Recovery From Psychotic Disorders in Rural Haiti: The Perspectives of Persons With Lived Experience of Psychosis, Family Caregivers, Health Care Providers, and Community Leaders

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This Thesis, Recovery from Psychotic Illness in Rural Haiti: A Qualitative Study of Lived Experience, presented by Joseph Reginald Fils-Aimé, and Submitted to the Faculty of The Harvard Medical School in Partial Fulfillment of the Requirements for the Master of Medical Sciences in Global Health Delivery in the Department of Global Health and Social Medicine has been read and approved by:

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Recovery from Psychosis in Rural Haiti:
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A Thesis Submitted to the Faculty of
Harvard Medical School
in Partial Fulfillment of the Requirements
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Recovery from Psychosis in Rural Haiti: A Qualitative Study of Lived Experience

ABSTRACT

The lived experience of psychosis in Haiti and in the Zanmi Lasante (ZL) mental health program is poorly understood, but crucial to document and explore in order to better facilitate the recovery of those suffering from psychosis. This thesis is based on a qualitative study, conducted in Mirebalais and Petite-Rivière de l'Artibonite, which used purposeful maximal variation sampling. It investigates the local knowledge, the lived experience, and the best paths to recovery from psychosis. Drawing on these research findings, it offers lessons for the design and improvement of services. This thesis presents novel research on the lived experience of recovery from psychosis in rural Haiti.

Persons with lived experience of psychosis and their families narrated their journeys before entering the ZL program and revealed experiences that were personally, socially and economically devastating. Family members involved in the care seeking and caregiving processes reported many structural constraints such as inaccessibility of care, poverty and stigma. They often faced moral quandaries and were forced to make impossible choices while desperately trying to take care of their loved ones. Structural violence appeared as a root cause of the inhumane conditions of the lived experience of people with mental illness in rural Haiti. Their experiences suggest a model of recovery that encompasses clinical recovery, social and spiritual connections, and the ability to fulfill one's social role. With this model of recovery in mind, implementers must seek to go beyond clinical improvement to facilitate the learning of

needed skills. They must also engage the community and accelerate structural changes that will allow persons with lived experience of psychosis to fulfill the social roles they value most. The findings of this study can inform the further development of appropriate rehabilitation programs and tools, and inform a national mental health system in Haiti that effectively facilitates recovery.

INTRODUCTION

The need for mental healthcare in Haiti is significant. Since its independence the country has endured a series of historic traumas and social disruptions overlaid on ongoing societal structural violence (Farmer, Nizeye, Stulac, & Keshavjee, 2006; Farmer, 2001). The public mental health system lacks the resources to respond to the medical, social and psychological needs engendered in the context of these long-term and acute crises.

The overarching goal of this study is to understand the process of recovery from psychotic illness in rural areas in the Central Plateau and the Artibonite Valley departments of Haiti from the perspectives of persons with lived experience of psychosis, their family caregivers, community leaders and local health care providers. The findings will inform the strengthening of the community-based model of mental health care that was developed following the 2010 Haiti earthquake by the collaboration of the Zanmi Lasante (ZL) and Partners In Health (PIH) mental health programs, and the Haitian government. The findings will support improved implementation of a recovery-oriented mental healthcare system and an emerging community-based care system with particular attention to the care of psychotic disorders and severe mental illness in an area serving 1.3 million people, or one-sixth of the population of Haiti.

This study has four specific aims: first, to probe and formulate, through qualitative methods, a synthesis of local knowledge and lived experience relevant to recovery from psychosis in Mirebalais and Petite-Rivière-de-l'Artibonite in Haiti; second, to understand what patients, family caretakers, healthcare providers, and community leaders know and can teach us about the process of recovery from psychosis, the path to recovery and their experience of the recovery process; third, to inventory the participants' reports about presence and absence of resources at the community level and their understanding of how those resources can help persons living with psychotic disorders to recover; and fourth, to formulate recommendations from local knowledge, experiences and perspectives of the participants for the development of more robust recovery-oriented mental health programs.

BACKGROUND INFORMATION AND STUDY SETTING

In Haiti the only two existing state psychiatric treatment centers are located in the capital, Port-au-Prince, and they are poorly equipped with regard to human resources, supplies and physical infrastructure. Data published in 2014 by World Health Organization (WHO) reported that there are only 7 psychiatrists in the country for a total population of more than 10 million people (WHO, 2015). All of those psychiatrists work in the capital city. As a result, most of the population (especially those who live in rural areas and in outlying cities) does not have access to formal mental health services. Mental health had not been a priority for the Haitian Ministry of Health (MOH) until the occurrence of a major earthquake centered in Port-au-Prince in January 2010. Even after the earthquake the MOH did not have the resources to give to mental health, and relied on the efforts of international non-governmental organizations (NGOs). Widespread acute psychological suffering provoked by this tragedy, therefore, brought the topic of mental healthcare onto the agendas of the Haitian government as well as those of non-governmental organizations (NGOs). Zanmi Lasante (ZL), a Haitian NGO linked to the international NGO Partners In Health (PIH), made a commitment to responding to the earthquake emergency and to seeking to serve the long-term mental health needs of the country by articulating a community-based model of mental health care. This commitment resulted from a meeting held between representatives of ZL, PIH and the Haitian MOH including the Minister of Health, Alex Larsen, who spoke in detail about the need for a mental health response to the emergency that would inform a long-term plan for mental health in the country. Minister Larsen spoke of the legacy of more than twenty-five years of ZL's engagement in Haiti and of the trust that this had engendered in the country for this NGO. He requested that PIH and ZL lead a mental health effort with the Haitian government that would serve the Haitian people (personal communication)[1].

ZL works in Haiti's Central Plateau and Artibonite departments and serves more than 1.3 million people. During its three decades of service, ZL/PIH has established a network of community health workers (CHW) that has proven effective and beneficial in detecting, referring and supporting patients in rural communities who live with tuberculosis, HIV and other chronic diseases. Since 2010, with the endorsement of the Haitian Ministry of Health (MOH), ZL/PIH has been building a community-based, culturally relevant model to deliver high quality mental health care (Belkin et al., 2011; Raviola et al., 2013; Raviola, Eustache, Oswald, & Belkin, 2012). This model provides hope for potential scale-up at a national level. To reinforce the provision of care, the team has designed and implemented packages of care for depression, epilepsy, and psychosis and severe mental illness for all categories of providers working within the care system including CHWs, physicians, nurses, and psychologists. An additional package of care for child and adolescent mental health problems has been developed for psychologists along with plans to expand child development-focused efforts. The psychosis and severe mental illness curriculum was launched in mid-2015 to train providers to provide high quality care to

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[1] Personal communication: G. Raviola, E. Eustache, A. Larsen, F. Leandre, J. Mukherjee, G. Thimothé. February 2010.

persons living with psychotic illness, a group of severe mental disorders whose sufferers are discriminated against and stigmatized (WHO, 2016).

This study seeks to support the improvement of this care delivery system, specifically with regard to this nascent care program for psychosis and severe mental illness, in order to better *accompany* those who are served and to optimally facilitate their recovery. The term *accompaniment* refers not only to clinical care, but also to the diverse supports, coordination and guidance offered to individuals living with illness by providers working in the system of care (Farmer and Gutierrez, 2013, p. 127). To improve accompaniment of service users, this work seeks to facilitate better understanding of the lived experience of, and recovery from, psychosis in the Haitian context. Given the lack of research about these topics in Haiti, there exists a significant knowledge gap regarding the basic concepts of psychiatric recovery in the Haitian historical, social, and cultural contexts, and about the lived experiences of persons with a history of psychosis and their family caregivers in rural Haiti. Recovery has been conceptualized by many in the US and other developing countries as the process of "reclaiming a meaningful life" (Davidson, 2006; Farkas, 2007b; Hopper, 2007; Myers, 2010; Slade et al., 2014; Slade, 2010). Such a conceptual definition however, needs to be operationalized depending on the context. Professor William Anthony, in a textbook about rehabilitation, provides the following widely used definition of recovery:

> "A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life with or without limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of a mental illness." (Anthony, 1993; Anthony et al., 2002, p. 31)

This definition has however has been informed primarily by first person accounts in the US and has been critiqued when it comes to its applicability to other contexts. What is recovery from psychosis in the Central Plateau and the Artibonite? What is the lived experience of persons with or recovering from psychosis and their family caregivers? What are the best paths to care and recovery and what local resources can facilitate recovery?

This qualitative research study seeks to describe local knowledge, community resources, and best pathways for recovery from psychotic disorders in the rural Haitian context, from the perspectives of persons living with psychosis, their family caregivers, healthcare providers, and community leaders. Its aims reflect on the ZL/PIH mental health program goals of improving the quality of mental health services for those living with severe mental illness in Haiti. I present the importance of this research in understanding the experience of people living with psychosis, the experience of their family caregivers, the care seeking process, and other perspectives on recovery. I place this study in the current global context in order to suggest ways that it may help to fill some existing knowledge gaps in the literature. I demonstrate the study's utility for policy and provision of mental health services in rural Haiti, its role as a qualitative evaluation of the ZL Mental Health program particularly with regard to care for psychotic disorders, and finally, its role as potential amplifier for the voices of the study participants living with psychosis.

Overview of Haitian academic literature on mental health, and its relationship to policy and service provision

The mental health-related academic literature in Haiti has had remarkable and productive periods. Dr. Louis Mars and several other Haitian psychiatrists promoted a Haitian ethnopsychiatric movement in the mid-20th Century. They founded a local scientific Journal (*Bulletin du Centre de Psychiatrie et de Neurologie)*, which published many articles. Their writings covered mental health prevention, psychopathology, the Haitian religion of Vodou, the sociology of mental illness, and described the expression of mental illness in the Haitian population. This was the achievement of a long period of advocacy by Dr. Mars who, as the first Haitian psychiatrist, had sought to bring formal psychiatric care to the country (Bijoux, 2010). In 1941, he founded the *Ligue Nationale d'Hygiène Mentale* (National League of Mental Hygiene). One goal of the league, wrote Dr. Mars, was to "evaluate in toto the dynamic character of Haitian culture and its influence on the incidence of the mental diseases" (Mars, 1947a). He also presented Mental Hygiene as "interested in a complete development of the person including educative, medical and economic" (idem). The league worked to prevent, screen, treat and educate about mental disorders and it advocated for building specialized schools and psychiatric hospitals. While advocating for treatment centers for both adults and children, the work of the League focused more on children (including those with mental retardation) consisting mostly of education of the population and working with schools on screening and treatment. His plan for "mental hygiene" entailed a multidisciplinary team including educators and ergotherapists, and he proposed treatment spaces incorporating gardens, chapels, and physical space for bibliotherapy (reading). Mars' "mental hygiene" plan also envisioned the rehabilitation and social inclusion of children with developmental delays (Mars, 1947a). His model of psychiatry considered the person living with the mental illness within his or her socioeconomic context.

In 1950, in an essay about Vodou *lwa* (Vodou deity) possession, Dr. Mars was the first to coin the term *ethnopsychiatry*. He presented ethnopsychiatry as a new scientific discipline deriving from both psychiatry and the social sciences and demonstrated its conceptual necessity both in Haiti and in post-colonial Africa (Mars, 1966; Mars, 1950). Mars defined the new discipline as "the science allowing to study, about a mental phenomenon, the close relationship between strictly psychological factors and the social, economic factors conditioning it" (Mars, 1950). While this conception was followed by others later joining the ethnopsychiatric movement, it applied primarily to elucidate the diagnosis and the understanding of the illnesses rather than the formulation of therapeutic approaches (Farmer, 1992).[2]

Meanwhile, Mars had been tirelessly advocating for a modern psychiatric center in the capital city as an alternative to the appalling asylum, “Camp Beudet,” the first psychiatric center in Haiti where persons with severe psychiatric symptoms had been kept since the late 1920s (Bijoux, 2010; Bordes, 1992). His dream was realized when the Haiti Psychiatric Institute (now the Mars and Kline Psychiatric Center), opened in 1959, with the help of three American pharmaceutical companies, an American psychiatrist Dr. Nathan Kline, and the Haitian government. With the advent of antipsychotic medications in the 1950’s and during an era when higher-resource nations such as the United States were decreasing the number of people held in psychiatric institutions and reintegrating them into their communities, (referred to as the “deinstitutionalization movement”) this center was internationally acclaimed as a model. In the December 19th 1958 issue, The Omaha World-Herald praised the opening of the center for being “the first [psychiatric] hospital in the world to rely primarily on drugs and outpatient care” rather than institutionalization. However, the center would subsequently fall short of that mission. During the Duvalier dictatorship, the promises of the center faded while the need for its service were increasing. Dr. Mars was named Haitian ambassador to the US and later to France, and was not present in the country to continue to advocate for the center. Three American psychiatrists succeeded him as directors of the center (Bijoux, 2011; Kline and Mars, 1960). The Ligue d’Hygiène Mentale stopped functioning. Due to worsening political repression under Duvalier, freedom of expression was stripped away from intellectuals and academics. The outpatient care

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[2] The paternity of *ethnopsychiatry* was later attributed to the Hungarian-French ethnologist, Georges Devereux, although the latter wrote that it is Louis Mars who has had started the discipline (Devereux, 1961; Nathan, 1999).

component anticipated from the Haiti psychiatric institute was never initiated. Consequently, the intended trajectory of the founders of Haitian psychiatry toward deinstitutionalization was not realized. Meanwhile, in the US, the rehabilitation paradigm eventually replaced the one of deinstitutionalization and later, in the 1990s, the concept of recovery was adopted as the Western standard therapeutic vision for persons living with psychiatric disabilities (Anthony et al., 2002).

Although in Haiti the allied fields of mental health, including psychology and psychiatry, knew some promising and productive periods at the beginning of the second half of the 20th century, academic research during this period was not focused on the personal, social, and contextual process of recovery. Reviewing the writings of that generation of authors enables one to see how they included rich descriptions of pathologies in the Haitian context, descriptions of Haitian customs and manners, and phenomenological studies that constituted, at that time, a very advanced grasp of the interactions between culture and psychiatry (Bijoux, 1974, 1975; Douyon, 1967; L Douyon, 1967; Mars, 1943, 1947b, 1950; Philippe and Romain, 1979; Philippe, 1975). On the other hand, those advanced understandings, although underpinned by respect for popular explanatory models, were primarily used to interpret the patients' idioms of distress and local presentations in order to apply Western medical treatments. They did not serve to build a system of care embedded in local ethnopsychiatric conceptions. In a historical analysis of Haitian psychiatry, in 1992 Farmer referred to this as a "co-optation" of the patients' explanatory models of illness (P. Farmer, 1992). The focus of the ethnopsychiatrists was more on the comprehension and interpretation of the illness representations and illness expression in the Haitian context than on establishing culturally appropriate approaches to therapy for recovery.

Conceptualization of Haitian mental health and recovery from illness in the post-earthquake period

The unprecedented and immeasurable toll of mental suffering caused by the Haiti 2010 earthquake occasioned also a peak of publications about mental health in Haiti. However, to date there has been no review of studies exploring local understandings and values of recovery in the academic literature on Haiti. In 2010 in the *Revue Haitienne de Santé Mentale*, Drs. Frantz Raphael and Yves Lecomte proposed models of community-based interventions responding to the lack of trained providers and the urgency of the need. They implemented such a program in Grand-Goave, the south of Port-au-Prince and recommended a transcultural psychiatry approach that “attempts to adapt itself to the culture of the service users. But the therapeutic modalities used are the ones of conventional psychiatry and are founded on its conceptions.” They have used this model in multicultural and Haitian communities in Canada (Douyon, 2010; Lecomte & Raphaël, 2010; Raphaël, 2010).

One research pilot-intervention in Haiti that is presented as recovery-oriented in the post-earthquake context was called *Soulaje Lespri Moun*[3] and was led by an American doctoral student, Leah Emily James. This intervention was directed to survivors of the earthquake living in IDP camps. It did not target psychosis in particular. It was a recovery-oriented pilot-intervention, but again, did not report exploration of the local context of the recovery process. This intervention does not answer the foundational question of what is recovery and how to achieve it in the Haitian context.

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[3] Creole for: “Relieving people’s spirit” (Relieving the spirit)

The current study reflects the awareness of the ZL/PIH mental health team at the time of the earthquake that, given resource constraints in the Haitian context combined with the complex legacy of Haitian psychiatry in addressing severe mental illness in communities, the concept of recovery would need to be examined specifically in order to best understand how to optimally support people living with mental illness and their families. The interest in that examination did not have to preclude delivery of services to people who needed them. And following the emergency mental health response to the earthquake, the rudiments of a community-base model to deliver mental health services in rural Haiti to people living with severe mental illness were put in place. This study is conducted at a moment when it can benefit from the experience of those who have ideally benefited from those services, but who also would have valuable experience and counsel to inform the improvement of our model.

Psychiatric Recovery in the Global Literature

A rich and growing academic literature regarding psychiatric recovery from severe mental illness has evolved since the 1990s, but there is a relative lack of research coming from Low-and Middle-Income Countries (LMICs). A striking exception, however, are the innovative psychiatric villages in several countries in Africa (Nigeria, Tanzania and Senegal), established more than 50 years ago. They were outpatient models in which patients could receive communal treatment from a multidisciplinary team including the family and traditional healers with linkage to a psychiatric hospital (Roberts, 2007; Schulman, 1980; Sloan and Vaughan, 2007). More recently, there have been a few more research about recovery from psychosis recovery-oriented interventions in developing countries (Bayetti, Jadhav, and Jain, 2016; James, 2012; Parker, 2012; Subandi, 2015). Nonetheless, there remains a clear lack of research about recovery and interventions targeting recovery in LMICs.

Within this vacuum, the need for knowledge concerning recovery in particular contexts has remained unmet. In a book published in 2012, *Recovery of people with mental illness: philosophical and related perspectives*, Adeponle, Whitley, and Kirmayer authored a chapter entitled “Cultural contexts and constructions of recovery” (2012). They note that the concept of recovery in the Western world (for example in USA, Canada, England, etc.) has been rooted in particular social, economic, politic and cultural contexts specific to those countries. Those contexts fed the definition and construction of recovery in those countries. For those authors, psychiatric recovery is a cultural construction. In 1988, Leon Eisenberg in an article entitled “Social Construction of Mental Illness” elaborated on the concept of the social construction of mental illness (Eisenberg, 1988). All of this converges on the idea that the conceptualization of recovery dominating the literature has developed from the North American and European culture and from the histories of their mental health movements.

The International Pilot Study of Schizophrenia and later International Study of Schizophrenia, started by the WHO in 1967 in 16 countries is one of the first impulses of the recovery movement. This series of longitudinal studies followed persons suffering from schizophrenia over two years, fifteen years and twenty-five years, and showed that about 50% of people with schizophrenia had a favorable outcome by the end of the study; they also consistently showed that schizophrenic patients in developing countries had better outcomes than those in developed countries (Harrison, 2001; Sartorius et al., 1996). The latter finding has generated debates about what could explain that difference in outcome (Harrison et al., 2001; Jablensky and Sartorius, 2008; Patel et al., 2006; Sartorius et al., 1996). In his article about the social construction of mental illness, Eisenberg explained the difference in outcome confronting the different ways mental illness might be constructed in those places. In fact, he argued, in the rich countries, mental illnesses were considered as more biological and chronic and consequently individuals with mental illness are expected to be in remission rather than cured; whereas in developing countries, they were seen as the consequence of external causes which allowed restoration of the self and therefore a cure with exorcism for example. His point was that the etiology and course of mental disorders are socially constructed and that the particular construction of mental illness in developing countries might have influenced the "better" outcome observed there. He argued that, "To speak of a natural history of schizophrenia – or any other disease, for that matter – is to employ a misleading phrase which implies the unfolding of intrinsic biological determinants" (Eisenberg, 1988, p. 5).

Sartorius, involved in those studies since the early phases, responded in 2008 to a critique qualifying as axiomatic the belief in international psychiatry that schizophrenia has a better course and outcome in developing countries (Patel et al., 2006). His conclusion in the article recognized the need for more research to explain the difference in course and outcome and stressed the importance of the social fabric in shaping the expression and course of schizophrenia. He warned of the "erosion of the social support systems, likely to be associated to the globalization" (Jablensky and Sartorius, 2008).

Post-Earthquake Mental Health Systems in Haiti, and the PIH/ZL Mental Health Program

Following initial meetings between PIH/ZL and the Haitian Ministry of Health (MOH) at which the MOH requested the assistance of PIH/ZL in supporting government efforts to develop a system of care for mental disorders, PIH/ZL committed resources to develop both an emergency mental health response, and a long-term system-building and capacity-building response to articulate a community-based mental health system (Raviola et al. 2012, 2013, personal communications, 2010). This effort at PIH/ZL was led by a close collaboration between two leaders at PIH and ZL: Dr. Giuseppe Raviola, a US psychiatrist with significant experience in mental health systems in low-resource settings; and Father Eddy Eustache, a Haitian psychologist and priest, and director of the psychosocial program at ZL which from 2005 to 2010 served people living with HIV and tuberculosis with a team of three psychologist working in collaboration with approximately 20 social workers. A collaborative team led by Raviola and Eustache worked to integrate knowledge of emerging best practices in emergency mental health response in disasters including the Interagency Standing Committee Guidelines of 2007, which place a focus on human rights-based and "do no harm" approaches. While noting the history of foreign NGOs working in Haiti seeking "trauma narratives" to bring donor funding to their work which may result in subsequent potential victimization of "vulnerable" groups (James, 2010), the team selected an approach that prioritized deferring to local knowledge and experience, while bringing current global knowledge in community mental health to bear on serving urgent mental health needs.

Initial qualitative work in collaboration with the Haitian social science research group INURED indicated that depression was a major priority for providers and leaders in the community. This work also indicated that traditional healers were amenable to more formal mental health services and collaboration with mental health providers such as psychologists. In 2011-12, depression care was used as a template for a trial of a collaborative, stepped-care model that integrated depression screening using a culturally adapted screening tool (Rasmussen et al., 2014). The tool is used to screen patients in need of support and to refer them for additional formal mental health evaluation by trained psychologists working from health centers and hospitals. The PIH/ ZL model has become a community-based mental health program that provides multidisciplinary care that is community-based, linking non-specialist care to clinics and hospitals for more specialized treatment depending on illness severity. Within this system CHWs identify, support, refer, and accompany mentally ill persons from their communities to health facilities in rural areas. At the health facilities, people are cared for by a multidisciplinary team composed of psychologists, primary care physicians, nurses and social workers. With the support of the Canadian government through funding by Grand Challenges Canada, a rollout of trainings, sustained clinical supervision, and monitoring and evaluation for priority conditions was undertaken from 2012-16 in order to improve the abilities of non-specialist providers at all of levels within the system to manage the most commonly seen mental disorders, including depression, psychosis and severe mental illnesses, epilepsy and child and adolescent disorders. Providers have been treating persons with psychotic illnesses since 2010, but a more formal psychosis curriculum and treatment package to standardize clinical management of persons with psychosis in the program, including the use of measures for clinical improvement and functioning, was not implemented until 2015. From January 2013 to December 2015 almost 1,000 patients living with psychotic illness were treated in this program (Table 1).

Table 1: Statistics on psychosis at ZL (from the ZL Monitoring and Evaluation department)

Zanmi Lasante Mental Health **(Since January 2013 until December 2015)**	
# Epilepsy Cases	1,360
# Patients with suicidal ideation	1,004
# Patients diagnosed with psychotic disorder	990
# Patients diagnosed with depression	1,935
# Mental health patient visits	10,835

By observing the operations and listening to the perceptions of program stakeholders, this study serves as a qualitative evaluation of the program with regards to the care provided to persons living with psychosis. These findings can provide insights that can be used to improve the quality of the PIH/ZL mental health program. The Mental Health Unit of the Haitian Ministry of Health has expressed great interest in both the PIH/ZL model and in this qualitative study, for its potential to inform policy and national strategic planning to eventually establish a community-based mental health system in the country that is both relevant and sensitive to local priorities, values, needs, and cultural context. The MOH unit has spearheaded efforts that led to the issue of a mental health component of the national health policy in October 2015 (MSPP, 2014). A review of the post-earthquake mental health response in Haiti can be found in *Psychiatric Clinics of North America* by Raviola and colleagues (Raviola et al., 2013).[4]

The Global Burden of Mental Disorders, the Sustainable Development Goals, and their Relevance to the Current Study

Mental disorders share a disproportionate percentage of the burden of disease globally. A revised estimate of the global burden of mental illness in 2015 showed that 32.4% of years lived with disability (YLDs) and 13% of disability-adjusted-life-years (DALYs) are due to mental conditions (Vigo, Thornicroft, and Atun, 2015). This is a revision of earlier estimates that these authors judged as having underestimated the burden of mental illness. Despite this share of the global burden of disease, little attention is paid to mental illness in global policies. The Millennium Development Goals (MDGs) have not mentioned mental health, the Sustainable

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[4] See Appendix 2 for the five skills sets built on the ZL pyramid of care.

Development Goals (SDGs) have so far vaguely mentioned the problem and clear indicators have not yet been defined. The consequences of such neglect at a global policy level contribute to ongoing lack of prioritization of mental health at government ministries of health and the persistence of a deplorable treatment gap for mental health around the world. In 2004, WHO reported that the treatment gap for mental disorders was between 76 and 85% in low and middle-income countries and from 35.5% to 50.3% in developed countries (Demyttenaere et al., 2004; Kakuma et al., 2011). According to 2004 estimates, every year thirty percent of the population would suffer from a mental health disorder while more than two thirds of those afflicted receive no treatment (Kohn et al., 2004). While there is neglect of mental health in rich countries, the treatment gap is much wider in developing ones and the burden of neuropsychiatric disorders is disproportionately carried by LMICs which bear 84.23% of the DALYs caused by neuropsychiatric disorders according to calculations made from the WHO “Disease and Injury Regional Estimates, 2004-2008” files[5] (Health and Project, 2010; WHO, 2009). There also remains a shocking disparity in the global distribution of resources for mental health. Many fewer resources exist and are invested for mental health in LMICs as shown in the map below (Fig.1). Many have recognized the effect of deeper structural problems such as poverty in contributing to this disproportionate toll of neuropsychiatric disorders in LMICs (DesJarlais et al., 1996; Kleinman and Patel, 2003).

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[5] Similar calculations have been made in other publications such as: The WHO mental health project: “Mental health and Development: Targeting People with Mental Health Conditions as Vulnerable Group.” For the purpose of this thesis, I redid those calculations from the WHO excel files available online for more precision. (WHO excel files available at: 2009 (http://www.who.int/healthinfo/global_burden_disease/estimates_regional/en/index.html)

This is where the SDGs will prove critical in addressing those gaps because they are designed to promote development with a more comprehensive approach (Sachs, 2012). In addition to addressing some of the structural drivers of mental illness, the SDGs need to specifically target mental disorders themselves and the toll they represent in the lives of people and societies because mental health is essential for the achievement of many of the other goals (Gureje and Thornicroft, 2015; Thornicroft and Patel, 2014). While measurable indicators for mental health are still under discussion (UN, 2016a, 2016b)[6], studies such as this one, showing the local barriers to quality mental health care, can amplify the voices of some of the most affected by this global mental healthcare disparity (Chisholm et al., 2007; Demyttenaere et al., 2004; Kleinman and Patel, 2003), and may point to some pathways to promoting social justice for the care of the persons living with mental illness (Raviola, Becker, and Farmer, 2011).

Fig. 1: On the global distribution of the human resources for mental health from the article published in the Lancet in 2007 by Shekhar Saxena and colleagues (2007). Saxena et al. redrew the map below from the WHO Atlas mapping the untenable shortage of mental professional in the low and middle-income countries as well as the marked disparities between their distributions (2007).

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[6] The UN Statistics Division confirmed also in an e-mail exchange with me on the 15th of May, 2016 that no change was made to the list of indicators that were in the February 2016 Report of the Inter-Agency and Expert Group on Sustainable Development Goal Indicators (IAEG-SDGs) - cited above as UN 2016a.

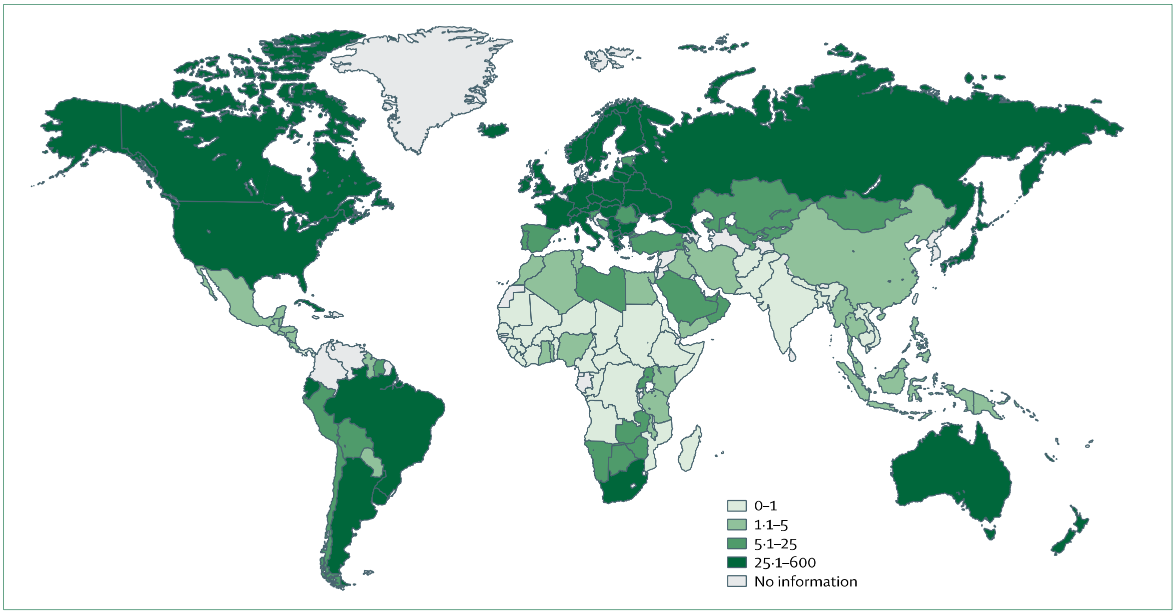

***Figure 1:* Human resources for mental health (psychiatrists, psychologists, nurses, and social workers) per 100 000 population**
Redrawn from WHO Mental Health Atlas,[5] with permission of WHO.

