and analysis.

In preparation for the study, the PI took two research methods courses at McMaster University, one on health research methods and one specific to qualitative research. She completed the TCPS2 core modules on research ethics. She also spent three months learning Hindi, in Canada with tutors as well as at the Landour Language school while living in Mussoorie, India.

Recruitment

Local Entry Point

This study partnered with Emmanuel Hospital Association (EHA), one of the largest non-profit health service providers in Northern India. While in Mussoorie, the PI worked with Dr. Kaaren Mathias, the Mental Health Programme Manager of EHA's Project Burans. Project Burans seeks to identify people with psychosocial disability (PPSD), facilitate access to care, and deliver low-tech supportive community-based interventions. Project Burans began in 2014 and since then has been running several psychosocial support groups. The psychosocial support groups are separated into groups for caregivers, and those for PPSD. They meet anywhere from once a week to once a month, and include an average of 5-10 people. The participants in this study's FGDs were women in the psychosocial support groups. Although the PI had been learning Hindi, to ensure the highest level of comprehension, a female research assistant (RA) named Pooja Pillai joined the research team. Ms. Pillai has a Master's in Medical Sciences and lives in the community. Throughout this research and prior to the PI's arrival, Dr. Mathias had been training Ms. Pillai in qualitative research methods.

Sampling: FGDs

This research used focus group discussions (FGDs), key informant interview (KIIs), and participant observation, conducted over three months. FGDs were conducted with the women in the PPSGs. To access the population of PSSG women, this research used purposive convenience sampling. Given that the women were already set up in Project Burans' support groups, the study enrolled support groups into the study, and obtained verbal consent individually (detailed below). This was almost total population sampling, as the FGDs were conducted with nearly all of Burans' support groups. In terms of inclusion criteria, the research sought to include PPSGs that had been active for at least six months, to ensure groups were fully established and could reflect on the impact of the group. Individual inclusion criteria included: Hindi or Garhwali-speaking women, part of Project Burans support groups, with common mental disorders, and capable of giving their own consent.. FGD sampling also made sure a mix of caregiver and PPSD groups were selected in order for understandings from both types of groups to be collected. Lastly, FGDs were conducted at the three project sites of Burans to ensure a range of diverse participants and responses (see Chapter 2 for detailed site descriptions).

Sampling: KIIs

The PI also conducted key informant interviews (KIIs) with local mental health professionals and key members of Project Burans. These individuals were purposively sampled to get a wide variety of responses and a better understanding of the local mental health context. Dr. Mathias had a wide variety of contacts that she connected with the PI. In terms of inclusion criteria, the KIIs included women or men over 18 years old, consenting and able to participate, who spoke Hindi or English.

Data Collection

Overall, 10 FGDs and 8 KIIs were conducted. Participant observation supplemented the KIIs and FGDs.

Focus Groups: Data Collection Process

Ten FGDs were conducted, with seven unique PSSGs, representing a total of 43 women. FGDs lasted from 45 to 70 minutes. The RA, Pooja Pillai, was the facilitator of the FGDs, while the PI was present to observe the process, ensure two recordings occurred (in case one was lost), and enable the FGDs to conclude in a timely fashion. The specific process of conducting FGD is detailed below, adding from notes written while in the field.

Before FGDs

Before arriving at the field site, the PI created an interview guide for the FGDs in Canada, with input from Dr. Mathias as well as Canadians with knowledge of the Indian context. This first guide was not specifically about support groups, but more about women with common mental disorders, and collective action possibilities. After ethics approval was given, and the PI arrived on site, the first month was spent getting to know the community and Project Burans' work. During this period, the initial guide was tested out on three separate support groups. The first preliminary FGD was conducted by one of Burans' project directors, an individual with significant facilitation experience. This gave the RA a better idea of how best to conduct FGDs. The PI made sure to visit the support groups the week before FGDs, in order for the women to get to know her.

After completing the preliminary FGDs, it was apparent that the first guide did not fit the context fully, and there were other areas of research that would be more useful for EHA and Burans. After discussion with Dr. Mathias on study areas that could benefit Project Burans and a few informal interviews with project workers and officers, a new FGD guide was created. The revised guide included 12 questions that covered: positive/negative impact of the support groups, factors that enabled PSSG success, how the support groups have/could in the future enable collective action, how to improve future support group formation, as well as questions around group ownership, group leadership, and long term sustainability of PSSGs (To view, see appendices). The guide was translated to Hindi, and then checked by the Project Burans project officer. Prior to

this research, Burans had not conducted any evaluation research on the support groups.

Based on the preliminary FGDs, adjustments were made to the FGD process. The PI and RA scrutinized the way questions were asked, with a search to eliminate any leading questions, as this had been a problem in the preliminary FGDs. The PI and RA learned the importance of integrating a lengthy debriefing after each FGD. The preliminary FGDs also gave the RA a chance to increase her skills at facilitation, and taught the PI about the realities of the field and what questions would be feasible.

During FGDs

On the day of the FGD, the community health worker (CHW) who leads the support group gathered the women together to meet the RA and the PI. All groups at the Mussoorie site had previously met the PI at least once (sometimes twice), whereas FGDs at the other two sites had not yet met her. This was because the PI was living in Mussoorie and therefore access to these sites was more feasible. To ensure privacy and accessibility, participants gathered in the houses of the one of the group members, and the CHWs ensured only group members were present. Prior to arrival at the home, the RA met with the CHW to explain the study's details and ensure the CHW understood the questions being asked. This helped improve the research for several reasons. The RA was not 100% fluent in Hindi, which meant the CHW could explain anything unclear. This also enabled the CHWs to help probe the group members for answers, and assisted the RA in improving her own explanation of the study questions.

After the women arrived, the RA collectively informed the women of the study's purpose and obtained oral informed consent individually, addressing any questions or concerns (To view consent form, see appendix). While written consent is an accepted process in community groups with high levels of education, the community groups engaged in this research often had limited literacy. Oral consent was therefore the preferred strategy for women participating in the FGDs, as it was more culturally appropriate and less threatening for participants. Informed consent emphasized the voluntariness of participation, confidentiality, the use of a voice recorder, and assurance

that participant's data were to be anonymous. Next, the demographics of the group were obtained (see **Table 1** below). Next, the twelve FGD questions were asked. At the end, the RA asked the women to share the most important points discussed today, and then she gave them a chance to ask any questions. As the questions were asked, the women were handed cold drinks and samosas to compensate them for their time (for more on compensation, see ethical considerations section).

After each FGD, the PI and RA debriefed with a tape recorder for 10-30 minutes, discussing the most important points, improvement plans, and ways this group was different to others. The personality of the RA helped make the women participating feel more at ease. The RA made sure the women understood that there would be no future consequences for them after sharing, in terms of access to Burans services. She put them at ease by showing them that she herself does not know everything about mental health, which provided a welcoming and inclusive atmosphere. She got along well with the participants, made jokes, and got them laughing. Even without her jokes, many of the participants joked with each other throughout the FGDs.

After FGDs

All FGDs at one site were completed within 24 hours of each other. Gaps of one to two weeks between the three sites enabled the PI to have time to refine the questions to improve ease of response and comprehension. The first round of FGDs included two FGDs each at Dehradun and Sahaspur sites, and three FGDs at the Mussoorie site. After this first round, a round of member checking was initiated to confirm the preliminary themes that were generated and to ensure that the research correctly represented the participants. One member checking FGD was conducted at the Mussoorie site and two at the Dehradun site. The Sahaspur site was not followed up with due to time constraints, and the fact that many of their support groups were newer and less successful.

After the various rounds of FGDs, recordings of the groups were sent for translation. After trying out several translators, one woman was selected because of her in depth knowledge of English, after completing her MSc in the Netherlands. She

transcribed and translated the recordings directly from oral Hindi to written English. Although a two step process including a first transcription of the recordings from oral Hindi to written followed by a translation to written English was considered, the time and cost were not feasible. With help from a book on proper transcription and translation, the PI instructed the translator to leave specific Hindi expressions written in Hindi, not to correct grammar, and to leave mental health words written in Hindi, among other instructions. After written transcriptions were complete, the PI instructed the RA to check the transcriptions to ensure they were translated correctly.

Table 1: Focus Group Discussion Demographics

FGD Site / #	Date	caregiver /PPSD	Age range	Months since group start	Meetings / month	Members Present/ Total	Education level: NS=no school, PS=primary school, HS=high school
DEHRADUN 1	17.06	Caregiver	15-50	2 months	2	7/9	Some NS, some HS
DEHRADUN 2	17.06	Caregiver	18-60	8 months	2	10/15	Most NS, few PS, 2 with HS
MUSSOORIE 1	21.06	Mixed	35-50	5 months	2-4	6 / 6	Some NS, some with PS or HS
MUSSOORIE 2	21.06	PPSD	25-70	8-9 months	2	5 / 5	Some NS, some with PS or HS
MUSSOORIE 3	22.06	PPSD	40-60	6-7 months	2	3/5	1 NS, 2 HS, 2 unknown
SAHASPUR 1	27.06	Both	35-50	7-8 months	1	5 /20	4 NS, 1 with university
SAHASPUR 2	27.06	Caregiver	16-35	5-6 months	2-3	7 / 20	N/A

Focus Groups: Limitations

There were many limitations of the FGDs and it process. To begin, the RA is not completely fluent in Hindi as she is from a Southern state where Malayalam is spoken. This meant that sometimes her phrasing of questions was awkward, and the CHW had to clarify the question's meaning. This was one reason for which the PI ensured that CHWs understood the questions being asked before FGDs began.

Some topic areas the women had less desire to discuss or difficulty discussing. This included women's ability to leave the home. The RA was sensitive to different groups' abilities to answer the questions, as well as the safety of FGD setting in terms of whether answers were audible by other community members. Additionally, some

of the questions did not seem as well understood, for example the questions about collective action, and whether it is currently occurring in their community. In general, abstract concepts were difficult to grasp, particularly for those who have not been to school. For this reason, the PI decided to move this question from question one to the end of the FGD guide, to ensure that the women initially felt confident in their responses. Furthermore, it became apparent that direct questions such as "how did you benefit from attending these groups?" were often ineffective at generating answers. The women sometimes initially answered that the groups were not beneficial to them, however, when the discussion continued and other questions were asked, they would praise the groups and tell stories of the positive impact they have had on their lives. This was attributed to a lack of education, as Burans staff members and local professionals noted that it is difficult for community members to reflect critically on a topic without schooling. However, the lack of ability to reflect critically may also be attributed the lack of invitation or space within the community to reflect and share ideas on community strengthening. Many of the answers to questions were collected indirectly, in the course of asking other questions. Therefore, one way the process could have been improved would have been investing more time into the development of the FGD guide.

It is important to note that over the course of getting to know the women in the PSSGs, their answers changed over time. One group began by stating that they had no problem leaving the house, however, by the end of the fourth session with them, they admitted that they lie to attend the groups. In some groups, the women were too shy to answer questions, and one woman dominated in the discussion. In times where one woman began to dominate, the RA tried to ask other women in the group for their opinion. Overall, some of the groups were notably less successful, and therefore we were unable to obtain answers on successes and mental health knowledge from them. Similarly, a social desirability bias seemed to be present, as many of the women gave simple "yes" answers. To get around that, the RA was instructed to phrase more open-ended questions and ask for clarification. Additionally, the process of member checking helped clarify areas where only "yes" answers had been given.

One last set of limitations includes the changes in the setting that may have affected FGD results. To begin, Ramadan, the Muslim month of fasting, coincided with many of the FGD dates. Considering it lasts a long period of time, the PI could not remain on the ground waiting for Ramadan to end. In some cases, women who were fasting could only offer limited responses due to the lack of energy midday. The women made several references during the groups to hunger and inability to think. In order to help adjust for this, subsequent FGDs were scheduled earlier in the morning, and meetings were held in locations that were easiest for women with low energy to access. The member checking FGDs were completed after Eid al-Fitr (July 7th), and therefore the confirmation of themes was done outside of the fasting period. Furthermore, only one site had a majority of Muslim participants whereas the other sites were predominantly Hindu. A second change in the setting was the onset of the monsoon season. This had a less prominent effect on the research, however, some effects can be noted, such as difficulty understanding recordings taken during pouring rain (loud noises on tin roofs), and less attendance or delayed attendance of women at FGDs during rainy periods.

Key Informant Interviews-Protocol

Key informant interviews (KIIs) were conducted throughout the three-month period. Consent was also obtained verbally, in the same process as described above for the FGDs. In total, eight KIIs were conducted (see **Table 2** below). Three interviews were conducted with mental health professionals who work either with Project Burans or at a private local hospital, Lehmann Hospital in Herbertpur, Uttarakhand. One of the three mental health professionals was a psychiatrist, and one mental health nurse, and one counselor. Within Project Burans, one of the project directors and two community health workers (CHWs) were interviewed. Additionally, one PSSG member that had been selected as the leader for her group was also interviewed. Outside of Project Burans, the president and vice president of a Disabled Persons Group (DPG) in the community of Sahaspur was interviewed. The DPG is a type of NGO that provides meetings and services for disabled individuals in the community. They have had tremendous success,

building up to over 400 members. Despite their main focus on physical as opposed to mental disabilities, they were interviewed to provide context for the community, and understandings of how best to create and sustain community groups within the disabled population. They stand as a strong model for long-term sustainable community-based programs in Uttarakhand.

Participants were asked questions about women's independence in the community context, ways the community helps or hinders women's independence, the support groups' ability for initiating collective action in the community, as well as questions about successful support group formation process and sustainability (see Appendix for guide). KII questions were similar for all participants; however, some person-specific questions were added depending on the interviewee. For example, the DPG was asked questions about their own groups, before offering advice on our groups. KIIs were most useful for providing the context of the community, gender inequality, and barriers women face day to day. All participants were able to confirm that women are often unable to leave the home, and the limits to their participation in programs like PSSGs that this causes.

