

The London School of Economics and Political Science

**SUPPORTING 'COMMUNITY' IN AN ERA OF GLOBAL MENTAL
HEALTH:**

**A CASE STUDY OF AN HIV-AFFECTED SOUTH AFRICAN
COMMUNITY**

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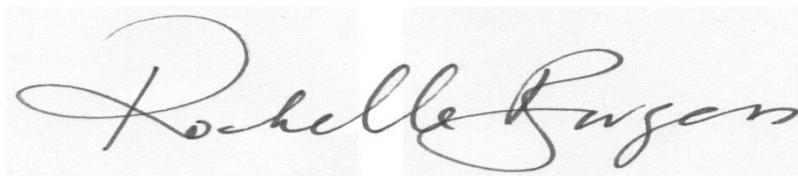
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DEDICATION

I dedicate this thesis to my mother, Donna Burgess, the first to teach me the truths of this life: that we are often stronger than we believe, and there is nothing we cannot handle, or find purpose enough to live (and cry) through.
As I promised you more than 20 years ago, my first 'book' is for you.

ABSTRACT

How may the mental health of socially deprived HIV/AIDS affected communities be supported in an era of 'global mental health'? To date, 'community' efforts have been informed by a largely biomedical and epidemiological body of evidence, distracting attention from lived realities, local contexts and their abilities to frame understandings of mental distress and treatment. This thesis seeks to contribute a productive critique of the Global Mental Health field, by expanding on some of the missing dimensions in their conceptualisations of health and healing. Through a focus on social psychological processes of community, knowledge and social change, it formulates a series of suggestions for how the Movement for Global Mental Health (MGMH) and other policy actors can build on their existing efforts, through establish health enabling contexts where communities actively participate in addressing mental distress, and tackling the contexts that constitute distress in locally relevant ways.

The thesis reports on a case study of KwaNagase (Manguzi), an HIV-affected rural community in KwaZulu-Natal, South Africa. It takes interest in the intersection of three respective groups, exploring how they understand, cope with, and work together in efforts to support mental well-being: 1) poor HIV/AIDS affected women experiencing mental distress; 2) community level supports (local NGOs and traditional healers); and 3) public health services (primary health sector). Data was collected over a three month period using multiple methods. In-depth individual interviews (n = 43) were triangulated by a motivated ethnography (Duveen and Lloyd, 1999) that explored local cultural, structural and symbolic contexts of community that frame understandings of mental health and delivery of care.

Grounded thematic analyses identified that women's understandings of mental distress were shaped by experiences of poverty, violence and HIV, which in turn, limited their ability to meet normative expectations linked to gender roles of 'mother' and 'wife'. Indigenous psychosocial coping strategies employed by women to tackle the aforementioned drivers of distress were underpinned by the presence or absence of social psychological resources that optimise health and well-being: agency, partnerships, critical thinking and solidarity. Primary mental health care actors' (NGOs and formal health service actors) understandings of women's distress were informed by an awareness of the structural and symbolic issues facing women in everyday life, aligning with the women's own understandings. Their best practices highlighted efforts to establish receptive social spaces – a critical dimension of health enabling contexts but were limited by symbolic and structural barriers such as stigma among providers, and general under-resourcing of the sector.

To overcome the limits facing community mental health services in Manguzi and similar contexts, the thesis concludes by highlighting a series of suggested actions to bolster identified community mental health competencies, and provides a tool kit of recommended strategies to support existing public sector efforts to promote mentally healthy communities.

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'To whom do I owe the woman I have become?' – Audre Lorde

When I said 'sure' to the suggestion that I do a PhD, my expectations were *completely* contrary to what transpired. Still, I would not change a thing. I am forever changed for the better by this journey, and am eternally indebted to those who supported me along the way.

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LIST OF ABBREVIATIONS

- AIDS:** Acquired Immunodeficiency Syndrome
- CMD:** Common mental disorders
- DSM:** Diagnostic and Statistical Manual of Mental Disorders
- EM:** Explanatory Models (Kleinman, 1980)
- GT:** Grounded Theory (Glaser, 1992)
- HIV:** Human Immunodeficiency Virus
- KZN:** KwaZulu-Natal (province)
- MGMH:** Movement for Global Mental Health
- MNS:** Mental, Neurological and Substance use disorders
- PMHC:** Primary mental health care
- PTSD:** Post Traumatic Stress Disorder
- SRT:** Social Representations Theory
- TNA:** Thematic Network Analysis (Attride-Stirling, 2001)
- WHO:** World Health Organization
- UNAIDS:** Joint United Nations Programme on HIV/AIDS
- UNDP:** United Nations Development Program

PREFACE

How can the mental health of communities in the developing world be best supported? Mental disorders are said to be highest in economically marginalised populations with women being among the worst off (Saxena, Thornicroft, Knapp, & Whiteford, 2007). Poverty, low education and food insecurity have been identified as key drivers (Lund et al., 2010; 2011). This is met by a corresponding neglect of mental health services in country health budgets resulting in “treatment gaps”, where low and middle income countries (LAMIC) report that between 75% and 90% of people with mental disorders do not to receive medical treatment (Patel, Boyce, Collins, Saxena, & Horton, 2011; Saxena, et al., 2007).

It is at this juncture that the Movement for Global Mental Health (MGMH)- an international coalition of actors and agencies, driven largely by clinicians and academics - seeks to intervene. Although its main advocates make frequent references to the social dimensions of mental ill-health (Lund et al., 2011), elsewhere I have argued that the overall momentum of the movement is guided by too much biomedical and epidemiological focus (Campbell & Burgess, 2012). The movement’s proposed solution - scaled-up services that emphasise the individual management of physical disease - emerges as a disconnect to the frequent citations of poverty and social injustice as drivers of mental ill-health (Lund et al., 2011; Patel, Boyce et al., 2011). The local realities of many individuals managing emotional distress in the developing world highlight the importance of attending to “sick societies” as much as “sick bodies” – making biological and psychological solutions to problems with clear systemic social drivers a dangerous distraction from the equal importance of creating social contexts that promote opportunities for improved mental health.

To guide actions in this area, there is a need for a greater evidence base that explores local understandings and responses to mental health issues. This thesis explores how global policy actors with an interest in promoting the mental health of socially deprived communities can work towards answering these questions. It employs an in-depth case study of an HIV-affected resource poor community exploring how three respective groups cope and work together in efforts to promote community well-being: poor and marginalised women experiencing mental distress; community level actors (NGO workers and traditional healers) and public health services personnel (primary mental health care services). It concludes with a suggested framework of action that could work in a complimentary way alongside existing established treatment practices, so that mental health practitioners in resource poor areas are enabled by policy and service spaces that are more attentive to value of supporting community coping alongside biomedical responses in promoting community mental health.

INTRODUCTORY COMMENTS

This is a thesis about community mental health care services in the context of social deprivation and HIV/AIDS. A project of this nature is increasingly important in an era where both mental health and HIV/AIDS have been defined as key global health concerns for the new millennium (UNAIDS, 2012; WHO 2001, 2005). Recent developments in HIV/AIDS research have highlighted the need for mental health supports in AIDS-affected regions, particularly in South Africa, where HIV and so-called depressive disorders are positioned as the second and third largest contributors to disease burden in the country respectively (Olley, Seedat & Stein, 2006)

Mental health has emerged as a priority health issue in the new millennium. The discourse of *'global mental health'* is receiving increasing attention in the context of recent statistics which identify Mental, Neurological and Substance use disorders (MNS) as a massive contributor to global disease burden, standing at 13% and exceeding that of cancer and cardiovascular disease. Parallel to the emergence of the term *'global mental health'* and its associated movement in 2007, has been the publication of two special editions in the leading medical journal *The Lancet*, the development of an international advocacy group called the Movement for Global Mental Health (MGMH), and a research and training centre for Global Mental Health at King's College, University of London. The crux of their efforts resides in a definition of *'global'* that focuses on the geographical in scope, and a series of assumptions regarding the universal nature and experience of mental ill-health. Mental ill-health is seen as impacted by a series of global social forces (such as climate change) and global social relationships (such as gender, class disparities) that transcend national borders, leading to calls for the development of global partnerships in order to tackle the problem:

The term global mental health encompasses mental health in any country of the world... related to both reducing the overall burden of health conditions and reducing ... health inequalities within and between countries. In addition the term 'global' refers to global influences on mental health...such as climate change...The responsibility for improving global mental health transcends national borders, class, race, gender ethnicity and culture; its promotion requires collective action based on global partnerships. (Collins, Patel, Joestl et al., 2011)

The prominence of mental health as a global issue was reiterated by the launch of the *Grand Challenges in Global Mental Health*, a manifesto of sorts that was

recently published in *Nature* (2011). This document, like the Lancet series that precedes it, implicitly defines 'mental health' in terms of MNS use disorders and identifies six goals for reducing its burden globally. Specific challenges in relation to these goals were derived through a collaborative process involving a scientific advisory board comprised of 594 researchers, advocates, programme implementers and clinicians, representing 60 countries and a range of disciplines. The top 25 challenges were identified based on their impact in the following areas: disease burden reduction, impact on equity, immediacy of impact and reduction. Of the top 25 challenges only two make reference to the role of the 'community' as a site or agent of intervention:

- *Support community environments that promote physical and mental well-being throughout life*
- *Provide effective and affordable community-based care and rehabilitation.*

Based on a body of work from the social sciences, particularly social psychology, sociology and anthropology, we can assume that the former will emerge as a multifarious task, which exceeds the domain of traditional biomedical science, whose curatively driven efforts are predominantly focused on the latter. The MGMH has been subjected to a fairly radical critique (led by Derek Summerfield whose work is addressed more intimately during later chapters of this work) that rejects the movement's conceptualisation of mental ill-health and the role of the biomedical in tackling it (Summerfield, 2008). In this thesis, my critique will be a more supportive one. It accepts the movement's definition of mental ill-health in a qualified way, holding that the movement only offers a *partial* picture of the challenges that communities may face regarding their mental well-being, and of the potential role of the biomedical in supporting community mental health. Against this background, this thesis seeks to explore some of the missing dimensions in the movement's conceptualisations of mental health and healing, with a particular interest in how the movement can be shifted in directions that best serve community mental health, through a more intensive focus on the hitherto relatively neglected community level of analysis, and through expanding its aforementioned cursory references to community.

I will argue that communities are key mediators between the individual and society, and are the sites where understandings, experience and context coalesce to determine the experience of mental distress, and how it is addressed. My starting point assumes that the notion of community is highly complex, and that communities

bounded by culture, space, or ideology can converge within a single individual (Howarth, 2001). Thus, I will argue that the promotion of 'healthy community environments' in order to optimize mental health and well-being will likely unfold as a process of managing both individual and societal concerns, within a matrix of factors that come to influence healthy life across a range of inter-locking social and individual dimensions (Campbell, 2003; Campbell & Cornish, 2010)

But what resources do communities need to promote mental health? Are HIV/AIDS-specific efforts required in this vein? Will the provision of mental health services alone be enough to promote community mental well-being? To explore these questions, this thesis presents a grounded in-depth case study of an HIV-affected community in South Africa, where I explore the complexities of delivering mental health services to socially challenged communities in the context of HIV and AIDS. Using triangulated methods and data sources, the case study explores how community life comes to impact the ways in which mental health is understood, and how it is addressed by a series of key actors involved with mental health services(see figure 1).

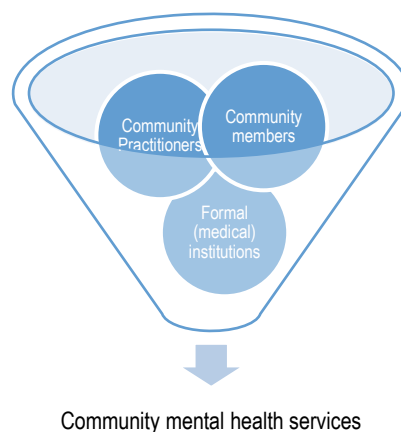


FIGURE 1: COMMUNITY MENTAL HEALTH SERVICES

For the purposes of this thesis, 'community members' are women who have been identified by biomedically-oriented researchers as being at risk of, or already managing, personal mental health issues, across a range of symptoms related to common mental disorders such as depression, anxiety and post-traumatic stress disorder. A focus on women aligns with the increased burden they face at the hand of both HIV and mental distress (MacLachlan et al., 2009; Moultrie, 2006; Pillay & Kriel, 2006). 'Formal (medical) institutions' are understood as those actors (in our case, public sector institutions) that are responsible for responding to mental ill-health at the community level. This group includes mental health nurses, allied health staff,

and psychiatrists. 'Community practitioners' are those actors who support the needs of community women – both medically and socially - in the community, and include NGO staff and traditional healers.

My analysis will seek to understand the way the engagement of these three group frames understandings of, and responses to, mental distress. My starting point here assumes that each of these groups 'represent' and understand mental health and illness in group and context specific ways, and that unacknowledged differences in such understandings limit the effectiveness of efforts to tackle mental distress at the community level. I will draw on social psychological frameworks that highlight the acknowledgement of a plurality of knowledge systems by all three groups, as the starting point for more effective service user and practitioner-patient engagements.

Furthermore, I will argue that there is an urgent need for the movement to pay more attention to issues of prevention, as well as the challenge of strengthening and supporting vulnerable community members to enable them to make optimal contributions to their own well-being, treatment and care. I will argue that the current medical-service-based emphasis of the movement would be enhanced by more conscious and explicit conceptualisations of what would constitute 'mental health enabling community contexts'. This has been explored through attention to the local realities of communities targeted by services (Campbell et al., 2004).

The importance of placing local understandings of mental health at the core of services has been championed by many critical voices in the field of mental health (Kleinman, 1988; Laing, 1960). While this has been acknowledged to a certain extent by researchers in the global mental health field (see Patel, Gwanzura, & Simunyu, 1995; Chipimo, Tuba, & Fylkesnes, 2011), I argue that findings generated from the current body of evidence do not provide much direction in outlining the contexts that would support the promotion of optimal mental health. One reason for this relates to the unduly limiting epistemological boundaries resulting from a biomedical focus on the identification and alleviation of symptoms within the space of narrow medically-defined notions of mental health that shape current research and intervention.

I draw on critical community psychology in arguing for the need to expand on what I see as an unduly narrow medical focus of the movement's current thrust. As a discipline, critical community psychology problematises the processes through which social contexts mediate individual representations and experiences of health and healing. As such, it looks towards the transformative opportunities that promoting awareness of these understandings may create for marginalised communities.

Within this thesis, this perspective unfolds in a process that focuses on community contexts – both place-based (i.e. poverty) and symbolic (i.e. knowledge systems) -- and the nature of the interactions of such contexts within the dynamics of social life within communities (Jovchelovitch, 2007). It maintains a critical eye on the ways in which these contexts facilitate or hinder active responses to health (Campbell & Cornish, 2010) – specifically, mental distress and the promotion of mental health.

A critical approach is particularly crucial given that many mental health services in the developing world are embedded in contexts marked by severe social and economic deprivation. Critical community psychology is a discipline dedicated to addressing such societal distress in communities. Backed by an ethos of empowerment and social change, critical community psychologists seek to help communities recognise - or at best, challenge - and where possible, ameliorate social and economic adversity that places their health at risk (Edwards, 2002).

Furthermore, this focus opens a much broader range of options for efforts to support the well-being of communities. With community-strengthening as its central pillar, promoting health moves beyond the provision of services for the ill, to a process that explores and addresses the reality of negotiating risks in daily life, and making communities better equipped to address their health. This would be a welcome addition to the current scope of mental health promotion activities in much of the developing world that zero in on efforts to address service and biomedical knowledge level paucities (Kakuma et al., 2010).

Over the course of eight chapters this thesis will seek to use the understandings generated about community mental health to outline suggestions for a framework that highlights some of the social, psychological and structural conditions needed for communities to optimize their mental health in the face of social deprivation and HIV/AIDS. This thesis seeks to provide a series of suggestions that could contribute to the ongoing work of local practitioners who support mental well-being in resource poor contexts. It explores what additional avenues may exist for practitioners to further their engagement along a continuum of treatment (where biomedical interventions are already well-established), while increasing their promotion of coping and supporting of local small scale social change. I identify the types of 'competencies' that practitioners could work to develop, that would enable communities to make the best use of existing, as well as new, resources that might be made available to communities vis-a-vis the global push to improve the mental

health and well-being of marginalised communities around the world (WHO, 2010). The chapters are outlined as follows:

Chapter One: Concepts-in search of a working definition of mental health for deprived communities.

This chapter traces a range of models that have emerged within the field of mental health, in the interests of outlining a perspective that enables the articulation of more transformative aims for communities facing HIV/AIDS and social deprivation (which are defined in this thesis to be a series of ‘small wins’ (Weick, 1988) that better position women to manage the everyday challenges they face that place their emotional well-being at risk). I focus on debates between mainstream and critical perspectives on mental distress and the ways in which they have sought to include communities as part of these definitions. I do this to reiterate the importance of local contexts and knowledge to the process of understanding and treating mental distress in these settings. I conclude with a framework for defining mental health that best suits the work with communities in developing country contexts, and which supports the notion of moving from the ‘treatment’ of community mental health to the ‘transformation’ of community contexts in order to enable good mental health.

Chapter Two: Contexts- South African perspectives on mental health and HIV/AIDS

This chapter continues the aforementioned debates, but focuses them on the specific challenges of addressing the mental health needs of AIDS-affected communities in South Africa, within an era of ‘global mental health’. This chapter concludes by outlining the motivations for, and details of, the project and research questions that guide the remaining chapters.

Chapter Three: Understanding, managing and transforming mental health: theoretical considerations

This chapter presents the theoretical considerations that support a critical exploration of community mental health services. I begin by outlining the notion of community, and constructing a definition that enables a more nuanced view of ‘community’ mental health services within this thesis; community as ‘place’, and symbolic space. Symbolic spaces within communities are conceptualised as knowledge systems, used to take account of the meanings people give to experiences of mental distress and mental health. Through assuming a social

psychological perspective of knowledge, via the theory of social representations (SRT), I am able to take account of the self, in relation to contexts of 'place' and others, in forming and enacting knowledge around mental health – which aligns with the model of community mental health that organises this thesis, as described earlier. The chapter concludes by outlining the notion of competent communities and its ability to contribute towards the transformation of symbolic spaces that also hinder women's mental health. It also presents the possible contributions of such a competencies approach to uncovering new avenues for community mental health services' roles in responding to and transforming states of mental distress in AIDS-affected communities.

Chapter Four: Research methods and design

This chapter outlines the methodological considerations that frame this work. It discusses the motivations behind the application of a case study framework in a study of mental health services. The generalisability and theory generative properties of case study methodology are defended. A range of methods that fulfil various dimensions of the case study exploration are outlined within this chapter, including the use of ethnography (vis-à-vis a motivated ethnographic approach which has been used in social psychological studies of knowledge); and applications of grounded theory. The chapter concludes with a presentation of procedures for data analysis, with reference to the intersection of grounded theory and thematic network analysis.

Chapter Five: Manguzi – a motivated ethnography of 'community'

This empirical chapter presents an ethnographic description of Manguzi. In doing so, it establishes the contexts which define Manguzi and which frame people's experiences of mental health, ill-health and the delivery of support. This chapter draws on a combination of pre-existing categories that shape many ethnographies of community: culture, institutions and socio-structural dimensions. It builds on emergent categories from a thematic analysis of ethnographic data sources – field diary, notes on clinic observations in the field and discussions; unstructured observations and analysis of key policy documents relating to mental health service delivery - with reference to historical and anthropological literature that explored these dimensions in similar South African communities.

Chapter Six: Mental health in the everyday

Chapter six explores women's understandings of mental health, using social psychological approaches to map out their indigenous knowledge system. Thus, this chapter examines in detail how women experience, cope - or fail to cope - with mental health-related challenges in the context of their everyday experiences. It begins with a map of the primary dimensions that shape women's understanding of their mental well-being, which emerges as a proxy of the contexts that frame Manguzi as a community, highlighted in chapter five. It then discusses how women cope with the identified challenges that place their mental health at risk, using four general coping strategies that draw on structural and emotional forms of support. It concludes with a discussion of entry into services, by exploring a selection of cases of women who after the point of 'breakdown', choose to draw on formal medicalised services. This final step is key in clarifying the link between mental ill-health in the everyday, and the mental health service sector that seeks to respond to women's needs. Findings from this chapter provide the foreground for later discussions of community mental health competencies (the ability to optimise coping successes and tackle coping failures) that are addressed in chapter eight.

Chapter Seven: Rethinking services for community mental health: the reality of primary health care settings

This chapter explores the ability of current primary health care approaches to community mental health to engage with the social dimensions of mental distress that are identified within chapters five and six. First, I explore practitioners' understandings of women's mental distress and how these understandings reflect an appreciation of the social and cultural complexities identified within chapter five and six. Second, I explore the way in which practitioners delivering formal mental health services through primary health care account for the successes and failures surrounding their practice. In addition, analyses highlight practitioners' implicit assumptions regarding what would constitute service level 'community mental health competency'. For better or worse, these public sector mental health practitioners remain the brokers to the delivery, and potential 'transformation' of community mental health, through their ability to create *receptive social environments* where women are supported and engaged in activities that result in the promotion of their own emotional well-being.

Chapter Eight: From treatment to transformation- community mental health competencies

In this concluding chapter, I pull together the accounts of factors facilitating the promotion of mental well-being from chapters five through seven to answer my final research questions: *How can primary mental health services develop more health-enabling engagements with communities in an era of global mental health? Are HIV/AIDS-specific services needed?*

In doing so, I develop a framework for the conceptualisation of *community mental health competency* that I argue might enable more critical and effective approaches to community mental health within global movement efforts. I argue that such an approach opens avenues for a more productive engagement with the complexities of working with deprived communities around issues of mental health – in a way that recognises the importance of context and roles of community. I conclude this chapter with a discussion of the strengths and weaknesses of this work, and the potential implications of this study for future research, policy and practice in areas of global mental health.

CHAPTER ONE: CONCEPTS - IN SEARCH OF A WORKING DEFINITION OF MENTAL HEALTH FOR DEPRIVED COMMUNITIES

This chapter has three aims. First, it seeks to establish a working definition for mental health to frame this thesis. To do so, I outline a range of models that have emerged in the field of mental health, focusing on debates between mainstream and critical approaches to mental distress and well-being. I also begin to flush out how these mental health models conceptualise and approach communities, such as service users within prevention and treatment domains. I do this to highlight the dearth of attention to local contexts in framing responses to mental health, and point towards a framework that may provide a better approach to accounting for the resources needed by HIV-affected communities to optimise their mental health.

1.1. CONCEPTS: WHAT IS 'MENTAL HEALTH'?

Throughout history the process of defining mental health has been a highly complicated endeavour. Historians, philosophers, physicians and activists have all weighed in on debates centring on the nature of mental health. Explanations run the gamut of potentialities; from biomedically and chemically driven illnesses of the brain and manifestations of unconscious conflicts of the mind, to controversial assertions of its use as an applied label in the process of societal control. The notion of mental health is not simply defined. The first section of this chapter engages with some of these notions, with the aim of achieving a working model of mental health for this thesis.

1.1.1 MAINSTREAM MODELS FOR MENTAL HEALTH: BIOMEDICAL MODEL

The biomedical model defines mental ill-health from a position that hinges on disease. Central to this model is the assumption that mental ill-health is caused by an issue within the body that results in psychological or psychiatric difficulties that impact on a person's ability to function within society. From its earliest applications during the Greco-Roman period as Hippocrates' *four humours* model (related to emotional and mental distress) to imbalances in body chemistry, medicalised models have been ultimately concerned with ill *bodies* (Gallagher, 1980). The medicalised model organises the treatment experience by scales and questionnaires that identify abnormality within discrete categories. By the early 19th century, somatogenic (biological) approaches to mental ill-health were solidified as the dominant approach to mental distress culminating with the scientific organisation of psychiatry as a discipline. However, there have been ebbs and flows in the precise shape of the model throughout history (Gallagher, 1980; Rees, 1982; Shorter, 1998).

The 18th century saw the emergence of the first wave of thinkers committed to the presentation of mental illness as organic in nature. Italian physician Morgagni, French physician Magnon, and German psychiatrist Grinsinger were among those who drove forward many biological explanations of disorder, and contributed to the establishment of Western Europe as the hub of psychiatric investigation by the early 19th century (Gallagher, 1980). Much of the research associated with developments of this era was driven by the clinical-pathological method: a process of reasoning back and forth from findings at autopsy to signs and symptoms shown by the patient prior

to their death in order to establish categories of mental disease. As a result, there were hundreds of names that displayed clinical disease labels such as 'wedding night psychosis' but did very little to explain the actual experience of distress and carried no correlation to actual brain pathology (Shorter, 1997).

Emil Kraepelin pioneered the first shift in medical approaches to mental ill-health through positioning of mental ill-health within the context of a life trajectory, and a desire to create a comprehensive psychiatry that took an interest in the gamut of experiences from the patient's dreams, to their cerebral cortex (Shorter, 1997). Over a series of editions of his revered text books chronicling the experiences of his patients, Kraepelin reduced the countless labels established by physicians working within clinical pathology to 13 categories. Two of these categories effectively shifted the ways in which mental health was approached, given their ability to divide psychotic illnesses without any obvious biological or organic cause into two streams. Those with a very clear affective or mood component became known as *manic-depressive psychosis*, and those without, *dementia praecox*. These two categories became the anchors for modern classification systems used around the world, and simplified the diagnostic and therapeutic process dramatically.

Kraepelin's primary goal for the development of this concrete classification system was linked to a deep commitment to supporting the patient; he believed the development of these categories carried the ability to provide patients with a more robust understanding of themselves, and what their lives may hold:

'The doctor's first task at the bedside is being able to form a judgement about the probable further course of the case... the value of a diagnosis for the practical activity of the psychiatrist consists of letting him give a reliable look at the future' (cited in Shorter, 2007, p.106-107).

Ironically, many critics (for example: Stoppard, 2000; Summerfield, 2008) now ascribe the use of these same classification systems as detrimental to the practice of psychiatry and the ability to connect with patients, insofar that the current uses of diagnostic categories have moved the doctor further from the patient experience. This distance from patients is a particular concern among cross-cultural psychiatrists, who note that social and cultural factors that contribute to how mental distress is experienced are sidelined by a mutual desire to classify symptoms according to existing global benchmarks. Kirmayer and colleagues (Kirmayer et al., 2006) discuss this precise limitation with reference to their work with aboriginal populations in Canada. This particular cultural group, which has been systematically disenfranchised from Canadian society, now constitute some of the most marginalised members of society, with the worst mental health outcomes. It is argued

that culturally insensitive diagnostic and treatment frameworks overlook the importance of dimensions such as culture to their experience and recovery from states of mental distress. For example, attention to context immediately draws attention to the negative impacts that result from the inability for this once culturally rich community to engage in culturally relevant practices, and limited opportunities to feel like active members of society.

The work of Sigmund Freud in the 19th century created the first shift away from the medical model's focus on ill bodies and instead focused on ill mind, and thus moved practitioner methods more closely to the realities of the patient experience, and its relationship to states of distress. Freud's work on psychoanalysis introduced the idea of the relationship between the unconscious and actionable realities of the individual. His focus on the relationship between past experiences and present day abnormal functioning created a pause in the development of the medical model, and enabled the popularisation of many clinical psychological approaches to mental health, which remain an active part of contemporary mental health practices internationally (Patel et al., 2007;WHO, 2010).

By the 1950s however, the psychoanalytic model fell out of favour, allowing the medical model to re-emerge at the head of mainstream approaches to mental health. In 1952, Kraepelin's system was translated into what remains the standard in approaching mental ill-health: *The Diagnostic and Statistical Manual of Mental Disorders* (DSM). The first edition of the DSM was established by the American Psychiatric Association in an attempt to establish a national system of classification. Decisions about what constitutes a positive diagnosis were embedded in dominant trends in thinking of the era -for example, inclusion of homosexuality, which remained a mental illness until the 1984 version of the manual (Shorter, 1997). Though the first two versions provided only vague descriptions of illness categories and actually did very little to help classification, the third edition was much more structured; organising the experience of emotional distress into very detailed checklists of experiences and criteria for diagnosis.

Since its earliest forms, responding to mental ill-health within a medical model has been associated with confinement, which has been a long standing source of criticism facing the field. Insane asylums first emerged during the Middle Ages as sites for the support of patients with mental illness. 17th and 18th century perspectives on mental ill-health deemed these conditions beyond rehabilitation and the asylums ultimately became the depository for those with mental distress when families could no longer manage the burden themselves (Parle, 2007; Shorter, 1997). Many

patients were chained and abused, and it was not until a major shift in thinking about the rehabilitative properties of the asylum that this came to an end. The humane treatment of asylum patients originated in Europe (Shorter, 1997) and its evolution, which shifted asylums from places of confinement to places of treatment (and thus, mental hospitals), has been largely attributed to Phillippe Pinel, a Parisian physician identified as the father of moral treatment (an approach that was prominent in early South African approaches to mental ill-health – especially in KwaZulu-Natal, the province of focus in this thesis) that promoted the strict, non-violent management of patients (ibid.).

Mental hospitals rose in popularity and became the predominant approach to dealing with mental distress worldwide by the late 1950s (ibid.). Over time, the mental hospital became synonymous with the mistreatment of the mentally ill, as the treatments used by practitioners became increasingly severe. Some of the more notable alternative treatment modalities included: sleep therapy, which involved patients being placed in insulin induced comas for extended periods of time; and electroshock therapy (ECT), developed during the 1930s, which postulated that consecutive electric shocks could rewire the brain and alter the personalities of patients previously deemed outside of rehabilitation (i.e. schizophrenics). Though varied in approach, these treatments were directed towards shifting a patient's behaviour so that it aligned with expected cultural norms of the time. By the 1970s, public opinion of mental hospitals and the associated therapeutic methods was so poor that a mass movement was initiated to dissolve these centres and reduce the amount of power that psychiatrists had over their patients. What is often described as the Anti-Psychiatry movement¹ eventually led to the deinstitutionalisation of mental health care and a shift from mental hospitals towards community located treatment and support of individuals with mental distress.

With the movement out of hospitals, and advancements in pharmaceutical research, confinement began to take on a pharmacological shape, with the rise in the use of drug therapies designed to shift patient behaviour to be more in line with standard norms. This was driven quite heavily by developments in pharmaceutical interventions and the inexorable links between the belief that imbalances in brain and neurochemistry were at the roots of distress. Over the past 50 years, the psychopharmaceutical industry has become one of the largest grossing industries in the world (Watters, 2010).

¹ See section 1.1.2 of this chapter for a full discussion of the critical field where Anti-Psychiatry is discussed.

By the end of the 20th century the medical model of mental ill-health was solidified as the dominant discourse in the field. Advances in genetics, pharmaceutical, and neurological sciences helped to crystallise the belief that mental ill-health was primarily the result of malfunctioning bodies – whether at the hands of hormonal imbalances, or genetic predispositions to a disorder. A biomedical approach, driven primarily by pharmaceutical interventions, is believed to provide a direct route to the alleviation of the symptoms that are a suspected result of these malfunctioning bodies, and currently sits at the helm, directing many responses to mental distress around the world.

International bodies such as the World Health Organisation (WHO) and affiliates have helped to solidify the anchoring of these particular approaches to mental distress as the gold standard in the field. However, this has not gone uncontested. Alternative approaches to the biomedical model have existed for decades, establishing a debate that has had far reaching implications for the notion of ‘mental health’.

1.1.2 CRITICISING THE MAINSTREAM: ALTERNATIVE MODELS FOR MENTAL HEALTH

There is a long and controversial history surrounding misuses of psychiatric services across the world (see Appignanesi, 2009; Parle, 2007). Resistance to the use of mental hospitals as locations of segregation, confinement and human rights violations has been associated with two critical schools of thought. Critical Psychiatry and Anti-Psychiatry are related perspectives that emerged as retaliation against the inappropriate use of mental hospitals, and that sought to challenge the dominant psychiatric conceptualisations of mental health as illness, and perhaps most importantly, to shift the ways that psychiatric patients themselves were perceived and addressed within psychiatric care.

The work of critical theorists and psychotherapists - such as: Michel Foucault and his work *Madness and Civilization: a History of Insanity in the Age of Reason* (1988); Tomas Szasz's *The Myth of Mental Illness* (1974); Robert Laing in *Self and Others* (1961); and David Ingleby's *Critical Psychiatry* (1981)- are united by their interests in social concerns with regards to mental health. Aneshensel et al.(1991) aptly outline the broad aims of sociological inquiry in the field of mental health as investigations that begin with an analysis of social structural arrangements, and look towards a range of potential health consequences, citing the importance of the effects of class, race, gender and other institutional or professional structures and norms on well-being. The aforementioned 'fathers' of the field can be parsed within this framework through examinations of either socioeconomic structures or power relationships between patients and practitioners, as seen within the work of Ingleby and Laing, or the psychiatric institution as a whole, within the writings of Foucault and Szasz. I will engage briefly with these works below, in order to highlight the facets of the most well-known alternatives to conceptions of mental health.

Laing (1961) was a practising psychiatrist who argued that psychiatry was limited by its lack of attention to patients' experiences of their mental ill-health, or to the wider set of social relationships in which patients were embedded. His work exploring the dynamics of schizophrenic patients' relationships with their families played a historically significant role in drawing attention to the tendency of medical professionals and caregivers to see mental illness as an individual problem, focusing on treatment at the individual level whilst ignoring the social influences on the development of mental distress. He also discussed the conservative role of psychiatry – encapsulated within its attempts to 'conserve' the social order by masking society's damaging effects on well-being, and thus reducing the likelihood of critique of the social settings that undermine peoples' mental well-being.

Critiques presented by Szasz (1974) and Foucault (1988) took interests in similar socio-political platforms but were driven by concurrent critiques of the validity of psychiatry as a science. For example, Szasz's (1974) seminal work *The Myth of Mental Illness* argues that, given the lack of an organic cause capable of explaining how a given individual communicates about herself and her individual worlds, it is impossible to establish illness based on criteria of this nature, as is done in psychiatric practices. On such grounds, psychiatric diagnosis then becomes a social construction for Szasz, centred on the labelling and control of individuals for socio-political means.

Foucault's *Madness and Civilization: a History of Insanity in the Age of Reason* (1988) takes a similar stance, but bases arguments on his power-knowledge concept. After charting the social contexts of mental illness he concludes that external cultural and economic interests have always defined how mental health is perceived. For Foucault, expert knowledge about 'abnormality' is ultimately informed by these interests, and thus, this knowledge is able to exercise power in modern societies to maintain these interests. Unlike Laing's work, which attempted to action a new form of engagement with patients out of his critiques (which are discussed later in this section), the critiques put forward by Foucault and Szasz were not aimed at the improvement of mental health practice, but rather, at the outright query of the relevance of a field of psychiatry as a whole. As such, many of their critiques failed to improve the ways in which patients with mental health issues were perceived, treated, or engaged with on a micro scale.

Other debates have converged upon the need to anchor responses to mental distress more closely to the failings of social structures. For example, David Ingleby's (1981) critical approach to psychiatry provides an excellent example of the types of reasoning often associated with social constructivist models. Ingleby proposed that mental illness is rooted in problems of living and results from a tension between human needs and the social situations which *should* provide for them. Thus, psychiatry's aim to facilitate coping serves only to

protect the efficient functioning of these institutions (work, family, education, politics) by converting the conflict and suffering that arises within them into symptoms of individual 'malfunctioning'; [providing] short-term technological solutions to what are at root political problems (Ingleby, 1981, p. 44).

Work with marginalised communities such as homeless populations continues to point to the influences of social inequity and failed social systems on mental well-being. In a recent report on a therapeutic intervention for homeless men in a Canadian urban setting, social factors such as inability to secure safe housing through provincial support systems were identified as the key barrier to maintaining gains in physical and mental health (Pretrenchik & Burgess, 2010).

Ingleby's concerns are particularly important in contexts where social deprivation sits at the centre of community life, as is the case for the community studied in this thesis. His perspective challenges psychiatrists to consider the importance of attending to broader societal issues as integral to the experience of mental health; for example, acknowledgement that poor mental health could be manifested as an outcome of life within failed social structures. Still, Ingleby's seminal work focuses more on debating the space of the 'social' in psychiatry, than discussing processes to 'action' the social within a critical psychiatric practice.

As previously mentioned, the work of Laing was among the first to examine how critical perspectives may be changed within the realm of practice, with an eye to engaging with the social dimensions of a patient's world as part of treatment (Thomas & Bracken, 2004). In *Self and Others*, Laing presents a series of case studies of schizophrenic patients in order to highlight the ways in which their symptom experience was read one way by practitioners, yet served very different and functional purposes, in patients' lives and relationships within their social worlds. His discussions of Joan, an institutionalised patient with schizophrenia, crystallise the ways in which disregarding patient voice and the objectification of patients leads to entire dimensions of a patient's life being overlooked:

Patients kick and scream and fight when they aren't sure the doctor can see them. It's a most terrifying feeling to realize that the doctor can't see the real you, that he can't understand what you feel and he's just going ahead with his own ideas... I had to make an uproar to see if the doctor would respond to me, not just to his own ideas (cited in Laing, 1961, p.178-179).

I needed to be controlled and know what [the doctor] wanted me to be. Then I'd be sure that you would want me. With my parents I couldn't be a boy and they never made it clear what else they wanted me to be except that. So I tried to die by being catatonic... I tried to be dead and grey and motionless. I thought mother would like that. She could carry me around like a doll.... I had to die to keep from dying (cited in Laing, 1961, p.191-192).

These passages highlight a range of alternative meanings behind patient experience that cannot be engaged with in a practice that approaches symptoms for the purpose of confirming diagnostic criteria to determine routes to treatment. To overcome this limitation in practice, Laing suggested the use of alternative forms of psychotherapy with schizophrenic patients that had more interpretative phenomenological roots, and took direct interest in engagement and unpacking of patient perspectives (Thomas & Bracken, 2004).

Laing's work has provided the ethos behind many critiques from service user advocacy movements in western country contexts. For example, mental health service user groups in the UK have drawn heavily on Laing's arguments in order to justify patient contributions to outlining treatment and care (Campbell, 2006; Laing, 1985; Rose, 2008).

Despite the progress made in the inclusion of patients on a practical level – through the proliferation of mental health service user movements, stakeholder groups and involvement in anti-stigma campaigns - contemporary critical voices such as Campbell (2006) and Rose (2008) argue that barriers to participation of users persist, which ultimately limit avenues to addressing patient needs overall.

To extend this argument to the field of global mental health, it seems that the inadvertent minimising of the patient and participant voice continues in many of the studies presented as evidence. In a recent qualitative study presenting explanatory models of depression in Indian women, Pereira and colleagues (Pereira et al., 2007) discovered that difficulties with interpersonal relationships and finances were the most common factors given by patients to explain the reasons behind their depression (as identified using DSM-IV/ICD-10 criteria). They also discovered that women rarely used psychiatric lexicon to describe their symptoms, instead referring to somatic complaints.

However, as part of recommendations for more culturally sensitive approaches to support, the authors pointed only to opportunities to bring diagnostic structures in line with the women's somatic complaints. They presented the importance of using these markers as more appropriate symptom markers of depression in the population, but missed an opportunity to advocate for services capable of responding to the social institutions, such as family, that were described as important to their patients' emotional distress. While their recommendations may facilitate the early identification of more serious cases of depression within biomedical practice, they do very little to address the socially constituted causal factors expressed and experienced by the women in this study. This misplaced focus relegates the material causes of distress to the background of intervention strategies and sidelines the explanations for the distress provided by the research participants.

The relationship between researcher and participant that emerges in studies like these mirrors the objective-subjective relationship between patient and practitioner observed and critiqued by Laing (1961). The limitations imposed by an objective-subjective relationship that leads to the discounting of the patient's voice may negatively impact the success of interventions responding to mental distress in varied contexts. The outcomes of Pereira's and colleagues (Pereira et al., 2007) aforementioned study would be drastically altered to the benefit of the community, if participant experiences were made the *subject* of the intervention instead of a route to the confirmation of illness categories. Positioning participants as the subjects of an intervention ultimately makes responding to local knowledge and experience an automatic part of the outcomes. This highlights the ongoing need for research and practice frameworks that place a higher value on local voice and experience in the field of global mental health (Fernando, 2012).

But how can patient narratives or 'local knowledge' about distress take centre stage as part of mental health practice? Answering this question crosses into the domain of a second branch of critical thought with relation to mental health. The field of cross-cultural psychiatry attempts to present an avenue for engagement with the cultural and social realities that determine mental health outcomes (Summerfield, 2008). It developed as a movement that incorporated both anthropological and psychoanalytical viewpoints with regard to culture specific conceptualisations of illness and acceptable social behaviour (Fernando & Campling, 1991). The field has a steeped interest in the relevance of the ability of local knowledge about cultural practices, religious beliefs, and local definitions of 'madness' to establish the need for alternative modes for dealing with mental health in communities.

Arthur Kleinman, a cross-cultural psychiatrist, proposed a conceptualisation of the field of psychiatry that sought to escape the application and work of western psychiatry in non-western cultures, which had become linked with colonialist ideals. His 'new cross-cultural psychiatry' (Kleinman, 1977) eschewed the pitfalls of a western biomedical approach that in his opinion had become increasingly dependent on universal categories and treatment modalities, and the labelling of cultural experiences as unimportant. Instead, he promoted an approach to exploring mental ill-health that was anchored in patient experience.

Patients and Healers in the Context of Culture (Kleinman, 1980) was concerned with two aims: 1) to highlight the value of understanding the patient experience in treatment; and 2) to promote the understanding that patient experience was, at its core, influenced by social and cultural experiences. These aims were nested in a desire to confront the inability of the medical model to fully alleviate distress facing many of his patients. In doing so, he advocated for the development of health services that reflected an understanding of and response to the multiple levels of patient experience (Kleinman, 1980, 2008, 1977).

Central to his approach is a social constructivist distinction between illness and disease. He postulated that responses to distress should be anchored to an understanding of this dichotomy and focus on addressing illness (the experience of disease), which is heavily shaped by the cultural and social realms of our lived world (Kleinman, 1980). Drawing primarily on his work exploring depression in China and the United States, he devised an approach to patient engagement rooted in the belief that the role of the practitioner was to take direct interest in the context of a patient's life history, experiences, and what he referred to as *social reality*:

Social Reality signifies the world of human interactions existing outside the individual and between individuals. It is the transactional world where everyday life is enacted, where social roles are defined and performed, and in which people negotiate with

each other ...under a system of cultural rules... [it] is constituted from and in turn constitutes meanings, institutions and relationships sanctioned by society (Kleinman, 1980, p. 35-36).

This focus on the importance of the social world to the illness experience is linked to an appreciation of the phenomenological concepts (in a similar vein to Laing), specifically the *life world* as conceptualised in Alfred Schutz's (1970) societal phenomenology. The life world is a concept understood by phenomenologists and sociologists as the horizon of all our experiences: the spaces where experiences gain meaning through personal and inter-subjective processes. The life world has been conceptualised as both a concrete and meta-physical space where life is 'lived' – the daily experiences of the day-to-day, where individuals draw on norms, regulations, patterns of behaviour and shared knowledge about experiences, both the novel and the commonplace (Jovchelovitch 2007).

With this in mind, Kleinman argued that social realities, which differ between patient and practitioner, must be understood in order to create more successful treatment interactions and a more reflexive psychiatric practice (i.e. practice that is more in-tune with patient realities and social world). Kleinman divided patients and practitioners in a complex inner system of mental health services with overlapping dimensions that were nonetheless, grounded in different social realities (see figure 2).

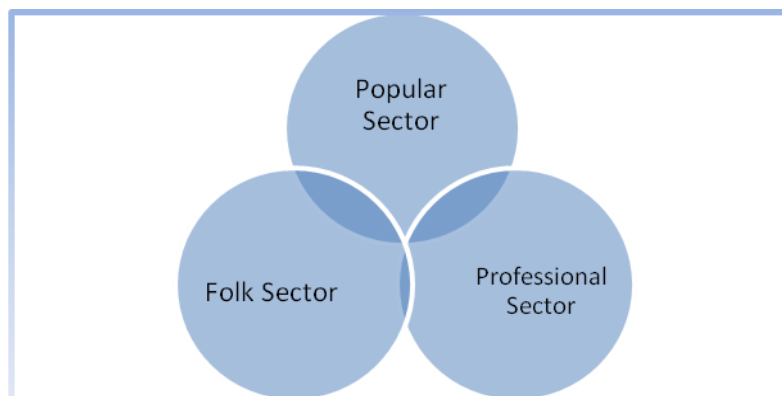


FIGURE 2: SECTORS OF A HEALTH SYSTEM (ADAPTED FROM KLEINMAN, 1980)

These sectors are analogous to those that Leslie Swartz applies to his conceptualisations of mental health in his book *Culture and Mental health: A Southern African View* (Swartz, 1998). Lay people, who compose the popular sector, are seen as the immediate determinant of care, given that it is these actors who '*activate their health care by deciding when and whom to consult, whether or not to comply, when to switch between treatment alternatives (sectors)*' (Kleinman, 1980p. 45). He felt that since these sectors overlapped, there must be a way to '*compare the systems of medical knowledge and practice constituted by and expressed in the different sectors of health care systems*' (Kleinman, 1980, p.104).

To make these comparisons first required an in-depth understanding of how each perspective made sense of the illness experience, which is achieved through the development of Explanatory Models (EM). According to this framework, EMs are the notions about an episode of sickness and its treatment that are used by the actors who converge in treatment spaces. EMs are shaped by a range of actors who are directly (such as patients) or indirectly (such as families or cultural norms) associated with health services. EMs are embedded in various cultural and social structural arrangements that are unique to their creator, but converge on a need to explain five major questions about illness: (i) aetiology; (ii) time and mode of onset of symptoms; (iii) pathophysiology; (iv) course of sickness – including both the degree of severity and type of sick role; and (v) treatment (Kleinman, 1980; 1988). Box 1 presents the eight questions used in a typical interview schedule that seeks to derive explanatory models.

Box 1: Kleinman's Interview Schedule for Explanatory Models

1. What do you call your problem? What name does it have?
2. What do you think caused the problem?
3. Why do you think it started when it did?
4. What does your sickness do to you? How does it work?
5. How severe is it? Will it have a short or long course?
6. What do you fear most about your illness?
7. What are the chief problems your sickness has caused for you?
8. What kind of treatment do you think you should receive? What are the most important results you hope to receive from treatment?

ADAPTED FROM KLEINMAN (1980), PATIENTS AND HEALERS IN THE CULTURAL CONTEXT, UNIVERSITY OF CALIFORNIA PRESS

EMs have been extensively applied by actors within global mental health fields in an effort to display cultural sensitivity. Studies from countries such as Zambia (Aidoo & Harpham, 2001; Chipimo, et al., 2011), Kenya (Muga & Jenkins, 2008), Zimbabwe (Patel, 1995) and Uganda (Okello & Neema, 2007) have been used to advocate the need for increased services in developing countries (Lund et al., 2010). Predominantly, findings from such studies use explanatory models to support the need for services located within a medical paradigm, while the contexts that form participants' models are not seen as a point of intervention. These contexts often describe the same societal ills that critical psychiatrists such as Ingleby highlight as points of concern and intervention in the field.

For example, EMs were recently applied in Zambia to derive analyses of mental health within AIDS-infected and non-infected individuals (Chipimo et al., 2011). Findings highlighted that the explanatory models of non-infected individuals were overwhelmingly marked by social and cultural experiences, than for AIDS-infected individuals. Findings

recommended that contextualised conceptual models be used to help define clinical features for understanding the clinical syndrome of mental distress, particularly among HIV-infected individuals, but made no mention of engaging with the socially constituted models, which were shared by both groups.

Such a response supports the view of critical cross-cultural psychiatrist Lawrence Kirmayer, who sees the above as an example of the ways in which Kleinman's desire to develop deeper understandings of socio-political contexts facing patients has been co-opted by the mainstream, and has become a tool for exploring the ways in which a medical symptom, diagnosis or practice reflects social, cultural, or moral concerns (Kirmayer, 2006). Kirmayer continues by describing the resulting polarisation of cross-cultural psychiatry along two streams. First, are the psychiatrists and psychologists grounded in clinical practice, who assume the cross-cultural portability of theory and practice in order to achieve practical outcomes. This results in the development of potentially useful tools for identifying mental distress within western medicalised frameworks (such as the need to include somatic markers for identifying depression in women), but has little emphasis on needed self-reflexivity about the role of their position as practitioner, and the realities of patient daily life that may play into treatment outcomes. Second, he describes a group of social scientists and researchers committed to advancing medical and psychiatric anthropology through scholastic endeavours, which do very little beyond establishing critiques that rarely improve the clinical practices between patients and practitioners.

The identification of socially driven models of mental health are relevant for promoting responses to mental distress that can respond to critiques, and for clarifying the processes through which social and AIDS specific factors come to influence the mental ill-health experience of communities - a gap this thesis seeks to contribute to. Yet, Kirmayer's (2006) arguments suggest that the critical field – responsible for providing such social models – is at a standstill. If so, then where does one begin to look for direction to move critiques forward into action? The first direction for a way forward may lie in adopting alternative frameworks for the definition of mental health in general. Till now, my discussion of both mainstream and critical perspectives has been hinged on the notion of mental health as the absence of mental illness. In 2001, with the launch of the WHO's world health report entitled *Mental Health – New Understandings, New Hope*, the framework for approaching mental health presented a definition that was weighted towards the importance of the biomedical, and was ultimately, disease oriented. The report asserts that:

*The importance of mental health has been recognized by WHO since its origin, and is reflected by the definition of health in the WHO Constitution as 'not merely the absence of disease or infirmity', but rather, 'a state of complete physical, mental and social well-being...'. In recent years this definition has been given sharper focus by many huge advances in the biological and behavioural sciences. These in turn have broadened our understanding of mental functioning, and of the profound relationship between mental, physical and social health... Today we know that most illnesses, mental and physical, are influenced by a combination of biological, psychological, and social factors. **We know that mental and behavioural disorders have a basis in the brain.** We know that they affect people of all-ages in all countries, and that they cause suffering to families and communities as well as individuals. **And we know that in most cases, they can be diagnosed and treated cost-effectively** (WHO, 2001, p. 4 - emphasis added).*

The above statement recognises a multi-dimensional definition of health while simultaneously speaking to a biomedically oriented approach to intervention and improvement of well-being. Within this framework, promoting mental health is clearly still linked to reducing a biologically driven illness.

However in 2005 mental health was officially re-defined by the WHO as '*a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community*' (WHO, 2005). This definition recognises mental health along three dimensions: 1) well-being; 2) effective functioning of an individual; and 3) effective functioning of a community, with a shift to a perspective of positive mental health. The work of sociologists Corey Keyes (1988; 2005;2007) and colleagues (Ryff & Keyes, 2005; Westerhoff & Keyes, 2010) have sought to operationalise these core elements of positive mental health, and in doing so, draw on a range of psychological and sociological notions of well-being.

For example, Ryff established six dimensions of psychological well-being, rooted in the Aristotelian notion of eudaemonia, which states that happiness results from the ability to realise one's own potential in life. Ryff drew on the psychological work of Erikson, Jung, Maslow and Rogers, in order to identify six elements of positive functioning that could describe the processes through which individuals operate to achieve their potential (see table 1). These are distinct from emotional well-being, which has been linked to the Aristotelian notion of hedonia summarised by Keyes (2007) as being related to feelings of happiness, satisfaction and interest in life. Keyes (1998) argued that well-being must also extend beyond individual fulfilment addressed within notions of psychological well-being, and look towards optimal social functioning, framed by an understanding of social embeddedness and engagement within one's community. He established five dimensions of social well-being that describe the processes through which overall social well-being is achieved. They draw on sociological and social psychological theorists such as Durkheim

and Merton, in arguing for the importance of these factors. Broadly speaking, social well-being is understood as the appraisal of one's circumstance in relation to one's environment (see table 1 below). In applying this particular framework to mental health, Keyes (2002) argued that it takes a combination of these dimensions to be considered mentally healthy, and suggested that these indicators are actually what constitute positive mental health.

TABLE 1: DIMENSIONS AND CRITERIA FOR PSYCHOLOGICAL AND SOCIAL WELL-BEING (ADAPTED FROM WESTERHOFF & KEYES, 2010)

Psychological well-being (Ryff, 1989; Ryff & Keyes, 1995)	Social well-being (Keyes, 1998)
<ol style="list-style-type: none"> 1. Self-acceptance: a positive and acceptant attitude towards aspects of self in past and present 2. Purpose in life: goals and beliefs that affirm a sense of direction and meaning in life 3. Autonomy: self-direction as guided by one's own socially accepted internal standards 4. Positive relation with others: having satisfying personal relationships in which empathy and intimacy are expressed 5. Environmental mastery: the capability to manage the complex environment according to one's own needs 6. Personal growth: the insight into one's own potential for self-development. 	<ol style="list-style-type: none"> 1. Social coherence: being able to make meaning of what is happening in society 2. Social acceptance: a positive attitude towards others while acknowledging their difficulties 3. Social actualization: the belief that the community has potential and can evolve positively 4. Social contribution: the feeling that one's activities contribute to and are valued by society 5. Social integration: a sense of belonging to a community

Keyes contended that individuals could be seen along a continuum of Flourishing and Languishing, where individuals displaying the former have high levels of subjective well-being, combined with optimal levels of psychological and social functioning. The latter refers to states of low subjective well-being, that are combined with lower levels of psychological and social well-being (Westerhoff & Keyes, 2010). Keyes (2005) continued his efforts to highlight the importance of these dimensions within mental health, through modelling a relationship between positive mental health and mental illness, through analysis of a representative sample of US adults between the ages of 25 and 74. The data provided strong evidence for a dual continuum model that presents mental illness and mental health as related but distinct dimensions: with one related to the presence or absence of mental illness, and the other to the presence or absence of mental health. The model was replicated in South African adults with confirmatory findings for the presence of this continuum (Keyes et al., 2008).

The importance of a dual continuum model for mental health is two-fold. By creating a framework that posits mental health and mental illness on a related but separated continuum, Keyes has effectively provided a solution to the perseveration of an 'either/or' argument that has dominated debates about mental health. In the field of global mental health, academics and practitioners fall along the dichotomy previously described by

Kirmayer (2006), evidenced by a body of work that seeks to either advance or transfer certain aspects of western practice to non-western settings (Pereira et al., 2007) or reprimand such efforts (Summerfield, 2008) without much practical suggestions for alternative modes of intervention and support.

If we apply a definition of mental well-being that makes use of a dual continuum, it clarifies a path for the role that both mainstream and critical voices play in shaping responses to mental health. The biomedical frameworks that govern classical psychiatry are best applied in charting responses for a mental illness continuum, perhaps focused on severe psychiatric conditions. Multi-disciplinary practitioners outside of psychiatry must then begin to focus on actively supporting the *mental health* continuum.

Kirmayer (2006) suggests the value of disciplines such as social psychology, sociology and cognitive science, in addition to traditional players, that have the ability to: (1) see culture as a core feature of human biology; and to (2) recognise psychological processes as located within the individual and are enacted within discursive processes that are fundamentally social. These fields have an equally active role to play through research and practice, as they shed light on the importance of relationships between self and society, and the mitigation of socially driven risks in responding to poor mental health.

What remains is for the social sciences to take up this call, through studies that can integrate the biological and the social within a framework of understanding of how mental health can be addressed. Within socially disparate communities, this will require a focus on not only addressing mental health, but identifying opportunities to transform the contexts that put mental health at risk, a desire that sits at the heart of this thesis.

An additional branch of critique that remains particularly relevant to this thesis given its focus on women is feminist critiques of psychology and psychiatry. Feminist positions on psychology and mental health sit at the intersection of 'critical' psychiatry and feminist theory. They take issue with both arguments, debating the validity of diagnostic categories themselves, as well as the reductionist approaches to assessment that prioritise individualistic and cognitive approaches to defining distress. These two issues are particularly disconcerting for feminist theorists, as they both contribute to a 'silencing' of the realities of women's conditions: where both categories, and the tools used to observe them, mute the very important ways in which women's participation in various realms of society result in the manifestations of emotional and physical distress. Appignanesi's recent (2009) historical account of women's interactions with 'mind doctors' reiterates second wave feminist critiques of psychiatric practice, where psychiatrists and psychologists essentially

...constituted the enemy, agents of patriarchy who trapped women in a psychology they attributed to her, stupefied her with pills or therapy, and confined her either to the madhouse, or the restricted life of conventional roles (Appignanesi, 2009, p.7-8).

In her contemporary account of social constructivist critiques of depression, Janet Stoppard (2000) outlines how such views of psychiatric practice emerged. She links these views to the realities presented by diagnostic categories found in DSM and ICD-10: judgements of 'normality' produced within the conceptual practice of experts. The true social constructivist nature of these categories emerges for feminists who point to the existence of categories that were exclusive to women, and remain inadequately supported by sound empirical evidence (Caplan, 1995, as cited in Stoppard, 2000).

She asserts that women's participation in services forces them to engage with a socially constructed notion of their normality, that defines new realities of their existence, in ways that given links to the biomedical, lack contextual or social relevance to the worlds outside their bodies. The ability for diagnostic procedures to allow categorical concepts defined by groups of men to become reified and labelled as a real entity, with a real physical existence in women's lives, is a core concern of many feminist psychologists. When women become associated with a medical domain –a consequence of their engagement with professionals - women's problems stand the risk of becoming unduly medicalised, and all of their experiences come to be viewed as signs of internal individual problems (Stoppard, 2000).

For Stoppard, even social approaches to defining women's distress are insufficient, in as far as the way in which the 'social' is defined. She suggests that existing definitions fail to extend the realities of women's local participation to the broader social contexts of women's worlds, and often neglect the structural, political and economic conditions of women's lives. Her critique of the social-stress models, a bio-psychosocial approach to defining distress, focuses on its inability to articulate how the "circumstances constituting the contexts of women's lives are *themselves* structured and organised socially" (Stoppard, 2000, p.84; emphasis added). By attending to the ability for local and immediate crisis concerns within women's life worlds to foster stress (and emotional distress), without linking these local crises to broader social or cultural histories that may expose women to these experiences in the first place, makes such approaches a moot effort.

This limitation rings true when reflecting on the bodies of evidence used to inform community mental health practices in many resource poor contexts. A plethora of studies that recognises or identifies contributions of social drivers such as poverty and violence as potential stressors that trigger bouts of mental distress, while still calling for biomedical responses to symptoms (for an example, see Lund et al., 2011) result in driving further focus on the symptoms of the distress. A corresponding minority of evidence exploring the realities of what it means to *experience* poverty and violence, in the contexts of particular

cultural practices and social histories, results in a lack of attention to how these 'social' issues shape women's experiences of mental distress.

Taking interest in broader conceptualisations of the social will lead to increased attention to building opportunities for women to transform the worlds that create their distress. But how might this be achieved within a mental health framework? The beginnings of exploring possible answers to such questions are addressed in approaches to mental health that link to broader notions of 'development', which I address in the subsequent section.

1.1.3 FROM COPING TO TRANSFORMATION: MOVING BEYOND THE BIO-PSYCHOSOCIAL

Our discussion to this stage has highlighted three key themes with regards to efforts to 'define' mental health. Firstly, that the notion of mental health is highly contested and continues to sit at the centre of debate between biomedical and social perspectives. Secondly, critical approaches have highlighted the importance of local knowledge, social relationships and societal factors in defining and responding to mental health, but have had inconsistent impacts in the domains of practice (Kirmayer, 2006; Thomas & Bracken, 2004). Finally, I suggested that a route to action critique (i.e. taking critiques forward in practical ways) might begin with the broadened scope and continued consideration of the social when defining mental health, as highlighted by Keyes' dual continuum that situates mental health along one continuum (comprised of psychological and social well-being), and mental ill-health (comprised of mental disorders) along the other (Keyes 2005).

In order to clarify the importance of these three issues to contexts of mental health care, the following section of this thesis discusses a developing area of interest: mental health and development. This model is able to incorporate the essence of a 'dual continuum', responding to mental ill-health, while paying equal measure to local knowledge and broader societal factors as conditions that promote well-being. The BasicNeeds model, which drives the work of the NGO of the same name that currently works with low and middle income country groups, and is affiliated with the global movement, is explored below, in order to show the model in context.

MENTAL HEALTH AND DEVELOPMENT: BASICNEEDS FOR MENTAL HEALTH

The BasicNeeds mental health and development model (MDH), positions community mental health within a framework that focuses on capacity building, research, management and sustainable livelihoods in communities where individuals with mental health needs are targeted for support.

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REASONS

Figure 3: BasicNeeds Mental Health and Development (MHD) Model - source: de Menil, Underhill & Raja, 2010

The model has roots in the field of development and attempts to separate itself from other models of intervention such as psychiatric models which, even in their most progressive forms, champion the right to *treatment and rehabilitation* within communities. A psychiatric model is seen as viewing people as patients first, leading to the desire to facilitate the delivery of treatment through a range of interventions at community levels. Conversely, the MHD model sees people not as patients, but rather as ‘people’; with fundamental rights to more than just appropriate services. In recent work reviewing the model’s implementation in six countries, deMenil et al. assert:

The thinking at its origin was that, just as a standard development programme would focus on farmers or women, using community groups as their basis, why shouldn’t they do the same for people with mental illness?
(de Menil et al., 2010, p.6).

Using the right to development as its cornerstone, the model supports: the right of communities to participate in all aspects of their broader social worlds (concentrating on the importance of local voice in determining areas of focus); and autonomy, education and work –capacities viewed as relevant to individuals with mental distress as they are to anyone else.

In this way, BasicNeeds considers itself as a development agency first, that happens to work with people with mental illness and epilepsy (de Menil et al., 2010).

The MHD model demonstrates the value in approaching communities as experts to a certain degree. Through a series of consultations, communities decide which aspects of the model suit their needs, determining the shape of the intervention as it moves forward. Mental health care users are seen for their 'untapped' potential, supported in the development of a range of skills that relate to their ability to live full lives beyond just the alleviation of their distress. Mental health care users and their families form the basis of interventions, and assess needs at a range of levels beyond those driven by biological illness alone. Attention to the 'voice' of users is consistent with many critical approaches to mental health discussed previously, and, attempts to take these critiques forward, via attention to multiple dimensions of community life.

The model's focus on livelihoods and economic development emerged through engagement with individuals with mental distress, and the acknowledgement that 'not only is mental health care a basic need, but...that people with mental illness or epilepsy have... needs that go beyond health care' (ibid.). Mental health care users actively contribute to income generating initiatives, building their self-efficacy within communities. The ability to make contributions to their broader social worlds through the use of economic efforts also helps to challenge broader community mental health stigma (Raja, 2008).

The model provides a clear example of attention to 'healthy communities' at multiple levels, where community members are seen as agents in the process, but only to a limited extent. The continued anchoring of the approach to illness categories (presence of a mental health problem) also places limits on community participation. For example, the notions of 'capacity' discussed within the model most often relates directly to participation in delivery of mental health services, where community members do not contribute to the design of their treatments. Interventions do not take on innovative forms, and the roles played by many community members link to the delivery of western-designed treatment packages, and monitoring adherence. In this way, the community site becomes reduced to a locus for delivery of services.

A recent special issue in the journal *Community Development* (2012) re-affirms the value of a community development approach to mental health. Work with marginalised communities in developed countries such as the UK and Australia promotes an argument for widening the definition of 'community' in mental health practice, and the valuable role that development plays within improving mental health. For example, Rose and Thompson's (2012) work with a low-income community in Sydney, Australia, highlights the successes seen when interventions cast a much wider net with regards to community, to include action

at levels of space (environmental infrastructure), people (promoting individual capabilities, like the BasicNeeds model above), and place (the socio-cultural and historic dimensions of community).

This broader conceptualisation of the many levels of the 'social' brings us closer to our desire to promote 'transformation', which for the purposes of this study, is defined as the ability for community members to engage simultaneously with both the causes (symbolic or place-based) and symptoms of distress in ways that result in small but meaningful gains. It is here that community and social psychological frameworks, which I will explore in greater detail within chapter three, make key contributions. Their attention to the 'intangibles' of our social existence – the psychosocial processes that underlie relationships to and interactions with social structures, such as systemic social issues and cultures - and how they shape how we feel, what we know and what we do with that knowledge, draw attention to the multiple factors that influence good health. Such a focus may also help to make explicit the symbolic dimensions of power, access and participation that run through our social worlds, and the impacts these have on the ability for communities to ensure their own mental well-being.

CHAPTER CONCLUSIONS

This chapter has provided an overview of well-established models of mental health. The biomedical model has framed the treatment of mental distress through the operationalisation of symptoms, and targeting of biomedically faulty systems that are believed to shape mental ill-health. Overtime, the perspective has come under criticism from a community of theorists and practitioners who assert that adherence to biomedical frameworks limits practice, devalues patient voice and participation, and is unable to target broader social, political and cultural contexts that are related to emotional distress. Though critical and cross-cultural psychiatry have effectively challenged the dominant perspective through providing an alternative theoretical discourse, in practice, their uptake has focused primarily on the improved interaction between patient and practitioner within biomedical frames, and often become occluded by a focus on the pragmatics (practice) of care. This is perhaps best exemplified by the application of Kleinman's EMs, which have identified important distinctions between paradigms used by patients and practitioners to make sense of mental health, but are applied in ways that prioritise the improvement of diagnostic markers for biomedical frameworks, rather than being used to attend to the contexts that shape patient paradigms, reflecting more of a co-option of critical discourse (Kirmayer, 2006).

Towards the end of this chapter I suggested that a way beyond the confines of this debate may lie in shifting definitions of mental health and ill health to a different model entirely – along the lines of a sociologically driven dual continuum model - which sees mental ill-health as existing along a separate, but related continuum to mental health, comprised of psychological and social dimensions of well-being. In doing so, we may establish a platform to promote a more critical engagement with the contexts that shape mental health through social and psychological channels. The mental health and development framework presents steps toward this aim, through a focus on a right to 'development' rather than a right to 'treatment'.

A much deeper and critical analysis that anchors individuals to the contexts that shape knowledge, and daily life, could likely provide greater insights into how communities are already managing their mental health in the face of HIV and social adversity, through efforts related to social and psychological processes. If this is the case, then we can begin to highlight the positive efforts to address mental health within communities that are already in play, and also highlight social and psychological resources needed in order for communities to take on more active roles to achieve states of mental well-being. This envisions a shift away from treatment and towards transformation of spaces that contribute to distress, in

small albeit meaningful ways. However, prior to engaging with this notion in greater detail, I pause to consider the current environment of mental health services within the location of this case study: South Africa.

CHAPTER TWO: CONTEXT- MENTAL HEALTH, HIV AND GLOBAL MENTAL HEALTH IN SOUTH AFRICA

The main aim of this chapter is to locate the aforementioned debates within the specific context of this work: addressing the mental health needs of poor AIDS-affected communities, in an era of 'global mental health'. In South Africa, there is an emerging cognisance of the complexity of the mental health and HIV/AIDS relationship (Kelly et al., 2008; Collins et al., 2006), and the need to increase access to mental health services more broadly. Currently, over five million South Africans are living with HIV (UNAIDS, 2012). Developments in HIV/AIDS research have highlighted the symbiotic relationship between HIV/AIDS and mental ill-health and the subsequent need for mental health supports in this population (Brandt, 2009; Kelly, 2008).

In this chapter I discuss the nature of the HIV/mental health relationship in general, and then address its specific manifestation in the South African context. It is imperative that we clarify how existing understandings of the concept of mental health emerges within the HIV field, but also, that we problematise the potential impacts of the perspectives that shape these understandings. This is important in trying to ascertain our current level of understanding about mental health within HIV/AIDS-affected communities, and directions for moving forward in the field.

First, I provide an overview of perspectives of mental health that exist within South Africa. I then approach current understandings of the relationship between mental health and HIV/AIDS within the country, and how it is being addressed. Throughout the chapter I revisit the overarching debate between critical and mainstream perspectives within South Africa. I conclude the chapter by introducing the project, my motivation for this work, and the specific research questions that drive this thesis.

2.1 MENTAL HEALTH IN SOUTH AFRICA: THE MEDICAL, MYSTICAL AND THE SOCIAL

The exploration of approaches to mental health in South Africa begs attention to a complex and politically charged history. This section explores approaches to defining mental health in South Africa, and presents how many of the paradigms addressed in the previous section have been taken up locally. I also explore how these approaches may have limited current understandings of the relationship between mental health and HIV/AIDS in socially disparate communities thus far, in order to illuminate the need for a project of this nature.

A myriad of approaches have been taken towards mental ill-health in South Africa. This pluralistic system cognisant of culture, medicine and society is a result of a history of coexisting models from the 18th century. In his analysis of the relationship between South African culture and mental health, Leslie Swartz (1998) divides mental health supports into three 'sectors' akin to those used by Kleinman in his discussions of cross-cultural psychiatric practice: popular, folk and professional. While he asserts that the professional system – which consists of the medically constituted services—is the most powerful in terms of access to structural and financial resources, as well as recognition of expertise, it remains a last resort for the majority of South Africans. He reports that between 70 and 90 percent of episodes are first dealt with in the popular sector— which is comprised of family members, neighbours, self-help groups and other social networks. When the burden of these experiences becomes too much to bear, folk sectors – comprised of traditional and faith healers— are consulted. It is only when both of these systems have failed, that community members will resort to medicalised services (Swartz, 1998).

The medical model of psychiatric practice arrived in South Africa in the late 1880s, transported by post-colonial psychiatrists from England, and progressed in parallel with many of the developments in Europe and the United States (Parle, 2007). The use of asylums – which were modelled in the vein of Pinel's moral treatment – formed a pillar of the medicalised approach to mental health from the end of the 19th to the mid-20th century. The classification system developed by Kraepelin was already being implemented by colonial South African psychiatrists in 1899 (Swartz, 1987). The model was inserted into a matrix of pre-existing models for understanding and dealing with mental distress. Traditional and spiritual black South African and Indian perspectives towards mental ill-health have always existed alongside western models. Accessing these domains as a first line of defence remains popular even today (Parle, 2007; Sorsdahl et al., 2009; Sorsdahl et al., 2010).

Traditional approaches to mental distress in South Africa were, like many non-western cultures, embedded in holistic models of health that avoided the typical mind-body

dualism of medical models. Healers in the Zulu tradition recognised a series of forms of emotional and mental distress, beyond the well understood forms linked to spirit possession (see Yen & Wilbraham, 2003b). According to Parle's comprehensive history of mental health in the Zulu region (current day KZN and location of this study), in the early 1900s traditional healers recognised multiple categories of both mental and physical ailments; from natural illnesses (*Umkhuhlane*), which included a range of experiences from the common cold, to more socially constituted forms of 'madness' such as *uhlanya* and *umhayizo*, which have been described as a form of hysteria marked by uncontrollable weeping (Parle, 2007). Restoring health in any instance often meant mitigating imbalances between the person, and their social world – undoing wrongs against others in the living and spiritual realms (ibid.).

The dominion of the biomedical over traditional or faith healing practices in response to symptoms of mental distress is a relatively new phenomenon within South Africa (ibid.). Its rise to dominance occurred alongside the progression of systematic oppression and segregation policies in the country. Scientific enthusiasm for eugenics and notions of mental superiority eventually led to the development of psychiatric practice that was explicitly shaped by scientific racism (ibid.). Legislation from as early as the late 1800s restricted the practice of traditional practitioners (with the exception of KZN, who had legal recognition to African herbalists under the Natal Native Code of 1891), outlining who they could support and in what ways (Flint, 2008).

The intensification of apartheid policies eventually led to the increased use of psychiatric research and practice as part of the atrocities carried out against black South Africans, particularly members of the Anti-Apartheid movement. Much of the anti-psychiatry and progressive cross-cultural psychology approaches seen internationally were taken up in South Africa as part of a resistance to these atrocities, led by a group of psychologists, psychiatrists, and other health and social care workers. The *Organisation for Alternative Social Service in South Africa* (OASSSA) sought to create a relevant psychology and psychiatry capable of overcoming the effects of a crippling apartheid society. They also actively denounced the application of western psychiatric and psychological approaches in South African contexts which sought to locate mental health as an attribute of problem individuals, with little attention to the impacts of the wider, often highly disabling, social contexts in which they were located (Hayes, 2000). Swartz and Foster (1984), as proponents of this critical perspective, attempted to radicalise psychiatric approaches by addressing the relationship between culture and mental illness in mainstream South African psychiatry, highlighting the importance of cross-cultural approaches in dealing with issues of class, language, race and gender (Swartz, 1987).

Victor Nell, another critical figure, suggested that psychology and psychiatry could best tackle mental health issues by taking root in social justice movements aiming to address fundamental causes of psychopathology. These were identified as: emotionally damaging infant and childhood experiences; poverty and degrading life experiences; powerlessness and low self-esteem; loneliness; social isolation and social marginality (Nell, 1994). However, Nell believed that for this conceptualisation of mental illness to be actualised, psychological services would have to be separated from medicalised services, to avoid psychiatric influences that ignore the importance of social, physical, spiritual and emotional well-being to mental health outcomes. Once this had taken place, the use of comprehensive service centres, staffed by a wide range of professionals associated with mental health and welfare services, could then work in tandem at the community level to address social issues. In such a system, single parents or unemployed individuals could seek social and emotional support within the same arena, giving mental health needs more immediate attention, within the contexts of the social conditions that foster it (ibid.). Unfortunately, Nell's dream has yet to materialise within South African approaches to treatment of mental distress – though some aspects of it emerge within the use of multi-disciplinary teams – which I address in more detail later in this chapter, and again in chapter five.

The end of apartheid in South Africa witnessed a commitment to a national health care system structured around universal primary health care (Petersen, 2000). This comprehensive approach to care was inclusive of mental health needs, in an attempt to respond to the heightened risk facing South Africans as a result of pervasive poverty, institutionalised economic and health disparities, political struggle and associated violence (Mosotho et al., 2008; Nell, 1994; Pillay & Freeman, 1996; Seedat et al., 1988). Fourteen years post-apartheid, the picture is much the same; poverty, unemployment, poor housing, and a sense of hopelessness still highlight the lived experiences of a large portion of the population.