Both global and local perspectives are important for mental health policy. However, due to the scarcity of research stemming from "on the ground" initiatives in developing countries that are focused on health service delivery, global mental health policy reflects a more "top-down" approach. With regard to the work described here, the direct link between this research, the ZL mental health program, and the Haitian MOH confers the ability to think of mental health policy from the point of view of those most concerned by it—in particular, the persons suffering from severe illness, and their caregivers. This research will facilitate voices from "the ground"—front line services—reaching policy level. This concurs with a view expressed by Feierman and his colleagues about the role anthropology can play in facilitating the flow of knowledge from the bottom, "the frontline," to the top, policy level (Feierman et al., 2010). While the work on the ground is informed by the global context, the voices of the patients and their caregivers will complement the work. Reviews of global mental health can be found, inter alia, in *Global Mental Health: Principles and Practices* edited by Vikram Patel and Harry Minas (Patel et al., 2013); in *Global Mental Health: Anthropological Perspectives* by Brandon Kohrt and Emily Mendenhall (Kohrt and Mendenhall, 2015)*;* and in *Reimagining Global Health: An Introduction* by Farmer and colleagues (Farmer et al., 2013).

Study Setting: Haiti's Central Plateau and Artibonite Departments

This study was conducted in two rural *departments* in the ZL catchment area in Central Haiti, and the Artibonite Valley, respectively: Mirebalais; and Petite-Rivière de L'Artibonite. As other rural areas in Haiti, they are comprised of a district that is more populated, usually around the market place, health center or hospital and other infrastructure, and of a more remote and less densely populated mountainous districts, lacking basic services. Study participants include persons coming from urban centers as well as those from remote rural places. Relevant demographic, social, economic, political and historical elements of the history of Haiti will be provided for additional context.

Haïti, Two Countries in one: Port-au-Prince and the *Peyi Andeyò* (The Outside-Country)

The marked divide between peasantry and the bourgeoisie living in Port-au-Prince and the concentration of all state services in the capital city have led Haitians to talk about Haiti as if it was divided into two countries: Port-au-Prince and the *Peyi Andeyò* ("Outside-country" representing all other provincial towns and the countryside) (Barthelemy, 1991). This has historical origins. In the wake of its independence in 1804, Haiti was standing on the ashes of what was formerly the richest French colony, Saint-Domingue, created through the elimination of the local indigenous population and the subsequent exploitation of the land and of people brought by force from the African Continent over several centuries. In 1804, the new nation of Haiti was the first free black republic, created by armed revolt and the liberation of slaves over the French slaveholders. The new Haitian elite, composed of freed men, descendants of colonizers and of independence war generals, denied the long overdue right to land ownership to the mass of former slaves who fought under their command for independence. The supreme leader of the war of independence, Jean-Jacques Dessalines, who planned an equitable distribution of wealth, was assassinated in 1806. Gerard Barthélémy, a French anthropologist, identified the dominant oligarchy as "*créoles*" (born in the colony) and the mass of former slaves, born in Africa or in "*marronage*[7]" in the colony, as "*bossal"*[8]. *Marronnage* in the colony of Saint-Domingue was the phenomenon by which persons escaped their conditions of slavery, and in most cases established independent communities living in poorly accessible places in the mountains, continuing to resist and undermine the colonial order through various strategies. The *Creole,* or post-colonial culture, writes Haitian sociologist Jean Casimir, continues to be a domineering culture with its particular model of production (the big plantations, French literature and fashion, etc.), with French as the official language, Catholicism as the state religion, and with ways of life that are modeled on the former colonizer. The *culture bossale* is the oppressed culture held mostly by Africans and those of African descent—those "whose fathers are in Africa," as Dessalines put it—and former *marrons*, (from the Spanish work *cimarrón,* wild), who would constitute the peasant mass after the independence of 1804 (Casimir 2001, p. 60).

Compelling the masses to unequal life conditions that included a mode of production reminding them of slavery, the post-colonial ruling classes promoted the flight of people to the mountains where there was no infrastructure at all and where the "oppressed culture" would survive, but was confined without the means to develop itself (Casimir, 2001, p. 148).

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[7] Defined later in the same paragraph

[8] Defined later in the same paragraph

Components of the oppressed culture include the small, familial, agricultural exploitations (*petite propriété*) (Pierre, 2015), the extended family as social unit living in a *lakou* (a compound usually on the common ancestor's land), *Vodou* religion, the Haitian traditional medicine, and *plasaj* (traditional form of marital union) instead of wedding in Christian religions, etc.. Other components include values of respect for seniors and for family ancestors, and a sense of communal familiarity (propinquity). Casimir sees this move away from the state as a continuation of the *maronnage* after independence (Casimir, 2001). This phenomenon persisted after independence since the state continued to be oppressive toward this population. The rural code, i.e. the civil and the penal laws as they affect the rural population, reflect many aspects of the *Code Noir*, the "Black Code" of the former colony (Blancpain, 2003). This situation contributed to the establishment of peasants in very remote mountainous areas, far from any basic infrastructure. The Haitian State has continued, to this day, to reinforce the exclusion and marginalization of this population. Though oppressed, the culture that was created in those rural communities survived with its particularities, its own values and way of organizing life. In his book *Le Pays en Dehors* (The Outside Country), Barthélémy qualifies the organization of life in the rural areas as an egalitarian system "without a state" (Barthélémy, 1991, p. 15).

The "Oppressed culture" in Religion in Haiti: "The Missing[9]" Religion

Catholicism was the official religion of Haiti until 1987. Since 1860 when Haiti signed the *Concordat* as part of its search of recognition among the powerful countries of that time, Catholicism dominated the religious arena and was presented as the religion of the vast majority

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[9] This title refers to the work of Amartya Sen in the *Missing Women* (Sen, 1992), showing how a group (in that case, women particularly in Asia) is missing in statistics because of structural violence such as gender inequality in its diverse manifestations.

of Haitians. However, Vodou, another religion that is widespread and has enormous importance in Haitian history and culture, is often overlooked or misrepresented. *Vodou is* a religion of African origin, developed in the Saint-Domingue colony and tinted with Catholic syncretism. The general revolt leading to independence was kicked off with a Vodou ceremony in the North of the country (Metraux, 1958; Price-Mars, 1928). It was the object of many organized persecutions through the 19th and first half of the 20th centuries. The prohibition on Vodou practices had not changed much from before independence and the time of slavery. As a consequence, Vodou is barely represented in statistics about religion in Haiti, and its true impact is unappreciated. Vodou is not a hierarchical religion nor is its organization clearly described from the perspective of governance or regulation. Only over the past several decades have attempts been made to have Vodou present as a national and political entity. The biochemist Max Beauvoir, who died recently, was the first *Ati national* (the highest Vodou authority in the country). Despite these efforts, there is not a clear regulation of the work of the Vodou priests.

We observe this absence of regulation in the Protestant sector as well. Protestant denominations have expanded since the 1920s (the time of the US military occupation of Haiti) and more extensively over the past three decades (Fontus, 2001; Hurbon, 2006) with 14.4% of the population Protestant in 1971, and 28.8% in 2003. Meanwhile, Catholicism, which was declared the religion of 84% of the population in 1950 is shown to have reduced to 55% in the last census conducted in 2003 (IHSI, 2009). In this 2003 census, Baptists and Pentecostals comprise 15.7% and 7.9% of the population, respectively, with 10.2 % of people practicing no religion. Francois Houtart and Anselme Rémy have considered those above-mentioned 2003 data and various cited surveys, proposing that Protestantism was about to become the religion of the majority in Haiti (Francois and Remy, 1997). Vodou comprises 2.1% in those official censuses

(CIA, 2016; IHSI, 2009); however, it is largely recognized that in the communities that are called Catholic or Protestant, many people also practice Vodou and hold religious beliefs that are characteristic to Vodou. In fact, the 2003 census carefully notes that the religious syncretism explains concomitant practice of Vodou and other religions (IHSI, 2009). Official statistics on religion are misleading and, without proposing that all or most Haitians are Vodou practitioners as some tend to, it is important to note that Vodou practitioners have been underreported in statistics about religion in the country. A thorough review of Vodou in Haiti can be found in *Ainsi Parla l'Oncle* by Jean Price-Mars (Price-Mars, 1928) and in *Voodoo in Haiti* by Alfred Métraux and translated into English by Charteris (Métraux and Charteris, 1972).

Health and socio-economic context of Haiti

Haiti remains one of the countries in the world with the harshest economic disparities with a Gini coefficient of 59.2 in 2013 (it is 47.1 in the Dominican Republic and 41.1 in the US) (World Bank, 2013). In 2012, the top 1% percent of the population lived on almost 50% of the total wealth of the population (Singh and Barton-Dock, 2015). According to a 2015 World Bank report, only 35% of Haitians have access to electricity and only 11% have access to it in the rural areas. Only 40% of the population living in the rural areas has a passable road in all weather. The same report found that "not having money" to go to health facility is the most important obstacle to access to care, and distance is the second most important one (Singh and Barton-Dock, 2015). In 2013, 59% of the Haitian population was below the poverty line and 24.38 % under the extreme poverty line. While extreme poverty has decreased in metropolitan areas, from 20% to 5% from 2000 to 2012 (Institut Haïtien de Statistique et d'Informatique (IHSI), 2014; Programme des Nations Unies pour le développement (PNUD), 2014; Singh and Barton-Dock, 2015), probably due in part to the flow of "cash-for-work" jobs created in the wake of the earthquake, from 2000 to 2012 it has increased in rural areas from 37.6% to 37.8%. Enormous disparities exist between the poverty rates in rural and urban areas. From 5% in Port-au-Prince, extreme poverty increases to 12% in other urban areas and to 37.8% in rural areas (Singh and Barton-Dock, 2015). The MOH estimated in 2012 that the formal system of healthcare covers only 47% of the population (OPS/OMS, 2012). This helps to explain the heavy reliance on traditional medicine described below. Expenditures on health and mental health are presented later in the section regarding the current mental health system.

Traditional medicine in Haiti

According to the MOH, 70% of people in Haiti rely on traditional medicine as their first option for care (OPS/OMS, 2012). We consider traditional medicine in its broad sense here. In Haiti it involves a range of treatment from using leaves, to massage, bone setting, and other forms of spiritual healing by *oungans*, Freemasons, and Christian spiritual healers. But often the spiritual healers also use herbal or those other kinds of treatments along with their spiritual ones as well. The *oungans* are also specialists of medicinal herbs.

Nicolas Vornax differentiated folk medicine (*médicine populaire),* which is a shared set of heterogeneous knowledge, practices and remedies, from specialized traditional medicine, managed by delivering practitioners, herbalists (*medsen fèy), and* Vodou health practitioners (Vonarx, 2008). What Vornax called *folk medicine* often rests on a religious frame. Folk medicine can be conducted by the one who suffers from the illness, a member of the family (often the oldest), or by a non-religious expert in the matter.

There are no systematic scientific studies of efficacy of Haitian Vodou practices on health-related issues; however, Kiev and Mars praised the assets of Vodou healing practices

(Kiev, 1961; Mars and Devereux, 1980; Mars, 1950). Globally, more studies are being done in LMICs assessing the effectiveness of traditional practices, including on the psychosocial components of such practices (Abbo, 2011; Abbo et al., 2012). A review conducted by Gareth Nortje reports that there is no evidence of their effectiveness for the treatment of severe mental disorders (Nortje et al., 2016).

Natural and "Unnatural" Disasters in Haiti

Farmer points to the unnatural contributors to the devastation caused by the 2010 Haiti earthquake in *Haiti after the Earthquake:* "The disaster on January 12, 2010, was an unnatural disaster at the dangerous intersection of a natural trigger (the magnitude 7.0 earthquake centered 13 km below the Carrefour neighborhood of Port-au-Prince) and an absolutely unnatural vulnerability created in Haiti by centuries of political, economic, environmental, and social forces" (Lyon, 2011b, p. 313). This qualification can easily apply also to the long series of disasters that Haiti has suffered in the past. The absence of environmental policies, of urban planning, the economic and social policies leading the impoverishment of the country, deforestation in rural areas, terrible living and housing conditions in slums and elsewhere, the absence of a healthcare system and of a disaster response system—all of these constitute the unnatural factors that have caused the ravages seen after the natural "triggers" of disasters.

Of the nations of Central America and the Caribbean region, Haiti ranks at the top for having, from 1971 to 2014, the highest number of natural disasters (Singh and Barton-Dock, 2015). In 2008 tropical storm Jeanne flooded the city of Gonaives in the Artibonite Department, killing approximately 3,000 people. A number of hurricanes, floods and landslides had plagued

Haiti leading up to the apocalyptic 2010 earthquake. The last major earthquake was in 1842, destroying the town of Cap-Haitian.

The toll of the January 12, 2010 earthquake is unimaginable. Estimates of deaths was 220,000 (Farmer, 2011b, p.119), with 1.5 million people displaced and the equivalent of 120% of the GDP buried under the rubble (Singh and Barton-Dock, 2015). The resulting mental health needs were overwhelming yet incompletely documented. It added to the already unmet needs and chronic traumas of the population. Dr. Bijoux, a psychiatrist who has been advocating for psychiatry in Haiti for decades, vividly evoked this revelation of needs, saying that, "it is when there is a fire in the slum that you come to notice how many disabled people were living there" (Bijoux, 2011). The cholera epidemic broke out ten months after the earthquake. The possible first case of cholera was a man with severe untreated mental illness (Ivers and Walton, 2012). There was not an adequate mental health system to take care of him. Lacking judgment, he drank from the river and became sick with cholera. Stigma, poverty and other structural barriers kept his family from taking him to the hospital, which led to his death. But after his death, his family and other people who cared for him at home got infected also with cholera. Again, the absence of an adequate health care delivery system contributed to the disaster of his death but is also linked to this broader disaster of the cholera epidemic toll, which killed 8540 people between October 2010 and February 2014 (UN, 2014).

Mental health throughout Haitian history

The historians of the colony of Saint-Domingue mention no structures to take care of psychiatric disorders. Gabriel Debien reported that madness and epilepsy were considered included within the category of "redhibitory diseases," meaning that if those diseases revealed themselves within one year after purchase, a slave could be returned to the seller (Debien, 1975). Those diseases could also depreciate the financial value of a crew of slaves in the slaver boat (Debien, 1975). Slave health in the colony, according to the same author, was conducted for the "conservation of the slaves," that is, the preservation of the labor force. Consequently they sometimes treated them against their will and restrained them in "barres" (two heavy pieces of wood placed on top of each other with two rings where the feet of the sick slave were placed). This practice is still used today in very remote areas to retain persons with florid psychosis. This provision of healthcare for preserving the labor power also explains why pregnant women were sometimes visited once a week by the plantation health practitioner to ensure the health of the baby in a context where the matrons and the mothers sometimes killed their babies to save them from a life of slavery (Casimir, 2001). After independence, Dr. Ary Bordes explains, mentally ill persons were "either kept at home or treated by healers in the countryside, or put in jail" (Bordes, 1992) when not wandering the streets (Bijoux 2011). The situation remained the same until the 1930's, after the American occupation.

The provision of healthcare during the American occupation strictly followed the distribution of US Marines on the Haitian landscape. No service was provided to the mentally ill. In 1926, after the Marines abandoned a military training camp at Pont Beudet, north of Port-au-Prince, the site of encampment was used to incarcerate mentally ill people and underage children in contravention with the police. This place still exists as one of the two psychiatric institutions of the country and is still called "camp'' (written 'kenp' in Kreyòl") by the population (Bordes, 1992, p. 161). In 1936, Dr. Mars started a campaign to improve psychiatric care, which would culminated in the foundation of the Haiti Psychiatric Institute, known today as the Centre Psychiatrique Mars and Kline, in downtown Port-au-Prince.

Mental Health in Contemporary Haiti

The foundational principle of the movement of Dr. Mars and his colleagues to establish mental health services in Haiti beyond the locked hospital have to date not been realized. There are still only two poorly equipped state psychiatric facilities in the country, both located in the capital city. The 2011 WHO *Atlas on Mental Health* reported statistics of 20 psychiatrists per 100,000 people with a rate of training of 0.01 per 100,000, the number of psychologists is 0.04 per 100,000, and the rate of training is 0.11 per 100,000 (Department of Mental Health and Substance Abuse, 2014). In 2014, according WHO, there were 0.07 psychiatrists per 100,000 people in Haiti, which equals 7 psychiatrists for 10 million people (WHO, 2015). By comparison, the Dominican Republic, a country sharing the same island, had 1.08 psychiatrists per 100,000 of people, 15 times more for a similar number of people (WHO, 2008, 2015).

The health budget for Haiti for 2013-2014 (the last one voted) represented 5.56% of the total budget (MEF[10] HAITI 2014), with the mental health budget only 0.61% of the Health budget (WHO, Department of Mental Health and Substance Abuse 2014). Usually over 90% of the budget is allocated for salaries and often none for services like medication. The 2015 World Bank report (op. cit.) informs us that 50% of the total health expenditure comes from NGOs. The current total annual budget for Mars and Kline, a hospital with sixty beds but housing more than 100 patients, is estimated to be $30,000 US (personal communication, E. Eustache and Dr. Jeanny Girard). Since the catastrophic 2010 earthquake, mental health was recognized as more of a priority by the MOH, but without financial commitment. The mission of coordinating and advancing mental health in the country remained with the inpatient mental health unit.

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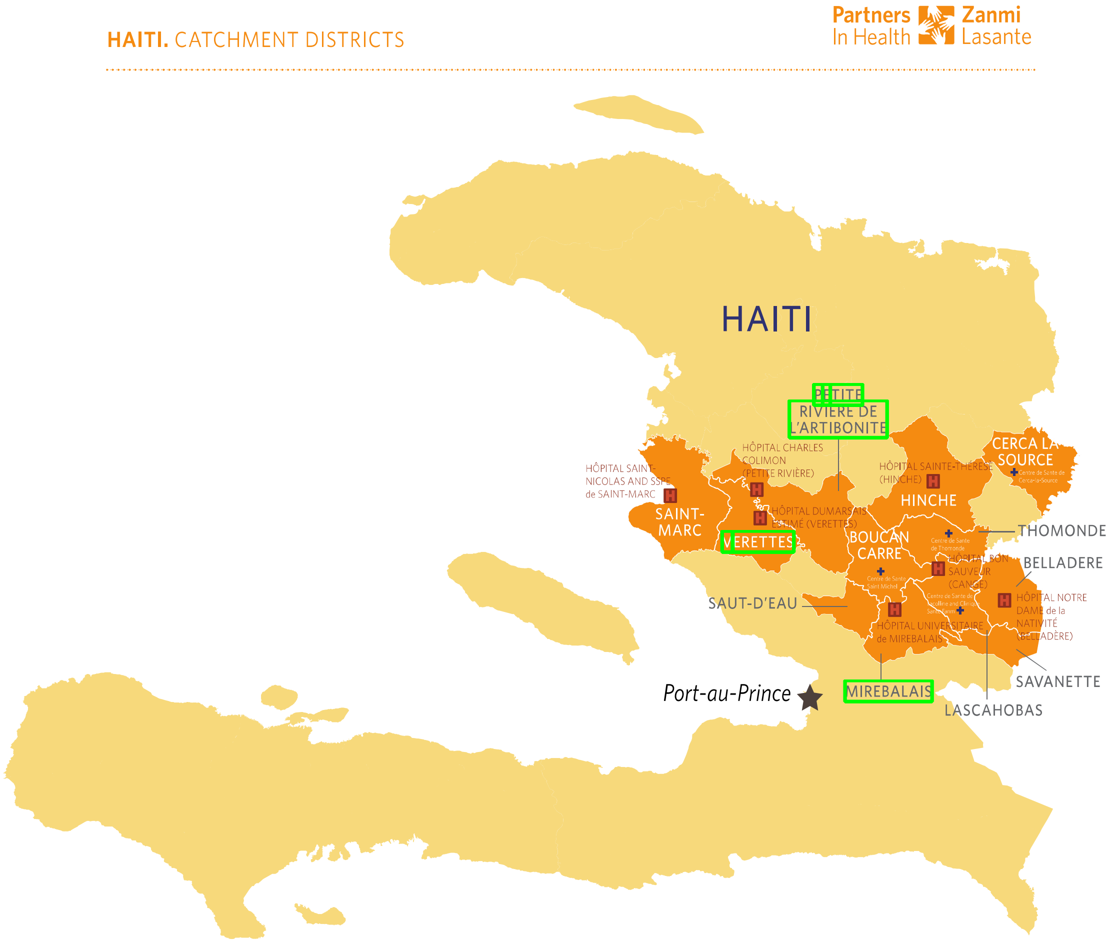
[10] MEF: Ministère de l’Économie et des Finances (Haiti Ministry of Economy and Finances)

The Study Sites: Mirebalais (Centre department) and Tirivyè (Artibonite department)

Fig. 2[11]. -



The terms *départments*, "*arrondissements*," and "*communes*" represent geographical, administrative and political subdivisions of the country. Haiti is divided into ten (10) *départments*, each department is subdivided into *arrondissements*, and each arrondissement is

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[11] The study sites are pointed to and written in green. The map is the courtesy of the PIH IT team on the 29th of April 2016.

subdivided into *communes*. Each commune is subdivided into *sections communales* and the *sections communales* usually run from level of the paved road or the level of the market town to very far in the mountains where no infrastructure exists at all. Site one of our work is in the *arrondissement* of Mirebalais, located in the Centre *département* (also known as the Central Plateau or *Plateau Central* due to its location and elevation in the hills), bordering the Dominican Republic and the only landlocked department in Haiti. Site two of our work is Petite-Rivière, a *commune* in the department of the Artibonite *département*, neighboring the Centre department on the east. PIH/ZL serves, collectively, 1.3 million people living in these two departments, about one-sixth of the population of Haiti.

Most of the study participants live in rural areas. Only three of them live in the market town. The informants in rural areas live in two or three room houses covered with corrugated tin roofs, walled with palm planks, or with mud clay applied to a grid of intertwined branches (*kay masonnen*). They are often in a *lakou*, a compound, where other family members of one of the couple also live. The lakou usually has a small plot of land for cultivation of fruits and other vegetables, most of which are seasonal. During our research the peasants in countryside were enduring several months without rain and all of the fields were experiencing significant drought.

Mirebalais is the second largest town (after Hinche) in the Central Plateau, with 689,705 inhabitants in 2010 (IHSI, 2012) (See map in Fig. 1). It hosts the University Hospital of Mirebalais (HUM), supported by PIH/ZL and where most of the patients in our study are followed. Mirebalais and the Central Plateau have a long history of political resistance. During the time of the French colonization, the mountains of Mirebalais (especially in the south of

Mirebalais, in Fon Dyab) sheltered many *marron* communities[12] (Casimir 2001, p. 63). Later, the region had been one of the main theaters of the peasants' struggle led by Charlemagne Péralte and Benoit Batraville against the American occupation. The American, Ulysses Weatherly, reported in his journals that the US occupiers built roads and other infrastructure for military purposes. Inhabitants in the Central Plateau report anecdotally that the places where they have roads are places where the marines needed to pass by with heavy machine guns to track the Haitian rebels. Weatherly alleged that in remote mountains building main highways would have been like building "body without limbs" for the people living there, and that "trails are the vital need". After violently shattering the revolt in that region, the US Marines established themselves there and opened a military hospital under five tents in the Meille area in the south of the city in 1920 (Bordes, 1992), in the same area where one hundred years later a UN military encampment will occasion the cholera outbreak (Chin et al., 2011).

The Centre department has a poverty rate of 34% compared to 44% in Northeast Haiti (the highest) and 10% in West, the lowest in the metropolitan area (IHSI 2014). The main economic activities in the area are commerce and agriculture. Until 2011, the only link between the Central Plateau and the capital was an unpaved road carved along steep mountains and cliffs. The department has suffered from deforestation, and migration to the Dominican Republic in search of work is very common. In 2001, almost 20% of the population had a parent living in the Dominican Republic (IHSI, 2002). However, the population of the Centre department is vibrant and the department has beautiful natural scenic areas. It hosts one of the major hydroelectric

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[12] Societies developed by those who are in marronnage. Marronage is defined earlier in the text.

dams of the country and the biggest river in the country flows across it to the Artibonite department and the sea.

ZL was founded in 1987 in Cange, a locality in the Centre department approximately 20 kilometers from Mirebalais. The organization progressively expanded from Cange to all of the other main towns in the Central Plateau and the Artibonite, and settled in Mirebalais in 2011 as a new main site in the post-earthquake situation due to the southernmost proximity of Mirebalais to the capital city Port-au-Prince. Since its opening in 2013, HUM has employed three psychologists, two social workers and a number of social workers assistants, and a visiting psychiatrist/fellow from PIH and Harvard Medical School, who together constitute the mental health team there. The leadership and clinical supervisory team of the ZL Mental Health program also make HUM their administrative base, traveling to the other sites from HUM, and also staffing a mobile mental health team that travels to hard-to-reach rural areas.

Petite-Rivière de l'Artibonite (or in Kreyòl, Tirivyè) is a commune in the lower Artibonite region, with 1,596,659 inhabitants in 2010 (IHSI, 2012). It shares borders with Verrettes and Mirebalais, two other areas where some of our informants live. Historically, Tirivyè was the scene of several memorable battles during the Haitian War of Independence. The most famous one is the battle of Crete-à-Pierrot, where a fortress remains. Later, during the American occupation, it was also the bastion of a group of *Cacos*, a group of peasants, characterized as "without land" by some, from the North and the Artibonite, who rebelled against many successive governments in the country from the end of the 19th to the beginning of the 20th centuries (Casimir, 2001). Agriculture is the main economic activity of Tirivyè. Considering the importance of agriculture as well as the history, peasants have always been engaged in efforts to have access to land since independence. The forced labor (*corvée*) and massive expropriation of the local population by US Marines in the first half of the 20th century triggered armed resistance in the region, in the Central Plateau and in many other places in the country.

The issue of land ownership has been an ongoing problem that the nation has not resolved since independence. The state owns 11% of all cultivable soil in the country (E. Pierre, 2015). Thus, the Artibonite, one of the main agricultural region in the country, is known for often having land-related conflicts, sometimes bloody, among people living there, and for resistance against outsiders.

The Artibonite is also recognized also as a region where Vodou traditions have been well conserved. Many highly symbolic and important Vodou pilgrimage sites (Lakou Souvnans, Lakou Soukri, Lakou Badjo) are found in Gonaives not far from Tirivyè. The proximity of the Artibonite River allows the production of rice as in the neighboring other communes. Rice production in Haiti has been victim of the imposition of neo-liberal economic policies on the country starting at the end of the 1980s that forced the government to decrease subsidies to farmers, and lower customs controls and taxes. This strongly impacted the lives of the farmers in the Artibonite including Tirivyè. These economic policies led to the invasion of the Haitian market with highly subsidized rice and other products from the US, and led to the subsequent shutdown of the production of rice in the Artibonite. U.S. President Bill Clinton, in an address to Congress, recognized and expressed an apology for the US policy (Farmer, 2011a; Hurbon, 1987; Soukar, 2005). The poverty rate in the Artibonite in 2003 was 68% and 89% for extreme poverty rate defined as having less than 1 U.S. Dollar per day.

The ZL/MOH health facility in Tirivyè, L’hôpital Charles Colimon, linked to a larger facility in the large nearby city of St. Marc, is a small hospital in a rural area that provides general consultations, emergency services, obstetrical and gynecology services, and hospitalization. Since 2010 there has been a psychologist, a social worker and several social work assistants, who are linked to and receiving supervision and support from the ZL Mental Health team based at Mirebalais, and who constitute the institutional mental health team there.

METHODS

The study design was cross-sectional and used well-established qualitative methods, which were optimally suited to the study aims. The data collection tools consisted of in-depth interviews, participant observation, focus groups, and field notes which were submitted to a systematic inductive process of analysis. The research methods have as their foundation a social constructivist paradigm (Bernard, 2006; Creswell, 2007) informed by several underlying principles. Some scholars have argued that recovery is a social and cultural construction (A. Adeponle, Kirmayer). Others have agreed that there is a personal component to recovery (Anthony et al. 2002; Deegan 1996; Farkas 1996, 2007a; Slade 2010). This personal component entails the involvement of his or her “local moral worlds,”[13] a concept described by Arthur Kleinman. The notion of Kleinman’s *local moral worlds* is defined, in the book *Pain as Human Experience*, as “particular, intersubjective, and constitutive of the lived flow of experience. They are not simply reflections of the macro-level socioeconomic and political forces, though they are strongly influenced by such forces. Within local moral worlds, the micro-level politics of social

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[13] In a class given at Harvard University in the summer of 2014, Kleinman defined “local world” as “the networks of relationships and communities in which we live and experience social life” or moral life, I could add, in the case of “local moral worlds.”

formation and social relationships, in the setting of limited resources and life chances, underwrite processes of contesting and negotiating actions" (Kleinman 1992, p. 171-172). This notion is used throughout this work to refer to those particular, but still intersubjective local contexts, say either in a poor *lakou* in the rural area, or in a psychiatric institution in Port-au-Prince in which our informants are negotiating moral actions. An open and participatory approach in this research also allowed the local contexts and voices to shape the research while avoiding the systematic bias of missing or dismissing realities that we did not know *a priori,* which do not fit our theory or our framework. Constructivism will allow us to be open and account for any ideas coming from any participants and thus will favor the voices of marginalized and forgotten people. This research could also be categorized under the advocacy/participatory paradigm (Creswell, 2007). Beyond seeking to understand, we aim to bring silenced voices forward and to advocate for change in their living conditions.

Two qualitative approaches are used in the design of this research so that it can respond to the interrogations that are posed. We use both a phenomenological approach, seeking to deeply understand the experience of the persons with lived experience of psychosis and their experience of the recovery process and an ethnographic approach through participant observation to capture how culture interplays with the experience of those who are suffering or who have suffered from psychosis (Creswell 2007, p. 151-159).

Study Participants, Procedures and Recruitment

We used a purposive maximal variety sampling approach to recruit respondents. This has allowed us to have a variety of different perspectives. The respondents included: persons with lived experience of psychosis; the caregivers of the persons with lived experience of psychosis who participated in the study; community leaders (including protestant pastors, Vodou priest [oungan] and teachers); CHWs, medical doctors and nurses; psychologists and social workers; and national policy leaders. Three focus groups were conducted, one with each of these three groups: 1) Psychologists and social workers; 2) Physicians and nurses; and 3) CHWs, religious leaders, traditional medicine providers and teachers. Concurrent to the focus group discussion interviews, we started the first phase of our in-depth individual qualitative interviews with persons with lived experience and their caregivers. After the first or the second interview, we selected a group for participant observation based on their willingness to participate and on the degree to which their cases illustrated the issues mentioned in the study.