Table 2: Key Informant Interview Occupations and Interviewer

KII interviewee	Interview Language	Conducted by
Mental health nurse	English	Nicola Gailits (N.G.)
Mental health counselor	English	N.G.
Psychiatrist	English	N.G.
Project Director, PB	English	N.G.
CHW, Project Burans	Hindi	Pooja Pillai (P.P)
CHW, Project Burans	Hindi	P.P
President + VP of Disabled Persons Group	Hindi	P.P
PSSG, group leader	Hindi	P.P

Key Informant Interviews-Limitations

Due to time constraints, the PI was not able to meet with and get to know the KII participants prior to their interviews. This differed from the process for the FGDs. It was

deemed less necessary as the interview participants were highly educated professionals and were not uncomfortable in the presence of a foreigner. Interviews with the mental health professionals were conducted on a Sunday evening, when participants may have been tired, or less enthused about participating as this was during their limited free time. Half of the KIIs were conducted in Hindi by the RA, and the PI was not present for these interviews. This may have caused inconsistencies in the KII process. Without a foreigner present, this may have changed the environment for the participant, however, it is unclear what effect it had. None of the KII participants were compensated for their time, which represents an oversight in the research. Many seemed willing and eager to contribute to discussions of community mental health. However, if repeated, it would have been better to have offered the KII participants a small gift as a token of respect for their time. There was no need to compensate them for transportation, as the PI and RA traveled to their homes or offices to meet them.

Participant observation-Protocol

Participant observation, an essential component of ethnography, supplemented the FGDs and KIIs in the form of field notes. Field notes were drawn primarily from the first month that the PI spent visiting each site, and therefore including observations of families visited regularly by Project Burans, their surrounding community, as well as notes on Burans itself. The activities observed therefore included PSSGs, self help groups, home visits, and meetings between Burans staff members. Notes were also taken on reflexivity, and how the PI's social location affected how the data was analysed. Notes were written at the PI's residence, and not in front of community members.

Participant Observation-Limitations

The fact that the PI was studying the community members and later taking notes was not explained to them. This represents an ethical limitation to this research. Many of the notes were about visits to groups or home visits. As Burans employees worked hard to talk to community members in their homes, it did not make sense to bring up information

about the PI's future note taking intentions, as there were more pressing issues at hand, particularly when homes with family members with severe mental disorders were visited. Furthermore, among a community where some family members have never attended school, understanding the concept of "research" was difficult.

Data Saturation

The research did not involve a systematic examination for data saturation, however saturation was reached in both the FGD data and also the KIIs with CHWs and project officers. The themes across the member checking FGDs were consistent. By the time member checking occurred and the last two KIIs were conducted, no new themes emerged from either FGDs or KIIs. KIIs consistently confirmed themes generated through FGDs, for the most part without prompting or asking. There was no search for negative cases, which could have strengthened the data collection process.

Data Confidentiality

For this study, limited information on the women was required. No mental health records, full names, or addresses were used. In the group setting, the only individual question asked was around age and education level for demographic purposes. When recordings were transcribed, any reference to a specific person or name was changed, and thus the data was anonymized. Only the PI has the original voice recordings, in Canada.

Data Analysis

The data was analyzed using thematic analysis, as outlined by Braun and Clarke (2006). Mixed coding was used, which includes both inductive and deductive coding. The CMH Competence Framework inspired several deductive codes around themes of "collective action." Other deductive codes included "successful support group qualities," as this theme followed from questions that had been directly asked. However, some of the most interesting codes that emerged were inductive, including "going out" and "speaking

freely." Initially, the RA and PI separately coded three data pieces (FGDs and KIIs), and then worked together to create a combined codebook, which enabled input from both a foreign and local researcher in analysis.

Member checking occurred after an initial round of emerging themes were collected. After member checking, triangulation between the PI, RA, and Dr. Mathias allowed for a discussion of themes and position within the local context. After several meetings, an initial concept map emerged, outlining the top themes and their interconnectivity. These meetings occurred after less than half the data had been fully coded and therefore the PI had to be careful for premature closure not to occur. As the rest of the data was coded back in Canada, remaining open minded helped to expand and revise the concept map (see final version in results section). It is also important to note that the themes generated were not only a result of the KIIs and FGDs, but they also integrated knowledge and learnings from field notes and immersion within the community. Lastly, conversations were also held over Skype with members of the McMaster supervisory team, which aided the data analysis process.

Nvivo 11 for Mac was used to aid in the development of themes. A rich coding strategy was applied, and therefore, the same content could be coded into multiple categories or themes. Nvivo's memos were used significantly: for each FGD or KII, one memo provided context for the data, with the transcribed debrief between the PI and RA that had occurred directly after the data collection. A second memo was written as data was coded, to brainstorm main themes and ideas emerging from the data, and describe particular themes in depth. Once coding was complete, meetings with Dr. Schwartz and Dr. Nouvet guided new iterations of the concept map and connectivity between themes.

Rigour

Overall, rigour in qualitative research can be summarized into four areas: credibility, transferability, dependability, and confirmability (Baxter & Eyles, 1997). Credibility, which refers to the "connection between the experiences of groups and the

concepts which the social scientist uses to recreate and simplify them through interpretation" is the most important aspect of rigour in qualitative research (Baxter & Eyles, 1997). This research aimed to increase its credibility in several ways. The first way credibility was addressed was with persistent and prolonged engagement with the community, including the first month of the study that was spent observing the community and Burans programs. This was crucial, as Baxter and Eyles (1997) emphasize that "the goal of the researcher is to represent adequately the realities of groups in such a way that not only does the scientific community but also the people who constructed the reality in the first place understand the (re)construction of that reality." Secondly, purposeful sampling of information rich cases alongside an acknowledgement of power relations and efforts to decrease power differentials increased the credibility of the research (See reflexivity section for more on power). Efforts to gain rapport with women who were involved in FGDs as well as member checking with FGD participants were other important techniques used. Lastly, several methods of triangulation were used to increase both credibility and dependability. Data triangulation (use of different sources of information i.e. community members vs. program officers), investigator triangulation (use of different investigators for research analysis i.e. PI and RA), methodological triangulation (use of different qualitative methods i.e. FGDs, KIIs, and observation), and environmental triangulation (use of different locations i.e. the three separate sites of research) were all used. This diversity of triangulation methods and credibility techniques provides a clearer understanding of the local context and its realities.

As Baxter and Eyles (1997) write, "while a qualitative study may reconstruct meanings as they apply to the experiences of only a very small sub-group, it is possible that these experiences may be common to a larger group." Transferability to other contexts (also known as generalizability) was given attention with purposeful sampling as well as thick description. Thick description included in depth interviews and descriptions on the community context and gender norms and roles prevalent in the area. A third area, dependability, involves describing changes happening during the course of the study in

the setting, and how the research was affected by these changes. Dependability is "largely concerned with documenting the research context" and for qualitative research, focusing on "the interpretations and their consistency from one interview transcript to another" (Baxter & Eyles, 1997). The PI compiled significant notes throughout the research on FGD process, rigour, and step-by-step instructions for conducting FGDs to ensure consistency across FGDs. These field notes on process, along with audio recordings of debriefs and interviews, provide low inference descriptors that increase dependability. Dependability in this research was also addressed with peer examination by Dr. Mathias as well as triangulation, as mentioned above.

The last area of qualitative rigour, confirmability, tackles "the degree to which findings are determined by the respondents and conditions of the inquiry and not by the biases, motivations, interests or perspectives of the inquirer" (Baxter & Eyles, 1997). Understanding the investigator's own stance on the research is first step towards addressing confirmability. More specifically, confirmabilty was increased with the use of an audit trail that included field notes, journals on reflexivity, audio recordings, and re-examinations of data multiple times.

Additional Ethical Considerations:

<u>Compensation</u>:

When the study was submitted for review by HiREB, the protocol stated that women attending the FGDs would be given 80 rupees and a provision of chai (tea) and snacks as a token of gratitude for participating in the study. Once arriving in the field, Project Burans stated that paying the women to attend would be inappropriate. The women normally attend the support groups on a weekly or bi-weekly basis, and therefore paying them to attend them for these specific meetings worried the Burans teams as it may have set a precedent for future meetings. The women were not paid to attend the meetings, and were instead provided with samosas and drinks. Transportation costs were not relevant in this case as the meetings were held directly in the women's community.

Childcare

The FGDs were held during the same period that the women would normally attend the support groups, and therefore childcare was not addressed specifically. Normally, the support groups are held at the best possible time for the women, which is often around 11am, when women have completed their chores and children may be in school. In total, young children were only seen at one FGD. This research could have brought the issue of childcare to the forefront with further discussions with Burans, but contextual resources were sufficient.

Informed Consent

It is important to note the lack of ethical considerations at the level of the local organization (EHA), understood by the Burans staff members, as well as the participants themselves. Initially, this research was given approval by Emmanuel Hospital Association because it was deemed not to need ethical revision and approval. At the level of staff members, including project officers and CHWs, the lack of training in ethics was apparent. However, this mirrored the knowledge of the women in the community. Many of the women did not have an understanding of what research is, and so it seemed very difficult for the women to be able to comprehend informed consent. Although they consented individually, the lack of this knowledge seemed apparent. This is a difficult problem, though, as abstract concepts like "research" may be difficult comprehend without a basic education, and therefore understanding confidentiality and voluntary participation in said research may be stretching the limits of comprehension. Excluding these populations due to their lack of education would be equally unethical, and therefore it is important that these challenges are documented and strategies are discussed.

Risks for FGD Participants

The risks for women participating in FGDs were minimized due to the support of Project Burans. The CHW who leads the group was always present at FGDs, and is the

one who knows the women the best. If necessary, she would have been able to refer the women to the psychiatrist if that had been needed. Overall, the women did not seem upset or distressed by the topics covered, which may be because questions were focused on positive aspects of the PSSGs and how they helped improve the women's lives. One area of physical risk for the women may have been the lack of privacy for some FGDs. A few FGDs were held in houses where father in laws or husbands were present in other rooms. The discussion of women's ability to leave the home may have been cause for concern. Domestic violence is extremely prevalent in the local population, and therefore it is possible that if a male family member overheard these group talks, he may become angry at the discussion of women's independence, and this could make the wife more susceptible to violence when she returns home. The RA was particularly good at reading the environment and making sure not to talk about the role of males in women's freedom of movement while they were present.

Benefits for FGD Participants

The women participating in the FGDs seemed to enjoy the process of involvement in FGDs. It enabled discussions around leadership and future direction for the groups, which may not have occurred otherwise. It also enabled reflection on the importance of the groups, and demonstrated to some women the benefits of these groups that may not have been clear in their minds. Additionally, the women seemed to enjoy the visit from researchers. One support group expressed that they were glad that the PI came to talk to them. They felt that some of the people in their own community do not care about their mental health, so it was nice for someone to come to see them from so far away. The FGDs therefore may also have made the women feel important.

CHAPTER 4: RESULTS SECTION

<u>Summary Of Findings:</u>

This study examined the factors influencing women's participation in psychosocial support groups (PSSGs), and the groups' impact on the women and their communities. Focus group discussions (FGDs) with women in the groups and key informant interviews determined women's inability to leave the home to be the principal factor affecting participation. Other factors at the community, household, and individual level were interwoven with overarching gender inequality. Within the group, successful PSSG qualities included group unity and support as well as the ability to work together as a group. Groups with these successful qualities impacted the women in five main areas: PSSGs created safe social spaces for the women, increased their MH knowledge significantly, and improved their mental health. These three impacts combined provided increased confidence and knowledge, which enabled women to begin speaking freely in their community. Lastly, women found the PSSGs expanded their mentalities and everyday boundaries, often changing their roles from the ones who needed help to those who help others.

PSSGs not only impacted the women but also the communities around them. FGDs revealed women's desire to engage with their community, now that they had been helped. Women identified previous collective action that had taken place as well as future priorities for community action. In terms of impact on the community's mental health, women in the PSSGs explained that they were sharing their newly acquired knowledge across their community, and helping others access mental health care by referring and accompanying them to services. These findings have been represented in a <u>Concept Map</u> at the end of this section.

PART 1 GOING OUT: FACTORS INFLUENCING PSSG PARTICIPATION

The combined 18 focus group discussions and key informant interviews revealed factors that helped or inhibited PSSG participation. The primary factor found to influence women's participation in the support groups was their freedom of movement. If a woman cannot leave the home, she cannot participate. Therefore, this section will examine participation factors, but with an overarching thread that connects to the ability to leave the home.

We found three levels of factors—at the community, household and individual level. Community level factors included community mindset around gender roles and religion. The main household level factor found was whether the family gave permission for the woman to attend the groups. At the individual level, factors included distance from home, personal determination, a woman's education level, employment status, her ability to make time for the groups, and the benefits that she saw in the groups. It is important to note that the categories of community, household, and individual all overlap significantly and influence each other. The concept map at the end of the chapter represents this section's results visually.

COMMUNITY LEVEL FACTORS

The factors in the section are interwoven pieces of an overarching fabric of gender (in)equality. One cannot focus on one of these factors in specific to increase PSSG participation, as they are inter-related. However, separating them into distinct factors enables the examination of the specific ways in which the women are held back in the community.

Community Mindset on Gender Roles

"Group Member (GM): Even if we want to come, they stop us."

<u>Not Allowed to Leave Home</u>

Gender inequality is very deeply entrenched in the community. This is reflected in what the women say about the difficulty they have in leaving their homes and their role at home, as well as what local mental health professionals and program leaders commented. When women join the support group, they are going against the community's role for women, and therefore often community members look poorly upon the women who do it, and question why women are getting together in groups. This makes it very difficult for women to participate in PSSGs. It is particularly difficult for women to leave the house for the first time because family members question why she is now suddenly leaving the home.

> *"Community Health Worker (CHW): People feel bad and do not like it. They say that the woman used to stay at home and now these people are taking her out.*

Support group members acknowledged the deeply rooted gender roles that exist within their community. Women are required to be present at home at all times to take care of the family, cook, clean, and tend to family members' needs. Families do not like women to leave the home unless it is with a purpose they deem admissible. Those interviewed cited the male dominated society in India as a reason for the restriction of women's freedom of movement. One male interviewed shared that often men in his community blame their father or mother for the reason their wife cannot leave the house, when it is they themselves who feel their wives shouldn't leave.