In South Africa there is a steady push for the scale-up of mental health services (see Lund, 2010a, 2010b; Lund & Flisher, 2003, 2006; Lund et al., 2010), arising from the need to rectify apartheid era segregated health sectors on the one hand; and on the other hand, the need to mitigate the proposed burden of mental ill-health in the general population believed to stem from the aforementioned social conditions and the impacts of the HIV/AIDS pandemic (Mosotho et al., 2008). For example, while South Africa boasts a highly evolved mental health care service sector in comparison to other low and middle income countries, there are major disparities across the country (Lund & Flisher, 2006; Lund et al., 2010), with medicalised services concentrated within the urban regions in more affluent cities. In

KwaZulu-Natal, mental health services are broken down into three large catchment areas. Area three, which services the community focused on in this research, is one of the most under serviced areas, with 20 specialised beds and one psychiatrist supporting 12 district hospitals (personal correspondence, Tertiary Principal Psychiatrist, KZN). In the face of such disparities, it is not surprising that South Africa, where the most dominant perspective remains the medical one (Swartz 1998; Parle 2008), would be so heavily influenced by the MGMH discourses concerning the scale up of treatment delivery, human resources and policy.

In 2002, South Africa passed the new mental health care act grounded in a discourse of human rights. It affirms the rights of mental health users; de-medicalisation of management of mental health care; calls for the integration of medical professionals and traditional healers in delivery of care; and deinstitutionalises most mental health services into primary care settings (South African Mental Health Care Act, 2002). However, there have been many roadblocks to the implementation of this act in practice. Petersen (2000; 2004; 2009) has highlighted some of the difficulties in integrating mental health into primary health care in the country. According to Petersen, comprehensive integrated mental health care may not be achieved through the addition of mental health to primary health care alone. She states that in order for comprehensive care to be successful, a paradigm shift within the entire primary health care system is needed and calls for increased emphasis on health promotion, empowerment of service users, and a mentality that takes the subjective experience of the patient into account.

Despite the early calls for a shifting of paradigms driving primary health care, Petersen's recent work signals the direction of South African concerns with mental health into alignment with global movement standards, encapsulated within advocating for the importance of task shifting (Petersen, Bhana, & Baillie, 2012a; Petersen & Lund, 2011; Petersen et al., 2012b). Task shifting policies stipulate that primary health care professionals are supported by cadres of community volunteers or non-specialist health professionals who are trained and supervised in the delivery of bio-psychosocial treatment regimens (Kakuma et al., 2011). However, the insertion of a new cadre of specialised yet low-level staff may not automatically increase the ability of primary mental health care to achieve its aims of equity collaboration across health and welfare sectors, social justice, and patient and practitioner empowerment – as barriers to primary care of the system remain (Dookie & Singh, 2012; Kautzky & Tollman, 2008; Lawn et al., 2008).

For example, the need to address the mental health of HIV/AIDS-affected communities has overstretched many primary health care settings (Kelly et al., 2008). Mental health sector resource deficits (Lund & Flisher, 2003, 2006; Lund et al., 2002) and

challenges facing the inclusion of the folk sector (Campbell-Hall et al., 2010; Sorsdahl, et al., 2009, 2010) are also major concerns. However, the complications facing primary health care extend beyond resources. Lehmann and Gilson's recent work (2012) highlights the complexities of power dynamics that limit and sometimes undermine policy intent within South African settings. A recent review of studies on mental health services within South Africa highlights a paucity of studies that explore how more symbolic concerns such as power or stigma influence the delivery of primary mental health in the country - a gap this thesis may contribute towards filling.

Consideration of the impacts of poverty and systemic social ills on mental health are also a concern. For example, Lund has recently reiterated the link between poverty and emotional distress (Lund, Breen, et al., 2010; Lund, et al., 2011); however, there appears to be a disconnect between what is viewed as a problem, and suggestions for solutions. Breaking the 'cycle' between poverty and mental illness is linked to scaling up mental health services, rather than interventions that operate to ameliorate local experiences of poverty. This position is understandable given mainstream psychiatry's own knowledge system, which demands adherence to a medicalised paradigm, and alignment with broader global voices that position scaling up mental health services in these areas as a priority (Prince et al., 2007). While some authors do articulate the need to extend prevention and health promotion efforts to tackle social conditions of concern in the country (e.g. Petersen, Bhana, & Swartz, 2012), there is much to learn about how this can be achieved through primary health care channels.

There is arguably some value in the use of medicalised frameworks in some contexts where community members experience mental distress and desire treatment. The impact of severe mental issues can be greatly reduced through some biomedical interventions that help to improve quality of life in meaningful ways. However, critical voices such as Ingleby, Summerfield and Swartz still call attention to the social milieu that surrounds these processes - cultural discourses, systemic poverty and human rights violations -and their contributions to emotional distress. In placing these sometimes combative positions together, it may suggest that while inserting more trained psychiatrists or psychologists into under-resourced areas may be necessary, it is far from sufficient in seeking to promote mentally healthy communities in areas of social distress.

What then, is away forward in areas where these social needs are so apparent and intrinsically linked to mental health outcomes? If community strengthening is a valid route, a logical first step involves exploring how mental health policies within South Africa approach the notion of 'community' in the first place.

South African theorists and practitioners have conceived of addressing such gaps in the formal sector through the inclusion of traditional practitioners and local community actors in the delivery of services, a desire linked to the history of acceptance of pluralistic models present in the country. Recommendations from the recently released *Mental Health and Poverty Project* (MHaPP – see Lund, 2010a), a research consortium examining mental health systems and policy in four African countries, suggest a plan for district mental health services that highlight an evolved role for various actors in community mental health services. In their proposed model, mental health assistants or counsellors (community members with bachelor level training in psychology), traditional healers, social workers, community health workers, community organisations and front line medical staff, provide the coalface for mental health services at primary and district level. The model incorporates a referral system that provides support to community level actors in the delivery of psychosocial rehabilitation, psychoeducation, prevention, promotion and early identification and referrals to primary health clinics (Lund et al., 2008).

In such a system however, two issues emerge. First, this structure may be hindered by the different understandings held by each group of actors that provide treatment to communities. South African traditional healers approach mental health within notions of spirituality, and reverence to the role of ancestors within lived experiences (Berg, 2003). Today, traditional healers remain a source of revered knowledge, associated to the important links to ancestral histories that remain important to many Zulu families.

Conversely, Yen and Wilbraham(2003a) argue that the position taken by psychologists and psychiatrists with regards to distress is linked to the biomedical paradigm and to maintaining the value of their work in the face of patients who have a preference for indigenous treatments. Nurses exist somewhere in between, employing a pragmatic and functional approach concerned with treating as many people as possible within resource strapped settings, leading to the categorisation of mental distress to physiological causes, which are easier to respond to under time constrained circumstances (Petersen, 2000).

Sorsdahl, Stein and Flisher (2010)recently explored traditional healer attitudes and beliefs on referral to doctors in South Africa, a contingency for the success of the MHaPP model. Unsurprisingly, many healers felt that while they would be happy to collaborate more closely with western doctors in a reciprocal matter where referrals work back and forth, they believed the feeling was not mutual; they were thus hesitant to engage effectively in referrals. While the authors of this paper suggest that the end goal should be to scale up efforts to include traditional healers in line with recommendations from the MHaPP and global movement trends, traditional healers are identified as a route to making referrals to

formal medical services, without mention of the potential role that traditional healers may also play in the alleviation of distress.

With this many actors convening in one space, it is important to have a deep understanding of what perspectives are brought to the table by each group. My study seeks to explore this by engaging with all the actors that are identified as supporting mental health in the community, across all sectors. This is done in the hope of filling the gaps in our understandings about the interactivity of these groups.

There remains a final gap in our understandings of the groups of actors in the primary mental health care system: service users. Given that current approaches to engagement with service users has explored those who have already been in contact with the formal sector of mental health, it is likely that the concerns between these groups will seem sufficiently aligned, as has been articulated in recent work (Campbell-Hall et al., 2010). However, this is not the full picture. Campbell-Hall and colleagues (*ibid.*) assert that we should also seek to involve those who have not yet engaged with services, in order to facilitate more locally relevant services. In my study, by accessing community members who would be 'potential' service users given their experience of mental ill-health symptoms, I can contribute to expanding recognition of their understandings and needs, and how they can be addressed. Existing studies about these groups are focused primarily on documenting risk of mental disorder in the broader community using psychometric indicators (Samouilhan & Seabi, 2010; Ward & Heidrich, 2009), providing a limited perspective on mental health needs that is now becoming widely recognised as being more than the biomedical.

2.2 MENTAL HEALTH AND HIV: THE COMPLICATED RELATIONSHIP

Mental health and HIV/AIDS have been empirically linked to similar societal factors in low income countries including South Africa, a relationship that I address in figure 4 below. Infection and spread of HIV has been linked to a bevy of social ills, such as poverty (Whiteside, 2000), violence and political instability (De Waal, 2006; Seckinelgin, 2012), lack of rights (Chopra & Ford, 2005) and gender inequality (Dunkle et al., 2004). Researchers have effectively linked the same conditions to mental distress (Lund, et al., 2011; Seedat et al., 2004; Ward et al., 2001; Wong et al., 2008), a parallel that reaffirms the intricacies of the relationship between these health outcomes. The panel on the left of the figure below highlights this relationship with arrows pointing towards each condition.

This co-morbidity has far reaching impacts on quality of life for HIV-affected individuals. The work of Ickovics and Meade (2002) and Cruess et al. (2003) highlight the ability for mental distress to influence uptake of and adherence to antiretroviral therapy and

T-cell counts. Specifically, patients with significant levels of mental distress have lower T-cell counts, and lower adherence to ARVs. In addition, disclosure of HIV/AIDS status has been shown to impact gravely on mental distress, causing many patients to isolate themselves in an attempt to combat stigmatisation and exclusion often associated with a positive diagnosis (Booyesen et al., 2007; Campbell et al., 2007).

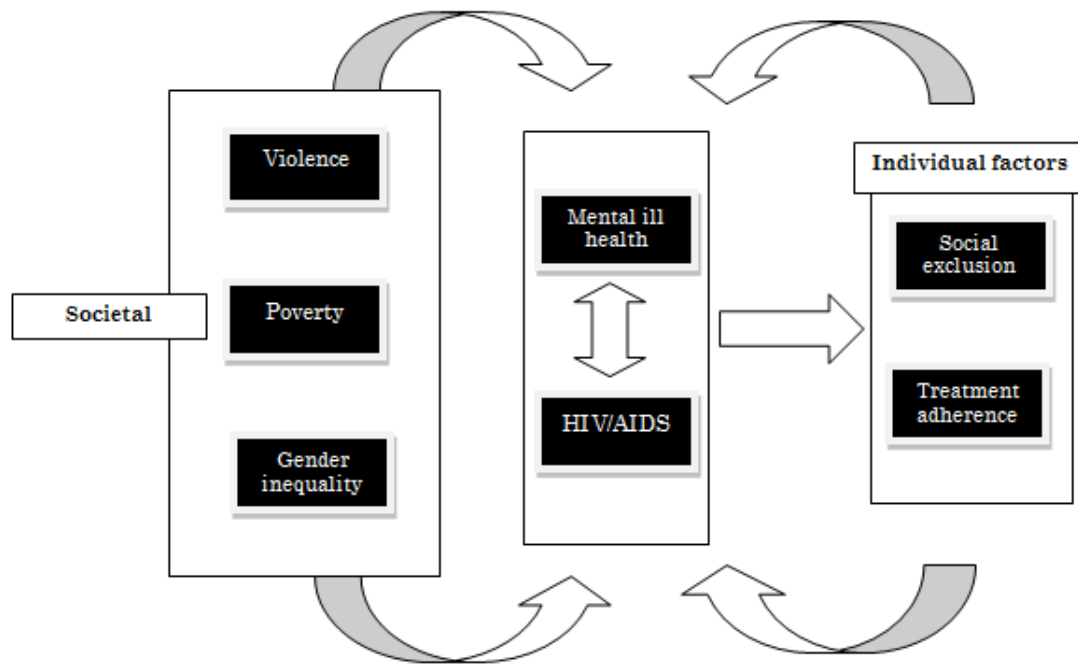


FIGURE 4: THE MENTAL HEALTH AND HIV RELATIONSHIP

Women have been shown to experience a greater deal of mental health issues as a result of their HIV status. Quinn and Overbaugh (2005) describe women, particularly those in the developing world, as bearing the dominant burden of the epidemic, due to the same socio-economic factors identified in figure 4, as well as a host of biological factors, such as hormonal changes or vaginal microbial ecology.

The centre panel of figure 4 engages with the presence of a co-morbid diagnosis (cases where the disorders are experienced simultaneously). In order to clarify this dimension of the relationship, it is best to embed this discussion within the context of intervention. The relationship is typically approached from one of two positions depicted in figure 5 below. The left of this figure focuses on the provision of mental health services for those affected by, or infected with HIV/AIDS (Andersen & Seedat, 2009; Mambwe et al., 2008; Myer et al., 2009). This requires a line of response that demands practitioners and policy-makers to mobilise resources to increase the availability of mental health care

supports for HIV/AIDS-affected communities. It is often suggested that these services should be designed to reflect the specific needs of these affected groups, despite many studies maintaining that there is still a great deal to be learned about what these specific needs may be (Brandt, 2009; Breuer et al., 2011; Petersen et al., 2013).

The right panel in figure 5 focuses on the need to address HIV/AIDS related services and concerns for those who experience mental health problems or other physical or mental disabilities (Hanass-Hancock & Nixon, 2009; Ramlall, 2010). In many cases, this involves a focus on severe mental disorders and addressing the increased risk faced by this group, as well as the compounded marginalisation that chronic mental health care patients face in their own communities in the light of a dual diagnosis (Ramlall, 2010).

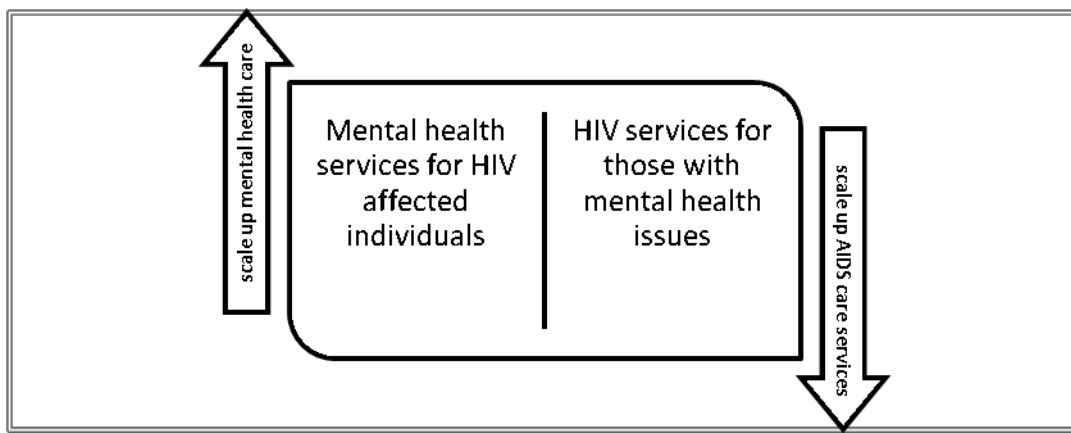


FIGURE 5: MENTAL HEALTH AND HIV: RELATIONSHIP AND RESPONSE

This thesis takes interest in the relationship shown in the left panel in figure 5, given its implications for the mental health service sector and a broader proportion of the population. There is a wealth of interest in common mental disorders (CMD) such as depression, anxiety and PTSD in the HIV/AIDS-affected and infected population (Freeman et al., 2008; Kimerling et al., 1999; Myer et al., 2008, 2009). The response taken forward from these studies suggests the importance of activity in two areas: provision of cost effective medicalised services; increased awareness about mental health issues. These categories of distress have also been criticised with regard to their treatment in developing country settings (Miller, Fernando, & Berger, 2009; Summerfield, 2004; Watters, 2010), in light of concerns over how western models conflict with local understandings of ill-health, suffering, and survival. I would argue that this aspect of the relationship could benefit from the contribution of social psychological voices, insofar that they are able to consider the importance of both the social and the psychological notions of well-being, as well as societal structures that interact within the process of community management of mental health.

Current evidence relating to the left panel in figure 5 has been dominated largely by epidemiological efforts. Such studies explore mental distress by looking across general populations and highlighting relationships between issues, including poverty (Burns & Esterhuizen, 2008), violence (Dinan & McCall, 2004), HIV status (Adewuya et al., 2007; Freeman et al., 2008; Mambwe et al., 2008; Myer et al., 2008), and caregiving (Heymann & Kidman, 2009; Kuo & Operario, 2011) - factors intrinsic to the experiences of many South Africans. However, there are very few existing studies that illuminate the nuances of this relationship – how understandings of mental ill-health, as well as structural and symbolic factors present in everyday life, contribute to the actual experience of mental distress and ultimately how it should be addressed.

There is still much to be learned about the nature of the relationship between HIV/AIDS and mental health (Brandt, 2009), and a great deal to understand about the type of services that will best meet the needs of individuals who experience mental distress as a result of both societal and HIV/AIDS related circumstances (Mambwe et al., 2008; Petersen et al., 2013). Developing studies that explore these issues will provide the best direction for outlining successful treatment responses for a community (Rose et al., 2008; Slade et al., 2005). This thesis will hopefully contribute to filling this gap in the literature. Furthermore, KZN, the location of my project, provides an ideal context to explore the impacts of the HIV pandemic on rural mental health outcomes and services, as HIV prevalence is the highest in the country at 25.8 percent (Setswe, 2009).

A recent review of studies looking at mental health in HIV/AIDS sufferers identified 27 articles published between 1994 and 2008 in African countries (Brandt, 2009). Of the 27 studies, 12 were completed within South Africa, and 11 were concerned with the categorisation of mental health issues within AIDS infected groups of individuals. In describing the prevalence of mental health problems, Olley, Seedat and Stein (2006) identified depression as the most common mental health problem in HIV infected individuals. Other types of mental distress identified in this population included anxiety (Els et al., 1999), and alcohol and substance abuse (Freeman et al., 2008). Post-traumatic stress was identified as a significant issue in three South African studies, however prevalence rates varied across each study, with percentages ranging from 4 percent in one study (Freeman et al., 2007) and 15 to 29 percent in another (Olley et al., 2006).

In general, women affected by HIV/AIDS have been shown to be at an increased risk for a range of mental health issues (Brandt, 2009). A study by Wingwood et al. (2008) associated stigma with greater depressive symptoms and poorer quality of life among low-income HIV-infected women, while additional findings from the work of Freeman and colleagues (2007) indicate that individuals who have been discriminated against or isolated

as a result of HIV were more likely to present with a mental disorder. General mental distress experienced by women has been shown to be further exacerbated when they have children (Freeman et al., 2008). In HIV positive women, drug and alcohol dependence, depression and PTSD were associated with previous experiences of rape (Olley, Abrahams & Stein, 2006). Interest in AIDS-affected caregivers in South Africa is increasing (Freeman & Nkomo, 2006; Kuo & Operario, 2009; Schroeder & Nichola, 2005; Townsend & Dawes, 2007), given studies that have linked the process of caring for orphaned children to poorer mental health outcomes. Beyond this, understandings of their experiences with mental distress have yet to be explored.

Addressing the mental ill-health of HIV-affected groups falls within MGMH efforts, via their desires to support the mental health of poor communities more broadly, and their use of the HIV/AIDS pandemic as a model to promote global awareness of mental health issues (Campbell & Burgess, 2012). The MGMH - equal part lobby group and research centre - is comprised of over 80 institutional partners worldwide. It seeks to unite academics, practitioners and organisations, as well as lay people and service users with interests in global mental health, who advocate for the expansion of mental health services in low and middle income countries (Prince, et al., 2007). The movement aims to address mental health needs in developing countries like South Africa through the promotion of research, 'best practice' and policy. It lists its three main objectives as: closing the 'treatment gap' in many developing nations, where the observed burden of disease far exceeds available services; protecting and preserving the human rights of the mentally ill in low and middle income regions, where knowledge and understanding of mental illness may be very limited; and promoting research on mental health so action can be informed by the 'best available scientific evidence' (Patel, 2012).

These international actors have focused a great deal on highlighting the need for increased services in regions like South Africa, and recognise the mental health and HIV relationship as an important part of this picture (Collins et al., 2006, 2011; Freeman et al., 2005). However, their focus on a scale up of medicalised support structures (Patel & Thornicroft, 2009; WHO, 2010) is likely to be misaligned with community understandings of emotional distress, and the prominence of social ills within experience of distress (Summerfield, 2008). I deal with the role that this global relationship plays within the South African context below but first, I begin with a broad overview of the movement for global mental health.

2.3 A MOVEMENT FOR GLOBAL MENTAL HEALTH: SOUTH AFRICAN CONCERNS

The gap between the potential need and available medicalised resources for supporting mental health, observed in South Africa and the rest of the developing world, has emerged as the crux for what is now widely understood as the field of global mental health. It is rooted within a shift in international discourse on mental health that began in 2001, when the WHO's Global Health Report, *New Understandings, New Hope* (2001, p. 3) highlighted mental ill-health as a public health emergency capable of crippling developing countries health systems. The report is considered a catalyst of the current movement. By the release of the 2002 report, 26.1 % of years lived with disability caused by non-communicable diseases in low-income countries could be attributed to neuropsychiatric disorders (WHO, 2005). Furthermore, the 2001 report stated that among 15 to 44 year-olds, the health burden caused by common mental disorders such as depression was exceeded by only one condition: HIV/AIDS, a key finding for AIDS-affected countries like South Africa (Freeman, 2004).

These findings sparked a widespread interest in the need to alleviate the potential unidentified burden of both psychoses and CMD in previously neglected populations, and promoted a flurry of investigation in African countries. For example, epidemiological interest in mental health and well-being has expanded exponentially in recent years. The identification of the potential burden caused by CMDs such as depression, anxiety or post-traumatic stress disorder (PTSD), has emerged as a priority interest given the longstanding associations between mental distress and social milieu such as poverty (Patel & Kleinman, 2003), violence (Kaminer et al., 2008), and political instability (Hess, 2009), and—as I alluded to earlier – the advancement of the HIV pandemic.

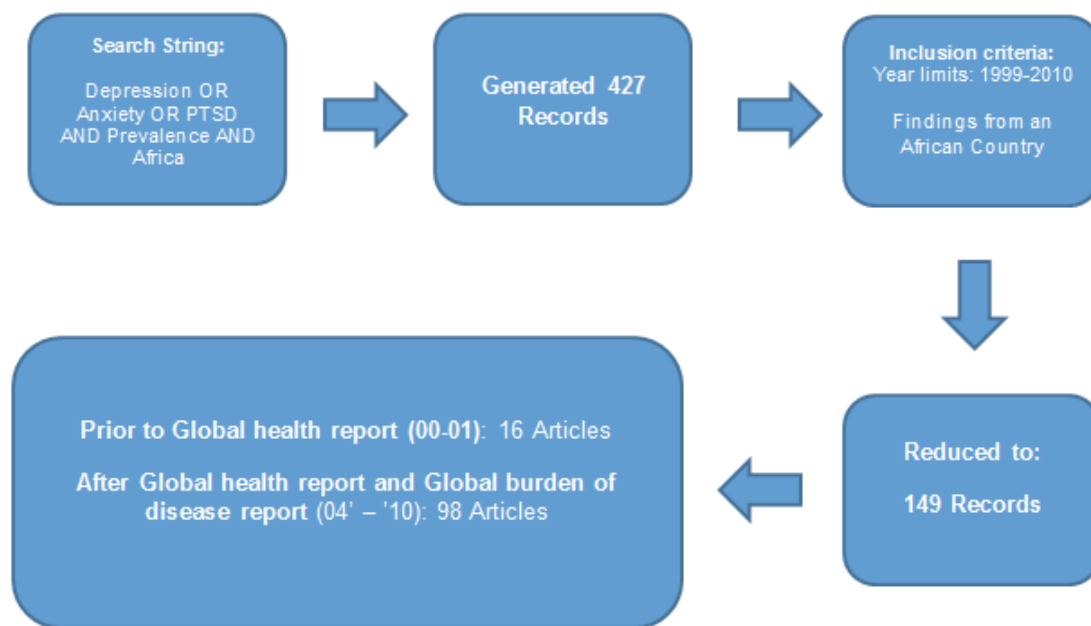


FIGURE 6: REVIEW STRATEGY FOR EXPLORING RESEARCH ON CMD IN AFRICA FOLLOWING RELEASE OF THE WORLD HEALTH REPORT

Continuing with this project’s focus on common mental disorders, I completed an abstract review of published studies on common mental disorders in the African region between 2000 and 2010, using the ISI Web of Knowledge database (which accesses sources from Web of Science, Biosis, Medline and Journal Citation Reports databases), which I detail in figure six above.

Based on this search, 16 articles discussing CMDs were published between 2000 and 2003 from the region. However, between 2004 and 2009, a total of 98 articles were produced, signalling a six-fold increase over a five year period. This review highlights not only the level of influence of this report in African regions, but potentially, how the approach to research in the field of mental health taken by global actors like the WHO, skews the development of studies towards the inclusion of only one dimension of experiences with mental health: the biomedical/epidemiological.

For example, the flurry of activity that occurred between the years of 2003 and 2010 in African countries was epidemiological in nature and exposed high levels of undiagnosed CMDs and other psychiatric illnesses in general populations. Country-level findings identified a lifetime prevalence of any psychiatric disorder (most often of the CMD variety) that was at 30% in South Africa (Stein et al., 2008). Corresponding reports on treatment access was bleak, with 25% of individuals having received treatment for the same disorders (Seedat et al., 2008). These findings successfully highlight the epidemiological attention given to the

issue within the country, but also present a challenge for the actors who now seek to respond: we have a great understanding that there *is* a gap between need and available medicalised resources, but know very little about how communities live with and through this experience, and thus, very little about how best to orchestrate a response.

In late 2007, the leading medical journal *Lancet* published a six piece series focused on empirically documenting the paucity of attention on mental health around the world (Saxena et al., 2007), as well as the importance of mental health as a public health concern (Prince et al., 2007). The five main articles in this series discussed issues such as: the relationship between mental health and other health issues (ibid.); inequitable access to resources (Saxena et al., 2007); treatment and prevention – situated within traditional health promotion models of increasing information and awareness of biomedical categories (Chisholm et al., 2007; Patel et al., 2007); under-staffed and under-resourced mental health systems (Jacob et al., 2007); and barriers to medical treatment and service delivery in low and middle income settings (Saraceno et al., 2007). The *Lancet's* concern with these issues is united by a desire to create systems where psychiatric services can be delivered in settings akin to those in the western world. Unsurprisingly, their discussions give little credence to how mental illness is conceptualised by the communities they seek to extend services to, or to the mechanisms that respond to well-documented influences of societal factors in expressions of mental distress.

In 2008, the Movement for Global Mental Health (www.globalmentalhealth.org) was launched in direct response to the *Lancet* series, 'Call to Action'. Spearheaded by many of the same academics who contributed to the *Lancet* series, the Movement has 90 institutional partners worldwide. It aligns itself very closely with the WHO's guidelines and many of the same actors who work within the MGMH group are also involved with the WHO's mental health directorate.

The MGMH and its partners currently stand poised to influence the manner in which mental health is addressed around the globe, shifting uniformly towards the scaling up of biomedical supports, and delivery of mainstream services to communities. In 2011 and 2012, additional special issues in the *Lancet* (Eaton et al., 2011) and *Harvard Psychiatry Review* (Patel, 2012) were produced. These collections affirmed the direction of the movement's plans for engagement with community members in local contexts, focusing primarily on task shifting- previously defined as the training of community volunteers to deliver psychological, psychiatric and psycho-educational programmes (ibid.).

Global movement pioneers Vikram Patel and Martin Prince (2010) recently outlined three pieces of evidence that have contributed to the advances seen in the field of global mental health in the last decade: 1) epidemiological research that has highlighted the burden

of mental disorders around the world; 2) effective drug and psychological treatment packages that are available and deliverable; and most importantly, 3) a body of cross-cultural research that dispels the myth that mental disorders are a figment of a 'western' imagination, and remain real and valid experiences to people all over the world. They assert that in light of these factors, the time for action is now, and they speak of the movement's role as activists who

...recently called for a special session of the UN General Assembly or for a summit on mental health—which may prove to be a fruitful way of galvanizing the global community, from donors to governments, to act on the evidence that we already possess (Patel, 2012, p.10).

The implications of this activity in framing global discourses on distress, and in shaping responses to socially embedded and HIV-related emotional distress in developing country contexts, must be considered. Contemporary critical psychiatrist Derek Summerfield has extended the concerns raised by critical theorists presented in chapter one within his critique of the field of global mental health. For Summerfield (2004), problems with psychiatric practice more broadly stem back to the European Enlightenment and the field's attempt to assess human pain, misery and madness via standardised terms subject to expert opinion. For him, the resulting mental health industry can only function based on the contingency that people believe that emotional experiences such as bereavement or sadness require professional intervention.

While much of his work originated in the critiques of the validity of a PTSD category cross-culturally (e.g. Bracken, Giller, & Summerfield, 1995; Summerfield, 2001), his general concern with the field of global mental health resides in the tendency of western models of mental distress to medicalise daily life experiences. He openly questions the value of labelling as a disease the emotional repercussions to a life in stressful situations (Summerfield, 2008; Summerfield & Veale, 2008). His concern is that in fragmented and unequal societies, the medicalisation of a natural response to human suffering reduces the remaining outlets for communities to expose the impacts of living under poor social conditions.

For Summerfield, then, mental health emerges as a concept similar to those of Ingleby (1980) and Keyes (2000), where states of mental health are optimised in situations where people experience 'a sense of social connectedness within a coherent social world'(Summerfield, 2012). In contexts marked by poverty and social inequality he asserts that many common mental disorders, in particular the ones that assume the greatest attention within the global movement (depression, anxiety), are better viewed as reactions to negative social circumstances (Summerfield, 2001). Summerfield argues that there is an

urgent need for the development of an 'ecologically valid' evidence base to inform mental health service provision in many low and middle income contexts, in the interests of developing conceptualisations of illness and strategies for healing that resonate with local worldviews and realities, and to build on indigenous strengths and support systems (Bracken et al., 2012).

This thesis seeks to answer his call to arms, by contributing to the establishment of ecologically and locally relevant bodies of evidence that can potentially promote efforts at engagement of communities within a global movement for mental health. It is the hope that arguments developed in this thesis can contribute to shifting the scales in favour of new lines of evidence in planning for mental health services and promotion efforts. Current efforts being tested within the global mental health field remain dominated by the biomedical model, and have seen only limited success. In an intervention trial exploring the efficacy of antidepressants in Ethiopia, Mogga and others(2006) reported that on follow-up, 26% of individuals with major depression at baseline met the criteria (based on DSM-IV standards) upon re-testing. In attempts to explain this finding, the authors clearly state limitations to the assessment tools used, but make no attempt to acknowledge the importance of accessing patients' subjective experiences of depression as a valid measure of distress and efficacy of response.

Mental health promotion efforts in South Africa currently prioritise secondary level promotion: the treatment or reduction of severity of cases of mental illness (Petersenet al., 2012). This includes coordinating awareness about mental health disorders in the general population, in an effort to target stigma (Kakuma et al., 2010); and articulating evidence for increasing access to cost-effective drug therapies to patients in resource poor settings (Seedat et al., 2008). A review of the primary care plan for mental health services (see figure 7 below) indicates that community is namely targeted through psychoeducation and community outreach.

Psychoeducation efforts follow a similar emphasis on the biomedical. A 2008 study piloting a psychoeducation programme for patients with depression focused on issues relating to understanding depression, the need to take medication, presenting depression as a widespread problem, and information on the possible side effects of medication (Seedat, Haskis, & Stein, 2008). There are relatively few rural community outreach programmes focusing on these efforts. One currently includes programmes delivered by the South African Depression and Anxiety Group. The use of speaking books, an innovative adaptation developed by the group in 1999, as part of support groups, deliver information about the particulars of common mental disorders such as depression, in an attempt to normalise these categories and provide information on accessing support for these issues. However,

even their efforts have been linked to biomedical paradigms that limit the space for strategies to respond to patient distress (Burgess, 2012).

TABLE 2: REFERENCES TO COMMUNITY IN KEY SOUTH AFRICAN PROVINCIAL AND NATIONAL MENTAL HEALTH POLICY

Document (year)	Aim of policy/document	References to community
South African mental health care act (2002)	Integrates MH services into primary health care services Seeks to clarify rights and obligations of MH users; establishes 72 hour observation points (district level care)	Focus: service user community – references to their right to care, right to refuse care Additional references to community: access to community care; services to promote integration within community (p. 8-9, 12)
Strategic implementation plan for delivery of mental health care services (KZN 2003)	Outlines how national policy is to be implemented at local level; outlines framework for delivery of care (see figure 13, chapter 7); seeks to attend to continuity of care across service levels with attention to community level actors	Focus: Community level actors are identified as: family members, community based organisations, NGO, community leaders (including traditional healers and faith healers) Suggested roles: promotion of mental health; referral to primary health clinic as is appropriate; support to mentally ill and their families; monitoring of compliance; implementation of home based rehabilitation and social integration (p. 11)
Standard treatment guidelines for common mental conditions (KZN 2006)	Delivery of psychopharmacological interventions for common mental disorders most often seen in primary care/psychiatric practice Disorders identified: schizophrenia, depression, anxiety, phobia disorders, substance abuse disorders	Focus: ‘Remember the person’: attention to side effects of medication, providing access to counselling supports (cognitive behavioural therapy - p. 11)
Policy for mental health psychosocial rehabilitation (KZN DoH, 2010)	Introduction of a comprehensive psychosocial rehabilitation programme to support mental health care users to optimise their quality of life	Focus: Attends to ‘social’ needs of patients by addressing mental health care users’ rights to vocational and life skills, training support

South African approaches to the involvement of community actors for mental health promotion and treatment align with global movement and international recommendations, arguing for multi-disciplinary teams to ensure the inclusion of alternative voices in mental health treatment and support programmes (WHO, 2010). A critical review of key mental health documents employed at the national and provincial levels identifies a series of ambiguities and vagueness surrounding references to community within said documents. Table 2 presents a summary of four key policy documents identified by formal mental health

service actors as critical to daily practice during my motivated ethnography (see chapter four for a full description of this methodology).

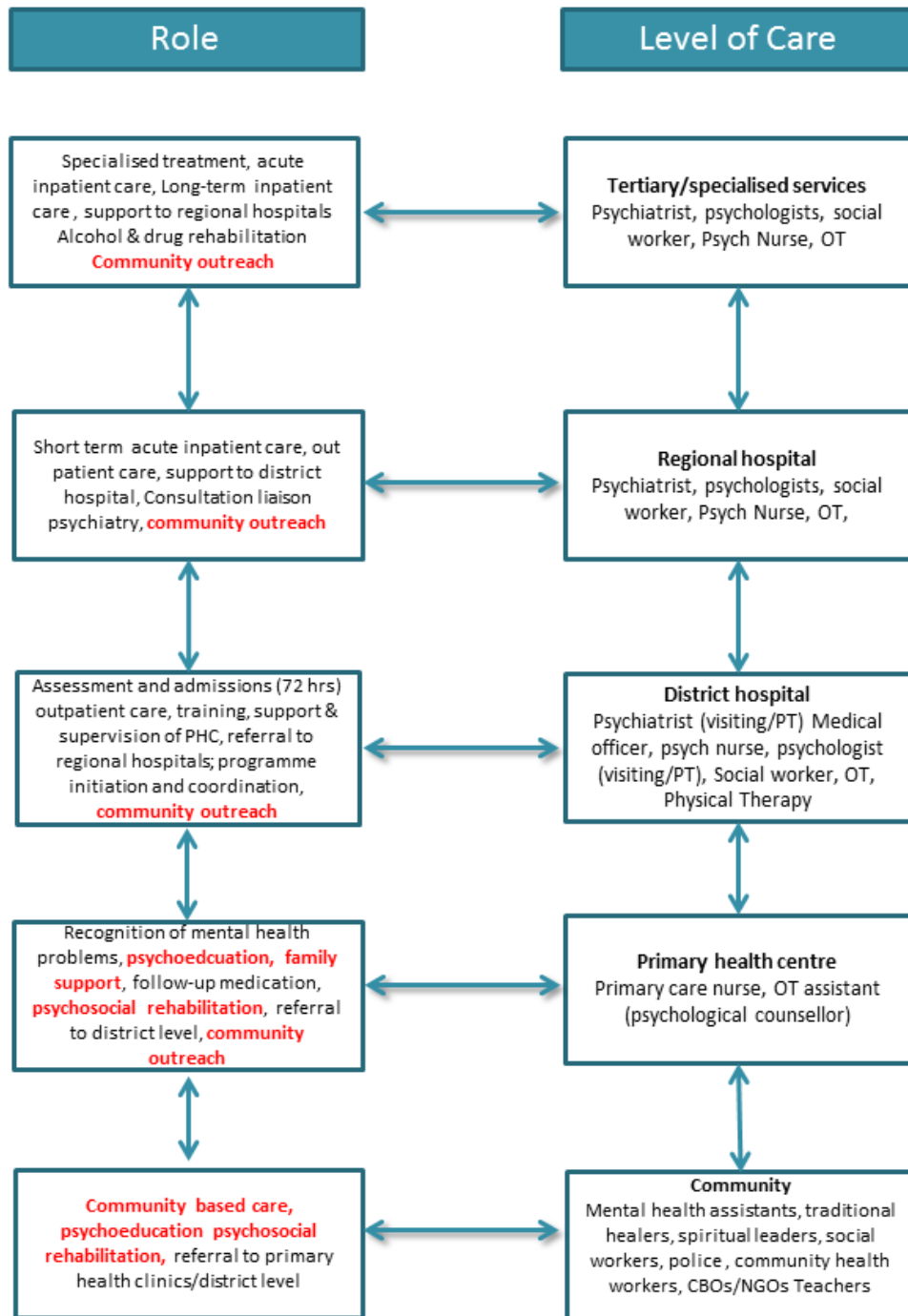


FIGURE 7: REFERENCE TO COMMUNITY IN PRIMARY MENTAL HEALTH CARE SYSTEM ADAPTED FROM DEPARTMENT OF HEALTH (2003)

In unpacking these documents, references to community and attempts to recognise aspects of the 'social' emerge. For example, the community 'level' of care is a central pillar of provincial implementation guidelines (KwaZulu Natal Department of health, 2003), and the psychosocial rehabilitation programme identifies the importance of social needs (such as employment and housing) in the lives of mentally ill patients.

However, these references oversimplify societal issues and ideas about community. The primary role outlined for community actors is related to the support of biomedical services: supporting compliance, promotion, and referral to 'appropriate' mental health services within biomedical frameworks. These actors are not seen as members of equal partnerships, with opportunities to contribute to the design of interventions, or conceptualisations of distress. With regards to the social, none of the aforementioned policies make direct reference to the broader social drivers that are at the heart of living in poor countries, and the ways in which social participation within these resource poor contexts come to bear on the lives of those with emotional distress; a fact that many critical theorists argue as an equally important dimension of the social that receives little attention (Stoppard, 2000; Thomas, Bracken, & Yasmeen, 2007).

The continued inability for less powerful community level voices to be taken seriously in shaping the actual practice is perhaps most clearly evidenced by ongoing barriers to multi-disciplinary efforts at service delivery (Campbell-Hall, et al., 2010; Skeen et al., 2010). This highlights the need for work that can clarify the factors that currently limit the inclusion of community actors, and that suggests ways forward for overcoming these barriers. In their discussion of a similar global-local relationship within mental health of British immigrant communities, Thomas and colleagues (2007) assert that:

Research... has shown that poverty, area of residence, and ethnicity are strongly related to admission rates in psychiatric hospitals. Although it is important to know this at one level, such knowledge says nothing of what it is like to be an unemployed Black or Asian man or woman in England whose daily life experience may be one of racial abuse and social exclusion (Thomas et al., 2007 p 177)...

While this may objectively fall beyond the domains of psychiatric practice, it does not in any way reduce its *relevance* to contemporary practice. In fact, for practitioners who work within socially deprived contexts, the formulation of these understandings about how living in these contexts comes to shape mental health becomes a critical dimension of practice (Kirmayer 2006). As such, I seek to step beyond the limits of previous studies, by drawing on a social psychological approach that enables a much broader dimension of the social which may be the first steps towards a response to calls to identify and promote contexts that support mentally healthy communities.

2.4: THE PROJECT: MOTIVATIONS AND PROJECT AIMS

When I began my journey into the study of Psychology over 12 years ago, I was guided by a desire to develop a greater understanding of how people and societies worked. I was excited by the unspoken choreographies that allow societies to function; how matrices of cultures and individuals with differing views of the world could somehow negotiate interactions; how we were simultaneously guided by understandings that were often as divisive as they were unifying. My personal experience with this dual nature of 'understanding' was all too familiar. I was raised within the boundaries of a culture where the set of rules that defined me as a woman were fairly closed, and yet was consistently pushed to participate in broader circles that called on me to question these boundaries (in particular, in higher education). Over the years, I expended great amounts of energy in trying to re-negotiate these meanings in efforts to make myself, and those around me, 'happy'.

My equally longstanding passion for social change has also been linked to my view of the multifarious nature of knowledge and how understandings of the world can empower or limit actors in social contexts. For example, in my work with marginalised groups such as people affected by HIV/AIDS or patients with mental health conditions, I witnessed the double edged sword of knowledge and its role in the experiences of such marginalised communities. The knowledge created by, for example, a diagnostic category or illness label provided by the biomedical community, could comfort as well as hinder, simultaneously leading to a range of social consequences at the hand of stereotypes, stigma, and negative representations that circulate within society and ultimately maintain marginalised states of being. Over the years, a commitment to supporting marginalised communities, and challenging the understandings that limit their participation, have become the primary motivators behind my work as a critical social psychologist and many of the theoretical and methodological approaches used within this thesis. I am an academic researcher with a passionate commitment to social change, and see research as a vehicle to help support local efforts of those who work at the frontlines of responding to failed social worlds and conditions of ill health.

When I arrived in South Africa in 2008 to complete an internship at the Health Economics and HIV/AIDS Research Division (HEARD), my interests in the relationship between HIV and mental health had already begun to take shape. My plans for my pending doctoral research were linked to the general topic area of mental health and HIV, and a desire to examine it from a perspective that was linked to a more grounded understanding of what it meant to 'live' with these conditions, in a vein quite similar to critical approaches to mental health described in chapter one. I believed that a work anchored in much broader

perspectives of well-being and 'mental ill-health' could contribute to a body of literature dominated by biomedical and epidemiological perspectives that limited the reach of patient voices. Around the same time, colleagues at HEARD were planning a national survey exploring the paired health outcomes of AIDS-affected families – specifically, HIV positive or negative caregivers and their children. A primary focus of the survey was on mental health outcomes, specifically symptoms relating to depression, anxiety and PTSD as defined by western and international psychiatric diagnostic categories. My colleagues approached me with the idea of linking my PhD project, which was interested in mental health services, to this survey. It seemed like an ideal arena for collaboration on the topic of mental health that could actively join two perspectives of the mental health puzzle, namely the biological and the social.

The survey constituted an exploration of mental health needs in a manner typical of mainstream health service research: epidemiological studies that index the need for services in the general population via positivistic approaches that reduce complex experiences to quantifiable measures (Bowling, 2009); a reduction that unfortunately removes from the diagnostic and treatment process the understandings associated with the experience of living in worlds that cause emotional distress.

The survey's symptom driven approach to defining mental well-being presented a partial picture of how local communities experience mental health and less on how they dealt with challenges of distress. Findings from the survey would provide sound evidence to argue for increased human resource commitments to the mental health service sector, which has been described as a crux to the success of a movement for global mental health. Beyond this however, the survey could not identify what role communities could play, or were already actively engaged in, to promote their own mental health. An alternative perspective to the issue was much needed, and I imagined that my background as a critical social psychologist provided an ideal avenue to engage in a grounded study of community mental health services.

My empirical and practical approach to working with communities for the purposes of improving health is best described within the frame of a social constructivist perspective. My stake in this perspective aligns with that of Lock and Strong (2010), who view social constructionism as an umbrella term, organising key tenets that may be applied across a range of epistemological perspectives - including societal approaches to phenomenology, sociology, and social psychology - all concepts that are interwoven throughout this thesis. First, they suggest that social constructivists are concerned with meaning and understandings as the central feature of human life. Humans are believed to exist within

complicated societies that are governed by our ability to interact with one another – interaction enabled through shared meanings.

This leads to the second tenet that embeds meaning and understanding in social interaction that is mediated by these often unconscious shared agreements about symbols that allow us to understand one another. Third, Social Constructivism postulates that ways of formulating meanings are inherently embedded in socio-cultural processes that are specific to cultural, historical and geographical contexts. Fourth, it proposes that people are socially constructed participants in their lives and, in many cases, *of* their lives. The latter emerges as most important, as it affords individuals to be recognised as agents in shaping their lives. This process of construction is handled in relation to the contexts that communities are embedded within; contexts that will ultimately limit or support the level of co-construction. Finally, attention to alleviating the limitations presented by certain contexts is linked to a commitment to a critical approach to the topic in question. In short, it is an approach that champions a revelatory process that identifies the negative implications of contexts, and proposes ways to tackle them.

These tenets emerge within my work as a critical community social psychologist and weave throughout this thesis. As a critical social psychologist with interests in community health, I am committed to problematising the spaces where health is lived (Guareschi & Jovchelovitch, 2004): the communities where people live, work, and engage in practices that determine health outcomes. In the process of this problematisation, I recognise context as crucial, and approach the notion of community as pluralistic – assuming that people will often claim membership to a range of typologies of community at any given time, given their symbolic nature (Cohen, 1995): communities demarcated by geography, class, race or ideology; all of which come to play a role in health outcomes. The social constructivist perspective outlined above similarly sees these communities as integral to defining not only who an individual is, but how they understand and live within their world. This is also a primary tenet of many social psychological investigations.

At the outset of this work, I diagrammatically presented the mental health service sphere as a system of interacting communities. First to consider are the community members who will make use of mental health services. For the purposes of this study, this community is constituted of women affected or infected with HIV/AIDS, and who manage a series of social challenges, including abject poverty and complicated familial contexts, as part of their daily existence. I have presented the relationship of these factors to poor mental health outcomes in earlier sections of this chapter. It is not sufficient for these contexts to be simply identified vis-a-vis epidemiological studies. These women will undoubtedly be shaped by their experiences of these contexts, in ways that will come to influence their

understandings of mental health, and ultimately, decisions made about the types of services they seek. Treating these contexts as crucial involves carrying our understandings of them across the scope of an investigation into mental health services designed on behalf of the community. Furthermore, it presents a key contribution of this work to the field of critical mental health of AIDS-affected communities.

Secondly, a collection of primary mental health care practitioners should be considered. Within contemporary notions of 'community' mental health using a primary care model, practitioners actually traverse multiple groups of actors who work across different levels of care within collaborative roles, and could include representatives from the church, NGOs and traditional healers. Their understandings of mental health may reside within similar realities of daily life and context, and they are envisioned as working in partnerships with formal medical services, and with the corresponding policies that inform practice. Formal medical practitioners are driven by a knowledge system that, by and large, is informed by many of the biomedical perspectives outlined in chapter one. How practitioner knowledge is actioned will also be shaped by the day-to-day realities associated with supporting mental health in deprived settings. Thus, in understanding contemporary community mental health systems, attention to context is crucial.

The location of this study, KwaNagase (Manguzi), is an ideal setting for such an exploration. Located in a typically rural South African setting, it presents a picture of both the contexts of HIV/AIDS, and the paucity of formal mental health services that shapes much of the country. Many of the dominant voices in the South African mental health field are closely linked to global actors and global academic and policy networks (Jacob et al., 2007; Lund et al., 2008), and it is likely that domestic efforts to reduce service paucities will continue to be influenced by this global discourse. Such a situation is cause for concern among contemporary (Summerfield, 2008; Watters, 2010; Thomas & Bracken 2004) and historical (Ingleby, 1981; Kleinman, 1988; Nell, 1994) critical theorists in the field of mental health, who point to: (i) the inability for positivistic biomedical paradigms to capture the wider social contexts that frame mental health and illness in marginalised settings; and (ii) their top down imposition of biomedical models of illness that are often at odds with the experiences and life world of patients. Such critiques point to the need to problematise the delivery of services based on biomedical/psychiatric paradigms in developing contexts, and how service use may be shaped by competing knowledge about mental health and well-being on a daily basis, as well as the complexities of community.

Our current understanding of these multiple perspectives is fairly shallow to date, particularly regarding service users in lower income countries, as existing studies provide only a partial picture of the experience of communities experiencing mental distress. My

study seeks to address this paucity through an empirical investigation that first, explores the knowledge systems that circulate about mental health within Manguzi, and how these are enacted by the groups of actors associated with mental health services. By taking an interest in the intersection of multiple understandings that converge within a shared space (such as that of service delivery), this work will also seek to highlight potential avenues to promote community members as more engaged and recognised actors within the space of community mental health services - hitherto absent from discussions of 'community' mental health. I will do this through a social psychological study of knowledge, in order to remain anchored to the ways in which social life and community contexts shape understanding, and how social life may also mediate mental well-being.

This is critical in supporting the burgeoning challenge to dominant views of mental distress, which continue to position biomedically faulty bodies as the locus of intervention. By contrast, my own approach takes as its starting point the assumption that these bodies are simultaneously located within the social contexts that provoke mental distress. I do so in order to argue for the importance for mental health services to take account not only of individual and biomedical factors, but also the social drivers of mental ill-health and the mitigation of the impacts of adverse social contexts as part of holistic approaches to mental health. A particular focus will be paid to HIV/AIDS related emotional distress as part of this picture. This will allow me to contribute to a better understanding of the requirements for HIV/AIDS related mental health services that acknowledge the realities of managing HIV and mental distress in socially disparate conditions.

This project will seek to tackle a series of research questions to achieve these aims, and ultimately, conclude with suggestions for the development of a framework to promote mental health and well-being that takes forward the capabilities of community members themselves, supporting their ability to capitalise on the available support systems - both medical and social- within a community. These questions are as follows:

- 1) *What are the contexts that frame people's experiences of mental health, illness and the delivery of support?*

Considerations of context are crucial to critical studies of mental health and mental health services. Current understandings of context have been generated largely at an epidemiological level, and successfully identify a list of factors related to mental health outcomes - however, these discussions of context remain flat and directed at identification and categorisation. In an effort to provide a more dynamic picture of the contexts that shape mental health, and highlight how contexts are inseparable from the experience of mental health, this thesis addresses the first research question through an ethnography of the

Manguzi community. This empirical chapter (chapter five) portrays a rich and complex picture of daily life, and how mental health issues emerge or are attended to within it.

- 2) *How do Manguzi women understand mental health in socially deprived and AIDS-affected communities? How are these understandings framed by everyday community contexts? How does this knowledge shape the processes used by women themselves in responding to mental health-related challenges?*

These questions are addressed within chapter six, and begin with a picture of mental health in the everyday. By looking at the life experiences of women, and how they make sense of their emotional distress, the analysis begins to identify some of the processes that link the realities of contexts of community, to the local understandings, experiences of and responses to mental distress.

- 3) *How do primary care mental health service actors conceptualise and respond to mental ill-health in their communities? How does the primary mental health system respond to women's mental distress? Do the actions of primary care services operate in ways that open up or close down opportunities for women to exercise agency in relation to their mental health?*

To answer these questions, chapter seven engages with an analysis that explores the understandings about mental distress that are used by a range of individuals who emerge as 'service providers' within Manguzi. It attends to the roles that understandings of the 'social' and community play within professionals' own accounts of the nature of the problem facing women in Manguzi, and how they actively respond to mental distress in light of these understandings.

- 4) *How can primary mental health services develop more health-enabling engagements with communities in an era of global mental health? Are HIV-specific services needed?*

In answering this final question, chapter eight reflects back across the previous empirical chapters to identify a series of potential markers for the promotion of mentally healthy communities. This concluding chapter unifies the smaller aims of the thesis into an overarching goal to provide descriptions that go beyond the generation of a list of 'protective' factors, seeking to consider 'protective processes' that emerge in efforts to promote or hinder the establishment of mentally healthy communities. In doing so, this chapter does not negate the contributions of existing efforts to support mental health in communities like Manguzi. Instead, it attempts to provide a series of modest recommendations stemming from findings from this thesis that point to additional routes to supplement existing policy and intervention efforts to support women like those at the heart of this thesis.

CHAPTER CONCLUSIONS

The South African context presents an ideal case to explore the way in which cultural and, to a lesser degree, social domains for understanding mental health converge on communities with mental distress. In the multi-disciplinary approaches desired by mental health policy in the country, notions of community are handled in cursory ways that do not speak to the complexities of 'community', nor appear to establish spaces to acknowledge and support pre-existing resilience. Instead, there is a much heavier focus on 'community' as a location for the delivery of services, with attention to the potential for community level actors to participate in the delivery of biomedical services, rather than viewing them as co-constructors and co-designers of services to promote mental health and respond to distress. It follows that in order to design services that best reflect the varied needs of socially deprived HIV/AIDS-affected communities, there is a need to further problematise the worlds where mental health is lived, and how these perspectives and understandings of mental health are formed. To do so, I will use a theoretical approach that utilises a socially grounded perspective of knowledge and understandings, as well as a cognisance of the interactivity between the person – as both biological and social being – and their lived worlds. I have alluded to the importance of knowledge throughout this chapter, and will take this up more seriously in chapter three, through an exploration of theories that will guide this work.

CHAPTER THREE: UNDERSTANDING, MANAGING AND TRANSFORMING COMMUNITY MENTAL HEALTH- THEORETICAL CONSIDERATIONS

This chapter will provide a framework for exploring the ability of community mental health services to establish health enabling environments in the contexts of social deprivation and HIV. The research questions presented at the end of chapter two are oriented towards the exploration of how subjective understandings of, and responses to, mental ill-health are influenced by facets of community, and the convergence of knowledge systems about mental health within a community.

This chapter begins with the development of a model of community that assumes and engages with complexity of context. I identify key perspectives of community that enable this end, such as community demarcated by place and symbolic space. In discussing place, I refer to the structural facets of a given location, such as geographical boundaries, institutions, and political and economic realities. Symbolic spaces refer to cultural practices and psychological phenomena such as identities or systems of knowledge - which define engagement with structural contexts. I argue that these perspectives cannot be considered in isolation, and the acceptance of their intersections enables a more accurate understanding of how community mental health can be delivered, and result in the transformation of states of emotional distress. This expands on the range of insights provided by the current bodies of mental health evidence that are largely epidemiological in approach, that focus primarily on the identification and categorisation of knowledge systems about mental ill-health in isolation from each other (rather than explore the realities of their intersections), and which view community in single dimensional ways.

In accessing dimensions of community of place and symbolic space, I draw on the notion of the 'life world', a concept initially developed by societal phenomenologist Alfred Schütz (Schütz & Wagner, 1970), and which later informed Arthur Kleinman's efforts to infuse greater inter-subjectivity in cross-cultural psychiatric practice.

In the second section of this chapter, I argue that by considering knowledge as a symbolic space within communities, we can better engage with how it is impacted by both the 'place' and 'space' aspects of a community. This is enabled by drawing on Social Representations Theory (SRT), a perspective that positions knowledge and understandings as a lens used to view, create, mediate and govern relations and social practices within everyday community life (Howarth, Andreouli & Kessi, 2013). This perspective allows for a mutual focus on the importance of various contextual realities in shaping understandings and action. I will argue that the perspective allows for a discussion of community mental health services to also open insights into how certain contexts fragment social worlds and lead to experiences of mental distress, which once elevated to our attention, can become the new targets of public health intervention.

This chapter concludes with a discussion of the social psychological tools needed to enable the ‘transformation’ of mental health – which as stated earlier, refers to the ability for community members to capitalise on opportunities to engage with both the causes (structural and symbolic) and symptoms of distress in treatment spaces. These theoretical elements illuminate how symbolic spaces of community – i.e. knowledge systems – can be targeted to promote more holistic and effective interactions within community mental health services, to promote ‘mentally healthy communities’.

3.1 IN SEARCH OF A SOCIAL PSYCHOLOGY OF MENTALLY HEALTHY COMMUNITIES

This section begins with a focus on the notion of community, to support the ultimate aim of this work: to formulate suggestions about support structures communities need to maximise their mental health and well-being. How community is defined will shape how we apply theories of knowledge to generate understandings of mental health, and as such, expanding the scope of community creates opportunities to highlight dimensions of community life that are important to supporting people in transforming their emotional and mental distress.

3.1.1 WHAT IS A COMMUNITY?

The notion of community is highly complex and a point of interest in many perspectives in the social sciences. A vast literature from anthropology, sociology and political sciences focuses on community across a plethora of dimensions: community bounded by location – such as a town or country; culture – relating to practices or ideals shared by a group of people such as African American groups (which may simultaneously represent community bounded by race); or ideology, such as religion or political positions. I clarify some of the typologies of community in Table 2 below.

Definition	Type of community
Community is an area that shares a geographical space, living/interacting on a frequent and supportive basis	Place (e.g. village community)
Community is a group of people who share a common history and set of beliefs	Religion (e.g. Muslim or Christian community)
Community is a group of people that share a common experience –for example exclusion or discrimination imposed by a wider society	Race (e.g. Black community)
A community is a group of people that share a common set of practices or traditions that govern daily life	Culture (e.g. Zulu culture)

TABLE 3 – NOTIONS OF COMMUNITY. ADAPTED FROM HOWARTH, 2001

As aptly noted by Caroline Howarth in her call for a Social Psychology of community:

...communities are highly contested social phenomena. We argue over them, we claim the right to speak for them... community conflicts make up the terrain of the assertion of identity, meaning, value and loyalty in our local-global age...we find that community is not a latent abstract concept; instead we find communities that give our daily practices, our political difference and understanding of ourselves significance (Howarth, 2001, p.1)

What is most interesting about the concept of community is perhaps the ability for individuals to hold multiple ‘memberships’ at any given time. The ability to conceive of this plurality is facilitated by the notion of community as symbolic, which is aptly handled within the work of Alexander Cohen (1985). In trying to elevate discussions of community from a level that

prioritises taxonomies and structural dimensions (consider the popularisation of Durkheimian logic of community as a collection of social facts that determine actions of individuals, or a positivist position that dominates health contexts and treats categories of community as something to be 'controlled' for), to one that promotes experience and meaning, Cohen asserts that phenomena such as culture (and potentially many of the dimensions identified above in Table 3) are important because they enable us to highlight dimensions of community that crystallise the importance of 'meaning'. Throughout his work *The Symbolic Construction of Community* (1985), Cohen provides a series of case studies to highlight that 'community can no longer be adequately described in terms of institutions and components, for [we] now... recognize it as symbol to which its various adherents *impute their own meanings*' (Cohen, 1985, p.74 - emphasis added).

In one such case study he highlights this fact in a description of Mbuti pygmies and Bira villagers in the Ituri rain forest of Zaïre. He describes these groups as divided along diverging ideologies of existence: the former governed by notions of social harmony, oneness with nature and a platonic sense of place and duty; while the latter is driven by hierarchical structures, superstition, and 'repositories of disharmony of noise and crisis' (ibid., p.95). However, they remain bound together by location and more interestingly, a shared cultural initiation ritual. For Cohen, the ability for these two polarised groups to engage in a shared ritual practice was enabled by the ability for each group to interpret these practices in ways that varied in line with their ideologies. In this example, Cohen highlights multiplicity in meanings as a vehicle through which a single dimension of community may achieve plurality. If community is constituted via meaning, then it is through these meanings that someone can hold multiple memberships, deriving meaning from each relationship, or dimension to suit a particular purpose. The plurality of 'communities' is precisely what makes it of such keen interest for social psychological investigation. In Howarth's (2001) extrapolation of a 'social psychology of community', she asserts that *communities* rather than the notion of a singular community are important to consider, and it is through applying a social psychological lens that individuals emerge as social beings who are constantly engaged in the process of belonging to, and being in, communities, to develop senses of self, individuality and commonality.

3.1.2 COMMUNITY MENTAL HEALTH: ATTENDING TO PLACE AND SYMBOLIC SPACE

For the purposes of this study, the notion of community assumes importance on two platforms: community as place and community as a symbolic space.

Firstly, because I am interested in informing policy around community mental health services, a position that considers community as 'place' is vital: a shared geographical space where the delivery of mental health supports vis-a-vis the formal health sector can be

coordinated. This approach could be accused of disregarding much of the advances in theorising community that lie at the heart of work conducted by Cohen, and more contemporary theorists of community such as Howarth (Howarth, Foster, & Dorrer, 2004; Howarth, 2001) and others (Anderson, 2006; Urry, 2007). These researchers assert that it is through a focus on the symbolic and relational dimensions of community that we are able to form better understandings of how community is experienced by those who constitute it, and ultimately, think more effectively about ways to mediate harmful dimensions of community.

Why then, do I seek to retain this particular notion of community as part of this study? From a pragmatically relevant position, communities bounded by space are inescapable within health service studies. Services are allocated within health districts, and practitioners are allocated to regions based on levels of population within a geographic community. Furthermore, a priority issue for the Grand Challenges for Global Mental Health seeks to determine how to provide effective community level services (Collins et al., 2011), a desire rooted within a similar perspective of community. In order for this work to contribute to the discourse that advocates for the shaping of these services, a similar perspective must be taken within this study. Furthermore, one cannot negate the influence of poverty on mobility within rural settings. Rural communities of place, such as the one at the heart of this thesis, are sites where many of South Africa's poorest remain at the mercy of shifting agrarian, informal or state subsidised economies (Neves & Toit, 2013). How such place based realities impact on mental health outcomes must remain at the heart of our attention.

In South Africa, the emphasis on community as place with regards to mental health services is driven by a primary care approach. Country level plans for community mental health services operate through a district health system, with a hierarchical structure for services and referral hinging on cooperation between various actors who work within a community demarcated by space (see figure 7 & 8).

However, within this structure the complexity associated with considering community solely as 'place' emerges. Ultimately, we see that for 'community' mental health services, we include a range of actors: traditional healers, social workers, primary health/remote clinics, district level hospitals, and a range of additional actors that play a role in the promotion of mental health.

**FIGURE REMOVED DUE TO
COPYRIGHT REASONS**

Figure 8: Framework for community mental health services in South Africa (Source: Mental Health and Poverty Project, 2008)

The issue here, as acknowledged by many critical theorists, lies in how each of these social actors makes sense of the problem of mental distress. For example, the meaning of an illness experience, marked by the same set of symptoms or behaviours, will be interpreted from varying perspectives within a mental health service sphere. A woman may consider her symptoms as a problem insofar as they limit her ability to participate in community life (bringing structural issues such as poverty into play); while a traditional healer will be interested in the same set of symptoms insofar as they highlight a dysfunction between the spiritual and social realms of an individual's ancestral lineage (bringing symbolic systems into play). Conversely, an occupational therapist will be interested in the same set of symptoms insofar as they allow a differentiation between physical or emotional dimensions of patient need. Finally, a psychiatric nurse or doctor will be interested in the same set of symptoms to investigate how well they map onto a particular disease category.

It thus becomes crucial to consider mental health service spheres as the meeting space of *communities*, containing multiple understandings, as acknowledged by the work of Kleinman (1980) and Swartz (1998). However, Kleinman's argument in particular, falls short in its consideration of how effectively all of the groups may participate within this space. There is a clear acknowledgement that supporting patients requires a commitment to understanding the world that patients inhabit (and in Kleinman's case, a particular emphasis on the cultural notions of that world). However, there is an absence of consideration of how the interaction between actors in a treatment space opens or closes spaces for patients to participate in or promote their own well-being. Current perspectives align interests in patient participation insofar as they are able to adhere to a particular treatment plan, designed by a practitioner.

Overlooking the problem with participation is likely enabled by a focus on improving biomedical treatment, or as Swartz recently argues, issues with pragmatics of treatment and care (Swartz, 2012). However, I suggest that this oversight may also be linked to Kleinman's (1988) assertion that actors are grounded in *different* social realities which would constitute and accept the presence of different understandings of a shared object of concern. However, it could be argued that the social reality or life world of social actors is shared, as Schütz contends that actors have:

a common surrounding to be defined by [a] common interest... To be sure [they] will have a different knowledge of the common surrounding, if for no other reason than that [one] sees it from 'there' and everything that [other] seeing from 'here'. Nevertheless, [one] may, within this common surrounding and within the zone of common interest, establish social relationships with the individualized other; each may act upon the other and react to the other's action... the other is partially within my control, as I am within his (Schütz, 1964, p.471).

If this is the case, Schütz gives all actors equal capabilities to inform action, or for the purposes of this thesis – action in response to mental distress. Despite coming from different points of view or 'zones of relevance', interaction between actors is promoted by a common stock of knowledge which in this case is the shared life world – creating opportunities for social actors to inform and shape the actions of one another.

In an effort to account for issues created from the convergence of intersecting communities, I propose a modified approach to considering community mental health services, depicted in figure 9 below. *Community as an interactive space* provides an improved picture of the ways in which successful mental health services rely on the interactions between a plethora of actors with varying perspectives on mental distress, appropriate response, and varying ability to direct that response. In revisiting figure 1 (reproduced below), the addition of text boxes highlight the complexities of these spheres with specific reference to Manguzi, the community of *place* considered in this thesis.

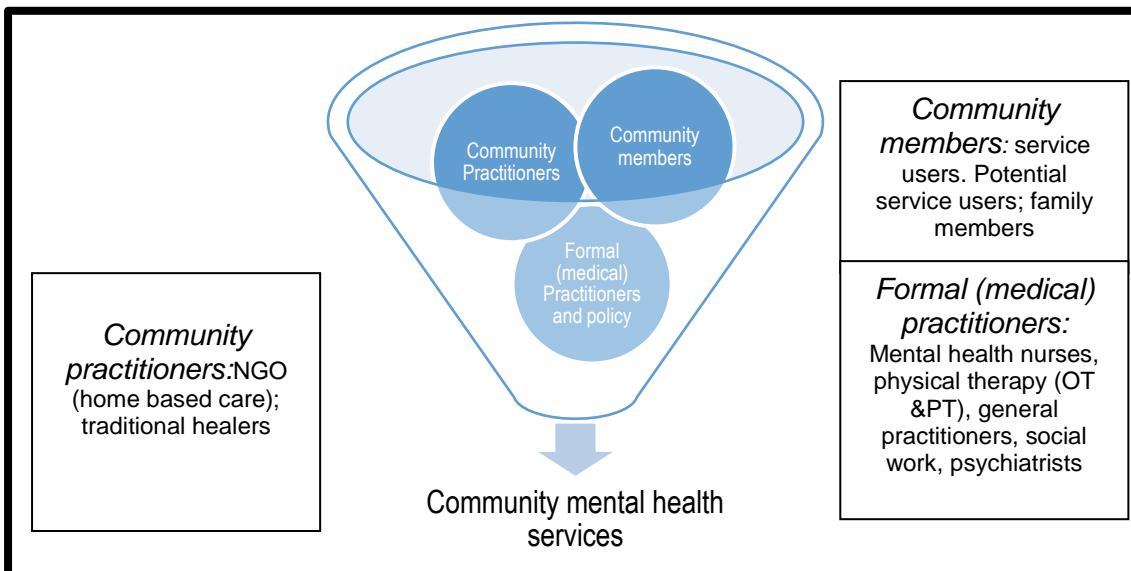


FIGURE 9: COMMUNITY MENTAL HEALTH SERVICES AS AN 'INTERACTIVE SPACE'

In this figure, overlapping communities remain bounded by a contained common place (symbolised by the container that houses the three groups). This is crucial, not only to facilitate service delivery, but also in order to account for the social and structural realities that will come to influence all 'communities' within the space. In this type of framework, the tangible impacts of poverty, violence, unemployment, poor educational outcomes, and a range of other social challenges that characterise many rural communities in South Africa, are not treated as static variables, or things to be 'controlled' for, but rather, active agents that will shape the lived experience and understandings of all communities within community mental health services. As Summerfield (2008) asserts, it is imperative to acknowledge the ability for fragmented social worlds (Ingleby, 1981) to form the backbone of everyday experience of communities and thus the everyday reality of mental distress.

To account for the importance of these everyday or aspects of 'place' in framing understandings of mental health, I draw on the concept of the 'life world' (Schütz, 1964; 1977) applied by Kleinman in his early efforts to engage with social reality. As outlined in chapter two, the life world is conceived as the horizon of all our experiences: the spaces where experiences gain meaning through personal and inter-subjective processes. It can be taken as both a concrete and meta-physical space where life is lived, impacted by both structural and symbolic factors. To Schütz, the goings-on of the everyday form the essence of the life world, and within it, the pool of common knowledge including norms, practices, laws and institutions that define our actions. This dependence on the 'social' is imperative for forming a relevant and holistic understanding of mental health, as highlighted in the work of Kleinman (1980) and others (Kirmayer & Looper, 2006; Whitley, Kirmayer, & Groleau, 2006). Taking account of the life world provides an opportunity to explore the ability for community to act as a locus of social knowledge (Howarth 2001; Jovchelovitch 2007), and importantly for this study, explore how knowledge and understandings are bridges between

contexts (both structural and symbolic) and action, in ways that shape participation for health and well-being. This has been largely overlooked within global mental health efforts, which are often situated within a discourse that emphasises biomedical forms of understanding about mental health, linking local conditions to biomedical categories, through diagnostic language and tools that obscure how notions of community are lived and come to frame experiences of distress. To reflect the importance of this issue, the first empirical chapter of this thesis is dedicated to mapping the life world of Manguzi as a community of 'interactive space', attending to place-based and symbolic dimensions in the everyday lives of its inhabitants.

Thus far, I have sought to develop a theory of community that takes account of structural and symbolic issues. I assert that through conceiving of community (and related mental health services) as 'interactive space', I am able to embrace the complexity of relationships between contexts, knowledge and action with relation to mental health. This also enables consideration of how a shared social world impacts the activities of multiple community actors convening within community mental health services. In developing this argument, I also alluded to the importance of knowledge as a symbolic space that makes structural issues such as poverty, or symbolic contexts such as cultural norms, 'concrete' through its ability to frame action. To uncover how knowledge forms in light of such concerns requires a perspective that accounts for both structural and symbolic aspects of community life. I turn to this within the subsequent section.

3.2 KNOWLEDGE AS SYMBOLIC SPACE: A SOCIAL PSYCHOLOGICAL PERSPECTIVE

The study of knowledge originates in the ideas of Socrates, and is often parsed along two plains: that which is related to human substance, knowledge of 'lay' peoples, everyday communities, and practices on the one hand; and a 'pure' knowledge, wisdom of a higher domain free from the impurities of those who produce it (objective knowledge), on the other (Jovchelovitch, 2007). With this distinction, Socrates began centuries of debate about the right to own, produce and value knowledge. Spanning the development of theories about knowledge from Descartes to Piaget, we have not escaped our fascination with the notion of what Jovchelovitch refers to as a 'true' knowledge, and its separation from knowledge of everyday life:

For many, the trick behind 'true knowledge' seems to be the progressive detachment of the internal structures of knowing from the subjects and communities... on one hand there is knowledge – objective, rational, cognitive; on the other hand there is life, subjective, emotional at times, irrational... true knowledge, which we achieve after many years of development and study... a platonic/Cartesian knowledge capable of understanding and describing and understanding the world as it is... is usually separated from contexts of everyday life (Jovchelovitch, 2007, p.98).

Within the global mental health field, the above emerges as an inescapable truth. True knowledge is produced by 'science', driven by calls for increased response controlled trials to determine next steps (see Patel et al., 2011) in treatment and care. This science largely produces socially de-contextualised understandings of mental ill-health, while critical voices at the margins advocate for 'life' driven understandings, seeking to draw attention to alternative voices of patients, alternative or lay practitioners and the abilities of traditions, languages, history and power to constitute the frame of reference for people's mental distress.

However, as argued by critical social psychologists (see Campbell & Cornish, 2010; Crossley, 2000), attention to these precise issues are key targets for promoting healthy community contexts, which is a desired aim of this thesis. As such, the relevance of a social psychological approach to mapping knowledge about mental health in Manguzi lies, primarily, in its ability to link understandings of, and corresponding action towards, mental distress to community life in its entirety. In summary, social psychological approaches to knowledge highlight the value of considering what we know, and how we come to know it, and its connection to participation in our social world. In this thesis, I adhere to the social representations perspective, viewed as a type of social knowledge inextricably linked to context, that comes to influence practice and participation within communities (Doise, 1993; Howarth, 2001, 2006c; Jovchelovitch, 2006; Marková, 2000). Within the following section I outline social representations theory (SRT) in more depth, to further our understanding of its contributions to transforming community mental health that take better account of issues of context and complexity in community participation for health.

3.2.1 SOCIAL REPRESENTATIONS

European social psychologists, led by Serge Moscovici, define social representations as the symbolic environments that people engage with to create or restore meanings and understandings about their social worlds. They are considered as the cornerstone of knowledge (Jovchelovitch, 2007) and are contingent on inter-subjectivity or relationship between social objects, self and meaningful others (Marková, 2000) (see figure 10 below).

Social representations are mediated, challenged, constructed, and maintained via collective interactions within and between communities, cultures, and individuals; characterised as being in constant flux, appearing and disappearing, constructed and deconstructed in our lives as they are needed (Moscovici, 1984).

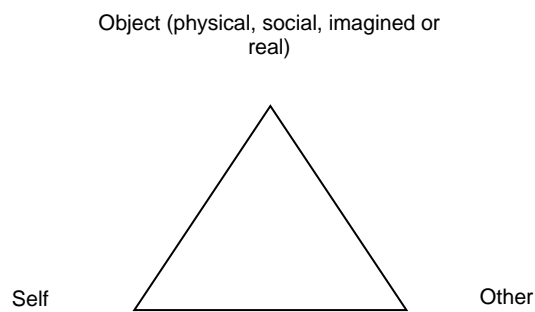


FIGURE 10 – THE INTER-SUBJECTIVE NATURE OF REPRESENTATION (I.E. KNOWLEDGE) ADAPTED FROM MARKOVA 2000

Moscovici's approach sought to expand on Durkheimian logic about representations, which viewed similar social subject matters (i.e. rules that govern and shape our actions) in a more passive domain. For Durkheim, representations are static reflections of how a given collective and uniform group conceives of themselves, are disconnected from psychological or biological laws of a person, and simply emerge within a given society to provide structure (Morrison, 2006).