Research timeline (Table 2)

Months **-----------** **Activities**	**June 2015**	**July 2015**	**August 2015**	**September 2015**	**October 2015**	**Nov. 2015**	**Dec 2015**	**Jan 2016**	**Feb. 2016**	**March 2016**	**April 2016**
Harvard IRB approval		X									
ZL IRB Application		X									
ZL IRB approval					X						
Focus Groups					X	X					
In-depth Interviews					X	X	X	X	X		
Participant observation						X	X	X			
Data analysis								X	X	X	X
Thesis writing									X	X	X

The study protocol was formulated after informally speaking with key informants, including one person with lived experience of psychosis, one community leader, one national leader and several local providers, in January 2015. After receiving Harvard and ZL IRB approval the study was begun on October 6, 2015, with the first provider focus group (the psychologist/ social workers FG). The first group invited to participate were the psychologists who are the leaders of the ZL mental health system. The psychologists also agreed to identify physicians, nurses, and social workers who have cared for persons with psychosis at their respective sites. With those other categories of providers the researcher followed the same recruitment process as he did for the psychologists. Written informed consent was obtained from all the providers. The recruitment of the persons with lived experience of psychosis happened also through the mediation of the psychologist in HUM and Tirivyè.

Persons with lived experience of psychosis were divided into two groups: 1) those already treated at a ZL health facility; and 2) those not yet treated and who were recruited directly in their community by the local investigator. For all of them, the psychologists working at the ZL health facility conducted a clinical assessment and verified whether they met the study inclusion criteria before asking them if they were interested in being contacted by the researcher about the study. The purpose of the clinical assessment and verification by the psychologists was to determine:

- Any illness that would makes it potentially harmful for the patient to participate in the research.
- The level of severity of the patient's cognitive impairment (according to their clinical assessment), allowing them to understand the nature of the research and to provide informed consent. The psychologist used a translated version the Mini Mental Status Exam (MMSE) to determine the level of severity of the persons with lived experience of psychosis (Folstein,

Folstein, & McHugh, 1975). The MMSE scale ranges from zero to 30, with 18 being the conventional upper threshold for moderate cognitive impairment. A score of 18 or above was chosen as an inclusion criteria for the study. Adjustments were made for persons with limited literacy or illiteracy based on the indications provided in the Folstein paper (cited earlier) and a study conducted in India among illiterate population (Derouesne et al., 1999; Folstein, Folstein, and McHugh, 1975; Ganguli et al., 1995). Professor Dérouesné gave permission to translate his version into Haitian Creole (personal communication through e-mail, 9/17/15).

- The psychologist checked whether they met the criteria for the study. The main inclusion criteria comprised: being a person of Haitian nationality of at least 18 years of age; having a history of psychosis (current or past), living in the HUM, Tirivyè or Verettes catchment areas, and having given informed consent. The full list of inclusion and exclusion criteria can be found in Appendix 4.

At the conclusion of the evaluation, if the person was assessed to be eligible for the study, the psychologist asked the patient whether s/he would be willing to be contacted and have his/her contact information passed on to a researcher in order to be invited to take part in the research project. From those responses the psychologist developed a list of potential participants, with the names of those who agreed to be contacted. From this list provided by the psychologists, the local investigator purposefully chose the participants meeting the inclusion criteria to be contacted. The researcher contacted them by phone or through their CHW to schedule a meeting with them at their convenience, in order to describe the study to them and to invite them to participate. Among six persons who were not yet on treatment before the study, and who were enrolled in care by the researcher during the recruitment phase in the communities, two of them did not make the list of the study because they did not meet eligibility criteria before the end of the study. They continued to receive care at the health facility, but did not take part in the study. The other four participants who ended up meeting the criteria while in care (n=4) had first been enrolled in care and were invited to participate in the study only after an evaluation by their provider (as described above), who decided whether or not they could participate in the study. One person from the complete list provided by the psychologists declined to participate, explaining that he would prefer to participate after he was cured. The persons with lived experience of psychosis were asked to designate one of their caregivers to be invited to participate in the study, and to provide consent for the participation of their relative in the study.

Most of the participants (92%) preferred to be met at home. A dual consent process was developed for the initial meeting at which time the study was described to the persons with lived experience of psychosis and the caregiver together and the consent forms were read to them. It was explained that, in order to ensure protection of their human rights, the agreement of the caregiver was a condition for the participation of the person with lived experience of psychosis. After clarification of any questions, misunderstandings or concerns, the participants were invited together to provide oral consent, which was recorded. All participants agreed to have the first interview the day of the consent and at the end of the initial meeting. A plan was made collaboratively to meet again if needed and convenient for the participants. The interview of the person with lived experience of psychosis and the interview with the caregiver were completed separately and individually, unless the interviewee preferred it otherwise.

Interviews with persons with lived experience of psychosis and family caregivers

Interviews with persons with lived experience and family caregivers were planned to be approximately one hour in duration, and in Haitian Creole. Although we had notified participants that we wanted to avoid taking too much of their time, participants often expressed an interest in speaking longer, with some going over two hours in duration. The interviews mainly covered demographic data, history of illness and treatment including history of care seeking, social functioning, current treatment and results, the lived experience of psychosis, perception of the experience of psychosis, personal vision of and hope for recovery, and resources for recovery.

Two assessment tools were used with each person with lived experience of psychosis to measure functioning and to develop a clinical profile. Besides the evaluation of the mental status exam by the site psychologist, the WHO Disability Assessment Schedule, 12-item version (WHODAS 2.0) and the Brief Psychotic Rating Scale (BPRS) were used in the interview. Figure 5 presents the average score for each symptom on the BPRS, aggregated for persons with lived experience of psychosis. The WHODAS 2.0, according the WHO manual (WHO, 2010) is a tool that can measure health and disability both at population and at clinical level. We used it at the latter level in this study. The WHODAS 2.0 measures the level of functioning in six different domains of life: 1) understanding and communicating, cognition; 2) moving and getting around, mobility; 3) attending to one's hygiene, dressing, eating and staying alone; 4) interacting with people, getting along; 5) domestic responsibilities, leisure, work and school; and 6) joining in community activity, participating in society. Vis-à-vis cross-cultural comparability, the manual informs that the WHODAS 2.0 was developed on the basis of a large cross-cultural study. It is directly linked to the International Classification of Functioning, Disability and Health adopted by 191 countries in 2001 (WHO, 2010). The same manual assures that: "Once developed, it [WHODAS 2.0] was tested in a variety of different cultural settings and health populations, and was found to be sensitive to change, regardless of the sociodemographic profile of the study group (Ustun et al., 2001; WHO, 2010; World Health Organization, 2001).

The BPRS measures the severity of 18 symptoms related to psychosis within the day or 2 - 3 days prior to the assessment using a scale from zero to seven. A symptom is graded zero when the symptom is not assessed; one (1) is when the symptom is not present; two (2) when very mildly present; three (3) when mildly present; four (4) when moderate; five (5) when moderately severe; six (6) when severe; and seven (7) when extremely severe. With 18 symptoms graded to 7, the maximum score of the BPRS for one subject is 126. A subject with total score between 0 (zero) and 30 has no notable illness; between 31 and 40 is minimally ill; between 41 and 53 is moderately ill; and over 53 is considered markedly ill. The BPRS is a clinician-administered test (Overall and Gorham, 1988). Translation into Haitian Creole was completed using the language in the previously developed ZL Mental Health Evaluation Form. There was no prior validation of the test in the study setting.

Informed consent was obtained with the same process to conduct *participant observation* with 6 persons with lived experience of psychosis. With their consent, the researcher accompanied each to a regularly scheduled activity. For example, the researcher accompanied some to church, to the field, to the health facility, and in several instances joined them in socializing in their community.

Interviews with providers and policy leaders

The providers interviewed were psychologists, social workers, physicians, nurses and CHWs. They all took part in focus groups following informed consent. The leaders included community leaders including one *oungan*, three protestant pastors, two school principals and teachers, and policy leaders (the director of the national mental health unit, the director of the ZL mental health department, the ZL psychiatric fellow employed by PIH with an academic appointment at Harvard, and the ZL community mental health coordinator). The community leaders took part in the one focus group with the CHWs and individual interviews were conducted with the national policy leaders.

Table 3. shows the total number of participants by category and study site and 4 shows the subgroup of persons with lived experience of psychosis by area where they live, and amount of time since the illness started.

Table 3 - Total number of participants by study site and by category

Categories	**Site** 1	**Site** 2	**Total**
Person with lived experience of psychosis	n=13	11	**24**
Family caregivers	n= 11	11	**22**
National policy leaders	n=5		**5**
CHW	n= 3	n=2	**5**
Religious leaders (oungan and pastors)	n=2	n=1	**3**
Doctors and Nurses	n= 8		**8**
Psychologists and Social workers	5	3	**8**
Total	-	-	**75**

Table 4. - Subgroups of persons with lived experience of psychosis

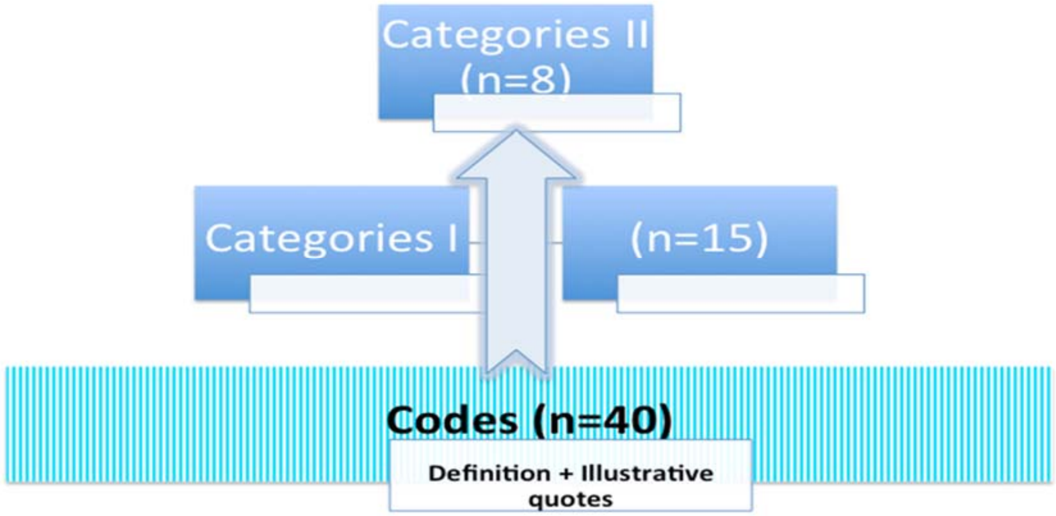
	Remote Rural Places *Men and Women*	**Close to the Village and Health Center** *Men and Women*	**Total** *Men and women*
Less than three years with the illness (according to patient or family)	n=3	n=4	n=4 (4 with less than 3 months)

Between 3 years and 10 years (according to patient or family)	n= 4	n=7	n=11
More than ten years with the illness (according to patient or family)	n=4	n=2	n= 6
Total	n= 11	n= 13	**n= 24**

Data Analysis and Management

The focus groups and all of the first interviews were recorded. Field notes were taken during all parts and phases of the research. Data collection ended on January 19th, 2016. The subsequent data analysis was an iterative and inductive process. First, the local investigator transcribed and reviewed the data. Using the qualitative data analysis software Atlas.ti 7, the local investigator started a process of data reduction with codebook development and coding in February, 2016. Each code had, in an Atlas.ti matrix, a label, a definition and an illustration (an excerpt from the data that illustrates the code). Through axial coding we constructed higher and higher level categories from the codes with the same model (label, definition and illustration) (Creswell 2007 P.151-159; Patton 2014, P. 452-453). The interpretation phase consisted in either linking the categories or framing them within broader theoretical concepts. Prominent qualitative researchers have used similar techniques and process (Ware et al., 2009). At the end of the analysis, in March 2016, we re-contacted some key informants who agreed to participate in a discussion regarding the results of the analysis, and to have their feedback. This constituted a member check aimed at validating the analysis.

Fig. 3 Inductive coding process[14]



Ethical Considerations

The population of persons with lived experience of psychosis represents a vulnerable group. The ethical issues posed by conducting research with this population were addressed at several levels in the study. First, the enrollment was done by the psychologist who had been taking care of the person. The psychologist asked them about their willingness to be contacted by a researcher only after checking all the predetermined criteria, which included the cognitive ability to understand the nature of the research and to consent. The psychologist also judged whether the study would potentially be harmful to the psychological wellness of the person. Only after this preliminary screening were they asked if they were willing to be contacted. If the answer was "yes", they were included on a list for the researcher's review, as described previously. Second, the consent form represents a dual consent process. The researcher explained to each person with lived experience that to ensure that their rights would not be violated they

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[14] This inductive analysis in this research started with 40 codes derived from interviews with the persons with lived experience of psychosis and the caregivers. From those 40 codes were built 15 categories level one (I), which themselves yielded 8 categories level two. (See Fig. II-1)

needed to designate another person who takes or who took care of them to consent for their participation in the study. This same caregiver would consent for him/herself in a separate process. Third, during the interviews or observations, the researcher was respectful, and always reminded the informants that they could choose not to answer any question, or to stop the session at any time, for any or no reason. The researcher is a trained mental health provider who could detect signs of distress and respond appropriately. Finally, the tools used where built in collaboration with the ZL mental health team, including a CHW and a person with lived experience of psychosis who was a mental health activist and educator in his community. This ensured that the project was well aligned with the local care system and with local culture and language terminologies.

IRB approvals were obtained from the Harvard University IRB, the ZL Research Committee and the ZL Ethics Committee.

RESULTS

We present descriptive and explanatory results produced from a systematic inductive process of analysis of data yielded from in-depth interviews, focus groups, and field notes. We begin by providing a view of the sample and the living contexts of the persons with lived experience of psychosis. We do so in two ways: first, we present the biosocial description of one informant in order to provide the reader with a more concrete and vivid conception of the contextual realities from which our data emanates. This case also provides an idea of the kind of participant observation that was conducted. Second, we present tables of descriptive statistics representing a demographic and clinical profile of the study sample. This case presentation is followed by the formal results of the study, consisting of the presentation of the categories inductively built through the analytic process.

A home visit with Maude[15]: the social context of a women recovering from psychosis

In many towns in Haiti, behind the hedges of concrete houses bordering the avenues and boulevards, is an unseen face of the community: the shantytown. The shantytowns frequently run from the avenues to the feet of the neighboring mountains. Mirebalais, although not a very commercial city, has had its shantytowns for years now.

"Maude", a 45 year-old woman, followed at the HUM for a psychotic illness for the past year and a half, arrived in one of those shantytowns in Mirebalais in the mid-90's with her mother, her three brothers and four sisters. Before moving to Mirebalais, the family was living in the mountains of Sarazen, an area whose market place borders another town in the Central Plateau, Lascahobas, at its eastern border. Her father was, like many rural inhabitants, a subsistence farmer and her mother was a *Madan Sara*. A *Madan Sara is a retailer* who buys fruits and other products from the countryside to sell them in the towns, especially the capital. When her father died, most of her younger siblings were infants and young children. This was during the difficult times of the 1991-1994 embargo against Haiti. Following his death their mother needed more steady income to take care of them all. Her uncle, who owned a piece of land in Mirebalais (at a time, she says, when the town was not yet crowded and land was still affordable), offered her mother a place to stay with the children. Her mother at that time intensified her commercial activities, buying foodstuffs from the countryside, as well as Port-au-Prince and a neighboring town, Archahaie, to resell them in Mirebalais. She built a small two-rooms house in Mirebalais, each room about three meters across, to stay with the children. The kids were going to school although they would sometimes lose a three-month session, or even a year of school, because of unpaid tuition. Maude managed to reach 12th grade, with only one year left to finish secondary school.

In 1997, Maude's younger brother, Sonson[16], at the age of 18, presented with the first signs of a mental illness. He spent six months totally withdrawn in a corner of the house, not saying a word to anyone. He grew sicker and sicker. He left the house and started to sleep under the trucks in the street and sometimes was severely beaten when, for instance, he took other people's belongings. Their mother never stopped caring for him; for example, she would ask people to hold him for her, so she could bathe him or feed him. She also prayed for his healing and visited many *oungans* in search of a solution for his problem. The mother explained how difficult it was for her to stop the son from breaking the already frail door of the house to go out the streets in the middle of the night. Exhausted as a caregiver, she decided to send her son to her home village, in Sarazen, where he would be "in less danger" she said, staying with relatives. But there, Sonson would be tied up in the house when he was agitated. She visited him regularly. Meanwhile, the mother developed tuberculosis. She was enrolled in

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[15] Pseudonyms are used to refer to the participants of the study
[16] Idem. Pseudonym

a program with a biosocial approach to care with a strong community network in Cange. This is how the head TB doctor in Cange at the time came to know about her son and how she took him from his home village to a psychiatric center in Port-au-Prince for the first time. For the first time, at that center, her son came to know some improvement.

But the treatment of Sonson came later and included many of the ups and down that other persons followed in the state psychiatric institutions go through. The mother received some level of economic support from her TB program, but going to pick up the medicines was very difficult and they were expensive. When interned in the institution, Beudet, Sonson would sometimes escape from the center and start wandering the streets of Port-au-Prince. The mother explained that she could find him because she knew the roads he usually took. But once she found him, since she could not control him, she became used to shadowing him all day long across Port-au-Prince so she didn't lose him. She recalled that she wasn't sure that people could recognize the difference between who was "crazy" or not, between them, because she was trotting after him, sometimes, barefoot, with her hair unkempt and without a head kerchief in the streets in Port-au-Prince. Sonson was finally taken to the countryside, in the mountains of Sarazen again.

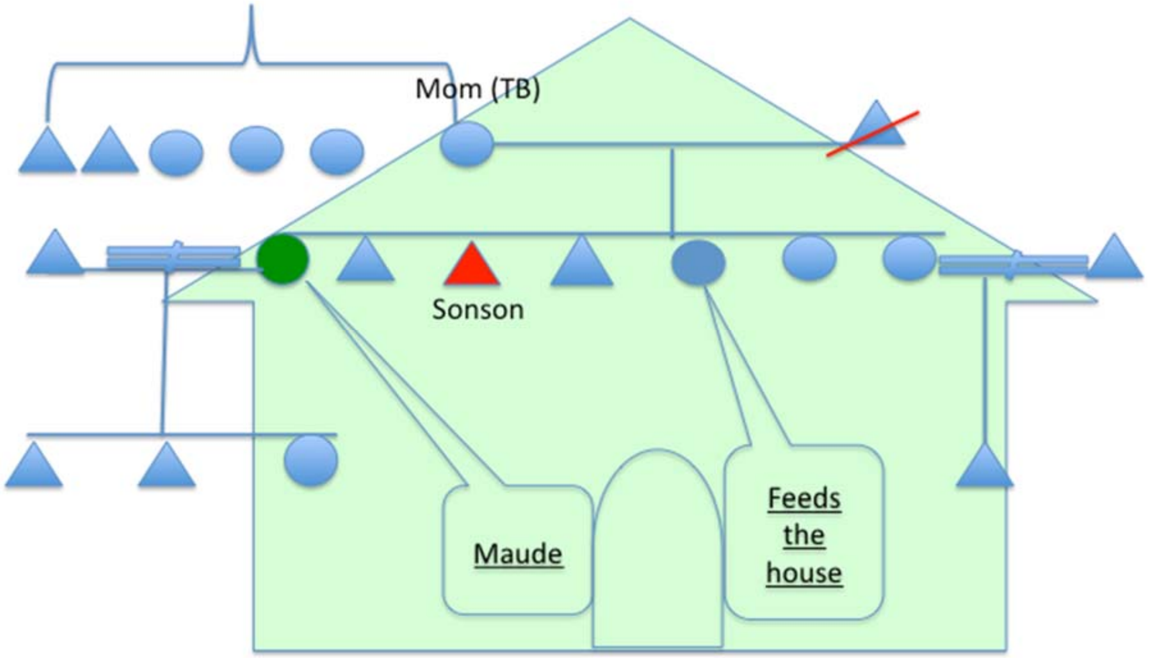
Meanwhile, Maude got married. She already had a girl. She was living not far from their mother in Mirebalais. In 2007, during her second pregnancy, Maude's husband would hit her. One day her mother, on her way back from the open market, found her crying. Her mother sought an explanation from the husband and took Maude home with her. She knew this was a heavy responsibility because Maude was pregnant but she could not tolerate her daughter being beaten. When the baby was born, the husband showed up only after several months. When he came, he apologized to her mother and brought something for the baby. He reconciled with Maude and they moved in together again. But, soon, he started to make Maude make "*move san*", causing angry emotions. Maude was pregnant with a third child, and her husband was again beating her. It was during that period that Maude's illness started. She started to run away, talked a lot, and was physically violent even against her mother.

Maude's oldest child, a daughter, went to stay with a relative, while the two boys stayed with the father, and Maude was sent to Sarazen, where her brother had already been languishing for years. Everyone in the household guiltily recounted, "they stayed there tied up for several years". They did not remember how many years. The mother rented one of the two rooms the family was sharing so she could take care of them and the other children. What ended their confinement was the passage of a group of Protestant missionaries in the area, who took them to Beudet. The years between her first internment at Beudet and her first visit to HUM were alternatively spent confined in the "Camp Beudet", locked at her mother's house, or wandering, floridly psychotic, on the streets of Mirebalais and in neighboring areas. Maude recollected her stays at Beudet as traumatic. The good moments she remembers were the ones when missionaries would come to the center to pray, distribute food, bibles and toiletries for them. Times outside of the "Camp" were even more traumatic if she was sick. Voices were commanding her to go to stay in the woods, but she reports that at night thugs would come and rape her there.

I first met Maude after she had authorized her psychologist to give her contact information for the research study, in October of 2015. Her daughter, who had a telephone, told me that she would wait for me at the house of her mother. It was about 2 PM, a time when the sun of Mirebalais is still at its hottest. The house was at the end of tortuous alley snaking from the main boulevard of the town of Mirebalais between, first, the big concrete buildings overlooking the boulevard, then between a heterogeneous field of huts, almost all covered with corrugated tin roofs, walled, some with degraded concrete, some with mud on the skeleton of intertwined straight branches (*klise*), and some with tarpaulins or a mix of diverse materials. Her house was covered also with corrugated tin and the walls were made of cement mud thrown on a wood weft. The part that faced the road and had a porch was the part that was rented. Their little room, in the rear part, had only one door with a long stick that served as a hook that stopped the door for being opened from outside when turned transversally at night. There was no window. A big bed, well-made with a white bed cloth, occupied 80% of the room. Other furniture included a table whose top had been pushed down by Sonson in a moment of agitation. The other corner had buckets where they kept water.

At the time of our interview everyone in the house was sweating. Their mother, a very warm, agile and cheerful woman, apologized for the heat, to which I answered that she should not worry at all about me and that I was used to the heat. Everyone, seven in total, was gathered inside the room to hear what I was there to say. They offered me a chair near the door. Maude sat on top of a bucket on my right side, and her oldest daughter was on the bed. Her younger sister, in her early thirties, who is now the only one providing food for the house with her commerce of used clothing bought in Port-au-Prince, was sitting on the ground near the table. Finally, another sister who has a baby was coming in and out of the house and Maude's mother, happy for my visit, was standing in front of me with the baby (her grandson), narrating to me the story of the family.

Fig. 4. - Kinship chart. –



My plan naturally changed given the presence of a large group. I was having a general conversation with everyone, and I planned a private conversation with Maude on another day. On this day, Maude was trembling. When I asked her how she was feeling, she explained that at her last appointment at HUM she could not find the diphenhydramine that she usually takes to manage the side effects of the Haldol. I made a plan to take her some right after my visit[17]. She was not trembling at my next visit. She invited me to go to her church with her. She explained to me how much her church matters to her; however, she had difficulty remembering what was taught in the church.

Maude planned to go to church that morning. On the road to the church with Maude, she showed me some shortcuts to go from one street to another that I never knew. We were running late, she was leading the walk with a very fast pace, sometimes even running. I noticed that she was a little tense. When I arrived in the church with her I realized how difficult it must have been for Maude to keep any of the teaching in her mind. It was a church covered with a tin roof, about 25 meters in length and 10 meters in width. A man welcomed me at the entrance and separated me from her. The ladies were on the right side and the gentlemen on the left. The married men sat behind and the unmarried men sat in front. After a first song, the officiant started the "lesson of the day". The points that were about to be made in the lesson were written with white chalk on a board. The board was full of verses and interpretations written in French. After an effort to read the board -I was sitting in the back- I had to give up. The preacher talked for more than two hours in French and Creole, translating the French into Creole, but also translating them into concrete examples naming members of the church who have done good things and bad things. The end of the lesson was mostly about people in the church who were circulating false information about him. At one point he stopped the lesson and intoned a song that everyone sang fervently. The song culminated with several members of the church being "filled with Holy Spirit" (*ranpli* in Creole), and visited by the Holy Spirit. Their bodies went into a trance state, moving frenetically, exclaiming "Béni soit l'Eternel" (Blessed be the Lord!) and speaking in tongues. A woman on Maude's bench was "*ranpli*", but Maude was apparently not. She was waving her hands in the air as a sign of worship. A moment of silence followed. The preacher resumed the lesson and ended it with another song. I left the church before Maude did. On my way back, I recalled that besides the difficulty of remembering the lessons (which I had trouble remembering also), she was also worried because she could not "*ranpli*", meaning that she could not experience that trance state caused by being visited and filled with the Holy Spirit.

Later, I expressed to Maude my appreciation that she had invited me to her church. I admitted to her that I had had difficulty seeing the board and remembering all the points, like her. I asked her whether she would authorize me to share my impressions with her psychologist. She agreed. While discussing her effort to better understand the lessons, Maude began to understand that not everything was her fault. We planned an appointment with the ophthalmologist for her, given her concerns about not being able to see the board well. We found some economic support for Maude so that her first daughter could return to school. Sonson, also followed by the mental health service at HUM, does not currently have signs of psychosis, but he still needs help in many day-to-day tasks. A member of the church where Maude goes had been accompanying Sonson to the hospital when he was recently psychotic and agitated. The last time I spoke with Maude, she had started a small business along the road close to where she lives.

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[17] In the research, I was also supposed to intervene as a ZL mental health provider to relieve any acute suffering during the interviews, observations or focus groups.

Maude's situation is typical in several ways. Most of the women in the sample, though not from the forgotten back alleys of a town, have the same economic background as she. Most have experienced the same abuses that she has. The lives of all my informants with lived experience of psychosis, as well as the lives of their caregivers, have been devastated by the occurrence of the disease. This was true for Maude and Sonson's mother, and the other girls in the family. Finally, although her claims of recovery include a clear spiritual goal that all others did not express, they all have many goals to which they aspire.

Demographic and clinical profiles of the sample

The tables below focus on the study participants with lived experience of psychosis. 54% (13) are women. The mean age of the all the persons with lived experience is 33 year-old with a standard deviation of 8.86. 42% (10) of those informants take more than one hour to arrive to the health facility where they are followed, 25% (6) take more than two hours and the rest of 33% (8) take less than one hour.

Below, we present tables showing a demographic and a clinical profile of our sample.

Table 5. Gender, age, income generating activity, living conditions and travel time to clinic described for persons with lived experience of mental illness.

Profile of persons with lived experience of psychosis		
Gender	Mean Age (STDEV)	Having an Income generating activity

54% women	33 (8.86)	50% (11)

Table 6. Living conditions and travel time to clinic described for persons with lived experience of mental illness.

Living Conditions (N)	67% (16) with relatives	25% (6) with partners	8% (2) alone
Travel time to clinic (STDEV)	Average: 1.15 hour (.9)	42% > 1 hour	25%> 2 hours

Clinical profile

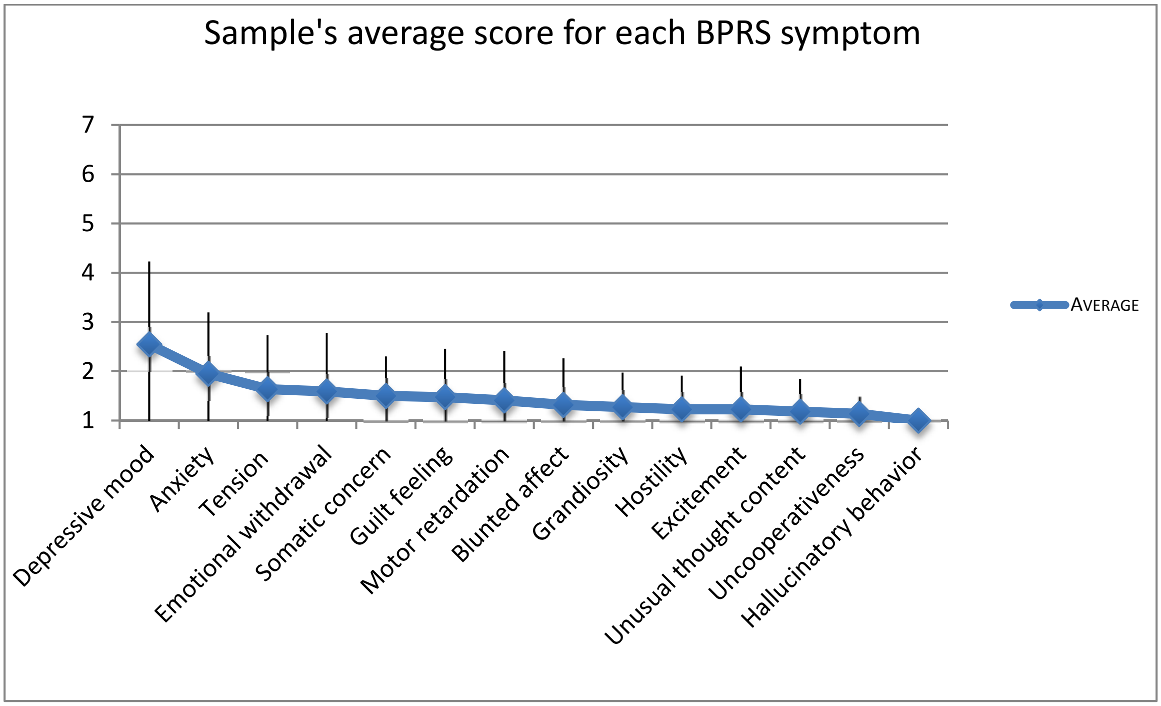
To provide an idea of the functioning and clinical profile of this sample of persons with lived experience of psychosis, we used a measure of functioning, the WHO Disability Assessment Schedule 2.0 (12-item version) (WHODAS) as well as a measure of clinical symptom severity, the Brief Psychotic Rating Scale (BPRS).