> *"GM1: People do not like it if women go out and roam everywhere. They think whatever they want. We are not able to go out even if we want to. It is because of so many responsibilities at home. We come out only for some work and not without purpose (faltu)."*

<u>Community Suspicion</u>

The community is often suspicious of women leaving the home, questioning them

about why they are leaving. This suspicion holds great power in restricting women's freedom of movement in the community. One woman who's husband passed away wasn't allowed to leave the house now because her son thinks people will be suspicious of what she's doing. Other women told stories of being followed when they left their home:

> *"GM: Even if we go to temple, from there they follow us. That's why we feel scared in coming out (Tabhi hum nikalte hue darte hain bahut jyada). This is how it is in our community."*

Religion

Participants highlighted religion as a factor that influences women's freedom of movement. The three communities where PSSGs were set up had both Hindu and Muslim families. All respondents agreed that it is more difficult for women from Muslim families to leave their homes in comparison to those in Hindu households. Although it may be a little easier in Hindu households, it still remains a pertinent issue.

One CHW talked about a community and the influence of Islam:

> *"CHW: The Hafiz ji (Muslim religious leader) in their madrasa (Islamic school) said that this is not according to the religion; you should not wear such clothes, or meet and sit with such people* (women who discuss mental health in groups)."

HOUSEHOLD LEVEL FACTORS

Attendance Conditional on Family Support

The family had the ultimate decisions on whether a woman was to leave or not, and therefore, whether or not she could participate in the groups. The mothers-in-law or the husbands were deemed to be the primary decision maker. The size of the family was found to affect her freedom of movement. Those living in joint families with other elders found it more difficult to leave when all the elder women were present, whereas those in nuclear families had an easier time. Participants shared that in order for a woman to leave, other family members may need to help out with housework. Convincing family members

to do this can be difficult.

> *"GM4: First we will have to seek permission from our husband, if he allows us to go."*

Some of the families were in fact unaware the women were attending PSSGs. When asking women about leaving their house, often times the answers changed over the course of getting to know them. Initially, in many groups it seemed that there was no problem leaving the home and that families were supportive. When further probed, many women did indeed admit to having trouble getting permission from family to leave the home. When probed even further, women admitted to lying in order to attend the meetings. Some families did not know they were at the meeting. In order to come, they made excuses of needing to buy something and then came to the meeting instead. This demonstrates the lengths the women will go to in order to attend the meetings.

First meeting:
> *"GM: We have no difficulties from home. Husband doesn't say anything, who else will say."*

Second meeting:
> *"Facilitator: Did anyone stop you in the beginning?*
> *GM4: At home they say what more to do, help who you want to help."*

Third meeting:
> *"GM4/GM5 together: Our family always has problems. They really wish that we should not go for the meetings.*
> *GM4: They tell us not to go.*
> *GM5: We like it, so we come."*

Further emphasizing the significance of family approval, when asked how to help women be able to attend, the majority of participants emphasized that engaging the family is the most important approach. Therefore, gaining the support of families is one of the greatest factors to facilitate participation. Program leaders or other group members must explain to families the importance of the groups, how they will benefit the family, and how the family should support her. If the family agrees, then she will be able to attend.

When asked about how to engage the family, one CHW said:

> *"CHW: If someone like this comes, we can talk to them and explain the problems. We can ask them why they are not sending their daughter in law. We can make them understand that when others are sending the women to work, earn and empower the situation of the family, why are they not doing so? The situation in the family is bad, you live in poverty but still you do not want your daughter or daughter-in-law to work."*

INDIVIDUAL LEVEL FACTORS

It is important to note that many of the factors below cannot be disentangled from the household dynamics and community context within which they are set.

Distance

How far the women have to travel away from the home is a factor in whether she will be able to attend the group. Generally, women in the community do not travel far from the home unaccompanied. If they need to go to the hospital, their husband would accompany them. Some women can travel to the market alone, and those who have jobs, may be able to travel greater distances, even to other cities. They are generally not allowed out in the evenings, therefore PSSG activities must take place during the day. For this reason, having support groups that were close by made it easier for the women to attend the group, as they often didn't need to ask for permission when the meeting was in a neighbour's house.

Personal Determination

Women had trouble working against the gender norms in place in their community. Sometimes women mentioned that some families want women to leave but they themselves don't want to leave. They have already been told that their place is in the home, they may not want to create conflict, and if their family does not support it, it may be best for them not to come. Participants suggested that they might also feel guilty leaving.

Group members interviewed stated that women need a personal drive to leave the house. One CHW explained that for a woman who has never been outside her homes, the biggest hurdle is making the first step to leave. Many of the women we spoke to had strong self-determination, which helped them to be able to increase their freedom of movement, and thus participate. There is great difficulty in separating women's motivation to leave the home, from the community's gender norms. Women's gender roles may be internalized to the point where they will not give themselves permission to leave, and if they do, there may be consequences for them deciding to leave. Physical safety and PSSG involvement will be elaborated on in the discussion section.

> *"GM: It depends on us. If we make a decision to do something; then not just family, even an outsider cannot say anything. First our spirits should be high (Sabse pehle apne hausle buland hone chahiye). If we keep thinking ourselves that they will not allow us, they will interfere. But, if we said once that, we have to go, we have to go. We have to strengthen ourselves first."*

Employment and Income Contribution

Findings revealed that for those who can leave the home, they do it easily, but for those who have trouble going out, they often cannot do it all. This relates to whether a woman is working or not, since their families are used to them going out and do not question them. They may stay out all day for work, and attend the support group at some point that day. Therefore, for those with jobs, PSSG participation is much easier.

One of the topics discussed during interviews was the possibility of adding a micro finance component to groups. This would allow them to collectively save money as a group, learn about banking and saving, and discuss relevant work they could do. These are called self-help groups (SHGs) and they are common across India. Informants interviewed believed this addition would improve household income as well as provide a more valid reason for the women to leave the house. Integrating PSSGs with SHGs will be expanded on in a second paper to follow this one.

Making Time

One very important individual level theme found was "making time." Many women in the focus groups claimed that they do not have enough time to attend the groups, often citing their many responsibilities at home. Some group members stated that women *do* have the time, and that they need to make time for the groups. Making the time to attend PSSGs seemed connected to having the time management skills to organize themselves, as well as seeing the benefits in attending the group. The women who may have the hardest time attending were those working full time, however, they managed to make the time.

> *"GM: Nowadays everyone says they do not have time if they are asked to do something. They refuse saying they don't have time. But there can be time, if one tries for it, right. When we will take out some time, there will be time, else not. If they keep sleeping whole day in the house, how can there be time?"*

Seeing the benefits:

One project officer explained that women living in rural areas have lots of free time during the day. He believes that the women pretend not to have time, but if they saw the benefits of the group, they would have the time. This important theme will be expanded on below.

Organizing time

One aspect of making time is a woman's ability to organize her day and complete her chores before leaving the house. If women are unable to organize their time, the group crumbles; when one woman doesn't come, others don't come, and attendance is not consistent. This is not easy task, and is easier for women who have been educated.

Seeing the Benefits

The last individual level factor affecting women's participation in PSSGs was their ability to see the benefit in participating. It was only after experiencing the benefits that women were able to see the importance of the groups, their affect on the women's

mental health, and then to advocate for the creation of more groups. This was a significant theme in our research, and was the only theme not related in some way to women's freedom of movement or gender norms.

<u>At the individual level</u>

Seeing the benefits is important at the individual level to get women motivated to leave the home and attend the group. Participants confirmed that only once women see the group's benefits will they come out of their homes. Participants explained that if women explained the benefits to other families or women, it may help increase participation.

> *"Facilitator: What can we do to help the women in this difficulty? How can we help them to come out of their homes?*
> *GM1: We can only tell them the benefits, the new things we learn and do, by being part of this group."*

<u>At the household level</u>

Families need to clearly see the benefits of the group before women will be able to easily participate. It is important to note that mental health stigma within the community makes it even more difficult for women to leave the house, as this is often not considered a valid reason for leaving the house. Explaining the benefits can be a problem if families only want financial, not intellectual benefits to come from group participation, however starting by introducing the groups and their benefits to the women is an important first step.

> *"CHW: The main thing is when the woman comes to the group, she should know the truth about the support group as to what is the purpose of the group. The woman should know the benefits of the group; what she can achieve and where she can take herself through the support group. I believe that woman can speak with her parent –in-laws once she understands all these things about the group."*

Education

Education is an extremely important factor influencing PSSG participation. It connects directly to participation: those who are educated participated more often and

more confidently within the groups. They were able to see the benefits of participating easier, and had more ease in leaving the home to attend the group. Many female community members have never attended school. Others have somewhere between 6 and 12 years of education.

From observing the groups, it was clear that the educated women in the groups tended to be younger women, and those of the age of mothers-in-law often had never been to school. Those without education tended to wait to hear first from the educated women, and believed that the educated women were the ones most suitable in leading the groups forward. Those with less education mentioned how this made them feel shameful or less useful. When talking about attending the PSSGs, one woman said:

> *"GM: Uneducated people are not able to do many things so I come"*

This goes against the traditional power model within the community where mother in laws generally have more leadership and voice over those younger than them. In Indian society, elder women are normally given the most respect, and have more decision making power. In the PSSGs, this was not the case. Young women were often selected to be the leaders of the groups due to their education level and confidence. In one case, a widowed woman was the group leader, as she has learned to be independent and has gained confidence in decision-making.

Other women disagreed with this sometimes, and stated that uneducated women can be just as wise and gain just as much from the groups. One CHW said that initially, families never used to let their women out but now with increased education, their children are able to go out. There was general consensus that things are changing, and women are getting educated more and more.

> *"Facilitator: Ok. So what type of work is done in it? Can you all tell?*
> *GM1: We are uneducated. How can we tell about these things?"*

> *"GM1: Both type of people participate. Educated ones understand easily but the uneducated ones also understand some things. It is not that the uneducated ones do not understand anything. There are also wise people in them."*

Numerous factors affect women's participation in PSSGs. Education as one example, impacts the extent to which women feel confident in contributing to meetings. However, education also equally impacts women's ability to leave the home and independently access resources. Across all three levels, it is clear that addressing each factor mentioned above will help enable more women to participate, however, the overlap between factors is significant, and an overarching focus on women's freedom of movement represents an important step to move forward in this community.

Part 2: SUCCESSFUL SUPPORT GROUP QUALITIES

In order to be a successful support group, we observed that PSSGs must have group unity and support. This means they bond together, have unity and trust among members, and support each other. The other important quality in groups is being able to work together.

Group Unity and Support

The group members admitted that initially, they felt shy sharing their intimate problems because they did not know each other. They talked about how over time a strong bond grew between them. It was easy to see at group meetings: the women laughed together, held each other, chatted on the side, and appeared to be very close friends.

> *"GM: There were people in our group who we didn't even know, but a relationship developed after coming in the group. The group formed and we came to know each other, now we think that we work in this group and take it forward."*

The group members highlighted the significance of being supported by their fellow group members. Some of the groups even refer to their group members as family. They tell each other of their problems. When someone has a similar problem to others, the group is able to talk her through it and provide support. The women also mentioned that they support each other outside the group, for example, if one of them falls ill, they will take care of each other.

> *"GM: I have been in depression from past 14-15 years. After going through all that, I want some peace (shanti) but I was not having peace. It was increasing. When I met these people, it made such a difference that if anything happens to us, they are here to help us and will not let anything happen to us."*

For the women, unity was one of the most important aspects of the group. This included ensuring that everyone was on the same page about helping one another, and that decisions were made with everyone's consent. In order to have unity, however, there must be trust within the group. As the women shared their problems, trust grew among the members, and became a foundation for their group's success.

Working together

"When we sit together so much can be done"

Working together as a group, as opposed to alone, enabled the women to achieve more as a collective unit. They saw that the more people involved, the stronger and more powerful their group became. Group members emphasized how everyone's problems cannot be solved individually, and for this reason it is important to have a strong group that can work together. Working together is related to being united, as they must be unified to work together effectively.

> *"Interviewer: What is the most important thing that people have learnt by participating in a support group?*
> *GM: The most important thing is coming together and working. Making others understand and also understanding ourselves. Nothing can be done alone but, when everyone stands together, a lot that can be done.."*

Part 3: IMPACT ON WOMEN

"GM: We have undergone so much change (Kaafi badlav aaya humme)"

The PSSGs had several impacts on the women: they created a safe social space for women, increased their mental health knowledge, and strengthened their psychosocial status. These effects combined enabled women to feel they could now speak freely in their community.

Safe Social Spaces

The PSSGs created a safe social space for women to discuss mental health, in an area with high mental health stigma and gender inequality. This space emerged as a result of the success of the PSSGs: the strong relationships and trust the women built with each other. The PSSGs became a platform for the women to feel safe sharing intimate problems and stories they would otherwise not be able to discuss in their community for fear of being mocked.

> *"GM: Even if we live nearby to each other, we do not share our problems with our neighbours. We hide our problems from them. Here, we both are open and we can share all our problems. I know how they are and they know how I am."*

> *"CHW: We develop a kind of relationship and they feel comfortable to share their problems. They share the problems they have in families, about drinking habit of their husbands. Some have husband who drink and beat them or misbehave. Those women do not understand much, but they ask for our advice as to what they should do, how they should talk to their husbands."*

New Mental Health Knowledge

The PSSGs gave women the opportunity to gain concrete knowledge about mental health, given to them by CHWs who live or work in their community. First and foremost, they learned that mental health exists, the types of mental disorders, and their names. The PSSGs, which target persons with psychosocial disability (PPSD) as well their caregivers, were therefore able to provide information on how to handle depression and anxiety for themselves and for others.

> *"GM: We came to know about others' problems, what problems can happen to others, how they can be overcome, how we can help others, how can we bring someone out from bad habits."*

Awareness of existence of MH

For the women, learning anxiety and depression are real entities that can be treated and removed from their lives was significant. The women were able to state specific symptoms, understand somatic symptoms such as headaches, and how those relate to mental health. Additionally, the knowledge created a place for awareness

raising within and beyond the groups.

> *"GM: We got success because of this only that we got to learn everything. Now we know how this illness is, the illness that you teach us: headache and no motivation to work. Then we understood that this thing can really happen. We didn't know anything before."*

<u>Decrease in stigma:</u>

Gaining knowledge decreased mental health stigma. Women described previously feeling the need to hide their mental health from others, but now being able to discuss it, after having learned about it. Before, they used words like "*paagal*" (meaning mad or crazy) to describe PPSDs, however, now they say that instead of calling them names, they bring them to the hospital. Therefore, group members now also acknowledge the importance of using hospitals to treat mental health, and are not only pursuing care through traditional healers.