Moscovici differentiates his position within the acknowledgement of individuals as active participants in establishing understandings. While agreeing that representations are collective (i.e. anchored within and shared by a community), Moscovici's concern with the interactive communicative triad between self, other and society (recall figure 9) assumes that representations are not always 'given', but that individuals co-construct their world through the process of establishing understandings. Howarth, a social psychologist and social representations expert reminds us that:

Social psychologists take particular interest in [social representations] operation due to its social constructivist approach to knowledge and understanding (Moscovici, 1984), and most importantly, acknowledgements of how social and cultural factors come to mediate our world through action (Howarth, 2002 p 147).

Though the theory has been described from slightly different positions across the field, it achieves consensus with an interest in explaining how sense-making processes and action are socially mediated (Duveen & Lloyd, 1990; Flick, 1998; Wagner et al., 1999). This is a divergence from traditional cognitive approaches to sense-making, such as attributions or attitudes, many of which are typically applied in health research. As Duveen & Lloyd (1990) and others (Howarth, 2006a) remind us, such approaches reduce cognition to a level where individual minds confront social worlds, by a conceptualisation of the social milieu as given, rather than something individuals can engage with and ultimately change. SRT takes on a phenomenological perspective, with individuals seen as living in and through social worlds. The importance of the 'consequences of participation in social life' (Duveen & Lloyd, 1990, p.3) is key in a study that seeks to explore how the experience of emotional distress, ill

societies, and others' understandings of those experiences, impact on mental health services for HIV/AIDS-affected individuals.

Social representations can be approached as a theory, or phenomenon. In this thesis, they are used as a theory of social knowledge in order to gain access to the understandings of the key actors within mental health service spheres, in contextually rich and locally relevant ways, so to inform suggestions for how to promote the establishment of mentally healthy community contexts. As Markova (2000) reminds us, there are many concepts within the theory of social representations that can be considered. However, I seek to explore only those which relate directly to the exploration of understandings and action towards mental health in the everyday: representational projects (Bauer & Gaskell, 1999; 2008). My focus on this particular dimension of the theory is not to exclude the importance of more popular applications in the field of social psychology – for example, social identity (Howarth, 2002) and stigma (see Campbell et al., 2011; Howarth, 2006b)–phenomena that inundate the current body of literature on mental health and well-being. Rather, in an effort to expand our applications of this theory, and to focus more intimately on the major themes that emerged from the empirical investigation, I attend more closely to the contributions made in viewing representations as projects of intention and action, as shown below.

The work of Bauer and Gaskell (1999, 2008) builds on SRT by exploring dimensions of intentionality and interactivity. For them, representations are established through an individual's need to understand the world, and by the desired outcome of activities– or 'projects' that are a part of their everyday experiences– and *intent* behind interactions to achieve these projects. Social representational approaches can therefore be useful beyond the symbolic, and towards the actionable (Foster, 2003). Thus, according to Bauer and Gaskell (2008), a social representation can also be considered as the product of multiple systems of knowledge, or understanding of a particular phenomenon, which interact in the process of shaping the outcome of a social object. Within this model, each group carries the potential to shape the way an object is viewed over time, bounded by the constraints of reality where the social object is contained or enacted. This is exemplified within their wind rose model (see figure 11 below).

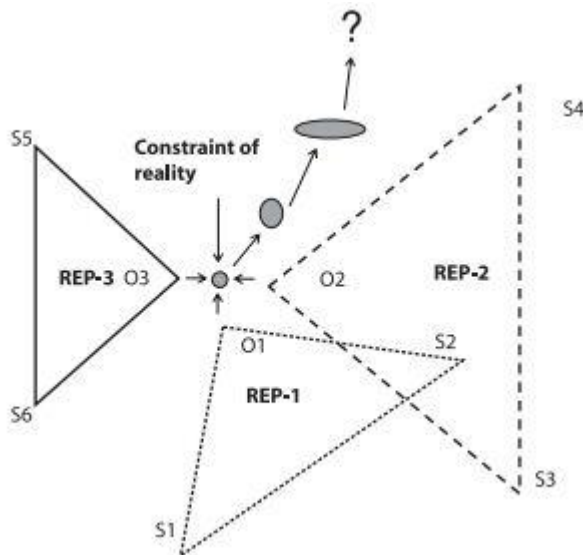


FIGURE 11: WIND ROSE MODEL OF REPRESENTATIONS (BAUER & GASKELL, 2008)

In the space of this thesis, such a perspective supports the accepted notion that different understandings of mental ill-health will lead to different projects of action in order to manage distress (recall Swartz, 1998; Kleinman 1980). However, it enables the consideration of how the success of various projects are shaped by contexts such as access to forms of power, capital or historical position within society, or place based aspects of community. More importantly however, it supports the desire to attend to how effectively different groups of actors can participate within the shared space of services to establish mental health enabling environments. The notion of multiple representational projects converging on a shared social object as displayed above (in this thesis, mental health) allows for attention to contexts of place, symbolic space, and participation – issues previously identified as important to developing locally relevant services. Such a position also enables an appreciation of the factors that promote or hinder the ability for a particular group’s voice to be heard within treatment spaces; findings that can help to direct action towards improving the local relevance of mental health services.

The object or the ‘*what*’ function of representations (Jovchelovitch, 2007) are understood as the issues that individuals or communities are grappling with in the process of using understandings. When mapping the ‘*what*’ of a representation, we are placing it in a historical and social context and occasionally drawing on our knowledge of others who have engaged with the issue before us. Jovchelovitch (2007) asserts that there are very few objects within the social world that have not been represented before, and as such, we will often draw on this collection of memories about an object to make it relevant in current contexts. Within SRT, this process is defined as anchoring; where a new object is linked to collective memories that exist within a life world (Moscovici, 1984). The ‘*what*’ of a representation highlights the importance of in-depth understandings of how people relate to

and interact with community life in the production and utilisation of knowledge. A history of anthropologists and cultural psychologists highlight that communities possess a log of methods for understanding and interacting with mental illness (See Kleinman, 1980). This affirms the desire of this thesis to maintain and expand engagement with community concepts of mental health– embracing its pluralities of how place and symbolic space contribute to understandings and efforts to address mental distress.

The ‘what’ of a knowledge system can also be thought of in terms of its content. Content is valued, given its contribution to the contextualisation of action that occurs in relation to it. As Jovchelovitch states:

Content matters because the themes, ideas and significations expressed in a representation reveal the symbolic links that are established by social actors and the resources that are brought to bear in the formulations they construct about the object world...the ‘what’ is related to the ‘how’, and it is in conjunction that they need to be understood (Jovchelovitch, 2007, p.180).

This is particularly important for this thesis as it reminds us that the shape and contents of a social world will be drawn on by communities in the process of making sense of and managing distress. How an individual communicates needs to others, and how they themselves respond to their emotional distress, is nested within their daily experiences of socially disparate conditions.

In this study, I will be seeking to uncover the content of community women’s and primary mental health care service actors’ social representations about mental health and distress. In positioning services as the meeting space of understandings, I will discuss how the meeting of these knowledges open or close down opportunities for the promotion of mentally healthy communities. By linking knowledge systems directly to contexts, we can begin to better understand how the dimensions of place and symbolic space in communities shape action in relation to mental health.

STUDIES OF MENTAL HEALTH WITHIN THE FIELD OF SOCIAL REPRESENTATIONS

Many highly regarded social representation studies have explored mental health-related topics. Moscovici’s seminal study into the social representations of psychoanalysis in French society (1961) highlighted the ways in which understandings of the tradition were employed by different groups in society for different purposes. Urban liberal opinion of the practice was highlighted by a sceptical endorsement of its practices– compared to a catholic perspective that assimilated interest, and a political communist stereotype that rejected it entirely. These positions were made possible through the development of three different representations of the issue, enabled by anchoring understandings to different ideals in their respective social worlds (Bauer & Gaskell, 1999). Denise Jodelet’s (1991) classic study which explores representations of madness in a French community highlighted taxonomy of perceptions of madness. There was an inherent need for community members living in

proximity to mentally ill patients to establish clear categories of 'mad' versus 'not mad' individuals, devoting practices and rituals so that community members could defend their position as the latter.

Many contemporary studies of representations of mental health have related to exploring public representations of mental ill-health (Rose, 1998, 2008; Rose et al., 2007); or representations held by various kinds of health professionals (Morant, 1997; Wagner et al., 1999). These studies have shown that media and practitioners will tend to make sense of people with mental distress along the plane of 'other' and 'sameness'. There has been much less investigation into the representations held by mental health users themselves within this paradigm, with the exception of Juliet Foster's work (2007).

Her 2003 study described service user representations as grounded in notions of control and location, rather than the 'otherness' and 'sameness' themes seen among lay populations and service providers. In short, patients either saw themselves as being controlled by or controlling their mental illness; and illness as something that was internal or external to themselves (Foster, 2003). Though representations differ along these two planes, they converge on the notion of mental illness as a journey, with representations changing and developing along the project of travelling this journey, influenced by varying situations, contexts, and interactions with others (ibid.). The value of such findings lies in the highlighting of how patient understandings of their experience differ widely from those external to that experience. Foster asserts that as clients use these concepts of control in their way of perceiving their mental health, they ultimately define their own notions of recovery and, in essence, what 'health' means— at times challenging notions of these ideals projected by the public and professionals. If this is the case, Foster effectively reaffirms the importance of discussions initiated by Laing(1961) when he introduced the importance of patient knowledge about their experience, and the value of a social psychological approach to exploring the understandings of mental health in order to facilitate more effective mental health services used in this study.

More recently, the theory has been applied by critical mental health theorist Diana Rose (Rose, et al., 2007; Rose, Thornicroft, & Slade, 2006), a critic in high income settings arguing for the importance of service user voice in treatment and evidence in the field.

To my knowledge, no study has applied social representations as a methodological tool to unpack the possibilities and hazards facing community mental health services, or to identify dimensions of health enabling environments in promoting community mental health. To apply social representations theory in this way, I seek to highlight how two key perspectives of the 'social' permeate knowledge and action about mental health. First, through structural (i.e. place) and symbolic social contexts that shape understandings about mental health, and second, through the relationships between community actors and contexts, in the delivery of mental health services.

In summary, a social representations approach to knowledge allows us to engage with knowledge and understandings as a symbolic dimension of community, which incorporates the effects of context and culture on action. Community psychologist Sandra Jovchelovitch outlines a series of potential consequences that can be achieved through the application of a social representations framework. Most important for this thesis, is the argument for the framework's ability to create the space to explore how mental health can be impacted by the realities of the social world, as championed by critical voices in the field, given that:

...forms of knowing linked to self, emotion and culture did not and will not disappear ... the functions they fulfill and the problems they address continue to be part of human experience and this is what guarantees their survival
(Jovchelovitch, 2007, p.125).

Second, it allows the rehabilitation of so-called local knowledge... [recognising that] they are different and need to be understood in terms of what they express and achieve in social life (Jovchelovitch, 2007, p.125-126).

This statement is critical in moving beyond the perspectives provided by current investigations into the pluralities of knowledge within mental health services. As highlighted in chapter one, while studies like those of Chipimo and colleagues (2011) recognise the presence of multiple forms of knowledge about mental health and admit to their social nature at community level, their response to this plurality is nested within a biomedical service provision approach, rather than a socially transformative approach to intervention:

Therefore, we recommend the use of contextualised conceptual models as a route to defining clinical features for understanding the conceptualisation of the clinical syndrome of mental distress for clinical and public health interventions
(Chipimo et al., 2011, p.12).

However, a social psychological framework reminds us that an in-depth exploration into the conceptual models used by distressed women can tell us a great deal in the way of identifying nodes of action around which people can be mobilised to promote well-being and positive mental health, beyond identification of symptoms. For example, this may be particularly relevant in highlighting indigenous coping practices already in use by women who are distressed.

3.3 PROMOTING 'TRANSFORMATION' IN COMMUNITY MENTALHEALTH SERVICES: COMMUNITY COMPETENCY

This chapter has thus far presented a theoretical framework that perceives community mental health services as a product of 'place' and 'symbolic space'. I have argued that the bridge between symbolic and structural contexts, and action to address mental ill-health, lies within the phenomenon of knowledge and understandings, which I access through the mapping of social representations about mental health and distress. Social representations are the ideal platform to study understandings, as it includes attention to similar notions of place and symbolic space in their construction. All of this is necessary if we are to expand on the current evidence base that informs community mental health practice and promotion in MGMH efforts, which to date remain largely biomedical and epidemiological in focus.

The question of what communities need for the promotion of health and well-being is a long standing concern in the fields of community health psychology, health promotion and community development. As stated in the introductory section of this thesis, the notion of community has surfaced as a new underrepresented concern within the 'grand challenges' for global mental health released in 2011. One in particular is a direct reflection of the concern for community contexts:

- *Support community environments that promote physical and mental well – being throughout life*

This position alludes to the importance of primary level health promotion, defined as efforts to promote optimal health and prevent the onset of mental disorders (Sturgeon, 2006). However, current efforts at prevention within the global movement cannot align with secondary level prevention, which emphasises early detection and treatment to reduce severity, facilitated by the implicit adherence to hierarchies of mental ill-health as biomedical in scope. In South Africa specifically, there are recent calls for increased primary mental health promotion efforts (Petersen et al., 2012); in particular, interventions to promote local resilience through strengthening protective factors in environments. However, Laverack (2012) warns against the use of top-down (pre-packaged and professionally driven) programmes in health promotion which are based on epidemiological evidence. He asserts that such efforts typically address population health issues through the promotion of healthy lifestyles – which:

[shift] focus away from awkward political issues concerning the underlying health determinants rooted in poverty and powerlessness (Laverack, 2012, p.64).

Given that mental health promotion in the global mental health field is driven by its evidence base of largely epidemiological and response controlled trials of western interventions, it is likely that resulting recommendations may miss the mark about what is

actually needed to promote mental health. Such recommendations are created in an absence of evidence outlining how place-based and symbolic dimensions of community (such as power) should be addressed. These arguments confirm the importance of attention to creating opportunities to ‘transform’ the existing notions of place and symbolic space that limit opportunities for mental well-being as part of community mental health treatment and promotion.

A critical social psychological position (introduced in chapter two) is ideal in contributing to such efforts. The prolific body of work by critical health and social psychologist Catherine Campbell (Campbell, 2003; Campbell et al., 2010; Campbell, Cornish, & Skovdal, 2012; Campbell & Jovchelovitch, 2000; Campbell & Murray, 2004) chronicles the unique contributions of this field in promoting health enabling community environments. Her work espouses that establishing healthy communities (most often in relation to HIV/AIDS) demands interventions that acknowledge both place-based and symbolic dimensions of community life.

In terms of the symbolic, social psychological constructs such as identity, social representations, stigma, and social capital have been positioned as key phenomena that may sway the success of community health interventions. In terms of structural constructs, the ongoing importance of poverty alleviation strategies, partnerships with more powerful stakeholders, and collective action to mobilise communities to participate in the improvement of their own health, have been promoted as necessary dimensions.

But how might the symbolic spaces that underpin the ‘transformation’² of mental distress be tackled in ways that do not exclude the importance of place on mental well-being? And can service spheres become a location to achieve these ends? While full answers to questions like this cannot be provided by any one study alone, debates on community mobilisation (See Campbell, 2013) argue that community health programmes run on a continuum from promoting social change, to facilitating every day coping. The promotion of community competencies, a popular exercise within the field of public health in recent years (Campbell, et al., 2007; Maton, 2000; Skovdal et al., 2009) is one route to promote coping in ways that better position communities to engage in local social change in ways that may also challenge contexts framing distress. A competent community may be loosely defined as one where people are able to work collaboratively to develop more empowering understandings of the challenges they face, and how best to respond to those challenges. The work of Campbell, Nair and Maimane (2007) has contributed a great deal to advancing the field with a social psychological framework of AIDS competent communities.

²*Transformation refers to the small but meaningful gains achieved by community members who, by leveraging partnerships or psychosocial resources, engage with both the causes (symbolic or structural) and symptoms of distress.*

Through the exploration of a research led community–strengthening intervention in the context of HIV/AIDS, they more formally define the notion as:

...One where community members work collaboratively to support each other in achieving: sexual behaviour change, reduction of stigma (a key obstacle to effective HIV/AIDS management, often deterring people from accessing prevention and care services); support for people living with AIDS and their caregivers; co-operation with volunteers and organizations seeking to tackle HIV-Prevention and AIDS-Care, and effective accessing of health services and grants, where these exist (Campbell et al., 2007, p.348).

Box 2: HIV/AIDS competencies

- 1) Knowledge and skills: access to HIV/AIDS related information and ability to apply this knowledge functionally
- 2) Safe social spaces: spaces for critical dialogue where people feel confident, willing and able to engage in debate about barriers to health-enhancing behaviour change
- 3) Ownership and responsibility: sense of ownership of the problem and a sense of responsibility for managing it
- 4) Confidence in local strengths: confidence in their ability to tackle the problem
- 5) Solidarity: strong local ties that they can draw on to make small contributions to tackling the problem
- 6) Bridging partnerships: bridges and partnerships between local communities and outside support networks and services

Source: Campbell et al., 2007, Campbell et al., 2008

Based on this definition, competent communities are able to tackle both structural and symbolic factors that relate to poor AIDS related outcomes, through formulating understandings about the contexts that shape their distress, and creating supportive contexts where these understandings can be translated into meaningful action. From here, six psychosocial resources were identified to facilitate or hinder AIDS Competence (see box 2).

Each of these criteria hinges on the role of dialogue, critical thinking, and participation in its achievement, and when present, are argued to improve communities' ability to respond locally to health challenges. Community competence frameworks suggest that community level programming should seek to foster these resources in hopes of creating communities that are empowered and more capable of navigating problems shaped by economic and

political processes beyond local control.

Drawing on notions of participation and/or dialogue has become a notion of 'best practice' within health programming. Notwithstanding this, the ways in which they are promoted within interventions remain a point of

FORM	TOP-DOWN	BOTTOM-UP	FUNCTION
Nominal	Legitimation	Inclusion	Display
<i>Instrumental</i>	<i>Efficiency</i>	<i>Cost</i>	<i>Means</i>
Representative	Sustainability	Leverage	Voice
<i>Transformative</i>	<i>Empowerment</i>	<i>Empowerment</i>	<i>Means/End</i>

Table 4: White's (1996) forms of participation. Adapted from White(1996).

contention. The appeal of participation resides in the belief that engaging local communities within projects that target their well-being will promote better acceptance of interventions and lead to improved health outcomes. However, the realities of participation in practice have long come to the fore. Sarah White's (1996) disaggregation of forms of participation highlights a spectrum of involvement that follows the use of the term within community level programmes, in a way that acknowledges the relative power available to groups (see table 4).

To place these dimensions in context, in Cornish and Campbell's (2009) discussion of necessary conditions for successful peer-education participatory programmes, they outline a South African case study of one such programme among sex workers. Among this programme's 'failings' were assumptions about power relations between sex worker peer-educators, which disregarded the local contexts surrounding women's engagement as 'peers' – local social contexts posited women against each other in competition for clients, which spilled over into a reluctance to recognise authority of other peer educators. The absence of an in-depth reflection into how local contexts operate was facilitated by the programme's *instrumental* approach to participation, where top-down actors dictate the norms of engagement and action, and bottom-up (community) actors simply respond. Peer-educators (bottom-up actors) were a means to delivery; they were unpaid, and 'reimbursed' through opportunities for travel and t-shirts. The conditions that shaped peer-educator participation were ignored, and their local knowledge of community issues were not utilised or contributed to the planning or delivery of the programme.

Current approaches to participation within global mental health align with similar instrumental and decontextualised approaches. For example, as part of a 'task-shifting' agenda, community mental health volunteers have been celebrated for their ability to supplement human resource deficits in mental health services. Volunteers are typically local agents, with a deep understanding of local context, and are trained in the delivery of mental health care at community level. However, local knowledge of volunteers is not seen as a valuable resource beyond their ability to bridge language boundaries, often articulating the need for increased training for volunteers to develop their biomedical knowledge about mental disorders (Kakuma et al., 2011). This same review also points to positive outcomes of task shifting in countries such as Sri-Lanka (Patel et al., 2010), but these are measured in the numbers of patients identified with disorders, and treatment delivered (Kakuma et al., 2011), saying little about how volunteers help patients manage the broader contextual issues shaping their distress.

Competencies, however, are more interested in this thesis' idea of 'transformation', which also aligns with White's notion of *transformative* participation; where bottom-up actors have a greater say in shaping the nature of responses, and outcomes have local relevance within target communities.

In light of the wealth of knowledge highlighting the futility of lower order forms of participation such as nominal and instrumental (White 1996; Campbell 2003; Campbell & Jovchelovitch 2000; Campbell & Cornish 2010), there is a clear need to revisit and problematise how participation impacts on community mental health services, something this thesis seeks to explore.

Dialogue has also been championed for its ability to establish gateways to empowerment and transformation, most prominently seen within Paulo Freire's (1973) work *Education for Critical Consciousness*. Within this revolutionary work, he disaggregates the form and importance of dialogue within processes of transformation, crystallised in his theory of *Conscientizacao* or *critical consciousness*. He argued that the use of horizontal dialogue (where individuals engaged in dialogue within non-hierarchical spaces, where each contribution was equally valued) created opportunities for participants to become aware of the ways in which contexts of their lived worlds contributed to states of disempowerment, and negative well-being.

In an earlier work evaluating the success of community mental health programmes in South Africa, I argued that community mental health programmes often created the *potential* for such spaces, but remained constrained by the biomedical paradigms that limited intervention to treatment only. This biomedical focus made it difficult to also support community desires to tackle the socio-structural realities cited as problematic that were identified during mental health related group discussions coordinated by such programmes (Burgess, 2012). Such findings highlight the limits that face dialogue cited by critiques of Freire's theories, such as contemporary health psychologist Cathy Vaughan (2010). Her argument asserts that a focus on challenging hierarchies within dialogue may simultaneously subvert attention from the realities of participants' parallel dialogues and engagement with broader social structures (Vaughan, 2011). She observes minimal attention to what happens once 'consciousness' has been achieved in dialogue (such as a lack of response to the broader social problems identified in mental health related group dialogues); and insufficient recognition of how the power embedded within broader social structures outside of programme spaces complicates efforts to dialogue being a fruitful engagement (ibid.). Vaughan argues for a more realistic view in our application of Freireian ideals – refusing to disregard his contributions outright, but noting and circumventing their limits within development practice:

Working within a Freireian framework poses inherent challenges and involves putting 'praxis' into 'practice' – that is, the critical and intentional reflection upon, and enaction of, strategies to foster a communicative space where dialogue and critical thinking are possible and where domination can be recognised and resisted. That the achievement of dialogue is a fraught and complex process does not mean that Freire's notion of dialogue is not useful in real settings, but it does suggest that the Freireian notion of genuine dialogicality is a Weberian ideal type of communication to strive towards, and against which communicative encounters can be assessed (Vaughan, 2011, p.63-65).

This critical perspective on dialogue is useful within a framework of community competencies that advocates for the importance of partnerships. Partnerships have been linked to positive health outcomes by many theorists. For example, Bourdieu (1986) argues that attention to different forms of social capital are as critical to health, as access to social networks, and economic capital may open pathways to social and cultural resources that may mediate health risk. Putnam's (2000) perspectives on partnerships are also relevant to mental health. *Bonding Social Capital*, are ties within communities that enable access to necessary structural and symbolic resources, and *Bridging Social Capital* involves the process of building ties beyond a particular community, to agents with access to alternate or greater numbers of resources required for improving one's context. For example, the MGMH exists as a network of global partners with access to economic (funding) and political (policy leverage) forms of capital, creating nodes for local community actors to potentially leverage in efforts to transform their local environments.

Health service spheres are also examples of bridging partnerships. Partnerships (mediated through dialogue) between practitioners and women emerge as a real life space where two knowledge systems meet – with unequal access to power. In line with Vaughan's (2011) critiques, more powerful brokers must have a willingness to engage with and respond to local concerns. They must be able to move beyond the simple recognition of the positions and understandings of local groups in relation to the shared 'object' of mental health, and be willing to accept this knowledge as a valid truth, and to include local definitions and understandings of the problem within efforts to work with the shared object of concern. Campbell and colleagues (2010) have encapsulated the importance of this through advocating for '*receptive social environments*' as spaces where the more powerful agents in partnerships take the voices of local communities seriously, displayed with clear action to address the voiced concerns of less powerful partners. Within this thesis, I conceive of such environments as treatment encounters where practitioners move beyond the recognition of local understandings and seek to accept patient knowledge as a valid truth (in line with critical and cross-cultural psychiatry described in chapter one); and also work actively to include the local definitions of the problem within their responses to distress.

The process of promoting more 'receptive social environments' within service spaces can be facilitated by an additional dimension of social capital – Woolcock's (1998) notions of '*linking*' social capital, defined as partnerships involving brokers who move between local community and external resources. They effectively speak both 'languages' to facilitate the transfer of resources to local levels. Brokers are able to move between multiple spheres, helping to translate key messages between brokers who have shared interests (Cornish et al., 2012).

Despite the complexities that surround the implementation of participation, dialogue and critical consciousness, the relevance remains for establishing such a framework for

community mental health in the contexts of a global movement for mental health. The value of this framework lies within three key capacities. First, competencies are rooted in psychosocial phenomena, which help to link mental health to daily functioning (Petersen, 2000), and can reflect both continuums related to mental distress – mental illness, as well as mental health as outlined by Keyes' (2005) framework. Secondly, Campbell et al. (2007) assert the relevance of their work in areas with high levels of HIV/AIDS, such as South Africa where this study is situated. Furthermore, such a framework may be effective in acknowledging the complicated relationship between mental health and HIV/AIDS. More importantly, they strive to extend this framework 'more widely for those working to create community contexts that support the possibilities of health in any marginalized setting' (Campbell et al., 2007, p.348).

Finally, developing such a framework from the outputs of a study of knowledge systems creates a very important opportunity to examine mental health services through a lens that emphasises local voice and social change, which must foreground a movement that so visibly operates within a power axis where larger, more established institutions (such as universities, international NGOs and multi-lateral organisations) begin to mobilise around the delivery of 'community' needs. Within this process, attention to the importance of notions of local voice, empowerment and perhaps most crucially, building partnerships, which lie at the heart of competencies, will highlight the very important (though predominantly eschewed) critique of these types of global-local relationships that currently drive the movement for global mental health.

The nature of many global-local partnerships is often a double edged sword. As Campbell and colleagues (2012) remind us, global partnerships are not to be fully discounted, as they provide communities with gateway access to much needed resources. For example, providing countries like South Africa with a solid platform to advocate with national governments for increasing budgetary allocations and services for mental health to address what is an undeniable level of need. However, these relationships have also been chastised for promoting representations of an issue that remain at odds with local understandings and experiences of distress (Campbell, et al., 2012; Seckinelgin, 2006) – and often solidify top-down flows of power and resources that may potentially only further marginalise communities who struggle to manage socially disparate contexts (Aveling, 2010). The promotion of community competencies implies a route to taking the best from these partnerships: their proxy for access to resources and empowerment, so that communities may be more cognisant of the ways in which they may exercise power within the frameworks of their participation (Cassidy, 2009).

Through exploring the symbolic and structural complexities of community mental health systems I believe the necessary conditions for promoting community mental health competencies will arise. These will be highlighted throughout the presentation of findings in

chapters five, six and seven, and will be re-presented within a collective summary in chapter eight, which responds directly to my final research questions: *How can primary mental health services develop more health-enabling engagements with communities in an era of global mental health? Are HIV/AIDS-specific services needed?*

CHAPTER CONCLUSIONS

This chapter has presented an overview of the theoretical considerations that promote a context driven, critical investigation of community mental health services. I began with an interest in developing a social psychology for the promotion of mentally healthy communities. To establish this, I developed a perspective of community that embraces its plurality: seeing community as combinations of place and symbolic space. This perspective supports the provision of a robust answer to my first research question: *What are the contexts that frame people's experiences of mental health, illness and the delivery of support?* It will utilise the notion of the life world (Schütz et al., 1970; Kleinman, 1980) to achieve this. These perspectives contribute to developing an ecologically and ethnographically sound analysis of mental health needs and realities of service delivery for communities, in an era of global mental health which remains driven by evidence from context reduced paradigms.

To explore how notions of place and symbolic space in community life shape decisions related to mental distress, an SRT approach (Moscovici, 1984) provides a platform through which these multiple facets can be appreciated simultaneously. This social psychological approach to knowledge is driven by attention to context, action, interactivity (through representational projects) and change – vis-a-vis the recognition that when multiple knowledge systems meet (in the space of a mental health service sphere), particular opportunities for participation around the shared object are either facilitated or hindered. This idea supports my desire to develop a theory of change that facilitates greater roles for lay community members in working towards the transformation of their mental distress in ways that are meaningful to their local experience. This aim is supported through the identification of community mental health competencies, which constitute the psychosocial resources to help communities tackle both the place based and symbolic dimensions of community life that frame experiences of mental distress. In later chapters, I will highlight how the contents of, and actions enabled by, knowledge systems of women and public mental health care actors illuminate targets for bolstering or establishing new community mental health competencies in resource poor communities.

Achieving these ends will require the application of a methodology that equally embraces complexities of contexts and change, which I outline in the subsequent chapter.

CHAPTER FOUR: RESEARCH METHODS AND DESIGN

This chapter will discuss the research design, data collection and analytical procedure that guide this thesis. As this study is centred on an in-depth exploration into community life, and how mental health manifests itself within daily life, a series of associated philosophical and ontological concerns shaped the selection of methods, as well as their deployment in field. In the following sections I will briefly discuss how these paradigms shaped the choices of methods and approach to analysis taken in this thesis.

4.1 CASE STUDY METHODOLOGY – EXPLORING THE REALITIES OF SUPPORTING MENTAL HEALTH

Sometimes we simply have to keep our eyes open and look carefully at individual cases- not in the hope of proving anything, but rather in the hope of learning something! (Hans Eysenck, as cited in Flyvbjerg, 2006 p.219).

Case studies have become a mainstay of qualitative investigations, particularly in the field of health. They have been used within both mental health and HIV/AIDS research, and have been useful in investigating both the processes and outcomes of services while remaining grounded in the broader social contexts within which they operate - an important consideration for the aims of this thesis. For example, Petersen and Ramsay's (1993) case study of mental health services in South African community post-apartheid, or Campbell, Nair and Maimane's (2007) case study of a South African community-based AIDS programme, highlighted how social contexts and relationships influenced the shape of services. The hallmark of the approach is linked to Yin's (2008) defence of the case study to emulate 'real life' – providing a unique opportunity to explore phenomena as they play out in reality (Flyvbjerg, 2006). These reasons indicate the value of a case study approach to investigating community mental health services within AIDS-affected communities.

However, there is a lengthy debate over the value of the case study to social scientific research. Stemming back to Miles' (1979) chastising of qualitative research methods (and conflation of the field of qualitative research with case study approaches), advocates of the case study have continually sought to affirm case study research as a necessary practice in the social sciences. In Yin's (1981) rebuttal to Miles' claims that qualitative data presented an 'attractive nuisance' (Miles 1979), he re-established a set of defining principles of case study approaches, that remain largely unchanged today (see Yin, 2008).

First, he disassociates the case study from its conflation with types of evidence. By highlighting its position as a research strategy, Yin asserts its importance vis-a-vis its perspective that sits in stark contrast to that of experimental designs, with the 'distinguishing characteristic of the case study [being] that it attempts to examine (a) a contemporary phenomenon in its real-life context, especially when (b) the boundaries between

phenomenon and contexts are not clearly evident' (Yin, 1981, p. 59). If this is the case, then the exploration of a phenomenon can (and often will) involve the use of an array of methods to embrace complexities of context. The use of participant observation, ethnographies, and other qualitative methods are most commonly linked to case study research strategies, which help to extend the case study beyond strategies such as experimentation (which focuses on the reduction and divorce of context), or history (which maintains a vested interest in the past), into engaging with the complexities of the everyday present and, depending on the type of case study attempted, the future.

The aforementioned dimensions of case study strategies are critical in directing this work. Throughout the first three chapters, I have indicated the value of social knowledge and attention to context in critical approaches to the study of community mental health. The commitment to contexts intrinsic to case study methodologies provides an ideal platform to make salient contributions that focus on the importance of context to the field of global mental health. Case study strategies hinge on maintaining proximity to context (Flyvbjerg, 2006), and through the application of a wide range of tools, can develop an understanding of contexts that is correspondingly rich, making the case study an apt selection for the methodological framework driving this work. As a framework that is not hinged to a single

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*BOX 3: MISUNDERSTANDINGS OF CASE STUDY RESEARCH
(FLYVBJERG, 2006)*

'best' method, for collecting data, case study strategies also afford the use of non-qualitative methods such as survey data, experiments, or histories, because they contribute further understandings of the contexts that shape the phenomenon or issue under exploration. This multiplicity of methods is

more formally referred to as triangulation, which I address in further detail in section 4.13.

However, the very desire of case study strategies - to produce context dependent knowledge of social settings - remains the primary source of critique of its application. Flyvbjerg (2006) aptly discusses five misunderstandings of case study research (see box 3 above), the first of which is associated directly with critiques relating to contexts of knowledge. In challenging this misunderstanding, he reminds us that all knowledge originates from the generation of a case, and that true 'expert' knowledge in any area only emerges through the collection of repeated cases, rich in context. He states that:

Common to all experts, however, is that they operate on the basis of intimate knowledge of several thousand concrete cases in their areas of expertise. Context-dependent knowledge and experience are at the very heart of expert activity....it is only because of experience with cases that one can at all move from being a beginner to an expert. If people were exclusively trained in context-independent knowledge and rules... they would remain at the beginner's level in the learning process (Flyvbjerg, 2006, p.222).

In this vein, our ability to know is only achieved through learning *in and through* context. This argument not only helps to defend the use of case study research as a methodology within this thesis, but further supports the use of a social psychological approach to community presented in chapter three, which allows us to remain driven by the symbolic and structural contexts that are elevated and explored through the application of case study research designs. It ensures that our investigation into mental health systems foregrounds context at all turns: through theory, research practice, and ultimately, discussions of future delivery practices. The latter issue brings us to what I feel to be the most valuable and ultimately controversial uses of case study research: the formulation of theory from a locally contextual study, which may be used to guide future projects. I address this within the following section.

4.1.1 THE CASE STUDY: GENERATING AND GENERALISING THEORY

One of the previously identified aims of this work was to suggest a potential framework of criteria for the promotion of mentally healthy communities in socially deprived settings in the form of *community mental health competencies*. In making such a statement I suggest that findings from this thesis could have implications beyond this particular community of place; that they may be *generalised* to other settings facing similar social and

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FIGURE 12: BASIC TYPES FOR DESIGNS FOR CASE STUDIES - SOURCE: YIN, 2008

mental health consequences. The assertion that one may generalise from the findings from a single case study has been a dominant line of critique facing case study methodology (Flyvbjerg, 2006). The notion of generalising the process through which knowledge from one context may be seen as valuable to another is a concern among those who question the external validity of findings from a case study. Flyvbjerg asserts that the ability to generalise from one case to another should be considered in the type of case that is at hand, and how the case was chosen. Yin (2008) provides an excellent platform for making this type of distinction. The design of case studies may take shape within two paradigms: single or multiple. As seen in figure 12, single case studies can be further subdivided into holistic and

embedded designs. Holistic single case designs consist of a single case within a single context, and focus on a single unit of analysis within that context; for example, the study of a paediatrics department within a hospital. When single case designs contain multiple units of analysis, they are considered embedded: with multiple parts seen as being affected by and contributing to a space of shared single context. This would translate to a study that looks at multiple outcomes of the clinical services and staff employed by a paediatrics unit.

Units of analysis are decided on using sampling techniques, and there is no limit to the number of units to be included in such designs. Yin (2008) asserts that embedded single case designs help to overcome many of the limitations of holistic case designs – primarily abstract level discussions of an issue, or when the nature of a study shifts during the course of a study (i.e. when evidence being collected points towards a different research question). By including various subunits within a case, embedded designs increase sensitivity to the research area, and attention to interactions that may occur between these subunits that contribute to the organisation of the field being observed.

This thesis aligns with an embedded design, which consequently mirrors the theoretical position towards community outlined for this work in chapter three: mental health services as an interactive space. Each group of actors considered in this study comprises a subunit of investigation, which is observed using a range of methods. The dimension of *community as place* ultimately emerges as the broader context where these subunits are situated. The dimension of community as *symbolic space* also attends to the intangible aspects of community life that contribute to actions relating to mental health – i.e. understandings or social representations of mental well-being and distress. The inclusion of community as place also helps to avoid what Yin presents as a key pitfall of embedded single case designs: a drift of focus, where attention hones on the subunit level only, which can relegate the original core interest – for this thesis, community mental health services – to the level of context. We are able to avoid this shift by attending to the actual contexts that shape mental health services via the inclusion of an ethnography of community that foregrounds our discussions of the subunits in question.

The use of a single case design is justified in the presence of one of five criteria: it is a) a critical test of existing theory; b) an example of rare or unique circumstances; c) a representative of a typical case; or serves d) a revelatory; or e) longitudinal purpose (Yin, 2008). A single case study of rural South African mental health services is most certainly an example of a representative or typical case justification. Many of the key contexts of concern – social deprivation, complex health conditions (such as management of HIV/AIDS) and an under-resourced formal mental health service sector (Burns, 2010)–are representative of contexts across the developing world, and the primary targets of the global movement for mental health actions (Patel & Prince, 2010).

The above arguments highlight a clear value to the in-depth exploration of the Manguzi community and, to return to the original issue of this section, the value of generating and generalising theory from the findings of an investigation of a single case. In the process of generalising, I do not seek to suggest that the specifics of what this context highlights as important will be universally valid with regards to mental health services. I do, however, seek to point to a framework whose tenets are shaped by context, which in turn often shapes response. The aim is to ensure that whatever theory is generated through a grounded single (embedded) case study design has potential to be relevant elsewhere, such that it becomes a framework for examining the contexts of other environments. This is what Yin (2008) describes as attempting to generalise findings to theory, where theory is able to be applied in novel settings and yield outcomes that are shaped by the new contexts of investigation. My previous discussion of community competencies re-emerges here as an ideal example. Campbell and colleagues' (2007) original conception of an AIDS-competent community used the examination of a single case study of an AIDS intervention in South Africa, to identify concepts such as 'safe social spaces'; social capital as integral to enabling communities to take advantage of the resources made available to them in relation to the intervention. This framework became a vehicle for the exploration of other contexts – such as AIDS-affected children (Skovdal et al., 2011; Skovdal & Ogutu, 2009) and ARV compliance (Campbell et al., 2011a).

But how then, do we move from specific context to theory? One argument, promoted by Glaser and Strauss, is that we may develop theories through the elevation of context specific information to theoretical concepts through a Grounded Theory Approach. Glaser and Strauss's exploration of the nuances of death and dying within hospital settings (1964) was mainly interested in describing the social processes used to mitigate experiences related to death and dying by the actors who populated the space: nurses, doctors, family members and patients, using a similar case study strategy attempted within this work. This thesis has a similar goal. It seeks to understand not only what mental health and mental ill-health means to a poor community in the contexts of systemic poverty and HIV/AIDS, but also, how these understandings relate to their daily life, and through what processes do those involved –community members, providers and support systems – manage these experiences. How I deal with the notion of grounded theory is explained in greater detail in section 4.2 of this chapter.

4.1.2 APPROACHING DATA WITHIN CASE STUDIES: TRIANGULATION

Yin (2008) asserts triangulation of data sources as the recommended approach for case study research, as a route to increasing the depth to which contexts that relate to the central issue may be explored. The notion of triangulation originated within mathematical principles, nested in the idea of approaching a central point in a space from differing intersecting points. When applied in the social sciences it is typically in relation to discussions about sources of data, and their convergence on the central research problem. Multiple sources, typically generated through multiple methods, are used to generate evidence to explain the phenomenon. This richness is thought to contribute to the confirmatory ability of case studies. This thesis seeks to generate a richness of understanding, through the use of multiple lines of evidence which explore the varied factors that contribute to how people understand and respond to mental distress in AIDS-affected communities. Triangulation in this project was achieved through the use of various modes of data collection. The types of informants align with the three groups of individuals identified in previous chapters (recall: community women; formal health service actors, and community service providers).

Within this work, the issue of ‘managing mental ill-health’ was approached using in-depth interviews with participants in each group. Ethnographic data was generated (in an effort to give a greater attention to the notion of Manguzi as a community of ‘place’, and provide grounding of context) through the collection of informal observations, field diaries, formal observations of clinic settings, and document analysis.

<i>Informant type</i>	<i>Quantity (n)</i>	<i>Data Source/Type</i>	<i>Method of documentation</i>
Community members	20	Interviews (in-depth)	Transcripts/worksheet ³
Formal Service provider (hospital based)	12		Transcripts/worksheet
Community Service provider (NGO based)	3		Transcripts/worksheet
Community Service provider (traditional/spiritual)	8		Transcripts/worksheet
Policy documents	7	Policy document analysis (critical literature review)	Relevant mental health documents provincial, national and international sources

TABLE 5: TRIANGULATED DATA SOURCES

The details of this process of generating ethnography are described in section 4.3.5 of this chapter. How these forms of data were analysed is discussed within section 4.4.

³ The worksheet referred to in this chart corresponds to the real time note pages completed during the interview, used to confirm quality of translated interviews and context of the interview. These are outlined in full in section 4.3.4

Overall, the triangulation of data sources and methods provides an opportunity to draw on multiple frames of view, to explore the impacts of the contexts created by HIV/AIDS and social issues on the mental health of communities. These contexts are shared by many South African communities, and a better understanding of how these contexts become concrete in the lives of those who live them, is a valuable exercise in seeking to understand how best to address the risks identified by a long standing body of epidemiological research that dominate the development and mental health fields.

4.1.3 THE LANGUAGE OF GROUNDED THEORY IN EXPLORING COMMUNITY MENTAL HEALTH SYSTEMS

As part of my desire to remain embedded within the contexts that shape understandings of mental health and practice within community mental health services, I assert that grounded theory— a principal, yet contested, approach to qualitative research – has additional positive contributions to make to this exploration. In the introduction to this thesis, I presented the tenets of Social Constructionism that have shaped my application of social psychology in the realm of community mental health, and which contribute to the desire for this work to produce recommendations for what constitutes a mentally healthy community in the contexts of social deprivation and HIV/AIDS. I have argued that within case study methodologies, generalisation of findings and the development of theory can be considered as valid outputs for case study research.

The use of grounded theory (GT) is pervasive in qualitative research studies (Stern & Porr, 2011) and is linked to case study research by Yin (2008), with regard to its value of triangulation and its desire to include context in its investigations (Mjøset, 2005). Founded in 1965 by sociologist Barney Glaser and social psychologist Anselm Strauss, GT is an approach to social science research based on the systematic generating of theory from data that is collected from social research settings. The methods associated with this particular approach to social research – which may best be summarised as a reiterative process of data collection, coding, comparison, and note taking stretching over time – are common to all forms of qualitative research (Glaser, 1992), and thus are often adapted successfully across a breadth of health-related fields where interests in social life are paramount.

It is worth reasserting that my work remains a case study design, and does not attempt to present itself as a grounded theory study. Rather, it is through a case study design that I am able to draw on other frameworks to facilitate my exploration of mental health services. In this process some concepts of grounded theory assume importance to this end, and grounded theory becomes *one of* the methods that can be part of a case study methodology. Specifically, this is through the application of a grounded thematic analysis. My justifications for this are explained below.

Stern and Porr (2011) reiterate the importance of four key principles that are paramount to every project that identifies itself as grounded theory: discovery over verification; explanation over description, emergence over forcing; and matrix operation⁴. These four 'ground rules' are derived from a series of monographs produced by Glaser in the 1990s (Glaser, 1992), wherein he addressed a division in thinking about the practice of grounded theory being promoted by his colleague Strauss in his later works with Corbin (Strauss & Corbin, 1990). The first, which is a key consideration within my work, is discussed below.

Discovery over verification: Stern and Porr state that grounded theorists seek to generate theory through direct exploration of the world around them, and not necessarily to prove already established theories. While Glaser (1992) asserts that grounded theory can be used in the development of theory, he does not exclude pre-existing concepts from inclusion within this process. The only determinant of what concepts are included is their relevance within the data itself, insofar that a theory is not 'imposed' but emerges as a logical way to explain the happenings of a social field that is already in action. This particular perspective is precisely what prompted my use of a case study for the generation and generalisation of theory; in this way, a theoretical concept— for example, identity – may emerge as a factor to be considered in understanding mental health based on the data. It also allows for the uncovering of mental health competencies – whereby the processes that communities engage in to mediate their mental distress, and the facilitators and hindrances of mental health services, can be identified and elevated to a conceptual level. Thus, one may begin to generalise contextually-driven results to theory, and formulate a starting point for developing more critical discussions about mental health services in the global mental health field.

In this thesis, engaging with processes and contexts related to the experience and management of mental ill-health was based on a key distinction between thinking about theory and the position of a researcher who engages in social research. Glaser (1992) parses his notions on this process along two lines: inductive and deductive reasoning, which emerge in relation to a project through stages of sampling, collection, field observation, analysis and writing of the final product.

Deductive reasoning, which forms the backbone of most scientific and social scientific study in positivistic traditions, presupposes a theory or framework prior to entering into the field. Hypotheses are created before the researcher has initiated an investigation; or a research hypothesis is logically deduced from pre-existing frameworks or understandings of the field (ibid.).

⁴The second and third principles are relevant to studies that seek to apply a grounded theory methodology— which is not relevant to this work, which remains nested within a case study methodology. Furthermore, seeking explanation over description is a tenet that is dealt with sufficiently within the justification of a single case study design.

Grounded theory, by contrast, aims to be inductive. It allows theory to be induced, or to emerge after starting the collection of data. This is facilitated by theoretical sampling – a process of data collection where an analyst jointly collects and codes data, and through in-field analysis, decides the sources of data and how much data to collect, in order to develop a theory as it emerges. This early integration within the data allows the researcher to produce what Glaser describes as theoretical sensitivity, an intense relationship between data and the theory, and the foundation of relevance and fit between the theory, and the social area being observed. Thus theory, because it is guided by understandings of the field as the research process unfolds, is better able to ‘explain how basic social processes resolve the basic social psychological problems that face the participants’ at the core of the study (Glaser, 1992; p.36). Such a perspective supports the process of mapping of the contents of the mental health knowledge field, as well as the contexts that shape the operation of social psychological processes that enable mental health competencies.

Grounded theory maintains the use of deductive logic, though in a way that seeks to overcome its traditional application in science. Deductive reasoning is used to help build connections between induced codes from data, back to other areas of the field. For example, allowing emerging data to confirm what additional groups or individual to sample for further data. – These connections help to generate hypotheses about the field of study as the research proceeds, which are proved or disproved by the collection of more data. By using this approach, Glaser maintains that the limits to exploration created by an a priori development of hypothesis shaped by pre-existing frameworks can be avoided. Thus a researcher, who may be guided by a general interest in an area or topic, can make shifts with regards to plans and focus very early on in the research process, so that the data gathered can be more reflective of what is happening in the field, and not limited by pre-conceived assumptions about who should and should not be observed. This is most evident in my sampling procedure for mental health ‘practitioners’ which I engage with in more detail in section 4.3.2.

The use of grounded theory in this manner is thus centred on a very tight relationship between theory and methods. The researcher is continually analysing while in the field, and field notes play a key role in highlighting potential categories and themes in the research, as they are reflections on what she is observing. This helps to shape theoretical sampling deductions, which anchor theory firmly in actual actions and processes within the field. Furthermore, it is through the use of grounded theory that I may move from a specific context to the general, enabling my case study analysis to generate theory. A grounded analysis begins with the community embedded within its context. Through an interpretive process of moving from the field to the theoretical, we begin to discuss findings in a more general way. This is achieved through a coding process that focuses on *invivo* coding (basic

codes that are direct excerpts from the text) and then moves to more generalised frameworks to describe processes (see section 4.4 of this chapter).

4.2 DEFINING COMMUNITIES: SELECTION OF PARTICIPANTS

Earlier in this work I outlined the complex nature of community and most importantly, how the social psychological perspectives of community were particularly important to this thesis. In this section, I will describe the ways in which I have defined the multiple communities investigated as part of this case study.

4.2.1 IDENTIFYING THE SERVICE USER COMMUNITY: SAMPLING FROM A LARGER SURVEY POPULATION

Participants were selected based on the severity of their scores on three psychometric tests completed in a community survey administered to 5000 caregivers and their children in the Umkhanyakude sub-district in KZN, as part of the larger 'Carer-Child Wellbeing' Project (2009-2011). The survey explored factors related to health and social well-being for caregivers and children in AIDS-affected communities in KwaZulu-Natal, and was managed by the Universities of Oxford, Brown and KwaZulu-Natal, The South African National Department of Social Development, National Action Committee for Children affected by AIDS and the Health Economics and HIV/AIDS Research Division. Patients were screened for symptoms relating to depression, anxiety and PTSD, which as discussed in my literature review, have been identified as significant health burdens in recent epidemiological work in the country (Havenaar et al., 2008; Herman et al., 2009; Myer, et al., 2008).

A crucial caveat bears stating here: I do not use these scales or my selection of cases across a mild, moderate and severe symptom expression (the process of which is detailed below) in a way that assumes their local validity to community experience. Rather, I do so in an attempt to gather a holistic picture of the emotional distress faced by and ultimately managed by women in these communities. By this, I refer to the ability for these diagnostic categories, which at their core are formed by salient emotional experiences, to potentially be relevant to a participant's experience of 'mental health'.

Depressive symptoms were measured using the Centre for Epidemiological Studies Depression Scale (CES-D). This 20-item scale was designed to measure depressive symptoms in the general population, based on DSM-IV criteria, and is one of the most widely used self-report depression instruments. It has been administered in South Africa as part of various studies (Hamad et al., 2008; Myer, et al., 2008; Smit et al., 2006), and has been used in both HIV-positive populations and township dwellers.

Participants rate their symptoms on a four-point scale, ranging from 'rarely or none of the time' to 'most of the time'. Scores range from 0 to 60, and scores with 16 or higher are believed to indicate probable depression. The cultural validity of this tool has been tested in South Africa, but with a discrete focus on translation processes to the Xhosa language. Smit and colleagues (2006) found a range of issues with the cultural appropriateness of this tool

when attempting to categorise emotions, which is the main outcome of this particular tool, and highlight a potential complication in its use cross-culturally.

To identify potential participants, raw scores were computed using simple sum functions in SPSS (version 17). Participants from the entire data set (as of October 2010) were then grouped based on the presence or absence of depressive symptoms, using cut-off scores that were in alignment with the larger study: low depressive symptoms (raw scores of 16 and under, coded as 0) and presence of depressive symptoms (raw scores 17 and over, coded as 1).

Anxiety was measured using the Beck Anxiety Inventory (BAI) a 21-item instrument designed to measure the prevalence of anxiety symptoms (Beck & Steer, 1991). The BAI is rated on a scale of 0 (minimal anxiety) to 3 (severe anxiety), with the cut-off points for total scores as follows: 0–7 (minimal anxiety); 8–15 (mild anxiety); 16–25 (moderate anxiety); and 26–63 (severe anxiety) (*ibid.*). The BAI, designed for use in clinical and research settings, has an average reliability coefficient of 0.92 and test-retest reliability of 0.75.

Raw scores were also computed using simple sum functions in SPSS. Participants were then grouped based on their raw scores into mild symptoms (raw scores of 0–22, coded as 0) moderate symptoms (raw scores of 23–35, coded as 1) and severe depressive symptoms (raw scores of 36 and over, coded as 2).

Post-traumatic stress was measured using the Life Events Checklist (LEC). Based on the experience or witnessing of a traumatic event (the status of which is outlined by DSM IV standards), certain participants completed the Harvard Trauma Questionnaire (HTQ). While the HTQ is 30 items long, for the purposes of the larger study, only the first 16 items based on DSM–IV criteria for PTSD were used. The HTQ has been described as being specifically for use in diverse cultural settings (see Mollica et al. 1992), though this has been questioned by many critical theorists in recent years (Fernando, 2008; Summerfield, 2001). HTQ has been administered in South Africa (Myer et al. 2008; Smit et al. 2006b) and with diverse populations including individuals from South African townships (Smit et al. 2006b). The cultural validity of the tool was tested in South African populations (Smit et al. 2006a). Scoring was carried out using a procedure outlined by Mollica and colleagues (1999) which assesses a minimum threshold of clinically significant PTSD symptoms. This threshold is calculated based on responses to questions that measure three symptom clusters of PTSD: re-experiencing of the event; avoidance or numbing; and hyper-arousal. If respondents have a score of three or four points on one of the four questions on re-experiencing symptoms, three of the seven questions on avoidance and numbing symptoms, and two of the five questions on hyper-arousal symptoms, they are categorised as having clinically significant levels of PTSD (*ibid.*).

REDUCING THE INFLUENCE OF A BIOMEDICAL PARADIGM: 'POOLING' OF DISORDERS IN DEFINING SYMPTOM SEVERITY

As a critical psychologist, many of my concerns with the use of the above tools remain similar to those employed by critical theorists outlined in chapter one. However, even within this position, I do not discount the potential importance such scales may hold in potentially supporting communities in some aspect - particularly given my adherence to a dual paradigm which considers the presence of mental ill-health to be an equal contribution to overall states of well-being, and a potentially necessary point of intervention.

'Pooling' of disorders would be unorthodox in a typical epidemiological approach to understanding distress, but recent work by mainstream MGMH actors have asserted that depression and anxiety can be considered as a combined concept of 'common mental disorders' due to a high level of comorbidity and similarity of their epidemiological profiles in many community settings (Patel et al., 2006).

However, the decision to 'pool' disorders was done here with different aims in mind linked to this study's critical social constructivist approach to understanding distress. Firstly, in trying to gain a picture of how the emotional well-being of each participant is established, I wanted to avoid valuing one type of emotional response over the other. If I had focused on one disorder, it would discount the importance of other facets of emotional distress being dealt with by community women. By including both sadness and anxiety related symptoms as part of the selection criteria, I would enable each participant, rather than a measure, to identify which emotional experiences were most important within the scope of their lived experiences.

Second, given that this thesis takes an explicit focus on women, I must remain aware of feminist critiques of the context deprived approach to gathering information using these scales. Stoppard asserts that they effectively obstruct practitioners from gaining knowledge about the situational realities women draw on in making sense of the items on these scales (Stoppard, 2000). Thus, I continue to query the appropriateness of biomedical illness categories derived from these scales to tell us much in the way of the lived experiences of distress in *any* context, and I operated under the hypothesis that disease categories imposed by these measures would carry little relevance to how women made sense of their experiences.

However, as part of broader efforts to have this work speak across disciplinary boundaries, and to inform the practice of the global movement who remain guided by DSM and ICD categories, to exclude them entirely from this thesis would limit the ability for my findings to support the practice of those who do seek to operate on the biomedical dimensions of distress. As such, the presence of symptoms associated with each 'disorder' type formed the inclusion criteria.

After individual categories were derived using the procedures outlined above, participants were randomly allocated based on the severity of their symptoms into clusters as follows:

Severe patients:

Severe cases were identified by selecting for participants who fulfilled the following criteria: anxiety coding of 2.0 and depression code of 1. In the absence of scoring criteria that created a 'mid' range of depression severity on the CES-D, raw scores were then parsed into groups, so that severe cases were scores of 36-60, with presence of PTSD (all three categories). This process generated a total of 19 potential participants. From this initial group, ten were randomly selected as potential participants.

Moderate symptom patients:

Participants were identified by selecting cases that fulfilled the following criteria: anxiety coding of 1.0 and depression raw score between 17 and 35, and two clusters of PTSD. This process generated a total of eight potential participants, of which all were selected for contact.

Mild symptom severity patients:

Participants were identified by selecting cases that had an anxiety code of 0, and depression raw score of 16 or less. Presence of one PTSD cluster was required for inclusion in this group. This generated 73 participants. A list of ten participants was randomly generated, and contact details secured.

4.2.2 IDENTIFYING THE PRACTITIONER COMMUNITY: A GROUNDED THEORY APPROACH

Understandings of mental health are continually shaped by longstanding discourses that are so ingrained into common and professional vernacular. It is difficult to enter into a study of this nature without some preconceived expectations about what 'mental health' is, and is not. Through the use of theoretical sampling as part of my grounded case study approach, I was able to circumvent the inevitable pigeonholing that accompanies mental health based research, and move closer to generating observations about the reality of primary mental health care services. A typical case study applied in the field of mental health would have involved sampling of expected categories of participants: doctors, nurses, mental health care users, family members. The application of theoretical sampling, which I defined earlier in this chapter, allowed me to expand beyond 'typical' actors associated with the provision of mental health supports, to those that acted within this capacity based on community definitions.

This approach unfolded over subsequent interviews and observations, each helping to identify preliminary codes and concepts that were useful in generating rich descriptions of

mental health in the community. Figure 13 below depicts the matrix of how this process played out in the field.

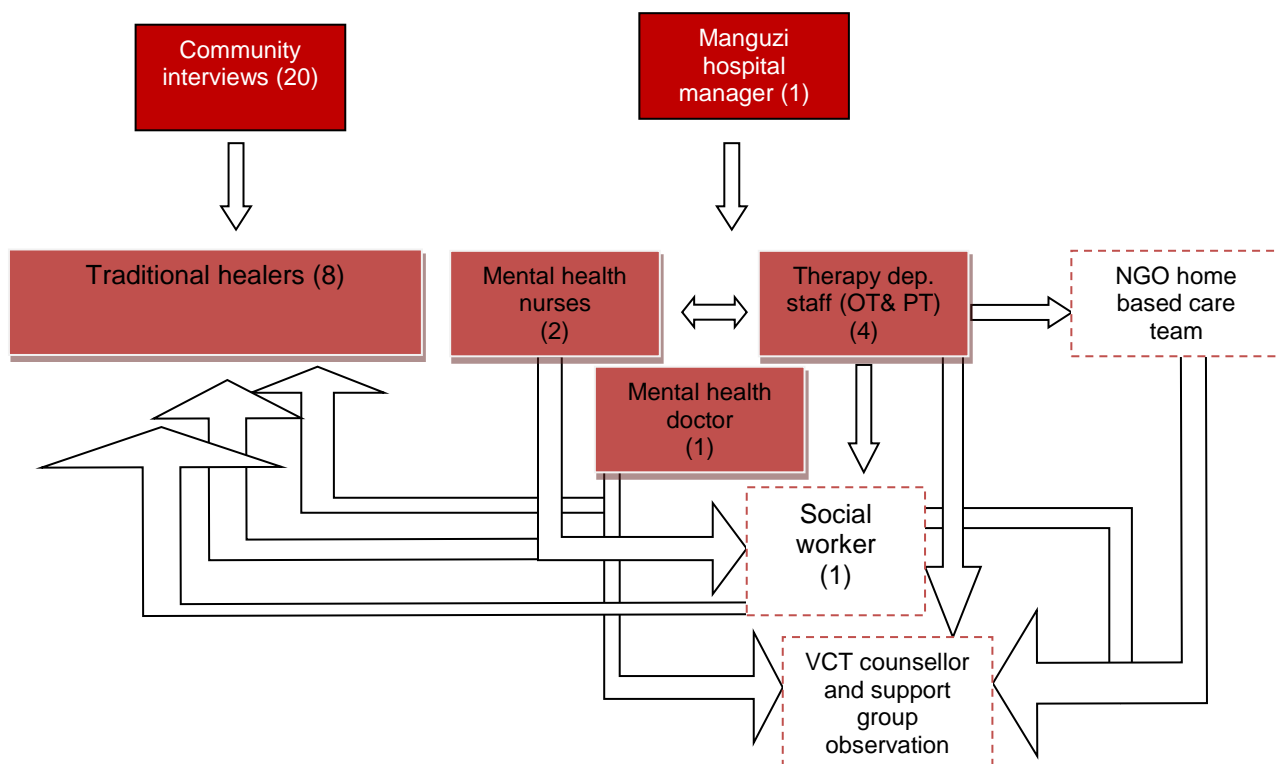


FIGURE 13: SAMPLING STRATEGY FOR COMMUNITY AND FORMAL SERVICE PROVIDERS

Bright red boxes signify the primary level where sampling originated. The next stage in sampling was based on preliminary readings of interviews and is indicated by the lighter red colour. The importance of these groups to the overall picture emerged through recurring themes across multiple interviews and reflection on data during field observations. Arrows point outwards towards the new 'group' to be identified. A primary indication of the salience of a group to the local mental health service system was the referral from numerous sources; for example, traditional healers and church leaders identified as important by participants in the formal health sector.

4.3 DATA COLLECTION: INTERVIEW PROCESS AND ETHNOGRAPHIC EXERCISES

4.3.1 FIELD WORKER TRAINING

Two field assistants (FAs) were hired through the local NGO where I was based. Eight applicants who worked as FAs for the larger quantitative survey applied for the positions, and were assessed based on their written and spoken English, demeanour and accuracy ratings measured during their employment on the larger survey. Three women were shortlisted for interviews, and a final two (aged 19 and 26) were selected following in-person interviews. Given their minimal work and research experience, training of FAs was a very involved process. Much of the training and procedures for data collection was informed by Leslie Swartz's *Culture and Mental Health: Southern African View* (1998). Training also supported a conscious effort to build local capacity within the community, and within the NGO. Given that work opportunities remain scarce within Manguzi, the use of local staff created an opportunity to build the qualifications of these women more broadly.

Training occurred over a five-day period at the NGO office. FAs were introduced to the particulars of my study, background information on common mental distress, and the ethos behind the research. I felt that exposing them to my personal connections to the work, and my opinions on why engagement with community members was important, would contribute to their ability to work independently, if need be, when I was conducting ethnographic observations with the hospital and NGO teams.

The training programme consisted of five sections. Section one covered the basic differences between qualitative and quantitative research. Qualitative research was presented as a type of investigation concerned with the 'what', 'how', 'why' and 'when' of people's experiences that could not be captured as part of the survey. Materials for this section were adapted from a qualitative training manual for community health workers developed by Mack et al. (2005) and introductory chapters of Bauer and Gaskell's qualitative methodology text (2000).

Section two focused on introducing the common mental health disorders with which the thesis is concerned: depression, anxiety and PTSD. Materials for this section were adapted from the *Where There is no Psychiatrist* training manual (Patel, 2002), specifically drawing on the vignettes about depression and anxiety. Our discussions focused on relationships between these stories and things the FAs may have experienced within their communities. However, the addition of a section where we discussed the near 'normalcy' of some of the life experiences and responses seen in these vignettes provided an opportunity to stress the differences in how a medical practitioner sees these symptoms, and what constitutes their criteria for illness – in most cases, the duration of symptoms (i.e. those lasting months or years).

During this session, a great deal of time was spent in critical discussion about how 'relevant' these categories were to life in Manguzi. We discussed how many of these emotional experiences described in the vignettes were common to both FAs sharing personal experiences about times when they experienced feelings that were similar to what was presented in the vignettes. This led to a discussion of a traumatic experience involving the death of a family member of one of the FAs, and her feelings about this experience. This provided an opportunity to point out the difference between what I had previously described as 'healthy' and 'illness', shown by her ability to manage her emotions around the experience.

The third session addressed protocol and procedures for obtaining consent (verbal and written) and the processes and sections of the interview. The bulk of the consenting script was identical to the previous study, and was retained in order to maintain some consistency for women who were being revisited as part of these interviews. Two new sections were added to explain the purpose of this qualitative study, the use of tape recorders and protection of identity regarding these recordings⁵.

The fourth and fifth days focused on practice interviews. I interviewed each FA in turn, observed while they interviewed each other, and finally took turns interviewing me. Each morning began with a revision session, and on Thursday morning I administered a test, which was marked and taken up orally to ensure they had understood the basic concepts presented over the week. The second half of the fifth day was spent contacting participants and scheduling community interviews that would occur over the following weeks.

Field worker training was ultimately designed to support my FAs' ability to work beyond the role of cultural brokers (defined by Swartz (1998) as the ability to provide relevant details about the community context and meaning of the patient/person being interviewed) and towards the role of a junior colleague – where their skills could contribute to a team approach for unpacking the details of an interview. This was particularly useful during our interview debrief sessions, which I outline in my section on quality control later in the chapter.

⁵ See appendix c for consenting script

4.3.2 INTERVIEW SCHEDULES AND INTERVIEW PROCESS

COMMUNITY WOMEN INTERVIEWS: SCHEDULE AND PROCEDURES

A total of 20 interviews were conducted with community members across five Izigodi. I conducted 14 interviews where FAs acted as my translators/interpreters and note takers. Swartz (1998) points to the work of Vasquez and Javier (1991) that identify common errors that arise within the process of using interpreters: omission, addition, condensation and substitution. In an effort to overcome these issues, I designated one FA as note taker during interviews, and one as interpreter, so I could check on content at later stages (see section 4.3.4). Interviews were contextualised by 85 hours of ethnographic observation, conducted using a motivated ethnography, which I detail below in section 4.3.5.

The six remaining interviews were conducted by the FAs independently during later stages of field work, while I was completing observations with the mental health team at Manguzi Hospital. During these interviews, one FA worked as a scribe and prompter, in order to make sure that all sections of the interview were completed. The other directed the interview, asking questions and handling consenting processes. During these interviews, the FAs were given a mobile phone in order to contact me should any complications arise. Such an incident occurred only once when a participant grew too tired to carry on. In line with protocol, the participant gave consent to include the partial interview in the database, and was provided with contact information for the NGO and other support agents in the community should she need assistance.

Interviews were distributed across each of the five izigodi, to ensure that I was able to gather an appropriate contextual picture of what the specific area and typical homesteads across the community were like. Semi-structured interviews were originally designed in the style of episodic interviews (Flick, 1997). This sought to maintain the narrative style approach common to health and well-being (Murray, 2000) and social representations (Murray, 2002) studies that value the establishment of free form narratives to explore the nuances of relationships within participants' life stories. Episodic interviews allow for more focused narratives, or stories about a specific incident, concept or experience. For the purposes of this study, I desired to build stories about their everyday life, and narratives around the mental health experiences that could potentially be linked to the responses women gave to questions in the larger epidemiological survey.

All original English interview schedules were developed by the author of this thesis, and divided into the following sections: introduction; warm-up and participant life history; support systems and services; explanatory models of common mental disorders (linking life to emotional experiences); coping strategies; and understandings of biomedical terminology relating to mental distress.

As previously outlined, community members were HIV/AIDS-affected caregivers who, based on their responses on the aforementioned mental health measures, had been identified as experiencing symptoms related to common mental disorders. This however, was unknown by participants themselves, as the protocol for the previous survey stipulated that only participants who had met diagnostic criteria for a mental disorder were provided with letters that advised seeking medical support. Thus, many community members who did not have exposure to such terminology would not conceive of their experiences within these disorder categories, rendering them irrelevant in making sense of their experiences, and potentially damaging, given that 'mental illness' remains a stigmatised label within many rural communities. To overcome this issue, a separate discussion of mental 'illness' conducted at the end of the interview to gain a grasp of broader community level opinions about mental ill-health was not individualised, in order to avoid a conflation of their experiences with 'mental illness' and potential stigmatisation

During the first interviews complications emerged in the use of less structured interview strategies (i.e. probing for open ended stories in the form of 'episodes'). Asking for 'stories' did not translate effectively to the women in the community, as it was interpreted in ways closer to children's stories, dissolving these women into laughter at the request from a grown woman seeking 'bedtime stories'. Instead, a series of very detailed prompts were developed to help participants reflect on material to be covered in the interviews. Prompting around the 'who', 'what', 'why' and 'how' associated with each service being explored was included. Prompts were used only as needed, and some women were able to develop full stories around their experiences with services and of their emotional distress. Regardless of the presence of prompts, a semi-structured flow was maintained in the interviews by allowing the participants' discussion of issues, most often raised during the life history portion of the interviews, to guide the order of the questions.

PRACTITIONER INTERVIEW SCHEDULES AND PROCEDURES

Interviews with practitioners driving the primary mental health care system in Manguzi were completed in English over a two month period. A total of 12 district hospital staff and three NGO staff were interviewed over the course of six weeks in Manguzi community, on days when I was conducting ethnographic observations. Many of the interviews were slotted into lunch hours and breaks in between patients, making our discussions and interviews a part of the daily clinic and hospital life, with many interviews including references to patients that we had engaged with. These interviews were conducted in English, and transcribed at the end of the week to further the theoretical sampling process.

Specialist interviews (with the regional and tertiary psychiatrists) were conducted in Durban during a two week period in December. One interview was conducted during a visit

to Town Hill, the main psychiatric referral hospital in the province. The second was a telephone interview with the lead psychiatrist in the Manguzi hospital catchment area. In-depth semi-structured interviews were shaped by similar themes to those with community women (see appendix b for interview schedule). The interview schedule for traditional healers was a modified version of the service provider schedule.

4.3.3 ENGLISH TO ZULU TRANSLATIONS

English interview schedules and consent forms were first translated into Zulu by an independent party, a lecturer on Zulu language and culture at a London-based university. All English and Zulu versions were approved by the London School of Economics ISP research ethics board, the University of KwaZulu-Natal ethics board, and the KwaZulu-Natal Department of Health research ethics committee. These translated forms were then revisited by the local FA staff to address any local variances in dialect. The final Zulu translations contained only small variances, which related to mental health concepts. For example, sadness/depression, originally translated to *nokudabuka*, was debated amongst the rural FA staff and changed to *ukuphathekakabi*, which literally translates to sadness of the heart. Anxious/anxiety, which was originally translated into *nokuzwisisa* was debated by the FAs for some time, in an attempt to find one word that best described the state/emotion often referred to in typical medical mental health discourse. Eventually, it was decided that three words would best convey the type of feelings associated with the ‘anxiety’ that was being probed by the survey: *ukwesaba*, which translates to being fearful or being worried; *ukuthuka*, which translates to being shocked at the unexpected, and being nervous about something; and *ukungakululeki*, which translates to ‘feeling uncomfortable with something in your environment’.

4.3.4 QUALITY CONTROL FOR COMMUNITY INTERVIEWS

One of the hazards of conducting cross-cultural research is the fact that the final versions of interview transcripts that the researcher analyses have been filtered through multiple translations – from the translation of English schedules, to Zulu, and then from Zulu responses back to English text. Each level of translation potentially increases the researcher’s distance from the data. In order to remain grounded within each interview, I included a series of procedures to ensure quality control: the creation of real time data interview sheets, and debriefing meetings following the interviews with community members. The post-interview discussions are strategies promoted by Swartz (1998) in an effort to overcome the problems of working across language barriers in mental health services.

Debrief meetings were an opportunity to flush out more details of the stories that were shared by community women that may have been initially condensed during the real-

time translations (Vasquez & Javier, 1991), and to give my FAs an opportunity to discuss any difficulties they experienced during interviews they conducted in my absence.

'Real time' data sheets were completed during every interview. The worksheet was an adapted interview schedule, with blank spaces where the FA could detail participants' answers to each question. Worksheets were returned to the FA who would listen to the original recording, filling out further details as needed. I reviewed each worksheet at the end of each day, tracing the 'story' from the interview, and checking that all the main areas of concern in the interview schedule were addressed. Interview recordings were then fully translated and transcribed into English documents by a third party transcription company with experience in health and HIV-related studies. English transcripts were back-checked against the work sheets from interviews, in order to confirm continuity across translation from Zulu to English. 20 percent of full transcripts were fully back translated by an independent research assistant with experience in qualitative interviewing techniques in Durban. During this process, only minor grammatical errors were identified.

4.3.5 SIT LIKE A LADY: AN EXERCISE IN ETHNOGRAPHY

Ethnography is traditionally used to investigate the social organisation of communities. The ethnographer's interpretive categories about the world they explore emerges through their reflexive analysis of the data collected during fieldwork. Ethnography has been characterised by Geertz (1973) in terms of the distinction between thin and thick descriptions. He asserts that to complete ethnography, a social researcher must embrace the complexities of a social field: its matrices of interactions, relationships and processes, in order to become 'thick'. He asserts that the researcher must then build interpretive accounts of our specific interests, and the intentions of the actors who are engaged in the situation. With this definition in mind, inclusion of ethnographic approaches in this thesis fits a desire to attend to context.

The application of ethnography as a data collection method within a case study paradigm also supports grounded theory approaches. Charmaz and Mitchell (2001) argue that ethnography has the ability to 'connect theory with realities, not just with research' (p. 161). Given that an aim of this work is to produce findings that are useful to practitioners who support HIV/AIDS affected women's realities, including ethnographic efforts in this thesis remains a useful exercise.

I also draw on ethnographic approaches to support the reflexive process between field and data to ensure the linking of realities to emerging theory. The social world where mental health is negotiated, observed through the ethnographic exercises, acts as a mirror for the emerging theory to be compared against during the analytical process, which for the most part, occurred following my physical departure from the field.

The use of ethnographies in social representations studies is also well documented. Jodelet's (1991) classic study of representations of madness in a French community uses a monographic approach (a method guided by many of the same premises as ethnography), driven by observations, interviews, and document analysis and collection of history, in the process of observing the lives and actions of a community. Her application of ethnography as a research approach diverges from its use in this thesis, though it serves the similar purpose of 'address[ing] a community in its totality and defin[ing] a field of analysis which is investigated in all its dimensions' (Jodelet, 1991; p.18).

The key distinction between the applications of ethnography as a *method* versus a *methodology* is in line with Duveen and Lloyd's (1993) *motivated ethnography*, an approach that streamlines ethnographic interests towards a specific context and purpose. In their study on the development of gender identities, ethnography of classroom settings was used to establish a description of gender as an organising dimension in classrooms. Their aim was to explore the ways in which gender structures classroom life, and thus reaffirming gender roles and identities in children.

In this thesis I sought to explore the 'complexities' of dealing with mental health in the community, and inserted myself as a participant within the aspects of daily life as they directly related to this. My completion of a motivated ethnography of services occurred through a series of what I call 'ethnographic exercises' that contributed to the development of a richer understanding of the contexts where my case study is situated. This was handled through:

- 1) Reading and analysis of histories and policies relating to mental health within South Africa and KwaZulu-Natal Province. Though this appears initially within chapter 2 as part of the literature review, I engage with it to a greater degree within chapter five, as a way to ground informal and formal observations collected within the field via field notes and diaries.
- 2) Participating in the daily practices of the community with emphasis on contexts that were linked to 'mental health' by the community actors and existing literature.
- 3) Documentation of these processes through structured and unstructured field notes.