Table 7. Scores for WHODAS 2.0 (12-item version) and for Mini Mental Status Exam

Measure (normal range)	WHODAS (0-48)	Mini mental State Exam (0-30)
Mean score (standard deviation)	10 (12.1)	25.2 (4.6)

The following table presents the average score for each symptom on the BPRS (described in the methods section under “Assessment tools”) aggregated for the group of persons with lived experience of psychosis in the study. Any symptoms from which nobody in the sample was suffering were removed from the graph. For example, "mannerism and posturing", "conceptual disorganization", "disorientation" and suspiciousness are not experienced by anyone and have been removed from the table for the sake of simplicity. No study subject was experiencing hallucinatory behavior, but we kept this symptoms in the graphic as an example of symptoms that nobody in the sample experienced.

Figure 5. BPRS sample's average score for each symptom with the standard deviation



The BPRS measures the severity of assessed symptoms with a rating from one to seven. A score of 0 is used when the symptom was not assessed, 1 for the symptom being absent, and 7 with the symptom being extremely severe. Twenty-two participants with lived experience of psychosis out of our total sample of 24 were assessed with the BPRS. The graph in Figure 5 shows that most of the symptoms are absent or very mildly present in the sample (below or equal to two). Depression and anxiety have the highest average score and the standard deviation shows that some participants had a score of four, which is “moderate” on the BPRS scale. Therefore, people in this subsample were not experiencing most symptoms, and were only very mildly experiencing some of the BPRS symptoms. Psychotic symptoms such as hallucinatory behavior, uncooperativeness, excitement, and hostility were not experienced by most and or only very mildly experienced by a few other participants. Three of the four symptoms mentioned above have not been included in the table because they were not experienced at all by anyone in the subsample.

An alternative way to look at the BPRS is to look at the total score of each subject. No participants in the study reached the cut-off level of 30. An average of the total scores of the subsample of persons with lived experience of psychosis is 20.3 (over a maximum score of 126) with a standard deviation of 6.9. There is therefore no notable illness among the persons with lived experience of psychosis in the study.

Qualitative Findings

The core of the results is constituted by data yielded from in-depth interviews and participant observation with people with lived experience of psychosis and their caregivers. We present this data here, followed by results from focus groups with ZL clinicians and community leaders, and interviews with policy leaders. The results collected from persons with lived experience and their caregivers are organized under two categories: 1) lived experiences; and 2) perspectives about the mental health system and about recovery.

Voices and lives of persons with lived experience of psychosis and their caregivers

1) The devastating effects of psychosis

Psychosis engenders negative consequences on the lives of the informants. The terrifying experience of the symptoms of psychosis, and the effects of the illness on functioning, the effects of stigma on the person and the family, the social isolation, and the emotional burden that result from the illness are all very significant. At first, people are disconcerted by the experience of psychosis and are looking for explanations. Many participants describe that they were initially afraid and baffled, not understanding what was happening to them:

> "It is a disease that I never understood. Until this moment we're talking, I don't understand this disease. It is a disease that God should never let befall people, not even animals because it's too hard." (P-015)

The illness, combined with stigma, has a devastating impact on the personal and social lives of the persons. A 32 year-old man stated: "To explain to you well, now, socially, I don't feel like I'm living. I don't feel like I'm a person. I'm very sad. And [with a big smile] having you for example visiting me is like the beginning of my life again."

He explained further later in the conversation:

> "You know, in society, when you have a mental problem, it's like you're a useless person. People don't trust you. This is why socially, you're dead. Even myself, I don't trust myself. Hence, I refused an offer to teach Bible in church on Sunday." (P-003)

The emotional burden on families is crushing. A participant with lived experience recalled the early stage of her illness:

> "I lost my good sense. I didn't know what I was doing. When it (the disease) took me, the entire family was like they were mourning; everyone was crying. Because I was breaking things, hitting people." (P-019)

A brother explained: "The experience of [his sister's name] disease was very difficult for me. I had a sadness ravaging my life, an infinite despair; I was afraid (C-005)."

And a sister confided that she could “not stop tears from pouring from her eyes” (C-015) during the acute illness of her older sister. We can see therefore pervasive and devastating effects of the illness in different dimensions on the lives of the sufferers and their families.

All this devastation leads people into a situation of despair. For some participants there exists a deep despair at the beginning and at moments where the quest for care is producing no result or is particularly challenging for both the sufferer and caregivers. Some study participants explained that this despair disappeared when they started to see the improvement brought about by the treatment started at ZL. Others reported the helpfulness of meeting the ZL psychologists and having them explained what is happening to them and what the management was going to be. One participant said that they never totally lost hope:

> “Once you have faith in God, you cannot lose hope; you know that he will deliver you out one day.” (P-014)

2) The Hazards of Care Seeking

Many respondents described difficult, unpleasant, or frankly dangerous experiences prior to enrolling in the ZL mental health program that people looking for care came across along the uncertain journey of looking for care for themselves or their loved ones. Families say that it is a natural and moral duty for them to do something, to care. This sense of a natural duty to care is an impetus for the long care seeking journey ahead. In spite of his despair at the beginning of the disease of his sister a man said:

> “Considering my position, it is a law for me to do all what I can; it is a duty for me to do all what I can. It is a duty for me to look for the money wherever it is to take her to hospital.” (C-005)

Another caregiver said that: “It is my natural position to help.” (C-006, C-012)

A mother of eleven children, one of them recovering from a psychotic disorder, narrated her journey of care seeking from the onset of the disease to enrollment at the HUM mental health service:

> "The first time he had the disease, I went to the camp [Camp Beudet] with him and I prayed. They gave him medicines. After that I went to the hospital of Lakolin. And then later, there was a hospital in Dufailly, I was used to go to with him; meanwhile, I was praying also. This hospital (HUM) was not yet open. I experienced very hard misery. Were it not thanks to Jesus, I wouldn't be here. The second time the disease came back, I gave him the rest of his medicines from Beudet that I had saved. But he was uncontrollable, so I had to go to the camp with him. There, they gave him a drug that caused plenty of trouble. This is when we came here [at HUM] with him and thanks God, we found the doctor who helped us with the boy." (C-010)

Another mother had other underage children at home while taking care of her third son suffering from schizophrenia:

> "I took time to arrive to the hospital because I owned nothing. Sometimes, I couldn't even find 100 Goud [the Haitian currency] for the transportation to the hospital. It was by foot that I was used to go picking up the medicines. I left by foot and walked in the middle of the night to arrive at the hospital and get the medicines...When the supply was over, I could not go again. And this is how the problems became chronic (rabi)... hmm... Problems, my son." (C-004)

The psychosis itself is therefore not the only thing that is destroying people's lives. The burden of the expenses imposed by the quest for help and seeking solutions to the disease also has catastrophic consequences. A caregiver declared:

> "About the finances, her problem really wrecked us. When we did not have money, we had to borrow, or take a loan. All our resources are ending. There is almost nothing." (C-005)

And another one:

> "It (the illness) really makes us spend a lot of money. We spent at the bòkò's house; we spent in transportation. The minute the disease started I spent money. It's very bad. We even had to sell the house we lived in before to find money to go to the hospital." (C-016)

Field observation also allowed us to tangibly experience some hardships about which people do not always spontaneously speak. One example is in Deslandes, a village between Ti-rivyè and Verrettes, where the only way to go to the closest hospital or closest market is to cross the Artibonite River in a little wooden boat with around a dozen of other people and goods. But the barriers to care seeking are not only at this level. People experience a range of obstacles at healthcare institutions. Those range from complexity of the procedures required before meeting the healthcare provider at HUM, to long waiting times that some of the patients attribute to lack of staff, to feelings of being misunderstood or not listened to by some providers, and finally to appalling conditions in government psychiatric institutions.

A lady who had been interned at Beudet enumerates some of the many horrors she experienced there:

> "Other people who are in the same room as you relieve themselves in the room. And if you don't hide in a corner they may splash you with the feces...If your parents are very attentive, they can come in and lay down sheets and pillow for you. But if you tear them, you won't find a thing to cover yourself with when it 's cold. You have no one to call until it is 8 AM to let you out so you can wash yourself…Sadness when you can't find any one to talk to." (P-005)

This is reported as having happened in a government psychiatric hospital. Maude also described the conditions when she was hospitalized:

> "At Beudet, [This psychiatric hospital], they are too hard with people. Even if the sick people may be difficult too, but it is not their fault. But, still they (the guards) are being hard with them, slapping them sometimes." (P-004)

Another person talks about the way they forcefully injected her with medication and concluded that: "It is good in Mirebalais. But in Beudet, it seems that they act more to capture [lock up] the person. If you are not good, you definitely stay not good. You don't see a mission to make you relive again (P-005)."

The care seeking journey is exhausting physically and economically, but also uncertain and sometimes hazardous. The types of "hazards of care seeking" described include: economic impoverishment; human rights violations; people as victims of abuses in government psychiatric institutions and during traditional treatments; the long, meandering, and often fruitless quests of seeking treatment; the uncertainty of the quest; the physical and moral exhaustion from those searches; and the difficulties and unpleasant experiences that they have had in healthcare facilities. The ZL mental health services in the study are presented as where the quest of those searches finally found some satisfying response.

3) The moral quandaries of caregiving

Caregiving refers here to the work of the relatives or close friends taking care of a person with a psychotic disorder instead of the work of the professional in traditional or conventional institutions such as clinicians in hospitals. This theme describes situations in which the family caregivers have to do something for the sick person, but have no or few good options to choose from. They represent tearing moral, practical dilemmas. Maude's mother, also mother to six other children, described her experience:

> "At that time, I had to take them to the countryside where they stayed tied up because they could not stay here (pointing at her small room for all the family). The boy usually relieved himself at any place where he was… It was thanks to God that some preachers saw them in the countryside and took them to the hospital." (C-004)

And Maude, the daughter of this woman, on her part, said:

> "Well! I did not like that they tied me up but it was because I was going away. I used to go the streets; sometimes, I spent the night outside in the bushes and thugs came and raped me." (P-004)

This situation leads to a moral quandary of caregiving: they don't want to tie up their loved one, but due to the inaccessibility of care, poor living conditions, the stigma and risk for the sick person to be abused if they go to disturb neighbors, the caregiver is left with no other choice than to restrain the sick family member to fulfill their caregiving responsibility and keep the sick person safe. A brother who had to tie up his sister when she was sick said:

> "I was scared. I was very worried that people would hit her, do mean things to her; that she would be hit by a car because she used to walk on the street and go very far. She used to walk naked in the streets; I think you can imagine all the bad the things that could happen to her." (C-005)

To further describe the challenges faced by caregivers, I here present the case of 35 year-old man that I have known for three years through my work as a mental health physician at HUM, where I took care of him with the rest of the HUM mental health team during his hospitalization for psychosis and agitation. His case complements the illustration of the moral dilemma of his wife, particularly in a context of destitute living conditions and competing priorities.

"Makso": An illustrative vignette of the moral quandary of a wife

"Makso" was admitted to HUM in mid-2013 for agitation and delusions. He arrived at the emergency room very agitated and violent. He had an erosive and infected lesion over his head, and several other ones in his limbs. His wife, "Liline", a very polite and gentle young woman, explained to us that he had been kept in a church in the neighborhood where they poured a caustic substance over his head, "trying to take the evil out of his head." Becoming more and more agitated, they tied him up at the church until his wife and his brother were told that the hospital provided treatment for people like Makso, and they decided to take him to the hospital.

At the hospital, after his stabilization over 24 hours in the emergency room, he was transferred to the internal medicine ward, which was a calmer place. The evolution and improvement of his symptoms was not steady. We noticed his stereotyped repetition of a movement where he would be sitting and laying back on the bed, holding fixed stares for a long time, and manifesting purposeless movements which required a one-to-one presence at his bedside. It was his wife who stayed with him at the bedside day and night, helped sometimes by his brother-in-law. We could not find an aid from the staff to help or relieve her from this. The ward had just opened and there was a shortage of staff. We thought he was experiencing catatonia and started a clinical protocol to address this. Around one week after admission, with only modest clinical improvement, his brother came to us and thanked us for our care, and said that he had been to an oungan who could do something for Makso. We listened to him and showed him appreciation for his care and search of treatment for Makso; and then, we explained to him what our diagnosis and plan was for his brother. We told him that we could not stop him and Makso's wife from leaving with Makso, but told him that we did not recommend his plan. He understood and admitted to us that the Vodou priest had come to the hospital to see Makso already. We told him that we had no problem with that as long as no substance was given to him to drink or to apply on his body by the Vodou priest, because in the hospital he was under our responsibility and we needed to have control over what was being put into his body. He agreed with this and he verified that only a little cross had been placed as pendant around Makso's neck.

Meanwhile, the treatment protocol, which had been developed carefully after consulting several US psychiatrists having experience with the diagnosis, was showing little improvement after four days. At this point, the wife, exhausted and having been sleeping on the floor outside of the ward, succumbed to the renewed insistence of the brother to leave the hospital. We came one morning and learned from the night shift team that they had left early in the morning.

I kept in touch, however, with Makso's wife and told her that we were always ready to help. She told me that Makso had been taken to an oungan in Grand-Bois, but since Grand-bois was not too far from Beudet, one of the two psychiatric centers of the country in Croix-des-bouquets (North of Port-au-Prince[18]), he would be taken there too. I called again several times afterward, to ask of any updates, and they reported that he was better and better. Makso spent more than one month at Beudet until his discharge, after which time he went to stay at his relatives "lakou" in Grand-bois. He could follow his appointments at Beudet with the help of his sister who was doing a bit of commerce in Croix-des-Bouquets. Since his internment, Liline came back to Mirebalais to take care of the kids there and went to visit him from time to time. This situation became clearer to me when, during my fieldwork, when I decided to understand the situation that underpinned the decision of Makso's family. I met Makso. We were glad to see each other and I decided to invite him to take part in my research study, to which he responded enthusiastically.

Makso comes from Grand-Bois, a landlocked area stuck between a northwest corner of the Department of West and the feet of mountains on which the Central Plateau lies. He moved to Mirebalais a few years ago, where he met Liline (who comes from Mòn Michèl, a very mountainous region and difficult to go to) with whom he will unite in "plasaj"[19]. He was doing little jobs in masonry; Liline was making laundry here and there for people for, often, derisory pays. They had rented a little piece of land that was in fact the land of the State but that powerful people in the community were renting for low prices. They were saving to build their family's house. When Makso became ill, they already had three kids, one of them was not yet weaned. They were, then, living in a one-room-3x4 meter house, covered with corrugated tin roofs, whose walls where made of a kind of tarpaulin. The house was located at the periphery of the town of Mirebalais, a place similar to those margins of other Haitian towns eroding progressively the greenery of the overlooking mountains.

In the conversation with Liline, Makso's wife, she explained how it was difficult for her when Makso was agitated in the house, which was not solid. In the hospital, she had to be with Makso all the

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[18] See Haiti map in appendix 3 (if needed)

[19] Plasaj is a form of non-religious union valued in Haiti, especially in the countryside. Its context is described more in the background section.

time but also had to take care of the kids at home. The neighbors help but could not do everything. Makso's brother helped also, but could only spend limited time helping. Most of Liline's close relatives are very poor and live in Mòn Michel.

She explained that she liked the care at HUM; she particularly appreciated how caring and patient the staff was, but when Makso was in Beudet, she could leave for a few days to be able to take care of the kids.

This is the complex situation in which Liline was making decision or following other relatives' decision for her husband.

The most recent part of Makso's story has an optimistic note that is worth mentioning here. After he got better, he moved back to Mirebalais again with Liline and his children. They are still living in the same house, surrounded by tent fabric and rusted tin. He thinks that God has cured him. Over the summer 2015, he found help to buy a sewing machine to start making clothes, buying used clothes (pèpè) in the market, repair them to resell. An oungan living by the road had let him install his machine in his front porch so that passersby can see him. Liline will be helping him in selling his products.

Their advice for our service in HUM is among other ones: "to continue the good work of providing medicines and caring for people, but also to have a separate place to keep persons who are severely mentally sick until they are ready to go back home." Liline also hopes: "that there could be a place for the parents of the hospitalized people to rest in the hospital." Something, the team did not pay attention to during Makso's hospitalization.

There are many things going on in this case, but one simple illustration of the moral quandary caregivers face is the wife making her decision while feeling pulled between the children, at home and whom she has to take care of, and the necessity of her presence at the bedside of he husband. The options that did not require her constant presence (the oungan and Beudet) prevailed.

Figure. 6 – Moral quandaries of caregiving

4) Eclecticism in the models of help seeking and in their explanations

By *eclecticism*, we mean the fact that the study participants have been looking for help from multiple sources, and that there exists a need to integrate different explanatory models. For example, a mother who claimed to have the power to exorcise people and believed that her son was the victim of the Devil, explained why she came to the doctor anyway:

> "Yes, because after God is the doctor. God bestows knowledge on the doctor, so he can provide solutions to our problems. But before that, we have to pray, and after go to the doctor." (P-010)

In other cases, the person is only an instrument in the hands of the divine:

> "My brother, let me tell you. They way God used the clinician, made him comfort all of my family members ...God used the doctor just to boost the morale of my family." (P-003)

Another lady who still believed that *lèt gate* [spoiled milk] went up to her head and caused her problem said:

> "This means it is not only the 'milk that goes up to my head,' there is a bit of persecution in it too. Sometimes, people come to do a treatment for me, but they take the money and give no remedy. It is when I started those medications that I started to feel some relief." (P-013)

We observed a coexistence of different explanatory models of mental illness. But, beyond the explanation, the views, the ways they make meaning of the illness, the cohabitation is also seen with the different sources that people use to find a solution for their health problems:

> "No, there is not only the doctor. If there is a need for the person to 'go out somewhere' [*pou fè yon soti*, meaning going to the vodou priest], I will go with the person. We do all what we can to find health." (C-015)

This was the response of a caregiver about the different options she uses to find help for her relative's mental health problem. Another person, in search for effective care, looked for solutions from several models of care:

> "The first time, we took her to the church and fasting ceremonies, nothing worked. After, we took her to bòkò, still, nothing worked. And our last recourse was the doctor, and this was where we found the solution." (#262_252 OC)

For these informants, both the care seeking and the explanatory models are eclectic.

5) Clinical care: "The headlight of the truck"

Study participants assert the effectiveness of the mental health services offered at ZL, and also of the importance of taking medication and remaining in care for recovery. One person compares mental health care to the "headlight of a truck":

> "Someone who has a similar problem and does not look for care is like a truck without headlight because there is no malady without remedy. Any disease can be treated but you need to look for the care that it requires. If one does not, the disease will have worse and worse effect him." (P-021)

Another person makes adherence to the clinical treatment an indispensable ingredient for recovery:

> "I cannot say that I want to be treated while I do not decide to stay on treatment. I say this is good. I will do it. I will respect my appointment. I will take my medicines on time. And if I do these things, that may allow me to have the chance to euhh… realize my dreams." (P-001)

Adhering to the clinical care is important, and is essential for recovery, the informants reported. The headlight of the truck, appointment after appointment, lights the road to recovery, to the possibility of realizing their dreams.

Being enrolled in the ZL mental health service also brought light to the participant journeys. The mother of one participant explains how she started to understand the disease and found hope when her son began to be treated at ZL:

> "I cannot tell you that I hoped that [the illness] would improve because I did not understand what was happening. The only thing is that I stayed calm, kept my trust in God and prayed. But when, we finally met the team [the ZL mental health team], we came to understand the disease. And then, we knew that thanks to God and to the team, everything can go better." (C-001)

Other participants also expressed that they found a significant improvement only after coming to the ZL mental health service.

<u>6) Recovery in connection</u>

People talked about achieving recovery in connection to friends, community, but also through the feeling of connection – in religion – to others and to God. After explaining the importance of medicines and economic support for her recovery, one of our informants added*:*

> "But other supports include a friend who could talk to you, spend time with you. If she is going to the river she takes you with her; she makes sure you change your clothes. If she notices that you like church, she takes you to church. That would help you regain control on your life." (C-005)

Beyond the personal and family space, recovery is also achieved in the community; recovery is achieved in connection with others. The following quote illustrates this:

> "In the community one thing that could help people is the entertainment places. Because the person with the mental problem could go there, chat a little bit and watch shows that are happening. Cheering your football team, that will help recreate the mind so as to start

> feeling that you do not have the problem any more. I mean like you are interacting with some people and that we are entertaining together." (P-001)

And Maude, from our first case, presented also the content of her recovery:

> "I would like God to improve my life because I am his servant. I was in a choir, was used to singing. Now I would like to take part in the choir again, but I cannot yet. They had stopped giving me the Holy Communion also, but I started receiving it again a few days ago." (P-004)

Connections with friends, and connecting with community through churches, to achieve goals, connection and engagement with larger community, finally connection with God are seen here as media to recovery.

<u>7) Being able to fulfill one's social roles</u>

In our study, recovery is also seen as the ability to fulfill one's social roles such as providing for one's family, sending one's children to school or, in the case of Maude, going on preaching missions. But they cannot fulfill those roles without the economic means:

> "There are people who take the medicines [from the pharmacy] and go with it at home, but who do not have the means to take the medicines because those medicines make you eat a lot. If the person cannot afford to eat, he cannot afford to take them either. And they make you sleep a lot; for instance, I start sleeping at 6 PM. Sometimes, I eat even in the middle of the night to tell you how much the medicine makes me eat. If someone does not have food and is taking this medicine, he can even die because it will not be easy for him. I said that I would like to find an activity [income generating activity] because I have kids at school, I don't like to be stay here, sleeping all day only because I have to manage to send the kids to school." (P-013)

The following quote further illustrates the call for economic empowerment for the purpose of fulfilling social roles:

> "I wish that God would cure me so that I can be useful to my children, a young woman like I am, even if I am getting old. But if God would make me healthy and strong, if I had a little business, I would be able to start providing for my children again. Even if I would not be able to respond to all of their needs, but I would help anyway." (P-004)

The statement of one participant who is now selling juices in a local market also speaks to the economic aspect of recovery:

> "Even if the medicines help, even if she is well supported, if she still has problems that are stressing her, her problem [disease] is not really resolved. So, maybe helping people to find money to face problems they have, a place to make their lives. If she did not find the activity she is doing she could still be having a problem." (C-005)

Study participants saw fulfilling their religious roles and parental roles, for example, as part of their recovery. Additionally, many of them saw working as not only a way to fulfill social roles but also to avoid ruminating and falling sick again, as a way to sustain health.

8) Professional caregiving as friendship

People talk about what they would want the ideal provision of care to look like. A young man who has fought psychosis and now is an activist for mental health in his community states:

> "One other thing that I appreciate in the system is that you, the providers, do not discriminate among people, you know. When you meet the person, you shake his hands, you welcome him. I think this is an important thing that I appreciate. There are many other things in the system that I appreciate for example, when you are in the room with the doctor, he makes you feel comfortable…He cares about you (*li pran ka ou*)." (P-001)

He and several other participants appreciate the fact that providers "*prank ka moun yo,*" care about the people they serve. The expression "*pran ka*" in Creole is used to refer to the action of being welcoming, open and attentive, and to care about what matters for the person with whom one is interacting. The next informant proposed this caring, attentive relationship as a model for professional caregiving. Later in the conversation, he added friendship and propinquity:

> "One thing I would suggest when a patient has just come is, in the moment, not to behave like a doctor or a psychologist. Act like you are the person's family, the patient's friend. Show that you are ready to help to provide him or her any service anywhere there is difficulty." (P-001)

Another man reported the fact that a friend had not visited him for a while. When I visited him he considered me a friend. He added that with that visit, “his social life has started again” (P-003).

Table 8. Summary table of results of persons with lived experience and their Caregivers

Thematic categories	**Definitions**	**Illustrations**
Devastating effects of psychosis	The “devastating effects of psychosis” are the negative consequences of the illness itself on the lives of the informants.	*“You know, in society, when you have a mental problem, it’s like you’re a useless person. People don’t trust you. This is why socially, you are dead. Even myself, I do not trust myself. Hence, I refused an offer to teach the Bible in church on Sunday.”*
Hazards of care-seeking	The “hazards of care seeking” designate a range of unpleasant to frankly dangerous experiences that people experience along the uncertain journey of seeking care for themselves or their loved ones.	“*In Beudet, [This psychiatric hospital], they are too hard with people. Sick people may be difficult too, but it is not their faults. But, still they (the guards) are being hard with them, slapping them sometimes.*” … “*It is good at Mirebalais. But at Beudet, it seems that they act more to capture [lock in] the person. If you are not good, you definitely stay not good. You don’t see a mission to make you alive again.”*
Moral quandary of caregiving	Family caregivers find themselves in a situation where the only thing they can do to protect the sick person is something that they don’t wish to do, such as tying them up in the house.	*“At that time, I had to take them to the countryside where they stayed tied up because they could not stay here (pointing at her 3x3 m room for all the family). The boy usually relieved himself at the very place where he was…It was thanks to God, some preachers saw them in the countryside and took them to the hospital.”*
Eclecticism in the illness explanation and care seeking models	By eclecticism, we mean the fact that our study participants have been looking for help from multiple sources, and integrate different explanatory models.	“*Yes, because after God is the doctor. God bestows knowledge on the doctor, so he can provide solutions to our problem. But before that, we have to pray, and after go to the doctor.”* … “*No, there is not only the doctor. If there is a need for the person to “go out somewhere” [pou fè yon soti, meaning going to the Vodou priest], I will go with the person. We do all that we can to find health.”*
Clinical care: “the headlight of the truck”	People talk about the importance, the effectiveness of the mental health services at Zanmi Lasante, and also the importance of remaining in care for recovery.	“*Someone who has a similar problem and does not look for care is like a truck without a headlight. Because there is no malady without remedy. Any disease can be treated, but you need to look for the care that it requires. If one does not, the disease will have worse and worse effect him.”*
Recovery in connection	People talk about achieving recovery in relationship, in connection to friends, and to community, but also through the feeling of connection in religion to others and to God.	*“In the community, one thing that could help people is places for entertainment. Because the person with the mental problem could go there, chat a little bit and watch shows that are happening. Cheering your football team, that will help recreate the mind so as to start feeling that you do not have the problem any more. I mean like you are interacting with some people and that we are entertaining together…”*
Being able to fulfill one’s social roles	Recovery is also seen as the ability to fulfill one’s social roles such as providing for one’s family, sending one’s kids to school, or in the case of Maude going to preaching missions.	“ *I wish that God would cure me so that I can be useful to my children. A young woman like I am, even if I am getting old. But if God would make me healthy and strong, if I had a little business, I would be able to start providing for my children again. Even if I would not be able to respond to all of their needs, but I would help any way.”*
Professional caregiving as friendship	People also talk about how they would want the care provision to look like	*One thing I would suggest when a patient has just come is, in the moment, not to behave like a doctor or a psychologist. Act like you are the person's family, the patient's friend. Show that you are ready to help to provide him or her with any service anywhere there is difficulty.”*

Results from the focus group and interviews with local providers and leaders

We summarize here key findings from three focus groups with providers (CHW, psychologists, social workers, physicians and nurses) and community leaders, and the findings from the interviews with policy leaders. All the providers and leaders alike stated that they think that the ZL mental health system is effective and appropriate. In addition they stressed, in particular, the burden of mental illness on patients, on families and on providers. The challenges most often reported included a lack of enough staff (CHW, psychologists, social workers); the low salary for psychologists; the stigma toward mental health in communities and in health facilities; and the poor economic situations of families.

1) The ZL mental health service: a humane system of care

When talking about the ZL mental health system, participant providers and leaders expressed their appreciation of the way the ZL mental health staff interacts with patients with care, patience and respect. A physician from the internal medicine service said in one focus group: “It has really touched me to see how humanely the providers from mental health treat their patients.” The psychologists also expressed appreciation of the system although they added that much was left to be accomplished. One psychologist said: “the ZL mental health system is a very good and unique system in Haiti; for example, pluridisciplinarity and integration can decrease stigma.” Although there was this appreciation of the ZL mental health system, ZL providers also stressed many areas where ZL has to do better.

2) The fragility of the multidisciplinarity

Psychologists taking part in the focus groups stressed the fragility of the mental health multidisciplinary system in health facilities due to the lack of training of the other providers, and a lack of sufficient sustained supervision and formal engagement in mental disorder-specific care pathways (depression, psychosis, epilepsy) leads to an increased burden of work for psychologists:

> "Multidisciplinarity and integration are great strengths but the psychologist will crush under the weight of this strength if it does not land down with appropriate training, identification and endorsement of roles by the other providers." (Psychologist-01)

One of the psychologists argued that the large number of referrals to a limited number of psychologists might lead to substandard quality of care:

> “Why are there tons of generalists in external clinic and one psychologist? While all generalists, all specialists are referring to the one psychologist? It may happen that we give bad quality of care because we are exhausted.” (Psychologist-02)

On the other hand a physician working at an outpatient clinic expressed a disappointment for not receiving enough supervision and training:

> “I feel that the psychiatrist at the hospital does not invest enough time for us in the hospital. Do you understand? This I feel it is a disappointment. If we have a psychiatrist, we should know the for example the drugs molecules very well.” (Physician-02)

3) Feeling of dehumanization of the clinical relationship under the reign of QI and reporting

The psychologists like the ZL mental system, which they find unique and effective. But following the progressive increase in the amount of documentation tools to use in the encounter, some of them expressed a loss of humane connection in their provision of care:

> “You don’t really have time to connect [with the patient], you have to check many boxes Ok, Ok, Ok…” And another provider added: "The system is more focused on the report about the patient than on patient herself." (Psychologist-03)

4) Envisioning a partnership with traditional healers

An MOH leader (L-03) underlined the idea of the need for collaboration with traditional providers and quoted what he heard in the meeting that was organized by ZL with approximately one hundred *oungans* in October 2014. They said: "We have no problem that we wash and that you rinse." This quote expresses the willingness of traditional providers to engage in collaborative work with the conventional mental health system, including the initial part of the process, and referring patients to the formal health system. Another policy leader (L-02) welcomes this collaboration and justifies it this way: "The *oungan* is closer; he considers his clients with esteem, respect and as his own family." And about collaboration with churches, this same leader reported that from what she saw in her practice: "People find an ear in the church."

In the focus group with community leaders that included CHWs, *oungans*, protestant pastors and teachers, the participants placed much emphasis on collaboration between facility-based clinicians and leaders in the community. Everyone advocated for reinforcing and enlarging the community network. An *oungan* participating in the focus group described ingredients of success for the Vodou healers in the communities: "Doctors ask symptoms, but we, *oungans*, tell and explain the symptoms to the patient; that makes them believe in us more."