> *"GM: So ma'am, now we know because we are getting information from this. Now around us…we used to be scared (phle darr bhi lagta tha) and hid such things, that if we told someone they will say that he had gone mad (paagal). But now we can openly talk about it and share with each other."*

<u>Knowledge for caregivers and their households:</u>

Many of the groups have caregivers in them and they emphasize how much the new knowledge helped them take better care of family members. They believed that if they didn't have this knowledge, the mental health of those in their community would decrease and there would be more fighting within households. The PSSGs helped decrease tension in their home, and taught them skills in conflict resolution.

Strengthened Mental Health

> *"GM: We all meet like a group and our hearts get better"*

As a result of learning new knowledge about mental health, having a space to share their problems, and being counseled individually and as a group, the women's mental health improved. Many of the women previously depressed shared that they had recovered.

> *"GM: The group told us about mental depression. There were two or three women in the group who had mental depression and now they are fine. They succeeded in coming together in the group because they got better. They came out of mental depression and we achieved success."*

Out of isolation:

Women in this context often become very isolated in their homes due to their restricted freedom of movement. Those who are caregivers of PPSDs may be further isolated due to stigma in the community. Even before they gain knowledge in the groups, however, the very act of leaving the home was of great benefit. For the women, and widows specifically, the groups were a way for them to leave the isolation of being home alone all day, and provide them with a positive environment. This also helped them escape their thoughts and anxieties. One of the mental health professionals commented:

> *"They are very isolated. Extremely isolated and somehow the support workers got them out of that and into a support groups and that in itself has to be a good thing."*

The women described the change in their mental health as a shift from loneliness and tensions, to harmony and peace. They spoke of returned functionality in their lives, such as being able to work. Women linked their improved psychosocial state directly to the new knowledge. The more they learned, the better they were able to cope themselves, and with their family.

> *"GM: We are getting knowledge and we are feeling good."*

Talking to improve MH

PSSG members emphasized that the act of talking with each other lessened their depressive symptoms. They were able to talk through each other's problems as a group. Some of the caregivers explained how leaving the family members they care for and learning of others with similar or greater problems to theirs, gave them strength. The CHWs were instrumental in the process of talking through problems. They brought the women together and started the discussions. One woman describes how she was initially reluctant to share her problems with the group, but then realized that this was an essential

part of her getting better.

> *"GM: The good thing that we have learnt is that, when we talk with someone our depression becomes less. We feel good by talking with others and we feel good when we collect everyone and speak with them."*

> (Talking about the CHWs) *"GM: We tell our problems to them and they bring you all to solve our problems. They know our hearts, we keep talking and half of our illness has got better by this only, we don't need medicines."*

Speaking Freely

Women who had participated in the PSSGs described a newfound ability to "speak freely," which became one of the most important findings in this study. To begin, it could not have occurred without the above three impacts: new knowledge, improved psychosocial status, and safe social spaces (see Concept Map at end of section). Secondly, this theme must be described in the context of dominant female gender oppression. Women in this study's communities do not normally share their opinions openly in front of their family, and often remain silent in discussions. Being part of the PSSG affirmed to the women they had a voice to share. They started to feel the confidence to speak up. Furthermore, these groups gave women access to new knowledge, which was knowledge on a subject that no one else had in their community. This gave women the power to speak about what no one else knew about. As their confidence in speaking increased, they felt that they could now "speak freely." Although many factors influenced "speaking freely," it is mainly attributed to obtaining new knowledge and confidence.

Knowledge:
Group members recognized that because they now had specific mental health knowledge, they were able to share their opinions authoritatively when they knew something.

> *"Facilitator: So you were not sending people before this?*
> *GM2: First we didn't have this much knowledge (phle humko itna gyaan nhi tha).*
> *Facilitator: Ok*
> *GM2: Now we have some knowledge and have become open to talk. First we used to shy off that they have come, but now we can openly speak."*

<u>New Confidence, Hesitation Gone:</u>

Women shared that when they were unable to speak, it was because they were not sure what they should say, and whether it was correct. After participating in the PSSGs, the women stated that their "jhijhak" or "hichkichat" (roughly translates to hesitation) is now gone. This seemed to encompass the new confidence they have to speak and not feel shy doing so. Group members acknowledged that seeing other women speak in front of them helped them feel confident to speak.

> *"Facilitator: Many women said that they are able to speak openly after joining this group. Is it true?*
> *GM1: When some women sit together we can talk openly. We are illiterate and live in the village. I myself felt so shy (sharam) even to speak to women. Whether you believe it or not but I never spoke openly with my daughter. I felt so shy (lajja). My daughter-in-law speaks about everything with me. I was always shy and worried as to what to speak to whom. When we come to group we have some confidence and knowledge that we can speak openly with others."*

> *"GM4: They think that they should also speak. The things hidden within them are also coming out now. They are telling them.*
> *Facilitator: And what do you think?*
> *GM1: This is true; the hichkichat (hesitation) goes away by speaking to each other. Some speak less and some speak more, so it is good when they are made to sit together. Like she (pointing at some member), she never used to speak but now she has started speaking in group."*

<u>Effect on households:</u>

As a result of the groups, one of the CHWs shared that now when he visits homes, he sees a change in the household interaction.

> *"CHW: Now the women sit with us and speak openly when we visit them in their homes. Earlier, the husband used to speak with us and the women would go inside. Now both of them sit together and talk to us."*

New Horizons: "We saw this new world and we liked it"

The women stated that the groups transformed them, expanding their boundaries, creating a change in attitudes and behaviours. The act of joining women together into a group exposed them to new possibilities and created an awareness of the opportunities in

front of them. It began a shift in their mentality, their role in their family, and how they could affect change in the community. They were able to see what other women and families around them were doing, and strive to do the same.

One woman explained how her group expanded her boundaries and created new possibilities:

> *"GM4: Yes everyone said about not being able to speak openly before joining the group. It was because we used to live in a small boundaries (chote dayre) before this. But now, when we go out in the group we know each other and share our problems. The boundaries widened and we got opportunity to speak and learn. We came to know that other people have a lot of talent and learnt from them. The boundaries kept on widening and now we are no longer frogs in a well (kunwe ke maindak) [this is a Hindi idiom used to describe someone who lacks exposure]. We saw this new world and we liked it."*

The groups also provided specific exposures, encouraging women to pursue education and employment after seeing other women. For example, one woman found new employment opportunities. The women in her group helped her access a market to sell her stitching work.

> *"GM: There is one benefit in coming to this project. Some people's thinking is changing now. They saw me and said that they wished their daughters were also educated like me. So they could also attend meetings. They have two daughters who are elder and taller than me. They regret now that, if only they had taught their daughters, they would have been able to sit with everyone. Just seeing me made a difference to them and I didn't have to say anything."*

This quote from one FGD particpiant summarizees the transformation women went through, from learning about mental health, gaining confidence, sharing information, and now helping others. It highlights the women's change in attitudes around mental health, and the new behaviours seen as a result of participating.

> *"GM: We have become confident by joining the group. We did not know anything initially but came to know about it from the group. When we have become part of the group, now we have learnt how to meet someone and share problems. Then only we are getting information about this and are able to share the information*

with others also. We didn't know what 'depression' was and hesitated to tell anything to each other. Now we have information about it, we can tell you or anyone else about our problems without hesitation. We are also able to help someone around us if the person has some problem. We feel good and we like it that when we meet each other and talk, there will be some change and something good out of it."

Part 4: REIMAGINING ROLES AS COMMUNITY MEMBERS

Initially, many participants reached out to receive help from the PSSGs, relying on the support of their group members and CHWs. After having been helped, the women were willing and able to help others in their community suffering from common mental disorders. Group members found their roles as community members to shift from the receiver of help, to the provider of help. Once recovered, group members were then able to help those around them access mental health information and care. The women were excited by this powerful shift in their role within the community.

This finding was quite significant within the study. It demonstrates the possibilities for women partaking in PSSGs in Northern India. It stands as a bridge between the sections on "impact on women" and "impact on community" (see Concept Map). With one foot on each side, the reimagination of roles as community members for the women transforms both the women themselves, as well as their community.

"GM: We help them ourselves. The change in us is that we help others."

The women said that the learning process and participation in PSSGs changed them. They now have an element of authority in an area; they are a source of information. One woman mentioned that her neighbours come to her when they have a problem, with the hope that she has a solution.

"Facilitator: With whom all do you share this knowledge and information? GM4: I have also spoken with my friends, my family members and relatives. My neighbours immediately come to me when they have any problem, hoping that I might have some solution for it."

The knowledge created a place of action for them. They transitioned from needing help to providing support for others, and felt changed as a result. They are now in the opposite shoes, and able to help where needed. As one of the women says:

> *"GM: It felt good that we are not able to just help ourselves but others also. We can help ourselves and others after knowing about it"*

Part 5: CHANGE IN COMMUNITY

This section examines the impact of the PSSGs on the community. The initial impact on the community was an increased desire for community engagement seen in the participants, both in mental health and non mental health areas. After the initial increase in desire for community engagement, the section is divided into themes which are mental health related collective action (knowledge sharing and helping increase mental health care access) as well as non-mental health related (group based collective action). Broadly, the section examines the concept of collective action, and how PSSGs can enable community-based collective action.

Desire for Community Engagement

Gathering women from the community together in support groups created a desire for community engagement, and a realization of the importance of helping those around them. Group members noted that participating in PSSGs encouraged them to begin thinking as a collective group about the community's wellbeing, and less self-interestedly. Along with making time to come to the group, they have started making time to take care of each other.

> *"GM: First no one had time for each other. No one had time to visit each other. If someone came to the house, then they would ask about their well being and returned back. Everyone had to look after their house. but now we try and take out time for everyone."*

> *"GM1: First we had bad thoughts about ourselves and also for others. When nothing good is happening for us, what good can we do? Now we think that we are ok, when we meet people and do good to them, they will do good to us."*

The women talked about thinking of others in their community who they don't know, those less fortunate. Although they continue to struggle and are managing their own mental health, they showed a collective sentiment of wanting to give back to those around them, now that they have been helped. They recognized that many others may have the same problems as them and will benefit from these groups. The women also emphasized that if Project Burans is no longer around in the future, it is important that they provide support where needed. This is the beginnings of longer term community thinking. It was difficult to determine how much desire for community engagement was present before the study; this topic will be readdressed in the discussion.

> *"We were fortunate that we reached you, but, there are some unfortunate ones who hide their illness, stay alone and troubled because they are not able to meet anyone. What will they do? So this type of people who are helpless, they might join us by seeing our good things and how much better we are now, and think to themselves, maybe I can also get better."*

Formation of New PSSGs

The women stated that the next step for them would be to tell others to join their group, and to create new groups. This reinforces women's desire for community engagement, however, in the area of mental health specifically. Not only do they want to help those in their community, they want specifically to help other women who are in the same situation as them. They have faith and hope that if they work together and try, they can create other groups like their own. To begin, they want to help get other women leave their houses to join the support groups.

> *"We should also call those people who stay in their homes. We should make them sit with us and listen to their problems. Help them."*

Their desire to pass along the help that they received is related to them having seen the benefits of the group. They have been helped and seen what group work can do. Group members emphasized a desire to help other community members understand they can recover from psychosocial disabilities as well.

Knowledge Sharing

"Knowledge increases when you share it. (Gyaan to jitna baanto utna hi badhta hai)"

The next two sections reveal ways that PSSGs impacted the community's mental health, beginning with knowledge sharing. Women were not only learning themselves about mental health, but they were sharing the information they obtained in the PSSGs with the members of their community. Now able to "speak freely," they began teaching others in their community about mental health. The occurrances of knowledge sharing happened informally, on an individual to individual basis. They passed information on to close family members, friends, neighbours, and even distant relatives.

"Today we are learning, tomorrow we will teach others. Then we will continue ahead lessening…everyone's troubles will be lessened."

"We think that if there will be more people, more people will have knowledge, will help everyone and everyone can get cured (humto sochte hain ki jyada log honge, tabhi sabko knowledge hogi, sabki madat ho sakegi, sab theek ho sakte hain.)

They felt that if they worked together, they could tell everyone, and everyone would improve their mental health.

"Collectively everyone can be helped, treatment is possible, this should be told."

For the women, reaching the point where they could share the information they learned was a measure of the PSSG's success. It relates to their ability to speak freely, and encompasses current success with sharing as well as future needs for more sharing.

"GM: Success is that we are able to tell others"

"GM: We can visit every home and tell everyone, give information…then only we will get success."

Importance of official organization:

Women mentioned that the information sharing would only be possible with the help of Project Burans. This was due to the fact that they are working with a legitimate

organization. They felt that community members around them deem the information official and take them seriously.

<u>Breaking down stigma:</u>
      The women's sharing of mental health knowledge is one way to break down stigma around mental health in the community. They believed that the more groups are made, and the more mental health is discussed, the less their community will hide from it.

> *GM1: Because everyone runs for fever, but this illness is something which people feel shy of whether it will be cure or not (ye beemari aisi hai sab sharam karte hain ki hoga ki ni hoga).*
> *GM2: They keep sitting and hide*
> *GM2: Hide from this illness*
> *GM1: So we think that if there will be more people, more people will have knowledge, will help everyone and everyone can get cured (Humto sochte hain ki jyada log honge, tabhi sabko knowledge hogi, sabki madat ho sakegi, sab theek ho sakte hain).*
> *GM1: Everyone can be ok.*

Increasing Access to Mental Health Care

> *GM: "I observed him for some time and realized that he needed counselling. Then I spoke to my sister and she told me that she is troubled due to his condition from past 1 year. Then I told her to get him checked at community hospital once and I will accompany her. Then last week we brought him to the hospital."*

This woman, like many others in the PSSGs, learned to observe mental health symptoms, evaluate them, determine an individual needs help, and then accompany the person to the doctor. CHWs shared that the women are able to correctly identify psychosocial disability in community members. Some women refer individuals directly to the CHW, and others also go to the hospital with them. In this way, the women are helping to increase access to mental health care.

      Not only are the women passively observing, but they are taking initiative and actively seeking care for community members. Their ability to refer individuals demonstrates the strength of the women's knowledge of mental health. One woman connected her group's ability to improve the community's mental health with their learning to speak freely.