Engagement with formal services was initiated by my induction meeting with hospital manager Dr. Makunde⁶, who introduced me to those who he felt were most involved with mental health at the hospital. My observations were organised within the contexts of: mental health clinics (at the hospital and at remote clinics); visits to the therapy department; field visits with the home based care team (to areas where mental health patients were located); and discussion with medical staff who engaged with mental health patients. They are organised in Table 6 below.

It was not in the interest of the research process to constantly remind participants of my position as a researcher. It is often in the interest of the ethnographer or participant

⁶ Name changed to ensure confidentiality

observer that those she interacts with come to forget her role as a researcher and simply become acquaintances or friends (see Hammersley & Atkinson, 2007). Also, due to the sensitive nature of some of the encounters, particularly within observations of patient sessions within clinics, it was important that my translator (when present) and I were seen as members of the mental health team. This often meant that I kept my note taking to a minimum in field, with intensive reflective sessions during spare time. At the end of every day, I would fill out each of these notes with reflective note taking, where I recorded details of the day's events and mental notes that I had made about interesting events or discussions in the field. Hand written diaries were divided into three sections – informal observations (and comments from conversations I had with community members), structured observations, and daily summaries (that were built around reflections). These notes were transcribed daily into a running Word document, with a date at the top of each page.

TABLE 6: STRUCTURED OBSERVATIONS

<i>Location of structured observation</i>	<i>Number of observations</i>	<i>Type of data recorded</i>
Hospital clinics	In-patient MH clinics (3 clinics x 8 hours)	Patient profiles/hx ; Reflective diaries on clinic setting/experience
	Multi-disciplinary team meetings (2 clinics x 3 hrs)	
Remote clinics (community)	Mental health/social work clinic (4 clinics x 8 hours)	Patient profiles/hx Reflexive diaries on clinic setting/experience
NGO	Meeting w/HBC and therapy dept. (1 meeting x 2 hours)	New Patient profiles/hx Reflexive diaries on clinic setting/experience
	HBC monitoring visit (9 hrs)	Patient profiles/hx Reflexive diaries on setting/experience
	Community HIV support group meeting (1 meeting x 3 hours)	Transcript of meeting Reflective diaries on clinic setting/experience

Patients were involved or discussed in structured observations in clinics and monitoring visits, and notes were organised around patient/participant histories: gender, age, social history, medical history and 'diagnosis'.

As previously mentioned it was also important for me to participate in typical Manguzi life as best as I could during my time in the community. My position as a welcome outsider

was something that I became cognisant of all too quickly, as described in the below excerpt from my first day at the NGO.

Jesse⁷ (director of the NGO) greets me with a great big smile, and a half hand shake-half hug that instantly makes me feel more welcome than the stares by the equally smiley, but relatively confused staff. Eventually they begin to make sense of me – that I am not Zulu – and it becomes a bit of a joke as they translate every name into English for my benefit – and while the one girl – whose name, both the English and Zulu versions, escapes me – goes round the room half mocking, half introducing me to everyone, I willingly accept my place as the butt of jokes, if it means some semblance of acceptance. It is a calling to my secret inner anthropologist: I should have learned the language better; for even after months of practicing and preparation my feeble clicks garner little more than chuckles and smiles from around the room (field note excerpt, November 2, 2010).

I sought to reduce this confusion, and the resulting distance it created by immersing myself in the life of the NGO and hospital staff as much as possible. I asked questions about as many things as I possibly could, learning and practising my Zulu with my field assistants, sharing my expertise in areas of child development and psychology with local staff, and consulting on a new community project being developed to support grandmother caregivers with financial management. By the end of the first week there was a much greater sense of normalcy surrounding my presence, which helped to alleviate the nervousness surrounding my decision to conduct interviews myself via translators. N, the older of my two FAs, originally asserted that it would be difficult for me to engage with community members as I was an outsider, and would have to ‘sit on the ground during interviews, and kneel until I was allowed to sit by the head of the house’ (field note excerpt, November 4, 2010), which she succinctly described as having to ‘sit like a lady’⁸ (field note excerpt, November 5, 2010). My western feminist critiques of what such notions even meant were of no relevance here. I told her that I had no issues with sitting on the ground, but to increase her comfort with my more active participation in the field, we spent an afternoon practising how to enter each home and sit in the traditional custom for women in Manguzi.

Within hospital settings I took a similar, though relatively disengaged, approach at reducing boundaries. The lack of senior mentorship for mental health providers in Manguzi caused my initial introduction as a ‘psychologist’ to be greeted with cheers. My constant reiteration that I was not a practising clinical psychologist - and thus could not sign off on forms, diagnostic decisions, or routes for treatment - was common in early sessions. Thus, I had to rely on other methods to increase comfort with my participation in the hospital community, wherein I immersed myself in many ‘non-clinical’ practices: taking meals and going for runs with hospital staff; attending ‘sundowners’ at the end of my days; and beginning those days in song and prayers with the NGO staff. This process was all a part of

⁷Name changed to ensure confidentiality

⁸During public gatherings and meetings, women in Manguzi most often sat on straw mats, with knees bent and tucked to one side of their bodies, most often the right. Many women who suffered from back issues and seek support from occupational therapists have muscular weaknesses that reflect prolonged sitting in this position.

my desire to integrate myself fully into the contexts of Manguzi life, so that my analysis could remain grounded within an understanding of the realities that face those who experience and support mental well-being as best as possible.

4.4 DATA ANALYSIS

The data collection methods explained sought to triangulate my research questions from a range of sources, each driven in some regard by sensitivity to context. The analytical procedures that establish the forthcoming empirical chapters serve a similar purpose. Chapter five, which presents the motivated ethnography of community as an interactive space, draws on empirical data through analysis of field notes using a 'global' level thematic analysis, as well as analysis of selected policy documents. Chapters six and seven draw on a hybrid of grounded theory and thematic analysis procedures in order to produce the content of knowledge systems and identify dimensions of community competence to promote 'transformation' of mental ill-health and more health enabling environments. Chapter eight is a synthesis of findings from across the first three chapters driving recommendations for community mental health competencies. The particulars of each of these procedures are outlined below.

4.4.1 ANALYSIS OF MOTIVATED ETHNOGRAPHY SOURCES TO SUPPORT DESCRIPTION OF COMMUNITY: GLOBAL THEMATIC ANALYSIS

The development of a motivated ethnography served to highlight the contexts that contribute to community as place and symbolic space with regards to mental health in order to build a 'thick' description (Geertz, 1973) of the mental health service sphere. The transcribed field note diary was analysed using computer assisted coding software. Atlas –TI (version 6.0) was used, and through multiple readings of the single document, global themes relating to dimensions of community were highlighted. Units of coded data consisted of larger passages with a minimum length of two paragraphs. The use of such large chunks of text for a unit of data contrasts with many thematic analysis procedures; for example, Attride-Stirling's (2001) network analysis procedures or related grounded theory analysis that make use of much smaller segments of data for coding, such as line by line. This 'broad' parsing of data was completed in order to maintain the richness of each description or comment, and to more likely highlight many of the complexities within these broad themes that comprise many ethnographic descriptions. Two global themes emerged from this analysis: community contexts and mental health services. These were then organised into components of 'place' or symbolic place where appropriate, and supplemented by review of similar themes from anthropological and historical texts

discussing similar issues in the KZN region, policy documents, and observational data I collected in the field. The coding framework for this analysis is presented below.

Table 7: Coding framework from grounded thematic analysis of motivated ethnography

Global Theme	Organising themes	Basic themes	Data sources
Community contexts	Structural contexts (place)	Poverty	Survey data: DoH household survey Field notes Case profiles Interviews (n= 20 community members)
		Social development	Survey data Field notes Case profiles Interviews (community members; NGO staff n= 3)
		HIV/AIDS	Survey data Field notes Case profiles Interviews (hospital staff; community women; NGO staff) Observations of NGO home visits
	Symbolic contexts	Family relationships: Marriage and polygamy	Regional anthropological studies (Hunter, 2010; Krige 1936; Sibisi 1977) Field notes Interviews (community women; NGO staff; Hospital staff n = 12)
		Behavioural norms: Good mother/woman	Interviews (community women n= 12) Regional anthropological studies (Hunter, 2010; Krige 1936; Sibisi 1977)
Mental health service sector	Delivery in primary health care (place)	Policy recommendations	Policy documents: 1. South African mental health care act (2002) 2. Strategic implementation plan for delivery of mental health care services (KZN 2003) 3. Standard treatment guidelines for common mental conditions (KZN 2006) 4. Policy for mental health psychosocial rehabilitation KZN DoH (2010) Literature review Interviews (n= 2 policy experts)
		Mental health systems funding constraints	Literature review Interviews (n= 2 policy experts)
		Human resource constraints	Literature review (chapter 2)
		Reality of policy in practice	Observations of clinic settings and practice (76 hrs)
	Traditional systems of healing (symbolic space)	Zulu perspectives on health and healing	Historical and anthropological texts (Parle, 2007; Flint 2008) Literature review (chapter 2) Policy documents: Traditional health practitioners act (2004) Interviews with traditional healers (n =8)

4.4.2 DEFINING KNOWLEDGE SYSTEMS AND COMMUNITY COMPETENCIES: GROUNDED THEMATIC ANALYSIS

A hybrid of grounded theory (Glaser, 1992; Stern & Porr, 2011) and thematic network analysis (Attride-Stirling, 2001) was used to map the content of the social representations that compose the knowledge field within primary mental health care services in Manguzi. From this analysis, components of a potential community mental health competency framework will also be identified. My decision to combine tenets from these related analytical procedures is rooted in my overarching interests in remaining anchored to the lived realities of 'contexts' throughout this work.

The purpose of a grounded theory analysis is to identify the core problem or issue of concern within the social field, and the processes that are already at work within a community engaged in mediating that problem (Glaser, 1992). This particular approach was selected given its ability to support the establishment of a community and contextually-driven definition of mental health, and a desire to uncover the ways in which community actors are already involved in addressing their own mental distress. In adopting a grounded theory approach I seek to display a level of 'trust' in the validity of communities' knowledge about the problems at hand, and their strategies to tackle them. Furthermore, this approach recognises the agency within communities which can be examined and elevated into theoretical concepts to help inform notions of 'best practice'. These efforts contribute directly to the desire to develop recommendations for community mental health competencies as I previously outlined in chapter three.

In my approach, I infuse these tenets of grounded theory with the more systematic approach of Attride-Stirling's thematic network analysis (TNA). The modifications to the TNA approach focus on the re-infusion of attention to context, and constant comparison, to the most basic level of data reduction. Rather than work with her basic level of simple codes, which to a certain degree removes context from the first level of analysis, I use Stern and Porr's (2011) method of in vivo codes as the first level of extraction. Such codes are direct summaries of text as the first level of data, which are used to establish basic codes/themes. This added dimension carries contextual issues along further, to ensure that the theoretical framework established is representative of community experiences and stories. Below, I present the stages of my analytical procedures, and outline how Attride-Stirling (2001) and Stern and Porr's (2011) approaches to grounded theory analysis contributed to each.

Step One: Open coding to generate in vivo codes

Within grounded theory analysis (Stern & Porr, 2011) and TNA (Attride-Stirling, 2001) the first step involves the coding of textual material in order to reduce data into meaningful segments of text. However, while Attride-Stirling states that coding should be guided by a

pre-established coding framework (which may be informed by theory, a set of theoretical constructs to be explored systematically, or recurrent issues within the texts), I chose to approach each text with the aim of allowing the data to generate a coding framework. This approach is referred to as 'open coding' within grounded theory. A line by line analysis is seen as the 'golden rule' (Glaser, 1991) within this approach, aimed at ensuring that nothing is missed within the data. In my adaptation of this process, interviews were analysed using line by line open coding. First, *invivo* codes (codes that were directly derived from the interview text) were generated for each interview, creating very descriptive accounts of what was happening within the data. This generated a secondary document that contained line by line *invivo* codes for each interview. These interviews were then coded again line by line, to organise these *invivo* codes into *basic themes*.

Step Two: Extracting basic themes from invivo codes

Following multiple reading of interviews and the reduction of data into direct summaries or *invivo* codes as described above, basic themes were generated to provide the basic unit for my thematic analysis. Within traditional TNA, basic themes are defined as

Simple premises characteristic of the data, which on their own say very little about the text or group of texts as a whole. In order for a basic theme to make sense...it needs to be read within the context of other Basic Themes (Attride-Stirling, 2001. p.388).

However, these 'simple premises', which only gain their meaning in the context of other codes, ultimately support the development of an interpretation of the issue that stands the risk of evolving in context reduced ways. Drawing on the *invivo* codes generated in step one helped to avoid this reduction. *Invivo* codes were entered into an Excel spreadsheet, where the remaining coding procedure was handled. In generating basic themes for analysis in chapter six, additional steps were conducted, where the 'contexts' present within an *invivo* excerpt were extrapolated and recorded, so that each basic theme could be reflected back against a context for subsequent interpretations occurring in step three. This step allowed me to continually carry the 'contexts of the life world' through my interpretation of the development of knowledge systems and processes at work within the activation of these knowledge systems. These contextual codes aligned with contexts of community identified in chapter five in all instances, except for one – which I describe in later chapters.

Step Three: Building basic themes into organising and global themes – elevating issues to theoretical and conceptual levels

In classical grounded theory analysis, open coding *begins* with a goal to generate an emergent set of categories, which work towards the development of a theory. According to Glaser (1991), this process allows the analyst to see the direction in which to take their work, before focusing on a particular problem – allowing the problem of the community to become evident through the comparisons of codes generated from each interview.

Glaser asserts that open coding operates with a set of rules that facilitate the elevation of the issues affecting the population to a theoretical or conceptual level. Stern and Porr (2011) recommend that analysts work towards the development of concepts and categories, through asking a series of questions through the process: *What is the data a study of?* (to remind the researcher what the study is about); *What category does this incident indicate?* (to support the generation of codes that relate in some way to other codes). In this thesis I applied these rules to the third stage of my analysis, which focused on the development of organising and global themes, which are defined within a TNA as:

Organising themes [are] middle order themes[s] that organise the basic themes into clusters of similar issues... that summarize the principal assumptions of a group of basic themes, so they are more abstract and more revealing of what is going on in the texts.... Their role is to enhance the meaning and significance of a broader theme that unites several organising themes...

Global themes are the super-ordinate themes that encompass the principal metaphors in the data as a whole.... like a claim in that it is a concluding or final tenet... as such global themes group sets of organising themes that together present an argument, or a position or an assertion about a given issue or reality.... [they] tell us what the texts as a whole are about within the context of a given analysis (Attride-Stirling, 2001, p.389).

Within a TNA, organising and global themes carry significant parallels between the basic elements of grounded theory analysis (concepts and categories). However, organising and global themes are differentiated by Attride-Stirling's extension of Toulmin's Argumentation Theory (Toulmin, 1958), which seeks structured methods for analysis of negotiation processes, in an effort to provide a clear and observable pathway that displays how data are used to help justify a particular claim about a social world.

By maintaining the use of organising and global themes, I seek to ground the theoretical recommendations made for community mental health competencies, within a clearly observable argument that moves from simple backings (basic codes, which are rooted within rich attention to context), to warrants (organising themes), which support a particular claim (the global theme). Furthermore, the open display of a clear argument driving theoretical concepts relating to a social world may help to overcome criticisms of the generalisability of data flowing from a local context-specific study. In the table below, I present an excerpt from the analysis completed in chapter six, to highlight the clarity enabled by adhering to a TNA procedure for the final phase of the analysis.

Table 8: Sample framework from grounded thematic analysis procedure

Coping strategy (global theme)	Process (organising theme)	Coping behaviour (basic theme)	Context and content (invivo codes)
Psychological framing	Acceptance	Self-talk/affirmations	I tell myself to just put my spirit down [calm down] when I worry about my troubles – there is nothing I can do
		Advice seeking (family)	I talk to my mother about my problems with my father-in-law – she tells me to focus on my children so I have let it go
		Advice seeking (friends)	After husband left I talked to a friend who advised me to stay and take care of children – I have accepted that men are men
	Faith/hope	Self-talk/affirmations	I tell myself to just put my spirit down [calm down] when I worry about my troubles – there is nothing I can do
		Advice seeking (priest)	I talk to the priest about my husband [drinking problem] and he says if we pray for him then it will get better

CHAPTER CONCLUSIONS

This chapter has outlined the context driven methodologies that guided this study. The selection of case study methodology helped to foreground and manage the complexity of context and community within a study of community mental health. Within my case study, I drew on a series of methods to further facilitate engagement with, and analysis of context- and how interactions within it, or reflected against it, come to provide more useful understandings of knowledge and how it shapes our behaviours. These methods included a motivated ethnography driven by selected ethnographic exercises, in-depth interviews, formulation of case profiles, and applications of grounded theory. The analysis of data was similarly informed by a desire to remain connected to contexts throughout, while providing a logical process of argumentation for theoretical concepts that emerged through analysis. To achieve this, I used a hybrid approach of grounded theory and thematic network analysis which resulted in a framework that provides a context-infused argument for how understandings of distress and context influence participation and action around community mental health.

This chapter presents the motivated ethnography of Manguzi, and the first empirical chapter of this thesis, which addresses the research question: ***what are the contexts that frame the experiences of mental health and illness, as well as the delivery of treatment and support?*** As argued in chapter three, approaching community as an 'interactive space' driven by intersections of place and symbolic space enables a more accurate understanding of how mental distress can be targeted and promoted by primary care services. In line with critical and cultural psychologists and psychiatrists (Kleinman 1998; Swartz 1998) I argue the importance of a perspective that acknowledges that the pursuit of insights about mental health must occur against the backdrop of community life; its social interactions, traditions, challenges and successes. Ethnographic approaches are a useful tool to support this form of exploration.

Ethnographic exercises (detailed in chapter four) provided a platform to consider how community life—in respect of its ability to shape understandings and knowledge systems that operate within various communities— influences not only how mental health is understood and experienced, but how the resolution of states of mental distress is approached. Findings from a global thematic analysis of ethnographic data sources – field diary, structured clinic observations, unstructured observations— are combined with interview excerpts and references to key mental health policy, and anthropological texts exploring communities in the KwaZulu-Natal province, to develop a 'thick description' of Manguzi. These symbolic, place-based and personal contexts of Manguzi become the scaffolding against which the analysis in chapter six and seven are built to insulate against the reduction of context in analytical procedures. The present chapter is divided into three sections, each punctuated by case profiles of women whose life experiences reflect the particular aspects of community addressed in each section.

This chapter begins with a discussion of the socio-structural dimensions of community: geographical boundaries, economic and housing conditions, epidemiological distributions of mental health issues and HIV in Manguzi. A discussion of how HIV impacts community life is followed by a discussion of how Zulu cultural norms relating to family, marriage and motherhood have changed over time in the region, and the impacts these changes appear to have on women's well-being. The second half of this chapter explores the institutions organised around mental health services in Manguzi. In doing so, structural and symbolic issues pertaining to the history of responding to mental health in KwaZulu-Natal, the province where Manguzi is situated, are discussed. The chapter concludes with a diagrammatic summary of the contexts of community that emerged from the motivated ethnography, providing the contours of the experience of mental distress and well-being in Manguzi.

Mango trees

Men under mango trees,
sit pondering their present futures,
and lamenting a not so distant past.
The heat is a shield
unrelenting, thick and surrounding everything.
It permeates the conversation
dampening each word with a moist reality that seeks to remind them
that this day, is one for struggling.
But they, do not struggle.
These men, they sit
under mango trees
sweat dripping from sparse beards
bottles of brew perspire in unison with their masters
each time it lifts to the lips – cool refreshing denial
pours down each throat.
But what is left to do
when the struggle has left you with barren lands for your home?
The body ages, sons and daughters move far from home
to distant universes where Baba cannot reach.
When the struggle has left you with mouths you cannot feed
free to be educated; but bare foot and sparsely clothed?
They finish and find no futures.
And the rains - when they do come,
do little else but dampen your floors, rattle on pots and pans
for the roof over your head is still made from sticks and stones.
The struggle, *a luta – continua*.
And the heat also continues,
so the men sit under mango trees.
Because that is all there is left to do.
But Women,
You watch them sit
While carrying your child,
Your future, the world
on your back.
Woman, for you there is much left to do.
While,
your men sit,
under mango trees.

(Field note excerpt, November 23, 2010)

5.1 COMPLEXITIES OF COMMUNITY: KWA NGWANASE, 'LAND OF THE KING'

In a tiny car that was, to be fair, more rust than car, I made the first friends of my field experience. Kim⁹ and her colleague were on a weekend break in Durban, and had kindly offered to give me a lift to Manguzi. Such trips were organised around stops at the upmarket Woolworths to stock up on essentials which, I soon discovered, equated to Lindor chocolate and bottled water. Kim was a junior physiotherapist nearing the end of her community service placement at Manguzi Hospital, and given the proximity of my Durban flat to two Woolworths, picking me up was a necessary kindness.

While pulling out of the drive, the seat next to me towering water and more assortments of chocolate than could be counted, Kim asked me about my work. When I explained that my time at Manguzi was driven by a desire to see how rural communities managed mental health services, she smiled silently, nodding in the absent way that most people do when one begins to explain research projects. When I asked her how big of an issue she thought mental ill-health was in Manguzi, Kim perked up – looked at me in the rear view mirror – and with a smile responded, *'Issue? That's an understatement. Trust me, you'll have no shortages of things to see, people to talk to, or "crazies" to meet'*.

5.1.1 COMMUNITY OF PLACE: STRUCTURES AND SOCIO-DEMOGRAPHIC CONTEXTS

KwaZulu-Natal (KZN), the province of interest for this study is known in South Africa for two things: consistently warm ocean tides and the HIV pandemic. Prevalence is the highest in the country at 37% (Burns, 2010), with a recent study of a rural community identifying rates as high as 57.5% (Welz et al., 2007). Its communities have become a key location to explore the contexts of HIV/AIDS, and a fitting location to explore supporting mental health within these contexts, given the presence of high mental illness risk factors. These are driven by the highest proportion of people living beneath the poverty line and the second highest murder rate in the country (Burns, 2010). Manguzi Hospital is located within the most under-resourced area for mental health in the province. At the time of field work, two full-time psychiatrists were responsible for overseeing a catchment area of 2,344,038 individuals (Chief Psychiatrist, Area 3 KZN province, personal correspondence, December 2010).

Manguzi is the largest town in the Umkhanyakude health district located in the northern tip of the province, an eight-hour drive from Durban and its specialised psychiatric services. The journey to Manguzi passes through a myriad of landscapes, growing more disparate with each passing kilometre. The paved roads fade into red earth and sand, and

⁹ Name changed to ensure confidentiality

gated communities are replaced by sparsely built structures with tin roofs with dirt floors. Arrival deposits you in a locale antithetical to Durban's mansion-lined streets and urban townships, a pillar to South Africa's staggering inequity (Gini co-efficient, 0.58) (Coovadia et al., 2009). The Umkhanyakude district is bordered by the Indian Ocean to the east, Mtubatuba in the south and Mozambique to the north, and is further subdivided into municipal sub-districts. The Manguzi Hospital catchment area is bordered by the Mozambique to the north, Indian Ocean to the east, Pongola River to the west, and Manzegwenya Plantation to the South, with a population of 106,251 distributed among 23,163 households (Department of Health KZN, 2010). The white shaded area in highlights the Umkhanyakude district.



FIGURE 14: RESEARCH AREA

The Manguzi sub-ward is further divided into a number of Izigodi¹⁰ ruled by local traditional leaders, or *Induna*. Community women interviewed were distributed among five Izigodi: *Phelendaba*, *Engozini*, *Skhemelele*, *Scabazini* and *Kwamahlangu*. In terms of the Izigodis' range in proximity to the Manguzi Hospital: Scabazini and Skhemelele were located the furthest away (approximately 100 kilometres drive); while Engozini was also the centre of town, and housed the hospital. Accessing the homes of many community members was hindered by the absence of paved roads, making some homesteads impossible to find. Field notes describing a trip to Kwamahlangu highlight a typical outing to a 'close' Izigodi:

2km shy of the Mozambiquan border, and just ten minutes out of town, you turn off the paved road and on to one that is... well not a road. Barren flat land stretches into the distance; suddenly we are driving through makeshift football fields, with posts

¹⁰The term *izigodi* refers to a regional division -or district- often marked by the proliferation of homesteads linked to a particular clan or surname. This is enabled through a traditional practice within polygamy described by Dalrymple (1983) that outlines the practice of fathers giving sons their own site to begin a family not very far from his original home. Families with large numbers of males have a higher likelihood of occupying a large geographical space within the community. The number of *izigodi* in the Manguzi sub-ward may reflect the proliferation of many homesteads within the region at some point in its history.

constructed of hollow tree trunks. Four wheel drive is a necessity, so are sunglasses today. Everything feels like its melting: car seats, the candy I bought for breakfast. It's dry and hot up here. I'm sure if you dropped an amber cigarette the whole place would go up in flames. The grass is window high on either side of the car, and envelopes us as we drive towards a spattering tree line at our horizon to the north. The GPS bids us to go left, and so we turn onto another 'road', marked only by grass flattened by the last NGO or government vehicle to pass this way en route to the remote clinic. On the way, we pass high school students, dressed in uniforms that make me sweat even more at the sight of them. The remnants of colonialism have them cloaked in heavy skirts extending well past the knee, long sleeved shirts, and cotton jumpers. God, it's almost criminal (field note excerpt, November 9, 2010).

The area is populated predominantly by African Zulu speakers, 52% of whom are women. Zulu culture dominates within the region, and shapes the structure of many households, behavioural norms that govern family units, and traditional belief systems around health and healing. The marital household, once considered central to all aspects of community life prior to the advent of colonialism in the late 1840s (Hunter, 2010), has shifted significantly in recent decades, but remains integral to understanding communities dominated by Zulu descendants. Prior to the advent of colonial rule in KZN, homesteads were led by male heads of the household, who could marry polygamously if they had enough resources to support each family to which a wife was affiliated. Krige's (1936) work provides one of the earliest accounts of the social system of Zulu peoples, presenting each Zulu village or household as a microcosm of Zulu political and social relations:

The village is a self-contained economic unit in which a complete life can be led. Each village has its own cattle that supply the milk and its own fields in which sufficient ...vegetables are grown to supply the needs of the inhabitants... the village is both the basis and the pattern of the political organisation of the tribe... [for example]the arrangement of the huts in the Zulu village is based upon the status of the different wives... the chief wife, or inkosikazi, occupies the indlunkulu (chief hut) which is situated at the top end of the kraal exactly opposite the main entrance...the inGqadi or right hand wife is a kind of supplementary great wife, so that if the indlunkulu fails to provide an heir, the eldest male of the inGquadi hut becomes inheritor on his father's death... the hut of the inGquadi wife is situated on the right hand side, i.e. to the right of the main entrance, looking up towards the chief hut (Krige, 1936, p.39-41).

In contemporary Manguzi, the search for participant homesteads often ended at the entrance to the remnants of these systems: roughly circular enclaves where, depending on the size of the household, multiple single roomed brick or hut structures would be arranged, in a way that bore little resemblance to the physical structures outlined by Krige, but which instead bore the marks of broader socio-political transitions. In the years post-apartheid, waves of structural development seeking to rectify massive inequities in access to basic services once again changed the structural shape of rural communities: building new homes, and constructing access points for electricity were primary developmental targets. According to the 2006 census, approximately 60 percent of the population in Manguzi resides in 'western style' housing of brick and mortar, while 40 percent still reside in traditional huts with reeds and thatch.

However, the realities of these cement structures are a far cry from ‘western style’ homes. My time spent on the homesteads of many community members presented structures that defied gravity in staying upright.



FIGURE 15: HOMESTEAD, SKHEMELELE IZIGODI, NOVEMBER 2010 ©OAKBAY JOHNNY

Furthermore, such survey data paints only a partial story of housing development – obscuring the process involved in obtaining and sustaining ‘western’ homes. Cement walls are topped with metal sheets as roofs, floors remain composed of earth and mud, or cold cement lined with discarded bags of maize or mealie meal. Many defined their homes as ‘not proper’ based on absence of modern wares – including microwaves or televisions. The images in the above photograph, along with stories of women like Bumi, whose family endured the painstaking processes to construct a single room concrete dwelling over five years by paying for materials brick by brick, provide a more accurate view of housing situations in Manguzi. Her 11 family and extended family members sleep together in the single room dwelling, reflective of conditions endured by many of the 60 percent of Manguzi community members believed to be in better standing given their association to ‘western style’ houses:

Ro: What do you think can help you deal with the things that make you anxious, or worried or sad?

Bumi: If the government can build a house for me because I don't have a means to build a house as you can see – the house we are living in... my husband built this house over a very long time, ...even though I'm not upset (sad) anymore, it hurts because I can't build a bigger house for us, or a room for just me and my husband so we can have privacy.

This is not to negate the positive waves of development that have touched Manguzi families. Access to marginal but steady incomes have enabled some the acquisition of larger ‘spoils’ of progress: some homes were fitted with televisions, some structures had multiple

rooms, and a few were well-off enough financially to have fully furnished homes. The excerpt below comes from field notes, and documents an occasion of arriving at one such home to interview a participant:

Our first interview of the day is with a woman named E... at 37, she lives in a two room house that is appears to be kitted out with all the finest wares, the inside is fully furnished, a freezer, and large television that is linked to a satellite dish which is precariously fixed to the roof outside. In the background, as we begin our interview, plays MTV, and I find myself distracted by a Chris brown music video, which I ask her to turn off (instead of just muting it) so we can actually begin.

However, such fittings did not always equate to overall security, or improved quality of life. What followed in P's interview highlighted ongoing financial insecurities and a desire to make changes to her living conditions following the death of her husband:

Ro: How did he die?

P: He was affected by generator at work where he was working in Durban...in March this year....It's hard because we have children and he used to support us, but now I'm left alone to take care for them.... I try to manage even though I don't have enough... I'm living in a two room house and I wish to complete my house but I'm earning too little at work....

R: Do any of your kids receive the child support grant?

P: No because I'm working for government [as hospital cleaner] and earn too much.

R: What do you do for extra money if what you work is not enough?

P: I'm not doing anything; there is nothing else I can do.

Employment opportunities in Manguzi remain scarce. 89 percent of males and 90 percent of females were identified as inactive or unemployed in the Umkhanyakude district in 2006 (Statistics South Africa, 2006), leading many to rely on social welfare grant income. In the same year, 48 percent of households in the district were identified as recipients of support grants, and 86 percent of all eligible pensioners received an old age grant.

Table 9: Social welfare grants identified as most common in Manguzi by NGO staff (Source: Coodovia et al., 2009)

Grant Type	Eligibility	Value (as of 2011)
Child Support grant	Child or parent's income does not exceed R 1,100/month until the age of 14	R 260/month/child
Disability grant	Based on medical assessment	R,1,130/month
Grant for older persons	Age 65 and older	R, 1,130/month

In my interview with W, the NGO staff member leading the paralegal team that assists community members in grants applications (and often receives referrals from hospital clinics), three grants were identified as most common in the Manguzi area. Table 9 details the value of these grants as of 2011. The largest grants are old age pensions and disability grants and are often used to support members of the extended family. Grant income provides families with some semblance of financial security in the face of few other options, but income provided by grants is often insufficient to support entire families.



FIGURE 16: RO (L) AND RA INTERVIEWING PARTICPANT, ENGOZINI IZIGODI, NOVEMBER 2010
SOURCE: FIELDPHOTOGRAPY, ROCHELLE BURGESS

The resultant picture of development in Manguzi remains highly complex, and points towards the ongoing difficulties managed by community members, even in the face of some

Box 4 - Case profile: Bumi

When I arrive at Bumi's house in Skhemelele, we have to wait for nearly 40 minutes for her to get back from her field. While I wait, I try to count the children. I get lost at around 8, but feel as though I may have counted some of them twice, two emerge from the house: two come running up from the field just to the left, others trickle in from the main road, behind trees, and one naked, running from a bath orchestrated by the eldest daughter somewhere behind the single room dwelling. Bumi arrives, a pile of sticks miraculously sat atop her head, buckets of water in each hand. She is bright, alive, the quintessential mother: all warmth. She smiles and laughs at my awkward Zulu, and my struggles to 'sit like a lady'. Occasionally, she calls out to her husband for clarification on questions I ask. He sits just five feet behind us, under a mango tree telling her how long they've been married, and the ages of their 6 children. They laugh about it over our heads, eventually giving up after barely scraping together the fourth child's age.

They have lived on that land for 15 years, but the brick single room structure that sits at the centre is five years old, as it took them that long to mobilize the resources her husband needed to build it. He has been unemployed for 15 years, and in that time, Bumi managed to run their household with proliferating numbers of children, one the income from one child support grant – 250 rand/month. These were some of her hardest times, as she was often very sad and worried all the time, and felt badly for her husband often. Their current home is still insufficient; she is saddened by lack of privacy the single bedroom provides, as parents and children all sleep in the same bedroom.

Bumi asserts that nothing in life makes her sad anymore and that since she was able to secure additional grants for her children there has an increase in her income and her feeling a relief from a lot of pressure around increasing family survival. She visibly struggles when talking about taking care of her siblings, four of whom have died from HIV. Taking care of them when they were very ill was a time of sadness. Most of her current worries stem from the impacts of this experience: she is now expected to care for nieces and nephews, stretching her own limited resources. When her sister's children visit and spend the night, (often coming for food and clothing) 11 of them share the one bedroom.

Bumi is also a member of her church prayer group, where she shares her concerns about her husband's unemployment, and difficulties running a household with insufficient funds with other women. She says that they are advised to pray together, and to find a way to accept the life of an 'older woman' now; acceptance that things are hard, but they must be grateful with what they have.

Field note case profile – November 18,2010

structural gains: an important consideration when evaluating the impacts of societal conditions on emotional well-being. Bumi's case study (box 4) encapsulates how a long-term struggle with poverty and unemployment shapes women's mental distress. A mother of six children, Bumi lives with her husband in a single room brick structure. She also supports the children of her four siblings who died from HIV-related causes. Her husband, who works informally as a repair man for families around town, has been unemployed for 15 years. They supported their growing family on the income from a single child support grant, which she describes as the saddest and hardest times of her life. Although she describes an improvement in her life through increased access to grant income, she articulates fear about the pending termination of these grants as her children get older.

5.1.2 'HE DIED OF THAT SICKNESS' - HIV/AIDS IN MANGUZI

Bumi's story also highlights another factor that emerged within the global thematic analysis of field data: HIV. Recalling the research questions presented in chapter two, this thesis takes interest in how women like Bumi experience the relationship between mental health and HIV, building on existing epidemiological markers of the relationships that currently dominate literature in the area.

On my first visit to Manguzi Hospital I was greeted by the hospital manager, who introduced me to Dr. M, the interim medical manager during my fieldwork. A tour of the facilities en route to the mental health 'ward' – which I soon discovered to be a large prefabricated office container – was the first order of business for one of three doctors on the hospital premises that day. We walked down a series of open-air corridors, with general male and female wards located on each side. Patients lay listless in beds reminiscent of 1950s films – nurses heaving to adjust pillows, in the absence of electronic adjustable beds which are the norm of many hospitals only eight hours away. HIV posters plastered every wall; every notice was punctuated the red HIV awareness ribbon. Eventually, we arrived at a large ward that backed onto an open green space, with patients wandering round or sat in blue worn and re-worn hospital outfits, barefoot, and with skeletal frames whose upright positions seemed the work of miracles. We had arrived at the drug resistant (DR)TB wards that, Dr. M informed me, primarily housed patients with co-morbid HIV. Dr. M informed me that most hospital efforts are related to managing HIV and AIDS in the community, and in an effort to hammer this home we moved onto the HIV clinic – housed in its own building at the front gates of the hospital:

This structure is a testament to modernity - pristine, gleaming white floors in the waiting room, rows of comfortable looking chairs that could have been exported from any doctor's office in London. The head nurse sat behind a large table where she directs patients to various areas – one to collect medicines, the other to collect test results. The chaos that marred the outpatient clinics on the opposite end of the hospital is not to be found here.... The only reminder that this clinic is situated within the same community are the presence of the community members themselves, who are so numerous they spill out from the waiting area, and onto the front steps, as sparsely clothed as those in the HIV-TB ward (field note excerpt, November 8, 2010).

To say that Manguzi is 'affected' by HIV is a statement that shines very little light on the reality of the situation. The prevalence rate in Manguzi is 36% based on the larger survey linked to this thesis completed in 2010-11 (Casale et al., 2013), exceeding the provincial prevalence of 25.8% (Setswe, 2009). Tholouwazi, the local NGO of focus in this study that works in collaboration with the district hospital (accepting referrals to address socially-driven needs of many patients, which will be discussed in greater detail in subsequent sections of this thesis), was developed in a response to HIV in Manguzi. However, in a tale common to many rural South African contexts, efforts were expanded to

address the broader basic life survival needs faced by many HIV-affected families. Further discussions with W highlight some of this complexity:

We started off trying to support HIV orphans, but now we are assisting all of the vulnerable people in the community – we are assisting them to get ID, or children to get birth certificates so they can access grants – we do a lot of organising workshops for the community and ... we explain to the community how they can apply for certificates and ID's for their children... grants are really the only way that people can survive.

In addition to Tholouwazi's many programmes, which include support with applications for birth certificates and IDs to facilitate grant applications, they help HIV support groups which are facilitated at satellite clinics across Manguzi Hospital's catchment areas. There is a loose structure to their operation, with some groups run by clinic nurses marginally supported by hospitals, while others are formed organically by women who start sharing stories while collecting their ARV prescriptions.

While in Manguzi I attended one of the groups facilitated by a satellite clinic in Phelendaba, supported by Tholouwazi, and identified as being linked to mental health. We approached a group beneath a large tree, in typical Manguzi fashion, with branches offering slices of reprieve from the walls of heat that close in from all sides under the midday sun. During the session, there are no mentions of 'mental illness', 'depression' or any of the mainstays of a support group for mental health. Rather, participants are dealing with more immediate survival concerns, with discussion flowing between two key issues. First, are their interactions with government officials who were to support a microfinance effort that have met largely with disappointment. Second, were the impacts of HIV on their family lives – particularly on their children. The major concern shared in the observed session related to their struggles in informing their HIV positive children about their status, amid increasing reports of suicide attempts among young adults who discover they are HIV-positive (a topic of mutual concern in meetings observed between hospital and NGO home-based care teams).

We are so worried about them (children) – they are having a hard time dealing with it [finding out their status] and we were told that we could send them to the camp – but we have heard nothing back from sponsors, we know nothing. This is frustrating for us! (looks to group) - stop me if I am wrong! - (shouts in agreement)

More than half of the patients observed within mental health clinics also reported links to HIV. Doctors in clinics described interacting with HIV-positive or affected individuals on a daily basis:

The TB ward, just regular TB, usually they have HIV as well, something like 80% overlap, and but you cannot initiate ARVs until they've been on their TBmeds for two weeks, so you see a lot of very sick, very weak people. So they start on the TB meds, and you just hope that you make it those two weeks until you can start them on ARVs.... And here's a whole ward of those people. – Physiotherapist (community service)

The actual inpatients are looked after by everyone, but HIV is seen the most, I don't know what the actual proportion, but definitely over 50% of patients are HIV positive, so all doctors will look after them at some point. – Mental health/MDR-TB doctor

An interesting theme that emerged from field notes was the ways in which people talked about HIV, without actually 'talking' about it. Among those who lost family members to HIV, it was as though the word could not be said, first being described as *'that disease which is killing everyone'* before using its name. HIV-positive individuals themselves, however, had no issues with discussing their HIV, openly disclosing it during interviews with some taking a sense of pride in their ability to manage and cope with the sickness. Sisi's case (box 5 below) is an example of this instance, and also highlights how emotional distress, impacted by contextual hardships also complicate the management of HIV. As a 35 year old HIV positive mother of two girls, Sisi reported that she became infected while caring for her mother who struggled with AIDS-related illnesses. She described the passing of her mother, who was her only parent (her father had deserted her mother soon after her birth), as the only time in her life when she contemplated suicide. Sisi experienced abandonment first by her father, and later by the fathers of her two children. The relationship with the father of her youngest is particularly strained: 'I couldn't even ask him for a pencil if the child needed it.'



FIGURE 17: OUTSIDE OF HIV SCREENING AND TESTING CLINIC, MANGUZI HOSPITAL (SOURCE, [HTTP://WWW.KZNHEALTH.GOV.ZA/MANGUZIHOOSPITAL.HTM](http://www.kznhealth.gov.za/manguzihospital.htm))

Sisi spoke openly about her HIV positive status, stating that despite being initially distressed after discovering her status, it is no longer an issue. She speaks positively of her work with other HIV positive community members, particularly proud of her initiative to start a support group. She does worry about what will happen upon her death given her daughters' abandonment by their fathers, and reports that each headache is a potential sign that 'this thing (HIV) may beat me'. At the time of the interview Sisi was not on ARV medications as her CD4 cell count was above the threshold. Despite being a recipient of a disability grant, she runs a small shop to supplement the marginal income. She identifies that her financial struggles persist, citing ongoing struggles in feeding and providing for her children as major worries and concern. Disputes with her eldest daughter are also a source of stress in her life – their constant arguments about Sisi's grandchild result in her daughter running away from home for days at a time, which 'hurts her heart' a great deal.

Box 5: Sisi's Case Profile

Sisi's home is just 20 minutes away from the centre of town. A small red structure sits off to the side, brick with a dirt floor. There are men scattered around the property, and two small children running about. The men sit beneath broad mango trees, the only shade offered from the searing heat. Sisi's grandfather – who is missing all of his teeth, but none of his vigour – interrupts our interview at least three times before we begin, talking to me rapidly in Zulu, each time equivalently perplexed by me describing myself as 'not from here'.

Sisi is HIV positive, and contracted the virus while caring for her mother. The death of her mother was a devastating experience, which she identifies as the only time that she had contemplated suicide. Sisi never knew her father, who deserted her mother soon after her birth. Her only remaining blood relatives are her brother and two daughters. Sisi is also estranged from the fathers of her children; one is in prison for theft and the other has abandoned them. She spoke openly about their conflict, his refusal to support his daughter, and the complicated court proceedings where she sued him for child support. Despite a promise to provide support, she asserts that she has never received anything from him.

Sisi speaks openly and easily about her HIV positive status. She admits that when she discovered that she was positive she felt some sadness, but it is no longer an issue, highlighted by the ease with which she speaks of it – almost flippantly, regurgitating the HIV prevention discourse on condom use with her men. She also describes her work with other community members who have HIV, and her decision to start a support group three years prior, to give people with HIV a safe place to talk about life struggles, and their feelings right after diagnosis. This emerges as a bright spot in her life. The only worry that she shares in relation to her status is what will happen upon her death, given the absence of the fathers of her children.

Sisi runs a small shop on her property, where she sells cigarettes and alcohol to men from around Engozini, where customers spend entire days smoking cigarettes, drinking palm wine (a traditional local home brew made from the fruit of palm trees). The small income she receives helps supplement her disability grant. She outlines the difficulties of living with a hearing condition that in her description, is reminiscent of tinnitus (she is unsure of the official diagnosis), that has plagued her since the age of 15 when she left school. Despite her dual sources of income, she discusses her financial struggles, often worried that she does not have enough to feed her children. High blood pressure is another issue that Sisi deals with, and because of this, she is constantly in fear of being 'stressed', and suffering from a stroke. Her eldest daughter is the greatest source of stress in her life – their constant arguments have resulted in her daughter running away from home and disappearing for days at a time. Their conflicts are over Sisi's grandchild, who is often left alone when her daughter disappears, often to spend days at a time with her boyfriend. When her daughter attempted suicide (while with her boyfriend), Sisi sought help from a support worker at the hospital to mediate between them, which improved their relationship. Regardless, Sisi cites this as being the major concern in her life, and something that 'hurts her heart' a great deal.

Sisi's story highlights that the management of HIV does not always play the central role or dominant concern shaping experiences of emotional distress in HIV positive individuals. In fact, HIV emerges as a small fragment of the stories, which stands in contrast to evidence that argues for the centrality of HIV in causing emotional distress in the lives of AIDS-affected individuals (Kelly et al., 2008). How this emerges as a picture for the whole corpus of interviews is addressed within chapter six.

5.1.3 SYMBOLIC DIMENSIONS OF MANGUZI: SHIFTING CULTURAL MORES OF FAMILY AND GENDER

Symbolic dimensions of Zulu communities have shifted in parallel with broader economic and structural developments, in ways that may influence the mental well-being of women in Manguzi. Historically, the social organisation and cultural practices within Zulu culture tended to limit women's access to multiple forms of power, or dictated that gains in power occurred as a proxy of relationships to men. Krige's early (1936) monograph details a nuanced system of family relations that portrays the patrilineal tendency of Zulu relations. Power, and recognition as a successful man, was wrapped up in the ability to develop and support your own homestead. To establish a homestead, validate a marriage, and mark the entry of boys and girls into adulthood, the payment of *lobola* (*bride price*) is mandatory.

Women were expected to leave their families behind, and join the husband's household. A woman's primary role within homesteads was originally linked to her ability to produce children – essential contributions towards a labour based rural economy (Hunter, 2010). Childbearing potential was viewed as crucial to supplementing labour for farming homesteads, making it common for reproductively challenged women to be exchanged for her sister, or *lobola* to be returned (Krige, 1936). In these times, polygamous relationships (a well-known aspect of Zulu culture) were permitted in cases where a man could afford *lobola* for each family, and maintain his wives in individual homes on his land.

These contexts helped to establish conceptualisations of marriage that were less about romantic love, and more about what Hunter (2010) refers to as *Provider love*, which anchors the value of love to the ability of a partner to provide for his family. This reflects the strong patrilineal basis of homesteads, which positions the man as most powerful, organising subsequent relations around him. Aunts, sisters, and grandmothers from the paternal line of a family were once traditionally greeted in ways that recognise the importance of the men within the newly constructed family unit:

Even women who are related on the father's side are considered as fathers, and behaved to as such, whilst a man on the mother's side is taken to be of the same status as the mother (Krige, 1936).

The discovery of diamond mines and subsequent increases in migrant labour in the late 19th century fuelled a shift away from agrarian economies, and divided households so

that men spent increasing amounts of time away from their rural homesteads, residing in informal settlements at the outskirts of mines and cities (Hunter,2010). These mines created opportunities for young men to increase their incomes and independence, and enable participation in traditional customs and rituals to substantiate marriage.

According to Sibisi(1977), the advances of migrant labour led to the extension of marriage contracts over many years, as men spent years saving the necessary income to purchase the basic contribution of cattle required to solidify a marriage contract. Women thus found themselves within more flexible relationships, 'incomplete' marriages, with many women still joining the husband's families before all of the steps leading to marriage were completed. Many women in Manguzi reported the continued presence of such realities – having been with their 'husbands' for many years. Many did not self-identify as married despite living with their partners and having raised multiple children together.

The implications of these periods of insecurity on women's mental well-being in contemporary Manguzi are potentially significant, as women in these circumstances will have to mediate between parents whose expectations remain locked in traditional paradigms surrounding the processes to 'legitimise' their roles within a new family. This is further complicated by the reality of current economic conditions which demands that many men spend extended periods of time away from their rural homes to earn their incomes (Neves & Toit, 2013), often drawing on cultural norms that accept the development of new partnerships and relationships with other women in urban areas.

Hunter (2010) asserts that the reliance on migrant labour simultaneously raised concerns about whether men would abandon their families in rural homesteads for a life in the city. Ultimately, women remained committed to their homesteads as long as men were able to pay remittances. His analysis suggests that notions of love and importance of partnership are wound up within the project of building a home. In this process, women assume the brunt of this effort in a new culture of absent men who work away from rural homesteads. In these new spaces however, women also achieved greater independence within their homesteads, making them defacto heads of their households, and enabling routes to decision making power within families, in order to maintain their survival. Historical accounts of the female role within the homestead have always centred on child rearing, collecting and preparing food, repairing the home, making rugs, and raising cattle allocated to her by her husband (Krige,1936). Thus, a woman became valuable to a man if she exhibited qualities associated with a vested commitment to maintaining that home, something succinctly summarised in the following quote from Hunter's anthropological research:

MH: What would happen if a man had to choose between a hardworking and a beautiful girl?

Mrs. Ndlovu: Everyone would notice a girl who worked hard at home, and the boys would place a great value on a hardworking girl who respected her parents (Hunter, 2010.p.44).

However, ongoing shifts in the economies of present day South Africa have once again modified dimensions of masculinity that have knock-on effects on family relationships, and women's well-being. Pervasive unemployment in rural regions such as Manguzi reduces opportunities for men to earn wages to supplement the absence of cattle, or make financial or structural contribution that exemplify the male manifestation of 'love'. Currently, many rural men engage in piecemeal labour, or receive income provided by a grant being given to a family member (recall section 5.1.1.). Hunter details how such shifts have left men in rural KZN with reduced opportunities to establish themselves as successful men in their communities. Inability to marry (because they cannot pay *lobola*) and the necessity to rely on women to bring income into the family unit, culminate in negative impacts on male self-esteem, which are manifested in alcoholism and aggression towards women in some family units:

Thulani said that he had lived with one woman since 1997... –but his inability to lobola her meant that he never visited her rural based family...[he] looked firmly at me before saying with conviction that he intended to pay lobola... he said 'marriage wins respect: a man who is married can't be told what to do'...

Most men, Phila said, like to stay with a woman to ensure that someone will wash, iron and cook for them. He cracked open a beer and told us, without much prompting, that drinking is one reason why men can violently beat women.... (Hunter, 2010, p.162).

Hunter's observations remain a daily reality for many families in Manguzi, with significant impacts on women's well-being. Of the 20 randomly selected community participants for this thesis, one was male identified (quoted below). Despite his exclusion from the in-depth analysis presented in subsequent chapters (in order to maintain the gendered focus of this study), his interview provided an insight into how his own life had been shaped by the psychosocial impacts of a grant based economy, migrant labour, and how minimal opportunities to contribute to family homesteads affected family relationships:

What makes me sad is my illness [TB]... this worries me.... I am unemployed for the past two years because of [it] and if I was working I would have something ... we have money from one child support grant and small money I make from fixing hoes, but that is it.... Being unemployed isn't right – it's child's play [for children] – J

In the above quotation, J refers to the loss of his job at a reserve a three hour drive away, a distance which forced him to live at the reserve. Migration of men in search of opportunities to achieve positive recognition as provider within their families were commonplace within stories of nearly all women interviewed in Manguzi. Stories of this type of 'absence' often drifted into discussion of 'abandonment', where men were described as taking on new partners, and failing to send remittances. The absence of formal Zulu marriage contract reduces men's obligations to rural homesteads, and among those who

maintain ties to rural homesteads, engaging in multiple partnerships persists, with general acceptance of this behaviour.

Hunter links this acceptance to the presence of cultural mores that help to maintain shadows of polygamy. The historical trajectory of the concept of '*isoka*' – or the hyper-masculine 'Don Juan or Casanova' (Hunter, 2010, p.52) – is described as gaining widespread use in communities in justifying multiple partners. For example, a man could have a more serious girlfriend who he is enroute to marrying (i.e. working to obtain finances needed to subsidise *lobola*), while maintaining another girlfriend on the 'side', without many repercussions.

Notions about women have also shifted in response to changing economies, but have yet to improve women's status in communities. Despite women's increasing access to the work force in South Africa (Ntuli & Wittenberg, 2013) independence gleaned from income security does not come without social and psychological repercussions. In his description of the evolution of the term *Isoka*, Hunter also addresses a new term for women who have economic independence and partners without marriage called '*isifebe*', which translates to loose women – a label carrying far greater negative implications than its male counterpart. Among women who remain in rural areas, their absorption of massive familial and cultural responsibilities in maintaining rural homesteads links them to older norms of womanhood, which are in turn linked to more positive labels and praise within the community.

Box 6: Case profile of Nomvula

Nomvula is a 52 year old woman, who is also HIV positive. Nomvula is not a Manguzi local like many others, and originates from Empangeni. Her story is one of struggle and loss that traces throughout her childhood up to her present day. The death of her father when she was a very small child, followed by the death of her mother when she was 15, are losses that she still thinks about and brings her to tears almost instantly. In thinking about these absences in her life, it is often in the context of wishing they were still alive to provide a source of support for her, which is always linked to financial contributions.

Her former partner (they were never married in a Zulu marriage or 'white dress' wedding) and the father of her three children moved her to Manguzi after she disclosed her status, where she now lives on his homestead, in Skhemelele. He remains in Empangeni, about a five hour drive from Manguzi, with a new girlfriend, who is also HIV positive but supports him financially as he no longer works. Nomvula is not as open about discussing her status when we first start the interview, though she does admit to it and calls it 'that disease' at the outset. As time moves on and she engages with the topic, it is not surprising that she avoids my eye. Nomvula was happily living with 'her man' for 15 years, when she noticed the classic signs of HIV: unexplained weight loss, loose fitting clothes, exhaustion. When she discovered her status and disclosed it to her partner, he accused her of bringing the virus into the home. She describes the scene of her attempted suicide, which he then asked her to keep quiet about.

Her sadness permeates everything; she wells up with tears very early on in the interview. Nomvula's husband does not support the family financially, and their only contact in recent years has been telephone calls where he promises to visit, but which never materialises. She supports her children off the income from one child support grant (250 Rand a month) and whatever she earns from washing clothes and linens for neighbouring cottages.

Her land is beautiful. She lives off a red earth road, fenced in with about four mud and stick structures on the property. At the centre is the house where she and her children sleep – built with the help of her son who collected wood from the neighbouring woods. Her only additional source of support is her nearby Zionist church that provides clothing for her children. Nomvula chooses not to have 'friends'; she feels as though she cannot trust other people in the community because they will gossip and tell others about her status. She says that she talks to her children, and doing so gives her strength to continue on. Her children constantly worry about her HIV status, in particular her middle child who ran away when he found out she was positive. Nomvula often sits up late at night worrying about things, what things to feed her children, the state of her home – the roof is in shambles, and pots are scattered around to collect the heavy rains. She rubs her head the entire time during the interview, and complains about the pains in her legs that she links to her HIV. Nomvula says her HIV is not an issue anymore, and since being put on ARVs she says it is not something she thinks about. She has not disclosed this to anyone other than her children. What she does openly worry about, is having enough food to take her ARVs as she has been told she cannot do so on an empty stomach, and how to feed and clothe her children. She compares herself constantly to other women who she feels must be happier than she is because they have loving partners, and family.

The positive aspect of this norm is likely the fodder for what many hospital staff members identified as a 'blind' commitment to the men who leave Manguzi. As remarked in one interview:

*Y: Most of the problems with the relationships that is happening here is that, many husbands of people are working in the cities, and when they are in the cities, they fall in love with other people there, and they don't support their homes, and their kids.... our communities [still have] lots of good patient women – the women are so patient, they wait for them, until they come back...
Ro: And women who are patient, is that something that you're taught to be as a woman in the community?
Y: Yes, and you try to start other things so you can survive.*

Notwithstanding this, the process of being 'left-behind' and 'starting other things so you can survive' can be incredibly difficult for women.

Nomvula is a HIV positive 52 year old woman whose life story is the product of these processes. Her case profile (see box 6) highlights the particular complexities of this issue. Nomvula was infected by

her partner of 15 years, who then exiled her to live in Manguzi on his family homestead with their children after she disclosed her status to him. She has never challenged his decision,

and despite repeated attempts to contact him for support, he remains absent, and Nomvula reports herself as feeling powerless. Women like Nomvula highlight the relative lack of power that some women perceive themselves to hold within their worlds. Participation within what continues to be a largely patriarchal society emerges as a factor which places a 'ceiling' on how women enact their agency as 'independent' women, despite the absence of men that leaves them as decision makers and heads of households. Nomvula's case also highlights the convergence of issues such as fragmented development, insufficient income to support her children and her home, and her marginalised status shaped by cultural norms where her husband still carries the power to dictate her 'exile' after the discovery of her status; resulting in a wholly fragmented social world, and significant levels of emotional distress. How this fragmentation actively begins to shape women's mental health outcomes is addressed in more detail in chapter six.

5.2 RESPONDING TO MENTAL HEALTH: FORMAL AND TRADITIONAL MENTAL HEALTH SERVICES

5.2.1 FORMAL MENTAL HEALTH SERVICES AND POLICY IN MANGUZI

In South Africa a district health system coordinates the operation of formal mental health services. District health systems shift the locus of care to smaller units, structuring services around the community. The system draws on a primary health care approach, which attends to five principles in promoting health and preventing illness: accessibility; public participation; health promotion; appropriate skills and technology; and intersectoral cooperation (WHO, 1978). District health sectors were implemented in South Africa as a route to decentralising services and providing more access to underserved and under developed regions that had been systematically excluded during the apartheid rule. The landmark 1997 White Paper on health in South Africa states that the purpose of the district health system was to strive for:

...overcoming fragmentation, equity, provision of comprehensive services, effectiveness; efficiency; quality; improved access to services; local accountability and community participation and... sustainability (White paper, 1997, p.28).

As previously stated, Manguzi is located in the Umkhanyakude Health District which is subdivided into municipal sub-districts. The Manguzi Hospital catchment area is located within the Umblabuyalingana sub-district, and contains five district and provincially funded hospitals. As shown in figure 18, these hospitals are widely distributed across the district. There are no specialised or tertiary hospitals within the area, and only 47 clinics to support these five hospitals. The northern regions of the province like Manguzi are drastically underserved in comparison to the city regions. Table 10 compares the provincial health

services within the Manguzi district to the Ethekewini district, where the capital city of Durban is located.

TABLE 10: HEALTH SERVICE STATISTICS, RURAL VS. URBAN COMPARISON

<i>Health statistics</i>	<i>Umkahanyakude district (Manguzi)</i>	<i>Ethekewini district (Durban area)</i>
Hospitals (total)	5	12
District and regional hospitals	5 (district only)	8
Specialised hospitals (including mental health)	0	3

Manguzi Hospital originated as a missionary hospital and was opened in 1944 by Methodist

Box 7: Manguzi satellite clinics	
Thengani*	KwaNdaba
Phelendaba*	Mahlunguhlu*
Volabusha	Mshudu*
Zibi	Gateway
Mboza	
ZamaZama	
Bhekabantu *	
	*clinics visited during observations

missionaries who arrived in the Kosi Bay region in 1917. Over the first few decades of the 20th century, the hospital developed from a single ward into a 107 bed unit with mobile clinics, an active outpatient

department, chapel, swimming pool and occupational therapists by 1973. In 1981 the hospital was turned over to the provincial government, and remained unchanged until Cyclone Démonia struck in 1984, after which a series of additions were completed including the development of its 11 remote clinics, development of the community based health programme, X-ray and ultrasound facilities, and specialist services such as dietetics, forensic and dental services.

At the time of fieldwork, Manguzi Hospital was a 300 bed unit, staffed by 11 doctors, 8 therapists, and many nurses. It services 106,251 people from 23,168 households based on a 2003 health population survey (KZN Department of Health, 2010). Due to the proximity of the hospital to the Mozambique border, the population varies depending on the number of illegal immigrants in the area, who typically comprise 5% of the hospitals' patients (ibid.).

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FIGURE 18: KZN PROVINCIAL HOSPITALS (MANGUZI TOP RIGHT CORNER) SOURCE: GOVERNMENT OF SOUTH AFRICA CENSUS DATA

Within the provincial mental health system, district hospitals like Manguzi are designed as 72 hour observation centres for mental health care. Under the Mental Health Care Act (2002), these centres are permitted to admit psychiatric patients for observation, diagnosis, and immediate management – during which time, a treatment or management plan can be decided on, and if necessary, referral to more specialised centres with specified mental health/psychiatric designated beds for longer term treatment can be coordinated.

The process of referral to a hospital with in-patient services is purposefully complex in order to compensate for the misuse of psychiatric confinement of activists during apartheid era uprisings. The national 1973 Mental Health Act was marked by typical apartheid practices that emphasised the ‘protection of society’ above the human rights and basic needs of patients with mental

illness. Treatment of patients under this act was deplorable: psychiatric institutions were often a storehouse for political insurgents, and individuals were stripped of their rights and committed on the whim of jealousies, vendettas and prejudices without due assessment to the validity of these claims (Burns, 2010).

The current system now dictates three criteria prior to being admitted to a psychiatric setting: 1) patients and families be notified of the procedure; 2) cases be monitored and signed off by local medical staff; and 3) review of each case by a centralised review board of specialised therapists must occur before the transfer of a patient to a longer term facility.

In practice however, this process appeared to establish little else but webs of bureaucracy at district level, with multiple admission forms required for each patient, needing to be signed off by medical officers at various levels. Discussions with local primary mental health care practitioners about the intersections between bureaucratic requirements and the

numbers of staff available on the ground, led to difficulties in effective implementation of the policy.

This mental health policy I think, that's my impression, needs to be reviewed again. Because 1) It has a lot of paper work that doesn't help the patient. Somebody has to write one two, forms again, and if a person is psychotic, how can you have get time to write all these papers? While trying to manage this patient [at the same time]?
- M, mental health nurse (interview)

Furthermore, the remoteness of Manguzi to other hospitals in the referral chain creates further impracticalities in delivering effective care for patients, turning protective procedures into barriers for patient care. The same mental health nurse spoke openly about the impracticalities of the policy, relating to review boards required by 72 hour centres:

And with this thing of review boards – I think, by right - that's my impression- it should be something that is allocated inside the hospital. For example, I have assessed after 72 hours, and find this person is still psychotic, then I take these forms, and say ok here, send to the review board, or one of the committee members of the review board, would you mind to assess this patient, and suggest if they should go to Madadene. But if that somebody is in Empangeni, which is 500 km from here, do you think that's possible? No. – M, mental health nurse (interview)

However, to house review boards at district level sites would require a level of HR that is impossible, given that studies highlight the dearth of resources available to mental health nationally, most of which are distributed unequally across provinces (Lund & Flisher, 2003; Lund et al., 2002). Earlier in Table 10 I highlighted the uneven distribution of hospitals between rural and urban areas. In KZN specifically, it has been stated that public mental health services have only a quarter of the number of psychiatrists and registrars/medical officers required by national norms (Burns, 2010).

At Manguzi Hospital the mental health team is driven by two psychiatric nurses who work in a small prefabricated building, with two offices, a small waiting area, and a consulting room used for assessments with visiting psychiatrists and psychologists. The 'ward' is shared with the social work department who occupies the second office, highlighting the direct relationship between mental health and social services in the Manguzi system. Hospital clinics are held twice weekly, which target outpatients who live in close proximity to the hospital. Very few new inpatients are seen during these clinics, where upwards of 40 patients and their families overflow the small waiting area, spilling out and down the ramp leading to the ward. Families are encouraged to attend with patients, which is described as essential to supporting compliance. In countless discussions with M, the junior mental health nurse on the team, he reiterates the importance of families within the space of supporting mental health patients.

In order to manage such a high volume of patients during hospital days, nurses see patients in tandem, dividing cases between them. Consultations run simultaneously in the same office. The sheer pandemonium of such a system is elaborated on within the following excerpt from field notes:

During psych clinics, the office operates in the strangest of ways, limited by the space limitations at the hospital. The two nurses hold a clinic each sitting with a separate patient who comes in, often with family, carrying their medical cards. People have been lining up for hours before hand, and between 8 am and 4 pm they will have to see everyone. Today, everyone equals 40 people on my very rough count... Inside the office where we see patients, there is no privacy and less space. Sometimes, men are asked to leave if women are talking about social or family histories, but other than that, you just keep on going. A woman I took a particular interest in because of the large gaps in her diagnostic history embodied this. She kept making sideways glances at the husband of another client, refusing to give more than uncomfortable nodding in response to our questions. Finally M (mental health nurse) asked the husband to step outside so she could have a bit more privacy, after which she opened up a great deal. Most of the patients are there for their injections. This happens behind a curtain that almost protects the client from being seen by other clients, but not from the nurses and I who sit on the other side of the desk. I lost track of how many bare bottoms I was flashed today (field excerpt, November 24, 2010).

Visits to remote satellite clinics are run twice weekly, where one psychiatric nurse and social worker travel to more distant areas to follow-up with patients unable to attend hospital clinics. In order to visit the 11 clinics, each clinic is visited once a month and multiple clinics are clustered into each day based on proximity. These visits ensure that more complicated patients can follow-up with the 'specialist' – who is most often the psychiatric nurse. While in Manguzi I visited the five clinics identified by the mental health team as having the highest population of mental health service users. A social worker and nurse share the same screening room during a clinic visit, seeing patients one at a time. These sessions are sparse as queues are often long, and travelling between clinics takes a minimum of an hour.

Policy dictates that in between visits from hospital staff patients are to be monitored by primary care nurses at satellite clinics, or home based care teams (hospital based or NGO teams). However, all of the psychiatric patients observed during visits to satellite clinics had not been seen by a practitioner of any kind since their last visit with the Manguzi team. During my interview with psychiatric nurse M, we were interrupted by a middle aged man exclaiming 'my doctor!' M reviewed the patient's chart while having an 'informal' consultation for 10 minutes through the window, discussing the patient's worries about his sickness. When they finished, the patient smiled warmly, shaking my hand before leaving. M explained what transpired, asserting the presence of stigma held by health services staff themselves, in particular among the most crucial aspects of the work force – primary health care nurses:

It's so bad. For example, somebody will come to the OPD (outpatient department) and say 'I've got this and this and this' and they [a nurse] will see a mental health condition (on the chart) and they will say 'go to psych, go to psych!' and they are just there for a simple (physical health) problem.... You know, he was asking me about his blood pressure – these clinic nurses, they just won't see patients. There is so much stigma they just tell them to wait to see us, even for little things that aren't mental health-related. They should be monitoring his blood pressure... and they are not. – Interview, M

NGO support staff, the other half of the community outreach strategy for supporting newly discharged patients from the hospital, appeared to hold similar reservations about patients with mental health-related issues. Towards the end of my interviews with community women, I decided to coordinate a home based care follow-up visit for a participant who was particularly low and isolated. The discussion with the HBC coordinator was disheartening at best, something I documented within the field notes excerpt below:

Another referral for the 'NGO' home based care team, and this time I receive a surprising answer – she informed me because [participant's name] is a mental health care user, it's likely that the home based care volunteers will not want to work with her, especially in the summer...she goes on to describe a local belief that the summer is worse for people in the community who are mentally ill – that they have more episodes, and are violent with volunteers. We talk about this for some time, she says she'll do the visit herself to make sure the woman gets seen, and bring a local volunteer with her when she goes. But the whole thing is worrying - Home based care is also connected very intimately with the psych clinic at the hospital, and for every patient who comes in as an emergency, the primary route to support them is the referral to the NGO– and if that doesn't work, then what exactly is happening with these women who are now considered 'mental health users'? (Field excerpt, November 22, 2010)

During structured clinic observations, I developed histories for a total of 20 patients: 11 patients who attended satellite clinics, three new patients admitted under the 72 hour observation system, three outpatients who were called in to see a visiting psychiatrist (who did not arrive for this appointment due to weather conditions) and three outpatients attending hospital clinics for follow-up treatment. During these sessions, patients detailed life stories that aligned with women introduced earlier in this chapter, and those who I explore more systematically in chapter six. The feature separating women observed within clinics (i.e. formal mental health service users) and those in the community emerged at the point of breakdown - a single life event in a line of socially constituted hardships that finally made things untenable. The case profile of patient X presented in box 8 illuminates this particular finding:

Box 8: Patient profile Patient X. Female, age 20

Social/medical history: Patient's father died in 2005 when patient was 15, suffered from extreme sadness after his death. Mother remarried, and had five children with new husband. Mother is described as providing very little support with finances or food for her and her brother. Her brother resorted to stealing to support them after her stepfather refused to help because they are not his biological children. Her brother was arrested (year not stated by patient) which led to her dropping out of school because of lack of money to pay for books or her uniform. She was unable to find work in the absence of her birth certificate or ID book. These events led to her first suicide attempt in 2007 where she injected rat poison and attempted hanging in the same attempt. A friend in her community took care of her at this time, and she was not brought into the hospital. She discussed her situation with a friend who helped her get a job as a domestic worker which she still holds (earning 300R/month). Though she does not live with her employers she states the family will occasionally help her out with food and check in on her.

Presenting issue: 2nd suicide attempt^{2nd} attempt occurred after she returned to her own home after a visit with her boyfriend (since 2006, happy relationship, a source of support). Her stepfather chased her away from the house, said that he does not want to support her, she is not his blood child, and he has no obligations to her. Her mother sided with her stepfather, mother says that there is nothing she can do to change his mind (says she's powerless to change it). The patient described having bouts of insomnia related to her worries and ongoing problems with her stepfather.

At the end of the discussion in clinic, the patient admits that she does not want to live with her mother and stepfather anymore. She describes her current social supports to be her boyfriend and the friend who brought her into hospital after this current attempt.

Action/treatment plan: multi-disciplinary team members hold on prescribing drugs till after blood tests, will re-consider anti-depressants, and make a primary referral to the social worker to help deal with family issues and support her in obtaining her birth certificate and ID book so she can increase access to employment that is self-sustaining.

This patient case highlights the relevance of community contexts to the experience of mental distress as outlined in section 5.1. The death of the patient's father in 2005 was the beginning of a chain of events that highlight the importance of family to her well-being— insofar that its fragmentation resulted in a severe state of distress. Gendered power relations quite likely informed her mother's decision to support her stepfather's rejection of the patient within the new family unit. They also inform the patient's own fears of confronting her stepfather. In the absence of her brother (who stepped in to provide support for her when their mother first began to pull away), she was able to turn to her boyfriend and a friend in the community who provided her access to employment. Unfortunately, in the absence of government documentation, she could not obtain a job that gave her full independence from her mother and stepfather, leading to a crisis point in his decision to kick her out of the house.

These issues underpin the patient's two suicide attempts. Luckily, in the presence of the multi-disciplinary team, she was able to receive attention to numerous issues of concern. The subsequent section begins to explore the roles played by allied health departments such as physiotherapy and occupational therapy, who work actively within multi-disciplinary teams and community mental health services in Manguzi.

5.2.2 DELIVERING PRIMARY MENTAL HEALTH CARE: ALLIED HEALTH DEPARTMENTS AND VISITING MENTAL HEALTH PROFESSIONALS

In addition to the psychiatric nurses on staff, the primary mental health care framework (see figure 19 below) relies on the support of allied health professionals, visiting professionals and social work services.

The therapy department, which houses both physical and occupational therapy, is located opposite the mental health/social work 'ward', separated by an open air square. It is permanently staffed by one occupational and physical therapist, two community outreach therapists (indigenous to the Manguzi area), and 4 first year therapists provided through the community service ('com-serve') programme. The programme is an addition to the health training in the country which requires that prior to accepting a permanent position within private or public service, students must complete a year of community service, where they work within rural, underserved populations across the country (Pillay, 2006). This results in the allocation of a young, inexperienced and transient work force to source many rural health posts.

Occupational therapy has more obvious links to mental health services, given their involvement with school assessments, work with individuals with mental retardation, and children with mental and physical developmental disabilities in the community. The heavy involvement of the physical therapy department is more surprising, and a result of what the therapy department assistant manager describes as necessity:

We'd see 20 chronic back pains, two sub-acute, and one acute – by the time they're chronic, the chances of being without yellow flags – is – 2 percent... maybe [a minority] have had sub –arachnoiditis, or – what else would give you – degenerative disc disease, or maybe they have actually something that really warrants them having chronic back pain – but that's really rare, usually it's major psychological issues. So anything longer than three months, you automatically think– uh, there's probably something here – and it's not just back pain, its neck pain, and Macarena pain – (does the motions) (laughs) you identify it usually because they come in with a certain expression on their face – they don't meet your eyes, their tone of voice, posture, posture in relation to the translator, or it's just a small fragment of a sentence that you pick up – or just a little more emphasis on money matters, or on support, just one thing they throw into the bigger picture, and ah ah ! – there it is. And you have to unpack that. – M, Therapy Department Assistant Manager/Physiotherapist

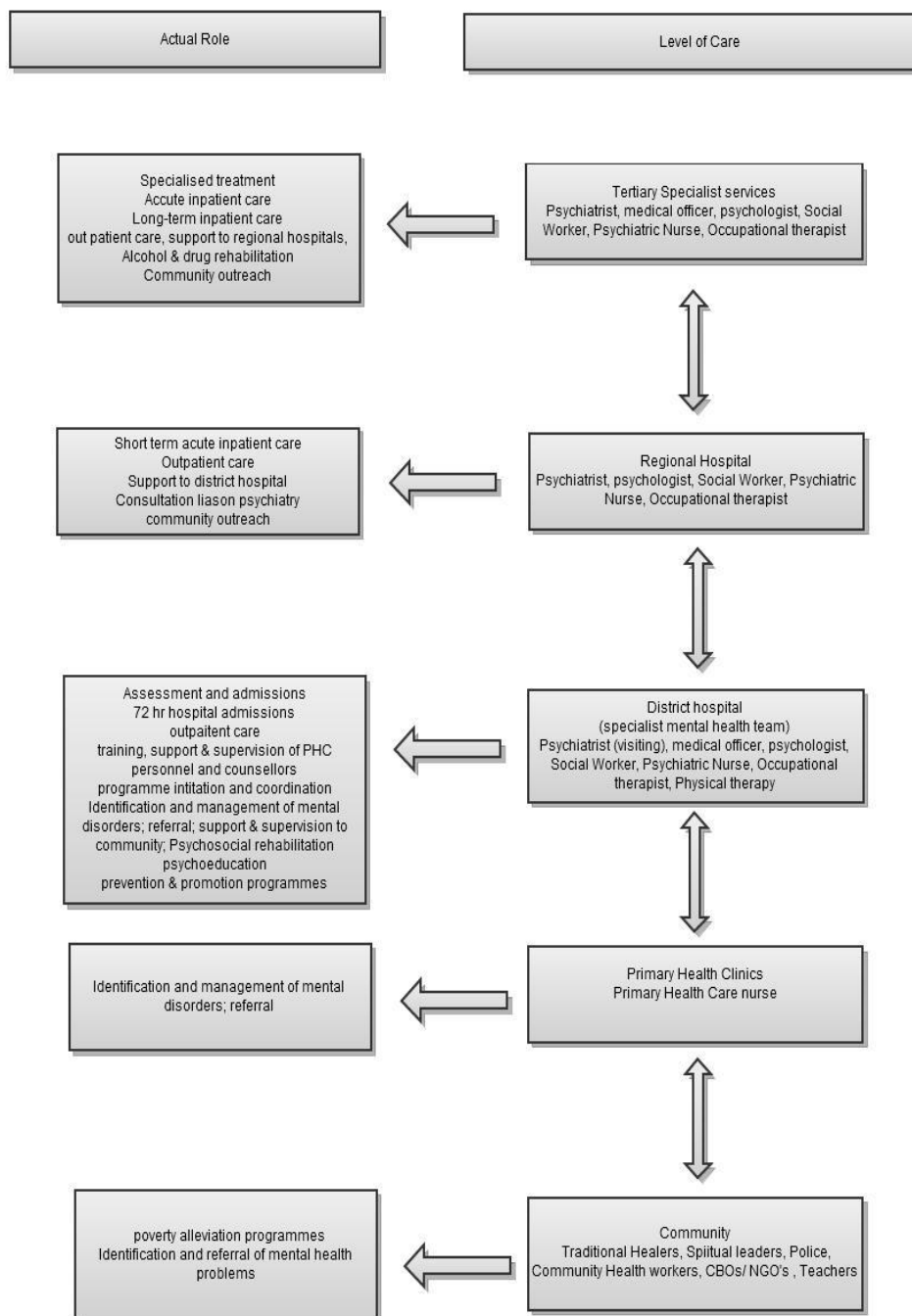


FIGURE 19: REALITIES OF ROLES AND RESPONSIBILITIES OF PMHC SYSTEM IN MANGUZI AT TIME OF STUDY

The holistic treatment of mental health conditions has been linked to the presence of multi-disciplinary efforts (Skeen, 2010). Once weekly, the psychiatric nurses, occupational therapist and social workers run a multi-disciplinary team clinic (MDT), designed to assess patient need across multiple dimensions. The team holds clinic within the mental health ward, assessing new in-patient cases that because of the hospital's designation as a 72 hour

site, will be discharged to the community. The coordination of these clinics is a product of the provincial rehabilitation policy for mental health (KZN Department of Health, 2008), which calls for multi-disciplinary planning of treatment and support of patients to promote rehabilitation and community integration following treatment.