He explained more and in a way that corroborated the statement of the policy leader that we have cited earlier:

> "There are several ways that I help someone who comes to stay in the *peristyle*[20] (Vodou shrine) for treatment. I feed them from my garden; I don't wait for their parents to do all

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[20] *Peristyle*: space in the *ounfò*, generally with a center pillar; in this space is held the Vodou ceremonies, and social dance parties. The *oungan* may also receive his guests, the people he is treating in the peristyle. *Ounfò*, according to Alfred Metraux is the religious center, grouping several parts such as houses where the families live, the houses of the spirits (*Kay mistè, Kay lwa, house of the lwa)*, the peristyle, and the surrounding environment including trees that shelter some spirits. (Metraux, 1958)

> that. If it is a man, I may ask: "What would you like to drink boss?" If they need a good soup, I don't begrudge cooking them one of my chickens. I consider them as my own sons and daughters." (*Oungan*-01)

This *oungan* had a son who was suffering from epilepsy. When he talked to a pastor who is a mental health CHW, he agreed to take the child to HUM. The child had since then been doing well and since then, the *oungan* accompanied the pastor to several community gatherings where they talked to people about the availability of treatment for mental illness at ZL. He gives an example of a case where the collaboration between *oungan* and formal health providers is needed:

> “Say–God forbid such a thing should happen– someone falls from a tree and breaks a leg because of an expedition that someone else sent to him. I, as a *oungan*, cannot repair the broken leg. I will send the person to the hospital. However, the expedition still needs to be taken care of, and that, the doctor cannot do it. It is the job of the *oungan*.” (*Oungan*-01)

He wished ZL could officially build collaboration with other *oungans* like him to “provide care to more people”:

> “What I would like and that would be very important is to see the *medical* part sit and talk (*chita pale*) with the *Vodou* part and to see that the *State* sits with us in order to set up a collaboration to help providing health care to more people in the country. For example, a relationship between those groups, that would allow that we could make a phone call to the hospital and send someone who was at the peristyle to the hospital so the doctor could make his part of the work.” (*Oungan*-01)

The conventional and the traditional systems of care agree on the need for collaboration. *Oungans*, pastors in the focus group, CHWs, formal clinical providers and national policy leaders agree with the idea.

5) Physicians’ push for separate psychiatric ward

Many generalist physicians and nurses taking part in the focus group spoke about the limitations of the care system with regard to human resources, supplies, infrastructures and policies (including protocols adapted to "integrated care" for hospitalized patients). With regards to hospitalization in wards, the physicians said they would push to have a separate ward from the internal medicine ward to hospitalize persons with psychosis.

> "As I already said, I think it is necessary to have an appropriate place for them to receive the mental health patient in the hospital so the management can be more comprehensive… Because there is not only the medicines, the patient needs to be an appropriate environment also." (Physician-02)

They also contend that the beliefs of patients and families about what caused their diseases was a major barrier to coming to the hospital as well as to remaining in care. They hypothesized that if people believe that a magical spell caused their disease, they will "logically" go the spiritual healers and not to the hospital.

6) The accompaniment approach to care and supervision

Most of the policy leaders stressed the importance of an approach to care provision that is biosocial, which is, "inherent to good psychiatry," as one of them said. The second suggestion of the same policy leader for both care and supervision is "the accompaniment model" that she defines as "working side-by-side, supporting one another, bidirectional learning." She argues that managing psychosis is overwhelming physically, intellectually and psychologically without adequate support. According to her, the accompaniment model would be effective in promoting learning for frontline providers as well as supporting them adequately. She applied the idea of the burden of managing psychosis to the general practitioners also, and contends that the absence of support added to the lack of exposure of our general practitioners (GPs), thus explaining their push for building a separate ward for mental health patients. That would keep the mentally ill patients away from them and help them avoid the stress of having to work on managing them. She reported meeting many GPs with a history of mental illness in their families, and she believed that having not yet dealt with this trauma might contribute to making it more difficult for them to deal with mentally ill patients: “It is a mental block related to the overall approach to medical care to mentally ill persons." So, in this case, an empathetic, caring and attentive approach to supervision is for her more than appropriate.” In both supervision and care provision those elements are important, according to this policy leader: “Accompaniment**,** and a biopsychosocial approach built on the foundation of humility and appreciation for the local context for all Haiti, history, culture, etc” (Leader-01).

7) “Scratching the surface”: the perspective of mental health policy leaders

Each of the five mental health policy spoke about the desperate need for mental health services and the inadequate resources that are mobilized. An MOH employee explained that: “People sometimes cannot do anything with a relative who is mentally ill, they give him to the hospital.” One of them stated that while the ZL program is on the right track, the services offered are “still scratching the surface,” meaning that the program still has many needs to address.

Table 9 - Summary table of results from the providers and leaders

Themes	**Definition**	**Illustrations**
The ZL mental service: a humane system of care	When talking about the ZL mental health system, participant providers and leaders expressed their appreciation of the way the ZL mental health staff interacts with patients with care, patience and respect.	A physician from the internal medicine service taking part in the discussion said in one focus group: *“It had really touched me to see how humanely the providers from mental health treat their patients.”* The psychologists also expressed appreciation for the system although they added that much was left to be accomplished. One psychologist said: “The ZL mental health system is a very good and unique system in Haiti; for example, pluridisciplinarity and integration can decrease stigma.”

A fragile multidisciplinarity	The lack of adequate training, psychological support and sustained supervision put the multidisciplinary model at risk	*"Multidisciplinarity and integration are great strengths but the psychologist will be crushed under the weight of this strength if it does not land with appropriate training, identification and endorsement of roles by the other providers."*
Feeling of dehumanization of the clinical relationship	With the forms and checklists they have to fill out during the clinical encounters, some of the psychologists expressed the feeling of a lack of humane connection in their provision of care.	"*You don't really have time to connect, you have to check many boxes Ok, Ok, Ok…"* And another provider added:*" The system is more focused on the report about the patient than on patient herself."*
The "we-wash-you-rinse" partnership	Traditional healers agree to partner with the formal health system and propose to do the part of the job.	Traditional and spiritual healers in a meeting said: "*We have no problem that we wash and that you rinse."* One said: "*Say – God forbid such a thing should happen- someone falls from a tree and breaks a leg because of an expedition that someone else sent to him. As an oungan, I cannot take care of the broken leg; I will have to send him to the hospital. There, the doctors will do the job of taking care of the leg, but the problem of the expedition remains. And this is my part of the job.*"
Physicians' push for separate psychiatric ward	Physicians claim that the mental health program should build a separate ward for its patients and not hospitalize them on internal medicine wards.	*As I already said, I think it is necessary to have an appropriate place for the to receive the mental health patient in the hospital so the management can be more comprehensive… Because there is not only the medicines, the patient needs to be an appropriate environment also."*
The accompaniment approach to care and supervision	Some leaders suggest empathic engagement, bidirectional learning as a model to provide supervision and direct care.	A policy leader says that in both supervision and providing care these elements are important: *"Accompaniment**, a** biopsychosocial approach built on the foundation of humility and appreciation for the local context for all Haiti, history, culture, etc."*
"Scratching the surface"	Leaders admit that the need for services is crushing and deep, and that the good efforts being done have not yet reached the heart, the roots of the issues.	About the ZL system a policy leader says: "Good model, locally adapted, family oriented but the reach is not enough. We are scratching the surface. Because of not enough CHWs, staff, logistical resources; and not enough support."

DISCUSSION

The goal of this study has been to explore the lived experiences and perspectives of persons with a history of psychosis, their family caregivers, their local providers, and local and national leaders, on illness, care and recovery. By doing so, this study hopes to understand how to better design and improve mental health services in central Haiti and in the lower Artibonite Valley. The specific objectives are aligned with the following research questions: 1) What comprises local knowledge regarding psychosis and recovery in rural Haiti, and what is the lived experience of both those who suffer from psychotic illness, and their family caregivers?; 2) What are the best pathways to recovery, and what local resources are available to meet the needs?; and 3) What recommendations can we draw from lived experience, local knowledge, and the perspectives of the study participants for improving or developing recovery-oriented mental health programs in Haiti?

I will present my interpretations of the results while placing them in their broader contexts (geographic, historic, socio-economic, institutional, political and global), relating them to each other, and comparing them to existing literature.

A. Structural violence in the lives of patients and caregivers

This study of the lived experience of psychotic illness revealed its pervasive impacts, which extend from the individual informant to include the family, psychiatric institutions and broader society. Ultimately, structural violence underpins, drives and entraps experiences of illness, as well as the process of care seeking and caregiving for everyone. We observe this situation successively in the individual experience, in the family's experience and in the institutions including the national psychiatric institutions in the capital city, ZL facilities in the rural areas, and religious healing structures in communities.

Terror and isolation from the experience of psychosis

The informants with lived experience of psychosis expressed feeling the devastation of the illness experience on their personal and interpersonal lives. They suffer from the onset of a new, sometimes mysterious disease in their lives, from terrifying symptoms to medication side effects. They suffer also in their interpersonal relations because of the symptoms, and also because of the stigma and fear they experience from the community. One of the informants used the phrase "socially dead" to describe the complete isolation that many experience with the onset of illness. His terminology, and use of the phrase, closely overlaps the term "social death" used by Kleinman to describe the deplorable isolation and loss of social networks experienced by those living with psychosis in China (Kleinman, 2009a; Yang and Kleinman, 2008). It is important to note that the informant who used the term social death was ultimately able to enroll in care, and was doing quite well clinically and functionally, going to church every Sunday. However, despite clinical gains and a few outward expressions of societal participation, after years of illness he still finds himself disconnected from his social network in ways that matter most to him. He does not have friends, he is separated from his former partner, and he cannot afford to send money to his children living with his partner in Port-au-Prince.

Stigma entails many kinds of mistreatment in communities, families and medical systems against the mentally ill. Abuses such as bullying, beating, and rape make one wonder about the extreme difficulty experienced and the tremendous courage it can require to reconstruct one's life after such suffering. While mistreatment can occur in the family, all patients questioned expressed that, although disapproving the fact of being tied up by family members in the house, they understood that their family members had few alternatives to doing that in a setting of lack of services. Many said that this was done for their protection. This reveals a very painful situation. Thinking of such practices, Kleinman has written that "protection becomes rejection" (Kleinman, 2009b). While being tied up appears clearly as a "rejection," in our study the sufferers did not experience it that way.

Mapping the care seeking journey.

The various impacts of psychotic illness on the family system can be seen at different points in the care seeking journey. At the onset of the illness, the family is often confused, as they try to make sense of what is happening and who can help. The experience is terrifying for the family and they do not always understand what is happening, which is reflected in this study. Overwhelmingly, the entire family system is saddened and deeply affected. Several persons with lived experience reported how the whole household was crying, at moments also agitated,but the family sees caregiving as a duty, a natural responsibility to care for the person and to seek help. This serves as an engine that will propel the care seeking journey in spite of the state of confusion, deep affliction, and exhausting effort that it imposes on various members of the family.

The help seeking process is started jointly by the members of the family, or the extended family if they are living close by. The pathways that were described in this study were usually plural, implying the care seeker tapping into several sources of care, and often at the same time. Most of the care seeking itineraries reported started with religious rituals. Concurrently they look for *medsin fèy* (traditional herbal medicine). Some also go to a third potential resource, one of the two psychiatric hospitals in Port-au-Prince, if they can afford it, or to a local hospital. Finally, after a period of internment in the psychiatric hospital or in an *oungan's* shrine, they come back home, without the expected results of cure, and they continue praying or send the person to the countryside in instances where they live in a city. All of the study participants went through some or all of these steps before coming to the study site and receiving care through the community-based system of ZL. Most often, several sources are tapped concurrently. The care seeking process may also stop at any of those moments. Often, families do not go to the psychiatric institutions in the capital city because they are too far.

Most study participants started their help-seeking within their regular church, but over time went to other churches or to healing ceremonies called *jèn*, (literally fasting ceremony, but devotees do not usually really fast) organized inside or outside of a church. Those are sometimes far from home and require substantial financial resources from the family. Some participants reported that their first recourse was to go a local *oungan*, and when effective results were slow to come, they went to another *oungan*, oftentimes farther and more expensive than the first one, and so forth. The quest for solutions in the religious sector does not exclude the use of traditional herbal medicine (prepared both by healers or by the families) that people in the family, in the *lakou*, or in the community, are suggesting. Sometimes, in their search for help, patients who have Vodou as their religion might have started to go to *oungans*' shrines, but not finding the expected results there, they shift and convert to a Protestant church.

One mother (C-016) reported that because she was desperately looking for treatment for her girl she "accepted to receive lies from people." Though she knows that a suggested treatment could very likely be a lie, and there is little chance that it would work, this small chance is felt at the desperate moment to be her best choice. When we met her, her daughter was not yet enrolled in care, and was psychotic. She said that her husband stopped going to *oungans* in search of solutions because they ran out of money. There is also a feeling of an imperative to seek care. We mentioned in the results and at the beginning of this section the way that families see caregiving as a natural duty. Knowing that the results of a traditional treatment interventions are probably not going to be helpful, there can also be an imperative to fulfill a family duty to find care, however effective or ineffective, in addition to a natural willingness and commitment to see their loved one getting better. These two factors together constitute a powerful motivation for the long care seeking journey that often unfortunately takes patients and families to the dead end of state psychiatric institutions that cannot properly take care of them, and to religious shrines where they encounter many abuses. People have a firm willingness to find a solution to their problem that works, and are also propelled by an imperative to fulfill a family duty to find care for their loved ones.

The moral quandaries of caregiving

Another milieu of the person's and the family's experience of illness is the healthcare facility. It is a huge financial burden on families to go to one of the state psychiatric centers in

Port-au-Prince from the Central Plateau or the Artibonite. Money is needed for transportation and several persons have to accompany the sick person, especially if the person is agitated. Once at the center there is an out-of-pocket payment system. They have to buy the medicines and supplies for the emergency phase of the treatment (such as syringes, injectable antipsychotics and sedatives). Information that I had gathered from physicians working at both of those state centers confirmed that there is also a fee for the hospitalization. This is only the tip of the iceberg because future visits and appointments will require even more financial resources. One national policy leader, who is also a clinician, said that it is not easy either for someone coming from the rural areas to go to the psychiatric centers because it is a new environment which is crowded and disorienting. Furthermore, many of those families do not have a place to stay when they go to those psychiatric centers. It often takes a whole day for the consultation and it is then difficult to find transportation back home in the evening. All of those factors explain that sometimes, some relatives cannot come back on time or do not come back at all after handing their sick relative to the center. Another national policy leader said “they give the patient to the center” (Leader #01).

There are also difficulties for people going to the ZL local health facilities. Families reported that it is very difficult to take public transportation with their relatives when they are agitated. In many places, the only transportation that they have access to after horses and donkeys are motorcycles, which are not safe, especially if they are with a person who is sick. In Deslandes, for example, people may have to take a small, flat, often crowded boat to cross a river with the sick person. Coming to the hospital often means that the family caregiver abandons another activity that could generate income for the family. Health care providers do not always take these considerations into account in the therapeutic process, and persons with lived experience and their families do not always talk about them in the clinic. Many unnoticed hardships such as these constitute hidden travails in the care-seeking journey.

It is difficult to overemphasize the economic, the physical, and the moral exhaustion that such a journey produces. Nadège Belizaire, in her Global Health Masters thesis on cancer care in Haiti, used the Haitian image of a *pelerinaj* (literally, pilgrimage) to describe this long, meandering journey (Belizaire, 2015). In the context of mental healthcare, it is a meandering, zigzagging, and exhausting pilgrimage indeed. With financial resources progressively depleting and other competing priorities in the family such as taking care of the other children, family caregivers face tearing practical moral dilemmas. This process of caretaking, lived as a duty, is endured between the collision of stigma, mistreatment in the community, destitute living conditions, structural constraints, and the family's role to protect the sick person. When deprived of options in the midst of all of this, family caregivers reach some points where the only thing they can do to protect the sick person is something that they do not wish to do, such as tying them up in the house or abandoning them at the psychiatric hospital.

Institutions and social factors as instruments of restraint

The experiences of the users and of the families that we have analyzed above are shaped by institutional and social factors. Those factors are the next level that we wanted to scrutinize in order to fully comprehend the reality of psychosis in the studied context. In the focus group with the community leaders, they reported several manifestations of that stigma in communities. People in the communities mock people with mental disorders and sometimes provoke and irritate them until they become violent. Making fun of mentally ill people even occurs in popular radio programs in Port-Au-Prince. The perceived causes of mental illness prevalent in society often reinforce the stigma associated with psychosis. For example, people in the community say that the person is “crazy because s/he is paying off what s/he has done”; that is, psychosis is a well-deserved punishment for some possible bad thing that the person had done. Our data do not allow us to establish a causal relationship between stigma and explanation of mental illness, but we can acknowledge that such views may drift close to justifying abuse or ignoring the conditions of the mentally ill. As we saw in our results, people with mental illness are often beaten. For example, Maude and her brother were beaten several times because they took other people’s belongings. People with mental illness are not protected when they wander the streets, leaving them highly susceptible to exploitation. One of the harshest forms of exploitation is sexual assault and rape.

In his 1963 book on stigma, Erving Goffman described the evolution of the term *stigma* and showed how stigma leads to inhumane abuses. He explained that the term stigma has evolved from meaning a body mark signifying a disgrace in ancient Greece, to meaning more the disgrace than the mark itself. Goffman explained the process by which, when in the presence of a stranger, his first appearance enables us to put him into a category and to give him an attribute. When we discover an “undesired differentness” in the stranger in front us, he is “reduced in our minds from a whole, usual person to a tainted, discounted one (1963, p. 3).” Goffman goes on:

> “By definition, of course, we believe a person with a stigma is not quite human. On this assumption, we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma theory and ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class.” (Goffman, 1963, p. 5)

But how does “differentness” get qualified as “undesired” in the Haitian context? Coleman et al. gave a clear response to this question in another context. What is ‘undesired differentness’, what is stigma is decided by the ‘value judgments’ of those who have power in the culture (Coleman, 1986, p. 211-232; Reidy, 1993). Coleman described the dynamics of stigma consisting of stereotyping (similar to the categorization that Goffman described), therefore inducing the fear of the “undesired” difference or of the unknown. The final step of the process of stigmatization consists in ‘social control,’ when the undesired differentness leads to some restriction of physical and social mobility, and access to opportunities that allow an individual to develop his or her potential (Coleman, 1986; Goffman, 1963; Reidy,1993). Understanding how stigma can be culturally constructed, it becomes both an individual and collective duty to uproot it in ourselves, in our institutions, and in our society.

In Haiti, there have been no large-scale campaigns to promote the rights and protection of people living with mental illness. There is currently no legislation to ensure the protection of the right of mentally ill persons. However, another manifestation of stigma related to severe mental illness in Haiti is worth particular attention. Many people (including health care providers) believe that a person who “got crazy, will always stay crazy,” and the saying goes “*qui a fou fourra*.” In a 1967 paper, Dr. Larmarque Douyon explained that it is not only in neuropsychiatry that there are patients who need life-long medication, and pointed out that conditions such as diabetes and hypertension require life-long medication as well. Furthermore, he explained that mental disorders are biological as well as social, and that if the social causes are not treated, the disease may come back. Finally, he unfortunately blamed families of the mentally ill for not strictly following the specialists’ directions and recommendations. Besides, those factors presented by Dr. Douyon, there is also the need to recognize the vicious circle of stigma in society that hinder the recovery of mentally ill people. There are also other structural factors in the health care system at large that contribute to creating obstacles to recovery. These include the lack of investments in system building and infrastructure for mental health care service delivery, and lack of proper regulation and oversight over care at the state and private institutions in the capital city.

Psychiatric and general health institutions have an important role to play in combating stigma and abuses. Unfortunately, some staff working at health care institutions in Haiti hold stigmatizing views of mental illness as well. Most all of the facility-based clinicians taking part in the focus groups admitted being afraid of people with psychosis. Without significant investment and deep work on the structure and components of the health system, stigma will stay ingrained in health care delivery systems, and abuses will be reproduced. Within the ZL system, this embedded stigma persists despite a significant systemic mental health education effort. With a lack of training of health professionals in mental health, many of those same prejudices and stigma in communities will continue to be repeated in state psychiatric institutions as well. Officials and former residents alike report physical abuses in state psychiatric institutions. Maude[21] explained that some sick persons interned in one of the state psychiatric centers would get slapped in the face or beaten when they were agitated or perceived as threatening to the guards.

There exists a severe lack of staff in those centers for all categories of providers. There are almost no psychiatric nurses in Haiti and only seven psychiatrists (WHO, 2015). The meager budget allocated to mental health does not allow enough staff nor does it allow training of the staff that they have. It does not even allow a minimal level of functioning. After the earthquake, the Mars and Kline psychiatric center received several more residents than it had in decades (the

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[21] Pseudonym. The case of this person is presented at the beginning of the results section.

current third-year cohort had 6 residents); they are still currently in training. The lack of budget for training could be part of the explanation. For example, to avoid abuse in the management of an agitation in a person with psychosis requires appropriate training and supervision for all categories of staff involved, including security guards. The insalubrity and inappropriateness of the physical spaces have greatly contributed to the humiliation and horrification of the experience of the mentally ill person. The Mars and Kline center was built with very progressive and promising ideals, but with the increasing demand and the meager resources, along with the Beudet center, it deteriorated to become a place where people are locked up and receive substandard treatments. Additionally, mental health providers are also stigmatized. In many training sessions of health providers and in meetings, there is a fear that the health provider taking care of “crazy persons” may end up being “crazy” themselves. Mental health professionals are therefore stigmatized along with the sufferers of mental illness, representing a stigma around mental disorders and mental health care delivery in general. Potentially, this general stigma around mental health is partly fueling the particular neglect of mental health. Additionally, the state of poverty of the country, and the country’s political problems, also have to be considered as factors influencing the neglect of mental health. Together, and overwhelmingly, these structural factors (stigma, poverty, political problems) and the severe lack of investment in mental health-related infrastructure are deep drivers of the abuses seen in the state psychiatric institutions.

In addition to stigma, another systemic barrier that hinders recovery in psychiatric institutions and in society is the absence of regulation and insufficient oversight on what is happening in mental health care delivery in general in the country. There is not sufficient legislation to protect mentally ill persons in the country. Legrand Bijoux listed laws that address the mentally ill in civil and penal codes. One article in the penal code states that, "there is no crime or offense if the perpetrator is mentally disabled at the moment of the act." The civil code's articles that Bijoux presented focus mainly on removing the civil rights of the mentally ill to decide by him or herself and to allow a person's forced hospitalization. The articles inventoried by Bijoux show that the law considered a mentally ill person as someone to be protected from, and not to be protected (Bijoux, 1975). The MOH Mental Health Unit is currently working on the critical issue of an absence of laws to ensure the rights of the persons with mental disorders. The absence of true legislation and of investments in mental health is the manifestation of deep systemic neglect. The Goffman and Coleman theories of stigma as culturally ingrained from dominant group values is a plausible explanation of how some categories of disease are stigmatized and dismissed in Haiti (Coleman, 1986; Goffman, 1963). A national leader confided to me in an interview that there are, indeed, bad practices happening in mental health in the capital city, but with such a small budget and the lack of political will, MOH mental health officials do not have the means to put in place appropriate oversight structures.

It is important to observe that there is no regulation of the spiritual healing organizations either. Vodou and Protestantism are the religions where the study informants had their healing ceremonies, and where many abuses have also occurred. From our experience, there are Catholic priests and Protestant pastors who perform dangerous exorcism ceremonies for people suffering from mental illness. In fact, one of the study participants treated at ZL was almost killed in such a ceremony, and presented to the HUM emergency department in an unconscious state. These groups are not regulated internally within their professional group, nor by the state. The national representation of Vodou, by an *Ati* (supreme national leader of the religion), and the emergence of various Vodou organizations, may help to design more effective regulations and better collaboration with Vodou priests and priestesses.

The Straight Jacket of Agency: The restrained agency of patients and family caregivers in the process of caregiving and care seeking.

We present now a perspective of the situation that takes into account the many constraints placed on persons in recovery and family caregivers, limiting their flexibility and options for caregiving and care seeking. We argue that when considering the mistreatment of persons with psychosis in their families and in psychiatric institutions, it is important to see the underlying structural constraints that shackle the agency of users, families and even providers. When we consider the living conditions of people and the structural constraints that they face, as well as the unavailability or inaccessibility of care, it makes it difficult for them to do something about the illness that is plaguing their loved one. Yet with their innate resources and knowledge, they try to do something. They look for solutions according to the knowledge they have, and according to what is available. In doing so, they still encounter many barriers and hazards. People are humiliated and have their rights and dignity trampled upon both in religious temples and psychiatric institutions. Who would be enthusiastic to take one's wife, daughter or husband to a place where they will be humiliated at great financial cost? A lady who was stigmatized in her neighborhood, in Port-au-Prince, and then hospitalized in Beudet, said it was such a relief for her when she could leave Beudet and join her relatives in Mirebalais to benefit from care from ZL at a new hospital.

Nor do families want to themselves mistreat their loved ones. It is always with a guilty tone or as a recourse of last choice that they admit having tied up a relative. Without access to care, torn between several life-saving priorities (e.g., working for providing food, care for other kids in the house or for the elderly), pushed to protect their loved ones from violence and rape in the community, people are often forced to act with lack of a better option. Therefore, when looking at the inhumanity with which mentally ill people are treated, we must also look at the deeper structural constraints underpinning the root causes of those human rights violations. A sustained situation is therefore perpetuated in which a suffering person and family are surrounded by structural constraints with fewer and fewer resources and options, which can lead to a point of surrender where families are cornered and cannot find anything else to do but something they would not want to do. We compare this to a *straight jacket* upon the agency of persons suffering from psychotic illness and their family caregivers, a manifestation of structural violence in the local worlds of our informants, in their bodies, in their deepest moral intimacies. In 2004, Farmer wrote in an article that: “Structural violence is structured and stricturing. It constraints the agency of its victims; it tightens a physical noose around their necks, and this garroting determines the way in which resources–food, medicine, even affection–are allocated and experienced” (Farmer, 2004, p. 315).

Another aspect that needs to be stressed is the insidiousness of this violence. It is less visible, which may contribute to observers blaming the families instead of the constraints involved. Under the violence imposed on persons with psychosis itself–that we must no less severely condemn and eradicate–there is an insidious and additionally virulent, pervasive, devastating violence that besieges people’s ability to always act in the sense of good. Families and people struggling with psychosis are more limited than others in what they can do. It is very difficult to take someone who is agitated to a hospital through several hours of rocky paths of Mòn Michèl. Even those living in the towns have difficulty taking public transportation with a relative who is mentally ill. Drivers either refuse them because of stigma, or they need to pay for transportation for several people so that they can ensure the safety of the person who is agitated. One of the study participants was able to go to a state psychiatric institution, but the care received there was bad in her view. So, she came back home with her son again. Providers at the state psychiatric institutions on their part deplore the lack of financial means, of training, supplies and logistical facilities to better take care of people. They themselves are appalled by the situation but feel powerless to change it. What is this kind of violence that forces, even if one wants to do good, to do bad? "If you look under the rug of civilization where it is dark and wicked, we are fierce and terrifying. You need to face that to discover the possibility for creating something better" whispered an informant of Kleinman in *What Really Matters,* a book exploring the moral experience through individual's stories (Kleinman, 2006, p. 13). Farmer, in the 2004 article cited earlier, defines structural violence as "the natural expression of a political and economic order that seems as old as slavery. This social web of exploitation, in its many differing historical forms, has long been global, or almost so, in its reach" (Farmer, 2004). If we compare this deeper violence to a malady, the violence that we see that horrifies us (violence in the family, church, and *ounfò*) is only its symptom.

Besides restraining people's agency, structural violence also has direct influence on the origin, course and outcome of mental disorders. A review conducted by Kleinman and Patel as well as one led by Crick Lund showed a positive correlation between poverty and common mental disorders (Lund et al., 2010; Patel and Kleinman, 2003). Other studies and reviews show the influence of poverty, socio-economic status or social deprivation on the origin, course and outcome of severe mental disorders (Saraceno, Levav, and Kohn, 2005; Wickham et al., 2014). "If psychiatry is the medical technique that aims to enable man no longer to be a stranger to his own environment" as Fanon said, how can we conceive of recovery in a context of poverty, and other structural violence (Fanon, 1964, p. 53)? Leon Eisenberg said that it is misleading to talk about a natural course of mental illness (Eisenberg, 1988). Considering the external influences on course of mental illness, one is entitled to wonder about the fictitious course of severe mental disorders amidst this structural violence– the intra-structural course of the disease. In the article "Experience of Psychosis in Javanese Culture," Good and Subandi suggested that there could be a circular interaction between social and cultural responses to psychosis and self-processes of psychosis that could interact with neurobiological processes of psychosis determining this way the course and prognosis of the disease (Good and Subandi, 2004). In the article titled "A Failure of Humanity," Kleinman pointed to our moral failure to show humanity in the face of the global mental health problems; but in the light of what precede, more than a failure, we see an evil system put in place that we know is systematically driving those atrocities (Kleinman, 2009b).

This is therefore a denunciation of both the failure of humanity to provide care and prevent abuses, and of the deeper "stricturing" of structural violence–to use Farmer's formulation –that influences the origin and evolution of those disorders and imposes a "straightjacket" on agency leading to lack of care, and favoring the occurrence of those mistreatments. This same reading, applied to the state psychiatric institutions also, helps us understand the wrenching dilemmas psychiatrists, residents and other providers experience. Yes, there are abuses and mistreatment happening in Vodou and Christian shrines, but the fact of failing to build an accessible, high quality mental health system should also be properly cast in the form of persistent and gross neglect.

B. Eclecticism in the models of help seeking and in their explanations

By eclecticism I mean that our study participants have been looking for help from multiple sources and to integrate different explanatory models. They integrate the model proposed by the formal mental health system into their existing framework. This is what a mother showed when she responded that God created the doctor to help her. We have already mentioned this point several times in the description of the care-seeking journey. In this section, we want to develop it further in order to provide an alternative position to a widespread assumption, both from some of the providers participating in the study and from the scholarly literature (Carrazana et al., 1999; Desrosiers and Fleurose, 2002), that holding magical or religious explanations of illness is a barrier to seeking and adhering to formal hospital- or clinic-supported care.

The first thing to stress is that people look for help. This search for help takes many forms and follows many models, which co-exist. The study participants go to religious temples, look for traditional herbal medicines, and do not consider that all of these are incompatible with medical care. They are not. While some patients believe that their problems have religious or magical origins, they think that both the medical and the religious are necessary for their recovery. This reflects eclectic approaches to care seeking.