> *"GM: If someone is in depression we can ourselves tell them to go to hospital. We can tell ourselves or Radha or in neighbourhood that go. This is the good thing that we learnt that we speak openly with others.*
> *Facilitator: How have your thoughts about mental health changed after joining the group?*
> *GM: The change in that is that, when we meet mentally ill people (ise ki mansik log jab milte hain humko) we tell them to go to hospital or take suggestion from us."*

Increased community awareness

One CHW shared that most people have an awareness of Project Burans and mental health in her community. She stated that some women even refer people to her from other communities or areas. Therefore, the reach of the PSSGs is not just to their friends and neighbours, but can extend outside of the community. This demonstrates the ability of PSSGs to increase community awareness. However, considering Project Burans' work extended to other community mental health programs in these communities, we cannot claim that PSSGs were the sole source of community awareness raising. The risks and limitations of this outcome will be expanded on in the discussion.

Group Based Collective Action (non-Mental Health related)

One of the focuses of this research was in examining collective action for the community, how the PSSGs related to collective action, what kinds of action have been done in their community, and what priorities the women have for more future collective action. Although there was some confusion around the term, the women generally understood collective action as work done by the community for the benefit of the community.

The aforementioned theme "working together" is closely tied to collective action (This is represented by a dotted line on the Concept Map). As the groups became stronger and their ability to work together improved, they could achieve more as a collective for the community. The women gave examples of the power of working together for the community to advocate for their rights. For instance, groups discussed how if they went to the government officials together, they would have an easier time obtaining identification cards.

Some of the groups were able to identify future priorities for collective action. This included actions such as cleaning up the environment or creating new roads. One group was adamant that they must obtain their Aadhar cards, which is a form of identification that gives them access to government subsidies.

> *GM4: The responsible people, like the Pradhan in town or village, we can go and tell them the problem of the village. We can tell the difficulties we face due to the problem and we have to get rid of it. If we all do it together then it can be done.*

> *"GM 6: There is so much of waste thrown here and there in our village. Everyone throws the garbage in the neighbourhood and do not maintain cleanliness. Not just others but even we are part of it. So there should be something like people come together and cleaning of our village should be done. Then there would be cleanliness and clean environment. It will be so good then and people will not fall sick also."*

When we asked about collective actions already taken, women mentioned having helped get toilets in the community, having gone to the Pradhan (village head) for flood damage help, having taken community members to hospital, having filled ditches in the roads. In some of the communities, they were already achieving collective actions before the groups started, and others did not have the same level of a community mindedness. Some of the CHWs are teaching women in their groups things beyond mental health, such as advocating for their rights. For example, the women are learning to file RTIs (Right to Information): citizens file them and receive rapid responses to written queries about government services. One of the groups, now fully formed, has chosen a leader, and is progressing forward on their own without their CHW. They recognize the effect of these groups on their community and the importance of them remaining active.

> *"Interviewer: All that you have learnt, how will it be useful for the community? Respondent: Community is getting help from this because first they had to go direct for anything. Many things have been solved for the community, because of support group formation. The work that they had to do; they do it themselves through support groups."*

One of the project managers acknowledged that community change is most

effective if done through the women in the community, because they have the time, keep their promises, and are the most invested in their children.

> *"[The women] really want to, you know, develop themselves, and there's a desire to learn how to be good children in their community. So if they commit, they do it. And we have seen that whatever program we are doing with the women, the chances of success are high."*

Figure 4: Concept Map of Study Results
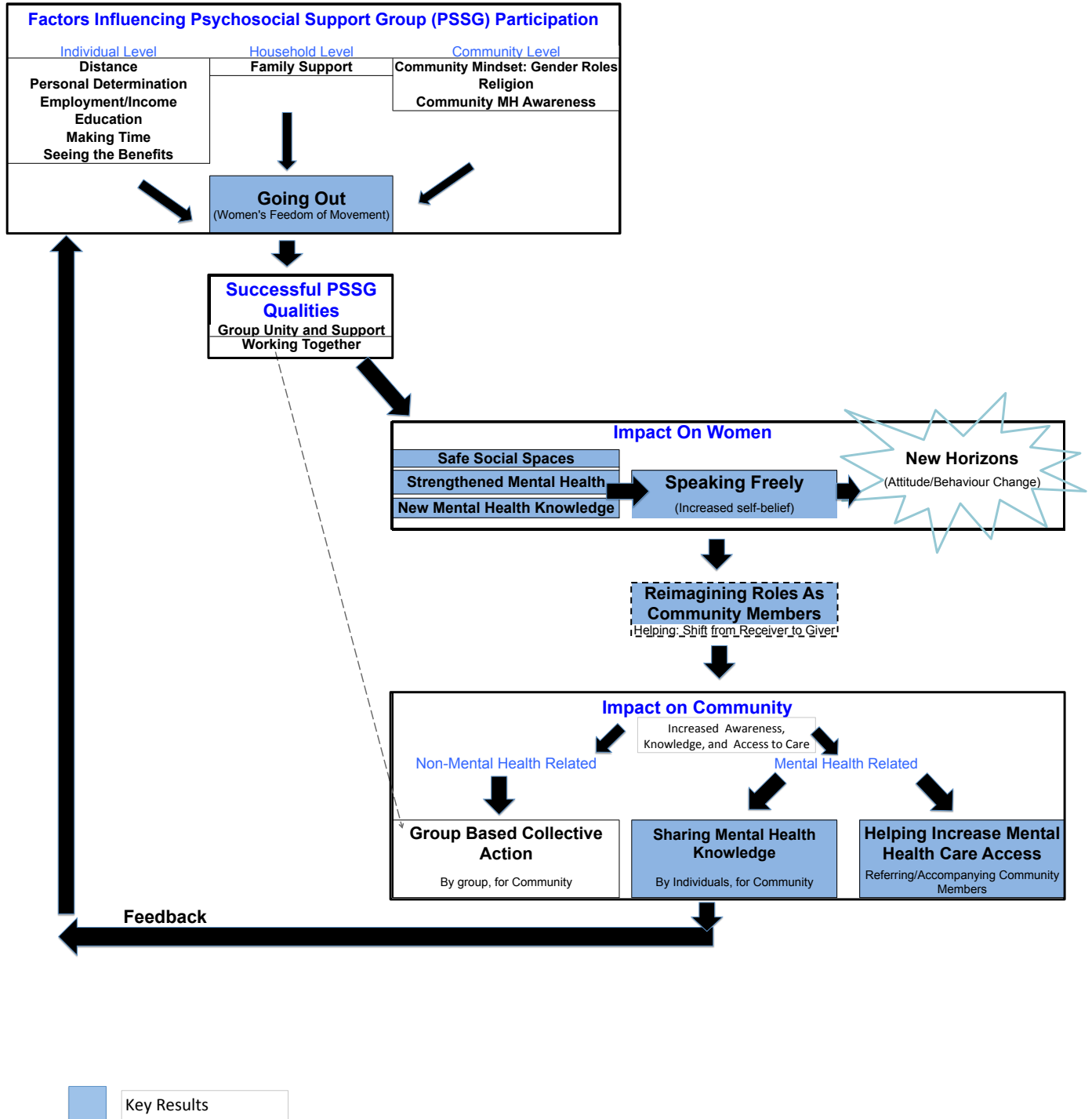
CHAPTER 5: DISCUSSION

The discussion chapter will begin by expanding on the way gender inequality is intrinsically tied to women's mental health in the North Indian context. The chapter will then turn its focus to compare this research with previous community mental health research that used PSSGs. A third section will examine the PSSG's impact on women, including the gender transformative aspects of the PSSGs. In terms of impact on community, this chapter will then broaden to a more theoretical and analytical level, incorporating Paulo Freire and Amartya Sen's concepts of conscientisation and individual capabilities. The chapter will conclude with considerations for further PSSG program use, along with the study's limitations, knowledge translation, and future research and policy recommendations.

In comparison to previous research on the topic, this study has several distinguishing aspects: its focus on Indian women using a group intervention as opposed to one on one counseling, the examination of factors influencing participation, and the investigation of the groups' impact on the community. No previous studies have examined PSSGs in Northern India, as the majority of Indian mental health research emerges from Southern states where the language, culture, and the state's mental health care system differ. In Northern India, the status of women is often much lower than in Southern India, as kinship structures in the region further marginalize women (Bloom et al., 2001). Research from Northern states is essential for capturing the contextual features that differ in providing mental health programs in this region.

I travelled to India to study mental health, and ended up studying gender inequality. In Northern India, mental health and gender inequality cannot be separated. From factors such as support group distance, to safe social spaces, to confidence gained, all aspects of the findings were rooted in the interplay of PSSG's impact on lives with the gendered production of those lives. For instance, *distance*, because women often were not permitted to travel far from home, *safe social spaces*, because there is nowhere women

feel they can discuss their mental health together, and *confidence*, because women are not supposed to speak up and voice opinions in this context.

This section will unpack a few key findings. To begin, this chapter will examine how the lack of women's freedom of movement impedes PSSG participation. From there, it will discuss the positive possibilities that PSSGs help to enable within the community: First, PSSG's role in strengthening community mental health, second, how the groups provide a gender transformative space resulting in women feeling the ability to "speak freely," and lastly, how PSSGs impacted not only the women but also the communities around them.

GENDER INEQUALITY AND MENTAL HEALTH: WOMEN'S FREEDOM OF MOVEMENT

One of our most critical findings was the extent to which women's lack of freedom of movement affected their ability to participate in PSSGs. Although numerous other factors affected participation at the individual, household, and community levels, none of these factors could be separated from freedom of movement. For instance, having a job or higher level of education necessitates leaving the home. Therefore, educated or employed women had an easier time being able to participate in groups as they were already able to leave the home to attend school or work.

Other studies have noted the lack of women's autonomy over their mobility across India. India's National Family Health Survey (NFHS) in 2005-06 found freedom of movement to be difficult for women across all parts of India: "Only one-third of women age 15-49 are allowed to go alone to the market, to the health centre, and outside the community" (Kishor & Gupta, 2009). Other studies found that between 71% (Mistry, Galal, & Lu, 2009) and 75% (Bloom et al., 2001) of women had to ask for permission to leave the home.

Worldwide, a woman's level of education is often one of the most important factors linked to her health. In our study, education was also found to be a significant factor affecting women's ability to see the benefits of the groups, be able to leave the

home, and feel confident participating. Although education is an essential factor, a North Indian study on women's autonomy found that "the impact of women's education on the use of maternal health care was roughly equal to that of their interpersonal control, as measured by their freedom of movement" (Bloom et al., 2001). Therefore, for the North Indian population, policies enabling increased freedom of movement may be equally or more important as those directed at improving education levels.

The importance of addressing Indian women's freedom of movement in order to address women's mental health cannot be understated. If women cannot leave their homes, they cannot participate in PSSGs, and thus cannot access the knowledge or support highlighted in the groups' success. Studies have shown how permission to leave the home affects access to health care. Mistry et al. (2009) found an association between permission to leave the home in rural India and pregnancy care service use. Bloom et al. (2001) studied an urban area of Uttar Pradesh (a Northern state in India), and found women's freedom of movement to be "a major determinant of maternal health care utilization among poor to middle-income women." Furthermore, one of the most important factors for healthcare utilization is the ability for women "to go where they wish, when they wish," and not only for them to be able to leave the home alone (Bloom et al., 2001). This is an important distinction for our study, as some women attended the groups but lied about it to their family. This indicates that some of the women attending the groups were allowed out of the home alone, but were not given permission to go where they wanted.

STRENGTHENING COMMUNITY MENTAL HEALTH WITH PSSGs

Research on effective community-based initiatives highlights the importance of understanding models for CMH services that build on local resources. In the context of rural Northern India, PSSGs helped women recover from depression or anxiety, and aided caregivers of family members with psychosocial disability. This occurred because of many factors: women were able to leave the isolation of their home, formed close bonds with group members, learned about mental health disorders and coping methods, as well

as were given an opportunity to talk through their problems. Women acknowledged that talking through their problems played a large role in their strengthened mental health. They described how the groups showed them that other women had the same problems, which made them feel supported about stresses in their own lives. Overall, participants described the change in their mental health as a shift from loneliness and tensions, to harmony and peace.

Despite the paucity of research on PSSGs in the Global South, one study of PSSGs for Rwandan women living with HIV found many of the same results as our study, with respect to the ways in which PSSGs improved mental and physical health. After participating in PSSGs, the Rwandan women reported sleeping better, decreased somatic symptoms, as well as a "return to health, work and normalcy" (Walstrom et al., 2013). Our study also found significant improvements in physical health, decreased somatic symptoms, and stories of recovery from anxiety or depression after group participation.

The process of mental health improvement was similar across the three studies. In Rwanda, PSSGs were also found to provide safe social spaces where the women were respected by one another, felt decreased loneliness and increased connection and unity, also to the point where they began to feel like family to one another (Walstrom et al., 2013). Rwandan women described the PSSGs as enabling strong new friendships and aspirations to help others with HIV (Walstrom et al., 2013). Similarly, in our study, women described the importance of the feelings of support from other group members, and how the strong bonds between group members created an environment women felt taken care of by one another. The Indian study of PAGs for widows also found that groups increased social connection and belonging, and provided safe social spaces for support (Kermode et al., 2008). The similarity between all three of the above studies demonstrates the transferability of this study's impact: across different populations, cultures, and regions of the Global South, PSSGs have been shown to strengthen women's physical and mental health. Lastly, it is important to highlight the changes in women's behaviours and attitudes that we found. Participation in PSSGs resulted in

women telling us about their increased use of hospital care, increased ease of speaking about mental health, and decreased household conflict due to better understanding of family.

PSSG IMPACT ON WOMEN: TRANSFORMED LIVES

<u>Reimagining Roles As Community Members</u>

One transformative aspect of participation in the PSSGs was that it enabled women to reimagine and recreate their roles as community members, which impacted the women as well as their community. After having been helped, the women expressed aspirations to help others around them also suffering from common mental disorders. They saw the benefits in creating supportive community networks. Initially, many of the participants were reaching out for help from the PSSGs, and relied on their support to improve their mental health, and as they recovered, some women no longer needed as much help. Several group members in each group were then able to help those around them access mental health information and care, while others had less time or interest to dedicate to this. Those involved spoke excitedly of this powerful shift in their role within the community, from a receiver of help, to a giver of help. Other studies have similar findings in the respect of increased desire for community engagement but have not taken this further. Walstrom et al. (2013) found increases in community helping behaviour from participants and Kermode et al. (2008)'s study also discovered a "reaching out" of the participants, involving an "awakening of a desire to help others in a similar situation."