The multi-disciplinary team is to be supported by a physician who approves changes and recommendations for patient treatment plans (blood tests, lumbar punctures, prescriptions for psychiatric medications), made during these consultations. Staff is allocated on a rotational basis, but in practice, this is met with reluctance from many staff physicians. During my interview with the 'mental health doctor' on rotation during field work, she highlighted what would later emerge (see chapter seven) as a general opinion towards mental health care and support among doctors at Manguzi:

We had a meeting just after the nurses' strike, about two or three weeks into [my] post, and they request someone to take on the responsibilities of the mental health post, and people weren't very... forthcoming [laughs]. – K, visiting mental health doctor

In hospitals, the value of care received for mental health patients is questionable. Allied health practitioners mentioned issues with stigma among medical practitioners. They described the ways that engagement with patients was avoided, enabled by a biomedical practice that relies heavily on drug restraints. As noted by one primary care professional:

*Mental health care is something that you can buck and turf here [hospital] and it's not going to affect you as a doctor... so you may end up with [a patient] for three days or something in your ward, and because she's 'crazy', you can just dope the Sh*t out of them and then they won't bug you. There's incentive from a therapy side to sort out [the complexities] because we end up dealing with the crap [side effects]*
– M, Therapy Department Assistant Manager/Physiotherapist

Support from mental health specialists is also organised on a rotational basis. At the time of data collection, a single senior psychiatrist was responsible for the entire health district, based a five-hour drive away at Madadene Hospital. This required the use of air hospital service to transport doctors between sites. Discussions with a policy specialist and psychiatrist at Town Hill in Durban (a specialised tertiary care centre that often provides support to Manguzi) outlined that monthly scheduled visits from psychologists and psychiatrists are coordinated in line with policy recommendations which stipulate monitoring and supervisory support to district level teams (Department of Health, 2010). These visits are far from regular, shaped by the broader contextual issues such as weather conditions. During the summer months (which overlapped with my time in Manguzi), storms are frequent and unpredictable. Both visits scheduled during the month of November 2010 from the visiting psychiatrist were cancelled due to poor flying conditions.

Social workers also play highly active roles within the community. They represent a formal recognition of the social determinants of mental health and HIV-related health issues,

working to mitigate family disputes, providing trauma and rape counselling and supporting access to social welfare grants. Accounts from community women like Sisi highlight the importance of social workers in ameliorating stressful family contexts and other social factors that influence women's mental distress.

The provincial psychosocial rehabilitation policy (2010) outlines direct links between mental health services and housing departments – listing social workers as gateways to addressing these structural dilemmas. Recent work by Skeen and colleagues (2010) reported on a country-wide assessment of collaborations between the provincial departments of health and other welfare services, specifically employment, housing, social welfare and criminal justice sectors. Respondents from this study identified that partnerships between the South African Police Services (SAPS) and mental health were the most developed and active. In Manguzi, social workers and mental health nurses identified a similar prominence of partnerships with police, designed to support monitoring of 'defaulters' – or patients who had stopped their treatment–or bringing in cases associated with drug abuse.

In light of the case profiles presented in this chapter, the contributions made by partnerships with police services emerge as an ill fit to the needs of women. Sisi's case highlighted that her engagement with police was unsuccessful. Thus, the types of partnerships needed to support women with emotional distress linked to contexts of poverty, HIV and relationships require further inquiry - something that is discussed below, and with greater detail in chapter six.

5.2.3 'INFORMAL' SUPPORT FOR MENTAL HEALTH: TRADITIONAL HEALING

In Manguzi the perspectives on the roles of traditional healers began to emerge through interviews with formal practitioners. Accounts of 'botched' traditional healing practices filtered through discussions of everyday care, but interestingly, sat alongside an appreciation of a role that healers could potentially play in their practice. In interviews with women in Manguzi, only a minority of women reported seeking support from traditional healers, despite national evidence which suggests that traditional practitioners (traditional and faith healers) play a notable role in the treatment of common mental disorders in the country, particularly among patients who were black, unemployed and with low levels of educational attainment (Sorsdahl et al., 2009) – as is the case in Manguzi. These contradictions pointed to the need to explore the role of traditional healing and faith based practice in Manguzi in greater detail.

I interviewed a selection of traditional healers working in two of the five Izigodi, spending an afternoon at each of their homes. Two men (one of whom invited his two wives –also healers– to participate in our discussion), and two women were interviewed. Both

women and one man were *Izangoma*, spiritual diviners or healers, and both men also practised within the traditional nature of *Izinyanga* - traditional doctors and herbalists.

Traditional healing practices in South Africa may be summarised as healing practices that are rooted within a healer's effort to help restore continuity between the 'self' and various aspects of the social world (Parle, 2008; Flint, 2008; Urbasch, 2002). This emphasis on the social in its many manifestations is longstanding within approaches to healing in Zulu culture. Flint's recent (2008) account of traditions of health and healing in KZN identifies two basic categories of illness within Zulu conceptualisations of health: natural diseases, and those resulting from ancestral discord.

Natural diseases include notions typically associated with the 'biomedical': fevers, coughs and colds, pain, inflammation, genetic disease, and any manner of illnesses. Treatments for such concerns are typically first addressed locally, most often by an *Izinyanga*. If illnesses last for extended periods of time, it was believed that the root cause could likely be traced back to ancestors, indicating the need for an *Izangoma* to ascertain the root cause behind the prolonged illness.

Ancestral disapproval is typically believed to result from breaking social and cultural mores, such as inappropriate burial procedures and ignoring family responsibilities. Flint (2008) notes that on some occasions, women who had fallen ill were criticised and chastised for bringing the ancestors of both their previous and new families to bear on their new world. The use of even illness as a route for judging and punishing women within Zulu culture further iterates the degree to which women are marginalised by the extremes of certain aspects of Zulu cultural mores. Though not a universal phenomenon across all Zulu communities, discussions in chapter six further illuminate the extent to which women who participated in this study felt limited by their relative lack of power within families.

Each of the traditional practitioners visited cited working with patients seeking help for social needs such as employment, failing businesses and support for debt or family conflicts. Their work with women tended to revolve around issues of inability to bear children, or fears that they or their children had been the target of witchcraft, sometimes believed to be delivered by mother-in-laws. While only a handful of the women in my sample reported visiting traditional healers, those who did, cited reasons which confirmed the roles that healers described above (see section 6.3.4).

Mental ill-health issues are understood within a framework that separates them from similar physical experiences linked to 'social' forms of distress created by systemic issues such as poverty, or bewitchment. Specifically, traditional healers have been identified as equating the presence of a mental illness with the presence of ancestral issues (Flint, 2008; Swartz, 1998; Berg, 2003).

For example, each of the healers interviewed within this study described their 'callings' in the context of a long-term illness, in some cases, bearing similarities to madness –that only improved upon accepting their duty to become healers. As noted by one healer:

Healer Engozini: I got the calling from my elders...one can ignore it and be a Christian but it can make someone become mad if you ignore your calling....

Ro: Is that how you became a Sangoma?

HE: I was sick.

Ro: What was wrong?

HE: I got married in a Zulu ceremony... I use to give birth but my children kept dying ... I went to traditional healers to find out what was wrong...I had headaches, body pain and I lost weight – people thought I was HIV positive. I could not even move.... I was told (by the healer) that my grandfather wanted me to take over as traditional healer in the family...after that I had six children!

A traditional healer's main objective when confronted with a class of illnesses with likely roots in ancestry (and the class of illnesses most commonly linked to western medicine's classification of 'mental disorders' - Urbasch, 2002), is to discern between those that manifest as a calling, and others which are the result of possession for other purposes. For example, in Parle's (2008) history of mental health in Zulu-Land, she takes interest in another type of 'mental illness', created by a spirit possession that was common among women during the mid-1800s: *Amandiki* – possession by spirits of ancestors who were never given proper sacrifice to ensure integration with other ancestors. These spirits were often seen as outsiders, causing havoc within communities through possessing people at random. The resulting treatment was often to replace the foreign spirit with one of a close male ancestor (Urbasch, 2002). The form of the possessing spirit was expressed at a time when patriarchy was under threat (due to shifts in male dominance of households as they moved away from homes to work as migrant labour for gold mines), and women simultaneously experienced the possibility of greater autonomy and increased responsibilities. Parle argues that a mass wave of hysteria which assumed this form was enabled through the ability of a history of spirit possession to establish a 'symptom pool' in many communities. Symptom pools, according to Shorter (1997) are defined as repertoires of culturally acceptable and recognisable ailments and behaviours, which become a route for people who are experiencing emotional distress or conflict to express their distress.

The value of the above discussion to this thesis resides within its ability to shed light on the broad scope of traditional healing approaches to defining distress, and the role of differential diagnosis within that process. Swartz (1998) and others (Flint 2008) reiterate the presence of diversity within traditional practices in South Africa. Recognition of, and response to, social ailments assumes separate sets of responses within practice. The following excerpts from healers interviewed in this study highlight the stark difference in practices concerning these two categories of distress:

Ro: Do people ever come to see you about being sad or anxious about being unemployed?

Healer, Phelendaba: Yes.

Ro: How do you help them?

HP: I take them outside for a bath because... that person has been bewitched ... we need to cleanse the bad spirit

*Ro: How do you heal patients with mental illness?
Healer, Engozini 2: I give them traditional herbs that they smell/inhale, and traditional medicine to drink ... this will clean the stomach so that everything inside that is the cause of mental illness will come out.*

The process of differential diagnosis serves only to ascertain the best route to restoring social balance through addressing these issues. This process, rooted within historical and cultural relevance to the local community, carries a wealth of potential to shift the nature of the roles that traditional healers play in supporting patients with socially rooted emotional distress as part of community mental health services. Common mental disorders (CMD), which are a particular focus of this work and a vested interest of the global movement actors (Patel et al., 2007), are the DSM categories that most consistently overlap with the socially anchored distress that may drive community members to seek support from traditional healing, making it an obvious point for drawing on local resources— beyond the current recognition of this outlet for referral. Traditional healing effectively casts a much broader net in its attention to dimensions of the social: ailments resulting from health driven, or relational (vis-a-vis witchcraft or ancestry) issues, gain importance because they impinge on a patient's abilities to live within their local social worlds— blocking abilities to engage in crucial activities such as having children, or supporting extended families.

One of the primary concerns surrounding the inclusion of traditional healers resides within the nature of outcomes from their treatment procedures. In a recent article by Sorsdhal and colleagues (2010), the dangers imbued within traditional practice are foregrounded as an issue that impacts their participation; they cite the high number of deaths linked to traditional healing practices in South Africa as reasons for concern among medical practitioners. These adages permeate much of discourse that surrounds accounts of traditional healing (Yen & Wilbraham, 2003b). However, a closer examination of the range of practices involved in traditional healer treatments for distress highlight stark distinctions in 'severity' of outcomes when treating conditions relating to 'common mental disorders' and 'mental illness'.

Yen and Wilbraham (2003a) also assert that a history of discursive constructions of African culture and 'madness' contribute to the ongoing chasm between traditional and biomedical practice. South African apartheid policies systematically sought to prevent African healers from gaining any formal legitimacy with regards to their practice. For example, the Natal Code of Black Law, 1891, made it illegal for healers to practise, and the Witchcraft Suppression Act (amended in 1970) made it illegal for a person to use the application of supernatural powers or witchcraft for personal gain. Although current practising healers are protected under the Traditional Health Practitioners Act (Government

of South Africa, 2005), the ability for traditional healing to contribute actively to the delivery of mental health services beyond ‘referrals’ will likely struggle to overcome the history of suppression that surrounds their practice. Despite the presence of current positive policies, traditional healing activity remains embedded within modern fears of negative outcomes relating to particular dimensions of traditional healing practice. As noted by a district

practitioner in her account of the opinions of colleagues towards traditional healing:

Doctors are really negative towards traditional healing, but they also see the worst of it: babies dying from having enemas up their bums... that's just not right either. – Sr. Occupational therapist



FIGURE 20: FEMALE ISANGOMA (TRADITIONAL HEALER) MANGUZI, NOVEMBER 2010 FIELD PHOTOGRAPHY, ROCHELLE BURGESS

Traditional healers continue to have limited opportunities to negotiate more active roles in relation to their participation within community mental health services. Figure 8 presented in chapter three positions traditional and spiritual healers – experts in their own right– within the same level of influence as a ‘lay person’. Tasks associated with their role are linked primarily with dissemination of biomedical information and referral: health promotion, campaigning, social support.

Theoretically, this acknowledges the importance of issues around ‘cultural fit’ within mental health, and seeks to rectify the historical division between these two systems – despite their long-term co-existence. However, in a system where the only role for traditional practitioners is one of ‘referral’, this ‘plurality’ is not effectively achieved as we continually provide a ‘funnel’ towards the formal sector. Parle asserts that while there has always been the presence of biomedical services for mental ill-health in South Africa, parallel systems of healing have also been available to intervene or fill the perceived limits to colonial psychiatry which arrived in South Africa during the mid-1800s.

The power and reach of Western medicine, however, as well as that of the colonial state...were contained and restrained by the strength and resilience of indigenous African societies. African conceptions of health and healing, as well as ways of

understanding the origin of disease and disaffection remained particularly strong... although the institutions of insanity in Natal would become important in the management of madness of people of all racial ethnic and class backgrounds, for the most part for whites, as well as for African and Indians, they represented only an alternative to much longer-established therapeutic traditions (Parle, 2008, p.36).

The current service model emerges as an effort to acknowledge what Leslie Swartz (1998) has long argued as the permeable boundaries between the sectors that patients may draw on in navigating responses to their mental health. However, the likelihood for this type of system to bear fruit within the contexts of Manguzi remains tenuous. First, Swartz draws attention to the most commonly known professional sector: actors working within biomedical

Box 9: Traditional healing family – interview

I arrived at the home of the third healer in awe. His is the only homestead I have seen thus far with fully constructed homes and huts in their traditional form, with, of course, the markings of progress at many corners: a total of four cars parked at various places, and a ring in the middle where he has four cattle grazing on the remnants of what would be grass. I am introduced by our driver, and we are sent to wait for him in his hut where he sees patients.

The floors are dirt with mats facing each other, and the space is filled with pots and bottles of darkened mixtures. Feathers hang from the walls around the circle; blankets are piled high on one side in a precarious tower threatening to tumble at any given moment. When he returns, my translator informs me that he wants to have his family sit in because 'there are four of you- there should be four of us. So it is balanced' I agree, of course, thinking this is probably the remnants of his experience of being at the opposite end of power balances with 'westerners', or the biomedical other he engages with so often.

I am nervous at first, when two of his four wives enter the room – they look at me skeptically, my 'sawubona' greeting only a mild relaxant to the energy that seems to have infused the small space. I begin by telling him that I want to learn his perspective on what traditional healers do in working with mental health. He is excited by this – and begins to describe his practice, and after a while, the others contribute as well: outlining how they help women seeking to have children, help men get their disgruntled wives back to fix broken homes; helping people attract customers to failing businesses.

When I ask him how he treats mental illness – he draws a parallel between his practice, and the biomedical – asserting that 'breathing in his fumes is the same as the injections that the doctors give – serving the same purpose to drive the madness out.' The important difference for his efforts, is that the injection is not permanent – you have to keep going back. He claims his inhalations are permanent- the spirit is out, and then gone. After some time, we begin to talk about the family's work with the hospital in the past. He describes training sessions around HIV, and a desire to learn more – in sessions where they actually share knowledge. He feels that there are things he can contribute to their practice, that he would like to show them, but feels doctors aren't interested: 'They just want us to know their treatments, and bring patients to them'. He is right. And I can't deny it.

November 24, 2010, Field note diary

paradigms, and the institutions that form direct linkages with them in the delivery of support. In Manguzi, this leads to the blending of professional public health service actors – medical and allied health professionals –and draws NGOs to work as extensions of their services. Traditional

healers also become extensions of the professional system, negating the ability for the culturally rich and meaningful knowledge held by traditional healers to inform a largely westernized approach to defining distress dominated by context-free, epidemiological evidentiary accounts, and even worse, continuing to harbour a disdain for and questioning of the validity of the practices of traditional healers (Urbasch, 2002).

The involvement of these actors aligns with what I presented in chapter three as instrumental forms of participation, where actors are brought into a space of action as a means to achieving the aims of more powerful agents (White, 1999). Manguzi healers' accounts of their participation within services revolved around feelings of 'exclusion' from the service sphere; driven by a general notion of mistrust (viewing medics as there to 'steal' their knowledge, rather than to 'share' knowledge), in line with recent studies in South Africa (Sorsdhal et al., 2010). The case profile of the family of healers I interviewed (see box 9) depicts a sense of mistrust – upon meeting me the healer invited his son and two wives to balance the scales, so that there were 'even numbers' of both groups, but more importantly, he discussed his feeling that the knowledge that they did have to offer was not valued or recognised by hospital staff with whom they engaged. The regional level psychiatrist reiterated a total absence of engagement with these traditional practitioners:

In our department we haven't done so [worked with healers] actively although of course there may be some mental health practitioners that are more active in engaging traditional healers. But certainly from, from where I am sitting institutionally, in the past four years of our involvement in this community, we haven't actively sought interaction with traditional healers. I mean I am aware that there would be instances within the interaction and so on but it's not, it's not any kind of formally planned and coordinated....for example, maybe you have communal mental health awareness or mental illness awareness meetings that kind of thing, those kind of activities where members of the community would be invited....but we haven't really had a coordination or a planned interaction with them.

Engagement with traditional healers in Manguzi appears to be fraught with complications. Barriers to and recommendations for overcoming these barriers are dealt with more intimately within later chapters of this thesis.

CHAPTER CONCLUSIONS

This chapter has developed an ethnographic description of Manguzi. The motivated ethnography sought to highlight the way in which mental ill-health is embedded within contexts of community that shape Manguzi. Figure 21 summarises the emergent findings from the motivated ethnography with women at the core of an expansive network of community level forces.

In section one, I outlined the socio-structural framings of community of 'place', the ways in which contexts that begin to influence mental health of women emerge. In section two, I outlined how similar contexts may also impact the ability for services to engage effectively with community women. This chapter serves as the background to a more focused analysis of the groups of actors that follow in subsequent chapters: community women, formal primary care professionals and their partnerships with 'informal' practitioners.

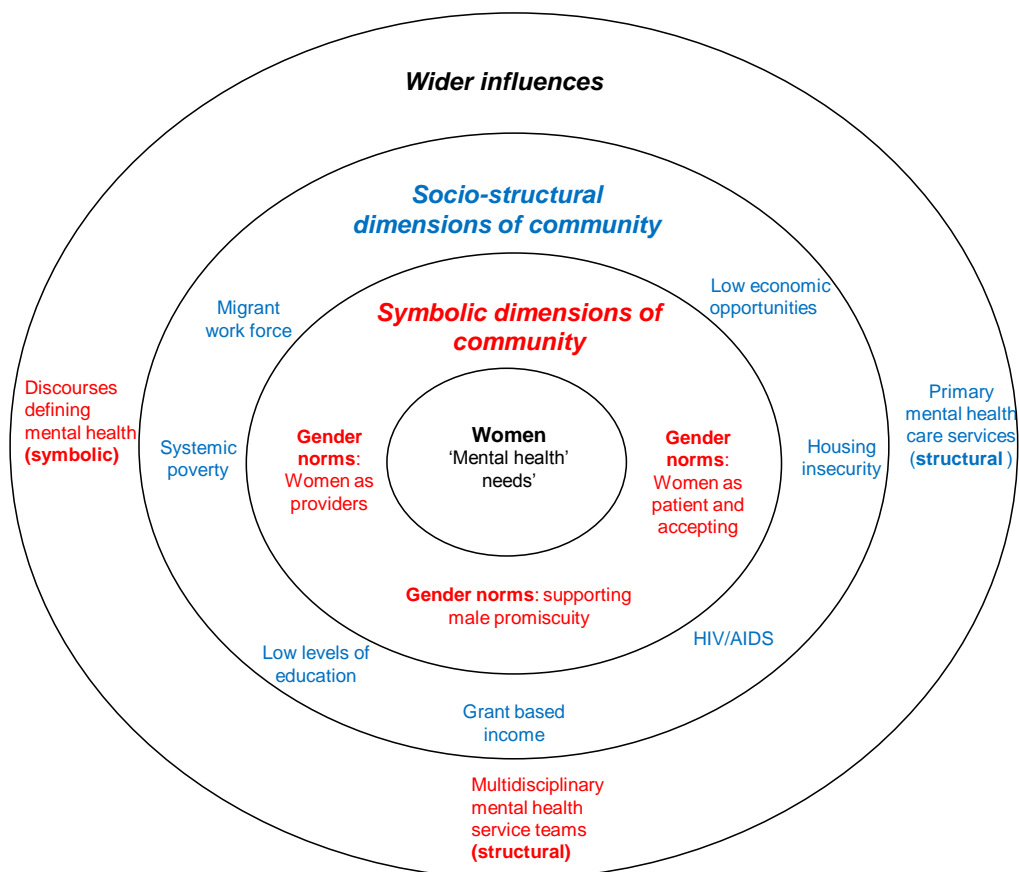


FIGURE 21: A VISION OF COMMUNITY WITH WOMEN AS CENTRAL FOCUS

Symbolic dimensions of community include traditional notions of mental health, and social norms about women's roles within communities. Socio-structural dimensions of

community are also identified, including issues of poverty and HIV/AIDS. The findings from this chapter become the stepping stones to our analysis in the chapters that follow, a point from which I am able to reflect to ensure that evolving understandings of mental health remain grounded in the realities of 'life' in Manguzi, an understanding of its complexities, and the realities of survival within its boundaries. The subsequent chapters turn to the development of a deeper and more systematic engagement with the social psychological processes of understanding, and responding to mental health within the contexts of Manguzi.

In chapter five, I presented a series of case profiles of women in an effort to highlight how women's lives were shaped by the complexities of Manguzi community. Chapter six begins to explore a cluster of more focused research questions concerning women's mental health in the community: ***How do women in Manguzi understand mental health? How are these understandings framed by contexts of community? How does this knowledge shape processes used by women to manage challenges related to their distress?***

In this chapter, I focus on the outputs of a grounded thematic analysis (recall section 4.4.2) of interviews of Manguzi women, to more intimately explore how the process of living within these contexts identified in chapter five shapes women's experience with, and understanding of mental illness. The first section of this chapter maps the dimensions of women's understandings of mental health – uncovering a representation of how women understand their own mental health and, mental health and illness as general concepts. From a social psychological perspective, each of these 'understandings' are valuable in uncovering how and why women respond to their emotional distress in the ways that they do, which is crucial in public health efforts to promote and respond to mental well-being.

Section two looks at how women attempt to manage their own emotional distress and mental health concerns, and how their underlying understandings of distress and their worlds enables these behaviours. This section concludes by exploring a selection of women observed within the motivated ethnography of clinics after their entry into formal primary mental health care services. , It follows the breakdown of indigenous coping strategies in an attempt to understand how their knowledge systems shaped their entry into formal mental health services.

6.1 MENTAL DISTRESS IN THE EVERYDAY – A REFLECTION OF LIFE IN MANGUZI

How do women in Manguzi understand mental health and distress? As outlined in chapter three, I access these understandings by mapping the content of women’s social representations of their emotional distress, a perspective on knowledge that acknowledges the abilities for symbolic and place-based contexts of community to mediate understandings and inform action.

TABLE 11: CHARACTERISTICS OF COMMUNITY WOMEN

Participant unique ID # and Initial	Age	Symptoms of emotional distress (mild, moderate, severe)	HIV context
121135 (E)	42	mild	Caregiver
121136 (T)	52	severe	Lost family member to HIV
121195 (Bumi)	68	mild	Lost family members to HIV
121208 (D)	32	mild	HIV positive
121120 (K)	76	severe	Caregiver (grandchildren)
121123 (P)	36	mild	Caregiver
121078 (Tr)	63	mild	Caregiver
121117 (N)	39	moderate	Lost family member to HIV
121077 (S)	35	mild	Caregiver
121252 (Sisi)	35	severe	HIV positive
121041 (C)	55	moderate	Caregiver
121071 (L)	42	severe	Caregiver
121022 (A)	42	severe	Lost family member to HIV; HIV positive
121076 (R)	43	mild	Lost family member to HIV
121024 (V)	45	moderate	HIV positive
121704 (Mi)	27	severe	HIV positive
121491 (Nomvula)	52	moderate	HIV positive
121359 (M)	48	severe	Lost family member to HIV; HIV caregiver (nieces/nephews)
121216 (Ti)	42	moderate	Caregiver (daughter)

Findings (summarised in tables in each section) highlight that women’s accounts of their own emotional distress were inexorably anchored to the contexts that framed their social worlds – many of which were initially identified by the motivated ethnography. The interview schedule for community women (see appendix A) attempted to draw links between their understandings of the ‘survey’ they completed, and the contexts of their daily lives.

Critiques led by Summerfield (2008; 2012) presented in earlier chapters have argued the importance of attention to social context when seeking to define the mental health of those who live in distressed settings – an argument that is well supported by data in this chapter.

Analysis identified four global themes describing the contexts which shaped women’s accounts of their emotional distress. The first three resonated with discussions in chapter five: strained or broken family relationships, poverty and HIV. The fourth theme relates to the negative impacts of inter-personal and social violence.

6.1.1 PROBLEMATIC RELATIONSHIPS: BEING IN THE FAMILY

Women highlighted five particularly challenging dimensions of their family life, summarised in the table below.

TABLE 12: THEMATIC ANALYSIS OF INTERVIEWS WITH DISTRESSED WOMEN.
GLOBAL THEME: PROBLEMATIC RELATIONSHIPS

Global theme	Organising themes	Basic themes	Associated 'life world' contexts	Example of in vivo codes
Problematic family relationships	Polygamous relationships	<ul style="list-style-type: none"> • Disputes with wives • Failure to support multiple households 	<p>Economic hardships</p> <p>Norms of male behaviour</p>	'Husband doesn't support my household after marrying new wife'
	Abandonment	<ul style="list-style-type: none"> • Husband deserted family • Partner does not send remittances 	Economic hardships	'Husband deserted us after leaving to work in the city'
	Loss of a family member	<ul style="list-style-type: none"> • Mother died • Father died • Brother died and lost support 	Economic hardships	'Father died leaving me to support the family'
	Family disputes	<ul style="list-style-type: none"> • Argued with parents about lobola • Argued with sister about supporting family 	Economic hardships	'My parents are mad that my boyfriend cannot pay lobola'
	Intergenerational issues	<ul style="list-style-type: none"> • Argued with daughter • Argued with step-children 	Norms of motherhood	'Daughter and I argue about living with her boyfriend'

Accounts of **polygamous relationships** often overlapped with the theme of **abandonment**. Both were included in all but two participant accounts of distress. Many had 'husbands' who were migrant workers, establishing a culture of 'absent' men who often

found new partners and eventually stopped sending remittances to their rural families. Accounts of such abandonment tended to fixate on the loss of such support, rather than the loss of love, as indicated by the following quotes by Nomvula:

Nomvula: And I am not happy at my home because I always think of this one person all the time.

Ro: Who is that?

N: The father of my kids.

R: What are you thinking about?

N: I think that most people who are happy are those who have their husband because they give them money and support them, but I always cry the whole night...

Women in Manguzi are likely shaped by the existing norms that continue to value the woman who remains committed – but who, as a result, must manage the fall out of losing her primary source of income to support her household, children and herself. The notion of provider love introduced in chapter five helps to explain how a woman comes to accept the abandonment. As articulated above, the absence of men’s contributions– which are signals of commitment to a marriage contract or partnership (with marriage on the horizon), the proxy on which abandonment becomes acceptable– leads to women’s experiences of distress.

When **family disputes** and **intergenerational issues** informed women’s distress, they were linked to norms defining a woman’s role within the family as a committed provider for children and other close relatives. Family disputes and intergenerational conflict emerged as rejection of these efforts, and was therefore linked to distress.

A lot of things make me sad, like when children don't pay attention to what I'm saying and they do things that are wrong... I tell them to come home straight from school, but they wander around and come home later – if something happens it will look like I don't take good care of them. – Ti

Ro: So what makes you feel badly or scared in your life ma? Can you tell me about that?

A: Oh, well... the problem with this child, she can do anything even if it means killing me. She will do it. She doesn't like me and tells my husband that I steal from her. She doesn't like me as her mother.

As previously mentioned, good motherhood is intrinsically linked to the status of the homestead: a woman’s success in this vein is reflective of the status of the family in some instances (Hunter, 2010). The inability to fulfil that role was a source of distress for participants. Accounts of deprivation and poverty permeated these stories, indicating that the lack of access to resources needed to participate within their world in ways that matched norms, acts as a process for the development of emotional distress.

A mother from Scabazini with eight children shared the following: *'It worries me to no end that my children don't go to school, all other children go to school but with mine it is impossible. And that makes me sad.'*

Another participant from Skhemelele mirrored this sentiment, sharing that ‘...[it would be better]if I can get a job to support my kids like other women, and have food because I even feel ashamed sometimes for not knowing what [to give them] to eat.’

The above quotes foreshadow the importance of poverty as a stand-alone context shaping women’s’ distress, which will be discussed in following sections in greater detail.

Fighting with siblings and parents over financial resources was also a source of distress. Women argued with their parents about boyfriends who were unable to pay *lobola*. Such findings linking negative emotional outcomes to the prolonged engagement periods shaped by socio-economic trends I first identified in chapter five. Disagreements with in-laws were shaped by expectations of women’s behaviour within their ‘new’ family unit. Women in Manguzi were expected to remain committed to her partner’s family regardless of the emotional costs, and the absence of their partners (via death or abandonment), as part of cultural marriage customs described in chapter five. P’s comment below relates to her need to live on the homestead of her late husband:

I’m living with the family which does not support me, even though I want to live somewhere [else] but I won’t be able to, I’m living with the family of my husband... that really hurts me emotionally. – P

Some women described the decision to join their husband’s family in order to support their children – despite the absence of finalised marriage contracts– and found such decisions did not further their efforts in this vein:

The situation [life situation/struggles with mother-in-law] makes me feel like I would have been better off staying at my own home – there is [still] not enough money and the children [still]suffer.

The **loss of a family member** viewed as integral to future security was linked to emotional distress. Women who had lost a mother reported of enduring sensations of sadness. The loss of brothers and fathers led to anxiety as it signified the loss of financial security and the need for a woman to assume all responsibility for the family in times of hardship.

...Just thinking that if my mom is still alive, I wouldn’t be living this life, she will be able to look after me...people who still have their mothers are happy. - Nomvula

When I think deeply I feel scared and then become depressed- I think about the issue that I am still young, but faced with challenges of heading the household now my father has died; there is no one but me. - S

6.1.2 POVERTY

Poverty was a driving feature of every woman’s life story, in line with the demographic profile presented within chapter five. The construction of this global theme is summarised in table 13.

Themes of **food and financial insecurity** highlight the ongoing influence of contexts of community in the ways that women frame their emotional distress. A mother’s sadness and worries about food and insufficient income were consistently tied to her ability to be a ‘good mother’ and provide for her children. For example, the quote below by T describes her distress at not being able to feed her children:

It’s impossible not to think about it [children needing food]. When you are at home sitting and the kids are gone without pocket money, you always have the thought about what are they eating while the other kids are eating, and you know that you didn’t give them [anything to eat].

TABLE 13: THEMATIC ANALYSIS OF INTERVIEWS WITH DISTRESSED WOMEN.
GLOBAL THEME: POVERTY

Global theme	Organising themes	Basic themes	Associated ‘life world’ contexts	Example of in vivo codes
Experiencing poverty	Food insecurity	<ul style="list-style-type: none"> • Not enough to feed children • Children go to school without food 	Norms of motherhood	‘I feel sad not knowing what to give my children to eat’
	Inadequate housing	<ul style="list-style-type: none"> • Husband deserted family • Partner does not send remittances 	Norms of relationships between men/women	‘The house I am living in is not right, the criminals can enter and kill us’
	Financial insecurity	<ul style="list-style-type: none"> • Grant income is insufficient • Income from part time job insufficient • Not enough money to meet children’s needs 	Norms of motherhood	‘We have a grant but it’s not enough to support the children’s needs’
	Unemployment	<ul style="list-style-type: none"> • There are no jobs • Husband cannot find work 		‘I am not working – there is nothing I can do, there are no jobs here’

Poverty was also linked to **inadequate housing**. Women emphasised the features of poorly constructed houses, such as leaking roofs that provided little protection from violent weather, inadequate spacing for the size of the family, and open windows that left them vulnerable to the experience of crime (a theme which is addressed in the following section). Poor housing was identified as a concern by all participants, and explicitly linked to distress in five women. The following is a classic example:

I’m living in an abusive way; take a look at this house it can fall at any time. If it rain[s] I need to put some dishes [out to catch] the rain, but the father of my kids is still alive, that really upsets me. – Nomvula

In the above quote we see how a woman understands her current conditions and resulting distress against the backdrop of norms defining partnerships. In this case, the intersection of her place-based concern regarding housing is linked to the processes of abandonment (mediated by a symbolic norm that accepts polygamous behaviour) and its associated financial insecurity.

Financial insecurity was an overarching factor shaping food and housing insecurities. Struggles with managing homes on menial and inconsistent income sourced from remittances, part time work or grants, influenced many accounts of women's distress.

We only rely on my husband to give us money to buy maize meal. The money he gives us is not enough to cover our needs... that's what really hurts me...I am not ok, you see when [my children] go to school and they ask for R1, you know very well there is nothing they can buy for R1, during lunch...they understand If I don't have, there is nothing I can do...I don't feel good because you wish for even a temporal job so you can help with certain things.–N

6.1.3 VIOLENCE

Women's accounts linked their emotional distress to three dimensions of exposure to violence: victimisation from crime, fear of crime (because of witnessing acts of violence) and being the target of vigilante justice. Experiences of violence were exacerbated by place-based contexts highlighted in chapter five. Inadequate housing conditions were linked to the fears of victimisation of crime.

TABLE 14: THEMATIC ANALYSIS OF INTERVIEWS WITH DISTRESSED WOMEN.
GLOBAL THEME: VIOLENCE

Global theme	Organising themes	Basic themes	Associated 'life world' contexts	Example of in vivo codes
Experiences of Violence	Victim of crime	<ul style="list-style-type: none"> • daughter raped • house broken into 	Inadequate housing Norms of motherhood/women	Daughter was raped by husband's drunk friend
	Witness of crime	<ul style="list-style-type: none"> • neighbour was robbed • neighbour was threatened by men 	Inadequate housing	Witnessed a mother in a nearby house get beat up by community members
	Vigilante/community justice	<ul style="list-style-type: none"> • members of community targeted my son 		Community members came to punish my son for alleged crime

Women acknowledged that other women in their community were being threatened or having their homes broken into – an understanding which made the vulnerability created by their own housing conditions that more salient. As described by one woman:

The house that I am living in is not right, the criminals can enter at any time- look at this window – I am not happy sister, with the way I am living. They have broken into the neighbour's house and stabbed a girl!

Women who were **victims of crime** or **targets of vigilante justice** also reiterated the complexities of relationships between mental health and other dimensions of 'community' in their accounts.

N's story of her family's situation following the rape of her daughter by a drunken friend of her husband highlights social complexities that establish feelings of desperation among women trying to provide for and protect their families, with limited access to power and resources:

My husband used to drink with friends at home, and one friend raped our young daughter – her father sent her out one day very late in the evening to buy cigarettes and that is when it happened ...and I was very hurt because... I am abused by the wife of the man who got her pregnant – we went to tell them that the child was pregnant because she was attacked on her way home, I only realised that she was pregnant in her six months just thought she had gained a little weight... My husband blamed me for the child getting pregnant so I couldn't ask him for money for food because he was angry about it.... Was not the first time one of our daughters got pregnant – my stepdaughter was the first and it seemed like I didn't discipline them – I tried to but she did not listen... We rely on my husband to give us money to buy things we need, and I have to take a portion from what he gives us to buy clothes for the children... That's what really hurts me because he doesn't give money to our daughter after she got pregnant, and she gets sent home because her shoes are sandals and not uniform.

N's distressing account drives home the interconnectedness of the contexts of community that shape the emotional well-being of women in Manguzi. Women here remain limited in their ability to exercise power within their homes, as they often lack individual economic agency, face the scrutiny of negative peers, and are simultaneously burdened by the cultural norms that dictate behaviour within marriages and partnerships. Sustaining a family without emotional repercussions becomes a near impossibility in the face of such broader systemic ills.

6.1.4 HIV/AIDS

One aim of this thesis is to provide a more contextually nuanced account of the ways in which HIV impacts on mental health, in the interests of contributing to debates regarding whether, and in what forms, AIDS-specific mental health services are needed.

All women interviewed were affected by HIV in one or more of the following ways: 1) they were themselves HIV positive; or 2) caregiving for AIDS-affected children/orphans; 3) or they had lost a family member to HIV. This provides an opportunity to better understand the

processes which underpin the emotional distress that has been linked to HIV/AIDS, through the epidemiological research that I reviewed in chapter two.

TABLE 15: THEMATIC ANALYSIS OF INTERVIEWS WITH DISTRESSED WOMEN.
GLOBAL THEME: HIV/AIDS

Global theme	Organising themes	Basic themes	Associated 'life world' contexts	Example of in vivo codes
HIV	Infected because of husband	<ul style="list-style-type: none"> • husband infected me with virus 	Norms around polygamy	'I found out I had this sickness and he told me not to tell anyone'
	Infected because of caregiving	<ul style="list-style-type: none"> • taking care of my mother and became infected 		'I was taking care of my mother and then found I was infected'
	Care giving for orphaned children	<ul style="list-style-type: none"> • take care of brother's children • take care of sister's children • take care of grandchildren 	Poverty Norms regarding family support	'After sister died her children came to stay with me – it is hard but I couldn't turn them away'
	Loss of independence due to pain/symptoms	<ul style="list-style-type: none"> • pains in legs because of sickness 	Poverty	My legs often hurt and I am tired, and I cannot work

Findings from chapter five highlighted the porousness of HIV in Manguzi: it is a condition that has touched the lives of everyone, overrun services, and directly affected community, formal hospital staff and traditional healers. However, despite the pervasive nature of HIV, it did not emerge as an independent driver of emotional distress.

Rather, HIV was discussed in relation to its impact on women's lives and families, how it intensifies experiences of poverty, through reduced economic capabilities. For example V, an HIV positive mother of three, pointed to how physical symptoms associated with her HIV (pains in her extremities) reduced her ability to provide for her family:

When I found out I was positive it really upset me because I was sick and was in a lot of pain and my hands and feet were in a lot of pain – so I couldn't do things on my own which made me very sad... I want to start medication to make sure I don't wake up one day very sick and unable to take care of myself and my children ... I don't want to wait until I am sick because then they send you to places where you can't do things on your own.

Comparisons between those infected and those who were affected by HIV highlighted the differences in accounts of the duration of periods of emotional distress. Among those who were infected with HIV, the majority of their emotional experiences related to HIV were episodic. This was mediated by their ability to accept their status, particularly because of the growing numbers of people in communities who are surviving with HIV due to the advent of anti-retroviral therapy.

When I first found out about my illness I was hurt...I was hurt such that I cried the whole night... I spoke to my aunt and she helped me and said to be patient... to look at so and so because they are alive, and once you have started taking treatment you are going to get better. –Mi

The understanding that HIV no longer presents an automatic death sentence has changed the ways in which HIV positive women in Manguzi think about their lives, which has a positive influence on their emotional well-being. Conversely, those who were *affected* by HIV/AIDS discussed emotional experiences that were more chronic, and managed over a longer period of time. This may have to do in a large part with the fact that their experiences of loss were tied into other expectations created by their life world. For example, T described the loss of her son and daughter-in-law to HIV after acting as a caregiver as a source of sadness in her life:

You see with my son it was painful, but it was not as painful as my daughter-in-law because her family did not help her, instead they said I was bewitching her, and they wanted to kill me. It was difficult (crying) because if I think about it I feel like crying all the time because I am the one who gave them money to come here and then they came and took her away.

The presence of a familial conflict between herself and her in-laws, also factors into her experience of distress. T had met the norms of a mother; caring for her son and daughter-in-law when they were ill, supporting them in whatever way she could. This was unrecognised by her extended family, which instead spread rumours about her in the community, contributing to the lingering impacts of the emotional experience.

The analysis thus far illuminates the importance of broadening our conceptualisation of the social in relation to women's mental distress. Women's representations of their mental distress are deeply anchored to their social worlds, beyond the presence of place-based contexts of community. For example, their sadness is often a product of interactions with various members of family and community that are fragmented by contexts of poverty, violence and HIV. The accounts of the 19 women discussed within this analysis affirm Summerfield's (2012) argument of considering mental distress as something that arises from living within impossibly 'fragmented social worlds'. Social deprivation, a lack of resources and power limit the ability of women to ensure positive relations with others – in this instance, partners, families, and other community members.

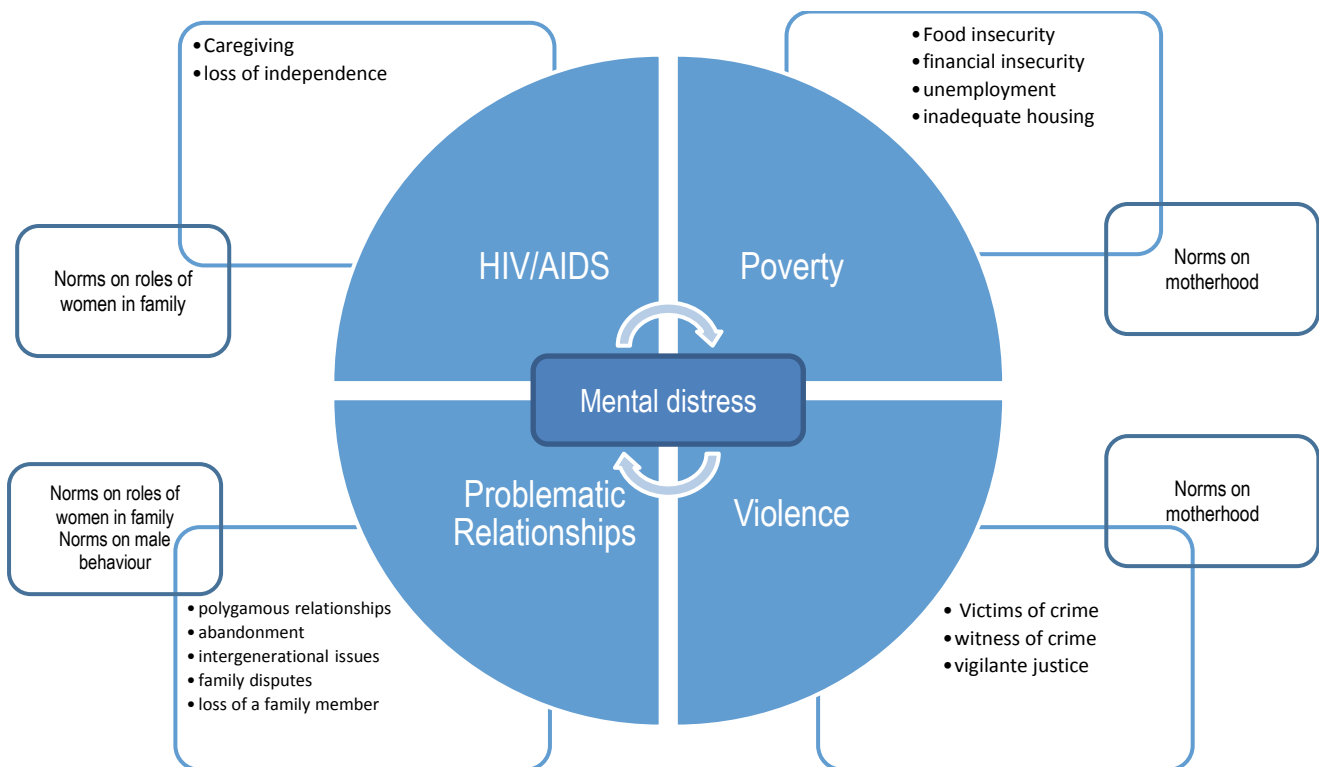


FIGURE 22: REPRESENTING MENTAL DISTRESS IN TERMS OF STRUGGLE WITH THE LIFE WORLD

In light of such findings, efforts to respond to women’s distress in such contexts should pay equal attention to rectifying this fragmentation in order to most effectively promote women’s positive well-being– something I take up more extensively in the final chapter of this thesis.

6.2 WHAT IS MENTAL HEALTH AND MENTAL ILLNESS?

Thus far, my analysis has mapped out the contents of women’s representations about mental health and distress. Emotional well-being, or ‘mental health’ is situated as the object, and is understood as a product of interaction between self and contexts of community, in particular, structural dimensions of community, relations between self and immediate important others, self and reflection on the general other, and the life world of the community (its norms, expectations for life, roles, etc.). This illuminates a picture of the ‘community’ as a multi-layered complex social construction enacted in women’s everyday lives, which is far more convoluted than the general ways in which ‘community’ is currently conceptualised within many mental health frameworks in South Africa (namely as a geographical area for public health intervention).

Before exploring how women respond to their mental distress, it is important to fully flush out the content of women’s representations of mental health and distress, which carries a history of ideas and practices relating to its management circulating within the life world.

Social representations theory suggests that in making sense of objects, individuals will anchor to concepts such as traditional norms when forming understandings or behaviours towards an object (Moscovici, 1967). In this case, what it means for a woman to have a mental health issue, and whose responsibility is it to address such mental ill-health problems, remain relevant to this study, and can be answered through revisiting ‘mental health’ that exists within the boundaries of the life world.

I felt it was imperative to create opportunities for women to reflect on these issues in a way that would not distress them, or involve my direct references to their own potential distress, which may have caused them to feel ashamed in a context where mental illness is highly stigmatised. I tried to exercise sensitivity here through approaching the topic in a roundabout way, asking them in general and impersonal terms to talk about what they felt it meant for a person to be ‘mentally healthy’, or ‘mentally unhealthy’. My analysis revealed that women viewed health and illness as a binary, associated with good and bad, consistent with the well documented stigmatisation of mental illness in South Africa (Kakuma et al., 2010). The dimensions of each of these labels are summarised in the tables below.

TABLE 16: MENTAL HEALTH - NEGATIVE POLARITY

<i>Global theme: mental ill-health as bad</i>	<i>Organising theme</i>	<i>Basic theme</i>	<i>Example text</i>
	Mental illness is just ‘crazy’.	<ul style="list-style-type: none"> • People who are mentally ill are crazy • People who are mentally ill are bad 	The person who is mentally ill is ‘crazy’
	Negative actions within community	<ul style="list-style-type: none"> • Violent with others • Disrupt community life 	‘Some are violent and even bit us...they try to escape hospitals and we run after them.’
	Breaking social norms	<ul style="list-style-type: none"> • Takes off all their clothing • Plays with garbage • Can’t take care of home 	‘He just roams around and pick up rubbish and when he sees young kids, he beats them. He will say things that are not making sense, he will just walk on the road, run, and stop cars’
	Response to mental illness	<ul style="list-style-type: none"> • Taken care of and put away • Treatment in hospital – nothing else to do 	‘There is nothing else to do except going to the hospital to take treatment’

A mentally unhealthy person was described as engaging in a series of socially unproductive behaviours: breaking social norms, committing negative acts towards others or themselves, the inability to take care of and provide for their homestead, and often, described simply as ‘crazy’. These descriptions were linked to people seen wandering in their everyday social settings. The response to mental illness was linked to hospital

treatment and confinement, which anchors to an understanding of mental illness as something that cannot be controlled by the community, but is in need of a biomedical paradigm. Swartz (1998) and Parle’s (2008) views of a longstanding willingness to accept multiple paradigms of illness in South African communities are thereby re-affirmed.

A mentally healthy person emerges as someone described as ‘good’; the type of person who contributes to her community, achieves economic success, and fulfils the roles expected of her, as mother and caregiver. This reiterates the importance of norms identified in chapter five that view a good woman as one who is resourceful, can survive, and participate in her social communities in ways that achieve some success. Such a woman emerges as someone with ‘good’ mental health.

TABLE 17: MENTAL HEALTH - POSITIVE POLARITY

<i>Global theme: Mental health as good</i>	<i>Organising theme</i>	<i>Basic theme</i>	<i>Example text</i>
	Positive contributions to family	<ul style="list-style-type: none"> • Take care of children and family members • Have a clean house 	'... cleaning the yard, taking care of him or herself, cleaning the children even when you visit his or her house, it should be clean.'
	Positive contributions to community	<ul style="list-style-type: none"> • Good deeds that are recognised by other people • If your neighbours are hungry will help them 	'your neighbours don't have maize meal, and you will ask your child to give them rather than looking at them suffering – that shows mental health'
	Resourcefulness	<ul style="list-style-type: none"> • Have a job/employed • Be stable/wealthy 	'Because he is working, it means he is mentally stable and wealthy'

In presenting the two ‘polarities’, key lessons emerge. What it means to be mentally healthy and unhealthy are anchored to norms of production and contribution to the community, which reiterate the validity of critiques of the movement’s limitations in defining mental health, seen for example in Read’s(2012)work in Ghana, where she highlighted that mental health was defined heavily in terms of the ability to function economically, or Summerfield’s (2008; 2012) assertions that health is best conceived of in the ability for others to maintain social coherence in their social worlds.

The implications of being identified as mentally unhealthy are aligned with a lack of productivity, and breaking with social norms within the community. From this position, we can assume that women will more likely be particularly invested in seeing themselves as mentally healthy – hinged on social role definitions of success linking to, even at the most marginal levels, survival (all women, regardless of their severity on scales, viewed themselves as mentally healthy). It is only within the realisation that they can no longer

cope, that they begin to critically engage with their emotional distress, or believe themselves to be in need of professional support.

Such findings implicate a need to reflect on current programmes targeting women's mental ill-health in such regions. Firstly, there is the likelihood that the presence of such representations will result in women who *never* consider themselves to be in need of mental health care being framed by biomedical expertise. Social constructions of women's roles may lead to an over-reliance on self-support and agency, which may increase women's propensity to imagine suicide as the only route to dealing with 'unmanageable' distress when they can no longer cope on their own (an outcome I discuss in greater detail in section 6.3). As mentioned in chapter two, current efforts at psychoeducation in mental health promotion –a key dimension of community mental health efforts within South Africa– are driven largely by one-directional transfer of information about different types of mental health issues from professionals to communities. For example, information programmes telling women to access services when they notice biomedical symptoms such as lack of sleep, or loss of appetite (symptoms of major depression), may prove an insufficient route to suicide prevention for women in contexts like Manguzi.

Furthermore, in mapping women's representations, we observe the conceptual gaps in many currently used psychometric scales – such as those used in the larger survey, which focus on biological symptomology of disorders, and do not engage with what section 6.1 identifies as the highly social nature of women's experiences of distress. When used in isolation such frameworks are weak contextual tools for conceptualising women's problems because they fail to identify dimensions of positive mental health and resilience that characterise women's daily lives; their exceptional ability to survive in staggeringly challenging situations, and to keep their families together, even in a patchy way as is often the case. These abilities signal to women the presence of 'mental health', and provide the fodder on which to continue. For a woman completing these measures, to be identified as 'mentally unhealthy' may cause her to re-label herself as such, exposing her to increased stigma, and decreasing existing self-agency if being identified with a mental health problem resonates with actions that reduce survival strategies.

Thus in Manguzi, a particularly dangerous outcome of the imposition of a non-indigenous, and asocial mental health knowledge system, derives from its inability to capture the existing strengths and capabilities that constitute women's survival strategies already at work as they manage their 'mental distress' everyday, obscuring the fact that even the most 'distressed' women may sometimes also be active agents in some aspects of their lives. The precise mechanisms of how women enact agency within their everyday worlds in relation to their emotional health, are explored below.

6.3 RESPONDING TO MENTAL DISTRESS: A PROJECT OF SURVIVAL

The analysis so far has positioned women's perspectives on their mental health as a relationship between structural (poverty) and symbolic aspects (norms) of community. In chapter three, it was argued that our actions are linked to representations through 'projects' or the spaces where representations come to life, are held, shaped, and which reiterate the importance of a representation's content (Foster, 2003). Analysis of interviews highlighted that women's accounts of coping strategies framed a project of survival – reiterating the validity of women's representations of mental distress as a product of social deprivation.

This section unpacks these coping strategies, to identify the processes that frame women's self-management of their distress within their everyday contexts. This section seeks to respond to calls for greater inclusion of the hitherto excluded voices of women in defining how their mental distress can be best supported. It also seeks to recognise and emphasise the positive potential of people with mental distress to participate in improving their health, control which enables a project of 'transformation' of the social worlds where mental distress is experienced.

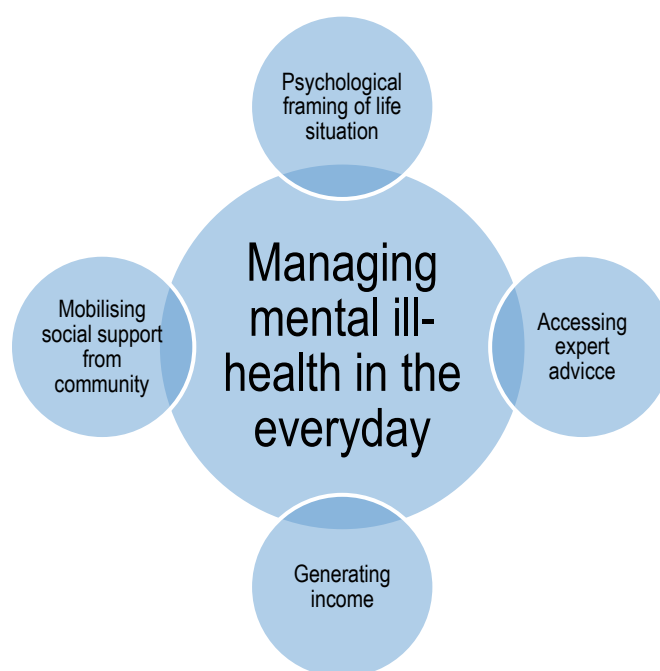


FIGURE 23: MANAGING MENTAL HEALTH IN THE EVERYDAY: PROJECT OF SURVIVAL

The thematic analysis outlined in chapter four identified four types of coping strategies which I display diagrammatically in figure 23: psychological framing of life situations; mobilising social support from community; generating income; and finally accessing expert advice. Summaries of sections from the larger coding frame introduce each of the following sub-sections.

6.3.1 PSYCHOLOGICAL FRAMING OF LIFE SITUATIONS

Psychological framing refers to women’s use of emotional coping strategies, such as self-talk, affirmations, and advice seeking, to mentally re-frame the negative or distressing contexts within their lives. In instances where women perceived the context as unalterable and inevitable, the process of acceptance was used as a route to framing their emotional distress. This was mediated by engagement with like peers, or family members.

TABLE 18: THEMATIC ANALYSIS OF INTERVIEWS WITH DISTRESSED WOMEN. COPING STRATEGIES GLOBAL THEME: PSYCHOLOGICAL FRAMING

Coping strategy (global theme)	Process (organising theme)	Coping behaviour (basic theme)	Context and content (in vivo codes)
Psychological framing	Acceptance	Self-talk/affirmations	'I was always upset when I think of how [my sister] was going to die. I was strong, I told myself that I could be positive too so I shouldn't discriminate and help however I can.'
		Advice seeking (family)	'I talk to my mother about my problems with my father-in-law – she tells me to focus on my children so I have let it go'
		Advice seeking (friends)	'After husband left I talked to a friend who advised me to stay and take care of children – I have accepted that men are men'
	Faith/hope	Self-talk/affirmations	'I tell myself to just put my spirit down [calm down] when I worry about my troubles – there is nothing I can do.'
		Advice seeking (priest)	'I talk to the priest about my husband [drinking problem] and he says if we pray for him then it will get better.'

For example, in instances where women encountered complicated family dynamics – such as difficult relationships with other wives, the abandonment of a partner and the often associated loss of financial support– and perceived them as unalterable, acceptance was used as a route to framing their emotional distress. We see this occurring in the following quote from Nomvula:

I am not happy in my marriage because the father of the household has left and is living in [another town] and I am left to take care of the house alone. I heard that he paid lobola for another wife and is living with her. I was very angry at first, but now I have accepted it and since forgot... there is nothing I can do, it is just how men are.

This acceptance of life ‘as is’ was highlighted in many of the responses of women in response to questions about how they ‘coped’ with factors that they related to their sadness or when faced with issues that they could not see a way out of, as in, for example, life in a violent community:

P: I am scared of living in this place
FA1: How do you deal with your fears – being scared of living in this place? Is there anything you think would help you?
P: I Don't have anything to do. I will just live here.
FA1: Do you talk to anyone about your fear of living in this place?
P: I talk to [friend's name]... sometimes she takes me to church and then I forget after that.

This quote highlights the role of interpersonal support in promoting acceptance in the face of inescapable circumstances. Discussions with friends often suggested that women accept things as they are; to stay strong because things would get better, or simply offer a sympathetic ear. The advice to 'accept' and 'let go' illuminates an understanding of particular issues being taken as 'given' and unchangeable within the community. The problem here resides in how acceptance entrenches women within emotionally harmful situations - which I address in later sections.

The above quote alludes to the second framing strategy used by women, which revolves around faith and hope. This strategy was mediated through 'advice seeking' strategies, with women turning to church leaders or other members of their congregation. Women who drew on faith and hope did so to frame similarly desperate and unchanging contextual factors, which helped sustain beliefs that things could improve. In some cases they reported that these strategies led to improvements in their lives, where women who made use of acceptance in the absence of hope/faith did not. The following quotes highlight how women used faith to frame a bad situation, in the process sustaining themselves in violent community contexts.

The scene of my community makes me unhappy...I wish to move out of this place but I don't have the means or a place to go... Sometimes I will talk to [my friend] ... she takes me to church and then I will forget about troubles after that – there is nothing more to do I just give it to God and pray to make things better- P

FA1: What do you pray about?
L: When you are not happy in your life you just ask them to pray for you so that you can get through it.
FA1: Does that help?
L: Esh, yes, it does. Because you know with God it gets better.

Both styles of psychological framing were evident within women's few references to managing HIV, particularly in early stages around the discovery of their status. Women described the use of personal affirmations to maintain hope in the face of a positive diagnosis. This was mediated via strategies of advice seeking and story sharing with peers, who advocated for hope and reminded them of the positives within a situation.

With regards to my status I have just told myself that I'm sick and my deep thinking about it will not help me. I have just accepted it, like I have also accepted that I have arthritis- D

When I was tested and found to have this illness [HIV] I was hurt and cried the whole night... I shared this sadness with my aunt...My Aunt told me to be patient, and that I am not the first one [to get HIV] I was wondering why this happened to me, I have no mother or brothers to help me with this problem. My Aunt advised to be patient, to remember all the people who are living and that treatment will make me better- Mi

The role of faith and hope in promoting survival in impossible conditions begins to signal the important part that church leaders play in mitigating emotional distress for women in Manguzi. The role of the church in mental health services is a largely unrecognised potential. While the 2008 community rehabilitation policy does make reference to the importance of community groups, including church leaders, their roles are vaguely articulated, and directly linked to the facilitation of community rehabilitation and treatment (supporting adherence), as well as promoting the full 'participation' of patients with mental health issues in the community. These roles do not fully acknowledge contributions of faith to general forms of wellness that are well documented, and provide evidence for their active inclusion in mental health treatment spaces. For example, Gill, Minton and Myers (2010) explored the influence of spirituality and religiosity on wellness in 167 American low-income rural women. Findings confirmed that wellness, which were defined as spirituality, self-direction, work, leisure, friendship and love was greatly mediated by the presence of spirituality and religiosity, particularly by variables such as interconnectedness. This suggests that what is most important about faith lies in its ability to facilitate two social phenomena: a) social cohesion and social engagement - additional dimensions of positive mental health emerged within my expanded definition of mental health as outlined in chapter one; and b) solidarity – a community competence argued as imperative to promotion of healthy communities (Campbell et al., 2007)

However, the passivity linked to adoption of an un-problematized faith-driven 'acceptance', which occurred within a small number of women (highlighted below), suggests that expanded roles for church-led spaces within community mental health require problematisation as well – something I take forward in chapter eight.

Ro: A church group is like a support group. Are you in a group at church?

P: Yes, we get together and we pray.

Ro: Do you talk about other things?

P: No, we just pray, we pray for each other when we are hurting emotionally.

6.3.2 MOBILISING SOCIAL SUPPORT FROM THE COMMUNITY

The previous quote anticipates the second coping strategy used by women in Manguzi. Social support is defined as relationships with significant others that have influence on physical health and adjustment (Pakenham, Dadds, & Terry, 1994). The benefits of social support in managing health problems is widely documented, particularly within HIV/AIDS-affected individuals (Lee et al., 2007; Brashers, Neidig, & Goldsmith, 2004; Casale & Wild, 2012). In using this term here, I refer to support that women derive through engagement with other individuals or groups within the community, in ways that result in what women regard as positive outcomes. Table 19 below summarises the coding framework for this analysis.

TABLE 19: THEMATIC ANALYSIS OF INTERVIEWS WITH DISTRESSED WOMEN.
GLOBAL THEME: PROBLEMATIC RELATIONSHIPS

<i>Coping strategy</i>	<i>Process</i>	<i>Coping behaviour</i>	<i>Context and content (in vivo codes)</i>
Mobilising social support	One-to-one support	Sharing stories (family)	'I will talk with my siblings about our troubles and we make each other laugh'
		Advice seeking (friend and family)	'When I worry about these things I will talk to the lady of the Nutuli clan and she will tell me to do my best and be patient'
		Sharing stories (friend)	'I talked about being abandoned with my friend because it made my stress go away'
		Sharing/pooling resources	'I pool resources together with the other families on the homestead to buy food'
	Group based support (bonding social capital)	Membership in support group	'When you find out you are positive you need someone to talk to – a friend you can trust so you can feel better so I started a support group'
		Membership in church/faith group	'When daughter-in-law's family was accusing me of bewitching their daughter who died (HIV) my church group comforted me and supported me.'

Social support was mobilised from both individuals and groups. One-to-one support was facilitated through sharing stories and advice seeking, often with friends and family members. With friends, women described either talking about how they were feeling, or actively seeking advice and solutions. Mothers and siblings were predominantly described as the source for the latter. The following quote from N and A, highlights a typical experience of sharing stories and seeking advice.

If I go to my aunt to share my story[about] how poor I am, my worries of how I bring up my children, she says please stay [at the homestead] and be patient and try what you can. But I find myself being afraid a lot. There are times when I don't feel alright because of my children, when they bring their problems to me [needing clothes/food] and I can't help. – N

When my husband left me, I was very upset. It makes me unhappy but I don't do anything, I just look [let it happen] I talked to a friend about this for comfort, she thinks I should stay [in town] and work and take care of my children... there is no reason for him doing it, men are just men–A

These quotes also highlight limitations to engagement with peers and family members. Often, advice from family and friends reinforced strategies of acceptance, which were also linked to psychological reframing strategies. Continued presence in extremely hurtful, damaging or dangerous situations was not a preferred choice, but a by-product of reduced access to power and economic opportunities. The question of why women stay in abusive environments is a long standing concern among feminist psychologists (Haaken, 2010). Reflecting back on the description of women's social representation of their emotional distress earlier in this chapter helps to shed light on this phenomenon in Manguzi.

In this particular context, women make sense of their emotional distress by accounting for the impacts of structural problems in their everyday lives. However, this is often mediated by cultural norms that inform relations between men, women and families. These norms present symbolic barriers to women's ability to envision strategies for future action, in the absence of other positive opportunities to define self-worth. Thus, there is likely to be some comfort in acceptance of something as unchangeable – as it takes the onus off the individual and places it back on the collective world, which dictates the way things are. Still, transforming these symbolic barriers to health-related action could be useful, if there were alternative strategies available to women once the acceptance was no longer an option. In the face of access to alternative support structures (something I discuss in chapter eight), challenging symbolic barriers could be approached through the promotion of critical thinking: a competency presented as crucial to health and well-being in chapter three. Specifically, women could be encouraged to think more constructively about how they could work around the behaviours of men in locally relevant ways, rather than to accept them as unchangeable conditions of their life worlds. The following quote by D provides an example of this critical thinking that occurred between women, with a more positive result:

I talk to my friend about our lives... we talk about building our own homes despite the fact that our husbands left us... she told me to stay and start collecting building materials and blocks to build my own house. If we are running short of food we share resources with each other. This is [always] helpful to me. – D

These small wins are an important part of the process of women beginning to transform the contextual issues at the heart of their emotional distress.

Previously, tangible supports such as provision of food or money were identified as highly valued among women. Many women pooled resources with friends, neighbours and family to coping with poverty and most often food insecurity:

When I am in trouble I consult the lady from Nutuli clan... she is the kind of person when we are running short of stuff in the house, we asked for it... and she will give us. I talk to her so I can forget about [things that bother me]... when you are stressed and you talked to somebody you feel relieved because she understands you... and she accepts it and helps me accept it. – N

These supports were distinct from emotional support obtained from family and friends. In their accounts, women identified this as far more significant than 'just talking'.

FA1: You talked about what things [with your friend]?

P: When I don't have salt I will go to her.

FA1: What else do you talk about?

P: Nothing.

FA1: Do you ever talk about how you feel or what you are worried about?

P: I used to talk about my family, household and how am I going to support them, and my friend will tell me to calm down and be patient and things will work out for me.

FA1: Did that help?

P: Yes it did.

FA1: Do you still talk to your friends about that?

P: No I don't.

FA1: Why not?

P: I have realized that I am old and need to accept other things...Just that you have a problem and you always go to your friend, it's not doing anything.... you need to let it go even though it [is] hard

However, reliance on others to supplement tangible needs in a poverty stricken context has limits of its own. A few women emphasised this in accounts that asserted women were ultimately responsible for their own homesteads, and that repeated requests for help would eventually alienate those around them:

I used to get money for groceries and to support the house from the father of the baby after that used to go to the neighbours and ask for food...They eventually started to say bad things about me, and said they would give me food with poison so we can die because we are a nuisance...This made me feel very badly - E

In addition to emotional and material help from individuals, women also spoke of group based support derived through participation in and membership of support groups (for HIV/AIDS), or church/ faith based groups. In the latter, women would pray together, and support each other in tackling place-based challenges. For example, women reported participation within savings groups that supported each other in entrepreneurial activities. P reported drawing on multiple group memberships following the death of her husband. The first was a savings group tackling place-based challenges:

Ro: How did you manage after your husband died? Was there anyone to help?

P: His brother helped us with the funeral.

Ro: Was there anyone else?

P: I am a member of a community support group for families. I became a member in March 2010 after my husband died...we support each other with finances to pay for costs of events... like funerals, weddings, graduations... We also support each other

in start-up funds for starting our own business like a shop, and encourage each other to save [individually]. We each contribute R30 a month.

The second was a church group, which worked at a symbolic level.

P: I go to a group of sisters from the church who advises me on life...how a widow is supposed to behave.... They tell me that I have to live without a man in the house for a year, until my husband's family give me permission ... I am not allowed to leave the homestead of my late husband or my children will suffer... I will agree with it for now, but I want to meet a new man in the future

Ro: Is this helpful for you?

P: (laughs) Yes...support from sisters at church is helpful because it guides me away from doing 'bad' things

Ro: What kind of bad things?

P: Bad things like meeting another husband, because that could lead me to become infected with HIV... This guidance is because of culture – I have to pay respect to husband and respect to the community – it's given to all women whether they choose to follow or not.

The nature of the discussions within church groups like P's above highlight why even within group contexts, talk therapies may result in the acceptance of contexts which promote the continuation of the emotional distress in women's life worlds. Work by Petersen and colleagues (2012) has also questioned the effectiveness of group based talk therapies such as interpersonal therapy (ITP), where in the KZN province, strategies suggested by peers in these groups promoted behaviours that accept the distressing home environments, rather than providing support in challenging the negative contexts that frame the women's distress.

6.3.3 INCOME GENERATION

All 19 women drew on income generation activities with varying degrees of success. Women described their efforts to etch out a living and support their children through part-time jobs: selling fruit and food at local schools, washing clothes and tilling fields and local farms.

TABLE 20: THEMATIC ANALYSIS OF INTERVIEWS WITH DISTRESSED WOMEN. COPING STRATEGIES: GLOBAL THEME: INCOME GENERATION

<i>Coping strategy</i>	<i>Process</i>	<i>Coping behaviour</i>	<i>Context and content</i>
Income generation	Individual agency	<ul style="list-style-type: none"> Part-time job Juggling financial resources 	<p>'For extra money I wash linens for the cottages on the reserve'</p> <p>Use money from grant to buy the materials to build a new house – 1 brick/month</p>
	Collective agency	<ul style="list-style-type: none"> Participate in savings group 	'After husband died I joined a community support group that encourages individual saving plans'

I run a tuck shop [small shop in rural area in metal hut-like structure] they pay me R200/month to do so – my husband recommended that I do it to offset my

expenses... it is better to do something even if it is just a little bit of money to make ends meet and care for my children - V

Although women were incredibly resourceful and driven by great amounts of individual agency in their efforts to secure an income, these strategies were precarious, and often unsustainable:

When I found out I was sick, he took me to this place, and he left... he doesn't care about me, and he is not giving me food... I am now washing linens for cottages. I use that income to pay for food, and supplies for the children at school- when I am in too much pain I cannot do my washing so there is no money to eat... sometimes I have no idea what to feed my kids. -Nomvula

Findings from chapter five identified that government grants were the primary source of income within many families. Recipients of larger grants – such as the disability grant– described juggling income to cover a range of expenses and family needs. This often included supporting external family members (children of deceased siblings, grandchildren away at university). Even much smaller grants were able to be ‘stretched’ to unbelievable limits, in order to support families:

It's ok, because now God is helping me and I am working and also receiving a grant, so things are OK. I have enough food to eat. It helps a lot to prevent the children from going to bed hungry. I use money from child support grants to buy food and cement to build a house for us, which really helps. – C

Only a minority of cases (two) identified grant income as successfully increasing their control over life circumstances. Other women described that their efforts in this vein often failed to generate significant improvement in their daily lives, and seeing these ‘failures’ as continued evidence to the desperation of their situations, and ongoing emotional distress:

Things that can stop me from being hurt? You can't be free if you don't have money. Money sets you free. Am I wrong? If you are borrowing from your neighbour they will soon be tired of you... You think that if I had money I would be doing this? Those who are working are doing it [hard work] for money. But if you have no money you sit and think deeply and become depressed. - P

6.3.4 ACCESING EXPERT ADVICE

Thus far I have painted a picture of women achieving marginal successes in managing the conditions related to their emotional distress. Here, success is defined by women’s ability to meet some survival needs within the contexts of their own lives, by leveraging low, albeit effective, levels of support systems– such as engagement with peers, church services and community partnerships to mitigate the causes of their distress. To a lesser degree, certain women took charge of their situations by drawing on expert advice within the management of their needs. Table 21 summarises the coding frame for this theme.

TABLE 21: THEMATIC ANALYSIS OF INTERVIEWS WITH DISTRESSED WOMEN COPING STRATEGIES. GLOBAL THEME: ACCESSING EXPERT ADVICE

<i>Coping strategy</i>	<i>Process</i>	<i>Coping behaviour</i>	<i>Context and content (in vivo codes)</i>
Accessing expert advice	Social capital (bridging)	Seeking medical/professional advice	'I saw a social worker to help me get a disability grant for HIV'
		Seeking medical treatment	'I visited the physiotherapist who gave me exercises to help with the pains in my legs'
		Seeking traditional healer advice	'After my husband died my children couldn't sleep so I asked the traditional healer for help'
		Seeking traditional healing	'I was sad that I could not have a baby so we saw the traditional healer who helped and I got pregnant after that'

All women described encounters with nurses or home based care services, often related to the management of physical health issues such as headaches, chronic pain in legs, and general pains. Women identified these conditions as limiting their productivity and ability to contribute to their homesteads.

'Unexplained' and chronic headaches are often used as cross-cultural markers for potential mental health problems, particularly depression. Though these symptoms posed red flags for allied health professionals to explore cases of psychosocial depression and complex social needs in women (see section 7.1), engagement with these professionals are typically infrequent, making primary care nurses the first port of call. Nomvula, whose case study I presented in chapter five, was one of the more distressed and isolated women I interviewed. Her main outlet was the nurse at the primary care clinic:

Ro: What did the nurse say?