The widespread presumption that believing that a magical spell caused the illness diverts patients and families away from formal healthcare, and exists also among the providers interviewed in the study. In one focus group the physicians and nurses often cited superstitious beliefs as the cause of non-adherence and as reason why people do not come to the hospital for care but go instead to the *oungan*. Farmer said that “effort to attribute explanatory efficacy to one variable leads to immodest claims of causality” (Farmer, 1996). This widespread presumption is an immodest claim of causality that Farmer himself had fought with regard to infectious diseases. But the day-to-day practice of working at ZL reveals well the other contributing factors such as poverty and geographical barriers. Therefore, some will finally cite as well other explanatory factors such as poverty. Psychologists, social workers and CHWs (as in Farmer's studies) tended to mention more economic, geographical and other structural barriers than religious beliefs. A study conducted in the Central Plateau in a place where the ZL mental health team has been running a monthly mobile clinic since 2012 showed that Vodou beliefs are not an obstacle for seeking formal treatment (Khoury et al., 2012). Factors such as economic barriers, geographic barriers, and quality of medical care were considered as bigger barriers to getting to a conventional health facility. Much earlier, in the 1990's, in a study of the representation of HIV/AIDS in a small village in the Central Plateau, Farmer recognized there was a cohabitation of several explanatory models. More than a mere juxtaposition, Farmer also revealed a process of integration of the new disorder (in that instance, AIDS) into an existing framework that helped to make meaning of the disorder (Farmer, 1990, 1994). How can one conceptualize and explain this eclecticism or in the case of Farmer's study, the syncretism in the explanatory model?

Speaking of illness as a moral event, Byron Good wrote that, "an effort to bring meaning to such events requires resort not only to theodicy, in Weber's term that is to answering 'why me?' (with an implied why me rather than him) but to the yet fundamental soteriological issues. What is the nature of suffering? What is the moral order that makes sense of it? What are the sources for hope to go forward in this context (Good, 1994, p. 134)?" We can therefore understand the co-existence and even the necessary complementarity of the religious and of the medical. Each is needed to respond to different medical and existential questions and to provide palliation for different dimensions of suffering.

Vodou integrates physical and spiritual healings; yet sometimes they are difficult to differentiate. Christian healing practices also, such as protestant (including Pentecostal) or charismatic healing ceremonies, integrate other practices as well. Furthermore, Christian religions in Haiti hold similar explanatory models than Vodou (*ekspedisyon*, sent illness, sent *zonbi, kout poud* [22]etc.). Only their modality of response is different. One mother in my sample told me she is an exorcist. She claims being able to identify which sent spirit is at the basis of the illness and to chase it. *Expedisyon, sent zonbi,* magical spells are all parts of her explanatory models as they are for the Vodou practitioners. In the healing ceremony, this mother went to Port-au-Prince, and those explanations are cited too. So, often, for Christians and Vodou practitioners, religious ceremonies, herbal treatments, and medical treatments (when possible) are concomitantly considered. But, obviously, this last option is not available for people in remote rural areas. Therefore, people continue to pray, to go to *jèn* even if they are making great clinical progress in the hospital and recognize that the medicines are helping. Others who are Vodou practicants continue to serve the lwas[23] also. When we consider our therapeutic approaches as *bio-psycho-social*, we need not to forget the *spiritual* that is somewhere between the psycho and the social, when it comes to persons to whom that part matters.

Vornax (2008) demonstrated in his work how Vodou as a system of care itself penetrated the other systems of care such as the herbal medicine, the birthing practices, the Christian

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[22] *Ekspedisyon* is a Haitian Creole word literally translated to “expedition.” In this context, it refers to a magical spell sent in order to cause harm to someone. *Sent illness*, in the Vodou nosology, is an illness that is explained as a result of someone wanting to do harm (for punishment or jealousy) and magically causing an illness to occur in another person.
As sent illness, a spirit including the spirit of a dead person can also be sent.
Kout poud, literally a blow of powder, would be the use of a substance in the form of powder to cause harm when in contact with the targeted person. Extensive explanation of those terminologies can be found the writings of authors such as Farmer, Métraux etc. (Farmer, 1990; Métraux and Charteris, 1972; Metraux, 1958)

[23] Vodou familial deity

healing ceremonies in sects like the Heavenly Host, the Catholic Charismatic Renewal, and also finally the formal medical sector in the countryside with some aid-nurses and nurses providing several forms of care. He also mentioned that those different spaces of care were not tightly compartmentalized and were open to influence by other ones. In this study, while concurring with Vornax's observation of the penetration of Vodou into different treatment systems, our data allow us to expand more on the inverse phenomenon: the penetration, or the integration of the medical into the popular system. A similar phenomenon has been described by Farmer also (Farmer, 1990, 1994). However, it is needed to point to the difference between our cases and Farmer's, that there is not a new disease in our study. This phenomenon of integration shows that the explanatory model that people hold does not exclude other models. On the contrary, in this case, it integrates them. That allows the population to adopt a new and helpful set of services while using their worldview to make sense of it. Anperè Sanon[24] (an *oungan* whom I interviewed and cited in the results) illustrated the necessity of the different systems to co-exist and to complement each other. He gives an example of a man who fell from a tree as the result of an expedition and broke his leg. The *oungan* as a spiritual healer does not have the job to take care of the leg. He has to send this person the hospital. However, the expedition still needs to be taken care of, and that, only the spiritual healer can do it.

In a study of duration of untreated psychosis in Jogjakarta, Indonesia, attempting to find an association between caregiver's explanatory models, help seeking behavior and duration of untreated psychosis, Marchira and colleagues (Marchira et al., 2015) discovered that first recourse to traditional healers did not predict prolonged duration of psychosis in that setting. The participants of that study already were engaged in medical treatment at the time of the study.

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[24] Pseudonym of a Vodou priest who participated in the study

Most caregivers taking part in the study held “both traditional and medical explanatory models at the same time.” The authors argue that caregivers could go to traditional healers at the very beginning of the illness, but that did not stop them from going to the hospital as well, if the traditional therapies did give the expected results. This suggests a certain pragmatism we observed in some of our cases also. People are looking for what works. That may lead people to go from one source of care to another or use several ones at the same time. Anne Becker used the term of *eclectic pragmatism* to describe similar help seeking models of Fijian villagers (Becker, 1995).

As in the Good study mentioned above, in a context of plural of use of sources of care, we cannot ignore the question of the perception of the family and the patient about which of the sources is promising the greatest effectiveness (1994). It is very logical that a source that is perceived as not helping enough will not be prioritized over one that is perceived as helping more. It is very understandable that this person has his or her own expectations and conception of the effectiveness of the care that is given. However, often health care providers do not elicit those expectations and conceptions with the patients and family in order to clarify what s/he can do and cannot do or what is perceived as most important to the recipients of care. The expectations are not commonly defined between provider, patient and family. One example of this omission happened when one of our informants stopped taking the medication given to him, and the psychologist contradicted his biblical understanding of the component of the self (as “body, spirit, soul”). The user felt that respect was not paid to his beliefs and expectations in the care relationship with the psychologist. That was enough to unbalance the clinical relationship, with the provider paternalistically imposing his view. As a result, based on their perceptions of whether the care is working or not, a user and caregiver may abandon a given system of care (either conventional or traditional) and go to or keep another one. The formal health care professional should not expect that sufferers and families should assume that the medical care is effective or more effective without seeing it in action, before they even know anything about it. The formal biomedical system of care needs, instead, to maximize the quality of its care and make it available to the user first.

The eclecticism in the care seeking model can be a result of pragmatism–where people are looking for what works for their problem–as well as of the complementary need to treat the spiritual component of the illness as well. We saw that the explanatory models of mental illness, including the perceived solutions for mental illness, do not exclude formal mental and medical care. They rather integrate them (Farmer, 1990; Good, 1977). All will lead to an eclectic search of care and a syncretic explanation of the search of care. However, with this plurality of sources of care, in the context of the limited resources, we can understand that they quickly exhaust their economic, physical and moral strengths. In this way, the running from here and there cannot continue anymore. The multiples sources compete for the meager resources, and the structural constraints may lead to competition among different sources of help. There exists also friction between seeking care and other priorities such as taking care of the other members of the family, such as children. Finally, having no or little resources, patients and family have to prioritize their choices according to accessibility and perception of effectiveness. The practical reality of care seeking remains a plurality of concurrent strategies, but the rational explanation (Good, 1977) of the process integrates syncretically different models. At the end was it really a matter of choice? What choice did people have? With all of those constraints in rural areas, the inaccessibility of conventional care, with their destitute living conditions, what choice do they really have?

C. Conceptions of recovery: A deeper response to a deeper malady

Aside from pointing to this deeper malady of the social fabric, the participants in this study also make an urgent call for deeper, stronger and larger remedies to this pathology. This call gushes forth from their conceptions of recovery, the different means they claim for it, and its components. All of the participants recognize that clinico-functional recovery, a sufficient improvement in symptoms making them able to function well in society, is necessary. Persons with lived experience of psychosis express that the ZL system of care is effective and they see their clinical care as essential to their recovery. One of the participants, cited in the results, compared it to the "headlight of a truck." Study participants explained that the medicines helped them significantly. They always cite the medicines when asked about what has helped them to get better. They present the biomedical care as an essential part of the recovery. Nonetheless, they also say that they need more than the biomedical care for their recovery. We now analyze two other components of recovery that stood out from the data: "recovery in connection" and "recovery as ability to fulfill one's social roles."

Recovery in Connection

Being able to connect with people goes beyond clinical recovery in the sense that it requires that other persons in the community are open to the connection. Additionally, persons with lived experience of psychosis expressed the need to feel connected to a larger community. In one quote earlier, the participant imagined enjoying a soccer match and cheering the same team as other people. This represents the search for a feeling of *communion*. But this, in turn, requires the presence of community infrastructures, the occurrence of community gatherings, and the availability of places for entertainment. Participants said that the environment and community resources allowing connections to happen are important to their recovery. Finally, comes the connection to the divine in the form of spirituality and worship. Spirituality is seen as a source of hope and important for people to make sense of their experience in many publications in the recovery field (Deegan, 1987, 2004; Domocmat, 2014; Leamy et al., 2011; Lukoff, 2007; Noordsy, Torrey, K. Mueser, et al., 2002; Onken et al., 2007). As we saw in the results, some of our study participants reported never having lost hope because of their faith. The need to feel connected to a group can also be lived while being connected together to God in a church. Maude's case is an example.

This notion of connectedness is central in a definition that Ware and colleagues have provided for social reintegration. They also noticed the "feeling of being part of a whole" (Ware et al., 2007). A review carried out by Mary Leamy and colleagues has also identified connectedness as part of the process of recovery (Leamy et al., 2011). Seeing connection as an essential component of recovery calls for attention to many necessary substrates of this connection, such as communication skills (for the person in recovery) and receptiveness (for the interlocutor), overcoming stigma, and pro-social infrastructures. It implies sewing back the torn social and ecological fabric around the person in recovery.

Using an ecological framework to review and analyze definitions of recovery in the literature in 2007, Steven Onken, and colleagues defined the ecological perspectives as follows: "Ecological perspective incorporates both the individual and the environment and focuses on the relationships between both, with greater emphasis on interactions and transactions" (Onken et al., 2007). Beyond an effective clinical treatment, the recovery-oriented program has to address relationships with other people, interactions with the community, stigma and information sharing about mental health, political violence and insecurity, poverty, community development and infrastructure, so that people can have places where they can come together (where they can commune).

Recovery as being able to fulfill social roles

The second main component of recovery expressed by the study participants is the importance to be able to fulfill one's social roles. This consists in being able, for instance, to send one's children to school, to feed them, and to go on church missions. In drawing implications for recovery-oriented services in the U.S., Farkas and several others pointed at the need for services to go beyond clinical services (Farkas, 2007b; Leamy et al., 2011; Onken et al., 2007; Slade, 2010). Farkas wrote: "Services need to be able to facilitate the goals of those who wish to get married, have families, and start their own businesses, as well as those who wish to live in some type of supported residence and work in a more sheltered employment situation" (Farkas, 2007b). Mike Slade, in 2014, made recommendations on how to support "personal recovery" in mental health services. He differentiated "personal recovery" from clinical recovery. *Personal* recovery is seen, according to him, as a "process able to be judged by the individual service user, that may not involve symptoms reduction or not result of actions of mental health services"; whereas, *clinical* recovery is an "outcome, judged by an observer, with great emphasis on symptom reduction and effective treatments by mental health services" (Slade, 2010). In a later paper he recommended that in supporting personal recovery services should focus on "ensuring access to a broad range of community oriented services (including housing, education, employment, peer support, recovery education, crisis support, support in everyday living, drug treatments, talking therapies and advocacy), and promoting social inclusion and human rights (Slade et al., 2014)." The findings of this study tell us that those aspects need even more focus and attention in rural Haiti where basic needs are often not met. Our participants say that "it is washing the hands to wipe them in the dirt" to give medications and psychotherapy without addressing those elementary issues.

To achieve those essential components of recovery, people need not only clinical care. They also need economic support either by giving cash directly or by helping them to start a little commerce or helping them to find a job. They need social skills, entrepreneurial skills, and psychological support to deal with stigma and to manage symptoms. We plead that those types of accompaniment are urgent necessities for a real recovery.

Recovering from the Trauma of Psychosis

One policy leader interviewed in this study recommended to pay special attention to recovery from the trauma of psychosis itself. The abuses from society and the failures to provide care imprint themselves in the lives of those with such experiences. The young man who said he felt "socially dead" corroborated that; indeed, he described being much troubled by memory of what happened and what he has done while sick. Receiving help on how to deal with these feelings, he said, would be very helpful. How does one remake a life after such destructive experience like Maude's? This is an additional consequence of structural violence and social suffering, and a potential explanation of how structural violence may shape the course of a mental illness.

Models of Recovery

There is not yet enough research in Haiti to compare the conceptualization and operationalization of recovery stemming from more than 40 years of research in the U.S. and some other wealthy countries (Davidson and Roe, 2007; Harrison, 2001; Sartorius et al., 1996).

The critiques of the "recovery movement" and this short exploratory research showed that, though approaching mental health care with the vision of recovery is important, the paths to recovery, the elements of recovery, the types of services organization that can facilitate recovery need to be locally developed. The U.S. model of recovery or recovery-oriented mental health services cannot be transposed onto Haiti. But the vision of recovery for mental health services–instead of a Krapelinian or solely biological conceptions of psychiatric care–can serve Haitian mental health services. Here, we lay out the main characteristics of the recovery process noted in the study and compare them to the American components of recovery while also presenting founded critiques formulated against the American model of recovery.

The three components of recovery that stand out from our findings are the clinico-functional recovery, the need for connection, and the need for fulfillment of one's social roles. Regarding clinico-functional recovery, the study participants all wish that symptoms would significantly decrease or disappear, and that they would have the psychological and physical ability to function well in their community. They think that the drugs have been determinant in their clinical improvement and they appreciate the fact that ZL provides free drugs for everyone. A participant still experiencing some symptoms like "seeing the environment very colorfully" and another "hearing sometimes voices" consider themselves as having recovered because they understand and keep control on what is happening, and because the symptoms have reduced to an extent that they can function normally in their community. Clinical recovery therefore leads to functional recovery. The person may be able to function, but if there is stigma in the community, poverty and other destitution plaguing his life, giving only the medication is "washing the hands to wipe them out in the dirt." Beyond the clinico-functional recovery, there need to be spaces, structure or a social fabric propitious to the establishment of the needed connections, and within which there is a movement toward the opportunity for real supports in enabling one's ability to fulfill one's social roles.

Recalling Anthony's definition of recovery from his textbook on psychiatric rehabilitation, he writes that recovery is "a deeply, personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life with or without limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of a mental illness (Anthony, 1993; Anthony et al., 2002, p. 31)." Slade used the same definition as Anthony to make his distinction between clinical and personal recovery reported earlier (Slade, 2010). The distinction between personal and clinical recovery is important because it gathers many other divergent or manichean perceptions of recovery, some more biological other more psychological (cure versus absence of disorders).

Farkas presented a working definition from US first-person narratives and members of the psychiatric survivor movement. It is, "the deeply personal process of changing one's attitudes, feelings, perceptions, beliefs, roles, and goals in life," and is conceptualized as, "the development of new meaning and purpose in one's life, beyond the impact of mental illness (Farkas, 2007b)." Farkas presents four key values of a recovery-oriented service: person involvement; person orientation; self-determination; and choice and hope. She stressed the importance of services to be able to support aspirations of users that go beyond clinical services.

In 2007, the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) developed a consensus statement containing ten fundamental components of recovery. The first two components are: self-direction; and individualized, and person-centered care (U.S. Department of Health and Human Services, 2007). Person-centered care is defined in the U.S. as: “the person with the illness is to be respected as the primary decision-maker in—and author of—his or her own life” (Davidson, 2011). There are many critiques of this definition of recovery. Pat Deegan, herself, wrote that, “Too often we project traditional ‘American’ values on disabled people, e.g., rugged individualism, competition, personal achievement, and self-sufficiency. Too often our program models have tacitly adopted these, and only these, values” (Deegan, 1988). In a paper applying an ecological frame to the recovery concept, Onken critiqued the prevailing definitions of recovery:

> “The description of recovery as a unique process generated by the willing and strong individual who combats the illness and emerges in society able to function inadvertently perpetuates the myth that those who are psychiatrically disabled must earn their way back into the mainstream of society.” (Onken et al., 2007)

His ecological framework places the disability not in the person alone, but at the interface between the person and his or her environment. He complements a 1988 definition of recovery from Deegan from a personal to a more ecological one. Deegan wrote that:

> "Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again...The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution." (Deegan, 1988, p. 15)

Onken added that: “this personal disposition toward positive recovery must be complemented by a facilitating environment” (Onken et al., 2007, p. 19).

Ademola Adeponle critiques the vagueness of the concept, and warns about the fact that it is culturally constructed (Adeponle et al., 2012). A recent paper, still in press, looking at implementation of “recovery-oriented” programs in India reviews and concurs with those critics (Bayetti et al., 2016). Citing other authors, especially McWade, the authors pose an essential question for development of recovery-oriented models in global mental health: how is it decided what life is livable and meaningful in a neoliberal context where there is pressures to deliver clear, measurable outcomes? Bayeti et al. show that transposing the Western recovery model without prior systematic questioning and research may lead to ignoring the structural barriers in the experience of mental illness, and to the, "disappearance of the social justice principles behind the recovery approach" (Bayetti et al., 2016, p. 9). For example, they point to the importance of family for the recovery process in India and deplore that the emphasis on individual might lead to exclusion of the latter from the process.

Similar considerations need to be made also regarding Haiti. Scholars have also pointed to a socio-centric or cosmogonic aspect of personhood in Haiti (Farmer, 1992; Kiev, 1961; Metraux, 1958; Philippe and Romain, 1979). Acting at the individual level only may not be enough to achieve recovery. Actions at the level of the community, on societal and structural levels, are also needed. This study's findings on the importance of connection for the persons in recovery corroborate this idea. If one says "person-centered" in Haiti, it still depends on what comprises the person, on how personhood is defined in Haiti. When asked about what helped them in their recovery, study participants first cited their parents or spouse, and the medicines. It would be wrong to push our study participants for self-reliance. The focus on the individual and on autonomy cannot be systematically applied to the individuals in the study sample. For some of the participants with restrained agency, promoting such notions could potentially cause more harm than good by inadvertently blaming the sufferers.

Nonetheless, there are elements that mental health program in Haiti can learn from the values promoted in the U.S. recovery model. For example, although the notions of person-centered care and self-determination should not be uncritically applied, they remind us of the necessity to put the person who is suffering at the center of the intervention, talking and listening to him or her, prioritizing his or her opinion in what concerns his or her health. They remind us of the important duty to respect the right of the person to participate in those decisions. In fact, the ZL mental health providers practice and value talking and listening directly to the patient even if psychotic. They create space in the therapeutic encounter to be alone with the patient and to listen to him or her, and they give paramount consideration to the patient's opinion.

Professional caregiving as friendship and accompaniment

Persons with lived experience appreciated the fact or wish that professional caregivers (such as psychologists, physicians, nurses) would behave like friends with them. They explain they like the way that psychologists at ZL care about them and empathetically listen to them. From what they have said, the benefits of this friendship, this propinquity, could increase their self-esteem, redefine them in the community, and facilitate their reinsertion. This idea of friendship is important because of those above-mentioned advantages, and also because it links with several concepts in literature and in rural Haitian culture.

Many have recognized a certain culture of familiarity and of proximity, in general, in the countryside of Haiti (Barthelemy, 1991; Bijoux, 1990). In a village every adult is called uncle, aunt, mommy, and daddy. Traditionally, a child or teenager growing up in a village is under the responsibility of all adults in the village, especially the adults from the same extended family. For example, any adult from the village who is close to a teenager's parents could punish him, if he does something bad. While there is the familiarity and propinquity, many peasants are discrete and refrain from easily expressing their personal emotions very openly. When someone from the rural area tells you about his personal matters, you become an intimate member of his or her family. You become a son, a daughter, a brother, and at least a friend (Barthelemy, 1991).

When some study participants emphasize the value of friendship in the provider-patient relationship, what are the implications of this claim? Should there be a reconsideration of the neutrality and distance taught by Western psychology? This question deserves further exploration beyond the scope of this study. However, it is worth noting that Larry Davidson, in the article "Promoting Recovery: What's love's got to do with it?" also recognized a similar need vis-à-vis a biomedically oriented American psychiatric system. He wrote that, "For the practitioner, in addition to honoring each person's autonomy, this requires a rethinking of the traditional therapeutic stance of abstinence or neutrality, inherited from psychoanalysis, in favor of a more engaged, compassionate stance that we suggest falls under the broad rubric of 'love'" (Davidson, 2011, p. 2).

Davidson cites Van Gogh, in a letter to his brother:

> "Like everyone else, I feel the need of relations and friendship, of affection, of friendly intercourse, and I am not made of stone or iron, so I cannot miss these things without feeling, as does any other intelligent and honest man, a void and deep need… Do you know what frees one from this captivity? It is every deep serious affection. Being friends…love, these open the prison by supreme power, by some magic force. Where sympathy is renewed, life is restored." (Van Gogh & Roskill, 1997, p. 126)

Marianne Farkas, in a personal conversation, called my attention to the fact that the friendship that persons in recovery are asking for may be less the personal relationship with the provider but more of a humane and respectful relationship. In places where persons seeking care are humiliated and mistreated this may be particularly relevant; however, at HUM, the same persons who requested the friendship-like relation also praised the way the staff care about them.

It therefore may not be in all cases that a request for friendship is used as a metaphor for respect and humanity as a result of clear disenfranchisement.

The idea of friendship is integrated into another important concept central to the mission of ZL/PIH: *accompaniment*. As a matter of fact, the proposition of friendship in professional caregiving calls for a personal investment from the provider, a commitment towards the patient to share his or her problems, joys etc. "Physical and social proximity are important to accompaniment," argues Paul Farmer (2013, p. 128). He cites an enlightening passage of Professor Roberto Goizueta's book *A Theology of Accompaniment,* in which the latter is taking about the Latino community in the U.S.: "As a society, we are happy to help and serve the poor as long as we don't have to walk with them where they walk, that is as long as we can minister them from our safe enclosures. The poor can then remain passive objects of our actions, rather than, friends with whom we interact" (Farmer and Gutierrez, 2013, p. 128). The persons with lived experience in our study, when asking for friendship, when expressing their appreciation of proximity, were defining this model of accompaniment in care that they want.

The word "accompaniment" comes from three Latin terms: *Ad*, *cum*, and *panis*; "ad" expresses the idea of an indirect object like "to", "at". "Cum" and "panis" are respectively "with" and "bread" (Merriam-Webster Dictionnary, 2016). Accompaniment is an action towards the one with whom you are breaking bread. Farmer defines "accompanying someone" as "to go somewhere with him or her, to break bread together, to be present with a beginning and an end" (Farmer and Gutierrez, 2013, p.127). Sharing bread or cassava with a cup of coffee together is a widespread custom in the rural areas of Haiti. Neighbors, the "*konpè*" or the "*kòmè*"[25] who come

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[25] *Compère, comère* (*Konpè* and *kòmè* in kreyol): designate for a parent someone who baptizes his or her child. It is sometimes used without this link among any friends. Etymologically, from

to share a cup of coffee, ideally will also come when there is a disease, a death, or a coming together to plow the field (called in Kreyol: *Konbit*). The concept of accompaniment originates from the Christian literature and designates a shift from a short evangelical mission without knowing the target populations that they wanted to convert, toward a type of mission where missionaries would go and spend time in the community that they wanted to convert, getting to know this community and engaging with it. Farmer (op. cit.) stresses that this kind of commitment is not easy. One prerequisite of it, I think, is sincerity and the privilege of being able to throw oneself selflessly into a journey with someone else and for someone else. The following question may be asked about Farmer's definition: Who determines the "somewhere" where we are going? In this instance, it is the person with lived experience of psychosis. Even if the journey has an end, it is not the provider or the *accompagnateur* who will decide when to stop it or to leave it; that would not be accompaniment; however, particularly in the instance of psychosis, the provider needs to learn how to accompany the person in making the decision and setting the goals. This is part of the role of psychiatric rehabilitation, which "emphasizes improving role performance (Anthony et al., 2002, p. 10, 49)."

Gregory Jerome, a ZL leader, reported in a paper in 2010 that ZL CHWs often do more that what they are expected to do by their employers. They give financial support from their own resources, they help with domestic tasks such as "laundry, cleaning," and even bathe people living with disability (Jerome and Ivers, 2010). The ZL mental health CHWs also do the same things. It is a relation of proximity, of propinquity and of relying on each other. They are in the community with the people; they feel that they have to help. "How can I advise someone to go to

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French: Com-père is co-father. Co-mère: co-mother. They both have a common parenting responsibility towards the child.

the hospital and not give him or her the transportation money if s/he does not have it?" one CHW has said to this researcher.

Accompaniment is a care delivery paradigm. When accompaniment is applied at all levels in the system, we begin to have an empathic system, where the task of empathy, of *pran ka,* caring for what matters for the person in recovery, is not only borne by the sole provider. It is also shared by the system, which accompanies both the provider and the users through other supports made available to the patients beyond the clinical one. The mental health system should be built in a way so that it systematically cares about people's lives, about what matters to people, to help them overcome the structural barriers that they face, and to help them to thrive. The empathy of the providers alone is, "washing the hands and wiping them out in the dirt," and the provider needs the empathy of the system as well.

Accompaniment needs to be strengthened and operationalized especially at higher levels such as supervision and management. Considering the ZL mental health system in particular, a Weberian look at the growth of the organization shows that we need to make sure that such practices are not lost on the way. And in case they are being routinized, we need to pay attention to how their core values are preserved (Waters and Waters, 2015).

Accompaniment or Partnership?

Partnership is a comparable model in the recovery literature that is proposed as a framework for professional caregiving (Corrigan, 2002, 2003; Noordsy, Torrey, Mueser, et al., 2002). The Oxford dictionary defines a partnership as follows, "An association of two or more people as partners." A partner is, "A person who takes part in an undertaking with another or others, especially in a business or company with shared risks and profits" (Oxford Dictionary, 2016). In the concept of partnership, the equality between the two partners is emphasized. Both partners, "take part," and decide to act toward a common goal. Partnership is a central theme in the recovery literature, a "mutual exchange between practitioners (who are expert in interventions that improve symptoms and disabilities) and consumers (who are expert in their disabilities and life goals)," wrote Patrick Corrigan, a renowned scholar of psychiatric disability in the U.S. (Corrigan, 2002). In our focus group with the CHWs, they explained how the treatment relationship usually starts. Often, after sharing information in the community about mental health, parents or persons with lived experience come to them and explain their problem and seek advice on how to benefit from the ZL mental health program. In the community of a CHW, people approach him anywhere in the community to ask his service. One CHW said that he is glad that the patients bear witness to what he did for them, and are telling other people to go to the hospital also. This is how the partnership starts and how both people benefit mutually from the relationship. While the CHWs is doing a part-time job, they receive the pride of seeing people telling others about good things they are doing and they accompany those people in the care journey.

Norma Ware reported similar relationships in a study of the factors explaining a successful adherence rate of HIV patients in Sub-Saharan Africa. In the settings studied, patients chose persons with ties with them to help them with the treatment. Those helpers were called *treatment supporters* in some places and *treatment partners* in others. The study noticed reciprocal expectations that drove both the patients and the "treatment partners" to do their parts of the job. The treatment partners, having social relationship with the sick persons, had the responsibility to help and the sick persons to adhere to treatment, to get better and decrease the need for support. The study concluded that the connected patients in those settings prioritized adherence as part of preserving social capital (Ware et al., 2009).

Accompaniment is not a paternalistic process. However, in rural Haiti, there needs to be the acknowledgement of a real social power imbalance between the *accompagnateur* and the accompanied, so the system can work on rebalancing this relationship acting both on the patient and the provider's side. The *accompagnateur* may be being accompanied himself by the one he is accompanying; it is a mutual accompaniment. The health practitioner will have the duty to be humble, to be ready to listen and to learn, and to be transformed. In most cases, in rural Haiti, the provider has better social privileges than the patient, and throwing oneself into the life of someone else may be seen as taking a risk. It is sharing the burden of the problem with the patient. In business, for example, two partners share the risks of bankruptcy and failure. It is important that the idea of partnership does not lead to a way of protecting the health system and the health practitioner by alleging that the patient, although facing many structural barriers, has his or her responsibilities in the failure too. We should be cautious not to blame the victims.

In Haiti, while we recognize that mental health patients must have a central place and role in the system, that they have to be involved on an equalitarian basis, one also needs to recognize that it is not yet the case, in reality. The egalitarian relationship has not taken place in the health system yet because of many reasons, including the scarcity of health services, their financial cost, and the poverty of the majority of the population. Additionally, there are reasons concerning social and economic class that place clinicians in a higher economic position than most patients, as well as historical and political reasons explaining that doctors mostly remain members of the higher social and economic class.

The saying *Aprè Bondye se Doktè*[26] (After God is the Doctor) is another expression of this inequality in the clinical relationship according to some. It may express a political awareness of the patient of this inequality, and of the inability of patients to discuss the prescriptions of the doctor. It does not necessarily means that they will accept anything that the doctor orders. In fact, in the paper "The birth of the Klinik" Farmer cites Jeanne Philippe, saying that Haitian patients are reticent and suspicious. She specified that it was worse in 1986, but that this might have always been the case (Farmer 1992, p. 264). The fact that it might have always been the case aligns with the fact that the population and particularly the peasantry have been oppressed since the days before, and after, independence (Casimir, 2001). Being reticent, not being too talkative with the doctor, may be related to the social class the doctor is associated with by the patient. If the doctor is assimilated to the oppressive political class, the exploitative bourgeoisie, the neo-liberal middle class or the contemptuous and careless intelligentsia, it is understandable that people will not be open and will be reluctant to confide with them.