The reimagination of roles for the women relates to Freire's concept of conscientisation. Conscientisation is "the process of constructing critical awareness about oneself and the world" (Campbell & Jovchelovitch, 2000). Conscientisation examines a person's ability to believe that she has power over her life course. Campbell explains that "people who lack the power to shape their life course in significant ways are less likely to believe that they can take control of their health, and thus less likely to engage in health-

promoting behaviours" (Campbell & Jovchelovitch, 2000). The shift noted by the women in the PSSGs, from a passive *receiver* of help to an active *provider* of help is similar.

Whether a woman will actively participate in PSSGs that help relieve her of anxiety or depression will be partially determined by her ability to believe that she can change her current condition. Initially, a woman may believe that controlling her life is completely out of her hands, which Freire calls the *intransitive* stage (Campbell & Jovchelovitch, 2000). Once she begins to participate in support groups, the space that is provided for mutual support and psychoeducation may initiate the beginning of *semi-transitive* change, where "people partly believe in themselves as motors of chance and to some degree they try to act in order to produce social change" (Campbell & Jovchelovitch, 2000). The PSSG program could be seen as a way to increase conscientisation in the surrounding community and the women who participated. Although this is true, we cannot forget that the power is not solely in her hands, and that there are numerous other gender-related factors that could likely impede her from accessing PSSGs. Whether it is in social support for each other, or physically escorting community members for care, raising consciousness levels of an individual's ability to change their own conditions represents an important first step for communities to help take on new responsibilities and choices to improve their health and strengthen their community.

Gender Transformative Aspects of PSSGs

Another significant area of PSSG impact for many of the women participating in the PSSGs was that it provided a gender transformative space. Despite living in communities with high gender inequality and mental health stigma, PSSGs contributed to increased confidence and mental health knowledge in the women, resulting in an ability to "speak freely." For some women, this resulted in an impact at the personal and household level. For example, one CHW reported a specific change at the household level. He stated that now when he visits homes, he finds women who were previously silent to be engaging in the family's discussions and decision-making. This means that

some women are starting to speak up in front of others, fighting against the community's gender norms that leave women out of discussions. Bringing the discussion back to Freire's concepts of empowerment, the act of speaking up and speaking out demonstrates a shift away from the *intransitive* stage and its feeling of powerlessness, towards higher levels of conscientisation where an individual "feels empowered to think and to act on the conditions that shape her living" (Campbell & Jovchelovitch, 2000). This important concept of speaking freely was also examined in a participatory action group study of the mental health of Indian widows (Kermode et al., 2008). The study very briefly mentioned participants' newfound ability to share their opinion in groups and "speak out," and the confidence it gave them (Kermode et al., 2008). Community based-mental health programs, and their ability to impact women in several gender transformative areas that should be further studied.

PSSG IMPACT ON COMMUNITY

Link to CMH Competence Framework

This study's inclusion of the PSSGs' impact on the community, founded on Campbell and Burgess (2012)'s community mental health (CMH) competence framework, allowed for an examination of collective action for mental health. The section of their framework "Partnerships for Action" involves local people being "aware of, and able to access, external organisations and agencies, including, for example, public health services, NGOs, charitable foundations, political groups" (Campbell & Burgess, 2012). In sharing stories of hospital use and care accompaniment, women in the support groups acknowledged increased awareness and access to mental health services. Furthermore, PSSGs were shown to provide a platform for women to gather together to achieve other community actions collectively, outside of mental health.

As part of the framework's "partnerships for action", Campbell and Burgess (2012) emphasize the importance of political participation and advocacy in the area of partnerships. They argue "against the common tendency for community projects to focus

too narrowly on building the knowledge, capacity and 'voice' of local community groups, without parallel efforts to create 'receptive social environments' in which more powerful groups are willing to listen to local peoples' needs and demands and assist them in achieving them" (Campbell & Burgess, 2012). This political aspect of CMH programs was not studied directly in the FGDs, nor was it revealed to be a central finding. Only one PSSG acknowledged the importance of the groups as an opportunity for collective action through political involvement: they described how collectively approaching their local *pradhan* (local governmental official) could help address and access environmental, educational, and governmental resources and services faster and more effectively. Further studies will need to examine local political powers and their influence on collective action for mental health in order to further assess how the CMH competency framework fits within this context.

Transformed Women, Transformed Communities

Skovdal, Ogutu, Aoro, and Campbell (2009) highlight how mental health research often positions those with psychosocial disability as helpless victims, ignoring strategies that could be used to cope and instead focusing on their distress. They emphasize how policies and interventions should focus on strengthening community support networks instead of increasing psychotherapy or drugs (Burgess & Campbell, 2014)

Our study demonstrates how community support networks can be strengthened: providing knowledge and support in the form of PSSGs can help women cope with anxiety and depression in their daily lives, as well as the community around them. Teaching the women about mental health also educated the community. The women emphasized their enthusiasm to share mental health information; as they saw it, the more people who know about mental health, the better it will be, as more people will be cured. Beyond sharing information, they began taking the initiative to accompany and refer community members for care. These are all types of collective actions for mental health that participation in PSSGs enabled, however, it is important to note that none of the community transformative aspects of the groups would be possible without the gender

transformative aspects, that is to say, without women being permitted to attend the groups.

Campbell and Jovchelovitch (2000)'s definition of social capital can be useful for understanding the community participation seen in this study. According to them, social capital includes "civic engagement or participation," a sense of community solidarity and strong local identity, and "reciprocal help and support between community members" (Campbell & Jovchelovitch, 2000). PSSGs helped to increase the social capital of the community in that women worked together, and built networks and leadership in a space where they could reflect on their health and begin to see a new way forward for their community. PSSGs also increased community organization and participation by bringing people together, creating a stronger sense of solidarity and support within community members. According to Campbell and Jovchelovitch (2000), "an important determinant of the success of participatory health promotional interventions is the extent to which they mobilize or create social capital." Therefore, PSSGs could be seen as important interventions in the promotion of mental wellbeing at the community level, while simultaneously addressing social capital.

Social capital and community empowerment are linked, and PSSGs can be seen as a way to increase community empowerment. Minkler and Wallerstein (2012) emphasize that the key to achieving real empowerment is focusing on having communities lead the change themselves. They define empowerment as "a social action process by which individuals, communities, and organizations gain mastery over their lives in the context of changing their social and political environment to improve equity and quality of life" (Minkler & Wallerstein, 2012). This definition emphasizes the element of control that is involved in empowerment, and in that way relates to Freire's concept of conscientisation. This is also addressed by Israel, Checkoway, Schulz, and Zimmerman (1994)'s community empowerment definition, which speaks of members using their skills collectively to meet the community's needs, resulting in "increased influence and control over the quality of life in their community" (153).

Notions around empowerment and control over one's life can also be connected to Amartya Sen and Martha Nussbaum's discussion of capabilities. Nussbaum (2001)

defines ten human functionings that are essential for wellbeing, one of which is control over one's environment (political and material). Similarly, Sen argues for a new approach to development that focuses on the expansion of freedoms, "seen in the form of individual capabilities to do things that a person has reason to value," including the freedom to choose and achieve (Sen, 2001). Models of community empowerment in Northern India will therefore need to address aspects of control in women's lives. Women will only be able to help transform communities if given the necessary freedoms to do so.

Building Awareness, Breaking Down Stigma

Three factors across the Global South as well as in India greatly affect the underuse of mental health services: this includes the lack of mental health knowledge and awareness (Kermode, Bowen, Arole, Joag, & Jorm, 2010), mental health stigma and discrimination (Corrigan, Druss, & Perlick, 2014), and the lack of skills in healthcare professionals to diagnose and treat mental health at all levels of care (Saraceno et al.). The collective action for mental health that PSSG participants demonstrated is significant because this can improve the community's awareness of mental health, encourage health-seeking behaviours, and help increase community access and use of mental health care. Knowledge sharing can help alleviate the high mental health stigma in Indian communities.

As knowledge sharing and accompaniment and referral to services by women in the community increases, these community-level changes will feedback into greater mental health awareness in the community. In turn, this may create a more supportive environment for women to attend PSSGs, and may enable them to leave the home for this purpose. However, this feedback loop emphasizes the importance of targeting women's freedom of movement, and its link to collective action for mental health. If women cannot leave the home to participate in the groups, this will disable their opportunity for collective action. As one woman in the groups shared with us:

> *"GM: How will we share with anyone when we don't go out?"*

CONSIDERATIONS OF PSSG PROGRAM USE

Beyond the way the groups were conducted, it is important to note the limitations of PSSGs as a whole. It is difficult to separate how much impact the PSSGs specifically had on the community, as opposed to other programs. Some study participants thought that most of the members in their community have some knowledge or awareness of mental health. PSSGs were not the only intervention in the community: the project included other programs such as community meetings about mental health, door-to-door information and counselling, as well as meetings with local government members and medical superintendents for the public hospital. Therefore, the increase in community awareness cannot be attributed solely to the PSSGs. Given that the PSSGs met on a regular basis and neither community meetings nor door-to-door visits occur as regularly, we have assumed that the change in the women's mental health occurred was due to group participation, however, this causality cannot be determined.

Despite the beneficial impacts discerned in this context, the effects of PSSGs in the future are uncertain, where PSSGs are implemented in communities that are not connected to a network of hospitals or mental health professional. If women gain mental health knowledge and understand they have a psychosocial disability but cannot access services for counselling or medication, this could be very distressing. It will set community members up to realize they have a problem, but they will not be able to be fully helped if they cannot access a hospital, or the hospital does not have medication available for common mental disorders, which is often the case in Uttarakhand. However, it is also unfair to the women in communities bereft of services to completely avoid these areas.

In terms of safety for the women participating, the effect of encouraging women to leave their home to participate in the groups must be considered. For women participating in microfinance groups, there is mixed evidence as to whether domestic violence increases or decreases with their new freedoms: studies have shown increases in some areas (Murshid, Akincigil, & Zippay, 2016) whereas other studies have shown decreases in intimate partner violence (Kim et al., 2007). Similarly, women's PSSGs must

examine the household effects and safety of women participating. Future PSSG programs should consider the possibility that women's absence from the home may upset her husband and increases her vulnerability to domestic violence. Thus, strategies to mitigate such risks need to be on the forefront of the program.

LEARNINGS FROM THE NORTH INDIAN CONTEXT

To return to the discussion in the introductory chapter on cross cultural mental health work, studies such as this one highlight the importance of understanding differences in symptoms, language, and treatment of mental health that vary across cultures and regions. The somatic symptoms women in North Indian contexts experience may be what Dr. Kirmayer calls "cultural idioms of distress." He emphasizes that "clinicians must learn to decode the meaning of somatic and dissociative symptoms, which are not simply indices of disease or disorder but part of a language of distress with interpersonal and wider social meanings" (Kirmayer, 2001). This is similar to Derek Summerfield's research that suggests that mental disorders should be viewed "as complex socio-cultural responses to adversity" (Summerfield, 2012). The social and cultural causes of depression that Kermode cited in the introductory chapter tie into this notion of "idioms of distress," given the immensely difficult context of gender oppression and poverty.

With Canada's extremely diverse population, it becomes more and more important for culturally appropriate care to be understood and examined further. A broken arm will look similar in every part of the globe, however, this is not true for mental health. Symptoms of depression are not limited to those that the DSM-V produces, and this is important for Canadian clinicians to understand. Furthermore, treatment of mental health should not only be limited to allopathic Western medicine such as anti-depressants. Research and time spent in India demonstrates that the importance of psychiatric pluralism should not be taken lightly. Every patient will respond to treatments differently, and in the Indian context, where individuals can access religious healing, ayurvedic

medicines, or allopathic medicine, research has shown that "each therapy was found by some to be helpful and by others to be ineffective" (Halliburton, 2004). Canadian practitioners could learn from this by widening the scope of their treatments and the options available for care.

Beyond diagnostic information, there is much for Canada to learn from community based mental health approaches such as PSSGs. With a great percentage of the population seeking mental health care and not enough psychiatrists to meet the demand, new approaches must be considered. While some would say that it is simple matter of training more psychiatrists, many researchers would disagree. We cannot afford to wait for more resources; we need new ways to address problems. For example, Vikram Patel's research on collaborative stepped care programs (V. Patel et al., 2010) point to one approach that is relevant across the Global North and South. Pairing this kind of individualized care with group-based approaches such as PSSGs may bring together Canadian communities, thereby improving individual patient's mental health and strengthening social networks and community bonds.

STUDY LIMITATIONS

To begin, discussing how the PSSGs impacted the women was often very difficult in cases where the women were too shy to respond, unsure of their answer, or possibly wanting to please us. Social desirability bias, when combined with a group of women often too shy to talk, meant that the answers we received were sometimes only composed of short "yes" responses. It was also the case that answers to questions changed over time, depending on how well we knew the group of women. One example, given in the results section, is of the group that initially said they had no problem leaving the house, but by the third time we met with them, they revealed that they had to lie to leave their home. Some of the groups we were able to visit two or three times, which enabled us to member check answers with the group and ensure the themes we generated reflected their responses. However, other groups we were only able to visit once. They told us directly that if we had come back a few more times they would not have been as shy around us.

Therefore, time was a constraint that limited our ability to follow each support group over a series of months.

Differences in language and culture must also be addressed. Although I spent three months learning Hindi and immersing myself within the community, conducting a study in a culture that is not my own has its limitations. In order to counter my lack of knowledge of North Indian culture, I made sure to triangulate my findings with Dr. Kaaren Mathias and Pooja Pillai (see more in methods section). Translations were done by the best possible community member available, however, due to the large amounts of data, there were passages where the meaning did not entirely translate. I did my best to have sections clarified by Pooja, however, there is always data lost in translation. Due to the nature of the study and the difficulty in asking women questions about gender inequality in their lives, more time experience speaking Hindi or living in the local context may have strengthened or even altered findings in some areas. Futhermore, this was my first qualitative study and therefore more experience would have increased the study's rigour. Lastly, there are limitations to our FGD interview process. The woman conducting the FGDs, Pooja Pillai, also works for Project Burans (the NGO's program). There are advantages to having an insider conduct the FGDs (see Methods section), however there are also drawbacks. The women may have been reluctant to share with us, or they may have believed that criticisms to the program would limit their future participation in the program (although we made sure to tell them that this would not be the case).