Nomvula: She gave me pills...I said I feel tired on my feet.

R: What did the nurse say to you?

N: She gave me pills....Pills for pain and something to rub on my legs

R: Did the nurse say it was arthritis?

N: They did not explain they just gave me pills and I took them once.

It helped, I was able to work on my mats[and generate income]...They did not explain because they gave me once those pills...and I always thought that they would give me [more] but they never did.

The treatment of physical pain alone has been cited as a 'failing' among mainstream mental health literature (Petersen, 1999). However, there are positive implications of these encounters for disadvantaged women whose emotional well-being is intrinsically linked to their own productivity. Nomvula's interaction did result in positive outcomes: the pain preventing her from completing part-time work to support her family was alleviated, even if only for a short while. Later in our discussion, another encounter with a nurse regarding her

inability to sleep caused by worries about her HIV positive status and the abandonment by the father of her children, was less successful:

Ro: When is the last time you had a peaceful sleep?

N: I can say this week...before I don't fall asleep until early in the morning – and then I have to wake up to take care of the kids

R: What are you thinking about if you can't sleep?

N: I think of this and that and committing suicide so that I can run away from this life of being (hurt by) people and my kids will see what to do for themselves.

R: Did you go to the clinic and talk to the nurse about this? About how you were feeling?

N: I went to the nurse in Empangeni (for HIV testing) once and told her. They gave me pills to sleep...I took them once, but she never gave me anymore.

Such findings suggest the persistent issues identified within earlier South African studies highlighting the complex role of nurses in addressing mental distress (Petersen, 2002). The reasons driving inattention to socio-emotional contexts of women's distress among primary health nurses has been attributed to lack of training and capabilities of nurses to handle mental health issues (Petersen, 1999; 2000). However, as I will address in chapter seven, stigma among the broader community, including primary health care nurses, may have a much larger role to play within these 'failed' encounters at the primary care level.

A minority of women described occasions where they sought guidance from experts to tackle symbolic and structural contexts at the core of their emotional distress. Social workers and teachers were sought out in efforts to mediate family issues or obtain assistance with grants. Traditional healers were sought by only a few women, in relation to deaths among family members and other family conflicts.

Once I visited a traditional healer... Sometimes I couldn't sleep at night

After my husband passed away we [children] started to see him in our dreams

Visions of the father made the children cry at night

It lasted for three months, so I decided to contact a traditional healer

The healer prayed over water [which is kept in the house], and we kept the water in the house –things got better after that. - P

Contrary to findings from recent studies stating that community members experiencing mental health problems first sought the support of traditional healers (Campbell-Hall et al., 2010), only a few women reported drawing on traditional healers in relation to mental health-related concerns. In fact– because many women reported strong affiliations to God and the church – engagement with healers was cited as rare or taboo, because church participation forbade it. This finding is of interest given the emphasis placed on mapping out roles for traditional healer participation in public mental health services. The local role played by healers is concerning for those who fear the negative repercussions of their treatments (Sorsdahl, et al., 2009). However, findings from this study indicate that women drawing on healers as a route of support for issues relating to common mental health disorders like depression and anxiety were exposed to treatment practices unlikely to result in patient mortality. Healing waters to be left outside the home, or to bathe with, and blessed

ropes were examples among women in this study. These symbolic practices overseen by traditional healers made positive contributions to mental well-being in view of their ability to balance social scales that may feed into the emotionally distressing experiences of patients, and should have a welcome place within mental health support frameworks.

This section identifies a series of strategies used by women in attempts to manage their emotional distress within their everyday lives. Their projects of survival are underpinned by the presence or absence of community competencies – which I described in chapter three as critical to the evolution of healthy communities. Women’s strategies invoked *agency*, *solidarity*, and *partnerships* to some success. The use of psychological reframing strategies highlights the absence of spaces where women can build *critical awareness* about the influence of norms in maintaining their distress, and opportunities to think about ways to shift their distressing environments in small but meaningful ways. This passive acceptance aligns with a lifetime in such dire conditions; facing the structural violence imposed by poverty and gender disadvantage (Farmer, 1996). The impacts of such conditions that have well-documented implications for health outcomes, should find equal weight as targets for intervention by primary health practitioners (Marmot et al., 2008) – an argument I develop further in chapter eight.

For women in Manguzi it appeared that drawing on formal primary health care practitioners carried some weight in their response strategies. I engage with cases of this instance and unpack what supports the decision to enter services in the final section of this chapter below.

6.3.4.1 VISITING FORMAL MENTAL HEALTH SERVICES: CRISIS POINT

In chapter five, I presented the case of Patient X, observed during a mental health clinic following a ‘crisis’ point in an ongoing line of social hardships that made her life increasingly intolerable. Additional patients observed in hospital settings were also brought in by family members following a suicide attempt (parasuicide). I explored the content of these patient histories by organising information along themes identified by the grounded thematic analysis of community women interviews. Patients identified that their distress and breakdown leading to parasuicide was shaped by contexts similar to those presented in section 6.1, and for some, access to coping strategies identified within section 6.2. This is summarised in table 22.

TABLE 22: THEMATIC SUMMARY OF PATIENT HISTORIES OF NEW ADMISSIONS FROM MOTIVATED ETHNOGRAPHY DATA

<i>Patient number, age, family account of presenting features</i>	<i>Contexts framing life story/distress</i>	<i>Available coping strategies</i>	<i>Contexts framing breaking point</i>	<i>Response</i>
1, Female 33 years -	<ul style="list-style-type: none"> • HIV positive • Loss of husband to HIV (2005) • Rape 2007 • Unemployed (Grant income) • Supporting alcoholic mother 	<p>Child support grant income</p> <p>Sharing stories (sister, lives too far away)</p>	<ul style="list-style-type: none"> • Event: suicide planning (self and children) • Flashbacks of rape episode make it difficult to sleep and complete daily tasks and support children • Mother runs away when drunk • Daily Worries about supporting her children if she dies (HIV) 	Fluoxetine management (improve sleep)
2, Female 20 years – friend found her running around after swallowing poison	<ul style="list-style-type: none"> • Father died in 2005 • New stepfather refuses to support her financially • Brother arrested for stealing to support her in absence of stepfather • Dropped out of school to find work – lacked ID book or birth certificate (first suicide attempt) 	<p>Sharing stories (friend)</p> <p>Friend helped her get job as domestic worker after first attempt</p> <p>Sharing stories – boyfriend</p>	<ul style="list-style-type: none"> • Event: suicide attempt (2nd) • Stepfather chased her away from family home – doesn't want to support her because she is not his child • Sleepless nights because worrying about family issues and ongoing problems with stepfather 	<p>Possible fluoxetine after bloods clear</p> <p>Social work referral</p>
3, Female 43 - husband found her wandering in woods aimlessly and described hearing voices	<ul style="list-style-type: none"> • HIV positive (infected by husband) • Migrant worker lives away from home during the week • Manages the house (3 children, 1 child with CP elderly mother-in-law) on her own 	<p>Sharing stories (mother-in-law)</p> <p>Income from husband</p>	<p>Event: schizophrenic episode - voices suggesting violence and running away from home</p> <p>Depression on discovering status</p> <p>Told that they are repossessing all of her appliances from home day before episode</p>	<p>Fluoxetine upon completion of 72 hour observation</p> <p>Referral to NGO for home based care</p>
4, Female 30- aunt found her with the rope in the woods after voices told her to commit suicide	<ul style="list-style-type: none"> • HIV positive (infected by husband) • Married with three children • Unemployed (self+husband) 	<p>Sharing stories and pooling resources (aunt)</p>	<p>Event: schizophrenic episode - voices telling her to commit suicide</p> <p>Lack of sleep/increased drinking in recent months</p>	Decision pending 72 hour observation

The behavioural features triggering family members to bring patients to services mirrored the features that community women described as signals of mental illness in section 6.2. As I outlined in chapter five, Parle (2008) describes a period in South African history where a display that mirrored a symptom pool (collection of behaviours/actions) related to madness were used by women as a subconscious reaction against shifts within their communities' worlds. Though there is not sufficient data in this study to develop an argument to support the idea of women in Manguzi drawing on agency in this way, practitioners voiced concern over issues of this type of 'malingering' – and how women drew on a certain set of behaviours as a cry for help, leading to immediate attention by families and service actors, which could be linked to a similar phenomenon.

Suicidal women get taken very seriously – taken to see a doctor... psychosocial problems who come into the hospital [that way]get help very quickly, if they are at home, they are having problems and then become psychotic, the community will bring them in and then they will get help – Occupational therapist assistant

For women in Manguzi struggling with social dysfunction, the ability to draw on a representation of mental illness that requires an immediate supportive response, opens a potential gateway to support at crisis points. If this were the case, then it is possible that women may find themselves to be at risk of misdiagnosis, with a mental health problem that is particularly stigmatised in the community. Practitioners also spoke of problems with misdiagnosis in daily practice (see chapter seven), making this a platform for interesting future study.

Data presented in table 22 above outlines some of the treatment strategies offered to women in these circumstances, which does indicate efforts to address the social sequelae of women's distress. However, the efficacy of these types of social responses within a primarily biomedical system remains questionable, and moves us into chapter seven where I focus on this in greater detail.

CHAPTER CONCLUSIONS

This chapter outlined Manguzi women's representations of mental health, framed around the twin concepts of suffering and survival. Women spoke of dimensions of poverty, community violence, and HIV and the resulting relationship difficulties, as key drivers of their distress. It is important to note that they were not passive victims of the great unhappiness and often insuperable social problems that they suffered, engaging in a range of varying effective coping strategies targeting survival. Women most often soldiered on, self-managing their distress through a range of cognitive and practical strategies. However, the use of experts emerged as an option for a minority of women, and within this, formal mental health services emerged as the more dominant source of support. For some women, suicide attempts (possibly fashioned around representations of mental illness which link them to immediate access to help from families and biomedical services) provided a gateway to public health services. The primary health system response to women's needs appeared to reflect attention onto the importance of community, albeit primarily towards dimensions of 'place'. In the next chapter I explore how these services, despite their explicitly biomedical framing of mental illness, are not completely blind to the social dimensions of the women's distress.

CHAPTER SEVEN: RETHINKING SERVICES FOR COMMUNITY MENTAL HEALTH: THE REALITY OF PRIMARY HEALTH CARE PRACTICE

Chapter six concluded with a discussion of women accessing formal health services, in anticipation of this chapter's concern with the ability of primary mental health services to respond to the gamut of social complexities at the core of women's distress. In chapter three, I suggested that effective community mental health services would be: a) able to engage with patient understandings of distress (Kleinman, 1980); and b) create a social space that is responsive to patient narratives. The latter embodies the concept of *receptive social spaces* (Campbell et al., 2010), originally argued as important to social and health movements, which I now extend to the arena of community competences for mental health (Campbell & Burgess, 2012)

The importance of promoting receptive social environments within this thesis refers to treatment encounters where practitioners move beyond the recognition of local understandings and seek to accept patient knowledge as a valid truth, and work actively to include local definitions of the problem within their efforts to respond to distress. This is a theoretically convincing argument, particularly in contexts where social disparities shape health outcomes. However, this currently remains an underutilised insight within mental health services. As such, this chapter explores how well primary health care services can promote these environments, despite the description of service settings as:

- I. The meeting place of two different representational systems: those of patients and of primary health sector professionals (Kleinman, 1980; Mishler, 1984; Swartz, 1998); and
- II. Limited by conflicts established by these opposing representational systems (people vs. systems) that undermine the ability of services to effectively help patients (Mishler, 1984; Barry et al., 2001).

This chapter proceeds as follows. First, I use practitioners' accounts of their daily practice to map the content of their representations of women's distress, exploring the influence of social and cultural drivers identified in chapters five and six. Findings highlight that professionals see the world similarly to community women, and are respectful of patient narratives. Second I review how practitioner's understandings framed a series of best practices that position women as 'subjects', rather than 'objects' of treatment. I also explore how multi-disciplinary and multi-sector collaborations, a benchmark for effective 'community engagement' in provincial (Skeen et al., 2010) and global movement policy recommendations (Thornicroft & Tansella, 2013) function in Manguzi. The chapter concludes with a discussion of problems affecting services. Issues appear to arise, not from a conflict in world views of patients and health workers, but in limitations arising from the structure and resourcing of public and mental health services, such as resource limitations, the

stigmatisation of mental illness even by professionals themselves, and policy ideals that appear to miss the mark in terms of their approach to social aspects of mental distress.

7.1. 'THEY NEED TO DO EVERYTHING...BUT THEY'RE TREATED LIKE SHIT' - HOW PRIMARY HEALTH CARE PROFESSIONALS UNDERSTAND WOMEN'S EMOTIONAL DISTRESS

The formal medical sector is recognised as occupying a dominant role within the mental health services, a consequence of the sector's access to structural forms of power (legislation validating their practice) and state funding (Swartz, 1998). The community mental health service model in South Africa is a primary health care model, which runs through district services that coordinate medical practitioners from a range of health disciplines across multiple levels of care, often in partnership with community actors. The meeting of representations implied in this type of system prompts this section's analysis of the social representations held by health professionals.

TABLE 23: CHARACTERISTICS OF PROFESSIONAL INFORMANTS

Position	Duration in local post	Gender, racial background	Place of birth
Doctor – District level (medical manager)	8 years	M, Black South African	South Africa (KZN)
Doctor – District level (mental health doctor)	1 year	F, White British	England
Doctor – Regional level psychiatrist	5 years	M, Black South African	South Africa (KZN)
Doctor – Tertiary level psychiatrist	10 years	M, Indian South African	South Africa (KZN)
Sr. Physiotherapist - District level (Therapy department assistant manager)	6 years	F, White South African	South Africa (Gauteng)
Jr. Physiotherapist - District level	1 year	F, White South African	South Africa (Western Cape)
Sr. Occupational therapist – District level	3 years	F, White South African	South Africa (KZN)
Occupational therapy assistant – District level	7 years	F, Black South African	South Africa (KZN – Manguzi)
Nurse (Psychiatry) – District level	4 years	M, Black South African	South Africa (KZN - Manguzi)
Nurse (Psychiatry) – District level	5 years	M, Black South African	South Africa (KZN)
Principal Social worker – District level	1 year	M, Black South African	South Africa
Voluntary counselling and Testing (VCT) programme coordinator	4 years	F, Black South African	South Africa (KZN-Manguzi)
NGO home based care coordinator (nurse)	5 years	F, Black South African	South Africa (KZN-Manguzi)
NGO paralegal programme coordinator (grant support)	3 years	F, Black South African	South Africa (KZN-Manguzi)

Analysis of interviews with primary mental health care (PMHC) professionals highlighted two global themes: the **prevalence of mental illness** within a biomedical paradigm, and professionals' efforts to **locate women's mental health** more broadly within various structural and symbolic contexts of Manguzi's life world. The 14 participants discussed in this chapter are health professionals representing actors across disciplines and levels of care (see table 23). These practitioners are from different backgrounds and include both men and women, with different links to Manguzi.

Section 4.3.2 outlined the purposive sampling strategy through which I recruited the key professionals delivering mental health services in Manguzi. The table below summarises my analysis of practitioners' understandings of women's distress (shown without *in vivo* codes).

TABLE 24: THEMATIC ANALYSIS OF INTERVIEWS WITH PROFESSIONAL INFORMANTS: UNDERSTANDING WOMEN'S DISTRESS

<i>Global theme</i>	<i>Organising theme</i>	<i>Basic theme</i>	
Prevalence of mental illness	Age effects	Younger women commit suicide Older women develop psychosocial depression	
	Gender differences	Drug related mania higher in men than women Women experience depression	
	Shifting diagnostic categories	Reduction in HIV psychosis cases High prevalence of MH issues in community Low levels of biological/major depression 'Schizophrenia' as form of response	
Locating mental health within the community	Family and social relationships	Poor relationships cause stress Family relationships cause MH problems Loss of an important person causes emotional distress Lack of family support causes distress Parasuicide in teens caused by failing Matric (final year of high school) Parasuicide in teens is caused by problems with boyfriends Distress caused by need to care for children	
		Poverty and deprivation	Poverty is the cause of parasuicide – no employment opportunities Depression is caused by poverty People are unemployed and they drink all day long Income motivator for people's participation
		HIV	Denial about status leads to parasuicide Anxiety/fear about disclosure of status
		Norms defining women's participation in community structures	Reliance and dependence on social support from family is important Role of men in families Women's lack of education maintains disempowerment Women are treated poorly in community

Practitioners' understandings reflected a biomedical discourse linked to accounts of the **prevalence of mental health issues**. The situation in Manguzi was described with reference to diagnostic categories, linking age and gender as variables that shape the nature

of mental distress. Their accounts align with national epidemiological data described in chapter two– which note that women are more affected by depression than their male counterparts (Tomlinson et al., 2009), and that males suffer from higher levels of substance abuse disorders (Olley et al., 2003). However, in evolving accounts of these trends, district-level professionals sought to **locate mental ill-health within the complexities of the life world**, identifying many of the symbolic and place-based contextual influences identified in findings from chapters five and six.

For example, professionals linked high levels of drug-related mental illness in men to unemployment and reduced opportunities for economic participation to fulfill roles as providers for their families. Unsuccessful suicide attempts (parasuicide) and psychosocial depression amongst women were repeatedly linked to poverty and deprivation, HIV, and family and other social relationships. The following quotes provide key examples:

Ro: ...so you said that you see a lot of patients that have – depression because of things that are happening socially-

Y: Yah..., the thing is just you find that people are depressed because of the things that happen to them, yah. With some there is a family conflict, with their husband, some is because of abuse, that is happening, like the other [woman] we saw, that was in the[hospital] ward, her kids were being abused by the husband, sexually, and the mom end up depressed...and the other thing is depressing [women] is when their kids are being abused, the family likes to say 'no, you mustn't take this to [the police] you mustn't report it - this is a family thing' and when it's a family thing, that means that they don't counsel each other on how they are going to cope with this and a mother can't do what she needs to do – protect her children.

Ro: Umm... so what sort of things are the cause of the 'pain in their heart'?

J: It's pretty varied....we get the tragic moms whose children are hungry and they don't know how to feed them,... there is one woman who her and her mother had both suffered community assault, they'd been accused of some crime,... she had just been very badly injured, then they'd ransacked her home, she had to move away.... A mother who had split from her husband because he had taken on another wife, and there had been some fight and she had to leave, but he insisted on keeping the children and she wasn't allowed to access them – and she tried to phone them once, and her life had been threatened... she was, like losing her mind, she wanted to see her children.

Practitioners also acknowledged the role of cultural norms in distress, identifying ways in which the norms promoted powerlessness, dependence on men, and acceptance of heavy burdens within family networks.

People here have a pretty tough life... and the culture is such that the women work very hard, and are expected to work very hard, whereas it's ok for the men to sit and do nothing. So, women take a lot of strain... they are kind of amazing, but sometimes it's too much, and they need help, but it's not socially acceptable to say that they aren't handling it, and they need help. – Jr. Physiotherapist

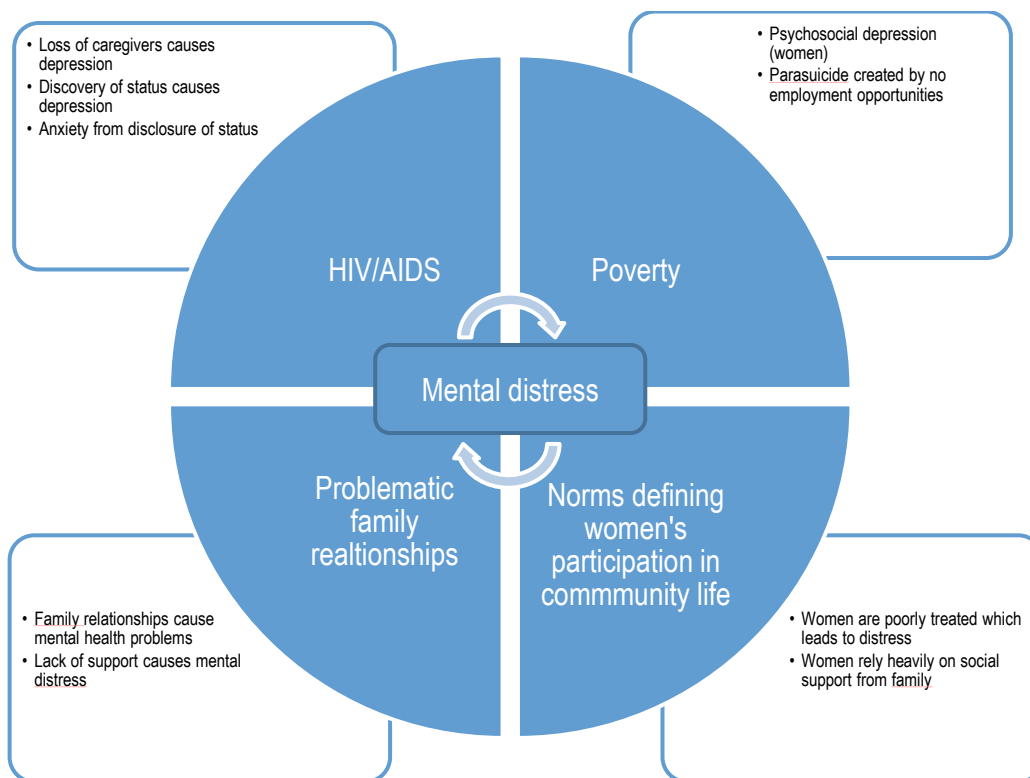


FIGURE 24: PRACTITIONER REPRESENTATIONS OF WOMEN'S DISTRESS

As summarised in figure 24 practitioner representational systems differed from women's in their explicit recognition of the centrality of their community norms. Conversely, women did not explicitly or self-consciously link these to their accounts of distress, and the impact of norms uncovered through my own analysis was enabled through reflection on the contexts of community identified in the motivated ethnography.

This finding appears to contradict a body of evidence that situates meaning systems of medical practitioners and those of their patients in oppositional life worlds (Crossley, 2000; Mishler, 1984). The work of Kleinman (1980; 1988) and other critical and cross-cultural psychiatrists is predicated on the belief that the world views of psychiatrists and medical practitioners are often diametrically opposed, which may result in the mistreatment and oppression of patients (Rose, 2008; Kleinman, 1988; Mishler, 1982). A British study (Barry, et al., 2001) highlighted that only a minority of doctors (6 out of 20) attempted to develop a mutual life world (where both doctors and patients predominantly use the voice of the patient's life world) during patient communication. Similar studies in African contexts about the nature of mental health practitioner meaning systems present mixed findings. In Kenya, district health nurses were reported as adhering to a strict medical model (Muga & Jenkins, 2008), while in Zambia (Aidoo & Harpham, 2001) practitioners drew on a bio-psychosocial model recognising some psychosocial factors. In Ghana (Ofori-Atta et al., 2010) practitioners also recognised the importance of social factors, but included negative representations of women as the 'weaker' sex, enabled by cultural framings of women as part of their systems of meaning.

The factor differentiating practitioners in this study from those discussed in the body of literature referred to above, was their scepticism about the value of the biomedical response in this particular setting:

[community definitions of mental illness] are around being mad, their definition is not like any of the other [categories], it's not mood disorders....and the other thing is, that if you tell them that they have mental illness, well if you're doing all these surveys and you tell them they're mentally ill, and they think 'hey my life really is shit' do you really want to be telling people that? They're so tough and they're so admirable and they're just bumbling along and trying to do the best that they can, on a day-to-day basis, and to suddenly, you go there...when someone tells you that you have something, then it's actually on your mind a lot and it's not helpful, particularly when its [because of] social problems and there's nothing that they can do about it.... I mean I'm sure it [mental ill-health] still needs to be addressed, but the poverty first perhaps, because...that would be like opening Pandora's Box.

– Mental health doctor

The similarity between practitioner and community women's representations may be accounted for in one of two ways. Firstly, many of the more critical practitioners were from outside of Manguzi, from more developed parts of the country, with one from the United Kingdom. With minimal incentives to live and work in such bleak and remote rural settings, many of these practitioners' decisions to move to Manguzi were related to personal commitments to health and social justice issues and a disdain for working in the private sector. Secondly, this could be explained by the presence of a common life world, where black South Africans have a shared experience with the realities facing many of the local patients, either as a native to Manguzi, or as a black South African from another part of the country. While these practitioners may approach the 'shared life world' of Manguzi from an alternate zone of relevance (i.e. a slightly different position shaped by their exposures to biomedical training and policies that shape their work- Schütz & Wagner, 1970), their personal experiences of the realities of Manguzi help to maintain an appreciation of the experiences driving women's distress. For example, the geographical remoteness of Manguzi dictates that to work there requires living there –and being surrounded daily by the realities of the life world: the staggering poverty; constant power shortages; poor access to drinking water; violence, and harrowing social stories of patients. These realities can be avoided in more cosmopolitan settings where health professionals may be able to retreat to spaces where they can escape the stark daily life miseries that many in Manguzi experience.

7.2 PROMOTING RECEPTIVE SOCIAL ENVIRONMENT WITHIN COMMUNITY MENTAL HEALTH SYSTEMS: BEST PRACTICE

Receptive social environments are defined in chapter three as spaces where practitioners move beyond the recognition of local understandings, seek to accept patient knowledge as a valid truth, and work actively to include local definitions of the problem within their efforts to respond to distress. They are a key dimension of health enabling communities, associated with the presence of actors who possess the willingness to engage with and facilitate local aspirations for change (Campbell et al., 2010). In the context of community mental health services, this mirrors my earlier arguments for a need to position women as ‘subjects’ of interventions rather than the ‘objects’ – where the latter are characterised by attention to symptoms and their treatment in isolation of the social and symbolic environments that produced them. In section 7.1, I described professionals’ social representations of women’s distress as being in virtual alignment with the women’s, displaying a common recognition of the complex social and symbolic aspects of the community of concern.

Their engagement with women in treatment spaces is clearly framed by this representation, as noted through health professionals’ accounts of efforts to address patients’ voiced concerns. Analysis identified three global themes describing the processes shaping these best practices (see table on next page).

Accounts highlighted the professionals’ use of **strategic counselling practices** in order to discover the root social cause of women’s somatic complaints, often described as back pain or ‘Macarena’ pain¹¹. They recognised that women typically had a reluctance to talk about their problems outright, resulting in the masking of feelings and distress within non-verbal cues, putting emphasis on certain words, or displaying a particular body language during discussions:

Patients will often use cues to point to the problem – a little emphasis on stress, money matters and lack of support and you think – ahh, yes, now I have to unpack that. – Therapy department assistant manager

Practitioners also described the **design of new systems and practices** to better meet the needs of women. For example, increased community outreach sessions were developed to ensure high risk ‘walking social cases’ were not lost to follow-up, as many women were hindered by financial and transportation barriers.

There’s no time at clinic to do proper counselling session...so a lot of time, we identify a walking social problem and tell them to come back – and never see them again, so we started (additional) twice a month visits to some of the residential clinics, hoping that we can catch and sort out some of these cases better. – Therapy department manager

¹¹Macarena pain is described by practitioners as pain that is not localised to any one area of the body – general pains in extremities, head, legs, etc.

TABLE 25: THEMATIC ANALYSIS OF INTERVIEWS WITH PROFESSIONAL INFORMANTS: BEST PRACTICE PROMOTING RECEPTIVE SOCIAL SPACES

<i>Global Theme</i>	<i>Organising theme</i>	<i>Basic Theme</i>	<i>Sample invivo code</i>
Creating and supporting new systems to increase engagement with women	New systems to increase patient access to supports	1. Extend rural outreach to increase access to more complex social cases 2. Develop new screening tool to assess psychosocial risk in PT patients	Started bi-monthly visits to rural clinics to follow-up with social cases that are too far to come back into hospital. Developed screening tool to help identify these 'walking social cases' in therapy dept. to transfer to psych.
	Increasing capacity of staff to communicate with women	1. Strong translators enable on-spot counselling in clinics 2. More translators to support non-Zulu staff in communicating with women	'Now that we have stronger translators I will lead questions and listen, and I have enough Zulu to pick out what's happening and direct good translators on when and how to probe'
Adapting current system for 'survival'	Practices to cope with staff inefficacies: postponing treatment	1. Avoiding counselling when in the presence of poor translators who mis-represent advice 2. Advocate for patient to avoid certain staff members to avoid being 'mis-managed'	Providing informal counselling – 'with poor translators I will refuse to deal with it, give [the patient] a placebo exercise and book them for another time when I can give them a decent counselling session' 'I tell them to wait until the man (head social worker) is there – and to avoid the old woman at all costs'
	Patient advocacy – support patients in navigating the system	1. Advocate for patient during their applications for grants to avoid their mismanagement 2. Strategic wording of grant applications to ensure patient access to support/care	Accompany patients to home affairs office and speak on their behalf because they are often ignored. Have to work within the system to get patients the help they need – only extreme disability cases will get grants, if patients can do the smallest things for themselves they are denied support, which is not fair, or appropriate.
Strategic counselling practices to identify 'social cases'	Recognising non-verbal cues to promote accurate response (social)	1. Counselling: Reading non-verbal cues to promote accurate treatment 2. Deconstructing/probing cases of chronic back pain to find underlying depression caused by social issues	'can identify because they come in with a certain expression on their face - they don't meet your eyes... a fragment of a sentence they say - emphasis on money matters or lack of support that they throw in, and you have to unpack that' Maybe there is something that would give you severe back pain, but that's really rare, anything longer than three months, - and it's not just back pain, neck pain and Macarena pain – psychosocial flags.
		Respond to survival needs	1. Counselling: depression+ poverty response: temporary food parcels and grant application 2. Support groups for women to engage in income generating activities

In order to increase the ability of allied professionals to deliver counselling sessions during manic hospital clinics, the occupational and physical therapy departments established a programme of local volunteer translators sourced from the local community. Translators were trained on how to describe symptoms, focusing on the importance of articulating

contexts relating to women's 'sadness of the heart'. Most often, translators assisted during sessions with younger non-Zulu speaking staff based in Manguzi on community service placements. Despite some successes, the scheme was not without difficulties, as the success of informal counselling sessions held during therapy clinics would rise or fall on what was lost in translation:

It depends on how complicated the case is...we're taught to ask about the nature of the pain... lots of detail, but here you can't do that, it's...on that level... I need to work on that with each translator...umm, a translator will quite often tell me the patient has pain in their spinal cord – so I don't know what's been lost in translation, I don't know how fine a distinction they make between various things. - Jr. Physiotherapist

To prevent the mismanagement of particularly difficult cases where social problems were a clear concern, practitioners engaged quite heavily in **patient advocacy**, describing how they worked within the system to ensure pathways to support, most often in response to distress caused by place-based challenges. This involved advising patients to avoid certain staff in key departments, whose levels of incompetence often resulted in the mismanagement of patients. Ironically, the largest frustration was with one of the social workers (one of the most important referrals for distressed women):

...we actually tell the patients – if you see the old fat woman, turn around and come back another day, you need the young lady, or the man – we just tell them straight away, you just waste your time...just a little patient advocacy...because this system is so dysfunctional you're not going to find the patient again. If he gets mismanaged by that doctor or social worker, they're going to get mismanaged for the next 20 years – Therapy assistant manager

The need to work around these issues highlights a key barrier to meeting social concerns within primary mental health services, an issue I deal with more intimately in the subsequent section. Practitioners across all disciplines spoke about the importance of responding to survival needs presented by patients during counselling sessions, targeting poverty and hunger through the administration of food parcels and grant assistance. Referring women to the social welfare department demanded advocacy and extra commitment from social workers, who often accompanied women to appointments to ensure they were seen.

Depression – most cases they are related to relationships, and poverty...where the cause is poverty, we recommend food parcels, or DG (disability grants). But most of the time, food parcels... we also check the issue of documents, because most of them don't get (social) assistance because they don't have the necessary documents... if you refer a patient to home affairs, it's better to book a car and take the person to home affairs...They[home affairs staff] don't take it seriously, or they will ignore the patient and they just stay, they wait– Principal social worker

Other staff described having to 'work within' the system by filling out applications in strategic ways so that access to supports was not automatically declined.

[we]have to learn to work within the system so patients who need support will get what they need – if you mark partial ability to complete tasks, patients will not receive

any support at all and the grant will be denied. If you can do anything for yourself, you likely receive nothing...- Occupational therapist

The above discussion highlights a series of efforts to deliver services that position the social milieu behind women's distress as a key point of intervention. In socially dire conditions where women lack power and voice, the importance of more powerful agents who give validity to the content of narratives are critical in contributing to women's local efforts to transform their distressing environments. As such, these best practices are examples of how primary care settings can operate as 'receptive social environments' and bolster community mental health competence. For example, in chapter five I described the development of support groups where women were supported in the development of income generation efforts by a primary health care professional. These groups were stopped through lack of funding. In their place, social work referrals to food parcels offer only temporary (up to six months) responses to enduring place-based issues of hunger which form the core of women's distress. However, more formalised funding structures built around initiatives like the aforementioned support groups may accomplish more long-term achievements in response to poverty, while promoting the competencies of agency, solidarity and dimensions of positive mental health.

Despite these positive efforts, practitioners still faced a series of challenges to what they felt was good practice. Problems appeared to be linked to the limited reach of many of the practitioners driving the 'best practices' identified in this section. The hierarchical system of services in Manguzi bestows the greatest power to individuals – particularly senior psychiatrists who are flown in for one-off visits – who are often (i) furthest away from the realities of Manguzi life, and (ii) have the most biomedically and least patient-sensitive world views. Both of these factors have been found to result in the mismanagement of patients in other settings (Mishler, 1984; Jain & Jadhav, 2009). The case study below describes a patient observed during a clinic visit, when the patient was called in to see the visiting psychiatrist (who did not make his appointment due to inclement weather conditions). The patient had been on antipsychotic medications since 2006 in response to a manic presentation at services. According to her patient file, her first visit was linked to the loss of her children after her husband abandoned her. Based on the lack of a full psychological screening and occurrence of just one manic episode, the psychiatric nurse was concerned about the validity of her diagnosis of schizophrenia and wanted to initiate a weaning process from her medications.

Box 10: Patient two; psychiatrist special referral

Female, Age 54

Social history: *Long history of problems with ex-husband – he left and when he did she lost custody of her children. Experienced depression and sadness related to the loss of her children that did not respond to counselling sessions with social work. She still argues with her children about them not supporting her – she currently has no job and no income. She was started on haloperidol (by community nurses) to manage her hearing of voices in 2006. When asked to describe what the voices say, she is unable to be very clear – says that that she can't really identify what they are saying but it comes across like they are preaching to her. She says she also feels an electrical shock that isn't scary to her, but that's what she feels when she hears them.*

Chart notes: *(hx/notes from visiting psychologist from 2006, prior to initiation of haloperidol) The psychologist describes that her obsession with the grant is something that will only exacerbate her symptoms, but that he didn't feel that she warranted receiving it at that time. M (Psych nurse) asserts that based on the psychologist's findings that she may be malingering to gain access to a grant.*

Presenting issue: *Her current complaint is linked to problems with forgetting where she puts things and ongoing psychosocial depression that is related to her unemployment, lack of support systems and ongoing difficulties that she faces in getting a grant. She describes the process of applying for a disability grant – during which time the signing doctor informed her that she didn't need a grant, she needed a boyfriend. Although she doesn't present with side effects from the psychotic medication that she is on, she asks – 'if I'm not sick then why am I taking all of these medicines? And why do other patients who receive these medicines also get grants, but I cannot?'*

In the patient's recounting of her history during that session, she described her experience of distress as a product of her difficult relationships with her children, whom she claimed did not support her, and as combined with her status as unemployed, she often went hungry. She has been trying to apply for a disability grant in relation to her diagnosis of schizophrenia, which she believes makes her eligible. In recounting her latest discussion with the doctor who needed to sign off on the forms at the social welfare office, she states that he told her that 'she didn't need a grant – she needed a boyfriend' – in order to help with her financial struggles.

What is particularly interesting about this case is its ability to tie together findings from chapter six about women's agency and the reality of services. The patient was a woman who, despite struggling with emotional distress, managed to draw on personal psychosocial resources of agency in seeking out access to services. In doing so, she entered into a partnership with health practitioners who she believed could provide her with access to resources needed to improve her circumstances – a display of efforts to use bridging social capital (Putnam, 2000). However, because the partnership was with a health professional who appeared to have very little interest in the woman's social realities (and even worse, responded to her distress in a hurtful way), she had difficulty accessing what she voiced as the type of support she needed.

My presentation of this case does not seek to query the validity of a bio-psychosocial model for severe mental disorders, which has been well documented (Tsoi, Hunter, & Woodruff, 2008). Instead, it seeks to confirm the importance for service systems to provide spaces that do more than just 'listen' to women's concerns, but have both the willingness and policy pathways to act on them. For example, the above patient's file indicated that she had already received access to food parcels, demonstrating the need to develop additional routes to support patients whose distress is linked to such place-based complications. Partnerships for health in settings marked by such complex social conditions

may not result in positive outcomes for women in the absence of actors who also have a willingness to engage with what is expressed by women (Vaughan, 2010). In the following section I elaborate on how issues such as power and stigma influence services, with an emphasis on the primary channel used to promote receptive social environments in services: multi-disciplinary team (MDT) meetings.

7.2.1 MEETING SPACES: MULTI-DISCIPLINARY TEAMS AND WORKING WITH 'COMMUNITY' ACTORS

Patient profiles from chapters five and six have highlighted the role of multi-disciplinary team assessments in the delivery of what I define as 'effective services' (via receptive social spaces that provide holistic care through creating genuine dialogue between professionals and patients, where each viewpoint is explained carefully and taken seriously by the other). Operation of these meetings was not always a smooth process. Analysis of professionals' accounts elucidated three global themes describing complications that arose in such multi-disciplinary team assessments (see table 26 below). Though policy stipulates that these meetings are to be held once a week, they occurred far less regularly, and during my month time in Manguzi only two multi-disciplinary team meetings were held. My practitioner informants (specifically, psychiatric nurses and therapy department staff) linked their infrequency to a lack of political will by medical doctors, the most powerful agents on these teams. **Hierarchical structures** within primary mental health policy gave signatory powers on all decisions made during these sessions to medical officers – who were rarely available. This policy limits the degree of meaningful influence on patient treatment plans held by often the most committed and insightful non-doctor professionals with deep understanding of community needs. The below quote by the senior occupational therapist highlights this frustration:

I don't think it (MDT) works very well –we need a doctor to be there. Because you can review a patient for months and months on end, but if you cannot change the meds then what are you doing?... I think it's good in the sense that social work, O.T. and the psych nurse know what's going on in the community, know at which clinics most of the problem cases are ... but it's so frustrating... the only people who are there are the allied health professions and nursing staff. –Senior occupational therapist

In chapter five, I alluded to how partnerships within primary mental health service model reflects instrumental forms of participation – which position lower tier health professionals such as nurses and NGO staff as 'handmaidens' who deliver programming planned by specialists. Data presented in this section highlights how even highly trained practitioners such as occupational and physical therapists find themselves 'trapped' within a system that prevents them from taking action to mediate the social contours of their patient's emotional distress.

TABLE 26: THEMATIC ANALYSIS OF INTERVIEWS WITH PROFESSIONAL INFORMANTS: WORKING IN MULTI-DISCIPLINARY TEAMS

<i>Global theme</i>	<i>Organising theme</i>	<i>Basic theme</i>	<i>Invivo code</i>
Bureaucratic hurdles to MDT/cross disciplinary work	Limited positional power and decision making abilities	Lack of control over budgets to plan for required services (support groups)	'You have to jump on opportunities to make things happen - waiting for funding to start programmes from hospital is impossible'
		Lack of positional power hinders response to pt needs	'Need to always get permission for prescribing meds and things off drug lists'
	Power dynamics between staff levels impact team efficacy	Hospital bureaucracy makes questioning diagnosis difficult Power dynamics b/w roles make contributing difficult	'It is hard to challenge a misdiagnosis of a patient because means challenging hierarchy in hospital - say I am undermining their integrity'
		Doctors must finalise decisions in MDT – absence impacts success	Multi-disciplinary team meetings don't work because meetings require a doctor to change prescriptions and review plans. Biggest challenge in mental health services is absence of psychologist or experienced social worker which means no one to fall back on for support.
Symbolic barriers to MDT/cross disciplinary work	Stigma among medical service providers	Primary health/hospital nurses do not want to help MH patients	Patients with psych histories on medical cards are treated differently by other medical staff - automatically sent to a psych nurse.
		Doctors refer to patients as crazy or 'mad'	'you need doctors who don't look at a psych patient and say " but you're crazy man, you're crazy" '
	Low value of MH by other disciplines	Value of non-medical services is low among doctors/management	Doctors and management consider physical therapy and mental health services as a nicety but not a necessity.
		Minimal interest in MH from medical staff	Took on mental health doctor post because no one else wanted to.
Views about role of traditional healing	Stigma among social service providers	NGO staff resist visiting with MH patients	'Home based care will tell them – you are insane – this makes our patients upset and difficult to manage sometimes'
		Social service departments will not talk to patients when they go alone	'Sometimes they will just wait all day and not get seen – but as soon as they (SASSA staff) see us – they get right in.'
	Traditional healers can make positive contributions to community mental health	Community sees traditional healers as first line response	People will always want to see their traditional healer.
		Community members have pride in traditional healing practices	Community members are proud about seeing traditional healers despite negative outcomes.
Current policy needs to include traditional healer knowledge Traditional healers have knowledge about 'cultural' cases		Current policy does not include traditional healers and it should. Difficult for staff to distinguish between the two paradigms (cultural and medical)– need to include traditional healers to do that.	
Biases against traditional healing practices	Traditional healers can support medical efforts	Traditional healers are a very important part of culture- provide a supportive function to the community.	
	There is a value to using dual systems	'I'm not against traditional healers at all – they a part in the psychosocial stuff that we can't do – as long as it's not critical '	
	Traditional healers only see spiritual/social causes of biological issues Traditional paradigms lack 'real evidence'	Traditional healer thinks the cause is from being bewitched because of ancestors, but cannot say if that's real because there is no evidence for that	
		Non-compliance linked to visiting traditional healers	People will stop and start medications to try to see a traditional healer.

<i>Global theme</i>	<i>Organising theme</i>	<i>Basic theme</i>	<i>Invivo code</i>
		Traditional healing results in poor health outcomes	Failed traditional healing practices have horrible outcomes for patients.

Practitioners noted that resource constraints played some role in the absence of doctors at meetings (only 11 doctors worked at the hospital at the time of data collection, with as many as three leaving each day to visit remote clinics). However, accounts indicated the presence of district doctors who displayed a lack of respect for the psychiatric discipline within the hierarchy of medical services, which led to a reluctance to participate in mental health treatment settings and difficulty in coordinating the efforts that demanded their presence:

You need doctors who don't look at a psych patient and say 'but you're crazy man! You're crazy!' support from the doctors is non-existent, mental health care is not a fashionable thing to go into... it's something that you can buck and turf, and it's not going to affect you as a doctor... you may end up with them for three days or something in your ward, but then you can just dope the shit out of them and then they won't bug you. There's incentive from a therapy side to sort it out because we end up dealing with the crap, but a therapist is never going to be the head of a multi-disciplinary team because you are not in the hierarchy to do so.-Therapy department manager

Perhaps more worrisome for PMHC services were accounts signalling the presence of stigma among the lowest tier of health care workers (NGO staff and primary care nurses). In chapter five, I indicated the presence of stigma among NGO home based carers who worked as extensions of health services, and were reluctant to help community members with mental health problems. Practitioner accounts appeared to confirm the presence of this stigma, noting that home based carers often remained hesitant to support mental health patients who were back in the community:

We don't use the word 'insane'... but they (NGO home based care workers) say 'You are so insane, you are so insane' to the patients... so then they become aggressive. So we tell them (NGO workers), that even if you are mentally disturbed, if you comply with the treatment, you can be alright... but this does not always work.... So they just leave them to us [at the hospital]. - Psychiatric nurse 1

Accounts also alluded to stigma among nurses:

...Nurses who are working at community clinics no longer see the mental health care users... When we go to clinics we are supposed to see new cases, or ones with problems who are referred to us by the nurse...but when the clinic nurse sees [any] mental health care users [who come for refills] she says 'I can't deal with these people' ... and tells them to come back [when we are at clinic]... they will say wait for your doctor, or your nurses. You see? So [because of] that stigma – they didn't catch up with (pills) from those clinics.-Psychiatric nurse 2

This is problematic given that this cadre of staff are viewed as the key to supplementing human resource deficits in primary mental health care, and due to their experiential local knowledge they also enable the delivery of culturally competent care

(Petersen, et al., 2013; Petersen, Lund et al., 2012; Petersen, Ssebunnya et al., 2011). Accounts from practitioners in this study indicate divergence from additional evidence in South Africa (Petersen 2011) and Kenya (Muga & Jenkins, 2008), where primary care nurses have linked their preference for the use of specialists in handling mental health services to being 'over-worked' and 'under-resourced'. However, if the problem underpinning nurses engagement is actually a proxy of stigma (which has been identified as a concern within health services in additional settings globally –see Thornicroft et al., 2007), it highlights a need to re-visit current efforts to engage primary health care practitioners across all tiers in mental health supports, something I touch on more in the final chapter of this thesis. Though my minimal engagement with primary health care nurses is a limitation to this aspect of the study, it was driven by the use of a purposeful sampling method (recall section 4.3.2) that targeted those identified as most active in the daily delivery of mental health services in Manguzi, which in its own right, is an interesting finding.

In chapter five, ethnographic data identified that the primary route to achieving the markers of 'best practice' (as specified in section 7.2) lay in the ability for practitioners to make referrals to social workers, who were always present within multi-disciplinary meetings. Social work pathways are included within PMHC policies and services, which is thought to contribute to a holistic response to mental ill-health. For example, by drawing on social workers, practitioners can respond to the poverty blighting the lives of nearly every patient, through: supporting welfare grant access; providing access to counselling for trauma and family disputes (delivered by social workers rather than psychiatric nurses); and making referrals to the local NGOs for additional social support or access to food parcels. However, in attending more closely to the realities of what social workers could actually achieve, it appears that they had their own difficulties in meeting patient needs: referrals for 'emergency' food responses were often temporary; and supporting patient applications for welfare grants consistently required face-to-face advocacy at related departments (SASSA) and home affairs. Social workers often lacked the time and resources to engage in these, to the extent required, to ensure that the benefits were made available to their patients.

S: Yes, where the cause [of depression] is poverty, we do recommend for food parcels, or DG (disability grants)...but most of the time, food parcels... and we also check the issue of identity documents, because most of them don't get grant assistance because they don't have the necessary documents ... but the problem is the working relationships.... Because if you refer a patient to home affairs, it's better to book a car and take the person to home affairs - if I write home affairs on a piece of paper, they won't go. They don't take it seriously or they will ignore the patient and tell them to wait... so they wait wait...but ultimately, it's a waste of time [to go with them], because other patients are waiting here to see us (laughs).

Ro: So you have to be in two places at once, very often

S: Yes, that's what's very hard, so you just attend with the patient, when [SASSA staff] see a social worker, they say you can just go through... we've done many workshops, even the central office of home affairs... but they don't understand this and I don't know – they just – (sigh) home affairs is the biggest problem.

The above quote highlights the high degree of burden facing the social work department. Their ability to effectively address the needs of women was blocked by issues beyond the control of social work or other professionals, as it required the mobilisation of actors outside the health sector to target women's needs.

The final group of community actors that are identified as playing a role in PMHC services are traditional healers. In chapter five, I presented a case study of one healer family. South African mental health policy currently carves out specific space for traditional healers, including: supporting referrals, monitoring for compliance, and supporting the process of integration of mental health patients within wider community networks (KZN Department of Health, 2010). These roles highlight a tendency towards instrumental forms of participation, where biomedical top-down actors dictate the actions of healers with regards to care.

However, practitioner accounts in this thesis reflected mixed opinions about healers, feeling that there were opportunities for increased participation and positive contributions given their status as a 'first line response' for some community members. Practitioners cited healers' deep knowledge about cultural discourses of mental distress (among those who believed there was validity to the cultural discourses surrounding 'callings' to traditional healing); and a personal belief in the overall value of pluralistic systems of care as valuable contributions to service delivery.

Somebody will say, I'm just hearing voices – people talkinguhhh, culturally, some will be ancestors, but medically, I mean a psychiatric perspective, they have auditory hallucination. So, it will be difficult for, I mean for, I mean sometimes difficult for us, to distinguish between ancestors, and, or, cultural things, plus this eh, hallucinations, delusions, and all that. That's why I'm saying we need to work hand in hand.
– Psychiatric nurse M

However most practitioners identified a limit to what traditional healers should be allowed to do, in line with the recognition of many adverse consequences associated with particular healing practices:

I'm not against traditional healers at all, they play a part – in the psychosocial stuff that we can't play (laughs) so, it's fine, as long as it's not like, critical, like you can't take a TB meningitis child to a traditional healer and that stuff, that's ridiculous.
–Therapy department assistant manager

Contrary to studies that highlight western-trained practitioners as resistant to mutual referral systems between traditional and biomedical practitioners (Campbell-Hall et al., 2010), my findings highlight that in Manguzi, professionals at district level in the PMHC system were favourable towards increasing healers' responsibilities. Specifically, there was a wide belief that the best way for traditional healing to be included within current policies was through their efforts to work locally to help distinguish between 'cultural' and 'biological'

cases of mental distress (which would require some mutual referrals), along with promoting compliance.

In interviews with traditional healing practitioners it was highlighted that some traditional healers already receive patients who return from engagement with formal mental health services, seeking support for what they felt to be an 'unaddressed' issue. As stated by one *Isangoma*:

...because they [patients] are pissed off....you can talk to him or her [a doctor] and he or she will give you injection and tablet and ...your mind feels as if you are okay, but after 15 or 30 minutes it comes back again. The doctors need to refer those people to us if they fail to treat that person...We registered and they told us that will meet and talk about people, that told us who to refer and send people to them... We learned (about their system) but they don't do that. They asked us to cook our traditional medicine and to tell them how we do it... nothing has happened... they take us for granted.

Frustrations among traditional healers in this thesis highlight that despite what has been described as shifts towards a positive policy environment for traditional health practices (van Rensburg, 2009), the current system still lacks outlets to make appropriate use of the resources traditional healers offer.

The final section of this chapter elaborates on the nature of barriers facing current community mental health systems, identified by my practitioner informants as hindrances to their work.

7.3 BARRIERS TO TREATING WOMEN'S MENTAL HEALTH – WEBS OF INEFFICIENCY AND 'DYSFUNCTION' IN COMMUNITY MENTAL HEALTH SERVICES

In this section, I discuss the factors identified by health professionals as barriers to supporting women's distress within formal community mental health services. District level medical practitioners (specifically, psychiatric nurses and therapy department members) repeatedly noted that the delivery of community mental health services emerged as an 'impossible' or 'dysfunctional' process. Three global themes emerged in the elaboration of these barriers: Resource constraints, environmental constraints and bureaucratic constraints (see table 27)

Resource constraints were noted in the areas of funding, human and structural resources, and time. Inadequate funding was described as a primary hindrance to the efforts to support mental health, meaning that important potential resources such as support groups for women were unsustainable, and health promotion (via health information strategies) and programming had not been run in the year of the study due to budgetary cuts. This was seen as a major issue, with strong community stigmatisation of mental illness seen as seriously undermining the likelihood that local community members would make an optimal contribution to helping to identify and refer patients appropriately, and to supporting compliance among patients:

The community has a lot of stigma... they have a stigma, but for those who have family members it is better because they get exposed to health education, so they are cooperative for the sake of their relatives... but for the other community usually we do some awareness[programmes]...we say don't call other people insane, because you've all got your own 'insanity' – except yours is controlled, and these people, who are handicapped, or who are disturbed psychologically, people are unaware even if they are doing something wrong, they aren't aware of it...so we need to help them do it.... It's the community's job to monitor – Psychiatric Nurse, 2.

Within preceding sections of this chapter, certain practitioners alluded to possible 'misdiagnoses' of patients in the community, for example, the belief that patients were being wrongly classified as schizophrenic when displaying symptoms of mania. This was linked to either a lack of knowledge of diagnostic categories among some nurses when handling diagnostic procedures, or inadequate support and resources to facilitate this process. Our informants highlighted shortages of diagnostic tools (at time of data collection there was no copy of the DSM or ICD-10 on premises at the hospital), the lack of technologies to support accurate and efficient differential diagnoses (CT scans were available at a hospital five hours away), and clinic environments that were non-conducive to 'counselling' – which was how practitioners referred to sessions where initial diagnosis was often made by psychiatric nurses or therapy staff who referred patients they encountered to the psychiatric department:

Umm, diagnosis seem to be very arbitrary, medication is also very arbitrary, there is a stroke patient in male ward that has been seen once or twice, and he was suddenly a bit confused, and we thought confusion is a warning sign that something is going on.... But here, confusion can mean, put him on haloperidol.
–Community service physiotherapist

At clinics often times there's no privacy, there's someone sitting beside you screaming, they can hear everything, people screaming teeth extraction, babies crying during immunisation it's a flippin' mess. Even here we have OT and PT in the same room – it's not a counselling environment.
–Therapy department assistant manager

The latter quote is also an example of environmental constraints facing delivery. **Spatial barriers** presented hospital environments as counterproductive to exploring patient histories for diagnosis. Findings from chapter five - regarding patient consultations during mental health clinics – have highlighted that each nurse sought to consult with and guide separate patients and their families simultaneously in one room. There were no partitions, no privacy, and no opportunities to effectively unpack private patient concerns.

TABLE 27: THEMATIC ANALYSIS OF INTERVIEWS WITH PROFESSIONAL INFORMANTS: BARRIERS TO SERVICES

Global theme	Organising theme	Basic theme	Example <i>in vivo</i> code	
Resource constraints leading to service complications	Inconsistent funding systems for MH programmes	Lack of funding for MH programming – cancelled programmes	Mental health promotion programmes for community were cancelled due to lack of funding.	
		Inadequate resources for diagnostic procedures	Lack of time in clinics to complete formal diagnosis	Psychotic label just means that they are acting a bit strange – not enough time on wards to do a full assessment.
			Lack of formal diagnostic procedures	No formal processes of doing a diagnosis – there is not even a DSM completed for the patients.
	Temporal barriers	Lack of needed differential diagnostic technologies (CT)	Lack of needed differential diagnostic technologies (CT)	Treatment is limited because of lack of available resources, which are needed to do differential diagnosis – nearest CT is 5 hrs away.
			Waiting lists for visiting psychologists/psychiatrists	Visiting psychologists come to Manguzi once/month - list is full months in advance
		Human resource constraints	Insufficient staff numbers	Yesterday there were only 2 doctors on site at the hospital. How can anything get done?
Gaps in skill level for MH posts	Counselling services have a gap in them- district level especially has HIV lay counsellor which is ten-day counselling course training - next level available is a clinical psych.			
Environmental constraints leading to service complications	Geographical barriers to service delivery	Weather dependent transport services for visiting specialists	Visiting psychologists travel here via helicopter – which is weather dependent. They often don't show up despite us organising pt. to travel in very long and expensive journeys.	
		MH review boards are held at impossible distances to advocate for patients	Review boards should be held within the hospital, on hospital grounds (actual location five - seven hours away).	
		Difficult to reach homesteads for visits/monitoring (rural landscapes)	Homesteads are scattered which makes visits hard to organise and patients hard to locate.	
	Spatial barriers to service delivery	Clinic spaces are not private or conducive to counselling	While doing counselling there will be a million people running in and out and the phone will be ringing and someone will ask you to meet someone on the wards - the setting is manic.	
		MH patients require designated space	An isolation ward may be useful for mental health care - not enough space to currently deal with patient intake. Unused space at hospital could be used for mental health services.	
Bureaucratic constraints leading to service complications	Complicated referral pathways	Referrals to feeder hospitals are impossible Medical co-morbidities make admissions to feeder hospitals difficult	We can only refer to one hospital with a limited number of beds. Patients with co-morbid medical issues won't get admitted to Neglewanze for mental health care	

Practitioners pointed to **geographical barriers** to service delivery – noting difficulties in locating and travelling to homesteads, which remain buried deep within wooded enclaves, making follow-up with patients on new treatment regimens nearly impossible.

Most troubling for a system that depends so heavily on mentorship from specialists, were the unreliability of systems to coordinate their visits. Transportation of visiting practitioners was provided by helicopter or plane access – which was at the mercy of unpredictable weather systems that categorised Manguzi:

Visiting psychologists and psychiatrists travel here by helicopter – which is weather dependent. They often don't rock up, despite us organising patients to travel in to see the specialist – like today, we called these patients in and now there is no one to see them. – Psychiatric Nurse 2, informal interview

Further **human resource constraints**, driven by hiring procedures that relied on pools of temporary or junior staff to support rural posts, increased the burden on the primary care system. Manguzi Hospital relied heavily on visiting doctors, training placements, and community service practitioners for staffing of allied and psychological/psychiatric services. The result established a human resource pool that was transient, and given their limited experience, often had difficulty managing the complex social realities that drove mental health needs at the community. The following quotes from the assistant manager of the physiotherapy department describe her experiences in this arena:

That's been the general consensus: 'why must we employ a senior [staff], if we can get two junior community service staff?' which is – really short sided and ridiculous because you're actually wasting money that way, if you put a junior, or a senior therapists to try and manage budgets and systems...it's a mess... they aren't equipped to handle the social disasters that these women often face, it's not surprising that they burn out.

And, regarding her efforts to advocate for a permanent psychologist on staff:

It's not that the hospital has been anti putting the post up – it's that no one has applied for it. The thing is, if you put the post up and you advertise and advertise once or twice and nobody applies then the post becomes frozen.... and you have to go through the whole process of un-freezing it again.

These sentiments were mirrored by the regional principal psychiatrist who supported the Manguzi Hospital:

*So we have a community service psychiatrist or psychologist (at regional level) who comes to us on a one year contract..... what happens then is that you...have to wait [for them] and you train them and so on and so forth.... after a few months or a year then they leave or they either move from that particular placement and they're placed in another part of the hospital and so on. So that contributes to the fluctuations in the kind of effectiveness and level of engagement in mental health services.
– Regional psychiatrist*

Finally, additional **bureaucratic barriers** were identified with regards to the realities of referral pathways, created by insufficient bed numbers at the regional hospitals to capacitate attempted district level referrals. These complicated treatment procedures,

establishing revolving door patterns, and difficulties treating patients with co-morbid conditions like HIV.

In a surprising contradiction to their views on the social drivers of mental distress, and the social obstacles to effective responses, practitioners' accounts of the barriers facing their work resounded strongly with areas linked to improving biomedical practice. Calls for a designated mental health service space where mental health patients could be kept away from other patients (reducing the need for physical restraints), increased beds at referral hospitals (so referral from district to regional and tertiary levels could be an easier process), and massive increases in human resources (so that there were more practitioners available to address the high level of mental health need felt to be present in the community), resonate with national calls for addressing the paucity of resources facing mental health in South Africa (Lund, 2010c; Lund & Flisher, 2003; Lund, et al., 2002).

Practitioners did not view their struggles in addressing women's voiced needs as a gap in policy. In fact, nearly all practitioners advocated that in order for current mental health policy to be successful, all that was required was the presence of a strong, passionate and engaged individual at the helm of district mental health services, who could advocate for their needs in the face of an already massively under-resourced health system across all health disciplines:

I've heard one person... she was a hospital manager, and before that she was a manager for a mental health care unit, and she was supporting the mental health care act and saying it does work. But I mean you're talking about a hospital manager... who knows what should happen, and is going to drive it, is going to make sure it's getting done...if you look at the circumstances you can see why ...she would say you, you do that, you, you do that, I'm going to review your ward, have you filled in this (form)... she's going to be the driver. Here, it's not going to work, you don't have a driver for it. -Physiotherapy assistant manager

Practitioner accounts of difficulties facing their practice emerge as a pragmatic concern and are comparatively less 'critical' than their anchoring of biomedical categories to social realities identified in section 7.1. What may be the explanation for this particular finding? In reflecting back to accounts of interacting knowledge systems presented in chapter three, Bauer and Gaskell's (2008) wind rose model asserts that the final determining factor for how a representation is enacted, and how the shape of a given shared 'object' wins out, is determined by two elements – the power of one group relative to the other, and the 'constraint of reality'. The final straw in hampering the expression of the critical perspectives of coalface health practitioners may lie within the simple reality that, despite social understandings of the problem, practitioners in primary health care structures remain *medical* practitioners, anchored to biomedical paradigms and frameworks, by virtue of their training and employment within biomedical (at best, bio-psychosocial) frameworks. This biomedical position is the zone of relevance (recall Schütz's arguments presented in chapter three) from which practitioners approach their work, reflected in the maintenance of

diagnostic categories as part of their representations outlined in section 7.1. Despite its contradiction with what practitioners articulate as the core social stresses in women's lives (which they still seek to respond to in clear ways), it is important to recall that the biomedical position is reinforced by broader and more powerful systems, with the clearest guidelines and processes of treatment delivery. For example, policy frameworks such as the provincial standard treatment guidelines presented first in chapter two (Department of Health, 2006), provide highly detailed referral pathways, advice on the administration of and access to first line pharmaceutical interventions, and psychological interventions (with CBT recommended in provincial treatment guidelines). These are a contrast to the vague piecemeal efforts available to practitioners to deliver social level responses, such as sparsely funded support groups. In this instance, practitioner's primary realities remain biomedical ones, meaning that the likelihood of their actions outside of this realm is minimal.

We observe the constraints of reality as a barrier to action around a representation, in the practitioners' realisation of the inability for their existing frameworks and training to tackle the core drivers of their patients' problems. Poverty, gender disadvantage and HIV are issues that are too broad and beyond the scope of their remit to address. Their best bet resides in improving the system that currently dominates their practice, so they can work to treat patients better. This is not to deny that some practitioners spoke eloquently of the need to have policy spaces shift to be more reflective of patient realities. Practitioners also spoke of the value of existing 'social' responses to make small improvements, for example emphasising the need for better funding for patient support groups. Thus, findings from this chapter suggests that for practitioners to build on their existing attempts to create receptive social environments where patient narratives had an opportunity to be heard, requires shifts in policy spaces that support action to target social issues in equal measure to current attention paid to biomedical frameworks. In the final chapter of this thesis, I will argue that this could be the starting point of an expanded primary mental health care service, which could potentially contribute to practitioner's vision for better community mental health services in Manguzi.

CHAPTER CONCLUSIONS

This chapter has identified a series of highs and lows within the realities of a tiered primary mental health care system, which seeks to place the notion of 'community' at its core. In some respects, particularly regarding the centrality of place-based challenges such as poverty and violence to experiences of distress, health practitioner knowledge systems showed a significant overlap with the knowledge system held by women, displaying a mutual recognition of the social nature of women's distress. However, the presence of this critical social discourse was not always enough to ensure that services provided a receptive social environment for mental health: that is, where women's concerns are the 'subjects' of interventions and practitioners work in meaningful ways to help women engage with the social milieu at the core of their distress.

While the overall importance of primary mental health care within rural health settings cannot be dismissed, findings from this chapter highlight some of the continued barriers to the efficacy of this structure of services, which do not appropriately engage with symbolic and place-based notions of community. Here I refer to factors that continue to hinder community mental health efforts in Manguzi through preventing decision making about the best course of treatment for patients. Of particular importance are community, and more importantly, practitioner stigma toward service users, and limited power available to front-line service providers such as psychiatric nurses, social workers and therapy department staff.

In figure 25 below, I summarise findings from this chapter that highlight a strikingly under-resourced and over-burdened system that despite best efforts, cannot provide a consistently supportive environment for women with socially-anchored mental health problems. It may even be possible that my findings support possible claims of 'irresponsibility' within policies that position community actors such as NGO staff and traditional healers as instruments of biomedical paradigms. In directing increased numbers of distressed women to hospitals and primary care centres through outreach programmes, services must be equipped to receive them, and findings from this chapter highlight that much work remains to be done in this area. Current pathways in the system that seek to target 'social' needs remain blocked by broader systemic issues (see solid coloured boxes below). Community support groups are cancelled due to lack of funding or unavailability of staff to run these programmes. Social workers face difficulties in securing long-term access to welfare services for patients, due to stigma across sectors, and limits of affiliated social sectors, as well as their own human resource constraints that limit their ability to advocate for women's needs. Community follow-up care is further complicated by a hesitance among primary health care nurses and local NGO staff to engage with mental health services, which culminates in district level staff continuing to shoulder the full burden of ensuring that these 'walking social cases' are not lost, or returned to emergent services with more severe

consequences (such as suicide attempts). These issues are points of immediate action in enabling primary care systems to better promote mental well-being.

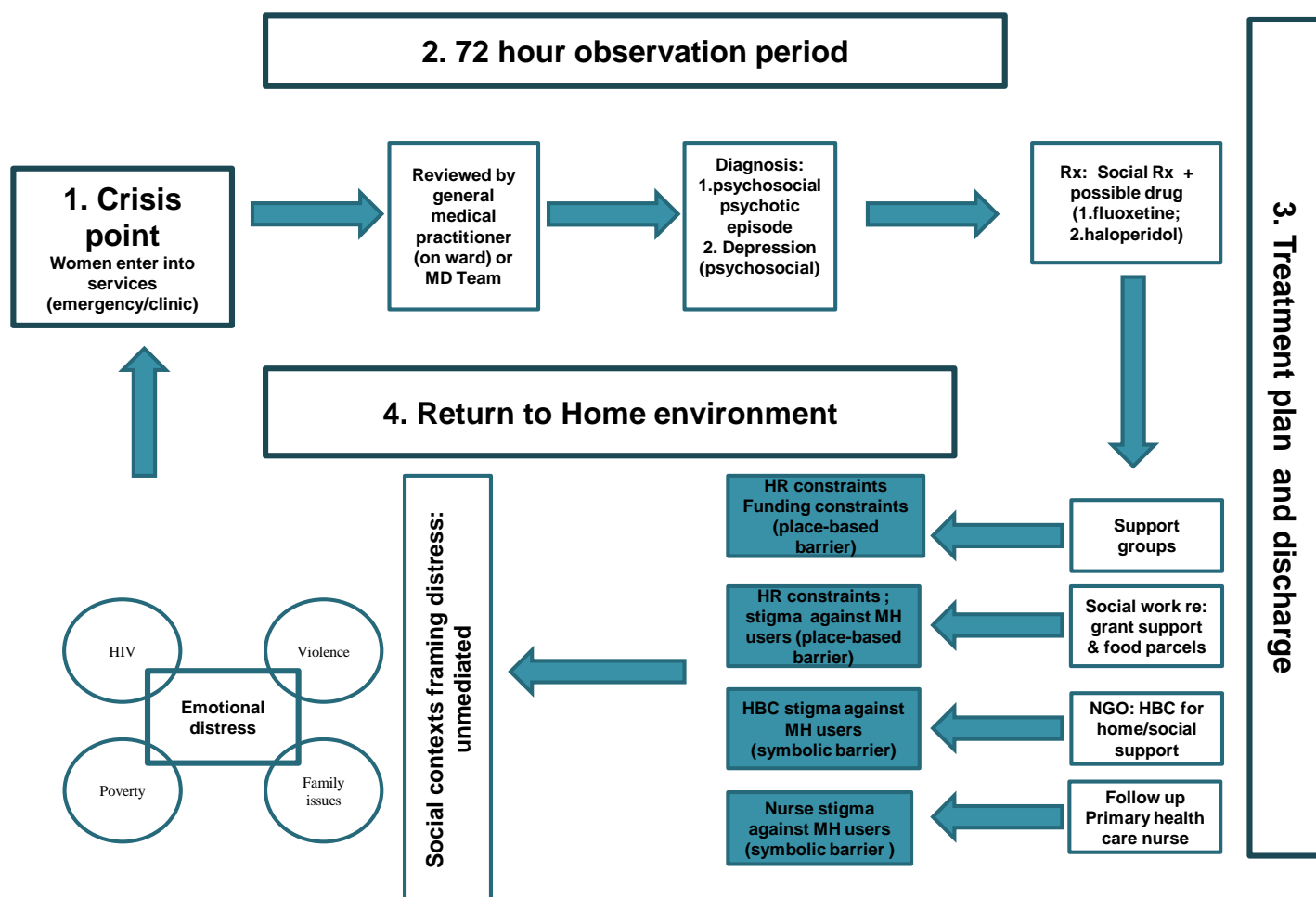


FIGURE 25: PATHWAY OF WOMEN THROUGH PRIMARY CARE MENTAL HEALTH SERVICES

My findings also highlight a worrying silence in the current system: namely the voices of women these services seek to support. Findings from chapter six identified the untapped potential among a group of women who, despite their distress, are equipped with agency, solidarity, and a willingness to build partnerships to address their needs – competencies identified as crucial for promotion of healthy community contexts – but who are confronted with a health care system that is unable to support them in doing so.

How might primary care or public health services interface with communities more effectively to develop competencies and change the reality of this treatment cycle? Solving this issue is too large an issue to broach within this thesis. However, the section on ‘best practice’ in this chapter begins to illuminate important potential directions in this vein. Within the final chapter of this thesis, I engage further with how the promotion of community mental health competencies may also contribute to shifting the outcomes of the treatment cycle in

figure 25. I return to findings from my three theoretical chapters, recasting them within a speculative framework that aims to provide guidance for mental health policy specialists seeking to deliver community mental health services in socially deprived settings.

CHAPTER EIGHT: FROM TREATMENT TO TRANSFORMATION- COMMUNITY MENTAL HEALTH COMPETENCIES

The presentation of my research questions in chapter two concluded with the following inquiry: *How can primary mental health services develop more health-enabling engagements with communities in an era of global mental health?* It has been argued that supporting the mental health of communities in low-income settings should be nested within primary health care services (Patel et al., 2013; Petersen & Lund, 2011; Petersen, Lund, & Stein, 2011; Inge Petersen, et al., 2011; WHO, 2010). However, as findings from chapter seven illuminate, the provision of mental health services to HIV-affected poverty-stricken women in Manguzi within a primary health care model is still fraught with challenges, and is limited by a background of under-resourcing and symbolic barriers, such as power struggles across hierarchical public health settings and stigma among health practitioners. Such findings highlight the need to consider contributions from expanded frameworks for supporting women's mental distress within the spaces of this system.

Community and critical health psychology –disciplines that drive this thesis (outlined in chapters two and three) - argue for the central role of community networks and mobilisation in supporting the health of marginalised people. This position opens a space to consider how alternative forms of engagement with community members by primary health care services can potentially contribute to improving the local realities of mental distress in places like Manguzi. In order to explore how this might be achieved, this chapter will draw on the following premises:

1) How key social actors (women with mental distress presented in chapter six) and primary mental health practitioners (presented in chapter seven) understand and experience the problem of mental ill-health; and

2) How both groups seek to tackle mental distress in relation to (i) women's accounts of their indigenous coping strategies (chapter six), and (ii) practitioners' accounts of their own best practices in supporting women.

These themes form the starting point for a discussion of strategies to support community mental health services in the identification and support of social contexts that are most likely to assist women to achieve mental well-being in resource-poor and HIV-affected communities.

Whilst the reach of the MGMH creates a locus for action around issues of mental distress, its approach could be greatly improved through the application of frameworks that cast a critical eye on the pitfalls that have derailed similar global health movements, such as the HIV/AIDS response which was hindered through the privileging of a biomedical focus and the neglect of wider community and social issues (Campbell, 2003). In presenting the case study of community mental health services in Manguzi, an attempt has been made to attend to these problematic issues through:

i) Contesting mainstream definitions of mental health and illness (chapters one and two) and contemporary definitions of 'community' (chapter three), currently used to coordinate the delivery of community mental health services, framed by wider discourses of global mental health that align with biomedical concerns; and

ii) Highlighting the ways in which MGMH recommendations for countries like South Africa are often at odds with the realities of how 'mental health' and 'community' are locally experienced in the everyday lives of women in challenging social situations.

Arguably, responses to global health challenges require attention to short, medium and long-term solutions (Campbell, 2003). The MGMH currently focuses intently on short-term responses of public health containment, encapsulated primarily by their calls for increased access to biomedical treatment strategies (Patel, et al., 2011; Patel & Prince, 2010). These efforts are largely reactive, and have no contextual grounding or impact on the key social drivers of women's distress as identified in this thesis.

Long-term strategies for tackling global mental health problems will clearly require attention to the alleviation of the systemic poverty or systems of gender discrimination that are linked to such dire life outcomes for communities in the developing world (Marmot, et al., 2008). In South Africa, the process of social development remains imperfect. While some gains have been reported in access to basic amenities such as electricity and drinking water (Coovadia et al., 2009), the motivated ethnography of chapter five highlights that many women continue to lack access to these and other basic needs, which often form the pillars of their mental distress. However, addressing these place-based challenges currently falls beyond the purview of public health services and requires coordination across provincial, national and international development partners alike: such as provincial and national departments of social development and the United Nations Development Programme (UNDP). The process of social change and large-scale transformation, required to further challenge the long-wave impacts of apartheid-era policies that have left much of South Africa under-developed, is a long and winding one, unlikely to be achieved quickly enough to help this generation of women with their immediate distress.

This thesis has pointed to the potential value of a medium-term response anchored in the recognition and strengthening of community competencies, as argued by critical health and social psychologists. By reflecting across findings from chapters five through seven I seek to develop a potential framework that could contribute to existing mental health service efforts to operate at community level. The contents of my proposed framework supports calls for increased primary health promotion strategies in the country (recall chapter three), but could also lay foundations for larger community mobilisation required to put pressure on government service structures as part of long-term strategies to achieve health enabling social change (Campbell, et al., 2010). I will organise these recommendations under the umbrella term of *community mental health competencies* – a theoretical framework that

takes its roots in critical approaches to involving communities in an associated global health domain of HIV via the conceptualisation of HIV-competent communities (Campbell, et al., 2007; Nhamo, Campbell, & Gregson, 2010).

This final chapter proceeds in five sections. First, I discuss how women's understandings of distress and their indigenous coping strategies inform the need for actions that further support women's agency and create opportunities for them to engage with poverty and gender-based norms that contribute to their distress. I also articulate what role primary health care practitioners may play in this process. In the second section I turn my attention to the service delivery. Here I link existing efforts to promote receptive social environments by practitioners described in chapter seven, with recommendations for primary health care practitioners and policy-makers to further support their efforts. The third section revisits the question of HIV-specific mental health services for CMD conditions. The final two sections discuss issues of quality, self-reflexivity, strengths and weakness of this thesis; concluding with possible implications of this work for future studies in the field of global mental health.