Cidna Valentin, current clinical supervisor of the ZL psychologists, wrote her doctoral thesis titled *Aprè Bondye se Doktè* (After God is the doctor) exploring the meaning of this common saying. Haitian physicians, interviewed in her research, held different and contradictory interpretations of this saying and of the relationship between Haitian patients and their physicians (Valentin, 2013). The physicians participating in that study were both Haitian and foreigners who worked with NGOs in the aftermath of the 2010 Haiti earthquake. Some of the physicians believed that patients would prefer an authoritarian physician who would dictate for them what to do. It is important, however, to place this saying in the context of the oppressed

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[26] *Aprè Bondye se doktè* (After God is the doctor) is a common saying in Haiti referring to the importance of the role of the doctor.

culture mentioned above, and of a possible reification of biopower in the clinic (Foucault, 1976). The power imbalance existing between the individual patient and the doctor or the health organization, the way the powerful health organization presents its priorities and services, may shape the acceptance and the behavior of the population of patients. Therefore, *accompanying to recovery* implies the acknowledgement of this power relationship and the active and sincere demonstration of respect, empathy, care, practical solidarity, openness and willingness to learn the values of the person in recovery and their families. Accompaniment encompasses the elements of partnership. To, "go somewhere with someone," with a "friend" with whom we are "interacting," who is not "a passive object of our action" as Goizueta wrote, is a partnership. The strategy of partnership has been one of PIH's since its foundation: partnering not only with patients, but with academic institutions, with local NGOs, with communities and with governments to deliver equitable and high quality healthcare.

Beyond straddling friendship and accompaniment in professional caregiving, study participants indicated a need for, "fulfilling social roles." We here present two concepts: *empowerment*; and the *capabilities approach*. We will define them here and show how they may help accompany persons in recovery to achieve the valued roles they want to achieve in society.

Empowerment

Empowerment has been an important and popular movement. In a historical analysis of the term, Anne-Emmanuèle Calvès showed that the notion gained ground in the context of the feminist movement in the 1980s (Calvès, 2009). She reported a definition by Indian activist Srilatha Batliwala: "a process of transforming power relationships between individual and social groups (as cited in Calvès 2009)." The author emphasized the need for multifaceted actions for this process of empowerment. Activists pushed for the adoption of the model of empowerment and international institutions, although late, started to adopt the concept. Calvès cited several definitions of the World Bank including one from a report by Deepa Narayan, describing empowerment as, “the expansion of assets and capabilities of poor people to participate in, negotiate with, influence, control and hold accountable institutions that affect their lives (as cited in Calvès 2009).” Those early definitions define empowerment as a complex process that requires multifaceted interventions and which is difficult to implement. As the mainstream started to adopt the term, the focus changed. It became more about the individualizing notion of power, and later a notion at the service of the status quo, co-opting the term and restricting its definition to fit the measurement toolkit for their interventions. Then, empowerment could be used meaning “individual capacitation,” economic support (through microcredit e.g.) or solely “political participation.” Today, it is difficult to know what one means when talking about empowerment in the international development field.

In mental health, a leader in the service user movement, Judi Chamberlin in her book referred to as the bible of the empowerment philosophy *On our own: Patient-Controlled Alternatives to Mental Health System* pointed at the issue of power in the therapeutic relationship as a core principle in the “mental patients’ liberation movement.” She develops this issue as “the right of patients and ex-patients to get the help they needed without giving up their basic human rights to self-determination” (Chamberlin, 1978). In 1997, she presented a working definition of empowerment coming from leaders among mental service users in the US. This definition has 15 “qualities,” and the closest to this idea of the “bottom up multifaceted transformation of power relationship” is the sixth quality, “redefine relationship to institutionalized power,” the ninth quality, “understanding that people have right,” and the tenth one, “effecting change in one’s life and one’s community.” The shift in the meaning of the word empowerment seems to have also in occurred within the recovery movement. In the framework proposed by Leamy and Colleagues, empowerment is one of the processes of recovery and it is broken down into: personal responsibility; control over life; and focusing upon strengths (Leamy et al., 2011). In their textbook on rehabilitation, Corrigan and colleagues present empowerment as the opposite of self-stigma (W. P. Corrigan, Mueser, Bond, Drake, & Solomon, 2008). In other publications, as reported in the Onken et al. review, "information and education about the illness, available treatments," are seen as information that can lead to power. Assimilating empowerment to information and education would be a significant transformation from the early definition of empowerment. According to the Onken review the concepts related to empowerment such as agency and choice are defined by some as inside the limits of the mental health systems and seen as if they were separated from the rest of the society that is strongly impacting them (Onken et al., 2007). In the more recent definition of Chamberlin, and in other definitions from the psychiatric rehabilitation literature (Chamberlin, 1997; Corrigan, 2002, 2003; Hoffman et al., 2011), we see also a focus more on the individual and on the individual clinical relationship as if this were happening in isolation from society. As the initial definitions of empowerment suggested, the power relationship cannot really substantially change without collective, societal change for vulnerable groups such as persons with lived experience of psychosis in rural Haiti.

Recovery and the capabilities approach

Empowerment in psychiatric recovery can be promoted by the *capabilities approach*.

> "A person's 'capability' refers to the alternative combination of functionings that are feasible for her to achieve. Capability is thus a kind of freedom: the substantive freedom to achieve alternative functioning combinations (or, less formally put, the freedom to achieve various lifestyles)." (Sen, 1999, p. 75)

Considering Sen’s capabilities approach for a person in recovery, the focus should be placed not on the treatment itself, but on the valued things that this treatment allows the user to achieve. The treatment should partake in enhancing the person’s capabilities. If the user wants to connect or work, to what extent does the treatment make that possible? Kim Hopper looked at how a capabilities approach (CA) could better help people with schizophrenia (Hopper, 2007). Among consequences of adopting a capability approach, Hopper mentioned that CA-informed initiatives should not be funded in isolation from other initiatives. CA implies, “the direct participation in public deliberations about symbolic representations of and material support for excluded people” (Hopper, 2007). So, there has to be a shift in power. “Affirming human flourishing as the orienting aim of public mental health is foremost,” wrote Hopper. CA has the potential to transform, as Hopper put it, the “near-toothless gospel of hope” preached in the recovery movement, “into workable guidelines and tools.” CA would “call the system’s bluff”, Hopper wrote (2007, p. 877).

ZL has a tradition of accompanying patients in realizing things they value through diverse strategies such as direct cash transfer, providing jobs or advocating for jobs for patients, sending children to school, and facilitating the entry of the patients into microcredits. These are first steps toward CA that are necessary also for persons with experience of psychosis. However, CA goes further. As we saw, it focuses not on the, “resources, but rather on the valued things that people are able to do as a result of having them” (Hopper, 2007, p. 874). For example, a person may have money but cannot successfully open a commerce because of stigma, or one may have a profession but not able to find a job for diverse reasons. So, CA implies changes at the level of society as well. People recovering from psychosis, beyond the clinical gains, beyond financial support, also need societal, structural changes so they can have true power.

In the context of the SDGs (Sachs, 2012), and approaching health and well-being from a triad of social inclusion, economic development and environmental sustainability, CA can be a framework for recovery-facilitating mental health services. CA is obviously connected to an important theme that the study participants raised: fulfilling social roles.

Considered in the framework of the CA, social roles are valued functionings that people want to achieve. We need to ask ourselves how our service approach empowers people to achieve that aim. On top of clinical treatment, our goal should be to accompany this person in fulfilling his or her social roles. Clinical improvement alone will not be enough. Rehabilitation services need to be established to teach people various skills they need in order to be able to play those social roles. Linking people to social networks, to jobs, microcredits, and helping them to start income-generating activities, are all identified by study participants as necessary for their recovery. Larger community-level actions such as stigma reduction and actions facilitating social reinsertion are also needed so that people can claim their desired roles. For this purpose also, the rights of people with mental illness need to be protected in society. Legislation to promote the rights of mentally ill people is therefore also urgently needed.

Providers and leaders "scratching the surface"

The interviews and focus groups with providers and national leaders are rich with criticism and proposals for the Haitian mental health system. Two major issues are found. One, there are efforts at several levels aimed at providing mental healthcare; and two, despite those efforts, the treatment gap is still immense. In working towards filling the gap for mental health, the providers and community leaders in the focus groups offered their critiques of the ZL system.

All categories of providers praise the system overall, but also point out the lack of resources such as human resources, logistical resources, and low salary. Added to that is what they identified as a lack of adequate training, supervision and psychological support for each member of the multidisciplinary team, which jeopardizes its sustainability. Leaders at ZL agree that this is an issue that needs to be addressed, but they need more on-site supervisors, and additional financial resources to expand training and supervision.

The psychologists' work burden is a major issue related to many of the themes presented here. The progressive addition of more and more monitoring and evaluation tools to use has increased stress experienced by the psychologists. Their expression of a feeling a dehumanization of the provider-patient relationship has been seen in the U.S. also for example in the context of increasing demands for documentation to fulfill bureaucratic requirements. In *Shattering Culture* a book edited by Mary-Jo Delvecchio Good and colleagues, Antonio Bullón reports a strikingly similar quote than the one we found: "Instead of documenting what we do, documenting is what we do" (Bullon, Mary-Jo DelVecchio, and Carpenter-Song, 2011, p. 200). And one of our psychologists said: "The system is more focused on the report about the patient than on the patient her or himself" (from a psychologist taking part in one of the focus group).

Physicians in the ZL mental health system

For the purpose of this discussion and from my personal experience as a physician in the ZL mental health system for four years, I can identify two main instances where physicians collaborate with the mental system: first, in the outpatient setting, psychologists take patients to them for medical evaluation and medicine management; second, on the wards (emergency ward or internal medicine ward), they take care of patients with a mental health comorbidity or a patient who is admitted specifically for a mental illness. Many physicians and nurses think that they should not have to deal with mentally ill patients. They often suggest that mental health "could use its grant to have a separate ward" with separate staff for mentally ill patients. A smaller number of physicians feel that the integrated system should be practiced in peripheral health centers, but not at HUM, for example. There are many aspects to this discussion, some very practical and technical, which are outside the scope of this thesis. They will be discussed in a recommendation report that I will write for the ZL mental health leadership.

Considering what the providers and leaders have said about the issue of separate space for mentally ill patients, we can see why some providers take that position. First, a national leader explains that they want to get rid of the emotional burden of dealing with mental illness; for her, it may be a defense mechanism. Second, some of them may be dealing with crushing problems in their own families including mental illness. They need support to deal with their problems and may not be able to stand reliving the same scenes. All of the policy leaders and the facility-based providers (psychologists, social workers, physicians and nurses) said that it is a very consuming and exhausting task to take care of floridly psychotic persons, when considering that they have been working all day with other challenging patients. A third contributor, despite some trainings carried out with a limited number of physicians over the past four years, is the lack of training and lack of theoretical and practical exposure to the medical management of psychosis. Finally, they also may be afraid of the patients, and stigma is embedded among health practitioners working in the ZL system.

Collaboration with traditional healers

Beyond expanding formal resources as suggested previously, collaboration with traditional providers is seen as a way to expand the service in the communities and provide more effective care. The *oungan*, the CHWs, the clinicians as well as the policy leaders agreed with that prospect. For the sake of clarity and rhetoric, we divide the traditional medicine into two parts (See Chapter 1): 1) traditional herbal (*medsin fèy*, herbal medicine), other chemical and physical treatments; and 2) spiritual healings. We must recognize that both kinds are often used together, and it can be difficult to tell apart the religious from the chemical aspect.

Treatment with leaves is very widespread in Haiti. Marilise Rouzier, a pharmacist at the Haitian State School of Medicine, in the wake of other authors, produced several publications about the use of many leaves of Haiti. A direction of traditional medicine is currently functioning at the MOH. Members of this direction who we met insisted on the asset that *medsin fèy* could represent for mental health (personal communications, August 2015). People of the countryside know leaves they can take for many medicinal purposes. For example when they cannot sleep, they may take *fèy kowosòl* (leave of soursop, *Annona muricata*), when have had an emotional upset (*sezisman*, shock) they may take *vèvèn* (Verbena, *Aloysia citrodora*) infusion.Research needs to be done to envision the development of this potential treatment (TRAMIL, 2005).

Spiritual acts often accompany the leaves but represent an entity by themself. Our mention of spiritual in this work refers to both Vodou and the healing practices of other religions including Catholicism, Protestantism, and Freemasonry. While Louis Mars and Ary Kiev have already praised the therapeutic capacities of Vodou, many studies in developing countries show that those spiritual healing practices are effective in psychosocial interventions (Kiev, 1961; Mars, 1950). However, the effectiveness of such practices has not been proven for interventions addressing severe mental illnesses according to a review published by Nortje, Gureje and other colleagues (2016).

According to what we have gathered, this is a list of reasons why collaboration with traditional medicine providers could be beneficial:

- Their leadership in the communities (they are known, and trusted by many);
- Their geographical accessibility;
- Their cultural proximity, and the fact that they share the same worldview, which may reassure people that they are not going to be judged;
- They offer a complementary approach to care for many cases (either in churches or *ounfò*);
- Concerning *medsin fèy (*herbal medicine), it will relieve a huge economic burden when research will show how it can work;
- And a harmonization of those different sources of help may decrease the exhaustion caused by the zigzagging journey of care seeking.

There are pitfalls of the collaboration that are related to the lack of knowledge about which practice is effective for what, and to the lack of regulation of the traditional medicine sector, especially because of countless accounts of abuses in spiritual and herbal traditional medicine.

Convergences and divergences

In this final part of the discussion, we stress some points of agreement and divergence that are noted between the different categories of study participants.

The first divergence relates to explanatory models of illness, and adherence to care. Whereas the patients and families never mentioned their religious beliefs as an impediment to their adherence, the physicians and nurses in the study do see religious and spiritual beliefs as major barriers to seeking care at a hospital and to a good adherence to medical treatment. The psychologists and social workers insist less on this aspect, and they explain lack of adherence also caused by socio-economic problems. I think that this may be due to the biopsychosocial approach that psychologists have learned to use in their work, as opposed to the more biologically-focused training for physicians.

The second divergence related to the hope of recovery from the perspectives of the families, and the perspective of the persons with lived experience of psychosis. In the study sample, most of the persons with lived experience of psychosis said that they never lost hope. They say that they always expected to recover. They admit that they might have been discouraged at some point and doubted at some point, but they always regained hope. This may be the result of a recall and selection bias, but what is certain is that all the persons with lived experience at the moment of the interviews, even if they had symptoms or side effects, were hopeful vis-à-vis recovery. Most of them had hope because of their faith in God.

On the other hand, the family caregivers often expressed that they had lost hope, they had been discouraged or that they still did not think that their relative would recover. The family caregivers insisted more on the productivity aspect of recovery and that may account for the different perspective. Concerning the effectiveness of care, the divergence takes a reverse form. The family of a person who was initially agitated might say that the person was “doing great,” while the sick person stated feeling bad despite the clinical improvement, because the person was sad, not yet functional as they may have been before, or experiencing side effects. The improvement of the tumultuous symptomatology brought perhaps greater satisfaction to the family members who were caring for the person, because the patient needed less surveillance and reduced the burden of caregiving, which gave the caregivers the opportunity to go about their other daily activities.

Summary of the discussion

The discussion has three main parts: 1) structural violence in the lives of the persons with lived experience of psychosis and their caregivers; 2) the eclecticism in the care seeking models and; 3) the necessity of a deeper response to a deeper malady.

1) Structural violence in the lives of the persons with lived experience of psychosis and their caregivers

The lived experience of psychosis is terrifying, isolating, and devastating. This devastation is exacerbated by poverty and other structural constraints. The care-seeking journey was uncertain, long, sinuous, impoverishing and hazardous in religious shrines and state psychiatric institutions. This journey is exhausting physically, morally and economically. At the collision of the progressive exhaustion of resources, the absence or inaccessibility of formal services, the bad quality of care, the stigma and mistreatment experienced in communities, and other family priorities, family caregivers face an agonizing practical moral dilemma in acting for the good of their sick loved ones. In looking at the mistreatment of the mentally ill in families, we also need to see a deeper underlying violence that drives the more visible violence seen in families, shrines or psychiatric institutions. The structural violence in action in their lives besieges families' agency, and forces families into situations where all options are poor. This is what we denominate the "straight jacket of agency." This perpetuates the mental illness and also the state of violence; furthermore, structural violence also influences the origin, course and outcome of the mental illness for the sufferer.

2) Eclecticism in the models of care and in their explanations

People desperately want and look for solutions to their problems. They look for care from different sources and they integrate Western explanatory models of illness into their existing framework or their existing worldview. The explanatory models held by the study participants are not seen, in this research, to be incompatible with coming to the hospital and adhering to medical treatment, although some clinicians believe that the explanatory models may hinder adherence, service users focus on structural barriers as their major impingement for adherence. Considering the moral and religious questioning that accompanies the occurrence of illness in the lives of most our study participants, we also understand that the religious explanatory models sometimes answer different kinds of question than medical models do. The religious models answer moral and existential questions that help people to make sense of the misfortune that has befallen them. In the light of those, beyond creating accessible services, it may be beneficial for formal mental health systems of care to integrate or promote coordination of several helpful sources of help, facilitating access to them along with the biopsychosocial treatment provided by the conventional system.

3) The necessity of a deeper response to a deeper malady

According to our participants, recovery is achieved through clinical improvement, functional improvement, and connection to other people: to friends; to the larger community; and also to the divine. Beyond the need to improve the quality of clinical care (with medication and psychotherapy), there is also a need to sew back the torn social fabric around the individual by helping to gain personal social skills so they can connect and fulfill their valued social roles, but also acting on the community by promoting openness to and greater acceptance of persons living with mental illness. Structural violence influences the origin, course and outcome of mental illness, devastating the sufferer's and the family caregiver's lives, therefore, breaking the underlying structural violence is necessary for long-term personal, family and community recovery. Accompaniment, as identified from participants' suggestions, can be a model at all levels in a recovery-facilitating system of care.

LIMITATIONS OF THE STUDY

As a qualitative study with purposeful sampling, this research did not aim to be generalizable. Instead, the aim was to study, in depth, the problem of recovery from psychosis in the Mirebalais and Ti-Rivyè areas of Haiti. This in-depth understanding of the situation may have implications for national and even global mental health, but its results are not generalizable to other settings than the ones described.

People with lived experience of psychosis and families did not express much criticism of the ZL mental health program. Most of them said that they appreciate everything, and since they are not health professionals, they cannot suggest improvements. I have to acknowledge the fact that I (the researcher who conducted the data collection) was a member of this program and that might have inhibited people from expressing their criticisms. Some participants, nonetheless, primarily providers and leaders in the system, but also persons with lived experience and caregivers, offered important critiques which we share in the results and suggested areas of improvement as well.

RECOMMENDATIONS

> If you look under the rug of civilization where it is dark and wicked, we are fierce and terrifying. You need to face that to discover the possibility for creating something better.
>
> (Kleinman, 2006, p. 13)

> "An understanding of poverty must be linked to effort to end it…
> The study of poverty, without an expressed concern with ending it is seen with a hermeneutics of suspicion by most people with whom I've lived and worked."
>
> (Farmer and Gutierrez, 2013, p. 21)

A special report with more practical recommendations from this study will be completed for ZL and the Haitian MOH. Here, we present the main points in which the problems raised in our discussion can be addressed. The devastation and exhaustion driven by the illness and the care-seeking process requires the establishment of a larger, more outreaching, and more empathic system. There is a need to maximize the quality of care with the following: better availability and variety of free drugs and other supplies; more training; better supervision; and, consequently, more specialists to ensure quality of care and sustain supervision-accompaniment. We need to broaden our presence in our area of service. This can be done through increasing the number of trained CHWs, partnering with new health centers and collaborating with traditional healers. Collaboration with traditional healers requires some prerequisites that further research, conversations, and political will can make happen. To increase the number of mental health specialists in the country, ZL can support their training as it has for other health specialties. The collaboration between the mental health service and the psychiatric center Mars and Kline for the training of the residents should continue and be reinforced. This includes, importantly, opening a psychiatric residency at HUM in collaboration with national leaders in psychiatry as a sure way to increase the number of psychiatrists in the country and to potentially expand the ZL model to the rest of the country.

The paradigm of accompaniment applied at all levels of the system can help to build a more empathic system of care that will help to realize all of the above-mentioned needs and demands. In an empathic care system, the individual provider, but also the whole system, care about the person, *pran ka moun nan,* (is a friend with people). Providers will respect patients' explanatory models and take them into account in their diagnosis and treatment. They will expressly leave space in the treatment process for cultural and religious practices that patients think can be helpful for them. They will care about what matters to their patients including their religion, culture, social problems, the barriers they face in their care seeking journey, and their dreams. But more importantly, they will work in a system that facilitates them to do so by providing the adequate training, the needed resources and platform. Indeed, the system has to accompany the providers in carrying the burden of giving care. Caring about the provider may include paying him or her a decent salary, and providing him or her with the necessary training, supervision, and psychological support.

Rehabilitation, stigma reduction initiatives, and social reinsertion involving social workers, CHWs, community leaders (religious, civil and political), can be provided as part of the accompaniment offered by the system. Accompaniment also implies specifically caring about the economic hardship that people face in the process of seeking care and that devastates their lives.

Free care and economic accompaniment will contribute in helping patients and families to extract themselves from the insidious cycle of poverty.

The actions above will take us just a little deeper under the surface, so that we collectively stop only "scratching the surface." Structural changes need to happen. Stronger advocacy and activism need to bring mental health onto the priority agenda of the MOH and of international donors. Investment budgets for mental health need to be increased. A national mental health system needs to be put in place. The ZL model is a good one for the MOH to consider, but ZL also has to support the MOH in its effort to establish mental health legislation in the country.

Continuing to partner and support the MOH is essential. With powerful partnership and sustained advocacy, we will be able to unlock the straight jacket constraining individuals, families, and institutions in delivering safe, effective, equitable and culturally relevant mental health services to the people of Haiti.

CONCLUSION

Delivering mental health care for people living with psychosis with emphasis on the vision of recovery is important to guide the care and not limit it to the mere symptoms' management. However, since the concept of recovery and the general pathways to recovery can be different from one context to another, they needed to be explored in the context of the Central Plateau and the Artibonite. The understanding of the lived experience of psychosis is also essential to designing or improving appropriate system to facilitate recovery. This qualitative research studying the perspectives of persons with lived experience of psychosis, of family caregivers, of community leaders and local providers is a novel work in studying recovery from psychosis in rural Haiti.

We observe that the lived experiences of persons with a history of psychosis prior to entering the ZL mental health system were terrifying, isolating and devastating for sufferers and families. The uncertain, long, and zigzagging quest for care leads to moral, physical and economic exhaustion. Study participants recognized the value of clinical care for their recovery. One of them has compared the ZL mental health care program to the “headlight of a truck,” designating how essential it has been for patients to move forward with their lives. Notwithstanding, their accounts also reveal many areas where the system needs to improve, especially with regard to accompanying users in being able to “fulfill their social roles.”

Experiences and conditions at Haiti’s state psychiatric institutions are appalling. Persons with a history of internment report various abuses and abject living conditions. The unavailability of humane and effective care in many places in the country, the stigma and other structural constraints placed on patients and caregivers, the lack of budget for mental health in the national budget and the general neglect of mental health call for a more profound understanding of the abuses on the mentally ill that are happening in families, communities and in psychiatric institutions. Often, caregivers in our study found themselves in situations where the only options they had were terrible ones cornering them into heartrending, personally traumatizing moral quandaries. There is a situation of structural constraint that is similar to the “straight jacket of agency” of the sufferer, of the family and of providers at health care delivery institutions. Recognizing this deeper cause of mistreatment in the system calls for a more comprehensive approach to solve it.

In this constrained situation, the quest for solutions, however, happens and is marked by eclecticism. With pragmatism, people go from one source of care to a supposedly better one, or use several ones concurrently. This pluralistic search for help can be engaged with juxtaposition or syncretization of different explanatory models. The use of different sources of help and explanatory models can also be explained by the need to respond to questions that are of religious, moral, or existential order, rather than to ones that the instrumental techniques of medicine are seeking to answer (etiology, pathophysiology etc.). Ultimately, we observed that this eclecticism was a rich resource rather than as a barrier. It is true that in the context of limited resources, using several sources of care may impose a strain on people and even push them to prioritize the source that is perceived as most effective over other ones. The role of the mental system, in this case is well indicated. It is to contribute in harmonizing the various care pathways that people seek, facilitating optimal use of those different sources of care for the individual and family, and to optimize the quality of care they receive, taking into account the perspectives of those most concerned by this care, the sufferers and the family caregivers.

We identified some suggestions for the system of care that the study participants have expressed, while better defining the components of their recovery in the rural Haitian context. Three main areas of recovery have been revealed: clinico-functional recovery; recovery in connection; and recovery as being able to fulfill one's social roles. The first area commands us to continue to improve and optimize our clinical services and care. The second one calls for larger involvement in the community through even greater engagement of CHWs and social workers, better linkage with traditional healers, greater reduction of stigma, greater linkage to social groups and opportunities, greater support of the public sector in creating legislation protecting the mentally ill, and in building infrastructure that will promote their well-being in communities.

Finally, giving medicine without helping to fulfill social roles and goals is “washing one’s hand to wipe it out in the dirt.” We need to practically take into account in our system not the mere clinical state of our patients, but also their valued roles and the goals that they are able to achieve with what they have and who they are. That implies the establishment of true rehabilitation services, and the development of and training in context-appropriate rehabilitation techniques. The CHWs and social workers at ZL can play a central role in this rehabilitation component. To solidify and expand the scope of the ZL program, more human resources (psychiatrists, psychologists, social workers, and CHWs) are needed. More training and better clinical supervision are necessary. Concretizing accompaniment as a delivery paradigm at all levels of the system of care may help to increase the quality and effectiveness of the care provided by the individual provider, but also may contribute to making a more empathic system of care that cares about what matters for the patients and families as well as for the providers.

Collaboration with traditional healers offers an avenue to build a much larger delivery platform; however, considering the lack of regulation of this sector, designing such collaboration will require more work than simply meeting with traditional healers. The focus of the sustainable development goals on social determinants of health may constitute an opportunity for the government to design sustainable structures and infrastructures that will break some structural constraints, facilitate social reinsertion, and promote well-being broadly.

Further investigations are needed to elicit the experiences and pathways of recovery in other parts of the country. By building upon this work and developing related studies in the future, specific steps toward recovery-oriented care in the Haitian context can be identified with the introduction of appropriate rehabilitation programs. Quantitative research, in addition, will support the design and validation of tools to monitor the recovery process in this setting.

EPILOGUE

Two of the study participants live in Mòn Michèl. The first time I went there, Mèsidye[27], the husband of Janèt[28], a participant with a past history of psychosis, came to meet me at the dam at Peligre at 7:00 AM. To arrive at Peligre so early, Mèsidye had to leave Mòn Michèl three hours earlier. The road to Mòn Michel was very rocky. At some places, it was difficult to even see where it was. Mèsidye asked me, "Dòk (Doctor), the road is very bad and steep, will you be

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[27] Not the real name.

[28] Not the real name.

able to make it?" I told him not to worry, and that I am used to walking such roads. I said, "*se nèg nan mòn mwen ye wi,* Mèsidye" ("I lived and grew up in the mountains, Mèsidye").

We met several people going down the mountain. Some were taking their babies to the hospital, some going to the market, and a few children were going to school. The road to Mòn Michèl gave a uniquely beautiful view of Lake Peligre. "It does not rain this season and the lake is low," complained Mèsidye. It was around 10:30 AM when we arrived at the hub of Mòn Michèl, where Zanmi Lasante has built a school. We took our first break there. We chatted a little with the people gathered there, the school director and the women selling fried snacks to the children. We still had to walk another thirty minutes to reach Mèsidye and Janèt's house. When we arrived, Mèsidye looked at me, smiled and said: *"Ou konn mòn vre wi Dòk Fils-aimé*" ("You are used to mountain, indeed, Dr. Fils-Aimé!"). Everyone laughed. They asked me where I was from and I told them about where I grew up, a similar area. We all made a quick connection together.

Throughout my fieldwork, my background as someone who grew up in the countryside and who worked for Zanmi Lasante for several years played an important role. This background helped me to make connections with the participants very quickly, helped me to better understand what was happening, and helped to ask deeper and more relevant questions. I was not only a researcher in the field, I was also a physician and mental health practitioner wherever I went. Once in Mòn Michèl, I saw two other people with mental illness who had never been to a health facility before. I made a plan with the CHW, Félix, and their relatives to take them to HUM for a workup and continue their treatment. When I was doing participant observation or visiting any patient, they would tell me about their drug's side effects and I would collaborate with their psychologist to take care of them. So, I was both a researcher and a clinician. This double role appeared also in Maude’s case, as well as in Makso’s case, which I narrated in this thesis. Being a clinician engaged with the program about which I was doing research, on the one hand, helped me attain deeper insights. On the other hand, however, it may have inhibited some participants from critiquing the program, even though I assured them of the confidentiality of the conversation. Above all, however, the moments spent with the participants, those pieces of their lives that they allowed me to share, were not only moments of data collection. They were moments of communion, of transformation and of vivification of my commitment to human well-being and social justice.