Monitoring and evaluation data from the NGO's PSSGs was not available to reinforce the study's results. As Cohen et al. (2012) write about their own PSSG study, "the lack of longitudinal, quantitative data makes it difficult to assess the extent to which participation in the SHGs has an influence on mental health outcomes." The same could be said about this study, and its lack of quantitative data to reinforce the qualitative findings. As pointed out by Kermode et al. (2008), without a control group, it is impossible to know the extent to which the program itself was what strengthened women's health. As they state, "the act of coming together may in itself have induced the

changes" (Kermode et al., 2008). Overall, other similar studies and programs looking to implement women's PSSGs will have more success if they ensure that the groups are embedded within other community mental health programs, and both qualitative and quantitative data are assessed.

KNOWLEDGE TRANSLATION AND DISSEMINATION

This study used integrated knowledge translation with Dr. Mathias as an integrated knowledge user, as her current project provided the PSSGs. During the study's completion, feedback on strengths and weaknesses of the groups were delivered to Dr. Maathias in order to help further focuses for strengthening themes and conclusions. The results of this research will be useful for the community, and future Project Burans interventions will be better able to understand approaches for increasing the participation of women in PSSGs. More specifically, strengths and weaknesses of particular groups as well as knowledge on the groups' impact will help Burans further strengthen its PSSGs. After completing the research, the PI generated a one page lay summary of findings that was given to Dr. Mathias. In early 2017, this summary will be returned to community members, CHWs, mental health professionals, Burans staff members, and any other participants. It will be translated in Hindi in order to be understood at the community level. Additionally, the PI created a one page document summarizing suggestions for PSSG improvements. These suggestions were generated from the KIIs as well as the FGDs.

Since completion, this study has presented its results in poster form at the Symposium on Health Systems Research, in Vancouver, Canada. The study's results were co-presented along with Dr. Kaaren Mathias on November 2016. The PI has also had her study accepted to the CUGH Global Health Conference, in Washington DC, where she will present a poster in April 2017. The PI also gave a one hour webinar of the study's results, along with a Q&A session, and how the results relate to health system strengthening. This was part of the PI's Queen Elizabeth Scholarship, and is available on

the McMaster Health Forum website for viewing (https://www.youtube.com/watch?v=qoUDmsBU33A). In the future, similar community mental health programs will better be able to argue for more resources to increase in PSSGs after completion of this research. Lastly, this research is aiming to be published in an international peer-reviewed in 2017.

RECOMMENDATIONS

The area of women's freedom of movement in India has been understudied, specifically in relation to the social determinants of mental health. Kermode et al. (2007) emphasize that Indian women's mental health is largely caused by cultural and socioeconomic factors such as child marriage, gender inequality, isolation, and poverty. Not only does an inability to leave the home cause isolation in this context, but it directly impedes access to already limited mental health care. Future research could connect our findings on women's freedom of movement with the social determinants of mental health.

Policies looking to increase women's economic participation must start at the level of gender norms in communities. The gender transformative aspects of our study signified an important first step for women's voices in North Indian communities. A woman's sense of competence and control as well as her mental health, is importantly linked to her economic participation and her ability to participate in decision-making (Kermode, 2007). Greater participation in similar initiatives may empower women to contribute to household and community decisions and participate economically, advancing both their health and social interests.

Community-based solutions like PSSGs can be instrumental in creating community partnerships, and should be looked to in order to strengthen current community mental health models. Ng et al. (2013)'s research examines principles of partnerships for community mental health (CMH) in the Asia Pacific. With a large mental health treatment gap and shortages of mental health staff in low resource regions, they emphasize that "there is an urgent need to develop mutual cooperation between multiple

sectors, including partnerships with families, service users, community agencies and links with the local governments." According to Ng et al. (2013), community groups can provide an important role in CMH partnerships. Given that "mental health professionals alone can deliver only a limited range of services" (Ng et al., 2013), PSSGs may provide a way to link communities with mental health care as well as share in the provision of care.

There is still significant work to be done on promoting community groups like PSSGs, as communities such as those in Northern India can have difficulty accepting the need for mental health care provision. However, PSSGs, as a type of community group, have one of the greatest chances of decreasing mental health stigma and being accepted at the community level. This is because community groups are "often the first contact point for help-seeking by mentally ill persons and their families" due to their reputation as "more culturally acceptable, more holistic and more accessible than the limited specialist mental health services" (Ng et al., 2013). Future research and policies should look to supporting culturally appropriate, community based models of mental health care. PSSGs can be used a model for other underserved communities, making sure to account for differences in local contexts. Lastly, PSSGs may offer support and pathways to recovery where there is little to no mental health treatment available.

CHAPTER 6: REFLEXIVITY AND CONCLUSION

Reflexivity

I have not lived a day in my life as an Indian woman, and I could never claim to understand the complexities or nuances of what it is like. Nevertheless, throughout my time in India, I felt some of the restrictions placed on women. Not feeling safe walking on the street. Having a man watch over you at all times, asking you where you're going and what you're doing. Feeling trapped. Being scared to travel alone. Although my experiences were incredibly challenging, they are not comparable to what life is like living as a rural Northern Indian woman with a psychosocial disability. At the same time, these experiences have influenced the course of my research.

As a woman conducting this research, my gender has brought with it significant preconceptions and perspectives, which can influence everything from my research question, to results and analysis. Someone else who was dropped into the community for a few days, or a male researcher, may have conducted different research. My strong values for equality, mixed with my personal exposure to local gender norms, created feelings of upset that may have influenced my research focus. For example, a different researcher may have seen this context and interviewed the male heads of the household for their opinions, which would have provided a different and important point of view. Although that would also be important research, my choice in focus on the women's voices was quite intentional. There are countless ways in which my social location, values, and beliefs, influenced my research. This section will recount a few stories to illustrate this.

About two months into the study, I began to see where my gendered notions led my research. I was conducting the FGDs with the PSSGs in Mussoorie and I felt that the male project officer should not be present for the FGDs. I thought that since we would be critiquing Burans, and possibly discussing topics such as women's freedom of movement, this might impede the women from feeling comfortable talking. At one FGD, I was

mistaken. When the project officer accompanied us to an FGD and I asked him to leave us alone, the group protested. They told us they would in fact feel better if he were to stay since they knew him well, and they did not know either the RA or me. This showed me how mistaken I could be in my gender-based assumptions.

In terms of my position, I came to the field as a young, white woman, of much higher socioeconomic status than the community women. I felt great discomfort as a white person working in the community. From my work colleagues to other Indian tourists on the street, everyone wanted to take a photo with me. At the beginning of my time with Burans, I asked the CHWs how the presence of a white woman would affect the FGDs. They believed that it would not affect the process. After visiting a few groups, I wasn't so sure. At one support group I visited, several of the women couldn't stop staring. The CHW asked the women how they were feeling that day, and one of the women said that she was glad that I was there. I took this an indication that I did not know them well enough, and that if I got to know them better they would see how similar we are. Even in full salwar kameez, sitting in the corner, I was the center of attention. To attempt to breakdown this barrier, I tried to have as much contact with the women as possible before the FGDs. Slowly, I believe, I succeeded at fading into the background of the group. In terms of the impact on my research, I wanted to be sure that the women did not answer differently with me present.

Although I studied Hindi for three months and learned to string together basic conversation, the women in the FGDs often spoke quickly with local slang, or in Garhwali. While I was present at the groups, I could understand very little of what was being said. This may in fact have played in my favour, as I wonder if the women would have responded differently if they knew that I could understand everything. Although unintentional, this may have been one factor that helped me blend into the background, and become forgotten in the discussion.

As a white woman specifically, a certain type of power dynamic was created with the staff members, which made me feel very awkward. I wanted to be treated as the equal of the other female CHWs. However, they called me "ma'am," and seemed embarrassed

or awkward in my presence. As such, I also tried to spend time with them, and eventually we became more comfortable together. These power dynamics greatly affect the research environment. Collaborative research becomes much more difficult when they view me as their superior. Although I had a clear interview guide and research process, I also wanted their input, however, I am unsure if they felt able to share all their opinions with me. With more time in the field, these power dynamics could have been improved, but not easily removed.

Another power dynamic was the one between Burans staff members and the women in the FGDs. In the beginning, I felt there were too many people present at an FGD. At one preliminary FGD, there were 2 CHWs, myself, the RA, as well as the male project officer. They were positioned such that the staff members sat on one side, facing the five or six women, who sat opposite them. I felt that this could create an uncomfortable power dynamic, with too many staff members present, positioned in what appeared to me as a face off. Although I could do nothing to remove staff members, I got up and sat myself down among the group of women. I wanted them to feel I was on their level, and listening from their side. I continued to do this throughout the FGDs, though I have no idea whether this was effective or if they would have preferred me to remain at a distance.

Conclusion

This research fills several important research gaps. Very little research has been conducted on the mental health of North Indian populations. The vast majority of mental health research originates from Southern states such as Goa, which differs significantly in their language, culture, and the state's mental health care system. This research is innovative because it analyzes and articulates learnings from new community-based models for improving mental health. Community-based solutions may offer support and pathways to recovery where there is little to no mental health treatment available (Mathias et al., 2015), while empowering local individuals. This research is also important because greater mental health competence and control may empower women to contribute to household and community decisions, and participate economically (Kermode et al., 2007). Understanding community models for women to improve their

mental health by increasing their agency and control will enable communities to have the ability to advance their own health and social interests.

Rural Northern India, a region of little mental health resources, deserves the attention of researchers and policymakers. However, there is no one "solution" to improving mental health across Northern India. Jain and Jadhav suggest that mental health care provision in rural areas of Northern area "may be ameliorated through the promotion of a better understanding of local communities by health professionals, the appropriate training of professionals, and the encouragement of multiple models for mental health services" (Jain & Jadhav, 2009). Therefore, along with providing physicians with proper training on common mental disorders, Jain and Jadhav make a call to supporting other mental health service models. This thesis research provides evidence for the significant impact of community-based psychosocial support groups, demonstrating PSSGs' ability to provide an effective program that can fit within a diverse mental health service model.

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Appendices
BURANS FLIP CHART: INTRODUCTION, WHAT IS MENTAL HEALTH, THE STORY OF ARUNA (Charts 1-3)

Chart 1

Introduction to Aruna and the group – estimated 15 minutes

- Start the group by introducing yourself and others. Talk about the purpose of this group and flip chart. Throw a small ball or pen to the next person. Ask them "Introduce yourself – tell us your name, and 2 interesting facts about yourself and your family". We are following a story of Aruna, and together we will learn from her story and seek to relate it to our lives. Read the story aloud.

➔ Check all in the group are comfortable with the story, then go on to ask as we think about her story, what do we think are thing things in her life story that would impact her mental health. Give the group prompts to think about her physical health, mind health, social health and spiritual health.

> *Aruna's Story- Aruna was 19 years old when she was married to Akshay. After marriage she moved into to live with Akshay's parents. Akshay used to have a small shop where he fixed cell phones and after five years they had three children, two daughters and one son. Three years ago Akshay was killed in a bus accident. It was the most sad and terrible thing for Aruna and for Akshay's parents. Six months after his death, Askhay's parents told Aruna she must move out from their home. She returned with the three children to her maternal home 50 km away. Now Aruna lives in a one room quarter in the same town as her mother who is a widow, and does domestic work in three different households. Her eldest daughter, Reeta is 14 years old, the second daughter Priyanka, is 12 years old and the youngest is 9 year old Siddarth. They are all studying in the government school.*

Chart 1

Introducing Aruna
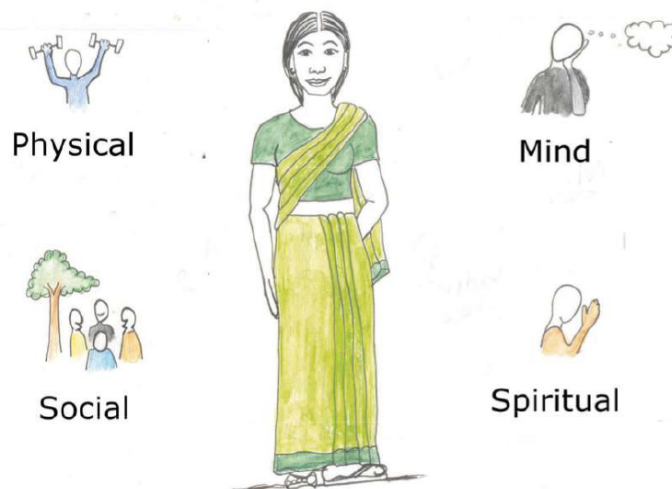
Chart 2

The Four dimensions of health - discussion and group work – estimated time – 10-12 minutes

- Look at the picture with Aruna and four logos symbolizing four dimensions of mental health.

- When we think of our own mental health, most of the time we only think about the absence of pain, sickness or diseases but there is much more to our mental health than this! What else is part of health? Through these sessions we are going to try and understand our mental health in four dimensions:

- Physical,

- Mind health,

- Social,

- Spiritual and cultural identity.

- Discuss with the group what are some of the things we need for mental health in each of these dimensions. Give an example of each of these for people in this community. Ask the group to form pairs with their neighbor and then to take 5 minutes each to sit together and talk with their neighbor asking each pair to think of an example in each dimensions.

- Use your marker to draw pictures or write words representing the different ideas group members have had. Make sure you give group members positive feedback for their contributions!

- The next page then shows some examples of the four different dimensions. Turn the page now and discuss these together.

Chart 2

4 Dimensions of mental health

Chart 3

Using the four spheres to think about my own life – 15 minutes

Using the pictures illustrated – discuss the meaning of the different pictures that are shown for physical, mind, social and spiritual health. Take time to talk through the different pictures and what they might mean. Then encourage the group members to think which sphere in their own lives is most healthy and to lay a small stone in that sphere e.g. they may have a good physical health and a good house and home so they choose that. Then ask group members to take turns to lay a small stone in the area where they are weakest. E.g. someone may say they have lots of tension – so they would mind health as their least healthy area.