8.1 SUPPORTING WOMEN'S PROJECTS OF SURVIVAL: COMMUNITY COMPETENCIES TO SUPPORT THE AGENCY OF WOMEN WITH MENTAL DISTRESS

In chapter six, my analysis was guided by the following research questions:

How do Manguzi women understand mental health in socially deprived and HIV-affected communities?

How are these understandings framed by their everyday community contexts?

How does this knowledge shape the processes used by women themselves in responding to mental health-related challenges?

Analysis identified that women in Manguzi understood their mental health in relation to their everyday experiences of living within what Summerfield (2012) has identified as 'fragmented social worlds'. Findings from chapters five and six illustrated the degree to which women in Manguzi were forced to manage intersecting social and cultural maladies, caused or exacerbated by extreme scarcity of resources. Chapter six also informed how women's representations of mental health and illness as general concepts reiterated the importance of social and economic productivity, where 'good mental health' was signalled by the ability to support and sustain families through successes in these areas.

Women's accounts uncovered a social representation of mental distress organised around four socio-structural concerns: conditions of, and relating to, poverty; violence; HIV; and family relationships. These findings corroborate epidemiological studies in South Africa, which identify links between similar social challenges and mental distress (Seedat, Stein, et al., 2008; Seedat et al., 2009; Stein, et al., 2008). However, findings from this thesis make crucial extensions that contribute to understandings about how relationships *between* socio-structural constructs and emotional distress unfold. For example, much of women's emotional distress (leading some to meet diagnostic markers for depression or anxiety) was linked to their inability to meet the standards of their representations of the roles of good mothers and 'good women' –due to place-based limitations of poverty, or gender-limiting roles about women's power within families.

Stoppard's(2000) work asserts the importance of acknowledging how the accumulation of ideas concerning how women are 'supposed to be', formed in the course of one's social interaction with their 'life world', can become a 'taken for granted, [knowledge], forming an implicit cultural backdrop to information circulating within society' (Stoppard 2000 p.104). These help to shape women's subjectivities, such that:

When a woman defines her identity in terms of being a wife, mother and housewife, she is likely to judge the adequacy of her endeavours against the socially constructed ideals of the good woman (Stoppard, 2000 p.105).

Findings from chapter five highlighted how norms of good motherhood and womanhood (symbolic dimensions of community), had the potential for significant impact on women’s experiences of distress. In chapter six, we saw the outcomes of this impact within women’s accounts of distress related to their need to provide adequate support to children and families (which they viewed as the ‘right’ thing to do), linked to their inability to meet these expectations.

Chapter six also elucidated the presence of four cognitive and practical coping strategies used by women: psychological reframing of the problem; mobilisation of peer support; accessing expert advice/support; and income generation efforts. These strategies uncovered that women’s actions in response to their mental distress – or their ‘projects’ (Bauer & Gaskell, 2008) – were linked to etching out survival in the contexts of symbolic and place-based dimensions of community life as defined in chapter five. For example, accepting mistreatment from men as something beyond their control (‘just men being men’), was linked back to the presence of limiting gender norms, while mobilisation of peer support in sharing food and financial resources, was a response to emotional distress shaped by poverty.

Uncovering these behaviours is particularly useful in our efforts to expand frameworks for supporting women’s mental distress. As Campbell and others (Campbell, et al., 2007; Nhamo, et al., 2010; Skovdal, et al., 2009) suggest, through the examination of indigenous coping strategies, points of intervention for helping to promote better health enabling environments can be discovered.

Table 28 below links the coping strategies identified in chapter six to the presence or absence (in italics) of a psychosocial competency first introduced in chapter three.

TABLE 28: WOMEN’S COPING STRATEGIES AND RELATED COMPETENCIES

Women’s coping strategy and dimension of community targeted (chapter six)	Psychosocial competency
Psychological reframing (symbolic aspect of community)	<i>Critical thinking</i> and action
Mobilising peer support (symbolic/place-based aspect of community)	Solidarity (bonding social capital), agency
Accessing expert advice/support (place-based aspect of community)	Partnerships (bridging social capital)
Income generation efforts (place-based aspect of community)	Agency (self and collective)

It can be seen from the table that critical thinking as a competency could be further supported by practitioners. This in turn could lead to a psychological reframing of challenging situations currently seen as ‘unchangeable’. For example, norms place the blame of ‘failing families’ on a woman’s individual success or failure as a mother – obscuring the role played by broader economic and political structures, such as reduced job and educational opportunities available for rural women that make managing families impossible. These

structures help to anchor many women within disadvantaged contexts. The potential for improvement can be created when women think about these broader issues and then plan to act around them instead, as highlighted in chapter six; a small number of accounts showed women recognising the problems caused by these norms. Such recognition supported decisions to engage in more active coping strategies, such as income generation activities with like-minded peers.

The women in this thesis who adopted acceptance as a coping strategy, ended up negating the self-affirming impacts of their participation in other, more positive coping strategies. Among women who engaged in self-blame, their engagement with other strategies were reduced, and in one case, led to extreme isolation and limited access to support.

The above competencies as discussed in this thesis reiterate the importance of studies that move beyond the epidemiological in describing women's mental distress. Summerfield (2004) and others (such as Skovdal, 2012) have argued about the dangers of medicalising everyday aspects of human suffering through reducing complex social experiences to largely decontextualised biomedical categories. If this work had concluded with a discussion that only described women's distress, it would have overlooked their active engagement in activities that are underpinned by theoretical concepts argued to be crucial for health and well-being. Furthermore, this thesis has identified that even among women who appeared stronger or weaker than others in the sample (based on their mental ill-health scores), stories of success emerged alongside those of significant struggles or failures. For example, regardless of the severity of their mental ill-health measures, all women described actions that drew on bonding and bridging social capital (defined in chapters three and six as the establishment of strong links within and across levels of community), to support themselves and their families at times of crisis. Understanding how women are already engaging with the contexts of their distress is useful in planning for how to best support their well-being.

Yet for many women, aside from acceptance of what many experienced as their intolerable failures to measure up to norms of womanhood and motherhood, other coping strategies were still limited by the realities of extreme conditions of disadvantage. For instance, chapter six highlighted that local social ties (or bonding social capital) could be as much of a cause of distress for women who faced ridicule from neighbours and family if requests for help were too frequent. Moreover, whilst advice-seeking (a form of mobilising peer support) has been characterised as an 'active' coping strategy (Moneyham et al., 1998), my thesis highlights that women's efforts to solicit advice from other friends and family members did not always promote agency. In many instances, peer advice urged women to accept difficult situations as unchangeable, in line with culturally-driven narratives.

Despite these limitations, I argue that supporting the small victories among women who come to recognise the impacts of structural and symbolic factors on their mental distress (and in doing so, avoid self-blame), remains a pivotal point of intervention for global mental health actors. This argument is supported by Freire's (1974) principle that connects thinking with action – in that thinking differently about the contexts where people live, leads to action to challenge limiting contexts. And while the actions of women in this thesis were small-scale at best (given the sheer scope of tackling rural poverty and gender norms), psychologist Weick (1984) argues that these small changes have important summative effects in contributing to change in the long term.

But how might global movement policy support these changes? Whilst global movement actors may have an understanding of the lived realities of community members, this thesis suggests that they need to supplement their delivery of treatment in primary mental health care settings by creating policy environments that promote small-scale but meaningful gains for patients, such as in accessing psychosocial resources (an example being those discussed in chapter six). Current recommendations for supporting women in an era of global mental health have espoused the value of group interpersonal therapy (IPT) and problem solving therapies (PST), which have been recently piloted in South Africa (Petersen et al., 2012; van't Hof et al., 2011). Both strategies are potentially useful insofar as they provide alternatives to pharmaceutical interventions for women in services that have been chastised for being overly medicalised. Perhaps more importantly, they establish settings where women are able to draw on dimensions of bonding social capital. Petersen and colleagues (2012) reported that women used IPT groups as opportunities to mobilise and coordinate funds to help each other care for sick children, and van't Hoff and others (2011) described how problem solving therapy, delivered in group format, created similar opportunities for the women to support each other in dealing with some problems framing their distress. However, it is worth noting that the above issues are not viewed as explicit goals or main outcomes of these interventions, but were considered positive side effects of the 'processes' of delivery.

Furthermore, the use of peer-led support groups may not always be the most effective way to counter the sense of hopelessness and helplessness that was often the very cause of women's distress. In their study of the dynamics of community support groups for emotionally distressed women in a similar community in KZN, Petersen and colleagues (Petersen et al., 2012) highlighted the way in which peers in support groups often urged one another to 'accept' negative situations that were unsafe for women and families - such as tolerating violent breadwinners in the absence of alternative sources of income. These findings highlight the limitations of well-intentioned efforts to develop community support programmes that respect and strengthen local responses to difficult circumstances. Findings presented in chapter six suggest the need to think more critically about how locally

relevant group-based support therapies may unintentionally be undermined by the very cultural mores that fuel women's poor mental health.

In light of the above factors, in what other ways can primary care services intervene in order to engage with women at the localities of their distress where they struggle to mitigate dire social circumstances? Elsewhere, I have speculated that a *mental health competent community* would be a community context where local people work together to facilitate more effective prevention, care, treatment and advocacy around issues of mental distress (Campbell and Burgess, 2012). In line with this statement, I suggest that primary mental health care services in South Africa can extend their current community efforts through policies that promote the competencies outlined in table 28 above, in the following two ways:

- 1) Expand the role of Mental Health Counsellors (MHCs), an existing cadre of workers within the primary mental health service hierarchy, to involve the coordination of groups that enable women's access to spaces of engagement that promote *social integration, solidarity* and support in making *meaningful contributions to their own lives*.
- 2) Work with women to identify and utilise helpful networks at local levels and external to the community

In 2004, Petersen outlined the parameters of community mental health counsellors (MHC), a cadre of health workers designed to supplement the primary mental health sector in South Africa and improve its ability to respond to local distress. While findings from chapter seven confirm the continued absence of these actors within many primary health care settings (despite the existence of a degree level training programme related to the post), the role for MHCs has been described by Petersen as functioning in three areas:

- 1) *The administration, scoring and interpretation of psychometric tests (around areas of intellectual and personality tests, as well as in relation to common mental health issues) and the completion of reports on these measures;*
- 2) *Skills in supportive therapy and counselling to help with emotionally related problems in communities;*
- 3) *Development and implementation of prevention programmes to address referral complaints in primary practice (in line with a secondary health prevention strategy that views early identification of disorders as a priority).*

Findings from chapter seven indicate that the MHC roles outlined in theory, has not materialised on the ground in Manguzi - with the work falling to psychiatric nurses, and allied health staff. Furthermore, what is proposed by these roles appears to be largely reactive in scope, leading a bio-psychological response to mental illness that focuses on technical and medical concerns such as increasing capacity to identify and treat individual cases mental illness. Findings from chapter six highlight the social anchoring of women's distress, and

the current scope of the MHC role does not appear to include a structure supporting patients distressing social contexts. The delivery of ‘supportive therapy’ encapsulated by interventions such as IPT is not explicitly designed to create opportunities for women to be supported in engagement with broader social concerns. Some of these factors, when combined, could suggest a misalignment between the recommended role of MHCs and women’s voiced concerns.

Given that chapter seven also highlights that upon entry into formal primary mental health care services (via referral or crisis) women are offered treatment responses that have minimal to no engagement with the social factors that frame distress, it appears that there may be cause to expand the scope of services provided by practitioners like MHCs.

In line with findings from this thesis and other studies that assert the importance of services that respond to the local voice of communities (Rose, 2008; Jain and Jadhav, 2009), I suggest that the role of MHCs could be expanded to also involve the facilitation of district-level funded support groups that support women’s agency by helping them to develop additional understandings of, and strategies to engage with, the social drivers of their distress. Four aims could drive these groups:

I. Help women combat their sense of isolation and maintain a sense of solidarity through meeting women in similar situations.

This aim is supported by women’s accounts that identified the value of close personal friendships and sharing stories with other women as helpful in alleviating their distress, in line with findings from additional South African studies (Petersen 2012; Schatz, Madhavan & Williams, 2011)

II. Where possible, help women identify the norms and self-belief that hamper their agency in coping with life problems.

III. Help them to brainstorm concrete ways in which they might tackle the impacts of negative social circumstances.

These aims are supported by findings from chapter six that highlight the a limited critical understanding of the role of symbolic and place based contexts on their lives among some women, and how this contributes to acceptance of challenging conditions such as abusive or neglectful partners. In these situations, the limitations placed on women’s participation in their daily lives by broader systemic conditions are often obscured. The value of brainstorming and discussion within a culture whose history promotes and celebrates ‘acceptance’ as part of an idealised notion of a ‘good woman’ is linked to the Freireian notion of critical consciousness (Freire, 1974). Critical consciousness is described in chapter three as a state of thinking achieved through communicative exchange that poses opportunities for

groups to identify the processes through which everyday challenges, linked to social and cultural issues, impact on health and well-being. Such discussions would become a useful platform for some women, considering how certain typically unconscious notions of defining themselves may contribute to the maintenance of their distress (Stoppard, 2000). Increasing women's critical engagement with their social worlds would hopefully create opportunities for alternative strategies to 'acceptance' to be developed, that would hopefully, contribute to mitigating impacts of damaging contexts and abusive relationships that occur during some women's efforts to maintain economic security.

IV. Facilitate access to more sustainable independent economic opportunities through combined interventions that provide access to cash transfers or microfinance opportunities.

The fourth aim of these district-level funded groups seeks to respond to problems identified in chapter six where, despite women's ability to draw on solidarity and independent or collective agency in leveraging resources to tackle food and financial insecurity, such efforts were consistently described as piecemeal and insufficient in addressing the full range of their problems. By linking MHC-run community groups with income generating opportunities supported by external agents with access to larger and more sustainable pools of resources, women would have the opportunity to make more substantial and independent contributions to their families, thus mitigating one of the core pillars of their distress. This aligns with arguments presented in chapter two that cite the ability to make meaningful contributions to one's social environment to promote dimensions of mental health (Westerhof & Keyes, 2010)

The above could be achieved through the use of intervention strategies like cash transfers, which are regular and predictable transfers of cash that provide recipients with flexibility to plan expenditures and meet basic consumption needs (Vincent & Cull, 2012). As outlined in chapter six, many women were already in receipt of such funds by way of child support grants or old age pensions. Given that many women cited grants as insufficient, the addition of further cash transfers for the specific use of promoting longer term income-generating activities could be a valuable addition to indigenous efforts to tackle the poverty blighting their lives. For example, Vincent and Cull (2012) provided a description of the positive outcomes of the Kalomo social cash transfer scheme in Zambia, stating that 29% of income transferred to households was invested in either purchases of livestock, farming inputs, or informal enterprise. At the end of the scheme, 52% of families indicated that they had generated extra income from their investments.

Recent evidence provides mixed findings on the impacts of cash transfers on mental health outcomes (Lund et al., 2011). A study exploring the value of social grants to improving

mental health in Johannesburg reported both positive and negative impacts on mental health – with women articulating that being recipients of grants meant that they were often labelled as lazy by others, and their dependence on the government seen as a ‘sign of weakness’ (Plagerson et al., 2011). Women in this thesis did not report such experiences – an outcome they may have avoided given that nearly half of families in Manguzi were identified as being grant recipients (recall chapter five). However, findings from the Johannesburg study support the use of transfers to bolster activities akin to those described in Zambia, which would give community members an opportunity to display active economic agency and avoid stigmatising labels.

Meeting these four aims within MHC-run support groups, or through psychological interventions such as IPT and PST, could help to increase their local relevance, the lack of which has been cited as a limitation during the piloting of both interventions (Petersen et al., 2012; van't Hof et al., 2011). In my recommendations, I have not explicitly defined what is meant by ‘meaningful’ contributions since the definition of such will be different in every setting, as it is important for space is provided for local articulations of the mental health problem to be expressed and taken forward.

This approach requires the coordinators of such groups to maintain a certain amount of openness toward local definitions of what constitutes valid responses to mental distress. Within the United Kingdom, the platform of social prescribing, defined as interventions that allow for local definitions of what qualifies as a meaningful contribution to distress (Friedli & Watson, 2004), has been useful in this vein.

Under the umbrella of social prescribing, practitioners are free to link patients in primary care with non-medical sources of support in the community, such as opportunities for learning, volunteering, mutual aid and self-help – sometimes in the absence of medical therapies. Studies in the UK city of Bradford (Thomas et al., 2007) have shown the success of similar efforts among black and other ethnic minority groups. Strategies in Bradford focused on developing sustainable solutions within the community that were practical and ethical, rather than technological and medical. Examples of successful interventions include: fitness groups for men who identify exercise as helpful in coping with their distress; and creative writing groups for women to share experiences of distress and oppression that they cited as being central to their distress.

Finally, the value of linking these groups to primary care settings (via their management by MHC), lies in the opportunity this creates to broaden the remit of what qualifies as ‘prevention’ for community-level health programming. Currently, mental health prevention and health promotion programmes focus on the secondary level of prevention, which disseminates information according to biomedical categories (Laverack, 2012; Petersen, Bhana, et al., 2012). In Manguzi, this was most often information relating to schizophrenia, substance abuse disorders, major depression, and HIV dementia. However,

promotion in this vein does very little to address the issues that sit at the heart of what people with these conditions often implicate as shaping their lived experiences in resource deprived settings. The availability of these groups –facilitated by public health officials – to patients and non-patients alike would help to engage those at risk and those affected by mental distress within a collective space. Furthermore, by funding these groups within the structures of the health system, these groups effectively tackle a problem in the current cycle presented in chapter seven (recall figure 25,) clearing a pathway for practitioners to engage with the concerns presented in patients’ life worlds as part of their practice.

In working with women to identify and utilise local and external networks, MHCs could be also be called upon to bolster the existing ‘bridges’ between women and the services at their disposal (suggested action 2). Women in Manguzi display some knowledge about the supports available to them; however, many could benefit from further information on how agents outside the local community – such as social welfare agencies – are able and required to help them. Resources are currently available within South Africa to guide MHC efforts in this vein. For example, Speaking Books, an invention developed by the South African Depression and Anxiety Group (SADAG), are a series of audio books that provide information (overcoming barriers of illiteracy) about how to access and engage with services, and could be used to help guide women’s efforts to self-promote their well-being (see: http://www.sadag.org/index.php?option=com_content&view=article&id=1760&Itemid=554).

Provincial investment in order to increase human resources for mental health will also contribute to enabling women’s mental wellbeing. Advocacy for increased investments in mental health human resources has been a long running argument articulated by South African mental health specialists for over a decade (Lund & Flisher, 2003; Lund, et al., 2002). A mandate securing the presence of a MHC at every sub-district site would go a long way to ensuring the presence and consistent availability of the groups described in this section.

However, while global movement recommendations for task shifting and sharing stipulate that the roles of mental health services can be devolved to volunteers or other actors within primary care structures (Kakuma et al., 2011), this does not equate to the use of just any practitioner. Findings from chapter seven highlight that the community practitioners working most actively to link women to locally and socially salient supports, were those who also held a shared appreciation of the social nature of women’s distress. Many of these practitioners were ‘local’ to the community – having lived there for many years -or were native to the region. For example, the occupational therapy assistant discussed in chapter seven, a Manguzi native who returned to work there following her training, carried the greatest appreciation of the local languages and cultural practices. She was often called on to deliver counselling sessions to identify root social causes of distress, and was also

responsible for the coordination of one of the few successful HIV support groups that also targeted women's socially constituted emotional distress. This is an example of the 'linking' social capital that Woolcock (1998) and others (Campbell et al., 2004; Cornish, et al., 2012) argued as being essential in helping women gain access to resources beyond those provided by local social relationships in families and the wider community.

However, the findings in chapter seven also demonstrated the limits faced by practitioners seeking to contribute to women's well-being within the service sector. In the following section I draw on findings from chapter seven to explore how primary health settings can increase their engagement with the spectrum of social dimensions that so actively shape women's experiences of distress.

8.2 SECURING RECEPTIVE SOCIAL ENVIRONMENTS WITHIN COMMUNITY MENTAL HEALTH SERVICES: SERVICE LEVEL COMPETENCIES

The research questions driving chapter seven were as follows:

How do primary care mental health service actors conceptualise and respond to mental ill-health in their communities?

How does the primary mental health system respond to women's mental distress?

Do the actions of primary care services operate in ways that open up or close down opportunities for women to exercise agency in relation to their mental health?

Findings from chapter seven identified the conceptualisation of mental distress by service actors in Manguzi as being aligned with that of women. Recognition was given to the centrality of poverty, HIV, problematic family and social relationships, and limiting social norms. The chapter also illuminated that the presence of this critical social discourse was not always sufficient to ensure that services addressed women's voiced concerns. This led to the establishment of parallel strategies to ensure that women's concerns were treated as the 'subjects' of interventions, including: patient advocacy; the development of new translation systems to increase engagement with women; and the use of strategic counselling strategies to uncover cues used by women who, due to cultural norms, were hesitant to speak about social problems within families. Coalface practitioners in Manguzi made concerted efforts to establish services as spaces where social responses were an equal part of care. However, these efforts were often cited as 'impossible', against the background of massive resource constraints – such as erratic funding for non-psychiatric interventions (e.g., support groups), or what was identified as stigma towards patients among low-tier health professionals such as primary care nurses.

This reality is reflected against recommendations emerging from MGMH actors who recently articulated the value of a 'balanced model' of care for global mental health (Thorncroft & Tansella, 2013). This model espouses the need for strategies balancing

availability of hospital and community-based mental health supports. It states that in low-resource settings like Manguzi, a focus on strategies that improve the recognition and treatment of people with mental illnesses in primary care is needed. This focus is balanced against the treatment of more complicated cases at specialised centres, which also support primary health care settings. This strategy positions the community as a site of intervention within an agenda driven by the pragmatics (practice) for delivery of biomedical services. However, as articulated by Swartz in a recent commentary on the global mental health field: 'People's perceptions and experiences may outweigh the global logics of pragmatism, treatment and cure' (Swartz, 2012, p.535). Findings from this thesis which validate Swartz's concerns include practitioners' experiences of struggle in achieving the demands of a pragmatic agenda for the delivery of biomedical treatment, not to mention barriers facing their parallel efforts to respond to the social contexts of women in distress.

In chapter three I argued that it is particularly important, in an era of global mental health, that receptive social spaces are available to listen to the voices of local communities. These environments should be marked by a willingness to take local demands seriously, and to support the actualisation of their concerns. The staffing of MHC posts with locally sensitive practitioners, suggested in section 8.1 in relation to the promotion of community mental health services is only one half of this process. The remainder lies within efforts at the level of formal services, to ensure that on the occasions when women make informed decisions to enter the formal services sector, the outcomes of their encounter will result in a mutual understanding of the 'issue' of concern, and the planning of steps to respond to it.

This is not an entirely 'new' call to action within the field of psychiatry. The process of developing 'explanatory models', developed by Kleinman (1980) and presented in chapter one, embraces patient narratives through promoting practitioner recognition of the realities of the life worlds of their patients as part of practice. However, as Kirmayer (2006) reminds us, these critical engagements were not always taken forward in practice. Instead they were 'co-opted' by more mainstream cross-cultural psychiatrists to support their interests in what Swartz (2012) identifies as an over-emphasis on the 'pragmatics' of patient care: such that over time, the value of explanatory models became anchored to their ability to highlight culturally and locally relevant markers of distress that could be linked up to western-derived disease models. More effective treatment is thus promoted through attention to what is now referred to in South Africa as 'culturally competent care' - defined as the ability to provide care within a service user's cultural frameworks and social realities as part of ensuring treatment adherence (Petersen et al., 2013).

There is a danger that a pragmatic approach may limit multi-dimensional responses to distress within service spheres, as was suggested by practitioner accounts in chapter seven of this work. In South Africa, the long standing debates around cultural paradigms of defining and addressing mental health problems may have inadvertently diverted attention

from providing equivalent focus on developing pathways to respond to the impacts of systemic social issues, as part of comprehensive mental health care. However, by shifting frameworks within the remit of 'good practice' to include an equal commitment to 'socially competent care', the place-based problems that members of communities like Manguzi face are more likely to be addressed within specific patient contexts, even if in marginal ways.

Within chapter seven, I noted that a primary reason behind the 'firewall' that hinders a truly social response even among 'critical' mental health practitioners was the 'constraints of reality', created by larger institutional discourses that emphasise biomedical responses. In reality, even critical practitioners remain anchored to a system which is, for better or worse, biomedically driven, with very few opportunities or resources available to respond to patients' lived realities.

Shifting policy arguments is undoubtedly a complex process, which many of South African researchers cited within this work have been actively engaged in for some time (see the work of Swartz, and Petersen throughout). This thesis does not claim to provide solutions to these debates, but provide further evidence for existing arguments that demand shifts in the way services are approached in this country. Figure 25 (p.222) highlighted a system where practitioner efforts to mediate the lived realities of women were continually blocked. These findings suggest a need for policy space that provides further outlets for practitioners to engage with the social realities of their patients. In this vein, recommendations three and four suggest possible avenues for supporting the actioning of existing critiques of policy, and in particular look towards providing practitioners with further options for engaging with the social contexts within which their patients' distress have evolved.

3) Developing training and treatment spaces that support practitioner engagement with patients mental health needs in culturally and socially sensitive ways

This action requires attention to the training of mental health practitioners, and the provision or development of tools that continually promote a 'dialogue' within the processes of screening and treatment planning. Ethnographic observations from chapter five and accounts from practitioners in chapter seven showed that women in Manguzi typically do very little speaking within treatment spaces, beyond descriptions of their biological concerns. It is only through the use of 'strategic counselling practices' that local practitioners were able to identify the root issues and gently coax women into spaces where they could explain their actual needs. This process was commonplace among local practitioners who drew on a dual-knowledge system, but less so among doctors or nurses outside of the multi-disciplinary team, who were described as stigmatising patients with mental health issues. In order for services to remain relevant to women's voiced concerns, the inclusion of strategic counselling efforts used by practitioners in chapter seven could be promoted as best

practice for *all* practitioners who are linked to mental health at the primary level, particularly if calls for task shifting and sharing maintain their prominence (Patel et al., 2010).

Screening procedures that are sensitive to contexts could be achieved through adaptation of methods for patient interviews, which shifts away from Western-imposed models (linked to the DSM categories) and towards paradigm-reduced models that shape engagement with patients. For example, the re-insertion of the explanatory model interview (Kleinman, 1980) as the baseline tool for completing initial mental health screenings in contexts like Manguzi, where there co-exists multiple knowledge systems with regards to mental health, may be one step in creating an interactive ‘dialogue’ about women’s distress. This style of interview forces practitioners to unpack the knowledge systems used by women to make sense of their experiences, creating a space where women’s needs, in addition to their symptoms, can be the ‘subjective’ focus of diagnosis and treatment planning.

On the occasions where the dialogue about the issue of concern results in a plan that is ‘social’ in nature, the system must display its ability to be a ‘receptive’ space for this outcome through the presence of more clearly articulated guidelines for the promotion of social responses. However, this must be accompanied by the dedication of long-term financial and human resource investments in order to prevent the continuation of a biomedical response in isolation of social intervention. This could take the shape of support groups described in section 8.1.

In South Africa, current practices around staffing for mental health posts similar to the MHCs rely heavily on community service positions or visiting practitioners (Pillay & Harvey, 2006; Pillay, Kometsi & Siyothula, 2009). Findings from chapter seven indicate a discontinuity of key ‘social’ responses created by the reliance on actors who are visiting or have little roots to the community. While the sourcing of local staff to fill these posts becomes a likely alternative, the importance of promoting spaces where dialogue about issues pertaining to mental health remain, in light of additional findings from chapter seven which identify additional symbolic barriers influencing delivery of socially anchored services. Specifically, stigma was reported at two levels of services – at the ‘primary care’ level, among nurses, and secondly among NGO staff. Services were further complicated by local doctors who showed a reluctance to participate in mental health service spaces, in line with what was described as a broader lack of respect for the discipline.

The presence of stigma among mental health care providers is well recognised internationally (Wahl & Aroesty-Cohen, 2010). However, current approaches to stigma-reduction within health services are typically driven by information-based sessions (or at best, focus group discussions) that do not typically engage with how stigma is developed (i.e., through unpacking and exploring people’s faulty knowledge systems), and provide no opportunities for dialogue about these issues. Emerging findings from mental health and HIV fields suggest that community conversations may be a potential intervention to meet this

need. Community conversations are intervention strategies that involve discussions among local people, guided by a trained facilitator to promote critical thinking and problem solving around key issues, while identifying local strengths to tackle their concerns (Campbell et al., 2013). These conversations often occur in spaces that are outside of traditional social environments, a strategy that has been linked to giving people the opportunities to develop new ways of thinking about issues (Fraser, 1990).

Campbell and colleagues' reports on the use of community conversations in Zimbabwe highlight their impact on HIV-stigma, through bringing people together to talk about HIV with facilitators, who ask challenging questions about the status quo and encourage new ways of thinking. This process leads to participants being able to reframe their understandings and approaches to people living with HIV. A recent study exploring the use of community conversations to tackle mental health stigma among black, minority and ethnic communities in Scotland (Knifton et al., 2010) highlighted a strategy where service actors discussed the roots of their beliefs of distress and had the opportunity to engage with mental health patients, which resulted in reductions in negative knowledge, attitudes and most importantly, behavioural intent among participants.

Further work by Pinfold and others (Pinfold et al., 2005) evaluated the Mental Health Awareness in Action (MHAA) programme in England, responsible for the delivery of anti-stigma educational interventions to police officers and 78 adults from different community groups supporting people with mental health problems. Findings identified that personal contact was predicative of positive changes in knowledge and attitudes toward people with mental health issues among different community groups, with the exception of professionals such as police officers. Their findings suggest that being aware of stigma (which is the aim of many strategies currently being used in South Africa) is not sufficient for reducing the behaviours that lead to stigmatising practices or changes in attitudes towards those with mental health issues, particularly among staff who witness it in its more severe incarnations (such as police officers).

In a review of anti-stigma programming in South Africa, Kakuma and colleagues (2010) reported that broad scale efforts to challenge stigma currently hinge on media and public awareness campaigns and community-based radio, along with workshops that simply transfer information about mental disorders in an effort to increase awareness.

As such, anti-stigma programming for practitioners involved in primary mental health care services - such as home based care volunteers who are the gateways to addressing the social needs of women within communities, or medical officers who must participate in care at regional hospitals - could benefit from adapting training to include spaces for dialogue, where ideas about mental ill-health and patients with such distress can be unpacked and engaged with in procedures similar to those seen studies such as Pinfold et al. (2005).

To further tackle stigma in the general community - through creating 'exposure' of people with mental health problems, as Knifton (2010) and others assert is needed - the use of community radio interventions may be useful. Community radio is an increasingly popular development strategy used in resource poor settings like India and Africa. It has been shown to provide opportunities for local community members to discuss the contexts that shape their everyday lives and to support debate about these issues (Fraser & Restrepo-Estrada, 2002; Manyozo, 2009). By involving patients with mental ill-health in the production of radio programmes, and allowing them to facilitate discussions about their everyday experiences (which often share many features of those who do not carry a particular diagnosis), those who listen to these programmes become aware of similarities that help to promote acceptance of persons or groups who represent a dangerous 'other', a strategy long championed as a crucial part of multi-culture and anti-racism strategies.

In section 8.1, I suggested that South African calls for increased health promotion strategies could be supported through extending membership to groups run by MHCs to women who are also at risk of developing mental health problems. This ultimately requires policies that explicitly reflect the importance of 'social' concerns impacting mental health, embracing calls to redress impacts of issues such as poverty, or gender disadvantage within 'health promoting activities' among practitioners (Laverack, 2012).

Further engagement with 'social' concerns with regards to mental distress should ideally move beyond the individual and family level focus, currently embodied within trauma and family counselling interventions described by social workers in chapter seven. Current policy suggestions to extend access to social welfare services such as improved housing facilities or grants as part of the KZN community rehabilitation strategy (2010) are steps in this direction, but are met by their own complications as seen in chapter seven.

For many, mental ill-health is linked to or triggered by some aspect of their social context: parental neglect (Jewkes et al., 2010), abusive partners (Golding, 1999; Marais et al., 1999), or stress. Many practitioners and theorists are growing increasingly aware of the fact that addressing a person's mental health requires dealing with the challenges of a person's particular social context. However, what makes a context like Manguzi different is that the challenges created by social contexts are less specific to the individual and more *systemic*. For example, abusive partners are linked to oppressive masculinities that are sustained by wider economic conditions that deprive men of economic sources of positive self-esteem as described in chapter five, and women's acceptance of male oppression is linked to their inability to secure economic independence from men. Thus, mental health practitioners who seek to address the social contexts of their patient's distress require a policy space that enables them to also engage with issues faced by their clients at a systemic and structural level, where possible, suggesting the value of my suggested action 4: *developing clearer*

pathways and policies that support practitioner's attention to broader dimensions of the social.

Examples of these types of policy environments can be found in Latin America, among countries who endorse a policy of Social Medicine. Social medicine, which dates back to the early 19th century, is a strategy that demands that practitioners and policy-makers give equal practical attention to the political and economic factors that produce health inequities (Briggs & Mantini-Briggs, 2009). This approach is differentiated from traditional public health concerns by its view of health and illness as having a relationship where social conditions such as economic production, marginalisation, political participation and culture, move individuals along the continuum between wellness and illness (Waitzkin et al., 2001; Yamada, 2003). Some may argue that attention to such socio-political concerns falls within the remit of primary health promotion; however, an over-arching social medicine agenda could help to ensure that attention to systemic social issues does not have to compete with more operationalisable actions in areas of secondary and tertiary health promotion efforts (such as the identification of disorders and launch of new treatment programmes).

Such a policy framework could open a more receptive space for practitioners to engage with cultural norms governing masculinities, as a point of intervention within health promotion efforts, and as a social determinant that must be tackled in parallel outside health service delivery. For a locale like Manguzi, this would mean that simultaneous community dialogues with men, in order to support receptive environments for acceptance of women's reflections on the state of their disempowerment. For example, these could be located within community conversations with men regarding issues around *their* roles within families, management of their feelings in relation to shifting norms and economic environments, and opportunities to carve out new more positive notions of 'masculinity'. A men's HIV support group in Cape Town was reported as a site that promoted discussions around the changing landscape of masculinity in contexts of the social, political and economic factors that also limit men's participation in families (Colvin et al., 2010). The success achieved with these and other community conversations with HIV-affected groups (Campbell et al., 2013) suggests a potential for their application in primary health engagement with contexts that frame experiences of mental ill-health.

Using community conversations to target masculinities has not been widely discussed, however new findings from Kenya (Gildea, Campbell & Mannell, in press 2013) highlight that in a focus group setting, HIV positive men openly discussed issues relating to their masculinities. Furthermore, a recent study from a therapeutic environment in North America recently argued about the value of the use of conversations with perpetrators of violence about hegemonic ideas of masculinity (Agusta-Scott, 2009). Within these conversation groups, facilitators called on men to establish and justify their position with

regards to their masculinities, and the problems stemming from these ideas. The process of evaluating their positions was described as leading to the formulation of new perspectives on their roles in abuse and relationships with their wives.

It is important to note that I make no overt claims for the ability for community conversations to automatically result in changed perspectives on men's roles in women's experience of mental distress, or to automatically increase awareness of the impacts of broader structural concerns on distress. These interventions arguably open up spaces for possibilities that have not previously existed; offering a chance to reduce the likelihood of women returning to family spaces where they could encounter increased abuse in response to their efforts to change the distressing contexts that plague their lives. Furthermore, men's groups could also serve as points of referral for men struggling with substance abuse related disorders, which were identified by practitioners in Manguzi as a significant burden, and which are linked to men's inability to manage the impact of new political economies on their opportunities to display positive notions of manhood.

I do not seek to idealise such spaces, which will certainly be highly contested and complex environments that require time for dialogues to shift old ways of thinking into new ways of acting. However, if these conversations were to be linked around opportunities for employment, such as skill-building activities, job training, or additional income generating opportunities, they could operate as incentives to promote the long-term participation needed to achieve such ends. Evidence emerging from the work of groups like Basic Needs (2008) highlights the success of linking income generating activities with mental health-related interventions.

Another recommended action is also linked to problems of stigma, in particular stigma that pervades general opinions about the roles of traditional healing practices within the area of mental health. In chapter five, I presented a picture of traditional healers that highlighted their broad attention to the social- a scope that likely helps to maintain their relevance to such large portions of the population. Traditional healers voiced a desire for opportunities to expand their existing knowledge base: my interview with a family of healers dissolved into a question-and-answer session about exactly what doctors believe mental illness is and the parallels to their own practices within these discourses. This desire for training on the part of traditional healers creates opportunities to expand their knowledge in additional capacities – including those linked to biomedical systems where appropriate. These findings informed my fifth suggested action of extending partnerships between traditional and medical practitioners (see Table 29)

TABLE 29: COMMUNITY COMPETENCIES AND ACTIONS FOR PROMOTING MENTAL HEALTH ENABLING CONTEXTS IN PRIMARY MENTAL HEALTH CARE SETTINGS

Level of action	Competency (and processes)	Suggested Action	Tools of delivery
Community	Agency	1. Expand the role of Mental Health Counsellors (MHCs); facilitate groups that enable women's access to spaces of engagement that promote social integration, solidarity and support in making meaningful contributions to their own lives.	• Community conversations
	Critical thinking Solidarity (bonding social capital)		• Cash Transfers • Micro-finance projects • Community radio
Services	Partnerships (linking social capital)	2. Work with women to identify and utilise helpful networks at local levels and external to the community	• Educational assistance (speaking books) • Mandate for 1 MHC per sub-district site
	Partnerships (bridging social capital; dialogue)	3. Promoting spaces that develop a critical practice of practitioner engagement with patients' mental health needs	• Introduction of new screening tool in primary settings (Explanatory model interview)
	Receptive social environments		• Training programmes for medical practitioners tackling stigma (community conversations)
	Receptive social environments	4. Developing clearer pathways and policies that support practitioner's attention to broader dimensions of the social.	• Mandatory funding for community level groups (see action 1) • Increase staffing capacity to social work departments at district level
Partnerships (dialogue)	5. Building mutual partnerships that make better use of community level actors	• Collaborative training exercises between medical practitioners and traditional healers	

However, it appears that there is corresponding need for spaces where formal medical practitioners can also develop a more open opinion towards traditional practice, something which has been advocated within recent studies (Sorsdhal et al. 2010). This process is supported by findings from chapter seven that highlight the ability of critical practitioners in Manguzi to see the value of more active inclusion of traditional healers as part of services – in particular in the possibility for traditional healers to make crucial differential diagnoses between cases anchored in cultural mores (such as 'callings') and biological ones. The contributions that they make in this regard could situate traditional healers as an output for referral *from* clinical practitioners.

The health risks associated with certain traditional practices cannot be negated – however it is likely that within spaces which target promotion of ‘mutual’ partnerships, traditional healers, who in this study showed a hunger for more knowledge about biologically-driven practices, could be educated about the negative impacts of some of their practices and perhaps identify ways to improve their own practice.

In summary, this thesis has uncovered the importance of five competencies to community mental health, first argued to be crucial in HIV-AIDS related contexts (Campbell, et al., 2007). These are suggestions that could contribute to the promotion of mental health-enabling social contexts and take account of both symbolic and place-based dimensions of community with regards to mental distress. In sections 8.1 and 8.2, I discussed five suggested actions and associated tools that could theoretically be used by mental health policy makers to support practitioners’ further engagement in community strengthening activities within primary mental health care services. These tools are revisited in table 29. These suggested actions would work in a complimentary way alongside existing established practices, so that mental health practitioners in resource poor areas could be provided with a policy and service space receptive to their efforts to support community coping, and build on biomedical efforts to promote mentally healthy communities.

8.3 DEALING WITH HIV/AIDS WITHIN MENTAL HEALTH SPACES: A (NOT SO) SPECIAL CASE?

The final research question posed in this thesis concerns a health issue that impacts on any effort to promote more effective responses to mental distress amongst marginalised rural South African women: HIV/AIDS. Much research has lauded the importance of developing AIDS-specific mental health services (Andersen & Seedat, 2009; Brandt, 2009; Breuer, et al., 2011; Collins, et al., 2006; Freeman, et al., 2008; Kelly, et al., 2008). As part of this study, I sought to explore the realities of how HIV/AIDS and common mental health concerns intersect within a community of women who were affected by HIV/AIDS. The degree to which HIV/AIDS permeates Manguzi life cannot be understated: data from chapters five, six and seven highlight the plight of women whose lives were touched by the virus at some stage. At first glance, data from this thesis seems to support the body epidemiological studies (reviewed in chapter two) that calls for the integration of mental health care into HIV/AIDS programming for HIV-positive and AIDS-affected women (Freeman et al., 2008; Freeman Patel, Collins et al., 2005).

However, what my findings actually suggest that there is nothing particularly salient about HIV that propels it to the status of a special case – at least within cases of common mental disorders such as depression and anxiety. In developing these arguments, I am in no way advocating against attention to the specific instances of HIV dementia or severe

conditions that require a set of treatment responses that is unique and well within the domains of psychiatry, or specialised services targeting the complex relationship between HIV/AIDS and individuals with disabilities. Yet it remains important to consider that women in this study spoke of HIV in relation to how it affected their ability to manage additional efforts to tackle the broader socio-structural issues that shape their mental health and HIV-related issues. As such, it could be argued that for mental health/HIV programming, a first line approach must seek to provide further opportunities for women to engage in *spaces that provide opportunities to develop social cohesion and be supported in making meaningful contributions to their lives.*, with efforts to empower women to tackle their poverty as a critical pillar of HIV and mental health programming, an argument supported by a 2013 study of HIV positive women diagnosed with depression in South Africa (Petersen et al., 2013).

The lack of centrality surrounding HIV/AIDS and its effects on the life stories of women living in a pandemic stricken community, may speak in part to how advances in responding to HIV/AIDS in recent years (such as accelerated roll-out of ARV treatment), have made strides in shifting conceptualisations of the illness away from a death sentence, and toward a chronic illness. Residual concerns reside in fears over providing for children; fears that could be alleviated through increased opportunities for women to make more meaningful contributions to their families. I am confident that participants' lack of attention to this topic was not driven by the sense of stigma or denial that has been a feature among the accounts of women in earlier studies of the pandemic (Campbell et al., 2008), and which continues to plague many women in the country. At no stage of any interviews did anyone show reluctance to discuss their personal experiences of the epidemic, and all informants were assured of confidentiality and anonymity of their contributions.

This final note on issues of confidentiality and anonymity draws attention to the pillars of research ethics, and to the final sections of this thesis, which reflect on the realities of research with marginalised populations and 'doing' development research with an eye towards informing health enabling 'social change'.

8.4 CONCLUDING REMARKS: REFLECTIONS ON THE REALITIES OF RESEARCH FOR 'SOCIAL CHANGE'

8.4.1 NOTES ON QUALITY CRITERIA: BEYOND 'VALIDITY' AND 'RELIABILITY'

In chapter three, I presented a discussion that argued the ability of case studies to make generalisations that would allow for concepts derived from this thesis to be extended to other settings. The ability to 'generalise' from one study to future contexts is determined by measures of external reliability and internal validity. However, Bauer and Gaskell (2000) have argued for a different approach to assessing the contributions made from context-driven small-scale studies –of which this thesis is an example. The proposed set of criteria

used to judge the scientific rigour of this work includes: triangulation and reflexivity, transparency and procedural clarity, corpus construction, thick description, surprise elements and communicative validation. In this section I address each of these in turn.

First, Bauer and Gaskell assert the importance of triangulation and reflexivity. In this thesis, triangulation was achieved through drawing on multiple forms of data and perspectives relating to the central idea of 'community mental health services'. I argued that to truly study the realities of these services we need to explore the system in its entirety: the perspectives of its multiple actors, the community where services are contained, and the practice of delivery in the everyday. This level of triangulation is rarely approached within studies outside the field of anthropology; and it is particularly limited within global movement evidence that is driven by epidemiological or intervention trials to test the efficacy of modifications of western models of therapy. As such, it is my hope that findings from this thesis can contribute to the current dearth of evidence that considers notions of mental health and related services in the contexts of patient realities.

Procedural clarity and corpus construction are the second and third elements of quality criteria that can be used to evaluate small-scale qualitative studies. In chapter four I developed what I hoped to be a transparent account of my methods, which were driven by a commitment to elements of grounded theory; this approach seeks to remain anchored to the context being researched. This attention to context also responds to the fourth quality indicator of 'thick description', solidified within an empirical chapter dedicated to the outputs of my motivated ethnography.

However, I remain aware of how my interests in producing an in-depth study of a single context simultaneously opens this thesis up to critique in its desire to make recommendations for applications in other settings. Still, what a study of this nature does support is the importance of exploring mental health within its contexts, prior to planning engagement with communities – which I presented to be malleable, contested, historically situated, and ultimately complex symbolic and structural entities. From this standpoint, I highlighted a series of concerns that were eventually elevated to theoretical dimensions, and it is this theory that creates room for application in new contexts. For example, I observed the importance of bonding social capital to women's self-help strategies, and how such dimensions of capital also can have negative ramifications. I then translated these context-specific findings under broader theoretical framing as part of my suggestions for promoting mental health competent communities: *Access to critical spaces that promote social integration and meaningful contribution*. In this essence, what constitutes as 'social integration' and 'meaningful contributions' remain empty containers that can be filled by a reading of the context of the new community that is the target of services. It is within this process that I hope to make broader contributions to promoting ethnographically sound practices within global movement efforts.

The fifth marker of quality within small-scale qualitative studies resides in the presence of ‘surprises’ within the process of analysis and write-up. There were a number of ‘surprises’ that emerged within this study; first the relatively minor role played by HIV within women’s stories – or rather, the way in which HIV has assumed a place as ‘one of many’ life concerns and not the primary concern around which successes rise or fall. In addition, the series of ‘best practices’ enacted by a collective of passionate and critical health professionals emerged from a grounded systematic analysis of accounts, which helped to inform the ‘service and practitioner’ dimension of competencies.

Finally, communicative validation is presented as the last marker of quality for qualitative research. This is a dimension that remains in progress: as part of my commitment to research that furthers policy aims, findings from this work are being shaped into a policy report for the KZN provincial department of health. As part of this process, I will disseminate findings to the regional psychiatrist and district health workers interviewed within this thesis, to ensure that recommendations accurately reflect their local needs. With regards to sharing my findings about women’s stories, this is a more complex process, which I engage with more intimately in the following section.

8.4.2 SELF-REFLEXIVITY: NOTES ON ETHICS

In chapter two, I acknowledged that I was driven by a critical social psychological framework. This is a discipline that overtly problematises the processes through which individuals mediate their social contexts, and looks towards the transformative opportunities that emerge within engagement with marginalised communities. In short, the practice of a critical psychologist could simultaneously be considered as the practice of ‘activism’ within communities - a similar process of seeking to ‘open’ the participants’ eyes to the realities of the world they inhabit - and of promoting action to change this world in meaningful ways. I acknowledge that this is a difficult task, and one that is not achievable by any single piece of research. My engagement with this community has been primarily a research driven one, limiting my ability to predict the true value of my findings to daily practices of care. However, the framework that emerged from my findings was grounded in ethnographic engagement with key actors in Manguzi, which would hopefully make my theoretical suggestions resonate with their daily realities to some degree. It is my hope that this resonance enables my findings make contribute in some way to the efforts of coal-face practitioners who work in Manguzi, and similar contexts.

Within the space of a thesis that seeks to argue the importance of ‘transformation’ and is driven by ‘activist’ roots, one may criticise the absence of data methodologies which promote these ends, such as Participatory Action Research (PAR). For example, the work of Rose (2003) has championed ‘user led research’ where mental health service users are actively involved with the setting of a research agenda, planning and collecting data, and its

analysis. Another example can be found in the work of Davis (2006) who engaged with I battered black women in inner city New York. She outlines a series of procedures that were added to her analysis to promote women's critical self-reflection. Discussion sessions with women she interviewed unpacked Davis' emerging coding framework. In asking women to reflect on how accurately these processes reflected their lived realities, she described the creation of opportunities for women to think in novel ways about their actions within their own social worlds, and helped reframe analysis in ways that were more attuned to women's emancipatory actions. Such types of methodologies would have undoubtedly made positive contributions to securing opportunities for local 'conscientisation' among women and practitioners; something I argue that some women would benefit from according to my findings from chapter six. The reasons behind my decisions not to include these methodologies are organised around two dimensions of 'reality' of the research practice. First, I consider the 'reality' of the worlds that we research. In this sense, I refer to the stigma about mental health that pervades many rural South African communities, discovered during my tenure living and working there as an HIV/AIDS researcher in 2008 and 2009. My thesis engaged with women who had yet to be self or publically recognised as mental health service users and thus were not directly at risk of being subjected to stigma around these categories. As such, I was hesitant to engage with women in ways that would potentially open them up to experiences of stigma within communities that are their largest sources of support. The second reality concerns old debates that surround much cross-cultural research – language barriers that exist between researcher and the 'researched'. I was consistently aware of how my inability to speak Zulu may have limited my efforts at truly grounded and critical cross-cultural examinations of mental health. My use of local translators helped to bridge some of these gaps, but the realities of working within and across multiple levels of translation can often create distance between the realities of women's stories and the way these stories are 'read' and then 're-told' through multiple voices (i.e. on spot translators, translation/transcription processes). Despite these difficulties, the importance of accessing women in such remote contexts is imperative and my engagement with them, no matter how complex, represented for some women, the first opportunity to be 'heard' by an outsider.

My position as an 'outsider' within interview spaces could have also impacted my findings through a series of demand characteristics that are now synonymous with the presence of western development workers. For example, the realities of what I represented to the women I interviewed were crystallised in the comments of Bumi at the end of her interview, who remarked: 'When you called, I thought it was the government calling to tell me I was getting access to electricity – since I told the last survey people that this is what I needed'.

This was perhaps the most difficult space to navigate within my work. My time in the field, and then for the months that followed in analysis, reiterated the realities of what women in poverty endure – and I was often devastated by the minute ways in which research can actively contribute towards women’s immediate struggles in this vein. This event highlighted the convergence and conflict of my efforts as an ‘activist’ in other areas of my life converged my practices as a researcher. My initial desires to elevate the stories of these women to theory that could be adapted in new settings, faced the reality of acknowledging the sometimes limited role of research in supporting the immediate survival concerns of the women whose voices I desired to elevate. However, facing this conflict helped me recognise the ultimate value of both forms of contributions: and the importance of research as a tool that supports the work of activists in fighting for daily survival in other areas (as seen in my efforts to share my findings with policy makers).

One way to work around the problem of demand characteristics in resource-poor research contexts is through systems of compensation for those participating in research. Issues around the ethics of biomedical research within resource poor contexts often include debates on the use of research incentives and remuneration; that is, steering away from payment for participation, as it is seen to promote the likelihood of community actors who are so extensively marginalised to assume undue risks in exchange for access to financial remunerations (Cook et al., 2003). My efforts to provide women with some recognition for their time and commitments to this work were further limited by the affiliation of this project to a larger survey, which recognised women’s participation within surveys by giving out certificates rather than tangible incentives. This practice of ‘non-financial’ incentives is a particularly frustrating practice that, while anchored to ‘evidence’ about ethics produced in the western world, holds very little practical value or relevance to the communities who are the focus of research.

I devised alternative methods to provide women with more meaningful recognition for their time: discussing the importance of the programmes run by the local NGO with all women and providing them with referrals so they could be supported by home based carers. I also spent a great deal of time bolstering the local capabilities of the NGO to deal with the women who I was referring their way: and currently still work as a technical advisor on programming with the NGO, remotely advising on programming and service delivery programmes. In one extreme instance, I gave a participant the money she needed to pay for transportation to her local clinic after she disclosed that she had not slept in three days due to her worries about her children and pain in her legs. My action within this particular instance would undoubtedly be deemed ‘unethical’ as it was outside of my accepted protocol, and the decision I made caused me anxiety for some time afterward. But to leave her there, in a space where she had no access to funds to pay for her transport to a clinic where she could receive help for debilitating pain, struck me as unethical with far more

serious repercussions. These debates are evidence for the imminent need to critically re-think what counts as 'ethical' within the spaces of qualitative global health research with some of the world's most vulnerable and disadvantaged groups. As qualitative interviews often create spaces where people come to feel safe and divulge some of their most complicated and painful truths, ethically responding to what is shared quite quickly falls into a grey area. As stated by Bhutta (2002), quoting health ethicists Darr and Singer's presentation on ethics in international health research: 'So long as all the ethicists are in the North, and the South is just the recipient of ethical principles, nothing will change.' The realities of development research and practice will continue to bring researchers face-to-face with such dilemmas and thus, the problematisation of the rules that govern our practices and interactions is mandatory.

8.5. MOVING FORWARD POLICY IMPLICATIONS AND FUTURE RESEARCH

8.5.1 FUTURE RESEARCH

As part of MGMH efforts, future research with groups of women like those at the heart of this thesis would benefit from applications that move from doing research ‘on’ women to doing research ‘with’ women. This involves more than just the use of women as ‘volunteers’ and training them on biomedical paradigms as is the current norm. It is also important to open a space for women’s knowledge about what constitutes mental distress to form the core of how mental health is defined and addressed in interventions. Though they were not used in this particular thesis, for communities where the immediate social environment was more ‘receptive’ to discussions of mental health, PAR methods could help to embed the development of conscientisation within the research process.

Discussions surrounding the misdiagnosis of cases of schizophrenia in primary care practice also present an important potential for future studies, as the implications of misdiagnoses of this regard have impacts not only on the lives of patients, but also on the burden placed on an already overstretched and under-resourced mental health service.

Finally, while my arguments for community mental health competencies evolve from a systematic ethnographically grounded analysis, they remain largely theoretical recommendations. As such, a useful future study could assess how well an intervention design rooted in the discovery of community mental health competencies results in improvements in the lives of community members, and how well it impacts on the efficiency of primary care systems.

8.5.1 POLICY IMPLICATIONS

As previously stated, this thesis has sought to highlight the importance of an ethnographically sound analysis of communities as part of efforts to promote mental health. In this vein I have outlined a potential methodological contribution to data collection and analysis for the global mental health field that draws on ethnographic practices in a limited time period, without sacrificing richness of context in seeking to understand local framings of knowledge. Such methods may help identify not only barriers to the potential success of a particular system or intervention (highlighted in chapter seven) but also, uncover indigenous practices within a community that may become the source of interventions aimed at improving and preventing mental health conditions (highlighted in chapter six, and section 8.1).

8.5.3 FINAL THOUGHTS

In the epilogue to his monograph *Rethinking Psychiatry*, Arthur Kleinman reflects on the importance of notions, such as culture and society, to practices of 'western psychiatry'. More than twenty years ago, he was hopeful that the discipline would develop a more cultural and critical practice which, by the twenty-first century, had managed to successfully:

'...transition towards a global psychiatry whose science and practices accommodate an international mental health agenda, cross-cultural differences, the social context and not least of all, the social sciences' (Kleinman, 1988, p.185).

In my journey of producing this thesis, I found myself disappointed in the discovery that many of his hopes had been not been realised.

However, what has transpired is a shift in momentum where western psychiatrists take interest in the practices and needs of a global psychiatry. Unfortunately, to date this has occurred in the absence of much internal critical reflection on the crucial questions about culture and the social. Instead, we find a field of 'global mental health' dominated by voices – mired within discourses of 'evidence-based practice', 'response control trials', and other strategies that actually reduce the ability for realities of culture and society to filter into their evidence pool and inform practices. In the few spaces where critique does happen, it resides at the fringes of the main axis of the movement, with little evidence of these critiques taken forward into practice.

It is my belief that the global movement has gathered enough momentum to make the changes that Kleinman so ardently desired to make a reality, for all of psychiatry, more than twenty years ago. It has the potential to change the ways that psychiatry and psychology operate as disciplines in relation to their patients, for no other reason than the realities of the contexts within they now work *demand* this. As the global mental health field delves into communities internationally, it also exposes a sea of social ills: poverty, war, violence. However, global mental health actors also carry opportunities for community members to gain access to resources that could support responding to those macro social issues, which as confirmed by this thesis, are the roots of emotional distress for many whom the global movement actors seek to support. We must continue to search for ways to build on the positives of these forms of encounters where possible.

Promoting a further shift of attention to the problematic social worlds that frame distress among psychiatrists need not take the shape of marches or protests as was once the case within movements around de-institutionalisation. This can be a quiet and process-driven revolution that begins with the systematic process of infusing the field of global mental health with methods and practices that emphasise a humanistic vision of 'people' and further attention to improving the worlds within which they live.

It is has always been my hope that findings from this thesis would contribute to a nascent evidence base within global mental health that re-iterates the importance of the above. Efforts to support the emotional distress of women in communities like Manguzi cannot work outside of the contexts that constitute that distress. This thesis has provided evidence to this effect through highlighting the fact that women's distress remains a product of fragmented social worlds. In the absence of a more locally and socially engaged practice, and despite its best intentions, the MGMH may never move beyond its current rhetoric of 'community involvement' into the reality of improved 'community mental health'.

Beyond this, it is my hope that my proposed framework for '*community mental health competence*' may provide suggestions for how primary care can move toward facilitating receptive social spaces where women are supported in preventing mental health issues, through action that targets the structural violence of their worlds alongside biomedical treatment efforts. If a movement for global mental health truly desires to 'promote contexts and environments that promote mental health'(Collins et al., 2011), then it must also attempt to embrace a practice that enables the contexts of local social change – or in some instances, global social movements - that poor communities need to address at the core of their distress. We may no longer be at the stages where we need to 'rethink' psychiatry. What we require now is the promotion of the practice of a psychiatry that sees an equal, if value, in a greater focus on the '*transformation*' of worlds where bodies live.

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APPENDIX A: CONSENTING SCRIPT AND INTERVIEW SCHEDULE (COMMUNITY WOMEN)

Consenting script – English version

1) Part 1: New introduction about the study

Thank you for agreeing to talk to me today. Earlier this year you talked to me/one of my colleagues about some of the things you experience in your life, and ways you cope with them. Now we are asking some people to tell us a bit more about some of their experiences.

Today I will ask you to share some stories you have about

- *How you cope with events in your daily life*
- *How your daily life is affected by your emotions*
- *Your understanding of the words 'mental illness'*
- *Some of the answers you gave on the survey*

The interview will take about one hour.

2) old consent (same as survey)

3) explanation about the tape recorder

We are using this tape recorder to make sure that we don't forget any of the stories that you tell us, or get them wrong. The stories you share with me will be used to help the government and NGO's so they can help the community. My manager will delete the recording after she has listened to it, and written down your stories. Everything will be kept in a locked area, and only the manager will have access to it. No one will be able to link the recording or the written story back to you. I am the only person who knows your name. Nobody will know that this is your voice on the tape recorder. My manager works with UKZN and Tholulwazi, and is supported by the department of health, who are aware that she is doing this study.

COMMUNITY WOMEN INTERVIEW SCHEDULE

Date of interview	
Patient ID #	
Interviewer Initials	

Introduction: Warm up/Engagement questions

Where were you born?

Do you have any brothers and sisters? where are they now? do you see them often?

Can you tell me a little about your parents? where are they now? how did they die? how did that feel?

Can you tell me about a happy story from when you were a child?

Did you go to school? why did you stop going?

How long have you lived in this house?

Are you married? how long have you been married? is it a happy marriage?

Do you have any children? How many children do you have? how old are they? are they in school?

What are the two hardest things about your life right now?

What are the two best things about your life right now?

Can you tell me a story that would describe what a typical day is like for you? / **Ungasixoxela indaba ukuthi wenzani zonke izinsuku?**

(Fill in the answers to these questions in the space below)

Section one: Episodes relating to previous questionnaire

1.1 In the survey you completed this year, people were asked about some of the support that they used. Can you tell me a story about a time where you needed support and you talked to a... / **Embuzo oqedwe nguwe kulonyaka, abantu bebebuzwa ngosizo oluhlukene, olusetshenziswa yibo uma bexineke noma benengcindezi. Ungangitshela indaba yaleso sikhathi udinga usizo ?**

Group 1: Health System/Isiqumbi 1: Isimo sosizo olungenamicilikishane

Subtype/ Izinhlobo	Yes (yebo)	No(Cha)	Story/reason why not
Nurse/ Unesi			what happened?
Psychiatrist/ udokotela wezengqondo			who was there? why did you do that?
Doctor / Udokotela			what did they say?
Telephone hotline/ Ucingo			What did they do?
Home based care			
Social worker			

Group 2: non health system support

Subtype/ Izinhlobo	Yes(Yebo)	No (Cha)	Story/reason why not
Friend/family member Umngane / ilunga lesihlobo			what happened? who was there?
Priest/pastor Umfundisi			why did you do that?
Traditional /faith healer Inyanga /umthandazi			what did they say?
Support group/ Iqembu lokusizana			What did they do?

1.3. A part of the survey talked about feeling anxious. Can you tell me a story about any time where you felt this way and what was happening in your life then? / **Enye inxenye yocwaningo ikhuluma ngokwesaba, ukuthuka, ukungakhululeki nokudabuka. Ungangitshela indaba oyikhumbula yo enjalo futhi kwenzekeni ngaleso sikhathi empilweni yakho?**

after this story ask:

Who helped you during that time? Ubani Okusizayo?

1.4 Another part of the survey talked about feeling sad. Can you tell me a story about anytime you can remember feeling this way and what was happening in your life then? / **Enye inxenye yocwaningo ikhuluma ngokuphatheka kabi nokudabuka. Ungangitshela indaba oyikhumbulayo enjalo futhi kwenzekeni ngaleso sikhathi empilweni yakho?**

Who helped you during that time? / Ubani Okusizayo?

Section two: Explanatory models of mental ill health (causes)

2.1 What are the things in your life that are most often linked to your sadness? / **Yini eyenza uphatheke kabi empilweni yakho?**

2.2 What are the things in your life that you find are most often linked to your anxiety/ **Yini empilweni yakho eyenza wesaba; wethuke, Ungakhululeki?**

Note to interviewer: in this section, please note down some of the key things that they say list as linked to their sadness/anxiety below. You will need these for the following section

Sadness/Ukuphathekakabi _____

Anxiety/Ukwasaba; Ukwethuka, Ukungakululeki

Section three: Coping and appropriateness of support

3.1 What are some of the ways that you cope with the things that make you sad like: _____ (Please read out examples from the list derived from the stories told in question 2) **Ubhekana kanjani ngezinto owakhuluma ngazo?**

Can you think of any stories that you'd like to share about this? / **Ungacabanga ngendaba ofuna ukusitshela yona?**

3.2 What are some of the ways that you cope with the things that make you anxious like: _____ (please read out examples from the list from question 2) **Ubhekana kanjani ngezinto owakhuluma ngazo?**

Can you think of any stories that you'd like to share about this? / **Ungacabanga ngendaba ofuna ukusitshela yona?**

3.3. Can you tell me how well you think the other supports you talked about earlier help you to deal with _____? (Note: read list of factors from question 2 here)/ **Ungangitshela ukuthi usizo owakhuluma ngalo olunye, lukusize kanjani _____?**

3.4 What do you think would help you cope with the things that make you sad and anxious?

Ucabanga ukuthi iziphi izinto ezingakusiza ukumelana Nokuphathekakabi , ukwesaba, ukuthuka, Nokungakululeki ?

Section four: Understandings of medical discourse (nature)

4.1 Sometimes doctors use different words to talk about what we've talked about today, like anxiety and depression. Have you ever heard those words? Can you tell me a story about the first time you heard these words? / **Amanye amalanga odokotela basebenzisa amagama amanye ukukhuluma ngalokhu esikhulume ngakho namuhla, ukwesaba noma ukphathekakabi. Ungangitshela ukuthi uqale nini ukuzwa la magama?**

4.2 What does the term "Mental Illness" mean to you? / **Kusho ukuthini kuwe lokhu 'Ukugula kwengqondo'?**

4.2.1. What are some of the stories you have heard in your community about mental illness/ **Uzwe ziphi izindaba emphakathini wakho 'Ukugula kwengqondo'?**

4.3 What does the term "Mental Health" mean to you? / **Kusho ukuthini kuwe lokhu 'Inqondo ephilile' ?**

4.3.1 What are some of the stories you have heard in your community about mental health?/**Uzwe ziphi izindaba emphakathini wakho Inqondo ephilile" ?**

Closing

You have shared a lot with me today. Can you think of any other stories that you would like to share? /
Ungitshela okuningi namuhla. Ungacabanga ngendaba enye ofisa ukungitshela?

IF HIV is mentioned by the person as being in the family:

How did it make you feel?

How does it affect you?

How do you cope with HIV?

Who do you take care of?

PRIMARY HEALTH CARE PRACTITIONER INTERVIEW SCHEUDLE

Date of interview	
Patient ID #	
Interviewer Initials	

Introduction: Warm up/Engagement question

Where are you from originally?

How long have you been working at manguzi?

What started your passion for _____ (field participant works in)

Can you tell me a story that would describe what a typical day of work is like for you?

What are the three biggest challenges you face at work?

What are the best things about your job?

What are the top three problems that you help support people with?

Section one: Episodes relating to previous questionnaire

1.1 What are some of the typical reasons why people come to you for support?

1.1 In the questionnaire that some community members completed this year, people were asked about the types of support that they use when they are depressed or anxious.

How often do people in the community come to you for help with being stressed or upset?

Can you think of a typical story that describes this?

1.3 Sometimes when people feel sad or stressed they also like to talk to

_____ (healers/socialworkers/family/friends) How often does this happen in your community?

1.4 Do you have any stories about patients who have done this? what happened to them?

Section two: Explanatory models of mental ill health

2.1 What are the things in the lives of your patients that they most often link to their sadness?

2.2 What are the things in the lives of your patients that they most often link to their anxiety?

2.3 Can you share a typical story of how your patients most often describe their sadness or anxiety?

Note to interviewer: in this section, please note down some of the key things that they describe as linked to their sadness/anxiety below. You will need these for the following section

Sadness _____

Anxiety _____

Section three: Coping and appropriateness of support

3.1 What are some of the ways that you provide support for your patients when they report sadness and anxiety?

3.2 Can you think of any stories that you'd like to share about this?

3.3 How do community members/patients typically respond to the support you provide?

3.4 Can you tell me how well you think the other supports you talked about earlier help your patients to deal with _____?

Section four: Understandings of medical discourse, relationship between mental health and HIV

4.1 How often do you come in contact with common mental disorders, such as depression and anxiety? Can you tell me a story about a typical experience when this happens?

4.2 What does a typical psych consult or patient at this hospital look like? can you think of any stories?

4.2 What does the term “Mental Health” mean to you? / **Kuthini kuwe ‘Impilo yengqondo’?**

4.3 What does the term “Mental illness” mean to you?

4.4 What are some of the ways the community understands these terms?

4.5 What is your understanding of the relationship between mental ill health and HIV?

4.6 Can you think of a story that best describes how you support the mental health of persons in the community who are impacted by HIV/AIDS?

4.7 What are some of the mental health needs of community members dealing with HIV/AIDS?

Section five: Understanding of Mental health policy in SA

5.1 Can you tell me what you know about the mental health policy in South Africa?/

5.2 Can you tell me a bit about your experience with helping your patients receive mental health supports in the community?

5.3 Are there any barriers to implementing mental health policy in this community?

Closing / Ukuvala

You have shared a lot with me today. Can you think of any other stories that you would like to share? / **Ungitshela okuningi namuhla. Ungacabanga ngendaba enye oyifuna ukungitshela?**

TRADITIONAL HEALER INTERVIEW SCHEDULE

Date of interview	
Patient ID #	
Interviewer Initials	

Introduction: Warm up/Engagement Section (Umbuzo wesingeniso)

Where were you born?

Wazalelwa kuphi?

Can you tell me a little about your family?

Ungangixoxela kafushane ngomndeni wakho?

Can you tell me about this community?

Ungangixoxela ngomphakathi walapha?

What are some of the good things about this community?

Iziphi ezinye zezinto ezinhle ngalomphakathi walapha?

What are some of the bad things about this community?

Iziphi ezinye zezinto ezimbi/ ezingathandeki ngalomphakathi?

When did you first get the call to be an isangoma? Can you tell me about that?

Waqala nini ukuba isangoma? Ungangixoxela ngobizo lwakho lobungoma?

Are there other Isangoma's in your family?

Bakhona yini abanye emndenini abayizangoma ?

How many people do you see in a week?

Abangaki abafikayo bezofuna usizo ngesonto/ ngeviki?

What did you do before you became an isangoma?

Wawenzani ngaphambi kokuba ube isangoma ?

What are your two favourite things about the work you do?

Iziphi izinto ozithanda kakhulu ngalomsebenzi wokuba isangoma?

What are the two hardest things about the work you do?

Iziphi izinto ezinzima kakhulu ngokuba isangoma?

Can you tell me a story that would describe what a typical day of work is like for you/

Ungangixoxela indaba echaza ngomsebenzi wakho ukuthi wenzani zonke izinsuku?

Section one: Episodes relating to previous questionnaire

Isigaba sokuqala: Isigigaba esihambisana nemibuzo yokuqala

1.4 What are some of the typical reasons why people come to you for support?

Iziphi ezinye zezizathu ezenza abantu bezofuna usizo lwakho?

1.1 In a questionnaire that some community members completed this year, people were asked about the types of support that they use when they are stressed or upset. Can you think of a time when someone came to you for help because of this? **Kwelinye iphepha lemibuzo amanye amalunga omphakathi aliphendula kulonyaka babuzwa ngezindlela abazisebenzisayo uma becindezelekile futhi bephatheke kabi.**

what things do you do to help people when they come for this reason? **Yiziphi izinto ozenzayo ukusiza abantu uma befika kuwe nalenkinga?**

Section two: Explanatory models of mental ill health

Isigaba sesibili: Umfanekiso osicacisa ukugula kwempilo yenqondo

2.1 What are the things in the lives of your patients that make them sad?

Yiziphi izinto ezenza iziguli zakho zidabuke ngempilo yazo?

2.2 What sort of things to your patients tells you make them anxious?

Iziphi izinto iziguli zakho ezikutshela ukuthi zizibangela incindezi noma ukwethuka?

2.3 Can you share a typical story of how your patients make sense of their sadness and anxiety? **Ungasixoxela ngokuthi iziguli zakho zikuchaza kanjani ukudabuka nokwethuka kwazo.**

Note to interviewer: in this section, please note down some of the key things that they describe as linked to their sadness/anxiety below. You will need these for the following section

Sadness/ukudabuka

Anxiety/incindezi

Section three: Coping and appropriateness of support

Isigaba sesithathu: Ukubhekana nokulungela usizo

3.2 How do patients respond to the support you provide? **Iziguli zibhekana kanjani nosizo olunikezayo?**

Section four: Understandings of medical discourse, relationship between mental health and HIV

isigaba sesine: ukuqonda ukuxhumana kokwelashwa phakathi kwesifo senqondo negciwane lesandulela ngculaza

4.1 Sometimes psychiatrists use different words to talk about what we've talked about today, like anxiety and depression. Do you know these words? When was the first time you heard them? / **Ngezinye izikhathi izazi zezifo zengqondo zisebenzisa amanyeamagama ukukhuluma ngalokhu esikhulume ngakho namuhla, njengokudabuka nencindezi. Ungangitshela ukuthi uqale nini ukuzwa la magama?**

4.3 What does the term "Mental illness" mean to you? / **Kusho ukuthini kuwe ukuthi 'Ukugula kwengqondo'?**

4.2 What does the term "Mental Health" mean to you? / **Kusho ukuthini kuwe ukuthi 'Impilo yengqondo'?**

4.5 What is your understanding of the relationship between mental ill health and HIV? **Ubuqonda kanjani wena ubudlelwano phakathi kokugula ngenqondo ne gcewane lesandulela ngculaza?**

4.6 If someone from the community comes to you because they are sad or anxious about their HIV status, what are some of the ways that you help them?

Uma othile emphakathini eza kuwe edabukile futhi ecindezelekile ngenxa yesimo sakhe mayelana nesandulela ngculaza, iziphi ezinye zezindlela omsiza ngazo?

4.7 How do they respond to what you do?

Bazizwa kanjani kulokho okwenzayo?

5.2 What happens if you cannot help someone who comes to you for their sadness or anxiety?

Kwenzakalani uma ungeke ukwazi ukusiza umuntu ofika kuwe edabukile futhi ecindezelekile?

Section five: Understanding of Mental health policy in SA

isiqephu sesihlanu: ukuqonda inqubomgomo yempilo yenqondo yase SA

5.3 Do you ever work with doctors from the hospital? what is that like?

Wake wasebenzisana nodokotela basesibhedlela? Kwakunjani?

5.4 What is your opinion of mental health services? what are they useful for?

Uyini umbono wakho ngosizo lwempilo yenqondo?Kuwusizo ngani?

5.1 Can you tell me what you know about the mental health policy in South Africa?/Ungangitshela ukuthi wazini ngenqubomgomo yempilo yengqondo eSouth Africa?

Do you think you can play a role in mental health services? what would that be?

Do you think you can play a formal role in HIV support? what would that be?

Closing / Ukuvala

You have shared a lot with me today. Can you think of any other stories that you would like to share? / **Ungitshela okuningi namuhla. Ungathanda ukucabanga ngenye indaba ongangitshela yona?**

APPENDIX B: COUNTRY LEVEL ETHICS APPROVAL



RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE: 031 260 3587
EMAIL: Ximbap@ukzn.ac.za

13 October 2010

Ms. R Burgess
School of Economics

Dear Ms. Burgess

PROTOCOL REFERENCE NUMBER: HSS/0794/010D
PROJECT TITLE: Re-presenting mental health: Integrating multiple meanings in responding to the mental health needs of AIDS affected communities in South Africa

FULL APPROVAL NOTIFICATION – COMMITTEE REVIEWED PROTOCOL

This letter serves to notify you that your response in connection with the above study has now been granted full approval by the Social Sciences & Humanities Research Ethics Committee:

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol

Yours faithfully

.....
PROF. S COLLINGS (CHAIR)
SOCIAL SCIENCES & HUMANITIES RESEARCH ETHICS COMMITTEE

cc. Supervisor – Dr. C Campbell
cc. Dr. A Misselhorn



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Reference : HRKM166/10
Enquiries : Mrs G Khumalo
Telephone : 033 – 3953189

27 October 2010

Dear Ms R Burgess

Subject: Approval of a Research Proposal

1. The research proposal titled '**Representing mental health: Integrating multiple meanings in responding to the mental health needs of AIDS affected communities in South Africa**' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at **Manguzi Hospital**.