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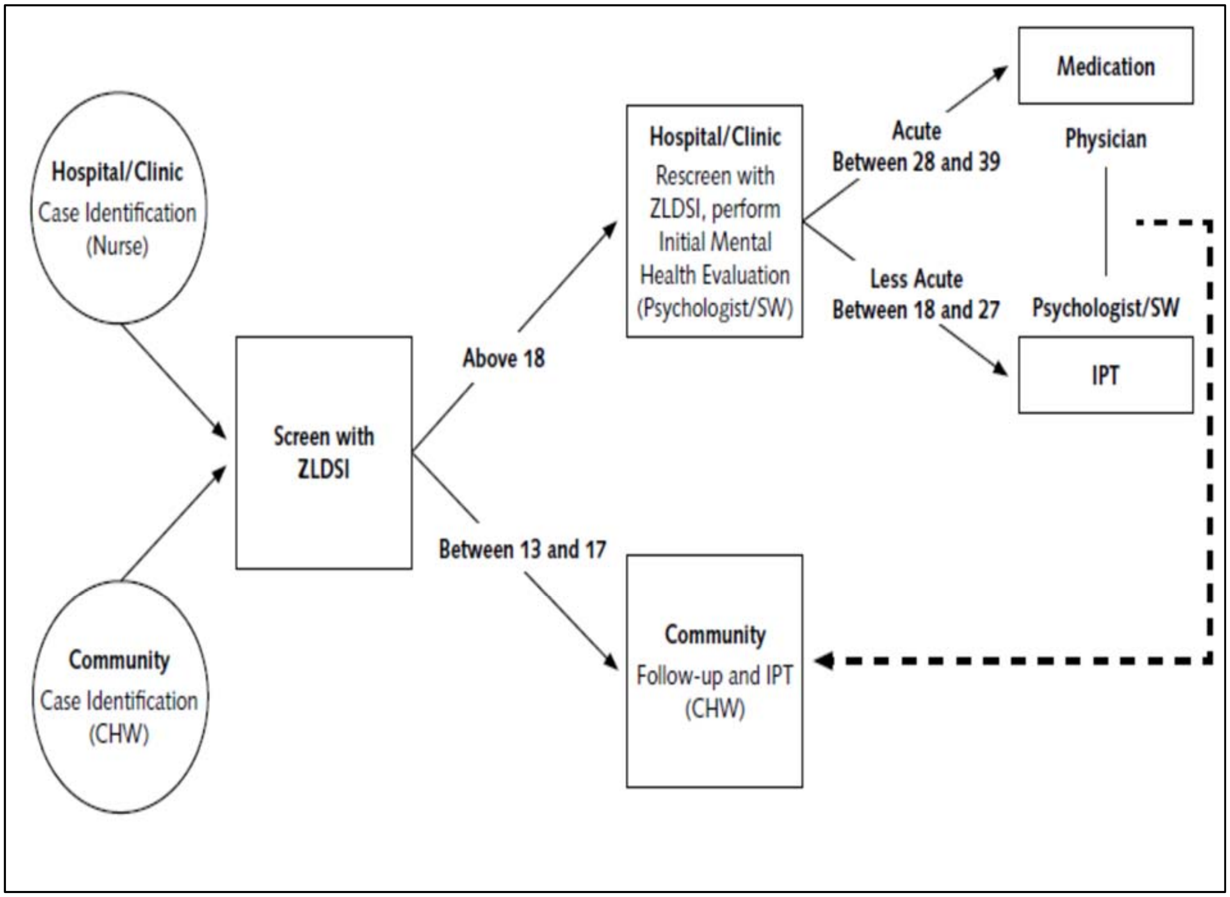
APPENDICES

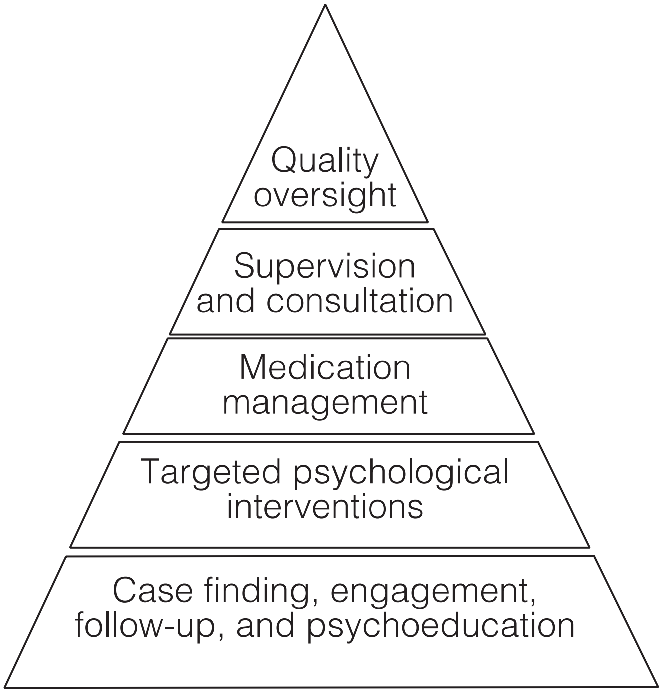
Appendix 1: Depression care pathway. The psychosis care pathway is similar to the depression one.



Appendix 2: The ZL mental health system 5x5 pyramid.

Figure 1

Five core groupings of skill sets on which to build a range of care pathways

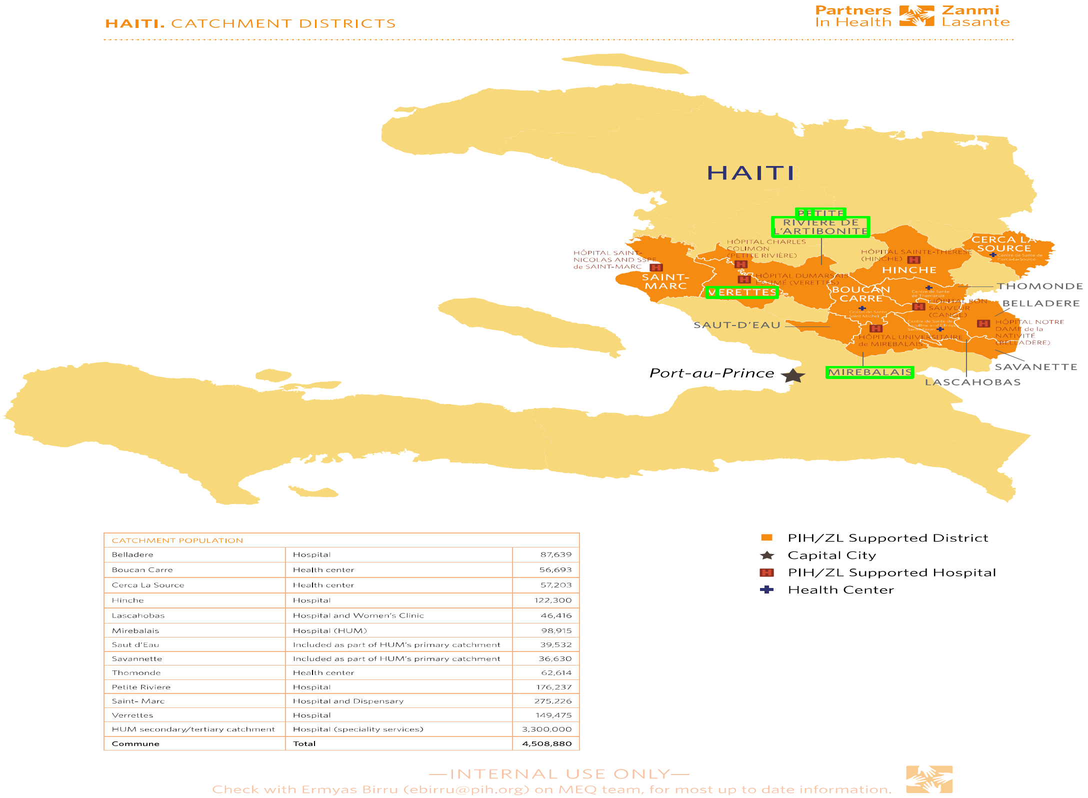


Copied form the article "Scaling Up for the "Bottom Billion": "5×5" Implementation of Community Mental Health Care in Low-Income Regions" published by Gary Belkin and colleagues (Belkin et al., 2011)

Appendix 3-a: Haiti on the global map

Retrieved from: http://www.worldatlas.com/webimage/countrys/namerica/caribb/ht.htm on the 10th of May 2016.

Appendix 3-b: ZL catchment area on the Haiti map. Designed by the PIH IT team - 2016.



CATCHMENT POPULATION		
Belladere	Hospital	87,639
Boucan Carre	Health center	56,693
Cerca La Source	Health center	57,203
Hinche	Hospital	122,300
Lascahobas	Hospital and Women's Clinic	46,416
Mirebalais	Hospital (HUM)	98,915
Saut d'Eau	Included as part of HUM's primary catchment	39,532
Savannette	Included as part of HUM's primary catchment	36,630
Thomonde	Health center	62,614
Petite Riviere	Hospital	176,237
Saint- Marc	Hospital and Dispensary	275,226
Verrettes	Hospital	149,475
HUM secondary/tertiary catchment	Hospital (speciality services)	3,300,000
Commune	**Total**	**4,508,880**

—INTERNAL USE ONLY—

Check with Ermyas Birru (ebirru@pih.org) on MEQ team, for most up to date information.

Appendix 4: Inclusion and exclusion criteria

4-a) List of inclusion criteria per categories of participants

2.1. List inclusion criteria

Person with lived experience of psychosis:

Persons who have a history of psychosis including those who currently have a psychotic disorder or who had it in the past.

We use the definition of psychosis of the Diagnostic and Statistical of Manual of Mental Disorders V (DSM-V, P.87)(American Psychiatric Association, 2013). DSM-V is the fifth edition of a diagnostic and classification manual published by the American psychiatric Association. The Zanmi Lasante mental health service as well as other mental health providers uses DSM's clinical criteria in their clinical practice. DSM is also used in other places in the World especially in research. I choose to use DSM instead of the International Classification of Diseases (ICD-1

0) published by WHO because the DSM-V provides diagnostic criteria additionally to the classification.

DSM-V defines "Schizophrenia and other psychotic disorders" by "abnormalities in one or more of the following five domains: delusions, hallucinations, disorganized thinking (speech), grossly disorganized or abnormal motor behavior (including catatonia), and negative symptoms."

We will include persons who meet or have met in the past the DSM-V criteria for:

- Schizophrenia 295.90 (F20.9)
- Schizophreniform disorder 295.40 (F20.81)
- Schizoaffective disorder
    - Bipolar type: 295.70 (F25.0)
    - Depressive type: 295.70 (F25.1)
    - Catatonia type: 293.89 (F06.1)
- Brief psychotic disorder: 298.8 (F-23)
- Delusional disorder: 297.1 (F-22)
- Other Specified Schizophrenia Spectrum and Other Psychotic Disorder 298.8 (F28)
- Unspecified Schizophrenia Spectrum and Other Psychotic Disorder 298.9 (F29)
- Bipolar disorder with psychotic features: 296.04, 296.44, 296.54, 296.64 (F31.5, F32.2, F32.3)

The numbers after the semi-colon represent the DSM-V diagnostic criteria code for the disease and the codes in brackets are the International classification of diseases' codes for the same disease.

Other inclusion criteria for persons with lived experience of psychosis will be:

- Participant identifies him or herself as of Haitian nationality
- Lives in the ZL catchment area of Hôpital Universitaire de Mirebalais or Tirivyè health center
- Participant is over 18 years of age
- Mild to Moderate cognitive impairment according to the psychologist assessment using the Mini-Mental Status Exam (MMSE)
- The person with lived experience of psychosis agrees to participate, gives consent and the family caregiver also gives consent to the participation of this person.

Family caregiver

- A person who has been taking care of the person with lived experience of psychosis where the latter lives.

- A family member (like spouse, parents, offspring, siblings) or only in case the patient does not have a family member, a person acting as caregiver that the patient will suggest will be included.
- Having accompanied this person in his or her treatment (western or traditional) process
- Being at least 18 year-old

Community Health Workers

- Being at least 18 year-old
- Working with the Zanmi Lasante mental health service to care for patients with mental disorders including psychosis
- Having worked with at least one patient with psychotic disorders
- Currently working in the area of the study setting of Hôpital Universitaire de Mirebalais or Tirivyè health center

Community leaders

- Being a leader in the area where the study is being conducted. That can include: vodou priest, other religious leaders, traditional healer, local political leader.
- Being at least 18 year-old

Facility-based clinicians (medical doctors, nurses, psychologists and social workers)

- Working in one of two sites where the study will take place, Hôpital Universitaire de Mirebalais or Tirivyè health center
- The nurses, medical doctors and social workers will have to be identified by the psychologist of the site as having worked with patients with psychosis.

Three national mental health policy leaders

- The director of the Mental Health Unit
- The director of national psychiatric center Mars and Kline
- A Haitian ethnopsychiatrist

4-b) List of exclusion criteria

2.2. List exclusion criteria

Persons with lived experience of psychosis

- Catatonia associated with another mental disorder: 293.89 (F06.1)

- Catatonia due to another medical condition: 293.89 (F06.1)

- Schizotypal personality disorder (F-21)
- Induced Psychotic disorder due to a medical condition or substance use (F-24)
- Suffering from an urgent or acute illness
- For the best interest of the patient, the site psychologist thinks that he or she should not, is not able to participate in the study and does not include him or her on the list of patients (Cf. section 6.1.)
- Severe cognitive impairment from the psychologist assessment using the MMSE.
- The main family caregivers does not consent for the patient to participate in the study

Family caregiver

- We will not include one same caregiver for two different patients. For the second patient, we will either have another caregiver or exclude the second patient.
- Hired caregiver will not be included

Community Health Workers

- No experience with psychotic patients

- Decline to participate

Community leaders

- Decline to participate

Facility-based clinicians (medical doctors, nurses, psychologists and social workers)

- No experience with mental health patients

- Decline to participate

The two or three national mental health policy leaders are

- Declines to participate

Appendix 5: Data collection materials (Interview and focus group guides)

5-a) **Guide of focus group discussion with Community leaders and community health workers**

Guide of focus group discussion with Community leaders and community health workers

Hello. Thank you very all much for agreeing to have this discussion with me about your experiences with people living with a mental illness, and about your ideas about recovery from psychotic illness. By "psychosis," we mean an illness that causes people to hear voices, see things, or feel like their mind is playing tricks on them.

During the discussion, I will ask you questions, but there are no right or wrong answers to these questions. What matters is *what you think,* and any information that you can provide to help us learn from your experience. The goal of this research is to use the responses to these questions to inform the improvement of services supporting people living with these kinds of illnesses.

I want to remind you some rules for this discussion. It is important to respect the other person and his or her opinion. We have to keep confidential what will be said in this focus group. Please do not mention names, addresses nor other information that can identify a person even if you are telling a story.

We will finish the discussion within 1 hour and a half. And after, we will take a snack together before leaving.

1- Please tell me about your current individual roles in the community, and your current profession.
2- What are your experiences with persons with mental illness? How do you understand their experiences with this illness?

   Probe: When and how did you start interacting with persons with psychotic mental illness? What are your relationships with this or these persons?

3- Please tell us about the role of the community leader or community health worker in regard to persons with psychotic mental illness.

How do you identify them? How do you manage to help them? What do you do for them to accompany them? What about your role in their life?

4- What did you think is happening to these persons?

5- Tell me about your personal experiences and feelings while you were helping this/these persons?

Probe: What did you feel at the beginning?

6- How is someone with symptoms of psychotic mental illness perceived in your community?

\- *Follow-up: What do people in your community think about someone suffering from such symptoms?*

7- How is someone with symptoms of psychotic illness interacted with in your community?

8- What are the challenges that you see for persons with psychotic illness?

Probes: What is the availability of care, of resources, of support? At what extent is stigma, or any fears that other people in the community have of mental illness and people living with mental illness, a challenge for those living with mental illness? How do you think patients and caregivers like you can cope with stigma?

9- How much support exists for persons with psychotic illness at your community level? And if there are, what are those supports?

Probes: Family, community, professionals?

What kinds of treatments exist in your community for psychosis?

Trying to have the participants not only talking about the biomedical treatment but also the traditional and non-biomedical treatments.

What support or resources do not exist and that they wish will exist? How can the work of *community leaders like you can be more supported?*

10- What do you think about the possibility for persons with psychotic illness to recover?

Probes: How much hope do you have that these persons can come back to a life that is meaningful for them again in this community?

11- Please tell me what you think about the treatments that are available for people living with psychotic illness.

Probe: What do you think about the accessibility of such treatment? What about the effectiveness of these treatments? What could be your suggestions regarding this matter?

12- What resources do you think are available or possible in this community that can help people recover from this illness?

Probe: If the participant answers the hospital, ask whether there are other disciplines, persons, activities, available or possible in the community that can help regain the meaningful life from the claws of psychosis.

13- What recommendations or suggestions would you propose to the designers of a program that is aiming to help people recover from psychotic illnesses?

14- Regarding the ways in which we can improve the ways people recover from mental illness, do you have anything else that you would like to add to what you have said, or anything in addition to tell me?

15-

Thank you very much for taking the time to share your thoughts and experience with me. This will contribute to help us to know how to build and improve recovery-oriented programs here and in other places in Haiti.

5-b) **Guide of focus group discussion with Community leaders and community health workers**

Guide of focus group discussion with Community leaders and community health workers

Hello. Thank you very all much for agreeing to have this discussion with me about your experiences with people living with a mental illness, and about your ideas about recovery from psychotic illness.

By “psychosis,” we mean an illness that causes people to hear voices, see things, or feel like their mind is playing tricks on them.

During the discussion, I will ask you questions, but there are no right or wrong answers to these questions. What matters is *what you think,* and any information that you can provide to help us learn from your experience. The goal of this research is to use the responses to these questions to inform the improvement of services supporting people living with these kinds of illnesses.

I want to remind you some rules for this discussion. It is important to respect the other person and his or her opinion. We have to keep confidential what will be said in this focus group. Please do not mention names, addresses nor other information that can identify a person even if you are telling a story. We will finish the discussion within 1 hour and a half. And after, we will take a snack together before leaving.

1- Please tell me about your current individual roles in the community, and your current profession.
2- What are your experiences with persons with mental illness? How do you understand their experiences with this illness?
   Probe: When and how did you start interacting with persons with psychotic mental illness? What are your relationships with this or these persons? How did this change over time?
3- Please tell us about the role of the community leader or community health worker in regard to persons with psychotic mental illness.
   How do you identify them? How do you manage to help them? What do you do for them to accompany them? What about your role in their life?
4- What did you think is happening to these persons?
5- Tell me about your personal experiences and feelings while you were helping this/these persons?

Probe: What did you feel at the beginning? What do you feel now?

6- How is someone with symptoms of psychotic mental illness perceived in your community?

- *Follow-up: What do people in your community think about someone suffering from such symptoms?*

7- How is someone with symptoms of psychotic illness interacted with in your community?

8- What are the challenges that you see for persons with psychotic illness?

Probes: What is the availability of care, of resources, of support? At what extent is stigma, or any fears that other people in the community have of mental illness and people living with mental illness, a challenge for those living with mental illness? How do you think patients and caregivers like you can cope with stigma?

9- How much support exists for persons with psychotic illness at your community level? And if there are, what are those supports?

Probes: Family, community, professionals?

What kinds of treatments exist in your community for psychosis?

Trying to have the participants not only talking about the biomedical treatment but also the traditional and non-biomedical treatments.

What support or resources do not exist and that they wish will exist? How can the work of community leaders like you can be more supported?

10- What do you think about the possibility for persons with psychotic illness to recover?

Probes: How much hope do you have that these persons can come back to a life that is meaningful for them again in this community?

11- Please tell me what you think about the treatments that are available for people living with psychotic illness.

Probe: What do you think about the accessibility of such treatment? What about the effectiveness of these treatments? What could be your suggestions regarding this matter?

12- What resources do you think are available or possible in this community that can help people recover from this illness?

Probe: If the participant answers the hospital, ask whether there are other disciplines, persons, activities, available or possible in the community that can help regain the meaningful life from the claws of psychosis.

13- What do you think are some of the strengths and weaknesses of the current services available?

Probe: How do you think those services might serve someone who has a mental illness as they are now? How might changes to the system improve care?

14- What recommendations or suggestions would you propose to the designers of a program that is aiming to help people recover from psychotic illnesses?

15- Regarding the ways in which we can improve the ways people recover from mental illness, do you have anything else that you would like to add to what you have said, or anything in addition to tell me?

Thank you very much for taking the time to share your thoughts and experience with me. This will contribute to help us to know how to build and improve recovery-oriented programs here and in other places in Haiti.

5-c) **Guide of focus group discussion with local clinicians (Group of Psychologists and social workers and the group of physicians and nurses)**

Guide of focus group discussion with local clinicians (Group of Psychologists and social workers and the group of physicians and nurses)

Hello. Thank you very all much for agreeing to have this discussion with me about your experiences with people living with a mental illness, and about your ideas about recovery from psychotic illness. By “psychosis,” we mean an illness that causes people to hear voices, see things, or feel like their mind is playing tricks on them.

During the discussion, I will ask you questions, but there are no right or wrong answers to these questions. What matters is *what you think,* and any information that you can provide to help us learn from your experience. The goal of this research is to use the responses to these questions to inform the improvement of services supporting people living with these kinds of illnesses.

I want to remind you some rules for this discussion. It is important to respect the other person and his or her opinion. We have to keep confidential what will be said in this focus group. Please do not mention names, addresses nor other information that can identify a person even if you are telling a story. We will finish the discussion within 1 hour and a half. And after, we will take a snack together before leaving.

1- Please tell me about your respective current professions and your roles with regards to people with lived experience of psychosis.
2- What are your experiences with persons with mental illness? How do you understand their experiences with this illness?
3- What do you think is happening to these persons?
4- Tell me about your personal experiences and feelings while you are helping this/these persons?

Probe: How do you feel when receiving these patients in your facility?

5- How is someone with symptoms of psychotic mental illness perceived in your facility?
  - *Follow-up: What do other professional and patients think about someone suffering from these illnesses?*

6- How is someone with symptoms of psychotic illness interacted with in your facility?

7- What are the challenges that you see for persons with psychotic illness?

Probes: What is the availability of care, of resources, of support? At what extent is stigma, or any fears that other professionals in the facility have of mental illness and people living with mental illness, a challenge for those living with mental illness? How do you think patients and clinicians like you can cope with stigma?

8- How much support exists for persons with psychotic illness at your facility? And if there are, what are those supports?

Probes: What kinds of treatments exist in your facility for psychosis?

What support or resources do not exist and that they wish will exist? How can the roles of clinicians like you be better supported to help these persons better?

9- Please tell me what you think about the treatments that are available for people living with psychotic illness in Haiti.

Probe: What do you think about the accessibility of such treatment? What about the effectiveness of these treatments? What could be your suggestions regarding this matter?

10- How do you think that the health system can better help persons with psychosis to recover?

- *What should be done in the health system to achieve that?*

11- What do you think about the possibility for persons with psychotic illness to recover?

Probes: How much hope do you have that these persons can come back to a life that is meaningful for them again in this community?

12- As you know, some psychotic disorders are chronic diseases, when do you consider that someone with psychosis has recovered?

13- What recommendations or suggestions would you propose to the designers of a program that is aiming to help people recover from psychotic illnesses?

14- Regarding the ways in which we can improve the ways people recover from mental illness, do you have anything else that you would like to add to what you have said, or anything in addition to tell me?

Thank you very much for taking the time to share your thoughts and experiences with me. This will contribute to help us to know how to build and improve recovery-oriented programs here and in other places in Haiti.

5-d) Interview guide for interview with family caregiver

Interview guide for interview with family caregiver

Hello. Thank you very much for agreeing to speak with me about your experiences with people living with a mental illness, and about your ideas about recovery from psychotic illness. By "psychosis," we mean an illness that causes people to hear voices, see things, or feel like their mind is playing tricks on them. During the conversation, I will ask you questions, but there are no right or wrong answers to these questions. What matters is *what you think,* and any information that you can provide to help us learn from your experience. Remember you can choose not to answer a question and you can stop whenever you wish. The goal of this research is to use the responses to these questions to inform the improvement of services supporting people living with these kinds of illnesses.

16- Please tell me about your family.

. The family's structure? The family strengths and weaknesses?

17- Please tell us what activities you do in your life.

18- What are your experiences with persons with mental illness? How do you understand their experiences with this illness?

Probe: When and how did you start interacting with persons with psychotic mental illness? What is your relationship with this or these persons?

19- Please tell us about your role as a close family member and/or a caregiver in regard to persons with psychotic mental illness.

How do you identify them? How do you manage to help them? What do you do for them to accompany them? What is your role in their life?

20- What did you think was happening to your family member when he got sick?

21- Tell me about your personal experiences and feelings while you were helping him/her?

Probe: What did you feel at the beginning?

- On a scale zero to ten how much did you have this feeling/s that you mention? Zero being not at all and ten, the highest level.

22- How is someone with symptoms of psychotic mental illness perceived and interacted with in your community?

Follow-up: What do people in your community think about someone suffering from such symptoms.

23- - Tell us about your life in the community as a person who is taking care of person with severe mental illness.

24- Please, tell us about the impact of your family member's illness on your family.

25- How much time have you spent taking care of your family member before, and throughout his or her illness?

26- What are the challenges that you see for persons with psychotic illness?

Probes: What is the availability of care, of resources, of support? At what extent is stigma, or any fears that other people in the community have of mental illness and people living with mental illness, a challenge for those living with mental illness? How do you think patients and *caregivers like you can cope with stigma?*

27- What are the supports and resources that exist for persons with psychotic illness at your community level?

Probes: Family, community, professionals?

What kinds of treatments exist in your community for psychosis?

Trying to have the participants not only talking about the biomedical treatment but also the traditional and non-biomedical treatments.

28- Please tell me what you think about the treatments that are available for people living with psychotic illness.

Probe: What do you think about the possibility to find such treatment? How are the results of these treatments? What could be your suggestions regarding this matter?

29- If you and your family choose to use hospital services, what challenges exist in using those services?

- What do you like and what do you not like about your family member receiving treatment at that facility?
- If you and your family member do not choose to use hospital services, what are the reasons?

30- What do you think about the possibility for persons with psychotic illness to recover?

Probes: How much hope do you have that these persons can come back to a life that is meaningful for them again in this community?

31- How do you envision the life of the person you are taking care of in the future?

32- According to you, how the person you are taking care of should be to say that s/he recovers?

33- What needs do you have as a person taking care of another person with severe mental illnesses?

34- What recommendations or suggestions would you propose to the designers of a program that is aiming to help people recover from psychotic illnesses?

35- Regarding the ways in which we can improve the ways people recover from mental illness, do you have anything else that you would like to add to what you have said, or anything in addition to tell me?

Thank you very much for taking the time to share your thoughts and experience with me. This will contribute to help us to know how to build and improve recovery-oriented programs here and in other places in Haiti.

5-e) **Interview guide for Interview with Service users**

Interview guide for Interview with Service users

Hello. Thank you very much for agreeing to speak with me about your experiences living with a mental illness, and about your ideas about recovery from psychotic illness. By "psychosis," we mean an illness that causes people to hear voices, see things, or feel like their mind is playing tricks on them. During the conversation, I will ask you questions, but there are no right or wrong answers to these questions. What matters is *what you think,* and any information that you can provide to help us learn from your experience. I am reminding you that you can choose not to answer a question and stop whenever you want. The goal of this research is to use the responses to these questions to inform the improvement of services supporting people living with these kinds of illnesses.

1-Please tell me about the illness from which you suffer.

Probes: Please tell me more about that

2-Can you tell me how it started? How do you understand your experiences with this illness?

Probes: What happened first? Next? How do you understand your illness—its cause?

3- What are the changes that happened in your life after you became sick?

Probes: How has it affected your relationships with family?

How has it affected your work/ability to earn a living?

How has it affected your relationships with others?

3- What happens when you get sick?

Probe: How do you feel when you get sick? How does it affect you?

4- To what extent does the illness constitute an obstacle or problem in your life?

Probes: Please tell me more about that.

5- To what extent is stigma, or any fears that others have of you or your illness, a challenge for you? How do you cope with stigma?

Probes: Do people treat you differently because of your illness? How?

6- What is the availability of resources to help you to cope with this illness?

Probe: What do you see as most helpful? Unhelpful?

7- Please tell me about what kind of help you have received for your illness. This includes treatments, but it can include other things that have been helpful.

Probes: This includes all kinds of treatments. Can you please provide me with examples about how they work? What happens during these treatment sessions? How helpful do you feel they are for you?

8- How do you conceive of, imagine or think of your recovery from your illness? What does "recovery from illness" mean to you?

9- Do you think that recovery is possible? How much hope do you have that you can recover?

10- How do you see your own role in your treatment and recovery process?

Probes: Do you feel that you have a sense of control in your treatment and recovery process?

11- What else do you see as most important for the success of your treatment and recovery process?

Probes: Please *tell us about the role of other people in your treatment and recovery process. Who has been most helpful, and why do you think so?*

12- Currently, how do you envision your future?

. *This question is looking for the possibility to recover (trying not to lead). If needed, ask: "What does recovering from this illness mean for you?" "What changes should happen so that you consider yourself recovered?"*

13- What resources do you think are available or possible in this community that can help you or other people recover from this illness?

Probe: If the participant answers the hospital, ask whether there are other disciplines, persons, activities, available or possible in the community that can help.

14- If you and your family choose to use hospital services, what challenges exist in using those services?

What do you like and what do you not like about receiving treatment at that facility?

If you and your family member do not choose to use hospital services, what are the reasons?

15- What recommendations or suggestions would you propose to the designers of a program that is aiming to help people recover from psychotic illnesses?

16- Regarding the ways in which we can improve the ways people recover from mental illness, do you have anything else that you would like to add to what you have said, or anything in addition to tell me?

Thank you very much for taking the time to share your thoughts and experiences with me. This will contribute to help us to know how to build and improve recovery-oriented programs here and in other places in Haiti.

5-f) **Guide of focus group discussion with policy leaders**

Guide of focus group discussion with policy leaders

Hello. Thank you very all much for agreeing to have this discussion with me about people living with a mental illness, and about your ideas about recovery from psychotic illness. By “psychosis,” we mean an illness that causes people to hear voices, see things, or feel like their mind is playing tricks on them.

During the discussion, I will ask you questions, but there are no right or wrong answers to these questions. What matters is *what you think,* and any information that you can provide to help us learn from your experience. The goal of this research is to use the responses to these questions to inform the improvement of services supporting people living with these kinds of illnesses.

We will finish the discussion within 45 minutes to one hour. You can choose not to answer any question and you can decide to stop the conversation at any moment you want. I will keep our conversation confidential.

36- Please tell me about your respective current position and your roles with regards to people with lived experience of psychosis.

37- What is the current situation of mental health in Haiti?

38- What is the current situation of persons with lived experience of psychosis and their caregivers in Haiti?

39- Can you tell us about how you think mental health is perceived in Haiti?

40- Please, tell us about how you think the Haitian culture interact with mental health. Both in terms of opportunities and in terms of barriers.

41- What are the local knowledge that you have learnt about mental in Haiti and how can they serve the improvement of patients?

42- What do you think about recovery from psychotic disorders?

43- As you know, some psychotic disorders are chronic diseases, when do you consider that someone with psychosis has recovered?

44- Do you and how do you think persons with psychotic disorders can recover?

45- What do you know can contribute to recovery in Haiti at those different levels:

- National
- Health facility
- Community F
- Family
- And individual level?

46- What local knowledge you think could be integrated into national policy to improve care for persons with psychosis?

47- How do you think local knowledge, practices and Haitian culture, at the different level we mentioned, can be integrated into national policy for better quality care for persons with psychosis.

48- What advice would give me to make this research more useful in contributing to a better mental healthcare system in Haiti.

49- What recommendations or suggestions would you propose to the designers of a program that is aiming to help people recover from psychotic illnesses?

50- Regarding the ways in which we can improve the ways people recover from mental illness, do you have anything else that you would like to add to what you have said, or anything in addition to tell me?

Thank you very much for taking the time to share your thoughts and experiences with me. This will contribute to help us to know how to build and improve recovery-oriented programs here and in other places in Haiti.