Physical	Mind
- Access to good primary health care that gives support and ideas that are not only drugs - Access to nutritious food with good variety and lots of fresh fruit and vegetables - Clean food/water & food/water security - Clean air - Physical activity most days - Staying away from harmful substances- smoking, drinking, drugs - Genetics/family history of illness - Gender equality	- Having autonomy and being able to make choices about our own lives - Being able to cope with the normal tensions of life - Maintaining healthy relationships - Being able to face and solve problems in life - Realizing our own abilities and working on being our best - Living with emotions and thoughts that keep us well - The absence of mental illness such as Depression, Anxiety or Schizophrenia - Access to mental health care including good primary health care, healing care, support groups, psychiatrists and counsellors.
Social	**Spiritual/Cultural/ Creative**
- Being free to participate in society and our community - Feeling that we belong in our place and among our people - Living with support and kindness from our family - Having friends we can talk with on feelings / thoughts - Being able to celebrate with others - Contributing and caring for those more needy - Living in a safe community - Access to local resources – eg police, NGOs, schools, municipal bodies - Working in a safe and healthy place - Having opportunity to study and learn - Living free from violence (e.g. in our home or bullying in our schools)	- Connecting to a religion and cultural group - Knowing a place where we can connect to God and being free to go there/ worship - Practicing forgiveness and compassion towards others - Using creativity – singing, drawing, weaving to connect to our inner learning and thoughts - Practising your cultural customs and traditions - Expressing gratefulness

Chart 3

4 Dimensions of mental health
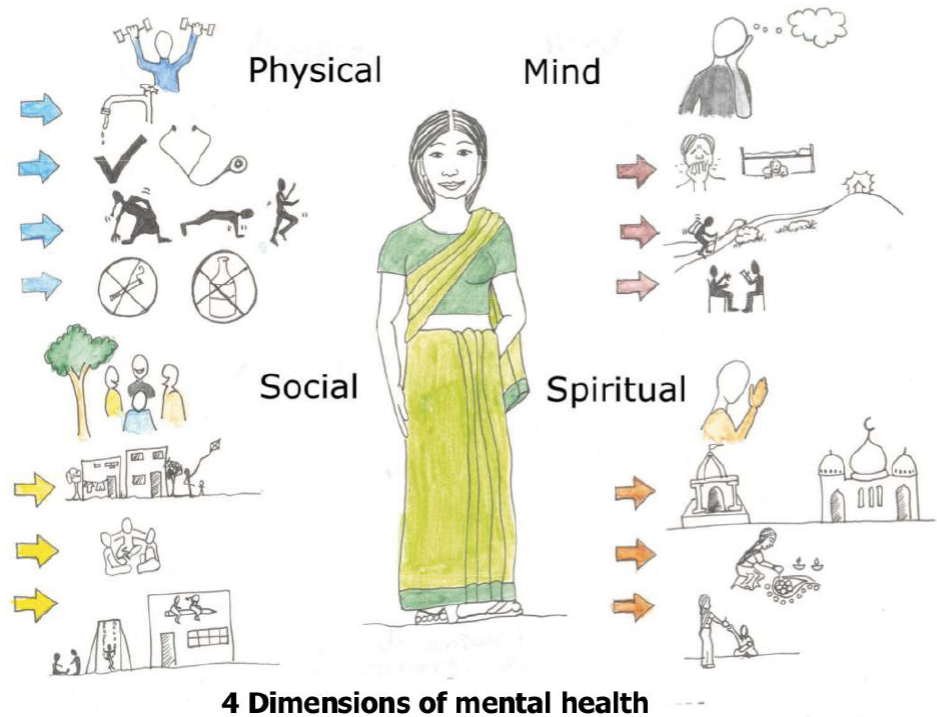
INFORMED CONSENT FORM FOR PARTICIPATING IN RESEARCH RELATED TO COMMUNITY MENTAL HEALTH COMPETENCIES

Dr. Kaaren Mathias, Nicola Gailits, Pooja Pillai
Emmanuel Hospital Association, Project Burans

Part I: Information Sheet
Introduction
I am Pooja Pillai (and I am Nicola Gailits), and we work with Project Burans and Emmanuel Hospital Association. I am a graduate student in Global Health from a Canadian University (Nicola Gailits speaking). We would like to invite you to be part of the research we are doing to understand the ways that communities can help manage their own treatment, care, and access to mental health problems. We will read aloud the study's information. Feel free to ask questions at any point.

Purpose of the research
The research's purpose is to understand how community members can work together to improve their community's mental health. More specifically, its purpose is to understand how working together, forming friendships, and daily activities can help North Indian women feel better.

Type of Research Intervention
This research will involve your participation in a group discussion (or interview) – the discussion will take between 1 hourof your time (and interviews will take 45 minutes to 1 hour of your time).

Voluntary Participation
Your participation in this research is completely optional. It is your choice whether you participate or not. If you choose not to participate you will receive all the same opportunities, as you would have otherwise with respect to Project Burans self help groups, support groups, and other programs. As well, if you would like to change your mind and leave, you may do so at any time and you will still receive compensation for coming here today.

Procedures
We will record this group discussion (or interview) and store that information on a digital recorder and through note taking. We will record your names and the place of the interview but no names will be attached to comments made when we write about our learning, so no one will know your name, or village, or household information. Any identifying information will be kept in a secure place, locked, where others cannot read it. If you change your mind, you can stop participating in this group discussion (or interview) at any stage.

Compensation, Benefits, and Risks

As a token of our gratitude for joining us today, we will provide you with chai and snacks (for interview a gift will be provided. Your participation in this research will provide us as well as your community with important understandings on how women can work together in their communities to improve mental health problems. As well, the publication of this research will increase understanding on mental health in women across all of Northern India. It can be difficult to discuss mental health though, and if you need to talk to someone, we have community support workers present today and can also refer individuals to the region's psychiatrist.

Sharing the Results

The knowledge that we get from this research will be summarised and given to the Pradhan of each community where we gather information.

Who to Contact

This proposal has been reviewed by the EHA ethics committee, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the IRB, please contact Dr. Kaaren Mathias.

Do you have any questions?

Part II: Certificate of Written Consent

I have been invited to participate in this research that seeks to understand how communities can work together to improve their mental health.

I understand the information above. I have had the opportunity to ask questions about it. I consent voluntarily to be a participant in this study.

Print Name of Participant_____

Signature of Research Coordinator _____

Date _____
          Day/month/year

Statement by the researcher/person taking consent

I have provided the information sheet to the potential participant, and to the best of my ability made sure that the participant understands it.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my

ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

 A copy of this p1 has been provided to the participant.

Name of Researcher taking the consent_____

Signature of Researcher taking the consent_____

Date _____

                Day/month/year

       Contact Information
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FOCUS GROUP DISCUSSION GUIDE

Demographic info: *Age, Education level, Site, support group members total, how long running, how often meets.*

Start with definition of collective action
1. Let's talk about collective/collaborative action for the community. What does collective or collaborative action mean to you?

(Once we agree on a definition, then ask:)
What types of things do you do in your community like this? (collective actions)
Do you think this group is a form of collective action?

2. **Let's talk about your group.**
What are some of the positive things that you have learned from joining this group?
How has participating in this group changed your ideas on mental health?
Has anything negative happened due to your participation in the group?
3. Do you think more communities should groups like this one?
        -Why? Why are they important?

4. You said that_____(*for eg. talking through problems/having support/learning about MH*) was a great part about these groups.
What has helped the group to be so successful?
Can you think of anything that would make them more successful?
What advice would you give us for new support groups to be formed?
        -Do the women involved need to be same caste, same age, same religion, same marital status, from same location.

5. After having joined this group, what new possibilities for collective action in your community do you see?
-Probes: What community problems could you address collectively?
                What would you do?
                Is starting other groups like this one in your community one of those
                things? What do you think about starting another support group?

-Now that we understand what new things you could do in your community, please rank your priorities for action from most important to less important:
        -(eg. Rank the following actions from 1-3: Helping solve new community problems, starting a new support group, telling the community about your mental health knowledge)

SUPPORT GROUP FORMATION AND PROCESS
6. Let's talk more about your group.
Whose support group is this?

Do you feel that this is YOUR group, or this is PROJECT BURANS' group?
How does that change your involvement in the group?
Do you want to be more involved in the group's organization? What are ways you would like to be more involved?

7. Let's imagine a new situation where your CHW does not lead the group anymore.
What do you think would happen to your support group if ____(insert CHW name) did not come back to lead your group every week?
How would you feel if _____ wasn't there? (Abandoned? Okay?)
What has happened in the past when the CHW can't organize or attend the group?

8. Would the group disappear or would you lead it on your own?
How would your group function on its own ? (without Project Burans' support)
Probes if unable to answer:
        Would someone take responsibility for organizing the group?
        Who would and how would you decide this?

9. What could make your group more likely to be able to continue on its own?
Probes: Would you need more training? (for example to learn how to lead the group)
             Would they need to be started differently? And if so, how?
             What would help you feel confident as a group to keep going?
             What would help groups understand from the beginning that they will
eventually be running the group on their own?

10. Do you know what an SHG (self help group) is?
What would be the positive aspects of making your group a combination group: both regular and an SHG (imagine 1st hour is SHG and 2nd hour is support group)
What would be the negative aspects of combining them?
Would having each support group also be an SHG group help to keep the group together? How?

12. These are all important questions when we think about the long term success for a collective action/collaborative action like support groups.

For example, there is a group in Sehaspur called the DPG (disabled persons group). They advocate for the rights of mentally and physically disabled people, helping them to get money from the government to help in times of disability. They started the group themselves, with 3 members. Then, with the help of an NGO (EHA), they got trainings and help, and grew bigger. Now they have 300 members, and have become their own organization. They go into other villages and start small DPG support groups, with their members.
This is a great of example of group that has formed on their own, with some help from an organization; however, the ownership of the group is their own. They are not dependent on an NGO to help them every week.

What do you think would be the positive aspects of your group taking action to do something like this?

What do you think would be the negative aspects of your group taking action to do something like this?

This would require energy and time. Does anyone here think they would go further on this? Please raise your hands.

Could your group learn to create new support in your community?

KII Guide (CHW questions)

Demographics:
How long have you been working for PB?
Highest level of education?

Demographics of groups
Are the women in your groups working? All ? None? How many?
In what ways does this help or hinder the support groups?
 (only probe if she can't answer…this could help since they have more confidence and are more motivated, or could hinder since they have less time).
What are the women in your caregiver support group doing when they are not working for 6 months?

Positive outcomes of PB:
What do you observe as the knowledge and skills the women involved with the Burans program are gaining?
How do you understand that these skills would be useful for them? For their community?
What could be done to support or augment these skills?

Successes
What are some of the most important things that women in support groups have learned or obtained from participating in these groups?
What has helps the group to be successful?
Can you think of anything that would make them more successful?
What advice would you give us for new support groups to be formed?
        -Do the women involved need to be same caste, same age, same religion, same marital status, from same location.
Why do you think some of the support groups unsuccessful and other are so successful?

I imagine that you have an affect on your support groups. What do you think are some of your personal strengths and weaknesses as a CHW ?
How does this affect your support groups' success?

Challenges
What are the biggest challenges in running these groups?
Let's talk about the limits to helping improve women's mental health in the community.
What prevents women from improving their mental health through support group? …
What are some of structures/actions that limit and reduce women's participation in their own health care? (Probe: Gender roles like staying at home and cooking, lack of agency, lack of help/support)

Going Out

How far are women allowed to go from their house alone?
Have you seen any change over time, and what do you think has contributed to this?

One thing we've noticed in many of the communities is that leaving the house to begin with seems to be a big challenge.
Why do you think this is ?
Which member of the family is most likely to stop a woman?
How could this be combated to help ensure more groups can be made?
     Others have suggested that maybe engaging the family and talking to them about what the women gain from the support groups would help allow women to be part of it.
     Does this already happen?
     If it doesn't, what do you think of doing this? Who in the family would be most important to convince?

Let's talk about the rest of the community. Women say they are monitored and watched by the rest of the community, and they are checking on where they are going, which may prevent them from going to a group. What could help the community to see the women in SGs differently?

Ownership
I also want to get a better understanding of what local women's ideas of ownership over their own lives. What kind of things do they feel ownership over?
Do they feel ownership over their health?

Do you honestly think the women feel that the groups are theirs, or that they are PBs'?
How does this change their involvement of the group?
Is there a different way that they could think about the groups?
Could a new mindset about the groups help women to be more involved in the group's organization?

Independence:
While you were there, we asks your groups what would happen if you weren't there to lead the group one week, and you saw there response. In reality, you know your group better than anyone else. What do you actually think would happen to your support group if you long came? What about other CHWs' support groups?

What could make the support groups more likely to be able to continue on their own?
     Would they need more training? What kind?
     Would they need more confidence?
     At the beginning when the group is formed, would it need to be framed differently, started with a different mindset to make it more independent?

What do you think if we started groups, and told them that by the end of 12 sessions, they would be running the group on their own. (This would take approx. 6 months, given most groups meet every 2 weeks). How would they react to this?

As a CHW, you have the ability to impact the women in your community. How do you imagine that YOU could help to increase the community's ownership over their support groups and increase the group's independent action?

Starting new groups
When we asked the women about starting new groups, there was at least one person in each group who was interested sometimes many more. It was hard to distinguish whether this was a real answer or not, as in the case where one woman said, "if its imagination, then I'm in".

Do you think creating new groups on their own is a reality for these women currently? Why?

Combining SHG and SH groups:
Explain the study.
What do you think of this idea?
What could be the positive aspects of making these support groups have an added component, and SHG component?
What could be the negative aspects of combining them?

We have discovered that it might be a good idea for these groups to have a secondary purpose, whether it be childhood nutrition, or community action, or an SHG component. This way the women get more benefits from the group, and have an easier time getting permission from their household.

What do you think of this?
What would be better, groups based around more community action and knowledge empowerment, or groups based around financial empowerment (SHG groups)?
-Do you think that the involvement of money can change the dynamics of a group? If so, how?

Lastly, why do you think some women cant distinguish between their SG and SHG ?

Collective action
What does community/collective action mean to you? What types of actions does it include?
After having joined support group, what new possibilities for collective action do these communities have?
What do you believe are the most urgent priorities for the community's MH and how could they take action collectively to achieve this?
Besides yourself, are there other individuals or organizations that you think could help strengthen the community's ability to work together to improve mental health.