2. You are requested to take note of the following:
 - a. Make the necessary arrangement with the identified facility before commencing with your research project.
 - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mrs G Khumalo on 033-3953189.

Yours Sincerely

Mrs E Snyman
Interim Chairperson, Health Research Committee
KwaZulu-Natal Department of Health

Date: 01/11/2010

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

APPENDIX C: SAMPLE INTERVIEW TRANSCRIPTS

Transcript community PT ID 121359 11.nov.2010

I: Hello mama.

P: Hello.

I: How you doing?

P: I'm good.

I: Thank you for allowing me to talk to you, I will ask you some few questions so that I can learn more about you.

P: Yes.

I: Where were you born?

P: In this area Kwandaba.

I: Do you have any brothers and sisters?

P: My brothers passed away.

I2: How many were they?

P: 6.

I: How did they die?

P: They had this disease.

I2: Come again.

P: HIV.

I: How long ago were they sick?

P: It was not that much long because the 1st one got sick at Mtuba and the others were sick on the following year aah same year when the one is sick this month the other one will follow and one passed away on the following month will be burring another one.

I: Did you take care of them?

P: Yes.

I2: How many did you look after?

P: 4 because the other one was having his wife.

I: How was that?

P: I was hurt.

I: Very sad?

P: I was very sad.

I: Do you still think about that?

P: A lots.

I: Can you tell me a little bit how was it taking care of them?

P: I took them to clinic and they did not tell what was wrong not until they were about to passed away and the mentioned that are sick because of this.

I: How did you cope with this? Did you do it for yourself or received help?

P: I did not get any help.

I: How did you feel for not receiving help?

P: It really hurts me because they left me with their children and I don't have anything while I'm supposed to look after them.

I: Are all this kids your brother's children?

P: These are mine but they live with my mother, their grandmother..

I: Do you help to take care of them?

P: Yes.

I: When you were sad about your brothers did you talk to anyone?

P: I did not talk to anyone.

I2: You did not talk to...?

P: I used to talk to my husband...iesh the death of my brothers really hurt me because I also think of how I am going to die. I also talked to my mother.

I: Are you sick?

P: I don't know and for now I don't know whether I'm sick or not.

I: Are you worried about getting sick?

P: Yes.

I: You said you talk to your mother?

P: Yes.

I: Tell me a little bit about your mother?

P: My mother lives in Manguzi with the kids of my sisters.

I: Sister! How many sisters do you have?

P: 6.

I2: Are you sisters alive?

P: They all passed away.

I: How did they die?

P: I have already mentioned.

I2: I thought you said your brothers!

P: No 1 brother and 4 sisters who passed away.

I2: How many sisters do you have mom?

P: We are 6 in my... 1 is... I'm just left alone.

I2: Yes.

P: I can say we are 7 and 5 has passed away and we are 2 who are alive.

I2: How many brothers? You said you have 6 sisters and 1 brother?

P: Yes.

I2: And that brother passed away?

P: Yes.

I: All from HIV?

P: Yes.

I: So your brother's kids are with your grandmother?

P: Yes.

I: And your sisters kids?

P: Close to their grandmother.

I2: How?

P: Because my sisters are old and close to grandmother.

I: Which one of your siblings still alive your sister or your brother?

P: Sister.

I: Do you talk to her?

P: Yes.

I: Where does she live?

P: At Ndaba area.

I: Do you talk about your sisters and brothers?

P: Yes.

I: Does that help you feel better?

P: Yes I feel better even though I don't really accept it because there comes a time when I think that we were many and we are only 2 now.

I: It still makes you sad?

P: It's not healed yet.

I: Can you tell me a happy story from when you were a child?

P: (*Laughing*) it was nice because I was young and life was good at home.

I: How was life like and what did you use to do?

P: I use to play.

I2: Anything that makes you happy while you were still young?

P: I really forget. (*Laughter*)

I: How long have you leaved in this house?
P: When did we live here father? We build this house on 2007
I: Where did you live before?
P: Live at Ndumo. We came here on 1987.
I: Did you go to school?
P: Never.
I: How long have you been married?
P: (asking the husband) when did we get married? 2008.
I: Were you married before that time?
P: No.
I: How many kids do you have?
P: 6.
I: Are they for this husband?
P: Yes.
I: How old are your kids?
P: Tell me (Mhloko husband) we get married on 1987? The 1st born on 1981, Dumisani 1988, Zinhle 1995, Bongumusa (laughter) I don't remember, but we do have their certificates.
I: Okay, do they go to school?
P: Yes not this one.
I: What are the two best things about your life right now?
P: I'm receiving grant and living on my own house.
I: What grants do you get?
P: Child support grant.
I: What are the two hardest things in your life?
P: The hardest things about me and my life?
I2: Yes.
P: My husband is not working.
I2: What else?
P: As you can see that house, we all sleep in it.
I2: How many of you?
P: 7 and children.
I2: How many adult?
P: 7.
I2: And how many children?
P: 7 an old boys are 3 and a girl.
I2: They are 7 11 in this house.
I: Who is it? 6 kids and who else?
I2: You said 6 kids and other 4?
P: For my sister's children.
I2: Are they living here?
P: They visit and leave.
I2: How long do they stand if they had pay a visit?
P: A week.
I: And when they are here they are 11?
P: Yes.
I2: Have you included your husband and you in that eleven?
P: No.
I: How many kids does your sister have?
P: 3.
I: So that is 9?
I2: You and your husband, who else?
P: Vusi and Dumisani.
I2: How are you related?

P: My children.

I2: How many kids do you have?

P: 6. (Laughter)

I2: Okay, we won't include 6 kids and who else your 3 sister's kids, you and your husband. Is there anyone else?

P: No.

I: All in there?

I2: Yes.

I: How does that feel?

P: Even though I'm not upset, but it hurt because I can't even build a house or our room with my husband so that we can be free.

I: Do you get grant for your sisters kids?

P: No grandmother is the one who is receiving grant for them.

I: How do you take care of you sisters kids?

P: If they are running short of something example soap they call me and I give them because what they getting is too little.

I2: Are you working?

P: No I'm not.

I: How does that makes you feel?

P: (Unclear 21:54)

I: What are your daily activities? Can you tell me?

P: I clean the yard and go to the field.

I: Who does the cooking?

P: My daughter use to help me when she's back from school.

I: Which daughter? The oldest daughter or?

P: The one in between.

I2: We use to ask people about the help they receive when they not feeling better. Can you tell us a story whereby you needed help and you speak to nurse? Have you eve talked to nurse when you needed help?

P: Yes.

I2: What happened?

P: I spoke to a nurse at the clinic because I was not feeling well on my body inside and outside

I: In your chest?

P: The whole body.

I: What was that like?

P: My body was weak.

I: What was happening around that time?

P: I had symptoms that I did not understand.

I2: Like what?

P: Umhlume.

I2: Is that all?

P: No.

I2: What else? Where does it occurred umhlume?

P: In my private part.

I: Was it hurt?

P: Yes.

I: What other symptoms did you have?

P: Nothing.

I: What were you doing in your life around that time?

P: Nothing.

I: How long did you feel the pain?

P: The whole moth.

I: What did the nurse say?

P: She gave me pills to have more strength.
I: Were you worried about anything around that time?
P: No.
I: Did the pills work?
P: Yes.
I: Have you felt like that again?
P: No.
I: When was it?
P: August.
I2: This year?
P: Yes.
I2: Have you talked to psychologist?
P: No.
I2: What is the reason or you never needed to?
P: Didn't need to.
I2: Have you ever talked to a doctor just doctor?
P: No.
I2: Why not?
P: Because I knew that if I have spoken to sister it won't be a problem.
I2: Have you ever called a toll free number when you needed help?
P: No.
I2: What is the reason for not talking to them?
P: I don't have.
I2: Have you ever talked to home based carers?
P: No.
I2: They visit this home?
P: No, I never see them.
I: When you were taking care of your brothers, they never helped you?
P: No.
I: Do you know why?
P: I don't know.
I: Would you want to?
P: Yes I needed them.
I: Did you know where to find them?
P: Yes I know.
I: Did you ever asked?
P: No.
I: Why not?
P: I don't have a reason.
I2: Have you talked to social workers?
P: My mother spoke to them.
I: About what?
P: About the children that they should receive help.
I2: Your sister's children?
P: Yes.
I: Did the social workers help?
P: Yes they helped her.
I: What did they help her with?
P: They helped her with food and after with money and they has stopped handing food to them since they getting money.
I: They helped you to get a grant?
P: Yes.
I: What was that like?

P: I was very happy because I knew that my sister's children will live a good life.

I: Did social workers help you to get grant for your kids?

P: Yes they did.

I: How was it like was it easy or hard to get grant?

P: It was hard.

I: Tell me about it.

P: As I have told you that my husband is not working, so I went to social workers and I told them and they helped me to get certificate.

I2: They helped you get grant or birth certificate?

P: Grant.

I: How did you feel that time?

P: Life was not easy.

I2: How?

P: *(Laughing)*

I: Were you very upset?

P: Yes.

I2: Have you talked to your friend when you needed help?

P: Yes.

I2: You talked about what?

P: When I don't have salt I will go to her.

I2: Have you ever had a situation whereby you really needed to talk to your friend?

P: No.

I: What else do you talk about?

P: Nothing.

I: Doesn't talk about how you feel or worried about?

P: I talk about my family, house and how am I going to support them and my friend will tell me to calm down and be patience things will work out for me.

I: Did that help?

P: Yes it did.

I: Do you still talk to your friends about that?

P: No I don't.

I: Why not?

P: I have realized that I am old and need to accept other things

I: You think it not good to talk to people?

P: Just that you have a problem and you always go to your friend, you need to let it go even though it is hard.

I2: Do you still talk to your friends?

P: No I don't.

I2: Why you don't talk to them or is it because you see that there is no need?

P: Yes.

I: Why?

P: Nothing.

I2: Have you talked to a preist?

P: No.

I2: Reason?

P: I don't have.

I2: Never needed to or they pray for you?

P: They do pray for me because I ask for a prayer.

I: Who?

P: A group of women at my church.

I2: How often do you see them?

P: It usually happens on Saturday.

I: Every Saturday?

P: Yes.

I: What did they do? They pray and what else?

P: They just pray.

I: Where do you they meet?

P: Church.

I: What do you pray about?

P: When you not happy in your life you just ask them to pray for you so that you can get through it.

I2: What are those things that hurt you in your life? What they do in church?

P: They pray all together if you not well emotional.

I2: In what?

P: If children abuse you.

I2: They abuse you?

P: No they don't.

I2: Do you have something that really makes you sad?

P: No I don't.

I2: Okay, have you spoken to a traditional healer or faith healer?

P: No.

I: Why not?

P: We don't talk to traditional healers, but we only speak to God.

I2: Have you talked to support group?

P: No.

I2: Why you don't talk to them?

P: No reason.

I2: Did you need them?

P: No.

I: A church group is a support group?

P: Yes I only speak to them.

I2: What do you talk about?

P: How to take good care of your home.

I: What else?

P: Nothing

I: What does that mean and what does that have to do if they say to behave like an old woman?

P: It means that's since my husband is not working and he ask even a short to wear just because I'm receiving grant for children if I am not receiving this grant how would life be!

I: And that is what worries you?

P: Yes.

I: Do you talk to other women about that?

P: Yes I do.

I: Do they have similar problems?

P: Yes they do say their problems are similar to mine, but they also tell me to accept and let it go.

I: Does it help talking to them?

P: Yes because I feel better afterwards.

I: How often do you talk?

P: Not always maybe 3 times a month.

I2: Other part of this research talks about fear, being nervous, depression or being ashamed. Can you tell me a similar story to that one and tell me what was happening in your life in that time

P: I was nervous when you called me and I asked what I have done.

I2: Anything else besides this one?

P: When I'm sitting I feel as if someone is coming behind me even though there is no one

I: What are you afraid of?

P: Afraid that if grant can stop what can I do, even though I go to field and sell but still it is not enough.

I: Is there any other thing that make you worry in a similar way?

P: No.

I: You spoke about your brothers and sisters death that it really hurt you. Is there anything else?

P: Nothing else.

I2: Other part of this research talks about being upset and angry can you tell us what was happening in your life when you felt this way since you spoke about your brother?

P: Worried that if my mother can pass we have to take good care of these kids.

I: Is your mother sick?

P: She is very old.

I: Do you take care of your mother as well?

P: I use to visit Manguzi and pay her a visit.

I: Do you see her now?

P: Yes.

I: How often?

P: Twice a month because I'm married and my husband won't allow me to always pay her a visit. I even call them if I don't make it out with visit.

I: How do you feel about that?

P: Not okay at all even though my sister's kids are old, but my mother life is not well because she is old.

I: Your mother is taking care of how many kids?

P: 6 children that she is living with.

I2: What is it that makes you sad in your life?

P: Nothing (*laughter*)

I2: Are you working?

P: No I'm not.

I2: How do you feel about that?

P: It doesn't upset me because I am not educated, but I like working.

I: What do you like to do?

P: Work in the field.

I2: Anything else?

P: No.

I: What did you grow in the field?

P: Meals, sweet potatoes, mfino.

I: Do you sell what you grow?

P: Yes I do.

I: Where at the market?

P: Market.

I: Anything that makes you anxious beside the grant?

P: Nothing.

I2: How many are receiving grant?

P: 5.

I2: Is that money enough?

P: No its not!

I2: Husband is not working, how do you feel?

P: Unhappy.

I2: Anything else?

P: Too many questions

I2: You said if grant can stop and if you can your mother can die those are things that make you unhappy when you think of it. Is there anything else?

P: No.

I2: How do you deal with the fact that your husband is not working?

P: Very hard because we rely on grant.

I: How long he been without work?

P: He was working at EGoli and he came while that child was young.

I2: How old was that child?
P: Maybe 1.
I: How old now like 17...how old now?
P: Born on 1995.
I: She's 15 and he hasn't been working for 15 years and when did they get grant?
P: I don't know because I started with this one while she was 1 year old and it was only her who was receiving the grant when my husband loosed the job.
I: It was hard?
P: Very hard.
I: So you not sad anymore because...?
P: Yes because I also receive grant for other kids.
I2: How do you deal with being unhappy?
P: It very hard because I have to support them and make sure they have something to eat.
I2: How do you deal with that?
P: Very hard.
I2: What is it that you do to face those challenges?
P: I go to field and sell.
I2: Is there anything else you do?
P: Nothing.
I2: Earlier on you spoke about nurse, who helped you, how did it help you?
P: They advised me.
I2: How?
P: Even though I did not get anything, but I was helped through that.
I2: You said you talk to your friend?
P: Yes.
I2: How does it help you?
P: She advise me sine we are not working that we should work on the field.
I2: Who came with an idea of working in a field is it you or your friend?
P: I came with an idea.
I2: How does your church group help you?
P: How?
I2: If you are upset.
P: We pray that is how it goes in my heart.
I2: How do they help you?
P: About what food or advice?
I2: Yes.
I: How?
P: They (gave me advice) advice me and we talk.
I: Talking and pray okay.
P: Yes
I2: What do you think can help you deal with the feelings that you have – your sadness in the heart, anxious and nervous?
P: If the government can build a house for me because I don't have means to build a house as you can see the house that we are living onto.
I: Who build this house?
P: Husband.
I2: Anything else?
P: My children are going to school, but after completing they will need to further their education and I don't have power to further their education, but if the government can help me on that.
I: Do you worry about that?
P: Yes.
I: All the time?
P: Yes.

I2: Sometimes doctors use words that we have spoke about today, depression and anxiety. Have they used these names on you?

P: I heard them from the doctor.

I: When did the doctor talk to you about this?

P: When I visited the doctor while I was not well emotional and he find that I have umhlume.

I2: When did it start and what did doctor told you?

P: He gave me pills.

I2: When did you heard of the name anxiety?

P: When he checked me and he spoke in English and I dint know what he that mean.

I: Did the doctor explain?

P: No.

I: Was it a doctor or nurse?

P: Nurse.

I2: What does this mean to you, to be mental disturbed?

P: Your mind is not working.

I2: Have you ever heard of this name or do you have people who are mental disturbed in your community?

P: Yes a boy a they even tell that he is mental disturbed.

I2: What do they say about him?

P: They say he is mentally ill.

I2: What is he doing?

P: Insane.

I2: I mean things that prove his mentally disturbed?

P: You can tell that his insane.

I2: What does community say about this person?

P: I don't know.

I: What does he do?

P: Eat dirty things.

I: Man or woman?

P: Man.

I: He eats from the ground?

P: Yes.

I: What else does he do?

P: Chasing people.

I2: Anything else he does?

P: Nothing.

I: Do you see him.

P: Yes he lives on that house.

I2: What does a health mind mean to you?

P: Means your mind is working and its health.

I2: Have you heard of this name in your community?

P: Yes.

I2: What were they saying about it?

P: I heard those saying Magumede have a good mind

I: People say that about what?

P: I don't know that question.

I: Do you think you mentally health?

P: Yes.

I: Why?

P: You can see the one with a health mind.

I2: What is it one does to show that he or she have a health mind?

P: Cook and do everything and you can tell that he or she has a health mind.

I: Is it because he or she can do everything she or he needs to do?

P: Yes.

I2: You told us a lots today can you think of a story that you want to tell us?

P: No I don't have! (*Laughter*) I want to know what is it that I will get after having so many questions.

I2: No direct benefits, but after this survey all the community will benefit just because you spoke on behalf of them.

P: That is why I was called. We don't have electricity, water and a house and that upset me. My kids are still in primary thanks because it close to us, but High school is very far they will have to move out from this house to a place where it will be close to them and I will have to pay.

I2: Do you have anything else?

P: That is all.

I2: Thanks for all the information you shared with us. All this will help your community and thanks for taking part in this survey

P: Thanks.

Chief Occupational Therapist, Manguzi hospital 15.11.2010.

I: Thanks again for chatting with me today we've done a lot of off the record chats, and they were really really helpful and because of that I thought you would be an ideal person to do an on the record chat with. Just to give you a bit of background again on what the study is looking at again, we- I – am trying to get a better idea of how mental health services work at the hospital, and your role within that, and your experiences in dealing with typical and atypical cases, and some of your thoughts of what 'mental health' is and how its' defined. I'm going to ask some easy questions to start, if you have any questions you can interrupt, if you feel like stopping, you're free to do so.

A: (laughs) I'll try my best

I: ok. So what is your official title?

A: Chief occupational therapist

I: And how long have you worked at Manguzi hospital?

A: since 2006

I: and where were you before that?

A: at Dundee hospital.

I: and where was that?

A: in rural northern Natal, its not as rural as this, but it's also... it's a small hospital there.

I: were you chief occupational therapist there as well?

A: no, I only became chief occupational therapist in September of this year.

I: so you've been working your way up. right on

A:yah.

I: so what made you want to become an occupational therapist?

A: (laughs) I wanted to study medicine. And when I went for all those aptitude tests and career pathing and all that kind of thing, they told me I'd be pretty bored as a doctor because I have a creative side. and I mean, what do you know at 16 about what you want to be, and all that, because I really wanted to be a doctor. But they said if I still wanted to stay in the medical field but have something a little more creative, I should look at O.T. So I didn't know what O.T. was, so I went and had a look at a hospital, and it's actually, really funny, it's our psych referral hospital, it was Madadene – so I went and spent a day at Madadene, and I was scared out of my witts, (laughs) it was really scary to see what was going on there. And I didn't think I wanted to be an O.T. anymore so much, but I still applied, because my mom thought it was a good thing to do. And I had been accepted to study interior design, so I was quite happy to go and do that. And the selection process for O.T's are quite stringent - or strict in this country, only 30 get selected and you have to go for psychological tests and evaluations and all of this kind of thing, and... I got selected as one of the thirty. So my mom was like it's a sign, you have to do this. So I thought, let's give it a bash, and yeah. So that's how I got here. So, there was no like "I want to help people for the rest of my life" kind of thing. It just happened.

I: a fortunate kind of accident.

A: (laughs), yea, it was, I don't regret it at all. I wouldn't change it for the world.

I: can you tell me what your first impressions of Madadene were like?

A: Ok I will be honest with you – they showed me the ward where the CP children were in cot beds, the sides were up, there was no one in the ward, there was no –eh, it was hot, it was stuffy, these kids had no toys no visual stimulation on the walls, it was the saddest place I've

ever been. And then I went to the where they have their geriatrics and dementia and that section, and we played a memory game with them, and the Gogo's were put into two groups, and they said ok, you guys are the lions and you guys are the elephants, and then we stuck two pictures on the wall, and they had to remember what the pictures were, and the team that remembered they were the team that won. It was a very simple memory game. And I thought it smelt terrible, and I thought "oh my gosh, I'll never work at Madadene" and then here I am at a government hospital. So, yah.

I: and do you still have much interaction with Madadene now?

A: no, no. I just know that we refer them (psych patients) there. And the reason why I didn't go to private O.T. was because I didn't think I was going to work in private for a long time after I studied so I wanted to see how a government hospital was going to be like, and Madadene was the closest one with an O.T. Department.

I: and how many hospitals have an active O.T department?

A: most of them. It's supposed to be a service that is um, like - provided - um, but with community service placements, it's been able to implement a lot at many rural hospitals, because they haven't been able to send people everywhere, because people don't want to go there. So with this com serve thing, it's really grown the O.T. services, or Rehab in general really.

I: and how long has com serve been required?

A: I believe it's been - I think it started - I stand to be corrected - I think it started in 2004... 2003-2004 was the first year you had to do community service for one year.

I: is that how you came out here as part of your community service?

A: No, I did my community service at Dundee, that's where I was posted. You get five choices, and you are allowed to select five choices, where you'd like to go. And then, on your five choices, you either get one of those, or you get second rounded and you get what's left.

I: and so, how different was Dundee to your experiences here?

A: Vastly. Manguzi had an already established therapy department, where as Dundee didn't have one. They had one - physio that came, and then left because of com serve, and then there was no one there again, and so service was never continued. So every time someone came and started something, it would break down. Whereas when I came here, Jabo was the O.T. here, she's the district rehab coordinator, she had been the O.T. here for maybe ten or more years, before I came. Maryeka had been here since 2003, 2002 - so the all the networking and like, the relevant stakeholders how we could make this rehab services really get everywhere was already done. So when you came from somewhere like Dundee, where you started seeing a little bit of working with the community rehab facilitators, or with the mobile clinic and that kind of thing, whereas here, you came here, and everything was done. you already had all those avenues to go down and , it was just - a lot, you could really see how rural rehab could work, coming to a place like this where the ground work had been done. So , that was, -yah, community rehab here was an eye opener.

I: right. I can imagine

A: and Maryeka just phoned me up one day, and we're still not sure how the universe put that in the working, but she just phoned and said listen I believe you're looking for a job, and we have one for you. And I said, yah I am looking, it was already November, and the whole year is coming to an end, and I didn't know what to do after com serve, I didn't want to go back to the city, or a city. And she said we're right on the Mozambique and south border, 20

kms from the ocean, a rural hospital setting, this is the kind of stuff we do, And I said, Sold. I'm in. and yah, (laughs) that was that.

I: so can you tell me what a typical day at work is like for you?

A: half past seven, you arrive – you usually try to do whatever adminy stuff you can, try to get it done in the morning because otherwise the day just runs away. We have meetings on Monday mornings, we have quality improvement meetings once a month. Umm, we have... in services, from like, either multi disciplinary services or in our own disciplines. Then we have Ward rounds, with a bit of a ward audit is done on Monday, to see who's there, what's left, what happening with the patients. And then, then you just start seeing patients, whatever is on the bench. Sometimes you have to go to clinic – I go to six clinics in a month, so my time, yeah, I go to clinics quite a bit. And then, the rest of my time is spent here, either in OPD, clearing the bench, and seeing different things like high risk babies that are discharged from the hospital, to CVA's hyperactive children, children with learning disabilities, it can really be anything that's O.T. related. In the last two weeks we've been seeing a lot of mental health care users coming through here. Everything, so you can't really see you see a lot of that, or yah.... Age groups, predominantly I see children, from ages 0-6, and 7 -17 so then school aged. Umm, and then, the wards obviously, there is a MDR-TB ward programme that runs, so sometimes I'm involved in that. And then also I have to do some managerial tasks, sometimes, but I'm not so good at those yet – I don't find myself sitting at my desk when there's patients to be seen, I'd rather just see patients and do management stuff a little later. But its like policy development and making sure we're following evidenced based practice and that our things are up to date. I audit all the files to make sure that the children who are discharged are going out, but I need to work at that definitely. (laughs)

I: So what are the top five reasons why people come to you for support?

A: for treatment? Like condition wise? like what sort of diagnosis do we see?

I: yah.

A: ok. Well I would say, the first one is developmental delay, we see a lot of that, I think that's very closely related to the education level of parents here, and also just HIV endemic is hectic, cuz' that also affects it. So I say developmental delay. And schools, like scholastic problems, not passing, learning disability, needing a special school placement, needing a school assessment, needing an IQ assessment. Um... Number three, would likely be burns, like, physical things, lots of kiddies come in here with burns. Four is hand patients – different hand conditions flex tendon injury, extensor tendon, trigger fingers, anything, osteo arthrists, and rheumatoid arthritis, anything with the hand we get to see here, this is the splinting area here. And then 5, is DG's. Grants – social grants.

I: so a lot of grants

A: yah, like because we do the child disability grant here, and the adult disability grant, and we do the grant in aid. So I would say we get grants, it's - grants are quite a biggie for us.

I: so when someone comes to see you for a grant, what's the process that they have to go through, what role do you play in that?

A: Well it's changed significantly. We used to do an assessment here, at the therapy department on really what could be done at home: can you carry water, can you plow a field. like It wasn't a standardized assessment, but of the activities you do at home – for example, we have that thing – what do you call it, a mortar and pestle, but it's just massive, and we would see if they could do actual things here, and then you know, comment on their ability to do it at home, and how the condition affected that. I think it was a little more of a holistic

thing, but it took a lot of time. And it wasn't always relevant, because a lot of people malingering, and try to get the grant. But now, all we do is furnish the SASSA office with a medical record history – So, what a patient does, is they come here, often they are therapy patients, or they have been seen by therapy, um, we go through their medical records, fill in the relevant details, and – can I fetch you a form and so you can see what it looks like?

I: Yes, please sure

A: so a patient gets this form from SASSA with their personal details in there, they need whoever is applying for the grant's fingerprint and signature or print on every page. You fill in what hospital you're from, the relevant clinical history, the medical tests and results, if its' applicable, like lab results, this is more if its a medical thing, for the doctors I think. Diagnosis, what we're going to do, what medication they're on, what their compliance is like, how long have they've been on treatment, what the prognosis is, when last they were admitted to hospital, what is the management of the current condition, then you just sign it, and say that it's the truth, and they have to attach a copy of their ID, and I attach the psychological report to that, because its relevant to the condition. Then this form is taken, put in a box here, at the end of the week its' taken down to Dr. Emiminan, or hte medical manager reviews all of these forms, to see they've been filled by the relevant person, and and and, then it gets taken to sassa, the patient is told that they have to wait three weeks, then go back to Sassa. Then Sassa will tell them when their date is to see the doctor.

I: Ok.

A: Now, they outsource that doctor, because the hospital doctor used to fill out the Sassa forms, and it was just, it was just quite bad – they would flock here and it was a lot of people. Now they outsource it, this particular lady, who was here, she actually went a few weeks ago, and the doctor had flown in, with the air mercy services, and the plane was leaving, and he said "sorry guys, those of you who are here today aren't getting seen" and they never saw their forms again, and the doctor left on the plane. So she was very worried, because she doesn't know what happened to her form, and she doesn't now know what to do, so she came to start the process all over again.

I: Oh gosh

A: So this happens a lot, sending the patients back and forth between SASSA and the hospital with these forms, Sassa says they need a letter, we say – uh, its been a real headache. This is the care dependency grant, this is for children who are disabled. So this part is filled in by the doctor, and this part is filled in by the O.T. So that's where the doctor comments on the medical, and you comment more on the functional – what the child can do ADL wise, Activity of daily living – communication, understanding, and at the bottom there, there are blocks that say full time care, part time care, able to care for themselves, or refer for further assessment. If you mark any of those ones, and not the full time care, the patient will not qualify for the CDG. That's what we've realized from past experiences. You might have a CP child who is hemi, and able to assist with dressing and assist with most things, and will not be able to be independent in life, and you mark part time care, and the patients grant will be denied. Eventhough all the information is there, usually a person sitting at SASSA, is not a medical doctor, and they can't make that judgement

I: Right

A: so now the medical doctor is there and is able to do that. Anyway I think that's good, and in a way, it's not so good. But so yah, that's the DG part of it.

I: ok. So you say you've seen a lot of mental health care users that you see coming through here. Can you talk about a little bit about that, maybe some of the typical patients that you see.

A: Most of the time, its depressed – depression. umm... and I don't know...hyperactivity in children probably isn't diagnosed as a mental health care issue, but we see a lot of that. But in adults we see a lot of depression, and chronic schizophrenia. yah. Those two are the biggest ones. They'll come in, and in your interview or assessment, you'll find - and they might be coming in with something like chronic back pain or for a DG, and when you start asking questions you find that the thought processes are very negative, there are no positive thought, there's no way of seeing, it's either living in the future or living in the past, yah, it's very negative. So and they don't – most patients don't understand that they are depressed, they don't understand that it's a sickness. It's just the way they feel, that's the way they are. That would be the majority one. And then intellectual impairment is also a big one. And I know there's not really any medication for that, but sometimes with behaviours, we don't medicate, but psych medicates. But here, what we advocate for is obviously schooling – what can we do skills training for the adults, really looking at making sure that they are safe in terms of reproductive health and safety, so that's what we advocate for here in terms of intellectual impairment.

I: Do you have the capacity to do skills training here?

A: I wish we had it here but we don't. we have some centres that we outsource, or send our children to, or rather our young adults to, because children don't go to skills training here, it has to be the young adults. We have one in Dundee,that we've placed people at, and there's one new center that just opened up in Empangeni that sounds very promising for us. Then we have a technical high school, but you need to be mild to borderline Intellectual impaired, and have a grasp of English to go there, so that's a little bit tougher to get in, but you learn technical skills like mechanics and fitting and training and all that kind of thing. At Dundee adult center where we've placed, the skills they learn there are more basic- cooking, sewing and beading, they have a workshop where the men sand down and restore old furniture, so that's the kind of thing more hand work and that kind of skill. And they also learn some money management, and how to look after their finances at the Dundee adult center. so that's been a really nice resource for me, because I'm from Dundee, and I had built up a relationship with that center when I was at working there as my community service, and I tried my luck when I got here and they said sure send some people down.

I: so how many people are you able to send? Are they able to get there easily?

A: yah, so we access a social responsibility budget through discovery health, umm, that ZUMAT flights, with Zuluand air mercy transport – and ZUMAT will pick us up here at the landing strip, and they will fly us to Dundee for the assessment, and I have not flown anyone there for a placement, because I went there and took them with me, then the placement is usually done. But for the assessment yah, ZUMAT will fly us there. We have placed three or four people there in the past two years. Two of them have not gone back, because they didn't like it – can imagine that it's very easy for an IP person to sit at home and rather and do nothing, than it is to go to a centre that's away from home where you have to learn independence and do all these things. Often the parents want that for their children, but as soon as the child is gone, and they aren't' children, these are young adults of 19-25, the ones that we've placed. It's tough, because you do all that work, and then they just come back.

I: yah.

A: and then the grant is stopped. Because we have a policy that if you aren't doing anything with the grant money, it's supposed to be helping you, you need to either show us that you can save the money, that you are building a house, that you are looking after yourself, in the future when your mom and dad may not be there, and you can prove that's happening, great. but if there is miss management or abuse of the DG, then it's usually stopped until the person can come and sort it out. Cuz otherwise you find that IP person is not seeing a cent of that money, they live in a little room in someone else's home, and what happens when his own family passes on – he has to have provisions for the future, a care giver needs to be identified and that kind of thing.

I: how often do you stop grants and that sort of thing?

A: well, we don't give a grant until the child, or young adult is placed. So even children on special schools list, once the child has gone through the assessment, and the school says yes, your child can come to the school, then the grant application - or even when the assessment is promising, and we say we can admit five of the children we asses- and then we start the process, and we are able, in, its not the norm, but in the cases where the child has to go back to school and the grant has lapsed, or they have found a special school and need the grant in a hurry, we can do that. There is DG grant book right here at the hospital, a doctor can see a child, you do your assessment and it's done. So it doesn't have to take a month, it can be fast tracked, but it's not the norm, it's for those emergency cases.

I: So in terms of those patients, where you see a lot of depression, what are some of the ways you support those patients – can you support them?

A: it's usually trying to get them to identify what it is, what are the stresses in their life. Working in a cognitively behavioural therapy based way. Identifying that which makes you sad, that which makes you stressed, that which is not nice, and trying to change your thoughts around that, and trying to make that (thinking)positive. And it's quite a challenge working with people...who are not educated, and to change that. Because often, they are so... they can't see what can be good from the situation. So it takes a while, for them to do it daily, and if you can't see them everyday, and its' quite difficult to see and make sure that they're doing it. We have home based care that we can refer to, and I think, tomorrow's there a home based care meeting, and its' going to deal with protocols and policy for treating certain conditions in home based care, and I'd like to see what they say about mental health care, because i think the home based care team that goes out now that has one of our CRF's in the team, don't have a psych nurse, don't have a social worker - how much can that home based care team do for a MHCU I'm not sure. We do have from past experiences, a lady that worked in HBC, who had an accident, but had to come out of HBC, who still knows exactly where her MHCU's are, and she's so on the ball referring them in if there is a problem, and if they default. So yah, we do work with cognitive behavioural therapy with depressed patients, trying to see if they can change it for themselves, their own thought patters, and then refer them to home based care, or Tholulwazi, or one of those support things. And what helps, but isn't always viable is if the patient is here with a family member. Someone who can support, and who can understand, what it is.that it's not just sadness and despair, its actually depression.

I: and in the cases that you can get a patient to understand that its' a diagnostic thing, that's it's a category help, does identifying it, giving it a label help them?

A: I think it sometimes helps when they understand that they can get medicine and it can help them to get better. a mood stabilizer that can help them, out of - and from there seeing themselves get better , that sometimes does help. Another one that we can refer to, is townhill hospital. That is a medical health care hospital in maritzburg, that's where the psychologists come from. Another thing that we can link to is the psychologists that come – the psychology clinic, they fly from town hill, and they come and see patients once a month. Usually that list is very full, but if you have an emergency, they will make time and squish it in.

I: how easy or difficult is the referral process to get a patient into town hill, or Madadene?

A: I have never referred someone to Madadene. Because of how the mental health care admission system works, with the forms, and you cannot have a patient for longer than 72 hours observation, you have to refer them out after three days, that's usually the doctor and psych nurse who's in charge of that part. But to get someone to town hill, it's in martizburg, that's very far away. We don't even have a bus to get our other patients who have to get to Nkosi albert. So it's on a patient's own steam, to get there. Otherwise they can get on the patient bus here to get to Durban, then get a taxi to petermaritzburg from there so it's quite a process to get a patient to town hill. Plus you also have to consult with the registrars and consultants whether or not there is a bed, and whether or not this is really a case for admittance there. So.

I: and how successful is the cognitive behavioural techniques, do they work? Do you find them helpful?

A: (pause.) Yes. They are helpful.

I: So that's a kind of training that could be used to beef up home based care.

A: Yes. and like (pause), there behavioural therapy, there behaviour is like, that because they think so negatively all the time. But I don't know if there is something more concrete, how you can beef up CBT with concrete stuff, so it's more concrete. I know there are things you can do basic mind exercises to think more positive about a thing, find a solution for a thing. but when it's an uneducated population, its' quite difficult when it's not tangible. When it's -

I: like 'the sun is shining today, that's a reason to be happy?'

A: exactly. Exactly.

I: what are some of the things that patients will typically relate to the cause of their sadness? if you get down to them thinking about what is making them depressed. What are some of the typical causation stories you hear from patients?

A: no money, no support. (pause) yeah. no money and no support, that's two of the biggies. I think financial stress is a really big one.

I: unemployment is a biggie here.

A: Its massive. so , its often you find someone coming in her looking for a grant, and the story comes out that there is no money. So money is usually the underlying factor or stressor.

I: what are your thoughts about the MDC? The multi disciplinary clinic?how well do you think it works?

A: I don't think it works very well – I think we need a doctor to be there. Because you can review a patient for months and months on end, but if you cannot change the meds then what are you doing? if you cannot prescribe or change the meds then what are you doing? I think it's good in the sense that social work, O.T. and the psych nurse know what's going on

in the community, know at which clinics most of the problem cases are and what we're trying to work towards is trying to start up support groups at the clinic for mental health care users. So that would be really good, so when you go to clinic, we go to a lot of clinics twice a month because of patient load. So with another therapist that we could dedicate to mental health, we could go with the psych nurse, and the social worker, and start doing groups at clinics, like cognitive groups, or starting more of the actual therapy – cuz at the hospital, they're here for three days and then they are out. So there's not a chance for the group to grow and develop cohesion and develop support system to be formed. I think just working together, the social work and O.T. - that clinic has so much potential to be a very good thing, but it's so frustrating for the psych nurse, as well as the rest of the team, that the rest of the team, the only people who are there are the allied health professions and nursing staff.

I: how likely is it that you'll get those support groups up and running? What are the main barriers to getting that going?

A: its really – time, and personnel – human resources. That's the two things that are biggies that are barriers to that. Because we used to have support groups in this area, the one mental health care user group started a chicken project, they sold chickens they had money, they came together they were treatment supporters for each other, they had their own little box with money, they never had a bank account, but I mean, that all fell to pieces when the CRF who was working here left and started nursing. It was one of his projects, while he was studying to be a CRF to start support groups in the community he did really well, he had a great insights into the MH population in this area, and what they wanted and it fell apart. So it's a big likelihood that it would be really successful. at Moswell, which is on the hill, in Embavuma, maybe three years ago, two years ago, they had very successful mental health care clinics, run at most of their clinics that was run by the psych nurse and it was really something that the whole district was very proud of, and was like wow that's amazing that you guys had that up and running. Like I mentioned before, we had those mental health care forums – that is where we learned about how they made their [clinics] work, and it was a great place, for learning.

I: can you tell me a bit more about the mental health care forums?

A: the mental health care forums were started in 2007, by – I wish I could remember her name, she works with Jabo, the mental health care coordinator at district level. And we did once a month, we had meetings, and sometimes it was once every two months, we had meetings where we discussed policy development, management of aggressive patients, what do they do what works, uh, successes like the clinics, support groups – we had (pause) yah, oh, like other things that hospitals did was get their MHCUs into a skills building programme, get them together started making things and sold things at a craft market it was really a platform for mental health care discussions.

I: it seems that a lot of the activities run by these support groups focused on income generation – would you say that's something that is almost pivotal in trying to respond to mental health care problems in the area? Particularly with depression and anxiety?

A: uh – I think it is pivotal, but I don't know if its' the most important thing. Because what is the point of teaching someone a skill if they can't do anything with it. So for me it would be ok if the person wasn't brushing his teeth or taking self care seriously, that he could now do that, but that would be a great skill, but they all want to do more – so yes, I'd say making

money, income generation, is a massive part of it. it's like an external motivator almost to do something, because I can get money if I do this.

I: do you ever hear stories about people who go to see isangomas for mental health related stuff in the community?

A: umm. That's interesting. I've heard of people going to isangomas's for epilepsy – but no I've never heard of someone going to a isangomas for mental health care – I'm sure they've taken people with schizophrenia, I'm sure of it.

I: right, but not for more common mental health care disorders, like depression and anxiety.

A: well I'm not sure that they are able to recognize it for what it is; so if it is something like anxiety or depression, I imagine that you would go to the isangoma and say I'm feeling like my ancestors are watching me, if you had an anxiety disorder, or someone has bewitched me, so who knows how many people are going out to see isangomas for issues like this. That would be very very interesting to see.

I: I am going to try to see some isangomas before I leave next week, just to see what people are talking about. Because my thought is similar to yours, in that I think that people are not conceiving of depression as something that is an illness,

A: right, they're no .

I: so they are talking about it in terms of the sadness or the lowness, or this thing in the stomach, or the shaking in the body and when they see the isangoma, that's what they are telling them. And then the isangoma will relate that too

A: The isangoma will relate that to ancestral stuff. Yes. While we here will go "oh you have a classic case of MDD- major depressive disorder. So it would be very interesting to see what comes out of that.

I: What is your opinion on the value of each [group's] opinion to the patient? do they think one opinion is more valuable than another

A: I think it has to do with their frame of reference, and their cultural mindset. And if you believe in that, if you believe your ancestors, and a lot of people do, and you don't see the western health care system as something to help you with that, then you won't believe that we can help you in the western setting. But if you fully believe in your isangoma and your traditional ways, then I think you'll go down that route. and a lot of people still do. They're quite sceptical of the western medicine here still. Because its still widely accepted to go to your isangoma. But I think if you understand that if ok, I do believe in my ancestors still and I should go to them to keep them happy and appease them, but the isangoma can't give me plaster for my broken leg or whatever, its' that – how culturally integrated are you, as a person, with your own culture. so I think that's what it is, knowing that western medicine also has a part to play, and a place. like anything. are um, you a little bit holistic?

I: yes

A: so in addition to a doctor, so maybe you will go to a reflexologist, someone who will balance your chakras – (laughs)so whatever it is. So in an uneducated area like this, you're just going to believe what your culture for years and years has been ingrained in you as this is what we do when we are sick. I mean, there is a little baby lying in Peads ward at the moment - you will get a fright if you see her. (sighs) she is very very sick, and she went and had a herbal enema, and started fitting after that. And this child can't open her eyes, her skin is peeling off her, its horrific. And the mom is so blaze about it.

I: is it?

A: yah, and she was so cheeky about it. I went in there this morning and I was like Sawabona, this is who I am I just want to see what's wrong with your daughter. And she was like "oh yah, I took her to a isangoma, and?" like challenging me to see what I was going to say about it. and I was like "oh, ok. what did he do?" Crazy woman - in my mind I said that.

I: I mentioned anxiety briefly before, do you see a lot of anxiety coming through the clinics and the wards?

A: um, I've seen an anxiety - I don't know if that's exactly what it is, but people are anxious about their statuses. And like, the lack of support. And how people are going to perceive them. and I can't be with anybody because I'm going to infect them, and people are thinking I'm infective and people can see I have got this thing and there's this real, like I can't speak to anyone and do anything because I have HIV and they're going to know. Snd I find that younger women, from 20 – 35 have got that, thoughts in their heads, when they are newly diagnosed, and they also have anxiety. There was one incident we had a few years ago, where this woman was classic anxiety disorder, but it happened after a traumatic rape incident. And a colleague of mine dealt with her, and she had to go to town hill, and she spent I think it was a month there, and therapy every day, and she's a lot better, she finished matric and went on and is doing much better. Just thinking, the anxiety I get in some patients about their status and disclosure, and support in the family, they are very anxious about that.

I: are there HIV support groups with regards to mental health

A: not that I know of

I: does the hospital run support groups for HIV patients?

A: not that I know of. There are the HIV module training, but that's it.

I: can you tell me a little bit more about the module training ?because I see patients coming in for module four, which I assume is the last one.

A: Yes, module 1 is about healthy living, how not to reinfect and things likes like that. I think module two is... like safe sex – I don't know if that goes with module one though. But module three and four is medicine. So you can ask M to just clarify that, but I'm pretty sure that's how it goes.

I: So that groups of people will come in to do that in a group setting.

A: yes. definitely.

I: so that seems like an ideal opportunity to do something, some sort of counselling or support.

A: yes. definitely. umm, cuz its just that, this group module thing, sometimes its run in a group, but only the first two are run in the group. Because the first two modules are not – three and four deal with treatment, so when you attend that you definitely have HIV. But one and two are is more like, a general everyone should know this, and run this in their lives, and you will save yourself if you aren't infected or even if you are infected. so you can't distinguish who in that group – just because of the confidentiality and the stigma that is attached to it.

I: right. What is your opinion of the relationship between mental health and HIV.

A: (pause) I think that MHCUs are at an increased risk for getting HIV. I battle with this ethically every time I see an intellectually impaired woman and she's not the depo injection or contraceptive pills or anything, because yes, she is responsible for her actions to the extent that she understands what she is doing, but if an intellectually impaired woman knows that sex is nice, and it feels good, but if she doesn't think about the consequences of that,

how much does she understand? so for me I just want to sledgehammer that – put them on family planning , but I can't, I can only advocate, but I can't say that. So for me I think they are at a high risk for abuse, and obviously then, infection. And then, I think – with regards to a family member who has to care for a mental health care user, and these are just my thoughts, I haven't seen any of it, but if you have a mental health care user living with you, and you are already looking after this person more so than you are any other family member. so now if you have HIV on top of that, I don't think it becomes more of a burden. Because the person has already been sick, so I think you'll just be taking care of them a little bit more. So in that instance, I don't think that caregivers will find it that much harder.

I: the woman that we saw in clinic last week, who had the young kid with CP and had the psychotic episode, and the interaction between her ARVs being the wrong treatment and her depression. So you see many women coming through the hospital with those narratives?

A: that was the second one I've seen, that had a psychotic episode due to having a depressed nature, having that predisposed thing for depression, and being on the wrong meds, or just being on meds and being HIV positive and suffering a psychotic episode. it's so out of character for them (the psychotic behaviour). and then afterwards, like The one girl, that's the one girl I saw a lot of anxiety in her. after her psychotic episode she was completely freaked out and didn't want to do anything by herself, um she's now, she walked in on Friday, she came here by herself, she knitted a hat, I gave her things to do at home, it was also income generating, told her, if you can do this, and she was very scared to get back into life. um because this had happened to her. but yah that was the only two cases. Its like, the narrative was the same, that lady had no supports... she had a massive amount of stress....

I: she was under a lot of stress

A: a massive amount of stress, she still has a massive amount of stress. She never used to be sick that lady. Her husband has many girlfriends, and he infected her. And that lady was here, last year and she was happy and she was bubbly so.

I: I can't even imagine what it's like to be a part of a culture where, your husband can infect you and there's -

A: and there's no recourse. Nothing.

I: nothing happens to him.

A: nothing. nothing at all.

I: and you just have to live with it. And so, these sorts of outbursts, and psychotic breakdowns, well, they seem to me like just nervous breakdowns that these women are having.

A: I think you're spot on with that. (laughs)

I: It just seems to make the most sense

A: and the medicine, the medicine if you're predisposed, and you already have all these stresses, and you have the wrong regime, its going to just push you over the edge. it's not helping, and it's just fuelling the fire. and can you imagine having to deal with all of that, and still be ok with life and still carry on and still treat your CP child – I don't know.

I: how much do you think culture plays a role in women's emotional health and the way they can deal with the things that happen to them?

A: massively. and I'm not just talking about here – if you look at other cultures I think women are so expected to just accept their role, women are not really given a voice and its still very old school and cave man, and even if you have an issue and have a problem, it's not really

culturally appropriate to go and sit down with your husband and chat about it. like in the older tradition, I'm sure if you're both from the western and you've studied its different even if you are living in this area, but if that hasn't happened then, you're still very much culturally married, then who do you chat to? your mother in law, and you may not be in her good books already for whatever reason. you have so much responsibility to be the mkhuti in the household to make sure everyone is looked after ; the mother in law, whoever lives on that homestead is your responsibility you have to cook, you have to clean you have to make sure your kids are at school you have to do everything, and who is your sound board, who do you chat to who do you let steam off to, apart from your other women friends , and so yah. I think this palce works because of women, but they don't have anywhere to say their say, and to let go of their frustration and goes with all of the things they have to deal with.

I: this may be a question that ben and Michael may be better able to answer, but do you notice a gender difference between how many women come in with psychotic episodes, are there more women than men

A: I haven't picked that up. I have, and I'd like you to ask them a little bit about that schizophrenia label, and its chucked on a lot to people in this area, and it's like you saw, without even formal diagnosis -not even checked, I mean there's not even a DSM IV done for that person. And that's just a basic thing to do.

I: is there, do they have access to a DSM, is it there, is it something are nurses trained on how to do it? do they think there is no point in doing it because a doctor is never there and has to sign off?

A: yes I think that may be the thing. Because, I saw a patient today, and I wanted to actually make a copy of it. It was an interview, stuck in the yellow folder, and I could get that folder because it was this person (taps the desk) and she was interviewed by the psychiatrist, dr. Soga, who used to come once a month and sit in on that clinic, and she was excellent, that was her passion mental health was her passion, and she resigned. But there is such a comprehensive interview in there, that if we used it in that clinic, it wouldn't matter if there was a doctor there or not, because we could have the DSM IV and then say that's it. So what Ben and I have been doing, and the social worker, is just doing a MSE, and writing whatever we found, and attaching the MSE in the file of the ward patient, so that when the doctor comes, we say: plan look at medicine, discharge via this this and this. and that's what we've been doing, so at least the doctor doesn't do nothing, and he can see this is what we've done in psych clinic, here is the MSE, this is our plan, you need to please review the meds, change the meds or put the patient on meds. so that's what we've done something. because otherwise, we sit there and help the patient nothing gets done. but unfortunately we can only do that for the people who are inpatients.

I: right

A: but if we had that other interview, it would be the inpatients, unless we stapled it into the psych file of every patient that came in – it would take a hell of a lot longer,- and I don't know if you've noticed how much those boys LOVE going through, and just same old meds and off you go, because they have 20 to 30 patietns every clinic so its not like they have the time.

I: can you tell me your interaction and exposure to south African mental health policy?

A: I reviewed the policy, the mental health care act – the 2002

I: yes

A:we went through that, when we had the mental health care forum, we had a session going through the mental health care act, getting familiar with it, learning what the forms mean,

what the rights mean, what all those things are that we need to do. so I familiarized myself with the act. but I found a very interesting document the other day, on the intranet, can I show you, deals with psychosocial rehabilitation for Mental health care users, and what they are entitled to have at a government hospital. I haven't printed it because it was too much and our printer was a bit screwy, but I have it now and I found it. It's in the district health intranet. the one that everyone can access.

I: would you say there are barriers to actually implementing policy?

A: yes, HUGE barriers. the mental health care act says that you have to hand deliver the forms, of every patient you've admitted to the general review board, that sits in empangeni, or Richards bay or wherever,

I: hand deliver?

A: yes you're not allowed to fax them, and you can post them, but they have to be in registered post, because of the confidentiality and all of those things. So you can imagine, that those forms take months to get to a review board. and patients don't get reviewed, and there's no going forward. So doctors are really lax to fill in all the forms because – well what's the point.

I: right.

A: and also time you're strapped for time we don't even have a facility here to place mental health care users, I've seen some shocking things here that mental health care users don't actually get seen for normal nursing care on the wards, because the nurses aren't mental health care nurses, and they refuse to see the patients. And we had to put a stop to that, because obviously that was ridiculous. but the patient wasn't getting his meds from the nurse because the nurse on the ward isn't a mental health care nurse, so they aren't going to see them.

I: is there any reason why the nurses are doing that? opinions about MHCUs

A: I think there is a big stigma attached to it, and people just aren't interested in it. I'm not sure how we're going to change that mindset – and yah, over the weekend you'll get an admission, and the person is aggressive, the doctor isn't phased, and they handcuff the patient to the bed. Monday morning we get in and the patient has a neuropraxia because he's been in handcuffs, and he's now got radial hand palsy. so you see some scary things, and I think mental health care policy has a lot to do with how we deal with patients. It looks so good on paper, we see so many good things, but to implement it on ground level, it doesn't work. If they could make the forms a little bit less, and where we could go with the patients a little bit more, it would help a lot. Because we can only refer to Madadene – and if Madadene is full, then we have to have all those forms, and a reason with a psychiatrist is backing us up, as to why we have to go somewhere else, where the next place is. Which I think is empangeni or Richards bay.

I: but Madedene only has 20 beds.

A: exactly. So if a patient cannot go to Madadene, then the patient must stay here longer, which we need to apply for, and the form needs to go to there for, and then they say that a patient can be kept longer, or not be kept longer, and say ok you can keep this patient for longer observation over 72 hours. so you can see that the policy -

I: the policy itself is a barrier to implementing the policy

A: yes. and the resources that we have. You can see also that we don't have enough human resources, if we had an isolation ward, or seclusion, not isolation, but just a ward for mental health care, it might be helpful. so this new building that you see here, that they built here for

the 2010 world cup, that they built for hemorrhagic fever, cuz we have so much of that here – we don't really, but yah (laughs) yah, we hopefully, can motivate to have that given to psych and mental health, so we could at least have something, and if we have something like that we can advertise for posts. and say, I have motivated for a psychologist at the hospital for three years, mareyka has motivated for seven years. I have looked up all the tests, but them in a budget, I did the financial projections to see why we need a psychologist here, and we didn't get anyone. we have the numbers to back up why we need a psychologist here, and so far, nothing.

I: what would you say is the big thing that is keeping a psychologist from coming out here?

A: money. I don't know what the new revised OC package will look like, but I imagine it would be very nice, very favourable. um, and nice. they earn a lot. and also I think psychologists are, they are not, at this age, they have usually settled after you finished your schooling and internships, for you to come on your com serve – I don't know why we haven't had a com serve psychologist. Next year, we are getting someone who is married to a psychologist who is coming here.

I: ooh, so will their husband or wife come with them?

A:yes, a wife or husband is coming. so hopefully we can have psychology out here, we can advocate for a post, and hopefully fill it with that person. And if we get another O.T. next year, which means we'll have three O.T.'s which make it alot easier to say, YOUR career is mental health care, and you have to do one two and three for your performance review. And hopefully its someone that likes mental health. Fefe was here, last year we had three O.T's , and she loved it she was starting to get the groups it was all going, and then (snaps fingers)it gets cut. and what do you do. you only have two people. one has to run opd, one has to go to clinic -. so yah. Hope it's been helpful !

I: it's been great, great. Thank you thank you.

Phelandaba Traditional Healer Family D+E+F-25 Nov.2010

I: Tell me what some of the main reason people come to you for help are? What are the main problems are they having?

P: The reason for living or?

I: For help?

P: There are different reasons.

I: Okay, what are some of the reason?

P: Some with headache, mental illness, stomach, being poison, with swollen legs, pain in your back, stroke, some looking for jobs, some looking for business or to have customers.

I: What are some of the ways you help people when they have pains, headache, pains in their feet and back?

P: If you are mental illness and you come here, I first burn traditional herbs to smoke and some traditional medicine to breathe in and this will hit your mind and comes out fesses so your head is not charging well to you brain veins and this medicine will hit in your mind and water will come out that is how we do it. You will then open your mouth and it will come out it self in your mouth and nose and your mind will come back to be mental health and after that you will fall asleep. This is our injection we are using. After some sleep your minds is back to mental health and ask where I am?

I: What do you think causes people to get mental illness?

P: Since I explain that it because of thinking too much, having some problems like debt and feel like committing suicide. If you think too much your mind automatically stop as you can see white people who are also made it because of thinking too much and even ending up loosing your house. Some are witched for example you love a girl and she becomes mental illness because you went to traditional healers for a traditional medicine for that girl to love you. But you find that it not working because you scream at night and ended up loosing her mind. There are many things maybe one was stealing and be trap.

I: Is there times when you will send somebody to the hospital if you could not help them?

P: Yes we do that because we work together with doctors, like if one don't have drip, blood, water we take him or her to hospital and than he or she comes back here.

I: Does that happen often when you bring people to the hospital?

P: Yes I have sent many people to hospital.

I: How long have you been traditional healer?

P: 1981.

I: What were you doing before that?

P: Studying I first went to...before I went I knew about traditional medicine and they show me, but I was working at EGoli. I was working as a faith healer before.

I: Can you explain to me what happened when you got your calling?

P: I was sick like I'm in a hole a coughing blood. I was working in a mine in Johannesburg. After that I got injured and my body changed to this color and I called home and they told me to come back. When I was back we went to traditional healer and I was told that it because of my ancestors.

I: Are there any traditional healers in your family?

P: Yes some passed away long time ago and some are still alive.

I: How many wives do you have?

P: 6.

I: Do they all live here with you?

P: 5 here and the other lives some where else 3 are traditional healers and 3 are not.

I: Okay, do you all work together?

P: Yes we work together.

I: What are some of the biggest problems that you help people with in the community?

P: They have problems with their ancestors and there is no peace in their families. Like we have people who do not believe on ancestors and let say you have passed away or your mother who and about her ancestors because you cant turn your back to your parents. And you end up thinking too

much and be mental illness. There are many things that people brought as I have explained. Some are looking for businesses, jobs some are sick so I am dealing with everything.

I: Were your wives already traditional healers when you married them or did they become traditional healers after you married them?

P: I trained them they came here knowing nothing and they were young.

I: How many people come to see you a week?

P: I don't know because I work until late and I close at 8 pm.

I: Do you see everybody in this room?

P: Some to that house and some go to that one and some to this one.

I: What the thing you like the most about being a traditional healer?

P: 3?

I2: Yes.

I: As many as you can.

P: Lots, I did not like it when I started, but now! I really love my job. My kids were all young and they are all grown now because of my job I was able to raise them up. I'm having my wives through my job and have lots of cows through my job I also have pigs, goat, new cars I have everything because of my job. I don't know how many cars I have so I am really happy with my job as a traditional healer. I have 3 and have more than 15 cars that I have bought through my job as a traditional healer.

I: And that is all being a traditional healer?

P: Yes.

I: What the hardest thing about being a traditional healer?

P: It hard in the beginning like when you studying for being a doctor, you start knowing nothing like when you studying for being a doctor you just go without knowing anything. When one come you don't know what is wrong with that person, but it better when you are working as a doctor because he or she will tell you what is wrong. But if you visit a traditional healer I am the one who is suppose to tell you what is wrong. So you need to learn and you need to learn all the traditional medicine that you need to give that particular person.

I: How did you learn? Did somebody teach you or your ancestors tell you?

P: I just put down my bones and show you and my ancestors will tell me.

I: What are some of the things that your patients like; did they tell you about feeling sad?

P: Yes they do like if one has an argument with her husband or a man may come and tell me that I have an argument with my wife and she left me with the kids so I help him to get his wife back.

I: What are some of the things that make your client sad?

P2: A lot of things like we don't get satisfaction when it comes to sexual intercourse and we can help in that also.

I: What about feeling anxious or nervous?

P: Yes they do children and adults for example and adult who is talking at night while he or she is sleeping and we help them.

I: What are some of the problems that cause that way?

P: If there is something wrong in your house like you are having enemies.

P2: Maybe it a Tokoloshi.

P: Like sometimes you dream as if you having sex with a man.

I: Do people ever come to you because one of the family members has die?

P: Yes.

I: So how do you help them? What sort of problems do they have?

P: Like if one was not sick, but if he or she was sick they don't come they also come if one had been shot, stab committed suicide.

P2: We know how to do it if he or she was stabbed...

I: Do you tell them by the bones?

P: Yes we can tell the reason why he or she was stab...

P2: Of if you want to pay revenge.

I: Do lot of people come for help to that?

P: Yes.

I: How do your patients respond to the help you give them?

P: Some they come back to say thank you, some buy some stuff which proves that they are happy.

I: Do you see lot of people because of their HIV?

P: I don't want to lie on that one because I help anyone with sickness with my traditional medicine without disclosing his or her sickness and they end up being okay...

P2: And they don't stop their treatment.

P: We don't tell them to stop using their treatment, but we can tell that this one is taking treatment and they hiding from us, but have traditional medicine that help when you have headache. But we don't tell because they don't tell us about their status.

I: Do you send them in hospital or you do them both if you see that one is HIV positive?

P: They know that they should go to hospital before they even come here.

P2: This is how it goes, if you talking your treatment we do give you our traditional medicine on your date when you running short of your medication we send you to hospital to check if it okay to use both our traditional medicine and your treatment and they find that it okay and they give them their medication and we also give them our traditional medicine.

I: So if they check their CD4 and it get worse do you tell them to stop one of the medicines?

P: We don't say anything we just say continues.

P2: Cannot be low, but it increase until they tell you that you won't get your pension because you are okay now.

I: Do people ever come to you for help because they are sad or anxious about their status?

P: Yes and some will explain, but people are so secretive even though they have it. We have helped 3 people who have even stopped receiving pension because they look health now.

P2: Someone is still here.

P: But I don't think she or he is here for now maybe she or he is at Manguzi.

I: How do you help them? Do you give them traditional medicine or you talk to them?

P: I explain to them that you should not hide if you...

P2: We talk to them.

I: How do patient respond to that?

P: They don't care and they even ask if I know how to treat this or that disease.

I2: Is there anyone who just tells you that they are HIV positive?

P: Some have called and they will come soon and they asked if I know how to treat this disease.

P2: Some were here in the morning.

I: And when they ask what do you say?

P: I tell them to drink medicine and you will be fine.

I: Have you ever...you said you work with some doctors in the hospital?

P: Yes.

I: Can you explain how that started?

P: I tell them that this person comes from me so would you please put drip or check blood on how it going.

I2: To heck HIV?

P: It up to them on what they check.

P2: Blood.

P: We don't say they should check his or her blood but we ask them to check his or her problem because we have failed to help.

I: Have you ever been to a class at tribal?

P: No I have my certificate.

I: Can you tell me what you think about it?

P: I wish there should more classes.

P2: Yes because there are lots of diseases so that we can learn about other disease like if one is having a problem with his or her skin and you are able to tell what is wrong with his or her skin.

P: Another thing is you should tell your kids about your life so that they can learn about it because I have learned about it and have a certificate. Like if you having sex with a girl without a condom they

should know that you get HIV through the blood it self not by having sex. If we both have cut and yours is 5 and mine are 10 it will be 15 I don't know if you understand what am saying?

I2: Yes I do. (*Laughing*)

P: HIV is not contracted through having sex.

I: Did you learn that from the meeting of from the practice?

P: We learned it, but I always have it in my mind.

I: Is there more that you would love to learn?

P: Yes a lots so that we can work together with the doctors and we do not get payed even though we help doctors but it only our client who pays us so we would be happy if a government can pay for us as well.

I: What do you think about how the hospitals treat the mental illness?

P: They are doing well.

I: Do you think that they can help everybody?

P: The thing is, at hospital they force even though it doesn't get them anywhere but if we can work together...

P2: Girl if trees are growing their mental illness also becomes high, but if they have been treated in a traditional way it don't comes back, but if treated in hospitals it comes back when trees grows every year.

P: Askies, because doctors are pissed off of disease because you can talk to him or her and he or she will give you injection and tablet and disturbed your mind and feel as if you are okay, but after 15 or 30 minutes it comes back again while the doctors need to refer those people to us if they fail to treat that person. We registered and they told us that will meet and talk about people that they should be like this and that. We learned but they don't do that, they asked us to cook our traditional medicine and to tell them we do it and nothing has happened because they take us for granted while this is nature, hospitals came after traditional healers. I'm old now but I never I don't have a hospital card I always use my traditional medicine and few of my children who have hospital card because I always tell them to drink my medicine.

I: Why is it that they get people who have mental illnesses, why does it get worse in the summer when the trees are growing?

P: It nature.

I: Does anybody in the community know that.

P: Yes let me make an example about the aloe that is in Jozini when it grows and fully of flower it gives everybody a fever.

I: Do the doctors know about this?

P: I think so, but they should know about this.

P2: Yes they know because they don't allow with aloe.

P: Yes because if we want to take aloe they don't allow us and be arrested because if we use aloe we...I wont explain much.

P2: We are killing the fever when it starts so no one will go to hospital.

I2: (*Laughing*)

P: Another example will be, for anyone when trees are growing everyone change and when it winter we all loose weight. Even cow they give birth.

I: Do you use aloe tree as the medication?

I2: Yes.

P: In winter you don't feel happy because of being cold and when it summer you feel happy. Aloe helps a lot even in animals.

P2: We even use it to chicken when they sick even on cow. It also helps in HIV and BP.

I: So is that something you give to patient with stroke?

P: Yes.

I: Have you ever heard the term anxiety or depression before?

P: What do they mean?

I2: They mean anxiety they is no meaning in a Zulu way.

P2: Like if somebody has died.

I2: Have you heard of those words?

P: No.

I: Do you hear those words in the community?

P: Yes like if you come across something that scare you.

I: What are some of the ways that you help people when they come in for help?

P: We give medicine.

I: Does it work or are they happy about it?

P: Yes.

I: What does the term mental illness mean to you?

P2: A person who is does crazy things which a mental health person cannot do.

I: What kind of wrong things?

P2: Like he or she can pee or toilet in front of you.

I: What does it mean to be mental health?

P3: A person who is doing the good things.

I: Do you think that there is a connection between mental illness and HIV?

P: Yes both look the same because when you having this disease you start having headache or may just have it and after be mental illness.

I: And do you see it happening in lot of patient?

P: Not in all.

P2: Some will be told that they HIV positive and they just accept it without having any problem and live a normal life.

P: Some if they find out that they are HIV positive they think that they are death and they don't even eat, while they will live. Some may test and test positive and the following month they test negative.

P2: How does that happen?

P: We are asking you.

I2: (*Laughing*)

I: Sometimes very rarely you can get a false positive in the test, the test can make a mistake that is why they make you go twice, and even if your 1st test was negative you still have to go the 2nd time and it positive. That is why you have to do it twice and 6 month you have to do it again because just to make sure. Because it might be that the virus isn't able to be detected or there is a mistake in the test.

P: If I test this month and the following month and get different result, what is it that make it different because I did not get the cure? Because that really hurt so what I'm saying is, if they find that I am HIV positive they should not tell until I come back the second time and do the test again and get my final result.

I: I agree with that, but they don't do that because the government is cheap.

P: We...

I2: Even if you are HIV positive they tell you to test again.

I: It an option?

I2: Yes.

P3: After a month.

I3: After 3 month.

P: I would be happy if...

P3: How long to get on treatment if you are HIV positive?

I3: If your CD4 count is below 200.

I: But if your CD4 is below 200 you very sick.

P3: If my CD4 is 250?

I: You sick but you do not qualify.

P3: The maximum of CD4 is 200?

I: Yes they try to get you before they get too low but basically if it get there you die.

I2: I have seen someone whose CD4 count is 90 and you cannot tell that he or she is HIV positive.

I3: I have seen someone who has 10 CD4 count and he is strong I could not believe it.

I: Really?

I3: Yes I was with Tyler and he did not believe as well.

I2: It depends on the body.

P2: My sister they told her that she have 5 CD4 count but now she is very fat and you cannot tell that she is HIV positive.

P: Why do doctors send us letters and they don't want to talk to us face to face?

I: The doctors did not send me, when I told them I want to learn how people learn in the community; I told them I will talk to people who provide service. Traditional healers provide important service that is why I want to talk to you. So he wont know that I talk to you not until I put a report in his desk that this is what important. This is what they do, this is how they do it and this is how the community feels about it, because I also talked to people in the community and asked them about their experiences about doctors and traditional healers. And people are very happy with the traditional healers and they keep going. This is all part of me trying to support traditional medicine being better accepted by the government.

P2: Can I ask you something? Do doctors know how to treat umhlume (something that grows in your vagina)?

P: No they don't. (*Laughter*)

I: Yes there are different types of sicknesses that cause that.

P2: Tell me 2.

I: The group of them called STI and one of them is called harpies.

P2: Do they know that sickness can be transfer to each other?

I2&3: altogether yes.

P2: Do they know where to find in it a man?

I: In man it does not look the same because the organ is different there can be spot in the penis and usual cannot see it like sores.

P2: For a woman it in her vagina and when you meet with a man it will attack to a man and for a man it will be in his bums and find that they give him medication and say he is HIV positive.

I: Sometimes those diseases may make you like to have those diseases to catch it easy.

P: You might have umhlume but not being HIV positive like you try to give birth but your children just die. for a woman it always itching in your vagina and have bitter water umhlume and when you give birth your child will suck this water and after 5 or 6 month your child will die even 10 years she or he might die without being sick.

I: Do you think more training to start back again?

P: Yes and I told you in the beginning.

I: I don't have any more question, do you have anything that you want me to know?

P: Can we share something with you and it will be up to you whether you ask or what and will explain. Because we won't tell you something that is unnecessary so you need to ask something that is necessary to you. Let say you do not have feelings for a man and we can help you to have it and your periods but doctors do not know if like you have 3 times period's a months or you don't know your periods or you don't have them at all. So we know how to help you get children. Or if you have your periods on the 1st, 2nd or 3rd that person cannot find children and doctors do not know that

P2: Since you said your mother is a Sangoma so let say your mother passed away, will you be able to see if you having a calling from your mother to become a Sangomas?

I2: No she did not mention that her mother is a Sangoma but she knows traditional medicines.

I: I guess if she lives here that what she will be called. She just uses traditional medicine.

P: Do doctors know how to help you if you can't find kids?

I: I don't know I think they try.

P: They don't know unless you want them help you to stop having children and if you want to have them again they also can help you, but they can't help you if you don't give birth at all.

I: Do you help a lot of women who can't have children?

P: Yes, in life we have a lot that we can doctors with even if they are well educated at the end they can be happy that we can tell them how to help the women who can't give birth and also help them on how to treat umhlume.

I: Thank you very much for the time.

P: Okay.

APPENDIX D: SAMPLE INVIVO TRANSCRIPT (PHASE 1 ANALYSIS)

PT121123, Mild severity

Two sisters and one brother

Lives within a close distance to family and siblings are still alive and live nearby.

Father passed away when she was 12 years old, doesn't remember

Mother is still alive, lives with one of sisters

Employed as an orderly at Manguzi hospital since 2002

Enjoys Job

Went to school for a short while when younger

Returned recently and currently completing grade 12

Not currently married

37 years old

Mother of three children – aged 17, 14, 9

All children are in school

Husband and father of children passed away in March 2010

Unexplained death at work, perhaps affected by a generator at work

Death has been hard because he used to support them and now she is left alone to take care of them

Doesn't receive any support from other family

Trying to cope but not able to do it all – living in a two bedroom house but it is unfinished and wants to complete it

Not earning enough money at work

Hardest thing in life right: has to live with husband's family who are not supportive of her

Wants to live somewhere else

Really hurt by the situation

Something that she can't explain and doesn't want to explain

Best thing about life: able to raise children, and has hopes that they will finish school and build houses of their own

"trying my best to give them all"

Had a great childhood because it was free from worry – as a child you are taken care of taken to school and given something to eat

Goes to see a nurse when things are 'not alright in life'- physically sick with a flu or cough

Never seen a psychiatrist because she doesn't have problems with her mental (health)

Sometimes think about getting sick, but it doesn't worry her.

Since her husband passed away has needed a friend for comfort

Don't want to live alone and thinking about it which would cause stress

Talked to friend about abandonment of husband – stopped coming back to visit and

Advice: Things will be fine, don't worry, and not to move out.

Husband was working in Durban for five years before he died. During the last two years, prior to death he did not make contact with the family at all, rarely sent money or answered phone calls

Sent money maybe after four months of calling

Was hurt by the situation

Talking to friend about it helped because "it made her stress free"

"I realized that if I don't talk (about things) I will have stress"

Stressful incident: Father in law did not want her to live in the house because she had a decent (full time) job while the husband had to work temporary jobs and father in law was jealous "did not want to see the family "living a healthy life"

Refusing to talk about "the life of this house"

Spends time with a group of sisters from the church who advise her on what life as a widow is supposed to be

Have to live without a 'man' in the house for a year, until 'they' give her permission to have another man

Not allowed to leave the homestead of the husband/partner or children will suffer

Will agree with it for now, but wants to meet a man in the future

Once visited a traditional healer

Sometimes can't sleep at night

After husband passed away she and her children started to see him in their dreams

Visions of the father made children cry at night

It lasted for three months

Decided to contact a traditional healer

Healer prayed over water [which is kept in the house]

Children found the passing of father difficult at first, but it didn't last long because they never lived with him and so "they did not know his love"

Member of a community support group for families became a member in march 2010 after husband died

In times of loss they support each other with finances to pay for costs of life events like: funerals, weddings, graduations

Also support each other in start-up funds for entrepreneur activities

Also encourage individual members to save on their own

Contribute 30 rand /month

Fund is not for everyday struggle i.e. running out of food

Previous survey and anxiety- felt anxious around the death of her husband

Did not believe the story about how he died, (uncertainty)

Brother in law helped out at the time, with preparations for the funeral

*initial response to question about 'help' initiates a response over financial support that brother in law gave with the funeral

When she was feeling sad about husband's death mother spent time with her and talked a lot about the situation, which was very helpful

*doesn't explain what they talked about.

Still think about husband's death, even though he hardly visited, she could call him if they ran out of food and she misses him
No one is there to give that support that since he's passed

Previous survey and sadness: repeats the issue of problems with in-laws as being the cause of sadness in her life
Discusses the problem with her mother
Advice: Mother advises her to stay at the house, because she built it
Also talks to brother and sisters for emotional support
They also will help with anything they can (siblings are also poor)

Coping with struggles since husband left is another source of sadness

Desire to start a business
Went back to school to get a better post at work to earn more money

Support from sister's at church is helpful because not doing 'bad' things
Bad things = meeting another husband, because could become infected with HIV
This advice is because of culture – pay respect to husband and respect to the community
Advice given to all women and then they choose to follow or not.

Never heard words 'anxiety' or 'depression'

Mental illness means to do things that are not the same as people who are normal

Mentally ill people do bad things and that are 'crazy' = talk strangely
Experience with neighbour who stands in the sun all day without moving
Feels sorry for him because no one cares for him
Talks to him and tells him to move because he understands
Hospital cases are violent and hit staff
Try to escape from the hospital, don't eat, turn on faucets and leave them running

Mental health means people who are doing the right things
The way they talk and treat people well at work, community members and family
People in the community will say someone is 'mentally healthy' when they are complimented on good behaviour in the work place

I don't know if I am mentally healthy, I may say yes, but others may say " I am not right"
*mental health is also about how others perceive you, not just your own belief of your mental health status
I am mentally healthy because I never run around naked

Dream of a better future: being successful and having everyone see that she worked her way up from being a cleaner to a matron (nurse), with a new husband who will pay Lobola for her, and driving a car,
Children to finish school without having any children of their own
For people who don't like her can see her success – especially father in law

